


WeShare user guide for improving
inclusion, diversity, and respect in
Quality of life and social and human
sciences focused Research





WeShare is engaged on improving inclusion, diversity, and respect in **Quality of life and social and human sciences focused** research. The points below serve as an initial guidance for researchers using the WeShare platform. Several projects are ongoing within our WeShare Research Group with the aim of generating evidence and tools to continuously update and feed this guidance – Learn more about it at the end of the page.

RECRUITMENT

1. Start at inclusion. Propose and explain the study to a potential candidate regardless of socioeconomic status, gender or age. Make sure patients understand what is stake in your research:

1) Take the time to give participants explanations before the inclusion: sometimes, patients decline or drop out of a study due to secondary misunderstandings. Before the inclusion, be sure to explain to the patient about: (a) study design (randomization, placebo, blinding, anonymization), (b) expected benefits and risks related to the study, (c) what is expected from the participant in the study including periodicity of answering PROs (d) reasons to stay enrolled, and the possibility to leave at any time, and (e) expected time to access the first results of the study.

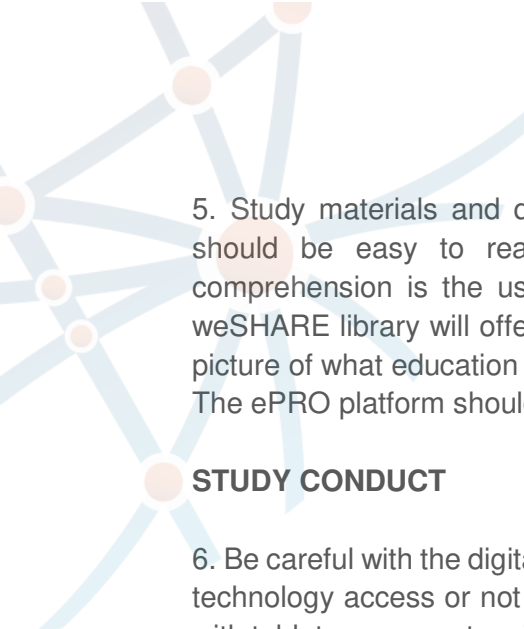
2) Create patient centered support information to allow agile communication with patients. Use different methods to deliver information about the research planned to boost inclusion and diversity in your recruitment: the use of various communication channels (direct contact with the physician, multidisciplinary team, patient community and associations, paper and virtual flyers, social media campaign, e-mail) could reach a more extensive and diverse research participation.

DATA COLLECTION

2. Collecting a minimum set of sociodemographic data in your study can give you a better understanding of the representation and diversity of your participants. It can also help to flag early on the recruitment process the lack of diversity. Depending on your research objectives it can also give you insights of social determinants of health and how social disparities impact oncology outcomes. WeShare proposes a minimum set of sociodemographic variables to be collected in your study.

3. When it comes to patient reported outcomes (PRO) utilization, whenever possible, opt for a validated questionnaire. Questionnaires ideally should be validated in the scope of your research, the language, and the population to be evaluated. WeShare proposes a library of validated ePROs, tested by the WeShare user committee.

4. Choose the number and the extension of the questionnaires adequately: A study with a high number or extensive questionnaires could reduce the patient's interest to participate and consequently reduce retention over time. Respect participants' time spent in the study by not applying repetitive or overly long questionnaires. If you have doubts of the acceptability, weSHARE patient and participant community can help you in selection and test the set of questionnaires.



5. Study materials and questionnaires should be adapted to the participants literacy and should be easy to read and understand. A key strategy for promoting participant comprehension is the use of plain language (sixth to eighth grade scholarly). In addition, weSHARE library will offer you a readability and understandability index, so you can have a picture of what education degree is needed for each questionnaire completion. The ePRO platform should also be easy to understand and navigate.

STUDY CONDUCT

6. Be careful with the digital divide. A digital navigator may be offered for patients with reduced technology access or not comfortable with the use of technology devices. In-person support with tablets or computers in the research centers may ease the process. A phone call support can also help patients navigate in the ePRO system. You may also have additional paper questionnaires in the research center or to be posted by mail.

7. Offer a flexible schedule and adequate time to research participation, including questionnaire answering, key informative interviews, and focus groups. Providing a flexible schedule on different days makes participation possible for participants with different availabilities. Offer digital navigation if using technology devices for qualitative research.

8. Consider providing study information material, ePROs, focus groups and key informative interviews in different languages. This allows the inclusion of foreigners or refugees that don't speak the official country idiom.

9. Acknowledge the participant's effort. Thank you messages or thank you gifts can be a form of valuing participation and may also improve study retention.

10. Don't forget to share the results of your study with the participants. You may prepare a specific informative material for study participants. Different communication channels can be used (social media, press, education days, etc). It is an opportunity to thank the participant and show how its participation accelerated research in the area studied.


Learn more about ongoing WeShare initiatives:

1) The participant in the center:

- A WeShare user's committee is being formed with patient and citizens representatives. This group will meet periodically with WeShare's research team, scientific coordinators and the technical infra-structure team in a living lab hosted by WeShare to co-create the platform.

2) Language matters for us:

- Understandability and readability scores give us a hint of how difficult a questionnaire may be for study participants. National and international authorities recommend that public materials should have a readability score not higher than sixth to eighth grade scholarly. WeShare is currently assessing the readability and understandability scores
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of our PRO library so that researchers can have this information when choosing a questionnaire.

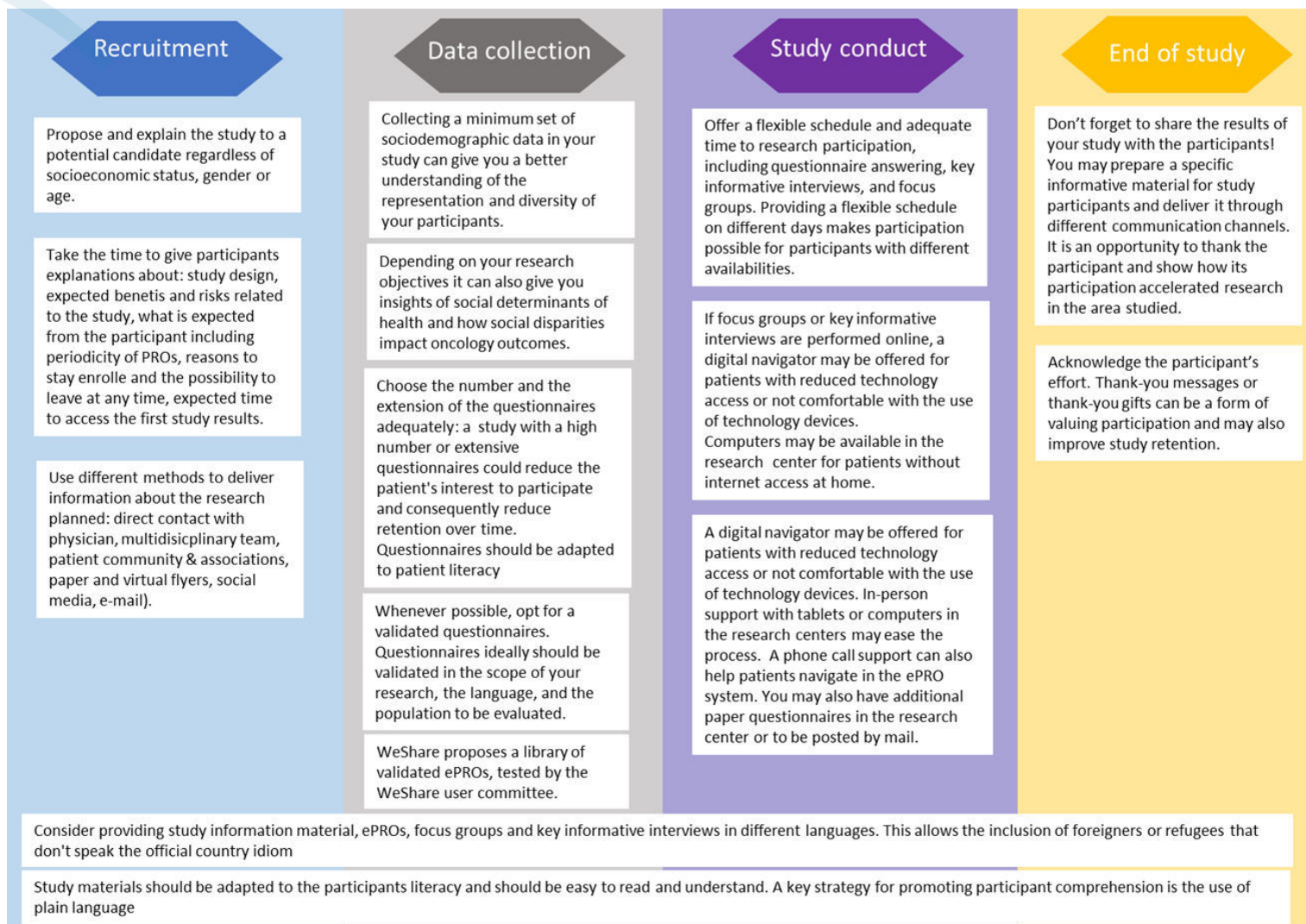
- Using a participant-friendly language may impact study retention and make questionnaires more pleasant for study participants. We are assessing participants' perspectives and experiences regarding the introductory questionnaire language used in our PRO library.
- WeShare is working to have the PRO library available in several languages as well as multi-language translation modules for study materials.


3) We want to understand and reduce barriers to study participation:

- Participants with lower economic income or educational level are frequently underrepresented in PRO research. WeShare will participate in qualitative and quantitative studies in partnership with ONGs dedicated to help vulnerable patients with cancer to understand potential barriers and facilitators for study participation.
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Initial WeShare User Guide for Inclusion, Diversity, and Respect in PRO research:





WeShare will continuously feed the initial user guide through its ongoing research projects and co-creation with We Share's user committee:

