
Report to the Foundation for Human Right (FHR)

Author: Professor Leslie London 30th March 2016

Contents

The Right to Health (RtH) Context 3
Universal Health Access as a Human Rights issue? 4
The South African Context for the Right to Health 6
What does the White Paper miss in relation to a rights based approach to health? 11
  1. Rationing 11
  2. Accountability 11
  3. Participation 12
  4. Vulnerable groups 13
  5. Equity and effectiveness 13
  6. Prevention and Environmental risk factors 14
  7. Institutionalising Prevention 15
  8. Limitations of rights 16
  9. What is understood by Access to Health Care 17
  10. Threats to other social security funds 18
  11. International agreements and State Obligations 18
  12. The centrality of a National Health Plan 19
  13. Policy disarticulation 20
What elements of the White Paper are potentially problematic for a rights based 21
approach to health?

Recommendations  25

Annex 1 Indicators of right to health (Backman et al, 2008)  28
**The Right to Health (RtH) Context:**

Even though the Alma Ata Declaration on Primary Health Care (PHC) declared health to be a right in 1976, it is only in the last decade or two that the links between Public Health and Human Rights have been given prominence in public policy, legislation and case law\(^1\). The Constitutional Court underwent a philosophical shift in assessing the States’ delivery of socio-economic rights: In *Soobramoney* it applied the rationality test but later in *Grootboom* and *Treatment Action Campaign* it realized the limitations of this test and developed the reasonable measures test i.e. criteria for assessing reasonable measures in the State’s programmes for the right of access to health care services as follows: It must be capable of facilitating the realization of the right; It must be comprehensive, coherent and coordinated; The State must make financial and other resources available for the programme; It must be balanced and flexible; It must make provision for short-, medium-, and long-term needs; It must be reasonably conceived and implemented; It must be transparent, and the public must be made aware of its contents; It must make short-term provision for those whose needs are most urgent and who are living in intolerable conditions.

It is particularly as a result of the HIV epidemic that increased attention has been directed to the links between a rights-based approach to health and the building of strong health systems. South Africa’s efforts to expand access to health care through a National Health Insurance (NHI) must therefore be seen within the context of an evolving body of legal and public health analysis, that seeks to understand how human rights and public health work synergistically to promote human well being.

The authoritative legal sources on the Right to Health (RtH) are Section 27 of the Constitution\(^2\), the International Covenant on Economic, Social and Cultural Rights (ICESCR)\(^3\) and the General Comment (GC) 14, which clarifies the scope and the content of the right to health\(^4\).

Section 27 of the Constitution provides for the “right to have access to health care services, including reproductive health care”. It places an obligation on the State not to overstep the right, and to “take reasonable and legislative and other measures, within its available resources, to achieve the progressive realization” of the right.

---

\(^1\) See Liebenberg, *Socio-Economic Rights*, 152-153.


Article 12 of the ICESCR recognises “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.” It prescribes specific steps for states to take in order to fully realise this right, including reducing “the stillbirth rate and of infant mortality and for the healthy development of the child”; improving “all aspects of environmental and industrial hygiene”; “the prevention, treatment, and control of epidemic, endemic, occupational, and other diseases”; and creating “the conditions which would assure to all medical service and medical attention in the event of sickness”. This is subject to the recognition that the state is not obliged to provide care it cannot afford, but it must make available care to the maximum of its available resources and it must progressively realise this right.

The General Comment 14 (GC 14), an expert interpretation of Article 12 on the Right to Health in the ICESCR, describes the right to health as “an inclusive right extending not only to timely and appropriate health care but also to the underlying determinants of health, such as access to safe and potable water and adequate sanitation, an adequate supply of safe food, nutrition and housing, healthy occupational and environmental conditions, and access to health-related education and information, including on sexual and reproductive health.”

GC14 goes on to define a minimum core as obligations on the state “(a) To ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups; (b); (c)… (d) To provide essential drugs, as from time to time defined under the WHO Action Programme on Essential Drugs; (e) To ensure equitable distribution of all health facilities, goods and services;…” [11]; paragraph 43. However, South African jurisprudence, as evidenced in the Constitutional Court decision on Prevention-of-Mother-to-Child-Transmission of HIV in the Treatment Action Campaign case, has eschewed the minimum core approach to health care services and preferred to go by the standard of reasonableness in determining whether measures adopted by the state are reasonable.5

The GC14 also emphasizes the obligation of states to provide international economic and technical assistance in order to realise the right and frames access to health care in terms of four key elements: geographic, financial, information and non-discrimination.

Universal Health Access as a Human Rights Issue?

The World Health Organisation (WHO) argued that Universal Health Coverage (UHC) is “by definition, a practical expression of the concern for health equity and the right to health”.6 The 2010 World Health Report refers to the 2005 WHA Resolution, which urges member states to include risk sharing in their financing systems for health care, to ensure good quality services,

sustainable financing, meeting the needs of the entire population, managing a transition process towards universal coverage that recognizes resource constraints, and sharing experiences internationally.\textsuperscript{7}

The 2012 UNGA Resolution states that UHC “implies that all people have access, without discrimination, to nationally determined sets of the needed promotive, preventive, curative and rehabilitative basic health services” (emphasis added), and acknowledges that “when managing the transition of the health system to universal coverage, each option will need to be developed within the particular epidemiological, economic, socio-cultural, political and structural context of each country in accordance with the principle of national ownership.”\textsuperscript{8}

The discussion on the Right to Health has been taken further in relation to thinking about health systems, principally by the work of the former Special Rapporteur on the Right to Health, Paul Hunt\textsuperscript{9}. Two influential publications emerged to sketch not just the synergy between human rights and health, as was pioneered by Jonathan Mann and colleagues, nor simply to identify the instrumental benefits of protecting human rights for health, but rather to think more systemically about how human rights can bolster entire health systems and to interrogate how health systems can be based on human rights. This theorization moves the right to health away from ideas of individualized entitlements to one where the irrevocably social nature of

\textsuperscript{7} The full text cited [in Ooms G, Latif LA, Waris A, Brolan CE, Hammonds R, Friedman EA, Mulumba M, Forman L. Is universal health coverage the practical expression of the right to health care? BMC International Health and Human Rights 2014, 14:3] is 1) “to ensure that health-financing systems include a method for prepayment of financial contributions for health care, with a view to sharing risk among the population and avoiding catastrophic health-care expenditure and impoverishment of individuals as a result of seeking care; (2) to ensure adequate and equitable distribution of good-quality health care infrastructures and human resources for health so that the insurees will receive equitable and good-quality health services according to the benefits package; (3) to ensure that external funds for specific health programmes or activities are managed and organized in a way that contributes to the development of sustainable financing mechanisms for the health system as a whole; (4) to plan the transition to universal coverage of their citizens so as to contribute to meeting the needs of the population for health care and improving its quality, to reducing poverty, to attaining internationally agreed development goals, including those contained in the United Nations Millennium Declaration, and to achieving health for all; (5) to recognize that, when managing the transition to universal coverage, each option will need to be developed within the particular macroeconomic, sociocultural and political context of each country; (6) to take advantage, where appropriate, of opportunities that exist for collaboration between public and private providers and health-financing organizations, under strong overall government stewardship; (7) to share experiences on different methods of health financing, including the development of social health-insurance schemes, and private, public, and mixed schemes, with particular reference to the institutional mechanisms that are established to address the principal functions of the health-financing system”


health (and, indeed, for most socio-economic rights) requires more than just individual freedoms or protections. For South Africans and Africans, the very essence of *Ubuntu* requires us to think more collectively about how to ensure the social good also is rooted in individual rights and vice versa.

With respect to health systems, Backman and Hunt point out that “... at the heart of the right to the highest attainable standard of health lies an effective and integrated health system.” For this system to realise the right to health, key elements are “transparency, participation, equity and equality, a comprehensive national health plan, a minimum “basket” of health-related services and facilities, disaggregated data, and system of monitoring and accountability. Without such an integrated system that meets recognized human rights standards, the right to the highest attainable standard of health is unlikely to be achieved. Backman and Hunt go on in a second paper to outline indicators for health systems that reflect a right to health approach. A number of these indicators point to how systems can be built to support the right to health— for example in ensuring the state has a comprehensive national health plan encompassing public and private sectors, which is based on a comprehensive national situational analysis that includes health and human rights impact assessments, explicit recognition of the right to health and an explicit commitment to universal access to health services. Further, the indicators speak to participation with marginalised groups in the development of the national health plan, to inclusion of strategies to address the underlying determinants of health, to promote access to health services and access to medicines or technologies recognised in the constitution.

Lastly, there is a small but growing body of literature pointing to the relevance of the right “to enjoy the benefits of scientific progress and its applications” (REBSP), a little addressed right in

---


11 The point about *Ubuntu* is that it infuses more than just collective thought and actively promotes a communitarian value system that is Afro-centric and less Euro-centred in relation to human rights and human well being. A more Afro-centred approach to literature used in analyzing the right to have access to health care assists with the organic transformation of understanding health rights and health systems within the South African context.


13 Backman and Hunt, Ibid.

14 Backman et al, see citation 7.

the ICESCR (Article 15), to understanding better how the right to health may be realized. By foregrounding science and scientific discovery as instrumental to improving the quality of life, the REBSP resonates with many right to health claims and is thus important for understanding how a health system might promote universal access to health care and the social determinants of health.

The South African Context for the Right to Health

South Africa’s constitution recognizes both the right to have access to health care services (in section 27) but also rights to many of the social determinants of health care, such as clean water, shelter, education, etc. Its jurisprudence is recognised globally for advancing the justiciability of socio-economic rights in general, given a Constitutional Court willingness to explore socio-economic entitlements consistent with the spirit of South Africa’s constitution. Thus, the Constitutional Court ruling in the Treatment Action Campaign case in favour of civil society litigants, and against a South African government that denied pregnant women access to antiretroviral therapy to prevent the transmission of HIV to their newborns was a seminal marker of how the right to have access to health care could find practical expression and enforcement. However, it is widely noted that the victory in the case was reliant on mass civil society education, awareness and mobilization across a number of constituencies to take effect. This was unlike the famous Grootboom case involving the justiciability of socio-economic rights (SERs), which considered the right of Mrs. Irene Grootboom and others to have access to adequate housing. They won their case against the government authorities seeking to evict them from their homes in an unplanned informal settlement, but failed to achieve any practical benefit from the court decision. This was principally because of a lack of a social movement to turn the court victory into programmatic action by the state. Tragically, Mrs Grootboom died before her family was allocated a house.

Now that South Africa has ratified the ICESCR in 2015, the South African state is obliged to domesticate the Covenant through legislative, budgetary and programmatic measures. The planned introduction of the NHI might therefore be seen as part of the state’s gradual move to align its health systems with the provisions required in terms of the ICESCR. That said, both the ICESCR and the South African constitution recognize the problem of resource constraints and the practical difficulties of realizing rights in the immediate future. The human rights framework therefore speaks to the state’s obligation to realise rights to the maximum available resources, which implies that there is a transparent plan with justifications for why certain limits must be accepted. Secondly, it places the obligation of progressive realization on the state, which means that it must, over time, gradually improve what is provided and map out how it will do so over time. At the very least, it should not withdraw or lessen health care

services it already provides (retrogression) and, of course, there should be no unfair discrimination in how it effects such policy changes.

The case of Mr. Soobramoney, who required renal dialysis from the state after his health insurance benefits in the private sector were exhausted, illustrates both the recognition that rationing of resources can be entertained in a human rights framework. But for it to be compatible with human rights, the rationing decision needs to be reasonable, rational, justifiable, transparent and evidence-based. All this is critically relevant to thinking about redesigning health systems for South Africa.

Lastly, there are many other health policies in South Africa evolving or under consideration, which are important to understanding the health context for the NHI and universal access to health care. These include long-standing policies such as Community Service for Health Professional Graduates (aimed at redressing urban-rural inequalities in health worker distribution) and more recent policies such as:

- The Re-engineering of Primary Health Care (with its sub-programmes involving School Health, Ward Based Outreach Teams, District level specialist teams and private practitioner contracting),
- The introduction of the Office of Standards Compliance to accredit all health facilities with a view to improving quality of care
- The Ideal Clinic Programme to strengthen primary care facilities
- The Hospital revitalization programme
- Investment in a Health Leadership Academy to build public sector management and leadership skills
- Introduction of new cadres of health workers (clinical assistants, rehabilitation assistants) and upscaling of existing categories (such as community health workers)

The White Paper – How does it meet human rights standards?

It is in this context that the Department of Health released a Green Paper on the National Health Insurance in 2011 and has subsequently updated that with the White Paper released in December 2015. The White Paper is explicitly presented as based on a human rights response to health inequalities in SA. It is premised on the notion that the implementation of the NHI “is consistent with the Constitutional commitment for the state to take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of the right to have access to health care services including reproductive health care (paragraph 3), that it will contribute to poverty reduction and redress of inequalities inherited from the past, and that the “… implementation of NHI is a reflection of the kind of society we wish to live in: one based on the values of justice, fairness and social solidarity.”

At the level of intention, the NHI is clearly set up as a rights based policy. It also locates its mandate in the idea of universal access to health care as core to the policy and therefore
commits to an NHI that focuses “... on ensuring progressive realisation of the right to health by extending coverage of health benefits to the entire population.” (paragraph 106).

In what ways does it meet a HR standard? Certainly at the broad hortatory level, the NHI sends a strong message of a rights based approach. In terms of the following principles, the NHI makes a clear stand in favour of a rights based-approach to health in South Africa:

- It explicitly recognizes the inequalities plaguing the health system in South Africa, particularly between public and private sectors, and presents a plan for redress;
- The NHI is based on expanding access to health care and recognizes health as a social good;
- It aims to remove discriminatory access based on income

Table 1 lists 25 indicators applicable to a national health insurance derived from the longer list developed by Backman and colleagues (2008) of right to health features of a health system (Annex 1). In considering the criteria used by Backman and colleagues as indicators of rights based health system, a number could be considered to be met in terms of the NHI. However, a number of elements are unclear or fall short of the current understanding of what a human rights approach to health systems might be. These are detailed in the next section.
Table 1. Right to Health Elements considered in the White Paper on a National Health Insurance for South Africa

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health information</strong></td>
<td></td>
</tr>
<tr>
<td>6 Does the state law protect the right to seek, receive, and disseminate</td>
<td>NHI White Paper is essentially silent on the right of access to health information; mentioned only in relation to how new treatment guidelines will be shared with patients; Patient Rights Charter</td>
</tr>
<tr>
<td>information?</td>
<td></td>
</tr>
<tr>
<td><strong>National health plan</strong></td>
<td></td>
</tr>
<tr>
<td>17 Does the state have a comprehensive national health plan encompassing</td>
<td>To the extent that the NHI plans to bring public and private providers together under a single payer plan, yes.</td>
</tr>
<tr>
<td>public and private sectors?</td>
<td></td>
</tr>
<tr>
<td>18 Has the state undertaken a comprehensive national situational analysis?</td>
<td>The White Paper is, to a partial extent, a national situational analysis. However, it has many gaps related to prevention.</td>
</tr>
<tr>
<td>19 Before adopting its national health plan, did the state undertake a</td>
<td>This is the current process of consultation underway. It is unclear the extent to which the state is pursuing a Health Impact Assessment (HIA) or a Right to have Access to Health Impact Assessment (RAHIA) – this is what the FHR is seeking to do.</td>
</tr>
<tr>
<td>health impact assessment?</td>
<td></td>
</tr>
<tr>
<td>20 Before adopting its national health plan, did the state undertake any</td>
<td></td>
</tr>
<tr>
<td>impact assessment explicitly including the right to health?</td>
<td></td>
</tr>
<tr>
<td>21 Does the state’s national health plan explicitly recognise the right to</td>
<td>Yes – explicitly so</td>
</tr>
<tr>
<td>health?</td>
<td></td>
</tr>
<tr>
<td>22 Does the state’s national health plan include explicit commitment to</td>
<td>Yes – explicitly so</td>
</tr>
<tr>
<td>universal access to health services?</td>
<td></td>
</tr>
<tr>
<td><strong>Participation</strong></td>
<td></td>
</tr>
<tr>
<td>23 Is there a legal requirement for participation with marginalised groups</td>
<td>No, the White Paper is unclear about participation in the process and no clear commitment to preference marginalised groups in the development of the plan.</td>
</tr>
<tr>
<td>in developing the national health plan?</td>
<td></td>
</tr>
<tr>
<td><strong>Underlying determinants of health</strong></td>
<td></td>
</tr>
<tr>
<td>24 What percentage of the rural and urban population has access to clean</td>
<td>No, the NHI does not concern itself with social determinants, so indicators are not evident.</td>
</tr>
<tr>
<td>water?</td>
<td></td>
</tr>
<tr>
<td>25 What are the CO2 emissions per capita?</td>
<td>No, the NHI does not concern itself with social determinants, so indicators are not evident.</td>
</tr>
<tr>
<td>26 Prevalence rate of violence against women</td>
<td>Only inasmuch as facility based routine data may be able to generate such statistics; no community-based prevalence data will emerge from the NHI unless the WBOTs are empowered to do surveillance</td>
</tr>
<tr>
<td><strong>Access to health services</strong></td>
<td></td>
</tr>
<tr>
<td>27 Proportion of women with a live birth in past 5 years who, in last</td>
<td>Yes, this can be generated by the NHI</td>
</tr>
<tr>
<td>pregnancy, were</td>
<td></td>
</tr>
</tbody>
</table>
seen 3 times+ by health professional, had blood pressure checked, blood sample taken, were informed of complications

<table>
<thead>
<tr>
<th>Medicines</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>28 Is access to essential medicines or technologies, as part of the fulfilment of the right to health, recognised in national legislation?</td>
<td>Access to essential medicine and technology is cited but not as a state rights obligation</td>
</tr>
<tr>
<td>32 What is the average availability of selected essential medicines in public-health facilities?</td>
<td>Yes, this can be generated by the NHI</td>
</tr>
<tr>
<td>33 What is the average availability of selected essential medicines in private-health facilities?</td>
<td>No, unless private facilities are part of the NHI, these data will not be surfaced</td>
</tr>
<tr>
<td>34 Percentage of 1-year-old children immunised against measles</td>
<td>Unclear. The DHMOs will be established with this responsibility but no elements of the White Paper provide a vehicle for seeing how the NHI will address this or monitor immunisations.</td>
</tr>
<tr>
<td>35 Percentage of 1-year-old children immunised against diphtheria, tetanus, and pertussis</td>
<td>Unclear. The DHMOs will be established with this responsibility but no elements of the White Paper provide a vehicle for seeing how the NHI will address this or monitor immunisations.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Health promotion</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>36 Does state law require comprehensive sexual and reproductive-health education during the compulsory school years for boys and girls?</td>
<td>No. The NHI talks in general about health promotion but provides no indicator how health promotion will be encouraged, let alone monitored</td>
</tr>
<tr>
<td>37 Proportion of 15–24-year-old boys and girls with comprehensive HIV and AIDS knowledge</td>
<td>No. The NHI talks in general about health promotion but provides no indicator how health promotion will be encouraged, let alone monitored.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>National financing</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>45 Is the per capita government expenditure on health greater than the minimum required for a basic effective public health system?</td>
<td>Yes, the NHI will increase per capita government spending on health</td>
</tr>
<tr>
<td>46 What is the proportion of households with catastrophic health expenditures?</td>
<td>Yes, the NHI will aim to reduce households vulnerable to catastrophic health expenditures.</td>
</tr>
<tr>
<td>47 Total government spending on health as percentage of gross domestic product (GDP)</td>
<td>Yes, the NHI will be able to generate these data</td>
</tr>
<tr>
<td>50 Proportion of national health budget allocated to mental health</td>
<td>Unclear how the NHI will enable this</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Additional safeguards</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>54 Does the state law require protection of confidentiality of personal health data?</td>
<td>NHI White Paper is essentially silent on protection of personal information – far short of the POPI requirements</td>
</tr>
<tr>
<td>55 Does the state law require informed</td>
<td>Although the White Paper does not specifically mention IC,</td>
</tr>
<tr>
<td>consent to treatment and other health interventions?</td>
<td>it does refer to the importance of patient rights; the NHA is very clear on patient rights if the White Paper is not.</td>
</tr>
<tr>
<td>---------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>

(Source: Backman et al, 2008)
What does the White Paper miss in relation to a Rights Based Approach to Health Care?

1. Rationing

The General Comment 14 makes the observation that “... when unable to provide health care available in other parts of the world, states are obliged to demonstrate their inability.”\(^{16}\) In deciding what is to be covered by the NHI, the state is justified\(^ {17}\) in rationing health care services since the demand for health care, whatever its effectiveness or appropriateness, will, by and large, exceed capacity of the state to supply. However, in coming to these decisions, it is not clear that the NHI White Paper has grasped the essence of what the GC14 expects in terms of rationing.

Firstly, it is expected that the state is able to demonstrate its inability to provide health care available in other parts of the world in a transparent manner based on evidence. This is partly accomplished in the White Paper by extensive discussion on expert groups that will help to determine benefits, treatment guidelines and approve new technologies.

However, a second key element of the GC14 is that non-discrimination should be as important as effectiveness in deciding on rationing. Equity in outcomes is more important in a human rights framework than equality of inputs. It is no good proposing to accept a service that is highly cost-beneficial if only a minority can practically make use of it.\(^ {18}\)

Thirdly, the GC14 is clear that a RBA to health implies the principle of participatory decision-making. National public health plans “shall be devised, and periodically reviewed, on the basis of a participatory and transparent process” \(^{11}\); paragraph 43f. “Thus, determining the health care priorities is not purely a matter of epidemiology, but also of people’s expressed priorities.”\(^ {19}\) As Backman and Hunt argue “In the context of health systems, this includes participation in identifying overall strategy, policy-making, implementation, and accountability” which means that “states have a human rights responsibility to establish institutional arrangements for the active and informed participation of all relevant stakeholders, including disadvantaged communities.”\(^ {20}\) The NHI is conspicuously weak on participation.


\(^{17}\) This is qualified by section 36 of the Constitution. The reasons for rationing health care services has to be very strong, and must serve a purpose that a reasonable person would consider incredibly important.

\(^{18}\) In adapting the GC14 to the South Africa context, the point made here needs to focus on unfair discrimination because discrimination is permitted in terms of the test of equality under the Constitution and the PEPUDA.


2. Accountability

In clause 8, it is stated that the NHI will assist in rendering the health system more responsive and accountable which is “likely to improve user satisfaction, lead to a better quality of life.” However, it is unclear how this accountability will be effected and what voice communities will have in decision-making, which appears largely wedded to a technocratic view of setting priorities (informed by burden of disease, cost and cost-effectiveness). Paragraphs 327 to 329 frames the governance of the NHI residing in ‘experts’ rather than the public so the opportunities for participation and accountability appear very limited, unlike experiences in Brazil or Thailand.

For example, it is stated in paragraph 133 that “All treatment guidelines will be routinely reviewed to take into account the assessment and appropriateness of new technologies.” It goes on to state, “Efforts will be put into place to ensure that the general public is provided with the relevant information to support access and ensure empowerment regarding these guidelines.” However, nothing is said here about how decisions as to what is included in the benefit package covered by the NHI. Who will be at the table to make these decisions and how transparent will such decisions be? What criteria will be used and will there be public participation? If so, in what form? It is hard to understand how ‘empowerment’ can happen in the absence of any meaningful participation in decision-making. What appears to be implied by this paragraph is that users will be better informed about services available so as to facilitate access. That is far from empowerment.

3. Participation

Even with regard to cost control, the solution proposed in the White Paper “to prevent inappropriate and excessive use of health services and to ensure long-term sustainability and affordability of the health system” is to impose gatekeeping and strict referral pathways (paragraph 148), with a financial penalty if such pathways are bypassed. The NHI White Paper misses the obvious opportunity to upscale community participation. It is well recognized in the literature that one of the benefits of community participation is greater community ownership and increased responsibility amongst users. Relying solely on coercive measures is not consistent with a RBA to health.

Only one paragraph (at 186) deals with the role of Clinic Committees as vehicles for community participation, despite the commitment to PHC as the heartbeat of the NHI. The National Health Act already make it mandatory for Health Committees to be established at all facilities or groups of facilities. However, the current policy hiatus with regard to HCs leaves the determination of their roles and functions to the discretion of provincial legislation. This is problematic for a number of reasons. Firstly, there is wide variability between provinces in their policies on health committees, which is not consistent with a
programme intended to enhance universal access to health on a National basis. Secondly, the roles of health committees can vary widely from limited decision-making to playing a meaningful role in oversight and governance. The White Paper skirts over this difference (talking generally about advice, advocacy and public health campaigns). The exact role recognized for HCs is very important if communities are going to have a say in service they receive. At present, there is considerable reluctance amongst providers and managers to cede power to communities in this context, and many committees simply end up as ‘helpers’ to the overworked staff, rather than exercising any leadership or representing the community in a meaningful way in engaging with the services. Even in paragraph 224, dealing with patient rights and patient-centred care, the paper is silent on the role of HCs promoting patient and community voice. The White Paper could have been much stronger about confirming the importance of meaningful decision-making at district level.

A further problem in the participation scenario is the atomisation of participation to facility level, so that HCs can only exercise ‘participation’ for their facility, when we know that decision-making occurs at far higher levels that local facility. The NHI omits any mention of how to address the insertion of community voices at all levels of the health system as has been successfully achieved in other countries, such as Brazil.

4. Vulnerable groups

Fourthly, the GC14 outlines how “the process by which the strategy and plan of action are devised, as well as their content, shall give particular attention to all vulnerable or marginalized groups” [11];paragraph43f. In the interests of equity, and consistent with the statement in paragraph 118 that vulnerable groups will be prioritized for access, one might well prioritise an intervention of lower cost-effectiveness that addresses the needs of a particularly vulnerable group.

It is therefore not clear that is what the White Paper has in mind in paragraph 17 when it talks about “Vulnerable groups such as children, orphans, the aged, adolescents, and people with disabilities, women and rural communities will be prioritized.” Rather, it seems these groups will be prioritized to receive the cards, but not prioritized in terms of the type of services offered, not the system customized to suit their needs. For example, for rural farm workers and rural populations, the transport costs of reaching health facilities are serious obstacles to access to care. Cleary and colleagues showed that high transport costs associated with treatments involving multiple consultations present a major stumbling block to access, but one that is easily amenable to health system interventions that include close-to-client services and subsidised patient transport. As evidence of a state obligation towards realizing the right to health, this gap represents a

---

significant omission on the part of the state. Despite the challenge of patient transport to services in rural areas being raised in submissions on the Green Paper, this issue has not been addressed in terms of vulnerability in the White Paper. The specific vulnerabilities related to migrants is discussed on page 25 below.

5. Equity and effectiveness: An underlying and unrecognised tension

Some of this conceptual confusion stems from the analysis of the State of Health System contained in the White Paper. For example, clauses 41 and 42 of the draft locate the challenges facing the health system as effectiveness and efficiency. Quite apart from effectiveness and efficiency is the question of equity and justice, to which the White Paper pays quite light attention. In setting priorities, equity is absolutely as important as effectiveness and efficiency and should not be relegated to an add-on, as it is in the White Paper.

It is therefore not clear how attention to effectiveness and efficiency alone will meet the vision of the NDP that by 2030 there should have been a significant shift in equity in health (paragraph 43). Ironically, the White Paper does recognize the tension between equity and efficiency but only in relation to financing mechanisms (paragraphs 262 onward). That the burden of funding the NHI should be both equitable and efficient is recognized, but unless the benefits are also equitable and not just efficiently managed and planned, the NHI will fail in its laudable objectives. For example, paragraph 389 deals with the selection of medicines and other health technologies to be funded by the NHI and outlines that the choice “will be based on burden of disease, efficacy, safety, quality, appropriateness and cost-effectiveness.” This mantra is repeated in paragraph 339 dealing with Essential Drugs. No mention is made of equity and prioritizing vulnerable groups. For example, medicines of marginal efficacy may be important for limited numbers of patients with Drug Resistant-TB as part of a cocktail of new drugs needed to provide back up for failed treatments. In all its general statements, the White Paper gives equity a prominent place (e.g. Paragraphs 51, 55, 103, 107, 330 and 429) but when it comes to specific measures related to decision-making, the only criteria given any detailed attention are evidence, effectiveness and efficiency.

6. The Glaring Omission: Prevention and Environmental Risk Factors

The GC 14 refers to the elements of the RTH as including (not limited to) “reducing the stillbirth rate and infant mortality; improving all aspects of environmental and industrial hygiene; preventing, treating, and controlling epidemic, endemic, occupational, and other diseases.” If you look at what the NHI is promising, it will certainly provide services that impact on the stillbirth rate and infant mortality, but will have very little to do with improving environmental and industrial hygiene; or preventing occupational diseases. And, although the NHI White Paper talks in general about the importance of prevention and how
PHC (and its emphasis on prevention) will be the heartbeat of the NHI (paragraph 158), nothing in the way it is designed gives any signal that the planners have thought about how the NHI model will preference prevention.

For example, the NHI White Paper laments the fact that, "[T]he current health system is characterised by an emphasis on curative services that leaves prevention by the wayside", but itself provides no roadmap for how prevention will be integrated into the NHI. No mention is made of reimbursement systems for providers that will explicitly reward prevention over cure. Rather, the discussion in paragraphs 343 to 360 on reimbursement mechanisms notes only that capitation will be suited for primary care service provision (but not for specialists or hospitals or emergency services who will be paid on a DRG-based capped budget basis) and that the potential exists to link reimbursement to immunisation rates (paragraph 351). In fact, the introductory paragraph on provider reimbursement mechanisms (paragraph 343) sets out a preoccupation with cost containment – meaning “cost-saving innovations ... affordability and availability of quality health care to the population” rather than using remuneration mechanisms to change the nature of services provided.

Further, the White Paper notes that “...to effectively reduce the burden of disease, requires a transformative and redistributive system as envisioned through the phased implementation of NHI.” (Paragraph 106). But, in fact, given the emphasis on purchaser provider split and on involving the private sector, it is likely that the NHI will massively emphasise curative services to the detriment of prevention. It is well recognized that most gains in better health outcomes come from upstream preventive interventions, often outside the health sector. Yet there is no ring fencing of funding for upstream prevention interventions, there is no talk of outcomes-based metrics that incorporate disease prevention in the reimbursement mechanisms. Indeed, the principles of the NHI outlined in paragraph 53 to 61 speak only of health care, rather than health or efforts to address the social determinants of health. Even in recognizing the importance of prevention and health promotion in addressing problems of NCDs, risk taking and moral hazard (Paragraph 138), the NHI White Paper does not explain how it will support the implementation of such programmes. The only comment made about prevention services is a very general statement in paragraph 393(a) dealing with purchasing of services. But given the facility-based focus of the NHI, it is unlikely that prevention will gain much foothold in competing for resources. The fact that non-personal health services will remain the responsibility of the District Health Management Offices (paragraph 187) suggests that it will be the rump Department of Health left with responsibilities for prevention while the NHI is primarily curative or preventive screening or immunisation of individual clients.

Indeed, in modeling the rising costs of health care (paragraphs 252 to 258), the authors include no prevention dividend at all and do not mention at all the idea that greater emphasis on prevention might save some costs. If PHC were to really be the heartbeat of the NHI, one would anticipate some benefits in reduced health care costs from
effective health promotion and prevention programmes. The overwhelming message, therefore, from the details of the NHI White Paper is that prevention remains a hortatory statement but not grounded in any programmatic or financial reality.

7. Institutionalising Prevention

The lack of programmatic attention to prevention is reinforced in the institutional arrangements (or lack thereof) for prevention. The only mention of any structure to ensure multi-sectoral collaboration to address ‘diseases of lifestyle’ is made in paragraph 190 which talks to the establishment of a National Health Commission drawing together stakeholders from government and non-governmental sectors. This is confusing as the White Paper also talks about a NHI Commission (paragraph 327), which will provide oversight over the NHI. It is unclear if this meant to be the same structure allowing for multi-sectoral collaboration to address diseases of lifestyle but it is unlikely that this structure could be both an accountability structure and an advisory structure for prevention. If that is the case, then there is no obvious articulation between the NHI itself and this National Health Commission or how the Commission can influence the workings of the NHI. Further, since ‘diseases of lifestyle’ are mostly diseases related to upstream determinants (tax, food production and distribution practices, marketing, advertising, transport policy, etc.), one would want to be very sure that such a Commission is free of vested interests.

It is possible that the Department of Health envisages itself remaining responsible for prevention activities. Paragraph 318 states that the Department of Health “will also remain a major provider of services.” What these services are is not stated. However, since District Health Management Offices will remain responsible for non-personal health services (paragraph 187) this suggests that it will be the rump Department of Health left with responsibilities for prevention, while the NHI is primarily curative or preventive screening or immunisation of individual clients. If it is envisaged that the DoH will primarily drive preventive services, the NHI will end up fragmenting a unitary health system and the risk of draining resources away from prevention may be aggravated. It is not clear what this paragraph implies. The primary role of a National Department of Health is to be the steward for a National Health System, whether it provides services directly or not.

8. Limitations of rights not recognized or not analysed appropriately

The trade-off of what current Medically Insured population will ‘lose’ against what the benefit will be is not discussed in light of a limitation of rights permitted under S36 of the Constitution and under the Siracusa principles and the provisions of the ICESCR. Paragraphs 395 to 399 outline the future role of medical schemes. The imposition of mandatory NHI membership on current members of medical schemes allowing the option to top up with complementary medical insurance cover is outlined. The NHI White Paper comments that
“streamlining covered health care entitlements to ensure value for money and to eliminate duplicative cover” ... will require “alignment of the health benefits offered by the medical schemes industry and those covered by the NHI Fund.” This is essentially a limitation of current choice of medical scheme members in the interests of the public good. As long as the net result of the introduction of NHI benefits does not result in regression (inability to access the same level of care needed), the limitation of choice on the part of current medical scheme members would most likely, if subjected to careful rights based analysis, meet the criteria for justified limitations of rights. However, it would be helpful if the policy were explicit about the basis on which this position is reached.

9. **What is understood by Access to Health Care: A lot is missing**

The AAAQ framework (Accessibility, Acceptability, Availability and Quality) from the GC14 frames access in terms of four dimensions – geographical access, financial access, informational access and non-discrimination. The NHI fails to pay sufficient attention to the elements of access OTHER than financial access.

9.1 Geographical access – rural populations are expected to get themselves to facilities when it is often not possible or practical without money (with the exception of chronic diseases (paragraphs 231 to 234)

9.2 Informational access – the NHI is silent on what information communities can expect and on language barriers to access. Many health care providers do not speak the languages of their patients and patients are expected to bring their own (unpaid) interpreters (often family members) if they want care translated. This is particularly problematic as it violates confidentiality, impairs effective communication and reduces the likelihood of good clinical outcomes.

9.3 Non-discrimination is key, but it is not clear the White Paper has fully captured how it might end up discriminating in practice against rural populations and populations dependent on poor-quality state services unable to meet accreditation standards. For farm workers, dependent on employers for access to services off the farm, there is additional discrimination implicit.

9.4 Even with Financial access, the lack of discussion on what constitutes appropriate rationing in a rights framework is thin. For example, in discussing affordability (paragraph 58), there is no acknowledgement of the criteria that needs to be met if rationing is deemed fair (as in Soobramoney). And, in discussing progressive realization of the right to health as a foundation of the NHI, the paper takes is a given that there is “an environment of resource constraint” without setting out what the constraints
are. For example, there are cogent arguments\textsuperscript{22} that South Africa’s Tax:GDP ratio, which government has pegged at a 25% target since 1996) is lower than countries of equivalent socio-economic development and that we should not assume the existence of constraints as a blanket justification that denies the need for increased government spending on public services. The discussion of the need for equity and efficiency in financing mechanisms (paragraphs 269 to 271) makes no mention of the need to question the financing enveloped imposed by current government fiscal policies.

Civil society has made a number of calls with respect to financing the NHI as a public investment. One is to increase corporate tax, particularly in relation to mining. There is no reference to this in the White Paper. The second is the need to increase tax on middle to high earners (redressing the tax relief afforded high income earners over the past decade). The White Paper recognizes the need for taxation to be progressive and limit the burden on low-earners. However, in calculating projected income, the White Paper applies a flat percentage increase across all income groups to derive anticipated surcharge income (Table 6). This is a highly regressive calculation and likely to aggravate inequality. Changes in tax liability to comprise the surcharge should match the progressive increases that currently operate in our tax regimen rather than be proportionately distributed across all income groups in the same quantum, as is the case in Table 6.

10. Threats to other social security funds

Moreover, the paragraphs that suggest that rationalization with other Social Security funds might help to ‘mobilise’ resources for the NHI (paragraph 418) is very disturbing. The Compensation Fund for Occupational Diseases and Injury (COIDA) is currently a morass of mismanagement that has not been addressed despite a decade of appeals for attention; the fund under the Compensation Commissioner for Occupational Diseases in Mines and Works Act (ODMWA) is technically bankrupt with a massively underfunded mandate to provide compensation to thousands of mine workers suffering from work related occupational diseases. It is unlikely in the extreme that these funds would in any way ‘mobilise’ additional resources for the NHI through rerouting funding for medical benefits via the NHI. At the very best (an unlikely scenario), they would bring in sufficient resources to cover the costs of medical benefits linked to compensation and come out even. There is no real evidence presented of ‘double dipping’ (paragraph 334) as stated, so it is not clear that there will any cost saving. Certainly, there would be no additional cash for supporting the NHI, unless there was to be a scaling back of entitlements to social security, which would be in

\textsuperscript{22} For example, Forslund D. The political budget crisis and alternatives to austerity, Part One. Daily Maverick 04 NOV 2015. URL HTTP://WWW.DAILYMaverick.CO.ZA/OPINIONISTA/2015-11-04-THE-POLITICAL-BUDGET-CRISIS-AND-ALTERNATIVES-TO-AUSTERITY-PART-ONE/#.VVW1REJ97CS
violation of Section 27(1)(c) of the Bill of Rights. It is possible that the White Paper is merely commenting on the need to integrate the medical benefits under the respective Social Security Funds cited in paragraph 332. This is not the same as resource mobilization for the NHI – rather it is, at best, a break-even arrangement to rationalize medical services linked to these funds. Unlike the redirection of tax subsidies for private medical insurance for state employees (Paragraph 419), the redirection of medical benefits from COIDA, ODMWA, RAF and UIF cannot be counted as ‘additional’ resources.

11. International Agreements and State Obligations: Opportunities to advance the Right to have Access to Health Care Services

Then, the approach in the White Paper does not locate the right to have access to health care services adequately within an international context. For example, the problems with respect to pharmaceuticals and laboratory testing are framed as a problem of over-utilisation and inappropriate use (for example, paragraphs 64 and 65) or as smarter systems for procurement and distribution of pharmaceuticals under existing systems (Paragraph 139). However, the price of pharmaceuticals is also key to access and largely big Pharma’s practice and markets determine price. That these are equally important obstacles to address in the rights based approach as improved efficiency is not addressed in the NHI White Paper. Yet measures to address the failures of the market with respect to medicines access are sorely missing in the NHI White Paper. The State, as part of its stewardship role, must be held accountable for implementing policies that not only make the procurement, distribution and use of pharmaceuticals more efficient, but also remove price barriers that prevent access to essential medicines, as has been the case with many conditions, such as, for example, drug-resistant TB. In other words, the state should not just focus on existing systems and drugs at current prices, but must think about novel ways to access needed pharmaceuticals, taking advantage of TRIPS flexibilities. In other words, the NHI must be nested in an appropriate IP and patient protection system that does not render drugs unaffordable – enabling access but rewarding innovation in pharmaceutical research and development.

Moreover, as a signatory to the ICESCR, and having it ratified in January 2015 (it came into force on 12 April 2015), South Africa is now obliged to consider how it can implement the Right to Enjoy the Benefits of Scientific Progress with respect to needed medicines. At the very least, efficient systems to process medicine registration and support for operational research to ensure newly developed drugs are rapidly progressed to programmatic delivery are needed. Support in different ways for research to develop new drugs, new diagnostic tools and new technologies that benefit the population equitably could take the form of direct research funding from government or leverage with donor partners or international development aid to ensure scientific progress is able to address priority conditions in the country. At the moment, the White Paper accepts as given the current situation, which is one largely created in an ad-hoc manner with a long-term view of the state obligation to
realise the right to have access to health care services.

12. The Centrality of a National Health Plan and Budget

One of the key aspects of a rights-based approach to health systems is the obligation on the state to devise a plan and budget. The General Comment 14 explicitly requires the development of a comprehensive national health plan (e.g., paragraphs 43[6] and 55) as part of the right to health. To some extent, the NHI is part of that process of the States’ devising a plan and budget. But it lacks the commitment to factoring human resources and participation into that plan. For example, the paragraph outlining the human resources needs for PHC services speaks of service to be “delivered by accredited integrated teams of providers” but makes no reference to the need for detailed human resource planning at District, sub-district and ward level - since not all practitioners will be needed in the same numbers or ratios or be available. Human resources planning has for a long time been noted as an important weakness in the NDoH when human resources are regarded as one of the key building blocks of health systems under the WHO Building Blocks model. The commitments indicated in paragraphs 227 to 230 (increasing outputs of different health professionals and retention in under-served areas) are welcome statement of intent, but would be considerably strengthened by indicating how targets for these commitments would be derived as part of a planning process.

This gap is also evident in the description of Ward Based Outreach Teams (paragraph 168), in which it is stated that an “additional 20,000 CHWs that are part of the WBPHCOTs will be deployed in those municipal wards where at least 60% of the households are poor.” It is widely recognized that CHWs exist in a labour relations limbo, outsourced in some provinces to NPOs and employed at wage levels far below a living income in others, often working in unconscionably poor working conditions. This situation is not sustainable for a health system and cannot be relied upon to provide universal access. To progressively realise the right to health through WBOTs, the state need to make explicit a timeline for regularizing the employment of CHWs, establishing fair employment conditions and remuneration and signaling how CHWs will be integrated and supported in delivery of services.

In similar vein, one might question how the NHI White Paper envisages a unitary and coherent health system when it creates a level of autonomy for Central Hospitals that appears to disengage them from other parts of the health system. Paragraphs 201 to 207 do not indicate how these national resources will support national objectives for the NHI.

13. Policy Disarticulation

The White Paper is strangely disarticulated from other Department of Health Policies. Even
though much is mentioned about other policies, there is not much by way of coherence in function across policies. For example, paragraphs 178 and 179 describe the experience of contracting of primary care providers in the pilot districts and paragraph 227 discusses retention of health workers in rural areas. However, the NDoH has a powerful policy tool to regulate the distribution of health care providers in the Certificate of Need (CoN), a provision in the National Health Act (NHA) which it briefly sought to implement in 2014 but which was turned down for technical reasons by the Constitutional Court. Yet, the White Paper appears to allocate that responsibility to the NHI Fund (Paragraph 332) by stating that, “Accreditation by the NHI Fund will be based on the health needs of the population.” This is a direct duplication of the Certificate of Need provisions in the NHA (sections 36 to 40).

The NHI White Paper also makes no reference to other policies such as Community Service and the CoN as tools to increase access for under-served populations to primary curative care. Nor does the NHI White Paper recognize the role of Non-governmental organisations active in rural health care as stakeholders in promoting access to care.
What elements of the White Paper are potentially problematic for a rights based approach to health?

The previous section identifies elements of the NHI policy which are insufficient to meet a rights based approach to health or which lack sufficient detail in key areas to reassure the public that an NHI will be able to meet its rights objectives. However, there are elements to the policy that are more than just weaknesses – they are in and of themselves threats to the right to health. These are detailed below.

Firstly, the provision for an NHI card will be essential to efficiency. But there are a number of potential threats posed by this requirement, which may affect people’s rights.

In the first instance, this provision is not consistent with (a) the large migrations of people in South Africa between provinces, and, (b) the commitment to continuity and portability described in paragraph 107. Moreover, the NHI White Paper implies that people will be penalized if they go outside of their designated area to seek care – which means people with poorer services will be disadvantaged by seeking better quality services outside their area – discrimination by SES. In clause 7, where the NHI White Paper argues that “means that people will be able to access health care services closest to where they live”, it is unclear whether the converse is implied – that people will NOT be able to access health care services if they are not closest to where they live. This is, of course, in contradiction to the stated aim of the NHI to ensure “… continuity and portability of health service benefits across the country.” (paragraph 107).

It is also well-recognised that services in the poorest districts of the country, often with the worst health outcomes, are the poorest services in the country and are the least likely to achieve accreditation with the Office of Standards Compliance (Paragraph 219) without massive investment of State resources to build up these public facilities. These are also areas where there is a dearth of private facilities. Thus, coupled with the penalties for using services outside of your residential area, this situation risks aggravating inequities in access to health care. In that sense, the White Paper fails to meet its own description of UHC (Paragraph 52(i)) where it is argued that, “The right to access quality health services will be on the basis of need and not socio-economic status.” Without attending to the inherent bias in the simplistic use of accreditation to count facilities in or out, the policy risks aggravating lack of access.

Secondly, there is no discussion about protection of personal information or consonance with the Protection of Personal Information (POPI) Act. Paragraphs 364 to 369 discuss the establishment of a patient registration system that is able to link electronic health records. At one level, this is absolutely critical for planning and will assist users if the benefits are realized. However, there are privacy concerns, which are not mentioned at all in the White Paper. Companies handling personal medical information frequently have intermediate companies managing their data (so-called ‘switching’ companies) and may have international corporate
links. Personal medical information is well known to be of higher durability and portability as a valued commercial asset. The risk of trading of such information for profiteering by private companies based outside South Africa is not recognized by the White Paper.

Thirdly, there is no discussion in the White Paper about international trade regulations, nor planned bi-national trade agreements being used to open the South African market generated by the NHI to private health care organisations operating outside South Africa. US institutions moved into Ghana shortly after Ghana introduced a NHI and it is likely the same would happen in South Africa, particularly with the preoccupation of the SA Government with hoping to encourage foreign direct investment (FDI).

Fourth, the way refugees are treated is potentially problematic. It sets up a clear distinction between migrants with status, migrants who have applied for status, and undocumented migrants. The distinction is not always a justified distinction to be made even if a legal one, on which to base differential access to health care. Secondly, the White Paper contradicts itself in a number of places on this matter. For example, paragraph 106 states clearly that the NHI is intent on “ensuring progressive realisation of the right to health by extending coverage of health benefits to the entire population...” whereas in the very next paragraph 107, the White Paper commits only to providing “universal health coverage for all South Africans.” The commitment to the ‘entire population’ rather than citizens is repeated again in paragraph 321 where the NHI Fund is described as using “monopsony power to strategically purchase services that will benefit the entire population.”

It is not clear how coverage can be extended to the entire population but universal health coverage is a matter dependent on your citizenship. The White Paper also appears to set up two-tier system with one set of benefits for South Africans and a lower level of benefits, framed as ‘basic health services’ following the language of the Refugees Act (Section 27.g). Setting up different packages of care appears to contradict the very basis of Universal Access. A further contradiction is that the White Paper states that asylum seekers would be entitled to emergency care (paragraph 122), but that undocumented migrants would have to pay for their emergency care (paragraph 123). Since the Bill of Rights frames access to emergency care as a right for ‘everyone’ (not just citizens or those who have been officially recognized as refugees) imposing the cost for emergency medical care on undocumented migrants appears to be highly discriminatory, as most undocumented migrants will likely not be able to pay for services essential to preserve their lives. Despite the fact that there is considerable research into the number of migrants in South Africa, their socio-economic status, their health care utilization and obstacles to care, none of these data are presented in the White Paper as a basis for

---

deciding on benefits for refugees. Similarly, sections 241 to 247 dealing with access to Emergency Care are silent on access for non-South Africans.

If the White Paper is setting out a basis for a limitation of rights – i.e. the rights of migrants who are not legally resident in South Africa – it must do so in accordance with section 36 of the Constitution and the Siracusa principles. The likely assumption behind the purpose of such a limitation (unstated in the White Paper) is that South Africa cannot afford care for all within its boundaries and that restriction of access of certain groups is necessary to secure the entitlements of others. However, no evidence is presented for such an argument, nor are alternative options explored for ensuring access. Thirdly, even if such a distinction justifying limitation of rights could be argued on a rights basis, it is (a) obligatory on government to ensure that such a limitation is not arbitrary, irrational, discriminatory or beyond review; and (b) not clear how this will be enforced practically without risking serious violations of the rights of migrants. For example, providing access to an asylum seeker for their HIV treatment but not their diabetes (which may or may not be the result of the medication they are receiving) is unethical. Further, when the patient with diabetes suffers a stroke, he or she will be treated as an emergency and resuscitated, but then, once recovered, left without access to treatment. This is neither humane nor an efficient use of health care resources, since an admission for stroke, an entirely preventable condition, is far more expensive than treating the diabetes in the first place. Lastly, the distinction between NCDs and Infectious diseases is increasingly becoming a false distinction with our massive patient burden on ARVs. If a patient with HIV develops Kaposi’s sarcoma (a malignant tumour) as a result of HIV, do we deny care for the sarcoma (which is eminently amenable to cure with appropriate treatment) but continue providing anti-retrovirals? On all counts, the distinction between legal migrants and others appears unsupportable, not only from a rights perspective, but also from an operational view.

Further, the White Paper implies that the health services to be afforded to migrants with legal status will not be equivalent to South Africans and permanent residents because they will be provided with “basic health coverage” (paragraph 121) rather than equivalent coverage under universal health care. Far from complying with section 27 (g) of the Refugees Act 130 of 1998 as amended, it seems this discussion seeks to establish exceptional status for legal migrants with reduced coverage – which would appear to be in violation of Section 27(g) and our international human rights commitments with regard to refugees.

Fifthly, the requirement for all hospitals to be accredited in order to participate in the NHI is well intended. But, as pointed out above, it is well recognized that the poorest districts and areas are the ones with hospitals most likely to be unable to achieve accreditation through the Office of Standards Compliance (OSC). This is because of years of underfunding, poor management, lack of support, staff demoralization and community distrust. Yet these are the hospitals located in areas with the highest need. It is likely that these communities will be further discriminated against through the policy. It is also unclear what the motivation will be
for hospitals to be accredited. Will they continue functioning in the absence of accreditation? If so, why would they make the effort? If not, then the Department of Health is failing in its role as steward for an equitable health system where all enjoy opportunities to access health care consistent with their constitutional rights. It seems the reliance on accreditation as the tool to improve quality of care might be a misapplied policy that will not benefit the poor; rather, using OCS as a benchmark without linking it to NHI accreditation might contribute to Quality Improvement without threatening access for the poorest communities. In that regard, the White Paper needs to set out what it will do ensure that public hospitals designated to serve a particular catchment population will be able to meet the OSC benchmark.

Sixth, in paragraphs 137 and 138, there is a risk of confusing risk-taking behavior with over-utilisation under the rubric of a discussion about moral hazards. Over-utilisation of services in ways that undermine others’ access to care is rightly a matter for improved systems, principally better referral systems and triage. However, linking ‘risk taking behaviour’ (such as smoking, taking excessive alcohol or eating poor diets with the knowledge that they are covered by NHI) to strict gatekeeping implies that patients may be denied care because they are deemed to have behaved irresponsibly. It is not clear how gatekeeping can contribute to control of this problem in any other way than to deny certain people care for lifestyle ‘choices’ they have made. This is a seriously flawed understanding of what the Right to Health entails. Certainly, people who have rights also have responsibilities to behave in ways that do not deny others the same entitlements to what they enjoy as rights. But it does not mean denying a patient care because they were drunk or smoke heavily. It is noted that paragraph 138 does note the need for health promotion and disease prevention programmes to provide ‘support’ but rather than ‘support’, the Paper should recognize that upstream prevention is THE appropriate response to these chronic conditions rather than as linked to a strict referral system and gatekeeping function. It is unfortunate that this section of the White Paper elides two different problems together when they should be discussed discreetly and separately. As it stands, the Paper risks permitting discrimination against patients based on perceived lifestyle choices and allowing prejudiced moral judgements about entitlements. This is wholly contradictory to a rights-based approach to health.

Lastly, in discussing Financial Risk Protection, the White Paper concentrates on direct costs of service provision. For example, in paragraph 85, the White Paper notes three forms of payment involved in Out-of-Pocket payments, none of which mention costs of patients reaching health care. However, there is compelling data that even when services are provided free at the point of contact, indirect costs to patients are a major obstacle for poor people to access health care. For example, Cleary and colleagues\(^2\) showed that transport to a facility was a major cost for patients, even when the direct costs at the facility were minimal. For patients who can walk to facilities, this is perhaps only an issue for those too ill for walking and for whom an ambulance would be required. But for rural areas, the costs of getting to clinic are sizeable. Moreover, for farm workers living on private farms, access to transport is at the behest of the farm owner.

\(^2\) Cleary et al, 2013 (above)
Thus, if the NHI is to be consistent with a rights-based approach, it must factor into its model, ensuring that hard-to-reach groups and groups whose autonomy is constrained (e.g. farm workers, prisoners, etc.) are provided with access to services.

**Recommendations**

1. The policy should develop an operationally implementable manner to manage the limitation of rights that might transpire in the interests of promoting the public good. Such limitation should meet the standards of Sections 27 and 36 of the Constitution and the Siracusa principles.

2. The entire policy should be permeated with an explicit elevation of the human rights principle of non-discrimination. It should not be the case that decisions can be made solely on the basis of effectiveness, as appears widespread in the White Paper at the moment.

3. The NHI must develop effective vehicles for participatory decision-making – not just in receiving new information on treatment protocols, but in identifying overall strategy, policy-making, implementation, and accountability. Moreover, the participation of vulnerable groups in these vehicles should be emphasised.

4. The role of statutory structures for community participation (Health Committees, Hospital Boards) should receive much greater amplification in the policy – both in terms of strengthening their governance roles, but also in terms of strengthening the articulation of participation structures at all levels of the health service.

5. The NHI needs to deal with vulnerable groups in a more sophisticated way. Giving certain groups of persons access to the NHI card is necessary but not sufficient to ensure their needs are being prioritised. In the way services are structured, delivered and supported, the needs of vulnerable groups should be reflected. For example, subsidised transport costs for certain groups of users, such as farm workers, should be prioritised.

6. The NHI desperately needs to have a preventive focus structured into its operations and governance; otherwise, it risks reverting to a model dominated by curative care. Environmental and occupational health are listed in the General Comment 14 as key elements of the Right to Health but are either totally absent or conspicuously weak in the way they are mentioned in the White paper. Prevention should be reflected in the financing of the NHI isasmuch as improved prevention services should deliver a prevention divided reducing health care costs.

7. The NHI must recognise the full spectrum of elements that make up access, not only geographic and financial – but also informational and non-discrimination. It should, for
example, ensure, within its available resources, access to interpreter services, progressively rolled out, for different groups, with particular emphasis on the disabled. For example, pilot work on developing South African Sign Language interpreter services for deaf patients\textsuperscript{25} highlight both the potential cost savings to the service, as well as the opportunity for an entirely different and qualitatively improved service for deaf patients. This latter example, also speaks to the need for services to be provided on a non-discriminatory basis. All of this should be clearly reflected in a future NHI.

8. There should be no retrogression of services and no loss of access to other social security benefits by virtue of the introduction of the NHI.

9. The NHI should be located within a much more active state, seeking to use opportunities provided by international agreements and conventions ratified to expand the envelope of access to care for people in South Africa. For example, the state should take advantage of TRIPS flexibilities with regards to accessing medicine, and through domestication of the ICESCR, pursue avenues to realise the Right to Enjoy the Benefits of Scientific Progress as part of strengthening our health system.

10. The NHI and its related plans, should be consistent with what is recommended by the GC14. It needs to be comprehensive and participatory; it needs to have a stronger and clearer commitment to expanding and upskilling human resources with clear targets.

11. It needs to present a clearer articulation of the NHI with other key policies in the health and related sectors.

12. The NHI needs to rethink its attempts to limit care to facilities closest to where one lives. This is likely to be highly discriminatory and likely to aggravate inequality.

13. The NHI needs to pay more attention to data privacy and protection, consistent with National Legislation, such as the POPI. A clear precedence of national law over any other jurisdiction should be established for any consultants, consortia or companies doing business with the NHI at any time.

14. The State must rethink its position on migrants. The current position is neither tenable from a moral or rights perspective and, further more, is practically impossible to implement. Rather than continuing to treat migrants as a ghost population, very concrete entitlements should be articulated.

15. Any possibilities that victim-blaming might be tacitly or implicitly accepted as a way to exclude ‘delinquent’ or ‘self-harming’ patients from care should be addressed upfront.

\textsuperscript{25} Personal communication, Dr Marion Heap 2016: Dr Heap is leading an extended project piloting professional SASL interpreter services for deaf patients in the Cape Metro Health District.
and an unacceptable practice that is rights violating.

16. The NHI should have a programme specifically focused on equity in access – with an ombud and a monitoring and evaluation commitment, that has teeth to exercise authority.

17. The commitment to a progressive taxation mechanism must be maintained in the final version. Moreover, the need to have a single payer as a key lever for reducing costs, is undeniable.
ANNEX 1: Indicators of right to health (Backman et al, 2008)

Recognition of the right to the highest attainable standard of health
1 Number of international and regional human-rights treaties recognising the right to health ratified by the state
2 Does the state’s constitution, bill of rights, or other statute recognise the right to health?

Non-discrimination
3 Number of treaty-based grounds of discrimination that the state protects out of: sex; ethnic origin, race, or colour; age; disability; language; religion; national origin; socioeconomic status, social status, social origin, or birth; civil status; political status, or political or other opinion; and property
4 Number of non-treaty-based grounds of discrimination that the state protects out of: health status (e.g., HIV/AIDS); people living in rural areas; and sexual orientation
5 General provisions against discrimination

Health information
6 Does the state law protect the right to seek, receive, and disseminate information?
7 Does the state law require registration of births and deaths?
8 Does the state have a civil registration system?
9 Does the state disaggregate data in the civil registration system on grounds of: sex, ethnic origin, rural or urban residence, socioeconomic status, or age?
10 What proportion of births is registered?
11 Does the state regularly collect data, throughout the territory, for the number of maternal deaths?
12 Does the state centralise these data for the number of cases of maternal deaths?
13 Does the state make publicly available these data for the number of cases of maternal deaths?
14 Does the state regularly collect data, throughout the territory, for the number of neonatal deaths?
15 Does the state centralise these data for the number of cases of neonatal deaths?
16 Does the state make publicly available these data for the number of cases of neonatal deaths?

National health plan
17 Does the state have a comprehensive national health plan encompassing public and private sectors?
18 Has the state undertaken a comprehensive national situational analysis?
19 Before adopting its national health plan, did the state undertake a health impact assessment?
20 Before adopting its national health plan, did the state undertake any impact assessment explicitly including the right to health?
21 Does the state’s national health plan explicitly recognise the right to health?
22 Does the state’s national health plan include explicit commitment to universal access to health services?

Participation
23 Is there a legal requirement for participation with marginalised groups in the development of the national health plan?

Underlying determinants of health
24 What percentage of the rural and urban population has access to clean water?
25 What are the CO2 emissions per capita?
26 Prevalence rate of violence against women

Access to health services
27 Proportion of women with a live birth in the last 5 years who, during their last pregnancy, were seen at least three times by a health-care professional, had their blood pressure checked, had a blood sample taken, and were informed of signs of complications

**Medicines**
28 Is access to essential medicines or technologies, as part of the fulfillment of the right to health, recognised in the constitution or national legislation?
29 Is there a published national medicines policy?
30 Is there a published national list of essential medicines?
31 What is the public per capita expenditure on medicines?
32 What is the average availability of selected essential medicines in public-health facilities?
33 What is the average availability of selected essential medicines in private-health facilities?
34 Percentage of 1-year-old children immunised against measles
35 Percentage of 1-year-old children immunised against diphtheria, tetanus, and pertussis

**Health promotion**
36 Does state law require comprehensive sexual and reproductive-health education during the compulsory school years for boys and girls?
37 Proportion of 15–24-year-old boys and girls with comprehensive HIV and AIDS knowledge

**Health workers**
38 Does the state have a national health-workforce strategy?
39 Does the state law include provision for adequate remuneration for doctors?
40 Does the state law include provision for adequate remuneration for nurses?
41 Do the state’s workforce policies or programmes include a plan for national self-sufficiency for doctors?
42 Do the state’s workforce policies or programmes include a plan for national self-sufficiency for nurses?
43 Do the state’s workforce policies or programmes provide incentives to promote stationing in rural areas of doctors?
44 Do the state’s workforce policies or programmes provide incentives to promote stationing in rural areas of nurses?

**National financing**
45 Is the per capita government expenditure on health greater than the minimum required for a basic effective public health system?
46 What is the proportion of households with catastrophic health expenditures?
47 Total government spending on health as percentage of gross domestic product (GDP)
48 Total government spending on military expenditure as percentage of GDP
49 Total government spending on debt service as percentage of GDP
50 Proportion of national health budget allocated to mental health

**International assistance and cooperation**
51 Does the state’s international development policy explicitly include specific provisions to promote and protect the right to health?
52 Does the state’s international development policy explicitly include specific provisions to support the strengthening of health systems?
53 Proportion of net official development assistance directed to health sectors

**Additional safeguards**
54 Does the state law require protection of confidentiality of personal health data?
55 Does the state law require informed consent to treatment and other health interventions?
56 Does the constitution protect freedom of expression?
57 Does the constitution protect freedom of association?
58 Does the state have a patients' rights charter?
59 Is the patients’ rights charter available in all official languages?

**Awareness raising about the right to the highest attainable standard of health**

60 Does the state have a national human-rights institution with a programme of budgeted activities to raise awareness of the right to health among the public?
61 Does the state have a national human-rights institution with a programme of budgeted activities to raise awareness of the right to health among doctors?
62 Does the state have a national human-rights institution with a programme of budgeted activities to raise awareness of the right to health among nurses?
63 Are human rights a compulsory part of the national curriculum for the training of doctors?
64 Are human rights a compulsory part of the national curriculum for the training of nurses?

**Monitoring, assessment, accountability, and redress**

65 Infant mortality rate
66 Mortality rate of children younger than 5 years
67 Maternal mortality ratio
68 Life expectancy

69 Does the state have a national human-rights institution with a mandate that includes the right to health?
70 Number of judicial decisions, nationally, that considered the right to health during 2000–05
71 Does the state have a national human-rights institution with a mandate to monitor international assistance and cooperation?
72 In the past report submitted by the state to the UN in relation to the International Covenant on Economic, Social, and Cultural Rights, was there a detailed account of the international assistance and cooperation in health that the state is providing?