



**School of Nursing**

**Title: End of Life care perspectives of older South Asians**  
**Focus Group Aide Memoire**

**Step1 Introduction**

1. Welcome

*“Good Morning everyone. I would like to thank you all for coming for this discussion. My name is..... I am carrying out a research project into end of life perspectives of older South Asians. We feel that by talking to people like you we can best find out opinions and experiences about these issues..Please feel free to talk about anything related to topic there are no right or wrong answers.....”*

2. Inform about house keeping, audio recording and need for group dynamics (need to give the opportunity to everyone in the group to talk)

3. Reassure regarding confidentiality and support measures and level of consent they are free to withdraw at anytime without giving a reason.

**Step 2: Ice Breaking Session**

1. Introductions

(Start from the moderator/researcher)

2. Request them to share their views about participation and purpose

*Would you please introduce yourself to the group with your preferred name (opportunity to pseudomise their names to co participants) and briefly tell us about why you interested to participate this discussion?*

### **Step 3: Focus on topic area**

#### **1. Experiences and thoughts about end of life care**

1. Can someone contribute a story about a person you know of or have heard about who became ill and died in your local community?
2. What does “good end of life care” mean for any South Asian people who may die in East London?
  - a. What things are most important in the last period of life for older South Asian people?
  - b. What are the things that might make a smooth end of life journey for older people in the South Asian community?
3. Where is the best place for older people in your community to be cared for at their end of life?
  - a) What is opinion about caring the people in home/ at their end of life?
  - b) What kinds of support are necessary if a person wishes to be cared for at home?

#### **2. Communicating about end of life care**

1. How do you feel about discussing end of life topics in your community?
2. Have you ever talk about end of life?
  - a. With whom did you discuss this?
  - b. Is there any thing that helps/stops you talking about these topics?

#### **3. Advanced care planning**

- 1) Have you ever heard of the idea of planning how one would wish to be cared for towards one’s own end of life?
- 2) Do any of you have a plan about your end of life?
- 3) If no, to whom you may feel comfortable to discuss about such planning
- 4) Would you like to be able to make plans?
- 5) If not, who do you think should be involved such planning?

#### **4. Using local end of life care services**

- 1) Would you tell me what kind of services that people who need end of life care get in your local community?
- 2) Have you heard about Hospice and Palliative care services?

(Before proceeding to next question, researcher will explain about Hospice and palliative care services to the participants)

- 3) What things would make hospice and palliative care services acceptable to older South Asian people?

## 5. Information about end of life and care towards the end of life

- 1) Have you feel that you have adequately informed about end of life and care towards the end of life
- 2) If not what kind of things do you like to be know end of life and care towards the end of life
- 3) What is the best way to inform about such information to reach effectively to your community peoples?
  - Types of information
  - Method of informing

## Step 4: Closing

- a) The Moderator/researcher debriefs and thanks the group.

*“We are reaching the end of the discussion. Does any one have anything to add before we conclude the session? Just before you go... Please fill in this form that contains your details. As I informed you your information will be kept highly confidential. Thanks for your contribution. Please feel free to have some refreshments....”*

- b) Inform about follow-up support strategies such as bereavement support, service information about St. Joseph’s Hospice.
- c) Participants will be given some refreshments. During this time, the researcher will aim to obtain any feedback about participating in the focus group and their comfort in taking part.