

Data Supplement S1. Supplemental material

Appendix S1. Instrument, containing Section 1 (pages 1-4) and Section 2 (pages 5-7)

When you are in the Emergency Department, you may interact with nurses, social workers, patient assistants or a **doctor, physician’s assistant or a nurse practitioner**. In this survey, we want to know your experience with the **doctor, physician’s assistant or nurse practitioner** who is the primary person taking care of you today. The survey uses the term “**doctor**” to refer to any one of these three people who would be your primary provider while you are in our Emergency Department.

Please let us know how much you **AGREE** or **DISAGREE** with statements that follow. (Circle the number)

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. I know enough about my health and my body to be involved in my medical decisions.	1	2	3	4	5
2. If you advocate for yourself or your loved one too much, the doctors might see you as difficult.	1	2	3	4	5
3. If given enough information, I am capable of participating in decisions about my medical care.	1	2	3	4	5
4. Whatever the doctor decides to do is ok with me, because s/he is the expert.	1	2	3	4	5
5. If something serious is going on with my health, I want to be involved in decisions about my health care.	1	2	3	4	5
6. I have had experiences making decisions together with a doctor.	1	2	3	4	5
7. In general, I would wait for a doctor to ask me to be involved <i>before</i> I get involved with decisions.	1	2	3	4	5
8. Generally, in the Emergency Department, the doctor does not usually ask for my input in decision-making.	1	2	3	4	5
9. Usually, I don’t understand the medical issues enough to be involved in decision-making.	1	2	3	4	5
10. Doctors often use words I don’t understand.	1	2	3	4	5
11. Generally, there is not enough time to discuss options in the Emergency Department.	1	2	3	4	5
12. I am comfortable asking the doctor to explain when I don’t understand the plan.	1	2	3	4	5
13. I am comfortable telling the doctor if I <i>disagree</i> with their plan.	1	2	3	4	5
14. Having written information about my options would help me be involved in decision-making in the Emergency Department.	1	2	3	4	5
15. Having a friend or family member with me would help me be involved in decision-making in the Emergency Department	1	2	3	4	5
16. Is there anything else that would help you be involved in your health care decisions in the ED?					

Appendix S1. Instrument, containing Section 1 (pages 1-4) and Section 2 (pages 5-7)

This next section is about your preferences regarding *involvement in decision-making*.

*The doctor (or physician's assistant/nurse practitioner) is the one who talks to you about your medical problems, possible treatments, and other medical decisions. Your doctor may consider two or more reasonable options for your care in these matters. **When there are two reasonable options, it might make sense for you to be involved in the decision-making.** To better understand your concerns, we want to know how much you want to participate and share in the doctor's decision-making process.*

In these examples, please rate how much you would like to be involved in making the decision.

17. In this example, the doctor has talked to you and examined you and believes there are *two reasonable options* regarding **TESTS** (like CT scans or ultrasounds) for you. There are potential harms and benefits to each option, like radiation to your body or how fast the test could be done. Your doctor can describe the potential harms and benefits of the options to you. What best describes your preference... **(Check only one)**

- I prefer to make decisions about which **tests** I will have.
- I prefer to make decisions about which **tests** I will have, *after seriously considering my doctor's opinion.*
- I prefer that my doctor and I *share responsibility* for deciding which **tests** I will have.
- I prefer that *my doctor make the decisions* about which **tests** I will have *after hearing and considering my input and opinions.*
- I prefer to leave all decisions regarding tests *to my doctor.*

18. In this example, your doctor has diagnosed your problem and believes there are *two reasonable options* regarding **TREATMENTS** for you (like different pills or a surgery). Each treatment option has potential harms and benefits, like different side effects. Your doctor can describe the potential harms and benefits of the options to you. What best describes your preference... **(Check only one)**

- I prefer to make decisions about which **treatments** I will have.
- I prefer to make decisions about which **treatments** I will have, *after seriously considering my doctor's opinion.*
- I prefer that my doctor and I *share responsibility* for deciding which **treatments** I will have.
- I prefer that *my doctor make the decisions* about which **treatments** I will have *after hearing and considering my input and opinions.*
- I prefer to leave all decisions regarding **treatments** *to my doctor.*

19. In this example, after the exam and testing, your doctor believes that being **ADMITTED or being DISCHARGED** (going home) would both be safe and reasonable options for you. Your doctor can describe the potential harms and benefits of these options to you. What best describes your preference... **(Check only one)**

- I prefer to make decisions about **admission** versus discharge.
- I prefer to make decisions about **admission** versus discharge, *after seriously considering my doctor's opinion.*
- I prefer that my doctor and I *share responsibility* for deciding about **admission** versus discharge.
- I prefer that *my doctor make the decisions* about **admission** versus discharge *after hearing and considering my input and opinions.*
- I prefer to leave all decisions regarding **admission** versus discharge *to my doctor.*

Appendix S1. Instrument, containing Section 1 (pages 1-4) and Section 2 (pages 5-7)

About You and Your Visit

20. Your Age: _____

21. Your Gender: _____

22. What was the main reason for this visit to the emergency room today?

- An accident or injury Other/not sure: _____
 A new health problem _____
 An existing health problem that got worse

23. Other than this visit, approximately how many times have you been to an Emergency Department in the past year?

- 0 (No other visits in the past year)
 1-2
 3-5
 6 or more

24. In general, how would you rate your overall health?

- Excellent Fair
 Very good Poor
 Good

25. What type of insurance do you have? (Check all that apply)

- Medicare No insurance
 Medicaid Other: _____
 Commercial (e.g. Anthem Blue Cross)

26. What is the highest grade or level of school that you have completed?

- 8th grade or less Some college or 2-year degree
 Some high school, but did not graduate 4-year college graduate
 High school graduate or GED More than 4-year college degree

27. Are you of Hispanic or Latino origin or descent?

- Yes, Hispanic or Latino No, not Hispanic or Latino

28. What is your race? (Please mark one or more.)

- White Native Hawaiian or Other Pacific Islander
 Black or African American American Indian or Alaskan Native
 Asian Other: _____

29. What language do you mainly speak at home?

- English Chinese
 Spanish Another language (please print): _____

SID: _____

Thank you. This is the end of Part 1.

Please return Part 1. Please complete Part 2 once you know whether you are going home or being admitted. It can be returned to the Research Staff or your nurse or doctor.

The rest of this page is for the research staff only.

1. Study ID: _____

2. Date of Visit (mm/dd/yy): ____ / ____ / ____

3. Time of day of arrival to ED:

- 1 6am – 11:59am
- 2 12 noon – 5:59pm
- 3 6pm – 11:59 pm
- 4 12 midnight – 5:59 am

4. ESI at presentation: (circle) 1 2 3 4 5 Unk

5. Disposition:

- 1 Admit
- 2 Discharge
- 3 Observation
- 4 Other: _____
- 5 Unknown

6. Site Code: BMC MS UCSF BF

7. RA Initials: _____

Appendix S1. Instrument, containing Section 1 (pages 1-4) and Section 2 (pages 5-7)

Part 2:
How was communication today?

During today's visit...

1. ...How much *effort was made* to help you understand *your health issues*? (Circle one number)

No effort at all was made

Every effort was made

1 2 3 4 5 6 7 8 9 10

2. ...How much effort was made to *listen to the things that matter most to you* about your health issues?
(Circle one number)

No effort at all was made

Every effort was made

1 2 3 4 5 6 7 8 9 10

3. ...How much effort was made to *include what matters most to you in choosing* what to do next? (Circle one number)

No effort at all was made

Every effort was made

1 2 3 4 5 6 7 8 9 10

Overall Experience

4. Would you recommend this emergency department to your friends and family?

- ¹ Definitely No
- ² Probably No
- ³ Probably Yes
- ⁴ Definitely Yes

5. Using any number from 0 to 10, where 0 is the worst care possible and 10 is the best care possible, what number would you use to rate your care during this emergency room visit? (Circle one number)

Worst Care
Possible

Best Care
Possible

0 1 2 3 4 5 6 7 8 9 10

Appendix S1. Instrument, containing Section 1 (pages 1-4) and Section 2 (pages 5-7)

Part 2:

Your Involvement Today

6. Did you and your doctor *discuss* any of the following *decisions* today? (That means, discuss more than one option, not just talk about one option.) *Check all that apply*

- Being admitted to the hospital versus going home
- Going to an observation unit, or physical rehabilitation versus going home or being admitted
- One test versus another test or no test (like CT scan, blood tests, or ultrasound)

Treatment options like:

- Medications (one medication versus another, or versus no medication)
- Antibiotics versus no antibiotics or another option
- Surgery or a procedure
- Different options for follow-up care after you leave the Emergency Department
- Breathing tubes, ventilators, or life support (ex. *“What would you want done if you stopped breathing on your own?”*)
- CPR and aggressive care versus comfort care
- Other: What option: _____
- No, I did not discuss any decisions with my Emergency Department doctors today.

7. Were you as involved in today’s decisions as you would have liked to be?

- Yes, I was as involved as I wanted to be
- No, I would have liked to be more involved
- Not Applicable, there were no decisions for me to be involved in today (**Stop here, you are done**)

If you answered “NOT APPLICABLE, there were no decisions” to Question 7, you can STOP HERE.

Think of a decision (any decision) that was made today during your ED visit. The following questions (on the next page) are about that decision.

Which decision are you thinking about? _____

Appendix S1. Instrument, containing Section 1 (pages 1-4) and Section 2 (pages 5-7)

Part 2:

**Please answer the following questions regarding the conversation about the decision that was made today:
Please mark your level of agreement with the following statements.**

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 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 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 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 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 an 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"/>

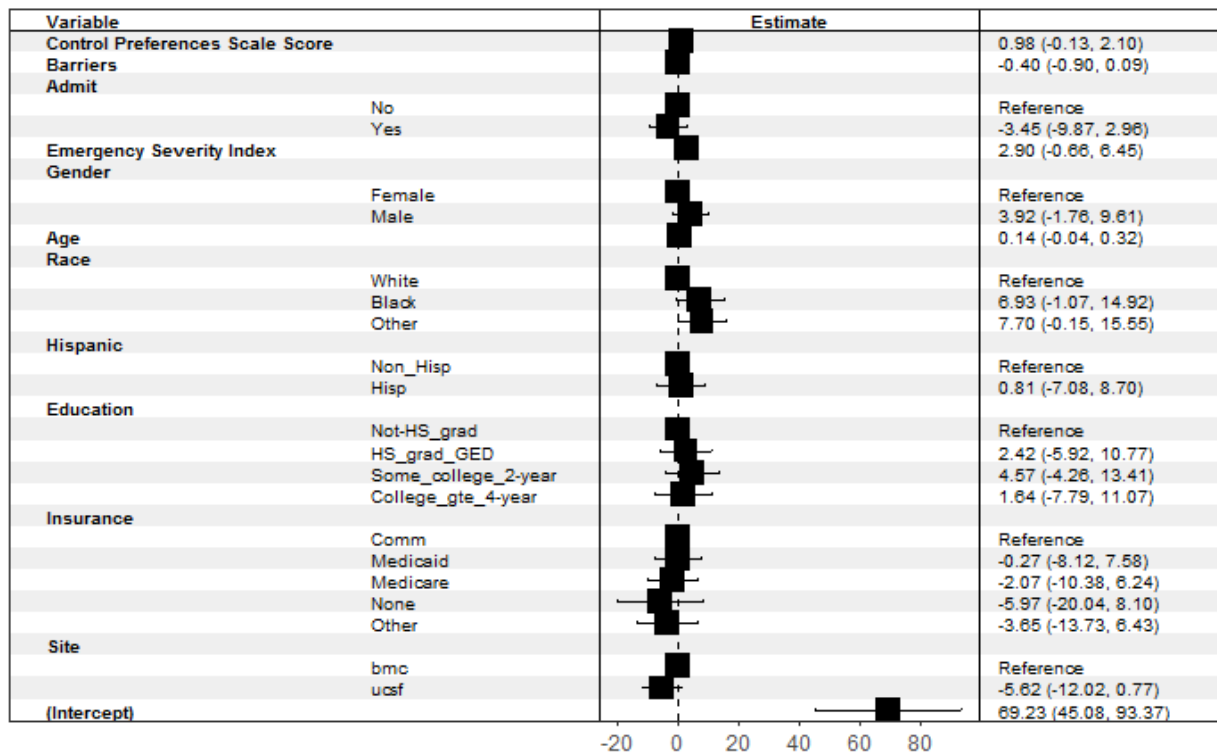
Thank you!

Appendix S2: Additional details on covariates used in exploratory analysis

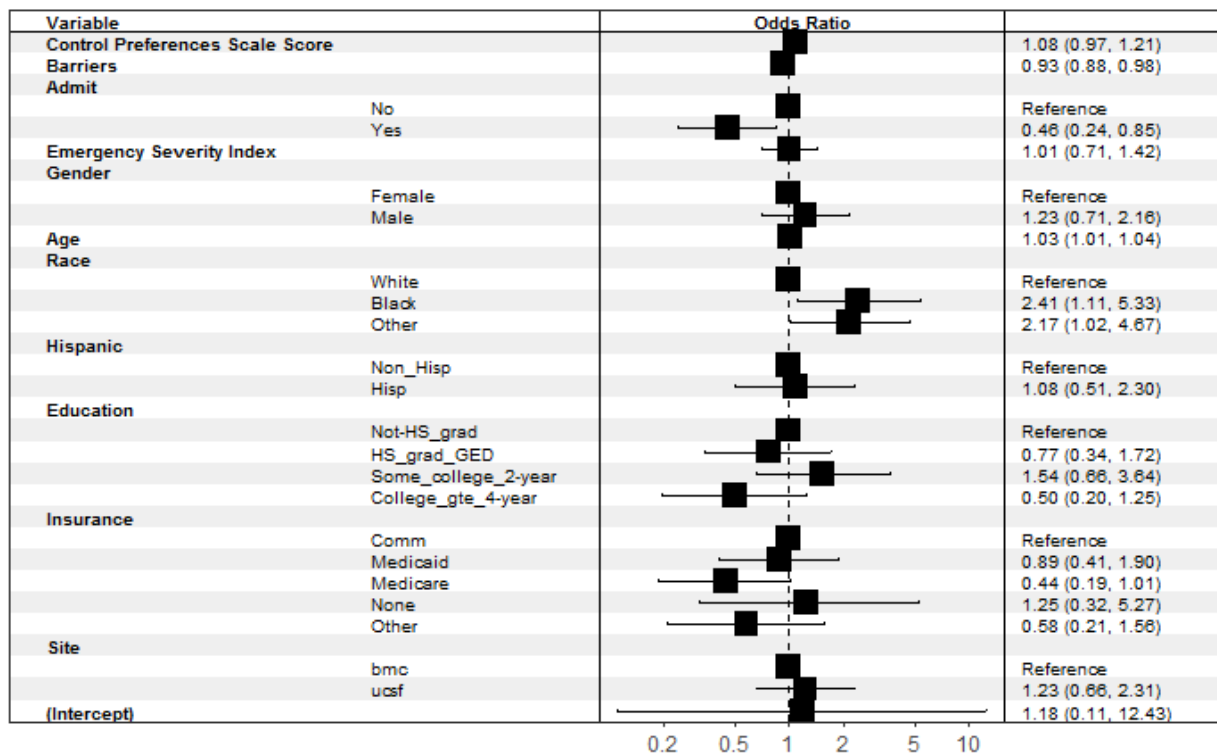
In Section I of the survey, we collected participants' perceived barriers to SDM, including health literacy; previous experience with SDM; comfort with self-advocacy; and concerns about the seriousness/emergent nature of the ED encounter. This data was summarized and used as a "barriers" covariate (with a mean of 30.5, standard deviation of 6.1, a range of 15-75, and a higher score indicating a stronger endorsement of barriers). Additionally, we used the Control Preferences Scale^{2,23} to assess participants' desired role in the decisionmaking process related to their treatment.

Appendix S3. Exploratory regression analysis

CollaboRATE Score (linear)

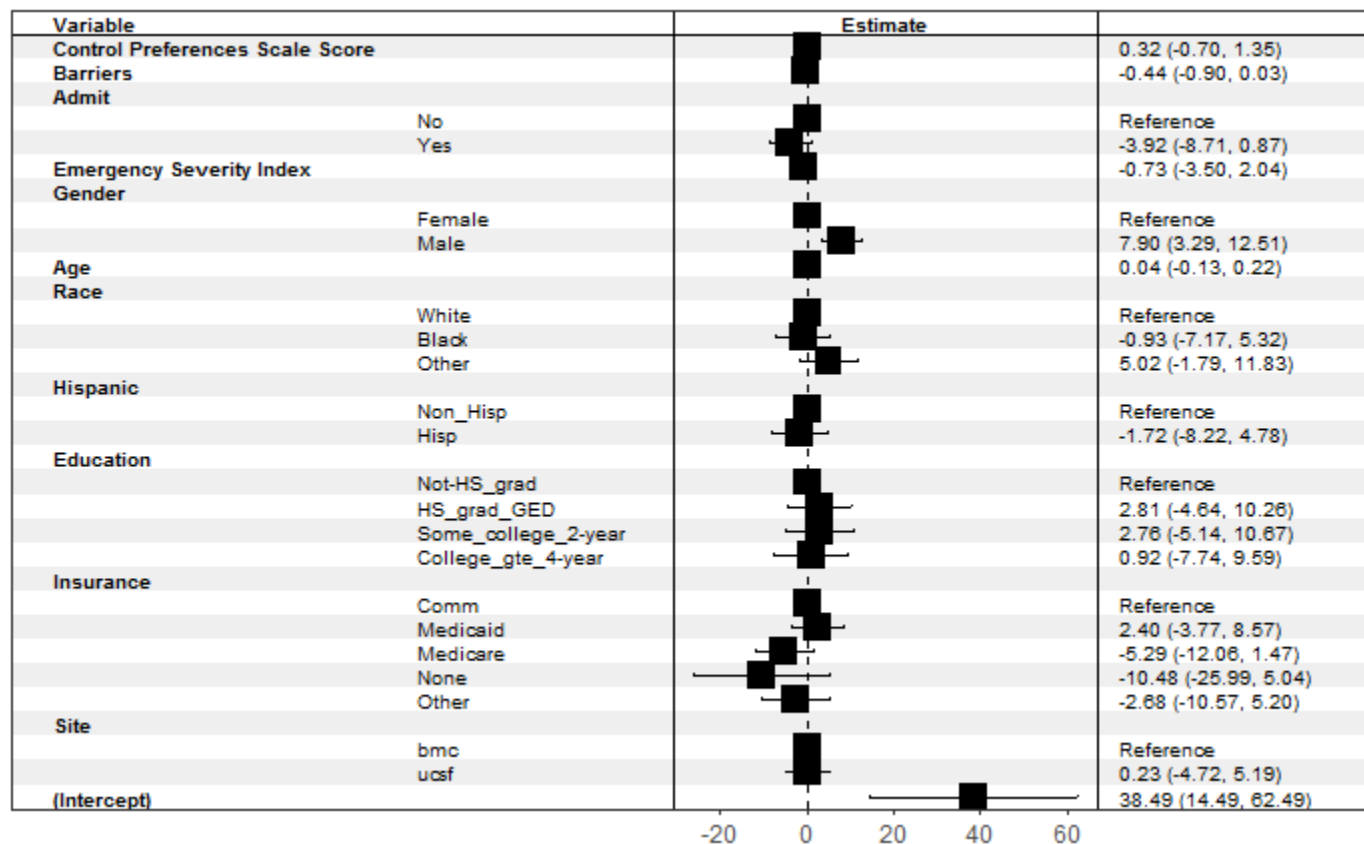


CollaboRATE - All 3 top-box (dichotomous)

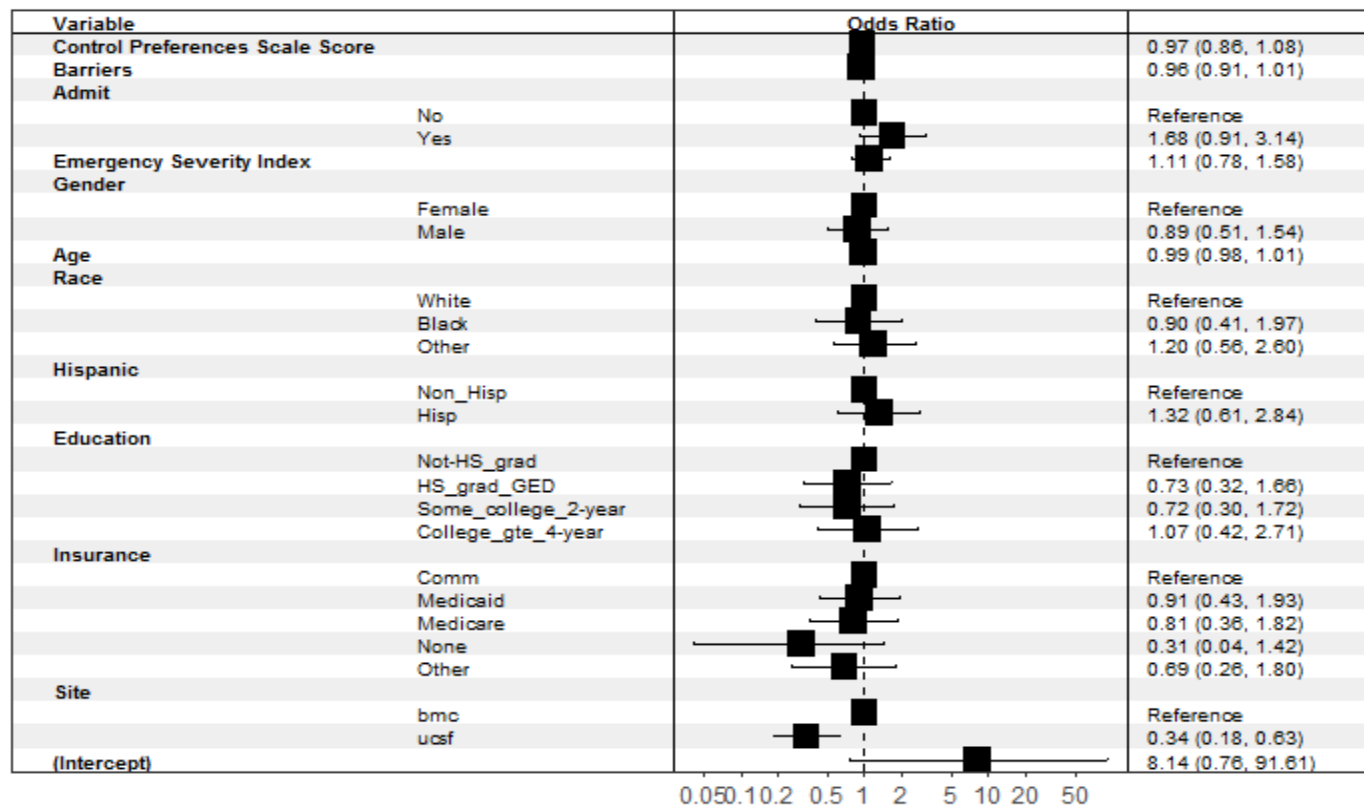


Appendix S3. Exploratory regression analysis (cont.)

SDM-Q-9 Score (linear)



Were you involved as you wanted to be? (Yes/No)



Box 1. CollaboRATE Scale

During today's visit...

1. ...How much *effort was made* to help you understand *your health issues*? (Circle one number)

No effort at all was made

Every effort was made

1 2 3 4 5 6 7 8 9 10

2. ...How much effort was made to *listen to the things that matter most to you* about your health issues? (Circle one number)

No effort at all was made

Every effort was made

1 2 3 4 5 6 7 8 9 10

3. ...How much effort was made to *include what matters most to you in choosing what to do next*? (Circle one number)

No effort at all was made

Every effort was made

1 2 3 4 5 6 7 8 9 10

Box 2. SDM-Q-9 Questions

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 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 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 option I prefer.

Completely	Strongly	Somewhat	Somewhat	Strongly	Completely
------------	----------	----------	----------	----------	------------

Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Agree <input type="checkbox"/>	Agree <input type="checkbox"/>	Agree <input type="checkbox"/>
--------------------------------------	--------------------------------------	--------------------------------------	-----------------------------------	-----------------------------------	-----------------------------------

7. My doctor and I thoroughly weighed the different 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 an 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"/>
---	---	---	--	--	--

Box 3. “Choice Awareness” question, developed by study team based on qualitative work and cognitive interviewing.

7. Were you as involved in today’s decisions as you would have liked to be?

- ¹ Yes, I was as involved as I wanted to be
- ² No, I would have liked to be more involved
- ³ Not Applicable, there were no decisions for me to be involved in today (**Stop here, you are done**)

If you answered “NOT APPLICABLE, there were no decisions” to Question 7, you can STOP HERE.