

INFORMATION FOR THE QUESTIONNAIRE PARTICIPANT**Version number:** [01]**Date of creation:** [03.07.2024]**Study title/name:** *"Mapping of cancer navigation/support programs worldwide"*, part of the EU Navigate *"Implementation and Evaluation of a Navigation Intervention for People with Cancer in Old Age and their Family Caregivers: An International Pragmatic Randomized Controlled Trial"*.**Sponsor:** European Union's Horizon Europe program (grant agreement no. 101057361)**Research team:**

1. Principal Investigator (applicant): Professor Katarzyna Szczerbińska, MD, PhD
2. Małgorzata Filipińska, MA, psychologist, psychooncologist

We would like to invite you to a mapping study of navigation programs dedicated to people with cancer and their families around the world. The study is conducted by Laboratory for Research on Aging Society, in the Department of Sociology of Medicine at The Chair of Epidemiology and Preventive Medicine, Medical Faculty, Jagiellonian University Medical College by the team led by Professor Katarzyna Szczerbińska, MD, PhD.

We hope that the presentation of the most important information about the study will allow you to decide whether to take part.

1. What is the purpose and nature of the study?

The main objective of the study is to map programs around the world that aim to support people with cancer and/or their family members. Mentioned programs should incorporate elements of a navigation intervention. To collect such information, we created an online questionnaire. In addition, if you agree to participate in the online interview, we will conduct interviews regarding the details of the programs mentioned in the questionnaire. The analyses will result in the identification of programs that overlap with navigation intervention, good practices, and recommendations for effective support of people with cancer.

2. What will I be asked to do?

You will be asked to complete an anonymous questionnaire about support programs in your country or within your area of activity. If you agree to take part in an online interview, you will be asked to provide your e-mail address, so that we can schedule an online meeting and send an invitation to the interview by e-mail.

3. How much time do I have to spend participating in the study?

The online questionnaire takes approximately 30 minutes to complete.
The estimated time for online interviews is 60-90 minutes.

4. Will I benefit directly from taking part in the study or what benefits will other people receive?

The survey provides an opportunity to express your opinion on support programs for people with cancer and their relatives. Based on the statements, we intend to develop recommendations that can help in the development of similar programs in the future.

5. Will the results of the study be made available to me?

All results of the research, analysis and procedures described above will be made available in the form of a scientific publication once the study has been completed.

6. Will the results of the study be made available to the public, e.g. to patients or other researchers?

It is anticipated that the results of this study will be published or presented at scientific conferences. In any publication or presentation, information will be provided in such a way that the participant cannot be identified.

7. What happens to my data after the survey is completed?

Please be assured that only certain members of the research team will have access to the full data, including your personal data. Once the data collection is complete it will be encrypted, the encryption key will be placed in a separate location from the original data and only the Principal Investigator, i.e. the Project Manager, will have access to it.

If you give your consent, your anonymised data, collected during this study, will be stored and shared and used in other related studies/projects in the future, both by researchers from this study and researchers from other research teams from UJ/UJCM and beyond. Data will be used for comparative analyses for the period 2024-2034.

If you agree, your anonymised/coded **data** received during this study will be stored and transmitted and used in the future by researchers in other countries, both within and outside Europe.

8. Can I withdraw from participation in the study?

Participation is entirely voluntary, and you are not obliged to do so. If you take part in the study, you may withdraw at any time without giving any reason and without any negative consequences or loss of benefits to which you are entitled, including the right to healthcare. In that case, please report this to the Laboratory for Research on Aging Society, Jagiellonian University Medical College by calling 502-186-434; or by writing to: pbss@uj.edu.pl or by letter to: Laboratory for Research on Aging Society, Jagiellonian University Medical College, Kraków, 8 Skawińska Street, room 059, level -1.

If you choose to withdraw, only the information you provided before you withdrew your consent to participate in the study will be used by the Research Team to prevent distortion of the study results.

9. Can I tell anyone about participating in the study?

Yes, you can tell other people about the study. For example, you can share link to the study or give them the contact details of the Principal Investigator. They can contact the Principal Investigator i.e. Katarzyna Szczerbińska or Małgorzata Filipińska to discuss their participation in the research project by calling 502-186-434; or by writing to: pbss@uj.edu.pl or by letter to: Laboratory for Research on Aging Society, Jagiellonian University Medical College, Krakow, at 8 Skawińska Street, room 059, level -1.

10. Who can I turn to if I have questions or concerns?

If you wish to further discuss any issues related to the study before deciding whether or not to participate in the study, please contact the Principal Investigator or any other member of the research team, i.e. Katarzyna Szczerbińska or Małgorzata Filipińska; **tel. 502-186-434**; e-mail: pbss@uj.edu.pl or at the Laboratory for Research on Aging Society, Jagiellonian University Medical College, Krakow, ul. Skawińska 8, room 059, level -1.

If you have any complaints or concerns about the ethical conduct of this research, you may contact the Office of the Jagiellonian University Bioethics Committee, which granted approval for this study. Any issues you raise will be treated confidentially.

If you agree to participate in this study, you will be asked to read and accept the Participant Consent Form.

This study was approved by the Bioethics Committee of the Jagiellonian University.

Thank you.

Katarzyna Szczerbińska
together with the Research Team