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29 November 2019

BY EMAIL

ATTN: Mr Sibongiseni Maxwell Dhlomo
Chairperson: Portfolio Committee on Health
National Parliament of South Africa
National Parliament of South Africa
C/O Ms Vuyokazi Majalamba (Committee Secretary)
Email: vmajalamba@parliament.gov.za

Dear Mr Dhlomo,

Re: Comments on Draft National Health Insurance Bill (B11-2019)

Genetic Alliance South Africa (GA-SA) is a non-partisan, non-profit, membership organisation uniting patient support groups, healthcare professionals and other stakeholders relevant to the care and prevention of congenital disorders (CDs). Based on collective membership of member groups, GA-SA represents almost 30 000 South Africans affected directly or indirectly by CDs, including rare diseases, inherited cancers and fetal alcohol syndrome. As both a registered NPO and PBP, the vision of GA-SA is for a united CD community that works towards a South Africa where those affected can readily access care and support. We strive to achieve this through our mission to unite, support and build capacity in the CD community through advocacy, networking, education, public awareness and research.

CDs, also known as birth defects, are defined as abnormalities in structure or function that are present from birth, whether manifesting at birth or later in life[1]. They may be caused by genetics, the environment a combination of these or unknown causes. CDs affect 1 in every 15 live births in South Africa[2] but are underreported via national surveillance by 98%[3] and as yet, are unprioritized as a health need in the country. Although the true contribution of CDs to the burden of disease is unknown due to the data deficit in South Africa – the proportion of deaths and disability due to CDs is known to increase in countries as they develop and transition epidemiologically. In developed countries, which completed this transition decades ago, CDs emerged and remain today as a leading cause of infant and child death – causing up to 28% of under-5 deaths[4]. Current lack of capacity in the community genetics sector in South Africa means that many of those affected remain undiagnosed or are misdiagnosed and the cause of death is incorrectly assigned. This prevents those affected, including the most vulnerable of our society (women, children and those living with disability) from having access to relevant, affordable health care. Early diagnosis and treatment can in some cases be lifesaving

[1] World Health Organization 2006. Management of Birth Defects and Haemoglobin Disorders. Report of a Joint who-March of Dimes Meeting. Geneva, Switzerland, 17-19 May 2006. *Human genetics programme, World Health Organization.* Geneva: World Health Organization.
[2] Malherbe, H.L., A.L. Christianson, and C. Aldous, *Need for services for the care and prevention of congenital disorders in South Africa as the country's epidemiological transition evolves.* S Afr Med J, 2015. **105**(3): p. 186-188.
[3] Lebese, L., C. Aldous, and H. Malherbe, *South African congenital disorders data, 2006 - 2014.* S Afr Med J, 2016. **106**(10): p. 992-995.
[4] World Health Organization, *World Health Statistics 2015*. 2015, World Health Organization: Geneva. p. 164.

and minimize the impact of CDs on early childhood development, reducing the degree of disability and improve quality of life by up to 70%[5].

OVERVIEW OF SUBMISSION

GA-SA applauds the Minister of Health for the release of the revised draft National Health Insurance Bill in 2019 and welcomes this opportunity to submit comments relating to this draft. If the National Department of Health elects to hold further public hearings or briefing sessions on the draft Bill, GA-SA would welcome the opportunity to participate.

These submissions detail GA-SA and constituency concerns that the National Health Insurance (NHI) Bill 2019 removes existing forms of access to healthcare services to certain categories of vulnerable populations, particularly, CD and rare disease patients.

The restrictive population coverage in the Bill is unlawful, unconstitutional, inhumane, negative for public health, and in conflict with the objectives of NHI, as well as the premise of Universal Health Care (UHC) as defined by the World Health Organization (WHO). Parliament has a duty to uphold the Constitution and not to enact laws that are known to violate the Constitution. With extensive court precedent indicating that these provisions would be unconstitutional, passing the Bill in its current form would be an infringement of the rule of law, exposing the public purse to inevitable, expensive, and wasteful litigation.

GA-SA submissions focus on the impact of the Bill on affecting CD (including rare disease) patients and caregivers and healthcare professionals supporting them. Numerous CD patients and their treatment will be affected by the implementation of the NHI Bill in its current format and will fail to meet the Constitutional criteria which the Bill seeks to achieve. Furthermore, the Bill as is will create further social injustice and inequalities to those South Africans who are treated for their CDs in both the public and private sectors. CDs, especially rare disorders, are often excluded when funding decisions are made and the current format does not seek to address this vital and marginalised issue.

These submissions also focus on the discriminatory nature of the exclusion of CD and rare disease patients, access to high cost innovative medicine, limited access to medical genetic services including diagnostics and the overall discrimination from having comprehensive and equitable access to the services provided by the NHI. Finally, they will address the need to ensure meaningful engagement and participation of CD and rare disease patients and caregivers in the various bodies established by the NHI Bill.

This submission does not include detailed comments on all sections of the current NHI Bill, rather those sections that could or would have an impact on our constituency should they be enacted.

GA-SA agrees that the current two-tiered health system is inequitable and that there is a need to change health funding. We also agree unequivocally that the right of everyone to access to health care services means that everyone should be able to access quality services on the basis of need, rather than on the ability to pay. However, we do not agree with the proposed changes to the health system and the establishment of the NHI Fund as laid out in the current form of the NHI Bill.

GA-SA made a submission on the 2018 Draft NHI Bill expressing concerns in the following areas:

a) **Access to Healthcare:**

Chapter 2 of the Constitution of the Republic of South Africa - the Bill of Rights is the cornerstone of democracy in our nation. It enshrines the rights of all people in our country and affirms the democratic values of human

[5] Czeizel, A., Z. Intôdy, and B. Modell, *What proportion of congenital abnormalities can be prevented?* BMJ, 1993. **306**: p. 499-503.

dignity equality and freedom. It also states that the state must respect, protect, promote and fulfil the rights in the Bill of Rights. Equality includes the full and equal enjoyment of all rights and freedoms.

GA-SA is concerned that the draft Bill in its current form does not effectively provide for the constitutional rights of South Africans affected by a common or rare congenital disease – and instead, limits their rights to access healthcare.

Many CDs and more rare conditions are complex conditions involving a number of body systems requiring care from a variety of different medical specialists and allied healthcare professionals. While CDs are collectively common affecting one in every 15 live births, some conditions are extremely individually rare, affecting 1 in 2 000 live births or less. Specific implications in terms of the draft Bill include:

- **Section 10(2)(c)** - Adhering to referral pathways determined by a health establishment to have their condition funded is not always an option for those affected by CDs and rare diseases.
- **Section 10(3)(b)** - For many of the extremely rare conditions, there is no 'cost-effective' intervention in existence. Interventions for many CD and rare disease may be novel and expensive (often off-label use) and there is usually no alternative treatment. No provision is made in the draft Bill for conditions without a 'cost effective' solution. Rather, provision is made for a sub-set of the population i.e. those that have diseases that are common and for which there are available and affordable interventions. The draft Bill excludes those South Africans for which no such 'cost effective' interventions exist, for example those affected by rare metabolic disorders such as Lysosomal storage diseases which are treated via enzyme replacement therapy. This is an expensive, life saving therapy to which there is no alternative.
- **Section 10(6)** - The draft Bill makes provision that a user may purchase health care services not reimbursed by the fund through private healthcare insurance. However, the Medical Schemes Amendment Bill[6] published for comment on 21 June 2018, states that the Registrar may, after consultation with the Minister, restrict the extent of benefits offered by a medical scheme having regards to the benefits and services offered under the NHI Fund (Amendment to Section 34 of Act 131 of 1998).

The circumstances under which a persons rights may be limited as stated in Section 36(1) of the Constitution must be reasonable and justifiable in open and democratic society based on human dignity, equality and freedom, taking into account all relevant factors, including — (a) the nature of the right; (b) the importance of the purpose of the limitation; (c) the nature and extent of the limitation; (d) the relation between the limitation and its purpose; and (e) less restrictive means to achieve the purpose.

These rights must be upheld through the draft Bill and access to care provided appropriately to all and not to the detriment of any requiring such healthcare.

b) FUND INCOME & COVERAGE

Section 3(b) of the draft Bill states that the Fund is the single public purchaser and financier of health services in the Republic of South Africa. However, there is no reference to the mechanism by which the fund will be financed and this needs to be clarified and detailed. A provisional funding framework should have been in place (i.e. a means to financially provide for the scheme) before the Bill was proposed. GA-SA's concern is the long-term viability of the NHI system since many pilot project sites already appear to be demonstrating financial problems. This has major implications for access to healthcare and the purpose for which the NHI Fund is created.

One potential option under discussion for the financing of the NHI fund is via a tax levied for South African taxpayers to cover these costs. The sustainability of this approach is questionable for a nation where 10% of

[6] Government Gazette Number 41726

the population pay over 90% of taxes. In addition, many GA-SA member patient groups are committed to facilitating aid families where there is a rare disease patient, e.g. Rare Diseases South Africa. The huge financial burden imposed on these affected families due to the cost of caring for a family member with a CD or rare disease is already immense. In many cases, a parent or family member has to stop working to become a full-time carer, decreasing their earnings. Should these families also be required to fund the NHI Fund from a portion of their taxable earnings, this will further decrease the amount available to them to obtain appropriate complementary cover. Should this be the case, Section (4)(a) of the draft Bill, which outlines an objective of the fund to establish and maintain an efficient fund through the consolidation of revenue so as to protect users against financial risk – may well result in vulnerable groups having to pay for a mandatory service that does not provide for their needs and pay additional costs for private services – resulting in huge financial risk.

Section 5(C) of the draft Bill provides for the fund to "…*design healthcare services as advised by the relevant committee of the Board which will be purchased by the Fund on behalf of users*". The question must be asked is how they will be considered to have services purchased that will actually cover the treatment of a less common condition. Also, how will they decide which conditions will be included? Patients affected by CDs and rare diseases will be required to contribute to the fund and register as a user but, as suggested by Section 5(C), will have no say in the purchase of services that will ultimately affect them. The NHI claims to prioritise services to those populations most in need and, by definition, this should include CDs and the rare disease community. From the current draft Bill it is unclear if these patients will be covered at all by the fund. Based on previously published NHI benefits framework, there is no provision made for coverage of the rarer disease patients. So, while these families will be required to register as users of the NHI fund, many will not have the treatment of their conditions funded.

GA-SA also raises the issue of 'cost effectiveness' relative to personal risk/cost and the overall socioeconomic impact which do not appear to have been considered. For example: conservative treatment of specific scoliosis patients (where the curve may be treated) involves physiotherapy and bracing (R40 000 per brace) versus spinal surgery (R200-300 000). Such major surgery should be the last resort, and only after the child has stopped growing – what is currently taking place in State since bracing is currently not available is that surgery is offered in all severe cases (even those that bracing would negate surgery) and at an early age, resulting in stunting. Many children remain undiagnosed resulting in repeated visits to healthcare facilities requiring time off school and work for their parents, transport costs and ultimately a reduced contribution to the workforce and economy.

Further general comments related to the financing of the fund:

- We are concerned about the reported fact that 85% of public hospitals and clinics could not be accredited to participate in an NHI system because they were unable to comply adequately with basic healthcare norms and standards, such as maintaining proper hygiene and having medicines available. To be overcome, these problems require significantly improved operational and financial management.
- For South African citizens to truly benefit from a universal health coverage system there will be a need for stronger accountability for wrongdoing and accountability amongst political and civil servants involved in the operation of the fund. Failure to do this will directly impact the entitled user/beneficiary's *right to life and to have access to health care services*. Furthermore, t*he state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights.*

c) CONTINUATION OF CARE & REFERRAL PATHWAYS

Section 10(2)(c) makes provision that a user must comply with referral pathways determined by a health establishment, failing which, the fund will not be liable to make payment of any service benefits. In the case of a less common CD, this is not viable.

While the draft Bill addresses the phases by which the proposed NHI will be implemented it fails to deal with the practical issue of continuation of care by existing treating healthcare practitioner during this phase. Patients already diagnosed with a CD (common or rare) prior to the implementation of NHI and the draft Bill may have already been receiving much needed treatment under the care of a specific sub-specialist or multidisciplinary team of specialists and allied health care professionals. A delay in receiving continued lifesaving care could prove fatal.

Often these practitioners are consulted by the patient due to the practitioners' specialty and expertise in treating a particular problem and not due to geographic convenience. With such a shortage of medical specialists in the country, geographical convenience is often a luxury many CD and rare disease patients do not have, particularly those outside of major urban areas boasting an academic facility where most such specialists are located.

In addition, the requirement specified in the draft Bill that patients adhere to referral pathways determined by a health establishment, which may commence with a patient being assessed by a nurse or other primary health care provider is a likely waste of time and resources in the case of CD and rare disease patients. While this may be an appropriate referral pathway for someone affected by a less severe and more common illness e.g. a common cold, the same standard of referral cannot be applied to all. The previous diagnosis and the treatment already received or ongoing by the patient must be taken into consideration to ensure the most effective, timeous access and reimbursement for certain conditions.

Our Patient's Rights Charter makes provision for *the right to choose a particular health care provider for services or a particular health facility for treatment, provided that such choice shall not be contrary to the ethical standards applicable to such health care provider or facility* and *not to be abandoned by a health care professional who or a health facility which initially took responsibility for one's health without appropriate referral or hand-over.*

Further the delays in accessing the appropriate treatment for a rare disease sufferer can have dire consequences and may even result in death. Provision is made in Section 11(2)(b) that a user of the Fund may only seek the services of a specialist without a referral from his or her healthcare provider in cases of an emergency.

GA-SA requests clarity in the draft Bill on the definition of emergency services and a clear definition of the process by which patients and healthcare practitioners of rare or specialised conditions, including CDs, are integrated into NHI healthcare services.

d) RIGHTS OF FUND USERS/PATIENTS:

4.1. Right to Informed Consent

The right to informed consent places responsibilities on the individual patient according to the Patient's Right Charter:

- *To take care of his or her own health;*
- *To utilise the health care system properly and not to abuse it;*
- *To know his or her local health services and what they offer;*

- *To provide health care providers with relevant and accurate information for diagnostic, treatment, rehabilitation or counselling purposes;*
- *To advise health care providers of his or her wishes with regard to his or her death;*
- *To comply with the prescribed treatment or rehabilitation procedures;*
- *To enquire about the related costs of treatment and/or rehabilitation and to arrange for payment; and*
- *To take care of the health records in his or her possession.*

To enable patients to uphold their right and excise their responsibilities they must have access to their health records. The draft Bill states that a user is entitled - *"to access to any information or records relating to his or her health in the custody of the Fund, in line with the provisions of the Promotion of Access to Information Act, 2000 (Act No. 2 of 2000), in order to exercise or protect his or her rights"*

We consider the process defined in the Promotion of Access to Information Act (PAIA), 2000 (Act No. 2 of 2000) (PAIA), too onerous for an individual and lacks the efficiency and speed by which a user/beneficiary may require such information. By linking the right to access health records to the PAIA, the draft Bill places undue burden on the individual to exercise both, their rights and responsibilities in this regard.

This undue burden will further impact the right of the patient to be given full and accurate information about the nature of one's illnesses, diagnostic procedures, the proposed treatment and risks associated therewith and the costs involved; and obtain a second opinion to a health provider of one's choice.

4.2. Rights relating to personal information

The PAIA defines *'personal information'* as *information about an identifiable individual, including, but not limited to*
(a) information relating to the race, gender, sex, pregnancy, marital status, national, ethnic or social origin, colour, sexual orientation, age, physical or mental health, well-being, disability, religion, conscience, belief, culture, language and birth of the individual;

(b) information relating to the education or the medical, criminal or employment history of the individual or information relating to financial transactions in which the individual has been involved; (c) any identifying number, symbol or other particular assigned to the individual;

(d) the address, fingerprints or blood type of the individual;

(e) the personal opinions, views or preferences of the individual, except where they are about another individual or about a proposal for a grant, an award or a prize to be made to another individual;

(f) correspondence sent by the individual that is implicitly or explicitly of a private or confidential nature or further correspondence that would reveal the contents of the original correspondence;

(g) the views or opinions of another individual about the individual;

(h) the views or opinions of another individual about a proposal for a grant, an award or a prize to be made to the individual, but excluding the name of the other individual where it appears with the views or opinions of the other individual; and

(i) the name of the individual where it appears with other personal information relating to the individual or where the disclosure of the name itself would reveal information about the individual,

but excludes information about an individual who has been dead for more than 20 years;

In Section 5(C) the draft Bill states:

"Without derogating from any other right or entitlement incurred under this Act or under any other law, and subject to affordability and within the means of the Republic of South Africa, a user is entitled - …"

"…to the protection of his or her rights to privacy and confidentiality in that he or she must grant written permission for the disclosure of personal information in the possession of or accessible to the Fund, unless the information -

(i) is shared amongst health care providers for the lawful purpose of serving the interests of users;

(ii) is required by accredited health care providers or suppliers or researchers for the lawful purpose of improving health care practices and policy; or

(iii) is utilised by the Fund for any other lawful purpose related to the efficient and effective functioning of the Fund…"

This provision is vague, lacks legal validity and will not withstand constitutional challenge as no law may limit any right entrenched in the Bill of Rights as defined in our Constitution. As currently drafted it means the patient is entitled to the benefits which they would ordinarily be entitled to under the Medical Schemes Act 131 of 1998 and the fund should not seek to replace these available. There is no alignment between the proposed section in the draft Bill and the Medical Schemes Amendment Bill.

4.3. PATIENT AND/OR CIVIL SOCIETY REPRESENTATION IN FUND PROCESSES AND COMMITTEES

The draft Bill excludes representation from either health related non-governmental organisations (NGOs), civil society or consumers in both the Benefits Advisory Committee and Health Benefits Pricing Committee.

It furthermore makes no provision for public and /or civil society representation, or public comment, in "*the design of the health care service benefits and goods"* and *"health care referral networks of users".* It is assumed that this will include which conditions are included/covered by the benefits and services.

It is our position that member representation of each of these groups must be included in these committees and process. Should they not be included, then any decisions made by the committee must be after public consultation, which should be within a formal process.

4.4. Accountability for Access to Healthcare

The draft Bill state that "*The Fund must, in consultation with the Minister, purchase comprehensive health service benefits on behalf of…",* while the Constitution makes the Minister of Health (the Minister), as representative of the executive accountable for access to healthcare for our citizens.

Our concern is that in the case where access to services or health technology occurs the dual accountability would lead to a situation where a patient is caught between the fund and the Minister.

In addition to the above, those protected by our Constitution do have the right to complain about health care services, to have such complaints investigated and to receive a full response on such investigation. In this instance the situation of the dual accountability created by the draft Bill will further complicate the complaint process as that defined currently in the draft Bill in relation to the fund.

e) COST COVERAGE

As set out in Section 12(1), the draft Bill indicates that the fund will only pay for health services for a condition that are purchased on the users behalf by the fund from certified and accredited service providers at no cost. Our concern with this provision as a CD community and rare disease community is that numerous common and rare CDs affect many body systems and as a result are treated simultaneously by a range of specialists – a multidisciplinary team of specialists and allied health care professionals.

More than 80% of CDs are genetic or partially genetic in their aetiology. Serious CDs and rare diseases are life limiting or chronically debilitating diseases often resulting in lifelong disability. They vary in birth prevalence from the more common disorders such as Down syndrome to those of such low prevalence (one in less than 2 000) that special combined efforts are needed to address them. While the contribution of CDs and rare diseases (which are individually rare but collectively common) are proportionally increasing in importance as mortality and morbidity from infectious diseases is decreasing – this is not being perceived as a health need due to the lack of empiric data in South Africa. As for many low and middle income countries, we lack the observed data via surveillance to provide the evidence base. This results in an underestimate of the true contribution of CDs to the burden of disease, these issues continue to remain unprioritized as healthcare issues, services remain neglected and patients remain undiagnosed and misdiagnosed. Tackling CDs and prioritising this growing health need is likely the only way that child mortality will be significantly reduced in the next 20 years. More importantly – there is a cost to not providing care for those affected and our acknowledgement and investment in these patients can make significant changes to their quality of life.

GA-SA is concerned that certain areas of specialty that are needed to treat CDs and rare diseases may not be funded by the NHI Fund or further may be in locations which cannot reasonably accessed by affected patients. Currently in South Africa, the 12 practising medical geneticists in the country are located in only three of the nine provinces, and the eight genetic counsellors in the state sector are in only two of the nine provinces[7]. If there is no relevant specialist in Province to diagnose a patient, how can the relevant treatment even be known let alone made available and accessed? How will this capacity, and supporting genetic testing through laboratories (i.e. NHLS) be increased and relevant geographical coverage be ensured so that services can be provided countrywide and universally to all?

f) DEFINITIONS

The following terms are used ambiguously in the draft Bill and need to be clearly defined in the context of their use in the draft Bill:

Page 6:

- Mandatory prepayment
- Active purchasing
- Undesirable, unethical

Page 7:

- Progressive realization
- Good quality personal health care services
- Universality and social solidarity

Page 13:

- Health establishment and health agency
- Beneficiary
- Page 17
- financial risk (according the definition in the Medical Schemes Act)
- Page 19

[7] Malherbe, H., et al., *The contribution of congenital disorders to child mortality in South Africa*, in *South African Health Review 2016*, A. Padarath, et al., Editors. 2016, Health Systems Trust: Durban. p. 137-152.

- Portablity (in this context)

Page 22:

- Quality health service benefits (for a rare disease patient this may mean novel, expensive therapies)
- Unreasonable grounds

Page 24

- Cost-effective (in this context)
- Adequate notice
- Reasonable opportunity

Page 27:

- Complementary health service benefits

Page 29:

- Comprehensive

COMMENTS ON 2019 NHI BILL

- Comparing the 2018 and 2019 version of the NHI Bill, we see very little change related to these issues highlighted previously. The concerns that we raised in our 2018 submission are, therefore, still relevant and we encourage the consideration of that submission.
- The contents of these submissions together with the highlighted concerns for patients suffering from CDs and rare diseases must be addressed. The intention of the Legislature to provide universal health coverage for the greater good of all South Africans should not have the effect that it impacts an area of the population that is already vulnerable due to the nature of the medical conditions which they are suffer from. This would lead to gross inequities.
- All patients are, in principle, entitled to access appropriate care. Patients suffering from conditions labelled as “rare” or “orphan” should be able to access care, in particular as they are deemed, in constitutional terms, to be vulnerable.
- The NHI Bill envisages the establishment of a complex and large fund that will be complicated to manage and tempting to loot from. Many contracts will be created that will require skilled HR capacity to manage – skills we do not presently have in the public service. New structures will be created with overlapping functions and unclear relations to each other, further complicating the political tensions already present in the health system. Excess capacity will be leveraged from the private sector to serve all health service users, but how this will be done in practice remains opaque. And maybe most importantly, it is unclear what will be done to address the underlying political and governance challenges that are the sand in the gears of our public service.
- Legally, section 27 of the Constitution requires that government takes reasonable measures progressively to realise the right of access to health care services. Reasonableness has been interpreted in this context

to require that the measures must be comprehensive, coherent and coordinated[8] and must be reasonably conceived and implemented.[9]

- We are of the view that considerable work is required to make the proposals of the NHI Bill coherent and reasonably conceived. Implementation of the NHI proposals also risks regression in access to health care services, a violation of section 27 of the Constitution.
- In addition to our specific recommendations, we urge that the NHI Bill should be considered together with the Medical Schemes Amendment Bill and the findings of the Competition Commission's Health Market Inquiry. The final report of the Health Market Inquiry contains valuable recommendations with direct relevance for NHI. In addition, the NHI Bill will impact medical schemes as well as the Medical Schemes Amendment Bill. A previous version of the Medical Schemes Amendment Bill was published for public comment, but it has not yet been submitted to parliament - the Department of Health should be asked to do so. The most rational approach is to consider all these various sources of evidence and various reforms holistically.

We cover 8 key themes in this submission:

A. Health system revolution through legislation;
B. The inclusion of civil society and health service users in all decisions and processes;
C. Governance under NHI;
D. Emergency Medical Services;
E. Transparency;
F. Financing NHI;
G. Competition law and the NHI;
H. Implementation of the recommendations of the Health Market Inquiry in the interests of NHI;

A. HEALTH SYSTEM REVOLUTION THROUGH LEGISLATION

1. The NHI Bill seeks to re-engineer the health system through what Schneider, Lehmann and Gilson[10] call "legislative, financial and compliance levers". In so doing it "ignore[s] the abundant global evidence that health systems function as complex adaptive systems" and are unlikely to "be controlled, let alone reoriented into completely new and better performance by strings pulled at the top, however necessary or well designed."
2. Legislation is, by its nature, a top-down enterprise. It is for this reason that section 59(1)(a) of the Constitution requires public participation in legislation making. But even ideal public participation in law making does not allow for the kind of iterative reform agenda that is needed for fundamental health systems change.
3. While legislation, early on in the process, is needed for some components of NHI (such as the establishment of the Fund), this is not the case for all aspects of NHI. Legislating on matters that are

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[8] ***Government of RSA and Others v Grootboom and Others*** **2001 (1) SA 46, para 39 and 40.**
[9] *Grootboom* para 40-43.
[10] https://www.spotlightnsp.co.za/2018/09/21/building-public-health-system-capacity-for-nhi-learning-from-disease-specific-successes-for-system-development/.

unclear (including reference to possible options for payment of health care services),[11] and establishing structures that will require testing and possibly change or abandonment (such as Contracting Units for Primary Care ("cups")) is problematic for a number of reasons:

a. First, legislating is an exercise in precision. One of the formative principles of the rule of law is that law, and legislation, must be accessible, intelligible, clear and predictable.[12] An Act is not merely a policy statement but is binding and must be capable of being understood and followed.

b. Second, while promulgating the various sections of an Act at different times allows for the phasing in of change, this kind of phasing does not meet the need for experimentation and learning which is the hallmark of lasting health systems change.

4. We propose that the scope of the NHI Bill be reduced to include only provisions that are certain and can be implemented. The Minister's extensive regulatory powers under section 55 will allow for decisions about mechanisms, options and structures to be made in the process of implementation.

5. Where a decision has not yet been taken (such as whether hospitals will be paid based on global budgets or Diagnostic Related Groups; or the type of taxes to be used to fund NHI), the options under consideration need not be provided in the legislation. Doing so makes the law less, rather than more, certain and may open the Bill up to legal challenge.

6. Similarly, where, as in the case of cups, much more work needs to be done to determine whether a structure is needed, what it should do, how it will operate, and how it will relate to other structures, there is no need to establish the structure in the Bill. Indeed, the Bill provides, in its amendments to the National Health Act 61 of 2003, and section 37 of the Bill that the roles of dhmos and cups overlap to a significant extent,[13] and that dhmos will be responsible for establishing cups[14] and performing their functions until they are able to perform their own legislated functions.[15] This makes clear that the structures themselves need not be legislated at this stage for their proposed functions to be filled. It seems more appropriate to begin the process of active purchasing of health care services without legislating the local structures that may eventually play some role in this purchasing. In this way, options can be tested, processes refined, and models developed without the need for legislative amendments.

7. We propose that rather than introducing, through legislation, structures that need to be developed, capacitated, tested, and possibly changed, we legislate a process for thoughtful experimentation and piloting and provide specifically for capacitation and stewardship. This allows for considered and lasting health systems change without adding layers of complexity and administration, at great cost, before knowing whether they are needed and how they will work.

[11] Such as the reference to fund transfers "based on a global budget or Diagnosis Related Groups" (emphasis added) in section 35(2).
[12] See T Bingham *The Rule of Law* (2010) Penguin Books.
[13] Including in relation to their obligation to manage and facilitate the provision of services.
[14] Section 31B(1) of the amendments to the National Health Act.
[15] Section 31B(6) of the amendments to the National Health Act.

8. In particular we propose the following:

    a. The amendment of section 35(2) to read "The Fund must transfer funds directly to accredited and contracted central, provincial, regional, specialised and district hospitals".
    b. The deletion of section 35(3).
    c. The deletion of section 37.
    d. The deletion of section 41(3)(a).
    e. The deletion of the details of different types of taxes in section 49(2)(a) which, it appears from the Memorandum to the Bill, are options but will not necessarily all be used as sources of funding for the Fund.
    f. The deletion of the amendment of the National Health Act that seeks to include section 31B.

THE INCLUSION OF CIVIL SOCIETY AND HEALTH SERVICE USERS IN ALL DECISIONS AND PROCESSES

9. The participation of the users of health care services in decisions and processes that determine their access to health care services is recognised as a key pillar of universal health coverage.[16] It is not a matter of representivity. Instead, it is a recognition that even technical decisions are not value-neutral, and of the importance of creating policy, implementation plans and execution that are responsive to the needs of people. Section 195 of the Constitution makes responsiveness and people-centredness an obligation of public administration. This goes beyond public participation processes in law-making and extends into involvement in governance structures and decision-making bodies.
10. The UN Political Declaration on Universal Health Coverage, 2019, to which South Africa is a signatory, recognises "that people's engagement, particularly of women and girls, families and communities, and the inclusion of all relevant stakeholders is one of the core components of health system governance, to fully empower all people in improving and protecting their own health..." States further commit to "engage all relevant stakeholders… to provide input to the development, implementation and evaluation of health- and social-related policies and reviewing progress for the achievement of national objectives for universal health coverage."
11. The NHI Bill envisages limited involvement of civil society and health care service users in the discussions of and decisions on NHI.
12. Provision is made for representatives of civil society and users in the Stakeholders Advisory Committee but not in the other two committees of the NHI Fund – the Benefits Advisory Committee and the Health Care Benefits Pricing Committee.
13. The Stakeholders Advisory Committee, the only place for civil society and health service users, has no clear function and is not designated as an advisory committee of the Fund, in spite of its name. Real

[16] D Rajan et al "Institutionalising participatory health governance: lessons from nine years of the National Health Assembly model in Thailand" *BMJ Global Health* 10 August 2019.

and meaningful participation of civil society and health service users is not, therefore, provided for, contrary to accepted practice around universal health coverage.

14. The Stakeholder Advisory Committee should be seen as key for facilitating public participation in the decision making of the Fund. If properly constituted and empowered, it will contribute invaluable evidence and expertise needed for the implementation of the NHI (including evidence collected through the Ritshidze Project, described above, for example). The Stakeholder Advisory Committee would be in a position to advise the Benefits Advisory Committee on issues relating to availability and suitability of health care services; and the Health Care Benefits Pricing Committee on the affordability of health care services. An example of a similar structure successfully performing an important participatory governance role can be found in the National Health Assembly in Thailand.

15. To remedy the shortcomings identified above, we propose the following:

    a. Amendment of section 25(2) and section 26(2) to include that the composition of the Benefits Advisory Committee and the Health Care Benefits Pricing Committee should include two members of the Stakeholder Advisory Committee that represent health service users and civil society.

    b. Amendment of section 27 so that it reads as follows:

    "*The Minister must, after consultation with the Board and by notice in the Gazette, appoint a Stakeholder Advisory Committee <u>as one of the advisory committees of the Fund</u>. The committee shall comprise of representatives from the statutory health professions councils, health public entities; organised labour, civil society organisations, associations of health professionals and providers, as well as patient advocacy groups in such a manner as may be prescribed*."

    c. Amendment section 15(3) to insert a provision on the advisory role of the Stakeholder Advisory Committee to read as follows:

    15(3) *The Board must advise the Chief Executive Officer on any matter concerning—*
    (h) the best practices to safeguard the rights of users, improve access to health care services and complaints management through the Stakeholder Advisory Committee.

16. In addition to the involvement of civil society and health service users in the committees of the Fund, consideration should be given to their involvement in other structures established under NHI. There is, at present, no National Health Act-required consultative structure at district level (which exists, albeit barely functions, at national and provincial levels). While the amendment to the National Health Act that establishes District Health Management Offices provides for the interaction between District Health Management Offices and community representatives through District Health Councils, there is no clear requirement for such community representatives to be appointed to District Health Councils under section 31(2) of the Act. There is merely a new obligation for District Health Councils to "promote community participation in the planning, provision and evaluation of health care services" in the new section 31(3)(ba).

17. Meaningful participation of health care users and civil society at all levels of the health system is, at present, sorely absent. The establishment of District Health Management Offices provides an

opportunity to change this, to ensure the responsiveness of health care services to the service users in the area.

18. We propose the amendment of section 31(2)(a)(iv) of the National Health Act to require that the five additional persons appointed to the District Health Council are health service users in the district and are appointed to represent such health service users. We further propose the development of a programme to capacitate District Health Councils and ensure that they are able to function as provided for in the Act.

GOVERNANCE UNDER NHI

19. The introduction of NHI will transform the current intergovernmental fiscal arrangements, eventually vesting all health financing in the NHI Fund. The size and function of the NHI Fund, and the constitutional imperative of good governance,[17] necessitates establishment of strong governance and improved accountability structures.
20. Chapter 4 of the Bill sets out the governing structure of the Fund (in the form of a board that is accountable to the Minister), as well as the powers and functions of the Board.
21. As currently presented, there is little separation between the Fund and the Minister and a centralisation of power with the Minister. The Minister is empowered to:

    a. Appoint the ad hoc advisory panel which interviews shortlisted candidates for the Board;[18]
    b. Appoint the candidates recommended by the advisory panel;[19]
    c. Appoint the chairperson of the Board;[20]
    d. Remove board members;[21] and
    e. Dissolve the Board.[22]

22. The Minister is also responsible for the appointment and removal of the Fund's Chief Executive Officer (CEO) based on the recommendations of the Board. Over and above this, after consultation with the Board, the Minister also appoints members of the Benefits Advisory, Health Care Benefits Pricing and the Stakeholder Advisory Committee.
23. One of the significant contributors to the current failures in the public health system is the blurring of lines between political and administrative leadership.[23]

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[17] The Constitution recognises the importance of good governance: Section 195 deals with basic values and principles governing public administration. These principles apply to organs of state (the proposed NHI Fund falls within the definition of an organ of state) and compels them to adhere to principles of good governance.

[18] Section 13(3)(a).
[19] Sections 13(3)(b) read with section 13(4).
[20] Section 14(1).
[21] Section 13(8).
[22] Section 13(9).
[23] Research on Governance in State Owned Enterprises by the Dullah Omar Institute warns against lack of transparency and centralisation of powers to the executive as this opens up room for political interference. The Institute proposes that in order for there to be accountability and transparency, there needs to be a degree of separation between the executive and the administration.

24. The centralisation of power in the Minister in relation to the NHI Fund and its governance and management constitutes a real threat to the independence of the Fund and its functioning. In light of this, we set out below some recommendations for amendment of the wording of the Bill to improve the resilience of the governance structure and protect it from undue political interference.

INDEPENDENCE

25. Section 12 of the Bill does not specifically provide for the independence of the Board, as stipulated in previous versions of the Bill. The independence of a board is critical for ensuring that the board can objectively fulfil its functions openly, with integrity and without fear or favour. It also enables the board to perform its oversight function. The establishment of an independent board will also instil public confidence in the Fund. We therefore recommend the insertion of the word independent in section 12 so that it reads—

> *"An independent Board that is accountable to the Minister is hereby established to govern the Fund in accordance with the provision of the Public Finance Management Act."*

26. Of course, the insertion of legislative language that stipulates that the Board must be independent does not, on its own, achieve the result. Independence must be built into the appointments to and functioning of the Board.

APPOINTMENT OF BOARD MEMBERS

27. In terms of section 13(2) and section 13(3) of the Bill, following the public nomination process for board member candidates, an *ad hoc* advisory body, appointed by the Minister, must conduct public interviews of the shortlisted candidates and forward its recommendations to the Minister for approval. It is not clear who is responsible for preparing the shortlist of candidates and the Bill is silent on the criteria for selecting members of the *ad hoc* advisory body.
28. It is important that appointment of board members and executives is done in a transparent manner that instils public confidence. For example, to inspire confidence in the new SARS commissioner, one of the recommendations made in the Report of the Commission on Inquiry into Tax Administration and Governance by SARS was that members selected for the interviewing panel "should be apolitical and not answerable to any constituency and should be persons of high standing who are able to inspire confidence across the tax-paying spectrum."24 The Report also recommends that there should be criteria against which to evaluate the attributes of the members of the [interviewing] panel.25 We therefore recommend that the panel must be composed of the following:

    i. Representation from the National Treasury – ideally an administrative head;
    ii. Director General of the National Department of Health;
    iii. Three members of the Portfolio Committee on Health (National Assembly), designated by that Committee, representing three different political parties;

[24] The Report of the Commission on Inquiry into Tax Administration and Governance by SARS 11 December 2018 http://www.inqcomm.co.za/Docs/media/SARS%20Commission%20Final%20Report.pdf Accessed 7 November 2019.
[25] Id at page 187.

iv. Persons with experience in governance and healthcare financing.

29. The Bill should set out the principles upon which appointment to the Board is based. For this, we recommend drawing from section 4(1)(b) of the Media and Development and Diversity Agency Act[26] which sets out that appointment of board members must be based on the principles of transparency and openness, public participation in the nomination process and publication of shortlisted candidates. We further propose that the published list of shortlisted candidates should contain the names of both the nominees and the nominators, similar to the requirements of the Road Accident Fund Act.[27] There must also be mechanisms in place to allow the public to make submissions regarding a recommended candidate, and all these submissions must be considered when selecting candidates for shortlisting. Once the board members have been appointed, the recommendations of the selection panel should be made public.[28]

    We propose amendment of section 13(2) as follows:

    13(2) "Whenever it is necessary to appoint a member referred to in subsection 13(1) to the Board, subject to subsection 13(8)(2), the Minister shall –

    (a) Issue in the Gazette and national news media a call for the public nomination of candidates who comply with the criteria in subsection 13(5), to serve on the Board; and
    (b) Publish a list of nominees received in response to such invitation, which list shall include the names of the nominators.

30. The composition of a governing structure is a key factor for the performance of an entity. In addition to its independence, it is imperative that the Fund's Board has the right balance of knowledge, skills, and experience.[29] It is also important that the appointment criteria is clear in specifying honesty, integrity and expertise as key considerations for appointment to the Board. The composition of the Board must also broadly reflect diversity across various attributes including age, race, gender and disability.

REMOVAL FROM THE BOARD AND DISSOLUTION OF THE BOARD

31. Section 13(8) of the Bill states that the Minister may remove a board member who is disqualified in terms of any law[30] or who is unable to continue to perform their functions of office *for any other*

[26] Media Development and Diversity Act 14 of 2002. The Media Development and Diversity is a Schedule 3 PFMA entity.
[27] Section 10(9)(b) of the Road Accident Fund Act 56 of 1996. The Road Accident Fund is a Schedule 3 PFMA entity.
[28] See recommendation made by The Report of the Commission on Inquiry into Tax Administration and Governance by SARS 11 December 2018, http://www.inqcomm.co.za/Docs/media/SARS%20Commission%20Final%20Report.pdf in relation to the appointment of the SARS Commissioner, page 188.
[29] The board must reflect a balance of expertise, and must include both people who are in practice and those in academia.
[30] Section 13(8)(a) of the Bill.

reason.[31] In terms of section 13(9), the Minister may dissolve the Board *on good cause*. Removal for "any other reason" and dissolving the Board "on good cause" is entirely at the discretion of the Minister and can thus be susceptible to political whims.[32] This undermines the independence of the Board. The threat of removal without any oversight, on any ground, and without due inquiry, would render board members unlikely to express views which may not align with that of the government or the majority board members.

32. We therefore recommend that a provision should be included to the effect that the removal of a board member in terms of sections 13(8) should be done only after due inquiry and upon recommendation by the Board.

33. The Bill is also silent on the procedure to be followed when replacing a member who has either resigned or has been removed from the Board.

34. Finally, there is no explicit requirement for board members to formally declare conflicting interests. We propose the amendment of section 13(8) as follows:

    13(8)(1) "The Minister may, after due enquiry, remove a board member on account of any or all of the following:

    (i) Misconduct;
    (ii) Inability to perform the duties of his or her office efficiently;
    (iii) Absence from three consecutive meetings of the Board without the permission of the Board, except on good cause shown;
    (iv) Failure to disclose an interest contemplated by section 16(3) or voting or attendance at, or participation in, proceedings of the Board while having an interest contemplated in section 16(2)(b); and
    (v) His or her becoming disqualified in terms of section 13(10).

    13(8)(2) "Whenever a position on the Board becomes vacant before the expiry of the term of office referred to in subsection 13(5), the Minister may appoint any other competent person, as contemplated by the Act, to serve for the unexpired portion of the term of office of the previous member irrespective of when the vacancy occurs.

35. The Bill should also be amended to insert a provision dealing with disqualification from appointment on the Board. We propose the insertion of a section 13(10) reading:

    "A person may not be appointed as a Board member if he or she –

    a. Is not ordinarily resident in South Africa;

[31] Section 13(8)(c) of the Bill.
[32] *Dawood v Minister of Home Affairs; Shalabi v Minister of Home Affairs; Thomas v Minister of Home Affairs* [2000] ZACC 8; 2000 (3) SA 936 (CC); 2000 (8) BCLR 837 (CC) at paras 54-5. See also *SOS Support Public Broadcasting Coalition and Others v South African Broadcasting Corporation SOC Limited and Others; SOS Support Public Broadcasting Coalition and Others v South African Broadcasting Corporation SOC Limited and Others* ZAGPJHC 289 on the unfettered discretion exercised in relation to executive appointments at the SABC.

b. Is an unrehabilitated insolvent;
c. Has been removed from an office of trust on account of misconduct; or
d. Has at any time been convicted (whether in the Republic or elsewhere) of theft, fraud, forgery or perjury.

36. The dissolution of a board is a drastic measure and the consequence is that an interim board is appointed to act for a maximum period of three months. In our view, a drastic measure such as this should not be unilateral but should be appropriately scrutinised and accompanied by parliamentary oversight. The dissolution of the Board should require an inquiry and must be based on specified, objective grounds for removal. Objective grounds for the dissolution of the Board may include poor or non-performance of functions and abuse of power. Under such circumstances, the Minister should be obligated to refer the matter to the National Assembly for consideration and where the National Assembly recommends that the Board be dissolved, the Minister has no discretion and must dissolve the Board. We also recommend that the National Assembly must play an oversight role in the appointment of the acting Board. As such, we propose the amendment of section 13(9) so that it reads as follows:

    13(9)(a) "The Minister must, after due inquiry and the adoption of a resolution by the National Assembly, dissolve the Board on account of any of the following:

    i. Failure to discharge its fiduciary duties;
    ii. Poor or non-performance of its duties as contemplated; or
    iii. Abuse of power.

FUNCTIONS AND POWERS OF THE BOARD

37. In addition to its role as the accounting authority of the Fund, section 15(3) of the Bill states that the Board must advise the Minister on a variety of matters. While some of the matters on which the Board must advise the Minister relate to matters about which the Minister must make a final decision (the services to be funded,[33] the pricing of services,[34] and the transition from the current health system to "full implementation" of the NHI Fund[35]), others are purely operational matters (the management and administration of the Fund,[36] terms and conditions of Fund employees,[37] and collective bargaining[38]).
38. Providing for this advisory role implies that the Minister is empowered to make decisions in relation to the issues on which the Board advises him/her. The operational matters on which the Board advises the Minister lie within the CEO's jurisdiction. Only the CEO is empowered to make operational decisions about the Fund, and thus it is the CEO who would benefit from such advice. We suggest, therefore, that the operational and governance advisory functions of the Board be separated and that the Board advises the CEO on operational and the Minister on governance matters.

[33] Section 15(3)(b).
[34] Section 15(3)(c).
[35] Section 15(3)(i).
[36] Section 15(3)(a).
[37] Section 15(3)(e).
[38] Section 15(3)(f).

ADVISORY COMMITTEES OF THE FUND

39. As noted above, there are three committees that are established as committees "of the Fund".[39] The committees are, however, appointed by the Minister, "after" rather "in" consultation with the Board,[40] and each has a representative of the Minister on the committee, and has its chairperson appointed by the Minister.[41]
40. A number of concerns about the Benefits Advisory Committee and the Health Care Benefits Pricing Committee arise. Section 25(3)(b) provides that a member of the Benefits Advisory Committee will cease to be a member when they are no longer a member of the institution that nominated them. There is no reason for this provision if the Benefits Advisory Committee is not, as appears to be the case, intended to be a representative committee. We propose that this section be removed.
41. Very little detail is provided about the Health Care Benefits Pricing Committee. This is surprising given the importance of this committee to the functioning of the Fund and of NHI in general. We propose that the process for the appointment of members of this committee and their terms of office should be the same as is laid out for the Benefits Advisory Committee. The role of the Health Care Benefits Pricing Committee should also be laid out in more detail.
42. The concentration of powers in the Minister in relation to the Benefits Advisory Committee and the Health Care Benefits Pricing Committee should be reconsidered. We propose that sections 25 and 26 be amended to provide for appointment of advisory committees by the Minister in consultation with the Board and for the chairpersons of each committee to be appointed by the committee itself.
43. Finally, there appears to be no link between the Benefits Advisory Committee and the Health Care Benefits Pricing Committee, bringing into question how rational rationing of health care services under NHI will work. Advice to the Fund and the Minister in relation to benefits and the price to be paid for those benefits should be aligned.

C.EMERGENCY MEDICAL SERVICES

44. The NHI Bill stipulates that the NHI Fund will purchase services from both public and private ambulance providers. The details of exactly how this will work is however still worryingly unclear.
45. Both public and private emergency medical services will be paid, according to section 35(4)(a) of the Bill on a "capped case-based fee basis with adjustments made for case severity, where necessary" and private ambulance services will be contracted individually by the NHI Fund but provinces, as "management agents", will provide public ambulance services.[42]
46. Confusingly, the Bill also provides that public ambulance services will "be reimbursed through the provincial equitable share".[43] How provinces can legally be instructed to pay for public ambulances on a capped case-based fee basis with adjustments for case severity when paying from the provincial equitable share is unclear.

[39] The Benefits Advisory Committee under section 25(1) and the Health Care Benefits Pricing Committee under section 26(1).
[40] See sections 25(1) and 26(1).
[41] Sections 25(6) and section 26(4).
[42] Section 32(2)(a).
[43] Section 35(4)(b).

47. A further complexity arises in the distinction between emergency medical services and ambulance services in the proposed addition of section 31A to the National Health Act. Section 31A(3)(k) provides that one of the functions of the District Health Management Office is to "facilitate the integration of public and private health care services such as emergency medical services but excluding public ambulance services". What this means, in the light of the definition of emergency medical services as "pre-hospital acute medical treatment and transport of the ill or injured", is unclear.
48. We suggest that further consideration be given to the provision of and payment for emergency medical services under NHI. NHI provides a good opportunity to substantially improve the quality of emergency medical service many people receive. This will however require that government strategizes more ambitiously and puts in place appropriate funding mechanisms, contract management and implementation structures. In particular, it requires care in managing the wider contracting of private ambulance services to avoid the problems seen in the Free State, Limpopo, Mpumalanga and the North West in which contracting of private ambulance services has led to alleged overcharging and sub-standard quality of service from the contracted private providers.[44]

D.TRANSPARENCY

49. Despite various provisions in the Public Finance Management Act 1 of 1999 and the Protection of Access to Information Act 2 of 2000 (PAIA), information relating to the public healthcare system often remains hidden from the public. This includes information on procurement, epidemiological information, and information on service delivery. Sometimes routine information is only released after a PAIA request has been submitted. In some instances, PAIA requests have been ignored – and while there are legal steps that can be taken in such cases, these come with legal costs which only few can afford, as well as significant delay. Lack of transparency is equally a problem in relation to the private sector.

50. To increase public trust in NHI and to reduce the risk of corruption under NHI, it is imperative that all NHI-related processes and decisions are as transparent as possible. In our view, this requires specific provisions in law to guarantee such transparency.
51. The NHI Act should unambiguously state that certain types of information should be made available to the public as a matter of routine and without the public having to submit requests for information in terms of PAIA. Such a provision would protect NHI from the current situation whereby PAIA is at times misused as an excuse to delay or deny access to information.

[44] See reporting by Spotlight here: https://www.spotlightnsp.co.za/2019/03/06/health4sale-limpopo-air-ambulance-service-grounded-after-dodgy-contract/; https://www.spotlightnsp.co.za/2018/10/17/health4sale-government-employee-represents-private-company-as-free-state-again-prepares-to-outsource-part-of-ambulance-service/; https://www.spotlightnsp.co.za/2018/05/18/health4sale-how-the-limpopo-department-of-health-went-rogue-to-protect-buthelezi-hems/; https://www.spotlightnsp.co.za/2018/04/25/health4sale-part-6-magashule-cleared-way-controversial-private-ambulance-company-cash/; https://www.spotlightnsp.co.za/2018/04/24/health4sale-part-5-controversial-private-ambulance-company-line-new-free-state-tender/; https://www.spotlightnsp.co.za/2018/04/23/health4sale-part-4-buthelezi-ems-running-taxi-service-not-ambulance-service-doctors-nurses/; https://www.spotlightnsp.co.za/2018/04/20/mpumalanga-department-health-broke-rules-controversial-ambulance-company/; https://www.spotlightnsp.co.za/2018/04/19/northwest-pays-double-dubious-private-ambulance-service/; https://www.spotlightnsp.co.za/2018/04/18/health4sale-north-west-blows-hiv-money-controversial-private-ambulance-service/

Types of information that the public should have routine access to include:

- Details of all transactions of the NHI Fund.
- Details of all decisions relating to the base benefit package under NHI.
- Minutes of all meetings of the Benefits Advisory Committee and details of its decisions.
- Details of all health technology assessments (HTA) and justifications for HTA decisions.
- Details of all decisions taken by the Office of Health Products Procurement relating to the selection of preferred suppliers, the award of tenders, and the white or blacklisting of specific companies.
- Details of all decisions by the NHI Fund or its agents to contract or not to contract certain facilities or groups of facilities.

52. There may be legitimate debate regarding how general or how specific law should be regarding an issue such as transparency. We have taken this in mind in the proposals we make below. Rather than listing every key piece of information that should be public, we have identified a series of key instances where small changes to the current wording of the Bill can in meaningful ways increase the transparency of the NHI system that will be created by the Bill.
53. In line with the above considerations, and with due consideration for the fact that law should not be overly specific, we propose the following changes to the Bill:
    a. The insertion of the word "transparent" in the preamble as follows:

        "create a single <u>transparent</u> framework throughout the Republic for the public funding and public purchasing of health care services, medicines, health goods and health related products, and to eliminate the fragmentation of health care funding in the Republic;"

    b. The amendment of section 6C to read as follows:

        "6(c) to have routine access to any information or records relating to his or her health kept by the Fund, as provided for in the Promotion of Access to Information Act, but without having to make a request in terms of the Promotion of Access to Information Act or having to provide any justification for accessing the information;"

    c. The insertion of the words "most transparent" into section 10(2) of the Bill as follows:

        "10(2) The Fund must perform its functions in the most cost-effective, <u>most transparent</u> and most efficient manner possible and in accordance with the values and principles mentioned in section 195 of the Constitution and the provisions of the Public Finance Management Act."

    d. The addition of the following provision as provision P in section 11(1) of the Bill:

        "11(1)(P) Routinely make as much information as possible available to the public regarding decisions and processes of the Fund and its committees, including, but not limited to, information on procurement and contracting decisions, health technology

assessments, epidemiological and demographic information, information pertaining to quality measurement, and information relating to fraud investigations."

e. The insertion of the words "in as transparent a manner as possible" in section 38(3) of the Bill as follows:

"38(3) The Office of Health Products Procurement must in as transparent a manner as possible"

f. The insertion in section 39(6) of the Bill of the words "such evaluations must routinely be made available to the public" as follows:

"39(6) The performance of an accredited health care service provider or health establishment must be monitored and evaluated in accordance with this Act, such evaluations must routinely be made available to the public, and appropriate sanctions must be applied where there is deviation from contractual obligations as per the law."

g. The addition of sub-section 7 to section 40 of the Bill as follows (drawing on the existing section 40(1)):

"40(7) Information must routinely be shared with the public regarding assessment of population health needs, financing, purchasing, patient registration numbers and characteristics, service provider contracting and reimbursement, utilisation patterns, performance management, parameters for the procurement of health goods, and fraud and risk management."

F. FINANCING NHI

54. Key to the delivery of equity, quality and universality in access to health care services under NHI will be the sustainable and affordable financing of NHI, and the efficient, equitable and effective expenditure of NHI funds.
55. The way that healthcare in South Africa is currently financed presents major obstacles to achieving this. Equity, efficiency and effective expenditure are rare throughout the system, in both its public and private forms.
56. On the one hand, public health care is massively underfunded, failing to make a break from a history of racial discrimination. As a result, the public health care system, which is relied on by about 84% of the population for their health care needs, has access to a similar amount of human, financial and capital resources as the private system, which serves only about 16% of the population. The NHI White paper found that "The benefit incidence of health care in South Africa is very 'pro-rich' with the richest 20% of the population receiving 36% of total benefits (despite having a 'health need share' of less than 10%) while the poorest 20% receive only 12.5% of the benefits (despite having a 'health need share' of more than 25%)."[45] This gross inequality plays out in unequal life expectancy, burdens of disease and quality of life between those with and without the means to access expensive private health services.

[45] At 17.

57. The public health sector is chronically short of staff, equipment and adequate infrastructure, while the private health sector has good access to medical professionals, equipment and modern, functional infrastructure. Provincial departments of health scrape by each financial year, using clever budgeting techniques to cross-subsidise compensation payments at the expense of suppliers and maintaining infrastructure. At the same time, hospital groups, private health care providers and medical schemes make profits that allow them to reward shareholders and invest in new capacity.
58. The Health Market Inquiry (HMI) has shown that for many years, people using private medical aids have been paying more and getting less. Monthly insurance payments have increased well above inflation (sometimes double) year after year while benefits have been tightened. The Final HMI Report found that private health care "is characterised by high and rising costs … and significant overutilization without stakeholders having been able to demonstrate associated improvements in health outcomes"[46]. It found "highly concentrated funders and facilities markets, disempowered and uninformed consumers, a general absence of value-based purchasing, practitioners who are subject to little regulation and failures of accountability at all levels."[47] The Council for Medical Schemes indicates that corruption and fraud in the private health sector amounts to about R22 billion annually.[48]
59. Wastage and inefficiency are highly prevalent in the public sector too, which incurs billions of Rand in irregular expenditure annually and where corruption, particularly in procurement, is also rife.[49]
60. It is also true that the public health sector massively subsidises the private through the training and development of medical professionals and research expenditure, among others.
61. Clearly, Universal Health Care can only be achieved by reforming the national health system so that available health resources are utilised much more effectively and efficiently and to the benefit of the entire population.
62. Based on National Treasury figures, in the 2019/2020 financial year, total spending on health care was about R490 billion. This is the total of R222 billion of consolidated spending on public health, R11 billion of donor funding and R250 billion of private sector spend. The latter includes R207 billion in medical scheme contributions, R35 billion of out-of-pocket expenses, R5 billion in contributions for health insurance products such as gap cover, and R2.6 billion spent by employers providing health services to their workers.[50]
63. Combining this funding into a single pool would result in SA spending almost 9% of its GDP on health care. This is a comparable amount to the United Kingdom, where universal quality health care is provided through the National Health Service. In theory, the same should be possible in South Africa if a comparable amount is spent more equally and effectively.
64. But achieving this will be difficult and will take time. Bringing all health care services up to the standards required by the Office of Health Standards Compliance (OHSC) will require significant additional investment, too. The 2017 report of the OHSC found that only 1% of public health

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[46] At 1.
[47] At 2.
[48] Statement by the Presidency "Justice sector closes in on health sector corruption, 02 October 2019. Available at: www.thepresidency.gov.za/press-statements/justice-system-closes-health-sector-corruption.
[49] Ibid.
[50] Kahn "The fatal flaws of NHI" *Business Day* 15 August 2019. Available at: www.businesslive.co.za/fm/features/2019-08-15-the-fatal-flaws-of-nhi.

facilities met National Core Standards.[51] Yet meeting these will be a requirement for accreditation with the NHI Fund. On that basis alone, a fully functioning NHI seems to be some way off.

65. Significant strides will also have to be made towards eliminating corruption in the health care system if the public is to get behind NHI. The Health Sector Anti-Corruption Forum spearheaded by the Special Investigations Unit must bring about convictions for those found to be involved in tender fraud, jobs for pals and other corrupt activities.
66. Regarding the way that financing of NHI, and by direct relation, the financing of public and private health care reform – are dealt with in the Bill and the Memorandum, we have concerns and questions in the following areas:

    a. The continued underfunding of public health in the budget, not just to plug shortfalls but to undertake the necessary quality improvements in the medium term that are necessary for the NHI transition
    b. The lack of transparency and public involvement in the costing of NHI and in developing appropriate financing plans
    c. The transfer of conditional grant funding, including the HIV/AIDS grant, to the NHI Fund
    d. The transfer of equitable share funding to the NHI Fund
    e. The phasing out of medical scheme tax credits
    f. The continued underspending of the NHI indirect grant by the National Department of Health
    g. The total lack of mention of the Health Market Inquiry in the Memorandum to the Bill.

AUSTERITY BUDGETING IS HARMING PUBLIC HEALTH AND DELAYING NHI

67. The move towards NHI is not supported in the budget. The Minister himself has recognised that in real terms, budget allocations for health have declined over the past decade.[52] CPI of about 5.0% and population growth of about 1.5% means that to break even with average inflation and demand, health funding must grow by at least 6.5% per year. However, demand for health care services and medical price inflation is higher than CPI, as evidenced in the double digit increases to medical scheme tariffs each year (in 2020 Discovery is proposing an almost 10% average increase). Moreover, as widely documented, personnel costs (i.e. Wages and benefits) continue to outstrip CPI inflation in government, including in health departments.
68. All this means that the average growth of consolidated health spending proposed in the 2019 Medium Term Budget Policy Statement (MTBPS) of 7.0% for the medium term (until 2022/23) will be insufficient to maintain, let alone transform levels of staffing, equipment and infrastructure, and hence improve quality, in the public health system. In the 2019 MTBPS the Treasury states that "given the macroeconomic and fiscal outlook, the estimates to roll out NHI that were published in the NHI Green Paper in 2011 and White Paper in 2017 are no longer affordable."[53]
69. The faulty logic of cutting back social expenditure to prioritise debt repayments, known as austerity, especially during difficult economic times, is now widely recognised by the IMF, the World Bank and

[51] 2016/17 Annual Inspection Report of the OHSC. Available at: http://ohsc.org.za/wp-content/uploads/OHSC-2016-17-ANNUAL-INSPECTION-REPORT-FINAL.pdf.
[52] "South Africa is facing a doctor shortage – here's why" *Business Tech* 20 October 2019. Available at: https://businesstech.co.za/news/government/346538/south-africa-is-a-facing-a-doctor-shortage-heres-why/.
[53] National Treasury, Medium Term Budget Policy Statement, 2019, at 37.

has been in mainstream scholarship for some time.[54] In periods of stagnation or recession, government can stimulate the economy through spending, interest rate cuts and other methods to spur a recovery. By doing the opposite, the downturn is reinforced and those who need protection from insecurity see their services and protections cut away at the very moment they are needed most.

70. We recommend that investing in health care is recognised as an investment in productivity and economic growth, as well as in equity and human rights. Implementation of an improved National Quality Improvement Plan (see our 2018 submission), the Health Market Inquiry recommendations and the NHI are exactly the kind of reform projects that could drive the socio-economic transformation that is necessary for higher, sustained and more inclusive economic growth.
71. There are multiple options[55] available to government to raise additional resources from wealth, income from wealth and high incomes to fund these investments. These include:

- Capacitating SARS to combat illicit financial flows, tax base erosion and illegal profit shifting, estimated annually at 4% of GDP by the Mbeki Panel[56];
- Ensuring wealthier South Africans pay their fair share. Statistic South Africa's recent report[57] reminds us that SA remains the most unequal country in the world. There is significant room for tax reform;
- Increasing the level of corporate income tax (the rate was 50% in 1990, even an increase to 35% would be of assistance);
- Ending corruption and the looting of state resources, estimated at more than R27 billion annually, and costing approximately 76 000 jobs;[58]
- Improving the financial capacity and accountability of government departments and entities that contribute to the R61 billion of irregular expenditure found by the Auditor General in 2018/19;[59]
- Turning around failing soes like Eskom, SAA, SABC and Denel, which are costing tens of billions of Rand in bailouts annually.

72. Despite these options, the budget allocations for implementing the National Quality Improvement Plan (NQIP) are far too little. The MTBPS states that R75 million will be allocated for this in 2020/21, R125 million in 2021/22 and R175 million in 2022/23. Given the scale of the challenges, it

[54] Sibeko, B. (2019). The cost of austerity: Lessons for South Africa. Institute for Economic Justice Working Paper Series, No 2. Engler, P. & Klein,M. 2017. "Austerity Measures Amplified Crisis in Spain, Portugal, and Italy," DIW Economic Bulletin, DIW Berlin, German Institute for Economic Research, vol. 7(8), pages 89-93. https://ideas.repec.org/a/diw/diwdeb/2017-8-1.html; OHCR. 2017. Report on austerity measures and economic and social rights. Available at: www.ohchr.org/Documents/Issues/Development/RightsCrisis/E-2013-82_en.pdf.

[55] Submission to the Select and Standing Committees on Finance, "Budgeting in an era of austerity" *Budget Justice Coalition*, 26 February 2019 at 26. Available at: https://budgetjusticesa.org/assets/downloads/Budget-Justice-Coalition-5-year-Review-Submission-to-Finance-Committees.pdf.

[56] State of Tax and Wage Evasion: A South African Guide 2019" *Alternative Information and Development Centre*, 2019. Available at: http://aidc.org.za/download/Illicit-capital-flows/Tax-Evasion-and-South-Africa.pdf.

[57] "Inequality Trends in South Africa: a multidimensional analysis" *Statistics South Africa*, October 2019. Available at: http://www.statssa.gov.za/?page_id=1854&PPN=Report-03-10-19&SCH=7680.

[58] "Corruption costs SA GDP at least R27 billion annually, and 76 000 jobs" *BusinessTech*, 01 September 2017.

[59] Presentation by the Auditor General to the Standing Committee on Public Accounts, 23 October 2019. Available at: https://pmg.org.za/files/191023_PFMA_-_AG_Roadshow.PPTX.

is far from clear if this amount will be sufficient to ensure that more facilities are ready for accreditation by the NHI Fund by 2022/23.

73. Section 8.1(c) of the Memorandum states that National Treasury has commissioned an intervention-based costing tool which provides estimates of "15 or so" interventions related to NHI. These include removing user fees, extending CCMDD, extending the rollout of arvs, increasing antenatal visits, rolling out capitation model for gps, cataract surgery programme, and establishing the Fund. The Treasury estimates in the 2019 MTBPS that the full roll out of these interventions would require an additional R33 billion annually from 2025/26, and foresees no additional allocations in Budget 2020 and the Medium-Term Expenditure Framework to pay for this.
74. Such budgeting constitutes an effective block on the road to NHI.
75. Clearly, many of the proposals contained in the NHI Bill, such as the 300+ cups and the 52 dhmos, will require additional funding to be implemented. Yet Section 8.4 of the Memorandum that the NHI Grant baseline will not be increased in the medium-term. The only foreseeable outcome of this budgeting is that many of the proposals in the NHI Bill will simply not be implemented.
76. At the same time, the ndoh continues to underspend on the NHI conditional grant, to the tune of R600 million in 2018/19[60] and R240 million so far in the first 6 months of the current 2019/20 financial year.[61] This underspending is simply not justifiable when budget constraints in provincial health departments are so severe. At 8.2 in the Memorandum, a recommendation is made that unspent funds (which relate mainly to goods and services)[62] are reprioritised for the filling of statutory posts at provincial level such as interns and community service.
77. This austerity budgeting – recognising the budget shortfalls at provincial level and using NHI funds to paper over some of the cracks – is not conducive to the long-term development of NHI. It clearly illustrates that the health budget overall is not sufficient to maintain or improve the public health system and fund the new commitments originating from the transition to NHI.

FUNDING THAT IS BEING TARGETED FOR THE NHI TRANSITION

78. As noted above, we do not see why it is necessary to include information on the types of funding that the NHI fund will be entitled to in Section 49(2) of the Bill. We therefore recommend that this section is deleted and details of the financing options under consideration are included in the Memorandum only.
79. We welcome that Section 2.4 of the Memorandum recognises that a carefully phased approach to financing and reforms aims to ensure that "health care should be seen as a social investment and not be subject to trading as a commodity". We agree with this principle and concur that a poorly planned transition to NHI would indeed risk a situation in which private actors in health care can exploit gaps and inadequacies. For health care to become a public good and a social investment, the health care system must operate efficiently and effectively at all times

[60] National Treasury, 2019 Budget Review. Available at: www.treasury.gov.za.
[61] National Treasury, 2019 Adjusted Estimates of National Expenditure, Vote 16 Health, October 2019. Available at www.treasury.gov.za.
[62] Ibid.

SHIFTING CONDITIONAL GRANTS TO THE NHI FUND

80. Section 49 of the Bill states that Health Conditional Grants will be transferred to the NHI Fund from 2021/22, amounting to about R50 billion. The Bill explicitly includes the Comprehensive HIV/AIDS and TB Grant as one that will be moved by this date.
81. No explanation is provided in the Bill or the Memorandum as to how this transfer will take place, or what implications it will have for the organisation and implementation of the HIV/AIDS programme, which more than 4 million people depend upon for life-sustaining anti-retroviral therapy.
82. Since it will, for a period, be the major source of funding for the nascent NHI Fund, we would like to know if the funding for this critical programme is at risk? We wish to see the implementation plan for this change as soon as possible so that we can work with the Department of Health and the Fund to ensure as seamless a switch as possible. It must be noted that a significant portion of total High Cost Innovative treatments are procured on a compassionate / donor basis by a donor community, who would also need to be brought on board for any major shift in the funding or implementation of these grants and programmes to take place.
83. The Bill is silent on how or where the medical aid reserves, amounting to Billions of Rands, will be dissolved or allocated. These funds are pooled from Medical Aid member fees, and clarity on their disbursement is required.

SHIFTING PROVINCES' EQUITABLE SHARE ALLOCATION TO THE NHI FUND

84. The Bill envisages that from 2022/23, the equitable share allocation to provinces to provide health care services will be transferred to the NHI Fund in part or in full.
85. Once money is consolidated in the Fund, which will have the power to invest surpluses and save money for emergencies or economic downturns,, subject to good governance and management, and political will, that pot of money should only grow year after year. This would be preferable to the current situation, where provincial government's decide how much of their equitable share allocation to spend on health each budget cycle.
86. We are reassured by Section 3(4) of the Bill which recognises that the Bill won't effect changes to the funding and functions of national and provincial departments until legislation contemplated in Sections 77, 214 and 227 of the Constitution has been affected. However, we recommend that function shifts are dealt with extremely carefully and planned and undertaken with the support of provinces and health care users so that both services and intergovernmental relations are not disrupted.
87. We also note that the equitable share formula will need to be reviewed in light of the proposed changes and call for public participation in the process of formulating and designing such changes.
88. Section 35(b) of the Bill states that "Public ambulance services must be reimbursed through the provincial equitable allocation." We are confused by this section since it is provinces' prerogative to spend their equitable share as they choose and cannot be told how to do so.

MEDICAL SCHEME TAX CREDITS

89. We note that, instead of subsidising private health care, the funding amounting to approximately R4 billion annually previously allocated to medical scheme tax subsidies will have been fully redirected to the NHI Fund by 2021/22.

90. These tax credits have to-date assisted lower-income earners to access medical aid plans and there is a legitimate concern that the removal of the tax credit, though it has also subsidised middle and higher income earners, will result in lower income earners no longer being able to afford their plans. This may result in the downgrade or termination of medical aid subscriptions by lower income earners, who will thus be added to the already oversubscribed public health system. This will only add to the burden of care in the public sector and without additional funding to compensate, which is not envisaged in the 2019 MTBPS or the Memorandum to the Bill, will put further pressure on public services.
91. We recommend that consideration be given by the National Treasury to tax and spending measures that may be undertaken in Budget 2020 and Budget 2021 to alleviate the impact of the withdrawal of medical scheme tax credits on low-income earners that may be pushed out of private medical insurance as a result.
92. We also recommend that the Department of Health work with the Council for Medical Schemes to design and implement measures aimed at retaining lower income earners in the medical scheme system in the medium-term, in line with the recommendations of the Health Market Inquiry. Improvements to incentives and benefits will likely not be enough to achieve this. Consideration will have to be given to lowering the fees paid by lower income earners and increasing the progressivity of scheme tiers and tariffs.

G. COMPETITION LAW AND THE NHI

93. The NHI Bill states in section 3(5):

> *The Competition Act, 1998 (Act No. 89 of 1998), is not applicable to any transactions concluded in terms of this Act.*

94. This clause is potentially problematic for the efficient functioning of the healthcare system. While the NHI Fund may require particular transactions to be exempt from the Competition Act (for example, to enable forms of collective bargaining), it would be an over-reach to exclude all transactions from the Competition Act and may have a detrimental effect on the Fund and on access to health care services.
95. The purpose of the Competition Act is to promote and maintain competition in the country in order to attain several goals, including promoting efficiency in the economy, providing consumers with competitive prices, promoting employment and social welfare of South Africans, and ensuring small and medium enterprises and historically disadvantaged people have opportunities for participation in markets. These are important national goals
96. The transactions referred to in the NHI Bill may involve various practices that are prohibited by the Competition Act, including, for example:
    - *Restrictive horizontal practices* which are agreements between firms or associations of firms that substantially prevent or lessen competition or involve particular listed practices, particularly collusion including directly or indirectly fixing purchase prices, selling prices and trading conditions, dividing markets or allocating customers, or collusive tendering.
    - *Restrictive vertical practices* that substantially lessen or prevent competition, for example, exclusive contracting or rebate structures which may exclude competitors from the market, maintaining high levels of concentration, as well as minimum resale price maintenance.

- *Abuse of a dominant position.* This includes a range of practices, for example, charging excessive prices, refusing to give a competitor access to an essential facility and exclusionary acts. Exclusionary acts include the following: requiring or inducing a supplier or customer not to deal with a competitor, refusing to supply scarce goods or services, selling goods or services on condition that the buyer purchases separate goods or services unrelated to the object of the contract, selling goods or services at predatory prices, buying up a scarce supply of intermediate goods or resources required by a competitor, and engaging in a margin squeeze.

97. Furthermore, in terms of the Competition Amendment Act, it is prohibited for a dominant firm in a *designated sector* (sectors have not been designated thus far):
98. To directly or indirectly, require from or impose on a supplier that is a small and medium business or a firm controlled or owned by historically disadvantaged persons, unfair prices or other trading conditions.
99. To avoid purchasing, or refuse to purchase, goods or services from a supplier that is a small and medium business, or a firm controlled or owned by historically disadvantaged persons in order to circumvent this.
100. As such, the Competition Act predominantly has strong protections for companies against exclusionary and anti-competitive behaviour with particular safeguards for SME and HDI businesses.

The role for competition law in relation to the NHI Fun.

101. There is a strong role for Competition Law to operate in a complementary manner to the NHI Bill to maximise benefits to the Fund, the industry and to individual patients. The Health Market Inquiry Report found that there are a range of inefficiencies in the private health sector, some of which will require regulations and other interventions to address. Making the Competition Act inapplicable to transactions concluded in terms of the NHI Bill may have several unintended consequences:

COLLUSION

102. Absent the application of the Competition Act, there may be an enhanced scope for collusion. Companies that are colluding in tendering for the Fund could argue that they are not subject to the Act as their conduct relates to a "transaction under the Act". This is of concern as collusion in medication and medical products is prevalent locally and internationally.
103. Firstly, there have historically been cases of explicit collusion in the medical sector in South Africa:
    - In 2008 Tiger Brands and Adcock Ingram Critical Care agreed to administrative penalties in terms of collusive behaviour in the supply of intravenous medical products supplied to private and public hospitals through collusive tendering, market allocation.[63]

[63] Competition Commission of South Africa, Press statement: Adcock Ingram Critical Care admits involvement in cartel and agrees to penalty representing 8% of turnover, 8 May 2008

- In 2010 a consent order was reached in relation to a tender for HIV test kits in which fines were levied on Hosannah Medical and Shekinah Medical.[64]

104. Secondly, there have been several cases of collusion that increased the price of medicines internationally, including several in the last year.

105. In August 2019, The UK Competition and Market Authority (CMA) entered into an agreement in which Aspen would pay GBP 8 million in damages to the CMA for collusion (including market sharing) that raised the prices of medicines sold to the NHS.[65] The US Department of Justice has charged pharmaceutical companies for price fixing, bid rigging and customer allocation that increased the prices of generic medication.[66]

106. Collusion in the supply of medical and pharmaceutical equipment is particularly concerning as there are several structural features of these markets which make them susceptible to collusion. This includes high levels of concentration and multi-market contact. As such, by excluding transactions engaged in by the Fund from screening and scrutiny by the competition authorities who have specialist knowledge and expertise in investigating and prosecuting collusion it is likely that the current Bill creates a gap in which potential collusion can go unchecked.

PROVISIONS RELATING TO DOMINANCE

107. It is possible that as the dominant purchaser of healthcare services, the Fund would be subject to the dominance provisions of the Act. This includes, for example, the prevention of predatory pricing and ensuring that the Fund as a dominant buyer does impose fair prices or trading conditions on SME or HDI businesses (if healthcare is designated). While this may constrain the Fund to some extent, these provisions exist to support business and competition and to maintain a healthy competitive environment, particularly for SME and HDI providers. The provisions therefore play an important counterweight to price in ensuring sustainability and diversity in supply. They prevent a scenario in which a focus entirely on costs leads to the exit of smaller and local industry competitors, leading to complete dependence on one or two large suppliers who then operate from a position of bargaining strength. As such, it is unclear as to why adherence with these provisions would be problematic for the Fund.

108. Furthermore, it can be noted that abuse of dominance in the sector has been assessed in other supply chains in the past. For example, in 2003 the Competition Commission reached settlements with Boehringer Ingelheim and glaxosmithkline in relation to antiretrovirals pricing for abuse of their dominant positions, leading to the companies agreeing to issue voluntary licences to generic manufacturers. This led to a reduction in prices for arvs. As such, there are

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64 http://www.compcom.co.za/wp-content/uploads/2014/09/Annual-Conference-Paper-Combatting-Bid-Rigging.pdf; ; Competition Commission v Shekinah Medical & Disposables & Hosannah Medical & Disposables available from http://www.saflii.org/za/cases/ZACT/2013/44.html

65 Competition and Market Authority UK, "Press release: CMA pharma probe secures £8m for the NHS", 14 August 2019, https://www.gov.uk/government/news/cma-pharma-probe-secures-8m-for-the-nhs

66 The United States Department of Justice, "Press release: Pharmaceutical Company admits to price fixing in violation of antitrust law, resolves related False Claims Act Violations." 31 May 2019, https://www.justice.gov/opa/pr/pharmaceutical-company-admits-price-fixing-violation-antitrust-law-resolves-related-false

likely other circumstances in which the Competition Act may directly lead to a more efficient and better outcome for patients.

THE ROLE OF EXEMPTIONS

109. It can be noted that the Competition Act allows for Exemption applications to be made. One potential concern historically has been that collective bargaining by practitioners and medical schemes, which was found to be anti-competitive. The South African medical Association (SAMA) and the Hospital Association of South Africa (HASA) were subject to consent orders and administrative penalties in 2003/4 which subsequently left a regulatory vacuum for price determination and has been argued to have led to increased prices in the private sector. There may be a concern that were the Competition Act to apply, a similar situation may result.

110. However, if this is a concern and collective bargaining by practitioners is seen as a more efficient means of negotiating, it would be better for the Fund to simply apply for an exemption for that particular type of transaction rather than simply removing the application of competition law to the sector as a whole. It can be noted that on a forward-looking basis, transactions negotiated under the NHI Fund can be structured with input from the Competition Authorities in a manner that is procompetitive or falls more distinctly within a clear regulatory framework. For example, the Competition Commission Healthcare Market Inquiry has recommended that a Supply Side Regulator determine such tariffs in a Multilateral Negotiating Forum that can be used as a mechanism for such negotiations. As such, there are various mechanisms that can be used by the Fund, which would work comfortably in parallel with the Competition Act and in cooperation with the Competition Authorities.

111. Given the important role that competition in markets can play in reducing the ability of firms to abuse their dominance, it is essential that the Competition Authorities continue to play a role in monitoring and prosecuting abuses in healthcare markets. Creating an environment where there are concerns over jurisdiction is likely to have a chilling effect on investigation in healthcare markets and supply chains. We therefore recommend that clause 3(5) of the NHI Bill be deleted and that the NHI Fund work together with the Competition Authorities to benefit from the alignment between the two legislative schemes.

H.THE IMPLEMENTATION OF HEALTH MARKET INQUIRY RECOMMENDATIONS IN THE INTERESTS OF NHI

112. As noted above, the final report of the Competition Commission's Health Market Inquiry makes clear the need for reform of the private health sector. Such reform, if undertaken, could start to build towards NHI through standardisation and quality monitoring. Several specific recommendations bear mentioning:

- The establishment of standardised base packages of services by medical schemes, which could become the NHI base package;
- The development of a supply-side regulator, the role of which could be expanded to include the public sector; and
- Quality measurement piloting in the private sector, which could form the basis for the monitoring of quality of care across the health system.

113. Even with the most optimistic assumptions about the timeline for implementation of NHI, the private sector in roughly its current form should be around for at least another six years. The private sector cannot be left in a state of dysfunctional regulation for all this time. And implementing key Health Market Inquiry report recommendations would allow for the better quality and efficiency monitoring: lessons that could be applied by the NHI Fund.
114. Appropriate regulation of the private sector, in line with the recommendations of the Health Market Inquiry, could help rather than hinder the effective implementation of NHI and we propose the prioritisation of the implementation of these recommendations.
115. In addition, we urge parliament to consider the NHI Bill in conjunction with the Medical Schemes Amendment Bill, since these two pieces of legislation are complementary and interdependent. It is also clear that the NHI Bill has implications for the functioning of medical schemes. Considering the two Bills together will also allow for a fuller consideration of the implications of the Health Market Inquiry for NHI.

WHAT HEALTH SERVICE USERS HAVE TOLD US ABOUT WHAT THEY WANT FROM NHI

116. There remains uncertainty in the public domain about what NHI is and how it will help in improving access to quality health care services for all. In order to provide information about NHI and to provide a channel for ordinary people to make input before parliament on the Bill, we engaged in the following processes:

- GA-SA member RDSA held community dialogues via online webinar open to all rare disease patients to provide opportunity to gain further information on the technicalities of the bill, and create a community voice in regards to what the community at large deemed insufficient. And as a way of informing TAC and community members about the NHI.
- RDSA attended various meetings and forums across various sections including a meeting held by SECTION27 to gain further insight on the process.

CONCLUSION

We trust that these submissions will be helpful to the Committee in its deliberations on the Bill and request an opportunity to make oral submissions at the oral hearings in Parliament.

We request that these comments are addressed and shortcomings rectified through further consultation with the various stakeholders and groups. True universal health coverage is where citizens can access health services without incurring financial hardship: a system of protection which provides the equality of opportunity for people to enjoy an attainable level of health. Such a healthcare service should be available to ALL registered users, and include promotive, preventative, curative, rehabilitative and palliative health services, regardless of socio-economic or health status of those persons at no cost impact to the registered user.

All South Africans affected by common and rare congenital disorders are entitled to access appropriate, timely care and efforts must be undertaken to ensure this especially vulnerable group are not excluded and left behind within the context of NHI.

Yours sincerely,

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