

# Evaluation Framework for Care Coordination & Telehealth Deployment

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**Abstract:** Chronic conditions are growing to pandemic proportions. There is evidence that chronic conditions may be managed successfully using telehealth, but this is not leading to large scale deployment. Organisational and structural changes are needed to progress from pilots to real implementations that are integrated in the care routines. The ACT project goes beyond the trial setting to assess programs implementing care coordination (CC) and telehealth (TH) in different EU regions. The aim is to identify best practice organisational and structural processes supporting integration and implementation of telehealth in a care coordination context for routine management of patients with long-term medical conditions. In this report we describe the framework of indicators for CC&TH outcomes and drivers that define data elements collected during the project. The evaluation engine is responsible for capturing, monitoring and evaluating CC&TH deployment, using collected data. The evaluation results contribute to the "best practice cookbook" that will facilitate CC&TH deployment at scale. This report also shares what we have learned from a data transfer test case.

## 1 INTRODUCTION

In the EU, some 10 million people suffer from heart failure (Braunschweig et al., 2011), 20 million have chronic obstructive pulmonary disease (ECC, 2013) and 60 million live with diabetes (IDF, 2013). Each year, these three conditions cost EU healthcare systems around EUR 125 billion. With Care Coordination (CC) and TeleHealth (TH) services, chronically ill people can be managed more effectively in their own homes through remote management systems and integrated networks of caregivers. The ultimate goal of these services is to improve health and support self-management of patients by giving them more independence, freedom and control over their management. Clinical studies have shown these services can help reduce hospital admissions, days in hospital and mortality rates (Inglis et al., 2010; Inglis et al., 2011; BMJ, 2012). However so far CC&TH has been mainly limited to pilot programs due to the difficulty of translating such research into practice. Clinicians need better reporting of how cases were selected for pilots and their representativeness.

The Advancing Care Coordination and Telehealth program (ACT) started in February 2013 and is a 2.5 year program, co-funded by the EU (ACT Project, 2013). It is the first of its kind, specifically designed to examine and overcome the structural and organisational barriers of the deployment of CC&TH. ACT focuses on improving CC&TH services for patients with chronic conditions, specifically Heart Failure, COPD, Diabetes, and multi-morbid patients. ACT looks at tailoring CC&TH services and solutions to specific needs at all acuity levels set out in the Kaiser-Permanente Acuity Pyramid (not only the 3%-5% at the tip primarily targeted by most TeleHealth studies). With the inclusion of CC, the regions and the healthcare experts will evaluate the integrated delivery of healthcare services between community care, primary care physicians, hospitals and informal care givers, and get feedback on how to organise these to provide optimal care. Describing the environment in which CC&TH is embedded addresses the current lack of representativeness in reported outcomes. In conjunction with the healthcare providers and the CC&TH expert team, ACT will investigate how the organisa-

tional and structural elements that influence effective deployment of CC&TH are currently being used and how they can be optimised.

Initially 5 European healthcare regions are involved: The Basque Country (SP), Catalonia (SP), Lombardia (IT), Scotland (UK) and Groningen (NL). More regions can join the consortium during the program. The areas that are addressed in the ACT program are patient & population stratification, care coordination and organisation, patient adherence & staff engagement, and outcomes & efficiency. The regions deploy and operate their own CC&TH schemes for heart failure, COPD and diabetes patients. A baseline assessment (month 9) is performed to assess the current state of CC&TH in the regions. Data from the regions are used to identify “best in class” processes, structures and ways of working. Several iterative assessments (month 14, 18, 24) of the regions will be done with the aim to create a best practices “cookbook”, allowing other healthcare authorities to develop their own CC&TH systems.

This paper describes the evaluation framework and engine that captures, monitors and reports CC&TH outcomes. Drivers are those aspects of a health care program that, when altered, affect one or more outcomes. An important role of the engine is the identification and evaluation of drivers that contribute to successful CC&TH deployment. The ACT program consolidates the understanding of the relation between drivers and outcomes in a “best practices cookbook” that can be used to improve existing CC&TH deployments and to configure future deployments. The remainder of this document is organised as follows. Section 2 describes evaluation frameworks related to CC&TH. The ACT indicator framework that captures CC&TH outcomes and its drivers is presented in Section 3. Section 4 describes the role and main components of the evaluation engine. Section 5 presents a feasibility study for the baseline assessment and the main lessons learned. We conclude this paper and discuss further work in Section 6.

## 2 RELATED WORK

*Telemedicine* has been defined as the application of information and communications technology (ICT) technology to provide and support healthcare when distance separates the participants (Ohinmaa et al., 2001). In the context of ACT telehealth refers to the use of various information and communication technologies (ICT) to assist in the management of an existing long-term medical condition of a patient by delivering clinical care and non-clinical services where

the health care professional and patient are not at the same location (Gaikwad and Warren, 2009). Non-clinical services may include promotion of health education or self-care. *Care coordination* can be perceived as the deliberate organisation of patient care activities between two or more participants in a patient's care (including the patient) to facilitate the appropriate delivery of healthcare services (McDonald et al., 2007).

Although telehealth and care coordination have been recognized as important aspects of high quality and efficiently delivered healthcare, much work remains to be done to illustrate how CC&TH could work in an optimal way and how they relate to important healthcare outcomes (e.g., hospitalisation, readmissions, mortality, and QoL). For this reason, many researchers have reviewed and evaluated certain aspects of CC&TH (Ekeland et al., 2010; Peikes et al., 2009). Apart from these efforts, several large-scale initiatives for evaluating healthcare delivery – and CC&TH as part of it – have emerged, yielding frameworks that systematically define healthcare-related indicators and apply them on the task of healthcare delivery assessment. This section describes the most important evaluation frameworks for the assessment of CC&TH.

The International Network of Agencies for Health Technology Assessment (INAHTA) has developed a framework for the assessment of telemedicine applications (Ohinmaa et al., 2001). The framework considered 3 types of assessment that are directly associated with the phases of a healthcare application lifetime. At each stage, the telemedicine application was compared to the baseline case (i.e., absence of telemedicine) to help authorities decide whether the telemedicine application is worth deploying. There are four assessment categories, e.g., general considerations, costs, economic evaluation, and sensitivity analysis.

Starting from 2009, the European Commission project MethoTelem developed a structured framework for assessing the effectiveness and contribution to QoC of telemedicine applications, which was named Model for Assessment of Telemedicine applications (MAST) (Kidholm et al., 2012). Using HTA Core Model as a starting point, MAST organized telemedicine outcomes to be assessed into 7 domains, namely 1) Health problem and description of the application, 2) Safety, 3) Clinical effectiveness, 4) Patient perspectives, 5) Economic aspects, 6) Organisational aspects, and 7) Socio-cultural, ethical, and legal aspects. Within each domain, there is a list of issues for consideration, which are called topics. MAST comprises 3 elements that need to be applied

sequentially in order to properly assess a telemedicine service: (1) Preceding Considerations, which aims to determine whether a telemedicine service should be assessed or not, (2) Multidisciplinary Assessment, is the core of MAST's assessment taking place in all the aforementioned domains, and (3) Assessment of Transferability, which attempts to assess the transferability of healthcare study results to new settings. Finally, the MAST manual (Kidholm et al., 2010) provides examples of outcomes measures within each domain and methods for collection them.

The National Telehealth Outcome Indicators Project (NTOIP) is a successful Canadian effort to identify and define a minimal set of simple yet meaningful outcome indicators that could be consistently applied in the evaluation of telehealth (Scott et al., 2007). The NTOIP study was conducted in 4 phases, namely 1) Strategy and approach, 2) Systematic review of the literature, 3) National experts workshop, and 4) Refinement and consensus. NTOIP developed the Telehealth Outcomes Development (TOD) framework, a conceptual and guiding scheme consisting of 5 domains (Outcome category, Outcome theme, Outcome indicator, Outcome measure, and Outcome tool) that clarifies the hierarchical relationships between outcome indicator elements. The project concluded to a list of 34 indicators, which are categorized into 4 themes (Quality, Access, Acceptability, and Cost). Within each theme, the 3 most relevant and appropriate for common use indicators were also specified.

In 2010, the Agency for Healthcare Research and Quality (AHRQ) has published a research report, entitled Care Coordination Measures Atlas, in order to help evaluators identify appropriate measures for assessing care coordination (McDonald et al., 2010). The purpose of this atlas is to (1) provide a list of existing measures of CC, organizing them along two dimensions, namely domains (i.e., mechanisms for achieving CC) and perspectives (i.e., the perspectives from which to measure these mechanisms), and (2) develop a framework for understanding how CC is "measured".

In 2011, the Institute for Healthcare Improvement (IHI) published a white paper that describes the methods for better coordination of care regarding patients with multiple health and social needs (such as chronic ill patients) in order to ensure that their health and life goals are improved (Craig et al., 2011). This framework targets the assessment of patients' emerging strengths and needs, in order to improve self-management, target use of care system, for support at critical times. The main aim of the framework is to achieve better health outcomes at lower costs.

### 3 INDICATOR FRAMEWORK

In business, performance of an organization is measured by *Key Performance Indicators* (KPIs). KPIs are different from business to business and need to be identified first. Due to the fact that CC&TH has not resulted into large-scale deployment yet, CC&TH KPIs do not exist yet. The ACT project takes lead in identifying CC&TH KPIs, and more importantly, the drivers for those KPIs. This section describes the indicator framework capturing the KPIs (outcomes) and drivers that will be assessed throughout the ACT programme.

In ACT we address the whole range of stratification (patient and population), engagement (patient and staff), care coordination and organisational structures, including telehealth solutions if relevant, and the relation to effectiveness & efficiency. The frameworks described in Section 2 provide a good overview of potential indicators relevant for specific areas within ACT. These indicators were obtained from literature and current regional practices, we re-structured the indicators into domains and subdomains to match the *context* and the *purpose* of the ACT project.

At this moment we established agreement on the (sub)domains in the framework. A description of the full framework of outcome and driver indicators is beyond the scope of this paper. For full details we refer to (Pauws et al., 2013). The definitions of indicators in the framework are under construction in collaboration with the regional partners and the work packages. To illustrate the framework and the methodology we provide the (sub)domains for the KPIs on efficiency and efficacy, and set for the stratification drivers. For both areas we start with a general description and a graphical representation of the (sub)domains for that work package. We provide a definition of each domain, a motivation for the relevance of that domain, and some example indicators of the subdomains. The (sub)domains are illustrated by pie charts (see Figure 1 and 2).

#### 3.1 Efficiency & Efficacy Outcomes

Efficiency & efficacy indicators capture the performance of the CC&TH service<sup>1</sup>. Figure 1 depicts the outcomes indicators (sub)domains and shows some high level indicators, e.g., *the number of patients per disease per age category*, and the system for referencing the indicators. In this case, indicator 1 is referenced by *7.A.II.1*, coding its correspondence to area

<sup>1</sup>Within ACT we consider indicators for efficiency & efficacy and patient adherence as KPIs for CC&TH.

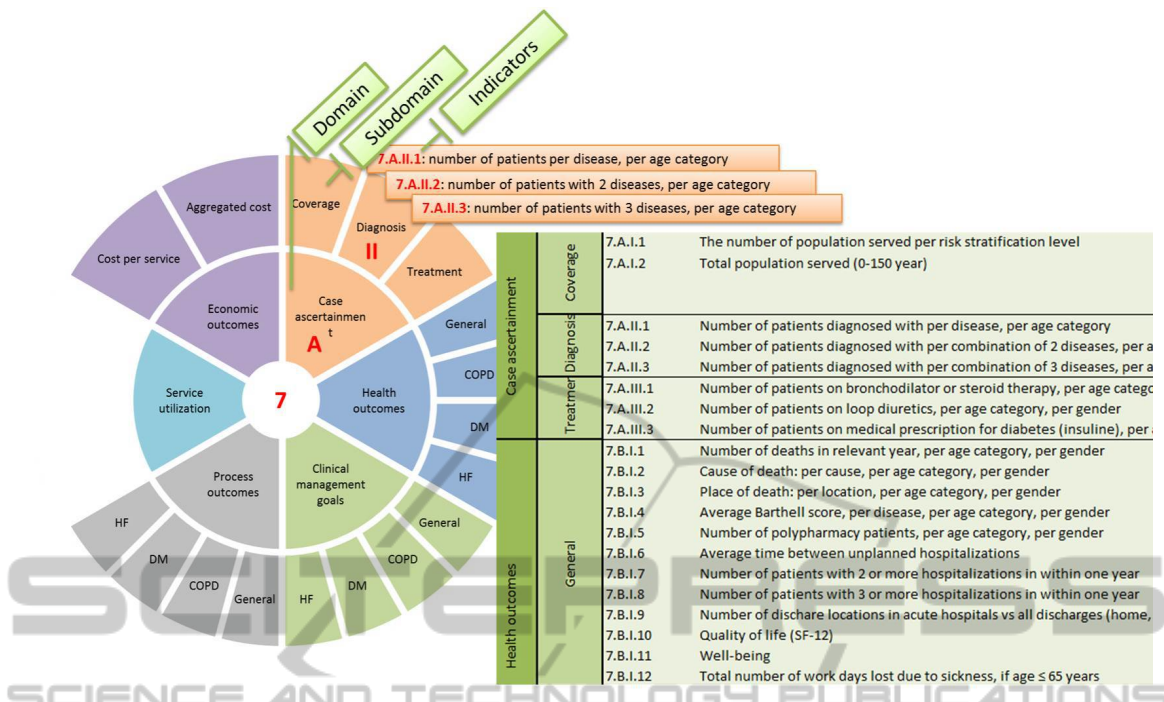


Figure 1: The indicators for the efficiency & efficacy area. The pie (left) shows the domains and subdomains for this area. The inner circle describes the domains, the outer circle the subdomains. Also three high level examples of indicators are provided. The table (right) depicts a fragment of a more detailed description of these indicators. A coding scheme for referencing the indicators is part of the framework.

7 (efficiency & efficacy), domain A (Case Ascertainment domain), subdomain II (Diagnosis subdomain). The table on the right provides a more detailed description of the indicator.

**Case Ascertainment Domain:** Case ascertainment domain indicators capture the extent and precision with which the service manages its population. Success of the service is captured by how well the diagnosis and treatment is for those on the service and how well the services addresses the needs of the entire population. Case ascertainment is addressed at a population level by means of registries, e.g., the comparison between (the number of) diagnosed patients in the registries and (the number of) patients treated by certain marker drugs may highlight issues in the identification and correct diagnosis and treatment of patients. The subdomains are the extent of (1) the addressed population demand (**coverage**), correct **diagnosis**, and correct treatment **treatment**.

**Health Outcomes Domain:** Health outcome domain indicators capture the effect of the CC&TH service on the patients physical and mental health (and deaths), functional limitations, and quality of life. Health outcomes have a direct meaning for the patient. Hospitalisation rate is also a health outcome

that will be analysed here. For the data collection purpose it is captured in the Service utilization domain. The subdomains consider the indicators per disease (**COPD**, **DM**, and **HF**) and one subdomain for **general** indicators that apply for each disease.

**Clinical Management Goals Domain:** Besides keeping patients outside the hospital, it is equally important to keep the patients stable, i.e. maintaining their clinical values within safe ranges. The clinical management goals domain indicators capture how well the patient is reaching the clinical goals set by guidelines and clinical protocols. Clinical management goals correspond to the clinical/analytical values. These have no direct meaning to the patient, but are relevant for the clinician. Here also general and disease specific subdomains are considered.

**Process Outcomes Domain:** Process outcomes domain indicators capture how well the care pathways are working in practice, and how well clinical guidelines and good practices are being followed. Adherence to clinical guidelines is recommended to apply evidenced-based medicine. Again, the general and disease specific subdomains are considered.

**Service Utilization Domain:** Service utilization domain indicators capture the effect of the CC&TH

service on the utilization of health care services. Here we measure the burden on the health care system, i.e., the use of health care services in numbers, from which economic outcomes can be derived. For example, the number of hospitalizations, AED visits and primary care visits.

**Economic Outcomes Domain:** Economic outcomes domain indicators capture the cost of health care service utilization. Here we measure the burden on the health care system in terms of cost. There is a subdomain for **cost per service** that captures the unit cost per service, such as the cost of an AED visit. The **aggregated cost** subdomain provides the total costs.

### 3.2 Population Stratification Drivers

This type of stratification is used to generate a map of the distribution of the population by health risk in a given sector or region. It serves the purpose of defining specific policies and interventions at population level. It will also serve for the generation of indicators useful for the follow-up of health outcomes. The evaluation engine should analyse the relation between drivers and KPIs. In the area of population stratification it will be interesting to see how stratification strategies contribute to the outcomes, e.g., does a stratification on cost savings lead to reduction in cost, and how does it affect health outcomes?

ACT abstracts from concrete stratification algorithms, which may be different from region to region. Instead, for population stratification we focus on the stratification process, i.e. which elements are included in the stratification. As part of the strategy to perform population-based stratification, we consider five different domains, some of them including several sub-domains, summarized in Figure 2.

**Methods Domain:** The domain includes the conceptual definitions guiding the population-based stratification and the description of the methodological steps followed to obtain the population-based indicators. Subdomains describe the stratification **purpose**, **processs** (e.g., information sources and method), **frequency**, and the **combination method** (e.g., how to combine resources for complex indicators).

**Diseases Domain:** Disease domain indicators provide information on the epidemiological impact of targeted diseases and their combination (co-morbidities) at population level (Murray and Lopez, 1997). The disease **severity** subdomain addresses the loss of function due to affected organs. Consensus classification of severity for major chronic diseases is reported in international clinical guidelines

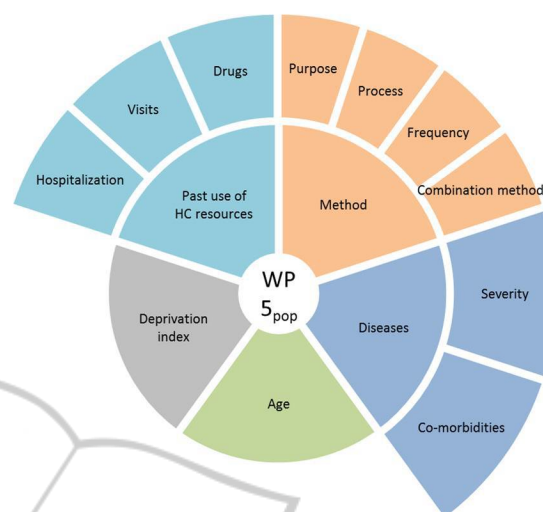


Figure 2: Population stratification indicators.

(i.e. NYHA, New York Heart Academy classification for heart failure; GOLD stages for Chronic Obstructive Pulmonary Disease, COPD). **Co-morbidities** are defined as concomitant diseases in a given patient. It is a common condition in chronic patients with a significant impact on health risk. A classical indicator to assess the impact of co-morbidities at population level is the Charlson index.

**Age Domain:** We examine the effect of age on survival, utilisation of healthcare resources and use of technologies (SIMPHS2, 2013).

**Deprivation Domain:** Deprivation Index is used to characterize socio-economical and educational status of the population. Deprivation index indicators characterize the poverty in an area. Poverty is related to health, education level, availability of means to sustain a healthy lifestyle and social support from the environment, and the availability to utilities, e.g. a network. Hence poverty is expected to impact health outcomes and adherence to the programs (Schuurman et al., 2007).

**Past Use of Healthcare Domain:** Use of healthcare resources within a given period of time (i.e., past 12 months) is expressed by indicators of disease burden on the health system. Three main sub-domains are currently considered, but this may need to be expanded to include novel modalities of interactions of the patient with the healthcare system using telehealth. We consider indicators in the subdomains that capture **hospitalizations**, **visits**, and **drugs**.

## 4 EVALUATION ENGINE

The evaluation engine refers to the organisational and technological infrastructure to collect, analyse and report CC&TH data. This section covers technology and the processes related to the evaluation engine.

The engine supports monitoring of KPIs to all stakeholders. It provides an overview of the targets and statuses of all KPIs. In addition, the evaluation engine evaluates the relation between the KPIs and the drivers in the areas of (1) optimisation CC&TH organisation and structures, (2) stratification, and (3) patient adherence & staff engagement. The engine should support the understanding how to improve the tailoring of care for co-morbid patients by exploring the drivers that lead to better health outcomes (captured by some KPIs), e.g., by applying specific stratification strategies, taking into account disease severity and frailty, but also considering the communication between various health care providers involved in the treatment of the co-morbid patient.

Within the ACT program, the Evaluation Engine makes data on CC&TH deployment (i.e. KPIs and driver configurations per region) transparent, interrogative and actionable to all partners and regions at pre-set moments in time.

A wide variety of “off-the-shelf” technologies is available from both commercial vendors and open source community. The selection of technologies for the prototype of the evaluation engine consists of several components. The content and access to the content is provided by the open source content management system Drupal<sup>2</sup>. Surveys are provided by a LimeSurvey<sup>3</sup> application. Shiny<sup>4</sup> allows the statistical analysis, performed in R(R Core Team, 2013), to be easily deployed in an interactive web application. In the ACT project there will be a limited number of data collections, therefore data access and integration can be performed manually in the R scripts. Data collection of the KPIs for population stratification and for efficiency & efficacy is currently done via a secure data transfer, but will be replaced by a data submission service in a next version.

## 5 FIRST EXTRACTION: LESSONS LEARNED

The ACT program is designed as a program of prospective data collection for the purpose of a mul-

titude of analyses. From an organisational perspective, data need to be collected at the regions, either with the help from ACT regional partners (e.g., KRONIKGUNE in the Basque Country or Telbios in Lombardy) or by third parties. Figure 3 depicts the (sub)domains of all ACT areas we have identified in agreement with the regional partners and the work packages. The figure also shows how data for the baseline assessment will be collected. Where systematic collection of data is available in local IT systems, data extraction is the preferred data collection method. Currently data extraction is only possible for population stratification and efficiency & efficacy. Surveys will be issued to gather information on the indicators from the other areas.

A small feasibility study has been performed to assess readiness for regions to share data. Currently, regions are assessing availability of the indicators in the framework and preparing their systems for baseline data extraction. The remainder of this section discusses the findings of the test extraction of the feasibility study. Two regions were successful in collecting and sharing their data. The following issues were revealed and need closer study. Clearly agreed and very precise indicator definitions are needed to achieve a transparent way of reporting across regions. For example, Catalonia reported mortality per 1.000 inhabitants, whereas other regions reported a total number of deaths. It should be clear if these numbers refer to patients that were only included in the risk set (one of the health plans) or to representatives of the local common population. The Basque Country shared, besides the raw number statistics on admission, adjusted measures for admission by taking into account patients that died during follow-up. Adjusted admissions were calculated by subtracting the number of dead from the number of admissions. Cooperation with the regions is necessary to achieve a common understanding of the indicators captured by a solid definition. This is a time consuming effort.

Access permissions and procedures differ per region and have been found to be a barrier during the test transfer. Data resides in different systems; some are easy to access while others require contracting third parties. Due to access restriction, Catalonia could not share data on length of stay combined with other variables (cause of admission, diagnosis, type of centre). Lombardy (Telbios) was not able to meet the data transfer request, as it concerned health outcome and resource utilisation data which are beyond the access privileges of Telbios. A third Lombard party, outside of ACT, Lombardy Informatics SPA owns, manages and controls these data. It is a publicly owned IT service company, founded by the Lombardy

<sup>2</sup><https://drupal.org/>

<sup>3</sup><http://www.limesurvey.org/>

<sup>4</sup><http://www.rstudio.com/shiny/>

<b>Data collection</b>	<b>KPIs</b>	<b>Drivers</b>		
		Stratification	Care Coordination	Adherence
<b>Data extraction</b>	<b>Efficiency &amp; Efficacy</b> 6 domains 17 subdomains	<b>Population Stratification</b> 5 domains 9 subdomains		
<b>Surveys</b>	<b>Patient Adherence</b> 4 domains 12 subdomains	<b>Patient Stratification</b> 4 domains 17 subdomains	<b>Care Coordination</b> 4 domains 15 subdomains	<b>Patient Adherence</b> 3 domains 11 subdomains <b>Staff Engagement</b> 6 domains 3 subdomains

Figure 3: Overview of indicator framework areas and the data collection method (survey or data extraction).

regional government.

If data are readily available from the regional ICT infrastructure (e.g., from existing reporting dashboards), data collection is straight-forward. It is anticipated that new indicators will need new queries, possibly from additional data sets, consequently a newly configured means in the ICT infrastructure. It is a significant effort to compose such a means especially for composite indicators (i.e., combined end points). For instance, in the Basque Country, mortality data for chronic patients were not available because that requires the configuration of a new dashboard. It is critical to arrive at an agreed set of indicators swiftly to plan for local ICT configuration effort and meet ACT project deadlines.

## 6 CONCLUSIONS

The indicator is part of the ACT program that is related to the evaluation framework and engine. Obviously, the program has just started and comprises of many more elements that are being under development. The indicator framework is the result of many discussions in the ACT consortium. The framework now describes the domains and subdomains that are considered relevant for deploying and monitoring CC&TH. In close collaboration with work package leaders, we recently have defined a list of indicators that will be collected in the regions. The current list is ambitious and contains many indicators that are probably not (readily) available at the regions.

It is expected that most regions will not be able to provide information on most indicators during the life-cycle of this programme. However, they are the indicators that the medical community and policy makers expect regions to work towards. In the past, many programs have published over-optimistic results based on managing a highly selected group of patients unrepresentative of the general problem. This has led to a loss of confidence and trust by the medical community in such reports, which must now be

corrected.

The evaluation engine covers the process of data collection, analysis and reporting, as well as the required underlying technology. This can be offered by a data warehousing approach where ETL tooling support data collection, the data warehouse stores historical data, and BI tools can be used to report and monitor data. Nowadays many solutions support the connection to statistical tools such as R and may even provide the resources to run and store the analysis. We need to explore the requirements with respect to data collection, analysis and visualisation to select the right product and vendor.

As a result of the test transfer we observed many differences between regions in IT systems access, accessibility of the data elements, levels of granularity of the data, and in the care coordination processes (e.g. the recruitment process). Agreed and precise definitions of the indicators are required for consistent data collection across the regions. Moreover, the agreement on the level of granularity needs further in-depth discussion within the ACT program.

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