European and National Policy and Practice in Ethnic Data Collection and Monitoring

Lynsey Kavanagh
Policy and Evaluation Worker
Pavee Point Traveller and Roma Centre
Presentation Overview

1. Overview of Ethnic Equality Monitoring
2. Data protection standards: CoE/EU/Ireland
3. Ethnic Equality Monitoring in Ireland
4. Challenges and sensitivities in ethnic data collection
5. Recommendations
Irish Travellers: Key Statistics

**Population**

36,224 (AITHS)

**Health**
- 29.1% Travellers under 9
- 2.5% Travellers over 65
- 17.5% one or more disability
- Infant Mortality Rate 3.5 times national average
- Suicide 6 times national average and accounts for approx 11% of all Traveller deaths.

**Accommodation**
- 20.2% Traveller own home
- 55.7% of Travellers lived in LA
- 30.3% no sewerage facilities
- 20% had no piped water source

**Employment**
- 84.3% unemployed
  - Males: 86.6%
  - Females: 81.2%

**Education**
- 69% completed Primary level
- 90% of Travellers ceased full-time education by age 17
- 1% completed Third level

Pavee Point Traveller and Roma Centre
Roma: Key Statistics
What is ethnicity?

UN Recommendations for 2010 census round (2nd revision 2006):

“Ethnicity can be measured using a variety of concepts, including ethnic ancestry or origin, ethnic identity, cultural origins, nationality, race, colour, minority status, tribe, language, religion or various combinations of these concepts [...] The subjective nature of the term (not to mention increasing intermarriage among various groups in some countries, for example) requires that information on ethnicity be acquired through self-declaration of a respondent and also that respondents have the option of indicating multiple ethnic affiliations.”
What is ethnicity?

- shared history;
- common cultural tradition;
- common geographical origin;
- descent from common ancestors;
- common language;
- common religion;
- distinct group within a larger community
Why collect information on ethnicity?

The Committee remains concerned that there is a lack of systematic and comprehensive data on children, **disaggregated by age, sex, ethnicity and by rural and urban areas** […] The Committee recommends that the State party undertake further measures, including through strengthening the role of the Central Statistical Office and other governmental departments and agencies to develop a **systematic and comprehensive collection of disaggregated data** in compliance with the Convention, which should be used for the creation, implementation and monitoring of policies and programmes for children. [The Committee on the Rights of the Child, 2016]

ECRI recommends that the authorities process the data collected in the census with full respect for the safeguards […] and use it to monitor the situation of groups of concern to ECRI by means of **disaggregating data by ethnic origin, language, religion and nationality**. [European Commission against Racism and Intolerance, 2013]

The Committee regrets that the data provided by the State party are outdated and not disaggregated […] The Committee recommends that the State party include in its next periodic report detailed and updated information on the actual and progressive realization of economic, social and cultural rights, **including statistical data disaggregated by year, sex, disability, ethnicity and other relevant criteria**. [The Committee on Economic, Social and Cultural Rights, 2015]
Why collect information on ethnicity?

• “Making the invisible, visible”

• Assist in devising targeted and cost-effective polices and services- improving efficiency

• Vital for service planning and delivery

• Awareness raising of public opinion and decision makers

• Measuring the extent and impact of discrimination

• Identifying targets, setting goals, evaluating policies

• Equality proofing policies and services

• Legal obligation (IHREC Act, 2014)
What is Ethnic Equality Monitoring?

Collection, storage, analysis and utilisation of ethnic data on a regular basis (Quirke, 2002). It is used to:

1. Report on access, participation and outcomes of Travellers, Roma and other minority ethnic groups;

2. Identify discrimination and highlight possible inequalities;

3. Investigate their underlying causes and take action on inequalities, disadvantages or discrimination identified and make reasonable accommodation of the individual service users;

4. Redress disadvantage or inequality identified through evidence-based policies;

5. Monitor and evaluate the efficacy of policies.
Ethnic Equality Monitoring in Practice

Implementation of an ethnic identifier

Ethnic data is collected in accordance with data protection law and human rights principles

Data is disaggregated and provided to key stakeholders such as policymakers and organisations representing minority ethnic groups

Data is analysed periodically and used to identify discrimination and inequalities

Data is used to inform evidence-based policies and equality proofed initiatives

Initiatives or policies are evaluated to ensure successful completion/outcomes and map further action
Ethnic Equality Monitoring Best Practice

• The use of a universal question within a human rights framework;

  • Collected data must be aggregated and anonymised to avoid identification of specific individuals;

  • Collected data must only be used for the purpose for which it was collected;

  • Disaggregated data must be available in a timely manner and analysed in consultation with organisations representing minority ethnic groups;

  • Ongoing monitoring and analyses of data used to design interventions and inclusive policies, promoting equality of access, participation and outcome for minority ethnic groups;

  • Evaluation of interventions and policies in consultation with key stakeholders and organisations representing minority ethnic groups.
Data Protection Principles

Convention ETS 108

Directive 95/46/EC

Data Protection Acts 1988 and 2003
Convention ETS 108

“To secure [...] for every individual [...] respect for his [or her] rights and fundamental freedoms and in particular his [or her] right to privacy, with regard to automatic processing of personal data.”

• First international instrument to provide guiding principles that Member States later adopted into national laws.
• Applies to all data processing carried out by private and public sectors.
• Data protection principles:
  • Data must be obtained and processed fairly;
  • Data must be retained for specified and justifiable purposes;
  • Data must not for used for intentions incompatible with these purposes nor retained for longer than is necessary.
Convention ETS 108 and ‘sensitive data’

- ‘Sensitive’ data includes: ethnicity, racial origin, political opinions, religion, physical or mental health, sexuality; criminal convictions and trade union membership.

- It is legal to collect ‘sensitive’ data under the following conditions:
  - Data is aggregated and anonymised to avoid the possibility of identifying specific individuals within the aggregated data;
  - Data is obtained fairly (voluntary informed consent); lawfully and for specified legitimate purposes;
  - Data must be accurate and adequate, relevant and not excessive to the purpose for which it is stored.
Directive 95/46/EC (‘Data Protection Directive’)

“Whereas the principles of the protection of the rights and freedoms of individuals, notably the right to privacy [...] give substance to and amplify those contained in the Council of Europe Convention of 28 January 1981 for the Protection of Individuals with regard to Automatic Processing of Personal Data” [11]

• Principal EU legal instrument on data protection.

• Designed to give substance to the principles in Convention ETS 108 and to expand them.

• Provides flexibility in Member States’ understanding of their national context.

• Permits national legislation to authorise the processing of ‘sensitive data’ subject to the provision of suitable safeguards.
Data Protection Acts 1988 and 2003 (DPA). Key principles:

1. Data must be obtained and processed fairly;
2. Data must be only kept for one or more specified, explicit and lawful purposes;
3. Data can only be used and disclosed in ways compatible with these purposes;
4. Data must be kept safe and secure;
5. Data must be accurate, complete and up-to-date;
6. Data must be adequate, relevant and not excessive;
7. Data can only be retained for no longer than is necessary for the purpose or purposes;
8. Personal data must be made available to an individual, on request.
“Similar to the international experience, national collections in Ireland have evolved over time in a largely uncoordinated fashion. This led to the development of isolated ‘silos’ with significant variation in quality, fragmentation, duplication, access problems, and increased costs.” [HIQA, 2014: 11]
Ethnic Equality Monitoring in Ireland

- Central Statistics Office (Census)
- Child and Adolescent Mental Health Service (CAMHS)
- Coombe Women & Infants University Hospital
- Cystic Fibrosis Registry of Ireland
- Department of Education and Skills (Primary Online Database (POD)
- Higher Education Authority (HEA)
- Irish Prison Service
- Health Protection Surveillance Centre (HPSC)
- National Drug Treatment Reporting System (NDTRS)
- Rotunda Hospital
- Social Inclusion and Community Activation Programme (SICAP)
- Temple Street Hospital
Challenges and Sensitivities

• Privacy, confidentiality and data misuse
• Participation
• Data collector discomfort
• Categorization and technical issues
• Time and associated costs
Combatting Challenges and Sensitivities

CSO: Census

Our Geels: All Ireland Traveller Health Study

National Drug Treatment Reporting System

Pavee Point Traveller and Roma Centre
Combatting Challenges and Sensitivities

- A **standardised and universal question** rooted in a human rights framework;

- A **public and targeted** campaign informing people why such data is collected;

- **Ongoing training and support** for data collectors to ensure they are equipped, confident and skilled in implementing, monitoring and evaluating ethnic data; and

- **Community participation** and active consultation with Pavee Point and other key stakeholders representing minority ethnic groups.
Recommendations

**Recommendation 1:** Official senior level endorsement of Ethnic Equality Monitoring (EEM)

**Recommendation 2:** Establish a National Steering Committee to develop a comprehensive EEM framework

**Recommendation 3:** The National Steering Committee to develop a clear EEM strategy in partnership with Travellers, Roma and other minority ethnic groups

**Recommendation 4:** Public sector bodies should introduce training and targeted recruitment for data collectors where applicable and appropriate.
Recommendations

**Recommendation 5:** Introduce a standardised ethnic identifier in routine administrative systems and in state surveys to comply with positive duty obligations, promote equality and combat discrimination. It is essential that the application of an ethnic identifier take place within a human rights framework.

**Recommendation 6:** Public access to disaggregated data

**Recommendation 7:** Mainstreaming data collection practices across public sector bodies
Conclusion

• Ethnic data is central to implementing, monitoring, and evaluating a vast range of human rights laws and policies.

• Ensures equal opportunity and access across all economic and social sectors of society.

• Data can provide evidence of the disparate impact of policies and practices on minority ethnic groups.

• Assist in devising targeted and cost-effective polices which promote equality of access, participation and outcome for minority ethnic groups.