



**A Quality Initiative Endorsed by Cancer Care Ontario in
Partnership with the
Program in Evidence-Based Care (PEBC)
Person-Centred Care Guideline**

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Guideline is comprised of three sections:

Section 1: Guideline Recommendations

Section 2: Guideline Modifications

Section 3: Background, Methods, Endorsement and Validation Processes

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Cancer Care Ontario Person-Centred Care Guideline: Endorsement and Adaptation of *CG 138: Patient experience in adult NHS services: improving the experience of care for people using adult NHS services*

Report Date: May 1, 2015

Disclaimer: This publication is an adaptation of content from *CG 138: Patient experience in adult NHS services: improving the experience of care for people using adult NHS services*, published by the National Institute for Health and Clinical Excellence (NICE) in 2012. The original publication is available from www.nice.org.uk/CG138. This adaptation has not been checked or approved by NICE to ensure it accurately reflects the original NICE publication, and no guarantees are given by NICE in regard to the accuracy of the adaptation. The NICE quality standard that this adaptation is based upon was prepared for the National Health Service (NHS) in England and Wales, and NICE guidance does not apply to Canada. The Person-Centred Care Guideline outlines a level of service that any person (i.e., patient, family member, caregiver) using adult oncology services in Ontario should expect to receive, namely person-centred care. The Person-Centred Care Guideline was endorsed in partnership with the PEBC and alongside an Expert Panel convened by the Person-Centred Care Program to advise on behaviours and practices of person-centred care.

Guideline Objectives:

The objective of this guideline is to establish a standardized set of recommendations for providing person-centred care in the delivery of adult oncology services in Ontario.

Target Population:

This guideline is intended for adults (18 years and older) in Ontario using oncology services and for their care providers.¹

Intended Users:

This guideline provides guidance for use by all clinicians and staff within adult oncology service settings, and for use by patients (and/or family members and caregivers) and their care providers to inform the provision of person-centred care.

Preamble:

¹ In this document adult oncology services (as referred to in the guideline) includes screening through to end-of-life or survivorship transition, and is applicable to inpatient cancer care. Context-specific language in the original guidance that was intended for NHS service delivery in the United Kingdom has been translated to reflect adult oncology services in Ontario.

Although the Person-Centred Care Guideline is cancer specific, many of its principles are relevant to any and all healthcare (and other) professionals that interact with patients, their family members and caregivers. The following guidance outlines a level of service that any person (i.e., patient, family member, caregiver) using adult oncology services in Ontario should expect to receive, namely person-centred care. Person-centred care is the evolution of patient-centred care, a nominal shift that signals to the system the profound importance of being treated as a person first, and as a patient second. Use of the term “person” over “patient” is also intentionally inclusive of family members and/or caregivers, and recognizes that a patient often experiences the healthcare system with a support system.²

Cancer Care Ontario defines person-centred care as an approach to care that involves partnering with patients and healthcare professionals to:

- give patients a voice in the design and delivery of the care they receive;
- enable patients to be more active in their journey in order to deliver better health outcomes and greater value through a wiser use of resources; and
- improve the patient experience.

As the above implies, patient engagement is a driving force of person-centred care, and an improved patient experience is a primary outcome of both person-centred care and patient engagement. Cancer Care Ontario defines patient experience as the sum of all interactions, shaped by an organization’s culture, that influence patient perceptions across the continuum of care (Adapted from the Beryl Institute).

This guideline is aligned with and/or makes reference to the following Cancer Care Ontario guidelines and legislation, where appropriate (in order of appearance):

- The Ontario Human Rights Code (see http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_90h19_e.htm);
- CCO’s Symptom Management Guides (SMGs; see <https://www.cancercare.on.ca/toolbox/symptools/>);
- The Personal Health Information Privacy and Access Act (PHIPAA; see <http://www.gnb.ca/0062/PDF-acts/p-07-05.pdf>);
- The Health Care Consent Act, 1996 (see http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_e.htm);
- The Freedom of Information and Protection of Privacy Act (FIPPA; http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_90f31_e.htm);
- The Substitute Decisions Act, 1992 (see http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_92s30_e.htm);
- Bill 8, Public Sector and MPP Accountability and Transparency Act, 2014 (see http://www.ontla.on.ca/web/bills/bills_detail.do?locale=en&Intranet&BillID=3000);
- Cancer Care Ontario’s Survivorship Evidence-based Series (EBS; see <https://www.cancercare.on.ca/toolbox/qualityguidelines/clin-program/survivorship/>);

² For the sake of brevity, this document uses the term “patient”, where appropriate, instead of “person”. It implies the notion of a person first, patient second, and includes family members and/or caregivers. As needed, “patient” will be replaced by the gender-neutral pronoun “they”.

- Effective Teaching Strategies and Methods of Delivery for Patient Education, 2009 (see <https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=60065>);
- Establishing Comprehensive Cancer Patient Education Services, 2006 (<https://www.cancercare.on.ca/toolbox/qualityguidelines/clin-program/patient-ed-eps/>); and
- Patient-Provider Communication 19-2, 2011 (<https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=44425>).

Recommendations:

Knowing the patient as an individual

Qualifying Statement: The following section highlights the importance of treating the patient as a person first. In an effort to translate the following recommendations into useable and sizeable practices for care providers, please do not minimize or dismiss the necessity of provider recognition and support of the value and intent of person-centred care as embodied in the set of recommendations below.

1. Develop an understanding of the patient as an individual, including their values, their attitudes, and their lived experiences as a patient of how the condition affects them as a person, and how their circumstances and experiences affect their condition and treatment. [Modified]
2. Ensure that factors such as physical or learning disabilities, sight, speech or hearing problems and difficulties with reading, understanding or speaking English and/or French are addressed so that the patient is able to participate as fully as possible in consultations and care. [Modified]
3. Ask the patient about and take into account any factors, such as their domestic, social (e.g., financial) and work situation and their previous experience of healthcare, that may:
 - impact on their health condition and/or
 - affect their ability or willingness to engage with healthcare services and/or
 - affect their ability to manage their own care and make decisions about self-management and lifestyle choices. [Modified]
4. Listen to and address any health beliefs, concerns and preferences (including values, attitudes, and lived experiences) that the patient has, and be aware that these affect how and whether they engage with treatment. Respect their views and offer support if needed to help them engage effectively with healthcare services and participate in self-management as appropriate. [Modified]
5. Avoid making assumptions about the patient based on their previous interactions with the healthcare system, their appearance or other personal characteristics. [Modified]
6. Ensure services are equally accessible to, and supportive of, all adults using adult oncology services in Ontario, taking into account geography, religion, culture, and the requirements of the Ontario Human Rights Code (where every person has a right to equal treatment with respect to services, goods and facilities, without discrimination because of race, ancestry, place of origin, colour, ethnic origin, citizenship, creed, sex, sexual orientation, gender identity, gender expression, age, marital status, family status or disability; see http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_90h19_e.htm). [Modified]
7. If appropriate, discuss with the patient their need for psychological, social, spiritual and/or practical (refers to financial constraints, medication coverage, housing concerns, etc.) support. Offer support and information to the patient and/or direct them to sources of support and information. Review their circumstances and need for support regularly.

Essential requirements of care

Qualifying Statement: The following section includes recommendations for healthcare professionals on how to ensure a positive patient experience. These include ensuring that:

- patients feel respected;
- patients' concerns are listened to and addressed;
- various aspects of patient care (e.g., nutrition, pain) are appropriately managed;
- patients are provided support to maintain independence; and,
- all of the above are done with patient consent.

Where appropriate, the section entitled "Patient Concerns" has been modified to align with Cancer Care Ontario's Symptom Management Guides.

Respect for the patient

8. All staff involved in providing adult oncology services in Ontario should:
 - treat patients and their family members and carers with respect, kindness, dignity, compassion, understanding, courtesy and honesty
 - respect the patient's right to confidentiality
 - involve the patient in discussions. [Modified]
9. Introduce students and anyone not directly involved in the delivery of care before consultations or meetings begin and let the patient decide if they want them to stay beforehand. Introductions can be conducted through a variety of means, including but not limited to in-person and verbal introductions, public notice, and/or website postings. [Modified]

Patient concerns

10. Be prepared to raise and discuss sensitive issues (such as sexual activity, continence or end-of-life care), as these are unlikely to be raised by some patients.
11. Listen to and discuss any fears or concerns the patient has in a non-judgemental and sensitive manner.
12. If symptoms of anxiety and/or depression are suspected, assess and follow best clinical practice guides (i.e., Cancer Care Ontario's Symptom Management Guides see <https://www.cancercare.on.ca/toolbox/symptools/>). [Modified]

Nutrition, pain management and personal needs

13. As nutrition and hydration are important throughout the cancer care continuum, ensure that the patient's nutrition and hydration are addressed as appropriate through each phase of the cancer continuum, respecting the patient's right for choice. [Modified]
14. Ensure that the patient's pain relief is well managed at all times. In case the patient is unable to manage this themselves:

- do not assume that pain relief is adequate
 - ask them regularly about pain
 - assess pain using the Edmonton Symptom Assessment Scale (ESAS) pain scale if necessary (for example, on a scale of 0 to 10)
 - provide pain relief and adjust as needed. [Modified]
15. Ensure that the patient's personal needs and symptoms (for example, relating to continence, personal hygiene and comfort) are regularly reviewed and addressed. Regularly ask patients who are unable to manage their personal needs what help they need. Address their needs at the time of asking and ensure maximum privacy.

Patient independence

16. Give patients using adult oncology services in Ontario the support they need to maintain their independence as far as possible. [Modified]

Consent and capacity

17. Obtain and document informed consent from the patient, in accordance with:
- The Personal Health Information Privacy and Access Act (PHIPAA; see <http://www.gnb.ca/0062/PDF-acts/p-07-05.pdf>)
 - The Health Care Consent Act, 1996 (see http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_e.htm)
 - The Freedom of Information and Protection of Privacy Act (FIPPA; http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_90f31_e.htm).
- [Modified]
18. Assess the patient's capacity to make each decision using directives in the Substitute Decisions Act, 1992 (see http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_92s30_e.htm).
- [Modified]

Tailoring healthcare service for each patient

Qualifying Statement: The principle behind this section of care is grounded in the philosophy of person-centred care as defined by Cancer Care Ontario, the legal frameworks within which we operate in Ontario (i.e., PHIPPA, FIPPA), and the evidence (i.e., white and/or grey literature). Language to reflect this has not been added to each recommendation but can be assumed as implied.

Where appropriate, the section entitled Feedback and complaints ensures and articulates alignment to Bill 8, Public Sector and MPP Accountability and Transparency Act, 2014.

An individual approach to services

19. Adopt an individualised approach to healthcare services that is evidence-based and tailored to the patient's needs and circumstances, taking into account their ability to access services, personal preferences and coexisting conditions. Review the patient's needs and circumstances regularly. [Modified]

20. Inform the patient about healthcare services and social services (for example, smoking cessation services) that are available locally and nationally. Encourage and support them to access services according to their individual needs and preferences. [Modified]
21. Give the patient evidence-based information about relevant treatment options and services that they are entitled to, even if these are not provided locally. [Modified]

Patient views and preferences

22. Hold discussions in a way that encourages the patient to express their personal needs and preferences for care, treatment, management and self-management. Allow adequate time so that discussions do not feel rushed.
23. Review with the patient at intervals agreed with them:
 - their knowledge, understanding and concerns about their condition and treatments; and
 - their view of their need for treatment.
24. Accept that the patient may have different views from healthcare professionals about the balance of risks, benefits and consequences of treatments.
25. Accept that the patient has the right to decide not to have a treatment, even if you do not agree with their decision, as long as they have the capacity to make an informed decision (see Recommendation 18) and have been given, and understand and appreciate the information needed to do this.
26. Respect and support the patient in their choice of treatment (and their right to choose), or if they decide to decline treatment. Provision of support is not in reference to the course of treatment itself. [Modified]
27. Ensure that the patient knows that they can ask for a second opinion from a different healthcare professional as long as it falls within the provider's expertise to enable the referral. If necessary, provide information on how the patient would go about this. [Modified]

Involvement of family members and caregivers

28. Clarify with the patient at the first point of contact (i.e., at each transition) whether and how they would like their partner, family members and/or caregivers to be involved in key decisions about the management of their condition. Review this regularly. If the patient agrees, share information with their partner, family members and/or caregivers in accordance with Recommendation 17 and FIPPA. [Modified]
29. If the patient cannot indicate their agreement to share information, ensure that family members and/or caregivers are kept involved and appropriately informed, but be mindful of any potentially sensitive issues and the duty of confidentiality in accordance with Recommendation 17. [Modified]

Feedback and complaints

Qualifying Statement: The Guideline Endorsement Committee felt there to be an aspect of quality to feedback worth emphasis and that the ability for the patient to provide quality feedback and a system address this feedback should be the standard.

30. Encourage the patient to give feedback about their care. Respond to any feedback given.
31. Provide patients with information about complaints procedures and help them to access these, in accordance with Bill 8, Public Sector and MPP Accountability and Transparency Act, 2014 (see http://www.ontla.on.ca/web/bills/bills_detail.do?locale=en&Intranet&BillID=3000). Patients should be encouraged to informally and formally (where possible) share their experience about their care. [Modified]

Continuity of care and relationships

Qualifying Statement: As defined in this section, continuity of care includes all transition points through all phases of the cancer continuum. The recommendations in this section align with Cancer Care Ontario's Survivorship Evidence-based Series (EBS; see <https://www.cancercare.on.ca/toolbox/qualityguidelines/clin-program/survivorship/>).

32. Assess each patient's requirement for continuity of care and their preference for how that requirement will be met. This may involve the patient seeing the same healthcare professional throughout a single episode of care, or ensuring continuity within a healthcare team. [Modified]
33. For patients who use a number of different services (for example, using services in both primary and secondary care, or attending different clinics in a hospital), ensure effective coordination and prioritization of care to minimize the impact on the patient.
34. Ensure clear and timely exchange of patient information:
 - between healthcare professionals in the circle of care (particularly at the point of transitions in care)
 - between the healthcare team and community services (with the patient's consent) (in accordance with FIPPA). [Modified]
35. All staff directly involved in a patient's care should introduce themselves to the patient. [Modified]
36. Inform the patient about:
 - who is responsible for their care and treatment
 - the roles and responsibilities of the different members of the healthcare team
 - the communication about their care that takes place between members of the healthcare team.
37. Give the patient information about what to do and who to contact in different situations, such as out of hours or in an emergency.

Enabling patients to actively participate in their care

Qualifying Statement: The following includes recommendations on communication, information, shared decision-making, and education programs. Shared decision-making refers to the mutually beneficial partnership of patient with healthcare professionals to collectively make decisions. This is not a legal model, but rather a model to create an environment in which the patient who is willing and able to share the responsibility of making decisions about their own treatment and care, is encouraged to do so.

The sections and corresponding recommendations are written in alignment with the following Cancer Care Ontario guidelines:

- Provider-Patient Communication 19-2 (<https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=44425>);
- Effective Teaching Strategies and Methods of Delivery for Patient Education, 2009 (see <https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=60065>); and
- Establishing Comprehensive Cancer Patient Education Services, 2006 (<https://www.cancercare.on.ca/toolbox/qualityguidelines/clin-program/patient-ed-eps/>).

Communication

38. Ensure that the environment is conducive to discussion and that the patient's privacy is respected, particularly when discussing sensitive, personal issues.
39. Maximise patient participation in communication by, for example:
 - obtaining permission before any physical examination
 - maintaining eye contact with the patient (if culturally appropriate)
 - positioning yourself at the same level as the patient
 - ensuring that the patient is appropriately covered (if applicable). [Modified]
40. Ask the patient how they wish to be addressed (including their preferred use of gender pronouns) and ensure that their choice is respected and used. [Modified]
41. Ask the patient about the most effective way of communicating with them and explore ways to improve communication. Follow legislation in the Accessibility for Ontarians with Disabilities Act (see http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_05a11_e.htm) as appropriate. Examples include using pictures, symbols, large print, Braille, different languages, sign language or communications aids, or involving a trained and certified interpreter, a patient advocate or family members. [Modified]
42. Recognize the accent, use of idiom and dialect of both the patient and of healthcare professionals when considering communication needs. [Modified]
43. Avoid using jargon and acronyms. Use words the patient will understand, define unfamiliar words and confirm understanding by using methods such as teach back. [Modified]

44. Use open-ended questions to encourage discussion.
45. Summarise information at the end of a consultation and check that the patient has understood the most important information.
46. Offer and ensure the patient has access to their personal health information (PHI). Answer any questions the patient may have about their PHI. [New]
47. All staff involved in providing adult oncology services in Ontario should have demonstrated competency in relevant communication skills.

Information

48. Give the patient information and the support they need to make use of the information in order to promote their ability to actively participate in care and self-management. [Modified]
49. Patients should be offered and have options to receive both oral and written information, as per their preference. [Modified]
50. Give the patient information in an accessible format (in compliance with the Accessibility for Ontarians with Disabilities Act) at the first and subsequent visits. Possible formats include using written information, pictures, symbols, large print, Braille and different languages. [Modified]
51. Explore the patient's preferences about the level and type of information they want. Based on this, give the patient clear, consistent, evidence-based, tailored information throughout all stages of their care. This should include, but not be limited to, information on and/or discussions regarding:
 - their condition and any treatment options;
 - where they will be seen;
 - who will undertake their care;
 - expected waiting times for consultations, investigations and treatments;
 - the medical aims of the proposed care to the patient; and
 - the risks, benefits and consequences of the investigation or treatment options (taking into account factors such as coexisting conditions and the patient's preferences). [Modified]
52. Ensure that mechanisms are in place to:
 - provide information about appointments to patients who require information in non-standard formats; and
 - alert services of any need for interpreters and accessible formats to be available at all transition points and in accordance with Accreditation Canada Required Organizational Practices. [Modified]
53. Ask the patient whether they want to be accompanied at consultations by a family member, friend or advocate, and whether they would like to take notes. Audio recording of the consultation is a legal issue and differs by jurisdiction but we encourage shared understanding and mutual agreement between the patient and the healthcare professional. [Modified]
54. Give the patient information to enable them to use any medicines and equipment correctly. Ensure that the patient and their family members and caregivers feel

adequately informed, prepared and supported to use medicines and equipment and to carry out self-care and self-management to the extent that they are willing. [Modified]

55. Advise the patient where they might find reliable high-quality information (we encourage information from organizations such as the Canadian Cancer Society, Cancer Care Ontario, etc.) and support after consultations. It should be made clear to the patient that there is no universal standard for creating quality patient information in Ontario and there is no single process for evaluating patient information quality. [Modified]
56. Give the patient regular, accurate information about the duration of any delays during episodes of care, the reason for the delay and expected wait times (following provincial standards of care). [Modified]

Shared decision-making

57. When discussing decisions about goals of care, investigations and treatment, do so in a style and manner that enables the patient to express their personal needs and preferences.
58. Give the patient the opportunity to discuss their diagnosis, prognosis and treatment options.
59. When offering goals of care, investigations or treatments (including all dose modifications, changes in treatment, etc.):
 - explain the patient's condition and any treatment options;
 - explain the medical aims of the proposed care to the patient;
 - explain where the patient will be seen;
 - explain who will undertake the patient's care;
 - explain expected waiting times for consultations, investigations and treatments;
 - openly discuss and provide information about the risks, benefits and consequences of the investigation or treatment options (taking into account factors such as coexisting conditions and the patient's preferences);
 - clarify what the patient hopes the treatment will achieve and discuss any misconceptions with them;
 - set aside adequate time to allow any questions to be answered, and ask the patient if they would like a further consultation; and
 - repeat these discussions over the course of treatment to ensure the patient's understanding. [Modified]
60. Accept and acknowledge that patients may vary in their views about the balance of risks, benefits and consequences of treatments.
61. Use the following principles when discussing risks and benefits with a patient:
 - Personalise risks and benefits, as much as possible.
 - Use absolute risk rather than relative risk (for example, "the risk of an event increases from 1 in 1,000 to 2 in 1,000," rather than "the risk of the event doubles").
 - Use natural frequency (for example, 10 in 100) rather than a percentage (10%).

- Be consistent in the use of data (for example, use the same denominator when comparing risk: 7 in 100 for one risk and 20 in 100 for another, rather than 1 in 14 and 1 in 5).
 - Present a risk over a defined period of time (months or years) if appropriate (for example, if 100 people are treated for 1 year, 10 will experience a given side effect).
 - Include both positive and negative framing (for example, treatment will be successful for 97 out of 100 patients and unsuccessful for 3 out of 100 patients).
 - Be aware that different people interpret terms such as rare, unusual and common in different ways. Use numerical data if available.
 - Use a blend of numerical and pictorial formats (for example, numerical rates and pictograms).
62. Use the principles of shared decision-making when patients are considering options to:
- ensure that the patient is aware of the options available and explain the risks, benefits and consequences of these;
 - regularly check that the patient understands the information; and
 - encourage the patient to clarify what is important to them, and check that their choice is consistent with this. [Modified]
63. Be aware of the value and availability of patient decision aids and other forms of decision support such as counselling or coaching. If suitable high-quality decision aids are available, offer them to the patient.
64. Give the patient adequate time to make decisions about investigations and treatments.

Education programs

65. Give the patient the opportunity to take part in evidence-based educational activities, including self-management programs that are available. Patient education programs should:
- have specific aims and learning objectives;
 - meet the needs of the patient (taking into account cultural, linguistic, cognitive and literacy considerations); and
 - promote the patient's ability to manage their own health, if appropriate. [Modified]

Table 1 Modifications to original recommendations

Recommendation number	Modification rationale
1	Modified to add values, attitudes and lived experiences
2	Added French to the language, as Ontario has two official languages
3	Added financial as an example of a social factor
4	Modified to add values, attitudes and lived experiences
5	Modified to add previous interactions with the healthcare system
6	Changed Equity Act 2010 to Ontario Human Rights Code to fit into the Ontario context; added formal definition of equal rights
7	Replaced financial with a broader term (practical) and added the definition
8	Modified to fit the Ontario context and to involve the patient in discussions
9	Modified to include multiple means of conducting introductions
12	Modified to fit the Ontario context
13	Removed specifics; added language to ensure nutrition and hydration are adequate at all times and throughout the cancer care continuum, and to respect the patient's right for choice
14	Modified to ensure pain relief is managed at all times, and not only addressed if the patient is unable to manage their own pain relief
16	Modified to fit the Ontario context
17	Modified to fit the Ontario context and legislation
18	Modified to fit the Ontario context and legislation
19	Modified to recognize the importance of evidence-based care
20	Modified to fit the Ontario context
21	Modified to recognize the importance of evidence-based care
26	Modified to emphasize the patient's right to choose and support
27	Modified to ensure that making a referral for a second opinion to a particular healthcare professional falls within the expertise of that provider
28	Modified to include all transitions and to include Ontario legislation
29	Modified to include Ontario legislation
31	Modified to add encouragement to the feedback process

32	Modified to include the patient's preference
34	Modified to fit the Ontario context
35	Modified to add all people that the patient may come into contact with, not just healthcare professionals
39	Modified to reflect cultural sensitivity and add obtaining permission before physical examinations
40	Modified to include asking patient's about their preferred use of gender pronouns
41	Modified to ask patients the most effective way of communication; modified to add Ontario legislation
42	Modified to recognize importance of differing communication needs, not to enable discrimination
43	Modified to add acronyms
48	Modified to provide more clarity
49	Modified to allow for the patient's to have options and choose as per their preference
50	Modified to add Ontario legislation
51	Modified to include the medical aims of the proposed care
52	Modified to add include all transition points (not just services) and Accreditation Canada practices
53	Modified to clarify use of audio recordings
54	Modified to include the patient's wants
55	Modified to fit the Ontario context
56	Modified to fit the Ontario context
59	Modified to include content from Recommendation 51 for emphasis
62	Modified to ensure that verifying the patient's understanding occurs regularly
65	Modified by combining two recommendations to avoid redundancy and provide more clarity

Table 2 Rejected recommendations and rationale

Original recommendation Number (CG-138)	Rejection rationale
13	On the grounds that, as written, the recommendation is provider-facing and therefore does not indicate a need to equip the patient with information beyond their care, as would be appropriate in a guideline aimed at directly improving the patient experience. Additionally, the benefit of all healthcare professionals being trained in providing adequate and appropriate nutrition appeared unnecessary and redundant, as long as the information was made accessible to the patient (by a specialist, through written materials, etc.).
18	From a legislative perspective, although we advocate for self-management and patient activation in line with the Ontario Cancer Plan, this is only the extent to which the patient is willing and able to do so. In accordance with the Health Insurance Act, when you are admitted to a hospital, medication is covered by the Ministry of Health and Long Term Care (Public Hospitals Act: http://www.e-laws.gov.on.ca/html/regs/english/elaws_regs_900552_ev002.htm)
48	The principle of information sharing and transparency is supported by the committee, but the specific recommendation is not relevant to the Ontario context. To match the intent of this recommendation, a new recommendation is proposed: Offer and ensure the patient has access to their personal health information (PHI). Answer any questions the patient may have about his/her PHI. [Recommendation 46]
67	The content of this recommendation is embedded into recommendation 65.

Background

Person-centred care is the evolution of patient-centred care, a change in name that signals to the system the importance of being treated as a person first, and recognizing that patients are not defined by their disease. Person-centred care recognizes that true high-quality care with direct impact to the patient experience requires a fundamental shift in our approach to healthcare.

In Ontario, there are a number of policy and legislative initiatives helping to drive the shift in healthcare culture from one in which patients and their families are expected to fit into existing services and have little input into the design and delivery of the services they receive, to a culture that centres care on the needs (healthcare and personal) of the individual receiving the care.

CCO identified person-centred care as one of five areas of strategic focus in its new Corporate Strategy. By continuing to drive improvement through person-centred care in the cancer and chronic kidney disease systems, CCO committed to:

- actively partnering with Ontarians in identifying, designing, planning and improving healthcare services;
- developing and implementing programs and resources that drive the adoption of person-centred care approaches to service delivery; and
- embedding expectations for evidence-based, person-centred quality care into our performance improvement approaches.

The adoption of a model of person-centred care requires a different conceptualization of how patients, those going through screening programs, family members, caregivers and providers are engaged with and work with healthcare professionals. Person-centred care is an approach to the planning, delivery and evaluation of healthcare that involves mutually beneficial partnerships between healthcare professionals, patients and families to:

- give patients a voice in the design, delivery and evaluation of the care they receive; and
- enable patients to be more active in their care experience in order to deliver better outcomes and greater value through wiser use of resources.

Prior to this guideline, clinical person-centred care practices and behaviours have not been formally defined or understood in the province. In hand with increasing evidence in support of person-centred care, there is a growing need for a standard definition and practice of the care approach. An environmental scan of Ontario's 14 Regional Cancer Centres, alongside a stakeholder consultation, confirmed this. Results demonstrated that cancer programs recognize person-centred care as a priority and are looking for guidance on how to translate the philosophy and theory into concrete practices and behaviours. The recommendations in this guideline aim to provide such framework.

Methods

Choice of guideline for endorsement

A literature search was conducted to identify evaluation strategies and indicators for measuring patient engagement and person-centred care. MEDLINE and EMBASE were searched for articles published from September 2001 through October 2014 using varied and strategic combinations of Medical Subject Heading search terms. The following terms were used for measuring patient engagement: engagement, partnering, accountability, collaboration, measurement, involvement, patient, service user, consumer and community. Due to the large amount of literature on related engagement, topics such as patient self-management, activation, shared decision-making, treatment adherence and compliance were excluded; the selection criteria was limited to focus on articles that specifically addressed patient engagement in the improvement of health services. Search terms for person-centred care included: patient- and family-centred care, patient-centred care, person-centred care, user-centred care, patient-focused care and patient-based care.

The literature search was supplemented by a search for gray literature using the Google search engine, websites of key healthcare organizations, reference lists and personal files. Searching was ceased when data saturation became evident and no new indicators were identified.

A total of 110 articles were identified, after removing duplicates and those articles that did not fit the search criteria. Only one guideline was found and was retrieved for full review. The guideline was selected for endorsement because of its scientific rigor (see Appendix 2 for AGREE II scores), relevance in that it formalizes person-centred practice and was easily transferable to the Ontario setting.

Description of Patient experience in adult NHS services: improving the experience of care for people using adult NHS services.

The National Institute for Health and Clinical Excellence (NICE) was commissioned by the NHS Department of Health “to produce a quality standard and guidance on patient experience in generic terms.” NICE funds the National Clinical Guideline Centre which developed the guideline. The result was a guideline that consists of 68 recommendations that focus on clinician/patient interaction and organizational issues as they pertain to improving patient experience.

The recommendations outline a level of service that people using adult NHS services should expect to receive in all setting in which NHS care is provided and from all staff involved in NHS services. This includes primary and community care (including dental care and hospital services). This guidance does not cover people using NHS services for mental health and caregivers of people using NHS services.

The multidisciplinary Guideline Development Group (GDG) responsible for producing the recommendations was comprised of four medical specialists, six patient and caregiver members, two nurses and four academics.

NICE used a pragmatic approach to ensure that GDG had multiple sources of evidence/information in order to establish what is important to patients when considering their experience of healthcare. Those sources were:

- a review of existing patient experience frameworks;
- a patient experience scoping study (a focussed thematic qualitative overview of literature in three disease areas to identify key themes/subthemes important to patients in relation to their experience of healthcare);
- a review of NHS survey results;
- a review of existing NICE recommendations related to patient experience; and
- systematic reviews of the literature on GDG-prioritized topic areas.

Systematic literature searches were conducted to identify evidence concerning continuity of care, risk communication and patient education programs per The NICE Guidelines Manual 2009. Searches were conducted on MEDLINE, Embase, CINAHL and The Cochrane Library using relevant medical subject headings, free-text terms and study type filters where appropriate. All searches were updated May 9, 2011.

The development of the recommendations was based on the GDG's interpretation of the available evidence, (existing NICE guidance, systematic literature reviews for specific interventions to improve patient experience), the balance of benefits and harms, costs and patient preferences. Where there was poor quality, conflicting or no evidence, then expert opinion and consensus were used.

The recommendations were subjected to a four-week public consultation and feedback process for quality assurance and peer review.

To update the guideline, NICE will ask a National Collaborating Centre or the National Clinical Guideline Centre to advise NICE's Guidance executive whether the evidence base has progressed enough to change the recommendations and warrant an update.

Formation of the Person-Centred Care Guideline Endorsement Group of Cancer Care Ontario

The Person-Centred Care Guideline Endorsement Group undertook this endorsement project; this group was organized by Cancer Care Ontario's Patient Experience Portfolio. The project was led by a small working committee (referred to as the Working Group in this document), whose members were responsible for reviewing the recommendations in *Patient experience in adult NHS services: improving the experience of care for people using adult NHS services* in detail and making an initial determination as to any necessary changes, drafting the first version of the endorsement document, and leading the response to the external review. The Working Group was comprised of two patient/family advisors, a medical oncologist, a radiation oncologist, the Regional Vice-President for Cancer Care for London Health Sciences, an advanced practice nurse, two Cancer Care Ontario staff members (Senior Manager, Person-Centred Care, and Policy Research Analyst, Person-Centred Care), as well as the Assistant Director of PEBC and a PEBC Health Research Methodologist (see Appendix 1 for membership). All members of the Person-Centred Care Guideline Endorsement Group contributed to the endorsement process, refinement of the endorsement document and approval of the final version of the document. No competing interests have been declared thus far; formal disclosure is underway and will be determined by April 6, 2015. Appendix 1 provides further detail. Individuals with competing interests were not allowed to participate as a member of the Working Group unless otherwise stated.

Endorsement process

The Working Group reviewed *Patient experience in adult NHS services: improving the experience of care for people using adult NHS services* in detail, and reviewed each recommendation of that guideline to determine whether it could be endorsed, endorsed with changes or rejected. This determination was based on the agreement of the Working Group with the interpretation of the available evidence presented in the guideline, the recommendation's applicability to the Ontario context, and the recommendation's acceptability and ability to be implemented.

Recommendations that were modified or rejected and the reasons thereof are listed in Tables 1 and 2.

Review and approval by the Person-Centred Care Guideline Expert Panel

The Person-Centred Care Guideline Expert Panel (see Appendix 1) reviewed the Working Group's initial determinations with respect to the recommendations and provided feedback. In a teleconference, each recommendation was reviewed and discussed by the Expert Panel and was either approved or modified and then approved. Once the final version of each recommendation and preamble was agreed upon, the Expert Panel voted to approve the guideline, first by section and then in full.

External review

Feedback was obtained through a brief online survey of healthcare professionals and other stakeholders who are the intended users of the guideline. The survey asked respondents to rate the overall quality of the guideline, its utility and value, and completeness of reporting. The survey also inquired as to foreseeable barriers or enablers to implementing the guideline.

Seventy-three people completed the survey. One individual (clinician, non-physician) provided comments only. Twenty-four were administrators, 19 were patient/family advisors, 14 were physicians, seven were clinicians (non-physician), one academic and either other professions. Representation came from throughout the province with 14 respondents from Champlain; eight from Toronto Central South, North Simcoe Muskoka and South West Regions; six were from Toronto Central North, Hamilton Niagara Haldimand Brant, Central West and Mississauga Halton; five from Erie St. Clair; three from South East and North East; two from Central East and North West; and one from Central and Waterloo Wellington. Key results of the feedback survey are summarized in Table 3. The main comments from the survey and the Working Group's modifications/actions/responses are summarized in Table 4.

Table 3. Responses to three items on the professional consultation survey

General questions: Overall guideline assessment	Number (%)				
	Lowest quality (1)	(2)	(3)	(4)	Highest quality (5)
1. Rate the overall quality of the guideline report.	0	2	8	46	17
	Strongly disagree (1)	(2)	(3)	(4)	Strongly agree (5)
2. I would make use of this guideline in my professional decisions.	2	4	17	19	31
3. I would recommend this guideline for use in practice.	1	4	10	26	32

4. What are the barriers or enablers to the implementation of this guideline report?

Barriers identified by the respondents include themes with the guideline, time, resources and people. It was felt that the guideline was very long and therefore it may not be read, and would be difficult to implement all the recommendations. As well, many of the recommendations are behaviours and more difficult to measure the implementation. It was felt another barrier may be time to learn about the guideline and how to use it as well as time for physicians and staff to do the recommendations. Another potential barrier identified was beliefs and resistance to change behaviours to match the recommendations, and even that physicians and staff may be unaware that they are not doing the recommendations. Language barriers were listed and the time that may be needed to find a translator.

Enablers included: having an evidence-based guideline; well-respected champions who conduct their practice in the recommend way across various disciplines; endorsement of the guideline by management and recognition of its importance; tools (cheat sheets, checklists, algorithms) for physicians and staff as well as tool for patients/supporters to assist them; and more education at the cancer centres about the recommendations and how to implement them.

Table 4. Modifications, actions and responses regarding main written comments from external review respondents

Main written comments	Modifications, actions and responses
1. This predominantly deals with psychosocial aspects of care but not the optimization of care plans for the individual patient based on clinical and	The intent of the guideline is to translate the philosophy of person-centred care into tangible practices and behaviours. Optimization of care plans for the individual patient is beyond the

<p>biological (genomic) findings and evidence-based care plans.</p>	<p>scope of this guideline, but standards may be developed based on core principles of the guideline.</p>
<p>2. Despite referencing the SMG's (Rec 12), the only symptoms referenced are depression & anxiety (with a link to the psychosocial oncology guidelines) and along with "Nutrition" and "Personal needs" is pain. The section addressing pain specifically is good in the details listed however its unclear why other physical symptoms are not included i.e. shortness of breath, fatigue etc. To single out pain is certainly appreciated and a step forward however to be comprehensively person centered I would suggest the other physical symptoms be included.</p>	<p>, The Working Group amended Recommendation 15 by expanding "personal needs" to "personal needs and symptoms".</p>
<p>3. One of the greatest information gaps for which there is clear evidence (and matches clinical experience) is around illness understanding for the context of incurable and progressive disease. The information section in my view is very treatment focused as opposed to disease or person focused. In my view decision-making is very poorly informed overall as patients are not fully appreciating the incurable and progressive nature of their disease (among the metastatic population). I would suggest this element be clearly outlined.</p>	<p>The Working Group amended Recommendations 57 & 59 by expanding "investigations and treatments" to "goals of care, investigations, and treatments."</p>
<p>4. Building on above, I strongly encourage using these guidelines as an opportunity to clearly outline what is meant by palliative care and the role for this care along the trajectory of illness.</p>	<p>The Working Group included a palliative care guideline in the preamble to define the role of palliative care.</p>
<p>5. The Communication section does not mention health literacy and this is critical. Recommend adding a paragraph to describe health literacy and the impact it can have on communication. In this context, it is important to state that healthcare professionals should communicate in plain language as a universal precaution, that patients should be engaged in the learning process, and that teaching should be augmented with patient education resources that are written in plain language</p>	<p>The Working Group finds that health literacy is captured in the use of the term "accessible" in Recommendation 50. Health literacy is also addressed in both Patient Education Guidelines that are linked to and referenced in the preamble, including: Effective Teaching Strategies and Methods of Delivery for Patient Education, 2009; and Establishing Comprehensive Cancer Patient Education Services, 2006.</p>
<p>6. Recommendation 61 discusses risk but</p>	<p>The Working Group finds that numeracy is</p>

does not mention numeracy. This should be added.	addressed in multiple recommendations.
7. Consider adding discussion about Complementary and Alternative Medicines (CAM) into the Communication section. This is often a contentious point for healthcare providers and patients. Recommend that you review the Canadian Cancer Society CAM pamphlet for guidance.	The Working Group feels that specific discussion regarding Complementary and Alternative Medicines is beyond the scope of the guideline. However, in principle, this is addressed in Recommendation 26.
8. Rec 12 -In light of the extensive provincial discussions on ESAS, it might be worthwhile to specifically reference it as reinforcement for all readers. Why not use ESAS as an example of a pain scale? This is an Ontario document - all cancer centres must use ESAS	The Working Group amended Recommendation 14 to include specific reference to ESAS. The pain scale has also been amended to match ESAS pain scale.
9. Would it be appropriate for the health care team to encourage all patients to have directives in place to address any eventualities (incompetence, DNR, wills etc.) - say a new Rec 19? It is an uncomfortable topic for many but better to have it early than late in the journey.	The Working Group finds this area to be beyond the scope of the guideline.
10. The introduction is confusing. Cancer Care Ontario is endorsing and then adapting the NHS guideline but only with rather strong provisions that seem to negate or question the accuracy of the adaptation.	The Working Group would like to clarify that the NHS is not responsible for any changes that Cancer Care Ontario makes to the recommendations.
11. Things I notice are not addressed patients who do not have OHIP therefore do not qualify for funding through Cancer Care Ontario yet do present at the Cancer Centre.	The Working Group finds this area to be beyond the scope of the guideline.
12. The CCO "Provider-Patient Communication" guideline #19 -2, 2008 is not referred to in this new guideline. I think it should be. Thanks.	The Working Group agrees and referenced and linked to this guideline.
13. Rec 9 - "Do you want them to stay?" should ask before the student is present as it can be intimidating to be asked in their presence.	The Working Group agrees and edited language in Recommendation 9 accordingly.
14. Preamble (p.2) refers to 'patients' only - exclude family, caregivers etc. and this is before the guideline qualifies that 'patient' in the remainder of the guideline	The Working Group addressed this in the preamble by use of an asterisk.

encompasses all. Recommend rephrasing.	
15. At Rec 6 there is a list of gender-based intersecting factors, I suspect taken from the Ontario Human Rights Code. I would suggest that you also add: religion, culture and geography (remote, rural and urban) as other important factors that influence person-centred care.	The Working Group agrees and included language to capture geography, religion and culture in in addition to the Ontario Human Rights Code in Recommendation 6.
16. Rec 2 - only specifies English and French, but what about barriers for those who speak neither?	The Working Group finds that support for those who speak other languages are addressed in Recommendations 41 & 50.
17. Rec 25 - add understand {and appreciate} - the two factors for capacity	The Working Group agrees and amended Recommendation 25 accordingly.
18. There is no reference to modification (unless I missed it) to assisting with ethical issues in shared decision-making. (pages 11...)	The Working Group added the reasons for modification.
19. Page 2 -correct your own definition of person centred care - #2 should read "Enable patients to be more active in their journey in order to deliver..." - the words "in order" are missing. I checked the Cancer Care Ontario patient engagement report to be sure.	The Working Group added the missing words to the definition.
20. Rec 43 -should read, "Use words the patient will understand, define unfamiliar words and confirm understanding by asking the patient to explain what was said." The expectation of using teach back to confirm understanding must be stated clearly. HCPs should NOT ask, "Do you understand?"	The Working Group agrees and amended Recommendation 43 by replacing "asking questions" with "confirm understanding by using methods such as teach back."
21. Rec 47 -is too vague. How do staff "demonstrate competency" and which communication skills are "relevant"? This statement is useless without qualifiers. Rework this to reflect the language used in "Maximizing your Patient Education Skills".	Competency of communication for the individual patient is beyond the scope of this guideline, but standards may be developed based on core principles of the guideline.
22. Rec 49 -requires addition of "pre-recorded audio", not just "oral" information. "Oral" could be interpreted as referring only to the conversation with the doctor/nurse which they may not recall.	The Working Group feels that the term "oral" allows for the patient to have options and preferences that "pre-recorded audio" doesn't.
23. Rec 52 -what is a "non-standard format"? Replace with "accessible format" to align	The Working Group agrees and replaced this

with #50.	term in Recommendation 52.
24. Rec 55 -It should be made clear to the patient that there is no vetting process for quality information in Ontario." What does this mean? There is no universal standard for creating quality patient information in Ontario. And there is no single process for evaluating patient information quality. However, there are tools in use in Ontario for evaluating written and on-line materials. This item requires a rewrite and rethink.	The Working Group agrees and amended Recommendation 55 accordingly.
25. Rec 61 -last bullet please remove "Think about" - replace with "Use a mixture of..." This is a guideline. Be clear!	The Working Group agrees and amended Recommendation 61 accordingly.

Updating the endorsement

This endorsement is valid until March 2016, at which time NICE will decide whether the evidence base has progressed significantly to alter the original guideline recommendations (CG-138) and warrant an update. Cancer Care Ontario's Person-Centred Care Program will then review the guideline and endorsement.

Appendix 1 - Members of the Person-Centred Care Guideline Endorsement Group

Expert Panel (* Working Group Members)

Members	Affiliation	Declaration of interest
Simron Singh*	Clinical Lead, Person-Centred Care, Cancer Care Ontario Medical Oncologist, Odette Cancer Centre, Sunnybrook	None
Lesley Moody*	Senior Manager, Person-Centred Care, Cancer Care Ontario	None
Neil Johnson*	Vice-President, Cancer Care for London Health Sciences Centre Regional Vice-President, South West Regional Cancer Program, Cancer Care Ontario	None
Christiaan Stevens*	Staff Radiation Oncologist, North Simcoe Muskoka Regional Cancer Program	None
Gail Larocque*	Nurse Practitioner, The Ottawa Hospital Cancer Centre	None
Rhonel B*	Patient/Family Advisor, Cancer Care Ontario	None
Carly G*	Patient/Family Advisor, Cancer Care Ontario	None
Hans Messersmith*	Assistant Director, Program in Evidence-based Care, Cancer Care Ontario	None
Hannah Shamji*	Policy Research Analyst, Person-Centred Care, Cancer Care Ontario	None
Caroline Zwaal*	Health Research Methodologist, Program in Evidence-based Care, Cancer Care Ontario	None
Leah Bergstrom	Aboriginal Patient Navigator, Simcoe Muskoka Regional Cancer Program	None
Cindy Quinton	Medical Oncologist Division Head, Systemic Therapy Trillium Health Partners	None

Frank Wagner	Bioethicist, Toronto Central Community Care Access Centre Assistant Professor, Department of Family and Community Medicine	
Mike Bell	Patient/Family Advisory Council Member, The Kingston General Hospital	None
Amy Lang	Director, Patient, Caregiver and Public Engagement, Health Quality Ontario	None
Esther Green	Provincial Head, Nursing and Psychosocial Oncology	None
Carol Rand	Director of Regional Cancer Programs, Juravinski Cancer Centre	None
Carol Mayer	Director of Research and Regional Clinical Lead, Supportive Care Oncology Program, Northeast Cancer Centre	None
Ross Baker	Director, IHPME MSc. Program, Quality Improvement and Patient Safety, University of Toronto Professor, IHPME MSc. Program, University of Toronto	Wrote a brief for the Canadian Foundation for Healthcare Improvement: A Review of Research Highlighting How Patient Engagement Contributes to Improved Care
Martin L	Patient/Family Advisor, Cancer Care Ontario	Missing Information
Joanne M	Patient/Family Advisor, Cancer Care Ontario	None
Patricia G	Patient/Family Advisor, Cancer Care Ontario	None
Patricia P	Patient/Family Advisor, Cancer Care Ontario	None
Alexandra Ginty	Regional Primary Care Lead, Cancer Care Ontario, Mississauga, Halton	None
Zal Press	Executive Director, Patient Commando Productions	None
Jennifer Catton	Project Manager, Prevention and Cancer Control, Cancer Screening, Cancer Care Ontario	None

Appendix 2 -AGREE II Scores

Domain	Patient experience in adult NHS services: Clinical Guidance
Scope and purpose	94%
Stakeholder involvement	92%
Rigour of domain	97%
Clarity and presentation	92%
Applicability	81%
Editorial independence	79%

References

National Institute for Health and Clinical Excellence. *Patient experience in adult NHS services: improving the experience of care for people using adult NHS services* (CG 138) London: National Institute for Health and Clinical Excellence, 2012. Available from www.nice.org.uk/CG138.