

PATIENT AND PUBLIC INVOLVEMENT QUESTIONNAIRE (PPIQ)

Version 1.0

January 2019

The logo for Ryerson University, featuring the text "Ryerson University" in white on a blue rectangular background. To the right of the blue rectangle is a vertical yellow bar.

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Evaluation of Committee Deliberations in Resource Allocation in Drug Funding Recommendations

We developed this self-administered instrument, called the Patient and Public Involvement Questionnaire (PPIQ) to assess the degree of involvement that all committee members have on drug recommendation committees when making recommendations regarding public funding of drugs. The focus of the PPIQ is to evaluate patient and public engagement in decision making. The questionnaire was developed using the following three phases: item generation, development of criteria, and item reduction.¹

The item generation phase consisted of 27 key informant interviews with patient groups, past or present government employees, representatives from Ministries of Health, advisory committee members and industry representatives as well as a literature review. Initially, 846 items were created from the interview data and this was augmented by a literature review. Following an internal review, 84 potential items were identified. An expert team of academic researchers with experience in drug reimbursement committees and members of the Canadian Agency for Drugs and Technologies in Health (CADTH), reviewed these items to identify missing items.

Using information from the item generation phase we developed nine criteria in which patient and public involvement could be judged. The following were the nine criteria identified to evaluate patient and the public involvement in healthcare resource allocation decision making: clarity regarding rationale and roles of patient and public members, sufficient support, adequate representation of relevant views, fair decision-making processes, legitimacy of committee processes, adequate opportunity for participation, meaningful degree of participation, noticeable effect on decisions, and considerations of the efficiency of patient and public involvement.¹

The PPIQ has been refined through an iterative process to develop items specific to drug reimbursement committees in Canada. We conducted two focus groups— one in-person and another online —with drug reimbursement committee members, industry representatives, government members, and patient group representatives in Canada to further refine the PPIQ. This process focused on the elimination of redundant items, addition of missing items, and ensuring each criterion for judging effectiveness was adequately captured by the listed items. In addition, we tested the sensibility of the questionnaire using Feinstein's components of sensibility: purpose and framework, overt format, face and content validity, and ease of use.

The PPIQ was created to be used as an evaluative tool to observe and support good governance for a committee. It uses a Likert scale to identify the degree to which committees have met the nine evaluation criteria (See Appendix 1 – Evaluation criteria of patient and public involvement in resource allocation decisions). Results from the PPIQ can be used to identify strengths and areas of improvement for the deliberative process as well as in member involvement within your committee. For example, some members may disagree that patient perspectives are adequately represented during committee deliberations. The PPIQ also includes an area with open comments which allows members to freely comment about their experiences on the committee.

1. Rosenberg-Yunger, Z. R. S., & Bayoumi, A. M. (2017). *Evaluation criteria of patient and public involvement in resource allocation decisions: a literature review and qualitative study. International Journal of Technology Assessment in Health Care*, 33(02), 270–278.

Part 1: COMMITTEE SELECTION AND REPRESENTATION

The purpose of this section is to better understand the process of selecting different types of committee members, like patient, public and professional members. These questions are also designed to understand whether the composition of the committee reflects the broader population at large.

1. There is appropriate representation of patient perspectives on the committee.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Moderately Agree	Moderately Agree	Moderately Agree	Moderately Agree	Moderately Agree	Moderately Agree

2. The committee has an appropriate number of patient members.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

3. There is appropriate representation of public perspectives on the committee.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

4. The committee has an appropriate number of public members.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor disagree	Moderately Disagree	Strongly Disagree	NA

5. I am a valued member of the committee.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor disagree	Moderately Disagree	Strongly Disagree	NA

6. I understand how each committee member was selected.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor disagree	Moderately Disagree	Strongly Disagree	NA

7. The process for *recruiting* committee members is transparent.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor disagree	Moderately Disagree	Strongly Disagree	NA

8. The process for *selecting* committee members is transparent.

☐

**Strongly
Agree**

☐

**Moderately
Agree**

☐

**Neither
Agree
nor
disagree**

☐

**Moderately
Disagree**

☐

**Strongly
Disagree**

☐

NA

9. The term length that I am serving on the committee is appropriate.

☐

**Strongly
Agree**

☐

**Moderately
Agree**

☐

**Neither
Agree nor
disagree**

☐

**Moderately
Disagree**

☐

**Strongly
Disagree**

☐

NA

10. I receive appropriate training to effectively serve on the committee.

☐

**Strongly
Agree**

☐

**Moderately
Agree**

☐

**Neither
Agree nor
disagree**

☐

**Moderately
Disagree**

☐

**Strongly
Disagree**

☐

NA

11. I receive adequate ongoing financial compensation to serve on my committee.

☐

**Strongly
Agree**

☐

**Moderately
Agree**

☐

**Neither
Agree nor
disagree**

☐

**Moderately
Disagree**

☐

**Strongly
Disagree**

☐

NA

12. I am given sufficient support to prepare for deliberations.

☐

**Strongly
Agree**

☐

**Moderately
Agree**

☐

**Neither
Agree nor
disagree**

☐

**Moderately
Disagree**

☐

**Strongly
Disagree**

☐

NA

13. There is appropriate [representation](#) of patient perspectives on the committee.

☐

**Strongly
Agree**

☐

**Moderately
Agree**

☐

**Neither
Agree nor
disagree**

☐

**Moderately
Disagree**

☐

**Strongly
Disagree**

☐

NA

Part 2: COMMITTEE DELIBERATIVE PROCESS

The purpose of this section is to better understand the deliberative process and your role within the committee.

14. Each member has an opportunity to speak at each committee meeting.

☐

**Strongly
Agree**

☐

**Moderately
Agree**

☐

**Neither
Agree nor
Disagree**

☐

**Moderately
Disagree**

☐

**Strongly
Disagree**

☐

NA

15. We have an explicitly defined process that facilitates all members' participation during committee deliberations.

☐

**Strongly
Agree**

☐

**Moderately
Agree**

☐

**Neither
Agree nor
Disagree**

☐

**Moderately
Disagree**

☐

**Strongly
Disagree**

☐

NA

16. I know the purpose of my role on the committee.

☐

**Strongly
Agree**

☐

**Moderately
Agree**

☐

**Neither
Agree nor
Disagree**

☐

**Moderately
Disagree**

☐

**Strongly
Disagree**

☐

NA

17. I know how to apply my skills to assist in deliberations.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

18. [Patient member](#)(s) adequately represent patient perspectives during our [committee deliberations](#).

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

19. [Public member\(s\)](#) adequately represent public perspectives during committee deliberations.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

20. During deliberations, clinical data presented by [professional committee members](#) is given the same consideration as patient experiences.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

21. Public perspectives are adequately discussed in our deliberative process.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Never	Not Often	Neutral	Very Often	Always	NA

22. Patient perspectives are adequately discussed in our deliberative process.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Never	Not Often	Neutral	Very Often	Always	NA

23. It is important to have a patient committee member.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

24. It is important to have a public committee member.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

25. [The Chair of my committee](#) ensures opportunities for all members to participate in committee deliberations.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

26. [The Chair of my committee](#) facilitates the consideration of *public* perspectives by all committee members.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

27. [The Chair of my committee](#) facilitates the consideration of *patient* perspectives by all committee members.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

28. When there is limited evidence, I am willing to rely on patient experiences to make recommendations.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

29. Patient group input, about the drug under review, is given the appropriate consideration relative to clinical evidence.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

30. When there is insufficient information about patient values in the patient group submission, my committee seeks out other information about patient values.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

31. My committee makes recommendations that reflect patient needs outlined in the patient group submission.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

32. I consider information in the patient group submission about patients' unmet health needs to be useful during deliberation.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

33. I consider individual patient experiences within the patient group submission to be valuable.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

34. I know whether the patient group submissions have disclosed conflicts of interest.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

35. I know whether the clinical experts have disclosed conflicts of interest.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

36. My committee makes recommendations that reflect public values.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

37. I am confident in using patient group evidence that has been *informed by* industry at arm's length.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

38. I am confident in using patient group evidence that has been *financed by* industry at arm's length.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

39. I am confident in using clinical experts that have been *financed by* industry at arm's length.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

40. The degree to which I perceive industry is involved in the patient group submission process affects the value I place on it.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

41. I consider patient group submissions, about the drug under review, to be more valuable when they meet submission guidelines about information requirements (relative to those that do not).

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

42. My committee makes recommendations that consider patient needs.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

43. There is appropriate [representation](#) of patient perspectives on the committee.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

44. Each member has an opportunity to speak at each committee meeting.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

45. We have an explicitly defined process that facilitates all members' participation during committee deliberations.

☐

**Strongly
Agree**

☐

**Moderately
Agree**

☐

**Neither
Agree nor
Disagree**

☐

**Moderately
Disagree**

☐

**Strongly
Disagree**

☐

NA

Part 3: EXTERNAL COMMUNICATION

The purpose of this section is to better understand how well the committee is communicating activities to external stakeholders (i.e., patient group submitters and general public).

46. Committee recommendations are written in accessible language that the public understands.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

47. The clinical 'reasons' for the drug recommendation are explicitly described.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

48. The economic 'reasons' for the drug recommendation are explicitly described.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

49. Patient perspectives are reflected in the 'reasons' for the drug recommendation when they are available.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

50. Public perspectives are reflected in the 'reasons' for the drug recommendation when they are available.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

51. Patient groups who have made submissions should be able to submit comments on committee recommendations before they are finalized.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

52. Individual members of the general public should be able to submit comments on committee recommendations before they are finalized.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

53. Our patient group submission guidelines are easy to find on our website.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

54. Appropriate effort is made to ensure that all committee members understand the evidence presented to the committee.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

55. I want to be able to give feedback to patient group submitters on their submission.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

56. I want the committee to be able to give feedback to patient group submitters on their submission.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

57. I want [staff](#) to contact patient group submitters for clarification on their submission.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

58. I want the patient group submitters to be able to contact my committee with questions about their submission.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

59. I want patient group submitters to have the opportunity to appeal my committee's recommendations.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly Agree	Moderately Agree	Neither Agree nor Disagree	Moderately Disagree	Strongly Disagree	NA

OPEN COMMENTS

The purpose of this section is to give you an opportunity to provide additional feedback.

- 1. What other general comments do you have about patient and public involvement in the drug recommendation process?**

- 2. Think back to a time when patient input was necessary in the drug recommendation process. Why was this so?**

3. Can you think of a time when public and patient input added value to the deliberation? Why was this so?

DEMOGRAPHICS

The purpose of this section is to assess the background characteristics of individuals who take the survey.

1. I want patient group submitters to have the opportunity to appeal my committee's recommendations.

☐ Female

☐ Male

☐ Other

2. What is your age?

(Years)

3. What level(s) of education you have completed? Please select all boxes that apply to you.

<input type="checkbox"/>	Some high school, no diploma	<input type="checkbox"/>	Some university
<input type="checkbox"/>	High school diploma or equivalent (for example, General Education Development i.e. GED)	<input type="checkbox"/>	Bachelor's degree
<input type="checkbox"/>	Some trade/ technical/ vocational/ business training	<input type="checkbox"/>	Professional Degree (Law, Medicine, Allied Health, etc.)
<input type="checkbox"/>	Diploma or certificate from trade/ technical/ vocational/ business training	<input type="checkbox"/>	Master's degree
<input type="checkbox"/>	Some community college, secondary or pre-university program	<input type="checkbox"/>	Doctorate Degree
<input type="checkbox"/>	Community college, secondary or pre-university program diploma	<input type="checkbox"/>	Other: <u>Please specify:</u>

4. Besides your current role on the committee, check the one box that best describes your current employment situation:

(Check one that most applies).

<input type="checkbox"/>	Employed in paid work
<input type="checkbox"/>	Self-employed
<input type="checkbox"/>	Out of work and looking for work
<input type="checkbox"/>	Employed in paid work
<input type="checkbox"/>	Retired
<input type="checkbox"/>	Unable to work
<input type="checkbox"/>	Other: <u>Please Specify:</u>

5. What is your current occupation?

<input type="checkbox"/>	Administration and/or clerical
<input type="checkbox"/>	Banking and finance
<input type="checkbox"/>	Caregiver
<input type="checkbox"/>	Customer service
<input type="checkbox"/>	Engineering
<input type="checkbox"/>	Government
<input type="checkbox"/>	Hospitality
<input type="checkbox"/>	Human resources
<input type="checkbox"/>	Information technology
<input type="checkbox"/>	Lawyer
<input type="checkbox"/>	Nurse
<input type="checkbox"/>	Pharmacist
<input type="checkbox"/>	Physician
<input type="checkbox"/>	Retail
<input type="checkbox"/>	Other: <u>Please Specify:</u>

6. The committee is composed of members that bring a variety of expertise and perspectives to the committee deliberations. What input do you bring to the committee deliberations?

(Check all that apply.)

<input type="checkbox"/>	Patient member
<input type="checkbox"/>	Public member
<input type="checkbox"/>	Researcher <u>Please specify:</u>
<input type="checkbox"/>	Ethicist
<input type="checkbox"/>	Pharmaco-economist
<input type="checkbox"/>	Healthcare provider <u>Please specify:</u>
<input type="checkbox"/>	Other: <u>Please specify:</u>

7. How long have you served as a member on this committee: (years)

8. What is the length of your term as a member on this committee: (years)

9. Have you served on any other committees? ☐Yes ☐No

If yes, please specify the committees you served on.

Committee	Length of participation on Committee
1) Click here to enter text.	(months) (years)
2) Click here to enter text.	(months) (years)
3) Click here to enter text.	(months) (years)

Glossary

Term	Definition
Chair of Committee	The Chair of the committee moderates committee deliberations and ensures that meeting regulations are being followed and all members have an opportunity to speak/participate and are fulfilling their responsibilities. ¹
Committee Deliberation	Committee deliberation can be defined as the examination of and discussion about an issue. This often involves weighing options in order to produce a recommendation. ²
Drug	A drug is a pharmaceutical compound/substance used to cure, mitigate, treat, or prevent illness. ³
Industry	Industry refers to an organized group that discovers, develops, produces, and/ or markets drugs for use as medications. ⁴
Patient Group	A patient group refers to an organized group that represents a patient population. Patient groups may be involved in disease education; provide help lines, emotional support, and access to treatment for patients. When a drug is under review, these groups are invited to provide input about patients' lived experiences with a medical condition related to the drug under review. ⁵
Patient Group Submission	A patient group submission is input from a patient group that identifies the priorities, unmet needs, expectations and preferences of patients to help inform those

	reviewing the drug and making formulary listing recommendations. ⁷
Patient Group Submitters	Patient group submitters are members of a patient group who have made a submission for a drug to an organization to use in the review of a drug and to provide a listing recommendation via a committee.
Patient Member	Patient members in this context are patients or caregivers who have lived experience with treatment or care of a medical illness or have developed first-hand experience through being a caregiver. Patient members have a demonstrated understanding of patient needs and priorities. ⁷
Professional Committee Members	Professional committee members, in this context are sometimes referred to as technical expert members. Through their training and backgrounds they bring the expertise and perspectives of, but not limited to, health professionals, economists, ethicists, epidemiologists, in making formulary listing recommendations. <small>1 (Note: see CDEC TOR)</small>
Public Meeting	A public meeting allows the public to observe committee deliberations regarding a drug under review. These meetings have been established by organizations to ensure that the public understands the way in which a committee evaluates all available evidence before making a recommendation on whether or not a drug may be approved for use. ⁸
Public Member	Public members are individuals who are members of the public and represent the

	general public perspective in drug advisory committee recommendations and not as a representative of any specific interest, group, or organization. ⁹
Representation	Representation refers to whether a full range of perspectives from affected interests is represented. ¹⁰
Staff	non committee members that support the committees administrative duties.
<p>(1) Canadian Drug Expert Committee Terms of Reference. https://www.cadth.ca/media/corporate/corp_committees/CDEC_TOR_e.pdf (2) Conflict of Interest Guidelines for CADTH Expert Committee and Panel Members. https://www.cadth.ca/sites/default/files/corporate/CADTH_COI-Guidelines-Committ-Panels_e.pdf (3) U.S. Food and Drug Administration. Glossary. 2015. http://www.fda.gov/AnimalVeterinary/ResourcesforYou/ucm268130.htm (4) Andrewvolkoff. (n.d.). Pharmaceutical industry. Retrieved December 5, 2018, from https://gmpnews.net/glossary/pharmaceutical-industry/ (5) Procedure for the CADTH Common Drug Review. 2014, Version 17, 1-64. https://www.cadth.ca/media/cdr/process/CDR_Procedure.pdf (5) Completing a patient group submission template: Guidance for patient organisations for HTA assessment and appraisal of medicines Version 2, issued Oct 2015 http://www.htai.org/fileadmin/HTAi_Files/ISG/PatientInvolvement/GuidanceandChecklist_October_2015_Web_Final.pdf (7) Profile of Patient Members for pan-Canadian Oncology Drug Review Expert Committee. http://www.hrassociates.ca/cadth-pcodr/15-055-Profile-Patient-Member(CADTHpCODR)_25015Jun.pdf (8) Scottish Medicines Consortium (SMC). Attending a Scottish Medicine Consortium Meeting. Information for Members of the https://www.scottishmedicines.org.uk/files/meetings_in_public/SMC_Meeting_In_Public_Observer_Factsheet__Glasgow_City_Hotel_.pdf (9) Canadian Optimal Medication Prescribing and Utilization Service Expert Review Committee (CERC) Terms of Reference. https://www.cadth.ca/media/compus/pdf/compus_cerc_tor_oct06_e.pdf (10) Rowe G, Horlick-Jones T, Walls J, Poortinga W, Pidgeo NF. Analysis of a Normative Framework for Evaluating Public Engagement Exercises: Reliability, Validity and Limitations. Public Understanding of Science 2008;17(4):419-441. (11) Rosenberg-Yunger, Z., & Bayoumi, A. (2017). Evaluation criteria of patient and public involvement in resource allocation decisions: a literature review and qualitative study. International Journal of Technology Assessment in Health Care, 33(2), 270-278. doi:10.1017/S0266462317000307.</p>	

Appendix 1: Evaluation criteria of patient and public involvement in resource allocation decisions

Criterion 1. Clarity Regarding Rationale and Roles of Patient and Public Members. The purposes of patient and public involvement should be clearly defined. This criterion may define whether a member's role is to represent the broader public view, the patient view, or both. Furthermore, rationale may define whether the objective of involvement is to consult with external patient advocacy groups or to actively partner with them in making decisions. This criterion corresponds to the following PPIQ items: 15, 16 and 17.

Criterion 2. Adequate Representation of Relevant Views. A full range of perspectives should be represented. This criterion may assess whether patient and public members are sufficiently representative of their constituencies and whether patient advocacy group submissions that are received from several groups adequately represent diversity. This criterion corresponds to the following PPIQ items: 1, 2, 3, 4, 17, 18, 19, 22, 23, 24 and 30.

Criterion 3. Fair Decision-Making Processes The processes and procedures used by the committee should ensure fairness in decision making from the perspective of patient and public representatives. This criterion corresponds to the following PPIQ items: 28, 29, 31, 36 and 42.

Criterion 4. Sufficient Support. Patient and public representatives should have sufficient support to fulfill their responsibilities. This criterion corresponds to the following PPIQ items: 10 and 12.

Criterion 5. Legitimacy of Committee Processes. Committees' processes should be accountable and transparent. This criterion may assess whether participants understand how decisions are made and whether stakeholders are able to appeal decisions. This criterion corresponds to the following PPIQ items: 6, 7, 8, 9, 34, 35, 37, 38, 39, 40, 44, 45, 46, 47, 48, 53 and 59.

Criterion 6. Adequate Opportunity for Participation Committees should have processes that allow public and patient representatives the opportunity to participate fully in discussions and to address power differentials. This criterion corresponds to the following PPIQ item: 14.

Criterion 7. Meaningful Degree of Participation. Committee deliberations should include meaningful patient and public participation. This criterion may assess the level of participation of public and patient members in decisions and the number and quality of patient advocacy group submissions. This criterion corresponds to the following PPIQ items: 5, 19, 20, 21, 26, 27, 32, 33 and 41.

Criterion 8. Noticeable Effect on Decisions Public and patient involvement should materially influence committees' recommendations. This criterion may assess how many decisions would have led to different conclusions had patient or public involvement not been present. This criterion corresponds to the following PPIQ items: 49, 50, 51, 52, 55, 56, 57 and 58.

Criterion 9. Considerations of Efficiency Committees should have sufficient resources to ensure effective participation, which should be used efficiently. This criterion may assess the time and money needed to make recommendations and the value obtained relative to the resources expended. This criterion corresponds to the following PPIQ items: 11, 13 and 25.

1. Rosenberg-Yunger, Z. R. S., & Bayoumi, A. M. (2017). Evaluation criteria of patient and public involvement in resource allocation decisions: a literature review and qualitative study. *International Journal of Technology Assessment in Health Care*, 33(02), 270–278.