Clarkson University
Documentation of Informed Consent to Participate in Research

Project Title: Prospective study of symptoms in people with and without joint hypermobility
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Institutional Review Board (IRB) approval number:26-36 **Approval valid until: 2/17/27**

You have been asked to be a part of the research described here. Participation is voluntary.

Summary of the study: This study aims to better understand why some people with flexible (hypermobile) joints develop long-term health problems while others do not.

People with very flexible joints are common, and many never have symptoms. Others go on to develop ongoing problems such as pain, fatigue, dizziness, or joint instability. This study will follow health science students over time to learn what factors may be linked to the development of these symptoms.

If you choose to participate, you will be asked to complete questionnaires about your health, symptoms, and daily function. You may also take part in simple physical tests, such as checking joint flexibility, balance while standing, neck movement control, and how your heart rate changes when you move from lying down to standing. The first visit is expected to take about 60–90 minutes. Each year after that, you will be asked to complete shorter follow-up surveys, which should take about 15–30 minutes.

This is a long-term study that may last 10 years or more. Participation each year is voluntary.

The risks of this study are minimal. Physical tests may cause mild discomfort, fatigue, or brief dizziness. Some survey questions may feel personal or uncomfortable. There is also a small risk of loss of confidentiality, but steps are taken to protect your privacy. None of these are any more than everyday life.

Please read the material below if you want to participate in this study.

What to expect:

If you take part in this study, you will complete surveys about your health and symptoms and may be asked to complete simple physical tests, such as checking joint flexibility and balance. You may also be contacted in the future to complete follow-up surveys once each year. Participation is voluntary, and you may skip questions or stop at any time without penalty.

If you have any questions about this research, please contact Samantha Maroccco, smarocco@clarkson.edu

Risks and discomforts to you if you take part in this study:

There are minimal risks associated with the data collection for this study. All of the questionnaires and physical tests are standard assessment tools used in health care, in physical therapy in particular. None of the movements to be assessed are unusual or more provocative than daily life. For example, a person with POTS might become dizzy when they go from lying down to standing up; however, this would be typical for this individual, and safer during research as they are being monitored.

There are minimal risks associated with privacy of health data. All of the data will be handled with the standard care used with actual patient health data. Furthermore, none of the data to be collected is considered 'sensitive' and none of the questions are likely to be distressing.

The benefits to you if you take part in this study:

People who take part in this study may not receive a direct personal benefit. However, some participants may better understand their symptoms and how these symptoms change over time. While we cannot diagnose any medical conditions through this study, we will tell you if any test results warrant follow up with your health care provider. For some people, this information may help them better understand their health and could reduce confusion or delays in the future.

The main benefits of this study are for learning and research. What we learn may help researchers and educators better understand symptom patterns in people with and without joint hypermobility. This information could help guide future research, education, and health care practices, including earlier identification and better support for people with these symptoms.

This study may also help improve how health sciences students and professionals learn about long-term symptom experiences in young adults.

What will you receive for taking part in this study? Participants will not receive any direct compensation for taking part in this study. However, they may learn more about these conditions and whether they have signs or symptoms that are commonly seen in the conditions being studied. Participants may also benefit from knowing that they are helping advance health science research, which is important for improving education and care.

What will happen to the information collected in this study?

The information you share in this study will be kept private. When you join the study, you will be given a study ID number. Your name and contact information will be kept in a separate file from your survey answers, so your identity is not linked to your responses.

Information that can identify you, such as your name or email, will be stored in a secure online folder at Clarkson University. Only the main researcher and approved research team members can see this information, and they must use secure logins to access it.

The information used for research will only include your study ID and your answers. Your name or contact information will never be included in reports, presentations, or publications.

Your identifying information will be kept for a limited time and then permanently deleted.

Research information that does not identify you may be kept longer to help with future learning and research.

Steps are taken to protect your privacy, but there is a small risk that confidentiality could be lost.

The information collected will be kept confidential to the extent that the law permits. The information collected in this study will be kept private and secure. Each participant will be given a study ID number. Your name and contact information will be kept in a separate file from your survey answers, so your identity is not connected to your responses.

Information that can identify you, such as your name or email, will be stored in a secure folder at Clarkson University and can only be accessed by the main researcher and approved research team members using secure logins.

The information used for research will only include your study ID and will not include your name or contact details. Results may be shared in reports or presentations, but no information that could identify you will ever be shared.

Your contact information will be kept for up to five years and then permanently deleted. Research data without identifying information may be kept longer for learning and research purposes.

What rights do you have when you participate in this study? Participation is voluntary. Choosing not to participate or stopping at any time will not result in any penalty, fine, or loss of benefits you are entitled to. If you have questions about your rights as a research participant or want to report any harm, injury, risk, or other concern, please contact the Clarkson University Institutional Review Board (IRB) for human subjects research at irb@clarkson.edu or (315) 268-6475.

You may stop participating at any time without penalty. No new information will be collected after you withdraw. Information collected before you withdraw may still be used for research purposes.

Conflict of Interest: The researchers have no financial interest in performing this study.

COVID-19: The study team has taken all CDC-suggested safety measures to minimize exposure to SARS-CoV-2 (the cause of COVID-19).

Informed Consent: Please sign below to confirm that the purpose of this research has been explained to you, and you have been informed of what to expect and your rights. Make sure all your questions are answered to your satisfaction. Your signature indicates that you agree to participate in this research. By signing, you also confirm that you are at least 18 years old. You will receive a copy of this consent form for your records.

Signature of volunteer: _____ **Date:** _____

Signature of researcher obtaining informed consent: _____ **Date:** _____