

# Why dealing with cultural aspects is important to engage citizens. ADLIFE project

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# Outline

1. ADLIFE project
2. User acceptance tests
3. ADLIFE Health Outcome Framework
4. Cultural adaptation of questionnaires



# ADLIFE Project Organisation

**ADLIFE. Integrated personalized care for patients with ADvanced chronic diseases to improve health and quality of LIFE**

- Dates: January 2020 – June 2024
- Coordinator: Kronikgune, Spain
- 13 partners from 9 countries



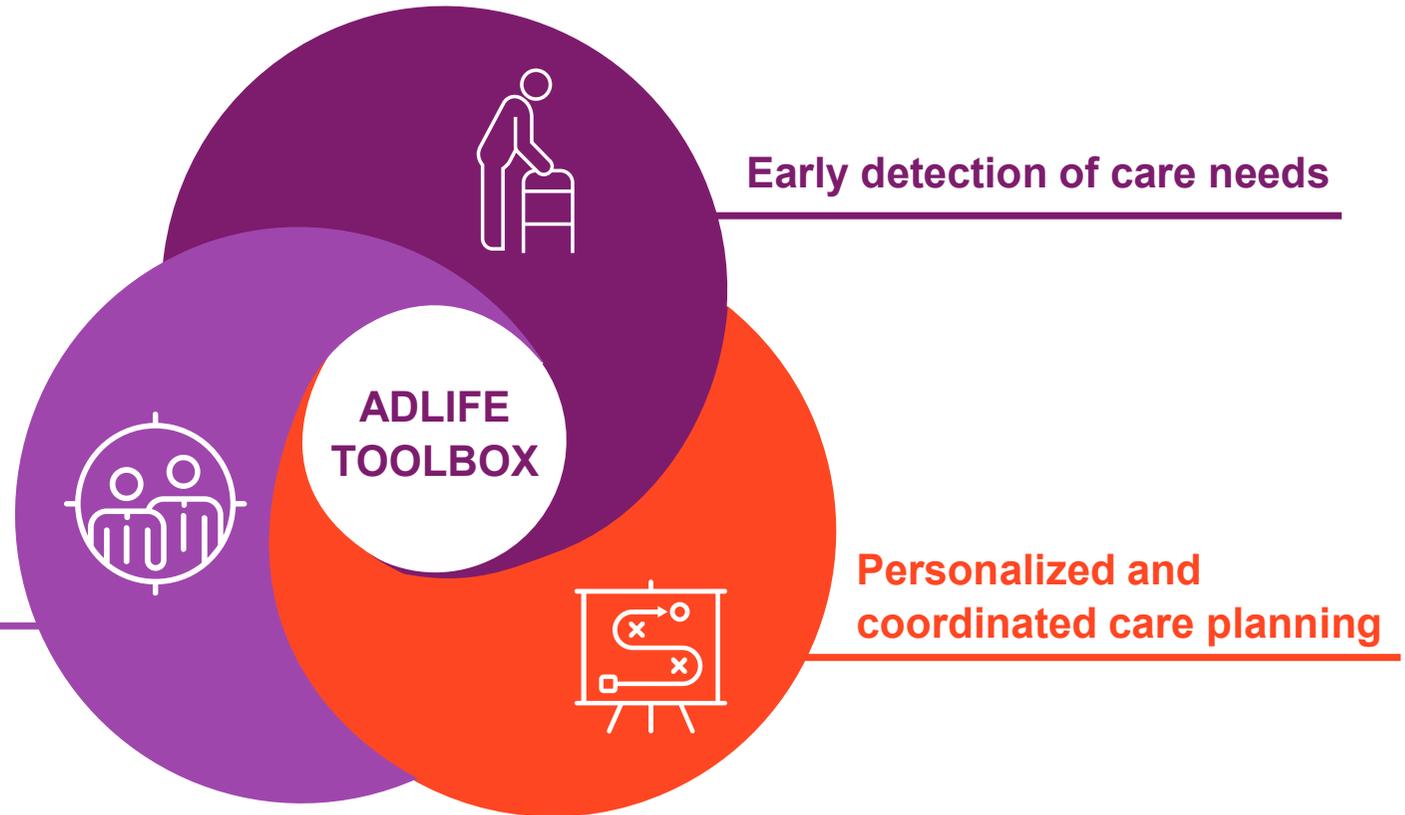


## ADLIFE Purpose

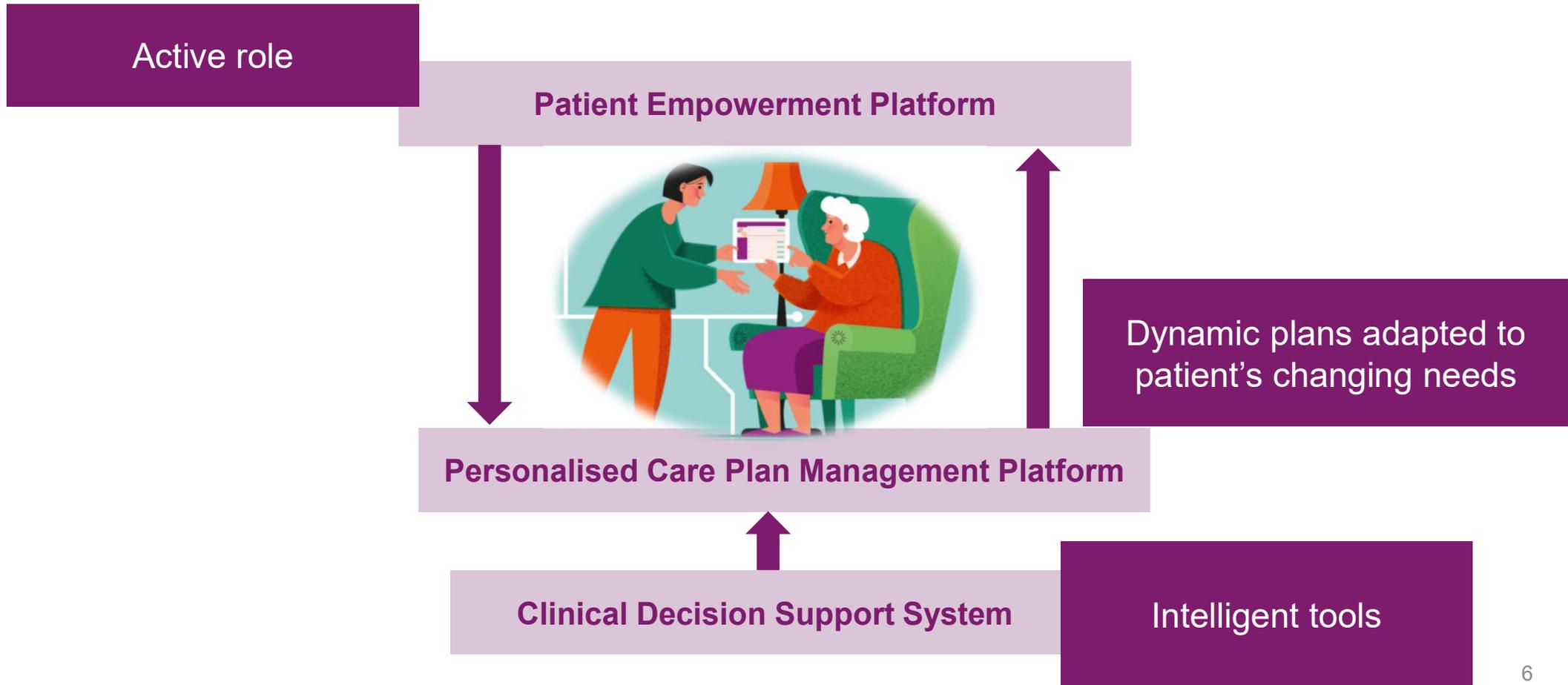
*Improve the  
quality of life  
of patients  
with advanced  
chronic diseases*

through intelligent integrated  
digital solutions  
that enable multidisciplinary care  
teams, patients and caregivers  
to achieve personalised, responsive  
and timely care

# ADLIFE Pillars

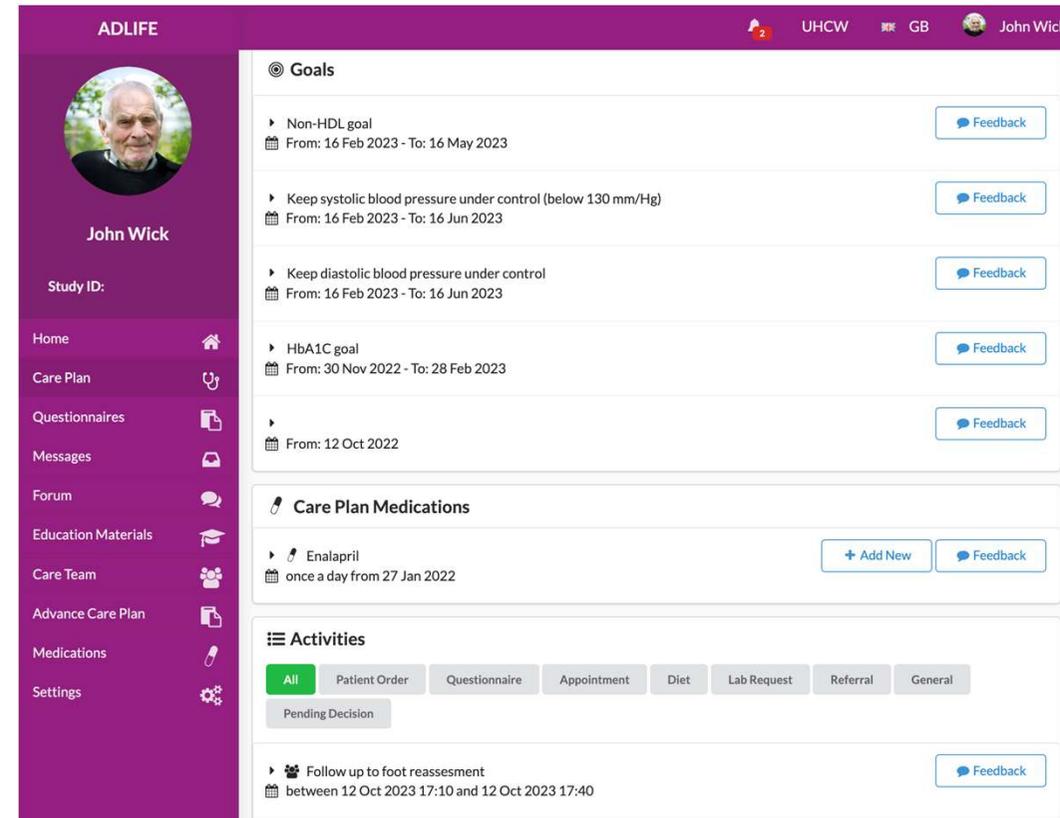


# The ADLIFE innovative toolbox



# User acceptance tests

- ❖ Pre-deployment usability studies
  - ❖ To assess the usability of the tools from representative target end-users and address the key issues in updates to the tools, ahead of the main pilot study
  - ❖ Pilot sites recruited participants similar to the ADLIFE study participants for their feedback on the tools
- ❖ Two user-facing ADLIFE tools were included in the study:
  - ❖ PCPMP: The *Personalised Care Plan Management Platform* (PCPMP) will be used by healthcare professionals in the pilot sites to create patient care plans based on each patient's baseline and most recent clinical data, following clinical guidelines.
  - ❖ PEP: The *Patient Empowerment Platform* (PEP) will be used by patients and their informal carers to view personalised goals and activities in the patient care plan, complete study outcome measurements, and receive information about useful interventions that they could try to include in their daily lives



The screenshot shows the ADLIFE user interface for a user named John Wick. The interface is divided into a left-hand navigation menu and a main content area. The navigation menu includes options for Home, Care Plan, Questionnaires, Messages, Forum, Education Materials, Care Team, Advance Care Plan, Medications, and Settings. The main content area is titled "Goals" and lists several health goals with associated dates and feedback buttons. Below the goals is a section for "Care Plan Medications" showing a medication named Enalapril. At the bottom, there is an "Activities" section with tabs for All, Patient Order, Questionnaire, Appointment, Diet, Lab Request, Referral, and General. The "All" tab is currently selected, showing a list of activities with feedback buttons.



# User acceptance tests preparations

- ❖ User guides for PEP and PCPMP have been prepared



- ❖ A walkthrough scenario has been prepared presenting key features of the platform in a step by step manner via a realistic scenario

- ❖ Sample realistic patient data, and care plan is created



- ❖ The tools have been deployed to our servers, user accounts have been created for participants

- ❖ Questionnaire for User Interaction Satisfaction v7 (QUIS7) questionnaires have been used to collect such feedback, with Likert scales for opinions and free-text comments for further explanations

- ❖ Assesed the following aspects: overall reaction, screen, terminology and tool feedback, learning, multimedia, training material and system capabilities.
  - ❖ The 9-point scale ranges from 1, representing a negative adjective, to 9, representing a positive adjective
  - ❖ A link to an online questionnaire was made available to participants via Qualtrics



- ❖ Ethical Board approvals have been obtained by three clinical sites from Spain, Germany and Sweden

- ❖ One site in the UK (England) has opted to collect feedback via a Patient and Public Involvement (PPI) approach





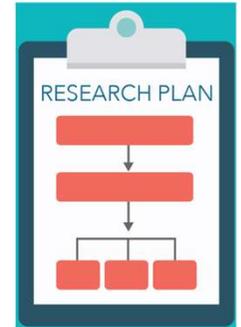
# User acceptance tests preparations

## ❖ Study protocol

- ❖ Participants are given a demonstration of the tool using a scenario that covers the key features
- ❖ Participants are provided with login credentials for them to access the test system and go over the scenario themselves
- ❖ Participants are then requested to complete the QUIS usability questionnaire to provide their feedback.
- ❖ A link to an online questionnaire was made available to participants via Qualtrics

## ❖ Results

- ❖ Data collection has taken place between April and June 2022 at the following sites: Germany (PCPMP and PEP), UK-England (PEP), Spain (PCPMP and PEP), and Sweden (PCPMP).
  - For the ADLIFE PCPMP tool, the following workshops were held for the usability studies:
    1. Germany: 16 Healthcare managers and professional were approached via email with instructions on tool demonstration, testing and questionnaire completion.
    2. Spain: 1 workshop with 10 healthcare professionals
    3. Sweden: 1 workshop with 3 healthcare professionals
  - For the ADLIFE PEP tool, the following workshops were held for the usability studies:
    1. Germany: 1 workshop was held with 3 patients
    2. Spain: 1 workshop with 4 patients and 3 carers
    3. UK-England: 2 workshops were held online with the first one with a live demonstration of the tool and the second one playing back the recording of the first demonstration. Both meetings were attended by 5 people (Workshop 1: 3 patients and 2 carers; Workshop 2: 4 carers and 1 patient).

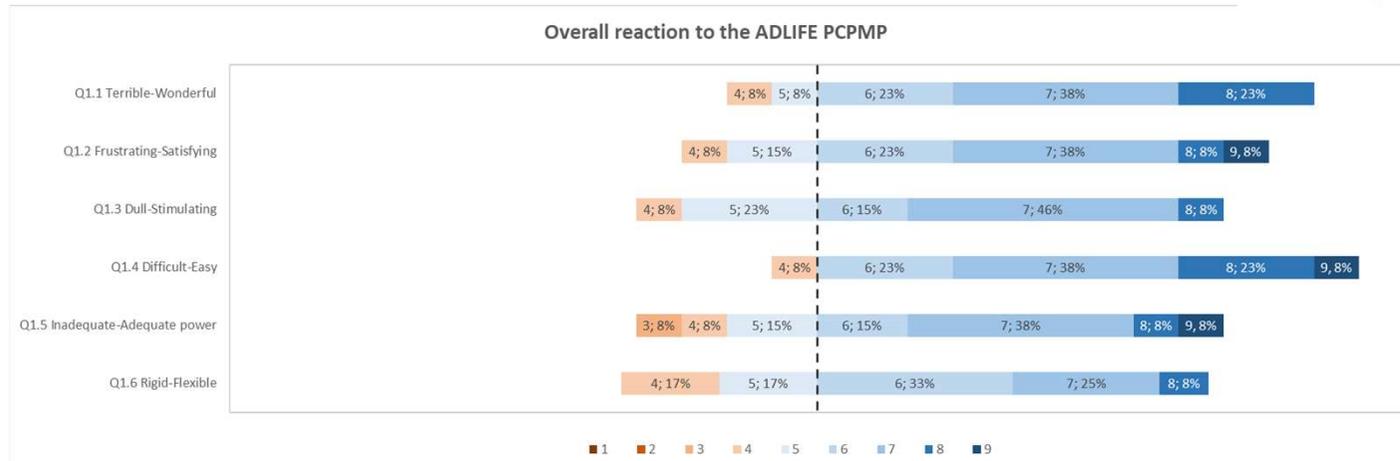




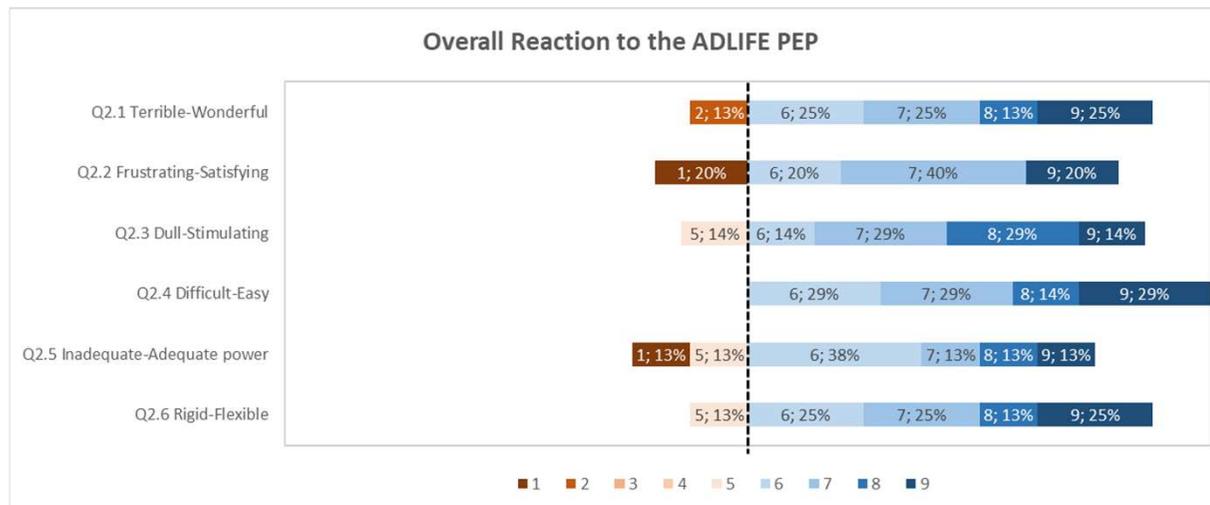
# User acceptance tests results



- The average score for the category is 6.40
- 92% of respondents found the PCPMP relatively easy to use



- The mean score for the category “Overall reaction” is 6.77
- Most respondents had a positive reaction to the ADLIFE PEP, with all respondents finding it easy to use





# User acceptance tests results

- ❖ Tools have been updated based on the feedback:
  - ❖ User guides have been updated
  - ❖ Medications are now enabled to be added by patients via PEP
  - ❖ PEP dashboard has been updated to collect daily patient feedback easily
  - ❖ It is now possible to disable forum and messaging from PEP
  - ❖ The process for adding images/pictures in PEP has been optimized
  - ❖ PCPMP: Physicians can navigate care plan parts as they wish independent of the wizard interface
  - ❖ PCPMP: Physicians can now see all the steps of care planning wizard as breadcrumbs
  - ❖ PCPMP: Patient List view has been updated
  - ❖ PCPMP: Goal view has been updated
- ❖ We will carry out Usability studies during and after pilot operation via QUIS questionnaires





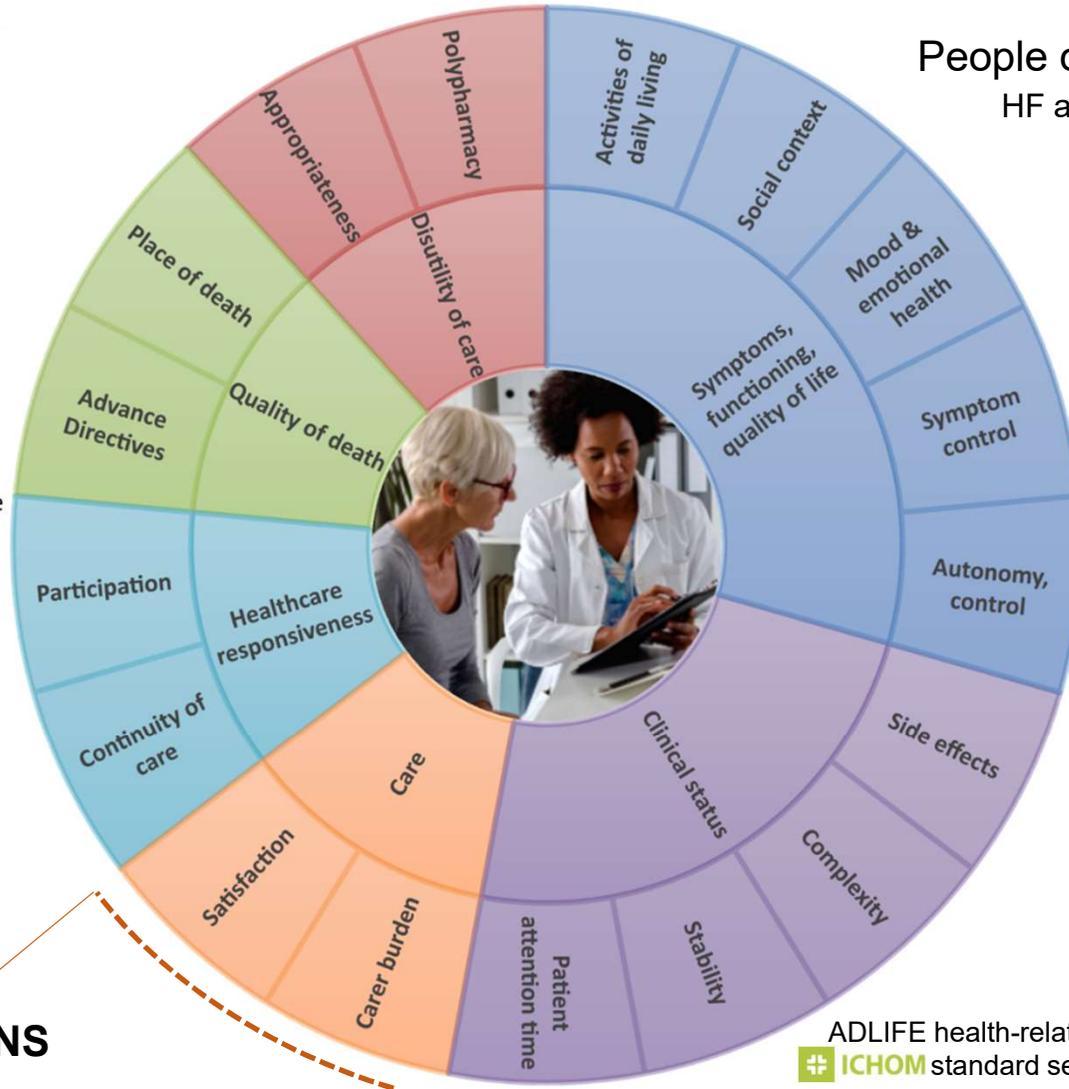
**ADLIFE**

# Health outcome framework

People over 55 with severe chronic disease  
HF and/or COPD with or without comorbidities

## AREAS

- Symptoms, functioning, quality of life
- Disutility of care
- Quality of death
- Clinical status
- Healthcare responsiveness
- Care



## DIMENSIONS

ADLIFE health-related outcomes based on and extended from  
# ICHOM standard sets (for Heart Failure and Older People)

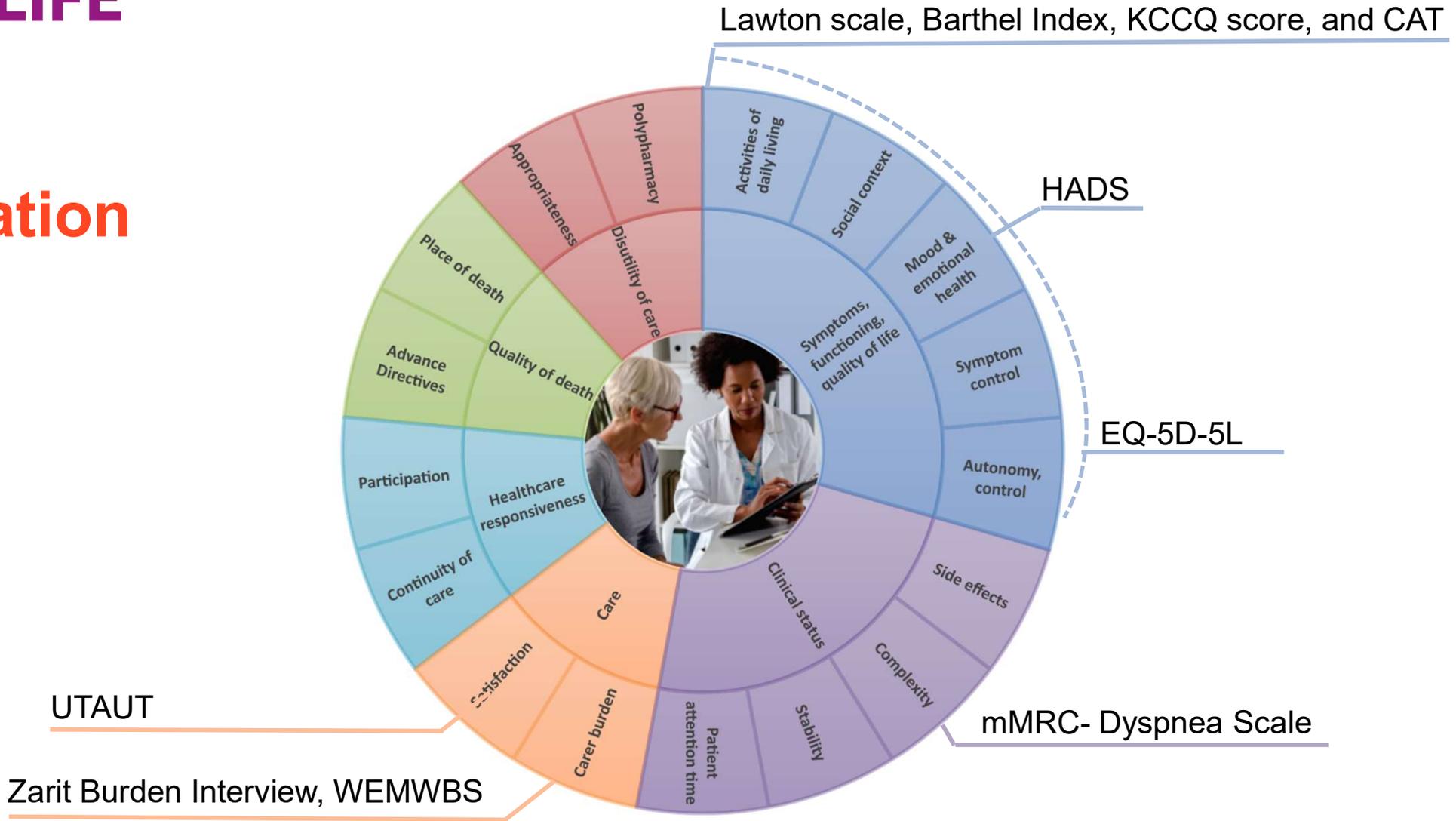


## PROMs in ADLIFE

- Questionnaires very commonly used for the collation of health data, particularly Patient Reported Outcome Measures (PROMS), tools completed directly by the subject or a proxy.
- Essential to consider how these tools can be transferred across languages and cultural settings.
- To enable researchers to achieve cultural diversity and reduce biases in their target populations, take part in international projects, and utilize tools that are adapted to different languages and cultures so their results can be compared across countries.
- In ADLIFE, PROMs will be employed to collect some of the main outcomes.



# Pilot evaluation



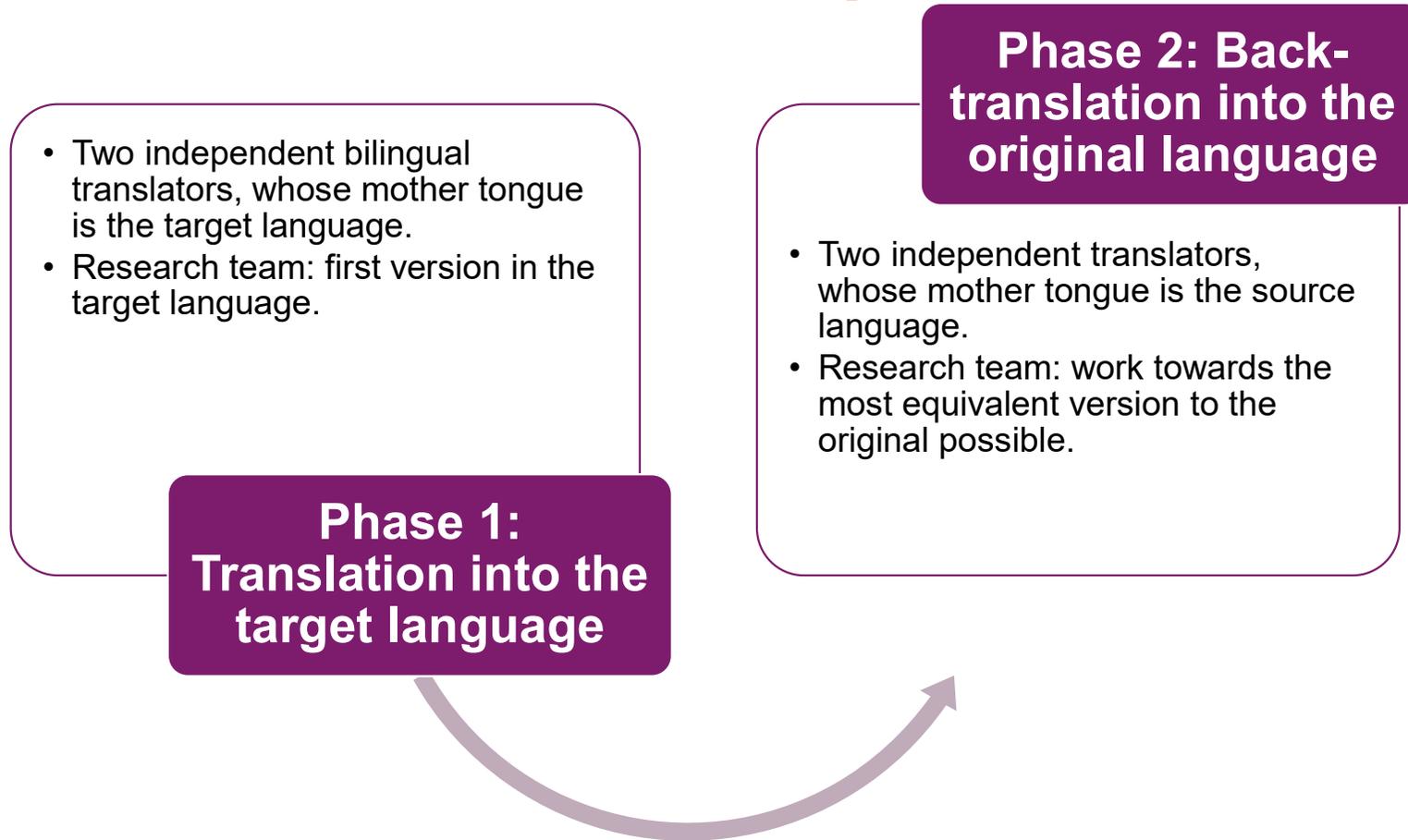


# ADLIFE's recommendation for translation and cultural adaptation

- Two independent bilingual translators, whose mother tongue is the target language.
- Research team: first version in the target language.

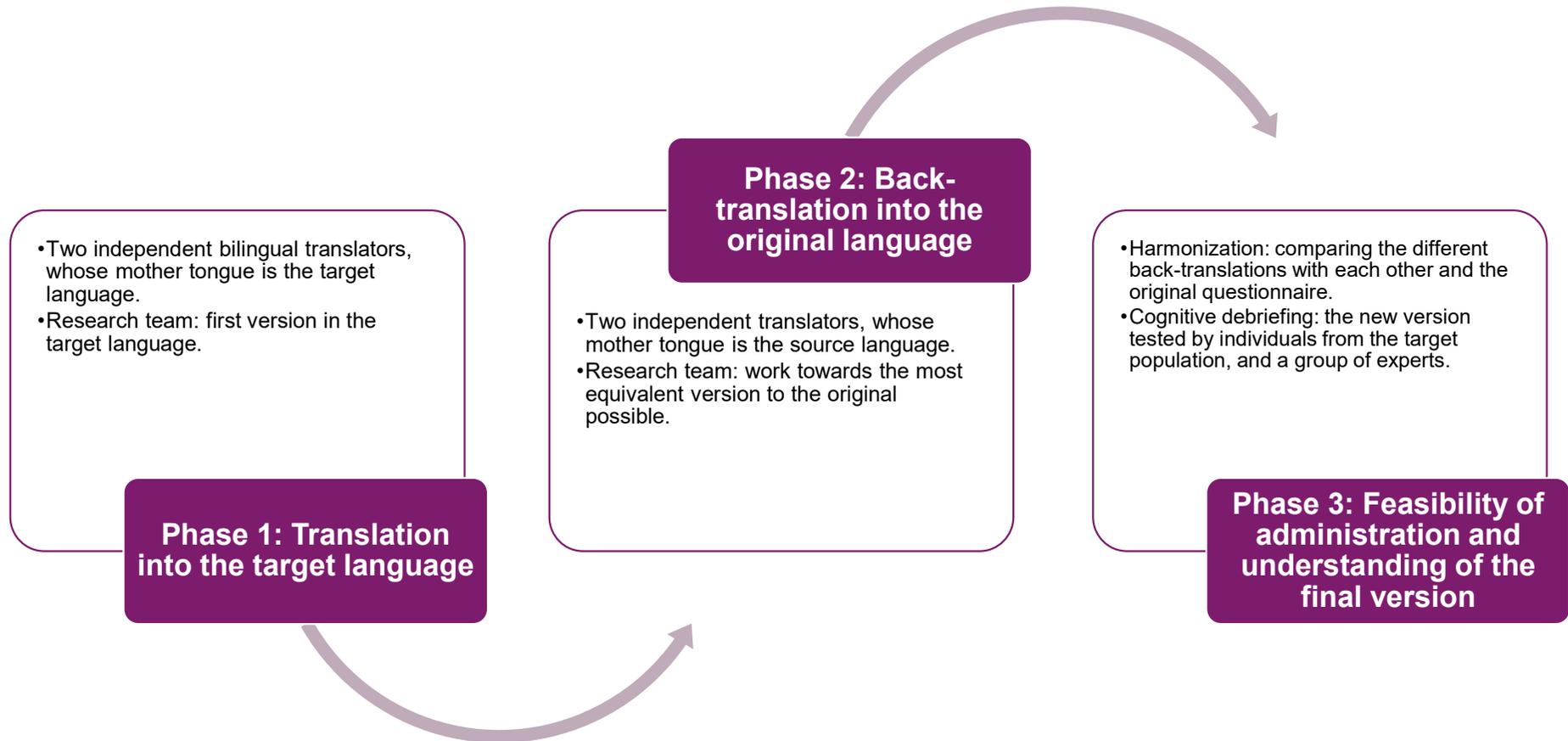
**Phase 1:  
Translation into the  
target language**

# ADLIFE's recommendation for translation and cultural adaptation





# ADLIFE's recommendation for translation and cultural adaptation



## Key step

**Cognitive debriefing**: to check if the translated text is perfectly understandable for the future users, the elderly in the case of ADLIFE.

### Questions:

#### Instructions:

- Were the instructions clear and easy to understand? If not, what should be changed?

#### Items:

- Did you experience any difficulties in answering this question? If yes, what was the difficulty?
- What do you think the question means? Explain it in your own words.
- Would you rephrase the question? If so, how?
- Is it an important question for your situation? Why?

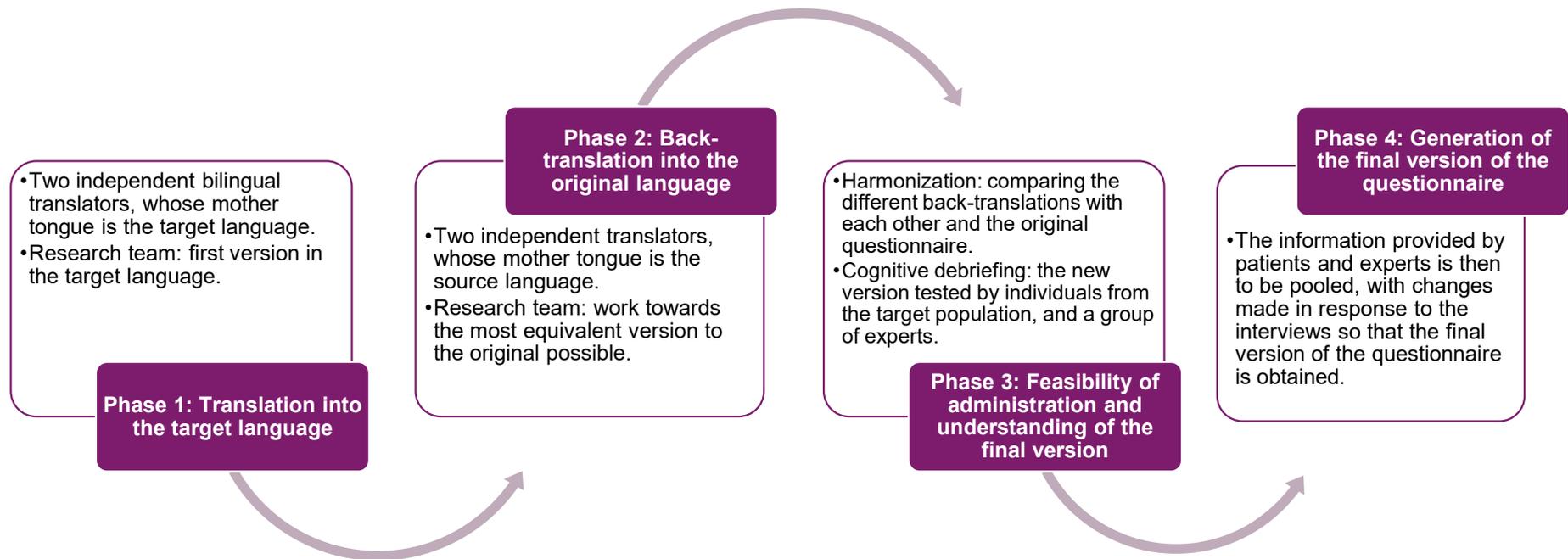
#### Response options:

- Did you find it difficult to understand the response options?
- What do you think each response option means? Please explain in your own words.

Items and/or response scales that are identified as problematic should be discussed by the research team. And the final version should be sent to the authors of the original version of the questionnaire.



# ADLIFE's recommendation for translation and cultural adaptation





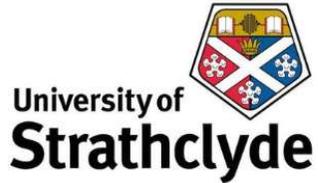
## References:

1. Hall, D. A., Zaragoza Domingo, S., Hamdache, L. Z., Manchaiah, V., Thammaiah, S., Evans, C., et al., (2018). A good practice guide for translating and adapting hearing-related questionnaires for different languages and cultures. *International journal of audiology*, 57(3), 161–175. <https://doi.org/10.1080/14992027.2017.1393565>
2. Beaton DE, Bombardier C, Guillemin F, Bosi-Ferraz M (2000). Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine* 25: 3186-91.
3. Guillemin F, Bombardier C, Beaton D (1993). Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. *Journal of Clinical Epidemiology* 46: 1417-32.
4. Acquadro C, Conway K, Hareendran A, Aaronson N, European Regulatory Issues and Quality of Life Assessment (ERIQA) Group. Literature review of methods to translate health-related quality of life questionnaires for use in multinational clinical trials. *Value Health*. May-Jun 2008;11(3):509-21. doi: 10.1111/j.1524-4733.2007.00292.x.

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**NTT DATA**



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