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

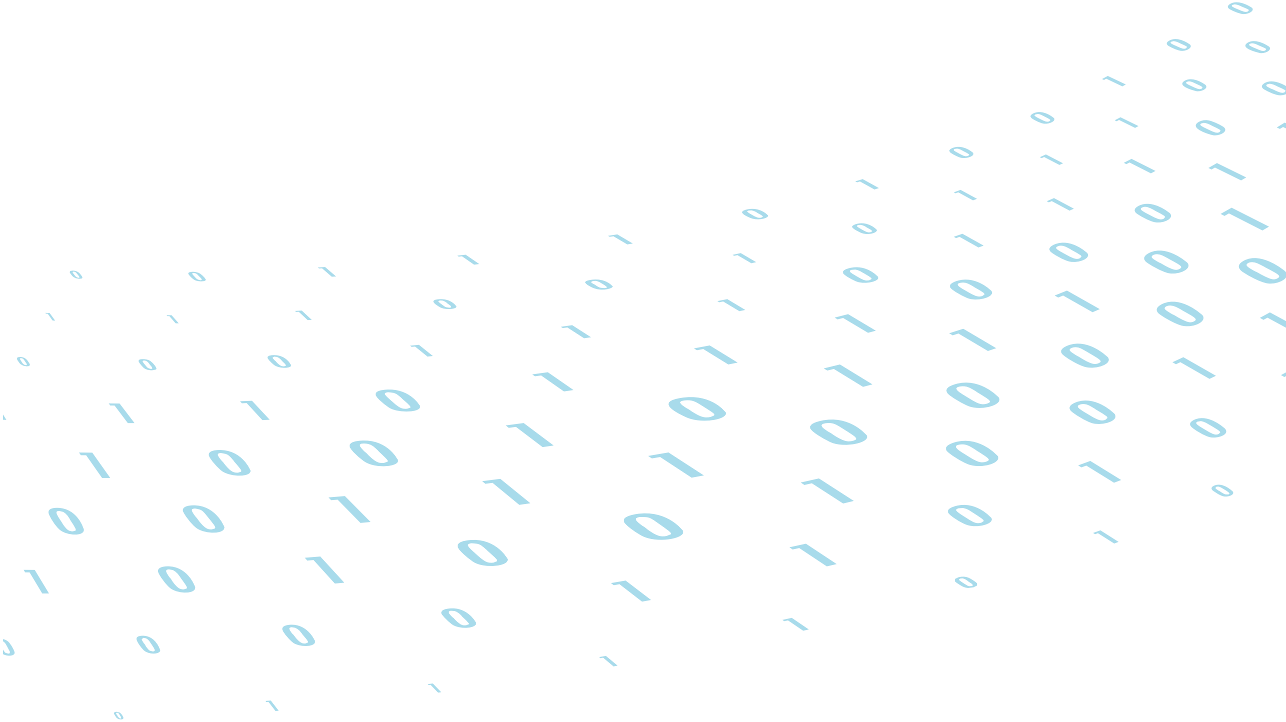
Schepens, M.H.J.

Citation

Schepens, M. H. J. (2024, February 29). *Measuring what matters: using claims data to evaluate healthcare outcomes and volume-outcome relationships*. Retrieved from https://hdl.handle.net/1887/3719801

CHAPTER 1

General introduction and thesis outline



1

General introduction and thesis outline

Aim of this thesis

The overall aim of this thesis is to contribute to the body of knowledge whether it is possible and useful to measure and improve quality of healthcare by using data that have already been collected for other purposes, so-called secondary data.

Challenges to the healthcare system

Since many years the sustainability of healthcare systems is tangible. Healthcare systems are facing persistent challenges, such as dealing with the ageing population, increases in chronic diseases, technological advances, and increasing healthcare costs.[1] At the same time, there is reduced availability of personnel. The performance of a healthcare system has a strong impact on a population's health. When health services are of high quality and are accessible to all, people's health outcomes are better. Many factors outside the health system also influence health status, notably income, education and the physical environment in which an individual lives.[2] In order to improve the sustainability of our healthcare system, transformation is inevitable. Reducing risks, providing safety, reducing costs, meeting increased healthcare demand with fewer professionals and also continuous improvement of quality are needed to face the challenges in our current healthcare system.[3]

Measuring quality of care

The World Health Organization uses the following definition: "Quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes. It is based on evidence-based professional knowledge and is critical for achieving universal health coverage."[4]

In order to be able to increase quality of care, measuring the quality of care and providing this information on different levels in healthcare, from macro (government, insurers, patient organizations, medical specialist organizations), meso (healthcare institutions) to micro (individual doctor and patient) is essential. Measuring quality of care is a prerequisite for tempering the rising healthcare costs while improving the quality of the delivered care.[5]

The first ideas of measuring quality of care date from the 19th century. The British doctor Sir Thomas Percival (1740-1804) proposed the idea of a hospital register to help doctors improve the quality of care.[6] A few decades later, Florence Nightingale (1820-1910), a reformer, statistician and nurse, called the lady with the lamp but perhaps less known also the lady with the data, systematically collected data of patients. She thus learned that poor sanitary practices were the main culprit of high mortality in hospitals and her work in statistics saved thousands of lives. Also, dr. Ernest Codman (1869-1940), an American surgeon, stated that evaluating outcomes of care in every patient is an intrinsic need and responsibility of every health care professional.[7] Codman is considered the founder of quality registries that have emerged internationally since the end of the 20th century.[8]

Practice variation in healthcare

Decades before national quality registries started to emerge, information on differences in healthcare service delivery became available. John Wennberg (1934) is the pioneer of unwarranted variation in the healthcare industry. He documented the geographic variation in the healthcare that patients received in the United States. In 1988, he founded the Darmouth Institute for Health Policy and Clinical Practice which addressed unwarranted variation in healthcare. Using claims data, Wennberg demonstrated that regional healthcare variation was not due to differentials in morbidity nor preference-based choices, but that it was partly due to healthcare supply itself. More services were not necessarily associated with better outcomes.[9 10] A few other countries, such as the UK, also began publishing a series of healthcare variation studies. However, in general, most countries did an do not have clear, valid and reliable insights into the geographic distribution of the use, costs and outcomes of healthcare, or into trends over time.[11] In the Netherlands, the first reports on healthcare variation in the 1990s were also based on claims data.[12] Although in general, claims data are not registered with the aim of improving quality of care and can also miss essential clinical characteristics of patients possibly explaining some practice variation, they were a good start for national discussions and a kick-off for quality registries.[13]

Volume-outcome relationships

One of the most researched cause of medical practice variation is the inverse relationship of hospital or surgical volume on the morbidity and mortality after high complex surgical procedures. Based on Medicare claims data John Birkmeyer, one of the pioneers of outcomes research, published data in the New England Journal of Medicine 20 years ago, demonstrating that volume was a proxy for quality of care for a number of complex cancer surgeries.[14] Since then, many studies have been published evaluating variation in outcome between procedures performed in high and low volume hospitals and by high and low volume surgeons.[15] In the Netherlands the volume-outcome debate on complex surgical procedures led to the development of quality standards with minimal volume criteria for these procedures and national quality registries, also called clinical audits, to gain further insight in the reasons behind variation in surgical outcomes and improve these outcomes by providing benchmarked feedback to the surgical teams in Dutch hospitals.

National quality registries

National quality registries (NQRs) are organized systems that collect data on patients diagnosed with a disease or condition or who undergo a certain procedure.[16] NQRs monitor quality of care and provide feedback on health outcomes, processes and structures. Thus, they may serve as platforms for generating hypotheses of underlying reasons for quality variation, interventions to improve quality of care as well as being platforms for research.[17] Benchmarking is an excellent way to learn from practices proven to have the best outcomes in order to improve the overall quality of care. The desired outcomes of interventions are the results of high-quality processes and (infra) structure.[18] There has been remarkable growth in the uptake of NQRs in the last few decades. Numerous national audits and databases have evolved over recent years. They raise awareness and give us some of the most powerful insights into the quality of healthcare and how it can possibly be improved and will be central to future data-aware health services built on a culture of continuous quality improvement.[19] A study of 13 NQRs in five countries demonstrated that NQRs have great potential to improve healthcare outcomes and lower healthcare costs.[20]

Measuring outcomes internationally

In 2012 ICHOM, International Consortium for Health Outcomes Measurement, was founded by Prof Michael Porter, Martin Ingvar and the Boston Consulting Group. Their mission is to unlock the potential of value-based healthcare by defining global sets of Patient-Centered Outcome Measures that matter most to patients and driving adoption and reporting of these measures worldwide to create better value for all stakeholders.[21] In 2012 ICHOM identified four areas of healthcare to define international standard sets of outcome measures. One of these was low back pain[22] and another was localized prostate cancer.[23]

ICHOM nowadays has published 40 standard sets covering different conditions and for specific patient populations. Although these standard sets exist, often an international comparison between NQRs is not yet feasible as quality indicators differ between registries.[24] In order to compare on an international level, it is necessary to harmonize NQRs and set international standards to measure the quality of care with similar indicators.[24]

Health insurers support transparency of outcomes

In 2013 the Association of Dutch Health Insurers composed a ‘Top 30 list’ of diseases for which outcomes should become transparent for patients and health insurance companies. At the same time the number of NQRs in the Netherlands increased and gradually structure, process and outcome indicators were shared publicly. The initial focus of most NQRs was on surgery, and slowly some NQRs started broadening their horizon to the areas of diagnostics, radiotherapy etc. However, transparency for some diseases hardly made any progress, even though many discussions between medical specialists, insurers and patient organizations had taken place.

For example, for prostate cancer and lumbar disk herniation there were numerous attempts to start NQRs and the international standard sets for outcomes for these diseases 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 for measuring outcomes of care for these diseases, was the start of the work conducted in this thesis.

Measuring outcomes in oncology

Now, more than ever, delivering high-quality care efficiently is key and top-priority for governments and clinical leaders. Managing costs without sacrificing quality is possible. Outcome data remove the blindfold and shine light on (the evalution of) results of procedures, processes, structures, and systems.

The first Dutch 'Quality of Cancer report' became available in 2010.[25] The taskforce concluded that the quality of care varies by hospital and by region. These differences are not limited to surgical procedures and postoperative mortality, but are also demonstrated in other parts of the care process. Differences are only partly explained by differences in procedural volume, specialization and infrastructure between hospitals. The second Dutch 'Quality of Cancer report' demonstrated that hospitals which performed more radical prostatectomies per year, had lower rates of positive surgical margins and lower complication rates.[26] Thus, on a national level, it was apparent that there was potential for improvement of outcome for cancer patients by reducing variation of outcomes between hospitals. In our first and second study **[chapter 2 and 3]** we compared outcomes of patients who underwent radical prostatectomy for prostate cancer in the Netherlands.[27] In **chapters 2 and 3** of this thesis the relationship between hospital volume and outcomes after radical prostatectomy are also reported.

Measuring outcomes in elective surgery

Outcomes of care are relevant not only in oncology, but in a wide array of healthcare. In an overview of disease burdens in the Netherlands from the Dutch Healthcare Institute, low back pain and herniated disk were at the top of the list, with over a million patients per year.[28] The painful lumbar spine, also represents the top ranking chronic healthcare complaint.[29] For patients with sciatica due to a lumbar herniated disk, the effectiveness of surgery is not without dispute. In the Dutch study by Peul et al., no significant differences were found between surgery and usual conservative care in any of the clinical outcomes after one and two years.[30] Eventhough an international set of outcome measures for low back pain has been available for almost a decade[24] and several attempts to establish an NQR for lumbar disk herniation were undertaken, in the Netherlands there was still no insight in outcomes relevant to patients before the initiation of the research included in this thesis. **Chapter 4** describes outcomes relevant to patients for those who underwent lumbar disk hernation surgery. These outcomes were studied by using claims data.

Challenge for national quality registries: reducing administrative burden

NQRs require continuous development in order to meet the requests and face current challenges, both specific to NQRs and the ones broader applicable to healthcare, such as increased pressure on funding. In addition, challenges were faced in extending NQRs into primary care and in covering care pre- and post-hospitalization. These challenges are partly related to technological challenges (linking information from different datasets) and partly due to changing and increasingly stringent rules on data sharing and information governance.[31] Also, NQRs tend to cover disease-specific areas, whereas broader national health topics cannot yet be covered by NQRs.

There is a substantial administrative burden related to gathering the data for NQRs. A recent study on the perceived burden due to registrations for quality monitoring and improvement in hospitals in the Netherlands showed that physicians and nurses spent an average of 52 minutes per day on administration for quality accountability purposes in general.[32] More than half (57%) of the indicators were gathered for accountability purposes (eg, quality indicators for the Healthcare Inspectorate), and only 25% for quality improvement (NQRs). Of the total numer of requested indicators, only 28% were outcome indicators.

Ideally, data are entered once in an Electronic Health Record (EHR), stored in a structured way and subsequently suitable for extraction for multiple purposes (care process, research, quality registries, and so on). Internationally, this type of data reuse is referred to as the COUMT paradigm ('Collect Once Use Many Times').[33] In the Netherlands, COUMT is put forward as a national goal.[34] In order to reduce the administrative burden for healthcare professionals, a novel approach to data-collection, storage and retrieval needs to be developed and applied. Clinical information models (CIMs) can be used for content standardization of information captured during the care process.[35 36] A CIM describes a (clinical) concept in a structured and detailed method. CIMs are models to structure data so they can be reused.[33] **Chapter 6** describes to what extent Dutch NQRs can be based on existing CIMs.

Using secondary data for evaluating public health trends

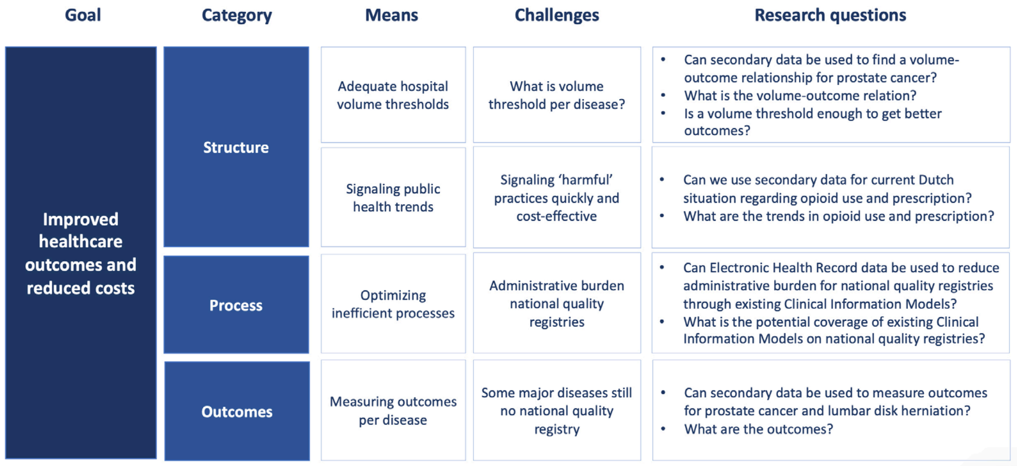
Most NQRs cover disease-specific areas and are not suited for investigating national health topics in a broader perspective. Yet, there is a plethora of secondary data available for healthcare research. **Chapter 5** focusses on the possibility to use claims data for getting insight into public health trends in extramural prescription of opioids in the Netherlands.

The importance of balanced opioid prescriptions practices was emphasized by the opioid epidemics in the US and Canada, facing a serious opioid misuse epidemic that started with increased prescriptions of oxycodone and eventually resulted in massive overdose mortality.[37 38 39] 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.[40]

Overview of this thesis in figures

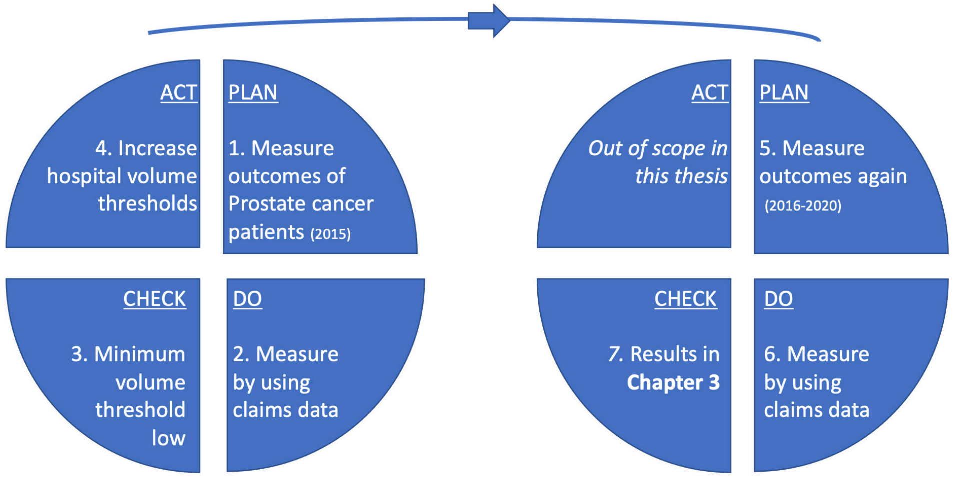
An overview of this thesis is summarized in figures 1 and 2.

Figure 1 Overview of this thesis in linear model



Goal	Category	Means	Challenges	Research questions
Improved healthcare outcomes and reduced costs	**Structure**	Adequate hospital volume thresholds	What is volume threshold per disease?	• Can secondary data be used to find a volume-outcome relationship for prostate cancer? • What is the volume-outcome relation? • Is a volume threshold enough to get better outcomes?
		Signaling public health trends	Signaling 'harmful' practices quickly and cost-effective	• Can we use secondary data for current Dutch situation regarding opioid use and prescription? • What are the trends in opioid use and prescription?
	Process	Optimizing inefficient processes	Administrative burden national quality registries	• Can Electronic Health Record data be used to reduce administrative burden for national quality registries through existing Clinical Information Models? • What is the potential coverage of existing Clinical Information Models on national quality registries?
	Outcomes	Measuring outcomes per disease	Some major diseases still no national quality registry	• Can secondary data be used to measure outcomes for prostate cancer and lumbar disk herniation? • What are the outcomes?

Figure 2 Overview of this thesis with additional questions depicted in a quality of care improvement cycle



Questions addressed in this thesis

In order to be able to determine the usability of using secondary data to measure and improve quality of care in an efficient manner we aimed to address the following questions in this thesis:

1. Can claims data be used to measure outcomes after radical prostatectomy and if so, what is the urinary incontinence rate after radical prostatectomy and does a volume-outcome relationship exist for urinary incontinence and hospital volume? **(Chapter 2)**.
2. What is the urinary incontinence rate after radical prostatectomy before and after increase of minimum hospital volume threshold and does a volume-outcome relationship exist for urinary incontinence and hospital volume? **(Chapter 3)**.
3. Can claims data be used to measure outcomes after lumbar disk herniation and if so, what are outcomes and variation in outcomes amongst hospitals after lumbar disk herniation in the Dutch population? **(Chapter 4)**.
4. Can claims data be used to describe trends in opioid use prescriptions and if so, what are the trends? **(Chapter 5)**.
5. Can Dutch national quality registries be based on existing clinical information models which use existing Electronic Health Record data and if so, what is the level of coverage? **(Chapter 6)**.

References

1 Johansen F, Loorbach D, Stoopendaal A. Exploring a transition in Dutch healthcare. J Health Organ Manag. 2018 Oct 8;32(7):875-890.

2 Health at a glance 2021: OECD Indicators. https://www.oecd-ilibrary.org/sites/ae3016b9-en/1/2/2/index.html?itemId=/content/publication/ae3016b9en&_csp_=ca413da5d44587bc56446341952c275e&itemIGO=oecd&itemContentType=book.

3 Institute of Medicine (US) Committee on Quality of Health Care in America. Crossing the Quality Chasm: A New Health System for the 21st Century.

4 https://www.who.int/health-topics/quality-of-care#tab=tab_1 Last visited 22nd of August 2022.

5 Porter ME, Teisberg. EO. Redefining Health Care. Harvard Business School Press 2006.

6 Percival T: Medical ethics; or a Code of institutes and precepts, adapted to the professional interests of physicians and surgeons. Manchester: S. Russell, 1803.

7 Neuhauser D: Ernest Amory Codman MD. Qual Saf Health Care 11:104-5, 2002.

8 Donabedian A: Ernest A. Codman, MD, the end result idea and The Product of a Hospital. A commentary. Arch Pathol Lab Med 114:1105, 1990.

9 Wennberg JE. Forty years of unwarranted variation--and still counting. Health Policy. 2014 Jan;114(1):1-2.

10 Robra BP. John E. Wennberg, Pionier der regionalen Versorgungsforschung: Was kann eine deutsche Versorgungswissenschaft von ihm lernen? [John E. Wennberg, pioneer of regional health services research: what does he teach us in Germany?]. Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz. 2014 Feb;57(2):164-8.

11 Westert GP, Groenewoud S, Wennberg JE, Gerard C, DaSilva P, Atsma F, et al. Medical practice variation: public reporting a first necessary step to spark change. International Journal for Quality in Health Care, 30(9), 731–735.

12 Casparie AF, Geschiere R, Post D, et al. Differences in health care provision between 11 ENT partnership practices in 2 health insurance catchment areas. Ned Tijdschr Geneeskd 1991; 135:754-758.

13 Deelen van. Praktijkvariatie in verrichtingen, zijn de data wel betrouwbaar. Medisch Contact.

14 Birkmeyer JD, Siewers AE, Finlayson EV, Stukel TA, Lucas FL, Batista I, Welch HG, Wennberg DE. Hospital volume and surgical mortality in the United States. N Engl J Med. 2002 Apr 11;346(15):1128-37.

15 Wouters MW, Jansen-Landheer ML, van de Velde CJ. The Quality of Cancer Care initiative in the Netherlands. Eur J Surg Oncol. 2010 Sep;36 Suppl 1:S3-S13.

16 Tan JCK, Ferdi AC, Gillies MC, Watson SL. Clinical Registries in Ophthalmology. Ophthalmology. 2019 May;126(5):655-662.

17 Fredriksson M, Halford C, Eldh AC, Dahlström T, Vengberg S, Wallin L, et al. Are data from national quality registries used in quality improvement at Swedish hospital clinics? Int J Qual Health Care. 2017 Nov 1;29(7):909-915.

18 Donabedian A. Evaluating the quality of medical care. 1966. Milbank Q. 2005;83(4):691-729.

19 Stewart K, Bray B, Buckingham R. Improving quality of care through national clinical audit. Future Hosp J. 2016 Oct;3(3):203-206.

20 Kuenen JW, Mohr R, Larsson S, Van Leeuwen W. Zorg voor waarde. Meer kwaliteit voor minder geld: wat de Nederlandse gezondheidszorg kan leren van Zweden. Available from: http://www.bcg.nl/documents/file65689.pdf. 2011 Accessed on: 11th July 2023.

21 https://www.ichom.org/mission/ Last visited 25th of August 2022.

22 Clement RC, Welander A, Stowell C, Cha TD, Chen JL, Davies M, et al. A proposed set of metrics for standardized outcome reporting in the management of low back pain. Acta Orthop. 2015;86(5):523-33.

23 Martin NE, Massey L, Stowell C, Bangma C, Briganti A, Bill-Axelson A, et al. Defining a standard set of patient-centered outcomes for men with localized prostate cancer. Eur Urol. 2015 Mar;67(3):460-7.

24 Baldewpersad Tewarie N, van Driel WJ, van Ham MAPC, Wouters MW, Rome RM, Høgdall CK, et al. Participants of the - Dutch Gynecological Oncology Group. An overview of Clinical Quality Registries (CQRs) on gynecological oncology worldwide. Eur J Surg Oncol. 2022 Jun 23:S0748-7983(22)00522-4.

25 Wouters MW, Jansen-Landheer ML, van de Velde CJ. The Quality of Cancer Care initiative in the Netherlands. Eur J Surg Oncol. 2010 Sep;36 Suppl 1:S3-S13.

26 Kloosterboer FM, Siesling S. Quality of Cancer Care in the Netherlands. 2014. Available (in Dutch) at : https://iknl.nl/getmedia/4e472aa9-4b00-45b1-aa63-b6abbfcd1504/Kwaliteit-van-kankerzorg_2014_rapportKWF_IKNL.pdf. Last visited: October 31st 2022.

27 Schepens MHJ, Ziedses des Plantes CMP, Somford DM, van Erkelens JA, Cremers RG, de Vries S, et al. Hoe vaak incontinentie na radicale prostatectomie? [Incidence of incontinence after radical prostatectomy using claims-based data]. Ned Tijdschr Geneeskd. 2018;162:D2294.

28 https://www.zorginstituutnederland.nl/actueel/nieuws/2018/12/03/zorg-bij-lage-rugpijn-kan-nog-verder-worden-verbeterd. Last visited 26th of August 2022.

29 Vos T, Flaxman A, Naghav IM, Lozano R, Michaud C, Ezzati M, et al. Global Health; Public Health Years lived with disability (YLDs) for 1160 sequelae of 289 diseases and injuries 1990–2010: a systematic analysis for the Global Burden of Disease Study 2010. Lancet. 2012;380(9859):2163–96.

30 Peul WC, van den Hout WB, Brand R, Thomeer RT, Koes BW; Leiden-The Hague Spine Intervention Prognostic Study Group. Prolonged conservative care versus early surgery in patients with sciatica caused by lumbar disc herniation: two year results of a randomised controlled trial. BMJ. 2008 Jun 14;336(7657):1355-8.

31 Stewart K, Bray B, Buckingham R. Improving quality of care through national clinical audit. Future Hosp J. 2016 Oct;3(3):203-206.

32 Zegers, M., Veenstra, G., Gerritsen, G., Verhage, R., van der Hoeven, H., Welker, G. Perceived Burden Due to Registrations for Quality Monitoring and Improvement in Hospitals: A Mixed Methods Study. International Journal of Health Policy and Management, 2022; 11(2): 183-196.

33 Joukes E, Cornet R, Keizer N de, Bruijne M de. Collect Once, Use Many Times: End-users don’t practice what they preach. Stud Health Technol Inform 2016;77:291-304.

34 Bestuurlijk akkoord medisch-specialistische zorg 2019-2022. Available at: https://eerstekamer.nl/9370000/1/j4nvjlhjvvt9eu4_j9vvkfvj6b325az/vkoyotm271z2. Accessed October 1, 2021.

35 Goossen WTF. Detailed Clinical Models: Representing knowledge, data and semantics in healthcare information technology. Healthc Inform Res 2014;20(3)163-72.

36 Oniki TA, Coyle JF, Parker CG, Huff SM. Lessons learned in detailed clinical modeling at Intermountain Healthcare. J Am Med Inform Assoc 2014;21:1076-81.

37 Manchikanti L, Fellows B, Ailinani H, Pampati V. Therapeutic use, abuse, and nonmedical use of opioids: a ten-year perspective.Pain Physician 2010; 13: 401–35.

38 Rudd RA, Aleshire N, Zibbell JE, Gladden RM. Increases in drug and opioid overdose deaths — United States, 2000-2014. MMWR Morb Mortal Wkly Rep 2016; 64: 1378–82.

39 Gardner EA, McGrath SA, Dowling D, Bai D. The Opioid Crisis: Prevalence and Markets of Opioids. Forensic Sci Rev. 2022 Jan;34(1):43-70.

40 van Amsterdam J, van den Brink W. The Misuse of Prescription Opioids: A Threat for Europe? Curr Drug Abuse Rev. 2015;8(1):3-14.