Feedback meetings on the translation of the SALVOVAR questionnaire

Information Sheet

Background and purpose of scale translation feedback sessions

SALVOVAR is a European clinical trial focusing on ovarian cancer (salvovar.eu), led by Hospices Civils de Lyon (HCL) and sponsored by ARCAGY-GINECO group in collaboration with the ENGOT network. As part of this project, we aim to explore decision-making processes related to cancer treatments across multiple countries, including France, the Netherlands, and Italy (among others). To achieve this, we will be gathering insights from patients and clinicians about their experiences with deciding on treatment options through self-report questionnaires. As the trial will take place in various countries, we need to ensure that these questionnaires are available for use across different languages and cultures.

We are therefore undertaking a process to translate and adapt the questionnaire following best practice guidelines. This involves assembling a team to first translate the questionnaire into the new language, and then testing the translated version with a group of people (patients and clinicians) who are native speakers of this language who can give us feedback on it. Your participation in this group of testers will help us ensure that the measures we use are valid and appropriate for use.

Who can take part?

We are looking for individuals who:

- Have experience with cancer treatment decision-making (either as a previous or current patient, or a clinician working in cancer care)
- Are native speakers of English, French, Dutch, or Italian
- Are available for a telephone or video conferencing call (e.g., Zoom, Skype, or Teams) in March – May, 2025
- Are aged 18 or over

You do not need to have been involved in a clinical trial or have a research background to take part.

What will participation involve?

You will be asked to read the translated questionnaire (including the instructions, questions and response options), and take part in a one-to-one telephone/video conferencing call to share your thoughts about the clarity, comprehensibility, and cultural and contextual appropriateness of the questions. We will ask you about your understanding of the items, any potential difficulties, and suggestions for improvement.

Please note that participation is voluntary. You will not be paid for taking part. If you agree to take part, you can also change your mind at any point and withdraw from the sessions without needing to provide a reason. Your decision to participate or not will not affect your treatment or any support you may receive, or your clinical work.

Time commitment and role duration

- We have been working hard to translate the questionnaires, and aim to conduct these testing and feedback sessions soon. For the English language translations, we expect this to be between March – May, 2025.
- We anticipate that this process will take about 20 to 30 min of your time, and we will work around your schedule to find a time which is suitable for you to meet.

- In the event that significant changes need to be made to the translations, we may invite you to take part in another call to review any updates or modifications to the questions.

Potential benefits of your participation

By participating in these feedback sessions, you can:

- contribute to the development of research methods that can be used in diverse countries and contexts
- help ensure that the measures used in SalvOvar (and future studies) are accurate and appropriate for use in different countries and languages
- ensure that the voices of users (i.e., cancer patients or clinicians taking part in research) are heard in the translation process

If you are interested, we will keep in contact to inform you about the outputs and results at the end of the project.

What happens with the information you provide?

- We will use your feedback to help ensure the measures we use are accurately translated and culturally adapted, making modifications where necessary. We will also collect basic demographic and background information (age, sex, location, education level, experience with cancer treatment decisions) so we can report general group characteristics.
- The information you provide will be fully anonymized, so your identity will not be linked to these data. Feedback sessions will be recorded, so that we can summarize your comments, but these recordings will be accessible only to the research team, and later destroyed after analysis. These summaries will be anonymized and your name will not be linked to your individual comments.
- At a later stage, we will aim to share the final translated and validated versions of the measures for broader use (with the agreement of the original scale developers), depositing them in public repositories and/or publishing in peer-reviewed journals. Your contributions will be acknowledged (we will confirm with you how you wish to be acknowledged).
- Individual data and correspondence regarding the study will be maintained until the end of the period of practical utility. All data will be processed in accordance with EU data protection legislation and stored digitally in a secure location.

How to take part

We welcome and value the insights and experiences of people from all backgrounds. If you meet the criteria for participation and wish to take part:

- Please complete the consent form and send it back to us. We will then get in contact with you to discuss the process arrange a suitable time to speak with you.
- If you have any questions or concerns about your participation, or if you need any assistance in completing the consent form, don't hesitate to contact us[1] at: laura.del-carpio@sjd.es.

[1] This research is being coordinated by SALVOVAR researchers: Alexandra Dima & Laura del Carpio (PRISMA Group, Fundació Sant Joan de Déu, Barcelona, Spain), and Julien Péron & Thibaut Reverdy (Hospices Civils de Lyon, Lyon, France). The study takes place within the PRISMA group at the Fundació Sant Joan de Déu, led by Antoni Serrano Blanco and Maria Rubio Valera.