Personalised Care of Patients with Heart Failure – International Survey on Patients' Needs and Perceptions

Thank you for participating in this survey about heart failure (a chronic, progressive condition in which the heart muscle is unable to pump enough blood to meet the body's needs for blood and oxygen).

Your input is highly appreciated. It should take you between 10-15 minutes to complete this questionnaire.

Information on the respondent

- Age range $[25-34/35-44/45-54/55-64/65-74/ \ge 75 \text{ years}]$
- Birth sex [female / male / I prefer not to answer]
- Country of residence
- Place of life [Multiple choice question, one answer possible]
 - o I live in a rural area
 - o I live in a town that has less than 1,000 inhabitants
 - o I live in a town that has between 1,000 and 50,000 inhabitants
 - o I live in a city that has between 50,000 and 1,000,000 inhabitants
 - o I live in a city that has more than 1,000,000 inhabitants
- Highest level of schooling completed [Multiple choice question, one answer possible]
 - o Primary education (typically up to 11 years of age)
 - Secondary education (typically up to 18 years of age)
 - Post-secondary education (typically over 18 years of age)
- How long have you been diagnosed with heart failure [Less than 1 year / 1–5 years / 6–10 years / 11–15 years / 16–20 years / ≥20 years]
- Do you have any other chronic diseases?
 [Please select all that apply]
 - I have high blood pressure
 - I have blood vessel disease
 - I have heart rhythm disturbances
 - o I have heart valve disease
 - o I have kidney disease
 - I have lung disease
 - I have diabetes (high blood sugar levels)
 - Other; please specify: _____

Survey questions

Question 1. How important are the following objectives for you as a patient?

[Please allocate a total of 100 points across the proposed answers]

- 1. Prolong my life as much as possible
- 2. Be able to live a normal life
- 3. Live independently for as long as possible
- 4. Reduce the number of hospitalizations
- 5. Reduce my symptoms
- 6. Allow me to have more physical activity
- 7. Improve my overall quality of life

Question 2. How would you evaluate the impact of the following symptoms on your quality of life?

[Please rank the most important symptoms from 1 to 5]

- 1. Shortness of breath when you exert yourself or when you lie down
- 2. Fatigue
- 3. Reduced ability to exercise
- 4. Dizziness
- 5. Swelling in your legs, ankles, feet
- 6. Swelling of your abdomen
- 7. Rapid weight gain from fluid retention
- 8. Persistent cough or wheezing
- 9. Rapid or irregular heartbeat
- 10. Increased need to urinate at night
- 11. Nausea
- 12. Lack of appetite

Question 3. How many pills do you take in a single day? (Please include only prescribed pills)

[Drop-down menu from 1 to 25, plus "Unsure" option]

Question 4. Of the total number of pills you reported taking in a day, how many are you taking for your heart?

[Drop-down menu from 1 to 25, plus "Unsure" option]

Question 5. How many different times per day do you take medications?

[Drop-down menu from 1 to 5, plus "Unsure" option]

Question 6. Which of the following apply to you?

[Please select all that apply]

- 1. I have no difficulties taking my medications as prescribed
- 2. Sometimes I forget to take my medications
- 3. Sometimes I don't take my medications because I can't afford to buy them
- 4. Sometimes I don't take my medications because I don't like the way they make me feel
- 5. Sometimes I take the initiative to reduce the doses of the medications I am taking
- 6. I don't take some of my prescribed medications because they don't make me feel better
- 7. I feel I have to take too many pills

Question 7. The following questions ask about your interaction with healthcare professionals

- 1. How many times did you see your cardiologist in the last 12 months? [Free text]
- How many times did you see a non-cardiologist specialist physician in the last 12 months?[Free text]
- 3. How many times did you see a heart failure nurse in the last 12 months? [Free text]
- 4. How many times did you see your general practitioner/family physician in the last 12 months? [Free text]
- 5. How many urgent care visits did you require in the last 12 months? [Free text]
- 6. What proportion of the consultations were remote/telemedicine consultations (by phone, video, etc.)? [0–20%, >20–40%, >40–60%, >60–80%, >80–100%]

Question 8. The following questions ask about your satisfaction with follow-up appointments for heart failure

- 1. I am satisfied with current arrangements for follow-up appointments [Strongly agree > Agree > Neutral > Disagree > Strongly disagree]
- 2. I would like to have more frequent appointments with a cardiologist [Strongly agree > Agree > Neutral > Disagree > Strongly disagree]
- 3. I would like to have more frequent appointments with a specialized heart failure nurse [Strongly agree > Agree > Neutral > Disagree > Strongly disagree]
- 4. I would like to have more opportunities to discuss my symptoms and my treatments [Strongly agree > Agree > Neutral > Disagree > Strongly disagree]

Question 9. How important for you are the following aspects of your relationship with health care professionals?

- 1. They provide me with general information about heart failure and its management [Very important > Moderately important > Neither important nor unimportant > Moderately unimportant > Very unimportant]
- 2. They advise me about diet, lifestyle and medication adherence [Very important > Moderately important > Neither important nor unimportant > Moderately unimportant > Very unimportant]
- 3. They take the time to explain test results, treatment decisions and reasons for changes [Very important > Moderately important > Neither important nor unimportant > Moderately unimportant > Very unimportant]
- 4. They listen to what I tell them about my symptoms and how they affect me [Very important > Moderately important > Neither important nor unimportant > Moderately unimportant > Very unimportant]
- 5. They involve me in treatment decisions [Very important > Moderately important > Neither important nor unimportant > Moderately unimportant > Very unimportant]

Question 10. The following questions ask about your satisfaction with the information you receive about heart failure and its management

- I have a clear understanding of heart failure and its consequences [Strongly agree > Agree > Neutral > Disagree > Strongly disagree]
- 2. I would like to receive more information about the disease and its consequences [Strongly agree > Agree > Neutral > Disagree > Strongly disagree]
- 3. I would you like to receive more information about my prognosis [Strongly agree > Agree > Neutral > Disagree > Strongly disagree]
- 4. I would you like to receive more information about heart failure treatments [Strongly agree > Agree > Neutral > Disagree > Strongly disagree]

Question 11. How do you prefer to obtain information about heart failure and its management?

[Please rank your 5 preferred sources of information from 1 to 5]

- 1. From my cardiologist
- 2. From a heart failure nurse
- 3. From my general practitioner
- 4. From a patient group/association
- 5. From printed documents (books, articles, leaflets)
- 6. From my own research on the Internet
- 7. From mobile health applications