

Becoming A Champion of Change: Influencing Government

Presented by:
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November 7th, 2014

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Goals for today

1. Learn about why and how we advocate
2. Understand CCC's 3 advocacy priorities
3. Discover how to meet with elected officials
4. Gain skills in becoming effective advocates



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Part 1: Advocacy

What is it?

Why do we
do it?

Who does
it?

To
whom?



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Advocacy – What is it?

- Social change, policy change, changing the status quo
- Raising awareness to Government
- Working in partnerships, coalition building
- Appealing for public support



Advocacy – Who does it?

Caregivers

Health care
professionals

“Credible”
institutions
(unions, think tanks)

Special
interest
groups
(disability rights,
seniors)

Ad Hoc Groups
(support and professional
groups or issue-specific
coalitions)

Politicians

Private
Industry

“You can” or
Anybody with a
passion

Celebrities

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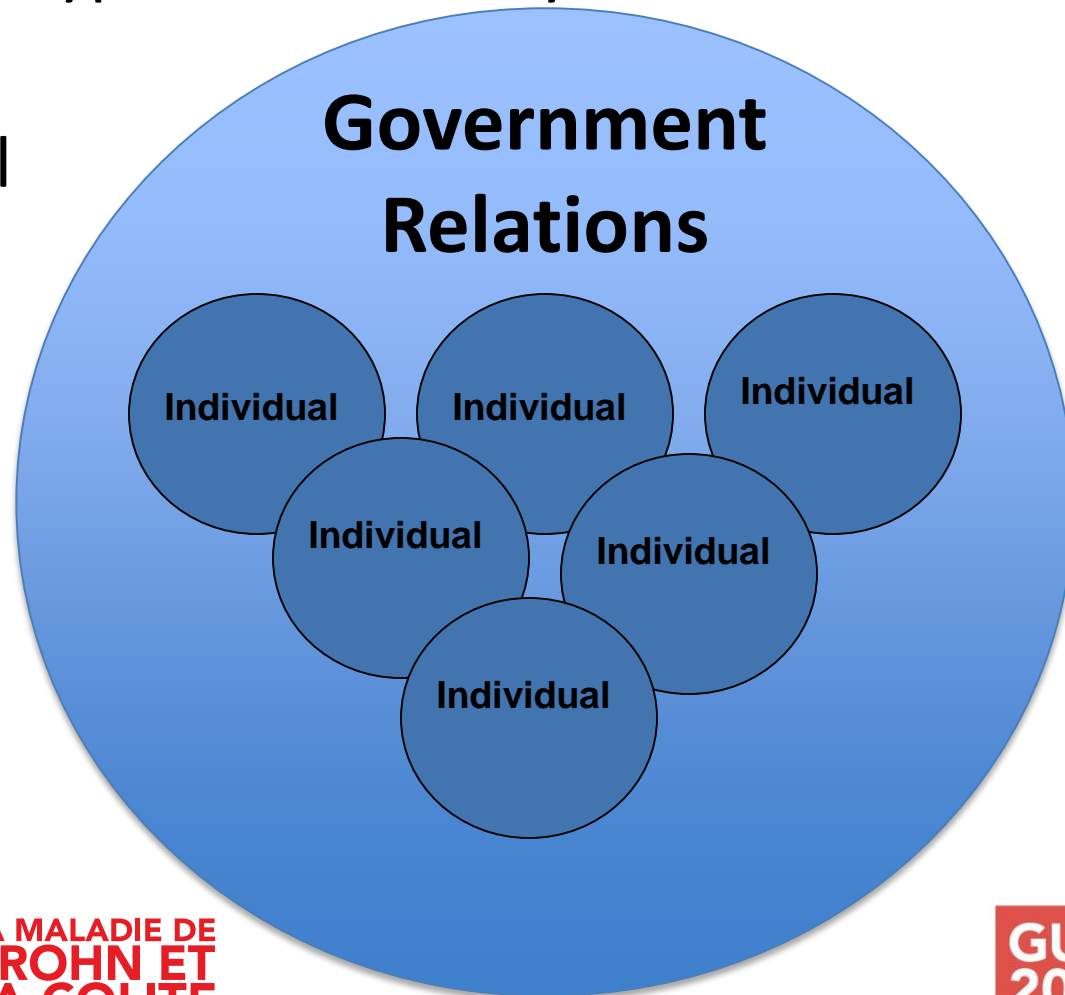
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Advocacy Types

There are two types of advocacy:

1. Individual
2. Systemic



Advocacy – Who we Advocate to?

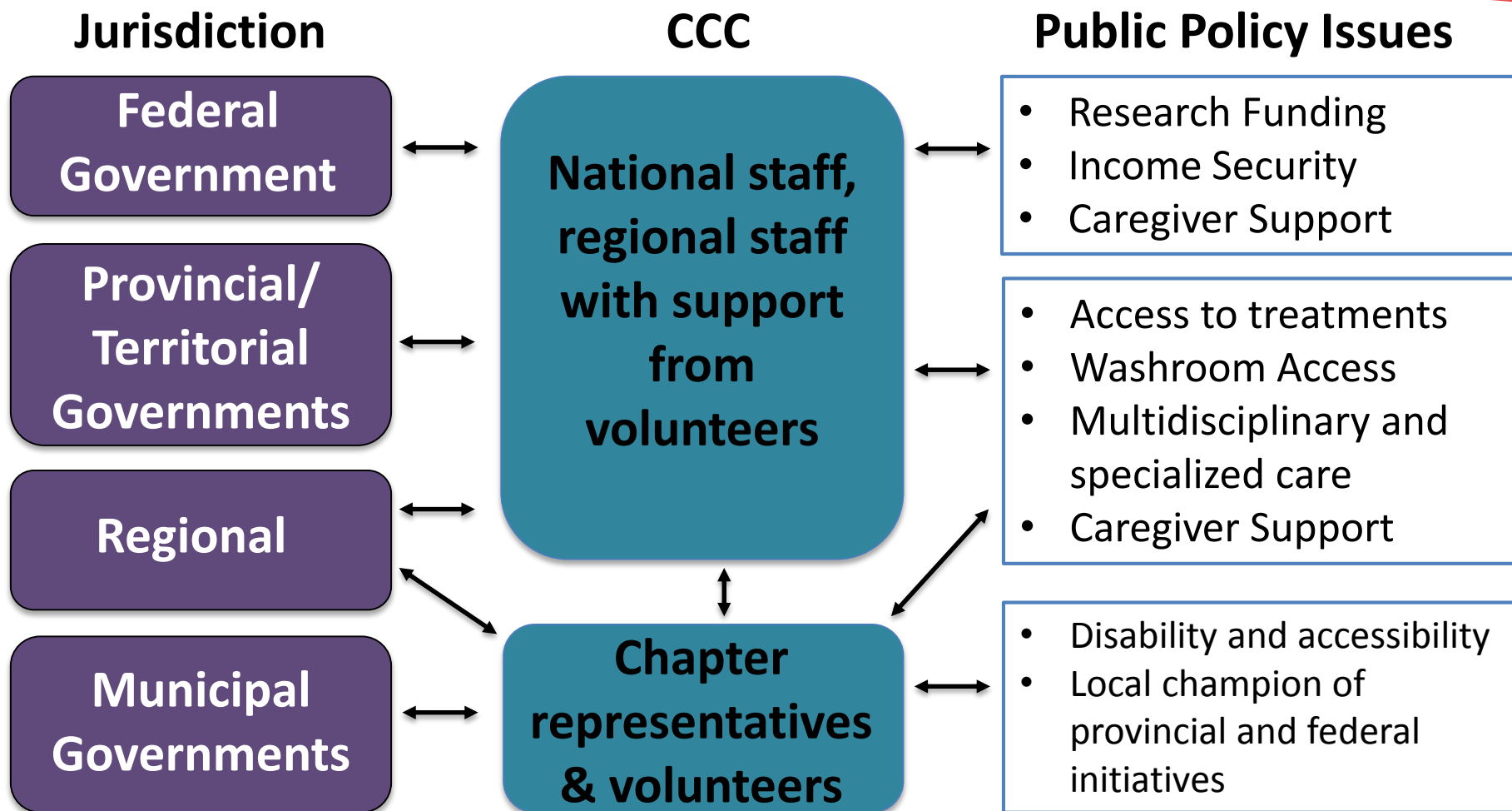
Elected Officials & Staff

- Members of Government
 - MPs, MLAs/ MPPs/ MNAs
- Cabinet Ministers
- Opposition (critics)
- Standing Committee (Health, Social, Economic)
- Municipal Councils
 - Accessibility Advisory Councils, transit authorities, etc...

Non-elected Officials

- Political staff
 - Assistant/aides
 - Advisors
 - Schedulers
- Civil Servants
 - Deputy councilors
 - Policy analysts/ advisors

Advocacy – Who we Advocate to?



Advocacy – Why is it needed?

- We are the experts on Crohn's and colitis
 - We want to be a leader in improving the lives of children and adults living with Crohn's and colitis
- We can advance our issues on political agendas
- We can provide practical solutions to problems
- We want public policy changes
 - Access to treatments, increased access to washrooms

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Part 2:

Crohn's and Colitis Canada's Three Advocacy Priorities



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Our Advocacy Issues



Improved access to
treatments



Increased access to
washrooms



Enhanced specialized
GI care

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Issue 1: Recommendations – Drug Access

- Increase the number of **approved** Crohn's and colitis treatments;
- Ensure that all Canadians have access to drug **coverage** through public plans
- Provide coverage for **therapeutic drug monitoring**

“Not every person with Crohn's and colitis has access to affordable treatments”

Issue 1: Context – Drug Access

Challenges:

- Drugs dispensed outside hospitals are not covered under the *Canada Health Act*
- Drug reimbursement is a mix of federal and provincial governments, private insurers, out of pocket
- Public formulary decisions are made province-by-province (and federally for some populations)
- Majority of Canadians obtain drug coverage privately, a significant proportion depend on public drug coverage

Statistics:

- 23% of new drugs approved by Health Canada from 2004 to 2010 made it to provincial formularies by January 1, 2012
- In contrast, 84% of the same drugs were covered under private sector drug plans

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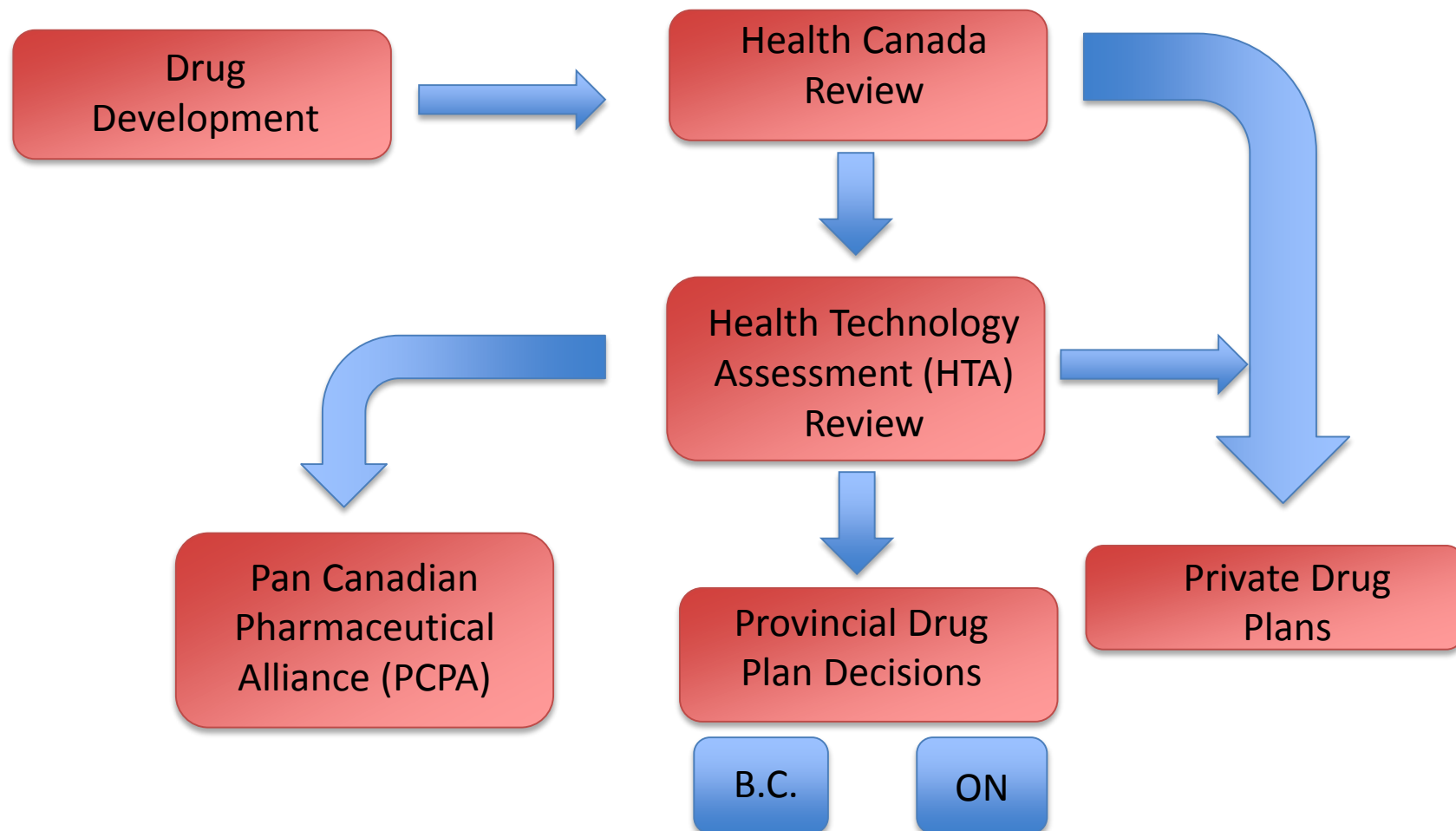
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Issue 1: Drug Life Cycle – Drug Access



Issue 2: Recommendations – Washroom Access

- Encourage provinces (and municipalities) to **enact legislation** (and by-laws) that guarantee access to public washroom facilities
- Encourage all levels of government to **participate in the GoHere** decal initiative

“Public washroom facilities are not always accessible. Sometimes they are open for customers or employees only.”

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Issue 2: Context – Washroom Access

Challenges:

- Not enough washroom facilities in public spaces
- Facilities that exist may have washrooms only for ‘customers’ or ‘employees’
- Canada lags behind in legislation that calls for open washrooms for people living with chronic conditions, disabilities or incontinence issues

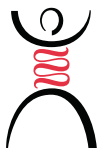
Statistics*:

- 73% said they experience between five to 20 bowel movements or false urges a day during active disease. 13% had more than 20 movements or urges a day
- 53% had to negotiate or share private details of their condition in order to use washrooms
- 78% chose to stay at home during a flare-up in fear of not accessing washrooms

* CCC survey in 2011 studying impact of access to washrooms with over 1,300 responses

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Issue 2: GoHere – Washroom Access

www.go-here.ca

- Go Here decals to identify open washrooms at businesses
- Development of GoHere mobile app
- Launch of washroom access cards



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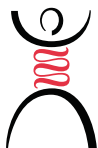
Issue 3: Recommendations – Specialized Care

- **Reduce wait times** to meet with a Gastroenterologist (GI) and improve time it takes for diagnosis
- Establish support for **multidisciplinary teams** to enhance patient care and support clinical research

“Most people receive care from medical practitioners who don’t specialize in IBD.”

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Issue 3: Context – Specialized Care

Challenges:

- Crohn's and Colitis are complex and should be managed by GI specialists, ideally in a multidisciplinary healthcare setting.

Statistics:

- IBD patients experience a total wait time of up to 18 weeks for a consultation and for a diagnostic endoscopy, which is 16 weeks longer than the recommended wait time target.

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Group Exercise (10 mins)

- 1) Each table will have one of the following priorities: access to treatments, washroom access and access to specialized care.
- 2) Identify 1 note taker and 1 presenter
- 3) Each group will create an action plan and answer the following questions:
 - a) **Who** do you know in your community that could assist with influencing policy change? Think outside the box.
 - b) What **additional information** do you require to meet with your locally elected official (MP, MLA/MPP/MNA, Councillor)?
 - c) As volunteers, what will keep you engaged in doing advocacy?

Part 3:

Effectively engaging Government



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Preparation and Follow Up

- **Request a meeting** with your representative by email or letter, follow up by phone
- Do your **research**, know your issue and learn about your Gov't representative
- Prepare your '**leave behind**' kit
- Take notes and fill in a **debrief** report for CCC
- Send a **thank you** letter and follow up on information you promised to send

Tips to an Effective Meeting with Government

- Develop a connection in introduction (identify their passion or something you have in common)
- Ask if they know about CD and UC, find out their connection
 - Assume they know nothing and you are the expert
- Introduce your issues
 - 30 second pitch of the problem
 - Present a solution * Don't ask for the world
- Be non-partisan



How You Can Take Action

Become an Advocacy Volunteer Ambassador (sign-up)

Volunteer on chapter/division board/committees

Join online actions, write your elected officials

Meet with your locally elected official

Contact us at advocacy@crohnsandcolitis.ca

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Group Exercise – Mock Meeting (5 mins)

Find a partner. One will play the role of a government official and the other a CCC advocate. Hold a mock government meeting.

- Advocate – tell your story and present the three key issues. *Are you effective?*
- Government Rep – ask questions and provide direction on next steps. *Are you convinced?*

Thank You

For more information:

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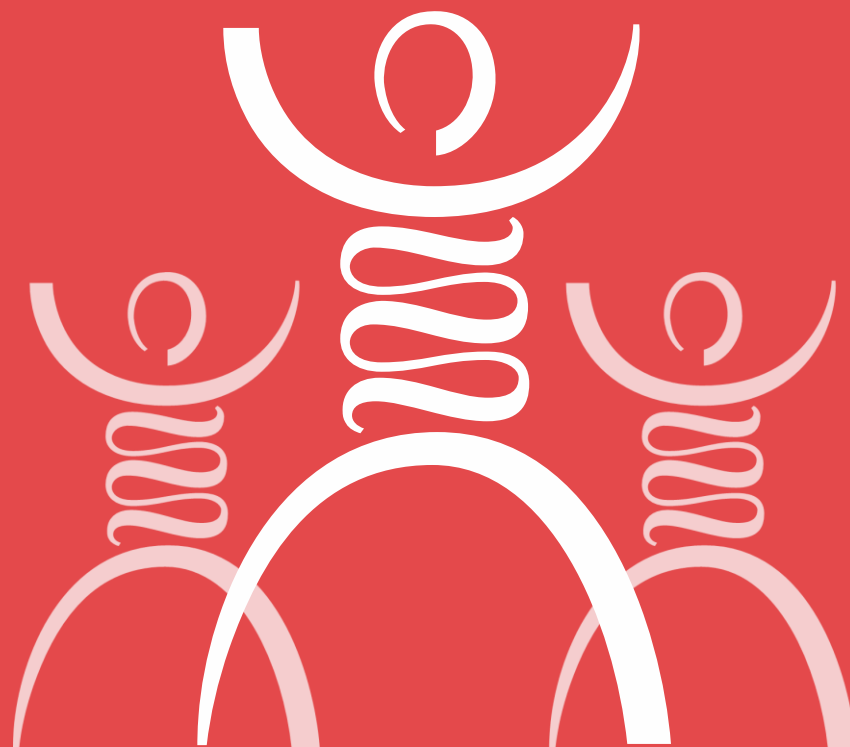


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