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

Sofia Gruskin & Laura Ferguson

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 bring 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. Thus 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).1 Every country in the world is party to at least one human rights treaty and all have made rights-related commitments relevant to health.2 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.” 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. 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, while others ask for such information as disaggregation by ethnicity of the reported number of births attended by skilled health personnel.

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.

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, 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.

**Indicators of health and human rights**

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. This can most plainly be seen in relation to the components noted previously as key aspects of a human rights approach. Some examples follow.

- 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.

**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. 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. 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, and the validity of this approach for a wide range of rights is increasingly under discussion in the human rights community. 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 as opposed to variables reflecting the system in which care is delivered. “Process indicators” are defined as measuring “programmes, activities and interventions”, which is different from the traditional public health definition of measuring the mechanisms through which interventions have an impact. 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.

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. 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
Estimates of prevalence of HIV infection among sex workers and intravenous drug users are sometimes

Example

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Designed by international organizations, early indicators of the number of people on ART included

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
locally 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 including
immigrants, sex workers and drug users.21

indicators be constructed to take into
account both health and human rights
considerations, but quantitative and
qualitative indicators would be consid-
ered 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 un-
disputed. 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 ten-
sion between public health and human
rights concerns surfaces here. Statisti-
cal validity requires carefully planned
sampling strategies, which become in-
creasingly costly, time-consuming and
complicated as categories of disagrega-
tion 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.27 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 inad-
vertent exacerbation of discrimination.

How are data collected?

The public health community’s inter-
est in the process of collecting data
is to a large extent centred around
determining ways to ensure reported
results are valid,24 whereas a human
rights perspective is concerned with the
processes of why and how data are col-
lected. Egregious examples within the
public health field, such as Nazi human
experimentation29 and the Tuskegee
Syphilis Study,30 have drawn attention
to ethical concerns but a human rights
perspective highlights the responsibil-
ity 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 appro-
priately 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 that 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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**Résumé**

**Utilisation d’indicateurs pour déterminer la contribution des droits de l’homme aux efforts en faveur de la santé publique**

Il existe un consensus sur la nécessité d’intégrer les droits de l’homme aux politiques et aux programmes sanitaires, malgré une certaine réticence à aller au-delà de la reconnaissance rhétorique de leur importance supposée. Pour déterminer ce qu’apportent réellement les droits de l’homme à l’efficacité des efforts en faveur de la santé publique, il faut avoir une idée claire de la forme que prend leur intégration dans la pratique et des modalités d’évaluation de leur contribution. En dépit de l’usage enhaissant des indicateurs dans le domaine de la santé publique, on ne dispose pas encore d’indicateur bien au point qui rende compte spécifiquement des préoccupations liées aux droits de l’homme et les indicateurs existants ne sont pas utilisés de manière systématique. Si l’on construit de plus en plus d’indicateurs du type “santé et droits de l’homme”, il est fréquent que ces indicateurs soient utilisés pour tirer des conclusions sur certaines interactions entre les droits de l’homme et la santé ou que des indicateurs du type “loi et politique” ou autres, relevant traditionnellement du domaine des droits de l’homme, servent à formuler des conclusions sur des résultats sanitaires. Pour rendre compte de la valeur ajoutée que les droits de l’homme apportent à la santé, il faut comprendre les différences entre les contributions représentées par ces indicateurs. Pour déterminer la valeur de différentes mesures de la progression de l’efficacité programmative, de l’amélioration des résultats sanitaires et de la promotion des droits de l’homme, il faut se poser les questions suivantes : quelle est la finalité visée dans la construction de l’indicateur considéré ? Quels sont ses utilisateurs ? De quelle nature est-il ? Dans quelle mesure fournirait-il des informations sur les populations vulnérables ? et comment les données sont-elles recueillies et exploitées ?

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**Resumen**

**Uso de indicadores para determinar la contribución de los derechos humanos a los esfuerzos de salud pública**

Se reconoce en general que es necesario integrar los derechos humanos en las políticas y programas de salud, pero hay aún cierta resistencia a ir más allá del reconocimiento retórico de esa necesidad. Si se quiere determinar el impacto real de los derechos humanos en la eficacia de las iniciativas de salud pública, es preciso conocer con claridad cómo se manifiesta en la práctica su incorporación a esos esfuerzos y cómo debe evaluarse su contribución a los mismos. Aunque el uso de indicadores está muy extendido en el campo de la salud pública, los indicadores concebidos para reflejar aspectos de los derechos humanos no están bien desarrollados o se usan de manera incoherente. Si bien se están elaborando cada vez más «indicadores de salud y derechos humanos», ocurre a menudo que los indicadores sanitarios se utilizan para extraer conclusiones sobre algún tipo de interacción entre los derechos humanos y la salud; o que indicadores relacionados con la legislación y las políticas, tradicionalmente empleados por la comunidad de derechos humanos, son utilizados para sacar conclusiones sobre los resultados sanitarios. A fin de calibrar el valor añadido que los derechos humanos suponen para la salud, es preciso entender bien la diferente contribución de esos indicadores. Para determinar el valor de las distintas medidas empleadas en lo que atañe a imprimir eficacia a los programas, mejorar los resultados sanitarios y promover los derechos humanos, hay que preguntarse cuál fue la finalidad perseguida al elaborar el indicador, quiénes lo emplean, qué tipo de indicador es, en qué medida aporta información sobre las poblaciones vulnerables, y de qué manera se recogen y usan los datos.
استخدام المؤشرات لتحديد إسهام حقوق الإنسان في تحقيق جهود الصحة العومية

هناك اتفاق عام على الحاجة إلى إدراج حقوق الإنسان في السياسات والبرامج الصحية، بالرغم من أن هناك نقص في الخروج عن تجاوز نطاق الأعراب الإشاذ بأحكامها. إن تعدد القيم الخلقية لحقوق الإنسان بالنسبة للجهود الصحية يطلب أن نحول كيف يمكن تطوير وتشييد قوة التدابير المختلفة لتطوير عقائدة البرنامج وتحسين المجالات الصحية وتوزيع حقوق الإنسان. ينطوي التساؤل بشأن الفترات المحددة من مسؤولية من أجل استخدام المؤشرات المطلوبة لتحقيق التقدم في الحصائل الصحية، فإن المؤثرات المتصلة للمؤثرات في مجال الصحة العامة يمكن قصيداً كيما، تفاوت الشروط، يمكن أن تكون مؤثرات غير ملائمة. بمجرد أن يكون تجسيد المعايير المطلوبة المحددة، يتم وضعها بشكل متزايد. إلا أنه، في الغالب يتم استخدام المؤثرات الصحية لاستباق الاستنتاجات حول بعض

الملاحظات

التعابير بين الصحة وحقوق الإنسان: أو أن نستخدم التعبير وتعابير الصحة أو المؤثرات الأخرى، والتي تكون في العادة مجال 대해서ن حقوق الإنسان في استباق استنتاجات عن المحاصيل الصحية. ولنぶりات على قيمة المحاصيل التي تضمن حقوق الإنسان على قنبلة، يتعزى فهي تضمن في هذه القيم من أن تحدد قيمة التدابير المختلفة لتطوير عقائدة البرنامج وتحسين المجالات الصحية وتوزيع حقوق الإنسان. ينطوي التساؤل بشأن الفترات المحددة من مسؤولية من أجل استخدام المؤشرات المطلوبة لتحقيق التقدم في الحصائل الصحية، فإن المؤثرات المتصلة للمؤثرات في مجال الصحة العامة يمكن قصيداً كيما، تفاوت الشروط، يمكن أن تكون مؤثرات غير ملائمة. بمجرد أن يكون تجسيد المعايير المطلوبة المحددة، يتم وضعها بشكل متزايد. إلا أنه، في الغالب يتم استخدام المؤثرات الصحية لاستباق الاستنتاجات حول بعض

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