Measuring what matters: using claims data to evaluate healthcare outcomes and volume-outcome relationships

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English summary

Healthcare systems are facing persistent challenges, such as dealing with the ageing population, increases in chronic diseases, technological advances, and increasing healthcare costs. Reducing costs, meeting increased healthcare demand with fewer professionals as well as continuous improvement of quality, are needed to face the challenges in our current healthcare system. Therefore, delivering high-quality care efficiently is key and top-priority for governments and clinical leaders. Challenges faced by the healthcare sector make it imperative to make optimal use of existing data for broader insights and improvements. In addition, a digital transformation in healthcare is a long overdue necessity. Several Dutch national programs were started to overcome these challenges.

The aim of this thesis was to evaluate whether claims data can be used to evaluate healthcare outcomes and volume-outcome relationships and to evaluate national trends in healthcare. Furthermore, an evaluation of the potential of using existing data for national quality registries was performed.

Subjects of this thesis related to the Integral Healthcare Agreement (IZA)

Every four years, new healthcare agreements are developed in the Netherlands. In 2022 the Integral Healthcare Agreement (Integraal Zorgakkoord [IZA]) was agreed upon by all relevant stakeholders.
The IZA encompasses several subjects which are related to this thesis:

- Appropriate care is value- and evidence-based, and involves shared-decision making between healthcare professionals and patients **[chapters 2, 3 and 4]**
  - Increased focus on outcome information, which is relevant for patients and enables patients to choose their treatment and their healthcare institution
  - Outcomes will be transparent for 50% of the disease burden in 2025
  - Increased efforts to gain knowledge on the effectiveness of care (healthcare evaluation) and to de-implement care, which is of low value
- Centralization of care: for complex oncological procedures, hospital volume thresholds around 50-100 will become the standard **[chapter 2 and 3]**
- Electronic exchange of data will become the standard, preferably via the Collect Once Use Many Times (COUMT) principle **[chapter 6]**

Claims data can be used to evaluate healthcare outcomes

In 2013 the Association of Dutch Health Insurers composed a Top 30 list of diseases and conditions for which outcomes should become transparent for patients and health insurance companies. Doctors, patients and health insurance companies agreed on indicators for quality of care for many disease areas. Transparency of healthcare quality started to expand. Regrettably, transparency in certain disease areas exhibited minimal advancement, despite the numerous dialogues among medical experts, health insurers, and patient advocacy organizations.

For example, for prostate cancer and lumbar disk herniation there were several attempts to start national quality registries (NQRs) and the ICHOM (International Consortium for Health Outcomes and Measurement) standard sets for outcomes for these conditions had been available for years. Yet, in 2017 no NQRs, with outcomes relevant for patients, were available for prostate cancer and lumbar disk herniation. The question whether claims data could be used to measure and describe outcomes of care for these conditions, was the start of the work conducted in this thesis.

We evaluated which of the ICHOM outcomes for localized prostate cancer and low back pain could be studied using claims data. We demonstrated that claims data can be used to evaluate urinary incontinence (UI), an important outcome measure for patents with prostate cancer undergoing radical prostatectomy (RP) **[chapter 2, 3]**. We found average national UI rates after radical prostatectomy in the range from 26% (urinary incontinence first study [2014-2015]; **chapter 2**) to 33% (urinary incontinence second study [2016-2020]; **[chapter 3]**). Our first prostate cancer study, published in 2018, demonstrated that the risk of UI was 30% lower when RP was performed in hospitals conducting more than 100 RPs per year as opposed to hospitals performing fewer RPs **[chapter 2]**. This first study was based on patients who had/underwent surgery between 1st of October 2014 and 30th of September 2015. The study results led to a stepwise increase in the national volume threshold for RP per hospital. The rationale behind this increase was predicated on the assumption that increasing minimum annual hospital RP volumes would yield improved functional and oncological outcomes. A second, subsequent, study was performed for patients operated in the period 2016 to 2020 to investigate the actual changes in RP hospital volume, and the trends in national and per-hospital rate of UI after RP **[chapter 3]**. A large variation in outcomes between hospitals was shown; five-year averages of UI per hospital varied from 19% to 85% **[chapter 3]**. While some high-volume centers also reported remarkably high UI outcomes, highest variation and highest UI rates were observed in low volume hospitals. Future studies are needed to evaluate which additional measures are needed to reduce variation in outcomes and to identify the optimal volume threshold per hospital and per surgeon.

Several undesirable outcomes after lumbar disk herniation surgery can also be studied using claims data. Studied outcomes were: percentage of patients with reoperations, nerve root block, opioid use and the combined outcome of these three outcome measures. Patients operated between 1st of July 2015 and 30st of June 2016, had the following undesirable outcomes: weighted mean of reoperations was 7.3%, nerve root block 6.7% and opioid use 15.6%. In total, 23.0% of patients with lumbar disk herniation had one or more undesirable outcomes after surgery and a large variation was observed between the different hospitals for all outcome measures **[chapter 4]**.

When no NQR is available, research based on claims data (when appropriately used) can contribute to the first insights and trends in the outcomes of care and the variation in outcomes amongst providers. When an NQR is in place, adding claims data to NQRs, can deepen our knowledge about longer-term outcomes of treatments, as most NQRs usually limit their data collection until one year after treatment.

Claims data can be used to evaluate volume-outcome relationships

Even though the literature is unambiguous, many European countries have not yet implemented policies towards centralization of radical prostatectomies (RP), except for the Netherlands and UK. In some European countries specialized prostate cancer centers with high patient volumes do exist. A major push for the centralization of RP in the Netherlands came from the results of our first nationwide study on urinary incontinence after RP **[chapter 2]**. The minimum volume threshold for radical prostatectomy in the Netherlands increased from 20 procedures annually until 2017, to 50 in 2018, and 100 from 2019 onwards. In our studies **[chapters 2 and 3]** we concluded that there is a relationship between hospital volume and urinary incontinence 12-15 months after RP. Over the years 2014 and 2015, patients operated in a hospital with ≥100 RP per year had a 30% lower risk on urinary incontinence than patients operated in low volume (<100 RP) hospitals. Over the years 2016-2020, patients operated in a hospital with >120 RP per year had a 52% lower risk on urinary incontinence than patients operated in low volume hospitals (≤120 RP).

We concluded that although the risk of post-RP urinary incontinence is lower for patients operated in high-volume hospitals, the rate of urinary incontinence on a national level did not decrease significantly in two years of centralization **[chapter 3]**. Other factors might have contributed to the non-significant decrease of the national rate of post-RP urinary incontinence, such as the increasing age of patients who had surgery in the study period. Non-measured factors, such as volume per surgeon and tumor stage, may also have contributed to the non-significant reduction of national post-RP urinary incontinence rates.

Despite the centralization of RP, a striking variation in outcomes after RP remained between all hospitals, even for those with relatively high RP volume **[chapter 3]**.

We hypothesize that when outcomes are not measured, large differences in outcomes between hospitals will persist. We suggest that a hospital volume threshold should always be accompanied by measuring outcomes, increased audit and feedback through Quality Assurance Programs (QAPs) and higher per-surgeon volume thresholds **[chapter 3]**.

In addition, one could also question whether an increase of the RP volume threshold in the Netherlands, has led to real or pseudo concentration of RP. Data of the National

Transparency Register shows the number of urologists per hospital performing RP, this number is constant over the years since it was measured; 60 urologists performing RP in 2018 and 62 urologists in 2021.

Claims data can be used to explore public health trends

Most NQRs cover condition-specific areas and are not suited for investigating national health topics in a broader perspective. Yet, there are several sources of existing data available for healthcare research. Claims data for example can be used to explore trends on a national level for a plethora of healthcare domains, such as end-of-life treatments or the use of opioids.

The importance of balanced opioid prescriptions practices was emphasized by the opioid epidemics in the US and Canada, facing a serious opioid misuse epidemic resulting in massive overdose mortality. In Europe, including the Netherlands, the medical use of opioids (mainly oxycodone) has also increased since 2009 and many questions on topics, such as the number of long-term users and the prescribers, still remained to be answered. **Chapter 5** focuses on evaluation of the extramural prescription of opioids in the Netherlands. We demonstrated that by exclusively using claims data, relevant information for healthcare professionals and policymakers about opioid use and prescription, can be acquired **[chapter 5]**. The yearly number of opioid users increased from 650,864 in 2010 to 1,010,474 in 2017 **[chapter 5]**. This increase was mainly driven by an increase in oxycodone prescriptions. We found that elderly and female patients most frequently used opioids. The ratio of short- versus long-term opioid users remained steady during the research period, with opioids being used for four months or longer in 21% of cases. General practitioners prescribed the largest share of opioids, but a growing number of prescriptions originated from medical specialists **[chapter 5]**. This suggests that claims data can also be used to explore trends on a national level for many other healthcare domains.

Barriers in working with claims data

The Netherlands is still lagging behind in effectively (re-)utilizing routinely collected health data for research purposes. A limited number of Dutch research papers using claims data has been published. We encountered several barriers in working with claims data during the research period of this thesis. Regrettably, the Netherlands has adopted an exceptionally strict interpretation of the General Data Protection Regulation (GDPR, in Dutch: AVG), leading to obstacles in accessing patient data for scientific research.

Existing clinical data can be reused for national quality registries

National quality registries (NQRs) are suitable for quality measurements, however they still have a disadvantage: a substantial administrative burden (double registrations) exists, which is related to gathering the data for NQRs. This could partly be explained by shortcomings in digital systems, which is perceived as a barrier for the potential success of NQRs. The impossibility of exchanging data between hospitals with different electronic health record (EHR) systems and the administrative burden of registration both should be more firmly on the political agenda. We investigated the potential of the use of clinical information models (CIMs) for data collection for NQRs.

CIMs can be seen as building blocks collecting different data elements. These building blocks are needed for multiple reuse of data and were first introduced in the Netherlands around 2010. The potential of using existing CIMs (also called clinical building blocks) in EHR systems for data collection for national quality registries is high. The average percentage of data elements for NQRs that can be captured from EHR systems by using existing CIMs is 83% **[chapter 6]**. This means that when CIMs are implemented, the administrative burden of healthcare professionals for NQRs can potentially be meaningfully reduced.

Conclusion

The overall aim of this thesis was to contribute to the body of knowledge whether it is possible to evaluate healthcare outcomes and volume-outcome relationships by using claims data. This thesis shows that claims data indeed has the potential to be used to measure outcomes of care, to evaluate quality of care by quality improvement cycles, and to evaluate trends in healthcare on a national and local level. Even volume-outcome relationships for certain procedures can be studied by using claims data. The knowledge that stems from this thesis, can be transferred to other healthcare domains and other diseases, and in this way contribute to improving outcomes for patients. Transparency of hospital-specific outcome information is a prerequisite for the continuous process of quality improvement and it is a legal right for patients to be informed about differences in quality of care per hospital.

Recommendations

The Dutch Integral Healthcare Agreement (In Dutch: IZA) has several ambitious goals for the coming years. Based on this thesis, several recommendations are made, which will support these IZA goals and benefit patients:

Appropriate care:

- Develop and implement NQRs, that include standard sets of outcomes that matter to patients, at least for those conditions with significant health burden and/or societal impact such as prostate cancer and lumbar disk herniation.

- Reconsider the strict interpretation of the GDPR (AVG in Dutch) and make claims data available for scientific research, more specifically the study of healthcare outcomes.
- Make use of existing data, such as claims data, to evaluate healthcare outcomes for more procedures, diseases and conditions. This reduces the administrative burden for healthcare professionals.

Centralization of care:

- Centralization of specific care can indeed increase the quality of care. When adopting centralization however, this should always be based on a scientific analysis of its effects. Centralization should not be a goal in itself, the goal is to improve outcomes.
- When volume thresholds are installed, it should be accompanied with measuring of outcomes.
- Centralization of care should be adapted to the specific procedure; procedures with high complexity in surgery only (such as radical prostatectomy), should be centralized around the best surgeons.

Electronic exchange of data:

- The five most used clinical information models (CIMs) should be implemented in all healthcare domains in the Netherlands while following the ‘Collect Once Use Many Times’ (COUMT) paradigm. The code- and value lists (such as the Operations Thesaurus) related to these five CIMs should also be implemented nationwide.
- Adherence to (inter)national code lists is a sine qua non for national implementation of CIMs and reuse of data.
- All national programs for data reuse should be in alignment with the COUMT-paradigm, more specifically a focus on multiple instead of single reuse of data.