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20 September 2018

BY EMAIL

ATTN: Dr Anban Pillay
Deputy Director – General
National Health Insurance
Email: anban.pillay@health.gov.za

Dear Dr Pillay,

Re: Comments on Draft Medical Schemes Amendment Bill (Gazette 41726 of 21 June 2018)

Genetic Alliance South Africa (GA-SA) is a non-profit, membership organisation uniting patient support groups, healthcare professionals and other stakeholders relevant to the care and prevention of congenital disorders (CDs), also known as birth defects. Based on collective membership of member groups, GA-SA represents almost 20 000 South Africans affected directly or indirectly by CDs, including rare diseases, inherited cancers and fetal alcohol syndrome.

CDs affect 1 in every 15 live births in South Africa[1] but are underreported via national surveillance by 98%[2] and as yet, are an unprioritized 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[3]. 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 and minimize the impact of CDs on early childhood development, reducing the degree of disability and improve quality of life by up to 70%[4].

SERVICE BENEFITS

Section 32(I) of the Medical Schemes Amendment Bill (the draft Bill) seeks to make fundamental changes to the nature of medical schemes benefits and the manner in which various conditions will be treated. This section of the draft Bill states that it makes provision for a comprehensive set of service benefits to be funded. The "comprehensive service benefits" are not defined and it is unclear if the term comprehensive will include the treatment of common and rare CDs which are currently funded by medical schemes.

[1] 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.
[2] Lebese, L., C. Aldous, and H. Malherbe, *South African congenital disorders data, 2006 - 2014.* S Afr Med J, 2016. **106**(10): p. 992-995.
[3] World Health Organization, *World Health Statistics 2015*. 2015, World Health Organization: Geneva. p. 164.
[4] Czeizel, A., Z. Intôdy, and B. Modell, *What proportion of congenital abnormalities can be prevented?* BMJ, 1993. **306**: p. 499-503.

We believe that this section of the draft Bill is contrary to the principle underpinning the current Prescribed Minimum Benefit's (PMBs) - to protect and to avoid incidents where individuals lose their medical scheme cover in the event of serious illness and the consequent risk of unfunded utilization of public hospitals.

It is evident that if the revised Section 32(I) is adopted in its current form that the number of CDs and rare diseases currently funded under the existing PMB legislation will now become unfunded – resulting in numerous deaths or major disability for numerous patients, who function extremely well due to the costly treatment they receive.
The rationale behind the Medical Schemes Act has always been to ensure cover for catastrophic and hospital-based care, which are unaffordable to individuals. However, going forward, GA-SA is unsure from the current form of the draft Bill that this will continue to be the case. It rather appears that the opposite is being proposed. In its current format, it is unclear from the draft Bill as to what a medical scheme will be required to fund and what they will not be required to fund.

While GA-SA does not object in principle to an amendment of the Medical Schemes Act, such an amendment must ensure that numerous chronic and serious conditions do not go unfunded or provide a legal matrix for a medical scheme to fund what was previously funded.

Also for further consideration in terms of funding and which has not been addressed in the draft Bill, is the relationship between funding and Regulations 15H(c) and 15I(c) in the Principal Act. These Regulations make provision for the fact that a Medical Scheme must pay in full for the treatment of a member's medical condition, this is not limited to the current list of PMB conditions, where all other treatment options have failed, have caused harm or would cause harm.

What is not widely known is that for many of the more rare congenital conditions is there is usually only one type of treatment available without an alternative. For example, Gauchers Disease is only treatable with enzyme replacement therapy. The only enzyme replacement therapy in South Africa to treat Gauchers Disease is Cerezyme. Without this treatment the patient will suffer and ultimately die.

NHI AND MSAB OVERLAP

It is unclear from the draft Bill and specifically section 34(3) as to the restrictions and extent of restrictions on what medical schemes may fund. It is further clear from this section that the benefits that medical schemes offer must not be the same as those offered by the fund.

Also unclear from this section of the draft Bill, is which conditions these restrictions on funding pertain to. It is of grave concern for GA-SA and our member organisations that the amendments to the Medical Schemes Act contained in this draft Bill do not address conditions such as those that are deemed to be congenital or rare. It further appears that the draft Bill, specifically in this section seeks to obviate the purpose for which a beneficiary seeks to obtain extra medical cover from a medical scheme.

DESIGNATED SERVICE PROVIDERS

Section 32(G) of the draft Bill makes provision for discounts when utilising designated service providers. While GA-SA supports this amendment, we are concerned that the nature of common and rare CDs often requires a sub-specialist medical professional or multidisciplinary team to treat the condition. In our experience, many of these sub-specialists do not have any funding relationship with a medical scheme which will result in these patients being prejudiced and at a disadvantage at being able to obtain a service at a more reasonable contribution cost.

What is also unclear from this section is the manner in which a Designated Service Provider (DSP) will be appointed and the plan for a situation where no DSP is appointed. While some CDs are common, others are rare resulting in limited treatment offered in public healthcare facilities due to the requirement that conditions will only be treated by sub-specialised healthcare professionals.

A further concern is linked to Section 32I when no DSP is appointed, and there is a cost cap on the amount that will be paid for a service. Does this mean that a patient cannot see a certain healthcare professional who would be charging a higher rate to that which would ordinarily be charged by a DSP? If this is the case, then this will limit access to healthcare for many patients affected by the more rare CDs. This is in complete contrast to what the NHI draft Bill seeks to achieve in terms of universal health coverage.

CENTRAL BENEFICIARY REGISTRY

Chapter 3 and 4 of the draft Bill makes provision for the establishment and maintenance of a Central Beneficiary Register. It is further made provision for, that the Minister of Health will prescribe what information is to be collected and stored in the Beneficiary Register.

It is stated that the purpose of the Beneficiary Registry is to establish a database that will aid in identifying and assessing risks within medical schemes and the NHI Fund and ultimately allow for better management of the rights and obligations of beneficiaries of medical schemes. The draft Bill further makes provision for the fact that the medical schemes and the NHI fund may be called upon to provide this information.

What is not made provision for, is whether information is anonymised or not, is the data subject, i.e. the Beneficiaries right to refuse the collection and processing of their data in terms of the Promotion of Access to Information Act (PAIA) 2000 (Act No. 2 of 2000) which is soon to be enacted in totality.

Section 19A is completely silent on what the consequences would be if a beneficiary of a fund or the NHI express that they do not want their information contained in a central database even if anonymised. Will a person who seeks cover from a medical scheme or from the NHI be forced to provide their information even in contrast to Section 14 of the Constitution? Will the refusal to submit to data collection result in both a medical scheme and the NHI Fund being prohibited to offer a person healthcare funding?

Such data, if used to determine benefits, could radically change a beneficiary's access to care which they require, on an annual basis when benefits of the schemes are determined. This could and would be absolutely detrimental to the provision of care in beneficiaries affected by a CD, particularly inherited and rare conditions.

COMPLAINTS AND APPEALS

GA-SA welcomes the proposed amendments to the current complaints and Appeals process at the Council for Medical Schemes. The current process is fraught with delays and problems with no solutions being proposed to rectify the backlog of complaints.

The complaints and appeals process is in dire need of suggestions to speed up the process and to improve its efficiency. GA-SA is of the view that in order to ensure that matters are heard before the Appeals Committee or the Appeals Board in a timeous manner, which is in line with ensuring that patients do not die during the process of obtaining funding, that the exchange of papers relating to the various appeals should be time barred much the same as Court processes. Currently in terms of Section 49 of the principal Act an appellant has 30 days in which

to file an appeal. The Respondent to the proceedings should also be required to provide their founding affidavit with a prescribed time and the replying affidavit of the Appellant the same.

In terms of Section 50 of the principal Act, an appeal to the Appeals Board must be filed within 60 days of the ruling of the Appeals committee being published. All answering and responding papers should further have a time barre in terms of filing. This will mean that the matters can be heard quicker as issues are ventilated on paper. This will free up time of the Appeals Committee and Appeals Board to hear more matters per sitting.

GA-SA further suggests that where the draft Bill proposes at Section 47(5) that a complainant must first attempt to settle the matter with the medical scheme concerned, that certain rules are put in place to facilitate this and that it is a requirement entrenched in the medical Schemes Act.

GA-SA agrees with the proposed contents of Section 49(3) in so far as an appeal does not suspend the operation of a ruling in terms of Section 47. Strict sanctions must be put in place for schemes that do not comply with this.

GA-SA further suggests that all rulings made by either the Appeals Committee or the Appeals Board of the Council for Medical Schemes should be precedent setting for all other matters with a similar set of circumstances or similar facts. This will prevent both the Appeals Committee and the Appeals Board from being backlogged with matters where a ruling has been made on the same or similar facts. These rulings should further be published, even if the parties to the ruling are anonymized.

CONCLUSION

GA-SA is concerned that the Medical Schemes Amendment Bill in its current draft does not consider and take note of the findings and recommendations made by the Health Market Inquiry, nor does it make appropriate provision to protect beneficiaries who are protected and who receive funding for CDs and rare diseases under the current Medical Schemes legislation.

We do not believe that it is the intention of the legislature to place an already vulnerable disease burdened community at any further risk than they already are by limiting their access and ability to have funded the treatment for congenital and often rare conditions.

No adequate transitional provisions are made in the draft Bill to change from funding under the current Medical Schemes Act to these amendments. This is certainly something that must be made provision for when considering the negative impact which these amendments will have for beneficiaries who require specialized treatment.

GA-SA is, as always, open to engaging with the Minister of Health and the Legislature to ensure that any amendments which are made to the Medical Schemes Act do not limit the access of those affected by CDs, especially the more rare conditions from the care which they require.

Yours sincerely,

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