

## Appendix 1: Results from rating scale questions

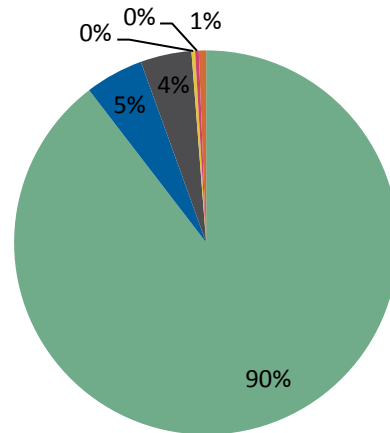
### Rating Scale

1 Strongly Agree; 2 Moderately Agree; 3 Agree; 4 Moderately Disagree; 5 Strongly Disagree

### Support

I was given enough time to make my decision to participate in the trial

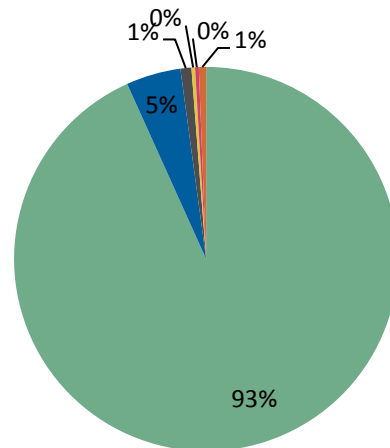
1 2 3 4 5 N/A or blank



99% Agreed

During the trial I have felt cared for by the research staff

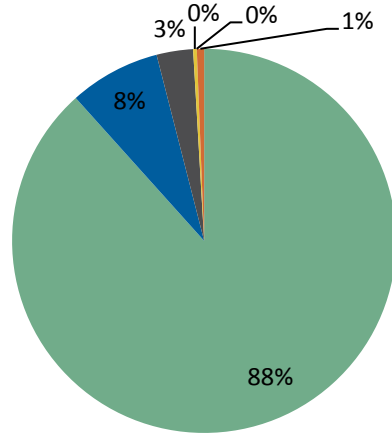
1 2 3 4 5 N/A or blank



99% Agreed

**I am given the opportunity to ask my doctor questions**

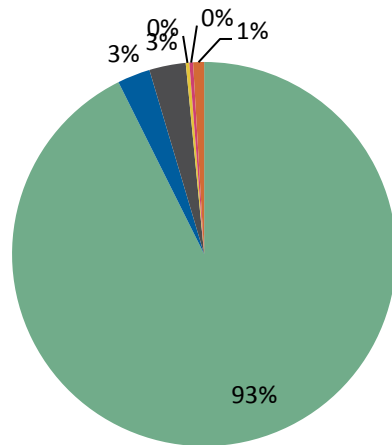
1 2 3 4 5 N/A or blank



**99% Agreed**

**I am given the opportunity to ask my nurse questions**

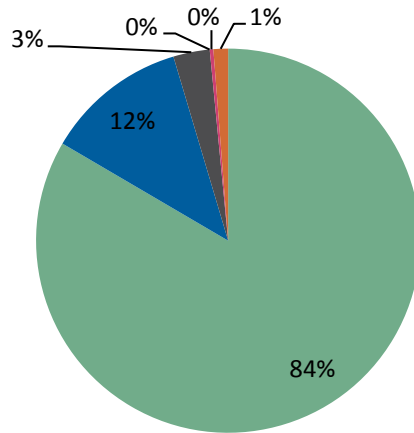
1 2 3 4 5 N/A or blank



**99% Agreed**

**The staff caring for me are able to answer my questions**

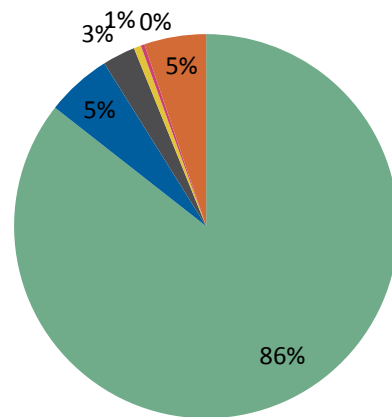
1 2 3 4 5 N/A or blank



**99% Agreed**

**My family/friends have felt welcome at my research visits**

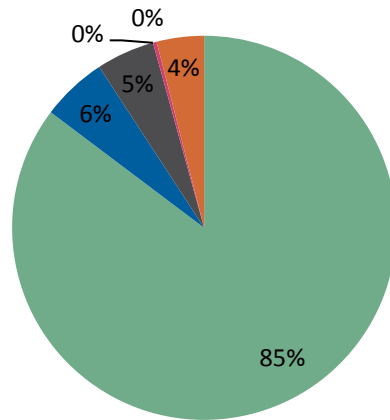
1 2 3 4 5 N/A or blank



**94% Agreed**

**My family/friends are involved in my care when I want them to be**

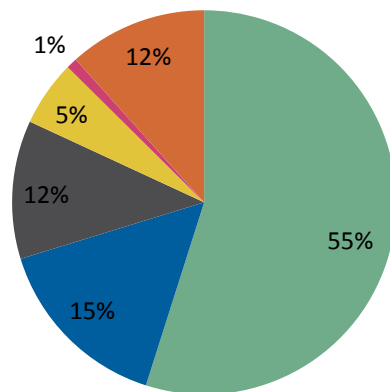
■ 1 ■ 2 ■ 3 ■ 4 ■ 5 ■ N/A or blank



**96% Agreed**

**I have been offered access to other healthcare providers who can support me**

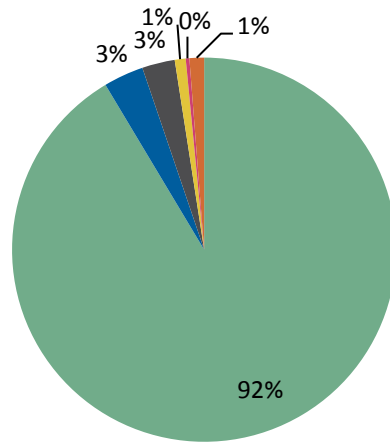
■ 1 ■ 2 ■ 3 ■ 4 ■ 5 ■ N/A or blank



**82% Agreed**

**If I feel unwell I know who to contact during the working week**

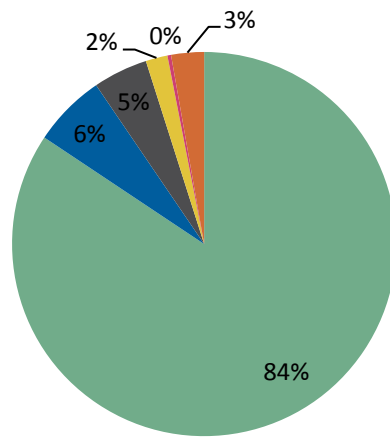
1 2 3 4 5 N/A or blank



**98% Agreed**

**If I feel unwell I know who to contact out of hours**

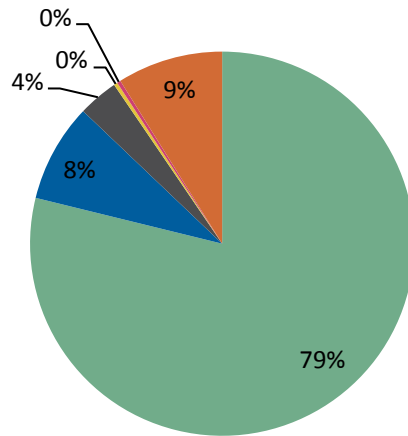
1 2 3 4 5 N/A or blank



**95% Agreed**

The staff I have spoken to when I have felt unwell have known how to help me

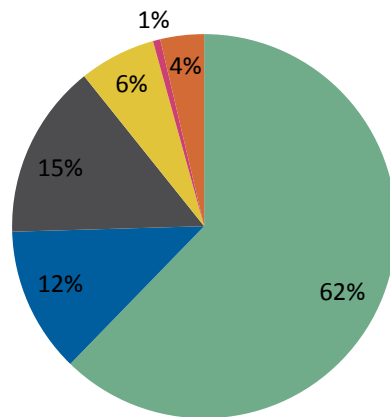
1 2 3 4 5 N/A or blank



91% Agreed

If I am unhappy about any aspect of my care or treatment I know how to make a complaint

1 2 3 4 5 N/A or blank

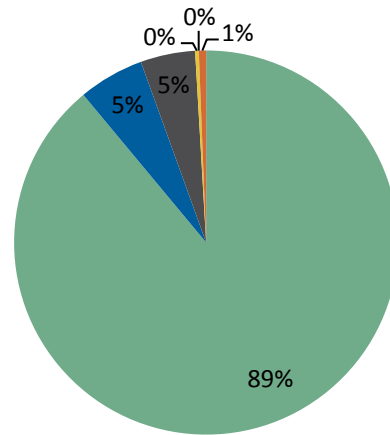


89% Agreed

## Communications

I am given enough time to answer questions

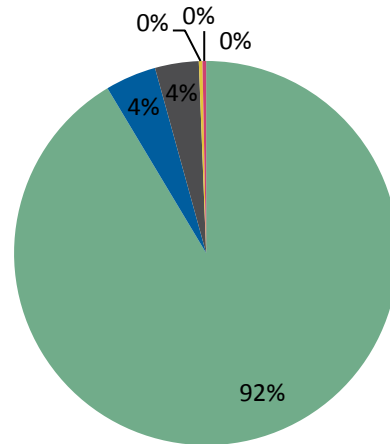
1 2 3 4 5 N/A or blank



99% Agreed

I was given enough information about the trial to make my decision to participate

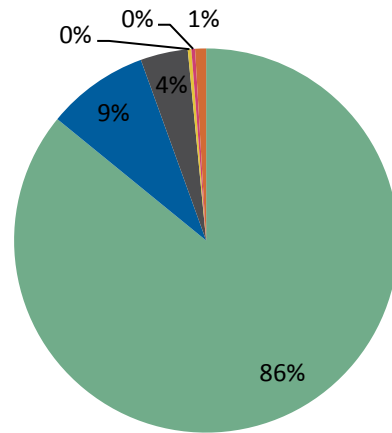
1 2 3 4 5 N/A or blank



100% Agreed

**The verbal information I received was easy to understand**

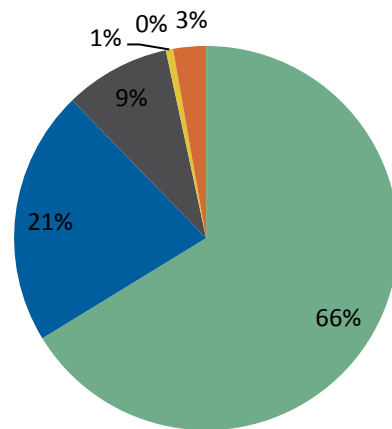
■ 1 ■ 2 ■ 3 ■ 4 ■ 5 ■ N/A or blank



**99% Agreed**

**The written information I received was easy to understand**

■ 1 ■ 2 ■ 3 ■ 4 ■ 5 ■ N/A or blank

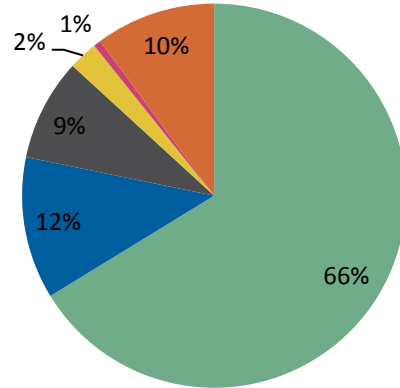


**96% Agreed**



**My GP is kept up to date regarding my treatment**

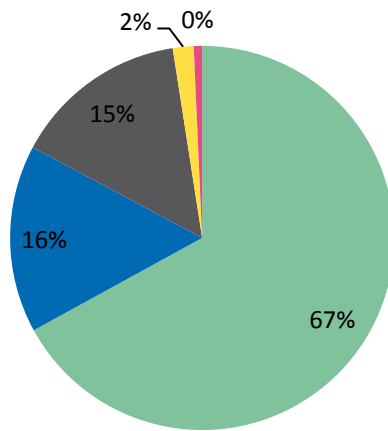
1 2 3 4 5 N/A or blank



**87% Agreed**

**The communication between my other healthcare professionals and the research team is effective**

1 2 3 4 5

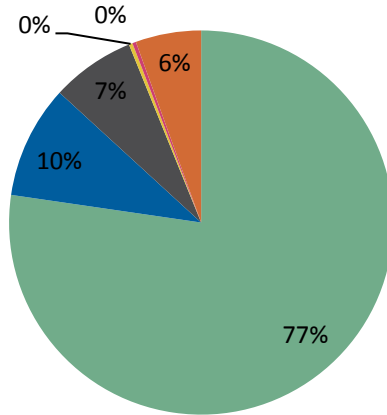


**98% Agreed**

## Support

### Participating in the trial has met my expectations

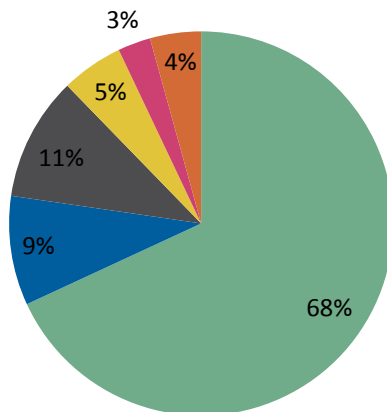
1 2 3 4 5 N/A or blank



94% Agreed

### Before being offered the opportunity to participate in this trial, I knew research happened in this hospital

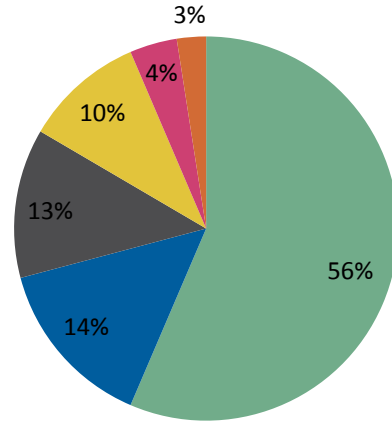
1 2 3 4 5 N/A or blank



88% Agreed

**I know who funds the research I am taking part in**

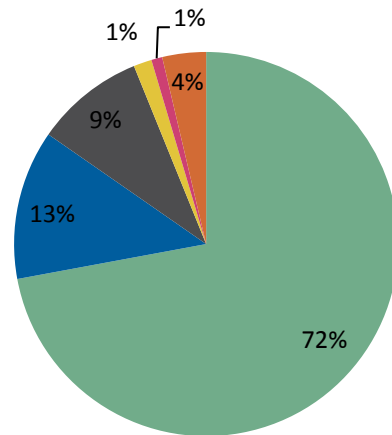
1 2 3 4 5 N/A or blank



**83% Agreed**

**I would participate in another early phase trial**

1 2 3 4 5 N/A or blank



**94% Agreed**

## Appendix 2: Summary of responses to open-text questions

### I would participate in another early phase trial

- Yes:
  - Due to the care received
  - Personal benefit
  - Benefit to others
- Unsure:
  - Depends on the trial (what it involved)
  - Unknown/too early to say
- No:
  - Currently getting no benefit from trial on
  - Due to the travel/side effects from current trial

### Quotes:

- 1: *I am monitored and kept aware of my progress*
- 1: *The care and attention given to me has been excellent*
- 1: *To help myself and others*
- 1: *I will try anything that helps! (possibly)*
- 4: *I feel my overall health has deteriorated over the past 6 weeks*
- 3: *Depends on my needs at the time*
- 2: *It would be dependent on what kind of trial and what was involved*
- 1: *To have the chance of putting something back into the NHS*
- 1: *I would welcome the opportunity to continue to receive first class treatment and monitoring*
- 1: *In early phase trials one usually gets the medication as opposed to possibility of placebo in later trials*
- 5: *I'm afraid this will be my last trial, I have been on 3 now already*
- 2: *Such trials are of benefit to both the individual and the wide community*
- 3: *Being closely monitored and CT scan means early detection of any growth or alteration of tumour is detected earlier*
- 1: *I would try anything to extend my life*
- 1: *Every trial helps people in the future*

### Is there any aspect of care that has been better than what you expected?

- Staff: friendliness; care received
- Attention / checks (e.g. scans, monitoring of treatment)
- Didn't know what to expect

### Quotes

- *All my care has been better than expected*
- *The nurses here are so professional. But it is their care and listening to me as a patient that has made the treatment easier. The study doctors are all so very dedicated. I have felt a human not a number.*
- *The care and kindness of the staff in the clinical trials unit*
- *Dedication of the research nurses*
- *The compassionate intent of the research nurses*
- *It has been helpful having the same team look after me, good continuity*
- *The personal care has been constantly of the highest standard with excellent communication at all times – both before and during treatment. Personal Research Nurse plays vital role.*
- *Excellent care at all times*

- *Care of staff has exceeded expectations especially that of the nurses engaged in the clinical process*

**Is there anything about the way in which you have been cared for that you would like to have been different?**

- Waiting times: long waits to see consultants; drugs from pharmacy; for blood results; referral in the first place
- No – exceeded expectations

**Is there anything else that would make your visits more comfortable?**

- Food
- Car parking
- Waiting times (would be good to be informed of the reason for the delay or an idea of how long the delay will be)
- Mostly answered 'No'

**Is there anything else you'd like to tell us?**

- Praising the care received
- Complimenting the staff (whole team)
- Grateful for being able to take part in the trial

Quotes

- *I am very pleased to help in a small way, and very grateful for the care of my nurses – thank you, I feel we have helped each other*
- *I have appreciated the opportunity to participate in this trial*
- *Staff are very reliant on working practices of other areas e.g. blood and pharmacy. This does cause problems due to delays*
- *Excellent team from top to bottom*
- *It would be nice to know the results of the research I have been participating in*
- *Have met some wonderful and inspiring people within the research unit – both patients and staff*
- *The NHS gets a bad press, but my experience has been excellent*
- *I would like to thank all concerned as going through this stage of my life has been an ordeal but with the care given it has made life bearable and helped my family cope better*
- *Feel really cared for as a person and not a number*
- *I am more than satisfied with all aspects of my treatment*
- *Not all delays within the XXX were explained soon enough.*
- *Not really other than to say all the staff have been really helpful, understanding, professional friendly in what are difficult circumstances, and very positive!*
- *Coming here makes you feel not so afraid*
- *I am grateful to have been accepted for the trial*
- *My care has been amazing. I can't thank the XXX unit enough for what they have done for me*