

Supplemental File 1: The ALPACA Study

1. Instruments to measure the process of shared decision making

Figure S1 CollaboRATE measure

collabo**RATE**TM

1. How much effort was made to help you understand your health issues?

0	1	2	3	4	5	6	7	8	9
No effort was made									Every effort was made

2. How much effort was made to listen to the things that matter most to you about your health issues?

0	1	2	3	4	5	6	7	8	9
No effort was made									Every effort was made

3. How much effort was made to include what matters most to you in choosing what to do next?

0	1	2	3	4	5	6	7	8	9
No effort was made									Every effort was made

From: Elwyn, Glyn, Paul James Barr, Stuart W. Grande, Rachel Thompson, Thom Walsh, and Elissa M. Ozanne. "Developing CollaboRATE: a fast and frugal patient-reported measure of shared decision making in clinical encounters." *Patient education and counseling* 93, no. 1 (2013): 102-107.

Figure S2 The 9-item Shared Decision Making Questionnaire (SDM-Q-9)

The 9-item Shared Decision Making Questionnaire (SDM-Q-9)

[Example] Please indicate which health complaint/problem/illness the consultation was about:

[Example] Please indicate which decision was made:

Nine statements related to the decision-making in your consultation are listed below. For each statement please indicate how much you agree or disagree.

1. My doctor made clear that a decision needs to be made.	completely disagree <input type="checkbox"/>	strongly disagree <input type="checkbox"/>	somewhat disagree <input type="checkbox"/>	somewhat agree <input type="checkbox"/>	strongly agree <input type="checkbox"/>	completely agree <input type="checkbox"/>
2. My doctor wanted to know exactly how I want to be involved in making the decision.	completely disagree <input type="checkbox"/>	strongly disagree <input type="checkbox"/>	somewhat disagree <input type="checkbox"/>	somewhat agree <input type="checkbox"/>	strongly agree <input type="checkbox"/>	completely agree <input type="checkbox"/>
3. My doctor told me that there are different options for treating my medical condition.	completely disagree <input type="checkbox"/>	strongly disagree <input type="checkbox"/>	somewhat disagree <input type="checkbox"/>	somewhat agree <input type="checkbox"/>	strongly agree <input type="checkbox"/>	completely agree <input type="checkbox"/>
4. My doctor precisely explained the advantages and disadvantages of the treatment options.	completely disagree <input type="checkbox"/>	strongly disagree <input type="checkbox"/>	somewhat disagree <input type="checkbox"/>	somewhat agree <input type="checkbox"/>	strongly agree <input type="checkbox"/>	completely agree <input type="checkbox"/>
5. My doctor helped me understand all the information.	completely disagree <input type="checkbox"/>	strongly disagree <input type="checkbox"/>	somewhat disagree <input type="checkbox"/>	somewhat agree <input type="checkbox"/>	strongly agree <input type="checkbox"/>	completely agree <input type="checkbox"/>
6. My doctor asked me which treatment option I prefer.	completely disagree <input type="checkbox"/>	strongly disagree <input type="checkbox"/>	somewhat disagree <input type="checkbox"/>	somewhat agree <input type="checkbox"/>	strongly agree <input type="checkbox"/>	completely agree <input type="checkbox"/>
7. My doctor and I thoroughly weighed the different treatment options.	completely disagree <input type="checkbox"/>	strongly disagree <input type="checkbox"/>	somewhat disagree <input type="checkbox"/>	somewhat agree <input type="checkbox"/>	strongly agree <input type="checkbox"/>	completely agree <input type="checkbox"/>
8. My doctor and I selected a treatment option together.	completely disagree <input type="checkbox"/>	strongly disagree <input type="checkbox"/>	somewhat disagree <input type="checkbox"/>	somewhat agree <input type="checkbox"/>	strongly agree <input type="checkbox"/>	completely agree <input type="checkbox"/>
9. My doctor and I reached an agreement on how to proceed.	completely disagree <input type="checkbox"/>	strongly disagree <input type="checkbox"/>	somewhat disagree <input type="checkbox"/>	somewhat agree <input type="checkbox"/>	strongly agree <input type="checkbox"/>	completely agree <input type="checkbox"/>

From: Kriston, L., Scholl, I., Hölzel, L., Simon, D., Loh, A., & Härter, M. (2010). The 9-item Shared Decision Making Questionnaire (SDM-Q-9). Development and psychometric properties in a primary care sample. *Patient education and counseling*, 80(1), 94-99.

Figure S3 SHARED measure

SHARED – A Patient Experience of Shared Decision Making Questionnaire

What was your experience of making this treatment decision with your [health professional/s] – for each statement, tick the box that matches best how much you agree with it:

		Disagree Strongly	Disagree	Not Sure	Agree	Agree Strongly
The [health] professional...						
1	talked about other options from the one I chose	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	talked about whether or not there was a medically best option for my [health problem]	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	gave their views about the options	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	asked for my views about the options	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I talked about...						
5	what was important to me about this decision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	why one option suited me better than another	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	the risks and benefits of the options for me and my health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I felt...						
8	it would be OK to choose any option we talked about	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	the decision made was the best one for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10	the [health] professional and I agreed which option was the best one for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

From: Bekker HL, Légaré F, Nye A, Walker W. SHARED – A Patient Experience of Shared Decision Making Questionnaire. (2012). University of Leeds, UK

2. Example topic guides for qualitative data collection

Table S1 Usability testing (1.2) – interview guide

<p>Intro</p> <ul style="list-style-type: none"> • Thank you and introduction • Explanation of project (assess to what extent), ask if there are questions • Ask for preferred mode for completing the survey (sms/email) and send the link • Check if ok to audio record → <i>switch on recording</i> • Explain purpose of the session: <ul style="list-style-type: none"> ○ We would like to test the survey that patients receive when booked in for surgery. ○ The focus is on functionality. It helps us make improvements to the process. ○ This session is NOT about the wording of questions, we are just interested in the usability ○ The text/email is a tester only, so the responses you give are not real • Explain specific tasks: <ul style="list-style-type: none"> ○ There are two surveys. 8 steps (3 questions) for the first one, 20 steps (9 questions) for the second one. ○ We will <ul style="list-style-type: none"> ▪ run through these steps and see how you get on with these ▪ might feel a little unnatural but is important you tell me what you think and what you see, what is clear/unclear, what is easy/not straight forward or difficult to complete ○ Say where there is a problem, e.g. that you had to press twice to proceed • Explain there will be questions at the end <p>Think-aloud exercise</p> <p>Start with 8 steps of CollaboRATE</p> <ul style="list-style-type: none"> • Prompts if participant doesn't talk <ul style="list-style-type: none"> ○ Can you tell me what you currently see? ○ What are you going to do next? ○ What can you see now? • Prompts to elicit views <ul style="list-style-type: none"> ○ Could you tell me what you think about Step X? ○ How do you feel about Step X? ○ What do you think about Step X? ○ How clear is Step X? ○ How easy is Step X? <p>Pause and ask follow-up questions</p> <ul style="list-style-type: none"> • “Having just completed the survey...” <ul style="list-style-type: none"> ○ How easy do you think is it to respond to the survey? ○ What do you think about the length of the survey? ○ What are your thoughts on the overall visual display? How visually appealing is the survey? ○ What would stop people from doing the survey? <i>Why?</i> ○ What issues can you think of people might encounter when completing the survey? <i>Why?</i> ○ What else would you change about how the survey is delivered? <i>Why?</i>

Table S2 Exploring views of under-served groups (1.3) – interview guide

Background

- Intro to interviewer (name, role and inability to answer care-related questions)
- Explain what SDM is and the main aim of the research project (focus on what SDM is vs isn't, current problem and relevance/importance to community)
- Reminder of anonymity, confidentiality and that interview can be stopped at any time.
- *Take questions*
- Reminder of recording and check participant is happy
- *Switch on recorder*

Explore context of SDM experience

Having just explained a bit more about what the research aims to do and what good shared decision making looks like, I am interested to hear from you...

- What is your experience with decision making for any healthcare treatment?
- How much involvement in decisions about surgical treatment would you prefer?
- Do you feel that, for whatever reason, you felt that you were/would be treated unequal to others in terms of making decision?

Exploring intervention components

- What do you think about the hospital using this survey to record people's experiences of how involved they felt in the surgical decision making?
- How do you feel about personal survey responses being passed on to the clinical team and you/the patient not being anonymous?
- What do you think needs to happen next to make sure you/ patients are given a voice and SDM is improved?
- How well do you think this process would work for everyone?