

Data requests to Dutch hospitals

Investigation of current hospital data requests

and

the **usefulness** of the **DHD data collections**

regarding data requests from other organizations

Mirjam Uittenbogaard

Msc stage Management, Policy-Analysis & Entrepreneurship in Health Sciences

Vrije Universiteit, Amsterdam

Dutch Hospital Data, Utrecht

October 2011



General information

Student

Name: Mirjam Uittenbogaard
Masters program enrolled in: Management, Policy-Analysis and Entrepreneurship
in Health Sciences, 1st year
Student number: 1714945
Date: October 2011
E-mail: mmuittenbogaard@gmail.com
Phone number: 06-12192092

Supervisor Dutch Hospital Data

Name: S.R. [Roos] Choudhury (until July)
Dr. I.M.A. [Inez] Joung (since July)
Address: Oudlaan 4
3515 GA Utrecht
E-mail: joung@hospitaldata.eu
Phone number: 030 - 273 95 21 / 06- 50210799

3

Supervisor VU University, Amsterdam

Name: Dr. D. [Daniel] Puente Rodríguez
Department: Athena Institute – Biology and Society
Faculty of Earth and Life Science, VU University
Address: De Boelelaan 1085
1081 HV Amsterdam
E-mail: d.puenterodriguez@vu.nl
Phone number: +31 (0)20 5982682 / +31 (0)20 5987031

Preface

This study is performed during an internship at the Dutch Hospital Foundation in Utrecht. Being part of the first year of my Msc study Management, Policy-Analysis and Entrepreneurship in Health Sciences at the VU University of Amsterdam, this placement has given me the opportunity to experience and participate in the daily practice of policy-making in the Dutch hospital care and national hospital data management. I have enjoyed the interviews with different professionals in several hospitals and expanding my knowledge and skills in this field. Therefore, I'm very thankful to the Dutch Hospital Foundation for this opportunity and would like to express my gratitude to the people which have contributed to this study.

First I would like to thank Mw. Roos Choudhury Msc, my daily supervisor, for her confidence to grant me this chance as well for her advice, help and expertise during the research. I am also very thankful for the counseling and on-going support by Dr. Daniel Puente Rodríguez from the VU University, and his instructive advices.

In addition, I would like to thank all respondents from the several hospitals for their contribution to this research and willingness to share their experience and opinions in these matters.

4

Besides, I want to thank the DHD colleagues for their support and help during these months. I've appreciated this very much. In particular I want to thank Bep Hersmis which taught me the principles of hospital data coding systems and enabled me to perform the IGZ analysis.

And, last but not least, I want to thank my intern fellows Nuzhet Nasim and Eefje van der Hoorn for their daily support and cheer during this memorable internship, as well as my parents, family and friends for the many moments of support and motivation.

Mirjam Uittenbogaard, *October 2011*

Summary

Due to several developments in the hospital care, in particular the implementation of regulated competition, the need for hospital data has substantially increased last years. Many external organizations request data from hospitals, such as governmental organizations, health insurers, sector and professional associations and patient groups. Although hospitals acknowledge the importance of collecting data, the current amount of data requests imposes a heavy work load on hospitals. Furthermore, it is suggested that due to a lack of mutual cooperation between the requesting organizations, there might be duplicates in data requests.

However, currently the situation of data requests to hospitals is unclear nor is there a comprehensive overview of these requests available. This knowledge is necessary to study duplicates between data requests.

The Dutch Hospital Data Foundation, founded by the NVZ and NFU, manages the National Medical Register (LMR), the National Outpatient Care Register (LAZR), the Hospital Annual Statistics Survey (EJZ), the General Hospitals' Payroll Costs Databank (LKG) and since 2012 also the National Hospital Care Basic Registration (LBZ). DHD intends to limit the administrative burden for hospitals as much as possible.

Therefore, DHD aims to investigate which hospital data requests are queried to Dutch hospitals and whether there are similarities between these data requests and the DHD data collections. In case of similarities, it might be possible to satisfy other data requests by deriving data from the DHD data collections, which would relieve hospitals.

Taking this together, the research question was: *Are the DHD data collections useful to satisfy hospital data requests from other organizations?*, with the following sub questions:

1. Which hospital data requests are queried by external organizations to Dutch hospitals?
2. Would it be possible to comply with data requests from other organizations by deriving hospital data from the DHD data collections?
3. How could DHD enhance the possibilities for using the DHD data collections to comply with requests for hospital data from other organizations?

Several research methods have been applied. Firstly, literature and internet research was performed to gather as many data requests as possible. Secondly, ten professional from several hospitals were interviewed. The selection was a balanced distribution of hospitals from all regions and types of hospital. The interviews were anonymous and semi-structured. Topics included were the data requests in these particular hospitals, the usefulness of the DHD data collections for other data requests and possibilities to enhance this usefulness. Thirdly, a case study was performed to analyse

the similarities with the DHD data collections. Based on the interviews, the Quality Indicators of the Dutch Healthcare Inspectorate (IGZ) were selected to analyse. Finally, participative observation was applied. The researcher visited a medical coder to observe the processes and people involved with the data registrations and coding for the LMR and DBC's.

In total, 66 data collections which regularly request hospital data from Dutch hospitals were found. Most hospital data requests were from professional associations (27) and collaborating hospitals (18 requests). The most common were about complications and incidents (19), a certain treatment (17) or disorder (13) or hospital-wide data (12). The overview of data requests will hopefully contribute to more efficient hospital data management, both internally in hospitals as at national level. Regarding the 34 quantitative IGZ indicators, 7 indicators were found to be completely derivable from the LBZ or EJZ, while 15 indicators partly could be derived. Expressed in sub-questions, 24% of the total amount of sub-questions could be derived. This was in accordance with the interviewee's, which indicated that many data requests (such as the IGZ quality indicators) request more detailed data than the DHD data collections. However, it was also suggested that if DHD would derive data from the DHD data collections for parts of data requests, this would relieve hospitals. Moreover, this would enhance the homogeneity and comparability of the (published) hospital data. At the moment, many hospitals are concerned about the reliability and comparability of hospital data from different hospitals, since there is confusion about the definitions, the used terminology and the way other hospitals gather their data.

Based on this research, two recommendations which could enhance the usefulness of the DHD data collections were made; firstly, to include the date at which the diagnose is made into the current LBZ data model and secondly, to link DHD data to other hospital data collections either by using the anonymised BSN number or a primary key.

The strengths of this research were the use of several research methods and the verification of the information provided with each hospital data requests (see Appendix 1) by the administrators of the data requests. Therefore, the presented overview contains very up to date information. Limitations of the study were time restrictions and the fact that knowledge about hospital data requests appeared to be very fragmented in hospitals. As a result, the overview is probably not complete. Further research into all divisions of a hospital, the goals and information products of hospital data requests is needed. In addition, hospital data request which were only performed once were excluded from this study. Probably these one-only data requests create a high work load for hospitals as well.

In sum, this study has led to the conclusion that the DHD data collections are useful for other hospital data requests, although they perhaps cannot completely satisfy data requests from other organizations. Firstly, they could facilitate the process of data disentanglement for parts of hospital

data requests, as shown in this study for the IGZ quality indicators. This would be a great help for hospitals. Additional research is needed to determine the possibilities of the DHD data collections regarding other data requests. Furthermore, the DHD data collections could play an important role in creating uniform, comparable hospital data. This is very relevant for hospitals, since the data is used for bench-marking and published to inform health insurers and patients. If DHD would derive data from the DHD data collections for several hospitals, the uniformity of the data for that data request would increase. In addition, there is a pressing need for clearness and uniformity regarding the definitions used in hospital data requests, as well as consistency of the used terminology between data requests. DHD, pursuing improvement of hospital data, could play a role in this.

Samenvatting

Door verschillende ontwikkelingen in de gezondheidszorg, zoals met name de invoering van gereguleerde concurrentie, is de vraag naar ziekenhuisgegevens de laatste jaren sterk toegenomen. Steeds meer externe organisaties vragen ziekenhuizen om gegevens, zoals toezichthoudende instanties, verzekeraars, branche- en patiëntenorganisaties en wetenschappelijke verenigingen. Betrokkenen in het ziekenhuis zien het belang van dataverzameling in, maar de huidige hoeveelheid gegevensuitvragingen is problematisch. Bovendien worden er mogelijk door weinig samenwerking tussen uitvragende organisaties overeenkomstige data meerdere keren uitgevraagd in verschillende uitvragingen.

Er is echter weinig zicht op de huidige gegevensuitvragingen. Er is geen actueel overzicht beschikbaar, wat uiteraard noodzakelijk om duplicatie in uitvragingen te onderzoeken. Dutch Hospital Data (DHD), opgericht door NVZ en NFU, beheert de LAZR (Landelijke Ambulante Zorgregistratie), LMR (Landelijke Medische Registratie), EJZ (Enquête Jaarcijfers Ziekenhuizen), LKG (Loonkostengegevens) en vanaf 2012 ook de LBZ (Landelijke Basisregistratie Ziekenhuiszorg). DHD streeft naar een zo gering mogelijke administratieve belasting voor ziekenhuizen.

In het kader hiervan heeft DHD zich ten doel gesteld om te inventariseren met welke gegevensuitvragingen ziekenhuizen te maken (kunnen) hebben, en of de gegevensverzamelingen van andere externe partijen aansluiten bij de gegevens die DHD verzamelt. In het geval van overeenkomsten zou mogelijkerwijs aan gegevensuitvragingen van andere organisaties voldaan kunnen worden door de gevraagde data af te leiden uit de DHD verzamelingen. Hierdoor zou de huidige registratielast voor ziekenhuizen kunnen verminderen.

De onderzoeksvraag die hier uit volgde was als volgt: *Zijn de DHD gegevensverzamelingen bruikbaar om te voldoen aan externe gegevensuitvragingen van andere organisaties?*

Het onderzoek bevatte drie deelvragen:

1. Met welke gegevensuitvragingen hebben Nederlandse ziekenhuizen te maken?
2. Is het mogelijk om aan gegevensuitvragingen van andere partijen te voldoen door data af te leiden uit DHD gegevensverzamelingen?
3. Hoe kan DHD de mogelijkheden om de DHD gegevensverzamelingen in te zetten voor andere gegevensuitvragingen vergroten?

Verschillende onderzoeksmethoden zijn toegepast. Door middel van literatuur- en internetonderzoek is getracht zo veel mogelijk gegevensuitvragingen te vinden. Daarnaast zijn tien professionals uit verschillende ziekenhuizen geïnterviewd. De selectie van interviewees was zodanig dat er een gevarieerde verdeling van verschillende typen ziekenhuizen uit verschillende regio's ontstond.

Tijdens deze semigestructureerde, anonieme interviews is gesproken over de gegevensuitvragingen in het desbetreffende ziekenhuis, de bruikbaarheid van de DHD gegevensverzamelingen ten opzichte van gegevensuitvragingen van andere partijen en mogelijkheden om deze bruikbaarheid te vergroten. Mede op basis van de interviewresultaten is er een casus geselecteerd om te analyseren op overeenkomsten met de DHD verzamelingen, namelijk de IGZ kwaliteitsindicatoren. Ook heeft de onderzoekster participerende observatie gebruikt door een medische codeur te bezoeken en de processen en betrokkenen te observeren bij de data registratie en codering voor de LMR en DBC's.

In totaal zijn er 66 gegevensuitvragingen gevonden die frequent aan meerdere ziekenhuizen uitgevraagd worden. De meeste uitvragen waren afkomstig van wetenschappelijke verenigingen van medisch specialisten (27) en gezamenlijke ziekenhuizen (18). De meest uitgevraagde onderwerpen waren complicaties en incidenten (19) of een specifieke behandeling (17). Het overzicht van gegevensuitvragingen zal hopelijk bijdragen aan een efficiënter gegevensbeheer, zowel intern in ziekenhuizen als op nationaal niveau. Van de 34 kwantitatieve IGZ indicatoren konden 7 indicatoren volledig en 15 indicatoren gedeeltelijk afgeleid worden van de LBZ of EJZ. Uitgedrukt in subvragen kon 24% van het totale aantal kwantitatieve vragen in de IGZ-indicatoren beantwoordt worden d.m.v. DHD gegevens. Deze resultaten kwamen overeen met de interviews, waarin aangegeven werd dat veel gegevensuitvragingen (zoals de IGZ) meer gedetailleerde informatie vragen dan de DHD dataverzamelingen. Aan de andere kant werd echter ook gesuggereerd dat het afleiden van data van de DHD verzamelingen voor delen van gegevensuitvragingen (zoals voor de IGZ) ziekenhuizen zeker zou verlichten. Bovendien zou dit de vergelijkbaarheid en homogeniteit van de data van verschillende ziekenhuizen ten goede komen. Meerdere interviewees gaven aan er nu zorgen zijn over de vergelijkbaarheid van gegevens tussen ziekenhuizen, omdat er onduidelijkheid is over definities, gehanteerde terminologie en de werkwijzen van andere ziekenhuizen.

Op basis van deze resultaten zijn twee aanbevelingen gegeven met betrekking tot het vergroten van de inzetbaarheid van de DHD dataverzamelingen voor andere gegevensuitvragingen, namelijk het toevoegen van de datum waarop de klinische diagnose gesteld is aan het LBZ-model en het linken van patiëntgegevens uit verschillende databases door middel van het geanonimiseerde BSN-nummer of een primary key.

Sterke punten van deze studie zijn het gebruik van verschillende onderzoeksmethoden en de verificatie van de beschrijvingen van de gegevensuitvragingen (Appendix 1) door de desbetreffende uitvragende organisaties. Dit is dus met grote zekerheid een actueel overzicht van uitvragingen. Beperkingen van deze studie waren de beperkte tijdsperiode en de hoge mate waarin kennis over gegevensuitvragingen versnipperd en verspreid is binnen ziekenhuizen. Het overzicht is daarom mogelijk niet compleet. Verder onderzoek in bijvoorbeeld alle afdelingen van een ziekenhuis, de doelen en informatieproducten van gegevensuitvragingen is noodzakelijk. Ook eenmalige

gegevensuitvragingen zijn niet onderzocht binnen deze studie, terwijl deze mogelijk ook een zware belasting kunnen vormen voor ziekenhuizen.

Samenvattend heeft deze studie geleid tot de conclusie dat de DHD data verzamelingen bruikbaar zijn voor andere gegevensuitvragingen, hoewel ze mogelijk niet in staat zijn andere gegevensuitvragingen volledig te beantwoorden. Ten eerste kunnen ze het proces van data verzamelen voor een gegevensuitvraag faciliteren door een gedeelte van de gegevensuitvraag te beantwoorden, zoals voor de IGZ kwaliteitsindicatoren. Dit zou ziekenhuizen zeker helpen. Verder onderzoek is nodig om te bepalen voor welke andere gegevensuitvragingen de DHD dataverzamelingen een rol zouden kunnen spelen. Bovendien kunnen de DHD dataverzamelingen een belangrijke rol spelen in het verkrijgen van uniforme, vergelijkbare ziekenhuisgegevens. Dit is van grote waarde voor ziekenhuizen, omdat deze data gebruikt worden voor benchmarking en om patiënten en verzekeraars te informeren. Door voor meerdere ziekenhuizen data af te leiden uit de DHD registraties, wordt de uniformiteit van de gegevens voor die gegevensuitvraag verhoogd. Daarnaast is er behoefte aan eenduidige definities en consistentie in de terminologie zoals gehanteerd in gegevensuitvragingen. Ook hierin kan DHD een rol spelen.

Table of content

Preface	3
Summary	4
Samenvatting	8
List of abbreviations	13
1. Introduction	14
1.1. Background	14
1.2. Problem definition	18
1.3. Study objectives	18
1.4. Central research question	18
2. Conceptual framework	19
2.1. Important concepts and definitions	19
2.2. The law of medical information	19
2.3. Strategic knowledge management	20
2.4. Visualisation of current hospital data processes according to both models	22
2.5. The (future) role of DHD within hospital data management	23
2.6. Research sub questions	24
3. Methodology	25
3.1. Study design	25
3.2. Study population	25
3.3. Inclusion and exclusion criteria applied to hospital data requests	25
3.4. Data collection methods and analysis	26
3.4.1. Literature and internet research for data requests	26
3.4.2. Interviews	27
3.4.3. Case analysis	28
3.4.4. Participative observation	29
3.5. Validation strategies	29
3.5.1. Triangulation	29
3.5.2. Verification	30
3.5.3. Interview procedures	30
4. Results	31
4.1. Overview of hospital data requests	31

4.1.1. Results and appendices	31
4.1.2. Hospital data requests to administrator and content	31
4.1.3. Explanation of categories	33
4.2. Derivability of the quality indicators from the DHD data collections	34
4.2.1. Structure of the IGZ quality indicators	34
4.2.2. Amount of indicators and questions derivable from data collections	34
4.2.3. Derivable indicators per chapter	35
4.2.4. DHD data collections used for the IGZ quality indicators	36
4.2.5. The missing information for the 27 partially or not derivable indicators	36
4.3. Usefulness of the DHD data collections regarding other data requests	38
4.3.1. Views of hospital professionals	38
4.3.2. Doubts about the comparability of hospital data	39
4.3.3. Partial delivery of the needed data by DHD to enhance uniformity	39
4.4. Enhancing the usefulness of the DHD data collections regarding other requests	41
4.4.1. Date of diagnose missing in LBZ	41
4.4.2. Linking DHD data collections with other databases	42
5. Discussion	43
5.1. Summary of results	43
5.2. Strengths and limitations of the study	44
5.3. Results discussed and compared with previous research	45
5.3.1. Results conform large number of data requests	45
5.3.2. Similarities between DHD data collections and other data requests	45
5.3.3. Additional reasons for the displeasures in hospitals	45
5.4. Implications of results	46
6. Conclusion and recommendations	48
6.1. Conclusion	48
6.2. Recommendations to DHD	49
6.3. Recommendations to hospitals	49
6.4. Recommendations to organizations which (intend to) request data from hospitals	50
References	51
Appendix 1. Overzicht van externe gegevensuitvragingen – inclusief beschrijving	53
Appendix 2. Overzicht van externe gegevensuitvragingen - geordend naar opdrachtgever	75
Appendix 3. Overzicht van externe gegevensuitvragingen – geordend naar onderwerp	78
Appendix 4. Hoeveelheid IGZ kwaliteitsindicatoren en subvragen afleidbaar van LBZ en EJZ -	81

List of abbreviations

	English	Dutch
BSN	Citizen's Service Number	Burger Service Nummer
CBO bv	Central Accompaniment Organization	Centraal BegeleidingsOrgaan
CBS	Central Agency for Statistics	Centraal Bureau Statistiek
CBV	Medical Procedures Table	Verrichtingenbestand
DIS	DBC Information System	DBC Informatie Systeem
DBC	Diagnose Treatment Combination (Dutch 'DRG')	Diagnose Behandeling Combinatie
DHD	Dutch Hospital Data	Dutch Hospital Data
EJZ	Hospital Annual Statistics Survey	Enquête Jaarcijfers Ziekenhuizen
GBA	Civil Registry	Gemeentelijke basisadministratie van persoonsgegevens
IGZ	Health Care Inspectorate	Inspectie Gezondheidszorg
JVZ	Financial Statement Healthcare	Jaarverslag Zorg
LAZR	National Outpatient Care Register	Landelijke Ambulante Zorgregistratie
LBZ	National Hospital Care Basic Registration	Landelijke Basisregistratie Ziekenhuiszorg
LKG	General Hospitals' Payroll Costs Databank	Loonkostengegevens bestand
LMR	National Medical Register	Landelijk Medische Registratie
NFU	Dutch Federation of University Medical Centers	Nederlandse Federatie van Universitair Medische Centra
NVZ	NVZ Dutch Hospitals Association	Nederlandse Vereniging Ziekenhuizen
NVVC	Netherlands Society of Cardiology	Ned. Ver. voor Cardiologie
NZa	Dutch Healthcare Authority	Nederlandse Zorgautoriteit
OMS	Order of Medical Scientists	Orde van Medisch Specialisten
VWS	Ministry of Public Health, Welfare and Sports	Ministerie v. Volksgezondheid, Welzijn & Sport
ZiZo	Transparent Care	Zichtbare Zorg
ICD-10	International Classification of Diseases, 10 th revision	

1. Introduction

1.1. Background

The importance of information in hospital care

Information about patients and hospital care services is a prerequisite for decision-making and planning in the hospital care field in the Netherlands. This is already shown by the definition of ‘information’ either according to its function, “*organized data or knowledge that provides a basis for decision-making*” (Shortliffe & Cimino, 2006, p. 949), or to its content, “*knowledge about how to achieve a goal and data about the starting point and the intervening terrain*” (Wyatt, 1995, p. 175). Both definitions show that information is an important resource for hospitals and related organizations. It is necessary for decision-making at all levels in a hospital care system, for instance a clinician taking a patient management decision, a hospital board planning the financial budget and a health insurer contracting hospitals (Wyatt, 1995).

The information used in hospital care can be divided into two categories, based on the type and use of the information – i.e. (1) information for primary use and (2) information for secondary use (Safran et al., 2006; Wyatt, 1995; Berg & Goorman, 1999). In a clinical setting individual patient data is needed, such as the patient history and diagnose (Ibid.). This data can be defined as *information for primary use*, which is used by health professionals to manage the care of individual patients directly in the context of care (Ibid.). Individual patient data is abstracted, accumulated and combined with data about facilities, staffing and other resources to create relevant and usable *information for secondary use* (Ibid.). This information is designed for non direct care use, such as hospital management, government policy, research, education, provider accreditation, patient advocacy, sector association activities, quality measurement and financial and commercial business (Safran et al., 2006). This study focuses on the latter category: information for secondary use, also referred to as hospital data.

Increasing interest of information for secondary use

Recently the importance of information for secondary use has increased substantially due to changes of the hospital care system (RIVM, 2010; Safran et al., 2006). The Dutch government aims to reform the hospital care system towards having a more market-oriented approach (van Kemenade, 2007). Within this demand-driven system health insurers negotiate with care providers to contract the best provider and patients have a free choice of care (RIVM, 2010). To enable these market principles,

transparency in hospital care is a precondition (Ibid.). Hospitals and health insurers need accurate, complete and timely information for their policy-making, benchmarking and negotiations, governmental organizations need data for their monitoring and national policy-making, while patients need information to choose the care they prefer (RIVM 2010, van Kemenade, 2007). Therefore, both the need and value of hospital data has increased.

Large increase in hospital data requests

As a result of these fundamental changes in the hospital care system, there has been a large increase in demand for hospital data in the last few decades (Safran et al., 2006). Many external organizations request data from hospitals for various objectives. A data request could be described as a request for hospital data from Dutch hospitals, either at patient or institution level, requested periodically by an external organization.

For some of these requests Dutch hospitals are required by law to supply the requested data. First, the Healthcare Inspectorate demands hospitals annually to provide a basic set of quality indicators, which they use to monitor and control the Dutch hospital care (IGZ, 2011). Secondly, the national quality program Transparent Care (Zichtbare Zorg, 2011) requests quality indicators to provide information for patients, health insurers and other hospitals. Finally, all hospitals are obliged to provide a Financial Statement (JVZ) to the Ministry of Health, Welfare and Sports (VWS) (CIBG, 2011). Hospitals which are members of the Dutch Association of Hospitals (Nederlandse Vereniging Ziekenhuizen – NVZ) and Dutch Federation of University Medical Centers (NFU) are required to supply data to a couple of national data registries (DHD, 2011a).

The Dutch Hospital Data foundation (DHD) manages these national hospital data collections. They are:

- The National Medical Register (Landelijke Medische Registratie - LMR),
- The National Outpatient Care Register (Landelijke Ambulante Zorg Registratie – LAZR),
- The Hospital Annual Statistics Survey (Enquete Jaarcijfers Ziekenhuizen - EJZ),
- The General Hospitals' Payroll Costs Databank (Loonkostengegevensbestand – LKG) (DHD, 2011b).

Moreover, The DIS organization (DBC Information System) requests DBC data (Diagnose and Treatment Combinations) of hospitals. The national DIS database contains information about all invoiced hospital care services (DIS, 2011).

As well as these hospital data collections many other organizations collect data as well, of which probably many are unknown. For instance, insurers need a lot of hospital data, including the quality indicators of the Association of Dutch health insurers (Zorgverzekeraars Nederland) (Zichtbare Zorg, 2010). Furthermore, many professional associations collect data to research and develop their

profession, such as the National Cardiovascular Data Registry by the Netherlands Society of Cardiology (NIVV) (NCDR, 2011). Finally, other requesting organizations are patient and consumer groups, governmental organizations and joint initiatives of hospitals. However, a complete overview of all these data requests is currently lacking.

Heavy work load arising from data requests

To satisfy all these information needs, hospitals spend a lot of time on gathering the relevant information (Broersen, 2010; Crul, 2010). Although hospitals acknowledge the importance of collecting data, they have difficulties with the large amount and continuous increase of data requests (Broersen, 2010; Crul, 2010). According to them gathering this data from internal databases is often labour-intensive and complex (Ibid.). In addition, requests are not always clear or efficiently constructed, which demands additional hours (Ibid.).

In Great Britain, collecting information for primary and secondary use was estimated to occupy a quarter of the work hours of British doctors and nurses (Wyatt, 1995). Today it is unclear how much time is spent by Dutch hospitals on data collecting for secondary purposes (Broersen, 2011). This is probably because multiple people are involved in the process of gathering the requested hospital data, ranging from medical specialists to administrative officers, and the way of registering internal information differs per hospital (Ibid.). It is clear though that the current amount of data requests imposes a heavy work load upon hospitals (Ibid.). Since this decreases the available capacity for their primary responsibility, delivering high quality care to the patients, this issue remains problematic (Berg and Goorman, 1999).

Multiple separate collections of hospital data

Furthermore, the burden due to data requests might be higher than necessary. Most data is requested by separately operating stakeholders, leading to multiple requests which might even request similar data (Broersen, 2010; Zichtbare Zorg, 2011; de Bekker, van Sambeek en Boendermaker, 2009). In hospitals it is suggested there is a lack of mutual alignment and cooperation between the requesting organizations, which results in duplicates or similarities in data requests (Ibid.). Taking this all together, the load due to data requests is very high, and might be even higher than necessary.

Similarities between hospital data requests not yet investigated

However, little information is available about the amount of data requests to hospitals and possible duplicates or similarities between them. Few studies have investigated this so far, probably due to the recent development and increase of the interest of hospital data. In 2009, the Dutch Healthcare

Authority (NZa) carried out a quick scan to investigate duplicates in data requests by monitoring organizations and sector associations to hospitals and insurers (de Bekker, van Sambeek en Boendermaker, 2009). This scan indicated that the number of similar data requests was limited (Ibid.). The duplicates were a consequence of insufficient cooperation between requesting organizations, differences between definitions of data and segmentation of sectors involved in hospital care (Ibid.). However, since this scan was performed new requests have been developed, such as additional indicators to the Health Care Inspectorate indicators, the new quality program Transparent Care and the National Hospital Care Basic Registration (Landelijke Basisregistratie Ziekenhuiszorg - LBZ), which is currently developed by DHD (DHD, 2011). Therefore, new accurate research into the hospital data requests is desirable.

The Dutch Hospital Foundation: aims and initiatives

Being founded by the hospital representative organizations NFU and NVZ, DHD aims to take care of the interests of hospitals and limit their administrative burden as much as possible. As part of this, DHD promotes and researches innovation in data collecting. For example, the National Medical Registration (LMR) and Outpatient Care Register (LAZR) are currently converted and integrated into the new National Hospital Care Basic Registration (LBZ). The LBZ is designed in a way that the requested data can be distracted from the internal databases in hospitals, which ought to reduce the administrative load due to the LBZ for hospitals.

To enable this even more DHD decided to investigate to what extent hospital data requests from other organizations are similar to the data collections of DHD (R. Choudhury, personal communication, February 9, 2011). In case of duplicates the national databases of DHD could be used for deriving data to deliver to other requesting organizations (Ibid.). The upcoming LBZ might offer new possibilities that should reduce the burden on hospitals even more.

Since DHD is founded by hospital representative organizations and currently already manages several national hospital data collections, it has the expertise and support of many hospitals to play an intermediary role between hospitals and requesting organizations. Therefore DHD's suggestion, to use the national data collections to satisfy other data requests, is an opportunity to decrease the administrative burden currently upon hospitals.

Lacking knowledge about data requests

However, to study the similarities between the DHD data collections and other data requests, the data requests which hospitals receive should be known. Currently, the situation of requests to hospitals remains unclear nor is there a comprehensive overview available (R. Choudhury, personal

communication, February 8, 2011). Without this knowledge, the usefulness of the DHD data collections in satisfying other data requests cannot be investigated.

1.2 Problem definition

Provided with the current state of knowledge about hospital data requests, this study aims to address the following problem:

Problem definition

Dutch hospitals experience a high work load due to the large amount of hospital data requests. An overview of the actual data requests is lacking, but is necessary to investigate the similarities between the DHD data collections and other data requests. To reduce the data request load for hospitals as much as possible, the usefulness of the DHD data collections in satisfying other data requests needs to be investigated.

1.3 Study objectives

This study aims to:

- First, to create an overview of the current external requests of hospital data to Dutch hospitals.
- Secondly, to investigate the usefulness of the DHD data collections in satisfying data requests from external organizations.
- Thirdly, to advise DHD how to enhance the possibilities for using the DHD data collections in satisfying other data requests.

1.4. Central research question

Are the DHD data collections useful to satisfy hospital data requests from other organizations?

2. Conceptual framework

This chapter explains the two theoretical models which were used in this study. First, section 2.1 contains an overview of the important concepts and definitions, as introduced in chapter 1. Section 2.2 describes the first model as defined by Berg & Goorman (1999), which discusses the process of creating information for secondary use. Secondly, Alavi and Leidner's conceptual model concerning knowledge management system (2001) is explained in section 2.3. In section 2.4 these models are applied to the current processes involved with national hospital data and section 2.5 describes the role of Dutch Hospital Data within these processes. Finally, section 2.6 presents the research sub-question.

2.1. Important concepts and definitions

- *Information for primary use* is patient information used by health professionals to manage the care of individual patients, directly in the context of care (based on Safran et al., 2006; Wyatt, 1995; Berg & Goorman, 1999).
- *Information for secondary use* is grouped and abstracted patient data combined with higher hospital level data for non-direct care use (Ibid.).
- *Hospital data, hospital information and information for secondary use* are all equivalents. This study uses the term *hospital data*.
- A *hospital data request* is a request for hospital data from Dutch hospitals, either at patient or institution level, requested periodically by an external organization.
- A *registry* is defined as a systematic collection of a clearly defined set of medical related data, held in a central database for a predefined purpose (based on Arts, de Keizer & Scheffer, 2002).
- The *DHD data collections* are the national hospital data registries as managed by DHD: the LMR, LAZR, EJZ, LKG and the upcoming LBZ.

2.2. The law of medical information (Berg & Goorman, 1999)

Goorman and Berg (1999) discussed the contextual nature of medical information from a sociological perspective. They argued that medical data is not just a transferable, independent commodity, but fundamentally entangled with the context of its production (figure 1). Medical data is adequately meaningful within the context of their use, but it might become meaningless or faulty outside the context of care (Ibid.). To create useful information for secondary use, the data need to be

disentangled from this context and translated into standardized, transportable data ('a single code') (Berg & Goorman, 1999).

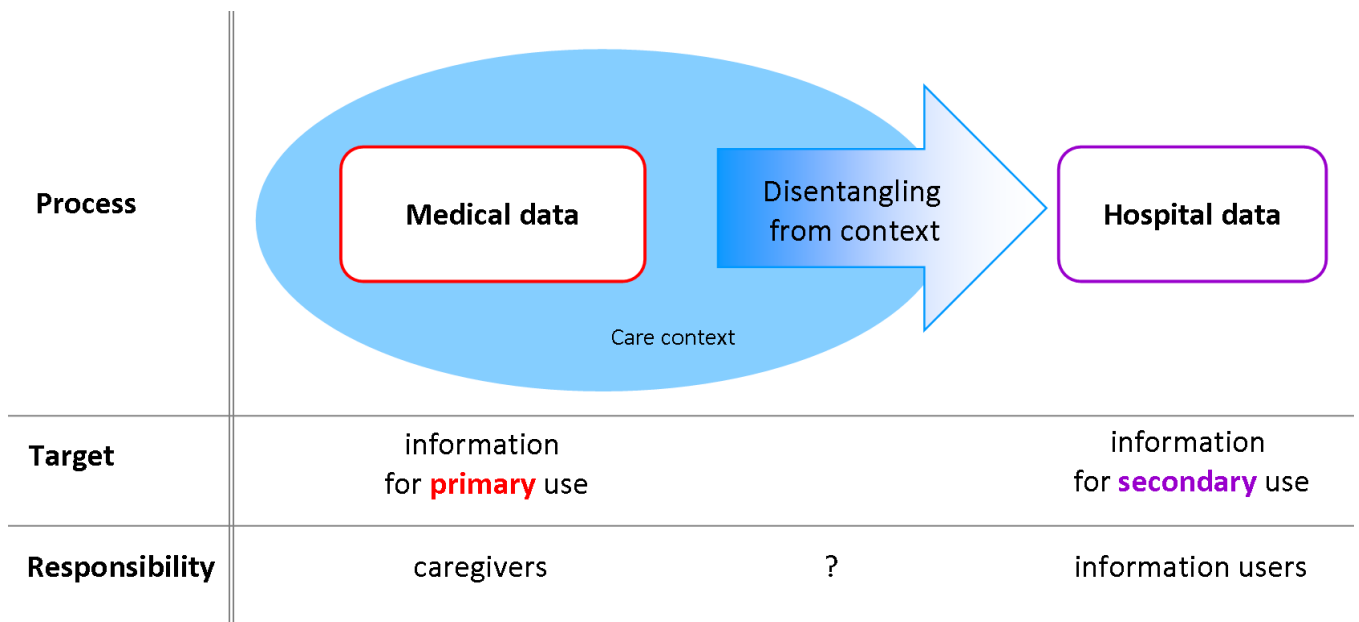


Figure 1. The process of creating information for secondary use, based on Goorman & Berg (1999)

Therefore, the authors present *'the law of medical information: the further information has to be able to circulate, (i.e. the more diverse contexts it has to be usable in), the more work is required to disentangle the information from the context of its production'* (Berg & Goorman, 1999, p. 52).

This approach towards hospital data and the involved processes to generate the data, as described by this model, enables a better understanding of the problem of the heavy work load for hospitals arising from the increasing number of hospital data requests. It shows both a probable cause for the problem as why it should be regarded as problematic. Firstly, it is labour-intensive to disentangle medical data from their primary context, and secondly this occupies part of the available time for care. In other words, this model perceives a high number of data requests as problematic, which is in accordance with the perspective of DHD. Therefore, DHD aims to limit the administrative burden due to hospital data requests as much as possible.

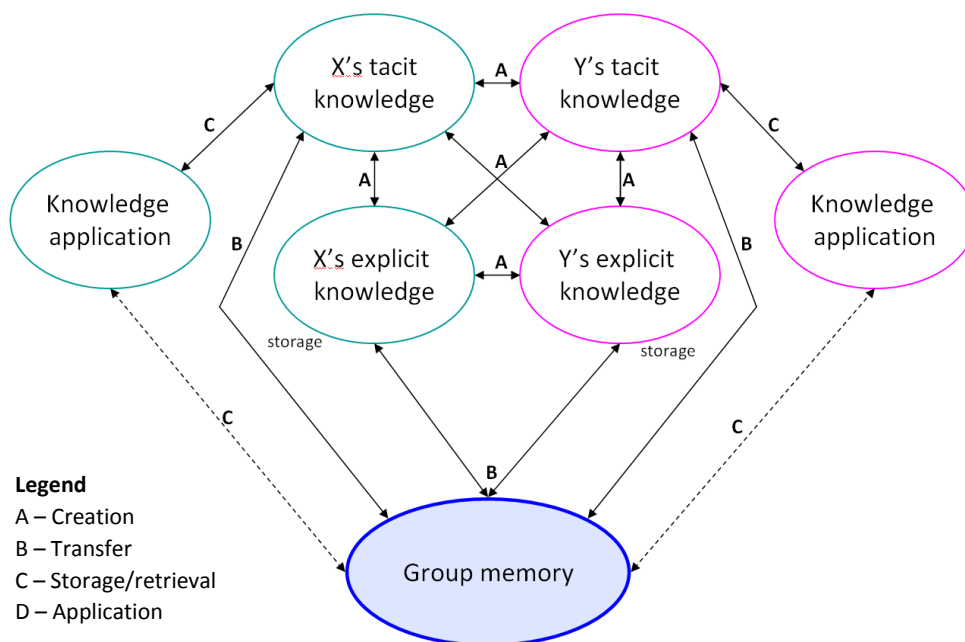
2.3. Strategic knowledge management (Alavi and Leidner, 2001)

The second model is a conceptual model of knowledge management systems, grounded in the sociology of knowledge, from the field of strategic management (Alavi & Leidner, 2001). Alavi and Leidner (2001) stated that knowledge is a significant organizational resource, which increases the organization's capacity for effective action. This is in agreement with the definitions of Shortliffe & Cimino (2006) and Wyatt (1995) of *information*, as mentioned above, which stress the importance of

information in decision-making and managing as well. Moreover, the organizational and managerial practice in the Dutch hospital care has become information-focused. For instance, hospitals have to provide transparent information about the quality of their services to patients and health insurers. This enables the implementation of market principles such as free choice (for patients) and contract negotiations (with insurers). Furthermore, hospitals need information about their provided services to monitor the quality of care. Taking this together, this strategic knowledge management model is applicable to Dutch hospital data management, since hospital data is indeed a significant resource for hospitals to develop effective policy.

Alavi and Leidner (2001) argued that not the knowledge existing in an organization per se, but the organization's ability to effectively use and apply their knowledge determines the competitive advantage of knowledge. This requires good knowledge management. The authors consider four processes which are essential to effective knowledge management, which are (1) knowledge creation, (2) storage/retrieval, (3) transfer and application.

(1)The creation of knowledge involves developing new content (Alavi & Leidner, 2001). For example, new explicit knowledge is created by merging, categorizing, reclassifying and synthesizing existing knowledge (Ibid.). Explicit knowledge is defined as 'knowledge articulated and codified in symbolic



form and/or natural language' (Alavi & Leidner, 2001, p. 110), while tacit knowledge is 'rooted in actions, experience and involvement in a specific context' (Alavi & Leidner, 2001, p. 113). In this research, the

Figure 2. Knowledge management processes (Alavi & Leidner, 2001)

creation of knowledge implies the disentanglement of information for primary use from the context of care into explicit hospital data. This disentanglement of information for primary use draws on tacit knowledge to create explicit knowledge.

(2)The storage, organization and retrieval of organizational knowledge, also referred to as a group memory, prevent forgetting or losing track of knowledge. This enables sharing and applying

information across time and space (Ibid.). Storage in this research could be registering hospital data in a (national) database.

(3) The transfer of knowledge is an important process of knowledge management, as the knowledge needs to be transferred to individuals or locations where it is needed and can be used (Ibid.).

Alavi and Leidner described that an frequently occurring problem within knowledge management is a poor storage of knowledge (Ibid.) Organizations do often not know what they know and where it is located (Ibid.). According to Alavi & Leidner, this inefficient data management decreases the capacity for effective action and decision-making.

Within the Dutch hospital care system, it is well-known that there are many hospital data collections going on, but it is not precisely known what they collect and where it is stored. By investigating the present hospital data collections, this research aims to contribute to effective hospital data management by mapping the transfers and storage of hospital data. In addition, it will investigate the possibilities of one of the group memories, the DHD data collections, for other hospital data requests.

2.4. Visualisation of current hospital data according to both models

When the models of Berg & Goorman and Alavi & Leidner would be applied to the national Dutch hospital data processes, the current situation could be visualised as shown in figure 3.

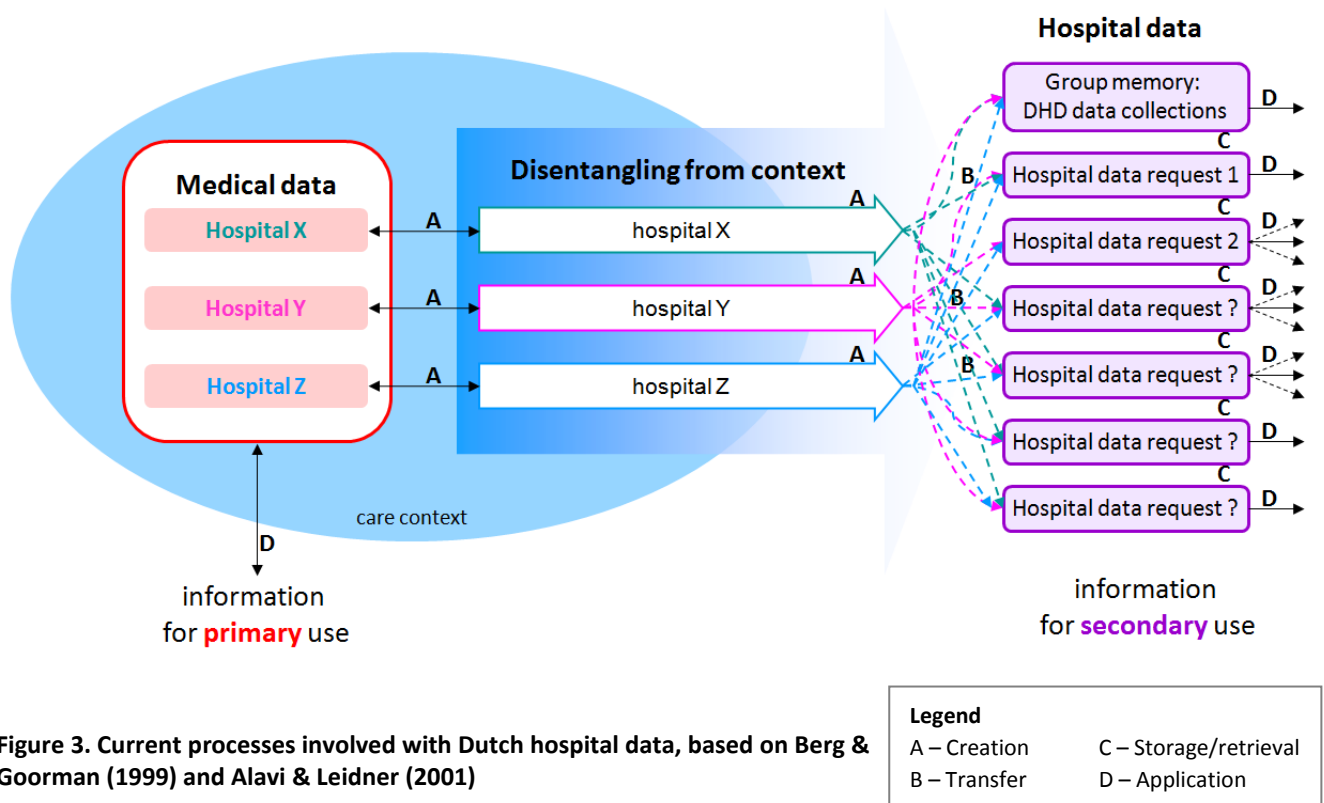


Figure 3. Current processes involved with Dutch hospital data, based on Berg & Goorman (1999) and Alavi & Leidner (2001)

Figure 3 visualises the many hospital data transfers which are carried out by hospitals due to many different hospital data collections. In addition, data is stored in many places for further application. The question marks symbolise the lacking knowledge regarding where the data is stored, in other words which hospital data collection are operating.

2.5. The (future) role of DHD within hospital data management

As described before, NFU and NVZ established the Dutch Hospital Data foundation in 2008. The aim of the founders was to create an organization which manages hospital data collections and the provision of high quality data to external organizations. Until now, DHD carried out the management of the data registries LMR, LAZR, EJZ and LKG; DHD retrieves and stores the LMR, LAZR, EJZ and LKG data from hospitals and is the central location where external organizations can retrieve this data. From the prospective of Alavi & Leidner (2001), DHD brings together the process of transferring the data of these four registries and creates a group memory to store them, where external organizations can request certain hospital data for application.

In addition, DHD aims to diminish the registry load for hospitals as much as possible. Therefore they suggested to use the national registries LMR, LAZR, DIS, EJZ, LKG and the future LBZ to satisfy data requests from external organizations (DHD, 2011c; Van Deijl & Plukker, 2007). External organizations, such as insurance companies and patient groups, could request data from DHD, which would derive the requested hospital data from the DHD data collections. In other words, DHD would take over part of the data creation process from hospitals together with the data transferring. This might lead to more effective data processes and would relieve hospitals.

The present study will focus on the usefulness of the suggestion of DHD, i.e. the possible use of the national DHD data collections to satisfy data requests from external organizations. The usefulness depends on the kind of data collected by other data requests and the similarities with the DHD data collections. However, to assess this, there are gaps in the available knowledge. Neither the amount of hospital data requests nor their content is known. Without precise knowledge of the contemporary hospital data requests, it would be unable to develop new data management strategies. In this study, I will try to bridge these major gap and to investigate and advice whether the DHD data collections are useful to satisfy other data requests.

2.6 Research sub questions

Taking this all together, the background information, problem statement and conceptual framework have led to the following research sub questions.

Research sub questions

1. Which hospital data requests are queried by external organizations to Dutch hospitals?
2. Would it be possible to comply with data requests from other organizations by deriving hospital data from the DHD data collections?
 - a. Can the hospital data requested in the quality indicators from the Dutch Health Care Inspectorate be derived from the DHD data collections?
 - b. Could the hospital data requested in other data requests be derived from the DHD data collections?
3. How could DHD enhance the possibilities for using the DHD data collections to comply with requests for hospital data from other organizations?

3. Methodology

Introduction

This chapter explains the methodology used in this study and the reasons for the chosen methods. Section 3.1 outlines the study design and section 3.2 defines the study population. Section 3.3 lists the criteria for the inclusion and exclusion of hospital data requests into the overview of data requests. Section 3.4 provides the methods used to collect the data to answer the research questions. Finally, section 3.5 looks at the strategies which were adopted to enhance the validity and reliability of the results.

3.1. Study design

This study is a qualitative exploratory study, which can be divided into three parts:

- The first section was to create an overview of the present hospital data requests, to answer the first research sub question and objective,
- The second section was to analyze the quality indicators of the Healthcare Inspectorate (IGZ) compared to the DHD data collections, addressing the second research sub question and objective,
- The third section was to advise DHD as regards how to enhance the possibilities for using the DHD data collections in satisfying other data requests, which was the third research question and objective.

3.2. Study population

Members of the NVZ and NFU were included in the study, which are 145 general and non-affiliated institutions (including 28 teaching hospitals (stz ziekenhuizen)) and 8 university medical centres. Since Independent Treatment Centres (ZBC's) and private clinics are not associated with the NVZ, they were not included into the research. The reason for selecting this population was that the study was performed for the sector associations NVZ and NFU and their associated hospitals.

3.3. Inclusion and exclusion criteria applied to data requests

The following criteria were applied when deciding which hospital data requests to include in the overview. Hospital data requests were included when:

- The data collection contained hospital data at patient level and/or at institute level, and;
- The data was collected nationally or regionally, and;

- The data was collected continuously or frequently from hospitals.

Hospital data requests were excluded when:

- The data was requested only once or a limited number of times, or;
- The data was collected from one or very few hospitals, or;
- The data was collected internationally, both from hospitals in the Netherlands and abroad.

These criteria were based on the aim to provide hospitals and external organizations with a comprehensive overview of permanent collections of hospital data requested from many Dutch hospitals. For this goal data requests which were performed only a limited number of times from only a very few hospitals had to be excluded as they are less useful for the long term. Data requests from international organizations were out of the scope of the study. Inclusion of these data requests would enlarge the study too much considering the research period.

3.4. Data collection methods and data analysis

To gather the data needed to answer the research questions, several methods of data collection and analysis were applied.

3.4.1. Literature and internet research for data requests

Firstly, literature research and research on the internet was performed to gather as many data requests as possible. Reports and web pages from the Ministry of Health, governmental organizations and (sector) associations of hospitals, insurers and medical professionals were researched.

3.4.1a. Variables in describing requests

To describe the hospital data requests shortly six variables were used, mainly based on the selection criteria as explained in § 3.3.

- The administrator
- The performer
- URL and/or contact information
- Description of the data which was requested
- Number of participants
- Frequency of data delivery by participants

3.4.2. Interviews

Information about hospital data requests is generally not published. Expertise in these matters is mostly found in the hospitals, but hard to obtain externally. Therefore, face to face semi-structured interviews with hospital employees were used to gain more insight in the practice of data requests. Interviews also provided the opportunity to discuss views and arguments to help establish the findings.

3.4.2a. Selection of hospitals

Ten hospitals were selected and approached to interview. The selection was a balanced distribution of hospitals from all regions and types of hospitals, to find as many national and regional hospital data requests as possible. One hospital did not cooperate due to other priorities. The final list of interviewed hospitals according to type and region are shown in Table 1. (Counties and university medical centres are not presented to maintain the anonymity.)

Region	Type of hospital			Total
	University medical centers*	General hospitals		
		General	Teaching (stz)	
West		✓	✓	3
East		✓	✓	2
North		✓		2
South			✓	2
Total	3	3	3	9

Table 1. Interviewed hospitals to type and region

* University medical centers are not presented to maintain the anonymity

3.4.2b. Interviewees

Within the hospital enquiries were made for the particular person or people who had the most expertise within hospital data requests and the DHD data collections. This approach was chosen since data management is organized differently per hospital. The final interviewees were managers or employees from the departments concerned with administration, finance, (business) information and/or control (you could here maybe specify the number of interviews with the type of position). One interview with a clinical doctor, involved in the management of certain data collections, was arranged as well, but was unfortunately cancelled.

3.4.2c. Interviews

The semi-structured interview protocol was developed in cooperation with DHD and VU University Amsterdam. Topics included were the data requests in these particular hospitals and the overview of data requests so far, the usefulness of the DHD data collections for other data requests and possibilities to enhance this usefulness, following the research sub questions. During the process of interviewing, the interview protocol was adjusted and improved based on the previous interviews. The interviewees were contacted firstly by email and secondly by phone. Interviews were taken in the hospitals in a separate and quiet environment. Most interviews were performed with one interviewee, in only two hospitals more people were present. The interviews were anonymous and only recorded after approval of the interview

3.4.2d. Analysis of interviews

All interviews were fully transcribed and coded. The transcripts were firstly open coded, secondly axial coded and finally selectively coded, to create useful and efficient qualitative data.

3.4.3. Case analysis

Next to the interviews, a case study was performed to research the usefulness of the DHD data collections. Since a thorough analysis of a certain case (i.e. one data request) provides detailed and accurate information regarding the usefulness of the DHD data collections in satisfying other data requests, one data request was selected to be analysed for similarities with the DHD databases.

3.4.3a. Case selection criteria

The selection of a hospital data request for the case analysis was based on four aspects. The first two aspects were the number of participating hospitals and the stability of the data request, based on the aim of getting long-lasting study results useful for many hospitals. Thirdly the degree of work due to the data request for hospitals and, fourthly, the expectations about similarities with the DHD data collections were considered, trying to make a significant contribution to reducing the administrative load. These aspects were also discussed during the interviews.

3.4.3b. Selected case: quality indicators from the Healthcare Inspectorate (IGZ)

Based on the aspects as described above, the quality indicators from the IGZ (version 2011) were selected to analyse. The quality indicators are an annual issue for all hospitals, since they are compulsory by law, and moreover, numerous and quite complicated to distract from internal hospital information systems. The quality indicators were compared with the following DHD data collections: the EJZ, the LGK and (mainly) the LBZ, which is the upcoming substitute of the current LMR and LAZR.

Since the LBZ is still in development (but almost finished), the most recent LBZ model, version 5.0, was used.

3.4.3d. Analysis of the quality indicators and the DHD data collections

During the case analysis every single indicator of the quality indicators of the IGZ (version 2011) was analysed for similarities with the data gathered by DHD in the EJZ, LKG and LBZ (model version 5.0). Therefore every counter, denominator or other kind of sub-question was investigated whether it was derivable from the DHD data collections, taking into account the criteria for selecting data, definitions, units and classifications used by the IGZ and DHD. The reasons why indicators were or were not derivable were grouped and analysed with simple statistics.

The medical oriented part of the LBZ model was principally used for the analysis, considering the possible bias in data from the financial oriented part of the LBZ model (the DBC codes) due to financial interests.

3.4.4. Participative observation

To gain a deeper understanding of the research topic and the processes involved with data storage and disentanglement in hospitals, participative observation was applied. The researcher visited a medical coder in a general hospital to observe the processes and people involved with the data registration, coding and delivery for the LMR and DBC's. Special attention was paid to processes to maintain the quality of data.

3.5 Validation strategies

During the research the validity and reliability of the results were watched closely by working systematically and considering the undertaken actions. Other strategies were also adopted, to enhance the validity and reliability of the results, which are described below.

3.5.1. Triangulation

Firstly, triangulation of data and methods was applied in this study. By using several methods of collecting data from different sources the results and recommendations to DHD were strengthened. The interviews with several people from different perspectives provided a more accurate interpretation of the data to back up the recommendations.

3.5.2. Verification

3.5.2a. Verification by interviewees

Every interviewee was asked to assess the overview with data requests (gathered so far) regarding accuracy of the information and completeness. In addition, results which came up during the research processes, such as from the analysis or interviews, were discussed with interviewees as well.

3.5.2b. Verification by the requesting organization

To verify the information given about hospital data requests in the final overview, all organizations were approached to check and complete descriptions of their hospital data request.

3.6.3. Interview procedures

3.5.3a. Anonymity

Since the sensitiveness and importance of hospital data is increasing due to the transition to a demand-driven system, anonymity of the interviewees was guaranteed. Prior to the interview, interviewees were informed about their privacy and asked for approval to record the interview. Enabling interviewees to discuss their views anonymously influences the reliability of results positively.

3.5.3b. Summary of results to interviewees

Every interviewee received a summary of the transcribed interview to validate, and if necessary correct, their input.

4. Results

Introduction

This chapter presents the results of this study in chronological order of the research sub-questions. First, section 4.1 outlines the findings of the research for hospital data requests. Section 4.2 presents the results of the case analysis of DHD data collections versus the IGZ quality indicators (sub-question 2a). Section 4.3 describes the views of the interviewees regarding the usefulness of the DHD data collections for other data requests (sub-question 2b). Finally, section 4.4 describes two recommendations to DHD arisen from the analysis and interviews.

4.1. Overview of hospital data requests

Research sub-question 1: Which hospital data requests are queried by external organizations to Dutch hospitals?

4.1.1. Results and appendices

In sum 66 hospital data request were found, coming from various types of organizations and covering a large range of subjects. Appendix 1 provides a comprehensive overview of all requests, including a short description of the administrator, the executor, contact information, the content of the data request, the number of participating hospitals and the frequency they delivered data. In Appendix 2, all hospital data requests are categorized according to the administrator and in Appendix 3 to their content. Table 2 shows the number of data requests in a brief overview, which is described in the section below.

4.1.2. Hospital data requests to administrator and content

As shown in Table 2, most hospital data was found to be requested by collaborating hospitals (18 requests) and professional associations (27, including 15 national complication registries). (The categories are explained in paragraph 4.1.3). From governmental organizations, such as the Ministry of Health and the Healthcare Inspectorate, 9 hospital data requests were found. The amount of data requests from patient associations to hospitals occurred to be low (1).

The regular hospital data requests of individual health insurers were not included, because they did not meet the criteria as stated in section 3.3. Some of these data requests rather varied over the years and/or were requested from one or very few hospitals. As a result, hospital data collections

from individual health insurers were not included in the overview. Nevertheless, it has to be noted that every hospital is confronted with regular hospital data requests from the health insurer(s) who purchase(s) services from their hospital.

Regarding the content of the data requests, we clustered the data requests, as shown in Table 2. The most common were about complications and incidents (19), a certain treatment (17) or disorder (13) or hospital-wide data (12). Below the categories are explained. Many data requests concerning complications and incidents, a specific disorder or treatment were national registration systems being established by professional associations, according to their specific profession.

Administrator	Content					
	Specific disorder	Specific treatment	Complications and incidents	Business/general information	Hospital-wide	Total
Professional associations	5	6	15	-	1	27
Collaborating hospitals	4	4	1	3	6	18
Governmental organizations	1	2	1	2	3	9
Collaborations of different organizations	2	3	-	-	1	6
Health insurers*	-	-	-	-	1	2
Patient associations	1	-	-	-	-	1
Other	-	2	2	-	-	4
Total	13	17	19	5	12	66

Table 2. Hospital data requests to Dutch hospitals according to principal and content

* Regular data requests from individual health insurers not included.

Overall the amount of hospital data requests from health professionals (i.e. the collaborating hospitals and professional organizations) was higher than expected, while the number of data requests from governmental organizations occurred to be lower than was assumed. However, among the latter category were four large hospital-wide or general data requests; the quality and safety indicators from the Dutch Healthcare Inspectorate (IGZ), the Transparent Care indicators (ZiZo) and the annual Financial Statement (JVZ). According to the interviewees these four data requests, together with the annual data requests from health insurers, were responsible for the major part of

the work load arising from the data requests. On the contrary, the data requests from health professionals mostly concentrated at a particular subject (such as a particular disease, treatment or complications in a certain specialism), which means they were not relevant to the whole hospital, but spread across the different departments in hospitals.

Patient associations were mostly found to obtain the required hospital data from databases of other external organizations, such as Transparent Care, or to collaborate with professional associations. As a consequence, the amount of data requests from hospitals appeared to be very low.

4.1.3. Explanation of categories

In the table above, the hospital data requests are categorized according to content and administrator.

Within the categories regarding the content, the categories *'Specific disorder'* and *'Specific treatment'* contain data requests which collect data related to one specific disorder or treatment, such as the Dutch Kidney Function Replacement Registry (Renine) from the Renine Foundation (Stichting Renine). To the category *'Business or general information'* belong data concerning the hospital employees, the facilitating company or the annual returns, such as the Hospital Annual Statistics Survey (EJZ) from DHD.

'Hospital-wide' refers to data collections containing hospital-wide data about quality of care, performance, safety and prevention or medical data, such as diagnoses and medical procedures. Among those are the quality indicators from the Healthcare Inspectorate (IGZ) and the DBC Information System database containing all invoiced DBC's (DIS).

In addition, the data requests were categorized according to the type of administrator. The category *'Professional associations'* contains data requests performed by associations of medical specialists, such as the National Cardiovascular Data Registry (NCDR) from the Netherlands Society of Cardiology (NVVC), and the national complications registries. *'Collaborating hospitals'* are all initiatives taken by hospitals which collaborate to collect data at national or regional level. Some examples are the National Trauma Registry (LTR) from the National Association for Trauma Centres and the data collections of DHD.

'Governmental organizations' includes the Ministry of Health, Welfare and Sports (VWS) and related organizations such as Dutch Healthcare Inspectorate (IGZ). To the category *'collaborations of different organisations'* belong initiatives from different types of organizations, for instance the PREZIES-network (Prevention of Hospital Infections by Surveillance), which is a collaboration of the National Institute for Public Health and the Environment (RIVM), the Central Accompaniment Organization (CBO) and the participating hospitals.

4.2. Derivability of the quality indicators from the DHD data collections

Research sub-question 2a. Can the hospital data requested in the quality indicators from the Dutch Health Care Inspectorate be derived from the DHD data collections?

Introduction

Research sub question 2 was divided into two questions. In the first paragraph, the results from the case analysis of the IGZ quality indicators will be presented. Secondly, the usefulness of the DHD data collections regarding other data requests in general will be discussed, based on results of the interviews.

4.2.1. Structure of the IGZ quality indicators

The basic set of quality indicators (version 2011) of the Dutch Healthcare inspectorate contains 34 quantitative indicators, divided over eleven chapters (IGZ, 2011). Every indicator consists of one or more sub-questions, such as counters, denominators, a table or numeric questions. Regarding the tables every cell was counted as one sub-question, resulting in 136 sub-questions in total.

	Derivable from DHD data collections	Amount	Share of total amount (%)
Indicators	Complete derivable	7	21 %
	Partly derivable	15	44 %
	Not derivable	12	35 %
	Total	34	100 %
Sub – questions	Derivable	33	24 %
	Not derivable	103	76 %
	Total	136	100 %

Table 3. Absolute and relative numbers of quantitative indicators and sub-questions of the IGZ quality indicators which were derived from the DHD data

4.2.2. Amount of indicators and sub-questions derivable from the DHD data collections

The case analysis of the IGZ quality indicators revealed that seven indicators could be derived completely from the hospital data gathered by DHD (Table 3). This means that all the hospital data required to answer these indicators (including all sub-questions) was available in the DHD data collections. In addition, 15 indicators were found to be partly derivable. For most of these indicators the denominator could be derived from DHD data, while the counter could not (13 out of 15). For

twelve indicators the needed data could not be gathered from the DHD data collections at all.

When expressed in sub-questions, only a quarter of the quantitative part of the basic set of quality indicators was found to be derivable from the DHD data collections (n=33, 24%). Half of them (17 of the 33 derivable sub-questions) belong to the seven complete derivable indicators. Among the indicators which were not or partially derivable were some extensive tables, resulting in a total amount of 103 sub-questions which could not be derived from the DHD data collections.

4.2.3. Derivable indicators per chapter

Table 4 presents the numbers of derivable indicators according to the several chapters of the basic set of quality indicators. Chapter 2 did not contain quantitative indicators. Most derivable sub-questions were found in chapter 1 (Surgical process), 5 (Oncology) and 6 (Heart and vessels) of which (respectively) 10, 5 and 9 sub-questions could be derived from the DHD data collections. Appendix 4 shows the amount of derivable indicators and sub-questions for each chapter in detail.

Nr	Chapter	Indicator			Sub-questions	
		Total amount in chapter	Completely derivable	Partly derivable	Total amount in chapter	Derivable
1	Surgical process	5	2*	2*	22	10
3	Nursery care	7	0	3*	21	3
4	Intensive care	2	1^	0	25	1
5	Oncology	7	2*	2*	19	5
6	Cardiovascular	6	2*	3*	17	9
7	Infectious diseases	2	0	1*	18	1
8	Gastroenterology	1	0	1*	2	1
9	Midwifery	1	0	0	6	0
10	Vulnerable populations	1	0	1*	2	1
11	General quality policy	2	0	2^	4	2
Total		34	7	15	136	33

Table 4. Number of derivable IGZ quality indicators and sub questions (version 2011) per chapter from DHD data collections

* derived from the LBZ

^ derived from the EJZ

4.2.4. DHD collections used for the IGZ quality indicators

The 22 quality indicators which occurred to be completely (7) or partly (15) derivable could be answered by using data from the LBZ and EJZ. As shown in Table 4 and 5 the major source was the LBZ, the upcoming substitute of the current LMR and LAZR. 30 sub-questions, divided over 19 indicators, requested similar data as collected in the LBZ. Only two of them requested data which needed to be gathered from the financial oriented part of the LBZ model, since they were based on DBC-codes (the denominators of the indicators 6.2 and 6.6). All other sub-questions (28) were derived from the medical oriented part of the LBZ model, mostly by combining data such as:

- medical procedures (CBV codes),
- diagnoses (ICD-10),
- dates (of start/end of admission), medical procedures, birth, death),
- type of care (clinical, outpatient, day admission),
- specialism, etc.

For three indicators the EJZ data was consulted. Indicator 4.1 (the amount of specialists available for the intensive care) contained only one sub-question, which could be derived from the EJZ data. For the two indicators regarding the general quality policy of hospitals (chapter 11) the denominator could be answered.

Derived from	Amount of sub-questions	Amount of indicators
LBZ	30	19
EJZ	3	3
Total	33	22

Table 5. DHD collections of hospital data used to answer IGZ quality indicators

4.2.5. The missing information for the 27 partially or not derivable indicators

Table 6 shows the reasons why 27 indicators could not or only partly be derived from the DHD data registries. It occurred not to be due to different definitions, classifications, etc. One indicator requested the number of patients which were passed away in and outside of the hospital, which has to be retrieved from the Civil Registry (GBA). This was indicated as *'out of the scope of hospital care'*. However, the major reason was that the indicators requested data which was not requested by any DHD registry. These data were out of the scope of the national DHD data collections. For instance,

Reasons	Number
Not requested by any DHD registry	26
Out of the scope of hospital care	1
Total	27

Table 6. Reasons why 27 indicators could not/only partly be derived from the DHD data collections

test scores for certain diseases or extra data about the treatment were necessary to complete the indicator. The missing data for these indicators is shown in more detail in Table 7.

38 sub-questions requested detailed information about the treatment

which was not available in the DHD data collections. For instance, the duration of artificial respiration and results of breast cancer surgeries are not requested by any DHD data registry. Three indicators asked for the exact point in time of the start of a certain treatment, such as thrombolysis. These were categorized into the separate category ‘point in time’.

Additional data necessary to complete the indicator or sub-question	Number of sub-questions which requested this data	Number of indicators which requested this data
Data concerning the treatment	38	6
Screening for a certain disease/symptom	26	9
Extra information regarding the diagnose	25	4
Classification of diagnose/symptoms	23	11
Point in time (of medical procedure/death)	8	4
Organisation of hospital	5	4
Registries from professional associations/specialists	3	3
Mortality of patients outside the hospital	1	1

Table 7. Additional data necessary to answer the 27 indicators and their 103 sub-questions which could not be derived (completely)

A quarter of the sub-questions queried whether there has been tested for certain diseases or symptoms (26), such as screening for malnutrition and surveillances for infectious diseases among patients, which is not collected on national level either. In addition, classifications of diagnoses or symptoms were frequently requested (23 sub-questions from 11 indicators), such as the TNM classification of carcinomas, or other additional information regarding the diagnose (25).

Four indicators could not be answered due to missing organisational information, such as the structure of departments of a hospital and their staff policy. Three sub-questions asked for the amount of cases entered in certain registries from professional associations.

4.3. Usefulness of the DHD data collections regarding other data requests

Research sub-question 2b: Could the hospital data requested in other data requests be derived from the DHD data collections, in general?

For this research sub-question input from the interviewees, the professionals from hospitals, has been used.

4.3.1. Views of hospital professionals regarding the usefulness of DHD data collections to satisfy other data requests

According to the interviewees, the major overlap between hospital data requests was regarding the diagnoses and medical procedures. Almost all data requests are based on these data. Regarding this, the LBZ (currently the LMR and LAZR) is a large national set of hospital data, containing diagnoses, medical procedures and patient information, which might be useful for other data collectors as well. However, since many data requests also query additional specific data, the DHD data collections (the LAZR, LMR and upcoming LBZ) are mostly too limited to satisfy other data requests, as illustrated by the next quotes.

‘Very specific information about certain specialisms is not included in the LBZ’.

‘Other requests are too specific; you need more than only the clinical diagnose or the postal code of the patient. Regarding the IGZ and ZiZo, they are more a combination of different fields and different registries. You always need data from a laboratory, radiology or another system as well to answer the questions completely’.

This detailed information, necessary to comply with most hospital data requests, is not available in the DHD data collections according to the interviewees.

Some interviewees roughly divided the data request into two groups. Next to the requests as described above which ask for detailed clinical hospital data, they mentioned requests for ‘general’ data. These data requests query data about the production and parameters of hospitals, such as the number of admissions, staff, the capacity and occupation of beds. It was suggested the DHD data collections could be useful for these requests for general data. For instance, they observed doublings between the data requested by the Hospital Annual Statistics Survey (EJZ) and the quantitative (DigiMV) section of the Financial Statement (JVZ). One interviewee mentioned that the EJZ has similarities with the data request from Prismant about the costs of the Facility management (Kosten facilitair bedrijf ziekenhuizen) as well.

4.3.2. Doubts about the comparability of hospital data

Concerning the usefulness of the DHD data collections to comply with other data requests, some interviewees pointed at the quality of hospital data. Although they acknowledged hospitals themselves are the leading actor regarding the quality their data (for example their LBZ data), they were concerned about the comparability of hospital data between hospitals, as illustrated by the next quotes.

'For instance a certain heart operation, how is this registered in hospital X, and how in hospital Y? How different are they?'

'When you supply honest, reliable data, you might be at the bottom of the list.'

Regarding this, it was suggested to be beneficial when DHD would derive hospital data from their data collections for multiple hospitals, as explained below.

4.3.3. Partial delivery of the needed data by DHD to enhance uniformity

During several interviews it was put forward that although the helpfulness of the DHD data collections to comply with other data requests is limited, it would be very helpful if DHD would partly deliver the data needed to complete a request, such as the indicators from the IGZ or ZiZo, to do some ground work for hospitals. The next quote shows this suggestion:

'DHD could already fill in as much of the IGZ and ZiZo questions as possible based on the data that DHD holds. That would result in lists with patient numbers, which we can use to look up the medical files to for the remaining counting's. That would have a surplus value.'

According to them this preliminary work would relieve hospitals, since the gathering of the data from the intern databases in hospitals is difficult and labour-intensive. Several organizations were mentioned which use this method as well; the Dutch Cancer Registry (NKR), the HIV registry and Transparent Care (ZiZo). Moreover, all hospitals would deliver data which would be obtained at the same way and based on one and the same interpretation of definitions. This would increase the homogeneity of the data, for at least a part of the total data request, as illustrated by the next quote.

'Imagine DHD would derive from their data collections data for a certain denominator, then every hospital would start with a list of patients based at one and the same derivation. That would be a large improvement regarding different or wrong interpretation of definitions and enhance uniform data.'

During the interviews it was emphasized that when DHD would provide hospitals with a part of the hospital data needed to complete the indicators, the data which would be derived from the DHD data collections should be supplied to the hospitals at patient level. This would be necessary to verify the data. Since most data are very sensitive due to the (increasing) competition between hospitals, it

was underlined the data should be checked with the most up to date and precise knowledge as available in hospitals.

4.4. Options to enhance the usefulness of the DHD data collections regarding other requests

Research sub-question 3: How could DHD enhance the possibilities for using the DHD data collections to comply with requests for hospital data from other organizations?

Based on the case analysis and interviews, two opportunities will be pointed out which might extend the usefulness of the DHD data collections (in particular the LBZ) for other hospital data requests.

4.4.1. Date of diagnose missing in LBZ

First, the analysis revealed that the content of the DHD data collections is not sufficient to complete the IGZ quality indicators. According to the interviewees, this probably will be the case for many other data requests as well, since they often request additional detailed data as well. To enlarge the scope of the LBZ data collection by including more data to the data model would require a proper consideration of the costs and benefits of this inclusion. The benefits might not counterbalance the charges which would be needed to collect the information at national level, or benefit the individual hospitals. For example, to request the point of time at which medical procedures were performed, as being requested for certain treatments by the IGZ quality indicators, would probably result in many additional administrative tasks for hospital(s) (employees), while only a few organizations would benefit. In other words, the function and purposes of a national data collection need to be kept in mind.

However, from the analysis it appeared that the date of diagnoses was necessary for several indicators. This might be valuable information for more data requests as well. Nevertheless, in the medical oriented part of the LBZ model the clinical diagnose is registered without the date at which this diagnose was made. To enhance the possibilities for the use of the LBZ, it could be considered to include the date of the clinical diagnose to the LBZ data model. When the date at which the clinical diagnose is made is registered in the Electronic Patient Dossiers, it might not be very labour intensive for hospitals to supply the data of the clinical diagnoses to the LBZ registry.

4.4.2. Linking DHD data collections with other databases

A second option which might broaden the possibilities of the DHD data collections for other hospital data requests is to enable to connect with other databases. Since the scope of the LBZ might be too small to comply with other requests, as mentioned above, linkages with other databases could be a different approach towards enhancing the possibilities of the DHD data collections. The LBZ could be connected to other hospital data collections either by using the anonymised BSN number or by developing a primary key.

As from 2014, when the LMR and LAZR will merge into the LBZ, anonymised BSN numbers will be registered in the LBZ. Until now, the LMR and LAZR contained hospital data, such as the diagnose and medical procedures, for every hospital admission. The new concept of the LBZ, in which the anonymised BSN number will be included as well, can create new insights about patients. By using this number, hospital data about certain patients from the DHD data collections could be joined with hospital data about these patients from other databases. This would create new possibilities for the LBZ regarding hospital data requests which aim at information about certain patients (groups) within a particular hospital.

However, the use of the BSN number in hospitals is quite recently introduced and not generally used yet. Therefore, connecting hospital data from several hospital data collections is not always possible. Especially earlier hospital data collections do not contain the anonymised BSN number. In case a data collection does not contain the BSN-number, it would be able to connect hospital data from the LBZ, LMR and LAZR with other databases by developing a primary key. For instance, a combination of a postal code, age and sex could link several databases.

5. Discussion

Introduction

This chapter discusses the results and their meaning. Firstly, section 5.1 provides a brief summary of the results. Section 4.2 considers the strengths and limitations of this study. In section 4.3, the results are discussed and compared with previous research. Finally, section 4.4 describes the implications of the results.

5.1. Summary of results

Research sub-question 1: Which hospital data requests are queried by external organizations to Dutch hospitals?

In summary, 66 data collections which regularly request hospital data from Dutch hospitals were found. Most hospital data requests were from professional associations (27, including 15 national complication registries) and collaborating hospitals (18 requests). The most common were about complications and incidents (19), a certain treatment (17) or disorder (13) or hospital-wide data (12).

Research sub-question 2: Would it be possible to comply with data requests from other organizations by deriving hospital data from the DHD data collections?

The case analysis of the DHD data collections and the IGZ quality indicators (version 2011) showed that 7 indicators were completely derivable from the LBZ or EJZ, while 15 indicators partly could be derived. The latter mostly were indicators of which only the denominator could be answered with the DHD data collections. Expressed in sub-questions, 24% of the total amount of sub-questions could be derived. The reason why many indicators were not (completely) derivable was mainly due to the scope of the LBZ, which was not comprehensive enough compared to the broad range of data or detailed level of information which is requested by the IGZ quality indicators. The most common missing information was extra data concerning the treatment or diagnose, whether there had been screening for certain diseases or symptoms and classifications of diagnoses or symptoms.

This was in accordance with the opinions of the interviewees, which perceived the usefulness of the DHD data collections for other data requests as limited. However, since the core of most data requests contains data about diagnoses and medical procedures, there are similarities with the LBZ. Moreover, it was suggested that DHD could derive data from the DHD data collections for data requests such as the IGZ and ZiZo indicators. This would enhance the homogeneity and comparability of the (published) hospital data and would relieve hospitals. At the moment, many hospitals are concerned about the reliability and comparability of hospital data between hospitals.

Research sub-question 3: How could DHD enhance the possibilities for using the DHD data collections to comply with requests for hospital data from other organizations?

Based on this research, two recommendations which could enhance the usefulness of the DHD data collections were made. Firstly, the current LBZ data model does not contain the date at which the diagnose is made, which would be worthy for other hospital data requests such as the IGZ quality indicators. Secondly, linkages with other databases are another approach to enhance the possibilities of the DHD data collections. The LBZ could be connected to other hospital data collections either by using the anonymised BSN number or by developing a primary key.

5.2. Strengths and limitations of the study

One of the strengths of this study, concerning the methodology, is the triangulation of methods. Several methods have been used to investigate the problem, for example literature research, a case analysis and interviews with professionals in hospitals. Together they have provided information from different perspectives and different levels of detail, which enabled the researcher to gain a comprehensive view of the research field. Very detailed information of the usefulness of the DHD data collections is gained by the case analysis of the IGZ quality indicators, while the interviews resulted in more general results. However, the interviews give power to the results through the expertise of the interviewees.

In addition, the hospital data requests and their descriptions included in the overview are checked by the administrator of the particular data request. This ensures that the overview provides correct and up to date information about the current situation of data requests to hospitals.

A limitation of this study is that the knowledge about hospital data requests appeared to be very fragmented in hospitals, which probably has affected the completeness of the overview of hospital data requests. Hardly any hospital emerged to have a centrally organised coordination of all hospital data supplied to external organisations. Hospital data requests are received by different divisions in hospitals, and also supplied by different divisions. Different professionals from different divisions were interviewed about the data requests in their hospital to gain as much as possible from the fragmented knowledge. Nevertheless, further research into all divisions of hospitals is recommended.

Besides, the period of time restricted the scope of the research. As a consequence, this research mainly focused at the administrator and content of hospital data requests and has analysed one data requests (IGZ quality indicators) for similarities with the DHD data collections. Further research in the goals and information products of the hospital data requests and their similarities with DHD data registries is necessary. It should also be mentioned that this research only focused at constant hospital collections, excluding hospital data request which were only performed once. These once-

only data requests probably affects the heavy work load in hospitals due to data requests as well, especially those from health insurers.

5.3. Results discussed and compared with previous research

5.3.1. Results confirm large number of data requests

The findings of the research for hospital data requests confirmed our expectations (Chapter 1). The overview of data requests shows that hospitals are indeed confronted with a large amount of data requests (Broersen, 2011), even though once-only requests of hospital data, such as from health insurers, were not included. Besides, the findings of the case analysis of the IGZ quality indicators illustrate the complexity of some of these requests. Numerous quality indicators asked for very detailed information or combined data from different resources. In addition, several interviewees showed their concerns about the increasing number of data requests, likewise others reported as well (Broersen, 2011).

5.3.2. Similarities between DHD data collections and other data requests

Regarding the supposed similarities between hospital data requests, on the one hand the case analysis of the IGZ quality indicators and the DHD data collections showed limited overlap, which is supported by the interviews as well. Likewise, the overview of hospital data requests indicates many requests which collect specific data about a particular subject, disease or treatment. On the other hand, during the interviews it was both mentioned that the diagnoses and medical procedures, as registered in the DHD data collections, are requested by many other hospital data requests as well and that there were duplicates between the data requests for ‘general’ data, concerning the production and parameters of hospitals. This study, of course, cannot be viewed as conclusive, and these matters deserve further study.

5.3.3. Additional reasons for the displeasures in hospitals concerning data requests

From this research it appears that the displeasures in hospitals about the large amount of data requests and supposed similarities between them might have additional reasons next to those which were put forward in chapter 1; insufficient cooperation between requesting organizations and segmentation of sectors involved in hospital care (Broersen, 2010; de Bekker, van Sambeek en Boendermaker, 2009). From the interviews it clearly appeared that there is an urgent need for uniform definitions, consistent use of terms and homogeneous formats by the organizations which request data. The current confusion about definitions, varying use of terms and formats and the frustrations among hospital employees which bring this along increases the burden. This was reported previously as well (Broersen, 2010; de Bekker, van Sambeek en Boendermaker, 2009). In

addition, it occurred that the aims of data requests are not always clear to hospital employees, especially those from insurers and governmental organizations. Together this affects the visions and attitudes towards hospital data request. In the quick scan of the NZa (de Bekker, van Sambeek en Boendermaker, 2009) it was put forward that as a consequence of these displeasures, hospitals probably suppose that the requests are not well organized either (de Bekker, van Sambeek en Boendermaker, 2009). The authors suggested that signals from hospital about similarities between data requests might be due to negative experiences, as they found a limited of actual duplicates in hospital data request (Ibid.)

Furthermore, the burden due to hospital data requests might be partly caused by the way how data are managed and organized in hospitals. During the interviews it was mentioned several times that the gathering of the right data to comply with data request can be very difficult. Next to the complexity of some of these requests, there has to be searched for the particular data within the hospital. Since it is not always known which data are registered and where they are hold, this can be quite labour-intensive. Likewise, during the interviews the researcher noticed that the knowledge about data (requests) was fragmented in hospitals. Most hospitals have no central place where it is known which data are registered and stored in-house and which are supplied to external organizations. The data management occurred to be not solely at national level not efficient, according to Alavi & Leidner (2001; see chapter 2), also internally in hospitals the data management could be more strategic.

5.4. Implications of results

The overview of hospital data requests might be a useful tool for hospitals which want to improve their intern data management, as well as for sector associations for national policy-making and further research. Moreover, this overview is helpful for any organization which needs certain hospital data, to research whether this particular data is already collected by another organization. Using others' data would prevent doublings in hospital data requests.

The LBZ and LKG are too limited to complete all quality indicators from the Dutch Healthcare Inspectorate (IGZ). However, the analysis showed that the LBZ en EJZ data are able to complete 7 indicators and to complete another 15 indicators partly (mostly the denominators of these indicators). For this reason, the DHD data registries are useful for hospitals for the gathering and disentanglement of the right data to comply with parts of the IGZ quality indicators, and possibly other data requests as well.

During the interviews it was put forward that deriving the data for these particular indicators by DHD would enhance the comparability and consistency of the final data which is published by IGZ. There are concerns in hospitals about the uniformity of definitions, as mentioned before, but also about

the interpretation of definitions. Different interpretations decrease the comparability of data, which becomes very relevant when data are used for bench-marking and published to inform health insurers and patients. DHD, pursuing improvement of the national hospital data, could play a role in enhancing the comparability of hospital data.

6. Conclusion and recommendations

Introduction

To conclude this study, Section 6.1 reflects at the study and the final conclusions to which this study has led. Finally, some recommendations are made to the Dutch Hospital Data Foundation (section 6.2), Dutch hospitals (section 6.3) and the organizations which (intend to) request data from hospitals (section 6.4).

6.1. Conclusion

This study began with the premise that Dutch hospitals experience a high work load due to the large amount of hospital data requests. Therefore, this study aimed to arrange an overview of these data requests and to investigate whether the DHD data collections would be usable to comply with requests from other organizations. This has resulted in an overview of 66 hospital data request, as presented in Appendix 1. This overview is available for all hospitals and will hopefully be useful to enhance the efficiency of their data management, as well to the sector associations for their national policy concerning hospital data.

This study confirmed again that the current hospital care reforms have largely influenced the Dutch hospital data management by increasing the amount of requested data. Moreover, we have seen that hospitals are concerned about the comparability and consistency of hospital data from different hospitals. This is very important, since the hospital data is used to inform patients and health insurers about the quality of the hospital care.

The results of the study lead to the conclusion that the DHD data collections could be useful for hospital data requests, although they perhaps cannot completely satisfy particular data requests. Firstly, they could facilitate the process of data disentanglement for certain parts of hospital data requests, as shown in this study for the IGZ quality indicators. The DHD data collections could answer 7 complete indicators and for another 13 indicators (mostly) the denominator. The interviewees indicated this would absolutely relieve hospitals. Besides, the current LMR and LAZR and the upcoming LBZ are large data sets with data about diagnoses, medical procedures and basic patient information, which is the core of many other data requests as well. Additional research is needed to investigate whether the DHD data collections are able to fully comply with certain data requests as well.

Furthermore, the DHD data collections could play an important role in deriving uniform, comparable hospital data from different hospitals. Based on this research a few recommendations will be made to DHD, hospitals and organizations which request hospital data.

6.2. Recommendations to DHD

Based on these findings, five recommendations are provided to DHD.

- Firstly, since the knowledge and organization of hospital data management occurred to be very fragmented in hospitals, this overview of hospital data requests is probably incomplete. Further research into hospital data requests is recommended, for example into all divisions of a certain hospital.
- Secondly, it is recommended to consider including the date of the clinical diagnose into the LBZ model. From this study it appears this might be a valuable addition to the LBZ to enhance the usefulness of the LBZ data for other data requests. Further research is necessary to analyze the benefits and costs for this inclusion into the LBZ.
- Furthermore, the anonymised patient number, which is included in the LBZ, or a primary key would create new possibilities to link hospital data from the LBZ with other databases.
- When considering the use of DHD data for other hospital data requests, it is recommended to pay attention to the quality of the data collections as well. When expanding the use of the DHD data collections, the quality of the data becomes more important. It clearly appeared during the interviews that there is pressing need for clearness and uniformity regarding the definitions used in hospital data requests, as well as consistency of these definitions between data requests. Currently, there is confusion among the involved people in hospitals. This affects the quality of data, not only from one particular hospital, but also the comparability of these data from several hospitals. The doubts in hospitals about the comparability of data from different hospitals affect their views whether de DHD data collections are usable to comply with other data requests as well. DHD, working on the improvement of national hospital data, could consider their role in these matters. Especially informing or instructing the involved employees in hospitals could improve both the local and national quality of the hospital data.
- In addition, hospitals are concerned about the growing amount of hospital data requests. For some of these requests, the utility and goals are doubted. Until now, most hospitals comply with most data requests. Further research for the goals and use of the data which are requested is necessary.

6.3. Recommendations to hospitals

At present, the Dutch hospitals are dealing with some far-reaching changes regarding the data processes; the implementation of the DOT and the LBZ, the replacement of the ICD-9 with the ICD-10 and the increasing amount of requests from external organizations. Moreover, in this increasingly

information-focused hospital care the value of the resource being ‘data’ keeps growing. As a consequence, the quality of the data is very important.

For hospitals it would be worthy to use these latest developments to reconsider their data management. These challenges are an opportunity to improve the internal data processes, such as the basic registry, the storage of data and to streamline the data which are supplied to external organizations. This would prevent inefficient and work performed twice. On the contrary, it would increase the capacity for effective action and policy-making with the data produced in-house. The overview and study results as presented in this study are recommended to all hospitals and will hopefully contribute to more efficient data management.

6.4. Recommendations to organizations which (intend to) request data from hospitals

Organizations which request data from hospitals are advised to communicate the goal of the data request clearly to hospitals. In addition, the terms which are used should be defined clearly, according to the current terminology. This will enhance both the compliance of hospitals and the quality of data which are gathered.

Secondly, to organizations which intend to enhance or start a hospital data request it is suggested to investigate first whether the needed data is already requested by another organization. The overview of hospital data requests as presented in this study might be helpful to prevent duplicates in hospital data requests.

In sum, it appeared that the DHD data collections might contain promising opportunities to enhance the national hospital data management, especially to increase the quality and comparability of hospital data. Additional research is needed to specify this challenging task for the Dutch Hospital Data Foundation.

References

- Arts D.G.T., Keizer de N.F., Scheffer G. (2002). Defining and improving data quality in medical registries: a literature review, case study and generic framework. *Journal of the American Medical Informatics Association*, 9:600-611
- Alavi M, Leidner D.E. (2001). Review: Knowledge Management and Knowledge Management Systems: Conceptual Foundations and Research Issues. *MIS Quarterly*, 25(1):107-136.
- De Bekker, van Sambeek en Boendermaker (2009). Rapport 'quick scan dubbele informatie-uitvraag'. *Nederlandse Zorgautoriteit*. Retrieved 17-04-2011 at <http://www.nza.nl/104107/138040/Rapport-quick-scan-dubbele-informatie-uitvraag.pdf>
- Berg M., Goorman E. (1999) The contextual nature of medical information. *Internat. Journal of Medical Informatics*, 36:51-60
- Broersen, S. (2010). Kwaliteit meten nuttig maar tijdrovend. *Medisch Contact*, 66(3):137-139
- CIBG (201). Over Jaarverslagen Zorg. Retrieved 17-04-2011 at <http://www.jaarverslagenzorg.nl/overjaarverslagenzorg/>
- Crul B. (2010). Registratiedruk. Editorial column. *Medisch contact*, 66(3):125
- Deijl van E., Plukker R. (2007). Startdocument Dutch Hospital Data. Version 3.0, 21-05-07.
- DIS (2011). Het landelijke informatiesysteem DIS. Retrieved 17-04 at <http://www.dbcinformatiesysteem.nl/>
- Dutch Hospital Data (2011a). DHD in een notendop. Retrieved at 17-02-11 at <http://www.dutchhospitaldata.nl/DHD/DHD.php>
- Dutch Hospital Data (2011b). Registraties. Retrieved at 10-02-11 at http://www.dutchhospitaldata.nl/Registraties/Over_Registraties.php
- Dutch Hospital Data (2011c). Datamodel. Retrieved at 07-03-11 at <http://www.dutchhospitaldata.nl/LBZ/Datamodel.php>
- IGZ (2011). Basissets kwaliteitsindicatoren. Retrieved at 17-04-11 at

<http://www.igz.nl/onderwerpen/handhavingsinstrumenten/gefaseerd-toezicht/kwaliteitsindicatoren/basissets/index.aspx>

Kemenade, Y.W. van (2007). Healthcare in Europe 2007. The finance and reimbursement systems of 11 European countries. Reed Business Elsevier, Maarsen. ISBN 978-90-352-2915-0

NCDR (2011). De NCDR. Retrieved at 14-06-11 at <http://ncdr.nl/>

RIVM (2010). Zorgbalans 2010. Voorwaarden voor gereguleerde concurrentie. Retrieved 16-02-11 at <http://www.gezondheidszorgbalans.nl/onderwerpen/verbindende-thema-s/bijlage-voorwaarden-voor-gereguleerde-concurrentie/>

Safran C., Bloomrosen M., Hammond W.E., Labkoff S.E., Markel-Fox S., Tang P., Detmer D. (2006). Toward a National Framework for the Secondary Use of Health Data. Report of a working conference of the *American Medical Informatics Association*, retrieved 21-02-11 at https://www.amia.org/files/workforthesecondaryuseofhealthdata_09_08_06_.pdf

Shortliffe H.E., Cimino J.J. (2006) Biomedical informatics. Computer Applications in Health Care and Biomedicine. Springer Science and Business Media, New York, 3rd edition. Retrieved 11-02-11 at http://books.google.nl/books?hl=nl&lr=&id=Wn-fFVuUguMC&oi=fnd&pg=PR5&dq=shortliffe+wiederhold+medical+informatics&ots=UbjnwVIW6m&sig=4uBe_hoBS3oHVUIBa-H1hGTjC_U#v=onepage&q&f=false

VWS (2009). Beleidsverslag 2009. Retrieved 17-02-2011 at http://www.rijksbegroting.nl/2009/verantwoording/jaarverslag,kst900004_4.html

Wyatt, J. (1995) Hospital information management: the need for clinical leadership. *British Medical Journal*, 311:175-178

Zichtbare Zorg (2011). Programma Zichtbare Zorg. Retrieved 17-04-2011 at <http://www.zichtbarezorg.nl/page/Programma-Zichtbare-Zorg>

Zichtbare Zorg (2010). ZN kondigt eigen gebundelde uitvraag in brief aan bij ziekenhuizen en ZBC's. Retrieved 14-06-2011 at

<http://www.zichtbarezorg.nl/page/Home/Nieuws?mod%5BBrickworkNewsModule%5D%5Bn%5D=400.com>

Appendix 1. Overzicht van externe gegevensuitvragingen – inclusief beschrijving

Geordend naar opdrachtgever

Nr	Gegevensuitvraag	Opdrachtgever
Overheidsgerelateerde organisaties		
1	Jaarverslag Zorg (JVZ)	
Opdrachtgever:	Ministerie van VWS	
Organisatie die de uitvraag verzorgt:	CIBG	
URL:	http://www.jaarverslagenzorg.nl/	
Wettelijk verplicht:	Ja, krachtens Regeling verslaggeving WTZi	
Contactpersoon:	CIBG T: 070- 340 69 00 E: jaardocumentmv@minvws.nl	
Omschrijving:	<p>Zorginstellingen moeten elk jaar verantwoording afleggen over de manier waarop zij het geld uit de AWBZ en Zorgverzekeringswet besteden d.m.v. het JVZ. Dit bestaat uit 3 onderdelen:</p> <ul style="list-style-type: none"> - het maatschappelijk verslag: bestaat uit informatievragen over a) uitgangspunten van de verslaggeving, b) profiel van de organisatie, c) governance, d) beleid, inspanningen en prestaties, -- de jaarrekening, -- DigiMV (kwantitatieve gegevens): productie, personeel, opbrengsten, bezoldiging, bouwcategorie, werkgebieden, bestuursstructuur, capaciteit, bestuur, toezicht, transparantie-eisen, kwaliteit, klachten, financiële gegevens en accountantscontrole. 	
Aantal personen of instellingen dat data aanlevert:	Alle Nederlandse ziekenhuizen (88 algemene en 8 academische ziekenhuizen)	
Frequentie van data verzameling:	Jaarlijks	
2	IGZ Basisset kwaliteitsindicatoren	
Opdrachtgever:	Inspectie Gezondheidszorg (IGZ)	
Organisatie die de uitvraag verzorgt:	Inspectie Gezondheidszorg (IGZ)	
Wettelijk verplicht:	Ja	
URL:	http://www.igz.nl/onderwerpen/handhavinginstrumenten/gefaseerd-toezicht/kwaliteitsindicatoren/basissets/index.aspx	
Contactpersoon:	IGZ E: loket@igz.nl T: 088 -120 5000	
Omschrijving:	<p>Door middel van ongeveer 50 kwaliteitsindicatoren vraagt IGZ allerlei gegevens op thema uit aan ziekenhuizen om te bepalen welke zorgprocessen in een ziekenhuis extra aandacht behoeven of om nader onderzoek vragen. In 2011 zijn deze thema's: operatief proces, verpleegkundige processen, intensive care, oncologie, hart en vaten, infectieziekten, maag-darm-lever, verloskunde, kwetsbare groepen en algemeen kwaliteitsbeleid.</p>	
Aantal personen of instellingen dat data aanlevert:	Alle Nederlandse ziekenhuizen (88 algemene en 8 academische ziekenhuizen)	
Frequentie van data verzameling:	Jaarlijks	

3 IGZ Veiligheidsindicatoren	
Opdrachtgever:	Inspectie Gezondheidszorg (IGZ)
Organisatie die de uitvraag verzorgt:	Inspectie Gezondheidszorg (IGZ)
Wettelijk verplicht:	Ja
URL:	http://www.igz.nl/onderwerpen/handhavingsinstrumenten/gefaseerd-toezicht/kwaliteitsindicatoren/basissets/index.aspx
Contactpersoon:	IGZ E: loket@igz.nl T: 088 -120 5000
Omschrijving:	<p>Voor het landelijke Veiligheidsprogramma 'Voorkom schade, werk veilig' (met als doel het verbeteren van patiëntveiligheid in ziekenhuizen op korte termijn) houdt de IGZ toezicht op de invoering van het programma en het behalen van de beloofde resultaten d.m.v. de volgende Veiligheidsindicatoren (2010-2012):</p> <ul style="list-style-type: none"> - HSMR, dossieronderzoek en onverwacht lange opnameduur - Vermijdbare sterfte en vermijdbare schade - De tien thema's: <ol style="list-style-type: none"> 1) Voorkomen van wondinfecties na een operatie, 2a) De behandeling van ernstige sepsis en 2b) het voorkomen van lijnsepsis, 3) Vroege herkenning en behandeling van de vitaal bedreigde patiënt, 4) Medicatieverificatie bij opname en ontslag, 5) Kwetsbare ouderen 6) Optimale zorg bij Acute Coronaire Syndromen 7) Vroege herkenning en behandeling van pijn 8) High Risk Medicatie: klaarmaken en toedienen van parenteralia 9) Verwisseling van en bij patiënten 10) Voorkomen van nierinsufficiëntie bij intravasculair gebruik van jodiumhoudende contrastmiddelen.
Aantal personen of instellingen dat data aanlevert:	Alle Nederlandse ziekenhuizen (88 algemene en 8 academische ziekenhuizen)
Frequentie van data verzameling:	Jaarlijks
4 Zichtbare Zorg indicatoren	
Opdrachtgever:	Ministerie van VWS
Organisatie die de uitvraag verzorgt:	Zichtbare Zorg
Wettelijk verplicht:	Ja
URL:	http://www.zichtbarezorg.nl/page/Ziekenhuizen-en-ZBC-s/Kwaliteitsindicatoren/Verplichte-indicatoren-2012
Contactpersoon:	ZiZo T: 070-3406900 E: helpdesk@zichtbarezorg.nl
Omschrijving:	<p>Kwaliteitsgegevens m.b.t. een aantal aandoeningen. De kwaliteit van de zorg rond deze aandoeningen wordt uitgevraagd d.m.v.:</p> <ul style="list-style-type: none"> - zorginhoudelijke indicatoren: kwaliteit van zorg die een instelling levert, m.n. op effectiviteit en veiligheid. - klantpreferentievragen: wensen en behoeften van patiënten m.b.t. keuze-informatie over de zorg die het ziekenhuis kan bieden bij de aandoening. <p>In 2011 zijn voor de volgende aandoeningen verplichte indicatoren uitgevraagd over verslagjaar 2010: beroerte, blaascarcinoom, cataract, chronische rhinosinusitis, colorectaal carcinoom, constitutioneel eczeem, cystic fibrosis, diabetes, heupvervanging, knie vervanging, licht traumatisch hoofdletsel, liesbreukoperaties, lumbosacraal radiculair syndroom,</p>

	mammacarcinoom, OSAS bij volwassenen, perioperatief voedingsbeleid, pijn bij bevalling, pijn bij kanker bij volwassenen, reumatoïde artritis, stressincontinentie bij de vrouw, varices, ziekte van adenoid en tonsillen. Daarnaast zijn er niet-verplichte aandoeningen indicatorensets, omdat deze nieuw ontwikkeld zijn. Voor deze aandoeningen zal pas later de aanleververplichting ingaan. In 2011 betrof dit de volgende aandoeningen: Acute urineweginfecties, baarmoederhalsafwijkingen, benigne prostaat hyperplasie, carpaletunnelsyndroom, chronische belemmering bloedstroom been, coeliakie, dementie, hartfalen, hartritmestoornissen, HIV/AIDS, IBD, longcarcinoom, longontsteking, maagcarcinoom, maligne lymfoom, melanoom van de huid, meniscus en voorste kruisband, migraine, nierstenen, osteoporose, Parkinson, prostaatcarcinoom, psoriasis en SOA.
Aantal personen of instellingen dat data aanlevert:	Alle Nederlandse ziekenhuizen (88 algemene en 8 academische ziekenhuizen)
Frequentie van data verzameling:	Jaarlijks
5 Registratie Wet Afbreking Zwangerschap (WAZ-registratie)	
Opdrachtgever:	Inspectie Gezondheidszorg (IGZ)
Organisatie die de uitvraag verzorgt:	IGZ
Wettelijk verplicht:	Ja, krachtens Wet Afbreking Zwangerschap
URL:	http://www.igz.nl/Images/2010-12%20Jaarrapportage%20WAZ%202009_tcm294-292695.pdf
Contactpersoon:	IGZ E: loket@igz.nl T: 088 -120 5000
Omschrijving:	Gegevens over alle abortussen (inclusief de zogeheten overtijdbehandelingen) in Nederland. Variabelen: aantal abortussen en overtijdbehandelingen naar kliniek of ziekenhuis, zwangerschapsduur bij behandeling, aantal eerdere zwangerschappen, aantal eerdere abortus provocatus, leeftijd van de vrouw, woonplaats naar land en, indien Nederland, naar provincie, burgerlijke staat, aantal levende kinderen, beraadtermijn, verwijzing, overleg met andere deskundigen, complicaties, nazorg, anticonceptiekeuze, nacontrole.
Aantal personen of instellingen dat data aanlevert:	117 instellingen (ziekenhuizen en abortusklinieken met een WAZ-vergunning)
Frequentie van data verzameling:	Per kwartaal
6 Kwartaalenquête ziekteverzuim	
Opdrachtgever:	Centrale Commissie voor de Statistiek
Organisatie die de uitvraag verzorgt:	Centraal Bureau Statistiek
Wettelijk verplicht:	Ja (CBS-wet)
URL:	http://www.cbs.nl/nl-NL/menu/themas/arbeid-sociale-zekerheid/methoden/dataverzameling/korte-onderzoeksbeschrijvingen/kwartaalenuquete-ziekteverzuim-art.htm
Contactpersoon:	CBS Infoservice T: 088-5707070 E: infoservice@cbs.nl
Omschrijving:	Het totaal aantal ziekte-dagen van de werknemers, in procenten van het totaal aantal beschikbare (werk-/kalender)dagen van de werknemers in de verslagperiode, uitgesplitst naar bedrijfssector, bedrijfstak/branches, bedrijfsklasse en bedrijfsgrootte.

Aantal personen of instellingen dat data aanlevert:	Responspercentage van de ondervraagde bedrijven en instellingen is 75%
Frequentie van data verzameling:	Per kwartaal
7 Letsel Informatie Systeem	
Opdrachtgever:	Min. van VWS en SZW, Europese Commissie
Organisatie die de uitvraag verzorgt:	Stichting Consument & Veiligheid
Wettelijk verplicht:	Nee
URL:	http://www.veiligheid.nl/onderzoek/letsel-informatie-systeem
Contactpersoon:	H.G.W.Sprik (Coördinator LIS) T: 020 5114523 E: e.sprik@veiligheid.nl
Omschrijving:	Persoons-, toedracht- en letselgegevens van ongevalsslachtoffers en zieken die zich voor behandeling melden bij een afdeling voor spoedeisende hulp (SEH) van Nederlandse ziekenhuizen (geslacht, leeftijd, locatie, activiteit, type letsel/locatie letsel/wijze behandeling, verwijzing, doorverwijzing, betrokken producten, letselmechanisme, oorzaak letsel, datum en tijd oplopen letsel)
Aantal personen of instellingen dat data aanlevert:	14 ziekenhuizen
Frequentie van data verzameling:	Continu
8 NVIC Monitor	
Opdrachtgever:	Ministerie van VWS
Organisatie die de uitvraag verzorgt:	Nationaal Vergiftigingen Informatie Centrum
Wettelijk verplicht:	Nee – geen meldingsplicht voor acute vergiftigingen
URL:	http://www.rivm.nl/Onderwerpen/Onderwerpen/V/Vergiftigingen
Contact:	nvic@umcutrecht.nl
Omschrijving:	De gemelde blootstellingen aan toxische stoffen, gemeld door artsen of andere hulpverleners bij het NVIC, onderverdeeld in verschillende productcategorieën, zoals geneesmiddelen, huishoudmiddelen, drank, drugs, industrieproducten, bestrijdingsmiddelen, planten, giftige dieren, cosmetica, etc, samen met de hoeveelheid en/of concentratie van de toxische stof, contactweg en leeftijd, geslacht en lichaamsgewicht van de blootgestelde patiënt.
Aantal personen of instellingen dat data aanlevert:	Alle ziekenhuizen (elke arts, apotheker of andere hulpverlener) in Nederland die advies nodig hebben bij een acute vergiftiging kunnen het NVIC raadplegen. De gegevens over die betreffende acute vergiftigingen waarbij het NVIC geraadpleegd is worden in de database opgeslagen (ong 50.000 per jaar)
Frequentie van data verzameling:	Continu
9 HIV-registratie	
Opdrachtgever:	Ministerie van VWS
Organisatie die de uitvraag verzorgt:	Stichting HIV Monitoring (SHM)

URL:	http://www.hiv-monitoring.nl/
Wettelijk verplicht:	Ja
Contactpersoon:	F. de Wolf (directeur SHM) E: f.dewolf@amc.nl
Omschrijving:	<p>Identificatie geanonimiseerde patiëntgegevens (uniek code nummer)</p> <p>Identificatie en codering HIV behandelcentrum en internist/kinderartsbehandelaar</p> <p>Gegevens HIV transmissierisico's</p> <p>Klinische gegevens HIV infectie</p> <p>Laboratoriumgegevens HIV infectie</p> <p>Klinische gegevens overige infecties</p> <p>Laboratoriumgegevens overige infecties</p> <p>Gegevens antiretrovirale therapie (ART)</p> <p>Resistentiegegevens HIV-1</p> <p>Klinische gegevens bijwerkingen/toxiciteit (ART)</p> <p>Laboratoriumgegevens bijwerkingen/toxiciteit</p> <p>Gegevens co-medicatie</p>
Aantal personen of instellingen dat data aanlevert:	26 instellingen met een vergunning voor verlenen van HIV zorg
Frequentie van data verzameling:	Per kwartaal
Wetenschappelijke verenigingen	
10 BHN Hartinterventie registratie	
Opdrachtgever:	Begeleidingscommissie Hartinterventie Nederland (BHN) , bestaande uit Ned. Ver. voor Thoraxchirurgie (NVT), Cardiologie (NVVC), Kindercardiologie (NVKC) en Anesthesiologie (NVA)
Organisatie die de data uitvraag verzorgt:	afdeling Klinische Informatiekunde (KIK) van het AMC te Amsterdam
URL:	www.bhn-registratie.nl
Contactpersoon:	Drs. M.I.M. Versteegh (voorzitter) - LUMC afdeling Cardio-thoracale chirurgie T: 071 526 9111
Omschrijving:	Landelijke registratie van patiënt- en medische gegevens van alle hartinterventies in Nederland (Open Hart Operaties (OHO's), Percutane Coronaire Interventies (PCI's), Kindercardiologische katheterinterventies). Gegevensregistratie op detailniveau
Aantal personen of instellingen dat data aanlevert:	Alle 16 Nederlandse hartchirurgische centra
Frequentie van data verzameling:	Continu, controle per kwartaal
11 BHN Wachlijstenregistratie	
Opdrachtgever:	Begeleidingscommissie Hartinterventie Nederland (BHN) , bestaande uit Ned. Ver. voor Thoraxchirurgie (NVT), Cardiologie (NVVC), Kindercardiologie (NVKC) en Anesthesiologie (NVA)
Organisatie die de data uitvraag verzorgt:	afdeling Klinische Informatiekunde (KIK) van het AMC te Amsterdam
URL:	www.bhn-registratie.nl

Contactpersoon:	Drs. M.I.M. Versteegh (voorzitter) - LUMC afdeling Cardio-thoracale chirurgie T: 071 526 9111
Omschrijving:	maandelijkse enquête m.b.t. wachttijden van hartcentra (mediane wachttijd, voorspelde wachttijd, totaal aantal patiënten op de wachtlijst, aantal patiënten dat langer dan 2 maanden en 3 maanden wacht)
Aantal personen of instellingen dat data aanlevert:	Alle 16 Nederlandse hartchirurgische centra
Frequentie van data verzameling:	Maandelijks
12 Landelijke Registratie Orthopaedische Implantaten (LROI)	
Opdrachtgever:	Nederlandse Orthopaedische Vereniging (NOV)
Organisatie die de uitvraag verzorgt:	Department of Advanced Data Management, LUMC te Leiden
URL:	https://www.msbi.nl/promise/Projects/NOV/NOV_LROI.aspx
Contactpersoon:	Ineke van der Veen (project designer) E: I.van_der_Veen@lumc.nl Marjon Smeets (projectmanager LUMC) E: m.m.a.j.smeets@lumc.nl T: 071-5269726
Omschrijving:	De LROI registratie beoogt een volledige registratie te zijn van alle in Nederland geïmplanteerde en/of gereviseerde heup- en knie-prothesen, om inzicht te krijgen in de "levensduur" van deze prothesen en zo bij te dragen aan de kwaliteit van zorg.
13 Nationale Intensive Care Evaluatie (NICE)	
Opdrachtgever:	Stichting NICE
Organisatie die de uitvraag verzorgt:	Stichting NICE i.s.m. afdeling Klinische Informatiekunde (KIK), AMC, Amsterdam
URL:	www.stichting-nice.nl
Contactpersoon:	Dr. D.W. de Lange, secretaris NICE, Universitair Medisch Centrum Utrecht E: D.W.delange@umcutrecht.nl, T: 088 756 1125 - 088 756 1116 (secretariaat)
Omschrijving:	Voor elke opgenomen patiënt een minimale dataset (ong 100 items), betreffende demografische gegevens, opname en ontslag gegevens, gegevens omtrent de fysiologische conditie (bv bloeddruk, hartslag, ademhalingsfrequentie, leucocyten, bilirubine etc) van de patiënt in de eerste 24 uur van IC-opname en enkele diagnostische variabelen (reden van IC opname, comorbiditeiten) bij opname. De minimale dataset is voor alle deelnemers verplicht. Daarnaast zijn enkele aanvullende facultatieve datasets gedefinieerd zoals de door de NVIC gedefinieerde kwaliteitsindicatoren (sommige gegevens hiervoor worden per dienst verzameld), een dagelijkse complicatieregistratie en een dagelijkse orgaanfalen-score.
Aantal personen of instellingen dat data aanlevert:	80 Intensive Care Units (ICU's)
Frequentie van data verzameling:	Gegevens worden dagelijks verzameld en maandelijks verstuurd naar de st. NICE
National Cardiovascular Data Registry (NCDR)	
14	<ul style="list-style-type: none"> ○ Cardiovascular Interventional Data Registry (CIDR) ○ Dutch ICD and Pacemaker Registry (DIPR)

Opdrachtgever:	Nederlandse Vereniging voor Cardiologie (NVVC)
Organisatie die de uitvraag verzorgt:	Stichting NCDR (National Cardiovascular Data Registry)
URL:	www.ncdr.nl
Contactpersoon:	E: bureau@ncdr.nl T: 020-3331080
Omschrijving:	Landelijke databases met technische en klinische gegevens over de in Nederland uitgevoerde verrichtingen in de cardiologie en vasculaire geneeskunde, incidentie en prevalentie van cardiovasculaire aandoeningen en registratie van complicaties en incidenten, voor kwaliteitsverbetering, wetenschappelijk onderzoek, onderwijs en opleiding, benchmarking, beroepsbelangen en public relations.
Aantal personen of instellingen dat data aanlevert:	89 ziekenhuizen (per 28-03-11)
Perinatale Registratie Nederland (PRN)	
15	<ul style="list-style-type: none"> ○ Landelijke Verloskunde Registratie 1^e lijn (LVR-1) ○ Landelijke Verloskunde Registratie 2^e lijn (LVR-2) ○ Landelijke Verloskunde Registratie huisartsen (LVRh) ○ Landelijke Neonatologie Registratie (LNR)
Opdrachtgever:	Ned. Ver. voor Obstetrie en Gynaecologie (NVOG), Ned. Ver. voor Kindergeneeskunde (NvK), Landelijke Huisartsen Ver. (LHV) en Kon. Ned. Org. van Verloskundigen (KNOV)
Organisatie die de uitvraag verzorgt:	Stichting PRN
URL:	www.perinatreg.nl
Contactpersoon:	E: info@perinatreg.nl T: 030-2823165 (direct)
Omschrijving:	Zwangerschapsgegevens, partusgegevens (bevalling), problematiek moeder, problematiek kind, onderzoeken/verrichtingen en medicatie tijdens zwangerschap, demografische gegevens moeder, overlegsituaties en overname vanuit de verschillende disciplines
Aantal personen of instellingen dat data aanlevert:	In principe alle praktijken van eerstelijns verloskundigen (± 500), verloskundig actieve huisartsen (± 50), gynaecologen (± 90) en neonatologen/kinderartsen (± 90), alsmede alle NICU's (10)
Frequentie van data verzameling:	In principe continu, in ieder geval jaarlijks
16 Risicogewogen mortaliteitsregistratie	
Opdrachtgever:	Nederlandse Vereniging voor Thoraxchirurgie (NVT)
Organisatie die de uitvraag verzorgt:	Nederlandse Vereniging voor Thoraxchirurgie (NVT)
URL:	http://www.nvtnet.nl/?page_id=10
Contactpersoon:	Prof. dr. L. van Herwerden (voorzitter commissie dataregistratie NVT) - UMCU T: (+31) 88 755 6179 E: L.vanherwerden@umcutrecht.nl
Omschrijving:	Data voor risicogewogen mortaliteitsregistratie

Aantal personen of instellingen dat data aanlevert:	Alle 16 Nederlandse hartchirurgische centra
Frequentie van data verzameling:	Per kwartaal
17 Nederland Signaleringscentrum Kindergeneeskunde (NSCK)	
Opdrachtgever:	Nederlandse Vereniging voor Kindergeneeskunde (NVK)
Organisatie die de uitvraag verzorgt:	Nederlandse Organisatie voor toegepast-natuurwetenschappelijk onderzoek (TNO)
URL:	http://www.nvk.nl/Onderzoek/NSCK.aspx
Contactpersoon:	R. Rodrigues Pereira E: nsck@tno.nl Annelies Lambion T: 0888 666206
Omschrijving:	Prevalentie van zeldzame of nieuwe aandoeningen bij kinderen van 0 tot 18 jaar
Aantal personen of instellingen dat data aanlevert:	alle kinderartsen in ziekenhuizen.
Frequentie van de uitvraag:	Maandelijks
18 Landelijke registratie blaaskankerbehandeling NVU	
Opdrachtgever:	Nederlandse Vereniging voor Urologie (NVU)
Organisatie die de uitvraag verzorgt:	Nederlandse Vereniging voor Urologie (NVU)
Contactpersoon:	B.P. Wijsman, Tweestedenziekenhuis Tilburg
Omschrijving:	Gegevens over de behandeling van blaaskanker, zoals bij DSCA.
Aantal personen of instellingen dat data aanlevert:	Alle urologen in Nederland
Frequentie van data verzameling:	Continu, on-line
19 Dutch Breast Cancer Audit (DBCA)	
Opdrachtgever:	Vereniging voor Chirurgische Oncologie (NVCO)
Organisatie die de uitvraag verzorgt:	Dutch Institute for Clinical Auditing (DICA)
URL:	www.clinicalaudit.nl/dbca
Omschrijving:	Registratie van borstkankerbehandelingen
20 Dutch Surgical Colorectal Audit (DSCA)	
Opdrachtgever:	Ned. Ver. voor Chirurgische Oncologie (NVCO) en GastroIntestinale Chirurgie (NVGIC) en de Dutch Colorectal Cancer Group (DCCG)
Organisatie die de uitvraag verzorgt:	Dutch Institute for Clinical Auditing (DICA)
URL:	www.dsca.nl
Omschrijving:	Registratie van resultaten van darmkankeroperaties. Door beroepsgroep, met als doel (spiegel)informatie voor kwaliteitsverbetering

Aantal personen of instellingen dat data aanlevert:	92 ziekenhuizen (in 2010)
21 Dutch Upper GI Cancer Audit (DUCA)	
Organisatie die de uitvraag verzorgt:	Dutch Institute for Clinical Auditing (DICA)
URL:	www.clinicalaudit.nl/duca
Omschrijving:	Registratie van slokdarm- en maagkankerbehandelingen
Landelijke complicatieregistraties Wetenschappelijke verenigingen	
22 Landelijke complicatieregistratie hartchirurgie volwassenen (LCRHV)	
Opdrachtgever:	Nederlandse Vereniging voor Thoraxchirurgie (NVT)
Organisatie die de uitvraag verzorgt:	Nederlandse Vereniging voor Thoraxchirurgie (NVT)
URL:	http://www.nvt.net.nl/index.asp?page_id=92
Contactpersoon:	Prof. dr. L. van Herwerden (voorzitter commissie dataregistratie NVT) - UMCU T: (+31) 88 755 6179 E: I.vanherwerden@umcutrecht.nl
Omschrijving:	Registratie van complicaties, de hartchirurgische interventie waarbij of waarna de complicatie is opgetreden en evaluatie van de kwaliteit van de uitgevoerde hartchirurgie
Aantal personen of instellingen dat data aanlevert:	Alle 16 Nederlandse hartchirurgische centra
Frequentie van data verzameling:	Per kwartaal
23 NIV Complicatieregistratie	
Opdrachtgever:	Nederlandse Internisten Vereniging (NIV)
Organisatie die de uitvraag verzorgt:	Nederlandse Internisten Vereniging (NIV)
URL:	www.internisten.nl/home/kwaliteit/complicatieregistratie
Contactpersoon:	Mevr. A. van Meelis (programmamanager kwaliteit) E: meelis@niv.knmg.nl , T: 030-2823226
Verdere landelijke complicatieregistraties (zonder beschrijving)	
24	Landelijke Heelkundige Complicatieregistratie (LHCR) Nederlandse Vereniging voor Heelkunde (NVvH)
25	Landelijke Complicatieregistratie NVA Nederlandse Vereniging voor Anaesthesiologie (NVA)
26	Landelijke Complicatieregistratie NVKG Nederlandse Vereniging voor Klinische Geriatrie (NVKG)
27	Complicatieregistratie Obstetrie en Gynaecologie Nederlandse Vereniging voor Obstetrie en Gynaecologie (NVOG)
28	Landelijke complicatieregistratie NVKNO Nederlandse Vereniging voor Keel-Neus-Oorheelkunde en Heelkunde van het Hoofd-Halsgebied (NVKNO)

29	Complicatieregistratie Kindergeneeskunde	Nederlandse Vereniging voor Kindergeneeskunde (NVK)
30	Landelijke complicatieregistratie MDL	Nederlandse Vereniging voor Maag-Darm-Lever artsen
31	Landelijke complicatieregistratie NVN	Nederlandse Vereniging voor Neurologie (NVN)
32	Landelijke complicatieregistratie NOV ORVECOS	Nederlandse Orthopaedische Vereniging (NOV)
33	Webbased NOG kwaliteitsregistratie	Nederlands Oogheelkundig Gezelschap (NOG)
34	Landelijke complicatieregistratie NVvP	Nederlandse Vereniging voor Psychiatrie (NVvP)
35	Landelijke complicatieregistratie VRA	Nederlandse Vereniging van Revalidatieartsen (VRA)
36	Landelijke complicatieregistratie NVU	Nederlandse Vereniging voor Urologie (NVU)
Gezamenlijke ziekenhuizen		
37 Landelijke Medische Registratie (LMR) (tot 2012)		
	Oprachtgever:	Dutch Hospital Data (DHD)
	Organisatie die de uitvraag verzorgt:	DHD
	URL:	www.dutchhospitaldata.nl/Registraties/LMR.php
	Contactpersoon:	dhr. dr. J.J. Pool, DHD E: pool@hospitaldata.eu, T: 030-2739521
	Omschrijving:	Medische en administratieve gegevens van patiënten die klinisch of in dagverpleging opgenomen zijn geweest in een ziekenhuis in Nederland (incl. in ziekenhuis geboren en, klinisch of dagverpleging maar excl. poliklinische bevallingen).
	Aantal personen of instellingen dat data aanlevert:	ca. 90 ziekenhuizen
	Frequentie van data verzameling:	Jaarlijks
38 Landelijke Ambulante Zorgregistratie (LAZR) (tot 2012 – daarna LBZ))		
	Oprachtgever:	Dutch Hospital Data (DHD)
	Organisatie die de uitvraag verzorgt:	DHD
	URL:	www.dutchhospitaldata.nl/Registraties/LMR.php
	Contactpersoon:	dhr. dr. J.J. Pool, DHD E: pool@hospitaldata.eu, T: 030-2739521
	Omschrijving:	Administratieve gegevens van patiënten die ambulante behandeld zijn op een (buiten-) polikliniek van een ziekenhuis in Nederland.
	Aantal personen of instellingen dat data aanlevert:	ca. 141 ziekenhuizen
	Frequentie van data verzameling:	Jaarlijks
39 Landelijke Basisregistratie Ziekenhuiszorg (LBZ) (tot 2012 – daarna LBZ)		

Opdrachtgever:	Dutch Hospital Data (DHD)
Organisatie die de uitvraag verzorgt:	DHD
URL:	www.dutchhospitaldata.nl/Registraties/Registraties_LBZ.php
Contactpersoon:	mw. drs. S.R. Choudhury, DHD, E: lbz@hospitaldata.eu., T: 030-2739521
Omschrijving:	Medische, administratieve en bekostiging gegevens van patiënten die klinisch of in dagverpleging opgenomen of poliklinisch (incl. buitenpoli) behandeld zijn geweest in een ziekenhuis. De LBZ is opgebouwd uit DIS gegevens en LBZ specifieke gegevens.
Aantal personen of instellingen dat data aanlevert:	Ca. 100 ziekenhuizen
Frequentie van data verzameling:	Per kwartaal
40 Enquête Jaarcijfers Ziekenhuizen (EJZ)	
Opdrachtgever:	Dutch Hospital Data (DHD)
Organisatie die de uitvraag verzorgt:	DHD
URL:	www.jaarenqueteziekenhuizen.nl
Contactpersoon:	dhr. C.A. Bor, DHD, E: bor@hospitaldata.eu, T: 030-2739521
Omschrijving:	enquête onder de algemene ziekenhuizen en UMC's naar productie en zorgaanbod in Nederland, en onder meer personeelssterkte en salariskosten (naar functie), medisch specialisten, bijzonder medische functies, specifieke functies.
Aantal personen of instellingen dat data aanlevert:	Ca. 90 ziekenhuizen
Frequentie van data verzameling:	Jaarlijks
41 Loonkostengegevens (LKG)	
Opdrachtgever:	Dutch Hospital Data (DHD)
Organisatie die de uitvraag verzorgt:	DHD
URL:	www.dutchhospitaldata.nl/Registraties/LKG.php
Contactpersoon:	dhr. C.A. Bor, DHD, E: bor@hospitaldata.eu, T: 030-2739521
Omschrijving:	Loonkostengegevens uit de salarisadministratie van de categorale en algemene ziekenhuizen, onder meer brutoloon, sociale lasten, salarisschaal, inpassing, functie, parttime-factor, persoonskenmerken
Aantal personen of instellingen dat data aanlevert:	Ca. 70 ziekenhuizen
Frequentie van data verzameling:	Jaarlijks
42 DBC-informatiesysteem DIS	

Opdrachtgever:	Ministerie van VWS
Organisatie die de uitvraag verzorgt:	DBC-Onderhoud/afdeling DIS
Wettelijk verplicht:	Ja obv WMG
URL:	http://www.dbcinformatiesysteem.nl/
Contactpersoon:	T: 030-2850811 E: info@dbcinformatiesysteem.nl
Omschrijving:	Het DIS bevat informatie over bijvoorbeeld de geleverde zorg, de kosten van de zorg Variabelen: DBC-code, verrichtingen, begindatum, einddatum, pseudo-identiteit, zorginstelling, zorgverzekeraar, specialisme, diagnose,
Aantal personen of instellingen dat data aanlevert:	-99 Ziekenhuiszorg (ZZ) -215 Zelfstandig behandel centra (ZBC) -2562 Geestelijke gezondheidszorg (GGZ) - 45 Forensische zorg (FZ)
43 Benchmark Facilitaire Kengetallen Ziekenhuizen	
Opdrachtgever:	Ziekenhuizen
Organisatie die de uitvraag verzorgt:	Hospitality Consultants i.s.m. Kiwa Prismant
URL:	http://www.hospitalityconsultants.nl/assets/files/Brochures/Benchmark%20FKZ%202011.pdf
Contactpersoon:	Tim van Asch T: 033-462555 E: t.vanasch@hospitalityconsultants.nl
Omschrijving:	Facilitaire organisatie algemeen, personeel facilitaire organisatie, leiding en beheer facilitaire organisatie, huisvesting, terreinen en energie, logistiek, voeding, schoonmaak en huishouding, linnenvoorziening, afval, beveiliging en bewaking, services.
Aantal personen of instellingen dat data aanlevert:	25 ziekenhuizen
Frequentie van data verzameling:	Jaarlijks
44 Dutch Diagnosis Registration Metabolic Diseases (DDRMD) (Diagnoseregistratie Metabole Ziekten Nederland)	
Opdrachtgever:	In 2001 opgericht samenwerkingsverband van aanvankelijk 8 klinisch metabole centra. Per 1-1-2011 is het metabole centrum in het LUMC opgeheven.
Organisatie die de uitvraag verzorgt:	WKZ/UMCU
URL:	https://ddrmd.nl/
Contactpersoon:	Dr G Visser, kinderarts metabole ziekten, Lundlaan 6, 3584 EA Utrecht E: Gvisser4@umcutrecht.nl E (algemeen): ddrmd@umcutrecht.nl
Omschrijving:	Een systematisch bijeengebrachte verzameling van gegevens betreffende: - alle patiënten in Nederland met een bevestigde metabole ziekte - zuigelingen die verwezen worden in verband met een afwijkende hielprikscreening op een mogelijke metabole ziekte.
Aantal personen of instellingen dat data aanlevert:	Artsen werkzaam in de zeven metabole centra in Nederland (UMCU, Vumc,

data aanlevert:	AMC,UMC St. Radboud, AZM, Erasmus MC en UMCG)
Frequentie van data verzameling:	Continue
45 Nederlandse Kankerregistratie (NKR)	
Opdrachtgever:	Integraal Kanker Centrum Nederland (IKNL)
Organisatie die de uitvraag verzorgt:	Integraal Kanker Centrum Nederland
URL:	http://www.iknl.nl/page.php?id=298
Contactpersoon:	Marjorie de Kok T: 030-2337097 of 024-3527356 E: m.dekok@iko.nl
Omschrijving:	Administratieve en demografische gegevens (patiënt-identificatiecode, geboortedatum, geslacht, postcode, gemeente/land van geboorte), brongegevens (instelling van diagnose, pathologielaboratorium, specialisme (op verzoek: specialist), instellingspatientnummer), diagnose/tumorgegevens (tumorvolgnummer, incidentiedatum, basis voor de diagnose, topografie en lateralisatie van primaire tumor en metastasen op afstand, multifocaliteit, morfologie, differentiatiegraad, WHO-graad hersentumoren, aantal onderzochte/positieve lymfeklieren, cTNM, pTNM, tumorresidu, tumoruitbreiding), tumorspecifieke gegevens, behandelingengegevens (initiële behandeling, datum behandeling, instelling behandeling, verrichtingen en volgorde daarvan), follow-up gegevens (status patiënt, datum laatste contact/overlijden), aanvullende gegevens (voor bepaalde regio's of specifieke tumoren)
Aantal personen of instellingen dat data aanlevert:	In alle academische en perifere ziekenhuizen worden gegevens geregistreerd, muv 3 instellingen waar de gegevens door het ziekenhuis zelf worden verzameld.
Frequentie van data verzameling:	Jaarlijks
46 Kankerregistratie IKZ	
Opdrachtgever:	Integraal Kankercentrum Zuid (IKZ)
Organisatie die de uitvraag verzorgt:	Integraal Kankercentrum Zuid
URL:	http://www.ikz.nl/page.php?id=160
Contactpersoon:	Erica Masseling, sectorhoofd Registratie T: 040 - 297 16 16 E: e.masseling@ikz.nl
Omschrijving:	Naast de NKR verplichtingen registreert het IKZ ook de basaalcelcarcinomen van de huid en co-morbiditeit en is er een actieve follow-up met betrekking tot de vitale status van de patiënten.
Aantal personen of instellingen dat data aanlevert:	10 ziekenhuizen, 6 PA-laboratoria, 2 radiotherapeutische instituten
Frequentie van data verzameling:	Dagelijks
47 NABON Mammaregistratie	
Opdrachtgever:	Nationaal Borstkanker Overleg Nederland (NABON)
Organisatie die de uitvraag verzorgt:	Nederlandse Kankerregistratie van het Integraal Kankercentrum Nederland en IKZ

URL:	http://www.nabon.nl
Contactpersoon:	prof. Dr. V.C.G. (Vivianne) Tjan-Heijnen E: vcg.tjan.heijnen@mumc.nl
Omschrijving:	<p>Deelname aan de NABON mammapregistratie en klinisch wetenschappelijk onderzoek</p> <p>Gestandaardiseerde verslaglegging patholoog</p> <p>Aandeel HER2, ER, PgR positieve bepalingen</p> <p>Pebehandeling / postoperatief in multidisciplinair team besproken</p> <p>Toepassen BI-RADS eindcategorieën verslaglegging mammadiagnostiek</p> <p>Adjuvante chemotherapie bij vroeg stadium mammacarcinoom</p> <p>Neoadjuvante systemische therapie bij T4 tumoren</p> <p>Percentage patiënten met neoadjuvante chemotherapie dat prebehandeling wordt gezien door de radiotherapeut</p> <p>Radiotherapie bij lokaal uitgebreid mammacarcinoom waarvoor ablatie mammacarcinoom</p> <p>Radiotherapie bij DCIS na borstsparende behandeling</p> <p>Wachttijden tussen verschillende verrichtingen</p> <p>Irradicaliteit bij eerste mammasparende operatie voor invasief mammacarcinoom / DCIS</p> <p>Okselklierdissecties bij pN0 status</p> <p>Lokaal recidief in de ipsilaterale borst/thoraxwand of regionaal als 'first event'</p> <p>Differentiatie beleid chirurgen</p>
Aantal instellingen data aanlevert:	75 van de 90 Nederlandse ziekenhuizen leveren op dit moment gegevens aan
Frequentie van data verzameling:	Continu met terugkoppeling 4 maal per jaar (in eerste instantie)
48 Pathologisch Anatomisch Landelijk Geautomatiseerd Archief (PALGA)	
Opdrachtgever:	Stichting PALGA
Organisatie die de uitvraag verzorgt:	Stichting PALGA
URL:	www.palga.nl
Contactpersoon:	E: lzv@palga.nl T:030-6868768
Omschrijving:	De PALGA-databank bevat pathologie-uitslagen vanuit alle pathologie-laboratoria in Nederland. Per pathologisch onderzoek worden de volgende variabelen vastgelegd: Identificatie van het laboratorium, identificatie van het pathologieonderzoek, ontvangstdatum van materiaal, startdatum onderzoek, identificatie van de patiënt, geboortedatum, geslacht, 1ste 8 posities van de eigen naam, naamcode (encrypt), voorletter, postcode (4 cijfers), woonplaats, geboorteplaats, conclusie van het onderzoek, diagnose in PALGA-terminen, diagnose in PALGA-codes, gestandaardiseerde gegevens baarmoederhals/cervix-onderzoek, BVO-onderzoeken.
Aantal instellingen dat data aanlevert:	58 pathologie-laboratoria
Frequentie van data verzameling:	Continue – uitslagen worden binnen 24 uur opgenomen in de landelijke databank door een automatisch elektronisch netwerk.
49 Landelijke Trauma Registratie (LTR)	
Opdrachtgever:	Ministerie van VWS
Organisatie die de uitvraag	Elk van de 11 Nederlandse traumacentra coördineert en beheert een

verzorgt:	regionale traumaregistratie. De gegevens van de 11 regionale registraties tezamen vormen de landelijke traumaregistratie. De coördinatie en het beheer van deze landelijke registratie wordt uitgevoerd door het landelijke netwerk acute zorg (LNAZ). De LNAZ is het samenwerkingsverband van de 11 centra en ondersteunt de centra bij de uitvoering van hun taken en onderlinge samenwerking, coördineert landelijke projecten en beleidsafstemming en behartigt de gezamenlijke belangen.
URL:	www.lnaz.nl
Contactpersoon:	Dr. L. [Leontien] Sturms (projectleider LNAZ) T: 013 539 3784 E: l.sturmselisabeth.nl
Omschrijving:	Het inclusie criterium is de acute opname ten gevolge van letsel/ongeval via de afdeling spoedeisende hulp (SEH), inclusief de patiënten die overlijden op de SEH en de overplaatsingen naar een ander ziekenhuis. De gegevensset is vastgesteld door de Nederlandse Vereniging voor Traumatologie en betreft de Amerikaanse Major Trauma Outcome Study (MTOS) set aangevuld met een prehospital (ambulance) gegevens. Hierbij worden gegevens verzameld zoals leeftijd en geslacht van de patiënt, de wijze van vervoer naar het ziekenhuis, de doorlooptijden, de fysiologische toestand van de patiënt, de letseldiagnoses, de letselerfst, de(IC) opnameduur en ontslagbestemming
Aantal personen of instellingen dat data aanlevert:	Alle ziekenhuizen die ongevalpatiënten opvangen op een SEH
Frequentie van data verzameling:	Doorlopende registratie
50 Incidentmeldingen radiotherapeutische centra	
Opdrachtgever:	PRISMA-RT (Prevention, Recovery and Information System for Monitoring and Analyses in RadioTherapy)
Organisatie die de uitvraag verzorgt:	PRISMA-RT
URL:	www.prisma-rt.nl/
Contactpersoon:	Petra Reijnders-Thijssen M.A. (secretaris) E: petra.reijnders@maastro.nl
Omschrijving:	Geanonimiseerde rapportages en analysegegevens van (bijna-)incidenten in de deelnemende instellingen
Aantal personen of instellingen dat data aanlevert:	17 radiotherapeutische instellingen
Frequentie van data verzameling:	Continue
51 LOPS-registratie	
Opdrachtgever:	Landelijk Overleg van Poliklinieken Seksuologie (LOPS)
Organisatie die de uitvraag verzorgt:	Rutgers Nisso Groep
URL:	http://www.rutgersnissogroep.org/subsite/productenendiensten/onderzoekspublicaties/downloadbare-publicaties-in-pdf/LOPS-2009.pdf
Contactpersoon:	drs J.H. Kedde, Rutgers Nisso Groep E: h.kedde@rutgerswpf.nl T: 030 2329821
Omschrijving:	Per patiënt worden de volgende gegevens geregistreerd; sekse, leeftijd, etnische achtergrond, partnerrelatie, seksuele voorkeur, aanmeldingsdatum, seksuele problemen, eventuele klacht bij de partner, verwijzer, intaker en hoofdbehandelaar, afsluitingsdatum, het aantal gesprekken, de wijze van

	afsluiten en waarheen eventueel wordt door- of terugverwezen.
Aantal personen of instellingen dat data aanlevert:	15 poliklinieken (8 academische en 7 niet-academische ziekenhuizen)
Frequentie van data verzameling:	Jaarlijks
52 Landelijke Prevalentiemeting Zorgproblemen (LPZ)	
Opdrachtgever:	Projectgroep LPZ (voorheen Landelijke Prevalentie Onderzoek Decubitus LOPD)
Organisatie die de uitvraag verzorgt:	Projectgroep LPZ
URL:	http://nld.lpz-um.eu/
Contactpersoon:	Universiteit Maastricht, CAPHRI School for Public Health and Primary Care, T: 043-3881559 E: LPZ@zw.unimaas.nl
Omschrijving:	Aanwezigheid, preventie en behandeling van zorgproblemen binnen de gezondheidszorg: decubitus, incontinentie, ondervoeding en smetten, vallen & vrijheidsbepalende maatregelen. De gegevens worden op 3 niveaus geregistreerd, namelijk cliënt-, afdelings- en instellingsniveau. – op cliëntniveau: demografische gegevens, preventie van de verschillende zorgproblemen (verplicht aan te leveren voor elke deelnemende instelling). Daarnaast zijn er ook aanvullende modules mogelijk waarin uitgebreider wordt ingegaan op de kenmerken van het zorgprobleem, de preventie en behandeling. – op afdelings- en instellingsniveau: soort afdeling en instelling, enkele kwaliteitsindicatoren.
Aantal personen of instellingen dat data aanlevert:	In 2010 hebben 391 zorginstellingen data aangeleverd, waaronder 5 academische ziekenhuizen en 46 algemene ziekenhuizen.
Frequentie van data verzameling:	Jaarlijks
53 Landelijke AbortusRegistratie (LAR)	
Opdrachtgever:	Gezamenlijke abortusklinieken
Organisatie die de uitvraag verzorgt:	Rutgers Nisso Groep
Wettelijk verplicht:	Nee, initiatief van abortusklinieken naast de wettelijk verplichte WAZ-registratie
URL:	http://www.rutgersnissogroep.nl/kennisbank/productenendiensten/onderzoek/publicaties/rapport-lar-2008.pdf http://www.rutgersnissogroep.nl/overderutgersnissogroep/pers/persbericht-11-februari-2010/
Contactpersoon:	Mw. dr. C. Wijsen (programmahoofd geboorteregeling) T: 030 2313431
Omschrijving:	Beraadtermijn, geboorteaar, woonprovincie, burgerlijke staat, leefsituatie, woonprovincie, aantal eerdere zwangerschappen, aantal eerdere abortussen, graviditeit in weken (zwangerschap), complicaties, anticonceptiekeuze voor abortus, anticonceptiekeuze na abortus, geboorteland vrouw, geboorteland moeder vrouw, geboorteland vader vrouw, ontstaan zwangerschap, anaesthesie (anesthesie), behandelmethode, complicaties.
Aantal personen of instellingen dat data aanlevert:	14 (van de 16) abortusklinieken
Frequentie van data verzameling:	Jaarlijks

54 Revalidatie Databank Wachttijden	
Opdrachtgever:	Revalidatie Nederland
Organisatie die de uitvraag verzorgt:	Revalidatie Nederland
Wettelijk verplicht:	Nee
URL:	http://www.revalidatie.nl/wachttijden - www.revalidatienederland.nl
Contactpersoon:	Revalidatie Nederland T: 030-2739384 E: info@revalidatie.nl
Omschrijving:	Landelijke databank met gegevens over wachttijden van de revalidatie-instellingen. Variabelen: Toegangstijd 1e consult volwassenen, toegangstijd 1e consult kinderen, verwachte wachttijd poliklinische behandeling volwassenen, verwachte wachttijd poliklinische behandeling kinderen, verwachte wachttijd klinische behandeling volwassenen, verwachte wachttijd klinische behandeling kinderen.
Aantal personen of instellingen dat data aanlevert:	24 revalidatieinstellingen
Frequentie van data verzameling:	Maandelijks
Zorgverzekeraars	
55 Kwaliteitsuitvraag Zorgverzekeraars	
Opdrachtgever:	Zorgverzekeraars Nederland (ZN)
Organisatie die de uitvraag verzorgt:	ZN i.s.m. Mediques
Wettelijk verplicht:	Nee
URL:	www.zn.nl
Contactpersoon:	E: info@zn.nl T: 030 - 698 89 11
Omschrijving:	ZN vraagt ziekenhuizen en zbc's om kwaliteitsinformatie over 15 aandoeningen zoals CVA, borstkanker, diabetes, galblaasoperatie en spataderen. Het is de bedoeling dat in 2012 de kwaliteitsuitvraag van Zichtbare Zorg de gevraagde informatie op zal leveren. Een aparte kwaliteitsuitvraag van ZN ten behoeve van de zorginkoop van zorgverzekeraars is dan niet meer nodig.
Aantal personen of instellingen dat data aanlevert:	Alle ziekenhuizen en zelfstandige behandelcentra
Frequentie van data verzameling:	Jaarlijks, 15 april

Patiëntenverenigingen	
56 Monitor borstkankerzorg	
Opdrachtgever:	Borstkanker Vereniging Nederland (BVN)
Organisatie die de uitvraag verzorgt:	Borstkanker Vereniging Nederland (BVN) i.s.m. Mediquest
URL:	http://www.borstkanker.nl/monitor_borstkankerzorg
Contactpersoon:	Mevr. Astrid Zaat E: zaat@borstkanker.nl
Omschrijving:	<p>Ter beoordeling van de ziekenhuizen voor de Borstkankermonitor gebruikt BVN met name gegevens van de Inspectie van Gezondheidszorg en Zichtbare Zorg. Daarnaast vroeg BVN in 2011 aanvullende gegevens uit aan ziekenhuizen m.b.t. multidisciplinaire patiëntbesprekingen. Echter, vanaf 2012 beoogt Zizo dit te includeren in de Zizo registratie, en zal BVN proberen de aanvullende vragenlijst tot een minimum te beperken. Het streven is om in de toekomst de vragenlijst niet meer nodig te hebben. Daarnaast leveren ziekenhuizen, na toestemming van de patiënten, e-mailadressen van patiënten aan voor deelname van de CQ index, betreffende hun ervaringen bij de geleverde zorg (dit wordt verzorgd door Mediquest).</p>
Aantal personen of instellingen dat data aanlevert:	90 ziekenhuisgroepen/ 117 ziekenhuislocatie
Frequentie van data verzameling:	Deze aanvullende vragenlijst wordt 1 x per jaar voorgelegd aan ziekenhuizen.
Samenwerkingsverbanden van organisaties met verschillende achtergronden	
57 Stroke Services prestatie-indicatoren	
Opdrachtgever:	stichting Kennisnetwerk CVA NL
Organisatie die de uitvraag verzorgt:	stichting Kennisnetwerk CVA NL
URL:	http://kennisnetwerkcva.nl/benchmark-1
Contactpersoon:	Ingrid Middelkoop (Coordinator werkgroep Benchmark) T: 06-13990734 E: info@kennisnetwerkcva.nl
Omschrijving:	<p>Kennisnetwerk CVA Nederland verzamelt data in het kader van de Helsingborg Declaration, een internationale WHO verklaring waaraan ook Nederland zich heeft geconformeerd. Hierin zijn doelstellingen vastgelegd t/m 2015 voor het verbeteren van de CVA (keten) zorg</p> <p>De data-uitvraag omvat 9 prestatie-indicatoren:</p> <ul style="list-style-type: none"> • percentage trombolysen, • deur-tot-naald tijd, percentage binnen 1 uur • mortaliteit één maand na het optreden van de beroerte, • verblijfplaats drie maanden na het optreden van de beroerte • functioneel herstel na drie maanden (Modified Rankin Scale) • Tijdigheid TIA-diagnostiek • Slikscreening • Ketenaansturing • Verblijfsduur in het ziekenhuis <p>Verder wordt de leeftijd en geslacht van de cva-patiënt en een benadering van de ernst van de beroerte (d.m.v het bepalen van de functionele toestand</p>

	na 4 dagen m.b.v. Barthel Index) uitgevraagd. Daarnaast: aantal infarcten/ bloedingen.
Aantal personen of instellingen dat data aanlevert:	In 2010: 47 van de 61 deelnemende Stroke Services
Frequentie van data verzameling:	Eenmaal per jaar
58 PREventie van ZIEkenhuisinfecties door Surveillance (PREZIES)	
Opdrachtgever:	PREZIES-netwerk (RIVM en de deelnemende instellingen)
Organisatie die de uitvraag verzorgt:	RIVM
URL:	www.prezies.nl
Contactpersoon:	Birgit van Benthem (birgit.van.benthem@rivm.nl)
Omschrijving:	<p>Het PREZIES-netwerk bestaat uit 5 verschillende surveillancemodules. Er is een module voor prevalentieonderzoek van ziekenhuisinfecties, dat optioneel te combineren is met thematisch onderzoek, namelijk 'beoordeling antibioticagebruik' en 'beoordeling gebruik van urineopvangmateriaal'. Daarnaast zijn er 4 modules voor incidentieonderzoek, namelijk:</p> <ul style="list-style-type: none"> - postoperatieve wondinfecties - wondinfecties na hartchirurgie - lijnsepsis - beademing-gerelateerde pneumonieën <p>De PREZIES surveillance onderdeel is van de Basisset prestatieindicatoren van de IGZ en werkt samen met het Veiligheidsprogramma. Voor alle modules geldt dat data op patiëntniveau worden verzameld. Het gaat hierbij om patiëntkenmerken, type operatie, type infectie, hulpmiddelen gebruik, relevante risicofactoren voor case-mix adjustment en procesmaten over infectiepreventie maatregelen in het kader van het VMS veiligheidsprogramma voor de thema;s postoperatieve wondinfecties en lijnsepsis.</p>
Aantal personen of instellingen dat data aanlevert:	In 2010 89 ziekenhuizen (prevalentieonderzoek: 53 ziekenhuizen, verschillende incidentiemodules: 82 ziekenhuizen)
Frequentie van data verzameling:	Prevalentieonderzoek: 2 x per jaar Incidentiemodule: gedurende het hele jaar (ongoing)
59 Population based HAematological Registry for Observational Studies (PHAROS)	
Opdrachtgever:	HOVON, drie integrale kankercentra (IKR, IKA en IKZ) en het institute for Medical Technology Assessment (iMTA)
Organisatie die de uitvraag verzorgt:	Stichting Hemato-Oncologie Volwassenen Nederland (HOVON)
URL:	http://pharosregistry.com/
Contactpersoon:	Marieke Koelink (PHAROS secretariaat) T: 020- 444 2124 / 444 4054 E: m.koelink@vumc.nl
Omschrijving:	<p>Gegevens van patiënten met non-hodgkinlymfoom (NHL), multiple myeloom (MM), chronisch lymfatische leukemie (CLL) en chronisch myeloïde leukemie (CML):</p> <ul style="list-style-type: none"> - patientgegevens/algemene informatie bij diagnose - resultaten laboratoriumonderzoek - comorbiditeiten bij/na vaststelling diagnose - infecties - adverse events - zorggebruik: opnames en polikliniekbezoeken

	<ul style="list-style-type: none"> - follow-up - kankerspecifieke behandeling - radiotherapie/transplantatie/supportive care - kuur - responsbepaling - overige ongewenste medische voorvallen (alleen bij NHL) - onderhoudsbehandeling (alleen bij NHL) - cytogenetics (alleen bij CML) - molecular biology, fish analysis, mutational analysis (alleen bij CML)
Aantal personen of instellingen dat data aanlevert:	NHL, MM en CLL: in 47 ziekenhuizen in 3 regio's van de Integrale Kankercentra, namelijk IKNL regio Amsterdam, IKNL regio Rotterdam en IK Zuid. CML: landelijk niveau
60 CONCOR (CONgenitale CORvitia)	
Opdrachtgever:	Concor-project , opgericht door Hartstichting en ICIN (Interuniversitair Cardiologisch Instituut Nederland)
Organisatie die de uitvraag verzorgt:	Concor-project
URL:	http://concor.net
Contactpersoon:	Lia Engelfriet-Rijk (onderzoeksverpleegkundige) T: 020-5667644 C: c.i.engelfriet@amc.uva.nl
Omschrijving:	Landelijke registratie en DNA-bank van volwassen patiënten met een aangeboren hartafwijking waarin per patient wordt vastgelegd: <ul style="list-style-type: none"> - Identificerende patiëntgegevens (geblindeerd) - Klinische gegevens - Alle opgetreden events, waarbij één event is aangemerkt als hoofddiagnose en andere events als nevend diagnoses, zoals operaties, complicaties, etc (vastgelegd m.b.v. de EPCC codering)
Aantal personen of instellingen dat data aanlevert:	Cardiologen vanuit 103 participerende ziekenhuizen
Frequentie van data verzameling:	Continue
61 NICU registratie neonatale gehoorscreeningsprogramma	
Opdrachtgever:	Neonatale Intensive Care Units (NICU's) in Nederland
Organisatie die de uitvraag verzorgt:	TNO te Leiden, Expertise Centrum Child Health
URL:	http://www.isala.nl/professional/afdelingen/neonatalegehoorscreening/Registrie/Pages/default.aspx
Contactpersoon:	Mw. Dr. H.L.M. van Straaten projectleider Zwolle Dhr. Dr. P.H. Verkerk, projectleider Leiden, LM Ouwehand, projectassistent E: lidy-marie.ouwehand@tno.nl
Omschrijving:	Het gehele screeningstraject: van test tot en met de eerste diagnostiek op het Audiologisch Centrum (AC). Variabelen: <ul style="list-style-type: none"> - geboortedatum - geboortegewicht - zwangerschapsduur - uitslag neonatale gehoorscreeningsprogramma
Aantal personen of instellingen dat data aanlevert:	Alle 10 NICU's in Nederland

Frequentie van data verzameling:	Continue
62 Registratie Nierfunctievervanging NEderland (Renine)	
Opdrachtgever:	Stichting Renine
Organisatie die de uitvraag verzorgt:	Stichting Renine
URL:	https://www.renine.nl/page?id=home
Contactpersoon:	A. Hemke (coördinator Renine) E: hemke@renine.nl T: 071-5795855 S. Vogelaar (coördinator Renine) E: vogelaar@renine.nl
Omschrijving:	<p>De registratie van Renine is patiënt- en mutatiegeoriënteerd.</p> <ol style="list-style-type: none"> 1. Patientbestand: naam van de patiënt (of, in voorkomende gevallen, een anonieme code), geboortedatum, geslacht, postcode, primaire diagnose en, indien van toepassing, doodsoorzaak. 2. Mutatiebestand: mutatie (start van een nierfunctievervangende behandeling, verandering van behandelingsvorm en/of van behandelend centrum, een transplantatie of overlijden), mutatiedatum, centrumcode, code voor de behandelingsvorm 3. Centrumgegevens <p>Sinds 2010/2011 worden ook kwaliteitsindicatoren opgevraagd (Renine+). Dit betreft kwartaalsgewijze informatie over oa dialysedosis, calciumfosfaathuishouding, ijzersuppletie, anemiebehandeling en vaattoegang.</p>
Aantal personen of instellingen dat data aanlevert:	80 dialysecentra
Frequentie van data verzameling:	- Reguliere mutatiegegevens: semi-continue (mutaties zo snel mogelijk opgenomen in de database, maar verschilt enigszins per centrum) - Renine+ verzameling: 1 x per kwartaal
Overige	
63 Centrale Medicatieincidenten Registratie (CMR)	
Opdrachtgever:	Koninklijke Nederlandse Maatschappij ter bevordering der Pharmacie (KNMP) en Nederlandse Vereniging van Ziekenhuisapothekers (NVZA)
Organisatie die de uitvraag verzorgt:	Nederlandse Vereniging van Ziekenhuisapothekers (NVZA)
URL:	http://www.medicatieveiligheid.info/view.cfm?page_id=7002
Contactpersoon:	Annemarie van der Aart (ziekenhuisapotheker en bestuurslid NVZA) T: 06 - 234 263 12
Omschrijving:	medicatie-incidenten in ziekenhuizen, openbaar apothekers en GGZ-instellingen
Frequentie van data verzameling:	Continue; wekelijkse screening meldingen
64 Landelijk Meldpunt voor Bijwerkingen (LAREB)	
Opdrachtgever:	Nederlands Bijwerkingen Centrum Lareb
Organisatie die de uitvraag verzorgt:	Nederlands Bijwerkingen Centrum Lareb

URL:	http://www.lareb.nl/
Wettelijk verplicht:	Ja (geneesmiddelenwet)
Contactpersoon:	Dr. E.P. van Puijenbroek T: 073 6469700 E: e.vanpuijenbroek@lareb.nl
Omschrijving:	Lareb registreert vermoede bijwerkingen van geneesmiddelen, zoals gemeld door artsen, apothekers of patiënten. Zowel zorgverleners als patiënten kunnen direct bij Lareb met een elektronisch formulier een bijwerking melden. Per jaar ontvangt Lareb ongeveer 5500 meldingen. Elke binnengekomen melding wordt afzonderlijk beoordeeld en opgeslagen in de bijwerkingendatabank. Variabelen: Geslacht, leeftijd, gebruikte geneesmiddel, bijwerking, afloop, comediatie, andere verklarende factoren.
Aantal personen of instellingen dat data aanlevert:	In 2010 hebben 93 ziekenhuizen bijwerkingen gemeld aan LAREB.
Frequentie van data verzameling:	Continu
65 Nederlandse Orgaantransplantatieregistratie (NOTR)	
Opdrachtgever:	Nederlandse Transplantatie Stichting (NTS)
Organisatie die de uitvraag verzorgt:	Nederlandse Transplantatie Stichting
URL:	http://www.transplantatiestichting.nl/cms/index.php?page=NOTR
Contactpersoon:	Cynthia Konijn E: c.konijn@transplantatiestichting.nl T: 071 5795830 / 06 53745973
Omschrijving:	Follow-up gegevens van nier-, pancreas-, lever-, hart-, long- en corneatransplantaties en van levende nierdonoren in Nederland
Aantal personen of instellingen dat data aanlevert:	10 transplantatieziekenhuizen
Frequentie van data verzameling:	Doorlopend
66 Landelijke Registratie Groeihormoonbehandeling bij kinderen (LRG)	
Opdrachtgever:	Kind & Groei
Organisatie die de uitvraag verzorgt:	Kind & Groei
URL:	http://www.kindengroei.nl/site/index.php?id=3
Contactpersoon:	E: info@kindengroei.nl
Omschrijving:	Gegevens van alle kinderen die in Nederland worden behandeld met groeihormoon

Appendix 2. Overzicht van externe gegevensuitvragingen – geordend naar opdrachtgever

	Opdrachtgever	Gegevensuitvraging
Overheidsgerelateerde organisaties		
1	Ministerie van VWS	Jaarverslag Zorg (JVZ)
2	Inspectie Gezondheidszorg (IGZ)	IGZ Basisset kwaliteitsindicatoren
3	Inspectie Gezondheidszorg (IGZ)	Veiligheidsindicatoren
4	Ministerie van VWS	Zichtbare Zorg indicatoren
5	Inspectie Gezondheidszorg (IGZ)	Registratie Wet Afbreking Zwangerschap (WAZ-registratie)
6	CBS	Kwartaalenquête ziekteverzuim
7	Min. van VWS en SZW, EC	Letsel Informatie Systeem
8	Ministerie van VWS	NVIC Monitor (Nationaal Vergiftigingen Informatie Centrum)
9	Ministerie van VWS	HIV-registratie
Wetenschappelijke verenigingen		
10	Begeleidingscommissie Hartinterventie NI (BHN)	BHN Hartinterventie registratie
11	Begeleidingscommissie Hartinterventie NI (BHN)	BHN Wachtlijstenregistratie
12	Ned. Orthopaedische Vereniging (NOV)	Landelijke Registratie Orthopaedische Implantaten (LROI)
13	Stichting NICE	Nationale Intensive Care Evaluatie (NICE)
14	Stichting NCDR	National Cardiovascular Data Registry (NCDR) <ul style="list-style-type: none"> ○ Cardiovascular Interventional Data Registry (CIDR) ○ Dutch ICD and Pacemaker Registry (DIPR)
15	Stichting PRN (KNOV, LHV, NVOG, NvK)	Perinatale Registratie Nederland <ul style="list-style-type: none"> ○ Landelijke Verloskunde Registratie 1^e lijn (LVR-1) ○ Landelijke Verloskunde Registratie 2^e lijn (LVR-2) ○ Landelijke Verloskunde Registratie huisartsen (LVRh) ○ Landelijke Neonatologie Registratie (LNR)
16	Ned. Ver. voor Thoraxchirurgie (NVT)	Risicogewogen mortaliteitsregistratie
17	Ned. Ver. voor Kindergeneeskunde (NVK)	Nederland Signaleringscentrum Kindergeneeskunde (NSCK)
18	Ned. Ver. voor Urologie (NVU)	Landelijke registratie blaaskankerbehandeling NVU
19	Ver. voor Chirurgische Oncologie (NVCO)	Dutch Breast Cancer Audit (DBCA)
20	NVCO, NVGIC, DCCG	Dutch Surgical Colorectal Audit (DSCA)

21	DICA	Dutch Upper GI Cancer Audit (DUCA)
Wetenschappelijke verenigingen - landelijke complicatieregistraties		
22	Ned. Ver. voor Thoraxchirurgie (NVT)	Landelijke complicatieregistratie hartchirurgie volwassenen (LCRHV)
23	Nederlandse Internisten Vereniging (NIV)	Landelijke complicatieregistratie NIV
24	Ned. Ver. voor Heelkunde (NVvH)	Landelijke Heelkundige Complicatieregistratie (LHCR)
25	Ned. Ver. voor Anesthesiologie (NVA)	Landelijke Complicatieregistratie NVA
26	Ned. Ver. voor Klinische Geriatrie (NVKG)	Landelijke complicatieregistratie NVKG
27	Ned. Ver. voor Obstetrie en Gynaecologie (NVOG)	Complicatieregistratie obstetrie & gynaecologie
28	Ned. Ver. voor KNO en Heelkunde van het Hoofd-Halsgebied (NVKNO)	Landelijke complicatieregistratie NVKNO
29	Ned. Ver. voor Kindergeneeskunde (NVK)	Complicatieregistratie Kindergeneeskunde
30	Ned. Ver. van Maag-Darm-Leverartsen	Landelijke complicatieregistratie MDL
31	Ned. Ver. voor Neurologie (NVN)	Landelijke complicatieregistratie NVN
32	Ned. Orthopaedische Vereniging (NOV)	Complicatieregistratie NOV ORVECOS
33	Ned. Oogheelkundig Gezelschap (NOG)	Webbased NOG kwaliteitsregistratie
34	Ned. Ver. voor Psychiatrie (NVvP)	Landelijke Complicatieregistratie NVvP
35	Ned. Ver. van Revalidatieartsen (VRA)	Landelijke Complicatieregistratie VRA
36	Ned. Ver. voor Urologie (NVU)	Landelijke Complicatieregistratie NVU
Gezamenlijke ziekenhuizen		
37	Dutch Hospital Data	Landelijke Medische Registratie (LMR)
38	Dutch Hospital Data	Landelijke Ambulante Zorgregistratie (LAZR)
39	Dutch Hospital Data	Landelijke Basisregistratie Ziekenhuizenzorg (LBZ)
40	Dutch Hospital Data	Enquête Jaarcijfers Ziekenhuizen (EJZ)
41	Dutch Hospital Data	Loonkostengegevens (LKG)
42	Ministerie van VWS	DBC-Informatiesysteem DIS
43	Ziekenhuizen	Benchmark Facilitaire Kengetallen Ziekenhuizen
44	Gezamenlijke metabole centra	Dutch Diagnosis Registration Metabolic Diseases (DDRMD / DRMZN)
45	Integraal Kanker Centrum Nederland (IKNL)	Nederlandse Kankerregistratie (NKR)
46	Integraal Kankercentrum Zuid (IKZ)	Kankerregistratie IKZ
47	Nationaal Borstkanker Overleg NL(NABON)	Mammaregistratie

48	Stichting PALGA	Pathologisch Anatomisch Landelijk Geautomatiseerd Archief (PALGA)
49	Ministerie van VWS	Landelijke Trauma Registratie (LTR)
50	PRISMA-RT	Incidentmeldingen radiotherapeutische centra
51	Landelijk Overleg van Poliklinieken Seksuologie (LOPS)	LOPS-registratie
52	Projectgroep LPZ	Projectgroep LPZ
53	Gezamenlijke abortusklinieken	Landelijke AbortusRegistratie (LAR)
54	Revalidatie Nederland	Revalidatie Databank Wachttijden
Zorgverzekeraars		
55	Zorgverzekeraars Nederland (ZN)	Kwaliteitsuitvraag Zorgverzekeraars
Patiëntenverenigingen		
56	Borstkanker Vereniging Nederland (BVN)	Monitor borstkankerzorg
Samenwerkingsverbanden van organisaties met verschillende achtergronden		
57	Stichting Kennisnetwerk CVA NL	Stroke Services prestatie-indicatoren
58	PREZIES-netwerk	PREventie van ZIEkenhuisinfecties door Surveillance (PREZIES)
59	HOVON, 3 integrale kankercentra en iMTA	Population based HAematological Registry for Observational Studies (PHAROS)
60	Concor-project	Concor (CONgenitale CORvita)
61	NICU's	NICU neonatale gehoorscreeningsprogramma
62	Stichting Renine	REgistratie Nierfunctievervanging NEDerland (Renine)
Overige		
63	Ned. Ver. van Ziekenhuisapothekers (NVZA)	Centrale Medicatie-incidenten Registratie (CMR)
64	Nederlands Bijwerkingen Centrum LAREB	Landelijk Meldpunt voor Bijwerkingen (LAREB)
65	Nederlandse Transplantatie Stichting (NTS)	Nederlandse Orgaantransplantatieregistratie (NOTR)
66	Kind & Groei	Landelijke Registratie Groeihormoonbehandeling bij kinderen (LRG)

Appendix 3. Overzicht van gegevensuitvragingen – geordend naar onderwerp

	Opdrachtgever	Gegevensuitvragingen
Aandoeningsspecifieke gegevens		
9	Ministerie van VWS	HIV-registratie
15	Stichting PRN (KNOV, LHV, NVOG, NvK)	Perinatale Registratie Nederland <ul style="list-style-type: none"> ○ Landelijke Verloskunde Registratie 1^e lijn (LVR-1) ○ Landelijke Verloskunde Registratie 2^e lijn (LVR-2) ○ Landelijke Verloskunde Registratie huisartsen (LVRh) ○ Landelijke Neonatologie Registratie (LNR)
16	Ned. Ver. voor Thoraxchirurgie (NVT)	Risicogewogen mortaliteitsregistratie
19	Ver. voor Chirurgische Oncologie (NVCO)	Dutch Breast Cancer Audit (DBCA)
20	NVCO, NVGIC, DCCG	Dutch Surgical Colorectal Audit (DSCA)
21	DICA	Dutch Upper GI Cancer Audit (DUCA)
44	Gezamenlijke metabole centra	Dutch Diagnosis Registration Metabolic Diseases (DDRMD / DRMZN)
45	Integraal Kanker Centrum Nederland (IKNL)	Nederlandse Kankerregistratie (NKR)
46	Integraal Kankercentrum Zuid (IKZ)	Kankerregistratie IKZ
47	Nationaal Borstkanker Overleg NL (NABON)	Mammaregistratie
56	Borstkanker Vereniging Nederland (BVN)	Monitor borstkankerczorg
59	HOVON, 3 integrale kankercentra en iMTA	Population based HAematological Registry for Observational Studies (PHAROS)
60	Concor-project	Concor (CONgenitale CORvitia)
Behandelingsspecifieke gegevens		
5	Inspectie Gezondheidszorg (IGZ)	Registratie Wet Afbreking Zwangerschap (WAZ-registratie)
7	Min. van VWS en SZW, EC	Letsel Informatie Systeem
10	Begeleidingscommissie Hartinterventie NI (BHN)	BHN Hartinterventie registratie
11	Begeleidingscommissie Hartinterventie NI (BHN)	BHN Wachtlijstenregistratie
12	Ned. Orthopaedische Vereniging (NOV)	Landelijke Registratie Orthopaedische Implantaten (LROI)
13	Stichting NICE	Nationale Intensive Care Evaluatie (NICE)
14	Stichting NCDR	National Cardiovascular Data Registry (NCDR) <ul style="list-style-type: none"> ○ Cardiovascular Interventional Data Registry (CIDR)

		o Dutch ICD and Pacemaker Registry (DIPR)
18	Ned. Ver. voor Urologie (NVU)	Landelijke registratie blaaskankerbehandeling NVU
48	Stichting PALGA	Pathologisch Anatomisch Landelijk Geautomatiseerd Archief (PALGA)
49	Ministerie van VWS	Landelijke Trauma Registratie (LTR)
51	Landelijk Overleg van Poliklinieken Seksuologie (LOPS)	LOPS-registratie
53	Gezamenlijke abortusklinieken	Landelijke AbortusRegistratie (LAR)
57	Stichting Kennisnetwerk CVA NL	Stroke Services prestatie-indicatoren
61	NICU's	NICU neonatale gehoorscreeningsprogramma
62	Stichting Renine	REgistratie Nierfunctievervanging NEderland (Renine)
65	Nederlandse Transplantatie Stichting (NTS)	Nederlandse Orgaantransplantatieregistratie (NOTR)
66	Kind & Groei	Landelijke Registratie Groeihormoonbehandeling bij kinderen (LRG)
Bedrijfsgegevens/algemeen		
1	Ministerie van VWS	Jaarverslag Zorg (JVZ)
6	CBS	Kwartaalenquête ziekteverzuim
40	Dutch Hospital Data	Enquête Jaarcijfers Ziekenhuizen (EJZ)
41	Dutch Hospital Data	Loonkostengegevens (LKG)
43	Ziekenhuizen	Benchmark Facilitaire Kengetallen Ziekenhuizen
Ziekenhuisbrede gegevens		
2	Inspectie Gezondheidszorg (IGZ)	IGZ Basisset kwaliteitsindicatoren
3	Inspectie Gezondheidszorg (IGZ)	Veiligheidsindicatoren
4	Ministerie van VWS	Zichtbare Zorg indicatoren
17	Ned. Ver. voor Kindergeneeskunde (NVK)	Nederland Signaleringscentrum Kindergeneeskunde (NSCK)
37	Dutch Hospital Data	Landelijke Medische Registratie (LMR)
38	Dutch Hospital Data	Landelijke Ambulante Zorgregistratie (LAZR)
39	Dutch Hospital Data	Landelijke Basisregistratie Ziekenhuiszorg (LBZ)
42	Ministerie van VWS	DBC-Informatiesysteem DIS
52	Projectgroep LPZ	Projectgroep LPZ
54	Revalidatie Nederland	Revalidatie Databank Wachtijden
55	Zorgverzekeraars Nederland (ZN)	Kwaliteitsuitvraag Zorgverzekeraars

58	PREZIES-netwerk	PREventie van ZIEkenhuisinfecties door Surveillance (PREZIES)
Complicaties en incidenten		
8	Ministerie van VWS	NVIC Monitor (Nationaal Vergiftigingen Informatie Centrum)
22	Ned. Ver. voor Thoraxchirurgie (NVT)	Landelijke complicatieregistratie hartchirurgie volwassenen (LCRHV)
23	Nederlandse Internisten Vereniging (NIV)	Landelijke complicatieregistratie NIV
24	Ned. Ver. voor Heelkunde (NVvH)	Landelijke Heelkundige Complicatieregistratie (LHCR)
25	Ned. Ver. voor Anesthesiologie (NVA)	Landelijke Complicatieregistratie NVA
26	Ned. Ver. voor Klinische Geriatrie (NVKG)	Landelijke complicatieregistratie NVKG
27	Ned. Ver. voor Obstetrie en Gynaecologie (NVOG)	Complicatieregistratie obstetrie & gynaecologie
28	Ned. Ver. voor KNO en Heelkunde van het Hoofd-Halsgebied (NVKNO)	Landelijke complicatieregistratie NVKNO
29	Ned. Ver. voor Kindergeneeskunde (NVK)	Complicatieregistratie Kindergeneeskunde
30	Ned. Ver. van Maag-Darm-Leverartsen	Landelijke complicatieregistratie MDL
31	Ned. Ver. voor Neurologie (NVN)	Landelijke complicatieregistratie NVN
32	Ned. Orthopaedische Vereniging (NOV)	Complicatieregistratie NOV ORVECOS
33	Ned. Oogheelkundig Gezelschap (NOG)	Webbased NOG kwaliteitsregistratie
34	Ned. Ver. voor Psychiatrie (NVvP)	Landelijke Complicatieregistratie NVvP
35	Ned. Ver. van Revalidatieartsen (VRA)	Landelijke Complicatieregistratie VRA
36	Ned. Ver. voor Urologie (NVU)	Landelijke Complicatieregistratie NVU
50	PRISMA-RT	Incidentmeldingen radiotherapeutische centra
63	Ned. Ver. van Ziekenhuisapothekers (NVZA)	Centrale Medicatie-incidenten Registratie (CMR)
64	Nederlands Bijwerkingen Centrum LAREB	Landelijk Meldpunt voor Bijwerkingen (LAREB)

Appendix 4. Hoeveelheid IGZ kwaliteitsindicatoren en subvragen afleidbaar van de LBZ - per indicator

§	Indicator	Aant. kwantitatieve vragen	Aant. vragen afleidbaar uit de LBZ
Hfst 1. Operatief proces			
1.1.2	Percentage gestandaardiseerde pijnmetingen bij postoperatieve patiënten	4	1
1.1.4	Percentage patiënten met op enig moment een pijnscore van boven de 7 in de eerste 72 uur na een operatie	2	0
1.2	Percentage heupfractuur geopereerd binnen kalenderdag	8	1
1.3	Percentage heroperaties bij een heupfractuur	6	6
1.5	Percentage cataractoperaties met een tijdsperiode tussen de operaties groter of gelijk aan 28 dagen	2	2
Totaal		22	10
Hfst 3. Verpleegkundige zorg			
3.1.2	Puntprevalentie decubitus en huidletsels door incontinentie ziekenhuisbreed	3	0
3.1.4	Incidentie decubitus en huidletsels door incontinentie bij een homogene patientenpopulatie	2	1
3.2.2	Screening op ondervoeding bij in kliniek opgenomen volwassenen	4	1
3.2.3	Screening op ondervoeding bij in kliniek opgenomen kinderen	3	1
3.2.5	Behandeling van ondervoeding	5	0
3.3.2	Risico op delirium - percentage afdelingen dat structureel bij opname van patiënten van 70 jr en ouder de risicoscore voor delirium vastlegt.	2	0
3.3.4	Screening op en observatie van delirium - fractie van de patiënten met een verhoogd risico op delirium (indicator 'Risico op delirium'), bij wie met een screeningsinstrument is beoordeeld of er sprake is van een delirium, ongeacht de uitkomst.	2	0
Totaal		21	3
Hfst 4. Intensive care			
4.1	Totaal aantal fte gergistreerde intensivisten beschikbaar voor de IC-afdeling	1	1
4.2	Beademingsuren per patient op een IC-afdeling	24	0
Totaal		25	1
Hfst 5. Oncologie			
5.2	Percentage patienten bij wie kankerweefsel is achtergebleven na een eerste borstsparende operatie	3	0
5.4	Resectie van de pancreas of delen hiervan	1	1
5.5	Percentage ongeplande reinterventies na resectie van een primair colorectaal carcinoom	2	2
5.6	Deelname aan de DSCA	2	1
5.7	Deelname aan de registratie van invasief blaascarcinoom	2	0

5.8	Volledigheid van gegevens van een cytostaticumaanvraag	7	0
5.9	Percentage positioneringscontrole bij prostaatbehandelingen	2	1
Totaal		19	5
Hfst 6. Hart en vaten			
6.1	Aantal patienten waarbij een AAA-operatie is uitgevoerd in het verslagjaar	1	1
6.2	Percentage sterfgevallen na eerste administratief consult (EAC) op de polikliniek cardiologie	2	1
6.3	Percentage ziekenhuissterfte na opname voor een AMI	4	0
6.4	Sterfte na percutane coronaire interventie (PCI)	3	2
6.5	Implanteren en/of wisselen van pacemakers	4	4
6.6	Door-to-needle time trombolyse	3	1
Totaal		17	9
Hfst 7. Infectieziekten			
7.1	Surveillance van ziekenhuisinfecties	16	0
7.2	CAP	2	1
Totaal		18	1
Hfst 8. Maag-darm-lever (MDL)			
8.2	MDL-scopie binnen 24 uur	2	1
Totaal		2	1
Hfst 9. Verloskunde			
9.1	Percentage spontane partus in de 'NTSV-groep'	6	0
Totaal		6	0
Hfst 10. Kwetsbare groepen			
10.2	Signalering kindermishandeling	2	1
Totaal		2	1
Hfst 11. Algemeen kwaliteitsbeleid			
11.1	Jaargesprekken	2	1
11.1	IFMS (Individueel Functioneren van Medisch Specialisten)	2	1
Totaal		4	2