Appendix 1A

Interview topic guide for patients/carers – modelling phase

Future Care planning for people with advanced heart disease

This interview is part of a research study funded by Marie Curie Cancer Research which aims to test new ways of providing care for people with advanced heart disease. The first phase of the study involves seeking views and comments from people who have heart disease and their families.

The aim of this guide is to support a structured approach to interviews and focus groups associated with the research study. The suggested topics are intended to provide a broad framework to encourage discussion and comment.

The interviewer will introduce himself/herself to the interviewee and explain the purpose of the interview. The interviewer will check that the consent form has been signed and that the interviewee remains in agreement to take part and that the interview can be recorded.

1. Do you feel that patients with advanced heart disease have adequate opportunity to discuss their condition, its treatment and their outlook with healthcare staff generally? What factors should trigger such discussions? What are the barriers to this? What things help? When is the best time to discuss these issues?

2. Do think it would be helpful to create a care-plan for patients with advanced heart disease? If so, when would be a good time to start thinking and talking about this? Do you think that these discussions should take place in hospital or at home? what details should be included in this plan? Who should be involved in completing and agreeing this plan? What would you perceive to be the barriers to including and excluding some items? Who do you think should have access to this care plan?

(Interviewer now shows example FCP)

3. In the example “Future Care Plan”, do you feel the layout and content are appropriate?
4. In the example “Future Care Plan”, which items do you feel should be included and which excluded? (see FCP example), Describe your concerns about these.

5. Do you have broader general concerns about this type of care plan and its uses by doctors and nurses?

6. In the example we have provided, should the updating and management of the contents be done by a community nurse, the GP or a hospital consultant or other people?

7. Should the patient and their family have a copy? How do we keep this updated?

8. In addition to, or instead of, this care plan, do you feel there is a need for more care or different care for people with advanced heart disease? If so, what do you think would help? Please give general and specific ideas if you have them.

9. We are planning to test new ways of providing care for people with advanced heart disease in a randomised research trial which will involve the use of the “care plan” discussed above combined with a special nurse to provide extra-supportive care. What are your views about doing such a research study? Do you think it is ethically acceptable for some people to have extra care services while others do not? Would you and your family have concerns about being involved in this type of research?