

National health registries - a “goldmine” for studying non-communicable disease occurrence in Norway - the NCDNOR project

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Abstract

To estimate occurrence of non-communicable diseases (NCDs) over the life course in the Norwegian population, national health registries are a vital source of information since they fully represent the entire non-institutionalised population. However, as they are mainly established for administrative purposes, more knowledge about how NCDs are recorded in the registries is needed. To establish this, we begin by counting the number of individuals registered annually with one or more NCDs in any of the registries.

The study population includes all inhabitants who lived in Norway from 2004 to 2020 (N~6.4 million). The NCD outcomes are diabetes, cardiovascular diseases, chronic obstructive lung diseases, cancer, and mental disorders/substance use disorders. Further, we included hip fractures in our NCD concept. The data sources used to identify individuals with NCDs, including detailed information on diagnoses in primary and secondary health care and dispensings of prescription drugs, are the Cancer Registry of Norway, The Norwegian Patient Registry, The Norwegian Control and Payment of Health Reimbursement database, and The Norwegian Prescription Database.

The number of individuals registered annually with an NCD diagnosis and/or a dispensed NCD drug increased over the study period. Changes over time may reflect changes in disease incidence and prevalence, but also changes in disease-specific guidelines, reimbursement schemes, access to, and use of health services.

Data from more than one health registry to identify individuals with NCDs are needed since the registries reflect different levels of health care services and therefore may reflect disease severity.

Keywords: Non-communicable diseases, Multimorbidity, Cohort study, Registries, Diabetes, Cardiovascular disease, Cancer, Chronic obstructive pulmonary disease, Substance-related disorders, Mental disorders.

Word count: 3090

Rationale

Cardiovascular disease (CVD), cancer, diabetes and chronic obstructive pulmonary disease (COPD) are the main non-communicable diseases (NCDs), accounting for a major share of the disease burden in Norway and other high-income countries¹. Mental health conditions have become part of the NCD framework². WHO Europe also includes musculoskeletal diseases in the NCD concept³. Premature NCD mortality in Norway has decreased by more than 25% since 2010⁴, along with optimistic reductions in tobacco use, alcohol intake, blood pressure and blood lipids in some, but not all population groups^{5, 6}. In contrast, there has been a dramatic increase in overweight and obesity especially in those with the lowest socioeconomic position (SEP)⁷. In Norway, there is still a large variation in cancer risk across educational levels⁸, with similar patterns for the other NCDs⁹⁻¹¹. There has been a substantial decrease in the incidence of myocardial infarction and stroke, and a shift towards less severe myocardial infarctions¹²⁻¹⁴. There also seems to be a decrease in type 2 diabetes¹⁰ and in preventable cancers such as colon cancer¹⁵. The number of cancer survivors is increasing, and the risk for other NCDs, or a second cancer is unknown¹⁶. Population-based studies of multimorbidity trends for NCDs including mental health and socioeconomic status are limited, and more longitudinal data on NCD multimorbidity including mental health are needed¹⁷. We still do not know the long-term consequences of the COVID-19 pandemic on NCD burden. NCD surveillance is therefore essential. Health registries are mainly established for administrative purposes but are a vital data source for health-related research because they are fully representative of the entire non-institutionalised population. A unique personal identifier for everyone included in each registry makes it possible to couple data from different registries on an individual level. Consequently, we can use more than one health registry to identify individuals with NCDs. Data from primary health care can be compared to data from the public specialist health-care services and further for dispensed prescriptions. In Norway, we can consolidate data from several national health and administrative registries and population-based cohort studies to study the combined effects of socioeconomic circumstances, life conditions, health behaviours, biological markers, and mental health throughout the life-course on NCD outcomes. The research project “A life-course approach to prevent non-communicable diseases

(NCDs) in an ageing population – NCDNOR” has adopted this approach to prevent premature NCD mortality and identify targets for prevention¹⁸. It is, however, not straight forward to identify individuals with NCDs using registry data only. In this paper, as a first step, we count the annual number of individuals registered with NCD-diagnoses and/or -drugs in each registry.

Design

Population

The source population in NCDNOR includes all inhabitants who lived in Norway during the period 1960-2020 (N~10 million). The study population in this paper is limited to the period covered by the data sources and includes inhabitants from the period 2004-2020 (N~ 6.4 million).

Health outcomes

We have included diabetes, CVD, COPD, cancer, and mental disorders/ substance use disorders (SUD) as the main NCD outcomes¹⁸. Since there is a high excess_mortality among patients with hip fractures in Norway, these are also included¹⁹.

Data sources

Data sources are national mandatory healthcare registries that cover the entire population (Figure 1). Diagnoses are coded according to the International Classification of Diseases, 10th revision (ICD-10) and International Classification of Primary Care, 2nd edition (ICPC-2). Prescription drugs are coded according to the Anatomical Therapeutic Chemical (ATC) classification system²⁰. Codes from the registries used to identify individuals with NCDs are provided in Supplementary Table 1.

The Cancer Registry of Norway (CRN) includes ICD-10 cancer diagnoses. Data are available from 1953, and are considered to be almost complete for all cancer cases (98.6%)^{16, 21, 22}. The ICD-10 codes in CRN are converted from ICD-7 and International Classification of Diseases for Oncology, versions 2 and 3 (ICD-O-2 and ICD-O-3) using a combination of topography and morphology.

The Norwegian Patient Registry (NPR) includes data from the specialist health care, including ICD-10 codes on main and secondary diagnoses since 2008²³. The registry covers all public specialist health-

care services in Norway, including hospitals, private institutions and medical specialists in outpatient clinics contracted to the regional health authorities.

The Norwegian Database for Control and Payment of Health Reimbursement (CPHR) is an administrative registry including mainly ICPC-2 diagnosis codes from primary health care²⁴. The registry also includes some ICD-10 codes corresponding to reimbursed outpatient contacts in NPR.

The Norwegian Prescription Database (NorPD) includes individual patient data on prescriptions dispensed at community pharmacies from 2004, classified according to the ATC system²⁰, as well as ICD-10 and ICPC-2 diagnosis codes specifying the indication for use for reimbursed drugs from 2009²⁵. This registry is now replaced by the Norwegian Prescribed Drug Registry.

Identifying NCDs in national mandatory registries

The unique personal identifiers allow follow-up of individuals within and between registries avoiding duplication of individuals present in several registries. We can therefore identify those who has been registered with specific ICD-10 or ICPC-2 diagnoses or been dispensed specific prescription drugs from pharmacies identified by ATC-codes. However, not all NCDs require a prescription or medical consultation on a regular basis. A person may have an NCD without being registered within a particular time period, like a calendar year. There is no absolute agreement upon mapping of each NCD to specific diagnosis codes/ATC-codes, and incorrect NCD registrations occur. As a result, trends over time in such registrations do not necessarily reflect changes in NCD occurrence in the population.

After presenting the results for each of the six NCD outcomes separately, we present results for multimorbidity (an individual has multiple NCDs that require treatment) and comorbidity (an individual with an “index NCD” has at least one additional NCD that requires treatment), grouping mental health disorders and SUD as one NCD. We present multimorbidity in terms of the number of individuals who were registered with each of the possible combinations of the five NCDs in 2019, and comorbidity in terms of the number of hip fracture patients in 2019 who were registered with combinations of the five NCDs during the same year.

All analyses were done in R version 4.0.3²⁶. We used packages “ComplexUpset”^{27, 28}, “pBrackets”²⁹ and “RColorBrewer”³⁰ for the UpSet plots.

Basic characteristics

Diabetes

The number of individuals registered annually with a diabetes diagnosis and/or a dispensed diabetes drug increased considerably over the study period (Figure 2a). Approximately the same number of individuals were registered in NorPD and CPHR, whereas fewer were registered in NPR. This is to be expected because NPR captures diagnoses from the specialist health care, whereas CPHR covers primary care and NorPD covers prescriptions issued by both primary care physicians and by specialists. Only 9.9% were registered in NorPD only, and among these, 41% were registered in NPR and/or CPHR the previous year. Similarly, 8.8% were only registered in CPHR and among these, 22% were registered in NorPD and/or NPR the previous year (data not shown). Thus, there is a good correspondence between the registries for diabetes.

Cardiovascular diseases (CVD)

For CVD, we show the number of individuals registered with chronic CVD conditions, excluding those registered with hypertension only (Figure 2b). The registry overlap for CVD is quite different from diabetes, with 45.3% of the individuals registered with CVD in only one registry, and only 23.7% registered in all three registries in 2019. There were more men and older individuals among those who were registered in more than one registry. In CPHR, the curve was almost flat over the last eight years, and in NorPD, the majority of the increase occurred before 2014. The peak in NorPD in 2013 may be explained by altered registration routines for reimbursement codes when electronic prescriptions were introduced in 2013, affecting CVD registrations when patients are prescribed multiple drugs with several CVD indications.

Chronic obstructive pulmonary disorders (COPD)

For COPD (Figure 2c) the trend over time differs considerably in NorPD compared to NPR. In NorPD the number of individuals doubled over the 12 years, whereas in NPR it is practically unchanged. In

2019, 96% of the patients in NPR were also in NorPD and/or in CPHR. A plateau in NPR and CPHR in recent years could be explained by less smoking in Norway. COPD is usually diagnosed and treated in primary health care. Only those with severe disease are admitted to hospital or monitored in outpatient departments in secondary care. The steeper increase in NorPD compared to CPHR is probably related to the development and use of long acting beta2-agonists (LABA) and muscarine receptor antagonists (LABMA). The age and sex distributions are similar for all registry combinations.

Cancers

For cancer (Figure 2d), data from CRN are included. Most individuals with cancer are followed with regular check-ups in hospitals or primary health care some years after diagnosis, whereas the majority are only registered once in CRN. To estimate the number of individuals with cancer in CRN, we therefore have used a 5-year retrospective window, e.g. 2015-2019 for 2019. The data from NPR and CPHR show the annual number of individuals registered with a cancer diagnosis. Data from NorPD are not included in Figure 2d since most individuals with cancer receive medication in hospitals, and drugs administered in institutions (including hospitals) are not registered in NorPD.

The number of individuals with cancer registered in NPR or CPHR exceeds the number of cancer cases registered in CRN with a five-year window. In 2019, a total of 45% of the cases registered in NPR or CPHR were not registered with a cancer diagnosis in CRN in the period 2015–2019. Of these, 60% were registered with a diagnosis in CRN in 2014 or earlier. Among those registered in NPR but not in CRN, 75% were diagnosed with skin non-melanoma (ICD-10 C44), probably basal cell carcinoma, that was not included in the CRN data. The registration is based upon information from several sources, and since 2010, CRN has also received data directly from NPR. Figure 2d also shows that there is an increasing gap between the numbers registered in CRN and NPR and CPHR which may reflect the improved survival among individuals with cancer, and that they continue to have check-ups or treatment beyond a 5-year period after the cancer diagnosis. The curves for NPR and CPHR are nearly identical, and 85% of those registered in either registry in 2019 were registered in both (data not shown). The age and sex distributions are similar for all of the main registry combinations.

Mental disorders

Mental disorders (Figure 2e) were most often registered in the primary health care (NorPD and CPHR) in 2019, with 41.2% of those with mental disorders being registered only in NorPD. However, the majority (55%) of the 41.2% were also registered with a diagnosis in CPHR and/or NPR before 2019. Only 1% were registered only in NPR in 2019. The high number of individuals registered only in NorPD may reflect how many psychotropic drugs (as they are defined in this project) may have a wider use than for those diagnosed with a mental disorder. This may also reflect that most mild to moderate mental disorders are treated or followed up within primary health care.

The number of individuals who were registered annually in NorPD with at least one prescription for a mental disorder increased from 336 000 in 2004 to 479 000 in 2019. This increase of more than 40% was also observed in the other registries. The trend may be due to a 17% increase in the Norwegian population and that the threshold for seeking treatment, has been lower rather than just an increase in incidence or prevalence. There was a distinctly older age profile in 2019 in those receiving prescriptions for psychotropic drugs, but no great differences between the registries regarding sex-distribution (~ 60% women).

Substance use disorders (SUD)

Most of the individuals within our definition of SUD (Figure 2f), were registered in NPR (70%), followed closely by CPHR (62%), indicating that many individuals are examined and diagnosed in specialised health care, but then followed up in primary health care. The low number of individuals registered in NorPD (29%) may reflect that most SUD are not treated with drugs. The sharp increase in NorPD between 2012 and 2013 was due to the marketing of nalmefene (Selincro[®]), an opioid antagonist³¹. The number of individuals diagnosed annually with SUD in NPR increased from 26 000 to 45 000 during the observation period. This increase of more than 70% was similar in the other registries (except for the increase due to nalmefene in NorPD). However, as for mental disorders, this may be due to an increase in seeking treatment, rather than an increase in incidence/prevalence. There was a distinctly younger age profile among those registered in NPR, with a major overrepresentation of males in all registry combinations, except for the NorPD-only category, where 68% were women.

Multimorbidity and comorbidity

In 2019, 24.9% of the “NCD population” were multimorbid, meaning that they were registered with at least two of the five NCDs in Figure 3. The majority (75.1%; N = 1 416 649) were registered with only one NCD (Figure 3). The high proportion with only one NCD may partly be explained by different age and sex distributions within the two largest NCD groups (mental disorders and SUD with median age 47 years and 60% women and CVD with median age 71 years and 45% women). Both the age and percentage of men increases with an increasing number of NCDs. Overall, 8742 and 550 individuals were registered with 4 and 5 NCDs, respectively.

Approximately 9000 new hip fractures occur every year in Norway. Among those who had a hip fracture diagnosis code (ICD-10 S72.0-S72.2) registered in NPR in 2019, 73.9% were comorbid with at least one of the five NCDs in Figure 4. While only 26.1% had no additional NCDs, 38.7% had one additional registered NCD and 25.0% had two additional registered NCDs. The most common comorbid NCD was CVD (53%), followed by mental and drug-related disorders (26%). Here, age slightly decreases with an increasing number of comorbidities, whereas the percentage of men increases. An exception is the group with no additional NCDs, where 69% are men.

Discussion

This is the first overview of the registration of NCDs and multimorbidity, including mental disorders and SUD, in Norwegian health registries. Changes over time in the number of registrations may be due to changes in disease prevalence, although changes in factors such as disease-specific guidelines, reimbursement schemes, coding practices, access to the health services, propensity to seek treatment, and marketing of new drugs (e.g. a new opioid antagonist drug with hope for a better drug treatment of alcohol use disorder³¹) may play a role. Therefore, NCD occurrence in registries is partly influenced by other factors than disease prevalence and must be interpreted with caution – e.g. people with disease-specific expertise should consider the possible contribution of other factors before drawing conclusions. Having access to more than one health registry means that we can identify individuals with NCDs at different levels of health care services, which can indicate disease severity. Still, to

estimate prevalence and incidence, we need to combine information from several registries for some NCDs, with more than one registration per year, whereas other NCDs may only need one registration during a period of several years (e.g. cancer). Nevertheless, we benefit from combining information from several registries. Regarding the use of dispensed drug prescriptions as a proxy for disease, some drugs can be used for different diseases, but from 2009 onwards the indication for reimbursed drugs are given as ICPC-2 or ICD-10 codes in NorPD, and most drugs used for chronic diseases are reimbursed. So far, we have not planned to perform any validation studies using medical records, although it might strengthen studies using health registries.

What are the strengths and weaknesses of a register-based approach?

A major strength is that the registries are mandatory, and that we capture the use of health care for all individuals throughout their life-course and can couple information from different registries by the unique personal identifier. Health registries lack information on confounders. However, they can be coupled to data from Statistics Norway on life conditions throughout the life course, including socioeconomic status, family situation, residency and immigrant status, as well as data from large population-based cohorts on self-reported diseases and health behaviours such as smoking, alcohol use, physical activity, and measures of height, weight, lung function and biomarkers such as blood pressure, heart rate, blood lipids. Such data will be used in NCDNOR to strengthen the register-based approach¹⁸.

A plausible weakness of using health registries is misclassification of diseases, which also can be due to different access to health care among vulnerable groups or different regions of Norway. In addition, some diseases progress faster and are more severe than others, which might result in different degrees of detection. The registries also capture different time periods due to different years of inceptions (Figure 1). Thus, the time of follow-up to identify diseases, health conditions and drug use is restricted to the period from 2008 (inception of NPR) if all registries are used.

Potential impact

The overall impact of using national health registries is that we can obtain public health knowledge that can be used to translate and implement research findings into promotion and prevention strategies for the entire Norwegian population^{32, 33}. The results might also serve as sources for clinical studies aiming to obtain evidence on personalised treatment and care throughout the lifecourse³². Furthermore, we can perform cost-effectiveness analysis and develop decision analytic models for use in health economic evaluations of different types of NCD-related interventions, and stimulate high quality public health research in the future. We can also study short and long-term effects of the COVID-19 pandemic on NCD morbidity and mortality. Systematic engagement with users and stakeholders throughout the research project will enhance the impact of the outcomes and support implementation of the results³³⁻³⁵.

Ethics

The Regional Committees for Medical and Health Research Ethics South-East has approved the project (nr 28561/2019/1203). We also have an approved Data Privacy Impact Assessment.

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The project has used data from the Cancer Registry of Norway, the Norwegian Prescription Database, the Norwegian Patient Registry and the Norwegian database for Control and Payment of Health Reimbursement. The interpretation and reporting of these data are the sole responsibility of the authors, and no endorsement by the registries is intended nor should be inferred. The manuscript has been text edited by Julie Whittle Johansen.

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Data sharing statement

The authors are not permitted to share data within this research project with others. However, interested readers can apply to the Norwegian Health Data Authority and Statistics Norway to obtain access to registry data. At the end of the project period, we will publish our Data Management Plan, describing how we handled our research data throughout the project.

Disclosures

The Authors declare that there is no conflict of interest.

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Figure captions

Figure 1. Selected health registry data sources in the NCDNOR Data linkage.

Figure 2. Number of individuals, all ages, registered in NPR, CPHR and NorPD at least once during the actual year (2004–2020) with the diagnosis/drug codes for NCDs in Supplementary Table 1. **a)**

Upper left panel: Number of individuals, all ages, registered in NPR, CPHR and NorPD at least once during the actual year (2004–2020) with the diagnosis/drug codes for diabetes in Supplementary Table 1. **Lower left panel:** The percentage of the 2019 “diabetes-population” (those registered in at least one of the three registries in 2019) registered in NPR, CPHR and NorPD, respectively. **Lower right panel:** From left to right: The percentage of the 2019 “diabetes-population” registered only in NorPD, only in CPHR, only in NPR, in NorPD and CPHR, in NorPD and NPR, in CPHR and NPR, and in all three registries. **Middle and top left panels:** The sex and age distribution of the patients in each of the registry-combinations in the lower right panel. The solid lines in the violin plots denote the median and quartiles of the age distribution. The violin plots are truncated at ages 20 and 90. **b) and c):** same as a) for CVD and COPD, but NorPD starts in 2009 since ICD-10/ICPC-2 reimbursement codes are used in addition to ATC codes. **d):** same as a) for cancer, but 1 year prevalence in NorPD is replaced by 5-year prevalence in CRN. **e) and f)** same as a) for mental- and substance use disorders (SUD).

Figure 3. Multimorbidity in the “NCD-population” (those registered with at least one of the five NCDs – COPD, cancer, diabetes, CVD and mental or substance use disorders (SUD) – in NPR, CPHR, or NorPD in 2019 or in CRN in 2015 –2019). **Lower left panel:** The number of individuals with each NCD, and the percentage that this constitutes in the “NCD population”. **Lower right panel:** Number of individuals and percentage of the “disease-population” registered with each of the possible NCD-combinations. Combinations with <0.1% are not shown. The percentages above the brackets show the proportion with 1, 2, 3, and 4 different NCDs. **Middle and upper left panels:** The sex and

age distribution of the patients in each of the registry-combinations in the lower right panel. The horizontal lines in the violin plots indicate median and quartiles. The median age and the percentage of men among those with 1, 2, 3, and 4 NCDs are shown in text.

Figure 4. Comorbidity of the five NCDs – COPD, cancer, diabetes, CVD and mental- or substance use disorders (SUD) – in the “hip-fracture-population” (those registered in NPR in 2019 with an ICD-10 diagnosis S72.0-S72.2). **Lower left panel:** The number of individuals and percentage of the “hip-fracture-population” registered in NPR, CPHR, NorPD 2019 or CRN 2015-2019 with each of the other NCDs. **Lower right panel:** Number of individuals and percentage of the “hip-fracture-population” registered with the possible NCD-combinations. Combinations with <0.1% are not shown. The percentages above brackets show the proportion with 1, 2, 3, and 4 different NCDs. **Middle and upper left panels:** The sex and age distribution of the patients in each of the registry-combinations in the lower right panel. Sex distribution is not shown for combinations with <5 men or <5 women. The horizontal lines in the violin plots indicate median and quartiles. Age distribution is not shown for combinations with <20 individuals. The median age and the percentage of men among those with 0, 1, 2, and 3 comorbidities are shown in text.

FIGURES

Figure 1

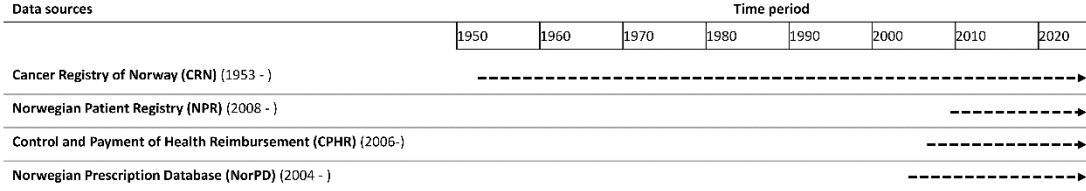


Figure 2

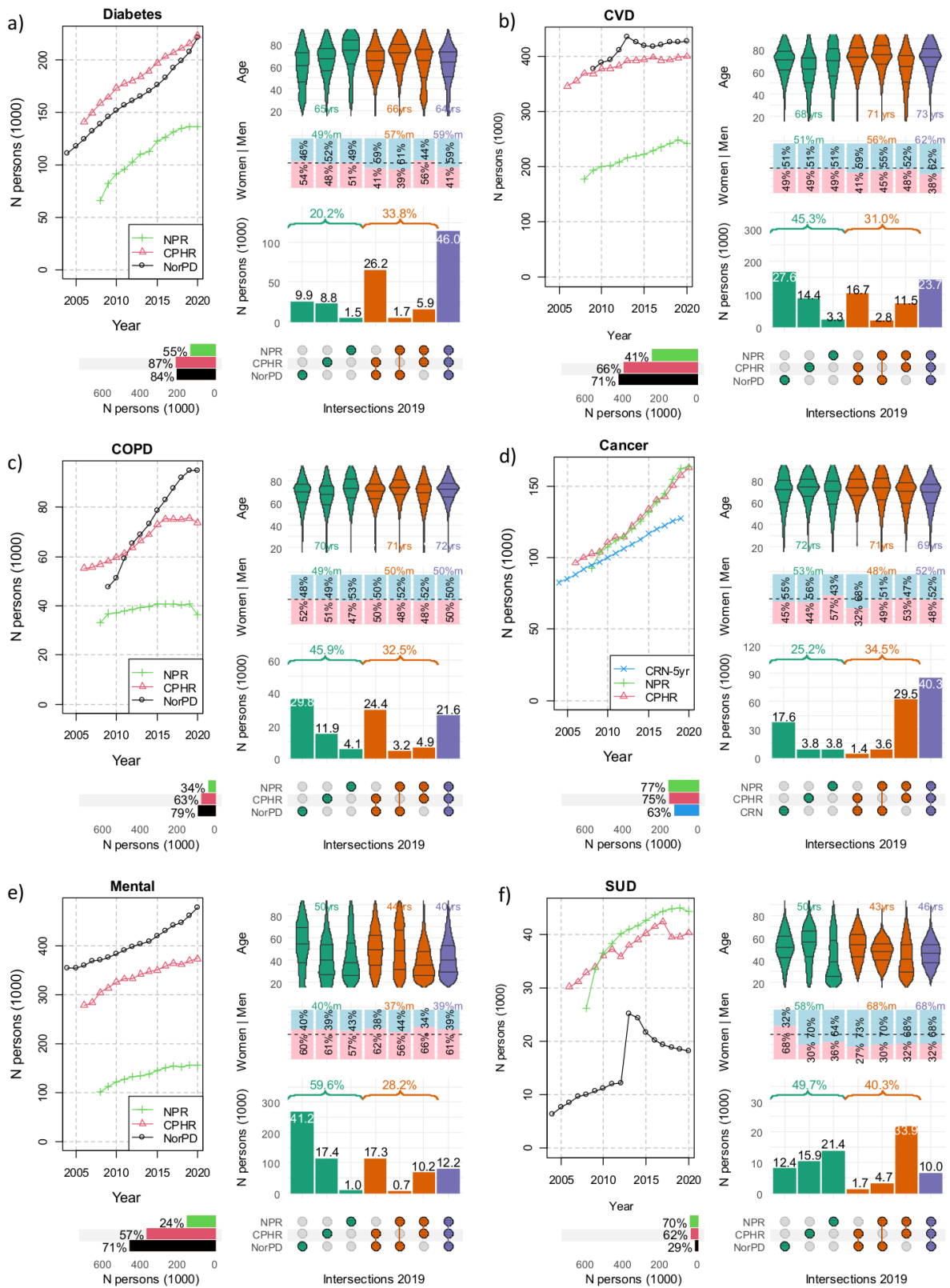


Figure 3

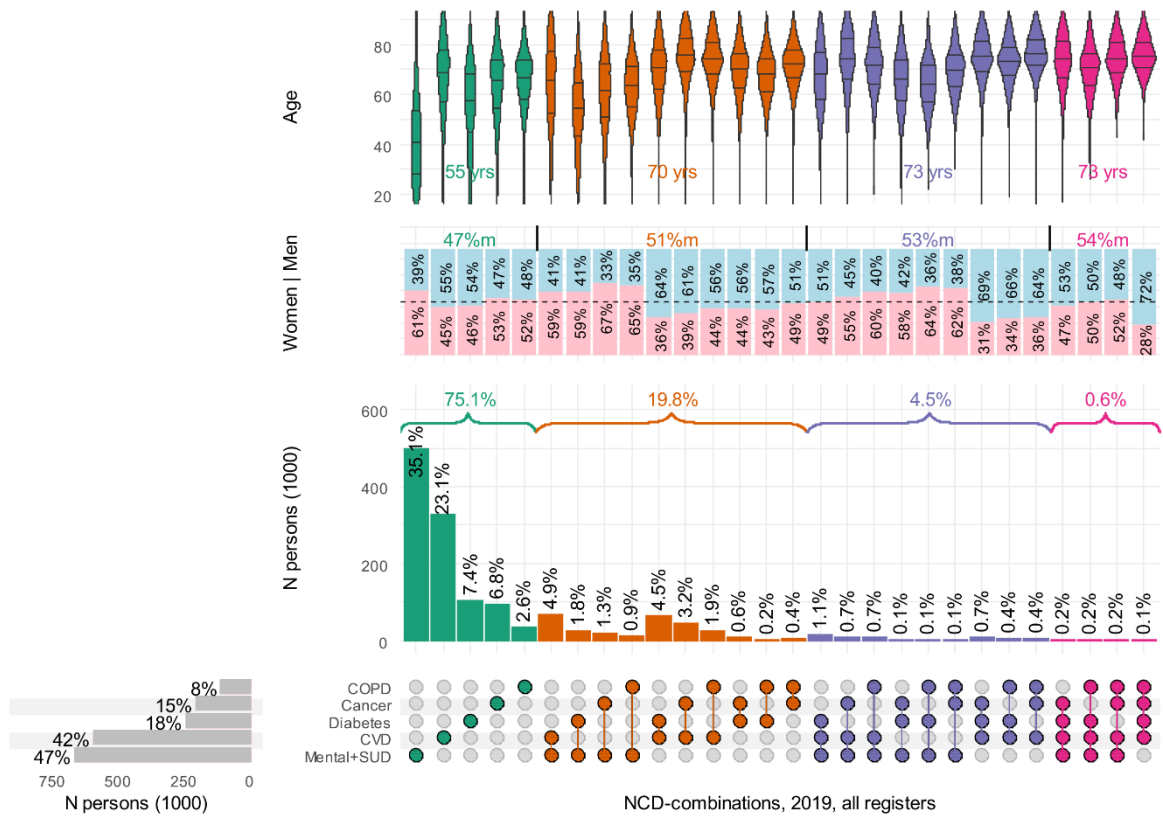
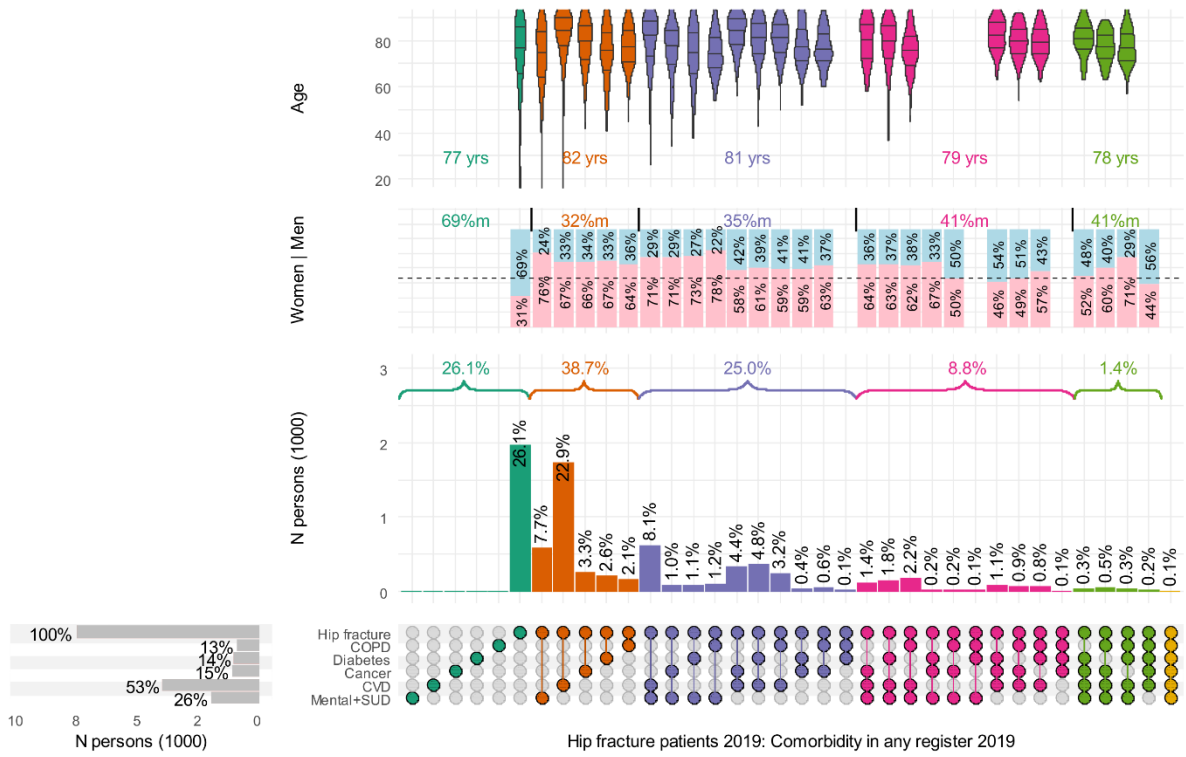


Figure 4



Supplementary Table 1. Diagnosis- and ATC-codes used to identify persons with non-communicable diseases (NCDs) described in Figure 2, 3 and 4.

| NCD | ICD-10 (NPR, CPHR) | ICPC-2 (CPHR) | ATC (NorPD) |
|------------------------------|---|--|---|
| a) Diabetes | E10-E14, O244 | T89-T90, W85 | A10A, A10B |
| b) CVD | I00-I99, except I00-I02, I10, I269, I281-I309, I312-I339, I40-I41, I76, I781-I789, I80-I81, I822, I824, I826, I828, I829, I83, I86, I871-I872, I878-I880, I888-I889, I95, I96, I973-I999 | K70-K99, except K86, K88, K93, K95, K96, K99 | B01, C, except C01C, C05, C10, <i>reimbursed with an ICD-10 or ICPC-2 code corresponding to the CVD definition for NPR and CPHR</i> |
| c) COPD | J43-J44 | R95 | R03AC R03AK, R03AL, R03BB, R03DA, R03DX07 <i>(except R03AC02, R03AC03, R03AC04), reimbursed with J43-44 or R95</i> |
| d) Cancer | C00-C96 | A79, B72-B74, D74-D77, R84-R85, L71, N74, S77, T71, U75-U77, W72, X75-X77, Y77-Y78 | NorPD replaced by CRN with 5-year look-back (ICD-10: C00-C96) |
| e) Mental disorders | F20-F48 | P72-P79, P82, P98 | N05A, N06A, N06BA |
| f) Drug-use disorders | F10-F19, G312, G621, G721, I426, K292, K700-K704, K709, K860, O354, P043, Q860 | P15-P16, P18-P19 | N07BB, N07BC |

NCD, Non-communicable diseases; ICD-10, International Classification of Diseases - 10th revision; ICPC-2, International Classification of Primary Care - 2nd edition; ATC, Anatomical Therapeutical Chemical system; NPR, Norwegian Patient Registry; CPHR, Norwegian database for Control and Payment of Health Reimbursement; NorPD, The Norwegian Prescription Database; CVD, Cardiovascular diseases; COPD, Chronic obstructive pulmonary disease; CRN, the Cancer Registry of Norway.