

Collective Position Data for Economic, Social, and Cultural Rights

Illustration: Aurélie Beatley



"What gets counted, counts." – Joni Seager

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GLOSSARY OF TERMS

- **BIG DATA**: A collection of digital data that is extremely large and grows over time. Usually gathered by private companies through their business operations (for example, social media or telephone companies) and then analyzed through software and automated methods to make predictions. Big data is very profitable as companies sell it to other businesses and often also to public bodies to help inform their choices and operations.
- **DATA**: Data is information that can be in the form of words (written or oral), numbers, drawings and images, photographs, sounds, **videos**, digital, etc. Data that comes in numbers is called **quantitative**, while data that comes in words and visuals is called **qualitative** (see p. 35 for more details on the purpose of these two types of data in the context of human rights). When data is analyzed and organized in ways that prove or support a specific conclusion it is called **evidence**.
- **DATA PROCESS OR PROCESSING**: Collecting, recording, storing, using, analyzing, combining, disclosing or deleting data.
- **DISAGGREGATED DATA**: Data that has been broken down by subcategories, such as: characteristic (gender, type of disability, age), identity (racial, ethnic, or linguistic minorities) or location (region, rurality) or other important status (income, wealth). Disaggregated data is essential to identify inequalities and patterns of discrimination.
- **ECONOMIC, SOCIAL AND CULTURAL RIGHTS (ESCR)**: ESCR are human rights concerning the basic social and economic conditions needed to live a life of dignity and freedom, relating to work and workers' rights, social security, health, education, food, water, housing, healthy environment, and culture. In 1966, ESCR were articulated as legal rights in the International Covenant on Economic, Social and Cultural Rights, as well as through other key human rights treaties and regional mechanisms.
- **HUMAN RIGHTS DATA**: Data related to human rights obligations and duties of states under international and domestic human rights law, whether qualitative or quantitative, and whether produced by states, civil society, academic sector, etc. It includes data about the enjoyment of specific rights by the general population and/or specific groups, and the progress in meeting human rights obligations, for instance development of legislation, policies and practices that advance or hinder the enjoyment of human rights,

and includes information about the process for making decisions that have an impact on human rights.

- **ESCR DATA:** Human rights data that relates to economic, social and cultural rights. In addition to data on the enjoyment of specific ESC rights, and on the progress in meeting ESCR obligations, ESCR data also includes budgetary allocation and expenditure (including through PPP and private contractors).
- **INFORMATION:** Information is data that has been analyzed, interpreted, organised, structured, or otherwise adapted so that it can be understood and used in a particular context.
- **INFORMED CONSENT:** Providing consent means giving permission to someone else to take an action that will or could affect their lives or wellbeing. To be meaningful, consent needs to have four main components: disclosure, voluntariness, comprehension and capacity. It should be explicit and require an active process for the individual, rather than a passive opt-out process. Consent is one of the grounds that needs to be met before processing personal information. See p. 80 for more information.
- **OFFICIAL DATA:** Data produced by public authorities, government institutions, national and regional statistical offices, intergovernmental bodies etc., often as part of formal monitoring and reporting processes.
- **PERSONAL DATA:** Any kind of information (a single piece of information or a set of information) that can personally identify an individual or single them out as an individual.
- **PRODUCTION AND USE OF DATA:** We use this phrasing throughout the collective position to refer to all actions and modifications of data, including but not limited to: design, collection, recording, production, processing, use, analysis, combining, storage, presentation, disclosure, and dissemination of data



INTRODUCTION

Data is necessary for the realization of human rights. Without it we cannot understand the prevailing human rights situation, we cannot make informed policy decisions, and we cannot assess the effectiveness of those policy decisions.

But there is a human rights data gap. As decision-makers and power holders increasingly rely on huge amounts of data to make policies and decisions about people's economic, social, and cultural rights, we cannot assume that this data is neutral or objective. Nor can we assume that the right kinds of data are collected. States are failing to produce and use the right kinds of data necessary for the advancement of human rights—to the extent that states' data practices sometimes pose a threat to human rights and reinforce existing inequalities.

Data processes such as the Sustainable Development Goals at the global level, censuses at the national level or environmental impact assessments at the local level tend to exclude affected communities and marginalized groups, which means they are unrepresented in data and have little say over what data is collected and how it is used. This is problematic because it renders entire subpopulations invisible to policy-makers and powerful actors, often resulting in further marginalization. There are countless examples. Women and girls are often absent in data—the gender data gap—which means that decisions are taken without taking into consideration the needs of women and girls, which in turn reinforces gender inequality. During the Covid-19 pandemic, many European countries failed to collect health data disaggregated by race, which meant they were unable to adequately respond to the needs of different groups. Even when relevant data is collected, it is often not made available to communities in ways that they can use it to participate in relevant decision-making processes, such as local development plans. And when communities decide to gather their own data to influence decisions that affect them directly, this is often disregarded as not objective and credible.

These examples are choices. Decision-makers choose to exclude groups and the things that are important to marginalized groups (whether intentionally or not) because of who has power and who does not. Our starting point for this collective position is, therefore, that **data is inherently political**. The first step in ensuring that data serves to enhance the enjoyment of human rights



is to recognize this fact. Then, in order to remedy the problems with the current system, we must demystify and democratize data. Often, the role that data plays in decision-making is to **replace difficult political conversations with choices masked as purely technical** in nature, for instance, when powerful actors say it is too onerous to establish truly participatory decision-making processes or that it is too difficult to collect disaggregated data or even that lived experience is not valid information upon which decisions should be made. This allows those in power to sidestep confronting more systemic problems, such as inequality, racism, patriarchy, in which they may be implicated.

This is unfortunately not a new problem. **Data has always been used by those in power to justify decisions that cement power over others.** Well before the current era of global sustainable development, certain kinds of data—those considered “scientifically objective”—have been used to mask and justify more political motivations, such as the domination and silencing of people. Colonial powers claimed to collect “scientific” information about colonized people for the purposes of their ‘betterment.’ Today’s sustainable development regime continues to adopt a position on data that is paternalistic and dominated by powerful actors, who continue to exercise power through the control of information. By **diminishing the knowledge and experiences of affected and marginalized communities** and designating it as inferior information, it effectively further sidelines the very communities it purports to serve.

In addition, the digitalization of all aspects of our lives has brought enormous power to **technology companies** and further reduced the power and control people exert on data and information, with serious implications on public decision-making processes. Vast amounts of data about us are collected in our private and public life every time we use telecommunication devices, digital or biometric IDs, internet services, payment platforms, etc. States—and corporate elites—increasingly use this data, which is gathered for purposes very different from policy-making, to perform a number of public functions, from service delivery to resource allocation and law enforcement. However, commercially-produced data provides a partial picture of society, based on an understanding of **people as consumers rather than as rights-holders**, and should not be used as the only basis for public decision-making. And as states outsource important public functions, technology companies are given the ability to shape people’s access to services, markets and opportunities, without adequate oversight and accountability from the public. The result is a significant **imbalance in power over public policies and practices**, and therefore over people’s lives, which warrants urgent attention from human rights and social justice advocates.

THE PURPOSE OF THE COLLECTIVE POSITION ON DATA AND ESCR

This historical legacy and what we know about how data operates today means **we must scrutinize and challenge data practices** because, though they are often framed as objective, that does not make them just. And while the principle of “**what gets counted, counts**”¹ should be our starting point, we also need to ask questions about who decides what gets counted, how it gets counted, and how data is used. Only in this way can we disrupt the very power dynamics that result in the exclusion and marginalization of rights-holders.

In line with ESCR-Net’s core principles,² and the ESCR-Net Common Charter for collective struggle,³ this collective position seeks to be a concrete point of reference for ESCR-Net members and broader civil society to **advocate for data that** centers rights-holders and affected communities, and in so doing, **enables more inclusive, democratic and effective decision-making.**

The position analyzes key gaps in how states produce and use data to make decisions that affect ESCR and identifies a **set of five principles and recommendations for states** to gather, analyze and use data in ways that advance ESCR and reduce inequalities. These principles are based on states’ well-established legal obligations regarding monitoring and the production and use of data to implement and advance the enjoyment of economic, social, and cultural rights.⁴

Moreover, as we witness the relentless increase in mass-scale gathering and use of personal data by the private sector—in what scholars have labeled as ‘surveillance capitalism’⁵—the collective position **re-affirms the role of states in producing data** that is **accurate, representative and relevant** for policy making, as well as to regulate the private sector to protect human rights.



FIVE PRINCIPLES OF A HUMAN-RIGHTS BASED APPROACH TO DATA

WHAT ARE THE FIVE PRINCIPLES?

EQUALITY AND NON-DISCRIMINATION: Data must be produced and used to eliminate discrimination and bring about substantive equality, and data processes and systems must themselves be free from discrimination and as inclusive as possible. To this end data must be **representative**, which states can achieve by **disaggregating** data and ensuring that rights-holders are able to **self-identify** when being counted in data.

HIGH QUALITY DATA: States have obligations to gather high quality human rights data. To be high-quality, data needs to have certain features, such as relevance, timeliness, accuracy, completeness, and consistency as well as addressing all aspects of economic, social and cultural rights, including **people's experience** in enjoying these rights. This requires states to use **human rights-relevant indicators**, **diversify the sources** and types of data, and **increase the use of qualitative data that reflects lived perspectives**.

PARTICIPATION: Data should meaningfully enable the participation of everyone, particularly marginalized groups, in shaping decisions that affect ESCR. To this end, **communities should be able to set the agenda** over what types of official data should be gathered and made available, and how their perspectives should be best reflected. In addition, communities should be placed in the position to **carry out their own monitoring** and data gathering initiatives free from threats, harassment, or interference from the state, corporate actors or other powerful entities. It is crucial that public bodies recognize data gathered by **communities as legitimate and valid** and that the results are taken into account when making public decisions.

TRANSPARENCY AND ACCESSIBILITY OF INFORMATION: Rights-holders have a right to access information that is of public interest, including information and data on the status of economic, social, and cultural rights and the steps states are taking to comply with their human rights obligations. This information and data must be **publicly available and accessible**, that is, all



rights-holders must be able to understand and use it without discrimination. Those seeking to access public information must be able to do so safely and without facing threats or harm.

PRIVACY: Human rights data must be produced and used in such ways as to protect the rights to **privacy and security of a person**. The right to privacy must be guaranteed across states' functions that entail the collection and processing of data, whether for the purposes of designing policies and decision-making around ESCR, or for the delivery of public services that underpin ESCR.

It is important to note that the principles are not mutually exclusive and relate to each other in important ways, for example, participation, which is dependent on transparency and the right to information, is required to ensure that data is of high quality and to ensure that data can be used to advance equality and non-discrimination. Where important linkages exist, we point them out in each principle.

Each principle outlined in this document follows the same format. First, we provide a definition with important contextual information; second, we provide the legal basis for each principle outlining what human rights law says about the principle and states' legal obligations; third, where relevant we identify sub-principles, that is, elements of the principle that are rooted in human rights law. Lastly, we provide recommendations for states to implement each principle.

TO WHAT AND TO WHOM THE FIVE PRINCIPLES APPLY?

The principles outlined in this collective position have been elaborated on the basis of obligations around economic, social and cultural rights, but are relevant to civil, environmental and political rights as well.

They apply to all official data and monitoring processes and practices, whether formal or informal, that affect, directly or indirectly, economic, social, and cultural rights. This includes data and monitoring processes associated with measures, whether laws, policies, programs, etc. to implement economic, social, and cultural rights, as well as measures that relate to economic, social, and cultural rights, for example, fiscal, social, and development policies.

The principles apply to official data on economic, social, and cultural rights, that is, state produced data, including entities within states tasked with data production and use, such as:

national statistical offices; ministries and departments responsible for economic, social, and cultural rights, such as ministries of education, health, work, social security, development, justice, and finance; national human rights institutions; parliamentary bodies; and local authorities.

The principles apply to all stages, where relevant, of the data life cycle, including the: design, collection, recording, production, processing, use, analysis, combining, storage, presentation, disclosure, and dissemination of data.

They also apply to non-state actors that take on state-like responsibilities, for instance, in the provision of public services and any privately-produced data that may hinder the enjoyment of economic, social, and cultural rights.

The principles apply to the data and monitoring processes of international organizations and agencies, such as: UN treaty bodies, UNESCO, UNICEF, the World Bank, the OECD, etc., which are often composed of states and publicly funded, many of which collect primary data on economic, social, and cultural rights, compile secondary data, and influence what kinds of data states collect.

The principles, as is the case with human rights law, apply in all contexts, including in emergencies, such as during and after armed conflict, in high-risk areas, as well as during and in the wake of natural disasters and pandemics.

HOW DID WE DEVELOPED THE COLLECTIVE POSITION?

In January 2019, 19 members⁶ of the ESCR-Net Monitoring Working Group met in Mexico to discuss the role of data in advancing economic, social, and cultural rights as well as gaps in existing data practices. Our common experience was that of a lack of availability of official data on economic, social, and cultural rights and where data did exist it was often not of the requisite quality. As a working group comprised mainly of about 40 civil society organizations, particularly grassroots and community-based organizations that collect data, we also discussed how our data, and data produced by communities more generally, is quite often dismissed as inferior to official data, particularly quantitative data, but actually has a major role to play in advancing economic, social, and cultural rights because it reflects communities' concerns and lived experiences. As a result, we all agreed on the need to challenge dominant narratives

around what kinds of data counts as legitimate and to propose a powerful vision for a human rights-based approach to data.

As a first step, we started to collectively identify an initial set of principles for how data on economic, social, and cultural rights should be produced and used, in line with human rights law. We combined this with our experiences as human rights researchers and advocates working with and/or coming from marginalized communities whose economic, social, and cultural rights are neglected by states. We also decided to strengthen this initial analysis to articulate a collective position on a human rights-based approach for economic, social, and cultural rights.⁷ Following the meeting in Mexico, we developed a document summarizing the set of principles identified, and sought further inputs and analysis from other members of ESCR-Net, particularly social movements,⁸ in line with ESCR-Net's core principles of social movement centrality and regional representation. On that basis, a group of six members⁹ embarked on a yearlong research and drafting process which led to an initial draft position on data and economic, social, and cultural rights launched in May 2021. The draft was then circulated among members of the Monitoring Working Group and key external stakeholders¹⁰ for further feedback and inputs, leading to a second and final review process which concluded in March 2022.

EQUALITY & NON-DISCRIMINATION

Human rights data must be produced and used in ways that are non-discriminatory and promote substantive equality.

States have well-established legal obligations to eliminate discrimination and to ensure equality, including through monitoring and the production of data.¹¹ This means that one of the objectives of human rights monitoring and data processes must be the identification and measurement of discrimination and inequalities in the enjoyment of rights. This is to ensure that decision-making regarding economic, social, and cultural rights is based on high quality data.



Furthermore, and equally important, monitoring and data processes must themselves be free from discrimination and as inclusive and transparent as possible. If the mechanisms and processes that are supposed to contribute to the elimination of discrimination and advancement of equality are themselves problematic from a human rights perspective, they are not fit for purpose and risk exacerbating the problems they seek to address.

There are several ways in which monitoring and data processes must comply with the rights to equality and non-discrimination. At a minimum, rights-holders cannot be excluded from or disadvantaged in data and monitoring processes, which includes being able to participate regardless of their membership of a group, their characteristics, or any other grounds prohibited by international, regional, or national human rights law. It also means that the research methods used are not discriminatory and that the data produced does not exclude anyone, particularly marginalized groups. To this end data must be **representative**, which can be achieved by **disaggregating data** and ensuring that rights-holders are able to **self-identify** when being counted in data (all these also contribute to data accuracy and relevance). Lastly, data must not be used in ways that perpetuate or aggravate existing inequalities or discrimination faced by marginalized groups, particularly those experiencing stigma. This applies to traditional decision-making as well as decision-making performed or supported by technology, such as algorithms.

The structure of this chapter is as follows: Firstly, the chapter will briefly introduce the rights to non-discrimination and equality and explain key data-related issues that have equality implications. Secondly, an overview of states' obligations under international law will follow. Lastly, the chapter will address specific obligations that states should meet to ensure that data is representative and in line with the rights to non-discrimination and equality.

RIGHT TO NON-DISCRIMINATION

The right to non-discrimination is a well-established right under international human rights law and is guaranteed at the beginning of most human rights instruments. Discrimination consists in treating someone differently without justification due to grounds¹² such as disability,¹³ race, color, sex, language, religion, descent, or other status.¹⁴ 'Other status' is generally included in human rights instruments in recognition of the fact that the list of grounds is non-exhaustive, because who is and is not marginalized can change according to time and place. Basically, any

group that has suffered historical discrimination, and is disadvantaged or marginalized as a result, is protected from discrimination.

The intersection of multiple grounds will also determine the extent to which people are able to enjoy their rights and experience discrimination. The concept of intersectionality helps identify and understand compounded forms of discrimination that people may experience due to the intersection of multiple factors. As CEDAW points out:

“ The discrimination of women based on sex and gender is inextricably linked with other factors that affect women, such as race, ethnicity, religion or belief, health, status, age, class, caste and sexual orientation and gender identity. Discrimination on the basis of sex or gender may affect women belonging to such groups to a different degree or in different ways to men. ”

DIRECT AND INDIRECT DISCRIMINATION VS. FORMAL (OR DE JURE) AND SUBSTANTIVE (OR DE FACTO) DISCRIMINATION:

There are various forms of discrimination:

- A) **DIRECT AND INDIRECT DISCRIMINATION:** Direct discrimination is when a person is treated less favorably than someone else in comparable circumstances.¹⁵ Indirect discrimination is when a practice, rule, policy, or requirement is outwardly neutral but has an adverse impact upon a particular group.¹⁶
- B) **FORMAL (OR DE JURE) AND SUBSTANTIVE (OR DE FACTO) DISCRIMINATION:** Formal discrimination exists in states' legal and policy frameworks.¹⁷ Substantive discrimination is experienced in practice, usually by groups who have suffered from historical or persistent prejudice.¹⁸

Discrimination can also be **systemic**. CESCR notes that, 'discrimination against some groups is pervasive and persistent and deeply entrenched in social behavior and organization, often involving unchallenged or indirect discrimination.'¹⁹ Systemic discrimination is a result of, 'legal rules, policies, practices or predominant cultural attitudes in either the public or private sector which create relative disadvantages for some groups, and privileges for other groups.'²⁰

RIGHT TO EQUALITY

The right to equality is broader than the right to non-discrimination and is grounded in the principle that all humans, 'are born free and equal in dignity and rights.'²¹

An important component of the right to equality is that states must not only eliminate discrimination but also take positive measures to bring about **substantive equality**,²² that is, everyone enjoys economic, social, and cultural rights to the same extent.

I. DATA EXCLUSION AS A FORM OF DISCRIMINATION

Data exclusion occurs as a result of data processes failing to take seriously the obligations to eliminate discrimination and advance equality. The exclusion of groups from data is nearly always a political choice. It is impossible for data to capture everything about people and the things that matter to them. This means that certain decisions need to be made about *who* and *what* is represented in data. And usually who makes these decisions will always influence what data is collected.

The consequence of excluding groups from data, whether purposefully or not, means that their situation, interests, needs, and other salient information is not captured. This is to say that any decisions based on that data will not be able to address the specific human rights issues faced by these groups. Exclusion in data, therefore, may contribute to exclusion in reality. As the feminist geographer, Joni Seager, states: 'what gets counted counts.'²³ For already marginalized groups, who tend to experience inequality across multiple axes, being left out of data can reinforce or exacerbate existing inequalities, or even create new forms of inequalities. States cannot ignore their international human rights obligations when making decisions about data collection. In particular, the legal obligation to eradicate all forms of discrimination requires states to gather data about protected groups and those most affected by inequalities to understand their situation and needs (see disaggregated data below). At the same time, states should ensure that the collection of data specific to protected groups does not lead to further discrimination and deepen inequalities. Indeed, too often data has been used to identify, expose and target people facing stigma and discrimination, or to curb dissent and prosecute those perceived as opponents (see section on security and privacy below). In deciding what kinds of data to gather, states should strike a balance between the duties to protect from discrimination and to take steps to eradicate discrimination and advance substantive equality.

TYPES OF DATA EXCLUSION

Exclusion from data can be intentional. The choice to not count specific marginalized groups, like LGBTQIA, indigenous people or some national minorities in censuses, for example, and thereby deny their identity and existence in official fora, is an intentional exclusion. In these instances, it is almost certainly a human rights violation. For example, in a recent case in Mexico, Techo Mexico brought an amparo against the national statistics office because it refused to collect census data on those living in informal settlements. In its judgment, the Supreme Court of Mexico found that this was a violation of the right to housing and ordered the national statistics office to generate data to the highest level of disaggregation (see disaggregated data below) so that the state has the necessary tools to fully comply with its commitment to protect, respect, and fulfil human rights.

Exclusion from data can take place when data is collected through digital means, for purposes other than public planning. States increasingly rely on digital datasets provided or sold by the private sector (for example internet and phone providers, social media, etc.) to inform their choices around access to public services and resource allocation. However, these datasets often do not provide an accurate picture of a population group. First of all, they exclude people who don't have digital presence—for example, because they don't have access to computers or smartphones or the skills to use them, or due to low literacy or existing social norms and barriers (for example, fewer women use smartphones than men²⁴). Secondly, as this data is gathered for commercial purposes and may not be suitable for policy-making²⁵. In addition, the sale or use of commercial data by third parties (including public bodies) raises a number of privacy and security concerns, including around informed consent (see section on privacy).

Exclusion from data can happen due to mis- or ill-defined measures. Sometimes the problem is not who is counted but the fact that key human rights information about that group is omitted from data. One example is the exclusion of all forms of unpaid work—performed mostly by women and girls—from traditional types of economic indicators, such as GDP. Unpaid work is vital for the functioning of societies and the production of wealth, but it is undervalued and unrecognized due to harmful gender stereotypes about the role of women and girls in families,

communities, and societies. This lack of data both obscures the issue and limits any information on the scale or nature of the issue, making it difficult to address the discrimination and inequality women and girls face.

Exclusion from data can be due to technical difficulties. In some situations, it is technically difficult to collect relevant data. This may be due to the context. For example, during an armed conflict, when a territory is occupied, or in times of fragility, it may be difficult for the state to collect data on economic and social rights because services at the core of rights-delivery may be disrupted, or because states do not have effective control of the territory, or it may be too dangerous to enter the conflict zone. Data may also be hard to collect given a group's unique characteristics. For example, migrants (including: refugees, internally displaced persons, and nomadic peoples) are hard to count because they typically move within a country and across borders. Some people, for instance, sex workers and undocumented migrants may be difficult to identify because of the precariousness of their situations.

Exclusion from data can be due to lack of resources and/or capacity. Data collection can be costly, requiring technical expertise and administrative capacity, which means that states often prioritize which data they collect.

Exclusion from data can occur because people are not able to self-identify. Not being able to choose how someone wants to be represented in data, based on identities and characteristics they consent to disclosing, leads to inaccurate data. (See section on self-identification below.)

II. DISCRIMINATION THROUGH ALGORITHMIC DECISION-MAKING

States are increasingly utilizing algorithmic or automated decision-making (ADM) to inform decision making around public services that underpin economic, social and cultural rights, and determine access to education, health, employment, social security etc. These systems are designed to scan and analyze large amounts of data, usually personal data, to make predictions, correlations, and 'derive information deemed useful to make decisions.'²⁶ The increasing use of these systems is possible thanks to the mass scale collection of data by private and public sectors.

Although ADM is often touted as neutral or a technocratic solution to improve the quality of decision-making and service delivery, several studies have shown that in reality they profile, monitor, predict, and punish rights-holders,²⁷ resulting in decisions that increase inequality in the enjoyment of economic, social, and cultural rights, or are outright discriminatory.²⁸ As the UN Special Rapporteur on contemporary forms of racism, racial discrimination, xenophobia and related intolerance, Tendayi Achiume, found:

“ as ‘classification technologies that differentiate, rank, and categorize’, artificial intelligence systems are at their core ‘systems of discrimination.’ [...] algorithms reproduce bias embedded in large-scale data sets capable of mimicking and reproducing implicit biases of humans²⁹ ”

ADM-based systems result in discrimination even when they are not designed with an explicit intent to do so. There are several ways in which an algorithm discriminates. First of all, the gaps and imbalances existing in data that the algorithm processes to reach its conclusions: as explained above, choice around data are not neutral and lead to a skewed and unrepresented picture of reality depending on who has gathered it and how. This data is then used by algorithms to identify patterns and make predictions of behaviors. Unrepresentative data does not allow generalizations about all groups of people and a pattern of behavior that holds true for some people may not be applicable to others. Secondly, the way algorithms are ‘trained’ to draw a certain conclusion may also lead to discrimination, especially

“ when the predicted outcome for a particular group is systematically different from other groups and therefore one group is consistently treated differently to others. For example, in cases where a member of an ethnic minority has a lower chance of being invited to a job interview because the algorithm was ‘trained’, based on data where their particular group performs worse, i.e. has worse outcomes than other groups. As a result, they may not be invited to a job interview. This can occur when the data used to train the algorithm include information regarding protected characteristics (e.g. gender, ethnicity, religion).³⁰ ”

This is particularly problematic as often misplaced categories are used as ‘proxies’ for race, ethnicity, gender, and other statuses, deeply reinforcing existing inequalities:

“ so-called ‘proxy information’ is sometimes included in the data. This may include the height of a person, which correlates with gender, or a postcode, which can indirectly indicate ethnic origin in cases of segregated areas in cities, or more directly, a person’s country of birth. Unequal outcomes and differential treatment, especially relating to proxy information, need to be assessed to see if they amount to discrimination³¹ ”

As the UNSR explains, these biases are strongly linked with the role exerted by North-based technology companies that design and sell algorithm-based systems across the world, and often in ways that raise serious privacy concerns (see section on privacy below):

“ AI systems are developed almost exclusively in a handful of technology companies and a small set of elite university laboratories, spaces that in the West tend to be extremely white, affluent, technically oriented, and male. These are also spaces that have a history of problems of discrimination, exclusion, and sexual harassment[...] There are also concerns about the unregulated, and in some cases exploitative, terms on which data are extracted from individuals and nations in the global South, by profit-seeking corporate actors in the global North who cannot be held accountable³² ”

Effective private sector regulation is therefore crucial to ensure ADMs do not reinforce inequalities, particularly in light of the broader context of data commercialization and growing use of digital technologies in the delivery of public services.

These factors are compounded by the lack of transparency and accountability around the use of ADM. It is extremely difficult to scrutinize the algorithms and data on which a system is operating, both due to technical complexity as well as commercial protection laws, which creates a ‘black box’ effect³³ where no one is able to understand exactly how it is functioning.

This inherent opacity and lack of transparency frustrates any efforts to make the system more accountable and ultimately fairer.

This is not to say that artificial intelligence and data-driven automated systems cannot be used to advance the equal enjoyment of economic, social, cultural rights. However, their role to inform public decision making around access to services should be closely scrutinized, especially when used to cut costs within the context of a reduction of public investments and increased privatization of services.

THE DISCRIMINATORY EFFECT OF ALGORITHMIC DECISION-MAKING IN AUSTRIA

In 2020, the Austrian employment agency, AMS, started using an algorithm to determine which jobseekers would receive AMS resources by sorting jobseekers into one of three categories. The first category would consist of those who are likely to find a job and would be offered minimal support; the second category, those who have a middling chance of getting a job—these people would receive most support and resources; and the final category, those unlikely to find work—these people would be offered access to different services rather than the expensive resources offered by the AMS.

However, when parts of the algorithm were made public, it became clear that the algorithm predicted who would be likely to find work based on factors such as gender, disability, citizenship, motherhood, and age, likely because the source data showed that being a woman, disabled, a foreigner, a mother, and/or old are associated with lower chances in the labor market. The algorithm then negatively weighted anyone with these characteristics, for example, a woman was negatively marked over a man with comparable experience and qualifications—a clear case of discrimination.

Paola Lopez, in a paper that examines the algorithm from a mathematical perspective,³⁴ notes that using past data that reflects inequalities and discrimination in society is problematic especially when the data is not interrogated or the algorithm is blind to these facts. When decisions are made, in this case, about the distribution of resources to unemployed people, algorithms

can not only reinforce existing inequalities but actually discriminate against people who are protected under human rights law.

In August 2020, the Austrian data protection authority declared the algorithm illegal and ordered its suspension.³⁵

LEGAL BASIS FOR THE PRINCIPLE OF EQUALITY AND NON-DISCRIMINATION

The rights to non-discrimination and equality are guaranteed by the International Bill of Rights, which consists of the Universal Declaration of Human Rights (UDHR),³⁶ the International Covenant on Economic, Social, and Cultural Rights (ICESCR),³⁷ and the International Covenant on Civil and Political Rights (ICCPR).³⁸

ICESCR's non-discrimination clause is the most relevant because it guarantees non-discrimination in relation to all economic, social, and cultural rights. It does not, however, provide a definition of what constitutes discrimination. However, the Committee on Economic, Social and Cultural Rights (CESCR) has defined discrimination (based on the definition found in the International Convention on the Elimination of All Forms of Racial Discrimination)³⁹ as: any distinction, exclusion, restriction, or preference or other differential treatment that is directly or indirectly based on the prohibited grounds of discrimination and which has the intention or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of Covenant rights. Discrimination also includes incitement to discriminate and harassment.⁴⁰

CESCR notes that states have immediate obligations to guarantee the right to non-discrimination and this applies across all rights provided for the ICESCR. In addition, ICESCR also mentions the rights to non-discrimination and equality in relation to specific economic, social, and cultural rights. For example, article 7 includes the 'right to equal remuneration for work of equal value' and 'equal opportunity for everyone to be promoted' in employment.⁴¹

There are human rights treaties that apply to specific groups of people. These deal with the specific forms of discrimination that marginalized groups often face, with highly specific normative content. Some focus exclusively on eliminating discrimination against specific

groups,⁴² while others deal with the human rights of specific groups—including how non-discrimination and equality applies to each group—through a wider normative scope.⁴³ A common feature of these treaties is that they provide for non-discrimination and equality clauses that apply across all substantive provisions of a treaty⁴⁴ and the substantive provisions are adapted to the specific challenges the subject group faces. Regional human rights treaties also guarantee the rights to non-discrimination and equality.⁴⁵

The right to non-discrimination is a right in itself and also subsumed in the right to equality.⁴⁶ The right to equality is most notably guaranteed under Article 26 of the ICCPR. According to the HRC: Article 26 not only entitles all persons to equality before the law as well as equal protection of the law but also prohibits any discrimination under the law and guarantees to all persons equal and effective protection against discrimination on any ground.⁴⁷ An important feature of Article 26 is that it provides for an autonomous right and does not relate only to the rights found in the ICCPR, rather it ‘prohibits discrimination in law or in fact in any field regulated and protected by public authorities.’⁴⁸ This includes rights found in other human rights treaties, including ICESCR.

Both CESCR and HRC⁴⁹ have made clear that states have obligations to take positive measures to achieve equality. CESCR states: States parties may be, and in some cases are, under an obligation to adopt special measures to attenuate or suppress conditions that perpetuate discrimination. Such measures are legitimate to the extent that they represent reasonable, objective and proportional means to redress de facto discrimination and are discontinued when substantive equality has been sustainably achieved. Such positive measures may exceptionally, however, need to be of a permanent nature, such as interpretation services for linguistic minorities and reasonable accommodation of persons with sensory impairments in accessing health-care facilities.⁵⁰

The Committee on the Elimination of Discrimination against Women expresses a similar position on temporary measures in relation to states’ obligations around intersectionality:

“ States parties must legally recognize [...] intersecting forms of discrimination and their compounded negative impact on the women concerned and prohibit them. They also need to adopt and pursue policies

and programmes designed to eliminate such occurrences, including, where appropriate, temporary special measures.⁵¹ ”

In its general recommendation on temporary special measures, the Committee states that temporary special measures are required to achieve equality, which it conceptualizes as substantive equality, that is, as ‘women’s de facto equality with men,’⁵² where, ‘Equality of results is the logical corollary of de facto or substantive equality.’⁵³

Substantive equality can be distinguished from **formal equality**, which relates to everyone being treated equally in law, that is, the elimination of formal discrimination and the equal and effective protection before and of the law.⁵⁴

For further information on the rights to equality and non-discrimination in international law, see the *Declaration of Principles on Equality*.⁵⁵ The rest of this chapter will address specific data-related obligations states should meet to fulfill the rights to non-discrimination and equality.

III. FULFILLING THE RIGHTS TO NON-DISCRIMINATION AND EQUALITY: THE NEED FOR REPRESENTATIVE DATA

A key way to fulfill the rights to non-discrimination and equality is to ensure that data used to develop policies and make decisions is representative. **Representative data** requires that everyone, regardless of their identity and/or characteristics, is accurately captured in data. Representativeness is a statistical concept that refers to how accurately any given sample matches reality. From a human rights perspective, for data to be representative it must capture information on all groups that are expressly protected under international human rights law as well as all contextually relevant groups. For example, socioeconomic status or income in countries where economic inequality is present or sexual orientation in countries where lesbian, gay, and bisexual people are systematically discriminated against.

For data to be representative from a human rights perspective it must also adequately capture the content of economic, social, and cultural rights as well as issues relevant to economic, social, and cultural rights. See high quality data for further information.

Representative data is a prerequisite for identifying which groups face inequalities in their enjoyment of economic and social rights, which is itself the basis for determining whether

human rights violations have occurred. Yet, worryingly, most, if not all, states do not collect sufficiently representative data.

States can ensure that data is sufficiently representative through two primary means:

1. ensuring that data is **disaggregated**
2. allowing rights-holders to be represented in data in accordance with how they **self-identify**.

1. DISAGGREGATION

In order for data to be representative of all relevant groups, states should make sure it is disaggregated as far as possible.

Disaggregated data refers to data that has been broken down by subcategories, such as: characteristic (gender, type of disability, age), identity (racial, ethnic, or linguistic minorities) or location (region, rurality) or other important status (income, wealth).

Aggregated data, or data that is not broken down by category, obscures important differences between groups. For example, in Pakistan the rate of children out of school at the primary level is 36%. But when broken down by gender, 40% of girls are out of school compared to 33% of boys. The national average conceals the fact that girls are more likely to be out of school.⁵⁶

It is important to note that not all data can be disaggregated. Generally, quantitative data (that which can be counted) on human rights outcomes and inputs can be disaggregated. Qualitative data, however, cannot. However, qualitative data is essential for ensuring the representativeness of data because it can illuminate perceptions, feelings, perspectives, context, and other non-numerical information, which are necessary to make sense of quantitative data.

In collecting disaggregated data, the harm that has been and continues to be done to marginalized communities must be acknowledged and mitigated. The British Columbia's Office of the Human Rights Commissioner (BCOHRC) notes that:

“ we must face the fact that this data has been used in support of colonization and systemic racism and oppression. Both historically and today, structurally oppressed communities have had to deal with the consequences of research used as a tool for control and surveillance, leading to further stigma and marginalization.⁵⁷ ”

BCOHRC cites the example of how disaggregated demographic data was collected by the Department of Indian and Northern Affairs Canada ‘on Indigenous households to support the establishment and operation of residential schools.’^{58 59}

PURPOSES OF DISAGGREGATED DATA

Disaggregated data is essential to properly address human rights issues, because it can:

- **reveal inequalities in the enjoyment of economic, social and cultural rights.** Disaggregated data provides vital information on who is and who isn’t enjoying their economic and social rights. For example, in a 2016 case in Argentina,⁶⁰ a court ordered that the ministry of education must collect education outcome data (e.g., drop-rates and attendance rates) disaggregated by disability. Failure to do so hinders the fulfilment of the rights to education and equality of people with disabilities.
- **allow for comparisons between the policy inputs and resources allocated to the economic and social rights of marginalized groups.**
- **reveal the scope and extent of inequalities in enjoyment and policy and budgetary inputs.** Not only can disaggregated data tell you who is disadvantaged but also the extent of the inequality between groups. Take, for example, data for the right to health indicator ‘infant mortality rate’ (the death of a baby before their first birthday) in the United States in 2015. While the national average (or the aggregated average) is 5.9 deaths per 1,000 births, this figure hides the fact that the infant mortality rate is significantly different if disaggregated by the ethnicity of the mother. Although the rate is 4.9 deaths among non-Hispanic white women, it is nearly double the national average for African-American mothers, at 11.25 deaths per 1,000 births.⁶¹ Gaps in



enjoyment this large can be indicative of structural inequalities that warrant further investigation. It is important to note, however, that the scale of the inequality does not have to be large to be problematic from a human rights perspective.

- **be used to identify patterns of inequalities**, that is, which groups are systematically disadvantaged across various economic and social rights, rather than in one domain. This is important because inequalities in one area, such as in education or health, are often accompanied by inequalities in another. This is because marginalization is often a result of structural issues, so the barriers that linguistic minorities, for example, face in accessing education are the same when they access healthcare services.
- **be used to identify multiple and intersectional inequalities**. Those who are most disadvantaged usually have multiple identities. For example, in Nigeria the out-of-school children's rate at the primary level is 35%. Broken down by gender, 33% of girls are out of school compared to 37% of boys. However, when this data is further broken down by location, 47% girls in rural areas are out of school compared to 15% of girls living in urban areas and 41% of boys living in rural areas and 14% for boys living in urban areas. When wealth is considered, 75% of girls living in rural areas from the poorest families are out of school compared to 6% of boys living in urban areas from the richest families. 35% may be the national average out-of-school rate, but this data actually conceals important information about who is most likely to be excluded from education.⁶²
- **provide the basis for an analysis of possible discrimination**. Without disaggregated data, it is difficult to prove that groups are actually discriminated against. This is particularly the case in instances of substantive and indirect discrimination, which are less obvious because they occur as a result of systemic inequalities, and where data is absolutely vital to show which groups are subject to possible discrimination and how and to what extent. However, inequalities do not always constitute discrimination. Further analysis must be performed to show that a state's action or inaction contributed or caused the inequality.⁶³
- **reveal the impact of policies and other interventions on specific groups compared to others**.

LEGAL BASIS OF DATA DISAGGREGATION

As part of their legal obligations to eliminate discrimination and ensure equality, states have an obligation to monitor non-discrimination and to collect disaggregated data. CESCR states in its general comment on non-discrimination:

“ States parties are obliged to monitor effectively the implementation of measures to comply with article 2, paragraph 2, of the Covenant. Monitoring should assess both the steps taken and the results achieved in the elimination of discrimination. National strategies, policies and plans should use appropriate indicators and benchmarks, disaggregated on the basis of the prohibited grounds of discrimination.⁶⁴ ”

In various general comments, CESCR consistently asserts that states must collect disaggregated data in relation to economic, social, and cultural rights.⁶⁵ For example, in its general comment on the right to just and favorable conditions of work, CESCR states:

Workers in the informal economy: Though these workers account for a significant percentage of the world’s workforce, they are often excluded from national statistics and legal protection, support and safeguards, exacerbating vulnerability. While the overall objective should be to formalize work, laws and policies should explicitly extend to workers in the informal economy and States parties should take steps to gather relevant disaggregated data so as to include this category of workers in the progressive realization of the right. For that purpose the informal economy should be included in the mandate of a respective monitoring and enforcement mechanism⁶⁶

In its general comment on education, CESR states: States parties must closely monitor education – including all relevant policies, institutions, programmes, spending patterns and other practices – so as to identify and take measures to redress any de facto discrimination. Educational data should be disaggregated by the prohibited grounds of discrimination.⁶⁷

Numerous human rights bodies have also specified that in order for states to fully comply with their legal obligations, they must collect disaggregated data.⁶⁸ For example, the Committee on the Elimination of Discrimination against Women in its general recommendation on statistical

data states that: ‘statistical information is absolutely necessary in order to understand the real situation of women,’⁶⁹ and recommends that states:

Should make every effort to ensure that their national statistical services responsible for planning national censuses and other social and economic surveys formulate their questionnaires in such a way that data can be disaggregated according to gender, with regard to both absolute numbers and percentages, so that interested users can easily obtain information on the situation of women in the particular sector in which they are interested.⁷⁰

Disaggregation is explicitly mentioned in one international human rights treaty, the Convention on the Rights of Persons with Disabilities (CRPD), which states:

The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties’ obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.⁷¹

2. SELF-IDENTIFICATION⁷²

From a human rights perspective, it is important that people are able to define their identities for themselves. This means that they are represented in data according to the identities they choose. For example, whether someone identifies as Indigenous or as part of an ethnic, linguistic, or religious minority group is a fundamental criterion for membership of that group. Similarly, gender and sexual orientation is for the person to define themselves. Self-identification prevents states from arbitrarily or purposefully imposing an identity or characterization on individuals or groups, which could result in harm.

A key element of self-identification is that individuals should have complete control over whether they disclose their identity, as well as which identities they choose to disclose. In situations where rights-holders are unwilling to self-identify, for instance, out of fear of being exposed or harmed, they must be given the freedom to opt out of disclosure. States should also respect the decisions of individuals and communities, allowing them to be counted under categories that the individuals and communities feel are relevant and appropriate. When there are multiple identities, people should be able to choose how they want to be represented.

LEGAL BASIS OF SELF-IDENTIFICATION

CESCR's general comment on non-discrimination clearly states that self-identification is the guiding principle in determining membership of a group: 'In determining whether a person is distinguished by one or more of the prohibited grounds, identification shall, if no justification exists to the contrary, be based upon self-identification by the individual concerned.'⁷³

In addition, instruments concerning the rights of Indigenous peoples highlight the importance of self-identification.

Article (1) (2) of the International Labour Organization's Indigenous and Tribal Peoples Convention (1989, No. 169) states: 'Self-identification as indigenous or tribal shall be regarded as a fundamental criterion for determining the groups to which the provisions of this Convention apply.'⁷⁴

Similarly, the UN Declaration on the Rights of Indigenous Peoples, which is non-legally binding but highly persuasive, states in Article 33 (1): 'Indigenous peoples have the right to determine their own identity or membership in accordance with their customs and traditions.'⁷⁵

GENERAL RECOMMENDATIONS FOR IMPLEMENTING THE RIGHTS TO NON-DISCRIMINATION AND EQUALITY:

1. States must ensure that official data captures the realities and experiences of all groups, placing particular attention towards the inclusion of marginalized groups protected under international, regional, and domestic laws or any other group who experiences unequal enjoyment of their rights.
2. Methodologies and other technical aspects of data and monitoring processes must acknowledge existing biases and should aim to overcome them instead of reinforcing them. This includes the development of new tools and indicators that allow the demonstration of significant differences among groups.
3. States should conduct human rights impact assessments of any data-based automated system used in relation to ESCR, whether public or private. The audit should analyze any impacts on different groups, including whether biases in source or training data can be addressed, whether human biases replicate existing inequalities, and how to ensure

transparency and accountability. Where an in-depth audit cannot be done, or where it is not possible to fully mitigate the impact of the system, states should refrain from using such systems.

RECOMMENDATIONS SPECIFIC TO REPRESENTATIVE DATA:

1. States must identify all groups who may experience possible discrimination and ensure they are represented in data.
2. States must ensure that data and monitoring processes involve rights-holders with diverse and intersecting identities at all stages of the data life cycle. This will result in data that reflects things that actually matter to these groups and individuals, while guaranteeing that the data is produced and used in ways that are sensitive and respectful to different identities. This is particularly important in the design stage of the data gathering process, to identify categories and indicators that allow for the capture of the most relevant information. See Participation for further information.
3. Data should be produced and published with the highest possible level of disaggregation, including all protected characteristics at the international, regional, and national levels, as well any other category relevant for inequality or discrimination purposes.
4. Disaggregated data must be consistently collected for all individuals included within a dataset so that the entire dataset can be disaggregated.
5. Even for projects or investigations where inequality and discrimination are not the primary focus, disaggregated data should be collected and analyzed: It is good practice, and equality and discrimination are often underlying factors in many situations, even when unexpected.
6. It is important that levels of disaggregation are carefully considered and relevant groups are consulted prior to data collection. See Participation for further information. This is because pre-selected categories may have the effect of excluding certain groups or may exacerbate stigmatization. For example, collecting data on the grounds of gender, where gender is understood as binary, may in some instances contribute to the marginalization of people who identify as non-binary, genderqueer, or transgender.

7. Groups must be self-defining, with relevant groups identified before data collection using a participatory approach, whilst also allowing for free responses that have not been anticipated.

HIGH QUALITY DATA

Human rights data must be of **high quality**, that is, it must have certain features that make it useful and actionable. Without high quality data, states and other duty-bearers cannot accurately understand the human rights situation, craft and evaluate appropriate policies, and more generally comply with their obligations to monitor the realization of human rights. States can increase the quality of their human rights data by **diversifying the types and sources of human rights data**, including by developing and using **human rights indicators**, producing and using more **qualitative data**, and empowering rights-holders to produce and use their own data (**'community-led data'**).

I. RELEVANCE AND QUALITY OF HUMAN RIGHTS DATA

Human rights data must be **relevant**, that is, it must be fit for its intended use. For human rights data, this means the data must be anchored in human rights law. At a minimum, human rights must capture both the normative content of economic, social, and cultural rights (i.e., what rights-holders are entitled to) and states' corresponding legal obligations to implement these rights. This includes the perspectives, concerns, and priorities of rights-holders and in particular affected communities.

Human rights data must also be contextually relevant because each country (and each sub-national unit) is unique. Countries differ in their level of development, economic systems, political and legal arrangements, culture, history, etc. and this needs to be taken into account from a human rights perspective. In addition, human rights data must conform to standard data quality dimensions, including:



- **timeliness:** it must be as up-to-date as possible so that decisions can be taken with the most current data
- **accuracy:** it must be error free and approximate the real-world human rights situation
- **completeness:** there should be no missing data
- **consistency:** data must have a degree of uniformity, for example, the same format should be used (dates, codes, definitions) to allow for comparability and interoperability (the combining of data from different sources)
- **accessibility:** it must be easy to understand and use for the intended user (see accessibility section in transparency and the right to information).

Whilst most states produce and use socioeconomic data and other human rights relevant data (for example, on the state of the economy or health and education outcomes), relatively few states produce data with the specific intention of ensuring economic, social, and cultural rights (for instance, data on the specific measures it has taken to realize human rights), which represents a significant human rights data gap that leads to gaps in implementation, which in turn leads to gaps in enjoyment. Traditionally, economic, social, and cultural rights measurement has been unsophisticated. For example, using socioeconomic data that gives a snapshot about the state of the economy, which is not specific enough to adequately measure human rights. More recently, human rights measurement has become more relevant to human rights but has mostly focused on outcomes, for example, the number of violations or the extent to which people are enjoying their human rights. And although this information is important, it is not the only facet of human rights that needs to be measured. Which laws and policies states have in place is as important as the actions they have taken to make human rights a reality. Measuring all three dimensions (commitments, efforts, results) gives a more detailed and nuanced understanding of the human rights situation. By piecing together each dimension we are better able to make an assessment of where things are going right or wrong.

ENSURING DEVELOPMENT DATA IS HUMAN RIGHTS-BASED

An important aim of this collective position is to make clear that under international human rights law, states have legal obligations to realize economic, social, and cultural rights through monitoring, which includes the production and use of data. Whilst states should also produce data for other purposes, and indeed most well-functioning states do, human rights data must be prioritized as a matter of legal obligation. In

most cases there is no conflict; data produced and used to advance equality, eliminate poverty, and for other social justice aims complements economic, social, and cultural rights data. However, economic, social, and cultural rights data and data used for socioeconomic purposes are not always synonymous, in the same way that measures to reduce poverty do not automatically advance human rights. With the adoption of the 2030 Agenda for Sustainable Development and other international development initiatives, there has been a tendency, according to the UN Special Rapporteur on extreme poverty and human rights, to elide development approaches and economic, social, and cultural rights.⁷⁶ However, given that the normative content and the SDG targets are not always aligned,⁷⁷ it is clear that states cannot claim that they meet their obligations to produce and use data for economic, social and cultural rights only by collecting data for development indicators. This is true particularly for internationally agreed indicators, which are standardized and non-contextualized, and which can be problematic when they create hierarchies between states based on narrowly defined criteria, often decided by powerful actors. Rather, human rights law requires that states produce and use economic, social, and cultural rights specific data. Furthermore, all other forms of officially produced data, including the processes and systems that generate them, must conform to human rights standards.

II. THE NEED FOR MORE QUALITATIVE DATA

Qualitative data, such as on lived experience, perceptions, concepts, and feelings, are a central element of human rights monitoring. This is because human rights enjoyment is not just a matter of *exercising* a right but also the *experience of exercising* the right. When implemented by states, work, education, social security and health are public services we engage with, and information about this experience is important from an enjoyment perspective. For instance, in designing social security systems, states must consider how people will engage with these systems, including what the main barriers are in order to mitigate them and ensure accessibility.

Qualitative data comes in words or visuals and usually describes something that cannot be counted in numbers, for instance, experiences, perceptions, concepts, and feelings. This type of data complements **quantitative data**, that is, data that can be measured and expressed numerically, such as the number of countries that have ratified a treaty, the proportion of workers in precarious employment, and proportion of urban population living in slums.

Quantitative data is suitable for understanding broad patterns across populations, demonstrating changes over time, and understanding the scope and scale of a problem, whilst qualitative data illuminates and contextualizes such data, often addressing questions around why something is happening and how it is affecting people. Both types of data need to be used in tandem to mitigate the limits of each and also to accurately capture the status of economic, social, and cultural rights.

For instance, if a country has a high rate of out-of-school girls, we need to gather qualitative data on the impact of being out of school, the reasons for being out of school, what could help get girls back into school, etc. Only with a complete picture can we understand and address the human rights situation. Simply knowing how many girls are out of school is not enough to craft relevant, responsive, and effective policy. Similarly, qualitative methods are essential for tackling poverty effectively—especially when grounded on lived experiences of people in poverty. As the UNSR on Extreme Poverty and Human Rights writes:

“ a qualitative approach(...) is much more appropriate to identifying the relational dimensions of poverty, i.e., the constraints that have their source in agency/social relations, often trapping people in poverty. Understood as a process of social exclusion, poverty can only be adequately described based on the dynamic of how poverty is caused and perpetuated, as experienced by the people affected.”⁷⁸

The need for qualitative data goes beyond people’s experience of these rights, however. Elements of economic, social, and cultural rights are qualitative in nature. The things that constitute a quality education cannot be measured solely with quantitative data, the rights to social security and housing include the element of ‘adequacy,’ and the highest attainable standard of mental and physical health will include subjective experiences, such as personalized care. Qualitative data is therefore necessary to understand essential elements of the content of economic, social, and cultural rights. As the Working Group on the Protocol of San Salvador set up by the Organization for American States (see below) states:

“ [qualitative ‘signs of progress’] are distinct because they do not originate from a predetermined category or from a given (statistical) measurement scale, but encapsulate the social actor’s definition of the situation and the

meaning that they ascribe to the phenomenon under evaluation, which is crucial for interpreting the facts.⁷⁹ ”

Despite the pressing need for more qualitative data, states have tended to prioritize quantitative data. This is due, in part, to the fact that quantitative data is often perceived as objective and therefore credible, despite the risk that over reliance on quantitative data reduces people and problems to numbers. At the same time, qualitative data is often devalued because of its subjective nature. This hierarchy effectively excludes rights-holders, their lived experience, and their knowledge from official data. Although qualitative data has limits (e.g., it is not extrapolatable), it can help us to better understand underlying conditions whilst ensuring that the voices, experiences, and priorities of affected communities are seriously considered in data and therefore policy-making processes.

The neglect of qualitative data means that certain aspects of economic, social, and cultural rights are overlooked and certain voices are excluded, both of which have real-world implications. By relying predominantly on quantitative data, states are able to adequately measure only certain dimensions of human rights, usually related to the level and extent of enjoyment or the scope of state efforts. Indicators measuring states' legal and political commitments (known as 'structural indicators,' see box below) have been almost entirely neglected, as have the qualitative dimensions of states' efforts and people's experiences of exercising rights. The Danish Institute for Human Rights argues that this is neither efficient nor cost-effective because 'structural and process indicators are often relatively easy to monitor and lend themselves to participatory and qualitative assessment processes.'⁸⁰

The imbalance between the perceived legitimacy of each type of data needs to be corrected. By using a human rights-based approach to data, we can start dismantling the notion that data generated by states and powerful actors is objective and credible, whilst data based on communities' experiences of a certain issue is biased and illegitimate. Both types of data bring vital information that need to be used together to give a fuller, more nuanced picture of human rights enjoyment and issues.

III. CIVIL SOCIETY AND COMMUNITY-LED DATA

The state is often the primary producer of human rights data. This is as it should be: States are the primary duty-bearer when it comes to human rights and have legal obligations to produce

human rights data. However, states cannot be the *only* producer of human rights data. This is because all data reflects certain values and biases and whilst states can do a lot to mitigate this, for example, by ensuring maximum participation in and independence of data processes, official data will always be top-down and relevant to its own interests, which might not align with the interests of affected communities, leaving data gaps on issues important to rights-holders.

One of the key ways to rectify this is by ensuring what the Danish Institute for Human Rights calls a ‘pluralistic ecosystem of human rights data.’⁸¹ This means that other actors (civil society, NGOs, academics, journalists, etc.) should be able—and in some instances be supported and empowered—to produce human rights data relevant to their interests, and this data and the analysis they perform should be taken seriously by states. Of crucial importance is data produced by rights-holders themselves. This type of data, known as ‘community-led data,’ should be considered a source of expert knowledge by states, and sought and utilized when relevant. (See principle on participation for further information.)

It is important to note that data produced by actors beyond the state (non-state actors) will also reflect certain biases and political values that can be detrimental to the realization of economic, social, and cultural rights. INGOs’ monitoring priorities, for example, may be determined by donors rather than the people they purport to serve and the same is true for academics and other actors within civil society. Although alternative perspectives are valid, it is important to interrogate all non-official forms of data (as well as official data) because they can push agendas that are not rooted in communities.

LEGAL OBLIGATIONS TO PRODUCE HIGH QUALITY HUMAN RIGHTS DATA

The legal basis for collecting high quality human rights data is closely tied to states’ legal obligations to monitor human rights: 1) as part of their obligation to domestically **implement** economic, social, and cultural rights; and 2) as part of their obligations to **report** to the relevant international and regional human rights bodies on the measures they have taken to comply with their human rights’ legal obligations contained within human rights treaties.

1. **DOMESTIC IMPLEMENTATION:** Article 2 (1) of the International Covenant on Economic, Social and Cultural Rights (1966, ICESCR) sets-out states’ legal obligation to domestically implement the rights guaranteed in its provisions. Domestic implementation is the

process whereby states turn their international legal commitments to economic, social, and cultural rights into enjoyment at the national level, through a variety of suitable means, for instance, the enactment of legislation, allocation of financial resources, and monitoring. States are free to decide which measures are most suitable, as long as they comply with their legal obligations, including obligations of *immediate effect* and *progressive realization*. Some aspects of rights require immediate action, for instance, eliminating all forms of discrimination across the enjoyment of rights, implementing free and compulsory primary education, and ensuring the right to form and join a trade union, whilst others, including the right to continuous improvement in living conditions, require incremental action. Most rights contain a combination of both types of legal obligations.

The Committee on Economic, Social and Cultural Rights (CESCR) has made clear that monitoring, whether of aspects of rights requiring immediate action or progressive realization, is mandatory for states and is in itself an immediate obligation of states.⁸² In its authoritative interpretation of Article 2(1), CESCR notes that states must, ‘monitor the extent of the realization, or more especially [sic] of the non-realization, of economic, social and cultural rights.’⁸³

CESCR, through its general comments⁸⁴ (quasi-legal documents interpreting the content and obligations relevant to specific rights and situations, and identifying best practice), identifies when states have legal obligations to monitor and produce and use relevant data. For instance, with regard to the right to just and favorable conditions of work, CESCR advises that states, ‘should establish a functioning system of labor inspectorates, with the involvement of social partners, to monitor all aspects of the right to just and favorable conditions of work for all workers.’⁸⁵ In the same general comment, CESCR also requires states to:

“ identify indicators and benchmarks to monitor the implementation of the right to just and favourable conditions of work. Such indicators and benchmarks should address the different elements of the right to just and favourable conditions of work... States parties should define the indicators that are most relevant to national implementation of the right.”⁸⁶

CESCR is also consistent in requiring states to monitor the implementation of other key rights, including the rights to: health,⁸⁷ education,⁸⁸ water,⁸⁹ and to take part in cultural life.⁹⁰ Each of these require that states set indicators and benchmarks so that progress can be closely monitored. In most cases, the obligation to monitor has immediate effect. For instance, in the General Comment on the right to adequate housing, CESCR states that: ‘Effective monitoring of the situation with respect to housing is another obligation of immediate effect.’⁹¹

Thematic treaties, protecting specific groups of people, also place legal obligations on states to monitor economic, social, and cultural rights, notably the Convention on the Rights of Persons with Disabilities (2007, CRPD), which includes an article dedicated to data and statistics requiring states to, ‘collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention.’⁹²

2. **REPORTING:** International human rights treaties are usually monitored by a body or mechanism empowered or established to oversee compliance with that treaty. This typically creates obligations on states to submit reports⁹³ on the measures they have taken to implement economic, social, and cultural rights. This requires states to undertake initial and periodic reviews at the national level through monitoring. The obligations to monitor for reporting purposes, as CESCR makes clear in General Comment 1 on state’s obligations to report, should not be seen as distinct from the states’ obligations to monitor in order to domestically implement and fully realize economic, social, and cultural rights. CESCR sets forth that states should monitor the ‘actual situation with respect to each of the rights on a regular basis and [be] thus aware of the extent to which the various rights are, or are not, being enjoyed by all individuals within its territory or under its jurisdiction.’⁹⁴

Beyond human rights treaties, the UN Fundamental Principles of Official Statistics emphasize that official statistical information must be of high quality, adhering to scientific or professional standards.⁹⁵

With regard to the content and scope of monitoring and data collection, in various concluding observations and recommendations on the implementation of economic, social, and cultural rights, CESCR, as well as other UN Treaty Bodies, has repeatedly referred states to OHCHR’s Framework on human rights indicators (see below).⁹⁶ In its guidance to states on reporting, CESCR also makes clear that:

“ qualitative, as well as quantitative, data’ are required for states to make an ‘adequate assessment of the [human rights] situation.’⁹⁷ ”

At the regional level, the Organization for American States (OAS) has set up a Working Group to examine the periodic reports of the States Parties to the Protocol of San Salvador, the main regional legal instrument to advance economic, social, and cultural rights. The WG developed comprehensive guidance for states to report about their compliance with the obligations contained in the Protocol of San Salvador⁹⁸ (although the reporting structure is also applicable to economic, social, and cultural rights obligations deriving from other international law instruments). To do so, the Working Group developed progress indicators focusing on the following rights: the rights to social security, health, education, and the rights to work (including trade unions rights), the right to a healthy environment, food and the benefits of culture. The reporting structure combines “quantitative indicators and qualitative signs of progress” and identifies three types of indicators [\(STRUCTURAL, PROCESS, AND OUTCOME\)](#), arranged into three conceptual categories: [\(I\) INCORPORATION OF THE RIGHT; \(II\) FINANCIAL CONTEXT AND BUDGETARY COMMITMENT; \(III\) STATE CAPABILITIES](#); and three crosscutting principles: [A\) EQUALITY AND NONDISCRIMINATION, B\) ACCESS TO JUSTICE, AND C\) ACCESS TO INFORMATION AND PARTICIPATION](#). The indicators are also used by the Working Group to develop its own analysis on the progress made by states to meet legal obligations.⁹⁹

OHCHR INDICATORS FRAMEWORK

In 2012, the OHCHR¹⁰⁰ developed a guide to measuring the implementation of human rights, proposing a conceptual framework (which has become the favored indicators model recommended by international and regional bodies)¹⁰¹ based on three types of human rights indicators:

Structural indicators measure the commitments made by states to meet their obligations regarding economic, social, and cultural rights, as reflected in the adoption of legal instruments and basic institutional mechanisms necessary for the promotion and protection of economic, social, and cultural rights.

Process indicators measure how the state is transforming its commitments into concrete realization of economic, social, and cultural rights, through various types of efforts (such as policies, inputs, budget allocation, and programs and measures to address specific issues) to implement its obligations with regard to economic, social, and cultural rights.

Outcome indicators measure the extent to which a population enjoys economic, social, and cultural rights. That is, they measure the impact of the state's efforts to implement the economic, social, and cultural rights through laws, policies, and programs.

In order to fulfil their monitoring obligations and produce high quality data, states should use the structural-process-outcome model to identify relevant indicators. These indicators should be as simple as possible, methodologically sound, universal and/or contextually relevant, and valid (measuring what they purport to measure from a human rights perspective).¹⁰² In addition, indicators must be benchmarked so that performance can be assessed.¹⁰³

RECOMMENDATIONS FOR PRODUCING HIGH QUALITY DATA

1. States must produce human rights data of the highest quality possible, by ensuring it is relevant, timely, accurate, complete, consistent, and accessible.
2. Human rights data must be rigorous, that is, it must be collected, produced, and analyzed in methodologically sound ways. States must develop and apply qualitative and quantitative indicators based on the OHCHR's structural-process-outcome framework to significantly increase the quality and relevance of human rights data.
3. States must produce and use more qualitative data to better capture the experiences and needs of people and groups who face systemic discrimination or unequal access to essential services.

4. States should support and empower affected communities to produce and use their own data, including by making resources available for community-led research and by increasing data literacy.
5. States should rely on and utilize community-led data in official data collection and/or decision-making processes that affect ESCR.
6. States must establish data governance frameworks to ensure high quality official data. States should adhere to agreed statistical principles, such as the UN Fundamental Principles of Official Statistic

PARTICIPATION

Participation is a human right. Everyone has the right to participate in and influence the decision-making processes that determine the economic, social, and cultural life of their community and country, and states have a legal duty to ensure community participation in all data and decision-making processes. Rights-holders also have a right to lead their own research and monitoring activities in furtherance of their human rights, free from threats, harassment, or interference from the state, corporate actors or other powerful entities. Any processes directly or indirectly affecting human rights which are not participatory are illegitimate from a human rights perspective.

As well as being a human right, participation is necessary for the realization of economic, social, and cultural rights. Rights-holders have firsthand knowledge on the enjoyment of economic, social, and cultural rights based on their lived experiences, which is vital information that warrants consideration in decision-making processes. In valuing and incorporating rights-holders' knowledge, expertise, and lived experiences, states can improve the quality of data they produce by ensuring it is relevant and increase the representativeness of data, for example, by better identifying marginalized groups and intersectionalities.

Participation is also about power. Human rights data and monitoring processes controlled solely by the state or other powerful actors have a tendency to replicate the power dynamics



that exist within society. This explains why rights-holders' knowledge and expertise, especially those of the most marginalized, are so readily overlooked in data and monitoring processes. Participation is therefore more than just having one's voice heard or influencing a decision, but a way to challenge power asymmetries that contribute to the marginalization of groups.

I. PARTICIPATION AND POWER

In her report on the right to participation of people living in poverty,¹⁰⁴ Magdalena Sepulveda, the former UN Special Rapporteur on extreme poverty and human rights, argues that powerlessness is at its core an inability to participate. She explains that a vicious circle exists where those who are least likely to enjoy their rights are also those least able to participate, which in turn can result in a further denial or deprivation of rights because of the missed opportunity to influence and shape the laws, policies, and other interventions that could have positively impacted on their enjoyment of human rights.

For example, someone who has been denied their right to education may not have the functional literacy skills required to participate in monitoring and data processes as they are currently operated (this is in itself problematic and such processes should be designed to facilitate the participation of affected communities according to their level of functional literacy). However, without the participation of people who have not received any formal education or only received poor quality education, education laws, policies, and other interventions cannot properly target those who are most excluded from education systems, creating a cycle that perpetuates marginalization and exclusion.

Similarly, decisions about land, housing and natural resources are very often made without meaningful involvement of the communities that will be affected by them. Therefore, they tend to respond to business or governments' interests rather than to communities' needs. As ESCR-Net member International Accountability Project puts it:

“ The most destructive and high-risk projects are consistently situated in the most economically and politically marginalized communities. Communities facing abuse by development often have limited political and economic power in their countries and do not have access to

information and decision-making spaces where development decisions are made. [...] ¹⁰⁵ ”

Consequently, lack of participation is a sign of a lack of enjoyment of human rights. Those least likely to enjoy their economic, social, and cultural rights are the most likely to be excluded from data and monitoring processes, especially as these processes can be perceived as somewhat technical in nature (in some cases they are designed and actively promoted as such, which is in itself a political choice about what really matters, in this case technicality over participation of rights-holders). It is a vicious circle that needs to be corrected through measures aimed at increasing and improving the quality of participation in line with a human rights-based approach. Such measures should include ensuring that monitoring and data processes are designed specifically to prioritize the participation of affected communities and the most marginalized groups, including by removing the barriers to participate, for instance, as mentioned above, by ensuring that, where appropriate, such processes are not technical in nature or require skills and expertise that communities may not have due to systemic discrimination. Ultimately, monitoring and data processes should be designed to fit the needs of rights-holders rather than the other way round.

A rights-based approach to participation, Sepulveda asserts, can and should subvert the power dynamics that serve to exclude rights-holders from policy processes. ‘Participation is a means of challenging forms of domination that restrict people’s agency and self-determination,’ Sepulveda says. ‘It gives people living in poverty power over decisions that affect their lives, transforming power structures in society and creating a greater and more widely shared enjoyment of human rights.’

TRANSFORMATION THROUGH PARTICIPATION: THE GRANDMOTHER PERSPECTIVE

In Canada, the British Columbia’s Office of the Human Rights Commissioner (BCOHRC) published a report to contribute to the development of a ‘policy initiative for the collection of race-based, Indigenous and other disaggregated data to address systemic racism.’ The report proposes that the collection of data be grounded in an approach that centers caring rather than control.

Gwen Phillips, of the Ktunaxa Nation, a BC First Nations Data Governance Initiative Champion, who is quoted in the report, says that: ‘First Nations governments are not wanting to operate with the Big Brother mentality,’ rather, ‘We need to know because we care.’ This approach is called the ‘grandmother perspective’ and is centered on the ‘importance of relationship: a reimagining of the community relationships within which data collection occurs and a primacy given to those relationships as both process and product as governments and organizations move toward data collection to address systemic inequities.’ This focus on transforming the process and the relationship between the state and the community allows for mutual trust, partnership, and respect. In this way, ‘relationship change precipitates systems change.’

II. NON-STATE ACTORS AND PARTICIPATION

Power asymmetries are also in play in non-official monitoring processes that affect economic, social, and cultural rights, such as those conducted by businesses, academics and researchers, journalists, NGOs, INGOs, and international and regional organizations.

For example, private companies carrying out infrastructure or extractive projects (e.g. mining) or any other operation that has social and environmental repercussions have the responsibility and legal obligation of conducting due diligence to assess any environmental, human rights and social impacts. Due diligence processes require meaningful participation of communities that may be affected by a project, in line with international law on the right to self-determination,¹⁰⁶ the UN Guiding Principles on Business and Human Rights,¹⁰⁷ and other international guidance,¹⁰⁸ which serve as a minimum guide on when, where, and how businesses should seek rights-holder engagement as part of their obligation to respect human rights. As illustrated below, projects affecting indigenous people should be conducted only with their ‘free, prior and informed’ consent.¹⁰⁹ However, a number of ESCR-Net members, particularly Indigenous groups who depend on land and natural resources for their livelihood and wellbeing, have stressed that impact assessments are carried out without meaningful community participation—sometimes with no participation at all—due to the skewed power relation between companies and communities. Increasingly, private companies occupy the traditional role of the state as not only the provider of public goods and services but the arbiter of processes to deliver

development outcomes. And where private interests clash with community priorities, the consequences can be devastating from a human rights perspective.¹¹⁰

Likewise, projects and programmatic work led by NGOs and INGOs which are detached from communities and, therefore, do not address their human rights needs—because, for instance, the project is donor dictated, are not human rights aligned.

III. FROM PARTICIPATION TO OWNERSHIP

Often participation can be perfunctory or reduced to single events, like holding consultations, sharing information with communities, or using community data collectors. This is not enough. Participation, from a human rights perspective,¹¹¹ must be ‘active, free and meaningful.’¹¹² In her 2014 report on participation, Catarina de Albuquerque, the former UN Special Rapporteur on the human right to safe drinking water and sanitation, sets out the elements of active, free, and meaningful participation.¹¹³ They include:

- **Involving people in setting out the terms of engagement:** Rights-holders should be able to determine the terms and modes of their participation from the outset rather than it being decided for them.
- **Creating spaces and opportunities for engagement:** States must create formal and informal spaces for participation, letting rights-holders decide the form and substance of their participation.
- **Enabling people to access participatory processes and eliminating barriers they face:** States must be proactive in ensuring that rights-holders can access spaces for participation by eliminating the barriers that prevent them from engaging, such as: language, literacy, meeting times, venue, advance registration and physical access, and short time frames for participation.
- **Guaranteeing free and safe participation:** Participation should be freely entered into by rights-holders, that is, with consent and free from coercion or conditions such as obliging rights-holders to participate or risk losing access to public services. Rights-holders, including those from stigmatized groups, must be able to give opinions, talk about their experiences, question and criticize the government, without fear of reprisals.
- **Ensuring access to information to enable people to form an opinion:** See section on accessibility and availability for further information.

- **Providing reasonable opportunity to influence decision-making:** Participatory processes that are for the purpose of realizing economic, social, and cultural rights must take into account rights-holders views and rights-holders must be able to influence decision-making.
- **Providing feedback on what proposals have been taken into account and why (or why not).**
- These elements of free, active, and meaningful participation apply as much to data and monitoring processes as to other policy processes, and apply to all stages of the policy cycle, from design to implementation to evaluation. In addition to, and expanding on the elements described above, ESCR-Net members have also identified the following key features of community participation in official data and monitoring processes.

Communities must set the agenda and have ownership of monitoring and data processes.

Communities must be involved from the outset in the design and planning of any policy, project, or intervention, to ensure that the data used to inform decisions addresses communities' needs and upholds their vision of human rights, social justice, and development. Concretely, this means communities should set the objectives and the criteria for determining success, including developing indicators and benchmarks, where relevant. Communities should also decide the data collection methods and how data will be analyzed, accessed, and used, by whom, when, and where. Communities have a right to be as involved as they want to be and should also decide the role they should play in data collection processes, given that it can require significant time, resources, and technical inputs from external actors. However, even in cases where the data collection is carried out by external stakeholders, communities should have control over the parameters within which the data collection takes place and over how data is used.

Communities must have real influence and power over official monitoring and data processes. Related to setting the agenda, when communities raise issues over their enjoyment of core economic, social, and cultural rights, for example, if they feel they are being discriminated against in access to primary education, public bodies have an obligation to take steps to eliminate that discrimination, which will require monitoring and the production of evidence to craft appropriate policy measures. In cases where core rights are not at stake, the burden shall be on the state to explain to communities why they will not take action on the issues they raise.



Data and monitoring processes must be accountable to communities. Data gathering initiatives should always be answerable to the communities from which the data was collected. Meaningful community participation necessitates community accountability at every step of the monitoring and data process. Data should be verified by those who live in the community and states and other actors should share back what actions they have taken or will take on the basis of the data collected. Reporting back should happen in a timely manner and in ways that simplify the data and makes it accessible.

Communities should be placed in the position to undertake their own monitoring and data gathering initiatives. Due to communities' marginalization as a result of structural inequality, communities often require external actors, such as NGOs or public officials, to facilitate participation in monitoring and data processes and policy processes more generally. This needs to be challenged by enabling communities to undertake their own monitoring and data initiatives, free from external influence, including by being trained to produce, analyze, use, and preserve more and better quality data. The results of such monitoring and data initiatives should be recognized by public bodies, and, where relevant, they should use community-generated data when making policy decisions. This is particularly important in relation to community monitoring of the implementation of public programs or policies, which takes place in a number of countries, particularly in relation to health and education services. These efforts should be expanded and adequately supported, and, where relevant, institutionalized.

'COMMUNITY OWNERSHIP' IN ACTION

ESCR-Net Board member Christiana Louwa, from the Elmolo Indigenous community and World Forum of Fisher People, Kenya, describes: "In Lake Turkana, Kenya, local communities hold great knowledge about fisheries. In Indigenous communities, women are charged with holding and transmitting stories to future generations orally.

“ But this indigenous knowledge is not documented by the government nor reflected in policies about small-scale fishers. Instead, the government wants to enforce their corporate data on us. Every group—whether it is us or a corporate—only wants to use data they are used to, they are comfortable with. And this is a challenge. ”

Another problem is that data don't come back to people. For instance, I heard in a conference that Lake Turkana fish had a worm. This is something the people at the lake who eat that fish need to know! But the researchers had not thought to bring that data back to the people.

Lastly, the language of international negotiation is problematic for us. We reject the word "stakeholder." We are "rights-holders." Conferences should not put us on an equal footing in negotiation with a corporate fishing company that wants access to our water, as our [human] rights should come before their [corporate] rights.

“ Another problem is they only prioritize scientific data – not community data. This sidelines communities who can't usually gather scientific data. This is why I want us to have our own data, that is commissioned by us, analyzed by us, and presented by us to the world. ”

IV. DATA SOVEREIGNTY

In addition to recognizing the importance of free, active, and meaningful participation in official data processes in the ways described above, ESCR-Net members have expressed the need to encourage and enable community-based data governance models, should communities wish them. As one of our members put it: “I want us to have our own data, that is, commissioned by us, analyzed by us, and presented by us to the world”.¹¹⁴

A potential model for community-based data governance is the Indigenous Data Sovereignty movement, which seeks to address the shortfalls of state-led data collection processes and strengthen customary and Indigenous institutions. Indigenous data sovereignty (IDS) is the ‘right of a nation, group of people, or individual to exert control over the governance of data collection, application, and ownership.’¹¹⁵ It is an important part of Indigenous autonomy and self-government, which is itself part of Indigenous peoples’ right to self-determination.

IDS has been developed by Indigenous peoples to meet their data needs to make decisions about the issues that are important to them—just as states require data to inform policy at the national level, firstly, so they are able to effectively govern and, secondly, because official data

rarely accurately represents or meets the human rights needs of Indigenous peoples (because, for instance, they constitute a small population sample or, more commonly, because the same asymmetries that marginalize groups in society are at force when it comes to data processes). Rainie et al explain:

“ Indigenous nations need data about their citizens, communities, lands, resources, and culture to make informed decisions. Yet few official statistics agencies, researchers, and data collectors make any meaningful concession to Indigenous rights in relation to Indigenous data. Despite being the rights holders in relation to data about them or for them, Indigenous peoples across nation-states remain peripheral to the channels of power through which consequential decisions about Indigenous statistics are made.¹¹⁶ ”

KEY PRINCIPLES OF INDIGENOUS DATA SOVEREIGNTY

Indigenous peoples strive to achieve IDS in two major ways: by decolonizing data and indigenizing data governance.

Decolonizing data is the process by which Indigenous peoples:

“replace external, nontribal norms and priorities with tribal systems that define data, control how it is collected, and influence how it is used. It results in findings—derived both from external data collected on Indigenous peoples and from internal data produced by Native nations—that reflect the understandings of those peoples.”¹¹⁷

Decolonizing data is also about Indigenous people being able to change and influence the narrative about them. An article in the Montana Policy and Budget Center highlights:

“ Too often, data is collected and presented in a way that perpetuates the narrative of poverty and need, painting a portrait of disparity and deficit. From health outcomes to economic indicators to educational attainment, mainstream data collection and presentation leaves little room to showcase the many strengths of indigenous people.”¹¹⁸ ”

Indigenizing data governance is the complementary process of:

“ implementing greater Indigenous data sovereignty. It is the act of harnessing tribal values, principles, and mechanisms—Indigenous ways of knowing and doing—and applying them to the management and control of a Native nation’s data ecosystem.”¹¹⁹ ”

LEGAL BASIS FOR THE PRINCIPLE OF PARTICIPATION

The principle of participation is rooted in the right to participate in the conduct of public affairs, which can be found in the International Covenant on Civil and Political Rights.¹²⁰ This right, the Human Rights Committee (CCPR) notes, ‘covers all aspects of public administration, and the formulation and implementation of policy at international, national, regional and local levels.’¹²¹ The right to participate should be understood in the broadest possible sense to include not just participating in democratic processes, such as elections and referenda, but also in all political processes that affect economic, social, and cultural rights. CCPR’s General Comment on the right to participate does not go into much detail about participating in such processes, except at the local level, as it states:

Citizens may participate directly by taking part in popular assemblies which have the power to make decisions about local issues or about the affairs of a particular community and in bodies established to represent citizens in consultation with government.¹²²

However, in general comments dealing with economic, social, and cultural rights, treaty bodies regularly emphasize the right to participate as an obligation of states in implementing substantive provisions. For example, in its General Comment on the right to social security,

CESCR states: ‘Beneficiaries of social security schemes must be able to participate in the administration of the social security system.’¹²³ And in its General Comment on the right to sexual and reproductive health, CESCR requires that states adopt and implement a national strategy ‘which is devised, periodically reviewed and monitored through a participatory and transparent process.’¹²⁴

The right to participate is a well-established right found in international human rights treaties applying to specific groups and contexts, including:

- Convention on the Elimination of All Forms of Discrimination Against Women¹²⁵
- Convention on the Rights of Persons with Disabilities¹²⁶
- International Convention on the Rights of All Migrant Workers and Members of their Families¹²⁷
- International Convention on the Elimination of All Forms of Racial Discrimination¹²⁸
- United Nations Declaration on the Rights of Indigenous Peoples¹²⁹

The right to participate is also found in human rights treaties at the regional level.¹³⁰ Of particular importance is the Regional Agreement on Access to Information, Public Participation and Justice in Environmental Matters in Latin America and the Caribbean (2018, Escazú Agreement), a groundbreaking legal instrument, which many ESCR-Net members were involved in the negotiation of. The Escazú Agreement recognizes the importance of the right to participation along with the rights to information and to access justice in protecting the environment and in promoting a vision of sustainable development that does not prioritize economic growth over communities and the environment.

The United Nations Declaration on the Right to Development (1986), although not legally binding, provides important guidance on the importance of participation: ‘The human person is the central subject of development and should be the active participant and beneficiary of the right to development.’¹³¹ As well as on what constitutes participation: Article 2 (2) makes clear that states have an obligation to formulate policies aimed at the improvement of the wellbeing of everyone ‘on the basis of their active, free and meaningful participation.’

With respect to corporate actors, the UN has published a significant amount of guidance stressing the importance of community engagement, including guidance on human rights and business,¹³² on the role of communities in advancing human rights in supply chains,¹³³ and on communities’ relationships to human rights in development more broadly.¹³⁴



Data sovereignty is based on the right to self-determination as applied to Indigenous Peoples. The right to self-determination ‘is the right of a people to determine its own destiny’.¹³⁵ According to the CCPR, the, ‘right of self-determination is of particular importance because its realization is an essential condition for the effective guarantee and observance of individual human rights and for the promotion and strengthening of those rights.’¹³⁶

Self-determination is a fundamental principle of international law and is included in the Charter of the United Nations,¹³⁷ which emphasizes its ‘universal recognition of the principle as fundamental to the maintenance of friendly relations and peace among states.’ It is also as an enumerated right found in both the International Covenant on Economic, Social, and Cultural Rights¹³⁸ and the International Covenant on Civil and Political Rights,¹³⁹ as well as in a number of other international and regional instruments.¹⁴⁰

Common article 1 of ICESCR and ICCPR on the right of self-determination has three components. Firstly, ‘All peoples have the right of self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development.’¹⁴¹ As articulated here, the right to self-determination is a collective right belonging to ‘peoples’ rather than individuals.

Secondly, peoples have the right to ‘freely dispose of their natural wealth and resources without prejudice to any obligations arising out of international economic co-operation, based upon the principle of mutual benefit, and international law. In no case may a people be deprived of its own means of subsistence.’¹⁴²

Thirdly, states have a legal obligation to respect’ and ‘promote’ the right to self-determination, including in administered territories.¹⁴³

The Committee on the Elimination of Racial Discrimination (CERD), which oversees the Implementation of the International Convention on the Elimination of All Forms of Racial Discrimination, has issued guidance on the right to self-determination stating that there are two aspects of the right to self-determination: internal and external self-determination

Internal self-determination, according to CERD, concerns the ‘rights of all peoples to pursue freely their economic, social and cultural development without outside interference.’¹⁴⁴ It is closely related to the right to participate in the conduct of public affairs—everyone must be allowed to participate in the political system and processes that a peoples have chosen for themselves.

External self-determination, according to CERD, ‘implies that all peoples have the right to determine freely their political status and their place in the international community based upon the principle of equal rights and exemplified by the liberation of peoples from colonialism and by the prohibition to subject peoples to alien subjugation, domination and exploitation.’¹⁴⁵

The United Nations Declaration on the Rights of Indigenous Peoples (2007, UNDRIP), which addresses the unique experiences of Indigenous peoples, reaffirms the right to self-determination of Indigenous Peoples¹⁴⁶ (both internal and external), where consultation and participation are key aspects. The UNDRIP affirms the right of indigenous people to provide ‘free, prior and informed consent’ before adopting and implementing legislative or administrative measures that may affect them, such as “the adoption of legislation or administrative policies that affect indigenous peoples” (Art. 19) and “the undertaking of projects that affect indigenous peoples’ rights to land, territory and resources, including mining and other utilization or exploitation of resources” (Art. 32). Indigenous peoples also have the right to ‘maintain and strengthen their distinct political, legal, economic, social and cultural institutions, while retaining their right to participate fully, if they so choose, in the political, economic, social and cultural life of the State.’¹⁴⁷ For example, UNDRIP asserts Indigenous peoples’ autonomy in establishing and controlling their own education systems¹⁴⁸ and media.¹⁴⁹ In recent years, Indigenous peoples have started to develop instruments of their own on IDS. For example, the Māori Data Sovereignty Network’s Te Mana Raraunga Charter¹⁵⁰ and the CARE Principles for Indigenous Data Governance.¹⁵¹

RECOMMENDATIONS FOR IMPLEMENTING PARTICIPATION:

1. States must ensure and implement the right to participate in data and decision-making processes by ensuring communities
 - set the agenda and have ownership of monitoring and data processes
 - have real influence and power over official monitoring and decision-making processes
 - are able to undertake their own monitoring and data gathering initiatives
 - are able to access relevant information they need to meaningfully participate in decision making.

- Data and monitoring processes must be accountable to communities.
2. States must ensure that data and monitoring processes are accessible to communities, including by taking measures to expand data literacy and access to information that communities need to meaningfully participate in decision-making.
 3. States must recognize the legitimacy of community-generated data, and instruct their national statistical offices and other relevant data and monitoring processes to use community-generated data in planning and decision-making.
 4. States must develop frameworks/structures that guide the uptake of community data to influence decision making. Such structures not only ensure that community data is actually adopted but also provides a systematized way of doing so.
 5. States should support communities in designing and carrying out monitoring projects and the production of community-generated data, including by
 - ensuring that communities have the resources to produce, analyze, and preserve more—and better—data
 - strengthening communities’ capacities to gather and use their own data
 - ensuring that those gathering data at community level, such as human rights and environmental defenders, can do so safely and free from threats, harassment and retaliation.
 6. In addition to recognizing the importance of meaningful participation in official data processes in the ways described above, it is paramount to encourage and enable community-based data governance models such as IDS.

TRANSPARENCY & ACCESSIBILITY OF INFORMATION

Transparency and the right to information have intrinsic value, but they are also instrumental in ensuring human rights. Transparency and the right to information underpin the right to participate, by ensuring that rights-holders are aware of and equipped with the necessary information to meaningfully engage in data and monitoring processes. Transparency and the right to information are also preconditions for ensuring the **accountability** of data and monitoring processes, as well as human rights more generally. One of the many uses of data

and information about economic, social, and cultural rights is to empower rights-holders to access justice.

I. TRANSPARENCY

Transparency International defines transparency as:

“ Characteristic of governments, companies, organizations and individuals of being open in the clear disclosure of information, rules, plans, processes and actions. As a principle, public officials, civil servants, the managers and directors of companies and organizations, and board trustees have a duty to act visibly, predictably and understandably to promote participation and accountability and allow third parties to easily perceive what actions are being performed.¹⁵² ”

Transparency facilitates awareness of and knowledge about how data and monitoring processes operate. This is important because data and monitoring processes are often perceived as technical, deterring people from participating or even engaging with important human rights information and data. (Of course, sometimes these processes are overly technical or actively promoted as such, which makes them inaccessible and counter to the right to participate.) Transparency also ensures that data and monitoring processes do not operate in secrecy, which deters corruption and promotes processes that are meaningful rather than purely for show, fostering public trust and legitimacy, and with it hopefully better outcomes.

Transparency extends to how decisions are made, by whom, why, and on the basis of what data and information. This requires that public bodies set-up processes to keep (and disseminate) relevant, consistent, and timely information on each stage of the decision-making process, in other words, to ensure information and data is **available**. This includes information and documentation on algorithms, increasingly used by public bodies, often in partnership with tech firms, in the delivery of public services. One of the biggest problems with algorithmic decision-making (ADM), aside from the lack of transparency in public private partnerships, is that algorithms, particularly those that incorporate machine learning, are often black boxes, that is, even those who create them do not know how or on what basis decisions are made.¹⁵³ See Equality & non-discrimination for further information on ADM.

Transparency is a requirement for public bodies, but it also applies to non-state actors, particularly corporations, when their operations affect, or will likely affect, economic, social, and cultural rights. The UN Guiding Principles on Business and Human Rights, for instance, make clear that as part of their duty to respect human rights, business enterprises should communicate externally about how they address human rights risks, including by providing accessible and adequate information.¹⁵⁴ However, too often corporations withhold information about planned projects and their impacts on local communities, thereby barring genuine participation and consultation processes and hiding from accountability.¹⁵⁵

TRANSPARENCY IN THE PRIVATE SECTOR TO PREVENT AND REDRESS HUMAN RIGHTS ABUSES

Transparency and the disclosure of information on the activities and operations of business enterprises have been vital in exposing human rights abuses. In 2016, 11.5m files were leaked from the database of the world's fourth biggest offshore law firm, Mossack Fonseca, known as the 'Panama Papers.' The documents were obtained by the German newspaper *Süddeutsche Zeitung*, who then passed them on to the International Consortium of Investigative Journalists (ICIJ), who in turn shared them with civil society and media outlets all over the world. The Panama Papers reveal the ways in which a number of wealthy individuals and groups use offshore tax regimes to evade and avoid taxes, and commit financial crimes. As a result of the investigation governments have so far been able to recover over \$1 billion in tax revenues¹⁵⁶—money that can now be spent on public services. In 2020, the Office of the United Nations High Commissioner for Human Rights (OHCHR) released, after years of delays, reportedly due to political pressure from powerful states,¹⁵⁷ a database of companies engaged in activities linked with Israel's illegal settlements, thereby undermining Palestinians' economic, social, and cultural rights.¹⁵⁸ In a joint statement to the Human Rights Council in October 2020, 11 organizations, including members of ESCR-Net, explained: In the occupied West Bank, including East Jerusalem, businesses not only profit from, but their activities also help maintain, facilitate, and sustain the illegal settlement enterprise, allow for de facto annexation, and contribute to the systematic denial of the basic rights of the Palestinian people, including self-determination and access to land and resources, with devastating socioeconomic impacts.¹⁵⁹

The publication of the database, as the organizations highlighted in the same statement: is a critical step to ensure corporate actors respect human rights, the environment, and international law.

“ Monitoring corporate involvement in human rights abuses through tools like the UN Database [is a] significant development in international efforts to stop corporate exploitation in situations of occupation and conflict, which are often rife with human rights violations and impunity.¹⁶⁰ ”

It should be noted that the update of the database continues to be stalled in spite of the original Human Rights Council resolution 31/36 (2016) mandating its annual update by the Office of the High Commissioner.

II. RIGHT TO INFORMATION

Ensuring the right to information is one of the main ways that public bodies can ensure transparency, but it is also a right in itself. The right to information, also known as access to information, freedom of information, and the right of access to information, includes the right of people to access personal information about themselves held by the state, as well as information that is of **public interest**, including information related to the functioning of public bodies and official data. The Special Rapporteur on the promotion and protection of the right to freedom of opinion and expression notes:

“ public authorities act as representatives of the public, fulfilling a public good; therefore, in principle, their decisions and actions should be transparent. A culture of secrecy is acceptable only in very exceptional cases, when confidentiality may be essential for the effectiveness of their work. There is consequently a strong public interest in the disclosure of some types of information. Moreover, access to certain types of information can affect the enjoyment by individuals of other rights. In

such cases, information can be withheld only in very exceptional circumstances, if at all.¹⁶¹ ”

States can guarantee the right to information in two main ways. Both methods presuppose that information and data is **available**, that is, public bodies have kept relevant, timely, and consistent records, and that any data produced reaches the standards described in high quality data.

Firstly, states must proactively make information and official data **publicly available**. For example, by making it available online.

Secondly, states must establish processes whereby rights-holders can request access to information. For instance, where there is low technical capacity of state institutions to manage and disseminate information, states must set-up clear, simple, and low to no-cost processes for requesting data and information from any public body. Requests for information should be answered in a timely and honest fashion and, if denied, reasons should be given that are in line with the restrictions permitted by international law (see section on legal basis for more information about limitations.) The first method should be the default method for all state-held information and data that is of public interest, including information and data on economic, social, and cultural rights.

TELEPHONE DATA IN INFORMAL SETTLEMENTS

When non-state actors perform state-like tasks or functions with regard to economic, social, or cultural rights, for example, providing private healthcare, they are subject to the same legal obligations as public bodies in terms of ensuring the right to information.

An example that illustrates this situation is the case promoted by ACIJ in Argentina, who filed a successful legal claim against a telephone company (Telefónica Sociedad Anónima) ordering the disclosure of information on the provision of services in informal settlements in the Buenos Aires metropolitan area. The legal claim followed a Resolution of the National Agency for Access to Public Information, which had

already established that the company has a duty to disclose information about its service provision in informal settlements.

ACIJ filed an information request due to the company's refusal to provide internet and telephone services in informal settlements. ACIJ was planning to use the evidence gathered through the information request to defend the right of informal settlements' residents to enjoy the right to access to internet on an equal footing with the rest of the population.

During the administrative process, the company stated that it was not obliged to provide georeferenced information on the telephone service as well as information on the provision of the internet service. However, the national body that guarantees compliance with the Law on Access to Public Information No. 27,275 stated that the company is an obligated subject with respect to that law and by Digital Argentina Law No. 27,078, compelling it to provide all the information requested. Despite the resolution being binding, the company did not comply with it.

Faced with this situation, ACIJ approached the court, holding that it is the responsibility of the judicial power to guarantee the right to access information for everyone (and especially for marginalized groups) in the face of sustained reluctance on the part of the company that provides public services. The case illustrates the obligations of private entities as regards the collection and publication of data in their possession when it concerns access to public services of groups who are experiencing discrimination in accessing their rights.

III. ACCESSIBILITY OF INFORMATION AND DATA

The right to information requires that states make every effort to 'ensure easy, prompt, effective and practical access to such information,'¹⁶² which includes ensuring that requests for information are either free or that any costs are not an impediment to access. Effectively, there should be no barriers, whether administrative, physical, or financial, to access information and data.

BARRIERS TO ACCESSING INFORMATION

Despite the fact that international human rights law is clear that everyone has the right to information and over 120 countries around the world have adopted comprehensive right to information laws, encompassing nearly 90 percent of the world's population,¹⁶³ the reality on the ground is that marginalized groups, and in some cases human rights defenders, still face significant barriers in accessing vital information that could help them secure their economic, social, and cultural rights.

In some cases, although there may be comprehensive legal and policy frameworks in place to ensure the right to information, rights-holders may not be aware of their right and, even if they are, do not know how to practically go about accessing information. Often the cost of freedom of information requests can be prohibitively high for those living in poverty. The digital divide can be a barrier particularly for poorer or more marginalized groups, who may not have access to digital tools to request or receive information, which governments tend to provide in digital formats. Although states may guarantee the right to information at the national and regional levels, at the local level, which is where decisions affecting rights-holders tend to take place, there is no effective right to information.

Finally, many ESCR-Net members, particularly social movements, have raised concerns about the inaccessibility of information on development or corporate projects, even when this is sought through formal requests. The lack of relevant, timely, complete information on the impacts of development projects, often in violation of the right to free, prior and informed consent,¹⁶⁴ hinders communities' ability to participate in consultation and decision-making processes, and to provide or withhold consent, where this is required. While private business actors have a duty to disclose information about their operations, the lack of a clear, accessible system and weak or non-existent enforcement mechanisms bar communities from accessing vital information that concern them directly. In other cases, states are reluctant to provide information about development projects taking place in areas that are deemed to be at 'high-risk' for national security.¹⁶⁵

The right to information, aside from being a right in itself, is also a precondition for the enjoyment of human rights and is vital to ensure transparency, participation, and accountability. It is, therefore, not enough that rights-holders have a right to access data and information, but that information must be **accessible**, otherwise people cannot read, understand, or make use of it, and therefore it is neither useful nor actionable.

There are no universally applicable accessibility standards when it comes to information and data (though things are clearer for data, see Open Data, below). However, there is some level of agreement on the fact that digital information must be available in an open (non-proprietary) format, for example, .txt., .pdf., .html., or .csv. Otherwise, accessibility should be understood as relative to who is accessing it, why, and for what purposes. Different groups and communities will require different adaptations. Those speaking minority languages will require access to information in their language; older people and those with no or limited access to the internet might perhaps require hard copies of information and data; whilst people with disabilities might require that information is available in Braille, large print, audio formats or easy reading, for example. Where groups are protected under the rights to equality and non-discrimination, failure to adapt information to their needs effectively restricts their right to information, which can be considered discriminatory.

In order to make information and data about economic, social, and cultural rights more accessible, states can employ a variety of strategies to disseminate information and data. For instance, they can use different means of communication (email, websites, mass media, billboards, signs, and leaflets), establish public bodies to advance public understanding of information and data, increase levels of digital literacy, and empower rights-holders and affected communities to be able to understand and use data and information.

OPEN DATA

According to the Open Definition, open data is non-personal data that can be freely used, modified, and shared by anyone for any purpose.¹⁶⁶ In order to satisfy this definition, open data must meet certain legal and technical requirements,¹⁶⁷ including:

- availability in machine readable formats



- availability in open formats
- no restrictions in access

it must be either in the public domain or have an open license.

The Open Data movement is inclusive of all types of data across sectors, particularly in the sciences and increasingly across governments, known as ‘Open Government Data.’ Open Government Data (OGD) is premised on the notion that official data is owned by the public, is a public good, and should thus be Open Data, available for everyone to use, for any purpose. OGD fosters more transparent, accountable, efficient, responsive and effective governments, and is instrumental in supporting measures for the realization of economic, social, and cultural rights, including empowering rights-holders, improving the efficiency and effectiveness of public services, finding innovative solutions to economic, social, and environmental issues, amongst others.

In 2015, Open Data Charter¹⁶⁸ was developed and six principles for how governments should publish data were established. The principles are:

1. **Open by Default:** As with the right to information, information and data should be proactively made publicly available rather than rights-holders having to request it.
2. **Timely and Comprehensive:** To ensure relevance, data should be published quickly and in a comprehensive way, preferably in its original, unmodified form.
3. **Accessible and Usable:** Data should be machine readable and easy to find, for example, by developing user-friendly portals and databanks. Data should also be free of charge, under an open license, for example, those developed by Creative Commons.
4. **Comparable and Interoperable:** Data should be comparable over time, sectors, geographic locations and datasets should be able to talk to each other.
5. **For Improved Governance and Citizen Engagement:** Open data allows rights-holders (and others in government) to have a better idea of what officials and politicians are doing. This transparency can improve public services and help hold governments to account.

6. For Inclusive Development and Innovation: Open data can help spur inclusive economic development within both the public and private sectors.

LEGAL BASIS OF THE RIGHT TO INFORMATION

The right to access information is part of the right to freedom of expression, guaranteed in Article 19 of the International Covenant on Civil and Political Rights (ICCPR), which reads:

“ Everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice.¹⁶⁹ ”

The Human Rights Committee (CCPR), which oversees implementation of the ICCPR, in its General Comment on the right to freedom of expression clarifies that Article 19 ‘embraces a right of access to information held by public bodies,¹⁷⁰ which includes information held by other (non-state) entities when they perform public functions. Such information includes: ‘records held by a public body, regardless of the form in which the information is stored, its source and the date of production.’¹⁷¹

In order to give effect to the right to access information, the CCPR recommends that states, ‘should proactively put in the public domain Government information of public interest.’¹⁷² This includes making every effort to ‘ensure easy, prompt, effective and practical access to such information.’¹⁷³ It also recommends enacting the necessary procedures to ensure the right to access information, such as passing freedom of/right to information legislation. Such procedures should:

“ provide for the timely processing of requests for information according to clear rules that are compatible with the Covenant. Fees for requests for information should not be such as to constitute an unreasonable impediment to access to information. Authorities should provide reasons for any refusal to provide access to information. Arrangements should be

put in place for appeals from refusals to provide access to information as well as in cases of failure to respond to requests.¹⁷⁴



Although the presumption is that all information belongs to the public, the ICCPR permits restrictions of the right to information in a narrow set of circumstances. Firstly, restrictions have to be provided by law, necessary and proportionate, and secondly, any restrictions can only be imposed on two legitimate grounds, which are:

- the respect of the rights or reputations of others
- for the protection of national security or of public order, or of public health or morals.¹⁷⁵

The right to access public information has also been recognized in the following human rights instruments:

- Convention on the Rights of the Child¹⁷⁶
- Convention on the Rights of Persons with Disabilities (CRPD)¹⁷⁷
- International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families¹⁷⁸

The CRPD is important because it recognizes the accessibility needs of people with disabilities in regard to information. Article 21 requires that public information be in ‘accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost,’ and further urges ‘private entities that provide services to the general public, including through the internet, to provide information and services in accessible and usable formats for persons with disabilities.’

The right to information is also a recognized human right across regional human rights regimes,¹⁷⁹ particularly in the Americas.¹⁸⁰ Of particular importance is the Regional Agreement on Access to Information, Public Participation and Justice in Environmental Matters in Latin America and the Caribbean (2018 Escazú Agreement, which came into force in November 2020),¹⁸¹ a groundbreaking legal instrument, which many ESCR-Net members were involved in the negotiation of. The Escazú Agreement recognizes the importance of the right to information, the right to participation, and the right to access justice in protecting the environment and promoting a vision of sustainable development which does not prioritize economic growth over communities and the environment. It is also the first binding instrument to protect environmental defenders, in a region where the rates of criminalization, security threats and human rights abuses against defenders is very high.¹⁸²



GENERAL RECOMMENDATIONS FOR IMPLEMENTING TRANSPARENCY AND ACCESSIBILITY OF INFORMATION:

1. Data and monitoring processes must be transparent. This requires that public bodies set-up processes to keep (and disseminate) relevant, consistent, and timely information on each stage of the decision-making process, in other words, ensuring that information and data is available.
2. States must guarantee the right to information by proactively ensuring that information and data on economic, social, and cultural rights is publicly available in accessible formats and must build capacity within public bodies to ensure that information of public interest is made available.
3. States must eliminate all barriers to accessing information by taking measures aimed at, for example, closing the digital divide, raising levels of digital and functional literacy, lowering the cost of accessing information, ensuring that rights-holders are aware of how to access information, and ensuring that the right to information extends to all levels of government.

RECOMMENDATIONS FOR GUARANTEEING THE RIGHT TO INFORMATION:

1. States must adopt right to information legislation in line with international standards and ensure that it is effectively implemented. More specifically, states must establish clear, simple, and low to no-cost processes for requesting data and information from any public body. Such processes must be responsive, timely and accessible.
2. States may only restrict access to information if the restriction is provided by law, necessary, and proportionate and only imposed on legitimate grounds, as permitted under international and regional law. In denying a request for information, states must put the refusal in writing, including the legal provisions and the reasons justifying the decision in each case, and inform the applicant of the right to challenge and appeal.

3. States must ensure that mechanisms are in place to challenge denials of requests for information.

RECOMMENDATIONS FOR REGULATING THE PRIVATE SECTOR:

1. States must ensure that non-state actors are transparent in their operations that affect economic, social, and cultural rights, and that detailed information about their business activities is made available to communities prior to seeking their informed consent, as well as during and after business operations, in line with FPIC requirements. This includes information on the nature, size, pace, reversibility and scope of any proposed project or activity; the purpose of the project as well as its duration; locality and areas affected; a preliminary assessment of the likely economic, social, cultural and environmental impact, including potential risks; personnel likely to be involved in the execution of the project; and procedures the project may entail.
2. States must regulate private providers of services related to economic, social, and cultural rights and ensure that they collect high quality human rights data and ensure that it is publicly available in accessible formats.

PRIVACY

I. DIGITALIZATION OF PUBLIC SERVICES

Access to public services, such as healthcare, education and social security, often requires people to disclose personal data and sensitive information to state agencies and departments or other service providers. The data gathered during service delivery is valuable for monitoring access to services and informing decision-making around the allocation of resources. However, this same data is sometimes shared with other arms of the state such as law enforcement, who use it to identify, target and punish individuals. For some groups of people, becoming 'visible' to the state can have harmful consequences. For example, in several countries undocumented

migrants are reluctant to seek access to healthcare due to the risk of their data being disclosed to immigration authorities, potentially resulting in removal or deportation.¹⁸³

While this was already the case with ‘non-digitized’ service delivery, the advent of digital technologies has led to a huge increase in the amounts of personal data gathered and has multiplied the ways in which this data is processed and shared, sometimes in breach of people’s privacy and with negative consequences on their lives. The former UN Special Rapporteur on extreme poverty and human rights, Phillip Alston, in its 2019 report¹⁸⁴ on ‘digital welfare states’ found that there is a ‘real risk of beneficiaries being effectively forced to give up their right to privacy and data protection to receive their right to social security, as well as other social rights.’ The use of automated mechanisms to identify, profile, surveil, target and punish, often in discriminatory ways (as discussed in the section on equality and non-discrimination), is a key example of this phenomenon.

Access to essential services should not be contingent on the disclosure of private data or, where that is necessary, safeguards must be in place to ensure the person’s privacy is not breached, for instance, by regulating how the data must be collected, analyzed, stored and shared.

While digital technologies are ostensibly introduced with the purpose of making public service delivery more effective, in many cases courts and human rights bodies have pointed at the need to strike a better balance between the purpose of these systems and the rights to privacy and enjoyment of ESCR.

UNLAWFUL USE OF ALGORITHM-BASED SYSTEMS IN SOCIAL WELFARE IN THE NETHERLANDS

One example is the System Risk Indication (SyRI), an algorithm-based government system used by the Dutch state to identify those most likely to commit social security fraud.¹⁸⁵ The system allowed government agencies to develop ‘risk models’ to single out individuals worthy of investigation and to process personal data from across government departments on the basis of categories such as gender, employment history, taxes, property ownership, education, health insurance, government permits, social assistance benefits. In 2020, the District Court of the Hague ruled¹⁸⁶ that the system does not strike a fair balance between the social interest the legislation serves

(combating fraud in the interest of economic welfare) and the right of the individuals affected by the legislation to respect of their private life. According to the court, the information produced through the system had a significant impact on the lives of people whose data was being processed, without sufficient protections to justify this interference. The court also ruled that the SyRI legislation did not contain sufficient privacy safeguards and was ‘insufficiently transparent and verifiable.’ The claimants, along with the UN Special Rapporteur on extreme poverty and human rights, also argued that SyRI ‘has a discriminatory and stigmatizing effect’ because it is deployed in low-income neighborhoods. The court agreed that there ‘is in fact a risk that SyRI inadvertently creates links based on bias, such as a lower socio-economic status or an immigration background.’ The court based its decision on Article 8 (right to family life) of the European Convention on Human Rights and the principles of the General Data Protection Regulation (GDPR, see more information below) effective in the European Union, which include transparency, purpose limitation, data minimization, accuracy, integrity, confidentiality, and accountability.

II. DATA COMMODIFICATION AND PRIVATIZATION

The issues described above are particularly problematic in light of the mass data gathering by information and communication technology companies in every aspect of our lives, whether in the private or public sphere. Indeed, every time we use digital devices (smartphones, laptops, fitness trackers, etc.) and services (search engines, social media, e-commerce sites, etc.) data about us and our behavior is collected. This data has a high commercial value and is used or sold to third parties to sell targeted advertising and predict consumers’ behavior in ways that people have no full control over—with far reaching consequences that extend beyond privacy issues.¹⁸⁷ The technology sector is also heavily profiting from the digitalization of public services by supplying technology platforms and systems to public agencies and retaining control over data about access to services gathered through these systems.

In the education sector, for example, Human Rights Watch (HRW) reports that as schools have pivoted to online learning due to global school closures as a result of the COVID-19 pandemic, EdTech firms providing digital learning platforms have been collecting children’s personal data (for example, their names, home addresses, behaviors, and other highly personal details), which HRW warns ‘can harm children and families when misused.’¹⁸⁸ This has happened because in many countries, the regulatory environment often does not address the processing of children’s data, which means that children’s right to privacy is not being adequately protected by governments. HRW further warns that EdTech products recommended by UNESCO and others ‘have drawn criticism over how they collect, share, and store vast amounts of data on children, enable intrusive surveillance, or allegedly collect information on children without parental consent.’¹⁸⁹

In the health sector, where health data and technology, particularly artificial intelligence, have found wide application to improve public health, clinical care, and patient management, personal data is not always adequately safeguarded. For instance, in 2015 the Royal Free London NHS Trust (one of the largest healthcare providers in the UK’s publicly funded National Health Service [NHS]) entered into a public private partnership (PPP) with DeepMind, an artificial intelligence subsidiary of Google, to develop an early warning system to detect a condition called acute kidney injury. As part of the partnership, the Royal Free transferred the sensitive health data of 1.6 million patients to the company, without the consent of those concerned. The Information Commissioner’s Office (the UK’s independent authority that upholds information rights in the public interest) found that this transfer of personal data violated the Data Protection Act.¹⁹⁰ But the impact on human rights goes beyond the right to privacy. The Human Rights, Big Data and Technology Project claims that whilst DeepMind provided the Royal Free with the tool for free, eventually they will sell the technology back to other NHS Trusts at an unknown price—a practice that ‘provides no guarantee that taxpayer money will be well-spent and risks disadvantaging less prosperous NHS trusts and their patients.’¹⁹¹ The Human Rights, Big Data and Technology Project goes on to highlight that such arrangements make corporate capture¹⁹² ever more likely and that public private partnerships:

“ could allow corporates to extract disproportionately high profits from public data sets without fairly compensating the NHS. This could further cement a potentially monopolistic position in the data-driven economy. Growing power asymmetries between the tech giants—who have the opportunity to exert an increasingly strong influence on policy making and

research in health-and everyday citizens pose a significant challenge for human rights accountability.’¹⁹³ ”

However, the tech sector has been influencing key regulatory spaces¹⁹⁴ to ensure that a handful of tech companies are able to expand mass data gathering while retaining control over the data and the ability to shape access to services, markets, and indeed people’s experiences and opportunities. The current scenario urges to re-think data protection and regulations to ensure people exert fuller control over their data¹⁹⁵ and that its processing and uses are aligned with human rights and in pursuance of common good.¹⁹⁶

III. SURVEILLANCE AND TARGETING OF HUMAN RIGHTS DEFENDERS

The right to privacy is particularly important in protecting human rights and environmental defenders (HRDs) in their work to defend and promote economic, social, and cultural rights. According to Front Line Defenders’ global analysis on the situation of HRDs in 2021, 358 HRDs were killed across 35 countries¹⁹⁷ and there were several hundreds of reported incidents of human rights violations, including detention, legal action, smear campaigns and verbal abuse, physical attacks, travel bans, torture, and interrogation. The majority of attacks were against HRDs working to defend the rights to land and environment, and indigenous peoples’ rights, and whose activities disrupted economic interests of corporations and powerful individuals.¹⁹⁸

Surveillance plays a key function in the context of attacks against HRDs. National security is too often used as a pretext to monitor and discourage opposition or attempts to hold power-holders accountable. States are using increasingly sophisticated technologies to monitor and control HRDs’ activities and to gather personal information that is used to intimidate, criminalize, discredit or publicly smear human rights defenders, in breach of their privacy and with real threats to their security and wellbeing. One of the most egregious examples is Pegasus, a spyware developed by the Israeli company NSO, which is able to hack phones by exploiting bugs and vulnerabilities in commonly used applications such as WhatsApp or iMessenger, without the ‘target’ being able to notice any malware activity.¹⁹⁹ Because the spyware also has the potential to activate the camera and microphone, it can also spy on anyone else with whom the target person is in contact. The spyware has been used by a wide range of governments, from Saudi Arabia²⁰⁰ and Israel to Poland, Hungary, France,²⁰¹ Bahrain, Jordan,²⁰² etc. to target political opponents, activists, lawyers, journalists, human rights defenders, particularly women,²⁰³ as well as thousands of ordinary citizens.²⁰⁴ In October 2021 ESCR-Net members Al Haq and Frontline Defenders found²⁰⁵ that the phones of six Palestinian



human rights activists from Al Haq and other Palestinian human rights organizations²⁰⁶ had been infected by the malware, some for several months. Three of the six activists work with human rights organizations that the Israel Minister of Defense designated as ‘terrorists’ under Israeli law. The designation was issued only a few days after the evidence of Pegasus had emerged. Evidence supporting the designation has not been disclosed publicly, but the Israeli government has been lobbying the US and European governments to cut ties and funding with the organizations.

Pegasus is not an isolated example. During the COVID-19 pandemic, many states and corporations have significantly increased their surveillance and tracking capacities purportedly to combat the pandemic, often without regular check and balances due to the extraordinary powers that have been granted within the context of the global public health emergency.²⁰⁷

LEGAL BASIS FOR THE RIGHT TO PRIVACY

The right to privacy protects individuals’ private lives from intrusions by others, including the state and non-state actors (such as businesses and private individuals).

The legal basis for the principle of privacy rests in the right to privacy, which is found in numerous human rights treaties, primarily the International Covenant on Civil and Political Rights (ICCPR, 1966), the sister treaty of ICESCR. The Human Rights Committee (CCPR), which oversees the implementation of the ICCPR, defines the right to privacy as the: ‘right of every person to be protected against arbitrary or unlawful interference with his privacy, family, home or correspondence as well as against unlawful attacks on his honor and reputation.’ Here ‘unlawful’ means that any interference must be provided for in law and ‘arbitrary’ means that any such interference must be in accordance with the aims and provisions of the ICCPR as well as ‘reasonable in the particular circumstances.’

UN mechanisms have relied²⁰⁸ on the definition of privacy as:

“ the presumption that individuals should have an area of autonomous development, interaction and liberty, a “private sphere” with or without interaction with others, free from State intervention and from excessive unsolicited intervention by other uninvited individuals ”

The right to privacy is also well-covered in thematic treaties dealing with specific groups, including:

- Convention on the Rights of the Child
- International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families
- Convention on the Rights of Persons with Disabilities.
- The right to privacy is also guaranteed at the regional level in region-specific human rights treaties.

UN bodies have extensively dealt with the issues of interferences on the right to privacy, and more specifically surveillance. The UN Special Rapporteur on the promotion and protection of the right to freedom of opinion and expression, David Kaye, held that “surveillance should only be authorized in law for the most serious criminal offenses.”²⁰⁹ Several UN human rights bodies have defined strict criteria for the use of surveillance, which should be consistent with the principles of legality, necessity and proportionality, subject to judicial authorization, reviewed on a regular basis, and in line with obligations under international law.²¹⁰ In particular, human rights bodies have repeatedly called on states to refrain from using surveillance technologies against HRDs, including by introducing adequate legislation to ensure an ‘enabling environment’ for HRDs and regulations on the sale, export and use of surveillance technologies.²¹¹

DATA PROTECTION²¹²

Data protection is a key way to protect the right to privacy and considered a right in and of itself in some human right frameworks. Data protection is commonly defined as the law designed to protect your personal information, which is collected, processed and stored by “automated” means or intended to be part of a filing system.

Because of the nature of human rights data, some human rights data will fall under the category of personal data or sensitive personal data, invoking data protection laws where they exist. Sensitive data does not make a person identifiable (unlike personal data), yet it relates to sensitive characteristics such as race or ethnic identity, sexual orientation, political opinions, physical and mental health, disability, criminal convictions or offenses, and biometric and genetic data. Although the processing of sensitive or personal data has implications for everyone’s rights and freedoms, for individuals from marginalized groups, for example, Indigenous peoples, undocumented migrants, the LGBTQIA+ community, sex workers, or for human rights defenders, the collection and disclosure of sensitive data carries heightened security risks, which need to be mitigated. However, because this data concerns groups at risk

of discrimination or groups that already face discrimination, it is important data is collected from a human rights perspective—otherwise human rights data would be unrepresentative and low quality, especially in uncovering discrimination, the extent and scope of the discrimination, and its impacts. Data protection frameworks serve to balance the rights of individuals with the legitimate processing of personal data. It permits the processing of sensitive data but there are stricter conditions and additional safeguards for the processing of that data.

Data protection laws should have certain features. Data protection laws should elaborate data principles, the rights of individuals in relation to their personal data, legitimate grounds for processing personal data, the obligations of data processors and controllers, accountability and governance structures, and data security considerations.

The rights of individuals in relation to their personal data can include: the right to be provided with and to obtain information about how their data is processed (including how and when it is used); the right to object to the processing of their data, or to rectify it; the right to an effective judicial remedy when their rights are breached, and to compensation for any damage caused. These rights also apply when it comes to automated systems based on the profiling of individuals, which means people should be informed about the profiling and how it takes place, for example of “inferences about sensitive preferences and characteristics, including when derived from data which is not per se sensitive,” and should have a right to access, rectify or delete their own data used for profiling.

As a general rule, personal data must be processed under a **lawful basis**, which means that data can only be processed according to grounds specified by law. Lawful grounds usually include: consent of the data subject, compliance with a legal obligation (including human rights obligations), performance of a contract with the data subject, public interest, and in some instances for scientific, historical, and statistical purposes. Both ‘compliance with a legal obligation’ and ‘public interest’ can be read as grounds for the collection of personal data needed to fulfill ESCR obligations.

For human rights purposes, sometimes careful evaluation is required when it comes to the disclosure of personal information and the principle of necessity. For example, human rights defenders, journalists, and civil society organizations may need to disclose personal information in order to reveal human rights abuses. The Office of the High Commissioner for Human Rights argues: In some cases, such as human rights monitoring, it is necessary and useful to publish

data that identifies individuals. This may occur when an individual has been the victim of a crime/human rights violation and the publication of information about the incident is necessary to hold the perpetrators to account. This should only be done where strictly necessary, and only where permission has been given by the individual concerned. In the case of persons who are deceased or who have been kidnapped, detained or disappeared, permission could come from their family or close associates. Data collectors should consider the impacts on the individual and on those associated with them in every case before publishing data of this nature.²¹³

CONSENT

The consent to provide personal data relates to the right to self-determination and autonomy. Providing consent is an explicit and active process—consent should not be implicit or passive. On the contrary, for consent to be meaningful, it must be informed, specific, unambiguous and given freely.

However, it is not always possible or appropriate to seek consent. As Privacy International explains: “in many situations where there is a strong power imbalance between the individual and the data processor (e.g. between employee and employer), consent cannot be freely given and therefore another legal ground must justify the processing of the personal data (e.g. performance of a contract).” The UK Information Commissioner's Office (the UK's independent authority that upholds information rights in the public interest) gives the following example: A housing association needs to collect information about the previous convictions of tenants and prospective tenants for risk-assessment purposes when allocating properties and providing home visits. However, it is inappropriate to ask for consent for this as a condition of the tenancy. A tenant applying for social housing may be in a vulnerable position and may not have many other housing options. So they may have no real choice but to sign up to the housing association's terms. Even if the processing is necessary to provide the accommodation, their consent is not considered freely given because of the imbalance of power.

In some countries, public bodies are exempt from obtaining consent when fulfilling their legal functions, which can be problematic and needs to be well-regulated to ensure that privacy and data protection can be maintained. Even when consent is

given, the data must be processed in ways that protects the rights of individuals and the principles listed below.

Data protection laws also identify **principles for data processing**. For instance, processing of personal data should be **fair and transparent** and done in a lawful manner, so that people's data is not used in ways they would not expect. In addition, the data should not be used for a **purpose** other than the one that the person consented to when they provided their data. If an agency wants to use the data for a different purpose it must seek the person's consent again and identify a legal basis for processing it.

Another relevant principle of data protection is **data minimization**, that is, states should gather and process only data needed to meet the specific purposes identified. A general test to be applied is to assess whether the same aim could be achieved with less data. The principles of fairness and of data minimization are crucial in the current context of mass-scale extraction and processing of personal data. As Privacy International reflects:

“ advancement in technology has radically improved analytical techniques for searching, aggregating, and cross-referencing large data sets in order to develop intelligence and insights. With the promise and hope that having more data will allow for accurate insights into human behavior, there is an interest and sustained drive to accumulate vast amounts of data. There is an urgent need to challenge this narrative and ensure that **only data that is necessary and relevant for a specific purpose** should be processed. ”

The principle of data minimization should not be read in contradiction with states' obligations to gather data disaggregated by sex, age and other personal characteristics to gain an accurate understanding of how different groups experience the enjoyment of ESCR. Instead, states should consider the least 'intrusive' ways to gain a representative picture of a population group and should limit the processing and sharing of this data to the purpose of human rights programming.

LEGAL BASIS OF DATA PROTECTION

ICCPR and ICRPD²¹⁴ recognize data protection as part of the right to privacy. In its General Comment on the right to privacy, the CCPR has stated:

“ The gathering and holding of personal information on computers, data banks and other devices, whether by public authorities or private individuals or bodies, must be regulated by law. Effective measures have to be taken by States to ensure that information concerning a person’s private life does not reach the hands of persons who are not authorized by law to receive, process and use it, and is never used for purposes incompatible with the Covenant. ”

Data protection laws have been most elaborated at the regional level. In Europe, the right to data protection is recognized under the Charter of Fundamental Rights of the European Union²¹⁵ and implemented by the European Union’s (EU) General Data Protection Regulation²¹⁶ (GDPR), which sets out a range of rights, including the right to be informed; the right of access; the right to be forgotten; the right to object; and rights in relation to automated decision making and profiling. In addition, the Council of Europe (which is distinct from the European Union) has also developed a treaty on data protection.²¹⁷ This treaty is of relevance because it has also been ratified and/or signed by non-European countries.²¹⁸

In Africa, two mechanisms regulate the processing of data, at the sub-regional and regional level:

- Economic Community of West African States (ECOWAS) Supplementary Act on Personal Data Protection (2010)²¹⁹
- African Union (AU) Convention on Cyber Security and Personal Data Protection (2014, Malabo Convention)²²⁰

In the Asia-Pacific region, data protection is covered by the Asia-Pacific Economic Cooperation (APEC) Privacy Framework (2004) and in the Americas, the Organization of American States has prepared preliminary Principles and Recommendations on Data Protection.²²¹

Lastly, data protection has received attention from the Organisation For Economic Co-operation And Development (OECD), which released Guidelines on the Protection of Privacy and Transborder Flows of Personal Data in 1980 (subsequently updated in 2013). The Guidelines

establish principles, such as that data collection should be limited and should only be obtained by lawful and fair means, with consent, where appropriate; data should only be collected for pre-specified purposes; and personal data should be protected by reasonable security safeguards against such risks as loss or unauthorized access, destruction, use, modification or disclosure of data. The Guidelines also set out how states should implement the principle of accountability and ensure the free flow of personal data subject to certain conditions.

GENERAL RECOMMENDATIONS FOR IMPLEMENTING PRIVACY:

1. States must ensure that the right to privacy is protected throughout all data and monitoring processes geared towards the production and use of human rights data, as well as the data governance structures that undergird these processes.
2. States should ensure that access to essential services is not contingent on the disclosure of private or sensitive data and, where that is necessary, safeguards must be in place to ensure the person's privacy is not breached, for instance, by regulating how the data must be collected, analyzed, stored and shared.
3. States must carefully regulate data processing by private actors and public bodies that could be used to harm specific groups or individuals or in ways that amplify existing inequalities.

RECOMMENDATIONS ON DATA PROTECTION:

1. States must implement the right to data protection, including through, but not limited to, the adoption of legislation, regulation, policies, and educational measures.
2. Data protection laws must comply with international and regional standards, and must elaborate data principles, the rights of individuals in relation to their personal data, legitimate grounds for processing personal data, the obligations of data processors and controllers, accountability and governance structures, and data security considerations.
3. While enforcing data protection rules, states should also pursue national and global regulations that meaningfully break the power monopoly of tech companies and



strive for data governance systems in which people exert fuller control over their data and knowledge.

4. States should refrain from entering into agreements with technology companies where private or sensitive data about people is retained or controlled by the company.

RECOMMENDATIONS ON SURVEILLANCE:

1. States should strictly regulate the use of surveillance technologies to comply with the principles of legality, necessity and proportionality, and ensure that they are pursuant to judicial authorization and oversight, reviewed under regular basis and in compliance with obligations under international law. The use of surveillance should not be justified under broadly-defined grounds such as national security.
2. States should ensure that surveillance technologies are not used to target human rights and environmental defenders, journalists and others who may be at risk due to their activities.

CONCLUSION

Data plays a crucial role in informing public policy and decision-making. Our starting point for this collective position is that data is inherently political. Often, data has been used by those in power to justify decisions that cement power over others, and replace difficult political conversations with choices masked as purely technical in nature. This has allowed those in power to sidestep confronting more systemic problems, such as inequality, racism, patriarchy and failed to advance human rights and social justice for all.

This position analyzes how today's data processes reinforce existing inequalities and patterns of exclusion, and suggests a set of five principles and recommendations for states to use data in ways that overcome existing injustices and advance ESCR for all. Drawing from international human rights law, these principles articulate an approach to data production that enables the participation of groups who tend to be marginalized or excluded, visibilize their issues, legitimize their experiences and make public decision-making more accountable and responsive to the needs of everyone. In other words, these principles seek to redistribute power and enable more democratic and participatory public decision-making.

We hope that this collective position can contribute to building a critical understanding of data that responds to the needs and experiences of grassroots groups and communities facing injustices, and inform the work and advocacy of civil society organizations working for the defense of economic, social and environmental rights - especially within our membership. We're also eager to bring this position into key discussion spaces -and explore practical applications- with human rights bodies and public institutions at international and national level, as well as multilateral organizations and agencies, and academia.



ENDNOTES

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² <https://www.escr-net.org/about-us/mission-and-governance>

³ <https://www.escr-net.org/common-charter-collective-struggle>

⁴ While we recognize the contribution of civil society in gathering and using data to advance human rights and accountability, ultimately it is states that must produce and use high quality data, and make it publicly available, in line with their human rights obligations.

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⁶ See: <https://www.escr-net.org/news/2019/building-alternative-narrative-escr-data>

⁷ Parallel to efforts to deepen the analysis around data and ESCR, the Monitoring WG also launched a project to support movements in gathering their own on issues of land, housing and natural resources: <https://www.escr-net.org/reclaimingourstories/>

⁸ The summary document was discussed with participants of the second women leaders exchange in Chiang Mai, Thailand in 2019 <https://www.escr-net.org/news/2019/women-articulating-shared-positions-and-advancing-collective-action-land-and-natural>

⁹ See acknowledgments section below

¹⁰ See acknowledgments section below

¹¹ CESCR (2009) *General Comment 20: Non-discrimination in Economic, Social and Cultural Rights (Art. 2, Para. 2 of the Covenant)* (Doc. E/C.12/GC/20) (CESCR General Comment 20) para. 41.

¹² The legal definition of discrimination is: “any distinction, exclusion, restriction, or preference or other differential treatment that is directly or indirectly based on the prohibited grounds of discrimination and which has the intention or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of [economic, social, and cultural] rights” CESCR. 2009. *General Comment 20: Non-discrimination in Economic, Social and Cultural Rights (Art. 2, Para. 2 of the Covenant)*, para. 7. (Doc. E/C.12/GC/20) (CESCR General Comment 20)

¹³ CRPD.

¹⁴ ICESCR, Article 2 (1).

¹⁵ CESCR General Comment 20, para. 10.



¹⁶ CESCR General Comment 20, para. 10.

¹⁷ CESCR General Comment 20, para. 9.

¹⁸ CESCR General Comment 20, para. 9.

¹⁹ CESCR General Comment 20, para. 12.

²⁰ CEDAW, General Comment 28, para 16; CESCR General Comment 20, para. 12.

²¹ UDHR, Article 1.

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²⁴ The Mobile Gender Gap Report 2020, GSMA <https://www.gsma.com/mobilefordevelopment/wp-content/uploads/2020/05/GSMA-The-Mobile-Gender-Gap-Report-2020.pdf> (Accessed 01/25/2022)

²⁵ Citing R Shearmur (2015), Linette Taylor writes "access to technology increasingly determines who can be seen: [...] those who use big data to study behavior or shape policy are seeing not society but 'users and markets'." L Taylor, 'What is data justice?' In *Big Data and Society*, 2017:1-14 <https://journals.sagepub.com/doi/full/10.1177/2053951717736335> (Accessed 01/25/2022)

²⁶ European Parliamentary Research Service (2019), *Understanding algorithmic decision making: opportunities and challenges*, available at [https://www.europarl.europa.eu/RegData/etudes/STUD/2019/624261/EPRS_STU\(2019\)624261_EN.pdf](https://www.europarl.europa.eu/RegData/etudes/STUD/2019/624261/EPRS_STU(2019)624261_EN.pdf)

²⁷ V. Eubanks, *Automating Inequalities: Automating Inequality: How High-Tech Tools Profile, Police, and Punish the Poor* (New York, Picador, 2018).

²⁸ See, for example, Committee on the Elimination of Racial Discrimination (2019) *Draft General recommendation No. 36: Preventing and Combating Racial Profiling: A call for contribution by 30 June 2019*, para. 32. (CERD/C/GC/36.); Algorithm Watch (2020) *Automating Society Report 2020*. Available at <https://automatingsociety.algorithmwatch.org/wp-content/uploads/2020/10/Automating-Society-Report-2020.pdf> (Accessed 02/24/2021)

²⁹ UN Special Rapporteur on contemporary forms of racism, racial discrimination, xenophobia and related intolerance (2020), *Racial discrimination and emerging digital technologies: a human rights analysis A/HRC/44/57*

³⁰ The EU Agency for Fundamental Rights (2018), *#BigData: Discrimination in data-supported decision-making* p. 5, available at https://fra.europa.eu/sites/default/files/fra_uploads/fra-2018-focus-big-data_en.pdf

³¹ Ibid

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³⁴ Lopez, P. (n.d.) *Reinforcing Intersectional Inequality via the AMS Algorithm in Austria*. Available at https://paolalopez.eu/wp-content/uploads/2019/11/LOPEZ_Preprint.pdf (Accessed 02/24/2021)

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³⁶ Universal Declaration of Human Rights, 1948, Articles 2 and 7.

³⁷ International Covenant on Economic, Social, and Cultural Rights, 1966, Article 2 (3).

³⁸ International Covenant on Civil and Political Rights, 1966, Articles 2 (2) and 26.

³⁹ ICERD, Article 1.

⁴⁰ CESCR. 2009. *General Comment 20: Non-discrimination in Economic, Social and Cultural Rights (Art. 2, Para. 2 of the Covenant)* (Doc. E/C.12/GC/20) (CESCR General Comment 20) para. 7.

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⁴² *E.g.*, Convention on the Elimination of All Forms of Discrimination against Women (adopted 18 December 1979, entered into force 3 September 1981) 1249 UNTS 13 (CEDAW) Articles 1-5; International Convention on the Elimination of All Forms of Racial Discrimination (adopted 21 December 1965, entered into force 4 January 1969) 660 UNTS 195 (ICERD) Articles 1-3.

⁴³ *E.g.*, Convention on the Rights of the Child (1989) Article 2; Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) 2515 UNTS 3 (CRPD) Articles 4-6 and 12; International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families (adopted 18 December 1990, entered into force 1 July 2003) 220 UNTS 3 (ICRMW) Article 1(1); Convention relating to the Status of Refugees (adopted 28 July 1951, entered into force 22 April 1954) 189 UNTS 137 (Refugee Convention) Article 3.

⁴⁴ *E.g.*, ICESCR; ICCPR.

⁴⁵ Articles 2 African (Banjul) Charter on Human and Peoples' Rights; Articles 3 African Charter on the Rights and Welfare of the Child; Articles 2 Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa; Article 2 African Youth Charter; Article 3 Arab Charter on Human Rights; Article 2 ASEAN Human Rights Declaration; Article 14, European Convention on Human Rights; Article 21, Charter of Fundamental Rights of the European Union; Article 3 Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights.

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¹⁰⁵ Read more at <https://accountabilityproject.org/work/>

¹⁰⁶ See above p. 43

¹⁰⁷ United Nations (2011) *Guiding Principles on Business and Human Rights*. (HR/PUB/11/04.)

¹⁰⁸ For example, the OECD Principles for Private Sector Participation in Infrastructure.

¹⁰⁹ See above p. 44 and <https://www.ohchr.org/EN/Issues/IPeoples/Pages/Free-prior-and-informed-consent.aspx>

¹¹⁰ See, for example, Front Page Africa (2021) *Independent Complaints Panel Finds Golden Veroleum Liable of Destroying Liberia's Forests*. Available at <https://frontpageafricaonline.com/front-slider/independent-complaints-panel-finds-golden-veroleum-liable-of-destroying-liberias-forests/> (Accessed 03/11/2021)



¹¹¹ Much conceptual work has been done to clarify and elaborate what a human rights-based approach to participation looks like. See, for example, Human Rights Council (2013) *Report of the Special Rapporteur on extreme poverty and human rights, Magdalena Sepúlveda Carmona*. (A/HRC/23/36)

¹¹² UNDRD, Article 2 (3).

¹¹³ UN General Assembly (2014) *Report of the Special Rapporteur on the human right to safe drinking water and sanitation*, Section III (A/69/213)

¹¹⁴ Christiana Louwa, Elmolo indigenous community and World Forum of Fisher People, Kenya, and ESCR-Net Board member, at the second grassroots women's leaders exchange, Chiang Mai, Thailand, 2019

¹¹⁵ British Columbia's Office of the Human Rights Commissioner (2020) Disaggregated demographic data collection in British Columbia: The grandmother perspective, p.86. Available at https://bchumanrights.ca/wp-content/uploads/BCOHR Sept2020_Disaggregated-Data-Report_FINAL.pdf (Accessed 02/16/2021)

¹¹⁶ Rainie, S., Kukutai, T., Walter, M., Figueroa-Rodriguez, O., Walker, J., & Axelsson, P. (2019) Issues in Open Data - Indigenous Data Sovereignty. In T. Davies, S. Walker, M. Rubinstein, & F. Perini (Eds.), Cape Town and Ottawa: African Minds and International Development Research Centre. Available at <https://www.stateofopendata.od4d.net/chapters/issues/indigenous-data.html> (Accessed 02/08/2021)

¹¹⁷ Rainie, S., Rodriguez-lonebear, D., Martinez, A. (2017) *Policy brief: Indigenous Data Sovereignty in the United States*. Tucson: Native Nations Institute, University of Arizona. Available at https://static1.squarespace.com/static/5d2633cb0ef5e4000134fa02/t/5d72cb394452727586b69c2e/1567804217938/policy_brief_indigenous_data_sovereignty_in_the_united_states.pdf (Accessed 02/08/2021)

¹¹⁸ Montana Budget and Policy Center (2019) *It is Time to Decolonize Data*. Available at <https://montanabudget.org/post/time-to-decolonize-data> (Accessed 02/08/2021)

¹¹⁹ Rainie, S., Rodriguez-lonebear, D., Martinez, A. (2017)

¹²⁰ ICCPR, Article 25.

¹²¹ Human Rights Committee (1996) *General Comment No. 25 (57)*, para.5. (CCPR/C/21/Rev.1/Add.7)

¹²² Human Rights Committee (1996) *General Comment No. 25 (57)*, para.6. (CCPR/C/21/Rev.1/Add.7)

¹²³ CESCR (2008) *General Comment No. 19: The right to social security (art. 9)*, para. 4 (d). (E/C.12/GC/19)

¹²⁴ CESCR (2016) *General comment No. 22: The right to sexual and reproductive health (article 12 of the International Covenant on Economic, Social and Cultural Rights)*, para.49 (b). (E/C.12/GC/22.)

¹²⁵ CEDAW, Articles 7, 8, 14 (2).

¹²⁶ CRPD, Articles 3 (c), 4 (3), 29, 33(3).

¹²⁷ ICRMW, Articles 41 and 42.

¹²⁸ ICERD, Article 5 (c).

¹²⁹ UNDRIP, Articles 5, 18, 19, 41. Indigenous peoples have both a right to participate in the conduct of public affairs and a right to maintain their own decision-making structures. Article 18, for example, states: ‘Indigenous peoples have the right to participate in decision-making in matters which would affect their rights, through representatives chosen by themselves in accordance with their own procedures, as well as to maintain and develop their own indigenous decision-making institutions.’

¹³⁰ African Charter on Human and Peoples’ Rights, Article 13 and 17; American Convention on Human Rights (Pact of San Jose), Article 23; European Convention on Human Rights, Article 3 of Protocol 1; Framework Convention for National Minorities, Article 15.

¹³¹ UNDRD, Article 2 (1).

¹³² UNCESCR (2017) General comment No. 24 on State obligations in the context of business activities; United Nations, E/C.12/GC/24; UN (2011) *Guiding Principles on Business and Human Rights*.

¹³³ “Community Engagement and Investment to Advance Human Rights in Supply Chains,” UN Global Compact. https://d306pr3pise04h.cloudfront.net/docs/issues_doc%2Fhuman_rights%2FHuman_Rights_Working_Group%2FCommunityEngage_Inv_SupplyChain.pdf

¹³⁴ “Human Rights in UNDP” Practice Note. https://www.un.org/ruleoflaw/files/HRPN_English.pdf.

¹³⁵ Unrepresented Nations and Peoples Organization (UNPO) (2017) Self-determination. Available at <https://unpo.org/article/4957> (Accessed 02/08/2021)

¹³⁶ CCPR (1984) General Comment No. 12: Article 1 (Right to Self-determination) The Right to Self-determination of Peoples, para.1.

¹³⁷ Charter of the United Nations (adopted 24 October 1945, entered into force 24 October 1945) 1 UNTS XVI (UN Charter), Article 1.

¹³⁸ ICESCR, Article 1.

¹³⁹ ICCPR, Article 1.

¹⁴⁰ See, for example, a list of provisions at Minority Rights Group International’s page Self-determination. Available at <https://minorityrights.org/law/self-determination/> (Accessed 02/08/2021)

¹⁴¹ ICESCR and ICCPR, Article 1 (1).

¹⁴² ICESCR and ICCPR, Article 1 (2).

¹⁴³ ICESCR and ICCPR, Article 1 (2). See, for example, United Nations United Nations and Decolonization. Available at <https://www.un.org/dppa/decolonization/en> (Accessed 02/08/2021)

¹⁴⁴ CERD (1996) General recommendation 21: The right to self-determination, para.4

¹⁴⁵ Ibid

¹⁴⁶ UNDRIP, Article 3.

¹⁴⁷ UNDRIP, Article 5.



¹⁴⁸ UNDRIP, Article 14.

¹⁴⁹ UNDRIP, Article 16.

¹⁵⁰ Available at

<https://static1.squarespace.com/static/58e9b10f9de4bb8d1fb5ebbc/t/5913020d15cf7dde1df34482/1494417935052/Te+Mana+Raraunga+Charter+%28Final+%26+Approved%29.pdf> (Accessed 02/08/2021)

¹⁵¹ Research Data Alliance International Indigenous Data Sovereignty Interest Group (2019) CARE Principles for Indigenous Data Governance. The Global Indigenous Data Alliance.

<https://usindigenousdata.org/care-principles> (Accessed 02/08/2021)

¹⁵² Read more at <https://www.transparency.org/en/corruptionary/transparency>

¹⁵³ Rijmenam, M., v. (2019) *Algorithms are Black Boxes, That is Why We Need Explainable AI*. Available at

<https://markvanrijmenam.medium.com/algorithms-are-black-boxes-that-is-why-we-need-explainable-ai-72e8f9ea5438> (Accessed 02/04/2021)

¹⁵⁴ United Nations (2011) *Guiding Principles on Business and Human Rights*, Section 2 (B) (21).

¹⁵⁵ Global Witness (2021) *Last line of defence*, available at

<https://www.globalwitness.org/en/campaigns/environmental-activists/last-line-defence/> (Accessed 03/03/2022)

¹⁵⁶ *Panama Papers helps recover more than 1.2 billion USD around the world*. Available at

<https://www.icij.org/investigations/panama-papers/panama-papers-helps-recover-more-than-1-2-billion-around-the-world/> (Accessed 04/02/2021)

¹⁵⁷ Al-Haq (2020) *Over 75 Organisations Commend UN High Commissioner for Human Rights, Michelle Bachelet, on the Release of the Database of Businesses Involved in Illegal Israeli Settlements*. Available at

<https://www.alhaq.org/advocacy/16637.html> (Accessed 04/08/2021)

¹⁵⁸ Human Rights Council (2020) Report of the Office of the United Nations High Commissioner for Human Rights (OHCHR). *Database of all business enterprises involved in the activities detailed in paragraph 96 of the independent international fact-finding mission to investigate the implications of the Israeli settlements on the civil, political, economic, social and cultural rights of the Palestinian people throughout the Occupied Palestinian Territory, including East Jerusalem*. (A/HRC/43/71)

¹⁵⁹ Al-Haq (2020) *Civil Society Urges States to Support the Annual Update of the UN Database of Business Enterprises Involved in Illegal Settlement Activities in the OPT and the Work of OHCHR*. Available at

<https://www.alhaq.org/advocacy/17417.html> (Accessed 04/08/2021)

¹⁶⁰ Al-Haq (2020) *Civil Society Urges States to Support the Annual Update of the UN Database of Business Enterprises Involved in Illegal Settlement Activities in the OPT and the Work of OHCHR*. Available at

<https://www.alhaq.org/advocacy/17417.html> (Accessed 04/08/2021)

¹⁶¹ United Nations General Assembly (2013) *Report of the Special Rapporteur on the promotion and protection of the right to freedom of opinion and expression*, para. 20. (A/68/362)



¹⁶² CCPR (2011) *General Comment 34: Article 19: Freedoms of opinion and expression*, para. 19. (Doc. CCPR/C/GC/34.) (CCPR General Comment 34)

¹⁶³ Article 19 (n.d.) *Access to information*. Available at <https://www.article19.org/issue/access-to-information/> (Accessed 04/08/2021)

¹⁶⁴ See above, f116 related to UNDRIP. For consent to be ‘informed’, information needs to be provided about a range of aspects, including the nature, size, pace, reversibility and scope of any proposed project or activity; the purpose of the project as well as its duration; locality and areas affected; a preliminary assessment of the likely economic, social, cultural and environmental impact, including potential risks; personnel likely to be involved in the execution of the project; and procedures the project may entail.

¹⁶⁵ For example, in Sri Lanka our member NAFSO highlighted challenges in accessing official information on development projects taking place in militarized areas of the country under the National Physical Plan (NPP).

¹⁶⁶ See <https://opendefinition.org/>

¹⁶⁷ See Open Definition 2.1 for further information.

¹⁶⁸ See <https://opendatacharter.net/principles/>

¹⁶⁹ International Covenant on Civil and Political Rights (adopted 16 December 1966, entered into force 23 March 1976) 999 UNTS 171 (ICCPR), Article 19 (2).

¹⁷⁰ CCPR General Comment 34, para. 18.

¹⁷¹ Ibid

¹⁷² CCPR General Comment 34, para. 19.

¹⁷³ Ibid

¹⁷⁴ Ibid

¹⁷⁵ Article 19 (3), ICCPR.

¹⁷⁶ Convention on the Rights of the Child, Article 13 (1).

¹⁷⁷ Convention on the Rights of Persons with Disabilities, Article 21.

¹⁷⁸ International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families, Article 13 (2).

¹⁷⁹ See, for example, Article 19 (2012) *International standards: Right to information*. Available at <https://www.article19.org/resources/international-standards-right-information/> (Accessed 03/27/2021)

¹⁸⁰ American Convention on Human Rights, Article 13 (1). For further information on the right to access information, see Special Rapporteur for freedom of expression (2009) Interamerican Commission On Human Rights, Organization Of American States, *Report 2009: The right of access to information*. Available at http://www.oas.org/dil/access_to_information_iachr_guidelines.pdf (Accessed 03/27/2021)



¹⁸¹ Regional Agreement on Access to Information, Public Participation and Justice in Environmental Matters in Latin America and the Caribbean (adopted 4 March 2018, entered into force 22 April 2021).

¹⁸² Global Witness (2021) *Last line of defence*, available at <https://www.globalwitness.org/en/campaigns/environmental-activists/last-line-defence/> (Accessed 03/03/2022)

¹⁸³ <https://www.opendemocracy.net/en/can-europe-make-it/making-migrants-visible-covid-19-counting-dilemma/>

¹⁸⁴ UN General Assembly (2019) *Report of the Special Rapporteur on extreme poverty and human rights (A/74/493)*

¹⁸⁵ Algorithm Watch (2020) *How Dutch activists got an invasive fraud detection algorithm banned*. Available at <https://algorithmwatch.org/en/story/syri-netherlands-algorithm/> (Accessed 01/25/2021)

¹⁸⁶ *Nederlands Juristen Comité voor de Mensenrechten et al. v. The Netherlands*, ECLI:NL:RBDHA:2020:1878. Case summary available at <https://www.escri-net.org/caselaw/2020/nederlands-juristen-comite-voor-mensenrechten-et-al-v-netherlands-ecliniRbdha20201878> (Accessed 01/25/2021)

¹⁸⁷ Zuboff, S. (2019)

¹⁸⁸ Human Rights Watch (HRW) (2020) *COVID-19 and Children's Rights*. Available at <https://www.hrw.org/news/2020/04/09/covid-19-and-childrens-rights> (Accessed 12/17/2020)

¹⁸⁹ Ibid

¹⁹⁰ Information Commissioner's Office (2017) *Royal Free - Google DeepMind trial failed to comply with data protection law*. Available at

<https://ico.org.uk/about-the-ico/news-and-events/news-and-blogs/2017/07/royal-free-google-deepmind-trial-failed-to-comply-with-data-protection-law/> (Accessed 12/17/2020)

¹⁹¹ Human Rights, Big Data and Technology Project (n.d.) *Beyond privacy: the right to health implications of data sharing partnerships in healthcare*. Available at <https://www.hrbdt.ac.uk/beyond-privacy-the-right-to-health-implications-of-data-sharing-partnerships-in-healthcare/> (Accessed 12/17/2020)

¹⁹² Corporate capture refers to the means by which an economic elite undermines the realization of human rights and the environment by exerting undue influence over domestic and international decision-makers and public institutions. See ESCR-Net's Corporate Capture Project page: <https://www.escri-net.org/corporateaccountability/corporatecapture> (Accessed 04/21/2021)

¹⁹³ Human Rights, Big Data and Technology Project (2021) *Health*. Available at <https://www.hrbdt.ac.uk/health/> (Accessed 12/17/2020)

¹⁹⁴ See for example: ESCR-Net letter raising concerns regarding the partnership between Microsoft and the UN Human Rights Office: [https://www.escri-net.org/sites/default/files/attachments/escri-net letter to ohchr on microsoft partnership.pdf](https://www.escri-net.org/sites/default/files/attachments/escri-net%20letter%20to%20ohchr%20on%20microsoft%20partnership.pdf); and more recently, a letter from the Just Net Coalition asking the UN Secretary General to "shelve plans for" a privately-funded High Level Multistakeholder Body <https://justnetcoalition.org/big-tech-governing-big-tech.pdf> (Accessed 12/17/2021)

¹⁹⁵ See <https://www.somo.nl/how-big-tech-is-becoming-the-government/>



¹⁹⁶ For further information, see: the Ada Lovelace Institute's page *Data for the public good*. Available at <https://www.adalovelaceinstitute.org/our-work/themes/data-for-the-public-good/> (Accessed 17/04/2021) and <https://botpopuli.net/rescuing-our-common-agenda-from-the-post-democratic-abyss/> (Accessed 02/17/2022)

¹⁹⁷ Front Line Defenders (2021) *Global analysis 2021*, p.6.

¹⁹⁸ *Ibid.*

¹⁹⁹ 'What is Pegasus spyware and how does it hack phones?' The Guardian, 18th July 2021, Available at <https://www.theguardian.com/news/2021/jul/18/what-is-pegasus-spyware-and-how-does-it-hack-phones>

²⁰⁰ 'Al Jazeera journalist: I was traumatized by Pegasus spyware' London Daily, Available at <https://londondaily.com/al-jazeera-journalist-i-was-traumatized-by-pegasus-spyware>

²⁰¹ 'Brussels, EU governments on collision course over pegasus spyware' Politico, 15th February 2022, available at <https://www.politico.eu/article/brussels-eu-government-collision-course-pegasus-spyware/>

²⁰² Read more at <https://www.accessnow.org/women-human-rights-defenders-pegasus-attacks-bahrain-jordan/>

²⁰³ *Ibid.*

²⁰⁴ The Guardian (2021)

²⁰⁵ These findings were later confirmed by Amnesty International and Citizens Lab. FLD report: <https://www.frontlinedefenders.org/en/statement-report/statement-targeting-palestinian-hrds-pegasus> (Accessed 02/ 25/2022).

²⁰⁶ In addition to Al-Haq; Defense for Children – Palestine; the Union of Agricultural Work Committees; Bisan Center for Research and Development; the Union of Palestinian Women Committees and ESCR-Net member Adameer

²⁰⁷ Read more at <https://privacyinternational.org/examples/tracking-global-response-covid-19>

²⁰⁸ See for instance the UN SR on the promotion and protection of the right to freedom of opinion and expression (2013), A/HRC/23/40, quoting Lord Lester and D. Pannick (eds.). *Human Rights Law and Practice*. London, Butterworth, 2004, para. 4.82.

²⁰⁹ UN Doc A/HRC/41/35 (28 May 2019)

²¹⁰ UN Human Rights Council Resolution on the Right to Privacy in the Digital Age, UN Doc A/HRC/RES/48/4 (7 October 2021)

²¹¹ A/HRC/RES/48/4 and UN General Assembly Resolution A/RES/76/174 (16 December 2021)

²¹² This section is based on Privacy International (2018) *The Keys to Data Protection: A Guide for Policy Engagement on Data Protection* and Human Rights Council (2018) *The right to privacy in the digital age: Report of the United Nations High Commissioner for Human Rights*, Section B. (A/HRC/39/29)

²¹³ Office of the High Commissioner for Human Rights (2018) *A Human Rights Based Approach to Data - Leaving No One Behind in the 2030 Agenda for Sustainable Development. Guidance Note to Data Collection and Disaggregation*, p.17.



²¹⁴ Article 31 of the ICRPD on statistics and data collection reads:

1. States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall: a) Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;

²¹⁵ Charter of Fundamental Rights of the European Union (adopted 7 December 2000, entered into force 1 December 2009) 2000 O.J. C 364., Article 8.

²¹⁶ European Parliament and Council of European Union (2016) *Regulation (EU) 2016/679*. (GDPR)

²¹⁷ Council of Europe Protocol amending the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (ETS No. 108) (adopted 18 May 2018) CETS No. 223.

²¹⁸ As of 21/12/2020: Argentina, Cabo Verde, Mauritius, Mexico, Morocco, Senegal, Tunisia, and Uruguay.

²¹⁹ Economic Community of West African States (ECOWAS) (2010) Supplementary Act AS/A.1/01/10 on Personal Data Protection within ECOWAS.

²²⁰ African Union (AU) (2014) Convention on Cyber Security and Personal Data Protection (adopted 27/06/2014) (Malabo Convention).

²²¹ Permanent Council Of The Organization Of American States Committee On Juridical And Political Affairs (2011) *Preliminary Principles And Recommendations On Data Protection (The Protection Of Personal Data)*. Available at http://www.oas.org/dil/CP-CAJP-2921-10_rev1_corr1_eng.pdf (Accessed 12/17/2010)