

# **DHSSPS & HPSS STATUTORY EQUALITY OBLIGATIONS**

## **INFORMATION REQUIREMENTS: DATA AVAILABILITY, QUALITY AND DEFICITS**

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## INTRODUCTION

In the Department of Health, Social Services and Public safety (DHSSPS) Information and Statistics, and Research, are viewed as policies in their own right rather than support functions to other policies.

This paper presents - in synoptic form - an overview of the information availability, quality and deficits required for DHSSPS and the HPSS to meet its statutory requirements, as known by Information and Analysis Unit (IAU) in the Department.

The document should be seen as a working paper, or an evolving document, which is subject to amendment.

Relevant information can be quantitative and qualitative, and can be derived from various sources - routine administrative systems and databases, population surveys, disease registries, research projects, focus groups, complaints received etc

The areas covered in this paper are:

- the routine HPSS administrative data systems accessed by the Department
- the FPS systems, whose accessibility is being enhanced by the recently established FPS Information and Research Branch of IAU
- population surveys commissioned or supported by the Department
- the NI Cancer Registry
- research projects.

The paper does NOT deal with information - quantitative and qualitative - collected by groups and organisations other than DHSSPS and the HPSS. These include academics, the voluntary and community sector, and groups representative of the nine equality categories.

In terms of fulfilling the statutory Equality duties, gaining access to these other data sources is an issue which must be addressed. The quality of these data must also be considered.

## MAIN POINTS

- A good information base is of critical importance in fulfilling the statutory Equality requirements related to Section 75 of the NI Act – relevant, reliable and up-to-date data to inform
  - screening of policies
  - equality impact assessments (EIAs)
  - monitoring of progress towards equality of opportunity
- Considerable challenges are posed by the need to collect, and make accessible for analysis, data which can be examined with specific reference to the nine equality groups of people. Three challenges relate to:
  - resource implications
  - readiness of public to supply, and willingness of HPSS staff to request information from individuals to identify their membership of each equality group.

The Human Rights Act 1998, came into force on 2 October 2000. Article 8 (1) states that *“Everyone has the right to respect for his private and family life, his home and his correspondence.”* The implications of this article need to be considered in collecting personal information from individuals in order to see which categories they fit into - particularly when it is not directly related to the reason for the contact, eg health care intervention.

Legal advice from the Office of First Minister and Deputy Minister (Communication from Human Rights Unit, OFMDFM, 13 October 2000) confirms that in general under the Human Rights Act, public authorities must not disclose or pry into matters which are confidential to an individual. Consequently, for example personal questions in a compulsory questionnaire may infringe the right to respect for private and family life. Article 8 (1) of the Convention which enshrines this right, however, is subject to a qualification in Article 8 (2) providing for restrictions in accordance with the law and which are necessary in a democratic society. Therefore, even if there is failure to respect the rights contained in Article 8 (1), it can probably be justified under Article 8 (2).

Obviously, it would depend on how Section 75 is applied in practice, but legal advice is that even in the unlikely event that there was held to be interference, it would be easy to advance justification arguments for the measures. The aim of

providing better public services for certain groups and protection against discrimination are likely to satisfy the requirements of Article 8 (2) that the measures are in accordance with the law and are proportionate.

The issue of compatibility of the Section 75 obligation with Article 9 of the Convention relating to freedom of thought, conscience and religion is also pertinent. Legal advice is that any question about religion or the subsequent use of that information would not interfere with the right to have a religion. The right of someone to hold and manifest any or no religious belief is not compromised by being asked to state his or her position.

- The NI Statistics and Research Agency (NI SRA) are taking the lead in trying to develop a consistent approach across Departments for analytical input to EIAs. A number of issues emerged in two seminars held in May and June 2000. The issues relate to
  - cost/burden on data providers of gathering new data
  - quantitative/qualitative methods
  - timing and nature of consultation
  - relationship to existing policy evaluations

An overview of these issues is available separately.

- The Equality Commission has established an Advisory Group to produce Practical Guidance for the conduct of EIAs. NI SRA is represented on this Group. A Draft Guidance document is currently out for consultation.
- OFMDFM Equality Unit Research Branch are intending to commission a programme of research related to the Equality Agenda
- A lot of information is available from HPSS routine administrative/operational systems, but serious deficits exist in relation to information availability and analysis
- Additional work is also necessary in respect of
  - population surveys
  - registration data

- Information sources that require substantial development largely concern output from routine administrative systems in the HPSS. In terms of general information (not necessarily related to the equality groups)
  - acute sector: quantity available is generally good
  - community care sector: limited amount exists
  - primary care sector: there are significant volumes of information, but a lot of it is either untapped or not quality assured
- Information development needs encompass
  - improving demographic data in relation to the equality groups (and NTSN)
  - improving measurement of inputs and processes
  - assessment of outputs and outcomes
  - quantitative and qualitative outcome measures
    - need data at individual patient/client level
    - Unique Patient Client Identifier (UPCI) will help
  - associated costs of care
- Development of substantial information and analytical agenda requires
  - detailed discussions with DLS and HPSS colleagues
  - scoping, feasibility studies and pilot work
- Lead time to develop new information to fill identified gaps can be several years
- If information exists, accessing it could be achieved within months, though considerable time could be required to improve the quality
- NTSN - consideration of ways to improve coverage and quality of routine administrative, and other information sources in relation to Equality requirements could usefully include additional needs in respect of New Targeting Social Need (NTSN). (For example, occupation data is recorded on some systems as free text; some potential exists for using IT programmes to convert many of these text descriptions to a coded classification system. Other work suggests considerable reluctance to asking for occupational data.)
- Need to
  - enhance dissemination and to share good practice within HPSS
  - work collaboratively in relation to statutory Equality obligations

- Following a workshop involving DHSSPS and the HPSS, a high level Equality Information Steering Group (EISG) has been established by the Department. The Chairman is Mr Don Hill, Deputy Secretary in the Department, and membership comprises representatives from the Department, the HSS Boards, Trusts and Agencies. (The inaugural meeting will be held on 27 February.)
- In progressing the Equality Information Agenda for the Department and HPSS the Group will
  - act strategically
  - take account of resource implications
  - develop a programme to collect, in a coherent and consistent way, the information that will be required both in the short term and longer term
  - build on the number of existing Information Liaison Groups between the Department, Boards and Trusts and be supported by them

## **INFORMATION DEFICITS IN HPSS ROUTINE ADMINISTRATIVE SYSTEMS IN RELATION TO THE NINE EQUALITY GROUPS (See Annex 1)**

### **General Points**

- Trusts can record on their systems a considerable amount of relevant data
  - What is the quality of this data? What are the gaps?
    - some of the relevant data items may not be recorded, even where systems would allow Trusts to do so
    - coverage is generally good with regard to
      - age
      - gender
    - coverage may be patchy, particularly with regard to
      - marital status
      - religion (ie religious denomination or community affiliation not 'religious belief' as in the legislation)
      - racial group

- disability
- coverage is virtually/non existent in relation to
  - persons with/without dependants
  - political opinion
  - sexual orientation
- Considerable reluctance has existed amongst many staff to ask clients/patients for information on their community affiliation or their racial group
- Different classifications/scales used on individual systems need to be aligned
- Consideration of how systems can be changed to record additional data is necessary

### **Comparisons with Census Data**

If postcode is held on a system then the data can be aggregated to ward level and comparisons made with demographic information from the 1991 Census on:

- age
- gender
- marital status
- religion
- long term illness

### **Specific Systems**

#### **Hospital Inpatients System (HIS)**

Trusts collect, and submit to Regional Information Branch (RIB) in the Department, data on

- age
- gender
- marital status

The Patient Administration System (PAS) also has facility for Trusts to record additional information on

- religion – concerns have been raised in the past about data quality

It is not known whether two categories are being recorded

- racial group
- disability

### **Mental Health Inpatients System (MHIS)**

Trusts collect, and submit to Department, data on

- age
- gender
- marital status
- religion
- disability

For both HIS and MHIS, postcode information is held by the Department. This could serve as a proxy measure at electoral ward/enumeration district level to input individuals'

- religion;
- political opinion; and
- race (this will not be applicable for all categories but could be used for Irish Travellers halting sites, for example).

Trusts may need to improve postcode recording (eg using Quick Address software).

### **Outpatients**

Trusts can record

- age
- gender
- racial group
- disability
- postcode

How complete is coverage? What is data quality?

### **NIRAES (A&E System used by several Trusts)**

NI RAES can hold data on

- age
- gender

- marital status
- postcode

How complete is coverage? What is data quality?

### **Community/PSS/Children Returns**

To record information on clients Trusts employ a number of different systems – IT and clerical – including SOS CARE and LCID. Information held on the various systems needs to be assessed in terms of both content and quality.

Aggregate information, included on the Children Order returns provided to the Department, includes data on

- age
- gender
- religion – but most cases are recorded as refused/not known
- racial group - but most cases are recorded as refused/not known
- disability.

The Department cannot analyse the data it holds by

- age
- gender etc

### **Child Health System (CHS)**

The Child Health System is owned by HSS Boards but maintained locally by HSS Trusts. Data is not collected centrally at present but a CHS Information Group has been set up to develop a regional Child Health database. The dataset will include the following fields:

- age
- gender
- marital status of parents
- disability
- electoral ward

## **Human Resource Management System (HRMS)**

This system holds records on all staff in the HPSS in NI. Formerly known as the Personnel Information Management System (PIMS) when the source was the Personnel System. PIMS is now linked with the Payroll System and has been named HRMS. It was hoped that the link with the Payroll System would make the System more accurate and up-to-date.

A snapshot of the staff employed at the end of each quarter is submitted to IAU. It contains an individual record for each member of staff employed at that time (approximately 50,000 records per quarter). It is possible to identify each employee's grade and post, employment status (permanent/temporary/full time/part time), pay scale and their employing Trust.

Data is available in the Department on:

- age
- gender
- marital status

Investigative work to establish the feasibility of obtaining additional fields is due to be undertaken before the end of March 2001. These fields include:

- disability
- number of dependants (children, adults)
- postcode

This information is summarised in tabular form in Annex 1.

## **Equality Opportunities Management System (EOMS)**

HRMS also has a subsidiary system, the Equal Opportunities Management System (EOMS). This system is derived from, is dependent on HRMS for much of its information, and contains the 'sensitive data' required to be held on all employees. Some information is held exclusively on EOMS and cannot be accessed by HRMS operators. Data available on each system is as follows.

HRMS

age  
gender  
marital Status  
persons with a disability  
dependants  
postcode

EOMS

age  
gender  
marital Status  
religion  
ethnic origin & nationality

This information is gathered via the employee's application form and is verified by the employee through a computer transcript taken from the information held on the EOMS system.

On an annual basis Trusts complete an annual monitoring return for the Equality Commission giving information about the religion and gender breakdown of their workforce and the composition of applicants for posts. In addition, they complete a three yearly review of policies and practice covering recruitment and selection, promotion and training opportunities, and submit a report to the Equality Commission. The system holds information on the Standard Occupational Classification (SOC) and management level of each grade. This is primarily to assist with monitoring requirements and internal monitoring reports.

This data is not collected centrally. In the past when required, Human Resources Directorate have contacted each Trust and requested an aggregate return of data.

This information is summarised in tabular form in Annex 1.

## **INFORMATION ON FAMILY PRACTITIONER SERVICES (FPS) ROUTINE ADMINISTRATIVE SYSTEMS IN RELATION TO THE NINE EQUALITY GROUPS (See Annex 1)**

### **General Points**

- Information is primarily garnered by the Central Services Agency (CSA) from FPS practitioners and patients
- There are around 30 million "item of service claims" – therefore it is a rich data source
- This information accounts for over 20% of the DHSS&PS expenditure
- Not all FPS activity is collected centrally (e.g. GP consultations). However, the activity that is collected is primarily for payment purposes. Therefore coverage is excellent but individual data items may not be complete.

### **Specific Systems**

#### **Central Health Index (CHI)**

This is a complete population register collected from GPs and patients directly. There are approximately 1,800,000 live registrations on the CHI system. In addition, there are 700,000 non-active/dead records stored along with the associated transaction details. CHI could be viewed as a prototype UPCI.

The information stored on the nine categories includes directly:

- age (date of birth)
- gender (male, female)
- marital status (females only - married, not stated)

The CHI also holds postcode<sup>1</sup> information.

- disability - in the last five years, CHI also holds medical exemption information on individuals. This information is used to create free primary care services certificates. This incomplete information can be used to indicate whether

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<sup>1</sup> There may be some difficulty when patients move house but do not tell GP or the GP fails to inform CSA. However, address information is keyed on to the CHI through Address Management System, therefore quality is improving.

somebody has a permanent disability. This information may be useful, but as somebody who is on income support does not require an exemption certificate to obtain free primary care services it lacks completeness.

In addition there are c80,000 more people registered on CHI than in Registrar General's population counts. This difference is caused by numerous factors, some of which interact with the nine equality groupings.

### **Dental Payment System**

This is the payment system for all dental claims (except hospital, community and private work). There are approximately 3,000,000 claims annually. This covers the vast majority of all dental work in Northern Ireland. Claims are collected directly from dentists. The CHI number is used in each claim form – so CHI equality information could be read across to dental claims. (Thus CHI comments hold here.)

In addition dental claims also gather specific information on

- disability – through disabled persons tax credit (incomplete) and children with special needs (incomplete).

### **Ophthalmic Payment System**

This is the payment system for all ophthalmic claims (except hospital and private work). There are approximately 400,000 claims annually. This covers around 50% of all ophthalmic work in Northern Ireland. Claims are collected directly from opticians/ophthalmic medical practitioners. Individual patient data is collected but **not** the CHI number. Work is being done to incorporate CHI number on the claim form and this is likely to be completed by the end of the year.

In addition ophthalmic claims also gather specific information on

- disability – glaucoma claims only.

### **Pharmaceutical Payment System**

This is the payment system for all pharmaceutical claims (except hospital and private work). There are 22,000,000 pharmaceutical items dispensed annually. This covers the vast majority of all pharmaceutical work in Northern Ireland. Claims are collected directly from pharmacists/dispensing doctors. Individual specific patient data is not collected, however the EPES project will change this. EPES is likely to start implementation by January 2002. A rich vein of data will then be available.

## **Medical Item of Service Claims**

This is payment system that deals with claims for item of services by GPs. There are approximately 1,000,000 claims annually. This covers a significant proportion of primary care work. Claims are collected from general practitioners. Individual specific patient data is collected on some claims, and on a subset of these CHI number is captured. (Thus CHI comments apply to those forms.)

## **FPS Practitioners**

Information is held on FPS practitioners in the HPSS. This information will cover some of the equality areas (eg age and gender) The wealth and quality of this information is being examined.

The information for CHI and DPS is summarised in tabular form in Annex 1.

## **INFORMATION DEFICITS IN POPULATION SURVEYS, CANCER REGISTRATION DATA, THE DRUG MISUSE DATABASE AND RESEARCH PROJECTS (See Annex 2)**

### **Population Surveys**

Information is asked routinely on

- age
- gender
- marital status
- religious denomination
  
- Proxy information on dependants is available through analysis of number and age of persons in the household and/or relationship to the head of household
  
- Disability - limited information is available
  
- No information is currently available on sexual orientation, ethnic origin or political opinion (though this might be 'proxied' by religion)

### **Cancer Registration Data**

Information is available only on

- age
- sex

### **Drug Misuse Database**

- Data collection started in April 2000; coverage and quality are not yet known
  
- Information is collected on
  - age
  - gender
  - religious denomination
  - ethnic origin - White, Chinese, Traveller, Indian, Pakistani, Other (specify)

### **Research**

- Will be dependent on individual projects.

This information is summarised in tabular form in Annex 2.

## Equality: Screening, Impact Assessments and Monitoring

The table below shows the systems from which DHSSPS currently retrieves data from the Trusts, or is held by the CSA, as appropriate, and the availability and quality of data for each system and for postcode.

| SYSTEMS              | Age | Gender | Marital Status | Religion | Racial Group | Disability | Dependants | Political Opinion | Sexual Orientation | Post Cod |
|----------------------|-----|--------|----------------|----------|--------------|------------|------------|-------------------|--------------------|----------|
| HIS (I)              | E   | E      | E              | NK       | NK           | NK         | N          | N                 | N                  | E        |
| MHIS (I)             | E   | E      | G              | G        | N            | G          | N          | N                 | N                  | G        |
| NIRAES* (I)          | NK  | NK     | NK             | N        | N            | N          | N          | N                 | N                  | NK       |
| COMMUNITY RETURNS(A) | E** | E      | N              | P        | P            | G          | N          | N                 | N                  | N        |
| CHS (Q)              | E   | E      | G (parents)    | N        | N            | NK         | NA         | N                 | N                  | P        |
| HRMS (I)             | G   | E      | NK             | N        | N            | NK         | NK         | N                 | N                  | NK       |
| EOMS(I)              | E   | E      | G              | G        | G            | G          | N          | N                 | N                  | G        |
| CHI (C)              | E   | E      | P              | N        | N            | P          | N          | N                 | N                  | E        |
| DPS (C)              | E   | E      | P              | N        | N            | P          | N          | N                 | N                  | E        |

### NOTES

(I) Individual level data

(A) Aggregate returns

(Q) The Department queries the database via the Board Database managers

(C) The system contains individual records and is maintained by the Central Services Agency.

E Quality of data is excellent

G Quality of data is generally good although there may be some gaps

P Quality of data is poor

\* The NIRAES system is used in A&E departments in some Trusts; RIB do not have direct access to this database.

\*\* This information is completed in age groups rather than for each individual

NA Not Applicable

N Field not available in at least some Trust sites/CSA, as appropriate

NK Field is recorded by Trusts but data quality is unknown

**SYSTEMS**

|                   |  |
|-------------------|--|
| HIS               | Hospital Inpatients System   |
| MHIS              | Mental Health Inpatients System  |
| NI RAES           | NI Regional A&E System   |
| COMMUNITY RETURNS | include Korner Community, Korner PSS<br>and Children Order/Children in Need<br>Returns |
| CHS               | Child Health System  |
| HRMS              | Human Resource Management System   |
| EOMS              | Equal Opportunities Management System  |
| CHI               | Central Health Index   |
| DPS               | Dental Payment Information System  |

**Availability of Equality Group information from population surveys, cancer registrations and the Drug Misuse Database - September 2000**

| <b>SURVEYS/DATABASES<sup>1</sup></b>  | <b>Age</b> | <b>Gender</b> | <b>Marital Status</b> | <b>Religion</b> | <b>Racial Group</b> | <b>Disability</b> | <b>Dependants<sup>3</sup></b> | <b>Political Opinion</b> | <b>Sexual Orientation</b> | <b>Geographic Identifier</b> |
|---|------------|---------------|-----------------------|-----------------|---------------------|-------------------|-------------------------------|--------------------------|---------------------------|------------------------------|
| <b>Continuous Household Survey</b>  | Y          | Y             | Y                     | Y               |                     | Y <sup>2</sup>    | Y                             |                          |                           | DC/Ward                      |
| <b>Family Expenditure Survey</b>  | Y          | Y             | Y                     | Y               |                     |                   | Y                             |                          |                           | DC/Ward                      |
| National Food Survey  | Y          | Y             | Y                     | Y               |                     |                   | Y                             |                          |                           | DC                           |
| Infant Feeding Survey   | Y          |               | Y                     | Y               |                     |                   | Y                             |                          |                           | Board or DC                  |
| <b>NI Survey of Health &amp; Social Wellbeing (NISHSW) 1<sup>st</sup> Sweep</b> | Y          | Y             | Y                     | Y               |                     | Y                 | Y                             |                          |                           | Postcode                     |
| NISHSW 2 <sup>nd</sup> Sweep  | Y          | Y             | Y                     | Y               | Not included        | Not included      | Y                             | Not included             | Not included              | Postcode                     |
| NI Omnibus Survey   | Y          | Y             | Y                     | Y               |                     |                   |                               |                          |                           | DC/Ward                      |
| <b>Young People's Behaviour &amp; Attitude Survey</b>                           | Y          | Y             | Not Applicable        | School as proxy |                     |                   | Not applicable                |                          |                           | School                       |
| <b>NI Cancer Registry</b>   | Y          | Y             |                       |                 |                     |                   |                               |                          |                           | Postcode                     |
| <b>NI Drug Misuse Database</b>  | Y          | Y             |                       | Y               | Y                   |                   | Y                             |                          |                           | Partial Postcode             |

<sup>1</sup> Brief descriptions are provided overleaf

<sup>2</sup> Longstanding illness or disability

<sup>3</sup> Information on number of persons in the household and/or relationship to head of household

Y = Yes      DC = District Council

**Continuous Household Survey (CHS)** – general survey collecting a wide range of information on households and individuals. The CHS has been carried out annually in Northern Ireland since 1983. Each year the survey has included questions on longstanding illness, self reported health, consultations with GP etc. Other health questions and questions on the elderly, carers, child care, smoking and drinking have been included either at regular intervals or on an ad-hoc basis.

**Family Expenditure Survey (FES)** – carried out annually in Northern Ireland since 1967. It provides reliable data on expenditure and income in relation to household characteristics. Each co-operating household is asked to provide information about the household, about incomes and about regular payments. In addition, each member of the household aged 16 and over is asked to maintain a detailed expenditure diary for 14 consecutive days, recording details of all expenditure in that period.

**National Food Survey (NFS)** – carried out annually in Northern Ireland since 1996. The survey collects information on domestic food consumption and expenditure by private households. By obtaining information simultaneously about the cost of food purchased the survey enables comparisons to be made of dietary and food expenditure patterns and the average prices paid for foods. Each participating household keeps a diary recording details of all items of food, soft drinks, alcoholic drinks and confectionery brought into the home for human consumption.

From 1 April 2001 the FES and NFS are to combine to become the EFS (the Expenditure and Food Survey). This will continue to meet the needs of users, offer improvements in data scope and quality and cost less.

**Infant Feeding Survey (IFS)** - The Department of Health (DH) has, since 1975 collected information about the feeding of infants from birth to nine months old in a series of quinquennial surveys. The first survey in 1975 was restricted to England and Wales, the second and third surveys (1980, 1985) included Scotland while the fourth and fifth surveys (1990, 1995) included Northern Ireland. The sixth survey in the series (IFS 2000) began in NI in the Autumn.

**Northern Ireland Survey of Health and Social Wellbeing (NISHSW)** – the first survey in this series was conducted in 1997 and the second will be carried out in Spring 2001. The first survey was comprised of two parts; the first part was an interview and the second was a physical appraisal by a nurse. The main areas covered by the interview section included a self assessment of general health, symptoms of specific health conditions, measures of health risk such as smoking and drinking, measures of social wellbeing such as stress related life events, perceived social support, problems of family life and parenting, use of health and social services. Not all of these areas will be covered in the second sweep of the survey, nor will it include the physical measures.

**Northern Ireland Omnibus Survey** – this is a household based survey which is run several times each year and provides rapid results. As well as collecting core information (age, sex etc) it also aims to be flexible to allow information to be collected for specific purposes. Recent health related modules have been on pharmacy usage, care in the sun and drug misuse.

**Young Peoples' Behaviour and Attitudes Survey** – this survey was run in Autumn 2000 in a sample of secondary schools throughout Northern Ireland. It collected a range of information from school children in 1<sup>st</sup>-5<sup>th</sup> form on attitudes to school, police, the environment, etc as well as health related information eg on smoking, drinking, illicit drug use and knowledge about drugs.

**Northern Ireland Cancer Registry (NICR)** – the NICR was set up in 1994 to provide information on cancers occurring in Northern Ireland. At present the Registry has information on the numbers of cancer deaths occurring in Northern Ireland in some cases as far back as 1911. It also has information collected by the old registry from 1959-1992; this information is limited and known to be incomplete.

**Drug Misuse Database (DMD)** – the DMD holds information about problem drug users presenting at an agency for treatment for the first time or those who have not attended within the previous six months. The provision of this information is a voluntary exercise requiring client consent. Data collection commenced on 1 April 2000 and at present six statutory and four voluntary agencies are contributing to the database.