行政院及所屬各機關出國報告
（出國類別：出國考察）

丹麥健康資料處理流程與管理方式考察報告

服務機關：中央健康保險局
出國人 職　稱：約聘助理研究員
姓　名：謝其政
出國地區：丹麥
出國期間：91年3月15日至91年3月25日
報告日期：91年5月17日

系統識別號:C09100247

公務出國報告提要

頁數: 63　含附件: 是

報告名稱:

丹麥健康資料處理流程與管理方式

主辦機關:

行政院衛生署中央健康保險局

聯絡人／電話:

劉彥秀／27029959

出國人員:

謝其政　行政院衛生署中央健康保險局　數據數理中心　助理研究員

出國類別: 考察

出國地區: 丹麥

出國期間: 民國 91 年 03 月 15 日 -民國 91 年 03 月 25 日

報告日期: 民國 91 年 05 月 16 日

分類號/目: J4／公共衛生、檢疫　J4／公共衛生、檢疫

關鍵詞: 健康資料處理

內容摘要: 全民健保資料庫擁有全國二千餘萬保險對象之完整個人醫療資料，於研究上的發展潛力十分雄厚，不過因涉及個人隱私，在資料的管理及提供上應有一套十分嚴謹制度，此次考察行程重點是瞭解丹麥處理健康資料方式以做爲國內參考。丹麥研究者需藉由健康資料進行研究時，要通過Data Protection Agency、 The Danish Council of Ethics與資料主管機關同意，Data Protection Agency負責審查資料處理過程中是否有有違反保護個人的情形，The Danish Council of Ethics專門針對健康相關研究，審查是否有侵犯個人的情形。主管機關依研究者需要判斷提供之內容。藉由這三個機制運作，確保研究者研究目的與個人資料之保護。此外，並成立了National Centre for Register-based Research，進行使用現有資料庫研究的諮詢與推展工作。

本文電子檔已上傳至出國報告資訊網

行政院及所屬各機關出國報告
（出國類別：出國考察）

丹麥健康資料處理流程與管理方式考察報告

服務機關：中央健康保險局
出國人 職稱：約聘助理研究員
姓名：謝其政
出國地區：丹麥
出國期間：91年3月15日至91年3月25日
報告日期：91年5月17日

摘要

全民健保資料庫擁有全國二千餘萬保險對象之完整個人醫療資料，於研究上的發展潛力十分雄厚，不過因涉及個人隱私，在資料的管理及提供上應有一套十分嚴謹制度，由國家衛生研究院研究資源處張益壽處長安排下，與其一同至丹麥參訪，此次考察行程重點是瞭解丹麥處理健康資料方式以做為國內參考。

丹麥研究者需藉由健康資料進行研究時，要通過 Data Protection Agency、The Danish Council of Ethics 與資料主管機關同意，Data Protection Agency 負責審查資料處理過程中是否有有違反保護個人的情形，The Danish Council of Ethics 專門針對健康相關研究，審查是否有侵犯個人的情形。主管機關依研究者需要判斷提供之內容。藉由這三個機制運作，確保研究者研究目的與個人資料之保護。此外，並成立了 National Centre for Register-based Research，進行使用現有資料庫研究的諮詢與推展工作。

目錄

目的

全民健保開辦至今已有七年，因醫療保險作業所需，本局擁有許多醫療相關資料，一段時間累積下來，資料內所包含之研究價值十分珍貴，幾乎是包含全人口資料，其完整性更是優越之處，可提供有興趣研究者許多研究題材。

然而，個人醫療資料多屬十分敏感且涉及個人隱私之部分，要提供研究者使用必須考量個人資料保護之問題。此外，從資料蒐集、整理到提供都應有一套明確且一致的標準，以作為實務操作上執行的準則。

因此，由國家衛生研究院研究資源處張益壽處長安排下，與其一同至丹麥參訪，此次至丹麥考察健康資料之處理，主要的重點為了解丹麥對於健康資料如何收集與處理的程序，以及提供研究者之模式，作為我國之參考，進而能發展出適合我國資料內容與研究模式之資料處理方式。

本報告之內容並未依考察之時間順序描述，而採基本介紹、資料內容、處理程序、研究者獲得資料方式、以及問題與對策之架構，將所有考察之內容整合其中，期望能透過一連串前後相連之步驟，能將丹麥在健康資料處理做完整性介紹。

過程

壹　丹麥健康照護制度之簡介

丹麥國家資料基本介紹

面積：43 千平方公里。

人口數：5,282 千人(1999)。

醫療保健支出占國內生產毛額百分比：8.3%(1999)。

平均餘命：男 72.9 歲 女 78.1 歲(1999)。

政治架構：三級制，State、County、Municipality。

貳　健康照護體系

一、基本醫療

一般 16 歲以上民眾要選擇加入 Group 1 或 Group 2 健康保險之中，加入 Group 1 者必須選擇一 General practitioner(GP)，GP 提供之醫療服務病人無須負擔費。GP 提供第一線狀況評估及醫療服務，亦肩負守門員(Gate Keeping)之角色，由其判斷就醫者之狀況，若需進一步診察或醫療者，GP 將病人轉診至其他 Specialist 或醫院去就診。

Group 1 內之民眾，若藉由 GP 之轉診接受 Specialist 之醫療照護，就醫過程無須自負任何費用。若非藉由 GP 轉診而自行至 Specialist 就診，則需自行負擔 Specialist 醫療費用。

選擇 Group 2 之民眾可以自由選擇 GP 或 Specialist，無須藉由 GP 之轉診可直接至 Specialist 就醫，於就醫時需自行負擔 GP 及 Specialist 所有之醫療費用。全人口中選擇 Group 2 的人口佔 1.7%。

無論選擇 Group 1 或 Group 2 之民眾，至醫院者無須負擔醫療費用。

二、牙醫

由Municipality組織牙醫醫療照護機構，負責照顧18歲以下未成年及殘障民眾，使其可以獲得免費的牙醫服務，其餘民眾於就醫時需部分負擔。

三、藥品

民眾至醫院就醫之藥品無需負擔費用，至其他醫療使用藥品需依不同比例部分負擔。

四、其他醫療

護理之家、居家照護、健康諮詢、老年及殘障人士之照顧，無須負擔費用。

參　健康照護系統之財務制度(如附錄二)

丹麥主要之行政體系分成3層，State、County、Municipality，在醫療制度上也依此架構負擔財務責任，其主要的財務來源為稅收，各層級可依實際需要改變徵收之稅率。

State負責對County、Municipality給予大額指定用途之補助(Block Grant)。

County負責支付GP(Capitation 及 Fee for service)、Specialist(Fee for service)、藥費(補助)、牙醫(Fee for service)、醫院(總額預算)、產前及產婦照護機構(總額預算)之費用。在醫院與產前及產婦之照護機構內之醫療人員(包括醫師)是採用薪水制。

Municipality負責居家照護及護理之家、18歲以下兒童之牙醫及老人與殘障者照護，直接補助這些機構，機構內醫療人員(包括醫師)是採用薪水制。

肆　健康資料之內容

此部分介紹丹麥有系統收載健康相關資料，主要分為門診、住診及其他相關資料三類。

一、門診

1.以每次就診為單位

產生門診之資料主要之目的為論量計酬制度(Fee-for-service)申報費用之用，因此以每次就診為單位，包含就診次數，每次就診執行的工作。

2.支付標準

依支付標準記載執行醫療工作。

3.無診斷資料

此類資料單純考量申報費用之目的，並無包含診斷相關資料。

二、住診

1.以每次住院為單位

按每次住院為單位，基本記錄包含住出院日期、住院日等資料。

2.包含診斷資料

包含一般病人醫療記錄之資料，含診斷資料。

3.包含檢查、檢驗、處置資料

資料內含醫院所執行檢查、檢驗、處置等資料。

4.無費用資料

因醫院方面並無支付標準，故無每項處置之費用。

三、其他相關資料

1.癌症登記

有專門收載癌症病人資料庫

2.死亡登記

包括死亡日期、死因等相關資料。

伍　National Board of Health 之簡介

National Board of Health 是非官方組織，與丹麥衛生部(Ministry of Health)合作關係密切，其主要之目標為：

一、持續監測健康以及發展健康相關議題。

二、對於衛生部及其他機構提出建議

三、管理健康專業人員

四、有關全國性健康資料收集之工作亦屬於 National Board of Health 工作範圍，由其負責資料之維護、管理，以及進行統計之工作。

陸　健康資料之收集與處理流程

此部分所指之健康資料只限於醫院住診資料，描述如何由各醫院傳送資料至 National Board of Health 之流程。門診部分資料僅傳送至 County，由各 County 自行處理，並無全國統一之資料庫，有關死亡資料與癌症資料，其收集程序不同，此部分不另行介紹。

一、醫院

各醫院將相關資料傳送至資料處理中心。

二、資料處理中心

屬於私人之機構，接受 National Board of Health 之委託，負責收集各醫院傳送來資料，進行基本資料處理程序，例如除錯、整理，最終處理成 National patient diagnosis register，傳送至 National Board of Health。

三、National Board of Health

接受由資料處理中心傳送來之 National patient diagnosis register，管理這個登記資料之使用。

柒　資料之管理

此部分介紹丹麥對於資料處理之管理，最重要原則係基於 2000 年 5 月通過之 Act on Processing of Personal Data，規範所有資料處理相關事項，不只限於健康資料，適用於任何型態資料，由法條內容與位階來看，應類似於我國個人資料保護法，以下特針對與本次考察行程相關內容提出說明：

一、此法係基於歐盟於 1995 年 95/46/EC 法案下原則所制訂，由此可得知歐盟其他國家應也有類似之法律。

二、要進行資料處理時，必須要有明確且特定的目的，資料處理要符合當初制定之目的。不過為了歷史、統計及科學的目的，資料處理可以不用符合當初訂立之目的。

三、不能收集及處理有關個人種族、信仰、哲學觀等資料，除非是有一些特定之

前提(有個人許可、為了公共利益等)，在這些前提中，特別列出為了統計、科學研究亦可從事此類型資料的處理工作。

四、在某些條件限制下，主管機關可提供個人 ID 作為辨識之用。這部分之規定提供了各個不同來源資料進行資料串連之可能性。

五、某些資料要處理時，要有 Data Protection Agency 的同意。在這規定中，於司法部之下成立了 Data Protection Agency，除了某些特別規定外，要處理資料必須告知 Data Protection Agency，有些資料處理更是需事先得到 Data Protection Agency 許可才可進行。

六、因研究目的所需資料處理需要經 Data Protection Agency 的同意。基於前幾項之說明得知，對於研究目的資料處理，於規定中較為彈性，例如針對一些比較敏感的資料，一般是不能處理，若為了研究的目的則可以處理。然而，在有關 Data Protection Agency 的規定中，一般需資料處理告知 Data Protection Agency，有些例外情形就不用告知，在此為了研究目的就不屬於所列例外情形，也就是針對研究目的資料處理，都必須經由 Data Protection Agency 同意，此部分比起前述規則，對於研究目的資料處理規定較為嚴格。

捌 The Danish Council of Ethics

關於資料處理之相關規定，除了 Act on Processing of Personal Data 外還有些額外限制。The Danish Council of Ethics 是另一個相關機構。

一、The Danish Council of Ethics 原本是 1987 年設於內政部之下的單位，衛生部成立後其組織移至衛生部之下。

二、這個 Council 主要是專門針對健康照護以及生物醫學研究領域中，處理有關倫理之問題，需要處理有關健康的資料時需此機構同意，其他方面之研究無需經由此程序。

三、於各個 County 設有 County Council of Ethics，類似於分支機構，各個 County 那所有與健康相關研究中需進行資料處理者，要經由此 Council 的同意。

玖　健康資料之取得

以上介紹有關健康資料管理的規定與執行機構，根據這些基礎，以下從研究者角度來看，介紹實際進行健康相關研究時，獲得資料及處理資料的方式。

一、Data Protection Agency

基於 Act on Processing of Personal Data 規定，要將研究方式，資料處理流程等相關內容通知 Data Protection Agency，並獲得 Data Protection Agency 之同意。

二、County Council of Ethics

健康相關研究，亦需將內容通知 County Council of Ethics 並獲得同意。

三、資料主管機關

獲得前兩單位同意後，再向資料主管機關提出申請，如前述，健康資料大部分在 National Board of Health，要向 National Board of Health 提出申請，以下介紹提出申請內容

1.資料負責人。

2.資料處理流程。

3.資料儲存方式。

4.工作完成後，於何時銷毀資料。

拾　取得健康處理之特性

研究者基於上述準則獲得研究所需健康資料，不過因提供原則與其他因素，造成使用健康資料研究在實際運作時有些特殊現象，以下介紹之：

一、因為資料之取得需 County Council of Ethics 之同意，丹麥之 County 獨立運作之程度頗高，故各個 County Council of Ethics 對於研究資料取得之同意並無全國性之標準，造成有些 County 同意某些研究而別的 County 對於類似不同意之情形。

二、有關資料內容及處理程序需事先同意，如果需變更處理方式，例如需進行事

前未提及的檔案作連結，或者變更處理資料人員時，皆須重新提出申請。

三、基於可以與其他檔案串連之原則，原則上研究所需資料對於個人 ID 並無任何加密措施。

四、資料主管機關提供資料時需收取費用，主要是以處理研究者資料所需之人力時間估計。

拾壹 Statistics Denmark

以上為健康資料處理基本介紹，於丹麥制度內有 Statistics Denmark 單位，專門負責國家統計與資料處理工作，以下介紹之：

一、Statistics Denmark 負責丹麥國家統計資料之製作及發佈工作。

二、由於維持統計資料公正性目的，Statistics Denmark 接受國家之補助，不過其運作不受政府機關控制，具有獨立董事會，決定 Statistics Denmark 的工作目標及內容。

三、依據規定，Statistics Denmark 因業務需要可以向政府機關、企業及個人要求資料，被要求者不能拒絕，否則會處罰。

四、除了發佈一般統計資料外，Statistics Denmark 也維護一些供研究者使用資料庫，研究者可以使用此類資料庫進行研究。Statistics Denmark 的資料庫主要特色為可以進行多個資料庫之連結，前述 National Board of Health 的資料庫，只限於健康方面，Statistics Denmark 則擁有各個領域資料庫可以相互連結，例如把就醫資料與就業、收入等資料連結，可進行更深入之分析。

五、研究者欲使用 Statistics Denmark 資料時，需經申請過程，獲得同意後，Statistics Denmark 依據研究者需要，製作所需之資料，放置於 Statistics Denmark 機構內專屬電腦室內，研究者必須親自至 Statistics Denmark 機構內操作，分析完成後只能將結果攜回，並不能將資料帶走。

六、研究者要分析 Statistics Denmark 資料尚有另一途徑，研究者提出經申請同意後，可藉由網路將分析程式傳送至 Statistics Denmark 執行，再將結果經網

路取回。不過這部分可以分析的資料庫有限制，沒有包含全部資料庫。

七、由於資料的敏感性，Statistics Denmark 對於資料處理比起前述所提到之規範有更嚴苛的限制，例如所有提供之統計資料都不能有能辨別出個人的可能，對於上述研究者使用之資料，Statistics Denmark 因應研究者需求製作資料時，對於個人資料有進行加密的動作，以保障個人之隱私。

八、Statistics Denmark 亦提供非研究目的之資料或資料庫，例如銀行可以提供存款客戶之 ID 給 Statistics Denmark，Statistics Denmark 可分析這些客戶的統計結果(年齡分布、性別分布等)給銀行。

九、Statistics Denmark 對於外界(研究者或非研究者)提供資料或資料庫，以及研究者至 Statistics Denmark 操作資料分析之儀器設備，Statistics Denmark 需藉由收費維持財務的平衡，因此 Statistics Denmark 的收費會比較高。

十、Statistics Denmark 製作資料庫中與健康有相關者有 3 個，Health Insurance Statistics、Hospitalization、The Register for Health and Social Condition。詳見附錄三。

拾貳　健康資料處理所面臨之問題

在丹麥健康資料處理當中，目前遭遇3個問題：

一、如前述資料取得部分所提到，各個 County Council 可以決定研究者是否可以處理某些資料，並沒有一致性的標準，造成研究資料取得的結果不明確。

二、收費方面無一定標準，各個擁有資料單位依我的原則訂定收費標準。

三、某些資料本身完整性及精確性不足，影響研究之結果。

拾參　健康資料處理改善方案

為了解決健康資料處理的困境，丹麥研究部(Ministry of Research)成立了一個委員會負責處理，至目前為止主要進行3個工作：

一、成立 National Centre for Register-based Research(NCRR)，負責提供諮詢及教育訓練工作。

二、專款補助 Statistics Denmark，使期能減少提供資料時收費，以及製作更多符合研究目的之資料庫。

三、專款補助 National Board of Health，促其改進一些資料庫之品質。

拾肆　National Centre for Register-based Research (NCRR)

在丹麥研究部改善資料處理方案中，成立了 NCRR，主要進行諮詢及教育訓練之工作，其成員由採用丹麥資料庫做研究有經驗的學者組成，一方面於 NCRR 內繼續進行研究，另一方面見由本身使用現有資料庫的經驗，提供其他研究者在使用時的諮詢。以下介紹 NCRR 自行提出的未來發展目標：

拾伍　對於研究者提供諮詢

一、建構各種諮詢管道

使研究者在使用丹麥的資料庫有困難時可有提供協助之機構。

二、製作介紹文件

製作使用丹麥資料庫可以參考之文件，使需要者有查詢的管道，建立可從網路上查詢的管道。

三、舉辦教育訓練課程

對需要進行研究的博士班學生進行資料庫之介紹，分析資料方法學上的訓練，辦理使用者心得交流研討會等工作。

四、進行使用資料庫作分析的推廣工作。

心得

綜觀我國健保資料庫，資料內容豐富性及完整性與丹麥相較之下並不遜色，有些部分甚至有超越之處，例如門診包含診斷資料是丹麥未及之處，丹麥研究者已採用當地資料進行許多具國際水準研究，於國際期刊亦有所聞，若能發揮健保資料庫功效，未來產生國際級研究是可預期的。

與丹麥資料管理人員訪談過程中，其對於資料的特性及準確性的掌握皆深具信心，顯示其對資料來源、收集流程與處理方式有相當程度的瞭解，才會對資料內容瞭解，進而對資料有信心。未來藉由標準化工作流程之建立，健保資料庫將會更為正確與完整，對於研究者也將會有更有品質的研究。

對於資料處理流程，丹麥有一套明確規則，此外，研究者的自律精神、尊重體制的態度也是維持制度運行不可或缺的條件，例如 Statistics Denmark 規定研究者只能將結果攜出，不能帶走資料，事實上還是有機會讓資料流通出去，不過未發生相關缺失。期望未來在我國運作中，藉由制度的設定及研究者的自律，能使整個運作能持續進行，不致產生重大缺失。

建議

丹麥 Act on Processing of Personal Data 規範處理個人資料一般原則，我國「個人資料保護法」屬類似之法案，丹麥制度提供借鏡之處乃設立 Data Protection Agency，負責與管理監測個人資料處理實際運作方式，我國應衡量本國情況，討論建立類似機構的作用及可能性。

有鑑於個人健康資料涉及更為隱私資料，處理過程中需十分強調隱私之保障，丹麥特於各個 County 成立 The Danish Council of Ethics，審核健康資料處理過程，我國亦可藉由成立類似機構以確保隱私保護，唯必須考量的重點為應有全國性組織或者標準，避免丹麥各 County 各有不同標準的現況。

目前採用健保資料進行研究者，程序為向國家衛生研究院提出申請以獲得資料，對於取得資料的資格並未有一套制式的標準，應考量研究者需要，研擬提供資料判斷準則。

目前健保資料因個人隱私考量，對於身份證字號加密處理，造成與其他資料庫連結的困難，於研究上限制了許多可能性，應考慮個人隱私與研究需要，制訂各個資料庫串連原則或作業規則，使得研究者在一定規範下從事資料庫連結的研究。

我國應仿照丹麥 National Centre for Register-based Research 之精神，設立一專屬機構，負責資料庫(健康資料或其他資料)使用者的諮詢與推廣等工作，使資料庫的功用發揮至最大，且降低研究者於使用資料時方生錯誤的機率。

附錄一

丹麥健康資訊考察行程行程表（3/15-3/25）

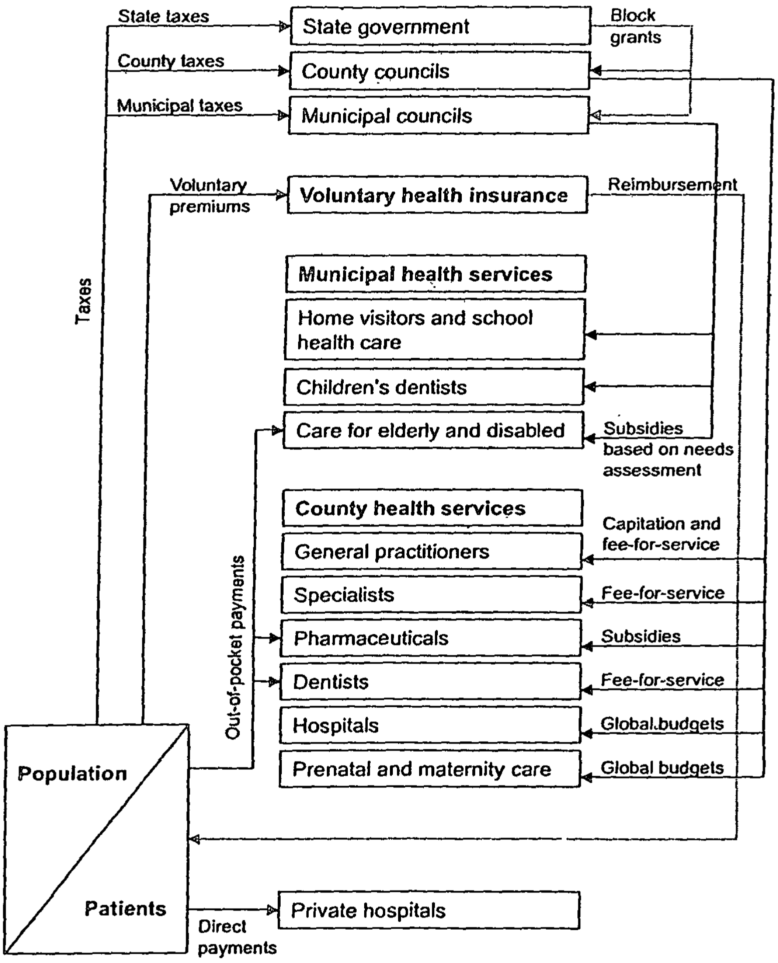
3/15-3/16： 台北至丹麥
3/18-3/22： 丹麥健康資訊考察行程
3/24-3/25： 丹麥至台北

3/18	3/19	3/20
哥本哈根大學生物統計系 (Department of Biostatistics, University of Copenhagen) 哥本哈根市	丹麥統計中心(Statistics Denmark) 國家健康委員會 (National Board of Health) 哥本哈根市	丹麥國家數據研究中心 (Denmark's National Centre for Register-based Research) 阿拉斯市(Aarhus)

3/21	3/22
丹麥國家數據研究中心 (Denmark's National Centre for Register-based Research) 阿拉斯市(Aarhus)	丹麥國家數據研究中心 (Denmark's National Centre for Register-based Research) 阿拉斯市(Aarhus)

附錄二

Financing flow chart



Health Care System in Transition Denmark P.12

附錄三之一

Declaration of Contents, Health insurance statistics

- Administrative Information about the Statistical Product
- Contents
- Time
- Accuracy
- Comparability
- Accessibility

0 Administrative Information about the Statistical Product

0.1 Name
Health insurance statistics

0.2 Heading
Social conditions, health and justice

0.3 Responsible Authority, Office, Person, etc.
Social and health.
Bjarne Lynnerup, tel.: +45 39 17 3104, e-mail: bly@dst.dk

0.4 Purpose and History
The statistics illustrate the relationship between social conditions and the public health insurance system. The statistics were compiled for the first time for the year 1984 on the basis of Statistics Denmark's Public Health Insurance Register which is based on data from the joint-municipal system of public health insurance used by the counties to settle accounts with doctors, dentists, etc.
In the years 1984, 1985 and 1986, the register was based on a 10 per cent sample, containing individuals born on the 14th, 15th or 16th day of a month; from 1987, the register covers all benefits and persons included in the agreements between the National Health Service Negotiating Committee (Sygesikringens Forhandlingsudvalg) and the organisations representing the various contributors. Whereas initially it was typically doctors who had agreements with the National Health Service Negotiating Committee, several new contributors have over the years made agreements and so they are included in the statistics.

0.5 Users and Application
Counties and research institutions.

0.6 Sources
The joint-municipal register for public health insurance
The Central Population Register, Statistics Denmark
The Register of Buildings and Dwellings, Statistics Denmark
The Employment Classification Module, Statistics Denmark

0.7 Legal Authority to Collect Data
The Act on Statistics Denmark (Lov om Danmarks Statistik), Section 6, cf. Order no. 599 of 22 June

2000.

0.8 Response burden

None.

0.9 EU Regulation

None.

1 Contents

1.1 Description of Contents

The statistics provide information on the number of recipients and benefits and the public spending in the public health insurance system within a calendar year. The statistics contain the benefits, for example consultations with general practitioners and specialist doctors, treatments by physiotherapists and chiropractors, etc., that are settled in the joint-municipal system, which means that some of the total expenditure in the public health system is not included in the statistics (for instance the basic fee for general practitioners, expenditures for medicine, travel insurance, private laboratories, etc.). In the statistics, certain benefits are included, although they are not included in the Act on the Public Health Service (Lov om offentlig sygesikring). These are health examinations of children and pregnant women and also vaccinations of children.

Over the years, more contributors have made agreements with the authorities (for instance laboratories, physiotherapists and psychologists). And so, an ever-increasing number of benefits are being counted.

Information about the family, occupation, sector and also housing status of recipients is included in the register.

1.2 Statistical Concepts

The population is made up of all the persons who have received benefits during a calendar year from the public health insurance system. The units are persons, benefits, contacts and amounts paid.
It is only some of the more than 3,000 benefits that involve contact between the recipient and the contributor; contacts are typically consultations and examinations, etc. while an examination at a laboratory for instance is not considered as a contact.

2 Time

2.1 Reference Period

The calendar year in which the benefit is received.

2.2 Date of Publication

The statistics are published annually.

News from Statistics Denmark is published in September, *Statistical News* published in November.

2.3 Punctuality

High.

2.4 Frequency
Annually.

3 Accuracy

3.1 Overall accuracy
As data in the joint-municipal register come from the statutory administration, the level of accuracy is considered to be high.
For an evaluation of the accuracy of those registers of Statistics Denmark that form a part of the Public Health Insurance Register, please refer to the description of these.

3.2 Sources of inaccuracy
Until 1996, children aged 0-15 years did not have their own CPR number, but were registered under the CPR number of the adult accompanying them, and a special marking shows that the benefit is given to a child.
However, this does not always take place. Therefore, the statistics contain an unknown number of men and probably in particular women, who ought to have been registered as children. Another factor contributing to the underestimation of the number of children is that an adult who has taken several children to the doctor and taken the same child to the doctors several times during one year, only features as one person (one child). From 1996, all persons apart from unnamed newborns have had their own public health insurance card with a CPR number, under which registration should take place.
Nevertheless, many children are still registered under the CPR number of the adult, and so the age and sex distribution of the children is made impossible. Furthermore, there is a risk of double counting of these children as they may be registered initially under the adult's CPR number and subsequently under their own number.

3.3 Measures on accuracy
In 1997, 1998 and 1999, 140,000, 80,000 and 50,000 persons respectively had a special children's marking.

4 Comparability

4.1 Comparability over Time
As more and more contributors have joined the system over the years, caution should be applied in connection with comparisons over time.

4.2 Comparability with other Statistics
The National Health Service Negotiating Committee publishes annual statistics on expenditures and benefits. The National Board of Health publishes periodical statistics on the population's use of the benefits. Both these statistics are compiled without the background information which is available from Statistics Denmark's register.

4.3 Coherence between provisional and final statistics
Only final figures are published.

5 Accessibility

5.1 Forms of dissemination

News from Statistics Denmark, Statistical News, The Statistic Bank, Statistical Yearbook

5.2 Basic material: Storage and usability

The register contains information on the persons who have received benefits from the system. The information can be used for other and/or more detailed statistics than the ones that are published.

5.3 Documentation

Documentation is available in QUOTA and WORD, and is being prepared in TIMES3.

5.4 Other Information

In *Statistical News* the contents and basis for the statistics are described in QUOTA and WORD and are being prepared in TIMES3.

附錄三之二

Declarations of Contents, Hospitalization

0 Administrative Information about the Statistical Product

0.1 Name

Hospitalization

0.2 Heading

Social conditions, health and justice

0.3 Responsible Authority, Office, Person, etc.

Social and Health
Lisbeth Laursen, tel. +45 39 17 31 03, e-mail: lil@dst.dk

0.4 Purpose and History

The purpose of the statistics is to contribute to a description of the relationship between social conditions and admissions to hospitals. 1990 is the first year covered by the statistics. Since then the content of the register has continuously been extended. E.g. in 1994 the register was supplemented with a number of new variables to describe the social conditions of children at family level. Since 1997 these types of information have been available for the entire population in the register.

0.5 Users and Application

Users
Municipalities
Counties
Ministries
Organizations
The news media
Private enterprises
Private individuals

Application
Public planning purposes
Research
Public debate

0.6 Sources

National Register of Patients operated by the National Board of Health and following registers operated by Statistics Denmark:

- The Population Statistics Register
- The Medical Register of Births and Deaths
- The Central Register of Buildings and Dwellings
- The Educational Classification Module
- The Employment Classification Module
- The Register of Prosperity Statistics
- The Register of Health Insurance Statistics

The Register of Transfer Payments

0.7 Legal Authority to Collect Data

Section 6 of the Act on Statistics Denmark as subsequently amended (by Act no. 1189 of 21 December 1992 and most recently by section 1 of Act no. 295 of 2 May 2000).

0.8 Response burden

No respondents as such.

0.9 EU Regulation

No EU regulation.

1 Contents

1.1 Description of Contents

The statistics cover admissions to somatic hospital departments within one calendar year. The statistics deal with the number of admissions, the number of bed days and the most important diagnosis. Furthermore, the statistics show how the use of hospitals varies with a range of social conditions, such as family, education, occupation, income, etc.

1.2 Statistical Concepts

The *population* of the statistics is admissions to stationary somatic hospital departments within one calendar year.

The statistical units are admitted people, admissions and bed days.

In the statistics the concept *admission rate* is used. It is defined as the part of a specific population group, which has been admitted during the year. The use of hospital varies highly with age. Therefore, in some of the statistics, an *age standardisation* has been effected.

The statistics are distributed by sex, age, diagnosis, region and a number of background variables: type of family, occupation, education, social benefit and type of dwelling. The register opens up a variety of possibilities for compiling many other types of statistics.

For every *person* who has been resident in Denmark during the calendar year the register stores the following information regarding the person's use of hospitals:

- Number of admissions and number of bed days within different groups of diagnoses
- Total number of different diagnoses
- Dominating diagnosis (the diagnosis for which most bed days in hospitals were recorded) according to groups in the classification of diagnoses (23 grouping and the S-list)

- Number of bed days with the dominating diagnosis according to the 23 grouping and the S-list
- Information on whether the person has been admitted or not within the latest 4 years, and if so, with which diagnosis.

Furthermore, the register stores information from a number of the registers of persons statistics operated by Statistics Denmark (cf. item 0.7):

- Family conditions
- Housing conditions
- Occupation and income situation
- Receipient of transfer payments
- Receipient of services from general practitioners, etc.
- Date of death and cause of death.

For every *admission* during the calendar year the register stores information on:

- Code for hospital and hospital department to which the admission took place
- Dates of admission and discharge
- Typeof hospitalization (emergency or non-emergency)
- Code for cause of admission
- In cases where the admission is caused by an accident the register contains information on the circumstances under which the accident happened
- Main diagnosis grouped according to the 23 grouping and the S-list
- Duration of the admission
- Number of days in relation to any previous admission in the calendar year.

The same background information as mentioned above is linked to the specific admission.

2 Time

2.1 Reference Period

The reference period is the calendar year in which the admission took place.

2.2 Date of Publication

The statistics are produced yearly.

The statistics are published in News from Statistics Denmark 4-5 weeks and in Statistical News about 2 months after Statistics Denmark has received the necessary information form the National Board of Health. The time of delivery of the data from the National Board has varied during the years. This has implied that the statistics have been published between 1 and 1½ year after the end of the reference period.

2.3 Punctuality

The statistics are normally published on time, cf. item 2.2.

2.4 Frequency

The statistics are published yearly.

3 Accuracy

3.1 Overall accuracy

The National Board of Health validates the National Register of Patients and the reliability of the data in the register is in general regarded as high.

In 1990 an evaluation of the quality of the data in the National Register of Patients was carried out. The result of this evaluation was that the administrative information (e.g. dates) had a high level of reliability while the medical data (e.g. diagnoses) had a lower level of reliability. However, as Statistics Denmark receives the codes of diagnoses at an aggregated level this is not assessed to be of major importance.

For an assessment of the reliability of the other registers of persons statistics, which are operated by Statistics Denmark and used in the register of hospitalization, reference is made to the specific declarations of contents of these registers.

3.2 Sources of inaccuracy

Coverage

The National Register of Patients is set up on the basis of reports from the specific hospital departments. Data concerning an admission has to be recorded when the admission ends. It is assessed that this happens close to 100 percent of all cases.

Collection/measuring

The National Register of Patients is an administrative register and Statistics Denmark receives one extract yearly.

Processing of data

Statistics Denmark carries out a validation/probability check of the extract from the National Register of Patients. As the extract is already validated by the National Board of Health only very few errors are detected: in about 0,5 percent of the data. In order to maintain the comparability with the publishing of the National Board of Health, no corrections are made in the data, but a marking indicating the type of error is made in the records of question.

3.3 Measures on accuracy

Not relevant

4 Comparability

4.1 Comparability over Time

The same primary data have been used since 1990 when the statistics were compiled for the first time.

On 1 January 1994 the new International Classification of Diseases (ICD10) was introduced. This replaced the former ICD8-classification. This implies that caution has to be exercised in comparing the disease pattern before and after 1 January 1994.

The information in the National Register of Patients on admissions caused by road traffic accidents is up to and including 1994 regarded as defective. Since 1995 the information is regarded as adequate.

When looking at the use of hospitals in 1995 the trade dispute among hospital nurses this year has to be taken into consideration.

The content of the background information in the register has continuously been extended, cf. item. 0.4. Consequently, some of the statistics cannot be found for all years.

4.2 Comparability with other Statistics

The National Board of Health issues yearly statistics about the activity at hospitals. These statistics are also based on the information in the National Register of Patients. The statistics on the population's use of hospitals are comparable with these statistics, except the definition of the group of people covered by the statistics: In most of the tabulations the statistics on the population's use of hospitals only cover people living in Denmark as of 1 January in the specific year. This implies that people who were born or immigrated to Denmark during the year are not covered by the statistics. Another difference is that the statistics in the population's use of hospital assign people according to their municipality/county as of 1 January in the specific year, while the statistics from the National Board of Health assign people according to their municipality/county as of the date of admission.

4.3 Coherence between provisional and final statistics

No provisional figures are calculated.

5 Accessibility

5.1 Forms of dissemination

The statistics are published in *Nyt fra Danmarks Statistik* (News from Statistics Denmark), *in Sociale forhold, sundhed og retsvæsen* (Social conditions, health and justice) appearing in the series Statistical News and in Statbank Denmark.
Yearly publications: Statistical Yearbook.

5.2 Basic material: Storage and usability

The *Register of Hospitalization* stores complete data on the population's use of hospitals at the level of individuals . Furthermore, complete data on all admissions at the level of individuals are stored. This information can be used in compiling other or more detailed statistics than those published.

5.3 Documentation

Complete documentation is available in TIMES.

5.4 Other Information

The primary data and the content of the statistics are described in Statistical News.

A booklet (in Danish) describing in detail the content of the register has been prepared. The booklet is delivered on request.

附錄三之三

Declaration of Contents, The Register for Health and Social Conditions

0 Administrative oplysninger om statistikproduktet

0.1 Navn

The Register for Health and Social Conditions

0.2 Emnegruppe

Social conditions, health and justice

0.3 Ansvarlig myndighed, kontor, person m.v.

Statistics Denmark, Incomes and Consumption, The Register for Health and Social Conditions
John Gilliam, tel: +45 3917 3228. E-mail: jlg@dst.dk

0.4 Formål og historie

The purpose of the register is to provide Statistics Denmark, the Ministry of Health and the National Board of Health with readily available information from public registers on the state of health of the Danish population and relevant socio-economic background conditions. Another purpose is to provide data for research in social medicine.

The register was established in cooperation between the three authorities, which had already established data for epidemiological research, for the Register of Occupational Cancer Statistics and for the Fertility Database. Besides these, a Register of Statistics on Hospitalisations has been created at Statistics Denmark to illustrate the social distribution of hospitalisations.

The collection of data for the register began in 1994, starting with data from registers with information available from 1977 onwards: The National Register of Patients, the Register of Population Statistics and the Employment Classification Module. This was followed in 1995 by the inclusion of data from the following registers: the Register of Causes of Death, the Register of Health Insurance Statistics and the Register of Coherent Social Statistics. In 1997 a final agreement was made defining the contents of the register, including data from three more registers: The Integrated Database for Labour Market Research, the Educational Classification Module and the Register of Building and Dwelling Statistics. At the time, specification was made for the future inclusion of data on medical births, voluntary abortions and deformations in birth. The first complete version of the register including available data for 1977-1995 was completed in the spring of 1998. The register has since been updated every year.

0.5 Brugere og anvendelsesområder

The Register for Health and Social Conditions is available for use by the authorities responsible for its contents and by researchers and other customer services offered by Statistics Denmark. The clauses of the original agreement on which the register is based specify the following:

The Ministry of Health uses the register for the illustration and evaluation of political initiatives in the field of health.
The National Board of Health uses the register for providing health analyses and statistics.
Statistics Denmark uses the register for general descriptions of the state of health of the Danish population.

Besides this, Statistics Denmark may present data from the register on a service basis, mainly in the form of specially designed model data sets to be made available for researchers attached to the research facility at Statistics Denmark.

0.6 Kilder

The data on the various subjects contained in the Register for Health and Social Conditions are based on sources at the National Board of Health and at Statistics Denmark:

Patients: National Register of Patients (National Board of Health)
Mortality Causes: Register of Causes of Death (National Board of Health)
Health insurance: Register of Health Insurance Statistics (National Board of Health and Statistics Denmark)
Demographic conditions: Register of Population Statistics (Statistics Denmark)
Employment and incomes: Employment Classification Module
Education: Educational Classification Module (Statistics Denmark)
Social benefits: Register of Transfer Payments (Statistics Denmark)
Housing conditions: Register of Buildings and Dwelling Statistics (Statistics Denmark)

The various registers from which data has been drawn at Statistics Denmark are described in more detail elsewhere in the declarations of contents provided for all statistical products.

0.7 Indsamlingshjemmel

Authorisation for the use of existing statistical registers at Statistics Denmark is given by the Act on Statistics Denmark as subsequently amended by Act no. 15 of 12th January 1972, by Act no. 386 of 13th June 1990 and most recently by Act no. 1025 of 19th December 1992. Permission to link information from these registers with registers for which the National Board of Health is responsible is defined in the regulations applying to the Register for Health and Social Conditions, as agreed upon between Statistics Denmark and the National Board of Health.

0.8 Respondentbyrde

None

0.9 EU-regulering

None

1 Indhold

1.1 Indholdsbeskrivelse

The register contains all persons who have been resident in Denmark since 1977.
The information in the register covers the following areas:

Hospitalised patients:
The National Register of Patients contains all patients discharged in the course of the year from hospitals treating somatic ailments since 1977. It contains information on admittances, treatment and discharges. Until 1994 it contained information on in-patients. From 1995 it includes information on out patients and casualty ward patients.

The data is organised on the basis of each discharge. A person can have been discharged more than once in the course of a year. For each discharge one or more diagnoses can have been recorded and for each diagnosis, one or more operations can have been recorded.

Register of Causes of Death:
This provides information on the circumstances and causes of death.

Health services:
This includes services received from doctors (practitioners or specialists) in the course of the year. The information provided is on the specialism of the doctor providing help and how often a given person has received help. Also included is the aggregate payment received by doctors in the year for treating each person.

Demographic conditions:
These include gender, age, marital status and citizenship, dated at the end of the year and births, deaths and migration dated at the time of occurrence.

Employment and incomes:
Information here is provided for each person's major occupation during the year. This includes labour market status, occupation (ISCO categories since 1995), industry (NACE since 1993), socio-economic group, income and degree of unemployment.

Education:
Information on education is collected from the population census from 1970 and data gathered from all educational institutions since then. It includes all completed school, vocational and further education up to the present and educational participation on all levels since 1977. The information is available in ISCED categories.

Social benefits:
Information on social benefits originates in the Register of Transfer Payments containing information on all contributions made for the purpose of maintaining income. The information includes various permanent and temporary benefits paid out in the course of a year. It is possible to specify the type of benefit: for unemployment, social assistance or sickness benefit, and to specify the proportion of assistance from each source.

At the same time, the information included facilitates an assessment of movements of persons from one type of assistance to another in the course of a year and of the extent of public assistance received by a person during a year, measured as the number of days payments have been made.

Housing:
Information on the housing of the entire population for all years since 1980 originates in the Register of Building and Housing Statistics. This covers all housing in Denmark, including various data describing houses (homes): type of house, ownership, installations and size. This information is related to all the individuals in the population via their home address.

1.2 Statistiske begreber

Health related data:

National Register of Patients.

-Admission and discharge information:

Type of patient in-patients more or less than one day, outpatients, casualty
Date for admission
Referred from - gp, specialist hospital department
Mode of admission - emergency or not
Discharged to - gp, specialist, hospital dept.
Contact reason - accident, suicide or violence
Accident - type of accident
Date of discharge

-Diagnoses and operations:

Operation (6 per diagnosis) Nordic classification.
Diagnosis: Primary diagnosis - other diagnoses ICD-10 code)

Register of Causes of Death

Place of death
Date of death
Mode of death
Primary cause of death
Secondary cause of death
Tertiary cause of death
Accident type
Autopsy
Type of death certificate

Health Services:

Type of assistance (by cause, i.e. treatment type)
Number of services provided (i.e. patient contacts for each type of assistance)
Gross fees paid (by health services to doctor)
Health insurance category of patient

Socio-economic data:

Demographic data:

Sex
Age
Residential municipality
Place of birth registration
Citizenship
Marital Status
Type of family
Status in family
Type of household
Type of communal household (institution etc)
Cohabitation with parent

Changes during the year:

Birth
Death
Emigration
Immigration
Adoption

Occupational, incomes, activity and unemployment data.

- Occupation and income:

Occupational status
Occupation (Statistics Denmark: DISCO88 code, as ISCO88)
Socio-economic group (Statistics Denmark: SOCIO group)
Degree of employment
Gross income
Taxable income

- Place of work or company:

Industry (NACE)
Privately or publicly owned company
Number of employed

- Unemployment:

Degree of unemployment during the year
Unemployment insurance association group
Part-time or full-time insured

Educational Data

Current education (participation)
Latest completed secondary education
Highest level of educational attainment

Social Benefits

-Type and size:

Unemployment benefit
Social security
Sickness benefit
Maternity benefit
Early retirement pension
Old Age pension
Job release payment

- Length of payment period:

No. of days per month or year
First and last type of benefit

Housing Conditions.

-Housing type and age:

Housing type
Year of construction
Ownership type
Use permit

- Size of housing:

Living area
No. of rooms
No. of occupants

- Installations:

Toilet
Bathroom
Central heating
Elevator
Kitchen

2 Tid

2.1 Referencetid

The period of reference for the Register for Health and Social Conditions varies according to the separate registers included:

1977: Patients, Deaths, Population, Occupation and incomes (but not unemployment- 1980)
1980: Education, Housing
1987: Health assistance

The register includes information from the commencing year until 1998 and subsequently receives an update for each following year. All the information included for a specific year relates either to the status at the end of the year or to events recorded during the year.

2.2 Udgivelsestid

The register is normally available 1 1/4 years after the latest recorded year.

2.3 Punktlighed

The data in the register is normally available within a few days of its most recent update.

2.4 Hyppighed

The register is updated annually.

3 Pålidelighed og usikkerhed

3.1 Samlet pålidelighed

As the Register for Health and Social Conditions is a secondary register, consisting of data provided by other registers, its accuracy depends on that of each of the donor registers. These are described elsewhere under the respective chapters.

3.2 Usikkerhedskilder

Some comments can be made as to the accuracy of data from the educational and employment modules as this has been improved over time.

Information about the completed education of the elderly part of the population can be marred by the age limit used in the 1970 census, where results pertaining to people over the age of 49 were excluded from the register. As a result, the level of information improves yearly from 1980 onwards.

Information about employment status is indirectly obtained from tax returns and income sources, and the model used for this can at best be considered the optimal on the basis of available sources. Occupations were before 1993 acquired from public pay transfer systems (for public employees) or local population registers supplemented by information on education or employment insurance organisations membership. As from 1993 privately companies of 10 or more employees provide occupational data about their employees along with statistics on earnings. The DISCO88 (the Danish ISCO88) was introduced as standard classification. Public employees' occupations have been coded according to the new standard since 1995, but coding practices have been altered throughout the period and became more stable in 1997. As from 1999 the DISCO88 has been adopted for public employees.

3.3 Tal for usikkerhed

None

4 Sammenlignelighed

4.1 Sammenlignelighed over tid

The principles of classification of some of the variables in the register have been altered in the period from 1977 until now. The classification of industries changed in 1980, and again in 1993. The classification of occupations changed in 1980 and 1995 while that of socio-economic groups changed in 1995. Criteria for receipt of public assistance changed in 1994.
The classification of diagnoses changed in 1994 from the ICD8 to the ICD10 standard.

4.2 Sammenlignelighed med anden statistik

The Register for Health and Social Conditions is a database in content similar to other epidemiological data collections, like the Register of Occupational Cancer Statistics. Statistics Denmark also has a Register of Hospitalisations, which includes data from some of the same registers as the register for health and social conditions.

4.3 Forhold mellem foreløbige og endelige tal

No provisional version.

5 Tilgængelighed

5.1 Distributionskanaler

The Register for Health and Social Conditions is a database whose information is made available for researchers and public authorities for scientific analysis or reports based on scientific and statistical investigations. Data is made available in the form of so-called model datasets, in which the researcher is provided with precisely the number of variables required for the specifically defined population to be included in the project. In order to obtain access to this information the Health Authorities must grant permission and the data must be paid for. Researchers are only given access to anonymised data under the strict control of Statistics Denmark.

5.2 Grundmateriale: Lagring og anvendelsesmuligheder

The register is stored in one integrated register at Statistic Denmark. Extracts of any size can be made directly from the register within days.

5.3 Dokumentation

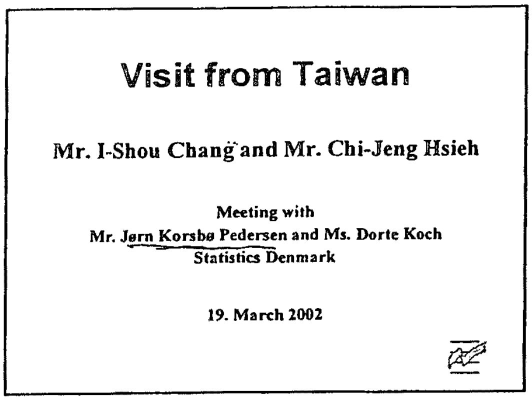
Documentation of the contents of the register and its variables can be obtained on request.

Contact:
John Gilliam
Incomes and Consumption
Register for Health and Social Conditions
Tel: +45 3917 3228
E-Mail: jlg@dst.dk

5.4 Øvrige oplysninger

附錄四

Statistics Denmark 19. March 2002

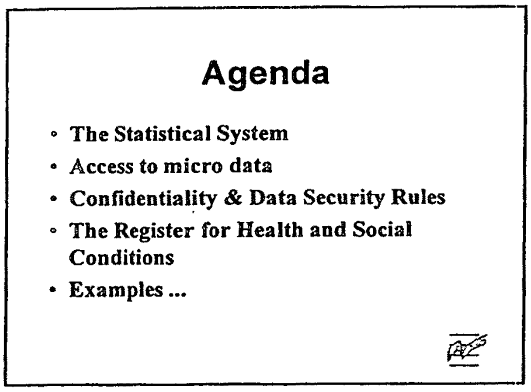


Visit from Taiwan

Mr. I-Shou Chang and Mr. Chi-Jeng Hsieh

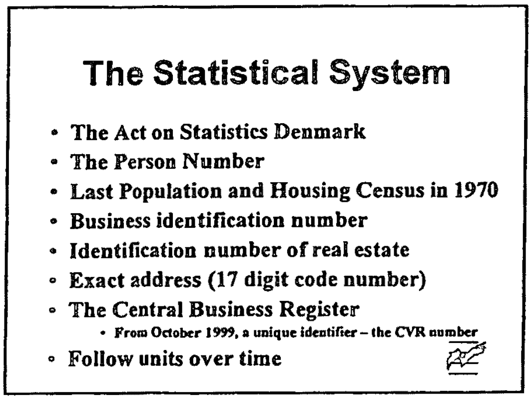
Meeting with
Mr. Jørn Korsbø Pedersen and Ms. Dorte Koch
Statistics Denmark

19. March 2002



Agenda

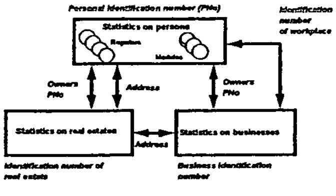
- The Statistical System
- Access to micro data
- Confidentiality & Data Security Rules
- The Register for Health and Social Conditions
- Examples ...



The Statistical System

- The Act on Statistics Denmark
- The Person Number
- Last Population and Housing Census in 1970
- Business identification number
- Identification number of real estate
- Exact address (17 digit code number)
- The Central Business Register
    - From October 1999, a unique identifier – the CVR number
- Follow units over time

The Combined Statistical System

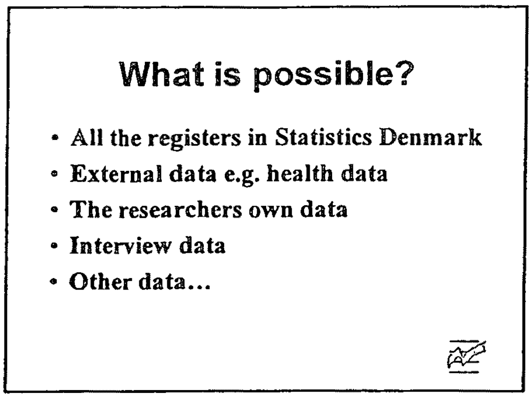


Dimensions I

- Demography
- Education
- Employment – Unemployment
- Income
- Wages
- Social benefit
- Crime
- Health

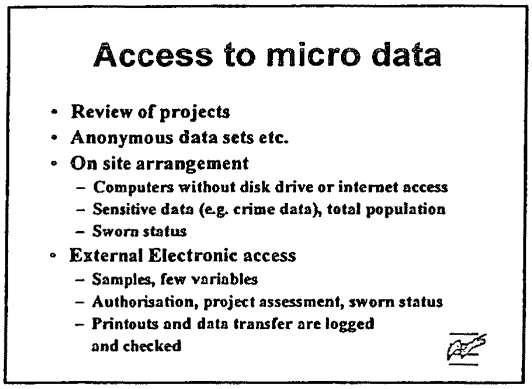
Dimensions II

- Housing statistics
- Home address
- Kind-of-activity
- Size of the workplace
- The composition of the work-force
- Workplace address
- Financial (turnover, exports, ownership code)
- Accounts (value added, loan and net capital, fixed assets etc)



What is possible?

- All the registers in Statistics Denmark
- External data e.g. health data
- The researchers own data
- Interview data
- Other data...



Access to micro data

- Review of projects
- Anonymous data sets etc.
- On site arrangement
  - Computers without disk drive or internet access
  - Sensitive data (e.g. crime data), total population
  - Sworn status
- External Electronic access
  - Samples, few variables
  - Authorisation, project assessment, sworn status
  - Printouts and data transfer are logged and checked

Who can get access?

... difficult!

- Universities
- Ministries
- Public research units
- Consultancy firms
- Labour market organisations
- Others...

Confidentiality

- Legislation
- Confidentiality policy
- Data security rules
- Responsibility/discipline
- Penalty

Penalty

Below is an extract from the section on the obligation of professional secrecy in the Danish Law on Publicity in Administration (Section 27, subsection 3):

An administrative authority can decide that a person who is not engaged in any public administrations has to respect the rules for professional secrecy with respect to confidential information, which has been made available by the authority to the person in question, without being under an obligation to do so.

Infringement of the above-mentioned is subject to section 152 of the Danish Penal Code:

Any person who has been or is engaged in any public administration and who passes on or makes use of confidential information unwarranted, which is accessible to the person in question, is punishable by penalty, simple detention or imprisonment of up to 6 months.

Imprisonment may be extended to 2 years, if the offence was committed intentionally for the mere sake of gain for the person himself or others, or in the case of aggravated circumstances.

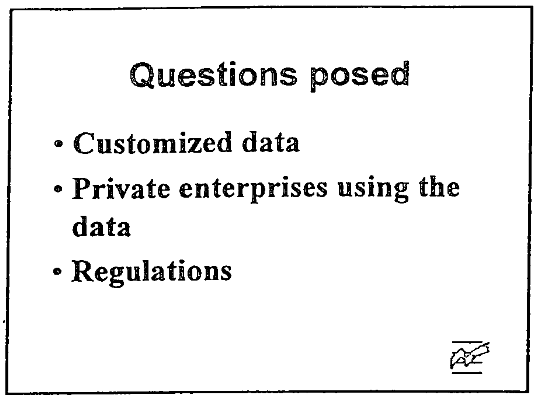
An item of information is considered confidential, if this is set out in an act or other legal provisions, or in cases where it is essential that this information remains secret in order to protect substantial considerations, with respect to public or private interests.

Payment

The researchers pay for:

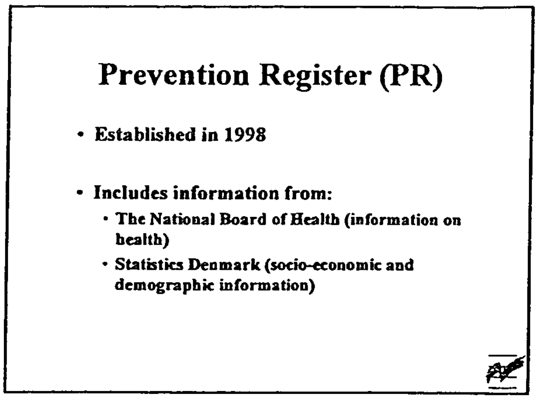
- The data
- Using the computer
- Using an office

New initiatives...



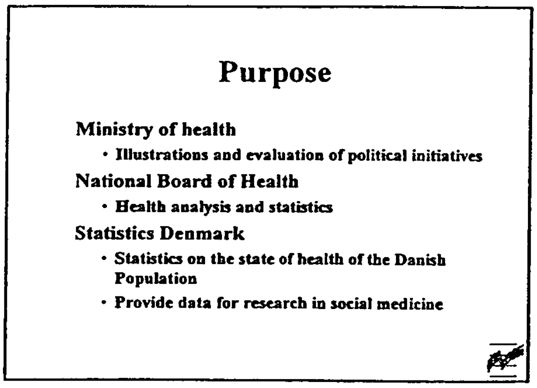
Questions posed

- Customized data
- Private enterprises using the data
- Regulations



Prevention Register (PR)

- Established in 1998
- Includes information from:
  - The National Board of Health (information on health)
  - Statistics Denmark (socio-economic and demographic information)

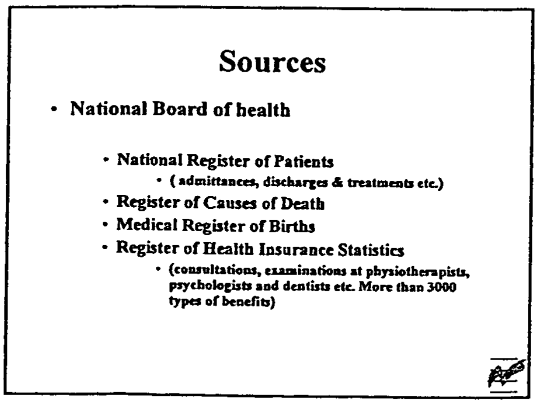


Purpose

Ministry of health
- Illustrations and evaluation of political initiatives

National Board of Health
- Health analysis and statistics

Statistics Denmark
- Statistics on the state of health of the Danish Population
- Provide data for research in social medicine



Sources

- National Board of health
  - National Register of Patients
    - (admittances, discharges & treatments etc.)
  - Register of Causes of Death
  - Medical Register of Births
  - Register of Health Insurance Statistics
    - (consultations, examinations at physiotherapists, psychologists and dentists etc. More than 3000 types of benefits)

Sources

- **Statistics Denmark**
  - **Register of Population Statistics**
  - **The Integrated Database for Labour Marked Research (IDA)**
  - **Employment Classification Module (AKM)**
    - **(employment and income)**
  - **Register of Transfer Benefits**
    - **(social benefits)**
  - **Register of Buildings and Dwelling Statistics**

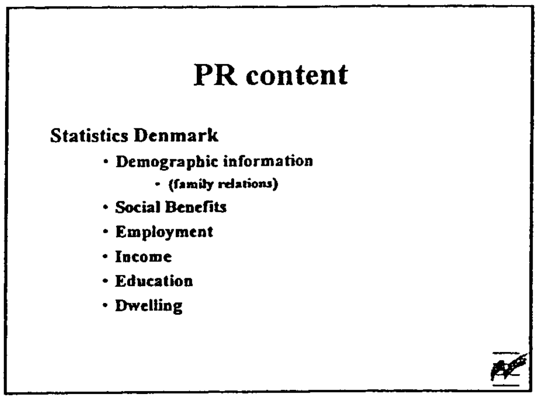
PR content

- **Population**
  - **People resident in Denmark 1977-**
  - **Updated until 1999**
- **Limitations**
  - **Health insurance 1987-**
  - **Social benefits 1984-**

PR content

National Board of Health

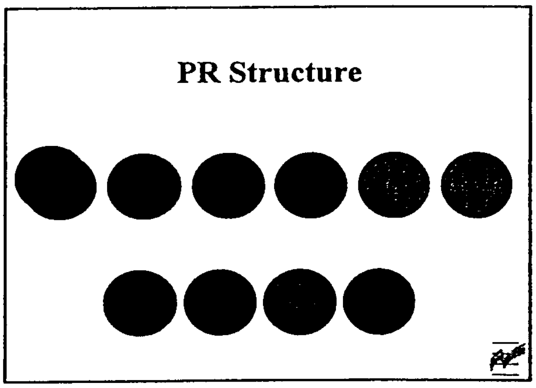
- **Admittances**
- **Discharges**
- **Diagnoses**
- **Operations**
- **Cause of Death (ICD-codes)**
- **Abortions**
- **Births**



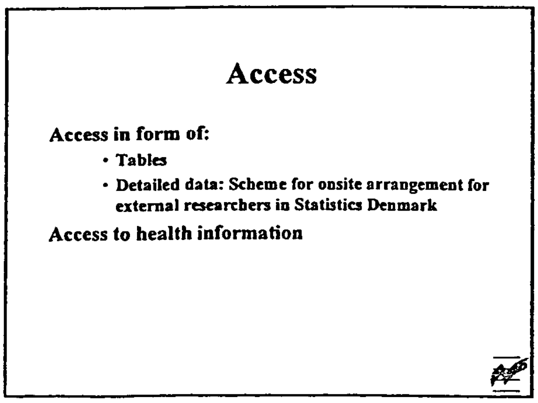
PR content

Statistics Denmark

- **Demographic information**
  - **(family relations)**
- **Social Benefits**
- **Employment**
- **Income**
- **Education**
- **Dwelling**



PR Structure

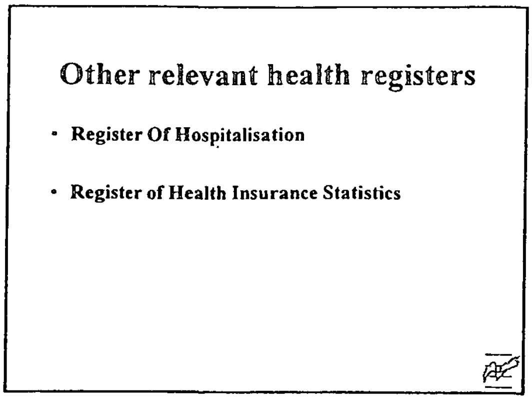


Access

Access in form of:

- **Tables**
- **Detailed data: Scheme for onsite arrangement for external researchers in Statistics Denmark**

Access to health information



Other relevant health registers

- Register Of Hospitalisation
- Register of Health Insurance Statistics

附録六

Access to micro data from Statistics Denmark

This paper describes the development since the early 1980s in the access to micro data from the registers of Statistics Denmark.

Register development

Denmark introduced the Person Number (the Personal Identification Number) in 1968 and it was used in a census for the first time at the Population and Housing Census in 1970. Accordingly, this became the first Danish register that uses the Person Number as an identification key. During the 1970s the first attempts were made to base the production of statistics on registers. In 1976 a register-based population census was conducted as a pilot project, but the registers were not sufficiently comprehensive and well-established until 1981, when a proper register-based population census was conducted containing most of the conventional population and housing census information.

Like in the other Nordic countries, the person and business registers in Denmark today cover a very substantial part of the production of statistics. The contents of the registers also cover many fields of research such as labour market research, sociology, epidemiology and business economics. The strength of the system is that the identification keys (Person Number, address, central business register number and property title number) render it possible to correlate the aggregated data both within a specific year and longitudinally across several years.

Interest in micro data

In the mid-1980s, Statistics Denmark experienced an emerging interest among various research environments and ministerial analysis divisions in applying micro data (individual data) for research and analysis purposes. One reason was that the development in computer technology made it technically possible to process large amounts of data according to advanced statistical models, such as multivariate models.

These environments put pressure on Statistics Denmark to disclose micro data; a request that Statistics Denmark was unable to grant because of the rules of confidentiality laid down by the Management and Board of Statistics Denmark. On the other hand, it was evident already at that time that not only were the registers of enormous importance to Statistics Denmark, but their research potential was so great that it would be very valuable to actually utilise them for research purposes. Therefore, Statistics Denmark had to find a solution to the problem of access, which complied with the existing legislation on registers while taking into account Statistics Denmark's own confidentiality principles.

Legislation

With the introduction of two acts on registers in 1979, Denmark saw the first statutory regulation concerning, *inter alia,* disclosure of micro data to researchers. As at 1 July 2000 these acts were replaced by the Act on Processing of Personal Data (lov om behandling af personoplysninger). The Act implements Directive 95/46/EC on the protection of individuals with regard to the processing of personal data and the free movement of such data within the European Union. The former Act primarily governed registration and disclosure of data in registers, while the new Act applies to all forms of processing of personal data. The new term, "processing", covers all types of processing of personal data, including registration, storing, disclosure, merging, changes, deletion, etc.

Previously, the setting up of a register was subject to the so-called register provisions, involving a rather time-consuming and laborious process. These provisions have been abolished, and now the individual authority makes decisions in concrete cases on processing; for example, the authority decides issues of disclosure of data for scientific purposes based directly on the provisions of the Act on the lawfulness of such disclosure.

The new Act introduced a duty of notification to the Danish Data Protection Agency. The purpose is to enable the Agency to supervise the processing of sensitive information carried out.

Accordingly, a scientific project involving processing of sensitive personal data is subject to notification to and approval by the Danish Data Protection Agency before such processing can commence. This applies to all surveys, whether they are conducted by a public administration, individuals or enterprises. The Agency has laid down special provisions on security in connection with the processing of sensitive data.

All in all, the introduction of the Act on Processing of Personal Data has provided potentially more favourable conditions for register-based research in Denmark. In particular, public authorities' basis for disclosing administrative data for research purposes has been enhanced and simplified in terms of administration, as they no longer need to consult the Danish Data Protection Agency; personal data applied for statistical purposes may be disclosed and reused with the permission of the Agency; data from one private research project may be disclosed to another project; there is full access to filing of data in the State archives; both private individuals and public authorities may process data on Person Numbers for scientific or statistical purposes; furthermore, the Act now explicitly stipulates that the data subject's right of access to personal data shall not apply where data are processed solely for scientific purposes.

In addition to the Act on Processing of Personal Data, the Danish Public Administration Act (forvaltningsloven) is of relevance. Under this Act, a public authority may impose a duty of non-disclosure on persons outside the public administration concerning the data disclosed. Statistics Denmark has applied this provision in connection with researchers' access to micro data under the scheme for the on site arrangement for external researchers at Statistics Denmark (cf. below), although no disclosure in a formal sense is made. Data - even anonymised data - must be treated as confidential. Breach of the duty of non-disclosure is punishable by simple detention or imprisonment.

Confidentiality principles of Statistics Denmark

As it appears from the above, current legislation permits disclosure, to a wide extent, of personal data for scientific purposes. However, the authority in question ultimately decides whether disclosure may take place, meaning that the authority may take other issues into consideration even if the Danish Data Protection Agency has approved the disclosure of data.

That is what Statistics Denmark has decided to do. This decision has been made so that the individual citizen or enterprise can be certain that the data supplied directly or indirectly to Statistics Denmark do not fall into the hands of any unauthorised persons. In the opinion of Statistics Denmark the risk of irreparable damage to the production of statistics outweighs the consideration for more or less convenient access to data by the individual researcher.

Thus, the fundamental principle is that data must not be disclosed where there is an imminent risk that an individual person or individual enterprise can be identified. This does not only apply to identified data, such as Person Numbers, but also to anonymised data, since such data are usually so detailed that identification can be made.

Since Statistics Denmark also considers it important that data can be applied for scientific purposes, special schemes for researchers have been set up.

Scheme for the on site arrangement for external researchers at Statistics Denmark

Since its overriding principle is not to disclose individual data, Statistics Denmark set up a scheme in 1986 for the on site arrangement for external researchers at Statistics Denmark. Under this scheme, researchers can get access to anonymised register data from a workstation at the premises of Statistics Denmark. Statistics Denmark creates the relevant datasets on the basis of the researcher's project description, the general principle being that the dataset should not be more comprehensive than necessary for carrying out the project. The researcher signs an agreement which stipulates that data are confidential and that individual data must not be removed from the premises of Statistics Denmark.

Organisational framework

In terms of organisation, the scheme is administered centrally by a separate division of Statistics Denmark, presently the Division of Research and Methods. The employees of this division also create a substantial part of the interdisciplinary datasets. However, datasets that concern only a single division of Statistics Denmark are usually prepared by the division in question. The scheme requires close cooperation between Research and Methods and the other individual divisions in Statistics Denmark. The advantage of such central organisation is that the individual researcher is fully aware of whom to negotiate with and who is responsible for the dataset supplied.

In 1996, Statistics Denmark opened a small branch in Århus, Jutland to grant researchers west of the Great Belt an opportunity to use the scheme on equal terms with researchers in Copenhagen. The branch is funded by the Danish National Research Foundation (Danmarks Grundforskningsfond). In terms of organisation, the branch is part of Research and Methods.

Research databases

As the researchers almost invariably request datasets that go across the individual registers in terms of both contents and time, the creation of specific datasets for a project often involves considerable work by Statistics Denmark and sometimes considerable costs for the researcher.

To reduce the cost of datasets for research purposes and solve special data problems, Statistics Denmark has set up a number of research databases. These databases are hardly ever used in the actual production of statistics, but are first and foremost a kind of intermediate products for the benefit of the research process.

The most frequently applied research database is the Integrated Database for Labour Market Research (IDA). One reason for creating the database was to solve a difficult problem of definition: Identity of enterprises over time, a task that individual researchers were unable to handle for reasons of both time and funding. Nine to ten man-years were spent on the task, which was funded by the Danish Social Science Research Council (Statens Samfundsvidenskabelige Forskningsråd) and Statistics Denmark. Since the establishment of IDA in 1991, Statistics Denmark has handled the updating of the database against user charges.

Other research databases include the Demographic Database, the Fertility Database, the Prevention Register (health data), the Social Research Register, etc. As the names imply, the databases cover many specialist fields: economy, labour market research, social research, epidemiology, etc.

A number of research institutes have paid for the creation of major research databases for the purpose of their own research.

Considerable growth

From the modest beginnings in 1986, the use of micro data has increased markedly under the scheme for the on site arrangement for researchers at Statistics Denmark. In 1997, 71 researchers used the on site arrangement, while in 2000 the figure had risen to 151.

Model and study datasets

Statistics Denmark has only to a very limited extent departed from the rule not to disclose micro data to researchers. To enable researchers to develop computer programs at their own workplaces, they have been granted an opportunity to borrow micro data, upon request, from very small populations (e.g., 1000 records). Only very few model datasets have been created in recent years.

However, Statistics Denmark has prepared some study datasets, so far based on the IDA database, for study programmes in economics/labour market policy and interdisciplinary data material for sociology studies. These datasets follow a few thousand persons over time according to a number of variables. Where possible, the data are scrambled so that the actual register data have been changed in ascending or descending order by a simple mathematical function. However, the fundamental characteristics of the data have been preserved. In this way, students get an opportunity to try out statistical models on realistic data.

Except for the above, Statistics Denmark has not applied scrambling procedures or special grouping techniques to the data that are made available to the researchers under the on site arrangement. The data appear as in the basic registers.

The technical solution

Until 1996, researchers under the on site arrangement were referred to making batch runs on Statistics Denmark's main frame. This meant that the only software available was SAS. Furthermore, most researchers were used to other platforms, such as UNIX, and therefore unfamiliar with the actual run and editing procedures.

In 1996, the Danish National Research Foundation funded the acquisition of a UNIX system, which has been used exclusively for projects under the on site arrangement. The advantages were obvious: the researchers got access to known technology and the choice of software became more varied. Besides SAS, researchers now have access to SPSS, STATA, GAUSS, etc. Statistics Denmark has repeatedly upgraded the technical solution since 1996, partly by acquiring an additional UNIX system, partly by increasing the disc capacity substantially several times.

The latest development - external electronic access

In the autumn of 2000, the Director General instructed a committee to examine whether to grant the users of Statistics Denmark's researcher schemes access to datasets from their own workplaces. The result of the committee work was a proposal to grant specially authorised research and analysis environments access to making batch runs on approved datasets of Statistics Denmark.

The Board of Governors of Statistics Denmark approved the scheme, which entered into force on 1 March 2001 following the completion of a pilot project.

A research or analysis environment can apply for an authorisation from Statistics Denmark. As at 1 February, 2002, 23 environments had been granted authorisation. The wording of the authorisation appears from the enclosed agreement.

Access is not granted for all datasets; particularly sensitive data (e.g., data on crime) are excluded from the scheme and data on enterprises are assessed carefully to avoid any problems of confidentiality. It is emphasised that the data consist of samples. If the researchers request access to total populations, the content of variables must be limited. The individual cases are assessed by a steering group consisting of the Directors of Statistics Denmark. The scheme will be assessed regularly by the Board of Governors of Statistics Denmark.

The technical solution is based on the use of the Internet. Like before, the data remain on the servers of Statistics Denmark.

Communications via the Internet is encrypted by means of a so-called RSA SecurID card, a component that secures Internet communications against unauthorised access. In practice the researcher rents a password key (a token) from Statistics Denmark. The token ensures that only the authorised person obtains access to the computer system.

The functionality at external access is largely the same as on the PCs under the on site arrangement. Printing and data transfer options are not available.

Printouts are sent to the researchers by e-mail, logged at Statistics Denmark and checked by random sampling by Research and Methods.

The external electronic access by researchers is a valuable step forward for everybody involved. Statistics Denmark remains in control of the data, which are not handed out, and the researchers can work with the majority of the datasets from their own workstations.

Researchers who are not comprised by an authorisation agreement can still use the existing scheme on the on site arrangement for external researchers from Copenhagen or Århus.

Statistics Denmark

AUTHORISATION

Statistics Denmark hereby grants

[Institution] represented by [Chief Researcher]

authorisation for

external electronic access to selected datasets at Statistics Denmark

Access via the Internet is subject to the following terms:

1. A project description must be submitted, which states the project objectives and renders it possible to select the data required for successful project execution.
2. Based on the project and data description, Statistics Denmark decides whether external electronic access to data can be granted for the specified project. If the authorisation is not granted, the researcher is referred to use the ordinary scheme for the on site arrangement for external researchers at Statistics Denmark.
3. The researcher to whom external electronic access is granted shall sign a special agreement with Statistics Denmark.
4. All datasets are confidential, cf. s 27(3) of the Danish Public Administration Act and s 152 of the Danish Criminal Code.
5. The researcher obtains access to make batch runs on Statistics Denmark's special researcher machines (UNIX system) from one or more PCs specially assigned for that purpose in the research/analysis environment. Access is denied for batch runs from remote PCs, PCs at home or PCs which cannot be properly supervised.
6. Only the client software assigned by Statistics Denmark may be applied in connection with the RSA SecurID card provided. A PC connected to Statistics Denmark may not be made available to unauthorised persons, and when the user leaves the PC, the PC must be either shut down or disconnected, i.e., protected from any unauthorised use.
7. The password of the individual researcher is personal and strictly confidential.
8. The researcher may not, directly or indirectly, download the dataset or any datasets derived there from. All transfers of output for printing or further statistical processing (in spreadsheets or similar) must be executed in accordance with the guidelines and methods laid down by Statistics Denmark. Statistics Denmark will create a log file of such authorised transfers. Furthermore, individual records may not be printed, and all output must be aggregated to an extent that eliminates any risk of direct or indirect identification of persons or enterprises. The researcher may not attempt to make such identification.
9. Statistics Denmark shall be entitled at unannounced visits to check that the rules of this agreement are observed.
10. The person signing this agreement on behalf of the research/analysis environment shall ensure that publications by the environment do not

contain any information that may identify individual persons or individual enterprises.

11. The person signing this agreement on behalf of the research/analysis environment undertakes personally to supervise or to appoint a person to supervise that the provisions of this agreement are observed.
12. In case of breach of the provisions of this agreement, the researcher in breach will be excluded from using any researcher schemes of Statistics Denmark permanently or for a period of not less than three years. Furthermore, in the case of breach hereof, this authorisation will be withdrawn for a period.

This agreement, which is signed in two copies, enters into force on [date] and may be terminated by either party at three months' notice.

Copenhagen, [date]

____

Jan Plovsing

Copenhagen, [date]

____

Chief Researcher

[illegible]

Steen Rasmussen, mSc (econ. stat.) :

Health Statistics : Collecting data - distributing information

March 19, 2002

Collecting data - distributing information

Any visit at a hospital causes registration:

- **Outpatients visits**
- **Emergency cases**
- **Non - emergency cases**
- **Trauma centers / casualty wards**

Moving to another hospital or replacement inside the same hospital causes a new registration.

Other kinds of registration:

- **Assistance**
- **Examinations**
- **Tests**
- **Interventions**

Collecting data - distributing information ได้แก่

Documentation → **Patients** Medical / Legal aspects

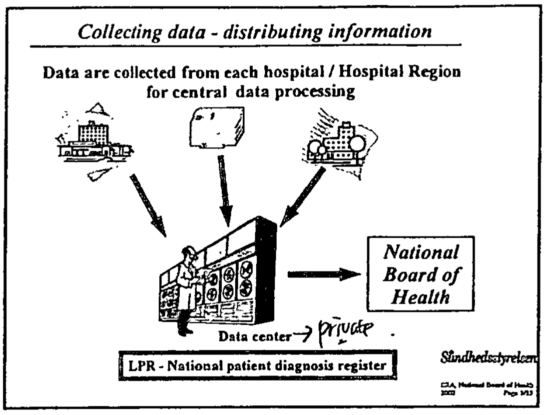
→ **Hospital resources**

→ **Nationwide planning**

Common standards set by the National Board of Health

Mandatory standard information

Additional information for Local needs



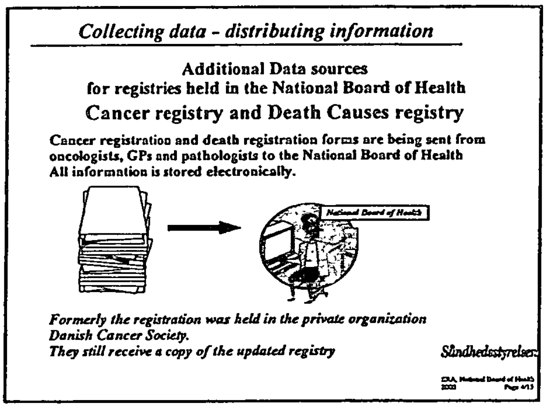
Collecting data - distributing information

Data are collected from each hospital / Hospital Region for central data processing

National Board of Health

Data center→ private .

LPR - National patient diagnosis register



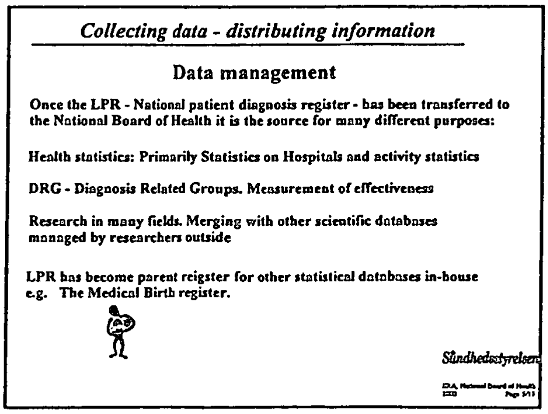
Collecting data - distributing information

Additional Data sources for registries held in the National Board of Health

Cancer registry and Death Causes registry

Cancer registration and death registration forms are being sent from oncologists, GPs and pathologists to the National Board of Health
All information is stored electronically.

Formerly the registration was held in the private organization Danish Cancer Society.
They still receive a copy of the updated registry



Collecting data - distributing information

Data management

Once the LPR - National patient diagnosis register - has been transferred to the National Board of Health it is the source for many different purposes:

Health statistics: Primarily Statistics on Hospitals and activity statistics

DRG - Diagnosis Related Groups. Measurement of effectiveness

Research in many fields. Merging with other scientific databases managed by researchers outside

LPR has become parent reigster for other statistical databases in-house e.g. The Medical Birth register.

Collecting data - distributing information

The Medical Birth Register

Data sources:

- ➨ **LPR** - National patient diagnosis register
- ➨ **CPR** - Centralised Civil Register

Registration forms:

- ➨ **Births at home**
- ➨ **Stillbirths**

Collecting data - distributing information

The Medical Birth Register

The register holds information on:

- ✓ **Liveborn**
- ✓ **Stillborn**
- ✓ **Twins, triplets .....**

.... and in the future:

- ✓ **Abortions**
- ✓ **Connections with the IVF - register**

Collecting data - distributing information

The Medical Birth Register

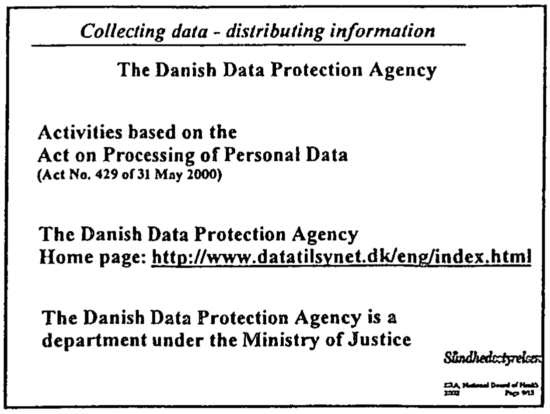
Get data for research projects

In accordance with

The Danish Council of Ethics
and
The Danish Data Protection Agency

Ongoing projects:

- **Implications of Breech Births**
- **Twins**



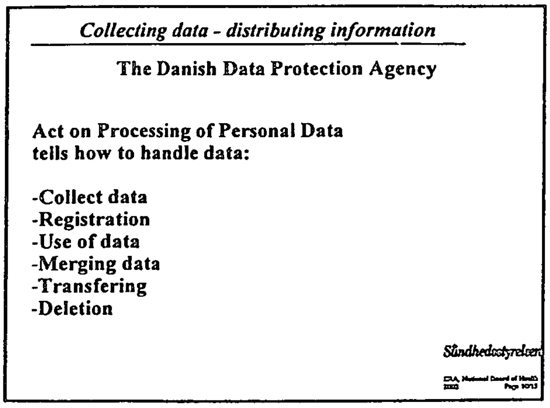
Collecting data - distributing information

The Danish Data Protection Agency

Activities based on the
Act on Processing of Personal Data
(Act No. 429 of 31 May 2000)

The Danish Data Protection Agency
Home page: http://www.datatilsynet.dk/eng/index.html

The Danish Data Protection Agency is a
department under the Ministry of Justice

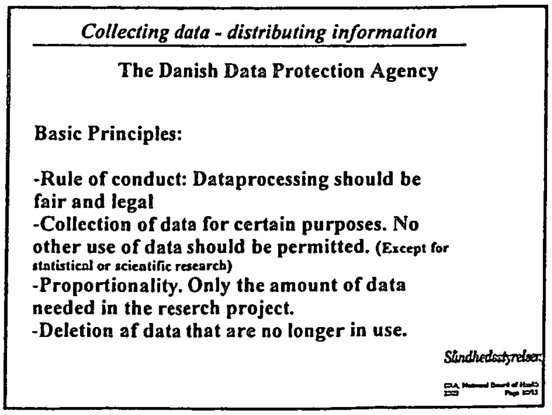


Collecting data - distributing information

The Danish Data Protection Agency

Act on Processing of Personal Data
tells how to handle data:

-Collect data
-Registration
-Use of data
-Merging data
-Transfering
-Deletion

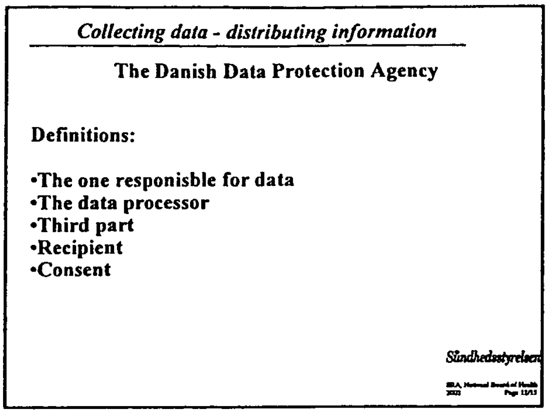


Collecting data - distributing information

The Danish Data Protection Agency

Basic Principles:

-Rule of conduct: Dataprocessing should be fair and legal
-Collection of data for certain purposes. No other use of data should be permitted. (Except for statistical or scientific research)
-Proportionality. Only the amount of data needed in the reserch project.
-Deletion af data that are no longer in use.

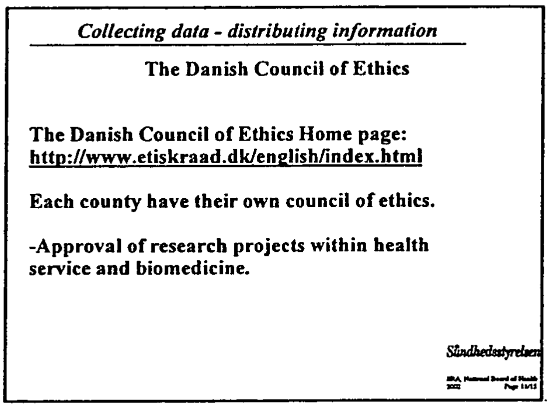


Collecting data - distributing information

The Danish Data Protection Agency

Definitions:

- **The one responisble for data**
- **The data processor**
- **Third part**
- **Recipient**
- **Consent**



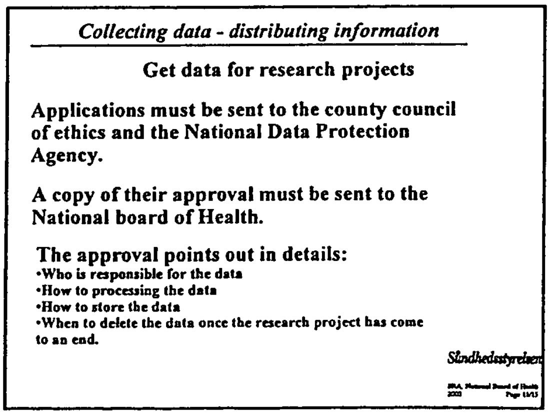
Collecting data - distributing information

The Danish Council of Ethics

The Danish Council of Ethics Home page:
http://www.etiskraad.dk/english/index.html

Each county have their own council of ethics.

-Approval of research projects within health service and biomedicine.



Collecting data - distributing information

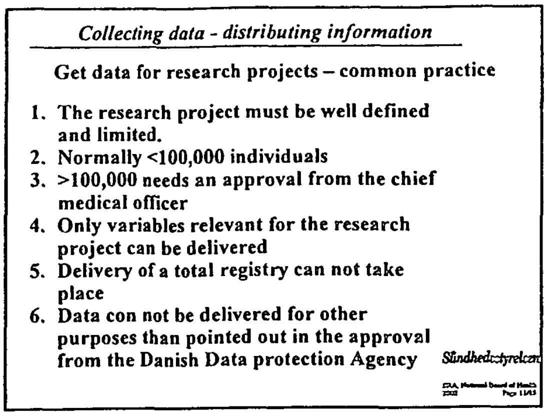
Get data for research projects

Applications must be sent to the county council of ethics and the National Data Protection Agency.

A copy of their approval must be sent to the National board of Health.

The approval points out in details:

- **Who is responsible for the data**
- **How to processing the data**
- **How to store the data**
- **When to delete the data once the research project has come to an end.**



Collecting data - distributing information

Get data for research projects – common practice

1. **The research project must be well defined and limited.**
2. **Normally <100,000 individuals**
3. **>100,000 needs an approval from the chief medical officer**
4. **Only variables relevant for the research project can be delivered**
5. **Delivery of a total registry can not take place**
6. **Data con not be delivered for other purposes than pointed out in the approval from the Danish Data protection Agency**

附錄、几

A A R H U S   U N I V E R S I T E T

**CENTER FOR
REGISTERFORSKNING**

Preben Bo Mortensen
Centerleder, professor

Outline of meeting at the National Center for Register-based research
21.03.2002

Dato: 21. marts 2002

Journalnr:
Direkte tlf: 8942 6820
E-post: pbm@ncrr.au.dk
Web: www.ncrr.au.dk

1. Background report:
What are the current obstacles for and against the utilisation of registers in Denmark?
How have one proposed to solve these problems?

2. The role of NCRR

3. Procedures for access

4. Description of the psychiatric database designed for nested case control studies and the national study population (see separate notes) designed for cohort-studies including data on family-members.

Center for Registerforskning
Det Samfundsvidenskabelige
Fakultet
Aarhus Universitet
Tåsingegade 1
8000 Århus C
Tlf: 8942 6819
Fax: 8942 6813
E-post: ncrr@au.dk

附錄九

Socio-Economic Differentials in Mortality in Denmark during the Period 1970-1995

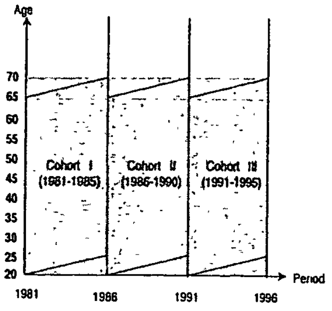
Otto Andersen
Lisbeth Laursen
Jørn Korsbø Petersen
Statistics Denmark

The experience

- Used by Statistics Denmark to analyse the relationship between mortality and social status
  - earlier only sex-age-marital status-region
- Used by epidemiologist to screen for occupations with high/low mortality
  - detailed occupational and control groups
  - specific causes of death
- The public interest has been big

The cohorts

- New cohorts starting with the upstart of the general Danish registerbased statistics
- Three cohorts: 1.1.1981, 1.1.1986,1.1.1991
- Each cohort is followed for 5 years in order to analyse the time trend in occupational mortality
- The cohorts can easily be linked together
- New cohort 1.1.1996 when causes of death are ready

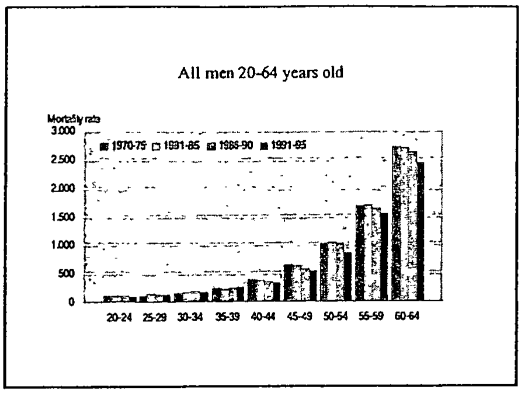


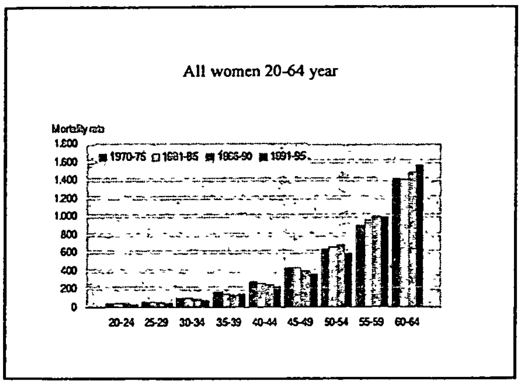
The data

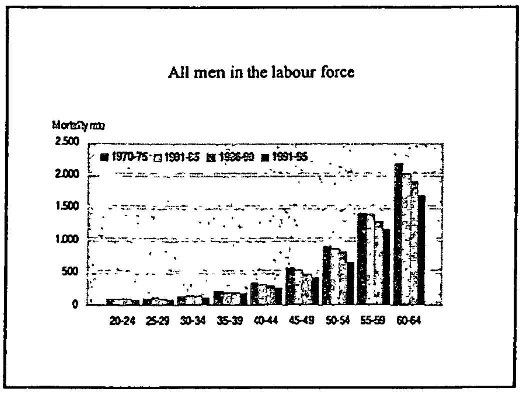
- Date of death and causes of death
  - (ICD 8 and 10)
- Occupation and Industry from registers
- Unemployment
- Family status
- Marital status
- Housing "standard"
- Education

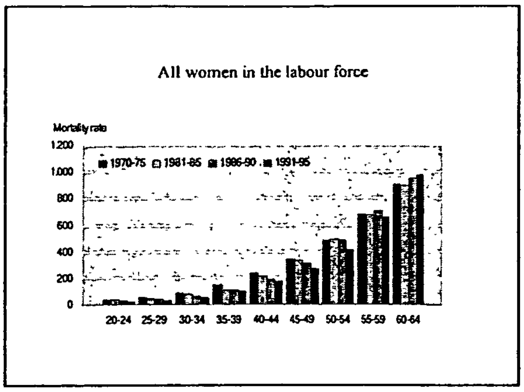
Methods

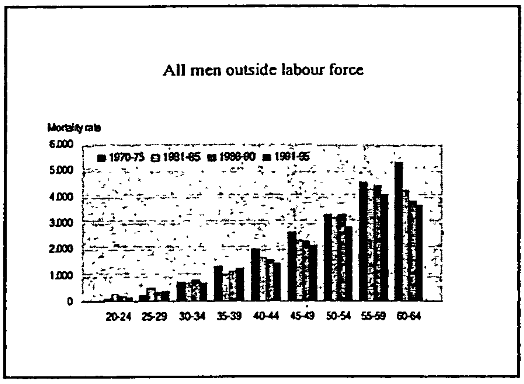
- Age-specific death rates
- SMR
- Average length of life between age 22.5 and 67.5 - a maximum of 45 years

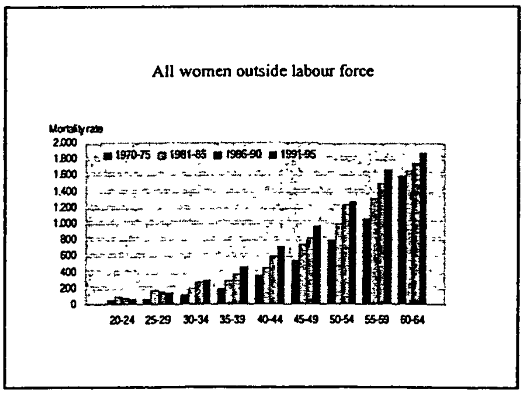

All men 20-64 years old

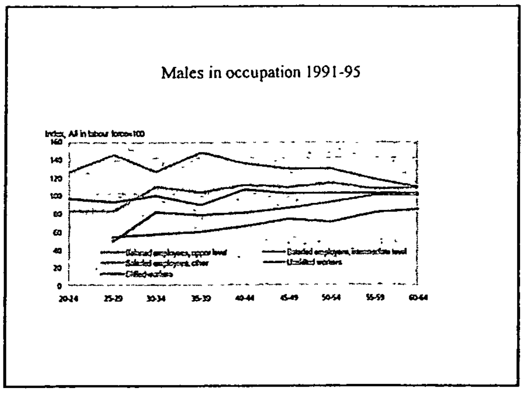

All women 20-64 year

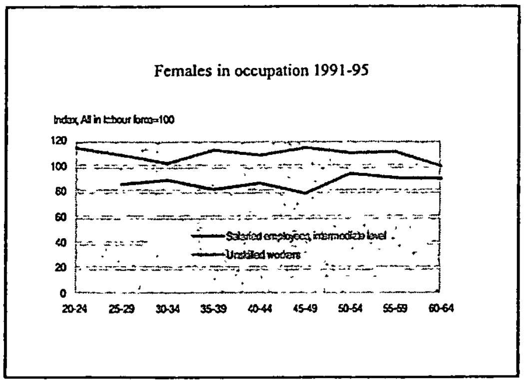

All men in the labour force

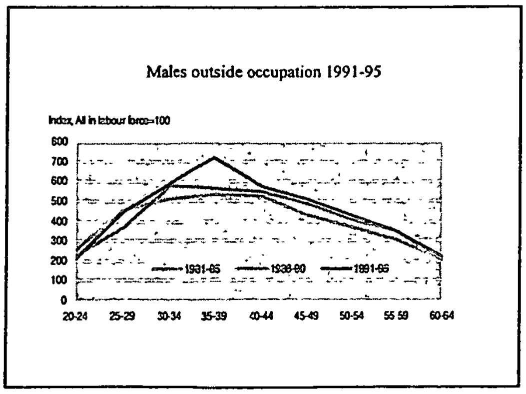

All women in the labour force

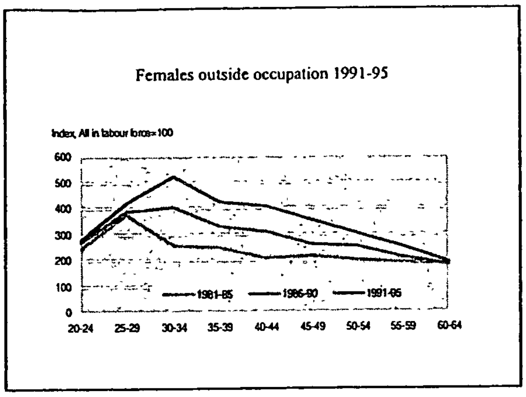

All men outside labour force


All women outside labour force

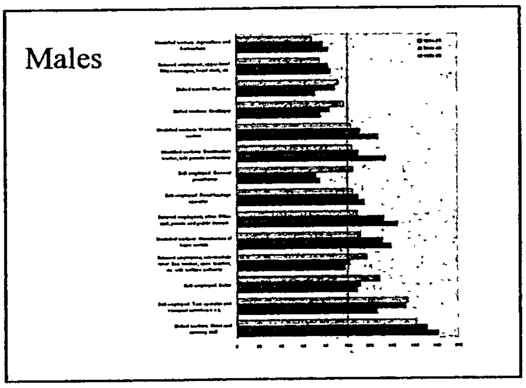

Males in occupation 1991-95


Females in occupation 1991-95

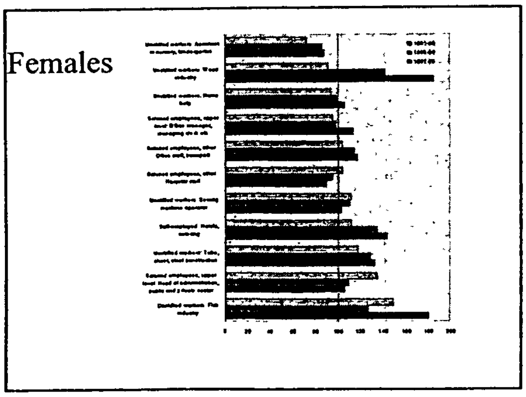

Males outside occupation 1991-95



Females outside occupation 1991-95



Males



Females