

## **Health Classifications in the Nordic Countries**

Historic development in a national and international perspective 2006

***Hälsoklassifikationer i de nordiska länderna***

*Den historiska utvecklingen i ett nationellt och internationellt perspektiv 2006*



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## *Hälsoklassifikationer i de nordiska länderna*

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**Björn Smedby och Gunnar Schiøler**

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## Preface

### *Förord*

At the present time, a new generation of experts working with classifications within the health sector is taking over. Although it is positive that young colleagues are interested in this important field, and that they are enthusiastic about this work, there is a risk that important knowledge about the development of the classification systems can be lost and forgotten.

Since the end of the 19th century, classification of diseases has been an international matter. From working only with mortality statistics, national and international authorities have realized more and more that there is a need for improved knowledge about all aspects of health care – including knowledge about diseases and their causes – as a means of improving population health. In this context classification systems are important tools.

During the years between the First and Second World Wars, the Nordic countries began to cooperate on health statistics and classifications. In the 1950s, influenced by international developments under the leadership of the World Health Organisation, they realized that this cooperation should be developed further. However, it became clear that the available statistics were developed in such different ways, that direct comparison of data from the five countries was difficult or even impossible.

I disse år sker der et generationsskifte i gruppen af nordiske eksperter, der beskæftiger sig med klassifikationer inden for sundhedsvæsenet. Lige så positivt det er, at der også blandt nye medarbejdere er interesse for og engagement i dette vigtige område, lige så sikkert er det, at der er risiko for, at vigtig viden og erindring om klassifikationernes udvikling kan gå tabt.

Siden slutningen af det 19. århundrede har sygdomsklassifikation været et internationalt anliggende. Fra kun at beskæftige sig med dødsårsagsstatistik har nationale og internationale myndigheder i større og større omfang erkendt behovet for øget viden om alle dele af sundhedsvæsenet og ikke mindst viden om sygdom og sygdomsårsager som middel til forbedring af folkesundheden. Klassifikationer er et vigtigt redskab i denne sammenhæng.

De nordiske lande havde allerede i mellemkrigsårene påbegyndt et begrænset samarbejde om helsestatistik og klassifikationer, og i 1950'erne indså man under indtryk af den internationale udvikling på området under Verdenssundhedsorganisationens ledelse, at de nordiske lande burde samarbejde også på dette område. Det viste sig imidlertid, at de statistikker, der var til rådighed, var tilvejebragt på et så forskelligt grundlag, at direkte sammenligning mellem de fem lande var vanskelig for ikke at sige umulig.



In 1966, this realization led to the formation of a committee under the Nordic Council of Ministers to remedy this shortcoming. The Nordic Medico-Statistical Committee (NOMESCO) has undertaken many tasks, first within health statistics, and later within coordination and development of classifications, with the aim of supporting common Nordic health statistics. Work with the development of classifications, and coordination with WHO and other international statistical bodies, led to the formation of a Nordic centre for classifications. After some years as a project under the Nordic Council of Ministers, in 1996 the Nordic Centre for Classification of Diseases was established as a Nordic institution financed directly by the health authorities of the five countries.

On the occasion of NOMESCO's 40th anniversary, and the 10th anniversary of the Nordic Centre for Classification of Diseases as a Nordic institution in its own right, these two Nordic cooperation projects have shown their justification and viability. We have therefore asked two experts who will soon be retiring from their work with Nordic classifications to impart their knowledge and experience in the form of this publication.

We wish to thank professor Björn Smedby and consultant Gunnar Schiøler for their willingness to undertake this task.

Tromsø, June 2006

*Mika Gissler*  
Chair

NOMESCO

*Formand*  
NOMESKO

Denne erkendelse førte i 1966 til dannelsen af en komite under Nordisk Ministerråd, som skulle råde bod på disse mangler. Nordisk Medicinalstatistisk Komite (NOMESKO) har påtaget sig mange opgaver først inden for helsestatistikken, men efterhånden også med koordination og udvikling af klassifikationer, som kunne understøtte en fælles nordisk helsestatistik. Arbejdet med udvikling af klassifikationer og med koordinationen til WHO og andre internationale statistiske institutioner førte efterhånden til dannelsen af et nordisk klassifikationscenter i Uppsala, som efter en årrække som projekt under Nordisk Ministerråd i 1996 blev omdannet til en fællesnordisk institution finansieret direkte af de fem landes sundhedsmyndigheder.

I anledningen af NOMESKO's 40 års jubilæum og i 10-året for klassifikationscenterets oprettelse som permanent nordisk institution har disse to nordiske samarbejdsprojekter vist deres berettigelse og levedygtighed, og vi har derfor fundet det af interesse at bede to eksperter, der nu er ved trække sig ud af det daglige arbejde med klassifikationer i Norden, give deres viden og erfaring videre i form af denne publikation

Vi takker professor Björn Smedby og overlæge Gunnar Schiøler, fordi de har villet påtage sig dette arbejde.

Tromsø, juni 2006

*Sveinn Magnússon*  
Chair

*Nordic Centre for Classifications in Health Care*

*Formand*  
*Nordisk Klassifikationscenter*

# 1 Introduction

## 1 *Inledning*

The use of classifications is the oldest known method for studying the incidence of diseases and their consequences. First medical researchers and later statisticians and others developed and used classifications to reveal secrets behind the influences of diseases on individuals and society, and in this way to find ways and means of preventing the often very serious consequences of diseases.

A classification of diseases must be based on current knowledge about the various conditions, their manifestations and their causes. From the time the first classifications of diseases saw the light of day more than 250 years ago until today, our knowledge about the causes of diseases and about related factors has expanded enormously. This means that today we can classify a great number of diseases based on their causes and nature. Consequently we can classify them more precisely and thus find new causal relationships, which are important for the treatment and prevention of diseases.

A classification of diseases, as we understand it today, came into existence in the middle of the 19<sup>th</sup> century on the initiative of the International Statistical Committee, which wanted to improve mortality statistics – at that time the most important, internationally available source of knowledge of the impact of diseases on the health of the population. Classifica-

Brugen af klassifikationer er den ældste kendte metode til at studere sygdommes forekomst og konsekvenser. Først har medicinske forskere og senere ikke mindst statistikere udviklet og brugt klassifikationer til at afsløre hemmelighederne bag sygdommes påvirkning af individer og samfund for derigennem at finde veje og måder til at forhindre de ofte meget alvorlige konsekvenser, de kan få.

En klassifikation af sygdomme må i følge sagens natur bygge på den viden, man på et givet tidspunkt har om de enkelte sygdomme, deres manifestationer og deres årsager. Fra de første sygdomsklassifikationer så dagens lys for mere end 250 år siden til i dag er vores viden om årsager og sammenhænge udvidet næsten eksplosionsagtigt. Det betyder, at vi i dag kan klassificere et meget stort antal sygdomme ud fra årsag og natur. Følgelig kan vi også klassificere dem meget mere præcist og dermed finde nye og afgørende sammenhænge, der er af betydning for at behandle og forebygge dem.

En sygdomsklassifikation i moderne forstand opstod i midten af det 19. århundrede på initiativ af den internationale statistikkomite, som ønskede at forbedre dødsårsagsstatistikken – den dengang vigtigste, internationalt tilgængelige kilde til viden om sygdommes betydning for folkesundheden. Man fik udviklet klassifikationer baseret på datidens viden og

tions were developed based on current knowledge. At the end of the century internationally accepted groupings of the most important conditions were defined, and the diagnoses were used as causes of death. The development of natural science and medical science in the 20<sup>th</sup> century led to great improvements in diagnostic possibilities and the accuracy of diagnoses. Diagnoses became more detailed – both as causes of death and as descriptions of diseases in general. Classifications of diseases – both national and international – were developed accordingly in terms of the number of classified diagnoses. Due to the legitimate statistical need for longitudinal studies of overall health problems, a corresponding development in the structure of classifications, and in the principles they were based on, did not take place, and the international classification of diseases in the 21<sup>st</sup> century can be directly traced back to the overall grouping that was laid down in the middle of the 19<sup>th</sup> century.

Classifications of causes of death, and slightly later diseases, were the first classifications that gained a footing in the health sector. A substantial incentive for this development was growing concern about the social problems that now come under the concept of public health – an internationally used term which is only partly covered by the Nordic terms “*folkhälsa*” and “*folkesundhed*”. Later, when medical knowledge and capacity created a foundation for considerable and important new activities in the health sector, other classifications were developed. Examples are classifications of surgical procedures, radiological examinations, laboratory tests and nursing procedures. All these classifications

mod slutningen af århundredet havde man internationalt accepterede grupperinger af de mest betydningsfulde sygdomsbilleder defineret, og diagnoserne anvendtes som dødsårsager. Det 20. århundredes natur- og lægevidenskabelige udvikling betød store fremskridt for de diagnostiske muligheder og deres præcision. En konsekvens var en stadigt større detaljering af diagnoserne – både som dødsårsager og som betegnelser for sygdomme i al almindelighed. Sygdomsklassifikationer – både den internationale og de nationale – udviklede sig tilsvarende med hensyn til antal klassificerede diagnoser. På grund af statistikens legitime behov for longitudinelle studier af de overordnede sundhedsproblemer, så man ikke en tilsvarende udvikling af klassifikationernes struktur og principper, og strukturen i det 21. århundredes internationale sygdomsklassifikation kan føres direkte tilbage til de overordnede grupperinger, som man fastlagde i midten af 1800-tallet.

Klassifikationerne af dødsårsager og noget senere sygdomme var de første klassifikationer, som fik indpas i sundhedssektoren. En væsentlig drivkraft i denne udvikling var den stigende opmærksomhed på de samfundsproblemer, som i dag internationalt samles under begrebet public health – et internationalt begreb, som kun delvis dækkes af nordiske termer som ‘*folkhälsa*’ og ‘*folkesundhed*’. Senere da den medicinske kunnen og formåen skabte grundlaget for betydelige og betydningsfulde nye aktiviteter inden for sundhedssektoren, kom andre klassifikationer til. Her skal blot som eksempler nævnes klassifikationer af operationer, af radiologiske undersøgelser, af laboratorieundersøgelser og af sygeplejeprocedurer. Alle med hver deres betyd-

## INTRODUCTION

have importance for monitoring, analyzing and administrating complex and expensive modern health care systems.

Modern computer technology makes collection of detailed data possible, and allows analysis and presentation of complex information. The situation was very different 150 years ago, when it was necessary to collect data and transform it into clear and understandable information manually. However, regardless of technical developments, classifications have the same central importance when dealing with crucial and complex elements in health care. Important areas of relevance for classifications include the incidence of diseases, use of resources, mortality, life expectancy, management and planning of health care systems and health institutions, and capacity and productivity studies. Other relevant areas are epidemiological and clinical research, development of new drugs and treatment, and evaluation of the need for and effects of public health measures in various sectors of society.

Thus within the activities of health professionals, development and use of classifications have a very central role. It is therefore important that users have access to information about the origins of the classifications, the principles for the grouping of the concepts that are classified, and their development over time. The Nordic countries were active in this field at an early stage, but did not really enter into international collaboration until after the Second World War, when WHO became the coordinating body for international health statistics. Since then, however, the somewhat similar Nordic countries have become more and more involved in global

ning for overvågning, analyse og administration af det meget komplekse og meget kostbare moderne sundhedsvæsen.

Nutidens computerteknologi muliggør en meget detaljeret opsamling af data og en præsentation og analyse af de ofte meget komplekse informationer, der er til rådighed. Dette i modsætning til situationen for 150 år siden, da nødvendigheden krævede at indsamlede data manuelt kunne omdannes til overskuelige og forståelige informationer. Klassifikationer har imidlertid uanset den tekniske udvikling den samme centrale betydning i behandlingen af de mest afgørende og vanskeligste elementer i sundhedsvæsenet. Det drejer sig om områder som sygdomsforekomst, ressourceanvendelse, dødsårsager og levetidsanalyser, ledelse og planlægning af sundhedsvæsnere og enkeltinstitutioner, kapacitets- og produktivitetstudier og meget mere, men også om epidemiologisk og klinisk forskning, udvikling af nye lægemidler og behandlingsmetoder samt vurdering af behov og effekt af public health-indsats på forskellige samfundsområder.

Udvikling og anvendelse af klassifikationer har altså en helt central plads i sundhedsprofessionernes virksomhed. Det er derfor vigtigt at brugerne har adgang til viden om klassifikationernes tilblivelse, principperne for deres ordning af begreberne og deres udvikling over tid. De nordiske lande har tidligt været aktive på dette område, men kom først for alvor ind i den internationale sammenhæng efter 2. verdenskrig, da WHO blev den koordinerende institution i international sundhedsstatistik. Siden har vores temmelig ensartede lande imidlertid med stigende energi engageret sig i den globale udvikling på området. Det

developments in this area, with growing enthusiasm. This has taken place through close cooperation between the countries. But there have also been different points of view, and disagreements at times, which have required time and good will to overcome. But the cooperation has mostly been fruitful and very useful. We have created common institutions for health statistics and classifications, and together we have developed classifications that are used uniformly in our health services. This has given us a common professional platform, with the result that we are heard in international fora in which health classifications and statistics are developed.

Nordic cooperation that has taken place, in work with classifications at the international, Nordic and country levels, will be described in this publication. The cooperation between the Nordic countries is unique, and is respected internationally. In spite of differences in language and culture, we have been able to develop uniform classifications, which have made it possible to produce the best possible comparable health statistics covering several countries.

Hopefully this book will make a useful contribution to the documentation of this long and fascinating history. During the process of writing this history, we have used numerous written sources both in archives and in published literature. Many of these references are in the list of references, but we are also indebted to many persons, who are or have been active in the Nordic cooperation on classifications. The work of NOMESCO during the early years is poorly documented in the archives, but we have received valu-

er sket i et tæt samarbejde landene imellem, men ikke uden afvigende synspunkter og til tider uenigheder, der har krævet tid og god vilje at overvinde. Mest har samarbejdet dog været frugtbar og meget nyttigt. Vi har skabt fælles institutioner for sundhedsstatistik og klassifikationer, og vi har sammen udviklet store klassifikationer, der bruges ensartet i vores sundhedsvæsen. Det har givet en faglig platform, der har betydet, at vi bliver hørt i de internationale fora, der beskæftiger sig med klassifikationer og statistik inden i sundhedssektoren.

Det er en del af dette nordiske samarbejde, der skal beskrives i denne publikation, som beskæftiger sig med forløbet af klassifikationsarbejdet internationalt, fælles nordisk og i de enkelte nordiske lande. De nordiske landes samarbejde er unikt og almindeligt respekteret internationalt. Vi har formået trods sproglige og kulturelle forskelligheder at udvikle ensartede klassifikationer, der har gjort det muligt at producere de bedst mulige sammenlignelige sundhedsstatistikker, der omfatter flere lande.

Forhåbentlig vil denne publikation give et nyttigt bidrag til belysningen af den lange og spændende historie. Under arbejdet med den har vi kunnet støtte os til mange skriftlige kilder både i arkiver og i publiceret form. I referencelisten kan mange af dem findes, men vi skylder også tak for den hjælp vi har fået fra personer, der er eller har været aktive i det nordiske klassifikationssamarbejde. De tidligste år i NOMESCO-samarbejdet er kun dårligt dokumenteret i arkiverne, men vi har fået værdifuld

## INTRODUCTION

able assistance from Johannes Mosbech (Denmark) and Dag Swenson (Sweden). The classification authorities in the Nordic countries have been most helpful in finding information and references, and we wish in particular to thank Asbjørn Haugsbø (Norway) and not least Sveinn Magnússon (Iceland) and Mika Gissler (Finland) who helped us to break the language barriers. We are indebted to Arno Forsius (Finland) and Lilja Jónsdóttir (Iceland) for their assistance. Last but not least, the assistance of Johannes Nielsen (NOMESCO), Martti Virtanen and Kristina Bränd Persson (Nordic Classification Centre) and Birthe Frimodt Møller (Danish Register of Injuries) has been invaluable.

Both authors are responsible for the content of this publication, but the responsibility for the writing has been divided between them. This explains that some parts are written in Swedish and others in Danish. Björn Smedby wrote chapters 2 and 3 and the DRG section of chapter 4 and Gunnar Schiøler the other chapters. Linda Grytten has translated the text into English.

hjælp fra Johannes Mosbech (Danmark) og Dag Swenson (Sverige). De nordiske klassifikationsmyndigheder har vist stor hjælpsomhed i fremskaffelsen af informationer og referencer, og specielt siger vi tak for hjælp til Asbjørn Haugsbø (Norge) og ikke mindst Sveinn Magnússon (Island) og Mika Gissler (Finland), som begge har hjulpet os over sprogbarriererne. Også Arno Forsius (Finland) og Lilja Jónsdóttir (Island) skylder vi tak for hjælp. Sidst men ikke mindst har hjælpen fra Johannes Nielsen (NOMESKO), Martti Virtanen og Kristina Bränd Persson (Det nordiske klassifikationscenter) samt Birthe Frimodt Møller (Det danske ulykkesregister) været uvurderlig.

Begge forfattere er sammen ansvarlige for indholdet i denne publikation, men ansvaret for udformningen af teksten har været delt imellem dem, hvilket forklarer at visse afsnit er skrevet på svensk og andre på dansk. Björn Smedby har skrevet kapitel 2 og 3 samt DRG afsnittet i kapitel 4 og Gunnar Schiøler de øvrige kapitler. Linda Grytten har stået for oversættelsen til engelsk.

## 2 The history of the classification of diseases

### 2 *Sjukdomsklassifikationens historia*

#### International developments

The first real classifications of diseases were developed in the middle of the 18th Century. The Frenchman François Boissier de Sauvages published *Nosologia methodica* in 1731, and later, in 1763, Carl von Linné published *Genera morborum*, which was based on Sauvage's classification. In 1785 William Cullens, in Edinburgh, published *Synopsis nosologiae methodicae*, which came to be the most important classification well into the 19<sup>th</sup> century

Linné's classification [1] – which is of special interest in relation to the Nordic countries – included 11 classes, 37 groups and 325 types of diseases, and was inspired by Linné's earlier work with classifications in the field of botany. For Linné and his contemporaries, interest in classifications was determined by the need for an overview of diseases and the need to systematize knowledge about diseases, in order to reveal the inherent order in nature. Because the medical knowledge that the work was based on was incomplete, a purely descriptive approach was necessary, and the classification was characterized by an underlying philosophy of nature that had a large speculative element – it was a philosophical system.

#### Den internationella utvecklingen

De första egentliga sjukdomsklassifikationerna tillkom i mitten av 1700-talet. Då publicerade först fransmannen François Boissier de Sauvages sin *Nosologia methodica* år 1731 och därefter Carl von Linné år 1763 sin *Genera morborum* som byggde på Sauvages klassifikation. År 1785 publicerades sedan i Edinburgh William Cullens *Synopsis nosologiae methodicae* som kom att bli den dominerande klassifikationen långt in på 1800-talet.

Linnés klassifikation [1] – som är av särskilt intresse i ett nordiskt sammanhang – omfattade 11 klasser, 37 ordningar och 325 arter av sjukdomar och var inspirerad av hans tidigare klassifikationsinsatser inom botanikens område. För Linné och hans samtid var intresset för en sjukdomsklassifikation betingat av ett behov av överblick och system i kunskapen om sjukdomarna för att avslöja naturens inneboende ordning. Den ofullständiga medicinska kunskap som arbetet byggde på nödvändiggjorde en rent deskriptiv ansats och klassifikationen präglades av en bakomliggande naturfilosofi med starkt spekulativa inslag – den blev ett filosofiskt system.

## THE HISTORY OF CLASSIFICATION OF DISEASES

It is interesting to note that Linné's classification does not seem to have had much influence on the list of causes of death that the clergy used for reporting deaths, that was introduced in connection with the early Swedish population statistics. The need for simple statistics and comparisons determined the way this was reported. The statistical approach has also characterized later work with classifications of diseases and causes of death.

In the middle of the 19<sup>th</sup> century, William Farr worked in London as the first publically employed medical statistician. He worked with statistics of deaths in the city. He pointed out the need for standardized nomenclature and classification. In 1853, together with his Swiss colleague Marc d'Espine, he was given the task by the first International Statistical Congress of making a proposal for a classification of causes of death.

Farr divided causes of death into five main groups:

- Epidemic diseases
- Constitutional, general diseases
- Local, anatomically ordered diseases
- Developmental disorders
- Injuries caused by violence

At the next international congress in Paris in 1855, Farr's proposal was mainly accepted, as a list of 139 codes. The list was revised several times during the 19<sup>th</sup> century, but was never generally accepted. However, the basic structure of

Det är intressant att notera att Linnés klassifikation inte tycks ha fått något egentligt inflytande på den lista av dödsorsaker som kom att gälla för prästerskaps rapportering av dödsorsaker som infördes i samband med den tidiga svenska befolkningsstatistiken. Då var det behovet av enkla statistiska översikter och jämförelser som fick styra utformningen. Den statistiska ansatsen har också dominerat för senare tiders arbete med klassifikationer av sjukdomar och dödsorsaker.

Vid 1800-talets mitt verkade i London William Farr som den förste offentligt anställde medicinska statistikern. Han arbetade med statistiska sammanställningar av dödsfallen i staden. Han påtalade behovet av en standardiserad nomenklatur och klassifikation. År 1853 fick han av den första internationella statistiska kongressen i uppdrag att tillsammans med sin schweiziska kollega Marc d'Espine göra ett förslag till en statistisk dödsorsaksklassifikation.

Farr delade in dödsorsakerna i fem stora grupper:

- Epidemiska sjukdomar
- Konstitutionella, generaliserade sjukdomar
- Lokaliserade, anatomiskt ordnade sjukdomar
- Utvecklingsrubbingar
- Skador orsakade av yttre våld

Vid den följande internationella kongressen i Paris 1855 antogs i stort sett Farris förslag som en lista med 139 rubriker. Denna lista reviderades flera gånger under senare delen av 1800-talet men blev aldrig allmänt accepterad.



Farr's classification was preserved in a new proposal that the Frenchman Jaques Bertillon put forward at the International Statistical Institute's meeting in 1893 in Chicago. At this meeting, the first International List of Causes of Death (ICD) was adopted. It was later decided that the list should be revised every tenth year. A series of international revision conferences was then held, under the initiative of the French Government, led by Bertillon until his death in 1922. Table 1 gives a list of the revision conferences, and shows the increase in the number of codes as a result of the revisions. The Health Organization of the League of Nations also participated in the work with the fourth (1929) [2] and the fifth (1938) [3] revisions.

Grundstrukturen i Farris klassifikation kom emellertid att leva kvar i ett nytt förslag som fransmannen Jaques Bertillon lade fram vid det internationella statistiska institutets möte 1893 i Chicago. Då fastställdes den första International List of Causes of Death (ICD). Man bestämde senare att listan skulle revideras vart tionde år. Så skedde också vid en serie internationella revisionskonferenser som den franska regeringen tog initiativ till och som leddes av Bertillon till hans död 1922. Serien av revisionskonferenser och det inflytande dessa haft på klassifikationens omfattning framgår av tabell 1. I revisionsarbetet för den fjärde (1929) [2] och den femte (1938) [3] revisionen deltog även Nationernas Förbunds hälsoorganisation.

**Table 1 The development of ICD**

Version	Year for revision	Number of codes
ICD-0	1893	161
ICD-1	1900	179
ICD-2	1909	189
ICD-3	1920	200
ICD-4	1929	200
ICD-5	1938	200
ICD-6	1948	952
ICD-7	1955	952
ICD-8	1965	1 040
ICD-9	1975	6 701
ICD-10	1989	12 420

In the work with revisions in the 1930s and 1940s, the increasing need for a classification that could also be used for morbidity statistics was identified, and proposals for classifications of diseases and injuries were presented in several countries, including Canada, Great Britain and the USA. However, a common international

I revisionsarbetet konstaterades under 1930- och 1940-talen ett ökande behov av en klassifikation som även kunde användas för morbiditetsstatistik och förslag till klassifikationer av sjukdomar och skador presenterades i olika länder, bl.a. Canada, Storbritannien och USA. En gemensam internationell klassifikation för

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classification of diseases and causes of death was first developed at the sixth revision conference in Paris in 1948, organized by the newly established World Health Organisation (WHO). It was given the name International Statistical Classification of Diseases, Injuries and Causes of Death (ICD-6) [4]. At the same time, an international form for death certificates was adopted, and standardized regulations for the selection of underlying cause of death were established, which was important for international comparability. Short lists suitable for tables of morbidity and mortality were also adopted. WHO published the classification in English, French and Spanish. Later, at the suggestion of the Scandinavian countries, an alphabetical register in Latin was developed by the Danish professor H.C. Gram [5].

Further revisions have all been made by WHO. The seventh revision (1955) [6] was limited to correction of errors and inconsistencies. The eighth revision (1965) [7] was more extensive, but retained the classification's structure and the general principle that as far as possible diseases were classified according to etiology rather than manifestation. During the time when ICD-7 and ICD-8 were used, the classification also began to be used for coding of hospital patient records and patient statistics. This led to several countries, including the Nordic countries, making national adaptations that allowed a greater level of detail (more about this below).

Initially, the ninth revision (1975) [8] was to be limited, but the interest of various groups of medical specialists for ICD-9 was so great, that the revision led to both restructuring of some sections

sjukdomar och dödsorsaker förverkligades dock först vid den sjätte revisionskonferensen som hölls i Paris 1948, organiserad av den nybildade världshälsoorganisationen (WHO). Den fick namnet International Statistical Classification of Diseases, Injuries and Causes of Death (ICD-6) [4]. Samtidigt fastställdes ett internationellt formulär för dödsbevis och enhetliga regler för val av underliggande dödsorsak, vilket var viktigt för den internationella jämförbarheten. Förkortade listor lämpade för tabulering av morbiditet och mortalitet fastställdes också. WHO publicerade klassifikationen på engelska, franska och spanska. På förslag av de skandinaviska länderna tillkom senare även ett alfabetiskt register på latin som utarbetats av den danske professorn H.C. Gram [5].

De följande revisionerna har alla skett genom WHO:s försorg. Den sjunde (1955) [6] begränsades till rättning av felaktigheter och inkonsekvenser. Den åttonde (1965) [7] var mer omfattande men behöll klassifikationens struktur och den allmänna principen att så långt som möjligt klassificera sjukdomarna efter etiologi snarare än manifestation. Under den tid som ICD-7 och ICD-8 gällde började klassifikationen alltmer användas även för indexering av sjukhusjournaler och patientstatistik, vilket ledde till att flera länder, däribland de nordiska, gjorde nationella anpassningar som erbjöd större detaljeringsgrad (mera härom nedan).

Den nionde revisionen (1975) [8] avsågs från början bli begränsad, men intresset för ICD-9 hade blivit så stort från olika medicinska specialistgruppers sida att revisionen ledde både till om-

and to increased level of detail. In addition, the so-called dagger-asterisk system was introduced. This allows, for some diseases, for the optional possibility to code not just the underlying general etiology but also the manifestation of the disease in different organ systems. Several other changes were also introduced in the regulations for the application of the classification for both mortality and morbidity.

For the tenth revision, it was no longer possible to keep the traditional ten-year interval, because work with the revision was so extensive. The revision conference was not held until 1989, and a few more years went by before ICD-10 could be published, now in the form of three different volumes: a systematic, tabular list (1992) [9], an instruction manual (1993) [10] and an alphabetical index (1994) [11]. ICD-10 involved a greatly increased number of codes and greater level of detail, primarily with the many clinical applications in mind. Despite a certain amount of criticism, the dagger-asterisk system was kept and extended. As a result of developments in medical knowledge, some restructuring was done, so that some diseases and groups of diseases were moved to other chapters. The number of chapters was increased, because some chapters were divided up, and because the so-called external cause codes were incorporated into the main classification. The code structure was changed from purely numerical to alphanumeric, in order to allow for a greater number of codes and more detailed codes.

The regulations for application of the classification were modified and expanded, regarding both mortality and morbidity. The primary application of

strukturering av vissa avsnitt och till ökad detaljeringsgrad. Man införde också det s.k. dagger-asterisksystemet, vilket innebar en valfri möjlighet att för vissa sjukdomar koda inte bara den bakomliggande generella etiologin utan även deras manifestation i olika organ-system. Flera ändringar infördes också i regelverket för klassifikationens tillämpning beträffande både mortalitet och morbiditet.

För den tionde revisionen kunde man inte längre behålla det traditionella tio-åriga intervallet på grund av revisionsarbetets stora omfattning. Revisionskonferensen hölls först 1989 och det dröjde ytterligare några år innan ICD-10 kunde publiceras, nu i form av tre olika delar; en systematisk del (1992) [9], en instruktionsmanual (1993) [10] och en alfabetisk del (1994) [11]. ICD-10 innebar ett starkt utökat antal koder och större detaljeringsgrad, främst med tanke på de många kliniska tillämpningarna. Trots viss kritik behölls dagger-asterisksystemet och utökades. Med anledning av den medicinska kunskapsutvecklingen gjordes flera omstruktureringar innebärande flyttning av sjukdomar och sjukdomsgrupper mellan kapitel. Antalet kapitel utökades genom uppdelningar och inkorporering av de s.k. yttre orsaks-koderna i själva huvudklassifikationen. Kodstrukturen ändrades från rent numeriska till alfanumeriska koder för att ge utrymme för flera och mer detaljerade koder.

Regelsystemet för klassifikationens användning modifierades och utvidgades beträffande både mortalitet och morbiditet. Klassifikationens primärt statistis-

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the classification for the purpose of statistics was emphasized by the name International Statistical Classification of Diseases and Related Health Problems, and the abbreviation ICD was kept.

A detailed description of the growth and development of the international classification is to be found in Volume 2 of ICD-10 [10]. Despite the comprehensive changes that have been made to ICD during its long development, one can still clearly trace the basic structure that was proposed by William Farr more than 150 years ago. Farr's work had a clear public health approach. The aim was that the statistics should be used as an aid in the fight against infections and for improving environmental health, for reducing maternal and child mortality, and for preventing occupational diseases and accidents. It can be said that the public health problems of the time have left their mark on the classification. But it should be emphasized that in large parts of the world it is these problems that actually are the all-pervading health problems today. In WHO's global perspective it is therefore still the public health aspects that are the most important in work with classifications.

### Early registration of mortality in the Nordic countries

Registration of causes of death started early in the Nordic countries, but in the beginning it took place without any real coordination between the countries. Also, to begin with, the Nordic countries did not participate actively in the international work with nomenclature under the leadership of Bertillon. As in several

ka användning underströks genom namnet International Statistical Classification of Diseases and Related Health Problems, och man bibehöll förkortningen ICD.

En utförlig historisk beskrivning av den internationella sjukdomsklassifikationens framväxt och utveckling återfinns i volym 2 av ICD-10 [10]. Trots de stora förändringar som skett under den långa utvecklingen av ICD kan man fortfarande tydligt spåra den grundstruktur som förslags av William Farr för mer än 150 år sedan. Farris arbete hade en klar public health-inriktning. Det innebar att statistiken skulle vara till ledning för infektionsbekämpande och omgivningshygien, för förebyggande av mödra- och barnadödlighet och för prevention av yrkessjukdomar och olycksfallsskador. Man kan säga att den tidens folkhälsoproblem har satt bestående prägel på klassifikationen. Men det är värt att påpeka att i stora delar av världen är det just dessa frågor som utgör de helt över-skuggande hälsoproblemen. I WHO:s globala perspektiv är det därför fortfarande public health-aspekterna som är de viktigaste i klassifikationsarbetet.

### Den tidiga nordiska dödsorsaksregistreringen

Registrering av dödsorsaker startade tidigt i de nordiska länderna men skedde till en början utan någon egentlig samordning mellan länderna. Från början deltog inte heller de nordiska länderna särskilt aktivt i det internationella nomenklaturarbetet under Bertillons ledning. Liksom i flera andra länder behöll

other countries, the countries kept their own nomenclature, though later they were also influenced by the international classifications that were developed at the beginning of the 20<sup>th</sup> century. In this section a short description is given of the early development of mortality statistics in each of the Nordic countries.

**DENMARK:** The first Danish list of causes of death came in 1831. It was developed by the Board of Health and included about 30 diseases or conditions. Later it was extended and gradually came to include about 70 diseases.

In 1875 a new classification was introduced, with a list of 113 codes in total. The list was partly influenced by William Farr, whose advice had been sought during development of the classification. This list was used for mortality statistics in 1875-1930.

In 1931 the *Inter-Scandinavian Nomenclature of Causes of Death from 1926* [12] began to be used. It had been developed through cooperation between Denmark, Norway and Sweden, though these countries did not otherwise participate in international cooperation with classification of causes of death. The classification included 150 causes of death, arranged in 18 large groups. The groups and the classification were adapted from Bertillon's international classification from 1920 (ICD-3), but were developed further. The Nordic classification had some influence on ICD-4, which was adopted in 1929. The Inter-Scandinavian Nomenclature of Causes of Death was used in Denmark during the years 1931-1940.

man parallellt sin egen nomenklatur även om man efterhand kom att ta intryck av de internationella klassifikationer som utarbetades i början av 1900-talet. Här skall först den tidiga utvecklingen av dödsorsaksstatistiken i vart och ett av de nordiska länderna i korthet beskrivas.

**DANMARK:** Den första danska listan över dödsorsaker tillkom 1831. Den utarbetades av Sundhedskollegiet och omfattade omkring 30 sjukdomar eller sjukdomsbilder. Den utvidgades efterhand och kom så småningom att omfatta omkring 70 sjukdomar.

År 1875 infördes en ny, fast gruppering genom en lista med totalt 113 nummer. Listan var delvis påverkad av William Farr, vilkens råd hade inhämtats vid utarbetandet. Denna lista användes i dödsorsaksstatistiken under åren 1875-1930.

År 1931 togs *Den interskandinaviske Dødsårsags-Nomenklatur från 1926* [12] i bruk. Den hade tillkommit genom samarbete mellan Danmark, Norge och Sverige som i övrigt inte deltog i det internationella dödsorsakssamarbetet. Nomenklaturen omfattade 150 dödsorsaker ordnade i 18 större grupper. Grupperna och systematiken anpassades till Bertillons internationella klassifikation från 1920 (ICD-3) men utvecklades vidare. Den nordiska listan kom att få ett visst inflytande på ICD-4 som fastställdes 1929. Den interskandinaviska listan användes i Danmark under åren 1931-40.

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In 1941, Denmark began to use the international list of causes of death (ICD-5), which was used in 1941-1950. From 1951, the international classification of diseases (ICD-6) began to be used, and continued to be used through 1957. For coding of death certificates, the English versions of ICD-5 and ICD-6 were used in the official mortality statistics. These versions were not translated into Danish.

During 1958-1968, the Danish version of ICD-7, which was issued in 1958, was used [13], and for the years 1969-1993 the five-digit Danish version of ICD-8 was used [14]. ICD-9 was never used in Denmark, and from 1994 Denmark went over to using the Danish ICD-10 revision [15]. (However, the international ICD-10 version is used for external causes, though it is not used for registering patient statistics in Denmark.)

An overview of the ICD revisions that have been used for mortality statistics in the Nordic countries is given in Table 2.

**FINLAND:** Until 1809 Finland had the same regulations as Sweden for the clergy's reporting of causes of death according to a standard list. In 1812 the list was revised, but only a few changes were accepted. A version from 1845 included about 60 groups of causes of death.

In 1878 changes were made that resulted in a reduction in the number of groups of causes of death, and that emphasis was placed on epidemic diseases and violent deaths. Finnish names of diseases were also added, in addition to Latin and Swedish.

År 1941 gick man i Danmark över till att använda den internationella dödsorsakslistan (ICD-5), vilken användes under åren 1941-1950. Från 1951 började man använda den internationella sjukdomsklassifikationen (ICD-6), vilken användes t.o.m. 1957. För kodningen av dödsbevis använde man i den officiella dödsorsaksstatistiken de engelskspråkiga versionerna av ICD-5 och ICD-6 som alltså inte översattes till danska.

Under åren 1958-1968 använde man den danska version av ICD-7 som utgavs 1958 [13] och för åren 1969-1993 den femsiffriga danska versionen av ICD-8 [14]. ICD-9 användes inte i Danmark och från år 1994 övergick man till att använda den danska ICD-10-revisionen [15] (dock beträffande yttre orsaker den internationella ICD-10 versionen som i övrigt inte användes för patientregistreringen i Danmark).

En jämförande översikt över vilka ICD-revisioner som använts i de nordiska ländernas dödsorsaksstatistik finns i tabell 2.

**FINLAND:** Fram till 1809 gällde i Finland samma regelsystem som i Sverige med församlingsvis rapportering av dödsorsaker enligt en särskild förteckning. År 1812 reviderades listan men endast mindre förändringar genomfördes. Ett förslag från år 1845 omfattade ett 60-tal dödsorsaksgrupper.

Från 1878 genomfördes en förändring som medförde en reduktion av antalet dödsorsaksgrupper och att tonvikt lades på epidemiska sjukdomar och våldsam död. Då infördes också finska sjukdomsbenämningar vid sidan av de latinska och svenska.

A new classification of causes of death was adopted by the National Board of Health and used from 1936. It included 192 causes of death divided into 18 chapters. The list was very similar to the international list of causes of death that was adopted in 1929 (ICD-4) [2]. This was used until ICD-6 [16a] was taken into use in 1952. The ICD revisions that were used later in the Finnish mortality statistics are shown in Table 2.

**ICELAND:** Registration of causes of death began in accordance with a special act of 1911, and in the same year, the Chief Medical Officer issued instructions regarding death certificates and registration of deaths. The original reports came from the clergy, who sent lists of deceased persons and causes of death to the district medical officers and the county medical officers, who checked the reports before they sent them on to the Chief Medical Officer. After editing, a national report of deaths and causes of death was published by the Central Bureau of Statistics. In addition, information about causes of death in the population have always been published in the Chief Medical Officer's annual reports about the health status of the population.

En ny dödsorsaksnomenklatur fastställdes av Medicinalstyrelsen att gälla från 1936. Den omfattade 192 dödsorsaker fördelade på 18 kapitel. Förteckningen anslöt sig nära till den internationella dödsorsaksnomenklatur som antagits 1929 (ICD-4) [2]. Den kom att gälla fram till dess ICD-6 [16a] togs i bruk år 1952. Vilka ICD-revisioner som därefter använts i den finska dödsorsaksstatistiken framgår av tabell 2.

**ISLAND:** Registreringen av dödsorsaker påbörjades enligt en särskild lag 1911 och Landsläkaren gav samma år ut anvisningar om dödsbevis och dödsregistrering. Grunduppgifterna kom från prästerna som sände sina register över döda och dödsorsaker via häradsläkarna och länsläkarna som granskade uppgifterna innan de vidarebefordrades till Landsläkaren. Efter redigering publicerades en nationell rapport över döda och dödsorsaker av Statistiska Centralbyrån (Hagstofa Íslands). Information om befolkningens dödsorsaker har dessutom alltid publicerats i Landsläkarens årliga rapport över befolkningens hälsotillstånd.

**Table 2** Overview of use of ICD versions in Nordic mortality statistics

ICD-revision (year for revision)	Denmark	Finland	Iceland	Norway	Sweden
ICD-5 (1938)	1941-1950	not used	1941-1950	1941-1950	not used
ICD-6 (1948)	1951-1957	1952-1953	1951-1970	1951-1957	1951-1957
ICD-7 (1955)	1958-1968	1954-1968	not used	1958-1968	1958-1968
ICD-8 (1965)	1969-1993	1969-1986	1971-1980	1969-1985	1969-1986
ICD-9 (1975)	not used	1987-1995	1981-1995	1986-1995	1987-1996
ICD-10(1989)	1994-	1996-	1996-	1996-	1997-

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During 1911-1940, an Icelandic classification of diseases was used for registration in the main Icelandic register. This register was mainly based on the Danish register that was used in Denmark at the time registration began. The main register included 155 groups, which in the national statistics were summarized in a smaller number of larger groups [17].

In 1941-1950, a register of causes of death that was an Icelandic translation of ICD-5 was used in Iceland. It was published with directives from the Office of the Chief Medical Officer [18].

From 1951, ICD-6 was used for registration of causes of death, translated into Icelandic and supplemented with Latin terminology [19]. ICD-7 was never used. Iceland went over directly to using the English language version of ICD-8 in 1971. A short list with 50 groups was used for the national statistics.

From 1981 ICD-9 was used for registration of causes of death. The classification was used at the three-digit level, that is to say without decimals, and the translation was adapted to national needs without Latin terms [20]. WHO's Basic Tabulation List with 56 groups was used for publication.

ICD-10 began to be used from 1996. The systematic, tabular list of the classification was translated into Icelandic [21]. Statistics at the country level are published according to a European short list with 65 groups.

**NORWAY:** From 1853, annual reports of causes of death were published according to a list of about 125 causes of

För registreringen i det isländska huvudregistret användes under åren 1911-1940 en isländsk sjukdomsklassifikation som i huvudsak byggde på det danska register som användes i Danmark vid tiden för registreringens början. Huvudregistret omfattade 155 grupper som i nationell statistik sammanfattades i färre större grupper [17].

Under åren 1941-1950 användes i Island ett dödsorsaksregister som var en isländsk översättning av ICD-5. Den publicerades med anvisningar från Landsläkarämbetet [18].

För registrering av dödsorsaker användes fr.o.m. 1951 ICD-6, översatt till isländska och kompletterad med latinska benämningar [19]. ICD-7 togs aldrig i bruk i Island utan man övergick direkt till den engelska versionen av ICD-8 år 1971. För nationell statistik användes en kort lista med 50 grupper.

ICD-9 började användas för dödsorsaker 1981. Klassifikationen användes på tresiffrig nivå, dvs. utan decimaler, och översättningen anpassades till nationella behov utan latinska benämningar [20]. Vid publicering använde man WHO:s Basic Tabulation List med 56 grupper.

ICD-10 togs i bruk för dödsorsaker 1996. Den systematiska delen av klassifikationen översattes till isländska [21]. Statistik på riksnivå har publicerats enligt en europeisk kortlista med 65 grupper.

**NORGE:** Med början 1853 publicerades årligen ”beretning om dødsorsaker” enligt en lista på omkring 125 orsaker.



death. Up through 1895, the list was arranged alphabetically and varied somewhat from year to year according to the causes of death that were reported. During 1896-1910 the list was replaced with a list of 142 causes of death, grouped systematically, and clearly influenced by the ideas of William Farr.

In the years 1911-1926, a new list was used, with 129 causes of death, systematically divided into 14 large groups. From 1927, the Inter-Scandinavian Nomenclature of Causes of Death, mentioned above, was introduced [12], and this classification was used in 1927-1940.

The international revision of 1938 (ICD-5) [3] corresponded well with the Norwegian approach. It was introduced in 1941 and used through 1950. This classification included 200 causes of death, divided into 18 chapters.

When WHO introduced the sixth revision (ICD-6) [4] in 1948, this was adopted in Norway, and from 1951 it was used for mortality statistics. The seventh revision (ICD-7) [6] was introduced in 1958, but it involved very small changes that had no significance for mortality statistics. The Central Bureau of Statistics used the English language versions of ICD-5, ICD-6 and ICD-7 for coding causes of death. Table 2 shows which years the different versions of ICD were used.

Fram till och med 1895 var listan alfabetiskt ordnad och varierade något från år till år med hänsyn till vilka dödsorsaker som anmäldes. Under åren 1896-1910 ersattes den av en lista med sammanlagt 142 dödsorsaker som var systematiskt grupperade med tydligt inflytande från William Farris idéer.

En ny lista med 129 dödsorsaker, systematiskt fördelade på 14 större grupper, användes under åren 1911-1926. Från 1927 infördes den ovannämnda interskandinaviska dödsorsaksnomenklaturen [12]. Den kom att gälla under åren 1927-1940.

Den internationella revisionen 1938 (ICD-5) [3] stämde väl med norskt synsätt och den infördes 1941 och användes sedan till och med 1950. Denna lista omfattade 200 dödsorsaker fördelade på 18 kapitel.

När WHO 1948 genomförde den sjätte revisionen (ICD-6) [4] antogs denna i Norge och tillämpades fr.o.m. år 1951 i dödsorsaksstatistiken. Den sjunde revisionen 1958 (ICD-7) [6] infördes 1958 men medförde ytterst små ändringar utan betydelse för dödsorsaksstatistiken. I kodningen av dödsorsaker har Statistisk Sentralbyrå använt de engelskspråkiga utgåvorna av ICD-5 t.o.m. ICD-7. Vilka år de olika ICD-versionerna använts framgår av tabell 2.

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**SWEDEN:** Sweden has the oldest continuous population statistics in the world. With the establishment of the so-called Tabellverket (tables filled in by the clergy on different themes) in 1749, one of the clergy's tasks was to report causes of death. This was done according to a list of 33 groups of common diseases and causes of death at that time. The groups in the classification of causes of death were changed several times, but the length of the list remained about the same. The clergy found it difficult to assess probable causes of death, and wished to be released from this task. Therefore, during the period 1831-1860, their duty for reporting was limited to deaths from smallpox and other epidemic diseases, childbirth, accidents, crime and suicide.

From 1861 reporting was again extended to include all deaths in the cities. A more extensive classification of causes of death in Swedish and Latin was adopted, which included 115 causes of death with 22 sub-groups for accidents. The list was divided into fewer groups in the national statistics. In 1874, a new nomenclature, prepared by the Swedish Medical Society, was introduced, which included 171 conditions grouped into 19 chapters. Some changes were made to the nomenclature and the groups in 1892.

From 1911, the requirement to report the cause of all deaths was introduced, and a new nomenclature for causes of death was introduced that included 101 groups arranged in 18 chapters, which were recorded in the national statistics under 68 headings of causes. The classification included an alphabetical list with about 500 search terms in Latin.

**SVERIGE:** Sverige har den äldsta kontinuerliga befolkningsstatistiken i världen. Vid det s.k. Tabellverkets tillkomst 1749 blev en av prästerskapets uppgifter att också rapportera orsakerna till dödsfall. Det skedde efter en lista på 33 grupper av då vanliga sjukdomar och dödsorsaker. Grupperna i dödsorsaksnomenklatur ändrades flera gånger men listan behöll ungefär samma omfattning. Prästerna som hade att bedöma vad som varit den sannolika dödsorsaken upplevde detta som betungande och ville bli befriade från uppgiften. Under perioden 1831-1860 begränsades därför rapporteringsskyldigheten till att omfatta dödsfall i smittkoppor och andra farsoter, barnsbörd, olycksfall, brott eller självmord.

Från 1861 utökades rapporteringen igen till att omfatta alla dödsfall i städerna och en mer omfattande dödsorsaksnomenklatur på svenska och latin fastställdes som innefattade 115 orsaker med 22 undergrupper för olyckshändelser. Listan sammanfattades i färre grupper i den nationella statistiken. 1874 infördes en ny nomenklatur utarbetad av Svenska Läkaresällskapet som omfattade 171 nummer fördelade på 19 kapitel. År 1892 gjordes vissa ändringar i nomenklaturen och dess grupperingar.

Från 1911 infördes krav på orsaksrapportering av alla dödsfall och en ny dödsorsaksnomenklatur infördes som innefattade 101 grupper ordnade i 18 kapitel, vilka redovisades i riksstatistiken under 68 orsaksrubriker. Till nomenklaturen hörde en alfabetisk förteckning med ca 500 sökbegrepp på latin.

The Inter-Scandinavian Nomenclature of Causes of Death, mentioned above [12], was introduced in Sweden in 1931. It had a slightly different grouping, and included 150 items in 18 chapters. This nomenclature had only Latin terms. A planned version with Swedish terms was never developed.

In 1951, a new Statistical Classification of Diseases, Injuries and Causes of Death was adopted by the National Board of Health, as a Swedish version of ICD-6, with Latin and Swedish terms [22]. The purpose of the classification was both for producing mortality statistics and for reporting diagnoses from hospitals. Table 2 shows which years the later versions of ICD were used for Swedish mortality statistics. In principle, the English versions of ICD were used for coding causes of death, and not the more detailed Swedish classifications, which were used in hospitals from 1964.

### Classifications for morbidity reporting in the Nordic countries

In all the Nordic countries, in addition to the classifications of causes of death, special lists were gradually developed for reporting epidemic diseases and other reportable diseases, and for reporting diagnoses for in-patients, though a long time passed before national reporting for hospitals was introduced.

In *Denmark*, it was not until 1945 that systematic reporting, and statistics on diagnoses from hospitals, were intro-

Den tidigare nämnda interskandinaviska dödsorsakslistan [12] infördes i Sverige 1931. Den hade en något förändrad indelning och omfattade 150 nummer i 18 kapitel. Denna nomenklatur hade endast latinska benämningar. En planerad version med svenska benämningar kom aldrig till stånd.

En ny statistisk klassifikation av sjukdomar, skador och dödsorsaker fastställdes av Medicinalstyrelsen år 1951 som en svensk version av ICD-6 med latinska och svenska benämningar [22]. Den var avsedd för såväl dödsorsaksstatistik som redovisning av diagnoser från sjukhus. Vilka år de efterföljande ICD-versionerna använts i den svenska dödsorsaksstatistiken framgår av tabell 2. För dödsorsakskodningen användes i princip de engelskspråkiga ICD-versionerna och inte de mer detaljerade svenska klassifikationer som togs i bruk på sjukhusen från och med 1964.

### Klassifikationer för sjukdomsrapportering i Norden

I alla de nordiska länderna utvecklades efterhand vid sidan av dödsorsaksnomenklaturerna särskilda förteckningar för rapportering av epidemiska och andra anmälningspliktiga sjukdomar liksom för rapportering av sjukhusvårdade patienters sjukdomar, även om det dröjde länge tills nationell rapportering från sjukhusen kom till stånd.

I *Danmark* var det inte förrän 1945 som man införde systematisk rapportering och diagnosstatistik från sjukhusen. Det

duced. It then became obligatory for hospitals to report statistics based on the National Board of Health's *List of Diagnoses*, which was developed by Professor H.C. Gram, with the assistance of various specialists [23]. A few years later, this list was considerably shortened in cooperation with WHO. The list included "diagnoses of all types of existing diseases". It included a large number of alphabetically arranged diseases that could be summarized in a short list with 23 groups. This list was used by hospitals in 1945-1959.

When the Danish version of ICD-7 [13] was published, this was used for hospitals' annual reports from 1960. It was supplemented with a short list of 99 groups, which formed the basis for national hospital statistics, and which was still used in a revised version. Since 1960, the obligatory Danish hospital statistics have thus been based on ICD. Table 3 shows which years the different versions of ICD were used for hospital statistics.

In 1923, the National Board of Health in *Finland* issued a circular to hospitals, giving a comprehensive classification of diseases. This was subsequently used for the annual reports for some hospitals. It included 348 diseases, arranged in 21 groups. Special lists were used for reporting epidemic diseases by boards of health.

In 1953 the National Board of Health published a nomenclature of diseases [16b] based on ICD-6 as a complement to the nomenclature of causes of deaths published the year before [16a]. When ICD-7 arrived this was not published in full in Finland but only as a publication

blev då obligatoriskt för sjukhusen med rapportering baserad på Sundhedsstyrelsens *Diagnoseliste* som hade utarbetats av professor H.C. Gram med bistånd av olika specialister [23]. Denna lista blev några år senare betydligt förkortad i samarbete med WHO. Listan innehöll "Diagnoser paa alle Arter af forekommende Sygdomme". Den omfattade ett stort antal, alfabetiskt ordnade sjukdomar som kunde sammanföras i en kortlista med 23 grupper. Denna lista användes av sjukhusen under åren 1945-1959.

Med utgivningen av den danska versionen av ICD-7 [13] infördes denna som grund för sjukhusens årsberättelser från och med 1960. Den kompletterades med en kortlista på 99 grupper som blev basen för den nationella sjukhusstatistiken och som fått fortsatt användning i reviderad form. Sedan 1960 har den obligatoriska danska sjukhusstatistiken sålunda byggts på ICD. Vilka år de olika ICD-revisionerna använts framgår av tabell 3.

Medicinalstyrelsen i *Finland* utgav 1923 i ett cirkulär till sjukhusen en omfattande sjukdomsnomenklatur som kom att användas för årsberättelserna från vissa sjukhus. Den omfattade 348 sjukdomar ordnade i 21 grupper. För hälsovårdsnämndernas rapportering av epidemiska sjukdomar gällde särskilda förteckningar.

År 1953 utgav Medicinalstyrelsen en sjukdomsnomenklatur [16b] baserad på ICD-6 som ett komplement till den dödsorsaksnomenklatur [16a] som hade utgivits föregående år. När ICD-7 blev aktuell utgavs inte denna i sin helhet i Finland utan enbart som ändringar och

with changes and additions in Finnish [24]. This was used from 1960 for the first discharge register based on reports from some Finnish hospitals. Table 3 shows which years the different versions of ICD were used for registering statistics on hospital discharges and diagnoses. Finnish versions of ICD were introduced in the following years: ICD-8 [25] 1969, ICD-9 [26] 1987 and ICD-10 [27] 1996.

tillägg på finska [24]. Denna användes sedan i det första utskrivningsregistret från 1960 med uppgifter från vissa sjukhus. Tiden för användningen av de olika ICD-revisionerna i registret framgår av tabell 3. Finska versioner infördes sålunda av ICD-8 [25] år 1969, av ICD-9 [26] år 1987 och av ICD-10 [27] år 1996.

**Table 3 Overview of use of ICD versions for Nordic hospital statistics**

ICD-version	Denmark	Finland	Iceland	Norway	Sweden
ICD-6	-	-	-		1951-1957
ICD-7	1960-1971	1960-1968	not used	sporadic use in the 1960s and 1970s	1958-1968
ICD-8	1972-1993	1969-1986	1971-1981	sporadic use in the 1970s and 1980s	1969-1986
ICD-9	not used	1987-1995	1982-1996	1988-1998	1987-1996
ICD-10	1994-	1996-	1997-	1999-	1997-

In *Iceland*, diagnoses for hospital patients were reported by Landspítalinn (the National Hospital) since the hospital was established in 1930, though without codes, using only terms, and with no consideration of the ICD system. ICD codes for hospital statistics were not systematically used until the English language version of ICD-8 [7] was taken into use in 1971. Table 3 shows which years the different versions of ICD were subsequently used for hospital statistics.

I *Island* redovisades diagnoser för sjukhusvårdade patienter vid Landspítalinn alltsedan sjukhusets grundande 1930, dock utan koder och endast med benämningar och utan hänsyntagande till ICD-systemet. Systematisk användning av ICD-koder inom sjukhusens redovisningar skedde inte förrän den engelskspråkliga versionen av ICD-8 [7] togs i bruk 1971. Vilka ICD-revisioner som därefter gällt framgår av tabell 3.

In *Norway*, more comprehensive statistics on patients in hospitals began to be produced at the beginning of the 1980s. Before then, annual reports from some hospitals contained statistics on diagnoses according to ICD-7 or ICD-8. There was no central collection of data, and no national

Mer omfattande patientdata från sjukhus i *Norge* började sammanställas först i början av 1980-talet. Dessförinnan förekom att årsberättelser från vissa sjukhus innehöll diagnosstatistik som kodats efter ICD-7 eller ICD-8. Någon central datainsamling förekom inte och inte hel-

## THE HISTORY OF CLASSIFICATION OF DISEASES

standards for annual reports. The reports of diagnoses that were produced were mainly done according to the Norwegian five-digit version of ICD-8 published in 1972 by the economic-medicinal information system ØMI [28]. National hospital statistics have been available from 1988 based on ICD-9 [29], and from 1999 based on ICD-10 [30].

As early as 1874, in *Sweden* a nomenclature of diseases was adopted that was different from the current nomenclature of causes of death. The nomenclature of diseases, also developed by the Swedish Medical Society, included 193 conditions grouped into 15 chapters. These two lists did not correspond with each other.

In 1914, the National Board of Health in Sweden adopted a new classification of diseases, including an alphabetical list. It was divided into 21 chapters and had 335 codes with Swedish and Latin terms. The alphabetical list included about one thousand search terms. The list was to be used “for making health reports”, in other words, not just for causes of death. Its primary use was probably for annual hospital reports.

The Swedish ICD-6 based classification of diseases, injuries and causes of death that was adopted by the National Board of Health in 1951 [22], was, as already mentioned, intended for use both for mortality statistics and for reporting diagnoses in hospitals. At the same time, the National Board of Health also issued instructions for reporting diagnoses in the annual medical reports from hospitals.

ler någon nationell standard för årsberättelserna. Den diagnosredovisning som förekom skedde efterhand främst enligt den norska femsiffriga version av ICD-8 som utgavs 1972 av det ekonomisk-medicinska informationssystemet ØMI [28]. Sedan 1988 finns rikstäckande sjukhusstatistik baserad på ICD-9 [29] och från 1999 baserad på ICD-10 [30].

Redan 1874 antogs i *Sverige* en sjukdomsnomenklatur som skilde sig från den samtidigt genomförda revisionen av dödsorsaksnomenklaturen. Sjukdomsnomenklaturen, också den utarbetad av Svenska Läkaresällskapet, omfattade 193 nummer fördelade på 15 kapitel. De båda förteckningarna korresponderade inte med varandra.

År 1914 fastställde Medicinalstyrelsen i Sverige en ny sjukdomsnomenklatur med åtföljande alfabetisk förteckning. Den var indelad i 21 kapitel och omfattade 335 ordningsnummer med svenska och latinska benämningar. Den alfabetiska förteckningen omfattade ett tusental sökbegrepp. Denna förteckning skulle användas “vid upprättande av sjukförslag och rapporter”, sålunda inte bara för dödsorsaker. Dess främsta användning torde ha varit sjukhusens årsberättelser.

Den svenska ICD-6-baserade klassifikationen av sjukdomar, skador och dödsorsaker som fastställdes av Medicinalstyrelsen år 1951 [22] var som redan nämnts avsedd för såväl dödsorsaksstatistik som redovisning av diagnoser från sjukhus. Medicinalstyrelsen utfärdade samtidigt anvisningar för hur diagnosredovisningen skulle ske i de medicinska årsberättelserna från sjukhus.

In 1964, the National Board of Health issued a new version [31] of the classification based on ICD-7, which had been used since 1958. The new classification was specially adapted for use for reporting individual based diagnoses from hospitals, and had been made more detailed by extending the codes at the decimal level to five-digit codes. Later a classification based on ICD-8 was used from 1969 [32], one based on ICD-9 from 1987 [33] and one based on ICD-10 from 1997 [34]. For reporting diagnoses for hospital patients, a Swedish short list with 99 groups was developed. This list was later made compatible with ICD-7, ICD-8 and ICD-9, so that it could also be used for longitudinal analyses.

*Cancer registers* have been established in all the Nordic countries, in Denmark in 1943, in Norway in 1951, in Finland in 1953, in Iceland in 1955 and in Sweden in 1958. For registering the location of tumours, ICD-7 from 1958 [6] has been used in the cancer registers in all the countries. Registration for earlier years was recoded to ICD-7. To a large extent this version has been adhered to, even after new revisions of ICD have been taken into use. This has been done in order to facilitate longitudinal analyses. Also the special oncology version of ICD, called ICD-O, has been used [35]. It was not until later that ICD-10 began to be used for registration of cancer, and several countries are now going over to using ICD-O-3 [36] parallel with ICD-10.

År 1964 utgav Medicinalstyrelsen en ny upplaga [31] av den sedan 1958 gällande ICD-7-baserade sjukdomsklassifikationen. Den nya klassifikationen var särskilt tillräntalagd för användning för individbaserad diagnosrapportering från sjukhusen och hade gjorts mer detaljerad genom utbyggnad av koderna på decimalnivå till femsiffriga koder. Därefter användes en ICD-8-baserad klassifikation som började tillämpas 1969 [32], en ICD-9-baserad från år 1987 [33] och en ICD-10-baserad från 1997 [34]. För översiktliga redovisningar av diagnoser hos sjukhusvårdade patienter utformades en svensk kortlista med 99 grupper. Denna lista gjordes efterhand kompatibel med ICD-7, ICD-8 och ICD-9 för att också kunna användas för longitudinella analyser.

*Cancerregister* inrättades efterhand i samtliga nordiska länder. Registreringen började i Danmark 1943, i Norge 1951, i Finland 1953, i Island 1955 och i Sverige 1958. För registreringen av tumörernas lokalisering har man i samtliga länders cancerregister använt ICD-7 från 1958 [6]. Tidigare års registreringar omkodades till ICD-7. Man har i stor utsträckning hållit fast vid denna version även sedan nya ICD-revisioner tagits i bruk i sjukvården i övrigt, detta för att underlätta longitudinella analyser. Härjämte har man använt den särskilda onkologiversionen av ICD kallad ICD-O [35]. Först under senare år har man börjat tillämpa ICD-10 vid cancerregistren och i flera länder övergår man nu till att använda ICD-O-3 [36] parallellt med ICD-10.

## 3 The growth of Nordic cooperation on classifications

### *3 Nordiskt klassifikationssamarbete växer fram*

#### The beginning of cooperation

As mentioned above, the early development of classifications of diseases and causes of death in the Nordic countries took place in the individual countries, relatively independently of each other, though the influence of the international work with nomenclature can be traced. A clear Nordic coordination first began to develop through an agreement in 1926 concerning the Inter-Scandinavian Nomenclature of Causes of Death [12]. However, this was followed up by separate national classifications, and it is not clear to what extent possibilities for comparisons between the countries were actually taken into account. At the revision meeting in Paris in 1948, the Nordic countries cooperated and also to a certain extent regarding the introduction of ICD-6 in the countries, for example with Latin terms. However, organized Nordic cooperation with health statistics did not take place.

After the end of the Second World War, international cooperation was resumed in many areas, and the Nordic Council was established. At its first meeting in 1953, it was suggested that the countries should establish cooperation in the field of

#### Samarbetets början

Som framhållits ovan skedde i de nordiska länderna den tidiga utvecklingen av klassifikationer för sjukdomar och dödsorsaker nationellt och relativt självständigt, även om ett inflytande från det internationella nomenklaturarbetet kan spåras. En tydlig nordisk samordning kom först till stånd genom överenskommelsen 1926 om en interskandinavisk dödsorsaksnomenklatur [12]. Denna följdes dock upp i separata, nationella klassifikationer och det är oklart i vilken utsträckning möjligheterna till jämförelser mellan länderna verkligen togs tillvara. Även vid revisionsmötet i Paris 1948 samverkade de nordiska länder liksom i viss utsträckning inför det nationella införandet av ICD-6, bl.a. när det gällde de latinska benämningarna. Något organiserat hälsostatistiskt nordiskt samarbete förekom dock inte.

Efter andra världskrigets slut återupptogs internationellt samarbete inom många områden och Nordiska Rådet bildades. Vid dess första möte 1953 föreslogs att länderna skulle inleda ett samarbete på hälsoområdet och försöka



health, and try to prepare comparable health statistics. Therefore, in 1955, a Nordic meeting of experts was held. However, it was established at the meeting that at that time there were no possibilities for publishing comparable Nordic health statistics. The definitions and classifications that were used were simply too different in the different countries. It was therefore recommended that common definitions for statistics on health and health care should be developed. But this intention did not lead to any immediate proposals. So, on the whole, no cooperation in this area took place during the next ten years.

In 1965, on the recommendation of the Nordic Council, a committee was established to develop a foundation for comparable health statistics in the Nordic countries. The Nordic Medico-Statistical Committee (NOMESCO) held its first meeting in Helsinki in 1966. The Committee organized a series of different working groups, based in the different countries, to work for example, with definitions, classifications, patient statistics and, somewhat later, mortality statistics. The actual work of NOMESCO was carried out in these working groups. A more detailed description of the early history and activities of NOMESCO is to be found in the report that was issued on the occasion of NOMESCO's silver jubilee in 1991 [37].

Issues related to the *classification of diseases* were first discussed in a series of working groups (ADEK, AREV and AKLASS), which worked in the period 1970-1988 under Swedish chairmanship, first Åke Sjöström and later Björn Smedby and with Dag Swenson as secretary. A lot of active work with this early

få till stånd jämförbar medicinalstatistik. År 1955 hölls därför ett samnordiskt möte med sakkunniga. Mötet konstaterade emellertid att det vid den tidpunkten inte fanns några förutsättningar för att publicera jämförbar nordisk medicinalstatistik. De använda definitionerna och klassifikationerna skilde sig helt enkelt alltför mycket mellan länderna. Man förslog därför att det skulle utarbetas gemensamma nordiska definitioner för statistik om hälso- och sjukvård, men intentionerna ledde inte till några omedelbara konkreta förslag. I stort sett hände dock inget beträffande samarbetet under de närmaste tio åren.

På rekommendation av Nordiska Rådet år 1965 tillsattes den kommitté som skulle skapa en grund för en jämförbar medicinalstatistik i de nordiska länderna. Nordiska medicinalstatistikkommittén (NOMESKO) hade sitt första möte i Helsingfors 1966. Kommittén organiserade en rad olika arbetsgrupper som var nationellt förankrade. De gällde t.ex. definitioner, klassifikationer, födelsestatistik, patientstatistik och något senare också dödsorsaksstatistik. Det egentliga arbetet i NOMESKO kom att utföras i de här arbetsgrupperna. En närmare beskrivning av kommitténs tidiga historia och verksamhet finns i den översikt som utgavs till 25-årsjubileet 1991 [37].

Frågor rörande *sjukdomsklassifikationen* diskuterades i första hand i en rad arbetsgrupper (ADEK, AREV och AKLASS) som verkade under perioden 1970-1988 under svenskt ordförandeskap av först Åke Sjöström och senare Björn Smedby och med Dag Swenson som sekreterare. Mycket aktiva insatser i

## THE GROWTH OF NORDIC COOPERATION ON CLASSIFICATIONS

cooperation with classifications was also done by Johannes Mosbech from Denmark, and Sakari Härö from Finland.

Thus, the first clearly stated aim of Nordic cooperation with classifications was to develop comparable Nordic health statistics. This cooperation speeded up when WHO published ICD-8 in 1967 [7]. All the countries then began to make their own translations. In NOMESCO's working group on classifications, experiences and ideas were exchanged. A proposal was also made for an extended Nordic version of ICD-8 for use in hospitals. Despite the fact that ICD-8 had more codes than previous versions, it was decided in the Nordic countries that it needed to be extended even more, primarily with a more detailed specification of diagnoses, by using five-figure codes throughout. The proposal was accepted in its entirety by Finland [25] and Sweden [32]. At that time, Norway had no statistics that required a more detailed classification. Denmark worked further with the proposal, and a couple of years later published a similar classification [14]. Iceland had not yet entered into NOMESCO cooperation. Thus, this meant that the ambition to develop a common Nordic ICD-8 for use in hospitals was not realised.

Therefore, one of NOMESCO's tasks was to function as a clearing house for classification issues. This involved collecting information about the national classifications and the changes made in them. This was an important prerequisite for work towards comparable health statistics.

detta tidiga klassifikationssamarbete gjordes också av Johannes Mosbech, Danmark, och Sakari Härö, Finland.

Det första klart uttalade syftet med det nordiska klassifikationssamarbetet var alltså att få till stånd en jämförbar nordisk medicinalstatistik. Samarbetet tog fart i samband med att WHO publicerade ICD-8 år 1967 [7]. Samtliga länder började då göra nationella översättningar. Inom NOMESCO:s klassifikationsarbetsgrupp utbytte man erfarenheter och idéer. Man gjorde också ett förslag till en utvidgad nordisk version av ICD-8 för sjukhusbruk. Trots att ICD-8 innehöll flera koder än tidigare fann man i Norden att den behövde utvidgas ytterligare, främst genom en finare specificering av diagnoserna med genomgående femsiffriga koder. Förslaget antogs i sin helhet 1968 av Finland [25] och Sverige [32]. Norge hade vid den tidpunkten inte någon statistik som krävde en mer detaljerad klassifikation. Danmark arbetade vidare på förslaget och kom ett par år senare 1971 ut med en liknande klassifikation [14]. Island hade då ännu inte inträtt i NOMESCO-samarbetet. Det innebar alltså att man inte lyckades med ambitionen att få en gemensam nordisk ICD-8 för sjukhusbruk.

En uppgift för NOMESCO blev därför att fungera som clearinghouse i klassifikationsfrågor. Det innebar att man samlade in uppgifter om de nationella klassifikationerna och de förändringar som vidtagits i dem. Detta var ju en viktig förutsättning för arbetet mot jämförbar hälsostatistik.

## The managing of ICD-9 in the Nordic countries

While this work was going on in the Nordic countries, in 1969, WHO began work with the next revision, ICD-9. At the beginning, very moderate changes were planned. NOMESCO suggested to WHO that the revision should be limited in extent, with regard to the need for continuity in registration of health data. However, during work with the revision, so strong demands for radical changes were made, that WHO abandoned its original aim of a limited revision.

When the revision conference was held in Geneva in 1975, WHO put forward a proposal that involved very comprehensive changes. The result was that all the Nordic countries opposed the proposal. They declared that they did not intend to accept ICD-9 but instead would continue to use ICD-8 with minor changes and wait for ICD-10. One reason was that they had already adapted ICD-8 by subdividing many of the codes, such as in the proposal for ICD-9. In addition, they had a comprehensive decentralized electronic application of the classification in hospitals, that made a transition to another version expensive and difficult.

NOMESCO's initial contact with WHO concerning classification issues was not entirely positive. WHO reacted to the Nordic countries' opposition to the proposal for ICD-9 with some irritation. On the other hand, WHO were aware that the Nordic countries had more experience of using ICD for patient statistics than most other countries, apart from

## De nordiska ländernas hantering av ICD-9

Redan medan det här arbetet pågick i Norden började WHO 1969 arbetet på nästa revision, ICD-9. Man planerade från början mycket måttliga förändringar. NOMESCO framförde till WHO att revisionen borde bli av begränsad omfattning med hänsyn till behovet av kontinuitet i registreringen av medicinska data. Under revisionsarbetet framkom emellertid så starka krav på radikala ingrepp att WHO övergav sin ursprungliga målsättning om en begränsad revision.

När revisionskonferensen hölls i Genève 1975 lade WHO fram ett förslag som var mycket långtgående. Det föranledde de nordiska länderna att gemensamt reservera sig mot förslaget. De deklarerade att de inte tänkte ansluta sig till ICD-9 utan i stället fortsätta att använda ICD-8 med smärre ändringar och invänta ICD-10. En anledning var att man i anpassningen av ICD-8 redan hade gjort många av de uppdelningar av koder som ICD-9-förslaget innehöll. Man hade dessutom en omfattande decentraliserad och datoriserad användning av klassifikationen på sjukhus som gjorde en övergång dyrbar och besvärlig.

Det kan konstateras att NOMESCO:s inledande kontakter med WHO i klassifikationsfrågor inte var särskilt positiva. Reservationen mottogs med viss irritation. Å andra sidan var man i WHO medveten om att de nordiska länderna hade mer erfarenhet av användningen av ICD i patientstatistik än de flesta andra länder utom möjligen England

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England and the USA. Therefore, they were also respected for their decision. For example, as a consequence, NOMESCO was subsequently invited to the annual meetings that WHO arranged with its Collaborating Centres for Classification of Diseases. The first meeting at which a person from the Nordic countries participated was in 1978 in São Paulo, when Åke Sjöström represented NOMESCO (see more about this below).

At NOMESCO, a project was then started to attempt to produce a joint Nordic revised version of ICD-8. It was named ICD-8 ¼, to indicate that the changes were to be limited. Comprehensive work was carried out under the leadership of Martin Osnes in Norway, to map out the differences between ICD-8 and ICD-9 – WHO showed much interest in this work – and the differences between the Nordic versions of ICD-8 [38, 39, 40, 41]. It became apparent that, despite the cooperation that had taken place, the differences were not insignificant. A joint Nordic ICD-8 ¼ was never developed, but valuable information was gained for interpreting differences in the statistics. Also, Norway obtained a good foundation for its version of ICD-8.

In 1980, there was a lively discussion within NOMESCO about the earlier decision not to implement ICD-9 in the Nordic countries, and the decision began to be questioned. It had then become clear that ICD-10, which the Nordic countries intended to wait for, would be considerably delayed. WHO estimated that it would be delayed by at least five and maybe ten years. In this situation it seemed unacceptable to stick to classifications based on

och USA. De nordiska länderna mötte därför också respekt för sitt ställningstagande. En konsekvens var till exempel att NOMESCO i fortsättningen kom att inbjudas till de årliga möten som WHO anordnade med sina Collaborating Centres för klassifikationsfrågor. Det första mötet med nordiskt deltagande ägde rum 1978 i São Paulo, då Åke Sjöström representerade NOMESCO (se mera härom nedan).

Inom NOMESCO startade man nu ett projekt för att försöka ta fram en gemensam nordisk reviderad version av ICD-8. Den kom att kallas ICD-8 ¼ för att markera den avsedda begränsade förändringen. Ett omfattande arbete gjordes under ledning av Martin Osnes i Norge för att kartlägga hur stora skillnaderna var mellan ICD-8 och ICD-9 – ett arbete som WHO visade sig mycket intresserat av – och dessutom hur mycket de nordiska ICD-8-versionerna egentligen skilde sig åt [38, 39, 40, 41]. Det visade sig att trots det samarbete som funnits var skillnaderna inte obetydliga. Någon gemensam nordisk 8¼ blev det inte, men man fick ett värdefullt material som grund för att tolka olikheter i statistiken. Norge fick dessutom ett bra underlag för sin ICD-8-version.

Under 1980 diskuterades livligt inom NOMESCO det tidigare beslutet att inte införa ICD-9 i de nordiska länderna och beslutet började ifrågasättas. Det hade då blivit klart att ICD-10, som de nordiska länderna avsåg att invänta, skulle bli betydligt försenad. Från WHO:s sida angav man minst fem, kanske tio års försening. I det läget framstod det som alltmer ohållbart att hålla fast vid ICD-8-baserade klassifikationer

ICD-8, which were becoming more and more out-of-date, especially as a Nordic ICD-8 ¼ revision had not been developed. For mortality statistics, there were good arguments for introducing ICD-9, in order to produce statistics comparable with the statistics from the many other countries that had gone over to using ICD-9.

However, it became apparent that there was a great deal of disagreement between the Nordic countries. Iceland was the first country that decided to go over to ICD-9, in 1982, but intended to use the English version without translating it. On the other hand, Denmark stuck to its intention to continue using its detailed classification from 1971 based on ICD-8. Opinions were divided in the other countries. Sweden was the first to decide to go over to ICD-9 [33] and Finland [26] and Norway [29] soon followed. Thus much of NOMESCO's work with classifications for several years was related to coordinating the introduction of ICD-9. However, it was not until 1987 that versions based on ICD-9 were introduced for patient statistics in hospitals in Sweden and Finland. ICD-9 was introduced in Norway in 1988, but in psychiatric institutions in 1987.

### Registration of diagnoses in primary health care

Another area in which there were differences of opinion between the Nordic countries about work with classifications was the area of classification of diseases in primary health care. As early as 1969, Sweden took the initiative for developing diagnosis-related statistics for non-admitted patient care and primary health

som tedde sig alltmer föråldrade, särskilt som man inte fått till stånd någon nordisk 8 ¼-revision. För dödsorsaksstatistiken fanns det särskilda skäl att införa ICD-9 för att få jämförbar statistik med övriga länder, vilka så gott som alla gått över till ICD-9.

Det visade sig dock att en stor oenighet fanns mellan de nordiska länderna. Island bestämde sig som första land att gå över till ICD-9 redan 1982, men avsåg då använda den engelskspråkiga versionen utan översättning. Danmark däremot vidhöll mycket starkt sin avsikt att hålla fast vid sin ICD-8 baserade detaljerade klassifikation från 1971. I de övriga länderna var meningarna delade. I Sverige mognade först beslutet fram att gå över till ICD-9 [33] och Finland [26] och Norge [29] följde strax efter. Därmed kom NOMESCO:s klassifikationsarbete under ett antal år att präglas av försök att samordna införandet av ICD-9. Först 1987 kunde emellertid de ICD-9-baserade versionerna tas i bruk för patientstatistik från sjukhus i Sverige och Finland samt från 1988 i Norge, där den dock infördes vid psykiatriska avdelningar 1987.

### Diagnosregistrering i primärvården

Ett annat område där det funnits motsättningar i klassifikationsarbetet mellan de nordiska länderna gäller klassificering av sjukdomar i primärvården. Redan 1969 togs i Sverige initiativ för att få till stånd diagnosrelaterad statistik från den öppna vården och primärvården. På uppdrag av Socialstyrelsen utarbetade

care. Commissioned by the National Board of Health and Welfare, Björn Smedby, in consultation with a general practitioner, Gustaf Haglund, developed “A provisional list of diagnoses for primary health care” [42], based on ICD-8. The list was adopted in 1970 for field trials in primary health care. It was translated into English and presented to WHO.

The Swedish list of diagnoses for primary health care was revised in 1976 by a Nordic working group, and an English version was published by NOMESCO the same year [43]. NOMESCO recommended the list for use in the Nordic countries as appropriate. This received opposition, primarily from Norway and Denmark. Bent Guttorm Bentsen, professor in general practice in Trondheim, who was strongly committed to international work with classifications in the field of general practice, wrote to the chairman of NOMESCO, regretting the publication of the list of diagnoses. He referred to the work that had been done by WONCA, the world organization of family physicians, which had resulted in the International Classification of Health Problems in Primary Care (ICHPPC) [44], and which had gained wide international acceptance. He meant that it should therefore be the only internationally approved abbreviated list of diagnoses beside ICD. He regarded the NOMESCO list as an “occupational accident” in a Nordic perspective.

The criticism was followed up from Norway and Denmark in the Danish *Ugeskrift for Laeger* (Weekly Medical Journal). Jo Telje, Bent Guttorm Bentsen and Peter F. Hjort recommended WONCAS' ICHPPC for use in Norway [45]. The Danish side reported a field

Björn Smedby i samråd med allmänläkaren Gustaf Haglund en “Provisorisk diagnoskod för öppen vård” [42] som byggde på ICD-8. Koden fastställdes 1970 för försöksvis användning inom den öppna vården. Listan översattes också till engelska och delgavs WHO.

Den svenska öppenvårdskoden reviderades 1976 av en nordisk arbetsgrupp och en engelskspråkig version publicerades av NOMESKO samma år [43]. NOMESKO rekommenderade kodlistan för användning i de nordiska länderna där så befanns lämpligt. Detta stötte på motstånd framför allt i Norge och Danmark. Professorn i allmänmedicin i Trondheim Bent Guttorm Bentsen som var starkt engagerad i allmänläkarnas internationella klassifikationsarbete skrev till NOMESKO:s ordförande och beklagade beslutet att publicera kodlistan. Han hänvisade till att det arbete som bedrivits av allmänläkarnas världsorganisation WONCA och som lett fram till International Classification of Health Problems in Primary Care (ICHPPC) [44] hade fått bred anslutning internationellt. Den borde därför enligt honom bli den enda internationellt godtagna förkortade diagnoslistan vid sidan av ICD. Det inträffade betraktade han som en “arbetsolycka” i nordiskt sammanhang.

Kritiken följdes upp från norsk och dansk sida i *Ugeskrift for Laeger*. Jo Telje, Bent Guttorm Bentsen och Peter F. Hjort förordade WONCAS:s ICHPPC för bruk i Norge [45]. Från dansk sida redovisades en utprovning av ICHPPC som också gav denna förkor-

trial of ICHPPC, which also gave this list support with certain reservations [46]. At this time, a short list was used in Finland, based on ICD-8 with 99 groups according to an American model. Thus NOMESCO's recommended version was mainly used in Swedish primary health services as the List of Diagnoses for Primary Health Care 1977 [47].

Differences of opinion between the Nordic countries have continued during later years in this respect. The simplified Swedish list of diagnoses for primary health care based on ICD was developed further in cooperation with Swedish general practitioners, and was published in 1987 as an ICD-9 based [48] and later as an ICD-10 based classification for primary health care [49], which has been widely used in Sweden. However, in Norway, WONCA's International Classification of Primary Care (ICPC) [50] – a further development of ICHPPC – was officially prescribed for physicians' reporting of diagnoses to the National Insurance Administration. It has also been fairly widely used in Denmark.

Also between WONCA and WHO a conflict developed that came to be serious and long-lasting. At the beginning of the 1980s, when preliminary work with ICD-10 was being carried out, WONCA began lobbying to get WHO to depart from the traditional ICD structure in favour of the structure of WONCA's classification. They meant that their classification should form the basis for ICD-10, and referred to WHO's Alma Ata Declaration about the importance of primary health care. Nothing came of this, and WONCA continued to develop ICPC on their own. Several attempts have been made to reconcile their differences, but it is only during the last

tade lista stöd om än med viss reservation [46]. I Finland användes vid denna tid en förkortad lista baserad på ICD-8 med 99 grupper efter en amerikansk förebild. Det blev därför i huvudsak inom svensk primärvård som den av NOME-SKO rekommenderade versionen kom att användas som Diagnoskoder i öppen vård 1977 [47].

Även under senare år har denna motsättning bestått inom Norden. Den ICD-baserade förenklade svenska primärvårdsklassifikationen vidareutvecklades i samverkan med svenska allmänläkare och gavs 1987 ut som en ICD-9-baserad [48] och senare även en ICD-10 baserad primärvårdsklassifikation [49] som fått bred användning i Sverige. I Norge har däremot WONCA:s International Classification of Primary Care (ICPC) [50] – en vidareutveckling av ICHPPC – blivit officiellt anbefalld för läkarnas rapportering av diagnoser till Rikstrygdeverket. Den har också relativt bred användning i Danmark.

Även mellan WONCA och WHO växte en motsättning fram som kom att bli djup och långvarig. Under förarbetet på ICD-10 under början av 1980-talet startade WONCA en lobby-aktion för att få WHO att lämna den traditionella ICD-strukturen till förmån för WONCA:s klassifikation som – menade man – borde styra grundutformningen av ICD-10 med hänvisning till WHO:s Alma Atadeklaration om primärvårdens betydelse. Av detta blev nu intet och WONCA fortsatte på egen hand utvecklingen av ICPC. Olika försök har gjorts att överbrygga motsättningarna men först under de allra senaste åren har en gemensam

few years that a joint working group with WHO and WONCA under the leadership of Martti Virtanen has been successful in almost reconciling the opposing views. Niels Bentzen, professor in general practice in Trondheim, and chairman of WONCA's classification committee, made an important contribution to uniting the two sides. Among other things, translation tables between ICD-10 and ICOC have been developed. In 2003, ICPC-2 [51] was approved as a "related classification" in WHO's family of classifications, which can be used in "family practice and primary care" as appropriate. A working group is working on improving the compatibility between ICD and ICPC.

### The establishment of a Nordic classification centre

The change in attitude of the Nordic countries to ICD-9, described above, facilitated the contacts with WHO, and the Nordic countries were drawn increasingly into the international work with classifications. Since 1978, NOMESCO was invited to send a representative to the annual one-week meetings with WHO and its Collaborating Centres for Classification of Diseases. For ten years, NOMESCO had observer status at the meetings, and was represented by delegates who were chosen so that the majority of the Nordic countries gradually gained experience from this international cooperation (see Table 4).

In this way, the Nordic countries began to be interested in having a designated WHO Collaborating Centre. WHO also showed interest in this. This was discussed further by NOMESCO and its

arbetsgrupp mellan WHO och WONCA under Martti Virtanens ledning lyckats att något så när jämka ihop de stridande viljorna. En viktig insats för samförstånd gjorde också Niels Bentzen, professor i allmänmedicin i Trondheim och ordförande i WONCA:s klassifikationskommitté. Bland annat har man tagit fram översättningstabeller mellan ICD-10 och ICPC. År 2003 blev ICPC-2 [51] antagen som en till WHO:s klassifikationsfamilj "related classification" som kan användas inom "family practice and primary care" där man så finner lämpligt. En arbetsgrupp arbetar för en framtida större kompatibilitet mellan ICD och ICPC.

### Ett nordiskt klassifikationscenter bildas

Den ovan beskrivna ändrade inställningen i Norden till ICD-9 underlättade också kontakterna med WHO och de nordiska länderna drogs alltmer in i det internationella klassifikationsarbetet. NOMESKO hade sedan 1978 inbjudits att sända en representant till de årliga, veckolånga mötena med WHO och dess Collaborating Centres för klassifikationsfrågor. Under ett tiotal år hade NOMESKO observatörsstatus vid mötena och företrädde av representanter som utsågs så att flertalet av de nordiska länderna efterhand kom att få erfarenhet av detta internationella samarbete (se tabell 4 nedan).

Härigenom väcktes tanken på att de nordiska länderna skulle sträva efter att få ett av WHO officiellt erkänt Collaborating Centre, något som WHO också förklarade sig intresserat av. Inom NOMESKO



working group AKLASS. However, it took several years before a solution was found to all the issues concerning organization and funding of a Nordic centre. There was initial discussion about where the centre should be situated, and both Sweden and Denmark officially showed their interest for being responsible for the Centre. So, it created some surprise in NOMESCO when the Danish side unilaterally approached WHO to gain support for placing the centre in Denmark. Continued negotiations, however, led to a decision in NOMESCO about Sweden as the base for the Centre. Not until NOMESCO's plenary meeting in 1987 the new centre was inaugurated at the Department of Social Medicine of Uppsala University where work with classifications had been based for several years, through Björn Smedby's chairmanship in AKLASS. The centre was named the WHO Collaborating Centre for the Classification of Diseases in the Nordic Countries. Björn Smedby was appointed as centre head.

The new centre was given double affiliation, to NOMESCO, which partly financed the classification work, and to Uppsala University, Department of Social Medicine. An independent board was established for the centre, comprising the five chairmen of the Nordic NOMESCO delegations. Guðjón Magnússon from Iceland became the board's first chairman. The Nordic Council of Ministers provided funding for the Centre for an initial period of four years, on the understanding that the work was carried out in close cooperation with NOMESCO and its working group AKLASS.

och dess arbetsgrupp AKLASS fördes diskussionen vidare. Det tog dock flera år innan alla frågor kring organisationen och finansieringen av ett nordiskt center kunde lösas. En viss diskussion förekom initialt om centrets placering och både Sverige och Danmark visade officiellt intresse för att få ansvar för centret. Det väckte därför någon förvåning i NOMESKO när man från dansk sida ensidigt närmade sig WHO för att få stöd för en placering i Danmark. De fortsatta förhandlingarna i NOMESKO ledde dock till att man enades om Sverige som bas för centret. Först i samband med NOMESKO:s plenarmöte 1987 kunde man inviga det nya centret som förlades till Socialmedicinska institutionen vid Uppsala universitet, där klassifikationsarbetet hade varit förankrat sedan flera år genom Björn Smedbys ordförandeskap i AKLASS. Centret fick namnet WHO Collaborating Centre for the Classification of Diseases in the Nordic Countries (på svenska: Nordiskt WHO-center för klassifikation av sjukdomar). Som föreståndare utsågs Björn Smedby.

Det nya centret fick en dubbel anknytning, både till NOMESKO, som delvis finansierade klassifikationsarbetet, och till Uppsala universitet genom placeringen vid den socialmedicinska institutionen där. Centret fick en fristående styrelse bestående av de fem ordförandena i de nordiska NOMESKO-delegationerna. Guðjón Magnússon från Island blev styrelsens första ordförande. Man lyckades förhandla fram separat finansiering till centret från Nordiska Ministerrådet för i första hand en fyra-årsperiod. Arbetet förutsattes dock ske i nära samarbete med NOMESKO och dess klassifikationsgrupp AKLASS.

## THE GROWTH OF NORDIC COOPERATION ON CLASSIFICATIONS

The plan of work that was developed for the Centre included close cooperation with WHO in the current work with revision of ICD-10, including being host for the Centre Heads Meeting in 1988 in Uppsala. The Centre was also to compile the experiences of the Nordic countries with the transition from ICD-8 to ICD-9, and study the effects of the changes in the classifications. A main task was to study the validity and quality of mortality statistics and hospital statistics in the Nordic countries. In addition, efforts should be done to organize courses for people who code causes of death in the Nordic countries, and a bibliography of Nordic and international literature on classifications should be developed.

The Centre was given the special task of coordinating the Nordic versions of ICD-10. An ad hoc working group was appointed to carry out this task in 1989, and its work continued until 1997, when it was converted into a permanent reference group for Nordic classification issues. The working group held a series of meetings and seminars, for example on coding of morbidity and the application of the dagger-asterisk system in ICD-10. Even though the Nordic countries developed their own versions of ICD-10, cooperation on ICD-10 was important. Proposals for short lists for reporting hospital statistics based on ICD-10 were also developed.

Work with a Nordic classification of accidents was carried out by the NOMESCO working group ARON, which was established in 1985 under the leadership of Henning Bay-Nielsen. Development of the Nordic Classification of Surgical Procedures was also carried out

Den verksamhetsplan som upprättades för centret omfattade nära samarbete med WHO i det pågående revisionsarbetet på ICD-10 inklusive värdskap för Centre Heads-mötet 1988, vilket förlades till Uppsala. Centret skulle också sammanställa de nordiska erfarenheterna av övergången från ICD-8 till ICD-9 och studera effekterna av klassifikationsändringarna. En huvuduppgift skulle vara att studera tillförlitlighet och kvalitet av uppgifterna i dödsorsaks- och sjukhusstatistik i Norden. Dessutom skulle utbildningsinsatser göras i form av kurser för nordiska dödsorsakskodare och en bibliografi över nordisk och internationell klassifikationslitteratur upprättas.

Samordningen av de nordiska ICD-10 versionerna angavs som en särskild uppgift för centret för vilket en ad hoc-arbetsgrupp bildades 1989 som verkade fram till 1997, då den ombildades till en permanent referensgrupp för nordiska klassifikationsfrågor. Inom gruppen hölls en serie arbetsmöten och seminarier, bl.a. om morbiditetskodning och tillämpningen av ICD-10:s dagger-asterisksystem. Även om de nordiska länderna utarbetade nationella versioner av ICD-10 blev samarbetet kring dessa betydelsefullt. Man tog också fram förslag till kortlistor för statistisk redovisning av sjukhusstatistik baserad på ICD-10.

Arbetet med en nordisk klassifikation av olycksfall låg dock kvar i NOMESCO-arbetsgruppen ARON som inrättats 1985 under Henning Bay-Nielsens ledning. Även utvecklingen av den nordiska operationsklassifikationen kom att läggas på en särskild NOMESCO-

by a special NOMESCO working group, established in 1989 with Henning Bay-Nielsen as leader. (The development of these two joint classifications is described in detail in separate sections below). Later, the Nordic Centre was given responsibility for maintenance and updating of these two Nordic classifications.

### A new organization for the Centre

After an evaluation carried out in 1990 in cooperation with WHO and the Nordic Directors of Health, the Nordic Council of Ministers extended its funding of the Centre until 1994. After this period, new types of funding were required. From 1995, the Centre receives funding directly from the countries' health authorities, in proportion to the Nordic distribution key, which is related to the countries' gross national product. Since that time, this funding has covered the basic activities of the Centre. However, special funding was allocated to the Centre when work with Diagnosis Related Groups (DRGs) began (more about this below).

Gunnar Schiøler from Denmark was appointed as the chairman of the new board, which was established in 1995. The new organization of the Centre also involved a broader range of activity for the Centre. Division of responsibility between NOMESCO and the Centre was clarified, such that all work with classifications was to be done at the Centre, and NOMESCO should concentrate on the area of health statistics. This meant that annual updating of the NOMESCO Classification of Surgical Procedures (NCSP) and further de-

arbetsgrupp inrättad 1989 med Henning Bay-Nielsen som ledare. (Utvecklandet av dessa båda gemensamma klassifikationer beskrivs ingående i separata avsnitt nedan.) Det nordiska centret har dock senare fått ansvar för vidmakthållande och uppdatering av dessa båda nordiska klassifikationer.

### Ny organisationsform för centret

Efter en utvärdering som genomfördes 1990 under medverkan av WHO och de nordiska hälsodirektörerna förlängde Nordiska Ministerrådet sitt projektstöd till centret till att gälla t.o.m. 1994. Här efter krävdes nya finansieringsformer. Från och med 1995 kom därför de nordiska ländernas hälsoadministrationer att direkt stödja centret med finansiering med andelar motsvarande den nordiska fördelningsnyckeln, vilken är relaterad till bruttonationalprodukten för länderna. Denna finansieringsform har sedan dess bestått för centrets basverksamhet. Särskilda medel tillfördes dock till centret när DRG-verksamheten startade (varom mera nedan).

Den nya styrelsen som tillsattes 1995 fick Gunnar Schiøler från Danmark som ordförande. Den nya organisationsformen innebar också en breddning av verksamheten vid centret. En klarare uppdelning av ansvarsförhållandena mellan NOMESCO och det nordiska centret skedde med sikte på att allt klassifikationsarbete skulle ske inom centret och NOMESCO:s arbete koncentreras till hälsostatistikens område. Det innebar att den årliga uppdateringen av den nordiska operationsklassifika-

velopment of the NOMESCO Classification of External Causes of Injuries (NCECI) should be done at the Centre. This was done with the assistance of special consultants for NCSP (Hubertus van Paaschen from Sweden, who was replaced by Glen Thorsen from Norway in 2001) and for NCECI (Birthe Frimodt-Møller from Denmark).

A secretariat was established for the regular work of the centre, with responsibility for meetings and publications. Telephone conferences were used to an increasing degree. The Centre was involved with comprehensive information activities, and in 1989 began to publish a biannual newsletter about classification issues, which was distributed to all the Nordic countries. This was replaced in 1999 by an electronic newsletter and information on the Centre's website. Kerstin Carsjö, research assistant, had special responsibility for the newsletter and the website, and also for making a list of international and Nordic literature about classifications. Several issues of a bibliography of literature about ICD and other health classifications were published. The third issue was published in 1994, and included 1 482 references [52].

One of the tasks of the Centre was research and development work. The Centre paid particular attention to the issue of the validity of mortality statistics and diagnoses for hospital patients. Dr Anna-Christina Nilsson, who worked at the Centre from 1988 until her death in 1995, made a large contribution with studies of the reliability of statistics on hospital diagnoses. Methodology was developed in a comprehensive Swedish study [53], and this methodology was subsequently used

tionen (NCSP) och vidareutvecklingen av olycksklassifikationen skulle ske vid centret. Detta skedde med hjälp av särskilda konsulter för NCSP (Hubertus van Paaschen från Sverige som 2001 efterträddes av Glen Thorsen från Norge) och för NCECI (Birthe Frimodt Møller från Danmark).

För det löpande arbetet vid centret inrättades ett kansli som svarade för mötesplanering och rapportsammanställningar. I växande utsträckning kom telefonsammanträden att användas. Centret svarade också för en omfattande informationsverksamhet och utgav med start 1989 ett halvårsvis utkommande nyhetsbrev i klassifikationsfrågor som distribuerades inom hela Norden. Det ersattes 1999 av ett elektroniskt nyhetsbrev och information på centrets hemsida. Forskningsassistenten Kerstin Carsjö hade särskilt ansvar för detta och svarade också för en sammanställning av internationell och nordisk klassifikationslitteratur. En bibliografi över litteratur om ICD och andra hälsorelaterade klassifikationer publicerades i flera upplagor. Den tredje utkom 1994 och omfattade 1482 referenser [52].

Till centrets arbetsuppgifter hörde också forsknings- och utvecklingsarbete där särskilt frågor om validiteten i diagnosuppgifterna i dödsorsaks- och slutenvårdsregister uppmärksammades. Dr Anna-Christina Nilsson som arbetade vid centret från 1988 till sin död 1995 gjorde stora insatser i genomförandet av studier av sjukhusdiagnosernas tillförlitlighet. Metoder för detta utvecklades i en omfattande svensk studie [53] och kom sedan att tillämpas också i en

in a Danish-Swedish comparability study. One of the conclusions was that problems with reliability of data, to a large extent, can be related to insufficient knowledge about the classification of diseases and the rules and guidelines for its use.

In 1999, Kristina Bränd Persson was recruited to carry out a Nordic study of the validity and comparability of patient statistics. The results of the study were published as a theme section in NOMESCO's annual publication *Health Statistics in the Nordic Countries* [54]. This study also identified problems related to application of the classifications.

In 2000, Kristina Bränd Persson replaced Kerstin Carsjö as research assistant and project coordinator at the Nordic Centre. These two persons have made substantial contributions to the work of the Nordic Centre. From 2003 when Björn Smedby, after more than 15 years, retired from his position as centre head, Martti Virtanen was appointed centre head and Kristina Bränd Persson assistant centre head.

Since the Nordic Centre is located in Sweden, conscious efforts have been made in several different ways to avoid the work being dominated by Swedish people. The Centre's Nordic character has been maintained by appointing a chairman of the board from another Nordic country. Expert advisers have been engaged mainly from other Nordic countries. Also, Martti Virtanen from Finland is now centre head. Apart from the expert advisers mentioned earlier, Lars Age Johansson from Sweden is officially attached to the Centre as expert adviser for mortality coding and mortality statistics (see below). Later, a con-

dansk-svensk jämförande studie. En slutsats var att brister i tillförlitligheten i stor utsträckning kan återföras på bristande kännedom om sjukdomsklassifikationen och dess regelverk.

Kristina Bränd Persson engagerades 1999 för en nordisk studie av validitet och jämförbarhet i patientstatistiken som publicerades som en temasektion i NOMESCO.s hälsostatistiska årsbok [54]. Även denna studie pekade på problem med olikheter i hur klassifikationerna tillämpas.

Kristina Bränd Persson efterträdde år 2000 Kerstin Carsjö som forskningsassistent och projektsamordnare vid det nordiska centret. Betydelsen av dessa båda personers mångåriga insatser har varit stor och bidragit till kontinuiteten i centrets arbete. När Björn Smedby efter mer än 15 år lämnade föreståndarskapet och fr.o.m. 2003 efterträddes av Martti Virtanen blev Kristina Bränd Persson även biträdande föreståndare för centret.

På grund av att det nordiska centret har varit placerat i Sverige har man på olika sätt medvetet försökt undvika en svensk dominans i arbetet. Att utseende av ordförande i styrelsen och anställningen av expertrådgivare som konsulter huvudsakligen har skett från de andra nordiska länderna har understrukt centrets samnordiska karaktär liksom att Martti Virtanen från Finland numera är föreståndare. Förutom de tidigare nämnda expertrådgivarna knöts 1996 Lars Age Johansson från Sverige formellt till centret som konsult för dödsorsaksfrågor (se nedan) och senare tillkom även en kon-

sultant was appointed to work with ICF (Tora Haraldsen Dahl from Denmark, during 2001-2002). Furthermore, much of the work has been carried out by working groups with members from different Nordic countries.

In order to emphasize the gradually enlarged area of responsibility and work for the Centre, from 1 January 2003 it was renamed the Nordic Centre for Classifications in Health Care.

### Nordic cooperation for coding of causes of death

As described earlier, mortality statistics are the oldest application of classifications in health care. From a global perspective, they are also the most important, since many countries only have the possibility to produce this type of health-related statistics. As a rule, the statistics include only one cause for each death. Thus, one of the conditions for comparable statistics is standardized rules for selection of the cause of death that shall be registered if several causes have contributed to the death. In connection with the adoption of ICD-6 in 1948 [4], an international form for death certificates was developed, and clear rules for the selection of underlying cause of death were adopted. The underlying cause is the one used in international mortality statistics.

A working group for mortality statistics in NOMESCO carried out an analysis of coding practice in the Nordic countries. The results were published in 1985 [55]. The study detected large differences between the countries. In the plan of work for the newly established Nordic Centre

sult för arbetet med ICF (Tora Haraldsen Dahl från Danmark under åren 2001-2002). Härtill kommer att mycket av arbetet skett inom arbetsgrupper med nordisk sammansättning.

För att markera centrets efterhand utvidgade ansvars- och arbetsområde ändrades namnet från och med 2003 till Nordiskt center för klassifikationer i hälso- och sjukvården.

### Nordisk samverkan kring dödsorsakskodning

Som framgått tidigare utgör dödsorsaksstatistiken den äldsta användningen av klassifikationer inom hälso- och sjukvården. I ett världsvitt perspektiv är det också den viktigaste, eftersom många länder endast har möjlighet att producera denna form av hälsorelaterad statistik. Som regel omfattar statistiken bara en orsak för varje dödsfall. En förutsättning för jämförbarhet är då enhetliga regler för valet av den dödsorsak som skall redovisas, om flera orsaker samverkat till döden. I samband med fastställandet av ICD-6 år 1948 [4] fastställdes ett internationellt formulär för dödsbevis och enhetliga regler för val av underliggande dödsorsak, vilken alltså är den som redovisas i den internationella dödsorsaksstatistiken.

En arbetsgrupp för dödsorsaksstatistik inom NOMESKO gjordes en analys av kodningspraxis i de nordiska ländernas som publicerades 1985 [55]. Den visade stora skillnader mellan länderna. I verksamhetsplanen för det nyinrättade nordiska klassifikationscentret angavs där-

for Classification of Diseases, it was therefore stated that the Centre should, among other things, study the reliability and quality of mortality statistics in the Nordic countries. Training people who code causes of death was seen as an urgent task, and the first training conference was held in 1988. Later, a series of meetings on coding of causes of death were held, where problem cases were discussed.

In 1996-1997, partly funded by NOMESCO, the Centre carried out a Nordic study of the prerequisites for coordinated mortality statistics [56]. Routines for producing the statistics in the different Nordic countries were documented. The study revealed larger differences than had been expected. It was therefore followed up with a series of Nordic meetings with coders of causes of death. At these meetings, comparable test coding of a number of death certificates from the participating countries was discussed. It was demonstrated that there were relatively large differences in coding of underlying cause of death. This gave rise to further training sessions and discussions related to application of computerized routines for coding. Over the last few years comparability in coding of causes of death has shown a tendency to improve, but the effect has been fairly modest. Experience with computerized coding support, which was first introduced in Sweden, has shown that automated coding gives better consistency than manual coding. The Swedish side has given support to the other countries during the introduction of automated coding. Following this the introduction of computerized coding has increased in the Nordic countries.

för att centret bland annat skulle studera tillförlitlighet och kvalitet i de nordiska ländernas dödsorsaksstatistik. Utbildningsinsatser för dödsorsakskodare sågs som en angelägen uppgift och en första utbildningskonferens hölls 1988. Därefter anordnades en serie möten kring dödsorsakskodning där kodningen av problemfall diskuterades.

Med delfinansiering från NOMESCO gjordes vid centret 1996-1997 en nordisk studie av förutsättningarna för en samordnad dödsorsaksstatistik [56], varvid produktionsrutinerna kartlades i de olika länderna. Kartläggningen visade större olikheter än vad man förväntat. Den kom därför att följas upp av en serie nordiska möten med dödsorsakskodare. Vid dessa möten diskuterades jämförande testkodningar av ett antal dödsbevis från de deltagande länderna. Man kunde konstatera relativt stora olikheter i kodningen av underliggande dödsorsak, vilket föranlett ytterligare utbildningsinsatser och diskussioner kring användningen av datoriserade rutiner för kodningen. Kodningsjämförelserna har under åren visat en tendens mot ökad samstämmighet i kodningen av dödsorsaker men effekten har varit tämligen blygsam. Erfarenheter av datoriserat kodningsstöd som först infördes i Sverige har visat att automatiserad kodning ger bättre samstämmighet än manuell kodning. Från svensk sida har stöd lämnats till de övriga länderna för införande av automatisk kodning. I ökande grad har därefter datoriserat kodningsstöd införts i de nordiska länderna.

Since 2000, NOMESCO's cooperation in the field of health statistics with the Baltic countries has also included mortality statistics. Annual Nordic-Baltic conferences have been held, and comparability studies of the quality of coding have been carried out. Comparisons of Nordic-Baltic coding are now carried out regularly 3-4 times a year, using small samples of death certificates from the participating countries. The computerized American ACME system is used as a standard reference for this purpose.

Nordic participation in WHO's international work on coding causes of death is discussed in a following section. In addition, the Nordic countries have been active in working groups and projects with EUROSTAT, which aims at documenting the quality and comparability of European mortality statistics.

Lars Age Johansson in Sweden has long been a central person in the work with quality and routines for coding causes of death. In connection with reorganization of the Nordic Centre in 1996, he was formally appointed by the Nordic Centre as expert adviser for mortality coding and mortality statistics.

### The Nordic Centre and international cooperation on classifications

When the Nordic Centre for Classification of Diseases was established, one of the stated aims was that the Nordic countries should be able to cooperate better with WHO, and have more influence within WHO in classification issues. Early, the Nordic countries par-

Sedan år 2000 har också NOMESKO:s samarbete på hälsostatistikens område med de baltiska länderna kommit att omfatta dödsorsaksstatistiken och årliga nordisk-baltiska konferenser med jämförande studier av kodningskvalitet har genomförts. De nordisk-baltiska kodningsjämförelserna görs numera löpande med små urval av dödsattester från de deltagande länderna 3-4 gånger per år. Härvid används det datoriserade amerikanska ACME-systemet som standardreferens.

De nordiska insatserna i det internationella arbetet beträffande dödsorsakskodning inom WHO berörs i följande avsnitt. Därutöver har de nordiska länderna varit aktivt engagerade i arbetsgrupper och projekt inom EUROSTAT som syftat till att kartlägga kvalitet och jämförbarhet för europeisk dödsorsaksstatistik.

En central person för arbetet med kvalitet och rutiner i dödsorsakskodningen har varit Lars Age Johansson, Sverige, som i samband med centrets omorganisation 1996 även formellt knöts till det nordiska centret som konsult för dödsorsaksfrågor.

### Centret och det internationella klassifikationssamarbetet

När det nordiska klassifikationscentret inrättades var sålunda ett av de uttalade syftena att de nordiska länderna härigenom skulle få en möjlighet att mer kraftfullt samverka med och påverka WHO i klassifikationsfrågor. De nordiska länderna drogs också tidigt in i en serie av



ticipated in a series of expert meetings that were arranged in connection with work with ICD-10. WHO employees visited the Nordic Centre, they met experts in different fields, and contacts were arranged with other specialists.

The most important event for international work was the annual one-week meetings with the Centre Heads from the ten centres in the various countries that WHO cooperated with in the field of classification of diseases (WHO Collaborating Centres for the Classification of Diseases). Most of the centres were organized to work with a specific language (English, French, Russian, Chinese etc.). In this respect, the Nordic Centre was atypical, since it represented a geographical area, albeit an area with languages with a certain degree of similarity to each other.

As shown in Table 4, the Nordic countries have participated in all the meetings that have been arranged since the Nordic Centre was established, and also at some of the meetings before then, through NOMESCO. They have contributed in a very active way, by presenting their experiences and by putting forward suggestions. Some contributions have been about rules for coding causes of death, reliability of mortality statistics and experience of computerized choice of underlying cause of death (see below). Other contributions have been about rules for coding morbidity and application of the dagger-asterisk system, coding of genetic diseases and complications of hospital treatment, specialist versions of ICD-10 and the relationship between ICD-10 and ICPC.

expertmöten som anordnades under arbetet på ICD-10. WHO:s tjänstemän besökte bl.a. det nordiska centret och träffade experter inom olika områden och kontakter förmedlades med andra specialister.

Den viktigaste arbetsformen för det fortlöpande internationella arbetet var de årliga, veckolånga mötena mellan cheferna för det tiotal centra i olika länder som WHO samverkade med när det gällde klassificering av sjukdomar (WHO Collaborating Centres for the Classification of Diseases). De flesta var organiserade för arbete inom ett visst språkområde (engelska, franska, ryska, kinesiska osv.). I det avseendet var det nordiska centret avvikande, eftersom det representerade ett geografiskt område, dock med viss språksamhörighet.

Som framgår av tabell 4 har de nordiska länderna deltagit i alla de möten som anordnats sedan centrets tillkomst och även under ett antal år dessförinnan genom NOMESCO. Man har medverkat mycket aktivt med presentationer av nordiska erfarenheter och förslag. Många av dessa har gällt regler för dödsorsakskodning, tillförlitligheten i dödsorsaksstatistiken och erfarenheter av datoriserat val av underliggande dödsorsak (se även nedan). Andra har berört regler för morbiditetskodning och tillämpningen av dagger-asterisk-systemet, kodningen av genetiska sjukdomar och komplikationer i samband med sjukhusvård, specialistversioner av ICD-10 och relationen mellan ICD-10 och ICPC.

## THE GROWTH OF NORDIC COOPERATION ON CLASSIFICATIONS

As a rule, the Nordic delegations have included several people, sometimes as many as 5-6 persons with competence in different areas, and representing the different Nordic countries. This continuous presence and broad representation with continuity of representatives has, of course, helped to give the Nordic countries a greater influence in international classification work, and in addition has drawn persons from several of the Nordic countries into the work. One can therefore assert that, to a large degree, the Nordic countries have achieved the aim of gaining greater international influence.

The Nordic Centre has been host for the annual meetings on three occasions: in Uppsala in 1988, in Copenhagen in 1997 and in Reykjavik in 2004.

An important new principle was introduced with the introduction of ICD-10, that is to *update* the classification between revisions. WHO, together with its Collaborating Centres, has developed a formalized process for how this shall be done. Suggestions for changes and additions to the classification are prepared in an international Update Reference Committee, and a decision is taken at the annual Centre Heads Meetings. The Nordic Centre has contributed actively to this work. It has been necessary to find a balance between the need for flexibility and the need for stability in the classification. The Nordic Centre has tried to put a check on suggestions for minor changes in order to maintain stability and to limit work with updating. One experience gained was that dissemination of information about changes and implementation of changes did not function well to begin with, and it took time for WHO to find solutions to these problems.

De nordiska delegationerna har som regel omfattat flera personer, ibland upp till 5-6 stycken med olika kompetens och representerande de olika nordiska länderna. Denna kontinuerliga närvaro och breda representation med lång personkontinuitet har naturligtvis bidragit till att ge de nordiska länderna ett starkare inflytande i det internationella klassifikationsarbetet och dessutom kommit att dra in personer från flera nordiska länder i arbetet. Man kan därför konstatera att man i hög grad uppnådde syftet att få ett större internationellt inflytande.

Vid tre tillfällen har det nordiska centret stått som värd för de årliga mötena; förutom det i Uppsala år 1988, även för mötet i Köpenhamn 1997 och mötet i Reykjavik 2004.

Med ICD-10 infördes en viktig ny princip, nämligen möjligheten att genomföra *uppdateringar* av klassifikationen mellan revisionerna. WHO har tillsammans med sina Collaborating Centres utvecklat en formaliserad process för hur detta skall gå till. Förslag till ändringar och kompletteringar av klassifikationen bereds i en internationell Update Reference Committee och beslut fattas vid de årliga Centre Heads-mötena. I detta arbetet har det nordiska centret aktivt medverkat. Det har där också gällt att finna balans mellan kraven på flexibilitet och stabilitet i klassifikationen. Man har från det nordiska centret försökt bromsa mindre viktiga ändringsförslag för att bibehålla stabilitet och begränsa uppdateringsarbetet. En erfarenhet som gjordes var att informationen om och genomförandet av beslutade ändringar till en början inte fungerade bra och det har tagit tid för WHO att finna bättre lösningar på detta.

**THE GROWTH OF NORDIC COOPERATION ON CLASSIFICATION**

**Table 4 Nordic representation at WHO's Centre Heads Meetings**

Place	Time	Nordic participants
London	1971 June	-
Caracas	1972 Feb.	-
Paris	1973 April	-
Edinburgh	1975 April	-
New Orleans	1976 Oct.	-
São Paulo	1978 Jan.	Å Sjöström
Moscow	1979 June	P Westerholm
Dublin	1980 Sept	G Magnússon
Meknès	1981 Sept	M Osnes
Caracas	1982 Dec.	H Bay-Nielsen
Beijing	1983 Nov.	B Smedby
San Francisco	1984 May	B Smedby
São Paulo	1985 April	B Smedby
Tokyo	1986 April	H Bay-Nielsen, B Smedby
Leningrad	1987 June	H Bay-Nielsen, B Smedby
Uppsala	1988 June	B Smedby, H Bay-Nielsen, K Carsjö, D Swenson, A Ruusinen (observers: R Berfenstam, JH Iversen, T Kruse, J Mosbech, AC Nilsson)
Paris	1989 Feb.	B Smedby, H Bay-Nielsen, T Kruse
London	1990 Mar.	B Smedby, J Mosbech
São Paulo	1991 April	B Smedby
Beijing	1992 April	B Smedby, M Brommels, K Carsjö
Washington	1993 April	B Smedby, K Carsjö, S Sørensen
Caracas	1994 Oct.	B Smedby, K Carsjö, G Schiøler
Canberra	1995 Sep.	B Smedby, K Carsjö, G Schiøler
Tokyo	1996 Oct.	B Smedby, LA Johansson, G Schiøler, M Virtanen
Copenhagen	1997 Oct.	B Smedby, K Carsjö, C Engblom, A Haugsbø, T Hogsnes, LA Johansson, OB Larsen, G Schiøler, D Swenson, M Virtanen
Paris	1998 Oct.	B Smedby, K Carsjö, LA Johansson, G Schiøler, M Virtanen
Cardiff	1999 Oct.	B Smedby, K Carsjö, LA Johansson, G Schiøler, M Virtanen
Rio de Janeiro	2000 Oct.	B Smedby, LA Johansson, M Mikkola, G Schiøler, M Virtanen
Bethesda	2001 Oct.	B Smedby, T Dahl, G Schiøler
Brisbane	2002 Oct.	B Smedby, T Dahl, LA Johansson, K Bränd Persson, G Schiøler, M Virtanen
Cologne	2003 Oct.	M Virtanen, LA Johansson, S Magnusson, M Ojala, K Bränd Persson, G Schiøler, B Smedby, S Talo, G Thorsen
Reykjavik	2004 Oct.	M Virtanen, LA Johansson, B Frimodt-Møller, K Bränd Persson, B Smedby, O Steinum, S Talo, G Thorsen (+ 10 observers)
Tokyo	2005 Oct.	M Virtanen, LA Johansson, K Bränd Persson, B Smedby, O Steinum, G Thorsen

Much of WHO's work with classifications has been directed at improving *mortality statistics*. Since 1996, the Nordic Centre has organized an international electronic discussion forum on issues related to causes of death [57], with Lars Age Johansson as coordinator. This Mortality Forum has been a big success, with active participants from about 40 organizations. It also functions as a training forum for coders, and has aided standardized application of the rules for coding causes of death. In 1997, WHO appointed an international reference group (Mortality Reference Group) with the task of making decisions about interpretation of the coding instructions for causes of death in ICD-10, and for recommending clarifications and changes needed to ensure standardized application of the classification. At the beginning, Lars Age Johansson functioned as secretary for the Mortality Reference Group, but has been chairman of the group since 2002. Many of the changes to ICD-10 have been introduced as a result of initiatives from this group.

Because of cut-backs in personnel and reduced funding at WHO's headquarters and its unit for classification issues, international work with classifications entered a crisis during the middle of the 1990s. The ten Collaborating Centres that existed at that time wrote to the Executive Board of WHO in 1996 and 1997 expressing their concern about the situation. They pointed out the central importance of classifications for health statistics and health policy. They requested increased funding for WHO's central classification unit, and a long-term plan for implementation of ICD-10 and devel-

Mycket av WHO:s klassifikationsarbete har varit inriktat på att förbättra *dödsorsaksstatistiken*. Det nordiska centret svarar sedan 1996 för ett internationellt elektroniskt diskussionsforum om dödsorsaksfrågor [57] med Lars Age Johansson som koordinator. Detta Mortality Forum har blivit en stor framgång med aktivt deltagande från ett 40-tal organisationer. Det fungerar också som utbildningsforum för kodare och har bidragit till enhetligare tillämpning av regelverket för kodning av dödsorsaker. År 1997 tillsatte WHO en internationell referensgrupp (Mortality Reference Group) med uppgift att fatta beslut om tolkning av ICD-10:s kodningsinstruktioner för dödsorsaker och föreslå sådana förtydliganden och ändringar som behövs för att säkerställa en enhetligt tillämpning av klassifikationen. Lars Age Johansson fungerade till en början som sekreterare i Mortality Reference Group men är sedan 2002 ordförande i gruppen. Många av de ändringar som genomförts i ICD-10 har skett på initiativ av denna grupp.

På grund av personalminskningar och resursinskränkningar vid WHO:s huvudkontor och dess enhet för klassifikationsfrågor råkade det internationella klassifikationsarbetet in i en krissituation under 1990-talets mitt. Detta föranledde de då existerande tio Collaborating Centres for ICD att 1996 och 1997 skriva till WHO:s styrelse och uttrycka sin oro över situationen. Man pekade på klassifikationernas centrala betydelse för hälsostatistiken och hälsopolitiken. Man efterlyste ökade resurser till WHO:s centrala klassifikationsenhet och en långsiktig plan för implementeringen av

opment of other health-related classifications. They declared that they were prepared to increase their participation in the partnership and to cooperate as necessary. They put forward detailed proposals concerning the organization of the annual meetings, and for how continual cooperation between the meetings could be ensured. WHO took the initiative to evaluate the central classification unit. Björn Smedby participated in this evaluation, which also indicated the need for increased funding.

This crisis situation became the start of a *reorganization* of the Centre Heads Meetings. They were given a more formalized structure, with several committees for the Family of International Classifications that WHO has responsibility for. Gunnar Schiøler from Denmark participated actively in the work of the committee that drew up guidelines for development of the “family” and the criteria for which classifications should be included. Committees were created not only for the issues mentioned above related to mortality and updating, but also for planning training and for implementation of ICD, and for electronic applications for classifications. Several Nordic representatives made important contributions to this development work.

As described in more detail below, WHO’s cooperation on classifications was later extended to include revision of the international classification of disability. A new classification was approved by WHO’s general assembly in 2001: the International Classification of Functioning, Disability and Health [58]. Work with an intervention classification (ICHI) [59] – more about this below –

ICD-10 och utvecklingen av andra hälsorelaterade klassifikationer. Man förklarade sin beredskap till ökade insatser i det partnerskap och samarbete som krävdes och lade fram detaljerade förslag beträffande de årliga mötenas organisation och formerna för det fortlöpande samarbete mellan mötena. WHO tog själv initiativ till en utvärdering av den centrala klassifikationsverksamheten i vilken Björn Smedby deltog. Även denna utvärdering pekade på behovet av resursförstärkningar.

Denna krissituation blev starten på en *reorganisation* av de s.k. Centre Heads-mötena till en mer formaliserad struktur med ett flertal kommittéer inom den Family of International Classifications som WHO ansvarar för. Gunnar Schiøler från Danmark deltog aktivt i arbetet i den kommitté som drog upp riktlinjerna för utvecklingen av “familjen” och kriterierna för vilka klassifikationer som kan ingå i den. Kommittéer skapades inte bara för de tidigare nämnda mortalitets- och uppdateringsfrågorna utan även för planering av utbildning och implementering av ICD och för elektroniska tillämpningar i klassifikationsarbetet. Flera nordiska representanter medverkade aktivt i detta utvecklingsarbete.

Som närmare berörs nedan har WHO:s klassifikationssamarbete efterhand vidgats till att omfatta även revision av den internationella handikappklassifikationen. En ny klassifikation antogs av WHO:s generalförsamling 2001 i form av ICF – the International Classification of Functioning, Disability and Health [58]. Arbetet med en interventionsklassifikation (ICHI) [59] – varom också mera nedan –

has begun, and its relationship to other international health-related classification such as ICPC and the Nordic ATC classification of medicinal products (Anatomical Therapeutic Chemical Classification System) [60] has been discussed. All this has meant that the annual Centre Heads Meetings have expanded and now have broader representation. They are now called WHO Family of International Classifications (WHO-FIC) Network Meetings. The network has a firmer organization, and is led by a planning committee, who organize activities and plan the annual WHO-FIC meetings. Since the new organization came into effect, the Nordic Centre has been represented in this planning committee.

In 2003, an expert group under the leadership of Björn Smedby, established by the EU Hospital Data Project, put forward a proposal for a *shortlist* of 130 diagnostic groups for comparable hospital statistics in the EU. The proposal took special account of the condition that the groups had to be able to be defined according to both ICD-9 and ICD-10, since many countries have not gone over to using ICD-10, but still use the American ICD-9-CM version. The proposed short list was tested by a Hospital Data Working Group, appointed by the Centre Heads Meeting in Brisbane in 2002, under the leadership of Björn Smedby. Using European test data collected by the EU project, supplemented with corresponding data from Canada and Australia, it was shown that many of the differences in the statistics from different countries to a large extent could be explained by differences in diagnostic culture, coding practice and rules for registration. An important task for WHO's classi-

har tillkommit och man diskuterar relationerna till andra internationella hälsorelaterade klassifikationer såsom ICPC och den i Norden utvecklade ATC-klassifikationen för läkemedel (Anatomical Therapeutic Chemical Classification System) [60]. Allt detta har inneburit att de årliga s.k. Centre Heads-mötena omvandlats till större möten med bredare representation. De kallas numera WHO Family of International Classifications (WHO-FIC) Network Meetings. Nätverket som alltså fått en fastare organisation leds av en ledningsgrupp som samordnar verksamheten och planer de årliga WHO-FIC-mötena. Det nordiska centret har sedan den nya organisationens tillkomst varit representerat i denna ledningsgrupp.

En expertgrupp under ledning av Björn Smedby tillsatt av EU Hospital Data Project lade 2003 fram förslag till en *kortlista* på 130 diagnosgrupper för jämförande sjukhusstatistik inom EU. Förslaget tog särskild hänsyn till förhållandet att grupperna måste kunna definieras utifrån både ICD-9 och ICD-10, eftersom många länder inte gått över till ICD-10 utan fortsatt att använda den amerikanska ICD-9-CM-versionen. Den föreslagna kortlistan kom att prövas inom en Hospital Data Working Group tillsatt vid Centre Heads-mötet i Brisbane 2002 under ledning av Björn Smedby. Med användning av europeiska testdata insamlade inom EU-projektet, kompletterade med motsvarande data från Canada och Australien, kunde man visa att många av de statistiska skillnaderna mellan länderna i stor utsträckning förklaras av skillnader i diagnostisk kultur, kodningspraxis och registreringsregler. Att utveckla tydligare regler för tillämpningen av ICD i sjuk-

fication work was therefore to develop clearer rules for application of ICD for hospital statistics. In 2005, the proposed short list was ratified by EUROSAT, OECD and WHO, and was published as the International Shortlist for Hospital Morbidity Tabulation (ISHMT) [61].

At the WHO-FIC meeting in 2005, it was decided to establish a new committee called the Morbidity Reference Group, with the task of developing standardized rules for application of ICD-10 for morbidity coding and morbidity statistics. Olafur Steinum from the Nordic Centre was appointed as one of the two leaders for this group. The organization of the present WHO-FIC Network is described in more detail on the website of WHO [62]. Agendas, reports and scientific papers from the latest WHO-FIC meetings are also available there.

husstatistik blir därför en viktig uppgift i WHO:s klassifikationsarbete. Den föreslagna kortlistan godtogs 2005 av såväl EUROSTAT som OECD och WHO och publicerades som International Shortlist for Hospital Morbidity Tabulation (ISHMT) [61].

Vid WHO-FIC-mötet 2005 beslöt man inrätta en ny kommitté kallad Morbidity Reference Group med uppgift att verka för mer enhetliga regler i tillämpningen av ICD-10 i morbiditetskodning och morbiditetsstatistik. Olafur Steinum från det nordiska centret har utsetts som en av två ledare för denna grupp. Den nuvarande nätverksorganisationen beskrivs mer ingående på WHO:s hemsida på Internet [62], där också dagordningar, rapporter och vetenskapliga ”papers” för de senaste WHO-FIC-mötena finns tillgängliga.

## 4 Development of Common Nordic Classifications

### *4 Utvecklingen av gemensamma nordiska klassifikationer*

#### The Nordic classification of external causes of injuries

##### *Background*

After World War II, when WHO took over responsibility for the international classification of diseases, use of this classification was extended to registering not only causes of death but also diseases [4]. ICD-6 was published in 1949 and during the following years its use as the basis for national and international statistics of morbidity became more and more widespread.

ICD-6 contained two alternative sub-classifications in the chapter for accidents, poisoning and violence. One was to be used for the nature of injury (wounds, fractures, burns, poisonings etc. – N-codes), the other for classifying external causes of injury (traffic accidents, falls, violence, self-inflicted injury – E-codes).

#### Den nordiske ulykkesklassifikation

##### *Baggrund*

Da WHO efter 2. verdenskrig overtog ansvaret for den internationale sygdomsklassifikation, blev dens anvendelsesområde samtidigt udvidet til ikke blot at omfatte dødsårsager, men også sygdomsregistrering [4]. Denne 6. revision (ICD-6) udkom i 1949 og fik i løbet af de følgende år stadig større udbredelse som grundlag for nationale og internationale morbiditetsstatistikker.

ICD-6 indeholdt to alternative klassifikationer i kapitlet om ulykker, forgiftninger og vold. Den ene kunne bruges til at angive skadens natur (sår, fraktur, forbrænding, forgiftning etc. – N-koder), den anden til at klassificere den ydre årsag til skaden (traffikulykke, fald, vold, selvpåført skade etc. – E-koder).



In subsequent revisions it gradually became possible to obtain more detailed registration of causes of injuries and their consequences. Up to and including ICD-8, the E-codes were included as an alternative classification of external causes of injury and poisoning and in ICD-9 as a supplementary classification. The principles have also been retained in the latest revision (ICD-10), though the concepts E-codes and N-codes are no longer used, and the codes have been placed in separate chapters of the main classification.

The E-codes included quite a lot of information on causes of injuries, but they were not systematized in relation to the dimensions that may be needed as criteria when classifying accidents in different groups. For example, both the accident-causing event and the injury-causing event were used in the main division. Also, the classification had no clear and logical structure, with the consequence that an accident could be coded with several different codes. In other words it was possible to group the codes in only one axis.

During the 1960s and 1970s several initiatives were taken to establish a more systematic registration of accidents, partly to obtain more knowledge in this field and partly to establish a foundation for effective preventive measures. In a global context it can be specially mentioned that, as part of the goals of Health for All by the Year 2000 (1978), WHO established an Accident Prevention Programme, and a steering committee was appointed to develop a set of accident indicators. One result of this was the development of a "basic data set".

Under de følgende revisioner udbygges også klassifikationen, således at det efterhånden blev muligt at foretage en mere detaljeret registrering af skadesårsager og deres følger. Til og med ICD-8 var E-koderne medtaget som en alternativ classification of external causes of injury and poisoning og i ICD-9 som en supplerende klassifikation. Principperne er bibeholdt også i den seneste revision – ICD-10 – selvom begreberne E- og N-koder ikke anvendes mere, og koderne er nu placeret som koder i selvstændige kapitler i klassifikationen.

E-koderne indeholdt ganske mange oplysninger om ulykkesårsager, men de var ikke systematiserede med hensyn til de dimensioner, der kan være ønskelige som kriterier ved sortering af ulykkerne i forskellige typer. Blandt andet anvendtes i hovedinddelingen både den ulykkesudløsende hændelse og den skadevoldende hændelse. Der var heller ikke nogen klar og logisk opbygning af klassifikationen, hvilket betød, at en ulykke ofte kunne rubriceres under flere forskellige koder. Med andre ord var det kun muligt at gruppere koderne i én akse.

I løbet af 1960erne og 1970erne fremkom flere initiativer til at få etableret en systematisk registrering af ulykker dels for at skaffe større viden om området dels for at etablere grundlag for en egentlig forebyggelsesindsats. I global sammenhæng skal specielt fremhæves, at WHO som led i målene beskrevet i Health for All by the Year 2000 (1978) etablerede et Accident Prevention Programme og en styrekomite blev nedsat til at udvikle et sæt ulykkesindikatorer. Et af resultaterne blev et "Basic Data Set".

*NOMESCO's early work with registration of accidents*

Prior to this initiative, the Nordic Committee for Consumer Issues had discussed the issue of a systematic multi-sectorial registration of accidents in the Nordic countries. This led to the appointment of a Nordic expert committee, which initiated a study of methods for registering accidents in the home and in leisure time.

The report from this study [63] was assessed at a seminar in Århus in September 1978. Participants in the seminar included Nordic representatives from consumer authorities, the health, environment and housing sectors, statisticians and traffic safety.

Some of the conclusions from the seminar were that a systematic registration of accidents was needed in the Nordic countries, and that the system should be designed to take account of common areas of activity within the various sectors (patient care, traffic safety, working environment and housing). In May 1979, the Nordic Social Political Committee forwarded the recommendations from the seminar to NOMESCO. Thus, NOMESCO became involved at a very early stage in work to create the necessary foundation.

NOMESCO had previously worked with the E-codes in ICD-8. In 1978-79, the working group on classification issues (AKLASS) had discussed a revision of WHO's classification with the aim of changing the structure of the E-codes. A proposal from the working group was subsequently considered at

*NOMESKO's tidligste arbejde med ulykkesregistrering*

Allerede forud for dette initiativ havde Nordisk Komité for Konsumentspørgsmål dog taget spørgsmålet om en systematisk ulykkesregistrering i de nordiske lande op på tværs af samfundssektorerne. Det førte til nedsættelse af en nordisk embedsmandskomité, der iværksatte et metodestudie om registrering af hjemme- og fritidsulykker.

Rapporten fra dette studie [63] blev behandlet på et seminar i Århus i september 1978. Seminaret havde samlet nordiske repræsentanter for forbrugermyndigheder, sundheds-, miljø- og boligsektorerne samt statistik og trafiksikkerhed.

Seminaret konkluderede blandt andet, at der var brug for en systematisk ulykkesregistrering i de nordiske lande, og at udformningen heraf burde ske under hensyntagen til berøringspunkter mellem aktiviteterne i de forskellige samfundssektorer (patientbehandling, trafiksikkerhed, arbejds- og boligmiljø). Nordisk Socialpolitisk Komité gav i maj 1979 seminarets anbefalinger videre til NOMESKO, som på denne måde meget tidligt blev inddraget i arbejdet med at skabe det nødvendige grundlag.

NOMESKO havde allerede forud for dette arbejdet med E-koderne i ICD-8. I arbejdsgruppen vedrørende klassifikationsspørgsmål (AKLASS) havde man i 1978/79 diskuteret en revision af WHO's klassifikation med henblik på en ændret struktur af E-koderne. Efterfølgende blev et forslag fra arbejdsgruppen

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the plenary meeting in NOMESCO in 1979, and in January 1980 NOMESCO organized a conference in Gothenburg, where guidelines for a Nordic registration of accidents were discussed.

The conclusion from the conference was that the E-codes were inadequate and that they should be revised to include basic information on the cause of the accident (e.g. traffic accident, fall) and the place of occurrence (e.g. home, workplace). It was also emphasized that unambiguous definitions should be developed that were common for the Nordic countries to ensure the best possible comparability of data. Another result of the conference was the formation of a working group (under AKLASS) with the task of developing a Nordic classification of places of occurrence.

In 1981 NOMESCO presented the report *Nordic Codes for Places of Occurrence*, which the Nordic Council of Ministers circulated among the involved Nordic authorities for consideration.

Some of the authorities expressed a wish to have a totally new classification – not only for place of occurrence. So NOMESCO proposed to the Council of Ministers that a revision of the codes for place of occurrence should be included in the work on a new multiaxial classification that had already begun.

Following this NOMESCO organized a seminar in Copenhagen in November 1982. The discussions were based on a working paper that presented the principles for a new classification. Participants in the seminar included representatives from the Nordic consumer organizations. Their wishes for registra-

drøftet på NOMESKO's plenarmøde i 1979 og i januar 1980 afholdt NOMESKO en konference i Göteborg, hvor man diskuterede retningslinier for en nordisk ulykkesregistrering

Det var konferencens konklusion, at E-koderne var utilstrækkelige og burde revideres, så de kom til at indeholde basale oplysninger om ulykkesårsager (f.eks. trafik- og faldulykker) og ulykkessted (f.eks. hjem, arbejdsplads osv.). Desuden lagde man vægt på, at der blev fastlagt entydige definitioner fælles for de nordiske lande for at sikre bedst mulig sammenlignelighed af data. Konferencen resulterede desuden i, at der blev nedsat en arbejdsgruppe under AKLASS, som fik til opgave at udarbejde en nordisk klassifikation af ulykkesteder.

I 1981 kunne NOMESKO præsentere rapporten Nordisk Ulykkespladskode, som af Nordisk Ministerråd blev sendt i høring hos nationale berørte nordiske myndigheder.

I en del af høringssvarene udtryktes ønsket om en helt ny klassifikation, ikke blot en af ulykkesstedet. NOMESKO foreslog derfor Nordisk Ministerråd, at en revision af ulykkesstedskoderne skulle indgå i det allerede påbegyndte arbejde med en ny multiaxial klassifikation.

Herefter afholdt NOMESKO et seminar i København i november 1982. Drøftelserne tog udgangspunkt i et arbejdsnotat, som præsenterede et forslag til principperne for en ny klassifikation. I seminaret deltog bl.a. repræsentanter for de nordiske forbrugerorganisationer, hvis ønsker til ulykkesregistrering var af betydning

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tion of accidents were of relevance for the final content of a classification of injuries that could also be used as a tool for the prevention of accidents. At this seminar guidelines for a multi-axial classification were prepared, and a working group was appointed with Henning Bay-Nielsen, Denmark as chairman. The secretarial functions were carried out by the secretary of NOMESCO Birthe Frimodt-Møller.

Each of the five Nordic countries appointed a reference group with representatives from the authorities and the consumer organizations. These groups were continually updated on the work and involved in discussions in order to ensure that the needs of all groups of users of the classification would be met in the future registration of accidents.

After the seminar in Copenhagen in 1982 the starting point for the working group was a classification structure with the following axes:

- a. *reason for contact* so that cases of accidents could be distinguished
- b. *place of occurrence* specifying the type of place in which the accident happened
- c. *mechanism of injury* giving the events that took place when the person was injured
- d. *activity* at the time of the accident, making it possible to distinguish accidents in the home, leisure-time accidents, accidents in the workplace, and traffic accidents both according to the official definition and other accidents in traffic. The second digit in the code classifies the person's movements when the injury occurred.

for en endelig udformning af en ulykkesklassifikation, der også kunne tjene som instrument i forebyggelsen af ulykker. På dette seminar udarbejdedes retningslinier for en multiaksial klassifikation og man nedsatte en arbejdsgruppe med Henning Bay-Nielsen, Danmark, som formand til at udarbejde et forslag til den nye klassifikation. Sekretariatsfunktionen blev varetaget af NOMESKO sekretær Birthe Frimodt-Møller.

De fem nordiske lande nedsatte hver en referencegruppe med repræsentanter for myndigheds- og forbrugerinteresser. Disse grupper blev holdt løbende orienterede om arbejdet og blev inddraget i diskussioner undervejs i processen, for at sikre at alle grupper af fremtidige brugere af klassifikationen kunne få dækket deres behov i den fremtidige ulykkesregistrering.

Efter seminaret i København i 1982 var arbejdsgruppens udgangspunkt en klassifikationsstruktur med følgende akser:

- a. *kontaktårsag*, så sygdoms- og ulykkestilfælde kunne holdes klart adskilte
- b. *ulykkessted*, der specificerer arten af de omgivelser, hvor ulykken finder sted
- c. *skadesmekanisme*, der angiver de hændelser der sker, når personen bliver påført en skade
- d. *aktivitet* i ulykkesøjeblikket, der gør det muligt at udskille hjemme- og fritidsulykker, arbejds- og trafikulykker, herunder færdselsulykker efter den officielle definition og andre ulykker inden for trafik. I kodens andet ciffer angives tillige personens bevægelsesmønster i skadesøjeblikket

Within this framework the classification should be able to satisfy the needs of the planned common Nordic registration of accidents. The increasing priority given to prevention of accidents in the health policies of the Nordic countries was important in this context. It was also important to recognize that preventive measures first and foremost involve many different sectors outside the health care system. Thus prevention of accidents is strongly dependent on legislation and other initiatives within the transport sector, the labour market and the housing sector. Implementation of effective preventive measures in all these fields is dependent on reliable knowledge obtained through systematic registration of accidents.

Therefore, the aims of a new classification of external causes of injuries had to be that it:

- was suitable as a general tool for routine registration of accidents by the health services
- could distinguish between all the major types of accidents in an appropriate way
- could serve as a tool in the management and planning of resources for the treatment and care of injured persons

In this way, accident registration by the health services should supplement existing registration of accidents in the workplace and traffic accidents, and at the same time remedy the lack of registration of accidents in the home and leisure-time accidents.

It may seem ambitious to take account of so many different aims, since it is neither realistic nor appropriate to request that all sections in the health services should be able to register accidents in so

Inden for disse rammer skulle klassifikationen kunne tilgodese de behov, der var knyttet til den planlagte fællesnordiske ulykkesregistrering. Vigtigt var i denne sammenhæng den stadig højere prioritet, forebyggelsen af ulykker fik i de nordiske landes sundhedspolitik og erkendelsen af, at en forebyggende indsats først og fremmest involverer flere forskellige sektorer uden for sundhedsvæsenet. Ulykkesforebyggelse er således stærkt afhængig af lovregulering og andre initiativer inden for trafiksektoren, på arbejdsmarkedet og i boligmiljøet. En virksomhedsindsats på alle disse områder kan kun ske på baggrund af pålidelig viden opnået gennem en systematisk ulykkesregistrering.

Målet for en ny ulykkesklassifikation måtte derfor være, at den:

- var egnet som et generelt instrument i sundhedsvæsenets rutinemæssige ulykkesregistrering
- på en hensigtsmæssig måde kunne adskille alle væsentlige ulykkestyper
- kunne tjene som et instrument til styring og planlægning af behandlingsressourcerne for skadelidte

Man ville hermed opnå, at sundhedsvæsenets ulykkesregistrering kunne supplere de eksisterende registreringer af arbejds- og trafikulykker og samtidig afhjælpe de mangler, der var i registreringen af hjemme- og fritidsulykker.

At tilgodese så mange og så forskellige formål kunne forekomme ambitiøst, idet det hverken er realistisk eller hensigtsmæssigt at kræve, at hver eneste enhed i sundhedsvæsenet ville være i stand til at foreta-

much detail. A condition of the new classification was therefore that it could be used at different levels of detail. At the national and Nordic levels, less detailed data would be adequate as a starting point, but at the regional level, and for scientific purposes, detailed data could be utilized to great advantage in prevention and planning. A common classification with several levels makes it possible to combine limited and specific national data with more detailed data at a lower level. This makes it possible to assess local and regional data and data from studies in relation to the situation at the national level.

The multi-sectorial interest for access to detailed data on accidents demands a classification that is understandable and thus usable for all professions, and that it does not become an exclusive tool meant only for the health sector.

### *Concepts and definitions*

As a first and important task the working group developed definitions for the concepts that were to be classified in the new classification of external causes of injuries. This work was, of course, to large degree based on earlier work – including ICD – within the field, but it was essential to have clear definitions, which in a later phase formed the foundation for the manual, which became part of the classification.

The central definition of an accident was taken from the report *Reporting Ac-*

ge en meget omfattende registrering. Det blev derfor også opstillet som et krav, at en ny klassifikation skulle kunne benyttes på forskellige detaljeringsniveauer. På nationalt – og fællesnordisk – niveau vil en begrænset, summarisk registrering som udgangspunkt være tilstrækkelig, men til såvel regionale som forskningsmæssige formål vil detaljerede data kunne udnyttes med stor fordel i forebyggelse og planlægning. En fælles klassifikation anvendt på flere niveauer gør det muligt at holde sådanne mere begrænsede og specifikke registreringer op mod nationale data på et mindre detaljeret niveau og dermed gøre det muligt at vurdere lokale og regionale registreringer og studier i forhold til det overordnede niveau.

Den tværsektorielle interesse for adgang til detaljerede data om ulykker stiller desuden krav om, at en klassifikation er forståelig og dermed anvendelig for alle faggrupper, så den ikke bliver et eksklusivt værktøj alene beregnet for sundhedssektoren.

### *Begreber og definitioner*

Som en første væsentlig opgave påtog arbejdsgruppen sig at fastlægge definitioner for de begreber, der skulle klassificeres i en ny ulykkesklassifikation. Dette arbejde byggede naturligvis i høj grad på tidligere arbejder – herunder ICD - inden for området, men det var væsentligt at få fastlagt klare definitioner, som i en senere fase dannede grundlag for den manual, som klassifikationen blev suppleret med.

Fra rapporten *Registrering av ulykker* overtog man den centrale definition af

*accidents*: an unintentional event characterized by a rapid force or impact which may manifest itself as an injury to the body.

The working group used the accident model in the Swedish *Information System on Occupational Injuries* (ISA) as a starting point. This model had been discussed at the seminar in 1982 and subsequently in the working group and the reference group in an attempt to develop unambiguous definitions of the concepts. At the seminar it was also decided that the mechanism of the injury is the term for what happens at the moment when the injury occurs. Seen in relation to the ISA-model, this concept covers a combination of injury, contact and in certain cases the preceding event(s).

Through further work with definitions, definitions that could be accepted and used in all the Nordic countries were developed.

### *The new classification of external causes of injuries*

In 1984 the working group submitted a report with a proposal for a Nordic classification of external causes of injuries. In addition to the considerations and conclusions of the working group, the report also included a proposal for a manual for the classification. As the working group also had the task of proposing requirements for an accident registration system that could be used in all the Nordic countries, it also presented a proposal for specific information that could be registered, but which could not be included in the classifica-

en ulykke: En ufrivillig hændelse, karakteriseret ved en hurtigtvirkende kraft eller påvirkning, som kan ytre sig i form af skade på kroppen.

Man tog desuden udgangspunkt i ulykkesmodellen i det svenske *Informationssystem om arbejtskador* (ISA). Denne model var blevet drøftet ved seminaret i 1982 og efterfølgende i arbejds- og referencegrupperne i et forsøg på at opstille entydige definitioner af begreberne. På seminaret vedtog man også, at skademekanisme betegner det, der sker i skadesøjeblikket. Set i forhold til ISA-modellen dækker begrebet kombinationen af skade-, kontakt- og i visse tilfælde forudgående hændelse(r).

Gennem det fortsatte definitionsarbejde nåede man frem til definitioner, der kunne accepteres og anvendes i hele Norden.

### *Den nye ulykkesklassifikation*

I 1984 kunne arbejdsgruppen aflevere en rapport med et forslag til en nordisk ulykkesklassifikation. Rapporten indeholdt udover arbejdsgruppens overvejelser og konklusioner også arbejdsgruppens forslag til en tilhørende manual. Da arbejdsgruppen også havde til opgave at stille forslag til de krav, der burde stilles til et ulykkesregistreringssystem, der kunne anvendes i hele Norden, var der tillige forslag til specifikke oplysninger som skulle kunne registreres, men som ikke kan indeholdes i en ulykkesklassifikation. Da klassifikationen var

tion. Since the classification was meant to be used instead of or parallel with the E-codes in ICD-8, the working group also evaluated the two classifications in relation to each other, illustrated by some examples.

The original idea was also to include an axis for classifying products that were contributory factors to the accident. However, a classification of products was not included in the first proposal. The development of such a classification would have been very time-consuming and would have made the introduction and use of the classification more complicated. However, the working group recommended that the classification should be evaluated after a short time and that necessary changes should be done and amendments made. In this connection earlier proposals for a module for traffic accidents and a revision of the activity module were referred to.

The report was considered at the plenary session of NOMESCO in June 1984 and published as the first version of the Nordic Classification for Use in Registration of Accidents [65].

### *Further developments*

During the following years, the Nordic Classification for Use in Registration of Accidents was tested in different places, and it was eventually used in limited projects in the Nordic countries. In Denmark it was also used in hospitals, where it totally replaced the use of E-codes from ICD-8 from 1987.

tænkt til anvendelse i stedet for eller parallelt med ICD-8's E-koder, havde arbejdsgruppen desuden lavet en vurdering af de to klassifikationer over for hinanden bl.a. belyst ved en række eksempler.

Oprindeligt var det tanken også at medtage en akse til beskrivelse af produkter, der indgik i ulykkesforløbet som medvirkende til skadens opståen. En produktklassifikation blev dog ikke medtaget i det første forslag. At lave en sådan klassifikation ville være meget tidskrævende og i første omgang bidrage til at gøre introduktionen og anvendelsen yderligere kompliceret. Derimod indgik det i arbejdsgruppens anbefalinger, at der inden for en kortere tidsramme skete en vurdering af klassifikationen og udarbejdet nødvendige og ønskelige ændringer og tilføjelser. Man pegede i den forbindelse på tidligere forslag om et modul for trafikulykker og for en revision af aktivitetsmodulet.

Rapporten blev behandlet på NOMESCO's plenarmøde i juni 1984 og derefter publiceret som første version af Nordisk Klassifikation til Brug i Ulykkesregistrering [65]

### *Den videre udvikling*

Efter publikationen af den nordiske ulykkesklassifikation blev den i løbet af de følgende år afprøvet forskellige steder og efterhånden taget i anvendelse ved registrering i afgrænsede projekter rundt omkring i Norden. I Danmark blev den desuden taget i brug ved registreringen på sygehusene, hvor den fra 1987 helt afløste kodning med brug af E-koder fra ICD-8.



As early as 1985 NOMESCO appointed the Working Group for Registration of Accidents in the Nordic Countries (ARON) to work with the further development of the classification and registration of accidents in the Nordic countries. This working group, which was a continuation of the original working group under AKLASS, continued to work with the classification of external causes of injuries, and three more essential modules were completed during the following years.

As had been mentioned in the first report, the registration of traffic accidents needed to be improved. Since this area required expertise that was not available within the framework of NOMESCO, the Nordic Committee for Research in Traffic Safety (NKT) was contacted. This organization established a working group to develop a classification of accidents involving vehicles [66]. This work resulted in a module for registration of accidents involving vehicles, which could be included in the classification of external causes of injuries.

Similarly, assistance was sought from the Nordic Expert Committee for Consumer Issues. They were asked to prepare a classification of products. The task was given to a working group under the committee, and the result was presented in a report in 1989 [67].

At the same time, ARON revised the first version and included an industrial module based on the industrial classification used in the labour market. With the inclusion of the two modules mentioned above for accidents involving vehicles and for products, the second version of the Nordic Classification for Use

Allerede i 1985 nedsatte NOMESKO Arbetsgruppen för Registrering av Olycksfall i Norden (ARON) til at forestå det videre udviklingsarbejde af ulykkesklassifikationen og registreringen af ulykker i de nordiske lande. Denne arbejdsgruppe, som var en videreførelse af den oprindelige arbejdsgruppe under AKLASS, fortsatte arbejdet med ulykkesklassifikationen, og yderligere tre væsentlige moduler blev færdiggjort i de følgende år.

Som allerede anført i den første rapport var der behov for at forbedre registreringen af trafikulykker – et område, der krævede ekspertise, som ikke var til rådighed inden for NOMESKO's rammer. Man henvendte sig derfor til Nordisk Komité for Trafiksikkerhedsforskning (NKT), der nedsatte en arbejdsgruppe til udarbejdelse af en klassifikation af køretøjsulykker [66]. Resultatet af dette arbejde blev et modul til registrering af køretøjsulykker, som kunne indgå som en del af ulykkesklassifikationen.

På tilsvarende måde søgte man assistance fra Nordisk Embedsmandskomité for konsumentspørgsmål til udarbejdelse af en produktklassifikation. En arbejdsgruppe under komitéen fik til opgave at gøre dette, og resultatet fremkom i en rapport i 1989 [67].

Sideløbende med disse arbejder foretog ARON en revision af den første udgave og supplerede den med et erhvervsmodul baseret på den erhvervsklassifikation, der anvendes på arbejdsmarkedet. Med tilføjelsen af de to nævnte moduler for køretøjsulykker og produkter kunne den samlede revision afsluttes med afle-

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in Registration of Accidents [68] was approved by the plenary session of NOMESCO in June 1990.

Based on the experience obtained, work with improving and revising the classification continued, and in 1996 ARON presented the third revised version. In this version two modules for registration of violence and self-inflicted injuries were included so that the classification now covered all types of external causes of injury. Also, the introduction with the description of the underlying principles and the structure of the classification was extended, and guidelines for the use of the classification were given in more detail. The classification was published in English, and at the same time the title was changed to NOMESCO Classification of External Causes of Injuries (NCECI) [69].

After the revision was finished and the NCECI was published, the working group was disbanded. Further maintenance of the classification is now done by the Nordic Centre for Classifications in Health Care on behalf of NOMESCO. An updated version of the classification will be completed in 2006. The fourth revision includes in particular further development of the modules on mechanism of injury and activity, in line with feedback about such improvements.

### *International relations*

During the preparation of a common Nordic substitute for the E-codes in ICD-8, contact had already been made with WHO and with the work that had

vering af 2. udgave af ulykkesklassifikationen, som blev godkendt af NOMESKO's plenarforsamling i juni 1990 [68].

Arbejdet med at forbedre klassifikationen og revidere den i forhold til indhentede erfaringer fortsatte, og ARON kunne i 1996 præsentere den tredje reviderede version. I denne revision blev der tilføjet to moduler til registrering af henholdsvis vold og forsætligt selvtilføjede skader, således at klassifikation nu dækkede alle typer af ydre årsager til skader. Desuden blev indledningen med beskrivelse af de tilgrundliggende principper og klassifikationens opbygning udvidet og vejledningen i anvendelsen gjort mere detaljeret. Klassifikationen blev udgivet på engelsk, og samtidigt ændredes titlen til NOMESCO Classification of External Causes of Injuries (NCECI) [69].

Efter afslutningen af arbejdet med revisionen og udgivelsen af NCECI nedlagdes arbejdsgruppen. Den videre vedligeholdelse af klassifikationen varetages nu på NOMESKO's vegne af Nordiskt center för klassifikationer i hälso- och sjukvården i Uppsala. En opdateret version af klassifikationen vil være færdig i 2006. Denne 4. reviderede udgave indeholder en videreudvikling af især moduler for henholdsvis skadesmekanisme og aktivitet i overensstemmelse med tidligere fremsatte ønsker om sådanne forbedringer.

### *Internationale relationer*

Allerede under arbejdet med en fælles nordisk afløsning af E-koderne i ICD-8 havde man kontakt med WHO og det arbejde, som der var iværksat med ud-

been started with developing a "Basic Data Set" for use in an improved registration of accidents. At meetings with members of staff at the WHO Regional Office for Europe in Copenhagen, views and considerations of importance for further work with the Nordic classification were exchanged. However, at this time WHO had no plans to prepare a classification for registering accidents with the aim of improving the knowledge base for prevention.

In May 1994, the first symposium on International Collaborative Effort on Injury Statistics (ICE injury) was convened in Washington organized by the National Centre for Health Statistics. The working group mentioned above, ARON, was invited to present the Nordic Classification for Use in Registration of Accidents and considerations concerning its use in prevention [70]. This became the inspiration to prepare a new type of classification in cooperation with WHO's Injury Prevention Project. An international working group with its secretariat in the Netherlands was given the task of preparing a proposal for such a classification. The group received a copy of the third version of NCECI, in English, which inspired the development of the international classification that was published much later. NOMESCO offered the Nordic classification as a basis for a WHO international classification. This was discussed both at a meeting in Geneva and at the annual Centre Heads Meeting in 1996 in Tokyo. NOMESCO had made a draft publication of NCECI for this meeting, as a proposal for a WHO trial version. However, partly because of lack of compatibility with ICD-10, the Centre Heads Meeting did not

viklingen af "Basic Data Set" til brug i en forbedret ulykkesregistrering. Ved møder med medarbejdere ved WHO's regionalkontor i København udvekslede man synspunkter og overvejelser, som havde betydning for det videre arbejde med den nordiske klassifikation. På dette tidspunkt var der imidlertid ikke i WHO planer om at lave en egentlig klassifikation til registrering af ulykker med henblik på et forbedret grundlag for forebyggelse.

I maj 1994 afholdtes det første symposium vedr. International Collaborative Effort on Injury Statistics (ICE injury), arrangeret af National Center for Health Statistics i Washington, USA. Den ovenfor nævnte arbejdsgruppe, ARON, blev indbudt til at præsentere den Nordiske ulykkesklassifikation og overvejelserne om dens brug til forebyggelse [70]. Dette blev inspirationen til at udvikle en ny type international klassifikation i samarbejde med WHO's Injury prevention project. En international arbejdsgruppe med sekretariat i Holland fik i opdrag at lave et oplæg til en sådan klassifikation. Gruppen havde modtaget en kopi af NCECIs 3. udgave på engelsk, som indgik som inspiration i udviklingen af den langt senere publicerede internationale klassifikation. NOMESCO tilbød tidligt WHO den nordiske klassifikation som et gennemarbejdet udgangspunkt for en af WHO udgivet international klassifikation. Dette blev drøftet dels ved et møde i Geneve dels ved det årlige møde for center heads i Tokyo i 1996. Til dette møde havde NOMESCO ladet fremstille et prøvetryk af NCECI som forslag til en 'WHO trial version'. Blandt andet på grund af manglende kompatibilitet med ICD-10 kunne Center head-mødet imidlertid ikke på det

recommend that NOMESCO's offer that WHO could take over the Nordic classification should be accepted. So cooperation did not develop further. However, Nordic experts have continued to participate in the work with the development of WHO's International Classification of External Causes of Injuries. In 2003, this classification was accepted and sent out for further field trials by the WHO Family of International Classifications Network (the organization that replaced the Centre Heads Meetings).

A substantial part of the Nordic region is arctic. The arctic area provides very different conditions in terms of the occurrence of injuries. With this in mind, at the beginning of the 1980s, ARON prepared a proposal for an addendum to NCECI, to meet the special needs of registration of injuries in the arctic areas. After field trials the addendum was published in English as a supplement to NCECI [71]. As part of the Nordic cooperation with the neighbouring regions in Eastern Europe, this classification was presented for use in the Barents Region in Russia.

### The Nordic classification of surgical procedures

#### *Background*

Although classifications of diseases have existed for a couple of centuries, and an international classification has been in use for more than 150 years, it was not until after World War II that interest for classifications of surgical procedures and other medical procedures gradually emerged.

foreliggende anbefale en accept af NOMESCO's tilbud, om at WHO kunne videreføre den nordiske klassifikation, og samarbejdet herom udvikle sig ikke videre. Nordiske eksperter har derimod deltaget aktivt i det videre arbejde med udviklingen af WHO's International Classification of External Causes of Injuries (ICECI), som i 2003 af WHO Family of International Classifications Network (afløseren for Center Head-møderne) blev accepteret og udsendt til videre international afprøvning.

En væsentlig del af det nordiske geografiske område er arktisk, hvilket betyder stærkt afvigende vilkår for skaders opståen. På denne baggrund udarbejdede ARON i begyndelsen af 1990'erne et forslag til et appendiks til ulykkesklassifikationen, som skulle imødekomme de særlige registreringsbehov som var gældende i de arktiske områder. Efter afprøvning udkom dette appendiks som supplement på engelsk til NCECI [71]. Som led i det nordiske samarbejde med nærområderne er denne klassifikation blevet præsenteret til brug i Barents-regionen i Rusland.

### Den fælles nordiske operationsklassifikation

#### *Baggrund*

Selvom klassifikationer af sygdomme har været kendt i et par hundrede år og en international klassifikation har været i anvendelse i mere end 150 år har man først efter Anden Verdenskrig set en interesse for gradvis udvikling af klassifikationer af operationer og andre medi-

These classifications have typically been developed for statistical purposes in individual countries, and an international classification as a parallel to WHO's classification of diseases (ICD) has never been developed. An attempt was made after the revision conference approving ICD-9 in 1975, when a classification of medical procedures proposed by WHO was considered. The conference recommended that the draft classification should be published, not as part of the classification of diseases, but as a supplement. After 2-3 years of field trials, it could be revised based on the comments received from the users. With this aim the classification was published in 1978 as the International Classification of Medical Procedures (ICMP) [72]. However, it was only used to a limited degree, and never attained the status of an international classification. In 1989 WHO abandoned the project. Recently work with an international classification of surgical procedures was resumed, to develop a classification which could be made available for countries that do not have the possibilities to produce national classifications themselves, or to use classifications from other countries (such as those from the USA, Australia, England, France and the Nordic countries). The result was the International Classification of Health Interventions (ICHI), which is a modified and abridged version of the Australian classification of procedures. It was approved by WHO-FIC as a beta-version at its meeting in 2003 and is now available on the WHO website for field trials [59].

cinske procedurer. Disse klassifikationer er typisk udviklet til statistisk brug i de enkelte lande og en international klassifikation som parallel til WHO's sygdomsklassifikation (ICD) er aldrig blevet til noget. Et forsøg blev gjort i forbindelse af konferencen, der fastlagde den 9. revision af ICD i 1975, hvor man drøftede et forslag til en procedureklassifikation udarbejdet af WHO. Konferencen anbefalede, at dette forslag blev publiceret ikke som en del af, men som et supplement til den internationale sygdomsklassifikation, som efter 2-3 års afprøvning kunne revideres på grundlag af indkommende kommentarer fra brugere. Klassifikationen blev som International Classification of Medical Procedures (ICMP) [72] udgivet i 1978 med dette sigte, men fik kun begrænset udbredelse, og fik aldrig status som en egentlig international klassifikation. I 1989 opgav WHO en videreførelse af projektet. Først i de seneste år har man arbejdet videre med mulighederne for at lave en international operationsklassifikation, som kan stilles til rådighed for lande, der ikke har mulighed for at udgive egne klassifikationer eller anvende klassifikationer fra andre lande (f.eks. USA, Australien, England, Frankrig, Norden). Resultater er blevet International Classification of Health Interventions (ICHI), som er en modifikation og forkortelse af den nationale australske klassifikation af procedurer. Den blev af WHO-FIC godkendt som beta-version på mødet i 2003 og er nu på WHO's hjemmeside tilgængelig til afprøvning [59].

### *Classifications of surgical procedures in the Nordic countries*

National classifications to meet the regulations for registering and reporting surgical activities in hospitals were gradually developed in the Nordic countries. Although these classifications had some common features regarding content and structure, they were also different, so that direct comparison of statistics was not possible.

In *Denmark* the first limited attempts at classification were closely related to the introduction of electronic registration. Based on that work the National Board of Health published the first real classification as a trial version in 1972 followed by the final version in 1973 [73] (with revised versions in 1980 and 1988). This classification was used for registration and statistics until the end of 1995.

In *Finland* the Hospital Association took responsibility for publishing a classification in 1983 [74]. This version and subsequent revised versions were used for registration and statistics from 1986 through 1996.

From 1982 *Iceland* used WHO's International Classification of Medical Procedures (ICMP) [72] for national registration and statistics until the end of 1996.

*Norway* used a national classification [75] until the end of 1998.

In *Sweden* the National Board of Health developed a national classification based

### *Operationsklassifikationer i de nordiske lande*

I de nordiske lande indførte man efterhånden nationale klassifikationer udviklet til at dække de aktuelle regler for registrering og indberetning af kirurgisk aktivitet på sygehuse. Disse klassifikationer havde en del fællestræk i indhold og struktur, men var alligevel ret forskellige, således at direkte sammenligning mellem statistikkerne ikke var mulig.

I *Danmark* var de første mere lokale klassifikationsforsøg knyttet til indførelsen af elektronisk registrering. På basis af dette arbejde kunne Sundhedsstyrelsen udgive den første egentlige klassifikation, som udsendtes i en prøveversion i 1972 efterfulgt af den endelige version i 1973 [73] (med nye versioner i 1980 og 1988). Denne klassifikation anvendtes i registrering og statistik indtil udgangen af 1995.

I *Finland* var det Sjukhusförbundet, der påtog sig udgivelsen af en klassifikation, der udkom i 1983 [74] og med opdateringer anvendtes ved registrering og statistik i perioden 1986-96.

*Island* tog i 1982 WHO's International Classification of Medical Procedures (ICMP) [72] i brug i den nationale registrering og statistik og brugte denne indtil udgangen af 1996.

I *Norge* anvendte man en national klassifikation [75] som var i brug til udgangen af 1998.

I *Sverige* tog man i Medicinalstyrelsen udgangspunkt i den amerikanske opera-

on the American classification of surgical procedures [76]. It was first published in 1963 [77] and was subsequently updated and revised. It was used in the hospital services and for national statistics until the end of 1996.

In all the classifications the emphasis was on surgical procedures in the traditional sense. But other procedures were also included to different degrees, such as diagnostic procedures and various types of resource-demanding interventions.

### *The Nordic list of surgical procedures 1989*

Thus each of the Nordic countries had developed their own registration of surgical procedures (and to a lesser extent also registration of other medical procedures). When NOMESCO was established in 1966, only Sweden had a sound basis for statistics on surgical procedures, and comparable statistics for the Nordic countries were not available at that time. However, the development of national classifications of surgical procedures continued, and from an early stage efforts were made to create coherence so that the statistics could be comparable. In the 1970s, under the initiative of NOMESCO, a Danish-Swedish Scandinavian List of Surgical procedures was prepared, which was used to a limited extent as a short list in the publication of statistics on surgical procedures in the two countries. The list, which included 119 classes in 15 groups, can be found in Version 2 of the Danish Classification of Surgical Procedures from 1980 [78].

tionsklassifikation [76], da man lavede den nationale operationsklassifikation, der blev udgivet første gang i 1963 [77]. Med løbende opdateringer og nye versioner anvendtes den i sygehusvæsenet og i den nationale statistik i perioden frem til udgangen af 1996.

I alle klassifikationer lå hovedvægten på kirurgiske indgreb i traditionel forstand, men man medtog også i forskelligt omfang andre procedure, som diagnostiske undersøgelser og ressourcekrævende interventioner af anden art.

### *Den nordiske operationsliste 1989*

De nordiske lande havde således uafhængigt af hinanden udviklet deres egne operationsregistreringer (og i mindre omfang også registreringer af andre medicinske procedurer). Da NOMESCO blev dannet i 1966 var det kun Sverige, der havde et anvendeligt grundlag til udarbejdelse operationsstatistikker, og sammenlignende operationsstatistik for de nordiske lande, kunne ikke komme på tale på dette tidspunkt. Udviklingen af de nationale operationsklassifikationer fortsatte imidlertid, og man gik ret tidligt i gang med at skabe en sammenhæng, der kunne bruges i fælles statistiske opgørelser. I 1970'erne havde man på NOMESCO's initiativ udarbejdet en dansk-svensk Skandinavisk Operationsliste, der som en forkortet liste blev anvendt begrænset omfang i de to landes publikationer af operationsstatistik. Listen, som er på 119 numre fordelt på 15 grupper, findes bl.a. publiceret i 2. udgave af den danske operationsklassifikation fra 1980 [78].

## DEVELOPMENT OF COMMON NORDIC CLASSIFICATIONS

Because of growing interest both nationally and internationally in the development of valid (and comparable) statistics on surgical activities in hospitals, the Scandinavian list was abandoned. A Nordic conference on surgical statistics was held in Sjusjøen, Norway in 1987. At this conference, under the auspices of NOMESCO, the possibilities for preparing a common Nordic classification of surgical procedures were discussed. However, due to the size of such a project, the first step was that NOMESCO initiated the preparation of a Nordic Short list of Surgical Operations, which could be used by each country for producing national statistics and for developing comparable Nordic statistics.

NOMESCO appointed a working group for this task, and the group laid down the main principles for the short list. The list should be able to isolate the most frequent conventional procedures. Some of these procedures may not be particularly demanding in terms of resources, but may nevertheless account for a considerable proportion of total surgical activity. The list should also be able to isolate procedures that may be carried out less frequently, but that may be very demanding in terms of resources. Newer surgical procedures such as extra-corporal shock wave lithotripsy and endoscopy connected with biopsies were included, but apart from this the list was limited to traditional surgical procedures. However, from the beginning, the working group was aware that the development could quite soon lead to a need for extending the limits.

In the preparation of the short list the working group used the existing four national classifications of surgical pro-

Den stigende både nationale og internationale interesse for udvikling af gode (og sammenlignelige) statistikker for den operative virksomhed på sygehuse- ne førte til, at den skandinaviske operationsliste blev opgivet. På en nordisk konference om operationsstatistik afholdt i Sjusjøen, Norge i 1987 drøftede man i NOMESCO's regi mulighederne for at indføre en fælles nordisk operationsklassifikation. På grund et sådant projekts omfang blev det første skridt imidlertid, at NOMESCO tog initiativ til udarbejdelsen af en Nordisk forkortet Operationsliste, som kunne anvendes af de enkelte lande i nationale operationsstatistikker og til udvikling af sammenlignelige nordiske statistikker.

NOMESCO nedsatte et udvalg til at løse denne opgave, og man fik her fastlagt de overordnede principper for den forkortede liste. Den skulle kunne isolere de hyppigste konventionelle operationer, som selvom de måske ikke hver for sig er specielt ressourcekrævende dog udgør en betragtelig andel af den kirurgiske aktivitet. Ligeledes skulle listen isolere mindre hyppige men meget ressourcekrævende operationer, som f.eks. organtransplantationer. Også nyere operationsbegreber som f.eks. ekstrakorporal litotripsi (ESWL) og visse endoskopiske indgreb blev medtaget sammen med endoskopier, der ledsages af biopsier, men herudover indskrænkede man sig til det traditionelle operationsbegreb. Man var dog fra begyndelsen klar over at udviklingen meget vel ret hurtigt kunne føre til behov for justeringer af disse afgrænsninger.

I udarbejdelsen af den forkortede liste anvendte man de fire eksisterende nationale operationsklassifikationer [74, 79,



cedures [74, 79, 80, 81]. The list included 130 classes, each defined in relation to the national classifications. Since its publication in 1989 [82] – with subsequent revisions – it has been used for the publication of national statistics and in NOMESCO's annual comparable Nordic statistics on surgical procedures, until it became possible to use statistics based on the common Nordic classification. However, statistics from Iceland based on ICPM could not be incorporated in the short list.

### *A common Nordic classification of surgical procedures*

As mentioned above, a suggestion for a common Nordic classification of surgical procedures had already been considered at the conference in Sjusjøen in 1987. The idea was supported by all the countries, but it was not until after the approval of the short list in 1989 that NOMESCO decided to start this major project and find the necessary financial backing for its completion. For this purpose a special working group was established, with Henning Bay-Nielsen from Denmark as its chairman.

The working group immediately began the work. The introductory meeting was held in Uppsala in May 1989. At a two-day meeting in November the same year in Vedbæk near Copenhagen, the overall principles for a common Nordic classification of surgical procedures were laid down. It was agreed that not all types of procedure and intervention could be included, but that the classification should be limited to procedures that were rele-

80, 81]. Listen kom til at omfatte 130 klasser, der hver for sig er defineret i relation til de nationale klassifikationer koder. Den har fra udgivelsen i 1989 [82] – med efterfølgende revisioner – været anvendt i publikationen af såvel nationale statistikker som NOMESCO's årlige sammenlignende nordiske operationsstatistikker, indtil man kunne anvende statistikker baseret på den nordiske klassifikation. Islands registreringer på grundlag af ICPM kunne dog ikke tilpasses den nordiske forkortede liste.

### *Fællesnordisk operationsklassifikation*

Som nævnt havde man allerede i 1987 på konferencen om operationsstatistik i Sjusjøen drøftet et forslag om udarbejdelse af en nordisk operationsklassifikation. Ideen fik opbakning fra alle sider, men først efter godkendelsen af den forkortede liste i 1989 vedtog NOMESCO at sætte dette omfattende projekt i gang og skaffe det fornødne økonomiske underlag for dets gennemførelse. Til dette formål nedsattes en særlig arbejdsgruppe med Henning Bay-Nielsen, Danmark, som formand.

Arbejdsgruppen gik hurtigt i gang med arbejdet. Man holdt det første indledende møde i Uppsala i maj 1989, og ved et 2-dages møde i november samme år i Vedbæk ved København fik man fastlagt de overordnede principper for en fælles nordisk operationsklassifikation. Der var herunder enighed om, at man ikke kunne medtage alle typer af procedurer og interventioner, men skulle holde sig til det for de kirurgiske fag rele-

## DEVELOPMENT OF COMMON NORDIC CLASSIFICATIONS

vant and of current interest for the surgical specialities. Thus some procedures that are outside the traditional surgical field, such as extra corporal lithotripsy, endoscopies and closed procedures would also be included. So the classification would basically include invasive procedures, procedures normally carried out under anaesthesia, and certain other types of surgery carried out for the purpose of diagnosis or therapy.

It was agreed that none of the existing national classifications could be used as the basis for a new classification, but that other classifications should be assessed to see if they could be used. The English classification was the primary classification that was in mind. Therefore it was decided to assess the possibilities for using a translation of this into the Nordic languages as a common Nordic classification. At a meeting in London in April 1990 the idea was received positively, and the English side had no reservations about such a project. The English classification was thoroughly assessed, but the working group concluded that, because of its composition and structure, it did not meet the requirements that had been agreed upon for a classification to be used as the basis for a common Nordic classification of surgical procedures. Therefore during 1990, the working group began to work on the development of a totally new classification.

At the beginning of 1991, the principles for the classification and the structure of the codes were prepared. This proposal was discussed with the surgical specialities at a Nordic seminar in November the same year. After this the preparation

vante og aktuelle – dvs. herunder også visse procedurer, der ligger uden for det klassiske kirurgiske område som for eksempel ekstrakorporal litotripsi, endoskopier, lukkede procedurer etc. Klassifikationen skulle således som udgangspunkt indeholde invasive procedurer, procedurer, der normalt udføres under anæstesi, samt visse andre procedurer i kirurgien med diagnostisk eller terapeutisk formål.

Der var enighed om, at ingen af de eksisterende nationale klassifikationer kunne anvendes som grundlag for en ny klassifikation, men man ønskede at undersøge om der var andre klassifikationer, der kunne anvendes. Det var først og fremmest den engelske klassifikation, man havde i tankerne, og det blev derfor besluttet at undersøge mulighederne for at anvende en oversættelse af denne til de nordiske sprog som fællesnordisk klassifikation. Ved et møde i London i april 1990 blev tanken meget positivt modtaget, og fra engelsk side havde man ingen forbehold over for et sådant projekt. En grundig gennemgang af den engelske klassifikation blev foretaget, men arbejdsgruppen måtte konkludere, at den ikke i logisk opbygning og struktur kunne møde de krav, man var blevet enige om som udgangspunkt for en fælles nordisk operationsklassifikation. Arbejdsgruppen gik derfor i løbet af 1990 i gang med at udvikle en helt ny klassifikation.

I begyndelsen af 1991 udarbejdede man principperne for klassifikationen og fastlagde kodenstrukturen. Dette forslag blev drøftet med de kirurgiske specialer på et fællesnordisk seminar i november samme år. Herefter fortsatte man i samar-

of the various chapters continued in cooperation with reference groups in all the Nordic countries. For each chapter the working group appointed one or two responsible editors, who prepared the final proposals in cooperation with the national groups. In total more than one hundred Nordic experts were involved in the project. The final proposal for the chapters was put together and edited by a small editorial committee.

To begin with the classification was available in an edition in which the chapters were written in the Nordic language that was the chapter editor's mother tongue. In line with NOMESCO's decision at the beginning of the project, the classification was translated into English and this version is now the common reference version for the national versions. This version was first published by NOMESCO in 1996 under the title *Classification of Surgical Procedures* [83], later renamed as *NOMESCO Classification of Surgical Procedures (NCSP)*.

### *Maintenance of the NOMESCO Classification of Surgical Procedures*

A classification can only form the basis for clinical registration and thus for reliable statistics if it is continually maintained. This is particularly true for a classification of surgical procedures, since, as a result of medical and technological developments, new methods and techniques are being developed all the time and these must be reflected in the registration.

When NOMESCO had completed its work and had published the classification

bejde med referencegrupper inden for specialerne i alle de nordiske lande udarbejdelsen af de enkelte kapitler. For hvert kapitel udpegede arbejdsgruppen en eller to ansvarlige redaktører, der i samarbejde med de nationale grupper lavede de endelige forslag. I alt var der i projektet involveret over 100 nordiske eksperter. Det endelig materiale blev sammenskrevet og redigeret af en mindre redaktionskomite.

Som udgangspunkt forelå klassifikationen i en udgave, hvor kapitlerne var skrevet i det nordiske sprog som var den kapitelansvarliges modersmål. I overensstemmelse med NOMESCO's beslutning ved arbejdet igangsættelse udarbejdede man derefter en fællesversion på engelsk som siden har været den fælles referenceudgave for de nationale versioner. Denne udgave blev publiceret af NOMESCO første gang i 1996 med titlen *Classification of Surgical Procedures* [83], senere med titlen *NOMESCO Classification of Surgical Procedures (NCSP)*.

### *Vedligeholdelsen af den nordiske operationsklassifikation*

En forudsætning for at en klassifikation kan danne grundlag for kliniske registreringer og dermed for troværdige statistikker er, at den løbende vedligeholdes. Dette gælder i særlig grad en operationsklassifikation, idet den medicinske og tekniske udvikling betyder, at der hele tiden fremkommer nye metoder og teknikker, som skal kunne synliggøres i registreringen.

Da NOMESCO havde afsluttet arbejdet med udgivelsen af operationsklassifika-

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of surgical procedures, it was natural that responsibility for maintenance of the classification should be given to the Nordic Centre for Classification of Diseases (from 2003 renamed the Nordic Centre for Classifications in Health Care).

Changes and amendments are made annually and are valid from 1 January. The changes are made in the common English reference version (NCSP-E), and they are reported to the authorities in each of the Nordic countries, so that they can be incorporated into the national versions from the time of validity. Requests for changes and amendments are discussed first in an "electronic forum", where views are obtained from experts and from members of the Reference Group for Nordic Classification Issues, and second at a meeting of the reference group, which prepares a recommendation to the Board of the Nordic Centre about which changes to the classification should be approved. This procedure means that the reference version of the classification is updated only once a year (1 January). But the procedure ensures that changes are carefully assessed and that they are accepted by the classification authorities in all the Nordic countries. NCSP version 1.10 [84] was valid from 1 January 2006.

### *NCSP in the Nordic countries*

Following NOMESCO's publication of the common classification of surgical procedures, the individual countries had responsibility to prepare the national versions in their own languages. Differences in organization of registration in the hospitals and in approval of the national translations meant that the introduction took place over several years.

tionen, var det naturligt, at ansvaret for vedligeholdelsen blev overgivet til Nordiskt center för klassifikation av sjukdomar (fra 2003 med navnet Nordiskt center för klassifikationer i hälso- och sjukvården).

Ændringer foretages årligt med gyldighed fra 1. januar. Ændringer foretages i den engelsksprogede referenceversion (NCSP-E) og meddeles de enkelte landes myndigheder, så de kan indpasses i de nationale versioner fra gyldighedstidspunktet. Ønsker om ændringer og tilføjelser behandles dels i et "elektronisk forum", hvor synspunkter indhentes fra eksperter og medlemmer af centerets Referensgrupp för nordiska klassifikationsfrågor, dels ved et møde i referencegruppen, som udarbejder en indstilling til centrets styrelse, om hvilke ændringer der skal godkendes i klassifikationen. Denne procedure betyder, at der kun indføres opdateringer af referenceversionen en gang om året (per 1. januar), men sikrer til gengæld at ændringerne er gennemarbejdede og accepteret af klassifikationsmyndighederne i alle de nordiske lande. NSCP version 1.10 [84] er gældende fra 1. januar 2006.

### *NSCP i de nordiske lande*

Efter NOMESCO's publikation af den fælles operationsklassifikation var det de enkelte lande, der havde ansvaret for udgivelse af de nationale udgaver på de respektive landes sprog. Forskelle i organisation af registrering på sygehusene og godkendelse af de nationale oversættelser betød, at introduktionen af klassifikationen skete over nogle år.

In *Denmark* a Danish version was already being prepared when the final editorial work was going on in NOMESCO, and therefore it was possible to publish the classification (NCSP-D) [85] in November 1995. It was taken into use in the hospitals from 1 January 1996. Later it was published in an electronic version on the website of the National Board of Health, and in this version updates are continually introduced, partly because of changes made in NCSP-E and partly as national codes that are mainly subdivision of the common Nordic codes.

The Danish version of NCSP was published as a second edition in 2005 [86] (valid from 1 January 2006). In this edition the classification has been modernized and the language has been adapted with more emphasis on Danish terminology. In addition, the many subdivision codes that have been added since the first edition was published have now been included. The electronic version is now based on this second edition of the classification.

*Finland* introduced its national version in both Finnish and Swedish in 1996 (NSCP-F) [87]. It was taken into use from 1997 and later supplemented with updating annexes in 1998, 1999, and 2000. The second edition came out in 2004 [88].

In *Iceland* a translation of NCSP was also introduced in 1996 [89], and this has been used for registering surgical procedures from 1 January 1997. Updated versions have been published in 2000 [90] and 2001 [91]. From 2002 the Directorate of Health has published revised electronic versions in Icelandic and English every year, and NCSP-plus from 2004 (see fur-

I *Denmark* havde man forberedt den danske version, allerede mens det sidste redaktionsarbejde pågik i NOMESCO og kunne derfor publicere klassifikationen (NSCP-D) [85] i november 1995, således at den kunne tages i brug på sygehusene fra den 1. januar 1996. Efterfølgende blev den publiceret i elektronisk form på Sundhedsstyrelsens hjemmeside, og i denne version bliver der løbende foretaget opdateringer dels med ændringer, der sker i NCSP-E deles med nationale koder, der fortrinsvis består af underopdelinger under de fællesnordiske koder.

Den danske version af NCSP udkom i 2. udgave i 2005 [86] (med gyldighed fra 1. januar 2006). I den udgave er der sket en modernisering og tilpasning af sproget med større vægt på dansk terminologi, og desuden er der medtaget de mange underkoder, der er kommet til siden den første udgave. Den elektroniske udgave er nu baseret på denne 2. udgave af klassifikationen.

*Finland* introducerede sin nationale version på både finsk og svensk i 1996 (NCSP-F) [87]. Den blev taget i brug fra 1997 og blev suppleret med opdateringsbilag i 1998, 1999 og 2000. 2. udgave af NCSP-F udkom i 2004 [88].

Også i *Island* introducerede man i 1996 en oversættelse af NCSP [89], og den har været anvendt i registreringen af operationer fra den 1. januar 1997. Opdaterede versioner er blevet publiceret 2000 [90] og 2001 [91]. Fra 2002 har Medicinaldirektoratet publiceret reviderede elektroniske versioner af NCSP på islandsk og engelsk hvert år og også

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ther below). The Icelandic version has been updated according to NCSP-E, but no national adaptations with addition of (sub) codes have been made. From April 2004 Landspítali University Hospital went over to using the national version (NCSP-IS) of NSCP-plus for registering surgical procedures. The Directorate of Health prepares statistics for this hospital based on this classification.

After some consideration *Norway* introduced its national version (NCSP-N) [92] from 1 January 1999. This edition included an addendum with selected national codes for non-surgical procedures, which have been included in updated versions. Such updated versions are now no longer published in print, but the 2006 version is available on the web. In addition, a combined edition of NCSP-N [93] and the Norwegian classification of non-surgical procedures has been published for use in out-patient care.

In *Sweden* the national version of NCSP (NCSP-S) [94] was ready at the end of 1996. It was taken into use for registration from 1 January 1997, and came in a second edition [95] in 2004 with updates and linguistic revisions valid from 1 January 2005. After recommendations from the specialist associations, the indications of localization, which in some chapters may be given by substituting the character 'y' in the last position with a digit, were not included in the first edition. However, after requests from the clinicians, about one tenth of these codes were included in later updates. The classification includes only a limited number of national codes specific for the Swedish version. The classification is also available on the web.

NCSP-plus fra 2004 (se videre neden). Den islandske version opdateres svarende til NCSP-E, men der er ikke foretaget nationale tilpasning med tilføjelser af (under)koder. Fra april 2004 overgik Landspítali Universitetsygehuset til at anvende den nationale version (NCSP-IS) af NCSP-plus i registreringen. Medicinaldirektoratet laver dette hospitals statistik på basis af denne klassifikation.

*Norge* kunne efter nogen overvejelse introducere sin nationale version (NCSP-N) [92] fra 1. januar 1999. Denne udgave indeholdt et tillæg med udvalgte nationale koder for ikke-kirurgiske procedurer, som er kommet i 3. oplag. Der udgives nu ikke længere opdaterede udgaver i bogform, men versionen fra 2006 er tilgængelig elektronisk. Desuden er der i 2006 udgivet en fælles udgave af NCSP-N [93] og den norske klassifikation af ikke-kirurgiske procedurer til anvendelse i registreringen af ambulante patienter.

I *Sverige* forelå den nationale udgave (NCSP-S) [94] i slutningen af 1996. Den blev taget i anvendelse i registreringen fra 1. januar 1997 og udsendtes i 2. oplag [95] i 2004 med opdateringer og sproglig revision med gyldighed fra 1. januar 2005. I første oplag havde man efter råd fra specialistforeningerne ikke medtaget lokaliseringsangivelserne, som i visse kapitler kan ske ved erstatning af 'y' i sidste position med et ciffer, der angiver den anatomiske lokalisering. Efterhånden er der dog efter ønske fra klinikerne kommet omkring en tiendedel af disse koder med i senere opdateringer. Klassifikationen indeholder kun et begrænset antal nationale koder specielle for den svenske version. Klassifikationen er desuden tilgængelig i elektronisk form

Outside the Nordic countries the classification is also used in *Estonia*, which was granted a licence to make an Estonian version (NCSP-EE) based on NCSP-E version 1.6.

### *Cooperation and further development*

After ten years of practical use of the common NOMESCO Classification of Surgical Procedures, it can be stated that the initiative taken by NOMESCO in 1989 has been a success. A classification has been developed that has proved to be suitable for clinical registration in the hospital services in six different countries. In the Nordic countries this has meant better comparability of statistics. The actual classifications can be excluded as the cause of differences in the statistics for the different countries. Differences now have to be explained by differences in clinical behaviour, coding practice and registration systems.

By using the Nordic classification centre, it has also been demonstrated that it is practically possible to continually update the classification, according to a common acceptance of clinically relevant changes and amendments, and to update the classification at intervals that do not hamper its use.

The common classification has also made it possible to develop the common Nordic patient classification system NordDRG, which is described below.

Common Nordic statistics and the maintenance of NordDRG has been possible because the Nordic Centre, on the basis of the national NCSP-versions (and supplementary classifications of

Udover de i nordiske lande anvendes klassifikationen også i *Estland*, som efter aftale har skabt en estisk version (NCSP-EE) baseret på NCSP-E, version 1.6.

### *Samarbejdet og den videre udvikling*

Efter ti års praktisk anvendelse af den fælles nordiske operationsklassifikation kan det konstateres, at det initiativ, som NOMESKO tog i 1989, har været en succes. Der er udviklet en klassifikation, der har vist sig velegnet til klinisk registrering i seks forskellige landes sygehuse. På nordisk plan har det betydet bedre sammenlignelighed på det statistiske område, og man kan i alt væsentlig udelukke de anvendte klassifikationer som årsag til konstaterede forskelle. Disse må nu søges i forskellig klinisk adfærd, kodepraksis og registreringssystemer.

Det har også vist sig muligt gennem det nordiske klassifikationscenter at opretholde og gennemføre en løbende opdatering af klassifikationen baseret på fælles accept af klinisk begrundede ændringer og tilføjelser og med opdateringsintervaller, der ikke virker hæmmende på klassifikationens anvendelse.

Den fælles klassifikation har også gjort det muligt at udvikle det fællesnordiske patientklassifikationssystem Nord-DRG, som er nærmere omtalt andetsteds.

Den fælles nordiske statistik fra NOMESKO og ikke mindst vedligeholdelsen af NordDRG understøttes effektivt af, at klassifikationscentret på grundlag af de nationale NCSP-versioner (og

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certain other interventions), has been able to compile into one list all the national classifications. Through this list the Nordic Centre can direct and control national differences and amendments. This collective Nordic version is available on the website of the Nordic Centre under the title NCSP-plus.

However, the success of the classification does not of course exclude the possibility that after ten years of clinical developments and new technology it is now relevant to consider a thorough revision of the classification. Over the last few years the reference group of the Nordic Centre has already discussed this and considered extending the classification to include medical interventions other than traditional surgical procedures. However no decisions have yet been taken about further work along these lines.

### Nordic cooperation on DRGs

As early as the middle of the 1980s, all the Nordic countries showed great interest in the American DRG system. Diagnosis Related Groups (DRG) is the term for a secondary classification system that aims to group hospital patients in groups that are medically meaningful and homogeneous in terms of use of resources. From 1983, this system was used for calculating reimbursements in the American Medicare system. In the Nordic countries, this system was seen primarily as an aid for documenting activity and for productivity studies, but gradually also as an instrument for output-based allocation of resources. Work with developing the system

supplerende klassifikationer af visse andre interventioner) har kunnet lave en sammenstilling af alle de nationale klassifikationer, der kan styre og kontrollere nationale afvigelser og udbygninger. Denne samlede nordiske version findes tilgængelig på centrets hjemmeside under betegnelsen NCSP-plus.

De opnåede fordele udelukker naturligvis ikke, at såvel den kliniske udvikling som nye teknologiske muligheder, nu efter ti år gør det tiltagende aktuelt at overveje en gennemgribende revision af hele klassifikationen. Dette har allerede gennem det sidste par år været drøftet præliminært i klassifikationscenterets referencegruppe sammen med overvejelser om en udvidelse af klassifikationen til også at omfatte andre medicinske interventioner end de traditionelle kirurgiske indgreb. Endnu er der dog ikke truffet beslutninger om videre arbejde med disse muligheder.

### Det nordiska DRG-samarbetet

Redan i mitten av 1980-talet kom stort intresse att riktas mot det amerikanska DRG-systemet i samtliga nordiska länder. Diagnosis Related Groups (DRG) är beteckningen på ett sekundärt klassifikationssystem som syftar till att gruppera sjukhusvårdtillfällen i medicinskt meningsfulla och med avseende på resursåtgång homogena grupper, vilket 1983 började användas för beräkning av ersättningar inom det amerikanska Medicare-system. I de nordiska länderna såg man i första hand systemet som ett hjälpmedel för verksamhetsbeskrivning och produktivitetsstudier men så småningom också som ett instrument för



took slightly different directions in the Nordic countries, but a common feature was that the work was based in the national institutes for health care, and not in the health authorities that had responsibility for classification issues. The health authorities adopted a wait-and-see attitude, and were partly critical to the system. In Finland, Norway and Sweden, the institutes developed "translation tables" between the national diagnosis and surgical procedures classifications and the corresponding American classifications, in order to make it possible to use the American programme for grouping the patients. The translation tables were based on ICD-8 or ICD-9 with regard to diagnoses, and on the national classifications of surgical procedures that were currently in use.

A new type of Nordic cooperation began when NOMESCO, on the recommendation of Mats Brommels in Finland, in 1993 decided to establish a working group attached to the Nordic Centre for Classification of Diseases, to assess the need for a Nordic DRG classification based on ICD-10 and the new NOMESCO Classification of Surgical Procedures. One of the problems with the imminent introduction of the new classifications was that the translation tables that had been used up to that time would no longer function. Some of the leading people in the national institutes who were interested in DRG, and some hospital managers, were therefore strongly opposed to the introduction of the new classifications.

prestationsstyrd resursfördelning. Utvecklingsarbetet fick delvis olika inriktning i länderna men gemensamt var att arbetet förankrades i de nationella sjukvårdsinstituten och inte i de nationella hälsomyndigheterna som hade ansvar för klassifikationsfrågor. Där förhöll man sig länge avvaktande och delvis kritisk. I både Finland, Norge och Sverige utarbetade sjukvårdsinstituten översättningstabeller mellan de nationella diagnos- och operationsklassifikationerna och motsvarande amerikanska kodverk för att göra det möjligt att utnyttja amerikanska grupperingsprogram. Översättningstabellerna var baserade på ICD-8 eller ICD-9 beträffande diagnoser och på de då gällande nationella operationsklassifikationerna.

En ny typ av nordiskt samarbete påbörjades i och med att NOMESCO på förslag av Mats Brommels i Finland 1993 beslöt att tillsätta en arbetsgrupp knuten till det nordiska klassifikationscentret för att bedöma behovet av en nordisk DRG-grupperare baserad på ICD-10 och den nya nordiska operationsklassifikationen. Ett av problemen vid det förestående införande av de nya klassifikationerna var nämligen att de översättningstabeller som man dittills hade använt inte längre skulle fungera. Vissa ledande DRG-intressenter vid sjukvårdsinstituten och bland sjukvårdshuvudmännen var därför starkt emot införandet av de nya klassifikationerna.

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The working group developed a proposal for a project plan, which was accepted by NOMESCO in 1994. The project involved producing a definition manual based on ICD-10, and using the new NOMESCO Classification of Surgical Procedures (NCSP) and groups based on the definition manual. A steering committee was established for the project, with Mats Brommels as the chairman. For several reasons, it was decided to follow the logic of the groups developed by the American Health Care Financing Agency (HCFA) as closely as possible. One reason for this was to facilitate the transition for use in the Nordic countries, as work with the corresponding American version had already begun. Also, this version was available free of charge (it was "public domain").

The project was organized in different phases. The first phase was the development of translation tables between ICD-10 and ICD-9-CM (which is the American clinical modification of ICD-9), and between the procedure codes of NCSP and ICD-9-CM. This was done in order to ensure greater flexibility for future use. It also became apparent that Norway would come to use these tables for some time. In the second phase, new DRG definitions were developed. In the third phase a grouper would be developed.

At this stage, Mats Brommels had to resign as chairman of the steering committee, because he was joint owner of a Finnish consortium that proposed to submit tenders for some of the project tasks. As centre head of the Nordic Centre, Björn Smedby took over as chairman of the steering committee. There was a great deal of work to be done with requirement

Arbetsgruppen formulerade ett förslag till projektplan som accepterades av NOMESKO 1994. Projektet innebar att man skulle ta fram en definitionsmanual baserad på ICD-10 och den nya nordiska operationsklassifikationen (NCSP) och en på definitionsmanualen baserad grupperare. En styrgrupp med Mats Brommels som ordförande tillsattes för projektet. Av flera skäl beslöt man sig för att lägga sig så nära som möjligt till logiken i den amerikanska grupperare som tagits fram av Health Care Financing Agency (HCFA), bland annat för att förenkla övergången för de nordiska användare som redan hade börjat arbeta med motsvarande amerikanska version och dessutom därför att denna version var fritt tillgänglig (den var "public domain").

Projektet sönderföll i olika faser. En första fas blev att utarbeta översättningstabeller mellan ICD-10 och ICD-9-CM (som är den amerikanska kliniska modifikationen av ICD-9) och mellan NCSP och ICD-9-CM:s procedurkoder, detta för att ge ökad handlingsfrihet för framtida användare. Det visade sig också att Norge skulle komma att använda dessa tabeller under en tid. I en andra fas skulle nya DRG-definitioner utarbetas och i en tredje skulle en grupperare utvecklas.

I det här skedet fick Mats Brommels träda tillbaka som ordförande i styrgruppen, eftersom han var delägare i ett finskt konsortium som avsåg att lämna ett anbud på vissa projektuppdrag och Björn Smedby fick som det nordiska centrets föreståndare ta över ordförandeskapet i styrgruppen. Det var åtskilligt arbete med kravspecifikationer, projekt-

specifications, project plans and drawing up contracts before the project's different stages could be implemented. But one matter was obvious: this clearly represented a Nordic project with commitment from the majority of the countries. It was only Denmark that was somewhat hesitating at the beginning, but which nevertheless was anxious to follow the work closely. The practical work was carried out primarily by Finnish project groups, in which Mats Brommels and Martti Virtanen played central roles, along with the company Datawell Oy, which developed the actual grouper. The work was supervised by an expert group under the leadership of Bjørn Buan from Norway. In this way, the limited competence available in the Nordic countries could be utilized in the most rational and cost-effective way.

The cost of the project was first divided between Finland and Sweden, with a small contribution from Iceland, since to begin with Norway and Denmark, despite their commitment to the project, stood on the sidelines. However, these two countries soon also became joint owners of NordDRG, which was what the final product was called. The different parts of the project were finally delivered at the end of 1995. The first classification was completed in 1996, and has been updated each year.

The Nordic Centre was given responsibility for further work with updating and developing NordDRG. A steering committee representing the owners, that is to say the health authorities in the Nordic countries, led the work. A Nordic network of experts was established, which participates actively in maintaining and developing NordDRG. The

planer och kontraktsskrivning innan projektets olika delar kunde sättas i verket. Men en sak blev uppenbar: det handlade här verkligen om ett nordiskt projekt med engagemang från flertalet länder. Det var egentligen bara Danmark som i början förhöll sig avvaktande men som ändå var angeläget att nära följa arbetet. Det praktiska arbetet kom främst att utföras av finska projektgrupper, där både Mats Brommels och Martti Virtanen kom att spela centrala roller liksom företaget Datawell Oy som utvecklade själva grupperaren. Arbetet övervakades av en expertgrupp under ledning av Bjørn Buan från Norge. Den begränsade kompetens som fanns i de nordiska länderna kunde på det här sättet utnyttjas mycket rationellt och kostnadseffektivt.

Kostnaden för projektet kom först att delas mellan Finland och Sverige med en mindre andel på Island under det att Norge och Danmark trots sitt engagemang i projektet tills vidare ställde sig vid sidan. Båda länderna kom dock att relativt snart också gå in som delägare i NordDRG som blev den slutliga produktens namn. Slutleveransen av projektets olika delar skedde i slutet av 1995. Den första grupperaren färdigställdes 1996 och har därefter uppdaterats årligen.

Ansvar för det fortsatta arbetet med uppdatering och vidareutveckling av NordDRG kom att läggas på det nordiska centret. En styrgrupp som representerar ägarna, dvs. de centrala hälsomyndigheterna i Norden, leder arbetet. Ett nordiskt expertnätverk inrättades som deltar aktivt i underhålls- och utvecklingsarbetet kring NordDRG. Det

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Nordic Centre runs an electronic discussion group, which makes it possible for qualified users in the Nordic countries to discuss issues regarding updating and development. Annual updates are made according to a set procedure and time plan.

NordDRG is an open system. The NordDRG manual that describes the structure and the logic of the system is available on the Nordic Centre's home page. Much of the work with development and maintenance of NordDRG has been done by Martti Virtanen, who came to be connected to the centre as classification expert. An important change that took place was that from the year 2000 Martti Virtanen was employed full-time at the centre with main responsibility for work with NordDRG. Because of NordDRG, the Nordic Centre received a substantial increase in financial resources from the owners.

The NordDRG grouper has different national versions and an English language version. The English version is based on the structure and logic that is common for all the versions. The national versions are slightly different. However, use of NordDRG as an instrument for allocation of resources and for the reimbursement systems is purely a national issue, and in this respect there are great differences between the countries. At present (2006) all hospitals in Norway use NordDRG. Three-quarters of all hospital districts in Finland and the same proportion of the Swedish counties use NordDRG. Since 2002, Denmark has used its own version (DkDRG), which is based on NordDRG. Since 2003, Iceland has tested out the English version of NordDRG. An Estonian

nordiska centret driver en elektronisk diskussionsgrupp som ger möjlighet för kvalificerade användare i Norden att diskutera uppdateringar och utvecklingsfrågor. De årliga uppdateringarna sker efter en fast procedur och bestämt tidtabell.

NordDRG är ett öppet system. NordDRG-manualen som beskriver strukturen och logiken i systemet finns tillgänglig på centrets hemsida. Alla förändringar som införs presenteras i särskilda dokument. En mycket stor del av arbetet med utvecklingen och vidmakthållandet av NordDRG har legat på Martti Virtanen som kom att knytas som klassifikationsexpert till centret. En viktig förändring var att Martti Virtanen från och med år 2000 kunde anställas på heltid vid centret med huvudansvar för NordDRG-arbetet. Det nordiska centret kom genom NordDRG att få ett viktigt resurstillskott från ägarna.

NordDRG-grupperaren produceras i olika nationella versioner samt i en engelskspråkig version som baseras på den för alla versioner gemensamma logiken. De nationella versionerna skiljer sig i vissa mindre avseenden. Användningen av NordDRG som instrument för resursfördelning och ersättningssystem är dock helt och hållet en nationell fråga och här finns stora olikheter mellan länderna. För närvarande (2006) använder samtliga sjukhus i Norge NordDRG liksom tre fjärdedelar av alla sjukvårdsområden i Finland och lika stor andel av de svenska landstingen. Danmark använder fr.o.m 2002 en nationell grupperare (DkDRG) baserad på NordDRG och i Island prövar man sedan 2003 den engelskspråkiga versionen. Genom särskilt

version of NordDRG has been used to a certain extent in Estonia since 2003, under a special contract.

To a large degree, NordDRG has been a Nordic project. Responsibility for further development of the DRG system has been divided between the countries. For example, Norway has worked with further development of the pediatric groups in NordDRG. Sweden has taken the lead in developing a classification for day-care and out-patient care. A Nordic version of this was developed in 2004. From an early stage, Finland had a system for reporting statistics on expenditure that could also be used in other countries, and a Nordic database on expenditure is now being built up. Different working groups are working with areas such as rehabilitation, coronary surgery and psychiatry.

The steering group for NordDRG organized the first Nordic DRG conference, which was held in Oslo in May 2004. In May 2006, a similar conference was held in Copenhagen. The purpose of the conferences has been to create a professional forum for discussions about DRG and its applications. National DRG conferences have also been held in each country. European and international conferences have also been arranged, at which the Nordic countries have been well represented.

It is no exaggeration to say that NordDRG has been a most successful Nordic project. Certainly, there are national differences, and, of course, there are different languages, which means that there are different versions of NordDRG. Despite this, NordDRG can be seen as a positive manifestation

avtal används sedan 2003 NordDRG i viss utsträckning även i Estland i en estnisk version.

NordDRG har blivit ett i hög grad nordiskt projekt. För vidareutvecklingen av NordDRG-systemet har man fördelat ansvaret mellan länderna. Norge gick t.ex. före med utveckling av de pediatriska grupperna i NordDRG och Sverige har haft ledningen när det gäller dagvårds- och öppenvårdstillämpningar. Från 2004 produceras en sådan version för nordiskt bruk. Finland hade tidigt kostnadsuppgifter som kunnat användas även av andra länder och en nordisk kostnadsdatabas byggs nu upp. Olika arbetsgrupper arbetar med utvecklingen inom områden som rehabilitering, hjärtkirurgi och psykiatri.

Styrgruppen för NordDRG tog initiativ till en första nordisk DRG-konferens som hölls i Oslo i maj 2004. I maj 2006 hölls en motsvarande konferens i Köpenhamn. Syftet med konferenserna har varit att skapa ett professionellt forum för DRG-relaterade diskussioner och tillämpningar. Nationella DRG-konferenser har också hållits i alla länderna. Även europeiska och internationella konferenser anordnas vid vilka nordiska deltagare varit väl representerade.

Det är ingen överdrift att påstå att NordDRG har blivit ett mycket framgångsrikt nordiskt samarbetsprojekt. Visserligen finns det nationella olikheter och naturligtvis olika språkversioner, vilket innebär att NordDRG föreligger i olika varianter. Detta hindrar inte att man kan se NordDRG som en vacker

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of what Nordic cooperation can achieve. The system is still under continual development in cooperation with medical and economic experts from the Nordic countries.

manifestation av vad nordiskt samarbete kunnat leda till. Systemet är under fortsatt kontinuerlig utveckling i samverkan med medicinsk och ekonomisk expertis från de nordiska länderna.

## 5 ICF – international developments and Nordic cooperation

### *5 ICF – internationell utveckling och nordiskt samarbete*

In 1980 WHO issued the first version of an international classification of handicaps: International Classification of Impairments, Disabilities and Handicaps (ICIDH) [96]. The development of this classification was decided by the WHO Assembly in 1976, and up until 1996 it was issued in five reprints with minor changes.

The classification had three parts – or axes – which could be used separately or together. The three parts were:

- a. impairment, congenital or caused by disease or injury
- b. disability
- c. handicap

Even though the classification was used to some extent in several countries, its use never became of great importance for international research and health statistics. Among the Nordic countries, Norway translated the classification fairly early, and a Swedish translation appeared in 1995. Official classifications in the national languages for mandatory use have never been published, and the classification has not gained much ground in the Nordic countries. Nordic cooperation regarding this classification has never been established,

I 1980 udsendte WHO den første version af en international handicapklassifikation International Classification of Impairments, Disabilities and Handicaps (ICIDH) [96]. Beslutningen om udviklingen af denne klassifikation blev truffet på WHO's generalforsamling i 1976, og den blev udsendt i fem genoptryk med mindre ændringer frem til 1996.

Klassifikationen bestod af tre dele – eller akser – der kunne anvendes hver for sig eller sammen. De tre dele var

- a. funktionstab, som kan være medfødt eller forårsaget af sygdom eller tilskadekomst
- b. tab af funktionsevne og
- c. handicap

Selvom klassifikationen fik en vis udbredelse i flere lande, blev anvendelsen aldrig af større betydning for internationalt samarbejde inden for forskning og sundhedsstatistik. Af de nordiske lande har Norge ret tidligt oversat klassifikationen og en svensk oversættelse kom i 1995. Officielle klassifikationer på de nationale sprog til obligatorisk anvendelse er ikke udkommet og klassifikationen har heller ikke i de nordiske lande fået større udbredelse, og der har ikke gennem NOMESKO eller klassifikati-

neither through NOMESCO nor through the Nordic Centre for Classifications in Health Care.

A major reason why ICIDH never became an internationally accepted classification lies in the fact that great changes took place in the understanding of handicap and the social rights of disabled people after it was published. In its conceptual framework and practical use ICIDH was very much a way to classify people, with no or little consideration of the total functioning of the person and the causes of the handicap. Moreover, no importance was attached to environmental factors, such as people, physical settings and technical aids.

onscenteret været noget nordisk samarbejde om den.

En væsentlig årsag til at ICIDH aldrig blev et internationalt anerkendt klassifikationsværktøj, findes i det forhold, at der efter dens fremkomst skete store ændringer i opfattelsen af handicap og handicappede personers sociale rettigheder. ICIDH var i sin begrebsverden og sin praktiske anvendelse i alt for høj grad en måde at klassificere personer på, som ikke tog noget eller kun ringe hensyn til individets samlede funktions-evne og årsagerne til et konstateret handicap og uden vægt på betydningen af omgivende faktorer som mennesker, fysiske rammer, hjælpemidler etc.

## The development of ICF

On this background, in 1993 WHO decided to revise ICIDH with the aim of creating a classification that should:

- a. be sufficiently simple to be meaningful in practical use
- b. be able to identify the disabled person's need for interventions
- c. give a comprehensive picture of the processes related to the consequences of diseases and
- d. be able to identify cultural variations so that the classification could be equally valid all over the world

so that the process leading to disability can be assessed objectively, can be registered and can form the foundation for a reaction.

## Udviklingen af ICF

På denne baggrund besluttede WHO i 1993 at gå i gang med en revision af ICIDH med det formål at skabe en klassifikation, som skulle

- a. være tilstrækkelig simpel til meningsfuld praktisk anvendelse
- b. kunne identificere den handicappede persons behov for interventioner
- c. give et sammenhængende billede af de processer der indgår i konsekvenserne af sygdomme og
- d. kunne identificere kulturelle variationer, så anvendeligheden kunne blive af samme værdi overalt i verden

således at den proces der fører til funktionsnedsættelse kan vurderes objektivt, registreres og danne grundlag for en reaktion.



Preliminary work with the revision was given to the WHO Collaborating Centres in France, the Netherlands and North America and also to some special working groups. In this way a broad spectrum of experts and user organizations became involved in the work with revision. Later, some other WHO Collaborating Centres working with classification of diseases also became involved in the work. This included the Nordic Centre for Classification of Diseases, which quite early on contributed to the revision by analysing “other and cross-cutting concerns”. This included overlapping between ICIDH and ICD-10. Anna Christina Nilsson performed an essential part of this work and gave a report at several international meetings on behalf of the Nordic Centre.

Throughout the revision process, the Nordic countries have participated in most of the international revision conferences and meetings. As early as 1995, an informal Nordic network of experts and other people interested in the work with ICIDH was established. Members of this network also participated in a revision conference in Paris.

The first more comprehensive revision meeting took place in Geneva in 1996. After this meeting the first draft – the ICIDH-2 alpha version – was circulated for field trials and at the same time sent to the collaborating centres for consideration. As part of this process the Nordic Centre convened a Nordic seminar in November 1996 in Uppsala. Participants included about 30 experts from the Nordic countries and representatives from WHO and the UN Statistical Department. The seminar did not result in a collective Nordic

Det indledende arbejde med revisionen blev overdraget til WHO Collaborating Centres i Frankrig, Holland og Nordamerika og desuden enkelte specielle arbejdsgrupper. Man fik herigennem inddraget et bredt spektrum af både fagfolk og brugerorganisationer i revisionsarbejdet. Efterhånden kom også en del af de WHO Collaborating Centres, der arbejder med sygdomsklassifikationen, med i arbejdet. Således har også det nordiske klassifikationscenter tidligt kunne bidrage til revisionen bl.a. med analyse af “other and cross-cutting concerns”, hvilket ikke mindst drejede sig om overlappningen mellem ICIDH og ICD-10. Anna Christina Nilsson udførte en meget væsentlig del af dette arbejde og rapporterede på centrets vegne ved flere internationale møder.

Norden har igennem hele revisionsprocessen været repræsenteret ved de fleste internationale revisionsmøder og konferencer, og allerede i 1995 havde man etableret et uformelt nordisk netværk af eksperter og interessenter i ICIDH-arbejdet. Deltagere i netværket deltog desuden i en revisionskonference i Paris.

Det første bredere revisionsmøde blev afholdt i Geneve i 1996, hvorefter man kunne udsende et første udkast – den såkaldte ICIDH-2 alfa-version – til afprøvning, samtidigt med at det blev sendt til høring i centrene. Som led i denne proces afholdt centeret i november 1996 i Uppsala et nordisk seminar om klassifikationen. Heri deltog ca. 30 eksperter fra de nordiske lande samt repræsentanter fra WHO og FN's statistiske afdeling. Seminaret resulterede ikke i et samlet nordisk høringssvar, men de

statement, but the expert opinions received from Denmark, Iceland, Finland and Sweden were forwarded to WHO as a contribution to the ongoing work.

The comments on ICIDH-2 alpha version were considered at a conference in Geneva, where Sonja Calais van Stokkom represented the Nordic Centre. She acted as expert for the Nordic Centre throughout the project. Here the principles for the subsequent ICIDH-2 beta-1 version were laid down. This was issued for field trials during the summer of 1997 with a protocol for the testing process. Later the same year the Nordic Centre participated in an ICIDH meeting in Canada. At this meeting, WHO was advised to postpone testing the new version, as not all the non-English speaking countries would be able to translate the classification within the given time frame.

The testing of ICIDH-2 beta-1 was prolonged until the end of 1998, and in the spring of 1999 the results were discussed at a conference in London. Participants from the Nordic Centre and the Nordic countries were present at this meeting. The conference resulted in the ICIDH-2 beta-2 version, which was circulated for further testing and consideration. In the spring of 2000 a preparatory meeting was held in Geneva, where the Nordic Centre was represented by the head of the centre. At the meeting WHO presented important changes not in line with the work done up until then, which caused a good deal of opposition from the experts from the participating centres. This was the beginning of closer cooperation between the centres, which continued until the end of the revision process. Prior to the next revision confer-

modtagne ekspertudtalelser, som man havde modtaget fra Danmark, Island, Finland og Sverige blev fremsendt til WHO som bidrag til det videre arbejde.

Reaktionerne på ICIDH-2 alfa-version blev behandlet på en konference i Geneve, hvor centeret var repræsenteret af Sonja Calais van Stokkom, der i hele forløbet har fungeret som ekspert for centeret. Her fastlagde man principperne for den efterfølgende ICIDH-2 beta-1 version. Denne udsendtes til afprøvning i sommeren 1997 sammen med en protokol for afprøvningen. Senere samme år deltog centerets i ICIDH-møde i Canada, hvor man anbefalede WHO at udsætte afprøvningen, idet alle ikke engelsksprogede lande ikke inden for den fastsatte tid kunne nå at oversætte klassifikationen.

Afprøvningen af ICIDH-2 beta-1 blev forlænget til udgangen af 1998, og i foråret 1999 kunne resultaterne heraf drøftes på en revisionskonference i London, hvor der var deltagelse også fra centeret og de nordiske lande. Konferencen resulterede i den såkaldte ICIDH-2-beta 2 version, som blev genstand for yderligere afprøvninger og høringer. I foråret 2000 afholdtes der et forberedende møde i Geneve, hvor centeret var repræsenteret ved forstanderen. Her præsenterede WHO væsentlige ændringer i forhold til det arbejde, der hidtil var udført, hvilket fremkaldte en del modstand hos eksperterne fra de deltagende centre. Dette blev indledning til et tættere samarbejde mellem centrene, som fortsatte frem til afslutningen af revisionsarbejdet. Forud for den næste revisionskonference i Madrid i november

ence in Madrid in November 2000, WHO presented an ICIDH-2 Prefinal Draft, which was substantially different from the ICIDH-2 beta-2 version. It included many fundamental and partly controversial proposals for changes, which had not been considered previously in the professional groups, which up until then had guaranteed the principles and quality of the content and structure of the classification. This, of course, caused many reactions both from the centres and from several of the experts who had contributed to the revision. In addition, the draft had been given the title the International Classification of Functioning, Disability, and Health.

At the meeting, at which the Nordic Centre participated along with various Nordic experts, and at some subsequent meetings with the network of centres and other interested parties, some changes and certain compromises were made. At the end of the same year WHO published the final proposal for the new classification, which was presented at the World Health Assembly for approval in May 2001. At the end of the year it was published as the International Classification of Functioning, Disability, and Health (ICF), both in English [58] and in the other five official languages of WHO (Arabic, Chinese, French, Russian and Spanish). Both a complete and detailed version and a short version [97] without subcategories were published. Both of these were presented at the annual Centre Heads meeting in Bethesda in October 2001.

The result was a classification which conceptually was a great step forward, in spite of the compromises and ambiguities that were accepted during and after the last revision conference. Its

2000 præsenterede WHO en ICIDH-2 Prefinal Draft, som meget væsentlig adskilte sig fra ICIDH-2 beta-2 versionen. Den indeholdt en række meget principielle og til dels kontroversielle ændringsforslag, som ikke forud havde været behandlet i de faglige fora, der ellers havde stået som klassifikationens garant for principperne og kvaliteten i indholdet og strukturen. Dette affødte selv sagt mange reaktioner både fra centrene og flere af de eksperter, der havde deltaget i revisionsarbejdet. Desuden havde forslaget for første gang fået titlen The International Classification of Functioning, Disability, and Health.

På mødet, hvor det nordiske center deltog sammen med forskellige nordiske eksperter, og under nogle efterfølgende møder med netværket af centre og andre større interessenter, tilkom der ændringer og visse kompromiser, og sidst på året kunne WHO publicere det endelige forslag til den nye klassifikation, som blev forelagt WHO's generalforsamlingen til godkendelse i maj 2001. Sidst på året blev den så publiceret som International Classification of Functioning, Disability, and Health (ICF) dels på engelsk [58] dels på de øvrige 5 officielle sprog i WHO (arabisk, kinesisk, fransk, russisk og spansk) i både en fuldstændig og detaljeret version og i en kort version [97] uden underopdeling af klassifikationens kategorier. Disse kunne alle præsenteres på det årlige Centre Heads-møde i Bethesda i oktober 2001.

Resultatet blev en klassifikation, som begrebsmæssigt er et stort fremskridt, om end man havde måttet acceptere kompromiser og uafklarede spørgsmål under og efter den sidste revisionskonference.

framework of concepts has become widely used by professionals working with disabled people and with rehabilitation. Previously, the discussion was between opposite points of view. One view represents the medical model, with cure of the underlying condition and adaptation and change of the person's behaviour as its main goal. The other view represents the social model, in which functioning is not seen as a characteristic of the individual but as a complex collection of conditions, many of which are created by the social environment. Hence the management of the problem requires social action and changes in the environment in the widest sense. In ICF these two opposing models are integrated by using a bio-psycho-social model.

The result of this complex solution is described in more detail in a series of papers in a special edition of the Swedish Journal of Social Medicine [98] from 2002, where many aspects of ICF and its use are discussed.

However, as a classification – and particularly as a statistical classification – ICF has not yet been able to fulfil all the requirements that were drawn up when work with revision began. It is no way a simple classification. Because of the demands related to the use of qualifiers, the total number of codes exceeds 1.5 million. Also, WHO has not developed clear and operational guidelines for the use of the component "Activity and Participation" or for the qualifiers. Thus, a very central part of the practical design of the classification is not yet finalized, and this makes statistical analysis and comparable studies very diffi-

Dens begrebsramme har hurtigt fundet udbredt anvendelse i faggrupper, der beskæftiger sig med handicappede og med rehabilitering. Tidligere har diskussionen stået mellem modsatrettede synspunkter, hvoraf det ene repræsenterer den såkaldte medicinske model og dermed har en helbredelse af den tilgrundliggende tilstand og personens tilpasning og ændring af adfærd som sit hovedmål. Det andet synspunkt bygger på det, der betegnes den sociale model, som ikke ser nedsat funktionsevne som en egenskab hos individet, men derimod en kompleks samling af betingelser, hvoraf mange er skabt af de sociale omgivelser, hvorfor løsningerne kræver sociale handlinger og ændringer i omgivelserne i videste forstand. I ICF integreres disse to modsatrettede modeller igennem anvendelsen af en bio-psyko-social model.

Resultatet af denne komplekse løsning er nærmere beskrevet i en række artikler i et særligt temanummer af det svenske Socialmedicinsk Tidsskrift [98] i 2002, hvor de mange aspekter af ICF og dens anvendelse er belyst.

Som klassifikation – og specielt som statistisk klassifikation – har ICF imidlertid endnu ikke kunnet opfylde en del af de krav, der blev opstillet ved revisionsarbejdets begyndelse. Det er på ingen måde en simpel klassifikation, der med de mange krav, der stilles til anvendelse af gradier (qualifiers), er kommet til at rumme et toltalt antal koder, der overstiger 1,5 millioner. Dertil kommer, at WHO ikke har forsynet klassifikationen med en entydig og operationel vejledning i anvendelsen af delklassifikationen "aktiviteter og deltagelse" og af gradierne. En meget central del af klassifikationens praktiske udformning er således ikke endelig fastlagt, og statistiske

cult. Finally, no proper guidelines have been developed for use of the many categories. Through extensive scientific projects, efforts are now being made to create so-called *core sets*. These shall have an agreed and limited number of codes (categories) for each disease/condition, so that it shall be possible to restrict the demands for registration to a practicable level and at the same time provide a clear framework for comparable studies and comparison of people's condition over time. A final solution has not yet been found for any of these problems, and it can be expected that it will take several years before the scientific, practical, clinical and statistical results of the revision will be seen.

At an early stage of the revision project, it was clear that special consideration would have to be given to the application of the classification for children and young people, since their development in terms of function and abilities differs from that observed in adults. Therefore, a working group has followed the work, with special attention to these problems. After the publication of ICF, the working group has continued its work, and a special version is now available for registration of children and young people. Under the name ICF-CY (children and youth), this version is now under testing and can be seen and downloaded from WHO's website [99].

## ICF in the Nordic countries

At an early stage, the Nordic countries and the Nordic Centre for Classification of Diseases became involved in revision of ICIDH. The project soon became a

analyser og sammenlignende studier er på denne måde vanskeliggjort. Endelig kan det også konstateres, at der ikke er udarbejdet egentlige vejledninger for anvendelsen af de mange kategorier. Gennem omfattende videnskabelige projekter arbejdes der i disse år blandt andet på at få fastlagt principper for såkaldte *core sets*, der med et aftalt og begrænset antal koder (kategorier) for hver sygdom/tilstand skal gøre det muligt at begrænse registreringskravene til et overkommeligt arbejde og samtidigt sikre faste rammer for sammenlignende studier og sammenligning af personers tilstand over tid. Ingen af disse problemer har endnu fundet en endelig løsning, og det må forventes, at der endnu går en årrække før man ser større videnskabelige og praktiske kliniske og statistiske resultater af revisionen.

Allerede tidligt i revisionsarbejdet var det klart, at der måtte tages særligt hensyn til en sådan klassifikations anvendelighed på børn og unge, hvis udvikling i funktioner og funktionsevne jo adskiller sig fra det, man ser hos voksne individer. En arbejdsgruppe har derfor fra starten fulgt arbejdet med særligt henblik på disse problemer. Efter udgivelsen af ICF har gruppen fortsat sit arbejde, og der foreligger nu en tilpasning til brug ved registrering af børn og unge. Under betegnelsen ICF-CY (children and youth) er denne version til afprøvelse og kan ses og hentes på WHO's hjemmeside [99].

## ICF i de nordiske lande

De nordiske lande og klassifikationscenteret blev ret tidligt involveret i revisionen af ICIDH. Dels blev arbejdet ret tidligt et fast punkt på de årlige Centre

regular item on the agenda of the annual Centre Heads meetings. Nordic experts became involved in the work through their international professional networks. Users became involved through their international organizations, which WHO involved at the beginning of the project.

Although interest in ICIDH was moderate in the Nordic countries, professionals soon took an interest in the revision project. Nordic participants were present at the large revision conferences in Paris, London and Madrid and at the many more technical meetings during the process. In particular, the Nordic countries were involved in the final testing of ICIDH-2 beta-2, which was partly or totally translated in the individual countries. The Nordic countries were able to present their views and influence the results to a large degree, through the active participation and coordinating efforts of the Nordic Centre.

When the classification was finally approved by the World Health Assembly in 2001, it was agreed that the Nordic Centre should continue to coordinate the activities of the Nordic countries with ICF, and continue to cooperate with WHO. First and foremost this meant coordination at the WHO-FIC Network meetings, which now have permanent ICF working groups, and where ICF is a regular item on the agenda.

Because of this the Nordic Centre in Uppsala has established an ICF reference group, which meets twice a year. The members are appointed by the Board of the Nordic Centre and by the classification authorities in the Nordic countries. The purpose of the group is to contribute to coordination and uniform use of ICF

Heads-møder, dels kom nordiske eksperter ind i arbejdet gennem de internationale faglige kontakter, og brugerne kom med i arbejdet gennem deres internationale organisationer, som WHO inddrog i arbejdet lige fra begyndelsen af projektet.

Selvom interessen i Norden for ICIDH kun havde været beskeden, blev der hurtigt blandt fagfolk en udbredt interesse for revisionsarbejdet. Der var nordisk deltagelse såvel i de store revisionskonferencer i Paris, London og i Madrid, som i de mange mere tekniske møder under processen. Særligt blev de nordiske lande inddraget i den afsluttende afprøvning af ICIDH-2-beta 2, som blev helt eller delvis oversat i de enkelte lande, og Norden kunne i høj grad fremføre sine synspunkter og opnåede indflydelse på resultatet gennem centrets aktive deltagelse og koordinerende indsats.

Da klassifikationen var endeligt vedtaget af WHO's generalforsamling i 2001 enedes man om, at det nordiske klassifikationscenter fortsat skulle forestå koordinationen mellem de nordiske landes arbejde med ICF og det fortsatte samarbejde med WHO. Dette betød først og fremmest koordinationen på møderne i WHO-FIC Network, som nu har sin faste ICF-arbejdsgrupper, og hvor ICF nu er et fast punkt på dagsordenen.

Centeret i Uppsala har derfor også oprettet en ICF-referencegruppe, der mødes to gange om året. Gruppens medlemmer er udpeget af centrets styrelse og de nordiske klassifikationsmyndigheder. Det er gruppens formål at bidrage til samordning og en ensartet anvendelse af ICF i Norden. Centret har desu-

in the Nordic countries. The Nordic Centre has also established a Nordic-Baltic network of persons who are interested in continued cooperation on ICF.

As part of ICF activities, the centre has organized four Nordic-Baltic conferences on ICF and its use (Stockholm 2000, Århus 2001, Helsinki 2002 and Tallinn 2005). These conferences have provided opportunities for exchange of information about possibilities and difficulties, and created the basis for the formation of professional networks between ICF users in the area.

All the Nordic countries except Iceland have translated and published the classification [100, 101, 102, 103] and also made the national versions available on the Internet. In Iceland the translation is in progress, and this will also be available on the Internet. The short version has also been published in some of the Nordic countries.

In the ICF reference group, the preparation of common Nordic guidelines for the use of ICF in various contexts has been discussed. The reason for this, of course, was the insufficient guidelines in the classification. But the initiative failed, partly due to lack of resources, which were not made available to the Nordic Centre, and partly because not enough experience with use of the classification has been gained, neither internationally nor in the Nordic countries, to provide an adequate foundation for such an effort. So the work is concentrated on providing an overview of ICF activities in the Nordic countries. This is an ongoing task, and it is too early yet to evaluate the extent to which ICF is presently used, or how important ICF may be in the future.

den etableret et nordisk-baltisk netværk af personer, som er interesserede i et fortsat samarbejde om ICF.

Som led i ICF-arbejdet har centeret stået for i alt fire nordiske-baltiske konferencer om ICF og dens anvendelse (Stockholm 2000, Århus 2001, Helsinki 2002 og Tallinn 2005). Disse konferencer har givet muligheder for gensidig orientering om muligheder og vanskeligheder og dannet grundlag for etablering af professionelle netværk mellem ICF-brugere i området.

Alle de nordiske lande bortset fra Island har oversat og udgivet klassifikationen [100, 101, 102, 103] og desuden gjort de nationale versioner tilgængelige på Internet. I Island er man ved at oversætte ICF og vil også lægge den ud på nettet. Også den korte version er udgivet i nogle af de nordiske lande.

I ICF-referencegruppen har man drøftet muligheden for at udarbejde en fælles nordisk vejledning til anvendelsen af ICF i forskellige sammenhænge. Baggrunden herfor var naturligvis den utilstrækkelige vejledning, der er til rådighed i selve klassifikationen, men initiativet er strandet på, at det dels kræver ressourcer, som centeret ikke har fået stillet til rådighed til dette område, dels at de internationale såvel som de nordiske erfaringer endnu ikke er så udbyggede, at der findes et reelt grundlag for et sådant arbejde. Det aktuelle arbejde koncentrerer derfor om at skabe et overblik over ICF aktiviteter i de nordiske lande. Dette arbejde pågår for tiden og det er endnu ikke muligt at vurdere omfanget eller dets betydning for ICF's anvendelse i fremtiden.

## 6 Epilogue

### *6 Epilog*

This presentation of Nordic cooperation on health classifications reveals both the positive results that can be achieved and the difficulties that are encountered when different countries and organizations with different professional and administrative development and traditions cooperate.

During the first few years the difficulties were probably most dominant. This was most clearly seen in the fruitless attempts to develop a common Nordic version of ICD-8, and later the countries' somewhat different approaches to ICD-9. In this field NOMESCO did not succeed during the early years in creating a solid foundation of classifications for comparable Nordic statistics. Differences in the development of health statistics in the Nordic countries and – despite many similarities – different clinical traditions created problems that were difficult to overcome.

However, the establishment of the Nordic WHO Collaborating Centre led to more permanent and coordinated international cooperation, which slowly had an influence on Nordic cooperation, and the implementation of ICD-10 was much more coordinated. The participation of the Nordic countries in the maintenance of ICD-10 has now been a well established common concern.

Despite initial problems in cooperation with classifications, on the occasion of

Når det nordiske samarbejde om klassifikationer i sundhedssektoren ses i sammenhæng, således som det er gjort i denne beskrivelse, afsløres både de positive resultater og de vanskeligheder et sådant samarbejde mellem forskellige lande og organisationer med forskellige faglig og administrativ udvikling og tradition byder på.

I de første år var vanskelighederne vel det der var mest dominerende. Tydeligst så man det i de forgæves forsøg på at få lavet først en fælles nordisk version af ICD-8 og senere landenes noget forskellige tilgang til ICD-9. På dette område lykkedes det ikke i NOMESCO's første år at skabe et solidt klassifikationsgrundlag for de sammenlignende statistikker i Norden. De nordiske landes forskellige udvikling af medicinalstatistikken og – trods mange ligheder – også forskellige kliniske traditioner var vanskelige at overvinde.

Etableringen af det nordiske WHO Collaborating Centre betød imidlertid et fastere og mere koordineret internationalt samarbejde, som langsomt påvirkede det nordiske samarbejde og indførelsen af ICD-10 var langt bedre koordineret. Nordens medvirken ved vedligeholdelsen af ICD-10 er nu et velfungerende fælles anliggende.

Trods de indledende vanskeligheder i samarbejdet om klassifikationer kan vi



NOMESCO's 40<sup>th</sup> anniversary, we can claim to have succeeded in developing a solid basis for reliable and valid common health statistics in the Nordic countries. With NOMESCO's classification of surgical procedures, classification of external causes of injuries, NordDRG, and a common understanding of ICD-10 and ICF, the Nordic countries have better possibilities than is usual in an international perspective to share common experiences, to develop comparative statistics, and to analyse differences and similarities.

However, this does not mean that the Nordic countries have reached the end of the road. The development continues, and with new and continually more sophisticated IT tools new possibilities for collecting and processing data arise, allowing us to acquire new knowledge about diseases and health. To some extent, classifications that were originally developed for statistical purposes have met the needs for professional nomenclatures, but they are inadequate to meet the needs arising from electronic medical records and other types of professional communication. So we are currently seeing a rapid development of very extensive terminology databases for use in the health sector. A relevant system in this context is SNOMED CT (Systematized Nomenclature of Medicine – Clinical Terms), developed in the United States, which WHO and many countries outside the English speaking world are presently looking at with great interest. The possibilities for mapping this database to international and national (Nordic) classifications have not yet been fully explored, but this will certainly present great challenges, particularly if good national versions are to be developed. For this reason

ved NOMESKOS 40 års jubilæum konstatere, at det er lykkedes at udvikle et solidt grundlag for gode og troværdige fælles statistikker for sundhedsvæsenet i de nordiske lande. Med NOMESKO's klassifikationer af operationer og ydre årsager til skade samt NordDRG og en fælles forståelse af ICD-10 og ICF har de nordiske lande bedre muligheder for at samle fælles erfaring og udvikle fælles statistik og analyse af forskelle og ligheder, end det er almindeligt i international sammenhæng.

Dette betyder dog ikke, at de nordiske lande er nået til vejs ende. Udviklingen fortsætter og med nye og stadig mere potente informationsteknologiske værktøjer åbner der sig hele tiden nye muligheder, for at indsamle og behandle data og dermed skaffe ny information og viden om sygdom og sundhed. Klassifikationerne, som primært er udviklet til statistiske formål, har i et vist omfang kunne dække behovet for faglige nomenklaturer, men er på ingen måde i stand til at tilfredsstille de behov, der afledes af den digitaliserede journal og øvrige faglige kommunikation. Vi ser derfor i disse år en hastig udvikling af meget omfattende terminologiske databaser for sundhedssektoren. Mest aktuell er den amerikansk udviklede SNO-MED CT (Systematized Nomenclature of Medicine – Clinical Terms), som WHO og mange lande også uden for den engelsktalende verden interesserer sig meget for i disse år. Mulighederne for kobling af denne database til internationale og nationale (nordiske) klassifikationer er ikke endeligt kortlagt, men vil givet blive en meget stor udfordring, ikke mindst hvis der skal laves gode nationale versioner. Blandt andet derfor er der stadig hos mange klassifikations- og termi-

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many experts in classification and terminology doubt whether this system can form the basis for a final global and generally accepted solution.

Developments in the future will probably lead to an integration of statistical classifications into one or more terminology databases, so that, with their electronic systems, users will not notice differences in purpose, principles and structure. In return, users will benefit speedily and effectively from the advantages that terminology databases offer when handling electronic medical records and using the enormous amounts of data on health and disease that are collected every day all over the world.

But statistical classifications will still be used, even though they may not be in the form of thick manuals on the desks of doctors and secretaries. Preliminary deliberations on the eleventh revision of the International Classification of Diseases have begun. It can be expected that substantial changes will be made in the structure of the classification, as the present classification is still characterized by principles based on the medical knowledge of more than 100 years ago. With current technological developments, we can expect improved and much more user friendly systems, that will benefit individual clinicians, statistical and clinical research, the prevention of disease and the promotion of the health of the population in general.

nologiekspertter tvivl om, hvorvidt dette system kan anses for grundlaget for en endelig generel og almindeligt accepteret løsning.

Fremtiden vil formentlig betyde, at de nødvendige statistiske klassifikationer bliver så tæt integreret i en eller flere terminologiske databaser, at brugerne i deres digitale systemer ikke vil mærke, at der er tale om forskellige formål, principper og strukturer, men til gengæld får en effektiv og hurtig adgang til de fordele som terminologiske databaser kan betyde for journalførelse og udnyttelse af de uendelige mængder af data, der hver dag samles ind om sygdom og sundhed ud over hele kloden.

Men statistiske klassifikationer vil man blive ved at anvende, også selvom de måske ikke bliver synlige som tykke opslagsværker på lægers og sekretærens skriveborde. De indledende overvejelser om den 11. revision af den internationale sygdomsklassifikation er sat i gang, og det må forventes, at der vil ske betydelige ændringer i udformningen, da klassifikationen endnu i dag bærer præg af principper udviklet på grundlag af den medicinske viden for over 100 år siden. Med den allerede nu kendte teknologiske udvikling må vi kunne forvente bedre og mere brugervenlige systemer til glæde både for den enkelte kliniker, for den statistiske og kliniske forskning og udviklingen i sygdomsbekæmpelsen og den almindelige folkesundhed.

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## Appendix 1. Abbreviations

### *Bilaga 1. Använda förkortningar*

NOMESCO = Nordic Medico-Statistical Committee

NOMESKO = Nordisk Medicinalstatistisk Komité

ADEK = Working group for definitions and classifications (NOMESCO)

ADEK = Arbejdsgruppe for definitioner og klassifikationer (NOMESKO)

AKLASS = Working group for classifications of diseases (NOMESCO)

AKLASS = Arbejdsgruppe for sygdomsklassifikationer (NOMESKO)

AREV = Working group for classifications (NOMESCO)

AREV = Arbejdsgruppe for klassifikationer (NOMESKO)

ARON = Working group for registration of accidents in the Nordic countries (NOMESCO)

ARON = Arbetsgruppen för Registrering av Olycksfall i Norden (NOMESKO)

ACME = Automated Classification of Medical Entities

ATC = Anatomical Therapeutic Chemical Classification System

DRG = Diagnosis Related Groups

EUROSTAT = Statistical Office of the European Commission

HCFA = Health Care Financing Agency (USA)

ICD (1) International List of Causes of Death (ICD-0 • ICD-5)

ICD (2) International Classification of Diseases, Injuries and Causes of Death (ICD-6 • ICD-9)

ICD (3) International Statistical Classification of Diseases and Related Health Problems (ICD-10)

ICD-O = International Classification of Diseases for Oncology

## APPENDIX 1. ABBREVIATIONS

ICE = International Collaborative Effort (on Injury Statistics) (ICE injury)

ICF = International Classification of Functioning, Disabilities and Health

ICF-CY = International Classification of Functioning, Disabilities and Health (children and youth)

ICHI = International Classification of Health Interventions

ISHMT = International Shortlist for Hospital Morbidity Tabulation

NCECI = NOMESCO Classification of External Causes of Injuries

NCSP = NOMESCO Classification of Surgical Procedures

NordDRG = Nordic Diagnosis Related Groups

OECD = Organization for Economic Co-operation and Development

SNOMED-CT = Systematized Nomenclature of Medicine – Clinical Terms

WHO = World Health Organization

WHO-FIC = WHO Family of International Classifications

WONCA = World Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians

## *Appendix 2*

### *Bilaga 2*

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