Appendix 1 – Invitation Email for Stakeholder Survey

Dear [Name],
We are writing because we value your opinion as a clinician and researcher in the area of cancer prevention and control.

Based upon a stimulating meeting last year at the NIH Dissemination & Implementation Science meeting, we are trying to identify ways to ***move shared decision making into practice in the context of cancer prevention and treatment***. While there is general agreement that shared decision making is a good idea, there is considerable evidence that it doesn't happen.

We think that by gathering recommendations from you and others with diverse perspectives, we will be able to propose an agenda for ***both action and research*** in this area. One final product of this work will be a publication on the interface of shared decision making and dissemination and implementation science and possibly other products depending on results and your recommendations.

We hope that you might be willing to take 5 -10 minutes to share your views. Here is the link to a very brief survey that we hope you will be willing to provide your perspective.
[Survey link]

If at all possible, please respond by [date].

Thank you for offering your recommendations!

Appendix 2 – Stakeholder Survey Questionnaire

Stakeholders' Views on Shared Decision Making
The questions below ask for your ideas on how to move shared decision making into practice. While there is general agreement that shared decision making is a good idea, there is considerable evidence that it doesn't happen.

Our goal is to gather recommendations from you, and others from a variety of roles, in order to propose an agenda for action and research in this area.

We hope that you might be willing to take about 5 minutes to share your views!

Thank you!

Russ Glasgow, Andy Tan, Dan Matlock, and Kathy Mazor

Which of the following best describes your role?

- ☐ patient advocate
- ☐ clinician
- ☐ health care system leader
- ☐ policy maker
- ☐ researcher
- ☐ funder

(If you hold multiple roles, please select the role in which you feel you have the greatest potential to influence practice.)

Below are situations where shared decision might be used. Please select the situation in which you feel that shared decision making is most important or that you know best.

- ☐ HPV vaccine
- ☐ PSA screening
- ☐ screening mammography
- ☐ genetic testing for cancer risk
- ☐ adjuvant chemotherapy for early stage breast cancer
- ☐ changing from curative treatment to a palliative approach
- ☐ other

(If you feel that SDM is critically important in more than one situation, please choose the situation that you feel MOST strongly about.)

Please specify "other": _____

[Respondents viewed the following questions with their selected situation inserted within these questions]

Think about the content area that you chose above ("[most_imp_situation]") when answering the following questions.

What could [role]s do to encourage UPTAKE (Adoption) of shared decision making in the context of [most_imp_situation]? Here, adoption refers to the initial decision to use shared decision making in a situation. _____

What could [role]s do to encourage UPTAKE (Adoption) of shared decision making in the context of [other_specify]? Here, adoption refers to the initial decision to use shared decision making in a situation. _____

What could [role]s do to encourage successful DELIVERY (Implementation) of shared decision making in the context of [most_imp_situation]? Here, implementation refers to integrating shared decision making into practice. _____

Overall, what specific steps are most needed to move shared decision making into practice?
_____

[Respondents who selected “other” viewed the following questions with their stated situation inserted within these questions]

Think about the content area that you chose above ("[other_specify]") when answering the following questions.

What could [role]s do to encourage successful DELIVERY (Implementation) of shared decision making in the context of [other_specify]? Here, implementation refers to integrating shared decision making into practice. _____

What could [role]s do to encourage MAINTENANCE (sustained use) of shared decision making in the context of [most_imp_situation]? Here, sustained use refers to the continued implementation of shared decision making over the long term. _____

What could [role]s do to encourage MAINTENANCE (sustained use) of shared decision making in the context of [other_specify]? Here, sustained use refers to the continued implementation of shared decision making over the long term. _____

Overall, what specific steps are most needed to move shared decision making into practice?
_____

Appendix 3 – Coding definitions for survey

BOLD terms mean it is a parent node; Underlined is a child node

Raise Awareness and or advocacy-This should be coded whenever the participant mentions the need to raise awareness or already acting to promote shared decision making. Look for keywords like encourage or advocate. This can be through flyers, conferences, communication, etc. Ex. "Practitioners' should be advocating for SDM by presenting the benefits at major conferences," should be coded here. Counter ex. "Flyers about SDM won't help the adoption of SDM in practices, policies need to be put into place to ensure SDM is happening," does not belong here.

Evaluation-This should be coded when the participant stresses the need to show or produce research to implement SDM. Ex. "Create studies that will show the effectiveness of SDM in healthcare organizations," should be coded here. Counter ex. "To implement SDM patients and their families need to be given more of a voice," does not belong here. It should also be coded for any mention of checking how the SDM process is going or reviewing the outcomes. Ex. "Health system leaders should routinely check if providers are using SDM," belongs here. Counter ex. "Show evidence that supports using SDM in healthcare practice," does not belong here.

Feasibility-This should be coded when evidence/research points to the feasibility of SDM in healthcare. This means the practice can be done easily, cost effectively, and be accepted. It relates to the process of SDM not the outcome. Ex. "Research studies should be conducted to show that SDM can be done easier than typical practices in healthcare," belongs here. Counter ex. "Evidence needs to be presented showing the benefits of SDM to patients," does not belong here. Note, this quote is part of this parent node but belongs in the outcomes child node.

Outcomes-This should be coded when the research generated shows the results of SDM. Ex. "increase the evidence base for shared decision-making, including demonstrating outcomes," belongs here. Counter ex. "It will be most effective if you demonstrate evidence showing how cost effective SDM in health care," does not belong here.

Process-Suggesting follow ups that revolve around the process of using SDM. Ex. "It should be reviewed if clinicians are using SDM in their practice." Counter ex. We should be checking if SDM is really working."

Other evidence-This category should be used if the quote involves using research to support SDM but it is unclear which child node it falls into or there is not a designated child node. Ex. "Conduct research focused on system based approaches," belongs here. Counter ex. "Research supporting the benefits to providers when they use SDM," does not belong here.

Support-This should be coded when the participant mentions the need for support to implement SDM, meaning training, tools, funding, etc. Ex. "Develop mechanisms for standardized time when SDM would be completed," belongs here. Counter ex. "Implementing SDM is solely up to the individual if they want to use it in their practice," does not belong here.

Training- This is for any mention for the need for training to implement SDM. Training can be given to anyone involved in the process. Ex. "train clinicians early on so they feel comfortable using SDM practices," belongs here. Counter ex. "Create tools that will make SDM easier to use," does not belong here.

Tools-This child node is for tools to support SDM. Note, they do not have to be specified. Ex. "Create easy access tools to help clinicians provide information about benefits and harms of SDM," belongs here. However, they can also mention specific tools, such as decision aids. Counter ex. "Patients should be trained on how SDM can be used in their treatment," does not belong here.

Funding or Reimbursement-This node is when the participant makes a money-oriented suggestion. This could fall under grants, reimbursement, etc. Ex. "Clinicians will use SDM if they are reimbursed for it," belongs here. Counter ex. "training should be accessible for all patients to understand SDM," does not belong here.

Culture-This node refers to the "culture" surrounding SDM. It refers to a suggestion stating it should become the norm of healthcare. Ex. "build a culture that prioritizes the patient and shared decision making as an integral part of the process for care," belongs here. It can also refer to a hierarchal change, system based. Counter ex. "develop standardized role plays or behavioral rehearsal, possibly have a designed clinician to initiate this conversation, make adherence checks a regular part of quality assurance procedures," does not belong here.
Other support-This child node is either for unclear quotes that belong in the support parent node, or another theme of support that is not yet designated. Ex. "More time is needed to discuss the benefits of SDM with patients," belongs here. Counter ex. "Design simple, non-time-consuming tools to incorporate SDM into practice," does not belong here.

Obtain stakeholders' involvement, discussion, and communication-This refers to any passage stating communication between stakeholders is key for implementation. This could either be involvement of the patient's families or clinicians and healthcare systems leaders. Ex. "The attitudes around SDM would be positively impacted if patients and families had more of a voice in the practice," belongs here. Counter ex. "To increase the use of SDM, more research should be conducted to show the benefits," does not belong here.

Level-This node is for where the change is targeted, meaning the patient, provider, system, or other role. Ex. "Encourage proactive patient education to insure an informed patient," this quote belongs in the awareness node but also benefits the patient and should be coded to the appropriate code. Counter ex. "research should be done to show effectiveness of SDM," this doesn't belong here. It is too vague to understand which level is benefiting.
Patient/Family-This child node is for a change targeted at the patient or their families. Ex. "Give us flyers to spread among patient communities so they know more about SDM practices," belongs here. Counter ex. "Perhaps create a website for providers to talk with one another about using SDM in their practice," does not belong here.
Provider/Practice- This child node is for a change targeted at the providers or the practice. Ex. "Develop standardized role plays or behavioral rehearsals for provider training," belongs here. Counter ex. "Encourage proactive patient education to create an informed patient," does not belong here.
System-This node is used when the change needs to be done at an organizational or system level. Keywords include "culture" or "system". Ex. "build a culture that prioritizes the patient and shared decision making as an integral part of the process for care". Counter ex. "A patient needs to be trained on how SDM works," does not belong here. It is the idea that there is acceptance for using SDM or it becomes the norm.
Other roles-This is for other targeted levels not specified by the child nodes, such as funders, policy makers, etc. Ex. Clinicians that actively use SDM should receive more monetary incentives," belongs here. Counter ex. "Providers and patients should work together to discuss the benefits of SDM in healthcare," does not belong here. This can be coded to the provider and patient node.
