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**Presentation to the Parliamentary Portfolio Committee on Health
on the impact of NHI on people affected by congenital disorders
8 February 2022**

Issues

- Definitions
- Access to healthcare
- Fund Income & coverage
- Continuation of care and referral pathways
- Rights of fund users /patients
- Cost coverage
- Progressive Reasalisation

Definitions

1. **Congenital disorders (CD)** = abnormalities in structure or function present at birth, whether obvious/manifesting at birth or later in life. May be caused by genetics/partial genetics (80%) or environmental issues.
2. **Rare diseases (RD)** = conditions occurring at a low prevalence i.e. less than 1 in 2000 of the population. Includes inherited, genetic and acquired conditions. Although individually rare, RD are collectively common.
3. **Most CD/RD are non-communicable diseases (NCD)**: and the first NCD experienced by people and need to be classified as such within the context of NHI. Many of the “diseases of lifestyle” are actually multifactorial CDs i.e. they have a genetic predisposition, highlighting the need for genetic services and integrating genetics into health promotion and disease prevention.
4. **Absent terms**: eg. People living with disability

Definitions

3. Ambiguous terms

- Mandatory prepayment
- Active purchasing
- Undesirable, unethical
- Progressive realization
- Good quality personal health care services
- Universality & social solidarity
- Health establishment & health agency
- Beneficiary
- Financial risk (definition in MSA)
- Portability (in this context)
- Quality health service benefits (including novel, expensive therapies)
- Unreasonable grounds
- Cost-effective (in this context)
- Adequate notice
- Reasonable opportunity
- Complementary health service benefits
- Comprehensive

Access to healthcare

- Many congenital disorders (CDs) and rare diseases (RD) are complex conditions involving a number of body systems requiring care from a variety of different medical specialists and allied healthcare professionals
- NHI does not affectively provide for/uphold constitutional rights of those with CD/RD: according to RSA Constitution (S 36(1)) *“must be reasonable, justifiable in open democratic society based on human dignity, equality and freedom, taking into account all relevant factors.”*
- Limits rights to access healthcare by those affected by CD/RD, specifically:
 - **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 CD/RD.
 - **Section 10(3)(b)** - No ‘cost-effective’ intervention in existence for many rare CD/RD. Interventions may be novel/expensive (often off-label use) with no alternative treatment. Bill excludes conditions without a ‘cost effective’ solution in favour of those where available/affordable interventions. E.g. of enzyme replacement therapy (ERT). Cannot be based on cost alone.
 - **Section 10(6)** – A user may purchase health care services not reimbursed by the fund through private healthcare insurance. But MSA amendment Bill states that the Registrar may restrict the extent of benefits offered by a medical scheme regarding benefits and services offered under the NHI Fund (Amendment to Section 34 of Act 131 1998).



Fund Income & Coverage

- 1. Section 3(b):** The Fund is the single public purchaser and financier of health services in the South Africa. 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) prior to the drafting of the Bill.
- 2. Section 4(a)**...to establish and maintain an efficient fund through the consolidation of revenue so as to protect users against financial risk. The financial burden imposed on families affected by CDs & RD is already immense (full time care, loss of earnings). If required to pay NHI Fund from taxable earnings, this will further decrease the amount available to obtain appropriate complementary cover, placing them at further financial risk. This may result in vulnerable groups paying for a mandatory service that does not provide for their needs and pay additional costs for private services not provided through NHI.
- 3.** Potential NHI financing via a tax levy has sustainability issues i.e. 10% of population pay >90% taxes.

Fund Income & Coverage

4. Section 5(C): 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”.

- Details on decision-making about which conditions included?
- Services purchased to cover the treatment of less common conditions? Based on previously published NHI benefits framework, there is no provision made for CD/RD coverage.
- What about less common conditions? Those affected by CD/RD required to contribute to the fund/register as a user have no say in the purchase of services.
- NHI claims to prioritise services to populations most in need - which should include CD/RD
- Unclear from draft Bill if these patients will be covered at all by the fund. So, while these patients/families will be required to register as users of the NHI fund, many will not have the treatment of their conditions funded.

5. ‘Cost effectiveness’ relative to personal risk/cost and the overall socioeconomic impact has not been considered. E.g. conservative treatment of scoliosis via physio & bracing (R50 000 per brace) versus spinal surgery (R200-300 000). Surgery should be last resort, and after the child has stopped growing to prevent stunting. Currently in State, surgery is only offering & limited to severe cases.

Fund Income & Coverage

- Concerns 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. These problems require significantly improved operational and financial management.
- For South African citizens to truly benefit from a universal health coverage system there is 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, *the state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights*.

Continuation of Care & Referral Pathways

1. **Section 10(2)(c):** *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.* This is not viable for CD & RD patients.
2. Implementation phases of NHI proposed but fails to deal with the practical issue of continuation of care by existing treating healthcare practitioner. Patients already diagnosed with CD/RD prior to NHI may already be receiving essential 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.
3. Practitioners' specialty and expertise in treating a particular condition and not due to geographic convenience. Geographical convenience is often a luxury many CD/RD patients do not have, due to the shortage of specialists, especially outside of major urban areas.
4. Adherence to referral pathways determined by a health establishment – starting with a patient assessed by a nurse or other primary health care provider. While appropriate for those affected by a less severe and more common illness e.g. a common cold, is a likely waste of resources for CD/RD patients. Standard referral cannot be applied to all.

Continuation of Care & Referral Pathways

5. Previous diagnoses and ongoing treatment must be taken into consideration to ensure the most effective, timeous access and reimbursement for CD/RD.
6. 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.*
7. **Section 11(2)(b):** a fund user may only seek the services of a specialist without a referral from his or her healthcare provider in cases of an emergency. Delay in accessing the appropriate treatment for a CD/RD may have severe consequences, including fatalities.

We request clarity on the definition of emergency services and a clear definition of the process by which patients and healthcare practitioners of rare or specialized conditions, including CDs, are integrated into NHI healthcare services.

Rights of fund users/patients

1. *Right to informed consent:*

- The right to informed consent places responsibilities on the individual patient (Patient's Right Charter).
- To enable patients to uphold their rights/exercise their responsibilities they must have access to their health records as outlined in Promotion of Access to Information Act (*PAIA, 2000*).
- The PAIA 2000 process is onerous for an individual, lacks efficiency and speed by which a user/beneficiary may require such information.
- Linking the right to access health records via PAIA, the Bill places undue burden on the individual to exercise rights and responsibilities. This may impact the patients rights to be given full, accurate information about the illnesses, diagnostic procedures, proposed treatment and associated risks and the costs involved; and to obtain a second opinion from a health provider of one's choice.

2. *Rights relating to personal information:*

- PAIA defines '*personal information*' as *information about an identifiable individual a) to g)*
- **Section 5(C)** draft Bill 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 the Constitution. Current it means the patient is entitled to the benefits they would ordinarily be entitled under MSA 131 of 1998 and the fund should not seek to replace these.
- Alignment is required between the proposed section of the draft Bill and the MSA amendment Bill.

Rights of fund users/patients

3. Patient and/or civil society representation in fund processes and committees:

Draft Bill excludes representation from either health related NGOs, civil society or consumers/users:

- in both the Benefits Advisory Committee and Health Benefits Pricing Committee.
- 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.

These groups must be represented in these committees and processes. If excluded, any decisions made by the committee require prior public consultation via a formal process.

4. Accountability for access to healthcare

- The draft Bill states that “*The Fund must, in consultation with the Minister (of Health), purchase comprehensive health service benefits on behalf of...*”
- The Constitution of RSA appoints the Minister of Health as representative of the executive accountable for access to healthcare for RSA citizens.
- This dual accountability (COI?) may result in a patient being caught between the fund and the Minister and \ further complicate the complaint process currently defined in the draft Bill in relation to the fund. The RSA Constitution gives the right to complain about health care services, have such complaints investigated and receive a full response on such investigation.

Cost Coverage

1. **Section 12(1):** 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. Many CD/RD affect many body systems and are treated simultaneously by a range of specialists – a multidisciplinary team of specialists and allied health care professionals.
2. >80% of CD/RD are caused by genetics/partially genetic. Serious CD/RD are life limiting or chronically debilitating diseases resulting in lifelong disability. Birth prevalence varies from more common disorders (eg Down syndrome 1 in 500 births) to rare conditions (<1 in 2 000).
3. The contribution of CD/RD to the disease burden is proportionally *increasing* in importance as deaths from other (infectious) conditions decreases, but remains unseen as a health need due to the lack of empiric data available South Africa.
4. This results in an underestimate of the scale of this health issue, so these conditions remain unprioritized, services neglected and patients remain undiagnosed and misdiagnosed, unable to access relevant care – impacting morbidity & mortality.
5. Areas of specialty needed to treat CD/RD may not be funded by the NHI Fund or may be in locations which cannot reasonably accessed by affected patients.
6. Currently in South Africa, the 12 practising medical geneticists in the country are located in only 3/9 provinces, and eight genetic counsellors in state in only 2/9 provinces.? How will this capacity, and supporting genetic testing (i.e. NHLS) be increased and relevant geographical coverage be ensured so that services can be provided countrywide and universally to all?

Progressive Realisation

- Children's rights are fundamental human rights and thus their right to access healthcare cannot be subject to progressive realisation.
- While it is stated that NHI will not “provide everything for everyone”, not providing health services for children affected by CD/RD is a violation of their fundamental human rights (Malherbe et al, 2016).

Capacity Building

- Capacity building efforts as part of the NHI need to include include medical genetics, which have declined as a result of competing health priorities over the past decades. Currently on 2 provinces (GP & WC) have medical geneticists and genetic counsellors in state. Freezing of posts results in qualified HCP emigrating or moving to the private sector.
- it is essential that nursing curricula are standardised and updated, including relevant content on genetics to take advantage of genetic discoveries to improve healthcare, especially in PHC settings where genetics training is currently inadequate.
- Specialised training is also required to develop genetic nurses and genetic nurse counsellors to supplement the shortfall of medical geneticists and genetic counsellors, as recommended in the 2001 Policy Guidelines for the Management and Prevention of Genetic Disorders, Birth Defects and Disabilities.
- For the comprehensive package of health services to be delivered through NHI, mandatory training is required to increase capacity to ensure these genetic services can be implemented as intended.
- Governments usually recognise the importance of developing comprehensive genetic services when the IMR reaches 30-40 deaths per 1000 live births as a means to achieve further significant reductions in child mortality. With an IMR of 28/1000 live births, SA is well beyond this point.

Conclusion

1. GA-SA and its membership do not believe that the draft Bill can be accepted in its current format.
2. We request that these comments are addressed and shortcomings rectified through further consultation with the various stakeholders and groups.
3. 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.
4. 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.**
5. All South Africans affected by CD/RD 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.



THANK YOU

We applaud the Minister of Health for the release of the draft National Health Insurance Bill and welcome this opportunity to submit comments to the PC on Health. If further public hearings or briefing sessions on the draft Bill are held, we would welcome the opportunity to participate.