



REPORT:
CITIZEN ADVISORY GROUP MEETING
Saturday, October 3, 2020

Citizen Advisory Group
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8:30 am—12:15 pm

AGENDA ITEMS

Item 1: Occupational Therapists (COTO): Guide to Discontinuation of Services

COTO is updating our Guide to Discontinuation of Services which includes rules occupational therapists must follow when they are thinking about discontinuing service with a client.

As we update this guide, we would like your feedback to understand what clients would expect from occupational therapists when discontinuing services.

Item 2: Physicians and Surgeons (CPSO): Continuity of Care Guide for Patients and Caregivers

CPSO is co-designing a Continuity of Care Guide for Patients and Caregivers with the Citizen Advisory Group (CAG).

CPSO would like to get CAG Members' feedback on the draft Guide and specifically hear from you about times where you took an active role in supporting the continuity of your care or the care of someone you help, as we'd like to include these examples or stories in the Guide to help show others how to do the same.

CITIZEN ADVISORY GROUP (CAG) REPORT

Saturday, October 3, 2020

Facilitator: Misha Glouberman

The session was called to order at 8:30 a.m. with welcoming comments and an outline of the day's program.

Members convened in small groups in Zoom ("breakout rooms") to meet fellow Members and provided initial comments and feedback about previous CAG meetings including:

- Previous meetings have been a positive experience;
- Members feel their voices have been heard by the Partner colleges (one Member highlighted the Members' involvement throughout the CPSO's ongoing draft *Advertising* policy consultation); and
- Using a virtual platform (Zoom) for video teleconferencing has allowed the CAG to continue to meet for engaging discussions.

DISCUSSION ITEMS:

ITEM 1: COLLEGE OF OCCUPATIONAL THERAPISTS OF ONTARIO (COTO) – GUIDE TO DISCONTINUATION OF SERVICES

Q. What was your initial impression of the document?

Members felt the document provided a lot of useful information for patients, particularly around patient rights, but thought that it could be made more patient-centered. Members offered the following comments and suggestions:

- The document seems to be more from the provider's side and not the patient's side: while it acknowledges the patient's point of view, there is greater need for the patient's perspective throughout the entire document;
- It doesn't seem to "close the loop" in some instances (e.g., in cases of services being resumed or if there are other options to discuss with patients as part of the process);
- While it contains good direction for providers and a lot of useful information for patients (especially around patient rights) some patients may not know it exists (and could have used this information with past instances when they saw an occupational therapist);
 - One Member described a past instance where the provider came into their home and told them what type of equipment to purchase: the Member didn't feel like

they were in control of the situation in any way and did not feel they were considered cooperative since there was no plan discussed by the provider.

- Consider the perspectives of newly immigrated patients and of those whose first language is not English (ESL): the discontinuation process and this document should be made simpler for them (e.g., they may have a problem with their provider, but it doesn't seem like their voice is heard here);
- The Practice Scenarios provided are useful for providers but examples, scenarios, or testimonials from patients would be helpful to include; and
- The document could be made more concise: it contains a lot of complicated wording and should be made easier to understand and follow (one suggestion was to remove some of the wording and add graphics like charts or tables instead).

Members were asked about the expectations they had of occupational therapists when services are being discontinued as well as to think about the language used throughout the document. Members were provided with the following list of specific questions to guide the breakout room discussions:

1. *As participants in health services, what are some of the basic expectations you have of healthcare providers/occupational therapists when services are being discontinued?*
2. *Consider situations where the discontinuation is unexpected (e.g., funding is no longer available or a referral to another health provider is not available). What do you expect in these cases?*
3. *Sometimes there is a breakdown in the therapeutic relationship or "fit" between the client and therapist which impacts the service, for example, conflicting opinion, expectations, and/or differing communication styles between people. What is reasonable to expect from a health care provider/occupational therapist in these types of sensitive situations?*

Is it clear what is meant by "a breakdown in the therapeutic relationship" or is there another way to phrase this?

4. *How can providers make the transition easier when services are being discontinued?*
5. *Please refer to our current Guide to Discontinuation of Services. As a member of the public, is it clear what is expected by a health care provider/occupational therapist regarding discontinuation? What is helpful about the current resource and what can be further clarified or added? Does reviewing this leave you with any unanswered questions from the lens of the public?*
6. *Currently one reason for discontinuation is listed as "the client has been given reasonable opportunity to achieve set client goals but has been unsuccessful due to lack of engagement, readiness, or motivation." We want to make sure our language is sensitive,*

and client-centred. Would you prefer that it is rephrased to “the client no longer actively participating in service?” Please feel welcome to provide other suggestions.

Members were asked about the expectations they had of occupational therapists when services are being discontinued and provided the following feedback and suggestions:

- Members highlighted the need for formal documentation and transparency throughout the process (e.g., documentation including the plan that shows why there was a discontinuation of services so it’s not only the provider keeping the documentation);
- Members indicated they would expect some documentation on how patients would find another occupational therapist or recommendations for other providers (e.g., including a checklist on where a patient can access another occupational therapist);
- Members felt the process needs to use a patient-provider partnership model that should include mutual goals and shared decision-making for both patients and providers when discontinuing services and transitioning to another provider:
 - If there is a partnership model, patients and providers are working together to achieve goals and trying to work around what is and isn’t working for the patient;
 - It seems only the provider has the choice to discontinue in this instance;
 - A partnership model would reduce the instances of discontinuation of services; and
 - The patient has a say in the process: it’s not a one-way street to provide services.
- There is a need to address gaps for vulnerable groups (e.g., those with disabilities or developmental delays or ESL) to make their experiences with these services better; and
- Concern that the client’s ability to pay for the recommended equipment from providers could potentially lead to a situation where discontinuation of services occurs before all of the client’s needs are fully met or the provider’s recommendations are fully carried out.

Members were then asked about the language and terminology used throughout the document.

Members thought the language could be more patient-friendly and more neutral and provided the following feedback:

- The words are not user-friendly: would suggest something more neutral and less harsh like “difference in opinion,” “difference in the plan,” or “bringing an end to the service;”
- The document doesn’t mention shared decision-making or partnership with the patient: should include language around decision-making with the patient (e.g., the document currently reads that if there’s a breakdown in the patient-provider relationship, the

provider carefully considers the issue and makes a decision; this working relationship is one of the most important benefits);

- The term “fit” is not ideal and needs elaboration as not all patients might understand what it means (e.g., the term needs to be all-encompassing; sometimes personalities don’t get along and similar issues should be explained here; reads one-directional and doesn’t include shared decision-making with the patient); and
- Sometimes when there’s a breakdown in the relationship a patient may be incorrectly considered “combative” by the provider and this may inadvertently stigmatize patients.

ITEM 2: COLLEGE OF PHYSICIANS AND SURGEONS OF ONTARIO (CPSO) – CONTINUITY OF CARE GUIDE FOR PATIENTS AND CAREGIVERS

Members broke out into smaller breakout room sessions and were provided the following list of questions for discussion regarding their initial thoughts about the document:

1. Is it easy to read and understand? (e.g., are the terms or concepts used clear and familiar?)
2. Is the information we’ve provided helpful? (e.g., Is it helpful to know what is required of doctors? Can you see yourself doing the things we’ve suggested?)
3. Is there anything we’re missing? (e.g., things you’d like to know more about? Other actions you could take?)
4. Do you have any stories or examples relating to each section of the *Guide* where you got involved in your care or the care of others you help to support continuity of care?

Q. What was your initial impression of the document?

Members enthusiastically endorsed the draft document as a helpful resource for themselves and other patients and caregivers to help them understand doctors’ responsibilities and their own role in facilitating continuity of care and to outline what actions they can take to engage themselves in their care.

Members described the draft document as useful, clearly written, and a great way to start conversations with their health care providers. Some specific comments and suggestions regarding the draft document as a whole included:

- Liked the “What you can expect” and “What you can do” boxes;

- Some patients in long-term care facilities or other settings may not always have access to a caregiver and the tools and resources provided here could be used to create a 'travelling file' for these patients to help promote the continuity of their care;
- Some Members felt it was concise enough while others felt it could be shortened;
- It would benefit from proper headings and numbering to make it easier to navigate and ensure the links included are up-to-date;
- It is very clear that the draft document applies to caregivers and their role within ensuring continuity of care (especially under the "What you can do" sections);
- Include information for patients regarding where or who to contact when they experience issues or if there is a breakdown in continuity of care (i.e., continuity of care for the individual patient and not just between doctors, hospitals, and the patient); and
- Include information for patients without a primary care provider on how to create or carry their own medical records and information (e.g., some patients may only have access to a walk-in clinic and there is no continuity of care guidance for these patients).

Members were sorted into breakout rooms to provide feedback on specific sections of the draft document to bring back to the larger group.

Members reviewed each section of the Guide in detail to ensure it reflected the direction previously provided and to determine whether the information and guidance provided resonated with them and would be helpful for other patients and caregivers.

As part of this discussion, Members shared many impactful stories and personal reflections on times they felt engaged in their care that will be anonymized in the final version of the document as examples for other patients and caregivers.

Members' feedback and suggestions for specific sections and final thoughts about the draft document are listed below.

Sections 1: "Communicating with your Doctor" and 2. "Booking appointments with your doctor"

Feedback:

- Glad to see information for time-sensitive or urgent issues included under this section.

Suggestions to include:

- Information on who is responsible for communicating information back to a patient's family doctor when the patient seeks care elsewhere (e.g., how a patient's family doctor would be informed about a patient's call to Telehealth);

- Information on how to create and carry a “file” to provide medical information in situations where a patient is not able to access their family doctor and visit a walk-in clinic (e.g., caregivers often carry a list of medications to ensure the right dose and availability for the patient; what the appointment was for; what was discussed, etc.); and
- Guidance on how to communicate your preference with communicating with your doctor (e.g., your doctor may have email but you might not so how to tell the doctor you would rather communicate by phone) and expectations around response times when using alternate methods of communication (e.g., emailing or texting).

Section 3. “When your doctor is not available”

Feedback:

- The draft document assumes all patients know English and have access to the internet.

Suggestions to include:

- Note that the draft document is written for pre-pandemic life and to acknowledge that there are special circumstances now (i.e., care might look a bit different now, e.g., virtual care vs. in-person care); and
- Information on how caregivers can communicate their role to doctors and members of the health care team (e.g., how caregivers can navigate communicating with the patient’s doctor when they are unable to attend appointments).

Sections 4. “Ordering tests and tracking results” and 5. “Communicating and following-up on test results”

As part of this discussion, Members highlighted some health system-level factors which may impact continuity of care that are beyond the control of individual doctors or the CPSO:

- Some Members expressed concern about the use of “no news is good news,” but CPSO confirmed doctors have the ability to use this strategy and expectations regarding its use is set out in the policy and that this draft document reflects the existing policy expectations.

Additional feedback:

- These sections were clear;
- Online test results are not very user-friendly for some and can lead to difficulties in accessing test information and it could also be communicated that not all results are available on an online portal; and
- Concerns around confidentiality and security breaches when accessing online test results.

Suggestions to include:

- What patients can do when delays occur in the system (e.g., what patients can do in the meantime while waiting for tests to be booked);
- Doctors could describe which tests are being done (not just why they're being done); and
- Information on how to contact doctors or labs for instructions or to clarify the directions (i.e., fasting) when sending patients for diagnostic testing.

Section 6. "Staying at the hospital (or other health-care setting)"

Feedback:

- Members were glad to see the section on information boards of hospital rooms included as it's important for patients and caregivers to know it's available to them as a source of information: sometimes patients and caregivers need to prompt providers to use the information board and it is a useful way to mutually provide contact information.

Suggestions to include:

- What role the family doctor has and what other community resources are available to patients and caregivers when the patient is discharged.

Section 7. "Going home from the hospital"

Feedback:

- Sometimes discharge instructions in hospitals aren't very clear (instructions should be clear, concise, and one suggestion was to provide contact information for any questions or concerns); and
- Clarify if this section applies to patients who are not admitted but are discharged from emergency rooms (i.e., more plain-language to clarify which patient stays it applies to).

Suggestions to include:

- Guidance on helping patients *after* being discharged from the hospital (e.g., what documentation should be gathered when being discharged to ensure this information is available to caregivers and other providers).

Section 8. "When specialist care is needed"

Feedback:

- Members felt this section was missing the patient choice in specialist and suggested the process could instead be a "partnership model" between the patient and the referring

doctor where both participate throughout the referral process (i.e., include patient insight and choice in specialist).

Suggestions to include:

- Find out what if anything you need to bring to a specialist appointment (e.g., a list of documents patients can prepare and bring when seeing a specialist); and
- How to request a referral from your family doctor and how to ask for a second opinion.

Section 9. "Going to a walk-in clinic"

Feedback:

- Some Members were concerned that walk-in clinics seemed to unfairly targeted and highlighted the benefits and services they provide; and
- The CPSO clarified that one of the common concerns heard during the consultation for the draft *Continuity of Care* policies were regarding breakdowns in communications from walk-in clinics to other healthcare providers in the system.

Suggestions to include:

- The solo physician practice model is not reflected in this section;
- Sometimes walk-in clinics may charge an extra fee for certain services; and
- It would be good to know and confirm what services are offered at walk-in clinics upon arrival.

Final thoughts

Members were concerned that many populations may not know how to navigate the health care system (including those without internet access) and suggested including a multi-lingual hard copy of the document (when finalized) in different medical offices so patients and caregivers will know what to expect from their health care professionals.

- Members suggested that if it the templates for health conditions and medication lists provided in the draft document also be made available as handouts at medical offices and hospitals there might be some more success in continuity of care.
- CPSO confirmed that they are looking into all available means of distribution and committed to considering Members' direction as part of this communication strategy.

The CPSO hopes the draft document will help patients and caregivers understand what is expected of doctors so that if patients and caregivers can recognise gaps in these expectations, they feel empowered enough to communicate these concerns with their doctors.

Members felt involved in shaping the document throughout the steps of the co-design process and confirmed that the draft document resonated with them: the information and resources provided here will help support patients and caregivers regarding continuity of care.

REFLECTIONS ON THE DAY

Q. What went well?

- The format of the meeting was excellent: very well-run and efficient;
- The facilitator kept things moving and was on task;
- Very good and enlightening exchanges of ideas;
- Really enjoyed meeting everyone in small breakout rooms and felt there was enough time spent in them for discussion;
- Moving between breakout rooms was very efficient;
- Having small breakout rooms and getting to meet different people in each session was very helpful;
- Really liked how representatives from the Partner colleges were able to provide input and answer questions which helped Members get through the agenda quite quickly;
- Thought it was really exciting to be part of a co-production with the CPSO: it's brave and the process takes much longer but as a patient participant it's a really good feeling;
- Validates Members and what they're saying: hoped other Partner colleges will also use this co-develop model for all their patient-based resources;
- Showed that CPSO listened to patients and created a document: phenomenal experience letting Members contribute, showing their contribution, and now through asking for more feedback from Members; and
- Really appreciated the opportunity to have a voice from the patient and caregiver perspective.

Q. What could be done differently?

- Did not feel that one hour of pre-reading time was realistic for both topics (found it challenging to go through two very different documents at different stages that were discussed at the same time);

- Would have liked to have seen representatives from Partner colleges in the breakout rooms with Members:
 - The CAG Partnership Chair noted that historically the Partners thought that these spaces were important for Members to have the opportunity to have these discussions without the Partners present but noted and appreciated that it may add value to include the Partners in these smaller discussions in the future.
 - The facilitator noted that it may be easier to engage with Partners when CAG meetings are held in-person since Partners sit around the side of the room as “observers” and answer Members if questions arise during these discussions.
- Would have been helpful to receive a hard copy of the pre-reading materials (it is hard to mark up the electronic version PDF version);
- Suggestion that Members be provided with the breakout room information and questions prior to the meeting to know what areas to focus on (or to ask Members which areas they want to focus on given their own expertise) ahead of time; and
- Suggestion that food could be provided (i.e., delivered for virtual meetings).

Adjournment

The members were thanked for their input and feedback, and the meeting was adjourned at 12:15 p.m.