

Supplementary File 1. Semi-structured Interview Guide

Study Title: Patient and Caregiver Experience with Long-Term Home Non-Invasive Ventilation in Kazakhstan: A Qualitative Study

Target Population: Patients receiving home Non-Invasive Ventilation (NIV) and their caregivers.

Introduction & Consent

- Introduction of the interviewer and study objectives (assessment of satisfaction and quality of life).
- Explanation of confidentiality measures (anonymization, data storage for 5 years, restricted access).
- Confirmation of voluntary participation and the right to withdraw at any time.
- Obtaining verbal informed consent.

Part 1: The Patient's Journey to Treatment

1. Initial Information

- Could you please tell me where you first learned, or who first told you, about the possibility of treatment using an NIV device?
- *Prompt: What had you heard about this type of treatment previously?*

2. Decision Making

- Who made the decision regarding your treatment? Was anyone close to you involved in this?
- *Prompts: Yourself, your relatives, your doctor.*

Part 2: Adaptation and Experience

3. Expectations

- What expectations did you have from this treatment?
- *Prompts: Reducing shortness of breath, reducing medication, ability to leave the house.*

4. Fears and Doubts

- Did you have the opportunity to talk about your doubts and fears? What specific fears did you have?

- *Prompts: Fear of the mask, fear of dependence on the machine, fear of falling asleep with the device.*

5. Implementation and Support

- When you started using the NIV device, was anyone close to you present? Is anyone helping you currently?
- *Prompts: Help with turning on the device, fitting the mask.*

6. Speed of Adaptation

- How quickly were you able to adapt to using the NIV device?
- *Prompts: Immediately, a few hours, a few days, a few weeks.*

Part 3: Outcomes and Quality of Life

7. Evaluation of Expectations

- Do you believe the use of the NIV device has met your expectations?
- *Prompts: Improvement in well-being, physical activity, mood; reduction in dyspnea or cough.*

8. Changes in Daily Life

- Has your daily life changed since starting NIV therapy?
- *Prompts: Fear of leaving home without the device vs. becoming more active/social.*

Part 4: Interaction with the Healthcare System

9. Medical Support

- Do you feel supported by medical professionals regarding the selection and use of NIV?
- *Prompt: Which medical staff in your region can you contact regarding NIV issues?*

10. Availability in the Region

- In your opinion, is NIV treatment accessible in your region?
- *Prompts: Awareness among local specialists, ability to adjust the device locally, availability of rental options.*

11. Patient-Centeredness

- Do you feel that medical professionals are interested in your recovery and understand your needs?
- *Prompt: Does the doctor dedicate enough time? Can you contact them additionally?*

12. Adherence

- Do you use the NIV device exactly as prescribed/discussed with the doctor, or do you rely on your own sensations?

13. Telemedicine

- Are you satisfied with the remote consultations (audio/video calls) provided by the specialized center?

Part 5: Quantitative Assessment

14. EQ-5D-3L Questionnaire

- The participant is asked to select the statement that best describes their health state today across 5 dimensions: Mobility, Self-Care, Usual Activities, Pain/Discomfort, Anxiety/Depression.
- Visual Analog Scale (VAS): Rating health from 0 (worst) to 100 (best).

Closing

- Open-ended question: "Is there anything else you would like to share?"
- Debriefing: Explanation of the study's goal (to help other patients and inform doctors).
- Thanks and closing remarks.