

# DEMOGRAPHIC AND SOCIO-ECONOMIC DATA STANDARDS FOR HEALTH INFORMATION SYSTEMS

## *The National Cardiovascular Information System (NCIS) as a Case Study*

### Briefing Paper

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**Central Statistics Office**  
An Phríomh-Oifig Staidrimh



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# 1. INTRODUCTION

Demographic and socio-economic data standards for health information systems are needed in Ireland in order to measure and promote equity of access to acute medical care and appropriate follow-up care in the community.

The National Anti-Poverty Strategy (NAPS) and the National Cardiovascular Information Systems (NCIS) Working Group plans to test some of the proposed standards for demographic and socio-economic data in specific modules of the National Cardiovascular Information System currently being developed. These data standards should also be meaningful in other settings where similar types of data are collected, such as national health surveys. If the pilot study is successful the next step will be to consider their possible use in other health information systems, particularly in patient care settings.

The NAPS NCIS Working Group hopes that by doing this work, it will

- Provide the basis to assess the NAPS target in relation to cardiac disease by using the National Cardiovascular Information System, and be applicable to other health information systems in relation to other NAPS targets;
- Stimulate a more comprehensive research programme into demographic and socio-economic issues in the health services and its health information systems.

The purpose of this Workshop on 'Demographic and Socio-Economic Data Standards for Health Information Systems' is to present, discuss and reach agreement on the proposed data standards before the pilot study in the National Cardiovascular Information System.

The purpose of this briefing paper is to:

- explain the context in which the project has developed;
- provide background information on the National Cardiovascular Information System;
- present the proposed data standards to be discussed in the workshop; and
- introduce the workshop.

## 2. BACKGROUND TO THE PROJECT

The importance of demographic and socio-economic factors as determinants of health status is well known. Generally those persons in poorer socio-economic groups have poorer health, live in less favourable circumstances and are more likely to have unhealthy lifestyles. They have less favourable access to resources that improve health including housing, education and the means to healthy eating and physical activity. They also have unequal access to health services for health promotion and disease prevention, treatment and rehabilitation. Those who are less well off may use some of the available services less than those persons in the upper socio-economic groups. All of these factors are reflected in the differences in mortality and morbidity between socio-economic groups, with a substantial, worsening gradient from those who are better off to the less well off<sup>1</sup>.

In tackling many of the issues raised above, it is of prime importance to record advantage / disadvantage in health information systems and to measure the factors that may be related to unequal access to and / or unequal use of health services. In recent times the number of persons within certain groups has increased. There has been growth in immigration into Ireland and migrants come from a greater number of countries. Some of these immigrants are refugees whilst others are economic migrants. There is thus more diversity in ethnic origin and in religions being practised in Ireland. The health services must address the needs of immigrants, have the means to estimate the impact on services and ensure that services are adequate. It is thus important to define all the groups in Irish society that may for one reason or another have inadequate access to or inappropriately low use of services.

While the importance of defining disadvantaged groups and the factors that may be related are recognised, demographic and socio-economic data are not routinely recorded in health information systems in Ireland. These data must be standardised not only across health information systems in hospitals and in the community but also must be compatible with information collected and used to provide the demographic and socio-economic profile of our population, e.g. data collected by the Central Statistics Office.

The availability of suitable data standards is only one aspect of recording such data. There are many other challenges and barriers in relation to data collection, such as,

- The low level of awareness of the importance of collecting these data.
- Competing priorities in health care settings, particularly acute situations where patient care has priority.
- The development of data collection methods that will be feasible in acute care settings
- The development of appropriate questions for sensitive areas of personal life
- The difficulties in correctly coding socio-economic status based on occupation

- The level of questioning required to fully determine accurate answers, especially in relation to marital status, economic status and social group.

The issues above are only some that need to be taken into account when developing and proposing data standards so that meaningful and accurate information is recorded.

Two strategies at present being implemented are the National Anti-Poverty Strategy (NAPS), which has targets for reducing health inequalities (by, amongst other things, improving the health of the disadvantaged), and the National Cardiovascular Strategy, which has as one of its targets to develop a National Cardiovascular Information System (NCIS). Both strategies recognised the importance of the establishment of good information systems in relation to their targets.

NCIS now has a number of standardised data sets that assess the care of patients with ischaemic heart disease in a number of areas of cardiology, viz., acute coronary syndromes (ACS), percutaneous coronary intervention (PCI), electrophysiology (EP) (insertion of pacemakers or implantable cardioverter defibrillators and ablation procedures), cardiac surgery, cardiac rehabilitation and secondary prevention in general practice. The inclusion of suitable demographic and socio-economic variables in these data sets will be very beneficial to the study of provision of health services overall, but in particular to the assessment of the NAPS target that relates to circulatory diseases.

## **2.1 National Anti-Poverty Strategy (NAPS)**

The National Anti-Poverty Strategy, which was launched in 1997, aims to reduce poverty and inequality in Irish society. The Government's review of the strategy published in 2002, *Building an Inclusive Society*<sup>2</sup>, specified a number of targets related to health (see Appendix 1) including a key health status target:

- To reduce the gap in premature mortality between the highest and lowest socio-economic groups by at least ten percent from circulatory diseases, cancers, injuries and poisonings by 2007.

The review also recognised that effective monitoring and evaluation systems are a key element of the strategy. However, the inadequacy of existing data for monitoring health inequalities and their determinants has been acknowledged in the *Annual Report of the Chief Medical Officer 2001*<sup>3</sup> and also in the *National Health Strategy*<sup>4</sup>.

It is against this background that the current initiative to seek to develop a consensus on feasible socio-economic variables for use in clinical settings is being undertaken.

## **2.2 The Cardiovascular Health Strategy and the National Cardiovascular Information System (NCIS)**

In order to achieve health and social gain in relation to cardiovascular diseases and to reduce inequalities, a comprehensive strategy was developed which was accepted and endorsed by the Government in 1999<sup>5</sup>. The Cardiovascular Health Strategy is closely related to the achievement of one aspect of the key NAPS health targets<sup>5,6</sup>.

The Cardiovascular Health Strategy has a well-elaborated implementation plan and addresses a health issue where considerable socio-economic differences are evident. The NCIS Steering Committee was appointed to oversee the development of an integrated national cardiovascular health information system. Data standards for priority modules of NCIS were agreed during Ireland's EU Presidency<sup>7</sup>. However, there was no agreement at European level on how to record demographic and socio-economic details and it was considered that these should be agreed at national level.

NCIS is therefore an ideal context in which to test demographic and socio-economic data standards which would be useful and feasible to collect in a variety of clinical settings.

The following sections describe how the NAPS NCIS Working Group was established to meet the needs of NAPS and of NCIS, the methodology used to develop the proposed draft data standards and highlight data collection issues for demographic and socio-economic variables.

## **2.3 The NAPS NCIS Working Group**

### Introduction

The NAPS NCIS Working Group was established in Autumn 2004. It comprised members of the Department of Health and Children (DoHC), the National Cardiovascular Information System (NCIS) team, the Institute of Public Health (IPH) and the Central Statistics Office (CSO) (see Appendix 4 for the membership).

The NCIS personnel are familiar with the current cardiovascular data. The DoHC has responsibility for achieving the NAPS health targets, the targets set out in the Cardiovascular Health Strategy and also for the implementation of NCIS. The IPH has prioritised the issue of health inequalities and has a role in undertaking research in the area of the NAPS targets for health. The CSO has responsibility for setting data standards at a national level and has expertise in data collection. The Economic and Social Research Institute (ESRI), which has expertise in population surveys as well as in issues relating to social class and social inequalities, was also consulted during the development of data standards.

The NAPS NCIS Working Group agreed that it would undertake a joint project to achieve consensus and to pilot the most appropriate and meaningful demographic and socio-economic data to collect on patients with cardiovascular disease. This will provide a template for use in other health information systems, including those of

particular relevance to NAPS, providing uniformity and comparability across all areas of the health services.

### Some guiding principles

A number of key requirements guided the Working Group:

- A number of different factors distinguish the lowest, highest and other socio-economic groups. Therefore, a number of different demographic and socio-economic variables need to be considered.
- The proposed demographic and socio-economic variables should be in line with national and international standards.
- The importance of presenting any proposals to experts within the health sector who have experience of data collection and an interest in the monitoring of health outcomes and health inequalities.
- That these data standards may be successfully used not only within NCIS, but also within other health information systems and that involvement of relevant experts and stakeholders is essential.

Three cardiovascular information systems were identified in which to pilot the proposed data standards. These are Coronary Heart Attack Ireland Register (CHAIR), the Cardiac Rehabilitation Information System (CRIS) and HEARTWATCH. These systems are computer-based, data in each being entered by professional personnel, viz. nurses, doctors, and cardiac rehabilitation coordinators.

### Methodology

The Working Group met on a number of occasions to discuss the data standards (variables, coding and definitions) and associated data collection issues for health information systems in order to monitor the NAPS and Cardiovascular Strategy targets and, in particular, to monitor health inequalities.

The Working Group reviewed data standards currently being used in health information systems and by the CSO in their surveys. Current European proposals were also reviewed. The CSO's Classification Section advised on the national data standards for certain variables. (See Appendix 2 for the list of information systems referenced).

A number of demographic and socio-economic variables are already being collected in the three NCIS modules. The full list is shown in Appendix 3. It became apparent that similar items were being collected differently, highlighting the importance of agreed data standards. Personnel were interviewed to discuss past experiences, identify concerns and explore possible solutions. These interviews covered both the data standards and the procedures for collecting the patient information.

### 3. NATIONAL CARDIOVASCULAR INFORMATION SYSTEM

Personnel working with the three NCIS data collections already have experience in collecting socio-demographic data. Directors of these information systems were asked to provide information on their systems, to identify the current or potential use of demographic and socio-economic data and the difficulties experienced in collecting the data.

#### 3.1 Coronary Heart Attack Ireland Register (CHAIR)

*Mr Brendan Cavanagh, Project Manager, CHAIR*

##### Overview of the System

CHAIR is a register that gathers information on hospital patients admitted with suspected or confirmed acute coronary syndromes (ACS) in order to improve the delivery of health care and to improve patient outcomes on discharge from hospital. ACS includes heart attack (myocardial infarction) and unstable angina.

The objectives of CHAIR are:

- To record, describe and analyse patient demographics, diagnostic and treatment details, and hospital outcomes;
- To facilitate the development of strategies to improve the quality of ACS patient care; and
- To contribute towards the development of a national plan for the pre-hospital and in-patient management of patients with ACS.

The CHAIR registry operates in the eight hospitals (voluntary and private) with acute coronary care facilities in Cork and Kerry.

The CHAIR pilot began in October 2002 at the Bon Secours Hospital, Tralee Co. Kerry. It was subsequently implemented in the other seven hospitals in the area and is due to continue throughout 2005. It is currently being evaluated.

The registered CHAIR patient:

- must have a confirmed or suspected ACS as an admission diagnosis
- must be  $\geq 18$  years old
- must be alive at the time of hospital presentation and survive to be admitted to hospital, and
- must not have an ACS that has been precipitated or accompanied by a significant co-morbidity such as a motor vehicle accident, trauma, severe gastro-intestinal bleeding, operation or procedure. In-patients who are hospitalised for any non-cardiac reason are not eligible for registration in CHAIR if they develop ACS symptoms.

If the patient is transferred out of a registry hospital, the data collection ends with the transfer. The patient may be re-registered at the same hospital - in which case CHAIR will register a second event for the same patient.

### Data Collection

A CHAIR Registration Officer (CRO) collects the data at each hospital.

CHAIR data is recorded on two forms:

- Personal data in the database within the hospital; and
- 'Anonymised' data (no name and no address) in the central database.

The identifiable data in the hospital database is information from the patient medical record and is used to improve patient care at local level. This data is only available to CROs and to certain hospital and medical staff. It has protection from public use by way of unique user IDs, passwords and physical access to the system.

The anonymised data is used for planning and research purposes and the patient cannot be recognised from this data. Unique identifiers (such as patient's name and address, consultant name and GP name) are removed prior to data transmission to the central CHAIR database. This ensures the confidentiality of patients' information.

In each hospital a CRO records personal and medical data on patients with a suspected or confirmed ACS on the CHAIR computer. As stated previously, this data is only accessible to the CRO and certain medical and hospital staff in that hospital.

The CRO may approach the patient to obtain certain information that may not be found on the patient medical record. This information, such as smoking status and occupation, is essential for the analysis of factors that affect risk and prevention of coronary heart disease.

CROs are not always in a position to interview patients. As CROs are not involved in the direct care of patients they try not to interfere with the work of clinical staff caring for the patients. CROs collect CHAIR information from patient records and other systems in the hospital. Even when CROs have been given permission to approach patients, the patients are often not well enough to be questioned. Also, patients relevant to CHAIR may be admitted and discharged over a weekend when CROs are not on duty.

## **3.2 Cardiac Rehabilitation Information Systems (CRIS)**

*Ms Rachel Flynn, Research Officer, NCIS, RCSI*

### Overview of the System

Recommendation 9.5 of the Cardiovascular Health Strategy *Building Healthier Hearts* (1999) proposed that a standard format of audit should be agreed nationally.

Professional audit has become an integral part of cardiac rehabilitation services to enable assessment of service quality including effectiveness and efficiency. The Cardiovascular Health Strategy recommended that the Irish Association of Cardiac Rehabilitation (IACR) should be responsible for agreeing the format and implementing a standardised audit system for Ireland.

National data standards for cardiac rehabilitation have been developed in the Royal College of Surgeons in Ireland as a result of the Cardiac Rehabilitation Information Systems project (CRIS). This was done in collaboration with the IACR and was piloted in paper format in a number of hospitals in 2004.

European data standards for acute coronary syndromes, percutaneous coronary intervention and electrophysiology were agreed through the Cardiology Audit and Registration Data Standards (CARDS) project, an initiative during the Irish Presidency of the European Union in 2004. Arising from the CARDS project, the European Society of Cardiology (ESC) Working Group on Cardiac Rehabilitation and Exercise Physiology agreed core European data standards for cardiac rehabilitation services, based on the CRIS data set. The IACR has now formally adopted the CRIS data standards for cardiac rehabilitation.

To maintain the momentum of the CRIS project, the NCIS Steering Committee proposed that centres start to collect data using the CRIS data set on all patients eligible to commence cardiac rehabilitation (phases I to III) from January 1<sup>st</sup> 2005. Phase 1 of the National Cardiovascular Information System (NCIS) includes the development and implementation of CRIS as one of the priority modules. However, as other modules of NCIS have not yet started, it is proposed in the interim that each cardiac rehabilitation centre collect information using either a paper-based or electronic database.

### Data Collection

Data using the CRIS standards may be collected using either a Microsoft Access database with predetermined drop down lists or a paper-based version with tick boxes. At some centres the cardiac rehabilitation co-ordinators (CRC) are using software packages (Tomcat or PATS) to manage patient care. The data collected in these will need slight modification in order to comply with the CRIS data standards for NCIS.

The CRC currently collects data on the patients attending cardiac rehabilitation using either of the above methods.

### **3.3 HEARTWATCH**

*Dr Sean McGuire, National Programme Director, ICGP*  
*Mr John Leahy, National Programme Manager, ICGP*

Recommendation 6.21 of the Cardiovascular Health Strategy *Building Healthier Hearts* (1999) proposed that secondary prevention for most patients should be provided in the general practice setting. The HEARTWATCH project, based on this assertion, is a national programme in general practice in association with other primary care professionals for the secondary prevention of cardiovascular disease in Ireland in patients with a history of Myocardial Infarction (MI), Coronary Artery Bypass Graft (CABG) or PCI. The Department of Health and Children and the Health Boards, in partnership with the Irish College of General Practitioners and the Irish Heart Foundation, have agreed the project. The aim of the project is to implement and evaluate the first phase of a structured programme of secondary prevention of cardiovascular disease.

The specific objectives are

- To examine the baseline levels of risk factors and therapeutic interventions relevant to secondary prevention and their trends over time.
- To examine the processes involved in implementing the programme including the referral process and patient retention.
- To record the incidence of cardiovascular events in patients participating in the programme.

A National Programme Centre, Independent National Data Centre and national and regional infrastructures and processes have been established to implement and manage the HEARTWATCH Programme. The programme targets 20% of the Irish General Practice and implements the guidelines devised by the Second Joint Task Force of European and other Societies on Coronary Prevention. Patients are seen on a quarterly basis and care is implemented according to defined clinical protocols.

The four main software suppliers of general practice software have formed a Health Informatics Association and each of these providers has made available a HEARTWATCH System Module for GP users to integrate with their current practice software. Data on 90% of patients and quarterly continuing care visits are sent electronically from the GP practice to the established Independent National Data Centre. Ten percent of practices return data via paper returns.

According to a report on HEARTWATCH published in December 2004 there are now in excess of 10,500 patients in the programme and 40,000 continuing care visits have taken place. The HEARTWATCH programme is now fully functioning and is currently undergoing an external evaluation.

## 4. PROPOSED DEMOGRAPHIC AND SOCIO-ECONOMIC DATA STANDARDS

### 4.1 Proposed list of variables

The list of variables proposed for inclusion is shown below.

#### For adult patients

- Sex
- Date of birth
- Marital status
- County of residence
- Living arrangements
- Type of accommodation
- Religion
- Country of birth
- Ethnicity
- GMS entitlement
- Private medical insurance
- Education
- Principal economic status
- Social group

#### For paediatric patients

- Sex
- Date of birth
- Marital status
- County of residence
- Living arrangements
- Type of accommodation
- Religion
- Country of birth
- Ethnicity
- GMS entitlement
- Private medical insurance
- Principal economic status
- Social group

### 4.2 Importance of each variable

In most health care settings sex (male / female) and date of birth are recorded. There are increasing demands on medical services due to ageing of our population. This requires that existing services may need to expand to cope with elderly patients who may have many co-existing chronic conditions.

Information gained from a patient's address may be very useful, especially if this indicates an area where there may be a high level of social deprivation (poverty, unemployment, poor housing, many of which may be rented). At present there is a limitation as to how useful the information gained from address is, but in future this should be improved with the availability of geo-coding and small area codes.

Information on living arrangements (alone or with another adult) is important to consider when establishing level of support at home for an ill patient.

Type of accommodation is useful in assessing some aspects of patients' economic status.

Religion is usually asked in order to ensure patients have the appropriate religious attention if required. However it is also important in considering the medical needs and mores of the many different religions that are becoming more evident due to the growth in immigration.

Country of birth and ethnicity would help to identify minority populations that may be more isolated due to living conditions and language barriers.

Whether or not patients have General Medical Services (GMS) entitlement or have private medical insurance would indicate the level to which services for the less well off in society are provided.

Socio-economic variables, i.e. education, principal economic status and social group are very important in terms of differentiating at-risk patient groups and monitoring the gap between the groups. In some surveys level of education completed has been associated with differences in variables relevant to health.

The Working Group had lengthy discussions on whether or not a variable based on occupational status should be included. The main reasons against its inclusion were the fact that it is a harder variable to collect accurately than most other demographic and socio-economic variables; it requires careful questionnaire design and coding instructions to ensure data quality; and its direct use is limited to those who are at work - data users need to be aware of the occupational status assigned to those who are currently not at work (e.g. retired - former work, persons on home duties and students - occupation status of a person whom they are dependent etc.).

However, occupation-based data is important as there is strong evidence to suggest associations between occupational status, health behaviours and outcomes. It adds an important dimension in capturing socio-economic characteristics and it complements other variables, such as, education. It is also clinically useful in indicating work-related hazard exposure. In addition, some of the national health targets and NAPS targets, in particular targets to reduce inequalities in mortality, are expressed in terms of socio-economic group. If we are to understand how to deliver health services that contribute to reducing the socio-economic gaps in mortality, etc. we need to understand how services are accessed by people from different socio-

economic groups, the services received by different socio-economic groups, and how effective those services are in the different socio-economic groups.

The Working Group agreed that it is important to test the feasibility and the usefulness of occupation-related information and propose to use social group (SG) to capture socio-economic status based on one's occupation. SG is a broader category of socio-economic group (SEG) that is derived from occupation and principal economic status by the CSO. There are three main reasons why SG was selected.

- It is a broader category, which reduces the burden on interviewers, while still dividing the population meaningfully
- Fairly even distribution of population in each category
- It is used in the Household Budget Survey and can be related to the census population classification.

#### **4.3 Data standards and data collection protocols**

The exact definitions, proposed questions and coding are presented in the attachments (see Demographic and socio-economic data standards for adults and Demographic and socio-economic data standards for paediatrics).

#### **4.4 Training and education**

It is important to provide training to administrative and clinical staff in health care settings in the variables to be collected in order that some of the barriers to data collection may be overcome or diminished.

##### General challenges

Understanding of the importance of the data by both data collectors and respondents is essential for the success of data collection. Therefore data collectors and respondents need to be informed regarding:

- the importance of each variable;
- why it is needed even though other patient details are collected;
- how this information will be used; and
- the benefits it offers to the clinic and patients, and to service planning.

Data collection staff should be provided with guidelines for interviewing and coding in order to achieve data quality and consistency. Ongoing feedback and input from those involved is also the key to successful operations.

##### Particular challenges in patient care settings

As well as the challenges that are common in all data collections, there are some issues that make data collection in patient care settings particularly challenging. For example:

- When the patient presents with an acute condition. In this situation obviously the treatment has the priority and, therefore the information system needs to allow for data collection after the acute phase
- Death of the patient. In this situation the interviewer may need to explain the purposes and the importance of data collection using the information from the training materials and ask questions to relatives. Clearly, this would require great sensitivity and would be challenging for those collecting the data.

The NAPS NCIS Working Group is promoting the NAPS agenda in the health sector, requiring changes in staff and organisational attitudes and behaviour. This work will require the development of education materials and a training programme.

## 5. QUESTIONS FOR WORKSHOP DISCUSSION

The NAPS NCIS Working Group would like the workshop participants' views in relation to the following:

1. Proposed list of variables:
  - a. Are there any other variables to be added? Are there any variables to be deleted?
2. Proposed data standards:
  - a. Are they clear?
  - b. Will they be useful?
  - c. Are they consistent with other important reference collections?
  - d. Are any modifications needed?
3. Issues for data collection:
  - a. Is it feasible to collect the desired information in the three proposed settings – CHAIR, CRIS, and HEARTWATCH?
  - b. What other issues regarding data collection in the patient care settings should be considered?
  - c. Are the suggestions regarding data collection practical?
  - d. Are any modifications needed?
4. Training and education:
  - a. Is it feasible to incorporate the education and training suggestions into existing training and education activities in CHAIR, CRIS, and HEARTWATCH?
  - b. Are any modifications needed?
5. What modifications might be needed to the data standards, data collection protocols, and training and education to allow their possible use in other health information systems?

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- <sup>7</sup> Background Paper for the Cardiology Audit and Registration Data Standards (CARDS) Conference during Ireland's Presidency of the European Union [http://www.escardio.org/NR/rdonlyres/0E011906-ADA9-4377-9331-91FC0A4A17F1/0/CARDS\\_Conf.pdf](http://www.escardio.org/NR/rdonlyres/0E011906-ADA9-4377-9331-91FC0A4A17F1/0/CARDS_Conf.pdf), European Society of Cardiology, 2004

# APPENDIX 1. NAPS HEALTH TARGETS

## Overall Objective

In the area of health, NAPS aims is to **reduce the inequalities in the health** of the population by:

- making health and health inequalities central to public policy
- acting on the social factors influencing health
- improving access to health and personal social services for those who are poor or socially excluded
- improving the information and research base in respect of the health status and service access for the poor and socially excluded.

## Health Status Target

- To reduce the gap in premature mortality between the lowest and highest socio-economic groups by at least 10 per cent for circulatory diseases, for cancers and for injuries and poisoning by 2007.

## Children

The overall objective, in line with the *National Children's Strategy* (November 2000) is to eliminate child poverty and to move to a situation of greater equality for all children in terms of access to appropriate education, **health** and housing, thus breaking the cycle of disadvantage and exclusion experienced by certain children in society.

- To reduce the gap in low birth weight rates between children from the lowest and highest socio-economic group by 10 per cent from the current level by 2007.

## Travellers

- To reduce the gap in life expectancy between the Traveller Community and the whole population by at least 10 per cent by 2007.

## Older People

The overall objective is to eliminate consistent poverty for older people and to improve their access to appropriate health, care and housing supports, and to support older people to live independent and fulfilling lives.

- By 2003, national guidelines will be put in place for the provision of respite care services to carers of older people.
- Access to orthopaedic services will be improved so that no one is waiting longer than 12 months for a hip replacement. This is an initial short-term action to improve quality of life for older people and it will be reviewed in 2003.

### People with Disabilities

The overall objective is to increase the participation of people with disabilities in work and in society generally and to support people with a disability, and their families, to lead full and independent lives.

- The Strategy will aim at improving access to planned respite care for carers of disabled people by 2003.

### Women

In relation to **women**, it should be noted that while a specific health target was not set, "*Building an Inclusive Society*" states that in relation to women

"The overall objective is to eliminate consistent poverty for women and to **improve access for women to appropriate health care**, education and employment, thus reducing the risk of poverty for such women and their families."

### Urban Poverty

The overall objective is to tackle social exclusion in urban areas in a comprehensive and sustained manner by ensuring the provision of adequate income and by **building viable and sustainable communities**, through improving the lives of people living in disadvantaged urban areas and **building social capital and community ownership of strategies:**

- The Strategy will aim to significantly reduce the harm caused to individuals and the community by the misuse of illicit drugs through a concerted focus on supply reduction, prevention, treatment, and research.
- The Strategy will aim at ensuring that the basic needs of all families, especially young parents, lone parents, older people, and ethnic minorities are met through **enhanced and better co-ordinated State support services.**

### Rural Disadvantage

- The Strategy will aim at improving access to employment, **health**, education and housing services for rural dwellers.

- The Strategy will aim at improving **transport services** to rural dwellers through a combination of State support and community-based provision.

### **Migrants and Members of Ethnic Minority Groups**

The overall objective in relation to migrants and members of ethnic minority groups is to ensure that members of ethnic minority groups resident in Ireland are not more likely to experience poverty than majority group members. The NAPS Review states that “very little quantitative information is available about the socio-economic situation of foreign-born residents in Ireland. It is not possible, therefore to define specific targets for this group as whole or for a particular ethnic groups at this stage”. **The overall policy approach is to tackle barriers to the integration of ethnic minority residents.**

## APPENDIX 2. LIST OF INFORMATION SYSTEMS REFERENCED

Name of info system	Variables				
	Occupation	Employment Status	Education	Place of Residence	Health entitlement
1. EUROCAT	Occupation (of mother and father)			Residence code	
2. National Cancer Registry	Occupation	Occupational Status		Patient address	
3. National Perinatal Reporting System	Occupation			County of Residence of mother and father	
4. National Psychiatric In-Patient Reporting system	Occupation	Employment Status		Patient address	
5. Sudden Infant Death Register	Occupation (of Mother?)	Employment Status	Education		
6. SLAN – Survey on Lifestyle and Nutrition	Occupation	Employment situation	Education	Place of Residence	Medical Card
7. HBSC – Health Behaviour of School Children	Occupation/ Employment Status of Parents (asked of both mother and father)		Class/year they are in	Place of Residence	
8. QNHS – Quarterly National Household Survey	Industry and Occupation	Employment details	Education		Medical Card
9. EU-SILC – Survey on Income and Living Conditions	Industry and Occupation	Employment details	Education		
10. National Drug Treatment Reporting System		Employment Status		Address	
11. Living in Ireland Survey		Employment Status			
12. HIPE				Patient Area of Residence	Medical Card
13. Medical Card Database				Place of Residence	
14. National Intellectual				Place of residence	

Disability Database					
15. National Physical and Sensory Disability Database				Place of Residence of client	
16. National Breast Screening Programme				Address	

## APPENDIX 3. CURRENT DEMOGRAPHIC AND SOCIO-ECONOMIC VARIABLES IN PROPOSED NCIS PILOT SITES

<b>EMPLOYMENT STATUS AND OCCUPATION</b>			
<b>Field names</b>	<b>Variable</b>	<b>Definition</b>	<b>Coding</b>
Employment status and occupation	<b>CRIS</b> Work Status three months prior to the event	Indicate the patient work status three months prior to the cardiac event	1= Full time employed 2= Part time employed 3= Self-employed full time 4= Self –employed part-time 5= Unemployed looking for work 6= Government training course 7= Looking after family/home 8= Permanently sick/disabled 9= Temporarily sick/injured 10= Student 11= Retired 12= Other
	<b>CRIS</b> Returned to work after phase 3 cardiac rehabilitation	Indicate if the patient returned to work or is intending to after phase 3 cardiac rehabilitation programme	1= no 2 =yes 3=other 99 =unknown
	<b>CHAIR</b> Employment status		1.Unemployed 2.Student 3.Retired 4.Household duties 5.Part-time employed 6.Full-time employed 7.Disability benefit 8.Other 9.Unknown
	<b>HEARTWATCH</b> Employment status		Self employed Retired Employed Unemployed If farmer – how many acres?
	<b>CHAIR</b> Social Class		1.Professional Worker 2.Managerial & Technical 3.Non Manual 4.Skilled Manual 5.Semi Skilled 6.Unskilled 7.Unknown

	<b>CHAIR</b> Occupation		Free text
	<b>HEARTWATCH</b> Occupation		Free text
<b>Education</b>	<b>CRIS</b> Age left full time education	Indicate the age in years that the patient completed full-time education including third level education as a child/adolescent. Example: If the patient finished full time education at the age of 15 but returned to full time education at the age of 40. Then 15 years would be considered the age the patient left full time education.	Free text
	<b>CHAIR</b> Educational Status		1.No Formal Education 2.Primary 3.Secondary 4.Tertiary Technical 5.University 6.Other 7.Unknown
<b>Residence</b>	<b>CHAIR</b> City/County/ Country	A city or county in the Republic of Ireland or a country or area outside the Republic of Ireland (e.g., Waterford City, Waterford County, Mayo, Germany, Africa)	List of 59
<b>Health entitlements</b>	<b>CRIS</b> Does the patient have a GMS card	Indicate if the patient has a General Medical Scheme Card	1= No 2= Yes
	<b>CHAIR</b> Health Cover		1.None 2.GMS 3.VHI 4.BUPA 5.Other 6.Unknown
	<b>HEARTWATCH</b> GMS Card Holder		0= No 1= Yes
	<b>HEARTWATCH</b> GMS Card Number		Free text

## **APPENDIX 4. NAPS AND NCIS WORKING GROUP MEMBERSHIP**

NCIS:	Emer Shelley Moira Lonergan Rachel Flynn
DoHC:	Anna-May Harkin Ciara O'Shea
IPH:	Kevin P. Balanda Yukiko Kobayashi
CSO:	Gerry Brady Tara Galvin Denis Murphy