



Disaggregated Data and Human Rights:

Law, Policy and Practice



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Preface

This report is the result of a broader collaborative project undertaken by the University of Essex Human Rights Centre Clinic (HRC Clinic) and the European Roma Rights Centre (ERRC). One of the objectives of the project was to identify existing law, policy and practice regarding the collection, processing and dissemination of disaggregated data based on ethnicity. It involved targeted case studies of state practice selected in consultation with the ERRC on the basis of requirements relating to the project, as opposed to a methodology specific to this report. The project included a thorough literature review, a focused assessment of current practice in Central and Eastern Europe, and identified examples of positive practice globally. The project was undertaken to support the long-term ERRC initiative of identifying existing disparities in relation to health issues suffered by Roma for advocacy and litigation purposes.

The collection and dissemination of disaggregated data proves essential in identifying, assessing and analysing possible human rights violations, and in developing, implementing and measuring the success of any legislation or policy designed to address such violations. Disaggregated data based on ethnicity is a key element in identifying the impact of policies on minority ethnic groups, such as Roma communities, which continuously face discrimination in health, education, and housing.

It is submitted that the collection and dissemination of disaggregated data is a necessary requirement for states to comply with their legal obligations to ensure equality and non-discrimination in progressively realising economic, social and economic rights. Specifically, if states are to report progress to treaty bodies, they will need to collect and analyse disaggregated data to assess the effectiveness of the steps they are taking. As will be examined in this report, it is possible for states to overcome issues related to privacy and data protection, and the potential misuse of the data. Key to overcoming these challenges is ensuring the participation of the population in the data collection. At the European level, the legal framework on data protection does not prevent the collection of disaggregated data, as long as appropriate safeguards are in place, such as individual's consent and consistent transparency during the process of collection and dissemination.

This report does not purport to be exhaustive, and should not be viewed as such, but rather, as an initial examination of the utility, possibilities and challenges associated with the collection and dissemination of disaggregated data. We hope this report provides further clarity on existing law, policy and practice regarding disaggregated data, a degree of practical guidance in the development of future policy and legislation, and serves as a basis for further research and analysis on the collection, processing and dissemination of disaggregated data in the promotion and protection of human rights.



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I. Introduction

The use of relevant and reliable indicators is crucial in order to assess human rights violations.¹ In this respect, the collection and dissemination of disaggregated data is essential to reveal the most deprived and vulnerable population groups and measure inequality and discrimination.² Data that is disaggregated is data that has either been broken down, or is possible to break down, into smaller, specific sub-groups with the same identifiable criteria such as sex, nationality or ethnicity. For example, data that is disaggregated by sex can be separated into two distinct sets of data: one belonging to men and the other belonging to women. Although the disaggregation of data is an important tool in identifying human rights concerns, the collection of such data raises issues of feasibility and practicality. For example, disaggregation by ethnicity encompasses objective (e.g. language) and subjective (e.g. self-identification) criteria, which may be difficult to identify and define, as they tend to evolve over time.³ Moreover, it is worth mentioning that such collection may have important implications such as cost, potential interference with the right to privacy, or other politically sensitive issues. These obstacles, among others, must be addressed and overcome.

Nevertheless, international human rights monitoring mechanisms have encouraged the disaggregation of data⁴ on the basis of the prohibited grounds of discrimination such as sex, age, race, and nationality, to name but a few.⁵ Regarding discrimination against Roma populations, the Committee on the Elimination of Racial Discrimination (CERD) indirectly requested disaggregated data by ethnicity to measure the respect of Roma's rights.⁶

Several important institutions have highlighted the importance of collecting and processing personal data on the grounds of ethnicity. A 2003 report from the United Nations (UN) Statistics Division points out that data disaggregated by ethnicity can improve access to various services including employment, education and training, social security and

¹ Office of the High Commissioner for Human Rights (OHCHR), 'Human rights indicators: A Guide to Measurement and Implementation' (2012), UN Doc. HR/PUB/12/5, p 21.

² *Ibid.*, p 68.

³ *Ibid.*

⁴ See 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).

⁵ Other grounds include colour, language, religion, political or other opinion, property, birth, disability, health status, nationality, marital and family status, sexual orientation and gender identity, place of residence, and other status.

⁶ Committee on the Elimination of Racial Discrimination (CERD), General Recommendation No XXVII on Discrimination against Roma, (2000), (Contained in document A/55/18, annex V), para 46: 'States parties include in their periodic reports, in an appropriate form, data about the Roma communities within their jurisdiction, including statistical data about Roma participation in political life and about their economic, social and cultural situation, including from a gender perspective, and information about the implementation of this general recommendation.'

health, transportation and communications.⁷ The report also notes that this practice could benefit the preservation of identity and consequently the survival of “distinct ethnic groups.”⁸ At the regional level, the Council of Europe has stated that due to a lack of collected statistics based on ethnicity and gender, the outcome of governments’ policies and programmes could not be accurately monitored, assessed and improved.⁹ This also means that successful practices cannot be identified and therefore recommended for implementation on a wider level.

This report aims to provide a general overview of the collection and dissemination of disaggregated data. Section II provides a general literature review on the collection and use of disaggregated data in several fields, including some guidelines for appropriate and adequate processing of such information. Section III sets out the international and European legal frameworks before considering the challenges in collecting and using disaggregated data in three European States – Italy, Romania and Bulgaria - in section IV. Finally, section V examines examples of positive practices in regularly collecting disaggregated data in Sweden, the United Kingdom (UK) and the United States (US), while sections VI and VII provide a brief conclusion and a list of key recommendations.

II. Academic perspective on the collection of disaggregated data

2.1 Benefits of collecting disaggregated data

The United Nations Independent Expert on minority issues has stated that collection of disaggregated data constitutes both an “essential means” of identifying the scale of social and economic problems experienced by ethnic groups and in developing “appropriate and effective policy and practice.”¹⁰ Indeed, Landman and Carvalho explain that when data is disaggregated based on grounds such as gender, region, religion and ethnicity, policy makers are able to discern the relative enjoyment of rights among members of different social groups and identify “*de facto* discrimination and exclusion.”¹¹ The UN Special Rapporteur on the right to health has argued that without disaggregating data, the extent of problems related to ethnicity and race would remain unknown to authorities who need such information to devise appropriate interventions and evaluate their effectiveness.¹² Regarding health more specifically, the Special Rapporteur has also stated that “from the human rights perspective” the aim should be to disaggregate data as widely as possible

⁷ United Nations Statistics Division, ‘Ethnicity: A Review of Data Collection and Dissemination’ (2003), p 2.

⁸ *Ibid.*

⁹ Council of Europe, Parliamentary Assembly, Resolution 1740, ‘The situation of Roma in Europe and relevant activities of the Council of Europe’, (2010), para 15(7).

¹⁰ Report of the UN Independent Expert on Minority Issues, ‘Mission to Hungary’ (2007), UN Doc. No. A/HRC/4/9/Add.2, para 100.

¹¹ Todd Landman and Edzia Carvalho, *Measuring Human Rights*, London and Oxford: Routledge, (2007), p116.

¹² Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of health, ‘Mission to Sweden’ (2007) UN Doc. No. A/HRC/4/28/Add.2, para 120.

with respect to “internationally prohibited grounds of discrimination,” including gender, race, ethnicity and socio-economic status.¹³

Research on the use of disaggregated data in the US indicates that racial and ethnic minorities can bear a disproportionate burden of poor health outcomes.¹⁴ This research by Kirby et al. on birth defects on Hispanic ethnic groups concludes that disaggregating birth defects data gives supplementary information which can be used to identify groups in society at considerably higher risk for developing specific types of birth defects.¹⁵ The study concluded that “national and State data systems need to reflect the diversity of their populations.”¹⁶ Similarly, Rodney and Copeland in their study of the health status of black Canadians report that whenever Canadian data based on race and ethnic categories are reported, disparities are observed; they conclude the lack of disaggregated data could hide health disparities.¹⁷ Stafford reaches a similar conclusion about the health status of Hawaiian and Pacific Islanders when he explains that advocacy groups have been pushing hard for more disaggregated health data to quantify the health issues facing these groups “in an effort to teach others about the disparities and needs that are in plain view within their communities.”¹⁸ Finally, regarding the use of disaggregated data in the USA, Perot and Youdelman report that this data is crucial to “facilitate the provision of culturally and linguistically appropriate health care; and identify and track similarities and differences in performance and quality of care in various geographic, cultural, and ethnic communities.”¹⁹

Relating this to the Roma context and based on the above research, it could be argued that if health data was disaggregated to include data on the enjoyment of healthcare by Roma populations, it might identify if and where their health needs were not being met. Indeed, as the Project on Ethnic Relations (PER) observes, it cannot be claimed that Roma share equal status with other groups in society if States fail to collect the necessary data to validate such a statement.²⁰ Although there are strong arguments on the importance of collecting disaggregated data, there are certain obstacles that may restrict, if not prevent, the collection of such data. Some of these obstacles are identified and addressed in the following sections.

¹³ *Ibid.*, para 119.

¹⁴ Russel Kirby, Joann Petrini, Caroline Alter and The Hispanic Ethnicity Birth Defects Workgroup, ‘Collecting and Interpreting Birth Defects Surveillance Data by Hispanic Ethnicity: A Comparative Study’ (2000), 61 *Teratology*, p 21.

¹⁵ *Ibid.*, p 27.

¹⁶ *Ibid.*

¹⁷ Patricia Rodney and Esker Copeland, ‘The Health Status of Black Canadians: Do Aggregated Racial and Ethnic Variables Hide Health Disparities?’ (2009) *Journal of Health Care for the Poor and Underserved*, Vol. 20, No 3, p 817.

¹⁸ Stephen Stafford, ‘Caught Between “The Rock” and a Hard Place: The Native Hawaiian and Pacific Islander Struggle for Identity in Public Health ’ (2010), *American Journal of Public Health*, Vol. 100, No 5, p 785.

¹⁹ Ruth T. Perot and Mara Youdelman, Racial, Ethnic, and Primary Language Data Collection in the Health Care System: An Assessment of Federal Policies and Practices (2001), Report of The Commonwealth Fund, p v.

²⁰ Project on Ethnic Relations, *Roma and Statistics* (Strasbourg, 2000), p 11.

2.2 Practical problems and safeguards in collecting disaggregated data

2.2.1 Privacy and data protection

One area of difficulty involving the collection of disaggregated data relates to privacy and data protection. In their study of racial, ethnic and primary language data collection in the US health care system, Perot and Youdelman report that participants in their study expressed a belief that there is a need for “mechanisms to safeguard privacy and security and prevent the misuse or abuse of data on minority populations.”²¹ The study found there was a fear about how the data might be used; specifically, that the affect could be “to divide rather than unify” by highlighting distinction between groups which may intensify existing divisions between different groups.²² The importance of confidentiality regarding personal data was highlighted in a case from Romania where the HIV positive status of a young woman was made public when the press published her photo along with other personal data, which was highlighted as a concern by the Federation for Children NGOs (FONPC).²³

The UN Independent Expert on Ethnic Minorities has recognised these “sensitivities” connected with collecting disaggregated data and states that suitable ways of addressing them must be found.²⁴ According to PER, Roma populations fear collection of data about them because there are no rules in place to protect them from misuse of data, “no system of accountability”, and no clear regulations on why data might be collected or who is allowed to collect data, or who monitors the process.²⁵ The Commission on Information on Accountability for Women’s and Children’s Health of the World Health Organisation (WHO) suggests that this problem can be alleviated by using “common terminologies” and agreeing on “minimum data sets” so that information can be “collected consistently, easily shared and not misinterpreted.”²⁶ In addition, the Commission urges that national policies on the use of health data should ensure that “data protection, privacy and consent are managed consistently.”²⁷

2.2.2 Cost of collecting disaggregated data

Another challenge associated with collecting disaggregated data, as identified by Perot and Youdelman, is the “costs and technical challenges involved.”²⁸ Indeed, Backman et al. recognise that the collection of disaggregated data is a huge task for many governments,

²¹ Ruth T. Perot and Mara Youdelman, *Racial, Ethnic, and Primary Language Data Collection in the Health Care System: An Assessment of Federal Policies and Practices* (2001), Report of The Commonwealth Fund, p 20.

²² *Ibid.*

²³ NGOs Federation for children - FONCP, *Alternative report to the UN Committee on the Rights of the Child, with reference to the Third Romanian Government Periodic Report for 2003-2007*, p 8.

²⁴ Report of the UN Independent Expert on Minority Issues, ‘Mission to Hungary’ (2007) UN Doc. No. A/HRC/4/9/Add.2, para 100.

²⁵ Project on Ethnic Relations, *Roma and Statistics* (Strasbourg, 2000), p 11.

²⁶ World Health Organisation, ‘Keeping Promises, Measuring Results: Commission on Information on Accountability for Women’s and Children’s Health’, (2011) p 14.

²⁷ *Ibid.*

²⁸ Ruth T. Perot and Mara Youdelman, *Racial, Ethnic, and Primary Language Data Collection in the Health Care System: An Assessment of Federal, Policies and Practices* (2001) *Report of The Commonwealth Fund*, p 17.

and due to “limited capacity, reliable disaggregated data are often unavailable.”²⁹ Furthermore, according to Ramsay, if disaggregated data is collected and does identify inequalities between different groups in society, measures that the government will need to take to combat this inequality will place additional financial pressure on the government.³⁰ However, such economic concerns are not unique to the collection of disaggregated data, particularly in reference to the realisation of economic, social and cultural rights, and therefore do not provide a legitimate justification for not collecting disaggregated data. The case studies of positive practice considered later in this report indicate the collection of disaggregated data can be incorporated into existing systems without putting an onerous burden onto States (see section V).

2.2.3 Fair representativeness

A further practical challenge with collecting disaggregated data is regarding the categories used to distinguish between groups. Stafford, who has studied the health status of Native Hawaiian and Pacific Islanders, makes some important points about how data should be disaggregated to properly represent the health needs of this group. He cites Taunuu Ve'e-Remmers who explains how health data collected about Native Hawaiians and Pacific Islanders has been combined with much larger data sets about Asian Americans.³¹ Stafford explains that, as a consequence, the particular health problems relevant to Native Hawaiian and Pacific Islanders are “dangerously masked” in that they cannot be specifically identified and researched.³²

The importance of self-identification within a minority group has been set out under article 3 of the European Framework for the Protection of National Minorities, which states that anyone who belongs to a national minority should be free to choose whether or not they are treated as part of that minority. It also states that there should be no discrimination “from this choice or from the exercise of the rights which are connected to that choice.”³³

According to PER, in order for “reliable” and “useful” data to be collected about Roma populations, it is important that Roma are made away of categories of self-identification and that “Romani ethnicity” is included as a distinct category.³⁴ This can help ensure that health problems particularly relevant to the Roma community are identified.

2.2.4 Misuses of disaggregated data

The European Observatory on Health Systems and Policies cites research showing that historical context can affect whether the collection of ethnic data in a society is regarded

²⁹ Gunilla Backman, Paul Hunt, Rajat Khosla, Camilla Jaramillo-Strouss, Belachew Mekuria Fikre, Caroline Rumble, David Pevalin, David Acurio Páez, Monica Armijos Pineda, Ariel Frisancho, Duniska Tarco, Mitra Motlagh, Dana Farcasanu, Cristian Vladescup, ‘Health Systems and the Right to Health: An Assessment of 194 Countries’ (2008) 372 *The Lancet*, p 2079.

³⁰ Kathryn Ramsay, ‘Disaggregated Data Collection: a Precondition for Effective Protection of Minority Rights in South East Europe’ (2006) *Minority Rights Group International*, p 2-3.

³¹ Stephen Stafford, ‘Caught Between “The Rock” and a Hard Place: The Native Hawaiian and Pacific Islander Struggle for Identity in Public Health’ (2010), *American Journal of Public Health*, Vol. 100, No 5, p 2.

³² *Ibid.*, p 4.

³³ European Framework Convention for the Protection of National Minorities (1955), article 3.

³⁴ Project on Ethnic Relations, *Roma and Statistics* (Strasbourg, 2000), p 20-21.

as acceptable.³⁵ This would appear true in the case of Roma communities. Indeed, PER states that “the Romani perspective on ethnic data collection is coloured, to a large extent, by its negative use against their communities in the past and the present.”³⁶ PER explains that Roma populations have been particularly sensitive about data collection given the way data collection was used against them by the Nazis during the Second World War.³⁷ Furthermore, according to PER, in more recent times data claiming to show “Roma misbehaviour” has been used by some governments to claim the Roma are not fit for citizenship.³⁸ The enforced fingerprinting of Roma in Italy (discussed in section 4.2) is a vivid example of this.

Milcher and Ivanov describe resistance from Romani organisations due to concerns that data disaggregated by ethnicity might be used to discriminate against them.³⁹ The fear of discrimination might explain why some ethnic minority groups may not be “willing to self-identify.”⁴⁰ This leads to the further problem of the Romani population being significantly underestimated in any surveys and censuses.⁴¹ The European Observatory on Health Systems and Policies identifies similar difficulties in migrant communities throughout Europe. Migrants are reluctant to reveal information about themselves because they “fear discrimination, stigmatization, exclusion or, in the case of undocumented migrants, even denunciation and deportation.”⁴² One approach to overcoming this obstacle is to permit Roma and other ethnic minority groups to participate directly in data collection, a practice consistent with human rights principles. Numerous human rights instruments have acknowledged the right of affected individuals or communities to participate in any decision-making processes.⁴³

³⁵ European Observatory on Health Systems and Policies, *Migration and Health in the European Union* (OUP, Maidenhead & New York, 2011), p 83.

³⁶ Project on Ethnic Relations, *Roma and Statistics* (Strasbourg, 2000), p 1-3.

³⁷ For more details see for example, Hilary Waldron, *Roma Rights 2011: Funding Roma Rights: Challenges and Prospects*, 2012.

Available at: www.errc.org/cikk.php?cikk=4062&page=8.

³⁸ Project on Ethnic Relations, *Roma and Statistics* (Strasbourg, 2000), p 1-3.

³⁹ Susanne Milcher and Andrey Ivanov, ‘The United Nations Development Programme’s Vulnerability Projects: Roma and Ethnic Data’, *Roma Rights Journal*, 22 July 2004, available at www.errc.org/cikk.php?cikk=1936: Note this research was specifically in respect to employment.

⁴⁰ *Ibid.*, p 2.

⁴¹ *Ibid.*

⁴² European Observatory on Health Systems and Policies, *Migration and Health in the European Union* (OUP, Maidenhead & New York, 2011), p 84.

⁴³ 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).

2.2.5 Participation in data collection

PER report that the collection of data is most effective at the local level, where Romani residents can be involved in the process and would have decision-making power over the use of data.⁴⁴ Milcher and Ivanov agree that one of the ways to solve the reluctance of minority communities to engage with the collection of data is to involve them and encourage full participation of the communities being surveyed.⁴⁵ This is especially important for Roma communities who often feel “isolated from the State” or “alien to the community.”⁴⁶ Moreover, due to the fear of self-identification discussed earlier, unless Roma are involved in the collection process, the data may not provide an accurate analysis of the real situation and therefore any subsequent government action will not truly meet the needs of the community they are trying to help.⁴⁷ PER suggests that in order for Roma to self-identify and participate in data collection, the process must be as “open, friendly, transparent, and encouraging as possible.”⁴⁸ In recommendations given to Hungary, the Independent Expert on Minority Rights suggests that to promote participation in data collection the government should initiate “confidence building and awareness raising measures amongst the Roma” and “allay fears that data collection will be used as a further means of continuing discrimination.”⁴⁹ A participant cited by PER cautioned that whilst Roma organisations ought to participate in data collection with “an appropriate degree of control over the process”, there should also be proven political will, backed by sufficient resources provided by the government.⁵⁰

III. International and European legal frameworks for the collection and dissemination of disaggregated data

3.1 International duty to collect and disseminate disaggregated data

Non-discrimination and equality before the law are two fundamental principles of international human rights law. The principle of non-discrimination prohibits any distinction, exclusion, restriction or preference which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise by all persons of all rights.⁵¹ All the international human rights treaties such as, *inter alia*, the International Covenant on Civil and Political Rights

⁴⁴ Project on Ethnic Relations, *Roma and Statistics* (Strasbourg, 2000), p 11.

⁴⁵ Susanne Milcher and Andrey Ivanov, ‘The United Nations Development Programme’s Vulnerability Projects: Roma and Ethnic Data’, *Roma Rights Journal*, 22 July 2004, p 8-9.

⁴⁶ *Ibid.*

⁴⁷ *Ibid.*

⁴⁸ Project on Ethnic Relations, *Roma and Statistics* (Strasbourg, 2000), p 23.

⁴⁹ Report of the UN Independent Expert on Minority Issues, ‘Mission to Hungary’ (2007) UN Doc. No. A/HRC/4/9/Add.2, para 100.

⁵⁰ Project on Ethnic Relations, *Roma and Statistics* (Strasbourg, 2000), p 14.

⁵¹ *International Convention on the Elimination of All Forms of Racial Discrimination* (1965), article 1(1).

(ICCPR)⁵², the International Covenant on Economic, Social and Cultural Rights (ICESCR)⁵³ and the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD)⁵⁴ oblige States to prohibit discrimination in all its forms and demand equality before the law. In order to uphold these fundamental principles, States must collect and assess disaggregated and comparative statistical data to remedy forms of discrimination that may otherwise go unnoticed and therefore unaddressed, in particular regarding disadvantaged, marginalised and vulnerable individuals and groups.⁵⁵

Under the ICESCR, the prohibition of discrimination is an obligation that requires immediate implementation.⁵⁶ In addition, States have an immediate obligation to take steps towards the progressive realisation of the rights⁵⁷ within maximum available resources;⁵⁸ such steps must be taken “within a reasonably short time” and “should be deliberate, concrete and targeted”⁵⁹ In order to so, States should notably adopt and implement appropriate legislation, policies and programmes, particularly in respect to vulnerable groups. Actions that deliberately result in retrogressive measures are justified only within certain very limited situations.⁶⁰ Thus, disaggregated data collection and dissemination is a key element in designing, implementing and assessing any measure taken by States. Also, General Comment No. 20 of the Committee on Economic, Social and Cultural Rights (CESCR) states that in order to assess both the steps taken and the results in tackling discrimination in economic, social and cultural rights, “[n]ational strategies, policies and plans should use appropriate indicators and benchmarks, disaggregated on the basis of the prohibited grounds of discrimination.”⁶¹ Similarly, CESCR demands disaggregation on the basis of the prohibited grounds of discrimination for educational data and health indicators.⁶² In addition, indicators assessing the different components of adequate water and social security should be disaggregated and cover all persons residing in the jurisdiction of the States parties or under their control,⁶³ as well as highlighting any measures that may be retrogressive in terms of accessing rights.

In respect to health, several treaty bodies have emphasised the importance of the collection and dissemination of disaggregated data since “[t]he disaggregation of health and socio-

⁵² *International Covenant on Civil and Political Rights* (1966), article 2(2).

⁵³ *International Covenant on Economic, Social and Cultural Rights* (1966), article 2(1).

⁵⁴ *International Convention on the Elimination of All Forms of Racial Discrimination* (1965).

⁵⁵ CESCR, *Guidelines on treaty-specific documents to be submitted by States parties under articles 16 and 17 of the International Covenant on Economic, Social and Cultural Rights* (2009), UN Doc. E/C.12/2008/2, Annex B, art 2(10); CEDAW, *General Recommendation No.25 on related dimensions of racial discrimination* (2000), para 6.

⁵⁶ *Limburg Principles on the Implementation of the International Covenant on Economic, Social and Cultural Rights* (1986), UN Doc. E/CN.4/1987/17, paras 22 et 35.

⁵⁷ *Ibid.*, para 21.

⁵⁸ CESCR, *General Comment No.3 on the nature of States parties obligations* (1990), para 9.

⁵⁹ *Ibid.*

⁶⁰ *Ibid.*

⁶¹ CESCR, *General Comment No. 20 on non-discrimination in economic, social and cultural rights* (2009), para 41.

⁶² CESCR, *General Comment No. 13 on the right to education* (1999), para 37; CESCR, *General comment No.14 on the right to health* (2000), para 57.

⁶³ CESCR, *General comment No.15 on the right to water* (2002), paras 53 and 54; CESCR, *General comment No. 19 on the right to social security* (2008), para 75.

economic data [...] is essential for identifying and remedying inequalities in health.”⁶⁴ In addition to the necessity of analysing programmes or policies put in place to ensure the realisation of the right to health, the collection of disaggregated data is relevant in two other ways. Firstly, the collection of disaggregated data can identify public health situations and how they may be impacting vulnerable or marginalised groups. This is evident in General Comment 14 on the right to health, which holds that it is a core obligation for States to “adopt and implement a national public health strategy and plan of action” utilising indicators and benchmarks to monitor progress, giving “particular attention to all vulnerable or marginalized groups.”⁶⁵ Secondly, the right to health includes the right “to seek, receive and impart information and ideas concerning health issues” without impairing the right “to have personal health data treated with confidentiality.”⁶⁶ Thus, the State has an obligation to ensure individuals can access information “concerning the main health problems in the community.”⁶⁷ The State must collect and disseminate disaggregated data to ensure adequate information is accessible. The CESCR acknowledged the issue of ensuring confidentiality, stating data should be available without having to infringe on an individual’s right to privacy.⁶⁸ The issue of respecting privacy would not then be considered a valid justification for not complying with the requirement to collect and disseminate data as the CESCR considers it is possible to both respect privacy and ensure sufficient data is available for assessment.

Moreover, the collection of disaggregated data is necessary for treaty bodies to monitor States’ compliance with human rights treaties. When States ratify human rights treaties, they have a legal obligation to report on the measures taken in order to comply with their obligations under these treaties.⁶⁹ The duty to collect and disseminate disaggregated data is a necessary part of the States’ obligation to report to treaty bodies. In this respect, the 2008 reporting guidelines produced by the CESCR stipulate that States should provide in their reports “[s]tatistical data on the enjoyment of each Covenant right, disaggregated by age, gender, ethnic origin, urban/rural population and other relevant status, on an annual comparative basis over the past five years.”⁷⁰ Other treaty bodies also mention in their respective guidelines the necessity for States to include disaggregated data when reporting.⁷¹

⁶⁴ CESCR, *General comment No. 14 on the right to health* (2000), paras 16, 20 and 63. See also CESCR, *General comment No. 14 on the right to health* (2000), para 16; CRC, *General Comment No 4 on Adolescent health* (2003), UN Doc. CRC/GC/2003/4, para 13; CRC, *General comment No. 15 on the right of the child to the enjoyment of the highest attainable standard of health* (2013), UN Doc. CRC/C/GC/15, paras 22, 109 and 117; CEDAW, *General Recommendation No. 24 on Article 12: Women and health* (1999), para 9.

⁶⁵ CESCR, *General comment No. 14 on the right to health* (2000), para 43(f).

⁶⁶ *Ibid.*, para 12(b).

⁶⁷ *Ibid.*, para 14.

⁶⁸ *Ibid.*, para 12.

⁶⁹ See for example; Navanethem Pillay, Strengthening the United Nations human rights treaty body system: A report by the United Nations High Commissioner for Human Rights, (2012), p 8; available at www2.ohchr.org/english/bodies/HRTD/docs/HCRReportTBStrengthening.pdf.

⁷⁰ Committee on Economic, Social and Cultural Rights (CESCR), *Guidelines on treaty-specific documents to be submitted by States parties under articles 16 and 17 of the International Covenant on Economic, Social and Cultural Rights* (2009), UN Doc. E/C.12/2008/2, Annex A, para 3(g).

⁷¹ CCPR, *Guidelines for the treaty-specific document to be submitted by States parties under article 40 of the International Covenant on Civil and Political Rights* (2010), UN Doc. CCPR/C/2009/1, para 25 and 34; CEDAW, *Compilation of guidelines on the form and content of reports to be submitted by States parties to the international*

The collection and analysis of disaggregated data helps to hold States accountable to their human rights obligations. This is reflected through various treaty bodies' general recommendations – authoritative, albeit not legally binding, texts. In this respect, the Committee on the Elimination of Discrimination Against Women (CEDAW) consistently requests States to collect and disseminate gender-disaggregated data.⁷² In respect to discrimination against Roma, the CERD provides that “States parties include in their periodic reports, in an appropriate form, data about the Roma communities within their jurisdiction, including statistical data about Roma participation in political life and about their economic, social and cultural situation, including from a gender perspective, and information about the implementation of this general recommendation.”⁷³ This provision implicitly includes the collection and dissemination of data disaggregated both by ethnicity and gender; to provide statistical data on Roma and gender within the community, data disaggregated by these two criteria must be provided for statistical analysis. In addition, the Human Rights Council (HRC), through the Universal Periodic Review (UPR) mechanism, has regularly recommended that States collect and generate disaggregated data in order to combat discrimination and fulfil their obligations under international human rights treaties.⁷⁴

human rights treaties (2003), UN Doc. HRI/GEN/2/Rev.1/Add.2, para C(4); CRC, *Treaty-specific guidelines regarding the form and content of periodic reports to be submitted by States parties under article 44, paragraph 1 (b), of the Convention on the Rights of the Child* (2010), UN Doc. CRC/C/58/Rev.2, para 14 and Annex; CERD, *Guidelines for the CERD-specific document to be submitted by States parties under article 19, paragraph 1 of the convention* (2008), UN Doc. CERD/C/2007/1, art 5, section II, para A(6); CRPD, *Guidelines on treaty-specific document to be submitted by states parties under article 35, paragraph 1, of the Convention on the Rights of Persons with Disabilities* (2009), UN Doc. CRPD/C/2/3, Annex, A.2, A.3.2(h), B, D; CAT, *Guidelines on the form and content of initial reports under article 19 to be submitted by States parties to the Convention Against Torture* (2005), UN Doc. CAT/C/4/Rev.3, para 22; CMW, *Guidelines for the periodic reports to be submitted by States parties under article 73 of the Convention* (2008), UN Doc. CMW/C/2008/1, para 5(a); CED, *Guidelines on the form and content of reports under article 29 to be submitted by States parties to the Convention* (2012), UN Doc. CED/C/2, paras 11, 23 and 36.

⁷² CEDAW, *General Recommendation No.9 on Statistical data concerning the situation of women* (1989); CEDAW, *General Recommendation No.17 Measurement and quantification of the unremunerated domestic activities of women and their recognition in the gross national product* (1991), para (a); CEDAW, *General Recommendation No.23 on Article 7, political and public life* (1997), para 47(d) and 50(a).

⁷³ CERD, *General Recommendation No.27 on discrimination against Roma* (2000), para 46.

⁷⁴ HRC, *Report of the Working Group on the Universal Periodic Review: Austria*, 18 March 2011, UN Doc. A/HRC/17/8, recommendation 93.31; HRC, *Report of the Working Group on the Universal Periodic Review: Namibia*, 24 March 2011, UN Doc. A/HRC/17/14, recommendation 96.16; HRC, *Report of the Working Group on the Universal Periodic Review: Sweden*, 16 June 2010, UN Doc. A/HRC/15/11, recommendation 95.28; HRC, *Report of the Working Group on the Universal Periodic Review: Czech Republic*, 23 May 2008, UN Doc. A/HRC/8/33, recommendation 15, para 44; HRC, *Report of the Working Group on the Universal Periodic Review: France*, 3 June 2008, UN Doc. A/HRC/8/47, recommendation 30, para 60; HRC, *Report of the Working Group on the Universal Periodic Review: Norway*, 4 January 2010, UN Doc. A/HRC/13/5, recommendation 17, para 105; HRC, *Report of the Working Group on the Universal Periodic Review: Portugal*, 4 January 2010, UN Doc. A/HRC/13/10, recommendation 4, para 103; HRC, *Report of the Working Group on the Universal Periodic Review: India*, 23 May 2008, UN Doc. A/HRC/8/26, recommendation 5, para 86; HRC, *Report of the Working Group on the Universal Periodic Review: Dominican Republic*, 4 January 2010, UN Doc. A/HRC/13/3, recommendation 21, para 87.

3.2 European framework governing data protection

The first data protection laws were enacted by European States in the 1970s, following the digitalisation data processing. After Sweden (1973) and Germany (1977) enacted such laws, many other European countries passed similar laws and established commissioners and special authorities to enforce them.⁷⁵

Contemporary data collection in Europe is primarily regulated by two types of international and national laws: laws on the protection of personal data which govern the processing and dissemination of information in order to ensure respect for privacy and data protection, and laws on statistics, which are concerned with the compiling of statistics through surveys and collection of data. This regional framework derives from two basic texts, the Council of Europe Convention ETS 108⁷⁶ and the European Directive 95/46/EC⁷⁷ (hereafter referred to as the Directive), which shall be examined in order to understand the rules regulating data protection and the possible exemptions to the collection of what may be considered “sensitive data”^{78, 79}.

3.2.1 Convention ETS 108

The Convention ETS 108 was adopted by the Council of Europe in 1981 and is open for signature by the Council Member States and for accession by non-member States. As of 17 February 2013, 44 States have ratified the Convention.⁸⁰ The Directive only applies to Members States of the European Union.

The Convention ETS 108 consists of three main sections: the first one relates to substantive legal provisions in the form of basic principles (Chapter I), while the second section refers to special rules on trans-border data flows (Chapter II and III) and the third section sets up mechanisms for mutual assistance and consultation between the State parties (Chapter IV).⁸¹

The central part of this Convention is Chapter II, which provides basic principles for ensuring the minimum protection with regard to automatic data processing of personal data.⁸² Article 5 provides general rules for the protection of personal data; it states that

⁷⁵ Patrick Simon, “Ethnic” statistics and data protection in the Council of Europe countries: Study report, *European Commission against Racism and Intolerance*, (Strasbourg, 2007), p 10.

⁷⁶ Council of Europe, *Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data*, (Strasbourg, 1981).

⁷⁷ Council and Parliament Directive (EC) 95/46 on the protection of individuals with regard to the processing of personal data and on the free movement of such data (1995) OJ L281.

⁷⁸ Sensitive data includes any information that might be considered private including an individual's ethnicity, religious belief, health status, and financial details. It can also relate to details that might be used to identify individuals such as date of birth, contact details, or place of employment.

⁷⁹ Patrick Simon, “Ethnic” statistics and data protection in the Council of Europe countries: Study report, *European Commission against Racism and Intolerance*, (Strasbourg, 2007), p 8.

⁸⁰ Note Turkey and Russia have signed but not ratified: Status of the Convention available at conventions.coe.int/Treaty/Commun/ChercheSig.asp?NT=108&CM=&DF=&CL=ENG.

⁸¹ Council of Europe, ‘Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data’, *Explanatory Report* (1981), para 18.

⁸² *Ibid*, para 20.

data should be collected lawfully for specified purposes and not exceed the information necessary for the specific purpose. Identification of the data subjects is not permitted beyond the purpose for which the data is stored.⁸³ This Convention does not set up an obligation for countries to process personal data based on the grounds of ethnicity and race; in fact it is only permissible if national laws of the Member States specifically ensure there are sufficient safeguards in place.⁸⁴ Furthermore, the data subjects have the right to keep track of their data and amend or erase the information if it has been processed in violation of domestic law.⁸⁵ The practicalities of this requirement will depend on how sensitive data is stored: if it is kept as anonymised instead of named data, it may not be possible to keep track of each individual's data.

Each State party should take the necessary steps to give effect to this “common core” in its domestic legislation, even if the manner of implementing it is left to the discretion of the individual States.⁸⁶ Indeed, the Convention ETS 108 does not allow any exemption to the general rules for the collection of personal data, unless a derogation is provided for by the Party's domestic law as a necessary measure in the interest of State security or public safety, monetary interests, suppression of criminal offences and protection of the data subject or of the rights and freedom of others.⁸⁷

3.2.2 Directive 95

The Directive establishes regulations in relation to the legal data processing rights of individuals, balancing the need to protect the privacy of individuals with the necessary “free movement of personal data within the European Union (EU).”⁸⁸ The Directive requires each Member State to establish an independent national agency empowered to collect and protect data.⁸⁹ Article 8 (‘Special Categories of Processing’) of the Directive prohibits the processing of data on grounds of ethnicity or race, unless an individual gives their consent for revealing such personal data or there are provisions in domestic law allowing the collection of sensitive data already in place.⁹⁰

⁸³ *Ibid.*

⁸⁴ Council of Europe, ‘Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data’ (1981), article 6.

⁸⁵ *Ibid.*, article 8.

⁸⁶ Council of Europe, ‘Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data’, *Explanatory Report* (1981), para 20.

⁸⁷ Council of Europe, ‘Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data’ (1981), article 9.

⁸⁸ Europa, ‘Summaries of EU Laws’, available at: europa.eu/legislation_summaries/information_society/data_protection/114012_en.htm. (last accessed 12 Dec 2012).

⁸⁹ *Ibid.*

⁹⁰ Council and Parliament Directive (EC) 95/46, article 8 (1): ‘Member States shall prohibit the processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, trade-union membership, and the processing of data concerning health or sex life. [Paragraph 2:] Paragraph 1 shall not apply where: (a) the data subject has given his explicit consent to the processing of those data, except where the laws of the Member State provide that the prohibition referred to in paragraph 1 may not be lifted by the data subject's giving his consent [...]’.

The Directive rules require similar safeguards as the Convention ETS 108 regarding the lawfulness, fairness and necessity of the collection of data,⁹¹ though it seems to be more open to possible exemptions. In fact, the same article states that further processing of data for historical, statistical or scientific purposes shall not be considered as incompatible, provided that Member States ensure appropriate safeguards exist. In this respect, the processing of data is legitimate where: the data subject has given consent; the processing of data is necessary for the controller⁹² to comply with a legal obligation; processing is necessary in order to protect the vital interests of the data subject or for the performance of a task carried out in the public interest.⁹³

3.3 Collecting data on ethnicity

Regarding the collection of “sensitive data” and, specifically, of data revealing racial or ethnic origin, both the Convention ETS 108 and the Directive 95 set out a general prohibition on the processing of personal data.⁹⁴ However, whilst the former affirms that the general rule can be derogated from only when domestic laws provide appropriate safeguards, article 8 of Directive 95 also states specific conditions under which the processing of sensitive data may be carried out (see section 3.2.2 above). In particular, the consent of data subjects, the protection of their vital interests and the establishment or exercise of legal claims are some of the conditions under which States or other public or private bodies would be allowed to collect ethnicity data.

Extending these requirements to health issues, article 8.3 of the Directive states the processing of sensitive data is legitimate if it is required for preventing, diagnosing or treating diseases and general management of health-care services. In these situations, the data should be processed by a health professional (or an individual similarly obliged to secrecy) within a domestic legislative framework established by competent bodies, providing an obligation of professional secrecy. Under article 8.4, Member States may lay down additional exemptions, subject to the provision of suitable safeguards.

3.4 Procedures to collect and process disaggregated data

After considering the exemptions for the processing of personal and sensitive data, the Directive states that specific procedures must be in place governing the collection of data and the rights of subjects to access their data. Articles 10 and 11 list the information which must be given to the data subject before the data collection occurs. They also cover situations where data is not collected from the subject but a third party. Article 12 sets out

⁹¹ Council of Europe, 'Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data' (1981), article 6.

⁹² The body determining the purposes and means of the processing of data.

⁹³ Council and Parliament Directive (EC) 95/46, article 7.

⁹⁴ Council of Europe, *Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data*, (Strasbourg, 1981); Council and Parliament Directive (EC) 95/46 on the protection of individuals with regard to the processing of personal data and on the free movement of such data (1995) OJ L281.

the data subject's rights to access information about how the data is processed, as well as possible disclosure of the data to third parties. It also permits the individual to claim for the amendment or erasure of data when the processing does not comply with the Directive.

Under article 28, each Member State is required to establish an independent authority for monitoring the accomplishment of data collection within both the European and national law. Any agency or body carrying out the processing of data should notify this authority before beginning the collection, unless specific exemptions are made by a State's law to simplify or derogate from this obligation. Such notification should give information on the reasons why the data collection is necessary, the categories of both the data and data subjects which would be collected, the categories of recipients to whom the recorded data may be disclosed and a description of the measures to be used – allowing assessment of their appropriateness.⁹⁵ Member States, through their supervisory authorities, should determine the processing operations likely to present specific risks to the rights and freedom of data subjects.⁹⁶

The transparency of data collection processes is considered by article 21: States must ensure the supervisory authority institutes a register to record every data processing operation (notified accordingly to article 18); this must be kept available for inspection by anyone. Even if data processing operations are not subject to the notification process under article 18 – minimum information on these operations (such as who is managing the process and whether there was the possibility of data transfer to third countries) should still be available on the register.

Another source referencing possible restrictions on data collection is article 8 of the European Convention of Human Rights (ECHR). It states that public authorities should not interfere with the right to respect for private and family life, unless national security, public safety or “the economic well-being of the country” is compromised or it is necessary in order to prevent crime or disorder, protect health or otherwise protect rights of others.⁹⁷ According to the European Network Against Racism, this article together with the above mentioned limits posed by the Directive and the Convention ETS 108, provide the most common reasons adopted by States in order to avoid the collection of disaggregated data on the ground of ethnicity.⁹⁸

3.5 Monitoring and evaluation mechanisms for National Roma Integration up to 2020

In 2011 the Member States of the European Union adopted the EU Framework for National Roma Integration strategies, as proposed by the European Commission.⁹⁹ This document addresses four key points of inclusion, underlying the particular discrimination faced by Roma

⁹⁵Council and Parliament Directive (EC) 95/46, article 19.

⁹⁶ *Ibid.*, article 20.

⁹⁷ European Convention on Human Rights (1950), article 8.

⁹⁸ European Network Against Racism, 'Social Inclusion and Data Collection', Fact Sheet 46, March 2012, p 7.

⁹⁹ European Commission Communication, 'An EU Framework for National Roma Integration Strategies up to 2020' COM, (2011) p 173.

in accessing certain services. In this respect, education, employment, housing, healthcare are defined as integration goals for Roma that should be pursued by Member States.¹⁰⁰ They are urged to set up appropriate monitoring and evaluation mechanisms aimed at measuring and ensuring the effectiveness of their national policies.¹⁰¹ The European Commission has the responsibility to assess the National Roma Integration Strategies, taking into consideration each Member State's periodic report before making specific recommendations to States.

In May 2012, the European Commission sent a communication to the European Council, the Parliament, the European Economic and Social Committee and the Committee of Regions about the state of implementation of the EU Framework for National Roma Integration.¹⁰² The Communication observes that few Members have satisfied the structural requirements, indicating that only Ireland, Latvia, Portugal, Slovakia are now able to evaluate the impact of their strategies on Roma, while only Belgium, Ireland, Spain, Latvia, Slovakia, Finland and Sweden have a review mechanism for adapting such strategies.¹⁰³ In this report, the Commission recommends that States:

- develop or use existing monitoring systems by setting a baseline, indicators and targets in collaboration, where possible, with the National Statistical Offices;
- ensure each programme makes provision for the assessment of its relevance, effectiveness, efficiency and impacts.¹⁰⁴

The Commission also emphasises the importance of Roma registering in the national census in order to access public services equally and recommends that States take steps to ensure this.

IV. Collection of disaggregated data in selected European States

4.1 Bulgaria

4.1.1 Legal framework

In terms of national legal framework on personal data, Bulgaria adopted the Personal Data Protection Act (PDPA) in 2002. Article 1(1) states that "this Law shall govern the protection of rights of individuals with regard to the processing of their personal data."¹⁰⁵ As set out in the European legal framework section 3.2 above, European standards allow data processing on the grounds of ethnicity and race only where the national law of the specific State provides sufficient safeguards in the collecting and processing of such data (see section 3.2). In fact, the Bulgarian PDPA prohibits the processing of such personal

¹⁰⁰ *Ibid.*

¹⁰¹ *Ibid.*

¹⁰² European Commission Communication, 'National Roma Integration Strategies: a first step in the implementation of the EU Framework' COM(2012) 226.

¹⁰³ *Ibid.*, p 12.

¹⁰⁴ *Ibid.*

¹⁰⁵ Personal Data Protection Act (2002).

data disaggregated by ethnicity or race. Article 5(1) of the Bulgarian PDPA states “it shall be prohibited to process personal data which [...] reveal[s] racial or ethnic origin”,¹⁰⁶ except in the field of labour legislation or by individual consent to process such data.¹⁰⁷ However, it is worth noting that this Act prohibits the *processing* of data disaggregated by ethnicity but does not reference the *collection* of such data.¹⁰⁸ It should be noted that collecting data without the authority to process it might arguably be a waste of resources, as data must be analysed in order to secure the maximum information. Raw data may indicate very obvious or simple trends but statistical analysis is necessary to understand complex situations. Identifying disparities suffered by Roma would require processing of the data using the criteria of ethnicity.

It is clear that current constitutional provisions are not sufficient to safeguard the processing of data on these grounds (as set out in the European standards).¹⁰⁹ Some civil society actors argue that government claims that the collection of disaggregated data is prohibited is just a very narrow interpretation of existing laws, simply used as an excuse for not doing something that may be perceived as politically controversial.¹¹⁰ Others argue, however, that a narrow interpretation of the PDPA, which restricts the collection of such data, actually provides an essential protection mechanism against the abuse of personal data on the grounds of ethnicity and supports the government's stance on this issue.¹¹¹

4.1.2 Institutional framework

Bulgaria set up the Commission for Personal Data Protection (CPDP), a national independent monitoring body responsible for regulating the collection of personal data.¹¹² The Bulgarian Ministry of Interior set the purpose of the Commission to guarantee “the security of the personal data processed in the framework of the Schengen Information System and to determine the conditions for data processing which must be observed.”¹¹³ The National Statistical Institute (NSI) collects, processes and disseminates data on total population, ethnicity, age, education, etc., through a national census conducted every 10 years.¹¹⁴ Although the census is the most common way data is collected in Bulgaria, data is not disaggregated by different indicators, so it does not provide data on Roma

¹⁰⁶ *Ibid.*, article 5(1).

¹⁰⁷ *Ibid.*, article 5(2).

¹⁰⁸ Open Society Foundations, ‘No Data-No Progress: Country Findings, Data Collection in Countries Participating in the Decade of Roma Inclusion 2005-2015’ (2010), p 19.

¹⁰⁹ As of private data, article 32 (1) of the Bulgarian Constitution only provides: ‘The privacy of citizens shall be inviolable. Everyone shall be entitled to protection against any unlawful interference in his private or family affairs and against encroachments on his honour, dignity and reputation.’

¹¹⁰ EUroma, Brief on Ethnic Data Collection, p 4.

¹¹¹ Patrick Simon, “*Ethnic*” statistics and data protection in the Council of Europe countries: Study report’, European Commission against Racism and Intolerance, (Strasbourg, 2007), p 20.

¹¹² www.cpdpg/ ‘is the independent Bulgarian state authority that provides protection of persons when processing their personal data and when accessing such data, as well as control of the compliance with the Law on Personal Data Protection’, website of the Bulgarian Ministry of Interior available at www.mvr.bg/en/shengen/data_protection.htm (last accessed 12 Dec 2012).

¹¹³ Website of the Bulgarian Ministry of Interior, available at www.mvr.bg/en/shengen/data_protection.htm (last accessed 12 Dec 2012).

¹¹⁴ National Statistical Institute, available at www.nsi.bg/pageen.php?P=88&SP=138 (last accessed 12 Dec 2012).

integration policies. This is one reason why the Committee on the Rights of the Child (CRC) recommends that Bulgaria should improve the work of the CPDP and along with the NSI, to collect and analyse consistently disaggregated data.¹¹⁵

Other institutions which collect personal data in Bulgaria include the Ministry of Education and its regional inspectorates, the National Health Information Centres, the Ministry of Regional Development, municipal administrators and non-governmental organisations (if registered with the Bulgarian CPDP).¹¹⁶ However, they all collect data irregularly and on a project-by-project basis, sometimes with no specific indicators and often subject to donors' requirements.¹¹⁷ Some of these bodies might publish their reports and make them publicly available, but as their information tends to be sporadically collected the disaggregated data is not robust.¹¹⁸

4.1.3 Data collected on Roma communities

The European Roma Policy Coalition Analysis of the National Roma Integration Strategy¹¹⁹ (NRIS) stresses that Bulgaria uses the NRIS as an instrument to disseminate data in areas of housing, employment, health and education. However, it is quite inefficient due to a lack of well-established monitoring, evaluation and implementation mechanisms and indicators of collecting information.¹²⁰ In considering the processes of collecting data on ethnicity or racial groups, Patrick Simon reports that questions related to sensitive data in Bulgaria's census questionnaire are left optional, i.e. Roma could choose whether or not to identify as such.¹²¹ For instance, data in the 2011 Bulgarian population and housing census reveals that Roma represent the third ethnic minority group in Bulgaria, i.e. 4.9 % or 325,343 of the total population in Bulgaria (7,364,570).¹²² However, the *Brief on Ethnic Data Collection* states that the number of Roma is much higher than the 2011 census' figures indicate, illustrating the weakness of the current system.¹²³ Consequently, the NRIS report underlines that those who did not identify as Roma in the 2011 census are likely to remain beyond the scope of any policy targeting Roma.¹²⁴

¹¹⁵ UNICEF, *Bulgaria: Country programme document 2013-2017* (2012), UNICEF Doc No. E/ICEF/2012/P/L.4, para 10: '[T]he 2008 Concluding Observations of the Committee on the Rights of the Child point to the need for systematic gathering and analysing of disaggregated data.'

¹¹⁶ Open Society Foundations, 'No Data-No Progress: Country Findings, Data Collection in Countries Participating in the Decade of Roma Inclusion 2005-2015' (2010), p 20.

¹¹⁷ *Ibid.*

¹¹⁸ *Ibid.*

¹¹⁹ National Roma Integration Strategy of the Republic of Bulgaria (2012-2020).

¹²⁰ European Roma Policy Coalition, 'Analysis of the National Roma Integration Strategies' (2012), p 39.

¹²¹ Patrick Simon, "Ethnic" statistics and data protection in the Council of Europe countries: Study report, *European Commission against Racism and Intolerance*, (Strasbourg, 2007), p 20: 'The method used [in Bulgaria] is to state explicitly on the questionnaire, or in the instructions given to census-takers, that questions relating to certain sensitive data are [...] optional!'

¹²² National Statistical Institute of Bulgaria, '2011 Population Census - main results', p 3.

¹²³ EUroma, *Brief on Ethnic Data Collection*, p 4: "However, in the case of Roma it is widely accepted that the figures provided by census data in the countries [Bulgaria either] this information is gathered are much lower than the actual figures".

¹²⁴ National Roma Integration Strategy of the Republic of Bulgaria (2012-2020), p 23.

4.2 Italy

4.2.1 Legal framework

The main law regulating the collection of personal data in Italy is the Personal Data Protection Decree No.196 enacted on the 30th June 2003.¹²⁵ The Decree follows the general rules outlined by the European laws on data protection discussed above. It defines data grounded on ethnicity as “sensitive data”, together with data on religion and political beliefs, adherence to organisations and/or associations or to union trades and/or political parties, health and sexuality. Article 20 of the Decree states that the collection of sensitive data is allowed only under specific guidelines, which should spell out the type of data to be collected, the permitted operations and their purposes.¹²⁶ Article 23 notably translates the necessity of an “explicit” data subject’s consensus for the processing of sensitive data by private and public economic bodies – as stated by article 8.2(a) of the Directive 95 – in “written” consensus.¹²⁷ Article 26 also highlights the requirement for authorisation by the *Garante* (watchdog)¹²⁸ before the collection of sensitive data is permitted.¹²⁹ Although this authorisation cannot be bypassed – apart from rare cases – exemptions to the subject’s written consensus obligation is possible in a number of situations.¹³⁰ Chapter 4 of the Decree defines which purposes of public interest may allow a public body to process sensitive data, such as the application of policies regarding citizenship, migration, asylum, refugee status,¹³¹ the enjoyment of civil and political rights¹³² or economic benefits^{133 134}.

There is a specific chapter which is dedicated to the processing of personal data in relation to public health.¹³⁵ Article 85 considers that some simplifications to the process of collecting sensitive data is possible in relation to the NHS’ activities if they involve matters of public concern such as the prevention and diagnosis of illness, cure and rehabilitation of patients, as well as planning, management and control of health services. When the treatment requires crucial information relevant for an individual’s health and safety,

¹²⁵ Legislative Decree No. 196, ‘Code concerning the protection of personal data’ (2003), OJ No 174, available from www.parlamento.it/parlam/leggi/deleghe/03196dl.htm (in Italian).

¹²⁶ *Ibid.*

¹²⁷ *Ibid.*

¹²⁸ The *Garante* (watchdog) is set up by Act No. 675 of 31 December 1996. It is the Italian Supervisory Authority for Personal Data Protection that is entrusted with the task of monitoring and auditing data banks (see article 4 of the Act). Processing sensitive data is allowed only with the data subject’s consent and with the authorisation of the Watchdog.

¹²⁹ Legislative Decree No. 196, ‘Code concerning the protection of personal data’ (2003), OJ No 174, article 26.

¹³⁰ Such as when the data processing is carried out by certain bodies or agencies; data subjects have regular contact with the organisation collecting the data; the data collection is necessary for the protection of third parties, legal defence or rights claims or the performance of a task carried out in the public interest.

¹³¹ Legislative Decree No. 196, ‘Code concerning the protection of personal data’ (2003), OJ No 174, article 64.

¹³² *Ibid.*, article 65.

¹³³ *Ibid.*, article 68.

¹³⁴ Article 73 of the Decree set up other administrative and social purposes legitimising the collection of sensitive data including, *inter alia*: social and psychological support, youth training and training for individuals experiencing social, economic or family problems, health care services, assistance for minors, vigilance and support for nomads’ stay, management of school canteens and provision of school materials, assignment of public housing and employment support and training.

¹³⁵ Legislative Decree No. 196, ‘Code concerning the protection of personal data’ (2003), OJ No 174, Chapter 5.

necessary personal data can be collected without the *Garante's* authorisation as long as the subject gives oral consent. If there is a public health situation where an individual's health may impact on the community's safety (for example if an individual was infected with a highly contagious disease), relevant data on that subject can be collected with their consent as long as the *Garante's* authorisation is obtained.¹³⁶

4.2.2 Institutional framework

In order to implement the European Directive 2000/43/CE for the equal treatment of persons irrespective of racial or ethnic origin, Italy created the National Office against Racial Discrimination (UNAR) in 2004 to promote equal treatment and work to remove racial and ethnic discrimination.¹³⁷ The UNAR has four principal aims:

- prevention of discrimination, through actions increasing public awareness;
- removal of discriminating situations;
- promotion of positive actions, studies, research, training, exchanges, notably establishing guidelines against discrimination;
- monitoring and assessing the application of rules against discrimination through statistical and qualitative control of cases of discrimination based on ethnicity and race.¹³⁸

Although this Agency appears to be active in the monitoring of racism and xenophobic situations, in the assessment of the opportunity for migrants to access services, housing, training, etc., there is no explicit mention of what procedures are in place to monitor effective access.¹³⁹

In its 2005 Report to the Prime Minister, the UNAR stated that it had approached the *Garante* in order to eliminate legal barriers in regards to processing sensitive data.¹⁴⁰ In 2006, the *Garante* clarified its position concerning the right to privacy in the collection and retention of sensitive data.¹⁴¹ The process requires not only the written consent of the affected party and the *Garante's* authorisation, but also the adoption of a specific statutory provision, which must specify the public interest served by the retention of the data, the type of data held and the operations carried out upon it.¹⁴² Furthermore, the body carrying out the investigation through sensitive data must be registered in the national statistical system in which the UNAR does not participate.¹⁴³ Subsequently in 2006, the UNAR asked for the permission to collect sensitive data through a simplified procedure.

¹³⁶ *Ibid.*, article 76.

¹³⁷ See www.equineturope.org/National-Office-against-Racial.

¹³⁸ *Ibid.*

¹³⁹ Ministry for Equal Opportunities, 'A Year of Activities Against Racial Discrimination', *Report to the President of the Council of Ministers on UNAR's activities* (2005), available at: www.pariopportunita.gov.it/images/stories/documenti_vari/UserFiles/Services/Pubblicazioni/rapporto_unar_2005.pdf (in Italian).

¹⁴⁰ *Ibid.*

¹⁴¹ Guarantor for the protection of personal data, 'Citizen's rights, data protection and activities of the Guarantor', *Annual Report* (2006), detailed report available at: www.garanteprivacy.it/web/guest/home/docweb/-/docweb-display/docweb/1423334 (in Italian) and summary available at: www.gdpdit/web/guest/home/docweb/-/docweb-display/docweb/1750262 (in English).

¹⁴² *Ibid.*

¹⁴³ *Ibid.*

As a result, a targeted Prime Ministerial decree was passed in 2007 which allows the UNAR to collect data on the racial and ethnic origins of potential victims of discrimination, superseding the general data processing rules because of the implication of a specific public interest.¹⁴⁴

4.2.3 Data collected on Roma communities

In May 2008, with the “state of emergency” declared by the “Nomad Emergency Decree”¹⁴⁵, a census of the Roma population residents in the territories of Lombardia, Lazio and Campania took place.¹⁴⁶ Three different European institutions judged that the fingerprinting and census measures that were implemented were either unnecessary or a violation of individual rights.¹⁴⁷ The European Parliament on 10 July 2008 urged the Italian government to refrain from collecting fingerprints from Roma and to not use any fingerprints already collected.¹⁴⁸ Then in March 2009, the Organisation for Security and Cooperation in Europe (OSCE) High Commissioner on National Minorities found that the measures taken, including the state of emergency declaration, were disproportionate to the security threat posed by either irregular migration or the Roma and Sinti settlements.¹⁴⁹

The European Committee of Social Rights also produced a judgement concerning the situation in *COHRE v. Italy*.¹⁵⁰ The Committee observed that the Italian authorities carried out interventions focusing on monitoring Roma and Sinti camps by means of identification and census of the people present in such camps, including through the fingerprints of inhabitants or the compilation and storage of photometric and other personal information in databases.¹⁵¹ The Committee stated that such data collection should respect international standards, in that sensitive data should be collected on a voluntary and self-identification basis, a collaboration with national and international monitoring bodies should be established in order to increase the response rate among vulnerable groups, and qualified staff should be associated with the reporting of multiple ethnic responses in order to ensure confidentiality throughout the process of collecting and producing data.¹⁵² Moreover, the Committee stated that the Italian government justified the necessity to collect this data with the need to improve health conditions of the persons concerned,

¹⁴⁴ Regulation No 132, ‘The treatment of sensitive and judicial data at the Presidency of the Council of Ministers’ (2007), OJ No 27, available from www.edizionieuropee.it/data/html/37/zn68_07_074.html (in Italian), Attachment 6.

¹⁴⁵ Decree of the President of the Council of Ministers, ‘Declaration of a state of emergency in relation to settlements of nomad communities in the regions of Campania, Lazio and Lombardy’ (2008), OJ No 122, available from www.stranieriinitalia.it/media/dl08052701.2008.d521.dpcm.emergenza.rom.pdf (in Italian).

¹⁴⁶ See for example, www.opensocietyfoundations.org/litigation/ec-v-italy, and www.theguardian.com/commentisfree/2008/jul/08/italy.race.

¹⁴⁷ The European Parliament, The Organisation for Security and Cooperation in Europe (OSCE) High Commissioner on National Minorities and The European Committee of Social Rights.

¹⁴⁸ European Parliament resolution of 10 July 2008 on the census of the Roma on the basis of ethnicity in Italy, P6_TA(2008)0361.

¹⁴⁹ OSCE Office for Democratic Institutions and Human Rights and OSCE High Commissioner on National Minorities, ‘Assessment of the human rights situation of Roma and Sinti in Italy’, *Report of a fact-finding mission to Milan, Naples and Rome* (2008), p 25.

¹⁵⁰ European Committee of Social Rights, *COHRE v Italy*, Complaint No 58/2009.

¹⁵¹ *Ibid.*, para 117.

¹⁵² *Ibid.*, para 119.

but had not demonstrated any form of programme implementation in response to the collection of information about the health of vulnerable groups. The judgement stated that the procedures of identification and census of Roma and Sinti amounted to an undue interference in the private and family life of the people concerned, particularly as the data was not used to address any social problem.¹⁵³ The Committee upheld the complaint that this situation constituted a violation of article E in conjunction with article 16 of the Revised European Social Charter.¹⁵⁴

On 17 July 2008, after the census had already been carried out in many camps in Milan, Rome and Naples, with considerably varied criteria and governmental bodies involved, the Italian Minister of the Interior issued guidelines providing instructions for the collection of data and fingerprints.¹⁵⁵ These guidelines exclude the collection of “non-appropriate data” for the purpose of the census, including indicators regarding ethnicity and religion.¹⁵⁶ Although welcomed by the OSCE High Commissioner on National Minorities in that it was a step towards regulating this chaotic on-going collection process,¹⁵⁷ the guidelines unfortunately allow discriminatory practices to remain hidden by preventing the collection of data disaggregated by ethnicity. This also came too late to prevent a significant amount of sensitive data from being processed. In 2011, the Council of State initially ruled that data collected in a manner not consistent with the Minister of the Interior’s rules should have been destroyed; however, the Government appealed this judgement and in 2012, the Council of State suspended its judgement given in 2011.¹⁵⁸ It has been alleged that such data remains in the Italian authorities databases and, moreover, that this data is used as part of the State’s measures to evict Roma and Sinti.¹⁵⁹

There are still real concerns on how the State is using disaggregated data collected outside of the present guidelines but the importance of such data was reiterated by CERD in 2012. The Committee invited Italy to compile disaggregated data on the ethnic composition of its population, relying on a voluntary, anonymous, and self-identification basis in order to address anti-discrimination policies.¹⁶⁰

¹⁵³ *Ibid.*, paras 126 and 130.

¹⁵⁴ *Ibid.*, para 162 and www.cohre.org/news/press-releases/european-body-slams-italy-s-treatment-of-roma .

¹⁵⁵ Ministry of the Interior, ‘Guidelines for the implementation of the President of the Council of Ministers’ orders No 3676, 3677 and 3678 in relation to settlements of nomad communities in the regions of Campania, Lazio and Lombardy’ (2008), available at: www.interno.gov.it/mininterno/export/sites/default/it/assets/files/15/0095_censimento_campi_nomadi_le_linee_guida.pdf (in Italian).

¹⁵⁶ *Ibid.*

¹⁵⁷ OSCE Office for Democratic Institutions and Human Rights and OSCE High Commissioner on National Minorities, ‘Assessment of the human rights situation of Roma and Sinti in Italy’, *Report of a fact-finding mission to Milan, Naples and Rome* (2008), p 25.

¹⁵⁸ ERRC, *Factsheet on the State of Emergency: Italy’s Disastrous Policies for Roma*, (2013); available at www.errc.org/article/factsheet-on-the-state-of-emergency-italys-disastrous-policies-for-roma/4114 .

¹⁵⁹ Open Society Foundations and Open Society Justice Initiative, ‘Roma in Italy: A Continued Emergency’, *Briefing to European Commission* (2012), paras 8-20.

¹⁶⁰ Committee on the Elimination of Racial Discrimination, *Concluding observations: Italy*, 9 March 2012, UN Doc. CERD/C/ITA/CO/16-18.

4.3 Romania

4.3.1 Legal framework

Law 677 of 2001, which transposes into domestic legislation the Directive 95/46/EC, prohibits the collection of data disaggregated by ethnicity unless certain conditions are in place.¹⁶¹ Article 1 states that the purpose of the law is to protect an individual's rights regarding personal, family and private life in relation to the collecting and processing of personal data.¹⁶² Article 4 sets out criteria for collecting and processing data, stating it must be collected for "specific, explicit and legitimate purposes".¹⁶³ All data must be processed fairly and within the rules set out in law. There are additional provisions for the storing of data, most notably a requirement that the data must be accurate and up to date. Sensitive data has special protection and can only be processed with the express written consent of the individual concerned.¹⁶⁴ The law also recognises the rights of the affected individual, such as the right to be informed about the processing, to access the information, and to oppose the processing at any time, provided that the person has legitimate reasons to do so.¹⁶⁵

It has been argued that there is evidence that public authorities in Romania are interpreting the law incorrectly and consequently avoiding collecting data on ethnicity.¹⁶⁶ Furthermore, Open Society Foundations reports that when ethnic data is being collected, it is "usually to support project grants that target Roma",¹⁶⁷ thus illustrating the benefit of such a policy.

4.3.2 Institutional framework

The National Authority for the Supervision of Personal Data Processing was set up under Law no. 102/2005 and is empowered by Law no. 677/2001 mentioned above. This organisation is responsible for the control and investigation of personal data processing conducted under Law no. 677/2001 and they are also empowered to impose sanctions, if it is found that the legal dispositions were infringed by the personal data processors as a result of self-notification or based on complaints filed by the people whose rights were infringed.¹⁶⁸

In 2004, the National Agency for Roma was established to replace the Office for Roma Issues; it was set up as an independent body under the General Secretary of Government and is responsible for the coordination of Romania's actions in relation to the Decade

¹⁶¹ Law No. 677/2001 on the Protection of Individuals with Regard to the Processing of Personal Data and the Free Movement of Such Data, Chapter III: Special Rules on Personal Data Processing, Article 7: Processing Special Categories of Data, para 1.

¹⁶² *Ibid.*

¹⁶³ *Ibid.*

¹⁶⁴ Bogdan Manolea, 'Institutional framework for personal data protection in Romania' (2005), p 6.

¹⁶⁵ *Ibid.*, p 5.

¹⁶⁶ Open Society Foundations, 'No Data-No Progress: Data Collection in Countries Participating in the Decade of Roma Inclusion 2005-2015' (2010).

¹⁶⁷ *Ibid.*, p 61.

¹⁶⁸ The National Supervisory Authority For Personal Data Processing website, available at: www.dataprotection.ro/index.jsp?page=home&lang=en (last accessed 17 Feb 2013).

of Roma Inclusion.¹⁶⁹ It monitors and assesses local and central government actions in respect to the Strategy for Improving the Condition for Roma.¹⁷⁰ However, Open Society Foundations states that even though the Agency had been offered and given assistance, they had still not produced a detailed strategy relating to monitoring and evaluation by 2010.¹⁷¹

The National Institute for Statistics in Romania collects national data on ethnicity through the census every ten years, but no other official, national statistics are collected on Roma in the intervening period.¹⁷² The European Roma Rights Centre identified that the lack of data disaggregated by ethnicity was negatively impacting the Government of Romania's ability to address issues that affect Roma communities.¹⁷³

4.3.3 The collection of disaggregated data

The Eurobarometer survey in 2011 found that only 36% of respondents from Romania believed their Government could keep personal data on the internet safe; this was the lowest level of confidence from all EU countries.¹⁷⁴ Only 21% of Romanian participants in the survey knew they were allowed access to their personal data held by others (47% thought there was no such protection and 32% did not know either way); this was the second lowest percentage of the EU countries.¹⁷⁵ It is not surprising that the Data Protection Authority, which is understaffed and has little real power, does not have an active voice in the public sphere.¹⁷⁶

A number of international institutions have recognised that Romania is failing to collect sufficient disaggregated data. In 2006, CEDAW¹⁷⁷ considered Romania's 6th periodic report¹⁷⁸, which focused on the implementation of the Convention on the Elimination of Discrimination against Women between 1998 and 2002. The experts on the Committee stated that Romania did not collect adequate disaggregated data on gender in order to be able to effectively assess whether the programmes implemented to benefit women were

¹⁶⁹ ERRC, 'Romanian Government to Establish New National Agency for Roma', 16 December 2004, available at: www.errc.org/article/romanian-government-to-establish-new-national-agency-for-roma/2102 (last accessed 17 Feb 2013).

¹⁷⁰ *Ibid.*

¹⁷¹ Open Society Foundations, 'No Data-No Progress: Data Collection in Countries Participating in the Decade of Roma Inclusion 2005-2015' (2010), p 61.

¹⁷² *Ibid.*, p 62.

¹⁷³ ERRC, 'Parallel report concerning Romania to the Human Rights Council, within its Universal Periodic Review, for consideration at its 15th session (21 January to 1 February 2013)', p 4-6.

¹⁷⁴ European Commission, *Data Protection in the European Union: Citizens' perceptions*. 2011 Flash Eurobarometer 225, p23; available at ec.europa.eu/public_opinion/flash/fl_225_en.pdf.

¹⁷⁵ *Ibid.*, p 30.

¹⁷⁶ European Digital Rights, 'Romania: Is really privacy a topic in the public debate?', 28 January 2009, available at: www.edri.org/edri-gram/number7.2/romania-privacy-in-public-debate.

¹⁷⁷ Romania ratified the Convention on the Elimination of all Forms of Discrimination against Women in 1982 (and the Optional Protocol in 2003).

¹⁷⁸ CEDAW, 'Consideration of reports submitted by States parties under article 18 of the Convention on the Elimination of All Forms of Discrimination against Women: Romania' (2003), UN Doc. CEDAW/C/ROM/6.

successful.¹⁷⁹ Particular reference was made to the lack of gender disaggregated data collected within the Roma community.¹⁸⁰ The Government response to the Committee stated that the National Agency for Roma had been set up to combat discrimination of the Roma community but admitted that they did not compile statistics disaggregating for gender.¹⁸¹

The necessity for the robust¹⁸² collection of disaggregated data in order to analyse the success of programmes implemented to improve the situation of children in Romania has been noted by the CRC.¹⁸³ A shadow report to the CRC compiled in 2007 by the NGO Federation for Children recommended that systems to collect data on children had to be improved, especially in relation to Roma and migrant children.¹⁸⁴ However, this report acknowledged that at the same time, measures had to be taken to ensure that any private information remains confidential.¹⁸⁵ In 2009, the CRC examined Romania's 3rd and 4th periodic reports and noted that even though the Committee had raised the issue before, Romania was still not collecting disaggregated data, which restricted the Romanian government's ability to evaluate progress. The State admitted that their data system was not utilised effectively but affirmed its intention to improve this, especially at the local level.¹⁸⁶ The issue of the collection of disaggregated data in Romania is listed on the UNICEF website as one of the remaining challenges in the social sector.¹⁸⁷ UNICEF states that there is an inability to "assess and analyse the situation of children, especially regarding disaggregated data highlighting disparities among children."¹⁸⁸

The importance of collecting disaggregated data in respect to health services is particularly important in relation to the high levels of infant mortality in Romania. While the infant mortality rate in Romania is reportedly the highest in the EU at 1.4%,¹⁸⁹ Roma communities suffer a 40% higher rate than the general population.¹⁹⁰

¹⁷⁹ *Ibid.*

¹⁸⁰ Committee on Elimination of Discrimination against Women 735th & 736th Meetings (General Assembly WOM/1564), 'More Gender-Based Disaggregated Data Needed To Evaluate Country's Programmes Benefiting Women', available at: www.un.org/News/Press/docs/2006/wom1564.doc.htm (last accessed 17 Feb 2013).

¹⁸¹ CEDAW, 35th Session. (2006) Responses to the list of issues and questions for consideration of the sixth periodic report, CEDAW/C/ROM/Q/6/Add.1.

¹⁸² Robust, in this context, would require participation of enough individuals from all communities to an extent that the data collected was representative of society.

¹⁸³ Committee on the Rights of the Child (CRC) 'UN Committee on the Rights of the Child: Concluding Observations: Romania' 2003, CRC/C/15/Add.199, para 16.

¹⁸⁴ NGOs Federation for children - FONCP, Alternative report to the UN Committee on the Rights of the Child, with reference to the Third Romanian Government Periodic Report for 2003-2007.

¹⁸⁵ *Ibid.*, p 39.

¹⁸⁶ State Party Examination of Romania's 3rd and 4th Periodic Reports: 51st Session of the Committee on the Rights of the Child. 25 May – 12 June 2009. As reported by NGO Group for the CRC.

¹⁸⁷ UNICEF, Romania: Overview, available at: www.unicef.org/romania/overview_1610.html (last accessed 17 Feb 2013).

¹⁸⁸ *Ibid.*

¹⁸⁹ European Observatory on Health Systems and Policies, 'Health Systems in Review: Romania', *Health Systems in Transition* (2008), Vol. 10, No. 3, p 10.

¹⁹⁰ Sorin Cace and Cristian Vladescu, 'The health status of Roma population and their access to health care services' (Bucharest, Expert Publishing House, 2004) as reported in European Observatory on Health Systems

V. Examples of positive practice regarding the collection of disaggregated data

5.1 Sweden

Sweden regularly collects disaggregated data in several fields and uses it to promote “good health, on equal terms, for the entire population with a special emphasis on vulnerable groups such as immigrants.”¹⁹¹ However, the collection of data on ethnicity is viewed as “unnecessary and undesirable”, and is actually forbidden by law in the country.¹⁹² Sweden has an historical association with the misuse of data recording ethnicity which some have argued has resulted in a fear related to collecting such data.¹⁹³ This is partly due to the previous negative uses of ethnic registration in Europe during the 1920's and 1930's.¹⁹⁴ Although stigma surrounding race exists in Sweden, data is still collected regarding health, living conditions, and country of birth through an annual survey.¹⁹⁵ Rather than focusing on ethnicity, the Swedish government uses migration status as an indicator for disparities in living conditions.¹⁹⁶

5.1.1 Collection of data disaggregated by migration status

In Sweden, the collection of health data and the policy formed around the analysis of the data are focused mainly on migrant groups, rather than on ethnicity.¹⁹⁷ When completing the annual survey on living conditions, respondents are classified as first-generation migrant, second generation, or not migrant.¹⁹⁸ Although ethnicity is not considered in the study, the data is disaggregated in respect to migrant status in order to determine which groups may face discrimination. Disaggregated data is advantageous in highlighting the disparities between groups. For example, studies have shown that “registered refugees had higher stillbirth, early neonatal mortality and pre-natal mortality rates compared to non-refugee women from the host countries.”¹⁹⁹ In addition, the data collected revealed that migrants in Sweden are at a higher risk of contracting HIV;²⁰⁰ of the reported cases of HIV in Sweden, only 13-38% of

and Policies , ‘Health Systems in Review: Romania’, *Health Systems in Transition* (2008), Vol. 10, No. 3, p 136.

¹⁹¹ Philipa Mladovsky, ‘Migrant Health in the EU’ in *Eurohealth, Health Worker Migration in Europe: Assessing the Policy Options* (2007), Vol. 13, No 1, p 11.

¹⁹² Bernd Rechel, Philipa Mladovsky, Walter Devillé, Barbara Rijks, Roumyana Petrova-Benedict, Martin McKee, ‘Migration and Health in the European Union’, *European Observatory on Health Systems and Policy Series*, (Open University Press, 2011), p 84.

¹⁹³ European Commission Against Racism and Intolerance, “‘Ethnic’ statistics and data protection in the Council of Europe countries’, 2007, p 66, available at: www.coe.int/t/dghl/monitoring/ecri/activities/themes/Ethnic_statistics_and_data_protection.pdf.

¹⁹⁴ Sophie Hyden, ‘Comment on Patrick L. Mason. Driving while black: Do police pass the test?’, *Swedish Economic Policy Review* 14 (2007), p 122.

¹⁹⁵ Philipa Mladovsky, ‘Migrant Health in the EU’ (2007), p 88.

¹⁹⁶ *Ibid.*

¹⁹⁷ *Ibid.*, p 187.

¹⁹⁸ *Ibid.*, p 91.

¹⁹⁹ *Ibid.*, p 143.

²⁰⁰ *Ibid.*, p 126.

those with the disease were Swedish nationals.²⁰¹ In addition, immigrants in Sweden have a higher rate of chronic hepatitis C.²⁰² These examples show that disaggregated data has the capability to expose inequality within sub-populations.

Sweden has been recognised as one of the European countries that provides methods for more successful integration of immigrants.²⁰³ This finding is “based on 140 indicators, including the rights of migrants in the workplace, opportunities for permanent settlement, family reunification policy and the enactment and enforcement of domestic laws to combat racism and prejudice.”²⁰⁴ However, flaws in the system also exist. A recent study revealed that high numbers of migrants classify their health to be poor and claim to suffer from physical and mental illnesses.²⁰⁵ Based on these factors, it becomes clear that disaggregated data is able to identify a problem, and through policy the issue may be resolved.

5.1.2 Lack of disaggregated data based on ethnicity

Statistics Sweden, the department that collects data on living conditions, creates surveys based on physical and mental health, long-term illness, disabilities, doctor and dentist appointments, and tobacco use.²⁰⁶ They use varying indicators to disaggregate the data, such as age, sex or household, level of education, foreign or Swedish background, and socio-economic group.²⁰⁷ However, as previously discussed, the surveys do not involve questions based on race or ethnicity so there is no way of disaggregating the data using these criteria. This means that any disparities or indirect discrimination suffered by specific racial or ethnic groups cannot be identified.

The Universal Periodic Review for Sweden, completed by the United Nations Association of Sweden in 2010, critiqued Sweden's use of disaggregated data. The report states that in order to promote equality and eliminate discrimination, Sweden must increase its use of disaggregated data, especially in the areas of racial or ethnic origin, religion, sex, and age.²⁰⁸ The report recommends that Sweden “collect disaggregated data in relation to as many of the internationally prohibited grounds of discrimination as possible to create indicators and benchmarks to measure progress made in Sweden's anti-discrimination work.”²⁰⁹ In order to assume its international human rights responsibilities, the report argued that Sweden must promote the use of disaggregated data as a means through which to reduce inequality and discrimination.²¹⁰

²⁰¹ *Ibid.*

²⁰² *Ibid.*, p 124.

²⁰³ Bernd Rechel, Philipa Mladovsky, Walter Devillé, Barbara Rijks, Roumyana Petrova-Benedict, Martin McKee, ‘Migration and Health in the European Union’, *European Observatory on Health Systems and Policy Series*, (Open University Press, 2011), p 47.

²⁰⁴ *Ibid.*, p148.

²⁰⁵ *Ibid.*, p 162.

²⁰⁶ Statistics Sweden, ‘Living Conditions Surveys’, available at: www.scb.se/Pages/ProductTables.aspx?id=12197 (last accessed 12 Feb 2013).

²⁰⁷ *Ibid.*

²⁰⁸ The United Nations Association of Sweden, Joint Submission for Sweden's First Universal Periodic Review in May 2010’ (2009), p 11.

²⁰⁹ *Ibid.*

²¹⁰ *Ibid.*

A Report of the Special Rapporteur on the right to the highest attainable standard of physical and mental health compiled in 2007 also highlights the importance of disaggregated data in relation to Sweden. The report affirms that Sweden collects disaggregated data on multiple grounds relating to health, however it is not common to collect data based on race and ethnicity.²¹¹ The Special Rapporteur also reports that ethnic minorities in Sweden suffer from poor health status in comparison with the rest of the population, emphasising the necessity to collect data based on race to expose the disparities.²¹² Although it is acknowledged that the collection of disaggregated data has been abused in the past, the Special Rapporteur urges that data be available on race and ethnicity in the health field in order to advocate for the right to health for all citizens and ethnic groups.²¹³ Without disaggregated data, it is difficult for authorities to understand the severity and cause of discrimination within the system, develop a programme to address the problem, and then assess the effectiveness of the programme.²¹⁴

5.2 United Kingdom

The UK has been identified as an example of positive practice for disaggregating data based on ethnicity.²¹⁵ UK legislation not only allows the collection of sensitive data on ethnicity, but also makes it a legal requirement.²¹⁶ This has led to a situation where ethnic data collection is routine and of little concern to the general populace.²¹⁷ As such, statistical data is regularly collected, often with the express intention of informing policy and practice.²¹⁸

5.2.1 Collection of data disaggregated by ethnicity

Legislation in the UK provides a framework in which disaggregated data can be collected. The Data Protection Act (1998) is central to this framework, as it includes actions that promote equal treatment by identifying inequalities as an exception to the prohibition on collecting “sensitive data,” and considers “racial or ethnic origins” as one of the areas where inequality may exist.²¹⁹ The Information Commissioner is the independent authority responsible for monitoring the application of this act and the Commissioner allows named

²¹¹ Report of the UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, ‘Mission to Sweden’ (2007), UN Doc. No A/HRC/4/28/Add.2, para 120-121.

²¹² *Ibid.*

²¹³ *Ibid.*

²¹⁴ *Ibid.*

²¹⁵ Open Society Foundations, ‘No Data-No Progress: Data Collection in Countries Participating in the Decade of Roma Inclusion 2005-2015’ (2010), p 17.

²¹⁶ Patrick Simon, “Ethnic” statistics and data protection in the Council of Europe countries: Study report’, *European Commission against Racism and Intolerance*, (Strasbourg, 2007), p 60.

²¹⁷ European Commission, ‘Comparative Study on the Collection of data to Measure the Extent and Impact of Discrimination in a selection of countries: Final Report on England’, *Measurement of discriminations Projects* (2004), p 3.

²¹⁸ Commission for Racial Equality, ‘The Duty to promote race equality: A Guide for Public Authorities (Non-Statutory)’, (2002) p 32.

²¹⁹ Data Protection Act (1998), Chapter 29, Schedule 3, Para 9; See also Patrick Simon, “Ethnic” statistics and data protection in the Council of Europe countries: Study report’, *European Commission against Racism and Intolerance*, (Strasbourg, 2007), p 60.

data to be processed without explicit consent, if the processing is necessary in order for an agency or organisation to comply with a legal obligation.²²⁰ The Race Relations Act (1976) originally created this obligation, stating that collecting statistical data based on ethnicity is a legal obligation. This act built upon the Race Relations Acts of 1965 and 1968, which targeted direct discrimination but were largely unable to achieve significant decreases in racial inequality.²²¹ As such, it was considered necessary to combat indirect discrimination, which first had to be located through the collection of statistical data.²²² The 2010 Equality Act, which replaced the Race Relations Act, upheld the legal obligation to collect data. As both acts explicitly include indirect discrimination as prohibited conduct,²²³ this necessitates the collection of data which is of sufficient standard to provide a statistical test of whether indirect discrimination has occurred.²²⁴

Since the amendment to the Race Relations Act in 2000, the obligation to collect disaggregated data has applied to local authorities, public authorities, and all firms with 150 employees or more. The 2010 Equality Act clarified this obligation, including the need to publish analysis of data to comply with the purpose of tackling inequality.²²⁵ Under the Equality Act and its Specific Duties of 2011, public bodies must publish information to show their compliance with the Equality Duty at least annually, and set and publish equality objectives at least every four years.²²⁶ This has led to the compilation and analysis of a range of data disaggregated on the grounds of ethnicity. However, it is worth noting there is no single repository in which this data is held, which may have implications for its consistent and complete processing.

There are also a number of regular surveys that collect data disaggregated by ethnicity in the UK, which are not directly obligated to do so by the Equality Act. The census, which first included a question on ethnicity in 1991, is the most obvious of these.²²⁷ But this group also includes the Health Survey for England, the Health Survey for Scotland, the General Household Survey and the British Household Panel Survey.²²⁸

Mainly due to the Race Relations Act, data disaggregated by ethnicity has been collected on a more wide scale and complete basis than data disaggregated by other characteristics,

²²⁰ *Ibid.*, p 60-1. See also Information Commissioner's Office, 'Data Protection: The Employment Practices Code' (2011), p 40.

²²¹ Hansard, Vol. 907, HC Deb 07 March 1976, c1580 Frederick Wiley and c1662, Alex Lyon.

²²² Hansard, Vol. 907, HC Deb 07 March 1976, c1580 Frederick Wiley.

²²³ Race Relations Act (1976), pt 1, para 1, sub para b, and Race Relations Act (1976)(Amendment) Regulations (2003), pt 1, para 1a; Equality Act (2010), pt2, c.2, para 19.

²²⁴ European Commission, Final Report on England, 'Comparative Study on the Collection of data to Measure the Extent and Impact of Discrimination in a selection of countries: Final Report on England', *Measurement of discriminations Projects* (2004), p 54.

²²⁵ Equality Act 2010.

²²⁶ Government Equalities Office, 'Equality Act 2010: Specific Duties to Support The Equality Duty, What Do I Need to Know? A Quick Start Guide For Public Sector Organisations' (2011), p 3.

²²⁷ Mair Ni Bhrolchain, 'The Ethnicity question for the 1991 Census: background and issues' *Ethnic and Racial Studies* Vol.13, Issue 4 (Oct 1990).

²²⁸ Bernd Rechel, Philipa Mladovsky and Walter Devillé, 'Monitoring the health of migrants' in Rechel, D., et al. (eds) *Migration and health in the European Union* (New York, 2011), p 92.

such as disability.²²⁹ However, the introduction of the Equality Act in 2010 can be seen as a move to change this, creating a single framework “with clear, streamlined law to more effectively tackle disadvantage and discrimination.”²³⁰ The Act includes discrimination on the basis of age, gender, race, religion, sexual orientation and disability, among other things.²³¹

Although the collection of disaggregated data collection has been an issue of debate in the UK in the past, it is not currently a topic of controversy. For instance attempts to include an ethnicity question in the census in 1979 created alarm, partly due to fears of data being misused in light of a Nationality Bill being considered at the time.²³² Nonetheless, these fears did not seem to materialise in relation to the 1976 Race Relations Act, seemingly revealing that a country’s fears about data collection are often tied to current trends and situations.²³³ Since this Act was introduced the collection of data disaggregated by ethnicity has become routine and, as noted before, the collection of such data is relatively uncontroversial. In the parliamentary debates surrounding the 2010 Equality Act there was no direct discussion of disaggregated data, as its necessity was assumed.²³⁴ Not only was it not debated, but disaggregated data was relied upon by members of parliament to support arguments.²³⁵ The only suggestion which seemed to criticise disaggregated data was in relation to compulsory pay audits, which were considered costly for the private sector considering the financial crisis.²³⁶ However, even in pointing this out, the opposition did not suggest that disaggregated data should be abandoned, but should only be required of those employers shown to be guilty of unequal pay. It was unanimously accepted that data collection is necessary to deal with discriminatory practices, and that the costs of this when there is inequality are largely irrelevant, as “equality is not just something for good times.”²³⁷

5.2.2 Collection of data disaggregated based on ethnicity in the health sector

There is clearly a commitment to “ethnic monitoring” in the UK government as they believe in the positive effects it can have. As stated in a guide published by the government for public authorities “[t]he aim of ethnic monitoring is not to collect ethnic data for its own sake, any more than the aim of consultation is to collect people’s views. The race equality scheme is about making race equality a reality and using monitoring, assessment and

²²⁹ European Commission, Final Report on England, ‘Comparative Study on the Collection of data to Measure the Extent and Impact of Discrimination in a selection of countries: Final Report on England’, *Measurement of discriminations Projects* (2004), p 53.

²³⁰ Equality and Human Rights Commission, presentation of the ‘Equality Act’ available at: www.equalityhumanrights.com/legal-and-policy/equality-act/ (last accessed 8 Dec 2012).

²³¹ Such as gender reassignment, marriage and civil partnership, as well as pregnancy and maternity.

²³² Mair Ni Bhrolchain, ‘The Ethnicity question for the 1991 Census: background and issues’ *Ethnic and Racial Studies* Vol.13, Issue 4 (Oct 1990), p 561-2; Also see Imogen Tyler, *Designed to fail: a bio-politics of British Citizenship* (2010) *Citizenship Studies*, 14 (1), p 61-74 for discussion of criticisms of racism against Nationality Act 1981 eventually enacted.

²³³ For example, the Nationality Act 1981 prevented Hong Kong residents automatically being British citizens; which was a key issue in the lead up to hand over of the Territory to China.

²³⁴ Hansard, Daily Deb, HC Deb 11 May 2009.

²³⁵ *Ibid.*, c617, John Bercow.

²³⁶ Hansard, Daily Deb, HC Deb 11 May 2009, c568, Theresa May.

²³⁷ *Ibid.*, c565, Theresa May.

consultation to achieve this.”²³⁸ This commitment is also present within the health service specifically: “there is general support from the National Health Service (NHS) for the principle of collecting ethnic data in a consistent manner.”²³⁹

The 2010 Equality Act applies to the NHS as a public authority.²⁴⁰ As such, there are a number of areas where health statistics in relation to ethnicity are legally required, for instance when recording hospital admissions, or in all secondary care except outpatient, accident and emergency care and community settings.²⁴¹ This data is relatively effectively and comprehensively collected; for instance in 2007-8 there was 86% coverage of ethnicity in hospital attendance statistics.²⁴² There have also been efforts to encourage data collection in areas where it is not yet mandated, for instance, new primary care incentives for general practices to collect ethnic group data from patients.²⁴³

In the area of health data there is a form of central repository, the NHS Information Centre for Health and Social Care, which is described as “England’s central, authoritative source of health and social care information”.²⁴⁴ It has the objective of being the “core source for official statistics published by the DH (Department of Health), CQC (Care Quality Commission) and other bodies for the purpose of accountability.”²⁴⁵ However it does not appear to be compulsory for data to be stored in this repository so it does not contain all data. It would also be incorrect to suggest that exhaustive data on ethnicity is available in the UK as while the Department of Health supports the principle of mainstreaming ethnic data collection coverage, datasets are not complete.²⁴⁶ For instance, comprehensive population level mortality data is available by country of birth groups, but not by ethnic group.²⁴⁷

There are currently efforts underway to improve the data available, in order to better assess the health situation in the UK. These are partially outlined in the Department of Health paper, *Improving Outcomes and Supporting Transparency. Part 1: A Public Health Outcomes Framework for England, 2013-2016*.²⁴⁸ In Appendix C, there is a consideration of whether ethnic data is available (as of November 2011) in reference to health indicators

²³⁸ Commission for Racial Equality, ‘The Duty to promote race equality: A Guide for Public Authorities (Non-Statutory)’ (2002), p 22.

²³⁹ NHS Information Authority, DSC Notice: 21/2000, p 1.

²⁴⁰ ‘Equality Act 2010’, Schedule 19, Part 1.

²⁴¹ Bernd Rechel, Philipa Mladovsky and Walter Devillé, ‘Monitoring the health of migrants’ in Rechel, D., et al. (eds) *Migration and health in the European Union* (New York, 2011), p 88.

²⁴² *Ibid.*

²⁴³ Hiranthi Jayaweera ‘Health and Access to Health Care of Migrants in the UK: A Race Equality Foundation Briefing Paper’ (2010), *Better Health Briefing* 19, p 2.

²⁴⁴ NHS: The Information Centre for Health and Social Care, ‘About us’, available at: www.ic.nhs.uk/about-us/more-about-us (last accessed 3 Dec 2012).

²⁴⁵ *Ibid.*

²⁴⁶ London Health Observatory, ‘How to Analyse Ethnic Differences in Health, Health Care, and the Workforce: A toolkit for the NHS’ (2006), p 13.

²⁴⁷ *Ibid.*, p 38.

²⁴⁸ Department of Health, ‘Improving outcomes and supporting transparency. Part 1: A public Health Outcomes Framework for England, 2013-2016’ (2012).

the department proposes to use. Of the 61 indicators which had been considered in relation to ethnic data, data was currently available for 40 of the indicators. Of the 21 indicators where data was not currently available, there were only 10 indicators where data was disaggregated by sex and age, but not by ethnicity.²⁴⁹

Currently a large amount of health data disaggregated by ethnicity is collected in the UK, but there is room for improvement in terms of coverage and effective organisation. The new guidelines discussed above suggest wide acceptance of collecting ethnicity data as positive practice, while acknowledging there is a need to increase the amount of data currently available.

5.3 United States

Given the extent of diversity in the US, disaggregated data has helped to show disparities between ethnicities and classes. In 1968, the U.S. Department of Education created the Civil Rights Data Collection (CRDC) to collect data in public schools in order to promote equality in the education system.²⁵⁰ The CRDC is mandatory as stated by several laws, including Title VI of the Civil Rights Act of 1964, Title IX of the Education Amendments of 1972, Section 504 of the Rehabilitation Act of 1973, and the Department of Education Organization Act.²⁵¹ A sample of school districts submits their data either through a web-based survey or through an electronic file.²⁵²

5.3.1 Collection of disaggregated data in schools and youth justice

Through the *No Child Left Behind* federal law of 2001, disaggregated data collection is required in schools in order to establish equality in the education system.²⁵³ During a hearing in the U.S. House of Representatives, government officials emphasised the importance of disaggregating data, especially based on ethnicity, in order to identify disparities in the system and promote equality.²⁵⁴ *No Child Left Behind* protects the privacy of the students by not permitting students to be individually identified.²⁵⁵ By evaluating student achievement based on sub-groups, such as race, special education students, and students with limited proficiency of English, schools are able to confirm if and when academic equality and progress is being achieved among all students.²⁵⁶

²⁴⁹ *Ibid.*, p 37-47.

²⁵⁰ US Department of Education, 'The Office for Civil Rights', available at: www2.ed.gov/about/offices/list/ocr/docs/crdc-2011-12-factsheet.html (last accessed 12 Feb 2013).

²⁵¹ *Ibid.*

²⁵² *Ibid.*

²⁵³ U.S. House of Representatives, 'No Child Left Behind: Disaggregating student achievement by subgroups to ensure all students are learning', *Hearing before the Committee on Education and the Workforce*, 109th Congress, Second session, Serial No. 109-43, 13 June 2006, available at: www.gpo.gov/fdsys/pkg/CHRG-109hhrg28431/html/CHRG-109hhrg28431.htm (last accessed 12 Feb 2013).

²⁵⁴ *Ibid.*

²⁵⁵ *Ibid.*

²⁵⁶ *Ibid.*

Disaggregated data has proven to be especially useful through school initiatives in various States. Through a programme called the “Socrates Data System,” schools are able to easily disaggregate data confidentially.²⁵⁷ In Lachat’s report about the data entry system, she explained that the database connects “student performance, student demographics, and students’ educational experiences, which had previously been in separate data files.”²⁵⁸ The programme has the ability to disaggregate data effectively and efficiently, so it has become extremely valuable as a means for schools to evaluate and understand trends among academic performance, therefore indicating which groups may be progressing at different rates.²⁵⁹ This is widely viewed as a successful measure which helps to prevent discrimination.²⁶⁰ In order to protect the privacy of individuals, data confidentiality agreements were created within each school district, following the regulations of the Family Educational Rights and Privacy Act (FERPA).²⁶¹ The professional behaviour and the steps taken to provide confidentiality demonstrate the importance of disaggregated data in the U.S. and the need to make it available and accessible.

The Office of Juvenile Justice and Delinquency Prevention (OJJDP) also has a programme through which they can disaggregate data to determine the backgrounds of the youth and possible factors influencing their involvement in criminal behaviour.²⁶² The system is called the Relative Rate Index (RRI) and it “compares rates of contact with the juvenile justice and law enforcement systems at various stages among different groups of youth. It can show if there are differences in arrest rates or court sentences, for example, between racial/ethnic groups that are not explained by simple differences in population numbers.”²⁶³

5.3.2 Collection of disaggregated data in the health sector

Disaggregated data is also valuable in the health field. Under the HHS Open Government Initiative, an aspect of the Affordable Care Act of 2010, the government aims to “increase the availability, quality, and use of data to improve the health of minority populations.”²⁶⁴ The programme seeks to ensure the public can access disaggregated data once it has been anonymised to encourage research to identify disparities, specifically noting that any programmes or actions promoted at a federal level will be required to collect data disaggregated by race and ethnicity for “external analysis.”²⁶⁵ This reveals how important it is considered to be at a national level to maintain equality between ethnicities and establish that the results are widely available for others to access.

²⁵⁷ See Jeffrey C. Wayman, Sam Stringfield & Mary Yakimowski, *Software Enabling School Improvement Through Analysis Of Student Data*, (2004), available at: www.csos.jhu.edu/CRESPAR/TechReports/report67.pdf.

²⁵⁸ *Ibid.*, p 38.

²⁵⁹ *Ibid.*

²⁶⁰ See for example the success of the UK in including Roma pupils in schools in Equality, ‘From Segregation to Inclusion: Roma pupils in the United Kingdom. A pilot research project’, November 2011, p. 60-61.

²⁶¹ *Ibid.*, p 39.

²⁶² National Center for Mental Health Promotion and Youth Violence Prevention, ‘The Importance of Disaggregating Student Data’, available at: www.promoteprevent.org/publications/prevention-briefs/importance-disaggregating-student-data (last accessed 12 Feb 2013).

²⁶³ *Ibid.*

²⁶⁴ United States Department of Health and Human Services, ‘HHS Action Plan to Reduce Racial and Ethnic Health Disparities: A Nation Free of Disparities in Health and Health Care’ (Washington, 2012), p 15.

²⁶⁵ *Ibid.*

Disaggregated data in the US has exposed disparities between ethnicities in healthcare. The HHS Open Government Initiative identified that “[r]acial and ethnic minorities have far lower rates of health insurance coverage than the national average, with approximately two of every five persons of Hispanic ethnicity and one of every five non-Hispanic African Americans uninsured.”²⁶⁶ The collection of disaggregated data has identified this issue, the significance of which is recognised by the government, and through the Affordable Care Act of 2010, the government aims to increase access to healthcare regardless of race.

Section 4032 of the Affordable Care Act discusses the collection of disaggregated data in the healthcare field. The legislation dictates that data must be collected on the basis of “race, ethnicity, sex, primary language, and disability status”²⁶⁷ at the “smallest geographical level such as state, local, or institutional levels.”²⁶⁸ The programme must develop national standards for sex, primary language and disability status, within the standards designated by the Office of Management and Budget Standards for race and ethnicity.²⁶⁹ This information is self-reported by the participant and protected by a security system to prevent individuals from being identified.²⁷⁰ Furthermore, health care providers must be surveyed in order to determine if the care patients are receiving is adequate.²⁷¹ The data collected will be available to other government agencies, non-governmental organisations, and the public.²⁷² The legislation also provides that data will be collected on rural underserved and frontier populations.²⁷³ The law dictates that funds will be appropriated each fiscal year from 2010 to 2014, which illustrates that the cost of such programmes is considered and taken into account.²⁷⁴

²⁶⁶ *Ibid.*

²⁶⁷ The Patient Protection and Affordable Care Act (2010), Title IV, Subtitle D, Section 4302 ‘Understanding health disparities: data collection and analysis’.

²⁶⁸ *Ibid.*

²⁶⁹ *Ibid.*

²⁷⁰ *Ibid.*

²⁷¹ *Ibid.*

²⁷² *Ibid.*

²⁷³ *Ibid.*

²⁷⁴ *Ibid.*

VI. Conclusion

There is a growing demand for the collection and dissemination of disaggregated data from a variety of stakeholders and institutions at both regional and international levels.²⁷⁵ Research carried out in different fields has shown the benefits of the collection and dissemination of such data, while also providing guidelines and safeguards to overcome possible technical, legal, political and economic issues. The collection and processing of disaggregated data, notably based on ethnicity, is essential for measuring the success of any policy implemented, especially those claiming to promote equal opportunities for all ethnic groups.²⁷⁶ Such data should be used to facilitate safeguarding measures preventing discrimination against ethnic minorities in various areas of socio-economic life (education, housing, employment, health, etc.). Data collection is essential in establishing existing baselines and ensuring there is progressive improvement of economic and social rights, as well as assessing the effectiveness of policies.

European legal standards do not prevent the collection of disaggregated data as long as appropriate safeguards are in place. Nevertheless, some States still do not have adequate laws, policies and practices in place, even though international and regional institutions have reiterated the importance of collecting disaggregated data in these countries. Examples of States' positive practice regarding the collection and dissemination of disaggregated data examined at the end of this report have shown that even if the "perfect system" does not exist, it is feasible to collect disaggregated data in a way that does not cause concern and benefits ethnic minorities. The major obstacle is the political aversion to collecting sensitive data, often attributable to historical reasons. In this respect, Sweden clearly illustrates such a dilemma since the country regularly collects disaggregated data on several grounds but prohibits the collection of data on ethnicity.

There is still work to be done throughout Europe in ensuring equal access to services for all and promoting non-discrimination, particularly in reference to the Roma community. An important aspect to this is ensuring policies are designed, implemented and assessed successfully, using an evidence-based approach. This requires robust collection and dissemination of disaggregated data in order to identify the impact of policies on minority ethnic groups. The only way this will be achieved is to engage the populations in the process of collecting data, ensuring adequate and safe use of the indicators in order to design, implement and monitor targeted policies.

²⁷⁵ DPKO and OHCHR, 'The United Nations Rule of Law Indicators: Implementation Guide and Project Tools' (2011), UN Publication sales No. E.11.I.13; Handisam, Swedish Agency for Disability Policy Co-ordination, 'National human rights indicators – small windows onto a wider context', Handisam Series (2011); Patrick Ball, 'Who Did What to Whom? Planning and Implementing a Large Scale Human Rights Data Project', *American Association for the Advancement of Science*, (Washington D.C, 1996).

²⁷⁶ 'Hillary Waldron, 'The Importance and Legal Basis for Collecting Data on Ethnicity to Improve Access to Education for Romani Children', 5 October 2012, available from www.errc.org/cikk.php?cikk=4062&page=8 (last accessed 12 Feb 2013). On the importance of principles of equality and equity for the formulation of indicators, see Siobhán McInerney-Lankford and Hans-Otto Sano, 'Human Rights Indicators in Development – An Introduction' (Washington, D.C., World Bank, 2010), p 34.

VII. Recommendations

1. The obligation to collect data disaggregated by specified grounds (including ethnicity) should be affirmed in relation to each State's commitment to realise the rights set out within human rights treaties;
2. The benefits of collecting and disseminating disaggregated data should be affirmed by relevant authorities; information about the benefits of the collection and dissemination of disaggregated data should be available and accessible to governmental officials and agencies, civil society and the public;
3. States must recognise the necessity to collect, process and disseminate disaggregated data in terms of achieving the right to health for minority groups such as Roma;
4. States must acknowledge that data protection and privacy regulations permit the collection of disaggregated data if guidelines are followed;
5. Clear guidelines should be developed and distributed indicating accepted international standards on collecting and disseminating disaggregated data on all specified grounds;
6. The guidelines should include the following:
 - Data must be collected, processed and disseminated in a way that protects sensitive data; important aspects that must be considered include:
 - a) Respect for an individual's right to privacy;
 - b) Any existing confidentiality agreements;
 - c) Ensuring the data is anonymised if necessary.
 - Communities should be consulted in respect to:
 - a) Self-identification;
 - b) Participating in the collection of data;
 - c) Other cultural issues.
 - Data should be processed and analysed to identify existing disparities.
 - Raw data should be made available to other monitoring bodies, organisations or groups identified and registered as relevant for their own statistical analysis.
 - States should initiate awareness raising campaigns to ensure members of society (with specific consideration for those groups who may have suffered historical discrimination):
 - a) Understand laws and policies in relation to the collection of disaggregated data;
 - b) Know how sensitive data is collected, processed and analysed, including who may have access to the information;
 - c) Appreciate how this data is used, and understand the possible benefits in terms of targeting future policies and programmes.
 - Sensitive data should be kept up to date and eliminated when no longer required



Human Rights Centre Clinic
www.essex.ac.uk/hrc/clinic