

Supplementary File 2: Generic version of letter sent to patient groups

July XX, 2019

Dear Dr. XXX,

We are conducting a study on the funding of national Canadian patient groups. The purpose of this study is to examine how much money groups receive from sponsors, analyze the policies and affiliations of patient groups to determine the types of funding that are permitted, whether any conditions are associated with receipt of the funding, and how the money is used.

We are requesting:

1. Any publicly available policy documents that describe your organization's criteria for accepting funding. An example of this might be a document that describes the process by which donations are considered and which donations may be accepted or refused. If this information exists and is publicly accessible, please either provide the url for the documents or attach them in your response email.
2. Any publicly available policy documents that describe your organization's position on how funds from acceptable sources are used. If this information exists and is publicly accessible, please either provide the url for the documents or attach them in your response email.
3. Any publicly available statements on your website that describe your organization's financial affiliations and donors, as well as the sum per annum that the organization receives from those donors. If this information exists on your website, please send us the url for that webpage.
4. Any publicly available statements on your website that list your organization's board membership including the names of the board members, employment information, and whether there are any current or former industry employees on the board. If this information exists on your website, please send us the url for that webpage.

The only information being requested from you is publicly available policy documents and website urls. Since all of this information is publicly available it will not be kept confidential. Any final publication from this research will name the organizations involved and indicate that its communications contact or equivalent, director, or his/her delegate was contacted to provide the title and source of publicly available publications and websites, as requested above but no names of any individuals in the organization will be disclosed. Organizations that do not respond or provide any information will also be identified in any final publication. No individuals will be named. As per general journal policy all raw data will be deposited in a publicly accessible website. Should your organization wish a copy of any final publication we will be pleased to provide one to your organization.

Please respond within one month of receipt of this email.

You can refuse to participate or withdraw from the study at any time without affecting the relationship with the researchers, York University or any group associated with this project.

In the event that you withdraw from the study, all associated data collected (individual responses and non-public documents) will be immediately destroyed wherever possible. However, publicly available information will be retained regardless of whether you withdraw from the study.

There are no potential risks to participating in this study.

You can contact Alison M. Collins-Mrakas, Senior Manager & Policy Advisor, Research Ethics at 416-736-5914 or acollins@yorku.ca for further information.

The research has been reviewed and approved by the Human Participants Review Subcommittee and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines.

Sincerely,

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