Exploring approaches used to identify, incorporate and report patient preferences in clinical guidelines

By

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Abstract

**Introduction:** Guidelines improve patient care and outcomes. Research shows that guidelines that address patient preferences are more likely to be used but few do. This study explored approaches used to identify, incorporate and report patient preferences in clinical guidelines.

**Methods:** This study included a scoping review and semi-structured qualitative interviews with guideline developers on approaches used to identify, incorporate, and report patient preferences during guideline development.

**Results:** Twenty-one full-text studies were included in the scoping review. Fifty national and international guideline developers (patients, clinicians, managers) participated in the qualitative interviews. A multitude of approaches were found for identifying patient preferences. Preferences are not being incorporated in all guideline steps, even though developers said they were, and are also being poorly reported in terms of how and where those preferences influence guideline development.

**Conclusions:** More research is needed on approaches to optimize identifying, incorporating and reporting patient preferences in clinical guidelines.
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List of abbreviations

G-I-N – Guidelines International Network

PEGD – Patient engagement in guideline development
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Chapter 1 Introduction

1.0 Introduction

Improving health care quality, the degree to which services increase the likelihood of desired health outcomes, is a global imperative. Guidelines are produced to provide recommendations on how to optimize care delivery and patient outcomes. However, guidelines are underused due to multiple determinants (facilitators and barriers) including patient-, clinician-, institutional, organizational, and system-level factors. Efforts to overcome challenges and improve guideline use, including educational material and meetings, opinion leaders, audit and feedback, and pay-for-performance, have had inconsistent and limited impact. Given the limitations and/or limited impact of these strategies, alternate strategies are needed to improve guidelines and/or the way they are implemented so that they are more likely to be used. Guidelines that are based on both research evidence and patient preferences enhance their relevance to patients, and are more likely to be used by patients and clinicians because they support patient-clinician communication about the benefits and risks of treatment options, leading to informed decision-making and treatment adherence. However, research has shown that many guidelines were not informed by patient preferences. Improving the development of patient-relevant guidelines is widely advocated; yet, little guidance exists on how to do so. Therefore, primary research is needed to generate insight on approaches used to develop patient informed guidelines. This thesis will synthesize published evidence on approaches for identifying, incorporating and reporting patient preferences in guidelines through a scoping review, then explore current practices for doing so among national and international guideline developers through qualitative interviews. This accumulated knowledge can be used by guideline developers or others to evaluate and/or improve guidelines.
through improving the processes by which guidelines are developed that ensure their patient-relevance.

Chapter 2 Background

2.0 Background

2.1 Guidelines improve health care quality

Guidelines are statements of synthesized scientific evidence that include recommendations on a given condition, disease, procedure or therapy intended to optimize patient care. Often informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options, guidelines are intended to improve the quality and outcomes of health services (1–3). Rather than dictating a one-size-fits-all approach to patient care, clinical practice guidelines offer an evaluation of the quality of the relevant scientific literature and an assessment of the likely benefits and harms of a particular treatment at a population level (3). This information enables health care clinicians to select the best care for a unique patient based on their preferences (3).

The use of guidelines can bring about many benefits. The purpose of guidelines is to take all the best and most current evidence and synthesize it into recommendations that improve the quality, consistency and effectiveness of care received by patients and their health outcomes (4,5). In addition to improving quality of care and improving consistency of care, they also decrease costs associated with preventable adverse events (6). Guidelines can also improve the consistency of
care by making it more likely that patients will receive an equal level of care regardless of their characteristics, where they are located, or by whom they are treated (5,7,8). Furthermore, guidelines can empower patients to make more informed health care choices and to participate in the decision making process (5,8).

Another potential beneficial impact of guidelines is to improve mortality and survival rates. In a study that looked at children with severe anemia, results showed that children managed according to the clinical guidelines had a reduced risk of inpatient mortality (P=0.001) (9). Another study that included 259 patients with atrial fibrillation found that the patients treated with the guidelines had a higher rate of survival during the first three years (P=0.049) (10). Adherence to management of chronic heart failure guidelines has shown improvements of long-term mortality risk (P=0.01) in 1014 patients with stable systolic heart failure (11). A Canadian randomized trial following radiotherapy guidelines for limited-stage small-cell lung cancer found that patients who receive thoracic irradiation at week three versus patients who receive it at week 15 are superior in progression-free survival (P=0.036) and overall survival (P=0.006) (12). Research shows that poor adherence to guidelines can lead to adverse effects including mortality (P=0.001) (13).

Guidelines are meant to benefit and improve the knowledge and behaviour among clinicians. One way of doing so is to provide clinicians with evidence-based recommendations in the form of clinical practice guidelines (henceforth, guidelines). Guidelines also advise health care professionals with the most up-to-date practices, thus helping them to optimize patient care (5,8). Health care professionals can look to guidelines when feeling uncertain about how best to
proceed or for reassurance about the appropriateness of a course of action when suggesting treatment options to patients (5,8). Guidelines can function as the basis for discussion and decision-making in patient-physician interaction (14–16). Considerable research has shown that guidelines improve care delivery by health care professionals. An Australian pilot study successfully implemented the Australian Wound Management Association Guidelines for the Prediction and Prevention of Pressure Ulcers for pressure risk management in a home nursing setting (17). This pilot study with 21 nurses and 218 clients was conducted and practice guidelines for pressure risk screening were adopted (17). Continuing after the pilot study, two years later the organization still continues to screen more than 90% of all clients (17).

Guidelines can also benefit and improve the knowledge and behaviour among patients. In the United States, a national survey study found that adherence to guidelines for screening, physical activity and medication use were associated with lower risks of diabetic complications and death (14). The European Randomized study of Screening for Prostate Cancer found that screening guidelines have a 21% relative risk reduction of death from prostate cancer (18). A nationwide population based cohort study conducted in Sweden that looked at screening guidelines for cervical cancer found that Pap tests have a 92% cure rate compared to just 66% among women who are diagnosed based on symptoms (19). Among 373 women that died from cervical cancer, more than 75% did not have a Pap test (19). The Canadian 24-Hour Movement Guidelines for Children and Youth contain recommendations for physical activity, screen time and sleep duration (20). The cross-national study sampling over 17,000 Canadians aged 10-17 years found that participants achieving any given recommendation or combinations of the recommendations within the guidelines have preferable health outcome scores compared with participants who do
not meet recommendations (20). This evidence suggests that guidelines are an important knowledge-based health care resource.

2.2 Guidelines are under-used

It is imperative to improve quality of care. Research has shown that guidelines are widely under-used resulting in suboptimal health services, and patient and health system outcomes (14,21–28). Patient care can vary widely with little consistency in clinical practice to the guideline recommendations (7). One Canadian study that looked at quality of care in end-of-life in 21,323 patients found that a significant proportion of Ontario cancer patients had indicators of poor quality end-of-life care (29). Results showed that 27% of the cohort had at least one emergency room visit and 5% had a visit to the intensive care unit with a 92% death rate in the unit (29).

Another study conducted in the United States for adults with depressive or anxiety disorders with 1636 eligible participants found that 83% of adults saw a healthcare provider but only 30% received appropriate treatment (30).

Runciman et al. found highly variable care overall and poor compliance with important indicators including poor compliance across conditions for the use of recommended risk assessment tools (24). For example, despite guidelines being in place and significant benefit from screening, there is an extensive amount of research that has shown non-adherence to having routine eye exams for patients with type II diabetes (14,15,27,31,32). One of the American studies found that only one-third of participants (29.9%, 284/949) adhered to guidelines in obtaining follow-up eye care within the recommended time frame (31). One study found that an
average of 25% of patients perceived recommendations to lack applicability specifically to individual patients (5). A Canadian population cohort study found breast cancer guidelines are not meeting their stated objective (7). These guidelines were developed to improve consistency in care to reduce the variation in the way that breast cancer was being treated (7). Research has shown that Canadian breast cancer guidelines did not correct variation in rates of procedures (7). Development and dissemination of the guidelines alone are not enough to create a significantly meaningful change in variation without including implementation strategies (7). Unfortunately, compliance is only modest despite resources and guidelines being available (3). One American study that utilized surveys reported that physicians’ compliance to guidelines was 54% from the assessment of chart reviews (8). Interestingly, when physicians were asked to self-report their compliance, an 11% difference was observed, where physicians reported a 65% compliance rate (8).

An American qualitative study based on telephone interviews with a random sample of adults found that participants received 54.9% of recommended care for 439 indicators of quality of care for 30 acute and chronic conditions as well as preventive care (33). A computer-assisted qualitative study and retrospective review conducted in Australia aimed to measure compliance with 522 expert consensus indicators that represented appropriate care for 22 common conditions in 1154 participants (24). This study found that 57% of adult participants receive appropriate care and compliance for health care providers ranges from 32% to 86% (24). Another Australian study for the prevention and management of venous thromboembolism clinical practice guidelines found that compliance is 51% with a range from 34% to 64% for 38 indicators (26). In an international comparisons study of patients with acute non-ST segment elevation myocardial
infarction in the United Kingdom, the United States and Sweden it was found that the care provided among the three countries differed substantially (25). For example, angiography and percutaneous coronary intervention were performed more often in the United States (76% and 44%) versus Sweden (65% and 42%) and the United Kingdom (32% and 22%) (25). An American study that conducted a cross-sectional, web-based survey found that only 57% of providers utilize the Centers for Disease Control and Prevention 2016 Guideline for Prescribing Opioids for Chronic Pain (34). A study from the Netherlands found that a significant amount of patients diagnosed from 2009 to 2012 did not receive adjuvant systemic therapy for early stage breast cancer despite a guideline-based indication (35). A cross-sectional, observational study from Spain found non-adherence to guidelines for the treatment of atrial fibrillation in three out of every five patients (36). A comparison study conducted in China found that no one (0/173) completely adheres to the guidelines, diagnosis, treatment and discharge, for treatment of advanced schistosomiasis japonica (37). With an extensive amount of research available outlining poor compliance and non-adherence, it is apparent that guideline misuse has resulted in variability in care, treatment and patient outcomes across the globe.

2.3 Determinants of guideline use

Given plentiful evidence of inconsistency in guideline use, and sub-optimal patient outcomes, considerable research effort has been dedicated to examining the barriers or challenges of guideline use. A variety of factors influence guideline use including patient, clinician, and guideline factors.
Numerous studies have identified patient factors that influence guideline use. One study that reviewed 5415 records to synthesize evidence of the public’s attitude towards clinical practice guidelines found patients are concerned that the guidelines may not apply or are not tailored to their own health care situations (38). Patient factors include lack of familiarity with guidelines or reluctance to follow guideline recommendations (39). Two qualitative studies found that patients are not familiar with guidelines for diabetes management and that they lack practical knowledge on diabetes (40,41). The first was a study conducted in Barbados of 21 patients in five structured focus groups that found that none of the participants had seen any guidelines for either diabetes or hypertension (40). The second study was conducted in the United States and 2308 participants were interviewed (41). The investigators found that the non-adherent group more often reported “fair to poor” medical and practical knowledge about diabetes (41). Patients mentioned not receiving sufficient medical information about their disease process and felt that their complaints were not being taken seriously by healthcare professionals (42). Another patient factor often observed in the evidence is socio-economic status. The cost of drugs for those that do not have insurance or coverage as well as the high cost of foods, especially healthy foods was reported (40). A United Kingdom (UK) systematic review found the most referenced patient factor was socio-economic deprivation reporting that non-attendance increased with higher socio-economic deprivation (32). A qualitative study that took place in urban and rural London found lack of awareness in both patients and clinicians to be the greatest barrier for diabetes eye examination attendance (15). Although patients were aware that diabetes could affect the eye, they were not aware that it could lead to blindness or that they could develop retinopathy without showing any symptoms (15). Clinicians often underestimated the difficulties patients had in taking time off work to attend the routine eye examination (15). One study identified 38 barriers
citing patients’ disagreement with guideline recommendations and poor communication from healthcare professionals as frequently mentioned barriers (42).

There are a number of barriers to guideline use that are specific to clinicians. Common barriers identified by clinicians include but are not limited to lack of time, pressure from patients, and guidelines being too long, too rigid or difficult to read (43). The study reported that four general practitioners and three radiologists stated that there were too many guidelines and not enough time to keep up with them (43). Both general practitioners and radiologists reported not having enough time (43). General practitioners reported that writing a referral was easier and took less time than discussing/arguing with patients on why they may or may not need the referral, however, radiologists reported being under time pressure from the large amount of referrals (43). Similarly, another study that surveyed 36 physicians also found that 44% reported time being a barrier and 53% reported that the guidelines were too rigid (44). The study also reported additional barriers such as 39% having limited access to the clinical practice guidelines at the point of care and 62% thought that the guideline recommendations were not appropriate or applicable in a given clinical situation for their patients (44). Ninety-six physician participants participated in a survey for guidelines in chronic myelogenous leukemia that identified barriers towards guideline use (45). 20% of respondents reported lack of time to search the guidelines as a barrier and only 51% of participants felt that the guidelines addressed all aspects of disease management (45). In a study that surveyed 575 registered nurses, 44% identified inadequate time or staffing or a heavy workload as a barrier to the use of guidelines (28). In an American study that looked at adult diabetes patients targeting cardiovascular disease risk factor levels, it was found that clinician’s lack of therapy or treatment intensification was found in 53-63% of all
patients (46). In a study that surveyed 264 general practitioners on perceived barriers to guideline adherence, 35% reported difficulty in changing their routines and habits to adjust to the guidelines even though 89% believed that guidelines were important in improving patient care (5).

Other studies show that factors relating to the guidelines themselves are barriers of guideline use (47). Some of the key mentioned barriers include a lack of easy access to guidelines, a focus on patients with single disease entity, a lack of clear intervention goals and a lack of user friendly versions of guidelines (47). The accumulation of evidence on barriers of guideline use was consolidated by a Norway study that identified all known determinants of guideline use through a systematic review, followed by consensus among an international expert group (48). Fifty-seven potential determinants of guideline use were identified and grouped into seven domains: guideline factors, individual health professional factors, patient factors, professional interactions, incentives and resources, capacity for organisational change, and social, political, and legal factors (48). Another study from the Netherlands developed a measurement instrument for determinants of innovations that included 29 relevant determinants (49). This instrument was developed to improve the understanding of critical determinants and improve planning for the implementation of innovations (49). It still remains unclear how best to improve adherence to evidence-based recommendations, making it difficult to improve the quality of care for patients (22). As accumulated research shows that multiple factors (guideline, patient, clinician, institutional, system-level) can influence guideline use, necessitating strategies to promote or support guideline use by patients and/or clinicians.
2.4 Interventions to promote guideline use

Many different types of interventions have been developed to implement and promote guideline use. Powell et al. synthesized published knowledge about guideline implementation interventions to create the Expert Recommendations for Implementing Change taxonomy, which includes 73 discrete implementation strategies, largely aimed at clinicians (50). Most commonly used interventions targeted to clinicians to promote guideline use include educational workshops/meetings/sessions (21), educational materials (51,52), opinion leaders (53) audit and feedback (54), pay-for-performance (54), and inter-professional collaboration (55). For example, interventions used to promote and assist tobacco cessation include proactive telephone support, automated text messaging programmes and printed self-help materials to help assist smokers wanting to quit (56). Face-to-face behavioural support can also increase quitting success rates (56). Another study reported clinical pathways for prescribing, multidisciplinary teams and multifaceted interventions are also other possible methods of increasing guideline uptake for clinicians (57).

Unfortunately, decades of research show that these strategies targeted at either patients or clinicians have had limited or inconsistent success in improving use of guidelines (45,58,59). The majority of intervention research has targeted clinicians. One study showed that a multidisciplinary team intervention is not effective in improving guideline use (60). Educational materials or meetings, the most commonly used strategy, are not consistently effective or have a small impact on professional practice (21). Printed educational materials for primary care physicians were reported to be ineffective and did not improve physician knowledge, behaviours
and patient outcomes (61). In a qualitative study of 108 hospital staff members, audits and feedback were employed to improve hand hygiene guideline compliance (62). The study reported that auditing did not encourage positive change and instead was time consuming, perceived as collecting inaccurate data and in turn created tension with staff members (62). One two-armed cluster randomized controlled trial consisting of 66 occupational physicians found that peer learning education sessions to enhance the physicians’ adherence to guidelines did not lead to earlier return to work in patients with common mental disorders who were guided by the physicians (58). Another study consisting of 96 physician participants for guidelines in chronic myelogenous leukemia reported having poor guideline adherence and that new interventions/initiatives to facilitate guideline use were deemed unnecessary by physicians (45). In this study, 35/96 physicians reported that any additional training, professional society endorsements, or availability of expert consultants would not encourage their use of the guidelines either (45).

Less research has targeted interventions at patients. Patient education was also found to be ineffective. One study found that patient education or self-management training as an intervention was not effective on its own to encourage adherence to medications in patients with heart failure (63). A double-blind, cluster randomized controlled trial for depression in dementia patients found that educational interventions had no significant effect on patient quality of life (64). While tailoring of interventions to pre-identified barriers of guideline use has been advocated, two studies that examined the effectiveness of a tailored interventions to implement guidelines found no significantly meaningful differences between the tailored and non-tailored groups (22,23). Aakhus et al. reported only a 1.6% point increase in the intervention group (51
general practitioners) compared to the control group (73 general practitioners) for adherence to recommendations for elderly patients with depression (22). Similarly, Lieshout et al. conducted a two-arm cluster randomized trial in 34 general practices with 34 nurses and found that the tailored intervention group who received communication skills training, online patient information and a clinical protocol for managing symptoms showed no effect on primary outcomes in cardiovascular patients (23).

2.5 Guidelines developed for patients

Historically, guidelines have been developed by clinicians, a traditional approach that was meant to improve implementation and use of guidelines by enhancing awareness and acceptance of guidelines, accommodating clinician preferences in guideline recommendations, and engaging clinicians in designing implementation strategies that were more likely to be effective (65–67). Given the limitations of this approach, alternate strategies are needed to improve guidelines and guideline implementation so that they are more likely to be used. An alternative approach is to generate guidelines that are relevant to patients. In 2004, a meta-analysis by Grimshaw et al. first identified that an important strategy for improving guideline use is to target patients who either adopted the recommended behaviour themselves or made clinicians aware of the guidelines (2). Subsequent research confirms this. For example, a Cochrane review of 66 randomized control trials of informational or educational interventions that aimed to improve attendance for diabetic retinopathy screening found that interventions targeted to patients were likely to be effective for improving attendance rate (68). A randomized controlled trial conducted in the UK found that mental health service users are able to more accurately represent the (disease) population and
contribute to guideline development and implementation based on the needs of that population (66). Patient representatives on guideline development panels are able to emphasize the important nuances of receiving a diagnosis and undergoing treatment, and articulate associated challenges as well as communication issues with their physicians (69). Two UK studies that looked at users of mental health services has shown that user input influences the need for “plain English” guidelines as an effective method for increasing implementation (66,67). It is important to engage patient stakeholders in guideline development and it is now considered an essential element (69). The National Institute for Health Care Excellence (NICE) and the Scottish Intercollegiate Guidelines Network (SIGN) now produce freely accessible patient versions of guidelines (70).

Improving the development of patient-relevant guidelines is widely advocated. Canada’s Strategy for Patient-Oriented Research has advocated that guideline development and implementation be improved by engaging patients in guideline development (71). The Institute of Medicine advocates that clinician and patient decision-making need to be enhanced by developing recommendations at the individual patient level instead of a “one size fits all” approach (72). The Appraisal of Guidelines for Research and Evaluation Consortium developed an assessment tool that specifically includes “the patients’ views and preferences have been sought” in order to make sure patient perspectives will be included in guideline development (73). The Grading of Recommendations Assessment, Development and Evaluation Evidence-to-Decision Framework allows a way of recording and reporting guideline developers’ judgements in a transparent way (74). The framework includes a section for patients’ values and preferences (74). The Guidelines International Network (G-I-N) PUBLIC Working Group has developed the
Toolkit on Patient and Public Involvement in Guidelines (75). The main objective of the G-I-N PUBLIC is “to support effective patient and public involvement in the development and implementation of clinical practice guidelines” (76). This led to the development of the G-I-N PUBLIC Toolkit: Patient and Public Involvement in Guidelines. The Toolkit assembles international experiences and best practice examples of successful patient involvement and aims at supporting guideline developers who consider involving patients in guideline development or dissemination (76). However, since the Toolkit has been based solely on experiences of guideline developers who attend G-I-N meetings, it is therefore not inclusive of empirical research nor does it represent current-day practices as it was first developed in 2010. Collectively, the above-mentioned resources recommend that guidelines specify patient preferences (i.e., how they were identified and how they contributed to guideline development) and include tools that support patient-clinician discussion of preferences regarding treatment options, side effects, and desired outcomes. The World Health Organization (WHO) guideline process also recognizes the importance of ensuring that the views of end users affected by guidelines are incorporated in the evidence to decision-making process (77). The need to take the views and preferences of end users into account is paramount. In addition, the inclusion of end users in guideline development processes facilitates the development of a highly robust product that is relevant and appropriate to the target audience (77).

2.6 Guidelines informed by patient preferences

Guidelines that are informed by and/or include patient preferences support development of the patient-clinician relationship and engagement of patients in their care (78,79). “Patient
preferences” has lacked a consistent definition and is often referred to as other terms. Brennan et al. defined patient preferences as “statements made by individuals regarding the relative desirability of a range of health experiences, treatment options, or health states (78).” Such guidelines support patient-clinician discussion about management options, risks and benefits, and outcomes (78,79), and may include point-of-care tools that help patient-clinician shared decision making (73,75). Patient preferences are fundamental components of evidence-base practice and are necessary for clinicians to involve patients in informed decision making (80,81). Guidelines are of interest to patients, with research showing that patients want to, and do, use guidelines (82–84). A Cochrane systematic review included two moderate quality trials showing that consumer-informed patient information material is more understandable, relevant, and increases patient knowledge (85). Sickle cell disease guidelines informed by preferences gathered from 107 patients/care partners, who then reviewed the guidelines, all said that the guidelines were understandable and intended to use the guidelines to discuss medical care with their clinicians (82). Another study looking at psychosis found that clinicians should listen to their patients’ preferences in order to choose more “user-friendly” treatment options that meet the needs of their patients (86). It also reported that taking patient preferences into consideration would improve patient outcomes and also raise adherence to treatment (86).

Guidelines that are informed by and/or include patient preferences support patient compliance with guideline recommendations (78,79). Guidelines that address patient preferences are more likely to be used because treatment recommendations are aligned with patients’ values and experiences (87–89). Incorporation of patient preferences in guidelines results in recommendations that are more patient-oriented because they were informed by, and
accommodate patient preferences (72,89). Additionally, patient preference data can also help developers understand why patients may refuse recommended care (90). Research also shows that guidelines tailored to patient preferences or guideline-prompted discussion about preferences improves guideline adherence by both patients and clinicians. Guideline-prompted elicitation of child and caregiver preferences resulted in higher asthma medication adherence one month after guideline implementation (91). Rathert et al. found that satisfaction was higher not only for patients but also for physicians and nurses as well (92). Research in general shows that patient engagement improves numerous patient outcomes such as satisfaction with care received, and health system outcomes such as cost-effective service delivery (92,93).

Research specifically shows that engaging patients and incorporating their preferences influences guideline processes and recommendations. A study by Armstrong et al. that compared guideline development with and without patient involvement found that involvement influenced the conduct of guideline development, scope, inclusion of patient-relevant topics, outcome selection, and planned approaches to recommendation development, implementation, and dissemination (69). Other studies comparing guideline questions or recommendations generated by patients and clinicians also found that patients articulated unique concerns related to lifestyle, psychosocial support, pain, quality of life, and renal disease outcomes (94), and broadened the scope of topics addressed in a fertility guideline (95).

Furthermore, even guidelines that do include patient preferences are not utilizing preferences in the dissemination and endorsement steps of guideline development (70). Dissemination and endorsement are key guideline development steps in order to distribute guidelines to the greater
patient population (70). An increased awareness for these guidelines and a need for patient
versions are critical in making guidelines usable for patients (70,96). Patient versions written
with patient preferences could allow patients to direct their own medical care (90). Additionally,
patient versions of the clinical practice guideline could further promote patient-physician
interaction and shared-decision making (97). Patients and clinicians often have difficulty using
guidelines for treatment-related risks and outcomes in part due to the fact that these guidelines
need to be tailored to their patient preferences (89,98–100). One of the most important findings
from Schipper et al. was that the participation of patients in the process of not only disseminating
the recommendations to other patients and patient organizations but also generating the actual
recommendation themselves was imperative (96). This was because of the discrepancies in
perspectives reported by professionals and patients (96). Clinical practice guideline
recommendations can only be determined applicable to a patient if information was obtained
from and provided by the patient (100).

2.7 Guidelines do not address patient preferences

Guidelines, however, often do not address patient preferences (38,70), with research showing
patients’ views are rarely taken into account (86). Studies that specifically evaluated whether
guideline developers and/or guidelines collect and use patient input when developing guidelines
has shown few had patient involvement (101–103). A 2008 survey of 31 international guideline
developers found that 58% included patients on guideline panels and 45% surveyed patients
regarding preferences (101). A Canadian systematic review that analysed 137 guidelines
published from 2008 to 2013 found that few described patient involvement in guideline
development or included preference discussion tools (102). An American study found that only 8% of 101 developer organizations required patient involvement on guideline panels, 13% asked patients to review draft guidelines, and 20% offered preference discussion tools in their guidelines (103). Only 27 out of 70 (39%) of osteoporosis clinical practice guidelines mentioned patient preferences, however, 19 out of those 27 guidelines mentioned the importance of patient preferences but did not support those statements with any references to a primary study or systematic review (81). Lugtenberg et al. found that the most frequently reported perceived barriers to guideline adherence were related to patient behaviour (30%) and patient preferences (23%) (5). This finding suggested that current guidelines do not adequately incorporate patient preferences, needs and abilities (5).

Even though many organizations recommend the inclusion of patients or patient advocates on clinical practice guideline development panels (72,76,77), guidelines often focus solely on physician perspectives (69,104). Guidelines have mostly focused on physicians often using that specific nomenclature over other more encompassing terms such as “clinician” even though they may be relevant to a wider range of healthcare professionals (104). This further perpetuates the idea that guidelines do not value the inclusion of patient preferences during the guideline development process. Most guideline development panels include physicians trained in specialties and subspecialties (105,106). They sometimes include other clinical experts, and experts in evidence synthesis and guideline development but they rarely include patient, family, caregiver or well public members (105,106). The lack of patient involvement in clinical practice guideline development diminishes the ability to realistically implement recommendations into practice.
2.8 Processes for addressing patient preferences

There is limited research on the methods used to capture patient preferences, and it is unclear which methods most efficiently and fully capture patient preferences in guidelines to support patient-clinician discussions about preferences, treatment decision-making and guideline use (87,88). The most commonly used approaches to identify preferences include: (1) involving patient representatives in guideline development groups, (2) consulting patients by survey, interview or focus group, or (3) synthesizing published research on patient preferences (69,87,91,92,106–124). Having patients/patient representatives on the guideline development panel in some or all of the development phases/steps as equal members allows patients to provide relevant information on their perspectives, experiences, values and preferences (108,124). Consulting patients and/or patient advocacy groups for either one time input or multi-round surveys, interviews, or focus groups to acquire patient preferences are sometimes preferred methods as it often represents a larger number of patients in the given population and allows them to build synergy (83,120). Preferences included through synthesizing published quality evidence, often in the form of a systematic review, can contribute to specific and multiple guideline development steps (112,125). Although these are the most common methods, it is important to note that other methods may/are utilized to acquire patient preferences to include in guideline development.

While some research as noted above describes different ways to identify patient preferences, less research has examined how to incorporate and report patient preferences in guidelines.
Armstrong et al. also proposed a framework (Table 1, page 22 to 25), of ways in which patient preferences could influence guideline development including: having patient nominated guideline topics, conducting and/or interpreting a systematic review to form conclusions, generating recommendations, and assisting with dissemination by endorsing guidelines, or developing patient summaries or preference discussion tools (121). The Armstrong et al. framework (121) mentioned no only ways preferences could influence guidelines, but also articulated why or for what purpose as well (See Table 1).

Armstrong et al. also interviewed patients involved in guideline development, which revealed the following challenges: difficulty understanding spoken language, use of medical terminology, physician resistance to patient participation, lack of content knowledge, group dynamics and insufficient time for discussion (120). Challenges in incorporating patient preferences in guidelines were also identified by Brouwers et al. and included time commitment, duration of the patient guideline development process, financial costs, a feeling of “tokenism” and reluctance to share personal experiences (123). A multi-method study that searched the literature and conducted qualitative interviews with physicians on patient preferences and shared-decision making identified similar challenges and barriers (126). The pressure of time and not having enough time to inform patients was reported (126). They also reported the difficulties in understanding the role and involvement patients wanted in decision making and also the lack of suitable information available specifically for supporting patient involvement (126). Finally, physicians report difficulties in integrating patient preferences as they were unreasonable or unrealistic (126). Given limited guidance and challenges experienced by both patients and
guideline developers, further knowledge about approaches used for identifying, incorporating and reporting patient preferences in guidelines is needed.

Table 1. Steps for continuous patient engagement in clinical practice guideline development

<table>
<thead>
<tr>
<th>Step in guideline process</th>
<th>Purpose of patient engagement</th>
<th>Methods of patient engagement</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Nominating guideline topics</td>
<td>Identify topics that are important to patients, caregivers, and the community&lt;br&gt;Propose topics to be investigated</td>
<td>Directly solicit topic nominations from public&lt;br&gt;Solicit topic nominations from patient advocacy groups&lt;br&gt;Review priorities published by patient advocacy groups&lt;br&gt;Review research on patients’ priorities and needs</td>
</tr>
<tr>
<td>2. Prioritizing guideline topic nominations</td>
<td>Solicit feedback on relevance and priority of topics&lt;br&gt;Discuss the urgency of addressing topics</td>
<td>Survey patient groups&lt;br&gt;Review research on patients’ priorities and needs&lt;br&gt;Engage patients on guideline committees determining priorities</td>
</tr>
<tr>
<td>3. Selecting guideline development group members</td>
<td>Help ensure that the Guideline Development Group (GDG) composition is both representative and trustworthy&lt;br&gt;Assess conflicts of interest of panel members from patient perspective</td>
<td>Review proposed panel members’ conflicts of interest&lt;br&gt;Approve proposed panel with ability to suggest changes&lt;br&gt;Directly engage patients, caregivers and advocates on selection of guideline development group members</td>
</tr>
<tr>
<td>4. Framing the question (including selection of comparators and outcomes)</td>
<td>Ascertain questions’ relevance and usefulness&lt;br&gt;Assess ‘real-world’ applicability&lt;br&gt;Identify outcomes of relevance to patients, caregivers, and the community&lt;br&gt;Incorporate other aspects of treatment</td>
<td>Perform focus groups on identified guideline topics&lt;br&gt;Review existing research on patients’ priorities and opinions&lt;br&gt;Solicit public comment on guideline topics prior to formalization of questions&lt;br&gt;Ask stakeholders to suggest materials about patient preferences that are not formally published (‘grey literature’)&lt;br&gt;Survey patients to rate importance of proposed outcomes&lt;br&gt;Post draft research plan for public comment/review&lt;br&gt;Directly engage patients, caregivers and advocates on GDGs</td>
</tr>
</tbody>
</table>
5. Creating analytic framework and research plan

- Help refine or expand scope of topic
- Identify potential harms associated with the questions posed
- Provide a ‘reality check’
- Verify logic of analytic framework
- Supplement with additional factors not documented in the literature
- Discuss proxies for a specific concepts (e.g. whether test scores and school performance are interchangeable)
- Suggest additional search terms
- Inquire about potential confounding factors
- Identify particular populations of interest and/or important multimorbidity to consider in search

6. Developing systematic review and forming conclusions

- Assist with critical appraisal of studies and evidence synthesis
- Assess believability of results
- Suggest alternative interpretations of evidence

7. Developing recommendations

- Assist in translating evidence-based conclusions into meaningful, clear, and respectful recommendations
- Assist in ensuring that recommendations foster partnership between physicians, patients and families
- Describe variability in patient preferences
- Help make recommendations easy to understand
- Provide input when there are gaps in the evidence
- Indicate which recommendations are counterintuitive (e.g. so that additional explanation can be provided)

8. Disseminating and implementing recommendations

- Endorse guidelines from patient perspective (either individually or in representation of patient)

Review existing research on patients’ priorities and opinions
Survey patients to rate importance of elements of proposed framework
Post draft research plan for public comment/review
Perform focus groups
Directly engage patients, caregivers and advocates on GDGs

Solicit feedback on draft evidence review from guideline development group lay participants even if they did not participate in analysis of evidence
Post draft evidence review for public comment
Directly engage patients, caregivers, and advocates on GDGs

Review existing research on patients’ preferences
Post draft recommendation statements for public comment
Perform focus groups
Directly engage patients, caregivers and advocates on GDGs

Consult patients, caregivers, and advocacy groups regarding barriers to dissemination and implementation
Armstrong et al. framework (121).

### 2.9 Background summary

The intended development and use of guidelines are to improve patient care and outcomes but patients and clinicians find guidelines are difficult to use and therefore guidelines are being underused. Research shows that guidelines that address patient preferences are more likely to be used; however, many guidelines do not address patient preferences, and it is unknown which methods most efficiently and fully capture patient preferences in guidelines. Long-term, the development of preference-relevant guidelines could improve guideline use, leading to improved
health service delivery, patient experiences and health among Canadians. Knowledge on current practices and associated barriers and facilitators for identifying, incorporating and reporting patient preferences in guidelines is needed.

**Chapter 3 Objectives**

**3.0 Objectives**

Guidelines that address patient preferences are more likely to be used; however, most guidelines are not informed by patient preferences. Limited research suggests that guideline developers and patient participants experience challenges in generating patient-informed guidelines, and limited guidance is available on how to do so. There is little up-to-date guidance and resources based on empirical evidence that describes current practices for identifying, incorporating and reporting patient preferences in clinical practice guideline development. Further research is needed to understand approaches used to identify, incorporate and report patient preferences in guidelines. Such research would help developers generate guidelines that are more likely to be used, ultimately leading to improved care delivery and patient outcomes. Knowledge about current practices in identifying, incorporating and reporting patient preferences can be gathered from published research, and from developers with experience in developing patient-preference oriented guidelines.

The overall aim of this research study was to explore approaches used for identifying, incorporating and reporting patient preferences in guidelines. This knowledge may lead to improved guideline development and improved guideline use. Barriers, facilitators and impact on
guideline development processes and outputs (i.e. guidelines, other products) were also explored.

The specific objectives of this study were to:

1. Synthesize published research to reveal approaches used to identify, incorporate and report patient preferences in guidelines
2. Explore current practice used and/or recommended by guideline developers (clinicians, patients, guideline managers) for identifying, incorporating, and reporting patient preferences in guidelines

Chapter 4 Methods

4.0 Methods

This research on patient preferences and the development of clinical practice guidelines was undertaken by Claire Kim (CK), a graduate student at the Institute of Health Policy, Management, and Evaluation (IHPME), guided by Anna R Gagliardi (ARG), a professor at the University of Toronto and senior scientist at Toronto General Hospital Research Institute (supervisor) and by Whitney B Berta (WBB), a professor at the University of Toronto (committee member). Melissa J Armstrong (MJA), a neurologist at the University of Florida, was a collaborator who provided feedback on the first objective.

4.1 Research design

This study included a scoping review of studies that examined how patient preferences are identified, incorporated and/or reported in guidelines. Simultaneously, qualitative interviews
were conducted with guideline developers (clinicians, patients, managers) on approaches used and/or recommendations to identify, incorporate, and report patient preferences during guideline development. The definition of preferences used for the scoping review and the qualitative interviews went beyond the formal definition and included any definition or synonymous term employed by researchers or developers including but not limited to: needs, values, views, opinions and perspectives. Findings from both study components were compared and compiled to generate insight on the processes, facilitators, barriers, and impact on guideline development processes and outputs (shorter-term outcome) and on guideline implementation and use (longer-term outcome). These findings were mapped against a framework for incorporating patient preferences in clinical practice guideline development.

4.2 Conceptual framework of patient preferences in guideline development

Given that the aim of this thesis was to generate insight on current practices, rather than employing or generating theory, the patient engagement in guideline development (PEGD) framework developed by Armstrong et al. (Table 1, p. 22-25) was used (121). PEGD identifies where in the guideline process patient preferences could inform the guideline development process but does not specify practices on how to identify, incorporate and report these preferences in each guideline step (121). The scoping review and guideline developer interviews identified existing research and currently used and/or recommended practices to identify, incorporate and report patient preferences in guidelines to reveal current practice. By exploring how to identify, incorporate and report patient preferences in published research and from guideline developers, this research confirmed and extended the framework.
4.3 Scoping review

4.3.1 Approach

A scoping review was conducted according to the methods of those who originated scoping reviews (127) and who refined methods for scoping reviews (128,129). It comprised of five steps: scoping, searching, screening, data extraction and data analysis (7,41,60,63). Similar in rigour to a systematic review, the purpose of a scoping review is to examine the nature of research activity for a particular topic (41). Such reviews do not synthesize outcomes reported across studies or assess their methodological quality, as is customary of systematic reviews, nor do they assume a theoretical stance. However, they can identify if sufficient research is available to conduct a future systematic review and/or identify knowledge gaps that warrant future research. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) criteria guided reporting of the methods and findings (98). Data is publicly available; thus institutional review board approval was not necessary. A protocol for this review was not registered.

The scoping review was exploratory as no other research exists that has previously examined revealing approaches to identify, incorporate and report patient preferences in clinical practice guidelines. The scoping review was conducted for this thesis to gain familiarity with the patient preferences literature, and to identify any gaps in the current research that could be explored in the qualitative interviews.
4.3.2 Eligibility

In defining the research questions for the scoping review, a set of eligibility criteria was created by CK and ARG to guide the search for evidence. The eligibility criteria were used for the initial search and screen, and were later updated and sent to WB and MJA. Feedback was received on the initial eligibility criteria from WB and MJA on November 28, 2018 and incorporated into the final eligibility criteria where an updated search and screen was conducted.

Eligible studies described research of any design on how to identify, incorporate and report patient preferences in guidelines that are relevant to patients and/or clinicians for any condition, health services, or setting of care. Populations refers to guideline developers (clinicians, patients, managers). More specifically, this encompasses: patients, including family, caregivers/care partners, patient advocates, or others with lived experience of the guideline-specific condition or experience with the healthcare system. Additionally, guideline managers, clinicians involved in developed guidelines or healthcare professionals who use guidelines were also included in the population. The intervention of interest referred to processes for: (1) identifying/gathering patient preferences; (2) steps in the guideline development process during which patient preferences would be considered or that could be influenced by patient preferences; and (3) how to report preferences in guidelines (i.e., embed in the recommendations versus explicitly states); these steps are tabulated in Table 2 (page 34). The comparisons criteria included studies that examined single or multiple processes, or compared processes. Outcomes included but were not limited to: identifying stakeholder (i.e., patients, developers, healthcare professionals) views, awareness or
knowledge about patient preferences or whether/how they should be considered and in what guideline development steps, explored, observed or described processes for identifying, incorporating or reporting preferences, examined facilitators or barriers of identifying, incorporating or reporting patient preferences in guidelines, or assessed the impact of patient preferences on processes used to identify, incorporate or report preferences; on guidelines and guideline-related products; on guideline use; or on patient, professional, organizational or system-level impact of guideline use. Study design included English language studies of any design that pertained to identifying, incorporating and/or reporting approaches to addressing patient preferences in guidelines. These included qualitative (i.e., interviews, focus groups, qualitative case studies, content analysis), quantitative (i.e., questionnaires, time series, before/after studies, prospective or retrospective cohort studies, case control studies), multiple or mixed methods or program evaluation studies. Studies were eligible if they were published from 2010 to present, as this date corresponds to the release of the Guidelines International Network (G-I-N) PUBLIC Toolkit, a compilation of evidence and expert opinion to that date on how to involved patients in guideline development. Once the Toolkit was released, guideline developers became more aware of the need to engage patient preferences and therefore had the knowledge that they needed to do so.

Studies were not eligible if they examined the effectiveness of clinical interventions (tests, procedures, treatment), did not collect or consider patient preferences, did not pertain to guideline use or development, did not incorporate patient preferences into guideline development, or are publications in the form of editorials, letters, commentaries, protocols, case studies, meeting abstracts or proceedings. Systematic reviews were not eligible but references
were screened to identify eligible primary studies. Guidelines or literature or systematic reviews used to develop guidelines were not eligible as these do not necessarily reflect practices actually being used to identify, incorporate and report preferences. The G-I-N PUBLIC Toolkit and guideline manuals, all of which are largely based on expert opinion, rather than primary evidence, were also not included.

4.3.3 Scoping

The scoping process involved becoming familiar with the literature on this topic. A preliminary search was conducted in MEDLINE using Medical Subject Headings including but not limited to [patient participation] and [guideline]. CK and ARG screened titles and abstracts of the preliminary search results, which were used to plan a more comprehensive search strategy with the help of a research librarian and to generate eligibility criteria based on the PICO (population, intervention, comparisons, outcomes) framework. CK and ARG reviewed eligibility criteria and created a screening tool that MJA and WBB reviewed and provided feedback. CK and ARG met to incorporate all feedback and finalize screening tool (Appendix 1).

4.3.4 Searching

The search strategy was developed by CK and ARG in conjunction with a medical librarian and complied with the Peer Review of Electronic Search Strategy reporting guidelines (130) (Appendix 2). A comprehensive literature search of MEDLINE, EMBASE, CINAHL, Scopus, OpenGrey and GreyLit was searched. MEDLINE, EMBASE, OpenGrey and GreyLit were
searched on February 15, 2018 from inception to that date. Scopus was searched on May 4, 2018 from inception that date and CINAHL was search on May 23, 2018 from inception to that date. An updated search was performed on September 20, 2018 for all six databases and again on January 2, 2019 following incorporation of feedback/update of the eligibility criteria. The references of all eligible studies were scanned to identify additional eligible articles.

4.3.5 Screening

To prepare for screening, CK and ARG independently screened titles and abstract for the first 25 search results and discussed any discrepancies. CK and another reviewer, Yalinie Kulandaivelu (YK), then independently screened the titles and abstracts of the first 25 search results. They proceeded to compare and discuss any discrepancies on how to interpret and apply the eligibility criteria. Thereafter, CK and YK screened all remaining titles and abstracts according to initial PICO-based eligibility criteria. Discrepancies were resolved by ARG. As titles and abstracts were screened, preliminary exclusion criteria were further elaborated. All items selected by at least one reviewer were retrieved. Full-text items were screened concurrent with data extraction. Following the updated eligibility criteria and updated search, all 1,965 searches were re-screened using the new eligibility criteria by CK.

4.3.6 Data collection

Data were collected in a standardized template form in Excel (Appendix 3). The data extraction form was developed by CK and ARG. Data extracted from each article included: study
characteristics consisting of author, publication year, country, study objective, research design, participants, patient preference results separated into identify, incorporate and report, and findings. A separate data extraction form was then created to extract barriers and facilitators (Appendix 3). To pilot data extraction, CK and ARG independently extracted data from the same two articles, and compared and discussed findings to refine the data extraction form. From there, two more iterations of extracting the same four articles, and comparing and discussing findings occurred. CK extracted data from all articles, which were independently checked by ARG.

**4.3.7 Data analysis**

Data synthesis was undertaken by CK and synthesis results were shared and discussed with ARG concurrently to ensure the validity and consistency of the interpretations that were made. Study characteristics (date published, country, research design), studies published per year (to assess if research volume is increasing over time), guideline topics, processes used to identify, collect and report patient preferences (based on the Armstrong et al. framework (121)), and reported impacts on guideline development processes and outputs, and on guideline implementation and use were summarized. Barriers and facilitators related to patient preferences and guideline development were also summarized in studies that reported it. Processes were mapped to the Armstrong et al. framework to confirm existing components; additional unique processes identified in included studies were added to the framework (Table 2). Details about processes, facilitators, barriers, and impacts were discussed narratively. Methodological quality of included studies was not assessed as this is not customary for a scoping review (127–129).
Table 2. Possible processes for identifying and incorporating patient preferences

Review of the background literature identified possible processes (1) and the development steps refer to the Armstrong et al. framework (2). Options included, but were not limited to:

<table>
<thead>
<tr>
<th>(1) Identifying/gathering patient preferences</th>
<th>(2) Steps in guideline development process during which patient preferences would be considered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guideline writing panel members</td>
<td>Nominate or prioritize guideline topics</td>
</tr>
<tr>
<td>Summary/systematic review of published literature</td>
<td>Select panel members (clinicians or patients)</td>
</tr>
<tr>
<td>Questionnaire</td>
<td>Establish or frame guideline questions</td>
</tr>
<tr>
<td>Interviews</td>
<td>Create analytic framework or research plan</td>
</tr>
<tr>
<td>Focus groups</td>
<td>Specify treatment or outcome preferences</td>
</tr>
<tr>
<td>Town hall</td>
<td>Specify risk tolerance preferences</td>
</tr>
<tr>
<td>Delphi technique / modified Delphi technique</td>
<td>Conduct/interpret systematic review</td>
</tr>
<tr>
<td>Public comment (online opportunity for comment on draft products for identifying patient preferences tables)</td>
<td>Develop preference data collection tools</td>
</tr>
<tr>
<td>Other consensus technique</td>
<td>Assist with collection or analysis of preferences</td>
</tr>
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<td></td>
<td>Interpret preference data</td>
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<td></td>
<td>Prioritize preferences</td>
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<tr>
<td></td>
<td>Generate recommendations</td>
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<tr>
<td></td>
<td>Generate preferences content to include in guideline</td>
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<td></td>
<td>Endorse/approve guideline</td>
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<td></td>
<td>Assist with dissemination</td>
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<td></td>
<td>Develop summaries/preference discussion tools</td>
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<tr>
<td></td>
<td>Evaluate processes</td>
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</table>

4.4 Interviews

4.4.1 Approach

Qualitative interviews were conducted with developers about the processes, facilitators, barriers and impacts of different approaches for identifying, incorporating and reporting preferences in guidelines. Interviews were needed because there was no guarantee the scoping review results
would afford the needed insights on identifying, incorporating and reporting patient preferences in guidelines and it was likely that qualitative interviews would reveal much richer information than the scoping review. National and international developers, including the individuals most responsible for patient preferences or guideline development at guideline development agencies, plus clinicians and patients involved in guideline development, were invited to participate in the study. An exploratory research design involving qualitative interviews was used. Qualitative research focuses on events and on the outcomes of these events from the perspectives of the individuals involved (131). This method was suitable for this study to explore what methods guideline developers are using to incorporate patient preferences within guidelines, and their experiences with these methods. More specifically, a qualitative descriptive research approach was used (132,133). This approach comprehensively summarizes in lay nomenclature specific events, experiences and the understanding or individuals or groups of individuals (132,133). In qualitative descriptive studies, data collection attempts to discover the “who, what and where of events” or experiences (134). This approach is well suited to answer questions about human behavior, perspectives and barriers (134). Using qualitative description allowed connections to be made between existing knowledge in the field and clinical experiences of the research group (135). A qualitative descriptive approach is not based on and does not generate theory. However, once qualitative interview data was analysed, the findings were further analysed by mapping them to the Armstrong et al. framework (121). This confirmed existing processes, and added additional processes. Reporting of methods and results followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines to enhance rigour (133,136).
Ethics approval was granted by both the University Health Network on July 24, 2018 and University of Toronto on October 4, 2018 prior to study recruitment. Participants provided written consent prior to being interviewed. There was no prior relationship between the participants and CK.

4.4.2 Sampling/recruitment

Participants were recruited through the Guidelines International Network (G-I-N). G-I-N is a global network of international experts founded in 2002 that supports and encourages intercollaboration on the development and implementation of clinical practice guidelines (137). G-I-N is a knowledge network that is open to individuals and organizations for those interested in work or research related to the development, implementation and use of clinical practice guidelines. G-I-N comprises 103 organizational and 156 individual members from 47 countries. Per their platform, G-I-N “seeks to improve the quality of healthcare by promoting systematic development of clinical practice guidelines and their application into practice by supporting international collaboration” (137). The organization had three objectives listed on their platform:

1. To provide a network and partnerships for guideline organizations, implementers, end users, researchers, students and other stakeholders

2. To assist members of the network in reducing duplication of efforts to improve efficiency and effectiveness of evidence based guideline development, adaptation, dissemination and implementation
3. To promote best clinical practice through the development of opportunities for learning and capacity building and the establishment of high quality standard of guideline development, adaptation, dissemination, and implementation (137).

G-I-N has set up groups to carry out a variety of activities. One of these is the G-I-N Public Working Group who developed the G-I-N PUBLIC Toolkit: Patient and Public Involvement in Guidelines. Originally released and presented in 2010 at the ninth G-I-N conference in Berlin, the Toolkit’s ten chapters have since been updated in 2012 and again in 2015:

1. How to conduct public and targeted consultation (2012)
2. How to include qualitative research on patient views in guidelines (2015)
3. How to recruit and support patients and the public in guideline development (2012)
4. How guidelines can involve people facing barriers to participation (2015)
5. How the chair can facilitate patient and public involvement (2012)
8. Involving patients in guideline dissemination (2012)
9. How guidelines can support patient involvement in the clinic (2012)

(76).

Originally, seventeen guideline developers who involve patients and/or incorporate patient preferences in guidelines from Canada and elsewhere (Australia, United States, Germany,
Ireland, Scotland, and England) committed to participate in this study. Additional developer organizations were recruited through the G-I-N and the G-I-N Secretariat agreed to circulate a recruitment message by email to its members. Organizations that developed at least one guideline on any clinical topic in the past five years were eligible. First, the individuals most responsible for patient involvement and/or guideline development from each organization were interviewed. Purposive sampling was used as the intent was to interview developers from different countries that represented different clinical topics. By way of snowball sampling and the known sponsor approach, they referred us to clinicians and patients involved in developing a recent guideline. Recruitment packages, which included a cover letter introducing the study as well as the consent form were e-mailed to individuals (Appendix 5 and 6). All participants provided informed consent prior to being interviewed. Due to the national and international nature of the study, recruitment packages were sent via e-mail for convenience and feasibility. The first round of recruitment e-mails were sent out October 11, 2018. The goal for recruitment was three people (1 representative, 1 clinician, 1 patient) from 15 guideline developer organizations for a total of 45 participants. This represented an estimate; in qualitative research, sampling of participants proceeds to thematic saturation concurrent with data collection and analysis. After the first round of recruitment e-mails, reminders were sent to individuals that had not responded two weeks later and again four weeks after initial the initial e-mail. Additional interviews were conducted to achieve purposive sampling according to divergent characteristics as thematic saturation was already achieved through independent analysis by CK and discussion among CK and ARG. Therefore, a round of tailored recruitment e-mails were sent out on November 21, 2018. Thematic saturation was an iterative process as sampling was concurrent with data collection and analysis. Saturation was assessed from the data being provided by the
guideline developers (patients, clinicians, managers) meaning that themes that emerged from interviews from each type of developer were compared to assess if interviews were contributing any more unique themes.

4.4.3 Data collection

Interviews were conducted by telephone via Momentum conferencing using toll-free numbers. Qualitative telephone data have been judged to be rich, vivid, detailed, and of high quality (138,139). Due to the nature of a multi-organization, nationwide and international study, cost, time and distance implications exist. Our team was aware that in-person interviews could be used for qualitative interviews as it allows researchers to observe the participant in-person, as the interview could be richer in terms of nuances and depth, which may otherwise go unnoticed (140). However, in-person interviews are not always feasible, especially when participants are geographically dispersed as was the case for this research study that included participants both nationally and internationally. A telephone interview is a versatile data collection tool that adapts well to the constraints of the study. Respondents have been described to be relaxed on the telephone, to be willing to talk freely, and to disclose intimate information (138). When compared to in-person interviews, using the telephone has advantages including: decreased cost, increased access to geographically disparate subjects, decreased space requirements and the ability to take notes unobtrusively (138). Telephone interviews also allow participants to maintain more anonymity and privacy, decrease social pressure, and increase rapport.
Before interviews were conducted, consensus was reached among CK and ARG over specific phrasing of questions and overall flow of the interview guide (Appendix 7 and 8). Questions were derived based on the Armstrong et al. Framework (121) and the current evidence available on patient preferences and clinical guideline development. The framework informed questions pertaining to the development steps/process and if patient preferences impacted or influenced any of those steps. Following the first two interviews the wording and flow of questions was further refined in order to optimize the structure of the interview but general domains were kept consistent. This process was completed again after the first 13 interviews to clarify wording and structure of questions. The interview guide introduced the study and informed developers that the purpose of the interview was to better understand how patient preferences were included in guideline development. Then the following questions were asked:

1. Please describe the way that you/patients were involved in guideline development.
2. What factors challenged your/patient involvement in guideline development, and how?
3. Please describe the impact of patient involvement on guideline development and recommendations.
4. How could patient preferences be better identified, incorporated and reported in guidelines?

(Appendix 7 and 8)

While interview questions did not directly reflect the PEGD framework domains at the outset of the interview, participants were asked open-ended, non-leading questions in hopes that they would describe their practice authentically, rather than providing responses that are perceived as desirable. Question prompts were built on factors identified through previous research such as...
approaches used to identify patient preferences, as well as those identified prospectively with successive interviews.

One-time, semi-structured telephone interviews were conducted. The first interview was conducted by ARG and observed by CK, and the second interview was conducted by CK and observed by ARG. Proceeding each interview, ARG and CK met to discuss what went well and areas of improvement. All interviews after that were conducted solely by CK. Interviews took place between October 31, 2018 and February 28, 2019. All interviews were audio recorded through Momentum conferencing with the participants’ permission and transcribed verbatim by a trained transcriptionist who was independent from the research team for data analysis. CK anonymized all transcriptions according to the Research Ethics Board requirements. To complement the audio recorded interviews CK maintained a folder of ‘notes’ during the interviews. This provided context to the interpretation of the audio recorded data. When necessary, CK also reviewed transcripts to verify interviews that had suboptimal or unclear audio.

4.4.4 Data analysis

Qualitative data analysis is the process that translates the data that has been collected into some form of explanation, understanding and interpretation of the people and situations being investigated. The strategy of content analysis is typically used in qualitative description. Content analysis aims to present the key elements of participants’ accounts, which are central to gain understanding on guideline developers. The basis of qualitative analysis, particularly of
Interview data, is simplifying participants’ accounts by looking for patterns or themes that can summarize the range of topics, views, experiences or beliefs voiced by the participants (142). Data were analyzed through, (a) familiarization with the data, (b) sorting through data to identify common patterns, themes, sequences and important features, (c) gradually deciding on codes consistent with the data from notes and interviews, and (d) examining these generalizations with reference to existing knowledge (142–146).

Interviews were analyzed to search for themes and confirm or reject orienting propositions (explanatory), identify influencing factors (exploratory) and describe processes (descriptive) related to addressing patient preferences. Unique themes were identified using a constant comparison method (147). The qualitative data were coded and analyzed. Quotes were first organized by content area/interview question and then overarching themes were developed to organize similar quotes. All transcripts were analyzed independently by CK and reviewed with ARG to confirm, expand or merge thematic codes. Quotes were organized by theme, subthemes and type of developer per each interview question to explore common and differing experiences and practices among developers. Content areas included: preferred approach to identify common and differing views, influencing factors and suggestions to optimize the reporting of preferences, patient-clinician discussion of individual patient preferences at the point-of-care, and guideline use. CK and ARG reviewed the coded data separately for two interviews and then compared their results. Allowing for multiple individuals to read and interpret the transcripts from the interviews is a key feature of content analysis, and aids in the depth and triangulation of the study.
4.4.4.1 Compared and compiled analysis

Findings from the scoping review and from the interviews were compared and compiled by mapping the collected data across the Armstrong et al. framework (121) to confirm existing processes and potentially add unique processes. Themes and exemplar quotes were mapped and reported by the domains of the framework; doing so helped to clarify the meaning of the findings and suggest ways to address patient preferences during guideline development. Methods for reporting were compared and compiled to explore how preferences were being reported in guidelines and recommendations. Barriers and facilitators were then separately analyzed to compare challenges and enablers of patient preferences in the guideline development process.

4.4.5 Reflexivity and rigour

Qualitative research is generally distinguished by the simultaneous collection and analysis of data where both mutually shape each other (148). Qualitative content analysis is similarly reflexive and interactive as continuous modifications will be made as new data and insights are introduced (134). Being reflexive requires researchers to reflect and articulate their position and subjectivities (i.e. worldview, perspectives and biases), so readers can better understand the analytical process (141).

Addressing elements of transparency, validity, reliability, comparison and reflexivity will help produce credible, rigorous and robust analyses (142,148). The credibility of the study is dependent on the researcher’s ability to capture an insider (emic) perspective and to represent
that perspective accurately. This study incorporated several strategies to enhance rigor: flexible yet systematic sampling, ensuring participants have freedom to speak during interviews, ensuring accurate transcription and data-driven coding, constant data comparison, being inclusive of the deviant case and ongoing attention to context (148,149).

Chapter 5 Results

5.0 Results

The scoping review explored how patient preferences were included in guideline development. This section details and presents the findings from the review and describes the thematic findings from the qualitative semi-structure interviews.

5.1 Scoping review

Eligible studies described research of any design on how to identify, incorporate and report patient preferences in guidelines that are relevant to patients and/or clinicians for any condition, health service, or setting of care. The outcomes from 21 eligible studies are summarized in Appendix 2. These tables describe study characteristics, research design, participants, patient preference results separated into identify, incorporate and report, and findings. These categories of extracted data can be found in Appendix 2. Raw data extracted from each article are available in Appendix 9.
5.1.1 Search results

A total of 1,965 studies were identified by searches, of which 1,888 were unique items, and 1,669 were excluded based on screening of titles and abstracts. MEDLINE yielded 761, EMBASE yielded 574, Scopus yielded 417, CINAHL yielded 212, GreyLit yielded one and OpenGrey did not yield any studies. Among 278 full-text articles that were screened, 257 were excluded because they: were an ineligible publication type (n=117), did not pertain to developing guidelines (n=84), did not collect or consider patient preferences (n=36), were not in English (n=12), were not the target population (n=5), or were a duplicate publication (n=3). No additional eligible primary studies were identified from references of systematic reviews. A total of 21 studies were eligible for review (Figure 1). Data extracted from included studies are available in Appendix 9 (69,81,92,96,107,108,112–114,117,118,146–154,155).
5.1.2 Study characteristics

Studies were published between 2011 and 2018 (Figure 2). Studies were conducted in The Netherlands (n=6), United States (n=5), Canada (n=5), Spain (n=2), England (n=1), Finland (n=1) and Australia (n=1). All 21 studies reported approaches used for identifying patient preferences. Few studies (7, 33.3%) reported how patient preferences were incorporated within guideline development and even fewer (3, 14.3%) included if and how patient preferences were reported in the guideline. With respect to research design, the most common were qualitative interviews or focus groups (9, 42.9%), followed by multiple methods studies (5, 23.8%), comparative, Delphi and case studies (each having 2, 9.5%) and one descriptive study (4.8%).
Figure 2. Number of studies published per year

5.1.3 Results

Results were reported under the three main headings of: identifying patient preferences, incorporating patient preferences and reporting patient preferences.

5.1.3.1 Identifying patient preferences

Identifying patient preferences referred to approaches and processes used in the guideline development process to identify patient preferences. This included, but was not limited to,
having a patient representative as a panel member, conducting focus groups, interviews, surveys, reviews of the literature, a Delphi or any other unique approach. Details such as the venue, format, content, frequency and discussion were included. The scoping review found six (28.6%) studies that used qualitative interviews as their approach to identifying patient preferences (97,114,149,153–155). Six more studies (28.6%) used a multiple methods approach (84,107,118,119,148,152). Both approaches of having a patient representative as a part of the guideline development panel (69,113,150) and conducting qualitative focus groups (115,154,159) each had three studies (14.3%). Two studies (9.5%) used a Delphi process (89,109) and one (4.8%) study had a separate patient panel (153).

5.1.3.2 Incorporating patient preferences

Incorporating patient preferences referred to the impact or influence of patient preferences on the guideline development process, the recommendations and/or outputs and products produced. Table 3 shows results from the studies included in the scoping review mapped against each of the 10 steps of the Armstrong et al. PEGD framework.

<table>
<thead>
<tr>
<th>#</th>
<th>Step</th>
<th>Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Nominating guideline topics</td>
<td>(113,115,118,159)</td>
</tr>
<tr>
<td>2</td>
<td>Prioritizing guideline topic nominations</td>
<td>(113,159)</td>
</tr>
<tr>
<td>3</td>
<td>Selecting guideline development group members</td>
<td>---</td>
</tr>
<tr>
<td>4</td>
<td>Framing the question (including selection of comparators and outcomes)</td>
<td>(118,119,159)</td>
</tr>
<tr>
<td>5</td>
<td>Creating analytic framework and research plan</td>
<td>---</td>
</tr>
</tbody>
</table>
6. Developing systematic review and forming conclusions
7. Developing recommendations
8. Disseminating and implementing recommendations
9. Updating
10. Evaluating methods and impact of engagement

Of the seven (33.3%) studies that reported incorporating patient preferences, none reported incorporating preferences in Steps 3: selecting guideline development group members, 5: creating analytic framework and research plan, 9: updating, and 10: evaluating methods and impact of engagement. Among seven studies that described incorporating patient preferences, five (23.8%) incorporated Step 7: developing recommendations. This was followed by Step 4: framing the questions (including selection of comparators and outcomes) with three (14.3%) studies. Both Step 2: prioritizing guideline topic nominations and step eight: disseminating and implementing recommendations were reported in two (9.5%) studies. One (4.8%) study reported incorporating patient preferences in Step 6: developing systematic review and forming conclusions.

Tong et al. conducted a descriptive study that addressed patient preferences in a guideline for early stage chronic kidney disease (159). Participants formed small focus groups and facilitated their own discussions that were recorded (159). This study completed the greatest number of steps (5/10) and incorporated patient preferences in the nomination and prioritization of guideline topics by including a topic addressing the spectrum and progressions of chronic kidney disease and the symptoms patients may experience in its earlier stages (159). Not only did patients create the scope and content of topics, they were also able to endorse and prioritize it.
Additionally, patients were able to identify and select outcomes of relevance, draft and influence guideline recommendations and suggestions for clinical care and develop a lay version of the guideline as well (159). A case study by Musila et al. that included three patient representatives on the guideline development panel for patients with osteoarthritis completed three out of 10 steps. Patients nominated and prioritized guideline topics and identified four additional topics as well (113). During the guideline development process patients modified and clarified a number of recommendations (113). O’Brien et al. reported incorporating patient preferences from qualitative interviews and focus groups into the recommendations for the clinical practice guidelines (114). In another qualitative focus group study, patient preferences for the clinical practice guideline contributed to nominating and formulating topics (115). In a multiple methods approach conducted by Serrano-Aguilar et al. completed three steps by carrying out a systematic review and a Delphi process to gain patient preferences, they reported incorporating preferences in nominating relevant topics which led to the identification of key questions (118). Van Der Ham et al. conducted interviews with patients with severe mental illness and completed three steps (119). Preferences formulated additional questions which subsequently generated recommendations and summary reports as well (119). Finally, Zhang et al. conducted a multiple methods approach by conducting a systematic review and consulting patient representatives and clinical experts to collect patient preferences which were used to significantly formulate recommendations (84).

5.1.3.3 Reporting patient preferences
Reporting patient preferences referred to how the preferences were actually reported in the guideline and whether they were explicit or embedded. Very few (3, 14.3%) studies (114,115,118) actually reported this information. Two (9.5%) of the studies stated that the patient preferences would be explicitly reported (114,118). In the qualitative study looking at HIV rehabilitation, it was noted that after each recommendation, it would be reported with explicit supporting quotations of where that patient preferences impacted the recommendations themselves (114). The other study was a multiple methods study that conducted a systematic review of the literature and a Delphi consultation (118). It noted that all key questions identified by patients included in the clinical practice guideline were explicitly reported in a separate table with patient preferences (118). The one study that reported patient preferences and experiences would be embedded in the final clinical guideline conducted qualitative focus groups with gynaecological patients (115).

5.1.3.4 Barriers and facilitators

The processes to address patient preferences in guidelines are not without barriers and challenges. Out of 21 studies, eight (38.1%) specifically reported barriers or challenges for generating patient-informed guidelines. The studies found the following barriers: difficulty in capturing complex issues, identifying the right or knowledgeable patient, meaningfully involving patients, time commitment, medical terminology, lack of consistent search terms and systemic/technical barriers.
Of the eight studies that reported barriers, two (25%) reported that it was hard to capture complex issues. Hämeen-Anttila et al. reported the difficulty in finding patients capable of representing the patient population, as opposed to just one experience or view (154). Similarly, van der Ham et al. reported that it was difficult to have a diverse representation of the patient population in the guideline development process (119). Another two studies found that the lack of consistent search terms was a barrier to including patient preferences. Utens et al. reported that searching, retrieving and synthesizing literature on patient preferences were difficult and found the lack of consistency used to define patient preferences made the evidence even more difficult to work with (156). Similarly, Zhang et al. found that relevant studies were difficult to identify due to the lack of standardized keywords (84). Den Breejen et al. reported barriers in identifying knowledgeable patients (158). Participants had difficulty understanding the purpose of the tool and had a hard time understanding instructions, making the tool hard to use for obtaining recommendations for the clinical practice guideline (158). Similarly, Bennett et al. also reported barriers in being able to communicate technical research methods as patient and caregiver participants lacked that knowledge (107).

Tong et al. found both time commitment and medical terminology to be notable barriers as some participants dropped out last minute making it difficult to achieve an adequate attendance rate and medical jargon was found to be a challenge amongst participants as well (159). Meaningfully involving patients was a reported barrier by Serrano-Aguilar et al. It was difficult to have the patient voice heard/have them speak up when facing a team of professionals and being easily overruled by professionals, causing the collaboration to degenerate into tokenism (118). Finally, Bennett et al. reported systemic/technical barriers, specifically the difficulties with adding
patient and caregiver stakeholders to the institutional review board protocol and involving them in larger conference calls (107). It is important to note that only one (12.5%) of the eight studies reported facilitators as well. Bennett et al. reported that training patient participants on research methods was helpful in facilitating participation and for in-person and virtual meetings (107).

5.1.4 Overall findings

This scoping review demonstrates that little research has examined approaches used to identify, incorporate and report patient preferences in guidelines. This scoping review found that studies involved patients in guideline development groups, consulted patients by survey, performed interviews or focus groups, or synthesized published research on patient preferences. The majority of studies used a qualitative approach in order to identify patient preferences. Fewer studies incorporated preferences. Of the studies that did, the following development steps were influence or impacted by patient preferences: nominating guideline topics, prioritizing guideline nominations, framing the questions, developing a systematic review and forming conclusions, developing recommendations, disseminating and implementing recommendations. Only a couple studies noted reporting patient preferences either explicitly or embedded within the guideline and recommendations. Overall, the evidence available poorly reported findings for patient preferences in guideline development.

5.2 Qualitative semi-structured interviews
This section presents thematic results from 50 semi-structured interviews (Appendix 9). The interviews were conducted by telephone using a teleconferencing service with guideline developers (clinicians, patients, managers). Participants were asked to describe the way patients were involved in guideline development, what factors challenged patient involvement in guideline development and how, the impact of patient involvement on guideline development and recommendations, and how patient preference could be better identified, incorporated and reported in guidelines. The research question, main themes of the interviews and subthemes from the codebook are discussed, defined and illustrated with exemplar quotes.

5.2.1 Participant recruitment

In total, 56 individuals from seven countries consented to participate in the interviews. Of those, 50 individuals were deemed eligible and completed interviews. Six of the Participants were deemed ineligible as they: did not meet eligibility criteria (4), had scheduling difficulties (1) or had technical difficulties (1). Participants included three types of guideline developers: clinicians (n=16), patients (n=17) and guideline managers (n=17). Participants were from Canada, the United States, Australia, The Netherlands, Ireland, Scotland and England (Table 4). Developers were from the following types of organizations: government, academic, international collaboration, professional society, disease foundation or managed care (Table 5).

<table>
<thead>
<tr>
<th>Table 4. Participants by country</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Country</strong></td>
</tr>
<tr>
<td>Canada</td>
</tr>
</tbody>
</table>
Table 5. Participants by organization type

<table>
<thead>
<tr>
<th>Type of developer</th>
<th>Manager</th>
<th>Clinician</th>
<th>Patient</th>
<th>Subtotal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Government</td>
<td>7</td>
<td>4</td>
<td>8</td>
<td>19</td>
</tr>
<tr>
<td>Academic</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>International collaboration</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Professional society</td>
<td>5</td>
<td>5</td>
<td>6</td>
<td>16</td>
</tr>
<tr>
<td>Disease foundation</td>
<td>2</td>
<td>3</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Managed care organization</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td><strong>Subtotal</strong></td>
<td><strong>17</strong></td>
<td><strong>16</strong></td>
<td><strong>17</strong></td>
<td><strong>50</strong></td>
</tr>
</tbody>
</table>

5.2.1.1 Participant views on preferences

Due to the fact that patient preferences have not been consistently defined, all participants were asked to define patient preferences and the aim or motivation behind addressing patient preferences. The theme of *patient centered care* and *shared decision making* were both reported by a few participants as definitions for patient preferences, however, most participants (21, 42%) defined “patient preferences” as *deciding patient outcomes including treatment choice and outcomes*:

Patient preference it really encompasses how the patient feels about interventions and outcomes (23M)
What their choices are; what they would choose for as far as treatment goes… the patients' choice of treatment (35C)

Patient preference is a perspective from a consumer in terms of how acceptable that particular treatment option would be to a patient in that circumstance (44P)

Many (19, 38%) participants defined “patient preferences” as *what matters to patients; patient values/priorities*:  
A broad category of means of identifying what matters to patients and how that’s included in guideline development… So what is a primary importance to them and that’s not necessarily what we always recommend but it’s something we should always be taking account of (22M)

A preference on what are their priorities (39C)

It’s really guided by what the patient prefers… sometimes some of those considerations that are important to patients aren’t necessarily addressed (24P)

When asked about the aim or motivation behind including patient preferences in the guideline development process the majority (34, 68%) reported wanting to *represent patient perspectives* and *make guidelines more relevant and beneficial* for the populations they would be affecting.
Many of these participants noted that patients had been providing feedback on a multitude of issues that were not being addressed in the guidelines and so they felt it was imperative to improve patient care by representing patient perspectives. This led to many manager and clinician developers to have a better understanding of preferences and expanded development panels to include more diverse voices.

To develop more relevant projects and guidelines for the consumers as well as the clinicians. So there’s a consumer engagement in buying to what you’re doing (17M)

Certainly we want to make our recommendations and our guidelines relevant to patients (39C)

I think it has another dimension to the care model. As clinicians and researchers I think you can get very focused on the theoretical but patients will give you that real-life perspective on how the guidelines impact them (54P)

Fewer participants (8, 16%) reported the motivation behind including patient preferences as a requirement of established standards or stakeholders and currently a trend in medicine. These participants felt that there is currently a “trend” in medicine to include more stakeholders and in some cases has become a requirement/mandatory to do so.

We would go through some kind of quality appraisal tools that would mean and you wouldn’t pass quality appraisal without having patients represented in some format (19M)
You see a trend towards more evidence-based, more, get more stakeholders involved; it’s all faces of guideline development including the patient. It’s also a trend in society, western world that you in the world of democracies that you once will have the citizens and the patient voice included...But it’s a trend and it’s a quality criteria, it’s a trending society in all western countries. So that’s why we do this (34C)

Well I believe you want an honest answer here. So I believe that they would like to have patient family advisors involved because that’s the trend and it’s trendy in medicine (32P)

In response to asking what information, guidance or resources were consulted, several (10, 20%) participants reported relying on GRADE or AGREE to guide their guideline development process. Most frequently, manager and clinician developers (17, 34%) reported that they sought out resources/information from other guideline developers, including international or national colleagues and/or specialists in the field:

We went to GIN a couple of years ago and (name here) did a presentation about patient preferences and she’s got a couple of studies that she has and I’ve used that definitely to take a look at you know how, how do reach patients and how to, how to have that effective consumer patient relationship and we’ve used some of the work that Armstrong’s group has used (38M)
Well the developers of <guideline> went through a very important process of meeting with other researchers in guideline developers; I believe …in <country>…to legitimize patient preferences and well, even more than patient preferences, consumer input into guidelines (31C)

It is interesting to note that a few (6, 12%) participants reported not finding or consulting any information or guidance, and instead, nine (18%) participants reporting that they relied on familiarity with the process from their experience:

It was based on the skills, knowledge and experience of the people working in the public involvement program. Those of who were here when <organization> was first formed have been working in patient and public involvement for some time and some of us have developed guidelines with patients before <organization> was formed as an organization. And so we brought with us personal knowledge and experience and practical knowledge and experience of how to do this (22M)

I mean many of us who worked on this have worked on other endeavours and projects before with this community and it’s sort of an accepted thing that you bring in community members (14C)

Well to be honest with this particular one that, I mean I had been involved as a patient advisor in various projects. So I mean at least for me I had a general sense. I mean I’ve read clinical practice guidelines and that, so there wasn’t like a lot provided and I
honestly, when I think of like the patients that are involved with that particular project you know they are pretty experienced (24P)

Of the patient developers, nine out of 17 (52.9%) reported that some information, background information or guidance was provided to them:

They let you know a little bit of the background of the department or whoever’s looking for the patient family advisor. And then you, they let you know a little bit about the project and then you’re on your own (32P)

So initially I was given kind of the general information in relation to what the group was actually doing; what the aims of the group were (47P)

5.2.2 Identifying patient preferences

Data from participant interviews are organized into three main categories of identify, incorporate and report. Additional categories included are: barriers, facilitators and suggestions for future practice. Themes reflecting views and experiences are discussed with exemplar quotes. Discrepant themes within and across guideline developers are discussed where relevant. A complete set of guideline developer (managers, clinicians, patients) data consisting of exemplar quotes organized by themes are available in Appendix 10. A summary of themes appears in each section.
5.2.2.1 Approaches and processes used to identify patient preferences.

Various approaches/processes were used to identify patient preferences. These approaches included: having patients on the guideline development panel, clinical experts identified patient preferences, qualitative approaches, quantitative approach, reviewing published literature or using multiple approaches. Participants either identified preferences using one approach or a multi-approach. A multi-approach refers to two or more approaches used to identify patient preferences. Of the 50 developers interviewed, 10 (20%) specifically addressed recruiting patients through advocacy groups or patient organizations. These participants mentioned partnering or working with patient advocacy groups by working side-by-side, contacting them directly or being linked up with these organizations.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient preferences were identified/gathered for guideline development</td>
<td>Having patients on the guideline development panel or committee</td>
<td>30</td>
</tr>
<tr>
<td></td>
<td>Clinical experts identified patient preferences</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Qualitative approaches</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Quantitative approaches</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>Reviewing published literature or conducting a systematic review</td>
<td>23</td>
</tr>
</tbody>
</table>

Patient preferences were identified/gathered for guideline development:

Having patients on the guideline development panel or committee

Out of 50 developers, 30 (60%) reported having patients on the guideline development panel or committee as an approach to identifying patient preferences for guideline development. The
patients were often referred to as patient representatives and were involved in all stages and activities of guideline development and treated as equal panel members.

The committee includes a patient or a patient representative. So they will have a voice in the discussions that are going on, on recommendations and that they will be asked and be able to input on what would patients value, what would patients prefer, what, how do patients view this and that way of managing a problem. So that’s how they are involved; that they are members of the committee (50M)

They were involved from the beginning… we involved the end-stakeholders right from the beginning of a project so that they have say on better uptake. So we had patients that were part of the guideline development team and the guideline is divided into seven sections. And so we had a community member representative on each of the sections that were being developed (12C)

Well the committee is I’d say maybe 15 people; mostly <specialists> and I am one of the two patient representatives on the committee (51P)

Clinical experts identified patient preferences

Out of 50 developers, six (12%) reported identifying patient preferences from clinical experts and through their experiences of what their patients had informed them on their preferences. Often times, these participants felt that clinical experts/clinicians could accurately identify patient preferences from the information provided by their own patients in clinic. Similarly, a
few participants reported working and representing vulnerable populations who may not have the physical or mental capabilities of participating in a study or panel to be able to express patient preferences directly. Both manager and clinician guideline developers reported using this approach but no patient guideline developers reported doing so.

I could argue that you know indirectly those clinicians were so experienced working with these people have built a clinical expertise on what the patients prefer as well. Like we’ve had quite a number of discussions where the physicians, so the guideline writers would then say, well you know that’s a nice recommendation but I’ve never had a patient that really wanted it that way you know (27M)

This is not just physicians, this is…45, I think there was some 45 <physicians> involved but there was also multiple professionals from across the country involved from OT’s, social workers, <specialists>, like you name it and that profession was likely to have representation at the table; nurses. So all, collectively all of their experience with folks with <condition> would also be represented there as well…these are <clinicians> who are in, on the ground floor in the trenches with patients day in, day out. So I think their ability to recognize patient preference would be and these are people who, they don’t just have their one percent of the population which was what everybody else has. These are people who have special interest in <condition>; so you know they would have practices that would be enhanced as far as the numbers go with people with <condition> in their practice. And they’re the ones that are doing the, reading the literature and writing the guideline. So I think, I think that’s pretty good as far as trying to pay attention to patient
preference. You’ve got, you’ve got probably the best team you can get because you’ve got people who are with the population (35C)

Qualitative approaches: focus groups

Out of 50 developer interviews 11 (22%) reported conducting focus groups. A smaller subset of participants reported using face-to-face meetings (4, 8%) and one-on-one interviews (1, 2%) as approaches to identifying patient preferences. Overall, these participants combined reported favourably in using qualitative approaches as they felt qualitative methods of acquiring patient preferences allowed for more in depth data versus quantitative methods.

The staff there were very receptive to having us come to their council meeting…So we had the opportunity to go; one time and meet with that group. So that’s how we addressed getting patient preferences into our <condition> guideline…So there was time to give a general background on who we were and what we were doing. And then had a discussion around some particular areas that the group was interested in, so we did not, we do not have patients sitting on our guideline development panels…working with the focus group where we had multiple people was a little better (48M)

We have used focus groups…one of the other members whose involved in the guideline itself; spoke to a group of <type of> people, <caregivers> and other carers involved in looking after <population> with <disease> and collected information through more group discussions (29C)
We would have focus groups and they would have you know different, different walks of life and being involved; not necessarily one-to-one meetings or that I would be aware from a patient of view; they’re more focus group (46P)

Quantitative approaches: survey

Out of 50 developer interviews 13 (26%) reported distributing a survey. Most participants that used the survey approach had done so in conjunction with another approach, thus taking a multi-approach to identifying patient preferences.

We have a survey, a pre-survey of what their expectations are and what they want to see in the guideline and we ask the questions. What kind of outcome do you want us to take a look at when we’re developing these guidelines…then we do post survey with them which is something that’s fairly new that we have implemented in the last six months; we do a pre and post survey. We’re making it a little bit more formal so that we are able to keep that information and documentation and track what our patients prefer when they help us develop the guidelines (38M)

We did a survey specific to experiences, like finding out their <related to disease> experiences and what their needs were (12C)

We were asked to participate in a few different surveys along with the medical professionals (55P)
Reviewing published literature or conducting a systematic review

Out of 50 developer interviews 23 (46%) reported identifying preferences by reviewing published literature and looking at the published evidence available on patients’ views, experiences and preferences or by conducting a systematic review. Even though many participants conducted systematic reviews of the literature/evidence, many noted the limitation with this approach as little research is available on patient preferences.

Yah, we solely went by what’s known in the literature, right? So we only looked at the published research on preferences by people with <disease> on primary care. And not only, not only patient preferences but there’s also a little bit work done on caregivers (27M)

We did the literature search we took into account first persons voice. So the literature that reported on first person, so anything that was related to the person with <condition> or their caregivers was given acknowledgement, special acknowledgement and that would have been considered a relevant piece of data and was designated as such so that when we came to the strength of our recommendation that was reflected in the strength of the recommendation (35C)

We needed to look at what else is out there or what else are we missing or what has been brought up before. So I think there was a systematic review which I wasn’t a part of; I think another group was part of that review to look at what the findings were and bring it to the big table (42P)
5.2.2.2 Overlap in preferences identified by different approaches

Many participants mentioned using a multi-approach in order to identify patient preferences. Of those participants, 22 reported that they identified overlap in preferences identified between at least two different approaches used. The approaches that overlapped were: between directly involving patients and what the literature reported, between what clinicians or clinical experts had to report and the literature, between various qualitative and quantitative approaches (including: patient panel members and survey results and ace-to-face meetings and e-mail discussions) and between patients and clinicians. This showed that various approaches used still generated similar/overlapping results.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
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</thead>
<tbody>
<tr>
<td>Identified overlap in patient preferences between approaches used</td>
<td>Directly involving patients and the literature</td>
</tr>
<tr>
<td></td>
<td>Clinical experts and the literature</td>
</tr>
<tr>
<td></td>
<td>Between patients and clinician experts</td>
</tr>
<tr>
<td></td>
<td>Between qualitative and quantitative approaches</td>
</tr>
</tbody>
</table>

Identified overlap in patient preferences between approaches used

Both manager and clinician guideline developers reported identifying overlap in preferences from different approaches used but no patient guideline developers did. Even though many participants found overlap in preferences identified, it is important to note that some participants who did find overlap were not initially or specifically looking for it.

So we you know we have them <patients> on the group. And we also carried out a patient focused literature search which identified a number of preferences for patients and
service users. But then we also went out and we spoke to <patients> themselves and again, it was the same issues that were coming up. So such as, you know patient preferences to take part in decision-making, patient preferences when it comes to transition between services…it was really just the same issues that were coming up all the time (08M)

Oh yes. Yah, definitely. And the more overlap it just reinforces that it’s an important priority, right? (39C)

5.2.2.3 Best approaches for identifying patient preferences

A few participants reported difficulty in knowing what the single best approach for identifying patient preferences would be. The majority of participants reported either directly involving patients or using multiple approaches to identify patient preferences as the best approaches to use.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficult to know which is the single best approach for identifying patient preferences</td>
<td>5</td>
</tr>
<tr>
<td>Directly involving patients as best approach</td>
<td>16</td>
</tr>
<tr>
<td>Multi-approach as best approach</td>
<td>12</td>
</tr>
</tbody>
</table>

Difficult to know which is the single best approach for identifying patient preferences

There were mixed views about what the best approach would be for identifying patient preferences. Out of 50 developers, five (10%) reported difficulty in knowing which approach
would be the single best process for identifying patient preferences. Both manager and clinician
guideline developers reported difficulty in knowing which approach would be best but no
patient guideline developers did.

I don’t think I can choose which works best… I think it’s a little bit more personal when
we have a patient on the panel but I don’t think that, that’s better or worse than doing the
search and the literature as a patient preferences (23M)

There are pros and cons to each, I’m not sure that I would pick one over the other
necessarily (48M)

**Directly involving patients as best approach**

Out of 50 developers, 16 (32%) reported directly involving patients as the best approach for
identifying patient preferences. This was often because participants felt that it was best to have
patients present to equally and continuously provide input along all development steps.

I think having patients on the working group or the expert panel works best because
there’s the interactions which is good and patients that are involved for the entire, the
entire approach especially if you have a patient that speaks beyond like their own
personal experience and they are sort of, their feeling for other people as well (28M)

The best approach is including community members and patients in the development of
guidelines at the, around having them at the table developing the guideline is the most
important one (12C)
I think just having the community at the table involving the people… Because often times there people who are like high up somewhere who are making the guidelines for people but not really communicating with the people that they’re making the guidelines for (42P)

**Multi-approach as best approach**

Out of 50 developers, 12 (24%) reported having a multi-approach as the best approach for identifying patient preferences. Participants felt as though a multi-approach was more thorough and holistic as each approach was meant to complement or build off each other.

I do think that all of these steps are complementary. I think they’re all part of each of the phases of guideline development… all of these steps are complementary and has worked for our organization that way (38M)

I honestly, you mean having them on the panel versus having feedback versus; I actually think you need to do it at multiple levels. Like I don’t know that it’s just simply that it’s as simple as one, one approach (39C)

I think all of them need to be undertaken to ensure that you’re getting as much information from a consumer perspective as possible…I think all of the processes helped in providing a sort of reasonably comprehensive amount of feedback (44P)
5.2.3 Incorporating patient preferences

Incorporate refers to the impact or influence of patient preferences on the guideline development process, the recommendations and/or outputs and products produced. This section maps results against the patient engagement guideline framework by Armstrong et al. Exemplar quotes will represent results from the interviews mapped against each of the 10 steps that will guide the themes. Patient preferences were incorporated in eight of the 10 development steps (80%).

<table>
<thead>
<tr>
<th>Theme</th>
<th>Number of participants</th>
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</thead>
<tbody>
<tr>
<td>Preferences incorporated in all development steps from outset</td>
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</tr>
<tr>
<td>Patient preferences influenced topic nominations</td>
<td>1</td>
</tr>
<tr>
<td>Patient preferences influenced the prioritization of guideline topics</td>
<td>5</td>
</tr>
<tr>
<td>Patient preferences impacted questions and outcomes</td>
<td>22</td>
</tr>
<tr>
<td>Patient preferences impacted research plan</td>
<td>2</td>
</tr>
<tr>
<td>Patient preferences impacted assessment and appraisal of evidence</td>
<td>2</td>
</tr>
<tr>
<td>Patient preferences impacted recommendation development</td>
<td>13</td>
</tr>
<tr>
<td>Patient preferences impacted dissemination and implementation of recommendations</td>
<td>6</td>
</tr>
<tr>
<td>Patient preferences influenced evaluation/feedback</td>
<td>7</td>
</tr>
</tbody>
</table>

Participants identified both specific development steps in which patient preferences were incorporated or reported incorporating preferences in all steps of development. Of the 50 interviews conducted, 18 (36%) participants reported having the patient preferences incorporated in all development steps from outset:

We’ve incorporated them into the entire process from the beginning and towards the end… we always want to make sure that the patient is involved in the most important parts of the process and having our patients involved every step of the way (38M)
Our patient representatives were involved in all steps of guideline development from the formation of guideline questions to the ranking of outcomes of priority; certainly it became important when we worked through, they were you know involved in the face-to-face discussions, all the conference calls and then they were really be critical when we started to work through the evidence in terms of when we got down to patient values and preferences (52C)

They were considered really in them all…but this was so, like every section of it, everyone was included…it was very much open floor discussion for everything. So there was no part of it that I was excluded for; equally there was no part of it that I was kind of singled out (47P)

5.2.3.1 Steps for continuous patient engagement in clinical practice guideline development

This section is mapped against the Armstrong et al. framework (121). Each step is listed in numerical order with the description of its purpose within patient engagement.

Step 1: Nominating guideline topics
Identify topics that are important to patients, caregivers, and the community; propose topics to be investigated.
**Patient preferences influenced topic nominations**

Results showed that patients were scarcely included in guideline topic nomination. Only one (2%) participant reported that patients were involved in nominating guideline topics.

People who are in advocacy and patients. So they are the ones who come up with guideline topics you know and they come up with a great number of guideline topics… the idea of what topic to focus on, yes, comes from the assembly’s which do include patient groups (50M)

Step 2: Prioritizing guideline topic nominations

Solicit feedback on relevance and priority of topics; discuss the urgency of addressing topics.

**Patient preferences influenced the prioritization of guideline topics**

Out of 50 participants, five (10%) reported prioritizing guideline topics, these five participants were either clinicians or patient developers. In this step, a list of guideline topics were already chosen and participants were able to prioritize which topics they felt were most important that they wanted included in the guideline.

Provide input in terms of final selection of topics that should be included (33C)

Yah it was again through email, the series of topics were generated and then we had a conference call to determine whether those topics were deemed to be appropriate and if there were other, there other topics that should be included (54P)
Step 3: Selecting guideline development group members

Help ensure that the guideline development group composition is both representative and trustworthy; assess conflicts of interest of panel members from patient perspective.

No participants mentioned or reported directly engaging patients, caregivers and advocates on the selection of guideline development group members. However, several participants noted connecting with patient advocacy groups to recruit patient participation. Additionally, five (10%) manager and clinician developers mentioned identifying patients with no conflicts of interest:

And I think it’s a real challenge to given that context, it’s a real challenge to identify someone speaking to patient preferences who does not inherently have a personal or intellectual conflict of interest (26C)

I think that also related to that, as I’ve noticed that a lot of our patient partners are disproportionately involved in some aspect of the healthcare system. So for instance, it might be that yah, they went through the <type of> experience but the <patient> who shows up is a nurse in the hospital. So once again, a somewhat biased opinion likely whether or not that’s true, I don’t know. I just, it’s just an observation… so there’s a disproportion of representation of people who have some interaction with the healthcare system as a professional even though it’s not directly in this field (33C)
Step 4: Framing the question (including selection of comparators and outcomes)

Ascertain questions’ relevance and usefulness; assess ‘real world’ applicability; identify outcomes of relevance to patients, caregivers, and the community; incorporate other aspects of treatment.

*Patient preferences impacted questions and outcomes*

Almost half of the participants reported including patient preferences in framing key questions and in outcomes and treatment outcomes relevant to patients, caregivers, consumers, and patient representatives. In this step, 22 (44%) of participants reported framing the questions, outcomes and other aspects of treatment.

During the guideline development their voice is especially important and pertinent to have during key question development. We have them at the table making sure that we, we include them when we’re ranking all of the outcomes that we want to use in our key questions (38M)

Questions first of all…so not just what they prefer in terms of a specific question but what questions we actually need to tackle (39C)

I got sort of the same briefing as all the <specialist> on grade and the approached used. I was given the opportunity to get involved in specific questions if I wanted… But I did express interest and I believe my feedback was considered but I’ve seen the changes for like the equity and economic questions (24P)
Patients were able to rate the importance of proposed outcomes and incorporate other aspects of treatment preferences:

So right now we approach patients after the working group has developed the outcomes and then we ask patients about the outcomes…we just get their opinions on how important each outcome is to them (13M)

Well part of what we do with the <organization> focus groups with patients is or those who might potentially be eligible for screening is to identify how they perceive the importance of a variety of outcomes and we get them to rank them on importance so that they can feed or confirm or modify what the <organization> panelists have already defined (20C)

The thought was to breakdown which group of items that were the most important and then we had like a break-out session discussion and then came back together to decide on, let’s say the five or six most important factors of, to, when it came to the treatment plan (56P)

Step 5: Create analytic framework and research plan

Help refine or expand scope of topic, identify potential harms associated with the questions posed; provide a ‘reality check’; verify logic of analytic framework; supplement with additional factors not documented in the literature; discuss proxies for a specific concepts (e.g. whether test scores and school performance are interchangeable); suggest additional search terms; inquire
about potential confounding factors; identify particular populations of interest and/or important multi-morbidity to consider in the search.

Patient preferences impacted research plan

Very little participants mentioned patient preferences influencing the design of the research plan. Out of all participants, two (4%) reported creating a research plan or design.

So they’re there and also they’re there to engage with us during kind of brainstorm what we need to do for the project (38M)

I think, yah now that I think back its like, I was at the <organization> meeting in 2015 and that’s where it began. So you know I was involved in the review of the grant, the design of the work (24P)

Step 6: Developing systematic review and forming conclusions

Assist with critical appraisal of studies and evidence synthesis; assess believability of results; suggest alternative interpretations of evidence.

Patient preferences influenced assessment and appraisal of evidence

Patients and/or patient preferences were seldom considered when appraising evidence or interpreting evidence. Out of all participants, two (4%) clinician developers reported assisting with assessing the literature and critical appraisal of the evidence.
For some topics patients can also help in assessing and grading the evidence…sometimes also in assessing the literature (34C)

Step 7: Developing recommendations

Assist in translating evidence-based conclusions into meaningful, clear, and respectful recommendations; assist in ensuring that recommendations foster partnership between physicians, patient and families; describe variability in patient preferences; help make recommendations easy to understand; provide input when there are gaps in the evidence; indicate which recommendations are counterintuitive (e.g. so that additional explanation can be provided)

**Patient preferences impacted recommendation development**

Participants reported that patient preferences influence the development of recommendations with some noting that preferences also impacted the language of the recommendations in order to produce the most clear and encompassing recommendations. Out of all participants, 13 (26%) reported patient preferences assisted in developing/generating the recommendations.

Absolutely, totally influences how we generate our recommendations so it influences our final guideline recommendations and all of the practical issues that we put into our guideline (15M)

Including patients in terms of formulating the draft recommendation maybe made but including input from them on…the recommendation and the explanation and how this could affect patients…and deciding sort of the wording of recommendation (39C)
Yes, that was all part of our role on that committee; certainly about the recommendations, the strength of the recommendations were all agreed by the full committee (44P)

Step 8: Disseminating and implementing recommendations

Endorse guidelines from patient perspective (either individually or in representation of patient groups); assist in developing patient- and family-level summaries of systematic review findings and guideline recommendations; assist in developing patient decision aids; identify barriers to implementation and possible solutions; facilitate engagement of other patients in dissemination; improve legitimacy and trustworthiness of guideline process such that recommendations are more likely to be implemented.

*Patient preferences impacted dissemination and implementation of recommendations*

Out of all the interviews, six (12%) developers reported disseminating and implementing recommendations to endorse guidelines through patients, advocacy groups and patient summaries and tools.

Including our patient representatives involved in developing patient-centred materials because we knew that that is going to be an important part of the dissemination (38M)

We also have a special community which endorse the guideline…including some, a few professors and other representatives of our organization within <country> (34C)
There was a final summary that was made up following each survey or each conference call summarizing participant’s responses and we were allowed or I was allowed to review the summary and give input as to whether or not I felt the summary was complete and accurate…The summary was as, a summary; it was a generalized report on what was discussed (30P)

Step 9: Updating

Identify when public or stakeholder views have changed such that a guideline requires update or reaffirmation.

No participants reported updating guidelines or having to update guidelines due to a change in patient preferences.

Step 10: Evaluating methods and impact of engagement

Identify if patients were engaged in a meaningful way; suggest options for improvement in future engagement strategies.

Patient preferences influenced evaluation/feedback

Out of all participants, seven (14%) developers reported discussing or providing feedback regarding patient preferences and engagement.
Public consultation the feedback that we receive, we go through that and anything that’s relevant or feedback specifically from consumers or anything relevant we will seek input from our consumers on the panel and then decide as a whole group including the consumers about the actual changes and sign them off (18M)

When a guideline is in the draft phase, so it’ll actually go out to all the members for feedback including patients. So that’s another thing, that’s another check that even once you’ve got the document all done, it’s not published yet but the draft form goes out to every, every member including the patients and they can make comments on that. A lot of that ends up being sort of qualitative you know general comments or whatever (39C)

I suggested that maybe after a year that we’d look at that stage and having kind of a questionnaire and a follow-up to see whether first of all, it was kind of effective and whether people were happy with it. But also the kind of, that the patient feedback element at that stage from a point of view of like did it, did it actually address what it was meant to address for the patients (47P)

5.2.4 Reporting patient preferences

5.2.4.1 Patient preferences reported in the guideline.
Participants either reported preferences explicitly or embedded them within the guideline or recommendations. Additionally, a theme that emerged solely from patient developers were that they had no idea how the preferences were or would be reported in the guideline.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preferences were embedded</td>
<td>25</td>
</tr>
<tr>
<td>Preferences were reported explicitly and/or in a separate section</td>
<td>13</td>
</tr>
<tr>
<td>No idea how preferences were reported in the guideline</td>
<td>4</td>
</tr>
</tbody>
</table>

Preferences were embedded

Out of 50 participants, half (25, 50%) reported that the preferences were embedded within the guideline and/or recommendations and not reported explicitly or separately.

At the moment we’re not really explicit on the patient preferences (08M)

There’s nothing that says, you know this is what a patient wants. It was, it was embedded within the guideline (14C)

I wouldn’t say there was a separate area of a separate part of this that would have that level of information. (46P)

Preferences were reported explicitly and/or in a separate section

Out of 50 developers, 13 (26%) stated that the preferences were explicitly reported in a separate section, directly following recommendations or noted in the guideline with comments. Out of all participants, only one patient developer reported that preferences would be reported both
explicitly and embedded within the guideline. They reported that for some of the recommendations the preferences were embedded, whereas others had been explicitly broken down.

Usually in the interpretation of evidence. There might be a section in the systematic review discussing patient preferences. But for each recommendation there’s in our guideline, there’s a section, a section II where we write the recommendation down and then we write the evidence that informs the recommendations and then we write the interpretation of the evidence and generally patient preferences are discussed at that point as well as in the systematic review; if there’s outcomes that have to do that with that, and there’s usually a section on the patient outcomes that are important and a write up in there (28M)

We will be writing this separately and there be, we’ll be writing as part of the methodology section, the introduction that how we involved the patients and the patient preferences in terms of selecting the key questions for the guideline. And then how we went on and incorporate, incorporated these patient preferences in terms of selecting the evidence and the outcome of the qualitative interview and also the group work information from the <type of> people…That’ll be fairly in depth information on how we took the patient preference into consideration (29C)

Each guideline will have a patient that will be able to contribute to, it will have a patient, how it relates to the patient, what the patient, what the patient would like to experience is that; so for example, let’s say…guideline addresses <treatment> use to treat <symptom>
and how it maybe harmful to the patient long term? And so the patient preference will highlight under the recommendation after the literature about how you know <treatment> use can increase <symptom> and will draw out symptoms and stop patients from maximizing their lives and being able to do normal daily activities because of <side effect> and <side effect> (53P)

No idea how preferences were reported in the guideline

Out of the 17 patient developers, four (24%) reported not having any idea as to how the preferences were going to be reported in the guideline, perhaps reflecting that they were involved in some but not all guideline development steps.

I believe that it’s, I had an influence. Of course, I don’t know what the final product is going to be but they took it seriously (32P)

5.2.5 Barriers

Participants noted a multitude of barriers and challenges of varying types associated with identifying, incorporating and reporting patient preferences in guideline development.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meaningfully involving patients</td>
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<tr>
<td>Identifying the right or knowledgeable patient</td>
<td>19</td>
</tr>
<tr>
<td>Hard to capture complex issues</td>
<td>17</td>
</tr>
<tr>
<td>Time commitment/scheduling</td>
<td>12</td>
</tr>
<tr>
<td>Patients feel intimidated or nervous</td>
<td>10</td>
</tr>
<tr>
<td>Clinicians attitudes</td>
<td>8</td>
</tr>
</tbody>
</table>
A few manager and clinician developers (7, 14%) reported that they had challenges in knowing how to *meaningfully involve patients* and to make sure the patient voice was heard. The largest proportion of participants (19, 38%) reported challenges under the theme of *identifying the right patient(s)* that would be: knowledgeable, vocal during discussions, with minimal bias, and/or willing to commit their time.

I think some of the challenges can be the patient…to really speak up at a meeting…about topics that can be quite complex (15M)

I’m not sure if it’s about being better equipped, it’s just getting the right patient. I’m sure there must be patients out there that actually have an understanding of the topic. It’s just accessing them. You know how do you get a patient that’s appropriate (19M)

And I think it’s a real challenge to given that context, it’s a real challenge to identify someone speaking to patient preferences who does not inherently have a personal or intellectual conflict of interest (26C)

More difficult for us given our non-medical background to be like really a contributing part of those discussions…sometimes you feel kind of useless with respect to voicing your concerns about…the areas you don’t know as much about…you’ve got fairly limited scope of expertise compared to the medical professionals on the team (21P)
A similar number of participants (17, 34%) reported that it was hard to capture complex issues, diversity and/or patients that truly represented the population:

It can be hard to capture the complex…to actually accurately capture the preference of the community is pretty immense. And so it can be hard to feel like you’ve actually really captured patient preference in a comprehensive way (01M)

You know other than that, I would say also increasing the diversity, that’s something I forgot to mention. I’ve also been, found that most of our partners have been you know white, English speakers. So increasing the ethnic, linguistic you know religious diversity of our patient partners; I think it would be a major goal you know (33C)

To have more voices there just means you’re able to; 1) capture more people, 2) to create guideline and actually the majority of people can actually understand, and 3) because no one wants to be a token; you know the representatives of their group… there’s a lot of minority communities that would read and take certain types of information differently… have more diverse voices is very, very important (10P)

Another barrier reported by 12 (24%) participants was time/commitment and scheduling/attending meetings. These participants reported that it was difficult to find patients willing to commit and volunteer their time as including patient preferences in guideline development can often be a long process. Additionally, there were difficulties scheduling
meetings when everyone would be available to attend with some patients reporting that they worked full-time, was a student, a parent or a caregiver.

Logistic challenges and setting up time to talk to people and they tell you to talk to other people and they tell you to talk to other people; so that whole process of setting up meetings jogged out for a long time (48M)

There’s not a lot of patient volunteers that want to get up at 6 o’clock in the morning. And there’s not a lot in it personally for them unless they’re incredibly invested in the topic (06C)

Face-to-face type of experience… also has some downsizes too, especially when it comes to scheduling a time that everyone can meet (10P)

Manager and patient developers (10, 20%) reported barriers that patients feel intimidated or nervous to ask questions. Out of these participants, seven were patients that reported this barrier. These patients reported fear around asking dumb questions because they lacked the medical knowledge and that sometimes it took a couple meetings before they felt comfortable speaking up.

So I’m sure you know there’s an aspect of intimidation when you’re in a topic of your conversation that you’re not familiar with as well (19M)
There could be a challenge where you feel like you are not being, you’re not going to be heard, right? But I think there was just my own personal…of fears of maybe not being taken seriously (42P)

Manager and clinician developers (8, 16%) reported that clinicians’ attitudes about patient preferences was a barrier. Clinicians were averse to being confronted or criticized by patients that were present on their panels and worried about legal ramifications of recommendations based on patient preferences. One developer reported that other clinicians felt including patients decreased the readability of guidelines.

I guess to some of the clinicians. It’s been a little bit challenging on the clinician front…So there was the clinicians, especially the older generation really had a hard time getting their head around that because it’s like they grew up in the model of that doing to the <patients> rather than informed decision-making if that makes sense? (17M)

Well some clinicians and academics you know don’t feel comfortable working with community members and they feel like it’s dumbing down academia… like no one ever said anything or did anything but like I do know that some clinicians and researchers on our team think that we take the involvement of patients too far. And that they think it’s sort of dumbing down academia…Like it’s taking a guideline that should be a high level clinical practice guideline but we are decreasing the readability, like you know to a lower, like to, not grade 6 but let’s say to a grade 9 level, English instead of a grade you know 12 level English. And so some clinicians like might not agree with that… The other sort
of challenge is if you have the patients right at the table and you word something kind of in an offensive way, it’s like, the patients right there, okay and they’re feeling they’re gonna get heard right away as opposed to if you have a guideline and there’s like offensive things in the guideline and it passes through multiple stages of editing before a patient sees it. So like you’re, so you’re putting yourself at risk of being kind of criticized or yelled at by a patient earlier rather than later (12C)

Manager and patient developers (8, 16%) reported that medical terminology was a barrier. Six of these participants were patients who expressed medical language, acronyms, and disease specific or technical nomenclature as major barriers.

The terms that are being used kind of foreign to them. They don’t understand these terms (50M)

Just trying to understand words that were used when it came between the researchers and of course the doctors and in asking the questions enough to understand to break it down for me from a patient…it was still a challenge trying to learn some of the more or less the words…some of the treatments or maybe some of the outcomes or maybe some of the results or biopsies or things of that nature (56P)

To summarize, of the seven barriers, the majority of them were process barriers: meaningfully involving patients, identifying the right or knowledgeable patient, hard to capture complex issues
and time commitment/scheduling (4, 57.1%). Of the seven barriers, two were patient barriers: patients feel intimidated or nervous and medical terminology (28.6%). Finally, one clinician barrier was identified: clinician’s attitudes (14.3%).

5.2.6 Facilitators

Participants noted a multitude of facilitators that helped with identifying, incorporating and reporting patient preferences in guideline development.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Training for clinicians</td>
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<tr>
<td>Training for patients</td>
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<tr>
<td>Patient advocacy groups</td>
<td>13</td>
</tr>
<tr>
<td>Expert help</td>
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<tr>
<td>Communication from guideline team</td>
<td>14</td>
</tr>
<tr>
<td>Point of contact for patients</td>
<td>13</td>
</tr>
<tr>
<td>Knowledgeable/experienced patients</td>
<td>13</td>
</tr>
<tr>
<td>Chair/moderator</td>
<td>12</td>
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</table>

A few (5, 10%) participants reported training for clinicians as a facilitator. Methods of training included: workshops, orientations and reading materials. Almost half of all participants (22, 44%) reported training for patients as a facilitator. Training took various forms such as one-on-one, in person, supplemental materials, videos, orientations, debriefing or teleconference sessions.

We do some training and we have what we call, introduction to <organization> training which focuses on the skills…to take part in guideline development; really just focuses on
communication skills, team-working skills and that assertiveness and also working with the evidence as well (08M)

There hasn’t and I think and to also to facilitate that, there was a fair amount of, say before they got to the meeting, making sure that there were phone calls to discuss what the process was going to look like, clarification of what the clinical questions that could be addressed, the kind of the range of clinical questions that could be addressed was explained. An overview of what a guideline development process was, a list of basic things like list of acronyms so that people could understand the healthcare professionals that they spoke (33C)

A one-on-one training with me to explain you know what the purpose was with the format of the guideline would look like, the questions; what would be addressed; how to, how to write what I wanted to be addressed in the correct format. And then later on they provided training with me inclusive to the whole panel; so myself as the patient representative and the providers about just the overview of the framework that would be used to guide the guidelines (53P)

Manager and clinician developers (13, 26%) pointed out that patient/advocacy organizations were helpful especially when recruiting patients.

We’ve also engaged with <organization> and they’ve also provided us with some representatives. For the most part, if we have a project about <disease>, then we engage a
patient advocacy group, like looking in <organization> and we work with them to provide their patients on our panel. So if the topic is related to the advocacy group that we contact and we partner with; so they become collaborators with our guidelines (38M)

There was an identifiable society or several societies that we could go to and ask for representatives… and go back to as a checkpoint and getting more than just an individual focus (06C)

A few (5, 10%) participants reported having access to expert help such as a knowledge translation team, qualitative researchers, research specialists or any other individuals who work in the field was helpful. Even more so, 14 (28%) manager and patient developers reported communication from the guideline team to be a facilitator with the majority of them citing the project manager as their main source of communication.

I interact with our patient by email a lot and monthly or quarterly check-ins really help. We do have a lot, a couple of checklists where we want to make sure that the guideline manager is able to engage with a patient and ensure that you know there’s regular check-ins with a patient during the development (38M)

<Name> was always there. She was always, she made herself available all the time to answer questions or provide feedback or interpretation… You know she did provide us with lots of information going in so that we could understand and interpret and then was always willing you know to follow-up with us if we had any further comments that we
thought of later or have any questions or something that would come to mind to the next
day. She made herself available all the time (40P)

Similarly, participants (13, 26%) also reported point of contact for patients as a facilitator. All
three types of developers mentioned the importance and helpfulness of allowing patients to have
a point of contact in case they had any questions or needed clarity.

On any project that’s meaningfully involving patients or community members. So we
have an academic point person that has some kind of long history with at least a member
of the group. So in this situation that was me. And so I would have individual or side
meetings with just the community members or just the patients before meeting, talking
about what the meeting would be about and then after the meeting as a debrief, so and
they can always come to me (01M)

So another thing that helped is we have assigned staff within our team, our guideline
development team to specifically be there to assist the patient partners throughout the
day. So there be like a little pre-meeting briefing that they’ll give the people even the day
of, after having prepped them over the telephone leading up to the meeting and then like
so at lunch, his name is <name>, <name> will go over and you know sit with the patient
partners, see if there’s anything emotionally that was too tough during the discussions.
See if there’s anything that was you know intellectually they didn’t understand. If there
was jargon being thrown up; that was, that they didn’t understand. And then he will either
explain it himself or seek out some of my…hey man, you know they didn’t get this or
that; come over and explain that to them and you know that kind of stuff to make sure that there’s a level of understanding which I think is obviously key for them to feel like they can be good participants or full participants (33C)

We were given a contact phone number. I was given a contact phone number with the opportunity to phone at any time, well within reason to ask questions (30P)

Having knowledgeable and/or experienced patients was another facilitator reported by 13 (26%) participants.

I think some of our patients are experts in their own right, in their patient navigation and they’re very engaged and very interested in learning. So having a very engaged patient really helps out but if they’re not quite familiar with the topic or, well I have to preface that all of our patients on the panel are either, were diagnosed with a disease or took care of someone who was diagnosed with a disease. So before they even walk in the room they know you know <disease>, they experience it or you know firsthand or someone that’s close to them experienced it firsthand. So they know that part of testing and navigating. So that really helps out when we choose our patient advocate that they have that knowledge about their own disease (38M)

We’re lucky right now in the new guideline project that I’m one of the co-Chairs in developing; is that we have a very articulate and very knowledgeable patient representative who doesn’t hesitate to bring up a point that I’m glad to say, most of our,
most if not all of our panel members have been respectful and have given due consideration and you know I think that’s ideal… You know if you have somebody who is knowledgeable, articulate and not intimidated then I think it can, it has worked very well (26C)

I, well I mean speak to a lot of patients. I, being a patient I’ve had this <disease> since I was <age> and I’ve been in communication with a lot patients in the last 20 years and have talked to them by the phone, through emails, in-person and I think that collected knowledge that I have of the disease and that I’ve heard from other patients I think has been valuable and has helped me you know with the guideline process and going through many multiple, multiple treatments myself, my own experience (51P)

Participants (12, 24%) also reported that the role of the chair or moderator that supports patient engagement was an important facilitator. This was because the chair acted as a moderator for the development panel and a facilitator for patients when they needed encouragement. This made the role of the chair crucial in ensuring that the views and preferences of the patient panel members were extracted and captured.

The chairman and you know the whole of the group; how much, how skilled they are in nudging participation from somebody who may feel you know on the periphery of the group. So some of the issues are related to the patient himself/herself and some are related to the chairman or….the chair and the whole group (50M)
You need to have a chair who’s also supporting patients...are support patients who have a very strong voice but also who has a weak voice that you can encourage them (34C)

We had very good chairs, we had excellent, the chairs of the review committee were very, very committed engaging the consumers in the process (44P)

Comparatively, one patient developer reported an opposite experience by reporting the chair as a barrier:

I definitely think the chair person in this case was very challenging...I think the chair person in this case had very strong preferences going in and wasn’t necessarily hugely open to maybe changing those and changing his opinion on the approach and that’s down to with the fact he’s in his whatever, 50’s, early 60’s and has been doing this for 30 years...he was difficult to be honest (47P)

5.2.7 What else guideline developers need

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-theme</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Framework or standardized approach</td>
<td></td>
<td>13</td>
</tr>
<tr>
<td>Explicit reporting of patient preferences in research and guidelines</td>
<td></td>
<td>13</td>
</tr>
<tr>
<td>Identifying more relevant, knowledgeable, diverse patient developers early on</td>
<td></td>
<td>24</td>
</tr>
<tr>
<td>Patient database/repository for organizations to utilize</td>
<td></td>
<td>10</td>
</tr>
<tr>
<td>Training participants</td>
<td></td>
<td>12</td>
</tr>
<tr>
<td>Communication</td>
<td>Medical terminology</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>9</td>
</tr>
</tbody>
</table>
All participants were asked “How could preferences be better identified and incorporated and reported in guidelines” and “What information or guidance or support would help” them or their organization. A multitude of suggestions were reported along with an imperative need for guidance on best approaches for identifying, incorporating and reporting patient preferences in guideline development. Developers (13, 26%) reported needing guidance, a framework or a standardized approach on how to go about including/collecting patient preferences. Results showed that many developers would find having some form of a standardized or systematic approach/framework as helpful to know how to go about collecting patient preferences, especially for those that are just starting to include patient preferences within guideline development.

There isn’t a whole lot of clear, I guess like policies or frameworks on how best to conduct patient oriented research…that would be helpful to have…some sort of resource…that’s like evidence-based that outlines what works and what doesn’t…having a policy or protocol would help…like a consolidated framework…maybe a centralized resource we can go and have, something that outlines best practices I guess, so that you can reference that and make sure that you’re conducting patient preferences in line with best practices that have been identified (13M)

To have a framework of how to do research on that…in RCT has this recipe and the systematic review as its own recipe. And you know if you want to do diagnostic thing,
you have a recipe. You should have a recipe for how to go about and have you know quality in what you’re doing to get at the preference, values and preferences of patients (09C)

Getting more a system, in collecting it in a more systematic way, right? And I really think that there could be a lot, I think this should be learned and it’s like a way that I think can support patient advisors getting involved in clinical practice guidelines, right (24P)

Manager and clinician developers (13, 26%) stated the need for explicit reporting of patient preferences in research and guidelines. Not only is more research on patient preferences needed, research needs to improve on explicitly reporting preferences. Similarly, if preferences were included in guidelines, they need to be better reported within the recommendations.

So I would want to see exactly how and where patients, engagement is the most meaningful to shape the guideline in a direction that improves the quality of care because I don’t think the evidence is telling us where that is right now (48M)

I suppose another option you know is to have a section that’s specifically addresses this. You know that section might vary depending on what your guideline is trying to accomplish. But you know either throughout the guideline or a section itself that references back to patient preferences about these topics you know (14C)
Almost half of all participants (24, 48%) reported that preferences could be better collected by identifying more relevant, knowledgeable, diverse patient developers early on and more holistically. Identifying the right patient representatives was highly mentioned by many participants emphasizing the importance of the type of patients needed in order to include patient preferences in guideline development. Since many organizations chose the approach of including a patient representative directly on the guideline development group or panel, it was vital that these patients were able to accurately characterize the patient populations needs and values.

Involving patients earlier is important…from the beginning from like topic selection to and like protocol development; so helping to develop the protocol of how we engage patients I think is important because if that’s who we’re engaging, we kind of need to know like how they want to be involved, what’s important to them (13M)

We need to find the right way to identify whose going to be involved and probably need more information once the guidelines out as to how helpful the patients find them you know (25C)

I just wish there was more diverse voices at the table... And not just diverse individual, by diverse the people who think differently; diversity of income levels, diversity of levels of education from people with no education to people with you know a PhD, diverse…people live. So you know if people live you know in an apartment versus people that live in houses (10P)
Within this theme emerged an important sub-theme, the need for a *patient database/repository for organizations to utilize* by manager and clinician developers (10, 20%). Participants reported that having a database of available patients or connecting with patient advocacy groups that have the repository of eligible patients willing to participate would be helpful to have and to utilize each time patient preferences are needed.

Utilizing not just you know the patients that are on the panels but if there is a point in time where you want a broader audience to answer you know specific preferences then having a group of patients at you know are willing to quickly take a survey for you (41M)

If there were a central resource to identify patient or patient advocacy groups that are excited and willing to be part of the guideline development process that would also be helpful (25C)

Participants (12, 24%) reported the need for *training participants*, this included having information on what guidelines are, an explanation of patient preferences, assessing quality of evidence and other research tools.

I think training would be good too. I think even to have the kind of a knowledge on you know how the guideline, the very background and basics of how guidelines written, what’s involved, what kinds of things they might be asked. You know have a, how the meetings take place, like what’s expected. I think using like a briefing on that before they start. I mean I tend to do that myself, but in a very unofficial capacity over the phone you know. There was no sort of kind of half-day workshop for anything like that. That
might help to make some structure a bit better though... But there was a lack of training for...on our part...how to best integrate them and I followed the same line that I did for all the other members of the team (19M)

I think we should have patients that are a bit more trained just to kind of get the questions that we want them to answer because I was on the phone call once and it was so confusing (09C)

Looking forward I think to engage broad, more broadly consumers from varying backgrounds and its variances; it would be useful to have some sort of consumer training... So some sort of you know pre-involvement training or workshop or in-service, whatever orientation, whatever you like to call it (44P)

Within this theme emerged a sub-theme solely from patient developers out of the 17 patient participants, seven (41.2%) reported the need for training and information on medical terminology. Patient reported struggling with abbreviations, scientific nomenclature and clinical knowledge on diseases/conditions but were eager to be provided with materials to become more informed in that area.

Whereas specifically for something like <topic>, like there’s a lot of abbreviations, there’s a lot of you know maybe phrases used that patients are not familiar with. And particularly where everyone else around the table has a medical or nursing background that kind of happens and there are times that you’re kind of, you’re trying to work out what, what exactly they’re talking about. Even to know the littlest things like you know
might be speaking about like a condition but they might use the abridge term for the condition that you didn’t, like for <disease> they called <abbreviation> (47P)

I think we really, need a tool as such as explaining, explaining the basics of the condition. So even though I am a patient and I experience <symptom>, a lot of time was spent explaining the different segments of <symptom> to me when that could have been explained early on so that you know I wouldn’t have confusion or I could have voiced my opinion earlier or the patient preference earlier if I better understood exactly the different categories of the you know of <symptom> or what the condition that we were addressing (53P)

Another theme that emerged from seven out of 17 patient developers (41.2%) and two out of 17 managers (11.8%) was the need for clearer lines of communication. Patients reported needing more updates on progress and timelines, clearer explanations/instructions and a point of contact.

I do think that it’s important to keep patients informed. So sending them results of the research and we don’t do this, but if you’re working with a patient on a proposal and you’ve submitted it and it’s taking a while to like to hear back from ethics or whatnot. Just even shooting them an email to let them know that it’s still in the works because I’ve been on the other end where you just kind of don’t hear anything for a while and you kind of aren’t sure if, what things are happening (13M)
There’d be like several weeks or months until we heard something again… maybe a strong reminder of okay, this is where we are, this is where you can expect us to go, this is when you should hear from us again… sometimes there would be so long in between meetings or communications that like this call; I feel dusty on what the process was and what happened (21P)

A few participants (4, 8%) reported the need for greater support for qualitative research. An improvement is needed on the perceived value of qualitative research and the importance of acquiring qualitative research skills/training. This is valuable in showing that patient preferences are important to healthcare systems or government.

I think again, this notion of trying to enhance the status of different research types. I think that would be really helpful so that the people really understand that there’s value in other forms of data in evidence (22M)

I think we also need to have greater support for sort of qualitative research that does sit down and look at patient preferences; so that when we go to create guidelines we have some foundational evidence that’s out there (52C)

It is important to note that a few participants (5, 10%) said they did not need any additional information, guidance or support. Few participants felt that additional support such as a workshop or a standardized set of instructions/guidance was not needed.
I don’t really know so much about a workshop because sometimes you do a workshop and you sort of forget don’t you, really what you’ve done at the workshop… I think it maybe there’s a thing for workshop but to be honest I wouldn’t go to it, if there was a workshop on patients, yah, like including patient preferences unless it was a bit more comprehensive (17M)

You know like anything, having a one size fits all would be, would be challenging (33C)

I don’t think there really anything further for me. I think that the information that was available for that guideline was very useful and valuable. So I wouldn’t say anything for that one (46P)

5.3 Compared and compiled results of scoping review and qualitative semi-structured interviews

The three tables below, separated into identify, incorporate and report, outline the high level findings of both the scoping review and the qualitative semi-structured interviews mapped against each other to compare results. The scoping review identified 13 out of 24 themes (52.2%) which was fewer than the qualitative reviews which identified 21 themes (87.5%). Out of 24 themes and subthemes, 12 (50%) were found in both the scoping review and the qualitative interviews. In each section, the qualitative interviews consistently identified more themes than the scoping review.
5.3.1 Identify

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
<th>Scoping review</th>
<th>Qualitative interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identify</td>
<td>Patient preferences were identified/gathered for guideline development</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>Having patients on the guideline development panel or committee</td>
<td>---</td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>Insight on patient preferences identified from clinical experts</td>
<td>---</td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>Patient preferences identified through qualitative approaches</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>Patient preferences identified through quantitative approaches</td>
<td>---</td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>Patient preferences identified by reviewing published literature or conducting a systematic review of the literature</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>Patient preferences identified through multiple methods approaches</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>Separate patient panel</td>
<td>X</td>
<td>---</td>
</tr>
</tbody>
</table>

Identified overlap in patient preferences between approaches used

<table>
<thead>
<tr>
<th></th>
<th>Scoping review</th>
<th>Qualitative interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identified overlap in patient preferences between approaches used</td>
<td>---</td>
<td>X</td>
</tr>
<tr>
<td>Difficult to know which is the single best approach for identifying patient preferences</td>
<td>---</td>
<td>X</td>
</tr>
<tr>
<td>Directly involving patients as best approach</td>
<td>---</td>
<td>X</td>
</tr>
<tr>
<td>Multi-approach as best approach</td>
<td>---</td>
<td>X</td>
</tr>
</tbody>
</table>

Out of all seven approaches identified, four (57.1%) were found in both the scoping review and the qualitative interviews. Both methods found that patient preferences were identified using the
following approaches: having patients be a part of the guideline development group, using qualitative approaches, conducting reviews of published literature/conducting systematic reviews and using multiple approaches. The interviews identified two (28.6%) additional approaches: clinical experts identifying patient preferences and quantitative approaches. The scoping review identified one (14.3%) additional approach: having a separate patient panel.

None of the studies in the scoping review looked for or reported overlap between approaches used or which approach would be best. Guideline developers from the qualitative interviews reported finding overlap in patient preferences between approaches used. Overlap of preferences was found in various combinations of approaches including: directly involving patients and the literature, clinical experts and the literature, between clinicians and patients and between qualitative and quantitative methods. The qualitative interviews were able to dive deeper into these areas of identifying patient preferences in order to find out what developers felt were the best approaches. Although some participants reported that it was difficult to know which single approach would be best for identifying patient preferences, the majority reported that either directly involving patients during the entire guideline development process as equal members or using multiple approaches would be best.

5.3.2 Incorporate

<table>
<thead>
<tr>
<th>Development steps</th>
<th>Scoping review</th>
<th>Qualitative interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1: Nominating guideline topics</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Step 2: Prioritizing guideline topic nominations</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Step 3: Selecting guideline development group members</td>
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</tr>
</tbody>
</table>
Findings from the scoping review were directly mapped against the development steps of the Armstrong et al. framework (121). Themes for incorporating patient preferences were mapped according to the Armstrong et al. patient engagement guideline framework. When comparing the scoping review and the qualitative interviews, results were mapped according to the development steps. Both methods found that preferences were incorporated in the following steps: nominating guideline topics, prioritizing guideline topic nominations, framing the questions, developing a systematic review and forming conclusions, developing recommendations and disseminating and implementing recommendations. Both the scoping review and qualitative interviews did not report findings for steps three and nine, selecting guideline development group members and updating, respectively. Only the qualitative interviews incorporated patient preferences in steps five and ten: creating an analytic framework and research plan and evaluating methods and impact of engagement. The qualitative interviews incorporated more development steps (8, 80%) than the scoping review (6, 60%). The interviews may have identified more development steps impacted by patient preferences as it also found more approaches used to identify patient preferences. These additional approaches may have allowed developers to incorporate patient preferences in more steps than approaches used in the scoping review studies.
5.3.3 Report

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
<th>Scoping review</th>
<th>Qualitative interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Report</td>
<td>Preferences were embedded and not listed separately or explicitly</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>Preferences were reported explicitly and/or in a separate section</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>No idea how preferences were reported in the guideline</td>
<td>---</td>
<td>X</td>
</tr>
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</table>

Both methods found that patient preferences were either reported explicitly or were embedded within the guideline. The qualitative interviews provided more insight on how patient preferences were reported as the scoping review only found three studies that mentioned how patient preferences were reported. More studies (2, 66.7%) noted patient preferences as being explicitly reported in the scoping review in contrast to only one (33.3%) study reporting patient preferences as embedded within the guideline. This result was different compared to the qualitative interviews that found more participants said preferences were embedded (25, 50%) within the guideline and/or recommendations, with fewer (13, 26%) participants recording preferences as explicit or in a separate section. Only the qualitative interviews had patients report that they had no idea how the preferences were or were going to be reported in the guideline.
5.3.4 Barriers and facilitators

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Scoping review</th>
<th>Qualitative interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meaningfully involving patients</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Identifying the right or knowledgeable patient</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Hard to capture complex issues</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Time commitment/scheduling</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Patients feel intimidated or nervous</td>
<td>---</td>
<td>X</td>
</tr>
<tr>
<td>Clinicians attitudes</td>
<td>---</td>
<td>X</td>
</tr>
<tr>
<td>Medical terminology</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Lack of consistent search terms</td>
<td>X</td>
<td>---</td>
</tr>
<tr>
<td>Systemic/technical barriers</td>
<td>X</td>
<td>---</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Facilitators</th>
<th>Scoping review</th>
<th>Qualitative interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Training for patients</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Training for clinicians</td>
<td>---</td>
<td>X</td>
</tr>
<tr>
<td>Patient advocacy groups</td>
<td>---</td>
<td>X</td>
</tr>
<tr>
<td>Expert help</td>
<td>---</td>
<td>X</td>
</tr>
<tr>
<td>Communication from guideline team</td>
<td>---</td>
<td>X</td>
</tr>
<tr>
<td>Point of contact for patients</td>
<td>---</td>
<td>X</td>
</tr>
<tr>
<td>Knowledgeable/experienced patients</td>
<td>---</td>
<td>X</td>
</tr>
<tr>
<td>Chair/moderator</td>
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<td>X</td>
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</tbody>
</table>

Both the scoping review and the qualitative interviews reported barriers and facilitators for identifying, incorporating and reporting patient preferences in clinical practice guideline development. Both the scoping review and qualitative interviews reported seven barriers. Out of nine total barriers found from both the scoping review and the qualitative interviews, five (55.6%) of those reported barriers were found in both. The five barriers were: meaningfully involving patients, identifying the right or knowledgeable patient, difficulty in capturing complex issues, time commitment/scheduling and medical terminology. Both the scoping review and the qualitative interviews identified two additional barriers. The scoping review reported the
additional barriers of: a lack of consistent search terms and systemic/technical barriers. The qualitative interviews also found: patients feel intimidated or nervous and clinicians attitudes.

Out of the eight facilitators, only one (12.5%) was found in both the scoping review and the qualitative interviews which was *training for patients*. This finding came from only one study in the scoping review, with no other studies reporting facilitators. This showed that the evidence may either not be interested in looking at facilitators or that there may not be any facilitators to report for including patient preferences in guideline development. The qualitative interviews identified seven additional facilitators: training for clinicians, patient advocacy groups, expert help, communication from guideline team, point of contact for patients and the chair/moderator. The participants from the qualitative interviews were able to identify eight total facilitators for patient preferences in guideline development.

It is important to note that few studies (8, 38.1%) actually reported any barriers or facilitators in the scoping review compared to the responses in the qualitative interviews. All participants in the qualitative interviews answered questions surrounding barriers and facilitators which shows the high importance in conducting qualitative interviews in order to achieve a more in-depth understanding of the barriers and facilitators associated with involving patient preferences in guideline development. Interestingly, almost none of the studies included in the scoping review reported any facilitators, even the ones that reported barriers. Comparatively, the qualitative interviews were able to shed light on important factors that really helped to facilitate acquiring patient preferences. These facilitators could potentially be utilized to help development groups to better identify, incorporate or report patient preferences during guideline development.
Chapter 6 Discussion

6.0 Discussion

The present study explored current approaches for identifying, incorporating and reporting patient preferences in clinical practice guidelines. This chapter discusses the results of the scoping review and the semi-structured interviews as they contribute to approaches being used. This chapter also considers strengths and limitations of the study, implications of the findings and offers suggestions for future research on patient preferences in clinical practice guidelines.

6.1 Research findings

This section considers how the research findings informed the overall aim of this thesis, which was to explore approaches used for identifying, incorporating and reporting patient preferences in clinical practice guideline development. The scoping review component of this study identified current evidence on patient preferences in guideline development and found little and poorly reported research, enhancing the value of the qualitative interviews as they offered insights not available through the literature review. This discussion considers some sub-sections from the background review in section 2.0 (Page 3 to 25).

6.1.1 Awareness/Knowledge of what constitutes patient preferences
While developers said that it was important to identify, incorporate and report patient preferences in guidelines to make them more relevant, they largely defined preferences as specific to treatment choice or outcomes, rather than acknowledging that patient preferences may encompass aspects of care other than clinical treatment. This narrow view of preferences may be why developers to date have largely addressed patient preferences when choosing guideline topics or generating guideline recommendations. While developers, in both published research and in qualitative interviews, employ various methods for identifying (i.e. engaging patients on panels or in qualitative interviews or focus groups) or collecting patient preferences from published research, they may not be doing so comprehensively if they hold a narrow view of what preferences are.

6.1.2 Identify

The literature review showed that the largest proportion of approaches used to identify patient preferences were: involving patient representatives on the guideline development group, consulting patients by survey, interviews or focus groups, and synthesizing published research (69,87,91,92,106–124). Both the scoping review and the qualitative interviews identified these approaches as well. Additionally, they found that using multiple approaches was also a method used by development groups to identify patient preferences. The scoping review identified an additional approach of having a separate patient panel in guideline development. The qualitative interviews were also able to identify an additional approach which was to consult clinical experts. Also, the qualitative interviews found that patient representatives were most frequently recruited through patient advocacy groups/organizations. Participants reported that having good

relationships with these patient organizations helped tremendously to facilitate not just recruitment of knowledgeable and experienced patients but also allowed them to easily find participants for qualitative and quantitative approaches such as taking part in a one-time interview or survey.

**6.1.2.1 Patients lack knowledge**

Previous literature found that patients lacked knowledge on their disease and medical information (40–42). The scoping review and qualitative interviews also identified difficulties in identifying knowledgeable patients as a barrier. The qualitative interviews further found that this lack of knowledge was on their condition/disease, and on the accessibility of the guidelines for their condition/disease, and in turn posed challenges for them to fully participate in shared-decision making even though they expressed wanting to be involved in their care. Similarly, the scoping review and qualitative interviews identified medical terminology as a barrier. This challenge was reported several times with the patient developers in the qualitative interviews. Often times, guideline development groups included clinicians, researchers and other medical/health professionals. This created a heavily scientific setting with a lot of medical jargon that was hard for patient developers to keep up with. The need for an information sheet or prior training on medical nomenclature was mentioned when asking participants about what additional support they would need to help facilitate patient preferences in guideline development.

**6.1.2.2 Representing the patient population**
Current evidence found that having patient representatives was significant to accurately represent the disease population as they were able to emphasize the important nuances of patient experiences and challenges in order to develop more relevant guidelines (66,69,71,77). Although both the scoping review and the qualitative interviews found that patient preferences were identified by including patients on the guideline development panel, only the qualitative interviews revealed that participants also noted having patients on the guideline development panel as a possible best approach to identifying patient preferences. Participants noted that including patients early on, from the very beginning and in all development steps, was essential to optimizing the representation of the patient preferences. Additionally, it is important to note that there were barriers to representing the patient population/disease group. Both the scoping review and the qualitative interviews showed that there are challenges in capturing complex issues. This included difficulties in having the patient representatives represent the larger patient population, especially when it came to diversity. Participants in the qualitative interviews reported the need for ethnic, linguistic, religious, socio-economic and geographical diversity. It would be beneficial to consider including multiple patient representatives to encompass the diverse patient population in order to accurately better represent the target group.

6.1.3 Incorporate

Some research showed that incorporating patient preferences influenced the guideline development processes and recommendations (69,85,95). Development steps found in the literature included patient preferences influencing the conduct of guideline development, the scope, topics, outcomes, the development of recommendations and implementation and
dissemination of the guideline. When mapped to the Armstrong et al. framework, preferences were incorporated in multiple steps including: nominating guideline topics (Step 1), prioritizing guideline topics nominations (Step 2), framing the questions (including outcomes) (Step 4), developing a systematic review and forming conclusions (Step 6), developing recommendations (Step 7) and disseminating and implementing recommendations (Step 8), respectively. Two steps the scoping review did not incorporate patient preferences in that the qualitative interviews did were: creating an analytic framework and research plan (Step 5) and evaluation methods and impact of engagement (Step 10). Reasons for this could be that studies did not include their research plan in or may have already had a research plan developed prior to incorporating patient preferences. Evaluation may have been conducted concluding the study and/or not yet published or published in another following study and therefore may not have been reported in the studies included in the scoping review.

Between the scoping review and the qualitative interviews, the interviews found the more steps in which patient preferences were incorporated. When mapped to the Armstrong et al. framework, preferences were incorporated in multiple steps including: nominating guideline topics (Step 1), prioritizing guideline topics nominations (Step 2), framing the questions (including outcomes) (Step 4), create analytic framework and research plan (Step 5), developing a systematic review and forming conclusions (Step 6), developing recommendations (Step 7), disseminating and implementing recommendations (Step 8) and evaluating methods and impact of engagement (Step 10). Additionally, the interviews found that several participants explicitly stated that preferences were incorporated in all development steps/throughout the entire development process. However, both the scoping review and the qualitative interviews did not
incorporate patient preferences in two steps: selecting guideline development group members (Step 3) and updating (Step 9). This may be because most guideline development groups will have already been formed including patient representatives. The majority of guidelines that studies and participants were developing were new guideline topics and therefore did not mention the need for updating a guideline. If the guideline being developed was an update, it was not explicitly reported anywhere. Therefore it is important to acknowledge that these findings may be highlighting a need for further research to explore why these gaps exist.

It should be noted that no additional ways to incorporate patient preferences in guidelines were identified in either the scoping review or qualitative interviews. Therefore, the Armstrong et al. framework served as a suitable framework for this research.

6.1.3.1 Gaps in the evidence

Neither the background review, the scoping review nor the qualitative interviews explicitly noted incorporating preferences in selecting guideline development group members or in updating guidelines. This identified a gap in the evidence that could potentially explain why it was also not identified in the qualitative interviews by guideline developers, who often looked to the literature to learn how to go about including patient preferences in guideline development. This further advances the importance of providing support for developers. Although developers did utilize patient advocacy groups/organizations to recruit participants, preferences themselves were not incorporated in selecting guideline development group members. This step could be better applied when addressing the barriers to include diverse representatives in these development
groups. By taking into account preferences from qualitative or quantitative approaches, representatives and other development group members could be more thoughtfully selected. Additionally, using patient preferences to update guidelines was not explicitly reported. There is a need for developers to address how patient preferences could be incorporated to impact updating the guideline during the development process. In some cases, guidelines that have already been developed go through updates to stay current and relevant as time progresses. Therefore, research is needed on incorporating patient preferences in updating guidelines so that preferences may be engaged in the most meaningful way.

6.1.4 Report

Although the background review did not find literature that mentioned how patient preferences were reported in the guideline, or methods used for reporting patient preferences in the guideline, the scoping review found a few studies that did. These methods included either explicitly reporting the preferences/reporting them in their own separate section or embedding them within the guideline. The qualitative interviews further validated this finding as participants also reported using those two methods. It is interesting to note that some patient developers specifically reported that they had no idea how preferences were or were going to be reported in the guideline. This exposed a gap in the development process where patients are not kept in the loop and identified possible communication issues. If patient representatives are to be included in all development steps, it is important that they know how their preferences will be reported in the guideline.
6.1.5 Barriers

While the background review addressed determinants of guideline use, the scoping review and qualitative interviews found determinants for including patient preferences in guideline development. A multitude of barriers were identified from the scoping review and the qualitative interviews augmented our understanding of these. Process barriers included participants that stressed challenges with: meaningfully involving patient representatives and ensuring their voices were equally heard, identifying the right or knowledgeable patient, hard to capture complex issues and time commitment/scheduling. In most cases, guideline development panels only included one patient representative and that logistically made it difficult to identify the “right patient” that was knowledgeable, representative of the diverse community, able to speak on a multitude of experiences and felt comfortable speaking up. Time commitment was a notable challenge as scheduling meetings with the entire development group was difficult. Additionally, platforms used to conduct some of the qualitative or quantitative approaches sometimes had technical difficulties which caused confusion amongst participants. Patient barriers were also mentioned where patient participants reported their struggles with the medical terminology and their struggles to keep up with scientific abbreviations and content. Patients felt intimidated or nervous to speak up about important issues due to fears of sounding “dumb” or being shut down by other members of the development group. This could also stem from another barrier: clinicians’ attitudes about patient preferences. Some participants noted difficulties with clinicians who were older in age or more traditional in practice and who did not see the value of including patient preferences. It was also thought that including patient preferences may dampen the academic integrity or rigor of the guidelines as well. This research also found that the lack of
consistent nomenclature/language used around patient preferences and guideline work made it difficult to search the literature.

6.1.6 Facilitators

A highly interesting finding was the lack of facilitators to the inclusion of patient preferences found in the literature reviewed in both the background and the scoping review. The scoping review included only one study that reported facilitators that helped the patient preferences process in guideline development. Aside from the mention that training patient representatives was helpful to including patient preferences in guidelines, the other facilitators were only identified through the qualitative interviews: training for clinicians, patient advocacy groups, expert help, communication from guideline team, point of contact for patients and the chair/moderator. In general, studies conducting this research are not reporting facilitators nor do they aim to identify them, suggesting that researchers do not value this facet of guideline implementation research. However, in contrast, interviewees identified numerous facilitators to the inclusion of patient preferences in guideline development. So while facilitators are deemed to be impactful, they have been overlooked in studies published in the literature thus far. The qualitative interviews identified the need to also train clinicians on patient preferences so that clinicians may better understand the importance and need for it. Again, having a connection with patient advocacy groups/organizations was reported as being helpful, not only for recruiting patients but also as a good resource to check in with to achieve a more collaborative relationship. This also could have facilitated recruiting knowledgeable and/or experienced patients. Additionally, several different types of people were reported as facilitators. Some facilitators
were help from experts/people who work in the field. Having a good project or guideline manager to facilitate communication was also key. Many participants felt that having that point of contact to ask questions to or check in with was extremely helpful in understanding confusing components or making them feel more comfortable. Having a good chair or moderator that helped navigate meetings and ensure that patient preferences were being captured was felt to be important.

6.2 Strengths and limitations

6.2.1 Scoping review

This study featured both strengths and limitations. We searched relevant databases of medical literature with a search strategy that complied with standards (130), and employed rigorous searching and screening processes. Grey literature was also searched and employed using the same rigorous searching and screening processes. Comparison of the characteristics of research on patient preferences in guideline development, which features a greater volume of research accumulated from inception, generates learning and insight on the type of studies needed for exploring approaches used to identify, incorporate and report patient preferences in guideline development.

A few issues may limit the interpretation and use of these findings. Although we searched the most relevant databases of medical literature with a search that complied with standards (130), and employed rigorous searching and screening processes, all relevant studies may not have been
identified. Electronic databases have been known to misidentify research or to mislabel studies with incorrect MeSH terms, therefore, any errors on the part of the database could affect the comprehensiveness of the search strategies if important articles were missed. Two grey literature databases were searched but most of the empirical research was found in indexed databases. Publication bias, or the tendency for journals to publish studies with positive results or surveys with high response rates, may have influenced the number and type of studies that were retrieved. Given the wide range of processes and outcomes measured and reported across included studies, it was not possible to pool findings. However, the purpose of this study was to assess the state of research on patient preferences in guidelines to serve as a springboard for ongoing research in this area.

### 6.2.2 Qualitative interviews

This research has many strengths, notably, that this study is the first in which all types of guideline developers (managers, clinicians, patients) in Canada, the United States and internationally have been interviewed using qualitative methods to investigate their current practice of including patient preferences in clinical practice guideline development. Strengths of recruitment include, rather than a convenience sample that we aimed to collect data from a representative sample of organizations, clinician types and varying health conditions. Another strength was the agreement between developers (managers, clinicians, patients) that helps to confirm validity of the findings, which were outlined by diverse quotes from each type of developer under most themes reported in the results.
Some limitations of the present study must be noted. Participants were recruited initially through the Guidelines International Network, a global network of clinical practice guideline developers, implementers, clinicians, researchers, policy makers, industry representatives and consumers with some vested interest in the clinical practice guidelines field. Therefore, some form of participant bias may have been present. Furthermore, participant bias may have occurred as people interested and invested in the network may have participated more readily as a means to further develop the research within the network. Additionally, ARG is an active member of the Guidelines International Network, which could have swayed participants to volunteer if they recognized her name on the study and thus have been more prone to participate in the interviews.

As with any qualitative study, there are limitations of transferability of the findings to other populations. We attempted to involved diverse perspectives by including participants from across the world, however, practices and experiences of participants who live in countries other than the ones noted in recruitment may not be accurately represented. Additionally, a limitation specific to patient participants is that those who were not satisfied with their care or had concerns may have a vested interest in participating in research studies compared to patients who were completely satisfied with their care, potentially biasing the results to reflect poorer patient experiences. However, most patients were recruited via snowball sampling and not by self-identifying themselves for the study, which may have led to increased participation by both patients who had positive and negative experiences.

Finally, with regard to the Armstrong Patient Engagement Framework, a potential limitation to this study is that the analysis for “incorporating patient preferences” may have been different if
we used a different framework. However, we thoughtfully chose to use the Armstrong et al. (121) framework because it was the most comprehensive, meaning it assesses many aspects of how patient preferences could impact or influence the guideline development process and the recommendations, which made it the most relevant method to assess incorporating patient preferences.

6.3 Future Directions

This study was exploratory in nature and identified many approaches used by guideline development organizations to identify, incorporate and report patient preferences in clinical practice guidelines. These findings alone are an important step in identifying not only current practice but potential best practices as well. As a national and international study, there are many opportunities for potential future directions.

The knowledge acquired from guideline developers, although global, may not capture current practices being used in countries not included in the participant group. Continuing this study to further investigate the impact of geography, differing health systems and community versus urban settings may be important for establishing differences in approaches used to identify, incorporate and report patient preferences in clinical practice guideline development.

The findings of this study provided insight with regard to current and possible best approaches for including patient preferences. An important next step in this research would be to continue this research with guideline developers to employ recommendations/suggestions made by
developers to better assist them with including patient preferences. Exploring the two most frequently mentioned “best approaches”, i.e., including a patient representative on the guideline development and using multiple approaches, may also be important for establishing the best practice approach for specifically identifying patient preferences. Another future direction could be to provide further insight regarding identifying the “right patient” and the potentially important role that patient advocacy groups/organizations hold in helping these organizations recruit patient participants.

Translating the findings from this research to implementation is of high importance – organizations that develop guidelines should be aware of current and possible best practices that have been shared with us on including patient preferences in clinical practice guidelines. By way of this information, guideline development groups may have increased confidence on how to go about identifying, incorporating and reporting patient preferences in guidelines. Additionally, a number of recommendations have been suggested and reported in this thesis and it would be imperative to understand how these recommendations could realistically be implemented to improve the guideline development process by consulting policy-makers and government or government associated organizations. These organizations or individuals may be able to provide information about funding or structural limitations that we lack expertise in. Policy-makers may have an interest in these findings as they apply directly to health services quality improvements and may be relevant to patient engagement policy initiatives that are already widely endorsed and may be able to bring about practice implementation strategies.
Finally, this research may act as a resource to update the Guidelines-International-Network PUBLIC Toolkit. The Toolkit, comprising of international experiences and best practice examples of successful patient involvement could be updated using the findings from this study in order to support guideline developers who are considering involving patients in the guideline development process.

6.4 Conclusion

In summary, this research thesis explored existing evidence on patient preferences in clinical practice guidelines and the current practices and experiences of guideline developers (managers, clinicians, patients) in identifying, incorporating and reporting patient preferences in guidelines. Conducting a scoping review and qualitative interviews with 50 guideline developers (managers, clinicians, patients) provided much needed insight on approaches/processes being used and how patient preferences were impacting/influencing the development process, guidelines themselves, and how that was all being reported in the guidelines. Several approaches were highlighted: patient representatives on the guideline development panel, insight from clinical experts, qualitative approaches, quantitative approaches, conducting a review of the evidence, and/or using multiple approaches. Preferences were incorporated in the following steps: nominating guideline topics, prioritizing guideline topic nominations, framing the question, creating an analytic framework and research plan, developing a systematic review and forming conclusions, developing recommendations, disseminating and implementing recommendations, and evaluating methods and impact of engagement. Preferences were either embedded within the guideline or they were explicitly reported and/or in a separate section. Key barriers to involving
patient preferences included: meaningfully involving patients, identifying the “right” patients, difficulty in capturing complex and diverse issues, time commitment/scheduling, patients feeling intimidated or nervous, clinicians’ attitudes towards patient preferences, and medical terminology. Recommendations to support and improve patient preferences in guideline development were suggestions including: a framework or standardized approach, the need for explicit reporting of patient preferences, identifying the “right” patient early on, a patient database or repository, training for developer participants, training for patients on medical terminology, clearer lines of communication during the development process and greater support for qualitative research.

In conclusion, while the findings of this study added value to the current literature on patient preferences and clinical practice guidelines, there is still much work to do in terms of understanding how to apply these findings to create meaningful change and improvement, as well as research questions that remain unexplored. As guideline development shifts around the world to include patient preferences and patient input, poor evidence is available on approaches in doing so. Synthesized research and interviews with developers revealed that, while developers may be identifying preferences and said to be incorporating preferences, it is not clear if and how those preferences are influencing guideline development. Developers could incorporate preferences in many more guideline development steps, and explicitly report both the preferences and how they influenced guideline development and recommendations. Given little prior research, numerous barriers, and little additional insight gained from developers, more research is needed on approaches to optimize identifying, incorporating and reporting patient preferences in guidelines. It is essential that questions pertaining to this are explored and
answered using high-quality health services research. This research is pertinent to guideline developers and guideline users as well as health services and health policy stakeholders.


Optimisation of guideline adherence is associated with lower mortality in stable patients with chronic heart failure. Int J Cardiol. 2014.


education meetings and workshops: Effects on professional practice and health care outcomes.

Cochrane Database of Systematic Reviews. 2009.


30. Young AS, Klap R, Sherbourne CD, Wells KB. The quality of care for depressive and anxiety


40. Adams OP, Carter AO. Knowledge, attitudes, practices, and barriers reported by patients receiving diabetes and hypertension primary health care in Barbados: A focus group study. BMC Fam Pract.


compilation of implementation strategies: Results from the Expert Recommendations for Implementing Change (ERIC) project. Implement Sci. 2015.


2009;24(8):988–90.


100. Mercuri M, Sherbino J, Sedran RJ, Frank JR, Gafni A, Norman G. When guidelines don’t guide:


119. van der Ham AJ, van Erp N, Broerse JEW. Monitoring and evaluation of patient involvement in


Appendices

Appendix 1. Scoping review screening tool

BACKGROUND
Guidelines are produced to provide recommendations on how to optimize care delivery and patient outcomes. However, past research has shown that guidelines are underused due to multiple determinants (facilitators and barriers) including patient-, clinician-, institutional, organizational, and system-level factors. Efforts to overcome challenges and more broadly implementing facilitators to improve guideline use, including educational material and meetings, opinion leaders, audit and feedback, and pay-for-performance, have had inconsistent and limited impact. Past research has shown that guidelines that are based on or identify patient preferences are more likely to be used by patients and clinicians. However, research has shown that many guideline developers have not addressed patient preferences when developing guidelines. Improving the development of patient-relevant guidelines is widely advocated; yet, little guidance exists on how to do so. Therefore, primary research is needed to generate insight on best practices for developing patient-informed guidelines.

OBJECTIVE
This scoping review will synthesize published evidence on approaches for identifying, incorporating and reporting patient preferences in guidelines.

ELIGIBLE
Eligible studies will describe research of any design on how to identify, incorporate and report patient preferences in guidelines that are relevant to patients and/or clinicians for any condition, health services, or setting of care.

Populations
- Patients, including family, caregivers/care partners, patient advocates, or others with lived experience of the guideline-specific condition or experience with the health care system
- Guideline developers including managers or clinicians involved in developed guidelines
- Health care professionals who use guidelines

Intervention
Refers to processes for: (1) identifying/gathering patient preferences; (2) steps in the guideline development process during which patient preferences would be considered or that could be influenced by patient preferences; and (3) how to report preferences in guidelines (i.e. embedded in recommendations versus explicitly stated). Options include, but are not limited to the following:

<table>
<thead>
<tr>
<th>Steps in guideline development</th>
<th>Processes for identifying patient preferences</th>
</tr>
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<table>
<thead>
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<th>Method</th>
<th>Examples</th>
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<tr>
<td>Interviews</td>
<td>Semi-structured interviews with patient representatives</td>
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<tr>
<td>Surveys</td>
<td>Patient-reported outcomes questionnaires</td>
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<tr>
<td>Focus groups</td>
<td>Focus groups with patient advocates and clinicians</td>
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<td>Narratives</td>
<td>Experiences of patients and caregivers during guideline implementation</td>
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<tr>
<td>Observation</td>
<td>Observation of guideline usage in clinical settings</td>
</tr>
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</table>

The table above summarizes the potential methods for identifying and incorporating patient preferences in guidelines. Each method is described with specific examples to illustrate how they can be utilized in practice.
Nominate or prioritize guideline topics
Select panel members (clinicians or patients)
Establish or frame guideline questions
Create analytic framework or research plan
Specify treatment or outcome preferences
Specify risk tolerance preferences
Conduct/interpret systematic review
Develop preference data collection tools
Assist with collection or analysis of preferences
Interpret preference data
Prioritize preferences
Generate recommendations
Generate preferences content to include in guideline
Endorse/approve guideline
Assist with dissemination
Develop summaries/preference discussion tools
Evaluate processes

Guideline writing panel members
Summary/systematic review of published literature
Questionnaire
Interviews
Focus groups
Town hall
Delphi technique / modified Delphi technique
Public comment (online opportunity for comment on draft products for identifying patient preferences tables)
Other consensus technique

Comparisons
- Studies may examine single or multiple processes, or compare processes

Outcomes
- May include but not be limited to:
  - Identify stakeholder (i.e. patients, developers, health care professionals) views, awareness or knowledge about patient preferences or whether/how they should be considered and in what guideline development steps
  - Explore, observe or describe processes for identifying, incorporating or reporting preferences
  - Examine facilitators or barriers of identifying, incorporating or reporting patient preferences in guidelines
  - Assess the impact of patient preferences on processes used to identify, incorporate or report preferences; on guidelines and guideline-related products; on guideline use; or on patient, professional, organizational or system-level impact of guideline use

Study design
- English language
- Published from 2010 to current, which corresponds to the release of the G-I-N PUBLIC Toolkit, a compilation of evidence and expert opinion to that date on how to involve patients in guideline development
  - Once the G-I-N PUBLIC Toolkit was released, guideline developers became more aware of the need to engage patient preferences and therefore had the knowledge to know that they needed to do so
- Qualitative (i.e. interviews, focus groups, qualitative case studies, content analysis)
- Quantitative (i.e. questionnaires, time series, before/after studies, prospective or retrospective cohort studies, case control studies)
- Multiple methods or mixed methods
- Program evaluation

NOT ELIGIBLE
- Systematic reviews are not eligible but references will be screened to identify eligible primary studies
- Examine the effectiveness of clinical interventions (tests, procedures, treatment)
- Did not collect or consider patient preferences
- Publications in the form of clinical practice guidelines, editorials, letters, commentaries, protocols, meeting abstracts or proceedings
- Guideline manuals
- G-I-N PUBLIC Toolkit
Appendix 2. Scoping review search strategy

Database(s): Ovid MEDLINE: Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE® Daily and Ovid MEDLINE® 1946-Present

Search Strategy:

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## Appendix 3. Data extraction form

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<td>Identify</td>
<td>Incorporate</td>
<td>Report</td>
<td>How were preferences reported in the guideline</td>
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<td></td>
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<td>Approaches and processes used to identify patient preferences</td>
<td>Did patient preferences impact (change/modify) or influence the guideline development process, the recommendations and/or outputs and products</td>
<td></td>
<td>• Explicit</td>
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<td>• Patient panel member</td>
<td>• Topics</td>
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<td>• Embedde d</td>
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<td>• Focus group</td>
<td>• Key questions</td>
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<td>• Not at all</td>
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<td>• Interview</td>
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<td>• Survey</td>
<td>• Patient summaries</td>
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<td>• Systematic review</td>
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<td>• Delphi</td>
<td>What did they do with the preferences they found and how did they put it in the guideline</td>
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<td>• Other Details such as</td>
<td>• In what guideline development steps and/or products (i.e., guideline, tools, etc.) were patient preferences incorporated</td>
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<td>• Discussion and voting</td>
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<td>Answer questions such as</td>
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<td>• What did they do at the meeting?</td>
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<td>• What are the specific of what was done?</td>
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</table>
### Appendix 4. Data extraction form for barriers/facilitators

<table>
<thead>
<tr>
<th>Study</th>
<th>Barriers</th>
<th>Facilitators</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>factors that challenge identifying, summarizing, or incorporating patient preferences, and how</td>
<td>factors that help with identifying, summarizing, or incorporating patient preferences, and how</td>
</tr>
</tbody>
</table>
Appendix 5. Qualitative interviews invitation letter

<date>

Hello:

As a patient, clinician or manager involved in developing guidelines or with an interest in using guidelines, you are being invited to take part in a research study involving a single telephone interview of approximately 20 minutes. We will explore the barriers, benefits and impact of different approaches to addressing patient preferences in the guideline development processes. The information provided by yourself and others will be used to compile exemplar guidelines that addressed patient preferences; that knowledge will be broadly shared with the national/international guideline community in a variety of ways.

Participation in this study is entirely voluntary. The telephone interview will be conducted using a toll-free teleconference services and scheduled when convenient for you. All communications will be audio-recorded and converted to text. You do not have to answer any questions that you do not wish to, and can stop participating at any time. Your answers will remain confidential and you will not be identified in the audio-recording, or in any report or presentation that may arise from the study. All data will be kept on a secure computer network. Only the Principal Investigator and Research Associate will have access to the original data, which will be destroyed ten years after conclusion of the study.

To participate, please review the consent form and return the signed form by e-mail (claire.kim@uhnresearch.ca). Many thanks for your participation.

Best regards,

Anna Gagliardi, PhD
Appendix 6. Qualitative interviews consent form

Consent Form for Participation in a Research Study

Title
How to best identify, incorporate and report patient preferences in guidelines

Principal Investigator
Anna R Gagliardi, PhD
Scientist, University Health Network and Professor, University of Toronto
416.340.4800 x6642, anna.gagliardi@uhnresearch.ca

Introduction
You are being asked to take part in a research study. Please read the information about the study presented in this form. The form includes details on study’s risks and benefits that you should know before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask the principal investigators and/or research coordinator to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish including your friends and family. Participation in this study is voluntary.

Background
Considerable cost and effort is being used to develop guidelines that are not being used. Research shows guidelines that address patient preferences are more likely to be used because they foster patient-provider discussions about preferences for potential risks and outcomes. Little guidance exists to help developers generate preference-sensitive guidelines. There is a need for insight on the best ways of identifying, incorporating, and reporting patient preferences in guidelines to support patient-clinician discussions about preferences, treatment decision-making and guidelines use. Findings will be adopted by the Guidelines International Network (G-I-N), and broadly shared with their membership. Findings may help national and international developers to optimize processes and infrastructure for addressing preferences in guidelines. This may lead to increased use of guidelines by patients and clinicians and, ultimately, improve person-centered health care delivery, and health among Canadians.

Procedures
As someone involved in developing guidelines or with an interest in using guidelines, you are being invited to take part in a research study involving a single telephone interview of approximately 20 minutes. We seek to interview 30 developers and end-users overall including patients, clinicians and managers. The interview will be conducted by telephone (you will be provided with a toll-free teleconference number), audio-recorded and converted to text. The
audio recordings will be kept only by the Principle Investigator and Research Associate until data analysis has been completed and will then be deleted. We will ask you about the barriers, benefits and impact of difference approaches to addressing patient preferences in the guideline development processes. The information provided by yourself and others will be used to compile and share guidelines that addressed patient preferences and to update the G-I-N PUBLIC Toolkit, a widely used manual that describes how to generate preference-sensitive guidelines.

Risks and Benefits

There are no direct risks or benefits associated with your participation in this study. This study will not affect any clinical care. Please be advised that questions may potentially cause discomfort.

Costs and Reimbursements

No reimbursement is associated with participation in this study.

Confidentiality

Your answers and comments will remain confidential. An anonymous research code will be used to identify your responses, and you will not be named in any report or presentation that may arise from the study. All data will be kept on a secure computer network. A list linking your study number with your name will be kept by the study doctor in a secure place, separate from your study file. Only the principal investigators and research coordinator will have access to the original data and the principal investigator will keep any personal health information about you in a secure and confidential location for 10 years. For this study we will collect your name, work address, and work telephone number. This will be collected to allow us to communicate with you. The UHN Research Ethics Board may access study records to ensure that the information was collected correctly and to make sure that the study has followed proper laws and guidelines.

Voluntary Participation

Your participation in this study is voluntary. You can choose not to participate or you may withdraw at any time with no consequences to your current or future employment status. You do not have to answer any questions that you do not wish to, and can stop participating at any time.

Rights as a Participant

By signing this form you do not give up any of your legal rights against the investigators, sponsor or involved institutions for compensation, nor does this form relieve the investigators, sponsor or involved institutions of their legal and professional responsibilities.

Conflict of Interest

Researchers have an interest in completing this study. Their interests should not influence your decision to participate in this study.

Questions

If you have any questions, concerns or would like to speak to the study team for any reason please contact Anna Gagliardi [phone: 416.340.4800 x6642; email: anna.gagliardi@uhnresearch.ca]. Please note that communication via e-mail is not absolutely secure. Thus, please do not communicate personal sensitive information via e-mail. If you have
any questions about your rights as a research participant or have concerns about this study, call the Chair of the University Health Network Research Ethics Board (UHN REB) or the Research Ethics office number at 416-581-7849. The REB is a group of people who oversee the ethical conduct of research studies. The UHN REB is not part of the study team. Everything that you discuss will be kept confidential.

**Consent**

This study has been explained to me and any questions I had have been answered. I know that I may leave the study at any time. I agree to the use of my information as described in this form. I agree to take part in this study.

______________________________
Your Name (please print)

______________________________
Your Signature

_______________
Date

*You will be given a signed copy of this consent form*

My signature means that I explained the study to the above-named participant and answered all questions.

______________________________
Name of Person Obtaining Consent

______________________________
Signature

_______________
Date
Appendix 7. Manager and clinician interview guide

Hello. Thank you for speaking with me about how best to identify, incorporate and report patient preferences in guidelines. We are speaking with you and other developers, including patients, clinicians and managers, and will summarize and share the information with you. You may choose not to answer any questions. Your responses will remain confidential – you and your organization will not be identified in any reports. Before we begin, do you have any questions?

1. What guideline development organization do you represent? What is your role in the organization? What is your role in guideline development?

2. What do the words ‘patient preferences’ mean to you or your organization? Not how you identify them, which we will discuss shortly, but what is the definition of preferences? 
*Prompt: what type of preference did you consider when developing your guideline?*

3. What was the aim or motivation of your organization to address patient preferences? 
*Prompt: Why did your organization decide to capture preferences?*

4. What information or guidance or resources did you consult to learn how to identify and incorporate patient preferences in guidelines? 
*Prompt: How did you know or decide how to do it?*

5. For how long has your organization been addressing patient preferences (collecting, incorporating, etc.)?

6. Is that done for some or all guidelines that your organization develops? If some, how is the decision made?

7. In what ways are patient preferences identified or collected? In other words, using what approaches or processes do you acquire that information? 
*SEE table below for prompts: ask about venues, format, content, frequency, etc.*
*IF they use more than one approach ask:*
  - Is there overlap between approaches in preferences identified?
  - Which approach do they believe works best? Why/for what reasons?

8. How are patient preferences incorporated in guidelines? In other words, in what guideline development steps are patient preferences considered? 
*SEE table below for prompts*

9. How were decisions made about the relevance of preferences or how to incorporate them? 
*Prompt: voting, consensus, etc.*

10. How were preferences reported in the guideline? *Prompt: embedded or explicit?*

11. What factors challenge identifying, summarizing, or incorporating patient preferences, and how?
Prompt for patient and clinician characteristics, attitudes, knowledge and behaviour; organizational capacity, medical terminology, disagreement between patients and clinicians, time commitment

12. What factors facilitated identifying, summarizing, or incorporating patient preferences, and how?
   Prompt for processes, tools, resources, involving patients with prior experience, training, debriefing patients, having smaller sub-group meetings, having skilled moderator

13. Please describe the impact of patient preferences on the guideline development process?
   Did you learn something from the patient preferences that modified the development process

14. How have patient preferences modified the recommendation? Prompt: can you give an example

15. Did patient involvement impact anything else?
   Prompt for influence on guideline topics, development group members, questions, analytic framework, operational plan, evidence syntheses, recommendations, and adjunct products (i.e. summaries, preference discussion tools)

16. What resources were used by your organization to identify, incorporate and report patient preferences? Prompt for people, time, money, etc. *apart from guideline development tasks; specific to capturing patient preferences

17. How could patient preferences be better identified, incorporated and reported in guidelines?

18. What information or education or tools would help support your or your organization when addressing patient preferences?
   Do you need instructions or an educational workshop

<table>
<thead>
<tr>
<th>Steps in guideline development</th>
<th>Processes for identifying patient preferences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nominate or prioritize guideline topics</td>
<td>Guideline writing panel members</td>
</tr>
<tr>
<td>Select panel members (clinicians or patients)</td>
<td>Summary/systematic review of published literature</td>
</tr>
<tr>
<td>Establish or frame guideline questions</td>
<td>Questionnaire</td>
</tr>
<tr>
<td>Create analytic framework or research plan</td>
<td>Interviews</td>
</tr>
<tr>
<td>Specify treatment or outcome preferences</td>
<td>Focus groups</td>
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<tr>
<td>Specify risk tolerance preferences</td>
<td>Town hall</td>
</tr>
<tr>
<td>Conduct/interpret systematic review</td>
<td>Delphi technique / modified Delphi technique</td>
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<tr>
<td>Develop preference data collection tools</td>
<td>Other consensus technique</td>
</tr>
<tr>
<td>Assist with collection or analysis of preferences</td>
<td>Other?? &lt;please specify&gt;</td>
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<tr>
<td>Interpret preference data</td>
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<td>Prioritize preferences</td>
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<td>Generate recommendations</td>
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<tr>
<td>Generate preferences content to include in guideline</td>
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<tr>
<td>Endorse/approve guideline</td>
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<tr>
<td>Assist with dissemination</td>
<td></td>
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<tr>
<td>Develop summaries/preference discussion tools</td>
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<td>Evaluate processes</td>
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<td>Other?? &lt; please specify&gt;</td>
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</table>

Many thanks for speaking with me today
Appendix 8. Patient interview guide

Hello. Thank you for speaking with me about how best to identify, incorporate and report patient preferences in guidelines. We are speaking with you and other developers, including patients, clinicians and managers, and will summarize and share the information with you. You may choose not to answer any questions. Your responses will remain confidential – you and your organization will not be identified in any reports. Before we begin, do you have any questions?

1. Have you been/are you involved with an organization that develops/has developed a guideline?
   - What guideline development organization are you a part of?
   - Did you work on one or more guidelines?
   - For how long (in years) have you been doing this?

2. What do the words ‘patient preferences’ mean to you or your organization? What is the definition of preferences?

3. What is your understanding of why <the organization name> wants/wanted to capture patient preferences?

4. What information or guidance or instruction did they give you so that you would know what to do or how to participate?

5. What was your role, and what did you do?
   - Using what approaches or processes did they collect patient preferences from you?
   - Which approach or process worked best?

6. How were your preferences used?
   - In what guideline development steps or decisions were your preferences considered?

7. How were decisions made about whether and how to consider or incorporate patient preferences?
   - If there was disagreement or to ensure that all voices were heard, did they use voting or any other process to reach final decisions?

8. How were preferences reported in the guideline?
   - Were they embedded or explicitly noted?
   - Did you feel or see that your preferences influenced the final decisions or products?

9. What was challenging to you or your involvement?
   - Did you experience any barriers to being involved or voicing your preferences?

10. What helped you to participate?
    - What information or processes or support was provided that helped you to participate?
11. Please describe the influence and impact of the preferences you or other patients expressed on the guideline development process? 
   *Did they learn something from the patient preferences that modified the development process?*

12. How have patient preferences modified the recommendation? *Prompt: can you give an example?*

13. Did patient involvement impact anything else?

   *Prompt for influence on guideline topics, development group members, questions, analytic framework, operational plan, evidence syntheses, recommendations, and adjunct products (i.e. summaries, preference discussion tools)*

14. What could have been done to better help you to participate?  
   - What information or education tools would have been helpful?

<table>
<thead>
<tr>
<th>Steps in guideline development</th>
<th>Processes for identifying patient preferences</th>
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<tbody>
<tr>
<td>Nominate or prioritize guideline topics</td>
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<td>Establish or frame guideline questions</td>
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<td>Specify treatment or outcome preferences</td>
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<td>Specify risk tolerance preferences</td>
<td>Town hall</td>
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<tr>
<td>Conduct/interpret systematic review</td>
<td>Delphi technique / modified Delphi technique</td>
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<tr>
<td>Develop preference data collection tools</td>
<td>Other consensus technique</td>
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<tr>
<td>Assist with collection or analysis of preferences</td>
<td>Other?? &lt;please specify&gt;</td>
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<tr>
<td>Interpret preference data</td>
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<tr>
<td>Prioritize preferences</td>
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<td>Generate recommendations</td>
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<tr>
<td>Generate preferences content to include in guideline</td>
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<td>Endorse/approve guideline</td>
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<td>Assist with dissemination</td>
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<td>Develop summaries/preference discussion tools</td>
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<td>Evaluate processes</td>
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<td>Other?? &lt; please specify&gt;</td>
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</tbody>
</table>

Many thanks for speaking with me today
## Appendix 9. Data extraction table

<table>
<thead>
<tr>
<th>Study</th>
<th>Clinical/Guideline Topic</th>
<th>Research Design Participants</th>
<th>Objective</th>
<th>Patient Preferences</th>
<th>Findings</th>
</tr>
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<tbody>
<tr>
<td>Armstrong 2018 USA</td>
<td>Amyloid positron emission tomography (PET) imaging in patients with or at risk for dementia</td>
<td>Comparative (parallel group study) Two guideline development groups, one including patient representatives (experimental group) and one involving physicians alone (control group) 18 participants two methodologists, two facilitators, one dementia content experts, two dementia imaging content experts, seven members of the guideline subcommittee with and without dementia expertise and four lay participants</td>
<td>To investigate the effect of patient and public involvement (PPI) on guideline question formation and validate a conceptual model of patient and public contributions to guidelines</td>
<td>One time, 1-day-long in-person guideline question retreat/meeting at American Academy of Neurology headquarters in Minneapolis, MN on July 15, 2016 Participants received training regarding the topic and guideline development at the meeting and split off into experimental and control groups for discussion The two groups were asked to develop questions for the amyloid PET guideline, identify relevant benefits and harms, and craft patient-language versions of proposed questions</td>
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<tr>
<td>Li 2018 Canada</td>
<td>Venous thromboembolism</td>
<td>Qualitative study (face-to-face)</td>
<td>To explore how panelists adhered to panel chairs typically consulted</td>
<td>Panel chairs typically consulted</td>
<td>---</td>
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</tbody>
</table>
to-face meetings)

48 members from 12 countries, 8 of whom were patient representatives

GRADE criteria and south to identify any emerging non-GRADE criteria when panelists used the Evidence to Decision framework

patient representatives as a source for assessment of patient values and preferences when patient values were the topics of interest. A patient representative from one of the panels was asked for their perspective on doing an ultrasound to assess for silent deep vein thrombosis and the patient vocalized the benefits and harms for the procedures. Content experts also shared their clinical expertise and experiences on patient values.

Bennett 2017 USA (107) Integrated Cardiovascular Health

Multiple methods using a Modified Delphi process and focus groups. 11 participants selected from questions important for patients and caregivers

1) identify two high-priority clinical questions related to multiple chronic conditions (MCCs), and 2) understand patients’ and family caregivers’ perceptions of

Focus group participants shared their personal challenges in making decisions about medication choices and whether to take medications, given their other diseases and

--- --- Two important treatment questions were identified and related patient-important outcomes relevant for people with MCCs to inform the process of development recommendations for clinical practice guidelines.
with MCCs and 16 participants discussed high-priority outcomes for people with MCCs. Four 90min focus groups.

Two sets of focus groups (n=27) with patients and caregivers with multiple chronic conditions.

Meaningful outcomes to inform benefit/harm assessments for these two high-priority questions. Focus groups were focused on identifying outcomes most important to patients with MCCs. Plus two Delphi rounds where the entire team including patient and caregivers reviewed guideline topics. This process was focused on choosing topics for evidence syntheses that can ultimately inform clinical practice guidelines relevant for people with MCCs.

The two questions were: “of people with diabetes, are there groups of people for whom the balance between benefits and harms would affect the choice of treatment?” and “should target blood pressure be different for some groups of people?”

- Participants prioritized 130 topics and then combined similar topics to further synthesize the topic list.
- Participants created 12 summary questions 10 of which were excluded as they were ranked a lower priority.

Participants specified outcome preferences in the form of five broad categories: physical function and energy, emotional health and well-being, avoidance of treatment...
<p>| Goodman 2017 USA (89) | Arthritis Delphi study Panel of 11 patients with rheumatoid arthritis and juvenile idiopathic arthritis | To report on the significant contribution of the patient panel and to describe a successful model for increased integration of the patients’ perspective in guideline development. | The patient panel reviewed the evidence synthesized by the guideline literature review panel as each PICO questions was discussed. The patients addressed the PICO questions that informed the guideline project, reviewed and discussed the data, and formally voted anonymously on the drafted recommendations that were formulated from the PICO questions. When consensus was not achieved when voting, there was further discussion. | --- | --- | The patient panel and voting panel both voted on 7 recommendations, the panels agreed on the direction as well as the strength of recommendations. |</p>
<table>
<thead>
<tr>
<th>Pinheiro 2017 USA (151)</th>
<th>Oncology</th>
<th>Multiple methods study (Questionnaire and clinic conversations)</th>
<th>To identify physician and patient information preferences, as well as their preferences on who should communicate this information and how, to inform guidelines for these conversations.</th>
<th>The patient questionnaire included a pick-list of 18 topics from which patients were instructed to choose the 8 topics they most wanted to be discussed. Patients were asked who/what should inform them.</th>
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<tr>
<td>Zhang 2017 Canada (84)</td>
<td>Informing health outcomes with patient preferences in all guideline topics</td>
<td>Multiple methods (22 systematic reviews were conducted and qualitative input) clinical experts to provide feedback according to their clinical experience, and consulted patient representatives</td>
<td>To provide an overview of a process for systematically incorporating values and preferences in guideline development.</td>
<td>Guideline panel members and patient representatives with and without previous experience in the condition of interest were asked to provide their views on the relative importance of the main outcomes and their experience related to the disease of interest.</td>
<td>Guideline panels used the information when formulating recommendations. Panel members also made judgments about the variability and uncertainty about the values and preferences information. In several cases, local values and preferences contributed</td>
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</table>

Clarifying discussion and the votes were repeated until 80% or higher consensus was achieved.

Patients most frequently selected a discussion with their nurse physician (85%) and written information (67%) as their preferred methods for receiving information. Less preferred methods included internet (29%), short video (12%), and receiving the information from another patient (8%).

Several types of studies were found addressing the importance of outcomes, including those reporting utilities, non-utility measures of health states based on structured questionnaires or scales, and qualitative studies. Guideline panels used the relative importance of outcomes based on values and preferences to...
significantly to the formulation of recommendations.

<table>
<thead>
<tr>
<th>Study</th>
<th>Disease</th>
<th>Study Type</th>
<th>Methodology</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>den Breejen 2016 The Netherlands (152)</td>
<td>Fertility</td>
<td>Qualitative interview study</td>
<td>Interviews with 12 infertile couples and 17 professionals</td>
<td>Infertile couples broadened the scope of the clinical practice guideline by adding patient-centred aspects of care (i.e. expectations on information provision, taboo on infertility, poor alignment of care, lack of attention to work, lack of support after treatment, too much standard treatment according to protocols, poor physical environment and time pressure) or addressing patient-centred aspects in professionals’ issues (i.e. the lack of emotional support and the lack of respect and autonomy).</td>
</tr>
</tbody>
</table>
| Fraenkel 2016 USA (153)      | Rheumatoid arthritis | Pilot comparative study         | To determine the feasibility and value of developing clinical                | The patient panel was able to develop recommendatio...
<table>
<thead>
<tr>
<th>Voting panel and 10-member patient panel (3 Caucasian men, 5 Caucasian women, 1 African American woman, 1 biracial woman)</th>
<th>practice guideline recommendations</th>
<th>evidence-based medicine and guideline development.</th>
<th>ns for 16/18 PICO questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Farrell 2016 Canada (109)</td>
<td>Deprescribing proton pump inhibitors, benzodiazepine receptor agonists and antipsychotics</td>
<td>National modified Delphi consensus process and scoping exercise 11 family physicians, 8 geriatricians, 36 pharmacists and 10 nurse practitioners from 8 Canadian provinces</td>
<td>To develop and apply a process for developing “deprescribing” guidelines by drawing on existing methods guidance (i.e. GRADE, AGREE II and input from clinical experts)</td>
</tr>
</tbody>
</table>

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<p>| Hämeeen-Anttila 2016 Finland (154) | Health technology assessment Qualitative study (focus groups) N=20, with 14 patient organization representatives. | 1) discover ways to involve patients in health technology assessment and clinical practice guideline processes, 2) describe challenges, and 3) find ways of informing patients about health technology assessments and clinical practice guidelines in Finland | One-day seminar consisting of 3, 1 hour focus group discussions. Focus group participants highlighted the important of gathering patient views from a group of patients, rather than individuals. | --- | --- | Focus group participants highlighted the importance of gathering patient views from a group of patients, rather than individuals. Surveys through patient organizations were the most frequently mentioned means of gathering patients’ views. Possible strategies to involved patients in health technology assessment and clinical practice guideline processes were incorporating patient representatives in the clinical practice guideline and health technology assessment groups, offering timely possibility to participate, and ensuring reporting with clear and unambiguous language. |
| Purification 2016 Canada (155) | Radiation therapy | Multiple methods (review and in-person workshop) | To present the rationale behind the selection of 12 guidelines as recommendations for successful integration of patient engagement in Canadian rational therapy service delivery. | Phase 1: environmental scan, a comprehensive literature search was carried out for patient engagement phase 2: internal and external review, patient representatives were recruited to sit on the steering committee and the patient engagement working group meetings phase 3: public review and finalization, the workshop was attended by leading patient engagement experts from across Canada, a third of attendees were patients. All phases made use of the perspectives, expertise, and first-hand experience of patient representatives. | --- | --- | Phase 1 allowed for the identifications of 18 guidelines, at the end of phase 2, the document had expanded from 18 to 21 guidelines. These 21 guidelines were brought to the day-long workshop in phase 3, the document underwent a final revisions in order to apply each guideline to a specific level of public engagement and concluded in 12 guidelines as recommendations. |</p>
<table>
<thead>
<tr>
<th>Author</th>
<th>Country</th>
<th>Theme</th>
<th>Methodology Description</th>
<th>Interview scheme focus</th>
<th>Formulated recommendations</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Utens 2016 The Netherland (156)</td>
<td></td>
<td>Pharmaceutical coverage</td>
<td>Qualitative study (semi-structured interviews) 7 Dutch researchers, 4 policy makers and clinical practice guideline developers, and 4 patient representatives with interviews lasting 45 minutes at most. To explore the opinions of Dutch stakeholders on how to integrate evidence on patient preferences in pharmaceutical coverage decisions and clinical practice guideline development, and which issues may be encountered.</td>
<td>The interview scheme focused on the definition of patient prefers; how to integrate evidence on patient preferences in decision-making; and barrier and facilitators.</td>
<td>---</td>
<td>The findings highlight the need to accommodate patient involvement and input into the professional and evidence-led process, and the need for additional resources. A dialogue-based approach appears a promising method, enabling a broad range of stakeholders to provide input tailored to the guideline topic and key research questions.</td>
</tr>
<tr>
<td>van der Ham 2016 The Netherlands (119)</td>
<td></td>
<td>Employment and Severe Mental Illness</td>
<td>Case studies and interviews. Nine guideline development group members (two patient representatives, one of whom during the process no longer formally represented a patient organization). Two of the twelve members of the advisory committee were patient representatives, one of whom joined halfway through the process. The aim of this study was to gain better insight into the quality of patient participation in the development of clinical practice guidelines and to contribute to approaches for the monitoring and evaluation of such initiatives.</td>
<td>Eight case studies and patient representatives in the guideline development group and advisory committee, and focus group discussions. Some 26 semi-structured interviews were undertaken in three phases of the guideline development process. These approaches were used to identify patient preferences for guideline topics and key questions.</td>
<td>Formulated recommendations concerning five key research questions. For each session, a summary report was produced and sent to the participants for a member check. Member of the guideline development group assessed the case descriptions and subsequently formulated additional questions.</td>
<td>---</td>
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<tr>
<td>Pittens 2015</td>
<td>The Netherlands (115)</td>
<td>Gynaecologic patients for resumption of (work) activities</td>
<td>Qualitative (focus groups)</td>
<td>To assess the effectiveness of the involvement of gynaecologic patients in the guideline development for resumption of (work) activities after surgery.</td>
<td>Three focus group discussions were organized to identify patients' perceived problems and needs concerning received peri-operative care and counselling in resumption of (work) activities. Patients were primarily consulted for the development of the patient version, although their input also influenced the recommendations for resumption of (work) activities after surgery.</td>
<td>Patients were involved in the development of the script for an instruction video, which was part of the web-based patient version of the clinical guideline, and patients tested the web-based patient version of the clinical guideline. Patients’ input for the clinical guideline contributed to the formulation of some additional topics for the recommendations, mainly being reflected in the tailoring of the topics for recommendations to more complex daily activities. For the web-based patient version, the contribution of patients to the intervention was substantial. Almost all topics introduced in the focus group will be part of the final clinical guideline.</td>
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<tr>
<td>Serrano-Aguilar 2015 Spain (118)</td>
<td>Systemic Lupus Erythematosus</td>
<td>Multiple methods (systematic review and Delphi-based consultation) (n=22, reported in 24 articles) systematic reviews. The guideline development group was 16 representatives from all relevant scientific and professional groups related to Systemic Lupus Erythematosus (SLE) management. A patient representative was also recruited. 102 patients participated in the consultation.</td>
<td>To incorporate patients' perspective in the design of a clinical practice guideline for SLE in Spain. First, a systematic review of the international literature focused on health problems and perceived health care needs by SLE patients. Second, a consultative and consensus process was carried out. Three open questions were explored (1) the main health problems and self-perceived needs of care associated with SLE, (2) unsatisfactory aspects of health care for SLE patients in the Spanish National Health Service, and (3) specific therapies of interest beyond Conventional treatments. Third, a</td>
<td>The research team reviewed the results of the systematic review, seeking to identify common and relevant topics. These topics were integrated with the issues that emerged from the patient consultative process and were presented at the first meeting of the guideline development group to feed the identification of key questions underpinning the clinical practice guidelines. Once a preliminary list of key questions was prepared, a research member compared Key questions identified by patients that were finally included into the clinical practice guideline are explicitly outlined in a table and preferences were checked to see if there was any overlap between approaches.</td>
<td>From the SR, most relevant health problems are classified as physical, psychological, familial, and socio-economic. Dissatisfaction is mainly due to unmet information needs and limited access to care. In the consultation (n=102), most frequently reported health problems were pain, fatigue, photosensitivity, mood disorders, renal damage, poor concentration, and memory loss. Dissatisfaction with poor coordination between primary and specialized care was reported. Information to improve self-management and on alternative therapies was requested.</td>
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A patient representative was recruited for the guideline development group from the beginning to the end of the clinical practice guideline development process. These questions with the issues highlighted by patients and by the systematic review to warrant their inclusion among the key questions. At a subsequent guideline development group meeting, the results of this comparison were presented and agreed after discussion. Relevant topics from both sources were merged and discussed by the guideline development group (including a patient representative) to set the key questions underpinning the clinical practice guideline.

<p>| Garcia-Toyos 2014 Spain (157) | Opioid Analgesic Use in Terminal Care | Qualitative study (semi-structured interviews) 42 terminal patients (n=22) and caregivers (n=20) | To identify the values and preferences of terminal patients and their caregivers regarding treatment with opioids and on the desirable outcomes; to investigate the motives for the acceptance or rejection of opioid treatment and to evaluate their beliefs and information received about these drugs | The interview script was developed from review of the literature and consultation with healthcare professionals involved in the clinical practice guideline preparation | --- | --- | --- |</p>
<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Dep/cancer</th>
<th>Study Type</th>
<th>To explore how clinical practice guidelines can be adapted to facilitate shared decision making</th>
<th>Two structured group discussions were conducted to build the interview scheme for the semi-structured interviews.</th>
<th>---</th>
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<th>Interviewees suggested including a separate chapter on the importance of shared decision making, to use language that encourages patient involvement, and to develop patient versions of guidelines.</th>
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<tr>
<td>van der Weijden</td>
<td>Depression or</td>
<td>Qualitative study (group discussions and semi-structured interviews)</td>
<td>75 experts in guideline development or shared decision making participated in group discussions at two international conferences. 20 health professional experts in depression or breast cancer, experts on clinical practice guidelines and/or shared decision making, and patient representatives were interviewed.</td>
<td>Two structured group discussions were conducted to build the interview scheme for the semi-structured interviews.</td>
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<tr>
<td>2013 The Netherlands</td>
<td>breast cancer</td>
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<tr>
<td>Den Breejen</td>
<td>Infertility and</td>
<td>Telephone interviews and an online wiki website/tool</td>
<td>The objective of this study was to assess the feasibility of the wiki as a participatory tool for patient participation in clinical practice guideline development.</td>
<td>In-depth interviews were conducted to obtain initial content for the wiki. Over 7 months, infertile patients were invited through advertisement or mailings to formulate new or</td>
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<td>2012 The Netherlands</td>
<td>adoption</td>
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<td>12 in-depth interviews with infertile patients and 298 unique wiki visitors and a guideline develop</td>
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A group that included 2 patient representatives was established to modify existing recommendations. The guideline development group assessed the eligibility of the final set of recommendations. The first part of the interview consisted of open-ended questions, related to thoughts underlying the identified influencing factors on adoption and potentials for improvement of the wiki.

| Tong 2012 Australia (159) | Early stage chronic kidney disease | Descriptive study | To describe a targeted approach for involving consumers actively in guideline development, by focusing on topic and outcome selection, and to discuss the impact on content and structure of the final guideline. Three peer-facilitated workshops to complete group-based exercises on topic and outcome selection for guidelines for early stage chronic kidney disease. Participants formed small groups and facilitated their own discussion, recorded their responses and presented them to the wider group. An additional guideline subtopic was included titled, “Symptoms, natural history, and outcomes of chronic kidney disease.” | --- | --- | by the guideline development group and all 21 recommendations were approved. |
A guideline development group of 12 members including 3 patients, 3 GPs, 3 orthopedic surgeons and 3 other health care professionals was created to develop a referral guideline for patients with chronic knee pain that explicitly incorporates patients’ preferences. Review of the literature and subsequent rapid reviews of areas of uncertainty and of existing clinical guidelines for the management of osteoarthritis of the knee. A questionnaire was mailed to the members of the guideline development group asking them to rate their agreement with the 12 recommendations for primary care as well as

| Musila 2011 England (113) | Referral for patients with osteoarthritis of the knee | Case studies | At its first meeting, the guideline development group defined key concepts: osteoarthritis of the knee, the referral decision and the concept of an appropriate referral. Four additional topics were identified: role of an x-ray of the knee, patient satisfaction after knee replacement, revision rates after primary knee replacement and age and sex-specific mortality according to the National --- | Members’ ratings of referral appropriateness for the 108 case scenarios were strongly influenced by symptom severity and patients’ preferences (P < 0.001 for both). Co-morbidity also influenced the group’s rating (P < 0.001), but its impact was relatively small. Age and body mass index (BMI) did not have a significant impact (P = 0.2 for both). The influence of patients’ preferences depended on the |
| O'Brien 2011 Canada (114) | HIV rehabilitation qualitative (interviews and focus groups) 28 participants including people living with HIV, researchers, clinicians, educators, and policy stakeholders with expertise in HIV and rehabilitation (12 in the first focus group, 4 in the second focus group, and 12 key information interviews) | Our purpose was to develop process recommendations and guiding principles for future clinical practice guidelines in HIV rehabilitation. Participants responded to a series of semistructured questions to explore recommendations and guiding principles for the development of clinical practice guidelines in HIV rehabilitation. Focus groups and interviews participants were specifically asked to discuss (1) their experience with, or general | Results of the focus group and interview data yielded recommendations and guiding principles for the development of clinical practice guidelines in HIV rehabilitation. Each of the seven process recommendations were reported with supporting quotations included. Twelve themes emerged that informed the development of guiding principles and were then grouped into three guiding principles for the development of clinical practice guidelines and were reported with supporting quotations. seven recommendations for the process of developing clinical practice guidelines in HIV rehabilitation that spanned areas of: flexibility scope adopting existing evidence from concurrent health conditions format interprofessional approach to development implementa | with the appropriateness of referral of patients described in the 108 care scenarios. 108 case scenarios were designed based on five patient characteristics presented: age, symptom severity, body mass, co-morbidity and patients’ preference for referral. Joint Registry. At the second meeting, following discussions of each rating, the group members had the opportunity to re-score their personal views. During this process, a number of practice recommendations were modified to clarify any perceived ambiguities and subsequently rescored. severity of symptoms (P for interaction <0.001). Patients’ preferences had a greater impact when knee symptoms were moderate or severe than when they were mild. |
knowledge of, the development or use of clinical practice guidelines; (b) considerations that should be taken into account when developing clinical practice guidelines in the context of HIV; (c) how guidelines in HIV rehabilitation might be used (i.e., purpose, scope); (d) who should be involved in HIV rehabilitation guideline development; and (e) who could use the guidelines.
Appendix 10. Consolidated themes and exemplar quotes from qualitative interviews

Participant views: Define patient preferences

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
<th>Manager</th>
<th>Clinician</th>
<th>Patient</th>
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<tbody>
<tr>
<td>What matters to patients</td>
<td></td>
<td>• a broad category of means of identifying what matters to patients and how that’s included in guideline development… So what is a primary importance to them and that’s not necessarily what we always recommend but it’s something we should always be taking account of (22M)</td>
<td>• A preference on what are their priorities (39C)</td>
<td>• It’s really guided by what the patient prefers… sometimes some of those considerations that are important to patients aren’t necessarily addressed (24P)</td>
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<td></td>
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<td>• So both their lived experience but also representing patients in general as to how they actually feel about the topic that we’re discussing. And what is important to them as a patient rather than just what the clinical evidence says (15M)</td>
<td>• I think that it is important to recognize that what physicians and guideline developers think is important may not necessarily be a priority that is shared by patients (26C)</td>
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<tr>
<td>Deciding patient outcomes</td>
<td></td>
<td>• that they help guide the experts in deciding what are the most important outcomes for patients (18M)</td>
<td>• it’s a patients desire to achieve one outcome over another (20C)</td>
<td>• Preferences that the patient needs when making certain decisions about their care...it differs based on what the patient needs (10P)</td>
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<td></td>
<td></td>
<td>• patient preference it really encompasses how the patient feels about interventions and outcomes (23M)</td>
<td>• we review the outcomes that might occur as a result of the interventions we are making guidelines around and we’re gathering input from a variety of patients as to how they value each of those outcomes because they’re often be, the double edge of a single sword or two sides of the same equation they’re the risks, they’re the harm and</td>
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then there's the avoided outcomes, the avoided harms that are the benefits. And what we do by getting preferences is find out what, how patients value those various options (20C)

| Treatment decision making | • What they desire…what they would desire based upon their treatment, so patient preferences are important in their decision-making when they are navigating their treatments (38M) | • There are different options available then you should inform patients about the benefit and harms of all those options…you have patients who prefer medicine or drugs; they feel safe when they use drugs. But you also have patients who hate drugs (34C) | • patient preference is a perspective from a consumer in terms of how acceptable that particular treatment option would be to a patient in that circumstance (44P) |
|                          | • issues they see as important and…what’s important to them when it comes to treatments and different care packages (08M) | • I think when you think about patient care and patient preference the whole idea is you know giving patients choice, helping them to arrive at care that’s appropriate for them and facilitating that; facilitating their ability to make the decision (35C) | • The individual requirements of the patient to best understand the needs of the drug in relation to their treatment or disease and to be able to maintain their most optimum quality of life while taking the medication (40P) |
|                          | Well I guess it’s what patients, what their values and their thoughts are on what they would like to happen in the process of their treatment (28M) | • There are different options available then you should inform patients about the benefit and harms of all those options…you have patients who prefer medicine or drugs; they feel safe when they use drugs. But you also have patients who hate drugs (34C) | • a patient is consulted about the care and treatment and given the options and so that they can then be actively involved in the decision-making process and actively choose what they want in care and treatment (49P) |

| Patient choice | • whether you like one alternative or another… having choosing option over the other option (23M) | • despite evidence in many instances there are still several options that you can pursue…the direction in which you go really should be informed by what’s most important to the patient (25C) | • Making choice based on what would work best for me as an individual dealing with the disease (21P) |
|                | • something that’s preferred to something else or either something else (17M) | • What their choices are; what they would choose for as far as treatment goes…the patients | • having choices… giving choices in terms of how they are given or receiving the care instead of just you know say, oh this is what we have and share (42P) |
|                |                                                                                         |                                                                                         | • expressing a choice and an informed |
Patient centered care

- so we believe that patient preferences is, well is the part of what we call person-centred care (12C)
- Well it’s actually a big part of person-centred care (31C)
- it means how patients want to be treated in order to give good quality of care (53P)

Shared decision making

- it’s ensuring that...we’re consulting with them throughout the journey that they’re involved in the decision-making process (18M)
- when I think of patient preference I think of shared decision-making (25C)
- talking to the patient to see, to let them know that the, as a clinician this is the information on the topic but that the patient has the right also in to share cared decision-making and to know, to be informed of all of the options and also has the option to tailor what their decision is for their care based on their preferences (12C)
- enabling shared decision-making to a greater degree (24P)
- it would be between a discussion that would happen between myself and the physicians that are taking care of me...I think it has to be made, decisions like that have to be made in consultation with the physician. So I can, I can let the doctor know what my preference is but the doctor to me will have more information that can help me understand that situation better that I might be facing and that can help fill in some blanks and then I would, for me I would always make the decision based with the doctors guidance (32P)

Participant views: Aim/motivation

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
<th>Manager</th>
<th>Clinician</th>
<th>Patient</th>
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<tbody>
<tr>
<td>Represent patient perspectives</td>
<td>• the point of talking with patients about their values and preferences was a lot of the times the evidence might say one thing, but that's not what actually, what people actually care about (13M)</td>
<td>•</td>
<td>• having an understanding of what people go through would probably help (42P)</td>
<td>• it’s important to try and get a consumer voice because some people might</td>
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<tr>
<td>To develop more relevant guidelines to increase uptake and benefit patients and patient</td>
<td>• advocating and reflecting the values of consumers throughout the whole organization... ensuring that the recommendation meets the needs of and what the real important issues are for consumers in their recovery from &lt;disease&gt; (18M) • patients bring another perspective which is very important and you know really healthcare really aims to improve patient outcomes (23M)</td>
<td>• assume that patients are not prepared to take any risks but in fact...the benefits outweigh the risks from the patient perspective...to take some risk. They just need to have them very clearly explained to them so they can make a more informed choice (44P)</td>
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<td></td>
<td>• to develop more relevant projects and guidelines for the consumers as well as the clinicians. So there’s a consumer engagement in buying to what you’re doing (17M) • we want the patients to be able to access them and sometimes our patients help us to explain things in terms in which other patients would also be able to understand (41M) • clinicians might say anything they want but if patients do not think that it is important; what clinicians say will not be implemented. So patients should be in the middle; should be at the centre of whatever decisions are made (50M)</td>
<td>• to make sure that they were relevant and that we were considering all of the facets that kind of encompass the healthcare and how the patients would also help with some of the knowledge translation; if they were aware of what some of the recommendations were for their particular areas because often what we’re dealing with are a rare condition (06C) • you’re making it such that you know if clinicians do take it up and to implement the guideline then the language will be such that patients will be happy with it and that you’ll have • Probably some of the information that they develop reaches people in a way that is most effective to have them respond (30P) • is like you know trying to identify some of those key elements that patients may have and that are ideally or really in some ways guided by the patient really in practice, right? I mean ultimately that the patient you know if you don’t incorporate preferences I would think you know you probably would get less adherence I guess in the big scheme of things (24P) • provide a consumer voice that would guide the adoption of or otherwise of that particular guideline...It’s not only because it’s important to</td>
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</table>
| Think about the population the guideline will be affecting | a higher uptake (12C)  
- More patients will actually get the benefit of your guideline (12C)  
- provide that voice and understanding of what it would mean for the patient but also because if there is a, it might…to a high likelihood that patients are going to adopt that treatment regime if in fact it’s something that we think they’re going to prefer as another treatment method (44P) | It was determined that because we were making recommendations that would directly affect patients and the public that those people should be part of the decision-making process… we knew that we were going to be making decisions that would affect people and that treatment in care that those people should have the opportunity to be part of that decision-making (22M)  
- I don’t think we should be having any conversation about patients or about diagnosing or treating patients without having a patient in the room (15M) | Well I think that when you have guidelines it’s useful to think about the audience or maybe not the audience; think about the population you know that it’s going to be affected by that guideline. And so, you want to sort of have that lens in mind (14C)  
- Well first of all, there is a movement among the <>world. But if you’re going to do research endeavours that you should have not only scientists of clinicians on your team but you should also have members of the community because this research is directly impacting their lives. And so, we really believe and they believe that there should be community members on your research team from the beginning (14C)  
- I think it has another dimension to the care model. As clinicians and researchers I think you can get very focused on the theoretical but patients will give you that real-life perspective on how the guidelines impact them (54P) |
| Currently a trend in medicine | • you see a trend towards more evidence-based, more, get more stakeholders involved; it’s all faces of guideline development including the patient. It’s also a trend in society, western world that you in the world of democracies that you once will have the citizens and the patient voice included…But it’s a trend and it’s a quality criteria, it’s a trending society in all western countries. So that’s why we do this (34C) | • Well I believe you want an honest answer here. So I believe that they would like to have patient family advisors involved because that’s the trend and it’s trendy in medicine (32P) | • the pendulum has definitely switched from you know physician kind of giving people informed consent and saying, you agree or disagree; to realizing that, oh no, this is a much more of a discussion. This truly is shared decision-making and recognizing that the literature can only support you so much. I mean if you, when you’re around long enough you start to realize that oh, this kind of level I evidence, 5 years ago is now no longer recognized as reliable anymore, that’s not what we’re doing. We’ve changed, we’re doing this now. So I think the, as prescribers and consumers because |
we’re all patients too, we start to realize that it is patients preference really matters; it’s a decision-making process where you’re given this is the facts, this is the way it is; the strength in the literature lies here (35C)

<table>
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<tr>
<th>Requirement of established standards or stakeholders</th>
<th>we try to follow the IOM or the National Academy of Medicine Standards for developing trustworthy guidelines. And one of those is to incorporate important stakeholders and one of those is patients (23M)</th>
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<tbody>
<tr>
<td>• You know I will be honest… at our most kind of cynical level or we could say that one of the motivations was, it was becoming obvious that this is something that is required by stakeholders. So for instance, if you want to get the guidelines published? If we want to give good uptake it is sort of becoming a standard that is required (33C)</td>
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<td>• So it is standard in &lt;disease&gt; work to include patients and community members right from the beginning in projects. And so, and then, so and then that makes our research more commonly done through a principal known as community-based research and then that fit quite well into the &lt;country&gt; model of integrated knowledge translation (12C)</td>
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<td>• we a strive to fulfill the recommendations from they, what used to be the Institute of Medicine, guidelines</td>
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<tr>
<td>• So it can nearly be a requirement now for some of the guidelines that they need to have that patient participation from the start (46P)</td>
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on guideline development and obviously patient preferences included are an important aspect of inclusion in that (26C)

Patients are needed to pass quality appraisal

we would go through some kind of quality appraisal tools that would mean and you wouldn’t pass quality appraisal without having patients represented in some format (19M)

- Well first of all, it’s a quality criteria (34C)

### Participant views: Information/guidance

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
<th>Manager</th>
<th>Clinician</th>
<th>Patient</th>
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</table>
| Did not consult any information or guidance | • we didn’t find anything out there in terms of guideline development that tells you how to engage patients or community members how to consider their preference (01M)  
• None to be honest (19M)  
• Actually zero. So yah, that’s a very good question you asked and you know now I’m curious what is out there. But we did, we did it without it… I have to admit, we’ve never sought clear guidance on it. But I also would not know where to start looking for it. So we kind of developed our own system and we have yet to see how that is received. If it’s really you know helping physicians in their clinical care | • So the short answer is no. We looked, we used the integrated KTE lens, not the patient preference in guideline lens (12C)  
• I’m not sure that we consult any formal place to do that… I’m not sure that we had formal guidance (14C) | • I don’t think there was any particular information (44P) |
| Some information, background information or guidance was provided | decision-making that way, right? (27M) | • They let you know a little bit of the background of the department or whoever’s looking for the patient family advisor. And then you, they let you know a little bit about the project and then you’re on your own (32P) |
| Relied on familiarity with process from their experience | | • So initially I was given kind of the general information in relation to what the group was actually doing; what the aims of the group were and following every meeting, before every meeting the information related to that meeting would come out (47P) |
| | | • I was provided with some information to help me with you know there’s a guideline that they were starting the process with (56P) |
| | • in our group of clinicians we almost all do some level of participatory research with community members…So we really had to use this research methodology or tradition that we’re more familiar with as our guiding framework for | • I mean many of us who worked on this have worked on other endeavours and projects before with this community and it’s sort of an accepted thing that you bring in community members (14C) |
| | | • I think most of it has been based on internal discussion |
| | • Well to be honest with this particular one that, I mean I had been involved as a patient advisor in various projects. So I mean at least for me I had a general sense. I mean I’ve read clinical practice guidelines and that, so there |
really know how to include in an equal way the preferences or opinions and expertise of community members (01M)
• we really did sort of build up a methodology for patient and public involvement and other developers are now learning from us (08M)
  it was based on the skills, knowledge and experience of the people working in the public involvement program. Those of who were here when <organization> was first formed have been working in patient and public involvement for some time and some of us have developed guidelines with patients before <organization> was formed as an organization. And so we brought with us personal knowledge and experience and practical knowledge and experience of how to do this (22M)

| Sought out resources from other groups | • So I’ve sort of sought other you know for other resources in terms of other, how other groups have done it (02M)  
| | • We looked to see what other groups are doing. I went to a, the GIN conference two years ago and went to a special workshop there… |
| among the committee of people who were involved in guideline development (26C)  
| | So it’s not new, you follow-up on what you did earlier (34C) |
| wasn’t like a lot provided and I honestly, when I think of like the patients that are involved with that particular project you know they are pretty experienced (24P) |
•
There’s been focus on groups and a study by <name> and we followed some of her ideas (28M). We went to GIN a couple of years ago and (name here) did a presentation about patient preferences and she’s got a couple of studies that she has and I’ve used that definitely to take a look at you know how, how do reach patients and how to, how to have that effective consumer patient relationship and we’ve used some of the work that Armstrong’s group has used (38M).

We are closely aligned. The other organization with whom I do a lot of work is the <organization> or the <organization which is the <organization name>. That organization is, it’s a research organization… And so there was a lot of discussion with them and best ways to integrate patients in. And I can tell you it is absolutely a work in progress (33C).

### Approaches and processes used to identify patient preferences

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<tr>
<td>Recruit patients</td>
<td>Advocacy groups</td>
<td>• We approached patient groups to identify patients (07M)</td>
<td>• we do try and identify patient representatives from advocacy groups (06C)</td>
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<td>• we partnered with patient advocacy groups not only to have their advocacy groups represented within our panels but also working side by side with patient advocacy groups to make sure that the guideline and the recommendations that we come up with are directly fed into the patient advocacy groups through their</td>
<td>• by going to one of the you know patient advocacy groups, we felt like in addition to getting a patient, we would have someone that had a greater voice; that had a connection to a large group of patients with that particular disease (25C)</td>
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<td>Involved in all stages and activities of guideline development</td>
<td>Having patients on panel/committee</td>
<td>dissemination (38M)</td>
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<td>• we always have patients on our panel. So they’re involved kind of throughout the process from you know selecting the questions and the outcomes (02M)</td>
<td>• the community was involved in the guideline itself from the very beginning. So we had community members as part of our panel from the very beginning; from the inception of that guideline (14C)</td>
<td>• Panel, yes…I would say it’s a guideline development panel (10P)</td>
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<td>• The committee includes a patient or a patient representative. So they will have a voice in the discussions that are going on, on recommendations and that they will be asked and be able to input on what would patients value, what would patients prefer, what, how do patients view this and that way of managing a problem. So that’s how they are involved; that they are members of the committee (50M)</td>
<td>• they were involved from the beginning…we involved involved the end-stakeholders right from the beginning of a project so that they have say on better uptake. So we had patients that were part of the guideline development team and the guideline is divided into seven sections. And so we had a community member representative on each of the sections that were being developed (12C)</td>
<td>• of the committee and to give kind of a patient’s perspective to the committee…everything was kind of round table (47P)</td>
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<td>• Clinical experts identified patient preferences</td>
<td>• I could argue that you know indirectly those clinicians were so experienced working with these people have built a clinical expertise on what the patients prefer as well. Like we’ve had quite a number of discussions where the</td>
<td>• This is not just physicians, this is…45, I think there was some 45 &lt;physicians&gt; involved but there was also multiple professionals from across the country involved from OT’s, social workers, &lt;specialists&gt;, like you name it and that profession</td>
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<td>• Well the committee is I’d say maybe 15 people; mostly &lt;specialists&gt; and I am one of the two patient representatives on the committee (51P)</td>
<td>• Panel, yes…I would say it’s a guideline development panel (10P)</td>
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physicians, so the guideline writers would then say, well you know that’s a nice recommendation but I’ve never had a patient that really wanted it that way you know (27M) 
- we met with the clinical lead of that guideline and asked him to provide his expertise on whether we are touching upon the points that he felt in the guideline development process; we were sort of you know…in getting patient judgement. So we used expert opinion (48M) was likely to have representation at the table; nurses. So all, collectively all of their experience with folks with <condition> would also be represented there as well…these are <clinicians> who are in, on the ground floor in the trenches with patients day in, day out. So I think their ability to recognize patient preference would be and these are people who, they don’t just have their one percent of the population which was what everybody else has. These are people who have special interest in <condition>; so you know they would have practices that would be enhanced as far as the numbers go with people with <condition> in their practice. And they’re the ones that are doing the, reading the literature and writing the guideline. So I think, I think that’s pretty good as far as trying to pay attention to patient preference. You’ve got, you’ve got probably the best team you can get because you’ve
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<th>Qualitative</th>
<th>got people who are with the population (35C)</th>
<th>We have used focus groups, so one of the, not myself, there is one of the other members whose involved in the guideline itself; spoke to a group of &lt;type of&gt; people, &lt;caregivers&gt; and other carers involved in looking after &lt;population&gt; with &lt;disease&gt; and collected information through more group discussions (29C)</th>
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<td>then we conduct a focus group. And the point of the focus group is to kind of clear up any confusion that might exist from completing the survey and just make sure that everyone has the same understanding (13M)</td>
<td>So we reviewed the interview guide for those qualitative interviews and focus groups with patients speaking about you know like a, you know those preferences and that sort of thing (24P)</td>
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<td>the staff there were very receptive to having us come to their council meeting. The council meet, So we had the opportunity to go; one time and meet with that group. So that’s how we addressed getting patient preferences into our &lt;condition&gt; guideline…So there was time to give a general background on who we were and what we were doing. And then had a discussion around some particular areas that the group was interested in, so we did not, we do not have patients sitting on our guideline development panels…working with the focus group where we had multiple</td>
<td>We would have focus groups and they would have you know different, different walks of life and being involved; not necessarily one-to-one meetings or that I would be aware from a patient of view; they’re more focused group (46P)</td>
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<td>Quantitative</td>
<td>The patients were part of each survey that we sent out to the guideline development group for recommendations (07M)</td>
<td>we did a cross-sectional survey with &lt;people&gt; living with &lt;disease&gt; in &lt;geographic area&gt; where we asked them their patient preferences and where they were getting information and what they wanted; with 490 women, we just completed the same type of survey with 280 men (12C)</td>
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<td>- we have a survey, a pre-survey of what their expectations are and what they want to see in the guideline and we ask the questions. What kind of outcome do you want us to take a look at when we’re developing these guidelines…then we do post survey with them which is something that’s fairly new that we have implemented in the last six months; we do a pre and post survey. We’re making it a little bit more formal so that we are able to keep that information and documentation and track what our patients prefer when they help us develop the guidelines (38M)</td>
<td>- we did a survey specific to experiences, like finding out their related to disease experiences and what their needs were (12C)</td>
<td>- I was given a several page survey asking me in levels from 0 to 10 on the impact the screening would have for me reading it…surveys were done individually (30P)</td>
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| Reviewing published literature | Yah, we solely went by what’s known in the literature, right? So we only looked at the published | there’s a very good prep on our part in terms of the types of evidence including consumer opinion | we needed to look at what else is out there or what else are we missing or what has been brought up before. So I think there was a systematic |
research on preferences by people with disease on primary care. And not only, not only patient preferences but there’s also a little bit work done on caregivers (27M)

- We did our own sort of literature review around the two guidelines that we chose to pilot this with which is the disease and disease and that was just kind of a quick scan of the literature to see what the literature had identified with respect to the patient preferences (48M)

- and the, it was also the literature that included consumer input, patient preferences and yah…we did literature reviews and I’m pleased to say there’s quite a movement of consumer inclusion and disease; literature searches that look at other focus groups or for evaluative work about the kind of healthcare that they receive (31C)

- we did the literature search we took into account first persons voice. So the literature that reported on first person, so anything that was related to the person with condition or their caregivers was given acknowledgement, special acknowledgement and that would have been considered a relevant piece of data and was designated as such so that when we came to the strength of our recommendation that was reflected in the strength of the recommendation (35C)

review which I wasn’t a part of; I think another group was part of that review to look at what the findings were and bring it to the big table (42P)
Overlap in preferences identified by different approaches

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<td>Identified overlap</td>
<td>Between involved patients and literature</td>
<td>• how our patients felt was very much in-line with the literature findings of what was very acceptable to our patients to say no, we can just be referred for the &lt;type of&gt; testing with some risk and information. And some were getting our results if we do have a &lt;type of&gt; mutation, then they got counselling in a timely manner (15M)</td>
<td>• Very much, yah. Yes is the short answer. Yes there was alignment for sure. The themes came out and quite consistent… But one of their themes is they have barriers to access things healthcare. It maybe physical barriers or communication barriers or people just not really paying attention to what they’re trying to communicate about their distress and needs or their preferences for that matter. So a big theme is about not being able to access, not being heard and not being able to provide their input. I think they also see a number of healthcare providers that’s quite dismissive and rude; part of it is summarized in the article that I was just telling you about. But barriers to access, not being heard and preferences not being honoured. Like people do things to them but not always listening to them. The other theme was people often look to caregivers rather than people with &lt;disease&gt; when they’re in appointments and we have to be able to overcome that barrier. I hope that</td>
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summarizes the common themes. And then they’re, you know there are various, the different research studies may had studied different aspects of that (31C)

- well there is surely overlap between what patients, the patient inputs would...patient input from focus groups and the patient input from literature searches and …research (34C)

<p>| Between involved clinicians and literature | I think they commented on our communication skills as physicians and I don’t think there were any, like I can remember a few articles because I was involved in the communication guideline and I remember they, the patients in the various studies commented on our ability to recognize the need for more time and our ability to recognize the need for more explanation in the physical exam. And these are things we, no there’s no surprises there. Those are, that’s a, those are things that play out in practice all the time (35C) |
| Between qualitative and quantitative methods | • Between the first and the second survey...sometimes it’s changed slightly, usually towards the higher range. So people have indicated that certain harms or benefits are actually more important to them than they identified in the first |</p>
<table>
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<th>Survey after discussing with the group (13M)</th>
<th>There was some, so like between the face-to-face and emails (17M)</th>
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<td>Between involved patients and clinicians</td>
<td>And we would often find like let’s say when a patient says something; one of our clinical nurse specialist may you know join in and go, oh yah, we’ve often found that. Or you know it often, will trigger a debate and you know even the clinicians will be able to row in and go, gosh, yes, we do see that a lot. Or you know there is great…it often validates something the people have been thinking (15M)</td>
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| Identified overlap but wasn’t looking for it | yah there was great consistency but we wouldn’t have done sort of very independent pieces and then try to look for consistency in that (15M)  
- I don’t think we’ve looked at it that far. Like if there’s something, if there’s overlap they’re definitely will be some overlap in the stuff that we do (38M) |  
|  | I mean I think that, that perspective is complementary to the perspective of clinicians who are anticipating what and trying to develop reasonable and focused pico questions (26C) |  
|  | yah there was great consistency but we wouldn’t have done sort of very independent pieces and then try to look for consistency in that (15M)  
- I don’t think we’ve looked at it that far. Like if there’s something, if there’s overlap they’re definitely will be some overlap in the stuff that we do (38M) |  
|  | Oh yes. Yah, definitely. And the more overlap it just reinforces that it’s an important priority, right? (39C) |  

Best approaches for identifying patient preferences

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| Difficult to know which is the best single method |  | so I don’t know if there’s one sort of, one right answer (02M)  
- I don’t think I can choose which works best… I think it’s a little bit more personal when we have a patient on the panel but I don’t think that, that’s better or worse than doing the search and the literature | I don’t know that, I certainly have an open mind to think that there maybe other approaches (26C) |  |
| Directly involving patients | • I think it’s actually important for them to be directly involved so that they are sort of key partners in that development process and they can identify those preferences. But a lot of times they can also bring in the perspective from a larger group of patients as well. So I think it’s really important that during those group meetings especially when you are moving from the evidence to make the recommendations, I think it’s really important. You know that they are involved in that process (08M) | • The best approach is including community members and patients in the development of guidelines at the, around having them at the table developing the guideline is the most important one (12C) • So I think that is, I think it is necessary to have them at the table and I think that it has helped us too (33C) | • I think just having the community at the table involving the people… Because often times there people who are like high up somewhere who are making the guidelines for people but not really communicating with the people that they’re making the guidelines for (42P) • I think that the in-person meetings worked best. It made me feel inclusive and it allowed me to see what they did with what my preference was instead of filling a questionnaire which I would know if it was utilized or taken seriously and there are sometimes when I verbally expressed patient preference I was able to provide clarification as needed and I was also able to be educated about why a different approach might happen instead of my preference (53P) |
are involved for the entire, the entire approach especially if you have a patient that speaks beyond like their own personal experience and they are sort of, their feeling for other people as well (28M)

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<th>Multi-approach is needed</th>
<th>I think it’s really important to have a multitude of approaches. I think though there are some people who believe that if we get the evidence correct; if we make sure that evidence is always reflective of what matters to patients then there’s no need for patients to be part of the decision-making. Though I think there’s something about the combination of actively researching and updating these important issues from a patients perspective and then their interpretation of that evidence in a multidisciplinary group that includes patients. So I think it’s really important that we have the direct experience of the individual patients with, who’ve experienced the condition under discussion that we have input of the breath of knowledge a patient organization and then we make sure that research evidence is properly looking at the things that matter to patients. So I think it’s a combination of those things that makes it really strong (22M)</th>
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<td>Well it’s a combination of things but of course the systematic review of the benefits and harms of the intervention is helpful. But it’s also helpful to get the input from the focus group because it allows you to determine what outcomes need to be prioritized and delivered in the shared decision-making kind of circumstances (20C)</td>
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<td>I honestly, you mean having them on the panel versus having feedback versus; I actually think you need to do it at multiple levels. Like I don’t know that it’s just simply that it’s as simple as one, one approach (39C)</td>
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<td>I think all of them need to be undertaken to ensure that you’re getting as much information from a consumer perspective as possible…I think all of the processes helped in providing a sort of reasonably comprehensive amount of feedback (44P)</td>
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<td>Both…through on-on-one interviews…and what the group was looking to do and then actually been….then being able to sit live in-person and hearing the doctors and the other researchers in the room talk about their approach and words that should be (56P)</td>
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complementary. I think they’re all part of each of the phases of guideline development… all of these steps are complementary and has worked for our organization that way (38M)

Incorporating

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<td>Preferences incorporated in all steps from outset</td>
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<td>• Preferences were incorporated right from the start of that guideline, from that initial sort of draft (17M)</td>
<td>• our patient representatives were involved in all steps of guideline development from the formation of guideline questions to the ranking of outcomes of priority; certainly it became important when we worked through, they were you know involved in the face-to-face discussions, all the conference calls and then they were really be critical when we started to work through the evidence in terms of when we got down to patient values and preferences (52C)</td>
<td>• I would say it’s been considered methodically from beginning to end (24P)</td>
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<td>• as we’ve evolved, we’ve incorporated them into the entire process from the beginning and towards the end… we always want to make sure that the patient is involved in the most important parts of the process and having our patients involved every step of the way (38M)</td>
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<td>• They were considered really in them all…but this was so, like every section of it, everyone was included…it was very much open floor discussion for everything. So there was no part of it that I was excluded for; equally there was no part of it that I was kind of singled out (47P)</td>
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<td>Patient preferences influenced topic nominations</td>
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<td>• people who are in advocacy and patients. So they are the ones who come up with guideline topics you know and they come up with a great number of guideline topics… the idea of what topic to focus on, yes, comes from the assembly’s which do include patient groups (50M)</td>
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<td>Patient preferences influenced the prioritization of guideline topics</td>
<td>• provide input in terms of final selection of topics that should be included (33C)</td>
<td>• yah it was again through email, the series of topics were generated and then we had a conference call to determine whether those topics were deemed to be appropriate and if there were other, there other topics that should be included (54P)</td>
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<td>Patient preferences impacted questions and outcomes</td>
<td>• patients are really involved when we are developing the key questions (23M) • During the guideline development their voice is especially important and pertinent to have during key question development. We have them at the table making sure that we, we include them when we’re ranking all of the outcomes that we want to use in our key questions (38M)</td>
<td>• So they really shape the nature of the core questions (20C) • questions first of all…so not just what they prefer in terms of a specific question but what questions we actually need to tackle (39C) • I got sort of the same briefing as all the &lt;specialist&gt; on grade and the approached used. I was given the opportunity to get involved in specific questions if I wanted… But I did express interest and I believe my feedback was considered but I’ve seen the changes for like the equity and economic questions (24P) • So developing questions, it was sent by email and we were asked if the questions made sense and if there was anything else that we would like to add (54P)</td>
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<td>Outcome(s)</td>
<td>• So right now we approach patients after the working group has developed the outcomes and then we ask patients about the outcomes…we just get their opinions on how important</td>
<td>• Well part of what we do with the &lt;organization&gt; focus groups with patients is or those who might potentially be eligible for screening is to identify how they the thought was to breakdown which group of items that were the most important and then we had like a break-out session discussion and then came back together to decide on, let’s say the 5 or 6</td>
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<td>Patient preferences impacted research plan</td>
<td>Patient preferences influenced assessment and appraisal of evidence</td>
<td>I think, yah now that I think back its like, I was at the &lt;organization&gt; meeting in 2015 and that’s where it began. So you know I was involved the review of the grant, the design of the work (24P)</td>
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<td>So they’re there and also they’re there to engage with us during kind of brainstorm what we need to do for the project (38M)</td>
<td>in the literature search sometimes patients can also help; particular if there are publications which are not included in PubMed or non-scientific materials which can also be very important. So then patients can also help and in, sometimes also in assessing the literature (34C)</td>
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<td>each outcome is to them (13M) • focusing primarily on outcomes to ensure we’re addressing patient important outcomes (23M)</td>
<td>So there was the literature search, we were, and so for each group and I told you there was three groups. We probably had a dozen people reading in each of the three groups and we were instructed</td>
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<td>perceive the importance of a variety of outcomes and we get them to rank them on importance so that they can feed or confirm or modify what the &lt;organization&gt; panelists have already defined (20C) • do we have the right outcomes that are you know patient important outcomes that they want to know about (25C)</td>
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<td>Patient preferences impacted</td>
<td>development and is absolutely, totally influences how we generate our recommendations so it influences our final guideline recommendations and all of the practical issues that we put into our guideline (15M)</td>
<td>And then at the end in terms of crafting specific recommendations that may include patient perspective in the actual recommendation (26C)</td>
<td>Yes, that was all part of our role on that committee; certainly about the recommendations, the strength of the recommendations were all agreed by the full committee (44P)</td>
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<td>Patient preferences impacted</td>
<td>when we’re drafting those recommendation statements they’re included (38M)</td>
<td>including patients in terms of formulating the draft recommendation maybe made but including input from them on…the recommendation and the explanation and how this could affect patients… and deciding sort of the wording of recommendation (39C)</td>
<td>what my recommendation was about providing education to … providers about what time and what increments, &lt;medication&gt; should be given to patients. So to, so that patients do not have to endure long wait times in the emergency room. And then another major one was about incorporating more day hospitals so that patients can receive care faster when they are experiencing &lt;crisis&gt; and return back to regularly scheduled life such as work or school instead of staying an extensive of time in the emergency room waiting for care (53P)</td>
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<tr>
<td>Patient preferences impacted</td>
<td>They are considered at the phase of making recommendations…So in deciding this trend or the recommendation whether it will be a strong recommendation or a weak recommendation while considering the quality of the evidence, we also consider what it means to the patients. What, you know again, you know patients values… So the weight of the recommendation will be influenced by the patient values and preferences (50M)</td>
<td>including our patient representatives involved in developing patient-</td>
<td>we also have a special community which endorse the guideline…includin</td>
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<td>There was a final summary that was made up following each</td>
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<td>Patient preferences influenced evaluation/feedback</td>
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<td>- public consultation the feedback that we receive, we go through that and anything that’s relevant or feedback specifically from consumers or anything relevant we will seek input from our consumers on the panel and then decide as a whole group including the consumers about the actual changes and sign them off (18M)</td>
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<td>- And then the recommendations themselves are then subject to consultation and we encourage patient organizations to comment on those recommendations from a patient’s point of view and to make sure that those are relevant and useful for patients (22M)</td>
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<td>- We’ve asked for feedback or to contact us if they want with their names and stuff and we’ll follow-up and have face-to-face</td>
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<td>- they are part of the review process for the you know review and editing for the manuscript before it’s submitted for publication (25C)</td>
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<td>- when a guideline is in the draft phase, so it’ll actually go out to all the members for feedback including patients. So that’s another thing, that’s another check that even once you’ve got the document all done, it’s not published yet but the draft form goes out to every, every member including the patients and they can make comments on that. A lot of that ends up being sort of qualitative you know general comments or whatever (39C)</td>
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<td>- I suggested that maybe after a year that we’d look at that stage and having kind of a questionnaire and a follow-up to see whether first of all, it was kind of effective and whether people were happy with it. But also the kind of, that the patient feedback element at that stage from a point of view of like did it, did it actually address what it was meant to address for the patients (47P)</td>
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<td>- so the guidelines were written as a draft, we reviewed them for interpretation and perception, ease of clarity that kind of information, that’s what they were looking for. They would then take that back to</td>
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<th>dissemination and implementation of recommendations</th>
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<tr>
<td>- centred materials because we knew that that is going to be an important part of the dissemination (38M)</td>
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<tr>
<td>- g some, a few professors and other representatives of our organization within &lt;country&gt; (34C)</td>
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<tr>
<td>- survey or each conference call summarizing participant’s responses and we were allowed or I was allowed to review the summary and give input as to whether or not I felt the summary was complete and accurate… The summary was as, a summary; it was a generalized report on what was discussed (30P)</td>
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<td>- survey or each conference call summarizing participant’s responses and we were allowed or I was allowed to review the summary and give input as to whether or not I felt the summary was complete and accurate… The summary was as, a summary; it was a generalized report on what was discussed (30P)</td>
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Patient preferences reported in the guideline

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<th>Subtheme</th>
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<th>Patient</th>
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<tr>
<td>Preferences embedded;</td>
<td>• At the moment we’re not really explicit on the patient preferences</td>
<td>• then the actual patient preference and the, was incorporated in the language of the guideline was embedded</td>
<td>• they were embedded in the discussions as well as into the guidelines as well</td>
<td>• they were embedded in the discussions as well as into the guidelines as well (42P)</td>
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<tr>
<td>not listed separately or</td>
<td>(08M)</td>
<td>(12C)</td>
<td>(42P)</td>
<td>(42P)</td>
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<td>explicitly</td>
<td>• They’re more embedded…the actual guideline that’s publish in &lt;journal&gt;; I believe it’s not explicit (13M)</td>
<td>• There’s nothing that says, you know this is what a patient wants. It was, it was embedded within the guideline (14C)</td>
<td>• I wouldn’t say there was a separate area of a separate part of this that would have that level of information. (46P)</td>
<td>(46P)</td>
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<td></td>
<td>• It’s not, it’s not explicit in our guideline (15M)</td>
<td>• I think it’s embedded. I mean its part of what we drew on in terms of resources and its part of what people are appointed to in the guidelines (31C)</td>
<td>• I would think they were embedded, yah (40P)</td>
<td>(40P)</td>
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<td></td>
<td>• There’s no separate section that says, you know this is what the</td>
<td>• It is embedded…like they’re part of it, we wouldn’t just…find it down in a… the patients just covered element 1.3 and 1.8 and 2.2 and 2.0; you know it didn’t go like that (36C)</td>
<td>• I would be saying it was embedded. Once a decision was made it was embedded within the guidelines (49P)</td>
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<td></td>
<td>patient said. It does just sort of weave throughout the manuscript</td>
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<td>(41M)</td>
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<tr>
<td>Preferences explicit</td>
<td>• It’s explicit as we have it… if there are any differences in opinion</td>
<td>• I think its way more towards explicit. Maybe not as explicit as it could be but it’s generally in that direction (20C)</td>
<td>• each guideline will have a patient that I’ll be able to contribute too, it will have a patient, how it relates to the patient, what the patient, what the patient would like to experience is that; so for example, let’s say…guideline addresses</td>
<td>(33C)</td>
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<td>or variations then we try and be as explicit as we can (18M)</td>
<td>• we will be writing this separately and there be, we’ll be writing as part of the methodology section, the introduction that how we involved the patients and the patient preferences in (36C)</td>
<td>(36C)</td>
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<td>• Usually in the interpretation of evidence. There might be a section in</td>
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<td>the systematic review discussing patient preferences. But for</td>
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<td></td>
<td>(18M)</td>
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<td>• they were embedded in the discussions as well as into the guidelines</td>
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<td>(42P)</td>
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each recommendation there’s in our guideline, there’s a section, a section II where we write the recommendation down and then we write the evidence that informs the recommendations and then we write the interpretation of the evidence and generally patient preferences are discussed at that point as well as in the systematic review; if there’s outcomes that have to do that with that, and there’s usually a section on the patient outcomes that are important and a write up in there (28M)

- They would be reported in the part of our guideline documentation that describes patient values and preferences… It’s an explicit separated section… So we’ll write a paragraph or so and say this is, this is our assessment of patient values and preferences and why our recommendation went in a certain direction. So there’s text in there that incorporate patient views (48M)

- terms of selecting the key questions for the guideline. And then how we went on and incorporate, incorporated these patient preferences in terms of selecting the evidence and the outcome of the qualitative interview and also the group work information from the <type of> people… And then obviously they’ll be separate information as part of the guideline which will be the patient leaflet will be the patient information along with the guideline will be another document which will be prepared in that. That’ll be fairly in depth information on how we took the patient preference into consideration (29C)

- it specifically talks about recognizing patient’s preferences and facilitating patient’s preferences, so accommodating it. So it’s not enough to say the patient can choose or not choose. Its how can you maximize the patient’s ability to choose… So we were always very aware of preference. We have a guideline specifically that addresses preference (35C)

- <treatment> use to treat <symptom> and how it maybe harmful to the patient long term? And so the patient preference will highlight under the recommendation after the literature about how you know <treatment> use can increase <symptom> and will draw out symptoms and stop patients from maximizing their lives and being able to do normal daily activities because of <side effect> and <side effect> (53P)

| No idea how it was reported in the guideline | • I have no idea how they reported further up. It was, the information was delivered to me through email (30P) | • I believe that it’s, I had an influence. Of course, I don’t | • |
know what the final product is going to be but they took it seriously (32P)
• I really can’t comment on that. I don’t know, I haven’t seen the final work yet (51P)

Barriers

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<td>Meaningfully involving patients</td>
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<td>• So our struggles in that, and you can maybe, you can imagine is that we’re working with people with an &lt;disease&gt;. So for this iteration for, so for this version of the guidelines we decided not to go there yet because it’s tricky. How do you do that in a meaningful way, right? (27M)</td>
<td>• another challenge is actually involving patients in a meaningful way. It’s not just having the patients at the table and they don’t say anything. And should been, and not to be like tokenistic but like to really meaningfully involve them in a respectful way, so that’s, you know a challenge (12C)</td>
<td>• a challenge to what extent do you include all these different patient views and the personalized patients views in the guideline itself or included in the implementation strategy (34C)</td>
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<td>• Making sure that they have, that they know that their voice does have weight (41M)</td>
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<td>Identifying the right or</td>
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<td>• It’s really hard… to find diverse patients who also have the…skills</td>
<td>• And I think it’s a real challenge to given that context, it’s a</td>
<td>• more difficult for us given our non-medical background to be like really a contributing</td>
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<td>knowledgeable patient</td>
<td>necessary to know of integrate within a panel...you know just bringing someone on a panel doesn't ensure that you’re hearing their voice (02M)</td>
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<td>• I think some of the challenges can be the patient...to really speak up at a meeting...about topics that can be quite complex (15M)</td>
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<td>• I’m not sure if it’s about being better equipped, it’s just getting the right patient. I’m sure there must be patients out there that actually have an understanding of the topic. It’s just accessing them. You know how do you get a patient that’s appropriate (19M)</td>
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<td>real challenge to identify someone speaking to patient preferences who does not inherently have a personal or intellectual conflict of interest (26C)</td>
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<td>• there were some barriers of course, just how do you find a good patient…it’s quite difficult to get a good patient representative (34C)</td>
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<td>part of those discussions...sometimes you feel kind of useless with respect to voicing your concerns about...the areas you don’t know as much about...you’ve got fairly limited scope of expertise compared to the medical professionals on the team (21P)</td>
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<td>• it’s not the best in terms, like there’s a, I’m not a science person. So I really have to look at the data and ask questions about it and try to understand what the, what the studies are showing (32P)</td>
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<td>Hard to capture complex issues</td>
<td>it can be hard to capture the complex...to actually accurately capture the preference of the community is pretty immense. And so it can be hard to feel like you’ve actually really captured patient preference in a comprehensive way (01M)</td>
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<td>• sometimes patient panels might be seen as being selected and note representative of you know a broader, the broader perspective of patient preference (02M)</td>
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<td>• You know other than that, I would say also increasing the diversity, that’s something I forgot to mention. I’ve also been, found that most of our partners have been you know white, English speakers. So increasing the ethnic, linguistic you know religious diversity of our patient partners; I think it would be a major goal you know (33C)</td>
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<td>• the choices they make, a lot,</td>
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<td>• to have more voices there just means you’re able to; 1) capture more people, 2) to create guideline and actually the majority of people can actually understand, and 3) because no one wants to be a token; you know the representatives of their group (10P)</td>
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there’s some similarities but there’s a lot of times there can be groups of patients that end up choosing one or choosing the other and the reasons are different because the priorities for patients can sometimes differ. So I do think that you know it can be challenging to capture that on a panel if for example, you only had, if you’re only getting the review of one person it can be because that person may have a different view than someone else in the exact same situation (39C)

| Time commitment/ Scheduling meetings | • you know sometimes our group meetings aren’t really suitable for working people; they take place between 9 and 5 (08M)  
• Logistically trying to get people all together across the country with different time zones and etc…patients would prefer face-to-face meetings but we just don’t have the capacity to make that happen with people on  | • There’s not a lot of patient volunteers that want to get up at 6 o’clock in the morning. And there’s not a lot in it personally for them unless they’re incredibly invested in the topic (06C)  
• time is always a big issue. And even finding time to meet with everybody, right? And it was those multiple levels  | • Face-to-face type of experience… also has some downsizes too, especially when it comes to scheduling a time that everyone can meet (10P)  
• for me I think was just the timing of the meetings. I mean being a parent and a student sometimes the timing doesn’t work (42P)  |
<table>
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<th>either ends of the country (13M)</th>
<th>Patients feel intimidated or nervous to ask questions</th>
<th>of meetings (35C)</th>
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<tr>
<td>• logistic challenges and setting up time to talk to people and they tell you to talk to other people and they tell you to talk to other people; so that whole process of setting up meetings jogged out for a long time (48M)</td>
<td>• So I’m sure you know there’s an aspect of intimidation when you’re in a topic of your conversation that you’re not familiar with as well (19M)</td>
<td>• it can be somewhat intimidating because with these clinical practice guidelines, like I said, there’s like a very, a lot of very strong &lt;specialists&gt; and researchers involved on the team… but sometimes it’s like you try to feel confident enough I guess to convey because on some of those smaller groups it was often just me as an individual patient. It’s not as bad in the larger groups because like there’s at least a few voices, like patient voices to be heard. But I would say that’s probably, I wouldn’t be surprised if that’s just like a barrier for a lot of people, right… it can be hard to speak up when you have a group of like 15 of these folks and you know. They all have very strong opinions and are not afraid to convey them you know so (24P)</td>
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<td>• others might find it a little bit either intimidating (50M)</td>
<td>• Well it’s a little intimidating because we’re not you know I’m not a scientist. I haven’t read studies in years and I’m getting the results of the studies and trying to...</td>
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<td>Clinicians attitudes about patient preferences</td>
<td>• There were a few recommendations where the physician panel and patient panel made different recommendations because they sort of viewed the trade-offs differently...there's always the challenge of sort of selling physicians on the panel and the important you know why do we need to consider patient preferences (02M)</td>
<td>• Well some clinicians and academics you know don't feel comfortable working with community members and they feel like it's dumbing down academia... like no one ever said anything or did anything but like I do know that some clinicians and researchers on our team think that we take the involvement of patients too far. And that they think it's sort of dumbing down academia... Like it's taking a guideline that should be a high level clinical practice guideline but we are decreasing the readability, like you know to a lower, like to, not grade 6 but let's say to a grade 9 level, English instead of a grade you take that in. I certainly don't have the knowledge that the other participants in the group have of the research (32P) • There could be a challenge where you feel like you are not being, you're not going to be heard, right? But I think there was just my own personal...of fears of maybe not being taken seriously (42P)</td>
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 know 12 level English. And so some clinicians like might not agree with that…The other, the other sort of challenge is if you have the patients right at the table and you word something kind of in an offensive way, it’s like, the patients right there, okay and they’re feeling they’re gonna get heard right away as opposed to if you have a guideline and there’s like offensive things in the guideline and it passes through multiple stages of editing before a patient sees it. So like you’re, so you’re putting yourself at risk of being kind of criticized or yelled at by a patient earlier rather than later (12C)

Medical terminology

- Yes, they have mostly on <healthcare setting> testing because that’s not, when our panel members talk about different acronyms that really gets the patient kind of confused and really is up the patient to voice out that they don’t understand what a specific term

- for clinical stuff I, you know it was very difficult to have a, and precise scientifically research stuff. I really didn’t have you know sort of an ability to have input into that (49P)
- Sometimes there was challenges...understand the medical, in the medical side of things (53P)
- Just the medical jargon (54P)
is but most importantly it is up to whoever is running that guideline meeting (38M)

- the terms that are being used kind of foreign to them. They don’t understand these terms (50M)

- just trying to understand words that were used when it came between the researchers and of course the doctors and in asking the questions enough to understand to break it down for me from a patient…it was still a challenge trying to learn some of the more or less the words…some of the treatments or maybe some of the outcomes or maybe some of the results or biopsies or things of that nature (56P)

Chair

I definitely think the chair person in this case was very challenging. And I think everyone would find, would have found that and you know I would say, the rest of the people were very open to you know to the group as a whole regardless of what your background was or wasn’t. I think the chair person in this case had very strong preferences going in and wasn’t necessarily hugely open to maybe changing those and changing his opinion on the approach and that’s down to with the fact he’s in his whatever, 50’s, early 60’s and has been doing this for 30 years…he was difficult to be honest (47P)

Facilitators

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<td>Communication skills, team-working skills and that assertiveness and also working with the evidence as well (08M)</td>
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<td>we train all the new patient members of our committees are offered a formal training… happens once every couple of months… So it covers things like critical approach of research evidence, systematic reviewing, health economics, how you go from research to recommendations… It’s to train them in the things that they might not otherwise be aware of that’s just statistics or economics… to ensure… at least the vocabulary that’s used in the committee discussions can be familiar to them and the concepts of things like opportunity costs and high quality evidence are familiar to them when they start their work on the committee (22M)</td>
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<td>I think giving the patients training in advance of meetings so they knew what to expect. I mean you, what the kind of format was going to be and meeting other patients who have been part of a group before the patients reported that was very useful (15M)</td>
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<td>we try and make sure that we’re, we gave them training very early on before they really got into coming up with the key questions and then we also gave them training again before workshop for them to kind of help them get oriented to the work of the panel and then in a nutshell it was all about having them appreciate how important their role was and how and when and how to intervene in the discussion and not to be just tokens (20C)</td>
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<td>There hasn’t and I think and to also to facilitate that, there was a fair amount of, say before they got to the meeting, making sure that there were phone calls to discuss what the process was going to look like, clarification of what the clinical questions that could be addressed, the kind of the range of clinical questions that could be addressed was explained. An overview of what a guideline development process was, a list of basic things like list of acronyms so that people could understand the healthcare professionals that they spoke (33C)</td>
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<td>now we know you should train the patients; you should not have one but either two and makes more patients represent the…working group. You need to train them (34C)</td>
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<td>questions; what would be addressed; how to, how to write what I wanted to be addressed in the correct format. And then later on they provided training with me inclusive to the whole panel; so myself as the patient representative and the providers about just the overview of the framework that would be used to guide the guidelines (53P)</td>
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<td>Training for clinicians</td>
<td>• So we do have a training session for all of our members; patients and physicians and clinicians (38M)</td>
<td>• we found in other projects that actually training the academic and clinicians on how to interact with patients that are sitting at the table who are bringing in other expertise but are equivalently like you know, like contributing to the guideline is as important (12C)</td>
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<td>Patient/advocacy groups or organizations</td>
<td>• a lot of times the patient representatives on the panel you know they’ll often be connected with patient organizations. So hopefully from there they’ve kind of heard of a breath of different experiences (02M) • having good patient organizations there who are willing to help to identify the preferences, it makes a bit easier if you can get the patient groups on board that can actually help us identify them…we ask for people who have experience of working in groups (08M) • I think a facilitator could be leveraging…existing patient networks…those groups because they’ve already got established patient relationships and people who are interested in being involved (13M) • we’ve also engaged with &lt;organization&gt; and they’ve also provided us with some representatives. For the</td>
<td>• there was an identifiable society or several societies that we could go to and ask for representatives…and go back to as a checkpoint and getting more than just an individual focus (06C) • we’re increasingly finding that networks of patients already exist; you have formed groups to particularly provide input into certain specific areas or themes (11C) • Well it helps if you have a good patient umbrella organization, definitely (34C) • Having a very close relationship with the patient groups (39C)</td>
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most part, if we have a project about <disease>, then we engage a patient advocacy group, like looking in <organization> and we work with them to provide their patients on our panel. So if the topic is related to the advocacy group that we contact and we partner with; so they become collaborators with our guidelines.

| Expert help | • a KT team…You know they have their methodology, they know how to get group, the patient on the phone and together and discussing about the, about the outcomes and the recommendations (09C) | • she did all that for all the international research and it was fabulous because it meant she took what was relevant, collated into a report so the rest of us could get through as opposed, like they went through hundreds of articles and to pick the most relevant ones and time wise and efficiency wise it was fantastic. And even from point of view, their focus was very specific on what they wanted. So the articles they pulled were the kind of most relevant of all and the research they pulled and it also meant they could kind of spread their net a lot wider because for | • So the KT science group was just so well-versed in how to do these focus groups that I mean I’d hate, I can’t imagine doing it better. And yah, they were, they certainly made it much more amenable and feasible because they brought so much expertise to the table (20C) | • This is, certainly to get the information into the way where we can properly write and represent this, it was very helpful having qualitative researchers (29C) |
most people you simply couldn’t be going through a couple hundred articles you know for every single thing (47P)

| Communication from guideline team | • I interact with our patient by email a lot and monthly or quarterly check-ins really help. We do have a lot, a couple of checklists where we want to make sure that the guideline manager is able to engage with a patient and ensure that you know there’s regular check-ins with a patient during the development (38M) | • this development group it was well established and it had a very good project manager who was able to provide that; that timeline at each of the meeting so that was clear… I would say that we had a good project manager… having a good project manager who is able to provide the background detail as well as the details that need to be discussed (46P) • I would have to say the girl who actually coordinates the group and is, she’s fabulous and she’s lovely… the coordinator was actually good and especially nice which makes a big difference. So you know even little things when you went to the first meeting, she met you, greeted you. She spoke to me on the |
phone in advance and talked me through kind of what the group was going to entail; all that kind of thing (47P)

- <name> was always there. She was always, she made herself available all the time to answer questions or provide feedback or interpretation… You know she did provide us with lots of information going in so that we could understand and interpret and then was always willing you know to follow-up with us if we had any further comments that we thought of later or have any questions or something that would come to mind to the next day. She made herself available all the time (40P)

| Point of contact for patients | On any project that’s meaningfully involving patients or community members. So we have an academic point person that has some kind of long history with at least a member of the group. So in this situation that was me. And so I would have individual or side meetings with just the | And I was on the call to answer any questions that any of them had (20C)  
- So another thing that helped is we have assigned staff within our team, our guideline development team to specifically be there to assist the | we were given a contact phone number. I was given a contact phone number with the opportunity to phone at any time, well within reason to ask questions (30P) |
| community members or just the patients before meeting, talking about what the meeting would be about and then after the meeting as a debrief, so and they can always come to me (01M) | patient partners throughout the day. So there be like a little pre-meeting briefing that they’ll give the people even the day of, after having prepped them over the telephone leading up to the meeting and then like so at lunch, his name is <name>, <name> will go over and you know sit with the patient partners, see if there’s anything emotionally that was too tough during the discussions. See if there’s anything that was you know intellectually they didn’t understand. If there was jargon being thrown up; that was, that they didn’t understand. And then he will either explain it himself or seek out some of my…hey man, you know they didn’t get this or that; come over and explain that to them and you know that kind of stuff to make sure that there’s a level of understanding which I think is obviously key for them to feel like they can be good participants or full participants. A (33C) |
| - we want to make sure that they get partnered with someone who’s skilled or more, more well-versed with the specific language that we use with <healthcare setting>, so there’s always that support system that they have (38M) | - the liaison person, the person who was actually coordination the group was always there as a point of kind of information if anyone needed any guidance or any information on us (47P) |
| - we make sure that they’re that we have an open line of communication with them (38M) | - I just got the email address of the person who’s linked to the project that sets everything up. So I’m comfortable in approaching that person if I feel the need too (54P) |

| Knowledgeable and/or | - I think some of our patients are experts in their own right, in their | - we’re lucky right now in the new guideline project | - I, well I mean speak to a lot of patients. I, being |
experienced patients

patient navigation and they're very engaged and very interested in learning. So having a very engaged patient really helps out but if they're not quite familiar with the topic or, well I have to preface that all of our patients on the panel are either, were diagnosed with a disease or took care of someone who was diagnosed with a disease. So before they even walk in the room they know you know <disease>, they experience it or you know firsthand or someone that’s close to them experienced it firsthand. So they know that part of testing and navigating. So that really helps out when we choose our patient advocate that they have that knowledge about their own disease (38M)

Chair or moderator that supports patient engagement

| • The role of the chair… it’s really incumbent upon the chair of the committee to try and manage that as well as possible and to bring the conversations back to the evidence as the primary guiding factor for the decision-making (22M) | • you need to have a chair who’s also supporting patients…are support patients who have a very strong voice but also who has a weak voice that you can encourage them (34C) | • we had very good chairs, we had excellent, the chairs of the review committee were very, very committed engaging the consumers in the process (44P) |
| we did do extra, like a separate phone call with just the patients and the chair to give them some general knowledge on what is a guideline, what is grade, you know what does a methodologist do, you know they often know some of | • the chair was a skilled negotiator and would have been dealt with appropriately and professionally (36C) | • The chair of the working group and <name> as the manager of the working group; they were incredibly good at taking on board |
the medical terms for their own condition but we also make sure and continue to encourage them to speak up when they don’t know (41M)

• the chairman and you know the whole of the group; how much, how skilled they are in nudging participation from somebody who may feel you know on the periphery of the group. So some of the issues are related to the patient himself/herself and some are related to the chairman or….the chair and the whole group (50M)

What else guideline developers need

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
<th>Manager</th>
<th>Clinician</th>
<th>Patient</th>
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</table>
| A framework or a standardized approach | • It's easier when you have some sort of structured format (07M)  
• There isn’t a whole lot of clear, I guess like policies or frameworks on how best to conduct patient oriented research…that would be helpful to have…some sort of resource…that’s like evidence-based that outlines what works and what doesn’t…having a policy or protocol would help…like a consolidated framework…maybe a centralized resource we can go and have, something that outlines best practices I guess, so that you can reference that and | • to have a framework of how to do research on that…in RCT has this recipe and the systematic review as its own recipe. And you know if you want to do diagnostic thing, you have a recipe. You should have a recipe for how do go about and have you know quality in what you’re doing to get at the preference, values and preferences of patients (09C)  
• Structured certainly helps (29C) |
<table>
<thead>
<tr>
<th>Explicit reporting of patient preferences in research and guidelines</th>
<th>I think that there should be an obligation and there is increasingly in the &lt;country&gt; for all people conducting research to explicitly include in their research protocols something about patient preferences and values and choices and the things that matter to them (22M)</th>
<th>I suppose another option you know is to have a section that’s specifically addresses this. You know that section might vary depending on what your guideline is trying to accomplish. But you know either throughout the guideline or a section itself that references back to patient preferences about these topics you know (14C)</th>
</tr>
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<tbody>
<tr>
<td>Identifying more relevant, knowledgeable, diverse patient developers early on</td>
<td>involving patients earlier is important…from the beginning from like topic selection to and like protocol development; so helping to develop</td>
<td>we need to find the right way to identify whose going to be involved and probably need more information once the</td>
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<td>I just wish there was more diverse voices at the table... And not just diverse individual, by diverse the people who think</td>
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<td>Patient database/repository</td>
<td>the protocol of how we engage patients I think is important because if that’s who we’re engaging, we kind of need to know like how they want to be involved, what’s important to them (13M)</td>
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<td>• but I think for us, having engaged with the consumer’s right from the beginning…to the idea sort of helped this process (17M)</td>
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<td>guidelines out as to how helpful the patients find them you know (25C)</td>
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<td></td>
<td>• I think I can see how sort of directly targeting patient groups in the beginning where you need specifically input from patients; kind of concentrated input, makes sense at that point where you’re, whereas later when you’ve got a document that’s pretty much like done (39C)</td>
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<td></td>
<td>• diversity of income levels, diversity of levels of education from people with no education to people with you know a PhD, diverse…people live. So you know if people live you know in an apartment versus people that live in houses (10P)</td>
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<td>• I think as well it’s just, it’s very important that the people who are kind of picked or you know who actually kind of go on the group. I think they do need to have some kind of background in the area that they just have a little bit of an understanding of the area (47P)</td>
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- When there’s a specific patient focus and there are patient groups that you can easily identify; that makes the process of finding the patient very easy (07M)
- utilizing not just you know the patients that are on the panels but if there is a point in time where you want a broader audience to answer you know specific preferences then having a group of patients at you know are willing to quickly differ differently;

- If there were a central resource to identify patient or patient advocacy groups that are excited and willing to be part of the guideline development process that would also be helpful (25C)
- I would say we would have a better pool of patient partners who had had difficult interactions in the clinical context of
| Training participants | • Take a survey for you (41M) | • The recommendations so that we could, we could improve the process. That’s my number one thing if I was gonna improve it (33C) | • Looking forward I think to engage broad, more broadly consumers from varying backgrounds and its variances; it would be useful to have some sort of consumer training… So some sort of you know pre-involvement training or workshop or in-service, whatever orientation, whatever you like to call it (44P) |
| Training participants | • I think training would be good too. I think even to have the kind of a knowledge on you know how the guideline, the very background and basics of how guidelines written, what’s involved, what kinds of things they might be asked. You know have a, how the meetings take place, like what’s expected. I think using like a briefing on that before they start. I mean I tend to do that myself, but in a very unofficial capacity over the phone you know. There was no sort of kind of half-day workshop for anything like that. That might help to make some structure a bit better though… But there was a lack of training for…on our part…how to best integrate them and I followed the same line that I did for all the other members of the team (19M) | • I think we should have patients that are a bit more trained just to kind of get the questions that we want them to answer because I was on the phone call once and it was so confusing (09C) | • Maybe a little introduction to you know I think it, for future if the patient representatives could have like their own session and maybe be taught a little bit more about the language that would be used in the conversations. And maybe a little bit about how the process works and you need to speak up and, I think that would be helpful for patient participants (51P) |
| Training participants | • You know how, so some of these training programs that are, are a little bit more intense than what we offer where they’re trained on how to review meta-analysis, analysis and | • There hasn’t been any formal training. I think if something could come out of your research if that would be something that would be helpful for across the board for that would be, that could be even across disciplines. That would be very useful (39C) | • |
systematic reviews. These are some of our more advanced patient advocates. We do have some patients that don’t have that much experience and you know they are there in our, in our patient, within our patient, guideline development group. So we will have maybe 2 or 3 different levels of patients that are you know either very, very highly qualified to do; you know to sit with a panel and ones that are probably just starting out with their navigation process. So they’re experts of their own health but not necessarily experts in how to determine whether a paper, a systematic review or you know a lit, looking at different literature. So I think having some kind of training program that’s similar to, up to that might be ideal but I don’t think that is really our focus right now (38M)

| Medical terminology | - Whereas specifically for something like <topic>, like there’s a lot of abbreviations, there’s a lot of you know maybe phrases used that patients are not familiar with. And particularly where everyone else around the table has a |
medical or nursing background that kind of happens and there are times that you’re kind of, you’re trying to work out what, what exactly they’re talking about. Even to know the littlest things like you know might be speaking about like a condition but they might use the abridge term for the condition that you didn’t, like for <disease> they called <abbreviation> (47P)

- I think we really, tool as such as explaining, explaining the basics of the condition. So even though I am a patient and I experience <symptom>, a lot of time was spent explaining the different segments of <symptom> to me when that could have been explained early on so that you know I wouldn’t have confusion or I could have voiced my opinion earlier or the patient preference earlier if I better understood exactly the different
| Communication | I do think that it’s important to keep patients informed. So sending them results of the research and we don’t do this, but if you’re working with a patient on a proposal and you’ve submitted it and it’s taking a while to like to hear back from ethics or whatnot. Just even shooting them an email to let them know that it’s still in the works because I’ve been on the other end where you just kind of don’t hear anything for a while and you kind of aren’t sure if, what things are happening (13M) | there be like several weeks or months until we heard something again… maybe a strong reminder of okay, this is where we are, this is where you can expect us to go, this is when you should hear from us again… sometimes there would be so long in between meetings or communications that like this call; I feel dusty on what the process was and what happened (21P) | Well from the get go, like even with this particular project even a, like a monthly email; here’s what we’re doing, we’re searching databases for relevant research studies, this could take several months; just like a more frequent update at the beginning. Now I’m used to it. Now I know how long it takes. You know that I might not hear from them for three months in between our meetings but at
the very beginning of that; it was like okay, well there certainly doesn’t seem to be much going on with this group and is it even a group anymore (32P)

| Greater support for qualitative research | • I think again, this notion of trying to enhance the status of different research types. I think that would be really helpful so that the people really understand that there’s value in other forms of data in evidence (22M) | • I think we also need to have greater support for sort of qualitative research that does sit down and look at patient preferences; so that when we go to create guidelines we have some foundational evidence that’s out there (52C) |
| No additional information, guidance or support needed | • I don’t really know so much about a workshop because sometimes you do a workshop and you sort of forget don’t you, really what you’ve done at the workshop… I think it maybe there’s a thing for workshop but to be honest I wouldn’t go to it, if there was a workshop on patients, yah, like including patient preferences unless it was a bit more comprehensive (17M) | • you know like anything, having a one size fits all would be, would be challenging (33C) • I don’t think there really anything further for me. I think that the information that was available for that guideline was very useful and valuable. So I wouldn’t say anything for that one (46P) |