

## Appendix 1: Topic Guide

### Introduction

#### Confirmation of Consent

**Thank you for agreeing to take part in this interview for a research project, which will help improve care for other people. If you would like to stop at any point, please let me know and I will switch off the recorder.**

**We'll start with a few questions about you...**

**Demographic data:**

**Patient / carer**

**Participant's age:**

**Identifies as M / F / non-binary / prefers not to say**

**Ethnicity:**

**(Medical condition):**

**Postcode:**

**The interview will be split into two sections. First I'd like to hear about your experiences with your healthcare and secondly I'd like to ask your opinion on how care could be improved for other people in the future.**

- 1. Can you tell me a little about yourself and your story? Can you tell me about the medical conditions you are living with? Have you had any memorable hospital admissions or any times you were particularly sick? At those times when you were particularly poorly, do you remember having any conversations about care planning and/or palliative care?**
- 2. Have you ever heard of the term "palliative care"?**
- 3. What does that term mean to you?**

*Prompts:*

*The World Health Organisation (WHO) says that "palliative care improves the quality of life of patients and that of their families who are facing challenges associated with life-threatening illness, whether physical, psychological, social or spiritual. The quality of life of caregivers improves as well." What do you think about this definition? Do you agree or disagree with it?*

- 4. Do you remember when you first heard the term "palliative care"?**

*Prompts:*

*Do you remember a particular conversation when palliative care was first discussed with you?*

*Who discussed this with you?*

*What triggered the discussion? Was it a particular event? Was it about a referral to a specialist palliative care service?*

*Had you thought of "palliative care" before a professional talked to you about it?*

- 5. How did you feel when you were identified as having palliative care needs?**

*Prompts:*

*Positive or negative feelings?*

*Are there any benefits to being identified as having palliative care needs?*

*Have you experienced any negative effects? / had any negative experiences?*

**6. Are there any benefits you can describe about having your “palliative care” needs identified?**

**7. Do you know whether you are on your GP practice’s palliative care register?**

*Prompts:*

*If yes:*

*Did your GP ask whether you could be included on the register?*

*Are there any benefits to being on the register?*

*If no:*

*Do you think there would be any benefit to being on a register?*

*What benefits would you consider to be most important?*

*eg relationship with the GP practice team / who do you call when poorly ...*

**8. There is a lot of work happening to develop tools to identify patients who have palliative care needs through a computer search. How would you feel if your GP identified that you had palliative care needs this way?**

*Prompts:*

*Positive or negative feelings?*

*How would you feel if your GP or practice contacted you because you had been identified this way?*

*What advice would you give to GPs or those developing these tools about how it feels as a patient to be identified?*

**9. How would you want your GP to communicate with you that you had been identified as having palliative care needs?**

*Prompts:*

*Would you prefer to find out via a letter, text, phone-call or a face-to-face appointment?*

*What information would you want to be told about palliative care?*

**10. Spending this time with you has been really valuable. Before we finish are there any other thoughts or reflections you would like to share?**

**Interview debrief**

**Thank you for sharing your experiences**

**Your experiences are vitally important in improving this aspect of care**