# Supplementary File 1 – Questionnaire

An Environmental Scan of Patient and Public Involvement Evaluations in Health Technology Assessment Internationally

**This questionnaire is also available online at:** <http://cadth.fluidsurveys.com/s/PPIEvaluation/>

The HTAi Patient and Citizen Involvement Group is interested to know about how you and your organization evaluate patient and public involvement activities. Please help promote good practice in evaluation by completing this questionnaire. For this project we define patient and public involvement as a range of activities with the goal to consult, engage, or communicate with patients and/or members of the public for the purpose of research, policy or program development. We are interested in any type of evaluation, including process and impact evaluations, assessments of participant satisfaction, or any other evaluative exercise in relation to patient and/or public involvement in HTA.

This questionnaire will take between 10 and 30 minutes to complete, depending on the level of experience you have had with evaluation and the detail you are willing to provide. You are able to save your responses part way through, to continue at a later time. You are also able to review your responses before submitting your completed questionnaire, but please note you must "Save" your responses before doing so.

We will share the results directly with individuals from each organization who complete this questionnaire, in the hopes we can learn from each other’s range of experiences. We will also share the results of this environmental scan through a report published on the HTAi website, and potentially also through presentations at HTA conferences and through a publication in an academic journal and/or book chapter.  Although most results will be presented in an aggregate form, it is possible that your organization and related information could be identifiable in a publication and it is likely that your organization will be identifiable within reports published on the HTAi website. As such, your submission of a completed questionnaire indicates your informed consent to include data from your organization in these publications.

Please note that each organization need only complete one questionnaire. If you are unable to complete this questionnaire on behalf of your organization, we would appreciate it if you could pass it on to the appropriate person and let us to whom so that we may follow up with that person directly. A hard copy of this questionnaire can be obtained from Laura Weeks: [lauraw@cadth.ca](mailto:lauraw@cadth.ca).

If you have any questions, please contact Laura Weeks, Scientific Advisor, CADTH and member of HTAi Patient and Citizen Involvement Group: lauraw@cadth.ca.

**SECTION 1: About your Organization**

In this section, we would like to learn information about you and your HTA organization.

1. **What HTA organization are you affiliated with?**

1. **What is your position or role within this HTA organization?**

1. **What is the structure of your HTA organization?**

* Department within Government ministry
* Quasi-governmental (e.g., CADTH, NICE)
* Academic research unit, group or institution
* Hospital unit, group or institution
* Other (please specify) | other

1. **At what level does your HTA organization operate?**

* Across more than one country
* National
* State or Provincial
* Regional
* Municipal or local
* Other (please specify):

**SECTION 2: Involving Patients and Members of the Public**

In this section, we would like to learn about whether and how patients and/or members of the public are involved within your HTA organization.

1. **In the HTA process, does your organization involve (select only one):**

* Patients (please answer question 6, but not question 7)
* Members of the public (SKIP to 7)
* Both patients and members of the public
* Neither patients nor members of the public. If neither, please describe the main reasons why your organization does not engage patients nor members of the public, and describe any future plans. (When done, please SKIP to Question 21, on page 10)

1. **How are PATIENTS involved in the HTA process in your organization (check all that apply)?**

* Participation in a working group or committee
* Identifying topics for assessment
* Refining the scope of an assessment (e.g., PICO)
* Designing research methods
* Identifying clinical outcomes
* Reviewing research protocol | -99.5
* Data collection
* Data analysis
* Writing reports
* Reviewing reports
* Appraising the evidence
* Making recommendations
* Sharing/disseminating results
* Other (please specify):

1. **How are MEMBERS OF THE PUBLIC involved in the HTAs completed by your organization (check all that apply)?**

* Participation in a working group or committee
* Identifying topics for assessment
* Refining the scope of an assessment (e.g., PICO)
* Designing research methods
* Identifying clinical outcomes
* Reviewing research protocol | -99.5
* Data collection
* Data analysis
* Writing reports
* Reviewing reports
* Appraising the evidence
* Making recommendations
* Sharing/disseminating results
* Other (please specify):

1. **How does your organization determine for which HTAs patients and/or members of the public are involved?**

1. **What are the main reasons your organization engages patients and/or members of the public in HTA activities (select all that apply)?**

* To promote capacity building (e.g., ability of patients of members of the public to collect information to inform an HTA)
* To promote fairness and inclusion of a range of stakeholders in the HTA process
* To enhance patient or public support of decisions
* To help ensure decisions reflect patient and public values
* To enhance patient and public understanding of HTA
* Other (please specify):

**SECTION 3: Evaluating Patient and Public Involvement**

In this section, we would like to learn about whether and how your organization has evaluated any patient or public involvement activities.

1. **Does your organization evaluate, or has your organization ever evaluated, patient and public involvement activities?**

* Yes
* No. If no, please list some of the main reasons your organization has not yet evaluated any PPI activities:

1. **What types of evaluations has your organization conducted in relation to patient and public involvement (select all that apply):**

* Participant satisfaction
* Process (i.e., evaluation of how activities are implemented, or how outcomes are achieved)
* Impact (i.e., evaluation of any changes that have occurred as a result of activities)
* Other (please specify):

1. **How frequently has your organization evaluated patient and public involvement activities (select one):**

* For every HTA
* Every six months
* Annually
* Every 2 years
* Every 3 years
* Longer than every 3 years
* Other (please specify):

1. **How does your organization determine for which HTAs patient and public involvement activities will be evaluated?**

1. **How are the results of your evaluation activities used within your organization?**

1. **How are the results of your evaluation activities published, or shared, within your organization or with other organizations? (check all that apply)?**

* We do not publish or share the results of our evaluation activities
* Published in an academic journal
* Published in lay publications or magazines
* Published on our website
* Presented at HTA or other conferences
* Published in a newsletter
* Other (please specify): | other

**SECTION 4: Lessons Learned Evaluating Patient and Public Involvement**

In this section, we are interested in learning about some of the lessons learned through your experiences evaluating your organization's patient and public involvement activities.

1. **What are some of the challenges faced during the evaluation(s)?**

1. **What changes have been made to your organization’s patient and public involvement activities as a result of evaluation(s)?**

1. **What are some of the aspects of your evaluation(s) that you feel helped the process run smoothly?**

1. **What are your organization’s future plans for evaluating patient and public involvement activities?**

1. **Are there any other insights you would like to share with other organizations who are planning to evaluate their PPI activities?**

**SECTION 5: Details of any Evaluations of Patient and Public Involvement**

The final piece of information we are interested in obtaining is as much detail as possible regarding the methods your organization follows when evaluating patient and public involvement activities as well as the results.

We are interested in any type of evaluation, including process and impact evaluations, assessments of participant satisfaction, or any other evaluative exercise.

Given this could represent a substantial amount of information and effort on your part, we offer four options for you (CHOOSE ANY ONE OPTION, AND COMPLETE THE APPROPRIATE SECTION BELOW).

Option 1: Do not provide any further details

Option 2: Speak with a project team member to describe your evaluations

Option 3: Share manuscripts or other reports that describe your evaluation activities

Option 4: Write a description of your evaluation activities within this questionnaire

Option 1: Please check here if you would not like/are unable to provide any of this detailed information.

□

Option 2: You may arrange a convenient time with a project team member to describe the evaluation methods you use and results of prior evaluation(s). If choosing this option, please provide your email address so that someone can contact you to establish a convenient time to talk.

□

Option 3: You may provide references to reports or manuscripts that describe the evaluation methods and results of prior evaluation(s).

If choosing this option, please attach them as files when returning this completed questionnaire to Laura Weeks (lauraw@cadth.ca). Alternatively, you may copy any URLs to documents on the internet in the space provided below.

Option 4: You may submit information in the form of a structured abstract to describe your evaluation methods and results of prior evaluation(s).

If choosing this option, please describe your evaluation in the space provided below. In your descriptions, please provide as much detail as you are able, and consider the following topics:

* Objectives of the evaluation
* Study design (e.g., pre-test/post-test, case study, qualitative descriptive, cross-sectional)
* Time horizon
* Perspective (e.g., patient, public, clinician, researcher, decision-maker)
* Description of any participants, or documents reviewed
* Data collection strategy
* Outcomes of interest (e.g., definition of “impact”)
* Data analysis strategy
* Summary of results.

If you are able, we would also appreciate copies of any templates or other evaluation forms or questionnaires used in your evaluation(s)

If you are, or have, completed more than one patient and public involvement evaluation following different methods or with different objectives, please provide up to 3 of your most informative examples.

1. **If you know of any key resources describing examples of evaluations or evaluation methods for patient and public involvement in HTA, please share them below:**

1. **Do you give permission for a study team member to contact you to clarify any of your responses on this questionnaire if necessary?**

* No.
* Yes. If yes, please provide your email address:

1. **If you know of any other people involved in evaluating patient and public involvement activities at other HTA organizations who would be willing to complete this questionnaire, please provide their name and/or contact information below so that we can be in touch with them.**

1. **We welcome any general feedback on this survey. If you have any feedback, please provide it here.**

1. **If you would be willing for us to contact you again in the future to seek further information regarding HTA stakeholders’ perspectives regarding patient engagement and evaluation, please provide your name and email address here.**

**Thank you for your assistance in completing this questionnaire and for providing us with information about your evaluation activities.**

If you have any questions, please contact Laura Weeks, Scientific Advisor, CADTH and member of HTAi Patient and Citizen Involvement Group: lauraw@cadth.ca.