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**Indicators of human rights and public health efforts**

## **Using indicators to determine the contribution of human rights to public health efforts**

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**Une traduction en français de ce résumé figure à la fin de l'article. Al final del artículo se facilita una traducción al español. المقالة لهذه الكامل النص نهاية في الخلاصة لهذه العربية الترجمة.**

### **Abstract**

There is general agreement on the need to integrate human rights into health policies and programmes, although there is still reluctance to go beyond rhetorical acknowledgement of their assumed significance. To determine the actual value of human rights for the effectiveness of public health efforts requires clarity about what their incorporation looks like in practice and how to assess their contribution. Despite the pervasive use of indicators in the public health field, indicators that specifically capture human rights concerns are not well developed and those that exist are inconsistently used. Even though “health and human rights indicators” are increasingly being constructed, it is often the case that health indicators are used to draw conclusions about some interaction between human rights and health; or that law and policy or other indicators, traditionally the domain of the human rights community, are used to make conclusions about health outcomes. To capture the added value that human rights brings to health, the differences in the contributions offered by these indicators need to be understood. To determine the value of different measures for advancing programme effectiveness, improving health outcomes and promoting human rights, requires questioning the intended purpose behind the construction of an indicator, who uses it, the kind of indicator it is, the extent to which it provides information about vulnerable populations, as well as how the data are collected and used.

### **Introduction**

Despite increasing attention paid to the apparent integration of human rights into public health policies and programmes, it is difficult to find concrete examples of the benefits that have been derived from linking human rights norms and standards to public health imperatives. There is a need to identify existing approaches that link human rights and health concerns and then to determine the best ways to assess their impact on the effectiveness and outcomes of health policies and programmes. As basic as it sounds, this approach requires clarity, not only in

defining human rights, but also in recognizing what incorporation of identified norms and standards should look like in practice.

In the interests of validity and comparability, from a public health perspective, assessment requires appropriate quantitative indicators. Implicit in the use of such indicators is a sense that they are both impartial and objective. Yet a human rights perspective suggests querying the assumed neutrality of an indicator: we should think about who uses it, for what purposes and in what ways. What occurs before, during and after the measurement process itself is equally important as what is being measured. Thus, the purpose of this paper is to begin to disentangle the diversity of approaches to health and human rights indicators and to suggest issues to consider in determining the value of existing approaches.

## Human rights and public health practice

Human rights bring into focus the relationship between the government, which is the first-line provider and protector of human rights, and individuals (who hold these rights as human beings).<sup>1</sup> Every country in the world is party to at least one human rights treaty and all have made rights-related commitments relevant to health.<sup>2</sup> While for many years it was unclear what the incorporation of human rights principles meant for public health practice, certain actions are increasingly considered part of a human rights-based approach to health (Box 1).

Although generally not incorporated so systematically, many of the interventions implied by the actions named in Box 1 are familiar to people involved in public health. Those that are not so familiar, such as ensuring transparency for how decisions are made, are unique contributions that the human rights field offers to public health. A difficulty lies in determining whether, by drawing attention to the human rights aspects of those actions traditionally in the domain of public health, the nature of the indicator appropriate for their measurement should remain the same or change. Additionally, the fact that institutions may engage differently with the same concepts and even the same indicators has implications for assessing the ways in which monitoring and evaluation are done across the fields of health and human rights.

## Indicators

A wide range of actors use indicators to capture human rights concerns relating to health including international and national human rights mechanisms, governments, health and development organizations and civil society.

In general terms, an indicator is “a variable with characteristics of quality, quantity and time used to measure, directly or indirectly, changes in a situation and to appreciate the progress made in addressing it”.<sup>3</sup> Table 1 lays out definitions and examples of the two types of indicators used to capture health and human rights concerns.

It is immediately apparent that many of the human rights indicators constitute measures that fall outside the traditional definition of a health indicator. To assess the degree to which human rights are respected, protected and fulfilled in the area of health is to expand the notion of what constitutes an indicator in this field. Inevitably this brings with it complications, some of which are explored in this paper.

### **Human rights indicators to measure health**

For those involved in monitoring the human rights compliance of States, indicators are primarily used to enhance the practice of accountability for health-related rights issues. In this context, interest in health arises primarily from its relevance to a range of rights, in particular when non-fulfilment of health-related rights is thought to impede fulfilment of a range of human rights. For example, human rights organizations may quantify violations in specific areas to highlight governmental failure to protect human rights relevant to health, e.g. sexual violence in conflict situations.<sup>4</sup> Further, some treaty monitoring bodies ask governments to show the kind of legislation that exists to protect population groups from discrimination in their access to health care,<sup>5</sup> while others ask for such information as disaggregation by ethnicity of the reported number of births attended by skilled health personnel.<sup>6</sup>

Attention to the use of such human rights indicators by actors in the health arena is rapidly increasing. To ensure a shared understanding of why and how they are being used, as well as transparency, it is important to make explicit the justification for the assumption that these indicators are grounded in international human rights law and they are linked to the field of health. Highlighting the legal bases from which such indicators are derived can also help to minimize bias in how they are used.

### **Health indicators to measure human rights**

Within the human rights field, compliance with human rights norms and standards and assessment of government accountability is often done through use of “traditional” health indicators. An example is infant mortality rates, which are used as a measure of State Party

compliance with their obligation to respect the child's right to life, survival and development, even though they were created as an indicator of population health.<sup>6</sup>

For those involved in health, the fact that health indicators draw attention to rights issues is generally a by-product of efforts to determine the appropriateness and effectiveness of policies and programmes. As one example, disaggregation of data on the basis of sex and age may be used to gauge usage of available health services,<sup>7</sup> but may also draw attention to larger underlying concerns related to inequities in access. In other instances, attention to human rights may be driven by a genuine, but nebulous, desire to “do good” and thus give insufficient attention to why a particular health indicator, or set of indicators, is assumed to measure human rights.

Even as indicators are frequently used for purposes beyond those for which they were originally intended, it is useful to consider whether health indicators ostensibly used to measure human rights would have been constructed differently if human rights considerations had formed part of their design, and also to consider the criteria that are or should be used to determine how health indicators are linked to specific human rights for valid inferences to be made.

### **Health AND human rights indicators**

With regard to the capture of information at the intersection of health and human rights, increasingly a third category of indicators exists – those created in the health field to capture information specifically relating to human rights issues in the design and delivery of health policies and programmes.<sup>8-11</sup> This can most plainly be seen in relation to the components noted previously as key aspects of a human rights approach. Some examples follow.

Assessment of laws that may present obstacles to effective HIV prevention and care for vulnerable populations provide a useful example of an indicator that brings to light issues equally of interest to both fields.<sup>12</sup> Laws that criminalize injecting drug use, sex work or consensual sex between men may deter people who engage in these behaviours from seeking HIV-related services even if they are available. Knowledge of the existence of such laws provides context within which the public health community can plan and implement programmatic activities, and can help the human rights community to inform advocacy and push for any legal reform necessary. These indicators could be improved by capturing not simply the existence of a law but also its quality, as well as the degree to which it is implemented.

Indicators relating to the participation of vulnerable groups bring several concerns relevant for both health and rights. For example, the Greater Involvement of People Living with

or Affected by HIV/AIDS (GIPA) principle draws its strength and legal grounding in the right to participation and has also been recognized as critical to effective HIV programming.<sup>13</sup> It is crucial that appropriate participation be sought from affected communities to ensure the acceptability of interventions to the population for whom they are intended. Additional thought is required on the way to determine in each instance which populations are considered vulnerable. This determines not only whose participation is solicited and measured, but also which populations are acknowledged to exist.

## Linguistic challenges

Semantics pose challenges as there are differences in understanding across the fields even when using the same terminology. For example, stigma and discrimination have precise definitions such that, in relation to health, “stigma” means being devalued by individuals or communities on the basis of real or perceived health status. “Discrimination” refers to the legal, institutional and procedural ways that people are denied access to their rights because of their real or perceived health status.<sup>14,15</sup> In public health, these terms are increasingly used but often without distinction. For example, several instruments ostensibly assess both stigma and discrimination within the context of HIV/AIDS.<sup>16-19</sup> While presumably excellent for their own purposes, most mix the definitions and concepts of stigma and discrimination, thereby detracting from the ultimate utility of the data from a human rights perspective for both advocacy and accountability purposes.

Along similar lines, in 2003 the United Nations Special Rapporteur on the Right to Health suggested that the categories of structural, process and outcome indicators be introduced into the monitoring of health-related human rights,<sup>20</sup> and the validity of this approach for a wide range of rights is increasingly under discussion in the human rights community.<sup>21</sup> While, to those working in the health field, this would seem to be a familiar delineation of indicators and an important step in bringing together the human rights and health fields, the differences in how these categories are defined is worthy of note. In human rights terms, “structural indicators” capture the existence of laws, policies and regulations considered key to the functioning of health systems<sup>20</sup> as opposed to variables reflecting the system in which care is delivered.<sup>22</sup> “Process indicators” are defined as measuring “programmes, activities and interventions”,<sup>20</sup> which is different from the traditional public health definition of measuring the mechanisms through which interventions have an impact.<sup>22</sup> The fields more or less come together in their definition of “outcome

indicators”, which aim to capture the impact of programmes, activities and interventions on health.<sup>20,22</sup>

Thus even when the same terminology is used, unless recognized and addressed, definitional differences between the health and human rights fields can lead to confusion and limitations in the presentation and use of the information collected.

## Using existing indicators

It is clearly preferable to first determine the concept that is to be assessed and then find an appropriate measure. However, given the veritable plethora of indicators already in existence, one should look at how existing indicators can be better understood and used to capture issues relevant to both health and human rights before giving consideration to the creation of any new indicators. For an indicator to be valid from both a health and human rights perspective, irrespective of why it was initially constructed, it is essential to determine the extent of its human rights sensitivity and its validity in public health terms. We propose a series of questions to help guide determination of the health and human rights appropriateness of any given indicator.

### **Why was it designed?**

The design of every indicator is influenced by the priorities shaping its use. An indicator will look quite different if its intended purpose is to inform strategy and programme development as opposed to monitoring targets and holding specific actors accountable. While in the end the issues of concern may be similar, decisions relating to such issues as specificity, comparability and cost will, to a large extent, be determined by the intended purpose of the indicator as well the interests of the entity funding its construction. Careful consideration and due attention to transparency are obviously required as to whose values are incorporated and the extent to which the indicator was designed with both health and human rights concerns in mind.

### **Who is using it?**

Beyond the question of whether an organization’s primary area of focus is health, human rights or both, the use of an indicator is likely to look different in the hands of a nongovernmental organization, a donor, a national government institution or an international organization. If the indicator is designed by one actor but used by others, it is unclear the extent to which all actors need to be aware of its original purpose in order for their efforts, including the interpretation and use of any data, to be valid.

### **What kind of indicator?**

Within the public health community, statistical significance achieved through use of quantitative indicators has long been seen as the gold standard for research and evaluation.<sup>23</sup> Attention to human rights concerns sheds light on the inadequacy of quantitative indicators alone for fully understanding and addressing a situation. Likewise, surveys of client perceptions of the availability, accessibility, acceptability and quality of health services (key aspects of the right to health) are useful for raising human rights concerns, but they too are inadequate in painting a full picture. In an ideal world, not only would indicators be constructed to take into account both health and human rights considerations, but quantitative and qualitative indicators would be considered together to allow for interventions shaped by a more complete picture of the issues at hand.

### **Does it provide information on vulnerable populations?**

Disaggregation of information to reflect where the needs are most acute is undisputed. The question ultimately boils down to what disaggregation criteria are applied and in response to whose demand. In light of the acknowledged importance of nondiscrimination and the recognized need for appropriately targeted interventions, at first glance it is problematic that most indicators do not capture information about specific population subgroups. An inherent tension between public health and human rights concerns surfaces here. Statistical validity requires carefully planned sampling strategies, which become increasingly costly, time-consuming and complicated as categories of disaggregation are added. Conversely, attention to human rights concerns would seem to suggest that disaggregation needs to go beyond sex and geographical location to include such factors as race, language, sexual orientation, and civil, political, social or other status.<sup>24</sup> Determining the appropriate level of disaggregation for any given setting requires conscious attention to both public health and human rights considerations to ensure the situation of vulnerable populations with respect to specific health issues is appropriately addressed without inadvertent exacerbation of discrimination.

### **How are data collected?**

The public health community's interest in the process of collecting data is to a large extent centred around determining ways to ensure reported results are valid,<sup>25</sup> whereas a human rights perspective is concerned with the processes of why and how data are collected. Egregious examples within the public health field, such as Nazi human experimentation<sup>26</sup> and the Tuskegee

Syphilis Study,<sup>27</sup> have drawn attention to ethical concerns but a human rights perspective highlights the responsibility of the researcher, policy-maker and health programmer to know the source of data in all instances. This helps to ensure not only that efforts are appropriately informed but also, if necessary, that data collection efforts be amended to ensure human rights violations do not inadvertently occur in the process.

### **How are data used?**

Once data are collected, there are issues to consider with respect to whether the information is made publicly available, released to the affected community with proper education or only known to a small subset of actors; concerns may exist in each of these scenarios. Transparency in how this decision is reached will help ensure legitimacy and accountability for any problems that may occur from subsequent use of the data. Attention to human rights considerations can also make an important contribution to the use of purportedly neutral health data and help to ensure these data do not end up unintentionally fostering stigma, discrimination or further violations of human rights. Table 2 draws on examples from HIV to highlight the sorts of issues raised by previous questions.

### **Conclusion**

Different types of indicators capture different sorts of data through diverse mechanisms. Consequently, effective assessment of health and human rights concerns may require innovative application of proven monitoring and evaluation methodologies, such as triangulation across different data sources. Such an approach would promote pioneering use of existing indicators thereby maximizing the potential use of existing data without further burdening monitoring and evaluation systems with new indicators.

The value of what can genuinely be called health and human rights indicators is not only to show progress, disparities and gaps within countries and globally: the process of measurement matters as much as the data themselves. Health and human rights indicators can show the extent to which governments and other entities are meeting their health-related human rights obligations, highlight areas where further efforts might lead to increased fulfilment of these obligations and, by extension, improve health outcomes. Drawing attention to all elements of a rights-based approach, indicators which genuinely capture both sets of concerns will ultimately help to determine whether policies and programmes that are the most effective in health terms are also those that have achieved the greatest level of compliance with human rights principles. Even

as clarifying these links is important, all of this will remain purely academic unless the data are used to improve support for affected communities. Although still young and fairly amorphous, the potential of health and human rights indicators for informing evidence-based policies and programmes underscores the need for their further development.

### **Competing interests:**

None declared.

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**Box 1. Actions constituting a rights-based approach to health:**

- Considering the legal and policy context within which interventions occur.
- Supporting the participation of affected groups, especially vulnerable groups, in all efforts that concern them.
- Working to ensure discrimination does not occur in the delivery of services nor in the health outcomes experienced among different population groups.
- Using human rights standards to deliver services in particular with respect to ensuring their availability, accessibility, acceptability and quality.
- Ensuring transparency and accountability both for how relevant decisions are made and their ultimate impact.<sup>28</sup>

**Table 1. The two types of indicators used to capture health and human rights concerns**

	<b>Definition</b>	<b>Examples</b>
Health indicator	A health indicator has been defined as a "variable that helps to measure changes in a health situation directly or indirectly and to assess the extent to which the objectives and targets of a programme are being attained". <sup>29</sup>	The number of maternal deaths is a raw statistic which takes on greater meaning when converted into an indicator of number of maternal deaths/live births/year, which can be tracked over time alongside programmatic activities. Other examples include: the percentage of the population that has sustained access to improved drinking water sources, the percentage of children aged less than 5 who sleep under insecticide-treated bed-nets, and total expenditure on health as a percentage of gross domestic product.
Human rights indicator	A human rights indicator has been defined as a measure that provides information on the extent to which human rights norms and standards are addressed in a given situation. <sup>21</sup>	Indicators of fulfilment of human rights would include, for example, the extent to which international human rights obligations are incorporated into national laws and policies relevant to maternal health. Human rights indicators also include indicators of violations such as quantitative summaries of human rights violations, legal audits and determination as to the existence and use of mechanisms for challenge and redress if violations are alleged to occur. <sup>30</sup>

**Table 2. Using HIV to highlight the issues raised by questioning indicators**

Question	Example
Why was this indicator designed?	Tracking the total number of people on antiretroviral therapy (ART) might suffice for monitoring governmental accountability and progress towards achieving universal access targets. However, to inform the provision of ART, a detailed breakdown of which populations are (and are not) accessing ART would be more useful.
Who is using the indicator?	Designed by international organizations, early indicators of the number of people on ART included women who were given prophylaxis to prevent vertical transmission of HIV to their infants. These numbers were initially used by other organizations who were unaware that data which appeared to show some degree of gender equity in access to ART were in fact masking the low numbers of women accessing ART outside the context of preventing vertical HIV transmission.
What kind of indicator is it?	The number of people who have been tested for HIV is a quantitative indicator often used in the field of HIV. However, this does not capture the quality of the HIV testing process such as the type of counselling, ensured confidentiality and appropriate referral, all of which are critical to people's ability to process the information presented both for behaviour change and to promote long-term connection with HIV-related services. Bringing together qualitative and quantitative indicators can not only improve use of services but provide a more accurate picture of the long-term impact of HIV testing on communities and more broadly.
Does the indicator provide appropriate information with regard to vulnerable populations?	Access to services for the prevention of mother-to-child transmission of HIV is often used as an indicator of coverage of HIV services. However, an aggregate figure can hide under-served populations: disaggregation by age, for example, might highlight adolescents as an under-recognized population; or disaggregation by locality might draw attention to the need to improve these services for remote rural populations.
How are data collected?	Estimates of prevalence of HIV infection among sex workers and intravenous drug users are sometimes presented as evidence of commitment to vulnerable populations. These estimates could be modelled from data collected from sex workers or drug users who voluntarily came forward for HIV counselling and testing, but the information equally could be collected at centres for rehabilitation where people are pulled off the streets, detained, tested without their consent and given no access either to their test results or to adequate care.
How are data used?	The withholding of information by government officials in the context of HIV, for example when governments refuse(d) to report accurately the numbers of people estimated to be living with HIV in their borders, is well known. Equally troubling have been documented instances of the inappropriate use of data fuelling stigma, discrimination and human rights violations such as occurred for people from communities identified in government statistical reports as having high rates of HIV infection such as immigrants, sex workers and drug users. <sup>31</sup>