CASE STUDY

ICHOM International Consortium for Health Outcomes Measurement

# BUILDING NATIONAL OUTCOMES REGISTRIES IN THE NETHERLANDS: THE DUTCH INSTITUTE FOR CLINICAL AUDITING (DICA)

MARCH 2016

## WHAT YOU WILL FIND IN THIS CASE STUDY

The Dutch Institute for Clinical Auditing, or DICA, is a payer-funded, not-for-profit organisation in the Netherlands that facilitates the development and maintenance of national outcomes registries around medical conditions. Since 2009 DICA has established over 19 registries using a model that benefits clinicians, payers and most importantly, patients. This case study describes how DICA was formed and its role in fostering value across the Dutch health care system, including the business case for payer investment in outcomes registries, benefits to stakeholders and positive early results in patient outcomes improvement and cost reduction.

DICA

DUTCH
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FOR CLINICAL
AUDITING

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Corresponding Author: Jason Arora, MD, MPH; j.arora@ichom.org



International Consortium for Health Outcomes Measurement (ICHOM)
UK Registered Company FC03211. Registered address: Regus I 1 Eversholt Street I London, NW1 2DN I UK
US Company Headquarters registered as 501(c)3. Address: 14 Arrow Street, Suite11 I Cambridge, MA 02138 I USA

## BACKGROUND

As payers and providers attempt to reduce health care costs globally, many are looking to value-based purchasing as a promising solution. This approach begins with defining and collecting outcomes data that represents true success in health care. Once there is a critical mass of outcomes data to leverage, providers begin to drive quality improvement projects that raise the standard and lower the cost of care by reducing unnecessary events such as complications and re-interventions. Payers, similarly, can also begin to focus purchasing on the highest value services in the system, incentivise providers on key outcomes, and tailor their provider networks based on robust outcomes data.

In order to standardise data collection across providers, collate a statistically significant critical mass of data for analysis and align medical professionals on best practices, many countries have adopted the registry model. In some countries, such as the UK, registries are led by professional medical societies (e.g., The Royal College of Surgeons) and alliances (e.g. the Healthcare Quality Improvement Partnership), and the data is used primarily for quality improvement purposes with little or no payer involvement. In others, such as Sweden, registries are also utilised by payers. The latter approach is highly dependent on a collaborative working relationship and culture of transparency between payers, providers and professional medical societies. Where Sweden has succeeded, many others have found it difficult to cultivate an environment in which stakeholders join forces in such harmony. However, a clinician-led, payer-funded initiative in the Netherlands is setting a world-leading example in multi-stakeholder collaboration around value, with exciting early results in both outcomes improvement and cost reduction.

## PAVING THE WAY FOR VALUE IN THE NETHERLANDS

Historically, different health care stakeholders in the Netherlands created disparate sets of success metrics to measure performance. Despite pressuring clinicians to report on both process and outcomes metrics, payers and other stakeholders had no truly comparative data to leverage in discussions with providers. Indeed, negotiations with providers were conducted without any "hard data" on performance. However, in 2009, there was a growing interest amongst medical professionals to define and understand their own outcomes in order to lead the growing quality agenda in the Netherlands. This interest had escalated to the professional medical society level, who successfully began to push for standardised outcomes measurement in their respective medical conditions. The Association of Surgeons of the Netherlands (ASN), for example, were strong advocates of quality measures that are developed and interpreted by the surgeons themselves.

## THE FIRST NATIONAL OUTCOMES REGISTRY: THE DUTCH SURGICAL COLORECTAL AUDIT (DSCA)

With seed funding from two pharmaceutical companies and ongoing funding from the Dutch Ministry of Health, the ASN proceeded to develop the first national outcomes registry in the Netherlands: the Dutch Surgical Colorectal Audit (DSCA). Funding was required to define the outcome metrics, set-up and manage the registry, support data collection across provider sites, and analyse and report data back to stakeholders.

To define the outcome metrics, the ASN brought together a group of clinical and methodological experts in the fields of colorectal cancer surgery, oncology, pathology, and epidemiology. This group worked together for several months to develop a dataset that comprised process, structure, and outcome indicators. Further, case-mix variables and other clinical indicators (patient, tumor and treatment characteristics) were identified. Once the indicators were defined, hospitals were invited to collect these indicators and submit their data via a secure web portal at standardised regular intervals.

By 2011, the DSCA had full participation from all Dutch hospitals providing care for colorectal cancer, with the registry also being formally integrated into the national quality assurance policy of the ASN. In doing so, the DSCA had provided a clear blueprint for the successful development and implementation of an outcomes registry.

## PAYER INVOLVEMENT AND THE FOUNDING OF DICA

Encouraged by the promise shown by the DSCA model, a collection of Dutch health insurers – the Association of Health Insurance Companies – convened to discuss how best to respond to the wider push for outcomes measurement across the Netherlands. As this shift was being spearheaded by professional medical societies, it became clear that there would be strong engagement from clinicians across the country in collecting the outcomes data. Payers saw this as an opportunity for a more unified approach that facilitated valid comparison of "hard" outcomes data across providers - a potentially more insightful approach to reimbursement for services and restructuring of provider networks.

The Association of Health Insurance Companies decided to fund the creation of a not-for-profit organisation and central foundation of professional medical societies that would develop – at least to begin with – ten further outcomes registries based on the DSCA model. This body, the Dutch Institute for Clinical Auditing (DICA), would sit as a neutral enabler between payers, providers and clinicians to facilitate collaboration around outcomes data.

## DICA TODAY

Today, DICA maintains 19 national registries covering a wide array of medical conditions: from breast cancer to Parkinson's Disease (**Table 1**). The organisation itself has grown to include over 60 individuals across numerous disciplines, including analytics, clinical medicine, information technology, administration, and law (**Figure 1**).

### TABLE 1 | DICA'S REGISTRIES AND ASSOCIATED MEDICAL CONDITIONS

| Registry | Medical condition |
|---|---|
| Dutch Surgical Colorectal Audit (DSCA) | Colorectal cancer |
| National Breast Cancer Audit (NBCA) | Breast cancer |
| Dutch Upper GI Cancer Audit (DUCA) | Gastric and esophageal cancer |
| Dutch Lung Surgery Audit (DLSA) | Lung surgery |
| Dutch Surgical Aneurysm Audit (DSAA) | Aneurysm Surgery |
| Dutch Melanoma Treatment Registry (DMTR) | Melanoma |
| Dutch Lung Radiotherapy Audit (DLRA) | Lung cancer radiotherapy |
| Dutch Pancreatic Cancer Audit (DPCA) | Pancreatic cancer |
| European Paediatric Surgery Audit (EPSA) | Paediatric surgery |
| Dutch Audit for Treatment of Obesity (DATO) | Bariatrics |
| Dutch Audit for Carotid Interventions (DACI) | Carotid surgery |
| Dutch Hepatobiliary Audit (DHBA) | Liver cancer |
| Dutch Gynaecological Oncology Audit (DGOA) | Gynaecological oncology |
| Dutch Spine Surgery Registry (DSSR) | Spinal surgery |
| Cerebrovascular Audit Benchmark (CVAB) | Cerebrovascular accident (CVA) |
| Dutch Parkinson's Insight Audit (DPIA) | Parkinson's Disease |
| Dutch Breast Implants Registry (DBIR) | Breast implants |
| Dutch Gastrointestinal Endoscopy Audit (DGEA) | Gastrointestinal disease |

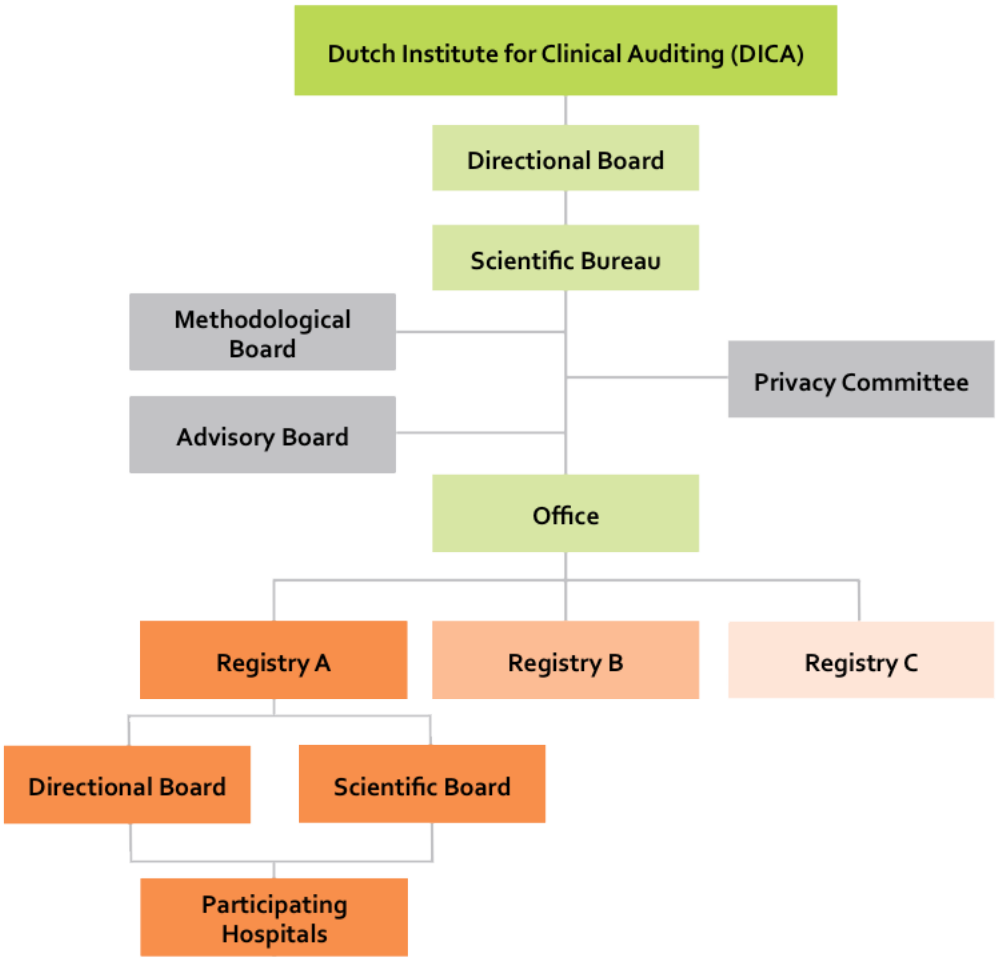



**Figure 1**: Organisational structure of DICA

## HOW DICA DEVELOPS OUTCOMES REGISTRIES

Based largely on the DSCA model, DICA now executes a standard process for developing outcome registries. Initially, it liaises with the relevant professional medical society to set up a Scientific Board of experts to define the dataset. This is undertaken with guidance from DICA, who form a Directional Board that sits in parallel withthe Scientific Board. DICA and the professional medical society then work with hospitals and medical professionals to drive adoption of the dataset and to facilitate the routine collection of outcomes data in clinical practice. The registry itself is managed by DICA, who performs risk adjustment and data analysis and report the data back to all stakeholders. DICA also forms a Privacy Committee to ensure that the data is protected at all times. See **Figure 2**.

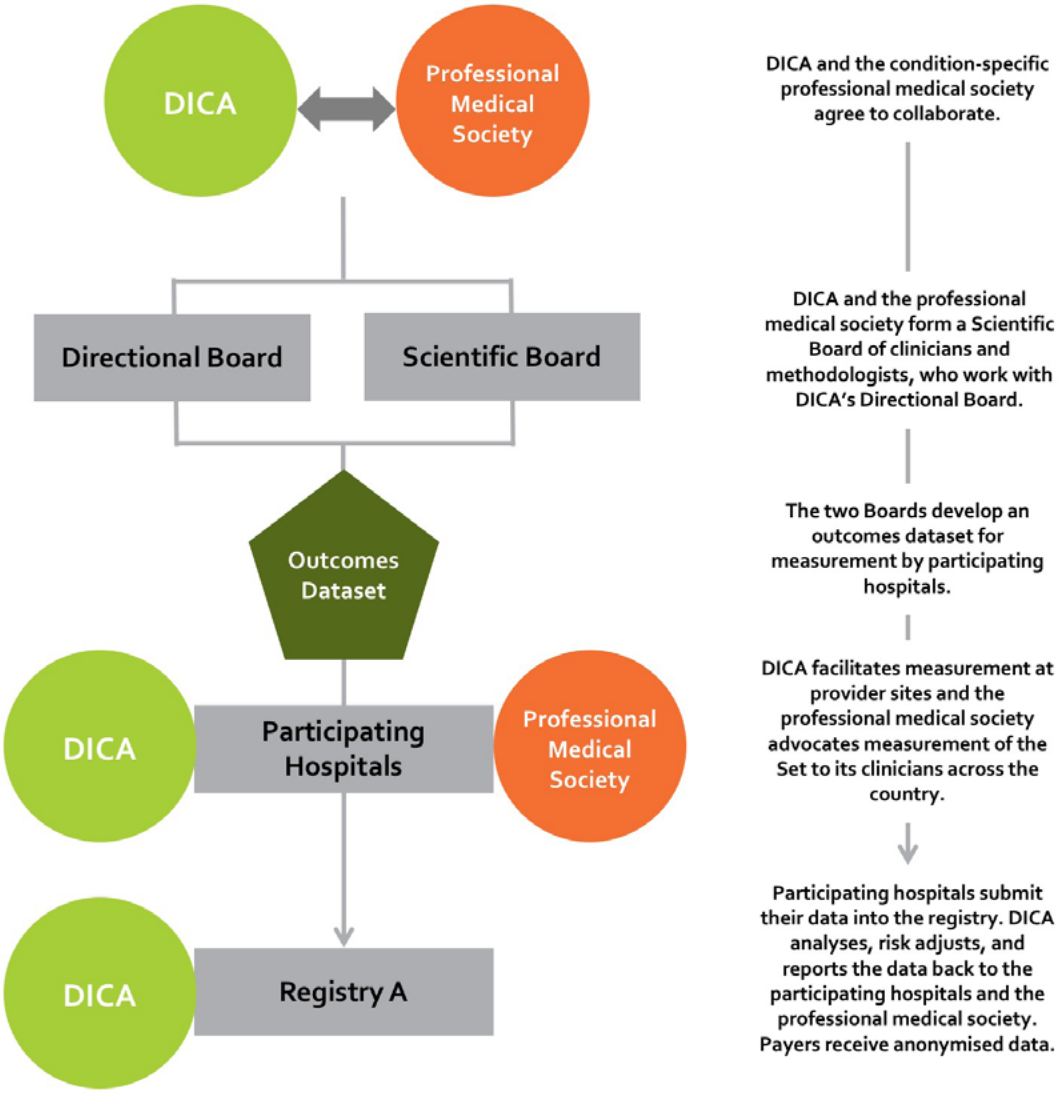



**Figure 2**: The process of forming a registry and the role of DICA and the professional medical society

Providers receive their own data back, professional medical societies receive aggregated data, and payers receive anonymised data. Payers are able to access the data once a year through an online "transparency portal", where hospitals choose which payers to deliver their data to. Hospitals can also select specific payers to view their dashboard results. However, most hospitals allow all payers to view their data. Participation in the registry is not mandatory, but non-participation typically leads to reductions in provider reimbursement of up to 20%.

In developing and maintaining outcomes registries, DICA performs five key activities:

### 1. Provide expert support

DICA provides clinical, epidemiological, methodological, logistical, technical and legal expertise across all registries through its central management structure. It also provides central implementation support by helping to reduce the administrative burden of data collection – for example, through the development of a user-friendly web portal for registry data submission.

### 2. Ensure data accuracy and privacy

DICA pre-defines the data format for submission, ensuring it is standardised across all implementing sites. It has also developed an accuracy module that alerts participants to erroneous and missing data. Finally, a third-party medical information management system de-identifies the data after submission and before it is received by DICA. This ensures that DICA only receives anonymised data for analysis.

### 3. Analyse data and provide dashboards

DICA performs risk-adjustment and full analysis on the data before reporting it back to participants in quality dashboards, on a weekly basis. These dashboards display results for process and outcome indicators, and baseline characteristics. This allows participants to compare their own results against other centres and national averages. Participant results are anonymised. See **Appendix Item 1** for some examples of DICA's quality dashboards.

### 4. Identify best practices

Based on reported data, DICA identifies the top-performing participants and seeks to identify and understand the processes that lead to their outcomes. Through this, it identifies best practices and works with professional medical societies to drive adoption of these best practices across hospitals in the Netherlands. For poorly performing hospitals, DICA convenes an independent audit committee to conduct a more comprehensive assessment and drive internal quality improvement. The identities of these hospitals remain confidential.

### 5. Foster communication between stakeholders

DICA organises an annual conference for providers, payers, clinicians, professional medical societies, government agencies and patient representatives to discuss the results from each registry. This enables cross-stakeholder discussions around value. In 2014, there were over 500 participants. DICA also publishes an annual report that displays the results of each registry. See **Appendix Item 2** for excerpts of DICA's 2014 annual report, and **Appendix Item 3** for photographs from DICA's 2014 annual conference.

## FUNDING MODEL FOR DICA'S OUTCOMES REGISTRIES

Funding for each DICA registry is divided into two phases over three years: the Pilot Phase in years 1-2 and the Structural Phase in year 3 (**Figure 3**). The Pilot Phase involves defining the dataset and initial implementation, and the Structural Phase involves ongoing measurement and reporting once the infrastructure is firmly in place.

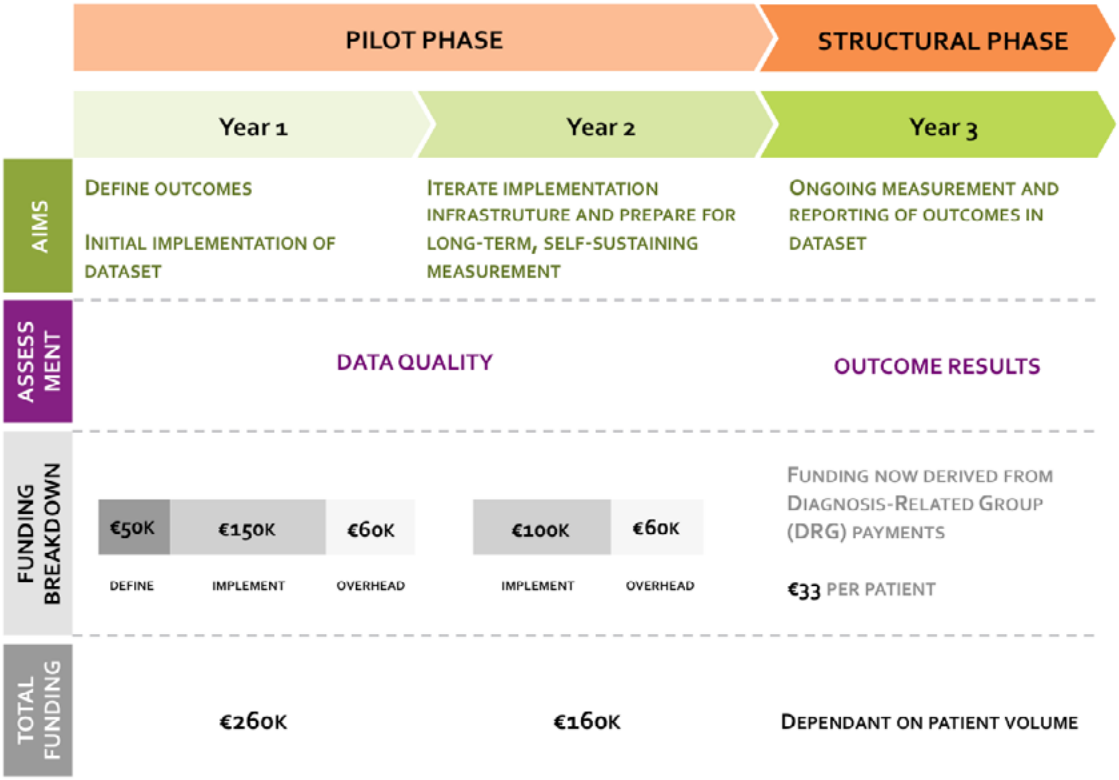



**Figure 3**: The development of a DICA registry over 3 years, including funding breakdown in Euros

Each individual hospital participating in a registry must make an initial investment and leverage its own internal resources for measurement of an outcomes dataset. This involves local project management, data collection infrastructure, IT calibration, and change management. Once the registry enters the Structural Phase, the costs of measurement are embedded in Diagnosis-Related Group (DRG) payments from payers, which are fixed, prospective payments for the care of patients based on diagnosis. If providers fail to measure these outcomes adequately, they risk losing reimbursement for the collection of this data.

## RESULTS ACHIEVED THROUGH DICA'S REGISTRIES

DICA's primary aim is to drive positive results in both outcome measures and cost reduction. The results presented in **Table 3** show both process and outcomes improvements for colorectal cancer nationally. Corresponding cost savings through reductions in complication rates were also observed between 2010 and 2012, as described below.

## OUTCOMES IMPROVEMENTS

**Colorectal cancer**

Between 2009 and 2014, 56,509 patients undergoing any type of resection for colorectal carcinoma were registered by all 92 hospitals providing colorectal cancer care in the Netherlands. Some patients (1.2%) were excluded from analyses due to incomplete records, whilst those included were corrected for differences in case-mix. Improvements in several process and outcome indicators were observed over the 5-year period. For example, there was a reduction in all complications following surgery from 33% to 30% for colon cancer, and 40% to 37% for rectal cancer. Complications included surgical, pulmonary (e.g. pulmonary embolism), cardiac (e.g. myocardial infarction), neurological (e.g. cerebrovascular accident) and infection-related (e.g. urinary tract infections) complications. Re-intervention rates had also reduced by 4%, from 17% to 13% percent. Overall in-hospital and 30-day mortality rate between 2009 and 2014 had reduced from 5.8% to 2.7% for colon cancer, and from 3.8 to 1.1% for rectal cancer – a reduction of between two and three-fold.

### RESULTS ON PERFORMANCE INDICATORS FOR COLORECTAL CANCER

| | Colon cancer | | Rectal cancer | |
|---|---|---|---|---|
| | **2009** | **2014** | **2009** | **2014** |
| **Process measures** | | | | |
| Cases discussed in preoperative MDT | 46% | 94% | 80% | 99% |
| Total colonoscopy | 61% | 84% | 76% | 88% |
| Preoperative MRI | | | 80% | 92% |
| ≥10 lymph nodes in sample | 73% | 92% | 58% | 84% |
| Mean hospital stay (days) | 13 | 9.1 | 15 | 12 |
| **Outcomes measures** | | | | |
| All complications | 33% | 30% | 40% | 37% |
| Re-intervention | 15% | 10% | 17% | 13% |
| Anastomotic leakage for patients undergoing primary anastomosis | 7.5% | 5.9% | 11.5% | 9.3% |
| Circumferential resection positive margin | N/A | N/A | 14% | 5.2% |
| In-hospital mortality and 30-day mortality | 5.8% | 2.7% | 3.8% | 1.1% |

**Breast cancer**
The National Breast Cancer Audit (NBCA) started in 2011 and similar trends have been observed, with improvements in both process and outcome measures. Outcomes improvements include a reduction in tumor-positive margins for both invasive breast cancer and ductal carcinoma in-situ (DCIS) following treatment (6.1% to 4.6%, and 25% to 19%, respectively), and an increase in immediate breast reconstruction following ablative surgery for both disease subtypes (15% to 20% and 39% to 44%, respectively).

TABLE 3 | RESULTS ON PERFORMANCE INDICATORS FOR BREAST CANCER

| | 2011 | 2014 |
|---|---|---|
| **Process measures** | | |
| Pre-operative MDT | 81% | 98% |
| Post-operative MDT | 90% | 98% |
| Time to operation ≤ 5 weeks | 80% | 88% |
| Pre-operative systemic treatment for invasive breast cancer | 10% | 12% |
| **Outcomes measures** | | |
| Tumor-positive margins for invasive breast cancer without primary systemic treatment | 6.1% | 4.6% |
| Tumor-positive margins for ductal carcinoma in-situ (DCIS) | 25% | 19% |
| Immediate reconstruction after ablative surgery for invasive breast cancer | 15% | 20% |
| Immediate reconstruction after ablative surgery for DCIS | 39% | 44% |

## COST REDUCTION

**Colorectal cancer**
Outcomes data from 6,700 patients across 29 hospitals between 2011 and 2012, representing approximately 1/3 of the Dutch national volume of patients treated for colorectal cancer, revealed that complications were associated with a significant increase in cost of patient care. These complications occurred after 1/3 of all procedures (over 60% of these were severe complications requiring re-intervention, a post-operative hospital stay of at least 14 days, or resulted in death). Nearly 1/3 of total hospital costs for colorectal cancer patients were spent on managing complications. Minor complications (occurring within 30 days after intervention) resulted in a 26% increase in cost compared to patients without complications, with severe complications resulting in a 196% increase in cost. The total cost for patients without complications was €62.6M. Mild complications resulted in nearly a €2M (2%) increase in total cost, and severe complications resulted in a €25.8M (29%) increase in total cost. Per patient increases in cost were 47% for mild complications, and 109% for severe complications. The most expensive complication, after adjusting for other complications, was thromboembolism. This resulted in an increase in cost of €5,141 per patient. See **Figure 4** for cost comparisons of colorectal cancer surgery patients with no complications, mild complications, and severe complications.

Since the start of the DSCA registry, complication rates for colorectal surgery patients have reduced (**see Figure 5**), and are expected to continue to do so as quality improvement project loops are completed. Since

complications represent a significant cost burden, this fall in complication rates represents a significant reduction in costs. For example, DICA reported a reduction in severe complication rates after implementation of the DSCA audit from 25% to 20% between 2010 and 2012. As described, in DICA's 2015 study by J.A. Govaert and colleagues , if a hospital were to perform 100 colorectal cancer procedures per year and had an average severe complication rate reduction of 10% between 2010 and 2012, this would lead to a saving of €120,000 (one major complication is associated with a €16,059 increase in cost). Subtracting the cost of participation in the DSCA (€13,350 per year), the overall profit for a single hospital would still be over €80,000. This provides a strong business case for outcomes measurement implementation.

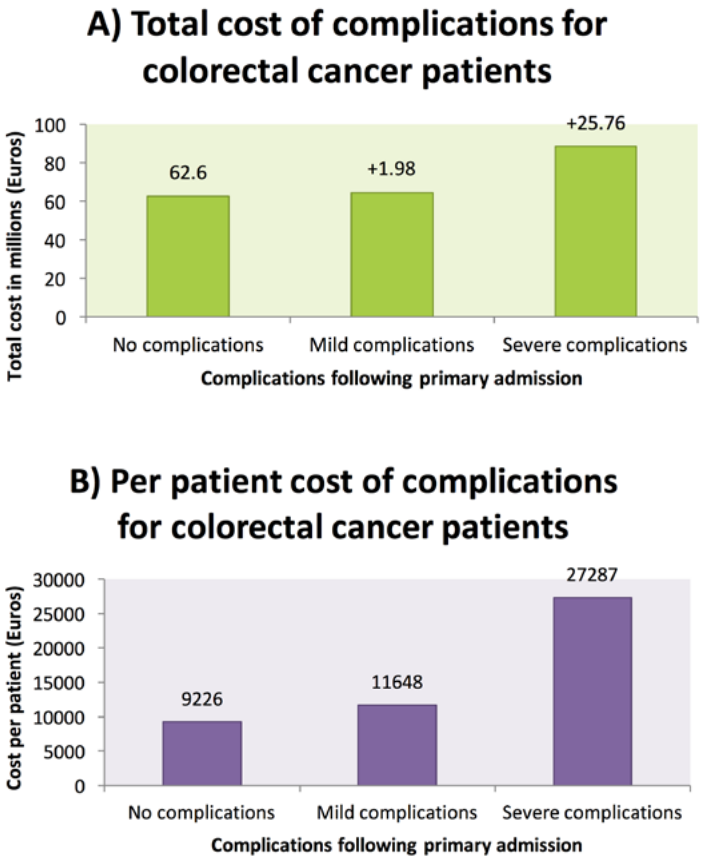



**Figure 4**: Comparison of cost of complications following primary admission for colorectal cancer patients. A: Total cost of for colorectal cancer patients with no complications, mild complications and severe complications. B: Per patient cost of for colorectal cancer patients with no complications, mild complications, and severe complications.

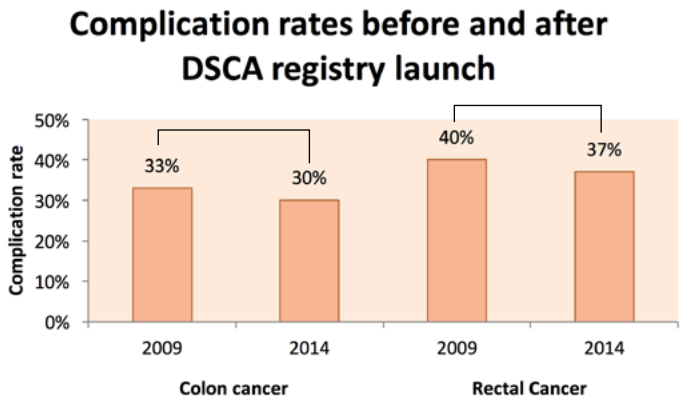



**Figure 5**: Complication rates (all complications) for colon and rectal cancer before and after launch of the DSCA registry.

## HOW DO THE DIFFERENT STAKEHOLDERS BENEFIT FROM THIS MODEL?

**Benefits for payers**

The availability of robust data on performance is extremely valuable to payers. In the short term, quality indicators are standardised across providers to facilitate comparison. In the medium term, payers can use this data to steer patients toward the providers that deliver the most value for their patients and tailor their networks based on quality. In the longer term, payers can reduce the cost of care by driving improvements in outcomes and care delivery. Further, payers can develop novel value-based payment models in which reimbursement is, at least partly, based on the outcomes achieved.

**Benefits for clinicians**

Clinicians have a clear opportunity to lead the growing push for global outcomes transparency via the development of outcomes datasets, ensuring collection and reporting of only the most clinically relevant data. Further, clinicians are able to track their own performance, compare themselves and their institutions to others, and – most importantly – improve the care that they provide to patients. This is a useful learning opportunity that fosters quality improvement at the grassroots level. Previously, metrics were defined and mandated by non-clinicians, resulting in a gulf in understanding and relevance around the indicators being measured.

**Benefits for providers**

The routine reporting of outcomes data is an incredibly rich source of targeted internal quality improvement opportunities, which helps providers improve their results and develop care pathways that are geared towards key outcomes. Hospitals that perform well can use their data as a promotional tool to gain a competitive advantage over other hospitals providing the same care. Those that do not perform well are in possession of key data that will help them improve.

## KEY SUCCESS FACTORS

1. **Leading role of clinicians and professional medical societies in defining and agreeing on outcomes data sets**. This approach supports clinician commitment and ownership, resulting in high participation rates, high-quality data in the registry, and the completion of quality improvement loops.

2. **Seed funding from payers or another stakeholder (e.g. life sciences)** is vital to launch the initiative and sets the tone for ongoing outcomes measurement and transparency as a financial driver of high quality health care.

3. **DICA an objective and neutral facilitator.** This catalyses the initiatives by traversing challenges related to legal, technical, methodological, logistical and most importantly – political – aspects of setting up and maintaining an active registry. The centralisation of resources also reduces costs for individual participating sites. Further, as DICA have nothing to gain from the data, they are best positioned to analyse and report it.

4. **Strong incentives for providers to participate.** The risk of losing reimbursement is a strong incentive to engage in the registries. This is more effective than issuing penalties.

5. **A web-based data collection system** is an important component of the audit as it facilitates easy and timely registration of patient data.

6. **Rapid online feedback** on outcomes for individual hospitals presented in relation to national averages and against the results of other anonymised hospitals provides regular, useful and tangible output from participation efforts.

7. **Platform for all stakeholders** to discuss results and quality improvement targets at annual

## WHAT TO EXPECT NEXT

DICA will continue to push the boundaries of value-based health care in the Netherlands through the generation of robust outcomes and financial data, and – increasingly – patient-reported outcomes data. Indeed, there is an increasing focus on developing outcomes datasets that are patient-centric. As part of this, DICA are collaborating with the International Consortium for Health Outcomes Measurement (ICHOM) to develop globally agreed ICHOM "Standard Sets" of patient-centered outcomes to facilitate international benchmarking around medical conditions, with a view to align national and international outcomes registries with these Standard Sets.

In outcomes measurement itself, DICA are helping hospitals reduce the burden of data collection through automated coordination of outcomes data that is otherwise collected and stored in different locations. This is key to reducing internal resource requirements of individual hospitals, which can still be a short-term barrier to outcomes measurement implementation. DICA are also continuing to develop more sophisticated dashboards for clinicians and hospitals to provide further insight into results for quality improvement and benchmarking.

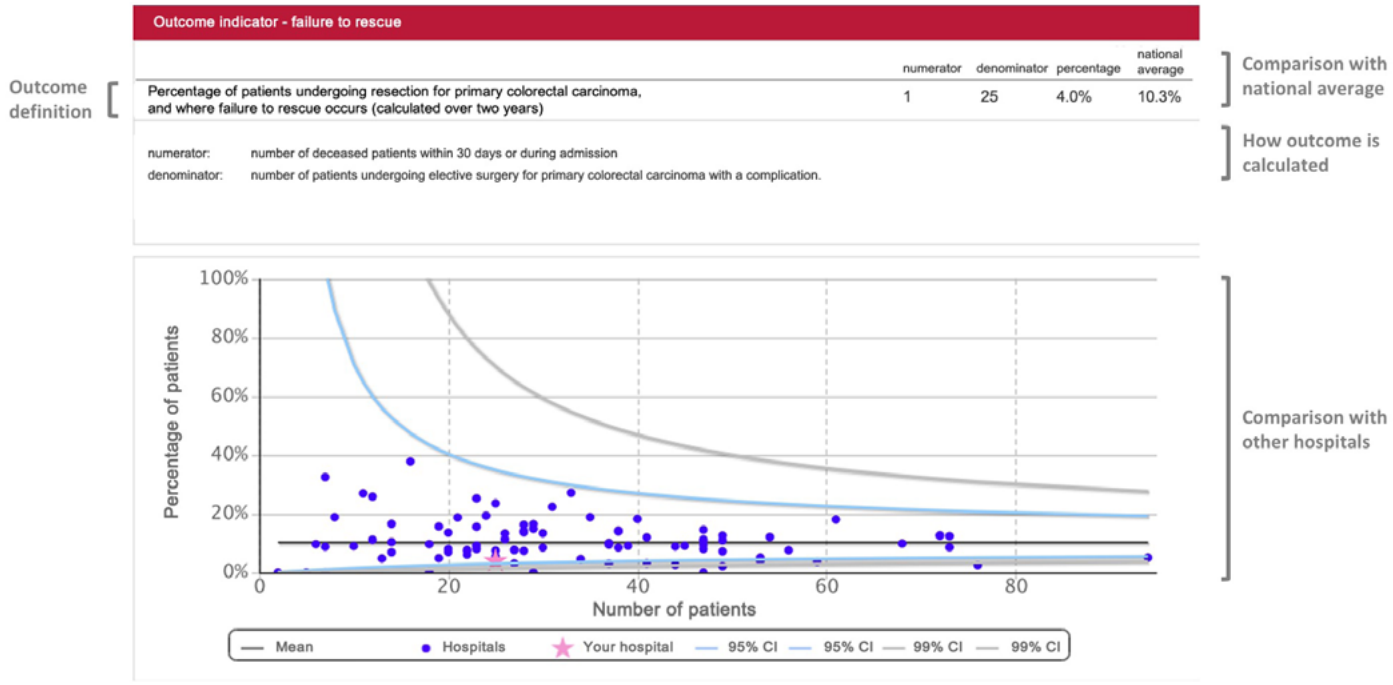
Looking ahead, Dutch payers will likely look to leverage DICA's national outcomes registries to adapt their payment models, with an increasing focus on outcome-based reimbursement. This will lay the foundation for value-based purchasing. Together with more cost-efficient care pathways developed through the analysis of outcomes data, the Netherlands is well on its way to developing a high-value model that other global health care systems will aspire to.

## SOURCES


- Interviews with Nicoline van Leersum, Annelotte van Bommel, Eric Hans Eddes; all DICA representatives. Wim Smit, MRDM (ICT-partner of DICA) representative
- DICA annual report 2013
- Kwaliteit vanuit financieel perspectief: beperkingen en kansen, presentation at 2014 DICA conference by Prof. Rob Tollenaar (DICA), Johannes Govaert (DICA) and Wouter van Dijk (X-IS)
- A case-based study on value based reimbursement for spine surgery and potential implementation in the Netherlands, Master thesis of Drs. Lotte M.E. Berghauser Pont, Nyeonrode Business Universiteit, 2014
- The Unit Costs of Inpatient Hospital Days, Outpatient Visits, and Daycare Treatments in the Fields of Oncology and Hematology Siok Swan Tan et al. Erasmus Universiteit Rotterdam, Institute for Medical Technology Assessment, Rotterdam, The Netherlands
- Van Leersum, N. J., et al. "The Dutch surgical colorectal audit." European Journal of Surgical Oncology (EJSO) 39.10 (2013): 1063-1070.
- Costs of complications after colorectal cancer surgery in the Netherlands: Building the business case for hospitals." Govaert, J. A., et al. "European Journal of Surgical Oncology (EJSO) (2015).

## APPENDIX

**Item 1:** Examples of DICA's quality dashboards for colorectal cancer, which includes information on both outcomes and cost for individual patients, departments and hospitals.




**Item 2:** An excerpts from DICA's 2014 Annual Report (in Dutch). Results are reported from each individual registry with key statistics and visual graphics for ease of understanding.


**Item 3:** Photographs from DICA's 2014 annual conference, clockwise from upper left – (A) DICA's Director and former Gastrointestinal Surgeon, Eric Hans Eddes, (B) Michael Porter, Professor at Harvard Business School and Co-Founder of ICHOM, (C) Panel of experts discuss the use of PROMs in outcomes registries, (D and E) Delegates from numerous stakeholders attend presentations and engage in discussions throughout the two-day event.

www.ichom.org
ichomteam@ichom.org