

## Supplementary File 1

### **Project: Choices and Challenges in End-of-Life Care and Decision-Making: A Nationwide Cross-Sectional Study of Critically Ill Older Adults in Bangladesh**

#### **Questionnaire for Low and Middle Income Countries**

##### **Section 1: Patient Information**

1. **Name and Address of the Hospital/Institution/Old Age Home:**
  
2. **Unit/Ward Name/Outpatient:**
  
3. **District Name of Residence:**

##### **Section 2: Demographics**

1. **Age**
  - 0–9 years (*Data collected from legal guardian*)
  - 10–19 years (*Data collected from legal guardian*)
  - 20–29 years
  - 30–39 years
  - 40–49 years
  - 50–59 years
  - 60–69 years
  - 70–79 years
  - 80+ years
2. **Gender**
  - Male
  - Female
  - Other
3. **Education Level**
  - No formal education
  - Primary
  - Secondary
  - Higher secondary

- Bachelor's
- Master's
- PhD
- 4. **Marital Status**
  - Single
  - Married
  - Widowed
  - Divorced
- 5. **Occupation**
  - Employed
  - Self-employed
  - Retired
  - Unemployed
- 6. **Living Situation**
  - Alone
  - With family
  - In hospice
  - In hospital
- 7. **Monthly Household Income**
  - < 10,000 BDT
  - 10,000-30,000 BDT
  - 30,001-50,000 BDT
  - > 50,000 BDT
- 8. **Area of Residence**
  - Urban
  - Rural
  - Semi-Urban
- 9. **Do you have children? If yes, how many?**
  - No children
  - 1
  - 2
  - 3
  - 4 or more
- 10. **What is your religious affiliation?**
  - Islam
  - Christianity
  - Hinduism
  - Buddhism
  - Other
- 11. **How often do you participate in religious activities?**

- Daily
- Weekly
- Monthly
- Rarely
- Never

### **Section 3: Health Information**

#### **1. Cause of Admission (Diseases)***(Select all that apply)*

- Stroke
- Heart Disease / Heart Failure
- Cancer
- COPD / Other Respiratory Diseases
- Diabetes
- Hypertension
- Liver Disease / End-Stage Liver Disease
- Kidney Disease / End-Stage Renal Disease
- Musculoskeletal Diseases
- Dementia / Depressive Disorders / Other Psychological Disorders
- Post-Operative Complications
- Other: \_\_\_\_\_

#### **2. Do you have health insurance?**

- Yes
- No

#### **3. Frequency of Visits to a Healthcare Facility**

- Now admitted
- Daily
- Weekly
- Monthly
- Rarely
- Never

#### **4. Do you have access to a caregiver?**

- Yes
- No

#### **5. What is your primary mode of transportation?**

- Walking

- Private vehicle
- Public transport
- Other

#### **Section 4: Awareness and Understanding of EOL Care**

1. **Are you aware of end-of-life (EOL) care options?** (End-of-life (EOL) care is the medical care and support given to people who are near the end of their life. EOL care can include: Physical comfort, Mental and emotional needs, Spiritual needs, Helping with daily living tasks, Family support.)
  - Yes
  - No
2. **If yes, what sources have informed your awareness?**
  - Healthcare providers
  - Family/Friends
  - Media
  - Internet
  - Other
3. **Do you understand the concept of palliative care?** (A medical care option that focuses on relieving symptoms and improving quality of life for people with serious illnesses. It can also include psychological and social support.)
  - Yes
  - No
4. **Have you discussed EOL care preferences with anyone?**
  - Yes
  - No
5. **If yes, with whom?**
  - Family
  - Friends
  - Healthcare providers
  - Other
6. **Are you aware of advance care planning?**
  - Yes
  - No
7. **Do you know what a DNR (Do Not Resuscitate) order is?**
  - Yes
  - No
8. **Have you ever heard of a living will?**
  - Yes
  - No
9. **Do you know what hospice care entails?** (A multidisciplinary approach that provides medical care, pain and symptom management, and psychological, spiritual, and practical support for patients and their families. Hospice care is typically provided during the final week before death.)
  - Yes

- No
- 10. **How would you rate your knowledge about EOL care?**
  - Very poor
  - Poor
  - Average
  - Good
  - Very good

## Section 5: Preferences for EOL Care

1. **Have you thought about your preferences for EOL care?**
  - Yes
  - No
2. **Preferred Location for Care at End of Life**
  - Home
  - Hospital
  - Hospice
  - Other
3. **What are your primary concerns regarding EOL care?**
  - Pain management
  - Emotional support
  - Financial burden
  - Family burden
  - Other
4. **What is your preferred place of death?**
  - Home
  - Hospital
  - Hospice
  - Other
5. **Would you prefer aggressive treatments or comfort care at the end of life?**
  - Aggressive treatments
  - Comfort care
6. **Do you wish to remain at home as long as possible?**
  - Yes
  - No
7. **How important is it to have family around at the end of life?**
  - Very important
  - Somewhat important
  - Not important
8. **Would you want to know if your condition is terminal?**
  - Yes
  - No
9. **Do you prefer to have all available treatments even if the benefits are uncertain?**
  - Yes
  - No
10. **How important is spiritual care at the end of life?** (Spiritual care is a type of counseling that addresses a person's spiritual and religious needs. It can help people cope with illness, trauma, loss, and other life

transitions. Spiritual care can also help people heal emotionally and physically, rebuild relationships, and regain a sense of spiritual wellbeing.)

- Very important
  - Somewhat important
  - Not important
11. **Do you want specific rituals performed before your death?**
- Yes
  - No
12. **Are you comfortable with the idea of hospice care?**
- Yes
  - No
13. **Would you like to avoid hospitalization if possible?**
- Yes
  - No
14. **How important is it for you to die with dignity?**
- Very important
  - Somewhat important
  - Not important
15. **Have you discussed organ donation?**
- Yes
  - No
16. **Would you prefer family involvement in EOL care decisions?**
- Yes
  - No
17. **Do you want to receive CPR if your heart stops?**
- Yes
  - No
18. **Are you open to receiving mechanical ventilation?**
- Yes
  - No
19. **Would you prefer to receive artificial nutrition and hydration?**
- Yes
  - No
20. **How involved would you like family to be in your care decisions?**
- Fully involved
  - Somewhat involved
  - Minimally involved
  - Not involved

## **Section 6: Preferences and Wishes at the End of Life**

1. **Have you documented your EOL care wishes?**
- Yes
  - No
2. **Do you wish to be kept informed about your medical condition at the end of life?**
- Yes
  - No
3. **What is your most important wish at the end of life?**
- Pain-free
  - Being with family

- Religious/spiritual support
  - Other
4. **Do you have any specific rituals you want performed?**
    - Yes
    - No
  5. **How important is it for you to have a say in your EOL care?**
    - Very important
    - Somewhat important
    - Not important
  6. **Are you comfortable with the idea of hospice care?**
    - Yes
    - No
  7. **Do you wish to avoid hospitalization at the end of life?**
    - Yes
    - No
  8. **Have you discussed your EOL preferences with a spiritual advisor?**
    - Yes
    - No
  9. **How do you want to be remembered by your loved ones?**
    - With love
    - With respect
    - With guilty feeling
    - With disgrace feeling
    - With dignity
  10. **Given your health condition, do you believe that euthanasia should be legal in this country?**  
(Euthanasia is the practice of ending the life of a patient to limit the patient's suffering. The patient in question would typically be terminally ill or experiencing great pain and suffering.)
    - Yes
    - No
  11. **Given your health condition, do you believe that physician assisted suicide should be legal in this country?** (Physician aid-in-dying, or physician assisted suicide refers to a physician providing a patient who requests aid-in-dying a prescription of lethal drugs or providing information about a lethal dose of sedatives that the patient can self-administer to end his or her life.)
    - Yes
    - No

## **Section 7: Stakeholders in EOL Decisions**

1. **Who do you believe should be involved in EOL decisions?**
  - Patient
  - Family
  - Healthcare providers
  - Legal representatives
  - Other
2. **Do you feel your family is supportive of your EOL preferences?**
  - Yes
  - No

3. **Have you appointed a healthcare proxy or power of attorney?** (A health care proxy appoints someone to make health care decisions on your behalf if you are unable to do so. A power of attorney appoints someone to handle your financial matters and make decisions on your behalf if you are unable to do so.)
  - Yes
  - No
4. **Do you trust your family to make decisions on your behalf?**
  - Yes
  - No
5. **Have you discussed your EOL preferences with your healthcare provider?**
  - Yes
  - No
6. **Do you think your healthcare provider understands your EOL wishes?**
  - Yes
  - No
7. **How often do you communicate with your healthcare provider about your condition?**
  - Never
  - Rarely
  - Sometimes
  - Often
  - Always
8. **Who do you trust the most to make healthcare decisions on your behalf?**
  - Spouse
  - Children
  - Parent
  - Healthcare provider
  - Other

### **Section 8: Family Dynamics and Support**

1. **Do you feel supported by your family in making EOL decisions?**
  - Yes
  - No
2. **Is there any family conflict regarding EOL decisions?**
  - Yes
  - No
3. **How dependent are you on your family for daily activities?**
  - Not at all
  - Somewhat
  - Very dependent
4. **Are family members willing to discuss EOL care openly?**
  - Yes
  - No
5. **How often do family members visit or care for you?**
  - Never
  - Rarely
  - Sometimes
  - Often
  - Always
6. **Do you feel isolated from your family?**

- Yes
  - No
7. **Do family dynamics influence your EOL care decisions?**
- Yes
  - No
8. **Are there specific family traditions that affect your EOL care choices?**
- Yes
  - No
9. **How involved are family members in your day-to-day care?**
- Not at all
  - Somewhat
  - Very involved
10. **Do you feel that family members understand your EOL wishes?**
- Yes
  - No

### **Section 9: Cultural and Ethical Considerations**

1. **Do cultural beliefs influence your EOL care preferences?**
- Yes
  - No
2. **Do you believe discussing death openly is appropriate?**
- Yes
  - No
3. **Do you feel there are ethical dilemmas in making EOL decisions?**
- Yes
  - No
4. **Are there cultural rituals or practices important to you at the end of life?**
- Yes
  - No
5. **How does your religion influence your EOL care preferences?**
- Significantly
  - Moderately
  - Slightly
  - Not at all
6. **Do you feel societal pressure regarding your EOL decisions?**
- Yes
  - No
7. **Does your religion specify certain EOL practices?**
- Yes
  - No
8. **Are you open to discussing EOL preferences with a spiritual advisor?** (A spiritual advisor is someone who helps people live a more religious life and provides guidance on their thoughts and beliefs. Such as- Psychotherapists, Spiritual counselors, Friends, Religious Speaker.)
- Yes
  - No
9. **Do cultural norms influence family involvement in your care?**
- Yes
  - No
10. **Do you feel discussing EOL care goes against cultural norms?**
- Yes
  - No
11. **Would you consider non-traditional therapies in EOL care?**
- Yes
  - No

## **Section 10: Socio-Economic and Financial Factors Affecting End-of-Life (EOL) Decisions**

1. **Do you feel that your socio-economic status influences your end-of-life care options?**
  - Yes
  - No
2. **Are financial concerns a major factor in your end-of-life decision-making process?**
  - Yes
  - No
3. **Do you believe you have sufficient financial resources to cover end-of-life care needs?**
  - Yes
  - No
4. **Have financial constraints affected your choice of end-of-life care?**
  - Significantly
  - Moderately
  - Slightly
  - Not at all
5. **Have you ever delayed seeking end-of-life care due to financial challenges?**
  - Yes
  - No
6. **Are family members contributing financially to your end-of-life care?**
  - Yes
  - No
7. **Do you have access to financial support, including community or government assistance, for end-of-life care?**
  - Yes
  - No
8. **Are you aware of financial assistance programs or community resources that can help with end-of-life care costs?**
  - Yes
  - No
9. **Have you considered fundraising or charity support to manage end-of-life care expenses?**
  - Yes
  - No
10. **Do you have health insurance that covers end-of-life care?**
  - Yes
  - No
11. **Are you currently receiving any government assistance for your healthcare needs?**
  - Yes
  - No
12. **Have you experienced any discrimination in healthcare settings due to your economic status?**
  - Yes
  - No
13. **Are there financial planning services available to help manage end-of-life care expenses?**
  - Yes
  - No

## **Section 11: Healthcare Provider Training, Support, and Involvement in End-of-Life (EOL) Care**

1. **Do healthcare providers openly discuss end-of-life care options with you?**
  - Yes
  - No
2. **Do you feel healthcare providers respect your cultural beliefs in EOL care decisions?**
  - Yes

- No
- 3. **Are healthcare providers sensitive to your emotional needs during EOL discussions?**
  - Yes
  - No
- 4. **How often do healthcare providers communicate EOL care options with patients?**
  - Never
  - Rarely
  - Sometimes
  - Often
  - Always
- 5. **How confident are you in healthcare providers' ability to manage EOL care?**
  - Very confident
  - Confident
  - Neutral
  - Not confident
  - Not at all confident
- 6. **Do healthcare providers clearly explain EOL care procedures and options?**
  - Yes
  - No
- 7. **Are your personal wishes documented and respected by healthcare providers?**
  - Yes
  - No
- 8. **Do you believe healthcare providers are adequately trained in EOL care?**
  - Yes
  - No
- 9. **What additional support do you think healthcare providers need to enhance EOL care?**
  - Training
  - Resources
  - Emotional support
  - Other
- 10. **Would you like to see more palliative care specialists involved in EOL services?**
  - Yes
  - No
- 11. **Do you think there is a need for additional EOL care training programs in your area?**
  - Yes
  - No
- 12. **Have you received sufficient information about EOL care options from your healthcare team?**
  - Yes
  - No
- 13. **Do you trust your healthcare team to respect your preferences in EOL decisions?**
  - Yes
  - No
- 14. **Are there challenges you've faced in receiving adequate support from healthcare staff for EOL care?**
  - Yes
  - No
- 15. **How often do healthcare providers update you on your EOL care plan and any changes?**
  - Regularly
  - Occasionally
  - Rarely

## **Section 12: Information of Data Collector/Accessor**

### **1. Name**

### **2. Degree**

- MBBS (Completed or ongoing)
- BPH (Completed or ongoing)
- BSc/BA/Bachelor (Completed or ongoing)
- MPH (Completed or ongoing)
- MSc/Masters (Completed or ongoing)
- FCPS Part-1/MRCP Part-1/MD Part-A or equivalent
- FCPS/MRCP/MD/MS (Completed) or equivalent
- PhD (Completed or ongoing)
- Other: \_\_\_\_\_

### **3. Affiliation/Working Place with Position**

### **4. Mobile Number and/or Email Address**