Paper

Eurostat Morbidity Statistics Pilot Data Collection the Netherlands

Eurostat Grant Agreement no. 835804 – 2018-NL-MORBIDITY

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1. Summary

From January 2019 to June 2020 the Netherlands participated in the Eurostat Morbidity Statistics Pilot Data Collection. Overall aim of the study was to investigate the feasibility for Member States to collect nationally representative, internationally comparable diagnosis-based information on morbidity.

Guidelines provided detailed definitions and methods to calculate the requested indicators. The indicators consisted of incidence by episode, incidence by person and / or period prevalence for a variety diseases or health problems. Totals had to be broken down by age, sex and residency. Based on previous studies it was anticipated that in most participating Member States information should come from several registrations with diagnostic information to cover all types of health care, and that sources should be linked on person-level to avoid double counting. To improve comparability between countries some adaptations were made to the official epidemiological definitions of incidence and prevalence, such as the requirement that at least one health contact with registration of diagnostic information had taken place in the year over which data were reported (or in case of period prevalence in the three most recent years).

In the Netherlands primary care data were considered important for most indicators.
No nation-wide source was available on primary care, but we were able to use Nivel Primary Care database (Nivel-PCD) with a coverage of eight percent of the population for 2016, the year over which data had to be reported. As other sources such as hospital discharges, diagnosis-treatment-combinations from both specialist somatic and mental health care, causes of death and dispensed medicines were available for the full population, the effect of this limitation was limited. Nivel-PCD is considered to be representative for the Dutch population and in the process of scaling up to the full population background information was used to further compensate for any lack of representativeness.

One challenge was to select the required diagnostic information for each health problem. The Eurostat list of indicators describes each health problem using the International Classification of Diseases, 10th edition (ICD10). In the Netherlands many sources use other classifications or descriptions of treatments.

In the present project information was compiled for 33 out of 35 indicators on the Eurostat list. In most cases four to five sources were combined. Generally, only two or three sources were required to find at least 95 percent of the total number of cases that were found using all available sources.

A sophisticated and flexible method was developed to extract information from the relevant sources and integrate the information into disease episodes using contact information on personal level from each source. Disease episodes are particularly important to determine incidence by episode or incidence by person. The flexible method also made it possible to calculate the effect of inclusion of one or more additional diagnostic codes, which was part of the piloting process.

Evaluation of the overlap between sources proved to be helpful to study validity of results.

Data collection on morbidity statistics using the guidelines that were provided was considered feasible, but information needed to identify, per indicator, the number of non-resident cases

proved to be limited. Future analysis using results from other Member States will give an impression of the international comparability.
Should morbidity statistics become part of a regular data collection, it probably will remain a time consuming exercise, as changes in availability or composition of sources are frequent.

2. Introduction

This report describes the work carried out in the Netherlands within the scope of Eurostat Morbidity Statistics Pilot Data Collection, co-funded by Eurostat (Grant agreement no. 835804 — 2018-NL-MORBIDITY).
The project started in January 2019, lasted 18 months and was carried out by Statistics Netherlands (CBS).
The overall objective of Eurostat Morbidity Statistics is to collect nationally representative, internationally comparable diagnosis-based information on morbidity.

The following specific objectives were formulated for the present Eurostat grant action:
- Objective 1: to build up a suitable administrative data infrastructure to collect diagnosis based morbidity statistics;
- Objective 2: to collect data on diagnosis based morbidity according to a shortlist of indicators;
- Objective 3: to develop suitable methodologies for estimating those variables for which administrative data sources are not fully available.

This pilot data collection aimed to study the feasibility of calculating morbidity indicators, such as the number of persons with a particular disease or health condition, or the occurrence of new cases with the disease or health condition, referred to as prevalence and incidence respectively.

In a previous data collection on Eurostat Morbidity Statistics it was assumed that for each disease a single 'best' data source could be identified to calculate incidence and/or prevalence. At the same time, data sources could differ for different diseases or measures. However, this assumption turned out to be unrealistic. Most countries would require a combination of data sources to cover different types of care providers or different parts of the population, using data linkage on a person-level. Strictly prescribed definitions would be needed to achieve comparability between countries.

The present pilot data collection in the Netherlands focused on diseases and health conditions of the 2018 Shortlist of Morbidity Indicators, List A, as presented in Table 1.

The method to be used was described in detail in the Methodological Guidelines, provided by Eurostat. The guidelines were based on previous pilot collections and inventories in the field of Eurostat Morbidity Statistics. These Guidelines also included the shortlist of indicators (Table 1) and provided per indicator suggestions for sources and diagnostic codes in other classifications. Not all sources use the International Classification on Diseases, 10th edition (ICD10) which is used to define the diseases and health problems on the shortlist.

Table 1: Shortlist indicators List A

nr	Disease/health problem	ICD10	Type of indicator
P1	Diabetes mellitus	E10-E14	incidence per person
P2	Diabetes mellitus	E10-E14	prevalence
P3	Dementia (incl. Alzheimer's disease)	F00-F03, G30	prevalence
P4	Mental and behavioural disorders due to use of alcohol (incl. alcohol dependence)	F10	prevalence
P5	Schizophrenia, schizotypical and delusional disorders	F20-F29	prevalence

P6	Mood (affective) disorders	F30-F39	prevalence
P7	Anxiety disorders	F40, F41	prevalence
P8	Parkinson's disease	G20	prevalence
P9	Multiple sclerosis	G35	prevalence
P10	Epilepsy	G40, G41	prevalence
P11	Hypertensive diseases	I10-I13, I15	incidence per person
P12	Hypertensive diseases	I10-I13, I15	prevalence
P13	Ischaemic heart diseases	I20-I25	prevalence
P14	Acute myocardial infarction	I21, I22	incidence per episode
P15	Acute myocardial infarction	I21, I22	incidence per person
P16	Heart failure	I50	prevalence
P17	Stroke	I60-I64	incidence per person
P18	Cerebrovascular diseases	I60-I69	prevalence
P19	Pneumonia	J12-J18	incidence per episode
P20	Asthma	J45, J46	incidence per person
P21	Asthma	J45, J46	prevalence
P22	Chronic lower respiratory diseases other than asthma (incl. COPD)	J40-J44, J47	prevalence
P23	Chronic obstructive pulmonary disease (COPD)	J44	prevalence
P24	Alcoholic liver disease	K70	prevalence
P25	Diseases of liver other than alcoholic	K71-K77	prevalence
P26	Diseases of liver	K70-K77	prevalence
P27	Rheumatoid arthritis	M05, M06	prevalence
P28	Arthrosis	M15-M19	prevalence
P29	Osteoporosis	M80-M82	prevalence
P30	Renal failure	N17-N19	prevalence
P31	Urolithiasis	N20-N23	incidence per person
P32	Intracranial injury	S06	incidence per episode
P33	Intracranial injury	S06	incidence per person
P34	Fracture of femur	S72	incidence per episode
P35	Fracture of femur	S72	incidence per person

In short, the following steps were needed for each indicator on the shortlist:

- Identification of suitable sources and finding a way to access them
- Definition of the best matching diagnostic description in case sources used other classifications than ICD10 which is used in the Morbidity Shortlist
- Determination of the required information from each source and extract it
- Use of the population register to add information on age, sex, and residency
- Calculation of indicators after the combination of sources and integration of information
- Making estimates in case of missing information
- Checking the plausibility of the results and define any quality issues

All procedures had to be well documented and saved for future use.

2.1 Recent history of Eurostat Morbidity Statistics and participation of the Netherlands

In 2009 the Netherlands participated in a first Eurostat pilot data collection, where Member States were asked to provide, per indicator, morbidity data based on the best (single) source. However, international comparability appeared to be very much depending on the type of source that was available. In the following 2015 European Project on Inventories of Morbidity Statistics (EPIMS), Member States were asked to provide information on the (combination of) sources that would be used to provide information on the diseases on the 2013 version of the Morbidity Shortlist, and the definitions that were (or would be) used to provide best national estimates. It did not include actual data collection. The Netherlands also participated in this EPIMS study.

Analysis of information of all participating countries resulted in 2017 in the Report of the European Project on Inventories of Morbidity Statistics. In subsequent meetings of the Task Force Morbidity Statistics, participating Member States agreed on a new pilot data collection, selecting the indicators that would be involved, accepting the need for the combination of data sources. Also the definitions had to be specified, to increase comparability of information between countries. For example, it was concluded that only information for the index year and two previous years would be used to identify prevalent cases, even though some countries would have the ability to study lifelong prevalence. Another important requirement to improve comparability was that a minimum of one health contact had to be registered in this three year reference period (in case of prevalence). Incident cases for chronic diseases would be determined for the full population and not only for persons that did not yet have the disease. It was recognized that these restrictions departed from official epidemiological definitions in favour of international comparability.

For some diseases and health problems, additional indicators were added for the present data collection, trying to avoid problems with different classification systems in primary care and hospital care in some countries.

Also, it was concluded that morbidity statistics on cancers and infectious diseases would be excluded from the new pilot data collection, as international data collection on these indicators already takes place and the addition of new international estimates using other definitions was considered to be confusing.

2.2 Guidelines, definitions, breakdowns and deliverables

Guidelines:

Based on the discussions in the Task Force Morbidity Statistics Eurostat presented in January 2019 the Guidelines which had to be used for the present pilot data collection (Morbidity Statistics: Methodological Guidelines for the 2019-2020 Pilot Data Collection). The manual has had a small update in September 2019.

The guidelines contain the context and history of morbidity statistics and give an overview of results from previous studies which led to the present pilot data collection. It provides definitions to be used, potential sources, operationalisation of definitions and breakdowns, and issues on quality.

It also includes in Annex A1 the final List of Indicators for the present data collection, using ICD10-codes to define each disease or health problem. Actually, the list contains two parts: List A consists

of 35 indicators on 29 different diseases or health conditions and should be piloted by all Member States; List B (8 indicators) was marked 'to be considered' and is not used by the Netherlands. In Annex A2, information is presented, per indicator, on potential sources, suggestions for diagnostic codes in other classification systems as suggested by member states in previous studies, and other special issues for piloting. Most of these 'issues for piloting' that generally referred to different choices in ICD10-definitions were included in the present study.

Definitions and breakdowns:
The guidelines provide several definitions that are presented for the indicators on the list and their breakdown variables.

Index year	The year to which the indicators refer. This had to be 2016 or the nearest year if not available, all indicators in the Netherlands give information on 2016. The index year is also referred to as 'reference year'.
Reference period	Period over which health contacts are included to calculate indicators. For the calculation of prevalence the reference period is three years: t-2, t-1, and t, t being the index year. This prevalence is also referred to as a three-year period prevalence. In the context of incidence, however, (see below) also health contacts in t-2 and t-1 were taken into account, to determine whether a (chronic) disease had to be considered as incident.
Incidence by person	The number of individuals who had a new diagnosis of a given health condition during the year over which is reported (the index year). A new diagnosis is defined as any contact of the individual with healthcare or related services where the disease was recorded for the first time in that period, where 'first time' for chronic diseases was generally operationalised as not present in two years before the year over which is reported. After combining data sources, a case that was considered incident in one source possibly was already present before in one of the other sources. After integration of information, cases were considered incident only when each of the sources did not mention a health contact for the disease in the two years before the year over which is reported.
Incidence by episode	The number of newly diagnosed episodes of disease or health problems which occurred with an incidence date during index year, counting any individual patient more than once if more than one episode of the disease occurred. A newly diagnosed episode of disease indicates that the patient did not previously have the disease (equal to incidence per person) or the patient did have the disease (during a previous episode) but was cured (the former episode of disease was ended). At least one contact with healthcare or related services occurred in each episode. After the linkage of data sources, disease episodes have to be formed to make sure that between two episodes in one source no health contact was known from other sources.
Period Prevalence (or three-year period prevalence).	Period prevalence means the number of individuals who had the health condition of interest during the index year, whether newly diagnosed (incident) or not. To determine prevalent cases all individuals were included who had the health condition of interest and who had a contact with healthcare or

	related services in connection with that condition during the index year or the two years before that year (the reference period, (t-2 to t)).
Health contact:	A health contact was defined broadly to allow for the variety of data sources and healthcare systems and might be (for example) a hospital admission, a consultation with a GP, a purchase of prescribed medicines from a pharmacy, or a granted claim for disability benefits. All health contacts taking place within the country had to be included, whether the individual was resident or non-resident. Health contacts of residents that took place outside the country also had to be included, but only provided there was also at least one healthcare contact within the country.
Incidence date	The date of the first recorded contact in the episode.
Age	Prevalence: the age of a person on July 1. Incidence: the age of a person at the start of the disease episode
(Non-) resident	Resident : all persons having their usual residence in the Member State on the reference date, according to the definition contained in regulation 1260/2013 on European demographic statistics. Non-resident: all persons who are not residents as defined above. In the present data collection persons are considered resident if they are present in the index year in the population registry, and have an address in the Netherlands.

Deliverables:

The main deliverables for the data collection are two templates in Excel provided by Eurostat (for the Netherlands marked 'NL'):

NL_MORB_DATA.xlsx: For each indicator the (estimated) number of persons/cases with the disease or health problem, broken down by age, sex and residency

NL_MORB_METADATA.xlsx: including:

- general metadata about the morbidity statistics data collection for the Netherlands (ESMS)
- per indicator: specific metadata per indicator
- a matrix showing the overlap of cases found in each pair of sources that are included. This matrix will be used to help with the understanding of the results, especially about the relative usefulness of different data sources for the estimation of diagnosis-based morbidity and the effects of different data sources on comparability between the countries.

These templates will not be published separately, but the most relevant information is reproduced in a more readable format in the present report with annexes.

3. Sources and Methods

3.1 Sources and coverage

In the Netherlands, not one single source is available that covers all health contacts from all types of care, including diagnostic information. Therefore, to obtain estimates for each of the Shortlist health problems, a combination of sources was required. The sources that were available for morbidity statistics cover most of the care provided in the public sector, although information on mental health care is limited. No data were available on the private sector, but in the Netherlands, the private sector is very small.

In the Dutch health care system, general practitioners (GP's) provide primary care and have a gatekeeper function to other types of care. Data on primary care is therefore considered indispensable for most indicators in Morbidity Statistics. GP's receive reports on treatments and results of medical examinations from hospitals and mental health care. It is known, however, that this information is not always complete, or available for analysis. Other sources are needed to add additional information from hospitals and mental health care. Also, some health problems may only become clear at the moment of death, which requires also information on causes of death.

Although information from primary care is considered indispensable, unfortunately not one single source on primary care is available in the Netherlands. Several networks of general practices exist, some in a specific region and some more widely spread across the Netherlands. One of them, Nivel Primary Care database, is widespread throughout the Netherlands, considered to be nationally representative, and suitable for use in Morbidity Statistics as it comprises both contacts and diagnostic information, and data can be linked on person-level to other sources. It covered in 2016 (the index year of the present study) about eight percent of the Dutch population. As each GP practice has a fixed population however, the epidemiological denominator is known and the source is suitable for the determination of incidence and prevalence measures. In the Netherlands, almost all inhabitants are registered with a GP practice and it is only possible to register with one GP practice at a time. As Nivel-PCD covers a relatively small part of the population, it is required to scale up the number of cases with a particular health problem to the national population. This is done by using a weighting method to correct at the same time for any remaining lack of representativeness. Other sources available for Morbidity Statistics also provide information that can be linked on person-level. These sources do cover the full population, so no problem exists of small overlap between more sources that cover only a part of the population. The additional sources provide information on care provided in hospitals, mental health care, on medication through pharmacies, and causes of death.

General practitioners provide general primary care for the non-institutionalised population. In 2016 (the index year) two percent of the population was institutionalised. Clearly this was particularly the case for older individuals. Of the 80-year-olds, four percent lives in an institution, on age 85 this is 11 percent, for 90-year-olds 23 percent and age 95 years and over 43 percent. Elderly women more often live in institutions than men of the same age. Overall, four percent of the population was 80 years or older in 2016. For the present pilot data collection on Morbidity Statistics, no source was available on the incidence and prevalence of health problems specifically in the institutionalised population. The only exception was dementia (incl. Alzheimer's disease, indicator P3). Data were available for the main reason for admission to long term health care, and 'psychogeriatric reason' was one of the options, assumed to be generally dementia. Also, persons could be classified as 'institutionalised' by using the registration of payments of personal

contributions for intensive long-term care. The combination of the two resulted in a separate estimate for dementia in the institutionalised population.

Information on mental health care is limited. The source 'Diagnosis Treatment Combinations Mental Health Care' (DTC-MHC) covers specialised mental health care, including inpatient health care up to one year. However, no data are available on diagnosis in basic mental health care. Primary mental health care is covered in Nivel-PCD. As the general practitioner is gatekeeper to both basic and specialised health care, diagnostic information should be available at the GP's. However, at least for specialised mental health care this diagnostic information at the GP did not match completely with the diagnostic information available in DTC-MHC.

In total, eight sources were used for Morbidity Statistics, seven containing information to select cases with particular health problems, and one only to identify the institutionalised population.

1. Nivel Primary Care Database (Nivel-PCD) on primary care by GP's, with information on the registered population and their disease episodes, containing information on diagnosis and health contacts
2. Hospital discharge register (HDR) with data on all admissions for day care, clinical care, and longer observations, including both primary and secondary diagnoses
3. Diagnosis Treatment Combinations Specialised Somatic Care (DTC-SSC) with DRG-like units used for payment of care in hospitals and independent treatment centers (admissions and ambulant care)
4. Diagnosis Treatment Combinations Mental Health Care (DTC-MHC) with DRG-like units used for payment of specialised mental health care
5. Dispensed medicines containing medication provided through pharmacies as far as covered by health insurance. It contains no diagnostic information.
6. (multiple) Causes of Death (CoD) with both underlying and secondary causes of death
7. CIZ Register of eligibility decisions to long-term care (LTC-E CIZ)
8. Co-payments for use of long term care (LTC-C CAK)

Each of the sources contains personal identifiers that enable linkage to the population registry. This registry provides information on age, sex, and resident status.

In Annex 6.1 an overview is given of the eight different sources with information on the owner, the type of care covered, the reason for registration, the type of information that is used for morbidity statistics and operationalisation of a health contact, strengths and weaknesses, and timeliness.

3.2 Methods

3.2.1 mapping ICD10-definitions to other classifications

Annex 6.2 presents the sources used per indicator, including the classification system. Two sources identified for morbidity statistics used the International Classification of Diseases, 10th edition (ICD10): the hospital discharge register, and the register on causes of death. For other sources, the requested ICD10-definitions identifying the diseases and health problems in the shortlist had to be 'translated' to other classification systems. Sometimes it was complicated to find full coverage of the requested ICD10-definition without including ICD10-codes belonging to other health problems.

Conversion process ICD10 to ICPC1:

International Classification for Primary Care, version 1 (ICPC1) is used in Nivel-PCD, the source on primary care that is used for most indicators. In previous editions of Eurostat Morbidity Statistics, a mapping was performed of ICD10 to ICPC1. The Dutch ICPC2-ICD10 mapping thesaurus was used to find all ICPC2 codes related to the ICD-10 codes requested (Okkes, Oskam, & Lamberts, 2005; http://www.transitieproject.nl). Then, the selected ICPC2-codes were translated back to ICD-10 codes and compared to the original ICD-10 codes requested, to check for any missing or surplus of ICD10-codes. ICPC2 codes were then compared with ICPC1 codes, which generally did not result in major differences except in indicators P1/P2 (diabetes mellitus), P18 (Cerebrovascular diseases), and P22/23 (COPD), resulting in slightly different selections of codes required using ICPC-1 compared to ICPC-2. Any missing or surplus ICD-10 (sub)codes were indicated in the metadata of each indicator.

Conversion process ICD-10 to DTC-SSC-descriptions:

Diagnosis Treatment Combinations (DTC) are the basis for payment in somatic specialist care (SSC). Each medical specialty has its own set of codes that often indicate a recognizable description of the treatments given. In total about 4400 different DTC's exists. From the descriptions, diagnostic information had to be derived. Fortunately, in 2016 a start was made to include also ICD10-codes. In the 2017 data, ICD10 codes were missing in 5 percent of the DTCs. This may be useful for future data collections. However, for the data required in the present pilot data collection of Morbidity Statistics (2014-2016), ICD10-codes were still not available for the bigger part. Also, the quality of this new ICD10-information remains to be checked. However, the new ICD10-information proved to be of great help in the selection of relevant DTC-codes for each of the indicators of the Shortlist.

All DTC-SSC's containing ICD10-information of 2016 and 2017 were pooled. First, per indicator, the ICD10-codes from the shortlist were used to find all corresponding DTC-SSC-codes. For most indicators, many different DTC-SSC codes were found. First of all, because all medical specialties have their own set of codes. More than one medical specialty may regularly be involved with the treatment of the disease and each specialty may have one or more separate codes that refer to the disease. For example, in the case of diabetes mellitus, each of the specialties ophthalmology, surgery, orthopaedics, internal medicine, paediatrics, geriatrics, and gastroenterology have one or more DTC-SSC-codes referring to diabetes, referring to complications or frequently occurring treatments. Another reason for the fact that many different DTC-SSC codes are found is that some DTC-SSC's can be used for many different diseases. In the case of diabetes, this can occur within the specialties mentioned above, but also in other specialties. For example, the specialism 'revalidation' has a code for 'Other disorders lower extremities'. Clearly, this DTC-SSC code also may be used in other health problems than diabetes.

Using the descriptions of the DTC-SSC-codes and the frequency with which they occur in combination with a certain ICD10-code, per indicator the most important codes were identified. For example, Parkinson's disease (defined by the single ICD10-code G20) corresponded to 73 different DTC-SSC-codes. However, two of those codes accounted for 96% of the cases, one in the medical specialty 'Neurology' (DTC-SSC-description Morbus Parkinson) and one in the specialty 'Geriatrics' (DTC-SSC-description Parkinson / Parkinsonism). Clearly, these two codes have a strong relationship with ICD10-code G20. For most indicators, two to five DTC-codes together covered more than 95% of the cases selected based on ICD10-definition.

Subsequently, we selected all DTC-SSC's with the best matching descriptions and listed the corresponding ICD10-codes, to check whether the selected DTC-SSC-codes referred only (or

predominantly) to the requested ICD10-codes, or whether also other ICD10-codes were found. For DTC-SSC-codes that frequently translate to ICD10-codes outside the definition, a choice had to be made between inclusion (and consequently to include too many cases) or exclusion (leading to missing cases). In case of doubt, different selections were used to study the impact of different choices on the final indicator calculated after the combination of sources.

Based on these two actions, selections of the DTC-SSC-codes have been made for each indicator.

Conversion process ICD10 to DSM-IV:
Diagnosis Treatment Combinations (DTC-MHC) are the basis for payment in specialised mental health care. DTC-MHC defines mental health problems using the Diagnostic and Statistical Manual of Mental Disorders version IV (DSM-IV). The coding table of DTC-MHC included both conversions of DTC-MHC descriptions to ICD9 and ICD10. Using the ICD10-definitions of the shortlist the corresponding DSM-IV codes could be selected.

Conversion process ICD-10 to ATC:
The register of dispensed medicines uses the Anatomical Therapeutic Chemical Classification System (ATC) to describe medication. In the register unfortunately no information is available on diagnosis, therefore the use of this source for Eurostat Morbidity Statistics was limited. Some ATC-groups however have names that suggest a use for specific diseases, such as N03 antiepileptics, N04 anti-Parkinson drugs, or N06D anti-dementia drugs. It is known, however, that some drugs in these groups may also be used for a variety of other diseases. A clear signal that this might be the case is a remarkable increase in the total number of cases found already by the combination of multiple sources, by adding such an ATC-group. For some indicators, a selection was made within the ATC-groups based on indications for use as mentioned in the 'Farmacotherapeutisch Kompas' (the Dutch Pharmacotherapeutic Compass) in combination with a study on the actual use of selected medication by subjects having and having not the disease in the Nivel-PCD.

In Annex 6.2 all diagnostic codes that are selected for use in Morbidity Statistics are presented, per indicator, per classification.

3.2.2 Weighting, scaling up

As the baseline source on primary health care (Nivel-PCD) covers about eight percent of the population, the number of cases found in this population had to be extrapolated to the full Dutch population. Any inconsistencies between the population characteristics of Nivel-PCD and the general Dutch population are taken into account at the same time using a weighting procedure. The method is comparable to methods used for interview surveys to control for non-response. The weighting variables that were used are demographic and socio-economic variables and included age, sex, income level, degree of urbanization, migration background, and person years (part of the year persons were registered with a Nivel-PCD practice). Weighting was performed using specialised software named Bascula[1].

In the case of indicator P3 (Dementia including Alzheimer's disease), an exception was made (see below).

[1] Nieuwenbroek en Boonstra, 2002 Bascula 4.0 Reference Manual. Interne nota BPA nr.279-02-TMO, CBS, Den Haag/Heerlen

3.2.3 Estimating indicators in the institutionalised population

Primary healthcare for nursing home patients generally is provided by an elderly care physician. People living in nursing homes therefore mostly are not registered in a general practitioner's practice and are not included in the Nivel primary care database. Preferably, the population in the Nivel primary care database should be extrapolated to the general population not living in nursing homes to obtain prevalent (or incident) cases in the noninstitutionalised population, and subsequently cases living in nursing homes should be added to obtain the total number of cases. However, diagnostic information on persons living in nursing homes is at present hardly available.

In the Netherlands, the access to nursing homes in recent years has been restricted to people who need constant supervision or care close at hand, 24 hours a day. Information is available on the main reason leading to the decision that a person is eligible for this long-term residential care. However, these 'reasons' are formulated in very broad terms (such as somatic disorder or limitation, psychiatric disorder or disability, intellectual disability, etc). This information is not sufficiently specific to be used as diagnostic information. One exception is 'psychogeriatric disorder or disability', assumed to include mostly dementia or Alzheimer's disease (indicator P3). It is expected that an important part of the total number of persons with dementia is living in nursing homes.
The nursing home population was defined by persons paying a co-payment for use long term care. For indicator P3 the number of persons with dementia found in the Nivel-PCD population were extrapolated to the non-institutionalised population, and subsequently (psychogeriatric) cases found in the nursing home population were added.

For future use, CIZ eligibility decisions may also provide useful ICD10-information. The quality and completeness however remain to be checked and the information remains limited to subjects entering long term care. Still no information will be available on incidence or prevalence of diseases that occurred after entering long term care, or existing health problems that were no primary reason for admission to long term care.

3.2.4 Estimating cases in the non-resident population

Most sources available for morbidity statistics referred to residents only. Nivel primary care database (Nivel-PCD) forms the basis of morbidity data for most indicators on the shortlist. The Nivel-PCD population consists of persons registered to the participating GP practices. Almost by default, the non-resident population is not registered to a Dutch GP practice. In need of care, non-residents may receive primary care by a GP, but this information is not included in Nivel-PCD in the same detail of information. Consultations with the GP by passers-by are paid (with the amount depending on setting and duration), but no information is available on diagnosis, nor does it include a personal identifier that can be linked to other data sources.
One of the sources on specialist medical care (DTC-SSC) did include cases from non-residents that were known in the population registry. These are persons that do not live in the Netherlands but who do have a personal identifier because of specific bond to the Netherlands (are working in the Netherlands, used to live in the Netherlands, etc). In the templates, these cases were presented as non-residents and added to the (extrapolated) total of cases found for residents to form the total.

3.2.5 A highly flexible software system for calculation of indicators.

The output of the morbidity statistics project exists of a list of indicators on incidence and prevalence of diseases, broken down by age, sex, and residency. These had to compiled by linking

different data sources on person-level and integrating information to follow predefined definitions as good as possible. Also, in the metadata template the overlap between sources had to be presented in a matrix. In the development of the software system it was decided that it should meet the following requirements:

- In the process of defining the exact diagnostic codes needed (see 3.2.1), it was important to be able to change codes easily and to show the effect on totals by calculating various alternatives
- minor changes in operationalization of the definitions, which could be expected when consulting experts, should be easily implemented in all indicators for all diseases, without repeating all calculations indicator by indicator
- plausibility checks could reveal that it might be better to exclude a particular source for a particular indicator. Inclusion or exclusion of sources had to be easy and it should be possible to study the effect of choices on the results
- to avoid typing errors, the generated output had to be as much as possible in the format of the templates that ultimately had to be delivered
- some flexibility was required in additional output which would facilitate discussions with experts, such as graphs, sources in order of the number of additional cases contributed, percentage of cases that were not known in primary care, etc. Part of this information had to be included in the present report, which would be more accessible than the mandatory templates.

The software system was build using SQL. An SQL database was built with separate tables for each of the sources, containing only diagnostic codes and dates of health contacts. It included also a population table with information on age, sex, and residency and an indicator for participation in the Nivel-PCD population.

With an SQL script, the required information is retrieved per indicator. The final indicators are calculated based on integrated information on person-level, using various sources. Procedures differed slightly by type of indicator (incidence per episode or person, prevalence), the type of health problem (chronic disease or not), and the use of the Nivel-PCD population or not (to know whether weighting/scaling up is required). All indicators were calculated at the same time to minimize the number of errors.

The output existed of an Excel workbook with separate worksheets for incidence per person, incidence per episode, prevalence, and sources and codes used. On the first worksheet, the indicator could be selected, and also all extra indicators that were calculated based on alternative selections of codes and sources. The use of one single worksheet made it possible to change formats and additional calculations and figures that automatically were available for all indicators.

At the end of the project, with all decisions made, the workbook could be extracted to one page per indicator, making all information available which had to be copied into the templates and into the present report.

3.2.6 Plausibility of results.

Per indicator, the linkage of data sources resulted in the total number of cases by age, sex, and residency, and also of the overlap between each pair of two sources. Before this information was copied to the data and metadata templates, the plausibility of results was checked with colleagues

and specialists . from the National Institute for Public Health and the Environment (RIVM) and the Netherlands institute for health services research (Nivel).
The following information was checked:

- Does the total number of cases and the calculated prevalence or incidence rates comply with results that were expected?
- Is the distribution of cases by age and sex as expected?
- Is the number of cases found in each source as expected? For this, we added a total number of cases in the matrix information, as the matrix often only showed overlap within the Nivel-PCD population, and totals in this population are different from totals presented in the data template, which are result of a scaling up procedure. Sources were also presented in decreasing order of number of cases contributed to the total number of cases, not counting any cases that were already found by previous sources.
- Does the overlap between primary care and hospital care (HDR, DTC-SSC) fit with assumptions?
- Is the overlap between HDR and DTC-SSC as expected? HDR includes only hospital admissions, but it includes both primary and secondary diagnoses. DTC-SSC on the other hand, includes also ambulatory care and care in independent treatment centres, but only (a proxy of) the primary diagnosis is available
- Is the number of unique cases provided by one single source as expected?
    - It is not expected that the source with information on medication delivers many unique cases that cannot be found in other sources.
    - With health problems that (almost) always also are treated in hospitals, a high contribution of unique cases by primary care is not expected
- In case of doubt on the selection of diagnostic codes: compare results on different selections, how large is the impact of choices after integration with other data sources? What is the right choice?

In some cases, the discussion on plausibility resulted in additional analyses. Results again were discussed with colleagues and specialists.

4. Results

4.1 Completeness of information

Results are presented for all indicators of List A of the shortlist, with the exception of P24 and P25 (alcoholic and non-alcoholic liver diseases). This resulted in 33 indicators.
P26 (liver diseases, assumed to be the total of P24 and P25, liver diseases) is presented. The reason for not presenting P24 and P25 is that primary care data uses the ICPC-classification and ICPC-code D97 (cirrhosis/other liver disease) cannot distinguish between both types of liver diseases. It was also not considered possible to make a reliable distribution of cases in primary care over the indicators P24 and P25. This would also complicate the interpretation of results after linking to other sources. Also in one of the hospital sources (DTC-SSC), it was not always possible to attribute DTC's to either P24 or P25.

Results are primarily presented in the detailed Eurostat templates, which are not part of this report.

Annex 6.3 provides an overview of results per type of indicator and per health problem.
It shows:

- the number of cases found in the Nivel-PCD population (where relevant) and the total (resident) population.
- information on the proportion of cases found in more than one source and the proportion that was present in only one source
- the proportion of cases found by source.

Indicators for which a relatively large proportion of cases were found in more than one source are the prevalence of diabetes mellitus (P2): 80% of prevalent cases was found in more than one source (mostly primary care and medicines) followed by P34/P35 fracture of femur (incidence, 71% of cases was present in two or more sources). On the other hand, the share of cases from only one source was high in the incidence of hypertensive diseases (P11) and prevalence of anxiety disorders (P7), with 93% of cases only in source.

Annex 6.4 contains more detailed results per indicator:

- Total number of cases found in the resident population[2] and (where relevant) in the Nivel-PCD-population
- Cases found by source
- Sources in order of additional cases found
- Overlap of cases between each combination of two sources[3]
- Figure showing the number of cases by age and sex
- Results of alternative choices that had been considered and also results on 'issues for piloting' as mentioned in Annex 2 of the Guidelines

4.2 Availability of breakdowns

All indicators are presented by age and sex, using 5 year age groups ranging from 0-4 years to 95 and over, including a subtotal for ages 65 and over. No data on age and sex were classified as

[2] Resident population, because the information on non-residents is only marginally available, and the resident population fits best with the Nivel-PCD population which is used in most sources.
[3] As in the metadata template, but using the actual names of sources in this study

'unknown', due to the fact that all sources were linked to the population registry which has no missing values for age and sex.
Information is presented separately for residents, non-residents, and a total. However, as expected, information on diagnose-specific use of health care was hardly available for non-residents (see 3.2.4). Only one source we had access to (DTC-SSC) provided information on non-resident cases. We could only use those subjects that could be linked to the population registry due to former residency in the country or because of the work situation.

4.3 Sources

In this pilot data collection, we decided to use and show per indicator all sources with relevant information. Although for some indicators the contribution from a particular source may be small, we decided still to present the results to facilitate future choices to be made in harmonizing morbidity statistics.

Annex 6.2 shows the sources which were used per indicator. Hospital discharges, DTC-SSC, and causes of death were used in all indicators, although the relative contribution in the number of cases varied widely per indicator.

Nivel-PCD with information on primary care was eventually used in 27 of the 33 indicators presented. However, reasons for not including Nivel-PCD varied:

- In indicator P14/P15 (acute myocardial infarction) and P34/P35 (fracture of femur) Nivel-PCD was not used, as the number of cases found only in primary care was unexpectedly high. It indicated the use of a different 'concept' of the disease or health problem in primary care and hospital care. Including primary care cases would increase the number of acute myocardial infarctions by 130 percent and the number of femur fractures by 34 percent.
- For indicator P27 (Rheumatoid arthritis) it was known from other studies that the diagnostic code in primary care (ICPC-1 L88) was also used for other forms of arthritis. As it was assumed that most patients with rheumatoid arthritis would also be known from sources on specialized somatic care it was decided not to use Nivel-PCD. Inclusion of primary care would result in an increase of 114 percent of the number of cases found.
- Finally, for indicator P30 (renal failure) no adequate ICPC-1 code was available to cover only renal failure. It is included in ICPC-code U99 (Urinary disease, other) which would lead to the inclusion of many other health problems than only renal failure.

Data on dispensed medicines were only used in the case of P1/P2 diabetes mellitus, P3 Dementia (incl. Alzheimer's disease), P8 Parkinson's disease, and P10 Epilepsy. In the case of P3, P8, and P10 a selection of medicines was used instead of the complete ATC-groups N06D (anti-dementia drugs), N04 (anti-Parkinson drugs) and N03 (anti-epileptics) as presented in Annex 6.2. For Parkinson's disease and Epilepsy Annex 6.4 shows the difference between the use of only a selection of medicines and the entire groups.

Both sources on long term care (reasons for and use of) were used in only one indicator (P3 dementia (incl. Alzheimer's disease)) This was the only indicator for which separate analyses in the institutionalized and non-institutionalized population were feasible.

5. Discussion

5.1 Effects of choices in diagnostic codes

Not all sources in the present study use ICD10, the classification system used by Eurostat to define the diseases and health problems on List A. Therefore a lot of effort has gone into selecting the combinations of diagnostic codes required in the other classifications.
For ICPC-1, used in primary care, this information was available from previous Eurostat studies with largerly the same list of indicators. In the Guidelines, Annex A2, the results of these exercises were summarised per indicator. Since the present study includes data collection, unlike the EPIMS Inventory, there was opportunity to study the effect of inclusion or exclusion of ICPC-codes in cases with imperfect mapping. Mapping often is not perfect, as an additional ICPC-code to achieve full coverage of the ICD10-definition may lead to the inclusion of too many ICD10-codes. Therefore, for some indicators, we studied the effect of varied selections.

For example, in P32/P33 (intracranial injury) the ICD10-definition is S06. In ICPC, the code N79 covers only concussion (ICD10-code S06.0). To also cover ICD10 S06.1-S06.9, the additional ICPC-code N80 is required. This is the selection currently presented in the Guidelines. However, this additional code also introduces ICD10 codes S02 Fracture of skull and facial bones, S07 Crushing injury of head, S08 Traumatic amputation of part of head and S09 Other and unspecified injuries of head. Inclusion of ICPC N80 increased the number of incident cases found in the primary care data with 134 percent, and the total number of incident persons (using all sources combined) was increased by 60 percent. Apparently, a part of the extra cases introduced by including N80 had already been identified in HDR or DTC-SSC. We decided not to include ICPC N80.

In the case of P5 (Schizophrenia, schizotypical and delusional disorders) the Guidelines Annex A2 proposes to use ICPC-1 code '72'. This should be **P**72 (Schizophrenia). But in addition, the ICD10-definition includes not only Schizophrenia (ICD10 F20) but also 'schizotypical and delusional disorders', ICD10 F21-F29. These codes would be accounted for by adding ICPC-1 P98 (Psychosis NOS / other). The addition of ICPC-1 P98 increased the number of prevalent cases by 40 percent. Based on the description of the indicator (both in text and in ICD10-codes) we decided to include ICPC P98.

According to the Guidelines, Annex 2, indicator P7 Anxiety disorders was covered by using ICPC-2 codes P74 (anxiety disorder/anxiety state) and P79 (phobia/compulsive disorder). For ICPC-1 however, only P74 (Anxiety disorder/anxiety state) was proposed. The description of ICPC P79 is almost the same in both versions. The number of prevalent cases found increased by 9 percent after including ICPC-1 P79 in our analyses. Based on the description of the indicator, and the advice also to use ICPC-2 P79, we decided to include ICPC-1 P79 in our analyses.

The source containing information on medications does not provide diagnostic information. As presented in 3.2.1 we made some effort to select medicines that were only used with Parkinson's disease (P8) or Epilepsy (P10), respectively. In the case of P8 Parkinson's disease, the selected medication was used in 76 percent of the total number of cases, 8 percent of the cases were found only because of this selection of medicines. Inclusion of the full group of ATC N04 (anti-Parkinson drugs) would have increased the total number of cases by 157 percent. Seventy percent of the

cases found using any N04 medication are unknown with Parkinson's disease in any other source. In the case of P10 Epilepsy, the number of cases would increase with 270% if the entire group of N03 anti-epileptics were included. Eighty percent of cases using N03 medication is not known with epilepsy from any other source.

In some cases we studied the effect of adjustments in the selection of ICD10-codes, although this is the basic definition of all indicators:
In P3 (Dementia (incl. Alzheimer's disease) our specialists also recommended including ICD10 G31 (Other degenerative diseases of nervous system, not elsewhere classified) to also include diseases as Pick disease and Lewy bodies disease, which belong to a more 'modern' interpretation of dementia. The addition of ICD10 G31 resulted in a 0.6 percent increase of the total number of prevalent cases found. We have decided to follow the advice of our specialists.

In indicator P4 (Mental and behavioural disorders due to use of alcohol (incl. alcohol dependence)) we found during the selection of DTC-SSC-codes that ICD10 T51 (Toxic effect of alcohol) was also frequently used in that source to indicate binge drinking. We studied the effect of including ICD10 T51 in HDR and CoD as well, but the effect was very small and it introduced some cases at a very young age. Is was decided not to include ICD10 T51 in HDR and CoD.
Likewise, the inclusion of ICD10 Z49 (Care involving dialysis) in the calculation of P30 (Renal failure) had no substantial effect and was not decided to include it.

Finally, we studies the effect of some 'issues for piloting' as mentioned in the Annex A2 in the Guidelines, referring to alternative choices in the ICD10-definitions put forward by Member States in previous studies.

In the case of indicator P16 (Heart Failure), the ICD10-definition was I50. However, Finland recommended expanding the set with I11.0 (hypertensive heart disease with (congestive) heart failure), I13.0 (hypertensive heart and renal disease with (congestive) heart failure) and I13.2 (hypertensive heart and renal disease with both (congestive) heart failure and renal failure). By using this broader definition, the total amount of cases was increased by only 0.04 percent.

Regarding indicator 22 (Chronic lower respiratory diseases other than asthma (incl. COPD), ICD10: J40-J44, J47) there was some discussion about the inclusion of J47 (bronchiectasis). Exclusion of this code resulted in a 2 percent reduction of cases found in the combination of HDR and COD, the sources using ICD10. However, the effect on the total number of cases was even smaller (a reduction of 0.2 percent). This is likely so much smaller because ICPC-1 code R91, along with ICPC1-code R95 used for primary care, also includes bronchiectasis (along with chronic bronchitis), so that subjects with bronchiectasis remain to be included based on primary care data. In ICPC-2, codes are slightly different and bronchiectasis seems part of ICPC-2 R99 (respiratory disease, other). We do not recommend to use that ICPC-2 code to complete ICD10 J47, as it also includes many other respiratory diseases.

In the case of indicator P27, rheumatoid arthritis, ICD10 M05-M06, Hungary indicated that ICD10-code M06.4 (Inflammatory polyarthropathy) had to be excluded. The effect of exclusion was small, resulting in a 0.07 percent reduction in the combination of HDR and COD, the sources that use ICD10. On the total number of cases found, the reduction was 0.01 percent.

5.2 Sources: coverage and completeness

The sources that were available for use in Morbidity Statistics covered most of the health care provided in the Netherlands.

For primary health care, only data for a sample of eight percent of the population was available through Nivel-PCD. However, due to Nivel's efforts to recruit representative general practitioners across the country, and the subsequent weighting method applied to make up for any remaining lack of representativeness, the source is suitable to use, also because all other sources are nation-wide.

With respect to Nivel-PCD two issues remain: one is that it does not cover the institutionalised population. By extrapolation the Nivel-PCD population to the total population, incidence and prevalent rates at all ages are assumed to be equal in both the institutionalised and the non-institutionalised population. This assumption probably is not true, as especially in recent years institutionalisation only applies to those who need care 24 hours a day and are clearly in poor health. In the case of dementia we had access to additional data to estimate prevalence in the institutionalised population. Probably, for dementia, the share of the total number of cases living in institutions is particularly large. New data may be available in the near future on diseases that were prevalent at the moment of eligibility decisions for access to long term care. This could allow a separate analysis of the institutionalised population possible for more diseases. However, this is only valuable when the diagnostic data on the institutionalised population is at least as detailed and complete as primary care data on the non-institutionalised population. For example, more than 20 percent of 85yr olds have diabetes mellitus. If diabetes mellitus is not the reason for access to long term care and no other diagnostic data are available on the institutionalised population, separate analyses for both groups may lead to a lower prevalence of diabetes in 85-year-olds because the diagnosis is not completely known in the institutionalised population.

The other issue is that for some chronic disorders (non-insulin-dependent diabetes mellitus, COPD, asthma and (more in the field of prevention) 'vascular risk management') so called 'multi-disciplinary coordinated care' (also known as 'chain care') was recently introduced. Several medical disciplines provide the required care together (for example, the general practitioner in collaboration with a dietician, a physiotherapist and/ or a remedial therapist) coordinated by the GP. This type of care is financed in a different way than other care provided by the general practitioner. The care provided within this new type of care is registered in separate database. In 2016, chain care contacts were not all covered by Nivel-PCD. This may affect prevalence and incidence data for corresponding indicators, as health contacts are part of the definitions used to calculate indicators. In Nivel-PCD a person may have an ongoing disease episode for (for example) diabetes, but apparently no recent health contacts. Using the definitions of Morbidity Statistics, we should not include part of the prevalent cases in Nivel-PCD due to the restriction that recent health contacts are required. It turns out that, in 2016, 94 percent of people with an ongoing diabetes episode in Nivel-PCD did have a registered GP-health contact in the past three years. After integration with other sources, this percentage increased to 96 percent. The effect of missing contacts is very limited. For incidence, however, the effect of missing health contacts is greater and more difficult to interpret. In Nivel-PCD we identify a subject as 'incident' if a health contact for the disease was registered in t but not in t-1 or t-2 (although the starting date of the episode ,as determined by Nivel, may have been many years ago). Since many recent health contacts may have

been registered in the chain care register but not in the GP register, the number of cases that will be identified as 'incident' from Nivel-PCD will be too large: the episodes marked as incident by Nivel (with a start in 2016) supplemented with the actually prevalent episodes with a contact in 2016 but not in 2014-2015. The number of incident episodes using only Nivel-PCD will double. However, after integrating with other sources (which will also provide health contacts in 2014-2015) the increase in incident episodes is reduced again to a rough estimation of 25 percent. As a result, incidence may be overestimated because of missing contact information from chain care. Recently, chain care contacts have become available, so this problem will be less in future analyses.

Data on mental health care are limited. Information on persons treated in the general practitioner's practice is available. The general practitioner is gatekeeper to other types of care, including mental health care, but it is not clear to what extent the GP receives information in return on diagnoses and health contacts, both of which are necessary for the calculation of the Morbidity Statistics indicators. Under age 18, information on both basic and specialised health care is limited as this type of care is financed differently starting 2015, when it became part of the Youth Act. No diagnostic information is available anymore.

The hospital discharge register (HDR) includes clinical admissions as well as day admissions and long-term observations. However, diagnostic information from day admissions is not fully covered, approximately 20 percent of this information is missing each year. For statistical purposes imputation is used, but cannot be used in Morbidity Statistics that require person-level data linkage. The direct consequences of this limitation are difficult to estimate, as missing diagnoses may be covered within the HDR during other admissions in 2016 or earlier years (as primary or secondary diagnosis), but also may be found in other sources such as primary health care or DTC-SSC on specialised somatic care. Therefore, the effect on total number of cases found cannot be estimated. We made an analyses within one year of HDR, to find the difference between the number of cases with and without the imputation of diagnostic information from day care patients, using only primary diagnoses. Indicators for which the relative contribution of day admissions was large are Multiple Sclerosis (88 percent of admissions is a day admission), and P20/P21 Asthma, with 37 percent. Due to missing diagnostic information on day admissions, the number of persons with one or more day admissions for epilepsy was 16 percent lower than it should be, and the total number of persons with an admission for epilepsy of any type (to be used for Morbidity Statistics) was 15 percent lower. However, on the total of cases found after combination of sources, HDR only contributed 1 percent of cases that were not already found in other sources. As part of these cases will be found anyway as HDR also contains secondary diagnoses, and data of 2014-2015 are used for this analysis, the number of missed cases probably will be minimal. In the case of asthma, the number of persons with a day admission is reduced by 18 percent by omitting imputed diagnoses, but the number of persons with any type of admission is only reduced by 7 percent. For P21/P22 asthma, HDR provided 2 percent of cases that were not found in other sources. Of these cases, 7 percent may not be found due to missing diagnostic information in HDR.

Regarding timeliness, for each source we estimated the availability of data for future Morbidity Statistics data collections. Results are presented in Annex 6.1, which presents the properties of the sources. In the case that a future data collection takes place with an index year of 2019, the latest data will be available for analyses in fourth quarter of 2021. However, a serious problem is expected on data from mental health care, due to the introduction of a new payment system.

5.3 Limiting the number of sources

All relevant sources for each indicator are presented, including the overlap between sources. However, for many indicators one or more sources attributed only a minor amount of extra cases. In the Guidelines (1.2.7) it is mentioned that 'data which is believed to be close to complete, for example where the only deficiency is a small proportion of cases (say, less than 5 percent of the total) treated in the private sector, could be treated as complete' (no adjustment of the estimates needed). Also in 3.1.3 the '5 percent' is mentioned as a cut-off point above which (in the case of the estimated share of non-residents in the population) an adjustment had to be made. With that percentage in mind, we present in Annex 6.6 the effect of reducing the total number of cases found to 95 percent, by omitting the least contributing sources of additional cases. First we ordered sources on number of (extra) cases contributed (percentages mentioned in Annex 6.4). Then we omitted the smallest sources until we reached 95 percent of the total of cases (and presented the actual percentage after this action). In the final column the percentage is shown that is left after removing one more source.

For most indicators four or five sources contributed to the total number of cases found. In almost all indicators this number could be reduced by one or two sources to find still at least 95 percent of cases. All indicators could be covered for 95 percent using only two or three sources (with the exception of P3 Dementia (incl. Alzheimer's disease), which requires a complex analysis in both institutionalised and non-institutionalised population). For one indicator, P2 (Diabetes mellitus, prevalence) one source appeared to be enough to cover 95 percent of cases found (Nivel-PCD).

5.4 Non-resident population

Incorporating cases for non-residents would be necessary to fully represent the burden on healthcare, while cases for residents represent the burden of disease in the population.
This conceptual distinction and the successful inclusion of nonresidents were considered to be of particular importance to some countries, such as those with a large cross-border flow of tourists or seasonal migrants.

In the present study it proved to be difficult to obtain suitable information about non-residents. Most sources have no, or limited, data on nonresidents by nature, such as the data collected in primary care in the population registered with the general practitioners practice. Other sources were only available to us after linkage to the population registry and subsequent selection of inhabitants. The good thing is that we did not have to show data with the label 'residence unknown'. If all sources included nonresidents, it would still have been difficult to use the precise definitions of incidence and prevalence at the same way as for residents. Since personal identifiers would not have been available, or would have been different in every source or every year, it would not have been possible to avoid double counting or define a case as incident by checking contacts in earlier years. Also, the epidemiological denominator for incidence or prevalence in nonresidents (being the total number of nonresidents present in the member state) would not have been known or used. The use of the resident population as denominator, still seems difficult to explain. Ultimately, it can be said that knowledge of incidence or prevalence of diseases among the nonresident population s unlikely to be a very good indicator of the burden on health care services. To estimate that burden, it might be more useful to estimate the total number of health contacts or use of different types of health care by non-residents.

5.5 Other institutionalized groups

The Guidelines called for some attention for other institutionalized population groups besides residents of nursing homes. The inclusion of long-term residents of psychiatric institutions was considered essential for the relevant indicators on mental health. In our Morbidity Statistics DTC-MHC includes health records up to one year of stay in a psychiatric hospital. In 2016 a total of 8650 persons[4] received institutionalized mental health care for longer than one year, but no information was available on the diagnosis. If we estimate that these persons all had one of the four mental illnesses in the list (P4-P8) and in the same distribution, the totals would increase with 0.5 percent each. Other groups mentioned were prisoners and military personnel. Also, no health records were available for these groups, but both groups are small compared to the total population, 35250[5] prisoners and 25000[6] in 2016, respectively.

5.6 International comparability

We still have some concerns regarding the use of morbidity statistics for international comparisons. Even in our own data landscape of multiple sources that can be linked on person-level, we note that choices when selecting diagnostic codes or inclusion of a particular source will make significant differences.

These choices are difficult to overcome in Guidelines. It depends heavily on the local situation in each country and the practical knowledge of participating consultants in the morbidity statistics projects which choices will be made.

As presented in Chapter 5, some indicators were calculated using two or more combinations of diagnostic codes or sources. Sometimes national specialists knew that certain codes in for example primary care were also used for health problems that did not fit exactly within the definition of the disease in the shortlist. This was the case, for example, in indicator P27 (rheumatoid arthritis). In other cases, this became apparent only after combining sources, as in P14/P15 Acute myocardial infarction and P34/P35 (fracture of femur). The number of cases that were known in primary care and not in specialized somatic care or cause of death seemed improbable. We decided to exclude primary care for these indicators and the effect on the total number of cases was enormous. This to illustrate that the effect of such choices easily can affect international comparability.

Also, the availability of sources can affect the totals found per indicator importantly. For example, in the Netherlands a source on specialized mental health care was available in recent years. It was used for indicators P3-P7 and although it did not cover basic mental health care (of which no diagnostic data were available) it had a huge impact on some indicators: it provided 23 percent of all cases in P5 (Schizophrenia, schizotypical and delusional disorders) and 12 percent in P6 (Mood (affective) disorders), 7 percent in P7 (Anxiety disorders), 5 percent in P4 (Mental and behavioural disorders due to use of alcohol (incl. alcohol dependence) and 1 percent in P3 (Dementia (incl. Alzheimer's disease). In the near future, however, this source will probably not be available anymore, due to a change in payment system. This will influence the total number of cases found in future morbidity statistics.

[4] long term care plus 2240 with 2-3 years specialized mental health care which is not included in DTC-MHC, https://mlzopendata.cbs.nl/#/MLZ/nl/dataset/40075NED/table?dl=3B0A7

[5] https://opendata.cbs.nl/statline/#/CBS/nl/dataset/82321NED/table?dl=3B12A

[6] https://opendata.cbs.nl/statline/#/CBS/nl/dataset/82808NED/table?dl=3B12C

Also, the availability of not only primary but also secondary diagnoses in HDR and causes of death is likely to lead to a higher number of cases found than if this information would not have been available.

We expect that a lot of work will have to be done to determine whether differences between Member States are the result of differences in health system administration and classification or result from a real difference in actual health of residents of different countries.

5.7 Terminology

In Morbidity Statistics the terms 'incidence by person', incidence by episode' and 'period prevalence' are used. In order to improve international comparability strict definitions are set for inclusion of cases, such as the requirement of a (recent) contact with healthcare services, and the limitation of a three-year reference period in case of prevalence.

Although we understand and agree with the decision, this leads to differences with the epidemiological definition, as some individuals with a chronic disease or disability, when they do not require healthcare intervention, are not counted in the case of prevalence. On the other hand, for example in the case of depression, any health contact in the previous three years is sufficient to count as a prevalent case. In the Netherlands, however, an episode of depression is considered closed (and not prevalent anymore) after one year without further contact with health services.

At national level, these differences are confusing. In the Netherlands we generally present both prevalence (without restriction of a recent contact) and '1 year care prevalence' (cases with one or more health contacts, because of the disease, in the past year). And incidence applies only to new cases, but not to prevalent cases with a health contact in the last year but not in the previous two years, as is the case in the Morbidity Statistics definition (for chronic diseases). Health authorities are not very enthusiastic about different figures on what seems to be the same subject. To avoid confusion it may be better to use a different terminology (for example three-year contact prevalence). Or at least realize that in any future presentation of results these limitations on the usual terminology are very clear and well documented.

5.8 Conclusion

With the exception of two out of the 35 indicators of the Morbidity Shortlist A, the pilot data collection was generally feasible. Due to the differentiated health system and the lack of detailed insurance data with diagnostic information, different sources had to be combined to cover all types of health care and the required diagnostic and health contact information. Fortunately, linkage on person-level was possible to avoid double counting of cases. For most indicators four to five sources were used to find as many cases as possible, but only two or three were required to cover 95 percent of all cases found.

The use of different classification systems was a real challenge, especially in one of the sources on specialized somatic care (DTC-SSC). Thanks to the flexible software system that was developed, we were able to test different combinations of diagnostic codes to study the net effect of inclusion or exclusion when in doubt. The system was also used to test remaining issues for piloting from previous studies on Morbidity Statistics.

The main problem was to make a reliable estimate of the morbidity among the non-resident population. Because these data are not available within our main source of primary care, it was

hardly possible to make a good estimate of this. We were limited to using data from a single source. Overall, however, the share of nonresidents in the population is not very high.
With respect to international comparability we expect a lot of work will have to be done to establish whether differences are the result of differences in health system administration and classification or result from a difference in actual health of residents of different countries.

The objectives for the present Eurostat grant action, as mentioned in the introduction, were all met:

- Objective 1: to build up a suitable administrative data infrastructure to collect diagnosis based morbidity statistics
- Objective 2: to collect data on diagnosis based morbidity according to a shortlist of indicators;
- Objective 3: to develop suitable methodologies for estimating those variables for which administrative data sources are not fully available.

6. Chapter 6: Annexes

6.1 Sources

Name	**Nivel Primary Care Database (In Dutch: Nivel Zorgregistraties Eerstelijn)**
Used acronym	**Nivel-PCD**
Owner/Provider	Nivel Netherlands institute for health services research
Type of care covered	Primary Care provided by general practitioners
Coverage	In 2016, data was available for 8% of the population. GP's generally do not include the institutionalized population. In the Netherlands, the GP works as gatekeeper to other types of care, and (almost) every person is registered with a (one) GP practice.
Type of information used	- Patient population of participating general practitioners practices in 2016, - Disease episodes per person that are 'active' in 2016, containing information on diagnosis, date of first and last contact and date of first and last prescription for the disease.
Reason for registration	Routinely recorded electronic health records (EHRs) from general practitioners (GPs), extracted by Nivel for research purposes
Operationalisation of health contact	Consultation with GP, prescription by GP, within a disease episode with the required diagnosis (defined by ICPC-1 codes).
Strengths and weaknesses	Strengts of the source are that the GP practices are selected to give a good representation of both GP practices and population, and that it uses disease episodes. A disadvantage is that the source does not cover the full population but only about 8%.
Timeliness:	2019 data expected to be available for morbidity statistics second quarter of 2021
Website or other online information	https://nivel.nl/en/nivel-primary-care-database Nielen and al 2019, Estimating Morbidity Rates Based on Routine Electronic Health Records in Primary Care: Observational Study; JMIR Med Inform 2019;7(3):e11929 https://www.ncbi.nlm.nih.gov/pubmed/31350839
Specific remarks:	As the other sources are available for the total Dutch population, Nivel-PCD is used as the basis for data linkage to other sources. The definition of 'episodes' in this source depends on the type of the health problem: for chronic disease diseases episodes are never closed, for other health problems an episode closes after a certain period without any further contacts with the GP (see Nielen 2019). For some indicators of morbidity statistics a 3-year prevalence was requested on health problems that were not considered as chronic in Nivel-PCD (mostly mental health problems). In that case, sometimes no episode for the disease was present in 2016-data. Therefore, also episodes from 2014 and 2015 had to be used. Fortunately, the Nivel-PCD population was quite stable in recent years.

Name	**Hospital discharge register (In Dutch: Landelijke Basisregistratie Ziekenhuiszorg (LBZ))**
Used acronym	**HDR**
Owner/Provider	Dutch Hospital Data (DHD)
Type of care covered	specialist medical care in hospitals
Coverage	Covers for the total population all discharges from all general and university hospitals and specialised hospitals with the exception of epilepsy clinics and long-stay centres for rehabilitation and asthma treatment. Independent treatment centers and private clinics are not included.
Type of information used	Primary and secondary diagnosis for hospital admissions (day care, inpatients, observations) including date of admission and discharge and both primary and secondary diagnostic information (ICD10 codes). Discharges in 2017 with admission in 2016 are included
Reason for registration	Information for individual hospitals and specialists for planning and benchmark purposes. Calculation of the Hospital Standardized Mortality Ratio's (HSMR) Research
Operationalisation of health contact	Health contact: (every) day spent in hospital during an admission with the requested diagnosis (registered as primary or secondary diagnosis upon discharge)
Strengths and weaknesses	Strengths of the source are that it uses ICD10 as classification system, and contains both primary and secondary diagnoses. Weakness is that is does not include ambulant care provided in hospitals, and incompleteness of diagnostic information in about 20 percent of day care admissions.
Timeliness:	Full data on 2019 (including discharges in 2020 of admissions in 2019) expected to be available for morbidity statistics first quarter of 2022. However, only relatively few hospital stays pass the turn of the year. By far most 2019 data will be available the first quarter of 2021.
Website or other online information	https://www.dhd.nl/producten-diensten/lbz/Paginas/Dataverzameling-LBZ.aspx
Specific remarks:	Diagnostic information was not available for 20 percent of day care admissions in 2014-2016. In more recent years this was 23 percent.

Name	**Diagnosis Treatment Combinations Somatic Specialist Care (In Dutch: Diagnose Behandeling Combinaties Medisch Specialistische Zorg)**
Used acronym	**DTC-SSC**
Owner/Provider	Dutch Healthcare Authority (NZa)
Type of care covered	specialist medical care in hospitals and independent treatment centers, including outpatient care
Coverage	Covers for the total population all Diagnosis Treatment Combinations that are performed in hospitals and independent treatment centers
Type of information used	Diagnosis Treatment Combinations (DTCs) are DRG-like units for which the costs are reimbursed under the statutory basic medical insurance. DTC's of somatic specialist care provide information, organised per medical specialism, on treatments (procedures performed) often with mentioning of diagnosis, and information on setting (inpatient/day patient/ outpatient), costs, start and end date of treatment, etc.

Reason for registration	Payment system
Operationalisation of health contact	A treatment code indicating a consultation with a physician or a medical operation. Not including laboratory results.
Strengths and weaknesses	Strength of the source is that it covers also ambulant care provided in hospitals and does include care provided by independent treatment centers. Weakness is the use of a classification system that is based on the most common treatments per medical specialism but does not directly translate to ICD10 or another international classification.
Timeliness:	Full 2019 data including DTC's started in 2019 and ended in 2020 are expected to be available for morbidity statistics fourth quarter of 2021.
Website or other online information	https://www.nza.nl/english https://www.nza.nl/zorgsectoren/medisch-specialistische-zorg (in Dutch)
Specific remarks	For statistical purposes we change to another provider, Vektis (www.vektis.nl). Via Vektis data will become available earlier and completeness is better. The content of the data, as far as use for morbidity statistics is concerned, is the same, but ICD10 is not included. However, the quality of ICD10-coding still has to be evaluated and may be added later.

Name	**Diagnosis Treatment Combinations Mental Health Care**
Used acronym	**DTC-MHC**
Owner/Provider	Dutch Healthcare Authority (NZa)
Type of care covered	specialized mental health care
Coverage	Covers for the total population all Diagnosis Treatment Combinations that are performed in psychiatric wards of hospitals, mental hospitals and independent psychiatrists and psychotherapists.
Type of information used	Diagnosis Treatment Combinations Mental Health Care (DTC-MHC) are DRG-like units that form the payment system of specialist mental health care. DTC's provide Information on diagnosis and detailed data on care provided (in terms of type of treatment, time spent, number and care level of overnight stays, start date, end date etc). All ambulatory specialized mental health care is included, and residential specialized mental health care until the first year of stay is completed.
Reason for registration	Payment system
Operationalisation of health contact	A treatment code referring to a contact with a patient, a nursing day, an outpatient treatment or the actual activity of opening a DTC in which diagnosis was registered.
Strengths and weaknesses	Strength is that both primary and secondary diagnoses are covered and an international classification is used that translates well to ICD10. Weaknesses are: - it does not cover basic mental health care, - registered diagnosis has influence on the price of the treatment, and that will sometimes influence registered diagnoses, - it takes lot of time before care provided during the full calendar year is available for analysis, as DTC's have a maximum duration of one year. A DTC started end year t will be closed end t+1. - The source will no longer exist after introduction of a new payment system in 2022. Recently, the degree of detail in the diagnostic information is already reduced (from 2017 onwards) and completeness is an increasing problem.

Timeliness:	It is not sure whether 2019 data will be available at all, due to the upcoming change in the payment system and reduction in diagnostic detail and completeness as of 2017. Would the data still be suitable for use, these will be available at the end of 2021.
Website or other online information	https://www.nza.nl/english https://www.nza.nl/zorgsectoren/geestelijke-gezondheidszorg-ggz-en-forensische-zorg-fz (in Dutch)
Specific remarks:	This data source probably will not be available in the near future.

Name	**Dispensed medicines**
Used acronym	**medicines**
Owner/Provider	National Health Care Institute
Type of care covered	prescribed medicines provided through pharmacies and covered by the health insurance. Contains no diagnostic information.
Coverage	Covers for the total population all medication provided through pharmacies which is covered by the basic health insurance.
Type of information used	medicines dispensed by a pharmacy that are reimbursed under the statutory basic medical insurance. No information on diagnosis, and medication provided during a hospital stay or in nursing homes are not included
Reason for registration	risk equalisation (risicoverevening) for health insurances purposes (to equalize risks (for high cost patients) between insurers.)
Operationalisation of health contact	Delivery of medication with an ATC-code required for the indicator
Strengths and weaknesses	Strength of the source is that is timely and complete. Weakness is that it does not has information on diagnosis, does not include medication provided in hospitals and institutions and is limited to medicines that are covered by the basic health insurance
Timeliness:	2019 data expected to be available for morbidity statistics first quarter of 2021
Website or other online information	https://english.zorginstituutnederland.nl/

Name	**(multiple) Causes of Death**
Used acronym	**CoD**
Owner/Provider	Statistics Netherlands (CBS)
Type of care covered	Causes of Death
Coverage	Causes of death are available for more than 98.4% of deaths in the Dutch population.
Type of information used	Causes of death as reported by physicians to the civil register of the municipality where the person died. Including both the underlying cause of death (CoD), i.e. the disease or injury initiating the chain of morbid events leading directly to death, and the non-underlying (i.e. intermediate or contributory) causes ('multiple causes of death')
Reason for registration	Statistical purposes
Operationalisation of health contact	date of death, usually the date of completion of the death form by the physician

Strengths and weaknesses	Strength: contains all diagnostic information that the attending physician considers relevant to determine the underlying cause of death Weakness: - for members of the Dutch population who died abroad, cause of death is mostly not available. - With respect to the 'multiple' causes of death (the additional diagnoses presented on the death form which are not considered to be the underlying cause of death) no information is available on completeness or validity.
Timeliness:	2019 data expected to be available for morbidity statistics third quarter of 2020
Website or other online information	https://www.cbs.nl/en-gb/our-services/methods/surveys/korte-onderzoeksbeschrijvingen/causes-of-death-statistics

Name	**CIZ Register of eligibility decisions to long-term care**
Used acronym	**LTC-E CIZ**
Owner/Provider	Care Needs Assessment Centre
Type of care covered	Long term care
Coverage	Covers for the total population all eligibility decision (reasons for admission) for use of long term care
Type of information used	eligibility decisions to long-term care
Reason for registration	An eligibility decision is needed to access long term care
Operationalisation of health contact	eligibility decision to long-term care of the requested type (only used in P3 (dementia), with reason for admission: psychogeriatric)
Strengths and weaknesses	Strength is that is the only source that gives information for the reasons why people enter long term care. Weakness is that information is very limited.
Timeliness:	2019 data expected to be available for morbidity statistics fourth quarter of 2020
Website or other online information	https://www.ciz.nl/ https://www.government.nl/topics/nursing-homes-and-residential-care/question-and-answer/how-can-i-apply-for-a-wlz-care-needs-assessment
Specific remarks:	Only used for indicator P3 (Dementia incl. Alzheimer's disease)

Name	**Co-payments for use of long term care (CAK)**
Used acronym	**LTC-C CAK**
Owner/Provider	Central Administration Office (CAK)
Type of care covered	Long term care
Coverage	Covers for the total population all copayments for use of long term care
Type of information used	co-payment of contribution to use of long-term care
Reason for registration	Registration of co-payments of contribution to use of long-term care
Operationalisation of health contact	co-payment of contribution to use of long-term care
Strengths and weaknesses	Strength is that it gives insight in the number of people using long term institutionalized care. Weakness is that it does not contain diagnostic information

Timeliness:	2019 data expected to be available for morbidity statistics fourth quarter of 2020
Website or other online information	https://www.government.nl/topics/nursing-homes-and-residential-care/question-and-answer/i-have-a-wlz-care-needs-assessment.-do-i-have-to-pay-towards-the-costs-of-my-care
Specific remarks:	Only used for indicator P3 (Dementia incl. Alzheimer's disease)

6.2 Classifications and diagnostic codes per indicator

Sources:

Hospital discharge register	HDR
Causes of Death	CoD
Nivel Primary Care Database	Nivel-PCD
Diagnosis treatment combinations Somatic Specialist Care	DTC-SSC
Diagnosis treatment combinations Mental Health Care	DTC-MHC
Dispensed medicines	Medicines
Long term care eligibility decisions	LTC-E CIZ
Long term care: co-payments	LTC-C CAK

Classification used per source:

Source:	Classification:	
HDR	International Classification of Diseases, 10th edition	ICD10
CoD	International Classification of Diseases, 10th edition	ICD10
Nivel-PCD	International Classification for Primary Care, version 1	ICPC-1
DTCSS	diagnoses/treatments described by medical specialism	DTC-SSC specific
DTC-MHC	Diagnostic and Statistical Manual of Mental Disorders version IV	DSM-IV
Medicines	Anatomical Therapeutic Chemical Classification System	ATC
LTC-E CIZ	Eligibility decisions	Eligibility decisions
LTC-C CAK	Co-payments for use of long term care	Co-payments

Sources used per indicator:

Indicator		Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medicines	CoD	LTC-E CIZ	LTC-C CAK
P1/P2	Diabetes mellitus	✓	✓	✓		✓	✓		
P3	Dementia (incl. Alzheimer's disease)	✓	✓	✓	✓	✓	✓	✓	✓
P4	Mental and behavioural disorders due to use of alcohol (incl. alcohol dependence)	✓	✓	✓	✓		✓		
P5	Schizophrenia	✓	✓	✓	✓		✓		
P6	Mood (affective) disorders	✓	✓	✓	✓		✓		
P7	Anxiety disorders	✓	✓	✓	✓		✓		
P8	Parkinson's disease	✓	✓	✓		✓	✓		
P9	Multiple sclerosis	✓	✓	✓			✓		
P10	Epilepsy	✓	✓	✓		✓	✓		
P11/P12	Hypertensive diseases	✓	✓	✓			✓		
P13	Ischaemic heart diseases	✓	✓	✓			✓		
P14/P15	Acute myocardial infarction		✓	✓			✓		
P16	Heart failure	✓	✓	✓			✓		
P17	Stroke	✓	✓	✓			✓		
P18	Cerebrovascular diseases	✓	✓	✓			✓		
P19	Pneumonia	✓	✓	✓			✓		
P20/P21	Asthma	✓	✓	✓			✓		
P22	Chronic lower respiratory diseases other than asthma (incl. COPD)	✓	✓	✓			✓		
P23	Chronic obstructive pulmonary disease (COPD)	✓	✓	✓			✓		
P26	Diseases of liver[1]	✓	✓	✓			✓		
P27	Rheumatoid arthritis		✓	✓			✓		
P28	Arthrosis	✓	✓	✓			✓		
P29	Osteoporosis	✓	✓	✓			✓		
P30	Renal failure		✓	✓			✓		
P31	Urolithiasis	✓	✓	✓			✓		
P32/P33	Intracranial injury	✓	✓	✓			✓		
P34/P35	Fracture of femur		✓	✓			✓		

1: indicator P24 and P25 (alcoholic and non-alcoholic liver disease) could not be included due to lack of specific ICPC-1 code (primary care)

Diagnostic codes used per classification per indicator:

P1/P2 Diabetes Mellitus

ICD10	
E10	Insulin-dependent diabetes mellitus
E11	Non-insulin-dependent diabetes mellitus
E12	Malnutrition-related diabetes mellitus
E1	Other specified diabetes mellitus
E14	Unspecified diabetes mellitus
ICPC-1	
T90	Diabetes
ATC	
A10	Drugs used in diabetes
DTC-SSC	
0303/0521	Surgery / pancreas transplantation
0303/0522	Surgery / islet transplantation
0303/0531	Surgery / kidney and pancreas transplantation
0303/0553	Surgery / Islet transplantation process receiver
0313/0082	Internal Medicine / Liver and pancreatic transplant recipient
0313/0083	Internal Medicine / Liver, pancreatic and intestinal transplant recipient
0313/0345	Internal Medicine / kidney and pancreas transplantation <= 365 days
0313/0347	Internal Medicine / kidney and pancreas transplant> 365 days
0316/7104	Pediatrics / diabetes mellitus
0316/7903	Pediatrics / Islet transplant pathway recipient
0316/7910	Pediatrics / Pancreas transplantation recipient
0316/7923	Pediatrics / Liver and pancreatic transplant recipient
0316/7924	Pediatrics / Liver, pancreatic and intestinal transplantation recipient
0318/0768	Gastroenterology and liver disorders / Liver, pancreatic and intestinal transplant recipient
0362/0400	Radiology / Islet transplant pathway receiver
0301/0754	Ophthalmology / NPDRP
0301/0755	Ophthalmology / Preprolif. DRP
0301/0757	Ophthalmology / PDRP
0301/0759	Ophthalmology / Other pathology DRP
0303/0432	Surgery / Diabetic foot (diabetes n.o.)
0303/0559	Surgery / Kidney and pancreatic transplantation recipient
0303/0560	Surgery / Pancreas transplantation trajectory receiver
0303/0562	Surgery / Liver and pancreatic transplantation recipient
0303/0563	Surgery / Liver, pancreas and intestinal transplantation recipient
0305/2065	Orthopedics / Diabetic foot
0313/0072	Internal Medicine / Islet transplant pathway receiver
0313/0078	Internal Medicine / Kidney and pancreatic transplant recipient
0313/0079	Internal Medicine / Pancreas transplantation trajectory receiver
0313/0221	Internal Medicine / Diabetes mellitus without secondary complications
0313/0222	Internal Medicine / Diabetes mellitus with secondary complications

0313/0223	Internal Medicine / Diabetes mellitus chronic pump therapy
0316/7113	Pediatrics / Diabetes mellitus with chronic pump therapy
0316/7114	Pediatrics / Diabetes mellitus other
0316/7909	Pediatrics / Kidney and pancreatic transplant recipient
0318/0767	Gastroenterology and liver disorders / Liver and pancreatic transplant recipient
0318/0902	Gastroenterology and liver disorders / Diabetes mellitus
0335/0222	Clinical Geriatrics / Diabetes Mellitus

P3 Dementia (incl. Alzheimer's disease)

ICD10	
F00	Dementia in Alzheimer disease
F01	Vascular dementia
F02	Dementia in other diseases classified elsewhere
F03	Unspecified dementia
G30	Alzheimer disease
G31	Other degenerative diseases of nervous system, not elsewhere classified
ICPC-1	
P70	Dementia
ATC	
N06D, excl N06DX02	Anti-dementia drugs excluding Ginkgo folium
DTC-SSC	
0330/0401	Neurology / Dementia syndromes
DSM-IV	
as1_2.02.01	Dementia of the Alzheimer's Type,
as1_2.02.03	Vascular dementia
as1_2.02.04-as1_2.02.10	Dementia due to other diseases
as1_2.02.13	Dementia NOS
LTC-E CIZ	
	Eligibility decisions for Long term care: psychogeriatric reason

P4 Mental and behavioural disorders due to use of alcohol (incl. alcohol dependence)

ICD10	
F10	Mental and behavioural disorders due to use of alcohol
ICPC-1	
P15	Chronic alcohol abuse (also includes ICD10 G31.2: Degeneration of nervous system due to alcohol)
P16	Acute alcohol abuse
DTC-SSC	

0313/0043	Internal Medicine / Symptom Complex due to chronic alcohol consumption
0316/8909	Pediatrics / Acute alcohol intoxication / binge drinking
DSM-IV	
as1_4.01	Substance-related disorders: Alcohol-related disorders
as1_5-13	alcohol induced disorders (such as anxiety, mood disorder, psychotic disorders)
as1_2	Delirium/dementia (sub code: due to alcohol)

P5 Schizophrenia, schizotypical and delusional disorders

ICD10	
F20	Schizophrenia
F21	Schizotypal disorder
F22	Persistent delusional disorders
F23	Acute and transient psychotic disorders
F24	Induced delusional disorder
F25	Schizoaffective disorders
F28	Other nonorganic psychotic disorders
F29	Unspecified nonorganic psychosis
ICPC-1	
P72	Schizophrenia
P98	Psychosis NOS/other (also includes ICD10 F53.1: Severe mental and behavioural disorders associated with the puerperium, not elsewhere classified)
DTC-SSC	
0329/0005	Psychiatry / Schizophrenia and other psychotic disorders
DSM-IV	
as1_5	Schizophrenia and other psychotic disorders

P6 Mood (affective) disorders

ICD10	
F30	Manic episode
F31	Bipolar affective disorder
F32	Depressive episode
F33	Recurrent depressive disorder
F34	Persistent mood [affective] disorders
F38	Other mood [affective] disorders
F39	Unspecified mood [affective] disorder
ICPC-1	
P73	Affective psychosis
P76	Depressive disorder (also ICD10 F41.2, Mixed anxiety and depressive disorder and F53.0: Mild mental and behavioural disorders associated with the puerperium, not elsewhere classified)
DTC-SSC	

0329/0006	Psychiatry / Mood Disorders
0335/0244	Geriatrics / Depressive Disorders
DSM-IV	
As1_6	Mood disorders

P7 Anxiety disorders

ICD10	
F40	Phobic anxiety disorders
F41	Other anxiety disorders
ICPC-1	
P74	Anxiety disorder/anxiety state
P79	Phobia/compulsive disorder (also includes ICD10 F42: Obsessive-compulsive disorder)
	P74+P79 Does not include ICD10 F41.2: Mixed anxiety and depressive disorder
DTC-SSC	
0329/0007	Psychiatry / Anxiety Disorders
DSM-IV	
As1_7	Anxiety disorders

P8 Parkinson's disease

ICD10	
G20	Parkinson disease
ICPC-1	
N87	Parkinsonism (corresponds to ICD10 G20-G22)
	too many ICD-codes included: G21: Secondary parkinsonism, G22: Parkinsonism in diseases classified elsewhere
ATC	
N04BA02	Dopaminergic agents: dopa and dopa derivatives: levodopa and decarboxylase inhibitor
N04BA03	Dopaminergic agents: dopa and dopa derivatives: levodopa, decarboxylase inhibitor and COMT inhibitor
N04BD	Dopaminergic agents: Monoamine oxidase B inhibitors
N04BX01	Dopaminergic agents: Other dopaminergic agents: tolcapone
N04BX02	Dopaminergic agents: Other dopaminergic agents: entacapone
	Other medication from group N04 (anti-Parkinson drugs) was not considered specific enough. Inclusion of full group N04 would increase total resident Parkinson cases almost 2,5 times.
DTC-SSC	
0330/0501	Neurology / Morbus Parkinson

0335/0252	Geriatrics / Parkinson / Parkinsonism (also correspondents to ICD10 G21 (Parkinsonism), but the number of cases is very small compared to 0330/0501

P9 Multiple sclerosis

ICD10	
G35	Multiple sclerosis
ICPC-1	
N86	Multiple sclerosis
DTC-SSC	
0330/0531	Neurology / Multiple sclerosis

P10 Epilepsy

ICD10	
G40	Epilepsy
G41	Status epilepticus
ICPC-1	
N88	Epilepsy
ATC	
N03AD01	antiepileptics: succinimide derivatives: ethosuximide
N03AF03	antiepileptics: carboxamide derivatives: rufinamide
N03AG04	antiepileptics: fatty acid derivatives: vigabatrin
N03AX10	antiepileptics: other antiepileptics: felbamate
N03AX14	antiepileptics: other antiepileptics: levetiracetam
N03AX15	antiepileptics: other antiepileptics: zonisamide
N03AX17	antiepileptics: other antiepileptics: stiripentol
N03AX18	antiepileptics: other antiepileptics: lacosamide
N03AX22	antiepileptics: other antiepileptics: perampanel
N03AX23	antiepileptics: other antiepileptics: brivaracetam
	Other medication from group N03 (antiepileptics) was not considered specific enough. Inclusion of full group N03 would increase total resident epilepsy cases almost four fold.
DTC-SSC	
0308/1515	Neurosurgery / Epilepsy: epilepsy surgery and cortical motor stimulation
0316/3503	Pediatrics / Epilepsy
0316/7708	Pediatrics / Status epilepticus
0330/0601	Neurology / Epilepsy generalized
0330/0602	Neurology / Epilepsy partial

P11/P12 Hypertensive diseases

ICD10	
I10	Essential (primary) hypertension

I11	Hypertensive heart disease
I12	Hypertensive renal disease
I13	Hypertensive heart and renal disease
I15	Secondary hypertension
ICPC-1	
K86	Essential hypertension without organ damage
K87	Hypertension with organ damage / secondary hypertension (also corresponding to ICD10 I67.4: Hypertensive encephalopathy)
DTC-SSC	
0313/0311	Internal Medicine / Hypertension
0316/4003	Pediatrics / Hypertension
0318/0901	Gastroenterology and liver disorders / Hypertension
0320/0902	Cardiology / Hypertension

P13 Ischaemic heart diseases

ICD10	
I20	Angina pectoris
I21	Acute myocardial infarction
I22	Subsequent myocardial infarction
I23	Certain current complications following acute myocardial infarction
I24	Other acute ischaemic heart diseases
I25	Chronic ischaemic heart disease
ICPC-1	
K74	Angina pectoris
K75	Acute myocardial infarction
K76	Other / chronic ischaemic heart disease
DTC-SSC	
0328/2455	Cardio Pulmonary Surgery / TMR
0313/0101	Internal Medicine / Symptomatic ischemic heart disease, not code 102
0313/0102	Internal Medicine / Unstable AP, myocardial infarction
0320/0202	Cardiology / Angina pectoris, stable
0320/0203	Cardiology / Angina pectoris, unstable
0320/0204	Cardiology / ST elevation myocardial infarction
0320/0205	Cardiology / Non ST elevation myocardial infarction
0320/0801	Cardiology / Follow-up after acute coronary syndrome
0320/0802	Cardiology / Follow-up after PTCA and / or CABG and / or ablation
0328/2320	Cardio-pulmonary surgery / CABG, vein grafts and max. 1 arterial graft
0328/2400	Cardio-pulmonary surgery / CABG (> = 2 art.grafts)
0328/2470	Cardio-pulmonary surgery / Plastic left ventricle + CABG
0328/2550	Cardio Pulmonary Surgery / CABG + MPL +/- TPL
0328/2555	Cardio Pulmonary Surgery / CABG (2 Art.) + MVR
0328/2560	Cardio Pulmonary Surgery / CABG (1art.) + AVR + MVR
0328/2570	Cardio Pulmonary Surgery / CABG (2 Art.) + AVR

0328/2585	Cardio Pulmonary Surgery / CABG + HOCM
0328/2630	Cardio Pulmonary Surgery / VT + CABG
0328/2635	Cardio Pulmonary Surgery / Maze + CABG
0328/2640	Cardio Pulmonary Surgery / VSR + CABG
0328/2645	Cardio Pulmonary Surgery / MPL + AVR + CABG
0328/2650	Cardio Pulmonary Surgery / MPL + CABG (2 Art.)
0328/2655	Cardio Pulmonary Surgery / AVR + CABG + HOCM
0328/2665	Cardio Pulmonary Surgery / Ao. root + CABG
0328/2785	Cardio Pulmonary Surgery / Maze + CABG or AVR + MPL +/- TPL

P14/P15 Acute myocardial infarction

ICD10	
I21	Acute myocardial infarction
I22	Subsequent myocardial infarction
DTC-SSC	
0320/0204	Cardiology / ST elevation myocardial infarction
0320/0205	Cardiology / Non ST elevation myocardial infarction

P16 Heart failure

ICD10	
I50	Heart failure
ICPC-1	
K77	Heart failure
DTC-SSC	
0313/0107	Internal Medicine / Decompensatio cordis
0316/3406	Pediatrics / Decompensatio cordis
0320/0301	Cardiology / Acute heart failure
0320/0302	Cardiology / Chronic heart failure
0335/0262	Clinical Geriatrics / Decompensatio cordis

P17 Stroke

ICD10	
I60	Subarachnoid haemorrhage
I61	Intracerebral haemorrhage
I62	Other nontraumatic intracranial haemorrhage
I63	Cerebral infarction
I64	Stroke, not specified as haemorrhage or infarction
ICPC-1	
K90	Cerebrovasculair accident (CVA)
	Also corresponds with ICD10 G46 (Vascular syndromes of brain in cerebrovascular diseases).
DTC-SSC	
0327/0313	Rehabilitation Medicine / CVA

0308/1205	Neurosurgery / Operative treatment of single non-complex aneurysm (other 1210)
0308/1210	Neurosurgery / Operative treatment of complex aneurysms and / or multiple aneurysms
0308/1240	Neurosurgery / Decompression cerebral infarction by means of craniotomy and possible dura dilation
0313/0121	Internal Medicine / Cerebrovascular accident / TIA
0316/3501	Pediatrics / Cerebral infarction
0316/3508	Pediatrics / Intracranial bleeding
0330/1101	Neurology / Subarachnoid hemorrhage
0330/1102	Neurology / Intracerebral hemorrhage
0330/1111	Neurology / Cerebral infarction
0330/1199	Neurology / Other cerebrovascular disorders
0335/0263	Geriatrics / CVA / TIA
8418/0101	Geriatric rehabilitation / CVA

P18 Cerebrovascular diseases

ICD10	
I60	Subarachnoid haemorrhage
I61	Intracerebral haemorrhage
I62	Other nontraumatic intracranial haemorrhage
I63	Cerebral infarction
I64	Stroke, not specified as haemorrhage or infarction
I65	Occlusion and stenosis of precerebral arteries, not resulting in cerebral infarction
I66	Occlusion and stenosis of cerebral arteries, not resulting in cerebral infarction
I67	Other cerebrovascular diseases
I68	Cerebrovascular disorders in diseases classified elsewhere
I69	Sequelae of cerebrovascular disease
ICPC-1	
K90	Cerebrovasculair accident (CVA)
	Also corresponds to ICD10 G46 (Vascular syndromes of brain in cerebrovascular diseases). ICD10-codes not included: I65: Occlusion and stenosis of precerebral arteries, not resulting in cerebral infarction I66: Occlusion and stenosis of cerebral arteries, not resulting in cerebral infarction I67: Other cerebrovascular diseases I68: Cerebrovascular disorders in diseases classified elsewhere I69: Sequelae of cerebrovascular disease
DTC-SSC	
0327/0313	Rehabilitation Medicine / CVA
0303/0402	Surgery / Carotid Pathology
0308/1205	Neurosurgery / Operative treatment of single non-complex aneurysm (other 1210)

0308/1210	Neurosurgery / Operative treatment of complex aneurysms and / or multiple aneurysms
0308/1240	Neurosurgery / Decompression cerebral infarction by means of craniotomy and possible dura dilation
0313/0121	Internal Medicine / Cerebrovascular accident / TIA
0316/3501	Pediatrics / Cerebral infarction
0316/3508	Pediatrics / Intracranial bleeding
0330/1101	Neurology / Subarachnoid hemorrhage
0330/1102	Neurology / Intracerebral hemorrhage
0330/1111	Neurology / Cerebral infarction
0330/1121	Neurology / Residual condition (acquired brain injury)
0330/1199	Neurology / Other cerebrovascular disorders
0335/0263	Clinical Geriatrics / CVA / TIA
8418/0101	Geriatric rehabilitation care / CVA

P19 Pneumonia

ICD10	
J12	Viral pneumonia, not elsewhere classified
J13	Pneumonia due to Streptococcus pneumoniae
J14	Pneumonia due to Haemophilus influenzae
J15	Bacterial pneumonia, not elsewhere classified
J16	Pneumonia due to other infectious organisms, not elsewhere classified
J17	Pneumonia in diseases classified elsewhere
J18	Pneumonia, organism unspecified
ICPC-1	
R81	Pneumonia
	Corresponds also to ICD10 codes: J10.0: Influenza with pneumonia, other influenza virus identified J11.0: Influenza with pneumonia, virus not identified A48.1: Legionnaires disease).
DTC-SSC	
0313/0401	Internal Medicine / Pneumonia nos
0316/3208	Pediatrics / Lower respiratory tract infection
0322/1401	Pulmonary Medicine / Pneumonia

P20/P21 Asthma

ICD10	
J45	Asthma
J46	Status asthmaticus
ICPC-1	
R96	Asthma
DTC-SSC	
0316/3202	Pediatrics / Asthma / BH (except allergic asthma)
0322/1201	Pulmonary Medicine / Asthma

P22 Chronic lower respiratory diseases other than asthma (incl. COPD)

ICD10	
J40	Bronchitis, not specified as acute or chronic
J41	Simple and mucopurulent chronic bronchitis
J42	Unspecified chronic bronchitis
J43	Emphysema
J44	Other chronic obstructive pulmonary disease
J47	Bronchiectasis
ICPC-1	
R91	Chronic bronchitis / bronchiectasis
R95	Emphysema / COPD
DTC-SSC	
0313/0601	Internal Medicine / Asthma, COPD, emphysema
0322/1241	Pulmonary medicine / COPD
0322/1404	Pulmonary Medicine / Bronchiectasis
0335/0272	Geriatrics / COPD

P23 Chronic obstructive pulmonary disease (COPD)

ICD10	
J44	Other chronic obstructive pulmonary disease
ICPC-1	
R95	Emphysema / COPD
DTC-SSC	
0313/0601	Internal Medicine / Asthma, COPD, emphysema
0322/1241	Pulmonary medicine / COPD
0335/0272	Geriatrics / COPD

P26 Diseases of the liver

ICD10	
K70	Alcoholic liver disease
K71	Toxic liver disease
K72	Hepatic failure, not elsewhere classified
K73	Chronic hepatitis, not elsewhere classified
K74	Fibrosis and cirrhosis of liver
K75	Other inflammatory liver diseases
K76	Other diseases of liver
K77	Liver disorders in diseases classified elsewhere
ICPC-1	
D97	Liver disease NOS

DTC-SSC	
0303/0554	Surgery / Liver transplantation process recipient
0313/0412	Internal Medicine / Liver abscess nos
0313/0941	Internal Medicine / Alcoholic liver disease
0313/0942	Internal Medicine / Drug hepatitis
0313/0943	Internal Medicine / Autoimmune hepatitis
0313/0945	Internal Medicine / Cirrhosis of the liver compensated
0313/0946	Internal Medicine / Cirrhosis of the liver decompensated
0313/0959	Internal Medicine / Other liver and bile duct disorders
0318/0701	Gastroenterology and liver disorders / Hepatitis general
0318/0707	Gastroenterology and liver disorders / PBC, PSC and autoimmune hepatitis
0318/0708	Gastroenterology and liver disorders / Cirrhosis compensated
0318/0709	Gastroenterology and liver disorders / Cirrhosis decompensated
0318/0714	Gastroenterology and liver disorders / Other acc. of liver and (portal) circulation
0318/0718	Gastroenterology and liver disorders / Acute liver failure

P27 Rheumatoid arthritis

I**CD10**	
M05	Seropositive rheumatoid arthritis
M06	Other rheumatoid arthritis
DTC-SSC	
0313/0521	Internal Medicine / Rheumatoid Arthritis
0324/0101	Rheumatology / Rheumatoid Arthritis

P28 Arthrosis

I**CD10**	
M15	Polyarthrosis
M16	Coxarthrosis [arthrosis of hip]
M17	Gonarthrosis [arthrosis of knee]
M18	Arthrosis of first carpometacarpal joint
M19	Other arthrosis
ICPC-1	
L89	Osteoarthrosis of hip, , (M15-M19; M13) also includes ICD10-M13 (other arthritis))
L90	Osteoarthrosis of knee
L91	Osteoarthrosis other (also includes ICD10-M13 (other arthritis))
DTC-SSC	
0303/0254	Surgery / Osteoarthritis nos (shoulder, knee, ankle)
0305/1401	Orthopedics / Arthrosis shoulder girdle / upper arm
0305/1501	Orthopedics / Arthrosis elbow / forearm
0305/1601	Orthopedics / Arthrosis hand / wrist
0305/1701	Orthopedics / Arthrosis pelvis / hip / thigh
0305/1801	Orthopedics / Arthrosis knee

0305/2001	Orthopedics / Arthrosis ankle and foot
0313/0514	Internal Medicine / Osteoarthritis
0324/0402	Rheumatology / Peripheral - hands
0324/0403	Rheumatology / Peripheral - hips / knees
0324/0404	Rheumatology / Peripheral - elsewhere
0324/0405	Rheumatology / Polyarthrosis
0335/0323	Geriatrics / Osteoarthritis

P29 Osteoporosis

ICD10	
M80	Osteoporosis with pathological fracture
M81	Osteoporosis without pathological fracture
M82	Osteoporosis in diseases classified elsewhere
ICPC-1	
L95	Osteoporosis
DTC-SSC	
0303/0151	Surgery / Osteoporosis
0305/1050	Orthopedics / Osteoporosis
0305/1395	Orthopedics / Osteoporotic collapse
0313/0233	Internal Medicine / Osteoporosis, osteomalacia
0324/0601	Rheumatology / Osteoporosis - primary
0324/0602	Rheumatology / Osteoporosis - secondary
0335/0322	Clinical Geriatrics / Osteoporosis

P30 Renal failure

ICD10	
N17	Acute renal failure
N18	Chronic kidney disease
N19	Unspecified kidney failure
DTC-SSC	
0303/0435	Surgery / Shunt surgery including revision for kidney disease
0303/0557	Surgery / Kidney transplantation route receiver
0313/0076	Internal Medicine / Kidney transplantation recipient
0313/0322	Internal Medicine / Acute renal failure with dialysis
0313/0323	Internal Medicine / Acute renal failure without dialysis
0313/0324	Internal Medicine / Chronic renal failure eGFR 30-60 ml / min
0313/0325	Internal Medicine / Chronic renal failure eGFR <30 ml / min
0313/0331	Internal Medicine / Continuous Ambulatory Peritoneal Dialysis (CAPD)
0313/0332	Internal Medicine / Automatic Peritoneal Dialysis (APD)
0313/0336	Internal Medicine / Chronic hemodialysis at home
0313/0339	Internal Medicine / Chronic hemodialysis in institution
0316/4006	Pediatrics / Renal insufficiency, chronic

P31 Urolithiasis

ICD10	
N20	Calculus of kidney and ureter
N21	Calculus of lower urinary tract
N22	Calculus of urinary tract in diseases classified elsewhere
N23	Unspecified renal colic
ICPC-1	
U14	Kidney symptom/complaint
U95	Urinary calculus
DTC-SSC	
0306/0011	Urology / Kidney stone
0306/0021	Urology / Ureter Stone
0306/0031	Urology / Bladder stone / corpus alienum
0313/0303	Internal Medicine / Urolithiasis

P32/P33 Intracranial injury

ICD10	
S06	Intracranial injury
ICPC-1	
N79	Concussion (corresponds to ICD10 S06.0 Concussion)
	N80 Head injury other was considered (corresponds to ICD10 S06.1-.9; but also to S02, S07-S09). Extra ICD10-codes included: S02 Fracture of skull and facial bones, S07 Crushing injury of head, S08 Traumatic amputation of part of head, S09 Other and unspecified injuries of head
DTC-SSC	
0303/0272	Surgery / Minor skull brain injury (commotio)
0303/0273	Surgery / Moderately severe skull brain injury (contusio)
0305/3501	Orthopedics / Commotio cerebri
0305/3502	Orthopedics / Contusio cerebri
0308/1305	Neurosurgery / Severe trauma capitis, operative treatment
0316/3524	Pediatrics / Trauma capitis (commotio, contusio)
0327/0314	Rehabilitation Medicine / Contusio cerebri
0330/1401	Neurology / Skull fracture
0330/1402	Neurology / Commotio / contusio cerebri
8418/0305	Geriatric rehabilitation / Intracranial trauma

P34 Fracture of femur

ICD10	
S72	Fracture of femur
DTC-SSC	
0303/0218	Surgery / Femur, proximal (+ collum)
0303/0219	Surgery / Femur other

0305/3019	Orthopedics / Femur proximal (+ collum)
0305/3020	Orthopedics / Femur other
8418/0303	Geriatric rehabilitation / Hip fracture

6.3 Summary of results, per indicator, per source

		Number of cases in		share of cases found in:		Share of cases found per source:						
		Nivel-PCD-population	**total resident population**	**more than one source**	**one source**	**Nivel-PCD**	**HDR**	**DTC-SSC**	**CoD**	**Medicines**	**DTC-MHC**	**LTC-E CIZ**
Incidence by episode												
P14	Acute myocardial infarction	n.a.	39840	54%	46%		71%	69%	16%			
P19	Pneumonia	18860	284240	14%	86%	87%	12%	14%	4%			
P32	Intracranial injury	6310	95540	13%	87%	55%	11%	47%	1%			
P34	Fracture of femur	n.a.	27100	68%	32%		80%	85%	8%			
Incidence by person												
P1	Diabetes mellitus	5130	76350	40%	60%	81%	12%	8%	1%	48%		
P11	Hypertensive diseases	19390	289310	7%	93%	82%	20%	5%	1%			
P15	Acute myocardial infarction	n.a.	38540	56%	44%		72%	69%	17%			
P17	Stroke	4760	72040	46%	54%	71%	42%	53%	9%			
P20	Asthma	12660	190420	7%	93%	90%	4%	13%	0%			
P31	Urolithiasis	4630	69030	22%	78%	88%	15%	26%	0%			
P33	Intracranial injury	6010	90780	14%	86%	53%	12%	49%	1%			
P35	Fracture of femur	n.a.	25950	71%	29%		83%	85%	8%			
Prevalence												
P2	Diabetes mellitus	73670	1104890	80%	20%	95%	24%	23%	1%	81%		

		Number of cases in		share of cases found in:		Share of cases found per source:						
		Nivel-PCD-population	**total resident population**	**more than one source**	**one source**	**Nivel-PCD**	**HDR**	**DTC-SSC**	**CoD**	**Medicines**	**DTC-MHC**	**LTC-E CIZ**
P3a	Dementia -noninstitutionalised[7]	5600		47%	53%	74%	18%	16%	5%	26%	10%	25%
P3b	Dementia -institutionalised		103780	49%	51%	3%	21%	4%	21%	13%	9%	96%
P3c	Dementia -total		180470									
P4	Mental and behavioural disorders due to use of alcohol (incl. alcohol dependence)	11520	173030	24%	76%	81%	24%	2%	1%		21%	
P5	Schizophrenia, schizotypical and delusional disorders	7330	111940	35%	65%	74%	6%	3%	0%		57%	
P6	Mood (affective) disorders	52580	787410	16%	84%	86%	2%	1%	0%		28%	
P7	Anxiety disorders	36800	551110	7%	93%	91%	2%	1%	0%		14%	
P8	Parkinson's disease	3590	54440	73%	27%	81%	27%	61%	4%	76%		
P9	Multiple sclerosis	2100	31130	71%	29%	84%	35%	80%	1%			
P10	Epilepsy	10290	154150	56%	44%	73%	23%	60%	1%	32%		
P12	Hypertensive diseases	168250	2516120	16%	84%	93%	18%	7%	0%			
P13	Ischaemic heart diseases	55660	835530	50%	50%	80%	35%	56%	2%			
P16	Heart failure	19810	304570	40%	60%	65%	35%	52%	8%			
P18	Cerebrovascular diseases	22200	335110	38%	62%	78%	35%	44%	4%			
P21	Asthma	76000	1137830	16%	84%	94%	5%	18%	0%			
P22	Chronic lower respiratory diseases other than asthma (incl. COPD)	37920	567730	33%	67%	88%	29%	28%	2%			
P23	Chronic obstructive pulmonary disease (COPD)	33590	502530	35%	65%	88%	30%	29%	2%			

[7] Dementia (incl. Alzheimer's disease). Noninstitutionalised: cases found in the Nivel-PCD-population ecluding cases using institutionalized long term care; Institutionalised: cases found in institutionalized population; total: cases found in institutionalized added with number cases in Nivel-PCD extrapolated to the noninstitutionalized population.

		Number of cases in		share of cases found in:		Share of cases found per source:						
		Nivel-PCD-population	**total resident population**	**more than one source**	**one source**	**Nivel-PCD**	**HDR**	**DTC-SSC**	**CoD**	**Medicines**	**DTC-MHC**	**LTC-E CIZ**
P26	diseases of liver	8180	122600	20%	80%	49%	33%	42%	2%			
P27	Rheumatoid arthritis	n.a.	86720	19%	81%		27%	92%	1%			
P28	Arthrosis	67840	1016990	33%	67%	74%	17%	52%	0%			
P29	Osteoporosis	30500	459190	15%	85%	66%	30%	20%	0%			
P30	Renal failure	n.a.	224900	25%	75%		63%	58%	5%			

6.4 Results per indicator, overlap between sources

Indicator: P1 Diabetes mellitus, incidence per person

Pilot Number:	P1
Disease:	Diabetes Mellitus
Measure:	Incidence by person
Definition:	ICD10: E10-E14
Data refer to:	2016

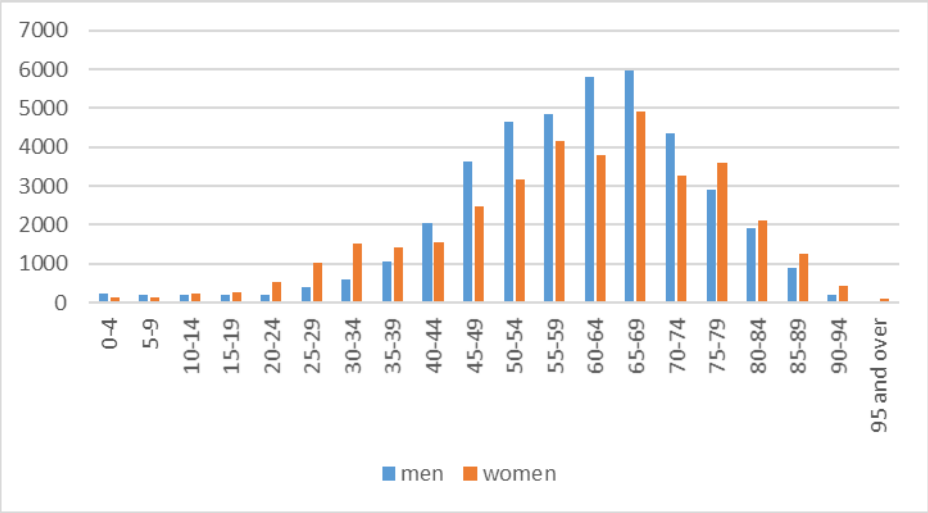
Total number of cases in total resident population:	76350
Total number of cases in Nivel-PCD:	5130

Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	4170	81%
HDR: Hospital discharge register	630	12%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	390	8%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication	2490	48%
CoD: Causes of Death	30	1%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional cases found:		**Added cases:**	**%**	**Cum%**
1	Nivel-PCD	4170	81%	81%
2	Medication	610	12%	93%
3	HDR	250	5%	98%
4	DTC-SSC	100	2%	100%
5	CoD	20	0%	100%

Overlap of sources:								
	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD	2240	310	230		1880	10		4170
HDR	310	230	170		350	10		630
DTC-SSC	230	170	100		270	0		390
DTC-MHC								
Medication	1880	350	270		500	10		2490
CoD	10	10	0		10	20		30
LTC-E CIZ								
Total								5130

Number of resident cases (total population) by age and sex,
P1 Diabetes mellitus, incidence per person



Indicator: P2 Diabetes mellitus, prevalence

Pilot Number:	P2
Disease:	Diabetes Mellitus
Measure:	prevalence
Definition:	ICD10: E10-E14
Data refer to:	2016

Total number of cases in total resident population:	1104890
Total number of cases in Nivel-PCD:	73670

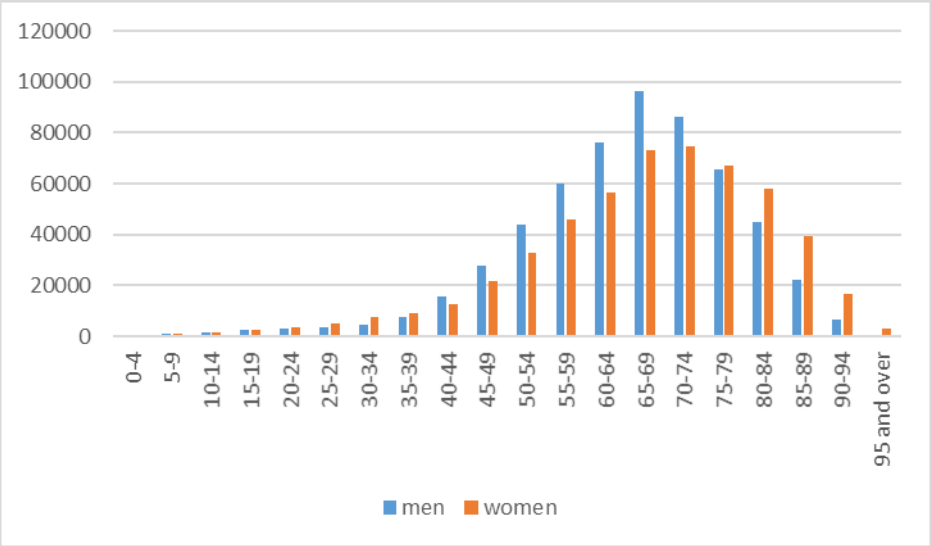
Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	70220	95%
HDR: Hospital discharge register	17590	24%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	16850	23%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication	59360	81%
CoD: Causes of Death	620	1%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional cases found:		**Added cases:**	**%**	**Cum%**
1	Nivel-PCD	70220	95%	95%
2	Medication	2420	3%	99%
3	HDR	690	1%	100%
4	DTC-SSC	330	0%	100%
5	CoD	20	0%	100%

Overlap of sources:

	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD	11880	16460	15780		56940	580		70220
HDR	16460	660	6620		15720	390		17590
DTC-SSC	15780	6620	330		16210	230		16850
DTC-MHC								
Medication	56940	15720	16210		1490	550		59360
CoD	580	390	230		550	20		620
LTC-E CIZ								
Total								73670

Number of resident cases (total population) by age and sex,
P2 Diabetes mellitus, prevalence



Indicator: P3 Dementia (incl. Alzheimer's disease), prevalence

Pilot Number:	P3
Disease:	Dementia (incl. Alzheimer's disease)
Measure:	prevalence
Definition:	ICD10: F00-F03, G30,G31
Data refer to:	2016

Total number of cases in total resident population:	180470
Total number of cases in institutionalized population:	103780
Total number of cases in Nivel-PCD (excluding institutionalized population):	5600
Total number of cases in non-institutionalized population (extrapolated from the noninstitutionalized Nivel-PCD population:	76690

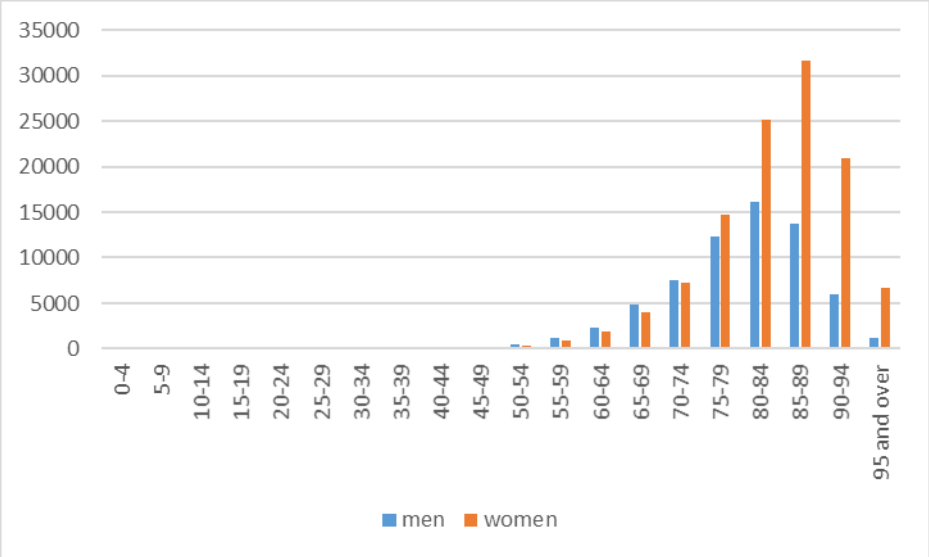
Cases per source, non-institutionalized Nivel-PCD population:	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	4120	74%
HDR: Hospital discharge register	1000	18%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	870	16%
DTC-MHC: Diagnosis treatment combinations Mental Health Care	560	10%
Medication	1470	26%
CoD: Causes of Death	260	5%
LTC-E CIZ: Long term care eligibility decisions	1390	25%

Sources in order of additional cases found in non-institutionalized Nivel-PCD population		**Added cases:**	**%**	**Cum%**
1	Nivel-PCD	4120	74%	74%
2	Medication	430	8%	81%
3	LTC-E CIZ	350	6%	87%
4	DTC-SSC	320	6%	93%
5	HDR	270	5%	98%
6	DTC-MHC	70	1%	99%
7	CoD	40	1%	100%

Overlap of sources, non-institutionalized Nivel-PCD population:								
	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	total
Nivel-PCD	1740	630	500	420	1050	170	1000	4120
HDR	630	250	120	90	270	80	290	1000
DTC-SSC	500	120	300	90	300	20	100	870
DTC-MHC	420	90	90	70	160	30	170	560
Medication	1050	270	300	160	300	60	310	1470
CoD	170	80	20	30	60	40	120	260
LTC-E CIZ	1000	290	100	170	310	120	270	1390
Total								5600

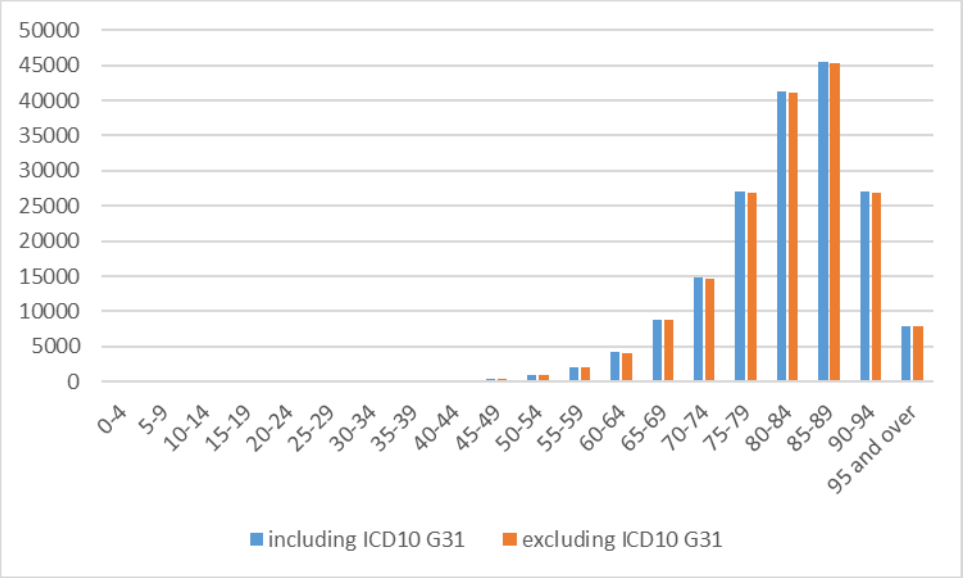
Overlap of sources, institutionalized population:								
	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	total
Nivel-PCD	200	840	200	450	640	600	3100	3370
HDR	840	1380	1400	2530	4050	4880	20010	21800
DTC-SSC	200	1400	250	740	1690	650	3990	4320
DTC-MHC	450	2530	740	270	2270	1850	9330	9730
Medication	640	4050	1690	2270	900	2470	12760	13900
CoD	600	4880	650	1850	2470	1000	20480	21770
LTC-E CIZ	3100	20010	3990	9330	12760	20480	49350	99200
Total								103780

Number of resident cases (total population) by age and sex,
P3 Dementia (incl. Alzheimer's disease), prevalence



Issue:

In the ICD10-definition only G30 is included and not G31. Our specialists indicated that G31 also should be included, to included also diseases as Pick disease and Lewy bodies disease, belonging to a more 'modern' interpretation of dementia. We compared total numbers using both variations.
Result: adding ICD10 G31 resulted in a 0,6% increase of the total number of prevalent cases found. We decided to follow the advice of our specialists.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40000
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30000
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10000
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0-4
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10-14
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25-29
30-34
35-39
40-44
45-49
50-54
55-59
60-64
65-69
70-74
75-79
80-84
85-89
90-94
95 and over
including ICD10 G31
excluding ICD10 G31

Indicator: P4 Mental and behavioural disorders due to use of alcohol (incl. alcohol dependence), prevalence

Pilot Number:	P4
Disease:	Mental and behavioural disorders due to use of alcohol (incl. alcohol dependence), prevalence
Measure:	prevalence
Definition:	ICD10: F10
Data refer to:	2016

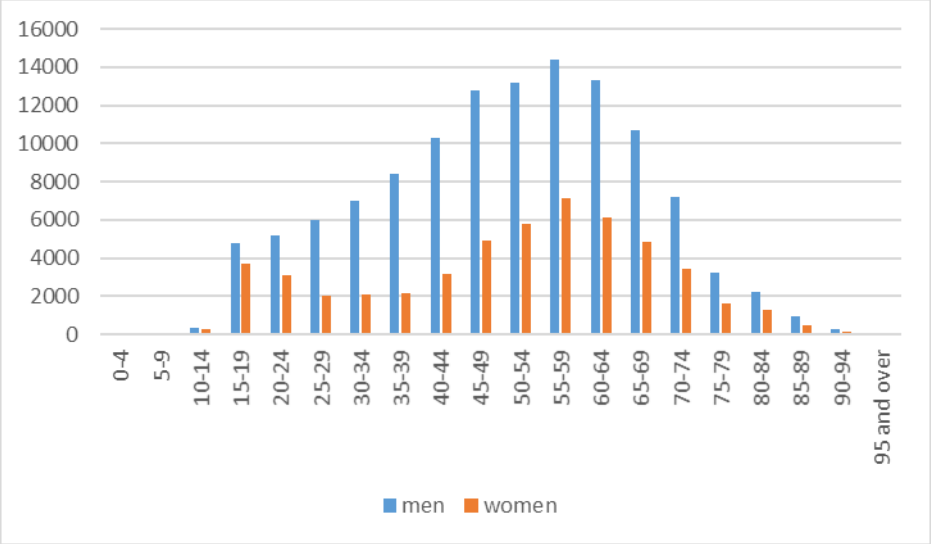
Total number of cases in total resident population:	173030
Total number of cases in Nivel-PCD:	11520

Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	9330	81%
HDR: Hospital discharge register	2740	24%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	200	2%
DTC-MHC: Diagnosis treatment combinations Mental Health Care	2370	21%
Medication		
CoD: Causes of Death	110	1%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional cases found:		**Added cases:**	**%**	**Cum%**
1	Nivel-PCD	9330	81%	81%
2	HDR	1560	14%	95%
3	DTC-MHC	560	5%	99%
4	CoD	40	0%	100%
5	DTC-SSC	30	0%	100%

Overlap of sources:								
	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD	6700	1180	140	1740		50		9330
HDR	1180	1460	120	400		40		2740
DTC-SSC	140	120	30	60		0		200
DTC-MHC	1740	400	60	560		20		2370
Medication								
CoD	50	40	0	20		40		110
LTC-E CIZ								
Total								11520

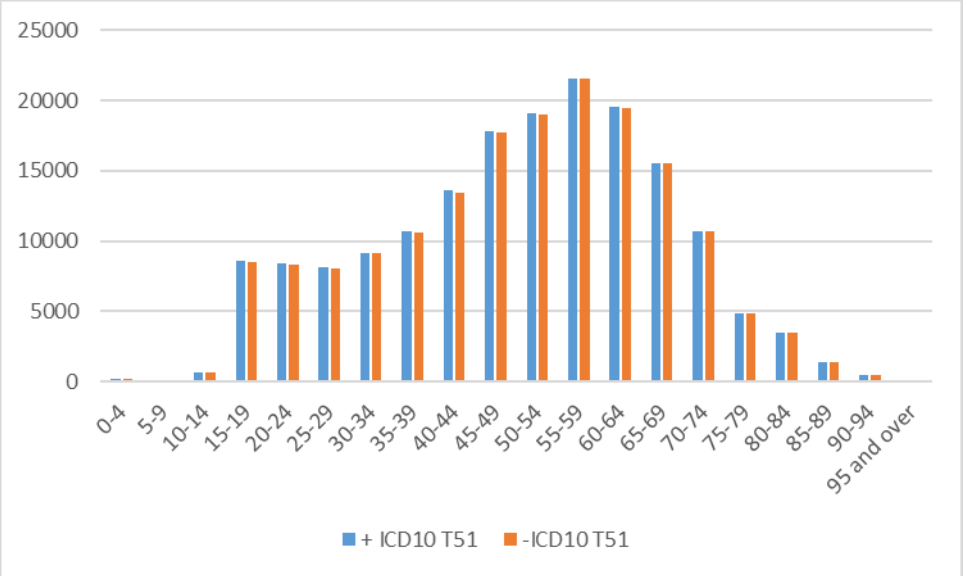
Number of resident cases (total population) by age and sex,
P4 Mental and behavioural disorders due to use of alcohol (incl. alcohol dependence), prevalence



Issue:

ICD10-code T51(Toxic effect of alcohol) was used frequently in DTC-SSC to indicate binge drinking. Analyses performed to study the effect of inclusion of T51 in HDR and CoD
Result: the effect was very small. It introduced some cases at very young age. Is was decided not to include T51 in HDR and CoD

P4 Mental and behavioural disorders due to use of alcohol (incl. alcohol dependence), prevalence with and without inclusion of ICD10 T51 (total residents).



Indicator: P5 Schizophrenia, schizotypical and delusional disorders, prevalence

Pilot Number:	P5
Disease:	Schizophrenia, schizotypical and delusional disorders
Measure:	prevalence
Definition:	ICD10: F20-F29
Data refer to:	2016

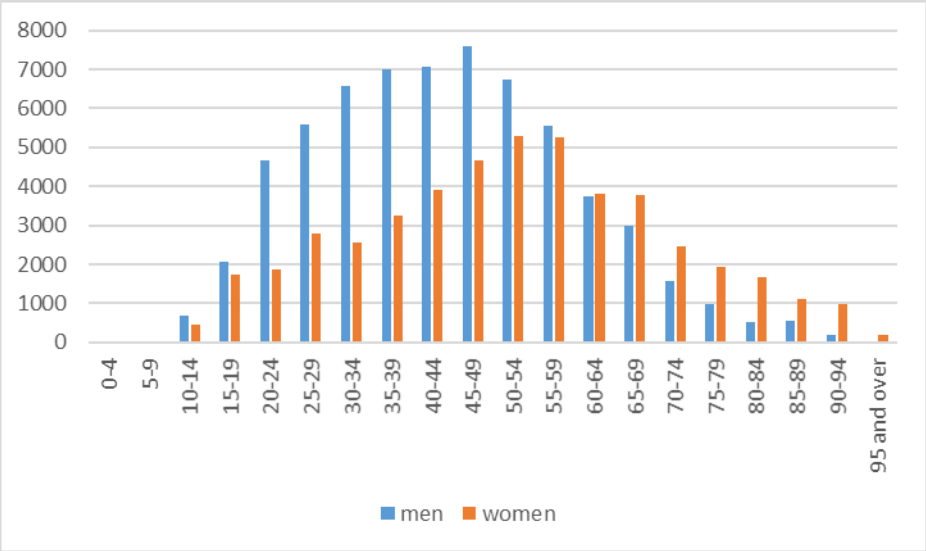
Total number of cases in total resident population:	111940
Total number of cases in Nivel-PCD:	7330

Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	5430	74%
HDR: Hospital discharge register	420	6%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	180	3%
DTC-MHC: Diagnosis treatment combinations Mental Health Care	4170	57%
Medication		
CoD: Causes of Death	20	0%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional cases found:		**Added cases:**	**%**	**Cum%**
1	Nivel-PCD	5430	74%	74%
2	DTC-MHC	1770	24%	98%
3	HDR	100	1%	100%
4	DTC-SSC	30	0%	100%
5	CoD	0	0%	100%

Overlap of sources:								
	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD	2970	240	110	2400		10		5430
HDR	240	90	80	280		10		420
DTC-SSC	110	80	30	120		0		180
DTC-MHC	2400	280	120	1670		10		4170
Medication								
CoD	10	10	0	10		0		20
LTC-E CIZ								
Total								7330

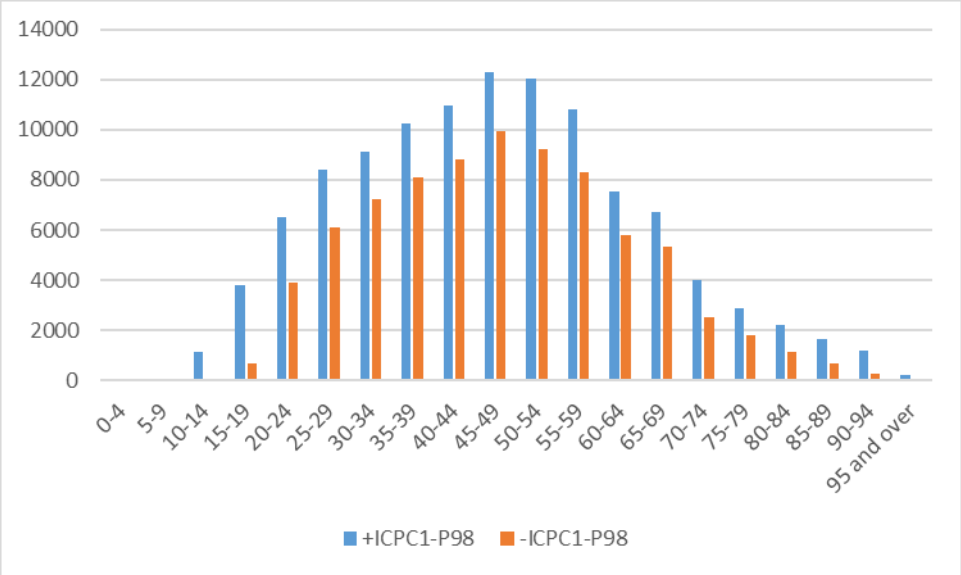
Number of resident cases (total population) by age and sex,
P5 Schizophrenia, schizotypical and delusional disorders, prevalence



Issue:

In the manual, page 102, ICPC-1 code '72' was suggested for Indicator P5. This should be **P**72 (Schizophrenia). But, the ICD10-definition includes also 'schizotypical and delusional disorders', ICD10 F20-F29, not only F20 (schizophrenia). Therefore, also ICPC-1 P98 (Psychosis NOS/other) was included.
Result: the number of prevalent cases increased with 40% by inclusion of ICPC-1 P98. Due to the description of the indicator we decided that P98 should be included, as presented above.

P5 Schizophrenia, schizotypical and delusional disorders, prevalence, with and without the inclusion of ICPC-1 code P98 (Psychosis NOS/other).



Indicator: P6 Mood (affective) disorders, prevalence

Pilot Number:	P6
Disease:	Mood (affective) disorders
Measure:	prevalence
Definition:	ICD10: F30-F39
Data refer to:	2016

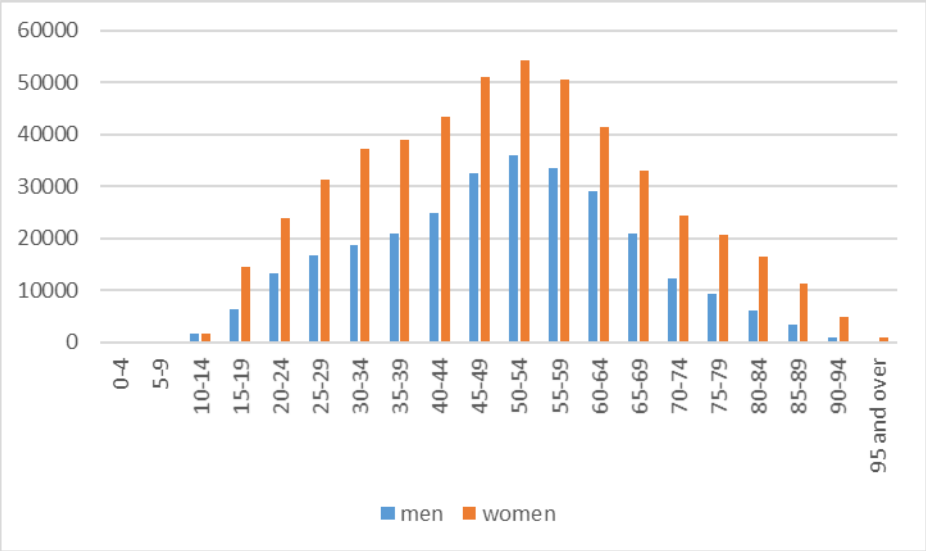
Total number of cases in total resident population:	787410
Total number of cases in Nivel-PCD:	52580

Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	45360	86%
HDR: Hospital discharge register	1220	2%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	780	1%
DTC-MHC: Diagnosis treatment combinations Mental Health Care	14530	28%
Medication		
CoD: Causes of Death	60	0%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional cases found:		**Added cases:**	**%**	**Cum%**
1	Nivel-PCD	45360	86%	86%
2	DTC-MHC	6620	13%	99%
3	HDR	350	1%	100%
4	DTC-SSC	230	0%	100%
5	CoD	20	0%	100%
6				
7				

Overlap of sources:								
	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD	36940	740	420	7910		30		45360
HDR	740	310	210	530		10		1220
DTC-SSC	420	210	230	290		0		780
DTC-MHC	7910	530	290	6430		10		14530
Medication								
CoD	30	10	0	10		20		60
LTC-E CIZ								
Total								52580

Number of resident cases (total population) by age and sex,
P6 Mood (affective) disorders, prevalence



Indicator: P7 Anxiety disorders, prevalence

Pilot Number:	P7
Disease:	Anxiety disorders
Measure:	prevalence
Definition:	ICD10: F40, F41
Data refer to:	2016

Total number of cases in total resident population:	551110
Total number of cases in Nivel-PCD:	36800

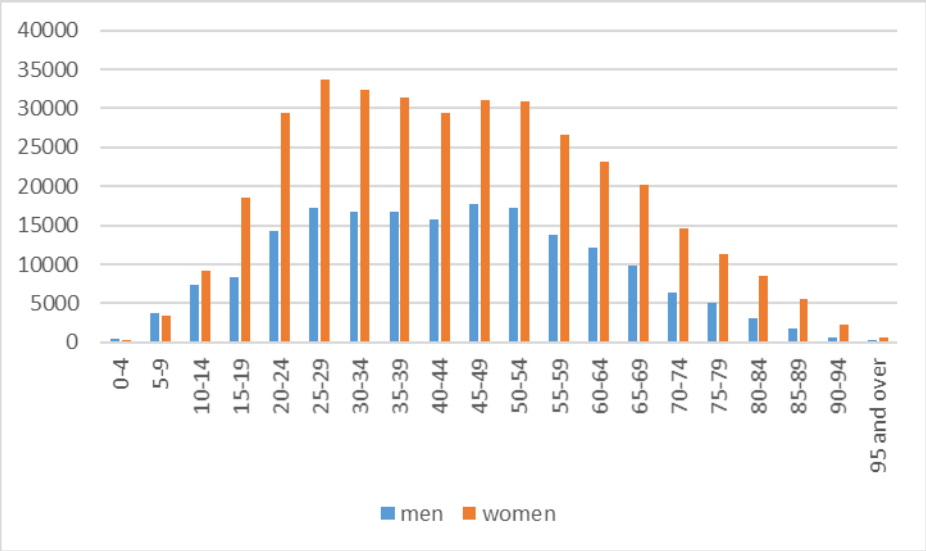
Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	33550	91%
HDR: Hospital discharge register	620	2%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	280	1%
DTC-MHC: Diagnosis treatment combinations Mental Health Care	5120	14%
Medication		
CoD: Causes of Death	10	0%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional cases found:		**Added cases:**	**%**	**Cum%**
1	Nivel-PCD	33550	91%	91%
2	DTC-MHC	2740	7%	99%
3	HDR	370	1%	100%
4	DTC-SSC	140	0%	100%
5	CoD	0	0%	100%

Overlap of sources:

	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD	30930	220	100	2380		0		33550
HDR	220	350	60	70		0		620
DTC-SSC	100	60	140	40				280
DTC-MHC	2380	70	40	2700				5120
Medication								
CoD	0	0				0		10
LTC-E CIZ								
Total								36800

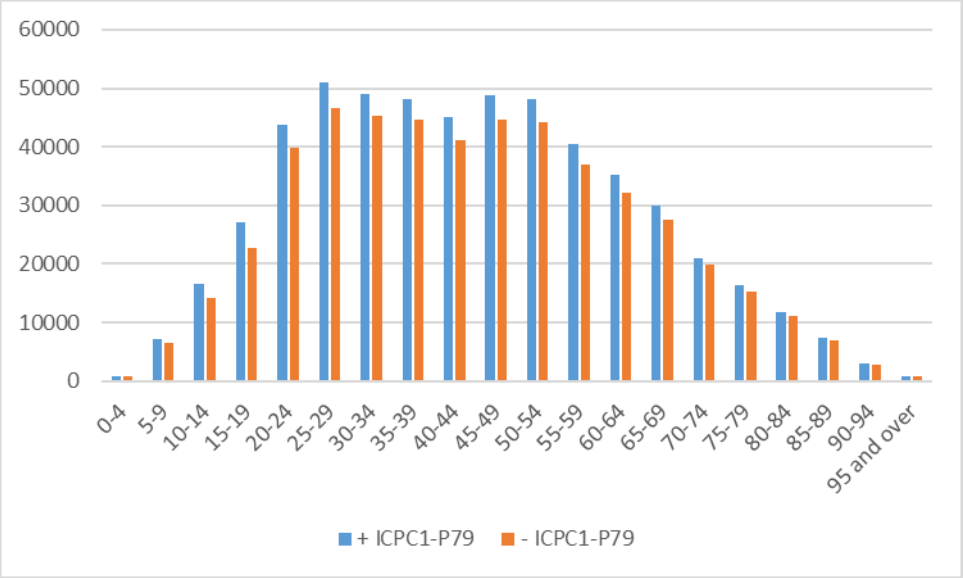
Number of resident cases (total population) by age and sex,
P7 Anxiety disorders, prevalence



Issue:

In the manual, page 103, ICPC-2 code P74 (anxiety disorder/anxiety state) and P79 (phobia/compulsive disorder) were suggested for Indicator P7. For ICPC-1 only P74 (Anxiety disorder/anxiety state) was proposed. However, the description of P79 in ICPC-1 (Other neurosis, 01. Phobia 02. Compulsive neurosis) is almost equal to ICPC-2.
Result: the number of prevalent cases increased with 9% by inclusion of ICPC-1 P79. Based on the description of the indicator and the advice to use also ICPC-2 P79 we decided that P79 should be included, as presented above.

P7 Anxiety disorders, prevalence, with and without the inclusion of ICPC-1 code P79 (Other neurosis).



Indicator: P8 Parkinson's disease, prevalence

Pilot Number:	P8
Disease:	Parkinson's disease
Measure:	prevalence
Definition:	ICD10: G20
Data refer to:	2016

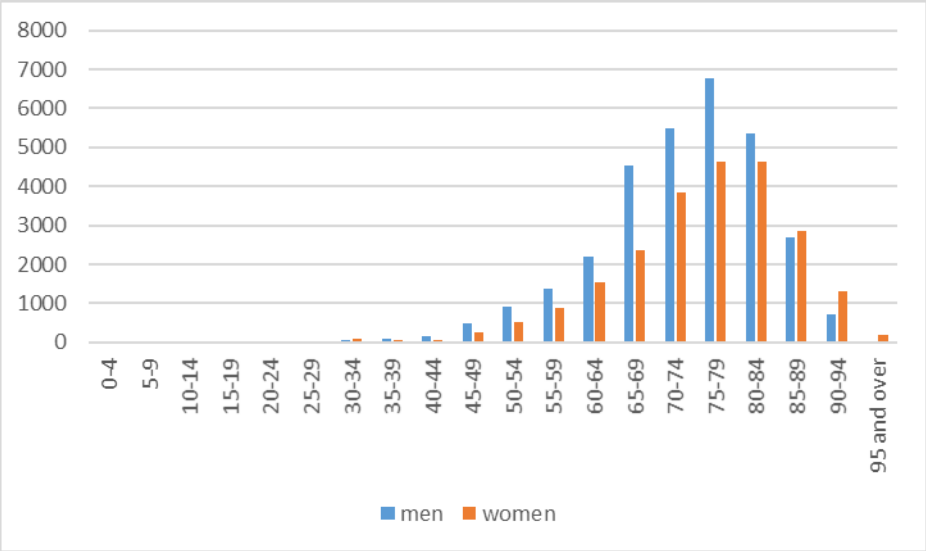
Total number of cases in total resident population:	54440
Total number of cases in Nivel-PCD:	3590

Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	2910	81%
HDR: Hospital discharge register	970	27%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	2170	61%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication	2740	76%
CoD: Causes of Death	130	4%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional cases found:		**Added cases:**	**%**	**Cum%**
1	Nivel-PCD	2910	81%	81%
2	Medication	480	13%	95%
3	HDR	110	3%	98%
4	DTC-SSC	80	2%	100%
5	CoD	10	0%	100%

Overlap of sources:								
	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD	500	800	1930		2260	120		2910
HDR	800	110	710		810	90		970
DTC-SSC	1930	710	80		1970	90		2170
DTC-MHC								
Medication	2260	810	1970		290	120		2740
CoD	120	90	90		120	10		130
LTC-E CIZ								
Total								3590

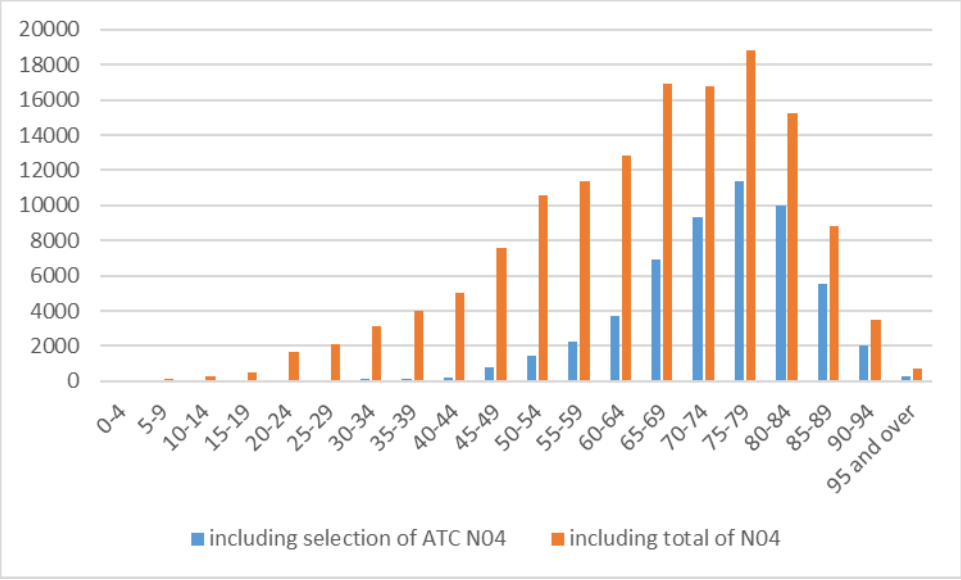
Number of resident cases (total population) by age and sex,
P8 Parkinson's disease, prevalence



Issue:

In the manual, page 104, medication of ATC-group N04 (anti-Parkinson drugs) is suggested for use. However, the number of cases found increases tremendously using the full group N04. Some of the medicines in the group are known to be used for other health problems.
Result: the number of prevalent cases would increase with 157% if the full group of N04 anti-Parkinson drugs would be included. 70 percent of cases using N04 medication are not known with Parkinson's disease in any other source.

P8 Parkinson's disease, prevalence, including the total of ATC-group N04 or only a selection



Indicator: P9 Multiple sclerosis, prevalence

Pilot Number:	P9
Disease:	Multiple sclerosis
Measure:	prevalence
Definition:	ICD10: G35
Data refer to:	2016

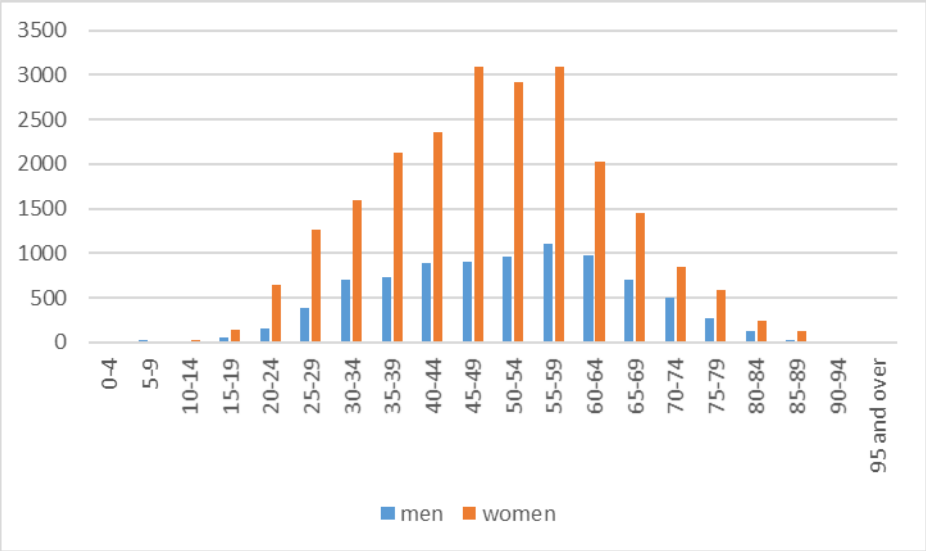
Total number of cases in total resident population:	31130
Total number of cases in Nivel-PCD:	2100

Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	1750	84%
HDR: Hospital discharge register	740	35%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	1670	80%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication		
CoD: Causes of Death	10	1%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional cases found:		**Added cases:**	**%**	**Cum%**
1	Nivel-PCD	1750	84%	84%
2	DTC-SSC	320	15%	99%
3	HDR	30	1%	100%

Overlap of sources:								
	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD	310	660	1350			10		1750
HDR	660	30	630			10		740
DTC-SSC	1350	630	260			10		1670
DTC-MHC								
Medication								
CoD	10	10	10					10
LTC-E CIZ								
Total								2100

Number of resident cases (total population) by age and sex,
P9 Multiple sclerosis, prevalence



Indicator: P10 Epilepsy, prevalence

Pilot Number:	P10
Disease:	Epilepsy
Measure:	prevalence
Definition:	ICD10: G40, G41
Data refer to:	2016

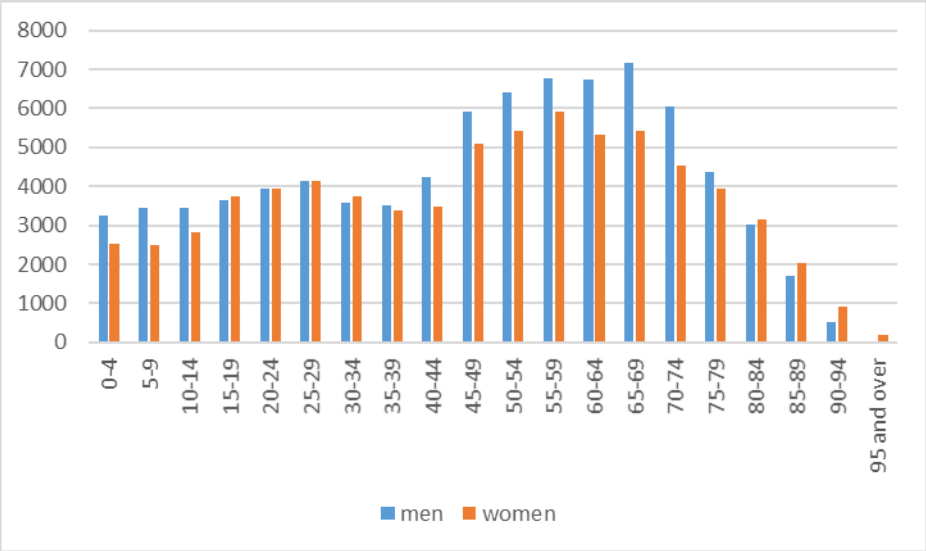
Total number of cases in total resident population:	154150
Total number of cases in Nivel-PCD:	10290

Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	7560	73%
HDR: Hospital discharge register	2320	23%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	6210	60%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication	3320	32%
CoD: Causes of Death	60	1%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional cases found:		**Added cases:**	**%**	**Cum%**
1	Nivel-PCD	7560	73%	73%
2	DTC-SSC	1890	18%	92%
3	Medication	540	5%	97%
4	HDR	290	3%	100%
5	CoD	10	0%	100%

Overlap of sources:								
	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD	2530	1520	4320		2340	30		7560
HDR	1520	280	1610		1140	40		2320
DTC-SSC	4320	1610	1260		2240	30		6210
DTC-MHC								
Medication	2340	1140	2240		410	30		3320
CoD	30	40	30		30	10		60
LTC-E CIZ								
Total								10290

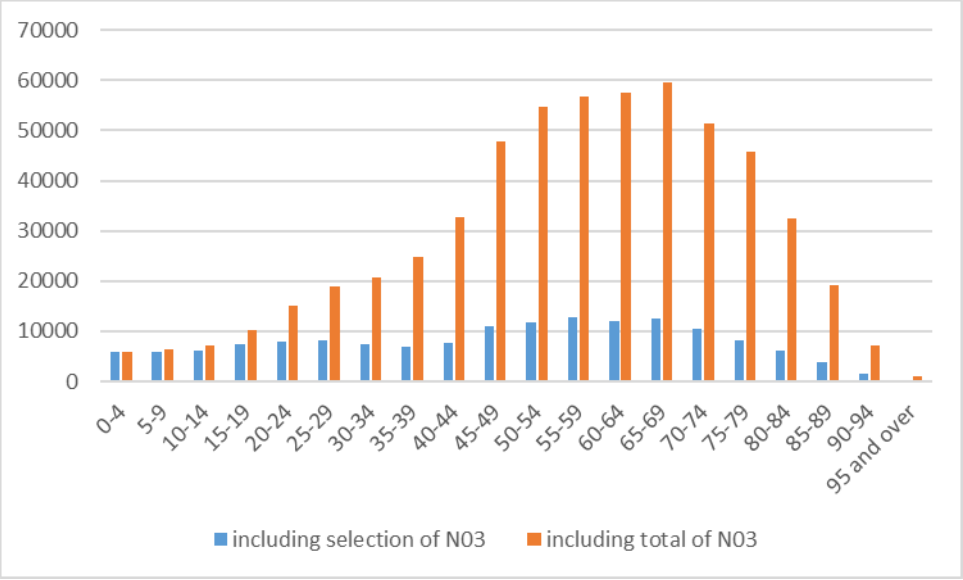
Number of resident cases (total population) by age and sex,
P10 Epilepsy, prevalence



Issue:

In the manual, page 105, medication of ATC-group N03 (anti-epileptics) is suggested for use. However, the number of cases found increases tremendously using the full group N03. Some of the medicines in the group are known to be used for other health problems.
Result: the number of prevalent cases would increase with 270% if the full group of N03 anti-epileptics would be included. 80 percent of cases using N03 medication is not known with epilepsy in any other source.

P10 Epilepsy, prevalence, including the total of ATC-group N03 or only a selection



Indicator: P11 Hypertensive diseases, incidence per person

Pilot Number:	P11
Disease:	Hypertensive diseases
Measure:	incidence per person
Definition:	ICD10: I10-I13, I15
Data refer to:	2016

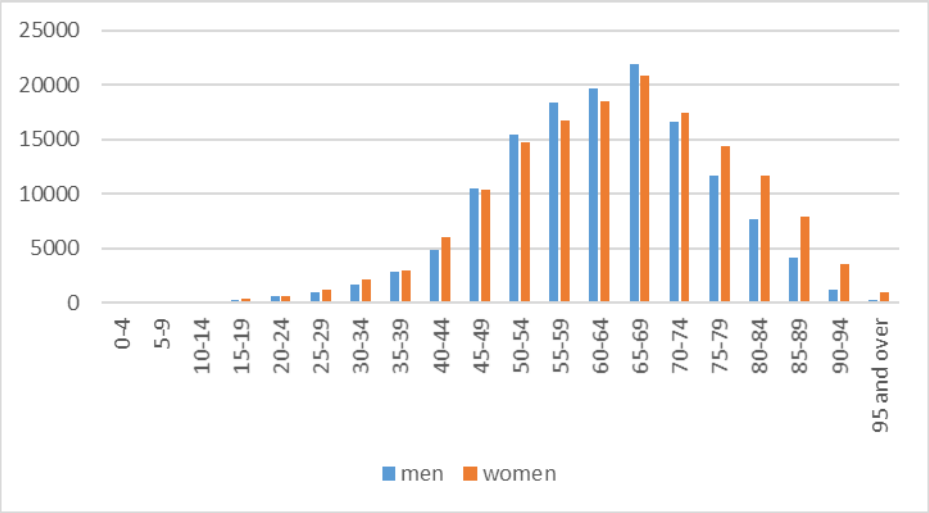
Total number of cases in total resident population:	289310
Total number of cases in Nivel-PCD:	19390

Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	15950	82%
HDR: Hospital discharge register	3850	20%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	920	5%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication		
CoD: Causes of Death	130	1%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional cases found:		**Added cases:**	**%**	**Cum%**
1	Nivel-PCD	15950	82%	82%
2	HDR	2960	15%	98%
3	DTC-SSC	400	2%	100%
4	CoD	90	0%	100%

Overlap of sources:								
	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD	14780	890	410			10		15950
HDR	890	2820	240			40		3850
DTC-SSC	410	240	400			0		920
DTC-MHC								
Medication								
CoD	10	40	0			90		130
LTC-E CIZ								
Total								19390

Number of resident cases (total population) by age and sex,
P11 Hypertensive diseases, incidence per person



Indicator: P12 Hypertensive diseases, prevalence

Pilot Number:	P12
Disease:	Hypertensive diseases
Measure:	prevalence
Definition:	ICD10: I10-I13, I15
Data refer to:	2016

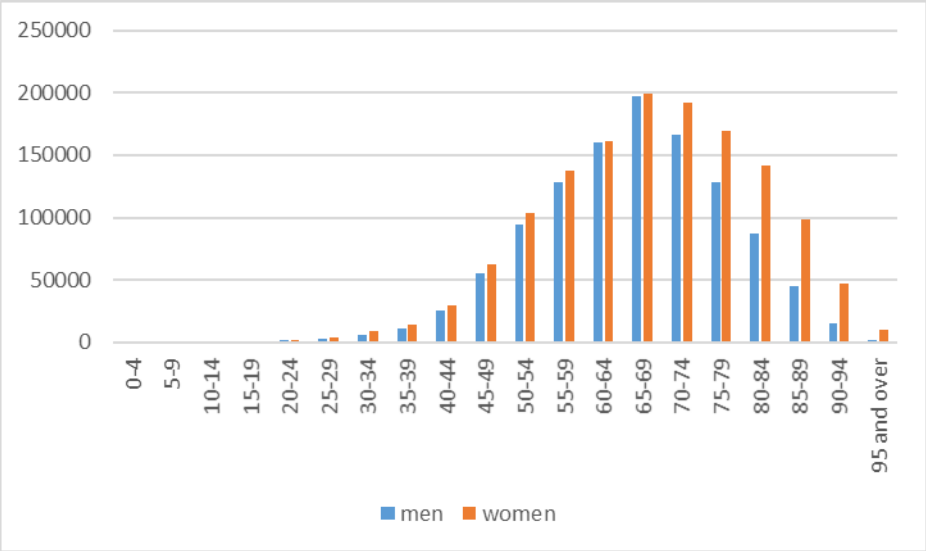
Total number of cases in total resident population:	2516120
Total number of cases in Nivel-PCD:	168250

Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	156810	93%
HDR: Hospital discharge register	29820	18%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	11350	7%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication		
CoD: Causes of Death	430	0%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional cases found:		**Added cases:**	**%**	**Cum%**
1	Nivel-PCD	156810	93%	93%
2	HDR	9330	6%	99%
3	DTC-SSC	2030	1%	100%
4	CoD	90	0%	100%

Overlap of sources:								
	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD	130120	20490	8680			280		156810
HDR	20490	8640	3300			160		29820
DTC-SSC	8680	3300	2030			20		11350
DTC-MHC								
Medication								
CoD	280	160	20			90		430
LTC-E CIZ								
Total								168250

Number of resident cases (total population) by age and sex,
P12 Hypertensive diseases, prevalence



Indicator: P13 Ischaemic heart diseases, prevalence

Pilot Number:	P13
Disease:	Ischaemic heart diseases
Measure:	prevalence
Definition:	ICD10: I20-I25
Data refer to:	2016

Total number of cases in total resident population:	835530
Total number of cases in Nivel-PCD:	55660

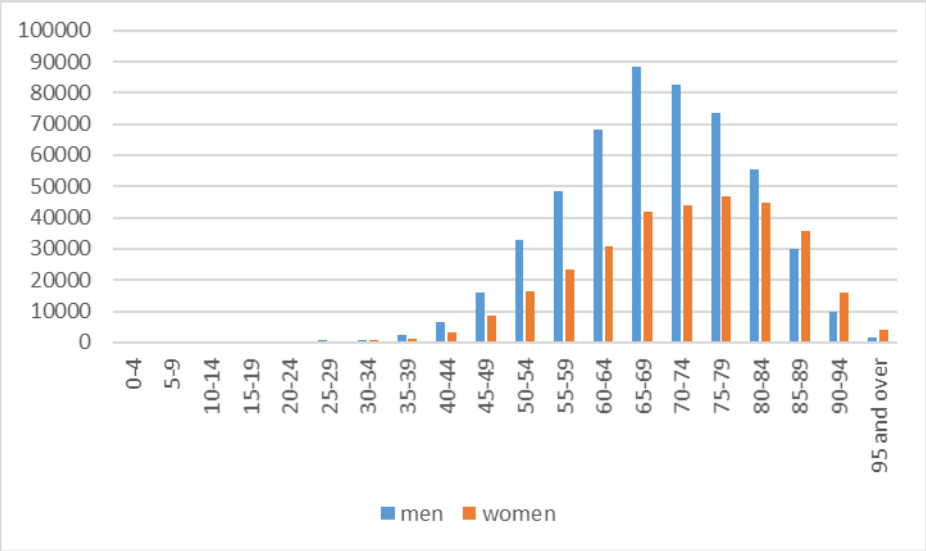
Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	44304	80%
HDR: Hospital discharge register	19293	35%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	31026	56%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication		
CoD: Causes of Death	847	2%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional cases found:		**Added cases:**	**%**	**Cum%**
1	Nivel-PCD	44300	80%	80%
2	DTC-SSC	8740	16%	95%
3	HDR	2330	4%	100%
4	CoD	280	0%	100%

Overlap of sources:

	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD	18740	14600	22290			390		44300
HDR	14600	2250	13790			400		19290
DTC-SSC	22290	13790	6360			280		31030
DTC-MHC								
Medication								
CoD	390	400	280			280		850
LTC-E CIZ								
Total								55660

Number of resident cases (total population) by age and sex,
P13 Ischaemic heart diseases, prevalence



Indicator: P14/P15 Acute myocardial infarction, incidence per episode (P14) and per person (P15)

Pilot Number:	P14/P15
Disease:	Acute myocardial infarction
Measure:	incidence per episode, per person
Definition:	ICD10: I21, I22
Data refer to:	2016

Total number of episodes in total resident population:	39840
Total number of persons in total resident population:	38540

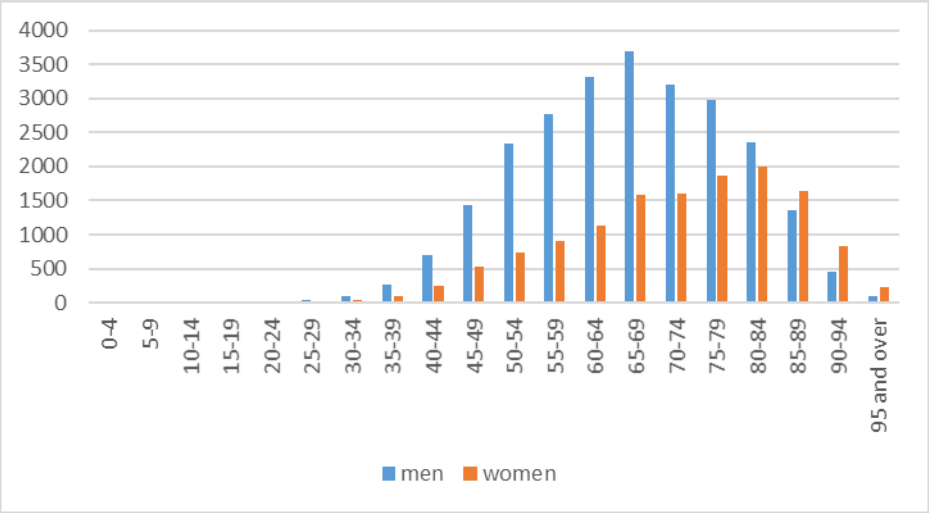
Episodes per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database		
HDR: Hospital discharge register	28200	71%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	27310	69%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication		
CoD: Causes of Death	6520	16%
LTC-E CIZ: Long term care eligibility decisions		
Persons per source		
Nivel-PCD: Nivel Primary Care Database		
HDR: Hospital discharge register	27720	72%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	26490	69%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication		
CoD: Causes of Death	6520	17%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional persons found:		**Added cases:**	**%**	**Cum%**
1	DTC-SSC	27720	72%	72%
2	HDR	5570	14%	86%
3	CoD	5250	14%	100%

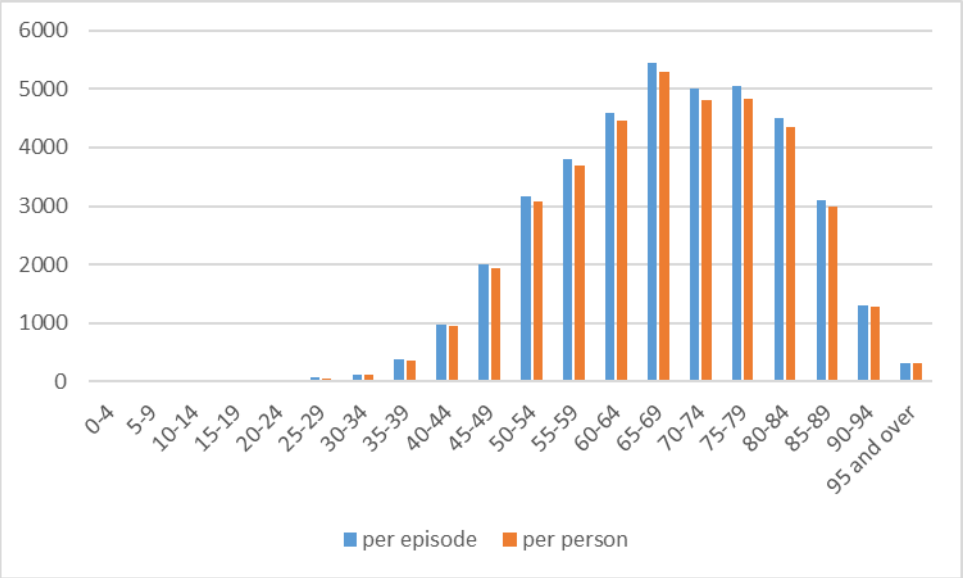
Overlap of persons in sources:

	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD								
HDR		6410	20930			960		27720
DTC-SSC		20930	5270			890		26490
DTC-MHC								
Medication								
CoD		960	890			5250		6520
LTC-E CIZ								
Total								38540

Number of resident cases (total population) by age and sex,
P15 Acute myocardial infarction, incidence per person



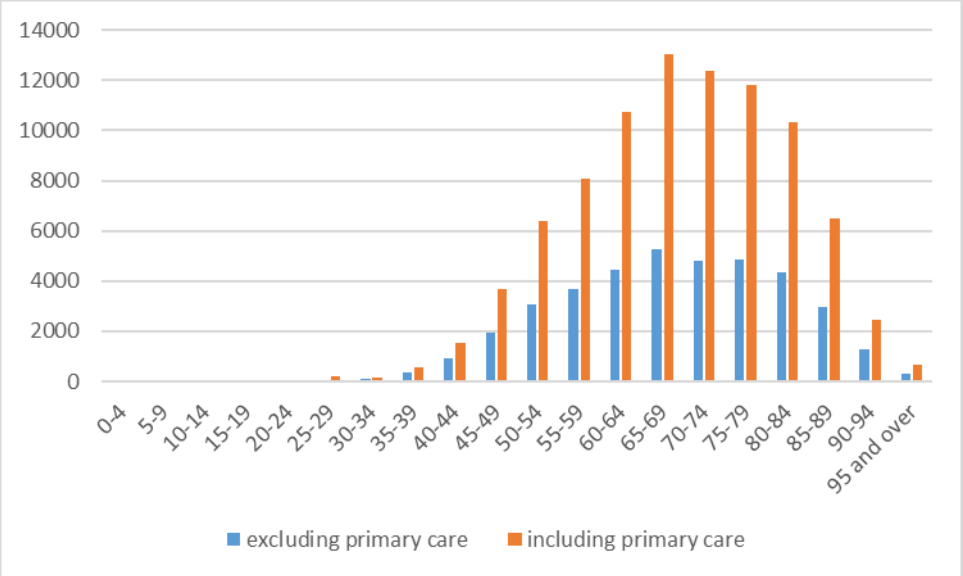
P14/P15 Acute myocardial infarction, incidence per episode and per person



Issue

Using primary care information, many incident acute myocardial infarctions were not found in hospital information or causes of death. Presumably, ICPC-code K75 (acute myocardial infarction) is also used for new (incident) episodes of care resulting from older infarctions.
Result: it seems unlikely that more than half of the acute myocardial infarctions are not presented in hospital or as a cause of death. In primary care, results indicate the reason for care provided, and less the myocardial infarction per se. It is decided not to use primary care for this indicator.

P15 Acute myocardial infarction, incidence per person, including or excluding primary care



Indicator: P16 Heart failure, prevalence

Pilot Number:	P16
Disease:	Heart failure
Measure:	prevalence
Definition:	ICD10: I50
Data refer to:	2016

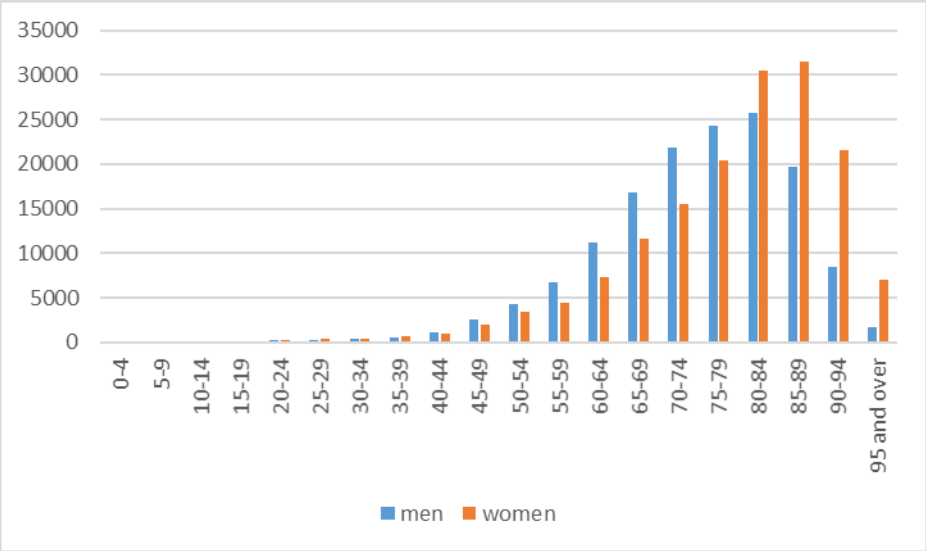
Total number of cases in total resident population:	304570
Total number of cases in Nivel-PCD:	19810

Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	12800	65%
HDR: Hospital discharge register	6870	35%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	10300	52%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication		
CoD: Causes of Death	1500	8%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional cases found:		**Added cases:**	**%**	**Cum%**
1	Nivel-PCD	12800	65%	65%
2	DTC-SSC	5050	25%	90%
3	HDR	1620	8%	98%
4	CoD	340	2%	100%

Overlap of sources:								
	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD	6200	3980	5250			920		12800
HDR	3980	1510	4180			780		6870
DTC-SSC	5250	4180	3760			630		10300
DTC-MHC								
Medication								
CoD	920	780	630			340		1500
LTC-E CIZ								
Total								19810

Number of resident cases (total population) by age and sex,
P16 Heart failure, prevalence



Issue

In the Guidelines, Annex A2, Finland recommended to expand the ICD10-definition (I50) with I11.0 (hypertensive heart disease with (congestive) heart failure), I13.0 (hypertensive heart and renal disease with (congestive) heart failure) and I13.2 (hypertensive heart and renal disease with both (congestive) heart failure and renal failure).
Result: Using this broader definition, the total amount of cases was increased by only 0,04 percent.

Indicator: P17 Stroke, incidence per person

Pilot Number:	P16
Disease:	Stroke
Measure:	incidence per person
Definition:	ICD10: I60-I64
Data refer to:	2016

Total number of cases in total resident population:	72040
Total number of cases in Nivel-PCD:	4760

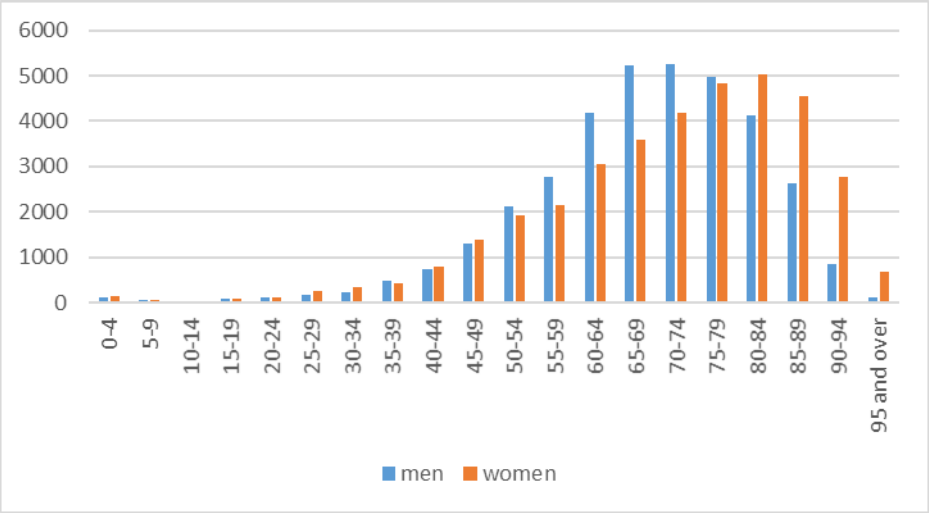
Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	3370	71%
HDR: Hospital discharge register	2010	42%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	2500	53%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication		
CoD: Causes of Death	430	9%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional cases found:		**Added cases:**	**%**	**Cum%**
1	Nivel-PCD	3370	71%	71%
2	DTC-SSC	1080	23%	93%
3	HDR	210	4%	98%
4	CoD	100	2%	100%

Overlap of sources:

	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD	1620	1400	1430			200		3370
HDR	1400	190	1500			280		2010
DTC-SSC	1430	1500	680			240		2500
DTC-MHC								
Medication								
CoD	200	280	240			100		430
LTC-E CIZ								
Total								4760

Number of resident cases (total population) by age and sex,
P17 Stroke, incidence per person



Indicator: P18 Cerebrovascular diseases, prevalence

Pilot Number:	P16
Disease:	Cerebrovascular diseases
Measure:	prevalence
Definition:	ICD10: I60-I69
Data refer to:	2016

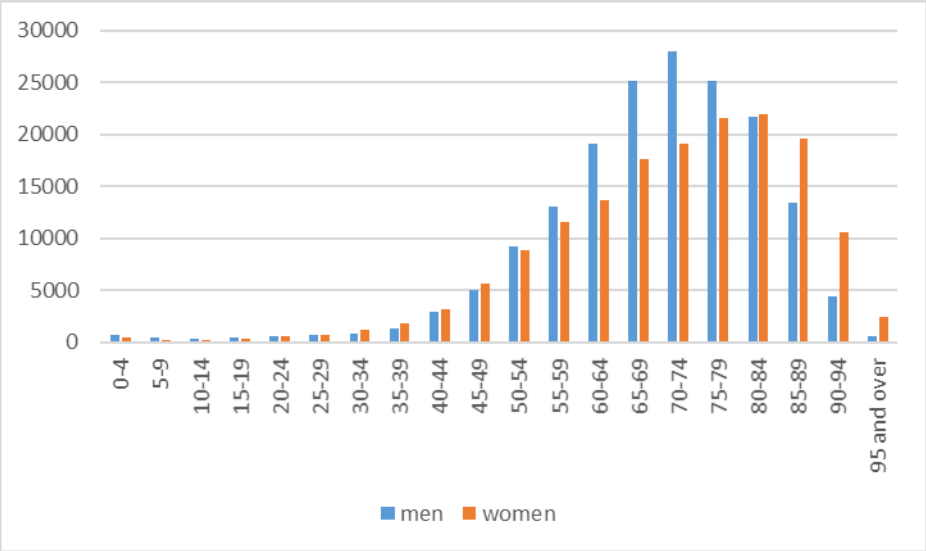
Total number of cases in total resident population:	335110
Total number of cases in Nivel-PCD:	22200

Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	17280	78%
HDR: Hospital discharge register	7720	35%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	9690	44%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication		
CoD: Causes of Death	820	4%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional cases found:		**Added cases:**	**%**	**Cum%**
1	Nivel-PCD	17280	78%	78%
2	DTC-SSC	3720	17%	95%
3	HDR	1030	5%	99%
4	CoD	160	1%	100%

Overlap of sources:								
	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD	10010	5490	5960			490		17280
HDR	5490	990	5490			520		7720
DTC-SSC	5960	5490	2520			420		9690
DTC-MHC								
Medication								
CoD	490	520	420			160		820
LTC-E CIZ								
Total								22200

Number of resident cases (total population) by age and sex,
P18 Cerebrovascular diseases, prevalence



Indicator: P19 Pneumonia, incidence per episode

Pilot Number:	P16
Disease:	Pneumonia
Measure:	incidence per episode
Definition:	ICD10: J12-J18
Data refer to:	2016

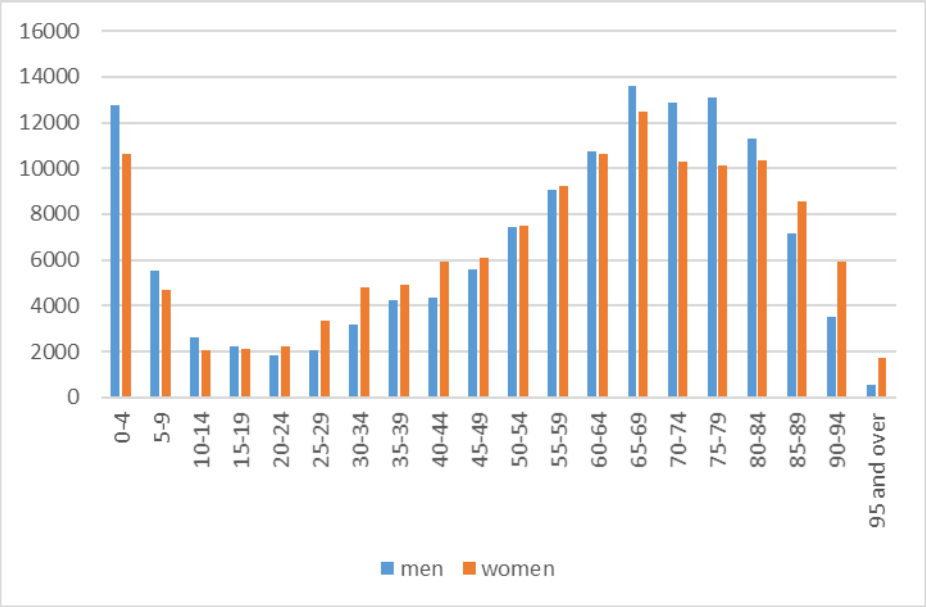
Total number of episodes in total resident population:	284240
Total number of episodes in Nivel-PCD:	18860

Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	16500	87%
HDR: Hospital discharge register	2320	12%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	2690	14%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication		
CoD: Causes of Death	840	4%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional episodes found:		**Added cases:**	**%**	**Cum%**
1	Nivel-PCD	16500	87%	87%
2	DTC-SSC	1330	7%	95%
3	HDR	590	3%	98%
4	CoD	440	2%	100%

Overlap of sources:								
	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD	14410	1340	1360			230		16500
HDR	1340	520	1120			210		2320
DTC-SSC	1360	1120	890			170		2690
DTC-MHC								
Medication								
CoD	230	210	170			460		840
LTC-E CIZ								
Total								18860

Number of resident cases (total population) by age and sex,
P19 Pneumonia, incidence per episode



Indicator: P20 Asthma, incidence per person

Pilot Number:	P20
Disease:	Asthma
Measure:	Incidence by person
Definition:	ICD10: J45, J46
Data refer to:	2016

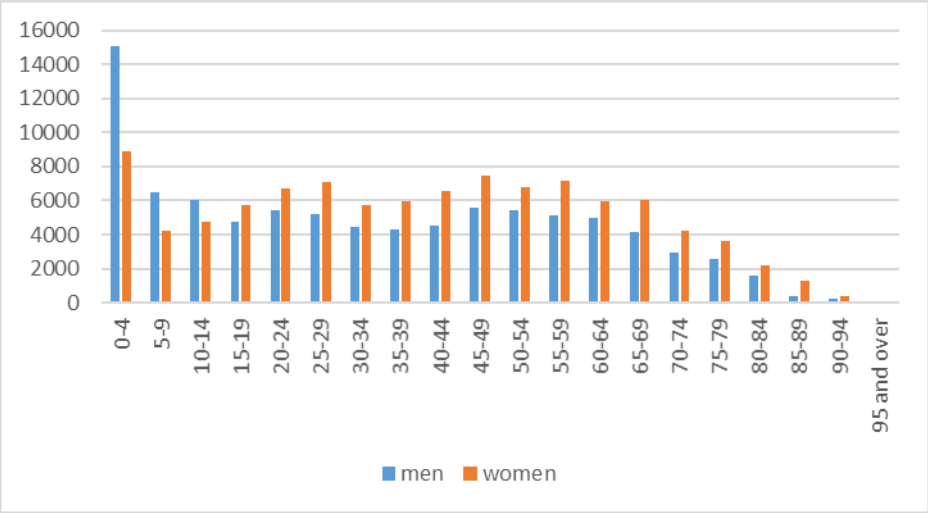
Total number of cases in total resident population:	190420
Total number of cases in Nivel-PCD:	12660

Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	11440	90%
HDR: Hospital discharge register	490	4%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	1620	13%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication		
CoD: Causes of Death	10	0%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional cases found:		**Added cases:**	**%**	**Cum%**
1	Nivel-PCD	11440	90%	90%
2	DTC-SSC	940	7%	98%
3	HDR	270	2%	100%
4	CoD	10	0%	100%

Overlap of sources:								
	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD	10660	180	680					11440
HDR	180	270	130					490
DTC-SSC	680	130	900					1620
DTC-MHC								
Medication								
CoD						10		10
LTC-E CIZ								
Total								12660

Number of resident cases (total population) by age and sex,
P20 Asthma, incidence per person



Indicator: P21 Asthma, prevalence

Pilot Number:	P21
Disease:	Asthma
Measure:	prevalence
Definition:	ICD10: J45, J46
Data refer to:	2016

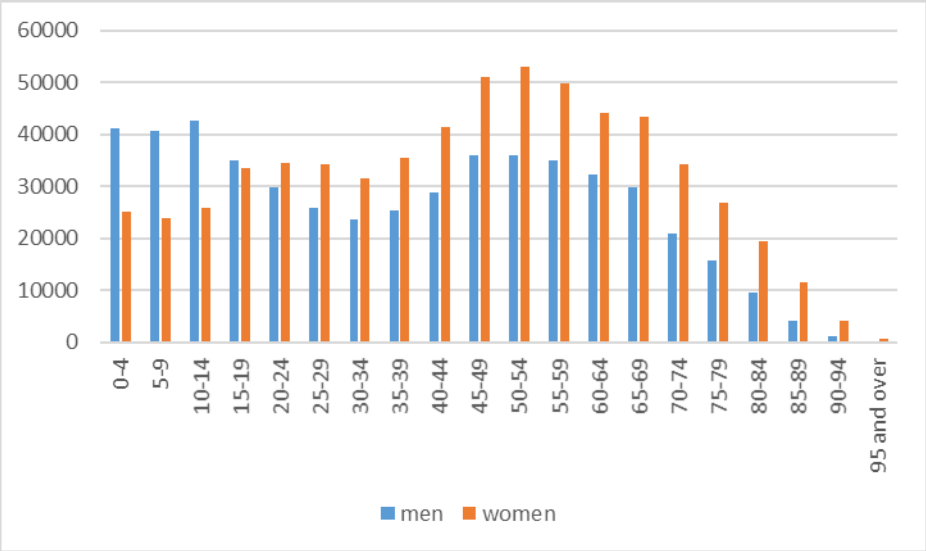
Total number of cases in total resident population:	1137830
Total number of cases in Nivel-PCD:	76000

Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	71290	94%
HDR: Hospital discharge register	4180	5%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	13970	18%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication		
CoD: Causes of Death	30	0%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional cases found:		**Added cases:**	**%**	**Cum%**
1	Nivel-PCD	71290	94%	94%
2	DTC-SSC	3890	5%	99%
3	HDR	810	1%	100%
4	CoD	10	0%	100%

Overlap of sources:								
	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD	59760	3090	10090			20		71290
HDR	3090	810	1940			10		4180
DTC-SSC	10090	1940	3610			10		13970
DTC-MHC								
Medication								
CoD	20	10	10			10		30
LTC-E CIZ								
Total								76000

Number of resident cases (total population) by age and sex,
P21 Asthma, prevalence



Indicator: P22 Chronic lower respiratory diseases other than asthma (incl. COPD), prevalence

Pilot Number:	P21
Disease:	Chronic lower respiratory diseases other than asthma (incl. COPD)
Measure:	prevalence
Definition:	ICD10: J40-J44, J47
Data refer to:	2016

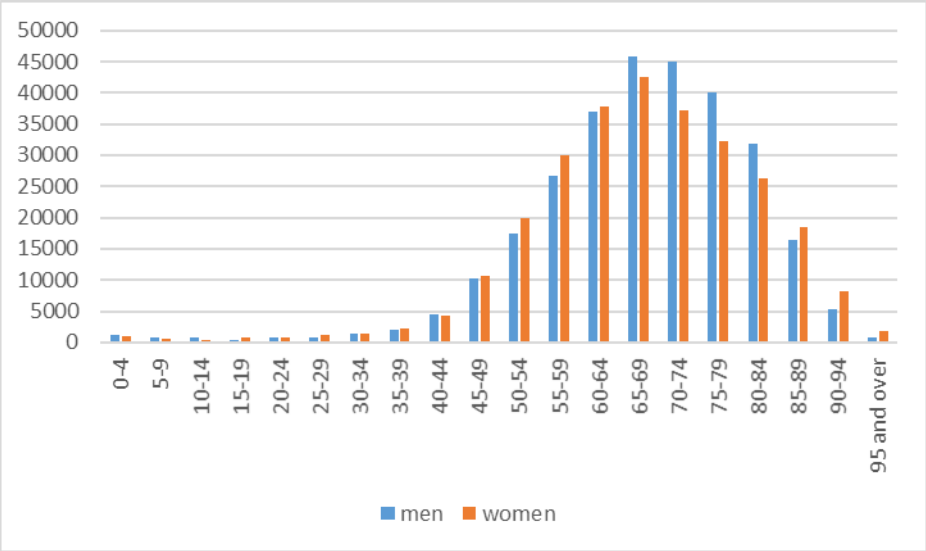
Total number of cases in total resident population:	567730
Total number of cases in Nivel-PCD:	37920

Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	33200	88%
HDR: Hospital discharge register	10840	29%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	10520	28%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication		
CoD: Causes of Death	780	2%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional cases found:		**Added cases:**	**%**	**Cum%**
1	Nivel-PCD	33200	88%	88%
2	HDR	3120	8%	96%
3	DTC-SSC	1520	4%	100%
4	CoD	90	0%	100%
5				
6				
7				

Overlap of sources:								
	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD	21120	7720	8530			630		33200
HDR	7720	2600	4730			560		10840
DTC-SSC	8530	4730	1510			430		10520
DTC-MHC								
Medication								
CoD	630	560	430			90		780
LTC-E CIZ								
Total								37920

Number of resident cases (total population) by age and sex,
P22 Chronic lower respiratory diseases other than asthma (incl. COPD), prevalence



Issue

In the Guidelines, some discussion remained on the inclusion of ICD10-code J47 (bronchiectasis) in the definition.
Exclusion of this code resulted in a reduction of 2 percent of cases found in the combination of HDR and COD, the sources that use ICD10. On the total number of cases however, the effect was small (reduction of 0,2 percent). This is probably so much smaller as ICPC-1 code R91, together with ICPC1-code R95 used for primary care, does also include bronchiectasis (together with chronic bronchitis), so subjects with bronchiectasis remain included based on primary care data. In ICPC-2, codes are different and bronchiectasis seems part of ICPC-2 R99 Respiratory disease other. We would not recommend to use that code to complete ICD10 J47, as it includes also many other respiratory diseases.

Indicator: P23 Chronic obstructive pulmonary disease (COPD), prevalence

Pilot Number:	P22
Disease:	Chronic obstructive pulmonary disease (COPD)
Measure:	prevalence
Definition:	ICD10: J44
Data refer to:	2016

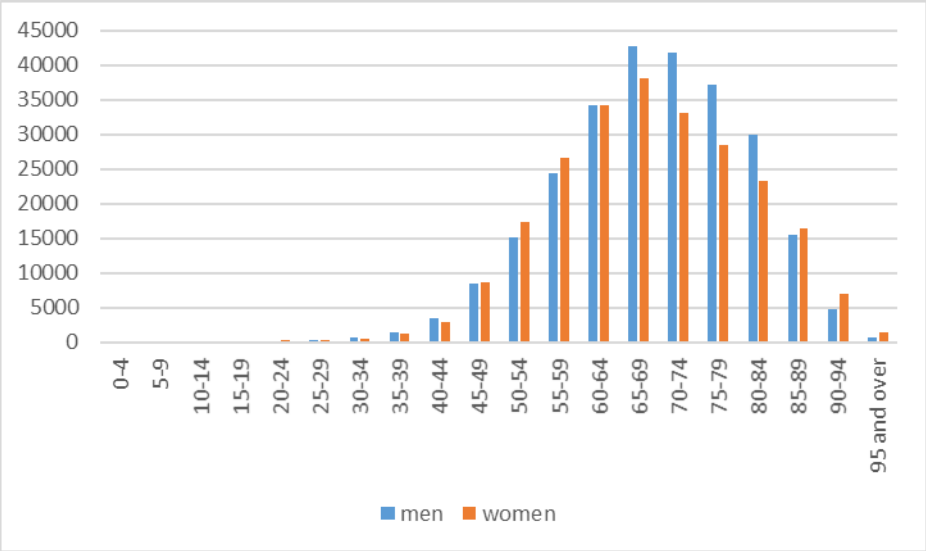
Total number of cases in total resident population:	502530
Total number of cases in Nivel-PCD:	33590

Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	29390	88%
HDR: Hospital discharge register	10060	30%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	9680	29%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication		
CoD: Causes of Death	760	2%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional cases found:		**Added cases:**	**%**	**Cum%**
1	Nivel-PCD	29390	88%	88%
2	HDR	2820	8%	96%
3	DTC-SSC	1300	4%	100%
4	CoD	80	0%	100%

Overlap of sources:								
	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD	18110	7250	7930			610		29390
HDR	7250	2330	4430			540		10060
DTC-SSC	7930	4430	1300			420		9680
DTC-MHC								
Medication								
CoD	610	540	420			80		760
LTC-E CIZ								
Total								33590

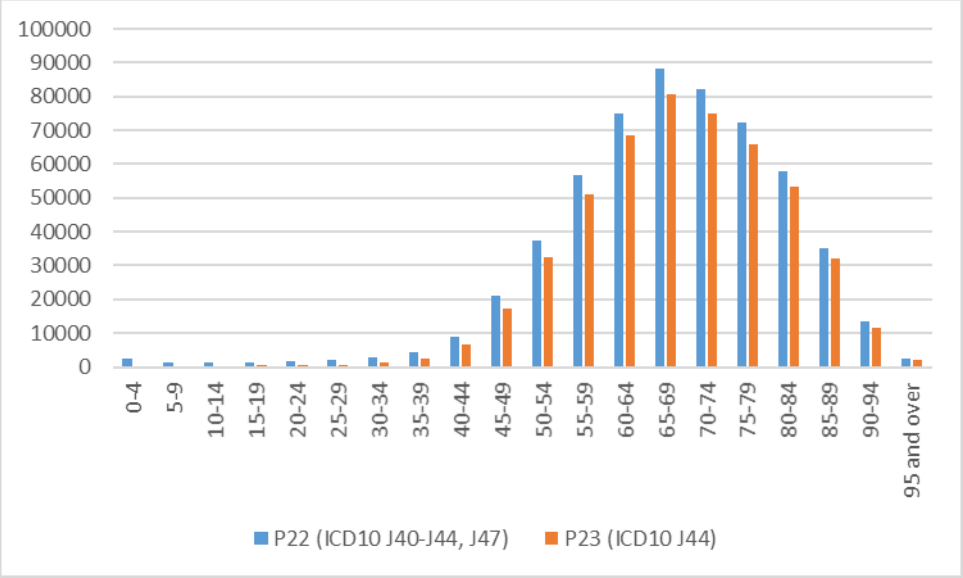
Number of resident cases (total population) by age and sex,
P23 Chronic obstructive pulmonary disease (COPD), prevalence



Issue

Indicator P22 (Chronic lower respiratory diseases other than asthma (incl. COPD)) and P23 (Chronic obstructive pulmonary disease (COPD) differ in a few ICD10 codes.
Result: P22 has 13% more cases, difference is rather small.

P22 (Chronic lower respiratory diseases other than asthma (incl. COPD)) versus P23 Chronic obstructive pulmonary disease (COPD), prevalence



Indicator: P26 diseases of liver, prevalence

Pilot Number:	P26
Disease:	Diseases of liver
Measure:	prevalence
Definition:	ICD10: K70-K77
Data refer to:	2016

Total number of cases in total resident population:	122600
Total number of cases in Nivel-PCD:	8180

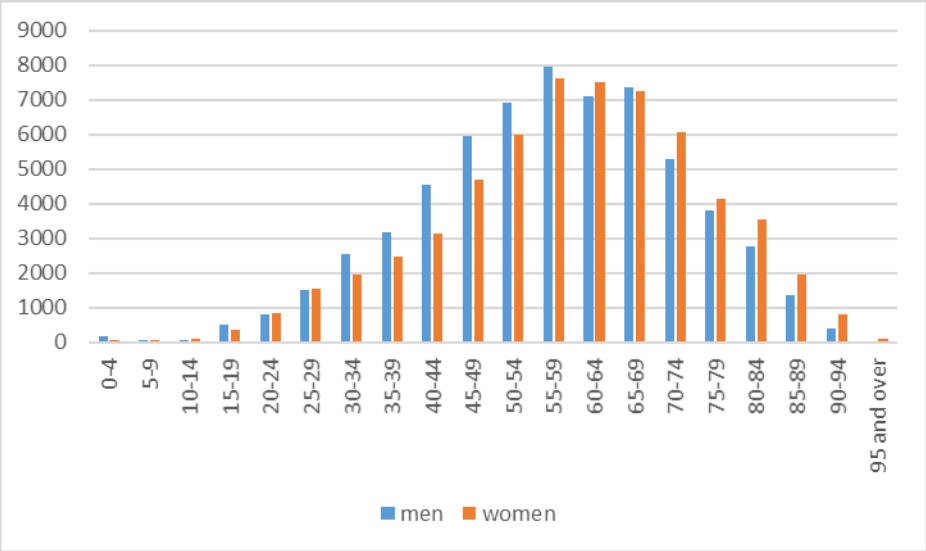
Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	4030	49%
HDR: Hospital discharge register	2680	33%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	3440	42%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication		
CoD: Causes of Death	170	2%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional cases found:		**Added cases:**	**%**	**Cum%**
1	Nivel-PCD	4030	49%	49%
2	DTC-SSC	2390	29%	78%
3	HDR	1690	21%	99%
4	CoD	70	1%	100%

Overlap of sources:

	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD	2820	570	1050			40		4030
HDR	570	1660	830			90		2680
DTC-SSC	1050	830	1970			60		3440
DTC-MHC								
Medication								
CoD	40	90	60			70		170
LTC-E CIZ								
Total								8180

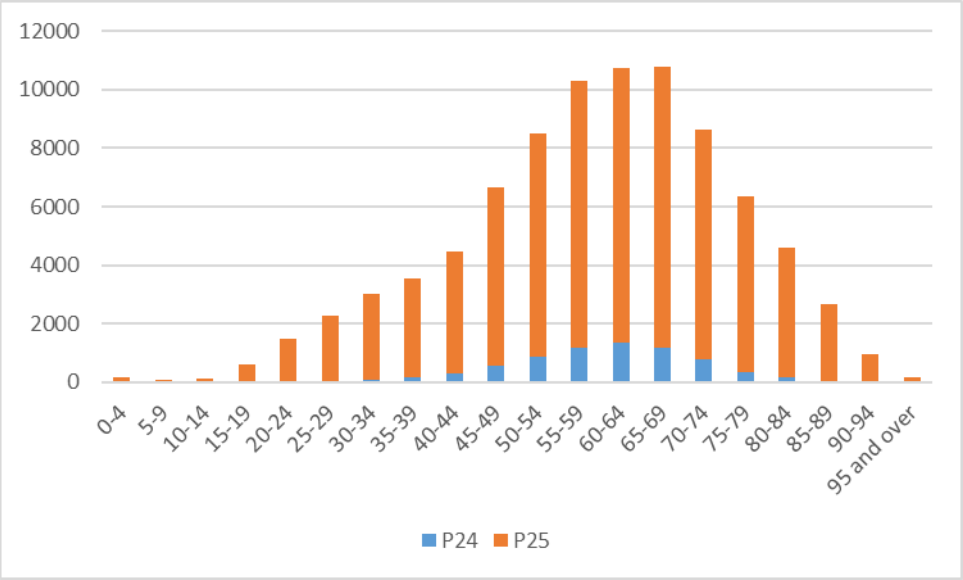
Number of resident cases (total population) by age and sex,
P26 diseases of liver, prevalence



Issue

Indicator P24 (Alcoholic liver disease) and (P25 Diseases of liver other than alcoholic) could not be produced due to the lack of separate ICPC-1 codes for both diseases. We calculated P24 and P25 based on hospital data and causes of death only, though also some items in DTC-SSC could not be distributed well between both indicators.
The total of P24+P25 (assuming that persons did not have both health problems) added up to 70% of P26 (which includes primary care).

P24 (Alcoholic liver disease) and (P25 Diseases of liver other than alcoholic), excluding primary care, prevalence



Indicator: P27 Rheumatoid arthritis, prevalence

Pilot Number:	P27
Disease:	Rheumatoid arthritis
Measure:	prevalence
Definition:	ICD10: M05, M06
Data refer to:	2016

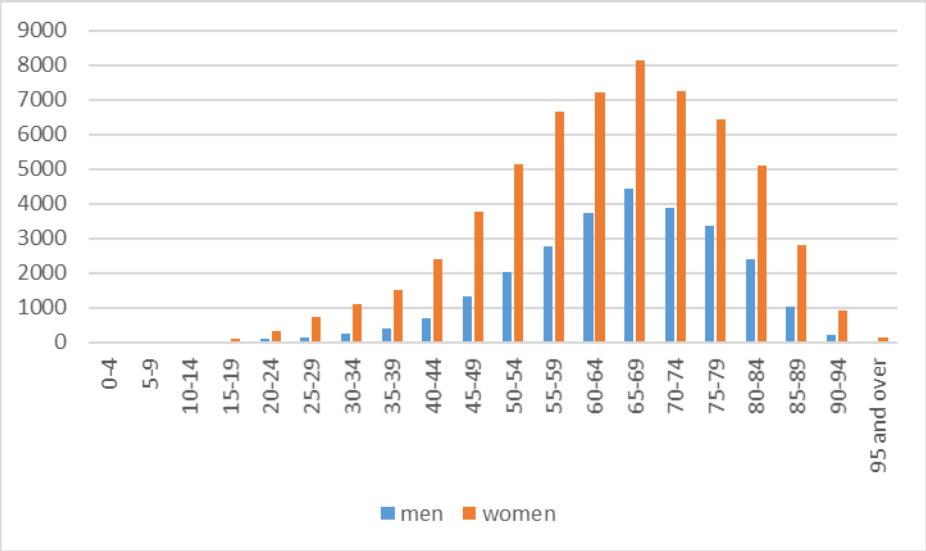
Total number of cases in total resident population:	86720
Total number of cases in Nivel-PCD:	

Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database		
HDR: Hospital discharge register	23270	27%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	79650	92%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication		
CoD: Causes of Death	730	1%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional cases found:		**Added cases:**	**%**	**Cum%**
1	DTC-SSC	79650	92%	92%
2	HDR	6800	8%	100%
3	CoD	280	0%	100%

Overlap of sources:								
	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD								
HDR		6750	16470			280		23270
DTC-SSC		16470	63000			400		79650
DTC-MHC								
Medication								
CoD		280	400			280		730
LTC-E CIZ								
Total								86720

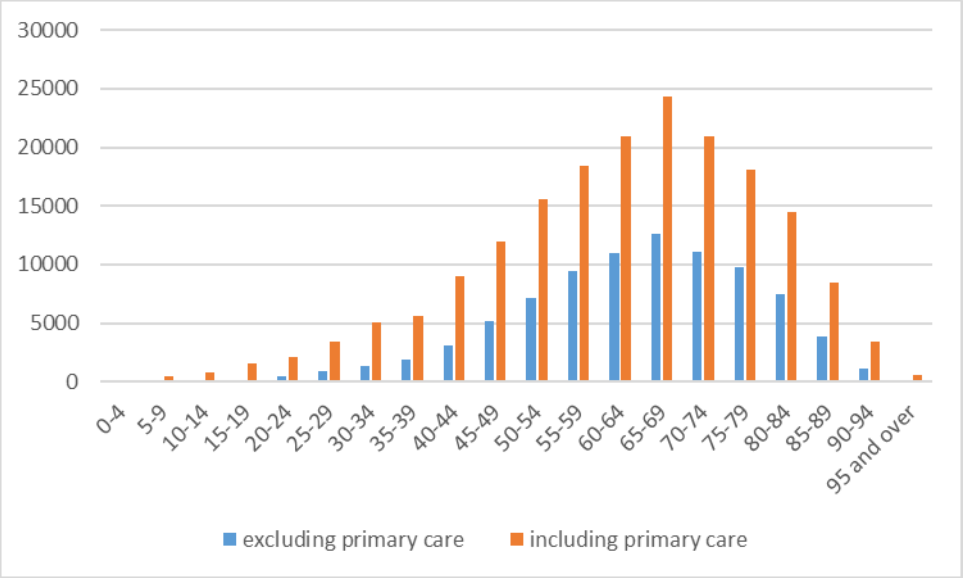
Number of resident cases (total population) by age and sex,
P27 Rheumatoid arthritis, prevalence



Issue 1

ICPC L88 (Rheumatoid arthritis / related condition includes 01. Rheumatoid arthritis and 02. Morbus Bechterew (ankylosing spondylitis). From other studies it is known that this ICPC-1-code is used for more than Rheumatoid arthritis only. We calculated the indicator without data from primary care, supposing that patients most of times will also have contacts in hospital. Also, the ICPC-1 code L88 includes Bechterew and Juvenile arthritis, which are not part of the ICD10-definition.
Including primary care, using ICPC-1 L88, would increase the total number of cases by 114%. Adding Bechterew and Juvenile arthritis from other sources to this analyses would increase the number by another 4%

P27 Rheumatoid arthritis, prevalence with and without primary care data (ICPC-1 L88).



Issue 2

In the Guidelines, Hungary mentioned that ICD10-code M06.4 (Inflammatory polyarthropathy) had to be excluded from the definition.
The effect of exclusion was small, resulting in a 0,07 percent reduction in the combination of HDR and COD, the sources that use ICD10. On the total number of cases found, the reduction was 0,01 percent.

Indicator: P28 Arthrosis, prevalence

Pilot Number:	P28
Disease:	Arthrosis
Measure:	prevalence
Definition:	ICD10: M15-M19
Data refer to:	2016

Total number of cases in total resident population:	1016990
Total number of cases in Nivel-PCD:	67840

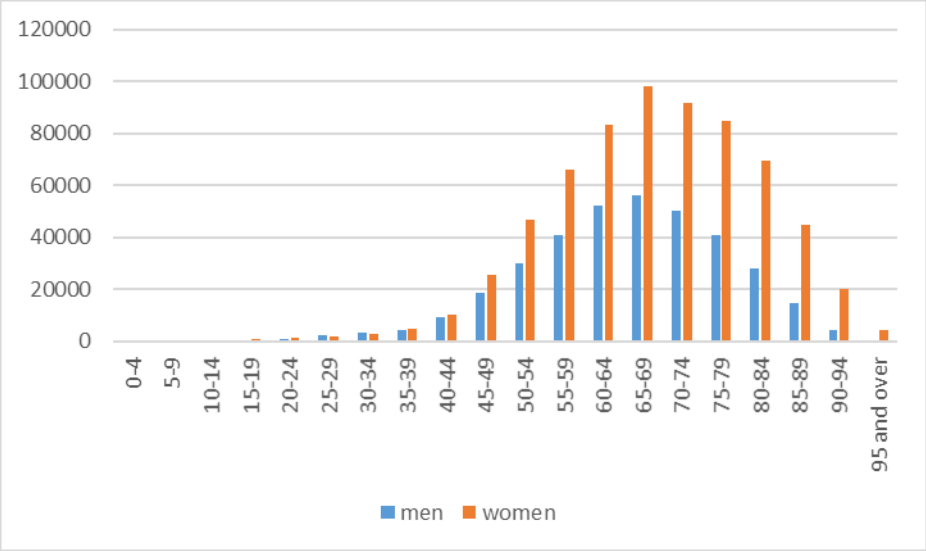
Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	50240	74%
HDR: Hospital discharge register	11690	17%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	35580	52%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication		
CoD: Causes of Death	30	0%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional cases found:		**Added cases:**	**%**	**Cum%**
1	Nivel-PCD	50240	74%	74%
2	DTC-SSC	16280	24%	98%
3	HDR	1310	2%	100%
4	CoD	10	0%	100%

Overlap of sources:

	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD	29950	8510	19300			20		50240
HDR	8510	1310	9410			10		11690
DTC-SSC	19300	9410	14400			10		35580
DTC-MHC								
Medication								
CoD	20	10	10			10		30
LTC-E CIZ								
Total								67840

Number of resident cases (total population) by age and sex,
P28 Arthrosis, prevalence



Indicator: P29 Osteoporosis, prevalence

Pilot Number:	P29
Disease:	Osteoporosis
Measure:	prevalence
Definition:	ICD10: M80-M82
Data refer to:	2016

Total number of cases in total resident population:	459190
Total number of cases in Nivel-PCD:	30500

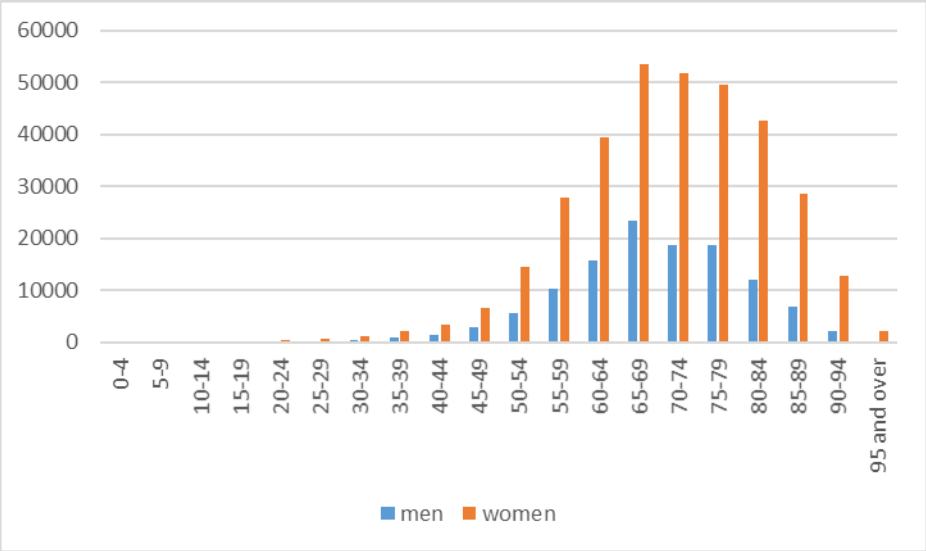
Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	20190	66%
HDR: Hospital discharge register	9240	30%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	6090	20%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication		
CoD: Causes of Death	30	0%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional cases found:		**Added cases:**	**%**	**Cum%**
1	Nivel-PCD	20190	66%	66%
2	HDR	7930	26%	92%
3	DTC-SSC	2370	8%	100%
4	CoD	10	0%	100%

Overlap of sources:

	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD	15810	1310	3530			20		20190
HDR	1310	7740	670			10		9240
DTC-SSC	3530	670	2370			0		6090
DTC-MHC								
Medication								
CoD	20	10	0			10		30
LTC-E CIZ								
Total								30500

Number of resident cases (total population) by age and sex,
P29 Osteoporosis, prevalence



Indicator: P30 Renal failure, prevalence

Pilot Number:	P30
Disease:	Renal failure
Measure:	prevalence
Definition:	ICD10: N17-N19
Data refer to:	2016

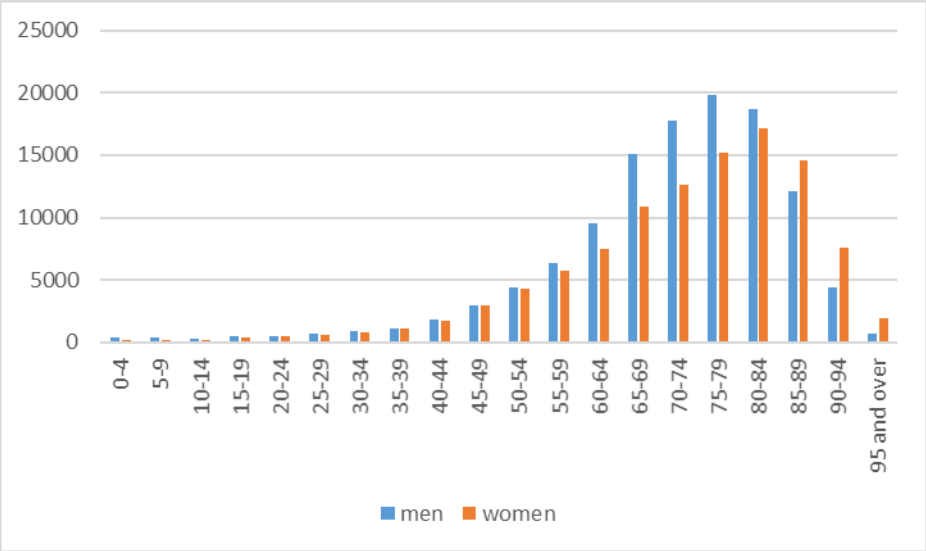
Total number of cases in total resident population:	224900
Total number of cases in Nivel-PCD:	

Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database		
HDR: Hospital discharge register	141290	63%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	130930	58%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication		
CoD: Causes of Death	11730	5%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional cases found:		**Added cases:**	**%**	**Cum%**
1	HDR	141290	63%	63%
2	DTC-SSC	79090	35%	98%
3	CoD	4520	2%	100%

Overlap of sources:								
	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD								
HDR		86370	51850			6440		141290
DTC-SSC		51850	78320			4130		130930
DTC-MHC								
Medication								
CoD		6440	4130			4520		11730
LTC-E CIZ								
Total								224900

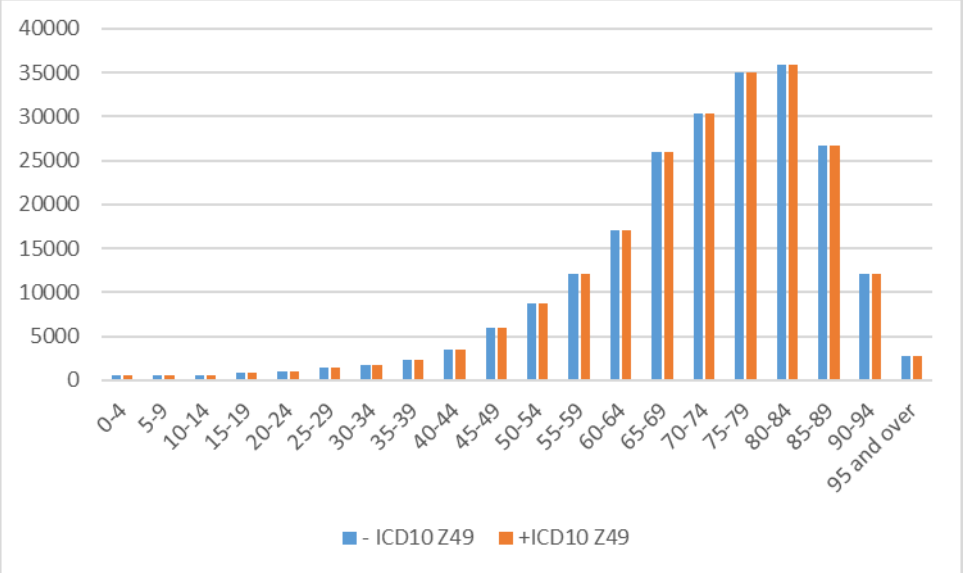
Number of resident cases (total population) by age and sex,
P30 Renal failure, prevalence



Issue

In DTC-SSC the ICD10-code Z49 (Care involving dialysis) was also frequently used. We performed an extra analyses using this ICD10-code also in HDR and CoD
Result: In HDR 295 extra cases were found, most already known from DTC-SSC or CoD. The netto difference was very small, only 20 extra cases were found. We decided to keep the original definition of ICD10 M80-M82

P30 Renal failure, prevalence, with and without extra ICD10-code Z49 (Care involving dialysis)



Indicator: P31 Urolithiasis, incidence per person

Pilot Number:	P1
Disease:	Urolithiasis
Measure:	Incidence by person
Definition:	ICD10: N20-N23
Data refer to:	2016

Total number of cases in total resident population:	69030
Total number of cases in Nivel-PCD:	4630

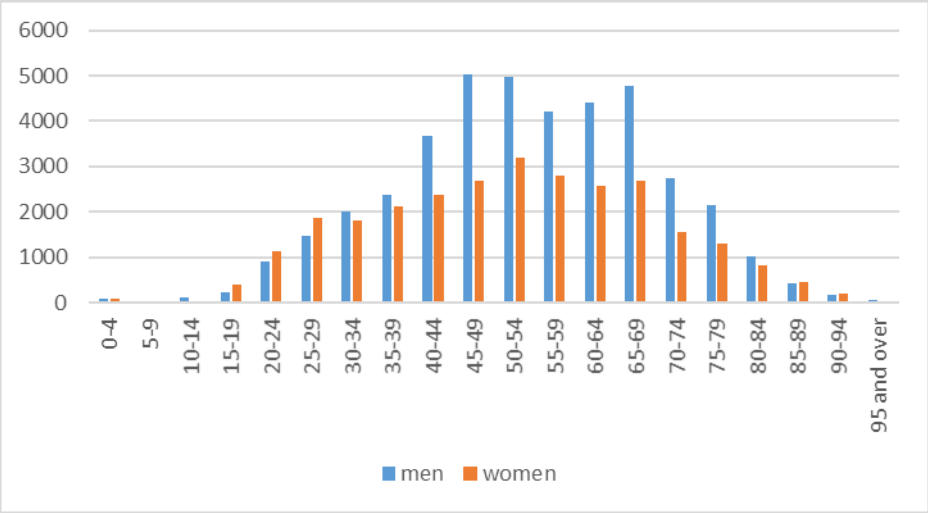
Cases per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	4070	88%
HDR: Hospital discharge register	690	15%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	1220	26%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication		
CoD: Causes of Death	0	0%
LTC-E CIZ: Long term care eligibility decisions		

Sources in order of additional cases found:		**Added cases:**	**%**	**Cum%**
1	Nivel-PCD	4070	88%	88%
2	DTC-SSC	470	10%	98%
3	HDR	90	2%	100%
4	CoD	0	0%	100%

Overlap of sources:

	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD	3170	480	750			0		4070
HDR	480	90	450					690
DTC-SSC	750	450	350			0		1220
DTC-MHC								
Medication								
CoD	0		0			0		0
LTC-E CIZ								
Total								4630

Number of resident cases (total population) by age and sex,
P31 Urolithiasis, incidence per person



Indicator: P32/P33 Intracranial injury, incidence per episode (P32) and per person (P33)

Pilot Number:	P32/P33
Disease:	Intracranial injury
Measure:	incidence per episode, per person
Definition:	ICD10: S06
Data refer to:	2016

Total number of episodes in total resident population:	95540
Total number of persons in total resident population:	90780
Total number of episodes in Nivel-PCD:	6310
Total number of persons in Nivel-PCD:	6010

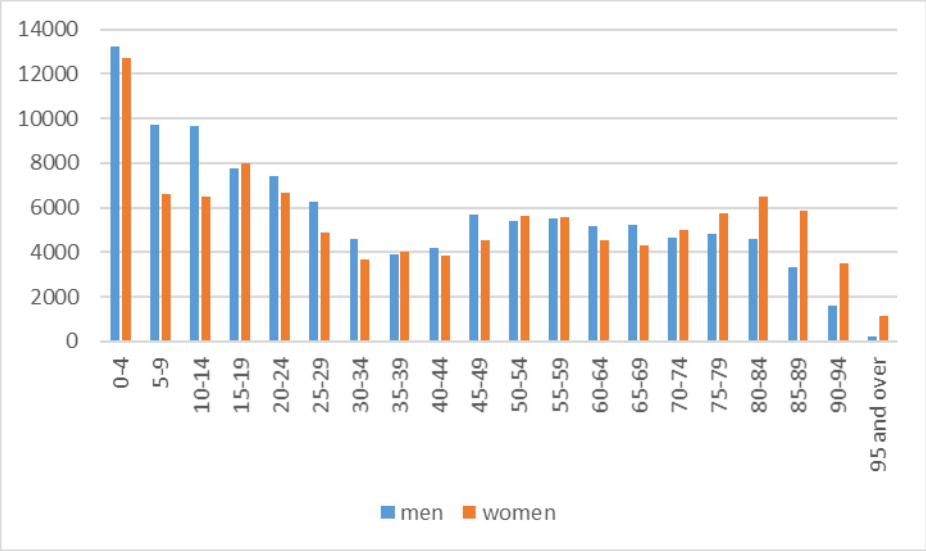
Episodes per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database	3460	55%
HDR: Hospital discharge register	720	11%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	2990	47%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication		
CoD: Causes of Death	80	1%
Persons per source		
Nivel-PCD: Nivel Primary Care Database	3210	53%
HDR: Hospital discharge register	720	12%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	2950	49%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication		
CoD: Causes of Death	80	1%

Sources in order of additional persons found:		**Added cases:**	**%**	**Cum%**
1	DTC-SSC	3210	53%	53%
2	Nivel-PCD	2490	41%	95%
3	HDR	260	4%	99%
4	CoD	50	1%	100%

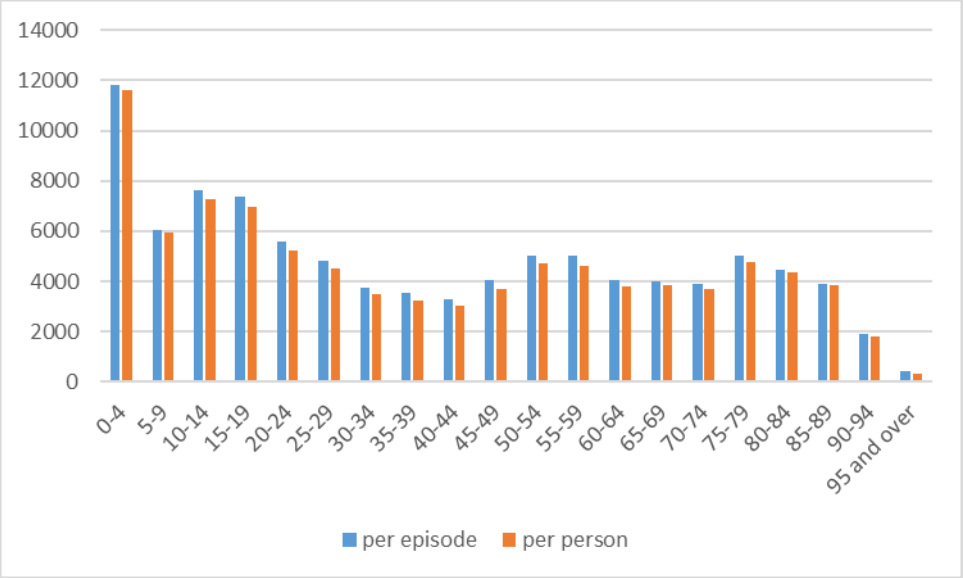
Overlap of persons in sources:

	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD	2710	130	470					3210
HDR	130	250	420			30		720
DTC-SSC	470	420	2150			10		2950
DTC-MHC								
Medication								
CoD		30	10			50		80
LTC-E CIZ								
Total								6010

Number of resident cases (total population) by age and sex,
P33 Intracranial injury, incidence per person



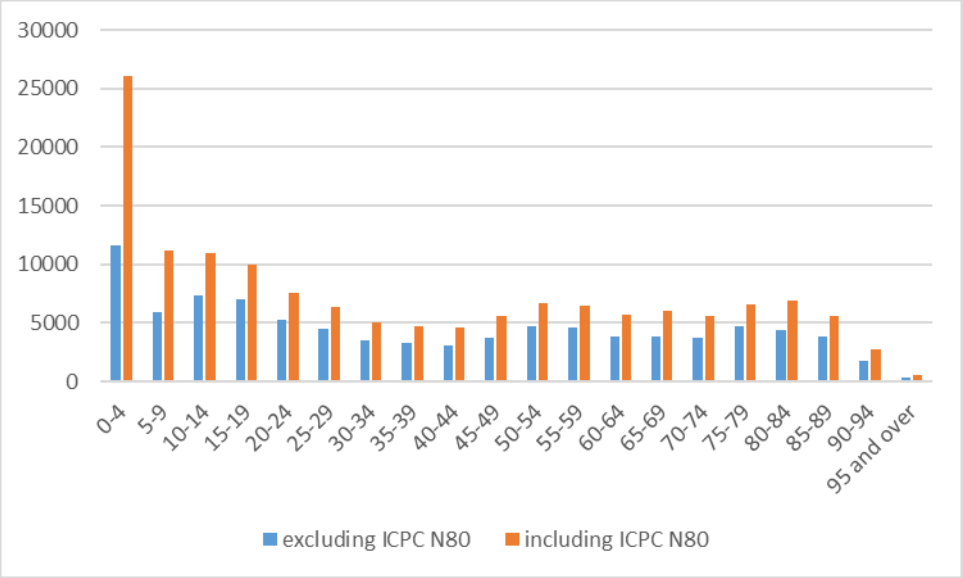
P32/P33 Intracranial injury, incidence per episode and per person



Issue

In the manual, page 122, ICPC-codes N79 and N80 are mentioned for use in selection of incident persons from primary care data. In our analysis, we used only ICPC-code N79 (concussion). For the full definition of ICD10 S06 (Intracranial injury), also ICPC N80 (Head injury other) would be needed. However, this leads to many other head injuries, not necessarily intracranial.
Result: The cases found in Nivel-PCD increased with 134% when including ICPC N80. The total number of incident persons increased by 60%. Apparently a part of the extra cases were already identified in HDR or DTC-SSC. We decided not to include ICPC N80.

P33 Intracranial injury, incidence per person, including or excluding ICPC-code N80



Indicator: P34/P35 Fracture of femur, incidence per episode (P34) and per person (P35)

Pilot Number:	P34/P35
Disease:	Fracture of femur
Measure:	incidence per episode, per person
Definition:	ICD10: S72
Data refer to:	2016

Total number of episodes in total resident population:	27100
Total number of persons in total resident population:	25950

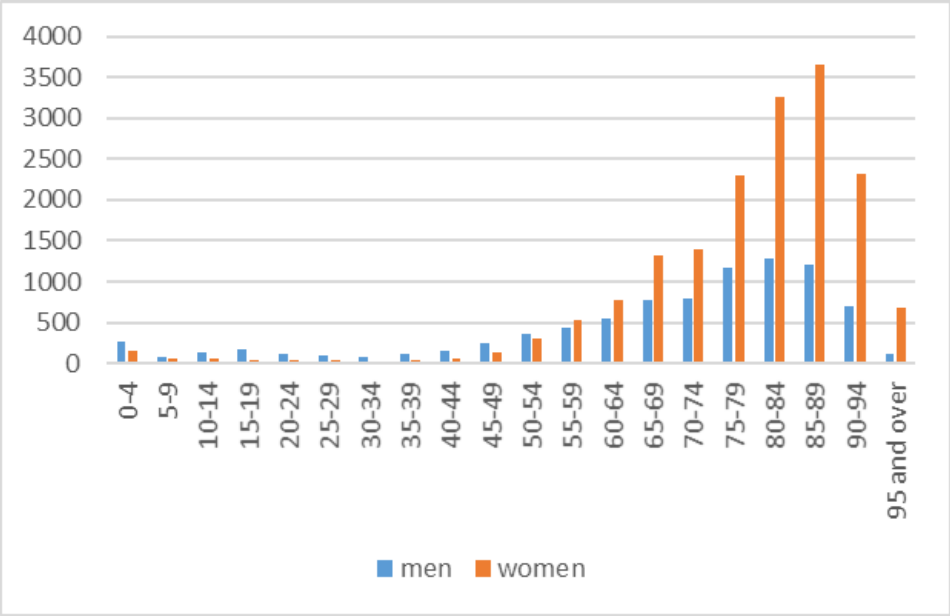
Episodes per source	**cases**	**% of total**
Nivel-PCD: Nivel Primary Care Database		
HDR: Hospital discharge register	21540	79%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	22930	85%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication		
CoD: Causes of Death	2030	7%
Persons per source		
Nivel-PCD: Nivel Primary Care Database		
HDR: Hospital discharge register	21440	83%
DTC-SSC: Diagnosis treatment combinations Somatic Specialist Care	21980	85%
DTC-MHC: Diagnosis treatment combinations Mental Health Care		
Medication		
CoD: Causes of Death	2030	8%

Sources in order of additional persons found:		**Added cases:**	**%**	**Cum%**
1	DTC-SSC	21980	85%	85%
2	HDR	3480	13%	98%
3	CoD	500	2%	100%
4				

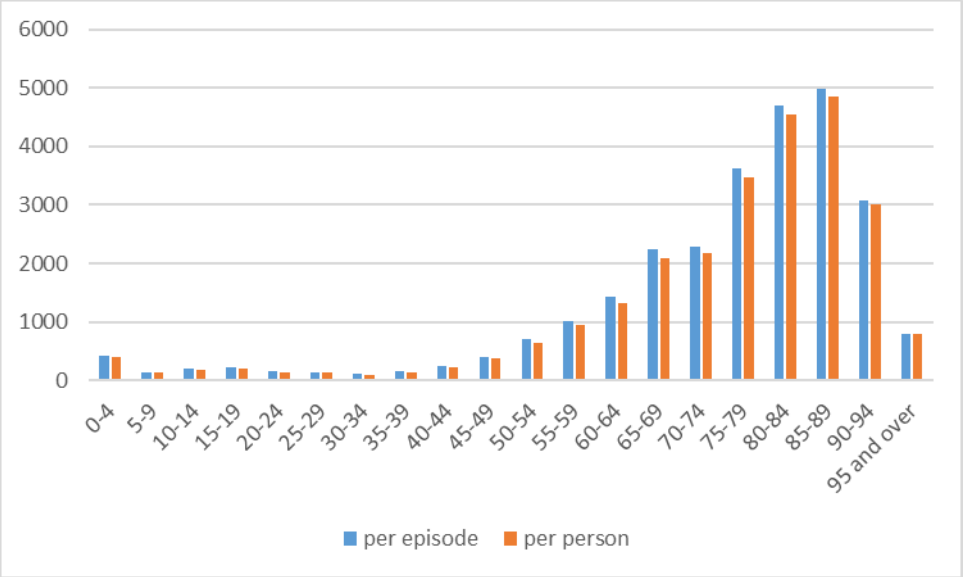
Overlap of persons in sources:

	Nivel-PCD	HDR	DTC-SSC	DTC-MHC	Medication	CoD	LTC-E CIZ	**total**
Nivel-PCD								
HDR		3170	17970			1340		21440
DTC-SSC		17970	3820			1220		21980
DTC-MHC								
Medication								
CoD		1340	1220			500		2030
LTC-E CIZ								
Total								25950

Number of resident cases (total population) by age and sex,
P35 Fracture of femur, incidence per person



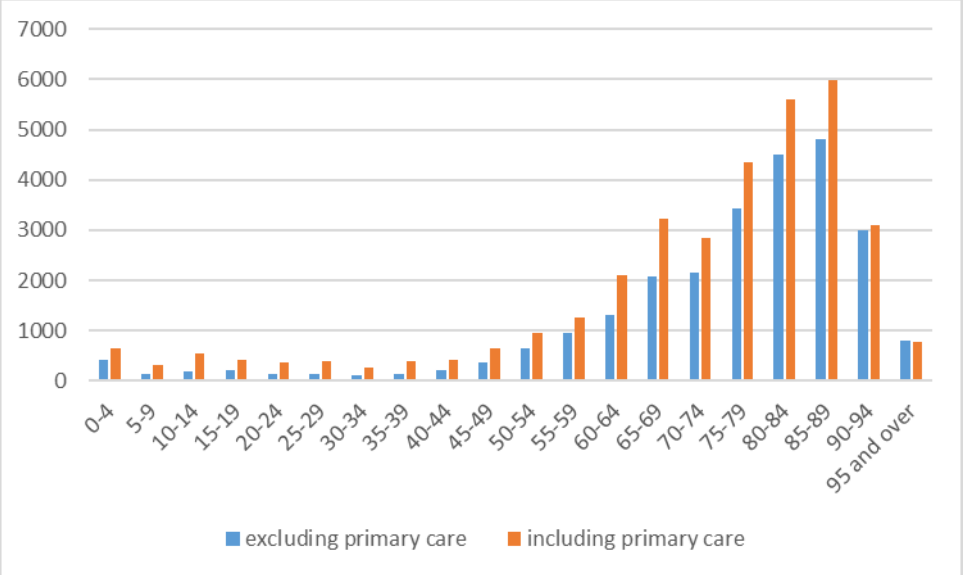
P34/P35 Fracture of femur, incidence per episode and per person



Issue

In the manual, page 123, ICPC-codes N75 (fracture of femur) is also mentioned as a potential source. We were surprised to find many primary care femur fractures that were not found in the other sources. We did analyses with and without Nivel-PCD.
Result: the total number of cases with incident femur fracture would increase with 34% by adding information from primary care. As it seems unlikely that so many cases would be presented only in primary care we decided not to use primary care data for this indicator. Incident cases with ICPC-1 N75 could be old fractures that for which it was again necessary to contact the general practitioner, but in depth analyses revealed that not all persons had a femur fracture whatsoever in hospital data in recent years, but several other fractures and traumas were found. It seems that in Nivel-PCD, ICPC-1 L75 is also used for other health problems.

P35 femur fracture, incidence per person, including or excluding Primary Care (ICPC-N75)



6.5 Comparison of Morbidity Statistics with the Health Interview Survey

Comparison of Morbidity Statistics indicators (2016) with results of the Health Interview Survey (2016-2017 combined)[8].

	P2 Diabetes mellitus, prevalence			**Diabetes mellitus**		
	Morbidity Statistics			Health Interview Survey		
	total	male	female	total	male	female
total	**6,5%**	**6,8%**	**6,2%**	**4,8%**	**5,2%**	**4,3%**
0-24	0,4%	0,3%	0,4%	0,4%	0,4%	0,3%
25-44	1,6%	1,5%	1,6%	1,0%	1,1%	1,0%
45-64	7,6%	8,6%	6,6%	6,5%	7,8%	5,1%
65+	21,0%	22,7%	19,6%	14,4%	15,5%	13,4%

	P6 Mood (affective) disorders, prevalence			**Had a depression in last 12 months**		
	Morbidity Statistics			Health Interview Survey		
	total	male	female	total	male	female
total 12+	**5,3%**	**3,9%**	**6,7%**	**8,1%**	**7,2%**	**9,0%**
12-24	2,3%	1,5%	3,1%	5,7%	4,8%	6,7%
25-44	5,5%	3,8%	7,2%	9,4%	8,5%	10,3%
45-64	6,8%	5,4%	8,2%	9,5%	8,9%	10,0%
65+	5,3%	3,8%	6,6%	6,3%	4,9%	7,5%

	P12 Hypertensive diseases, prevalence			**Hypertension in last 12 months**		
	Morbidity Statistics			Health Interview Survey		
	total	male	female	total	male	female
total 12+	**17,1%**	**15,5%**	**18,6%**	**16,2%**	**15,2%**	**17,3%**
12-24	0,2%	0,2%	0,2%	1,5%	1,1%	1,9%
25-44	2,5%	2,2%	2,7%	5,4%	5,2%	5,6%
45-64	18,8%	18,2%	19,4%	20,6%	20,3%	20,9%
65+	48,1%	45,0%	50,7%	37,6%	35,0%	39,8%

	P13 Ischaemic heart diseases, prevalence			**Serious heart condition in the last 12 months, such as heart failure or angina pectoris?**		
	Morbidity Statistics			Health Interview Survey		
	total	male	female	total	male	female
total 12+	**5,7%**	**7,1%**	**4,3%**	**2,0%**	**2,1%**	**1,8%**
12-24	0,0%	0,0%	0,0%	0,2%	0,1%	0,3%
25-44	0,4%	0,5%	0,3%	0,5%	0,3%	0,7%
45-64	5,1%	6,9%	3,3%	2,0%	2,5%	1,5%
65+	18,4%	23,9%	13,7%	5,5%	5,9%	5,2%

[8] Health Interview Survey: http://opendata.cbs.nl/statline/#/CBS/nl/dataset/83384NED/table?dl=3AB12

	P15 Acute myocardial infarction, incidence per person			Myocardial infarction in last 12 months		
	Morbidity Statistics			Health Interview Survey		
	total	male	female	total	male	female
total 12+	**0,3%**	**0,3%**	**0,2%**	**0,3%**	**0,4%**	**0,2%**
12-24	0,0%	0,0%	0,0%	0,0%	0,0%	0,0%
25-44	0,0%	0,1%	0,0%	0,0%	0,1%	0,0%
45-64	0,3%	0,4%	0,1%	0,4%	0,6%	0,2%
65+	0,8%	1,0%	0,6%	0,8%	0,9%	0,8%

	P17 Stroke, incidence per person			Stroke, cerebral haemorrhage/infarction in last 12 months		
	Morbidity Statistics			Health Interview Survey		
	total	male	female	total	male	female
total 12+	**0,5%**	**0,5%**	**0,5%**	**0,5%**	**0,5%**	**0,4%**
12-24	0,0%	0,0%	0,0%	0,0%	0,1%	0,0%
25-44	0,1%	0,1%	0,1%	0,2%	0,1%	0,2%
45-64	0,4%	0,4%	0,4%	0,5%	0,7%	0,4%
65+	1,6%	1,6%	1,5%	1,2%	1,2%	1,1%

	P18 Cerebrovascular diseases, prevalence			Ever had a stroke, cerebral haemorrhage or cerebral infarction		
	Morbidity Statistics			Health Interview Survey		
	total	male	female	total	male	female
total 12+	**2,3%**	**2,4%**	**2,2%**	**3,0%**	**3,3%**	**2,7%**
12-24	0,1%	0,1%	0,1%	0,3%	0,4%	0,2%
25-44	0,3%	0,3%	0,3%	0,8%	0,6%	1,0%
45-64	1,8%	1,9%	1,7%	3,1%	3,7%	2,6%
65+	7,4%	8,3%	6,7%	8,3%	9,5%	7,3%

	P19 Pneumonia, incidence per person[9]			Bronchitis or pneumonia during the last 2 months, (excluding. chronic bronchitis)		
	Morbidity Statistics			Health Interview Survey		
	total	male	female	total	male	female
total	**1,6%**	**1,6%**	**1,6%**	**2,0%**	**1,9%**	**2,2%**
0-24	1,0%	1,0%	0,9%	1,3%	1,6%	1,0%
25-44	0,8%	0,7%	0,9%	1,5%	1,4%	1,7%
45-64	1,4%	1,4%	1,4%	2,1%	1,7%	2,5%
65+	3,9%	4,4%	3,5%	3,7%	3,3%	4,0%

[9] P19 Pneumonia officially is on incidence per episode, but we also calculated per person

	P21 Asthma, prevalence			Asthma in last 12 months		
	Morbidity Statistics			Health Interview Survey		
	total	male	female	total	male	female
total	**6,7%**	**6,1%**	**7,3%**	**5,7%**	**5,0%**	**6,4%**
0-24	6,8%	7,6%	6,0%	5,3%	5,8%	4,8%
25-44	5,8%	4,9%	6,8%	5,7%	4,5%	6,9%
45-64	7,0%	5,8%	8,2%	6,0%	4,6%	7,4%
65+	7,1%	5,7%	8,3%	5,7%	4,8%	6,4%

	P22 Chronic lower respiratory diseases other than asthma (incl. COPD), prevalence			COPD, chronic bronchitis or pulmonary emphysema in last 12 months		
	Morbidity Statistics			Health Interview Survey		
	total	male	female	total	male	female
total	**3,3%**	**3,4%**	**3,2%**	**4,3%**	**4,1%**	**4,6%**
0-24	0,2%	0,2%	0,2%	1,1%	1,3%	0,9%
25-44	0,4%	0,4%	0,4%	2,1%	1,7%	2,5%
45-64	3,9%	3,8%	4,1%	6,0%	4,9%	7,1%
65+	11,3%	13,0%	9,8%	10,1%	11,0%	9,3%

	P26 diseases of liver, prevalence			Cirrhosis of the liver in last 12 months		
	Morbidity Statistics			Health Interview Survey		
	total	male	female	total	male	female
total 12+	**0,8%**	**0,9%**	**0,8%**	**0,3%**	**0,4%**	**0,2%**
12-24	0,1%	0,1%	0,1%	0,0%	0,0%	0,0%
25-44	0,5%	0,6%	0,4%	0,2%	0,4%	0,0%
45-64	1,1%	1,2%	1,1%	0,5%	0,8%	0,3%
65+	1,4%	1,5%	1,4%	0,3%	0,3%	0,4%

	P27 Rheumatoid arthritis, prevalence			Chronic arthritis (chronic rheumatism, rheumatoid arthritis) in last 12 months		
	Morbidity Statistics			Health Interview Survey		
	total	male	female	total	male	female
total	**0,5%**	**0,3%**	**0,7%**	**6,5%**	**4,3%**	**8,6%**
0-24	0,0%	0,0%	0,0%	0,5%	0,4%	0,5%
25-44	0,2%	0,1%	0,3%	3,4%	2,3%	4,5%
45-64	0,7%	0,4%	1,0%	9,7%	7,2%	12,2%
65+	1,5%	1,1%	1,8%	15,3%	9,2%	20,7%

	P28 Arthrosis, prevalence			Arthrosis of hips or knees in last 12 months		
	Morbidity Statistics			Health Interview Survey		
	total	male	female	total	male	female
total 12+	**6,9%**	**4,9%**	**8,8%**	**14,0%**	**10,3%**	**17,7%**
12-24	0,2%	0,1%	0,2%	0,7%	0,5%	0,9%
25-44	0,9%	0,9%	1,0%	3,3%	3,3%	3,4%
45-64	7,6%	5,9%	9,2%	17,9%	14,5%	21,3%
65+	19,5%	13,7%	24,4%	34,8%	23,1%	45,0%

6.6 Reduction of sources

Combinations of sources needed for 100% and 95% of cases

Indicator[10]	Combination used to reach percentage of cases (most contributing source to least contributing source):			% of cases covered omitting next smallest source:
	100%	**At least 95%**	**% covered**	**%**
P1 Diabetes mellitus, incidence per person	Nivel-PCD Medication HDR DTC-SSC CoD	Nivel-PCD Medication HDR	98%	93%
P2 Diabetes mellitus, prevalence	Nivel-PCD Medication HDR DTC-SSC CoD	Nivel-PCD	95%	-
P3 Dementia (incl. Alzheimer's disease), prevalence[11]	Nivel-PCD Medication LTC-E CIZ DTC-SSC HDR DTC-MHC CoD	Nivel-PCD Medication LTC-E CIZ DTC-SSC HDR	98%	93%
P4 Mental and behavioural disorders due to use of alcohol (incl. alcohol dependence), prevalence	Nivel-PCD HDR DTC-MHC CoD DTC-SSC	Nivel-PCD HDR DTC-MHC	99%	95%
P5 Schizophrenia, schizotypical and delusional disorders, prevalence	Nivel-PCD DTC-MHC HDR DTC-SSC CoD	Nivel-PCD DTC-MHC	98%	74%
P6 Mood (affective) disorders, prevalence	Nivel-PCD DTC-MHC HDR DTC-SSC CoD	Nivel-PCD DTC-MHC	99%	86%

[10] For diseases or health problems with both incidence per person and per episode, only 'per person' is included.

[11] Non-institutionalised Nivel-PCD population. In the institutionalised population (defined using LTC-U CAK), LTC-E CIZ is the only source to provide cases.

P7 Anxiety disorders, prevalence	Nivel-PCD DTC-MHC HDR DTC-SSC CoD	Nivel-PCD DTC-MHC	99%	91%
P8 Parkinson's disease, prevalence	Nivel-PCD Medication HDR DTC-SSC CoD	Nivel-PCD Medication HDR	98%	95%
P9 Multiple sclerosis, prevalence	Nivel-PCD DTC-SSC HDR CoD	Nivel-PCD DTC-SSC	99%	84%
P10 Epilepsy, prevalence	Nivel-PCD DTC-SSC Medication HDR CoD	Nivel-PCD DTC-SSC Medication	97%	92%
P11 Hypertensive diseases, incidence per person	Nivel-PCD HDR DTC-SSC CoD	Nivel-PCD HDR	98%	82%
P12 Hypertensive diseases, prevalence	Nivel-PCD HDR DTC-SSC CoD	Nivel-PCD HDR	99%	93%
P13 Ischaemic heart diseases, prevalence	Nivel-PCD DTC-SSC HDR CoD	Nivel-PCD DTC-SSC	95%	80%
P15 Acute myocardial infarction, incidence per person	DTC-SSC HDR CoD	DTC-SSC HDR CoD	100%	86%
P16 Heart failure, prevalence	Nivel-PCD DTC-SSC HDR CoD	Nivel-PCD DTC-SSC HDR	98%	90%
P17 Stroke, incidence per person	Nivel-PCD DTC-SSC HDR CoD	Nivel-PCD DTC-SSC HDR	98%	93%
P18 Cerebrovascular diseases, prevalence	Nivel-PCD DTC-SSC HDR CoD	Nivel-PCD DTC-SSC HDR	99%	95%

P19 Pneumonia, incidence per episode	Nivel-PCD DTC-SSC HDR CoD	Nivel-PCD DTC-SSC HDR	98%	94%
P20 Asthma, incidence per person	Nivel-PCD DTC-SSC HDR CoD	Nivel-PCD DTC-SSC	98%	90%
P21 Asthma, prevalence	Nivel-PCD DTC-SSC HDR CoD	Nivel-PCD DTC-SSC	99%	94%
P22 Chronic lower respiratory diseases other than asthma (incl. COPD), prevalence	Nivel-PCD HDR DTC-SSC CoD	Nivel-PCD HDR	96%	88%
P23 Chronic obstructive pulmonary disease (COPD), prevalence	Nivel-PCD HDR DTC-SSC CoD	Nivel-PCD HDR	96%	88%
P26 diseases of liver, prevalence	Nivel-PCD DTC-SSC HDR CoD	Nivel-PCD DTC-SSC HDR	99%	78%
P27 Rheumatoid arthritis, prevalence	DTC-SSC HDR CoD	DTC-SSC HDR	100%	92%
P28 Arthrosis, prevalence	Nivel-PCD DTC-SSC HDR CoD	Nivel-PCD DTC-SSC	98%	74%
P29 Osteoporosis, prevalence	Nivel-PCD HDR DTC-SSC CoD	Nivel-PCD HDR DTC-SSC	100%	92%
P30 Renal failure, prevalence	HDR DTC-SSC CoD	HDR DTC-SSC	98%	63%
P31 Urolithiasis, incidence per person	Nivel-PCD DTC-SSC HDR CoD	Nivel-PCD DTC-SSC	98%	88%
P33 Intracranial injury, incidence per person	DTC-SSC Nivel-PCD HDR CoD	DTC-SSC Nivel-PCD HDR	99%	95%

P35 Fracture of femur, incidence per person	DTC-SSC HDR CoD	DTC-SSC HDR	98%	85%

6.7 List of abbreviations

AMI	**Acute Myocardial Infarction**
ATC	Anatomical Therapeutic Chemical Classification System
CAK	Central Administration Office
CBS	Statistics Netherlands
CIZ	Care Needs Assessment Centre
COD	Causes of Death register
COPD	Chronic Obstructive Pulmonary Disease
DHD	Dutch Hospital Data
DRG	Diagnosis-related Groups
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders version IV
DTC-MHC	Diagnosis Treatment Combinations Mental Health Care
DTC-SSC	Diagnosis Treatment Combinations Specialised Somatic Care
EPIMS	European Project on Inventories of Morbidity Statistics
ESMS	Euro SDMX Metadata Structure
FTE	Full Time Equivalent
GP	General practitioner
HDR	Hospital discharge register
ICD10	International Classification of Diseases, 10th edition
ICPC	International Classification for Primary Care
LTC-C CAK	Co-payments for use of long term care
LTC-E CIZ	Register of eligibility decisions to long-term care
Nivel	Netherlands institute for health services research
Nivel-PCD	Nivel Primary Care Database
RIVM	National Institute for Public Health and the Environment
SQL	Structured Query Language

Explanation of figures

Empty cell	Figure not applicable
.	Figure is unknown, insufficiently reliable or confidential
*	Provisional figure
**	Revised provisional figure
2019–2020	2019 to 2020 inclusive
2019/2020	Average for 2019 to 2020 inclusive
2019/2020	Crop year, financial year, school year, etc., beginning in 2019 and ending in 2020
2017/18–2019/20	Crop year, financial year, etc., 2017/18 to 2019/20 inclusive

Due to rounding, some totals may not correspond to the sum of the separate figures.

Colophon

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