The NOREPOS* Hip Fracture Database: Method for collection and quality assurance of hip fracture data from Norwegian hospitals 1994-2008

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* NOREPOS (The NORwegian EPidemiologic Osteoporosis Studies) is a collaboration

between epidemiologic osteoporosis studies, which are sub-studies within large population-

based surveys in four districts of Norway (Tromsø, Nord-Trøndelag, Hordaland, Oslo). The

NOREPOS Hip fracture Database includes all hospitalizations for hip fracture in Norway.

SUMMARY

- During 2009-2011, NOREPOS (Norwegian Epidemiologic Osteoporosis Studies) established a database consisting of all hip fractures treated in Norwegian hospitals during the 15-year period 01.01.1994 - 31.12.2008.

- Hip fracture data were retrieved by a system developed by the Norwegian Knowledge Centre for the Health Services, which was linked to the Patient Administration System (PAS) in 48 hospitals/health trusts performing hip fracture surgery in Norway.

- All stays in hospital with a primary or secondary diagnosis code matching the ICD-9 code 820 (all subgroups) or the ICD-10 codes S72.0, S72.1, and S72.2 were retrieved.

- Information about secondary diagnoses (up to 20) and surgical procedures (up to 31) from all patients with a hip fracture diagnosis was obtained.

- A combination of surgical procedure codes, diagnosis codes, and time between hospital stays was used to separate hospital admissions for *incident* fractures from re-hospitalizations/complications. Based on accompanying diagnoses codes and surgical procedure codes, all records were classified to represent an *incident* hip fracture; a *possible* hip fracture, or an *not incident* hip fracture. Orthopaedics were consulted during the classification process. The *incident* hip fractures 1) had surgical procedure codes characteristic for a primary hip fracture surgery (including surgical procedure code indicating hemiarthroplasty occurring without any accompanying reoperation codes) or 2) was the individual's first or only admission but had no surgical procedure codes. The *possible* hip fractures were hospital stays with information indicating an *incident* hip fracture but they had additional ambiguous diagnosis codes and/or surgical procedure codes. Based on results from our validation study, both hospitalizations classified as *incident* or *possible* were counted as *incident* fractures.

- A patient`s second hip fracture was counted only if the hospitalization was registered more than three weeks after the first – and both hospitalizations were classified as either *incident* or *possible* (see description above). A maximum of two hip fractures were counted per person.

- A total of 139,913 hospital admissions (in 126,026 subjects) were classified as *incident* hip fractures.

- Hip fracture data from each hospital were carefully evaluated. In case of irregular patterns over time, hospitals were contacted. Incomplete data were discovered for four hospitals in the first five years of the registration period, and data were lost at one of the hospitals in 1997 due to conversion to a new PAS.

- To assess the validity of our classification of records, the NOREPOS hip fracture database was merged with local hip fracture registries from Oslo and Tromsø. The combined Cohen's kappa for the comparisons was 0.95.

INTRODUCTION

In 2009-2010, all hip fractures treated in Norwegian hospitals during a 15-year period from 1994 (the first year almost all somatic hospitals in Norway used electronic Patient Administration Systems (PAS)) up to and including 2008 were retrieved electronically, providing a historic database of hip fractures.

The linkage process

The fracture data were collected in order to be linked in an encrypted way to the following databases:

- Cohort of Norway (CONOR) (10 health surveys in Norway 1994-2003)(1, 6)
- NOREPOS (bone mineral density (BMD) measurements from four study sites – 1994-2001) (2, 10)
- Statistics Norway (socioeconomic, demographic, country of birth and family data, Census 1960, 1970, 1980,1990 and 2001) (4)
- The National Population Register (date of death, change of residency, emigration)
- The Cause of Death Registry (cause of death) (1994-2009)
- The Norwegian Waterworks Register 1994-2008
- The Norwegian Prescription Database (NorPD)(3)

The purposes of creating this large hip fracture database were among other things:

- To establish the incidence of and survival after hip fractures in the Norwegian population
- To study whether incidence and survival rates of hip fracture differ as a function of time
- To study whether incidence and survival rates of hip fracture differ according to socioeconomic status and geographic location
- To explore the effects of possible mediating variables including smoking, body mass index and physical activity, nutritional factors, and drinking water quality
- To be able to disclose areas with excess fracture incidence not recognized by analyses comparing administrative units such as counties (using Geographical Information System – GIS)
- To study associations between water quality variables from the Norwegian Waterworks Register, BMD and hip fractures
- To investigate whether use of anti-osteoporosis medication among hip fracture patients are equally distributed according to social background and geography, and to study the association between drug-use in general - and hip fractures and death.

DATA COLLECTION
A system called FS (Forskning i sykehus; "Research in hospitals") was used to extract data from the hospitals. The FS-system is a modular system of MS Access databases. It is designed and developed by System Architect Tomislav Dimoski in close cooperation with the developers of Patient Administration Systems (PAS) or IT specialists within the hospitals. The system has also been used for other purposes and validated (9).

Hospital data
The program was installed at the hospital and the system imported the data from PAS, and constructed a dataset that described a hospital stay. The FS-system generated encrypted personal identifiers and encrypted hospital stay identifiers and selected the index admission upon specific criteria.

All hospitalizations occurring between 1994 and 2008 given a diagnosis code for hip fracture were retrieved using the hospital component of the FS-system. These codes included:

ICD-9: 820 with all subgroups
ICD-10: S72.0, S72.1, and S72.2

Additional information retrieved for each record were:
Hospital
Hip fracture code as main or secondary diagnosis
Main diagnosis code
Secondary diagnosis codes (up to 20 codes)
Surgical procedure codes (up to 31 codes)
Date and time of admission
Date and time of discharge
Gender
Year of birth
Age at discharge

The transfer of the data was handled by the Norwegian Knowledge Centre for the Health Services NOKC through contacting the 48 hospitals/health trusts (Appendix) in Norway where hip fractures have been treated during 1994-2008.

Combination of data via Statistics Norway
The FS-system exported a limited set of background data from the hospital to Statistics Norway (SSB) - and the hip fracture data (with an encrypted personal identifier for each patient) to NOKC.

Data treatment at the Norwegian Knowledge Centre for the Health Services (NOKC)
The FS-system at the NOKC reconstructed the pieces of information coming from PAS, and Statistics Norway into a dataset describing a patient's index admission within one or several hospitals. If a patient was transferred between hospitals, the FS-system identified the transfer.
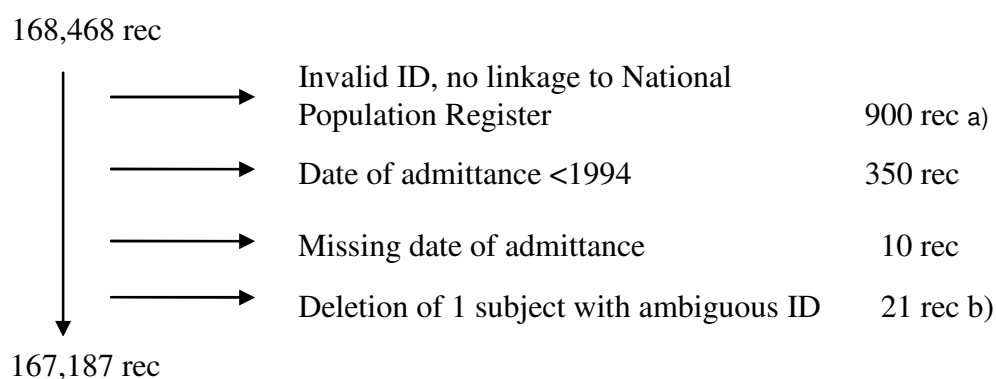
Data file preparation at the Norwegian Institute of Public Health
Trough a complex system of personal identifiers and temporary identification numbers, the hip fracture data were received by the researchers at the Norwegian Institute of Public Health as pseudonymous data - i.e. each record contained a unique number unable to trace back to the person's identity. The data were managed in the statistics software SPSS for Windows, version 17.

Each hospital stay for a patient was recorded as a record in the data file, and transfers were cataloged as part of the index admission. However, for admissions involving transfers to other hospitals, or transfers between departments or units within a hospital where time at discharge from the first unit did not correspond to time at admittance to the next unit, each unit stay would represent a record, and one hospital stay for a patient could thus result in two or more records. The number of hospital stays per patient varied from 1 to 54.

As each record in principal, but not consequently so in practice, corresponds to a hospitalization, they will henceforth be referred to as "records" and not as "hospitalizations".

The dataset received from the Norwegian Knowledge Centre for the Health Services included 168,468 records (Figure 1), and after data-cleaning, a total of 167,187.

168,468 rec

Invalid ID, no linkage to National Population Register	900 rec a)
Date of admittance <1994	350 rec
Missing date of admittance	10 rec
Deletion of 1 subject with ambiguous ID	21 rec b)

167,187 rec

Figure 1. Number of hospital stays (records) in the data file through the data clearance process. The NOREPOS Hip Fracture Database 1994-2008

a) 900 records had invalid IDs, and could not be identified as they had no corresponding running numbers in the National Population Register (NPR). At one hospital NOKC were able to scrutinize the records with invalid ID. Of 21 such records 18 were foreigners, 1 had incorrect ID in PAS (correct ID found in NPR) and 2 were not found in the NPR despite that they were Norwegians living in Norway. Thus we assume that a large proportion of these 900 are likely to be foreigners who have no Norwegian ID or have received a temporary identification number in the system
b) One patient who had 21 records was excluded as the project specific ID-number was associated with several identities (different years of birth) (discovered when the hip fracture database was linked to the file with socioeconomic data).

Ethics and approvals
The electronically retrieval of data from PAS and the combination of the data were approved by the Data Inspectorate of Norway, the Regional Committee for Medical and Health Research Ethics, the Norwegian Directorate of Health and all the owners of the registers and databases mentioned above. All participants in CONOR and NOREPOS have given their written informed consent.

CODING OF DATA AT THE NORWEGIAN INSTITUTE OF PUBLIC HEALTH

The aim was to categorize all records into one of three categories (*incident, not incident, or possible hip fracture*), and three intermediate variables (A-C) were made to accomplish this categorization.

Intermediate variables *(A-C)*
(numbers in brackets are values of the variable)

A. *Diagnosis code* (variable referred to as "hip fracture code")
- as main diagnosis (1)
- as secondary diagnosis (2)
- missing code; applicable only for 19 records (0)

B. *Presence or absence of other ICD-9/ICD-10 diagnosis codes* (variable referred to as "other diagnosis codes")
- No other diagnosis code except hip fracture (1)
- Diagnosis code for sequela /mechanical complications following hip fracture surgery (2)
- Diagnosis code for rehabilitation or medical conditions which are common after hip fracture surgery, e.g. deep vein thrombosis or pressure sore (3)
- As above but as primary diagnosis as opposed to secondary diagnosis (4; later abandoned)
- All other (no relevant) diagnosis codes (5)

C. *Presence or absence of certain specific surgical procedure codes* (The NOMESCO Classification of Surgical Procedures; NCSP, and Klassifikasjon av operasjoner. 3. versjon. Oslo: Statens helsetilsyn/Statens institutt for folkehelse, 1994) (variables referred to as "procedure codes")
- No surgical procedure codes (1)
- Surgical procedure codes common for a primary hip fracture (2)
- Surgical procedures which may represent both primary hip fractures and revisions, i.e. hemiarthroplasty or total hip replacement (3)
- Surgical procedures which always imply revision (4)
- Both of the above, i.e. 2 and 4 (5)
- All other (no relevant) surgical procedure codes (6)

Based on these intermediate variables, three different categories were made:
1. *incident* hip fracture
2. *not incident* hip fracture
3. *possible* hip fracture

Possible hip fractures were divided into several subgroups (category 3+ 31-37) according to combination of diagnosis and procedure codes and this resulted in the categories in Table 1. Hospitalizations coded as 2 or 3 (see Table 1) were excluded, whereas categories 31-37 were kept.

Table 1. Categories of conclusion regarding hip fracture.The NOREPOS Hip Fracture Database 1994-2008

Value	Category	Criteria
1	An incident hip fracture	Procedure codes typical for a primary hip fracture surgery (procedure codes = 2 or procedure codes = 5)
2	Not an incident hip fracture	Procedure codes that always imply revision (procedure codes = 4)
3	Not an incident hip fracture	Hospital stay lacking procedure codes. Including hip fracture code only. It is not the first or only hospital stay for the individual.
31	Possible hip fracture, subgroup I	Hospital stay lacking procedure codes. Including hip fracture code only. It is the first or only hospital stay for the individual.
32	Possible hip fracture, subgroup II	The patient has received hemiarthroplasty or total hip replacement and it seems to be a primary operation; there are no present codes that imply that this may be a revision. Procedure codes=3 (not 2 or 4), and other diagnosis codes ≠ 2.
33	Possible hip fracture, subgroup III	There are procedure codes, but no relevant such (procedure codes = 6)
34	Possible hip fracture, subgroup IV	The hip fracture is main diagnosis. The hospital stay includes codes for rehabilitation but no procedure codes. (hip fracture code=1; other diagnosis codes=3; procedure codes=1)
35	Possible hip fracture, subgroup V	Hospital stay with hip fracture as secondary diagnosis, includes diagnosis codes for rehabilitation or medical complications, but no surgical procedures or no relevant surgical procedures. (hip fracture code=2; other diagnosis codes=2 or 3; procedure codes=1 or 6)
36	Possible hip fracture, subgroup VI	Hospital stay with hip fracture as secondary diagnosis, includes diagnosis codes for rehabilitation or medical complications, and hemiarthroplasty or total hip replacement. (hip fracture code=2; other diagnosis codes=2 or 3; procedure codes=3)
37	Possible hip fracture, subgroup VII	Hospital stay with hip fracture as primary diagnosis, hemiarthroplasty or total hip replacement as procedure codes, and including diagnosis codes for sequela/mechanical complications. (hip fracture code=1; other diagnosis codes=2; procedure codes=3 (not 2 or 4).)

Time between hospital admissions or transfers
After giving each record a conclusion regarding fracture status, time between hospital stays was taken into consideration. (Multiple records for the same incident had been recorded if time between two hospital admissions was >0 (for example if a patient was transferred to

another hospital). Likewise, if time between internal hospital transfers (between wards) was >0, multiple records had been recorded for the same hospital stay).

We counted only one fracture if time between two records was less than three weeks (504 hours). The rationale was that the majority of hospitalizations occurring within 0-3 weeks after the first fracture are due to re-hospitalization rather than new hip fractures.

If two records occurred <504 hours apart, one of the records were coded as *not incident* fracture (=2). Generally, if two records with conclusion incident (1) or possible (33-37) hip fracture occurred <504 hours apart, the latest record was recoded into *not incident* fracture.

However, there were some exceptions:
If possible records (conclusion 33-37) occurred before (<504 hours) an incident record, the incident record was counted (possible was recoded into *not incident* fracture).

If 31 (the individual's first entry, missing surgical procedure codes) occurred (<504 hours) before 32 (hemiarthroplasty), 31 was recoded into *not incident* fracture.

If 32 (hemiarthroplasty) occurred (<504 hours) before an incident record, 32 was recoded into *not incident* fracture.

Deletion of records classified as *not incident* fracture
All records classified as *not incident* fracture were deleted (n=27,274), and a total of 139,913 hospitalizations were kept in the dataset.

**Table 2.** Number of records in final dataset by category of conclusion* The NOREPOS Hip Fracture Database 1994-2008

Conclusion*	n	Percent of all fractures
1	108,555	77.6
31	7,277	5.2
32	15,737	11.2
33	6,075	4.3
34	941	0.7
35	859	0.6
36	169	0.1
37	300	0.2
Total	139,913	

*The different categories are described in Table 1.

Recoding of possible fractures
The codes 31 and 32 were coded as incident, whereas 33-37 were coded as possible. These decisions were based on discussions in a group of experienced orthopedics and epidemiologists with in-depth knowledge in the field.
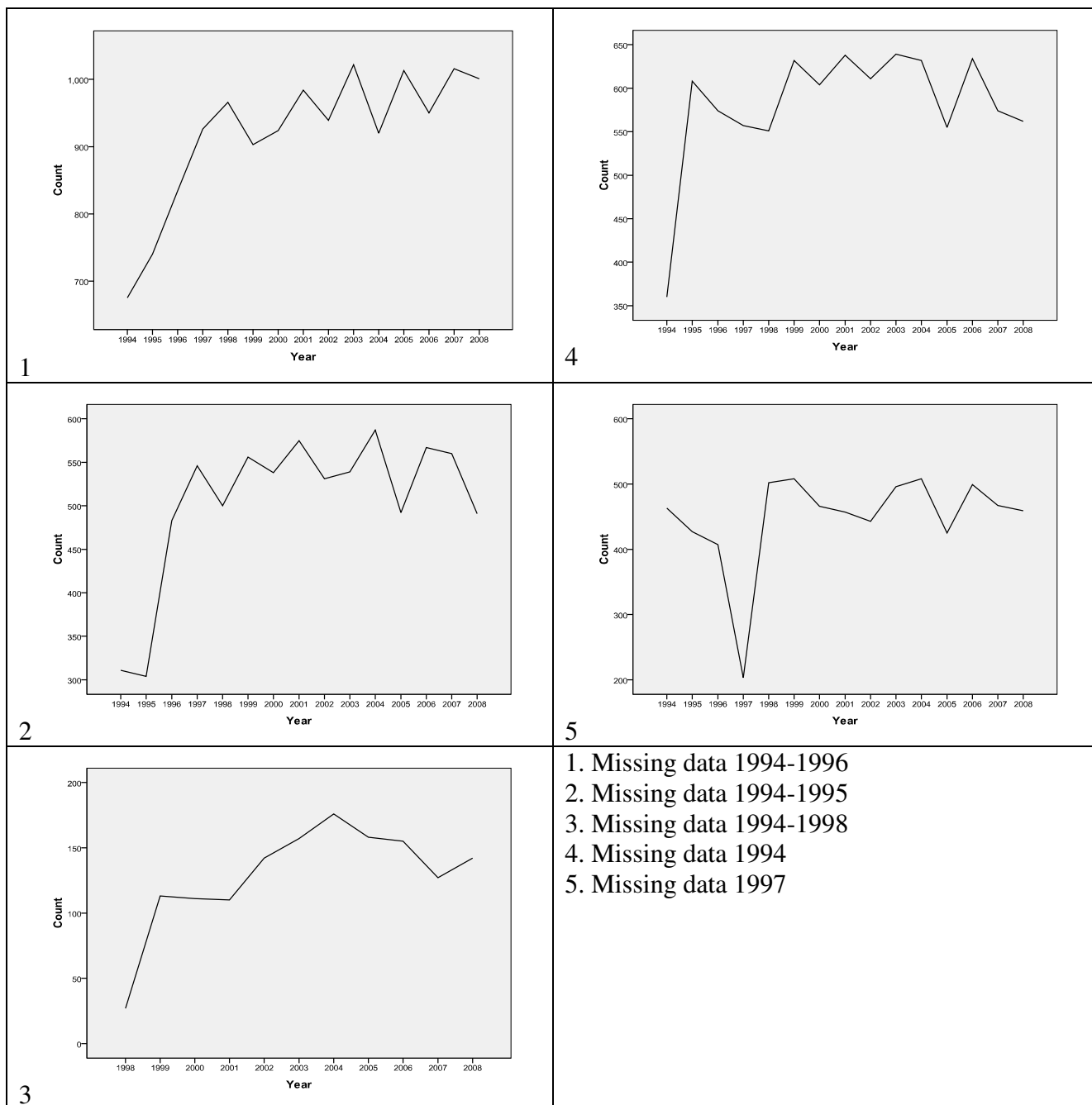
Figure 2. Number of *incident* fractures by year at hospitals with incomplete data. Data from the other 43 hospitals/hospital trusts (not shown) were either stable or irregularities could otherwise be explained. The NOREPOS Hip Fracture Database 1994-2008

VALIDATION OF THE DATA AGAINST THE NORWEGIAN PATIENT REGISTRY

Data in the Norwegian Patient Register (NPR) were not personal identifiable before 2008 and is therefore likely to overestimate the number of fractures in this period. The comparison in Figure 3 shows a different pattern in 1997 and 1998 compared to most later years which might be explained by the incomplete data in the beginning of the registration period (see Figure 2). There was also a peak in 2003-2004 in NPR data but not in NOREPOS, which possibly is an artifact caused by changes in the organization of hospitals in NPR.
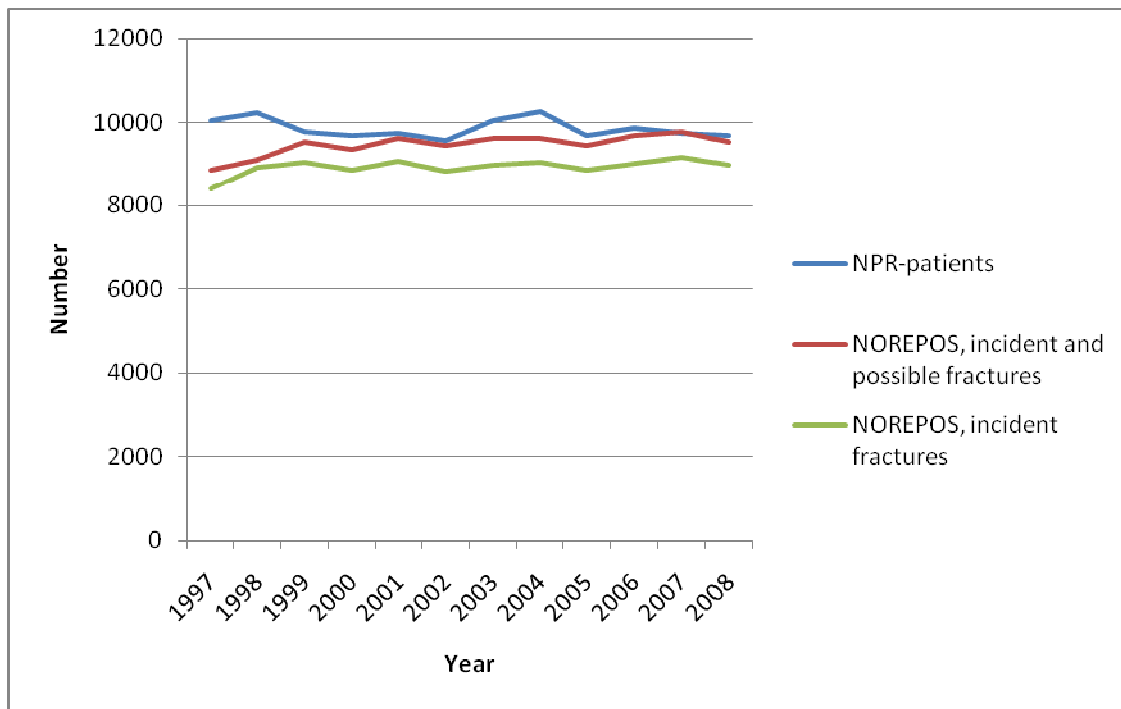
Figure 3. Comparison of data in the NOREPOS Hip fracture database with data from the Norwegian Patient Registry 1997-2008.
Abbreviations: NOREPOS; Norwegian Epidemiologic Osteoporosis Studies, NPR; Norwegian Patient Register
 "NPR-patients" are subjects hospitalized at least once during a calendar year in a specific institution. Subjects hospitalized in another institution or another calendar year are counted more than once as "patients". NOREPOS-up to two fractures were counted per person.

VALIDATION OF THE DATA WITH LOCAL FRACTURE REGISTRIES

The Oslo Health Studies
This database includes data from all hip fracture patients at five hospitals in Oslo (2000-2006) who participated in The Oslo Study II (2000). The Oslo Health Study (2000-2001) and the Oslo Immigrant Study (2002) (5). Response rates and selection problems in the Oslo Health Studies have been published (7).

There was a wider search in this hip fracture data collection compared to that used in the NOREPOS hip fracture database. The search protocol used for searches in PAS for the Oslo Health Studies database included S72 with all subgroups (fractures of the femur) as well as the diagnosis codes T02.3, T02.5, T02.6 (fractures at several sites of one or two under-extremities). In addition, a search for the surgical procedure codes NFB (Primary prosthetic replacement of hip joint), NFJ with all subgroups (fracture surgery of femur) and TNF40 (traction of hip or thigh) was also performed for the Oslo Health Studies database. This was in order to capture possibly miscoded hip fracture admissions. The hip fractures in The Oslo Health Studies database were verified in patients' medical records and thus represent true hip fractures.

Comparison of hip fractures from The Oslo Health Studies and NOREPOS:

Table 3. Validation of the NOREPOS* hip fracture database by individual comparison with hip fractures verified in medical records from The Oslo Health Studies.

Hip fracture		The Oslo Health Studies		
		No	**Yes**	**Total**
NOREPOS*	**No**	31,512	9	31,521
	Yes	10	286	296
	Total	31,522	295	31,817

* NOREPOS - Norwegian Epidemiologic Osteoporosis Studies. All hip fractures coded as incident and possible in the NOREPOS Hip Fracture Database were included.

Agreement
A total of 286 patients had one or more fractures according to both databases, while they both concluded "no fracture" for 31,512 subjects.

Misclassifications
A total of 10 subjects were coded as fracture in the NOREPOS database only (blue in table 3). The reasons for the misclassification was incorrect ICD coding in PAS (5 had a metastasis fx, 1 had a fall, but no fracture, 1 had an old fx, 3 had other fx (femur shaft, distal femur, humerus)). On the other hand, 9 subjects (red in table 3) were classified as "no fracture" by the NOREPOS database, but had a fracture when verified in patient journals. The reasons for the discordances were as follows: 2 records occurred after follow-up in The Oslo Health Studies (i.e. was probably correct classified), 3 fx were missing for unknown reason, 1 had ICD 10 higher than S72.2 (but was a hip fx), 2 records did not have an ICD-code (only NFB/NFJ), 1 record coded as "no fracture" by the NOREPOS-database.

The Tromsø study
Participants who met to the fourth health study in Tromsø were included (Tromsø 4) in 1994-1995 (N=26,957). The fracture registry was based on computerized records in the radiographic archives at the University Hospital in Tromsø. These archives contain the national personal identification number, time of investigation, fracture codes and descriptions. All radiographic examinations coded abnormal on participants in the Tromsø IV survey were reviewed to ascertain the fracture code, to identify exact fracture type and anatomical location, to distinguish consecutive fracture cases from one another and to capture fractures that had not been coded correctly. In addition, the discharge records were checked with respect to hip fractures. The registry in Tromsø does not include subtrochanteric fractures. The fracture registry in Tromsø has been validated (8).

Fracture data was available from Tromsø 4 until 31. December 2008.
Comparison of fractures from Tromsø 4 and NOREPOS:

Table 4. Validation of the NOREPOS* hip fracture database by individual comparison with hip fractures verified in the x-ray registry in Tromsø

Hip fracture		Tromsø 4		
		No	**Yes**	**Total**
NOREPOS*	**No**	26,187	48	26,235
	Yes	38	684	722
	Total	26,225	732	26,957

*NOREPOS - Norwegian Epidemiologic Osteoporosis Studies. All hip fractures coded as incident and possible in the NOREPOS Hip Fracture Database were included.

Agreement
A total of 684 patients had one or more fractures according to both databases, while they both concluded "no fracture" for 26,187 subjects.

Misclassifications
As the registry in Tromsø did not include subtrochanteric fractures as hip fractures (but as femur fracture), some of the misclassifications are due to this.

In 38 subjects a fracture was registered in NOREPOS but not in the Tromsø archives (blue in table 4). Because Tromsø register all types of fractures, it was discovered that 15 of these subjects had a femur fracture (including subtrochanteric fractures), whereas two subjects had a pelvis fracture. A total of 14 of the 38 subjects had been registered with a hip fracture in other hospitals in Norway than at the Tromsø University Hospital. Thus they were not misclassified.

In 48 cases (red in table 4) a fracture was registered in Tromsø but not in NOREPOS, but further information about these 48 cases is not available.

Calculation of Cohen's kappa
Comparisons from the two health studies (Table 3 and Table 4) were summarized before calculations were performed. The combined Cohen`s kappa was 0.95.

Appendix. List of hospitals included in the NOREPOS Hip Fracture Database

- Finnmark Hospital, Kirkenes
- Finnmark Hospital, Hammerfest
- University Hospital of North Norway, Tromsø
- University Hospital of North Norway, Harstad
- University Hospital of North Norway, Narvik
- Nordland Hospital, Bodø
- Nordland Hospital, Lofoten
- Nordland Hospital, Vesterålen
- Helgeland Hospital, Mo i Rana
- Helgeland Hospital,Sandnessjøen
- Helgeland Hospital, Mosjøen
- Namsos Hospital
- Levanger Hospital
- St. Olavs Hospital, Trondheim University Hospital
- Orkdal Hospital
- Kristiansund Hospital
- Molde Hospital
- Ålesund Hospital
- Volda Hospital
- Førde Health Trust (21.4.2006-31.12.2008)
- Førde Health Trust – Førde Central Hospital (1.1.1994-21.4.2006)
- Førde Health Trust – Nordfjord Hospital (1.1.1994-21.4.2006)
- Førde Health Trust – Lærdal Hospital (1.1.1994-21.4.2006)
- Bergen Health Trust - Haukeland University Hospital
- Bergen Health Trust – Voss Hospital
- Haraldsplass Diaconal Hospital, Bergen
- The Coastal Hospital in Hagevik
- Fonna Health Trust – Odda Hospital
- Fonna Health Trust – Stord Hospital
- Fonna Health Trust - Haugesund Hospital
- Stavanger Health Trust – Stavanger University Hospital
- Blefjell Hospital, Rjukan
- Blefjell Hospital, Kongsberg
- Blefjell Hospital, Notodden
- Telemark Hospital Skien/Porsgrunn
- Ringerike Hospital including Hallingdal sjukestugu
- Innlandet Hospital Trust
- Østfold Hospital Trust (Fredrikstad, Moss, Halden, Sarpsborg, Askim)
- Vestfold Hospital (Tønsberg, Larvik, Sandefjord)
- Buskerud Hospital, Drammen
- Akershus University Hospital
- Aker University Hospital HF (including Ski)
- Ullevål University Hospital
- Rikshospitalet University Hospital
- Diakonhjemmet Hospital, Oslo
- Lovisenberg Diaconal Hospital, Oslo
- Asker and Bærum Hospital Trust
- Sørlandet Hospital HF (Kristiansand, Arendal, Flekkefjord, Mandal)

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