Cancer Practice Guidelines
Status Report Update: All Cancers

Capacity Enhancement Program of the Cancer Guidelines Advisory Group

May 2012

Available at www.cancerview.ca/sage
Executive Summary

The Canadian Partnership Against Cancer Corporation (the Partnership) is an independent cancer organization funded by the federal government to implement the first pan-Canadian cancer control strategy. As one action group of the Partnership, the Cancer Guidelines Advisory Group and one of its key initiatives, the Capacity Enhancement Program (CEP), is mandated to champion a Canadian strategy around the use and application of evidence as it applies to the development of practice guidelines for cancer control.

One key aspect to success of the national strategy was the development of the SAGE Directory (Standards and Guidelines Evidence), a publically accessible database of quality appraised cancer control guidelines. The SAGE Directory was designed to act as a catalyst to raise the standard in the science of developing practice guidelines, to reduce the duplication of effort amongst guideline developers, and to provide a resource to enable greater evidence-based decision making by patients, clinicians, policy and system leaders across Canada.

Since 2008 the CEP has conducted regular updates to the SAGE Directory. In March 2011, SAGE comprised 1158 English language clinical practice guidelines published between 2003 and 2010. An update of the database completed in March 2012 identified an additional 701 practice guidelines published between 2010 and January 2012. The focus of this report is to provide an analysis of the new guideline data (2010 to 2012) by summarizing the demographic characteristics, development methods, scope and content, and quality of the clinical practice guidelines. 133 cancer guideline development groups, representing government supported agencies and health care professional organizations, developed the 789 cancer clinical practice guidelines. Canada is a world leader in the development of cancer control guidelines, with approximately 20% of all the guidelines produced by Canadian provincial/territorial cancer agencies, cancer organizations or other professional bodies. The bulk of the remaining guidelines were developed in the United States of America or within Europe.

Overall analyses were also performed for comparative purposes and to provide an overview of the entire body of cancer control guidelines (2003 to 2012). These analyses of 2042 guidelines indicate there is room for improvement in the reporting of guideline development methods, the use of systematic review, filling gaps in knowledge, and the avoidance of duplication in cancer control practice guidelines. Within SAGE, guideline-reporting quality was assessed using the AGREE II instrument that evaluates the quality of guideline reporting according to six domains. The overall quality of the clinical practice guidelines was found to be at a moderate to low level. Clinical guidelines scored highest in the Scope and Purpose (63%) and Clarity and Presentation (73%) domains of the AGREE II instrument and lowest in the Stakeholder Involvement (41%), Applicability (27%), and Editorial Independence (39%) domains. With an overall mean domain score of 45% in Rigour of Development, it is clear that the reporting of methodological rigour could be improved across guideline development groups.

New changes to the SAGE Directory include updated processes to make the quality appraisal component more manageable. A quality threshold requirement has been added, whereby all historical guideline development groups need to score at least 50% on the Rigour of Development domain in order to be quality appraised in update searches. All Canadian records by default will receive quality appraisal measures and at this time do not need to meet the thresholds. Newly added records for which historical performance data are unavailable are also eligible for quality appraisal. As a

While numerous clinical practice guidelines have been produced for the major disease types of lung, breast, gastrointestinal, and genitourinary cancers, there is less guidance available for more rare cancer types such as neurological tumors and sarcomas. There also remain components of the continuum of care for which there is limited guidance available specifically for cancer. Few guidelines were identified that were specific to cancer prevention and
Health promotion, survivorship, recovery, or rehabilitation. With the ever-increasing number of both new cancer cases and cancer survivors, more effort will need to be directed toward providing guidance on both the prevention of cancer and the ongoing support needs of cancer survivors.

**Background**

Clinical practice guidelines are guidance products developed by expert panels to help health care professionals and patients make informed decisions about the most appropriate health care for specific clinical circumstances (1). Guidelines can also inform best professional practices or organization of care models within a health care system and policy decisions (2). A guideline is often developed in response to uncertainty around the best clinical, administrative or policy-related practices, presence of a new or emerging care option, or where variation in practice or organization of health services could potentially compromise the quality of care delivered. They can be useful components of a quality improvement initiative, help mitigate unwanted practice variation, and facilitate access to health care options that are effective (2).

It is generally accepted that a well-designed clinical practice guideline requires the input of a multidisciplinary group of content experts, often also involving stakeholders such as patients, an explicit and systematic methodological approach, and a commitment to the time and resources needed to complete the job well. Given the significant amount of time and resources required to produce clinical practice guidelines on cancer and the increasing number of guideline developers, it is important that duplication of guideline coverage be avoided where possible in order to optimize efficiency.

To be effective, safe and credible, guidelines need to be of high quality. Guidelines of highest quality provide clear descriptions of scope and purpose, use rigorous methodology including a systematic review of the evidence on which recommendations are based, present recommendations clearly, take into account the preferences of the guidelines target population, provide information on how to implement the recommendations, and are transparent with respect to influence of the funding source and authors’ potential conflicts of interest (3).

The Capacity Enhancement Program, on behalf of the Cancer Guidelines Action Group of the Canadian Partnership Against Cancer, has undertaken an initiative to systematically identify, synthesize and analyze existing publicly available cancer control guidelines in the field. This report provides an overview of all guidelines for cancer with a focus on clinical practice guidelines. This report, in combination with the publicly available online SAGE Directory of Cancer Guidelines resource (www.cancerview.ca/SAGE), are intended to encourage and promote the optimal use of evidence in decision-making, improve outcomes for cancer patients, the cancer system, and reduce duplication of effort in the cancer practice guideline enterprise by supporting opportunities for collaboration.

**Cancer: A Clinical Snapshot**

In Canada, there were an estimated 177,800 people newly diagnosed with cancer in 2011 (excluding 74,100 cases of non-melanoma skin cancer) and approximately 75,000 deaths from cancer (4). The majority of new cancer cases in Canada are the following types: lung, colorectal, prostate and breast cancer.

Cancer risk is determined by age, genetics, a wide range of environmental and lifestyle factors and interactions among these factors (5-7). Cancer prevention measures and screening programs have been undertaken in order to reduce the incidence of cancer, and to detect cancer earlier. Tumours that are diagnosed early before they spread beyond the primary disease site into adjacent organs or to distant sites are generally associated with a better prognosis. Primary modalities of therapy for cancer include surgery, radiotherapy, and systemic therapy (chemotherapy and biological
The optimal choice of therapy is dependent on cancer type and the degree to which the cancer has progressed. In addition to primary therapy for treatment of the tumour, patients require supportive care to meet physical, psychosocial, spiritual, and informational needs. Cancer survivors often face numerous physical and psychosocial challenges as a result of their disease and long-term treatment effects.

Cancer Guidelines Status Report

Guidelines play an important role in the improvement of cancer control. Guidelines for cancer control have been developed both within Canada and worldwide. Examples of established cancer guideline developers include Canadian provincial guideline organizations and international guideline development groups such as the American Society of Clinical Oncology (ASCO), National Comprehensive Cancer Network (NCCN), European Society of Medical Oncology (ESMO) and the National Health Service (NHS). In addition, a growing number of government supported agencies and healthcare professional organizations are contributing to the cancer guideline enterprise.

This status report provides an analysis of the body of publically available English-language cancer control guidelines. The questions of interest were:

- What is the reporting quality of the body of English language cancer guidelines?
- Which groups are developing cancer guidelines?
- Do cancer guidelines address relevant clinical issues across the cancer control spectrum?
- Is there duplication in cancer guideline development and are there gaps that are not being addressed?

A content analysis of guideline recommendations is beyond the scope of this report, and the assessment of French-language guidelines is not feasible at this point in time.

Methods

A systematic literature search of the published literature, guideline databases, and websites of selected guideline developers was conducted to identify the body of English language cancer practice guidelines released in the public domain through publication or web-based posting from June 2010 to January 2012. This search strategy updates and is similar to the original literature search that was performed in 2008 and covered the literature from 2003 to 2008. Details regarding the search strategy and guideline evaluation process are described in a separate report (www.cancerview.ca/SAGE). Guidelines providing organizational guidance or professional practice recommendations but not patient-centered clinical practice recommendations were excluded from the analyses. The analyses contained in this report focus on the new data (2010 to 2012) but overall analyses (2003 to 2012) were also conducted.

Guidelines were assessed for quality using the AGREE II instrument, a 23-item tool comprised of six domains each designed to evaluate a separate dimension of guideline quality (refer to appendix 2) (3). These domains include **Scope and Purpose**, **Stakeholder Involvement**, **Rigour of Development**, **Clarity and Presentation**, **Applicability**, and **Editorial Independence**. Each guideline was assessed for quality by a minimum of two raters using a 7-point scale for each item. Domain scores are calculated by summing up all the scores of the individual items in a domain and scaling the total as a percentage of the maximum possible score for that domain (8). Mean and range domain scores are reported when assessing the quality of a group of guidelines. Individual item scores are presented as an overall mean across raters on the 7-point scale; a score ≥ 5 on the 7-point scale was considered a high score for analyses of individual AGREE II items.

Guideline quality assessment is a timely and resource intensive endeavour. In order to sustain the SAGE Directory and
stimulate developers towards continuous quality improvement, a minimum quality threshold was applied to all eligible guidelines identified in the 2010 to 2012 update. The quality threshold was based on AGREE II Domain 3, Rigour of Development. This domain includes AGREE items 7 through 14 which relate to the process used to gather and synthesize the evidence, and the methods used to formulate and update the recommendations. Guidelines developed by organizations previously included in the SAGE Directory that averaged at least 50% in Domain 3 on previous AGREE II quality assessments received an AGREE II quality assessment for the update. The quality threshold did not apply to new or Canadian developer organizations.

Data pertaining to cancer clinical practice guidelines were extracted and summarized into three categories for this report:

- **Demographic Characteristics**
  - Overall
  - By jurisdiction (continent/country, Canadian province)
  - By developer

- **Development Methods**
  - Use of systematic review methodologies
  - Types of evidence
  - Reporting of implementation strategy
  - Reporting of audit criteria
  - Reporting of conflict of interest

- **Scope and Content**
  - Continuum of care

Frequency data and AGREE II mean domain scores were calculated using Microsoft Excel software with custom data filters for analyses of each guideline subset of interest.

**Results**

**A. Overall Cancer Guideline Demographics**

To date, a total of 2042 cancer guidelines have been identified using four systematic searches; 645 guidelines were retrieved between 2003 and 2008 (Phase 1), 608 were found from 2008 to 2010 (Phase 2), and 701 were identified between 2010 and 2012 using 2 systematic searches (Phase 3). The remaining 88 guidelines are currently in development and have yet to be published (Table 1). In recent years there has been a steady increase in the number of cancer guideline publications and more developers are documenting their upcoming guidelines (Table 2). Of the 2042 cancer guidelines identified, 1777 guidelines contain a clinical practice component to the recommendations (Phase 1: n=602, Phase 2: n=556, Phase 3: n=619) and therefore can be scored using the AGREE II instrument. The remaining 265 guidelines are either still in development or listed as organizational and professional guidelines and therefore not eligible for quality assessment using the AGREE II tool.
Table 1: All Cancer Practice Guidelines

<table>
<thead>
<tr>
<th>Phase</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 (2003-2008)</td>
<td>645</td>
</tr>
<tr>
<td>2 (2008-2010)</td>
<td>608</td>
</tr>
<tr>
<td>3 (2010-2012)</td>
<td>701</td>
</tr>
<tr>
<td>In development</td>
<td>88</td>
</tr>
<tr>
<td><strong>Grand Total</strong></td>
<td><strong>2042</strong></td>
</tr>
</tbody>
</table>

Notes: represents number of guidelines

Table 2: Number of Cancer Guidelines by year

<table>
<thead>
<tr>
<th>Year Published</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>2003</td>
<td>94</td>
</tr>
<tr>
<td>2004</td>
<td>94</td>
</tr>
<tr>
<td>2005</td>
<td>131</td>
</tr>
<tr>
<td>2006</td>
<td>186</td>
</tr>
<tr>
<td>2007</td>
<td>183</td>
</tr>
<tr>
<td>2008</td>
<td>146</td>
</tr>
<tr>
<td>2009</td>
<td>279</td>
</tr>
<tr>
<td>2010</td>
<td>487</td>
</tr>
<tr>
<td>2011</td>
<td>305</td>
</tr>
<tr>
<td>*2012</td>
<td>49</td>
</tr>
<tr>
<td>In development</td>
<td>88</td>
</tr>
<tr>
<td><strong>Grand Total</strong></td>
<td><strong>2042</strong></td>
</tr>
</tbody>
</table>

Notes: represents number of guidelines; *2012 guidelines reflect January only

B. Application of Quality Threshold

The Phase 3 search returned a total of 701 clinical, organizational and professional practice guidelines. Of these, 619 contain a clinical practice component, and as such were eligible for quality appraisal. For appraisal, quality thresholds were applied to the subgroup of clinical practice guidelines. Canadian developed guidelines were exempt from the minimum quality threshold, and as such 147 practice guidelines were included in the analyses. Guidelines produced by development groups new to the SAGE Directory were included in the analyses as well (n=111). Of the remaining sample of clinical practice guidelines (n=361), 107 were developed by development groups, which met the minimum quality threshold, and were included in the analyses. Guidelines produced by development groups not meeting the minimum quality threshold (n=254) were not included in the overall quality analyses for Phase 3. Table 3 summarizes the subgroups of guidelines for analyses. Considering all cancer guidelines (2003-2012) that have been assessed for quality (n=1523), overall, the guidelines were appraised as being of moderate quality with the Scope and Purpose and Clarity and Presentation domains scoring the highest (Table 4).

Table 3: Number of Cancer Guidelines Receiving a Quality Assessment in 2010-2012

<table>
<thead>
<tr>
<th>Guideline Category</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guidelines Developed by Canadian Organizations</td>
<td>147</td>
</tr>
<tr>
<td>Non-Canadian Guidelines with an Average Rigour of Development Score of ≥ 50%</td>
<td>107</td>
</tr>
<tr>
<td>Guidelines Developed by New Organizations</td>
<td>111</td>
</tr>
<tr>
<td><strong>Grand Total</strong></td>
<td><strong>365</strong></td>
</tr>
</tbody>
</table>
Table 4: All Cancer Clinical Guidelines (2003-2012)

<table>
<thead>
<tr>
<th>AGREE II domain score (mean score and range across guidelines [%])</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>Clinical Practice Guidelines</td>
</tr>
</tbody>
</table>

Note: represents number of guidelines.

The subgroup of 254 clinical practice guidelines not meeting the minimum quality threshold requirement did not receive an AGREE II quality assessment, however they were indexed within the SAGE Directory. This subgroup demonstrates similar trends with respect to disease site and continuum of care by focusing on the diagnosis and treatment of gastrointestinal and genitourinary disease sites (Tables 5 and 6). The majority of historical low performers are produced in North America, however, this is proportionally reflective of the jurisdictional breakdown of all SAGE records in that the majority of all English language guidelines are produced in North America (Table 7).

Table 5: Guidelines not meeting minimum threshold by Disease Site

<table>
<thead>
<tr>
<th>Cancer Disease Site</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>31</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>53</td>
</tr>
<tr>
<td>Genitourinary</td>
<td>51</td>
</tr>
<tr>
<td>Gynecological</td>
<td>22</td>
</tr>
<tr>
<td>Head and Neck</td>
<td>19</td>
</tr>
<tr>
<td>Hematological</td>
<td>33</td>
</tr>
<tr>
<td>Lung</td>
<td>23</td>
</tr>
<tr>
<td>Neuro-oncology</td>
<td>8</td>
</tr>
<tr>
<td>Ophthalmic</td>
<td>2</td>
</tr>
<tr>
<td>Sarcoma</td>
<td>8</td>
</tr>
<tr>
<td>Skin</td>
<td>13</td>
</tr>
<tr>
<td>Not disease site specific</td>
<td>31</td>
</tr>
<tr>
<td>Pediatric</td>
<td>10</td>
</tr>
</tbody>
</table>

Notes: represents number of guidelines.
Table 6: Guidelines not meeting minimum thresholds by Continuum of Care

<table>
<thead>
<tr>
<th>Component of the continuum of cancer care</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevention and promotion</td>
<td>21</td>
</tr>
<tr>
<td>Screening and surveillance</td>
<td>34</td>
</tr>
<tr>
<td>Diagnostic assessment</td>
<td>166</td>
</tr>
<tr>
<td>Staging</td>
<td>122</td>
</tr>
<tr>
<td>Treatment</td>
<td>179</td>
</tr>
<tr>
<td>Post-treatment follow-up</td>
<td>108</td>
</tr>
<tr>
<td>Survivorship/Recovery/Rehabilitation</td>
<td>23</td>
</tr>
<tr>
<td>End-of-life (Palliative care)</td>
<td>11</td>
</tr>
<tr>
<td>Psychosocial and Supportive care</td>
<td>60</td>
</tr>
</tbody>
</table>

Notes: N represents number of guidelines.

Table 7: Guidelines not meeting minimum thresholds by Jurisdiction

<table>
<thead>
<tr>
<th>Jurisdiction</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>United Kingdom*</td>
<td>7</td>
</tr>
<tr>
<td>United States of America</td>
<td>155</td>
</tr>
<tr>
<td>Europe</td>
<td>86</td>
</tr>
<tr>
<td>Asia</td>
<td>5</td>
</tr>
<tr>
<td>Middle East and North Africa</td>
<td>7</td>
</tr>
<tr>
<td>International</td>
<td>8</td>
</tr>
<tr>
<td>Grand Total</td>
<td>268</td>
</tr>
</tbody>
</table>

Notes: N represents number of guidelines; *United Kingdom produces a substantial number of guidelines and has been analyzed separately and removed from the “Europe” category.

**a) Cancer Guidelines Overview (2010-2012)**

The updated systematic literature and web-search identified 701 English-language cancer clinical, professional, or organizational guidelines published between 2010 and 2012, of which 619 were clinical practice guidelines. The remaining 82 guidelines provided professional practice or organizational recommendations and did not address patient-centered clinical topics; therefore these guidelines were excluded from analyses in this report. Upon applying the rigor of development threshold, 365 guidelines (59%) were critically appraised. Forty-one of the 365 clinical guidelines also provided additional professional practice or organizational recommendations. A total of 129 guidelines (35%) reported that they were updates of previous guidelines.

Overall, the quality of reporting of the 365 clinical guidelines, as assessed by the AGREE II instrument, were on the moderate to low end of the quality scale (Table 8). The guidelines scored the highest in the Clarity and Presentation and Scope and Purpose domains and lowest in the Applicability and Editorial Independence domains.
### Table 8: Cancer Clinical Guidelines (2010-2012)

<table>
<thead>
<tr>
<th>AGREE II domain score (mean score and range across guidelines [%])</th>
<th>Scope and Purpose</th>
<th>Stakeholder Involvement</th>
<th>Rigour of Development</th>
<th>Clarity and Presentation</th>
<th>Applicability</th>
<th>Editorial Independence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical Practice Guidelines</td>
<td>365</td>
<td>65 (22-97)</td>
<td>41 (2-89)</td>
<td>45 (4-89)</td>
<td>73 (30-94)</td>
<td>29 (0-79)</td>
</tr>
<tr>
<td>Canadian Organizations</td>
<td>147</td>
<td>71 (28-97)</td>
<td>36 (8-72)</td>
<td>51 (4-89)</td>
<td>76 (39-92)</td>
<td>28 (8-73)</td>
</tr>
<tr>
<td>Guidelines meeting threshold</td>
<td>107</td>
<td>63 (22-92)</td>
<td>49 (2-89)</td>
<td>48 (12-77)</td>
<td>72 (30-94)</td>
<td>37 (6-79)</td>
</tr>
<tr>
<td>New Organizations</td>
<td>111</td>
<td>63 (31-92)</td>
<td>40 (14-86)</td>
<td>35 (8-89)</td>
<td>69 (36-92)</td>
<td>23 (0-71)</td>
</tr>
</tbody>
</table>

*Note: represents number of guidelines.*

### b) Cancer Guidelines by Jurisdiction

The literature search identified that the majority of 2010-2012 English-language cancer guidelines meeting the inclusion and criteria were produced in Canada (n=147), while other top producers were from UK (n=66), Europe (n=53), United States (n=49), and international collaborations (n=24) (Table 9). The remaining guidelines were produced in Australia/New Zealand (n=13), Asia (n=9), and the Middle East (n=4). A tally of all cancer guidelines (2003-2012) (Table 10) shows that American developers are the top producers of English cancer guidelines (n=627). Canada and Europe were the other two top producers, publishing 584 and 424 cancer guidelines, respectively.

### Table 9: Cancer Guidelines Reporting Quality by Jurisdiction (2010-2012)

<table>
<thead>
<tr>
<th>Jurisdiction</th>
<th>N</th>
<th>Scope and Purpose</th>
<th>Stakeholder Involvement</th>
<th>Rigour of Development</th>
<th>Clarity and Presentation</th>
<th>Applicability</th>
<th>Editorial Independence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Canada</td>
<td>147</td>
<td>71 (28-97)</td>
<td>36 (8-72)</td>
<td>51 (4-89)</td>
<td>76 (39-92)</td>
<td>28 (8-73)</td>
<td>43 (0-88)</td>
</tr>
<tr>
<td>USA</td>
<td>49</td>
<td>66 (22-97)</td>
<td>44 (2-72)</td>
<td>45 (10-80)</td>
<td>71 (30-92)</td>
<td>24 (4-67)</td>
<td>44 (0-83)</td>
</tr>
<tr>
<td>Europe</td>
<td>53</td>
<td>59 (22-86)</td>
<td>38 (16-72)</td>
<td>32 (12-72)</td>
<td>66 (33-92)</td>
<td>21 (0-52)</td>
<td>30 (0-88)</td>
</tr>
<tr>
<td>UK*</td>
<td>66</td>
<td>64 (39-89)</td>
<td>52 (19-89)</td>
<td>51 (12-89)</td>
<td>73 (53-94)</td>
<td>24 (6-63)</td>
<td>32 (0-79)</td>
</tr>
<tr>
<td>Middle East</td>
<td>4</td>
<td>57 (33-78)</td>
<td>21 (14-25)</td>
<td>13 (8-19)</td>
<td>72 (61-78)</td>
<td>12 (6-17)</td>
<td>48 (33-54)</td>
</tr>
<tr>
<td>Asia</td>
<td>9</td>
<td>58 (44-67)</td>
<td>39 (25-61)</td>
<td>32 (15-50)</td>
<td>75 (64-86)</td>
<td>23 (17-48)</td>
<td>23 (0-67)</td>
</tr>
<tr>
<td>Australia/NZ</td>
<td>13</td>
<td>69 (44-92)</td>
<td>58 (31-83)</td>
<td>53 (30-72)</td>
<td>84 (69-89)</td>
<td>30 (6-60)</td>
<td>47 (0-88)</td>
</tr>
<tr>
<td>International</td>
<td>24</td>
<td>58 (31-78)</td>
<td>35 (19-56)</td>
<td>30 (16-52)</td>
<td>64 (36-81)</td>
<td>20 (0-38)</td>
<td>25 (0-58)</td>
</tr>
</tbody>
</table>

*Notes: N represents number of guidelines; USA, United States of America; NZ, New Zealand; *United Kingdom produces a substantial number of guidelines an has been analyzed separately an removed from the “Europe” category.*
Table 10: Cancer Guideline Numbers by Jurisdiction (2003-2012)

<table>
<thead>
<tr>
<th>Jurisdiction</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Canada</td>
<td>584</td>
</tr>
<tr>
<td>United States of America</td>
<td>627</td>
</tr>
<tr>
<td>Europe</td>
<td>424</td>
</tr>
<tr>
<td>United Kingdom*</td>
<td>251</td>
</tr>
<tr>
<td>Middle East &amp; North Africa</td>
<td>13</td>
</tr>
<tr>
<td>Asia</td>
<td>37</td>
</tr>
<tr>
<td>Australia/ New Zealand</td>
<td>37</td>
</tr>
<tr>
<td>International</td>
<td>105</td>
</tr>
<tr>
<td><strong>Grand Total</strong></td>
<td><strong>2042</strong></td>
</tr>
</tbody>
</table>

Notes: N represents number of guidelines; *United Kingdom produces a substantial number of guidelines and has been analyzed separately and removed from the “Europe” category.

c) Canadian Cancer Guidelines

Of the 147 guidelines developed in Canada, 66 were produced in Alberta and 81 were produced in other provinces, primarily in Ontario (n=49) or as a National collaboration (n=16). The AGREE II quality of reporting ratings for the Canadian guidelines are presented in Table 8. Guideline reporting quality varied noticeably across the provinces. In general, many Canadian guidelines scored poorly on the Stakeholder Involvement, Rigour of Development, Applicability, and Editorial Independence domains. Guidelines produced in Ontario or on a national level scored highest overall when considering all of the six AGREE II quality domains. Specifically, Ontario scored well above the others in the Editorial Independence, Scope and Purpose and Rigour of Development domains. It is important to note that no new cancer guidelines by Quebec and Manitoba were identified in the updated search.

Considering all Canadian cancer guidelines published between 2003 and 2012 (n=548), Ontario is the top provincial producer (n=285), whereas in contrast Quebec and the New Brunswick have published 1 guideline each (Table 12). As a Nation, 52 cancer guidelines have been produced as a collaborative effort between provinces.

Table 11: Cancer Guidelines Quality of Reporting by Canadian Province (2010-2012)

<table>
<thead>
<tr>
<th>Canadian Province</th>
<th>N</th>
<th>Scope and Purpose</th>
<th>Stakeholder Involvement</th>
<th>Rigour of Development</th>
<th>Clarity and Presentation</th>
<th>Applicability</th>
<th>Editorial Independence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alberta</td>
<td>65</td>
<td>67 (44-86)</td>
<td>24 (14-50)</td>
<td>43 (19-69)</td>
<td>72 (50-83)</td>
<td>22 (10-50)</td>
<td>31 (0-71)</td>
</tr>
<tr>
<td>BC</td>
<td>4</td>
<td>60 (33-86)</td>
<td>32 (19-56)</td>
<td>30 (6-80)</td>
<td>70 (52-92)</td>
<td>31 (15-40)</td>
<td>8 (8-8)</td>
</tr>
<tr>
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<td>79 (64-89)</td>
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<td>51 (4-88)</td>
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Note: represents number of guidelines; BC, British Columbia; NWT, Northwest Territories.
Table 12: Canadian Cancer Guidelines Province (2003-2012)

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<td>Nova Scotia</td>
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<td>Northwest Territories</td>
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<td><strong>Canada Total</strong></td>
<td>548</td>
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</table>

d) Cancer Guidelines by Developer

Overall, 133 guideline development groups, representing government supported agencies and health care professional organizations, developed the 365 cancer clinical practice guidelines. Quality of reporting for the 38 development groups that produced two or more guidelines between 2010 and 2012 are reported in Table 13. The range of AGREE domain scores varies widely by guideline development group. Mean domain scores ranged from 38% to 86% for Scope and Purpose, 18% to 80% for Stakeholder Involvement, 13% to 78% for Rigour of Development, 50% to 88% for Clarity and Presentation, 11% to 58% for Applicability, and 0% to 77% for Editorial Independence. Table 14 provides a list of developers with five or more publications in the SAGE Directory of cancer guidelines. Cancer Care Ontario, the National Comprehensive Cancer Network, the National Health Service, European Society of Medical Oncology, Alberta Health Services and the American College of Radiology have been identified as the top cancer guideline producers.

Table 13: Cancer Guidelines Quality of Reporting by Developer\(^a\) (2010-2012)

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<tr>
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<th>N</th>
<th>Scope and Purpose</th>
<th>Stakeholder Involvement</th>
<th>Rigour of Development</th>
<th>Clarity and Presentation</th>
<th>Applicability</th>
<th>Editorial Independence</th>
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<td>23 (14-42)</td>
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<td>77 (35-89)</td>
<td>82 (58-92)</td>
<td>29 (15-56)</td>
<td>74 (46-83)</td>
</tr>
<tr>
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<td>50 (19-86)</td>
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<td>72 (53-89)</td>
<td>47 (10-79)</td>
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<td>38 (17-58)</td>
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<tr>
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## AGREE II domain score (mean score and range across guidelines [%])

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<th>Stakeholder Involvement</th>
<th>Rigour of Development</th>
<th>Clarity and Presentation</th>
<th>Applicability</th>
<th>Editorial Independence</th>
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<tr>
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<td>58 (50-64)</td>
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<td>20 (13-33)</td>
<td>4 (0-13)</td>
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### Notes:
- represents number of guidelines.
- Only developers who produced 2 or more guidelines from 2010 to 2012 are included in Table 13.
- See Appendix for a list of guideline developer abbreviations.

### Table 14: Cancer Guideline Developers<sup>a</sup> (2003-2012)

<table>
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<th>Guideline Developer&lt;sup&gt;b&lt;/sup&gt;</th>
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Cancer Practice Guidelines Status Report: All Cancers

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</tbody>
</table>

Notes: represents number of guidelines.

a Only developers who produced 5 or more guidelines from 2003 to 2012 are included in Table 14.

b See Appendix for a list of guideline developer abbreviations.

C. Cancer Guideline Development Methods

Information on development methods was collected for all 701 cancer clinical guidelines identified in the 2010 to 2012 update search. 401 of these guidelines (57%) included in their reports all of the four key components of a research question (PICO = population, intervention, comparison, and outcome), 125 (18%) reported three components, 67 (10%) two components, 23 guidelines (3%) reported one component, and 85 (12%) reported no components of a PICO research question. The mean score across raters for the AGREE II item on whether the health questions were specifically described (item #2, see appendix 2), was 4.9 out of a maximum score of 7.

One hundred and eighty two guidelines (26%) explicitly reported eligibility criteria, and 169 guidelines (24%) provided literature search terms used to search for the evidence. A total of 383 guidelines (55%) described the literature search process including reporting databases that were searched; however, only 89 guidelines (13%) provided a complete and reproducible literature search strategy (within the document or as a separate but accessible link). Of the 516 guidelines that explicitly reported using at least one evidence source for data, 293 guidelines reported using an existing guideline as part of their evidentiary base. In addition, 263 guidelines reported making use of existing systematic reviews, 241 used an existing meta-analysis, and 397 guidelines reported including randomized controlled trials (RCTs) as part of the evidentiary base. At least one of guidelines, systematic reviews, meta-analyses, or RCTs were reported in all 516 guidelines that explicitly reported the evidence sources used; none of the guidelines reported using lower quality study designs exclusively (e.g. case series, retrospective studies, or single arm phase II studies).

The mean score across raters for the AGREE II item regarding provision of guidance on guideline implementation (item #21) was high (≥ 5 on the 7-point scale) for only 58 of the 365 guidelines (Mean=3.4, SD=1.3). The mean score for AGREE II item #19 regarding description of audit criteria to measure guideline uptake was ≥5 in 56 guidelines (Mean=3, SD=1.4). Ninety-nine guidelines rated highly on the AGREE II item #23 regarding reporting of conflict of interest information (Mean=3.6, SD=1.6).
D. Scope and Content of Cancer Clinical Guidelines

Guideline content data for disease site and continuum of care are described below. Each subsection has two tables. Tables 15 and 17 are based on the 365 guidelines critically appraised guidelines identified in phase 3. Overall and subcategory scores have been provided. There are three subcategories: Canadian, Non-Canadian Passes and New Developers. Canadian guidelines are produced by developers in Canada from provincial, national and other collaborative groups. Non-Canadian Passes refers to guidelines produced outside Canada, which have passed the threshold criteria for rigour. New Developers contain guidelines that have not been subjected to threshold criteria, as there were no previous guidelines to which the criteria could be applied. The second table in both subsections (Tables 16 and 18) includes all 2042 guidelines, which contain overall numbers for each topic as well as a breakdown according to the document development year.

a) Cancer Guidelines by Disease Site

Table 15 outlines the number and quality of reporting of guidelines according to the AGREE II instrument in relation to cancer type for which they provide recommendations. Thirty-four percent of the 365 AGREE applicable guidelines were on the topic of the four most prevalent cancers: breast, lung, colorectal, and prostate. One guideline was specific to ophthalmic cancers and 50 were general or non-disease site-specific covering an array of cancer sites. Few guidelines were identified that provided recommendations for the following cancers: neuro-oncology, sarcoma, and ophthalmic tumours. Guidelines covering gynecological cancers rated the highest for the Rigour of Development domain (mean domain score of 52%) while the ophthalmic guideline rated the lowest (mean domain score of 22%).

Considering all 2042 guidelines identified between 2003 and 2012, the majority of guidelines are on the topic of a gastrointestinal disease site followed by genitourinary, breast and lung (Table 16). This holds true even when broken down by year as the four major disease sites remain as high interest topics over the last decade. A large number of non-disease site specific or general cancer guidelines have been produced (n=316), whereas only a few guidelines covering pediatric, sarcoma or ophthalmic cancers have been published.

Table 15: Cancer Guidelines Quality of Reporting by Disease Site (2010-2012)

<table>
<thead>
<tr>
<th>Cancer Disease Site</th>
<th>N</th>
<th>Scope and Purpose</th>
<th>Stakeholder Involvement</th>
<th>Rigour of Development</th>
<th>Clarity and Presentation</th>
<th>Applicability</th>
<th>Editorial Independence</th>
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</table>
Note: N represents number of guidelines. Canadian represents Canadian developers. N-CAD Passes represents groups with guidelines previously reviewed who succeeded in passing the quality threshold. N-CAD New Groups represents new groups entered into SAGE who published guidelines only in Phase 3.

Pediatric-specific guidelines have not been included in the disease site categories above.

Table 16: Cancer Guidelines by Disease Site and Year (2003-2012)

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<th>2010</th>
<th>2011</th>
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Note: represents number of guidelines.

Pediatric-specific guidelines have not been included in the disease site categories above.

b) Cancer Guidelines by Continuum of Cancer Care

For each of the nine components of the continuum of cancer care, Table 17 provides the number and reporting quality of guidelines that provided recommendations for that component. Scope of content and coverage varied considerably among guidelines, ranging from guidelines on overall management of a particular cancer to guidelines on a specific treatment modality for a particular cancer or for a specific stage of cancer. The component of cancer care that was most commonly addressed was treatment (274 out of 365 guidelines), followed by diagnostic assessment (124 guidelines) and post-treatment follow-up/staging (95 and 94 guidelines respectively). Fewer guidelines were identified that addressed cancer survivorship, recovery, and rehabilitation and palliative care (6 guidelines each). It is important to note that many guidelines addressed more than just one element of the cancer continuum (as reflected by the number of guidelines in Table 17).
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<td>End-of-life (Palliative care)</td>
<td>10</td>
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<td>50 (19-64)</td>
<td>37 (6-80)</td>
<td>76 (61-92)</td>
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Table 17: Cancer Guidelines Reporting Quality by Continuum of Cancer Care (2010-2012)
Cancer Practice Guidelines Status Report: All Cancers

AGREE II domain score (mean score and range across guidelines [%])

<table>
<thead>
<tr>
<th>Component of the continuum of cancer care</th>
<th>N</th>
<th>Scope and Purpose</th>
<th>Stakeholder Involvement</th>
<th>Rigour of Development</th>
<th>Clarity and Presentation</th>
<th>Applicability</th>
<th>Editorial Independence</th>
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<td>47 (17-89)</td>
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<td>75 (50-92)</td>
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<tr>
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<td>68 (39-92)</td>
<td>55 (19-89)</td>
<td>51 (12-76)</td>
<td>76 (33-94)</td>
<td>39 (6-79)</td>
<td>33 (0-88)</td>
</tr>
<tr>
<td>New Developers</td>
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<td>72 (33-89)</td>
<td>48 (19-86)</td>
<td>42 (16-89)</td>
<td>72 (56-92)</td>
<td>29 (0-71)</td>
<td>34 (0-88)</td>
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</table>

**Note:** N represents number of guidelines. Canadian represents Canadian developers. N-CAD Passes represents groups with guidelines previously reviewed who succeeded in passing the quality threshold. N-CAD New Groups represents new groups entered into SAGE who published guidelines only in Phase 3.

Table 18: Cancer Guidelines by Continuum of Cancer Care and Year (2003-2012)

<table>
<thead>
<tr>
<th>Component of the continuum of cancer care</th>
<th>N</th>
<th>2003</th>
<th>2004</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>In Progress</th>
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</thead>
<tbody>
<tr>
<td>Prevention and promotion</td>
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<td>11</td>
<td>18</td>
<td>12</td>
<td>19</td>
<td>21</td>
<td>15</td>
<td>17</td>
<td>36</td>
<td>23</td>
<td>3</td>
<td>2</td>
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<tr>
<td>Screening and surveillance</td>
<td>334</td>
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<td>29</td>
<td>28</td>
<td>36</td>
<td>39</td>
<td>30</td>
<td>35</td>
<td>76</td>
<td>36</td>
<td>4</td>
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<td>43</td>
<td>55</td>
<td>46</td>
<td>116</td>
<td>235</td>
<td>138</td>
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<td>4</td>
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<td>56</td>
<td>38</td>
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<td>102</td>
<td>25</td>
<td>3</td>
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<td>1442</td>
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<td>62</td>
<td>97</td>
<td>134</td>
<td>122</td>
<td>103</td>
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<td>220</td>
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<td>192</td>
<td>96</td>
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<td>2</td>
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<td>6</td>
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<td>28</td>
<td>10</td>
<td>5</td>
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<td>18</td>
<td>14</td>
<td>34</td>
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<td>31</td>
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<td>5</td>
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<td>35</td>
<td>49</td>
<td>46</td>
<td>35</td>
<td>64</td>
<td>129</td>
<td>80</td>
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</table>

Thirteen guidelines out of the 701 identified between 2010 and 2012 were comprehensive and provided recommendations for at least seven components of the cancer care continuum; 450 provided recommendations for more than one component, and 243 provided recommendations for one component only. Of those that provided recommendations for one component of the continuum only, the treatment component was the most common: 136 were specific to treatment, 30 were specific to staging, 22 addressed supportive care only, 21 were specific to screening/surveillance, 17 were specific to diagnostic assessment, nine were specific to post-treatment follow-up and seven addresses only prevention/promotion. No guidelines were identified that solely addressed survivorship/recovery/rehabilitation or end-of-life care of cancer patients.

Of the 502 guidelines that addressed treatment of cancer, 308 provided recommendations for chemotherapy, 255 provided recommendations for radiotherapy, 277 for surgery, 122 for biological therapy, and 59 for
hormonal therapy, either alone or as part of combined modality treatment.

Table 18 shows a similar distribution of guidelines by continuum of care when all cancer guidelines (n=2042, 2003 to 2012) are considered. Treatment remained the most commonly addressed component with diagnostic assessments, follow-up and staging as popular topics for guideline recommendations. Survivorship/Recovery/Rehabilitation and Palliative care remained least frequently addressed.

Discussion
The current status report of English-language clinical practice guidelines on cancer published from 2003 to 2012 indicates that numerous guidelines have addressed this topic with a wide range of scope. While this report indicates extensive coverage of several disease sites and components of the continuum of cancer care, it is evident that several areas require improved attention. In addition, the quality review of these guidelines suggests areas for improvement in terms of the evidence-based principles contained in the methods associated with the Rigour of Development domain.

Relatively few guidelines reported the use of an explicit and systematic methodological approach, defined in this report as specifically describing a research question (based on PICO components and AGREE II item # 2), a minimum of one data source, pre-specified eligibility criteria, and a reproducible literature search. It should be noted that the AGREE II tool is an assessment of information that is reported in the guideline and supporting documentation. As per protocol, no attempt was made to obtain additional information outside of what was made publically available by guideline developers. Thus, what actually happened in the guideline development process may or may not align with what is reported. Although not all practice guidelines are intended to formally follow rigorous guideline development methods, developers should consider doing so and report sufficient process details when such methods are used. Specific areas for improvement include defining the clinical question(s) covered by the guideline, description of evidence selection criteria, methods for formulating recommendations, and explicit links between recommendations and the evidence or consensus opinion upon which the recommendations are based. In addition, all guidelines should provide information on funding sources and other factors that may contribute to potential conflicts of interest. Developers should also consider increasing the applicability of their guidelines in actual practice settings by providing advice or tools on how to put recommendations into practice and consider monitoring or auditing criteria. Of the Canadian cancer guideline developers, guidelines produced in Ontario or on a National level were of the highest reporting quality when considering all six quality domains.

Conclusions
Overall, 133 guideline development groups, representing government supported agencies and health care professional organizations, developed the cancer practice guidelines identified in this updated report. Canada is a world leader in the development of cancer control practice guidelines, with approximately one third of all the guidelines produced by Canadian provincial/territorial cancer agencies, cancer organizations or other professional bodies. The bulk of the remaining guidelines were developed primarily within the United States of America or within Europe.

Over two-thirds of guidelines (n=254) reviewed did not meet the minimum quality requirement, and therefore did not receive a quality assessment using the AGREE II instrument. Assessment of guideline reporting quality of the included 365 clinical practice guidelines (2010-2012) indicates that the overall quality of reporting was moderate to low, with much variability across domains. Guidelines scored the highest in the Clarity and Presentation and Scope and Purpose domains with scores of 73% and 65% respectively. The domains of Editorial Independence (38%), Applicability (29%) were lowest
performing. With an overall mean domain score for Rigour of Development of 45% for all cancer guidelines, it is clear that the reporting of rigour could be improved across guideline development groups, a key component of an evidence-based approach.

Guideline development methods and scope and content varied greatly among documents. One third of the guidelines in this update had a topic component of gastrointestinal cancer (n=406), and another third (n=316) covered general cancer topic and were not disease site specific. Extensive coverage was observed for guidance on treatments, diagnosis and staging. More records in this update, as compared to previous years presented guidelines with topics on post-treatment, follow-up and psychosocial and supportive care.

In general, there is room for improvement in reporting of guideline development methods, use of systematic review, and avoidance of duplication in cancer control practice guidelines.
References
### Appendix 1: Abbreviations of guideline development groups

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<th>Abbreviation</th>
<th>Full name of developer</th>
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<td>American Association of Neurological Surgeons</td>
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<tr>
<td>ACCP</td>
<td>American College of Chest Physicians</td>
</tr>
<tr>
<td>ACOG</td>
<td>American Congress of Obstetricians and Gynecologists</td>
</tr>
<tr>
<td>ACR</td>
<td>American College of Radiology</td>
</tr>
<tr>
<td>ACS</td>
<td>American Cancer Society</td>
</tr>
<tr>
<td>ADASP</td>
<td>Association of Directors of Anatomic and Surgical Pathology</td>
</tr>
<tr>
<td>AHPBA</td>
<td>American Hepato-Pancreato-Biliary Association</td>
</tr>
<tr>
<td>AHRQ</td>
<td>Agency for Healthcare Research and Quality</td>
</tr>
<tr>
<td>AHS</td>
<td>Alberta Health Services (formerly Alberta Cancer Board)</td>
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<td>APPHON</td>
<td>Atlantic Provinces Pediatric Hematology Oncology Network</td>
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<td>ASBMT</td>
<td>American Society for Blood Marrow Transplantation</td>
</tr>
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<td>ASCO</td>
<td>American Society of Clinical Oncology</td>
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<tr>
<td>ASCRS</td>
<td>American Society of Colon and Rectal Surgeons</td>
</tr>
<tr>
<td>ASGE</td>
<td>Association of Directors of Anatomic and Surgical Pathology</td>
</tr>
<tr>
<td>ASTRO</td>
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</tr>
<tr>
<td>AUA</td>
<td>American Urological Association</td>
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<tr>
<td>BAD</td>
<td>British Association of Dermatologists</td>
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<td>BCCA</td>
<td>BC Cancer Agency</td>
</tr>
<tr>
<td>BCSH</td>
<td>British Committee for Standards in Haematology</td>
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<td>Breast Health Global Initiative</td>
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<td>BPS</td>
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<td>BSG</td>
<td>British Society of Gastroenterology</td>
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<td>BTS</td>
<td>British Thoracic Society</td>
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<td>CAP</td>
<td>College of American Pathologists</td>
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<td>Canadian Association of Psychological Oncology</td>
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<td>CTFPH</td>
<td>Canadian Task Force on Preventative Health Care</td>
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<td>CUA</td>
<td>Canadian Urological Association</td>
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<td>European Federation of Neurological Societies</td>
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<td>European LeukemiaNet</td>
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<td>European Neuroendocrine Tumor Society</td>
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<td>EORTC</td>
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<tr>
<td>ESGC</td>
<td>European Society of Gynecological Cancer</td>
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<td>Abbreviation</td>
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<td>FNCLCC</td>
<td>National Federation of Centers Against Cancer (FNCLCC)</td>
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<td>ICDG</td>
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<td>ICSI</td>
<td>Institute of Clinical Systems Improvement</td>
</tr>
<tr>
<td>ICUD</td>
<td>International Consultation on Urologic Diseases</td>
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<tr>
<td>IMNWG</td>
<td>Interdisciplinary Multinational Working Group</td>
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<tr>
<td>IMWG</td>
<td>International Myeloma Working Group</td>
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<td>ISUP</td>
<td>International Society of Urological Pathology</td>
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<td>JSH</td>
<td>Japan society of Hepatology</td>
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<td>NANETS</td>
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<td>NBOCC</td>
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<td>NCCN</td>
<td>National Comprehensive Cancer Network (American)</td>
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<td>National Health and Medical Research Council - Australia</td>
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<td>National Health Service (England)</td>
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<td>NZGG</td>
<td>New Zealand Guidelines Group</td>
</tr>
<tr>
<td>ONS</td>
<td>Oncology Nursing Society</td>
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<tr>
<td>SEOM</td>
<td>Sociedad Española de Oncología Médica – Spanish Society of Medical Oncology</td>
</tr>
<tr>
<td>SIGN</td>
<td>Scottish Intercollegiate Guidelines Network</td>
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<tr>
<td>SIOG</td>
<td>Société Internationale d’Oncologie Gériatrique – International Society of Geriatric Oncology</td>
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<td>SKH</td>
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<td>SMH</td>
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<td>SOGC</td>
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<td>SSAT</td>
<td>Society for Surgery of the Alimentary Tract</td>
</tr>
<tr>
<td>TOP</td>
<td>Toward Optimized Practice (TOP) Alberta</td>
</tr>
<tr>
<td>USPSTF</td>
<td>United States Preventive Services Task Force (American)</td>
</tr>
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</table>
Appendix 2: Appraisal of Guidelines Research & Evaluation (AGREE) II tool summary (3)

Domain 1: Scope and Purpose
1. The overall objective(s) of the guideline is (are) specifically described.
2. The health question(s) covered by the guideline is (are) specifically described.
3. The population (patients, public, etc.) to whom the guideline is meant to apply is specifically described.

Domain 2: Stakeholder Involvement
4. The guideline development group includes individuals from all relevant professional groups.
5. The views and preferences of the target population (patients, public, etc.) have been sought.
6. The target users of the guideline are clearly defined.

Domain 3: Rigour of Development
7. Systematic methods were used to search for evidence.
8. The criteria for selecting the evidence are clearly described.
9. The strengths and limitations of the body of evidence are clearly described.
10. The methods for formulating the recommendations are clearly described.
11. The health benefits, side effects, and risks have been considered in formulating the recommendations.
12. There is an explicit link between the recommendations and the supporting evidence.
13. The guideline has been externally reviewed by experts prior to its publication.
14. A procedure for updating the guideline is provided.

Domain 4: Clarity of Presentation
15. The recommendations are specific and unambiguous.
16. The different options for management of the condition or health issue are clearly presented.
17. Key recommendations are easily identifiable.

Domain 5: Applicability
18. The guideline describes facilitators and barriers to its application.
19. The guideline provides advice and/or tools on how the recommendations can be put into practice.
20. The potential resource implications of applying the recommendations have been considered.
21. The guideline presents monitoring and/or auditing criteria.

Domain 6: Editorial Independence
22. The views of the funding body have not influenced the content of the guideline.
23. Competing interests of guideline development group members have been recorded and addressed.