

A Human Rights-Based Approach to Sámi Statistics in Norway



List of Abbreviations

CEDAW Convention on the Elimination of Discrimination Against Women

CRC Convention on the Rights of the Child

CRPD Convention on the Rights of Persons with Disabilities

ECA European Court of Auditors

ECHR European Convention on Human Rights

ECRI European Commission Against Racism and Intolerance

ECtHR European Court of Human Rights

ESC European Social Charter

FRA EU Fundamental Rights Agency

GDPR EU General Data Protection Regulation

ICCPR International Covenant on Civil and Political Rights

ICERD International Convention on the Elimination of Racial Discrimination
ICESCR International Covenant on Economic, Social and Cultural Rights
ILO Conv. No. 169 The International Labour Organisation's Indigenous and Tribal

Peoples Convention No. 169

Istanbul Convention Council of Europe Convention on Preventing and Combating

Violence against Women and Domestic Violence

OECD Organisation for Economic Co-operation and Development

OHCHR Office of the High Commissioner for Human Rights

SDGs Sustainable Development Goals

SAMINOR Study The Population-based Study on Health and Living Conditions in

Regions with Sámi and Norwegian Populations

SER Sámi Parliament Electoral Roll

STN Area The Area of the Sami Parliament's Grant Scheme for Business

Development

UDHR Universal Declaration of Human Rights

UNDRIP United Nations Declaration on the Rights of Indigenous Peoples

UNPFII United Nations Permanent Forum on Indigenous Issues

Contents

Foreword	4
Terminology and Core Concepts	7
1. Summary	11
2. Recommendations	19
3. The Relationship Between Human Rights and Statistics 3.1 Implementation of Human Rights in Norwegian Law 3.2 General Human Rights Obligations 3.3 Specific Treaty Obligations Regarding Data Disaggregation 3.4 UN Treaty Body Reporting 3.5 The Obligations in a European Context 3.6 The Obligations in an Indigenous Context 3.7 The 2030 Agenda for Sustainable Development	23 25 25 27 29 32 36 40
4. Human Rights Indicators 4.1 Types of Indicators 4.2 Types of Data Sources	43 43 46
 5. Sámi Statistics in Norway 5.1 Historical Perspective 5.2 The Situation Today 5.3 Existing Sources of Statistical Data on the Sámi People 5.4 The Sámi Parliament's Perspective 	49 49 56 59 73
6. Examples of Gaps in Sámi Statistics 6.1 Sámi health 6.2 Violence and Abuse in Sámi Communities 6.3 Discrimination and Hate Speech Against Sámi People 6.4 Sámi People with Disabilities	79 80 82 84 87
7. The Risks and Challenges Associated with Sámi Statistics 7.1 Human Rights Safeguards 7.2 Difficulties Quantifying Indigenous and Ethnic Group Representation 7.3 Privacy, Confidentiality and Data Protection 7.4 Misuse of Statistical Data	91 92 93 96 100
8. International Examples of Indigenous Statistics 8.1 Global Overview 8.2 Europe 8.3 Indigenous Statistics Programs in Comparable Countries 8.4 Australia 8.5 New Zealand	105 105 107 111 112 117
List of References	193

Foreword

The Norwegian National Human Rights Institution (NIM) has a legislative mandate to "promote and protect human rights". This includes an obligation to "contribute to strengthening the implementation of human rights" in Norway by providing specialist advice, as well as monitoring, reporting and awareness-raising functions. It also means that NIM should point out any deficiencies in legislation, policies or practices that increase the risk of human rights violations.

Enhancing State authorities' awareness of their human rights obligations in specific areas is a critical aspect of this work. By identifying strengths and weaknesses in the authorities' efforts to meet these obligations, we can also shine a light on those areas where the State can do more to safeguard the rights and freedoms of people within its jurisdiction.

In this report, NIM reviews the human rights framework in relation to the collection of Sámi statistics. The report outlines the human rights-based approach to indigenous statistics, explaining why disaggregated data is essential for the implementation of indigenous rights, but also why appropriate safeguards must be in place to protect

indigenous peoples' data and prevent its misuse.

The report also considers the difficult history of Sámi statistics in Norway to better understand the sensitivity associated with the collection of ethnicity data. It then examines the data sources that are available in Norway today to assess whether they provide an adequate evidence-base for human rights monitoring, for preventing discrimination and for improving policy and service delivery on issues of importance to Sámi communities.

With a view to building this report on a sound foundation, we have asked relevant stakeholders, such as Sámi organisations, public bodies and research communities working in this area, to offer input on how the State can improve its approach to Sámi statistics. NIM has held meetings with representatives from the Sámi Parliament, the Expert Analysis Group for Sámi Statistics, the Data Protection Authority, the Sámi University of Applied Sciences, the Centre for Sámi Health Research, the Museum of Cultural History, the Center for Legal Informatics and the Center for Medical Ethics, among others. In drafting the report, we

¹ NIM-loven of 22 May 2015 [The NIM Act], s. 1.

² NIM-loven, s. 3.

³ See for example: NIMs strategy at p. 7, where we have, inter alia, determined that NIM shall "influence and contribute to stronger protection of human rights".

have also directed enquiries to a number of other bodies and have received a lot of feedback. These stakeholders have different professional approaches to this topic and a range of different perspectives on the questions raised in the report. Our mandate is not to provide all of the answers to these questions, but to provide a human rights perspective on the complex topic of indigenous statistics and to contribute to further discussion around this.

NIM also participated in the Sámi Parliament's seminar on 'Sámi visibility in public statistics and central registers' on 20 November 2019, where we received valuable input from Sámi Parliament representatives, Sámi community members and other key stakeholders. We would like to extend our gratitude to all contributors.

NIM understands that the collection of statistical data regarding Sámi ethnicity is a complex and sensitive topic and that there are a range of views within Sámi communities on this. Our role is to provide a human rights perspective on this issue in accordance with our mandate as National Human Rights Institution. Ultimately, it is for the Sámi people, through the Sámi Parliament as their representative institution, to decide whether the benefits of data disaggregation outweigh the potential risks, and to ensure that adequate safeguards are in place to protect Sámi people's statistical data. We hope this report will make a useful contribution to the Sámi Parliament's deliberations in this regard.



Adele Matheson Mestad, Director



Peter Dawson, Advisor



Terminology and Core Concepts

Statistical data: Statistical data refers to standardised information collected from a census, official survey or other administrative source for the purpose of analysis, most often by national statistics offices and/or government agencies.

Disaggregation: Disaggregation refers to the separation of statistical data into component parts or smaller units to identify and measure trends, patterns and disparities among and between population groups.

Ethnicity: Definitions of ethnicity vary depending on national circumstances, but generally focus on a group or community's shared understanding of their history, territorial origins, ancestry, cultures, traditions, languages and religions.⁴ Ethnicity is a relational term in that it describes the social relationship between groups who consider themselves culturally distinct from each other.⁵ Generally, the concept of ethnicity focuses on identity or cultural affiliation and is distinct the concept of race, which is outdated in a scientific or biological sense and has historically focused more on physical characteristics. Ethnicity is also distinct from nationality, which generally focuses on a person's country of origin or political relationship with the state. However, there may be some overlap between these different terms.

Indigenous peoples: There is no universally accepted definition of indigenous peoples, but the UN working definition and the definition adopted in Article 1 of ILO Convention No. 169 focus on peoples that are descended from the populations which inhabited a country or a geographical region at the time of conquest or colonisation or the establishment of present state boundaries and who self-identify as such in accordance with their own cultural

⁴ United Nations Statistics Division, Principles and Recommendations for Population and Housing Censuses, UN Doc. ST/ESA/STAT/SER.M/67/Rev.3, 2017, p. 204.

See for example: Thomas Hylland Eriksen, Ethnicity and Nationalism, Anthropological Perspectives, London: Pluto Press, 2010 (3rd ed.), p. 11–12.

practices, languages, social institutions, legal and political systems.⁶ Indigenous peoples often maintain deep connections to their traditional lands and territories, which they are determined to preserve, develop and transmit to future generations as the basis of their continued existence as distinct peoples. Indigenous peoples often form non-dominant sectors of society and have often been subjected to discriminatory and assimilationist policies throughout their history.

The Sámi people: The Sámi are indigenous peoples whose traditional territory (Sápmi) stretches across the northern and central parts of Norway, Sweden and Finland, and the Kola Peninsula in Russia. The Sámi have their own languages, which belong to the Finno-Ugric language group, as well as their own cultures, traditions, knowledge systems and traditional livelihoods, which include fishing, hunting and reindeer husbandry. While relatively few Sámi people make their living from reindeer herding and fishing today, these practices remain central to Sámi culture and identity. Historically, the largest proportion of Sámi people have lived in Norway, although the exact size of the population today is unknown. Within Norway, the Sámi traditional territory includes some municipalities where the majority of the population is Sámi, but in most areas, especially along the coast, the Sámi are a minority. Many Sámi also live outside of Sápmi in the southern parts of Norway, including the cities of Oslo, Bergen and Stavanger.

Ethnic minorities, national minorities and indigenous peoples: Ethnic groups that are numerically inferior to the rest of the population and are in a non-dominant position may be considered 'ethnic minorities'. However, the terms 'national minority' and 'indigenous peoples' have a more limited scope. In Member States of the Council of Europe, minority groups with long-standing ties to a country may be defined as 'national minorities' in accordance with the European Framework Convention for the Protection of National Minorities. Indigenous peoples, on the other hand, have a historical continuity with pre-invasion and pre-colonial societies that are now prevailing on their territories. As such, indigenous identities tend to be based on different claims and relationships with the state than other ethnic minorities, particularly in relation to their traditional territories. While indigenous peoples may be considered ethnic minorities, not all ethnic minorities are indigenous.

- ⁶ ILO Convention No. 169, art. 1; José Martínez Cobo, *Study of the Problem of Discrimination Against Indigenous Populations*, United Nations Sub-Commission on Prevention of Discrimination and Protection of Minorities, UN Doc. E/CN.4/Sub.2/1986/7/Add.4, 1986, para. 379; Kommunal- og moderniseringsdepartementet (KMD), *Hvem er urfolk?* [Who are indigenous peoples?], 13 February 2020.
- ⁷ Francesco Capotorti, *Study on the Rights of Persons Belonging to Ethnic, Religious and Linguistic* Minorities, United Nations Sub-Commission on Prevention of Discrimination and Protection of Minorities, 1977, p. 96.
- See for example: Meaghan Williams and Robert Schertzer, "Is Indigeneity like Ethnicity? Theorizing and Assessing Models of Indigenous Political Representation" Canadian Journal of Political Science 52, no. 4 (2019) p. 677–696.

A detailed analysis of the academic literature regarding definitions of ethnic minorities, national minorities and indigenous peoples is beyond the scope of this report. For our purposes, it is sufficient to note that there are various ethnic minority groups in Norway, including but not limited to, the Sámi people (who are recognised in Norway as indigenous peoples), as well as the Jews, Kvens/Norwegian Finns, Forest Finns, Roma and Romani/ Tater (who are recognised in Norway as national minorities).

Note: While disaggregated data is relevant to all ethnic minority groups in Norway, this report focuses on Sámi statistics and does not address the specific situation of national minorities or other ethnic groups in any detail. The question of statistical data for national minorities and other ethnic groups may be considered at a later date and in consultation with the groups concerned.

⁹ Note: there is some overlap between the historical collection of data pertaining to the Sámi people and data pertaining to national minorities in Norway, which is briefly discussed at 5.1.



1. Summary

In this report, NIM seeks to raise awareness of the human rights-based approach to indigenous statistics and to clarify how this applies to Sámi statistics in Norway.

In international human rights forums, the collection and disaggregation of statistical data on indigenous peoples is regarded as an important component of the fulfilment of States' human rights obligations. Despite this, Norway does not currently disaggregate statistical data by ethnicity or indigenous status due to difficulties in quantifying ethnic group represenation, concerns over privacy and data protection and the potential for misuse of data (particularly in light of historical misuse). The few Sámi-specific data sources that are available in Norway are fragmented and do not provide an adequate evidence base for human rights monitoring, for preventing discrimination or for improving policy and service delivery on issues of importance to Sámi communities. This summary is Chapter 1.

In Chapter 2, we provide recommendations to the Sámi Parliament, Statistics Norway and the Data Protection Authority. The recommendations are aimed at promoting a facts-based dialogue between all relevant stakeholders regarding the need to improve the quality and representativeness of Sámi statistical data, as well as the need for human rights safeguards to protect such data and prevent its misuse. We do not

recommend that particular data collection methods or safeguards be adopted, but rather that all options be considered in light of the human rights framework outlined in this report, and that each stakeholder apply their area of expertise to assist in moving this discussion forward.

Chapter 3 of the report deals with the relationship between human rights and statistics and discusses relevant recommendations from international human rights bodies. In particular, we highlight the importance of disaggregating statistical data in order to measure and address disparities in the enjoyment of human rights by different groups according to the prohibited grounds of discrimination, including ethnicity and indigenous status. Disaggregated statistical data is also crucial in enabling indigenous peoples to exercise their distinct collective rights according to treaty and customary law, including the right to self-determination, as well as rights to lands, resources, cultures and languages. Without such data, it is difficult for indigenous peoples to measure the changes that are occurring within their communities to inform their own decisionmaking processes, self-governance and development planning.

There is no explicit legally binding human rights obligation on States to disaggregate statistical data by ethnicity or indigenous status, but it is very difficult for States to fulfil their human rights obligations without such data. Most UN Treaty Bodies, both in their Reporting Guidelines and General Comments, have noted that States should disaggregate official statistics by ethnicity and/or indigenous status. Many have also made specific recommendations to Norway on this topic, noting that the absence of such data prevents Norway from monitoring the enjoyment of Sámi and minority rights, measuring discrimination and developing measures to overcome it. In addition to these recommendations, more specific treaty obligations regarding data disaggregation are found in the Convention on the Rights of Persons with Disabilities (CRPD) and the Council of Europe Convention on Preventing and Combating Violence against Women and Domestic Violence (Istanbul Convention).

The need for ethnicity data has also been emphasised by a range of human rights bodies within both the Council of Europe and the European Union, such as the European Commission Against Racism and Intolerance and the European Commission's High-Level Group on Non-Discrimination, Equality and Diversity. Other human rights bodies and experts have called on States to ensure data disaggregation on the basis of indigenous identifiers, including the UN Permanent Forum on Indigenous Issues and the UN Special Rapporteur on the Rights of Indigenous Peoples. Similar recommendations have been made by the Organisation for

Economic Co-operation and Development (OECD). Finally, data is also a central element of the UN's 2030 Agenda for Sustainable Development, and adopting States, including Norway, have committed to disaggregate statistical data by ethnicity and indigenous status under Sustainable Development Goal 17.

In Chapter 4, we consider the types of statistical indicators that are required for human rights monitoring. The UN Office of the High Commissioner for Human Rights (OHCHR) has developed a comprehensive framework for the design of human rights indicators, as well as the methodology for their use and analysis. This framework emphasises that human rights indicators require data that is disaggregated by the prohibited grounds of discrimination, including ethnicity and indigenous status, otherwise the particular situation of the people who are most vulnerable to human rights abuses will remain invisible. The framework also emphasises that different data sources should be combined to provide more comprehensive and credible human rights monitoring, including data from administrative registers and population-based surveys. In addition to disaggregating data under general human rights indicators, it is also necessary to develop specific indicators for the distinct collective rights of indigenous peoples, including for example rights related to indigenous peoples' lands and territories, cultures, languages and traditional economic activities.

In Chapter 5, we discuss the history of Sámi statistics in Norway, the situation today and the existing sources of statistical data on the Sámi people. Key developments in the history of Sámi statistics in Norway are considered, including official census collections from the mid-nineteenth century until the mid-twentieth century and the role that they played in informing assimilationist polices and discriminatory practices and research. We also discuss the growing demand for Sámi statistics to monitor living conditions and inform evidence-based policymaking over the past 30 years, and how this has led to the use of geographically based Sámi statistics, as well as the establishment of the Centre for Sámi Health Research and the Expert Analysis Group for Sámi Statistics.

The role of Statistics Norway and the Norwegian statistical system is explained, including the use of administrative registers and population-based surveys in compiling official statistics. We also discuss the four main data sources which are currently used or could be used to produce Sámi statistics in Norway – the STN Area data, the SAMINOR Study, the Sámi Parliament Electoral Roll (SER) and the Sámi language variable in the Central Population Register. The strengths and weaknesses of these data sources are examined in light of the human rights framework outlined earlier.

Finally, this Chapter looks at the Sámi Parliament's recent proposal to introduce a Sámi ethnicity variable in the Central Population Register. As a starting point, there seems to be broad agreement within the Sámi Parliament that the current approach to Sámi statistics in Norway is inadequate and that proposals for improvement should be investigated. However, while some Sámi politicians have supported the collection of Sámi-specific data in administrative registers, others have been more sceptical. The historical misuse of statistical data and the resulting distrust in data collection among the Sámi people remains a key issue, as well as concerns regarding privacy, data protection and the potential for misuse of data. For some, these concerns can be addressed through institutional, legal and technical safeguards, while others oppose any form of official registration of Sámi ethnicity.

It is clear that several stakeholders have legitimate concerns regarding proposals to collect data on Sámi ethnicity in administrative registers, most of which are grounded in the historical misuse of such data. However, it is also clear that there are some misconceptions and a general lack of awareness regarding the rationale for and methods of ethnicity data collection today, as well as the human rights safeguards which must be in place as a prerequisite for data collection. For this reason, it is crucial that efforts to promote a facts-based dialogue regarding Sámi statistics continue, both internally within the Sámi Parliament and Sámi communities, as well as externally with the Norwegian authorities.

Chapter 6 deals with human rights issues affecting the Sámi people today that are difficult to address effectively due to gaps in the available statistical data. While a

detailed analysis of every issue and the associated knowledge gaps is beyond the scope of this report, we highlight four examples of themes that we believe have significant knowledge gaps from a human rights perspective – health, violence and abuse, discrimination and hate speech and disabilities.

In each of these areas, there is very little administrative data available on the Sámi people and the self-reported survey data that is available is geographically limited, has relatively small sample sizes and is only collected every 8-10 years. While smaller academic research studies shed some light on these human rights issues, the available statistical data is insufficient from a human rights perspective. Without an ethnicity variable in administrative registers, there are no reliable national figures on Sámi people's access to and interactions with public services, comparable to those available for the broader Norwegian population and for immigrant groups. This makes it difficult to delve deeper into the issues identified in academic research, to develop appropriate policy and service delivery responses and to assess the effectiveness of those responses over time.

The risks and challenges associated with Sámi statistics are discussed in **Chapter 7**, as well as the human rights safeguards which must be in place to address them. In particular, we consider the difficulties of quantifying indigenous and ethnic group representation, concerns regarding privacy and the processing sensitive personal data, and concerns regarding the potential misuse of ethnicity data.

While constructing questions on ethnic or indigenous identity for use in official statistical collections is complex and varies between countries, several international human rights bodies have provided detailed guidance on this topic. According to the human rights-based approach to data, the identification of indigenous peoples and ethnic minorities in official statistical collections should be based on selfidentification by the individuals concerned, who should also have the option of indicating multiple or no ethnic affiliations. Furthermore, the Sámi ethnicity criteria used in the SER and SAMINOR Study are consistent with these international recommendations and are now widely accepted in Norway as the standard framework for determining Sámi ethnicity.

Several stakeholders in Norway have also expressed legitimate concerns regarding the privacy and confidentiality of individual data subjects should an ethnicity variable be introduced in official statistical collections. However, there are a number of legal safeguards in place to protect the right to privacy and to ensure compliance with data protection regulations in Norway, all of which apply to the activities of national statistics offices. These safeguards are discussed in detail in this Chapter.

In addition to general privacy and data protection safeguards, it is essential that the Sámi people exercise collective control over their own statistical data, in accordance with international human rights law and the principle of indigenous data sovereignty. Data collection processes

should be participatory and based on the consent and self-identification of data subjects. Statistical data should also reflect the priorities and aims of indigenous peoples themselves and indigenous representative institutions should participate as equal partners in all stages of data planning, collection, analysis and dissemination.

Questions have also been raised in Norway over whether the collection of ethnicity data would itself be contrary to privacy and data protection law. However, several European human rights bodies have confirmed that European data protection law establishes conditions under which the collection and processing of ethnicity data is allowed. The Director of the Norwegian Data Protection Authority has also confirmed that Norwegian data protection law allows for the collection of ethnicity data, provided that appropriate safeguards are in place.

The misuse of statistical data is also an important consideration, as history shows that when ethical and human rights safeguards are not in place, ethnicity-based data can be misused for discriminatory purposes. Today, it is prohibited under both international and Norwegian law to use statistical data to discriminate against indigenous peoples and other minority groups, and there are several institutional safeguards in place to prevent this from happening. However, there may still be instances where the misuse of statistical data to stigmatise a vulnerable group does not reach the threshold of unlawful discrimination. Both the UN's Fundamental Principles on Official Statistics and the International Statistical

Institute's Declaration on Professional Ethics emphasise that national statistics offices should take steps to prevent predictable misinterpretation or misuse of data in this regard.

The potential for misuse of indigenous peoples' data can also be reduced by respecting the principle of indigenous data sovereignty. This includes ensuring that indigenous peoples participate in the collection, analysis and dissemination of data about their communities, and that data governance structures are accountable to indigenous representative institutions. Specific measures should also be adopted to ensure the rationale for and methods of ethnicity data collection are clearly communicated to Sámi communities in a culturally safe and responsible manner.

It is important to note that discussions regarding the potential risks and challenges of collecting data on Sámi ethnicity in Norway are often based on an incorrect assumption that no such data is collected today. There are, however, several existing data sources which include Sámi identifiers, such as the SAMINOR study, the SER and the new Sámi language register. Indeed, data on the most politically active Sámi people in Norway (those registered in the SER), while not used for general statistical purposes, is already linked to the Central Population Register, made available for electoral research and displayed publicly prior to Sámi Parliament elections.

Most of the risks and challenges associated with ethnicity data already exist in Norway, including the potential for breaches of privacy, confidentiality or the misuse of data for discriminatory purposes. Therefore, the question is not really whether data on Sámi ethnicity should be collected in Norway, but rather whether the data that is already collected meets the standards of quality and representativeness required for human rights monitoring, and whether adequate safeguards are in place to protect such data. If the human rights-based approach is adopted, statistical data can be a powerful tool in empowering the Sámi people to claim and exercise their rights and in holding the State accountable for its human rights obligations.

Finally, in **Chapter 8** we consider international examples of indigenous statistics. We provide a general overview of ethnicity and indigenous data collection globally, as well as a more detailed examination of the situation in Europe and of the indigenous statistics programs in two comparable countries – Australia and New Zealand.

Studies indicate that approximately 66% of countries include some form of ethnicity variable in their official statistical collections. The regions where an ethnicity variable is most common are Oceania (84%), North America (83%), South America (82%), followed by Asia (64%) and Europe (50%), while countries in Africa (41%) are the least likely to collect data on ethnicity. Of the 90 countries that are known to include indigenous peoples, about half (51%) separately

identify indigenous peoples in their national statistical collections.

No other European country which includes indigenous peoples disaggregates official statistics by indigenous status. As such, the most relevant examples of data disaggregation for our purposes come from countries like Australia and New Zealand, both of which have robust indigenous statistics programmes and share a number of political, legal, social and cultural similarities with Norway. Both of these countries collect disaggregated statistical data on indigenous peoples through self-identification questions in their national censuses, administrative registers and population-based surveys, and have dedicated indigenous statistics programmes developed and managed in partnership with indigenous peoples. As a result, there are detailed, high-quality statistics on the demographic composition and living standards of Indigenous peoples in Australia and New Zealand. In both countries, disaggregated data on indigenous peoples has been crucial in human rights monitoring, anti-discrimination initiatives, policy development and reform, as well as indigenous people's own decision-making processes.

It is important to note that there are historical and socio-cultural differences between indigenous peoples around the world and it should not be assumed that all aspects of the indigenous statistics programmes in Australia and New Zealand are directly applicable to the situation of the Sámi people in Norway. However, indigenous

peoples share many common experiences and challenges in relation to statistical data and there are many similarities between Norway, Australia and New Zealand in this regard. As such, it may be useful to learn from the approaches of other countries that have been been collecting indigenous data in a safe and responsible manner for decades.

Unlike Australia and New Zealand, Norway no longer conducts a traditional question-naire-based census. However, this should not be considered a barrier to the comparability of indigenous statistics programmes in each country. Many of the countries that include indigenous identifiers in their census questionnaires, such as Australia and New Zealand, also include the same questions in administrative registers and population-based surveys, both of which are used in Norway. Australia and New Zealand are also moving towards administrative-based censuses in the future.

NIM understands that the collection of Sámi ethnicity data is a complex and sensitive topic and that several stakeholders have legitimate concerns regarding privacy, data protection and the need to ensure Sámi control of data. At the same time, the current approach to Sámi statistics in Norway makes it extremely difficult to develop evidence-based policy responses to the human rights issues affecting Sámi individuals and communities. As we demonstrate in this report, the Sámi people do not have to choose between higher quality statistics and safeguarding their rights to self-determination, privacy and data protection.

The human rights framework outlined in this report provides detailed guidance on the rationale for and the methodology of indigenous data collection, as well as the human rights safeguards which must be in place to protect indigenous peoples' data. Implementing this framework in Norway will require the cooperation of several institutions with different mandates and expertise, alongside community awareness-raising efforts. For this reason, NIMs recommendations are aimed at promoting cooperation and awareness-raising, not only in terms of the need for higher quality Sámi statistics, but also the safeguards required to protect Sámi people's data.



2. Recommendations

Although there is no legally binding human rights obligation on States to disaggregate statistical data by ethnicity or indigenous status, NIM believes that the current approach to Sámi statistics in Norway does not provide an adequate empirical basis for monitoring the equal enjoyment of the Sámi people's human rights. Therefore, NIM makes the following recommendations.

Recommendation 1

The Sámi Parliament should increase its efforts to promote dialogue within Sámi communities, between Sámi political parties and with the Norwegian authorities, regarding the need for more adequate statistical data on the Sámi people and the safeguards which must be in place to protect such data. Specific efforts should be made to:

- Raise public awareness of the human rights-based approach to data and bestpractice models internationally;
- Consider possible options for improving the quality and representativeness of Sámi statistics; and to
- Address any concerns regarding the rationale for and methods of ethnicity-based data collection.

Recommendation 2

The Data Protection Authority should consider providing the Sámi Parliament with an assessment of the current approach to Sámi statistics in Norway, as well as any proposals to introduce new data sources or collection methods, to assess whether they comply with the requirements of privacy and data protection law. In particular, the assessment should consider:

- Institutional, legal and technical safeguards to ensure the privacy and confidentiality of all statistical data pertaining to the Sámi people; and
- Data governance arrangements to ensure the effective participation of the Sámi Parliament at all stages of data planning, collection, analysis and dissemination.

Recommendation 3

Statistics Norway should consider providing the Sámi Parliament with an assessment investigating options for improving the quality and representativeness of Sámi statistics in Norway, with a view to ensuring that such statistics can be used to monitor relevant human rights indicators. The assessment should be made in consultation with all relevant stakeholders, including the Expert Analysis Group for Sámi Statistics and the Sámi Health Research Centre, among others. Options for improving both register and survey data should be considered, including:

- Introducing questions in administrative registers which allow people to voluntarily self-identify as Sámi;
- Using the Sámi Parliament Electoral Roll for statistical purposes;
- Expanding the scope of the SAMINOR Study to include a geographically representative sample of the Sámi population in Norway;
- Establishing new Sámi-specific population-based surveys and including self-identification questions for Sámi respondents in Statistics Norway's existing surveys where appropriate; and
- Providing tools and capabilities for Sámi institutions to collect their own statistical data on issues that are important to their communities.





3. The Relationship Between Human Rights and Statistics

High-quality statistical data can be a powerful tool in empowering individuals and groups to claim and exercise their rights, and in holding States accountable for their human rights obligations.

Human rights are universal legal standards enshrined in international and domestic law that protect the fundamental freedoms and entitlements of all people. But the main challenge for human rights is not in setting universal standards, it lies in ensuring that those standards are implemented on the ground. Closing the so-called 'implementation gap', or the difference between international commitments and national compliance, depends in part on the availability of appropriate tools to evaluate the human rights situation in a given country. Statistical data is one such tool.

On a general level, the idea of using statistical data to monitor the implementation of human rights is inspired by the idea that "what gets measured gets done", or put another way "no data, no problem, no

action".¹⁰ When used properly, it can provide a concrete follow-up methodology and create a culture of accountability and transparency in government.

3.1 Implementation of Human Rights in Norwegian Law

Norway is party to most of the main international human rights conventions adopted by the United Nations and the Council of Europe, and Norwegian courts follow a general principle that domestic law should be interpreted in accordance with international law. However, human rights treaties do not have direct effect in Norwegian law unless they are directly incorporated by an act of Parliament.

On 21 May 1999, the Norwegian Parliament passed the *Human Rights Act (1999)*, which

Office of the United Nations High Commissioner for Human Rights (OHCHR), Human Rights Indicators: A Guide to Measurement and Implementation, UN Doc. HR/PUB/12/5, 2012.

elevates five key human rights conventions to a special status in Norwegian law. These are the European Convention on Human Rights (ECHR), the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic, Social and Cultural Rights (ICESCR), the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) and the Convention on the Rights of the Child (CRC). Under Article 3 of the Human Rights Act, these conventions prevail in the event of a conflict with normal domestic legislation.

The Norwegian Constitution was also amended as part of its bicentennial anniversary in May 2014 to add several human rights and to strengthen existing constitutionally enshrined human rights. The human rights chapter of the Constitution includes the rights to life, liberty, equality, privacy, a fair trial, freedom of religion, expression, assembly and movement, as well as rights related to children, work, the environment and the Sámi people. Under Article 92, all public bodies must respect and safeguard the rights enshrined in the Constitution and in the human rights treaties to which Norway is a party. The Supreme Court of

Norway held in the *Holship Case* that while Article 92 strengthens the position of constitutional rights, it still leaves the domestic incorporation of international human rights treaties to the discretion of Parliament.¹¹

The International Convention on the Elimination of All Forms of Racial Discrimination (ICERD), has been implemented in Norwegian law by the Equality and Anti-Discrimination Act (2018).

In addition to Article 27 of the ICCPR, the most important international instruments on indigenous rights are the Indigenous and Tribal Peoples Convention No. 169 (ILO Convention No. 169) and the UN Declaration on the Rights of Indigenous Peoples (UNDRIP).¹² Norway was the first country to ratify ILO Convention No. 169 in 1990 and voted in favour of adopting the UNDRIP in 2007. While ILO Convention No. 169 is legally binding on ratifying States, the UNDRIP was adopted as a UN General Assembly Declaration, so it is not legally binding in itself. However, the provisions of the UNDRIP are largely based on existing rights in international human rights treaties, as also expressed in treaty body interpretations of these rights.13

¹¹ HR-2016-2554-P, paras. 65-70.

¹² International Labour Organisation (ILO) Convention No. 169, 1650 UNTS 383 (27 June 1989, entered into force 5 September 1991); United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), UN Doc. A/ RES/61/295 (2 October 2007, adopted 13 September 2007).

See for example: James Anaya, Report of the Special Rapporteur on the Rights of Indigenous Peoples, UN Doc. A/HRC/9/9, 11 August 2008, paras. 85–86; United Nations Permanent Forum on Indigenous Issues (UNPFII), Report of the 8th Session, UN Doc. E/C.19/2009/14, 18–29 May 2009, annex para. 9; Expert Mechanism on the Rights of Indigenous Peoples (EMRIP), Free, Prior and Informed Consent: A Human Rights Based Approach, UN Doc. A/HRC/39/62, 10 August 2018, para. 7; Human Rights Committee, General Comment No. 23: Article 27 (Rights of Minorities), UN Doc. CCPR/C/21/Rev.1/Add.5, 8 April 1994; Committee on the Elimination of Racial Discrimination, General Recommendation No. 23: Indigenous Peoples, UN Doc. A/52/18, Annex V, 18 August 1997; Committee on Economic, Social and Cultural Rights, General Comment No. 21: Right of Everyone to Take Part in Cultural Life, UN Doc. E/C.12/GC/21, 21 December 2009.

Furthermore, the adopting States commit to "take the appropriate measures, including legislative measures, to achieve the ends of the Declaration".¹⁴

Key provisions of international instruments regarding indigenous peoples' rights are implemented, to varying degrees, in Norwegian law, including through Section 108 of the Norwegian Constitution, the Human Rights Act (1999), the Sámi Act (1987) and the Reindeer Husbandry Act (2007), among others.

The recommendations of UN Treaty Bodies are not legally binding. According to the preparatory works for the Human Rights Act (1999), they shall be given "significant weight" when viewed purely in the context of international law, while their importance in individual cases in Norway "may vary depending on how clear the recommendation is and to what extent a given case is similar to the situation the Committee was probably envisaging when writing the recommendation" [translated by the author]. 15 UN Treaty Bodies also publish so-called 'general comments', in addition to specific recommendations to States. The weight accorded to these general comments is unclear and the Norwegian courts are yet to consider their importance.

Similarly, the recommendations of other international human rights bodies and experts are not legally binding, including

those issued by the Permanent Forum on Indigenous Issues and the various UN Special Rapporteurs (at the UN level) or the European Commission and the European Commission Against Racism and Intolerance (at the European level). However, while such bodies may not have the power to impose sanctions or compel compliance, they do, to varying degrees, utilise follow-up mechanisms within the international system to encourage implementation of their recommendations. Most international human rights bodies are comprised of independent experts in their field, and their assessments may carry considerable weight as authoritative interpretations of international law or best practice in the area.

At the same time, it is important to emphasise that there will be nuances that cannot be fully accounted for here, and which may, in a given scenario, mean that international recommendations should be attributed greater or less importance.

3.2 General Human Rights Obligations

The collection and disaggregation of statistical data to allow for comparison between different segments of the population has long been regarded as an important component of the fulfilment of States' human rights obligations. ¹⁶ While this was implicit in earlier human rights treaties and then elaborated on by Treaty Bodies, more recent treaties include specific references to data disaggregation, for example the *Convention*

¹⁴ UNDRIP, art. 38.

Ot.prp. nr. 93 (2008–2009) p. 32; Geir Ulfstein, "Høyesteretts anvendelse av traktatorganers tolkningspraksis" Lov og Rett nr. 7 (2016).

¹⁶ OHCHR, A Human Rights Based Approach to Data, 2018, p. 7.

on the Rights of Persons with Disabilities (CRPD) and the Council of Europe Convention on Preventing and Combating Violence against Women and Domestic Violence (Istanbul Convention).¹⁷ There is no explicit legally binding human rights obligation on States to disaggregate statistical data by ethnicity or indigenous status, but it is very difficult for States to fulfil their human rights obligations without such data. In the international human rights framework, the legal basis for the collection and disaggregation of statistical data on indigenous peoples and ethnic minorities is twofold.

Firstly, States are required to take necessary steps to give effect to human rights, ¹⁸ and to submit regular reports to UN Treaty Bodies which are established to monitor their progress over time. ¹⁹ This necessarily requires States to provide Treaty Bodies with relevant statistical data to help them make an informed assessment. ²⁰ Statistical data is particularly important in monitoring the pro-

gressive realisation of economic, social and cultural rights, such as the rights to work. social security, education, an adequate standard of living, health and housing.21 While the ICESCR recognises that States may be unable to guarantee the full realisation of such rights immediately, States Parties must take steps, to the maximum of their available resources, with a view to achieving progressively the full realisation of the rights in the Convention.²² States are, according to the Committee on Economic, Social and Cultural Rights, required to move expeditiously towards this goal and have an obligation not to take retrogressive measures.23 Without relevant statistical data, it is difficult to assess whether States are improving or regressing in this regard.

Secondly, States are required to pursue a policy of eliminating discrimination through all appropriate means; to guarantee the enjoyment of all human rights without discrimination; and to adopt special measures

See for example: Article 31 of the CRPD and Article 11 of the Istanbul Convention, under which States must collect and disaggregate relevant statistical data at regular intervals.

International Covenant on Civil and Political Rights (ICCPR), 999 UNTS 171 (16 December 1966, entered into force 23 March 1976) art. 2; International Covenant on Economic, Social and Cultural Rights (ICESCR), 993 UNTS 3 (16 December 1966, entered into force 3 January 1976) art. 2; International Convention on the Elimination of Racial Discrimination (ICERD), 66 UNTS 195 (21 December 1965, entered into force 4 January 1969) arts. 2–7; Convention on the Elimination of Discrimination Against Women (CEDAW), 1249 UNTS 13 (1 March 1980, entered in to force 3 September 1981) arts. 3–5; Convention on the Rights of the Child (CRC), 1577 UNTS 3 (20 November 1989, entered into force 2 September 1990) art. 4; Convention on the Rights of Persons with Disabilities (CRPD), 2515 UNTS 3 (13 December 2006, entered into force 3 May 2008) art. 4.

¹⁹ ICCPR, art. 40; ICESCR art. 16; ICERD, art. 9; CEDAW, art. 18; CRC, art. 44(1); CRPD, art. 35.

²⁰ See for example: Committee on Economic, Social and Cultural Rights, General Comment No. 1: Reporting by States Parties, UN Doc. E/1989/22, 27 July 1981, paras. 6–7.

²¹ Ann Janette Rosga and Margaret Satterthwaite, "The Trust in Indicators: Measuring Human Rights" *Berkeley Journal of International Law* 27, no. 2 (2009) p. 253–315.

²² ICESCR, art 2.

²³ Committee on Economic, Social and Cultural Rights, *General Comment No. 3: The Nature of States Parties' Obligations*, UN Doc. E/1991/23, 14 December 1990, paras. 9–10.

to secure the substantive equality of vulnerable or disadvantaged groups. 24 This necessarily requires the disaggregation of statistical data to measure disparities between different groups according to the prohibited grounds of discrimination, including ethnicity, nationality, age, sex, sexual orientation, gender identity, religion and disability. In countries with relatively high standards of living, such as Norway, aggregate data may not reveal underlying disparities hidden within the broader population, and the experiences of smaller minority groups may remain invisible, particularly in relation to discrimination and disadvantage.

Without disaggregated data, it is difficult for UN Treaty Bodies, States and other actors to determine whether there are inequalities between different groups in the enjoyment of their human rights, and whether adequate steps are being taken to address them.

In Norway, it has been argued that the collection of ethnicity data would itself be discriminatory.²⁵ This is an understandable position, particularly in light of the history of

Norwegian assimilation policies. However. the Committee on the Elimination of Racial Discrimination has clearly stated that "the principle of non-discrimination requires that the characteristics of groups be taken into consideration".26 Under international human rights law, equality does not mean uniform treatment, and special measures are required to effectively address the structural and systemic inequalities faced by particular groups.²⁷ In this sense, the collection of ethnicity data for the purposes of monitoring the enjoyment of human rights and addressing discrimination is, by definition, not discriminatory. Indeed, data disaggregation is essential in devising special measures to prevent and address discrimination against particular ethnic groups.28

3.3 Specific Treaty Obligations Regarding Data Disaggregation

In addition to the recommendations outlined above, more specific treaty obligations regarding data disaggregation are found in the CRPD and the Istanbul Convention.

- ²⁴ Charter of the United Nations, 1 UNTS XVI (24 October 1945) art. 1(3); Universal Declaration of Human Rights (UDHR), UN Doc. A/810 (10 December 1948) art. 2; ICERD, arts. 2, 5, 1(4), 2(2); ICCPR, arts. 2(1), 26, 27; ICESCR, art. 2(2); CRC, art. 2; CRPD, art. 5; CEDAW, arts. 2, 5; International Convention on the Protection of the Rights of All Migrant Workers and their Families (CMW), 220 UNTS 3 (18 December 1990, entered into force 1 July 2003) art. 7.
- 25 See for example: Rita Heitmann, "Avvis forsøk på etnisk registrering" [Reject attempts at ethnic registration] Sagat, 20 December 2018.
- ²⁶ Committee on the Elimination of Racial Discrimination, General Recommendation No. 32: The meaning and scope of special measures in the International Convention on the Elimination of All Forms of Racial Discrimination, UN Doc. CERD/C/GC/32, 24 September 2009, para. 8.
- ²⁷ ICERD arts 1(4) and 2(2); Committee on the Elimination of Racial Discrimination, General Recommendation No. 32; Committee on Economic, Social and Cultural Rights, General Comment No. 20: Prevention of discrimination, UN Doc. E/C.12/GC/20, 2 July 2009, paras. 36–39.
- ²⁸ Human Rights Council, *The Role of Prevention in the Promotion and Protection of Human Rights: Report of the OHCHR*, UN Doc. A/HRC/30/20, 16 July 2015, paras. 33–34.

The CRPD was opened for signature by the UN in 2007 and was ratified by Norway in 2013.²⁹ The purpose of the Convention is to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity".³⁰ In particular, the Convention clarifies how all human rights apply to persons with disabilities and identifies areas where adaptations must be made to effectively secure these rights.

Article 31 of the CRPD requires States
Parties to collect appropriate disaggregated
statistical data to help assess the fulfilment
of their obligations under the Convention
and to identify and address the barriers
faced by persons with disabilities in exercising their rights. The Committee on the Rights
of Persons with Disabilities, in its General
Comment No. 7, provides the following
advice to States regarding the collection
and disaggregation of statistical data:

States Parties should establish a unified data-collection system to collect quality, sufficient, timely and reliable data, disaggregated by sex, age, ethnicity, rural/urban population, impairment type and socio-economic status, regarding all

persons with disabilities and their access to the rights under the Convention.³¹

The Istanbul Convention was opened for signature by the Council of Europe in 2011 and came into force in Norway on 1 November 2017.32 The purpose of the Convention is to prevent, prosecute and eliminate all forms of gender-based violence.33 The Istanbul Convention has a strong emphasis on the prevention of violence perpetrated by private individuals, requiring States to take "necessary legislative and other measures to exercise due diligence".34 In Article 12 of the Convention, States are obligated to take all necessary steps, including legislative and other measures, to prevent the occurrence of violence and abuse. Article 12(3) highlights that preventive measures "shall take into account and address the specific needs of persons made vulnerable by particular circumstances".

In the *Explanatory Report*, which provides further guidance on the nature of obligations under the Istanbul Convention, vulnerable individuals are, inter alia, described as "persons of national or ethnic minority background".³⁵ This means that ratifying States must take into account the specific needs of indigenous people and ethnic minorities that are particu-

²⁹ Prop. 106 S (2011-2012).

³⁰ CRPD, art. 1.

³¹ Committee on the Rights of Persons with Disabilities, General Comment No. 7: The participation of persons with disabilities, including children with disabilities, through their representative organisations, in the implementation and monitoring of the Convention, UN Doc. CRPD/C/GC/7, 9 November 2018, para. 91.

³² Prop. 66 S (2016-2017).

³³ Council of Europe Convention on Preventing and Combating Violence against Women and Domestic Violence (Istanbul Convention), CETS No.210 (11 May 2011, entered into force 1 August 2014) arts. 2 and 3.

³⁴ Ibid, art. 5; Council of Europe, Explanatory Report to the Istanbul Convention, CETS No.210, 2011, paras. 57-60.

³⁵ Council of Europe, Explanatory Report to the Istanbul Convention, para. 87.

larly vulnerable to violence when devising and implementing preventative measures.

The Istanbul Convention also requires States to collect adequate data and research on violence, adopt evidence-based policy responses to violence and ensure effective coordination of services. Article 11 of the Convention sets out three main requirements for data collection and research. Firstly, States shall "collect disaggregated relevant statistical data at regular intervals on cases of all forms of violence covered by the scope of this Convention".36 Secondly, States shall "support research in the field of all forms of violence covered by the scope of this Convention in order to study its root causes and effects, incidence and conviction rates, as well as the efficacy of measures taken to implement this Convention".37 Finally, States shall "endeavour to conduct population-based surveys at regular intervals to assess the prevalence of and trends in all forms of violence covered by the scope of this Convention".38

The Explanatory Report sets out in greater detail the types of data that need to be collected, analysed and disseminated in order to devise and implement measures to address violence.³⁹ The Council of Europe highlights the need for both survey data and administrative data, noting that they serve

different purposes and answer different questions:

While the first [survey data] can shed light on the level of severity and frequency as well as on the socioeconomic and cultural factors leading to violence against women and domestic violence, the second [administrative data] can contribute to address capacity issues of government agencies and evaluate the effectiveness of services provided for victims of such violence.⁴⁰

3.4 UN Treaty Body Reporting

There are nine core UN human rights treaties, and each has a committee of independent experts to monitor its implementation and hold States accountable for their human rights obligations. Most UN Treaty Bodies, both in their Reporting Guidelines and General Comments, have noted that States should monitor the progressive and non-discriminatory realisation of human rights through the collection and disaggregation of statistical data. Several Treaty Bodies have also made specific recommendations to Norway on this topic.

The UN's harmonised guidelines on Treaty Body reporting recommend that States "should provide relevant statistical data, disaggregated by sex, age, and population

³⁶ Istanbul Convention, art. 11 (1)(a).

³⁷ Ibid, art. 11 (1)(b).

³⁸ Ibid, art. 11(2).

³⁹ Council of Europe, Explanatory Report to the Istanbul Convention, paras. 74–82.

⁴⁰ Ibid, para. 79.

groups" to allow for comparison over time regarding the implementation of treaty obligations. ⁴¹ The more detailed Treaty Body reporting guidelines for the ICESCR, ICERD, CRC and CEDAW also recommend that States submit relevant statistical data disaggregated by age, sex, gender, nationality, ethnic origin, indigenous origin, religion, disability, place of residence and socioeconomic status. ⁴²

The Committee on Economic, Social and Cultural Rights recommends that States "provide disaggregated and comparative statistical data on the effectiveness of specific anti-discrimination measures and the progress achieved towards ensuring equal enjoyment of each of the Covenant rights by all, in particular by disadvantaged and marginalised individuals and groups".⁴³

In its concluding observations to Norway in 2020, the Committee on Economic, Social and Cultural Rights said it was "concerned about the absence of data, disaggregated by ethnic or indigenous origin, which makes it difficult to assess the level of enjoyment of Covenant rights by the Sámi and persons belonging to ethnic minority groups".⁴⁴ The

Committee recommended that Norway "improve the data collection system to collect data disaggregated by ethnic or indigenous origin with a view to tracking progress in the realisation of Covenant rights and designing effective and targeted measures to increase the level of their enjoyment towards full realisation".

In its concluding observations to Norway in 2019, the Committee on the Elimination of Racial Discrimination said that it "regrets the lack of statistics on the ethnic composition of the population and of socio-economic indicators on the enjoyment of rights by persons belonging to various ethnic groups".46 The Committee recommended that Norway develop methods for data disaggregation in dialogue with ethnic minorities in order to provide an empirical basis for monitoring the enjoyment of their socio-economic rights. The Committee made similar recommendations to Norway in 2011, 2006 and 2003, emphasising that Norway's concerns over the collection of ethnicity-based data can be addressed by ensuring that such data is collected on a voluntary basis, with full respect for the privacy and anonymity of the individuals

⁴¹ United Nations Secretary-General, Compilation of Guidelines on the Form and Content of Reports to be Submitted by States Parties to the International Human Rights Treaties, UN Doc. HRI/GEN/2/Rev.6, 3 June 2009, p. 7 (para. 26).

⁴² Ibid, for ICESCR see p. 28 (para. 3g), p. 29 (para. 10); for ICERD see p. 60 (para. 6); for CRC see p. 96 (paras. 1 and 4), p. 97–104; for CEDAW see p. 65 (para. A.4.2).

⁴³ Ibid, ICESCR, p. 29 (para. 10).

⁴⁴ Committee on Economic, Social and Cultural Rights, Concluding observations on the sixth periodic report of Norway, UN. Doc. E/C.12/NOR/CO/6, 6 March 2020, para. 12.

⁴⁵ Ibid, para. 13.

⁴⁶ Committee on the Elimination of Racial Discrimination, *Concluding observations on the combined twenty-third* and twenty-fourth periodic reports of Norway, UN Doc. CERD/C/NOR/CO/23-24, 2 January 2019, paras. 5–6.

concerned, in accordance with international human rights law.⁴⁷

In 2018, the Committee on the Rights of the Child recommended that Norway "disaggregate data by ethnicity, as the absence of such data prevents the State Party from gaining the knowledge needed to measure discrimination based on ethnicity and develop measures to overcome it".⁴⁸ The Committee further recommended that Norway "ensure that data collected on sexual abuse and exploitation of children is disaggregated by age, sex, disability, location, ethnic and national origin and socioeconomic background".⁴⁹

In 2017, the Committee on the Elimination of Discrimination Against Women recommended that Norway collect disaggregated data on violence and abuse against women. The Committee also recommended improved and disaggregated data collection on "the health situation of Sámi women and on the impact of the measures taken to overcome intersecting forms of discrimination in the health sector". 51

In its concluding observations to Norway in 2019, the Committee on the Rights of Persons with Disabilities said it was "concerned about the lack of consistent statistics on persons with disabilities and the lack of human rights indicators in the available data, which makes it difficult for the State Party to develop appropriate policies". 52 As such, the Committee recommended that Norway "collect, analyse and disseminate data on its population disaggregated by sex, age, ethnic origin, type of impairment, socio-economic status, employment, barriers encountered and place of residence, and data on cases of discrimination or violence against persons with disabilities".53

In its concluding observations to Norway in 2018, the Human Rights Committee said it was "concerned about the persistence of hate crimes and hate speech, including on the Internet, against Romani people/Tater, Roma, migrants, Muslims, Jews and Sámi persons" and was also "concerned at the lack of systematic registration of cases and collection of comprehensive data on hate crimes and hate speech".54 The Committee

⁴⁷ Committee on the Elimination of Racial Discrimination, Concluding observations on the 16th periodic report of Norway, UN Doc. CERD/C/63/CO/8, 10 December 2003, para. 8; Concluding observations on the 17th and 18th periodic reports of Norway, UN Doc. CERD/C/NOR/CO/18, 19 October 2006, para. 13; Concluding observations on the 19th and 20th periodic reports of Norway, UN Doc. CERD/C/NOR/CO/19-20, 8 April 2011, para. 6.

⁴⁸ Committee on the Rights of the Child, Concluding observations on the combined fifth and sixth periodic reports of Norway, UN Doc. CRC/C/NOR/CO/5-6, 4 July 2018, para. 9.

⁴⁹ Ibid, para. 18(f).

⁵⁰ Committee on the Elimination of Discrimination Against Women, Concluding observations on the ninth periodic report of Norway, UN Doc. CEDAW/C/NOR/CO/9, 22 November 2017, para. 25(d).

⁵¹ Ibid, para. 39(c).

⁵² Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Norway, UN Doc. CRPD/C/NOR/CO/1, 7 May 2019, para. 49.

⁵³ Ibid, para. 50.

⁵⁴ Human Rights Committee, Concluding observations on the seventh periodic report of Norway, UN Doc. CCPR/C/NOR/CO/7, 25 April 2018, paras. 16–17.

recommended that Norway "streamline the national registration of reports of hate crimes and hate speech and systematise the regular collection of data on these crimes, including the number of reported cases, investigations launched, prosecutions and convictions" 55

3.5 The Obligations in a European Context

The right to equality and non-discrimination is one of the core values of the Council of Europe and is guaranteed in Article 14 and Protocol No. 12 of the ECHR. ⁵⁶ These provisions provide a non-exhaustive list of the prohibited grounds of discrimination, which include race, colour, language, sex, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status. ⁵⁷

The need for ethnicity data has long been emphasised by a range of European institutions. For example, the European Court of Human Rights (ECtHR) has, in several cases, relied on disaggregated statistical data as evidence that a general measure or practice indirectly discriminates against a particular ethnic group.58 Similarly, the European Committee on Social Rights, which monitors state compliance with the European Social Charter (ESC), has noted that it is difficult to assess allegations of discrimination against ethnic minorities without reliable disaggregated data.⁵⁹ The European Court of Auditors (ECA) has also called for the collection of ethnicity data at the EU and national levels to enable effective policymaking for ethnic minorities.60 The Conference of European Statisticians notes that ethnicity data is relevant in order to understand the situation of different ethnic groups and to monitor the enjoyment of their human rights, and provides several recommendations to countries that choose to collect such data.61

At the Council of Europe level, the institution which has been most active in this area is

⁵⁵ Ihid

⁵⁶ Note: Norway is not a party to Protocol No. 12. At the Council of Europe level, the right to equality and nondiscrimination is further safeguarded in Article E of the revised European Social Charter (ESC).

⁵⁷ Note: at the EU level, the right to equality and non-discrimination is further safeguarded in the *Treaty on the Functioning of the European Union*, the *Charter of Fundamental Rights of the European Union*, the *Race Equality Directive* (2000/43/EC) and the *Employment Equality Directive* (2000/78/EC).

⁵⁸ D.H. and others v. The Czech Republic, No. 57325/00, 13 November 2007, paras. 136–137, 188; Hoogendijk v. the Netherlands, No. 58641/00, 6 January 2005, p. 21; Zarb Adami v. Malta, No. 17209/02, 20 June 2006, paras. 75-78.

⁵⁹ European Roma Rights Centre v. Greece, No. 15/2003, 8 December 2004, paras. 27–28; European Roma Rights Centre v. Italy, No. 27/2004, 7 December 2005, para. 23.

⁶⁰ European Court of Auditors, *EU policy initiatives and financial support for Roma integration: significant progress made over the last decade, but additional efforts needed on the ground,* 2016, p. 11, rec. 8.

⁶¹ United Nations Conference of European Statisticians, *Recommendations for the 2020 censuses of population and housing*, UN Doc. ECE/CES/41, 2015, para. 701.

the European Commission Against Racism and Intolerance (ECRI),62 which for many years has highlighted the need for ethnicity data in order to develop measures aimed at addressing discrimination and inequality. In its first General Policy Recommendation in 1996. ECRI recommended that Member States of the Council of Europe disaggregate data by ethnic origin to assist in assessing the situation of ethnic groups that are particularly vulnerable to racism and intolerance, noting that "it is difficult to develop and effectively implement policies in the areas in guestion without good data".63 In 2013, ECRI recommended that Member States disaggregate administrative data by ethnic origin in order to assess the extent of racial profiling by the police and criminal justice system.64

As part of its monitoring mandate, ECRI has also made specific recommendations to several European States regarding the lack of adequate statistical data on the position of different ethnic groups and their experiences of discrimination and disadvantage.

In its fourth report on Norway in 2009, ECRI recommended that the Norwegian authorities collect data on ethnicity in order to monitor discrimination and patterns of disadvantage, while ensuring that this is done with due respect for the principles of confidentiality, informed consent and voluntary self-identification.65 ECRI also noted that the current Norwegian practice of using proxies for ethnic origin, such as parental country of birth, does not provide an accurate representation of ethnic diversity in Norway.66 In its fifth report on Norway in 2015, ECRI did not repeat their earlier recommendation regarding the need for ethnicity data, but made several recommendations regarding the need to improve statistics on incidents of hate speech and racist and homo/transphobic violence.67

At the European Union (EU) level, the European Commission⁶⁸ has also expressed concern over the lack of 'equality data' in Europe, which it defines as data used to monitor the prevalence, causes and effects of discrimination and inequality on the

- Note: ECRI is an independent human rights monitoring body established by the Council of Europe which specialises in combating racism, discrimination, xenophobia, anti-Semitism and intolerance in Europe. ECRI differs from other Council of Europe monitoring bodies in that it is not convention-based, so Council of Europe membership automatically subjects States to ECRI's mandate. ECRI does not receive State reports but rather produces country reports based on information gathering and onsite visits. ECRI also produces General Policy Recommendations on particular issues of importance.
- ⁶³ European Commission Against Racism and Intolerance (ECRI), General Policy Recommendation No. 1, CRI(96)43rev, 4 October 1996.
- ⁶⁴ ECRI, General Policy Recommendation No. 11 on combating racism and racial discrimination in policing, CRI(2007)39, 4 October 2007, p. 11.
- 65 ECRI, Report on Norway: fourth monitoring cycle, CRI(2009)4, 24 February 2009, para. 131-136.
- 66 Ibid.
- ⁶⁷ ECRI, Report on Norway: fifth monitoring cycle, CRI(2015)2, 24 February 2015, p. 35–36.
- ⁶⁸ Note: the European Commission is the executive branch of the EU. While Norway is not a member of the EU, Norway does participate in various activities of the European Commission, including the European Commission's Subgroup on Equality Data discussed below.

grounds of racial or ethnic origin, religion or belief, age, disability, sexual orientation and gender identity. 69 The European Commission first published a Handbook on Equality Data in 2007, and then a revised version in 2016, outlining the kinds of equality data which should be gathered by EU Member States, the methodology for data collection and the safeguards needed to protect such data.70 The Handbook notes that while all EU Member States have taken steps to produce equality data with respect to some of the prohibited grounds of discrimination, there is no systematic approach within or between countries and existing data is often inadequate or underutilised for human rights monitoring.

The current lack of data collection can to a large extent be attributed to an 'awareness gap', meaning that there is a lack of awareness about how equality data can be collected and what benefits this can bring. There are also misgivings and misunderstandings in relation to what data collection entails in practice and what impact privacy and data protection laws have on data collection [...]

The issues at hand can also sometimes be rather complex, requiring expertise in multiple areas of law and social science. These factors at least partly explain the current lack of action in this area.⁷¹

According to the European Commission's Director-General for Justice and Consumers:

The lack of solid data relating to equality and discrimination limits our understanding of both the extent to which discrimination affects our everyday life and how best to tackle it. Only through independent and sound information outlining the reality of EU citizens can we truly go forward in the quest for an equal society across Europe.⁷²

In 2017, the European Commission conducted a comprehensive review of equality data collection practices in EU Member States,⁷³ and a separate review specifically on the collection of data related to ethnicity.⁷⁴ The latter report found that while "signs are emerging of gradual improvement in ethnic data collection" among EU Member States, there is significant variation in national

⁶⁹ European Commission, Joint report to the European Parliament and Council on the application of Council Directive 2000/43/EC of 29 June 2000 (Racial Equality Directive) and of Council Directive 2000/78/EC of 27 November 2000 (Employment Equality Directive), COM(2014)2, 17 January 2014, p. 5–6.

⁷⁰ Timo Makkonen, *European Handbook on Equality Data*, European Commission, 2016.

⁷¹ Ibid, p. 13.

⁷² Ibid, p. 7; Note: the Directorate General for Justice and Consumers is one of 33 directorates within the executive branch of the EU with expertise and responsibility for a specific policy area, similar to a ministry in a national government. Directorates-General prepare proposals for their Commissioners which are then put forward for voting by the European Commission.

⁷³ Mark Bell et al., *Analysis and Comparative Review of Equality Data Collection Practices in the European Union:*Legal Framework and Practice in the EU Member States, European Commission, 2017.

⁷⁴ Lilla Farkas, Analysis and Comparative Review of Equality Data Collection Practices in the European Union: Data Collection in the Field of Ethnicity, European Commission, 2017.

approaches and the sharing of best practices is uncommon.⁷⁵ The report identified good practices in ethnic data collection in several European countries, including the United Kingdom, Ireland, the Netherlands and Belgium, but underscored that "there is a clear need for harmonising practices and providing methodological guidance to national stakeholders".⁷⁶

In acknowledging these issues, the European Commission's High-Level Group on Non-Discrimination, Equality and Diversity established the Subgroup on Equality Data in February 2018, with a view to supporting Member States in their efforts to improve the collection and use of equality data.⁷⁷ The Subgroup on Equality Data comprises representatives from the European Commission, the EU Fundamental Rights Agency (FRA) and Eurostat, as well as representatives from 15 EU Member States and Norway. State representatives include relevant governmental departments, national statistical institutions and equality bodies.78 To date, the Subgroup has produced a set of Guidelines on Improving the Collection and Use of Equality Data; a Compendium of Practices on Equality Data; and a Diagnostic Tool for mapping existing sources of equality data.⁷⁹

The Guidelines note that most European countries share common gaps and challenges in this area, including "imbalances in equality data collection on different grounds of discrimination" and "incomplete identification of population groups at risk of discrimination due to over-reliance on proxies".80 While data is increasingly disaggregated by gender, age and disability in Europe, there has not been the same progress with regard to ethnicity data, and ethnic groups who experience discrimination or inequality are often invisible within official statistics.81 To address these issues, the European Commission recommends that States, among other things, map existing sources of equality data to identify and address data gaps; ensure comprehensiveness and representativeness of equality data; build institutional capacity to collect robust and reliable equality data; establish a data hub on equality and non-discrimination; mainstream equality data into EU and national surveys; and facilitate effective use of equality data.82

⁷⁵ Ibid, p. 5.

⁷⁶ Ibid, p. 36.

⁷⁷ European Union Agency for Fundamental Rights (FRA), Subgroup on Equality Data, February 2019.

Note: the subgroup includes state representatives from Belgium, Bulgaria, Croatia, Hungary, Estonia, Finland, Germany, Greece, Ireland, Italy, Lithuania, Netherlands, Romania, Spain, the United Kingdom, as well as Norway.

Teuropean Commission Subgroup on Equality Data, Guidelines on improving the collection and use of equality data, 2018; FRA, Compendium of Practices on Equality Data, 2019; FRA, Diagnostic Mapping Tool on Equality Data, 2019.

⁸⁰ European Commission Subgroup on Equality Data, *Guidelines on improving the collection and use of equality data*, p. 6–7.

⁸¹ Ibid.

⁸² Ibid, p. 10-17.

3.6 The Obligations in an Indigenous Context

As described above, the general requirement to disaggregate statistical data by ethnicity is based on the need to measure disparities in the enjoyment of human rights by different ethnic groups, and to develop measures which address discrimination and inequality. This also applies to the specific situation of indigenous peoples, who are often among the most marginalised and disadvantaged ethnic groups in their societies.83 However, statistical data on indigenous peoples is not only needed to address discrimination and disadvantage, it is also crucial in enabling indigenous peoples to exercise their rights according to treaty law and customary law, including their collective right to self-determination, as well as their rights to lands, resources, cultures and languages.

The international instruments that are most relevant to the rights of indigenous peoples in this regard are Article 27 of the ICCPR, ILO Convention No. 169 and the UNDRIP.

Under Article 27 of the ICPPR, persons belonging to ethnic, religious or linguistic minorities "shall not be denied the right, in community with the other members of their group, to enjoy their own culture, to profess and practise their own religion, or to use

their own language". The Human Rights Committee, which monitors the implementation of the ICCPR, has adopted a broad interpretation of Article 27, noting that indigenous cultures are closely linked to a way of life associated with the use of lands and resources. Article 27 may require States to adopt positive legal measures to protect indigenous peoples' traditional economic and social activities, and to ensure their effective participation in decisions which impact their way of life.

Similarly, under ILO Convention No. 169 and the UNDRIP, indigenous peoples have the right to maintain and strengthen their institutions and to exercise control over their economic, social and cultural development in keeping with their own needs and priorities.85 Indigenous peoples also have the right to full and effective participation in all matters that concern them, through their own representative institutions, and the right to be actively involved in administering economic and social programmes for their communities.86 In addition, indigenous peoples have the right to own, use, develop and control their traditional lands and resources,87 as well as the right to maintain and develop their cultures, traditional knowledges and languages.88

⁸³ UNDRIP, art. 2; Committee on the Elimination of Racial Discrimination, General Recommendation No. 23; United Nations Department of Economic and Social Affairs, Promoting Inclusion through Social Protection: Report on the World Social Situation 2018, UN Doc. ST/ESA/366, 2018, ch. VII.

⁸⁴ Human Rights Committee, General Comment No 23, paras. 3.2, 7; Ivan Kitok v. Sweden, No. 197/1985, 27 July 1988, para. 3.2; Chief Bernard Ominayak and Lubicon Lake Band v. Canada, No. 167/1984, 26 March 1990, para. 32.2; Apirana Mahuika et al. v. New Zealand, No. 547/1993, 27 October 2000, para. 9.4.

⁸⁵ ILO Convention No. 169, art. 7(1); UNDRIP, arts. 3, 4 and 5.

⁸⁶ ILO Convention No. 169, art. 6; UNDRIP, arts. 18, 19 and 23.

⁸⁷ ILO Convention No. 169, arts. 13-19; UNDRIP, arts. 25 and 26.

⁸⁸ ILO Convention No. 169, arts. 4, 23, 28 and 30; UNDRIP, arts. 5, 11, 12, 13, 14, 31, 34.

As distinct peoples with a collective right to self-determination, indigenous peoples are entitled to adequate statistical data to inform their own decision-making processes, self-governance and development planning.⁸⁹ Without such data, it is difficult for indigenous peoples to measure the changes that are occurring within their communities for planning and policy purposes, to present their needs and priorities to government and to assess the effectiveness of existing programmes.

The UN Principles and Recommendations for Population and Housing Censuses highlight the importance of collecting statistical data on indigenous peoples:

Facilitating the collection of data on indigenous peoples for national and international needs can serve to improve socio-economic and active participation of indigenous peoples... [and] can also assist indigenous communities in assessing their conditions of living and give them the information they need to participate and advocate in the development of programmes and policies affecting their communities, such as those impacting health

systems, models of economic production, environmental management and social organisation.⁹⁰

Since its first session in 2002, the UN Permanent Forum on Indigenous Issues (UNPFII) has continuously called on States to ensure data disaggregation on the basis of indigenous identifiers.91 In 2004, the UNPFII held an Expert Workshop on Data Collection and Disaggregation for Indigenous Peoples, identifying several challenges related to indigenous statistics, and outlining the steps which should be taken by States to address them.92 In particular, the UNPFII emphasised that self-identification guestions should be included in official statistical collections and that indigenous peoples should fully participate as equal partners in all stages of data planning, collection, analysis and dissemination.93 The UNPFII recommendations are discussed in more detail below at 7.1.

At the 2014 World Conference on Indigenous Peoples, States reaffirmed their commitment to provide financial and technical assistance to indigenous peoples for the enjoyment of their rights, including by "working with indigenous peoples to disaggregate data".94

⁸⁹ Tahu Kukutai and John Taylor eds., Indigenous Data Sovereignty: Toward an Agenda, Canberra: ANU Press, 2016.

⁹⁰ United Nations Statistics Division, Principles and Recommendations for Population and Housing Censuses, p. 205–206.

⁹¹ UNPFII, Recommendations on Data and Indicators, 2017.

⁹² UNPFII, Report of the Workshop on Data Collection and Disaggregation for Indigenous Peoples, Un Doc. E/C.19/2004/2, 10 February 2004, paras. 31–33; UNPFII, Report on the fourth session, UN Doc. E/2005/43, 16–27 May 2005, paras. 84–88.

⁹³ Ihid

⁹⁴ United Nations General Assembly, Outcome document of the high-level plenary meeting of the General Assembly known as the World Conference on Indigenous Peoples, Un Doc. A/RES/69/2, 22 September 2014, para. 10.

In following up on this commitment, the UN Special Rapporteur on the Rights of Indigenous Peoples has noted the efforts of several States to include indigenous identifiers in statistical data, but remains "deeply concerned that the particular situation of indigenous peoples often remains invisible within national statistics". Similarly, the 2019 edition of the UN's State of the World's Indigenous Peoples Report highlights the "persistent invisibility of indigenous peoples" in official statistics as a key barrier to the implementation of indigenous rights internationally.

In 2019, the Organisation for Economic Cooperation and Development (OECD) released the first ever global study on indigenous economies and regional development, which underscored the importance of high-quality indigenous data.⁹⁷ The report recommends that OECD Member States adopt the following measures to improve indigenous statistics and data governance:

 Develop and apply an agreed national definition of indigenous peoples for statistical purposes that is consistent with relevant principles of international law (self-identification, descent and belonging to a group);

- Include indigenous representatives in the governance of national statistical agencies;
- Implement specific population-based surveys on issues that are important to indigenous peoples and address gaps in the statistical framework;
- Provide regular reporting of indigenous wellbeing outcomes;
- Implement protocols and agreements to enable the pooling of data between different agencies to increase sample sizes and the availability of data;
- Adapt data collection methods to the needs of indigenous peoples through interview-administered surveys in indigenous languages that include communities in the data collection process;
- Provide tools and capabilities for indigenous organisations to collect their own data on issues that are important to their communities;
- Improve the quality and reliability of indigenous business data by introducing a consistent indigenous business identifier into the system of national statistics;

⁹⁵ Victoria Tauli-Corpuz, Report of the Special Rapporteur on the Rights of Indigenous Peoples: Rights of indigenous peoples, including their economic, social and cultural rights in the post-2015 development framework, Un Doc. A/69/267, 6 August 2014, paras. 47–52.

⁹⁶ United Nations Department of Economic and Social Affairs, State of the World's Indigenous Peoples, 4th ed, UN Doc. ST/ESA/371, 2019, ch. 2.

⁹⁷ OECD Regional Development Policy Committee, *Linking Indigenous Communities with Regional Development*, 2019, p. 25–27, 29, 33.

- Record indigenous land rights in register systems that are transparent and easily accessible; and
- Provide indigenous communities with the authority, data and technical support to develop land use plans, land codes and zoning maps that clearly identify natural resources and areas of protection on ecological and cultural grounds.

The priorities and data requirements of international human rights bodies, States and indigenous peoples will not always align, and for this reason it is essential that indigenous peoples themselves play a key role in data governance. In countries where official statistics have been disaggregated by indigenous status for many years, the focus has now shifted to ensuring indigenous peoples have the tools and capabilities to collect their own data and to control the data that public authorities collect about them. This concept has become known as 'indigenous data sovereignty' and refers to the rights of indigenous peoples to access, use and have governance over the collection, ownership and application of their own data.98 Indigenous data sovereignty networks have been established in Australia, New Zealand, Canada and the United States and the concept is increasingly being recognised in international human rights forums.99

In 2019, the UN Special Rapporteur on the Right to Privacy presented the UN Human Rights Council and the UN General Assembly with a set of international standards on the protection of health-related data, which includes a separate chapter on indigenous data sovereignty. The standards emphasise that indigenous peoples are not only entitled to disaggregated data, but also have the right to:

- Exercise control and governance over indigenous data, including the creation, collection, access, analysis, interpretation, management, security, dissemination, use, reuse, infrastructure and all other data processing of indigenous data;
- Access and co-decide on indigenous data that is contextual and disaggregated;
- Have indigenous data that is relevant and empowers sustainable selfdetermination and effective selfgovernance for indigenous peoples;
- Have indigenous data structures that are accountable to indigenous peoples;
- Have indigenous data that is protective and respects the individual and collective interests of indigenous peoples;

⁹⁸ Kukutai and Taylor, Indigenous Data Sovereignty, ch. 1.

Stephanie Carroll Rainie, Desi Rodriguez-Lonebear and Andrew Martinez, Policy Brief: Indigenous Data Sovereignty in the United States, University of Arizona Native Nations Institute, 2017; Te Mana Raraunga Maori Data Sovereignty Network, Principles of Maori Data Sovereignty, 2018; Maiam nayri Wingara Indigenous Data Sovereignty Network, Briefing Paper, 2018.

¹⁰⁰ Joseph A. Cannataci, UN Special Rapporteur on the Right to Privacy Recommendation on the Protection and Use of Health-Related Data, UN Doc. A/74/277, 5 December 2019.

- Ensure that the physical and virtual storage and archiving of indigenous data enhances control for current and future generations of indigenous peoples. Whenever possible, indigenous data shall be stored in the country or countries where the indigenous people to whom the data relates consider their traditional land to be;
- Have indigenous data collected and coded using categories that prioritise the needs and aspirations of indigenous peoples as determined by them; and
- Ensure that the collection, use and interpretation of indigenous data upholds the dignity of indigenous communities, groups and individuals. Data processing of indigenous data that stigmatises or blames indigenous peoples can result in collective and individual harm and should be actively avoided.¹⁰¹

More work is needed to implement the concept of indigenous data sovereignty in Norway and this should be considered a priority when developing proposals to improve the quality and representativeness of Sámi statistics.

3.7 The 2030 Agenda for Sustainable Development

The 2030 Agenda for Sustainable Development is the UN's global action plan for combatting poverty and inequality, promoting sustainable development, building peaceful societies and protecting human rights. It includes 17 Sustainable Development Goals (SDGs) and 169 associated targets, which are monitored by the UN High-level Political Forum on Sustainable Development. The Danish Institute for Human Rights has published a guide to the SDGs which proposes that over 90% of SDG targets are directly linked to core international human rights standards and overlap considerably with the recommendations of international human rights monitoring bodies.¹⁰²

The 2030 Agenda pledges to "leave no one behind" and emphasises the need for data disaggregation to measure progress towards its implementation. In SDG target 17.18 for example, States commit to "increase significantly the availability of high-quality, timely and reliable data disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location and other characteristics relevant in national contexts".

Both the Office of the High Commissioner for Human Rights (OHCHR) and the UNPFII highlight that States should ensure that

¹⁰¹ Ibid, ch. IV.

¹⁰² Danish Institute for Human Rights, *Human Rights and the 2030 Agenda for Sustainable Development: Lessons Learned and Next Steps*, 2018.

¹⁰³ United Nations General Assembly, Transforming Our World: The 2030 Agenda for Sustainable Development, UN Doc. A/RES/70/1, 21 October 2015.

official statistical collections include indigenous-identifiers, particularly self-identification and language, in order to capture the inequalities faced by indigenous peoples across all the SDGs.¹⁰⁴ Similarly, the UN General Assembly encourages States to include disaggregated data on indigenous peoples in their voluntary national reviews for the High-level Political Forum on Sustainable Development in order to measure progress and ensure that no one is left behind.¹⁰⁵

The UN Department of Economic and Social Affairs notes that reliable disaggregated data on the situation of particularly vulnerable groups is crucial to the implementation of the SDGs:

Without such data, some groups remain 'invisible' in national statistical analyses. For example, a high national literacy rate may obscure low literacy rates in indigenous communities that would become apparent with disaggregated data. Detailed data must be collected, analysed and published so that policymakers can take action to identify and address disparities and ensure that indigenous and other vulnerable communities are not left behind.¹⁰⁶

In his introduction to the 2019 Report on the Sustainable Development Goals, the UN

Under-Secretary-General for Economic and Social Affairs notes that progress in data disaggregation has been too slow:

The lack of accurate and timely data on many marginalised groups and individuals makes them 'invisible' and exacerbates their vulnerability. While considerable effort has been made to address these data gaps over the past four years, progress has been limited. Increased investment is urgently needed to ensure that adequate data are available to inform decision-making on all aspects of the 2030 Agenda.¹⁰⁷

Norway actively promotes the implementation of the 2030 Agenda and the Norwegian Prime Minister co-chairs the UN Secretary General's SDG Advocacy Group. Norwegian government departments are allocated responsibility for following up on the implementation of relevant SDGs and report annually on their progress to Parliament. However, in Norway's 2019 Progress Report for the 2030 Agenda, there are very few references to the Sámi people.108 The lack of reliable and comprehensive data on the Sámi people in Norway undermines the ability of the Norwegian authorities to accurately monitor the implementation of the SDGs and develop measures to overcome inequality and discrimination.

¹⁰⁴ See for example: OHCHR, UNPFII, *Briefing Note: Indigenous Peoples' Rights and the 2030 Agenda*, September 2017

¹⁰⁵ United Nations General Assembly, Rights of indigenous peoples, A/RES/72/155, 17 January 2018, para. 15.

¹⁰⁶ United Nations Department of Economic and Social Affairs, State of the World's Indigenous Peoples, 2019, ch. 2.

¹⁰⁷ United Nations Statistics Division, Sustainable Development Goals Report 2019, 9 July 2019, p. 3.

¹⁰⁸ Norwegian Ministry of Finance and Ministry of Foreign Affairs, *One year closer 2019: Norway`s progress towards the implementation of the 2030 Agenda for Sustainable Development*, 3 July 2019.



4. Human Rights Indicators

Human rights indicators are an essential tool for monitoring the implementation of human rights standards, informing evidence-based policymaking and promoting accountability and transparency.

Specific information, including statistical data, that can be used to assess and monitor the implementation of human rights are known as "human rights indicators". The OHCHR has developed a comprehensive framework for the design of human rights indicators, as well as the methodology for their use and analysis.¹⁰⁹

4.1 Types of Indicators

The three types of indicators commonly used in human rights assessments are structural, process and outcome indicators. ¹¹⁰ All three types of indicators are equally important, as they correspond to different stages or levels of human rights implementation.

For example, Article 24 of the CRC recognises the health rights of all children, including the right to have access to education on health and nutrition. There are several aspects or attributes of this right that require separate

Types of Human Rights Indicators

- ★ Structural indicators assess whether States have made a commitment to protect and promote human rights, for example through the ratification of international treaties or the adoption of laws and policies:
- ★ Process indicators assess whether States' human rights commitments are actually implemented in practice through concrete measures; and
- Outcome indicators assess the impact or results of States' efforts to implement human rights and whether overall targets have been reached.

OHCHR, Human Rights Indicators: A Guide to Measurement and Implementation; Note: FRA has also developed human rights indicators for the European context based on the OHCHR framework, see https://fra.europa.eu/.
 Ibid, p. 34–38.

indicators to adequately measure its implementation. One **structural indicator** may be the time frame and coverage of a national policy on child health and nutrition. A corresponding **process indicator** may be the proportion of school children who are educated on health and nutrition issues. While an **outcome indicator** may be the proportion of children classified as underweight, overweight and obese.

Information Used for Human Rights Indicators

- ★ **Objective** information based on observable and verifiable facts;
- Subjective information based on perception, opinion or assessment;
- ★ Information that is articulated in a quantitative form, such as numbers, percentages or indices; and
- ★ Information that is articulated in a qualitative form, such as narrative responses to interviews and questionnaires.¹¹¹

Human rights indicators can also be based on objective, subjective, quantitative and qualitative information. For example, an **objective quantitative indicator** for the right not to be subjected to violence may be the number of people who formally reported cases of domestic violence to the police or health services in a given time period, while

a subjective quantitative indicator may be the number of people who, when surveyed, say they feel unsafe at home or in public spaces. An objective qualitative indicator may be the time frame and coverage of a policy or action plan to address domestic violence, while a subjective qualitative indicator may be the first-hand accounts of domestic violence victims regarding the accessibility of support services.

Different types of indicators will require different data sources and collection methods (discussed below at 4.2). For instance, objective quantitative indicators generally require data from administrative registers because they relate to individuals' interactions with public services, while subjective quantitative indicators require data from censuses or population-based surveys because they relate to individuals' selfreported experiences. Objective qualitative indicators generally require expert assessments from equality bodies or human rights institutions because they relate to legal and policy analysis, while subjective qualitative indicators generally require data from interviews and focus groups because they relate to individuals' narrative responses.

When selecting structural, process and outcome indicators for a specific human rights standard, it is also important to include indicators for relevant cross-cutting human rights norms and principles, such as equality and non-discrimination, participation and access to an effective remedy.¹¹² These

¹¹¹ Ibid, p. 16–18.

¹¹² Ibid, p. 38-41.

norms and principles are considered crosscutting because they are essential to the enjoyment of all other human rights standards. For example, an indicator regarding access to an effective remedy for the right not to be subjected to violence may be the proportion of victims of domestic violence with access to appropriate medical, psychosocial and legal services. An indicator regarding effective participation may be the proportion of targeted populations reporting satisfaction with how involved they feel in decision-making and the implementation of programs regarding domestic violence.

In order to capture the cross-cutting norm of equality and non-discrimination, all types of indicators require data that is disaggregated by the prohibited grounds of discrimination, including age, sex, gender, nationality, ethnicity, indigenous status, religion and disability.113 Otherwise, it is only possible to measure a country's overall progress under each indicator, and the particular situation of the people who are most vulnerable to human rights abuses will remain invisible, such as women, children, the elderly, religious or ethnic minorities and indigenous peoples. Statistical data should also be used to monitor the human rights of groups who face multiple and intersecting forms of discrimination or disadvantage, such as indigenous women and children, elderly indigenous people and indigenous people with disabilities. In the examples provided above, disaggregated statistical data may reveal that indigenous children are more likely to suffer from particular health and nutrition problems, or that indigenous women are more likely to be admitted to hospital as victims of domestic violence, or that indigenous women find support services inaccessible or culturally inappropriate.

In addition to disaggregating data under general human rights indicators, it is also necessary to develop specific indicators for the distinct rights of different population groups. For example, indicators developed to monitor the implementation of the nine core human rights treaties may not be adequate for monitoring indigenous peoples' rights under ILO Convention No. 169, the ICCPR or the UNDRIP. The monitoring of these rights may require process indicators such as the proportion of schools offering indigenous language education to students and the proportion of indigenous peoples' traditional territories covered by a formal process for identifying and recognising indigenous land rights. Associated outcome **indicators** may include the proportion of indigenous people who report understanding some words in an indigenous language or who report speaking an indigenous language at home, the proportion of indigenous people with ownership or usufruct rights over land under both general and indigenous land tenure systems and the proportion of indigenous people participating in traditional economic activities (in the Sámi context this would include traditional handicrafts, reindeer herding and fishing, for example).

For this reason, the Danish Institute for Human Rights has partnered with several

¹¹³ Ibid, p. 68-70, 127-129.

other organisations to develop the Indigenous Navigator framework, which is a set of open-source tools and resources which can be used by National Human Rights Institutions, equality bodies and indigenous peoples themselves to systematically monitor the implementation of indigenous peoples' rights. 114 The framework includes a comprehensive matrix of international human rights instruments relevant to indigenous peoples and associated indicators to assess their implementation.115 Many of the indicators used in the Indigenous Navigator framework require statistical data from administrative registers and population-based surveys that is disaggregated by indigenous status.

4.2 Types of Data Sources

The OHCHR emphasises that different data sources should be combined to provide more comprehensive and credible human rights monitoring. 116 The three most important data sources in this respect are:

- Censuses:
- Administrative registers; and
- Population-based surveys.

Census data refers to information on the structure and key characteristics of the entire population of a country, usually collected through a long-form census questionnaire every 5–10 years. Administrative data refers to information collected by

government departments and public authorities, including data from national population registers and other administrative records systems. **Survey data** refers to information collected through questionnaires or interviews from a smaller, but representative, sample of the target population. Statistics Norway no longer conducts a traditional questionnaire-based census, but administrative data and survey data are very relevant to the Norwegian context (see below at 5.2).

Administrative registers are critical for human rights monitoring because they include quantitative data generated at the interface between State authorities and members of the public, providing important insights on the effectiveness of policies, programmes and services. Populationbased surveys are also an important source of information, as they provide more specific self-reported quantitative or qualitative data that can fill gaps in administrative data. Population-based health surveys may also provide clinical and anthropometric measurements and biobanking. However, voluntary surveys generally have much smaller sample sizes and lower response rates. Neither administrative data nor survey data alone can provide a complete assessment of a human rights situation in any given context, they are both equally important.

¹¹⁴ Note: the Indigenous Navigator framework is supported by the European Union; the Danish Institute for Human Rights; the ILO; the Asia Indigenous Peoples Pact; the Forest Peoples Programme; the Tebtebba Foundation; the Indigenous Peoples Major Group for Sustainable Development; and the International Work Group on Indigenous Affairs (IWGIA), see https://nav.indigenousnavigator.com.

¹¹⁵ The Indigenous Navigator, *Indicators for Monitoring the UNDRIP*, 2019.

¹¹⁶ OHCHR, Human Rights Indicators: A Guide to Measurement and Implementation, p. 58–65.

Both administrative data and survey data should be disaggregated by the prohibited grounds of discrimination, including ethnicity. In the indigenous context, this means that administrative registers and populationbased surveys should include specific questions which allow for the self-identification. of indigenous peoples. The OHCHR notes that while the decision to disaggregate census, administrative or survey data by ethnicity will depend on national circumstances, practical relevance and feasibility, disaggregation is generally considered necessary insofar as it helps to address inequalities and discrimination on prohibited grounds.117

For example, we know that violence and abuse in indigenous communities is a key human rights issue in several countries, including Norway. And Article 11 of the Istanbul Convention specifically requires ratifying States to collect and disaggregate relevant statistical data on all forms of violence (see above at 3.3). As noted in the Explanatory Report to the Istanbul Convention, data from administrative registers and data from population-based surveys provide different types of information, both of which are essential in addressing violence and abuse.118 In Norway, there is very little administrative data available on violence and abuse in Sámi communities, and the survey data that is available is geographically limited and is only collected every 8-10 years (see below at 6.2).

Administrative registers can provide data on the number of indigenous people who are admitted to hospital or specialised support services as victims of violence or abuse, and the number of cases investigated by police or prosecuted in the courts where the victim is indigenous. Administrative data may also indicate whether services provided to indigenous people are accessible, effective and culturally appropriate, and whether there are any capacity or expertise issues among service providers.

Population-based surveys, on the other hand, can provide data on the self-reported prevalence of violence and abuse against indigenous people (which is often higher than formally reported cases). It may also provide insights into the economic, social and cultural factors that contribute to violence or to a lack of trust in police and support services.

If the datasets provide a representative sample of the target population, both administrative and survey data can show whether the situation is different for indigenous people living in urban or rural areas, or for indigenous men and women.

Without both administrative and survey data on indigenous peoples, it is difficult to develop and evaluate policy responses to address violence in indigenous communities, such as the action plan currently being developed by the Norwegian Government.¹¹⁹

¹¹⁷ Ibid, p. 70.

¹¹⁸ Council of Europe, Explanatory Report to the Istanbul Convention, paras. 75 and 78.

¹¹⁹ The Norwegian Government's Action Plan on violence is currently being developed (2020).



5. Sámi Statistics in Norway

The difficult history of Sámi statistics in Norway has a profound impact on the situation today and provides valuable lessons for improving Sámi statistics in the future.

5.1 Historical Perspective

From the mid-nineteenth century until the mid-twentieth century, the Sámi people and Norway's five national minorities, the Jews, Kvens/Norwegian Finns, Forest Finns, Roma and Romani/Tater, were subjected to invasive and discriminatory research based on pseudo-scientific theories of racial superiority, such as Social Darwinism and eugenics. These theories, now discredited, sought to separate humans into racial categories and place them on an evolutionary scale from the most 'primitive' to the most 'civilised' based on physio-anthropological features. For example, researchers at the University of Oslo were particularly interested in measuring the skulls of Sámi people, as well as excavating, measuring

and photographing Sámi skeletal remains.¹²⁰ In some cases, research was used to justify the belief that 'the Nordic race' was at the top of the evolutionary ladder, while indigenous peoples, including the Sámi people, were at the bottom.

Official population statistics produced in Norway during this period, while separate to race research, were influenced by the same theories of racial superiority.¹²¹ From the midnineteenth century until the mid-twentieth century, census data was used to inform assimilation and security policies which attempted to 'Norwegianise' the Sámi and national minorities into an ethnically homogenous Norwegian population.¹²² Norwegian boarding schools were a crucial element of

¹²⁰ Jon Røyne Kyllingstad, *Anatomisk institutt og det germanske herremenneske [Anatomical Institute and the Idea of a Germanic Race]*, UiO Museum of University History, 25 October 2012.

¹²¹ Espen Søbye, "Demografi, statistikk og rasisme" [Demographics, statistics and racism] Agora, no. 3–4 (2014) p. 67; Arnfinn H. Midtbøen and Hilde Liden, Diskriminering av Samer, Nasjonale Minoriteter og Inn-vandrere i Norge: En Kunnskapsgjennomgang [Discrimination against Sami, National Minorities and Inn-Migrants in Norway: A Knowledge Review], Institutt for samfunnsforskning, report no. 1, 2015.

¹²² Eva Josefsen, *Selvopplevd diskriminering blant samer i Norge* [Self-perceived discrimination among Sami in Norway], Norut NIBR Finnmark, report no. 3, 2006; Henry Minde, "Assimilation of the Sámi: implementation and consequences" *Gáldu Journal of Indigenous Peoples Rights*, no. 3 (2005).

these policies, as they removed Sámi and Kven children from their cultural and linguistic environments and stigmatised those who failed to comply with this process. ¹²³ At the time, the Norwegian authorities believed it was necessary to document the perceived decline of Sámi and Kven cultures and languages through statistical data in order to build a uniform national identity and to demonstrate Norway's presence in the regions bordering Finland and the Soviet Union.

In this sense, official statistics were part of the state apparatus used to discriminate against the Sámi people. The Sámi Parliament explains how this history affects the collection of statistical data on the Sámi people today:

A long-term effect of the Norwegianisation of the Sámi and the Kven people is that questions about ethnicity may be perceived as offensive and as invading private space. It is far from certain that all who perceive themselves as Sámi or Kven... [will answer] questions in keeping with their self-perception and/or their linguistic and ethnic backgrounds. Some do not have a sense of their Sámi or Kven roots since family networks have kept quiet about it for several generations [translated by the author].¹²⁴

From 1845 to 1930, most Norwegian censuses registered the number of Sámi and Kven people on the basis of ancestry/ descent (herkomst/avstamning). From 1890 to 1930, questions on Sámi and Kven languages were also included in addition to the guestions on ancestry/descent.125 The number of people registered as Sámi in Norway throughout this period ranged from around 15,000 to 20,000. The exact methods used to identify Sámi and Kven individuals during census counts are unclear. In some cases, individuals may have identified as Sámi themselves, but registration may also have been based on census officials' own perceptions of a respondent's language, housing conditions, clothing or familial relationships. 126 Although Sámi and Kven people were Norwegian citizens, they were never referred to as Norwegian in official statistics because Statistics Norway adopted a race-based definition of nationality which characterised the Sámi and Kven as socially and culturally inferior to Norwegians. 127

Official statistics during this period were separated according to racial categories (fordeling etter rase) such as 'pure Norwegian', 'predominately Norwegian', Sámi, Kven or 'mixed' (rene norske, overveiende norske,

¹²³ Lars Ivar Hansen, Henry Minde and Bjørnar Olsen, Samenes historie [The history of the Sami], Oslo: Cappelen Damm Akademisk, 2004, p. 18–52; Eivind Bråstad Jensen, Skoleverket og de tre stammers møte [The school administration and the meeting between three tribes], Tromsø: Eureka, 2005, p. 223; Minde, "Assimilation of the Sámi", p. 1–33.

¹²⁴ Sámi Parliament, Proposal for Ethical Guidelines for Sámi Health Research and Research on Sámi Human Biological Material, 2017, p. 34–35.

¹²⁵ Note: The 1865 census also included questions on language, but these were not used for statistical analysis and did not reappear until 1890.

¹²⁶ Søbye, "Demografi, statistikk og rasisme", p. 88.

¹²⁷ Ibid, p. 88, 91.

lapp, kvæn, finn og blandet). The criteria used to distinguish between these groups varied greatly between censuses, with respondents sometimes categorised according to linguistic criteria and at other times according to ancestry/descent, which makes it difficult to use historical census data to measure changes in the size of the Sámi or Kven population over time.¹²⁸

In the 1946 census, it was deemed inappropriate to include specific questions on ancestry/descent due to their association with biological theories of race and the use of population registers to identify minorities for the purposes of ethnic cleansing during the Nazi occupation of Europe in World War II. However, in the lead up to the 1950 census, several public authorities urged Statistics Norway to resume the collection of statistics regarding the Sámi and Kven. Statistics Norway, despite their reservations, decided as a compromise to include questions on Sámi and Kven languages in some selected municipalities within the three northernmost counties (Nordland, Troms and Finnmark). As a result, there were only 8,778 people registered as Sámi in the 1950 census and this figure was never accepted as accurate. In the 1950 Census Booklet, Statistics Norway provided the following justification for the decision to reintroduce language questions:

Racial mixing has now occurred to such an extent that it can often be very difficult to determine which race large groups of the population belong to. Furthermore, a large proportion of the Sámi and Kven now live exactly the same way as the rest of the population, and have completely adapted to Norwegian culture and traditions. The cultural divide now follows linguistics to a greater extent, and can therefore be best elucidated by the linguistic distribution of the population [translated by the author].¹²⁹

In 1970, at the request of the Nordic Sámi Council, Statistics Norway included an additional four questions on Sámi ethnicity and languages in a separate census questionnaire for residents of 45 select municipalities within the three northernmost counties (Nordland, Troms and Finnmark). The main reason for including the separate questionnaire was that "Sámi organisations believed that in order to perform their work they needed better statistical information on the scope and distribution of the Sámi population and data on their living conditions" [translated by the author]. The 1970 census was the last to collect any Sámispecific data.

¹²⁸ Ibid, p. 92–93; Eivind Torp, "Registrering av etnisitet i folketellinger" [Registration of ethnicity in censuses] Heimen 23, no. 2 (1986) p. 72; Einar Lie and Hege Roll-Hansen, Faktisk talt – Statistikkens historie i Norge [The history of statistics in Norway], Oslo: Universitetsforlaget, 2001, p. 140.

¹²⁹ Statistics Norway, Folketellingen 1. desember 1950 [The Census 1 December 1950], booklet 8, p. 20-21.

¹³⁰ Vilhelm Aubert, *Den Samiske befolkning i Nord-Norge* [The Sámi Population in Northern Norway], Statistics Norway, 1978, p. 16.

Sámi Self-Identification Questions Included in the 1970 Census ¹³¹						
The separate questionnaire in the 1970 Census asked respondents the following self-identification questions:						
 Was Sámi your first spoken language? (For children who have not yet learned to speak, tick the box 'Yes' if Sámi is believed to be the first spoken language.) ☐ Yes ☐ No 						
■ Was Sámi the first language spoken by at least one of your parents? □ Yes □ No □ Don't know						
Was Sámi the first language spoken by at least one of your grandparents?						
☐ Yes ☐ No ☐ Don't know						
 Do you consider yourself to be Sámi? (Parents or other guardians decide whether children under the age of 15 should be considered Sámi.) ☐ Yes ☐ No ☐ Uncertain ☐ Do not wish to answer 						

Statistics Norway asked Professor Vilhelm Aubert from the University of Oslo to analyse the results of the 1970 questionnaire, as well as earlier censuses, and describe the characteristics and living conditions of the Sámi population. The results showed that there were a total of 113,874 people living in the three counties that received the Sámi-specific questionnaire. Of these, 10,535 people responded that Sámi was their first language; 16,808 people responded that Sámi was the first language of at least one of their parents; and 19,635 people responded that Sámi was

the first language of at least one of their grandparents. When asked about self-identification, 9,175 people responded that they considered themselves Sámi, while 2,632 people said they were uncertain about what to answer and 1,813 said they did not want to answer.¹³³

Aubert noted that the effects of the 'Norwegianisation' process, which he measured in the shift from Sámi to Norwegian language between generations, varied greatly between different areas.¹³⁴ In those areas where Sámi people made up a larger

¹³¹ Ibid, p. 129, note: translated by the author.

¹³² Ibid.

¹³³ Ibid, p. 21–23.

¹³⁴ Ibid, p. 118-119.

proportion of the population and/or the process of assimilation started later, such as inner Finnmark, Skånland and parts of Nordland, both Sámi self-identification and the use of Sámi languages remained relatively strong. However, in the rest of Finnmark and most of Troms, the children and grandchildren of Sámi speakers were less likely to self-identify as Sámi or report speaking a Sámi language. In the areas where Norwegian settlement had historically been most noticeable, especially along the coast, there was a strong social stigma associated with being Sámi and it was common for people to avoid revealing their Sámi identity in public.135 For example, in the 1930 census, 61% of people in Kvænangen municipality were registered as speaking a Sámi language or having Sámi ancestry. 136 In 1970, only 5.1% of people stated that Sámi was their first language and 1.1% stated that they regarded themselves as Sámi. 137

Aubert concluded that there were roughly 28,000 people registered with some Sámi affiliation in the counties of Nordland, Troms and Finnmark in 1970, including those who were not sure if their grandparents spoke Sámi and those who did not want to answer the self-identification question. However, he stressed that there was most likely

significant underreporting of Sámi affiliation due to the social stigma and the framing of the questions, which he said gave the impression that identifying as Sámi would mean respondents were not counted as Norwegians. 138 He also emphasised that several significant Sámi areas were excluded from the questionnaire, including the entire Southern Sámi area, the larger cities in Troms and Nordland counties (including Tromsø, Harstad, Narvik and Bodø) and the rest of Southern Norway (including Oslo, Bergen and Trondheim). 139 On this basis, he said that there were probably at least 40,000 people in Norway whose life was in some way affected by their Sámi ancestry. 140 Aubert also speculated that:

An attempt at mapping the Sámi population in Oslo could indicate that Oslo is one of the larger Sámi municipalities in the country. Young people from northern Sámi communities have often gone to Oslo, Bergen, Trondheim or other places in southern Norway when they first travel out of their hometown. Often, these visits to the south are relatively short-lived for education or temporary employment. But many also stay in southern Norway [translated by the author].¹⁴¹

¹³⁵ Minde, "Assimilation of the Sámi"; Torunn Pettersen and Magritt Brustad, "Same Sámi? A comparison of self-reported Sámi ethnicity measures in 1970 and 2003 in selected rural areas in northern Norway" *Ethnic and Racial Studies* 38, no. 12 (2015) p. 5–7.

¹³⁶ Aubert, Den Samiske befolkning i Nord-Norge, p. 40.

¹³⁷ Ibid, p. 26.

¹³⁸ Ibid, p. 18.

¹³⁹ Ibid, p. 19.

¹⁴⁰ Ibid, p. 114.

¹⁴¹ Ibid, p. 19.

Despite Aubert's own reservations regarding the methodology used in the 1970 census, and the fact that almost 50 have years have now passed, his rough estimate of the total Sámi population in Norway (40,000) is still used today and his speculation that Oslo may be the largest Sámi municipality is still considered by many as fact.¹⁴²

In the 1970s and 1980s, protests over the damming of the Alta/Kautokeino river put Sámi rights on the national political agenda for the first time, triggering a series of institutional and legal reforms. These included the adoption of section 110a of the Norwegian Constitution, the Sámi Act (1987), the ratification of ILO Convention No. 169 and the establishment of the Sámi Parliament as an elected representative body for the Sámi people. By the late 1980s, "the framework for 'being Sámi' in Norway had changed significantly",143 with voters required to meet several ethnicity-based criteria for registration on the Sámi Parliament Electoral Roll (SER) (discussed in more detail below at 5.3.3). As a result of these reforms, it became increasingly accepted to publicly acknowledge one's Sámi affiliation, but the sensitivity surrounding the use of Sámi identifiers in statistical collections remained.

At the same time, there was a growing need for statistical data on the Sámi people to monitor living conditions and inform evidence-based policymaking. In 1995, an official report highlighted the lack of adequate statistics on the health and living conditions of the Sámi people as a key barrier to improving health services.¹⁴⁴ In 1999, the first President of the Sámi Parliament, Ole Henrik Magga, said:

The ability to present facts in the form of figures has gained its own value in public debate. Therefore, it is crucial that we are able to bolster our arguments with numbers [...]. And we will soon reach a point where we are involved in realising many of the principles that we have fought for. Therefore, we must be very specific in our thinking moving forward. Resolutions are not enough. This is true in many areas where goals have been set and measures have been initiated. We need statistical indicators to measure their impact and their various dimensions [translated by the author].145

However, the growing demand for Sámi statistics could not be reconciled with the scepticism towards ethnicity data collection among both public authorities and Sámi

¹⁴² Torunn Pettersen, "40 000 i 40 år – må det være sånn?" [40,000 in 40 years – must that be it?] *Nordlys*, 10 October 2011; Norwegian Centre against Racism, Jurddabeassi, "Samisk myteknuser" [Sámi Mythbusters].

¹⁴³ Pettersen and Brustad, "Same Sámi?", p. 6.

¹⁴⁴ NOU 1995: 6, p. 391.

¹⁴⁵ Ole Henrik Magga, Behovet for samisk statistikk i samisk forskning og høgere utdanning [The need for Sámi statistics in Sámi research and higher education], unpublished lecture, 1999, referenced in Torunn Pettersen, "Etnisk identitet i offisiell satistikk – noen variasjoner og utfordringer generelt og i en samisk kontekst spesielt" [Ethnic identity in official satistics – some variations and challenges in general and in a Sámi context in particular] Diedut, no. 3, 2006.

communities, so the only workable solution was to produce Sámi statistics on a geographical basis. 146 When the Norwegian Government compiled a report on equality and living conditions in 1999, the Sámispecific figures were based on data from the municipalities in Finnmark that received grants from the Sámi Development Fund (Samisk utviklingsfond). 147 These figures did not relate to the Sámi population as such, but rather to a geographic area within the Sámi traditional territory in which all residents could apply for funding from the Sámi Parliament.

The geographic approach was adopted again in 2006, when Statistics Norway began producing a biannual publication called Sámi Statistics (Samisk Statistikk). Then in 2009, the Sámi Development Fund was renamed the Sámi Parliament's Grant Scheme for Business Development (Sametingets Tilskuddsordninger for Næringsutvikling). The relevant geographic area (now known as the STN Area) has been expanded several times since then to include more municipalities. While the STN Area was never intended to provide a representative sample of the Sámi population, it is still used as a proxy for Sámi settlement areas in northern Norway and as the basis for official Sámi statistics today (discussed in more detail below at 5.3.1).

Given the limitations of the geographic approach to official Sámi statistics, the only way to build a stronger evidence base for Sámi policy in Norway has been through smaller academic research projects. A key development in this regard was the establishment of the Centre for Sámi Health Research by the Ministry of Health in 2001. In 2003-2004, the Centre conducted the first Population-based Study on Health and Living Conditions in Regions with Sámi and Norwegian Populations (the SAMINOR Study). Unlike official statistical collections, the SAMINOR Study includes selfidentification questions for Sámi respondents, allowing the data to be disaggregated by Sámi ethnicity (discussed in more detail below at 5.3.2).

In 2005, the Sámi Parliament and the Norwegian Government agreed on a set of consultation standards (Prosedyrer for konsultasjoner mellom statlige myndigheter og Sametinget).¹⁴⁸ Section 8 of the standards provides for the establishment of an Expert Analysis Group for Sámi Statistics, with a mandate to strengthen the evidence base for Sámi policy, including by analysing available statistical data and identifying any knowledge gaps. The Expert Analysis Group was formally established in 2007, with members appointed every four years by the Ministry of Local Government and

¹⁴⁶ Torunn Pettersen, "Sámi ethnicity as a variable: Premises and implications for population-based studies on health and living conditions in Norway", PhD thesis, UiT The Arctic University of Norway, 2014, p. 35–36.

¹⁴⁷ Meld. St. 50 (1998–1999): Utjamningsmeldinga: Om fordeling av inntekt og levekår i Norge [The Equality Report: On distribution of income and living conditions in Norway]; Pettersen, "Sámi ethnicity as a variable", n. 15

¹⁴⁸ Kommunal- og moderniseringsdepartementet (KMD), *Prosedyrer for konsultasjoner mellom statlige myndigheter og Sametinget*, 11 May 2005.

Modernisation (KMD) in cooperation with the Sámi Parliament.¹⁴⁹ The group produces an annual report called *Sámi Numbers Speak* (Samiske Tall Forteller), which contains articles on a range of topics relevant to the Sámi people, including those for which there are not yet official statistics available.

The first article published in Sámi Numbers Speak 1 (2008) summarised the data sources which could be used to compile Sámi statistics in Norway. 150 In this article, Paul Inge Severeide discussed the limitations of the geographic approach to official Sámi statistics, noting that a "statistical Sámi population" could instead be constructed from the existing data sources that contain Sámi self-identification questions. In Sámi Numbers Speak 9 (2016), Jon Todal reviewed earlier articles from the publication in which the authors had commented on a lack of adequate data, noting that, in several areas, ethnicity-based register data would have provided more relevant information than the STN Area data. 151

Researcher at the Sámi University of Applied Sciences and Coordinator of the Expert Analysis Group for Sámi Statistics, Torunn Pettersen, says: The need for individual-based statistical data on the Sámi population and their living conditions has been pointed out over time by various Sámi institutions including the Sámi Parliament. The need has also been gradually recognised by the Norwegian authorities. At the same time, it is far from given how one can or should go about collecting such data. And regardless of how such data collection is anchored and organised institutionally, final data quality will depend on individual Sámi practices – the extent to which each person chooses to respond when given the option of ticking one or more boxes regarding Sámi affiliation on a data collection form.¹⁵²

5.2 The Situation Today

Statistics Norway (Statistisk Sentralbyrå – SSB) is the national institution responsible for coordinating the compilation, analysis and dissemination of official statistics in Norway. Until recently, Statistics Norway had compiled official population statistics using three primary sources:

- A ten-yearly national census questionnaire;
- Administrative registers; and
- Population-based surveys.

¹⁴⁹ Note: more information about the Faglig analysegruppe for Samisk statistikk [Expert Analysis Group for Sámi Statistics] can be found at http://samilogutmuitalit.no/en and https://www.regjeringen.no/no/tema/urfolk-og-minoriteter/samepolitikk/.

¹⁵⁰ Paul Inge Severeide, "Datagrunnlaget – begrensninger og muligheter" [The data basis – limitations and possibilities] in *Samiske tall forteller 1*, Kautokeino: Sámi University of Applied Sciences, 2008, p. 15.

¹⁵¹ Jon Todal, "Datagrunnlag for samisk statistikk – Tilrådingar baserte på artiklar i Samiske tall forteller 1–8" [Data basis for Sámi statistics – Recommendations based on articles in Sámi Numbers Speak 1-8] in Samiske tall forteller 9, Kautokeino: Sámi University of Applied Sciences, 2016, p. 148.

¹⁵² Quote approved by Torunn Pettersen, April 2020.

In 2011, Statistics Norway stopped sending out a national census questionnaire, so official population statistics are now compiled almost entirely using data from administrative registers, supplemented by smaller population-based surveys. The Nordic countries have a long tradition of using data from administrative registers for statistical purposes, but this has increased significantly in recent decades in order to reduce costs and the response burden on individuals. The role of Statistics Norway has thus become less about collecting statistical data and more about coordinating and analysing the data collected by other public authorities.

In 2019, the Norwegian Parliament passed a revised version of the Statistics Act (Statistikkloven),153 which among other things, provides for the establishment of a National Statistics Programme. The programme will clarify the statistical areas to be covered by Statistics Norway and the public authorities that are responsible for supplying relevant data. Under Section 6(3) of the Act, Statistics Norway must consult with all relevant public authorities and users of statistics before the programme is adopted. Under Section 10 of the Act, public authorities have a general duty to disclose information relevant to the compilation of official statistics as requested by Statistics Norway, including information contained in administrative registers. 154

Administrative Registers Accessed by Statistics Norway

Statistics Norway currently has access to around 80 administrative registers, including:

- ★ The Central Population Register maintained by the Norwegian Tax Administration;
- ★ The Register of Business Enterprises and the Central Coordinating Register for Legal Entities maintained by the Brønnøysund Register Centre;
- ★ The Land, Property and Building Register or 'Cadastre' maintained by the Norwegian Mapping Authority;
- ★ The Register of Employers and Employees, the Payroll Register, the Tax Return Register and the social security registers maintained by the Labour and Welfare Service;
- ★ The Immigration Database maintained by the Directorate of Immigration;
- The various health registers maintained by the Health Directorate, as well as the Birth Register and Cause of Death Register maintained by the Norwegian Institute of Public Health; and
- ★ The National Education Database maintained by Statistics Norway and the various education registers maintained by municipalities, the State Educational Loan Fund and the Education Directorate.

¹⁵³ Statistikkloven of 21 June 2019 [The Statistics Act].154 Ibid. s. 10.

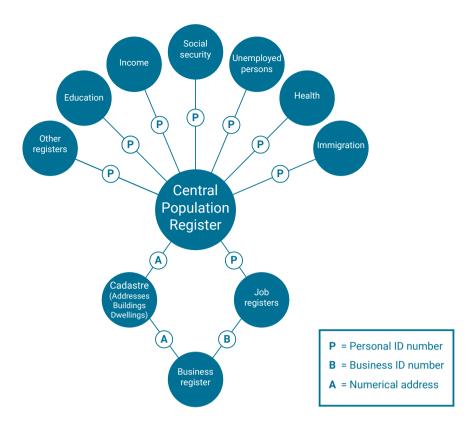


Figure 1: The Norwegian Register-Based Census System, adapted from a diagram published by Andersen and Utne, 2011¹⁵⁷

The information contained in administrative registers generally includes personal identification numbers, organisation numbers and/or addresses, which allows Statistics Norway to link data from various registers and describe the correlations between them without incurring major expenses. For example, data from the Immigration Database can be linked to data from the National Education Database in order to compile statistics on the level of education among immigrants in Norway.

Several administrative registers in Norway include variables which identify people by immigrant status, refugee status, gender, age and disability, allowing official popula-

tion statistics to be disaggregated for these specific groups.¹⁵⁵ However, information on citizens' ethnic backgrounds is not collected in administrative registers, so official population statistics cannot be disaggregated for the Sámi people. 156 We do not know the size of the Sámi population in Norway, the geographic, age or gender distribution of Sámi people or how any of these population characteristics are changing over time. There is no basis for producing official statistics on the socio-economic status of the Sámi population, so there are no national figures on Sámi health, housing, employment, education, social security or economic development, for example.

¹⁵⁵ Note: disaggregated statistical data can be found for immigrant groups, refugees, women, children, elderly persons and persons with disabilities at Statistics Norway's website, https://www.ssb.no.

¹⁵⁶ Anders Sønstebø, Samisk Statistikk 2018, Statistics Norway, 2018, p. 4, 7.

¹⁵⁷ Espen Andersen and Harald Utne, *Censuses in a register-based statistical system: Norwegian experiences*, Statistics Norway, 2011, p. 2.

Surveys Conducted by Statistics Norway

In addition to collating data from administrative registers, Statistics Norway also conducts several population-based surveys, including:

- ★ The Labour Force survey (quarterly);
- ★ The Housing Survey (monthly);
- ★ The Norwegian component of the European Student Survey (3-yearly);
- ★ The Living Conditions Survey (yearly);
- ★ The Media Use Survey (yearly);
- ★ The Alcohol, Tobacco and Drug Use Survey (yearly);
- The Norwegian Life Course, Ageing and Generations Survey (five-yearly longitudinal study);
- ★ The Survey on School Teacher Competence (ten-yearly); and
- ★ The Survey on Study Choices (two-yearly).

Statistics Norway does not conduct any Sámi-specific surveys and does not include Sámi self-identification questions in its general surveys. Ordinarily, Statistics Norway could use personal identification numbers to send more targeted surveys to specific sub-groups within the population without including individuals who have no interest in the survey topic. For example, the Survey on School Teacher Competence is only sent to a sample of individuals who are marked as primary or secondary school teachers in the employment registers maintained by the Norwegian Welfare Service (NAV). But without an ethnicity variable in administrative registers, it is difficult to construct a nationally representative sample of the Sámi population which could then be sent more targeted surveys. Statistics Norway has proposed a methodology for constructing such a sample by linking several existing and historical data sources on the Sámi population, but this would be contingent on access to the Sámi Parliament Electoral Roll (SER), which is not currently used for general statistical purposes (discussed in more detail below at 5.3.3).158

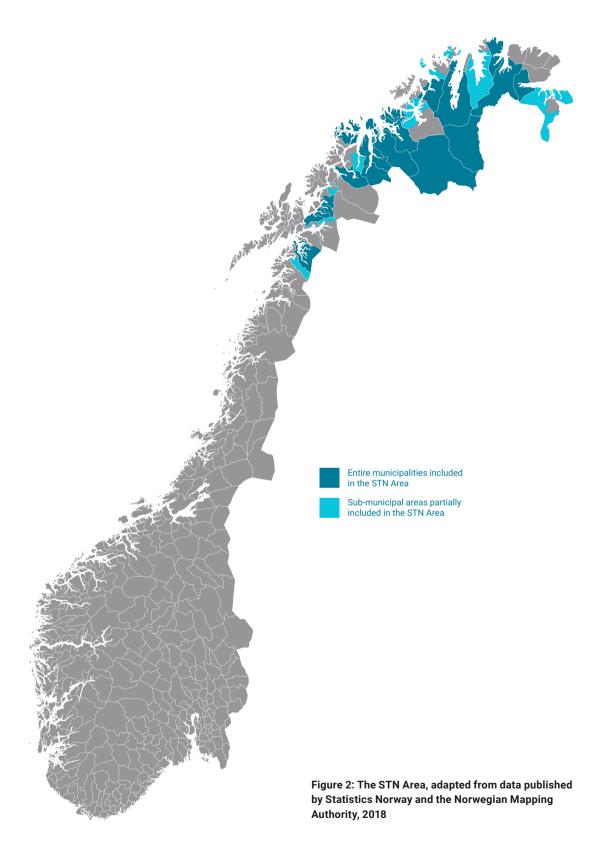
5.3 Existing Sources of Statistical Data on the Sámi People

There are four main data sources which are currently used or could be used to produce Sámi statistics in Norway. These are:

- The STN Area data;
- Population-based studies, such as the SAMINOR Study;¹⁵⁹

¹⁵⁸ Bjørn Are Holth and Magnar Lillegård, Statistikk over Samiske språkbrukere i Norge. En kartlegging av eksisterende datakilder og vurdering av fremgangsmåter for statistikk [Statistics on Sámi language users in Norway. A mapping of existing data sources and assessment of statistical methods], notater 2017/34, Statistics Norway, 2017.

¹⁵⁹ Note: other population-based studies have included self-identification questions for Sámi respondents, such as the Norwegian Arctic Adolescent Health Study (2003–2005), the survey From Rural to Urban Living (Fra bygd til by) (2014), the Public Health Surveys of Troms and Finnmark County (May 2019) and of Nordland County (January 2020), but these will not be discussed in any detail in this report. Most of these surveys have adopted self-identification questions identical or similar to those in the SAMINOR Study.



- The Sámi Parliament Electoral Roll (SER); and
- The Sámi language variable in the Central Population Register.¹⁶⁰

While each of these sources are useful for different purposes, most are either restricted to small geographic areas and/or cannot be disaggregated by Sámi ethnicity, making it difficult to use them for monitoring the human rights situation of the Sámi population as a whole. The only source which covers the entire country and includes Sámi self-identification questions, the SER, is not currently used for general statistical purposes. The four main sources of statistical data on the Sámi people are discussed in more detail below.

5.3.1 The STN Area Data

Since 2006, Statistics Norway has published official Sámi statistics, most of which have been compiled on a geographical basis using administrative data pertaining to the so-called "STN Area". The STN Area refers to selected municipalities north of the Saltfjellet mountain range that are either wholly or partially included in the Sámi Parliament's Grant Scheme for Business Development (Sametingets Tilskuddsordninger for Næringsutvikling – STN). In 2019, the STN Area included 21 entire municipalities and 10 sub-municipal areas,

with 13 located in Finnmark, 14 in Troms and 4 in the northern part of Nordland. 161 These municipalities are sometimes referred to as 'Sámi settlement areas' (Sámiske bosetningsområder) because of their long association with the Sámi people and their specific funding arrangements with the Sámi Parliament for the development of Sámi culture and industry. This should not be confused with the Administrative Area for Sámi Languages (Forvaltningsområdet for samisk språk), which is a separate area in which Sámi languages have a special status and public authorities have additional obligations regarding communication and education in Sámi.

Statistics Norway, the Sámi Parliament and the Expert Analysis Group for Sámi Statistics have all commented on the weaknesses of collecting Sámi statistics on a geographical basis. 162 From a human rights perspective, there are two main problems with the STN Area data. Firstly, the STN Area does not provide a representative sample of the Sámi population because it does not include any of the larger towns or cities in northern Norway (including Tromsø, Bodø, Alta and Kirkenes), any of the Southern Sámi areas (including Snåsa, Røyrvik, Røros, Hattfjelldal and Trondheim) or the rest of southern Norway (including Oslo, Bergen and Stavanger). Secondly, it is unclear whether the data is

¹⁶⁰ Note: in addition, there is a register of Sámi reindeer herders, a register of kindergartens that offer Sámi language instruction and a register of primary and secondary school students graduating with grades in Sámi language. These sources will not be discussed in any detail in this report.

¹⁶¹ Sámi Parliament, *Virkeområdet for tilskudd til næringsutvikling – STN området* [Scope for grants for business development – STN Area], 23 November 2018.

¹⁶² Sønstebø, Samisk Statistikk, 2018, p. 8; Sámi Parliament, Proposal for Ethical Guidelines for Sámi Health Research, p. 35; Sámi Parliament, The Sámi Parliament's 2018 Report to CERD, 2018, para. 60; Todal, "Datagrunnlag for samisk statistikk" [Data basis for Sámi statistics], 2016, p. 148.

even representative of the Sámi population within the STN Area, as it is not disaggregated by ethnicity and includes a substantial number of non-Sámi residents. For these reasons, it is difficult to draw any reliable conclusions from the STN Area data regarding the human rights situation of the Sámi people.

The best available data on the geographic distribution of the Sámi population is from the SER, which although it does not include all Sámi people, shows that there are Sámi people living in almost every municipality in Norway. Of the 18,103 people registered to vote in Sámi Parliament elections, only 39% are from the 21 municipalities which are included in the STN Area in their entirety, while a further 23% are from the 10 municipalities which are partially included in the STN Area. This means that 40–60% of the Sámi people registered to vote in Sámi Parliament elections do not live within the STN Area and are thus not represented in Statistics Norway's only official publication of Sámi statistics. Given the evidence that a growing proportion of Sámi people are living in Norwegian cities,163 and the general trend towards indigenous urbanisation in many countries,164 it is likely that the STN Area will become even less relevant to the production of Sámi statistics in the future.

Researcher at Oslo Metropolitan University (OsloMet), Mikkel Berg-Nordlie, says:

The current situation regarding Sámi statistics makes research on Sámi experiences, attitudes, social situation etc. extremely difficult. The STN Area data excludes urban areas, which is particularly troubling in a period of Sámi urbanisation. Already Aubert noted that it was a weakness in his dataset that urban areas were not included. Places like Tromsø, Oslo, Alta, Trondheim and Bodø are the homes of many Sámi now. How will their voices be heard, and their situations described, through statistical research?¹⁶⁵

The Sámi Parliament is currently considering whether the STN Area will continue to be used to set the geographical boundaries for their business development grants. ¹⁶⁶ The reason for this is that the size of the STN Area has increased significantly in recent years while the Sámi Parliament's budget for business development has actually been reduced. A range of alternatives are being considered, including abolishing the STN Area entirely. If the STN Area were to be changed or abolished, there would obviously be implications for the production of official statistics based on the STN Area.

¹⁶³ Kjetil Sørlie and Ann Ragnhild Broderstad, Flytting til byer fra distrikstområder med Sámisk bosetting [Relocation to cities from Sámi settlement areas], Norwegian Institute for Urban and Regional Research and Centre for Sámi Health Research, 2011.

¹⁶⁴ See for example: Emily Brand, Chelsea Bond and Cindy Shannon, *Indigenous in the City: Urban Indigenous Populations in Local and Global* Contexts, Poche Centre for Indigenous Health, 2016, p. 4.

¹⁶⁵ Quote approved by Mikkel Berg-Nordlie, April 2020.

¹⁶⁶ Sámi Parliament, Bærekraftig næringsutvikling [Sustainable Business Development], Case Number 18/3122, Document 19/19555, 2019.

not least the Sámi Statistics publication produced by Statistics Norway.

5.3.2 The SAMINOR Study

The Population-based Study on Health and Living Conditions in Regions with Sámi and Norwegian Populations (the SAMINOR Study) is conducted by the Centre for Sámi Health Research at UiT - the Arctic University of Norway, and aims to enhance knowledge of the health and living conditions of both Sámi and Norwegian populations in northern and central Norway.167 To date, two surveys have been completed, SAMINOR 1 (2003-2004)168 and SAMINOR 2 (2012-2014),169 with a third survey currently being planned for 2022-2024. The SAMINOR Study is unique because it is designed to specifically target the Sámi population and respondents are asked self-identification questions regarding Sámi ethnicity.

The SAMINOR dataset can be accessed for research purposes and potentially linked to data from other administrative registers for research purposes, using respondent's personal identification numbers, but this must be done in accordance with the Health Register Act (Helseregisterloven), the

Personal Data Act (Personopplysningsloven) and the EU General Data Protection Regulation (GDPR) and requires approval from the National Research Ethics Committees and the SAMINOR Project Board. A Data Protection Impact Assessment (DPIA) may also be necessary. All research projects that are granted access to the SAMINOR data must adhere to the Ethical Guidelines for Sámi Health Research and Research on Sámi Human Biological Material, adopted by the Sámi Parliament in 2019.

The SAMINOR 1 Survey took place in 2003-2004 in collaboration with the Norwegian Institute of Public Health (Folkehelseinstituttet) and included 24 municipalities in central and northern Norway.¹⁷⁰ There were 16,865 participants, 36% of which reported a Sámi background. The SAMINOR 2 Survey took place in 2012-2014 and was divided into two stages.171 Stage 1 was the SAMINOR 2 Questionnaire Survey conducted in 25 municipalities, with 11,600 participants aged 18-69, 34% of whom had a Sámi background. Stage 2 was The SAMINOR 2 Clinical Survey (including a clinical examination and blood tests) conducted in

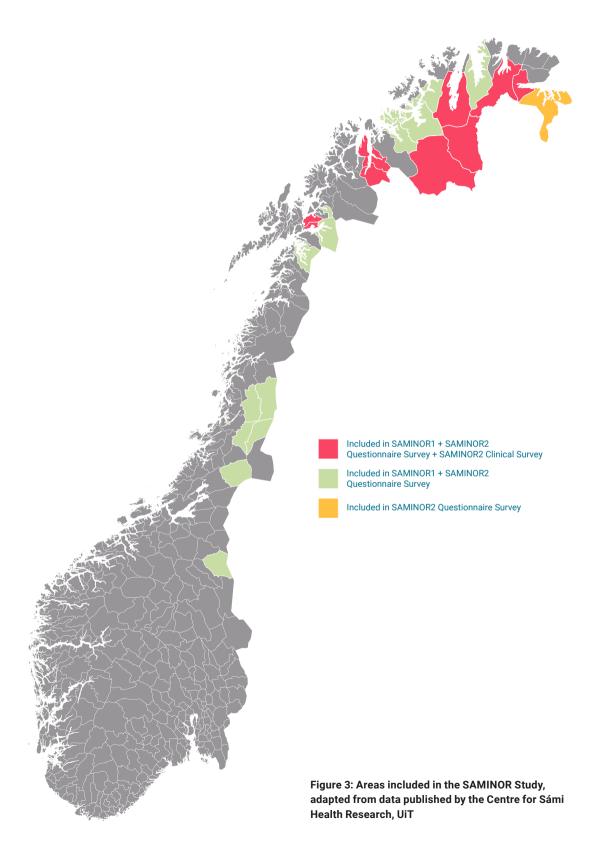
¹⁶⁷ More information on the SAMINOR Study can be found at the UiT website, https://en.uit.no/forskning/forskningsgrupper.

¹⁶⁸ Eiliv Lund et al., "Population Based Study of Health and Living Conditions in Areas with both Sami and Norwegian populations-The SAMINOR Study" *International Journal of Circumpolar Health* 66, no. 2 (2007) p. 113–128.

Magritt Brustad et al., "A population-based study on health and living conditions in areas with mixed Sami and Norwegian settlements – the SAMINOR 2 questionnaire study" International Journal of Circumpolar Health 73, no. 1 (2014); Ann Ragnhild Broderstad, Solrunn Hansen and Marita Melhus, "The Second Clinical Survey of the Population-based Study on Health and Living Conditions in Regions with Sami and Norwegian Populations – the SAMINOR 2 Clinical Survey: Performing Indigenous Health Research in a Multiethnic Landscape" Scandinavian Journal of Public Health (published online ahead of print 6 May 2019).

¹⁷⁰ Lund et al., "The SAMINOR Study".

¹⁷¹ Brustad et al., "The SAMINOR 2 questionnaire study".



10 municipalities with the support of local health workers. In the clinical survey, there were 6,004 participants, 54% of whom had a Sámi background. The SAMINOR 3
Survey is planned to cover about 40 munici-

palities in northern and central Norway, including all of Finnmark county and also larger parts of Troms, Nordland and Trøndelag counties than in previous SAMINOR surveys.

Self-Identification Questions Used in the SAMINOR Study						
The SAMINOR surveys ask respondents the following self-identification questions:						
What language(s) do/did you, your parents and your grandparents speak at home? (Put one or more crosses for each line)						
	Norwegian	Sami	Kver	n Oth	er, describe:	
Maternal grandfather:						
Maternal grandmother:						
Paternal grandfather:						
Paternal grandmother:						
Mother:						
Father:						
Myself:						
What is your, your father's and your mother's ethnic backgrounds? (Put one or more crosses for each line)						
	Nor	wegian	Sami	Kven	Other, describe:	
My ethnic background is	:					
My father's ethnic backg	round is:					
My mother's ethnic back	ground is:					
■ What do you consider yourself to be? (Put one or more crosses)						
Norwegian Sami	Kven	Oth	er, describ	e:		

¹⁷² Broderstad, Hansen and Melhus, "The SAMINOR 2 Clinical Survey".

In constructing the survey area, the Centre for Sámi Health Research tried to select municipalities in which 5-10% of the population were likely to be Sámi, based on the results of the 1970 Sámi-specific census questionnaire as well as historical and local anecdotal knowledge. All residents within the survey area and target age range received an invitation to participate along with the questionnaire, with Statistics Norway providing logistical support for the mail-out of the SAMINOR 2 Questionnaire Survey. The definition of ethnic groups is a core question in the SAMINOR Study, ascertained by eleven different questions regarding home language, ethnic background and self-perceived ethnicity. Answering options are Norwegian, Sámi, Kven and Other, with the possibility of providing more than one answer. The questions include both objective and subjective criteria: Sámi language, ethnic background and self-perceived ethnicity/identity, making it is possible to categorise the participants into indigenous versus non-indigenous groups in several different ways. Newer publications based on the SAMINOR data rely more on selfperception.

The SAMINOR survey data has mostly been used in academic research, including 51 published scientific papers, 7 PhD theses, 8 master theses and several articles in the Sámi Numbers Speak publication. While this research undoubtedly provides important insights into the health and living conditions

of the Sámi people, it does not provide an adequate evidence base for comprehensive human rights monitoring. This is because the SAMINOR Study only includes self-reported survey data (as opposed to register data),¹⁷³ has a relatively small sample size, is limited to selected municipalities in central and northern Norway, and is only conducted every 8–10 years. As noted above at 4.2, administrative data and survey data are both equally important in human rights monitoring. While survey data plays an important role in filling gaps and adding context to administrative data, it cannot replace it.

The Leader of the Centre for Sámi Health Research and the SAMINOR Study, Ann Ragnhild Broderstad, said in her speech at the Sámi Parliament's statistics seminar in November 2019:

If the healthcare system is to provide a better clinical service adapted linguistically and culturally for different patient groups, then we must have adequate health data that is disaggregated not only by gender, age and place of residence, but also by Sámi ethnicity. While the SAMINOR study provides us with some of this information, it is not good enough, because we only do it every ten years in selected municipalities. We need both register and survey data that is updated annually to reflect the changes that are happening in Sámi

¹⁷³ Note: this is not a criticism of the self-identification questions which are used in the SAMINOR Study to collect information on Sámi ethnicity, but rather an observation about the limitations of self-reported survey data more generally.

society at all levels [translated by the author]. 174

5.3.3 The Sámi Parliament Electoral Roll

The Sámi Parliament was established as the elected representative body of the Sámi people in Norway under the Sámi Act (1987) and was first opened by H.R.H King Olav V in 1989.¹⁷⁵ The Plenary Assembly of the Sámi Parliament has 39 representatives from seven constituencies, with elections held every fourth year. The Sámi Act (1987) also provides for the establishment of the

SER, which is a separate register of Sámi people who are eligible to vote or stand as a candidate in Sámi Parliament elections.

The SER is the only existing data source capable of providing a nationally representative sample of the Sámi population. As of 30 June 2019, there were 18,103 people registered on the SER, spread across some 419 municipalities. The number of people registered in the SER has increased by more than 300% since 1989.

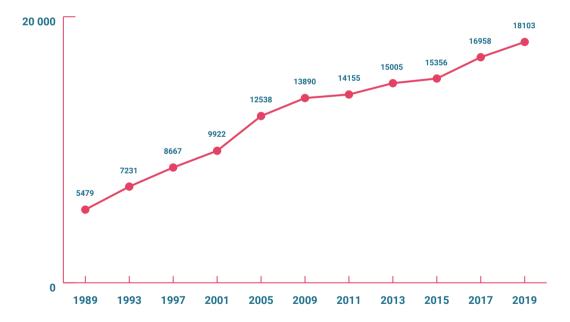
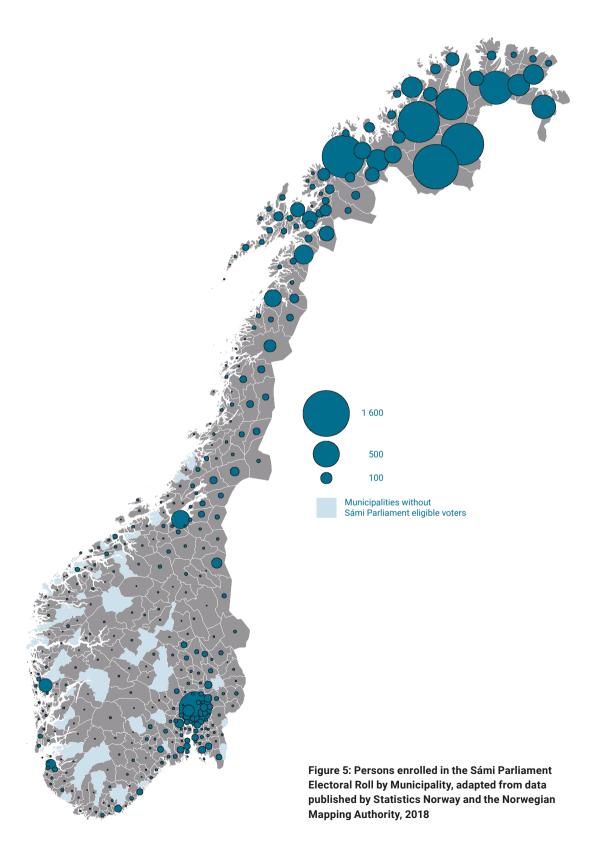


Figure 4: Number of enrolments in the Sámi Parliament Electoral Roll, adapted from data published by the Sámi Parliament, 2019

¹⁷⁴ Presentation by Ann Ragnhild Broderstad, Seminar – Samisk synlighet i offentlig statistikk og sentrale registre – muligheter og utfordringer [Seminar on Sámi visibility in public statistics and central registers], Sámi Parliament, 20 November 2019.

¹⁷⁵ Sameloven of 12 June 1987 [the Sámi Act].



Criteria for Enrolment in the Sámi Parliament Electoral Roll

The criteria for enrolment in the SER are based on both subjective and objective indicators of Sámi ethnicity. Under section 2-6 of the Sámi Act (1987), a person may be registered in the SER if they make a declaration to the effect that they:

- Consider themselves to be Sámi; and
- Have Sámi as their home language; or
- Have a parent, grandparent or greatgrandparent with Sámi as their home language; or
- Are the child of a person who has been registered in the SER.

When the SER was first introduced in 1989, individuals seeking to be included in the register had to apply to their municipality of residence. 176 Applications were processed separately by each municipality and were not merged into a single register. This created a number of administrative difficulties, particularly when voters relocated to a new municipality. From 2001, the Sámi Parliament began compiling an overall voter register with the assistance of the Central Office for Population Registration (Sentral-kontoret for folkeregistrering), but municipalities were still responsible for the practi-

calities of registration and the electoral roll was not directly linked to the Central Population Register. Since 2004, the SER has been compiled and managed by the Sámi Parliament and directly linked to personal data in the Central Population Register, making it much easier to automatically update voters' details if they relocate and to check whether candidates are residents in their constituency.

Under section 2-6 of the Sámi Act (1987) and section 3-1(p) of the Population Register Act (2016), when a person is entered into the SER by the Sámi Parliament, this is linked to their personal data and registered in the Central Population Register. Under section 1-3 of the Population Register Act, the Norwegian Tax Administration (Skatteetaten) is the authority responsible for maintaining and processing the Register. The Regulations on Sámi Parliament Elections set out the conditions for access and use of the SER. Under section 81(1) of the Regulations, access to the SER may only be granted in the following circumstances:

- To public servants, when necessary for the purpose of providing the relevant service; or
- To researchers for scientific purposes, when there is consent from the Sámi Parliament; or
- To others, when there is consent from the Sámi Parliament.

¹⁷⁶ Fagutvalget for utredning om valgordning til sametingsvalget, *Ny valgordning til Sametinget* [New Election Scheme for the Sámi Parliament], 4 April 2007, p. 31.

¹⁷⁷ The Sámi Act, s. 2-6; Folkeregisterloven of 9 December 2016 [the Population Register Act], s. 3-1.

¹⁷⁸ Forskrift om valg til Sametinget of 19 December 2008 [Regulations on Sámi Parliament Elections].

There are also separate provisions regarding access to the SER for the individuals included in the register and for political parties compiling electoral candidate lists. Under section 8 of the Regulations, the Sámi Election Board must publish the SER and make it available for public inspection at a specified time and place prior to election day, and provide a procedure for claiming errors. Under section 9, anyone who believes they have been wrongly included or omitted from the SER may demand that the Sámi Parliament correct the error. Under section 12 of the Regulations, parties compiling an electoral candidate list are entitled to a copy of the SER, but can only use it for political purposes and cannot link the data contained in the SER to other public registers. They must also return their copy of the SER to the Sámi Parliament or shred it within 6 months of the election.

Section 81(3) of the Regulations would allow the Sámi Parliament to grant SSB access to the SER for statistical purposes. While section 12(3) of the Regulations prohibits parties that are compiling an electoral candidate list from linking the SER to other public registers, this provision is limited to that specific context and would not prevent SSB from linking the SER to other registers if they were granted access. In a legal and technical sense, it is thus fairly simple to use the SER for statistical purposes if the Sámi Parliament chooses to do so, particu-

larly as it is already a part of the Central Population Register.

There are several ways the SER could be used to compile Sámi statistics. For example, the SER could be linked to other administrative registers, such as health, education or employment registers, to compile anonymised statistics on Sámi living standards. Individuals registered on the SER could also be invited to participate in more targeted population-based surveys on issues of importance to Sámi communities. However, there is some opposition within the Sámi Parliament to the use of the SER for general statistical purposes (see below at 5.4). To date, the Sámi Parliament has only granted external access to the SER to those conducting electoral research, which has included sending surveys to individuals registered in the SER on issues related to voting, political participation and civil society.¹⁷⁹

Indeed, the SER was originally named the 'Sámi Register' (Samemanntall) but was renamed the 'Sámi Parliament Electoral Roll' (Sametingets valgmanntall) in 2008 through an amendment to the Sámi Act (1987). 180 A specialist committee set up by the Sámi Parliament (Selle-utvalget) recommended the change in order to clarify that the SER "is not a register of the Sámi population, but rather an electoral roll for those who wish to make their Sámi identity politically relevant in Sámi Parliament elections" [translated by

¹⁷⁹ See for example: Institutt for samfunnsforskning, *Sametingsvalgundersøkelsen 2017* [The Sámi Parliamentary Election Study 2017], project no. 10187, 2020.

¹⁸⁰ Ot.prp. nr. 43 (2007-2008).

the author].¹⁸¹ While this change has since been interpreted by some to indicate that the SER is not to be used for general statistical purposes, the Committee that recommended the change also underscored that it would have no impact on the ability of the Sámi Parliament to approve access to the SER for research or social purposes under 2-6 of the Sámi Act (1987) and section 81(1) of the Regulations.¹⁸²

When compared to the STN Area data currently used to produce official Sámi statistics, the SER would potentially provide a more representative sample of the Sámi population in Norway. Unlike the STN Area data, which includes both Sámi and non-Sámi people and only covers a limited geographical area, the SER is comprised solely of Sámi people and covers the entire Norwegian landmass.

However, it is important to note that the eligibility criteria for the SER, as set out in section 2-6 of the Sámi Act, were specifically designed to determine eligibility for the right to vote and stand as a candidate in Sámi Parliament elections. People who fall outside the SER may nonetheless be considered Sámi and enjoy protection as such under Norwegian law.¹⁸³ This may include, for example, Sámi people who do not meet

the language criteria set out in the Sámi Act. There are also several reasons why Sámi people who fulfil the criteria for inclusion in the SER may choose not to register, including:

- A lack of political interest in general or in Sámi policy issues specifically;
- Disagreement with the existence or activities of the Sámi Parliament;
- A belief that the activities of the Sámi Parliament are not particularly relevant to their lives;
- Opposition or scepticism towards ethnic registration and/or reluctance to declare one's Sámi identity in public.

For example, a study on citizenship identity among Sámi living in the core Sámi areas of northern Norway conducted in 2013 found that of the 745 people surveyed who were eligible for registration in the SER, only 549 people were actually registered.¹⁸⁴ A recent research project coordinated by the Institute for Social Research (Institutt for samfunnsforskning) on "the boundaries of Sámi politics" (Samepolitikkens grenser) has considered, among other things, the reasons why people with Sámi affiliation choose not to register in the SER or do not meet the criteria for doing so.185 There may well be Sámi people who have chosen not to register in the SER but would register their

¹⁸¹ Ibid, s. 4.3.

¹⁸² Ibid.

¹⁸³ Susann Funderud Skogvang, "Kven er eigentleg same?" [Who is actually Sámi?] *Morgenbladet*, 11 December 2017

¹⁸⁴ Per Selle, Anne Julie Semb and Kristin Strømsnes, "Citizenship identity among Norwegian Sami in core Sami areas" Citizenship Studies 17, no. 6-7 (2013) p. 712–727.

¹⁸⁵ Institutt for samfunnsforskning, Samepolitikkens grenser: Innenfor- og utenforposisjoner i samisk samfunnsbygging [The Boundaries of Sámi Politics: Inside and outside positions in Sámi community building], project no. 10159, 2019.

Sámi affiliation in a separate register for statistical purposes. Conversely, there may also be Sámi people who are registered in the SER who would choose to deregister if a decision was made to use the SER for statistical purposes.

5.3.4 The Sámi Language Variable in the Population Register

In the 2016 'Language of the Heart' Report, an Expert Committee identified the lack of statistical data on Sámi languages as a key issue, recommending that methods be developed for the registration of Sámi languages in the Central Population Register (Folkeregisteret).186 That same year, the Ministry of Finance (Finansdepartementet) presented proposals for the modernisation of the Central Population Register, and during the consultation process, the Sámi Parliament requested that voluntary registration of Sámi languages be introduced, noting that it was extremely difficult to develop measures to protect and promote Sámi languages without comparable data.187 This was supported by the Ministry of Local Government and Modernisation (Kommunal og moderniseringsdepartementet - KMD) and the Sámi Language Council (Samiske språkutvalget), provided that appropriate safeguards were put in place to protect privacy and confidentiality.

In 2016–2017, the Population Register Act and associated statutory regulations were amended, making it possible to register the use of three official Sámi languages (North, South and Lule Sámi) in the Central Population Register. The Sámi Parliament also requested the inclusion of three more vulnerable Sámi languages (Ume Sámi, Skolt Sámi and Pite Sámi), as well as information about individuals' level of language proficiency (oral and written), but these requests were not accommodated.

In October 2019, the Sámi Parliament and the Tax Administration launched the website form allowing individuals to register as a user of the North Sámi, Lule Sámi and/or South Sámi languages. 189 Registration is voluntary and more than one language can be selected. The purpose of the registration is to enable the compilation of statistics which will assist in developing measures to protect and safeguard Sámi languages. People who register as a user of a Sámi language will not automatically receive official communications from public authorities in that language. In order to register, individuals must log in to the Tax Administration's secure identification portal and select the option to 'register Sámi language'.190

¹⁸⁶ NOU 2016: 18, p. 24.

¹⁸⁷ Prop. 164 L (2015-2016) para. 9.5.

¹⁸⁸ Folkeregisterloven of 9 December 2016 [the Population Register Act], s. 3-1(q); Folkeregisterforskriften of 14 July 2017 [the Population Register Regulations], s. 3-1-1(q).

¹⁸⁹ Tom S. T. Hansen and Mette Ballovara, "Nå vil Norge registrere alle som snakker Sámisk" [Now Norway will register everyone who speaks Sámi], *NRK Sápmi*, 22 October 2019.

¹⁹⁰ Note: The option to register as a user of Sámi languages can be found on the Skatteetaten website, https://skatt.skatteetaten.no/web/minfolkeregisterside/skjema/meldSamiskspraak.

Sámi Language Questions Used in the Central Population Register

After following the prompts to register as a user of a Sámi language, the Tax Administration website form asks respondents to check one or more of the following boxes if they can speak, write and/or read that language:

- □ North Sámi
- ☐ Lule Sámi
- ☐ South Sámi

While the new variable in the Central Population Register is an important step towards building a stronger evidence base for the protection of Sámi languages, it has several limitations with regard to broader human rights monitoring.

Firstly, there are a substantial number of Sámi people who don't speak a Sámi language and will thus be excluded from the register. This means that it will not provide a representative sample of the Sámi population which can be used to disaggregate general population statistics in areas such as health, education or employment for example. Secondly, even if a significant number of people register as users of a Sámi language, it will not be possible to assess whether that figure is increasing or decreasing over time as a proportion of the total Sámi population (because the total Sámi population is unknown). Thirdly, the

register does not collect information on whether an individual identifies as Sámi, so it may include a number of non-Sámi Norwegians who have also learnt a Sámi language. Finally, as registration requires individuals to actively seek out an online form on the Tax Administration website, the uptake will largely depend on the success of a public awareness campaign and it may take several years before the figures can be used for statistical purposes.

5.4 The Sámi Parliament's Perspective

Proposals to collect some form of "individual-based" statistical data on the Sámi population have been discussed within the Sámi Parliament for many years. 191 These discussions have generally focused on the need for higher quality Sámi statistics as an evidence base for Sámi policy on the one hand, and the risks associated with collecting ethnicity data on the other. While some Sámi politicians have supported the collection of Sámi-specific data in administrative registers, others have been more sceptical. As a starting point though, there seems to be broad agreement within the Sámi Parliament that the current approach to Sámi statistics in Norway is inadequate and that proposals for improvement should be investigated.

The President of the Sámi Parliament of Norway, Aili Keskitalo, says:

As indigenous people, the Sámi have the right to self-determination. By virtue of

¹⁹¹ See for example: Sámi Parliament, Samiskrelatert statistikk i Norge [Sámi-related statistics in Norway], Case Number 04/1725, Document 06/810, 2006.

this right, we freely determine our political status and freely pursue our economic, social and cultural development. Having access to Sámi statistics is necessary in order to exercise the right to self-determination in an adequate and meaningful way. At the same time, we know that our status as Sámi people has been used against us in the past, which has created deep wounds and a distrust of the State. Sámi statistics must therefore be owned and managed by the Sámi ourselves.¹⁹²

In its 2018 submission to the Committee on the Elimination of Racial Discrimination, the Sámi Parliament stated that "reliable statistics are a prerequisite for being able to develop indicators to determine how well the Sámi's financial, social and cultural rights under the Convention are satisfied... [and to] facilitate Sámi social planning, especially as related to public services for Sámi language users". 193

In its submission to the Ministry of Finance consultations regarding a new law for the collection of official statistics, the Sámi Parliament stated that official statistics in Norway do not include adequate data on the Sámi people and analysis of their socio-economic situation.¹⁹⁴ They further noted that Sámi statistics should be included in Statistics Norway's regular statistics programme and that the Sámi Parliament should be consulted on this.

Similarly, in its submission to the Norwegian Government's recent white paper on Sámi language, culture and social life, the Sámi Parliament stated that:

Norway lacks adequate Sámi statistics. The geographically based statistics produced today by Statistics Norway provide a picture of the challenges in some Sámi communities, but are far from good enough as a basis for informed public debate and political decisions. The Sámi Parliament believes that there is a need to investigate how statistics can be improved. There is also a need to consider the possibility of collecting data on an individual basis in order to produce Sámi statistics [translated by the author].¹⁹⁵

In December 2018, the Sámi Parliament considered the following three proposals:

- The Sámi Parliament shall review and adopt Ethical Guidelines for Sámi Health Research;
- The Sámi Parliament shall investigate the possibility of establishing an external expert committee to provide collective and dynamic consent to Sámi health research projects on behalf of the Sámi people; and
- The Sámi Parliament shall investigate the possibilities and prerequisites for

¹⁹² Quote approved by Aili Keskitalo, April 2020.

¹⁹³ Sámi Parliament, 2018 Report to CERD, para. 60-61.

¹⁹⁴ Sámi Parliament, *Høringsuttalelse NOU 2018*: 7 [Hearing submission on Official Report 2018:7], 28 June 2018.

¹⁹⁵ Sámi Parliament, Merknad til Meld. St. 31 (2018–2019) [Comment on White Paper 31 2018–2019], p. 10.

possible registration of Sámi ethnicity in the Central Population Register and in the health registers.¹⁹⁶

While the first and second proposals were relatively uncontroversial and the Ethical Guidelines for Sámi Health Research were later adopted in 2019, the third proposal regarding possible registration of Sámi ethnicity in administrative registers proved to be more divisive. As such, further parliamentary debate on the registration of Sámi ethnicity in administrative registers was postponed and the Sámi Parliament arranged a seminar on the topic in November 2019 to coincide with their committee meetings. The speakers at the seminar were Peter Dawson, Advisor at NIM; Bjørn Erik Thon, Director of the Data Protection Authority; Ann Ragnhild Broderstad, Director of the Centre for Sámi Health Research; Torunn Pettersen, researcher at the Sámi University of Applied Sciences; Mikkel Eskil Mikkelsen, NSR representative in the Sámi Parliamentary Council; and Jørn Are Gaski, Labour Party representative in the Sámi Parliament.197

A range of views were presented at the seminar and there was robust discussion between panellists and audience members regarding the opportunities and challenges associated with Sámi statistics. Several speakers commented on the shortcomings of the current approach to Sámi statistics in Norway and the need for more adequate statistical data, while also emphasising the need for safeguards to protect the privacy of data subjects and to ensure the effective participation of the Sámi people at all stages of data collection. The historical misuse of statistical data and the resulting distrust in data collection among the Sámi people was highlighted as a key concern. For some panellists and audience members, these concerns could be addressed through institutional, legal and technical safeguards, while others opposed any form of official registration of Sámi ethnicity.

Sámi Parliament representative, Jørn Are Gaski, emphasised during the seminar that while the registration of Sámi ethnicity may provide better statistics, it also crosses a threshold which may lead to less confidence in the Sámi Parliament, less security and, not least, potentially fewer enrolments in the Sámi Parliament Electoral Roll. Gaski further noted that the Sámi Parliament should look for opportunities to achieve the same results using methods that don't awaken such strong emotions and resistance in Sámi communities.¹⁹⁸

It is clear that several stakeholders have legitimate concerns regarding proposals to

¹⁹⁶ Sámi Parliament, Etiske retningslinjer for Samisk helseforskning [Ethical Guidelines for Sámi Health Research], Case Number 18/5159, 2018.

¹⁹⁷ Sámi Parliament, Seminar: Samisk synlighet i offentlig statistikk og sentrale registre – muligheter og utfordringer [Seminar: Sámi visibility in public statistics and central registers – opportunities and challenges], 20 November 2019.

¹⁹⁸ This is NIMs understanding of some of the key points made by Jørn Are Gaski in his presentation. For the full presentation, see Seminar – *Samisk synlighet i offentlig statistikk og sentrale registre – muligheter og utfordringer* [Seminar on Sámi visibility in public statistics and central registers], Sámi Parliament, 20 November 2019.

collect data on Sámi ethnicity in administrative registers, particularly in light of the misuse of ethnicity data in the past. However, it is also clear that there are some misconceptions and a general lack of awareness regarding the rationale for and methods of ethnicity data collection (see above at Chapter 3), as well as the human rights safeguards which must be in place as a prerequisite for data collection (see below at Chapter 7). For this reason, it is crucial that efforts to promote a facts-based dialogue regarding Sámi statistics continue, both internally within the Sámi Parliament and Sámi communities, as well as externally with the Norwegian authorities.





6. Examples of Gaps in Sámi Statistics

Gaps in statistical data aren't just problematic from an analytical perspective, they have real impacts on people's everyday lives and make it difficult to develop evidence-based responses to human rights issues.

Gaps in Sámi Statistics

There are several human rights issues affecting the Sámi people today that are difficult to address effectively due to gaps in the available statistical data. These include human rights issues related to:

- * Sámi health;
- * Sámi languages and cultures;
- ★ Sámi businesses, employment and traditional livelihoods;
- * Sámi education;
- * Sámi land rights;
- * Sámi housing;
- ★ Discrimination and hate speech against Sámi people;
- ★ Violence and abuse in Sámi communities:
- * Sámi women;
- * Sámi people with disabilities;
- * Elderly Sámi people; and
- * Sámi children and youth.

A detailed analysis of every human rights issue affecting the Sámi people and the associated knowledge gaps is beyond the scope of this report. Therefore, NIM has decided to provide more detailed examples of four areas of Sámi statistics that we believe have significant knowledge gaps from a human rights perspective - health, violence and abuse, discrimination and hate speech and disabilities. In each of these areas, there is very little administrative data available on the Sámi people and the selfreported survey data that is available is geographically limited, has relatively small sample sizes and is only collected every 8-10 years. While smaller academic research studies shed some light on these human rights issues, the available statistical data is insufficient for comprehensive human rights monitoring and for developing and implementing evidence-based responses.

6.1 Sámi health

6.1.1 Survey Data

When compared to other indigenous peoples around the world, there are generally fewer health discrepancies between the Sámi people and the broader Norwegian population. Nevertheless, the SAMINOR survey data indicates that self-reported health is poorer among Sámi respondents when compared to other Norwegians, with the worst health reported by Sámi people who have a lower socio-economic status, those who have experienced discrimination and those who live in the areas that were most affected by Norwegian assimilation policies. 200

Academic studies based on the SAMINOR survey data have found statistically signifi-

cant differences between Sámi and non-Sámi respondents in rates of obesity, self-reported angina pectoris, chest symptoms and other cardiovascular risk factors. ²⁰¹ While there are few ethnic differences in the prevalence of diabetes in the northern Sámi areas, the rate of diabetes among Sámi people in the southern Sámi areas is more than twice that of the non-Sámi population in those areas. ²⁰² However, this finding must be interpreted with caution, as the sample size in southern Sámi areas is small.

Other studies indicate that Sámi people experience higher rates of psychological distress than the broader Norwegian population, are less likely to seek help for mental health issues and are less satisfied with

¹⁹⁹ Magritt Brustad, "Helse i Samisk befolkning – en kunnskapsoppsummering av publiserte resultater fra befolkningsundersøkelser i Norge" [Health in the Sámi population – a summary of published results from population-based surveys in Norway] in Samiske tall forteller 3, Kautokeino: Sámi University of Applied Sciences, 2010, p. 16–73.

²⁰⁰ Ketil Lenert Hansen, Marita Melhus and Eiliv Lund, "Ethnicity, self-reported health, discrimination and socio-economic status: a study of Sami and non-Sami Norwegian populations" *International Journal of Circumpolar Health* 69, no. 2, 2010, p. 111–128.

²⁰¹ Tove Nystad et al., "Ethnic differences in the prevalence of general and central obesity among the Sami and Norwegian populations: the SAMINOR study" Scandinavian Journal of Public Health 38, no. 1, 2010, p. 17–24; Bent-Martin Eliassen et al., "Ethnic difference in the prevalence of angina pectoris in Sami and non-Sami populations: the SAMINOR study" International Journal of Circumpolar Health 73, no. 1, 2014; Susanna R.A. Siri et al., "Distribution of risk factors for cardiovascular disease and the estimated 10-year risk of acute myocardial infarction or cerebral stroke in Sami and non-Sami populations: The SAMINOR 2 Clinical Survey" Scandinavian Journal of Public Health 46, no. 6, 2018, p. 638–646.

²⁰² Ali Naseribafrouei et al., "Ethnic difference in the prevalence of pre-diabetes and diabetes mellitus in regions with Sami and non-Sami populations in Norway – the SAMINOR1 study" *International Journal of Circumpolar Health* 75, no. 1, 2016.

primary healthcare and mental health services.²⁰³A study which linked data from the 1970 census to the Cause of Death Register found that, between 1978 and 1990, the suicide mortality rate for Sámi people was 27% higher than the rest of the population in northern Norway.²⁰⁴

Smaller qualitative research studies based on focus group interviews, while not a sound basis for generalisations, suggest that ethnic discrimination and marginalisation may contribute to ethnicity-related health differences between Sámi and non-Sámi populations.²⁰⁵ There may also be a reluctance to seek medical assistance within the Sámi population due to sociohistorical processes, cultural norms and

language barriers, which are reinforced by the commonly held assumption among healthcare professionals that the Sámi "take care of their own". ²⁰⁶ However, there is no evidence that Sámi people today seek medical help to a lesser extent than non-Sámi living in the same geographic areas. ²⁰⁷

Most of the academic research studies mentioned above rely on self-reported survey data, most commonly from the SAMINOR Study. As such, researchers generally acknowledge the potential for selection bias and note that it is impossible to assess whether the sample survey population is representative of the Sámi population as a whole. They also tend to acknowledge that the survey data only

²⁰³ Ketil Lenert Hansen and Tore Sørlie, "Ethnic discrimination and psychological distress: a study of Sami and non-Sami populations in Norway" *Transcultural Psychiatry* 49, no. 1, 2012, p. 26–50; Ketil Lenert Hansen, "Indigenous health and wellbeing" *International Journal of Circumpolar Health* 69 (Circumpolar health supplements vol. 7) 2010, p. 367; Berit Andersdatter Bongo, "Samer snakker ikke om helse og sykdom – Samisk forståelseshorisont og kommunikasjon om helse og sykdom. En kvalitativ undersøkelse i Samisk kultur" [Sámi do not talk about health and illness – Sámi insights and communication about health and illness. A qualitative study in Sámi culture], PhD thesis, UiT The Arctic University of Norway, 2012; Margrethe Bals et al., "Internalization symptoms, perceived discrimination, and ethnic identity in indigenous Sami and non-Sami youth in Arctic Norway" *Ethnicity and Health* 15, no. 2, 2010, p. 165–179; Tore Sørlie and Jens-Ivar Nergård, "Treatment Satisfaction and Recovery in Saami and Norwegian patients following psychiatric hospital treatment: a comparative study" *Transcultural Psychiatry* 42, no. 2, 2005, p. 295–316; Tove Nystad, Marita Melhus and Eiliv Lund, "Samisktalende er mindre fornøyd med legetjenesten" [The monolingual Sámi population is less satisfied with primary health care] *Tidsskrift for Den norske legeforening* 126, no. 6, 2006, p. 738–40.

²⁰⁴ Anne Silviken, Tor Haldorsen and Siv Kvernmo, "Suicide among Indigenous Sámi in Arctic Norway, 1970–1998" European Journal of Epidemiology 21, no. 9, 2006, p. 707–713.

²⁰⁵ Hansen and Sørlie, "Ethnic discrimination and psychological distress"; Bent-Martin Eliassen et al., "Marginalisation and cardiovascular disease among rural Sámi in Northern Norway: a population-based cross-sectional study" BMC Public Health 13, no. 522, 2013; Siv Kvernmo and Sonja Heyerdahl, "Acculturation strategies and ethnic identity as predictors of behaviour problems in arctic minority adolescents" Journal of the American Academy of Child & Adolescent Psychiatry 42, no. 1, 2003, p. 57–65.

²⁰⁶ Bodil Hansen Blix and Torunn Hamran, "They take care of their own": healthcare professionals constructions of Sami persons with dementia and their families' reluctance to seek and accept help through attributes to multiple contexts" *International Journal of Circumpolar Health* 76, no. 1, 2017.

²⁰⁷ Anne Lene Turi et al., "Health service use in indigenous Sami and non-indigenous youth in North Norway: A population based survey" *BMC Public Health* 9, no. 378, 2009; Susan Hansen, "Are there differences in health care utilization in areas with both Sami and non-Sami populations in Norway? The SAMINOR 1 study", master thesis, UiT The Arctic University of Norway, 2015.

relates to selected municipalities in central and northern Norway, and therefore cannot be used to draw general conclusions regarding the health of the Sámi population nationally or in other areas of Norway. This also means that there is an over-representation of survey participants from municipalities in northern Norway where Sámi people are in the majority, which could affect the results given the evidence that marginalised Sámi living in Norwegian dominated areas in the south are more likely to report poorer health outcomes.208 A final problem often acknowledged by researchers is that the available survey data is only collected every 8-10 years, making it difficult to link datasets and monitor small changes over time.

6.1.2 Administrative Data

Without an ethnicity variable in Norwegian health registers, there is no administrative data on Sámi health and living conditions, including in areas such as life expectancy and mortality, hospitalisations for preventable and chronic diseases, obesity and nutrition, oral, ear and eye health, mental health, suicide and self-harm, substance abuse, antenatal and early childhood care or access to primary healthcare. This means that Sámi people do not have access to the same quality of health statistics as the broader Norwegian population and immigrant groups. Without high-quality adminis-

trative data on Sámi health, it is difficult to delve deeper into the issues identified in academic research, to develop appropriate policy and service delivery responses and to assess the effectiveness of those responses over time.

There is some register data available on health and living conditions within the STN Area, but as described above at 5.3.1, this data includes a substantial number of non-Sámi residents and does not include any of the larger towns or cities in northern Norway, any of the Southern Sámi areas or the rest of southern Norway.

6.2 Violence and Abuse in Sámi Communities

6.2.1 Survey Data

Academic research studies indicate that Sámi people are significantly more likely to report experiencing violence and abuse than non-Sámi Norwegians. The SAMINOR 2 survey data shows that of the 1,242 Sámi women who responded to the survey in those 25 select municipalities, 49% reported experiencing some form of violence or abuse in their life, compared to 35% of non-Sámi women (including emotional, physical and sexual violence).²⁰⁹ The figures were also higher for Sámi men, 40% of whom reported experiencing some form of violence or abuse in their life, compared to 23% of

²⁰⁸ See for example: Eliassen et al., "Marginalisation and cardiovascular disease"; Naseribafrouei et al., "Ethnic difference in the prevalence of pre-diabetes".

²⁰⁹ Astrid Margrethe Anette Eriksen et al., "Emotional, physical and sexual violence among Sami and non-Sami populations in Norway: The SAMINOR 2 questionnaire study" *Scandinavian Journal of Public Health* 43, no. 6, 2015, p. 588–596; Astrid Margrethe Anette Eriksen, "Vold, overgrep og helseplager blant samer i Norge" [Violence, abuse and health problems among Sami in Norway] in *Samiske Tall Forteller* 12, Kautokeino: Sámi University of Applied Sciences, 2019, p. 27–50.

non-Sámi men.²¹⁰ There was a strong link between experiences of violence during childhood and mental illness and chronic pain as an adult.

Research conducted by the Norwegian Centre for Violence and Traumatic Stress Studies (NKVTS) also indicates that police and support services lack specialist expertise in Sámi languages and culture, making it more difficult for them to protect people with a Sámi background.²¹¹ NKVTS notes that while research indicates that Sámi people exposed to violence are in need of culturally and linguistically adapted measures, there is a lack of data on the extent to which these needs are addressed and included in the design of services for Sámi people exposed to violence.²¹²

The same issues regarding geographically limited, self-reported survey data outlined above also apply here. While the SAMINOR figures regarding violence and abuse indicate a serious human rights problem, they do not provide any information on the rates of violence and abuse against Sámi people in Norway's other municipalities, the differences between urban and rural areas, or the number of Sámi people reporting incidents of violence to police, health or support services. Furthermore, geographi-

cally limited survey data that is only collected once a decade will not be adequate in assessing the implementation of Sámispecific measures in the Government's new national action plan on violence nor in meeting the data-related obligations set out in the Istanbul Convention (see above at 3.3).

6.2.2 Administrative Data

There are several administrative registers in Norway which collect data pertaining to violence and abuse. These include the crisis centre registers maintained by the Directorate for Children, Youth and Family Affairs (Barne, ungdoms og familiedirektoratet -BUFDIR), the crime registers maintained by the police and the National Criminal Investigation Service (Kriminalpolitisentralen -KRIPOS), and the municipal health registers maintained by the Norwegian Institute of Public Health (Folkehelseinstituttet).²¹³ Statistics are compiled annually from these registers and are used in conjunction with population-based surveys and academic studies to track changes over time and improve policies and services.

None of these registers collect information regarding Sámi ethnicity, so it is not possible to compile Sámi-specific figures on violence and abuse comparable to those available for the broader Norwegian

²¹⁰ Ibid

²¹¹ Nasjonalt kunnskapssenter om vold og traumatisk stress (NKVTS), Om du tør å spørre, tør folk å svare: Hjelpe-apparatets og politiets erfaringer med vold i nære relasjoner i samiske samfunn [If you dare to ask, people dare to answer. Support services and police experiences with domestic violence in Sámi society], report no. 2, 2017.

²¹² Ibid, p. 63, 104

²¹³ Note: more information on the crisis centre registers, crime registers and municipal health registers can be found on the BUFDIR website, https://bufdir.no/Statistikk_og_analyse, and the Folkehelseinstituttet website, https://www.fhi.no/nyheter/2019/statistikk-anmeldte-voldstilfeller/.

population or for immigrant groups. For example, there are no national statistics on Sámi people's access to and interactions with crisis centres, police or health services, or on the number of formally reported cases of violence and abuse involving Sámi people, the types of offences committed, the age and gender of victims and offenders, the nature of their relationship, the outcome of investigations, or how any of these figures are changing over time.

6.3 Discrimination and Hate Speech Against Sámi People 6.3.1 Survey Data

Studies indicate that Sámi people are significantly more likely to report experiencing discrimination and hate speech than non-Sámi Norwegians. In the SAMINOR 2 Questionnaire Survey, 32% of respondents with self-identified Sámi ethnicity and 50% of respondents with a "strong Sámi connection" (those who answered yes to all three Sámi ethnicity criteria) reported having been discriminated against at some point, compared to 14.3% of non-Sámi respondents.²¹⁴ The most common form of discrimination experienced by Sámi respondents was ethnic discrimination (33% of Sámi respondents

compared to 2% of non-Sámi). Sámi respondents also reported higher levels of gender-based discrimination (9.3% versus 2%), age discrimination (3.4% versus 1.3%) and discrimination based on sexual orientation (1.2% versus 0.4%).215 Hansen analysed these results in 2016 for the Sámi Numbers Speak publication, noting that "there are still large gaps in knowledge about discrimination and bullying of Sámi people" and recommending that the Norwegian authorities "establish a system to monitor the extent of discrimination encountered by Norway's indigenous population" [translated by the author].216 These figures are consistent with the 2019 Public Health Survey in Troms and Finnmark, which found that one in three Sámi respondents reported experiencing discrimination, most often because of their Sámi background.217

In 2018, the Norwegian Institute for Social Research conducted a survey on experiences of hate speech among members of minority group organisations in Norway, including LGBT, Jewish, Muslim, Sámi and disability organisations.²¹⁸ There were 174 Sámi respondents in the survey, most of whom were members of the largest Sámi

²¹⁴ Ketil Lenert Hansen, "Selvopplevd diskriminering av samer i Norge" [Self-reported experience of discrimination against Sámi in Norway] in Samiske tall forteller 9, Kautokeino: Sámi University of Applied Sciences, 2016, p. 124.

²¹⁵ Ibid, p. 135-136.

²¹⁶ Ibid, p. 144.

²¹⁷ Marita Melhus and Ann Ragnhild Broderstad, Folkehelseundersøkelsen i Troms og Finnmark: Tilleggsrapport om samisk og kvensk/norskfinsk befolkning [The Public Health Survey in Troms and Finnmark: Additional report on the Sámi and Kven/Norwegian Finn population], Centre for Sámi Health Research, 2020, p. 48.

²¹⁸ Audun Fladmoe, Marjan Nadim and Simon Roland Birkvad, Erfaringer med hatytringer og hets blant LHBT-personer, andre minoritetsgrupper og den øvrige befolkningen [Experiences of hate speech and anger among LGBT people, other minority groups and the rest of the population], Institutt for samfunnsforskning, report no. 4, 2019.

organisation and political party in Norway, the Norwegian Sámi Association (Norske Samers Riksforbund – NSR). The results showed that:

- 65% of Sámi respondents reported being exposed to derogatory comments, compared to 18% of non-Sámi respondents.
- 53% of Sámi respondents reported being exposed to hate speech, compared to 10% of non-Sámi respondents.
- 15% of Sámi respondents reported being exposed to concrete threats, compared to 4% of non-Sámi respondents.²¹⁹

Research also indicates that discrimination against Sámi people leads to poor health and conditions such as chronic muscle pain, cardiovascular disease, obesity, diabetes, metabolic syndrome, anxiety and depression.²²⁰

6.3.2 Administrative Data

The most relevant administrative data currently available on the Sámi people's experiences of discrimination and hate speech in Norway is the data collected by the Equality and Discrimination Ombud (Likestillings og diskrimineringsombudet – LDO) and the various police districts across

the country. While some of this data can be disaggregated to produce Sámi-specific figures, there is a lack of consistency and standardised approaches in reporting. NIM has also made several recommendations regarding the inadequacy of statistics on hate speech and hate crimes in Norway more generally.²²¹

Between 2007 and 2015, the LDO received 2,438 enquiries regarding discrimination on the grounds of ethnicity, representing 16% of all enquiries to the LDO.222 Of the ethnicitybased enquiries, 424 were filed as formal complaints, representing 22% of all complaints. In 2017 it was reported in the media that the LDO received 12 complaints and approximately 50 requests for advice related to discrimination on the basis of Sámi ethnicity between 2007 and 2016.223 This indicates that Sámi cases account for approximately 2–3% of all ethnicity-based enquiries to the LDO. There is likely to be significant under-reporting of discrimination and hate crimes against Sámi people, with research studies suggesting less than 2% of Sámi victims report their experience to the LDO.224

In 2018, there were 624 cases in Norway that were recorded by police as hate

²¹⁹ Ibid, p. 33–34.

²²⁰ Ketil Lenert Hansen, "Ethnic discrimination and health: the relationship between experienced ethnic discrimination and multiple health domains in Norway's rural Sami population" *International Journal of Circumpolar Health* 74, no. 1, 2015.

²²¹ Note: a summary of NIMs recommendations regarding statistics on hate speech and hate crimes can be found in NIMs Annual Report 2019, Document 6 (2020–2021), p. 38.

²²² Likestillings og diskrimineringsombudet (LDO), *Ombudets statistikk*, 2007–2015.

²²³ Inga Ragnhild Holst, "Legg samene i rør", Ávvir, 31 January 2017.

²²⁴ Hansen, "Selvopplevd diskriminering av samer i Norge".

crimes.225 This figure has more than doubled since 2014, with all police districts in Norway seeing an increase in the number of cases recorded as hate crimes. However, the Police Directorate notes that there are varying competences in police districts regarding the detection and registration of hate crimes, which could affect the number of cases recorded.226 Racial or ethnic affiliation was recorded as the basis of discrimination in 73% of the cases, but only Oslo Police District publishes data on the particular ethnic groups targeted in the crime. There were 238 cases recorded as hate crimes in the Oslo Police District in 2018. with 57% relating to ethnic affiliation and only one reported case relating to Sámi ethnicity.227 There are no figures on the proportion of reported hate crimes relating to Sámi ethnicity in the other police districts of Norway.

The LDO and the police do not collect data on whether a complainant identifies as Sámi, but rather whether a complainant's Sámi ethnicity was the basis of the alleged discrimination. This means that there is no administrative data on whether Sámi people experience higher rates of discrimination and hate speech on the basis of their

gender, sexuality, age, disability or other grounds.

The Directorate for Children, Youth and Family Affairs (Barne, ungdoms og familiedirektoratet - BUFDIR) has developed indicators to measure the health and living conditions of immigrants, Sámi people and national minorities in Norway, as well as the effects of discrimination on these groups. In April 2020, BUFDIR launched a knowledge portal to collate relevant research and statistics, with the Sámi-specific figures based on data from the STN Area and the SAMINOR Study. 228 In the knowledge gaps section of the portal, BUFDIR notes that research and statistics on the Sámi people are geographically limited, and that more knowledge about Sámi people living outside of these areas is needed.

The background research on the development of the indicators was completed by the FAFO Research Foundation in 2016.²²⁹ FAFO notes that, unlike immigrant-status, information on ethnicity is not collected in administrative registers, making it difficult to compile detailed statistics on living conditions and rates of discrimination and inequality among the Sámi and national

²²⁵ Politidirektoratet, *STRASAK-rapporten: Anmeldt kriminalitet og politiets straffesaksbehandling 2018* [STRASAK Report: Review of Crime and Criminal Procedure 2018], 2019, p. 82–84.

²²⁶ Ibid, p. 82.

²²⁷ Oslo Police District, Anmeldt hatkriminalitet 2018 [Review of Hate Crime 2018], 2019, p. 8-11.

²²⁸ BUFDIR, Samer, nasjonale minoriteter og personer med innvandrerbakgrunn: Statistikk og forskning om likestilling og levekår [Sámi, national minorities and persons with immigrant backgrounds: Statistics and research on equality and living conditions], 2020.

²²⁹ Magne Bråthen, Huafeng Zhang and Jon Rogstad, Indikatorer på diskriminering av innvandrere, urfolk og nasjonale minoriteter [Indicators of discrimination against immigrants, indigenous peoples and nationalminorities], FAFO, 2016.

minorities.²³⁰ The only alternative, according to FAFO, is to continue using the STN Area data as a proxy for the northern Sámi population and to use smaller surveys which adopt respondent driven or chain referral sampling to identify Sámi people living outside of the STN Area in the south.²³¹

The Institute for Social Research (Institutt for samfunnsforskning) also notes that there are significant knowledge gaps on the nature and extent of discrimination against Sámi people in Norway, primarily because Sámi ethnicity is not recorded in administrative registers.232 In addition to data on the prevalence of direct discrimination, there is a need for more information on systemic and indirect discrimination and how this may influence health and living conditions, education and labour market participation, as well as trust in and experiences with public services.233 For example, administrative data from education and employment registers shows that young people with immigrant backgrounds are less likely to get an apprenticeship when compared to other students with the same grades.²³⁴ The Institute for Social Research highlights that:

Because there are no systematic statistics regarding the Sámi population, it is impossible to conduct good research on, for example, participation in education or employment, which might otherwise have served as a useful basis for comparing, for example, the transition from education to work for Sámi and non-Sámi candidates with equal grades. The SAMINOR Study is very important in this context, as it is based on a large amount of survey material that has formed the basis for several reports and research articles on topics related to ethnic discrimination and bullying. However, a survey can never replace good register data [translated by the author].235

6.4 Sámi People with Disabilities 6.4.1 Survey Data

Statistics Norway conducts several population-based surveys which include questions on disability, such as the annual Labour Force Survey. Generally, these surveys indicate that people with disabilities represent between 15% and 18% of the Norwegian population (roughly 600,000 people) and have poorer self-reported health, employment rates and access to public services.²³⁶ These surveys do not include questions on

²³⁰ Ibid, p. 8, 31-39.

²³¹ Ibid, p. 26.

²³² Midtbøen and Liden, Diskriminering av Samer, Nasjonale Minoriteter og Inn-vandrere i Norge, p. 8.

²³³ Ibid, p. 16

²³⁴ Håvard Helland and Liv Anne Støren, "Vocational Education and the Allocation of Apprenticeships: Equal Chances for Applicants Regardless of Immigrant Background?" *European Sociological Review* 22, no. 3, 2006, p. 339–351.

²³⁵ Midtbøen and Liden, Diskriminering av Samer, Nasjonale Minoriteter og Inn-vandrere i Norge, p. 42.

²³⁶ BUFDIR, Statistics on disabilities in Norway, 3 October 2019.

Sámi ethnicity, so there are no comparable figures for the Sámi population. Some researchers have speculated that there could be around 13,000 Sámi people with a disability in Norway, but this is based on the assumption that the Norwegian Sámi population is around 75,000 people (extrapolated from Aubert's 1970 estimate of 40,000) and that the rate of disability among the Sámi population is similar to the broader Norwegian population (around 17%).²³⁷

Most studies which have examined the situation of Sámi people with disabilities in Norway have focused on rates of self-reported discrimination. The SAMINOR survey data indicates that Sámi people are twice as likely as non-Sámi people to report experiencing discrimination based on their disability, mostly when receiving medical care, in employment, in stores, restaurants and online.²³⁸

These findings are consistent with a qualitative study conducted by the Nordic Centre for Welfare and Social Issues (Nordens velferdssenter – NVC) between 2014–2015, which involved 31 semi-structured interviews.²³⁹ The study found that people with disabilities and a Sámi background faced multiple linguistic and cultural barriers in

accessing healthcare, education and employment, as well as widespread bullying and discrimination. The study also identified a lack of knowledge and cross-cultural awareness among Norwegian service providers regarding Sámi people with disabilities and found that support services were mostly tailored to the needs of the majority.

Similarly, in 2017 the Institute of Social Education at UiT the Arctic University of Norway conducted a study on the living conditions among Sámi and non-Sámi people with intellectual disabilities in selected municipalities in northern Norway.240A total of 93 persons with an intellectual disability were included in the study, 30 of whom had a Sámi background, so it must be noted that the sample size of the survey was very small. The study found that the people surveyed who had both an intellectual disability and a Sámi background had poorer mental health and were more exposed to bullying and violence than those without a Sámi background.²⁴¹ For example:

 33% of Sámi respondents reported being afraid of being beaten when going outside alone close to their homes, compared to 17% of non-Sámi respondents;

²³⁷ Ketil Lenert Hansen, "Diskriminering av samer med funksjonsnedsettelse" [Discrimination against Sámi with disabilities] in *Samiske tall forteller 10*, Kautokeino: Sámi University of Applied Sciences, 2017, p. 87–88.

²³⁸ Ibid, p. 84.

²³⁹ Line Melbøe et al., *Situasjonen til samer med funksjonsnedsettelser* [The situation of Sámi with disabilities], Nordic Welfare Centre, 2016.

²⁴⁰ Hege Gjertsen et al. Kartlegging av levekårene til personer med utviklingshemming i Samiske områder [Mapping the living conditions of people with intellectual disabilities in Sámi areas], UiT the Arctic University of Norway, 2017

²⁴¹ Hege Gjertsen, "Mental health among Sami people with intellectual disabilities" *International Journal of Circumpolar Health* 78, no. 1, 2019, p. 4.

- 48% of Sámi respondents reported that someone had teased them during the last year, compared to 29% of non-Sámi respondents:
- 33% of Sámi respondents reported that someone had threatened to hurt them during the last year, compared to 11% of non-Sámi respondents; and
- 19% of Sámi respondents reported that someone had hurt them during the last year, compared to 11% of non-Sámi respondents.²⁴²

6.4.2 Administrative Data

Without an ethnicity variable in administrative registers, there are no reliable national figures on the number of Sámi people with a disability in Norway, their population characteristics, living conditions or interactions with the healthcare system and other public services. For example, the small qualitative studies mentioned above indicate that Sámi people with disabilities face unique barriers to accessing healthcare, education and employment, but there is no administrative data available to assess the extent of these barriers or whether policy interventions are improving the situation. There is some register data available on the number of people within the STN Area who receive disability

benefits, but as described above at 5.3.1, this data has significant limitations.

In recent years, there has been an increasing focus on the need for more detailed administrative data on persons with disabilities in Norway, including by the UN Committee on the Rights of Persons with Disabilities, Norwegian disability advocates and in the 'Kaldheim Committee Report' of 2016.²⁴³ In response, Statistics Norway has been developing a methodology for compiling register-based statistics on persons with disabilities, with the first release expected in 2020.244 This new approach to disability statistics in Norway will draw on the various health registers that collect data on persons with disabilities whenever they come into contact with the healthcare system or access other public services. Statistics Norway will then be able to combine data from other administrative registers to disaggregate disability statistics by gender, age, geography, income level, immigrant status and membership of other vulnerable population groups.²⁴⁵ This data will contribute to more effective and evidence-based policymaking, service delivery and anti-discrimination measures for people with disabilities, but none of these benefits will be available to the Sámi people.

²⁴² Ibid, p. 4-6.

²⁴³ NOU 2016: 17; Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Norway; Arne Jensen and Pål Strand, Personer med funksjonsnedsettelse Utredning av mulighetene for å etablere offisiell levekårsstatistikk basert på opplysninger fra ulike registre [Persons with disabilities Investigation of the possibility of establishing official living conditions statistics based on information from various registers], notater 2018/32, Statistics Norway, 2018.

²⁴⁴ Håkon Torfinn Karlsen, Joachim Wettergreen and Arne Jensen, *Utredning av ny levekårsstatistikk for personer med funksjonsnedsettelsel* [Investigation of new living conditions statistics for persons with disabilities], notater 2019/42, Statistics Norway, 2019.

²⁴⁵ Ibid, p. 10.



7. The Risks and Challenges Associated with Sámi Statistics

The human rights framework not only outlines the reasons why disaggregated data on ethnicity and indigenous status is important, but also why human rights safeguards must be in place as a prerequisite to collecting such data.

The Norwegian Government has, on several occasions, provided the following four reasons for not disaggregating official statistics by ethnicity:

- Difficulties quantifying indigenous and ethnic group representation when ethnic identity is a subjective and fluid concept;
- Concerns regarding privacy and confidentiality when processing sensitive personal information related to ethnicity;
- Concerns regarding the potential misuse of statistical data that may contribute to the discrimination or stigmatisation of vulnerable groups; and

 Scepticism towards data collection among Sámi and minority groups due to the historical misuse of data.²⁴⁶

These concerns are reasonable and there are legitimate risks and challenges associated with indigenous statistics. The problem in Norway is that these risks and challenges have often been presented as insurmountable, whereas the consensus among international human rights bodies is that they can be addressed through institutional, legal and technical safeguards in ethnicity data collection. The human rights-based approach to data, which includes specific safeguards to protect indigenous peoples' data, has thus received little attention in Norway.

²⁴⁶ Committee on the Elimination of Racial Discrimination, *Combined twenty-third and twenty-fourth periodic reports submitted by Norway*, UN Doc. CERD/C/NOR/23-24, 2 November 2017, paras. 79–83; Karin Abraham, "FN: Norge må innføre bruk av etnisitet i offisiell statistikk" [UN: Norway must introduce "ethnicity" into official statistics], *Minerva*, 11 January 2019; Hans Rustad, "FN-komite vil at Norge registrerer etnisitet" [UN Committee wants Norway to register ethnicity], *Document.no*, 12 January 2019.

It is also important to note that discussions regarding the potential risks and challenges of collecting data on Sámi ethnicity in Norway are often based on an incorrect assumption that no such data is collected today. There are, in fact, several existing data sources which include Sámi ethnic identifiers, such as the SAMINOR study, the Sámi Parliament Electoral Roll (SER) and the new Sámi language register (see above at 5.3). The SER, while not used for general statistical purposes, is already linked to the Central Population Register, made available for electoral research and displayed publicly prior to Sámi Parliament elections.

The question is not really whether data on Sámi ethnicity should be collected in Norway, as this is already the case, the key issue is whether the data that is already collected meets the standards of quality and representativeness required for human rights monitoring, and whether adequate human rights safeguards are in place to protect such data. If not, the possibilities and prerequisites for improving Sámi statistics should be investigated.

7.1 Human Rights Safeguards

The OHCHR emphasises that while disaggregated data on indigenous peoples and other ethnic groups is essential for human rights monitoring, such data should only be collected if appropriate human rights safeguards are in place.

The OHCHR has defined the following six principles of the human rights-based approach to data, which should guide data collection in all circumstances:

- Participation of relevant stakeholders should be maintained in all data planning, collection, dissemination and analysis, and specific measures should be taken to ensure meaningful participation of the most marginalised population groups;
- Disaggregation of data should be based on key characteristics identified in international human rights law (including ethnicity) to identify and measure inequalities among population groups, which may require alternate sampling and data collection approaches;
- Self-identification should form the basis of all questions about personal identity (e.g. ethnicity, religious beliefs, sexual orientation gender identity) to ensure they are voluntary, allow for multiple identities and do not create or reinforce existing discrimination or stereotypes;
- Transparency should underpin all activities of data collectors to ensure open and accessible information about their operations and their data collection methodology;
- Privacy must be maintained to ensure that sensitive personal information collected for statistical purposes remains strictly confidential and that individual data subjects cannot be identified through publicly accessible data; and
- Accountability should be maintained to ensure that all public bodies, including national statistics offices, respect human rights in the conduct of their

operations and that statistical data is used to increase accountability.²⁴⁷

The UNPFII has also acknowledged that there are several risks and challenges associated with the collection and disaggregation of statistical data on indigenous peoples, many of which overlap with the concerns expressed by the Norwegian Government.²⁴⁸ The UNPFII nevertheless recommends that such data should be collected, provided that States implement specific safeguards to protect indigenous peoples' data and ensure the effective-participation of indigenous peoples in the process.

The UNPFII recommends that States, when collecting and disaggregating data on indigenous peoples, ensure that:

- Indigenous peoples fully participate as equal partners, in all stages of data planning, collection, analysis and dissemination:
- Questions on indigenous identity are based on the principle of selfidentification and are developed with indigenous peoples' free, prior and informed consent;
- Data collection responds to the priorities and aims of indigenous peoples themselves and includes relevant rightsbased indicators;

- Data collection institutions employ and train indigenous peoples and use indigenous languages where possible;
- Data collection reflects the full diversity of indigenous communities, including those living in remote, rural and urban areas, as well as indigenous women, children, the elderly and indigenous people with disabilities;
- Data is returned to the indigenous peoples concerned for their own use;
 and
- Appropriate safeguards are in place to ensure the confidentiality and privacy of indigenous data subjects and to ensure compliance with human rights law, data protection regulations and the Fundamental Principles of Official Statistics.²⁴⁹

7.2 Difficulties Quantifying Indigenous and Ethnic Group Representation

Several stakeholders in Norway have noted that one of the main challenges with disaggregating data by ethnicity is deciding whether to use subjective, objective and/or surrogate measures of ethnic identity, and whether this information should be collected through self-identification questions or some other source. ²⁵⁰ Subjective measures focus on an individual's own perception of their ethnicity, while objective measures focus on ancestry or language use, and surrogate measures use geographically

²⁴⁷ OHCHR,A Human Rights Based Approach to Data.

²⁴⁸ UNPFII, Report of the Workshop on Data Collection and Disaggregation, para. 31.

²⁴⁹ Ibid, para. 31–33; UNPFII, Report on the fourth session, paras. 84–88.

²⁵⁰ Sámi Parliament, Proposal for Ethical Guidelines for Sámi Health Research, p. 33-34.

limited areas or country of birth as a proxy for ethnicity. Another related challenge is the fact that many people identify with multiple ethnicities and an individual's ethnic affiliations may change over their lifetime. While these issues are complex and vary between different countries, they have been considered in detail by several international human rights bodies.

The UN Special Rapporteur on Racial Discrimination has stated that:

Ethnicity is multidimensional and... should be treated with movable boundaries. The principle of self-identification, therefore, addresses the related concern of how ethnic categories should be determined and on what basis should individuals be classified... It would be arbitrary to categorise individuals automatically, based on an assumption or perception of the agent collecting the data, which could easily equate to stigmatisation and prejudice.²⁵¹

The Committee on the Elimination of Racial Discrimination, the OHCHR and the UNPFII have all stated that the identification of indigenous peoples and ethnic minorities in statistical data should be based on self-

identification by the individuals concerned, who should also have the option of indicating multiple or no ethnic affiliations.²⁵²

The UN Principles and Recommendations for Population and Housing Censuses also underscore that questions on indigenous identity should be based on the voluntary self-identification of the respondent and that multiple questions should be used to accurately capture the diversity of indigenous peoples, such as questions on indigenous origin/ancestry, indigenous identity/ self-perception and indigenous languages. Due to the sensitive nature of questions pertaining to indigenous peoples, statistical offices should ensure that the public are informed of the potential uses and need for such data, that adequate data-protection safeguards are in place and that indigenous peoples participate at every stage of the process.253

Similarly, the European Commission and the Conference on European Statisticians recommend that ethnicity questions should primarily be posed in terms of 'ethnic origin', supplemented by questions on ethnic identity/self-perception and languages, and that these should be based on the free self-declaration of the individual concerned with

²⁵¹ Mutuma Ruteere, Report of the Special Rapporteur on Contemporary Forms of Racism, Racial Discrimination, Xenophobia and Related Intolerance, UN Doc. A/70/335, 20 August 2015, paras. 56–57.

²⁵² Committee on the Elimination of Racial Discrimination, Concluding observations on the combined twenty-third and twenty-fourth periodic reports of Norway, paras. 5–6; OHCHR,A Human Rights Based Approach to Data; Committee on the Elimination of Racial Discrimination, General Recommendation No. 8 Concerning the Interpretation and Application of Article 1 (1) and (4) of the Convention, UN Doc. A/45/18, 22 August 1990; UNPFII, Report of the Workshop on Data Collection and Disaggregation, para. 33; OHCHR and UNPFII Secretariat, Briefing Note: Indigenous Peoples' Rights and the 2030 Agenda.

²⁵³ United Nations Statistics Division, *Principles and Recommendations for Population and Housing Censuses*, p. 205–206.

the option of indicating multiple or no ethnic affiliations.²⁵⁴

In countries where data on indigenous identity is collected through self-declaration questions, it is common to collect information on the number of people who regard themselves as indigenous (subjective), the number of people who report having indigenous ancestry or origin (objective) and/or the number of people who speak an indigenous language (objective). However, figures on the number of people who regard themselves as indigenous are generally used as the basis for producing indigenous statistics. This is to ensure that data is as representative as possible, given the fact that many indigenous people, for a variety of reasons, do not speak their language fluently and because some people who have an indigenous ancestor may not regard themselves as indigenous.

One way to avoid confusion between the concepts of self-identification, ancestry and language is to include all three questions in statistical collections, as is the case in New Zealand (discussed in further detail at 8.5.2). In countries where indigenous self-identification questions are included in official statistical collections, it is possible to measure the proportion of indigenous population growth that is attributable to the birth rate and the proportion attributable to people identifying as indigenous later in life.²⁵⁵

Statistics Norway currently uses geographical areas as a surrogate measure of the Sámi population, which is problematic for a number of reasons (discussed above at 5.3.1). By contrast, the SER and the SAMINOR Study determine Sámi ethnicity on the basis of self-identification questions, including one on Sámi identity/self-perception and several questions on Sámi languages. The Sámi language questions effectively merge the concepts of indigenous ancestry and language because the use of Sámi languages within three generations is considered a reliable proxy for Sámi ancestry. The SER and SAMINOR criteria are consistent with international recommendations on the topic and are now widely accepted in Norway as the standard framework for determining Sámi ethnicity.

A separate but related challenge in Norway is that Statistics Norway no longer conducts a traditional questionnaire-based census (as discussed above at 5.2). This certainly makes the collection of statistical data on indigenous peoples more complicated, but it by no means prevents it. Many countries that include indigenous identifiers in their census questionnaires, such as Australia, New Zealand and Canada, also include the same questions in administrative registers and population-based surveys. These countries are also moving towards an administrative-based census in the future and the availability of administrative data on indigenous peoples has been a key concern.

²⁵⁴ Makkonen, *European Handbook on Equality Data*, p. 55–56; Conference of European Statisticians, *Recommendations for the 2020 censuses of population and housing*, 2015, paras. 700–712.

²⁵⁵ See for example: Australian Bureau of Statistics (ABS), *Understanding the Increase in Aboriginal and Torres Strait Islander Counts*, Catalogue No. 2077.0, 17 October 2018.

When Canada decided to replace their long-form census questionnaire with a voluntary household survey in 2011, the quality and coverage of indigenous data suffered, and the long-form census was quickly reintroduced. In New Zealand, census records are now being linked with data across the government system through the Integrated Data Infrastructure (IDI), in preparation for a shift to an administrative-based census. Researchers in New Zealand have highlighted that Māori data governance and data quality must be prioritised during this process. 258

7.3 Privacy, Confidentiality and Data Protection

Several stakeholders in Norway have expressed legitimate concerns regarding the privacy and confidentiality of individual data subjects should an ethnicity variable be introduced in official statistical collections. However, there are a number of legal safeguards in place to protect the right to privacy and to ensure compliance with data protection regulations in Norway. As State institutions, national statistics offices and other public authorities are themselves

human rights *duty-bearers*. This means they have an obligation to respect, protect and fulfil human rights in all of their activities, including in the planning, collection, analysis and dissemination of statistical data.

The right to privacy is recognised in Article 8 of the ECHR, Section 102 of the Norwegian Constitution, Article 12 of the Universal Declaration of Human Rights (UDHR) and Article 17 of the ICCPR.259 The UN Human Rights Committee notes that the collection of personal information by public authorities or private bodies must be regulated by law, and that States must adopt effective measures to ensure that such information is not made available to unauthorised parties or used for purposes incompatible with the rights protected in the ICCPR.²⁶⁰ According to the UN's guiding principles on statistics, individual data collected by statistical agencies must be anonymised, strictly confidential and used exclusively for statistical purposes.261

Under the Statistics Act (statistikkloven), Statistics Norway must adhere to strict confidentiality and information security

²⁵⁶ Janet Smylie and Michelle Firestone, "Back to basics: identifying and addressing underlying challenges in achieving high quality and relevant health statistics for indigenous populations in Canada" *Statistical Journal of the IAOS* 31, no. 1, 2015, p. 67–87.

²⁵⁷ Kukutai and Taylor, *Indigenous Data Sovereignty*, p. 3–4.

²⁵⁸ Tahu Kukutai and Donna Cormack, "Census 2018 and Implications for Māori" New Zealand Population Review 44, 2018, p. 131–151.

²⁵⁹ Note: the rights to privacy and the protection of personal data are also recognised in Articles 7 and 8 of the *European Charter of Fundamental Rights*, but Norway is not a party to this charter.

²⁶⁰ Human Rights Committee, General Comment No. 16: Article 17 (Right to Privacy): The Right to Respect of Privacy, Family, Home and Correspondence, and Protection of Honour and Reputation, UN Doc. HRI/GEN/1/Rev.9 (Vol. I), 8 April 1988.

²⁶¹ United Nations General Assembly, Fundamental Principles of Official Statistics, UN Doc. A/RES/68/261, 3 March 2014, principle 6; United Nations Statistics Division, Principles and Recommendations for Population and Housing Censuses, p. 25, 133.

requirements, and ensure that statistical data is anonymised so that individual information is not disclosed directly or indirectly. When dealing with statistical data related to small or geographically limited population groups, Statistics Norway implements specific safeguards to reduce the risk of data being used to identify individual data subjects.²⁶²

Personal data is also protected under the EU General Data Protection Regulation (GDPR), which came into force in Norway on 20 July 2018, after its inclusion in the EEA Agreement and subsequent incorporation into the Personal Data Act.263 Under Article 5 of the GDPR, personal data must be processed lawfully, fairly and in a transparent manner, consistent with the 'purpose limitation' and the principles of data minimisation, accuracy, storage limitation, integrity, accountability and confidentiality. The purpose limitation requires that personal data be collected for specified, explicit and legitimate purposes and not be further processed in a manner that is incompatible with those purposes. If personal data is further processed for archiving purposes in the public interest, or for scientific or historical research purposes, or for statistical purposes, it must be subject to appropriate technical and organisational safeguards in accordance with Article 89(1) of the GDPR. The lawful bases for processing personal data and special categories of sensitive personal data are set out in Article 6 and Article 9 of the GDPR respectively.

Article 6 of the GDPR

Under Article 6 of the GDPR, the processing of personal data must be based on at least one of the following six lawful grounds:

- * the data subject has given consent;
- processing is necessary for the performance of a contract to which the data subject is party;
- ★ processing is necessary for compliance with a legal obligation to which
 the data controller is subject (the basis
 for processing must be laid down by
 Union or Member State law);
- processing is necessary in order to protect the vital interests of the data subject;
- ★ processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the data controller or in a third party to whom the data is disclosed (the basis for processing must be laid down by Union or Member State law); or
- processing is necessary for the purposes of furthering the legitimate interests of the data controller or a third party, except where such interests are overridden by the fundamental rights and freedoms of the data subject.

²⁶² The Statistics Act; Statistics Norway, *Personopplysninger i statistikken* [Personal data in the statistics], 2019.

²⁶³ Personopplysningsloven of 15 June 2018 [The Personal Data Act].

Article 9 of the GDPR

Under Article 9 of the GDPR, personal data relating to ethnic origin is considered a special category of personal data and is therefore subject to further conditions in addition to those in Article 6. As a general rule, the processing of sensitive personal data, is prohibited *unless* at least one of ten exceptions apply, including where:

- ★ The data subject has given consent;
- Processing is necessary to carry out obligations or exercise specific rights in the fields of employment or social security;
- Processing is necessary for reasons of substantial public interest;
- ★ Processing is necessary for research purposes or statistical purposes;
- ★ Processing is necessary for the purposes of preventive or occupational medicine, or the provision and management of health or social care systems and services; or
- ★ Processing is necessary for reasons of public interest in the area of public health, such as ensuring high standards of quality and safety of health care.

If any of these exceptions apply, the collection of sensitive personal data must also "be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject".²⁶⁴

The requirements in Article 6 and Article 9 of the GDPR must also be read in conjunction with Chapter 3 of the Personal Data Act, which provides additional safeguards for the processing of sensitive personal data. Under section 7 of the Personal Data Act, the processing of sensitive personal data which is necessary for reasons of substantial public interest may be authorised by either the Data Protection Authority (in particular cases) or in regulations, and such authorisation shall stipulate conditions to protect the fundamental rights and interests of data subjects. Under section 9 of the Personal Data Act, sensitive personal data may be processed without the consent of the data subject if the data controller has consulted with the Data Protection Officer and it is determined that the processing is necessary for archival purposes in the public interest, purposes related to scientific or historical research or statistical purposes, and that the public interest clearly exceeds any disadvantages to the individual.

In addition to general privacy and data protection safeguards, it is essential that the Sámi people exercise collective control over their own statistical data, in accord-

²⁶⁴ EU General Data Protection Regulation (GDPR), Regulation 2016/679 (27 April 2016, entered into force in the EU 25 May 2018 and in Norway 20 July 2018), art. 9(2).

ance with international human rights law and the principle of indigenous data sovereignty (see above at 3.6).

While the abovementioned safeguards provide a comprehensive framework for the protection of personal data, it is important to note that the risk of data being used for unintended purposes in the future cannot always be mitigated by data governance arrangements or privacy, confidentiality and information security requirements.²⁶⁵ For example, there may be circumstances where a court order provides access to health register data for policing purposes or where unauthorised parties gain access to administrative registers in order to initiate cyber-attacks.²⁶⁶ These risks already exist today in relation to existing data sources on the Sámi people, such as the SER, the SAMINOR Survey data and the Sámi language register, and would potentially exist if new Sámi-specific data sources were introduced. For this reason, it may be necessary to review the current approach to Sámi statistics in Norway, as well as any proposals to introduce new data sources, to determine whether additional institutional. legal and technical safeguards are required to protect against such risks.

Ouestions have also been raised in Norway over whether the collection of ethnicity data would itself be contrary to privacy and data protection law.²⁶⁷ The European Commission, FRA, ECRI and the ECA have all confirmed that, despite some State arguments to the contrary, European data protection law establishes conditions under which the collection and processing of ethnicity data is allowed.²⁶⁸ Similarly, the UN Special Rapporteur on Racial Discrimination notes that "the collection of personal data as vital to fighting discrimination and fostering equality meets the criteria of being a 'substantial public interest'... under the European data protection regime".269

Despite this, there is still a misconception in some European States that the collection of ethnicity data is either infeasible or prohibited under EU data protection law.²⁷⁰ The UN Special Rapporteur on Racial Discrimination notes that some States may use the issue of data protection to conceal an underlying fear that disaggregated data will reveal inequalities or lead to additional funding for anti-discrimination measures.²⁷¹A recent study prepared for the European Commission by various country experts on equality data also notes that, in some European countries, there is little recognition that ethnicity-

²⁶⁵ Kieran C. O'Doherty et al., "If you build it, they will come: unintended future uses of organised health data collections" *BMC Medical Ethics* 17, no. 54, 2016.

²⁶⁶ Ibid.

²⁶⁷ See for example: Rita Heitmann, "Ulovlig, skremmende og historieløst" [Illegal, scary and historyless] *Sagat*, 18 December 2018.

²⁶⁸ European Commission Subgroup on Equality Data, *Guidelines on improving the collection and use of equality data*, p. 7; European Court of Auditors, *EU policy initiatives and financial support for Roma integration*, p. 47.

²⁶⁹ Ruteere, Report of the Special Rapporteur, para. 39.

²⁷⁰ Lilla Farkas, Analysis and Comparative Review of Equality Data Collection in the Field of Ethnicity.

²⁷¹ Ruteere, Report of the Special Rapporteur, para. 40.

based discrimination or disadvantage is a problem and therefore little political support for collecting and disaggregating data on different ethnic groups.²⁷² The UN Special Rapporteur on Extreme Poverty and Human Rights has even called on the European Commission to create an infringement procedure for Member States that continue to misinterpret EU data protection directives as not permitting data collection on the basis of ethnic origin.²⁷³

The Director of the Norwegian Data Protection Authority, Bjørn Erik Thon, in his speech at the Sámi Parliament's statistics seminar in November 2019, confirmed that Norwegian data protection law allows for the collection of ethnicity data, provided that appropriate safeguards are in place:

Is it possible to register Sámi ethnicity, conduct research regarding the Sámi people and compile Sámi statistics legally and without this conflicting with privacy law? My answer to this is yes. However, this requires a solid rethinking of, among other things, how such registration should take place, what legal basis to use and how to ensure Sámi control of research. And, of course, how

to safeguard important privacy principles, such as data minimisation. But we believe that the legal safeguards can be developed, and we make our expertise available in this important work. Then the question is whether the Sámi Parliament really wants this and whether you need it. This is a political question that you must decide [translated by the author]. 274

7.4 Misuse of Statistical Data

The potential for misuse of statistical data is also an important consideration, as history shows that when ethical and human rights safeguards are not in place, ethnicitybased data can be misused for discriminatory purposes.²⁷⁵ Data collection systems have been used in the past to identify minorities and vulnerable groups for the purpose of ethnic cleansing, particularly during the Nazi occupation of Europe in WWII and the Rwandan genocide of 1994.276 Data collection systems have also been used in several countries to inform policies which discriminated against indigenous peoples, including the Sámi people in Norway (as discussed above at 5.1).277

²⁷² Bell et al., Analysis and Comparative Review of Equality Data Collection Practices in the European Union: Legal Framework and Practice, p. 52.

²⁷³ Philip Alston, End-of-mission statement on Romania by the Special Rapporteur on Extreme Poverty and Human Rights, 11 November 2015, para. 6(i)(d).

²⁷⁴ Presentation by Bjørn Erik Thon, Seminar – Samisk synlighet i offentlig statistikk og sentrale registre – muligheter og utfordringer [Seminar on Sámi visibility in public statistics and central registers], Sámi Parliament, 20 November 2019.

²⁷⁵ William Seltzer and Margo Anderson, "The Dark Side of Numbers: The Role of Population Data Systems in Human Rights Abuses," *Social Research* 68, no. 2, 2001, p. 481–513.

²⁷⁶ Ibid. paras. 42-45.

²⁷⁷ Sámi Parliament, *Proposal for Ethical Guidelines for Sámi Health Research*, p. 19–20.

For these reasons, many Sámi people today are justifiably skeptical of data collection activities that include questions regarding Sámi ethnicity, including those associated with academic research and official statistics. It is therefore crucial that any proposals aimed at increasing the availability and quality of Sámi statistics give due regard to the historical pain and trauma associated with data collection and provide adequate safeguards to prevent the misuse of data.

Much has changed since 1970 when Sámi-specific questions were last included in Norway's official statistical collections. At that time, the Sámi people were not recognised in the Norwegian Constitution, and there was no Sámi Act, Sámi Parliament or Sámi Electoral Roll. Nor was there a National Human Rights Institution, an Equality and Anti-Discrimination Act or Ombudsman, a Personal Data Act or a Data Protection Authority. There were no Norwegian Research Ethics Committees or ethical guidelines for indigenous research. At the international level, there were no international instruments regulating the collection of official statistics or protecting the rights of indigenous peoples. Since 1970, countries with similar histories to Norway regarding the misuse of indigenous peoples' data, such as Australia and New Zealand, have all reformed their data collection systems to include self-identification questions for indigenous peoples. International human rights monitoring bodies have also developed a comprehensive set of recommendations to ensure statistical data on indigenous peoples is collected in a safe and responsible manner.

Today, it is prohibited under both international and Norwegian law to use statistical data to discriminate against indigenous peoples and other minority groups, and there are several institutional safeguards in place to prevent this from happening.²⁷⁸ However, there may still be instances where the misuse of statistical data to stigmatise a vulnerable group does not reach the threshold of unlawful discrimination. For example, statistical data is sometimes used reductively to perpetuate negative stereotypes about particular groups, and figures are sometimes published without explanation or analysis of the factors which account for disparities.

A 2007 report commissioned by ECRI on ethnicity data in Europe notes that:

The problem is a relatively general one: any description of a group as unduly suffering certain disadvantages can be interpreted in two ways. For example, the fact that far more immigrants than 'natives' are unemployed in most European countries reflects a major social problem which requires corrective action. Analysis of levels of educational attainment, and of other variables linked with social capital and employability, also highlights a greater risk of unemployment, which might be considered

²⁷⁸ European Commission Subgroup on Equality Data, *Guidelines on improving the collection and use of equality data*, p. 3.

discriminatory. However, xenophobic and populist movements take the same findings and use them to demand that immigration be stopped, and jobless persons of immigrant origin expelled. Much the same thinking is applied to statistics which show that vulnerable groups have more problems at school or poor housing conditions: these groups are seen either as the victims of discrimination and injustice, or as a burden on society.²⁷⁹

There is little that can be done to control how third parties will interpret data once it is published, but the potential for misuse partly depends on what data is collected and how it is presented. Both the UN's Fundamental Principles on Official Statistics and the International Statistical Institute's Declaration on Professional Ethics emphasise that national statistics offices should take steps to prevent predictable misinterpretation or misuse of data in this regard.²⁸⁰

For example, crime statistics that are disaggregated by ethnicity may be used to develop measures which address structural and systemic discrimination in the criminal justice system, but they may also be misused by others to argue that certain ethnic groups have some kind of 'natural' propensity towards criminal behaviour. In this example, the potential for misuse can be reduced by ensuring that crime statistics

also include data on underlying causes or risk factors, such as low income and education, difficult living conditions and social exclusion, and on the prevalence of racial profiling by police or harsher sentencing by courts.²⁸¹

Unfortunately, negative stereotypes about the Sámi people already exist in Norway, and while disaggregated data could potentially be used by some to perpetuate these stereotypes, it could also be used to promote a more informed and evidence-based public discussion on issues of importance to Sámi people. The same is true for disaggregated statistical data pertaining to gender, age, disability and immigrant-status, which is already collected and published in Norway, presumably based on a determination that the benefits of such data outweigh the risks.

The potential for misuse of indigenous peoples' data can also be reduced by respecting the principle of indigenous data sovereignty (see above at 3.6). This includes ensuring that indigenous peoples participate in the collection, analysis and dissemination of data about their communities, and that data governance structures are accountable to indigenous representative institutions. All too often, indigenous peoples have been defined by official statistics as a problem to be solved and data has been used to support narratives of failure with little input from indigenous peoples themselves. To

²⁷⁹ Patrick Simon, *Ethnic statistics and data protection in the Council of Europe countries: Study Report*, European Commission against Racism and Intolerance, 2007.

²⁸⁰ United Nations General Assembly, *Fundamental Principles of Official Statistics*, principle 4; International Statistical Institute, *Declaration on Professional Ethics*, 2010.

²⁸¹ Simon, Ethnic statistics and data protection in the Council of Europe countries.

avoid this situation in Norway, the collection of statistical data pertaining to the Sámi people should only take place if there is a robust Sámi data governance partnership that provides clear accountability back to the Sámi Parliament. Specific measures should also be adopted to ensure the rationale for and methods of ethnicity data collection are clearly communicated to Sámi communities in a culturally safe and responsible manner.

Ultimately, it is for the Sámi people, through the Sámi Parliament as their representative institution, to decide whether the benefits of data disaggregation outweigh the risks and to ensure that adequate safeguards are in place to prevent misuse. However, if the appropriate human rights safeguards are in place, it is certainly possible to disaggregate statistical data by Sámi ethnicity in a safe and responsible manner.



8. International Examples of Indigenous Statistics

There are numerous examples of countries comparable to Norway collecting data on ethnicity and indigenous status in a safe and responsible manner, in order to support human rights monitoring and evidence-based policymaking. In many cases, these countries have addressed the same risks and challenges often raised in Norway as barriers to ethnicity data collection.

8.1 Global Overview

There have been several international studies on ethnic classification in official population statistics. In 2003, the United Nations Statistics Division reviewed the censuses of 147 countries held between 1995-2003 and found that 95 countries (65%) asked one or more guestions on ethnicity, while 12% of countries also included a specific question on indigenous status.282 Morning's 2008 study had similar results, with 87 (63%) of the 138 censuses analysed including some form of ethnicity variable, while 15% included a specific question on indigenous status.283 If these results are combined with data from subsequent studies (discussed later in this section), 66% of the 158 countries and territories that have been reviewed collect statistical data on ethnicity.

Of the countries and territories reviewed, the regions where an ethnicity variable is most common are Oceania (84%), North America (83%), South America (82%) and Asia (64%). Morning's 2008 study included 36 European countries and found that 44% collected ethnicity data, but a more detailed study of all European countries put this figure at 50%.²⁸⁴ Countries in Africa (41%) were the least likely to collect data on ethnicity.

While earlier estimates regarding indigenous-specific datasets were based on the number of census questionnaires that included terms like 'Indigenous', 'Aboriginal', or 'Tribe', Peters' 2011 study employed a more detailed approach, noting that several countries used other indigenous-identifiers in statistical collections, such as the names

²⁸² United Nations Statistics Division, Ethnicity: A Review of Data Collection and Dissemination, 2003, p. 4.

²⁸³ Ann Morning, "Ethnic Classification in Global Perspective: A Cross-National Survey of the 2000 Census Round" *Population Research and Policy Review* 27, 2008, p. 239–272.

²⁸⁴ Simon, Ethnic statistics and data protection in the Council of Europe, p. 35.

of particular indigenous groups.²⁸⁵ This study found that 43 (23%) of the 184 countries reviewed collected statistical data on indigenous peoples in their censuses, either through an indigenous-specific variable or a general ethnicity variable with an output category for indigenous peoples.²⁸⁶ Since then, this figure has risen to 46 countries. This means that of the 90 countries and territories that are known to include indigenous peoples, about half (51%) separately identify indigenous peoples in their national statistical collections.²⁸⁷

In recent years, there has been a significant increase in the number of Latin American countries that include indigenous-specific questions in their statistical collections. In the 1990 census round, only two countries in Latin America included self-identification questions for indigenous peoples, but by the 2010 round this had jumped to 21 countries.²⁸⁸ Prior to 1990, some countries in the region used linguistic criteria as a proxy for quantifying indigenous communities, but as indigenous peoples were increasingly recognised

as rights-holders rather than policy-objects, Latin American countries began shifting to self-identification criteria consistent with international recommendations.²⁸⁹

The reform process has been led by the UN's Economic Commission for Latin America and the Caribbean (ECLAC), which has identified "ending the statistical silence" on indigenous peoples as a key priority for the region and provides states with technical assistance to "support the inclusion of questions regarding indigenous peoples in censuses and administrative records".290 ECLAC has worked with governments, national statistical offices, indigenous organisations and academia to operationalise the recommendations of international human rights bodies and adapt them to the regional context.291 Together, they have developed minimum standards for the inclusion of indigenous peoples in statistical collections, which cover everything from the design of indigenous self-identification questions to dissemination and analysis of results, stressing the effective participation

²⁸⁵ Evelyn J. Peters, "Still invisible: enumeration of indigenous peoples in census questionnaires internationally" *Aboriginal Policy Studies* 1, no. 2, 2011, p. 68–100.

²⁸⁶ Ibid, p. 80.

²⁸⁷ Kukutai and Taylor, *Indigenous Data* Sovereignty, p. 4; National Institute of Demographic and Economic Analysis (NIDEA), *Unpublished data from the Ethnicity Counts? Project*, University of Waikato, 2015.

²⁸⁸ United Nations Department of Economic and Social Affairs, *State of the World's Indigenous Peoples*, 2019, p. 44.

²⁸⁹ United Nations Economic Commission for Latin America and the Caribbean (ECLAC), Guaranteeing indigenous people's rights in Latin America – progress in the past decade and remaining challenges, UN Doc. LC/L.3893/Rev.1, November 2014, p. 34–35.

²⁹⁰ ECLAC, ECLAC Supports Statistical Visibility and Participation of Indigenous Peoples in the 2030 Agenda, Press Release, 15 July 2016; UNPFII, ECLAC Response to UNPFII Questionnaire to the UN system agencies, funds and programmes and intergovernmental organizations, December 2018.

²⁹¹ ECLAC, Contar con todos: caja de herramientas para la inclusión de pueblos indígenas y afrodescendientes en los censos de población y Vivienda [Counting everyone: a toolkit for the inclusion of indigenous and Afro-descendant peoples in population and housing censuses], UN Doc. LC/R.2181, December 2011.

of indigenous peoples as a prerequisite at all stages of the process. The quality and coverage of indigenous statistics in the region is continuing to improve, particularly after Latin American and Caribbean states adopted the *Montevideo Consensus on Population and Development* in 2013, which includes several provisions aimed at increasing the statistical visibility of indigenous peoples.²⁹²

There are several explanations for the regional variations in ethnic data collection. It has been suggested that the disaggregation of data by ethnicity and indigenous status may be more accepted in the Americas and Oceania, where many countries have settlercolonial histories, ethnically diverse populations largely descended from recently arrived migrants and official policies on multiculturalism.293 In Asia and Africa, the invisibility of indigenous peoples within national statistics is largely attributed to a lack of institutional capacity or financial resources and a reluctance among public authorities to formally recognise indigenous groups.294 In Europe, the reluctance to disaggregate statistical data by ethnicity may be related in part to the abuse of ethnic registers during World War II and the fact that many European countries have had ethnically homogenous populations for much of their history.²⁹⁵ Furthermore, very

few European countries include indigenous peoples, so debates regarding data disaggregation focus primarily on the integration of immigrants, rather than the self-determination of indigenous peoples.

8.2 Europe

In 2006, ECRI undertook a consultation process with national statistical offices, data protection authorities, equality bodies and NGOs on the issue of ethnic data collection in Europe. The resulting report found that of the 42 member States of the Council of Europe that were included in the study, 22 collected statistical data on ethnicity (either through questions on 'ethnic origin' or through the proxy of 'nationality'), 24 on religion and 26 on language.²⁹⁶ With the exception of the United Kingdom and Ireland, the majority of European countries that collected ethnicity data were located in Central and Eastern Europe. Most Western European and Scandinavian countries did not collect data on ethnicity, but some did collect and publish statistical data on citizens with an immigrant background, based country of birth data going back three generations.297

The report highlighted that concerns over data protection and privacy are often raised by European states as barriers to the collection of ethnicity data, when the opposition

²⁹² ECLAC, Montevideo consensus on population and development, UN Doc. LC/L.3697, 12-15 August 2013, paras. 86, 90, 94, 110 and 111.

²⁹³ Morning, "Ethnic Classification in Global Perspective", p. 245–246.

²⁹⁴ Kukutai and Taylor, *Indigenous Data* Sovereignty, p. 25; Peters, "Still invisible", p. 78.

²⁹⁵ Peters, "Still invisible", p. 78; Simon, Ethnic statistics and data protection in the Council of Europe, p. 38.

²⁹⁶ Simon, Ethnic statistics and data protection in the Council of Europe, p. 35.

²⁹⁷ Ibid, p. 36.

may actually be based on political beliefs regarding the legitimacy of ethnicity as a descriptive category, even for anti-discrimination purposes. In many European states, the "cost/benefit analysis of the pros and cons of compiling ethnic data comes down on the side of doing nothing".²⁹⁸

Simon notes that despite a significant increase in the number of countries collecting ethnicity data since the 2010 census round in response to recommendations from international human rights bodies, there is still an "enduring resistance of 'statistical blindness' to ethno-racial diversity in Europe". 299 He further notes that this is becoming difficult to maintain as ethnic diversity in Europe increases, along with the need for statistical data to monitor discrimination and implement effective equality policies. While many European governments remain skeptical of ethnicity data collection, the Eurobarometer survey indicates that 68% of Europeans support providing sensitive personal information regarding their ethnic origin in statistical collections if it could help to combat discrimination and inequality.300 While Norway is not included in the Eurobarometer survey, in Denmark

and Sweden over 80% of respondents supported ethnicity data collection.³⁰¹

Like Norway, neither Sweden nor Finland include self-identification questions for Sámi people in their official statistical collections. In the absence of an official indigenous statistics programme, academic researchers have attempted to find more creative solutions. In Sweden, researchers constructed a sample of the Sámi population by linking available data sources from 1960-2000, such as reindeer herding registers and the Sámi Parliament of Sweden's Electoral Roll, and then extrapolating that data to include ancestors, siblings and descendants.302 In Finland, a sample of the Sámi population in two northern municipalities (Utsjoki and Inari) was created by cross-referencing various data sources from 1979-1998, including the national population register and an earlier genealogical study, as well as the personal knowledge of the study's lead author.303 While these sample populations may be useful in an academic context, they rely on historical data sources which adopted varying methodologies and definitions of Sámi ethnicity, and as such cannot substitute regularly updated, high-quality register data.

²⁹⁸ Ibid, p. 69-70.

²⁹⁹ Patrick Simon, "The failure of the importation of ethno-racial statistics in Europe: debates and controversies" *Ethnic and Racial Studies* 40, no. 13, 2017, p. 2326–2332.

³⁰⁰ European Commission, Special Eurobarometer 493 on Discrimination in the EU, 2019, p. 179.

³⁰¹ Ibid, p. 180.

³⁰² Sven Hassler, Per Sjölander and Ann Jessica Ericsson, "Construction of a database on health and living conditions of the Swedish Sami population" in *Befolkning och bosättning i norr: Etnicitet, identitet och gränser i historiens sken*, Umeå University Centre for Sami Research, p. 107–124; Sven Hassler et al. "Causes of death in the Sami population of Sweden, 1961–2000" *International Journal of Epidemiology* 34, no. 3, 2005, p. 623–629.

³⁰³ Leena Soininen, Sari Järvinen and Eero Pukkala, "Cancer incidence among Sami in northern Finland, 1979–1998" *International Journal of Cancer* 100, no. 3, 2002, p. 342–346.

The OECD notes that the lack of comprehensive and comparable longitudinal data on the Sámi people in Norway, Sweden and Finland means that "the contributions, conditions and experiences of Sámi are largely rendered invisible, which makes it challenging to direct policies towards this community or to understand whether they are having a positive or negative impact". 304

The only European country which includes self-identification questions for indigenous peoples in official statistical collections is Russia. Indigenous peoples are defined in Russian law as peoples of the North, Siberia and Far East who "live on their traditional ancestral territories, adhere to their original way of life, and believe themselves to be independent ethnic entities, with a population under 50,000 people" [translated by the author].305 In the 2010 Russian census, 316,011 people self-identified with at least one of the 47 officially designated indigenous groups, with 1,771 people identifying as Sámi.306A further 800,776 people identified with three numerically larger groups that would otherwise qualify as indigenous (the Yakuts, Komi and Komi-Permyak).307 While indigenous-specific questions are

included in the Russian census, they are not used to disaggregate statistical data in other socio-economic areas and there is no systematic approach to the compilation of indigenous statistics. ³⁰⁸ As such, knowledge of the health and living conditions of the many indigenous peoples in Russia, including the Sámi, is still quite poor and is of limited use from a human rights perspective. ³⁰⁹

³⁰⁴ OECD Regional Development Policy Committee, *Linking the Indigenous Sami People with Regional Development in Sweden*, 2019, p. 53.

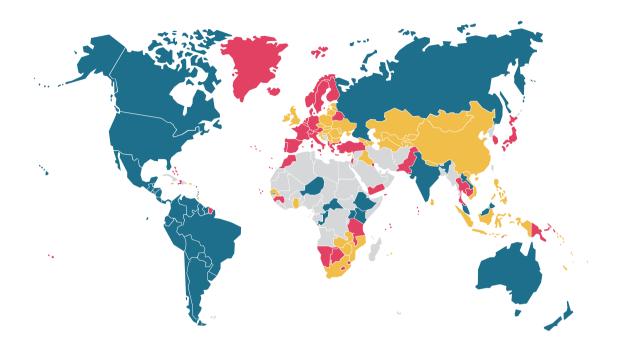
³⁰⁵ See the *Federal Law of 22 April 1999* on the Rights of Indigenous Numerically Small Peoples of the Russian Federation and the *Federal Law of 5 June 1996* on National-Cultural Autonomy.

³⁰⁶ T. Kue Young and Peter Bjerregaard, "Towards estimating the indigenous population in circumpolar regions" *International Journal of Circumpolar Health* 78, no. 1, 2019, p. 9.

³⁰⁷ Ibid

³⁰⁸ International Work Group for Indigenous Affairs (IWGIA), *The Indigenous World 2019*, 2019, p. 44; Peter Bjerregaard, "Regional Studies of Indigenous Health: Europe and Russia" in *The Oxford Research Encyclopedia: Global Public Health*, Oxford University Press, 2019.

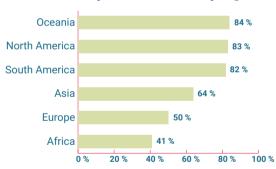
³⁰⁹ Per Sjölander, "What is known about the health and living conditions of the indigenous people of northern Scandinavia, the Sami?" *Global Health Action 4*, no. 1, 2011.





- Countries/territories that collect statistical data on ethnicity (including ethnic origin, nationality, ancestry, race and cultural group).
- Countries/territories that don't collect statistical data on ethnicity or indigenous status.
- Countries/territories not included in any of the studies.

Ethnicity data collection by region





105 (66 %) of the 158 countries and territories included in the studies collected statistical data on ethnicity.



46 (51 %) of the 90 countries and territories known to include indigenous peoples collected statistical data on indigenous status.



53 (33 %) of the 158 countries and territories included in the studies did not collect statistical data on ethnicity or indigenous status.

This data is based on the following studies:

Morning, Ethnic Classification in Global Perspective, 2008 Simon, Ethnic Statistics and data protection in the Council of Europe countries, 2007 Peters, Still invisible: enumeration of indigenous peoples, 2011 ECLAC, Guaranteeing indigenous people's rights in Latin America, 2014. The representations in this map are simplified for illustrative purposes only and do not imply official recognition of particular territories or borders.

8.3 Indigenous Statistics Programs in Comparable Countries

No other European country which includes indigenous peoples disaggregates official statistics by indigenous status. As such, the most relevant examples of data disaggregation for our purposes come from countries like Australia and New Zealand, both of which have robust indigenous statistics programmes and share a number of political, legal, social and cultural similarities with Norway. All three countries are liberal democracies and constitutional monarchies that regularly top the UN's Human Development Index, and all three countries are home to indigenous peoples who constitute a relatively small proportion of the national population. There are other relevant examples of indigenous statistics programmes, including those in Canada and several South American countries, but a detailed analysis of these is beyond the scope of this report.

It is important to note that there are historical and socio-cultural differences between indigenous peoples around the world and it should not be assumed that all aspects of the indigenous statistics programmes in Australia and New Zealand are directly applicable to the situation of the Sámi

people in Norway. However, indigenous peoples share many common experiences and challenges in relation to statistical data and there are many similarities between Norway, Australia and New Zealand in this regard.

In Norway, Australia and New Zealand, indigenous data has been used in the past to inform assimilationist policies and discriminatory research, but in recent years has become increasingly important for evidence-based policymaking, as well as indigenous peoples' own decision-making processes and self-governance.310 In all three countries, race-based definitions for population groups are no longer used and official definitions of indigenous peoples focus instead on self-reported ethnicity and ancestry.311 In all three countries, there is a long history of intermarriage between indigenous peoples and other ethnic groups and it is common for indigenous people to have multiple ethnic affiliations.³¹² Factors such as geographical location, skin colour or other physical traits are not considered important to indigenous identity in Norway, Australia or New Zealand, despite indigenous people in all three countries facing

³¹⁰ See for example: Kukutai and Taylor, *Indigenous Data Sovereignty*; Sámi Parliament, *Proposal for Ethical Guidelines for Sámi HRealth Research*; Pia Solberg, *Indigenous internal selfdetermination in Australia and Norway*, PhD thesis, University of New South Wales, October 2016.

³¹¹ See for example: Per Axelsson and Peter Sköld eds., *Indigenous Peoples and Demography*, New York: Berghahn Books, 2011.R

³¹² See for example: John Weinstock, "Assimilation of the Sámi: Its Unforeseen Effects on the Majority Populations of Scandinavia" *ScandRinavian Studies* 85, no. 4, 2013, p. 411–430; Genevieve Heard, Bob Birrell and Siew-Ean Khoo, "Intermarriage between indigenous and non-indigenous Australians" *People and Place* 17, no. 1, 2009, p. 1–14; Zarine L. Rocha, "(Mixed) Racial formation in Aotearoa/New Zealand: framing biculturalism and 'mixed race' through categorisation" *Kōtuitui: New Zealand Journal of Social Sciences Online* 7, no. 1, 2012, p. 1–13.

similar stereotypes regarding indigenous authenticity. 313

Unlike Australia and New Zealand, Norway no longer conducts a traditional question-naire-based census. However, this should not be considered a barrier to the comparability of indigenous statistics programmes in each country. As noted above at 7.2, many of the countries that include indigenous identifiers in their census questionnaires, such as Australia and New Zealand, also include the same questions in administrative registers and population-based surveys, both of which are used in Norway. Australia and New Zealand are also moving towards administrative-based censuses in the future.

8.4 Australia

8.4.1 Programmes and Strategies

The Australian Bureau of Statistics (ABS) has a dedicated *Aboriginal and Torres Strait Islander Statistics Program*, led by a separate department known as the National Centre for Aboriginal and Torres Strait Islander Statistics.³¹⁴ The ABS also has several strategies and initiatives for indigenous statistics, all of which are grounded in the principles and rights recognised in the UNDRIP.³¹⁵ These include:

- An Indigenous Community Engagement Strategy, which aims to build strong relationships with indigenous communities and to deliver accessible, appropriate and relevant statistics to meet their needs. The Strategy is led by local teams of Indigenous Engagement Managers.
- A Roundtable on Aboriginal and Torres Strait Islander Statistics, which is comprised of indigenous representatives and meets twice a year to provide advice to the ABS on indigenous data quality, engagement strategies and statistical literacy strategies.
- A Reconciliation Action Plan, which sets out clear and measurable actions to drive the organisation's contribution to reconciliation, such as promoting respect for indigenous cultures, increasing indigenous recruitment and retention and building stronger relationships with indigenous communities.
- An Indigenous Communication Strategy, which aims to increase awareness within indigenous communities of the role and function of the ABS and the importance of identifying as indigenous in the census by developing culturally appropriate information and involving indigenous leaders as ambassadors.

³¹³ See for example: Siv Eli Vuolab, Negotiating an Urban Indigenous Identity: expectations, prejudices and claims faced by urban Sámi in two contemporary Norwegian cities, master thesis, UiT The Arctic University of Norway, November 2016, p. 14; Sarah Maddison, "Indigenous identity, 'authenticity' and the structural violence of settler colonialism" Identities: Global Studies in Culture and Power 20, no. 3, 2013; Ashlea Gillon, Donna Cormack and Belinda Borell, "Oh, you don't look Māori: Socially assigned ethnicity" MAI Journal 8, no. 2, 2019.

³¹⁴ Australian Bureau of Statistics (ABS), *Aboriginal and Torres Strait Islander Statistics*, Catalogue no. 1006.0, 30 September 2015.

³¹⁵ Kukutai and Taylor, Indigenous Data Sovereignty, ch. 15.

The National Indigenous Data Improvement Support Centre has also developed National Best Practice Guidelines for Collecting Indigenous Status in Health Data Sets. 316

The Guidelines help to ensure consistency and promote confidence in the collection of indigenous data by health professionals.

Prior to the 2001 census, the ABS established a Census Consultative Group on Ancestry in order to develop a method for measuring ethnic and cultural diversity in the Australian population.³¹⁷ The group undertook research and consultations on the need for such data and the user requirements for its collection and dissemination. They concluded that major policy issues in Australia required data on ethnicity and recommended the inclusion of an ancestry question in the census.

8.4.2 Questions on Ethnicity and Indigenous People

In Australia, statistical data on indigenous peoples and ethnic groups is collected through self-identification questions. These were introduced by the ABS in response to widespread community interest in the ethnic and cultural diversity of the Australian population, and to meet the growing need for disaggregated data to inform effective policymaking and service delivery for indigenous peoples and particular ethnic groups.

Ouestions on indigenous identity have existed in various forms since 1981, with the current Standard Indigenous Question (SIQ) adopted in 1995.318 The SIQ asks individuals whether they identify as Aboriginal; Torres Strait Islander; as both; or as neither. Questions on ethnicity/ancestry have existed since 1986, with the current question (ASCCEG) introduced in 2001.319 The ASCCEG asks individuals to indicate up to two 'ancestries' that they identify with, either by choosing from seven commonly reported ancestries or by writing a response in a text field. These are complemented by a number of other datasets related to a person's origin, including Birthplace of Parents, Country of Birth, Religious Affiliation and Language Spoken at Home.

The SIQ and ASCCEG are used in all ABS data collections, including the census and other statistical surveys, as well as the data collection forms and administrative registers of particular government departments, service providers and community organisations.

8.4.3 Data Sources

There are two main sources of disaggregated data on indigenous peoples and ethnic groups in Australia:

 The ABS Census of Population and Housing, which is conducted every five years and includes questions on a wide

³¹⁶ Australian Institute of Health and Welfare, National Best Practice Guidelines for Collecting Indigenous Status in Health Data Sets, 2010.

³¹⁷ ABS, Understanding the Census and Census Data: Ancestry, Catalogue no. 2900.0, 8 November 2017.

³¹⁸ ABS, Indigenous Status Standard, Catalogue no. 1200.0.55.008, 8 October 2014.

³¹⁹ ABS, Australian Standard Classification of Cultural and Ethnic Groups, Catalogue no. 1249.0, 18 December 2019.

range of topics. The last census was held in 2016, with a response rate of 95.1%. 320

The data collection forms and administrative registers of government agencies and indigenous community organisations, including hospitals, schools, universities, correctional services, health services, tax and welfare institutions.

In addition, there are three data sources specifically related to indigenous peoples:

- The National Aboriginal and Torres Strait Islander Social Survey (NATSISS), which is conduct every six years and provides self-reported information on a range of key areas of social interest for Aboriginal and Torres Strait Islander people. The last NATSISS was conducted in 2014/2015, with a geographically representative sample of 11,178 Aboriginal and Torres Strait Islander people.³²¹
- The Australian Aboriginal and Torres Strait Islander Health Survey (AATSIHS), which is also conducted every six years and provides information on a range of key health indicators for the Aboriginal and Torres Strait Islander population. The last AATSIHS was conducted in 2018/2019, with a geographically repre-

sentative sample of about 6,500 households.³²²

The Longitudinal Survey of Indigenous Children, which is conducted annually by the ABS and the Department of Social Services to collect data on the social, emotional, educational and developmental pathways and outcomes of indigenous children.³²³

8.4.4 Findings

The latest census results indicate that of Australia's 24.6 million inhabitants, 28% were born overseas, while another 21% were born in Australia with at least one parent born overseas. This means that roughly half of all Australians are first or second-generation immigrants. Australians reported over 190 different countries of birth and 300 different ancestries in the 2016 census. Ancestry is related to the cultural or ethnic group with which a person most closely identifies and is not always connected to their country of birth. There are over 300 different languages spoken in Australia and 21% of Australians speak a language other than English at home. Disaggregated statistical data on employment, education, health and housing etc. is available for various ethnic minority groups.

In 2016, 649,200 people in Australia identified as being of Aboriginal and/or Torres

³²⁰ ABS, Census: Aboriginal and Torres Strait Islander Population, Press Release, 27 June 2017.

³²¹ ABS, National Aboriginal and Torres Strait Islander Social Survey 2014-15, Catalogue no. 4714.0, 28 April 2016.

³²² ABS, Australian Aboriginal and Torres Strait Islander Health Survey 2018-19, Catalogue no. 4715.0, 11 December 2019

³²³ Australian Government Department of Social Services, *The Longitudinal Study of Indigenous Children*, 8 January 2019.

Strait Islander origin, representing roughly 2.8% of the population (up from 2.5% in 2011, and 2.3% in 2006).324 More than half of the indigenous population is under the age of 25 and the proportion of Indigenous Australians living in urban areas has increased from 73% to 79% since 1996. Approximately 150 indigenous languages are spoken in Australia, but only 10% of indigenous people speak their language at home. Almost two thirds (62%) of Indigenous Australians identify with a clan, tribal or language group and the same proportion are regularly involved in indigenous cultural events.325 70% of Indigenous Australians watch indigenous TV, while 28% listen to indigenous radio. While Indigenous people make up 2.8% of the total Australian population, they represent just 0.5% of total business owners in Australia.

Spatial datasets indicate that the total area of land owned, managed or co-managed by Indigenous Australians, as well as land over which Indigenous Australians hold special usufruct or procedural rights, is 306 million hectares (40% of the Australian landmass). In Australia, Indigenous land claims are addressed under land rights and/or native title legislation, with determined land rights and native title tenures now covering 33% of the Australian landmass and undetermined

native title claims over a further 33%.³²⁷ The National Native Title Tribunal also publishes detailed statistics on registered native title determinations and whether they were reached by consent or litigation, as well as the Indigenous Land Use Agreements negotiated between indigenous peoples, companies and governments.³²⁸

Disaggregated data collected by the ABS and other public authorities indicates that Aboriginal and Torres Strait Islander people continue to face significant human rights issues and are the most disadvantaged people in Australia under almost every statistical indicator.³²⁹ For example:

- There is an 11-year life expectancy gap between Indigenous and non-Indigenous Australians;
- The total burden of disease for Indigenous Australians is 2.3 times the non-Indigenous rate, with chronic diseases responsible for 70% of the disease burden gap;
- 38% of Indigenous Australian households own their own house, compared to 66% of non-Indigenous households and Indigenous Australians are twice as likely to rent.

³²⁴ ABS, Census: Aboriginal and Torres Strait Islander Population, Press Release, 27 June 2017.

³²⁵ ABS, National Aboriginal and Torres Strait Islander Social Survey 2014-15.

³²⁶ Robert Dillon et al., Development of the Australia's Indigenous forest estate (2013) dataset, Australian Government Department of Agriculture, report no. 15.6, 2015, p. 20.

³²⁷ Jon Altman and Francis Markham, "Burgeoning Indigenous Land Ownership" in Sean Brennan et al. eds., From Mabo to Akibo: A Vehicle for Change and Empowerment? Sydney: The Federation Press, 2015, p. 126–142.

³²⁸ National Native Title Tribunal, Statistics, 24 April 2020.

³²⁹ Australian Government Productivity Commission, Overcoming Indigenous Disadvantage: Key Indicators, 2016.

- Indigenous Australians are three times more likely to live in social housing and make up 20% of the homeless population.
- 72% of Indigenous Australian households access the internet from their dwelling, compared to 84% of non-Indigenous households.
- 61.5% of Indigenous Australians aged 20 to 24 have completed secondary school, compared to 87.9% of non-Indigenous Australians.
- 46.8% of Indigenous Australians aged 20 to 64 have completed or are currently enrolled in higher education, compared to 70% of non-Indigenous Australians.
- The unemployment rate for Indigenous Australians is 20.8%, compared to 6.2% for non-Indigenous Australians.
- Indigenous Australians are half as likely as non-Indigenous Australians to earn a weekly household income of \$1,000 AUD or more.
- Indigenous Australians are 13 times more likely to go to prison and account for 27.4% of the total prison population.
- 23.4% of Indigenous Australians have a disability, 1.7 times the rate for non-Indigenous Australians, and 14% of

- Indigenous Australians provide unpaid assistance to someone with a disability.
- 21.8% of Indigenous Australians report experiencing violence and Indigenous women are 32 times more likely to be hospitalised due to violence.
- Indigenous children who live in households with a member of the Stolen Generations (Indigenous people who were forcibly removed from their families by state authorities) are significantly more likely to experience socioeconomic disadvantage.³³⁰

8.4.5 Policy Responses

Since 2002, the Australian Government Productivity Commission has produced the *Overcoming Indigenous Disadvantage Report* every two years, measuring 52 key indicators of indigenous wellbeing.³³¹ The project is led by a Steering Committee made up of representatives of indigenous peoples, the Australian Government and the Australian Bureau of Statistics. The report measures progress in a range of areas, including governance, leadership and culture, early childhood, education, health and safety.

The Productivity Commission also produces the *Indigenous Expenditure Report*, to measure government expenditure on Indigenous Australians across 150 categories.³³² In 2015-16, total government expenditure on Indigenous Australians was estimated

³³⁰ Australian Institute of Health and Welfare, *Children living in households with members of the Stolen Generations*, 11 June 2019.

³³¹ Australian Government Productivity Commission, Overcoming Indigenous Disadvantage.

³³² Australian Government Productivity Commission, Indigenous Expenditure Report, 2017.

to be \$33.4 billion AUD, a real increase from \$27.0 billion AUD in 2008-09. Roughly 82% of expenditure was on mainstream services and programmes available to all Australians, while 18% was on targeted services specifically for Indigenous Australians.

Policy frameworks and action plans, like the State Government of Victoria's Indigenous Family Violence Agreement, rely on disaggregated data to measure implementation. Programs to support indigenous business growth and economic development also rely on disaggregated data. 334

Indigenous statistics have also been an important driver for policy reform. For example, the Australian Human Rights Commission produced a report in 2005 urging Australian governments to close the indigenous health and life expectancy gaps by 2030, which led to the formation of the Close the Gap Campaign in 2007. In 2008, the Australian Government and all State Governments, committed to seven Closing the Gap targets in the National Indigenous

Reform Agreement, with the Prime Minister reporting annually to Parliament on progress. The Campaign Steering Committee also publishes a report every year with suggested areas for reform. Just two of the seven Closing the Gap targets are on track to be met, prompting the Australian Government to work more closely with Indigenous Australians to refresh the targets and develop new priorities. Indigenous Australians continue to call for the indicators to better reflect their own values and priorities, and for a stronger emphasis on Indigenous-led solutions.

8.5 New Zealand

8.5.1 Programmes and Strategies

Statistics New Zealand began developing a Māori statistics framework in 1995, with the resulting discussion paper 'Towards a Māori Statistics Framework' released in 2002.³³⁹ The He Arotahi Tatauranga Māori Statistics Framework was then launched in 2014.³⁴⁰ The first Māori social survey, Te Kupenga, was held in 2013 and work began on the Tatauranga Umanga Māori project to collect

³³³ State Government of Victoria Department of Health and Human Services, *Dhelk Dja: Safe Our Way: Strong Culture, Strong Peoples, Strong Families*, 2018.

³³⁴ Supply Nation and First Nations Capital, *Indigenous Business Growth*, 2018.

³³⁵ Australian Government National Indigenous Australians Agency, *Closing the Gap*, 2019.

³³⁶ Australian Human Rights Commission, Close the Gap: Indigenous Health Campaign, 21 March 2019.

³³⁷ Maggie Walter et al., "Refreshed Close the Gap targets will focus on progress and achievement", *NITV News*, 14 February 2019.

³³⁸ Maggie Walter et al., *Indigenous Data Sovereignty Briefing Paper 1*, Miaim Nayri Wingara Data Sovereignty Group and the Australian Indigenous Governance Institute, 2018; Nicholas Biddle, "Four lessons from 11 years of Closing the Gap reports", *The Conversation*, 14 February 2019.

³³⁹ Statistics New Zealand, Towards a Māori Statistics Framework, 2002, http://archive.stats.govt.nz/browse_for_stats/people_and_communities/maori/towards-a-maori-stats-framework.aspx; Karen Coutts, John Morris and Ngareta Jones, "The Māori statistics framework: A tool for indigenous peoples development" Statistical Journal of the IAOS 32, no. 2, 2016, p. 223–230.

³⁴⁰ Statistics New Zealand, *He Arotahi Tatauranga*, 12 November 2014) http://archive.stats.govt.nz/browse_for_stats/people_and_communities/maori/how-to-think-maori-info-needs/he-arotahi-tatauranga.aspx.

data on Māori authorities and businesses in 2015.

8.5.2 Questions on Ethnicity and Indigenous People

In New Zealand, statistical data on the indigenous Māori people is collected through self-identification questions. Ethnicity questions have been included in New Zealand's official statistical collections in some form since 1986, with the current Statistical Standard for Ethnicity developed in 2001. The ethnicity question asks people which ethnic group they belong to, with eight pre-filled responses (including Māori) and an open-ended 'other' category.³⁴¹

In addition to the standard ethnicity question, official statistical collections in New Zealand also include questions on Māori descent, iwi (Māori tribal groups), and te reo Māori (the Māori language).342 Māori ethnicity refers to cultural affiliation, while Māori descent refers to ancestry or genealogy. Statistics New Zealand is legally required to collect data on both under the Statistics Act 1975 and Electoral Act 1993. The ethnicity variable asks people whether they identify as Māori, either as their sole ethnic group or one of several. Whereas the Māori descent variable asks people whether they are a descendent of a Māori person (of any generation), with the option of identifying up to five

iwi (Māori tribal groups). Iwi data is fundamental to the treaty settlement process in New Zealand and allows for the monitoring of post-settlement outcomes.

8.5.3 Data Sources

There are three main sources of disaggregated data on the Māori people and ethnic groups in New Zealand:

- The NZ Census of Population and Dwellings, which is conducted every five years and provides a comprehensive overview of life in New Zealand. The most recent available results are from the 2013 census, which had a response rate of 92.9%.³⁴³
- Administrative data from government departments, including the Department of Internal Affairs, Birth and Death Registrations, the Ministry of Health and health service providers, the Ministry of Education, and the Ministry of Social Development, as well as iwi and other Māori community organisations.³⁴⁴
- The New Zealand Health Survey (NZHS), which is conducted annually by the Ministry of Health and provides information about the health and wellbeing of all New Zealanders. The last NZHS was con-

³⁴¹ Statistics New Zealand, Statistical standard for ethnicity, 1 September 2017.

³⁴² Statistics New Zealand, 2013 Census QuickStats about Māori, 3 December 2013.

³⁴³ Note: the most recent New Zealand census was held in 2018, but not all of the Māori-specific results were available at the time of writing.

³⁴⁴ Christine Bycroft, et al., Identifying M\u00e4ori populations using administrative data: A comparison with the census, Statistics New Zealand. 2016.

ducted in 2017-18 with a sample size of 14,000 adults and 4,000 children.³⁴⁵

In addition, there is one Māori-specific survey:

■ The 'Te Kupenga' survey, which is conducted every five years by Statistics New Zealand and provides self-reported information on Māori health, wellbeing, spirituality, language, culture, customs, and social, cultural, and economic development. The results of the survey are presented in a publication called 'Te Ao Mārama', with the most recent available results from 2013.³⁴⁶

8.5.4 Findings

In 2013, over a million New Zealanders were born overseas, representing roughly 25% of the total population.³⁴⁷ The number of New Zealanders who could speak more than one language increased from 15.8% in 2001 to 18.6% in 2013. Of the total New Zealand population, 3.7% could speak the te reo Māori language, with a quarter of those being children.

In 2013, 598,605 people in New Zealand identified with the Māori ethnic group, representing 14.9% of the total New Zealand population (4.24 million), with almost half these people identifying Māori as their only ethnic-

ity.³⁴⁸ By contrast, 668,724 people said they were of Māori descent, representing roughly 16% of the total New Zealand population. The gap between these figures represents the proportion of people of Māori descent who do not identify with the Māori ethnic group. Approximately 80% of people of Māori descent specified at least one iwi (Māori tribal group), while 17% said that they did not know their iwi. 21% of Māori people reported that they could hold a conversation in Māori language, a decrease from 2006 (23.7%) and 2001 (25.2%).

Aproximately 1.5 million hectares (6% of the total New Zealand landmass) is classified as Māori land, most of which is concentrated in the centre and the east coast of the North Island.³⁴⁹ This includes over 27,000 freehold land titles which are governed by trusts, incorporations, administrators, and other organisations, and typically have anywhere between 10 to 2000 owners or beneficiaries.

The 2013 Te Kupenga Survey on Māori wellbeing found that:³⁵⁰

 70% of Māori adults said it was important for them to be involved in things to do with Māori culture and spirituality.

³⁴⁵ New Zealand Ministry of Health, *Ngā tapuae me ngā raraunga: Methods and data sources*, 2 August 2018.

³⁴⁶ Statistics New Zealand, Te Kupenga 2013, 6 May 2014; Statistics New Zealand, Te Ao Mārama 2016, July 2016.

³⁴⁷ Statistics New Zealand, 2013 Census QuickStats about culture and identity, 15 April 2014.

³⁴⁸ Statistics New Zealand, 2013 Census QuickStats about Māori.

³⁴⁹ Garth R. Harmsworth and Alec Mackay, *Land resource assessment and evaluation on Māori land*, Whenua Sustainable Futures with Māori Land Conference, Rotorua, New Zealand, 21–23 July 2010.

³⁵⁰ Statistics New Zealand, Te Kupenga 2013, 6 May 2014.

- 89% of Māori adults said they knew their iwi (Māori tribal group).
- 62% of Māori adults had been to their ancestral marae (sacred communal meeting ground) and 34% had done so in the last 12 months.
- 55% of Māori adults had some ability to speak the te reo Māori language, compared to 42% in 2001 (with much of this increase coming from younger speakers), and 11% were fluent speakers.
- 83% of Māori adults said their whānau was doing well and 84% had face-to-face contact with whānau they didn't live with (whānau is a holistic concept of extended family and kinship networks).

Disaggregated statistical data from the New Zealand census and administrative registers indicates that:³⁵¹

- There is a 7-year life expectancy gap between indigenous and non-indigenous people in New Zealand. In 2013, life expectancy at birth was 73 years for Māori males and 77.1 years for Māori females, compared to 80.3 years for non-Māori males and 83.9 years for non-Māori females.
- The Māori infant mortality rate is 1.5 times higher than the non-Māori rate.

- 33% of Māori people have a disability, compared to 24% of non-Māori New Zealanders.
- Māori people are twice as likely as non-Māori people to commit suicide and significantly more likely to be hospitalised for intentional self-harm.
- Māori people are 3 times more likely than non-Māori to be hospitalised for assault or attempted homicide and 2.5 times more likely to die from assault or homicide.
- Māori people are twice as likely as non-Māori to die from cardiovascular disease, 1.5 times more likely to die from cancer, twice as likely to be diagnosed with asthma or diabetes, and 3 times more likely to be hospitalised for acute rheumatic fever.
- Māori adults are about 1.5 times more likely than non-Māori adults to have an anxiety or depressive disorder.
- Māori children and adults are more likely than non-Māori to have experienced an unmet need for primary health care, with the most common reasons including a lack of childcare, lack of transport and cost.
- 40.9% of all Māori students participate in Māori language education at school

³⁵¹ New Zealand Ministry of Health, *New Zealand Health Survey*, 13 February 2020; New Zealand Ministry of Education, *Education Counts: Quick Stats about Māori Education*, 2019.

8.5.5 Policy Responses

Disaggregated data is used by Māori organisations and government departments in New Zealand for a variety of reasons, including to develop, monitor and report on initiatives with precision and certainty.352 For example, the Ministries of Māori Development; Education; Health; and Business, Innovation and Employment each have strategies which contain specific Māori outcomes and require relevant data to assess their performance and the impact of their policies. The Ministry of Social Development also uses disaggregated data in its annual Social Report, which monitors progress under a range of indicators for indigenous wellbeing.353 Disaggregated data is also required to determine the number and size of Māori electorates, as the New Zealand Parliament includes dedicated Māori seats.

The New Zealand Treasury has recently developed a Living Standards Framework (LSF) to determine budgetary priorities and measure wellbeing in a more holistic way, rather than relying solely on economic indicators of prosperity.³⁵⁴ As part of this process, Māori perspectives and approaches to wellbeing have been incorporated into a separate Indigenous Living Standards Framework, which also requires disaggregated data.³⁵⁵

Māori researchers and organisations continue to call for more comprehensive, relevant and high-quality data, as well as greater Māori control over data planning, collection and dissemination.³⁵⁶

³⁵² Kukutai and Taylor, *Indigenous Data Sovereignty*, ch. 16.

³⁵³ New Zealand Ministry of Social Development, The Social Report, 2016.

³⁵⁴ New Zealand Treasury, Living Standards Framework: Introducing the Dashboard, 4 December 2018.

³⁵⁵ New Zealand Treasury, An Indigenous Approach to the Living Standards Framework, 1 February 2019.

³⁵⁶ See for example: Gabrielle Baker, "Stats NZ won't release iwi data, and that's a problem", *The Spinoff*, 1 May 2019.



List of References

Laws and Regulations

Folkeregisterloven of 9 December 2016 [the Population Register Act].

Folkeregisterforskriften of 14 July 2017 [the Population Register Regulations].

Forskrift om valg til Sametinget of 19 December 2008 [Regulations on Sámi Parliament Elections].

NIM-loven of 22 May 2015 [The NIM Act].

Personopplysningsloven of 15 June 2018 [The Personal Data Act].

Sameloven of 12 June 1987 [the Sámi Act].

Statistikkloven of 21 June 2019 [The Statistics Act].

Legislative Preparatory Works

Meld. St. 50 (1998–1999): Utjamnings-meldinga: Om fordeling av inntekt og levekår i Norge [The Equality Report: On distribution of income and living conditions in Norway].

NOU 1995: 6. NOU 2016: 17. NOU 2016: 18. Ot.prp. nr. 43 (2007–2008). Ot.prp. nr. 93 (2008–2009).

Prop. 106 S (2011–2012). Prop. 164 L (2015–2016). Prop. 66 S (2016–2017).

Supreme Court of Norway Cases

HR-2016-2554-P.

Sámi Parliament Statements and Decisions

Sámi Parliament, *Bærekraftig næringsut-vikling* [Sustainable Business Development], Case Number 18/3122, Document 19/19555, 2019.

Sámi Parliament, Etiske retningslinjer for Samisk helseforskning [Ethical Guidelines for Sámi Health Research], Case Number 18/5159, 2018.

Sámi Parliament, *Høringsuttalelse NOU 2018*: 7 [Hearing submission on Official Report 2018:7], 28 June 2018.

Sámi Parliament, *Merknad til Meld. St. 31* (2018–2019) [Comment on White Paper 31 2018–2019].

Sámi Parliament, *Samiskrelatert statistikk i Norge* [Sámi-related statistics in Norway], Case Number 04/1725, Document 06/810, 2006.

International Conventions and Declarations

Charter of the United Nations, 1 UNTS XVI (24 October 1945).

Convention on the Elimination of Discrimination Against Women (CEDAW), 1249 UNTS 13 (1 March 1980, entered in to force 3 September 1981).

Convention on the Rights of Persons with Disabilities (CRPD), 2515 UNTS 3 (13 December 2006, entered into force 3 May 2008).

Convention on the Rights of the Child (CRC), 1577 UNTS 3 (20 November 1989, entered into force 2 September 1990).

Council of Europe Convention on Preventing and Combating Violence against Women and Domestic Violence (Istanbul Convention), CETS No.210 (11 May 2011, entered into force 1 August 2014).

EU General Data Protection Regulation (GDPR), Regulation 2016/679 (27 April 2016, entered into force in the EU 25 May 2018 and in Norway 20 July 2018).

International Convention on the Elimination of Racial Discrimination (ICERD), 66 UNTS 195 (21 December 1965, entered into force 4 January 1969).

International Convention on the Protection of the Rights of All Migrant Workers and their Families (CMW), 220 UNTS 3 (18 December 1990, entered into force 1 July 2003).

International Covenant on Civil and Political Rights (ICCPR), 999 UNTS 171 (16 December 1966, entered into force 23 March 1976).

International Covenant on Economic, Social and Cultural Rights (ICESCR), 993 UNTS 3 (16 December 1966, entered into force 3 January 1976).

International Labour Organisation (ILO) Convention No. 169, 1650 UNTS 383 (27 June 1989, entered into force 5 September 1991).

United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), UN Doc. A/RES/61/295 (2 October 2007, adopted 13 September 2007).

Universal Declaration of Human Rights (UDHR), UN Doc. A/810 (10 December 1948).

European Court of Human Rights Cases

D.H. and others v. The Czech Republic, No. 57325/00, 13 November 2007.

European Roma Rights Centre v. Greece, No. 15/2003, 8 December 2004.

European Roma Rights Centre v. Italy, No. 27/2004, 7 December 2005.

Hoogendijk v. the Netherlands, no. 58641/00, 6 January 2005.

Zarb Adami v. Malta, No. 17209/02, 20 June 2006.

Statements and Reports from European Human Rights Bodies

Bell, Mark, Isabelle Chopin, Lilla Farkas, Catharina Germaine, Stefanos Grammenos, Thomas Huddleston, Timo Makkonen, Michelle Troost and Marcel Zwamborn, Analysis and Comparative Review of Equality Data Collection Practices in the European Union: Legal Framework and Practice in the EU Member States, European Commission, 2017.

Council of Europe, *Explanatory Report to the Istanbul Convention*, CETS No.210, 2011.

European Commission Against Racism and Intolerance (ECRI), General Policy Recommendation No. 11 on combating racism and racial discrimination in policing, CRI(2007)39, 4 October 2007.

European Commission Against Racism and Intolerance (ECRI), *General Policy Recommendation No. 1*, CRI(96)43rev, 4 October 1996.

European Commission Against Racism and Intolerance (ECRI), Report on Norway: fifth monitoring cycle, CRI(2015)2, 24 February 2015.

European Commission Against Racism and Intolerance (ECRI), Report on Norway: fourth monitoring cycle, CRI(2009)4, 24 February 2009.

European Commission Subgroup on Equality Data, Guidelines on improving the collection and use of equality data, 2018.

European Commission, Joint report to the European Parliament and Council on the application of Council Directive 2000/43/EC of 29 June 2000 (Racial Equality Directive) and of Council Directive 2000/78/EC of 27 November 2000 (Employment Equality Directive), COM(2014)2, 17 January 2014.

European Commission, Special Eurobarometer 493 on Discrimination in the EU, 2019.

European Court of Auditors, *EU policy* nitiatives and financial support for Roma integration: significant progress made over the last decade, but additional efforts needed on the ground, 2016.

European Union Agency for Fundamental Rights (FRA), Compendium of Practices on Equality Data, 2019.

European Union Agency for Fundamental Rights (FRA), *Diagnostic Mapping Tool on Equality Data*, 2019.

Farkas, Lilla, Analysis and Comparative Review of Equality Data Collection Practices in the European Union: Data Collection in the Field of Ethnicity, European Commission, 2017.

Makkonen, Timo, European Handbook on Equality Data, European Commission, 2016.

Simon, Patrick, Ethnic statistics and data protection in the Council of Europe countries: Study Report, European Commission against Racism and Intolerance, 2007.

Statements and Reports from United Nations Human Rights Bodies

Alston, Philip, End-of-mission statement on Romania by the Special Rapporteur on Extreme Poverty and Human Rights, 11 November 2015.

Anaya, James, Report of the Special Rapporteur on the Rights of Indigenous Peoples, UN Doc. A/HRC/9/9, 11 August 2008.

Cannataci, Joseph A., UN Special Rapporteur on the Right to Privacy Recommendation on the Protection and Use of Health-Related Data, UN Doc. A/74/277, 5 December 2019.

Capotorti, Francesco, Study on the Rights of Persons Belonging to Ethnic, Religious and Linguistic Minorities, United Nations Sub-Commission on Prevention of Discrimination and Protection of Minorities. 1977.

Committee on Economic, Social and Cultural Rights, Concluding observations on the sixth periodic report of Norway, UN. Doc. E/C.12/NOR/CO/6, 6 March 2020.

Committee on Economic, Social and Cultural Rights, General Comment No. 20: Prevention of discrimination, UN Doc. E/C.12/GC/20, 2 July 2009.

Committee on Economic, Social and Cultural Rights, General Comment No. 3: The Nature of States Parties' Obligations, UN Doc. E/1991/23, 14 December 1990.

Committee on Economic, Social and Cultural Rights, General Comment No. 1: Reporting by States Parties, UN Doc. E/1989/22, 27 July 1981.

Committee on Economic, Social and Cultural Rights, General Comment No. 21: Right of Everyone to Take Part in Cultural Life, UN Doc. E/C.12/GC/21, 21 December 2009.

Committee on the Elimination of Discrimination Against Women, Concluding observations on the ninth periodic report of Norway, UN Doc. CEDAW/C/NOR/CO/9, 22 November 2017.

Committee on the Elimination of Racial Discrimination, *Combined twenty-third and twenty-fourth periodic reports submitted by Norway*, UN Doc. CERD/C/NOR/23-24, 2 November 2017.

Committee on the Elimination of Racial Discrimination, Concluding observations on the combined twenty-third and twenty-fourth periodic reports of Norway, UN Doc. CERD/C/NOR/CO/23-24, 2 January 2019.

Committee on the Elimination of Racial Discrimination, *Concluding observations on the 16th periodic report of Norway*, UN Doc. CERD/C/63/CO/8, 10 December 2003.

Committee on the Elimination of Racial Discrimination, *Concluding observations on the 17th and 18th periodic reports of Norway*, UN Doc. CERD/C/NOR/CO/18, 19 October 2006.

Committee on the Elimination of Racial Discrimination, *Concluding observations on the 19th and 20th periodic reports of Norway*, UN Doc. CERD/C/NOR/CO/19-20, 8 April 2011.

Committee on the Elimination of Racial Discrimination, General Recommendation No. 8 Concerning the Interpretation and Application of Article 1 (1) and (4) of the Convention, UN Doc. A/45/18, 22 August 1990.

Committee on the Elimination of Racial Discrimination, General Recommendation No. 32: The meaning and scope of special measures in the International Convention on the Elimination of All Forms of Racial Discrimination, UN Doc. CERD/C/GC/32, 24 September 2009.

Committee on the Elimination of Racial Discrimination, *General Recommendation No. 23: Indigenous Peoples*, UN Doc. A/52/18, 18 August 1997.

Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Norway, UN Doc. CRPD/C/NOR/CO/1, 7 May 2019.

Committee on the Rights of Persons with Disabilities, General Comment No. 7: The participation of persons with disabilities, including children with disabilities, through their representative organisations, in the implementation and monitoring of the Convention, UN Doc. CRPD/C/GC/7, 9 November 2018.

Committee on the Rights of the Child, Concluding observations on the combined fifth and sixth periodic reports of Norway, UN Doc. CRC/C/NOR/CO/5-6, 4 July 2018.

Conference of European Statisticians, Recommendations for the 2020 censuses of population and housing, 2015.

Expert Mechanism on the Rights of Indigenous Peoples (EMRIP), Free, Prior and Informed Consent: A Human Rights Based Approach, UN Doc. A/HRC/39/62, 10 August 2018.

Human Rights Committee, *Apirana Mahuika* et al. v. New Zealand, No. 547/1993, 27 October 2000.

Human Rights Committee, *Chief Bernard Ominayak and Lubicon Lake Band v. Canada*, No. 167/1984, 26 March 1990.

Human Rights Committee, Concluding observations on the seventh periodic report of Norway, UN Doc. CCPR/C/NOR/CO/7, 25 April 2018.

Human Rights Committee, General Comment No. 23: Article 27 (Rights of Minorities), UN Doc. CCPR/C/21/Rev.1/Add.5, 8 April 1994.

Human Rights Committee, *Ivan Kitok v. Sweden*, No. 197/1985, 27 July 1988.

Human Rights Committee, General Comment No. 16: Article 17 (Right to Privacy): The Right to Respect of Privacy, Family, Home and Correspondence, and Protection of Honour and Reputation, UN Doc. HRI/GEN/1/Rev.9 (Vol. I), 8 April 1988.

Human Rights Council, The Role of Prevention in the Promotion and Protection of Human Rights: Report of the OHCHR, UN Doc. A/HRC/30/20, 16 July 2015.

Martínez Cobo, José, Study of the Problem of Discrimination Against Indigenous Populations, United Nations Sub-Commission on Prevention of Discrimination and Protection of Minorities, UN Doc. E/CN.4/Sub.2/1986/7/Add.4, 1986.

Office of the United Nations High Commissioner for Human Rights (OHCHR), Human Rights Indicators: A Guide to Measurement and Implementation, UN Doc. HR/PUB/12/5, 2012.

Office of the United Nations High Commissioner for Human Rights (OHCHR) and United Nations Permanent Forum on Indigenous Issues (UNPFII) Secretariat, Briefing Note: Indigenous Peoples' Rights and the 2030 Agenda, September 2017.

Office of the United Nations High Commissioner for Human Rights (OHCHR), A Human Rights Based Approach to Data, 2018.

Ruteere, Mutuma, Report of the Special Rapporteur on Contemporary Forms of Racism, Racial Discrimination, Xenophobia and Related Intolerance, UN Doc. A/70/335, 20 August 2015.

Tauli-Corpuz, Victoria, Report of the Special Rapporteur on the Rights of Indigenous Peoples: Rights of indigenous peoples, including their economic, social and cultural rights in the post-2015 development framework, Un Doc. A/69/267, 6 August 2014.

United Nations Conference of European Statisticians, *Recommendations for the 2020 censuses of population and housing*, UN Doc. ECE/CES/41, 2015.

United Nations Department of Economic and Social Affairs, *Promoting Inclusion through Social Protection: Report on the World Social Situation 2018*, UN Doc. ST/ESA/366, 2018.

United Nations Department of Economic and Social Affairs, *State of the World's Indigenous Peoples*, 4th ed, UN Doc. ST/ESA/371, 2019.

United Nations Economic Commission for Latin America and the Caribbean (ECLAC), Contar con todos: caja de herramientas para la inclusión de pueblos indígenas y afrodescendientes en los censos de población y Vivienda [Counting everyone: a toolkit for the inclusion of indigenous and Afrodescendant peoples in population and housing censuses], UN Doc. LC/R.2181, December 2011.

United Nations Economic Commission for Latin America and the Caribbean (ECLAC), Montevideo consensus on population and development, UN Doc. LC/L.3697, 12–15 August 2013.

United Nations Economic Commission for Latin America and the Caribbean (ECLAC), Guaranteeing indigenous people's rights in Latin America – progress in the past decade and remaining challenges, UN Doc. LC/L.3893/Rev.1, November 2014.

United Nations General Assembly, Fundamental Principles of Official Statistics, UN Doc. A/RES/68/261, 3 March 2014.

United Nations General Assembly, Outcome document of the high-level plenary meeting of the General Assembly known as the World Conference on Indigenous Peoples, Un Doc. A/RES/69/2, 22 September 2014.

United Nations General Assembly, *Rights of indigenous peoples*, A/RES/72/155, 17 January 2018.

United Nations General Assembly, Transforming Our World: The 2030 Agenda for Sustainable Development, UN Doc. A/RES/70/1, 21 October 2015.

United Nations Permanent Forum on Indigenous Issues (UNPFII), Report of the 8th Session, UN Doc. E/C.19/2009/14, 18–29 May 2009.

United Nations Permanent Forum on Indigenous Issues (UNPFII), Report of the Workshop on Data Collection and Disaggregation for Indigenous Peoples, Un Doc. E/C.19/2004/2, 10 February 2004.

United Nations Permanent Forum on Indigenous Issues (UNPFII), Report on the fourth session, UN Doc. E/2005/43, 16–27 May 2005.

United Nations Secretary-General, Compilation of Guidelines on the Form and Content of Reports to be Submitted by States Parties to the International Human Rights Treaties, UN Doc. HRI/GEN/2/Rev.6, 3 June 2009.

United Nations Statistics Division, Ethnicity: A Review of Data Collection and Dissemination, 2003.

United Nations Statistics Division, *Principles* and Recommendations for Population and Housing Censuses, UN Doc. ST/ESA/STAT/ SER.M/67/Rev.3, 2017.

United Nations Statistics Division, Sustainable Development Goals Report 2019, 9 July 2019.

Books

Altman, Jon and Francis Markham, "Burgeoning Indigenous Land Ownership" in Sean Brennan, Megan Davis, Brendan Edgeworth and Leon Terrill eds., From Mabo to Akibo: A Vehicle for Change and Empowerment? Sydney: The Federation Press, 2015. Axelsson, Per and Peter Sköld eds., Indigenous Peoples and Demography, New York: Berghahn Books, 2011.

Bjerregaard, Peter, "Regional Studies of Indigenous Health: Europe and Russia" in The Oxford Research Encyclopedia: Global Public Health, Oxford University Press, 2019.

Hansen, Lars Ivar, Henry Minde and Bjørnar Olsen, *Samenes historie* [The history of the Sami], Oslo: Cappelen Damm Akademisk, 2004.

Hylland Eriksen, Thomas, *Ethnicity and Nationalism*, *Anthropological Perspectives*, London: Pluto Press, 2010 (3rd ed.).

Jensen, Eivind Bråstad, Skoleverket og de tre stammers møte [The school administration and the meeting between three tribes], Tromsø: Eureka, 2005.

Kukutai, Tahu and John Taylor eds., Indigenous Data Sovereignty: Toward an Agenda, Canberra: ANU Press, 2016.

Lie, Einar and Hege Roll-Hansen, Faktisk talt – Statistikkens historie i Norge [The history of statistics in Norway], Oslo: Universitetforlaget, 2001.

Journal Articles

Bals, Margrethe, Anne Lene Turi, Ingunn Skre and Siv Kvernmo, "Internalization symptoms, perceived discrimination, and ethnic identity in indigenous Sami and non-Sami youth in Arctic Norway" Ethnicity and Health 15, no. 2, 2010.

Blix, Bodil Hansen and Torunn Hamran, "They take care of their own": healthcare professionals constructions of Sami persons with dementia and their families reluctance to seek and accept help through attributes to multiple contexts' *International Journal of Circumpolar Health* 76, no. 1, 2017.

Broderstad, Ann Ragnhild, Solrunn Hansen and Marita Melhus, "The Second Clinical Survey of the Population-based Study on Health and Living Conditions in Regions with Sami and Norwegian Populations – the SAMINOR 2 Clinical Survey: Performing Indigenous Health Research in a Multiethnic Landscape" Scandinavian Journal of Public Health (published online ahead of print 6 May 2019).

Brustad, Magritt, Ketil Lenert Hansen, Ann Ragnhild Broderstad, Solrunn Hansen and Marita Melhus, "A population-based study on health and living conditions in areas with mixed Sami and Norwegian settlements – the SAMINOR 2 questionnaire study" International Journal of Circumpolar Health 73, no. 1 (2014).

Coutts, Karen, John Morris and Ngareta Jones, "The Māori statistics framework: A tool for indigenous peoples development" Statistical Journal of the IAOS 32, no. 2, 2016.

Eliassen, Bent-Martin, Marita Melhus, Ketil Lenert Hansen and Ann Ragnhild Broderstad, "Marginalisation and cardiovascular disease among rural Sámi in Northern Norway: a population-based cross-sectional study" BMC Public Health 13, no. 522, 2013. Eliassen, Bent-Martin, Sidsel Graff-Iversen, Marita Melhus, Maja-Lisa Løchen and Ann Ragnhild Broderstad, "Ethnic difference in the prevalence of angina pectoris in Sami and non-Sami populations: the SAMINOR study" *International Journal of Circumpolar Health* 73, no. 1, 2014.

Eriksen, Astrid Margrethe Anette, Ketil Lenert Hansen, Cecilie Javo and Berit Schei, "Emotional, physical and sexual violence among Sami and non-Sami populations in Norway: The SAMINOR 2 questionnaire study" Scandinavian Journal of Public Health 43, no. 6, 2015.

Gillon, Ashlea, Donna Cormack and Belinda Borell, "Oh, you don't look Māori: Socially assigned ethnicity" *MAI Journal* 8, no. 2, 2019.

Gjertsen, Hege, "Mental health among Sami people with intellectual disabilities" International Journal of Circumpolar Health 78, no. 1, 2019.

Hansen, Ketil Lenert and Tore Sørlie, "Ethnic discrimination and psychological distress: a study of Sami and non-Sami populations in Norway" *Transcultural Psychiatry* 49, no. 1, 2012.

Hansen, Ketil Lenert, "Ethnic discrimination and health: the relationship between experienced ethnic discrimination and multiple health domains in Norway's rural Sami population" International Journal of Circumpolar Health 74, no. 1, 2015.

Hansen, Ketil Lenert, "Indigenous health and wellbeing" *International Journal of Circumpolar Health* 69 (Circumpolar health supplements vol. 7) 2010.

Hansen, Ketil Lenert, Marita Melhus and Eiliv Lund, "Ethnicity, self-reported health, discrimination and socio-economic status: a study of Sami and non-Sami Norwegian populations" *International Journal of Circumpolar Health* 69, no. 2, 2010.

Hassler, Sven, Robert Johansson, Per Sjölander, Henrik Grönberg and Lena Damber, "Causes of death in the Sami population of Sweden, 1961–2000" International Journal of Epidemiology 34, no. 3, 2005.

Heard, Genevieve, Bob Birrell and Siew-Ean Khoo, "Intermarriage between indigenous and non-indigenous Australians" *People and Place* 17, no. 1, 2009.

Helland, Håvard and Liv Anne Støren, "Vocational Education and the Allocation of Apprenticeships: Equal Chances for Applicants Regardless of Immigrant Background?" European Sociological Review 22, no. 3, 2006.

Kukutai, Tahu and Donna Cormack, "Census 2018 and Implications for Māori" New Zealand Population Review 44, 2018.

Kvernmo, Siv and Sonja Heyerdahl, "Acculturation strategies and ethnic identity as predictors of behaviour problems in arctic minority adolescents" Journal of the American Academy of Child & Adolescent Psychiatry 42, no. 1, 2003.

Lund, Eiliv, Marita Melhus, Ketil Lenert Hansen, Tove Nystad, Ann Ragnhild Broderstad, Randi Selmer and Per G. Lund-Larsen, "Population Based Study of Health and Living Conditions in Areas with both Sami and Norwegian populations-The SAMINOR Study" International Journal of Circumpolar Health 66, no. 2 (2007).

Maddison, Sarah, "Indigenous identity, 'authenticity' and the structural violence of settler colonialism" *Identities: Global Studies in Culture and Power* 20, no. 3, 2013.

Minde, Henry, "Assimilation of the Sámi: implementation and consequences" *Gáldu Journal of Indigenous Peoples Rights*, no. 3 (2005).

Morning, Ann, "Ethnic Classification in Global Perspective: A Cross-National Survey of the 2000 Census Round" *Population* Research and Policy Review 27, 2008.

Naseribafrouei, Ali, Bent-Martin Eliassen, Marita Melhus and Ann Ragnhild Broderstad, "Ethnic difference in the prevalence of prediabetes and diabetes mellitus in regions with Sami and non-Sami populations in Norway – the SAMINOR1 study" International Journal of Circumpolar Health 75, no. 1, 2016.

Nystad, Tove, Marita Melhus and Eiliv Lund, "Samisktalende er mindre fornøyd med legetjenesten" [The monolingual Sámi population is less satisfied with primary health care] *Tidsskrift for Den norske legeforening* 126, no. 6, 2006. Nystad, Tove, Marita Melhus, Margritt Brustad and Eiliv Lund, "Ethnic differences in the prevalence of general and central obesity among the Sami and Norwegian populations: the SAMINOR study" *Scandinavian Journal of Public Health* 38, no. 1, 2010.

O'Doherty, Kieran C., Emily Christofides, Jeffrey Yen, Heidi Beate Bentzen, Wylie Burke, Nina Hallowell, Barbara A. Koenig and Donald J. Willison, "If you build it, they will come: unintended future uses of organised health data collections" *BMC Medical Ethics* 17, no. 54, 2016.

Peters, Evelyn J., "Still invisible: enumeration of indigenous peoples in census questionnaires internationally" *Aboriginal Policy Studies* 1, no. 2, 2011.

Pettersen, Torunn and Magritt Brustad, "Same Sámi? A comparison of self-reported Sámi ethnicity measures in 1970 and 2003 in selected rural areas in northern Norway" *Ethnic and Racial Studies* 38, no. 12 (2015).

Rocha, Zarine L., "(Mixed) Racial formation in Aotearoa/New Zealand: framing biculturalism and 'mixed race' through categorisation" Kōtuitui: New Zealand Journal of Social Sciences Online 7, no. 1, 2012.

Rosga, Ann Janette and Margaret Satterthwaite, "The Trust in Indicators: Measuring Human Rights" *Berkeley Journal* of International Law 27, no. 2 (2009). Selle, Per, Anne Julie Semb and Kristin Strømsnes, "Citizenship identity among Norwegian Sami in core Sami areas" Citizenship Studies 17, no. 6-7 (2013).

Seltzer, William and Margo Anderson, "The Dark Side of Numbers: The Role of Population Data Systems in Human Rights Abuses," Social Research 68, no. 2, 2001.

Silviken, Anne, Tor Haldorsen and Siv Kvernmo, "Suicide among Indigenous Sámi in Arctic Norway, 1970–1998" *European Journal of Epidemiology* 21, no. 9, 2006.

Simon, Patrick, "The failure of the importation of ethno-racial statistics in Europe: debates and controversies" *Ethnic and Racial Studies* 40, no. 13, 2017.

Siri, Susanna R.A., Tonje Braaten, Bjarne K. Jacobsen, Marita Melhus and Bent-Martin Eliassen, "Distribution of risk factors for cardiovascular disease and the estimated 10-year risk of acute myocardial infarction or cerebral stroke in Sami and non-Sami populations: The SAMINOR 2 Clinical Survey" Scandinavian Journal of Public Health 46, no. 6, 2018.

Sjölander, Per, "What is known about the health and living conditions of the indigenous people of northern Scandinavia, the Sami?" Global Health Action 4, no. 1, 2011.

Smylie, Janet and Michelle Firestone, "Back to basics: identifying and addressing underlying challenges in achieving high quality and relevant health statistics for indigenous populations in Canada" Statistical Journal of the IAOS 31, no. 1, 2015.

Søbye, Espen, "Demografi, statistikk og rasisme" [Demographics, statistics and racism] *Agora*, no. 3-4 (2014).

Soininen, Leena, Sari Järvinen and Eero Pukkala, "Cancer incidence among Sami in northern Finland, 1979–1998" *International Journal of Cancer* 100, no. 3, 2002.

Sørlie, Tore and Jens-Ivar Nergård, "Treatment Satisfaction and Recovery in Saami and Norwegian patients following psychiatric hospital treatment: a comparative study" *Transcultural Psychiatry* 42, no. 2, 2005.

Torp, Eivind, "Registrering av etnisitet i folketellinger" [Registration of ethnicity in censuses] *Heimen* 23, no. 2 (1986).

Turi, Anne Lene, Margrethe Bals, Ingunn B. Skre and Siv Kvernmo, "Health service use in indigenous Sami and non-indigenous youth in North Norway: A population based survey" *BMC Public Health* 9, no. 378, 2009.

Ulfstein, Geir, "Høyesteretts anvendelse av traktatorganers tolkningspraksis" *Lov og Rett* nr. 7 (2016).

Weinstock, John, "Assimilation of the Sámi: Its Unforeseen Effects on the Majority Populations of Scandinavia" *Scandinavian Studies* 85, no. 4, 2013.

Williams, Meaghan and Robert Schertzer, "Is Indigeneity like Ethnicity? Theorizing and Assessing Models of Indigenous Political Representation" *Canadian Journal of Political Science* 52, no. 4 (2019).

Young, T. Kue and Peter Bjerregaard, "Towards estimating the indigenous population in circumpolar regions" *International Journal of Circumpolar Health* 78, no. 1, 2019.

Reports

Andersen, Espen and Harald Utne, *Censuses* in a register-based statistical system: Norwegian experiences, Statistics Norway, 2011.

Aubert, Vilhelm, *Den Samiske befolkning i Nord-Norge* [The Sámi Population in Northern Norway], Statistics Norway, 1978.

Australian Government Productivity Commission, *Indigenous Expenditure Report*, 2017.

Australian Government Productivity Commission, Overcoming Indigenous Disadvantage: Key Indicators, 2016.

Australian Institute of Health and Welfare, Children living in households with members of the Stolen Generations, 11 June 2019. Australian Institute of Health and Welfare, National Best Practice Guidelines for Collecting Indigenous Status in Health Data Sets, 2010.

Brand, Emily, Chelsea Bond and Cindy Shannon, Indigenous in the City: Urban-Indigenous Populations in Local and Global Contexts, Poche Centre for Indigenous Health, 2016.

Bråthen, Magne, Huafeng Zhang and Jon Rogstad, Indikatorer på diskriminering av innvandrere, urfolk og nasjonale minoriteter [Indicators of discrimination against immigrants, indigenous peoples and national minorities], FAFO, 2016.

Brustad, Magritt, "Helse i Samisk befolkning – en kunnskapsoppsummering av publiserte resultater fra befolkningsundersøkelser i Norge" [Health in the Sámi population – a summary of published results from population-based surveys in Norway] in Samiske tall forteller 3, Kautokeino: Sámi University of Applied Sciences, 2010.

Bycroft, Christine, Giles Reid, Justine McNally, Fran Gleisner, *Identifying Māori populations using administrative data:* A comparison with the census, Statistics New Zealand, 2016.

Danish Institute for Human Rights, Human Rights and the 2030 Agenda for Sustainable Development: Lessons Learned and Next Steps, 2018.

Dillon, Robert, Jeya Jeyasingham, Sid Eades, Steve Read, *Development of the Australia's Indigenous forest estate (2013) dataset*, Australian Government Department of Agriculture, report no. 15.6, 2015.

Eriksen, Astrid Margrethe Anette, "Vold, overgrep og helseplager blant samer i Norge" [Violence, abuse and health problems among Sami in Norway] in Samiske Tall Forteller 12, Kautokeino: Sámi University of Applied Sciences, 2019.

Fagutvalget for utredning om valgordning til sametingsvalget, *Ny valgordning til Sametinget* [New Election Scheme for the Sámi Parliament], 4 April 2007.

Fladmoe, Audun, Marjan Nadim and Simon Roland Birkvad, Erfaringer med hatytringer og hets blant LHBT-personer, andre minoritetsgrupper og den øvrige befolkningen [Experiences of hate speech and anger among LGBT people, other minority groups and the rest of the population], Institutt for samfunnsforskning, report no. 4, 2019.

Gjertsen, Hege, Line Melbøe, Gunn Elin Fedreheim, Ingrid Fylling, Kartlegging av levekårene til personer med utviklingshemming i Samiske områder [Mapping the living conditions of people with intellectual disabilities in Sámi areas], UiT the Arctic University of Norway, 2017.

Hansen, Ketil Lenert, "Diskriminering av samer med funksjonsnedsettelse" [Discrimination against Sámi with disabilities] in *Samiske tall forteller 10*, Kautokeino: Sámi University of Applied Sciences, 2017.

Hansen, Ketil Lenert, "Selvopplevd diskriminering av samer i Norge" [Self-reported experience of discrimination against Sámi in Norway] in *Samiske tall forteller* 9, Kautokeino: Sámi University of Applied Sciences, 2016.

Hassler, Sven, Per Sjölander and Ann Jessica Ericsson, "Construction of a database on health and living conditions of the Swedish Sami population" in Befolkning och bosättning i norr: Etnicitet, identitet och gränser i historiens sken, Umeå University Centre for Sami Research.

Holth, Bjørn Are and Magnar Lillegård, Statistikk over Samiske språkbrukere i Norge. En kartlegging av eksisterende datakilder og vurdering av fremgangsmåter for statistikk [Statistics on Sámi language users in Norway. A mapping of existing data sources and assessment of statistical methods], notater 2017/34, Statistics Norway, 2017.

International Work Group for Indigenous Affairs (IWGIA), *The Indigenous World 2019*, 2019.

Jensen, Arne and Pål Strand, Personer med funksjonsnedsettelse Utredning av mulighetene for å etablere offisiell levekårsstatistikk basert på opplysninger fra ulike registre [Persons with disabilities Investigation of the possibility of establishing official living conditions statistics based on information from various registers], notater 2018/32, Statistics Norway, 2018.

Josefsen, Eva, Selvopplevd diskriminering blant samer i Norge [Self-perceived discrimination among Sami in Norway], Norut NIBR Finnmark, report no. 3, 2006.

Karlsen, Håkon Torfinn, Joachim Wettergreen and Arne Jensen, *Utredning av ny levekårs-statistikk for personer med funksjons-nedsettelsel* [Investigation of new living conditions statistics for persons with disabilities], notater 2019/42, Statistics Norway, 2019.

Melbøe, Line, Bjørn-Eirik Johansen, Gunn Elin Fedreheim, Ketil Lenert Hansen, Situasjonen til samer med funksjonsnedsettelser [The situation of Sámi with disabilities], Nordic Welfare Centre, 2016.

Melhus, Marita and Ann Ragnhild Broderstad, Folkehelseundersøkelsen i Troms og Finnmark: Tilleggsrapport om samisk og kvensk/norskfinsk befolkning [The Public Health Survey in Troms and Finnmark: Additional report on the Sámi and Kven/Norwegian Finn population], Centre for Sámi Health Research, 2020.

Midtbøen, Arnfinn H. and Hilde Liden, Diskriminering av Samer, Nasjonale Minoriteter og Inn-vandrere i Norge: En Kunnskapsgjennomgang [Discrimination against Sami, National Minorities and Inn-Migrants in Norway: A Knowledge Review], Institutt for samfunnsforskning, report no. 1, 2015. Nasjonalt kunnskapssenter om vold og traumatisk stress (NKVTS), Om du tør å spørre, tør folk å svare: Hjelpeapparatets og politiets erfaringer med vold i nære relasjoner i samiske samfunn [If you dare to ask, people dare to answer. Support services and police experiences with domestic violence in Sámi society], report no. 2, 2017.

New Zealand Ministry of Social Development, *The Social Report*, 2016.

New Zealand Treasury, An Indigenous Approach to the Living Standards Framework, 1 February 2019.

New Zealand Treasury, Living Standards Framework: Introducing the Dashboard, 4 December 2018.

Norwegian Ministry of Finance and Ministry of Foreign Affairs, *One year closer 2019:*Norway's progress towards the implementation of the 2030 Agenda for Sustainable Development, 3 July 2019.

OECD Regional Development Policy Committee, *Linking Indigenous Communities with Regional Development*, 2019.

OECD Regional Development Policy Committee, *Linking the Indigenous Sami* People with Regional Development in Sweden, 2019.

Oslo Police District, *Anmeldt hatkriminalitet* 2018 [Review of Hate Crime 2018], 2019.

Politidirektoratet, STRASAK-rapporten: Anmeldt kriminalitet og politiets straffesaksbehandling 2018 [STRASAK Report: Review of Crime and Criminal Procedure 2018], 2019.

Rainie, Stephanie Carroll, Desi Rodriguez-Lonebear and Andrew Martinez, Policy Brief: Indigenous Data Sovereignty in the United States, University of Arizona Native Nations Institute, 2017.

Sámi Parliament, Proposal for Ethical Guidelines for Sámi Health Research and Research on Sámi Human Biological Material, 2017.

Sámi Parliament, The Sámi Parliament's 2018 Report to CERD, 2018.

Severeide, Paul Inge, "Datagrunnlaget – begrensninger og muligheter" [The data basis – limitations and possibilities] in *Samiske tall forteller 1*, Kautokeino: Sámi University of Applied Sciences, 2008.

State Government of Victoria Department of Health and Human Services, *Dhelk Dja: Safe Our Way: Strong Culture, Strong Peoples, Strong Families*, 2018.

Statistics New Zealand, *Te Ao Mārama 2016*, July 2016.

Statistics New Zealand, *Te Kupenga 2013*, 6 May 2014.

Supply Nation and First Nations Capital, *Indigenous Business Growth*, 2018.

Sønstebø, Anders, *Samisk Statistikk 2018*, Statistics Norway, 2018.

Sørlie, Kjetil and Ann Ragnhild Broderstad, Flytting til byer fra distrikstområder med Sámisk bosetting [Relocation to cities from Sámi settlement areas], Norwegian Institute for Urban and Regional Research and Centre for Sámi Health Research, 2011.

Todal, Jon, "Datagrunnlag for samisk statistikk – Tilrådingar baserte på artiklar i Samiske tall forteller 1–8" [Data basis for Sámi statistics – Recommendations based on articles in Sámi Numbers Speak 1-8] in Samiske tall forteller 9, Kautokeino: Sámi University of Applied Sciences, 2016.

Vuolab, Siv Eli, Negotiating an Urban Indigenous Identity: expectations, prejudices and claims faced by urban Sámi in two contemporary Norwegian cities, master thesis, UiT The Arctic University of Norway, November 2016.

Walter, Maggie and Raymond Lovett, Gawaian Bodkin-Andrews and Vanessa Lee, Indigenous Data Sovereignty Briefing Paper 1, Miaim Nayri Wingara Data Sovereignty Group and the Australian Indigenous Governance Institute, 2018.

Websites

Australian Government National Indigenous Australians Agency, *Closing the Gap*, 2019, https://www.niaa.gov.au/indigenous-affairs/closing-gap.

Australian Bureau of Statistics (ABS), Aboriginal and Torres Strait Islander Statistics, Catalogue no. 1006.0, 30 September 2015, https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/1006.0~2015-16%20 to%202018-19~Main%20Features~Aboriginal%20and%20Torres%20Strait%20 Islander%20Statistics~24.

Australian Bureau of Statistics (ABS), Australian Aboriginal and Torres Strait Islander Health Survey 2018-19, Catalogue no. 4715.0, 11 December 2019, https://www.abs.gov.au/ausstats/abs@.nsf/mf/4715.0.

Australian Bureau of Statistics (ABS), Australian Standard Classification of Cultural and Ethnic Groups, Catalogue no. 1249.0, 18 December 2019, https://www.abs.gov.au/ausstats/abs@.nsf/mf/1249.0.

Australian Bureau of Statistics (ABS), Census: Aboriginal and Torres Strait Islander Population, Press Release, 27 June 2017, https://www.abs.gov.au/ausstats/abs@. nsf/mediareleasesbyReleaseDate/02D-50FAA9987D6B-7CA25814800087E03?OpenDocument.

Australian Bureau of Statistics (ABS), ndigenous Status Standard, Catalogue no. 1200.0.55.008, 8 October 2014, https://www.abs.gov.au/ausstats/abs@.nsf/mf/1200.0.55.008.

Australian Bureau of Statistics (ABS), National Aboriginal and Torres Strait Islander Social Survey 2014-15, Catalogue no. 4714.0, 28 April 2016, https://www.abs.gov.au/ausstats/abs@.nsf/mf/4714.0. Australian Bureau of Statistics (ABS), *Understanding the Census and Census Data:*Ancestry, Catalogue no. 2900.0, 8 November 2017, https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/2900.0main+features100612016.

Australian Bureau of Statistics (ABS), Understanding the Increase in Aboriginal and Torres Strait Islander Counts, Catalogue No. 2077.0, 17 October 2018, https://www.abs. gov.au/ausstats/abs@.nsf/mf/2077.0.

Australian Government Department of Social Services, *The Longitudinal Study of Indigenous Children*, 8 January 2019, https://www.dss.gov.au/about-the-department/publications-articles/research-publications/longitudinal-data-initiatives/foot-prints-in-time-the-longitudinal-study-of-indigenous-children-Isic.

Australian Government Productivity Commission, *Overcoming Indigenous Disadvantage*, www.pc.gov.au/research/ongoing/ overcoming-indigenous-disadvantage.

Australian Human Rights Commission, Close the Gap: Indigenous Health Campaign, 21 March 2019, https://www.humanrights.gov.au/our-work/aboriginal-and-tor-res-strait-islander-social-justice/projects/close-gap-indigenous-health.

BUFDIR, Samer, nasjonale minoriteter og personer med innvandrerbakgrunn: Statistikk og forskning om likestilling og levekår [Sámi, national minorities and persons with immigrant backgrounds: Statistics and research on equality and living conditions], 2020, https://bufdir.no/Statistikk_og_analyse/Etnisitet/.

BUFDIR, Statistics on disabilities in Norway, 3 October 2019, https://bufdir.no/en/ English_start_page/Disabilities_in_Norway/ Statistics_on_disabilities_in_Norway/.

European Union Agency for Fundamental Rights (FRA), *Subgroup on Equality Data*, February 2019, https://fra.europa.eu/en/project/2019/subgroup-equality-data.

Kommunal- og moderniseringsdepartementet (KMD), *Hvem er urfolk*? [Who are indigenous peoples?], 13 February 2020, https://www.regjeringen.no/no/tema/urfolk-og-minoriteter/.

Kyllingstad, Jon Røyne, Anatomisk institutt og det germanske herremenneske [Anatomical Institute and the Idea of a Germanic Race], UiO Museum of University History, 25 October 2012, https://www.muv.uio.no/uios-historie/fag/medisin/basalemed-fag/anatomi-herremenneske-jkyllingstad-300608.html.

Likestillings og diskrimineringsombudet (LDO), *Ombudets statistikk*, 2007–2015, https://www.ldo.no/en/diskriminert/nyheiter-og-fag/ldos-statistikk/.

Maiam nayri Wingara Indigenous Data Sovereignty Network, *Briefing Paper*, 2018, https://www.maiamnayriwingara.org/.

National Native Title Tribunal, Statistics, 24 April 2020, http://www.nntt.gov.au/ Pages/Statistics.aspx. New Zealand Ministry of Education, Education Counts: Quick Stats about Māori Education, 2019, https://www.educationcounts.govt.nz/publications/maori/maori-medium-and-english-medium/5851/ nga-haeata-o-aotearoa-2019.

New Zealand Ministry of Health, New Zealand Health Survey, 13 February 2020, https://www.health.govt.nz/nz-health-statistics/national-collections-and-surveys/surveys/new-zealand-health-survey.

New Zealand Ministry of Health, *Ngā tapuae* me ngā raraunga: Methods and data sources, 2 August 2018, https://www.health.govt.nz/our-work/populations/maori-health/tatau-ka-hukura-maori-health-statistics/nga-tapuae-me-nga-raraunga-methods-and-data-sources.

Norwegian Centre against Racism, Jurddabeassi, "Samisk myteknuser" [Sámi Mythbusters], http://samiskmyteknuser.no/#myte17.

Sámi Parliament, Seminar: Samisk synlighet i offentlig statistikk og sentrale registre – muligheter og utfordringer [Seminar: Sámi visibility in public statistics and central registers – opportunities and challenges], 20 November 2019, https://www.sametinget.no/Arrangementer/Seminar-Samisk-synlighet-i-offentlig-statistikk-og-sentrale-registre-muligheter-og-utfordringer.

Sámi Parliament, Virkeområdet for tilskudd til næringsutvikling – STN området [Scope for grants for business development – STN Area], 23 November 2018, https://www.sametinget.no/Tjenester/Naering/Virkeomraadet-for-tilskudd-til-naeringsutvikling-STN-omraadet.

Statistics New Zealand, 2013 Census Quick-Stats about culture and identity, 15 April 2014, http://archive.stats.govt.nz/Census/2013-census/profile-and-summaryreports/quickstats-culture-identity.aspx.

Statistics New Zealand, 2013 Census QuickStats about Māori, 3 December 2013, http://archive.stats.govt.nz/Census/2013-census/profile-and-summary-reports/quickstats-about-maori-english.aspx.

Statistics New Zealand, He Arotahi Tatauranga, 12 November 2014) http://archive.stats.govt.nz/browse_for_stats/people_and_communities/maori/how-to-think-maori-info-needs/he-arotahi-tatauranga.aspx.

Statistics New Zealand, Statistical standard for ethnicity, 1 September 2017, http://archive.stats.govt.nz/methods/classifications-and-standards/classification-related-stats-standards/ethnicity.aspx.

Statistics New Zealand, *Towards a Māori Statistics Framework*, 2002, http://archive.stats.govt.nz/browse_for_stats/people_and_communities/maori/towards-a-maoristats-framework.aspx.

Statistics Norway, *Personopplysninger i* statistikken [Personal data in the statistics], 2019, https://www.ssb.no/omssb/personvern/personvern-og-datasikkerhet.

Te Mana Raraunga Maori Data Sovereignty Network, *Principles of Maori Data Sovereignty*, 2018, https://www.temanararaunga.maori.nz/.

The Indigenous Navigator, *Indicators for Monitoring the UNDRIP*, 2019, http://indigenousnavigator.org/images/Documents/Tools/Navigator_UNDRIPIndicators.pdf.

United Nations Economic Commission for Latin America and the Caribbean (ECLAC), ECLAC Supports Statistical Visibility and Participation of Indigenous Peoples in the 2030 Agenda, Press Release, 15 July 2016, https://www.cepal.org/en/comunicados/cepal-apoya-visibilidad-estadistica-participacion-pueblos-indigenas-la-agenda-2030.

United Nations Permanent Forum on Indigenous Issues (UNPFII), ECLAC Response to UNPFII Questionnaire to the UN system agencies, funds and programmes and intergovernmental organizations, December 2018, https://www.un.org/development/desa/indigenouspeoples/wp-content/uploads/sites/19/2019/01/SE180877-Report-to-UNPFII_ECLAC_Dec2018-def-latest-version.pdf.

United Nations Permanent Forum on Indigenous Issues (UNPFII), *Recommendations on Data and Indicators*, 2017, https://www.un.org/development/desa/indigenouspeoples/mandated-areas1/data-and-indicators/recs-data.html.

Media Articles

Abraham, Karin, "FN: Norge må innføre bruk av etnisitet i offisiell statistikk" [UN: Norway must introduce "ethnicity" into official statistics], *Minerva*, 11 January 2019.

Baker, Gabrielle, "Stats NZ won't release iwi data, and that's a problem", *The Spinoff*, 1 May 2019.

Biddle, Nicholas, "Four lessons from 11 years of Closing the Gap reports", *The Conversation*, 14 February 2019.

Hansen, Tom S. T. and Mette Ballovara, "Nå vil Norge registrere alle som snakker Sámisk" [Now Norway will register everyone who speaks Sámi], *NRK Sápmi*, 22 October 2019.

Heitmann, Rita, "Avvis forsøk på etnisk registrering" [Reject attempts at ethnic registration] *Sagat*, 20 December 2018.

Heitmann, Rita, "Ulovlig, skremmende og historieløst" [Illegal, scary and historyless] Sagat, 18 December 2018.

Holst, Inga Ragnhild, "Legg samene i rør", Ávvir, 31 January 2017.

Pettersen, Torunn, "40 000 i 40 år – må det være sånn?" [40,000 in 40 years – must that be it?] *Nordlys*, 10 October 2011.

Rustad, Hans, "FN-komite vil at Norge registrerer etnisitet" [UN Committee wants Norway to register ethnicity], *Document.no*, 12 January 2019.

Skogvang, Susann Funderud, "Kven er eigentleg same?" [Who is actually Sámi?] *Morgenbladet*, 11 December 2017.

Walter, Maggie, Emily Banks, Raymond Lovett and Katherine Thurber, "Refreshed Close the Gap targets will focus on progress and achievement", *NITV News*, 14 February 2019.

Other Sources

Bongo, Berit Andersdatter, "Samer snakker ikke om helse og sykdom – Samisk forståelseshorisont og kommunikasjon om helse og sykdom. En kvalitativ undersøkelse i Samisk kultur" [Sámi do not talk about health and illness – Sámi insights and communication about health and illness. A qualitative study in Sámi culture], PhD thesis, UiT The Arctic University of Norway, 2012.

Harmsworth, Garth R. and Alec Mackay, Land resource assessment and evaluation on Māori land, Whenua Sustainable Futures with Māori Land Conference, Rotorua, New Zealand, 21–23 July 2010.

International Statistical Institute, *Declaration* on *Professional Ethics*, 2010.

Kommunal- og moderniseringsdepartementet (KMD), *Prosedyrer for konsultasjoner mellom statlige myndigheter og Sametinget*, 11 May 2005. National Institute of Demographic and Economic Analysis (NIDEA), *Unpublished* data from the Ethnicity Counts? Project, University of Waikato, 2015.

Magga, Ole Henrik, Behovet for samisk statistikk i samisk forskning og høgere utdanning [The need for Sámi statistics in Sámi research and higher education], unpublished lecture, 1999, referenced in Torunn Pettersen, "Etnisk identitet i offisiell satistikk – noen variasjoner og utfordringer generelt og i en samisk kontekst spesielt" [Ethnic identity in official satistics – some variations and challenges in general and in a Sámi context in particular] Diedut, no. 3, 2006.

Solberg, Pia, Indigenous internal selfdetermination in Australia and Norway, PhD thesis, University of New South Wales, October 2016.

Presentation by Ann Ragnhild Broderstad, Seminar – Samisk synlighet i offentlig statistikk og sentrale registre – muligheter og utfordringer [Seminar on Sámi visibility in public statistics and central registers], Sámi Parliament, 20 November 2019.

Presentation by Bjørn Erik Thon, Seminar – Samisk synlighet i offentlig statistikk og sentrale registre – muligheter og utfordringer [Seminar on Sámi visibility in public statistics and central registers], 20 November 2019.

Hansen, Susan, "Are there differences in health care utilization in areas with both Sami and non-Sami populations in Norway? The SAMINOR 1 study", master thesis, UiT The Arctic University of Norway, 2015.

Pettersen, Torunn, "Sámi ethnicity as a variable: Premises and implications for population-based studies on health and living conditions in Norway", PhD thesis, UiT The Arctic University of Norway, 2014.

Institutt for samfunnsforskning, Sametingsvalgundersøkelsen 2017 [The Sámi Parliamentary Election Study 2017], project no. 10187, 2020.

Institutt for samfunnsforskning, Samepolitikkens grenser: Innenfor- og utenforposisjoner i samisk samfunnsbygging [The Boundaries of Sámi Politics: Inside and outside positions in Sámi community building], project no. 10159, 2019.

Statistics Norway, Folketellingen 1. desember 1950 [The Census 1 December 1950], booklet 8.

Federal Law of 5 June 1996 on National-Cultural Autonomy (Russia).

Federal Law of 22 April 1999 on the Rights of Indigenous Numerically Small Peoples of the Russian Federation (Russia).

© Norwegian National Human Rights Institution 2020

Paper: 130 g Scandia 2000 Layout and print: 07 Media

Page 104:

Page 122:

Front page: Photo credit: Manta photo/iStock photo.
Page 6: Photo credit: Lightscape/Unsplash.
Page 10: Photo credit: Maylat/iStock photo.
Page 18: Sokki Adventure in Kautokeino.

Photo credit: NIM.

Page 21: Photo credit: Svein H. Lian/EN-TIL-EN Media.
Page 22: Photo credit: Cylon photo/iStock photo.
The Yellow Bird Apache Dancers perform at the opening of the fourth session of the Expert Mechanism on the Rights of

Indigenous Peoples.

Photo credit: UN photo/Marc Ferré.

Page 48: Photo credit: Siv Eli Vuolab/Sámi Parliament.
Page 77: Photo credit: Denis Caviglia/Sámi Parliament.
Page 78: Photo credit: UN Photo/Rick Bajornas.
Page 90: Photo credit: Marianne Hoy/iStock photo.

Participants in the General Assembly Hall during the opening ceremony of the 15th Session of the United Nations Permanent

Forum on Indigenous Issues.

Photo credit: UN Photo/Rick Bajornas.
Photo credit: Matthias Tillen/Unsplash.