

Connect

Engaging Canadians on Health Policy Matters

December 2014



Welcome to the December 2014 edition of CONNECT!

In today's CONNECT!:

- Recent developments at CADTH
- Janssen's recent roundtable on patient involvement in the life-cycle of new medicines
- Patient navigators in Canada

As this is our last edition in 2014, the Janssen Community Relations team would like to wish you all a joyous holiday season and a very Happy New Year!



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Recent Developments at CADTH

We'd like to update you on recent developments at the [Canadian Agency for Drugs and Technologies in Health \(CADTH\)](#):

- The agency has produced videos on patient input, [which can be viewed on YouTube](#).
- The agency has provided tips on patient submissions, encouraging patient groups to be specific about the advantages and limitations of current treatments.
- Elaine MacPhail, who played an important role in establishing CADTH's process for patient group input, has announced her retirement.
- Ken Bond, who recently joined CADTH as Director of Strategic Initiatives, will be responsible for patient engagement at the agency.



Janssen Roundtable on Patient Involvement in the Life-Cycle of New Medicines

In October 2014, Janssen engaged with national patient group representatives to discuss patient involvement throughout the lifecycle of medicines. This was an opportunity for our colleagues with global responsibilities for Janssen and patient group

representatives to exchange on best practices, challenges and potential solutions on positioning patients at the centre of healthcare decisions.

A number of themes emerged from these discussions, including:

- patients should be engaged at every step of the lifecycle of medicines, including early on in the drug development process, the regulatory process, the health technology assessment (HTA) process, the funding decisions and real world evidence studies
- what value means from the perspective of patients needs to be captured, as value often means something very different from the perspective of payers or healthcare providers
- patients need to be involved in determining what is important to them and how this should be measured



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- the HTA process should be broadened to factor in criteria beyond drug costs
- more transparency is needed on how patient input is factored into the HTA process
- more weight should be put on patient input in the context of reimbursement recommendations
- patient groups face many challenges when developing submissions for HTA processes,

including patient literacy issues and difficulties locating patients due to privacy laws

A more detailed summary of these discussions is available upon request. As well, if you are interested in sharing your perspectives on this topic, including any best practices, Janssen would love to hear from you! You can contact us at: RA-JOICA-JanCanaCONN@ITS.JNJ.com.

Patient Navigators

In the past decade, patient navigators have become more common in the healthcare environment in Canada. The role of patient navigators is typically to help patients understand the healthcare system and access the care they need. While their responsibilities vary depending on the navigation program, they can include:

- scheduling appointments
- arranging transportation
- accompanying patients
- connecting patients to the right doctors or resources
- health education
- counselling
- helping patients access available therapies

In Canada, one of the first navigation programs was established in 2001 in Nova Scotia in its cancer care system. Given its success, many other provinces followed suit and patient navigation programs can now be found in nearly all provinces. These programs typically focus on people living with cancer and navigators are often nurses by profession. Some jurisdictions, such as Nova Scotia and Quebec, require that navigators meet certain requirements before they can take on this role, officially.

Navigation programs are now being used in areas other than cancer, such as chronic disease management. These navigators are sometimes called “health system



navigators”, as they often help address system-related barriers, such as ensuring better case management and effective use of resources as well as providing patient education.

Some navigation programs have evolved towards adopting more culturally sensitive approaches. For instance, many programs have been introduced across Canada to serve Aboriginal communities and a program in Toronto was created specifically for the Chinese Canadian population. Generally, these navigators are “peers”, and can include people from the same culture and community and even cancer survivors. These navigators are able to address language and cultural needs or gaps.

Some navigators are specifically focussed on assisting



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patients with drug coverage. For instance, the Oncology Drug Access Navigators of Ontario (ODANO) is a provincial organization that helps maximize the appropriate funding for cancer patients. These navigators help facilitate drug coverage by:

- accessing government funding through programs such as Ontario's Exceptional Access Program
- accessing compassionate use programs
- finding other reimbursement programs for unfunded drugs

Recently, the Canadian Cancer Action Network (CCAN) hired a Patient Health Technology Assessment Navigator to assist patient advocacy groups in navigating the pan-Canadian Oncology Drug Review (pCODR) process.

This ongoing pilot project, which is a first in Canada, is meant to provide patients groups with the required support to optimize their patient input submissions to pCODR, as well as develop, identify and support opportunities for patient and caregiver involvement in the pCODR process.

Finally, family members and caregivers also play an important navigation role by providing emotional support, accompanying the patient through his or her journey and advocating for patients when needed. They can also help optimize the role of professional patient navigators by providing them with information on patient preferences and pushing for better and more coordinated services when necessary.



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