A mechanism to achieve equality, through the use of Ethnic monitoring – Experience and learning

Ethnicity, Human Rights and Data Collection seminar.
National University of Ireland Maynooth
13th May 2013

Brigid Quirke
Outline of presentation

- Rationale for equality proofing/ethnic monitoring?
- Policy context
- What is ethnicity?
- What is equality proofing?
- What is ethnic monitoring?
- International evidence on need and challenges to ethnic data collection
- Process, Challenges, Learning and outcomes to date from pilot initiative.
- Examples of outcomes from other Irish data sets
- Data protection and codes of practice
- Concluding observations
Mainstreaming Equality ???
“Despite the range of measures taken by the Government, the Traveller community continues to encounter high levels of discrimination, as a consequence of which they experience inequalities in the enjoyment of several economic, social and cultural rights. I am particularly concerned about their poorer health status compared with the rest of the population, and I call on the Government to take immediate measures to address their health situation without delay”.

Magdalena Sepúlveda, the United Nations independent expert on the question of human rights and extreme poverty, taken from her statement issued (Jan 2011) on her recent mission to Ireland.
Roma, Sinti and Travellers have considerably poorer health status than the majority of the European population: they have a lower life expectancy and a higher infant mortality rate than majority populations in all countries examined.
Why Collect data?

- “If you don’t ask, you don’t know, and if you don’t know, you can’t act”

The Making of Public Health Data: Paradigms, Politics and Policy
Nancy Krieger J Pub Health Policy
1992; 13:412-427
Health inequalities for BME (Black, Minority, Ethnic communities)

- Ethnic minorities suffer worse health, premature death and experience discrimination when trying to access health services.
- The emerging evidence base suggests that socioeconomic factors and the experience of racism may be amongst the most important causes of these disparities.
- Experience of racism has an adverse effect on indicators of both mental and physical health.
Key results from the AITHS

- **Life Expectancy**
  - In 1987 the gap in life expectancy between Traveller women and settled women was 12 years. The gap in 2008 is 11 years.
  - In 1987 the gap in life expectancy between Traveller men and settled men was 10 years. The gap in 2008 is 15 years.

- **Mortality/Deaths**
  - Traveller men have four times the mortality rate of the general population.
  - Traveller women have three times the mortality rate of the general population.

- Suicide is 6 times the rate of general population.

- The infant mortality rate for Travellers is 3.5 times the rate of the general population (4 infant deaths per 1,000 in the national population compared to 14 infant deaths per 1,000 in the Traveller population).
Trust Issues in AIHTS

- Trust emerged as a major issue from the focus groups, lack of trust has a direct impact on the level of engagement of Travellers with health services.

- In the AITHS study the level of complete trust by Travellers in health professionals was only 41% this compares with a trust level of 82% by the general population in health professionals.

- Issues of treatment with respect and dignity, over 40% of Travellers had a concern that they were not always treated with respect and dignity.

- Quality of care received over 50% had concerns of the quality of care they received when they engaged with services.
Attitudes of Settled People to Travellers

- 60.1% would not welcome a Traveller as a member of the family
- 63.7% reject Travellers on the basis of their ‘way of life’
- 18.2% would deny Irish Citizenship to Travellers
- 72.3% support Travellers ‘to live their own way of life decently’ – down 20.7% since 1989

Source: ‘Emancipation of the Travelling People’ 2010 Micheál Mac Gréil, S.J., NUI Maynooth
Policy and Legislative Framework

- Employment Equality Act 1998
- Equal Status Act 2000
- Allows for affirmative /positive action
- Planning for Diversity: National Action Plan against Racism (NPAR)
- National Anti-Poverty Strategy
- HSE National Intercultural Health Strategy.
- KPI /KRA in HSE National Service Plans 2012/2013
HSE Commitments

- Key result areas that are listed in the plan and that must be reported on a quarterly basis include expansion of the ethnic identifier into core... Renewed efforts are underway in these areas, with use of an ethnic identifier a core criterion in all projects planned or supported via Social Inclusion. The importance of an Ethnic Identifier in planning and improving health services will continue to be emphasized throughout the HSE.

Intercultural Health Strategy Update

Public Health Policy Framework – HSE submission

- **Data to Support Planning, Monitoring and Evaluation:** Availability of data to support an evidenced based public health approach is a critical feature of any modern, credible policy. Limitations in collection and analysis of data have proved a significant barrier to such an approach and a strong emphasis on this should permeate the policy framework. Aspects of equality monitoring to measure and compare health status, uptake of services, and associated health outcomes of different groups is crucial in data collection. In this regard, implementation of an ethnic identifier forms an integral, good practice element of equality monitoring and should be a priority action of the framework.
Data about the population requiring and using health services is critical to effective service delivery. Increasing cultural and ethnic diversity is accompanied by a growing urgency for development of systems to collect ethnic equality related data. Without such information, it is not possible for an organisation to be certain that its services are responsive to the needs of all groups and address possible inequalities.

“Research demonstrates that disparate outcomes relate both to the specific needs of ethnic groups and to barriers in addressing such needs within systems of health care orientated towards the needs of dominant groups.” (Fanning and Pierce: Ethnic Data and Social Policy in Ireland, 2004).
What is Ethnicity?

An ethnic group can be broadly defined as a group of people who share certain background characteristics such as:

- Common ancestors
- Geographical origin
- Language
- Culture
- Religion
- Provides a distinct identity as seen by members of the group as well as by others
Equality Proofing

Equality proofing

- Is a an integrated and systematic approach to ensure that discriminated and marginalised groups are provided with the necessary means and resources to participate in society as equal citizens. (NESF 2010)

The objectives of an equality proofing process can be summarised as follows:

- To promote full and effective equality:
- To eliminate the inequalities that lead to poverty and social exclusion.
- To achieve a society that guarantees the inclusion of all groups and one that values rather than discriminates against differences.
Why monitor Ethnic data?

- The collection and use of ethnic group data enables health services to identify and respond to health inequalities as experienced by different social groups in terms of health status, access to health care, experience of health care and health outcomes (CRE, 2002).
- A powerful rationale for the collection and use of ethnic group data is therefore that of social justice. Equality is a core founding principle of the NHS (Delamothe, 2008).
Role of Ethnic Monitoring?

The role of ethnic monitoring in addressing health inequalities has four principal components:

- to enable an accurate assessment of service users’ needs so that services and service delivery can, as much as possible, be personalised and culturally appropriate;
- to enable effective clinical management of patients given that the prevalence and course of many conditions can vary according to ethnicity;
- to enable comparisons to be made of the uptake of services by different groups, thereby ensuring equitable allocation of resources and the provision of services according to need;
- to enable the NHS to meet the requirements of the Race Relations (Amendment) Act 2000.

(DH, 2005a)
Race equality in general, and ethnic monitoring in particular, needs drive, ownership and commitment from the top of the organisation ... this is true of all NHS bodies and councils and is also true of [the Department of Health]. Ethnic monitoring must be part of an overall strategy to improve service provision for minority ethnic communities that has broad level support. (DH, 2005a, p. 27)
Experience in UK

In the UK, a similar need to close the health gap for ethnic minorities is recognised by bodies such as the Department of Health and professional associations. Furthermore, following the implementation of the Race Relations Amendment Act 2000 in April 2001, a statutory duty has been laid upon the NHS and other UK public service agencies to ‘have due regard to the need to eliminate unlawful discrimination’, and to ensure that every new action or policy considers the implications for racial equality [8].
NHS Experience

• Given what we know about the ethnic dimension of health inequalities, effective ethnic monitoring has a fundamental role to play in identifying and reducing inequalities and ensuring that all social groups benefit equally from the services of the NHS.

• A consistent message from the literature on access is the need for better ethnic monitoring data in the NHS, and for greater use to be made of this data in order to justify its collection. Low completion levels may partly be due to the perceived sensitivity of this area on the part of healthcare workers [9–10], and also possibly because the information collected may be insufficiently detailed for clinical care and health service planning purposes [2].
UK critique

The UK recognise officially the need for ethnicity data for monitoring purposes (Raleigh, 2008). However, there are still too few examples of good practice and, despite improving collection rates, ‘the data are worthless unless they are used to target need and reduce inequalities’ (Raleigh, 2008, p. 646). The failure to use ethnicity data to inform and improve practice has been a persistent barrier to improved collection rates: too few data are recorded and those that are recorded are too little used to inform practice. Until ethnic monitoring is mandated and enforced across primary and secondary care, there is neither any incentive nor, in the absence of enforcement, any real imperative to collect the data.
International learning on barriers to collecting ethnic data

There are a number of reasons for the lack of routinely collected ethnicity data, including:

• difficulties in obtaining an accurate classification;
• reluctance to request data for fear of giving offence;
• no meaningful incentive to collect or provide data;
• reluctance on the part of service users to supply data;
• inability to supply data owing to language barriers;
• lack of understanding as to how data can or will be used.

(Adapted from Iqbal et al. 2008)
Ethnic Identifier Pilot Project

Recommendation 8 + 9 in National Travellers Health Strategy

“A pilot project will be initiated during 2002 to collect information on ethnicity (including Travellers and other ethnic groups) from the HIPE and/or Perinatal Systems.”

“The results of this pilot will be evaluated with a view to extending identification of ethnicity to other relevant health information systems as part of the implementation programme for the National Health Information Strategy.”

“Making significant progress on in tackling Traveller health status will be difficult unless an adequate system can be put in place to gather data on an ongoing basis on Traveller Health. This data, effectively the baseline from which progress can be measured and by which services can be planned and monitored, is now an urgent necessity.” Section 5.4 p32, National Travellers Health Strategy 2002-2005
Ethnic Identifier Pilot Project

- Working group set up by NTHAC, including Pavee Point, Economic Social Research Institute (HIPE), and the Department of Health to design, initiate and pilot ethnic identifier.
- Pavee Point carried out the pilot project on behalf of working group in partnership with the teams in Tallaght and the Rotunda Hospital.

Who Consulted on question design?
- NCCRI
- Cairde
- SPORASI
- ACCESS Ireland
- Rotunda & Tallaght Hospital
- Tallaght Refugee Service/Drop-in Centre
- Integrating Ireland
- The Equality Authority
- Tallaght Intercultural Action
- Immigrant Council of Ireland
- Migrant Right Centre
- Irish Refugee Council
ETHNIC SELF-IDENTIFICATION QUESTION PILOT PROJECT

To which one of the following groups do you consider you belong? In the group selected, please tick one box.

White
- Irish
- Irish Traveller
- British
- Roma
- Any other White background

Black or Black Irish
- African
- Any other Black background

Asian or Asian Irish
- Chinese
- Any other Asian background

Other including mixed background
- Please specify

Do not wish to answer the question
- 

For Official Use Only

Unable to answer
- 

Discharged from ward
- 

Discharged from hospital
- 

Unavailable (e.g., in X-ray)

<table>
<thead>
<tr>
<th>Day 1</th>
<th>Day 2</th>
<th>Day 3</th>
<th>Day 4</th>
<th>Day 5</th>
<th>Day 6</th>
<th>Day 7</th>
<th>Day 8</th>
<th>Day 9</th>
<th>Day 10</th>
</tr>
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</table>

Initials
Information on Ethnicity Pilot Project

What is the Ethnicity Pilot Project?

The Ethnicity Pilot Project is a study supported by the Department of Health and Children to collect information on the ethnicity of hospital patients. The study is taking place in two hospitals, Tallaght and the Rotunda, and will last for a number of months. At the end of the study, the results will be evaluated to look at the possibility of collecting ethnicity information across the whole public hospital system.

What is Ethnicity?

An ethnic group can be broadly defined as a group of people who share certain background characteristics such as common ancestors, geographical origin, language, culture and religion. This provides a distinct identity as seen both by members of the group and by others.

Why is it important to know about Ethnicity?

Information on ethnicity is important in planning and delivering appropriate services. It can assist in identifying specific health issues and in addressing issues of equality in service delivery. The Equality Authority has identified ‘ethnicity’ as a specific area where information is needed in order to measure progress on equality. Please note that we are not asking about citizenship or nationality, but about the ethnic group to which you feel you belong.

How to answer the Ethnicity Question?

The objective of the question is to find out which group you feel best represents you. You are asked simply to tick the appropriate box. If none of the groups applies to you, then space is provided to specify your group. Answering the question is voluntary, and the last box can be ticked if you do not wish to participate in the study. The level of care you will be offered at this hospital will not be affected by your decision to complete the form.
Key Learning from the Ethnic Identifier Pilot Project

- Clear rationale for collection and use of data to facilitate equality of access, participation and outcome for service users
- Consultation and participation of all key stake holders
- Reassurance on confidentiality; participation voluntary; data collection by self-identification only and use of data limited to pilot.
- Provide ‘Anti-racism training’ for staff and management of the institution where data is collected.
- Development of Anti-racism codes of practise’ and Equality policies (Minorities more confidence to identify themselves, if know less risk of discrimination)
- Development and piloting of a clear question and process based on a literature search on experience from other countries
Learning contd.,

- Need for self identification and not ascription of ethnicity
- Analysis and dissemination of dissaggregated data to both providers and users including NGO’s on a regular basis
- Present data in an accessible/usable format
- Make it available to staff and representative organisations on an ongoing basis to monitor access to services
- Data needs to be analysed within an equality and human rights framework i.e. data being collected for the sole purpose of promoting equality of outcome for all from the services.
- Data needs to be made available to inform policy and monitor and evaluate existing strategies and interventions
- Development of a ‘Code of Practice in relation to the collection and use of Ethnicity data’
- Data protection and confidentiality of data (including protection of small area data)
Challenges

• Some Health Personnel had a problem asking people to identify their ethnicity.
• Some local ethnic minority groups had fear of increasing discrimination and needed to be reassured of confidentiality.
• Health data systems brought in from other countries, sometimes inflexible to adding ethnic questions
• Not all computer system between and within hospitals and health boards are compatible
• Concerns on the capacity of the existing health data information systems to analyse data.
• Data is not often analysed at source and takes place centrally, so there can be a long time gap between collection and analysis. (HRB/HIPE)
• When data is analysed, health personnel not always comfortable with making this information available to front line staff or representative organisation.
Outcomes to date

- Based on successful pilot, the question was integrated in the Census by the CSO in 2002.
- The HRB added the question to their NDTRS database and are successful collecting, analysing and disseminating data to inform local service providers.
- Rotunda and Temple street collecting ongoing data.
### National Drug Treatment Reporting System (NDTRS)

#### B. Demographic details

<table>
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<tr>
<th>4. Gender (circle)</th>
<th>1. Male</th>
<th>2. Female</th>
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</thead>
<tbody>
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<td>5. Age (years)</td>
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<td>6. Date of birth</td>
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<td></td>
<td>Day</td>
<td>Month</td>
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<td>7a. Living with whom (circle)</td>
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<td>2. Parents/family</td>
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<tr>
<td>3. Friends</td>
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<td>4. Partner (alone)</td>
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<td>5. Foster care</td>
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<tr>
<td>6. Alone with child</td>
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<td>7. Other</td>
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</tr>
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<td>10a. Nationality (circle, if other please specify)</td>
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<tr>
<td>2. Irish traveller</td>
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<tr>
<td>3. Other</td>
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<td>9. Not known</td>
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<tr>
<td>7b. Living where (circle)</td>
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<tr>
<td>1. Stable accommodation</td>
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<tr>
<td>2. Institution (prison/residential care/halfway house)</td>
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<tr>
<td>3. Homeless</td>
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<td>4. Other unstable accommodation</td>
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<td>9. Not known</td>
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<td>8. Area of residence (DED, see pink book or Appendix 4)</td>
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<tr>
<td>8b. Community Care Area (see Appendices 4/5)</td>
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<td>11. Employment status (circle)</td>
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<td>2. Unemployed</td>
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<tr>
<td>3. FAS/training course</td>
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<td>4. Student</td>
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<td>5. Housewife/husband</td>
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<td>6. Retired/unable to work</td>
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<td>8. Other (specify)</td>
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<td>12b. Education: highest level completed (circle)</td>
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<td>6. Special needs education</td>
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<td>7. Still in education</td>
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Trend in answering the question

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<th>2009</th>
<th>2010</th>
<th>Total</th>
</tr>
</thead>
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<td>15,128</td>
<td>16,687</td>
<td>19,144</td>
<td>50,959</td>
</tr>
<tr>
<td>White Irish Traveller</td>
<td>251</td>
<td>283</td>
<td>450</td>
<td>984</td>
</tr>
<tr>
<td>Any other white background</td>
<td>591</td>
<td>675</td>
<td>904</td>
<td>2,170</td>
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<tr>
<td>Black African Background</td>
<td>29</td>
<td>28</td>
<td>24</td>
<td>81</td>
</tr>
<tr>
<td>Any other black background</td>
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<tr>
<td>Chinese background</td>
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<td>Other</td>
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<td>Do not wish to answer this question</td>
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<td>422</td>
<td>235</td>
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<td>0</td>
<td>609</td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>17,154</strong></td>
<td><strong>18,193</strong></td>
<td><strong>20,886</strong></td>
<td><strong>56,233</strong></td>
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</table>
Ethnicity profile of people assessed for drug treatment

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<tr>
<th>Ethnic background</th>
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<th>2010</th>
<th>Total</th>
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<tr>
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<td>0</td>
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<td></td>
<td>17,154</td>
<td>18,193</td>
<td>20,886</td>
<td>56,233</td>
</tr>
</tbody>
</table>
Main problem substance

2007: 52% alcohol, 48% drugs

2008: 43% alcohol, 57% drugs
The statistics for the Traveller community show that between 2007 and 2010 a total of 1098 Travellers sought and accessed drug treatment facilities; 162 in 2007 and 427 in 2010. Alcohol was reported as the main problem substance among those presenting for treatment, this was followed by opiates (heroin, methadone and other types), and then cocaine (Health Research Board 2010).

‘This is the first time that ethnicity data has been reported in the NDTRS. And our experience shows that it is possible to record ethnic identifiers if a respectful approach is used. Accurate data are necessary in order to plan appropriate services and develop strategies, so it is important that service providers ensure where possible that ethnic identifiers are recorded correctly’. (NDTRS)
# Rotunda Hospital Statistics: 2010

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<thead>
<tr>
<th>Ethnic Group</th>
<th>% Ethnic Group</th>
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<tbody>
<tr>
<td>White Irish</td>
<td>47.52%</td>
</tr>
<tr>
<td>Other White background</td>
<td>30.93%</td>
</tr>
<tr>
<td>Other Asian Background</td>
<td>7.35%</td>
</tr>
<tr>
<td>Black African</td>
<td>6.51%</td>
</tr>
<tr>
<td>Asian Chinese</td>
<td>1.82%</td>
</tr>
<tr>
<td>Other Black Background</td>
<td>1.55%</td>
</tr>
<tr>
<td>White Irish Traveller</td>
<td>1.14%</td>
</tr>
<tr>
<td>Roma</td>
<td>1.47%</td>
</tr>
<tr>
<td>Asian Irish</td>
<td>0.16%</td>
</tr>
<tr>
<td>Black Irish</td>
<td>0.13%</td>
</tr>
<tr>
<td><strong>Refused to answer</strong></td>
<td><strong>0.3%</strong></td>
</tr>
<tr>
<td><strong>Not known</strong></td>
<td><strong>1.12%</strong></td>
</tr>
</tbody>
</table>
Rotunda Analysis:

- Majority of patients comfortable & confident to self identify:
  - Oct ‘08 to Jan ‘09 = 97.8%
  - Year 2009 = 97.95%
  - Project rolled out to all areas in hospital
  - Year 2010 = 98.58%
- Not known: Ethnic group not listed
  - Added data field of ‘OTHER – Not On List’
Progress made:

- Implemented fully in OPD of both Hospitals by Q1 2009.
- Due to ease of implementation in OPD rolling out throughout other front line areas successful
- Staff were confident in asking the question
- Patients were confident in how the information would be used
A majority of respondents (53.8%) agreed that an ethic identifier is helpful. There was a highly significant difference according to jurisdiction. A clear majority in NI, where there is an ethnic identifier used by some providers, agreed (78.3%), whereas respondents in ROI were more divided, just half said yes (50.2%) and around a fifth (18.4%) did not know. There was also a significant difference according to professional grouping to this question, with GPs (30.7%) least likely and the other category most likely to agree (65.9%) and hospital staff in the middle (48.0%).
In the UK, the commission for Racial Equality has, in its Race Relations Code of Practice in Primary Health Care Services (1992) identified the main components of effective data gathering and monitoring systems:

1. An understanding that ethnic monitoring of services is an integral part of a general race equality strategy which also includes employment matters, training programmes, reviews of policies and procedures.

2. Consultation with the local communities to explain why monitoring is being introduced, and to obtain their views on questions such as the ethnic classification system.
3. Confidentiality arrangements of individual records.

4. The designation of senior officers with overall responsibility for introducing and maintaining the system.

5. Monitoring ethnic records on a regular basis with analytical reports produced at least every six months (with especial attention paid to access issues by front line workers and NGO’s).
Concluding remarks

- Implement commitments to role out the ethnic identifier for the purpose of promoting equality and addressing inequalities.
- Promote a Universal question (Everyone identified)
- Ensure Self Identification (Choice)
- Inclusion of importance of ethnic monitoring in the forthcoming Health Information Bill
- Lobby for amendment to the ESA to include positive duty/ NI section 75
Mary Robinson

, “Statistics, Development and Human Rights”, is nothing less than a quest for a science of human dignity. This is a vital endeavour. When the target is human suffering, and the cause human rights, mere rhetoric is not adequate to the task at hand. What are needed are solid methodologies, careful techniques, and effective mechanisms to get the job done.

Mary Robinson


Quoted in Human rights indicators – a guide to measurement and implementation