

RESEARCH REPORT:

Policy and Practice in Ethnic Data Collection and Monitoring

COUNTING US IN - HUMAN RIGHTS COUNT!



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Abbreviations And Acronyms

AITHS	All Ireland Traveller Health Study
CEDAW	United Nations Convention on the Elimination of all Forms of Discrimination Against Women
CERD	United Nations Committee on the Elimination of Racial Discrimination
CESCR	United Nations Committee on Economic, Social and Cultural Rights
CMW	United Nations Committee on the Protection of the Rights of All Migrant Workers and Members of their Families
CoE	Council of Europe
CRC	United Nations Committee on the Rights of the Child
CRPD	United Nations Convention on the Rights of Persons with Disabilities
CSO	Central Statistics Office
DES	Department of Education and Skills
DJE	Department of Justice and Equality
DPA	Data Protection Acts
ECHR	European Convention on Human Rights
ECRI	European Commission against Racism and Intolerance
ECTHR	European Court of Human Rights
EEM	Ethnic Equality Monitoring
ENAR	European Network Against Racism
EU-LFS	European Union Labour Force Survey
EU-SILC	European Union Statistics on Income and Living Conditions
FCPNM	Framework Convention for the Protection of National Minorities
FRA	European Union Agency for Fundamental Rights
HIA	Health Information and Quality Authority
HSE	Health Services Executive
ICCPR	International Covenant on Civil and Political Rights
ICERD	International Convention on the Elimination of All Forms of Racial Discrimination
ICESCR	International Covenant on Economic, Social and Cultural Rights
IHREC	Irish Human Rights and Equality Commission
NCCRI	National Consultative Committee on Racism and Interculturalism
NDTRS	National Drug Treatment Reporting System
NGO	Non-governmental organisation
NRIS	National Roma Integration Strategy
NTRIS	National Traveller and Roma Inclusion Strategy
OECD	Organisation for Economic Co-operation and Development
OHCHR	Office of the High Commissioner for Human Rights
OSF	Open Society Foundations
PSED	Public Sector Equality Duty
QNHS	Quarterly National Household Survey
SICAP	Social Inclusion and Community Activation Programme
SILC	Survey on Income and Living Conditions
UNDP	United Nations Development Programme
UNESCO	United Nations Educational, Scientific and Cultural Organisation
UNHRC	United Nations Human Rights Council
UNICEF	United Nations Children's Fund

Foreword

In Pavee Point we believe that the interests of Travellers or Roma cannot be well served if we do not have evidenced based policymaking. The best way to ensure that inequalities are addressed is through the collection, monitoring and evaluation of ethnically disaggregated data. Without data disaggregated on the basis of ethnicity we cannot provide the evidence to highlight the existence of systemic or indirect discrimination and inform good policy and practice. Pavee Point believes that accurate data and ethnic monitoring is required in the struggle to protect the human rights of potentially discriminated minorities and to promote equality and counter discrimination. It should be used in the design of appropriate anti-discrimination policies and to assess their effectiveness over time.

There remains a significant gap in the availability of reliable and comprehensive data in relation to the socio-economic, political and legal situation of Traveller and Roma communities in Ireland. This is crucially linked to the lack of statistical and research data by ethnicity. Currently, ethnicity is not included as an administrative category in official data collection systems or in state surveys such as the QNHS and SILC. This results in serious gaps in knowledge about the situation and needs of Travellers and Roma and absence of evidence based policies and practices to ensure the needs of minority ethnic communities are met. The lack of data contributes to significant obstacles in gathering evidence about racism and discrimination, making it difficult for relevant stakeholders to monitor effectively the implementation of any measures to combat discrimination.

Since 1993, Pavee Point has advocated for the collection of disaggregated data on the basis of ethnicity, inclusive of Travellers and Roma, within a human rights framework. This means there must be a universal question, which is answered voluntarily, and on the basis of self-identification, and that the collected data is aggregated and anonymised to avoid identification of specific individuals. Data must only be used for the purpose for which it was collected, must be available in a timely manner and must be analysed in consultation with organisations representing minority ethnic groups. The availability of accurate and timely data will contribute to increased awareness of inequality and the identification of appropriate target policies and interventions to eliminate identified disparities.

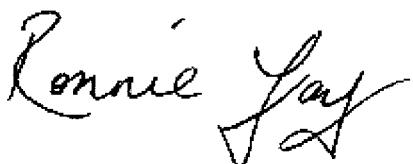
Ethnic equality monitoring, as a tool to inform and support our work with Travellers and Roma is a key strategic goal of Pavee Point and it has been the main driving force for the application of an ethnic identifier in Ireland since 1993. This was in conjunction with the Government's Task Force on the Travelling Community (1995) report that recognized the need to collect data to inform evidence-based policy, identify discrimination and promote equality. Pavee Point lobbied ardously on the issue and worked to ensure that Travellers were included in the national census, which resulted in the introduction of the 'ethnic/cultural background' question in 2006.¹ These efforts resulted in higher levels of self-disclosure among Travellers within the services and the national census,² with Census 2011 reporting a 32% increase of Travellers voluntarily self-identifying since the previous Census in 2006. The CSO acknowledged that the involvement of Pavee Point and other local Traveller organisations led to a seamless data collection process, providing considerably more accurate statistical data, and thus resulting in a much more effective use of limited resources (Healy, 2013).

The increased disclosure rates amongst Travellers are attributed to the persistent efforts of Pavee Point and local Traveller organisations in their promotion of voluntary self-identification within the community. Pavee Point continues to work closely with the CSO to support the collection of data in the census and encourage self-identification among Travellers and Roma. In addition to the CSO, Pavee Point has worked in partnership with various public bodies including Pobal, the National Drug Treatment Reporting System (NDTRS), the Irish Prison Service, the Rotunda Hospital, Connolly Hospital, Tallaght Hospital and Temple Street Hospital to ensure that data collection adheres to equality and human rights standards and data collectors are equipped with the necessary skills and confidence to monitor and evaluate ethnic data within a human rights framework. The implementation of an ethnic identifier within the census and services indicates that ethnic data can be collected with the right methodological approach, including the manner in which the question is asked, building confidence among the community and ensuring that individuals clearly understand the rationale for collecting data.

As part of our ongoing efforts to campaign for ethnic data collection within a human rights framework in Ireland, we established *Counting Us In: Human Rights Count*. This one year project is supported [in part] by a grant from the Foundation Open Society Institute in co-operation with the Open Society Initiative for Europe of the Open Society Foundations (OSIFE). The project focuses on advocating for the inclusion of an ethnic identifier in official data collection in Ireland and that implementation is in line with relevant human rights standards.

Pavee Point would like to acknowledge the OSIFE in supporting *Counting Us In: Human Rights Count*. We would also like to thank the members of the National Traveller and Roma reference group for their active participation and valuable feedback. The project has enabled us to conduct this research and focus our energy on further developing awareness about the value and need for ethnic equality monitoring with both statutory providers and Traveller and Roma communities.

We urge policymakers in this area to take on board the recommendations of this report and progress a clear Ethnic Equality Monitoring Strategy in partnership with Travellers, Roma and other minority ethnic groups without further delay.



Ronnie Fay
Co-Director, Pavee Point Traveller and Roma Centre

1. The question is largely perceived as a compromise, with the addition of the word 'cultural,' as Traveller ethnicity is not recognised by the Irish State, despite recommendations from several UN treaty-monitoring bodies, European institutions, equality and human rights bodies within Ireland, the Joint Committee on Justice, Defence and Equality and UN Member State recommendations during the Universal Periodic Review (UPR) process in 2011. Additionally, it was understood the 'ethnic/cultural background' question would evolve to reflect the changing ethnic composition of the Irish population; this has not been the case and the 2006 question remains in the upcoming census.

2. Travellers became more confident to self-identify once they were informed of the data collection process and were assured that data was anonymised.

Executive Summary

This report has been prepared by Pavee Point Traveller and Roma Centre (henceforth Pavee Point) in response to the data deficit on minority ethnic groups in Ireland, specifically the dearth of data on Irish Travellers and Roma. Pavee Point has been working to challenge racism and promote Traveller and Roma inclusion in Ireland since 1985. The organisation works from a community development perspective and promotes the realisation of human rights and equality for Travellers and Roma in Ireland. The group is comprised of Travellers, Roma and members of the majority population, who work together in partnership to address the needs of Travellers and Roma as minority ethnic groups experiencing exclusion, marginalisation and racism.

Travellers are a minority ethnic group, indigenous to the island of Ireland. Travellers maintain a shared history, language, traditions and culture. Nomadism was an integral part of Traveller culture, but many Travellers are no longer nomadic, either by choice or due to the lack of support for and criminalisation of nomadism. According to the 2011 Census, there are 29,495 Irish Travellers living in the Republic of Ireland, accounting for approximately 0.64% of the total population. These figures reflect a count of ascertained Travellers only³ and may be considered a conservative estimate, as the *All Ireland Traveller Health Study* (2010)⁴ establishes the Traveller population at 36,224 in the Republic of Ireland. Given its relatively small population and lack of ethnic identifiers in official data collection systems, the Traveller community is consistently absent from official statistics, particularly in the State's submissions to the European Union.⁵ Nevertheless, despite representing less than 1% of the nation's population, Travellers are widely recognised as one of the most marginalised and severely disadvantaged groups in Irish society. Similarly, Roma have been identified by various human rights organisations and monitoring bodies as a socially disadvantaged group who experience structural and systematic discrimination across Europe. According to Thomas Hammarberg, previous Council of Europe Commissioner for Human Rights, "Europe has a shameful history of discrimination and severe repression of the Roma. There are still widespread prejudices against them in country after country on our continent" (Hammarberg, 2006: para 14). Considered as one of the largest minority ethnic groups in Europe, 'Roma' is used as an umbrella term for people who self-identify as belonging to Roma, Sinti, Kale and

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3. This was based on self-identification as a Traveller. However, there may have been some reluctance by individuals to self-identify as Traveller because concerns of about prejudice or official interference.
 4. The All Ireland Traveller Health Study is the most comprehensive analysis of Traveller health undertaken in Ireland to date, with findings unveiling various health inequalities facing Irish Travellers on both sides of the border. Working in collaboration with researchers at University College Dublin, Traveller organisations and advocacy groups were able to obtain an unprecedented 80% response rate from members of the Traveller community (AITHS Team, 2010:32).
 5. This includes SILC and QNHS data provided to Eurostat, the statistical office of the European Union. Eurostat provides the European Union with statistics at European level, enabling comparisons between countries and regions.

other groups with a nomadic tradition, this includes Irish Travellers.⁶ Given its broad definition, it is difficult to establish a precise count of the Roma population in any given country, as EU Member States vary in their interpretation and application of the term. There is very little accurate and reliable data available about Roma in Ireland because data is collected on nationality rather than ethnicity. However, conservative estimates place the Roma population in Ireland between 3,000 and 6,000, with most deriving from Romania and Slovakia (Pavee Point, 2002; Pavee Point and HSE, 2012; Drew et al., 2012). This lack of data presents serious challenges in developing effective policies and appropriate services for Roma in Ireland.

Ethnic equality monitoring in Ireland remains the exception rather than the norm, with only a small number of public bodies routinely collecting, monitoring and evaluating ethnic data. Generally, where ethnic data collection exists it is not used constructively, primarily resulting in very poor statistical information. In addition to the lack of systematic and consistent data, ethnic identification has been ascribed to minority groups including Travellers and Roma, rather than the application of a universal question on ethnicity through voluntary self-identification. Information is not disaggregated,⁷ analysed or provided to relevant stakeholders within an appropriate timeframe. Such practices reflect a significant breach and disregard for human rights standards and data protection principles. Various national and international institutions, such as the Advisory Committee to the Framework Convention for the Protection of National Minorities⁸ (FCPNM), the European Commission against Racism and Intolerance⁹ (ECRI) and Committee on the Elimination of Racial Discrimination¹⁰ (CERD) have observed Ireland's data deficit and have urged the State to develop a standardised approach to data collection in accordance with relevant human rights standards. This report observes that there is a clear and urgent need to mainstream data collection practices by developing a standardised and integrated approach to ethnic data collection in Ireland, in line with relevant human rights standards,¹¹ as well as obligations under European Union institutions.

Statutory bodies and policymakers have increasingly supported the need for reliable and ethnic data to inform efficient, well-targeted, and well-implemented policies to combat discrimination and advance social inclusion (Goldston, 2006; Makkonen, 2007). Ireland requires disaggregated data as part of its strategic planning, as currently policymakers operate within a vacuum, lacking accurate and reliable information to develop and plan cost-effective and evidence-based social and development policies. Put simply, unless policymakers have information on the extent and causes of inequalities they will not be able to develop effective interventions and policies and to monitor progress. Information on ethnicity is necessary to develop knowledge on discrimination, establish objectives, monitor progress towards equality, evaluate the effectiveness of policy initiatives and develop targeted funding for innovative initiatives that deliver better outcomes to minority ethnic groups. Further, ethnically disaggregated data is critical to informing policy decisions and promoting equality of access, participation and outcomes in the areas of health, education, accommodation and employment. The collection and monitoring of ethnic data can be used to eliminate forms of discrimination in addition to justifying positive and affirmative action to ensure that the specific needs of minority ethnic groups are met (ECRI, 2006), which is permitted under the Equal Status Act 2000.

Despite the well-documented benefits of ethnic equality monitoring, there are a number of sensitivities and barriers to the collection of disaggregated data, including privacy and confidentiality, data misuse, participation, data collector discomfort, categorization and technical issues, time and associated costs (Donse et al., 2013; Fremont and Lurie, 2004). These tensions underline the need for adequate training and support for data collectors to ensure they understand the rationale for seeking such sensitive information and can alleviate the concerns of data subjects effectively and efficiently. Such sensitivities

6. The Council of Europe broadly defines "Roma" as, "Roma, Sinti, Kale and related groups in Europe, including Travellers and the Eastern groups (Dom and Lom), and covers the wide diversity of the groups concerned, including persons who identify themselves as Gypsies." (CoE, 2012b:4).

7. Disaggregated data is statistical data which is further broken down into categories based on for example, nationality, ethnicity, age, sex, or other indicators.

8. The Framework Convention for the Protection of National Minorities (FCPNM) is the Council of Europe's most comprehensive text for protecting the rights of persons belonging to national minorities. FCPNM is the first legally binding multilateral instrument devoted to the protection of national minorities worldwide. It was adopted on 10 November 1994 by the Committee of Ministers and it entered into force on 1 February 1998. It has 39 member states to date, including Ireland.

9. The European Commission against Racism and Intolerance is a human rights body of the Council of Europe, composed of independent experts, that monitor issues of racism, xenophobia, anti-Semitism, intolerance and discrimination on grounds such as "race," national/ethnic origin, colour, citizenship, religion and language (racial discrimination); it prepares reports and issues recommendations to Member States (CoE, 2014: para 1).

10. The Committee on the Elimination of Racial Discrimination (CERD) is the body of independent experts that monitors implementation of the Convention on the Elimination of All Forms of Racial Discrimination by its State parties.

11. Key human rights principles to data-collection processes include, voluntary self- identification, participation and data protection.

highlight the importance of consultation and active participation of key stakeholders such as Pavee Point and other NGOs in the data collection, analysis and evaluation process as they can encourage self-identification among minority ethnic groups and can provide valuable insight into formulating and monitoring effective development programmes.

This report draws on a wide range of national and international experiences of ethnic equality monitoring and aims to contribute to the existing body of knowledge advocating the use of ethnic data as a tool to support inclusive policies, combat discrimination and promote equality of access, participation and outcome for minority ethnic groups in Ireland. The objectives are twofold: (i) to confirm the legality of ethnic data collection by reviewing relevant data protection legislation in Irish, European and international human rights law (ii) to examine the challenges and sensitivities in collecting ethnic data and identify best practice. This report also examines the extent to which Ireland currently engages in ethnic data collection and whether statistical data is used to inform policy.

The recommendations from this report provide a framework for the more effective collection and application of ethnic data in Ireland. Key recommendations include the need for official senior level endorsement of ethnic equality monitoring to ensure that public sector bodies¹² routinely collect and publish ethnic data to inform good policy and practice. This includes the development of dedicated Ethnic Equality Monitoring (EEM) strategy in partnership with Travellers, Roma and other minority ethnic groups and implemented by all public sector bodies including Departments of Health, Justice and Equality, Education and Skills, Environment, Community and Local Government. Similarly, this report recognises the need for training and support for relevant government departments (HR, statistics and/or other sections) and data collectors across the public sector to ensure they are equipped, confident and skilled in implementing, monitoring and evaluating ethnic data. This includes the mandatory provision of anti-racism and cultural awareness training for all relevant staff and the resourcing of Traveller and Roma organisations to provide this training. While appropriate training and support for staff is fundamental to the success of ethnic equality monitoring, this report also recommends the targeted recruitment of data collectors from minority ethnic groups. Targeted recruitment of data collectors has been shown to have a significant impact on participation and willingness of minority ethnic groups to engage in the data collection process, in addition to illustrating positive role models from minority ethnic communities within the system.

The report concludes that there is a significant and compelling demand for a standardised approach to data collection in Ireland and the implementation of an ethnic identifier across all routine administrative systems, state agencies and surveys. The current status quo of an uncoordinated approach to data collection on an ad-hoc basis is inefficient and counterproductive as policymakers are unable to use small pockets of data to successfully devise cost-effective and sustainable policies. Equally, statutory agencies are unable to proactively plan efficient and effective services. Mainstreaming data collection practices, including the use of compatible data software would maximise the utility of data and equip both policymakers and statutory bodies with essential information required to make strategic and evidence-based decisions regarding policy and subsequent statutory actions.

12. This includes government bodies, local authorities, the HSE, Universities and Institutes of Technology, any other person, body, organisation or group financed wholly or partly out of moneys provided by the Oireachtas and certain companies where the Government is a stakeholder as per the Irish Human Rights and Equality Commission Act (2014).

Introduction

1.1 BACKGROUND

The issue of ethnic¹³ data collection is one that is contentious and often the subject of intense national and international debate. Since it adopted its first General Policy Recommendation in 1996, the European Commission against Racism and Intolerance (ECRI),¹⁴ acknowledging the difficulty in developing and effectively implementing positive policies to combat racism and intolerance without comprehensive data, recommended governments of Member States to implement a system of equality monitoring by collecting ethnic data:

In accordance with European laws, regulations and recommendations on data-protection and protection of privacy, where and when appropriate, data which will assist in assessing and evaluating the situation and experiences of groups which are particularly vulnerable to racism, xenophobia, anti-Semitism and intolerance. [ECRI, 1996: 6]

While a number of European states welcomed ECRI's recommendation to collect ethnic data for anti-discrimination law and policy purposes, data collection practices across Europe vary (Simon, 2007) with the United Kingdom being the only European country to systematically collect, monitor and evaluate ethnic data in compliance with public sector equality duty (PSED) obligations.¹⁵ The discrepancy in data collection practices reflects contrasting interpretations of data protection laws by Member States, with some interpreting data protection laws prohibitively, omitting the collection of ethnic statistics, while others use specific provisions of those same laws to collect ethnic data (ECRI, 2007: 7; Goldston, 2001).

Despite the Commission's subsequent recommendations to the Irish authorities to establish and implement a system of "ethnic data collection to assess and redress any racial discrimination that may exist in the country" (ECRI, 2007:32), Ireland has yet to incorporate an ethnic identifier across all official data collection systems. Consequently, this results in a

13. While the term 'ethnicity' remains largely contested among policymakers and academics, for the purpose of this document, 'ethnicity' refers to the shared identity or similarity of a group of people on the basis of one or more factors proposed in both case law and academic literature outlined in section 1.3.

14. The European Commission against Racism and Intolerance is a human rights body of the Council of Europe, composed of independent experts, that monitor issues of racism, xenophobia, anti-Semitism, intolerance and discrimination on grounds such as "race," national/ethnic origin, colour, citizenship, religion and language (racial discrimination); it prepares reports and issues recommendations to Member States (CoE, 2014: para 1).

15. The UK public sector equality duty requires public bodies, and those carrying out public functions, to have "due regard to the need to eliminate discrimination [...] to advance equality of opportunity [...] and foster good relations between those who share a protected characteristic (e.g. race) and those who do not" (Equality Act, 2010: 149[1]).

significant knowledge gap about the situation and needs of minority ethnic communities in Ireland and an absence of evidence-based policies and practices to ensure the needs of those communities are met. This deficit of disaggregated data poses significant challenges for service providers as they find it difficult to plan provision of their services effectively or to measure equality of access, participation and outcome for minority ethnic groups in Ireland. This was clearly identified in the Task Force Report of the Travelling Community (1995) as the planning process of services was seriously obstructed by lack of accurate information on the needs of service users (Pavee Point, 2002). The report recommended the implementation of mechanisms to identify, collate, and analyse data on the access and outcomes for Travellers of the various services including health, education and training, taking into consideration relevant data protection legislation (Task Force on the Travelling Community, 1995).

The recommendation of ethnic data collection by the Task Force Report of the Travelling Community (1995) has been reiterated numerous times since its publication by Pavee Point and a wide range of national¹⁶ and international bodies including the European Commission¹⁷ (2011) and the UN Committee on Economic, Social and Cultural Rights (CESCR) which recommended that "national strategies, policies and plans should use appropriate indicators and benchmarks, disaggregated on the basis of the prohibited grounds of discrimination" (CESCR, 2009; para 41) in order monitor and evaluate the actions taken to tackle discrimination in economic, social and cultural rights. Furthermore, Travellers and Roma are identified as one of the most vulnerable groups by EU institutions and according to the Council of Europe (CoE), "no European government can claim a fully successful record in protecting the human rights of the members of these minorities" (CoE, 2012a: 11). Consequently, Roma and Travellers are targeted under various EU strategies, including Europe 2020 and the EU Framework for National Roma Integration Strategies (NRIS) up to 2020. This creates obligations for the Irish State to unequivocally include Travellers and Roma in all relevant strategies, which address the inclusion of vulnerable and marginalised groups.¹⁸ NRIS has a strong economic and social focus, requesting all Member States, including Ireland, to develop and implement dedicated long-term strategies to promote Roma integration in four key areas: access to education, healthcare, employment, and housing and essential services. It also seeks to allocate sufficient targeted resources to achieve progress. However, in order to effectively comply with these obligations, Ireland must possess reliable data about specific target groups to inform policy responses and enhance the measurability of inequality and outcomes for marginalised groups at risk of discrimination. To date, the Irish State has failed to fulfil its responsibility and this is clearly reflected in disappointing EU progress reports on Ireland's implementation of the EU framework for NRIS (European Commission, 2012; 2013; 2014; 2015). The Fundamental Rights Agency (FRA) is currently working with Member States to develop process and outcomes indicators in the implementation of the NRIS. FRA actively encourages States to collect and use equality data, inclusive of ethnicity to populate these indicators.

The Framework does not adequately tackle the challenges of Roma exclusion, which are inextricably linked to pervasive hostility and discrimination against the Roma people. Member States had to submit their national strategies by the end of 2011 and the European Commission provides yearly assessments to the European Parliament and Council of the European Union on progress made towards the targets on the four key areas. It is important to note that the conclusions submitted by the Council are semi-binding for States. The approach with the NRIS was to some extent balanced by the Council of the European Union, as it is authorised to take suitable action to tackle discrimination and invite the Commission to "pursue rigorous monitoring of the implementation of Council Directive 2000/43/EC." From 2016, Member States will report on measures taken under the Council Recommendation on effective NRIS, which will serve as a framework for monitoring. This will add to a transparent monitoring system in which reporting from Member States and civil society will be included int the Commission's annual assessment (Jourova, 2015). In general, the adoption of the Framework is a major step forward and has the potential to make a difference by 2020 if efforts at all levels are maintained.

Moreover, Section 42 of the recent Irish Human Rights and Equality Commission Act 2014 (IHREC) specifically outlines "positive duty" obligations on public sector bodies¹⁹ to have regard for the need to eliminate discrimination, promote equality and ensure human rights are respected. It is important to note that "positive duty" places a commitment on public authorities to be proactive and advance equality and human rights practices within the public sector. While there is

18. This includes migrants and minority ethnic groups.

19. This includes, government bodies, local authorities, the HSE, Universities and Institutes of Technology, any other person, body, organisation or group financed wholly or partly out of moneys provided by the Oireachtas and certain companies where the Government is a stakeholder as per the Irish Human Rights and Equality Commission Act (2014).

no explicit legal requirement for public bodies to collect or analyse equality data,²⁰ it is important in the context of public sector bodies' obligations to comply with the Act, specifically Section 42. Without reliable information on ethnicity it will not be possible for public bodies to demonstrate that they have met statutory obligations. Access to accurate information on the situation of service users is essential to implementing this positive duty requirement and demonstrating that the general duties to eliminate discrimination and the promotion of equality and opportunity are being met.

Disaggregated data is critical for strategic planning, informing policy decisions and promoting equality of access, participation and outcome in the areas of health, education, accommodation and employment. Information on ethnicity is necessary to develop knowledge on discrimination, establish objectives and monitor progress towards equality, influence budgetary allocations and evaluate the effectiveness of policy interventions. Disaggregated data in this sense is mutually beneficial, as it enables policymakers to identify issues and trends that are emerging in relation to minority ethnic groups and develop informed policies and strategies, while at the same time, equipping those particular groups with comprehensive evidence to advocate for positive policies to address inequalities identified. However, it is important to note that minority ethnic groups are not homogeneous and therefore that ethnic data must also be disaggregated by gender and other relevant factors, such as age, disability, citizenship and so forth to ensure that particular groups within minority communities are not excluded from policies. This is particularly pertinent for minority women such as Travellers and Roma who experience intersectional discrimination on grounds of gender and ethnicity²¹ (CoE, 2012a). With disaggregated data and contextual analysis, policy initiatives and systems of implementation can be designed and evaluated with Traveller and Roma women in mind.

This report discusses the topic of ethnic equality monitoring and considers its relevance and importance in light of national and international debates. The report is divided into four sections. Section one focuses on context and defines key terms and outlines important contextual information in relation to Travellers and Roma in Ireland. Sections two and three provide a brief overview of both European and Irish interpretations of data protection laws and data collection practices, paying particular attention to the issue of 'sensitive data.' Section four explores the sensitivities and barriers to ethnic data collection and considers how to overcome such challenges by working in partnership with Traveller organisations and other NGOs in the design, collection and analysis of data. The final section concludes with the recommendations on improving ethnic data collection in Ireland by specifically locating it within a human rights framework.

1.2 TRAVELLERS AND ROMA IN IRELAND

1.2.1 TRAVELLERS

Travellers are a minority ethnic group, indigenous to the island of Ireland. Travellers maintain a shared history, language, traditions and culture (Dublin Travellers and Education Development Group, 1992). While nomadism is a fundamental part of Traveller culture many Travellers are no longer nomadic, either by choice or due to the lack of support for and criminalisation of nomadism by the Irish state²² (Pavee Point, 2011a). Travellers are explicitly named as a group protected from discrimination under Ireland's equality legislation (Employment Equality Acts 1998 and 2004 and the Equal Status Act 2000 and 2004). Yet despite legislative protection, Travellers experience discrimination in a number of settings, including education, employment and access to public places such as shops and pubs. According to the 2011 Census, there are 29,495 Irish Travellers living in the Republic of Ireland, accounting for approximately 0.64% of the total population.

20. Equality data refer to, "all types of disaggregated data used to assess the comparative situation of a specific discriminated group or group at risk of discrimination, design public policies so that they can contribute to promoting equality and assess their implementation" (Abdiyeva, 2014: 3).

21. This places huge restrictions on Traveller and Roma women's access to employment, education, health, social services and decision-making. This discrimination occurs both within the mainstream society in a context of anti-Traveller and anti-Roma racism, and also within their communities by reason of their sex. According to the CoE (2012), Roma women have a greater risk than non-Romani women of being exposed to all forms of violence against women, specifically domestic violence, trafficking and exploitation while facing additional obstacles in accessing protection (1). Traveller and Roma women who are affected by domestic and sexual violence face significant barriers to mainstream services and protections, placing them at further risk of gender-based violence. This is directly linked to their intersectional identity as women, as members of a minority ethnic group and as ethnic minority women (Pavee Point, 2015).

22. This refers to the Housing (Miscellaneous Provisions) Act and the Roads Act. Section 10 of the Housing (Miscellaneous Provisions) Act empowers Local Authorities to remove Travellers, who are camped unofficially, to an unofficial site anywhere within a five-mile radius of where they are. While Section 24 of this Act (also referred to as the 'Trespass Law') makes trespassing on land with an 'object' such as a caravan, a criminal offence. The Roads Act empowers Local Authorities and Gardai to remove temporary dwellings in certain circumstances.

These figures reflect a count of ascertained Travellers only²³ and may be considered a conservative estimate, as the All Ireland Traveller Health Study (2010)²⁴ establishes the Traveller population at 36,224 in the Republic of Ireland.

Despite representing less than 1% of the nation's population, Travellers are widely recognised as one of the most marginalised and severely disadvantaged groups in Irish society (O'Connell, 2002: 49; Heron et al., 2000: 95; Doyle, 2004:247-249) as they experience structural and systematic discrimination, state neglect and active prejudice. This has been observed both nationally and internationally by human rights organisations and monitoring bodies. Both the Advisory Committee of the FCPNM and ECRI reflected on the dire situation of Travellers in Ireland in their 2006 reports. Similarly, in a report on his visit to Ireland, Thomas Hammarberg, previous Council of Europe Commissioner for Human Rights, asserted, "Travellers have been subjected to discrimination and racism in the fields of education, employment, housing, healthcare, media reporting and participation in decision making" (Commissioner for Human Rights, 2008: 28).

More recently, the Seanad Public Consultation Committee expressed its concern that "Travellers in Irish society suffer high levels of racism and discrimination, including indirect discrimination" (Houses of the Oireachtas, Seanad Éireann, Seanad Public Consultation Committee, 2014:8). The UN International Covenant on Civil and Political Rights Committee (2014) reiterated this sentiment, expressing concern with the lack of progress for Travellers since the previous review in 2008, specifically in the areas of accommodation, equality and ethnic recognition. In its recommendations, the Committee encouraged Ireland to "adopt an effective policy and action plan, developed in consultation with Traveller and Roma communities, to redress situations of inequality" (UN Human Rights Committee, 2014: 7). This is similar to suggestions provided by Thomas Hammarberg, the UN Committee on the Elimination of Racial Discrimination (2011), and more recently in the concluding observations of the UN Committee on Economic, Social and Cultural Rights (CESCR, 2015). CESCR (2015) expressed its disappointment in Ireland's failure to provide the Committee with updated and disaggregated data,²⁵ making it extremely difficult to measure substantive progress of economic, social and cultural rights in Ireland (2). The Committee has urged the State to provide "updated information on the actual and progressive realisation of economic, social and cultural rights, including statistical data disaggregated by year, sex, disability, ethnicity and other relevant criteria" in its next periodic review (CESCR, 2015: 2). This was echoed by the UN Committee on the Rights of the Child (CRC) in their latest *Concluding Observations on the Combined Third and Fourth Periodic Reports of Ireland* (2016), urging the State to ensure that "data is disaggregated to clearly allow monitoring of the situation of Traveller and Roma children." The Committee further recommended "data and indicators be shared among the ministries concerned and used for the formulation, monitoring and evaluation of policies" (2016:4).

Historical and persistent experiences of anti-Traveller racism and discrimination have resulted in significant exclusion in the areas of health, accommodation, education, employment and participation in decision-making. In the most recent Traveller health study, indices of Traveller health were extremely poor, with the current state of Traveller health comparable with the levels found in the settled²⁶ population of the 1940's (AITHS Team, 2010:95; Pilson, 2011:5). In a national survey (MacGréil, 2010) commissioned by the Economic and Social Research Institute (ESRI), 40% of respondents reported that they would be unwilling to employ a Traveller. Additionally, the survey revealed that 18.2% of respondents would deny Irish citizenship to Travellers, and 79.6% of those surveyed responded that they would be reluctant to purchase a house next to a Traveller. Such hostile attitudes, largely informed by misconceptions, unveil the extent to which Travellers in Ireland experience racism and prejudice from the majority population, amplifying their precarious and marginalised position within Irish society. This is further compounded by the Government's refusal to acknowledge Traveller ethnicity, despite exhaustive recommendations²⁷ from several UN treaty-monitoring bodies (CERD, CEDAW, CRC, UNHRC, CESCR), European institutions (ECRI, FCPNM, CoE), equality and human rights bodies within

23. This was based on self-identification as a Traveller. However, there may have been some reluctance by individuals to self-identify as Traveller because of concerns about prejudice or official interference.

24. The All Ireland Traveller Health Study is the most comprehensive analysis of Traveller health undertaken in Ireland to date, with findings unveiling various health inequalities facing Irish Travellers on both sides of the border. Working in collaboration with researchers at University College Dublin, Pavee Point, local Traveller organisations and advocacy groups were able to obtain an unprecedented 80% response rate from members of the Travelling community (AITHS Team, 2010:32).

25. According to the Committee, it "regrets that the data provided by the State party are outdated and not disaggregated and that the replies to the list of issues do not include sufficient data, which makes it difficult for the Committee to assess the actual and progressive realisation of economic, social and cultural rights in the State party, including the impact of the measures taken during and after the economic crisis" (CESCR, 2015:2).

26. For the purpose of this document, 'settled,' 'majority population' or 'general population,' refers to those who do not identify as being a Traveller.

27. Former Commissioner for Human Rights Thomas Hammarberg (2008) explicitly recommended active dialogue between the Traveller Community and the authorities in relation to ethnic recognition.

Ireland, including the Irish Human Rights and Equality Commission, the Joint Committee on Justice, Defence and Equality and UN Member State recommendations during the Universal Periodic Review (UPR) process in 2011.

Pavee Point welcomed recommendations from the Joint Committee on Justice, Defence and Equality urging the Taoiseach or the Minister for Justice and Equality to "make a statement to Dáil Éireann confirming that this State recognises the ethnicity of the Travelling community" (Houses of the Oireachtas, 2014: 7). The Committee report has also recommended that the Government should contact the relevant international bodies, confirming that this State recognises the ethnicity of the Traveller community. This is the first report of its kind whereby an elected all-party committee advocated for the recognition of ethnicity and is a significant achievement in the steps towards acknowledgment of Traveller ethnicity. However, despite unanimous support and recommendations by the Joint Committee on Justice, Travellers have not been formally recognised as a distinct ethnic group. Pavee Point has recommended that the Government prioritise this action, as ethnic recognition would validate Travellers rights to self-determination. The lack of recognition of Travellers as a minority ethnic group has been accompanied by a denial of the racism that Travellers experience. Racism is inextricably linked to Travellers' social exclusion in Irish society and to say otherwise simply denies their lived experience and only serves to further marginalise Travellers. Recognition would also ensure Travellers are included in all State anti-racism and inter-cultural initiatives and forge a new dialogue as to how the State interacts with Travellers in the future.

1.2.2 ROMA

The European Court of Human Rights (ECtHR) has identified the Roma not only as a minority ethnic group but also as a socially disadvantaged group with particular needs.²⁸ Roma are considered one of the largest indigenous minority ethnic groups that trace their historical origins to Northwest India (European Commission, 2015). EU institutions use 'Roma' as an umbrella term for people who self- identify as belonging to Roma, Sinti, Ashkali and other groups with a nomadic tradition- including Irish Travellers²⁹ (Pavee Point, 2015). The Council of Europe (CoE) (2012) broadly define "Roma" as:

Roma, Sinti, Kale and related groups in Europe, including Travellers and the Eastern groups (Dom and Lom), and covers the wide diversity of the groups concerned, including persons | who identify themselves as Gypsies. [CoE, 2012b:4]

While each of these groups share a history of discrimination and marginalisation in European societies, it is important to note that they are not homogenous and remain culturally distinct from one another. Such a broad definition makes it difficult to establish an account of the exact population of the Roma in any given country, as EU Member States vary in their interpretation and application of the term. While it is widely acknowledged that Roma throughout Europe are dramatically undercounted (Chopin et al., 2014; European Roma Rights Centre, 2004; Project on Ethnic Relations, 2000), or in the case of Ireland, simply not counted at all in official data collection efforts.³⁰ According to the CoE (2012b) and the Fundamental Rights Agency (FRA) (2015), it is estimated that ten to twelve million live in Europe, approximately six million of whom reside in the European Union. In most of these countries Roma face considerable barriers to basic rights, particularly in relation to accessing health care, accommodation, education³¹ and employment,³² and are often disproportionately affected by poverty (Pavee Point, 2014a; FRA, 2014a; 2014b, 2012; CoE, 2012a) According to Thomas Hammarberg, "Europe has a shameful history of discrimination and severe repression of the Roma. There are still widespread prejudices against them in country after country on our continent" (Hammarberg, 2006: para 14). In several Member States, a majority of people hold hostile views on Roma (Italy: 85%, France: 66%, Greece: 53%, UK: 50%) (Jourová, 2015).

28. This was reinforced in *Yordanova and Others v. Bulgaria*, where the Court recognised the "underprivileged status of the applicants' group" in relation to accommodation.

29. According to the Department of Justice and Equality (2011) from an Irish perspective and with regard to the umbrella term used to define Roma, "the vast majority of Travellers/Roma in the Irish State are indigenous Irish Travellers" (3).

30. This includes national censuses and other administrative data collection systems. While Travellers are included in some data collection systems in Ireland (i.e.) the national Census, Roma are generally excluded and are enumerated on the basis of nationality rather than ethnicity.

31. According to FRA (2014a), segregation of Roma children in education is a persistent issue as many marginalised Roma children attend segregated schools or classes (Slovakia: 58 %, Hungary: 45 %, Greece: 35 %, Czech Republic: 33 %, Bulgaria: 29 %, Romania: 26 %). Furthermore, the Czech Republic and Slovakia report that more than 20 % of Roma children under the age of 15 attend 'special schools and classes' designated for children with mental disabilities (46-48). This, despite the European Court of Human Rights conclusion in 2007 (*D.H. and Others v. The Czech Republic*) that assigning Roma children to 'special schools' on the basis of their ethnic origin violates the government's obligation to ensure children's access to education without discrimination.

32. According to FRA (2014b), over one half of Roma (54%) reported feeling discriminated against when applying for paid work (Czech Republic: 74 %, Greece, Italy, France, Poland: 64-68 %).

The issue of segregated and 'special' education also continues to persist as many marginalised Roma children attend segregated schools or classes (Slovakia: 58%, Hungary: 45%, Greece: 35%, Czech Republic: 33%, Bulgaria: 29%, Romania: 26%) (Jourová, 2015). In the Czech Republic and Slovakia for instance, more than 20% of Roma children up to the age of fifteen attend special schools and classes designated for children with mental disabilities. Pavee Point have also echoed concerns of European institutions and groups such as the European Roma Rights Centre over increased anti-Roma violence in Europe and the strengthening of extremist and openly racist groups that propagate hate speech and organise anti-Roma marches (Pavee Point, 2014b). Many of the violent anti-Roma attacks have targeted families and children and have included firebombing, shootings, stabbings and beatings, resulting in several deaths (Vágólgyi, 2014; Pavee Point, 2014b; European Roma Rights Centre, 2012; 2011; Rorke, 2012). Ireland is not an exception, as discrimination and racism resulting in violence also remains a serious reality for many Roma residing in Ireland (Pavee Point, 2014).

According to the Department of Justice and Equality (2011), the Roma community in Ireland is largely comprised of individuals of Romanian, Hungarian, Polish and Czech Republic origin, all of whom are EU citizens, and as such, are protected by the provision of the European Communities (Free movement of Persons, No. 2) Regulations 2006 and therefore are not obliged to register their presence in the State (DJE, 2011:3; Drew et al., 2012:3). Additionally, Roma ethnicity is not included in the "ethnic/cultural background" question on the Irish Census, and public institutions, including the Central Statistics Office (CSO), do not collect data on Roma ethnicity. Conservative estimates however, place the Roma population in Ireland between 3,000 and 6,000³³ (Pavee Point, 2002; Pavee Point and HSE, 2012; Drew et al., 2012). The absence of official data on Roma in Ireland presents serious challenges for service providers in locating and addressing the needs of Roma groups in their local areas. The UN International Covenant on Civil and Political Rights Committee (ICCPR) has expressed concern at the lack of data concerning the Roma community in Ireland and at instances of discriminatory acts against the Roma community, including the forced removal of Roma children from their families into State care on the basis of their appearance (UN Human Rights Committee, 2014: 7). Many Roma families in Europe live in poverty, deprivation, and precarious living conditions due to a lack of access to employment and restrictive social welfare measures (FRA, 2014a; UNICEF, 2007; Milcher, 2006; UNDP, 2002). As a result, those who are unable to obtain employment must rely on charities and families or 'voluntary repatriation' to their country of origin (Çalgar and Mehling, 2013; Gunther, 2012; CoE, 2012a; Severance, 2010).

Furthermore, due to a long history of discrimination throughout Europe and the application of the Right to Reside and the Habitual Residence Condition (HR),³⁴ Roma are placed in very vulnerable situations. This is a key cause of poverty and a barrier to accessing adequate accommodation, education and healthcare and has been recognised by numerous international bodies and reports including ECRI (2013), the Special Rapporteur on Extreme Poverty and Human Rights (2011) and by CESCR (2015) who observed the gendered effect that Habitual Residence Condition has on particularly vulnerable women.³⁵ In their recommendations, the Committee advised Ireland to review the HR Condition in an attempt eliminate its discriminatory impact on access to social security benefits, specifically "among disadvantaged and marginalised individuals and groups, and ensure the consistent application of the criteria by providing clear guidelines and training to the relevant officials" (CESCR, 2015:6). This was reiterated recently by the CRC (2016). Recognising the devastating impact of the HR Condition on parent's access to Child Benefit payments, specifically Traveller and Roma parents, the Committee recommended that Ireland, "make Child Benefit payments a universal payment that is not contingent of the fulfilment of Habitual Residence Condition" (CRC, 2016:17). The Committee also urged Ireland to

33. According to the CoE (2015), approximately 37,500 Roma live in Ireland, this figure is inclusive of Irish Travellers and Roma; this figure has been provided by the Department of Justice (2011).

34. Habitual residence is a condition which applicants must satisfy in order to qualify for certain social welfare assistance payments, including child benefit. Habitual residence essentially means an applicant must be able to prove a close link to Ireland. Five factors are considered to determine habitual residence (Department of Social Protection, 2015):

1. the length and continuity of residence in the state or in any other particular country;
2. the length and purpose of any absence from the state;
3. the nature and pattern of the person's employment;
4. the person's main centre of interest;
5. the future intentions of the person concerned as they appear from all the circumstances.

All applicants applying for social protection are required to meet the habitual residence condition, including Irish citizens and EU citizens. Application of the Habitual Residence Condition has placed migrants, Travellers (who move across jurisdictions, generally from the UK to Ireland) and Roma in Ireland (and indeed returning Irish immigrants) in very vulnerable positions, whereby they cannot access any support services.

35. In its concluding observations, CESCR highlighted their concerns about the "discriminatory effect of the HR Condition on women who are victims of domestic violence, the homeless, migrants, Travellers and Roma in accessing social security benefits. It is also concerned at the lack of understanding of, and clear guidelines for, the relevant officials on the criteria applicable to decide on the HR" (CESCR, 2015: 6).

undertake concrete and comprehensive measures to "address the structural discrimination against Traveller and Roma children, particularly with regards to access to education, health and an adequate standard of living" (16).

While the Irish Government has developed a National Roma and Traveller Integration Strategy³⁶ (NTRIS) as required by the European Commission, the current strategy is completely inadequate and was developed without participation or consultation of Roma or Travellers. In their 2013 assessment of Ireland's NTRIS, the European Commission found that Ireland merely met 4 out of 22 criteria,³⁷ placing Ireland in the bottom third of assessed countries. Specifically the Commission observed that the strategy did not tackle forms of multiple discrimination against Roma women nor did it enforce anti-discrimination legislation at a local level and/or co-operate with National Statistical Offices (European Commission, 2013: 3-4). Subsequent assessments by the Commission continue to raise serious concerns in relation to the lack of targets, indicators, related timeframes and funding mechanisms. The Department of Justice and Equality has responded to these observations by initiating a revision of the National Traveller and Roma Integration Strategy³⁸ in consultation with various stakeholders, including Pavee Point. It is anticipated that the revised strategy will be published in late 2016, which will include a focus on cultural identity, gender equality and inclusion, employment, children and youth, health, anti-discrimination and equality, accommodation, Traveller and Roma communities and public services. However, in the interim, specific measures to ensure that Roma rights are respected, protected or fulfilled remain absent, leaving Roma largely exposed and vulnerable to discrimination. While some ethnic data collection initiatives have commenced, for instance the Social Inclusion and Activation Programme (Pobal, 2014), the National Drug Treatment Reporting System (Carew et al., 2013) and the Department of Education and Skills (DES, 2015), data mainstream programmes, services and strategies remain outstanding.

1.3 DEFINING ETHNICITY

Ethnicity is listed as one of the nine grounds on which discrimination is outlawed under equality legislation in Ireland.⁴¹ Historically, ethnicity was often conflated with the term 'race,' an essentialist ideology used to separate and classify groups taxonomically based on biological traits (American Anthropological Association, 1998). Arbitrarily defined by those in positions of power, 'race' was commonly imposed upon groups rather than based on self-ascription.⁴² While both race and ethnicity are used interchangeably, ethnicity is generally understood as a fluid concept, rooted in self-identification and encompassing a range of socially constructed characteristics (Barth, 1969; Royce, 1982; Anderson, 1983; Makkonen, 2007). Initially theorised by sociologist Max Weber (1922[1978]), ethnicity was conceptualised as a social construct rather than a genetic product. In his definition of ethnic groups Weber (1922[1978]) notes:

Those human groups that entertain a subjective belief in their common descent because of similarities of physical type or customs or both, or because of memories of colonisation and migration. [Weber, 1922[1978]:389]

Weber's classic definition radically redefined the way in which ethnicity was interpreted, by emphasising subjectivity rather than objective criteria. Further disentangling the concept of ethnicity from race, anthropologist Frederik Barth characterised ethnicity as biologically self-perpetuating, bounded, sharing fundamental cultural values, forming a field of communication and interaction, conscious of a category identity which is recognised by others (Barth, 1969:10–11). Embedded in social, historical and political contexts, ethnicity is a dynamic and fluid concept that remains 'essentially contested' (McVeigh, 2007: 91) among academics, policymakers and civil society (Barth, 1969; Wallman, 1979; McVeigh, 2007; Brown and Langer, 2010). Following Weber and Barth, and acknowledging the subjective and multifaceted nature of

³⁶This strategy is Ireland's Framework for National Roma Integration Strategies (NRIS) and will function as the Government's main policy tool for ensuring and promoting Traveller and Roma inclusion in Ireland.

³⁷For a comprehensive review on the Ireland's Progress report in implementing the National Roma Integration Strategy European Commission 2013 report) see: http://ec.europa.eu/justice/discrimination/files/roma_country_fac_tsheets_2013/ireland_en.pdf

³⁸Given the historical context and assimilative connotation associated with the word 'integration,' Pavee Point and other local Traveller/Roma organisations lobbied the DJE to amend the name of the strategy and consequently, Ireland's revised strategy is the **National Traveller and Roma Inclusion Strategy**.

³⁹. The Social Inclusion and Community Activation Programme (SICAP) is a national programme that aims to tackle poverty, social exclusion and long-term unemployment through local engagement and partnership between disadvantaged individuals, community organisations and public sector agencies.

⁴⁰. The National Drug Treatment Reporting System (NDTRS) is an epidemiological database on treated drug and alcohol misuse in Ireland.

ethnicity, most social scientists recognise, at a general level that ethnicity refers to belonging to a particular group and "sharing its conditions of existence" (Anthias and Yuval-Davis, 1992:5; Eriksen, 1993). Additionally, it has become widely accepted (Anderson, 1983; Bates, 2006; Horowitz, 1985; Varshney, 2001) that some or all of the following features largely define an ethnic group:⁴³

- a shared history;
- a common cultural tradition;
- a common geographical origin;
- descent from common ancestors;
- a common language;
- a common religion;
- a distinct group within a larger community

These principles are also imparted in the historic *Mandla v Lee* (1983) decision in the British House of Lords, which gave definitive consideration to the issue of ethnicity. In his analysis, Lord Fraser outlined the criteria to establish ethnicity, which included:

(1) A long shared history, of which the group was conscious as distinguishing it from other groups, and the memory of which it kept alive; (2) a cultural tradition of its own, including family and social customs and manners, often but not necessarily associated with religious observance. In addition [...] (3) either a common geographical origin or descent from a small number of common ancestors, (4) a common language, which did not necessarily have to be peculiar to the group, (5) a common literature peculiar to the group, (6) a common religion different from that of neighbouring groups or from the general community surrounding it, and (7) being a minority or being an oppressed or a dominant group within a larger community. [Mandla v Lee, 1983: 2AC548]

In addition to influencing the wider academic discourse on ethnicity, *Mandla v Lee* became the benchmark for legal cases concerned with the question of ethnicity; including the landmark *O'Leary and Others v Allied Domecq and Others* case, which applied the criteria outlined above to recognise Irish Travellers as an ethnic group (McVeigh, 2007). This objective criteria continues to be subject to debate in the absence of a universally accepted definition of ethnicity. However, it is constructive to draw on emerging case law as well as academic definitions in conceptualising the term, particularly in light of Ireland's obligation to proactively advance equality and human rights practices. Ethnic equality monitoring is one tool that can facilitate this process.

1.4 WHAT IS ETHNIC EQUALITY MONITORING?

Ethnic equality monitoring (EEM) or ethnic monitoring, is the process used to collect, store, analyse and utilise data about the ethnic composition of a population on a regular basis (Quirke, 2002; NCCRI, 2007). It is the systematic collection and use of data to ensure that policymakers respond appropriately to the diverse needs of a population and to establish mechanisms to promote equality and opportunity. According to Johnson (2002) ethnic monitoring is:

A process whereby information about the relevant aspects of people's ethnic origins is collected, recorded and used to establish patterns, which can be compared with other information about their relationship with society and need. [Johnson, 2002: 77]

This is vital to reduce inequalities and enhance outcomes for marginalised groups. It is also fundamental to effectively equality proof,⁴⁴ enhance performance of services, improve service delivery and to improve wider social cohesion (Quirke, 2002).

41. The prohibited grounds of discrimination are outlined in both the Equality Act 2000 and the Employment Equality Act 1998 and includes; gender, marital status, family status, age, race, religious belief, disability, sexual orientation and membership of the Traveller community.

42. The definition of racism contained in the UNESCO Declaration on Race and Racial Prejudice (1978) argues that racism is not about biological traits or colour, but rather, prejudices concerning hierarchy, inferiority and superiority based on racial or ethnic ascription or "any theory involving the claim that racial or ethnic groups are inherently inferior" (Article 2: 62). According to Eriksen (1993), it is important to stress that despite its suspect historical application to particular groups, race exists as a cultural construct, irrespective of 'biological' reality.

43. According to the OHCHR (2010) an autonomous definition of the term "ethnic minorities" is established by objective criteria rather than a decision by that State party.

44. According to the National Economic and Social Forum (1996) equality proofing is an "integrated and systematic approach to ensure that discriminated and marginalised groups are provided with necessary means and resources to participate in society as equal citizens" (4).

According to Quirke (2002), analysed data must be:

1. Provided to relevant stakeholders such as policymakers and organisations representing minority ethnic groups;
2. Used to inform policy; and
3. Used to both monitor and evaluate strategies.

Additionally, this process should be understood as more than a technical exercise in data collection and analysis. Rather, it is a dialogue and a mutually beneficial democratic process, to strengthen accountability and transform power relations between stakeholders (Theis, 2004: 104). Ethnic equality monitoring can be specifically used to (Quirke, 2002; Aspinall and Anionwu, 2002):

- Report on access, participation and outcomes of Travellers, Roma and other minority ethnic groups;
- Identify discrimination and highlight possible inequalities;
- Investigate their underlying causes and take action on inequalities, disadvantages or discrimination identified and make reasonable accommodation of the individual service users;
- Redress disadvantage or inequality identified through evidence-based policies;
- Monitor and evaluate the efficacy of policies.

Ethnic equality monitoring is not a simple solution to eradicate discrimination. It is a powerful tool that can highlight areas of concern, specifically subtle processes of inequality and discrimination which otherwise may go undetected (Wagman, 2002). This is particularly true if data is collected and analysed without having been adequately disaggregated. Using data from the national census as a baseline, ethnic equality monitoring can be understood as contextualising inequality as it provides insight into the socioeconomic situation of individuals and their collective identities. Ethnic equality monitoring allows inequalities in society to be investigated at the level of individuals, is population based and a current source data, and accordingly, reflective of contemporary reality (Aspinall and Anionwu, 2002). Data can be used in the absence of ethnic data collection, however, the measurement of policy outcomes remains fractured, simply contingent on the energies and resources of local initiatives or organisations to collect data, making it difficult to compare across agencies and areas. Comprehensive data is vital to develop and implement effective programmes and enforceable standards to ensure non-discrimination, facilitate the provision of culturally appropriate services, identify/track similarities and differences in performance and quality of care in various geographic, cultural, and ethnic communities.

Ethnic Equality Monitoring and EU/CoE Standards

There has been an emerging dialogue between Member States around the need for ethnically disaggregated data. The European Commission (2000/43/EC) has recognised the critical role of disaggregated data in initiating anti-discrimination policies and increasing its capacity to promote diversity and equality and ensure social cohesion (Open Society Foundations, 2010: 11-12). The Commission continues to stress the need for more specific and reliable information to support EU policies. Directive 2000/43/EC ('Race Equality Directive') explicitly states that Member States should take "adequate measures to promote social dialogue [...] with a view to fostering equal treatment, including through the monitoring of the workplace practices." Article 13 of the Directive states that Member States should designate a body or bodies for the promotion of equal treatment of all persons without discrimination on the grounds of racial or ethnic origin. These bodies are to conduct independent surveys, publish reports and make recommendations on any issue relating to discrimination. Further in recognising the importance of using statistical data in legal proceedings, particularly with regard to indirect discrimination, the Directive states:

The appreciation of the facts from which it may be inferred that there has been direct or indirect discrimination is a matter for national judicial or other competent bodies, in accordance with rules of national law or practice. Such rules may provide in particular for indirect discrimination to be established by any means including on the basis of statistical evidence [Council Directive 2000/43/EC: para 15]

However, while some Member States have embraced ethnic equality monitoring through the collection of ethnic data, others have been hesitant,⁴⁵ expressing legal and moral concerns and as a consequence, current policies on collecting ethnic data remain inadequate in most of Europe. The rationale from reluctant Member States is preservation of individual privacy against potential abuses, which have historically occurred in both totalitarian and democratic countries⁴⁶ (Seltzer, 2005; Seltzer and Anderson, 2000). Although these concerns have validity in some instances, they may be an expedient solution for some Member States to avoid grappling with legal and policy complexities and highlighting internal failures to combat discrimination. Interestingly, while Member States such as France, Germany and Sweden⁴⁷ vehemently refuse to

45. Countries such as Bulgaria, France, Germany, Hungary, Ireland, Romania, and Sweden have resisted these recommendations and do not collect ethnic data (Open Society Foundation, 2014:6).

46. Under the Fascist regimes of World War II, governmental records of national origin and descent were used to identify and persecute Jews, Roma, and other minority groups. Similarly, in Rwanda identification cards revealing the holder's ethnicity were used to locate Tutsi victims in the 1994 genocide (Seltzer and Anderson, 2000). Other examples of human rights abuses include the internment of Japanese Americans during WWII; the forced removal of Native Americans from their territorial lands in the United States in the nineteenth century; and the forced migration of minority populations in the Soviet Union in the 1920s and 1930s (Seltzer and Anderson, 2000: 484).

47. In Sweden, police authorities established illegal databases of Romani people in a program originally designed for counterterrorism operations (Gardell, 2013).

engage in ethnic data collection, espousing national values of upholding privacy they simultaneously engage in ethnic profiling,⁴⁸ violating privacy and the principle of equal treatment⁴⁹ (Open Society Foundations, 2012; Open Society Institute, 2009).

It is important to stress that ethnic data can be generated and utilised in ways that protect the privacy of individuals and groups while simultaneously providing essential information to assist policymakers combat racism and discrimination and develop equality measures to fulfil objectives prescribed by EU anti-discrimination legislation (Open Society Foundations, 2010: 12). This section serves as a background to ethnic data collection within the European Union. It outlines the relevant European legislation and international human rights conventions that govern data collection. Additionally, the section explores the issue of 'sensitive data' and provides an overview of the various interpretations by EU Member States.

2.1 EUROPEAN LEGISLATION

Following the emergence of information technology in the 1960s, European countries expressed the need for more comprehensive regulations to secure individual's personal data.⁵⁰ Subsequently, the 1970s witnessed an increase in the adoption of data protection/privacy laws by Member States in an effort to protect privacy and safeguard personal data (Simon, 2007; FRA, 2014a). These laws were followed by the adoption of Directive 95/46/EC⁵¹ ('Data Protection Directive'), which outlined the main principles of data collection for Member States and the Council of Europe's Convention ETS 108 for the protection of individuals with regard to automatic processing of personal data. Convention ETS 108 was the first international instrument to provide guiding principles that Member States later adopted into national laws (Simon, 2007). The Convention applies to all data processing carried out by private and public sectors⁵² and primarily seeks to regulate transnational flows of personal data and protect individuals against data protection breaches.

The principles established in the Convention require that personal data be obtained and processed fairly, retained for specified and justifiable purposes and not used for intentions incompatible with these purposes nor retained than is necessary. Data must be accurate, adequate, relevant, non-excessive and should serve a legitimate aim. In addition to providing specific guarantees on the collection and processing of personal data, Convention 108 ETS (Article 6) also outlines the appropriate legal provision when processing 'sensitive' data, such as ethnicity, racial origin, political opinions, religion, physical or mental health, sexuality, criminal convictions and trade union membership. Comparably, Directive 95/46/EC permits the collection of sensitive data provided that an individual consents and data is adequately anonymised.

2.2 'SENSITIVE DATA' AND CHALLENGES FOR MEMBER STATES

All EU Member States have ratified Convention ETS 108 and transposed the EU Data Protection Directive into national laws. This provides a somewhat coherent approach to data protection in a European context, although there are varied interpretations and distinctions between specific categories of data including, 'regular' personal data and 'special categories' of data, which are also referred to as 'sensitive' data. Both Directive 95/46/EC and Convention 108 ETS define these special categories of data and the conditions that may apply to their collection. In Convention ETS 108 special categories of data refer to:

Personal data revealing racial origin, political opinions or religious or other beliefs, as well as personal data concerning health or sexual life, may not be processed automatically unless domestic law provides appropriate safeguards. The same shall apply to personal data relating to criminal convictions.

[Convention ETS 108, Article 6]

48. According to the EU Network of Independent Experts on Fundamental Rights (2006), ethnic profiling is the "practice of classifying individuals according to their race or ethnic origin, religion or national origin, in order to facilitate decision-making in law enforcement" (9). Ethnic profiling is discriminatory, inefficient and violates basic human rights (Open Society Foundations, 2015).

49. Other countries that have reportedly engaged in ethnic profiling include Bosnia and Herzegovina, Bulgaria, Finland, Germany, Hungary, Italy, Latvia, Lithuania, the Republic of Moldova, Poland, Portugal, the Russian Federation, Serbia, Spain, Switzerland, Turkey and Ukraine (CoE, 2012a).

50. Personal data refers to data relating to a living individual who is or may be identified either from the data or from the data in conjunction with additional information that is in, or possibly can come into, the possession of the data controller (Data Protection Commissioner, n.d.a; para 6). This can include names, addresses, dates of birth, mobile phone numbers, etc.

51. Generally referred to as the 'Data Protection Directive,' this Directive clearly defines the obligations of Member States to protect individuals right to privacy with respect to the processing of personal data and the free movement of such data.

52. This includes data processed by judiciary and law enforcement authorities.

Directive 95/46/EC defines special categories of data as, "racial or ethnic origin, political opinions, religious or philosophical beliefs, trade-union membership, and the processing of data concerning health or sexual life" (Article 8.1). The processing of special categories or 'sensitive' data is subject to rigorous requirements and while a persistent view among many European states is that their legislative framework prohibits collection of 'sensitive' data, specifically, data disclosing racial or ethnic origin, this perception is erroneous. According to ECRI (2006):

There exist certain myths around the issue of ethnic data collection, which have to be deconstructed. The most persistent and erroneous view in many European countries is that their legislative framework does not allow for collection of data broken down by categories such as nationality, national or ethnic origin, language or religion. Although a comprehensive picture of all relevant legislation in all member states of the Council of Europe is not available, experience has shown that in most countries, national legislation does not formally prohibit the collection of this type of data, but only restricts it and makes it conditional on the respect of certain safeguards. [ECRI, 2006: para 32]

Indeed international law largely supports the application of a universal question and the principle of self-identification, allowing individuals to decide which ethnic, religious or linguistic group(s), if any, they identify with (UNDP, 2010).

The Committee on the Elimination of Racial Discrimination (CERD) also supports the principle of self-identification⁵³ and suggest that the manner in which individuals are identified as belonging to ethnic groups should, 'be based upon self-identification by the individual concerned' (Recommendation VIII). While both Convention ETS 108 and Directive 95 firmly set out a general prohibition on the processing of personal data, there are exemptions, and the general rule can be derogated when domestic laws provide adequate safeguards. According to the Convention ETS 108, **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.**

Further, Directive 95/46/EC (Article 8) outlines specific conditions under which the processing of sensitive data may be carried out. This includes: the explicit consent of data subject, the protection of their vital interests and the establishment or exercise of legal claims. Directive 95/46/EC also provides flexibility in Member States' understanding of their national context, permitting national legislation to authorise the processing of sensitive data 'for reasons of substantial public interest'⁵⁴ (Article 8.4). However, Member States interpretations of this provision vary. For instance, the United Kingdom recognises combating discrimination and ensuring substantive equality as an issue of public interest and systematically collects and analyses⁵⁵ sensitive data, including ethnicity. While other Members States such as Sweden and France, do not consider promoting equality as a public interest issue, and therefore, sensitive data is not included in national data collection practices (Abdiikeeva, 2014).

2.3 DISAGGREGATED DATA AND INTERNATIONAL HUMAN RIGHTS

While all EU Member States have adopted Directive 95/46/EC and ratified Convention ETS 108, they are also bound by their obligations to major human rights conventions⁵⁶ under the auspices of the United Nations and the Council of Europe. Under international human rights law, the state has a commitment to ensure that its national laws and institutions identify and tackle the manifestations, root causes and effects of discrimination, and to rectify any violations to individuals' right to equal

53. General comment No. 23 (1994) on the rights of minorities of the Human Rights Committee proposes that article 27 of the International Covenant on Civil and Political Rights imposes related obligations on State parties towards ensuring the survival and continued development of the cultural, religious and social identity of the minorities concerned, thus enriching the fabric of society as a whole.

54. This is subject to the provision of suitable safeguards.

55. The United Kingdom uses data to develop and evaluate equality policies, with such data perceived as a significant tool informing national policy planning.

56. This includes, the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic, Social and Cultural Rights (ICESCR), the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD), the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT) and the Convention on the Rights of the Child (CRC). Additionally, all EU Member States have ratified or signed the Convention on the Rights of Persons with Disabilities (CRPD).

treatment. This principle of non-discrimination is firmly rooted in all human rights instruments such as Articles 2 and 26 ICCPR, Article 1(1) CERD, Article 2(2) ICESCR, Article 2 CRC, Article 7 CMW and Article 5 CRPD. In order to uphold this fundamental principle, Member States must collect and evaluate disaggregated and comparative data to resolve forms of discrimination that may otherwise be disregarded and unaddressed, specifically as it relates to marginalised and vulnerable individuals and groups (Donse et al., 2013:14).

Equally, the right to protection of privacy is also guaranteed in a number of international human rights conventions, with the European Convention on Human Rights (ECHR) and the International Covenant on Civil and Political rights (ICCPR) providing a framework for the right to privacy under Article 17 ICCPR and Article 8 ECHR, respectively. In general, international human rights monitoring mechanisms have encouraged the disaggregation of data⁵⁷ on the basis of the prohibited grounds of discrimination such as ethnicity, sex, disability, religion, language, social or regional affiliation. The use of relevant and reliable indicators is crucial in order to assess human rights violations and to reveal the most deprived and vulnerable population groups and measure inequality and discrimination (OHCHR, 2012). Correspondingly, several institutions have highlighted the importance of collecting and processing personal data on the grounds of ethnicity. The Advisory Committee to the Framework Convention for the Protection of National Minorities consistently stresses the importance of ethnic data in the combating discrimination.

Similarly, in several of its general policy recommendations, ECRI urges states to collect data that will assist in assessing the situation of groups vulnerable to discrimination. The UN Statistics Division (2003) also argue that ethnically disaggregated data can improve access to various services including employment, education and training, social security, health, transportation and communications. The United Nations guidelines for states on the submission of core reports request information about the 'main ethnic and demographic characteristics of the country and its population,' while CERD, regularly impresses upon states the importance of collecting such information. Further, the Organisation for Economic Co-operation and Development recommends a human rights approach to the collection of data, emphasising the autonomy of an individual to voluntarily self-identify⁵⁸ and maintain control of data relevant to them. This approach is articulated in both the Convention ETS 108 for the protection of individuals with regard to automatic processing of personal data and in Directive 95/46/EC on the protection of individuals with regard to the processing of personal data and on the free movement of such data.

In addition to voluntary self-identification, protection from discrimination is also rooted in EU directives on equal treatment, specifically Directives 2000/43/EC ('Race Equality Directive') and 2000/78/EC ('Employment Equality Directive'). A significant tenet of the two directives is that they do not simply focus on individual experiences, but rather, on institutional and societal patterns and practices (Makkonen, 2006). The principles laid down in both Directives include a clear and comprehensive definition of discrimination and require States to create a national body for the promotion of equal treatment with an adept framework to provide independent assistance to victims of racial and ethnic discrimination (Makkonen, 2006:18). Specifically, Article 13 of the Racial Equality Directive requires that the national body or bodies must include 'conducting of independent surveys concerning discrimination,' and 'publishing of independent reports and making recommendations on any issue relating to such discrimination.' These proactive Directives, although not explicitly requiring the collection of ethnic data, strongly encourage Member States to adopt ethnic equality monitoring in their jurisdictions as a tool to measure and combat discrimination.

While the European Union has a significant role to play in promoting ethnic equality monitoring, the EU legal framework lacks oversight to mandate the collection or production of disaggregated data. Further, it is difficult to evaluate the effectiveness and practical implementation of the directives. According to the Open Society Foundations (OSF), Migration Policy Group (MPG) and the European Network against Racism (ENAR) (2014) it is critical to operate at an EU member-state level to renew the debate on equality data collection and "foster a change of attitudes among authorities and the public on this issue in light of the limited powers of the EU and international human rights institutions to enforce data collection obligations" (2-3).

57. This includes CEDAW, General Recommendation No 9 on Statistical data concerning the situation of women (1989), General Recommendation No 19 on Violence against women (1992), and General Recommendation No 23 on Article 7, political and public life (1997); CRC, General Comment No 4 on Adolescent health (2003), General Comment No 5 on General measures of implementation of the Convention on the Rights of the Child (2003); CRC, Concluding observations on the combined third and fourth periodic reports of Ireland, Recommendation No 18 and Recommendation No 70(a) (2016); CERD, General Recommendation No 25 on related dimensions of racial discrimination (2000), and General Recommendation No 34 on Racial discrimination against people of African descent (2011); CESCR, General Comment No 20 on Non-discrimination in economic, social and cultural rights (2009).

58. Self-identification implies that the data subject determines the characteristics that apply to him or her (such as belonging to a specific ethnic group).

Yet, in practice, all Member States collect data that reveal race or ethnicity using alternative criteria or proxies⁵⁹ such as place of birth, nationality, country of birth of parents, citizenship, language spoken at home, migration background (Abdikeeva, 2014:9), and in the case of Roma, appearance (Wagman, 2002) or Travellers, address or surname name. While these categories may be used to reveal an individual's ethnicity, they do not provide accurate information in relation to discrimination and are often obtained without seeking appropriate consent from the data subject (Abdikeeva, 2014:10). Critics of proxy based data collection argue that it disenfranchises minorities, questions their right to self-identification, disregards their discrimination experiences and further stigmatises minority ethnic groups (Chopin et al., 2014: 58; Simon, 2007: 41). According to the Open Society Foundations (OSF) and the Migration Policy Group's (MPG) (2006) guidelines on the collection and use of equality data to fight discrimination in Europe, in the context of ethnic data collection, proxy data "cannot be used for the purposes of developing or monitoring policies aiming at ensuring equality and fighting for discrimination on the basis of ethnic/racial or any other group protected by anti-discrimination law" (5). The guidelines state that proxy data frequently fails to accommodate the "interests of the groups at risk of discrimination, ensure equality or be useful in the fight against discrimination" (OSF and MPG, 2006: 5). Moreover, given that the collection of ethnic data is permitted under the European data protection regime, the use of proxies is unnecessary and raises serious doubts in terms of compliance with provisions outlined in Directive 95/46/EC (Chopin et al., 2014).

59. Danish, Swedish, German and French ethnic data is very limited with no collection of information on voluntary self-declared ethnicity. These countries primarily rely on proxies such as country of birth, lines of descent and citizenship status (Law et al., 2009).

Ethnic Equality Monitoring in Ireland

Ethnic equality monitoring in Ireland remains largely fragmented, with only a small number of public bodies⁶⁰ routinely collecting and monitoring ethnic data. This has resulted in "isolated 'silos' with significant variation in quality, fragmentation, duplication, access problems, and increased costs" (HIQA, 2014: 11). Further, ethnic data is often poor in quality data with little distinction between minority ethnic groups and low rates of completeness.

Often ethnicity has been ascribed by a data collector to minority groups including Travellers and Roma, rather than the application of a universal question on ethnicity through voluntary self-identification. Information is not disaggregated, analysed or provided to relevant stakeholders within an appropriate timeframe. These practices reflect a serious disregard for human rights standards and data protection principles. In light of recent "positive duty" obligations on public sector bodies to eliminate discrimination, data collection practices must adhere to relevant data protection rules and human rights standards. This positive duty requires public sector organisations to have regard to eliminate discrimination, promote equality of opportunity, and protect human rights under the Irish Human Rights and Equality Commission Act 2014. Public bodies are required to assess the human rights and equality issues they believe to be relevant to the functions and purpose of the body, to identify the policies, plans and actions in place or proposed to be put in place to address those issues, and to report on developments and achievements in that regard.

This section examines ethnic equality monitoring in Ireland, focusing specifically on data protection legislation and current data collection practices and analyses. This section also explores the gaps and key target areas for data and considers how ethnic equality monitoring can effectively inform policy and practice by presenting two case studies for which ethnic data is systematically collected and utilised to inform practice.

3.1 DATA PROTECTION LEGISLATION

In Ireland, data protection is governed by the Data Protection Acts 1988 and 2003 (DPA). The Data Protection Act, 1988 was enacted following Ireland's ratification of the 1981 Strasbourg Convention and established the office of the Data Protection Commissioner (DPC). This was later amended by the enactment of the Data Protection Act (Amendment) 2003, which brought Irish data protection law into compliance with the requirements of EU Directive 95/46/EC (Data

60. This includes the Central Statistics Office, Rotunda Hospital, Temple Street Hospital, National Drug Treatment Reporting System (NDTRS), Pobal, Department of Education and Skills (DES), Higher Education Authority (HEA), Irish Prison Service, Rotunda Hospital, the Health Protection Surveillance Centre (HPSC), the Child and Adolescent Mental Health Service (CAMHS) and the Cystic Fibrosis Registry of Ireland.

Protection Commissioner, n.da). Aiming to strike a balance between the right to privacy and the right to freedom of expression, the Acts protect personal data and provide specific requirements in relation to the collection, processing and handling of personal data.⁶¹ The Acts are clear in their approach to the collection of personal data, asserting that information about individuals must be: accurate, only made available to particular individuals and only used for specified purposes. Additionally the Acts state that an individual possesses the right to access personal information relating to them and have any errors corrected, blocked⁶² or have the information erased. In such cases, the data subject may also require the data controller⁶³ to notify parties who had previously previewed the incorrect data within a 12-month period, unless this proves impossible or involves a disproportionate effort (Data Protection (Amendment) Act 2003, Section 6:12). The DPA clearly states that organisations or individuals that possess personal data have a duty of care to the data subject.⁶⁴ If data subjects suffer damage through the mistreatment of personal information, they are entitled to seek compensation in court (Data Protection (Amendment) Act 2003, Section 6:29). In summary, there are eight key principles to the Data Protection Acts (Data Protection Commissioner, n.db):

- 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.**

However, despite clear principles laid out in the Acts, considerable confusion remains about the legality of data grounded on ethnicity as it is considered 'sensitive' by the DPA. Sensitive data is defined in the DPA as any personal data that indicates:

- a. The racial or ethnic origin, the political opinions or the religious or philosophical beliefs of the data subject;**
- b. Whether the data subject is a member of a trade union;**
- c. The physical or mental health or condition or sexual life of the data subject;**
- d. The commission or alleged commission of any offence by the data subject; or**
- e. Any proceedings for an offence committed or alleged to have been committed by the data subject, the disposal of such proceedings or the sentence of any court in such proceedings.**

Exceptionally stringent rules apply to the collection and use of sensitive data in Ireland, as data collectors must adhere to the specific conditions that have been created to maintain the fundamental rights and freedoms of data subjects (Data Protection (Amendment) Act 2003, Section 6:12-13). In addition to complying with the eight key principles outlined in the DPA, sensitive personal data shall only be processed following explicit and unambiguous consent⁶⁵ by the data subject. While the data collector cannot circumvent explicit permission, exemptions to consent are possible in a number of circumstances. Section 2B of the DPA outlines the conditions, for which the processing of sensitive data is permissible, including, where the processing of such data is mandated by employment law, that the data is vital to prevent injury to the data subject, the processing of data has been carried out through legitimate activities of non-profit organisations in respect of its members or other persons in regular contact with the organisation and the processing of such data is necessary for medical purposes.⁶⁶

61. The DPA applies to individuals or organisations in Ireland that collect, store or process data about living people on any type of computer or in a structured filing system (Corbett et al., 2012:1).

62. This involves marking the data in a way that prevents the processing or making it impossible to process the data for purposes to which it is marked.

63. A data controller is the individual or the legal person who controls and is responsible for the keeping and use of personal information on computer or in structured manual files (Data Protection Commissioner, n.dc: para 1).

64. This includes a data controller or a data processor (Data Protection Act 1998, Section 7).

65. Consent does not have to be in writing; however, it is necessary to be able to prove consent is given.

66. See Data Protection Act (Amendment) 2003, Section 2 for a comprehensive overview of the specific conditions governing the processing of sensitive data in Ireland.

3.2 DATA COLLECTION PRACTICES IN IRELAND

Collecting data on ethnicity is complex because of the subjective, multifaceted and fluid nature of ethnic identification (Afkhami, 2012). Consideration must also be given to data protection issues that arise in the course of collecting data on ethnicity. In Ireland, there is, in general, a lack of data on the ethnic composition of the national population, as government datasets do not routinely collect subjective characteristics such as ethnicity. This results in significant gaps in knowledge about the situation and needs of minority ethnic groups such as Travellers and Roma and absence of evidence based policies and practices to ensure the needs of those communities are met. This data deficit also contributes to substantial obstacles in gathering evidence about racism and discrimination, making it extremely difficult for relevant stakeholders to challenge anti-Roma and Traveller discrimination and promote equality of access and outcome for members of minority ethnic groups.

Pavee Point has continuously lobbied⁶⁷ for the introduction of an ethnic identifier in routine administrative data systems as a tool to inform service planning, challenge discrimination and promote inclusion. While these efforts have been met with significant challenges, particularly under the recent guise of 'austerity' requirements, in which Traveller organisations and projects experienced disproportionate funding cuts of up to -80% (Harvey, 2013), the work has also experienced considerable progress. After significant lobbying directed at civil servants working in the Department of Education and Skills (DES) and high-level targets working in service provision,⁶⁸ the DES recently introduced an ethnic identifier in their Primary Online Database (POD).⁶⁹ Until 2014, Traveller children were the only group asked to identify their ethnic background (Chopin et al., 2014). Pavee Point was strongly opposed to this practice as it was not within a human rights framework and only served to make Traveller children feel further isolated within the education system. According to DES (2015), data will assist in establishing a comprehensive statistical profile of the diversity of the Irish school population and assist in monitoring and evaluating the progress of children from various ethnic and cultural groups.⁷⁰ This information is necessary for the development and implementation of appropriate policies and interventions. The Department have made a commitment to extend ethnic identification to post primary schools but this has yet to be implemented.

Similarly, Pobal⁷¹ introduced an ethnic identifier in their Social Inclusion and Community Activation Programme (SICAP) monitoring system in January 2015. Other public bodies⁷² collecting ethnic data include, the National Drug Treatment Reporting System (NDTRS), Higher Education Authority⁷³ (HEA), Irish Prison Service, the Health Protection Surveillance Centre (HPSC), Rotunda Hospital, Child and Adolescent Mental Health Service (CAMHS)⁷⁴ and the Cystic Fibrosis Registry of Ireland. Pavee Point have worked in partnership with all of these bodies to ensure that data collection is equality proofed and data collectors are equipped with the necessary skills and confidence to monitor and evaluate ethnic data within a human rights framework. Equally, Pavee Point has worked vigorously to generate awareness among Traveller and Roma communities to promote voluntary self-identification in an effort to combat low levels of disclosure in data collection process. These efforts have resulted in higher levels of self-disclosure among Travellers within the services and the national census,⁷⁵ with Census 2011 reporting a 32% increase of Travellers voluntarily self-identifying since the previous Census in 2006 (CSO, 2012a).

67. Ethnic data collection is a key strategic goal of Pavee Point and it has been the main driving force for the application of an ethnic identifier in Ireland since 1993. This was in conjunction with the Government's Task Force on Travelling Community (1995) report that recognised the need to collect data to inform evidence-based policy, identify discrimination and promote equality. Lobbying efforts include parliamentary questions, direct meetings with elected representatives, civil servants and service providers and the publications of position papers and submissions. Further efforts include raising issues at national Traveller and sectoral committees, linking with European and UN developments and profiling visibility to issues in shadow reports to various UN and Council of Europe committees.

68. Lobbying includes parliamentary questions, direct meetings with elected representatives, civil servants and service providers and the publications of position papers and submissions relating to education.

69. POD is a live Database, allowing the data collector to update information throughout the year (DES, 2014).

70. The Department of Education and Skills have adapted the 'ethnic/cultural background' question from the 2006 and 2011 Censuses of Population into their POD database and is inclusive of Irish Traveller and Roma. Despite its inclusion of Roma and Travellers, Pavee Point recognises the problematic and restrictive nature of ethnic categories listed in the POD database. For a full list of the POD parameters see: <http://www.education.ie/en/Publications/Statistics/Primary-Online-Database-POD-/POD-Full-List-of-Parameters-in-POD-Mainstream-School.pdf>.

71. Pobal is a not-for-profit organisation that manages various funding programmes on behalf of the Irish Government and the EU.

72. According to the Catalogue of National Health and Social Care Data Collections (HIQA, 2014), the Irish Childhood Diabetes National Register (ICDNR) and the National Perinatal Epidemiology databases: Perinatal Mortality Surveillance System, Severe Maternal Morbidity Audit and Surveillance of Homebirths Databases also collect ethnic data.

73. The Higher Education Authority (HEA) is the statutory planning and development body for higher education and research in Ireland. The HEA has advisory powers throughout the third-level education sector. It also is the funding authority for the universities, institutes of technology and other designated higher education institutions (DES, n.d.).

74. CAMHS includes both Travellers and Roma in their ethnic data collection process.

75. Travellers became more confident to self-identify once they were informed of the data collection process and were assured that data was anonymised.

3.3 USING DATA TO INFORM POLICY

While Ireland has made improvements in the area of ethnic data collection as more agencies and public bodies begin to adopt ethnic identification in data collection systems, there are a number of data collection gaps that impede progress. For instance, ethnicity is not included in the Survey on Income and Living Conditions (SILC), Ireland's household survey on income and living conditions. SILC is the only data source in Ireland, which combines health status, income and other socio-economic predictors such as class, education and family origin. This key source of equality data in Ireland reports on a number of key national poverty indicators, such as the 'at risk of poverty' rate, the consistent poverty rate and rates of enforced deprivation. SILC data also plays a critical role in meeting Irish national requirements in the areas of poverty, social exclusion and household income. Further, Ireland's SILC data is included in Eurostat's⁷⁶ comprehensive European Survey on Income and Living Conditions (EU-SILC), which is comparable cross-sectional and longitudinal multidimensional data on income, poverty, social exclusion and living conditions in EU Member States. Since 2010 and the establishment of the Europe 2020 strategy,⁷⁷ EU-SILC data is being used for monitoring the poverty and social inclusion in the EU. However, reporting on ethnicity is not a requirement under EU/Eurostat regulations and therefore Travellers and Roma who are recognised as the most marginalised and severely disadvantaged groups are excluded. The exclusion of Travellers, Roma and otherwise vulnerable minority ethnic groups from this prominent dataset obscures experiences of marginalisation and makes such groups invisible and immune from targeted policies for social inclusion. This also impedes on EU Member States' ability to strategically implement sound policies to promote participation, access and equality of outcome in their respective countries.

In addition to their SILC data, EU Member States must carry out a Labour Force Survey (LFS) to provide information on key labour market indicators. Again, similar to SILC, EU/Eurostat regulations do not require LFS surveys to collect ethnic data. The Quarterly National Household Survey (QNHS) is the Irish implementation of the EU- LFS. Replacing the annual April Labour Force Survey (LFS) in 1997, the QNHS is a nationally representative survey of private households in Ireland providing statistical data on key labour market indicators. Used primarily by the EU/Eurostat, government departments, research centres and universities involved in labour market research, the QNHS provides essential inputs to national policy makers. The QNHS has a larger sample than SILC and is designed to produce quarterly labour force estimates that include the official measure of employment and unemployment in the state. However, unlike SILC, the QNHS does not contain data on income or material deprivation. Statistics reported in the Irish QNHS are included in Eurostat's European Union Labour Force Survey (EU LFS) and the data is considered a key source for European statistics about the situation and trends in the European labour market. While the main purpose of the QNHS is the production of quarterly labour force estimates, there is also a provision for the collection of data on 'social topics' through the inclusion of special survey modules. Previous topics have included Equality, Sports and Physical Exercise, Pension Provision and Health Status and Health Service Utilisation.

With the exception of its special module on Equality, the QNHS does not collect information on ethnicity. While this module provided important information in relation to patterns of discrimination in Irish society, it failed to include a representative sample of groups who experience extreme levels of discrimination and social exclusion (i.e.) Travellers, asylum seekers, older people, homeless people and people with disabilities. This is largely due to its exclusionary criteria⁷⁸ of only surveying those living in private households. The QNHS defines a private household as, 'any one persons or group of persons (not necessarily related) with common housekeeping arrangements, separately occupying all or part of a private, house, flat, apartment or other private habitation' (CSO, 2012b: para 10). People living in institutions and Travellers living on halting sites are therefore excluded. In the United Kingdom, the equivalent labour force survey, which is disaggregated by ethnicity, has found that overall unemployment rates amongst minority ethnic groups are higher than in the general population. It also found that levels of unemployment varied considerably between minority ethnic groups on the basis of age and gender (United Kingdom Department for Work and Pensions, 2014).

76. Eurostat is the statistical office of the European Union situated in Luxembourg. Its task is to provide the European Union with statistics at European level that enable comparisons between countries and regions.

77. Europe 2020 is the European Union's ten-year jobs and growth strategy. It was launched in 2010 to create the conditions for smart, sustainable and inclusive growth, with greater coordination of national and European policy.

78. The QNHS excludes individuals residing in institutions (including prisoners), residential care settings, hospitals, assisted living and nursing homes.

In its reports, the QNHS acknowledges the small sampling size of Travellers, yet to date it has not taken proactive steps or developed inclusive measures to redress the lack of representation in its sampling. Similar to SILC, the sampling methods of the QNHS effectively mask inequalities by omitting the experiences of Travellers and other marginalised groups; groups that should be otherwise targeted for inclusion based on their de facto exclusion from the mainstream labour market. It also highlights the importance of assuming an inclusive and equitable research method such a stratified random sampling⁷⁹ strategy, which can be used to mitigate representative issues and ensure accurate and comprehensive reporting.

Clearly, there is an urgent need to mainstream data collection practices by developing a standardised and integrated approach to ethnic data collection in Ireland, in line with relevant human rights standards,⁸⁰ as well obligations under the European Union institutions by the Irish State. Furthermore, without a mandate, Member States are not required to collect ethnic data for European surveys such as SILC and QNHS. It is imperative that Ireland supports the collection of ethnic data and contributes to modifying the requirements for EU social surveys. Moreover, it is important that the EU adopt guidelines and recommendations for Member States to collect safe and inclusive equality data. Such reforms are critical given the role of data from such studies in framing policy both nationally and within the European Union. Adopting a strategic approach to data collection will result in better use of resources and increased efficiencies, as it would reduce costs by avoiding data collection duplication, increasing coverage and driving faster data collection. It would also assist in the compilation of reliable cross-sectoral data, permitting comparability internationally.⁸¹

Further, data collection systems must also incorporate an appropriate and inclusive methodology that reflects a representative sample of minority respondents. In order to facilitate this process and ensure that data collection and analysis are located within an equality and human rights framework, active consultation and participation with Traveller organisations and representative groups must occur (OHCHR, 2015; Pavee Point, 2002). Active engagement with NGOs and relevant stakeholders with diverse experience, knowledge and expertise during the development, design and implementation of an ethnic identifier is critical as stakeholders often provide the intermediary link between data collectors and data subjects. In addition to creating a more mutually beneficial data partnership, it also provides the opportunity to explain the purpose and benefits of data collection and build mutual trust with the communities involved. This is essential to increasing self-identification and generating evidence-based data to inform policy and practice.

Case Study 1:

The evolution of the 'ethnic/cultural background question' on the national Census offers useful insights into how active engagement and working in partnership with stakeholders can yield successful results in data capture.

The Central Statistics Office has been the primary body responsible for collecting population data for the census since 1821. The census provides national, regional and local demographic information, which is essential for planning the provision of health care, education and employment. The census also determines the allocation of members of Dail Eireann to constituencies as outlined in Article 16.2 of the Irish Constitution.⁸² While statistics collected by the Central Statistics Office (CSO) every five years provide an enumerated account of people living in Ireland on census night, not all ethnic groups are included in the 'ethnic/ cultural background' question, and as a consequence, groups such as Roma remain absent from the official demographic statistics. Further, it wasn't until relatively recent that a question on ethnicity was included in the census in the Republic of Ireland (King-O'Riain, 2007).

In 1994, Pavee Point approached the CSO to include an ethnicity question to identify the numbers of Travellers residing in Ireland.⁸³ This proposition was largely a result of Pavee Point's intense advocacy and lobbying efforts through the Task

79. A stratified random sample is a population sample that requires the population to be divided into smaller groups, referred to as 'strata'. Random samples of the population can be taken from each stratum, or group. This is particularly useful when describing or comparing particular segments of the population. The key advantage of this method is that it guarantees that each subgroup will be represented within a relatively large group of individuals in that sample.

80. Key human rights principles to data-collection processes include, a universal question, voluntary self- identification, participation and data protection.

81. Given the variety of collection practices among Member States, no reliable micro database has been produced to permit a European cross-country analysis (ENAR, 2012).

82. The census determines the allocation of members of Dail Eireann to constituencies as outlined in Article 16.2 of the Constitution (Bunreacht na hÉireann) as it states that the ratio between the number of members to be elected at any time for each constituency and the population of each constituency, as ascertained at the last preceding census.

Force on the Travelling Community and while the CSO acknowledged that it was too late to amend the census form, they agreed to include an extra category on the form permitting enumerators to report on the accommodation type (King-O'Riain, 2007). Using accommodation as a proxy, enumerators ascribed Traveller status to those households that objectively appeared as 'members of the Travelling community' (CSO, 1998: 244). According to the 1996 Census the number of Travellers counted in halting sites, encampments, caravans and mobile homes was 10,891, representing 3% of the overall population (CSO, 1998). This figure was recognised as an undercount by both Traveller organisations and the CSO, and in an effort to include a racial/ethnic question, the CSO invited submissions from a wide range of stakeholders⁸⁴ in preparation for the 2001-02 census. Despite receiving submissions from various stakeholder groups, the Irish government rejected the addition of the race/ethnicity question on the census 2002, citing that the revised format had not been piloted and the question was deemed too 'sensitive' (King-O'Riain, 2007: 524). Consequently, a comprehensive ethnic identification question did not appear on the Census 2002 form. Instead, Travellers were the only group asked to state their ethnic status,⁸⁵ this, despite a significant increase in minority ethnic groups in Ireland during this time (Pavee Point, 2002). While Pavee Point welcomed the inclusion of Travellers in the census, it was disappointed that a universal question on ethnicity was not posed to all census participants and were concerned that Travellers would perceive the question as further stigmatising their community.

Again, in 2003 the CSO requested submissions in anticipation of the 2006 census. Each of these stakeholders urged the CSO to include ethnic identification in the census as a method of identifying inequality. This was a direct result of intense lobbying efforts and consultation sessions with Pavee Point and the National Consultative Committee on Racism and Interculturalism (NCCRI). Subsequently, the 'ethnic/cultural background' question was introduced in the 2006 census. The question was perceived as a compromise by Pavee Point, with the 'cultural' background including Irish Travellers who otherwise would have been excluded due to the State's non-recognition of Traveller ethnicity. It was also largely understood that the 'ethnic/cultural background' question would evolve to reflect the changing ethnic composition of the Irish population; this has not been the case. The standard question developed in 2006 remains unchanged and will appear in Census 2016.

The number of people enumerated as Irish Travellers in Census 2011 was 29,573, an increase of 32% since census 2006. This increase is attributed to a greater disclosure amongst the Traveller population following collaboration between Pavee Point and the CSO in the inclusion of the ethnic question in census. In preparation for the 2006 census, the following Traveller-specific actions were implemented by Pavee Point with the support of CSO:

- Consultation with Pavee Point in the development of census questionnaires;
- Training provided by Pavee Point for census enumerator managers;
- Information and knowledge share;
- Development and dissemination of information DVDs to Travellers (explaining the purpose and benefits of the census and how to complete the form);
- Dedicated website on census fieldwork;
- Liaising and mobilisation of support for census among local Traveller organisations through the provision of awareness raising and training sessions;
- Operation of troubleshooting telephone hotline; and
- Dissemination of census results.

The CSO has acknowledged that the involvement of the Traveller organisations has led to a seamless data collection process, providing considerably more accurate statistical data, and thus resulting in a much more effective use of limited resources (Healy, 2013). The increased disclosure rates amongst Travellers is largely attributed to the persistent efforts of Pavee Point and local Traveller organisations in their promotion of self-identification within the community. Pavee Point continues to work

83. *The inclusion of Travellers in the Census was recommended by the Report of the Task Force on the Travelling Community (1995), which proposed that the CSO "include the Travelling Community as a separate heading in its classification of households in all future Censuses of Population"* (Task Force on the Travelling Community, 1995: 35).

84. *The CSO received 75 submissions in total from various stakeholders. This included government departments (Equality, Justice and Law Reform, Foreign Affairs, the Environment), community organisations (Pavee Point, NCCRI, Combat Poverty, Focus Ireland), in addition to Political Parties (Sinn Fein), Labour unions (Irish Congress of Trade Unions), local county councils and individuals, including ex-enumerators (King-O'Riain, 2007: 521).*

85. See <http://www.cso.ie/en/media/csoie/census/documents/censussampleform2002.pdf> for an example of the 2002 Census form.

closely with the CSO to support the collection of data in the census and encourage self-identification among Travellers and Roma. While Roma ethnicity is not listed as an option in the 'ethnic/cultural background' question, Pavee Point have worked in partnership with the CSO to develop appropriate resources and actions in an effort to support Roma to self-identify using the 'other' category in Census 2016. This includes the development and dissemination of information DVDs explaining the census process and rationale for census questions, including the 'ethnic/cultural background.' Pavee Point also hosted a number of information workshops for Roma to raise awareness about the value of census data collection and encourage self-identification. While Pavee Point welcomes these positive actions and continues to encourage Roma to self-identify, it has been quite challenging given the low levels of trust and engagement with State bodies. This is in the context of fears around ethnic profiling and child protection concerns,⁸⁶ an issue that has been exacerbated by the removal of two blonde Roma children from their families in October 2013 based simply on their appearance.

Case Study 2: NDTRS

International research has highlighted the need for service providers to become familiar with the ethnicity of their service users as cultural awareness can facilitate better communication and establish trust, which can ultimately lead to better outcomes for those particular service users (Carew, 2014). Moreover, without a systematic understanding of service users, services cannot effectively prioritise or target interventions and resources, thus, leading to ineffective services and inefficient allocation of resources. The National Drug Treatment Reporting System (NDTRS) provides a useful insight into how recording ethnicity can be used to understand the diverse needs of services users, and equally, how data can be used to develop effective policies to meet those specific needs.

The National Drug Treatment Reporting System is an epidemiological database on treated drug and alcohol misuse in Ireland. It was established in 1990 in the Greater Dublin Area and was extended in 1995 to report on all areas of the country. The reporting system was initially developed in accordance with the Pompidou Group's Definitive Protocol and subsequently revised in line with the European Monitoring Centre for Drug and Drug Addiction's Treatment Demand Indicator Protocol. Service providers at drug treatment centres⁸⁷ throughout Ireland use this reporting system and collect data on each individual who attends for first treatment or returns to treatment for problem drug or alcohol use within a twelve month period. Personal information such as gender, accommodation, education, socioeconomic information, nationality and ethnicity⁸⁸ is collected, anonymised and forwarded to the NDTRS for analysis (Bellerose et al., 2011; Carew et al., 2011). The inclusion of an ethnic identifier question in routine data collection allows the NDTRS to accurately record useful information on ethnicity for planning health services as it:

- Identifies patterns of substance use and risk behaviours;
- Explores patterns of service utilisation;
- Provides information for evidence-based service planning including obtaining and justifying funding and personnel;
- Analyses trends in treated alcohol and drug use over time.

Prior to 2007, Travellers and other minority ethnic groups were not enumerated in the NDTRS, as ethnicity was not recorded in the dataset. Instead, the NDTRS relied on information from Pavee Point and other local Traveller organisations reporting the increasing visibility of cannabis and cocaine use among Traveller men (Carew et al., 2013; Hurley, 1999). In 1999, Pavee Point conducted mixed-methods research on drug misuse within the Traveller Community. Using questionnaires, focus groups and consultative meetings with local Traveller groups, Pavee Point found that cigarettes, alcohol and cannabis were the substances most frequently used by Travellers, followed by ecstasy, amphetamines and

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84. The CSO received 75 submissions in total from various stakeholders. This included government departments (Equality, Justice and Law Reform, Foreign Affairs, the Environment), community organisations (Pavee Point, NCCRI, Combat Poverty, Focus Ireland), in addition to Political Parties (Sinn Fein), Labour unions (Irish Congress of Trade Unions), local county councils and individuals, including ex-enumerators (King-O'Rain, 2007: 521).

85. See <http://www.cso.ie/en/media/csoie/census/documents/censussampleform2002.pdf> for an example of the 2002 Census form.

86. Fears over child protection concerns among Roma must be examined in the context of previous experiences elsewhere in Europe, whereby assimilationist policies have resulted in the disproportionate number of Roma children placed in state care (Pavee Point, 2014:23).

87. Treatment for problem substance use in Ireland is provided by statutory and non-statutory services, including general hospitals, psychiatric hospitals, community-based services, residential centres, and prisons (Carew et al., 2013:342).

88. According to the NDTRS, ethnicity should not be ascribed by health professionals. For a full list of the NDTRS parameters see: http://www.hrb.ie/fileadmin/Staging/Documents/In_House_Research_Info_Systems/ADRNU/NDTRS/NDTRS_Protocol_Part_2_2013.pdf

solvent misuse. Heroin misuse within the community was reportedly low. The research also highlighted the lack of awareness among drug treatment service providers of Travellers service users.

In an effort to promote a more comprehensive data collection system and following recommendations from Pavee Point, local Traveller organisations, mainstream drug services and the National Advisory Committee on Drugs (NACD)⁸⁹ (Van Hout, 2011), the NDTRS adopted ethnic identifiers in their datasets comparable with those used by the CSO in the census. Similar to the introduction of the 'ethnic/cultural background' question in the census, the number of individuals seeking treatment for problem substance and identifying themselves as Travellers increased exponentially by 163% between 2007 and 2010 (Carew et al., 2013). Again, the increase of Travellers self-identifying within drug treatment services is chiefly attributed to the diligent work of Pavee Point and other local Traveller organisations in building the confidence of community members engaging with the services to voluntarily self-identify. Without these efforts and assuring the community that self-identification would be treated sensitively and would not result in adverse treatment, it is more than likely that the NDTRS would not have received such an overwhelming disclosure rate.

Nevertheless, the NDTRS (Carew et al., 2013) acknowledges that current figures may be under-representative of the actual number of Traveller service users. This may be attributed to reluctance among some Travellers to disclose their ethnicity for a number of reasons including lack of trust with the service providers and/or a provider's failure to explain the reasons for the ethnicity question (Carew et al., 2013; Cafferty, 2011). Similarly, there may be reluctance from health staff to ask the question. In its explorative research on Traveller experiences of engaging in drug and alcohol support services in Ireland, *Pavee Pathways: Good Practice Guidelines for Drug & Alcohol Services Working with Travellers*, Pavee Point (2011b) found that only 7% Travellers surveyed recalled being asked their ethnicity on first engagement with their primary service. Respondents reported feeling slightly uneasy with the question being asked, as a clear rationale was not provided at the time. Moreover, 83% Travellers surveyed noted that their ethnicity was not asked, with the remaining 10% unsure if they were asked about their ethnicity. This highlights the need for further training for data collectors to ensure they understand the rationale and benefits of ethnic equality monitoring for both the service user and the service provider.

Further, while ethnic data allows the NDTRS to quantify the number of Travellers availing of treatment services, it also provides valuable information for the formulation of interventions and effective policies. Prior to the implementation of the ethnic question in the NDTRS, there was a common perception among service providers and Traveller organisations that substance misuse, specifically opiate use and risky injecting behaviours, was particularly prevalent among Traveller men. However, ethnic data provided by the NDTRS found that Traveller women reported higher rates of opiate use and risky injection behaviours than their counterparts. Additionally, the data reflected that more Traveller women injected at the time of entry to treatment and shared injecting equipment than any other group reported during this period (Carew et al., 2013: 353). The findings present a challenge to health services, particularly in relation to the high level of sharing needles. This has implications for the delivery of needle exchange services and health services as intravenous users who share equipment are at a greater risk of becoming infected with HIV and the hepatitis C (HCV). The NDTRS has recommended that targeted measures are required to address some of these issues, including outreach initiatives specifically addressing the needs of Traveller women with problem substance use.

The NDTRS acknowledges that data collection in the Irish addiction services shows that it is possible to record valuable information on ethnicity. Admittedly, while the NDTRS has only been collecting data since 2007, the current analysis provides constructive baseline data on Travellers accessing addiction services from which services can build. The use of an ethnic identifier allows the NDTRS to form a profile of service users, ensure they are meeting their specific needs and facilitates an analysis of drug use trends amongst particular cohorts of their client group. However, the NDTRS also recognises the limits to their efforts, as other health and allied services do not collect similar data. According to the NDTRS, drug and alcohol misuse remains a serious issue in Ireland, presenting difficult and multiple challenges for service providers. In light of the current economic climate, it is a priority to develop targeted appropriate and cost-effective addiction services. Therefore, services must take into consideration the diversity of their service users and consider the specific needs and vulnerabilities of Travellers and other minority ethnic groups with problem substance use. The NDTRS advocate for the recording of ethnicity in routine assessments, arguing that accurate data is vital in service planning and delivery (Carew et al., 2013).

89. NACD was established in 2000 to advise the Government in relation to the prevalence, prevention, treatment, rehabilitation, and consequences of problem drug use in Ireland, based on the analysis of research findings and information.

Challenges and Sensitivities in Promoting Positive Outcomes

The potential benefits of ethnic equality monitoring are clear to many, including equality bodies, service providers, statisticians, academics and NGOs⁹⁰ (Chopin et al., 2014). However, there are a number of sensitivities⁹¹ and barriers to the collection of disaggregated data, including privacy and confidentiality, data misuse, participation in the data collection process, data collector discomfort, categorical and technical issues, time and associated costs (Donse et al., 2013; Fremont and Lurie, 2004; Hussain-Gambles et al., 2004). These challenges are addressed in the following sections.

4.1 CHALLENGES IN DATA COLLECTION

4.1.1 PRIVACY, CONFIDENTIALITY AND DATA MISUSE

Despite international and national legislation to protect individual's privacy, data confidentiality and the potential for data misuse are frequently cited as major challenges to data collection (Baker et al, 2005). In their research on ethnicity, race and primary language data in the US health care system, Perot and Youdelman (2001) found participants were ambivalent about the collection of their personal data and believed that data may be used for discriminatory purposes in an effort to "divide rather than unify" (20). In an attempt to mitigate these fears, participants expressed the need to adopt "mechanisms to safeguard privacy and security and prevent the misuse or abuse of data on minority populations" (20).

Similarly, there are reservations among some Travellers and Roma that the collection of data will be used to discriminate and stereotype their communities. This is particularly heightened for Roma who may have experienced data abuse in the form of ethnic profiling, segregation, forced sterilisation, genocide and violence⁹² (Chopin et al., 2014). Reluctance from individuals to disclose their ethnic identity to collectors is directly linked to the lack of trust of data collectors, which is quite often attributed to previous negative experiences of discrimination (Donse et al., 2013; FRA, 2009; Milcher and Ivano, 2004). This omnipresent fear of discrimination due to voluntary self-disclosure leads to the further problems of minority

90. This includes Pavee Point and the majority of local Traveller organisations, Migrants Right Centre Ireland (MRCI), National Traveller Money Advice and Budgeting Service (MABS), National Women's Council Ireland (NWCI), The National Traveller Women's Forum (NTWF) and European Network Against Racism (ENAR).

91. This section does not purport to be reflective of all challenges and sensitivities in data collection and should not be viewed as such.

92. According to the Project on Ethnic Relations (2000), "the Romani perspective on ethnic data collection is colored, to a large extent, by its negative use against their communities in the past and the present" (3). This includes the use of ethnic data by Nazis in WWII to persecute Roma communities. Further, some governments have used data purporting to illustrate 'Roma misbehaviour' as a justification that Roma were unfit for citizenship (1).

ethnic groups such as Travellers and Roma being considerably underestimated in surveys and censuses (Donse et al., 2013). The European Observatory on Health Systems and Policies (2011) identifies related difficulties in migrant communities throughout Europe as migrants are reluctant to reveal information about themselves due to "fear [of] discrimination, stigmatization, exclusion or, in the case of undocumented migrants, even denunciation and deportation" (84).

Correspondingly, according to the European Union Minorities and Discrimination Survey (EU-MIDIS) (FRA, 2009),⁹³ some Roma disclosed that they were unwilling to provide their ethnic background to data collectors, due to previous negative experiences of systematic oppression and discrimination. Comparably, Travellers are not always willing to disclose their ethnicity without establishing a rapport with the data collector. This was clearly highlighted in the *All Ireland Traveller Health Study*, which showed that over half of all Travellers (53%) were worried about experiencing unfair treatment following disclosure of their ethnic identity. This research also reported that merely 41% of Travellers had complete trust in health professionals treating them. This figure is compared with a trust level of 83% by the general population (AITHS Team, 2010:181). Comparably, less than one half (48%) of all Travellers surveyed believed that in general most people could not be trusted. Issues of trust and negative experiences with structured services have a direct impact on the level of engagement of Travellers in health and related services (AITHS Team, 2010: 111).

4.1.2 PARTICIPATION

According to Milcher and Ivano (2004), avoiding mistrust among minority ethnic groups is possible if communities are involved in the data collection, analysis and evaluation process. This is illustrated in the participation rates of Travellers in the *All Ireland Traveller Health Study*. Despite reservations and distrust among Travellers, Pavee Point and other Traveller organisations worked in partnership with researchers at University College Dublin and obtained an unprecedented 80% response rate from Travellers during the study (AITHS Team, 2010:32). The innovative methodology of the research included building trust with the community and actively engaging with Traveller organisations in the design, collection and analysis of data. This exceptionally high participation rate of Travellers indicates that sensitive data can be collected with the right approach, including the manner in which the question is asked, building confidence among the community and ensuring that individuals clearly understand the reasons for collecting data, and how the data will be used and stored. It is vital that Pavee Point and other NGOs are involved in the data collection, analysis and evaluation process as they can assist in raising awareness about the benefits of ethnic data among minority ethnic groups and can provide valuable insight into formulating and monitoring effective development programmes (Ramsay, 2006). Additionally, the recruitment of data collectors from minority ethnic communities as in the *All Ireland Traveller Health Study* is another obvious method of ensuring trust and participation.⁹⁴ Such an inclusive and participatory approach adheres to fundamental human rights principles and has been recognised as best practice by Pavee Point, various international human rights instruments,⁹⁵ academics, international stakeholders such as FRA, ECRI, UNDP and many NGOs and advocacy groups (Chopin et al., 2014; Carew et al., 2013; Donse et al., 2013; Open Society Foundations, 2010; Bhopal, 2007; Milcher and Ivano, 2004).

4.1.3 DATA COLLECTOR DISCOMFORT

Equally, reluctance or discomfort from data collectors to ask individuals their ethnic background has been identified as a potential barrier in the collection of ethnic data (Carew et al., 2013; Donse et al., 2013; Bhopal, 2007; Regenstein and Sickler, 2006; Hasnain-Wynia and Baker, 2006; Hasnain-Wynia and Pierce, 2005; Perot and Youdelman, 2001). Data

93. This was the first comprehensive survey data sampling 25,000 ethnic minority and immigrant people across 27 EU Member States.

94. In the *All Ireland Traveller Health Study*, Pavee Point identified more than 40 Primary Healthcare for Traveller Projects, which included approx 320 Traveller Community Health Workers and 40 project coordinators who were trained to a standardised level as enumerators. This had many advantages over using non-Traveller enumerators and those from outside the Traveller community, both in terms of their acceptability to Travellers, and also their local knowledge of where Travellers lived in the region (AITHS Team, 2010: 40).

95. Committee on Economic, Social and Cultural Rights, General Comment 7 The right to adequate housing (Art. 11.1): forced evictions, UN document E/1998/22, annex IV (1997); United Nations Declaration on the Rights of Indigenous Peoples, UN GA Resolution 61/295 (2007); Report of The United Nations Conference On Environment And Development, 1992 A/CONF.151/26 (Vol. I), Principle 10; Convention on the Rights of Persons with Disabilities, article 4.3; Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities, General Assembly resolution 47/135 (1992), article 2.3; United Nations Convention on the Rights of the Child, article 12.2; Committee on Economic, Social and Cultural Rights, General Comment 15, The right to Water, UN Document E/C.12/2002/11 (2002), paragraph 48 and 12c).

collectors may feel uncomfortable about asking sensitive questions such as ethnicity believing that it might offend or create a barrier in establishing trust with the individual. Additionally, staff may not fully appreciate the rationale for collecting ethnic data and do not feel confident asking individuals to disclose their ethnicity, which can lead the data collector to guess or ascribe ethnicity based on proxies. This essentially diminishes the individual's autonomy to self-identify and can lead to inaccurate data (Hasnain-Wynia and Baker, 2006; Baker et al. 2005). Furthermore, some data collectors may be reluctant to ask individuals their ethnicity because it might lead to perceptions that minority ethnic groups receive differential treatment (Hasnain-Wynia and Baker, 2006; Hasnain-Wynia et al. 2004).

4.1.4 CATEGORIZATION AND TECHNICAL ISSUES

Comparably, ethnic datasets are by no means exhaustive or representative of all groups within a population. Such limited listed categories may appear vague and exclusionary, causing confusion among data collectors and data subjects (Wynia and Baker, 2006). Indeed the UN's Principles and Recommendations for Population and Housing Censuses argue that due to the subjective nature of ethnicity, information must be "acquired through self-declaration of a respondent and also that respondents have the option of indicating multiple ethnic affiliations" (Hasnain-Wynian and Baker, 2006). Statisticians also emphasise that respondents should be able to indicate more than one ethnic affiliation and argue that in general, datasets should take into consideration the following (Chopin et al., 2014: 27):

- affiliation with ethnic groups is distinct from language and/or religion;
- affiliation with an ethnic group should not be confused with citizenship;
- free self-declarations / open questions should be used;
- instructions should be provided on determining the ethnicity of children of mixed couples;
- the basic criteria and classification procedures should be documented; and
- classification is contingent on national concepts—there are no international recommendations.

In order to overcome categorization challenges, statisticians recommend consultation, publicity and information campaigns, data protection and disclosure control, testing questions carefully, using competent enumerators, dissemination and communication of the statistics to stakeholders and adherence to the essential principles of official statistics (Chopin et al., 2014: 27):

It is important to note that coded categories are not intended to exclude groups, but rather to prevent the data collection process from becoming too complex and ensuring that majority of the population can identify themselves accurately. Additionally, it is difficult to disaggregate and detect statistical significance for smaller groups. As per the UN Principles and Recommendations, an effective way to mitigate this issue is to encourage open-ended questions and self-disclosure whereby data subjects who do not 'fit' into listed ethnic categories disclose their ethnic background using the 'other' category (Hasnain-Wynian and Baker, 2006). This improves data accuracy and allows maximal flexibility and adaptability. Additionally, ethnic categories and datasets should not be perceived as static, but rather, they should evolve over time in accordance with self-identification and composition of the population.⁹⁶ Countries such as the United States and the United Kingdom have responded to complexity and fluidity of ethnic categories and continuously amend ethnic and racial⁹⁷ categories in national censuses to reflect the changing ethnic profile of their populations. For instance, the U.S. decennial census provides essential data, demographic and otherwise, that inform the allocation of vast government resources. The census results serve as the basis for federal, state, and local public policies, ranging from funding new infrastructure projects to providing increased job opportunities for workers. Revisions or additions to ethnic/racial categories in the census have been made each decade, which highlights the complexity of collecting data on identity and classification.⁹⁸

96. It is important to recognise that the ethnic composition of countries often shift due to exogamy (marriage outside the community) and immigration, facilitating the emergence of new ethnic categories.

97. The United States census includes both racial and ethnic categories. The U.S. Census Bureau collects race data in accordance with guidelines provided by the U.S. Office of Management and Budget (OMB), and these data are based on self-identification. Racial categories included in the census questionnaire generally "reflect a social definition of race [...] and not an attempt to define race biologically, anthropologically, or genetically" (U.S. Department of Commerce, 2013: para 2).

98. The evolution of the US census questions reflects the historical/political context and demographic profile of the US population. In the early decades of the nation's history, the census collected minimal data on race that served to sustain a system of governance that sanctioned slavery. The first census specifically identified White males and females only, with the remainder of the population described as "other free persons" and "slaves." The first post-slavery census in 1870 expanded the categories for racial and ethnic identification with the addition of Chinese and American Indian. Subsequent censuses have shifted in accordance with the political landscape and currently the census offers five racial categories, two ethnic categories and the option to select more than one ethnic/racial category.

Similar to the Irish Census in 1996, U.S. census enumerators were previously responsible for ascribing ethnic/racial categories to individuals prior to 1970. The earliest U.S. censuses used slave status as a proxy for a racial category, with the only race options being "free White persons, slaves, or all other free persons" (U.S. Bureau of the Census, 1973; Sandefur et al., 2001). Racial and ethnic categories were revised over time and individuals and pejorative terms such as 'mulatto,' 'quadroon,' and 'octoroon' were included in the census to reflect mixed African American and white descent⁹⁹ (Nobles, 2000; Sandefur et al., 2004). Asian groups were also added to the U.S. census form in the late 1800s, with Chinese, Japanese, and Filipino as the first Asian groups to appear on the census. This field was later amended to include Korean, Vietnamese, Asian Indian, and other Asian groups (Sandefur et al., 2004).

Two of the major changes to the U.S. census were the introduction of the Hispanic origin question in 1970¹⁰⁰ and the option to select more than one racial¹⁰¹ category in 2000. These were direct responses to changes in the population and recognition of the country's multiethnic composition. The U.S. has acknowledged the value of adapting ethnic/racial categories as collecting accurate, detailed data on race, ethnicity, and national origin has progressed the understanding of differential indicators and outcomes among population subgroups. In particular, the inclusion of Hispanic origin data has permitted researchers to identify and investigate health disparities between Hispanic subgroups, between Hispanics and non-Hispanics, and between new immigrants and Hispanics who are second-plus generation Americans (Lowenthal, 2014). Consequently, the data has been used to prioritise and address disparities and to implement strategies aimed at achieving health equity among all population groups.

U.S. legislation has also underlined the importance of ethnic data in achieving equitable health outcomes. For instance, the Patient Protection and Affordable Care Act (PPACA), or Affordable Care Act (ACA) for short (also known as 'Obamacare') includes provisions to increase access to providers, promote workforce diversity and cultural competence, strengthen data collection and research efforts, and expand prevention and public health efforts (United States Congress, 2010). The ACA provides increased funding to support cultural competence training and education materials. The ACA also fortifies national data collection and research efforts by requiring all federally funded health programs and population surveys to collect and report data on ethnicity, race and primary language in addition to supporting research on health disparities (United States Congress, 2010).

Furthermore, ethnic data is not simply used to inform U.S. national policymaking as private health insurers such as Kaiser Permanente, one of the nation's largest health insurers, insuring 10.1 million individuals, collect and monitor service user's ethnic data. According to Kaiser Permanente, collecting ethnic data has closed the gap in colorectal cancer screening of Latino members by 41% (Kaiser Permanente, 2014b) and controlled high blood pressure rates by 49% in African-American members over a twenty-four month period. These efforts are not without merit as Berny Gould, senior director, Quality, Hospital Oversight and Equitable Care notes, "culturally responsive care and evidence-based medicine have empowered our physicians and health care teams to do what is best for all of our patients" (Kaiser Permanente, 2014a: para 7).

Each of these tensions highlights the need for adequate training and support for data collectors to ensure they understand the reasons and benefits of ethnic monitoring for both the service user and service providers.¹⁰² The training should also include cultural awareness and anti-racism and should be delivered by experienced trainers. Hasnain-Wynia and Baker (2006) argue that it is imperative to provide compulsory and regulatory training and support to data collectors to ensure that they understand the rationale for seeking such sensitive information and can alleviate any concerns of data subjects effectively and efficiently. According to Hasnain-Wynia and Baker (2006) the main components of staff training should include (Hasnain-Wynia and Baker, 2006: 1514):

99. According to the 1850, the expansion included more detail on racial mixture. With regard to "color or race," enumerators' instructions specified:

Be particularly careful to distinguish between blacks, mulattoes, quadroons, and octoroos. The word "black" should be used to describe those persons who have three-fourths or more black blood; "mulatto," those persons who have from three-eighths to five-eighths black blood; "quadroon," those persons who have one-fourth black blood; and "octoroon," those persons who have one-eighth or any trace of black blood.[64]

100. Despite the long history of Hispanic residents in the United States, there was no systematic effort to count this group separately in the Census until the 1970s following decades of lobbying by civil rights groups.

101. Currently the United States offers five race categories (American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander and White) and two ethnicity categories (Hispanic or Latino, Not Hispanic or Latino) in their census categories. Each of these categories provides an option to self-identify ethnic/ racial origins. For instance, when selecting the Hispanic or Latino category respondents can specify their ethnic origin as- Mexican American, Chicano, Puerto Rican, Cuban, Argentinean, Guatemalan, and so on.

102. Pavee Point Travellers and Roma Centre provides this training on request.

- A 'script' that outlines the rationale for collecting the information, how to ask the questions, and addresses how the information will (and will not) be used;
- Case examples to teach how staff should answer questions from individuals who express concerns or who ask for more information about why this information is being collected; and
- How to record/code the information.

4.1.5 TIME AND ASSOCIATED COSTS

Further, another challenge associated with collecting disaggregated data is cost, including the increased cost implications of translation/validation of questionnaires, training staff in cultural sensitivity and technical costs, particularly in relation to the varied database systems and software utilised by data collectors preventing the compilation of reliable cross-sectoral data and comparability (Iqbal, 2013; Donse et al., 2013; Backman et al., 2008; Hasnain-Wynia and Baker, 2006; Hasnain-Wynia et al. 2004; Hussain-Gambles et al., 2004; Perot and Youdelman, 2001). According to Hasnain-Wynia and Baker (2006), many hospitals in their research indicated they did not collect ethnic data due to costs, citing that "time constraints during the registration process" (13) obstructed collecting such information. Yet, in their study, Baker et al. (2006) found that the average time required to collect patients' self-described ethnicity was 37 seconds. Baker et al.'s (2006) research shows that it is possible to rapidly collect detailed information on ethnicity with open-ended questions that allow people to self-identify.

Moreover, disaggregating and analysing data has costs. Although research in this area is limited, there is some evidence that indicates that the collection and use of disaggregated data, can save money and create economic, social and environmental value (Independent Expert Advisory Group on a Data Revolution, 2014:17). According to a recent report commissioned by McKinsey & Company, (Tong et al., 2013)¹⁰³ disaggregated data has the potential to transform every sector of the economy and provide more than \$3 trillion in global economic value annually.¹⁰⁴ Further, in its market assessment of public sector data in the UK, the Department for Business, Innovation and Skills found that the economic value of data for use and re-use was estimated at £5 billion per year (Tong et al., 2013). This includes £400 million in savings per annum¹⁰⁵ as the value of lives saved from reduced death rates among cardiac patients and £15-58 million per annum in timesavings for users in the transport sector utilising real time transport data.¹⁰⁶ Ultimately, obtaining accurate disaggregated data requires coordinated regional, national, and local efforts. While the collection of disaggregated data is challenging for many countries due to limited capacity (Backman et al. 2008: 2079) economic considerations should not be used as an excuse for not collecting data, as it is a long-term investment¹⁰⁷ that can yield social and economic returns in the future (Independent Expert Advisory Group on a Data Revolution, 2014; Islam et al., 2010).

More recently, the HSE National Social Inclusion Office (2013) has recognised the economic value of including ethnicity in health datasets as it builds a comprehensive profile of service users, leading to significant cost savings as it "supports people to access services at an earlier stage of their health problem rather than later when treatment is more costly" (para 2). Disaggregated data also, "plays an important role when commissioning and planning services and supports public bodies to assess whether equality policies are working" (HSE, 2013: para 2). The HSE National Social Inclusion Office continue to support ethnic equality monitoring within a range of health services and have developed an online training programme, *First Steps in Ethnic Equality Monitoring*, is accessible to all health staff through the Health Services e-Learning and Development service (HSEland). The training is targeted at hospital/community healthcare staff involved in data collection, directors/managers of healthcare services, data analysis personnel, health or social researchers as well as staff of community or voluntary sector organisations.

103. McKinsey & Company is a global management consulting firm with clients including businesses, governments, non-governmental organisations, and not-for-profits.

104. These sources of value include "new or increased revenue, savings, and economic surplus that flow from the insights provided by data as diverse as census demographics, crop reports, and information on product recalls" (Chui et al., 2014: 7).

105. According to the Department's (2013) assessment, publishing data on adult cardiac surgery is estimated to have reduced mortality rates, which has an economic value in excess of £400 million per annum (11).

106. Findings indicated that using live data from Transport for London in apps can save transport users time to the economic value of between £15 million and £58 million per annum (11).

107. Investment is specifically required to ensure uniform software across all national data collection systems.

Conclusions

Clearly, the collection and analysis of ethnically disaggregated data constitutes a key tool for combating discrimination and promoting equality of outcome. This has been recognised nationally and internationally, and is evidenced by the insistence of the Committee on the Elimination of Racial Discrimination (CERD) on the inclusion of information on "the demographic composition of the population" in State Parties' reports to the Committee. Permitted in both Irish and European¹⁰⁸ data protection legislation and encouraged by international human rights monitoring mechanisms,¹⁰⁹ the collection of accurate, comprehensive ethnic data is central to implementing, monitoring, and evaluating a vast range of human rights laws and policies and to ensure equal opportunity and access across all economic and social sectors of society. Data can also provide evidence of the disparate impact of policies and practices on minority ethnic groups and assist policymakers in devising targeted and cost-effective policies which simultaneously promote equality of access, participation and outcome for minority ethnic groups.

Despite reluctance of Member States to collect ethnic data, research has indicated broad support among Europeans for the collection of ethnic data to combat discrimination and promote equality. According to The European Commission's (2007) Special Eurobarometer research, *Discrimination in the European Union*, 75% of respondents supported the idea of disclosing their ethnic status, "if that could help to combat discrimination" (European Commission, 2007). This was further confirmed in the European Union Minorities and Discrimination Survey (EU-MIDIS) (FRA, 2009), which found an overwhelming support among minority ethnic groups in Ireland and Sweden, followed by support from minority ethnic group respondents in France and Germany (60%). This highlights individuals' willingness to provide information that is considered personal and sensitive for the purpose of promoting equality of access, participation and outcome.

Despite lobbying efforts by Pavée Point and countless recommendations from national¹¹⁰ and international bodies, Ireland has yet to standardise ethnic data collection practices and incorporate an ethnic identifier across all routine

108. A close examination of Directive 95/46/EC and Convention 108ETS in section two and an overview of the Irish Data Protection Acts in section three confirm that the collection of ethnic data is considered "sensitive" and as such, is subject to specific safeguards.

109. Including CEDAW, General Recommendation No 9 on Statistical data concerning the situation of women (1989), General Recommendation No 19 on Violence against women (1992), and General Recommendation No 23 on Article 7, political and public life (1997); CRC, General Comment No 4 on Adolescent health (2003), and General Comment No 5 on General measures of implementation of the Convention on the Rights of the Child (2003); CERD, General Recommendation No 25 on related dimensions of racial discrimination (2000), and General Recommendation No 34 on Racial discrimination against people of African descent (2011); CESCR, General Comment No 20 on Non-discrimination in economic, social and cultural rights (2009).

110. The National Intercultural Health Strategy 2007–2012 acknowledged the development of an ethnic equality monitoring system as an integral component of the development of a more equitable health service, with the implementation of an ethnic identifier across all Irish health services a priority (HSE, 2008:102).

administrative systems and state surveys such as SILC and the QNHS. The use of ethnic statistics on an ad-hoc basis, results in a significant knowledge gap about the situation and needs of Travellers and Roma and other minority communities in Ireland. This data deficit also poses significant challenges for policymakers as they lack comprehensive population data to develop and implement equality proofed policies to ensure that the needs of those communities are met. This report has highlighted that there is an urgent need for more frequent and comprehensive disaggregated data across all Irish administrative systems given the diverse ethnic composition of the Irish population. It has also emphasised the need for Ireland to support the collection of ethnic data and contribute to modifying the requirements for EU social surveys. Equally the report has stressed the need for Member States to have clear guidelines from the EU for the collection of inclusive equality data.

The paucity of demographic data on minority ethnic groups reveals 'the low or uneven priority' that has shaped policy responses to such groups in Ireland (NCCRI, 2001:3). At present there is a unique opportunity for Ireland to affirm its commitment to advance equality and human rights by developing consistent approaches to ethnic data collection in accordance with human rights standards. Ireland needs data to develop evidenced based policy, plan service provision and identify gaps in services or discrimination. This report has highlighted the best practice in ethnic data collection:

- **A universal question** rooted within a human rights framework, whereby everyone is asked to identify the group to which they belong, not just minorities;
- **A public and targeted campaign** informing people why such data would be collected and affirming a commitment to human rights principles and ethical use of such data in accordance with the Data Protection Acts and Convention ETS 108;
- **Ongoing training and support** for data collectors to ensure that they are equipped, confident and skilled in implementing, monitoring and evaluating ethnic data collection in accordance with relevant human rights standards and good practice principles;
- **Community participation and active consultation** with Pavee Point and other key stakeholder groups throughout the process, in particular for (OSF and MPG, 2015: 5):
 - i. the definition of data collection purposes;
 - ii. the definition of categories;
 - iii. the definition of questions asked in pursuit of the data collection purpose;
 - iv. the actual collection of data (diverse enumerators/interviewers trained to deal with the sensitive issues relating ethnic data collection);
 - v. the analysis and evaluation of the data collected; and
 - vi. the dissemination of the data.

This endeavor would be timely given recent recommendations from the CRC (2016) and CESCR (2015) and the enactment of the Irish Human Rights and Equality Commission Act 2014 (IHREC), which specifically outlines "positive duty" obligations of public sector bodies¹¹¹ to have regard for the need to eliminate discrimination, promote equality and ensure human rights are respected.

Furthermore, while this report has examined the benefits of ethnic equality monitoring, it has also described a number of sensitivities and barriers to the collection of disaggregated data, including but not limited to privacy and confidentiality, data misuse, participation in the data collection process, data collector discomfort, categorical and technical issues, time and associated costs (Donse et al., 2013; Fremont and Lurie, 2004; Hussain-Gambles et al., 2004). Such challenges should not be understood as a justification not to collect ethnic data. Indeed the *All Ireland Traveller Health* study clearly illustrates that many of these issues can be mitigated and that sensitive data such as ethnicity can be successfully collected with the correct approach, including building trust, ensuring empowerment and highlighting the benefits of collecting data. This provides clarity and assurance to both the data collector and data subject and such an inclusive and participatory approach has been recognised as best practice by Pavee Point, international human rights bodies, academics and international stakeholders.

¹¹¹. The definition of public body includes, government bodies, local authorities, the HSE, Universities and Institutes of Technology and certain companies where the Government is a stakeholder.

However, while active participation and ongoing consultation with key stakeholders is imperative to the ethnic equality monitoring process, ongoing support and training of data collectors is equally vital to ensure that they understand the rationale for seeking such sensitive information and can alleviate any concerns of data subjects effectively. The main components of staff training should include a code of practice, a standardised script that outlines the rationale for collecting information and case examples of how staff should respond to questions regarding the storage and use of data and instructions of how to adequately record and code information. Training should include mandatory cultural awareness and anti-racism components and should be delivered by minority ethnic groups and their representative organisations. Equality and anti-discrimination objectives should be included in employment criteria, specifications and annual performance reviews or appraisals of staff, including supervisors and managers.

Finally, this report recognises that ethnic equality monitoring is not a simple solution to eradicate discrimination. Rather, it is a powerful instrument in the fight against racism and discrimination which permits policymakers to respond appropriately to the diverse needs of a population and to establish mechanisms to promote equality of access, participation and outcome. Making ethnic equality monitoring a high political priority and locating it within a human rights framework subject to specific safeguards is central to devising inclusive policies for minority ethnic groups in Ireland. This will require investment from policymakers, private and public bodies and key stakeholders to ensure that ethnic equality monitoring becomes standard practice. However, this investment should be understood as a reciprocal endeavor, resulting in both financial and social returns for all stakeholders involved.

Recommendations

Ethnic equality monitoring is essential in order to identify incidences and patterns of racism and discrimination and to develop cost-effective and evidence-based social policies to address them. This has been widely recognised by various national and human rights international bodies and organisations, academics, NGOs and members of minority ethnic groups (EU-MIDIS, 2009). The absence of accurate or any data is frequently described as "one of the biggest obstacles to the development, implementation, assessment and transferability of evidence-based policies whose impact can be effectively evaluated" (European Commission, 2010: 24). The lack of ethnic data in Ireland is apparent, with only a handful of public bodies routinely collecting, monitoring and evaluating ethnic data. The recent introduction of the Irish Human Rights and Equality Commission Act 2014 (IHREC) places positive duty requirements on public sector bodies to assess human rights and equality issues relevant to their functions and purpose of the body, to identify the policies, plans and actions in place or proposed to be put in place to address those issues, and to report on developments and achievements in that regard. According to Crowley (2002) ethnic data collection must be understood as part of a broader equality data strategy. As such, there is a need for a coordinated and national strategic approach to data collection, informed by data protection legislation and human rights principles.

In an effort to tackle this data deficit and to ensure equality of access, participation and outcome for minority ethnic groups, this report recommends a dedicated Ethnic Equality Monitoring (EEM) Strategy to be developed and implemented by all public sector bodies for capture of data on the participation of Travellers and Roma (in addition to other minority ethnic groups) in all thematic areas, including in the Departments of Health, Justice and Equality, Education and Skills, Environment, Community and Local Government. The proposed EEM Strategy and key actions would result in much more effective and efficient service provision. It would simultaneously demonstrate how public bodies are meeting their positive duty obligations and should be adopted in order to demonstrate compliance with their legal obligation.

Recommendation 1:

Official senior level endorsement of Ethnic Equality Monitoring (EEM)

- 1.1** 'Senior Officials Group on Social Inclusion' endorsement and support is needed to ensure that government and state agencies conduct ethnic equality monitoring (inclusive of Travellers and Roma) to inform good policy and practice.
- 1.2** 'Senior Officials Group on Social Inclusion' should endorse the formation of a National Steering Committee to develop and drive a comprehensive EEM Strategy (see Recommendation 2). The National Steering Committee will report to the 'Senior Officials Group' on Social Inclusion on a periodic basis.
- 1.3** 'Senior Officials Group on Social Inclusion' endorsement should cover:
 - 1.3.1** Promoting effective consultation between public sector bodies¹¹² and Travellers, Roma and other minority ethnic groups in the collection, monitoring and evaluation of ethnic data.
 - 1.3.2** Identifying mechanisms and resources required to implement and review ethnic equality monitoring within a human rights framework nationally.
 - 1.3.3** Public and targeted campaign to inform people of the reasons of why such data is collected and affirm a commitment to human rights principles and ethical use of such data. Traveller organisations, Travellers and Roma must be central to this process.
 - 1.3.4** Standard collection and publication of ethnic data across all routine administrative systems in line with human rights principles.

Recommendation 2:

Establish a National Steering Committee to develop a comprehensive EEM framework

- 2.1** A National Steering Committee should be established to drive the development of an EEM framework and monitor progress. The committee should include officials from the Irish Human Rights and Equality Commission (IHREC), Central Statistics Office (CSO), Office of the Data Protection Commissioner (DPC), Health Information and Quality Authority (HIQA), relevant government departments, Traveller, Roma and other minority ethnic group organisations.
 - 2.1.1** In driving the implementation of the EEM Strategy, the committee should ensure that ethnic categories evolve over time in consultation with minority ethnic groups and in accordance with self-identification and composition of the population. The committee should also consider the identification of intersectional categories covered under the nine equality grounds.¹¹³
 - 2.1.2** The committee should monitor and evaluate the implementation of the Strategy and report on an annual basis to the 'Senior Officials Group on Social Inclusion.' The committee should also provide progress reports to the National Statistics Board and make recommendations.

¹¹². This includes, government bodies, local authorities, the HSE, Universities and Institutes of Technology, any other person, body, organisation or group financed wholly or partly out of moneys provided by the Oireachtas and certain companies where the Government is a stakeholder as per the Irish Human Rights and Equality Act (2014).

¹¹³. As per the Equal Status Act, 2000, the nine grounds include (1) gender; (2) marital status; (3) family status; (4) sexual orientation; (5) religion; (6) age; (7) disability; (8) race and (9) membership of the Traveller Community.

Recommendation 3:

The National Steering Committee to develop a clear EEM Strategy in partnership with Travellers, Roma and other minority ethnic groups

3.1 The National Steering Committee should develop a clear EEM Strategy in partnership with Travellers, Roma and other minority ethnic groups. In working to fulfill its mandate, the committee must identify:

- Concrete time-specific targets;
- Key performance indicators;
- Monitoring and evaluation mechanisms for measurable outputs;
- Sufficient funding for research on the development of standard guidelines and codes of practices in relation to the collection, analysis, use and dissemination of data;
- Budgets for actions identified in the Strategy;
- Implementing bodies for the Strategy; and
- A nominated individual at Senior Level who will have responsibility for actions outlined in the Strategy and accountability for the timely completion of targets.

3.2 The National Steering Committee must ensure that the Strategy makes provision for the development, piloting and implementation of guidelines and codes of practice within relevant sectors.

3.2.1. Guidelines and codes of practice must be rooted in a human rights approach and developed in partnership with Traveller organisations, Travellers and Roma.

Recommendation 4:

Public sector bodies should introduce training and targeted recruitment for data collectors where applicable and appropriate. To include:

4.1 Training and support for relevant government departments (HR, statistics and/or other sections) and data collectors across the public sector to ensure that they are equipped, confident and skilled in implementing, monitoring and evaluating ethnic data.

4.1.1 This includes the mandatory provision of anti-racism and cultural awareness training for all relevant staff and the resourcing of Traveller and Roma organisations to provide this training. This training should be embedded in professional training programmes and staff induction (where applicable).

4.2 Relevant to the size and scale of public body, the appointment of Human Rights and Equality Officers with responsibility for initiating, monitoring and overseeing the implementation of EEM. This will include embedding procedures in everyday work processes so that EEM becomes an institutionalised practice and ensures continuity regardless of staff-turnover.

4.3 Equality and anti-discrimination criteria as part of any future staff recruitment process. Person specifications should include commitment to anti-racist and equality perspectives.

4.4 Equality and anti-discrimination objectives in performance reviews and appraisals of staff, including for supervisors and managers.

4.5 Targeted recruitment of data collectors from minority ethnic groups (as appropriate).

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.

- 5.1** Implementation of an ethnic identifier across all routine administrative systems and statutory agencies to monitor equality, participation and outcomes and to inform policy development and service delivery.
- 5.2** Implementation of an ethnic identifier across all state surveys such as SILC and the QNHS, to monitor equality, participation and outcomes and to contribute to national and EU policy and practice.
- 5.3** Data controllers should disclose the methodology used to collect ethnic data and where appropriate develop inclusive measures to redress the lack of representation in sampling. Stratified random sampling is one method to be considered.
- 5.4** Datasets should use standard ethnic classifications developed by the CSO to ensure consistency and cross-comparability of data. In line with best international practice, the CSO should regularly update ethnic classifications in accordance with self-identification and composition of the population.
- 5.5** Ethnic data must be disaggregated by gender and other relevant equality grounds to ensure that particular individuals within minority groups are included in policy and service planning. This is particularly pertinent for minority women such as Travellers and Roma who experience intersectional discrimination on the basis of gender and ethnicity.
- 5.6** Collected data should be used to develop responsive and effective inclusion policies, and to monitor and assess their impact on Traveller and Roma communities.

Recommendation 6:

Public access to disaggregated data

- 6.1** Disaggregated data should be made available to key stakeholders and to the wider public in an accessible and user-friendly format on a bi-annual basis.
- 6.2** Data should be published on government, department and CSO websites.

Recommendation 7:

Mainstreaming data collection practices across public sector bodies

- 7.1** Identification of resources that can support data collectors to collect standardised data and then, once collected, to maximise the utility of data.
- 7.2** Mainstream ethnic data collection practices through the development of a co-ordinated and standardised approach to data collection, including the utilisation of compatible data software, in line with relevant human rights standards and good practice principles.

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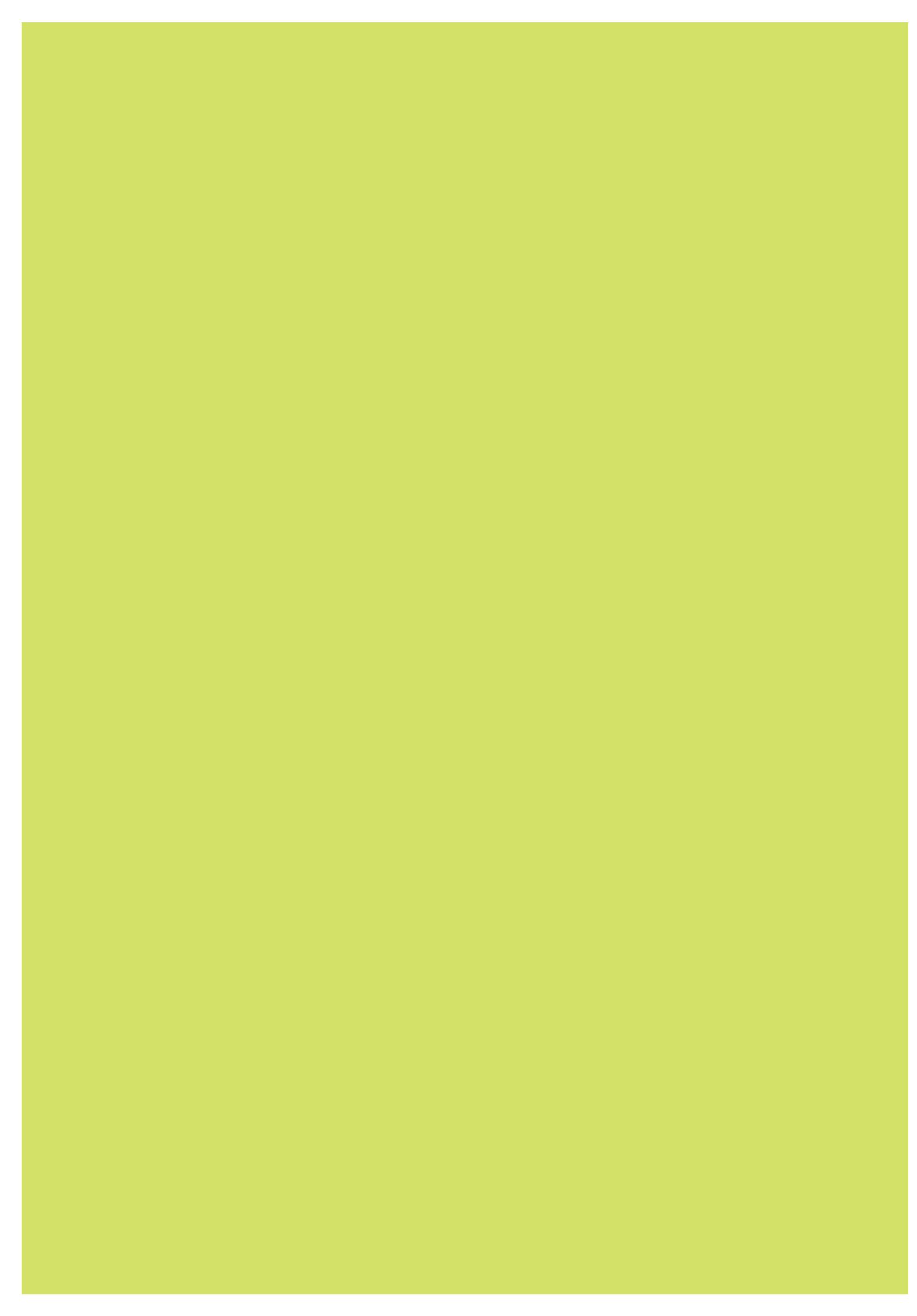
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