

# ACCESS TO COMPLAINTS MECHANISMS FOR VICTIMS OF HEALTHCARE DISCRIMINATION: A DEVELOPMENTAL IMPERATIVE

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## Introduction

“[O]ver thirty years into the [HIV] epidemic, stigma remains high ... and access to justice in the context of HIV is very low.”<sup>2</sup>

Southern Africa carries a disproportionately high share of the HIV burden. Stigma and discrimination are amongst the most significant barriers to effective HIV prevention and treatment.<sup>3</sup> Indications are that stigma and discrimination remain high, not only amongst people living with HIV, but also amongst those most vulnerable to HIV, including sex workers, lesbian, gay, bisexual and transgender (LGBT) persons, people who use drugs, prisoners and others.

In order to combat stigma and discrimination in healthcare, research indicates that interventions need to focus on individual, environmental, and policy levels.<sup>4</sup> To be effective, policies and laws need to be routinely monitored and implemented.<sup>5</sup> Advancing accountability and redress for discrimination in healthcare is therefore invaluable not only to realising the human rights of those who experience stigma and discrimination, but also vital to ensuring an effective response to HIV in the region.

Sustainable Development Goal<sup>6</sup> (SDG) 16 draws on the principles of access to justice, accountability of public institutions, and inclusion. This paper considers how complaints mechanisms may be used and improved to ensure the realisation of SDG 16 in the context of healthcare discrimination.

## Discrimination in Healthcare in Southern Africa

### Healthcare discrimination is unlawful and unethical

The right to freedom from discrimination is central to international human rights law.<sup>7</sup> The

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2 Joint United Nations Programme on HIV/AIDS (UNAIDS) “Guidance Note: Key Programmes to Reduce Stigma and Discrimination and Increase Access to Justice in National HIV Responses” (2012) 5.

3 *Id.* 2.

4 L Nyblade et al. “Combating HIV stigma in healthcare settings: what works?” (2009) 12 *J Int AIDS Soc.*

5 *Id.*

6 *Transforming Our World: The 2030 Agenda for Sustainable Development* (25 September 2015) A/RES/70/1.

7 See article 2 of the Universal Declaration of Human Rights (UDHR) A/810 (10 December 1948); article 2(2) of the International Covenant on Economic, Social and Cultural Rights (ICESCR) (16 December 1966) 993 UNTS 3; articles 2(1) and 26 of the International Covenant on Civil and Political Rights (ICCPR) (16 December 1966) 999 UNTS 171; and articles 2 and 28 of the African Charter on Human and Peoples’ Rights (African Charter) (1982) 21 ILM 58.

prohibition against discrimination under international and regional African law<sup>8</sup> includes both direct<sup>9</sup> and indirect<sup>10</sup> discrimination. The grounds of discrimination that are prohibited are considered non-exhaustive<sup>11</sup> and include health status, actual or perceived HIV status,<sup>12</sup> age, disability, marital or family status, sexual orientation,<sup>13</sup> and gender identity. Because the rights to non-discrimination and equality are both self-standing as well as applicable to the enjoyment of other human rights, jurisprudence on the right to health under international law<sup>14</sup> and regional African law<sup>15</sup> is inclusive of the obligation to ensure these rights are enjoyed without discrimination. The Committee on Economic, Social and Cultural Rights (CESCR) has stated, for example, in relation to the right to health under the International Covenant on Economic, Social and Cultural Rights (ICESCR), that healthcare and services must be available, in sufficient quantity, services must be accessible (physically and economically) to all without discrimination, and must be culturally acceptable and of good quality.<sup>16</sup>

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.<sup>17</sup>

Under domestic laws, freedom from discrimination and the right to equality have been strongly entrenched in southern African constitutions.<sup>18</sup> Regional jurisprudence is further developing to

8 See *Good v Republic of Botswana* (African Commission on Human and Peoples’ Rights (ACHPR) Recommendation) 313/05 (26 May 2010) para. 219.

9 UN Committee on Economic, Social and Cultural Rights (CESCR) “General Comment No. 20 Non-Discrimination in Economic, Social and Cultural Rights (Art. 2, para. 2, of the International Covenant on Economic, Social and Cultural Rights)” (2 July 2009) para. 10(a).

10 *Id* para. 10(b).

11 *Id* paras. 27 to 35. See also *Good v Republic of Botswana* (African Commission on Human and Peoples’ Rights (ACHPR) Recommendation) 313/05 (26 May 2010) para. 218.

12 See also UN Human Rights Committee (HRC) Concluding Observations of the Human Rights Committee: Republic of Moldova (4 November 2009) para.12.

13 See *Zimbabwe Lawyers for Human Rights and Associated Newspapers of Zimbabwe v Zimbabwe* ACHPR Recommendation 284/03, para. 155.

14 Article 25 of the UDHR 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 “[t]he 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) A/RES/44/25 (1989); article 12 of the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) A/34/46 (1980).

15 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.”

16 Open Society Institute et al. *Human Rights in Patient Care - A Practitioner Guide Armenia* (2009) 33; see also CESCR “General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant)” (11 August 2000) para.12.

17 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.”

CESCR “General Comment No 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant)” (11 August 2000) para. 43.

18 See sections 3 and 15 of the Constitution of Botswana (1966); sections 4 and 18 of the Constitution of Lesotho (1993); sections 4 and 20 of the Constitution of Malawi (1994); article 10 of the Constitution of the Republic of Namibia (1990); section 9 of the Constitution of the Republic of South Africa (1996); sections 14(3) and 20 of the Constitution of the Kingdom of Swaziland

affirm that lesbian, gay, bi-sexual and transgender (LGBT) persons,<sup>19</sup> sex workers,<sup>20</sup> prisoners and non-citizens,<sup>21</sup> have the right not to be discriminated against in the enjoyment of health services. Penal Code provisions that prohibit same-sex sexual activities and activities relating to sex work, for example, do not preclude LGBT persons or sex workers from otherwise enjoying rights and services without discrimination. Furthermore, ethical obligations that govern the conduct of healthcare professionals and nurses generally require that patients be treated with dignity and without discrimination and that patient-confidentiality is respected.

### Experiences of healthcare discrimination

The Joint United Nations Programme on HIV/AIDS (UNAIDS) defines HIV-related discrimination as:

“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 in 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.”<sup>22</sup>

Many studies have been undertaken on stigma and discrimination in Southern Africa, including studies at national levels through a tool called the People Living with HIV Stigma Index.<sup>23</sup> Due to restrictive criminal law environments and institutionally-sanctioned social prejudice, these evaluations are often not fully reflective of the experiences of “key populations”<sup>24</sup> and “vulnerable populations.”<sup>25</sup> In a 2016 research report by the Southern Africa Litigation Centre (SALC Report),<sup>26</sup>

Act (2005); articles 8 and 11 of the Constitution of Zambia (1996), subject to the Constitution of Zambia (Amendment) Act (2 of 2016); and section 56 of the Constitution of Zimbabwe (2013).

- 19 *Attorney General v Rammoge and Others* Court of Appeal of the Republic of Botswana (2016) CACGB-128-14.
- 20 *S v Mwanza Police, Mwanza District Hospital* Malawi High Court (2015) (unreported). For an analysis of the decision see A Meerkotter and I Southey-Swartz “Malawi High Court Rules that Mandatory HIV Testing is Unconstitutional” *Southern Africa Litigation Centre: Blog* (20 May 2015) available at <http://www.southernafricalitigationcentre.org/2015/05/20/malawi-high-court-rules-that-mandatory-hiv-testing-is-unconstitutional/> (last accessed: 24 October 2016).
- 21 *Attorney General and Others v Tapela and Others* Botswana Court of Appeal (2015) CACGB-096-14.
- 22 UNAIDS “Reduction of HIV-Related Stigma and Discrimination” (2014) 2.
- 23 The following Southern African countries have undertaken implementation of the People Living with Stigma Index at the time of writing: The Democratic Republic of Congo, Lesotho, Malawi, Mauritius, Mozambique, South Africa, Swaziland, Zambia and Zimbabwe. More information on the Index and reports following its implementation are available on the People Living with Stigma Index website, available at <http://www.stigmaindex.org/> (last accessed: 24 October 2016).
- 24 “Key populations are defined groups who, due to specific higher-risk behaviours, are at increased risk of HIV irrespective of the epidemic type or local context. Also, they often have legal and social issues related to their behaviours that increase their vulnerability to HIV. ... The key populations are important to the dynamics of HIV transmission. They also are essential partners in an effective response to the epidemic.” World Health Organisation (WHO) “Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care of Key Populations” (2016) xii.
- 25 “Vulnerable populations are groups of people who are particularly vulnerable to HIV infection in certain situations or contexts, such as adolescents (particularly adolescent girls in sub-Saharan Africa), orphans, street children, people with disabilities and migrant and mobile workers. These populations are not affected by HIV uniformly across all countries and epidemics.” *Id.*
- 26 Southern Africa Litigation Centre “Accountability and Redress for Discrimination in Healthcare in Botswana, Malawi and Zambia” (2016) available at <http://www.southernafricalitigationcentre.org/1/wp-content/uploads/2016/09/Discrimination-in-healthcare.pdf> (last accessed: 24 October 2016).

anecdotal accounts of discrimination in healthcare against sex workers, LGBT persons, women living with HIV and persons with disabilities in Botswana, Malawi and Zambia are described. While these accounts do not indicate the prevalence of healthcare discrimination, the context, form and experiences of discrimination narrated highlight the dual vulnerabilities faced by these persons when accessing healthcare: the vulnerability to discrimination and abuse, and the difficulties faced in seeking accountability and redress when violations occur.

Respondents in the SALC Report described discriminatory conduct and practices that included being denied treatment, being subjected to physical and verbal abuse, failures to observe patient confidentiality, failures to conduct proper informed consent procedures, and sexual coercion and abuse. Sex workers recounted particular vulnerability to sexual coercion and abuse by healthcare workers and of being verbally abused or denied treatment when accessing treatment for sexually transmitted infections. LGBT persons described having to conceal their identities and healthcare needs, or having to avoid accessing healthcare at all, in order to avoid discrimination or being reported to police by healthcare workers. Women living with HIV described being denied information about their health and treatment and of being segregated from other healthcare users when accessing HIV treatment, practices that were perceived to exacerbate stigma. Persons with disabilities had significant difficulties physically accessing healthcare services, obtaining information about their health and treatment, and difficulties receiving treatment confidentially and with respect for their dignity, autonomy and privacy.

### **Barriers to accountability and redress**

The SALC Report describes further that when these phenomena occur, the healthcare users and even community-based organisations (CBOs) and non-governmental organisations (NGOs) interviewed did not know how to access relief. Few were aware of their legal rights and healthcare workers' ethical obligations to treat them without discrimination and with due regard to their human dignity. Even fewer were aware of the avenues to complain when conduct fails to meet these standards. CBOs and NGOs highlighted that significant barriers exist for healthcare users to access justice for healthcare discrimination in the courts, including financial cost, physical distance, and difficulties accessing evidence to prove legal claims. Complaint options outside of formal court process (including complaints at facility-level, to health professions and nursing councils, national human rights institutions and specialised complaints bodies) were largely unknown.

Moreover, key populations and vulnerable populations were fearful of reporting discrimination and abuses in healthcare. Many were particularly afraid of being denied access to healthcare services if reporting an incident. For example, healthcare users in rural areas may be entirely reliant on a single healthcare professional in the health centre in their community for treatment and services, leaving them vulnerable to treatment denial and reprisals when reporting abuses. LGBT persons and sex workers were afraid that if they reported discriminatory conduct, their sexual orientation, gender identity, health status or occupations would be revealed to community members and families. They feared this would expose them and their dependents to social repercussions, loss of livelihood, targeting by law enforcement, and violence. For them, the prospect of holding abusers accountable was unrealistic.

## Accountability and Right to a Remedy

Healthcare users who experience human rights violations and discrimination have a right to a remedy. It is an established principle of law that for every right there must be a remedy.<sup>27</sup> International and regional human rights law obliges States to ensure everyone has access to an effective remedy for acts violating fundamental rights.<sup>28</sup> States must make available “adequate, effective, prompt and appropriate remedies, including reparation” for victims of human rights violations.<sup>29</sup> Processes to ensure access to an effective remedy do not need to be limited to the courts.

The obligation to provide access to an effective remedy requires States to ensure that, in practice, people can use these remedies.<sup>30</sup> Processes must be affordable and accessible,<sup>31</sup> and rights holders must have sufficient information to enforce their rights.<sup>32</sup> The United Nations Human Rights Committee has explained that the right to an effective remedy requires States to adapt remedies appropriately to take account of the special vulnerabilities of certain persons.<sup>33</sup> In a decision of the African Commission on Human and Peoples’ Rights, *Jawara v The Gambia*,<sup>34</sup> 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.”<sup>35</sup>

These obligations are embodied and given developmental significance in SDG 16, which stresses “equal access to justice for all” and “inclusive” institutions.<sup>36</sup> Accountability is a closely linked concept in SDG 16.<sup>37</sup> Strengthening accountability in the context of healthcare has the potential not only to advance the human rights of healthcare users but also to improve healthcare systems and democratic governance. Through the effective use of complaints processes, healthcare facilities and government institutions can access vital information to identify trouble areas and develop strategies to improve services, systems and policies. These outcomes can contribute to improving

27 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.

28 See UDHR article 8; and ICCPR article 2(3); see also article 25(a) of the Protocol to the African Charter on Human and People’s Rights on the Rights of Women in Africa (“Maputo Protocol”) (11 July 2013).

29 “Basic Principles and Guidelines on the Right to a Remedy and Reparation for Victims of Gross Violations of International Human Rights Law and Serious Violations of International Humanitarian Law” (21 March 2006) A/RES/60/147; see also “Declaration of Basic Principles of Justice for Victims of Crime and Abuse of Power” (29 November 1985) A/RES/40/34.

30 See HRC CCPR “General Comment No. 3: Article 2 (Implementation at the National Level)” (29 July 1981); CEDAW “General Recommendation No. 28 on the Core Obligations of States Parties under Article 2 of the Convention on the Elimination of All Forms of Discrimination against Women” (16 December 2010).

31 See “General Recommendation No. 28” para. 34; HRC “General Comment No 32: Article 14, Right to equality before courts and tribunals and to fair trial” (23 August 2007).

32 See HRC CCPR “General Comment No. 3: Article 2 (Implementation at the National Level)” (29 July 1981); CEDAW “General Recommendation No. 28 on the Core Obligations of States Parties under Article 2 of the Convention on the Elimination of All Forms of Discrimination against Women” (16 December 2010) para. 2; CEDAW “General Recommendation No 26 on Women Migrant Workers” (5 December 2008) para. 26.

33 HRC “General Comment No. 31: The Nature of the General Legal Obligation Imposed on States Parties to the Covenant” (26 May 2004) para 15.

34 Communication 147/95.

35 *Id* para. 32.

36 *Transforming Our World: The 2030 Agenda for Sustainable Development* (25 September 2015) A/RES/70/1, paras. 16.3 and 16.7.

37 For the purposes of this paper, “accountability” is understood as the answerability of an office or duty and includes access to information, transparency in decision-making, and rules of procedural fairness or due process, LC Reif *The Ombudsman, Good Governance, and the International Human Rights System* (2004) 79.

self-regulation by healthcare providers. In addition, effective complaints systems can improve user confidence, citizen participation and service-provider morale.<sup>38</sup>

## Healthcare Complaints Processes

There exist a number of options for healthcare users to relay complaints outside of the court system. These may include internal or facility-level complaints processes, health professions and nursing councils, and national human rights institutions (NHRIs). As shown above, to fulfil the right to an effective remedy, these processes ought to be available, effective and sufficient. It is argued here that in order to ensure effectiveness, certain procedural fairness standards should be observed in these processes; and in order to ensure availability, these processes need to include protections for vulnerable complainants who may otherwise find these processes inaccessible.

### Internal and facility-level processes

In the SALC Report, healthcare users, CBO and NGO respondents from Botswana, Malawi and Zambia, were typically unaware of complaints options outside of the court process. Those who were aware of extra-judicial options generally referred to internal or facility level complaints processes. These are complaints that would be made within the healthcare system or at the healthcare facility where the violation occurred. These types of complaints may include informal use of suggestion boxes, verbal complaints to healthcare workers, or more formalised complaints to supervisors, superiors and managers within the facility or healthcare system.

Facility-level and internal complaints have the potential to advance availability of remedies to healthcare users; they are typically accessible at point-of-care and do not require formal submission procedures that may otherwise constrain persons with restricted abilities to read, write, or gather relevant evidence. In addition, these processes have the potential to provide sufficient remedies for complainants: health facilities should be able to adapt problematic policies, discipline employees, and provide redress to injured parties.

However, the SALC Report found vastly disparate and inconsistent accounts of how complaints are handled within the healthcare systems in Botswana, Malawi and Zambia. This suggests the absence of uniform processes and decision-making criteria. These processes are vulnerable to ineffectiveness because there are no determinable criteria to ensure decisions are made fairly, impartially, or in good time, if at all. To the extent that decisions on internal healthcare complaints at public healthcare facilities can be considered to be “administrative” decisions that affect the interests of both complainants and possibly healthcare workers, these processes should be subjected to principles of administrative fairness.

In the absence of clear complaints-handling processes, concerns about confidentiality might preclude complaints from vulnerable populations. Clearly structured options for anonymous, third-party and confidential complaints should be developed in addition to procedures that ensure treatment-access during the complaint resolution process. This will guarantee complainants are able to access these processes safely and effectively.

38 T Vian “Complaints Mechanisms in Health Organisations” (2013) 6 *U4 Brief* 1.

## Health Professions and Nursing Councils

Health professions and nursing councils are typically statutory bodies established to regulate their respective professions. One of their functions is the discipline of members who fail to observe professional ethics and codes of conduct. Healthcare users can initiate a disciplinary process through filing a complaint against a registered healthcare worker. The remedial scope of these disciplinary processes are typically limited to the professional discipline of the relevant healthcare worker. This could include warnings, fines, suspensions or being struck from the register of professionals.

Procedures in these bodies are formalised and sometimes classified as judicial proceedings. While typically not subject to strict rules of evidence, regulatory and legislative rules generally mandate an investigatory stage and a disciplinary hearing, and establish an independent body charged with determining the outcome of the process. Accused persons are usually allowed to lead evidence, to cross examine witnesses, and have a right to legal representation. However, the rights of complainants vary: in some cases there is no right of appearance or legal representation but complainants are at a minimum entitled to information on the status of their complaint.

These complaints processes may be very important in jurisdictions that suffer from significant shortages of healthcare workers and health systems investment. As a strategy for advancing accountability and human rights, suing individual healthcare workers in courts may be undesirable for persons who are sympathetic with the constraints under which healthcare workers operate and how system failures can exacerbate individual abuses. In addition, health systems and facilities may be reluctant to punish or fire healthcare workers, fearing the consequences of pushing much-needed staff out of the system. Professional complaints bodies, however, are able to hold their peers accountable through varied sanctions that can be tailored to the gravity of the offence, ensuring a consensus of standards of behaviour from within the profession and allowing for opportunities to continue to train and develop healthcare workers when they fail in fulfilling their ethical obligations.

The SALC Report indicates that health professions and nursing councils in Botswana, Malawi and Zambia currently handle a relatively low volume of complaints and are, at times, reticent to engage with concepts of human rights and discrimination. Options for vulnerable complainants are more limited due to the more formalised processes. However, some councils have the power to order interim measures to protect vulnerable complainants<sup>39</sup> and some are open to receiving informal, third-party or anonymous complaints.

From opinions expressed by a number of CBO and NGO respondents in the SALC Report, there is a sense of distrust toward health profession and nursing councils as their impartiality is doubted when having to decide against their peers. In order to ensure effectiveness of these institutions, it is important that the procedural rules established by regulations and legislation governing these councils are observed and enforced. In addition to these norms, courts in the region have recognised

39 For example, the Nursing and Midwifery Council of Botswana has the power to make interim orders to protect the physical or mental health of any person during the conduct of an investigation into misconduct, regulation 9 of the Nurses and Midwives (Disciplinary) Regulations (2011).

that natural justice principles apply to the proceedings of health professions and nursing councils.<sup>40</sup> To this extent, while complainants do not enjoy many procedural rights under legislated provisions governing the councils' procedures, to the extent that they have an interest in the proceedings, they should enjoy natural justice protections, including a right to be heard and to a reasoned decision.

### National Human Rights Institutions

National human rights institutions (NHRIs), such as human rights commissions or ombudspersons with human rights mandates, may provide an additional avenue for healthcare users to seek accountability and redress when experiencing discrimination. Due to the inquisitorial nature of NHRI processes, it is doubtful whether legal standards of administrative fairness or natural justice are applicable to their proceedings. In addition, the outcome of complaints filed with these bodies are seldom binding. However, these institutions may provide meaningful avenues to pursue accountability for systemic discrimination. They also offer a wide range of discretionary complainant protections due to their procedural flexibility. This could include anonymous, confidential or third-party complaints.

While unlikely to offer meaningful remedial outcomes for individual complainants, NHRIs are well-positioned to make authoritative interventions and recommendations on broader, structural issues. Due to their investigatory powers (which often include powers to summon witnesses and to search and seize evidence), NHRIs may be important means for complainants, CBOs and NGOs to access information or evidence. Additionally, NHRIs can often convene public inquiries and mediate negotiations with government officials, offering prospects for information gathering, consultation and government-engagement that may otherwise be unavailable to complainants.

### Conclusion

SDG 16 places accountability and access to justice on the global development agenda and commits States to making accountability and justice-processes more equitably accessible. Improving healthcare services and effectively addressing HIV are similarly pressing developmental imperatives and human rights concerns in Southern Africa. Stigma and discrimination in healthcare – against persons living with HIV and those most vulnerable to HIV – obstruct the achievement of these goals.

Complaints processes have the potential to provide access to remedies for victims of discrimination and to improve accountability at national, facility and individual levels within the healthcare system. To ensure that these processes adequately fulfil the human right to a remedy, they must be available, effective and sufficient for complainants. As has been highlighted in this paper, of particular concern is that these processes adhere to principles of procedural fairness where applicable and that they protect the confidentiality and personal information of those complainants who are vulnerable to secondary victimisation. Ensuring safety for key populations and vulnerable populations is an important component of ensuring equal access to these procedures.

<sup>40</sup> See *Wells v Botswana Health Professions Council and Another* 2009 1 BLR 467 HC; *Wang v Health Professionals Council of Zambia* (2012/HK/339) (2013) ZMHC 24; and *Moodley v Health Professions Council of South Africa and Another* (2011) 3 All SA 88 (GNP), (2010) ZAGPPHC 242.