

End of Life care perspectives of older South Asians

Provisional Topic guide for further Interviews and focus groups

Step1 Introduction

1. Self introduction

“Good Morning Mr or Mrs..xxxx. I would like to thank you for coming for this important 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...As you aware that I was conducting this project from last May-2008. At present I am continuing my interviews particularly to understand some more issues around the topics in-depth. Please feel free to talk about anything related to topic there are no right or wrong answers.....”

2. Inform about House keeping, audio recording

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

Step 2: Focus on Topic Area

1. Providing end of life care at Home

- a) What are the issues in caring at Home?
- b) What are the experiences around when they will be cared at Home and when not been cared?
- c) How and who will take Decisions around providing end of life care at Home?

- d) Why caring end of life person as per his Ideal place of die at home is not possible?
- e) What makes them to die even cared by home at last stage for example Muslims to get certificates of death

2. Caring person at end of life care

- a) What are the support needs of the individual and family during care of person with end of life?
- b) What is the knowledge about and use of service providers for caring person with end of life care?
- c) How the family supports each others while caring end of life?
- d) What are views/experiences around providing end of life care at Hospital?

3. Gender in end of life care

- a) How end of life preferences differ with women vs men
- b) What and how women's role in end of life decision making for herself and for husband
- c) Experience of caring older south Asian women and men at their end of life
- d) What are the views of Men about end of life care of women?

4. end of life discussions and decision making: God's plan?

- a) If yes how and when the How and when can be these topics initiated?
- b) What helps and what stops them to involve in this discussions
- c) Could you like to share any experiences of involving such discussions while caring the people who faced end of life?

Step 3: Closing

- a) Researcher debriefs and thanks for their participation.

“We are reaching the end of the discussion. Do you have anything to add before we conclude the session? As I informed you your information will be kept highly confidential. Thanks for your contribution. Please feel free to contact me if any further information you need about this study....”

- b) Inform about post study support strategies such as Bereavement support, Service information about St. Joseph’s Hospice.
- c) Please do not feel as though you have nothing to contribute as we are interested in your experiences and opinions.
- d) Request participants to refer any of their friends/relatives, who can be invited to the study.