

Appendix

Pre-Curriculum Patient Experience Survey Questionnaire

1. Have you previously participated as a patient representative in a clinical practice guideline development?
 - a. Yes
 - b. No
 - c. May be
2. Were you informed about your roles and responsibilities?
 - a. Yes
 - b. No
 - c. May be
3. Have you received any training for active participation?
 - a. Yes
 - b. No
 - c. May be
4. Please describe your roles and responsibilities as a patient representative in the guideline development.
5. Did you feel that you were able to actively participate?
 - a. Yes
 - b. No
 - c. May be
6. Did you feel that your voice was heard and reflected in the guideline?
 - a. Yes
 - b. No
 - c. May be
7. How would you rate your overall experience?

Excellent	1	2	3	4	5	Poor
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8. Please provide us with additional comments/feedback.

Workshop with Patient Representatives on ASH SCD Guideline Panels
Message for Chairs and panel members

Date:

Facilitators:

Patient representatives:

Objectives

1. Learn about how guideline panels work and understand the critical role of patients.
2. Discuss how to optimize patients' engagement.
3. Develop messages from the patients for the chairs and panels.

Challenges associated with being a patient representative on a panel

1. Discussion is very technical
2. Difficult to relate to some topics
3. Uncertain when/how to participate /intervene
4. Concerns related to the disease management questions panel trying to make recommendations that do not address other issues encountered by patients' i.e. stigma of being an SCD patient
5. Patient representatives can get left behind in some discussions
6. Patient representatives and experts are sometimes not on same page as far as how they approach or are oriented to an issue
7. Feel intimidated at times
8. Patient perspective sometimes sidelined for extended periods of the process
9. Patient representatives feel like tokenism / box checked as opposed to full-fledged participants

Messages to chairs and panels

1. Consider how other (non-PICO) questions can be addressed by the guidelines, e.g., through good practice statements or implementation considerations e.g. making sure that the effect on psychological well-being as it relates to some interventions.
2. Research gaps are an important problem for Sickle Cell Disease. The patient representatives want to be involved in defining the research agenda.
3. For relevant criteria in the Evidence to Decision (EtD) framework, try to ensure the patient's perspective is addressed. Involve the patient representatives to obtain their experience as it relates to the criteria.
4. Consider checking in with patient representatives to ensure that they feel that their voice is heard.
5. Patients may not always concur with a final recommendation but are willing to cede to a greater good despite personal reservations.
6. As patient representatives and advocates we are trying to reach the average MD treating SCD patients and not the dedicated and insightful panel members.

In response to the challenges associated with panel involvement and as a reflection of many of the patient-focused issues the patient representative group wishes to advocate for, patient and family-centered questions/ scripts were formulated that could help patient representatives become more engaged. When forming recommendations or discussing EtD domains, please give the patient representatives opportunities to raise one or more of these issues.

Questions/scripts for patient representatives to consider using during recommendations:

1. How would you explain the importance of this topic/issue to a patient or family?
2. For this issue, is the transition from adolescent to adult care relevant? Is this handled differently in kids?
3. How would this issue or recommendation be individualized so that the decision is shared and matches the patient's specific circumstances?
4. Does this recommendation ensure/encourage a patient-centered approach?
5. Will this recommendation, as written, encourage physicians to present all options/alternatives to the patient?
6. How can this recommendation encourage shared decision-making and/or improve compliance with the recommendation?
7. How can we ensure that this question empowers patients and families as advocates?
8. How can we ensure that this doesn't affect some patients unfairly?

Post-Implementation Survey Questionnaire

Webinar-Online Workshop

1. How useful was the webinar to increase your knowledge of participating in a guideline development?
2. How useful was the webinar in learning skills needed to actively participate in the guideline development?
3. After the webinar, how confident were you in your ability to participate in the DC guideline development recommendation process?
4. What do you think of the overall quality of the webinar?
5. Please let us know the areas that you feel need improvement/additional feedback for future online patient training workshops.

In-Person Workshop

1. How useful was the workshop to increase your knowledge of participating in a guideline development?
2. How useful was the workshop in learning skills needed to actively participate in the guideline development?
3. After the workshop, how confident were you in your ability to participate in the DC guideline development recommendation process?
4. What do you think of the overall quality of the workshop?
5. Please let us know the areas that you feel need improvement/additional feedback for future online patient training workshops.

General

1. How useful was the combination of webinar and in-person workshop in patient training for guideline development?
2. Do you have any feedback for the clinical practice guideline panel members about patient engagement?