Guideline Development Steps	REVIEW 1: Existing Guidance	REVIEW 2: Barriers and Facilitators	REVIEW 3: Conflict of Interest	REVIEW 4: Impact
1. Organization, Budget, Planning and Training				
1. Establish the structure of the guideline development group and determine the roles, tasks, and relationships among the various groups to be involved (e.g. oversight committee/body to direct guideline topic selection and group membership, working group consisting of experts and methodologists to synthesize evidence, a secretariat to provide administrative support, guideline panel to develop recommendations, and stakeholders and consumers for consultation). (see Topics 3, 4 & 6)	**Patients, Patient organizations, Providers** Patients and service users should be involved very early or from the beginning of the development process. Identify the aims and goals of the guideline development group, the purpose of the work, the methods in a collaborative way. (Duff 1996)	**BARRIER: [...to engaging patients/public]: UNCLEAR PATIENT/PUBLIC INVOLVEMENT GOALS:** Patient and public involvement goals are often largely implicit or articulated in vague terms by their organisations, which makes it difficult to assess success or failure. This can overlap with differing organizational interests and priorities regarding patient involvement. Patients who are engaged in guideline development may have different understandings of the goal of their involvement; some patients may believe that their involvement is a mechanism to change their own healthcare or disclose personal health problems, which may derail the guideline development group from its true purpose. (Boivin 2010; Carter 1995; Lanza 2000) **BARRIER: [...to engaging patients] DELIBERATE EXCLUSION:** Working groups choose not to participate in a patient engagement model because they feel like the clinical practice guideline topic is too complex to require patient input. Guideline developers also make the deliberate choice not to involve patients because they feel that patient contributions will be too general for the question the specific guideline is trying to answer. Respondents from patient organizations do not always see the added value of participation either, as according to them professionals have the knowledge needed to develop a good guideline [Brouwers 2018; Van de Bovenkamp 2015]		

2. Perform a thorough assessment of the proposed guideline development project with respect to financial and feasibility issues concerning the guideline development group (e.g. availability of resources to complete the project, expected commitment from guideline panel and staff, etc.).		**BARRIER [...to engaging patients/caregivers/advocates/providers]: LACK OF ORGANIZATIONAL RESOURCES:** Resource constraints were a concern across many studies. The high level of coordination required to carry out stakeholder engagement in a guideline development project was a potential barrier to the approach. There may be a lack of infrastructure resources to deal with the logistics of consultations, especially in smaller organizations. GDGs and coordinating groups may not have the capacity to organize proper training, to use or create necessary documents, or to use certain engagement methods. This can leave participants and coordinators frustrated by their inability to fulfill their responsibilities (Ilott 2006; Rapu 2005; Hameen-Antilla 2016; Brouwers 2017; Van Wersch 2001; Den Breejen 2014). **BARRIER: [... to engaging patients/caregivers/advocates/providers/payers services/policymakers/program managers/PI]: UNEQUAL ACCESS TO RESOURCES:** Some participants felt that the guideline development process favoured those with access to and the ability to use the Internet and technology. One study noted that a patient representative had trouble carrying out her work because she had no printer and the documents she needed were soft copy only (Jarret 2004; Kredo 2018). **FACILITATOR [...to engaging providers of healthcare]: ORGANIZATIONAL INVESTMENT IN STAKEHOLDER ACTIVITIES:** Several professional bodies had invested considerable resources in stakeholder relations. For example, incorporating stakeholding activities in their business plan and including these in the job		

		description of professional body coordinators (Rapu 2005). This can facilitate better engagement as the process would become a part of the organization's everyday work. GDGs may also develop and incorporate strategies into their guideline development processes for future use (Ilott 2006; Rapu 2005; Van der Ham 2015).		
3. Obtain organizational approval to proceed with the guideline project.				
4. Prepare a budget for the development of the guideline, outlining the estimated costs for each step (e.g. working group and staff remuneration, outsourcing of certain tasks to outside organizations or groups, travel expenses, publication and dissemination expenses, etc.).	**Patients, Patient organizations** Consider stakeholder engagement activities in the project budget (Wedzicha 2011)			
5. Determine whether guideline panel members will be provided any payment or reimbursement for their time or will work as volunteers.	**Patients, Patient organizations, Providers, Principal investigators** Obtain funds to support stakeholder engagement including financial support for patients and service users (Duff 1996)	**BARRIER [...to engaging patients]: FINANCIAL BURDEN:** Financial costs can get in the way of participation. Travel costs incurred by in-person meetings represent barriers to engagement (Chalmers 2017). **FACILITATOR [...to engaging patients/caregivers/advocates/providers]: FINANCIAL COMPENSATION:** Guideline development organizations may facilitate stakeholder involvement by obtaining funds to financially compensate stakeholders, particularly for patient representatives. This may include reimbursement for travel, printing, and other costs. (Duff 1996; Armstrong 2017; Boivin 2010; Rapu 2005; Brouwers 2017; Brouwers 2018; Chalmers 2017; Jarret 2004). **FACILITATOR: [...to engaging providers of healthcare] PROFESSIONAL INCENTIVES:** Providers of healthcare would appreciate a token of recognition for their time, effort and		

		energy contributed towards guideline development. This could include professional accreditations, financial support such as honoraria, and tailored resources (Rapu 2005; Illot 2006)		
6. Obtain or secure funding for the development of the guideline, with attention to conflict of interest considerations. (see Topic 7)	**Patients** Obtain funds to support stakeholder engagement including financial support for patients and service users (Duff 1996) Consider stakeholder engagement activities in the project budget (Wedzicha 2011) **Patient organizations** Consider stakeholder engagement activities in the project budget (Wedzicha 2011)			
7. Outline and arrange the administrative support that will be required to facilitate the guideline development process (e.g. a secretariat of the working group to organize and obtain declaration of interests, arrange group meetings, etc.).		**FACILITATOR: [...to engaging patients/caregivers/advocates/providers]: ADVANCE PREPARATION:** Providing resources, especially hard-copy documents, before meetings and offering opportunities for clarification can help all GDG members contribute effectively. This may include supplying meeting agendas and talking points, questions, guidance and terms of reference documents, and/or materials to take notes with. GDG members should be aware of the resources and training provided in advance to patient representatives. There should also be a point of contact for participants; those in charge should make time to return calls and keep track of their contacts. It is particularly helpful for patients to meet with the chairs prior to meetings (and particularly the first meeting) so that they know what to expect and get to know some other people in the meeting prior to joining larger group meetings (Chalmers 2017; Jarret 2004; Brouwers 2018; Armstrong 2017; Lanza 2000).		
8. Plan and prepare for training and support that will be required for those involved in the	**Patients** Assess the training needs of consumer	**BARRIER: [...to engaging patients] LACK OF CONTENT KNOWLEDGE:** Patient		

guideline development process (e.g. conflict of interest related education or training for guideline panel members, teaching sessions for patients to be involved in the guideline group, etc.). (see Topics 4 & 6)	participants, provide adequate training to support collaboration (Armstrong 2017) Conduct face-to-face / online training for group members to develop project plan and determine scope (Brouwers 2018) Offer group members training and support to ensure understanding and facilitate participation (Freitheim 2006) Provide training in guideline and research methodology (Duff 1996) Offer training in guideline development and research methodology to stakeholders (Devlin 2018) Develop training for patients/patient representatives (Wedzicha 2011) Conduct a meeting with patient participants to explain context of guidelines (Chalmers 2017) Professionalise the process by defining desired skills/qualities/background of panel members a priori and providing methods training (MacLennan 2017) **Public** Conduct face-to-face / online training for group members to develop project plan and determine scope (Brouwers 2018) Offer group members training and support to ensure understanding and facilitate participation(Freitheim 2006) **Patient organizations** Conduct face-to-face / online training for group members to develop project plan and determine scope (Brouwers 2018) Provide training in guideline and research methodology (Duff 1996) Develop training for patients/patient representatives (Wedzicha 2011) **Providers** Assess the training needs of professional	participants felt that they had a lack of content knowledge.They were uncomfortable with the thought of talking to a group of experts and did not want to appear uninformed or unhelpful because they might not have understood the issues being discussed. Unless they are educated about the guideline topic or have specific prior knowledge and training, then patients may stay quiet during group discussion. Additional barriers included the need for in-depth scientific discussion, which may not always be accessible for patients or carers, leading to the concern that discussions may be stifled if conversations are constantly being interrupted for lay explanations. [Armstrong 2017; Chalmers 2017, Den Breejen 2014; Brouwers 2018; Brouwers 2017] **BARRIER [...to engaging patients]: NEED FOR TRAINING:** Participants were concerned that insufficient academic education, guideline process training, and/or computer skills would hinder the development process. In addition, one study reported that while 'professional' members of GDGs "tend to be those leading the relevant field who possess the concomitant personal and professional skills, there is no analogous and established training route to becoming a [patient] professional", so participants' experiences and judgements may be dismissed in the guideline development group. One study highlighted that special considerations would be needed to engage children in guideline development, as "clear requirements to give children a voice in the process of guideline development do not exist". (Van Der Bovenkamp 2015; Van Der Ham 2014; Selby 2017; Harding 2011; Shalkers 2017).

	participants ,provide adequate training to support collaboration (Kelson 2012) Offer group members training and support to ensure understanding and facilitate participation (Freitheim 2006) Provide training in guideline and research methodology (Duff 1996) Offer training in GRADE and review methodology (English 2017) Professionalise the process by defining desired skills/qualities/background of panel members a priori and providing methods training (MacLennan 2017) **Principal investigators** Offer training in evidence-based medicine methodology to stakeholders (MacLennan 2017) Appoint an advisory group to oversee the guideline development process (Dunning 2012)	**FACILITATOR [...to engaging patients/public] PROVISION OF TRAINING:** A recurring theme throughout the studies was the need for training or education and support for participants to facilitate better understanding of the guideline development process - although some participants felt that training would only be needed if patients were providing more than their own experiences or working directly with developers. Training on how to effectively participate could be provided before and during involvement. This could include information about clinical guidelines, research methodology, evidence frameworks, and basic statistics. Training could come in the form of orientation sessions by teleconference or in-person, by watching a video of a guideline development group in action, or through mentoring opportunities from other patient/public representatives. Working group members should be notified of the level of training and resources that patients receive before meetings. As mentioned in one study, it should also be noted that some patients, if they are dedicated enough, can train themselves by reading the literature or attending courses on their own time (Boivin 2010; Chalmers 2017; Brouwers 2017; Hameen-Antilla 2016; Duff 1996; Jarret 2004; Brouwers 2018; Van de Bovenkamp 2015).		
9. Set a timeline for the completion of the guideline and target dates for the completion of milestones in the guideline development process.		**BARRIER [...to engaging patients/caregivers/advocates/providers of healthcare]: INSUFFICIENT TIME:** Time was a frequently cited barrier across multiple studies. This includes insufficient time for discussion and recommendation formulation, as well as the time-consuming nature of travel and attending meetings. Participants may feel rushed or unable to fulfill their responsibilities. For example, challenges were encountered in getting responses from professional bodies		

		within the four-week consultation deadlines, and these problems were more severe for organisations with limited capacity (under 2,000 members) (Ilott 2006). One study noted that it was difficult to keep patients interested in attending meetings because of conflicts with patients' work or personal lives (Brouwers 2018). A lack of dedicated time for guideline development may also lead to GDG members working voluntarily on their own time and afterhours (Armstrong 2017; Atkins 2013; Brouwers 2017; Brouwers 2018; Chalmers 2017; Den Breejen 2014; Ilott 2006; Kredo 2018).		
10. Determine what, if any, legal considerations are relevant for the planned guideline (e.g. reimbursement policies for orphan drugs).				
11. Prepare a protocol for the entire guideline that can be completed as the project progresses in order to keep the guideline development group on track, including an outline of the overall goals and objectives for the guideline, the timeline, task assignments, steps that will require documentation of decisions, and the proposed methodology for all steps (i.e. those covered in this checklist, for example the methods for forming the guideline group, selection of topics to be covered in guideline, consensus methods, consultation methods, evidence search and selection methods, etc.).				
2. Priority Setting				
1. Decide on a process for priority setting of guideline topics needed and who will be responsible for directing the process (e.g. priorities set by oversight committee at headquarters of sponsoring organization, priorities referred by government ministries of health or by professional societies).				

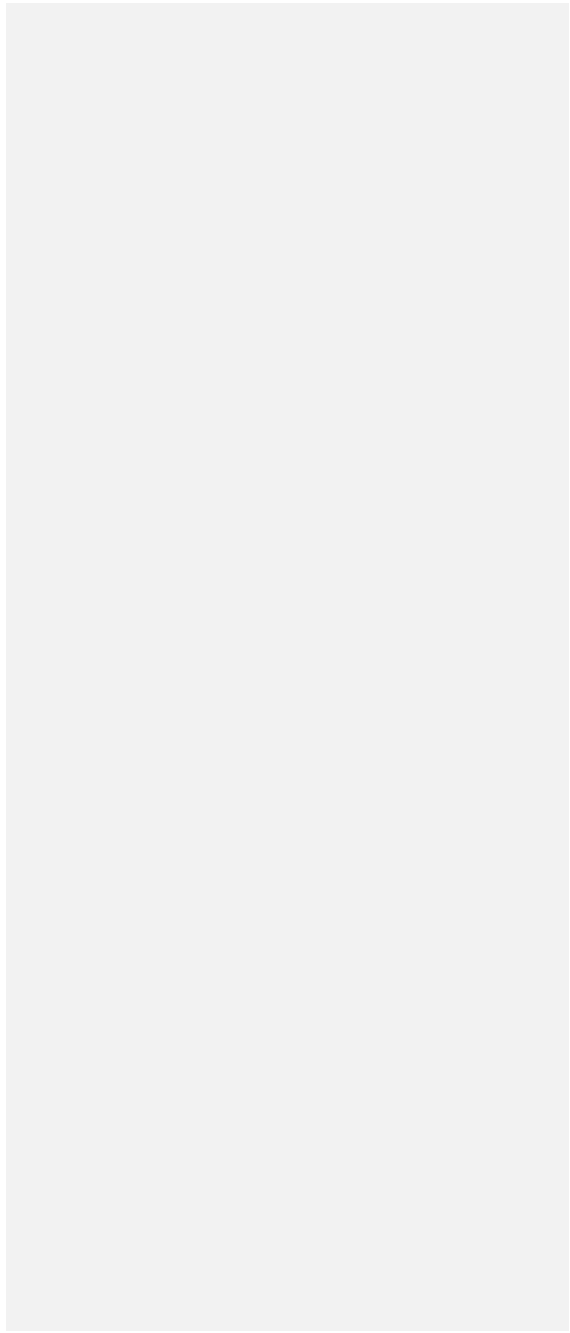|				
2. Apply a systematic and transparent process with specific criteria for the proposal of a guideline topic during priority setting (e.g. high prevalence and burden of disease, avoidable mortality and morbidity, high cost, emerging diseases or emerging care options, variation in clinical practice, rapidly changing evidence, etc.).				
3. Involve appropriate stakeholders in the priority setting process and guideline topic selection (e.g. clinicians, professional societies, policymakers, payers, the public). (see Topic 6)	**Patients** **Patient organizations** Link panel members with organizations to canvas opinions on priority setting and outcome measures (MacLennan 2017) Identify priorities and objectives through multinational patient survey (Chalmers 2017) Integrate consumer values into priority setting for guidelines (Fretheim 2006) **Public** Conduct stakeholder forums to generate topics for guideline development (Duff 1996) Solicit feedback on relevance and priority of topics. Discuss the urgency of addressing topics (Armstrong 2017) Use an open invitation to identify priority guideline topics from relevant organizations (Shin 2014) **Providers** Discuss with stakeholders practice areas of greatest benefit to patients that require guidelines. Include a physician leader (Wise 1995) Rank, prioritize and vet topics for guideline development (Shin 2014) **Principal Investigators** Conduct stakeholder forums to generate topics for guideline development (Duff 1996) Solicit feedback on relevance and priority of topics. Discuss the urgency of addressing topics (Armstrong 2017)			

	Use an open invitation to identify priority guideline topics from relevant organizations (Shin 2014)			
4. Consider and decide how different perspectives about the importance and resources required for implementing the guideline recommendations will be considered (e.g. patients, payers, clinicians, public health programs). (see Topic 11)	**Patients** Patients should drive priority topic rankings (Devlin 2018)			
5. Search for any existing up-to-date guidelines covering the proposed topic and assess their credibility (e.g. AGREE II). Determine whether existing guideline(s) can be adapted or if a completely new guideline should be developed. (see also Topic 10)				
6. Discuss the need or opportunity to partner with other organizations that develop guidelines to determine whether a collaborative effort will be sought for the development of the guideline, or any part of the guideline.				
7. Perform a scoping exercise for the proposed guideline topic with respect to implementation issues and barriers to change (e.g. if developed the guideline is likely to improve health outcomes, implementation of healthcare recommendations is feasible, resources are available, etc.).				
8. Select or provide a consensus method to be used to agree on the priorities set and the guideline topic selected (e.g. voting, Delphi consensus). (see Topic 4)				
9. Document the priority setting process and guideline topic selected to ensure transparency.				
3. Guideline Group Membership		BARRIER: [...to engaging patients] LACK OF RECOGNITION: Patients often cite feelings of isolation, lack of recognition, and unresponsive guideline groups as barriers to their participation. If patients are ignored and		

Commented [OPM1]: Unsure where to categorize these ones.

		their contributions are not acknowledged, they will not be as invested in the guideline development process (Chalmers 2017; Ilott 2006; Kredo 2018). FACILITATOR: [...to engaging patients] EMPOWERMENT: Empowering and fostering self-determination in patients can facilitate their participation in guideline development. Personal motivators that empowered patient engagement included feeling of appreciation from the members of the GDG, acknowledging patient effort, providing information and reading material in advance, and/or pre-specifying mechanisms of soliciting opinions. Panels can also give the option of passing on questions or submitting written answers if patients feel uncomfortable in discussions, as well as creating separate spaces for patient vs patient-caregiver feedback (Armstrong 2019; Chalmers 2017; Ilott 2006; Armstrong 2017; Brouwers 2017). FACILITATOR [...to engaging patients/patient advocates]: PRIOR GDG EXPERIENCE: Participants, particularly patient advocates, who had experience sharing their opinions in multidisciplinary groups and committees felt more confident in guideline development groups. Protected opportunities to share patient feedback, such as dedicated slots on meeting agendas, also helped patients to feel more capable of contributing. (Jarret 2004; Van Wersch 2001; Armstrong 2017).		
1. Seek multidisciplinary representation for the guideline development group, including members from the target audience, patients and carers, frontline clinicians, content experts, methodology experts, and experts in health economics, to fulfill the roles required	**Patients** Recruit patients from known organizations (Brouwers 2018) Draw members from known patient and professional networks (Devlin 2018) Contact all relevant stakeholder groups	BARRIER: [...to engaging patients] PATIENT REPRESENTATION: Some participants were uncertain about whether patients and service users were being properly represented by the representatives in the guideline development group. Self-		

(e.g. for the working group, guideline panel). (see also Topic 6)	directly to ensure a broadly representative guideline development group membership (Freitheim 2006) Who and when to include them depends on the interests of the specific patient or user representative, their confidence, resources, skills and the needs of the guideline development process. For some topics patients/users and patient/user representative organisations may be involved to ensure a representative voice (Duff 1996) Guideline panels should have at least one patient member (Maclennan 2017) Consider whether patients would have substantively different perspectives than caregivers and whether these groups should be engagement independently or together (Khodyakov 2019) Include a patient/user representative who also collaborates with health care professionals on clinical guidelines development group. Avoid tokenism (Duff 1996) Identify all potential stakeholders including providers directly involved in clinical management in primary and secondary care, policymakers making decisions about resource utilization and patients, and then decide who needs to be involved in guideline group (Eccles 2012) **Public** Contact all relevant stakeholder groups directly to ensure a broadly representative guideline development group membership (Freitheim 2006) **Patient organizations** Discuss team composition with relevant associations (van der Weijden 2018) For some topics patients/users and patient/user representative organisations may	selection may occur and service user perspectives may be insufficiently articulated. Participants pointed out that it may be difficult to find appropriate persons from the target group who would be capable of representing the larger patient population. In one study, it was difficult to represent the diversity of the target group in the guideline development process with respect to ethnic diversity and health conditions (van der Ham 2015). In the other direction, some patients did not consider themselves appropriate patient representatives and did not fully participate in development activities (Chalmers 2017; Van Der Ham 2014; Brouwers 2018; Hameen-Antilla 2016; van der Ham 2015; Lanza 2000).		

	be involved to ensure a representative voice (Duff 1996) **Providers** Draw members from known patient and professional networks (Devlin 2018) Contact all relevant stakeholder groups directly to ensure a broadly representative guideline development group membership (Freitheim 2006) Discuss team composition with relevant associations (van der Weijden 2018) Utilize physician leader in recruiting additional team members with written letters (Wise 1995) Who and when to include them depends on the interests of the specific provider or user representative, their confidence, resources, skills and the needs of the guideline development process. (Duff 1996) Guideline panels should preferable include additional allied medical professionals such as nurse practitioners, social workers, health care economists **Principal investigators** Contact all relevant stakeholder groups directly to ensure a broadly representative guideline development group membership (Freitheim 2006) **Purchasers** Establish a system for communicating with purchasers/ commissioners (Duff 1996) **Unspecified** Assemble a multidisciplinary team of key stakeholders to develop the guideline (Eccles 2012) Groups should include or have access to individuals with the necessary technical skills, including information retrieval, systematic			

	reviewing, health economics, group facilitation, project management, writing and editing. (Fretheim 2006)			
2. Decide on methods for recruitment and enrollment of members for the guideline development group (e.g. widespread advertising of posts, competitive appointment by interview, etc.).	**Patients** Utilize surveys and known contacts to recruit patients into Guideline Development Group (Chalmers 2017) Select members from established contacts, patient groups, forums and other interest groups (Duff 1996) Recruit patients from known organizations using email (Brouwers 2018) Draw participants from known patient and professional networks (Devlin 2018) Selection procedure for non-medical members of the guideline panel should be equally transparent as selection of medical members (MacLennan 2017) Invite stakeholders to nominate members to the guideline development group (Rapu 2005) **Patient organizations** Select members from established contacts, patient groups, forums and other interest groups (Duff 1996) Working with a patient advocacy organization can help identify patients, caregivers and others who can provide input on patient needs, feasibility of the proposed engagement process and appropriate compensation (Khodyakov 2019) Recruit patients from known organizations using email (Brouwers 2018) **Providers** Select members from established contacts, patient groups, forums and other interest groups (Duff 1996) Use an established registry to recruit panel members (Khodyakov 2019)	**FACILITATOR: [to engaging patients] SELECT REPRESENTATIVE PATIENTS:** Several studies mentioned the importance of recruiting the right kind of patients to participate in guideline development. Certain political and social skills are needed to be able to contribute, and some authors suggested using the network approach to select the most competent and dedicated participants. Project leaders should have clear eligibility criteria in mind when recruiting patient representatives; a "job description" may help to specify the knowledge and experiences needed. Project leaders should consider diversity as they are recruiting - this includes perspectives, roles, ethnicities, and other differences within the patient group. Involving multiple patient representatives may facilitate peer support and representation. It could be helpful to include a patient advocate in the guideline development group or to engage multiple patients in the working group. It is important to remind patient representatives that they are representing others, not just their own personal experience. In order to properly consult marginalized patient sub-groups, it may be necessary to pay special attention to their inclusion (Armstrong 2017; Boivin 2010; Brouwers 2018; Chalmers 2017; Den Breejen 2014 Harding 2020; Van Der Ham 2014; Van Wersch 2001). • Sub theme: Patients may be upset by discussions around certain topics, such as life expectancy calculations. It would be prudent to avoid recruiting recently-diagnosed patients, as they may be more emotionally vulnerable and overwhelmed, and to leave		

	Draw participants from known patient and professional networks (Devlin 2018) **Principal investigators** Select members from established contacts, patient groups, forums and other interest groups (Duff 1996) Invite stakeholders to nominate members to the guideline development group (Rapu 2005)	discussion of sensitive topics to more experienced patients (Chalmers 2017; Brouwers 2017). **FACILITATOR: [...to engaging patients] RECRUIT KNOWLEDGEABLE REPRESENTATIVES:** Recruit patients that are familiar with the guideline topic. Patient panelists should be knowledgeable and unbiased, have relevant expertise, and be willing to actively contribute and ask questions. Several potential groups were identified – such as patient trainers, peer support patients, and patient representatives in hospital ethics committees – that could be utilized without extra training because they are already experienced in illustrating patient views. The 'helicopter view' that certain patient representatives have is considered beneficial, meaning that they have an overview of a wide range of experiences from a range of service users. [Brouwers 2018; Hameen-Anttila 2016; Van der Ham 2014; Armstrong 2017]		
3. Achieve a topic-appropriate balance of expertise and adequate representation for the guideline panel (e.g. experts and primary care physicians who form the target audience, gender and geographical distribution of panel members), which may be iterative if additional members are required as the target audience and topics within the guideline are refined. (see Topic 5)	**Patients** Screen patients to confirm experience with the disease/condition (Khodyakov 2019) Patients help to ensure the guideline development group is representative and trustworthy (Armstrong 2017) Patient/user representatives should reflect the make-up of the community they represent Different patients/user reps may be needed for different stages of the process (Duff 1996) **Providers** Include representatives from other disiplines as appropriate (Shin 2014) **Principal investigators** Include persons familiar with systematic review and GRADE methodology as guideline group members (Englsh 2017)	**BARRIER [...to engaging patients]: SPOKEN LANGUAGE:** Two studies highlighted the potential for language and manner of speaking to become barriers to patient engagement. For example, there may be a requirement for participants to speak only English, leading to lack of representation from other linguistic groups. Participants also expressed concern that physicians from other countries who are members of the GDG may have accents or speak differently, making it difficult to understand discussion (Chalmers 2017; Armstrong 2017) **FACILITATOR [...to engaging patients]:** Most participants said that physician race or ethnicity would not matter, but several African-American participants indicated that they		

		would be more comfortable if there was a physician of the same race on the panel.		
4. Consider the optimum group size for the guideline development group, particularly the guideline panel (e.g. too small of a group may lack sufficient experience, content expertise and wide representation, too large of group may lack cohesiveness and effective group interaction).	Weigh the desire for wide representation against the need for a cohesive working group (Eccles 2012) A guideline panel of 16-20 seems adequate and each needs to be given an opportunity to discuss the evidence and reach consensus (English 2017) Account for attrition and assemble a panel with adequate size and composition (khodyakov 2019)	**BARRIER: [...to engaging patients] TOKENISM:** Multiple studies cited concern that patient and service user engagement was tokenistic. Instead of being fully integrated members of guideline development groups, some participants felt they were included merely to fill a quota. In one study (Armstrong 2017), some participants felt that they would be comfortable as the only patient representative on a panel, whereas others said this would make them feel like they didn't belong and would be intimidating. Those who expressed feeling more comfortable with the idea of serving as the sole patient representative were older and described more experience with physicians or group dynamics (Armstrong 2017; Atkins 2013; Brouwers 2017; Chalmers 2017; Jarret 2004).		
5. Outline roles for the guideline group members and the tasks they will be responsible for (e.g. forming a writing team, group reporter(s) to take meeting minutes and document decisions made, providing methodology consultation, conducting systematic reviews and obtaining other evidence, providing patient perspective, providing specialist clinician perspective, etc.).	**Patients** Establish explicit criteria on who should participate in guideline development and why; select chair and other positions and define their roles in the group (Kunz 2012) Decide on roles of team members (van der Weijden 2018) Discuss roles/responsibilities of group members (Brouwers 2018) Discuss and select chair/roles for members (Devlin 2018) Ensure that all participants know their role and the roles of others in the group (Duff 1996) **Caregivers** Discuss roles/responsibilities of group members (Brouwers 2018) **Providers**	**BARRIER: [...to engaging patients]: UNCLEAR ROLES AND RESPONSIBILITIES**: There was a lack of clear discussion about patient and service user representative roles and tasks in the guideline development groups, causing representatives to be uncertain as to what was expected of them. This can lead to participants misinterpreting why they were selected and what they are supposed to do in the group. This can extend to the roles of other groups and organizations, creating confusion over how to use resources and which groups to involve (Van Der Ham 2014; Van Der Ham 2016; Lanza 2000; Jarret 2004; Carter 1995). **FACILITATOR: [...to engaging patients] CLARIFY PATIENT ROLES:** Patient roles and the purpose of patient involvement must		

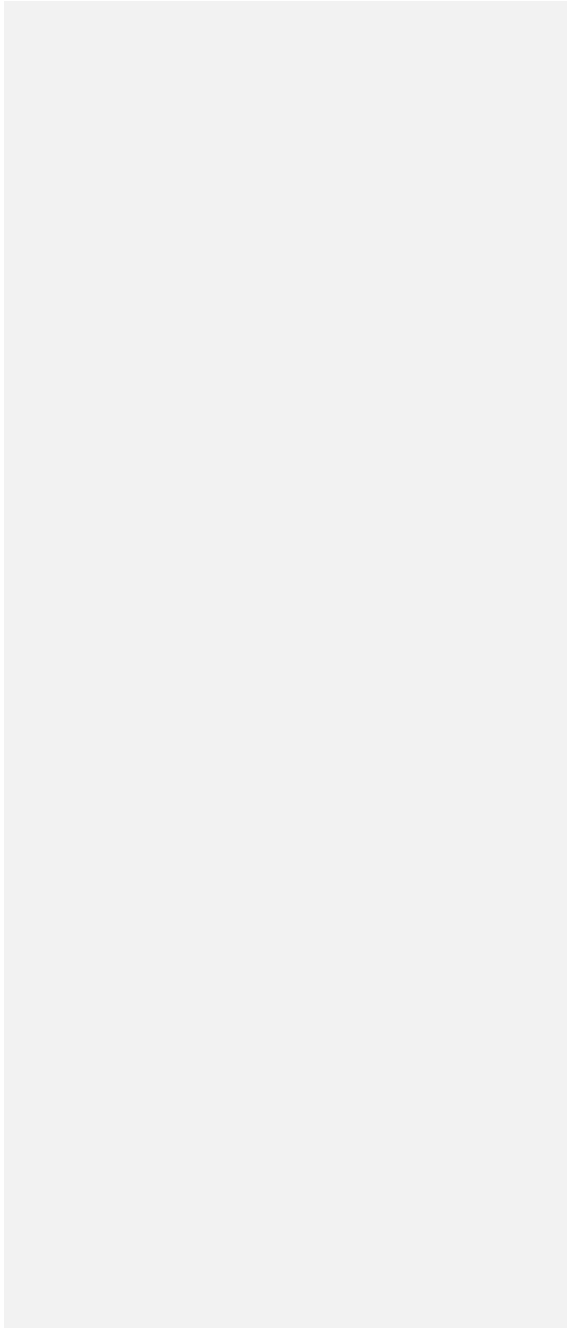|				
	Establish explicit criteria on who should participate in guideline development and why; select chair and other positions and define their roles in the group (Kunz 2012) Discuss roles/responsibilities of group members (Brouwers 2018) Discuss and select chair/roles for members (Devlin 2018) Ensure that all participants know their role and the roles of others in the group (Duff 1996) **Principal investigators** Establish explicit criteria on who should participate in guideline development and why; select chair and other positions and define their roles in the group (Kunz 2012) Establish group aims and member roles (Eccles 2012) Delegate tasks to subgroups of members (Kunz 2012) Ensure that all participants know their role and the roles of others in the group (Duff 1996)	be clearly communicated. Patients should understand what is expected of them, as well as the roles of others in the group. This can be done through orientation meetings where patients can be told about and ask questions about the purpose and limits of their role. To clarify overall participant roles, guideline group members should have a strong understanding of their own and others' experiences, clear project objectives and principles, and consistency in GDG nominations are also needed (Boivin 2010; Chalmers 2017; Den Breejen 2014; Duff 1996; Brouwers 2018; Lanza 2000; Brouwers 2017; Carter 1995; Rapu 2005).		
6. Select group leader(s), or chair(s), experienced in group facilitation, maintaining constructive dynamics, identifying and resolving conflicts, remaining neutral and objective, and having methodological expertise and content expertise.	**Patients** Establish explicit criteria on who should participate in guideline development and why; select chair and other positions and define their roles in the group, the chair should be experienced in group facilitation, maintaining constructive dynamics and managing conflicts early . The chair has a crucial role in ensuring input from external stakeholders such as industry and the public and following a policy to deal with their input.(Kunz 2012) Select an effective leader who can guide the group and ensure a positive group process (Fretheim 2006) Use a neutral 'umpire' or facilitator to help group dynamics and ensure members hear each other (duff 1996)	**FACILITATOR: [...to engaging patients/caregivers] SKILLED MODERATOR/CHAIR:** In order to give patients more voice in guideline development groups, studies suggested appointing a skilled moderator with "a great deal of sensitivity" to lead the group. In one study (Jarret 2004), patient and caregiver members described a good chair as inclusive, skilled, open, honest, and able to influence GDG discussions. Two facilitation techniques were suggested for effectively engaging patients during meetings: notifying working group members of the training and resources that patients receive before meetings, and designating breaks for patient input in meeting agendas. An effective GDG chair can also help to enforce accessible discussions by asking patients for their		

	Public Select an effective leader who can guide the group (Fretheim 2006) **Providers, Principal investigators** Establish explicit criteria on who should participate in guideline development and why; select chair and other positions and define their roles in the group (Kunz 2012) Select an effective leader who can guide the group (Fretheim 2006) **Program managers** Select an effective leader who can guide the group (Fretheim 2006)	opinions, asking professionals to explain their terminology, and protecting participant boundaries (Armstrong 2017; Brouwers 2018; Duff 1996; Harding 2010; Jarret 2004).		
7. Document the guideline group member selection process and roles to ensure transparency.	**Patients, Providers** Establish explicit criteria on who should participate in guideline development and why; select chair and other positions and define their roles in the group (Kunz 2012) **Principal investigators** Establish explicit criteria on who should participate in guideline development and why; select chair and other positions and define their roles in the group (Kunz 2012) Discuss member conflicts of interest (Eccles 2012)			
4. Establishing Guideline Group Processes		**BARRIER: [...to engaging patients] LACK OF CONFIDENCE:** Lack of confidence was a commonly cited barrier to patients sharing their opinions in guideline development groups, especially if they did not have prior experience participating in guideline development. Some patients did not want to appear uninformed or unhelpful when talking with experts and felt that their experiences were not as important as professional opinion (Chalmers 2017; Armstrong 2017; Brouwers 2018; Harding 2010)		

		FACILITATOR [...to engaging patients/caregivers/advocates/providers of healthcare]: PRACTICAL, TECHNICAL, AND EMOTIONAL SUPPORT: Support is needed throughout the development process for all GDG members. Providers of healthcare described their employers as fully supportive of their doing guideline development activities in work time, and support took the form of both time and encouragement. Patients would benefit from support within their own patient organizations as well as collaborating centres. This can be either process-related support, such as monitoring of service user representatives and their needs throughout the process by the project manager, or content related support, for example by organising collective input from the service user organisation that is represented. GDG leaders should also consider contracting with local agencies or consultants to support engagement in certain geographic areas (Den Breejen 2014; Van der Ham 2014; Duff 1996; Ilott 2006; Jarret 2004; Selby 2017).		
1. Establish how and how often communication with guideline panel members and other groups will take place, who will be responsible for making the arrangements, and consider when to deviate from this approach.	**Patients** Decide on communication modes and frequency (Devlin 2018) Establish a system for group communication. Ensure that all participants know how to contribute to the group. Allow participants to decide how they wish to, and feel able to contribute to developing guidelines (Duff 1996) Establish coordinated meeting intervals and medium (eg. face to face, teleconference) (van der Weijden 2018) Clarify time commitment needed from GDG members and ensure a mandatory commitment to be present for all meetings so that the stakeholder group is not underrepresented (Shin 2014)	**FACILITATOR: [...to engaging patients and providers of healthcare] IN-PERSON vs. ONLINE ENGAGEMENT:** Direct, in-person engagement can encourage patients to participate. This may include holding structured workshops in person whenever possible as well as prompting patients during discussions. In-person meetings should be held at venues which are physically accessible. Where travel is prevented through ill health or other issues, teleconference facilities should be offered to avoid excluding patients' valuable contributions (Selby 2017; Armstrong 2017; Chalmers 2017). For providers of healthcare, there is a preference to network, collaborate and provide feedback in-person rather than online and to participate		

	Patient organizations, Principal investigators Establish a system for group communication. Ensure that all participants know how to contribute to the group. Allow participants to decide how they wish to, and feel able to contribute to developing guidelines. Work in small groups to avoid large committee-style meetings (Duff 1996) **Providers** Decide on communication modes and frequency (Devlin 2018) Establish a system for group communication. Ensure that all participants know how to contribute to the group. Allow participants to decide how they wish to, and feel able to contribute to developing guidelines. Work in small groups to avoid large committee-style meetings (Duff 1996) Clarify time commitment needed from GDG members and ensure a mandatory commitment to be present for all meetings so that the stakeholder group is not underrepresented (Shin 2014) Establish coordinated meeting intervals and medium (eg. face to face, teleconference) (van der Weijden 2018)	in structured discussions (Selby 2017). Patients and caregivers also reported online engagement processes to be a convenient way to overcome physical, geographical, and time constraints (Brouwers 2018; Armstrong 2019). The convenience of an online approach was amplified by the asynchronous nature of the engagement process. Participants found the engagement process accommodating given that they could complete each round at their convenience rather than finishing all of it in one sitting (Armstrong 2019).		
2. Set expectations and awareness of the group process through an introduction, training, and support for the guideline development group members (e.g. setting ideal conditions for group discussion and decision-making).	**Patients** Make introductions of group members at start of meetings (Chalmers 2017) ==Discuss roles and responsibilities of group members and establish a positive working group dynamic== **Caregivers** Create an agenda for meetings to facilitate discussions (Brouwers 2018) **Providers** Create an agenda for meetings to facilitate			

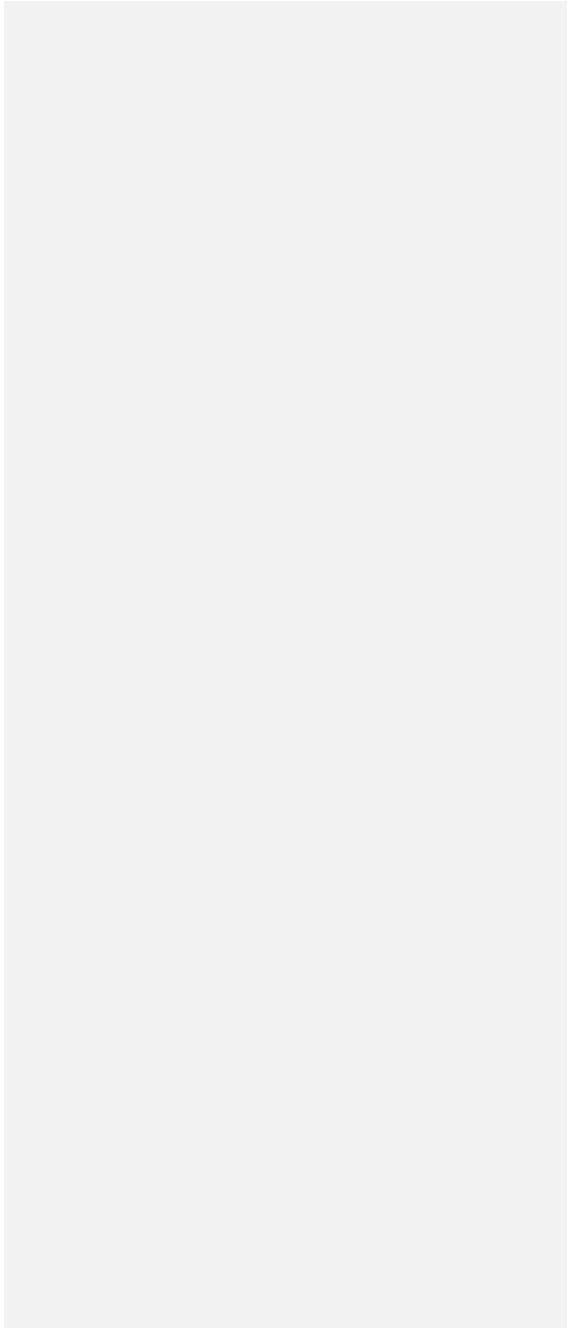|				
	discussions (Brouwers 2018) **Principal investigators** Develop norms of behaviour for the group (Eccles 2012)			
3. As part of the training for the guideline development group, ensure that group members understand what the process and proposed methods will be and that they need to be adhered to (e.g. consensus methods that may be used, anonymous or non-anonymous voting, assessment of evidence, group discussion and contributing ideas).	**Patients** Discuss voting roles of patient members, avoid jargon and confirm patient understanding regularly, take breaks regularly (Chalmers 2017) **Principal investigators** Use formal consensus processes to achieve agreement (Kunz 2012)			
4. Aim to set optimal conditions for group members to be provided equal opportunities to contribute and for their ideas and arguments to be given appropriate consideration (e.g. during group discussion, decision-making, and when formulating recommendations).	**Patients, Patient organizations, Providers, Principal investigators** Utilize a neutral facilitator to ensure positive group dynamics (Duff 1996)	**BARRIER: [...to engaging patients]: POWER IMBALANCES:** Power differences between professionals and patients may cause issues within the GDG. If some personalities in the group are stronger than others, especially if members are posturing or power positioning, it may influence how patient representatives participate in discussions. GDG meetings might be dominated by some to the exclusion of others. Perceived power imbalances can come from various sources - patients may not be comfortable if their own physician is on the panel, patients may interpret the use and explanation of jargon as a display of power, and discussion chairs or leaders may not consider patient input. This can also extend to the national level, where territoriality and "turf protection" can interfere with coordination and development efforts (Harding 2010; Armstrong 2017; Atkins 2013; Kredo 2018; Carter 1995). **BARRIER: [...to engaging patients] UNEQUAL INFLUENCE ON DECISION-MAKING:** There may be inequality in GDG members' influence on decision-making, especially if there is a perceived hierarchy of		

opinion where the perspectives of patient representatives are considered to be less valuable than those of healthcare providers. Some GDG members may feel that patients do not easily fit into the decision-making structure. This can lead to limited influence of patient input, overturned group consensus, and a general undermining of the patient focus in guideline development. On the other hand, patients may not realize that their input is only one part of the guideline process and that the GDG is not obligated to follow the patients' recommendations. One study (Atkins 2013) reports that unequal influence was seen by some GDG members as beneficial for decision making by preventing unfocussed discussion. (Atkins 2013; Van de Bovenkamp 2015; Rapu 2005; Harding 2010; Jarret 2004; Lanza 2000).

BARRIER: [...to engaging patients] TECHNICAL LANGUAGE/JARGON: Patients thought meeting dialogue was sometimes overly technical and that professionals' use of jargon was like "speaking a foreign language". Many patients may not be familiar with the medical language spoken and ask for clarification of terms and abbreviations. Patients without some research knowledge reported difficulties grasping the concept of the evidence framework and the statistics surrounding it. Some patients who found the documents and reading too technical or scientific said they were helped by the Chair, who took time to explain, but some decided that they had no contribution to make on these issues and felt excluded. Such patients were reported to be "participating observers of technical language to which they could hardly offer any input" [Brouwers 2018; Jarret 2004; Van Wersch 2001; Harding 2010]

		FACILITATOR: [...to engaging patients] OFFER EXPLANATIONS: A pivotal success factor seemed to be the extent to which people explained terms to one another. Project chairs can meet with patients prior to meetings so that patients can have an explanation of the context of the expected discussion. GDG members can also use natural breaks in discussion to explain to patients in lay terms what is being discussed and ask patients specific questions where their input is needed. Some people linked this with an (often subtle) display of power which could be redistributed. Others felt these strategies contributed by preventing unhelpful assumptions from influencing proceedings. [Harding 2010; Chalmers 2017]		
5. Establish methods for dealing with conflict or disputes among group members and dysfunction in the group process.				
6. Provide opportunities for discussion and feedback about the group process throughout the guideline development project.	**Patients** Utilize small groups/ subcommittees to help with patient understanding (Chalmers 2017) Create a threaded discussion board and remind participants via email when rounds are open and/or comments are posted, solicit comments from all group members and ensure no single person dominates the conversation. Assign each member a group ID that reflects their stakeholder category but allows anonymity (Khodyakov 2019) **Principal investigators** Provide members with equal opportunities to contribute, and give each contribution appropriate consideration (Kunz 2012)			
7. Establish a method for structured and timely distribution and archiving of documents used and produced in the guideline development.				

8. Set a quorum for meetings (e.g. 75% of group must be present to formulate guideline recommendations), but expect that all group members attend all meetings as far as possible.				
9. Set or plan meeting times and locations (virtual or in-person) in advance and prepare a scope and specific agenda for each meeting.	**Patients** Create an agenda for meetings to facilitate discussions (Brouwers 2018) Consider meeting venues that are accessible to patients (Chalmers 2017)			
10. Keep a record of all meetings with minutes and determine whether or not to make them publically or internally available (e.g. who attended, what was the agenda, what decisions were made, what next steps will be).				
5. Identifying Target Audience and Topic Selection				
1. Identify, define and/or review the primary audience (e.g. primary care physicians, health program managers) and secondary audience(s) (e.g. hospital administrators) for the guideline and determine how many audiences can be addressed with the guideline.				
2. Consult appropriate stakeholders about the target audience(s) identified to ensure they are applicable for the guideline topic and no relevant audience is missed. (see Topic 6)				
3. Establish a method and criteria to generate and prioritize a candidate list of topics to be addressed within the guideline (e.g. where evidence is most confusing or controversial, where there is currently uncertainty or inconsistency in practice, questions about screening, diagnosis, and treatment, etc.).	**Patients** Patients should drive priority topic rankings (Devlin 2018) Identify topics using established/known information systems such as patient and health care professional forums (Duff 1996) Ensure topic selection takes account of consumer values and is not only determined by professional or other interests (Kelson 2012) Patients can help identify important topics			

	and special population of interest (e.g. comorbidities). Survey patients to prioritize nominated topics and rate importance of proposed outcomes and elements of proposed analytic framework (Armstrong 2017) Conduct wide consultation on the scope of the guidelines or recommendations with those outside the guideline development group (Fretheim 2006) **Caregivers** Ensure topic selection takes account of consumer values and is not only determined by professional or other interests (Kelson 2012) **Public** Ensure topic selection takes account of consumer values and is not only determined by professional or other interests (Kelson 2012) Lay participants can review draft evidence (Armtrong 2017) **Patient organizations** Identify topics using established/known information systems such as patient and health care professional forums (Duff 1996) Consult patient organizations on what issues guideline should address (Wedzicha 2011) **Providers** Identify topics using established/known information systems such as patient and health care professional forums (Duff 1996) Establish criteria for identifying topics for which guidelines are needed (English 2017) Consult patient organizations on what issues guideline should address (Wedzicha 2011) Rank, prioritize and vet topics submitted			

	based on prespecified domains and scales (Shin 2014) Conduct wide consultation on the scope of the guidelines or recommendations with those outside the guideline development group (Fretheim 2006) **Principal investigators** Identify topics using established/known information systems such as patient and health care professional forums (Duff 1996) Establish a criteria on which to base judgements and decisions about topics selected for guideline development (Eccles 2012) Establish criteria for identifying topics for which guidelines are needed (English 2017) **Policymakers** Establish criteria for identifying topics for which guidelines are needed (English 2017)			
4. Consult appropriate stakeholders to ensure all relevant topics for the guideline have been identified and will meet the needs of the target audience(s). (see Topic 6)	**Patients** Solicit topic nominations from the public and patient advocacy groups. Patients can help identify important topics and special population of interest (e.g. comorbidities) (Armstrong 2017) Conduct face-to-face interviews with patients and caregivers to obtain their management concerns (Dunning 2012) Identify topics using established/known information systems such as patient and health care professional forums (Duff 1996) Ensure topic selection takes account of consumer values and is not only determined by professional or other interests (Kelson 2012) **Caregivers** Solicit topic nominations from the public and patient advocacy groups. (Armstrong 2017)			

	Conduct face-to-face interviews with patients and caregivers to obtain their management concerns (Dunning 2012) **Patient organizations** Solicit topic nominations from the public and patient advocacy groups. (Armstrong 2017) **Providers** Discuss needs/request of clinicians (Dunning 2012) Ensure topic selection takes account of consumer values and is not only determined by professional or other interests (Kelson 2012) Identify topics using established/known information systems such as patient and health care professional forums (Duff 1996)			
5. Select or provide a consensus development method to be used by the group in agreeing on the final topics selected to be addressed within the guideline (e.g. Delphi method, nominal group technique).				
6. Document the processes of identifying the target audience(s) and selection of topics for the guideline to ensure transparency.				
6. Consumer and Stakeholder Involvement		FACILITATOR: [...to engaging patients] ACKNOWLEDGEMENT: Patients are more likely to contribute if they feel appreciated by other members of the guideline development group and/or that their input matters. This can be done by providing financial support or other resources, involving patients in publications if they meet the criteria for authorship, and other acknowledgements or rewards for participation. Encouragement and support from other guideline group members, family and friends, and other sources can keep patients invested in guideline development efforts (Brouwers 2017; Rapu 2005; Chalmers 2017; Jarret 2004)		

		FACILITATOR: [to engaging patients] ENSURE MEANINGFUL INVOLVEMENT: Working groups should decide whether patient input during guideline development is essential and whether patients will be able to meaningfully contribute during meetings. To avoid tokenism, patients and service users should be involved as equals in decision-making processes. Leadership should ensure that these groups' opinions are incorporated into guideline development. Experienced participants could also help to facilitate meaningful patient engagement, especially if they have already interacted with medical professionals in a similar environment. Involving patients and service users in all different phases of the process instead of serving as occasional consultants makes their involvement more meaningful - one study suggested creating a permanent patient reference group. Alternatively, another study (Selby 2017) had no formal patient or public involvement to prevent tokenism (Chalmers 2017; Atkins 2013; Van Der Ham 2014 and 2016; Brouwers 2017; Brouwers 2018 Jarret 2004; Selby 2017).		
1. Identify the appropriate stakeholders to involve and consult with in the development of the guideline to incorporate views of all those who might be affected by the guideline (e.g. professional groups, health managers, policy makers, industry representatives).	**Public** Establish, from the start, a system to facilitate input from stakeholder including the public and industry and a policy on how the guideline development group will deal with the feedback (Kunz 2012) **Providers** Invite stakeholders to submit questions and evidence for consideration (Rapu 2005) Solicit feedback on topics from providers, with set time to receive response (Shin 2014) **Product makers**			

	Invite industry to review sections on scope, study design and conduct (Kunz 2012) Establish, from the start, a system to facilitate input from stakeholder including the public and industry and a policy on how the guideline development group will deal with the feedback (Kunz 2012)			
2. Identify the appropriate consumers to involve and consult with in the development of the guideline (e.g. individual patients, carers who provide non-reimbursed care and support to patients, members of the public as potential patients and as funders of healthcare through taxation, community organizations that represent the interests of patients, and advocates representing the interests of patients and carers).	**Patients** Offer patients the opportunity to choose level of involvement- whether via newsletter/email update/full involvement- in all activities (Chalmers 2017) Include consumers as guideline group members to integrate consumer values into the clinical questions (Kelson 2012) **Public** Solicit feedback from public on topics and draft guidance (Armstrong 2017) **Patient organizations** Involve patient organisations wherever possible as they provide peer support, training and, in some cases, resources to aid patients (Chalmers 2017)	**BARRIER: [...to engaging patients]: INTIMIDATION:** Intimidation may be a barrier to patient representatives. Healthcare professional panel members are usually highly-trained and have experience working with other professionals, but patient members may not have any training or experience at all, leading to hesitancy in commenting or questioning in the group discussions. This may be amplified if there is only one patient representative in the GDG. Some patients indicated that they did not want to appear uninformed or unhelpful, especially if the medical terminology and issues discussed are very complex. These participants may compare themselves to other GDG members or feel that they carry less influence, which can undermine confidence (Brouwers 2017; Duff 1996; Jarret 2004; Armstrong 2017; Brouwers 2018; Harding 2010; Atkins 2013).		
3. Establish methods for consumer and stakeholder involvement and maintain a registry of stakeholders for the guideline (e.g. enrollment of consumer and stakeholder members to participate directly on the guideline panel, announce call for separate consumer and stakeholder meeting(s) or workshop(s), electronic distribution of documents and feedback, open period for review of documents and feedback).	**Patients** Offer patients the opportunity to choose level of involvement- whether via newsletter/email update/full involvement- in all activities (Chalmers 2017) Utilise focus group discussions and interviews to illicit stakeholder input (van der Ham 2016) Utilize surveys, consultation and focus group, patient forums, to obtain patient/user opinions (Duff 1996) Utilize open forums/meetings to solicit input and address concerns about guidelines from key stakeholders and to review draft	**FACILITATOR: [...to engaging patients/providers/payers/policymakers/Pls]: NETWORK APPROACH:** Studies suggested that a network approach (e.g. formation of a network of organizations or individuals in guideline development) could facilitate future engagement. GDGs can use these networks to identify potential members and/or to share learning, operational systems, and resources among organizations. In order to encourage follow-up, GDGs should decide on the communications mechanisms that they will use to maintain their network - emails, newsletters, and journals were common		

| | documents and provide their perspectives (patients, payers, product makers, professional organizations). (Eccles 2012) Conduct patient surveys, web consultation, interview, personal testimonials, as appropriate to gain insights from stakeholders (Wedzicha 2011) Consult consumers for comments on draft guidelines (Kelson 2012) Link panel members (patients) with large international and national organizations to provide broader feedback (McLennan 2017) Screen participants to ensure they meet participation criteria (Khodyakov 2019)

Caregivers
Utilize surveys, consultation and focus group to obtain patient/user opinions (Duff 1996) Consult consumers for comments on draft guidelines (Kelson 2012) Utilise focus group discussions and interviews to illicit stakeholder input (van der Ham 2016) Screen participants to ensure they meet participation criteria (Khodyakov 2019)

Public
Utilize open forums/meetings to solicit input and address concerns about guidelines from key stakeholders (Eccles 2012) Utilize a Citizens council to integrate the values of members of the public (Kelson 201)

Patient organizations
Utilise focus group discussions and interviews to illicit stakeholder input (van der Ham 2016) Utilize open forums/meetings to solicit input and address concerns about guidelines from key stakeholders and to review draft documents and provide their perspectives (patients, payers, product makers, | choices. Updates can be done through email or webcast with select groups of stakeholders (Carter 1995; Den Breejen 2014; Van der Ham 2014; Jarret 2004; Ilott 2006; Rapu 2005). | | |

	professional organizations). (Eccles 2012) **Providers** Engage stakeholders as advisors or experts to the guideline development group (Rapu 2005) Utilise focus group discussions and interviews to illicit stakeholder input (van der Ham 2016) Send letters to providers with details on goals, processes for adaptation, dissemination and implementation (Wise) Utilize open forums/meetings to solicit input and address concerns about guidelines from key stakeholders and to review draft documents and provide their perspectives (patients, payers, product makers, professional organizations). (Eccles 2012) **Product makers** Utilize open forums/meetings to solicit input and address concerns about guidelines from key stakeholders and to review draft documents and provide their perspectives (patients, payers, product makers, professional organizations). (Eccles 2012)			
4. Provide information (e.g. training and introduction sessions) for consumers and stakeholders involved directly on the guideline panel to clarify roles and maximize contributions (e.g. evaluating evidence objectively, avoiding recommendations based on self-interests).				
5. Determine the roles, tasks and timing for consultation with consumers and stakeholders not directly participating on the guideline panel (e.g. at specific milestones during the guideline development process including opportunities to comment on priority setting, topics for the guideline, identifying target audience, identifying patient-important	Identify the roles of each potential stakeholder member and outreach outcomes for each member (patient representatives obtain feedback from the community)			

outcomes, identifying additional evidence, point to consequences that the panel has not considered, review the final guideline draft, etc.).				
6. Develop or adopt standard templates for consumer and stakeholder input and comments during consultation, with clear instructions or training modules to ensure effective input.				
7. Offer adequate time for consumer and stakeholder feedback and consultation.	Release each proposed recommendation for a 2 week open comment period allowing all relevant stakeholders and consumers to review and submit additional items, if needed (Shin 2014)	**FACILITATOR [...to engaging patients/caregivers/advocates]: ADEQUATE TIME FOR REVIEW/FEEDBACK:** All participants should understand the time commitment necessary to develop guidelines. Patients should be given sufficient notice of meetings and allocated enough time to understand the materials and provide feedback (Brouwers 2018; Chalmers 2017; Duff 1996)		
8. Set a policy and process for handling consumer and stakeholder feedback and dealing with different perspectives (e.g. ensure that diverse perspectives are taken into account in making decisions, provide transparent rationale for judgements made, provide an appeal process for stakeholders, publish consultation comments and the guideline development panel's responses).	**Public** Develop a policy on how feedback will be solicited (eg, posting draft on internet, contacting stakeholders directly), considered and incorporated into the final guidelines (Kunz 2012) **Product makers** develop a policy on how feedback will be solicited (eg, posting draft on internet, contacting stakeholders directly), considered and incorporated into the final guidelines (Kunz 2012)	**FACILITATOR: [...to engaging patients] VALUE ALL CONTRIBUTIONS:** The inclusion of patient representatives in decision-making is valuable and beneficial in formulating recommendations. Guideline development groups should value all contributions equally and try to include all GDG members' views in the project's scope. This does not necessarily mean including patients in all meetings, but they should be included when their input would be most relevant and useful. Patients and caregivers should be given autonomy in decision processes and be offered opportunities to gather feedback and receive input (Den Breejen 2014; Rapu 2005; Jarret 2004; Van de Bovenkamp 2015; Armstrong 2019; Chalmers 2017). **FACILITATOR (SS): [...to engaging patients]: TRANSPARENT DECISION PROCESSES:** The use of feedback sheets,		

	indicating how input from service user representatives was processed, functioned as a facilitator by providing insights into how decisions were made (van der Ham 2014)		
9. Document the enrollment and selection of consumers and stakeholders for the guideline panel and the involvement and consultation with all other consumers and stakeholders to ensure explicit and transparent methods.			
7. Conflict of Interest (COI) Considerations			
1. Set a policy for declaration of interests (DOI) of individual participants at admission to the project, including potential guideline panel members prior to their involvement (e.g. what interests should be disclosed, financial, intellectual, academic/clinical, competitive interests of the professional society).	**Patients** Assess conflicts of interest of panel members from patient perspective (Armstrong 2017) Members should complete a coflict of interest and confidentiality form pror to involvement in a project or task force (Chalmers 2017) Members complete and submit COI forms annually (Devlin 2018) Disclose and address any potential conflicts of interest (Kelson 2012) Approve membership based on written Declarations of Interests (van der Weijden 2018) **Caregivers** Disclose and address any potential coi (Kelson 2012) **Public** Disclose and address any potential coi (Kelson 2012) **Providers** Members should complete a coflict of interest and confidentiality form pror to involvement in a project or task force (Chalmers 2017) Members complete and submit COI forms annually (Devlin 2018) Approve membership based on written Declarations of Interests (van der Weijden 2018)		

	Principal investigators Members should complete a coflict of interest and confidentiality form pror to involvement in a project or task force (Chalmers 2017) Submit written disclosure of all potential COI (Eccles 2012)			
2. Set a policy for determination of conflicts of interest (COI) and an approach for collecting and updating COI declarations (e.g. how and what level of financial interest should be disclosed, how long a period of time should be covered by the disclosure, who will judge what constitutes a conflict).	**Patients, Providers** Members complete and submit COI forms annually (Devlin 2018) **Principal investigators** Individual members should label where COI bears on specific recommendation (s) (Eccles 2012)			
3. Provide clear instructions and training to the potential guideline group members on how to complete the COI disclosure, including a list of the members who must declare COI and the types of interests to declare including examples.				
4. Set a policy for management of COI (e.g. individuals with COI not categorically excluded from guideline development but excused from voting on specific recommendations related to the area of conflict, chair should have no COI, evidence summaries prepared by un-conflicted methodologists,).	**Patients, Providers** Conflicted members refrain from discussions and voting around questions on which they have conflicts (Devlin 2018) **Principal investigators** Members with important COI should be recused from making recommendation(s) (Eccles 2012) Exclude members with un resolveable COI from guideline development group (Eccles 2012) Assess conflicts of interest and ensure that panel members do not vote on or influence any issues where they are conflicted (MacLennan 2017)	**BARRIER: [...to engaging patients] CONFIDENTIALITY CONCERNS:** Some participants may refrain from sharing their opinion due to fears surrounding confidentiality or judgement. Patients may be worried about privacy issues, stigma, and/or denial when sharing personal experiences. Patients may be under the care of a member of the guideline development group. This might not be a barrier for all patients, but it is possible that patients may feel coerced to participate or hide their true opinion if it is at odds with their physician's opinion. Some patients may fear that they will lose access to hospital care if they do not participate or agree with professional members (Chalmers 2017; Lanza 2000; Armstrong 2017; Brouwers 2017). **FACILITATOR: [...to engaging patients]: MANAGE COI and CONFIDENTIALITY:**		

		Project chairs should consider how they will manage patients' conflicts of interest, especially if patients are receiving care from another guideline group member. While patients who had good relationships with their physicians felt comfortable sharing their opinions, this is not always the case. Chairs should take special care to maintain patient confidentiality and ensure that physicians do not disclose any personal patient information to the panel members without consent (Chalmers 2017; Armstrong 2017).		
5. Set a policy to manage COI with respect to funding of the guideline development activities (e.g. advocate for public funding, no commercial sponsorship, commercial sponsorship from entities unrelated to topic of guideline, commercial support for non-direct activities such as translation, no single-source sponsor).				
6. Disclose and publish the funding source and describe the role of the sponsors and support provided for the development of the guideline.				
7. Explicitly disclose, publish and describe conflicts of interest of the guideline group members, particularly where the conflicts bear on specific recommendations.				
8. (PICO) Question Generation				
1. Establish methods for generating the questions for the guideline, prioritizing questions, and selecting and ranking outcomes.	**Patients** Formulate a guiding philosophy to serve as a framework for guideline development (Dunning 2012) Contact patient organizations to ask them which issues they think the guidelines should address (Wedzicha 2011) **Providers** Brainstorm focus points to be addressed by the guideline (Shin 2014)			

	Formulate a guiding philosophy to serve as a framework for guideline development (Dunning 2012) Submit questions for consideration by the guideline development group (Rapu 2005)			
2. Generate and document the key questions (e.g. clinical, health, policy, cost-effectiveness) to be answered in the guideline using a standard format (e.g. PICO) and determine the criteria by which the questions generated will be prioritized if it is not feasible to answer all questions (e.g. survey guideline panel members, survey stakeholders).	**Patients** Identify outcomes of relevance to patients, caregivers, the community and identify populations of interest or outcomes/comparators of relevance using focus groups in addition to literature (Armstrong 2017)			
3. Explicitly describe the population to whom the guideline is meant to apply. Take into consideration specific characteristics of the population, such as prevalence of multiple comorbidities in the population, geographical setting, and equity issues (e.g. plausible reasons for anticipating differential relative effects across disadvantaged and advantaged populations).	**Patients** Identify outcomes of relevance to patients, caregivers, the community and identify populations of interest or outcomes/comparators of relevance using focus groups in addition to literature (Armstrong 2017)			
4. Determine if regulatory approval is a requirement or not for considering interventions (e.g. for international guidelines this may be not relevant as regulatory approval may not be present for all target countries).				
5. Explicitly describe the intervention(s) and comparator(s) to be considered in the guideline and develop an analytic framework depicting the relationships among interventions and outcomes. Identify whether or not multiple (treatment) comparisons should be included.				
6. Identify the important outcomes (e.g. outcomes along the clinical pathway; morbidity, quality of life, mortality), including both desirable (e.g. benefits, less burden,	**Patients** Identify outcomes of relevance to patients, caregivers, the community and identify populations of interest or			

savings) and undesirable effects (e.g. harm, burden, costs, and decrease in patient autonomy). Do not ignore important outcomes for which evidence may be lacking,	outcomes/comparators of relevance using focus groups in addition to literature (Armstrong 2017) **Providers** Brainstorm focus points to be addressed by the guideline (Shin 2014)			
7. Determine the setting (e.g. countries, hospitals) or include it in the considerations about the population (i.e. population cared for in tertiary care hospitals).				
8. Mandate a preference for patient-important outcomes over surrogate, indirect outcomes. Consider appropriateness of surrogate outcomes along the causal pathway when data for a patient-important outcome is lacking.	**Patients** Identify outcomes of relevance to patients, caregivers, the community and identify populations of interest or outcomes/comparators of relevance using focus groups in addition to literature (Armstrong 2017)			
9. Rank the relative importance of the outcomes, taking into consideration the values and preferences of the target population.				
10. Determine or develop a process for determining a priori the magnitude of effect for the individual outcomes that is judged as important to the target population.				
11. Involve all guideline group members and consult consumers and stakeholders to ensure broad representation from the target population in generating the questions and selecting and rating the important outcomes.				
12. Document the methods of question generation and prioritization, selection and ranking of outcomes, and stakeholder and consumer consultation to ensure they are explicit transparent.				
13. Ensure the guideline protocol outlines the target population, target condition, outcomes, and key questions considered to help direct the evidence review.				

9. Considering Importance of Outcomes and Interventions, Values, Preferences and Utilities				
1. Decide whether the relative importance of outcomes and interventions, values, preferences or utilities of consumers and stakeholders (e.g. patients and target audience) to inform decisions and deliberations during the guideline development will be elicited indirectly or directly (e.g. review of the published literature vs. consultation with consumers).	**Patients** Identify outcomes of relevance to patients, caregivers, the community and identify populations of interest or outcomes/comparators of relevance using focus groups in addition to literature (Armstrong 2017)			
2. Establish methods for consultation with consumers and stakeholders to obtain information about the relative importance of outcomes and interventions, values, preferences or utilities (e.g. involvement of consumers on guideline panel, surveys or focus groups with broader representation of consumers).	**Patients** Discuss how patients can contribute evidence to the review (Duff 1996) Conduct interviews with patients and carers to ascertain and incorporate their concerns into the guiding philosophy for the guideline's development (Dunning 2012) Utilize workshops, focus groups, literature reviews and or interviews to illicit patient preferences that can feed into other aspects of the guideline development process (Kelson 2012) Solicit feedback on what matters to patients (MacLennan 2017) Identify patient needs through literature reviews, survey or focus group (van der Weijden 2018) **Caregivers** Conduct interviews with patients and carers to ascertain and incorporate their concerns into the guiding philosophy for the guideline's development (Dunning 2012) Utilize workshops, focus groups, literature reviews and or interviews to illicit patient preferences that can feed into other aspects of the guideline development process (Kelson 2012)			

	Public Discuss how patients can contribute evidence to the review (Duff 1996) Utilize workshops, focus groups, literature reviews and or interviews to illicit patient preferences that can feed into other aspects of the guideline development process (Kelson 2012) **Patient organizations** Discuss how patients can contribute evidence to the review (Duff 1996) **Principal investigators** Solicit feedback on what matters to patients (MacLennan 2017) Identify patient needs through literature reviews, survey or focus group (van der Weijden 2018)			
3. Determine if a structured approach for assessing the confidence in the obtained importance ratings, values, preferences and utilities (i.e. quality of the evidence in them) will be used.				
4. Determine if modelling will be used to integrate the relative importance of outcomes and interventions, values, preferences or utilities and how modelling will be done.				
5. Determine whose perspective(s) will be considered when obtaining information about the relative importance of outcomes and interventions, values, preferences or utilities and when making decisions or formulating recommendations (e.g. patients, public, society, clinicians).	**Patients** Conduct survey for pts to rate importance of proposed outcomes (Armstrong 2017)			
6. Consider and document approaches for dealing with conflicting relative importance ratings for outcomes and interventions, values, preferences or utilities (e.g. patient vs. carer, patient vs. public).				

7. Document the methods of obtaining information about the relative importance of outcomes and interventions, values, preferences or utilities to ensure they are explicit and transparent.				
8. Document if ethical considerations, such as whether recommendations should give special consideration to certain patient groups or conditions (e.g. elderly, rare disease, those affected by health inequalities).				
9. Decide how to consider ethical or moral values in making healthcare recommendations (e.g. by considering religious, social, or cultural convictions).				
10. Deciding what Evidence to Include and Searching for Evidence				
1. Follow systematic review methods (either full systematic reviews or rapid systematic reviews depending on the topic and organization's framework) or provide a rationale for why this is not done.	**Patients**, **Caregivers, Patient organizations** Include patients on guideline development groups to assist with additional search terms and critical appraisal of studies (Armstrong 2017)			
2. Develop a protocol for locating, selecting, and synthesizing the evidence (e.g. conduct a search for existing systematic reviews, new systematic review and grey literature search) and determine the types of evidence to include (e.g. databases searched, types of studies, inclusion and exclusion criteria, searching for specific studies on adverse effects or deciding to abstract information on adverse effects from studies on benefit).	**Patients** Identify relevant publications from structured literature review, and grey literature (Dunning 2012) Develop an explicit inclusion/exclusion criteria and search the appropriate databases (van der Weijden 2018) **Providers** Identify relevant publications from structured literature review, and grey literature (Dunning 2012) Develop an explicit inclusion/exclusion criteria and search the appropriate databases (van der Weijden 2018)			
3. Decide who will develop the search strategies and perform searching and	**Patients**	**BARRIER [...to engaging patients]: LACK OF EBM SKILLS:** Multiple studies mentioned		

selection of evidence (e.g. working group of guideline development group, outsource to external agency, form a relationship between guideline development group and external agency to collaborate on development of the guideline).	Include patients on guideline development groups to assist with additional search terms and critical appraisal of studies (Armstrong 2017)	the concern that the search, review, and discussion of scientific literature may be too complex for patient representatives. The average patient's lack of skills - for both guideline development and literature review - was frequently cited as a barrier to engagement, for example: "He didn't have the sort of skills – his contribution could only be [...] from his experience that couldn't meaningfully be fed into that process" (Brouwers 2017; Hameen-Antilla 2016; Kredo 2018; Shalkers 2017; Van De Bovenkamp 2015; Van Der Ham 2014).		
4. Critically appraise existing systematic review(s) selected to be included using a validated tool (e.g. AMSTAR) to ensure it is of adequate quality and appropriate for use in the guideline.	**Patients** Include patients on guideline development groups to assist with additional search terms and critical appraisal of studies (Armstrong 2017)			
5. If an existing systematic review is updated or requires updating, determine how new evidence will be included and how those who conducted the review will be contacted and possibly involved in the update.				
6. If a new systematic review is required, conduct an assessment to determine if adequate resources (e.g. time and funding) are available to conduct a full systematic review.				
7. If resources are limited, consider applying a rapid assessment methodology and explicitly describe the methodology, noting important limitations, uncertainties, and the need and urgency to undertake a full systematic review.				
8. Establish methods for identifying additional evidence and unpublished data (e.g. suggestions from guideline panel members, consulting with stakeholders).	**Patients, Caregivers, Patient organizations** Include patients on guideline development groups to assist with additional search terms (Armstrong 2017)	**FACILITATOR: [...to engaging patients/caregivers] ELICIT PATIENT KNOWLEDGE BEYOND GDG MEMBERSHIP:** There are opportunities to access patient input from other sources over and above patient membership of the GDG.		

		Patient organizations have good channels for gathering information from the patient perspective. One possible means of gathering patient views were surveys distributed by the patient organizations. Focus groups with patients and carers were also sources that guideline group members (including patient members) could draw on to inform their own contributions to the GDG. Patients and caregivers appreciate interactive processes that include feedback loops (e.g. Delphi) and opportunities to directly engage with and learn from other patients. The iterative nature of data collection can foster better participant engagement by increasing their willingness to share and discuss their opinions and experiences with others, resulting in the development of new and shared perspectives. (Hameen Antilla 2016; Jarret 2004; Armstrong 2017).		
9. Set a policy for handling expert input (i.e. expert opinion is not evidence per se and should not be used as evidence; rather, experience or observations that support expert opinions should be described, identified and, if possible, appraised in a systematic and transparent way, e.g. in the conceptual framework).		**BARRIER: [...to engaging patients] DEVALUATION OF EXPERIENTIAL KNOWLEDGE:** The strong focus on evidence-based medicine and the system used to evaluate the scientific studies and categorize them in terms of the strength of the evidence makes it hard to give the experiential knowledge of patients a place in the guideline as it does not fit this categorization structure. GDG members may have different ways of defining evidence, ranging from rigorous scientific trials to "evidence of experience". Within this, the medical knowledge of professionals is considered superior to the experiential knowledge of patients, and that this might be even more the case with children than with adults, suggesting that children's experience of illness is excluded from guideline development (Schalkers 2017; Van de Bovenkamp 2015; Atkins 2013; Harding 2011). Several professionals indicated that it is often difficult		

		to integrate input from patients into the guideline because it generally focuses on aspects of care, such as the organisation of care or the patient-provider relationship, which are often not the focus of a guideline (Van der Ham 2014). A single study also suggested that there are similar challenges engaging providers of healthcare and ensuring an appropriate balance between the evidence base, expert opinion and practitioner feedback (Selby 2017)		
10. Document and publish the search and selection of evidence, judging eligibility, range of evidence included, and search strategies used to ensure the methods are explicit and transparent.				
11. Summarizing Evidence and Considering Additional Information				
1. Summarize the evidence using a concise summary (e.g. evidence table, evidence profile or summary of findings table) of the best available evidence for each important outcome, including diagnostic test accuracy, anticipated benefits, harms, resources (costs), the quality of evidence rating, and a summary of the relative and absolute results/estimate of effect for each outcome.				
2. Provide a summary of the additional information needed to inform recommendations (e.g. qualitative narrative summary, evidence table), including values and preferences, factors that might modify the expected effects, need (prevalence, baseline risk, or status), effects on equity, feasibility, and the availability of resources.	**Patients** Solicit feedback and suggestions on critical appraisal and alternate evidence interpretation (Armstrong 2017) Formulate a guiding philosophy to serve as a framework for guideline development (Dunning 2012) Include patient feedback obtained from survey/interviews as summaries for guideline group members (Wedzicha 2011) **Caregivers** Solicit feedback and suggestions on critical appraisal and alternate evidence			

	interpretation (Armstrong 2017) **Patient organizations** Solicit feedback and suggestions on critical appraisal and alternate evidence interpretation (Armstrong 2017) Include patient feedback obtained from survey/interviews as summaries for guideline group members (Wedzicha 2011) **Providers** Formulate a guiding philosophy to serve as a framework for guideline development (Dunning 2012) Submit evidence for consideration by guideline development group (Rapu 2005)			
3. Establish methods for obtaining information about resource use and cost (e.g. searching for existing economic evaluations, developing economic model, performing cost-effectiveness analysis).				
4. Identify the costs, resource use, and, if applicable, cost-effectiveness and describe the nature of the costs (patient, community, society) (e.g. affordability considerations, estimates of resource use and acquisition costs weighed directly against evidence of benefits and harms of an intervention).				
5. Document the methods in which the additional information is to be incorporated with the synthesized evidence to ensure transparency (e.g. formal consensus on patient values, consensus on equity issues, formal economic analysis, consideration of disaggregated resource use data in a qualitative manner,).				
6. Provide training about the use of the evidence tables and opportunities for discussion to ensure all members of the guideline panel are familiar with the tables and use them in the appropriate manner.				

7. In addition to the evidence summary, make available the full systematic review(s) and the original studies and other sources of evidence for the guideline panel to inform deliberations (e.g. set up a collaborative website and/or make available at meetings and via electronic communication).				
12. Judging Quality, Strength or Certainty of a Body of Evidence				
1. Select a framework outlining the criteria to be considered in rating the quality of evidence (e.g. GRADE, USPSTF). Avoid modifying grading tools.	**Patients** Include patients directly as guideline members to appraise and assess believability of findings (Armstrong 2017) Use qualitative/expert opinion to rate the quality of the evidence gathered (Dunning 2012) **Caregivers, Patient organizations** Include patients directly as guideline members to appraise and assess believability of findings (Armstrong 2017) **Providers** Use qualitative/expert opinion to rate the quality of the evidence gathered (Dunning 2012)			
2. Decide who will be responsible for appraising the quality of evidence (e.g. un-conflicted methodologists participating in the working group).	**Patients** Include patients directly as guideline members to appraise and assess believability of findings (Armstrong 2017) Use qualitative/expert opinion to rate the quality of the evidence gathered (Dunning 2012) Conduct wide consultations to encourage feedback on evidence used to inform guidelines or recommendations (Fretheim 2006) **Caregivers, Patient organizations** Include patients directly as guideline members to appraise and assess believability			

	of findings (Armstrong 2017) **Providers** Use qualitative/expert opinion to rate the quality of the evidence gathered (Dunning 2012)			
3. Assess the quality of evidence for each important outcome.	**Patients** Conduct wide consultations to encourage feedback on evidence used to inform guidelines or recommendations (Fretheim 2006)			
4. Assess the overall quality of evidence (e.g. lowest quality of evidence from outcomes rated as most important or critical, or highest quality of evidence when all outcomes point in the same direction).	**Patients** Conduct wide consultations to encourage feedback on evidence used to inform guidelines or recommendations (Fretheim 2006)			
5. Report the quality of evidence assessed for the outcomes and the body of evidence.				
6. Document the judgements made in appraising the quality of evidence to ensure they are transparent and explicit.				
13. Developing Recommendations and Determining their Strength				
1. Apply a framework outlining the factors to be considered to arrive at a recommendation.				
2. Plan and share the logistical details of the consensus meeting(s) during which recommendations will be formulated with the participants, including distribution of documents required for the meeting (e.g. evidence summaries, evidence-to-recommendation tables), setting an agenda for the meeting(s) and selecting a consensus development method to be used by the group in agreeing on judgements (e.g. Delphi method, nominal group technique).				
3. Review the factors of the framework that influence the recommendation, including the direction and strength (e.g. the types of evidence and information relevant to the				

analysis focusing on the balance between desirable and undesirable consequences informed by the quality of evidence, magnitude of the difference between the benefits and harms, the certainty about or variability in values and preferences, resource use, equity and other factors).				
4. If applicable, make provisions for formulating recommendations in situations where there is insufficient evidence or very low quality evidence (e.g. conditional recommendation with judgements laid out transparently, no recommendation if the guideline panel feels there is substantial risk that their decision may be wrong, recommend that the intervention be used in the context of research complemented by guidance for what are the best management options until further research becomes available).				
5. Make provisions for formulating research recommendations and decide where to report them (e.g. in the guideline appendix, suggesting the specific research questions, specific patient-important outcomes to measure and other relevant aspects of what research is needed to reduce the uncertainty about the benefits and/or undesirable downsides of the intervention).				
6. Formulate the recommendations and summarize the rationale for each recommendation (e.g. narratively or in a table), including details about the judgements made by the group and the explicit link between the recommendation and evidence supporting the recommendation.	**Patients** Conduct a 3 or 4 round engagement process to determine the patient-centeredness of the draft recommendations. (Khodyakov 2019)			
7. Select a method for rating the strength of the formulated recommendations to inform the audience of the guideline about the degree of the guideline group's confidence about following that recommendation.				

8. Select a consensus development method to be used by the group in rating the strength of recommendations (e.g. Delphi method, nominal group technique, voting).				
9. Provide suggestions about whether the recommendations are appropriate to serve as performance measures/quality criteria (e.g. management options associated with strong recommendations based on high- or moderate-quality evidence are particularly good candidates for quality criteria, when a recommendation is weak, discussing with patients the relative merits of the alternative management strategies and appropriate documentation of this interaction may become a quality criterion).	**Patients**, **Caregivers, Patient organizations** Include patients as GDG members to assist in translating evidence-based conclusions into meaningful, clear, and respectful recommendations (Armstrong 2017)			
10. Document the judgements made in formulating the recommendations and determining their strength to ensure they are transparent and explicit.				
14. Wording of Recommendations and of Considerations of Implementation, Feasibility and Equity				
1. Decide on standardized wording to use for recommendation statements to ensure clarity and to maintain consistency throughout the guideline, avoiding wording that may be vague and nonspecific.	**Patients** Engage patients in guideline development group to help make sure recommendations are easy to understand (Armstrong 2017) **Patient organizations** Discuss specific wording for all non-conflicted recommendations/statements (Devlin 2018) Present draft to relevant stakeholder(bodies) for feedback on content, understanding, readability (van der Weijden 2018) **Providers** Discuss specific wording for all non-conflicted recommendations/statements (Devlin 2018) Present draft to relevant stakeholder(bodies) for feedback on content, understanding, readability (van der Weijden 2018)			

	Principal investigators Discuss specific wording for all non-conflicted recommendations/statements (Devlin 2018)			
2. Write the recommendations in a way that is actionable with sufficient information so that it is not necessary for guideline users to refer to other material in order to understand the recommendation.	**Patients** Engage patients in guideline development group to help make sure recommendations are easy to understand (Armstrong 2017)			
3. Provide clear direction or an interpretation aid to describe the implication of the strength of recommendation for clinicians, patients, policy makers, and any other target audience groups.				
4. Indicate in the recommendation statements the population for which the recommendation is intended, the intervention being recommended, and the alternative approach(es) or intervention(s).				
5. Include remarks that describe the context, feasibility and applicability of the recommendation and highlight key considerations such as equity issues and specific conditions that might apply to the recommendation (e.g. whether the conditions outlined apply to a specific subpopulation, specific types of the intervention, for certain values and preferences, when certain resources are available, etc.).	**Patients**, **Providers** Present draft to relevant stakeholder(bodies) for feedback on content, understanding, readability (van der Weijden 2018)			
6. Report the quality of evidence and the strength of recommendation in proximity to the recommendation statement.	**Patients**, **Providers**, **Principal investigators** Discuss specific wording for all non-conflicted recommendations/statements (Devlin 2018)			
7. Establish methods to be used by the group in agreeing on the final wording of recommendation statements (e.g. review and approval, formal consensus).	**Patients**, **Providers**, **Principal investigators** Discuss specific wording for all non-conflicted recommendations/statements (Devlin 2018)			
8. Report the recommendations in a way that is comprehensible and visible (e.g. do not embed recommendations within long				

paragraphs, group recommendations together in a summary section).				
15. Reporting and Peer Review				
1. Develop or adopt a standardized format for reporting the guideline, with specific structure, headings, and content.				
2. Decide on the format(s) to be prepared for the guideline product(s) (e.g. full guideline, full guideline with technical report/systematic reviews, brief guideline for clinicians or policymakers, consumer version for patients) that will correspond to the dissemination plan. (see Topic 16)	**Patients** Provide opportunity for patients to review and approve the guideline and patient versions (Wedzicha 2011)			
3. Decide who will be responsible for writing the guideline product(s) (e.g. sub-committee of the guideline working group) and decide on authorship (e.g. individual authors, organization as author, working group as author). (see Topic 1)				
4. Conduct a review of the final draft of the guideline report(s) by all members of the guideline development group, allowing sufficient opportunity for feedback, editing and revisions.	**Patients** Review content to ensure it focuses on patients and reflects patients' ideas, values and preferences (Chalmers 2017)			
5. Seek approval from all members of the guideline development group for the final document(s).				
6. Initiate organizational (i.e. internal) peer review.				
7. Decide on the method(s) of external peer review, to review the final document(s) for accuracy, practicality, clarity, organization, and usefulness of the recommendations, as well as to ensure input from broader and important perspectives that the guideline group did not encompass (e.g. invited peer review, public consultation period with incorporation of feedback and responses	**Patients** Provide opportunity for patients to review and approve the guideline and patient versions (Wedzicha 2011) **Providers** Post the guideline document on the academy website and inform stakeholders via press release, targeted inquiries, to provide feedback (Shin 2014)			

from the guideline development group, submitting to peer-reviewed publication).	Stakeholder feedback is important for quality assurance and peer review, providers should provide feedback on draft recommendations (Rapu 2005)			
8. Document the internal and external peer review process and, if applicable, publish consultation comments and the guideline development group's responses.				
16. Dissemination and Implementation				
1. Prepare an active dissemination plan with various approaches to enhance the adoption of the guideline (e.g. make guideline available online, develop formal relationships with those in health care systems responsible for guideline dissemination and implementation to support guideline uptake, press conference, social media strategy, dissemination at professional society meetings, publish guideline in a journal that is accessed by the target audience).	**Patients** Make guidelines accessible for patients to read (Chalmers 2017) Make guideline versions available available online, and on social media for patients and professionals (Wedzicha 2011) Patients and other users can use networks, conferences, presentations, local media to disseminate guidelines (Duff 1996) Share and provide feedback to group members and participants via email/online, conferences or webinars (Khodyakov 2019) **Caregivers** Share and provide feedback to group members and participants via email/online, conferences or webinars (Khodyakov 2019) **Public** Patients and other users can use networks, conferences, presentations, local media to disseminate guidelines (Duff 1996) **Patient organizations**, **Providers** Make guideline versions available available online, and on social media for patients and professionals (Wedzicha 2011) Patients and other users can use networks, conferences, presentations, local media to disseminate guidelines (Duff 1996) **Principal investigators**			

	Patients and other users can use networks, conferences, presentations, local media to disseminate guidelines (Duff 1996)			
2. Develop or adapt tools, support, and derivative products to provide guidance on how the recommendations can be implemented into practice (e.g. mobile applications, integration with clinical decision support systems, make guideline adaptable as an educational resource for target audience for education outreach).	**Patients**, **Patient organizations** Make guideline versions available available online, and on social media for patients and professionals (Wedzicha 2011) **Providers** Develop education programs to explain how guidelines are to be used (Dunning 2012) Make guideline versions available available online, and on social media for patients and professionals (Wedzicha 2011)			
3. Make considerations for adaptation of the guideline and provide specific instructions for how target end users who would like to adapt the guidelines to other contexts can do so in a systematic and transparent way (e.g. modifying a recommendation based on local resources and baseline risk, implications that deviate from the judgements made by the guideline panel).	**Patients**, **Caregivers**, **Patient organizations** Directly engage patients, caregivers and advocates in the development of lay summaries and patient decision aids (Armstrong 2017)			
4. Set rules and regulations for translation of the guideline into other languages (e.g. allow translation by third party organizations following approval by the guideline group, include staff responsible for translation in guideline working group).				
17. Evaluation and Use				
1. Conduct an internal evaluation (i.e. self-assessment) of the guideline development process, including the guideline panel meeting(s) held to formulate recommendations, by asking guideline group members for feedback.	**Patients** Utilize survey and evaluation tools to gather feedback on the development process and outcomes (Brouwers 2018) Interview stakeholder to explore the impact of their involvement and solicit feedback on group processes (MacLennan 2017) Conduct a patient survey to solicit feedback on meaningful engagement and ways to improve engagement strategies (Armstrong			

	2017) **Caregivers**, **Patient organizations, Principal investigators** Utilize survey and evaluation tools to gather feedback on the development process and outcomes (Brouwers 2018) **Providers** Interview stakeholders to explore the impact of their involvement and solicit feedback on group processes (MacLennan 2017)			
2. Consider pilot testing the guideline with the target end users (e.g. with members of target audience and stakeholders who participated in the guideline development group).				
3. Provide criteria and tools for target end users to monitor and audit the implementation and use of the guideline recommendations (e.g. identify outcomes that should change with implementation and suggest methods for measuring the outcomes).				
4. Provide support and tools for prospective evaluation of the guideline to determine its effectiveness after implementation (e.g. using randomized evaluations where possible, using before-after evaluations cautiously due to uncertainties regarding the effects of implementation).				
5. Consider the potential involvement of the guideline development group in prospective evaluation(s) of the guideline (e.g. partnering with organizations that implement the guideline to plan evaluation studies).	**Patients**, **Providers** Conduct outreach visits and participatory observations (van der Weijden 2018)			
6. Plan to collect feedback and evaluations from users to identify how to improve the intrinsic implementability of the recommendations in subsequent versions of the guideline.	**Providers** Collect data on the useability of the guidelines using a questionnaire (Dunning 2012)			

18. Updating				
1. Set a policy, procedure and timeline for routinely monitoring and reviewing whether the guideline needs to be updated (e.g. update systematic review every 3 years to determine if there is any new evidence available).	**Patients** Identify when public or stakeholder views have changed such that a guideline requires update or reaffirmation using website for feedback (Armstrong 2017) **Providers** Develop mechanism and time for guideline update (Wise 1995)			
2. Decide who will be responsible for routinely monitoring the literature and assessing whether new significant evidence is available (e.g. consider involvement of experts not previously involved in the guideline development group to periodically review the guideline).				
3. Set the conditions that will determine when a partial or a full update of the guideline is required (e.g. if only certain recommendation statements need to be updated, or whether many recommendations are out of date making the entire guideline invalid, or when recommendations are necessary for newly available treatments).	**Patients** Identify when public or stakeholder views have changed such that a guideline requires update or reaffirmation using website for feedback (Armstrong 2017) **Providers** Develop mechanism and time for guideline update (Wise 1995)			
4. Make arrangements for guideline group membership and participation after completion of the guideline (e.g. rotating membership every 1-2 years, selection of a new group at time of updating, continuing participation by guideline panel chair).				
5. Plan the funding and logistics for updating the guideline in the future (e.g. securing ongoing funding, standing oversight committee to oversee the updating process).		**BARRIER: [...to engaging patients/providers/policy/Pls]: INSUFFICIENT RESOURCES TO SUPPORT UPDATES:** Two studies reported barriers to maintaining stakeholder engagement for guideline updates. In one study, lack of ongoing funding prevented the secretariat from keeping the original GDG engaged in		

		guideline activities (Selby 2017). Van der Ham et al. (2014) also suggest that it can be difficult for patients to 'catch up' and meaningfully contribute if they were not involved in the original guideline.		
6. Document the plan and proposed methods for updating the guideline to ensure they are followed.				