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Complete List of Authors:	Lexchin, Joel; York University Faculty of Health, School of Health Policy and Management; University of Toronto Faculty of Medicine, Department of Family and Community Health Batt, Sharon; Dalhousie University, Halifax, Bioethics Goldberg, Devorah; York University Faculty of Graduate Studies, School of Health Policy and Management Shnier, Adrienne; York University Faculty of Health, School of Health Policy and Management
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Disclosure of relationships between Canadian patient groups and pharmaceutical companies: an observational study

Joel Lexchin (0000-0001-5120-8029), Sharon Batt (0000-0003-0612-0513), Devorah Goldberg, Adrienne Shnier

Joel Lexchin, professor emeritus, Faculty of Health (School of Health Policy and Management, York University), 4700 Keele St., Toronto, ON, Canada M3J 1P3

Sharon Batt, adjunct professor, Department of Bioethics, Dalhousie University, 5849 University Ave, Room C315, PO Box 15000, Halifax, NS, Canada B3H 4R2

Devorah Goldberg, graduate student, Faculty of Graduate Studies (Graduate Program in Health), York University, 4700 Keele St., Toronto, ON, Canada M3J 1P3

Adrienne Shnier, adjunct professor, Faculty of Health (School of Health Policy and Management, York University), 4700 Keele St., Toronto, ON, Canada M3J 1P3

Correspondence:

Dr. Joel Lexchin
School of Health Policy and Management
York University
4700 Keele St.
Toronto, ON, Canada M3J 1P3
Tel: +416-209-4885
Email: jlexchin@yorku.ca

Structured Summary

Objectives

This study investigates the information and policies that Canadian patient groups post on their publicly available websites about their relationships with pharmaceutical companies.

Design

Observational study.

Setting

Canadian patient groups.

Participants

Ninety-seven national patient groups with publicly available websites.

Interventions

Collection of information about: total annual revenue for the latest fiscal year, year revenue was reported, revenue from pharmaceutical company donors, purpose of the donation, presence of donors' logos on the website and hyperlinks to donors' websites, previous and current employment information about board members and staff, external audits about the group's finances, and whether the group endorses products made by donors. Analysis of publicly available policies looking at: board and/or advisory board, acceptance of donations and revenue generation, independence of decision-making, endorsements, assistance to and/or interactions between patient members from a donor or another company/person acting on behalf of a donor and audits/monitoring/compliance.

Primary and secondary outcome measures

Number of patient groups posting different types of information on their websites and having policies covering different topics about relationships.

Results

Fifty-three (54.6%) of 97 groups reported donations from pharmaceutical companies but only 1 (1.0%) gave the total amount. Thirty-seven (38.1%) groups showed the logos of pharmaceutical companies on their websites and 20 (54.1%) had hyperlinks to pharmaceutical company websites. Twenty-five (25.8%) groups endorsed pharmaceutical products produced by brand-name companies that had donated to the groups. Twenty-six (26.8%) groups had policies that dealt with relations with pharmaceutical companies. The topic that was most frequently mentioned was acceptance of donations and revenue generation (16 (16.5%) groups).

Conclusions

Pharmaceutical industry funding of the included patient groups was frequent. Despite this, relatively little information was provided on patient group websites about their relationships with pharmaceutical companies. Only 26 out of 97 groups had policies that directly dealt with their relationships with pharmaceutical companies.

Article Summary

Strengths and limitations of this study

- This is the first Canadian study to examine patient groups relationships with pharmaceutical companies.
- Information posted on groups' websites and policies guiding the relationships were analyzed.
- Ninety-seven national groups were included.
- Information was presented in multiple different places on groups' websites and some relevant information may have been overlooked.
- Results may not be representative of other Canadian patient groups.

Introduction

Patient groups serve an important function within the healthcare system for their members with a specific condition, providing information, education and support, contact with others facing the same health condition and assistance in navigating the health care system. Within this mandate, they often lobby Health Canada, the federal drug regulator, to approve new drugs and provincial governments for specific products to be funded for their membership. They advocate for more research into conditions afflicting their populations, sit on important policy committees and speak for patients with healthcare professionals and healthcare institutions such as hospitals. Patient group leaders often act as the voice of patients in the media.[1 2]

Since the Canadian federal government rolled back funding of patient groups in the mid 1990s [3] groups have sought new sources of revenue. Many patient groups receive money from pharmaceutical companies. This source of revenue has created concerns about a conflict of interest (COI) between corporate sponsors with a vested interest in supporting product sales and the patient groups and the potential for groups to adopt positions that favour their funders. Some groups have lobbied provincial governments to have their sponsors' drugs included on provincial formularies.[4 5] Ninety-three patient groups made 372 submissions to either the Common Drug Review or the pan-Canadian Oncology Drug Review, both part of the Canadian Agency for Drugs and Technology in Health (CADTH), about whether these agencies should recommend that provincial drug plans fund medications. When groups had a conflict with the company making the drug, they were in favour of funding in 193 (85.0%) out of 227 submissions, neutral in 30 (13.2%) submissions and opposed in 4 (1.8%).[6]

The actions by groups described above highlight the need to systematically investigate how patient groups report financial information on their publicly available websites, for example, whether they report receiving donations from pharmaceutical companies, and whether they have policies to guide their relationships with their pharmaceutical company donors. Transparency in reporting is a first step to enabling all affected parties (patient group members, the medical community, governments, policy makers and funders) to assess the independence of groups from these funding sources. This study investigated the transparency of patient groups about these funding links. We assessed key information about the organization: how much financial information patient groups post on their websites – specifically, information about donations and the use of donations, the composition and employment histories of their boards and staff. Equally important, we examine whether the groups have COI policies to guide their interactions with companies.

Methods

List of patient groups

In the absence of a single national list of Canadian patient groups, on April 22-23, 2019 we searched the websites of all provincial and territorial drug plans to see if they had a list of patient groups that provided input to their decision-making processes. Only Ontario and British Columbia (BC) had such lists: BC Pharmacare registers groups that may provide public input into its drug coverage review process (121 groups) [7] and the Ontario Ministry of Health and Long-Term Care registers advocacy groups eligible to provide patient evidence submissions on drugs listed on the drug review schedule of the Ontario Public Drug Program (102 groups).[8] Additional sources for patient groups were those registered with the pan-Canadian Oncology Drug Review, (44 groups) [9] and the membership of the Best Medicines

Coalition, an alliance of patient advocates with a shared goal of gaining access to "safe and effective medicines that improve patient outcomes" (27 groups).[10]

We removed duplicates from our list and limited the groups to those that met the following criteria: Canadian, national in nature, self-identified as patient groups and had an active website that we could search for information.

Contacting patient groups

In addition to gathering information on patient groups' websites, we contacted each patient group's communication contact or equivalent by email in the week of July 13, 2020 to ensure that our data collection would not miss any publicly available, relevant documents. (Supplementary File 1 provides a generic version of the email which was modified for each individual group.) The nature of the study was explained including that we were collecting only publicly available information, that while groups would be identified no individuals in those groups would be named and that all the information we collected would be placed in a publicly available website. In the email, we asked for documents that would help us determine how transparent groups are with respect to their relationship with donors: 1) the organization's criteria for accepting funding; 2) the organization's position on how funds from acceptable sources are used; 3) the organization's financial affiliations and donors, the sum per annum that the organization receives from those donors; and 4) the organization's board membership including the names of the board members, employment information, and whether there are any current or former pharmaceutical industry employees on the board. (Revenue Canada does not require registered charitable organizations to submit audited financial statements, but organizations need to file annual reports that include basic financial information along with a list of directors. These statements do not include the names of individual donors and the amount that they donated nor any background information about the directors.) If no response was received, a reminder email was sent out after 7 weeks. Any documents received were stored in a password protected web-based site.

Construction of data extraction form

We initially carried out a focused literature search to identify research on patient group relationships with industry and COI disclosure and developed a preliminary data collection tool.[11-16] This preliminary tool was then sent to 5 experts in the area (LB, AFB, QG, BJM, LP) and modified based on their comments. The resulting tool was then pilot tested by two authors (JL and AS) who independently abstracted information from 5 Australian patient groups. Results were compared and the tool was modified based on this pilot test. It was then converted into REDCap, a data management tool. The same two authors carried out a second pilot test, using 5 Canadian patient groups and modified the tool one final time.

Data extraction

Using the final version of our REDCap tool, between September 2020 and April 2021 we extracted the following information, if it was available, from the group's website: total annual revenue for the latest fiscal year, year revenue was reported, revenue from pharmaceutical company donors, purpose of the donation, presence of donors' logos on the website and hyperlinks to donors' websites, previous and current employment information about board members and staff, external audits about the group's finances, and whether the group endorses products made by donors (Supplementary File 2).

We also examined websites for the presence of COI policies, codes and guidelines (collectively referred to as policies) that covered one or more of the following a priori defined content areas: board and/or advisory board, acceptance of donations and revenue generation, independence of decision-making, endorsements, assistance to and/or interactions between patient members from a donor or another company/person acting on behalf of a donor and audits/monitoring/compliance. Any policy potentially related to relationships with industry donors was collected and assessed for relevancy; only those covering one or more of the issues listed above were included in the analysis. If a policy was available, we recorded whether specific information was present or absent, however, we did not evaluate the strength of the policy (Supplementary File 3). In order to be eligible, the document had to be explicitly identified as a policy. By-laws and legal documents were excluded.

All four authors independently extracted information from the websites of 23-24 different patient groups and each author did a secondary review of 5 additional websites. Groups of two authors compared their evaluations for these 5 to ensure uniform extraction and then compared information in extraction forms for 1 out of every 5 of the remaining groups. Differences were resolved by consensus and if consensus could not be reached a third author made the final decision.

Best Medicines Coalition (BMC) has a Code of Conduct Regarding Funding [17] that applies to all its member groups. We considered the code applicable to a group if it was posted on the group's website or if the website had a hyperlink to the code. Similarly, if groups hyperlinked to other codes or policies, such as the Canadian Consensus Framework for Ethical Collaboration [18] we also considered those codes or policies as applicable to the group. If a group indicated on its website that a code or policy was available on request, but the policy was unavailable otherwise, we did not include it.

Data analysis

We only report descriptive data in the form of the number and percent of groups with the different types of information on their websites and with policies covering the different aspects of relationships with pharmaceutical companies. For the purpose of reporting our results, groups were anonymized but the names of the groups, not linked to their responses, are available in Supplementary File 4.

Ethics statement

The Human Participants Review Committee of the York University Office of Research Ethics assessed our ethics application and replied that an approval certificate was not required as this research was not subject to review.

Patient and public involvement

Patient groups were contacted for information about their relationships with pharmaceutical companies. There was no other patient or public involvement in this study.

Results

We initially identified 100 different groups that met our inclusion criteria and contacted all 100 by email, but during the course of the study two groups merged and the websites of two other groups disappeared leaving a sample of 97 groups (Figure 1) (Supplementary File 4). Eight groups provided policies in response to our request, all of which were publicly available on their websites except one that was publicly available on request from the group. Fifteen groups responded but did not provide policies, an additional 14 groups specifically stated that they did not want to be involved in the project and 60 groups did not reply.

Between the material that patient groups sent us directly and those we sourced from the groups' websites, we collected 846 pieces of material (financial statements, documents, policies, codes, reports) for analysis, with a median of 6.0 pieces per group (interquartile (IQR) range 2.5, 10.5) (Supplementary File 4).

Information on patient group websites

Fifty-three (54.6%) of 97 groups reported donations from pharmaceutical companies but only 1 (1.0%) gave the total amount - $516,000 (1.0%) out of total revenue of $54.1 million that it received from pharmaceutical companies. None of the other groups reported the percent of its total revenue from companies. Nine (9.3%) groups gave dollar ranges for donations, 17 (17.5%) gave the total value of donations from all sources but none gave the exact amount of any single donation and 8 (8.2%) broke donations down into separate categories (for example, corporate, foundations, individuals). Four (4.2%) disclosed the purpose of donations.

Forty-eight (49.5%) groups displayed the logos of their donors on the groups' websites, including 37 (38.1%) that showed the logos of pharmaceutical companies. Thirty-one (64.6% of those displaying logos) provided a hyperlink to their donors' websites (Table 1), including 20 (54.1%) groups that had hyperlinks to pharmaceutical company websites. Sixty-seven (69.1%) of groups did not endorse any products, while 30 (30.9%) endorsed specific products made by their donors, for example by expressing approval for their funding or availability, including 25 (25.8%) groups that endorsed pharmaceutical products produced by brand-name companies that had donated to the groups.

Table 1: Number of patient groups (percent) reporting information about revenue and donations

Total annual revenue	Donations in general				Pharmaceutical company donations			Donor information on website			
	Dollar range of individual donations	Total value of donations	Breakdown of total donations by source (e.g., corporate, individuals)	Purpose of donations	Number of groups reporting donations	Value of donations from pharmaceutical companies	Percent of total revenue from pharmaceutical company donations*	Donor logo		Hyperlink to donor website	
42 (43.3)	9 (9.3)	17 (17.5)	8 (8.2)	4 (4.2)	53 (54.6)	1 (1.0)	1 (1.0)	**Any donor**	**Pharmaceutical company donor**	**Any donor**	**Pharmaceutical company donor**
								48 (49.5)	37 (38.1)	31 (32.0)	20 (20.6)

*Calculated from information on website

Fifty-three (54.6%) groups had a brief synopsis about their board members but only 6 (6.2%) had detailed past employment histories. Seventeen groups (17.5%) disclosed that board members had current or past employment with a pharmaceutical company. Four (4.1%) groups gave pharmaceutical industry employment histories about their staff (Table 2).

Table 2: Number of patient groups (percent) reporting employment information about board members and staff

Board members					**Staff**	
General employment history			**Pharmaceutical industry employment history disclosed**		**Pharmaceutical employment history disclosed**	
None*	**Brief synopsis**	**Detailed†**	**No**	**Yes**	**No***	**Yes**
38 (39.2)	53 (54.6)	6 (6.2)	80 (82.5)	17 (17.5)	93 (95.9)	4 (4.1)

*Board members (staff) not named or no information about employment history
†For example, year ranges with position, job title, employer

No groups had external (or internal) audited reports about their activities, for example, whether they followed their policies or how their donations were used.

Patient group policies

Twenty-six (26.8%) groups had policies that dealt with relations with pharmaceutical companies (Table 3). None of the members of BMC referred to the BMC Code on their website. There were policies on 7 separate topics related to patient group-company relationships: composition and authority of the board, acceptance of donations and revenue generation, independence of decision-making, endorsements, material assistance to patient group members by a donor, other interactions between patient members of the group and a donor, and independent monitoring of activities and compliance with policies. The topic that was most frequently mentioned was acceptance of donations and revenue generation (16 (16.5%) groups) and the least covered topic was independent audits of finances, monitoring of activities and compliance with policies audits (5 (5.2%) groups). The median number of topics covered per group with policies was 4 (IQR 2, 6).

Table 3: Topics related to relationships with pharmaceutical companies covered by patient group policies

Patient group number*	Topic of policy						
	Composition and authority of board	Acceptance of donations and revenue generation	Independence of decision-making	Endorsements	Material assistance to patient group members by a donor	Other interactions between patient members of the group and a donor	Independent monitoring of activities and compliance with policies
1	x	x	x	x	x		
2	x	x	x	x	x	x	x
3	x	x	x	x	x		
4	x	x	x	x	x	x	x
5							
6							
7							
8		x		x		x	x
9		x	x	x			
10		x	x	x			
11		x	x	x			
12	x	x	x	x	x		
13		x	x	x	x	x	
14	x	x					
15		x	x	x			
16	x	x	x	x		x	
17							
18	x	x	x	x	x	x	x
19				x			
20							

21	x						
22	x	x			x		
23			x				
24						x	
25		x		x			x
26	x						
Total	11	16	13	15	8	7	5

*Patient groups have been anonymized

Table 4 provides details about how many groups regulated individual aspects of each of the 7 topics referred to above. Neither of the three groups that have policies covering employment of board members required their current or previous employment to be made public on the group's website. One group prohibited people who currently or previously worked for any donor from being on the board, while 2 allowed this.

Table 4: Number of patient groups with policies covering different topics of relationships with pharmaceutical companies

Particular topic of relationship covered by policy	Number of groups with policy
Composition and authority of board	
Current or previous employment of board members should be made public	0
Board membership allowed for people who currently or previously worked for a donor	3 (1 no, 2 yes)
Acceptance of donations and revenue generation	
Source of donations should be made public	6 (yes)
Amount of donations should be made public	0
Purpose of donations should be made public	0
Donations can be tied to donor-initiated project	10 (5 yes, 5 no)
Donations require approval by board or executive director	11 (5 yes, 6 no)
Independence of decision-making	
Group has total independence in decision-making	13 (yes)
Donors allowed to directly organize seminars, lectures, projects or meetings	2 (1 yes, 1 no)
Endorsements	
Names of donors and/or their logos can be displayed on group's website except to identify donor and amount of money donated	8 (4 yes, 4 no)
Endorsements of products and/or companies allowed	14 (3 yes, 11 no)
Hyperlinks to donors' websites allowed	4 (yes)
Patient group can directly or indirectly cooperate with companies in lobbying, testifying, addressing legislators, regulators, or policymakers, writing articles or policy briefs, etc.	7 (4 yes, 3 no)
Material assistance to patient group members by a donor	
Donor allowed to directly pay for conference travel and accommodation for group representatives and participants	1 (yes)
Donor allowed to directly pay staff salary or provide staff support for group	2 (1 yes, 1 no)
Other interactions between patient members of group and donor	
Donor allowed to provide information to patient members of group about products donor makes	4 (2 yes, 2 no)
Donor allowed to access membership data or membership lists	2 (1 yes, 1 no)
Donor allowed to provide patient group members with advocacy materials	3 (1 yes, 2 no)

Donor allowed to provide gifts of noneducational value to patient group members	1 (no)
Donor allowed to provide information to patient group members about policies or positions adopted or suggested by the donor	1 (no)
Independent monitoring of activities and compliance with policies	
Monitoring of compliance with group's policies	3 (no)
Actions if group is not compliant with its policies	2 (1 yes, 1 no)
Audit of what activities donor money has been spent on	2 (1 yes, 1 no)
Public availability of results of audits, monitoring, compliance	2 (no)

Sixteen (16.5%) groups had policies about all donations, but only 6 (6.2%) of these policies stated that the source of donations had to be made public and no group required public reporting of the amount of donations. Similarly, no group required that the purpose of donations be publicly disclosed. Five (5.2%) groups did not allow donations to be tied to a donor-initiated project and 5 (5.2%) groups did allow this type of donation.

Thirteen (13.4%) groups had policies that covered group independence and all stated that the group had total independence in decision-making. However, only 2 (2.1%) groups dealt with whether donors are allowed to directly organize seminars, lectures, projects or meetings (1 permitted such activities, the other did not).

The policies of 15 (15.5%) groups covered endorsements and the display of donors' names and logos. Four (4.1%) groups did allow and 4 (4.1%) did not allow the name and/or logo of donors to be listed on their websites except to identify the donor and the amount of money that the donor gave. Eleven (11.3%) groups did not allow endorsements of products and/or companies while 3 (3.1%) did. Four (4.1%) groups allowed hyperlinks to donors' websites.

Eight (8.2%) groups had policies that regulated material assistance to patient group members by a donor and 6 (6.2%) groups had policies on other types of interactions between patient members of the group and donor. In the case of the former, 1 (1.0%) group allowed donors to directly pay for conference travel and accommodation for group representatives and participants and 2 (2.1%) groups had policies covering whether donors were allowed to directly pay staff salary or provide staff support for the group (1 = yes, 1 = no). In the case of the latter, 2 (2.1%) groups did, and 2 (2.1%) groups did not allow donors to provide information to patient members of the group about products the donor manufactures and 2 (2.1%) groups controlled whether donors were allowed to access membership data or membership lists (1 = yes, 1 = no).

Three (3.1%) groups mentioned that there was no monitoring of compliance with the group's policies, while 2 (2.1%) groups had policies about actions that could be taken if the group was not compliant with its policies (1 = action would be taken, 1 = no action would be taken). Two (2.1%) groups mentioned whether there was an audit of the activities on which donor money had been spent (1 = audit, 1 = no audit).

Discussion

In general, we found that pharmaceutical industry funding of the included patient groups was frequent, with over half (54.6%) indicating that they had received donations from companies in this sector. Despite this, relatively little information was provided on patient group websites about their relationships with pharmaceutical companies. Only a single group reported the total amount of revenue from this source, none gave the exact amount from individual donors, and only 8 groups stated the purpose of the donations. The employment history of people on patient group boards was typically not given, making it impossible to determine if they had a past or present history of working for a pharmaceutical company. Similarly, only 4 groups provided employment histories of their staff. On-the-other hand, some practices were common. Almost 40% of the groups 37 (out of 97) displayed the logos of pharmaceutical company donors on their websites including 20 groups that hyperlinked to pharmaceutical company websites.

We also observed that only 26 out of 97 groups had policies that directly dealt with their relationships with pharmaceutical companies. Even when groups did have such policies, those policies often did not cover key aspects of these relationships. For example, only half of the 26 policies stated that the group had complete independence of decision-making and no group's policy covered current or previous employment of board members. Worryingly, an even smaller minority of groups had policies that dealt with topics such as material assistance to patient group members by a donor and having independent monitoring of activities and compliance with policies.

On-the-one hand, our results show that in the absence of policies most groups do not make key information public about relationships with pharmaceutical companies including the purpose of donations that they received. But our findings also suggest that, in practice, some groups may follow unwritten policies. For example, although product endorsements were only dealt with in 14 policies, 67 groups did not have any product endorsements on their websites.

With some variations, our findings are broadly in line with studies from other countries that analyzed information and policies on patient group websites. Ball and colleagues studied patient organizations in Australia, Canada, South Africa, the United Kingdom and the United States (US) and found that corporate donations were acknowledged in only 7 out of 37 annual reports and, similar to our results where 1 out of 97 groups gave enough information to show the proportion of funding from pharmaceutical companies, none of the groups in the Ball et al paper gave this information.[15] Thirty-six (52.9%) out of 68 Australian groups that received industry funding disclosed the use that they made of the money,[19] whereas only 4.2% did so in our study. Three out of 157 Italian patient and consumer groups (6%) reported the amount of funding from pharmaceutical companies, 25 (54%) reported the activities funded but none reported the proportion of income derived from drug companies.[20] None of 24 American dermatology organizations reported the exact amount or use of donations.[12] A systematic review that included 5 studies that examined patient groups' websites found that a median of 75% reported receiving funding from pharmaceutical companies [21] compared to 54.6% in our study. Another 9 studies in the review reported that between 0% and 50% of groups disclosed the amount of funding that they received, between 0% and 6% of groups reported the proportion of their budget coming from company funding, and a median of 22% of organizations reported on how the funding was used.

In the international study of patient groups by Ball and colleagues, one third of websites showed one or more company logos and/or had links to websites of pharmaceutical companies [15] compared to 20.5% in our study. Forty-nine out of 133 Australian groups had company logos, web links or advertisements on their websites and 6 had board members that were currently or previously employed by pharmaceutical companies.[19] Among members of the US National Health Council,[22] 24 of 47 patient advocacy organizations had policies that addressed institutional conflict of interest [23] while less than one-fifth of Australian groups had publicly available policies on corporate sponsorship.[19] In a systematic review, the prevalence estimates of organizational policies that govern corporate sponsorship ranged from 2% to 64%.[24] In our case, 16.5% of groups had policies about donations and revenue generation.

Limitations

As Canada has no centralized database of industry funding of patient groups, we relied on information reported on groups' websites about their pharmaceutical industry funding and we had no way of verifying the accuracy of the information. We identified patient groups to include in our study based primarily on whether they provided advice to government institutions. However, this may constitute a biased sample of Canadian patient groups and other groups may differ in terms of which information is made public and the extent of their policies. We only looked at whether policies existed for certain topics and did not evaluate the strength of the policies. Other documents may have covered areas that were of interest to us, but if these documents were not identified as policies we may have missed them. Finally, we asked groups about their policies in 2019 and started collection information from their websites in September 2020. It is possible that some groups subsequently updated their websites or policies, although we verified that the information was current to April 2021.

Conclusion

In the past few decades, patient groups in Canada have evolved rapidly to play a consequential policy role in agencies like Health Canada, provincial and territorial health ministries, Common Drug Review, pan-Canadian Oncology Drug Review, Quebec's Institut national d'excellence en santé et en services sociaux, and other provincial and territorial drug programs. Government organizations have also increasingly made it a practice to include patient and public representation in decision-making. By speaking from patients' experience, groups can add to our understanding of patients' needs and suggest useful system changes, including in drug policy. However, other than the law governing charitable organizations, which makes few requirements for public reporting of corporate donations, patient organizations are not answerable to any national regulatory or governing body. It is left to the groups themselves to decide what information they will reveal on their websites about corporate donations and whether they develop policies to guide their interactions with their donors. Our study found that most groups had no explicit policies guiding these interactions and that in general very limited information is disclosed.

The inconsistencies we discovered are not surprising given the absence of external requirements and the varied histories, mandates and resources of the groups themselves. Each group exists to serve its particular patient constituency, not the public at large, and the absence of requirements for public accountability is not the fault of the organizations. A few groups have taken the initiative to adopt strong transparency policies in their relations with the pharmaceutical industry and we applaud the example they set.

Patient groups have an important role to play in the health care system as a voice for their membership. However, in order to truly act as an independent voice for patient and not for their pharmaceutical industry sponsors, groups need to adopt a much more transparent approach to reporting on their relationships with companies and to develop policies that clearly define the extent of those relationships. If they are unable or unwilling to take this step, then federal and provincial governments should mandate the disclosure of industry funding information by groups.

Figure 1 caption:

Selection of patient groups

Acknowledgements

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Contributorship statement

AS came up with the idea for this study. JL and AS developed the data extraction tool. JL, AS, SB and DG gathered and analyzed the data. JL wrote the first draft of the manuscript. AS, SB and DG revised the manuscript. JL, AS, SB, DG approved the final version of the manuscript.

Competing interests

In 2017-2020, Joel Lexchin received payments for being on a panel at the American Diabetes Association, for talks at the Toronto Reference Library, for writing a brief in an action for side effects of a drug for Michael F. Smith, Lawyer and a second brief on the role of promotion in generating prescriptions for Goodmans LLP and from the Canadian Institutes of Health Research for presenting at a workshop on conflict-of-interest in clinical practice guidelines. He is currently a member of research groups that are receiving money from the Canadian Institutes of Health Research and the Australian National Health and Medical Research Council. He is a member of the Foundation Board of Health Action International and the Board of Canadian Doctors for Medicare. He receives royalties from University of Toronto Press and James Lorimer & Co. Ltd. for books he has written.

Sharon Batt has received payment for commissioned briefs related to patient advocacy and industry funding from the National Federation of Nurses Unions and the Canadian Health Coalition.

Devorah Goldberg and Adrienne Shnier have no competing interests to declare.

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Data sharing statement

The raw data used for analysis of information on patient groups' websites and their policies is available on request.

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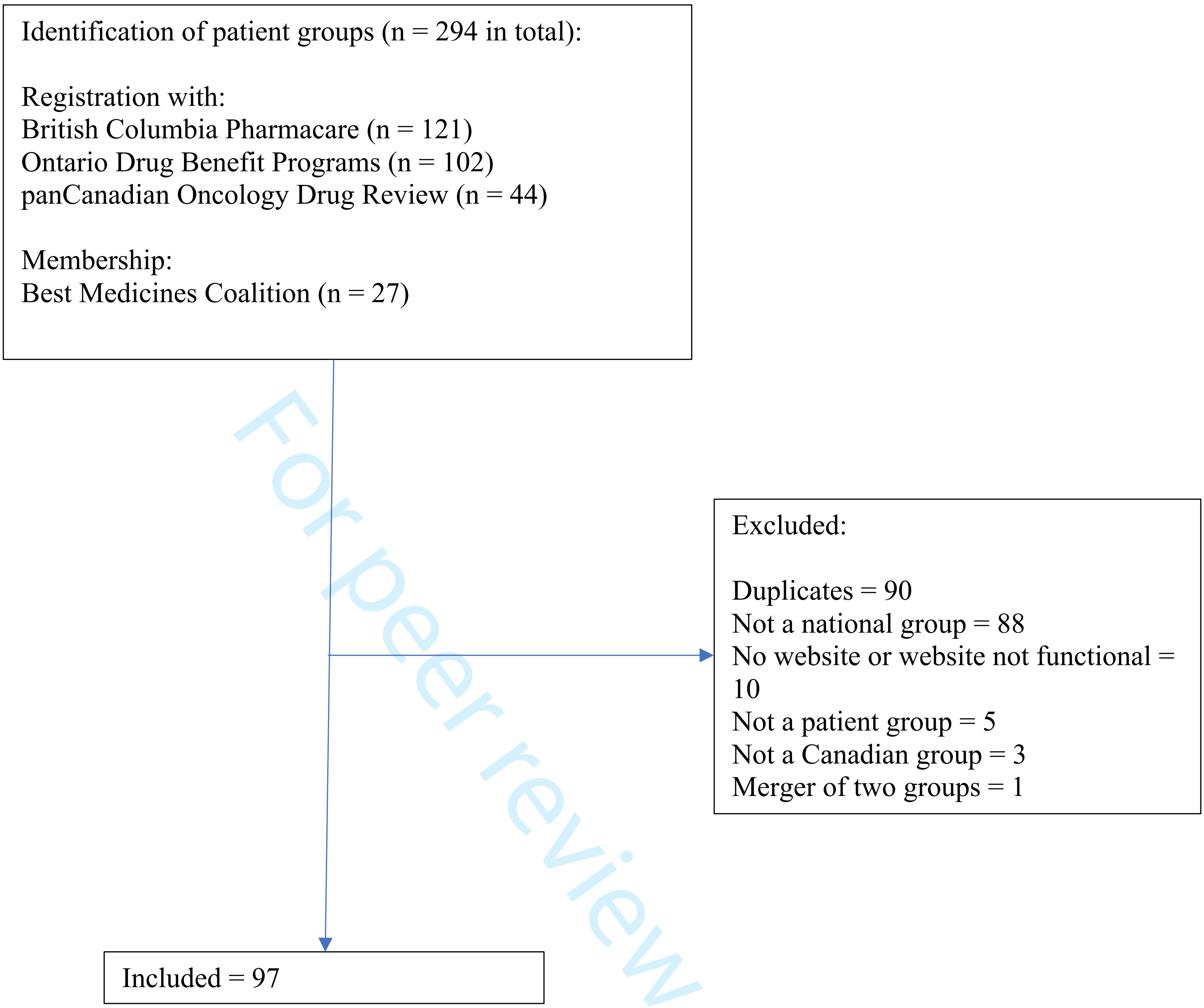

Identification of patient groups (n = 294 in total):
Registration with:
British Columbia Pharmacare (n = 121)
Ontario Drug Benefit Programs (n = 102)
panCanadian Oncology Drug Review (n = 44)
Membership:
Best Medicines Coalition (n = 27)
Excluded:
Duplicates = 90
Not a national group = 88
No website or website not functional = 10
Not a patient group = 5
Not a Canadian group = 3
Merger of two groups = 1
Included = 97

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.

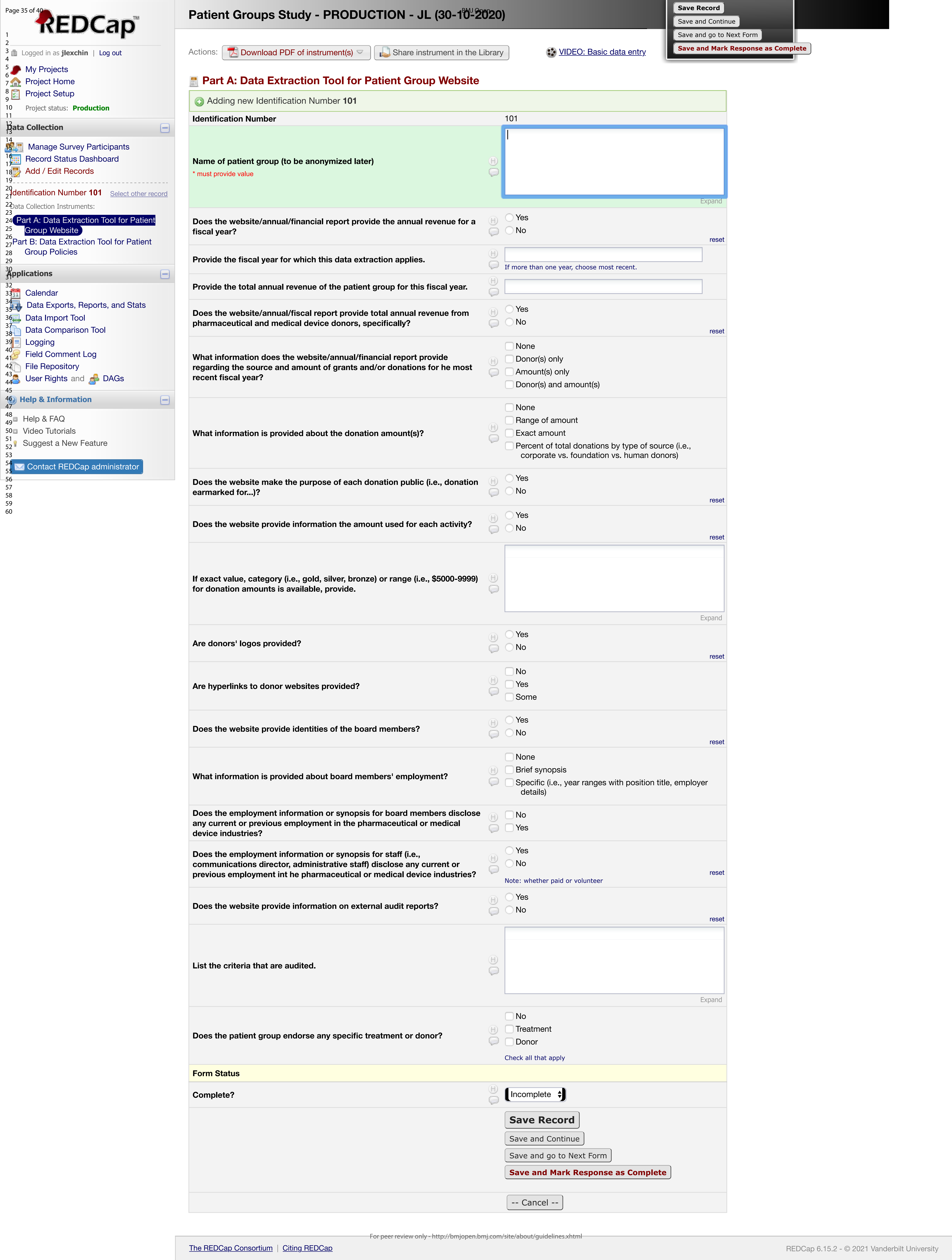
There are no potential risks to participating in this study.

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 Sub-committee and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines.

Sincerely,

Adrienne Shnier Ph.D., J.D.	Joel Lexchin MD
Adjunct Professor, School of Health Policy and Management	Professor, School of Health Policy and Management
York University	York University
Email: ashnier@yorku.ca	E mail: jlexchin@yorku.ca



Patient Groups Study - PRODUCTION - JL (30-10-2020)

Part A: Data Extraction Tool for Patient Group Website

Adding new Identification Number **101**

Identification Number	101
Name of patient group (to be anonymized later) * must provide value	
Does the website/annual/financial report provide the annual revenue for a fiscal year?	○ Yes ○ No
Provide the fiscal year for which this data extraction applies.	If more than one year, choose most recent.
Provide the total annual revenue of the patient group for this fiscal year.	
Does the website/annual/fiscal report provide total annual revenue from pharmaceutical and medical device donors, specifically?	○ Yes ○ No
What information does the website/annual/financial report provide regarding the source and amount of grants and/or donations for he most recent fiscal year?	☐ None ☐ Donor(s) only ☐ Amount(s) only ☐ Donor(s) and amount(s)
What information is provided about the donation amount(s)?	☐ None ☐ Range of amount ☐ Exact amount ☐ Percent of total donations by type of source (i.e., corporate vs. foundation vs. human donors)
Does the website make the purpose of each donation public (i.e., donation earmarked for...)?	○ Yes ○ No
Does the website provide information the amount used for each activity?	○ Yes ○ No
If exact value, category (i.e., gold, silver, bronze) or range (i.e., $5000-9999) for donation amounts is available, provide.	
Are donors' logos provided?	○ Yes ○ No
Are hyperlinks to donor websites provided?	☐ No ☐ Yes ☐ Some
Does the website provide identities of the board members?	○ Yes ○ No
What information is provided about board members' employment?	☐ None ☐ Brief synopsis ☐ Specific (i.e., year ranges with position title, employer details)
Does the employment information or synopsis for board members disclose any current or previous employment in the pharmaceutical or medical device industries?	☐ No ☐ Yes
Does the employment information or synopsis for staff (i.e., communications director, administrative staff) disclose any current or previous employment int he pharmaceutical or medical device industries?	○ Yes ○ No Note: whether paid or volunteer
Does the website provide information on external audit reports?	○ Yes ○ No
List the criteria that are audited.	
Does the patient group endorse any specific treatment or donor?	☐ No ☐ Treatment ☐ Donor Check all that apply
Form Status	
Complete?	Incomplete

REDCap

Logged in as **jlexchin** | Log out

My Projects
Project Home
Project Setup
Project status: **Production**

Data Collection

Manage Survey Participants
Record Status Dashboard
Add / Edit Records

Identification Number **101** Select other record

Data Collection Instruments:
Part A: Data Extraction Tool for Patient Group Website
Part B: Data Extraction Tool for Patient Group Policies

Applications

Calendar
Data Exports, Reports, and Stats
Data Import Tool
Data Comparison Tool
Logging
Field Comment Log
File Repository
User Rights and DAGs

Help & Information

Help & FAQ
Video Tutorials
Suggest a New Feature

Contact REDCap administrator

Patient Groups Study - PRODUCTION - JL (30-10-2020)

Save Record
Save and Continue
Save and Mark Response as Complete

Actions: Download PDF of instrument(s) | Share instrument in the Library | VIDEO: Basic data entry

Part B: Data Extraction Tool for Patient Group Policies

Adding new Identification Number **101**

Identification Number	101
Patient group name (to be anonymized later)	
Does the patient group have a relevant publicly available policy?	● Yes ○ No reset Policy document must be clearly identifiable as a policy/guidance document.
Do/es the policy document/s cover any of the following content areas?	☑ Board and/or advisory board ☑ Acceptance of donations and revenue generation ☑ Independence of decision-making ☑ Endorsements ☑ Assistance to patient members from a donor, or another company/person acting on behalf of a donor ☑ Interaction between donor, or another company/person acting on behalf of a donor, and patient members ☑ Audits, monitoring, and compliance ☑ None of the above ☑ Other Choose all that apply. None of the above = Policy available, but does not address any of our categories.
Does the organization's policy state that the names of board members must be provided on its website?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow people who currently work for a donor, or who have a financial relationship with a donor, to participate on an advisory board?	☐ No ☐ Yes ☐ No policy
Does the organization's policy state that current and/or previous employment information for board members must be disclosed on its website?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow people who previously worked for, or currently work for, or have a financial relationship with a donor, to participate on the executive body of the board of the organization?	☐ No ☐ Yes ☐ No policy
Does the organization's policy require the board and/or executive director to approve donations prior to receipt?	☐ No ☐ Yes ☐ No policy
Does the organization's policy provide any other regulation of board membership?	Expand
Does the organization's policy state that the source of donations and amount must be disclosed publicly?	☐ No ☐ Yes, source ☐ Yes, amount ☐ Yes, source and amount ☐ No policy
Does the organization's policy allow for the acceptance of grant or donation money that is contingent on a donor-initiated project?	☐ No ☐ Yes ☐ No policy
Does the organization's policy permit the acceptance of grants from only particular donors?	☐ No ☐ Yes ☐ No policy
Does the organization's policy state that the purpose of accepted donations must be publicly disclosed?	☐ No ☐ Yes ☐ No policy
Does the organization's policy permit accepting money from exclusively a single donor?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow only a fixed amount of its annual revenue to be provided by a single donor?	☐ No ☐ Yes ☐ No policy
Does the organization's policy set a fixed limit on the percentage of its annual revenue that it will accept from donors in total?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow for "sponsorship packages", i.e., what benefits donors get form donations of a certain amount (e.g., exhibit space, company's name on all room keys, etc.).	☐ No ☐ Yes ☐ No policy
Does the organization's policy state that the organization has total independence in its decision making?	☐ No ☐ Yes ☐ No policy
Does the organization's policy state that the patient group retains final and complete control over all decisions it makes, all materials, and pronouncements that carry its name?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow for the name of any donor to be listed on its website under any circumstances, except to identify the name and/or logo of the donor and the amount of money received, i.e., for an endorsement?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow for the endorsement of any specific treatment or any specific donor?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow for a hyperlink to be provided to a donor's website?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow for the patient group to directly or indirectly cooperate with companies in lobbying, testifying, addressing legislators, regulators, or policymakers, writing articles or policy briefs, etc. (e.g., submit its own letter and support donor's position)?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to directly organize seminars, lectures, projects, or meetings?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to directly provide funding for seminars, lectures, projects, or meetings?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to directly contribute to printing costs?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to directly plan/arrange recreational services, lodging or travel for representative of the organization or participants?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to directly pay for conference travel and accommodation for organization representatives or participants?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to directly sponsor research grants, study fellowships, internships, or other opportunities administered by the organization for people in the field?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to provide donations in kind, e.g., facilities, administration, training materials, books for libraries, website design?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to directly pay staff salaries or provide staff support?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow for any other assistance from donors or other companies acting on behalf of donors?	Expand
Does the organization's policy allow donors to provide information to patient group members about products that the donor makes?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to provide gifts of educational value to patient group members (e.g., webinars, books, brochures)?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow for donors to provide gifts of non-educational value to patient group members?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to provide patient group members with advocacy materials?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to provide a nurse/social worker/etc. to assist patient group members with treatment?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to survey patient group members, access membership data or membership lists, or otherwise gain information about members?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to provide expert opinions about products or policies?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to provide opportunities to patient group members to learn about lobbying/advocacy techniques?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to encourage individual lobbying/advocacy activities for patient group members?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to provide information to patient group members about policies or positions adopted or suggested by the donor?	☐ No ☐ Yes ☐ No policy
If the organization's policy regulates any other areas of interaction between patient group members and donors, list.	Expand
Does the organization's policy provide for any independent monitoring of their policies?	☐ No ☐ Yes ☐ No policy
Does the organization's policy provide for an independent audit regarding on what activities donor money has been spent?	☐ No ☐ Yes ☐ No policy
Does the organization's policy provide for publicly available results of the independent monitoring?	☐ No ☐ Yes ☐ No policy
Does the organization's policy provide for what happens if the organization is not compliant with its policies? (i.e., internal review if noncompliance.)	☐ No ☐ Yes ☐ No policy
Form Status	
Complete?	Incomplete
	Save Record Save and Continue Save and Mark Response as Complete
	-- Cancel --

The REDCap Consortium | Citing REDCap

Supplementary File 4: Names of patient groups, websites and

	Name of group	Website	Notes	Number of pieces of information analyzed
1	AboutFace Craniofacial Family Society	www.aboutface.ca		3
2	Advocacy for Canadian Childhood Oncology Research Network	http://www.curesforourkids.com		4
3	aHUS Canada/SHUa	www.ahuscanada.org		8
4	ALS Society of Canada	https://www.als.ca		8
5	Aplastic Anemia and Myelodysplasia Association of Canada	www.aamac.ca		3
6	Arthritis Consumer	www.jointhealth.org		15
7	Asthma Canada	https://asthma.ca		22
8	Best Medicines Coalition	https://bestmedicinescoalition.org		10
9	Bladder Cancer Canada	https://bladdercancercanada.org/en/		8
10	Brain Tumour Foundation of Canada	https://www.braintumour.ca		4
11	Canadian Arthritis Patient Alliance	www.arthritispatient.ca		24
12	Canadian Breast Cancer Network	https://www.cbcn.ca/en/		10
13	Canadian Cancer	www.cancer.ca		8
14	Canadian Cancer Survivor Network	www.survivornet.ca		7
15	Canadian Council of the	www.ccbnational.net		7
16	Canadian Digestive Health Foundation	https://cdhf.ca		2
17	Canadian Epilepsy Alliance	http://www.canadianepilepsyalliance.org		3
18	Canadian Hemophilia	https://www.hemophi		8
19	Canadian Hospice Palliative Care	http://www.chpca.net		10
20	Canadian Liver	www.liver.ca		7
21	Canadian Mental Health Association	https://cmha.ca		3
22	Canadian Mesothelioma Foundation	http://cmfonline.org		1

23	Canadian MPN Network	http://canadianmpnnetwork.ca		2
24	Canadian Organization for Rare Disorders	www.raredisorders.ca		4
25	Canadian Pain Coalition	https://www.facebook.com/CanadianPai		0
26	Canadian PBC Society	www.pbc-society.ca		1
27	Canadian Pemphigus and Pemphigoid	http://pemphigus.ca		1
28	Canadian Pituitary Patient Network	https://canadianpituitary.org		0
29	Canadian PKU & Allied Disorders Inc.	www.canpku.org		6
30	Canadian Psoriasis Network	www.canadianpsoriasisnetwork.com		1
31	Canadian Pulmonary Fibrosis Foundation	www.cpff.ca		2
32	Canadian Skin Patient	www.canadianskin.ca		2
33	Canadian Society for Mucopolysaccharide & Related Diseases Inc.	www.mpssociety.ca		1
34	Canadian Society of Intestinal Research	https://www.badgut.org		1
35	Canadian Spondylitis	http://www.spondyliti		1
36	Canadian Treatment Action Council	www.ctac.ca	Website broken as of March 10, 2021	Not applicable
37	Cancer Advocacy Coalition of Canada	http://www.canceradvocacy.ca	Name now changed to: Cancer Survivors	1
38	Carcinoid-NeuroEndocrine	www.cnetscanada.org		1
39	Centre for ADHD Awareness, Canada	www.caddac.ca		1
40	Chronic Lymphocytic Leukemia Patient Advocacy Group (CLL	www.cllpag.ca	Name now changed to: CLL Canada	3
41	Chronic Myelogenous Leukemia Society of Canada	http://cmlsociety.org	Name now changed to: CML Society	8
42	Chronic Pain Association of Canada	www.chronicpaincanada.com		1

43	CNIB (Canadian National Institute for the Blind)	www.cnib.ca		8
44	Colorectal Cancer Canada	https://www.colorectalcancercanada.com		11
45	Consumer Advocare Network	http://survivornet.ca/en/partners/consumer_advocare_network	Website broken as of March 10, 2021	Not applicable
46	COPD Canada	www.copdcanada.in		3
47	COPD Canada Patient	www.copdcanada.ca		0
48	Craig's Cause Pancreatic Cancer Society	http://www.craigscause.ca		1
49	Crohn's and Colitis	www.crohnsandcolitis		4
50	Cystic Fibrosis Canada	www.cysticfibrosis.ca		5
51	Diabetes Canada (Canadian Diabetes	www.diabetes.ca		24
52	Eczema Society of	https://eczemahelp.ca		19
53	FH Canada Patient Network	https://thefhfoundation.org/global-fh-canada	Name now changed to: FH Foundation	18
54	Food Allergy Canada (Anaphylaxis Canada)	https://foodallergycanada.ca		14
55	Foundation Fighting Blindness	https://ffb.ca	New website: https://www.fightingblindness.org	18
56	Foundation for Prader-Willi Research Canada (FPWR Canada)	https://www.fpwr.ca		2
57	GIST Sarcoma Life Raft Group Canada	https://liferaftgroup.ca/welcome/		4
58	HeartLife Foundation	www.heartlife.ca		1
59	Hep C Awareness.com	www.hepcawareness.		0
60	HS Aware - Now appears to be HS	www.hsaware.com	New website: Hsaware.ca	3
61	Huntington Society of Canada	https://www.huntingtonsociety.ca		24
62	Hypertension Canada	https://hypertension.ca/about-us/		7
63	Kidney Cancer Canada	https://www.kidneycancercanada.ca		13
64	Leukemia & Lymphoma Society of Canada	https://www.llscanada.org		9

65	Lung Cancer Canada	http://www.lungcancercanada.ca		6
66	Lupus Canada	www.lupuscanada.org		9
67	Lymphoma Canada	https://www.lympho		22
68	Mastocytosis Society Canada	https://www.mastocytosis.ca/en/		17
69	Melanoma Network of Canada	https://www.melanomanetwork.ca		35
70	Millions Missing Canada	https://www.millionsmissingcanada.ca		5
71	MS Society of Canada	www.mssociety.ca		74
72	Myeloma Canada	https://www.myelom		38
73	National Gaucher Foundation of Canada	www.gauchercanada.ca		10
74	Neuroblastoma Canada	http://neuroblastoma.		4
75	Osteoporosis Canada	www.osteoporosis.ca		19
76	Ovarian Cancer Canada	https://ovariancanada		21
77	Pancreatic Cancer Canada	http://www.pancreaticcancercanada.ca		20
78	Parkinson Canada	https://www.parkinso		18
79	Patient Commando	www.patientcomman		8
80	People in Pain Network	www.pipain.com		8
81	Polycystic Kidney Disease (PKD) Foundation of Canada	www.endpkd.ca	Name now changed to: PKD Foundation of Canada	5
82	Prostate Cancer Canada	http://www.prostatecancer.ca	Now part of Canadian Cancer Society as of February 1, 2020	Not applicable
83	Pulmonary Hypertension	www.phacanada.ca		15
84	Rethink Breast Cancer	https://rethinkbreastcancer.com		8
85	Robbie's Rainbow	http://robbiesrainbo		6
86	Sarcoma Cancer Foundation of Canada	http://sarcomacancer.ca		3
87	Save Your Skin	www.saveyourskin.ca		4
88	Scleroderma Society of Canada	www.scleroderma.ca	Name now changed to: Scleroderma Canada	5
89	Sjogren's Society of	www.sjogrenscanada.		6

90	Soft Bones Canada	www.softbonescanad		13
91	The Canadian Continence Foundation	www.canadiancontinence.ca		9
92	The Endometriosis Network	https://endometriosisnetwork.com	Name now changed to: The Endometriosis Network Canada	4
93	The Isaac Foundation	https://www.theisaacfoundation.com		0
94	Thyroid Cancer Canada	www.thyroidcancerca		6
95	Tourette Syndrome Foundation of Canada	https://tourette.ca		14
96	Trigeminal Neuralgia Association of Canada	www.tnac.org		1
97	Tuberous Sclerosis Canada Sclerose	https://www.tscanada.ca		7
98	Type 1 Together	www.type1together.c		4
99	Wounds Canada (Canadian Association	https://www.woundscanada.ca		12
100	Young Adult Cancer Canada	https://www.youngadultcancer.ca		10

BMJ Open

A cross-sectional study of national patient groups in Canada to examine their disclosure of relationships with pharmaceutical companies

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2021-055287.R1
Article Type:	Original research
Date Submitted by the Author:	15-Dec-2021
Complete List of Authors:	Lexchin, Joel; York University Faculty of Health, School of Health Policy and Management; University of Toronto Faculty of Medicine, Department of Family and Community Health Batt, Sharon; Dalhousie University, Bioethics Goldberg, Devorah; York University Faculty of Graduate Studies, School of Health Policy and Management Shnier, Adrienne; York University Faculty of Health, School of Health Policy and Management
Primary Subject Heading:	Health policy
Secondary Subject Heading:	Health economics
Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, MEDICAL ETHICS, Health economics < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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For peer review only

A cross-sectional study of national patient groups in Canada to examine their disclosure of relationships with pharmaceutical companies

Joel Lexchin (0000-0001-5120-8029), Sharon Batt (0000-0003-0612-0513), Devorah Goldberg, Adrienne Shnier

Joel Lexchin, professor emeritus, Faculty of Health (School of Health Policy and Management, York University), 4700 Keele St., Toronto, ON, Canada M3J 1P3

Sharon Batt, adjunct professor, Department of Bioethics, Dalhousie University, 5849 University Ave, Room C315, PO Box 15000, Halifax, NS, Canada B3H 4R2

Devorah Goldberg, graduate student, Faculty of Graduate Studies (Graduate Program in Health), York University, 4700 Keele St., Toronto, ON, Canada M3J 1P3

Adrienne Shnier, adjunct professor, Faculty of Health (School of Health Policy and Management, York University), 4700 Keele St., Toronto, ON, Canada M3J 1P3

Correspondence:

Dr. Joel Lexchin
School of Health Policy and Management
York University
4700 Keele St.
Toronto, ON, Canada M3J 1P3
Tel: +416-209-4885
Email: jlexchin@yorku.ca

Structured Summary

Objectives

This study investigates the information and policies that Canadian patient groups post on their publicly available websites about their relationships with pharmaceutical companies.

Design

Cross-sectional study.

Setting

Canadian national patient groups.

Participants

Ninety-seven patient groups with publicly available websites.

Interventions

Each patient group was contacted by email. Information from patient groups' websites was collected about: total annual revenue for the latest fiscal year, year revenue was reported, revenue from pharmaceutical company donors, purpose of the donation, presence of donors' logos on the website and hyperlinks to donors' websites, previous and current employment information about board members and staff, external audits about the group's finances, and whether the group endorses products made by donors. Analysis of publicly available policies looking at: board and/or advisory board, acceptance of donations and revenue generation, independence of decision-making, endorsements, assistance to and/or interactions between patient members from a donor or another company/person acting on behalf of a donor and audits/monitoring/compliance.

Primary and secondary outcome measures

Number of patient groups posting information on their websites about their relationships with pharmaceutical companies; the presence and contents of patient group policies covering different topics about relationships with pharmaceutical companies.

Results

Fifty-three (54.6%) of 97 groups reported donations from pharmaceutical companies. Forty-one (42.3%) groups showed the logos of pharmaceutical companies on their websites and 22 (53.7%) had hyperlinks to pharmaceutical company websites. Twenty-five (25.8%) groups endorsed pharmaceutical products produced by brand-name companies that had donated to the groups. Twenty-six (26.8%) groups had policies that dealt with relations with pharmaceutical companies.

Conclusions

Pharmaceutical industry funding of the included patient groups was frequent. Despite this, relatively little information was provided on patient group websites about their relationships with pharmaceutical companies. Only 26 out of 97 groups had publicly available policies that directly dealt with their relationships with pharmaceutical companies.

Article Summary

Strengths and limitations of this study

- This is the first Canadian study to examine patient groups' disclosure of their relationships with pharmaceutical companies.
- National patient groups were identified from lists of groups registered to comment on national and provincial drug funding decisions.
- A novel data extraction form was developed based on previous surveys and was pilot tested and revised based on comments from experts in the field.
- Our methodology could not distinguish between groups that failed to disclose industry funding and those that received no industry funding.
- Some national patient groups may not have been included because they lacked a website or were not registered to comment on drug funding decisions at the time our list was compiled.

Introduction

Patient groups serve an important function within the healthcare system for their members with a specific condition, providing information, education and support, contact with others facing the same health condition and assistance in navigating the health care system. Within this mandate, they often lobby Health Canada, the federal drug regulator, to approve new drugs and provincial governments for specific products to be funded for their membership. [1 2]

Since the Canadian federal government rolled back funding of patient groups in the mid 1990s [3] groups have sought new sources of revenue. Many patient groups receive money from pharmaceutical companies. This source of revenue has created concerns about a conflict of interest (COI) between corporate sponsors with a vested interest in supporting product sales and the patient groups and the potential for groups to adopt positions that favour their funders. Some groups have lobbied provincial governments to have their sponsors' drugs included on provincial formularies.[4 5] Patient groups are able to make submissions to the Common Drug Review and the pan-Canadian Oncology Drug Review, both part of the Canadian Agency for Drugs and Technology in Health (CADTH), about whether these agencies should recommend that provincial drug plans fund medications. Between 2013 and 2018, these evaluations almost always supported funding the drug, whether the groups had a financial conflict with the company making the drug, a conflict with another company or no conflict with any company.[6]

In addition to the widespread concerns in health policy about pharmaceutical industry funding,[7] financial transparency is an important value in the non-profit sector, which depends heavily on donations, volunteer labour and public trust.[7 8] Furthermore, non-profit organisations with registered charity status are indirectly subsidized by taxpayers and thus have a public responsibility to be open about their finances.

No study has systematically investigated how transparent Canadian patient organisations that participate in drug funding assessments are about their relationships with the pharmaceutical industry and how they report financial information; for example, whether they report receiving donations from pharmaceutical companies, and whether they have policies to guide their relationships with their pharmaceutical company donors. While there are other possible approaches to retrieving information on these and related topics, notably disclosures from companies, if they exist,[9-11] and interviews with patient group members,[4] we focus on the information on groups' publicly available websites. Unlike Australia and several European countries where industry self-regulation requires companies to disclose their funding to patient groups, in Canada only Ontario has passed such a law and it lies dormant under the current government.[12] Websites are the most easily accessible source of information for interested parties and are the method most patient groups use to make their financial accounts available to the public.

Transparency in reporting is a first step to enabling all affected parties (patient group members, the medical community, governments, policy makers and funders) to assess the independence of groups from these funding sources and the objectivity of the information that they provide. In determining the transparency of Canadian patient groups, we adapted the survey methodology used by researchers in other jurisdictions[13-18] to investigate the transparency of how patient groups report their funding links generally and in particular with pharmaceutical companies. We assessed key information about the organization: how much financial information patient groups post on their websites – specifically, information about donations and the use of donations, the composition and employment histories of their boards and staff. Equally important, we examine whether the groups have COI policies to guide their interactions with companies.

Methods

List of patient groups

In the absence of a single national list of Canadian patient groups that advocate on drug policies, on April 22-23, 2019 we searched the websites of all provincial and territorial drug plans (Supplementary File 1) using the terms “registered”, “patient group”, “advocacy group”, “patient engagement” and “patient organization” to see if they had a list of patient groups that provided input to their decision-making processes. Only Ontario and British Columbia (BC) had such lists: BC Pharmacare registers groups that may provide public input into its drug coverage review process (121 groups) [19] and the Ontario Ministry of Health and Long-Term Care registers advocacy groups eligible to provide patient evidence submissions on drugs listed on the drug review schedule of the Ontario Public Drug Program (102 groups).[20] Additional sources for patient groups were those registered with the pan-Canadian Oncology Drug Review, (44 groups) [21] and the membership of the Best Medicines Coalition, an alliance of patient advocates with a shared goal of gaining access to “safe and effective medicines that improve patient outcomes” (27 groups).[22] The decision to only include groups that were nationally based was made because of the limited resources available to our team.

We removed duplicates from our list and limited the groups to those that met the following criteria: Canadian, national in nature, self-identified as patient groups and had an active website that we could search for information.

Contacting patient groups

In addition to gathering information on patient groups' websites, we contacted each patient group's communication contact or equivalent by email in the week of July 13, 2020 to ensure that our data collection would not miss any publicly available, relevant documents that were on their websites. (Supplementary File 2 provides a generic version of the email which was modified for each individual group.) The nature of the study was explained including that we were collecting only publicly available information, that while groups would be identified no individuals in those groups would be named and that all the information we collected would be placed in a publicly available website. In the email, we asked for documents on their websites that would help us determine how transparent groups are with respect to their relationship with donors: 1) the organization's criteria for accepting funding; 2) the organization's position on how funds from acceptable sources are used; 3) the organization's financial affiliations and donors, the sum per annum that the organization receives from those donors; and 4) the organization's board membership including the names of the board members, employment information, and whether there are any current or former pharmaceutical industry employees on the board. (Revenue Canada does not require registered charitable organizations to submit audited financial statements, but organizations need to file annual reports that include basic financial information along with a list of directors. These statements do not include the names of individual donors and the amount that they donated nor any background information about the directors.) If no response was received, a reminder email was sent out after 7 weeks. Any documents received were stored in a password protected web-based site.

Construction of data extraction form

We initially identified research from our personal files and those of other experts on patient group relationships with industry and COI disclosure and developed a preliminary data collection tool.[13-18] This preliminary tool was then sent to 5 experts in the area (LB, AFB, QG, BJM, LP) and modified based on their comments. The resulting tool was then pilot tested by two authors (JL and AS) who independently abstracted information from 5 Australian patient groups. Results were compared and the tool was modified based on this pilot test. It was then converted into REDCap, a data management tool. The same two authors carried out a second pilot test, using 5 Canadian patient groups and modified the tool one final time.

Data extraction

Using the final version of our REDCap tool, between September 2020 and April 2021 we extracted the following information, if it was available, from the group's website: total annual revenue for the latest fiscal year, year revenue was reported, revenue from pharmaceutical company donors, purpose of the donation, presence of donors' logos on the website and hyperlinks to donors' websites, previous and current employment information about board members and staff, external audits about the group's finances, and whether the group endorses products made by donors (Supplementary File 3).

We also examined websites for the presence of COI policies, codes and guidelines (collectively referred to as policies) that covered one or more of the following a priori defined content areas: board and/or advisory board, acceptance of donations and revenue generation, independence of decision-making, endorsements, assistance to and/or interactions between patient members from a donor or another company/person acting on behalf of a donor and audits/monitoring/compliance. Any policy potentially related to relationships with industry donors was collected and assessed for relevancy; only those covering one or more of the issues listed above were included in the analysis. If a policy was available, we recorded whether specific information was present or absent, however, we did not evaluate the strength of the policy (Supplementary File 4). To be eligible, the document had to be explicitly identified as a policy. By-laws and legal documents were excluded.

All four authors independently extracted information from the websites of 23-24 different patient groups and each author did a secondary review of 5 additional websites. Groups of two authors compared their evaluations for these 5 to ensure uniform extraction and then compared information in extraction forms for 1 out of every 5 of the remaining groups. Differences were resolved by consensus and if consensus could not be reached a third author made the final decision.

Best Medicines Coalition (BMC) has a Code of Conduct Regarding Funding [23] that applies to all its member groups. Consistent with our goal of examining only publicly available information, we considered the code applicable to a group if it was posted on the group's website or if the website had a hyperlink to the code. Similarly, if groups hyperlinked to other codes or policies, such as the Canadian Consensus Framework for Ethical Collaboration [24] we also considered those codes or policies as applicable to the group. If a group indicated on its website that a code or policy was available on request, but the policy was unavailable otherwise, we did not include it.

Data analysis

We only report descriptive data in the form of the number and percent of groups with the different types of information on their websites and with policies covering the different aspects of relationships with pharmaceutical companies. To report our results, we anonymized groups but their names, not linked to their responses, are available in Supplementary File 5.

Ethics statement

The Human Participants Review Committee of the York University Office of Research Ethics assessed our ethics application and replied that an approval certificate was not required as this research was not subject to review.

Patient and public involvement

Patient groups were contacted for information about their relationships with pharmaceutical companies. There was no other patient or public involvement in this study.

Results

We initially identified 100 different groups that met our inclusion criteria and contacted all 100 by email, but during the study two groups merged and the websites of two other groups disappeared leaving a sample of 97 groups (Figure 1) (Supplementary File 5). Eight groups provided policies in response to our request, all of which were publicly available on their websites except one that was publicly available on request from the group. (We did not request that policy as we only wanted to analyze policies that were available on websites.) Fifteen groups responded but did not provide policies, an additional 14 groups specifically stated that they did not want to be involved in the project and 60 groups did not reply.

Between the material that patient groups sent us directly and those we sourced from the groups' websites, we collected 846 pieces of material (financial statements, documents, policies, codes, reports) for analysis, with a median of 6.0 pieces per group (interquartile (IQR) range 2.5, 10.5) (Supplementary File 5).

Information on patient group websites

Fifty-three (54.6%) of 97 groups reported donations from pharmaceutical companies. The remainder may have received donations or not reported them or did not receive any donations. Only 1 of those 53 (1.9%) gave the total amount - $516,000 (1.0%) out of total revenue of $54.1 million that it received from pharmaceutical companies. None of the other groups reported the percent of its total revenue from companies. Nine (9.3%) groups gave dollar ranges for donations, 17 (17.5%) gave the total value of donations from all sources but none gave the exact amount of any single donation and 8 (8.2%) broke donations down into separate categories (for example, corporate, foundations, individuals). Four (4.2%) disclosed the purpose of donations.

Fifty-one (52.6%) groups displayed the logos of their donors on the groups' websites, including 41 (42.3%) that showed the logos of pharmaceutical companies. Thirty-one (60.8% of those displaying logos) provided a hyperlink to their donors' websites (Table 1), including 22 (53.7%) groups that had hyperlinks to pharmaceutical company websites. Sixty-seven (69.1%) of groups did not endorse any products, while 30 (30.9%) endorsed specific products made by their donors, for example by expressing approval for their funding or availability, including 25 (25.8%) groups that endorsed pharmaceutical products produced by pharmaceutical companies that had donated to the groups. Twenty-eight patient groups' websites did not contain any of the items listed in Table 1 and the median number of items was 3.0 (interquartile range 0.0, 5.0) (Supplementary File 6).

Table 1: Number of 97 patient groups (percent) reporting information about revenue and donations on their websites

Total annual revenue	**Donations in general**				**Pharmaceutical company donations**			**Donor information on website**			
	Dollar range of individual donations	**Total value of donations**	**Breakdown of total donations by source (e.g., corporate, individuals)**	**Purpose of donations**	**Number of groups reporting donations**	**Value of donations from pharmaceutical companies**	**Percent of total revenue from pharmaceutical company donations***	**Donor logo**		**Hyperlink to donor website**	
42 (43.3)	9 (9.3)	17 (17.5)	8 (8.2)	4 (4.2)	53 (54.6)	1 (1.0)	1 (1.0)	**Any donor**	**Pharmaceutical company donor**	**Any donor**	**Pharmaceutical company donor**
								51 (52.6)	41 (42.3)	31 (32.0)	20 (20.6)

*Calculated from information on website

Fifty-three (54.6%) groups had a brief synopsis about their board members but only 6 (6.2%) had detailed past employment histories. Seventeen groups (17.5%) reported that board members had current or past employment with a pharmaceutical company. Four (4.1%) groups gave pharmaceutical industry employment histories about their staff (Table 2). Supplementary File 7 shows the reporting pattern by individual patient groups.

Table 2: Number of patient groups (percent) reporting employment information about board members and staff on their websites

Board members					Staff	
General employment history			Pharmaceutical industry employment history reported		Pharmaceutical employment history reported	
None*	Brief synopsis	Detailed†	No	Yes	No*	Yes
38 (39.2)	53 (54.6)	6 (6.2)	80 (82.5)	17 (17.5)	93 (95.9)	4 (4.1)

*Board members (staff) not named or no information about employment history
†For example, year ranges with position, job title, employer

No groups had external (or internal) audited reports about their activities aside from financial statements, for example, whether they followed their policies regarding industry donations or how these donations were used.

Patient group policies

Twenty-six (26.8%) groups had publicly available policies on their websites that dealt with relations with pharmaceutical companies (Table 3), including 9 of the 20 members of BMC that were part of our sample. (In discussing the contents of those policies, we refer to the percent of groups with policies and not the percent of all groups.) None of the members of BMC referred to the BMC Code on their website. Policies on 7 separate topics were related to patient group-company relationships: composition and authority of the board, acceptance of donations and revenue generation, independence of decision-making, endorsements, material assistance to patient group members by a donor, other interactions between patient members of the group and a donor, and independent monitoring of activities and compliance with policies. The topic most frequently mentioned was acceptance of donations and revenue generation (16 (61.5%) groups) and the least covered topic was independent audits of finances, monitoring of activities and compliance with policies audits (5 (19.2%) groups). The median number of topics covered per group with policies was 4 (IQR 2, 6).

Table 3: Topics related to relationships with pharmaceutical companies covered by 26 patient group policies reported on websites

Patient group number*	Topic of policy						
	Composition and authority of board	Acceptance of donations and revenue generation	Independence of decision-making	Endorsements	Material assistance to patient group members by a donor	Other interactions between patient members of the group and a donor	Independent monitoring of activities and compliance with policies
1	x	x	x	x	x		
2	x	x	x	x	x	x	x
3	x	x	x	x	x		
4	x	x	x	x	x	x	x
5							
6							
7							
8		x		x		x	x
9		x	x	x			
10		x	x	x			
11		x	x	x			
12	x	x	x	x	x		
13		x	x	x	x	x	
14	x	x					
15		x	x	x			
16	x	x	x	x		x	
17							
18	x	x	x	x	x	x	x
19				x			
20							

21	x						
22	x	x			x		
23			x				
24						x	
25		x		x			x
26	x						
Total (%)	11 (42.3)	16 (61.5)	13 (50.0)	15 (57.7)	8 (30.8)	7 (26.9)	5 (19.2)

*Patient groups have been anonymized

Table 4 provides details about how many of the 26 groups with publicly available policies regulated individual aspects of each of the 7 topics referred to above. For example, “Composition and authority of board” asked whether the policy covered 5 different aspects of the relationship but in Table 4 we only present numbers for 2 of these aspects. Neither of the three groups that have policies covering employment of board members required their current or previous employment to be made public on the group’s website. One group prohibited people who currently or previously worked for any donor from being on the board, while 2 allowed this.

Table 4: Topics of relationships with pharmaceutical companies covered by policies on websites of 26 patient groups

Particular topic of relationship covered by policy	Number of groups with policy mentioning topic	Policy positive about topic	Policy not positive about topic
Composition and authority of board			
Current or previous employment of board members should be made public	0	0	0
Board membership allowed for people who currently or previously worked for a donor	3	2	1
Acceptance of donations and revenue generation			
Source of donations should be made public	6	6	0
Amount of donations should be made public	0	0	0
Purpose of donations should be made public	0	0	0
Donations can be tied to donor-initiated project	10	5	5
Donations require approval by board or executive director	11	5	6
Independence of decision-making			
Group has total independence in decision-making	13	13	0
Donors allowed to directly organize seminars, lectures, projects or meetings	2	1	1
Endorsements			
Names of donors and/or their logos can be displayed on group’s website except to identify donor and amount of money donated	8	4	4

Endorsements of products and/or companies allowed	14	3	11
Hyperlinks to donors' websites allowed	4	4	0
Patient group can directly or indirectly cooperate with companies in lobbying, testifying, addressing legislators, regulators, or policymakers, writing articles or policy briefs, etc.	7	4	3
Material assistance to patient group members by a donor			
Donor allowed to directly pay for conference travel and accommodation for group representatives and participants	1	1	0
Donor allowed to directly pay staff salary or provide staff support for group	2	1	1
Other interactions between patient members of group and donor			
Donor allowed to provide information to patient members of group about products donor makes	4	2	2
Donor allowed to access membership data or membership lists	2	1	1
Donor allowed to provide patient group members with advocacy materials	3	1	2
Donor allowed to provide gifts of noneducational value to patient group members	1	0	1
Donor allowed to provide information to patient group members about policies or positions adopted or suggested by the donor	1	0	1
Independent monitoring of activities and compliance with policies			
Monitoring of compliance with group's policies	3	0	3
Actions if group is not compliant with its policies	2	1	1
Audit of what activities donor money has been spent on	2	1	1
Public availability of results of audits, monitoring, compliance	2	0	2

Sixteen (61.5%) groups had policies about all donations, but only 6 (23.1%) of these policies stated that the source of donations had to be made public and no group required public reporting of the amount of donations. Similarly, no group required that the purpose of donations be publicly disclosed. Five (19.2%) groups did not allow donations to be tied to a donor-initiated project and 5 (19.2%) groups did allow this type of donation.

Thirteen (50%) groups had policies that covered group independence and all stated that the group had total independence in decision-making. However, only 2 (7.7%) groups dealt with whether donors are allowed to directly organize seminars, lectures, projects or meetings (1 permitted such activities, the other did not).

The policies of 15 (57.7%) groups covered endorsements and the display of donors' names and logos. Four (15.4%) groups did allow and 4 (15.4%) did not allow the name and/or logo of donors to be listed on their websites except to identify the donor and the amount of money that the donor gave. Eleven (42.3%) groups did not allow endorsements of products and/or companies while 3 (11.5%) did. Four (15.4%) groups allowed hyperlinks to donors' websites.

Eight (30.8%) groups had policies that regulated material assistance to patient group members by a donor and 6 (23.1%) groups had policies on other types of interactions between patient members of the group and donor. In the case of the former, 1 (3.8%) group allowed donors to directly pay for conference travel and accommodation for group representatives and participants and 2 (7.7%) groups had policies covering whether donors were allowed to directly pay staff salary or provide staff support for the group (1 = yes, 1 = no). In the case of the latter, 2 (7.7%) groups did, and 2 (7.7%) groups did not allow donors to provide information to patient members of the group about products the donor manufactures and 2 (7.7%) groups controlled whether donors were allowed to access membership data or membership lists (1 = yes, 1 = no).

Three (11.5%) groups mentioned that there was no monitoring of compliance with the group's policies, while 2 (7.7%) groups had policies about actions that could be taken if the group was not compliant with its policies (1 = action would be taken, 1 = no action would be taken). Two (7.7%) groups mentioned whether there was an audit of the activities on which donor money had been spent (1 = audit, 1 = no audit).

Discussion

In general, we found that pharmaceutical industry funding of the included patient groups was frequent, with over half (54.6%) publicly declaring on their websites that they had received donations from companies in this sector. Despite this, relatively little information was provided on patient group websites about their relationships with pharmaceutical companies. Only a single group reported the total amount of revenue from this source, none gave the exact amount from individual donors, and only 8 groups stated the purpose of the donations. The employment history of people on patient group boards was typically not given, making it impossible to determine if they had a past or present history of working for a pharmaceutical company. Similarly, only 4 groups provided employment histories of their staff. On-the-other hand, some practices were common.

Over 40% of the groups (41 out of 97) displayed the logos of pharmaceutical company donors on their websites including 22 groups that hyperlinked to pharmaceutical company websites. The use of logos is ambiguous and could be interpreted as transparency; alternatively, the image of logos on a site could be interpreted as promotion for the company in question, especially if a link brings a patient to the company’s web page, which might contain information about a new treatment for the patient’s condition.

Collectively, our observations can be seen as an indication that groups are not committed to being transparent about their relationships with pharmaceutical companies and/or are too closely tied to those companies.

That message about relationships is reinforced in our observation that only 26 out of 97 groups had publicly available policies on their websites that directly dealt with their relationships with pharmaceutical companies. Even when groups did have such policies, those policies often did not cover key aspects of these relationships. For example, only half of the 26 policies stated that the group had complete independence of decision-making and no group's policy covered current or previous employment of board members. Worryingly, an even smaller minority of groups had policies that dealt with topics such as material assistance to patient group members by a donor (2 of 26 policies) and having independent monitoring of activities and compliance with policies (3 of 26 policies).

On-the-one hand, our results show that in the absence of publicly available policies most groups do not make key information public about relationships with pharmaceutical companies including the purpose of donations that they received. But our findings also suggest that, in practice, some groups may follow unwritten policies. For example, although product endorsements were only dealt with in 14 policies, 67 groups did not have any product endorsements on their websites.

With some variations, our findings are broadly in line with studies from other countries that analyzed information and policies on patient group websites. Ball and colleagues studied patient organizations in Australia, Canada, South Africa, the United Kingdom and the United States (US). Corporate donations were acknowledged in only 7 out of 37 annual reports and none of the groups gave enough information to show the proportion of their funding coming from pharmaceutical companies;[13] our results found even fewer groups gave enough information (1 out of 97 groups). In another study, 36 (52.9%) out of 68 Australian groups that received industry funding disclosed the use that they made of the money,[25] whereas only 4.2% did so in our study. Three out of 157 Italian patient and consumer groups (6%) reported the amount of funding from pharmaceutical companies, 25 (54%) reported the activities funded but none reported the proportion of income derived from drug companies.[26] None of 24 American dermatology organizations reported the exact amount or use of donations.[17] A systematic review that included 5 studies that examined patient groups' websites found that a median of 75% reported receiving funding from pharmaceutical companies [9] compared to 54.6% in our study. Another 9 studies in the review reported that between 0% and 50% of groups disclosed the amount of funding that they received, between 0% and 6% of groups reported the proportion of their budget coming from company funding, and a median of 22% of organizations reported on how the funding was used.

In the international study of patient groups by Ball and colleagues, one third of websites showed one or more company logos and/or had links to websites of pharmaceutical companies[13] compared to 22.7% (22 of 97 groups) in our study. Forty-nine out of 133 Australian groups had company logos, web links or advertisements on their websites and 6 had board members that were currently or previously employed by pharmaceutical companies.[25] Among members of the US National Health Council,[27] 24 of 47 patient advocacy organizations had policies that addressed institutional conflict of interest [28] while less than one-fifth of Australian groups had publicly available policies on corporate sponsorship.[25] In a systematic review, the prevalence estimates of organizational policies that govern corporate sponsorship ranged from 2% to 64%.[29] In our case, 16.5% of groups had policies about donations and revenue generation.

The fact that results from multiple jurisdictions spanning the period of time from 2003 to 2021 are so similar speaks to a number of issues. First, it indicates how pervasive the relationships between patient groups and the pharmaceutical industry are. Second, it demonstrates that the lack of patient groups' policies governing this relationship is widespread and that patient groups, wherever they are located, do not see this absence as a problem. Finally, the persistence of the results shows that challenges to the status quo have not produced any substantial movement in the behaviour of patient groups.

Limitations

As Canada has no centralized database of industry funding of patient groups, we relied on information reported on groups' websites about their pharmaceutical industry funding and we had no way of verifying the accuracy of the information. It is difficult to know what time-spans patient groups consider as relevant when disclosing funding. Some groups may disclose corporate funding in the current fiscal year; others may include only the previous year, and some may include more years. Some groups may have steady corporate income from the same sources, whereas other may only receive intermittent donations from different companies. We identified patient groups to include in our study based primarily on whether they were national and provided advice to government institutions about funding new drugs. However, this may constitute a biased sample of Canadian patient groups and other groups may differ in terms of which information is made public and the extent of their policies. We only looked at whether policies existed for certain topics and did not evaluate the strength of the policies. Other documents may have covered areas that were of interest to us, but if these documents were not identified as policies we may have missed them. Only 37 of the 97 groups that we contacted by email responded and out of those only 8 sent us publicly available policies. Some websites were quite complex and the location of information varied from one organization to another; in addition, we may have missed policies on the websites of groups that did not respond or did not send us material. Some groups may have had non-publicly available policies on relevant topics and those would not have been included. Finally, we asked groups about their policies in 2019 and started collecting information from their websites in September 2020. It is possible that some groups subsequently updated their websites or policies, although we verified that the information was current to April 2021.

Conclusion

In the past few decades, patient groups in Canada have evolved rapidly to play a consequential policy role in the Common Drug Review, pan-Canadian Oncology Drug Review, Quebec's Institut national d'excellence en santé et en services sociaux, and other provincial and territorial drug programs that decide which drugs will be included on drug formularies. By speaking from patients' experience, groups can add to our understanding of patients' needs and suggest useful system changes, including in drug policy. However, groups with funding from the very companies whose drugs are under review may be influenced by their industry sponsors unconsciously,[30] through a complex process of corrupted knowledge systems,[31] or through a transactional system of "asset exchange".[32] While transparency does not protect a group against such influence, openness about funding sources is a basic ethical responsibility in science, in democratic systems of governance, and in non-profit organizations. Internationally, websites are the most common means of information disclosure in non-profit organisations, but they are recognized as inadequate to meet the standards of accountability the sector requires.[8]

Other than the law governing charitable organizations based in Canada, which makes few requirements for public reporting of corporate donations and specifically does not require organizations to declare the names of individual donors or the amount of the donations, patient groups are not answerable to any national regulatory or governing body. It is left to the groups themselves to decide what information they will reveal on their websites about corporate donations and whether they develop policies to guide their interactions with their donors. Our study found that most groups had no explicit publicly available policies guiding these interactions and that in general very limited information is disclosed.

The inconsistencies we discovered are not surprising given the absence of external requirements and the varied histories, mandates and resources of the groups themselves. Each group exists to serve its particular patient constituency, not the public at large, and the absence of requirements for public accountability is not the fault of the organizations. A few groups have taken the initiative to adopt strong transparency policies in their relations with the pharmaceutical industry and we applaud the example they set.

Patient groups have an important role to play in the health care system as a voice for their membership. However, they need to act, and be seen to act, as independent voices for patients. Whether this is possible while engaged in relationships with the pharmaceutical industry is a question of active debate;[33] we agree with analysts who would have patient groups decrease, and ultimately end, their dependence on industry funding.[34] Unfortunately, while governments in Canada actively seek to engage patient groups in their policy processes, they do not provide them with funding to support these activities.[3 35] Those groups that have relationships with industry need to adopt a much more transparent approach to reporting on their relationships with these companies and to develop policies that clearly define the extent of those relationships. We recommend as a first step to achieving this goal, that groups convene a series of regional and national workshops, similar to one recently held in Australia, to develop independent guidance for groups looking for assistance in enacting sponsorship policies.[36]

Figure 1 caption:

Selection of patient groups

Acknowledgements

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Contributorship statement

AS came up with the idea for this study. JL and AS developed the data extraction tool. JL, AS, SB and DG gathered and analyzed the data. JL wrote the first draft of the manuscript. AS, SB and DG revised the manuscript. JL, AS, SB, DG approved the final version of the manuscript.

Competing interests

In 2017-2020, Joel Lexchin received payments for being on a panel at the American Diabetes Association, for talks at the Toronto Reference Library, for writing a brief in an action for side effects of a drug for Michael F. Smith, Lawyer and a second brief on the role of promotion in generating prescriptions for Goodmans LLP and from the Canadian Institutes of Health Research for presenting at a workshop on conflict-of-interest in clinical practice guidelines. He is currently a member of research groups that are receiving money from the Canadian Institutes of Health Research and the Australian National Health and Medical Research Council. He is a member of the Foundation Board of Health Action International and the Board of Canadian Doctors for Medicare. He receives royalties from University of Toronto Press and James Lorimer & Co. Ltd. for books he has written.

Sharon Batt has received payment for commissioned briefs related to patient advocacy and industry funding from the Canadian Federation of Nurses Unions and the Canadian Health Coalition. In 2018, she received royalties from UBC Press for a book on industry funding of patient groups. She is a member of the executive of the Nova Scotia Health Coalition and a member of Independent Voices for Safe and Effective Drugs.

Devorah Goldberg and Adrienne Shnier have no competing interests to declare.

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Data sharing statement

The raw data used for analysis of information on patient groups' websites and their policies is available on request.

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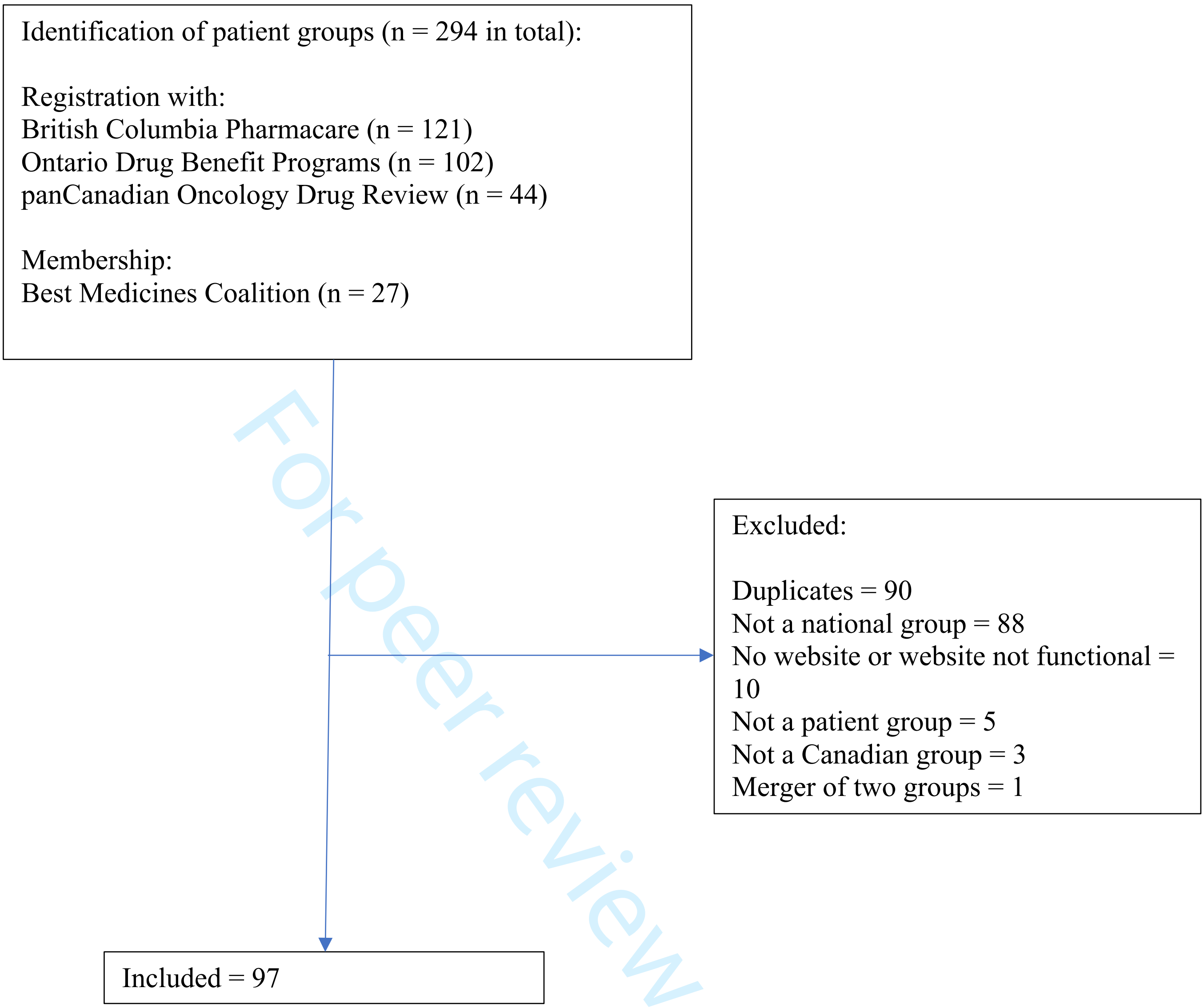

Identification of patient groups (n = 294 in total):
Registration with:
British Columbia Pharmacare (n = 121)
Ontario Drug Benefit Programs (n = 102)
panCanadian Oncology Drug Review (n = 44)
Membership:
Best Medicines Coalition (n = 27)
Excluded:
Duplicates = 90
Not a national group = 88
No website or website not functional = 10
Not a patient group = 5
Not a Canadian group = 3
Merger of two groups = 1
Included = 97

Supplementary File 1: Search for patient groups registered to make submissions

Provincial/territorial drug plans	**Website**	**Search date**
Alberta	https://www.alberta.ca/drug-benefit-list-and-drug-review-process.aspx	April 22, 2019
British Columbia	https://www2.gov.bc.ca/gov/content/health/health-drug-coverage/pharmacare-for-bc-residents/drug-review-process-results/your-voice#patient-group	April 22, 2019
Manitoba	https://www.gov.mb.ca/health/pharmacare/	April 22, 2019
New Brunswick	https://www2.gnb.ca/content/gnb/en/departments/health/MedicarePrescriptionDrugPlan/NBDrugPlan.html	April 22, 2019
Newfoundland and Labrador	https://www.gov.nl.ca/hcs/prescription/	April 22, 2019
Northwest Territories	https://www.hss.gov.nt.ca/en/services/supplementary-health-benefits/extended-health-benefits-specified-disease-conditions	April 22, 2019
Nova Scotia	https://novascotia.ca/dhw/pharmacare/	April 22, 2019
Nunavut	http://66.240.131.202/en-ca/Provincial-Coverage/nunavut/drug-benefit-programs	April 22, 2019
Ontario	https://www.health.gov.on.ca/en/pro/programs/drugs/patient_evidence/registered_advocacy_groups.aspx	April 22, 2019
Prince Edward Island	https://www.princeedwardisland.ca/en/information/health-pei/drug-programs	April 22, 2019
Quebec	https://www.ramq.gouv.qc.ca/en/citizens/prescription-drug-insurance	April 22, 2019
Saskatchewan	https://www.saskatchewan.ca/residents/health/prescription-drug-plans-and-health-coverage/extended-benefits-and-drug-plan/saskatchewan-drug-plan	April 22, 2019
Yukon	https://yukon.ca/en/health-and-wellness/medical-professionals/find-drug-coverage-information	April 22, 2019
Agencies, organizations	**Website**	**Search date**
Best Medicines Coalition	https://bestmedicinescoalition.org/members/	April 23, 2019
pan-Canadian Oncology Drug Review	https://web.archive.org/web/20210228191917/https://www.cadth.ca/sites/default/files/pcodr/Submit%20%26%20Contribute/pcodr-registered-patientadgrps.pdf	April 23, 2019

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.

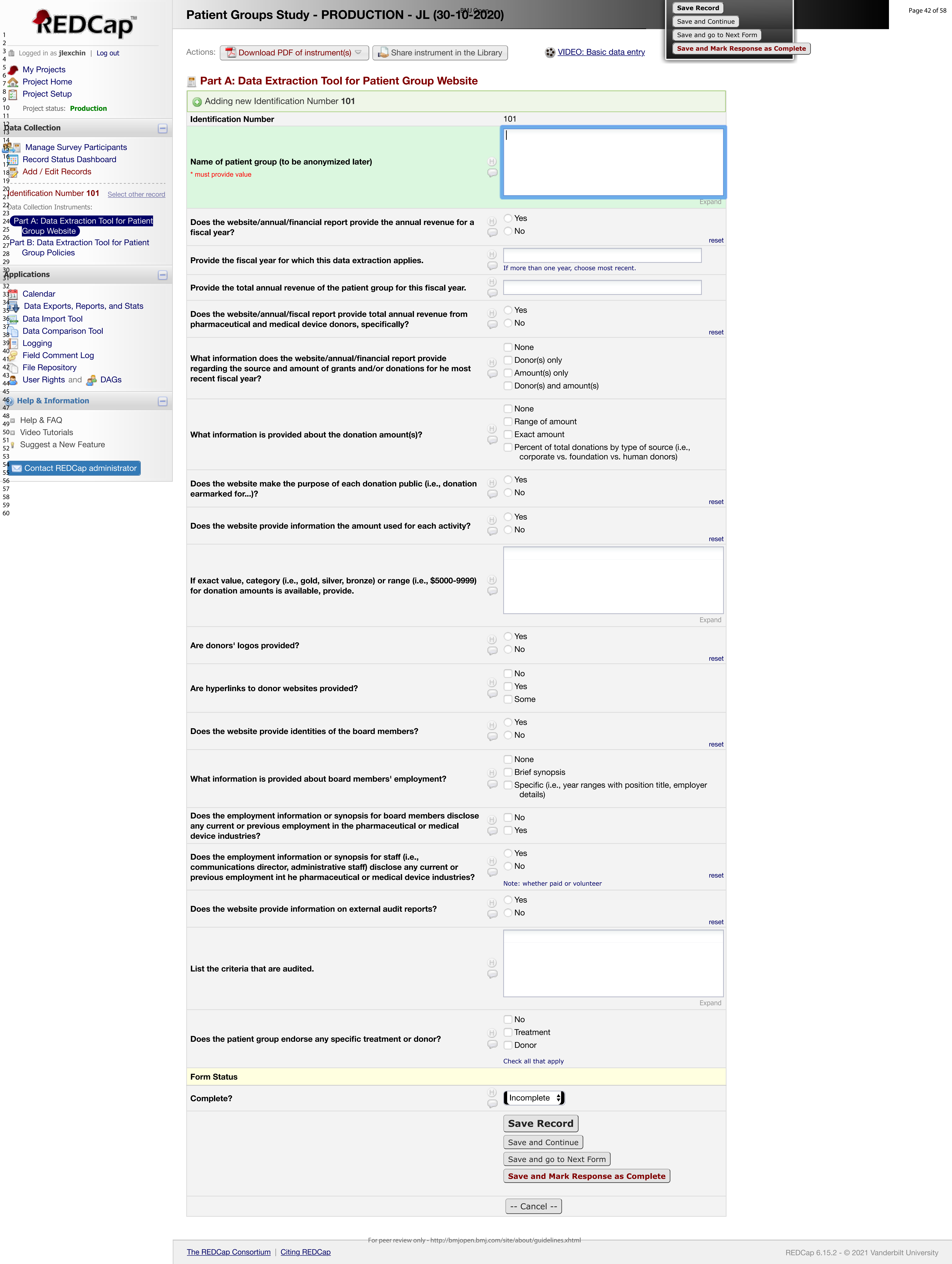
You can contact Alison M. Collins-Mrakas, Senior Manager & Policy Advisor, Research Ethics at 416-736-5914 or acollins@yorku.ca for further information.

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

Sincerely,

Adrienne Shnier Ph.D., J.D.
Adjunct Professor, School of Health Policy and Management
York University
Email: ashnier@yorku.ca

Joel Lexchin MD
Professor, School of Health Policy and Management
York University
E mail: jlexchin@yorku.ca



Patient Groups Study - PRODUCTION - JL (30-10-2020)

Part A: Data Extraction Tool for Patient Group Website

Adding new Identification Number **101**

Identification Number	101
Name of patient group (to be anonymized later) * must provide value	
Does the website/annual/financial report provide the annual revenue for a fiscal year?	○ Yes ○ No
Provide the fiscal year for which this data extraction applies.	If more than one year, choose most recent.
Provide the total annual revenue of the patient group for this fiscal year.	
Does the website/annual/fiscal report provide total annual revenue from pharmaceutical and medical device donors, specifically?	○ Yes ○ No
What information does the website/annual/financial report provide regarding the source and amount of grants and/or donations for he most recent fiscal year?	☐ None ☐ Donor(s) only ☐ Amount(s) only ☐ Donor(s) and amount(s)
What information is provided about the donation amount(s)?	☐ None ☐ Range of amount ☐ Exact amount ☐ Percent of total donations by type of source (i.e., corporate vs. foundation vs. human donors)
Does the website make the purpose of each donation public (i.e., donation earmarked for...)?	○ Yes ○ No
Does the website provide information the amount used for each activity?	○ Yes ○ No
If exact value, category (i.e., gold, silver, bronze) or range (i.e., $5000-9999) for donation amounts is available, provide.	
Are donors' logos provided?	○ Yes ○ No
Are hyperlinks to donor websites provided?	☐ No ☐ Yes ☐ Some
Does the website provide identities of the board members?	○ Yes ○ No
What information is provided about board members' employment?	☐ None ☐ Brief synopsis ☐ Specific (i.e., year ranges with position title, employer details)
Does the employment information or synopsis for board members disclose any current or previous employment in the pharmaceutical or medical device industries?	☐ No ☐ Yes
Does the employment information or synopsis for staff (i.e., communications director, administrative staff) disclose any current or previous employment int he pharmaceutical or medical device industries?	○ Yes ○ No Note: whether paid or volunteer
Does the website provide information on external audit reports?	○ Yes ○ No
List the criteria that are audited.	
Does the patient group endorse any specific treatment or donor?	☐ No ☐ Treatment ☐ Donor Check all that apply
Form Status	
Complete?	Incomplete

Patient Groups Study - PRODUCTION - JL (30-10-2020)

Part B: Data Extraction Tool for Patient Group Policies

Adding new Identification Number **101**

Identification Number	101
Patient group name (to be anonymized later)	
Does the patient group have a relevant publicly available policy?	● Yes ○ No reset Policy document must be clearly identifiable as a policy/guidance document.
Do/es the policy document/s cover any of the following content areas?	☑ Board and/or advisory board ☑ Acceptance of donations and revenue generation ☑ Independence of decision-making ☑ Endorsements ☑ Assistance to patient members from a donor, or another company/person acting on behalf of a donor ☑ Interaction between donor, or another company/person acting on behalf of a donor, and patient members ☑ Audits, monitoring, and compliance ☑ None of the above ☑ Other Choose all that apply. None of the above = Policy available, but does not address any of our categories.
Does the organization's policy state that the names of board members must be provided on its website?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow people who currently work for a donor, or who have a financial relationship with a donor, to participate on an advisory board?	☐ No ☐ Yes ☐ No policy
Does the organization's policy state that current and/or previous employment information for board members must be disclosed on its website?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow people who previously worked for, or currently work for, or have a financial relationship with a donor, to participate on the executive body of the board of the organization?	☐ No ☐ Yes ☐ No policy
Does the organization's policy require the board and/or executive director to approve donations prior to receipt?	☐ No ☐ Yes ☐ No policy
Does the organization's policy provide any other regulation of board membership?	Expand
Does the organization's policy state that the source of donations and amount must be disclosed publicly?	☐ No ☐ Yes, source ☐ Yes, amount ☐ Yes, source and amount ☐ No policy
Does the organization's policy allow for the acceptance of grant or donation money that is contingent on a donor-initiated project?	☐ No ☐ Yes ☐ No policy
Does the organization's policy permit the acceptance of grants from only particular donors?	☐ No ☐ Yes ☐ No policy
Does the organization's policy state that the purpose of accepted donations must be publicly disclosed?	☐ No ☐ Yes ☐ No policy
Does the organization's policy permit accepting money from exclusively a single donor?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow only a fixed amount of its annual revenue to be provided by a single donor?	☐ No ☐ Yes ☐ No policy
Does the organization's policy set a fixed limit on the percentage of its annual revenue that it will accept from donors in total?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow for "sponsorship packages", i.e., what benefits donors get form donations of a certain amount (e.g., exhibit space, company's name on all room keys, etc.).	☐ No ☐ Yes ☐ No policy
Does the organization's policy state that the organization has total independence in its decision making?	☐ No ☐ Yes ☐ No policy
Does the organization's policy state that the patient group retains final and complete control over all decisions it makes, all materials, and pronouncements that carry its name?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow for the name of any donor to be listed on its website under any circumstances, except to identify the name and/or logo of the donor and the amount of money received, i.e., for an endorsement?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow for the endorsement of any specific treatment or any specific donor?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow for a hyperlink to be provided to a donor's website?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow for the patient group to directly or indirectly cooperate with companies in lobbying, testifying, addressing legislators, regulators, or policymakers, writing articles or policy briefs, etc. (e.g., submit its own letter and support donor's position)?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to directly organize seminars, lectures, projects, or meetings?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to directly provide funding for seminars, lectures, projects, or meetings?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to directly contribute to printing costs?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to directly plan/arrange recreational services, lodging or travel for representative of the organization or participants?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to directly pay for conference travel and accommodation for organization representatives or participants?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to directly sponsor research grants, study fellowships, internships, or other opportunities administered by the organization for people in the field?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to provide donations in kind, e.g., facilities, administration, training materials, books for libraries, website design?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to directly pay staff salaries or provide staff support?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow for any other assistance from donors or other companies acting on behalf of donors?	Expand
Does the organization's policy allow donors to provide information to patient group members about products that the donor makes?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to provide gifts of educational value to patient group members (e.g., webinars, books, brochures)?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow for donors to provide gifts of non-educational value to patient group members?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to provide patient group members with advocacy materials?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to provide a nurse/social worker/etc. to assist patient group members with treatment?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to survey patient group members, access membership data or membership lists, or otherwise gain information about members?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to provide expert opinions about products or policies?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to provide opportunities to patient group members to learn about lobbying/advocacy techniques?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to encourage individual lobbying/advocacy activities for patient group members?	☐ No ☐ Yes ☐ No policy
Does the organization's policy allow donors to provide information to patient group members about policies or positions adopted or suggested by the donor?	☐ No ☐ Yes ☐ No policy
If the organization's policy regulates any other areas of interaction between patient group members and donors, list.	Expand
Does the organization's policy provide for any independent monitoring of their policies?	☐ No ☐ Yes ☐ No policy
Does the organization's policy provide for an independent audit regarding on what activities donor money has been spent?	☐ No ☐ Yes ☐ No policy
Does the organization's policy provide for publicly available results of the independent monitoring?	☐ No ☐ Yes ☐ No policy
Does the organization's policy provide for what happens if the organization is not compliant with its policies? (i.e., internal review if noncompliance.)	☐ No ☐ Yes ☐ No policy
Form Status	
Complete?	Incomplete

Supplementary File 5: Names of patient groups, websites and

	Name of group	Website	Notes	Number of pieces of information analyzed
1	AboutFace Craniofacial Family Society	www.aboutface.ca		3
2	Advocacy for Canadian Childhood Oncology Research Network	http://www.curesforourkids.com		4
3	aHUS Canada/SHUa	www.ahuscanada.org		8
4	ALS Society of Canada	https://www.als.ca		8
5	Aplastic Anemia and Myelodysplasia Association of Canada	www.aamac.ca		3
6	Arthritis Consumer	www.jointhealth.org		15
7	Asthma Canada	https://asthma.ca		22
8	Best Medicines Coalition	https://bestmedicinescoalition.org		10
9	Bladder Cancer Canada	https://bladdercancercanada.org/en/		8
10	Brain Tumour Foundation of Canada	https://www.braintumour.ca		4
11	Canadian Arthritis Patient Alliance	www.arthritispatient.ca		24
12	Canadian Breast Cancer Network	https://www.cbcn.ca/en/		10
13	Canadian Cancer	www.cancer.ca		8
14	Canadian Cancer Survivor Network	www.survivornet.ca		7
15	Canadian Council of the Blind	www.ccbnational.net		7
16	Canadian Digestive Health Foundation	https://cdhf.ca		2
17	Canadian Epilepsy Alliance	http://www.canadianepilepsyalliance.org		3
18	Canadian Hemophilia	https://www.hemop		8
19	Canadian Hospice Palliative Care	http://www.chpca.net		10
20	Canadian Liver	www.liver.ca		7
21	Canadian Mental Health Association	https://cmha.ca		3

22	Canadian Mesothelioma Foundation	http://cmfonline.org		1
23	Canadian MPN Network	http://canadianmpnnetwork.ca		2
24	Canadian Organization for Rare Disorders	www.raredisorders.ca		4
25	Canadian Pain Coalition	https://www.facebook.com/CanadianPainCoalition/		0
26	Canadian PBC Society	www.pbc-society.ca		1
27	Canadian Pemphigus and Pemphigoid Foundation	http://pemphigus.ca		1
28	Canadian Pituitary Patient Network	https://canadianpituitary.org		0
29	Canadian PKU & Allied Disorders Inc.	www.canpku.org		6
30	Canadian Psoriasis Network	www.canadianpsoriasisnetwork.com		1
31	Canadian Pulmonary Fibrosis Foundation	www.cpff.ca		2
32	Canadian Skin Patient Alliance	www.canadianskin.ca		2
33	Canadian Society for Mucopolysaccharide & Related Diseases Inc.	www.mpssociety.ca		1
34	Canadian Society of Intestinal Research	https://www.badgut.org		1
35	Canadian Spondylitis	http://www.spondyli		1
36	Canadian Treatment Action Council	www.ctac.ca	Website broken as of March 10, 2021	Not applicable
37	Cancer Advocacy Coalition of Canada	http://www.canceradvocacy.ca	Name now changed to: Cancer Survivors	1
38	Carcinoid-NeuroEndocrine Tumour Society Canada	www.cnetscanada.org		1

39	Centre for ADHD Awareness, Canada (CADDAC)	www.caddac.ca		1
40	Chronic Lymphocytic Leukemia Patient Advocacy Group (CLL	www.cllpag.ca	Name now changed to: CLL Canada	3
41	Chronic Myelogenous Leukemia Society of Canada	http://cmlsociety.org	Name now changed to: CML Society	8
42	Chronic Pain Association of Canada	www.chronicpaincanada.com		1
43	CNIB (Canadian National Institute for the Blind)	www.cnib.ca		8
44	Colorectal Cancer Canada	https://www.colorectalcancercanada.com		11
45	Consumer Advocare Network	http://survivornet.ca/en/partners/consumer_advocare_network	Website broken as of March 10, 2021	Not applicable
46	COPD Canada	www.copdcanada.info		3
47	COPD Canada Patient	www.copdcanada.ca		0
48	Craig's Cause Pancreatic Cancer Society	http://www.craigscause.ca		1
49	Crohn's and Colitis	www.crohnsandcoliti		4
50	Cystic Fibrosis Canada	www.cysticfibrosis.ca		5
51	Diabetes Canada (Canadian Diabetes Association)	www.diabetes.ca		24
52	Eczema Society of Canada	https://eczemahelp.ca/		19
53	FH Canada Patient Network	https://thefhfoundation.org/global-fh-canada	Name now changed to: FH Foundation	18
54	Food Allergy Canada (Anaphylaxis Canada)	https://foodallergycanada.ca		14
55	Foundation Fighting Blindness	https://ffb.ca	New website: https://www.fightingblin	18

56	Foundation for Prader-Willi Research Canada (FPWR Canada)	https://www.fpwr.ca		2
57	GIST Sarcoma Life Raft Group Canada	https://liferaftgroup.ca/welcome/		4
58	HeartLife Foundation	www.heartlife.ca		1
59	Hep C Awareness.com	www.hepcawareness.com		0
60	HS Aware - Now appears to be HS	www.hsaware.com	New website:	3
61	Huntington Society of Canada	https://www.huntingtonsociety.ca		24
62	Hypertension Canada	https://hypertension.ca/about-us/		7
63	Kidney Cancer Canada	https://www.kidneycancercanada.ca		13
64	Leukemia & Lymphoma Society of Canada	https://www.llscanada.org		9
65	Lung Cancer Canada	http://www.lungcancercanada.ca		6
66	Lupus Canada	www.lupuscanada.org		9
67	Lymphoma Canada	https://www.lymphoma.ca		22
68	Mastocytosis Society Canada	https://www.mastocytosis.ca/en/		17
69	Melanoma Network of Canada	https://www.melanomanetwork.ca		35
70	Millions Missing Canada	https://www.millionsmissingcanada.ca		5
71	MS Society of Canada	www.mssociety.ca		74
72	Myeloma Canada	https://www.myelom		38
73	National Gaucher Foundation of Canada	www.gauchercanada.ca		10
74	Neuroblastoma Canada	http://neuroblastoma.ca		4
75	Osteoporosis Canada	www.osteoporosis.ca		19
76	Ovarian Cancer Canada	https://ovariancanada.org		21
77	Pancreatic Cancer Canada	http://www.pancreaticcancercanada.ca		20
78	Parkinson Canada	https://www.parkinson.ca		18

79	Patient Commando	www.patientcommando.com		8
80	People in Pain Network	www.pipain.com		8
81	Polycystic Kidney Disease (PKD) Foundation of Canada	www.endpkd.ca	Name now changed to: PKD Foundation of Canada	5
82	Prostate Cancer Canada	http://www.prostatecancer.ca	Now part of Canadian Cancer Society as of February 1, 2020	Not applicable
83	Pulmonary Hypertension Association of Canada	www.phacanada.ca		15
84	Rethink Breast Cancer	https://rethinkbreastcancer.com		8
85	Robbie's Rainbow	http://robbiesrainbow.ca		6
86	Sarcoma Cancer Foundation of Canada	http://sarcomacancer.ca		3
87	Save Your Skin Foundation	www.saveyourskin.ca		4
88	Scleroderma Society of Canada	www.scleroderma.ca	Name now changed to: Scleroderma Canada	5
89	Sjogren's Society of Canada	www.sjogrenscanada.org		6
90	Soft Bones Canada	www.softbonescanada.ca		13
91	The Canadian Continence Foundation	www.canadiancontinence.ca		9
92	The Endometriosis Network	https://endometriosisnetwork.com	Name now changed to: The Endometriosis Network Canada	4
93	The Isaac Foundation	https://www.theisaacfoundation.com		0

94	Thyroid Cancer Canada	www.thyroidcancerc	6
95	Tourette Syndrome Foundation of Canada	https://tourette.ca	14
96	Trigeminal Neuralgia Association of Canada	www.tnac.org	1
97	Tuberous Sclerosis Canada Sclerose Tubereuse	https://www.tscanada.ca	7
98	Type 1 Together	www.type1together.ca	4
99	Wounds Canada (Canadian Association of Wound Care)	https://www.woundscanada.ca	12
100	Young Adult Cancer Canada	https://www.youngadultcancer.ca	10

Supplementary File 6: Information about revenue and donations on individual patient groups' public websites

Patient group number ‡	Total annual revenue	Donations in general				Pharmaceutical company donations			Donor information on website			
		Dollar range of individual donations	Total value of donations	Breakdown of total donations by source (e.g., corporate, individuals)	Purpose of donations	Number of groups reporting donations	Value of donations from pharmaceutical companies	Percent of total revenue from pharmaceutical company donations*	Any donor logo	Pharmaceutical company donor	Hyperlink to any donor website	Hyperlink to pharmaceutical company donor
1												
2	x	x				x			x	x	x	x
3						x			x	x		
4	x		x			x			x	x		
5	x		x			x			x	x	x	x
6												
6						x			x	x	x	x
7	x		x						x			
8												
9						x			x	x	x	x
10												
11	x					x			x	x	x	x
12	x			x								
13												
14						x						
15	x					x						
16	x		x			x			x	x	x	x
17												
18												
19												

20	x			x		x			x	x	x	x
21	x											
22	x					x			x	x		
23					x						x	
24	x	x				x						
25	x		x				x	x			x	
26												
27												
28						x			x	x	x	x
29	x		x						x		x	
30						x			x	x	x	x
31	x		x			x			x	x		
31	x					x			x	x		
32						x						
33	x			x		x					x	x
34												
35						x						
36												
37	x					x			x	x	x	x
38												
39	x					x			x	x	x	x
40		x							x		x	
41						x			x	x		
42											x	
43	x					x			x	x	x	
44									x			
45	x					x						
46												

47												
48	x		x									
49	x	x				x			x	x		
50	x	x				x			x	x	x	x
51	x			x		x			x	x	x	x
53												
54	x	x	x	x	x	x			x	x	x	x
55						x			x	x	x	x
56												
57	x		x									
58						x			x	x		
60												
61	x	x				x			x	x	x	x
62	x			x		x			x		x	
63						x			x	x		
64	x	x				x			x			
65						x			x	x	x	x
66												
67												
68												
69						x						
70	x		x			x			x	x		
71	x		x	x		x			x	x	x	x
72	x					x			x	x		
73												
74	x	x				x			x	x		
75	x					x			x	x		
76	x		x			x			x	x		

77	x					x			x	x		
78	x		x	x	x	x			x			
79												
80												
81	x		x									
82						x			x	x		
83									x			
84						x			x	x	x	
85	x											
86					x	x			x	x	x	x
87						x			x	x	x	x
88						x			x	x		
89						x			x		x	
90						x			x	x	x	x
91												
92												
93	x		x						x			
94												
95	x		x									
96						x			x	x		
97												
Total	**42**	**9**	**17**	**8**	**4**	**53**	**1**	**1**	**51**	**41**	**31**	**20**

‡Patient groups have been anonymized
*Calculated from information on website

Supplementary File 7: Information about employment of board and staff on individual patient groups' public websites

Patient group number‡	Board members					Staff	
	General employment history			Pharmaceutical industry employment history reported		Pharmaceutical employment history reported	
	None*	Brief synopsis	Detailed†	No	Yes	No*	Yes
1		x		x		x	
2	x			x		x	
3		x		x		x	
4	x			x		x	
5	x			x		x	
6		x		x		x	
7			x		x	x	
8	x			x		x	
9	x			x		x	
10	x			x		x	
11	x			x		x	
12			x	x		x	
13		x		x		x	
14		x		x		x	
15		x		x		x	
16		x		x		x	
17		x			x	x	
18		x		x		x	
19		x		x		x	
20		x		x		x	
21		x		x		x	
22	x			x		x	
23	x			x		x	
24	x			x		x	
25		x		x		x	
26		x			x	x	
27	x			x		x	
28		x		x		x	
29		x		x		x	
30		x			x	x	
31	x			x		x	
32	x			x		x	
33		x		x			x
34		x		x		x	
35	x			x		x	
36	x			x		x	
37	x			x		x	
38		x		x		x	
39			x		x	x	

40	x			x		x	
41		x			x	x	
42			x		x		x
43	x			x		x	
44		x			x	x	
45	x			x		x	
46		x			x	x	
47	x			x		x	
48		x		x		x	
49		x		x		x	
50	x			x			x
51		x			x	x	
52		x			x	x	
53	x			x		x	
54		x		x		x	
55	x			x		x	
56	x			x		x	
57		x		x		x	
58		x		x		x	
59		x		x		x	
60	x			x		x	
61		x			x	x	
62	x			x		x	
63	x			x		x	
64		x		x		x	
65	x			x		x	
66		x		x		x	
67			x		x	x	
68		x		x		x	
69	x			x		x	
70	x			x		x	
71		x			x	x	
72	x			x		x	
73		x		x		x	
74			x	x		x	
75		x		x			x
76		x		x		x	
77		x		x		x	
78		x		x		x	
79		x		x		x	
80	x			x		x	
81		x		x		x	
82	x			x		x	
83		x		x		x	
84		x			x	x	
85		x		x		x	

86	x			x		x	
87	x			x		x	
88		x		x		x	
89		x		x		x	
90		x		x		x	
91		x			x	x	
92	x			x		x	
93		x			x	x	
94	x			x		x	
95		x		x		x	
96	x			x		x	
97		x		x		x	
Total	**38**	**53**	**6**	**80**	**17**	**93**	**4**

‡Patient groups have been anonymized
*Board members (staff) not named or no information about employment history
†For example, year ranges with position, job title, employer

STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation	Page No
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2-3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	5-6
Objectives	3	State specific objectives, including any prespecified hypotheses	6-7
Methods			
Study design	4	Present key elements of study design early in the paper	7-8
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	7-10
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	10-11
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	9-10
Bias	9	Describe any efforts to address potential sources of bias	
Study size	10	Explain how the study size was arrived at	
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	10-11
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	
		(*b*) Describe any methods used to examine subgroups and interactions	
		(*c*) Explain how missing data were addressed	
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy	
		(*e*) Describe any sensitivity analyses	

Continued on next page

Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	11
		(b) Give reasons for non-participation at each stage	11
		(c) Consider use of a flow diagram	11
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	11-12
		(b) Indicate number of participants with missing data for each variable of interest	
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)	
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	
		Cross-sectional study—Report numbers of outcome events or summary measures	
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	12-20
		(*b*) Report category boundaries when continuous variables were categorized	
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	
Discussion			
Key results	18	Summarise key results with reference to study objectives	21
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	24-25
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	25-27
Generalisability	21	Discuss the generalisability (external validity) of the study results	25
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	30

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.