

STUDY FACT SHEET FORM

Please keep this form in case you have any questions

Study Information: You can call Erik Fromme, MD (617) 384-8864 (please leave a voicemail) with questions about this research study. Calls will be returned during business hours, M-F, 9-5.

Study Contact email: Erik_Fromme@dfci.harvard.edu

A Guide to Being Mortal: Testing the What Matters to Me Workbook

Who are we?

We are researchers from Ariadne Labs, a joint center of innovation at the Brigham & Women's Hospital and the Harvard T.H. Chan School of Public Health.

What is the purpose of this study?

Ariadne Labs and The Conversation Project have developed the What Matters to Me Workbook for seriously ill patients and their caregivers. The Workbook's purpose is to help patients and caregivers prepare to talk about their goals, values, and preferences for care, especially with their health care team. The aim of this project is to ensure that the What Matters to Me Workbook is as useful, easy-to-use, acceptable, and harm-free as it can be to people regardless of age, gender, education, race, etc.

Who is sponsoring this work?

The Cambia Health Care Foundation

How did you get my name and how many people will take part in this study?

We obtained your name from our community contacts because you indicated interest in learning more about the study. Approximately 60 patients and caregivers will take part in this study.

Who is eligible to participate?

We are looking for adults (18+) who are living with a serious or terminal illness and who have a caregiver (family member, friend, health care proxy) who is interested in participating with them. Since the goal of the Workbook is to foster a useful conversation about values, goals, and preferences, we are asking patients and caregivers to participate together.

What will happen if I take part in the study?

If you agree to take part in this research study, you will be asked to complete the What Matters to Me Workbook, complete a survey, and participate in an interview about your experience using the Workbook. The interview will be recorded, transcribed, and analyzed for themes pertinent to the study. You will be interviewed alone or with your partner by 1-2 research staff.

The workbook can be completed in less than an hour, but you may wish to spend more time thinking about your answers. The interview will take no more than 60 minutes of your time. The survey can be completed online in 15 minutes or less but will take longer if we do it over the phone.

How may I benefit from being in this study?

We hope that this work will contribute to knowledge regarding serious illness conversations. This is also an opportunity for you both to develop familiarity and comfort with advance care planning questions and to be better prepared for future health decisions.

Do I have to participate in the study?

No, participation in the study is completely voluntary. Both of you are free to withdraw at any time without consequences.

What are the possible risks or discomforts involved from being in this study?

The primary risk to our subjects will be some level of emotional discomfort in discussing topics related to their goals, values, and preferences for care if they were to get sicker. There is also a risk of breach of confidentiality or privacy. We take your confidentiality and privacy very seriously and use several layers of security to minimize those risks, for example by using code numbers instead of real names and using HIPAA compliant communication and storage.

What if I have questions about my rights as a research participant?

If you'd like to speak to someone not involved in this research about your rights as a research subject, or any concerns or complaints you may have about the research, contact the MassGeneralBrigham Human Research Committee at (857) 282-1900.