

Participant Information Sheet

Title of Project:

Capability, Comfort, and Calm in Chronic Myelogenous Leukemia

Organization:

University of Texas at Austin, Value Institute

Names of Project Team:

Meghan Banta: Seattle, Canada - Executive Director for Supply Chain in Swedish Health

Shannon Jackson: Vancouver Canada - Hematologist at St. Paul's Hospital

Wolfgang Mueller, from Austria working in Switzerland for Roche Diagnostics exploring Value-based Healthcare

Alex Perez, Galveston, Texas - Surgeon educator specialized on the management of complex diseases

Rebekah Scott, Austin, Texas - 3rd year medical student at Dell Medical with former working experience as patient advocate

Morgan Wortham: from Reno, Nevada working at Renown Health Hospitals as IT manager

Organizational Project Champion(s):

Shannon Jackson

1. Invitation

We would like to invite you to take part in the above project which involves an interview about what it is like to live with Chronic Myelogenous Leukemia (CML). Before you decide it is important for you to understand why the project is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. If you have any additional questions or want to contact the project team, please email Rebekah Scott (rebekah.e.scott@utexas.edu).

2. What is the purpose of this project?

The purpose of this project is to assess outcomes that matter most to people living with CML, and this may include obstacles to receiving care, unmet health care needs, and gaps in care. The focus of the project will be the experiences that people living with CML had during the first year after initial diagnosis.

The long-term goal is to use the information we learn in the interviews to improve clinical tools and resources to better assess and measure outcomes that matter to CML patients. In the future, it might help with the construction of tools and electronic medical record (EMR) functions that collect information regularly over time and allow sharing of these outcomes with CML patients.

3. Why have I been invited to participate?

You have been invited as we are looking for adults of all ages and stages of life with chronic phase CML.

4. What will I be asked to do?

You will be asked to participate in an Experience Group session, a method to understand what matters to people with certain medical conditions such as CML that the University of Texas at Austin Value Institute has developed. It is based on qualitative research methods that use an informal discussion among patients about living with their medical condition and generally takes around 75-90 minutes. Only people with a very similar situation and experience will be invited to the Experience Group session, and you don't need to prepare for the session. You are the expert!

5. Are there any possible benefits from participation in this project?

You will help us to learn and understand what really matters to people living with CML. We believe that we can identify areas for improvement for the care system for people with CML. Once the project has been completed we will inform you by email and provide you with information on how to access findings.

6. Are there any possible risks from participation in this interview?

During the Experience Exchange session, we will ask all participants to keep discussions confidential, but we cannot guarantee it.

7. What if I change my mind during or after the interview and/or project?

At any point in time you are free to withdraw from the interview and project, and you don't have to provide an explanation.

8. What will happen to the information when the interview is over?

We will maintain the confidentiality of all recorded data, all participants will remain anonymous in any publications, or presentations and the recordings will be destroyed after the project has completed in August 2022.

9. How will the results of the project be published or shared?

The results of the project will be integrated into a poster presentation in the context of our Master's of Science program, which is the final deliverable of the experiential learning project program.

In addition we plan to create a small report, a presentation, as well as a leaflet / flyer delivered to hematology practices that talk about “Themes that matter to patients with CML and recommendations about how to fill the gaps in care delivery”.

10. What if I have questions about this project?

If you have any additional questions or want to contact the project team please email Rebekah Scott, rebekah.e.scott@utexas.edu.