



# ECMC Patient Experience Survey



The Experimental Cancer Medicine Centre Initiative is jointly funded by Cancer Research UK, the National Institute for Health Research in England and the Health Departments for Scotland, Wales and Northern Ireland

# What we'll cover today

**BACKGROUND** to the survey

**SUMMARY OF FINDINGS**

**NEXT STEPS**

# Why?

- ECMC Research Nurse Network Group aims to promote quality care for patients taking part in early phase research.

Remit includes:

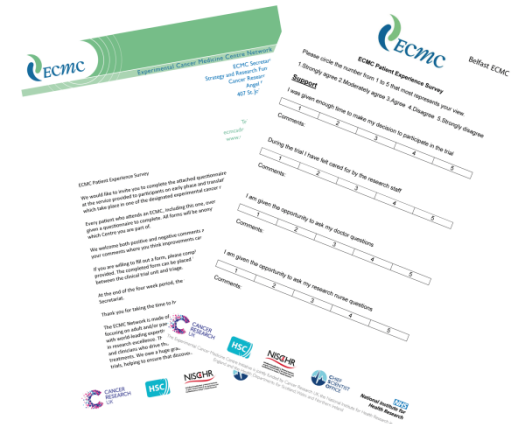
- Identify priorities for the development of the group and take them forward
- Facilitate the sharing of expertise and experience across the ECMC Network
- Previous work included 24 triage/sample handling
- Ask the patients
- Is multicentre activity possible

# National Cancer Patient Experience Survey

- **Asks cancer patients across England for their views on their care**
- Question categories include: seeing your GP, deciding the best treatment for you, clinical nurse specialist
- Only three questions in the survey are related to research:
  - Q29. Have you seen information about cancer research in your hospital
  - Q30. Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research
  - Q31. If yes, did you then go on to take part in cancer research?

# The Survey

- Based on a survey created at Oxford
- Developed by the ECMC Research Nurse Steering Committee
- Questions in three categories; rating scale & open-text questions
- Reviewed by patients
- Survey with an accompanying letter given to patients
- Survey conducted in 15 ECMC locations during March 2015



The image shows a patient experience survey form from ECMC. The form is titled 'ECMC Patient Experience Survey' and includes a header with the ECMC logo and the text 'Experimental Cancer Research Network'. The survey is divided into three main sections: 'Please circle the number from 1 to 5 that most represents your view', 'I strongly agree 2 Moderately agree 3 Agree 4 Disagree 5 Strongly disagree', and 'During the last 12 months, how often have you been asked to participate in the full survey?'. The form also includes a 'Comments' section and a 'Thank you for taking the time to complete this survey' message. The bottom of the form features logos for various partner organizations, including Cancer Research UK, HSC, NISHR, and others.

# The Findings

Individual centres have their results for local action

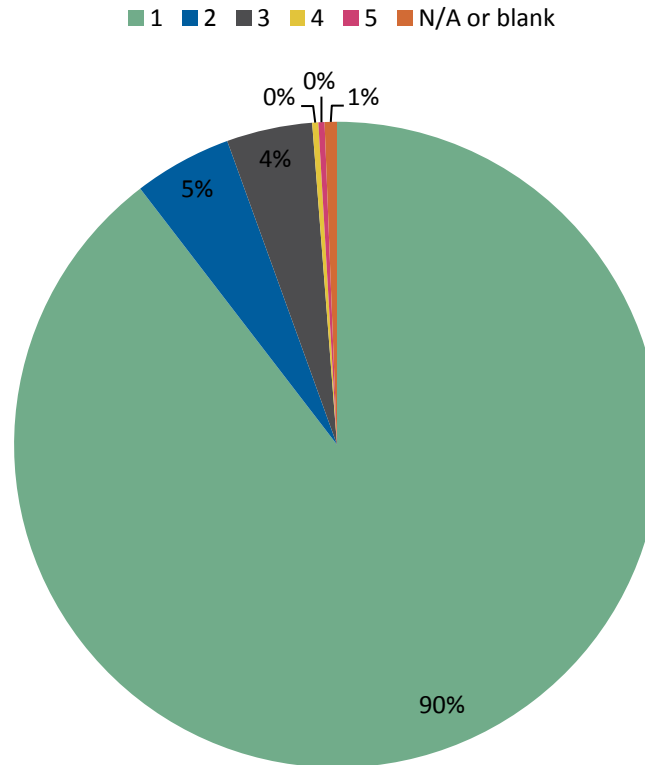
Overall extremely positive

Total questionnaire returned : 326

Range: 3 - 72

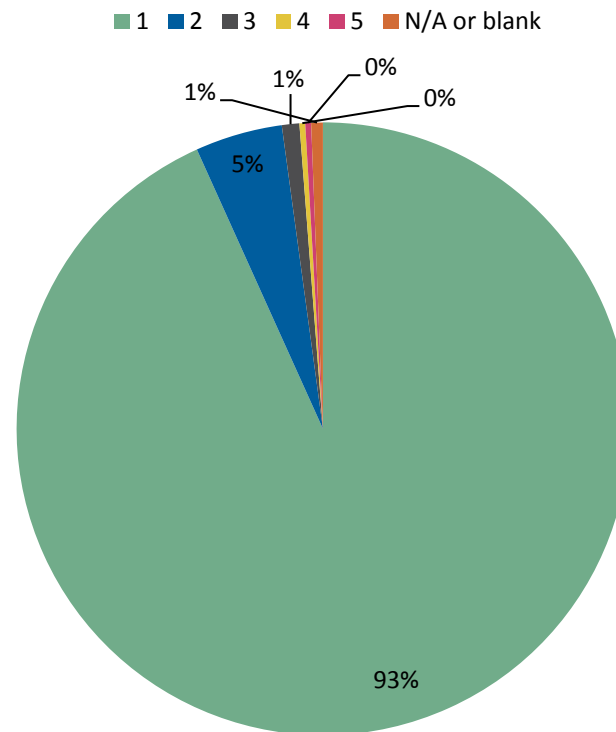
Score: 1 strongly agree – 5 strongly disagree

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



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

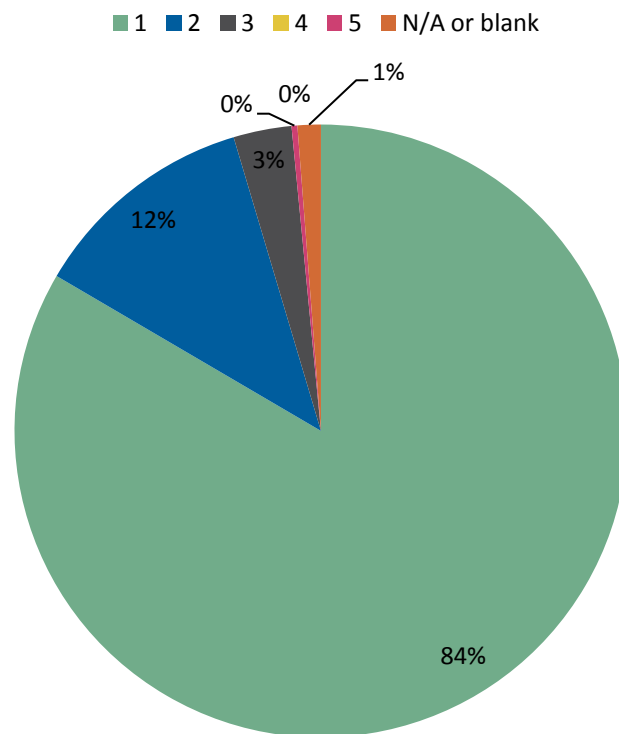
# During the trial I have felt cared for by the research staff



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

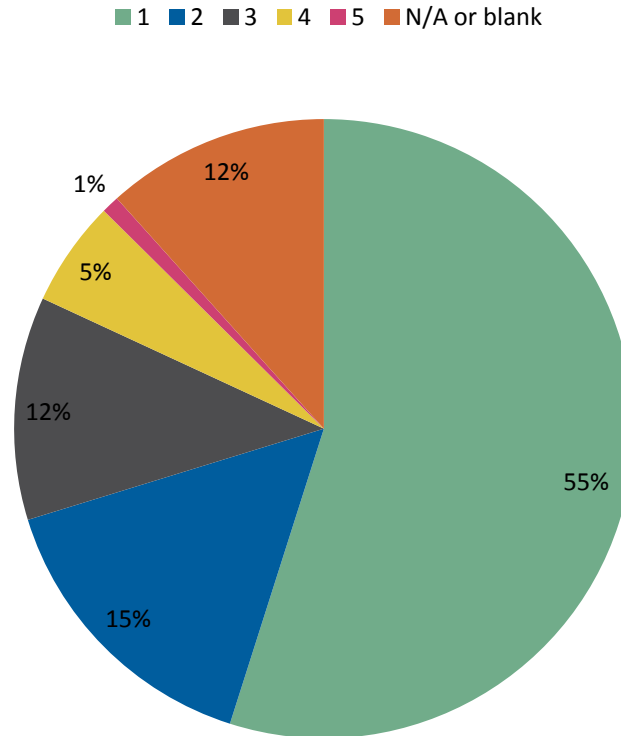


# The staff caring for me are able to answer my questions



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

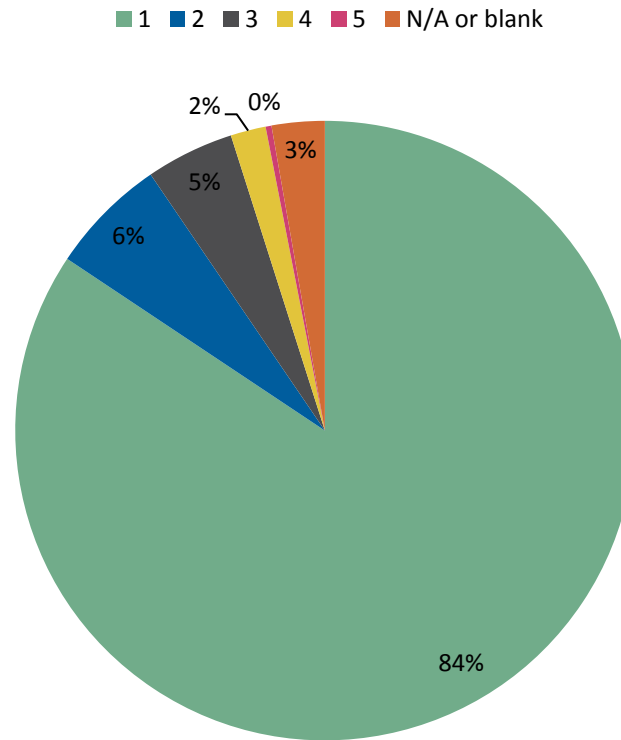
# I have been offered access to other healthcare providers who can support me



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

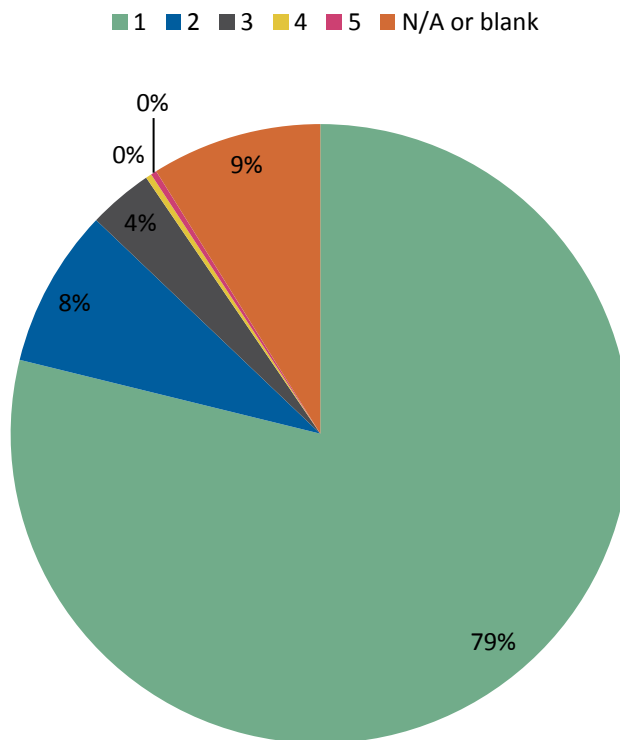


# If I feel unwell I know who to contact out of hours



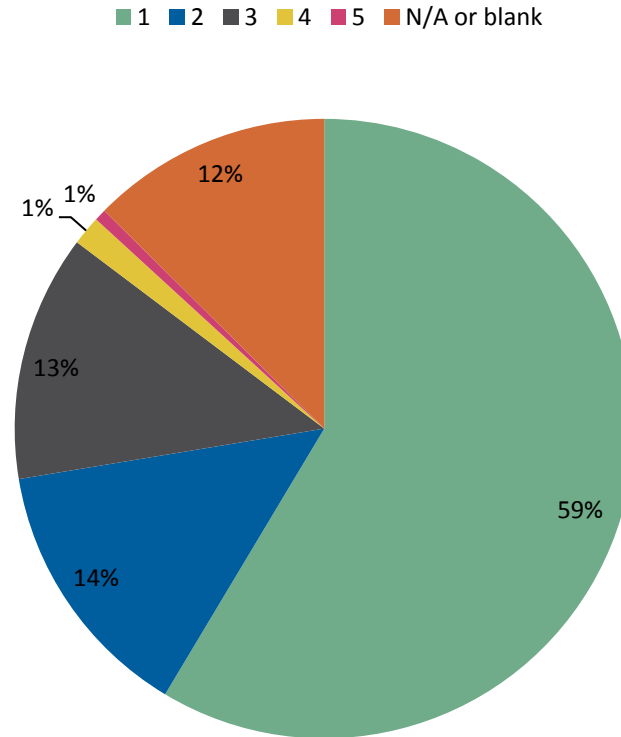
1 Strongly Agree; 2 Moderately Agree; 3 Agree; 4 Moderately Disagree; 5 Strongly Disagree

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



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

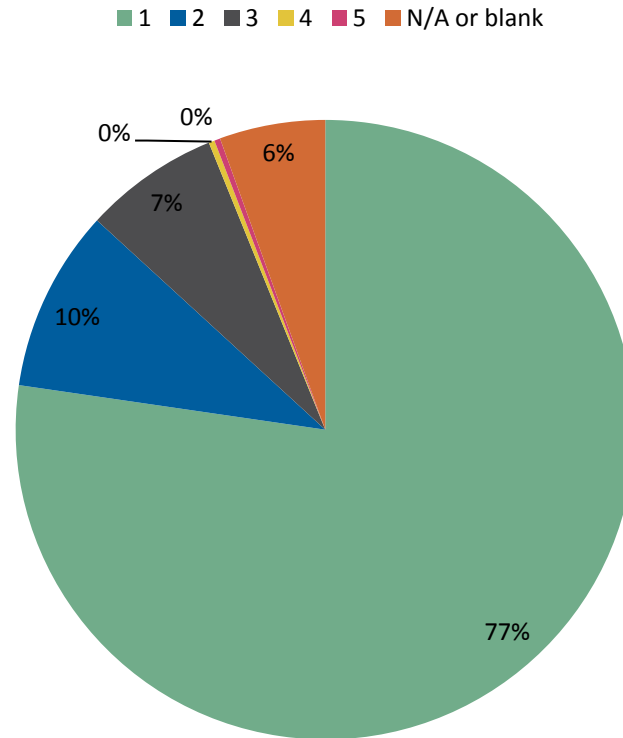
# The communication between my other health care professionals and the research team is effective



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



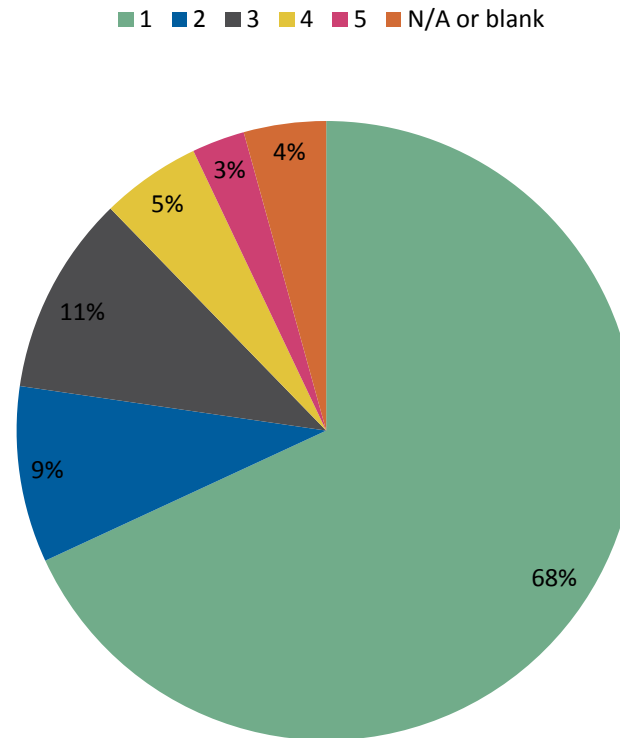
# Participating in the trial has met my expectations



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



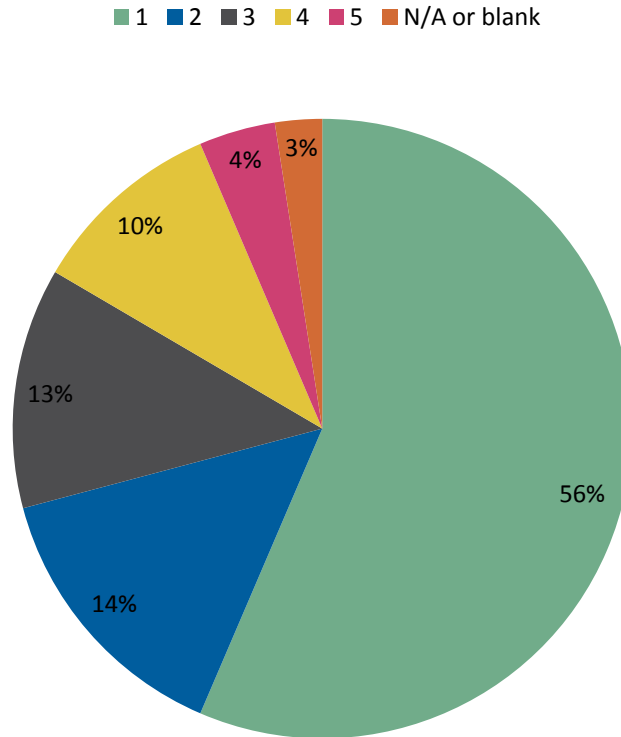
# Before being offered the opportunity to participate in this trial, I knew research happened in this hospital



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



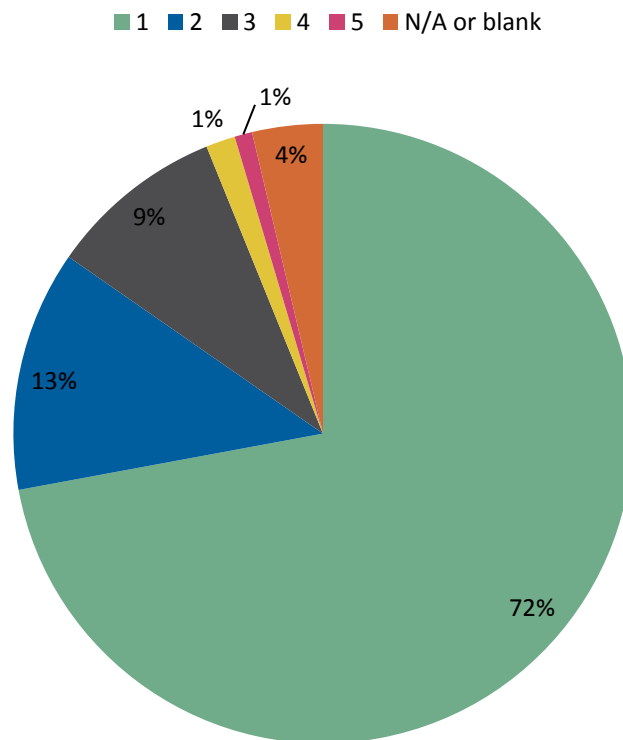
# I know who funds the research I am taking part in



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



# I would participate in another early phase trial



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



# Free text: is there anything else you'd like to tell us?

- I have felt cared for and my wellbeing at the top of all the nurses agenda on every visit
- not really other than to say all the staff have been really helpful, understanding, professional friendly in what are difficult circumstances, and very positive!
- I would like to thank the research people for providing a taxi for me
- I have been astonished at the quality of the treatment and patience by everybody.
- coming here makes you feel not so afraid
- the doctors and nurses have been brilliant, the atmosphere in the unit is friendly and happy - like an extended family. Treatment results wonderful
- I am grateful to have been accepted for the trial
- the XXX clinical trials unit is fantastic, great environment, very well organised. Staff are the cream of the NHS

# Free text: is there anything else you'd like to tell us?

- This trial has given me back my life and enabled me to look to the future. Thank you.
- I'm grateful for the opportunity of having participated though admittedly disappointed that it didn't have the outcome I had hoped for. However I was never promised a guarantee of success.
- the personal touch is very important to me and being able to discuss anything without a time limit. Feel really cared for as a person and not a number.
- If it wasn't for research I wouldn't be writing this today.
- The whole team on the research unit have been very professional and caring towards me, and I feel that being in a trial is something worth doing.

# Feedback from nurses running the survey

- How easy to run?
  - Easy to run but did need someone responsible for it to ensure it was considered each day
- Would you repeat the survey?
  - Yes – but after 2 years or longer
- positive experience – able to share findings with colleagues
- “isn't it good to know that our patients do really think good things of us! If nothing else, the survey has made me feel good about what we do!”
- “Over all I found it quite an uplifting experience, and I was able to share with my colleagues some of the (anonymous) positive feedback.”

# Next steps

- NCRI Poster
- Publication in Cancer Nursing Journal
- Review survey findings at next Nurses Group
- Sharing information with the ECMC funders

# Acknowledgements

- Oxford ECMC: drafted original survey
- All who reviewed/commented on the survey
- All the ECMCs who took part and the research nurses who administered the survey and inputted the data
- Imperial Statistician