ANNEX 2

Metadata of data sources inventoried (according to Eurostat template no. 2)

1. Netherlands Cancer Registry (NKR)
2. Netherlands Tuberculosis Register (NTR)
3. Netherlands Information Network of General Practice (LINH)
4. Continuous Morbidity Registration – Nijmegen (CMR-Nijmegen)
5. Registration Network of General Practitioners Associated with Leiden University (RNUH-LEO)
6. General Practice Registration Network Limburg (RNH)
7. Transition Project
8. Hospital Discharge Register (HDR)
9. Causes of Death register (COD)
10. CVZ drug register
11. NEMESIS
12. Continuous Registration of Morbidity – Sentinels (CMR)
13. Continuous Quality of Life Survey - Health interview survey (HIS)
14. Dutch Injury Surveillance System (ISS)
15. Electronic notificationsystem Osiris (Osiris)
16. Dutch HIV/AIDS monitoring foundation (SHM)
17. Electronic notificationsystem SOAP (SOAP)

Template n°2: Broad description and evaluation of the data sources inventoried

Number and name of the source	Netherlands Cancer Registry
Name in national language	Nederlandse Kankerregistratie
Used acronym of the source	NKR
General information	
General description	The purpose of the NKR is to gain insight in the nature and extent of the cancer problem in the Netherlands, and to deliver data for clinical and epidemiological studies of cancer. Besides examining incidence, prevalence and survival trends, geographical differences, and research into the causes of cancer, the Dutch Cancer Registration is also used for clinical research into prognostic factors, care patterns and the evaluation of screening programs and treatments. Data from the registration oalso form a good basis for the planning of care facilities.
Purpose	*Rationale for data collection (primary purpose) : *Does the source fulfil Administrative needs (reimbursement) ☐ Health statistics needs (activities of health care services) ☒ other needs (please specify): Associated with IARC (International Agency of Cancer Research), ENCR (European Network Cancer Registries), and EUROCARE (EUROpean CAncer REgistry-based study on survival and CARE of cancer patients) *Link to morbidity statistics: no link ☐ used for national health statistics (Statistics Netherlands) ☐ used for regular statistics of National Public Health Institute/Ministry ☒ other (please specify): National cancer statistics of NKR, international statistics of IARC, EUROCARE, ENCR
Owner	*Name of the institution:

	Details (address, website): Vereniging Integrale Kanker Centra Postbus 19001 3501 DA UTRECHT http://www.ikcnet.nl/
Provider	*Name of the institution: Details (address, website): Vereniging Integrale Kanker Centra Postbus 19001 3501 DA UTRECHT http://www.ikcnet.nl/
Copyright, legal basis, reliability, sustainability of provision	*Copyright restriction in using the data yes ☒ no ☐ *Legal basis yes ☐ no ☒ If yes name and year of the Act: n.a. *Payment/financial compensation yes ☐ no ☒ *Reliability guarantee yes ☐ no ☒ If yes how/why? *Sustainability guarantee yes ☐ no ☒ If yes how/why?
Data provided	
Type of data collection	administrative data source ☐ register ☒ census ☐ selected health institution sentinels ☐ self report survey ☐ health examination survey ☐ other:

	voluntary reporting ☒ mandatory reporting ☐ statutory reporting ☐ other: individual records ☒ aggregated records ☐ Individual records are collected by the registry; aggregated data are provided to national users, such as RIVM
Periodicity of data collection and updating mechanisms	*Periodicity of data collection: Daily ☒ Weekly ☐ Monthly ☐ Yearly ☐ every X year (for instance every 5 years), specify year interval: *Periodicity of updating mechanisms: Daily ☐ Weekly ☐ Monthly ☐ Yearly ☒ every X year (for instance every 5 years), specify year interval:
Method of data collection	*Clarify the method of data collection: Data records of all patients with cancer in a hospital are included (intake records and discharge diagnoses) or whose disease has been confirmed by pathology research laboratories and/or haematology laboratories. The registry represents over 95 percent of all cases of cancer in the Netherlands. The registration is a tumor registry, which means that more tumors from one patient may be registered. The standard set of data that is collected is based on coding of the WHO and the IACR, so that international data comparison is possible. The localization and tissue typing are coded using the International Classification of Diseases for Oncology (ICD-O). The stage of the tumor is recorded according to TNM classification. *Data available in: electronic form (micro-data) ☐

	electronic form (aggregated data) ☒ paper form only ☐
Useful available variables for the purpose of morbidity statistics	Name, short description Available in the data source: Administrative and demographic data: • patient identification • date of birth • sex • zip code • city / country of birth. Data Source: • location (which hospital, laboratory) of diagnosis Diagnosis / tumor data: • tumor number (the order indicated when a patient more than one tumor is detected) • incidence date (date of diagnosis) • basis for the diagnosis • topography and lateralization (the location of the tumor) • morphology (tissue typing) • number of examined lymph nodes • stage, size and / or extent of malignancy. Treatment Data: • initial treatment • location of treatment Follow-up data: • patient status, indicates whether the patient is alive • date of death / date of last contact.
Starting date of data collection, year of newest update	*Starting date of data collection: 1988 *Year of newest update: 2009 *Break in series yes ☐ no ☒ If yes, when, and why?……………

Timeliness, time of preparation of data (months, t-reference year)	Month and year of availability of the data: approximately 2 years (t+2)
Dissemination format (by provider and by statistical users)	hard copy ☐ publications ☒ electronic/online-database ☒ website address/link: http://www.ikcnet.nl/ CD-Rom ☐ Other ☐ specify:
Diagnosis	
Diagnosis generated by health care professional All diagnoses or only main diagnosis recorded All diseases or only selected diseases recorded ICD-codes can be derived? Classification used (ICD-9, ICD-10, ICPC, …) Information about coding rules and procedures Validation of the diagnosis	yes ☒ no ☐ all diagnoses (main and secundary) ☒ main diagnoses only ☐ all diseases ☐ selected diseases ☒ yes ☒ no ☐ Classification used : ICD-O, TNM; convertible to ICD10 Information about coding rules and procedures (if available):according to guidelines WHO and IACR. Was the diagnosis validated? yes ☐ no ☒ If yes, description of the procedure:
Registered units: person or episode related information	Person ☐ Episode ☐ Both ☒
Type of information derived from the source	(describe type of information and time-frame covered) 10-year survival 10-year prevalence

	15-year prevalence 1-year incidence
Coverage	
Population covered:	Total population ☐ Part of population ☒, please specify: approximately 95% of all cancer cases
Demographic / socioeconomic breakdowns	
Sex	yes
All ages/specific groups	all ages
Citizenship	no
Geographical information (national, regional, NUTS2, other)	yes
Socioeconomic situation	no
In-patients/out-patients-ambulatory	all
Public/private providers, all health care providers	all relevant health care providers.
Adjustment for under reporting/over reporting: reason and magnitude (estimation of the bias)	unknown
Assessment	
Health policy programmes that could affect the value of the parameter	No, NKR registration functions independently
Impact of the national organization of the health care system (e.g. registration of referrals, access to specialists)	No impact, but a change in the level of financing of the registry may have an impact
Strengths of the data source	Detailed and thorough registration process; data nearly complete
Weakness of the data source	Some cancer cases of patients that died outside the hospital are missed
Future of the data source	Likely to be continued

Update of metadata Metadata updated after interim report?	Date: 23-11-2010 yes ☐ no ☒

Template n°2: Broad description and evaluation of the data sources inventoried

Number and name of the source	Netherlands Tuberculosis Register
Name in national language	Nederlands Tuberculose Register
Used acronym of the source	NTR
General information	
General description	The Dutch Tuberculosis Register (NTR) is an accessible, anonymous, dynamically updated database in which relevant data about the prevalence of TB and TB infection in the Netherlands are being registered, including the results of treatment. The NTR is the basis for the tuberculosis policy in the Netherlands (see purpose).
Purpose	*Rationale for data collection (primary purpose) : *Does the source fulfil Administrative needs (reimbursement) ☐ Health statistics needs (activities of health care services) ☒ other needs (please specify): -surveillance of tuberculosis in NL; -providing information for regional and national policy reviews and policy (re)determination; -providing information for research and education; -quality of national TB control. *Link to morbidity statistics: no link ☐ used for national health statistics (Statistics Netherlands) ☐ used for regular statistics of National Public Health Institute/Ministry ☒ other (please specify): Publications of Netherlands KNCV Tuberculosis Foundation, international users EuroTB, WHO
Owner	*Name of the institution:

	Details (address, website): KNCV Tuberculosefonds Postal address: Postbus 146, 2501 CC Den Haag Visiting address adres: Parkstraat 17, 2514 JD Den Haag Tel.: +3170-4167222, Fax: +3170-3584004 E-mail: info@kncvtbc.nl http:www.kncvtbc.nl
Provider	*Name of the institution: Details (address, website): KNCV Tuberculosefonds Postal address: Postbus 146, 2501 CC Den Haag Visiting address adres: Parkstraat 17, 2514 JD Den Haag Tel.: +3170-4167222, Fax: +3170-3584004 E-mail: info@kncvtbc.nl http:www.kncvtbc.nl
Copyright, legal basis, reliability, sustainability of provision	*Copyright restriction in using the data yes ☐ no ☒ *Legal basis yes ☒ no ☐ If yes name and year of the Act: Statutory notification of tuberculosis cases according to the Wet Publieke Gezondheid 2008 (Public Health Act, 2008) *Payment/financial compensation yes ☐ no ☒ *Reliability guarantee yes ☒ no ☐ If yes how/why? Since suspected incident TB cases require notification with the appropriate agencies, and the NTR receives information from these agencies, the NTR can be regarded as reliable. *Sustainability guarantee yes ☒ no ☐ If yes how/why? legal obligation
Data provided	
Type of data collection	administrative data source ☐

	register ☒ census ☐ selected health institution sentinels ☐ self report survey ☐ health examination survey ☐ other: voluntary reporting ☐ mandatory reporting ☒ statutory reporting ☒ other: individual records ☐ aggregated records ☒
Periodicity of data collection and updating mechanisms	*Periodicity of data collection: Daily ☒ Weekly ☐ Monthly ☐ Yearly ☐ every X year (for instance every 5 years), specify year interval: *Periodicity of updating mechanisms: Daily ☐ Weekly ☐ Monthly ☐ Yearly ☒ every X year (for instance every 5 years), specify year interval: Quarterly
Method of data collection	*Clarify the method of data collection: Data on TB-reports are collected electronically, through a secure internet environment (OSIRIS-NTR). This internet environment is only accessible for authorized staff of regional health services (GGD-staff). The reporting of tuberculosis in Osiris-NTR consists of four parts. The first part is the statutory reporting to the Dutch health care inspection, which is passed as soon as possible. Shortly after establishing the disease tuberculosis, the available (lab) diagnostic data of the patiënt are reported to the NTR (second part). After treatment has ended, data on treatment results are

	reported to the NTR (third part). As of January 1 2004 a fourth part was added to Osiris-NTR, which includes the results of investigation of contacts of the patient. *Data available in: electronic form (micro-data) ☐ electronic form (aggregated data) ☒ paper form only ☒
Useful available variables for the purpose of morbidity statistics	Name, short description Diagnosis New / recurrent Age Gender Geographical region Microscopic analysis of sputum and BAL Determination Result of treatment Reason for treatment cessation DOT intake
Starting date of data collection, year of newest update	*Starting date of data collection: 1900 *Year of newest update: 2008 *Break in series yes ☒ no ☐ If yes, when, and why?.............. The current method of data collection (the first three parts) started in 1993.
Timeliness, time of preparation of data (months, t-reference year)	Month and year of availability of the data:varies per year
Dissemination format (by provider and by statistical users)	hard copy ☒ publications ☒ electronic/online-database ☒ website address/link: http://www.kncvtbc.nl CD-Rom ☐ Other ☐ specify:

Diagnosis	
Diagnosis generated by health care professional	yes ☒ no ☐
All diagnoses or only main diagnosis recorded	all diagnoses (main and secundary) ☐ main diagnoses only ☒
All diseases or only selected diseases recorded	all diseases ☐ selected diseases ☒
ICD-codes can be derived?	yes ☒ no ☐
Classification used (ICD-9, ICD-10, ICPC, …)	Classification used : ICD-9
Information about coding rules and procedures	Information about coding rules and procedures (if available):in PDF available on website, in Dutch
Validation of the diagnosis	Was the diagnosis validated? yes ☐ no ☒ If yes, description of the procedure:
Registered units: person or episode related information	Person ☐ Episode ☐ Both ☒
Type of information derived from the source	(describe type of information and time-frame covered) 1-year incidence of TB per 100.000 persons 1-, 3-, and 5-year prevalence of TB in percentages and absolute numbers of persons 1-, 3-, and 5-year prevalence of latent TB-infections in percentages and absolute numbers of persons
Coverage	
Population covered:	Total population ☒ Part of population ☐, please specify:
Demographic / socioeconomic breakdowns	

Sex	yes
All ages/specific groups	all ages, in 3-, 7-, and 10 years age categories
Citizenship	yes
Geographical information (national, regional, NUTS2, other)	yes
Socioeconomic situation	no
In-patients/out-patients-ambulatory	all
Public/private providers, all health care providers	all (but mainly public providers, i.e. GPs, hospitals, regional health services, nursing homes)
Adjustment for under reporting/over reporting: reason and magnitude (estimation of the bias)	n.a.
Assessment	
Health policy programmes that could affect the value of the parameter	n.a.
Impact of the national organization of the health care system (e.g. registration of referrals, access to specialists)	n.a.
Strengths of the data source	Reliable registration process, compete population coverage
Weakness of the data source	To date, treatment outcomes cannot be stratified in age and gender categories. Only incidences can be stratified by age and gender.
Future of the data source	will be continued
Update of metadata Metadata updated after interim report?	Date: may 2011 yes ☒ no ☐

Template n°2: Broad description and evaluation of the data sources inventoried

Number and name of the source	Netherlands Information Network of General Practice
Name in national language	Landelijk Informatie Netwerk Huisartsenzorg
Used acronym of the source	LINH
General information	
General description	LINH holds longitudinal data on morbidity, prescriptions and referrals of about 350.000 individuals. Data are collected in a representative network of about 92 general practices, spread throughout the Netherlands.
Purpose	*Rationale for data collection (primary purpose) : *Does the source fulfil Administrative needs (reimbursement) ☐ Health statistics needs (activities of health care services) ☒ other needs (please specify): data are derived from the GP's electronic information system with individual patient records; this system is also partially used for financial declaration purposes. The LINH register itself, however, is not used for administrative needs. *Link to morbidity statistics: no link ☐ used for national health statistics (Statistics Netherlands) ☒ used for regular statistics of National Public Health Institute/Ministry ☒ other (please specify):
Owner	*Name of the institution: Details (address, website): NIVEL, PO box 1586, 3500 BN Utrecht, the Netherlands www.nivel.nl

Provider	*Name of the institution: Details (address, website): NIVEL, PO box 1586, 3500 BN Utrecht, the Netherlands www.nivel.nl
Copyright, legal basis, reliability, sustainability of provision	*Copyright restriction in using the data yes ☒ no ☐ *Legal basis yes ☐ no ☒ If yes name and year of the Act: *Payment/financial compensation yes ☐ no ☒ *Reliability guarantee yes ☐ no ☒ If yes how/why? *Sustainability guarantee yes ☐ no ☒ If yes how/why?
Data provided	
Type of data collection	administrative data source ☐ register ☐ census ☐ selected health institution sentinels ☒ self report survey ☐ health examination survey ☐ other: voluntary reporting ☒ mandatory reporting ☐ statutory reporting ☐ other: individual records ☒ aggregated records ☐

Periodicity of data collection and updating mechanisms	*Periodicity of data collection: Daily ☐ Weekly ☐ Monthly ☐ Yearly ☒, i.e. half-yearly every X year (for instance every 5 years), specify year interval: *Periodicity of updating mechanisms: Daily ☐ Weekly ☐ Monthly ☐ Yearly ☒ every X year (for instance every 5 years), specify year interval:
Method of data collection	*Clarify the method of data collection: Data are extracted from the electronic medical records used in the practices to file patient information. Recording data for LINH hardly interferes with daily practice. *Data available in: electronic form (micro-data) ☒ electronic form (aggregated data) ☐ paper form only ☐
Useful available variables for the purpose of morbidity statistics	Name, short description Per diagnoses: episode (yes/no), start/end, number of contacts during episode, new episode/ existing problem. Per person: registration period with GP in reporting year. Note: the patient population also includes persons with no GP-contacts
Starting date of data collection, year of newest update	*Starting date of data collection: 2002 *Year of newest update: 2007 *Break in series yes ☐ no ☒ If yes, when, and why?……………

Timeliness, time of preparation of data (months, t-reference year)	Month and year of availability of the data: december t+1
Dissemination format (by provider and by statistical users)	hard copy ☐ publications ☒ electronic/online-database ☒ website address/link: www.linh.nl: www.statline.nl CD-Rom ☐ Other ☐ specify: researchers of eligible institutions under the Act on Statistics Neththerlands (2003), can have access to (linked) micro-datafiles for specific research purposes and under explicit conditions of confidentiality. Because of the confidentiality requirements, the microdata can only be used on site at Statistics Netherlands, or via remote execution or remote access. The owner of the LINH has to give permission for access to linked LINH-datafiles at Statistics Netherlands.
Diagnosis	
Diagnosis generated by health care professional	yes ☒ no ☐
All diagnoses or only main diagnosis recorded	all diagnoses (main and secundary) ☒ main diagnoses only ☐
All diseases of only selected diseases recorded	all diseases ☒ selected diseases ☐
ICD-codes can be derived?	yes ☒ no ☐
Classification used (ICD-9, ICD-10, ICPC, …)	Classification used : ICPC-1
Information about coding rules and procedures	Information about coding rules and procedures (if available): With every contact with the patient, (including prescriptions), the diagnosis is registered using ICPC-codes. Using an algorithm, contacts appearing to belong to the same problem are aggregated to an episode. The diagnosis of the episode is the diagnosis of the last contact.
Validation of the diagnosis	Was the diagnosis validated? yes ☐ no ☒ If yes, description of the procedure:
Registered units: person or episode related information	Person ☐

	Episode ☐ Both ☒
Type of information derived from the source	(describe type of information and time-frame covered) incidence and prevalence, 2002-2007
Coverage	
Population covered:	Total population ☐ Part of population ☒, please specify: Data are collected in a representative network of about 92 general practices with about 350,000 individuals. Nursing home patients are not included, as in the Netherlands GPs do not attend to nursing homes patients. For the rest of the population the GP has a gatekeeper role in the health care system. For some health care services, however, referrals of the GP are not necessary (e.g. physiotherpy); the regulations for this change over time.
Demographic / socioeconomic breakdowns	LINH-data are linked to the population registry, which enables breakdowns with all factors mentioned below
Sex	yes
All ages/specific groups	yes, all ages can be distinguished
Citizenship	yes
Geographical information (national, regional, NUTS2, other)	postal codes are available, but not every part of the country is covered sufficiently to present regional data
Socioeconomic situation	yes (household income can be linked)
In-patients/out-patients-ambulatory	ambulatory (although GP-visits to patients staying in the hospital and in homes for the elderly are included)
Public/private providers, all health care providers	public (all GPS are public providers)
Adjustment for under reporting/over reporting: reason and magnitude (estimation of the bias)	For calculation of incidence, LINH data are only relevant for diagnoses that require a visit to the GP before contacting other health care providers. For prevalence, LINH data are useful for diagnoses that require a contact to the GP at least once a year. Other diagnoses will be underestimated. Using the linkage to the national population registry, over- or underrepresentation of certain groups in the population are adjusted for by using a weighting procedure.
Assessment	

Health policy programmes that could affect the value of the parameter	Attention to certain diseases in the media may result in more patients contacting their GP for a check, for example for diabetes. Also the establishment of programmes for integrated health care over different health care sectors (e.g. for diabetes or stroke) may influence the number of GP contacts.
Impact of the national organization of the health care system (e.g. registration of referrals, access to specialists)	Since 2006 there is a statutory public health insurance for the whole population; this includes GP care. However, a change in free access to for example a physiotherapist (without referral by the GP) can directly influence the number of patients with certain complaints registered by the GP.
Strengths of the data source	General practices throughout the country, full coverage of contacts throughout the year. As gate-keeper in the health care system GPs register most of the diagnosed morbidity in the population.
Weakness of the data source	No data on nursing home patients, participating GP practices are not based on a statistical sampling process, incomplete linkage to population register because of the limited resolution power of the linkage key (but a weighting procedure is applied to correct for this)
Future of the data source	Very likely to be continued in the next decade or so
Update of metadata Metadata updated after interim report?	Date: november 2010 yes ☐ no ☒

Template n°2: Broad description and evaluation of the data sources inventoried

Number and name of the source	Continuous Morbidity Registration - Nijmegen
Name in national language	Continue Morbiditeit Registratie - Nijmegen
Used acronym of the source	CMR-Nijmegen
General information	
General description	Local General Practitioner Registration Network that generates epidemiological data regarding primary care conditions, for education and research purposes.
Purpose	*Rationale for data collection (primary purpose) : *Does the source fulfil Administrative needs (reimbursement) ☐ Health statistics needs (activities of health care services) ☒ other needs (please specify): *Link to morbidity statistics: no link ☐ used for national health statistics (Statistics Netherlands) ☐ used for regular statistics of National Public Health Institute/Ministry ☒ other (please specify):
Owner	*Name of the institution: Details (address, website): Huisartsgeneeskunde UMC St Radboud Nijmegen Postbus 9101 6500 HB Nijmegen http://www.nmp.net.ms/

Provider	*Name of the institution: Details (address, website): Huisartsgeneeskunde UMC St Radboud Nijmegen Postbus 9101 6500 HB Nijmegen http://www.nmp.net.ms/
Copyright, legal basis, reliability, sustainability of provision	*Copyright restriction in using the data yes ☐ no ☒ *Legal basis yes ☐ no ☒ If yes name and year of the Act: n.a. *Payment/financial compensation yes ☐ no ☒ only handling fees *Reliability guarantee yes ☐ no ☒ If yes how/why? *Sustainability guarantee yes ☐ no ☒ If yes how/why?
Data provided	
Type of data collection	administrative data source ☐ register ☐ census ☐ selected health institution sentinels ☒ self report survey ☐ health examination survey ☐ other: voluntary reporting ☒ mandatory reporting ☐ statutory reporting ☐ other: individual records ☒

	aggregated records ☐ Individual records are collected by the registry; aggregated data are provided to national users, such as RIVM
Periodicity of data collection and updating mechanisms	*Periodicity of data collection: Daily ☒ Weekly ☐ Monthly ☐ Yearly ☐ every X year (for instance every 5 years), specify year interval: *Periodicity of updating mechanisms: Daily ☐ Weekly ☐ Monthly ☐ Yearly ☒ every X year (for instance every 5 years), specify year interval:
Method of data collection	*Clarify the method of data collection: Contact based general practice registration network (4 practices, 9 GP's, 13.500 patient population). GP's register all morbidity that is presented by patients, even if not the main reason for GP visit. Information derived from telephone consults, nurse practitioner contacts, hospital discharge records are used as well. *Data available in: electronic form (micro-data) ☐ electronic form (aggregated data) ☒ paper form only ☐
Useful available variables for the purpose of morbidity statistics	Name, short description Administrative and demographic data: • patient identification • birth • sex • zip code

	• date of entry in patient population Data Source: • location (which practice, GP) Diagnosis data: • diagnosis • incidence date (date of diagnosis) Treatment Data: • initial treatment • prescription data Follow-up data: • patient status, indicates whether the patient is alive • date of death / date of last contact.
Starting date of data collection, year of newest update	*Starting date of data collection: 1971 *Year of newest update: 2009 *Break in series yes ☐ no ☒ If yes, when, and why?……………
Timeliness, time of preparation of data (months, t-reference year)	Month and year of availability of the data: approximately t+2
Dissemination format (by provider and by statistical users)	hard copy ☐ publications ☒ electronic/online-database ☒ website address/link: http://www.nmp.net.ms/ CD-Rom ☐ Other ☐ specify:
Diagnosis	
Diagnosis generated by health care professional	yes ☒ no ☐

All diagnoses or only main diagnosis recorded All diseases or only selected diseases recorded ICD-codes can be derived? Classification used (ICD-9, ICD-10, ICPC, …) Information about coding rules and procedures Validation of the diagnosis	all diagnoses (main and secundary) ☒ main diagnoses only ☐ all diseases ☒ selected diseases ☐ yes ☒ no ☐ Classification used : E-Codes (based on ICD-7) Information about coding rules and procedures (if available):n.a. Was the diagnosis validated? yes ☐ no ☒ If yes, description of the procedure:
Registered units: person or episode related information	Person ☐ Episode ☐ Both ☒
Type of information derived from the source	(describe type of information and time-frame covered) any period incidence, any period prevalence
Coverage	
Population covered:	Total population ☐ Part of population ☒, please specify: Regional: Eastern Middle Netherlands, in and around Nijmegen
Demographic / socioeconomic breakdowns	
Sex	yes
All ages/specific groups	age groups
Citizenship	no

Geographical information (national, regional, NUTS2, other)	no; local network in one region
Socioeconomic situation	no
In-patients/out-patients-ambulatory	all, but mostly ambulatory (patients in nursing homes are excluded; patients in hospitals and homes for the elderly are included)
Public/private providers, all health care providers	public (all GPs are public providers)
Adjustment for under reporting/over reporting: reason and magnitude (estimation of the bias)	unknown
Assessment	
Health policy programmes that could affect the value of the parameter	Attention to certain diseases in the media may result in more patients contacting their GP for a check, for example for diabetes. Also the establishment of programmes for integrated health care over different health care sectors (e.g. for diabetes or stroke) may influence the number of GP contacts
Impact of the national organization of the health care system (e.g. registration of referrals, access to specialists)	Since 2006 there is a statutory public health insurance for the whole population; this includes GP care. However, a change in free access to for example a physiotherapist (without referral by the GP) can directly influence the number of patients with certain complaints registered by the GP.
Strengths of the data source	As gate-keeper in the health care system GPs register most of the diagnosed morbidity in the population.
Weakness of the data source	Local network; no data on nursing home patients
Future of the data source	Will be continued
Update of metadata Metadata updated after interim report?	Date: 02-08-2010 yes ☐ no ☒

Template n°2: Broad description and evaluation of the data sources inventoried

Number and name of the source	Registration Network of General Practitioners Associated with Leiden University
Name in national language	Registratie Netwerk Universitaire Huisartspraktijken - Leiden en Omgeving
Used acronym of the source	RNUH-LEO
General information	
General description	Local General Practitioner Network that collects primary care data for scientific research, student education, GP training, and improvement of quality of care.
Purpose	*Rationale for data collection (primary purpose) : *Does the source fulfil Administrative needs (reimbursement) ☐ Health statistics needs (activities of health care services) ☒ other needs (please specify): *Link to morbidity statistics: no link ☐ used for national health statistics (Statistics Netherlands) ☐ used for regular statistics of National Public Health Institute/Ministry ☒ other (please specify):
Owner	*Name of the institution: Details (address, website): LUMC department of Public health and Primary Care Postbus 9600, 2300 RC Leiden http://www.lumc.nl/con/4070/83231/90119055728221/90202045508221/

Provider	*Name of the institution: Details (address, website): LUMC department of Public health and Primary Care Postbus 9600, 2300 RC Leiden http://www.lumc.nl/con/4070/83231/90119055728221/90202045508221/
Copyright, legal basis, reliability, sustainability of provision	*Copyright restriction in using the data yes ☐ no ☒ *Legal basis yes ☐ no ☒ If yes name and year of the Act: n.a. *Payment/financial compensation yes ☐ no ☒ only handling fees *Reliability guarantee yes ☐ no ☒ If yes how/why? *Sustainability guarantee yes ☐ no ☒ If yes how/why?
Data provided	
Type of data collection	administrative data source ☐ register ☐ census ☐ selected health institution sentinels ☒ self report survey ☐ health examination survey ☐ other: voluntary reporting ☒ mandatory reporting ☐ statutory reporting ☐ other: individual records ☒ aggregated records ☐ Individual records are collected by the registry;

	aggregated data are provided to national users, such as RIVM
Periodicity of data collection and updating mechanisms	*Periodicity of data collection: Daily ☒ Weekly ☐ Monthly ☐ Yearly ☐ every X year (for instance every 5 years), specify year interval: *Periodicity of updating mechanisms: Daily ☐ Weekly ☐ Monthly ☐ Yearly ☒ every X year (for instance every 5 years), specify year interval:
Method of data collection	*Clarify the method of data collection: Episode based General Practice Registration Network (20 GP's, 4 practices, 30.000 patients). GPs register starting date of every condition episode plus diagnosis in electronic health records. Fifteen months after last contact for the condition at hand the record is being terminated. Condition episodes are registered on the problem list when they have become chronic (or frequently intermittant). Although not all patients who have conditions on the problem list visit their GP yearly, these conditions are being monitored by the GP, e.g. through prescriptions. *Data available in: electronic form (micro-data) ☐ electronic form (aggregated data) ☒ paper form only ☐
Useful available variables for the purpose of morbidity statistics	Name, short description Administrative and demographic data: • patient identification • birth • sex • zip code

	• date of entry in patient population Data Source: • location (which practice, GP) Diagnosis data: • diagnosis • incidence date (date of diagnosis) Treatment Data: • initial treatment • prescription data Follow-up data: • patient status, indicates whether the patient is alive • date of death / date of last contact.
Starting date of data collection, year of newest update	*Starting date of data collection: 1989 *Year of newest update: 2009 *Break in series yes ☐ no ☒ If yes, when, and why?……………
Timeliness, time of preparation of data (months, t-reference year)	Month and year of availability of the data: approximately t+2
Dissemination format (by provider and by statistical users)	hard copy ☐ publications ☒ electronic/online-database ☒ website address/link: http://www.lumc.nl/con/4070/83231/90119055728221/90202045508221/ CD-Rom ☐ Other ☐ specify:
Diagnosis	
Diagnosis generated by health care professional	yes ☒ no ☐

All diagnoses or only main diagnosis recorded All diseases or only selected diseases recorded ICD-codes can be derived? Classification used (ICD-9, ICD-10, ICPC, …) Information about coding rules and procedures Validation of the diagnosis	all diagnoses (main and secundary) ☒ main diagnoses only ☐ all diseases ☒ selected diseases ☐ yes ☒ no ☐ Classification used : ICPC1 Information about coding rules and procedures (if available):n.a. Was the diagnosis validated? yes ☐ no ☒ If yes, description of the procedure:
Registered units: person or episode related information	Person ☐ Episode ☐ Both ☒
Type of information derived from the source	(describe type of information and time-frame covered) any period incidence, any period prevalence
Coverage	
Population covered:	Total population ☐ Part of population ☒, please specify: Leiden en surroundings
Demographic / socioeconomic breakdowns	
Sex	yes
All ages/specific groups	age groups
Citizenship	no
Geographical information (national, regional, NUTS2, other)	no; local network in one region

Socioeconomic situation	no
In-patients/out-patients-ambulatory	all, but mostly ambulatory (patients in nursing homes are excluded; patients in hospitals and homes for the elderly are included)
Public/private providers, all health care providers	public (all GPs are public providers)
Adjustment for under reporting/over reporting: reason and magnitude (estimation of the bias)	unknown
Assessment	
Health policy programmes that could affect the value of the parameter	Attention to certain diseases in the media may result in more patients contacting their GP for a check, for example for diabetes. Also the establishment of programmes for integrated health care over different health care sectors (e.g. for diabetes or stroke) may influence the number of GP contacts
Impact of the national organization of the health care system (e.g. registration of referrals, access to specialists)	
Strengths of the data source	As gate-keeper in the health care system GPs register most of the diagnosed morbidity in the population.
Weakness of the data source	Local network; no data on nursing home patients
Future of the data source	Will be continued
Update of metadata Metadata updated after interim report?	Date: 02-02-2010 yes ☐ no ☒

Template n°2: Broad description and evaluation of the data sources inventoried

Number and name of the source	General Practice Registration Network Limburg
Name in national language	Registratienet Huisartspraktijken Limburg
Used acronym of the source	RNH
General information	
General description	Local General Practice Registration Network in the province of Limburg, with the purpose to have an automated and anonymous patient sampling frame, with a set of background and relevant health variables, for scientific research, education and health care purposes. Focus is on long-term health problems.
Purpose	*Rationale for data collection (primary purpose) : *Does the source fulfil Administrative needs (reimbursement) ☐ Health statistics needs (activities of health care services) ☒ other needs (please specify): *Link to morbidity statistics: no link ☐ used for national health statistics (Statistics Netherlands) ☐ used for regular statistics of National Public Health Institute/Ministry ☒ other (please specify):
Owner	*Name of the institution: Details (address, website): Maastricht University Department of General Practice Postbus 616, 6200 MD Maastricht http://www.hag.unimaas.nl/

Provider	*Name of the institution: Details (address, website): RNH secretariate Maastricht University Department of General Practice Postbus 616, 6200 MD Maastricht http://www.hag.unimaas.nl/rnh/default_oudesite.htm
Copyright, legal basis, reliability, sustainability of provision	*Copyright restriction in using the data yes ☐ no ☒ *Legal basis yes ☐ no ☒ If yes name and year of the Act: n.a. *Payment/financial compensation yes ☐ no ☒ only handling fees *Reliability guarantee yes ☐ no ☒ If yes how/why? *Sustainability guarantee yes ☐ no ☒ If yes how/why?
Data provided	
Type of data collection	administrative data source ☐ register ☐ census ☐ selected health institution sentinels ☒ self report survey ☐ health examination survey ☐ other: voluntary reporting ☒ mandatory reporting ☐

	statutory reporting ☐ other: individual records ☒ aggregated records ☐ Individual records are collected by the registry; aggregated data are provided to national users, such as RIVM
Periodicity of data collection and updating mechanisms	*Periodicity of data collection: Daily ☒ Weekly ☐ Monthly ☐ Yearly ☐ every X year (for instance every 5 years), specify year interval: *Periodicity of updating mechanisms: Daily ☐ Weekly ☐ Monthly ☐ Yearly ☒ every X year (for instance every 5 years), specify year interval:
Method of data collection	*Clarify the method of data collection: Problem list based General Practice Registration Network (22 practices, 65 GP's, 88.000 patient population). GPs register conditions that can be regarded as chronic (>6months existence or expectation, or potential future health problem). Prevalence and incidence of conditions of less than one year are being underestimated (because GPs may not qualify the condition as chronic upon first contact). *Data available in: electronic form (micro-data) ☐ electronic form (aggregated data) ☒ paper form only ☐
Useful available variables for the purpose of morbidity	Name, short description

statistics	Administrative and demographic data: • patient identification • birth • sex • zip code • date of entry in patient population Data Source: • location (which practice, GP) Diagnosis data: • diagnosis • incidence date (date of diagnosis) Treatment Data: • initial treatment • prescription data Follow-up data: • patient status, indicates whether the patient is alive • date of death / date of last contact.
Starting date of data collection, year of newest update	*Starting date of data collection: 1987 *Year of newest update: 2009 *Break in series yes ☐ no ☒ If yes, when, and why?……………
Timeliness, time of preparation of data (months, t-reference year)	Month and year of availability of the data: approximately t+2
Dissemination format (by provider and by statistical users)	hard copy ☐ publications ☒ electronic/online-database ☒ website address/link: http://www.hag.unimaas.nl/rnh/default_oudesite.htm CD-Rom ☐ Other ☐ specify:

Diagnosis	
Diagnosis generated by health care professional All diagnoses or only main diagnosis recorded All diseases or only selected diseases recorded ICD-codes can be derived? Classification used (ICD-9, ICD-10, ICPC, …) Information about coding rules and procedures Validation of the diagnosis	yes ☒ no ☐ all diagnoses (main and secundary) ☒ main diagnoses only ☐ all diseases ☐ selected diseases ☒ focus on chronic diseases yes ☒ no ☐ Classification used : ICPC1 Information about coding rules and procedures (if available):n.a. Was the diagnosis validated? yes ☐ no ☒ If yes, description of the procedure:
Registered units: person or episode related information	Person ☐ Episode ☐ Both ☒
Type of information derived from the source	(describe type of information and time-frame covered) any period incidence, any period prevalence
Coverage	
Population covered:	Total population ☐ Part of population ☒, please specify: Province of Limburg
Demographic / socioeconomic breakdowns	

Sex	yes
All ages/specific groups	age groups
Citizenship	no
Geographical information (national, regional, NUTS2, other)	no; local network in one province
Socioeconomic situation	no
In-patients/out-patients-ambulatory	all, but mostly ambulatory (patients in nursing homes are excluded; patients in hospitals and homes for the elderly are included)
Public/private providers, all health care providers	public (all GPs are public providers)
Adjustment for under reporting/over reporting: reason and magnitude (estimation of the bias)	unknown
Assessment	
Health policy programmes that could affect the value of the parameter	Attention to certain diseases in the media may result in more patients contacting their GP for a check, for example for diabetes. Also the establishment of programmes for integrated health care over different health care sectors (e.g. for diabetes or stroke) may influence the number of GP contacts
Impact of the national organization of the health care system (e.g. registration of referrals, access to specialists)	
Strengths of the data source	As gate-keeper in the health care system GPs register most of the diagnosed morbidity in the population.
Weakness of the data source	Local network; no data on nursing home patients
Future of the data source	Will be continued
Update of metadata Metadata updated after interim report?	Date: 02-08-2010 yes ☐ no ☒

Template n°2: Broad description and evaluation of the data sources inventoried

Number and name of the source	Transition Project
Name in national language	Transitieproject
Used acronym of the source	Trans
General information	
General description	Local General Practitioner Registration Network designed for episode oriented epidemiological research in the GP practice, by registering all elements of patient-GP contacts using ICPC.
Purpose	*Rationale for data collection (primary purpose) : *Does the source fulfil Administrative needs (reimbursement) ☐ Health statistics needs (activities of health care services) ☒ other needs (please specify): *Link to morbidity statistics: no link ☐ used for national health statistics (Statistics Netherlands) ☐ used for regular statistics of National Public Health Institute/Ministry ☒ other (please specify):
Owner	*Name of the institution: Details (address, website): Transitieproject foundation, http://www.transitieproject.nl/
Provider	*Name of the institution: Details (address, website): Transitieproject foundation, http://www.transitieproject.nl/

Copyright, legal basis, reliability, sustainability of provision	*Copyright restriction in using the data yes ☐ no ☒ *Legal basis yes ☐ no ☒ If yes name and year of the Act: n.a. *Payment/financial compensation yes ☐ no ☒ only handling fees *Reliability guarantee yes ☐ no ☒ If yes how/why? *Sustainability guarantee yes ☐ no ☒ If yes how/why?
Data provided	
Type of data collection	administrative data source ☐ register ☐ census ☐ selected health institution sentinels ☒ self report survey ☐ health examination survey ☐ other: voluntary reporting ☒ mandatory reporting ☐ statutory reporting ☐ other: individual records ☒ aggregated records ☐ Individual records are collected by the registry; aggregated data are provided to national users, such as RIVM

Periodicity of data collection and updating mechanisms	*Periodicity of data collection: Daily ☒ Weekly ☐ Monthly ☐ Yearly ☐ every X year (for instance every 5 years), specify year interval: *Periodicity of updating mechanisms: Daily ☐ Weekly ☐ Monthly ☐ Yearly ☒ every X year (for instance every 5 years), specify year interval:
Method of data collection	*Clarify the method of data collection: Episode based General Practice Registration Network (9 GP's, 5 practices, 13.500 patients). GP's register starting and ending date of every condition episode plus diagnosis in electronic health records. For the construction of episodes all contact based information is being used, such as health interventions, referrals, lab results, prescriptions, etc. New episodes can also start after telephone consults. *Data available in: electronic form (micro-data) ☐ electronic form (aggregated data) ☒ paper form only ☐
Useful available variables for the purpose of morbidity statistics	Name, short description Administrative and demographic data: • patient identification • birth • sex • zip code • date of entry in patient population Data Source:

	• location (which practice, GP) Diagnosis data: • diagnosis • incidence date (date of diagnosis) Treatment Data: • initial treatment • prescription data Follow-up data: • patient status, indicates whether the patient is alive • date of death / date of last contact.
Starting date of data collection, year of newest update	*Starting date of data collection: 1985 *Year of newest update: 2009 *Break in series yes ☐ no ☒ If yes, when, and why?…………..
Timeliness, time of preparation of data (months, t-reference year)	Month and year of availability of the data: approximately t+2
Dissemination format (by provider and by statistical users)	hard copy ☐ publications ☒ electronic/online-database ☒ website address/link: http://www.transitieproject.nl CD-Rom ☐ Other ☐ specify:
Diagnosis	
Diagnosis generated by health care professional All diagnoses or only main diagnosis recorded	yes ☒ no ☐ all diagnoses (main and secundary) ☒ main diagnoses only ☐

All diseases or only selected diseases recorded ICD-codes can be derived? Classification used (ICD-9, ICD-10, ICPC, …) Information about coding rules and procedures Validation of the diagnosis	all diseases ☐ selected diseases ☒ yes ☒ no ☐ Classification used : ICPC 1 and 2 Information about coding rules and procedures (if available):n.a. Was the diagnosis validated? yes ☐ no ☒ If yes, description of the procedure:
Registered units: person or episode related information	Person ☐ Episode ☒ Both ☐
Type of information derived from the source	(describe type of information and time-frame covered) any period prevalence any period incidence
Coverage	
Population covered:	Total population ☐ Part of population ☒, please specify: GP population in Amstelveen and Franeker
Demographic / socioeconomic breakdowns	
Sex	yes
All ages/specific groups	age groups
Citizenship	no
Geographical information (national, regional, NUTS2, other)	no; local network in two communities
Socioeconomic situation	no

In-patients/out-patients-ambulatory	all, but mostly ambulatory (patients in nursing homes are excluded; patients in hospitals and homes for the elderly are included)
Public/private providers, all health care providers	public (all GPs are public providers)
Adjustment for under reporting/over reporting: reason and magnitude (estimation of the bias)	unknown
Assessment	
Health policy programmes that could affect the value of the parameter	Attention to certain diseases in the media may result in more patients contacting their GP for a check, for example for diabetes. Also the establishment of programmes for integrated health care over different health care sectors (e.g. for diabetes or stroke) may influence the number of GP contacts
Impact of the national organization of the health care system (e.g. registration of referrals, access to specialists)	Since 2006 there is a statutory public health insurance for the whole population; this includes GP care. However, a change in free access to for example a physiotherapist (without referral by the GP) can directly influence the number of patients with certain complaints registered by the GP.
Strengths of the data source	As gate-keeper in the health care system GPs register most of the diagnosed morbidity in the population.
Weakness of the data source	Local network; no data on nursing home patients☐
Future of the data source	Will be continued
Update of metadata Metadata updated after interim report?	Date: 02-02-2010 yes ☐ no ☒

Template n°2: Broad description and evaluation of the data sources inventoried

Number and name of the source	Transition Project
Name in national language	Transitieproject
Used acronym of the source	Trans
General information	
General description	Local General Practitioner Registration Network designed for episode oriented epidemiological research in the GP practice, by registering all elements of patient-GP contacts using ICPC.
Purpose	*Rationale for data collection (primary purpose) : *Does the source fulfil Administrative needs (reimbursement) ☐ Health statistics needs (activities of health care services) ☒ other needs (please specify): *Link to morbidity statistics: no link ☐ used for national health statistics (Statistics Netherlands) ☐ used for regular statistics of National Public Health Institute/Ministry ☒ other (please specify):
Owner	*Name of the institution: Details (address, website): Transitieproject foundation, http://www.transitieproject.nl/
Provider	*Name of the institution: Details (address, website): Transitieproject foundation, http://www.transitieproject.nl/

Copyright, legal basis, reliability, sustainability of provision	*Copyright restriction in using the data yes ☐ no ☒ *Legal basis yes ☐ no ☒ If yes name and year of the Act: n.a. *Payment/financial compensation yes ☐ no ☒ only handling fees *Reliability guarantee yes ☐ no ☒ If yes how/why? *Sustainability guarantee yes ☐ no ☒ If yes how/why?
Data provided	
Type of data collection	administrative data source ☐ register ☐ census ☐ selected health institution sentinels ☒ self report survey ☐ health examination survey ☐ other: voluntary reporting ☒ mandatory reporting ☐ statutory reporting ☐ other: individual records ☒ aggregated records ☐ Individual records are collected by the registry; aggregated data are provided to national users, such as RIVM

Periodicity of data collection and updating mechanisms	*Periodicity of data collection: Daily ☒ Weekly ☐ Monthly ☐ Yearly ☐ every X year (for instance every 5 years), specify year interval: *Periodicity of updating mechanisms: Daily ☐ Weekly ☐ Monthly ☐ Yearly ☒ every X year (for instance every 5 years), specify year interval:
Method of data collection	*Clarify the method of data collection: Episode based General Practice Registration Network (9 GP's, 5 practices, 13.500 patients). GP's register starting and ending date of every condition episode plus diagnosis in electronic health records. For the construction of episodes all contact based information is being used, such as health interventions, referrals, lab results, prescriptions, etc. New episodes can also start after telephone consults. *Data available in: electronic form (micro-data) ☐ electronic form (aggregated data) ☒ paper form only ☐
Useful available variables for the purpose of morbidity statistics	Name, short description Administrative and demographic data: • patient identification • birth • sex • zip code • date of entry in patient population Data Source:

	• location (which practice, GP) Diagnosis data: • diagnosis • incidence date (date of diagnosis) Treatment Data: • initial treatment • prescription data Follow-up data: • patient status, indicates whether the patient is alive • date of death / date of last contact.
Starting date of data collection, year of newest update	*Starting date of data collection: 1985 *Year of newest update: 2009 *Break in series yes ☐ no ☒ If yes, when, and why?……………
Timeliness, time of preparation of data (months, t-reference year)	Month and year of availability of the data: approximately t+2
Dissemination format (by provider and by statistical users)	hard copy ☐ publications ☒ electronic/online-database ☒ website address/link: http://www.transitieproject.nl CD-Rom ☐ Other ☐ specify:
Diagnosis	
Diagnosis generated by health care professional All diagnoses or only main diagnosis recorded	yes ☒ no ☐ all diagnoses (main and secundary) ☒ main diagnoses only ☐

All diseases or only selected diseases recorded ICD-codes can be derived? Classification used (ICD-9, ICD-10, ICPC, …) Information about coding rules and procedures Validation of the diagnosis	all diseases ☐ selected diseases ☒ yes ☒ no ☐ Classification used : ICPC 1 and 2 Information about coding rules and procedures (if available):n.a. Was the diagnosis validated? yes ☐ no ☒ If yes, description of the procedure:
Registered units: person or episode related information	Person ☐ Episode ☒ Both ☐
Type of information derived from the source	(describe type of information and time-frame covered) any period prevalence any period incidence
Coverage	
Population covered:	Total population ☐ Part of population ☒, please specify: GP population in Amstelveen and Franeker
Demographic / socioeconomic breakdowns	
Sex	yes
All ages/specific groups	age groups
Citizenship	no
Geographical information (national, regional, NUTS2, other)	no; local network in two communities
Socioeconomic situation	no

In-patients/out-patients-ambulatory	all, but mostly ambulatory (patients in nursing homes are excluded; patients in hospitals and homes for the elderly are included)
Public/private providers, all health care providers	public (all GPs are public providers)
Adjustment for under reporting/over reporting: reason and magnitude (estimation of the bias)	unknown
Assessment	
Health policy programmes that could affect the value of the parameter	Attention to certain diseases in the media may result in more patients contacting their GP for a check, for example for diabetes. Also the establishment of programmes for integrated health care over different health care sectors (e.g. for diabetes or stroke) may influence the number of GP contacts
Impact of the national organization of the health care system (e.g. registration of referrals, access to specialists)	Since 2006 there is a statutory public health insurance for the whole population; this includes GP care. However, a change in free access to for example a physiotherapist (without referral by the GP) can directly influence the number of patients with certain complaints registered by the GP.
Strengths of the data source	As gate-keeper in the health care system GPs register most of the diagnosed morbidity in the population.
Weakness of the data source	Local network; no data on nursing home patients☐
Future of the data source	Will be continued
Update of metadata Metadata updated after interim report?	Date: 02-02-2010 yes ☐ no ☒

Template n°2: Broad description and evaluation of the data sources inventoried

Number and name of the source	Hospital Discharge Register
Name in national language	Landelijke Medische Registratie
Used acronym of the source	HDR
General information	
General description	The HDR is a register with data about hospital discharges covering all general and university hospitals and specialised hospitals with the exception of epilepsy clinics and long-stay centres for rehabilitation and asthma treatment. Private clinics are not included. Inpatients as well as day cases are registered, with the exception of day patient care for childbirth, psychiatric treatment and rehabilitation treatment. For each hospital discharge administrative data of the admission are registered, as well as diagnoses and procedures.
Purpose	*Rationale for data collection (primary purpose) : *Does the source fulfil Administrative needs (reimbursement) ☐ Health statistics needs (activities of health care services) ☒ other needs (please specify): The HDR also provides information for individual hospitals and specialists for planning and benchmark purposes. The HDR is also used for research purposes and for international data collections by Eurostat, OECD and WHO. *Link to morbidity statistics: no link ☐ used for national health statistics (Statistics Netherlands) ☒ used for regular statistics of National Public Health Institute/Ministry ☒ other (please specify):
Owner	*Name of the institution: Details (address, website):

	Dutch Hospital Data (DHD), Oudlaan 4, 3515 GA Utrecht Postal address: Postbus 9696 3506 GR Utrecht Phone: +0031 30 273 95 21 Fax: +0031 30 273 97 80 E-mail: dutch@hospitaldata.eu
Provider	*Name of the institution: Details (address, website): Dutch Hospital Data (DHD), Oudlaan 4, 3515 GA Utrecht Postal address: Postbus 9696 3506 GR Utrecht Phone: +0031 30 273 95 21 Fax: +0031 30 273 97 80 E-mail: dutch@hospitaldata.eu
Copyright, legal basis, reliability, sustainability of provision	*Copyright restriction in using the data yes ☒ no ☐ *Legal basis yes ☐ no ☒ If yes name and year of the Act: *Payment/financial compensation yes ☐ no ☒ In general users have to pay for HDR data; Statistics Netherlands pays only handling fees *Reliability guarantee yes ☐ no ☒ If yes how/why? *Sustainability guarantee yes ☐ no ☒ If yes how/why?
Data provided	
Type of data collection	administrative data source ☐ register ☒ census ☐ selected health institution sentinels ☐ self report survey ☐

	health examination survey ☐ other: voluntary reporting ☒ mandatory reporting ☐ statutory reporting ☐ other: individual records ☒ aggregated records ☐
Periodicity of data collection and updating mechanisms	*Periodicity of data collection: Daily ☐ Weekly ☐ Monthly ☐ Yearly ☒ every X year (for instance every 5 years), specify year interval: *Periodicity of updating mechanisms: Daily ☐ Weekly ☐ Monthly ☐ Yearly ☒ every X year (for instance every 5 years), specify year interval:
Method of data collection	*Clarify the method of data collection: When the patient is discharged, the specialist fills in the medical information on the discharge form. The diagnoses are coded according to the ICD-9-CM by specialised medical coders in the hospital or by the specialist. The medical information is combined with the administrative admission and discharge data from the Hospital Information System and stored in the local computer system in the hospital. From this system data are sent periodically to the national database owned by DHD. Statistics Netherlands receives yearly datafiles from DHD and links the discharge data to the population register, which enables person-based statistics and linkage to socio-economic information.

	*Data available in: electronic form (micro-data) ☒ electronic form (aggregated data) ☐ paper form only ☐
Useful available variables for the purpose of morbidity statistics	Name, short description Type of admission (day patient / inpatient), length of stay, date of discharge, main diagnosis, max. 10 secundary diagnoses, sex, age, postal code, and Statitics Netherlands adds a pseudonimized personal identification number after linkage to the population number.
Starting date of data collection, year of newest update	*Starting date of data collection: 1963, but from 1995 on it is possible to link the admissions to persons (because the population register is available in electronic form since 1995). *Year of newest update: 2008 *Break in series yes ☒ no ☐ If yes, when, and why?.............. With every new ICD-classification there is a possibility of a break for some diseases. The latest was in 1981, when the ICD-9-CM was introduced in the Netherlands for the coding of diagnoses in the LMR.
Timeliness, time of preparation of data (months, t-reference year)	Month and year of availability of the data: december, t + 1
Dissemination format (by provider and by statistical users)	hard copy ☒ publications ☒ electronic/online-database ☒ website address/link: www.statline.nl www.nationaalkompas.nl, www.prismant.nl CD-Rom ☐ Other ☒ specify: researchers of eligible institutions under the Act on Statistics Nethterlands (2003), can have access to (linked) micro-datafiles for specific research purposes and under explicit conditions of confidentiality. Because of the confidentiality requirements, the microdata can only be used on site at Statistics Netherlands, or via remote execution or remote access. For each research project the researcher should ask permission of DHD to use the HDR datafiles at Statistics Netherlands.
Diagnosis	

Diagnosis generated by health care professional All diagnoses or only main diagnosis recorded All diseases or only selected diseases recorded ICD-codes can be derived? Classification used (ICD-9, ICD-10, ICPC, …) Information about coding rules and procedures Validation of the diagnosis	yes ☒ no ☐ Clarification: the specialist fills out the medical data on the discharge form. Trained medical coders (mostly) or specialists (sometimes) code the data acoording to the ICD-9-CM all diagnoses (main and secundary) ☒ main diagnoses only ☐ all diseases ☒ selected diseases ☐ yes ☒ no ☐ Classification used : ICD9-CM Information about coding rules and procedures (if available): Yes, available at Prismant by documentation and by special trainings. Was the diagnosis validated? yes ☐ no ☒ If yes, description of the procedure: The diagnosis is not validated, but in 1998 a study on the reliability was performed. In this study 5.745 forms of discharges from the hospitals were checked on correctness of the registration in the computer system. 99% of the administrative data were correct. Of the main diagnosis 84% was coded correctly (of 2.023 main diagnoses checked).
Registered units: person or episode related information	Person ☐ Episode ☐ Both ☒
Type of information derived from the source	(describe type of information and time-frame covered) Diagnoses data can be analyzed at event level (discharges) as well at personal level. Longitudinal data are available from 1995 onwards. Statistics Netherlands has published statistics by diagnosis on: the number of inpatient admissions and day cases (absolute and relative numbers), the number of persons per 10 000 inhabitants with one or more admissions in a year, and the number of persons per 10 000 inhabitants with a first admission in a specific year (with a retrospective period of 5 years). These data are disaggregated by sex, age, and other variables.
Coverage	

Population covered:	Total population ☒ Part of population ☐, please specify:
Demographic / socioeconomic breakdowns	Hospital admissions are from 1995 on linked to the population registry, which enables breakdowns with all factors mentioned below.
Sex	Yes
All ages/specific groups	Yes, all ages can be distinguished
Citizenship	yes
Geographical information (national, regional, NUTS2, other)	yes, all levels possible
Socioeconomic situation	yes; linkage with income is possible (and irregularly published)
In-patients/out-patients-ambulatory	day cases and inpatients
Public/private providers, all health care providers	public hospitals
Adjustment for under reporting/over reporting: reason and magnitude (estimation of the bias)	Because the HDR is not a mandatory register, complete coverage is not guaranteed. Up to 2004 only about 1% of the hospitalisations were not registered on microlevel. In 2005 3% of the hospitalisations were missing, and this percentage increased to around 12% in 2007-2008. Statistics Netherlands corrects for this underreporting by weighting procedures. The statistics are also adjusted for incomplete linkage to the population register (this is necessary because of the limited resolution power of the linkage key, which is date of birth, sex and truncated postal code)
Assessment	
Health policy programmes that could affect the value of the parameter	In 2000 a government policy plan was launched (with raised budgets) to reduce the waiting lists for a number of treatments in hospitals. As a result of that hospital admissions for some treatments have increased more from 2001 onwards than in the years before. This affects clinical prevalence and incidence measures for these treatments.
Impact of the national organization of the health care system (e.g. registration of referrals, access to specialists)	The launch of a new (DRG-like) mandatory and labour-intensive registration system for reimbursements for hospital treatments negatively affected the coverage of the voluntary HDR. The LMR only covers inpatient and day care hospitalisations of public hospitals. The number of private hospitals was very low for many years, but has increased in recent years.
Strengths of the data source	For diagnoses where hospital admission is indicated, the person-based hospital statistics provide valuable information for morbidity statistics. In other cases the HDR can give supplementary information to complement other data sources (e.g. through linkage of GP-data to the LMR)
Weakness of the data source	It is not mandatory to register in the HDR. For this reason the coverage has decreased in the last years.

Future of the data source	Uncertain, the coverage of LMR has decreased in recent years. However, there are indications that coverage will increase again in future.
Update of metadata Metadata updated after interim report?	Date: December 2010 yes ☐ no ☒

Template n°2: Broad description and evaluation of the data sources inventoried

Number and name of the source	Causes of Death register
Name in national language	Doodsoorzakenregister
Used acronym of the source	COD
General information	
General description	Register of Causes of Death on the basis of statutory notification by physicians. The register is used for the official national statistics on causes of death
Purpose	*Rationale for data collection (primary purpose) : *Does the source fulfil Administrative needs (reimbursement) ☐ Health statistics needs (activities of health care services) ☒ other needs (please specify): *Link to morbidity statistics: no link ☐ used for national health statistics (Statistics Netherlands) ☒ used for regular statistics of National Public Health Institute/Ministry ☒ other (please specify): Used for research purposes and international data collections of Eurostat, OECD sand WHO.
Owner	*Name of the institution: Details (address, website): Statistics Netherlands, P.O. Box 24500, 2490 HA Den Haag www.cbs.nl
Provider	*Name of the institution:

	Details (address, website): Statistics Netherlands, P.O. Box 24500, 2490 HA Den Haag www.cbs.nl
Copyright, legal basis, reliability, sustainability of provision	*Copyright restriction in using the data yes ☒ no ☐ *Legal basis yes ☒ no ☐ If yes name and year of the Act: Article 12a of the 'Wet op de Lijkbezorging' (Act on disposition of corpses) *Payment/financial compensation yes ☐ no ☒ *Reliability guarantee yes ☐ no ☒ If yes how/why? No guarantee of reliability; but research has indicated that the reliability of the coding of causes of death at Statistics Netherlands is relatively high (Harteloh P, de Bruin K and Kardaun J. The reliability of cause-of-death coding in The Netherlands. Eur J. Epidemiol (2010) 25:531-538). *Sustainability guarantee yes ☒ no ☐ If yes how/why? The data collection is mandatory
Data provided	
Type of data collection	administrative data source ☐ register ☒ census ☐ selected health institution sentinels ☐ self report survey ☐ health examination survey ☐ other: voluntary reporting ☐ mandatory reporting ☐ statutory reporting ☒ other:

	individual records ☒ aggregated records ☐
Periodicity of data collection and updating mechanisms	*Periodicity of data collection: Daily ☒ Weekly ☐ Monthly ☐ Yearly ☐ every X year (for instance every 5 years), specify year interval: *Periodicity of updating mechanisms: Daily ☐ Weekly ☐ Monthly ☒ Yearly ☐ every X year (for instance every 5 years), specify year interval:
Method of data collection	*Clarify the method of data collection: The information is based on the statutory notification of causes of death by the physician treating the deceased at the time of death or by the pathologist. For every death a cause-of-death form is completed by the physician, which is sent, together with the death certificate to the population registration in the municipality in which the death took place. The cause-of-death form is subsequently sent to Statistics Netherlands. Statistics Netherlands links the information of the forms with the population register and codes the causes of death according to the WHO guidelines.The resulting causes fo death register is stored in a flat ASCII file. *Data available in: electronic form (micro-data) ☒ electronic form (aggregated data) ☐ paper form only ☐
Useful available variables for the purpose of morbidity statistics	Name, short description Primary cause of death, max. 3 secundary causes of death, sex, age, postal code, place of death (e.g. hospital, at home), date of death, personal identification number that enables linkage to population register and other registers.

Starting date of data collection, year of newest update	*Starting date of data collection: 1901 *Year of newest update: 2009 *Break in series yes ☒ no ☐ If yes, when, and why?………….. With every new ICD-classification there is a possibility of a break for some diseases. The latest was in 1996, when the ICD-10 was introduced in the Netherlands for the coding of causes of death.
Timeliness, time of preparation of data (months, t-reference year)	Month and year of availability of the data: May t+1 Preliminary monthly data are published in m+3
Dissemination format (by provider and by statistical users)	hard copy ☒ publications ☒ electronic/online-database ☒ website address/link: www.statline.nl CD-Rom ☐ Other ☒ specify: Researchers of eligible institutions under the Act on Statistics Netherlands (2003), can have access to micro-datafiles for specific research purposes and under explicit conditions of confidentiality. Because of the confidentiality requirements, the microdata can only be used on site at Statistics Netherlands, or via remote execution or remote access. In some cases (see article 42a, Act on Statistics Netherlands, 2003), microdata on causes of death can also be delivered to the researcher.
Diagnosis	
Diagnosis generated by health care professional All diagnoses or only main diagnosis recorded All diseases or only selected diseases recorded ICD-codes can be derived? Classification used (ICD-9, ICD-10, ICPC, …) Information about coding rules and procedures	yes ☒ no ☐ all diagnoses (main and secundary) ☒ main diagnoses only ☐ all diseases ☒ selected diseases ☐ yes ☒ no ☐ Classification used : ICD-10 Information about coding rules and procedures (if available):According to WHO guidelines

Validation of the diagnosis	Was the diagnosis validated? yes ☐ no ☒ If yes, description of the procedure:In some cases, when the description on the causes of death form is not clear, Statistics Netherlands contacts the physician for further information.
Registered units: person or episode related information	Person ☒ Episode ☐ Both ☐
Type of information derived from the source	(describe type of information and time-frame covered) Primary causes of death are published, as well as external causes of mortality, including number of deaths due to (traffic) accidents, suicides, etc. Data are disaggregated by age, sex and region. Secondary causes of death are available on request. By linkage to the population register, the causes of death can also be linked to some other health registers, e.g. the hospital discharge register.
Coverage	
Population covered:	Total population ☒ Part of population ☐, please specify:
Demographic / socioeconomic breakdowns	Causes of death data are linked to the population registry, which enables breakdowns with all factors mentioned below
Sex	yes
All ages/specific groups	yes, all ages can be distinguished
Citizenship	yes
Geographical information (national, regional, NUTS2, other)	yes, all levels possible
Socioeconomic situation	yes; linkage with (previous) income is possible (but not regularly published)
In-patients/out-patients-ambulatory	all deaths; place of death is recorded (hospital, nursing home, at home, etc.)
Public/private providers, all health care providers	not applicable

Adjustment for under reporting/over reporting: reason and magnitude (estimation of the bias)	no
Assessment	
Health policy programmes that could affect the value of the parameter	no
Impact of the national organization of the health care system (e.g. registration of referrals, access to specialists)	no
Strengths of the data source	Coverage, reliability of coding, sustainability, timeliness
Weakness of the data source	Depends on the accuracy and comprehensiveness of reporting of causes of death by physicians
Future of the data source	Will be continued; statutory basis
Update of metadata Metadata updated after interim report?	Date: February 2010 yes ☐ no ☒

Template n°2: Broad description and evaluation of the data sources inventoried

Number and name of the source	CVZ Drug register
Name in national language	CVZ Drug register
Used acronym of the source	CVZ
General information	
General description	Register of supplied prescribed drugs reimbursed by basic insurance
Purpose	*Rationale for data collection (primary purpose) : *Does the source fulfil Administrative needs (reimbursement) ☒ Health statistics needs (activities of health care services) ☐ other needs (please specify): *Link to morbidity statistics: no link ☐ used for national health statistics (Statistics Netherlands) ☒ used for regular statistics of National Public Health Institute/Ministry ☐ other (please specify):
Owner	*Name of the institution: Details (address, website): CVZ P.O. Box 320 1110 AH Diemen www.cvz.nl

Provider	*Name of the institution: Details (address, website): CVZ P.O. Box 320 1110 AH Diemen www.cvz.nl
Copyright, legal basis, reliability, sustainability of provision	*Copyright restriction in using the data yes ☒ no ☐ *Legal basis yes ☐ no ☒ If yes name and year of the Act: *Payment/financial compensation yes ☐ no ☒ *Reliability guarantee yes ☐ no ☒ If yes how/why? *Sustainability guarantee yes ☐ no ☒ If yes how/why? Sustainable as long as the register is used for financial compensation of health insurance companies for high risk patients
Data provided	
Type of data collection	administrative data source ☒ register ☐ census ☐ selected health institution sentinels ☐ self report survey ☐ health examination survey ☐ other: voluntary reporting ☒ mandatory reporting ☐ statutory reporting ☐ other: Reporting is in the interest of the data suppliers (health insurance companies) and therefore complete

	individual records ☒ aggregated records ☐
Periodicity of data collection and updating mechanisms	*Periodicity of data collection: Daily ☐ Weekly ☐ Monthly ☐ Yearly ☒ every X year (for instance every 5 years), specify year interval: *Periodicity of updating mechanisms: Daily ☐ Weekly ☐ Monthly ☐ Yearly ☒ every X year (for instance every 5 years), specify year interval:
Method of data collection	*Clarify the method of data collection: CVZ annually collects and provides a file with the supplied drugs that are reimbursed by basic health insurance. This information is provided by health insurance companies, and is used to equalize risks (for high costs patients) between insurers. Based on the past drugs use (especially for certain chronic conditions), the data are used at the individual level as a predictor for the costs of care (Pharmaceutical Cost Groups (FKG)) in the following calendar year. FKGs are used to divide insured persons in cost groups. Depending on the characteristics and cost groups of the insured population, health insurance companies can get financial compensation. Insurers therefore have an interest in complete delivery of the data. CVZ only performs checks of article numbers and costs. Statistics Netherlands links the CVZ data to the population register, which enables follow-up research and linkage to other health and socio-economic register data. *Data available in: electronic form (micro-data) ☒ electronic form (aggregated data) ☐ paper form only ☐

Useful available variables for the purpose of morbidity statistics	Name, short description prescriptions of drugs - ATC-code, background characteristics of the user, e.g. age and sex
Starting date of data collection, year of newest update	*Starting date of data collection: 2006 *Year of newest update: Statistics Netherlands will publish the first statistics in 2011 *Break in series yes ☐ no ☐ If yes, when, and why?.............. The contents of the drugs data can change when there are changes in the basic health insurance.
Timeliness, time of preparation of data (months, t-reference year)	Month and year of availability of the data:
Dissemination format (by provider and by statistical users)	hard copy ☐ publications ☐ electronic/online-database ☒ website address/link: www.cvz.nl www.cbs.nl/statline CD-Rom ☒ Other ☒ specify: researchers of eligible institutions under the Act on Statistics Netherlands (2003), can have access to (linked) micro-datafiles for specific research purposes and under explicit conditions of confidentiality. Because of the confidentiality requirements, the microdata can only be used on site at Statistics Netherlands, or via remote execution or remote access. CVZ has to give permission for access to linked datafiles at Statistics Netherlands.
Diagnosis	
Diagnosis generated by health care professional	yes ☒ no ☐ I.e. the drug prescriptions (not the diagnoses) are generated by physicians
All diagnoses or only main diagnosis recorded	all diagnoses (main and secundary) ☐ main diagnoses only ☐
All diseases or only selected diseases recorded	all diseases ☐ selected diseases ☐
ICD-codes can be derived?	yes ☐ no ☒ Except for drugs that are exclusively used for certain diseases

Classification used (ICD-9, ICD-10, ICPC, …) Information about coding rules and procedures Validation of the diagnosis	Classification used : ATC Information about coding rules and procedures (if available): According to WHO guidelines Was the diagnosis validated? yes ☐ no ☐ If yes, description of the procedure:
Registered units: person or episode related information	Person ☒ Episode ☐ Both ☐
Type of information derived from the source	(describe type of information and time-frame covered) Diabetic drug use is used in this pilot for morbidity estimates of diabetes
Coverage	
Population covered:	Total population ☒ Part of population ☐, please specify: The basic health insurance is mandatory for the Dutch population; therefore the register covers nearly all inhabitants. Only the drugs supplied under basic insurance are covered.
Demographic / socioeconomic breakdowns	
Sex	yes
All ages/specific groups	yes, all ages can be distinguished
Citizenship	yes
Geographical information (national, regional, NUTS2, other)	yes, all levels are possible
Socioeconomic situation	yes; linkage with income is possible
In-patients/out-patients-ambulatory	only out-patients
Public/private providers, all health care providers	all health care providers (excl. inpatient drug supplies)

Adjustment for under reporting/over reporting: reason and magnitude (estimation of the bias)	not applicable
Assessment	
Health policy programmes that could affect the value of the parameter	Health policy programmes that influence drug use for certain conditions will have impact on the derived statistics
Impact of the national organization of the health care system (e.g. registration of referrals, access to specialists)	Changes in the basic health insurance (i.e. the types of insured drugs) influence the contents of the register
Strengths of the data source	National (nearly complete) coverage; automatically generated data
Weakness of the data source	Dependant on the contents of the basic health insurance; drugs supplied to inpatients are not covered
Future of the data source	Will be continued as long as the system for risk compensation of health insurers will be continued
Update of metadata Metadata updated after interim report?	Date: December 2010 yes ☐ no ☒

Template n°2: Broad description and evaluation of the data sources inventoried

Number and name of the source	Netherlands Mental Health Study and Incidence Survey-2
Name in national language	NEMESIS-2
Used acronym of the source	NEMESIS-2
General information	
General description	National survey (3 waves) into the mental health of the Dutch population aged 18 through 64, with the purpose to refresh epidemiologic data on psychiatric morbidity in the Dutch population, including addiction disorders.
Purpose	*Rationale for data collection (primary purpose) : *Does the source fulfil Administrative needs (reimbursement) ☐ Health statistics needs (activities of health care services) ☒ other needs (please specify): *Link to morbidity statistics: no link ☐ used for national health statistics (Statistics Netherlands) ☐ used for regular statistics of National Public Health Institute/Ministry ☒ other (please specify):
Owner	*Name of the institution: Details (address, website): Trimbos Institute (Netherlands Institute of Mental Health and Addiction) PO Box 725 3500 AS Utrecht The Netherlands www.trimbos.org

Provider	*Name of the institution: Details (address, website): Trimbos Institute (Netherlands Institute of Mental Health and Addiction) PO Box 725 3500 AS Utrecht The Netherlands www.trimbos.org
Copyright, legal basis, reliability, sustainability of provision	*Copyright restriction in using the data yes ☐ no ☒ *Legal basis yes ☐ no ☒ If yes name and year of the Act: n.a. *Payment/financial compensation yes ☐ no ☒ *Reliability guarantee yes ☐ no ☒ If yes how/why? *Sustainability guarantee yes ☐ no ☒ If yes how/why?
Data provided	
Type of data collection	administrative data source ☐ register ☐ census ☐ selected health institution sentinels ☐ self report survey ☒ health examination survey ☐ other: voluntary reporting ☒ mandatory reporting ☐ statutory reporting ☐ other:

	individual records ☒ aggregated records ☐ Individual records are collected by the registry; aggregated data are provided to national users, such as RIVM
Periodicity of data collection and updating mechanisms	*Periodicity of data collection: Daily ☐ Weekly ☐ Monthly ☐ Yearly ☐ every X year (for instance every 5 years), specify year interval: 3 *Periodicity of updating mechanisms: Daily ☐ Weekly ☐ Monthly ☐ Yearly ☐ every X year (for instance every 5 years), specify year interval: 3
Method of data collection	*Clarify the method of data collection: NEMESIS-2 is a large scale longitudinal survey on mental health disorders with three three-year intermittent waves among the general population aged 18 to 65 years. In the first wave, which took place between the end of 2007 and mid 2009, 6.646 face to face interviews were held using the 'Composite International Diagnostic Interview 3.0'. A multi-stage, stratified random sampling procedure was used to select potential respondents. The response rate was 65.1%. Amongst others, respondents were asked about mental health problems in their entire life time and in the past year. *Data available in: electronic form (micro-data) ☐ electronic form (aggregated data) ☒ paper form only ☐
Useful available variables for the purpose of morbidity	Name, short description

statistics	Physical health mental health substance use / abuse care seeking behaviour care needs psychiatric diagnoses treatment (carreers) quality of life
Starting date of data collection, year of newest update	*Starting date of data collection: 2007 *Year of newest update: 2010 *Break in series yes ☐ no ☒ If yes, when, and why?……………
Timeliness, time of preparation of data (months, t-reference year)	Month and year of availability of the data: approximately t+2
Dissemination format (by provider and by statistical users)	hard copy ☒ publications ☒ electronic/online-database ☒ website address/link: http://www.nemesis.gfk.nl/meer/ CD-Rom ☐ Other ☐ specify:
Diagnosis	
Diagnosis generated by health care professional	yes ☒ no ☒
All diagnoses or only main diagnosis recorded	all diagnoses (main and secundary) ☒ main diagnoses only ☐
All diseases or only selected diseases recorded	all diseases ☐ selected diseases ☒
ICD-codes can be derived?	yes ☒ no ☐

Classification used (ICD-9, ICD-10, ICPC, …) Information about coding rules and procedures Validation of the diagnosis	Classification used : DSM IV TR Information about coding rules and procedures (if available):n.a. Was the diagnosis validated? yes ☐ no ☒ If yes, description of the procedure:
Registered units: person or episode related information	Person ☐ Episode ☐ Both ☒
Type of information derived from the source	(describe type of information and time-frame covered) life time prevalence 1 year prevalence 6 mo prevalence 1 mo prevalence
Coverage	
Population covered:	Total population ☐ Part of population ☒, please specify: non-institutionalized population, aged 18-65 years
Demographic / socioeconomic breakdowns	
Sex	yes
All ages/specific groups	age groups
Citizenship	no
Geographical information (national, regional, NUTS2, other)	levelof urbanisation
Socioeconomic situation	yes
In-patients/out-patients-ambulatory	non-institutionalized populationl
Public/private providers, all health care providers	n.a.

Adjustment for under reporting/over reporting: reason and magnitude (estimation of the bias)	no; but weighting factor was used to correct for non-reponse
Assessment	
Health policy programmes that could affect the value of the parameter	no
Impact of the national organization of the health care system (e.g. registration of referrals, access to specialists)	no
Strengths of the data source	National survey with structured interview with trained interviewers, international measurement instrument (CIDI)
Weakness of the data source	Institutionalised population is excluded; ages 65+ are excluded
Future of the data source	Will be continued (2 more waves)
Update of metadata Metadata updated after interim report?	Date: 02-08-2010 yes ☐ no ☒

Template n°2: Broad description and evaluation of the data sources inventoried

Number and name of the source	Continuous Registration of Morbidity - Sentinels
Name in national language	Continue Morbiditeits Registratie - Peilstations
Used acronym of the source	CMR - Peilstations
General information	
General description	The Continuous Morbidity Registration - Sentinels constitute a representative group of 61 Dutch GPs in 44 practices. Their patient population covers about 0.8% of the Dutch population and is spread by region and city and countryside. Participating GPs, the Medical Sentinels, provide weekly electronic information on certain diseases, events and operations. One of the main topics of the CMR - Sentinels is 'seasonal flu' (influenza-like illness). Since 1970, the CMR - Sentinels GPs record the number of patients that they consult with an influenza-like illness (ILI), as not everyone with self-reported "flu" has been infected with the influenza virus. As such, this GPRN has only been used in estimating morbidity statistics for influenza.
Purpose	*Rationale for data collection (primary purpose) : *Does the source fulfil Administrative needs (reimbursement) ☐ Health statistics needs (activities of health care services) ☒ other needs (please specify): To gain insight into certain medical conditions, events and operations (morbidity) reported by the participating GPs, the Sentinel Physicians. This contributes to policy support for the government. *Link to morbidity statistics: no link ☐ used for national health statistics (Statistics Netherlands) ☒ used for regular statistics of National Public Health Institute/Ministry ☒ other (please specify): ECDC, EUROFLU, FLUNET

Owner	*Name of the institution: Details (address, website): NIVEL Postal address: Postbus 1568 3500 BN Utrecht Tel: 030 272 97 00 Tel.: +3130-272 9700 E-mail: g.donker@nivel.nl http://www.nivel.nl/oc2/page.asp?pageid=12135
Provider	*Name of the institution: Details (address, website): NIVEL Postal address: Postbus 1568 3500 BN Utrecht Tel: 030 272 97 00 Tel.: +3130-272 9700 E-mail: g.donker@nivel.nl http://www.nivel.nl/
Copyright, legal basis, reliability, sustainability of provision	*Copyright restriction in using the data yes ☐ no ☒ *Legal basis yes ☐ no ☒ If yes name and year of the Act: *Payment/financial compensation yes ☐ no ☒ *Reliability guarantee yes ☐ no ☒ If yes how/why? *Sustainability guarantee yes ☐ no ☒ If yes how/why?
Data provided	

Type of data collection	administrative data source ☐ register ☐ census ☐ selected health institution sentinels ☒ self report survey ☐ health examination survey ☐ other: voluntary reporting ☒ mandatory reporting ☐ statutory reporting ☐ other: individual records ☐ aggregated records ☒
Periodicity of data collection and updating mechanisms	*Periodicity of data collection: Daily ☒ Weekly ☐ Monthly ☐ Yearly ☐ every X year (for instance every 5 years), specify year interval: *Periodicity of updating mechanisms: Daily ☐ Weekly ☐ Monthly ☐ Yearly ☒ every X year (for instance every 5 years), specify year interval:
Method of data collection	*Clarify the method of data collection: The GPs register patients who consult them for an acute influenza-like infection. Not everyone with self-reported 'seasonal flu' is infected with the influenza virus. Therefore, in at least two patients per week who present themselves at the GP with flu like symptoms, the sentinel GP collects a cotton with saliva from throat and nose. These specimens are sent to the National Institute of Public Health and the Environment (RIVM). They check whether

	there is a virus in the cotton, and if so what kind of virus. In addition, the National Influenza Center (NIC, Erasmus University Rotterdam) analyzes viral isolates that are sent by the virological laboratories of various hospitals. The counts of the CMR - Sentinel GPs are combined with the virus isolation data from the RIVM and the NIC, and are being published in the flu season published in the Influenza and the Influenza Newsletters File on the NIVEL site. Influenza is also a European level measured by the ECDC. Information about the activity of the influenza virus on a global scale is available on the website Flunet. Flunet data are based only on laboratory results. *Data available in: electronic form (micro-data) ☐ electronic form (aggregated data) ☒ paper form only ☐
Useful available variables for the purpose of morbidity statistics	Name, short description Age Geographical region Reason for contact
Starting date of data collection, year of newest update	*Starting date of data collection: 1970 *Year of newest update: 2010 *Break in series yes ☐ no ☒ If yes, when, and why?……………
Timeliness, time of preparation of data (months, t-reference year)	Month and year of availability of the data: lagging behind approximately two weeks.
Dissemination format (by provider and by statistical users)	hard copy ☒ publications ☒ electronic/online-database ☐ website address/link: http://www.nivel.nl/oc2/page.asp?pageid=12135 CD-Rom ☐ Other ☐ specify:

Diagnosis	
Diagnosis generated by health care professional All diagnoses or only main diagnosis recorded All diseases or only selected diseases recorded ICD-codes can be derived? Classification used (ICD-9, ICD-10, ICPC, …) Information about coding rules and procedures Validation of the diagnosis	yes ☒ no ☐ all diagnoses (main and secundary) ☐ main diagnoses only ☒ all diseases ☐ selected diseases ☒ yes ☒ no ☐ Classification used : ICPC Information about coding rules and procedures (if available): Was the diagnosis validated? yes ☒ no ☐ If yes, description of the procedure: For a part of the patients who present themselves at the GP with flu like symptoms a laboratory confirmation of the diagnosis is sought.
Registered units: person or episode related information	Person ☐ Episode ☐ Both ☒
Type of information derived from the source	(describe type of information and time-frame covered) 1-year incidence of self-reported Influenza per 100.000 persons, July 2006-July2008
Coverage	
Population covered:	Total population ☐ Part of population ☒, please specify: Network of GP practices, representative of the Dutch population.
Demographic / socioeconomic breakdowns	
Sex	no

All ages/specific groups	all ages, in 5 years age categories
Citizenship	no
Geographical information (national, regional, NUTS2, other)	yes
Socioeconomic situation	no
In-patients/out-patients-ambulatory	ambulatory
Public/private providers, all health care providers	public
Adjustment for under reporting/over reporting: reason and magnitude (estimation of the bias)	no
Assessment	
Health policy programmes that could affect the value of the parameter	"Hoesten of niezen, zakdoek kiezen" [Coughing or sneezing; use your handkerchief]. Public awareness programme about colds and the flu, promoting personal hygiene during flu season)
Impact of the national organization of the health care system (e.g. registration of referrals, access to specialists)	
Strengths of the data source	Representative of the Dutch population
Weakness of the data source	Not everybody with flu-like symptoms goes to their GP.
Future of the data source	will be continued
Update of metadata Metadata updated after interim report?	Date: June 2011 yes ☒ no ☐

Template n°2: Broad description and evaluation of the data sources inventoried

Number and name of the source	Continuous Quality of Life Survey - Health interview survey
Name in national language	Permanent Onderzoek Leefsituatie (POLS) - Gezondheidsenquête (GE)
Used acronym of the source	HIS
General information	
General description	The national Health interview Survey of the Netherlands is a continuous survey among the non-institutionalised population, with 9,000 - 10,000 respondents yearly. The survey includes self reported health status, including a number of specific conditions; disability; use of medical services and prevention programmes; and life style.
Purpose	*Rationale for data collection (primary purpose) : *Does the source fulfil Administrative needs (reimbursement) ☐ Health statistics needs (activities of health care services) ☒ other needs (please specify): *Link to morbidity statistics: no link ☐ used for national health statistics (Statistics Netherlands) ☒ used for regular statistics of National Public Health Institute/Ministry ☒ other (please specify): Used for research purposes and international data collections.
Owner	*Name of the institution: Details (address, website): Statistics Netherlands, PO Box 4481, 6401 CZ Heerlen, www.cbs.nl
Provider	*Name of the institution:

	Details (address, website): Statistics Netherlands, PO Box 4481, 6401 CZ Heerlen, www.cbs.nl
Copyright, legal basis, reliability, sustainability of provision	*Copyright restriction in using the data yes ☒ no ☐ *Legal basis yes ☒ no ☐ If yes name and year of the Act: Not yet a legal basis, but there will be a Eurostat regulation from 2014 onwards *Payment/financial compensation yes ☐ no ☒ *Reliability guarantee yes ☐ no ☒ If yes how/why? *Sustainability guarantee yes ☐ no ☒ If yes how/why? Eurostat regulation will be an impetus for sustainability
Data provided	
Type of data collection	administrative data source ☐ register ☐ census ☐ selected health institution sentinels ☐ self report survey ☒ health examination survey ☐ other: voluntary reporting ☒ mandatory reporting ☐ statutory reporting ☐ other: individual records ☒ aggregated records ☐

Periodicity of data collection and updating mechanisms	*Periodicity of data collection: Daily ☒ Weekly ☐ Monthly ☐ Yearly ☐ every X year (for instance every 5 years), specify year interval: *Periodicity of updating mechanisms: Daily ☐ Weekly ☐ Monthly ☐ Yearly ☒ every X year (for instance every 5 years), specify year interval:
Method of data collection	*Clarify the method of data collection: up to 2009: CAPI and subsequent a PAPI questionnaire from 2010 onwards: mixed mode design: CAWI or CATI or CAPI and subsequent a CAWI or PAPI questionnaire *Data available in: electronic form (micro-data) ☒ electronic form (aggregated data) ☐ paper form only ☐
Useful available variables for the purpose of morbidity statistics	Name, short description Age, sex, and variables about the prevalence of certain conditions, e.g. migraine or severe headache, diabetes, psoriasis, chronic eczema, high blood pressure, back problems, arthrosis, rheumatoid arthritis, stroke, myocardial infarction, cancer, depression, anxiety disorder. eczema
Starting date of data collection, year of newest update	*Starting date of data collection: 1981 *Year of newest update: 2009 *Break in series yes ☒ no ☐

	If yes, when, and why?…………… break between 1988-1989 and between 2000-2001 because of revisions of the questionnaire; the breaks can be repaired
Timeliness, time of preparation of data (months, t-reference year)	Month and year of availability of the data:March-June t+1
Dissemination format (by provider and by statistical users)	hard copy ☐ publications ☒ electronic/online-database ☒ website address/link: www.cbs.nl CD-Rom ☐ Other ☐ specify:
Diagnosis	
Diagnosis generated by health care professional	yes ☐ no ☒
All diagnoses or only main diagnosis recorded	all diagnoses (main and secundary) ☐ main diagnoses only ☒
All diseases or only selected diseases recorded	all diseases ☐ selected diseases ☒
ICD-codes can be derived?	yes ☒ no ☐ Diseases have been translated in terms of broad ICD10-codes; but the respondent is not aware of this.
Classification used (ICD-9, ICD-10, ICPC, …)	Classification used : ICD-10 (in broad terms, see above)
Information about coding rules and procedures	Information about coding rules and procedures (if available):No, it is self-report
Validation of the diagnosis	Was the diagnosis validated? yes ☐ no ☒ If yes, description of the procedure:
Registered units: person or episode related information	Person ☒ Episode ☐ Both ☐
Type of information derived from the source	(describe type of information and time-frame covered) self-reported prevalence, most often in the past 12 months; in some cases (stroke/cerebral

	haemorrhage, myocardial infarction/heart attack, cancer): life time prevalence; in addition, respondents are asked whether they have consulted or have been treated by a GP or a specialist for the condition.
Coverage	
Population covered:	Total population ☐ Part of population ☒, please specify: Institutionalised population is excluded
Demographic / socioeconomic breakdowns	
Sex	yes
All ages/specific groups	yes, age >= 12 years
Citizenship	yes
Geographical information (national, regional, NUTS2, other)	yes
Socioeconomic situation	yes
In-patients/out-patients-ambulatory	All
Public/private providers, all health care providers	n.a.
Adjustment for under reporting/over reporting: reason and magnitude (estimation of the bias)	No; but response is weighted to the national (non-institutionalized) population
Assessment	
Health policy programmes that could affect the value of the parameter	No, but attention to certain diseases in the media and launching of integrated health care programmes for certain diseases (e.g. diabetes; stroke) may affect the number of health care contacts and the awareness and recollection of the respondent
Impact of the national organization of the health care system (e.g. registration of referrals, access to specialists)	-
Strengths of the data source	Continuous survey; internationally harmonized questionnaire in EHIS
Weakness of the data source	Self report may not be reliable to measure diagnosed morbidity

Future of the data source	Expected to be continued
Update of metadata Metadata updated after interim report?	Date: December 2010 yes ☐ no ☒

Template n°2: Broad description and evaluation of the data sources inventoried

Number and name of the source	Dutch Injury Surveillance System
Name in national language	Letsel Informatie Systeem
Used acronym of the source	ISS (in Dutch: LIS)
General information	
General description	The Dutch Injury Surveillance System (LIS) records statistics of people treated at Emergency Departments (EDs) of a selection of hospitals in the Netherlands, injured due to an accident, an act of violence or self-harm. These hospitals form a representative sample of the general and university hospitals in the Netherlands providing a 24 hours accident and emergency service. This enables extrapolation of the recorded injury cases to national estimates, and subsets of cases provided the numbers are large enough.
Purpose	*Rationale for data collection (primary purpose) : *Does the source fulfil Administrative needs (reimbursement) ☐ Health statistics needs (activities of health care services) ☒ other needs (please specify): -Providing data for epidemiological research -Providing input for prevention programmes and national or regional policy -Providing management information fort the participating hospitals *Link to morbidity statistics: no link ☐ used for national health statistics (Statistics Netherlands) ☐ used for regular statistics of National Public Health Institute/Ministry ☒ other (please specify): ISS data are used for the European Injury Database (IDB), hosted by the European Commission. The IDB is the only data source in the EU that contains standardised cross-national data on home and leisure accidents in Europe.

Owner	*Name of the institution: Details (address, website): Consumer Safety Institute PO Box 75169 1070 AD Amsterdam The Netherlands email: info@veiligheid.nl www.veiligheid.nl
Provider	*Name of the institution: Details (address, website): Consumer Safety Institute PO Box 75169 1070 AD Amsterdam The Netherlands email: info@veiligheid.nl www.veiligheid.nl
Copyright, legal basis, reliability, sustainability of provision	*Copyright restriction in using the data yes ☒ no ☐ *Legal basis yes ☐ no ☒ If yes name and year of the Act: *Payment/financial compensation yes ☒ no ☐ *Reliability guarantee yes ☐ no ☒ If yes how/why? *Sustainability guarantee yes ☐ no ☒ If yes how/why?
Data provided	
Type of data collection	administrative data source ☐ register ☒

	census ☐ selected health institution sentinels ☐ self report survey ☐ health examination survey ☐ other: voluntary reporting ☐ mandatory reporting ☒ statutory reporting ☐ other: participating hospitals have to provide information on all injury patients visiting the Emergency Department (ED) individual records ☒ aggregated records ☐
Periodicity of data collection and updating mechanisms	*Periodicity of data collection: Daily ☒ Weekly ☐ Monthly ☐ Yearly ☐ every X year (for instance every 5 years), specify year interval: *Periodicity of updating mechanisms: Daily ☐ Weekly ☐ Monthly ☐ Yearly ☒ every X year (for instance every 5 years), specify year interval:
Method of data collection	*Clarify the method of data collection: Every hospital has its own method for collecting the information that is registered in the Dutch Injury Surveillance System. In consultation with the Consumer Safety Institute, the registration is integrated into the daily activities of the ED to the greatest possible extent. In general, most hospitals work as follows: When a patient reports to the ED, the receptionist fills in an ED form for the hospital’s administrative records. Usually this is entered into the Hospital Information System (HIS). If the

	patient has an injury or displays symptoms of poisoning, injury event information will also be noted. In the course of treating the patient, hospital staff members also record information regarding the treatment and add additional details to the event information. Discharge information is also registered. Hospitals can record the required information in various ways. If the hospital has a Hospital Information System (HIS) into which the Dutch Injury Surveillance System is integrated, the relevant data can be entered directly into the HIS. The other hospitals can make use of stand-alone ISS software. It is also possible to export data from the HIS, which can in turn be imported into the Dutch Injury Surveillance System and added to. The hospitals send the entered data to the Consumer Safety Institute electronically. The name, address and any other information that may identify a patient is not included, thereby ensuring that the Dutch Injury Surveillance System complies with the regulations of the Personal Data Protection Act At Consumer Safety Institute, the data are recorded in a central database, will be checked and used for statistical analyses. *Data available in: electronic form (micro-data) ☒ electronic form (aggregated data) ☐ paper form only ☐
Useful available variables for the purpose of morbidity statistics	Name, short description Sex, age, type of injury event, injury mechanism, activity, location, products involved, referral, type of injury, location of injury, treatment, follow up
Starting date of data collection, year of newest update	*Starting date of data collection: 1986 *Year of newest update: 2009 *Break in series yes ☐ no ☒ If yes, when, and why?……………
Timeliness, time of preparation of data (months, t-reference year)	Month and year of availability of the data: t+1
Dissemination format (by provider and by statistical users)	hard copy ☒ publications ☒ electronic/online-database ☐ website address/link: CD-Rom ☐

	Other ☐ specify:
Diagnosis	
Diagnosis generated by health care professional All diagnoses or only main diagnosis recorded All diseases or only selected diseases recorded ICD-codes can be derived? Classification used (ICD-9, ICD-10, ICPC, …) Information about coding rules and procedures Validation of the diagnosis	yes ☒ no ☐ all diagnoses (main and secundary) ☒ main diagnoses only ☐ all diseases ☒ selected diseases ☐ yes ☒ no ☐ Classification used : Data are registered with help of a coding system owned by the Consumer Safety Institute (owner of ISS), which is compatible to the ICE-CI WHO standard (International Classification of External Causes of Injuries), which in turn is compatible to the ICD-10 classification). Information about coding rules and procedures (if available): available through the provider Was the diagnosis validated? yes ☐ no ☒ If yes, description of the procedure:
Registered units: person or episode related information	Person ☒ Episode ☐ Both ☐
Type of information derived from the source	(describe type of information and time-frame covered) Incidence (mean of a 5 year period)
Coverage	
Population covered:	Total population ☐ Part of population ☒, please specify: Patients treated at de ED department of a selection of

	hospitals in the Netherlands, because of an injury due to an accident, an act of violence or self-harm. These hospitals form a representative sample of the general and university hospitals in the Netherlands providing a 24 hours accident and emergency service.
Demographic / socioeconomic breakdowns	
Sex	Yes
All ages/specific groups	All ages, age in years
Citizenship	No
Geographical information (national, regional, NUTS2, other)	Yes
Socioeconomic situation	No
In-patients/out-patients-ambulatory	Patients treated at the Emergency Departments
Public/private providers, all health care providers	Emerengy Departments of public hospitals
Adjustment for under reporting/over reporting: reason and magnitude (estimation of the bias)	Yes, for only a 14 hospitals are included (multiplied by a factor of approximately 10)
Assessment	
Health policy programmes that could affect the value of the parameter	Changes in policies and financing of the health care system
Impact of the national organization of the health care system (e.g. registration of referrals, access to specialists)	Changes in treatment guidelines
Strengths of the data source	Continuous registration of large number of cases.
Weakness of the data source	selection of hospitals, only data about external causes but not the resulting injuries
Future of the data source	to be continued
Update of metadata Metadata updated after interim report?	Date: June 2011 yes ☐ no ☒

Template n°2: Broad description and evaluation of the data sources inventoried

Number and name of the source	Electronic notificationsystem Osiris
Name in national language	Elektronisch meldysteem Osiris
Used acronym of the source	Osiris
General information	
General description	Osiris registrationsystem for notifiable infectious diseases
Purpose	*Rationale for data collection (primary purpose) : *Does the source fulfil Administrative needs (reimbursement) ☒ Health statistics needs (activities of health care services) ☐ other needs (please specify): Facilitating data for surveillance statistics *Link to morbidity statistics: no link ☐ used for national health statistics (Statistics Netherlands) ☒ used for regular statistics of National Public Health Institute/Ministry ☒ other (please specify): Surveillance on morbidity due to infectious diseases
Owner	*Name of the institution: Details (address, website): Municipal health services (www.ggd.nl)
Provider	*Name of the institution: Details (address, website): RIVM (National Institute for Public Health and the Environment) Antonie v. Leeuwenhoeklaan 9,3721 MA Bilthoven, The Netherlands (www.rivm.nl)
Copyright, legal basis, reliability, sustainability of provision	*Copyright restriction in using the data yes ☒ no ☐

	*Legal basis yes ☒ no ☐ If yes name and year of the Act: 2008 *Payment/financial compensation yes ☐ no ☒ *Reliability guarantee yes ☒ no ☐ If yes how/why? Although 100% reporting cannot be guaranteed *Sustainability guarantee yes ☒ no ☐ If yes how/why? Collection of data obliged by law
Data provided	
Type of data collection	administrative data source ☐ register ☒ census ☐ selected health institution sentinels ☐ self report survey ☐ health examination survey ☐ other: voluntary reporting ☐ mandatory reporting ☒ statutory reporting ☐ other: individual records ☒ aggregated records ☐

Periodicity of data collection and updating mechanisms	*Periodicity of data collection: Daily ☒ Weekly ☐ Monthly ☐ Yearly ☐ every X year (for instance every 5 years), specify year interval: *Periodicity of updating mechanisms: Daily ☐ Weekly ☐ Monthly ☐ Yearly ☒ every X year (for instance every 5 years), specify year interval:
Method of data collection	*Clarify the method of data collection: Municipal health services register all cases of certain infectious diseases which are notified to them by general practicioners, specialists and labororatories *Data available in: electronic form (micro-data) ☒ electronic form (aggregated data) ☐ paper form only ☐
Useful available variables for the purpose of morbidity statistics	Name, short description: first day of disease, laboratory diagnostics and results, symptoms
Starting date of data collection, year of newest update	*Starting date of data collection: 1988 *Year of newest update: 2011 *Break in series yes ☒ no ☐ If yes, when, and why?.............. In 2003 the electronic registration in Osiris started. In Dec 2008 a new public health law and new notification criteria were adopted
Timeliness, time of preparation of data (months, t-reference year)	Month and year of availability of the data: t+1

Dissemination format (by provider and by statistical users)	hard copy ☐ publications ☐ electronic/online-database ☒ website address/link: https://osiris.rivm.nl/osiris.htm CD-Rom ☐ Other ☐ specify:
Diagnosis	
Diagnosis generated by health care professional	yes ☒ no ☐
All diagnoses or only main diagnosis recorded	all diagnoses (main and secundary) ☐ main diagnoses only ☒
All diseases or only selected diseases recorded	all diseases ☐ selected diseases ☒
ICD-codes can be derived?	yes ☒ no ☐
Classification used (ICD-9, ICD-10, ICPC, …)	Classification used : ICD-10
Information about coding rules and procedures	Information about coding rules and procedures (if available):
Validation of the diagnosis	Was the diagnosis validated? yes ☒ no ☐ If yes, description of the procedure:Laboratory confirmation
Registered units: person or episode related information	Person ☒ Episode ☐ Both ☐
Type of information derived from the source	(describe type of information and time-frame covered) Incidence, 2007
Coverage	

Population covered:	Total population ☒ Part of population ☐, please specify:
Demographic / socioeconomic breakdowns	
Sex	yes
All ages/specific groups	yes
Citizenship	no
Geographical information (national, regional, NUTS2, other)	National
Socioeconomic situation	no
In-patients/out-patients-ambulatory	all
Public/private providers, all health care providers	all
Adjustment for under reporting/over reporting: reason and magnitude (estimation of the bias)	no
Assessment	
Health policy programmes that could affect the value of the parameter	Changes in the list of notifiable diseases
Impact of the national organization of the health care system (e.g. registration of referrals, access to specialists)	no
Strengths of the data source	Webbased, thus accessible from every location, reliable registration
Weakness of the data source	Mostly registration of epidemiological data, no link with laboratory databases. Difficult clustering of cases.
Future of the data source	Continued
Update of metadata Metadata updated after interim report?	Date: May 2011 yes ☐ no ☒

Template n°2: Broad description and evaluation of the data sources inventoried

Number and name of the source	Dutch HIV/AIDS monitoring foundation
Name in national language	Stichting HIV Monitoring
Used acronym of the source	SHM
General information	
General description	Stichting HIV Monitoring (SHM), the Dutch HIV monitoring foundation, was founded in 2001. Based in Amsterdam, SHM was appointed by the Dutch Minister of Health, Welfare and Sport as the executive organisation for the registration and monitoring of HIV-infected patients in the Netherlands. Its mission is to further the knowlegde and understanding of the epidemiology and the course of treated and untreated HIV infection.
Purpose	*Rationale for data collection (primary purpose) : *Does the source fulfil Administrative needs (reimbursement) ☐ Health statistics needs (activities of health care services) ☒ other needs (please specify): *Link to morbidity statistics: no link ☐ used for national health statistics (Statistics Netherlands) ☒ used for regular statistics of National Public Health Institute/Ministry ☒ other (please specify):
Owner	*Name of the institution: Details (address, website): Stichting HIV Monitoring, Meibergdreef 9, 1105 AZ, Amsterdam, www.hiv-monitoring.nl

Provider	*Name of the institution: Details (address, website): Stichting HIV Monitoring, Meibergdreef 9, 1105 AZ, Amsterdam, www.hiv-monitoring.nl
Copyright, legal basis, reliability, sustainability of provision	*Copyright restriction in using the data yes ☒ no ☐ *Legal basis yes ☒ no ☐ If yes name and year of the Act: *Payment/financial compensation yes ☐ no ☒ *Reliability guarantee yes ☐ no ☐ If yes how/why? *Sustainability guarantee yes ☐ no ☐ If yes how/why?
Data provided	
Type of data collection	administrative data source ☐ register ☒ census ☐ selected health institution sentinels ☐ self report survey ☐ health examination survey ☐ other: voluntary reporting ☒ mandatory reporting ☐ statutory reporting ☐ other: individual records ☒ aggregated records ☐

Periodicity of data collection and updating mechanisms	*Periodicity of data collection: Daily ☒ Weekly ☐ Monthly ☐ Yearly ☐ every X year (for instance every 5 years), specify year interval: *Periodicity of updating mechanisms: Daily ☐ Weekly ☐ Monthly ☐ Yearly ☒ every X year (for instance every 5 years), specify year interval:
Method of data collection	*Clarify the method of data collection: data are collected from patient files and laboratory databases *Data available in: electronic form (micro-data) ☒ electronic form (aggregated data) ☐ paper form only ☐
Useful available variables for the purpose of morbidity statistics	Name, short description age, age at diagnosis, year of diagnosis, gender, sexual preference, region of origin, country of infection
Starting date of data collection, year of newest update	*Starting date of data collection: 1998 *Year of newest update: 2011 *Break in series yes ☐ no ☒ If yes, when, and why?...............
Timeliness, time of preparation of data (months, t-reference year)	Month and year of availability of the data: june, december (t+1)
Dissemination format (by provider and by statistical users)	hard copy ☒

	publications ☒ electronic/online-database ☐ website address/link: CD-Rom ☐ Other ☐ specify:
Diagnosis	
Diagnosis generated by health care professional All diagnoses or only main diagnosis recorded All diseases or only selected diseases recorded ICD-codes can be derived? Classification used (ICD-9, ICD-10, ICPC, …) Information about coding rules and procedures Validation of the diagnosis	yes ☒ no ☐ all diagnoses (main and secundary) ☒ main diagnoses only ☐ all diseases ☐ selected diseases ☒ yes ☒ no ☐ Classification used : ICD-10 Information about coding rules and procedures (if available): n.a. Was the diagnosis validated? yes ☒ no ☐ If yes, description of the procedure: regular checks of samples of data
Registered units: person or episode related information	Person ☒ Episode ☐ Both ☐
Type of information derived from the source	(describe type of information and time-frame covered) incidence and (point) prevalence, 2007
Coverage	
Population covered:	Total population ☐ Part of population ☒, please specify: the register contains the HIV-positive population, but

	intends to include all HIV-positives in The Netherlands
Demographic / socioeconomic breakdowns	
Sex	yes
All ages/specific groups	yes
Citizenship	yes
Geographical information (national, regional, NUTS2, other)	yes
Socioeconomic situation	no
In-patients/out-patients-ambulatory	yes
Public/private providers, all health care providers	all HIV treatment centres
Adjustment for under reporting/over reporting: reason and magnitude (estimation of the bias)	only in reporting
Assessment	
Health policy programmes that could affect the value of the parameter	-
Impact of the national organization of the health care system (e.g. registration of referrals, access to specialists)	-
Strengths of the data source	nationwide, longitudinal data
Weakness of the data source	labour intensive data collection
Future of the data source	Continued
Update of metadata Metadata updated after interim report?	Date: May 2011 yes ☐ no ☒

Template n°2: Broad description and evaluation of the data sources inventoried

Number and name of the source	SOAP
Name in national language	Electronic notificationsystem SOAP
Used acronym of the source	SOAP
General information	
General description	Registrationsystem for sexually transmitted infections (STI), diagnosed in STI centres. In the Netherlands there are 28 STI centres, mostly within the Municipal Health Services. The STI centres are set up in addition to regular first line care, and provide low treshold STI/HIV testing and care, free of charge, targeted at high-risk groups and people who want to be tested anonymously.
Purpose	*Rationale for data collection (primary purpose) : *Does the source fulfil Administrative needs (reimbursement) ☒ Health statistics needs (activities of health care services) ☒ other needs (please specify): Facilitating data for surveillance statistics *Link to morbidity statistics: no link ☐ used for national health statistics (Statistics Netherlands) ☐ used for regular statistics of National Public Health Institute/Ministry ☒ other (please specify): Surveillance on morbidity due to STI
Owner	*Name of the institution: Details (address, website): Municipal Health Services (www.ggd.nl)
Provider	*Name of the institution: Details (address, website): RIVM (National Institute for Public Health and the Environment)

	Antonie v. Leeuwenhoeklaan 9,3721 MA Bilthoven, The Netherlands (www.rivm.nl)
Copyright, legal basis, reliability, sustainability of provision	*Copyright restriction in using the data yes ☒ no ☐ *Legal basis yes ☐ no ☒ If yes name and year of the Act: *Payment/financial compensation yes ☐ no ☒ *Reliability guarantee yes ☐ no ☒ If yes how/why? *Sustainability guarantee yes ☐ no ☒ If yes how/why?
Data provided	
Type of data collection	administrative data source ☐ register ☒ census ☐ selected health institution sentinels ☐ self report survey ☐ health examination survey ☐ other: voluntary reporting ☒ mandatory reporting ☐ statutory reporting ☐ other: individual records ☒ aggregated records ☐

Periodicity of data collection and updating mechanisms	*Periodicity of data collection: Daily ☒ Weekly ☐ Monthly ☐ Yearly ☐ every X year (for instance every 5 years), specify year interval: *Periodicity of updating mechanisms: Daily ☐ Weekly ☐ Monthly ☐ Yearly ☒ every X year (for instance every 5 years), specify year interval:
Method of data collection	*Clarify the method of data collection: Municipal health services register all STI consultations. All visitors are tested for chlamydia, gonorrhoea, syphilis and HIV, other STIs are tested on indication. Also epidemiological data is collected. *Data available in: electronic form (micro-data) ☒ electronic form (aggregated data) ☐ paper form only ☐
Useful available variables for the purpose of morbidity statistics	Name, short description: date of consultation, gender, age, ethnicity, tests performed within consultation including test results
Starting date of data collection, year of newest update	*Starting date of data collection: 2004 *Year of newest update: 2010 *Break in series yes ☐ no ☒ If yes, when, and why?……………
Timeliness, time of preparation of data (months, t-	Month and year of availability of the data: June (t+1)

reference year)	
Dissemination format (by provider and by statistical users)	hard copy ☒ publications ☒ electronic/online-database ☒ website address/link: http://osiris.rivm.nl/soap CD-Rom ☐ Other ☐ specify:
Diagnosis	
Diagnosis generated by health care professional All diagnoses or only main diagnosis recorded All diseases or only selected diseases recorded ICD-codes can be derived? Classification used (ICD-9, ICD-10, ICPC, …) Information about coding rules and procedures Validation of the diagnosis	yes ☒ no ☐ all diagnoses (main and secundary) ☒ main diagnoses only ☐ all diseases ☐ selected diseases ☒ yes ☐ no ☒ Classification used : Information about coding rules and procedures (if available): Was the diagnosis validated? yes ☒ no ☐ If yes, description of the procedure:Laboratory confirmation
Registered units: person or episode related information	Person ☒ Episode ☐ Both ☐
Type of information derived from the source	(describe type of information and time-frame covered) incidence, 2007
Coverage	

Population covered:	Total population ☐ Part of population ☒, please specify: visitors of STI centres
Demographic / socioeconomic breakdowns	
Sex	yes
All ages/specific groups	yes
Citizenship	no
Geographical information (national, regional, NUTS2, other)	national
Socioeconomic situation	classification based on 4-digital zipcode
In-patients/out-patients-ambulatory	ambulatory
Public/private providers, all health care providers	public
Adjustment for under reporting/over reporting: reason and magnitude (estimation of the bias)	no
Assessment	
Health policy programmes that could affect the value of the parameter	aimed at 'high risk' groups, a change in definition may affect the data
Impact of the national organization of the health care system (e.g. registration of referrals, access to specialists)	a change in accessability of the centers affects the data
Strengths of the data source	Webbased, thus accessible from every location, reliable registration
Weakness of the data source	Since it is anonymous, the data does not allow identification of repeated visits by the same individual or linking to data from other sources
Future of the data source	Continued
Update of metadata Metadata updated after interim report?	Date: May 2011 yes ☐ no ☒