Continuing towards optimization of bladder cancer care in Canada: Summary of the third Bladder Cancer Canada-Canadian Urological Association-Canadian Urologic Oncology Group (BCC-CUA-CUOG) bladder cancer quality of care consensus meeting

Wassim Kassouf, MD[1]; Armen Aprikian, MD[1]; Fred Saad, MD[2]; Neil Fleshner, MD[3]; Nimira Alimohamed, MD[4]; Rodney H. Breau, MD[5]; Fadi Brimo, MD[6]; Joe Chin, MD[7]; Peter Chung, MD[8]; Tony Cornacchia[9]; Ferg Devins[9]; Libni Eapen, MD[10]; Bernie Eigl, MD[11]; Adrian Fairey, MD[12]; David Guttman[9]; Jason P. Izard, MD[13]; Niels Jacobsen, MD[12]; Claudio Jeldres, MD[14]; Girish Kulkarni, MD[15]; Aly-Khan Lalani, MD[16]; Michele Lodde, MD[17]; Himu Lukka, MD[16]; Ron Moore, MD[12]; Chris Morash, MD[5]; Scott North, MD[18]; Tammy Northam[9]; Michael Ong, MD[19]; Nick Power, MD[7]; Ricardo Rendon, MD[20]; Robert Purves[9]; Bobby Shayegan, MD[21]; Randy Smith[9]; Alan So, MD[22]; Srikala S. Sridhar, MD[23]; Alex Zlotta, MD[3]; D. Robert Siemens, MD[13]; Peter C. Black, MD[22]

[1]Departments of Urology, McGill University Health Centre, Montreal, QC, Canada; [2]Division of Urology, Université de Montréal, Montreal, QC, Canada; [3]Departments of Surgery (Urology) and Surgical Oncology, Princess Margaret Cancer Centre and the University Health Network, University of Toronto, Toronto, ON, Canada; [4]Division of Medical Oncology, University of Calgary, Calgary, AB, Canada; [5]Divisions of Urology, University of Ottawa, Ottawa, ON, Canada; [6]Department of Pathology, McGill University Health Centre, Montreal, QC, Canada; [7]Division of Urology, Western University, London, ON, Canada; [8]Department of Radiation Oncology, Princess Margaret Cancer Centre and the University Health Network, University of Toronto, Toronto, ON, Canada; [9]Patient representative, Bladder Cancer Canada; [10]Division of Radiation Oncology, University of Ottawa, Ottawa, ON, Canada; [11]BC Cancer Agency, Vancouver, BC, Canada; [12]Division of Urology, University of Alberta, Edmonton, AB, Canada; [13]Departments of Urology and Oncology, Queen's University, Kingston, ON, Canada; [14]Division of Urology, University of Sherbrooke, Sherbrooke, QC, Canada; [15]Department of Surgical Oncology, Princess Margaret Cancer Centre and the University Health Network, University of Toronto, Toronto, ON, Canada; [16]Division of Medical Oncology, McMaster University, Hamilton, ON, Canada; [17]Department of Urology, Université Laval, Quebec City, QC, Canada; [18]Division of Medical Oncology, University of Alberta, Edmonton, AB, Canada; [19]Division of Medical Oncology, University of Ottawa, Ottawa, ON, Canada; [20]Division of Urology, Dalhousie University, Halifax, NS, Canada; [21]Division of Urology, McMaster University, Hamilton, ON, Canada; [22]Department of Urologic Sciences, University of British Columbia, Vancouver, BC, Canada; [23]Department of Medical Oncology, Princess Margaret Cancer Centre and the University Health Network, University of Toronto, Toronto, ON, Canada

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In early 2016, a Canadian multidisciplinary committee published a white paper entitled, "Recommendations for the improvement of bladder cancer quality of care in Canada: A consensus document reviewed and endorsed by Bladder Cancer Canada (BCC), Canadian Urologic Oncology Group (CUOG), and Canadian Urological Association (CUA)."[1] This was a summary and report of the committee's consensus deliberations during the first two-day BCC-CUA-CUOG bladder cancer quality of care meeting (BCQCM) held in late 2014.

One of the recommendations from the report was to perform a Delphi process to establish a set of quality indicators across important categories of bladder cancer care.[1] This process was undertaken, and led to a 2017 publication listing 60 quality indicators for consideration.[2] In November 2016, another multidisciplinary committee consisting largely of the same members met at a second BCQCM, which focused on the patient journey and optimizing management. The report of this second BCQCM was published in 2018.[3] The following is a summary of the third national BCQCM. The objectives for the meeting were as follows:

- To provide an update on the status of the Canadian Bladder Cancer Information System (CBCIS) and its potential future impact;
- To set benchmarks for the core quality indicators selected at the second BCQCM;
- To discuss the desirability and feasibility of an annual Canadian bladder cancer forum;
- To review barriers and enablers of bladder preservation for invasive bladder cancer;
- To examine and discuss the future of bladder cancer research, with a focus on patient engagement and priorities; and
- To review issues and concerns from the patient perspective and BCC.

Multidisciplinary consensus committee

- Urologists/urologic oncologists: Wassim Kassouf (Chair)*, Armen Aprikian*, Peter C. Black*, Rodney H. Breau, Joe Chin, Adrian Fairey, Neil Fleshner*, Jason P. Izard, Niels Jacobsen, Claudio Jeldres, Girish Kulkarni, Michele Lodde, Ron Moore, Chris Morash, Nick Power, Ricardo Rendon, Fred Saad*, Bobby Shayegan, D. Robert Siemens*, Alan So, Alex Zlotta
- Medical oncologists: Nimira AliMohamed, Bernie Eigl, Aly-Khan Lalani, Scott North*, Michael Ong, Srikala S. Sridhar
- Radiation oncologists: Peter Chung, Libni Eapen, Himu Lukka
- GU pathologist: Fadi Brimo
- BCC patient representatives: Tony Cornacchia, Ferg Devins, David Guttman, Tammy Northam, Robert Purves, Randy Smith

*Members of the steering committee

I. Update on the Canadian Bladder Cancer Information System (CBCIS)

The CBCIS is a prospective database that collects de-identified information about bladder cancer patients from 14 centers across Canada. Developed as a not-for-profit joint venture between BCC and the Research Institute of McGill University Health Centre (RI-MUHC), the CBCIS is designed to provide up-to-date information on all aspects of patient care and outcomes. While BCC is the founding sponsor, the CBCIS also receives financial support from Canadian industry partners.

The database includes patients who have been diagnosed with bladder cancer within 12 months prior to inclusion in the study, regardless of prior disease history. A diagnosis can include a recurrence in a patient with a prior history of disease, diagnosis of metastasis, or a completely new diagnosis. Patients with low-grade Ta tumors are excluded. The CBCIS captures more than 1000 variables for every patient, including information on surgery, systemic therapy, radiation, and clinical trials.

The CBCIS database will be used to identify areas to improve the quality of care and enhance education on best practices for management of bladder cancer in the short- and long-term. It may also be used as a platform to measure some of the quality-of-care indicators that were identified during the BCQCM (see section II for details on the indicators). The database can also serve as an invaluable source of information for further research initiatives. Medical professionals will be able to assess clinically current methods of treatment and identify areas for research focus.

Recruitment to the CBCIS is underway at 14 participating centers. At the time of the third BCQCM (data cutoff January 11, 2019), total enrollment was 2537 patients, with mounting accrual as centers join.

II. Center performance and benchmarking of quality indicators

One of the primary goals of the BCQCM initiative has been the development of a "scorecard" that can be used to track performance and subsequent impact on clinical outcomes across the healthcare system, quantify adherence to best practices, and provide data for benchmarking and quality improvement. One of the key concepts about scorecards is that the performance measures should reflect the critical performance issues of the day, which might change and require adjustment over time. Furthermore, it is recognized that in the development of a scorecard, it is essential to: have expert advice/consensus; keep the measures limited and strategic (and avoid the inevitable pressure for 'measure creep'); and ensure quality of the collected data.

Prior to the second BCQCM, a Delphi process was used to produce an evidence- and consensus-based list of 60 quality indicators spanning the bladder cancer care continuum.[2] At the second meeting, the participants narrowed this list down to a core group of 13 items to be included in a scorecard (Table 1).[3] The wording of some of the indicators developed during the Delphi process was modified during the meeting.

Prior to the third BCQCM meeting, a survey was circulated to the multidisciplinary consensus committee members at centers across the country, requesting information about the 13 chosen indicators, with the goal of using these data to help meeting participants arrive at consensus benchmark values. The two questions asked for each indicator were: 1) What do you think is an appropriate benchmark (with the underlying principle being that if these benchmarks are met, quality of bladder cancer care in Canada would improve)? and 2) What is the current status at your center for this indicator?

During the third BCQCM, the results of the survey were presented, together with any supporting data or information from the literature. Participants were then asked to reach consensus on a benchmark for each indicator.

Below, we provide details on the deliberations on each of the 13 quality indicators, including the survey results, along with the consensus benchmark selected. These are summarized in Table 1.

Table 1. Indicators and benchmarks for bladder cancer quality of care scorecard

Group	#	Indicator	Benchmark
Structure	1	Annual surgical volume of radical cystectomy by each surgeon performing this procedure	>6
Process	2	Percent of patients with TURBT completed <3 weeks after cystoscopy	>80%
	3	Percent with pathology reports available within one week after TURBT	>75%
	4	Percent of patients with no neoadjuvant chemotherapy who had radical cystectomy within six weeks of last TURBT	>90%
	5	For patients with high-risk NMIBC, percent who had intravesical BCG induction course with at least one year of maintenance	>70%
	6	For patients with MIBC, percent who received any curative-intent definitive therapy (radical cystectomy or radiation-based therapy)	>80%
	7	Percent of patients with adequate lymph node dissection defined as >14 nodes	>85%
	8	Percent of patients with MIBC being seen by medical oncologist (or discussed at a multidisciplinary tumor board) preoperatively for consideration of neoadjuvant chemotherapy	>90%
	9	For patients with MIBC and receiving neoadjuvant chemotherapy, percent who completed a minimum of three cycles of cisplatin-based combination therapy	>80%
	10	Percent of metastatic patients receiving second-line systemic therapy after receiving first-line systemic therapy	>70%
	11	Percent of patients with MIBC on TURBT being referred to radiation oncology preoperatively for consideration of radiotherapy	>50%
Outcome	12	Percent with positive soft tissue margin at radical cystectomy	<10%
	13	Percent of patients deceased within 90 days post-cystectomy	<5%

BCG: bacillus Calmette-Guerin; NMIBC: non-muscle-invasive bladder cancer; TURBT: transurethral resection of a bladder tumor.

1. Annual volume of radical cystectomy per surgeon

For this indicator, observational data from various sources has suggested that the minimum number of radical cystectomy per surgeon below which the quality of care diminished ranges between 5 and 10 cases per year.[4-10] This was the only indicator for which evidence supporting a particular benchmark was presented.

The survey respondents were asked to choose between five different choices for minimum surgeon volume as the benchmark for this quality indicator. Among the 22 respondents, the most common responses were 12 (7/22; 32%) and eight (6/22; 27%) radical cystectomies per individual surgeon per year.

In terms of what is currently happening at the centers, the majority of respondents (13/21) indicated their centers performed >20 annually. When asked about the number of radical cystectomies done by the lowest-volume surgeon at their institutions, 40% (6/20) indicated a volume of <5 surgeries annually; 25% (5/20) indicated 6–10; 20% (4/20) chose 11–15; and 15% (3/20) indicated the annual volume was >20 for their lowest-volume surgeon. For the entire center, 71% of respondents stated that the annual surgical volume was greater than 45.

The Société Internationale d'Urologie (SIU)-International Consultation on Urological Diseases (ICUD) recently recommended that institutions performing radical cystectomies should have a minimum annual surgical volume of 25–30 per year, with a group minimum of two surgeons.[11] Participants pointed out that in the literature, including Canadian data,[9] there is likely harm when the annual surgeon volume falls below six.

The consensus of the group suggested that the benchmark be >6 radical cystectomies per year per surgeon.

2. Percent with transurethral resection of a bladder tumor (TURBT) completed within three weeks of cystoscopy

Previously published data from the province of Quebec showed that the average time between first cystoscopy and first TURBT was 18 days.[12] For the pre-meeting survey, the participants were asked to select a benchmark time from cystoscopy demonstrating a bladder tumor to TURBT. Less than four weeks received the highest response (10/21 respondents; 48%) followed by less than six weeks (8/21; 38%). For the question about what is currently happening in their centers, 50% of respondents (10/20) indicated that the majority of TURBTs were completed within six weeks after cystoscopy.

During deliberations at the meeting, the participants highlighted that the patient perspective needs to be considered. Waiting for testing after receiving a diagnosis of any kind of cancer has a detrimental effect on patients. Many participants agreed that the benchmark for this indicator should be set to as short a duration as possible while still being achievable. The suggestion was made to use three weeks as the duration, with most participants agreeing to this timeframe.

The consensus was >80% of TURBTs should be performed within three weeks of diagnostic cystoscopy.

3. Percent with pathology reports available within one week after TURBT

While there are no published data showing an evidence-based benchmark for benefit or harm in this indicator, there is guidance available for cancer pathology reports in general. For example, the Quebec Association of Pathologists recommends that cancer-related pathology reports be provided within five working days for samples not requiring additional cuts or studies (benchmark 80%),[13] while Cancer Care Ontario sets a target of 14 calendar days for surgical resections, with a benchmark of 85%.[14]

The pre-meeting survey asked the participants what benchmark should be used for time from TURBT to the final pathology report accessible in the patient's chart. The most frequent responses were less than 14 days (9/22 respondents; 41%) and less than seven days (8/22; 36%). In terms of what is actually happening at their centers, seven of 21 respondents (33%) indicated that the time from TURBT to final pathology is typically <21 days; five of 21 respondents (24%) indicated that it was typically <14 days; another five of 21 respondents indicated <10 days; and four of 21 respondents (19%) said <7 days.

After discussion and input from the genitourinary (GU) cancer pathologist on the panel, it was decided that the threshold should be one calendar week, and the quality indicator should be modified to the percentage of patients who have their report accessible within one week after TURBT. During the deliberations, it was estimated that approximately one-quarter of cases would require some extra pathology work.

Therefore, the benchmark was set at >75% of patients should have the pathology report accessible within one week after TURBT.

4. Percent of patients without neoadjuvant chemotherapy undergoing radical cystectomy within six weeks from TURBT

In Quebec, the recommendation is that surgery for any cancer be performed within 28 days, with a benchmark of 90%.[15] The pre-meeting survey asked the participants to indicate the desired benchmark for the percentage of patients (without neoadjuvant chemotherapy) having radical cystectomy within six weeks from last TURBT. There was a range of opinions, with eight of 22 respondents (36%) choosing a threshold of >50%, and five each (23%) selecting >80% or >90%. Of the 21 respondents who indicated what is currently happening at their centers, 13 (62%) said that the proportion of patients undergoing cystectomy within six weeks from last TURBT was 50–60%. Six (29%) indicated a range of 70–80% of patients.

The meeting participants reached a consensus to select a benchmark of >90% for this indicator.

5. For patients with high-risk non-muscle-invasive bladder cancer (NMIBC), percent who had intravesical bacillus Calmette–Guerin (BCG) induction course with at least one year of maintenance

In the pre-meeting survey, the participants were asked to provide their benchmark for the percentage of patients receiving intravesical BCG induction course with at least one year of maintenance. There was a range of responses, from >60% to >90%, with the latter being the most common response. In terms of recent experience at their centers, there was also a range of responses, with the most common answer being 70–90% of patients fitting these criteria.

During the meeting, the participants discussed how not all patients would be expected to be able to complete a year of intravesical BCG therapy.

The consensus was a benchmark of >70% of patients with high-risk NMIBC should receive an induction course of BCG with at least one year of maintenance if no disease recurrence.

6. For patients with MIBC, percent who received any curative-intent definitive therapy (radical cystectomy or radiation-based therapy)

There was a range of responses, from >75% to >90% of patients receiving any curative-intent definitive therapy. The most common response was >80%. When asked what is currently happening at their institutions, the most common response was >85% of patients receiving a curative-intent definitive therapy, with the same range of response (>75% to >90%).

The meeting participants opted to select a benchmark of >80%.

7. Percent of patients with adequate lymph node dissection, defined as >14 nodes

While there are no data available to guide benchmarking of this indicator, the GU cancer pathologist on the panel stated that this quality indicator would be of particular importance to pathologists. The pre-meeting expert survey showed that the majority of respondents believed a >90% benchmark would be most appropriate for this indicator, with smaller proportions of respondents choosing less aspirational benchmarks between >60% and >85%. With respect to what is happening now at their centers, the most common response

to the survey question was that >90% of cases at the respondents' centers achieve adequate dissection of >14 nodes (approximately one-third of respondents). However, there was also a fairly even distribution of responses from >60% to >85%.

With respect to the benchmark, after some discussion among the participants, the consensus was to select >85% of patients should have >14 nodes removed with radical cystectomy.

8. Percent of patients with MIBC being seen by medical oncologist (or discussed at a multidisciplinary tumor board) preoperatively for consideration of neoadjuvant chemotherapy

In the pre-meeting survey, the respondents had a range of opinions for the best benchmark for the proportion of patients being seen (or discussed at a multidisciplinary tumor board) for consideration of neoadjuvant chemotherapy, from >60% to >90%, with >80% being the most commonly selected response. In terms of recent experience, the survey respondents again gave the same range of answers, with the most common being >90%.

There was extensive debate among the meeting participants about whether or not this indicator was appropriate, as it was decided upon at the second quality of care meeting, or if it should be changed to also include radiation oncology consultation (e.g., proportion of patients seen by both medical oncology and radiation oncology or discussed at a multidisciplinary tumor board involving both specialties). It was decided that the indicators would remain as decided on at the previous meeting.

The participants decided on a benchmark of >90% of patients with MIBC should either be seen by medical oncologist or discussed at a multidisciplinary tumor board.

9. For patients with MIBC receiving neoadjuvant chemotherapy, percent who completed a minimum of three cycles of cisplatin-based combination therapy

The pre-meeting survey results showed that the benchmark preferred by more than half of the respondents was >90% of patients completing at least three cycles of cisplatin-based combination therapy. For the question about recent experience, the most common answer was also >90%, although there were some respondents who indicated that lower proportions of patients achieved these criteria at their institutions.

The medical oncologists at the meeting discussed how even in expert hands, not all patients would be capable of completing three cycles of cisplatin-based therapy, but the great majority should be able to.

The consensus benchmark selected was >80% of patients who initiate neoadjuvant chemotherapy should receive a minimum of three cycles.

10. Percent of metastatic patients receiving second-line systemic therapy after receiving first-line systemic therapy

The pre-meeting expert survey showed a range of responses for the preferred benchmark of patients who are offered second-line systemic therapy after having received first-line chemotherapy. The most selected response was >90%. In terms of what is happening currently at their institutions, the most common response was that 40–50% of patients are currently offered a second-line systemic treatment after first-line chemotherapy.

At the meeting, the participants agreed to alter the wording of the quality indicator to reflect the proportion of patients "*receiving* second-line *systemic* therapy after receiving first-line *systemic* therapy" rather than as it was previously written "*offered* second-line systemic therapy after receiving first-line *chemotherapy.*" The change from "chemotherapy" to "systemic therapy" in the first-line part of the indicator is meant to reflect the evolving therapeutic environment, in which immune-oncology is likely to play an increasingly important role among systemic therapies. In terms of the definition of first- and second-line, the participants agreed that it would be as described in clinical trials.

The benchmark selected by consensus for this indicator was >70% of metastatic patients receive second-line systemic therapy after receiving first-line systemic therapy.

11. Percent of patients with MIBC on TURBT referred to radiation oncology preoperatively for consideration of radiotherapy

In the pre-meeting survey, there was considerable variation in the responses selected for this indicator. The most common response was >40%, with smaller proportions selecting higher benchmarks of >50% to >80%. Most respondents indicated that, in recent experience at their centers, 40–50% of patients are being referred to radiation oncology, with much smaller numbers of respondents indicating that the proportions were higher (up to >80%) at their institutions.

The final consensus was to use a benchmark of >50% of patients with MIBC should be referred to radiation oncology preoperatively for consultation.

12. Percent with positive soft tissue margin at radical cystectomy

For this outcome indicator, there was reasonable consensus in the pre-meeting survey, with the vast majority of respondents selecting a benchmark of <10%. Also, with respect

to recent experience, a similar proportion of respondents indicated that the proportion of patients with positive soft tissue margin at radical cystectomy at their centers was <10%.

The group quickly reached consensus on this indicator, with a selected benchmark of <10%.

13. Percent of patients deceased within 90 days post-cystectomy

For the pre-meeting survey question asking for expert opinion on the recommended benchmark for this indicator, almost all the respondents selected an answer of <5%, with the most popular answer being <3%. In terms of recent experience, approximately half of the respondents selected 3–4% 90-day post-cystectomy mortality, while a similar proportion reported a 1–2% rate in their institutions.

Participants reached consensus for a benchmark of <5% for this indicator.

III. Update on centers of expertise

This was a topic of extensive discussion and debate at the first two quality of care meetings.[1,3] The group had decided on criteria that could be used to define centers of expertise. The criteria have not yet been assessed across institutions. As a pilot study, it is thought that the information being collected by the CBCIS can soon be used to identify those participating 14 institutions that fit the selected criteria. During the meeting, the suggestion was made that there could be a listing of "centers for second opinion" that patients can access when they want to seek a second opinion. It was also proposed that BCC could have a list of institutions that hold regular comprehensive multidisciplinary tumor boards, to which patients could be presented for discussion. Each tumor board has a checklist of information required for a second opinion (e.g., histology, surgical report, etc.). A tumor board report will then be sent to the treating physician and inserted in the patient's medical file. As an initial step, it was decided that BCC would compile a list of contacts for comprehensive GU cancer multidisciplinary tumor boards across the country. However, this concept needs to be further evaluated, as the list need to be kept continuously updated to ensure that individual tumor boards include the participation of all multidisciplinary members (refer to criteria defined in the previous BCQCM report).

IV. Canadian bladder cancer forum (CBCF): Concept development

The concept of an annual CBCF was proposed as a way to further enhance care of bladder cancer in Canada. There were several motivations suggested for developing this dedicated, bladder-specific forum: to position Canada as global leader in care and management of bladder cancer patients; to promote clinical and translational research collaboration by building on existing strengths in Canada; to coordinate clinical trial activity across the country; to attract new talent and trainees to the bladder cancer community; to promote patient-centered care and research; and to raise funds for national bladder cancer projects, grants, etc.

The suggestion at the BCQCM was to model a bladder cancer-specific forum on the Kidney Cancer Research Network of Canada (KCRNC)'s annual Canadian kidney cancer forum (CKCF). The participants universally supported the initiative for a bladder-specific meeting, along with achieving deliverables (e.g., flushing out concepts for multicenter grant submissions, consensus statements) and research goals clearly defined at such an event. With respect to the existing BCQCM meetings, which have taken place approximately every two years, it was anticipated that this would be included in the program of the annual CBCF.

For next steps, Drs. Wassim Kassouf and Peter Black agreed to investigate this proposal further and potentially hold the inaugural meeting in 2020.

V. Bladder preservation for invasive bladder cancer: Barriers and enablers

The BCQCM program included an in-depth discussion of bladder preservation for invasive bladder cancer. The session included a presentation from the U.K. perspective by Professor Robert A. Huddart (Royal Marsden NHS Foundation Trust and Institute of Cancer Research in London, U.K.) and a presentation from the Canadian perspective by Dr. D. Robert Siemens, followed by group discussion.

Professor Huddart pointed out that in the U.K., bladder preservation is used more frequently than anywhere else in the world. To give some perspective on the role of non-surgical management of bladder cancer, the situation in bladder cancer was compared to that of anal cancer. Both types of tumors have seen well-conducted studies involving a combination of chemotherapy and radiation. In anal cancer, the key study was ACT1, which used combined 5-FU/MMC for chemotherapy and 60Gy/31f radiotherapy.[16] In bladder cancer, the key study was the BC2001 study, which also combined chemotherapy (5-FU/MMC) with radiotherapy (64Gy/32f).[17] In each of these studies, the locoregional failure rates and overall survival were similar. In anal cancer, this has led to the widespread uptake of this approach as the preferred strategy. However, in bladder cancer, radical cystectomy remains the recommended definitive curative approach for most patients. Professor Huddart discussed whether radical cystectomy should be considered as the default option since it is a morbid operation that not only

has a dramatic impact on patient quality of life, but also is also associated with significant complication rates.

He provided some potential reasons for the bias towards cystectomy, including the need for centers to meet government-mandated quality standards in surgical volumes (i.e., need to perform a minimum number of radical cystectomies per year). He also discussed how there might be a general lack of confidence among practitioners to use bladder-preservation strategies as an option. Professor Huddart speculated that the complex multidisciplinary pathways involved in bladder cancer care are also a barrier to the more widespread adoption of bladder-sparing strategies. To illustrate the complex nature of the care pathways, he showed details of a clinical trial (SPARE) that was designed to compare bladder-sparing with radical cystectomy in MIBC.[18-20] Recruitment to this trial was challenging, with final enrollment (n=45) below the predefined target of 110 patients.[18] Among the reasons identified for poor enrollment were difficulty of providing balanced and clear trial information that underscored the equipoise of the clinical question, complicated recruitment pathways, and breakdown in communication among the multiple professionals involved.[19,20]

"Educational inertia" was also cited as a potential reason for low uptake of bladder-sparing strategies, with opinion leaders having been taught that cystectomy is the "gold standard," which is reinforced through expert-authored clinical practice guidelines and through education of surgical and oncology fellows. He showed how clinical practice guidelines are written in such a way as to greatly favor radical cystectomy, citing the European Association of Urology guideline, which includes 14 pages and 22 recommendations discussing radical cystectomy and only three pages on bladder preservation, of which only 1.5 pages are for curative treatment.[21]

Professor Huddart also reviewed several potential "enablers" of bladder-sparing strategies. Foremost among these is multidisciplinary care. He discussed how multi-professional clinics and team meetings help facilitate inter-specialist communication and are more likely to result in consideration of bladder-sparing strategies than more siloed care.

Clearly written clinical practice guidelines could also be enablers of bladder-sparing. Professor Huddart discussed the process involved in the development of guidelines for the National Institute of Clinical Excellence (NICE) in the U.K. The process involves clear constitution/rules, with multi-professional involvement, an independent chair, lay representation, an independent evidence review team, defined questions, and declared conflicts of interest.[22] He believes that the bladder cancer guideline endorsed by NICE offers a balanced approach to treatment selection in its recommendations: "Offer a choice of radical cystectomy or radiotherapy with a radiosensitizer to people with muscle-invasive urothelial bladder cancer for whom radical therapy is suitable. Ensure that the choice is based on a full discussion between the person and a urologist who performs radical cystectomy, a clinical oncologist, and a clinical nurse specialist."[22] In the explanatory text, the authors wrote that they "could identify no conclusive evidence that one modality was better than the other. Thus, the recommendation is that all patients should have full discussion of the pros and cons of both treatments, ensuring that patients get chance to see a specialist in both."

Another potential enabler that Professor Huddart discussed was the strategy of selective bladder preservation based on chemotherapy response. In this model of care, the patient would receive three cycles of upfront chemotherapy. Those who responded (pT0/1 on cystoscopy and imaging) would go on to a conservative treatment approach, with radical cystectomy reserved for treatment failures. Those patients who did not adequately respond to the initial chemotherapy (pT2+ on cystoscopy) would go on to immediate cystectomy.[23] This method was retrospectively evaluated among 94 successive patients with T2–T4aN0M0 bladder cancer treated between January 2000 and June 2011 at a single U.K. center.[23] Among the 89 patients who were assessed for response, 78 (88%) demonstrated response. Seventy-four of these responders had radiotherapy, with the remaining four opting for cystectomy. On multivariate analysis, only response was associated with significantly improved progression-free survival, disease-specific, and overall survival. After a median followup of 39 months, 14 of the 74 responders (19%) to neoadjuvant chemotherapy who did not have upfront cystectomy required salvage cystectomy.

Other markers have been proposed to help predict response to radiotherapy, which could also become enablers of bladder-sparing,[24] but nothing has yet proven to be reliable.

Table 2. Barriers and enablers to bladder-sparing strategies for muscle-invasive bladder cancer (MIBC) in Canada

Predominant barriers	Predominant enablers
Belief that radiotherapy has inferior survival compared with cystectomy	'Champions' who believe in radiotherapy and advocate for its adoption
Lack of referral from urology to radiation oncology	Belief by urologists that radiation oncologists should present radiotherapy options to all MIBC patients
Belief by urologists that there is a high overall failure rate of first-line radiotherapy	Institutional policy that all MIBC patients should be seen by multiple specialists
Absence of 'champions' advocating for the use of radiotherapy in MIBC patients	System-level factors for patient referral (i.e., automatic multidisciplinary referral process; nurse navigator)
Inadequate multidisciplinary collaboration and/or system-level factors conducive to discussing cases (i.e., lack of multidisciplinary clinics)	Patient-driven consultations seeking alternatives to cystectomy

Finally, Professor Huddart said that patients themselves could be enablers of bladder preservation. Fully educated patients may choose bladder-sparing more often than we are currently seeing in practice. Healthcare professionals need to acknowledge patients as key decision-makers.

Dr. Siemens' presentation on the situation in Canada included a review of a population-based study examining patterns of referral to radiation oncology in Ontario.[25] This study showed that approximately one-third of all patients with MIBC in routine practice are seen by a radiation oncologist (RO). Factors associated with an increased referral rate included advanced age, greater comorbidity, and earlier year of diagnosis.

Dr. Siemens also reviewed a qualitative study involving 13 Canadian urologists, 11 ROs and 10 medical oncologists (MOs), which showed that among these professionals, there were several key barriers and enablers to bladder-sparing in MIBC (Table 2).[26]

Furthermore, a web-based survey of Canadian urologists, ROs, MOs designed to further investigate barriers and enablers was published in 2017.[27] A total of 64 urologists, 29 Ros, and 26 MOs responded. In terms of outcomes, the participants reported comparable five-year survival rates for cystectomy (51%) and radiotherapy with concurrent chemotherapy (50%).[27] Despite this, the urologist respondents reported that they referred a median of only 20% of patients to RO, and ROs treated half of the patients referred (median response: 5/10). MOs reported that they referred a median of 2/8 patients not referred to RO by urology. The key enablers to referral among urologists were 'beliefs about consequences,' 'social and professional role,' and 'environmental context and resources.'[26]

It appears clear that both strategies (bladder-sparing and radical cystectomy) are associated with good overall outcomes. There is a need for practitioners to offer either option to those patients who are candidates for both. Patient education is also a key. There is a BCC resource for patients discussing the options, which may be helpful for counselling about treatment strategies. Educating healthcare professionals is also important; there needs to be more Canadian champions (including all interested specialists, not just ROs) talking about this topic across the country.

VI. Patient-driven research: Engagement and priorities

During this segment of the program at the third BCQCM, participants discussed the recently completed project in kidney cancer that was developed to identify the top 10 research priorities in kidney cancer, as determined by patients, caregivers, and expert clinicians.[28] This was presented by Dr. Michael Jewett, one of the co-principal investigators.

The process, established by the James Lind Alliance, involved five steps: establishing a steering group and inviting potential partners; identifying perceived uncertainties; refining questions and uncertainties; prioritization — interim and final-stage; and knowledge translation.[29]

Perceived uncertainties were gathered by means of online and paper surveys, which were promoted through social media. There was a total of 225 surveys completed, which revealed a total of 246 uncertainties. Following interim ranking and literature review, the list was reduced to the top 29 research priorities. A final, one-day prioritization workshop was then convened involving a multidisciplinary team (including healthcare professionals, patients, and caregivers) and independent observers, during which there was discussion and debate about what the top 10 research priorities should be. Finally, the participants reached consensus on the top 10 research priorities in kidney cancer.

Dr. Jewett said that while there was nothing on the list that was a surprise, the priorities at the top of the list were not as he would have anticipated when the process began. Some of the key benefits of the process and its outcome were that they helped legitimize research strategies and facilitate funding requests and publication priority. Apart from the tangible benefits, however, he stressed that one of the most important results of the process was that the process itself fostered a sense of community across disciplines in kidney cancer. Among the drawbacks, he explained, were that the process was time-consuming and expensive, and that the requests for funding as the result of this process have not been as successful as hoped for. In terms of applicability to the bladder cancer field, there was broad agreement across meeting participants that this process could be repeated for bladder cancer in Canada. It was discussed that the experience gained in the kidney cancer process could be applied to streamline the bladder cancer process and eliminate some of the problems encountered during the kidney cancer research priority process. Dr. Jewett offered to lend his assistance to any such effort. Dr. Nimira AliMohamed offered to take the lead on the initiative moving forward.

VII. Issues and concerns from Bladder Cancer Canada

Mr. Ferg Devins, Chair of the BCC Board of Directors, gave an overview of BCC's recent activities, including demonstration of some new patient information tear sheets with facts on MIBC on one side and NMIBC on the other side. He also mentioned that in 2019, BCC's 10-year anniversary year, the organization is expanding funding for research; there will now be two $50 000 BCC-funded research grants per year where previously there was one. Their fundraising model is also being refined in an effort to bring in even more funds, with the potential for a social media "challenge" similar to the very successful "Ice Bucket Challenge" for ALS. BCC continues to grow; there was a 32% increase in overall membership over 2017, the highest number of new members

since 2011, with dramatic increases in numbers of members coming both from social media and from hospitals.

Roadblocks/delays to diagnosis

Mr. Randy Smith, a bladder cancer survivor and volunteer patient support coordinator with BCC, gave an overview of perceived roadblocks and delays to diagnosis, as gathered through BCC's call-in lines. He explained that BCC receives calls from bladder cancer patients and from people not diagnosed with bladder cancer who are concerned about signs and symptoms.

He listed some of the key issues identified by patients impacting on time to diagnosis: speed of identifying the cause of underlying blood in the urine; not using cytology and abdominal imaging as part of the workup for hematuria; inconsistent wait time for pathology results (up to a month in some cases), and primary physician lack of urgency and the slow process of setting up and getting a referral. He asked the participants for input on how these issues might be addressed. One of the main areas for improvement that was identified during the discussion was to educate primary care physicians. There is a clear need for better, accessible diagnostic tools for microscopic hematuria at the primary care level, and for education on bladder cancer diagnosis in general. It was suggested that BCC reach out to industry partners to inquire about the feasibility of having their sales and education forces devote some of their time to educating primary care practitioners about bladder cancer diagnosis and the importance of microscopy to confirm dipstick testing. The participants at the meeting also recommended having a scripted answer from BCC's medical advisors about what to say to patients who call in concerned about having microscopic hematuria, based on CUA guidance.

Delays/variability in treatment

Mr. Smith also reviewed perceived delays and inconsistencies in bladder cancer treatment among patients calling in to BCC. These include long or inconsistent wait between diagnostic testing (cystoscopy to TURBT); inconsistent use of staging tools (e.g., computed tomography scans, bone scans, etc.); variable wait times and availability of urologists, particularly in rural communities; and differences in BCG regimens across the country. It was discussed that the measurement and assessment of quality indicators as discussed above (section II) is designed to help quantitate these delays and variability in treatment.

Screening for initial bladder cancer or recurrence

Mr. Robert Purves is a bladder cancer survivor and Director and Treasurer on the BCC board. He discussed the patient perspective that novel urine markers are commercially available in the U.S. but not in Canada and questioned whether BCC should be advocating for enhanced access to these tests. Participants at the meeting voiced their concerns about the level of evidence available with these new technologies, saying that it is currently insufficient to recommend these modalities over existing strategies to improve care. It was discussed that there needs to be some patient education in this regard: the lack of availability of these tests in Canada is due to a lack of evidence of their clinical utility. The participants did recognize, however, that should there be evidence that emerges showing enhancement of care with new technologies, BCC should play a central role in advocating for its availability and accessibility in Canada.

Cysview® and blue light cystoscopy (BLC)

Ms. Tammy Northam, BCC's Executive Director, led a discussion on BLC with Cysview® for use in TURBTs. Among the participants at the meeting, five indicated they are currently using this technology in select cases. Others said they are waiting for hospital approval.

Although there is strong evidence that it is beneficial in reducing recurrences, participants identified hospital budgets as the key roadblock to more widespread use of this technology. Combined advocacy efforts with patients and urologists can have an impact on hospital decision-makers.

It was discussed that the manufacturers of Cysview® have been unsuccessful in obtaining provincial funding for BLC anywhere in the country. Some group members at the meeting felt that the additional benefit provided to patients by BLC was less compelling. There was also some concern about patient perception of centers based on whether or not they have new technologies.

Participants recommended that when novel treatments or devices are being evaluated, BCC should have a review process with their medical advisory board to determine whether BCC efforts should include advocating for access to the product and, if so, how this could be done.

The emotional side of bladder cancer

Mr. David Guttman, bladder cancer survivor, honorary board member and co-founder of BCC, discussed the emotional aspects of bladder cancer. He stressed that emotional support is a need of every patient with bladder cancer, regardless of his or her diagnosis, prognosis, or stage. They all have fears, concerns, and anxieties throughout the care pathway. Mr. Guttman advocated for the incorporation of peer support for all patients with bladder cancer. As part of their checklist of things to provide their newly diagnosed patients, Mr. Guttman asked that physicians (or other members of the care team — nurses, ostomy care) refer their patients to BCC, with a specific mention of the discussion forum and potential for

peer support. If patients choose, BCC can then match them with peers to discuss their disease and have many of their emotional needs addressed. Specifically, for people who are at the stage where they are faced with radical cystectomy as the next stage of their journey, matching with a peer who has been through that process can be very helpful.

VIII. Next steps

The most important next steps discussed at the conclusion of the meeting were:

- Use the CBCIS database to provide the preliminary data on some of the quality of care indicators measured across 14 centers;
- Identify centers across Canada that have a comprehensive multidisciplinary tumor board and compile contact information for these centers;
- Plan the first CBCF for 2020; and
- Evaluate whether a patient-driven research priority bladder cancer project needs to be undertaken in Canada.

Competing interests: Dr. Kassouf has received grants/honoraria from Amgen, Astellas, and Janssen. Dr. Aprikian has received grants/honoraria from Abbvie, Amgen, Astellas, and Janssen; and has participated in clinical trials supported by Astellas. Dr. Saad has attended advisory boards for and received payment/honoraria from AbbVie, Amgen Astellas, Bayer, Janssen, and Sanofi; and has participated in clinical trials supported by Amgen Astellas, Bayer, Janssen, and Sanofi. Dr. Fleshner has been an advisory board member or consultant for Abbvie, Amgen, Astellas, Bayer, Ferring, Hybridyne Health, Janssen, and Sanofi. Dr. Alimohamed has been an advisory board member for Astellas, AstraZeneca, Janssen, Merck, and Pfizer. Dr. Chung has received grants/honoraria from Sanofi. Dr. Eapen has received grants/honoraria from Abbott and AstraZeneca; and has participated in numerous clinical trials. Dr. Eigl has received honoraria and travel support from Astellas, AstraZeneca, Bayer, Janssen, Merck, and Roche. Dr. Fairey has received speaker honoraria from J&J and Roche. Dr. Izard has been an advisory board member or consultant for Abbvie, Astellas, Ferring, Janssen, and Sanofi; and has participated in clinical trials supported by Astellas, AstraZeneca, and Merck. Dr. Lalani has received honoraria for ad hoc consultation or advisory board meetings from BMS, Eisai, Ipsen, Merck, Pfizer, Rocher and TerSera; and has participated in clinical trials supported by Merck. Dr. Lukka is on a speahers' bureau for Astellas; has received grant support and honoraria from Abbvie, Actavis, Amgen, Astellas, Bayer, Ferring, Janssen, and Tersera; own stocks in Vertex Pharmaceuticals; and has participated in clinical trials supported by Bayer and Janssen. Dr. Morash has attended advisory boards for AbbVie, Astellas, Ferring, Janssen, and Sanofi. Dr. North has attended advisory boards for Astellas; has received grants/honoraria from Astellas, Janssen, and Sanofi; and has participated in clinical trials supported by Astellas, Janssen, and Sanofi. Dr. Ong has received honoraria from Asetllas, AstraZeneca, Bayer, BMS, EMD Serono, Janssen, and Merck; and has received a research grant from AstraZeneca and a GUMOC grant from Astellas. Dr. Rendon has attended advisory boards and has been a speaker for Amgen, Astellas, Ferring, and Janssen. Dr. Shayegan has received grants/honoraria from AbbVie, Astellas, Janssen, and Sanofi; and has participated in clinical trials supported by Astellas and Janssen. Dr. So has been a speaker for Amgen, Astellas, and Janssen. Dr. Sridhar has attended advisory boards for Astellas; has received grants/honoraria from Astellas, Janssen, and Sanofi; and has participated in clinical trials for Agenisys, Imclone, OGX, Roche, and Sanofi Aventis. Dr. Zlotta. Dr. Siemens has participated in clinical trials supported by Amgen, Astellas, Ferring, and Janssen. Dr. Black has attended advisory boards for AbbVie, Amgen, Astellas, Biocancell, Cubist, Janssen, Novartis, and Sitka; has been a speaker for AbbVie, Janssen, Ferring, Novartis, and Red Leaf Medical; has received grants/honoraria from Pendopharm; has participated in clinical trials supported by Amgen, Astellas, Ferring, Janssen, and Roche; and has received research funding from GenomeDx, iProgen, Lilly, and New B Innovation. The remaining authors report no competing financial or personal interests related to this work.

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Correspondence: Dr. Wassim Kassouf, Departments of Urology, McGill University Health Centre, Montreal, QC, Canada; wassim.kassouf@muhc.mcgill.ca