

MUSC “MUSC Research Preferences Questionnaire” FAQs

Question: Is there a Spanish translation of the questions?

A: No, not at this time, however, this will be available in the future.

Question: Does this message have anything to do with my clinical care or upcoming visits/procedures?

A: No, the questionnaire is about research preferences has nothing to do with your clinical care or visits/procedures you are about to receive or will receive in the future. Your clinical care will not change in any way based on how you reply about your research preferences. If you have any questions regarding your clinical care or any scheduled appointments, please contact your doctor’s office directly.

Question: Will samples be available to anyone across the world?

A: Researchers who wish to use any of these biological samples will be required to submit a proposal to an Institutional Review Board (IRB) that reviews requests for research. If the IRB approves the request, only de-identified samples will be available to the researchers. Because the sample is de- identified, the researchers will not know who donated it, and therefore will not be possible for any researchers to contact you regarding any results of testing that the researchers perform on your samples.

Question: What type of research might be done on my samples?

A: Samples will be stored for use by researchers in the future, so we don’t know for sure right now what type of research might be done. Some research however, might involve genetics research. All researchers, however, who wish to use samples from the sample bank will be required create a detailed proposal of their study and submit it to the Institutional Review Board (IRB) which is a group that reviews requests for research, in order for review and approval in order to obtain the samples and data. No research will be performed on the samples unless it has been reviewed and approved by the IRB.

Question: Will results from any research done on my samples be in my medical record or cause me problems obtaining life or health insurance?

A: No. All efforts will be made to protect confidentiality and privacy. Your samples will not be stored in connection with any of your personal information. The samples will be assigned a unique identification number that cannot be traced back to you. Because the information will only be provided to researchers in a de-identified format, results from any tests performed on those samples will not be included in your medical record because researchers will not know to whom the sample belongs. There is not a key to link the sample back to you.

Question: How might people contact me if I’m eligible for a study?

A: You could be contacted a number of different ways such as through your MyChart account, by email, phone or letter.

Question: How will researchers who aren’t involved in my care know I might be eligible for a study?

A: Researchers who wish to contact MUSC patients to invite them to participate in a study will be required submit a proposal to an Institutional Review Board (IRB) which is a group that reviews requests for research. If the IRB approves the request the researcher can receive the contact information for patients who have 1) indicated that they want to be contacted for future research and 2) meet the

general criteria for their approved research study. Participating in a study is voluntary and just because you agree to be contacted about a study opportunity in no way means that you have to participate in a study. It is your choice to participate or not, any time you are invited.

Question: What happens if I say yes to future contact but I'm traveling and unavailable to participate?

A: Participating in a study is voluntary and just because you might be contacted about a study opportunity in no way means that you have to participate in the study. It is your choice to participate or not any time you are invited. If it is not a convenient time to participate because of travel, you can decline to participate without it changing the clinical care you might receive in the future.

Question: MUSC no longer takes my insurance, can I be involved with research there?

A: Each research study is different; there are some research studies that do not involve billing your insurance company. By completing the preferences questionnaire, you are not consenting to any specific research study. If you say yes to being contacted about future studies and are contacted about a study, the research staff contacting you will be able to tell you what visits and procedures are involved in the study and if your insurance would be billed for any procedures or tests. After speaking with the research staff about what is involved in a specific study, it is entirely your decision whether or not you would like to participate.

Question: What if I have moved and MUSC is not my primary medical provider?

A: Every study is different. Not all studies require that you have a primary care or established doctor at MUSC for participation. Certain studies may also compensate or reimburse for travel time if you agree to participate, while others may not. There are some studies that require frequent visits to MUSC, and others that do not require as many. By agreeing to be contacted about future studies, you are merely agreeing to allow research staff at MUSC to contact you about specific studies that you might qualify for. When that research staff member contacts you, he/she will be able to provide you with these specific details. At that point, you can decide whether you are interested in participating.

Participating in a study is voluntary and just because you might be contacted about a study opportunity in no way obligates you to participate. If it is not a convenient time to participate for any reason, you can decline to participate.

Question: By answering that I DO NOT agree to be contacted about future research, does this mean that my doctor will no longer approach me about participating in research trials when I go for a clinic visit?

A: No. Your doctor can still suggest trials that he/she feels may assist with your clinical care. If you do not agree to be contacted about future research, it means that researchers who are NOT involved in your clinical care will not contact you about research opportunities.

Question: What if I don't have a computer at home, just an iPad/tablet/smartphone?

A: Some iPads/smartphones/tablets can access the questionnaire by using an internet browser, such as Safari, and navigating to mychart.mushealth.com. After you log into your MyChart account you can locate your research preferences questionnaire by clicking on "My Medical Records" and then "Questionnaires."

Question: How do I access the questionnaire?

- Login to MyChart with your username and password
- On the top menu bar, click “My Medical Record”
- In the menu that appears click “Questionnaires”
- Next click on “MUSC Research Preferences”
- Answer the two questions with your personal choices
- Click “Continue” at the bottom of the page.
- On the new page that opens, confirm your personal choices
- Click “Submit Questionnaire” at the bottom of the page