CITIZEN ADVISORY GROUP MEETING REPORT

Saturday, October 13, 2018

9:30 am – 3:30 pm

Facilitated by: Misha Glouberman

College of Physiotherapists of Ontario
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IN ATTENDANCE

Citizen Advisory Group	13 participants
Facilitator	Misha Glouberman
Partnership Chair	Lisa Pretty, College of Physiotherapists of Ontario (CPO)
Partnership Coordinator	Olivia Kisil, College of Physiotherapists of Ontario (CPO)
Sponsoring partnership Representatives	o Craig Roxborough, College of Physicians and Surgeons (CPSO) o Erin Tilley, College of Nurses of Ontario (CNO) o Elizabeth Almeida, College of Nurses of Ontario (CNO) o Lisa Gibson, College of Audiologists and Speech-Language Pathologists of Ontario (CASLPO)
Note Taker	Carol Ann Burrell

1. INTRODUCTIONS, ORIENTATION AND CHECK-IN

a. WELCOME

Meeting facilitator Misha Glouberman opened the meeting by welcoming the participants and introducing himself to the group. He described his role in the meeting and outlined the agenda for the day. Misha asked the group participants to take two minutes to chat one-on-one with someone from the group to get to know a little bit about another person at the meeting.

b. GENERAL UPDATE AND FOLLOW-UP FROM PREVIOUS MEETING

Lisa Pretty, Citizen Advisory Group Partnership Chair and Communications Director at CPO explained that previous group feedback had indicated that the group would benefit from hearing how their meeting input on projects was being used and/or implemented. She shared the following general update:

- Olivia Kisil has replaced Beth Ann Kenny as the Citizen Advisory Group Partnership Coordinator. It was clarified that both Lisa and Olivia work at the College of Physiotherapists of Ontario (CPO).

- Following up from the last Citizen Advisory Group meeting, Lisa reported that:
  - Feedback on the College of Massage Therapists of Ontario website was helpful. Modifications were made to the site, language was improved, and the College went back to the design firm to incorporate some of the suggested changes made by the group
  - Risk areas for patients was also discussed at the previous meeting. The policy specialists were able to pull ideas from the meeting report that were helpful in completing their work.

- Lisa will be presenting at the CNAR conference next week where she will talk about the Citizen Advisory Group (CAG) model. She noted that there is a lot of interest from regulators who would like to learn more about how the Citizen Advisory Group is set up and structured, and what value the partnership has experienced through this collaboration.

- Five requests from Colleges have been received recently asking for input from the Citizen Advisory Group. Participants will receive an email about these requests soon.

c. INTRODUCTION OF SPONSORING PARTNERSHIP REPRESENTATIVES IN ATTENDANCE

Lisa Pretty introduced the following sponsoring partnership representatives and explained that they were in attendance in order to hear feedback from the group first-hand, as well as provide clarity and answer questions if necessary:

- Craig Roxborough, College of Physicians and Surgeons (CPSO)
- Erin Tilley, College of Nurses of Ontario (CNO)
- Elizabeth Almeida, College of Nurses of Ontario (CNO)
- Lisa Gibson, College of Audiologists and Speech-Language Pathologists of Ontario (CASLPO)

d. PARTICIPANT INTRODUCTIONS

Introductions – Part I

By a show of hands, it was determined that today's meeting is the first for three participants, while 10 participants have attended at least one other meeting.

Citizen Advisory Group members were organized into smaller break-out groups to:

- Introduce themselves and discuss what they are hoping will come out of today's meeting and how they hope to contribute.
- Discuss the rewards and/or challenges of participating in the group; new members of the group were encouraged to ask veteran group members any questions they might have.

Following discussion in the break-out groups, participants were asked if there are any **questions** that didn't come up in the small groups or what **feedback** was shared about **participating in the Citizen Advisory Group**:

- It is important that results and feedback from contributions are shared with the group
- It is good to recognize that participants' input has value
- It was noted that the group is open
- Time is a challenge – more time would be nice, but it was recognized that Misha runs the meeting very efficiently
- It can be harder to attend meetings because of personal schedules and insufficient notice of meetings

Introductions – Part II

The group was then reorganized into four new break-out groups for the morning session (one group of four, three groups of three).

Each of the 13 group participants then introduced themselves to the whole group and provided context to their **reasons for participating**, including:

- Learning and understanding
- Voicing their opinion and providing feedback as a patient and/or caregiver
- Professional development and interest

e. REVIEW OF GOALS AND OUTCOMES

Expectations of the group *(as established previously and reviewed at this meeting):*

- Give feedback, find out if suggestions are helpful and/or implemented, and understand why if they are not helpful/implemented
- Contribute to improved care
- Establish a concrete mandate
- Learn as group how to better contribute and give feedback; grow, evolve and get better
- Continue to be heard and valued
- Get to know each other

If the meeting goes well, the group will *(as established previously and reviewed at this meeting)*:

- Understand the role of the group
- Have a clear sense of where the group is going
- Know that opinions are valued and respected
- Input will be taken onboard
- Leave with a sense of accomplishment, feel good about their participation, learn
- Gain a greater understanding of how the Colleges work
- Know what the group can and cannot change/influence

If the meeting goes poorly *(as established previously and reviewed at this meeting)*:

- It will be boring
- Technical language/jargon will be used with no explanation
- Engagement will be unsuccessful – no follow-up, feel like a waste of time and money, input is not valued and/or utilized
- Confusing, too many tangents
- No clear sense of next steps
- Participants don't get to know one another or don't like each other
- Poorly facilitated

What the group thought went well or liked about the previous meeting:

- Covered a lot, pace was good, meeting moved quickly
- Participants got along, everyone participated
- Pre-information was interesting and well presented
- Sub groups changed, participants met more people
- Misha was effective and listened
- College representatives answered questions and were able to hear feedback first-hand
- Food was good
- Meeting space was comfortable/suitable

What the group didn't like about the previous meeting:

- Lighting
- Survey was sent out with short notice

The group's Confidentiality Policy was reviewed:

- "We are adults"
- Participants should share with the group what they are comfortable sharing
- Outside of the group, participants can share information learned during the meetings in a broad sense, but should not share specifics (i.e. names of individuals)

Additional feedback

The break-out groups reviewed the meeting outcomes above and then shared additional feedback:

- Some concern was expressed about inconsistent communications in between meetings. Lisa Pretty explained that with Olivia Kisil taking over as the Partnership Coordinator, the group can expect to experience improved responsiveness.
- Careful consideration should be given to how much information the group is asked to review and how many discussion items are included on the agenda. It was noted that one big agenda item could easily require an entire day.
- It is good for participants to know what is happening with the Citizen Advisory Group even if someone cannot attend or are not invited in participate in a specific project.

2. CONTINUITY OF CARE - *College of Physicians and Surgeons of Ontario (CPSO)*

The College of Physicians and Surgeons of Ontario (CPSO) provided the group with pre-reading about Continuity of Care, including an article written for patients to explain why continuity of care is important, as well as draft policies and the rationale behind some of the key expectations contained in the drafts.

At the meeting, participants were asked to discuss various questions in the smaller break-out groups first and then provide feedback to the whole group. The feedback received is outlined below.

a. CONCERNS ABOUT CONTINUITY OF CARE

What are your greatest concerns around continuity of care?

- Lack of communications among all the disciplines
- Concern that physicians don't have the authority they should within the whole system; they need a voice
- Lack of thoughtful communication
- In the ER:
  - professionals are not working together
  - shift changes disrupt continuity and proper transfer of information
  - lack of regular hospital beds exacerbates the problem
- Having multiple doctors and treatment plans creates uncertainty and lack of confidence
- Patient transfer process to a new institution:
  - creates barriers to effectively sharing patient information
  - increases cost to the system
- If a patient is moved to a nursing home:
  - care is fragmented
  - follow up does not happen as it should
- There is a burden on the patient ("like a puzzle that needs to be solved") to figure out how to continue receiving proper care
- There is a burden on the system due to inefficiencies and lack of collaboration
- Doctors are not open to receiving new information from nurses, don't ask nurses questions, and don't listen to nurses about a patient's care (the "God factor")
- Caregivers and family members are left out of the information loop and are not properly consulted

Group members shared several personal examples of inadequate continuity of care. Following are a few of the stories:

- *A 32-year-old woman passed away in ER and it was not understood exactly how this happened. Six different doctors were providing care, professionals were not working together to come up a firm diagnosis; she went into liver failure; she was put on the donor list but got bumped off the list, and then, sadly, died in the ER quite unexpectedly.*

- *A mother-in-law needed to be transferred to another institution; however, no patient information was provided to professionals caring for her during the transfer. Lack of understanding of her condition caused the patient considerable anxiety, but if the transfer had been better managed and patient information was shared, anxiety to the patient could have been avoided or at least minimized.*

- *A family member was transferred from one institution to another. In preparation for the transfer, the patient endured two hours of tubing, etc. at the original institution, and then two more hours of redoing the tubing, etc. at the second institution. The group member acknowledged that liability issues were likely to be at play in this circumstance, but there was no communication from professionals about what was going to happen as a result of the transfer. Nor was there any way to voice concerns and/or discuss alternatives to putting the patient through four hours of uncomfortable procedures.*

- *A family member who had had a stroke was in the hospital for four months and then transferred to a nursing home. Four months later, the family member had not been seen by a doctor at the nursing home.*

Group members were polled using a scale of 1 to 5 (5 = high; 1 = low) on the following questions:

How good is the healthcare system in terms of continuity of care?

	Score	Votes
High	5	0
↓	4	1
	3	3
	2	7
Low	1	1

How good is your own physician in terms of continuity of care?

	Score	Votes
High	5	6
↓	4	2
	3	5
	2	0
Low	1	0

How good are other physicians* in terms of continuity of care?

	Score	Votes
High	5	0
↓	4	1
	3	3
	2	7
Low	1	0

* *experience on an episodic basis*

Additional group feedback from this group poll:

- Continuity of care is most challenging with physicians when you are the caregiver and the patient is elderly (i.e. a group member's father is hard-of-hearing and has Alzheimer's; communication from the doctor doesn't come back to the family because the patient is not able to understand)

b. BALANCE OF RESPONSIBILITY IN CONTINUITY OF CARE

What is the balance of responsibility between physicians, patients, caregivers and families in minimizing the breakdown in continuity of care?

- In a hospital setting, team meetings should involve the patient and/or care giver/family to get the whole picture; everyone should have an equal voice, including patient and care giver/family
- Generally, experiences are positive when a patient has a critical condition (i.e. a patient is in ICU)
- Generally, experiences are not positive when a patient has a non-critical condition (i.e. a patient is on a ward)
- Asking questions is seen as "trouble making"
  Note: the entire group appeared to agree with this observation
- Onus is on the patient to be proactive and follow up (i.e. using patient portals to see test results)
- Even in a perfect world, there is still some onus on the patient to follow up
- Use technology (i.e. patient portals) to:
  - facilitate communication
  - share information among all parties
  - take some of the responsibility/onus away from the doctor
  - allow a caregiver or family member to more easily participate and help with a patient's care
- If a patient is going to be responsible and proactive, they need information and must be adequately empowered and guided to take on that responsibility. This can be achieved through:
  - improved communication (i.e. knowing that patient portals exist, how to access patient portals, that changes have been made to the system)
  - better use of technology
  - additional guidance to immigrants or those new to the system
- Patient portals have been life-transforming; you can ask questions, look for trends/changes that might affect your health and then see the doctor to ask questions and share concerns
- Physicians and other health care professionals are doing the best job they can (i.e. one group member said his doctor told him he works 70 - 80 hours/week and says the paper work is onerous)

c. HOW CPSO CAN IMPROVE CONTINUITY OF CARE

Background Information

To help participants provide pertinent feedback to this question, Craig Roxborough from the College of Physicians and Surgeons (CPSO) provided background information on what CPSO can do to ensure continuity of care:

- Keep in mind that an individual doctor is working among a number of other doctors and health care professionals, as well as within a system where there are different goals and challenges
- CPSO doesn't want to burden doctors with system-level changes; instead, they are looking at areas where doctors themselves are able to change/improve, such as:
    - Improving access – (i.e. getting appointments, having a plan in place for patients to contact an alternative doctor when they are away)
    - Having a process for patient follow up
    - Enhancing communication between doctors when referrals occur
    - Improving the hospital discharge process by empowering the patient and also ensuring appropriate communications with the family doctor

Questions from the group

Craig Roxborough from the College of Physicians and Surgeons (CPSO) answered the following questions:

Does CPSO have a role in advocating for system changes?

A: Advocacy is not the CPSO's typical role; the Ontario Medical Association (OMA) is often well positioned to help advocate for change in the system and we are communicating with them and other partners to help identify opportunities for improvement.

Will the group be going through each of the draft policies and asked to provide feedback?

A: Not today, but CPSO wants to hear from participants if they have specific feedback on the draft policies. This feedback can be provided directly to CPSO.

Can the CPSO talk to different groups about continuity of care issues?

A: The CPSO sets expectations for how physicians practice; But the CPSO is working with others, including the OMA, to help address continuity of care issues.

Given what you know about CPSO's role, what would you like to see CPSO do to improve continuity of care?

- Develop and mandate a policy that will improve access to physicians and increase confidence in the communications process. Address issues such as:
    - Increased speed of returning phone calls
    - Allow booking appointments online
    - Provide alternative ways to reach physicians
    - Allow patients to leave a message when they call a physician's office
    - Empowering front-line staff to respond to patient questions to ease frustration and improve access
    - Use email to communicate with patients
    - Share email address of office administrator to improve communication and book appointments
    - Having an internal system for ensuring communications method/technology is working (i.e. logs and receipts)
    - Allow specialists to contact patients directly to confirm appointments; simplify communication between GP and specialist to avoid "broken telephone" scenarios

- Address the issue of patient privacy and how to ensure there are not unintended barriers to care and access to information

- Prioritize implementing the "easy wins" first, and then develop longer-term aspirational goals (i.e. implementing a policy around returning phone calls is an easy win; use technology to improve this)

- Advocate for physicians' input to be valued above the interests of administration

- Make use of technology mandatory

- Implement an education campaign (i.e. posters everywhere) to promote awareness and understanding (i.e. how to access test results online)

- Hold meetings/conferences to address mistrust between physicians

- Promote understanding and acknowledgement that technology breaks down; don't treat patients as pests for asking questions or following up

- CPSO to have some control or influence over what is taught at the university level, teach continuity of care best practices

The group was asked to choose their top four choices from among the following **ideas for CPSO to implement to improve continuity of care:**

Ideas	Votes
Develop policy about communications	9
Allow online appointment booking	8
Make technology mandatory	5
Be able to email a physician's office	5
Implement an education campaign	4
Address privacy as a barrier to patient info	3
Be able to leave a message at a physician's office	3
Advocate for physicians' input over interests of administration	3
Share email address of physician's office administrator	3
Simplify broken telephone with respect to specialist referrals	3
Have a system to ensure technology is working	2
Address mistrust among physicians	2
Look for easy wins	1
Acknowledge that technology breaks down	1
Have control/influence over what is taught at academic institutions	1

3. NURSES CODE OF CONDUCT - *College of Nurses of Ontario (CNO)*

The group was reorganized into four new break-out groups prior to this next segment of the agenda.

The College of Nurses of Ontario (CNO) provided the group with a Draft Code of Conduct to review in advance of the meeting. In response to a question from the group about what "conduct" means, Erin Tilley, College of Nurses of Ontario (CNO) explained that the Nurses Code of Conduct describes the expected behaviour of nurses. Today's discussion is intended to be about what behaviours the public should expect from nurses.

Participants were asked to discuss various questions in the smaller break-out groups first and then provide feedback to the whole group. The feedback received is outlined below.

a. EXPECTATIONS WHEN RECEIVING CARE FROM NURSES

What do you expect when receiving care from nurses (i.e. conduct and behaviour)?

- Respect; treat patients as they would treat their loved ones
- Knowledgeable
- Open to feedback and respect patient's own expertise
- Advocate for the patient so that the patient can advocate for themselves

> *Group member personal example:*
>
> *One group member was in hospital for surgery. The night before her surgery, the nurse advised her to refuse to go into surgery the next morning until she had spoken to the surgeon—so that she could have an important conversation with the surgeon about the procedure. This advice was considered to be extremely important as the group member did not know that she could do this and did not know how to resolve her issue around access.*

- Professional and assured
- Communication—know the audience with whom they are speaking, use audience-appropriate language and avoid jargon/technical language
- Spend equal time on bedside care, compared with paperwork
- Non-judgmental; don't stigmatize marginalized communities
- Talk carefully and respect confidentiality (i.e. be careful about speaking loudly at the nurses' station)
- Be an educator

b. DRAFT CODE OF CONDUCT – CONTENT

Prior to small group discussions, the following points were made:

- Nurse Practitioners, Registered Nurses and Registered Practical Nurses would be subject to the Code of Conduct.
- Indigenous people are explicitly mentioned in the Draft Code of Conduct as an acknowledgement of the Truth and Reconciliation Commission. Additionally, in looking at marginalized groups, it acknowledges there are health inequalities for the indigenous population.

How well does the Draft Nurses Code of Conduct reflect your expectations in receiving care from nurses? *Group members were polled using a scale of 1 to 5 (5 = high; 1 = low)*

	Score	Votes
Completely reflects expectations	5	4
↓	4	8
	3	1
	2	1
Does not reflect expectations at all	1	0

In terms of content, what kept your score from being a 5?
What should be different? What is missing?

- Good language, but general public literacy is low, so the Code may not be easily understood
- General statements are good, but the advocacy part needs to be more explicit
- More is needed about partnering; make this more explicit and more central to the Code
- Add in the word "advocate" to the Code; it is not used anywhere in the document
- More elaboration on ethical framework (Principle 6) needed
- Regarding special mention of Indigenous communities in the Code (Principle 2), disagreement emerged in the group:
    - Some thought since everyone should be treated equally, there is no need to specifically mention Indigenous communities
    - Others thought that it was important to acknowledge Indigenous communities due to current cultural sensitivities and historical inequities
- Address self-care (emotional health, adequate rest, burn-out, etc.) and hygiene, as these affect quality of care
- Include acknowledgement of family care, not just patient care; more needed to acknowledge family and caregiver's role in the patient's care

- Address the need to be prepared for uncommon occurrences, implement individualized care, and that actions are informed by evidence

The group was asked to choose their top two choices from among the following **suggested changes/additions to the Draft Nurses Code of Conduct:**

Suggested changes/additions	Votes
More about partnering, make this ore explicit and more central to the Code	2
Add the word "advocate" to the document	6
More elaboration on the idea of ethical framework (Principle 6)	2
Indigenous issues don't need their own special mention	1
Address self-care (emotional health, adequate rest, burn-out) for nurses, as it affects the quality of care	6
Add in something around family care, not just patient care	4
Address issue of hygiene	0
Be prepared for uncommon occurrences, implement individualized care, actions are informed by evidence	0
Add in reference to being well rested	0
More needed to acknowledge family and caregiver's role in the patient's care	2

The group was asked to vote for one of the following **statements regarding mentioning indigenous communities in the Code**:

Statement	Votes
Indigenous communities need special mention in the Code	8
Indigenous communities don't need special mention in the Code	4

c. DRAFT CODE OF CONDUCT – LANGUAGE

Prior to small group discussions, the following points were made:

- There are other standards of practice for nurses, and the primary audience for these documents is the nurse. For the Code of Conduct, it is a goal to make sure the public understands the document as well as the nurse.
- The CNO is looking to make the Code public, so they would like the group's feedback on whether this is important and how to best do that.

How clear is the language in the Draft RN Code of Conduct?
Group members were polled using a scale of 1 to 5 (5 = high; 1 = low)

	Score	Votes
Extremely clear	5	1
↓	4	11
	3	1
	2	1
Not clear at all	1	0

In terms of language, what kept your score from being a 5?
What should be different? What is missing?

- Language was a little high level; need to lower reading level; "fewer $100 words"
- Needs to be shorter
- Lots of repetition - that can be either a good or bad feature
- Using examples is effective
- Detail in the Code was well received; the principles are clear and the bullets make it specific and concrete
- Needs infographics; a shortened "highlights" version with links should be developed
- The points are framed in the positive (as opposed to in the negative) which was well received and appreciated
- Glossary needs to be more connected to the document in the hard copy version
- Online version should have pop-ups for glossary words
- When CNO makes further revisions, it should come back to the individual group members for detailed feedback
- Code is a good PR tool; engenders respect for nurses

d. PREFERENCE FOR TERM "PATIENT" OR "CLIENT"

Prior to small group discussions, the following points were made:

- Historically, CNO's documents have used the term "client". They have used "client" because "patient" is not a term used in all practice settings (i.e. in retirement homes). But CNO has received feedback that the term "client" doesn't resonate with the public. More recently, CNO has been using the term "patient" because of this. (For reference, the New Zealand Code uses the term "health consumer".)

Which term, "patient", "client" or something else, would you prefer and is most clear to you?
The group was asked to choose one preferred term

Preferred Term	Votes
Patient	9
Client	0
Something else (i.e. "user")	1

Additional feedback about the terms

- Client sounds like a commodity, money, business
- Client implies there is a choice of options within the health care environment when there is not
- Patient is an empathetic term, client is cold
- "If you are a nurse, then I am patient"

e. HOW CNO CAN PROMOTE THE CODE OF CONDUCT TO THE PUBLIC

How can CNO make the public aware of this Code with the broader goal of letting patients know what they can expect from receiving nursing care?

- Share short and digestible pieces of information from/about the Code
- Use infographics
- Post anywhere nurses practice
- Post on website
- Develop a "do you know" series with a link to web site
- Publish in medical publications
- Include in hospital patient information packages
- Provide to patients when they register
- Promote through hospital TV channels
- Distribute via various communication vehicles, social media, conference presentations (i.e. Health Charities Coalition)
- Create short YouTube videos, presented by nurses
- Create jpegs so that the information can be tweeted (can't tweet PDFs)

<u>Additional information shared by CNO regarding the process</u>

- Group members can provide individual feedback through the CNO survey (see the latest e-newsletter for the link) or send feedback to Olivia and she will forward to CNO
- Next steps: The Draft Code of Conduct will go to the CNO Board in December for approval, but may need further revision. This is still to be determined.

3. WRAP-UP

Group participants were asked to provide feedback on the following questions:

a. Meeting Evaluation

What went well at today's meeting:

- Topics were really relevant
- Topics were very meaty, but because of the specific feedback being sought, it wasn't necessary to spend all day talking about just one topic
- No lack of discussion
- Well-paced; enough time, not rushed
- Reorganizing participants into new break-out groups was effective
- Good food, especially the cake
- Having College representatives at the meeting to ask questions and provide clarity was helpful
- College representatives valued being there to hear participants' passion and personal stories
- Misha managed the process effectively
- Having more diversity within the group was better ("not all older, white women")
- It was helpful to have some of the same people from previous meetings attend this meeting; it was easy to engage because of familiarity with each other; builds a productive group dynamic
- Materials were sent to participants with enough time to read in advance
- Olivia did a great job communicating and responding
- Swivel chairs were appreciated; participants could turn to see other participants while they were speaking

What could have been done differently at today's meeting, or could be done differently next time?

- More updates needed
- Clearer instructions needed on how to get into building on the weekend
- CPSO survey didn't work correctly

b. Next steps and follow up

Lisa Pretty shared the following information with the group:

- Dates for in-person meetings have been booked:
    - February 2, 2019
    - May 4, 2019

- The Partnership has decided that if another in-person meeting is needed, they will schedule one.

- Some Colleges have made requests for feedback. Group members were asked to watch their email for these requests.

- The Partnership is trying to recruit more participants to fill gaps in all of the areas of practice. Please send referrals to Olivia.

- A final report from this meeting will be distributed in a couple of weeks and will be shared with the entire group, including those who did not attend.

- The link to the CPSO's Continuity of Care consultation will be shared with the broader group if they are interested in providing additional feedback.

- Olivia will send an e-newsletter out on semi-regular basis. The next one will be sent in December.

- Will look into when College council meetings are scheduled and will circulate information back to group. Council meetings are open to the public, but members may only observe; they cannot present or speak

One of the group members commented that the occupational therapists survey was very good and wondered if the survey was closed. Lisa confirmed that only the first 20 responses would be included in the survey results.

The participants were thanked for their valued time and feedback.