



Community Engagement and Consultation: What We Learned This Past Year



Canadian Association for Population Therapeutics
Association Canadienne pour la Thérapeutiques des Populations

Land Acknowledgement

We acknowledge the land we are hosting this webinar on the traditional territory of many nations including the Mississaugas of the Credit, the Anishnabeg, the Chippewa, the Haudenosaunee and the Wendat peoples, and is now home to many diverse First Nations, Inuit and Métis peoples.

We also acknowledge that Toronto is covered by Treaty 13 with the Mississaugas of the Credit.

Reference: City of Toronto, Land Acknowledgement for Toronto



Elena Lungu (moderator)
CAPT Board Member
**Patented Medicine Prices
Review Board**



Shanna Trenaman
CAPT Student Representative
PhD student Dalhousie University



Dr. Judith Glennie
Former CAPT Executive
J.L. Glennie Consulting Inc.

Agenda

Welcome and Introductions	Elena Lungu
Student Perspectives	Shanna Trenaman
2019 Stakeholder Survey	Elena Lungu
Key Informant Interviews	Judith Glennie
CAPT Advisory Panel on Scientific Direction	Judith Glennie
Closing Comments	Elena Lungu



Who are we?



Our **mission** is to advance population-based research of therapeutic interventions to improve the health outcomes of Canadians by:

- Bringing together diverse perspectives.
- Facilitating open exchange of ideas and collaboration.
- Influencing policy and practice.

Our long-term **vision** is to become the recognized Canadian leader for linking population-based therapeutic research, policy, and practice to optimize health outcomes.



Student Perspectives

Shanna Trenaman

Background

- Online survey conducted in March 2019
- Target audience consisted of current/past members, partners, and those with a connection to our work (n=698)
- Student insights sought to:
 - (a) Further support the CAPT strategic planning process in 2019
 - (b) Help inform the development of Student Program goals
 - (c) Provide feedback with relation to student priorities, experiences and perspectives on future CAPT direction

The top **three areas of interest** to students right now were defined as:

1. Research & development/RWD (real-world data)
2. Health policy & clinical practice issues **and** regulatory approvals & safety monitoring
3. Pharmacoeconomic models & analyses

We received some great ideas about how we might further improve student experiences with CAPT, including:

"Workshops on pharmacoepidemiology methods at the Annual Conference"

"More interactive components at the Annual Conference. Pre-workshop day was great"

"Speed-dating"

"Panels with discussion or roundtable discussions."

"Offer a training symposium for students; workshops and training sessions throughout the year; more webinars like the Health Canada webinar"

"Student mentorship program would be really helpful as we don't always have exposure to such training experience."

"Profiling the work of members would be insightful for students who are still exploring options after graduation."

Opportunities: Student Program

*Networking across
sectors and engaging
one-on-one with your
peers during the
Annual Conference*

ANNUAL CONFERENCE SAVE THE DATE!

Driving Health Innovation:
Harnessing the Power and Value of Real-World Evidence
MaRS Discovery District, Toronto, ON



October 21-22, 2019

Abstract submission opens **May 1, 2019**, closes **June 30, 2019**

Conference registration opens **July 1, 2019**

www.capt-actp.ca



Why attend this year as a student?

2019 ANNUAL CONFERENCE WHY YOU SHOULD ATTEND



SCIENTIFIC PROGRAM

Enjoy a robust two-day scientific program to hear engaging panelists and speakers discuss hot topics.



ABSTRACTS

Share your research as one of 70+ oral or poster presentations, and have it published in the *Journal of Population Therapeutics & Clinical Pharmacology*.



NETWORKING

Connect with approximately 200 leaders in fields such as health policy, academia, research, advocacy and government to expand your professional networking.



TRAVEL BURSARY

Eligible students and patient groups with an interest in attending the two-day event may apply for a travel bursary.



STUDENTS & PATIENT GROUPS

Eligible students and patient groups pay a reduced registration fee and for those with an accepted abstract, CAPT-ACTP waives the registration fee.

...AND MUCH MORE!

Driving Health Innovation: Harnessing the Power and Value of Real-World Evidence

OCTOBER 21-22, 2019, MARS DISCOVERY DISTRICT, TORONTO, ON

JOIN US TO DISCUSS

- Privacy, data sharing and access
- Innovative ways to use data/ big data applications to health
- Artificial intelligence and machine learning in data
- Linking RCTs to RWE/RWD on phase 4 trials
- RWE to inform reimbursement
- RWE to drive policy change

PARTNER WITH US

- Five different sponsorship levels available, with sponsors recognized in event signage and the scientific program
- Complimentary registration for sponsors

To explore partner opportunities:
sponsorship@capt-actp.ca

IMPORTANT INFORMATION

Abstract submission opens **May 1, 2019** and closes **June 30, 2019**.

Early bird online conference registration opens **July 1, 2019**.

Visit www.capt-actp.ca for conference updates.

For further information, please contact: peggy.kee@sunnybrook.ca

Opportunities: Student Program

Submitting an oral or poster abstract, and being published in a journal



**Driving Health Innovation:
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Value of Real-World
Evidence**

October 21-22, 2019
MaRS Discovery District
Toronto, ON

Abstract Submission Now Open

www.capt-actp.ca

Online submission process closes June 30, 2019.

Opportunities: Student Program

*Applying for a
student travel bursary
to help you attend the
annual conference in
Toronto, Ontario*



Opportunities: Student Program

Highlighting your achievements, sharing your expertise or covering issues that matter most to you in your field



Opportunities: Student Program

*Generate interest in
your work with a
“**Student Spotlight**”
in our quarterly online
e-Bulletin*



If you have any questions about the Student Program:

Shanna Trenaman
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Please follow us on LinkedIn or Twitter **@CAPT_ACTP**

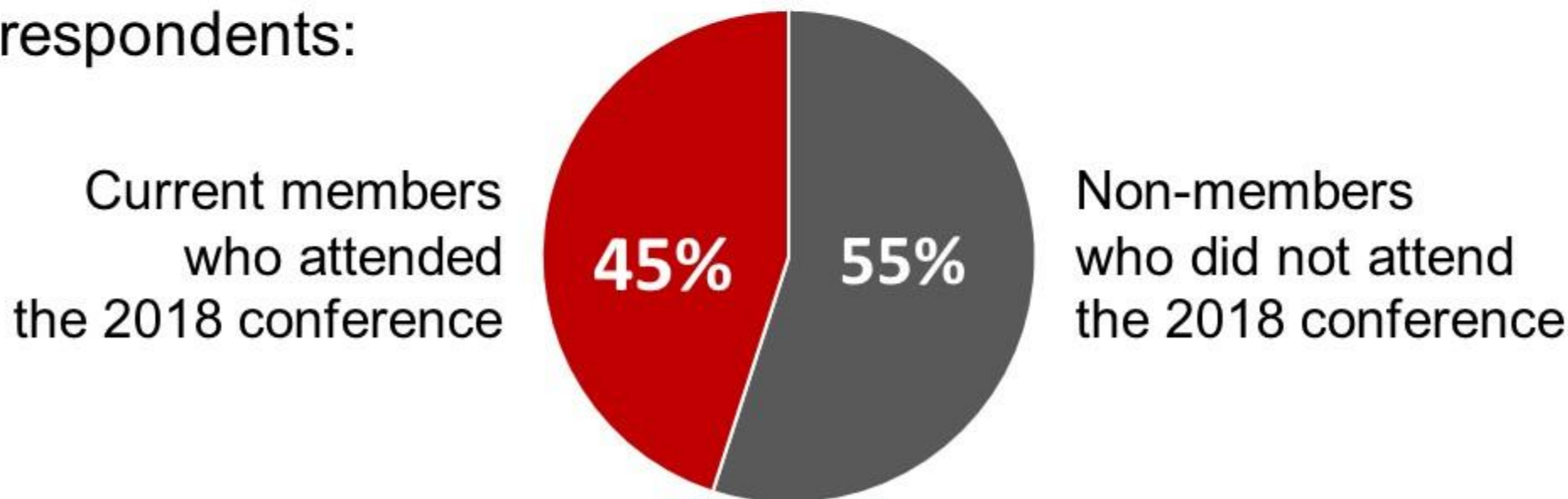


2019 Survey Results

Elena Lungu

Background


- CAPT conducted an online survey in March to better understand priorities, experiences, and perspectives on future direction
- Our target audience consisted of current/past members, partners, and those with a connection to our work (**n=698**)
- We received **87 responses** with a 100% completion rate
- Of the respondents:



When asked to **indicate their primary affiliation**, the majority of survey respondents were from consulting and industry sectors, followed by:

- Academia
- Student population
- Research
- Government
- Patient
- Healthcare professional
- Other (defined as “HTA” or health technology assessment)

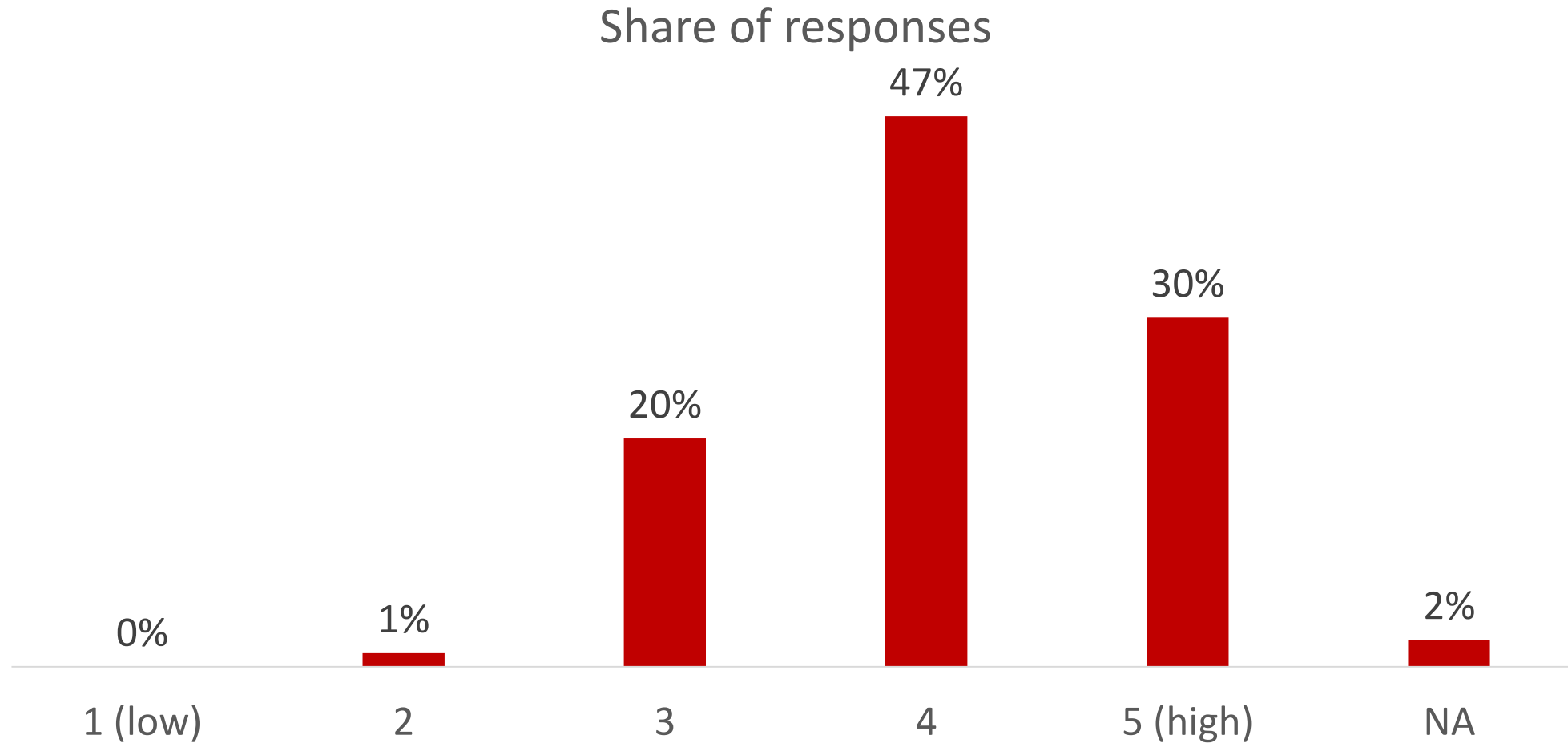
Top attributes **CAPT currently achieves** (in order of ranking)

- 
1. Offers a neutral environment to exchange ideas & collaborate
 2. Facilitates dialogue around innovative policies & practices
 3. Allows for innovativeness, flexibility & diversity in its programming
 4. Delivers customized learning experiences
 5. Is an information resource for decision-making about therapeutic interventions

Top areas of interest **CAPT should address** (in order of ranking)



Experiences with CAPT (respondent rated)



**Top areas of
improvement
for CAPT**
(order of
ranking)



1. Host educational opportunities for members beyond the annual conference/workshop

2. Organize pan-Canadian satellite forums for multidisciplinary scientific discussion or dissemination of data

3. Develop policy positions in population therapeutics to further influence policies/practice

4. Keep regularly informed of CAPT-ACTP activities via email, social media, website

5. Profile the work of members across the spectrum

6. Offer a student mentorship program

Five key themes emerged during the survey analysis.

1. Education
2. Communication
3. Collaboration and engagement
4. Policy
5. Conference

Insights

Education	Offer new educational opportunities (live and on-demand webinars/webcasts, lecture series), offer workshops and rounds, training symposium for students, multi-sector roundtables
Communication	Increase frequency to provide regular electronic updates from CAPT (more e-blasts/communication about CAPT “impacts”), host satellite meetings in-between AGM

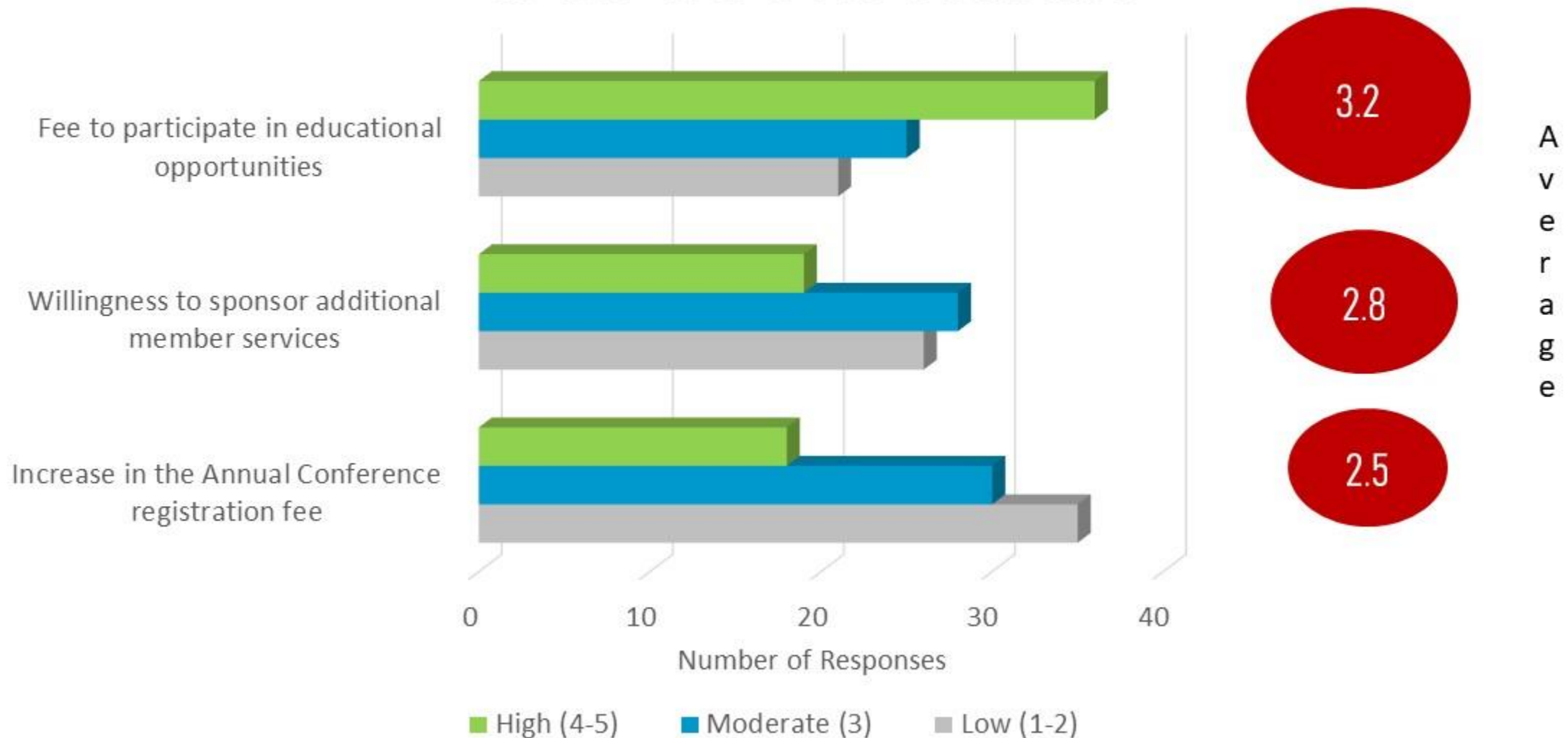
Insights

Collaboration and engagement	Increase member input (more polling of members, involve in planning and strategy development), continued partnerships (pre-workshop example), involve members more (working groups, local chapters), more patient perspectives, create joint initiatives with others
Conference	Host concurrent sessions, change location, introduce “speed dating/speed-networking” approach, more independent, academic research

Insights

Policy	Establish policy positions, help improve practices, hold specific policy focused forums, create policy working group(s) or health policy subcommittees, engage students in literature research, produce white paper(s)
Other reflections	Student mentorship program, act as a “curator” of RWE information, facilitation of greater networking for researchers/focus on research, enhance the relevancy of CAPT (“extend the visibility/inter-engagement of members”)

Feedback on the level of support for changes to the CAPT fee structure





Key Informant Interviews

Dr. Judith Glennie

Introduction

- Stakeholder insights gathered in 2018 via key informant interviews
- Audience: government decision-makers and/or government bodies who are data users or generators
- Explored areas such as: value proposition of CAPT, what people perceived CAPT to be, and opportunities for differentiation between CAPT and other entities

Why conduct interviews?

1. It was time for CAPT to focus on strategic plan renewal.
 - The last strategic planning exercise was at least 8 years ago, when the association was operating in a different environment
 - Government represents an important CAPT stakeholder group and participant in CAPT events
2. The “marketplace” has changed:
 - There are more options for the limited time stakeholders have to attend events
 - CAPT wanted to explore, through consultation, our niche
3. CAPT needed to identify the right direction and focus for the next 3 to 5 years, as well as invite different perspectives by connecting with those who knew CAPT well and those who did not.

Key Informant Interviews: General Feedback

- CAPT Annual Conference is balanced; more academic leaning, which is appealing to government
- Like CAPT because it brings all perspectives together to the table.
- Great opportunity for CAPT, as independence of its members is unique and provides opportunity to create unique partnerships (local, national, international), particularly academic community engagement with decision makers.
- Slight variability in perceptions re: involvement and/or influence of industry.
 - Most former payers with CAPT experience do NOT see undue influence by industry.
 - Perception (based on content of CAPT website) of someone not very familiar with CAPT is that there is not sufficient transparency and so leaves question of whether industry may have an influence.

Insights

- Need for CAPT engagement strategy, communications plan.
 - Where does CAPT fit in the landscape? What is the unique value added?
- Need for ongoing engagement between CAPT and leaders in key sectors.
 - Normal Board turnover means that CAPT loses relationships as people move on
- Is the CAPT mandate too broad?
 - Vision is too ambitious and aspirational
 - Need to “refine work”, do one or two things and do them well to make sure you have impact
- Opportunity for CAPT to take a more concrete leadership role in RWE that supports solution development.
 - A place is needed for conversation (RWE and analytics)
 - Lots of work needs to be done in RWE (solutions to issues and use of data for decision-making)
 - Promote an environment for sharing/identifying future problems (in an unbiased manner)
 - Work together to resolve some of the issues (how do we get it to work, its role in the health system, and how it makes a difference to patients)



CAPT Advisory Panel on Scientific Direction

Composition and Key Responsibilities

- Comprised of members reflecting areas such as scientific expertise, academia, health sector and patient advocacy
- Provides a thriving virtual forum to share knowledge, experiences and expertise with the Scientific Program Committee in an advisory capacity.
- Helps further identify new or emerging topics of interest with respect to population therapeutics.
- Produces recommendations, where feasible, to the Scientific Program Committee to promote and achieve a scientific program that promotes knowledge translation, networking, and collaborative calls to action.

Background

Advisory Panel provided feedback to CAPT in April 2019 to help inform CAPT's strategic goals. Suggestions included:

- Extending outreach efforts/strategies to include the patient community
- Utilizing available statistical data to better understand members, sectors, and experiences
- Focusing on building a “brand or identity” for CAPT in the current environment
- Leveraging the independence of CAPT to promote open dialogue
- Considering opportunities to develop position statements
- Generating value-added outputs to support member engagement

Panel Feedback: CAPT Awareness

- Differentiate CAPT from others by identifying CAPT brand (uniqueness/identity)
 - yet consider learnings from, for example, CADTH especially with respect to policy maker engagement
- Consider a role of science to policy “interpreter” for CAPT - an opportunity to balance, translate and/or teach
- Be cognizant of the proportion of industry engagement with respect to CADTH and CAPT; and, gathering lessons learned from CADTH, manage those relationships with policymakers in mind
- Pursue greater insights by extending outreach efforts/strategies to include the patient community.

Panel Feedback: Scientific Approach

- The focus on research is a key part of CAPT's branding, so important to:
 - Showcase more research
 - Strategically explore methods
 - Focus more on data
- Consider how CAPT is ideally positioned to gather input and put forth recommendations on various science policy issues as a multi-disciplinary entity.
- Leverage the independence of CAPT to further promote open dialogue and sharing of diverse perspectives as a unique value proposition.
- With respect to methods, strategically position CAPT as a “beacon” of what is happening internationally.
 - This might allow CAPT to serve as a curator of sorts within the Canadian context, as well as introduce a role for CAPT to collect, translate and teach methods.
 - Might also be applied to what is going on in the patient arena internationally & how that be applied in Canada
- There may be an opportunity for CAPT to incorporate current/hot topics into its agenda better than others (e.g. CDISC, cancer drug trials & need for data downstream)

Panel Feedback: Member Value

- Revisit previously defined “weaknesses” (not having a tradition re: creating position statements) to consider how they might be reframed as opportunities in today’s landscape.
 - Consider generating a range of outputs that may be of value to members: pre-conference workshop reports, conference summaries, publication of white papers in areas like RWE, etc.
- Consider any barriers that might impede or influence stakeholder engagement with CAPT, including budget restrictions that limit the ability for some to attend the CAPT conference.
- Utilize available statistical data to better understand members, sectors, and experiences.
- CAPT has increased its presence on Twitter, so perhaps other tools should be considered or pursued such as a new CAPT profile on LinkedIn.

Closing Reflections

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If you have any questions, please contact:

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Please follow us on LinkedIn or Twitter **@CAPT_ACTP**

Learn more about us: **www.capt-actp.com**