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865 Carling Ave., Suite 600
865, avenue Carling, bureau 600
Ottawa, Ontario
Canada K1S 5S8

CADTH - Patient Community Liaison Forum Teleconference
Wednesday February 10th 2016, 11:00-12:00 EDT

Attending from Patient Community Organizations: Connie Côté (HCCC) chaired the meeting, Gail Attara (BMC), Lynette Hillier (CCAN), Paulette Eddy (BMC), Seema Nagpal (HCCC), Wayne Critchley (CORD).

Attending from CADTH: Alexandra Chambers, Director, pCODR**;** Chander Sehgal, Director, CDR and Optimal Use; Ken Bond, Director, Strategic Initiatives; Helen Mai, Policy and Strategy Analyst, pCODR, Sarah Berglas, Patient Engagement Officer; Tamara Rader, Patient Engagement Officer.

Apologies: Louise Binder (CCAN), Durhane Wong-Rieger (Advocare)

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1. Welcome / Approvals
Agenda and summary of December meeting (once correction made) approved.

2. Updates from Patient Community Members
Canadian Organization for Rare Disorders shared they are preparing to address the Legislative Assembly of Ontario on International Rare Disease Day on February 29th, a rare day. CORD will also host a Rare Disease Day Conference and Gala, March 9-10th in Ottawa.

Health Charities Coalition Canada shared their members are preparing a position paper on access to prescription drugs.

3. CADTH Update
The preliminary program is now available; workshops on Sunday 10 April, and panel sessions 11 – 12 April. The 2016 CADTH Symposium proudly meets all five of the charter's clauses, and has been deemed a Patient's Included conference. Conference registration is open; $100 for patient group representatives, plus cost of workshops. Those those who can't attend, follow discussion at #CADTHsymp and join the webinar broadcasting a session live.

CADTH will shortly be publishing our revised process for Therapeutic Reviews, incorporating feedback from 2015 consultation. Of significance to patient groups, CADTH is extending the period for groups to collect, prepare and submit patient input. As input will be received by CADTH after the project protocol is finalized, CADTH encourages patient groups (and patients, families, caregivers) to directly comment on the draft project scope, which will be open for stakeholder feedback, at the very beginning of project. In February, CADTH will start a new Therapeutic Review on drugs for diabetes.

It was asked if CADTH plans to formally evaluate patient engagement. Members shared that patient groups continue to question the value of the process and what it seeks to achieve. As part of Health Canada's funding agreement with CADTH, an external evaluation on all aspects of CADTH's operations is being conducted during 2016. Several individuals from patient group will be interviewed confidentially.

ACTION: Joselyn Chismore can provide an outline of the evaluation at a future teleconference.

A question was raised of the pilot program for clinician engagement in pCODR. The current pCODR process includes input from three oncologists to help interpret data, provide context, and develop the main conclusions of the Clinical Guidance Report. Proposed changes to the pCODR process aim to expand

CADTH's reach into the clinical community to gain insight into local issues and identify areas of unmet need. The pilot process is similar to patient input for pCODR. Clinician need to register, declare potential conflicts of interest, be affiliated with a cancer body and currently treat patients. An FAQ and template for input is available online. CADTH intends to evaluate this pilot initiative after 25 cancer drug submissions with clinician input have been received, or sooner as may be appropriate, and will consult with stakeholders on any significant changes to the pCODR process.

It was asked if clinician engagement will happen for CDR. It has been considered by CADTH, but there are no immediate plans to introduce a similar program for CDR. It is important that we evaluate this pilot under the pCODR process on its successes before considering plans to expand the initiative. The drugs reviewed by CDR are diverse; few drugs are for the same disease area. A secondary consideration is the volume of reviews through CDR and concern that additional evidence synthesis would slow the process. Instead CADTH is currently looking to broaden the pool of clinical experts involved in drug reviews, including international experts.

4. Example Based Guide on use of Patient Input

CADTH will be adjusting the current patient input template for CDR to help patient groups better gather and and more easily submit information that is most often used by the CADTH CDR team and expert committee. For example, instead of asking groups to describing the disease in general, we'll encourage groups to describe what patients, families and caregivers would like therapies for the disease to achieve,and what it would mean for patients' and families' daily lives and quality of life if treatment could achieve these outcomes.

We'd like for the new guide to closely align to the new template. We'd still like to create a working group to collaborate on the development of the guide and provide comment on the template.

ACTION: Sarah to prepare a short description of the project to share with all, including support needed from groups and a time frame for next steps.

5. In person April meeting

All members felt that opportunity to meet in person was valuable. While CDEC / pERC public and patient members were welcome to listen to the meeting, it was not seen as necessary for the members to present to the group. Topics to be addressed during the April meeting include: discussion on the goals of the forum, if these goals are being met for all participants and how might the forum evolve, if necessary, to achieve these goals.

ACTION: CADTH to circulate additional times on April 10-12 for members to identify meeting preferences and availability. Completed.

6. Next Steps and Adjournment

Next meeting will be an in-person meeting, in Ottawa on Sunday 10th April, 11am – 1pm, at Shaw Centre. Durhane Wong-Rieger (or designate) to chair April's meeting.