3. Analytical framework

3.1 What is the meaning of “stigma and discrimination”?

Introduction

Research participants, including focus-group participants, NGO and CBO interviewees, and key informants from complaints mechanisms, were invited to give meaning to the terms “stigma” and “discrimination” in their own words. This was done to ensure participants had the conceptual freedom to identify practices and behaviours experienced as discriminatory or stigmatising. Some rich definitions were offered by the participants:

Stigma

NGO and CBO respondents broadly understood stigma as being a prejudicial, degrading or debasing attitude which results in a shameful or disgraceful stereotype, label or status imposed on a person. Respondents, in addition, included notions of exclusion, outcasting, disassociation and isolation in their understandings of stigma. These respondents, in all three countries, distinguished between social stigma and self-stigma:

“[Stigma is the] status of an individual when he is not taken as he is. [A] status that makes you not the same as others. [It is the] disassociation of a group or individual because of a certain status they have.” (NGO respondent – Lilongwe, Malawi)

“Self-stigmatisation means persons with disabilities withdrawing from public life and affairs with the thought that society neglects them and that they are less human than others. Therefore in the health sector societal stigma is linked to the fact that the disability of a person is sometimes directly the cause of their health problem.” (NGO respondent – Lusaka, Zambia)

Key informants from complaints mechanisms in the three countries emphasised notions of dishonour, humiliation and ridicule of a person or group and the results of stigma in terms of isolation, disempowerment and social withdrawal.

“It is a set of negative and often unfair beliefs that a society or group of people have about something.” (Complaints mechanism respondent – Malawi)
Discrimination

Focus-group participants across categories had inter-related understandings of stigma and discrimination, drawing on the causal relationship between the two ideas:

“Discrimination, it can be in a way of ... not being treated the same. Like in our case just because of what you are or what affects you, people will definitely isolate you in a certain manner. Also discrimination leads to stigma when a person is being discriminated, you will be labelled and people begin to call you all sorts of things. So I think discrimination and stigma are interrelated in a way.” (LGBT respondent – Kitwe, Zambia)

Some civil society and CBO respondents shared the idea of discrimination as stigma enacted:

“[Discrimination] is the manifestation of the stigma behaviour. For example, when a nurse calls the police because a transman has presented an [identity document] which is different from their gender presentation.” (NGO respondent – Gaborone, Botswana)

In explaining discrimination, focus-group participants captured, in their own words, three constituent elements of discrimination of: (1) prejudicial treatment that is (2) different to how others are treated, and (3) because one belongs to a particular group:

“Being treated unfavourably with a comparison to another person. Like when a certain group of people are being denied to enjoy a certain treatment which another group is enjoying.” (LGBT respondent – Zambia)

Sex worker respondents picked up on notions of power and social status:

“[Discrimination is] a misunderstanding between two or more people where one of the parties considers themselves superior to another in one way or other. The individual claiming superiority can do so due to their position, power and wealth.” (Sex worker respondent – Selebi Phikwe, Botswana)

Persons with disabilities participating in focus groups, in addition highlighted notions of indirect discrimination, in experiences where reasonable accommodation of differential needs was not provided:

“We are made to stay in the queue for a long time, even when they are giving out medical papers they don’t consider that we may have difficulties. Discrimination is when you make other people in society feel oppressed or deprived of that which others are enjoying. This refers to differences in treatment based on how we live here; they can look at how we look and what have you and judge you based on your disability.” (Person with disabilities respondent – Ndola, Zambia)

NGO and CBO respondents similarly described discrimination as including notions of unfair, differential treatment based on a person’s status or identity:

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“Discrimination is a kind of abuse but not all abuse is discriminatory – it is selective abuse; the unequal treatment of equals.” (NGO respondent – Lilongwe, Malawi)

“Systematically or systemically treating a patient or client seeking healthcare services differently – by either the service provider or communities – on the basis of that person’s race, sex, origin, colour, age, disability, religion, conscience, belief, culture, language, tribe, ethnic, social or economic status.” (NGO respondent – Lusaka, Zambia)

Key informants from complaints mechanisms generally provided less detailed understandings of discrimination but referred predominantly to prejudicial treatment that differentiated between persons. In some cases, respondents gave dismissive or defensive accounts of the term:

“Some cases are blatant, clear ‘discrimination’ while others are not. The term discrimination is not a concept that we ... employ. We classify such behaviours towards patients as professional misconduct, as nurses and midwives are expected to work by the regulations provided.” (Complaints mechanism respondent – Malawi)

“[Discrimination is] a perception where one feels they are being denied a service because of their medical condition.” (Complaints mechanism respondent – Zambia)

**UNAIDS describes HIV-related stigma and discrimination in the following ways:**

**HIV-related stigma** refers to the negative beliefs, feelings and attitudes towards people living with HIV, groups associated with people living with HIV (e.g. the families of people living with HIV) and other key populations at higher risk of HIV infection – such as people who inject drugs, sex workers, men who have sex with men, and transgender people.

**HIV-related discrimination** refers to the unfair and unjust treatment (act or omission) of an individual based on his or her real or perceived HIV status. Discrimination in the context of HIV also includes the unfair treatment of other key populations, such as some social contexts, women, sex workers, people who inject drugs, men who have sex with men, transgender people, people in prisons and other closed settings and, in some social contexts, women, young people, migrants, refugees and internally displaced people. HIV-related discrimination is usually based on stigmatising attitudes and beliefs about populations, behaviours, practices, sex, illness and death. Discrimination can be institutionalised through existing laws, policies and practices that negatively focus on people living with HIV and marginalised groups, including criminalised populations.*

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International human rights law

The right to freedom from discrimination is central to international human rights law. Article 2(1) of the International Covenant on Civil Political and Rights (ICCPR) obliges States to respect the rights of all individuals in its jurisdiction—

“without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.”

Article 26 of the ICCPR provides for the right to equality in the following terms:

“All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.”

Article 2 of the African Charter on Human and Peoples’ Rights similarly provides for the right to freedom from discrimination and article 3 creates a broad right to equal protection.

The prohibition against discrimination under international and regional African law includes both direct and indirect discrimination. The grounds of discrimination that are prohibited are considered non-exhaustive and include health status, actual or perceived HIV status, age, disability, marital or family status, sexual orientation, and gender identity.

The Convention on the Rights of Persons with Disabilities (CRPD) prohibits discrimination against persons with disabilities. NGO respondents described the CRPD’s vision of “discrimination” in the following words:


See, also, article 2 of the Universal Declaration of Human Rights (UDHR) United Nations General Assembly (UN GA) Res 217 A (III) UN Doc A/810 (10 December 1948); and article 2(2) of the International Covenant on Economic, Social and Cultural Rights (ICESCR) (16 December 1966) 993 UNTS 3, amongst others.


See, also, Article 18(3) (for specific provisions on the prohibition of discrimination against women) and article 2(1) of the Protocol to the African Charter on Human and People’s Rights on the Rights of Women in Africa (“Maseru Protocol”) (11 July 2013).


As above, at para 10(b).


See, also, UN Human Rights Committee (HRC) Concluding Observations of the Human Rights Committee: Republic of Moldova (4 November 2009), at para12.

See, for example, Zimbabwe Lawyers for Human Rights and Associated Newspapers of Zimbabwe v Zimbabwe (African Commission on Human and Peoples’ Rights Recommendation) 284/03, at para 155.

Botswana has not yet ratified the CRPD, Malawi ratified the CRPD in 2009, and Zambia did so in 2010.
3. ANALYTICAL FRAMEWORK

“Discrimination according to the CRPD is about distinction, exclusion, and restriction on the basis of disability with the purpose of nullifying or impairing the enjoyment or recognition of the right to access quality health. So any form of different treatment or inaccessibility or denial to quality health on the basis of disability is discrimination. This includes failure to provide reasonable accommodation to the health facility and restriction of informed consent to medical care and treatment.” (NGO respondent – Lusaka, Zambia)

Because the rights to non-discrimination and equality are both self-standing as well as applicable to the enjoyment of other human rights under regional and international law, jurisprudence on the right to health under international law and regional African law is inclusive of the obligation on states to ensure these rights are enjoyed without discrimination. The Committee on Economic, Social and Cultural Rights has stated, for example, in relation to the right to health under the International Covenant on Economic, Social and Cultural Rights (ICESCR):

“Health care and services must be available, in sufficient quantity, accessible (physically and economically) to all without discrimination, culturally acceptable and of good quality.”

While the right to health under international law is understood as subject to “progressive realisation” by States, the obligation not to discriminate in the provision of services and to provide those services equitably, paying attention to vulnerable and marginalised populations, is immediately realisable.

3.2 Effects of stigma and discrimination

Stigma and discrimination undermine people’s dignity and violate human rights protections. In addition, stigma and discrimination by healthcare workers and in healthcare facilities is prejudicial to the provision of quality care that is critical to ensure adherence to HIV treatment and the adoption of HIV-preventative behaviours, and creates barriers to accessing adequate care and

53 Article 25 of the Universal Declaration of Human Rights UN GA Res 217 A (III) UN Doc A/810 (10 December 1948) provides: “Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services”. Article 12(1) of the ICESCR provides that: “The States Parties to the present Covenant recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.” See, also, article 24 of the Convention on the Rights of the Child (CRC) UN GA Res 25 (XLIV) UN Doc A/RES/44/25 (1989) and article 12 of the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) UN GA Res 54/180 UN Doc A/34/46 (1980).

54 Article 16 of the African Charter provides: “1. Every individual shall have the right to enjoy the best attainable state of physical and mental health. 2. State Parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick.”

55 Botswana has not yet ratified the ICESCR, Malawi ratified the ICESCR in 1993, and Zambia did so in 1984.


57 The Committee identified the following, amongst others, as “minimum core” obligations of the right to health: “(a) To ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalised groups; … (e) To ensure equitable distribution of all health facilities, goods and services.”
Among others, discrimination in healthcare may inhibit affected persons from taking HIV tests or may delay testing beyond the point of optimal treatment initiation. Affected persons may refrain from seeking healthcare or from disclosing important information to healthcare providers to enable appropriate care. Affected persons may travel to different areas outside of their communities to access ART in secret, which may result in inconsistency in taking treatment. Healthcare workers living with HIV may also themselves experience difficulties accessing care from their own colleagues, in an environment of stigma and discrimination.

- The Joint United Nations Programme on HIV/AIDS (UNAIDS) has stated that “over thirty years into the epidemic, stigma remains high … and access to justice in the context of HIV is very low.”
- The World Health Organisation (WHO) has stated that countries “should work towards implementing and enforcing antidiscrimination and protective laws, derived from human rights standards, to eliminate stigma and discrimination against people from key populations.”
- Civil society organisations have recognised that despite progress in combatting HIV in sub-Saharan Africa, stigma and discrimination and human rights violations against people living with and at higher risk of HIV continue to undermine effective HIV responses.

3.3 The role of mechanisms for accountability and redress

International human rights law

“If we had effective and responsive complaints systems we would have seen a lot of improvements in the healthcare system. Healthcare workers should know they are accountable to the Health Professions Council and the public. Healthcare workers also don’t always know when what they are doing is discriminatory.” (NGO respondent – Lusaka, Zambia)

It is an established principle of law that for every right there must be a remedy. International human rights law affirms States’ obligations to ensure everyone has the right to an effective remedy for acts violating fundamental rights. The ICCPR provides for the right to an effective remedy in Article 2(3):

59 See, for example, D Carr et al. Achieving a Stigma-Free Health Facility and HIV Services: Resources for Administrators (2015).
61 Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations, note 2 above.
63 The Latin maxim ubi jus ibi remedium (‘where there is a right there is a remedy’) is often cited as an embodiment of this idea.
64 See article 8 of the UDHR.
“Each State Party to the present Covenant undertakes:
(a) To ensure that any person whose rights or freedoms as herein recognized are violated shall have an effective remedy, notwithstanding that the violation has been committed by persons acting in an official capacity;
(b) To ensure that any person claiming such a remedy shall have his right thereto determined by competent judicial, administrative or legislative authorities, or by any other competent authority provided for by the legal system of the State, and to develop the possibilities of judicial remedy;
(c) To ensure that the competent authorities shall enforce such remedies when granted.”

The right to equality before the law under Article 14(1) further specifies the entitlement to a fair and public hearing by a competent, independent and impartial tribunal enshrined by law in the determination of their rights and obligations. States are obliged under international law to make available “adequate, effective, prompt and appropriate remedies, including reparation” for victims of gross violations of human rights law.65

The United Nations Human Rights Committee (HRC) has explained that the right to an effective remedy under the ICCPR requires states to appropriately adapt remedies to take account of the special vulnerabilities of certain persons.66 The Committee understands that the provision further requires that reparations are made when a person’s rights have been violated, which can involve, where appropriate, compensation as well as:

“restitution, rehabilitation and measures of satisfaction, such as public apologies, ... guarantees of non-repetition and changes in relevant laws and practices, as well as bringing to justice the perpetrators of human rights violations.”67

States are further obliged to provide access to an effective remedy to ensure that, in practice, people can use these remedies.68 Processes must be affordable and accessible,69 and rights holders must have sufficient information to enforce their rights.70

Article 7 of the African Charter on Human and Peoples’ Rights provides that “every individual shall have the right to have his cause heard”. The Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Women in Africa, also requires that states “provide for appropriate

67 As above, at para 16.
69 General Recommendation No 28, as above, at para 34; HRC General Comment No 32: Article 14, Right to Equality before Courts and Tribunals and to Fair Trial (23 August 2007).
70 See, for example, General Comment 3, note 68 above; General Recommendation No 28, note 68 above, at para 2; CEDAW General Recommendation No 26 on Women Migrant Workers (5 December 2008), at para 26.
remedies to any woman whose rights or freedoms … have been violated”.71

For the purpose of this research, access to accountability and redress is understood to embody these principles of international human rights law relating to the right to an effective remedy as including both substantive and procedural protections for rights holders.

**Accountability and redress for healthcare discrimination**

In order to combat stigma and discrimination in healthcare, research indicates that interventions need to focus on individual, environmental, and policy levels.72 A lack of clear policies and guidance relating to HIV-positive healthcare users and other vulnerable populations reinforces discriminatory behaviours amongst healthcare workers.73 To be effective, such policies need to be routinely monitored and implemented.74

For the purpose of this report, “complaints” are understood to include any process or conduct in which a person can hold a healthcare worker or institution accountable, demand redress for wrongs experienced, or relate dissatisfaction with an experience, conduct or policy, in a healthcare setting. This includes both formal and informal processes and behaviours from direct confrontation of an individual healthcare worker to seeking legal redress in the courts.

Access to accountability and redress for healthcare users who experience discrimination in healthcare is an important component of reducing stigma and discrimination and in the fight against HIV and AIDS while serving a number of other functions for healthcare systems.75 Importantly, this need not be isolated to litigation in courts. Strategies for accountability and redress can include the use of decentralised complaints mechanisms, quasi-judicial processes at health professions counsel level and with national human rights institutions, and the use of the legal process and advocacy outside of the courts. Aside from providing redress for individual grievances and deterring undesirable conduct by service providers, complaints systems can also provide an opportunity for healthcare facilities and governments to access information which is vital to improve services, systems and policies at a systemic level and to identify trouble areas, which can contribute to improving self-regulation by healthcare providers. In addition, effective complaints systems can improve user confidence and citizen participation, and improve service-provider morale.76

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71 Article 25(a) of the Maseru Protocol note 45 above.
72 L Nyblade et al., note 58 above.
73 As above.
74 As above.
76 T Vian, note 75 above, 1.
What makes a good complaints process?

In order to evaluate the efficacy of the complaints processes in providing for accountability and redress, it is necessary to determine the features of a good complaints process. In a decision of the African Commission on Human and Peoples’ Rights, Jawara v The Gambia, three elements of an effective remedy were set out: availability, effectiveness and sufficiency. The Commission stated:

“A remedy is considered available if the petitioner can pursue it without impediment, it is deemed effective if it offers a prospect of success, and it is found sufficient if it is capable of redressing the complaint.”

Broadly speaking, a good complaints’ system can be considered available if it is accessible and easy to use. Accessibility should include physical accessibility and safety concerns for vulnerable populations. User needs in the community must be accommodated to ensure availability including considerations of literacy levels, access to telephonic communications, diverse needs of persons with disabilities, and language and cultural preferences. For these reasons, some analysts recommend multiple entry points for complaints lodging, including options of parties laying complaints on behalf of others or making anonymous complaints. Ease of access is further measurable on the clarity of rules or processes in place on how reports are made and to whom.

A measurement of the effectiveness of a complaints process can include the extent to which a complainant is able to access information about the status of their complaint and to which they can participate in the complaints proceedings. The transparency, efficiency, independence and accountability of the complaints system also contribute to its effectiveness by ensuring a complainant has an objective prospect of succeeding in pursuing redress.

Sufficiency is measurable by the capacity of the complaints system to deliver redress for the complainant. Research indicates greater efficacy and trust of complaints systems where they are empowered to provide some level of redress beyond advisory functions. The remedial powers of a complaints body are therefore important together with the prospect of enforcement.

For the purposes of a qualitative analysis of the effectiveness of the complaints systems detailed in Chapter 5, the table below indicates a series of indices taken from the human rights principles on which the evaluation is based.

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77 147/95-149/96 (2000), at para 32.
79 As above, at 3.
80 As above, 2.
# Indices to assess the effectiveness of complaints systems

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<tr>
<th>Available</th>
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<tr>
<td><strong>Physical accessibility</strong></td>
<td>• How are complainants outside of urban centres able to access the system to make a complaint?</td>
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<tr>
<td></td>
<td>• Is the system accessible for persons with disabilities to complain independently?</td>
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<tr>
<td><strong>Financial accessibility</strong></td>
<td>• Are there cost implications for complainants?</td>
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<tr>
<td></td>
<td>• Is legal assistance needed to succeed in a complaint?</td>
</tr>
<tr>
<td><strong>Safety for vulnerable populations</strong></td>
<td>• Can a person or organisation complain on behalf of another?</td>
</tr>
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<td></td>
<td>• Is there a possibility to complain anonymously?</td>
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<tr>
<td></td>
<td>• Can a complainant request that their identity be concealed?</td>
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<tr>
<td><strong>Diverse entry points</strong></td>
<td>• Must the complaint be in writing?</td>
</tr>
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<td></td>
<td>• How many options are there for methods of submitting a complaint?</td>
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<td></td>
<td>• Does the body provide assistance to persons in making complaints?</td>
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<tr>
<td><strong>Clarity of rules and procedures</strong></td>
<td>• Were NGO and CBO respondents aware of these procedures and how to access them?</td>
</tr>
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<td></td>
<td>• Did any respondents give examples of engaging this body to refer any healthcare-related complaints?</td>
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<tr>
<td></td>
<td>• Are the rules and procedures formalised in policy or law?</td>
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<td></td>
<td>• Was there a disparity between how key informants described processes and the formal procedures as written in law or policy?</td>
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<tr>
<th>Effective</th>
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<tr>
<td><strong>Complainant access to information and right to make representations</strong></td>
<td>• Is the complainant entitled to information on the status of their complaint, and is that entitlement guaranteed in law or policy?</td>
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<td></td>
<td>• Is the complainant entitled to present evidence or make representations during investigatory and decision-making processes?</td>
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<td></td>
<td>• Are both complainants and accused parties entitled to legal representation, or is only the accused entitled? In the alternative, are neither entitled to legal representation?</td>
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<tr>
<td><strong>Transparency</strong></td>
<td>• Are procedures publically accessible?</td>
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<td>• Are decision-makers required to give reasons for their decision?</td>
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### 3. ANALYTICAL FRAMEWORK

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<thead>
<tr>
<th>Efficiency</th>
<th>Independence</th>
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<tbody>
<tr>
<td>• How long does a complaint take to resolve?</td>
<td>• How are decision-makers appointed?</td>
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<tr>
<td>• How many complaints are dealt with in a year?</td>
<td>• Are there protections to ensure the independence of the decision-makers?</td>
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<tr>
<td>• Is the body’s budget sufficient?</td>
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<tr>
<th>Sufficient Scope of redress</th>
<th>Enforcement powers</th>
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<tr>
<td>• Can decision-makers impose sanctions on accused parties?</td>
<td>• Is the complaints body’s decision binding on the accused?</td>
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<td>• Can decision-makers require that the complainant’s loss is redressed (e.g. order compensation, restitution or an apology?)</td>
<td>• Can the complaints body make binding decisions against the government?</td>
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<tr>
<td>• Can the decision-maker impose systemic or policy change?</td>
<td>• Does the complaints body have external support for the enforcement of its decisions?</td>
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<tr>
<td>• Are complaints processed systemically to ensure information feedback into the healthcare system?</td>
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<tr>
<th>Appeal or review</th>
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<tr>
<td>• Is the decision of the complaints body subject to appeal by complainants?</td>
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<tr>
<td>• Is the decision of the complaints body subject to review by complainants?</td>
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