

April 4, 2018

Kelci Gershon
Manager
Strategic Policy and Planning Division
Ministry of Health and Long-Term Care

Re: Feedback regarding the Health Sector Payment Transparency Act regulations

Dear Kelci Gershon,

The Canadian Arthritis Patient Alliance (CAPA) is a grass-roots, patient-driven, independent, national organization with members across Canada and supporters both Canadian and International. CAPA believes the first expert on arthritis is the individual who has the disease and their perspective is unique in that it reflects the needs and lived experiences of patients throughout various aspects of the health care system. The CAPA operating model is unique whereby the Board of Directors are all volunteers and people living with inflammatory arthritis. We are a hands-on “virtual” organization with an average of 10 hours per week of paid administrative support and 2 hours per month for accounting services.

To support CAPA’s continued operations and ensure the patient voice is heard in policy debates in Canada, we depend on funding support from many sources including: non-profit organizations, industry, government and individuals who believe in what we do. We believe it is important to transparently report transfers of value received from industry and other supporters and do so publicly on [our website](#).

The attached appendix outlines our perspectives, considerations and suggestions relating to the proposed regulations to support the Health Sector Payment Transparency Act. We would like to thank the Ministry of Health for providing the opportunity for all groups, including patient groups, to contribute to the discussions and proposed solutions relating to this regulatory package.

Sincerely,



Laurie Proulx
2nd Vice-President
Canadian Arthritis Patient Alliance

Appendix

Low Threshold

The proposed threshold of \$10 is quite low and it is our opinion this amount is not significant enough to influence the behaviour or interests of recipients. As an alternative, we propose a higher threshold of \$500-\$1000 which is a more significant amount whereby a conflict of interest or change of behaviours is more plausible.

Exceptions to reporting requirements

Although clarification was requested concerning the application of section 6(6) of the regulations, there continues to be a lack of clarity concerning the meaning of this clause. There is concern that this section does not require the disclosure of rebates provided by generic drug companies to pharmacies. If this is the case then these transfers of value should **not** be excluded from the application of the regulations. It is important to ensure full disclosure of information to patients and transparency for all health care providers including pharmacists.

Funding for Patient Groups

CAPA receives a number of unrestricted and restricted grants from a variety of industry groups. We are concerned that funding received from industry which supports our operations is at risk given the increased scrutiny on transfers of value. Although we wholeheartedly agree with being transparent in disclosing our sources of funding, it is felt that other sources of funding including **government funding**, be made available to ensure organizations like CAPA can continue to operate on our modest budget. We are primarily volunteer-driven and the funding we have enables us to pay for travel and ensure participation at important conferences to ensure the patient perspective is heard. This government funding should be made easily accessible to patient groups, like CAPA, in order to ensure democratic values are supported in Ontario.

Use of information by patients and the general public

The disclosure of transfers of value seems in principle to be important and relevant information to patients. On its face, it would seem that knowing what transfers of value have been received by their physician is a positive step forward in terms of transparency and determining a conflict of interest. However, it might be difficult for patients to interpret whether a real or perceived conflict of interest exists and in some cases, the use of the information may complicate the patient-physician relationship. It is recommended that the Ministry of Health develop a number of considerations and questions to guide patients in using or interpreting this newly available information. For example, how might a patient initiate a dialogue with their health care provider concerning payments received from industry? What sort of payments or payment amounts might raise suspicions on the part of patients?

Descriptions of Transfers of Value

Section 8 of the proposed Regulation outline the various descriptions of the transfers of value under the Act. When reviewing these descriptions, it was difficult to determine which category would apply to the grants CAPA receives from industry. The grants CAPA receives are generally restricted or unrestricted. When they are restricted grants, there is discussion concerning which activities the grant would support. These activities are not considered charitable donations as we are not a registered charity, nor are they for event sponsorship, space rental or facility fees or for a public awareness campaign.

We were also not sure if a partnering agreement (subsection 15) adequately describes the funding agreements we have with industry. CAPA develops its own strategic plan annually and approaches potential funders with ideas suitable for funding. CAPA drives the ideas and projects that are funded by industry, and each project is typically supported by more than one company. In other cases, funding is provided to cover a variety of operating costs and is not project specific. Once funding is received, we **independently** execute our own projects at arms-length from the funders. The term “partnering agreement” suggests that the industry funder has some say in what we do and how we do it. As a result, we suggest alternate wording such as “restricted or unrestricted grants” and additional context can be provided in a text space (e.g. up to 250 words) to describe the nature of the activities supported by the funding.

Expand the scope to recipients across Canada

Clarification was provided by staff at the Ministry of Health where they confirmed that transfers of value are to be disclosed to recipients in **Ontario**’s health care system. The response provided raised additional questions, such as do the provisions of the regulations extend to organizations with some operating capacity in Ontario but are incorporated in another province or do the regulations apply to organizations incorporated in Ontario only. We urge you to work with the other provinces and territories to introduce similar legislation in order to ensure transparency in the reporting of transfers of value across Canada.

Co-pay assistance to patients

Many pharmaceutical companies offer co-payment programs to provide financial assistance to patients for high priced drugs. It is unclear whether the money provided to support these patients to access catastrophic drug costs would be disclosed under these proposed regulations. We recommend that these payments **not** be subject to these regulations to protect vulnerable patients who are facing financial difficulties and to respect their privacy.

Record retention

As previously noted, we are primarily a volunteer-driven, virtual organization without any physical office space. For this reason, we recommend that clarification be added to the regulations to indicate that electronic records of the transactions are sufficient to meet the requirements of the Act.