**Sample Interview Guide: Discordance between the perceptions of clinicians and families about end-of-life trajectories in hospitalised dementia patients**

1. **Clinician Question Guide**

Qualitative questions

“I’m interested in finding out more about your specific experience working both with patients with dementia and patients who are dying in the acute setting”.

Have you had any professional experience within palliative care or geriatric settings (Yes/No)

* *If yes, please describe to me what this experience involved*

How much experience have you had working with patients with dementia and their families in hospital?

Have you ever had any formal training around managing end-of-life care for patients with dementia?

When/Do you consider dementia to become a terminal condition?

* *(Physicians) How do you prognosticate this? What comorbidities are involved?*

Do you feel patients with dementia have any unique needs at the end of life?

* *If so, describe these.*

What factors do you take into consideration when deciding a patient needs withdrawal of active treatment?

What strategies do you use when communicating about withdrawing treatment to families of patients with dementia?

What are some of the challenges of working with families around end of life care for patients with cognitive impairment?

Is there anything I have not asked that you feel is important to discuss?

1. **Family Interview Guide**

Background

Tell me a little bit about [relative]…

* *How long had [relative] had dementia?*
* *How did the dementia affect [relative]’s life?*
* *How did the dementia affect your relationship with [relative]?*
* *How would you describe [relative]’s health in the past few months?*

Admission

What lead to [relative] being admitted to hospital?

Describe the experience of being a caregiver whilst [relative] was a patient?

End of life care

Tell me about the events leading up to [relative’s] death…

Would you be able to describe how you came to understand that [relative] would pass away/die?

* *Physical signs*
* *Communication with team*
* *Other*

Was there any discussion with the treating team around the possibility that [relative] would not recover?

* *If yes, how did this communication occur? Telephone, family meeting, in person, etc.*

Quality of care

How do you feel about the support provided to you and your family in the last days/hours of [relative’s] life?

* *How do you feel about the way you were treated by staff before and after* [relative’s] *death?*
* *How do you feel about the communication between you and the staff before and after the death?*
* *What did you feel your main needs were during this time? (emotional, practical, spiritual)*

Is there anything you want to tell me about your experience of [relative’s] death that I have not asked?