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To whom it may concern

Re: Tax Deductible Gift Recipient (DGR) Reform Opportunities Discussion Paper

The Australian Federation of AIDS Organisations (AFAO) welcomes the opportunity to provide comments on the Tax Deductible Gift Recipient (DGR) Reform Opportunities Discussion Paper.

AFAO is the peak national organisation for Australia's community HIV response. We are recognised nationally and globally for the leadership, policy expertise, coordination and support we provide. Through advocacy, policy and health promotion, we champion awareness, understanding and proactivity around HIV prevention, education, support and research. AFAO is particularly concerned to ensure that an evidence-based approach guides Australia's HIV response and public policy that impacts upon this response. Our members include Australia's state and territory AIDS Councils, national peak organisations representing communities affected by HIV, and fifteen affiliate organisations. We are registered with the Australian Charities and Not-for-Profit Commission (ACNC) and endorsed as a DGR.

AFAO's submission responds to references in the discussion paper regarding advocacy conducted by organisations with DGR status.

Recommendation

AFAO recommends that 'advocacy' should not be over-generalised or defined in ambiguous terms such that it limits critical communications between organisations and government that are conducted in an environment of goodwill and respect and that propose solutions to critical public policy issues.

Issues

Our comments relate to the following questions in the discussion paper:

4. Should the ACNC require additional information from all registered charities about their advocacy activities?

As a national peak organisation, AFAO's engagement with government is informed by years of cross-sectoral communication with the community, research institutes and professional medical bodies. This engagement, referred to as a 'partnership', enables AFAO to play a critical intermediary role in providing government with the trusted, credible information it requires to make evidence-informed decisions regarding developments in HIV science, technology and medicine, and their intersections with community-based HIV education programs. The provision of this information is welcomed and appreciated by government and, in many cases, requested by government. Conversely, AFAO supports

The Australian Federation of AIDS Organisations (AFAO) is the national federation leading the HIV community response. AFAO's members are the AIDS Councils and former AIDS Councils in each state and territory; the National Association of People With HIV Australia (NAPWHA); the Australian Injecting & Illicit Drug Users League (AIVL); Anwernekenhe National HIV Alliance (ANA); and Scarlet Alliance, Australian Sex Workers Association.

our membership and stakeholders in social and clinical research to understand regulatory processes and the rationale for government-decision making. These communications provide solutions to problems, and improve the acceptability of government initiatives and political outcomes. In the context of HIV, this supports government efforts to deliver the *National HIV Strategy* and meet its obligations as a signatory to the United Nations' *Political Declaration on HIV/AIDS*.

The benefits of the advocacy undertaken by AFAO will be illustrated through a case study on HIV pre-exposure prophylaxis (PrEP).

PrEP is a new HIV prevention technology. It is recommended for people who are at high risk of HIV and is administered by taking one pill every day. The pill is a combination of two medications that are listed on the Pharmaceutical Benefits Scheme for use by people living with HIV. PrEP is extremely effective and has the capacity to dramatically reduce the burden of HIV in Australia. However, PrEP is very expensive to purchase over the counter and access is conditional on Australia's regulatory environment for approving medications. The optimal outcome for making PrEP available in Australia is for the product to be listed on the Pharmaceutical Benefits Scheme with HIV prevention purposes.

Delays in the PrEP becoming available through the Pharmaceutical Benefits Scheme have led to a disconnect between the supply of PrEP in Australia and the demand for this product by consumers. Consequently, individuals who are seeking access to PrEP are left to lawfully import the product. As awareness of PrEP has increased, several state governments have funded large, short-term clinical trials that have enabled interim access while pharmaceutical companies sought registration on the Australian Register of Therapeutic Goods and listing through the Pharmaceutical Benefits Scheme. These developments have enabled access for individuals who have high levels of health literacy and are located in those states operating a trial. The situation has, however, created an environment of unequal access to PrEP in Australia.

AFAO is playing an intermediary role in briefing the Department of Health, and the Minister for Health, about developments in PrEP demand and access. These updates are informed by our ongoing communications with suppliers of the medication who are navigating Australia's regulatory framework, and our community based membership who are supporting individuals to access PrEP through the personal importation scheme and/or clinical trials.

AFAO's position as a national peak organisation allows us to communicate the complex environment of PrEP access to the Department of Health and the Minister. This ongoing dialogue is informing solutions to access gaps. In the case study provided, it is difficult to distinguish the advisory aspects of our engagement with government and the advocacy or influencing aspects. As a non-government organisation with a mission to end HIV transmission in Australia, our work will always be driven by our purposes, including to advocate and influence for better outcomes in HIV public policy.

AFAO is concerned that the paper provides no guidance on what constitutes 'advocacy', and that advocacy could be determined by the government of the day when the work of non-government organisations with DGR status should be at an arms length from government.

AFAO recommends that advocacy should not be over-generalised or defined in ambiguous terms such that it limits critical and ongoing communications between organisations and government that are valued, conducted in an environment of goodwill and respect and propose solutions to critical issues.

7. What are stakeholders' views on the proposal to transfer the administration of the four DGR Registers to the Australian Tax Office? Are there any specific issues that need consideration?

AFAO has no concern with the proposal to designate responsibility for DGR registration with the Australian Tax Office. This proposal would streamline registration and reporting to one agency and reduce regulatory burden and inconsistency in the various application processes. AFAO remains concerned however that streamlining the registration process may be part of a wider strategy to limit or impede advocacy by organisations, without guidance as to how such advocacy is to be defined.

11. What are stakeholders' views on the idea of having a general sunset rule of no more than five years for specifically listed DGRs? What about existing listings, should they be reviewed at least once every, say, five years to ensure they continue to meet the 'exceptional circumstances' policy requirement for listing?

AFAO is concerned that the inception of a sunset rule, or periodic review of DGRs to assess whether an organisation meets certain criteria provides the regulator with the authority to revoke DGR status based on activities that might be construed as advocacy, in the absence of opportunity for consultation on how that term is defined.

Yours sincerely



Adj A/Prof Darryl O'Donnell
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