

# Patients' Priorities For Cancer Research: A Pilot Study

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## BACKGROUND

- There is increasing interest in involving patients in the development of clinical trials. However, little is known about patients' views on priorities for cancer research and the majority of research ideas are proposed by clinicians or scientists.
- The Macmillan Listening Study<sup>1</sup> identified 15 research themes, of which the top 3 were:
  - Impact on life and how to live with cancer
  - Risk factors and causes
  - Early detection and prevention
- We performed a 4 week pilot patient survey to investigate the views of patients at the Royal Marsden (RM) on which areas should be priorities for cancer research.

## METHODS

- The PACER survey questionnaire was comprised of demographic questions and a list of 12 research themes which respondents were asked to rank according to their perceived priority.
- Questionnaire distribution:
  - Paper questionnaires were available from reception/stands at a number of locations at both RM sites (Chelsea and Sutton).
  - A member of research staff distributed questionnaires for 2 weeks at each site.
  - Reception staff in the West Wing Clinical Research Centre and Drug Development Unit distributed questionnaires.
  - 315 patient members of the RM Foundation Trust were posted a questionnaire or emailed a link to the online survey.
- Patients' responses were put into rank order (highest ranked theme = score 12, lowest theme = score 1, unranked theme = score 0). For themes with the same rank, the average score was used. The theme with the highest overall score was identified as the highest research priority.

## RESULTS

Table 2: Patient demographics (n = 780)

Characteristic	N (%)*
<b>Age</b>	
< 45 years	119 (15%)
46 – 60 years	234 (30%)
61 – 75 years	326 (42%)
> 75 years	85 (11%)
<b>Gender</b>	
Male	310 (40%)
Female	427 (55%)
<b>Aim of treatment</b>	
Curative	396 (51%)
Palliative	296 (38%)
<b>Current position in treatment pathway</b>	
Currently undergoing treatment	397 (51%)
In follow-up/remission	229 (29%)
Other (e.g. not yet started treatment or palliative care)	127 (16%)

\* Some data missing as not all patients answered every question

Figure 1: Type of cancer

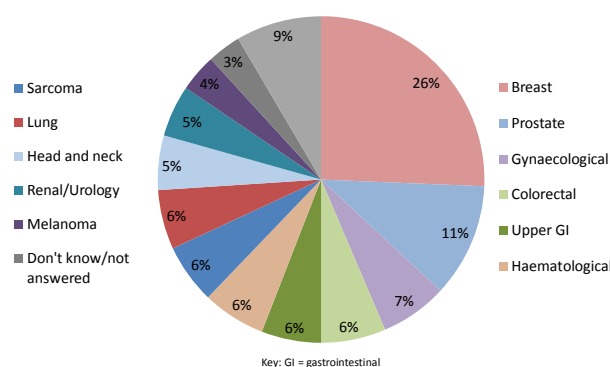


Figure 2: Impact of a dedicated researcher on questionnaire response rates

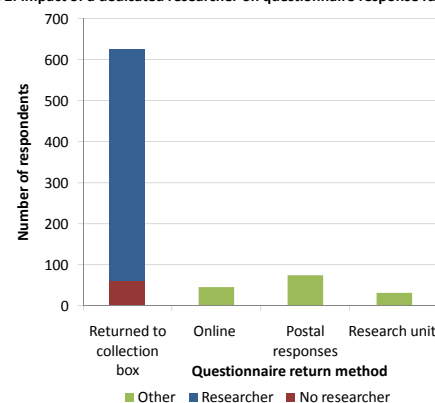
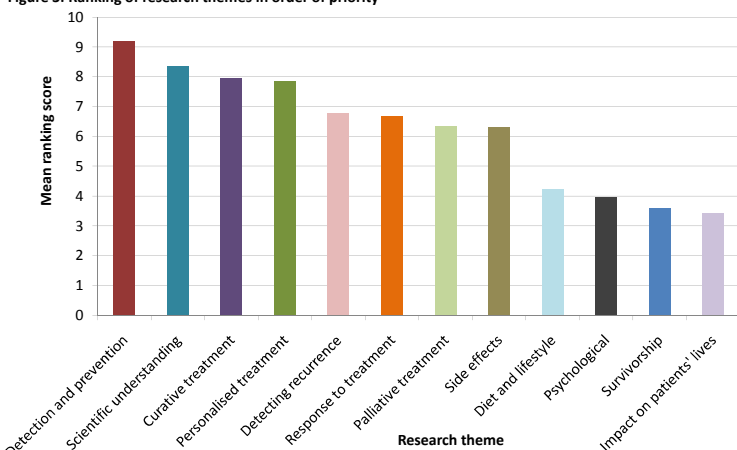


Figure 3: Ranking of research themes in order of priority



- The top 4 research priorities were similar for the majority of tumour types, with the exception of patients with lung cancer.
- The rankings for the patients with lung cancer were:
  - Curative treatment
  - Detection and prevention
  - Scientific understanding
  - Palliative treatment
- 72% of patients with lung cancer were treated with palliative intent (compared to 21 - 54% of patients with other types of tumours).
- Patients treated with palliative intent ranked the "palliative treatment" theme higher than patients treated with curative intent

Table 1: Research themes and explanations

RESEARCH THEMES
<b>Scientific understanding of cancer</b> Investigating which gene mutations cause cancer, how cancer grows and spreads and how it can become resistant to treatment
<b>Detection and prevention of cancer</b> Developing new tests to help diagnose cancer (e.g. scans, blood tests), improving understanding of early cancer symptoms
<b>Methods of selecting the best treatment for an individual patient</b> Finding ways of identifying patients who could be spared chemotherapy or predicting which treatment will work best (e.g. by looking at the molecular profile of patients' cancers)
<b>Impact of diet and lifestyle on cancer</b> Assessing whether diet/exercise/lifestyle can increase the risk of cancer or influence prognosis/treatment effectiveness
<b>Treatment to improve the number of patients who are cured of cancer</b> Developing new drugs or surgical/radiotherapy techniques
<b>Managing/reducing side effects of cancer and its treatment</b> Assessing new drugs or surgical/radiotherapy techniques that might have fewer side effects, improving the treatment of side effects (e.g. nausea, rash, pain, numbness)
<b>Methods of monitoring how well the cancer is responding to treatment</b> Developing new types of scans or blood tests to quickly identify whether a treatment is working
<b>Impact of cancer on the lives of patients and their families</b> Investigating how cancer and cancer treatment impacts on patients' work, financial situation, exercise, sleep
<b>Psychological or emotional effects of cancer on patients and their families</b> Assessing how to cope with a diagnosis of cancer/the worry of the cancer coming back/the fear of dying, investigating the impact on patients' families and ways of improving support
<b>Impact of cancer on patients after treatment has been completed</b> Assessing the longer-term impact of cancer on patients, e.g. effect on energy levels, body image, sexual or bowel function
<b>Ways of detecting if the cancer has come back</b> Developing new types of scans or blood tests to quickly/easily detect if the cancer has come back
<b>Treatment to prolong the life of patients with cancer that can't be cured</b> Investigating new surgical/radiotherapy techniques or drugs

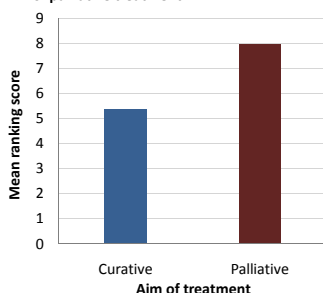
Table 3: Effect of age on ranking of research themes

Ranking	< 45 years	46-60 years	61-75 years	> 75 years
1	Detection and prevention	Detection and prevention	Detection and prevention	Detection and prevention
2	Scientific understanding	Curative treatment	Scientific understanding	Scientific understanding
3	Curative treatment	Scientific understanding	Personalised treatment	Personalised treatment
4	Personalised treatment	Personalised treatment	Curative treatment	Curative treatment
5	Palliative treatment	Detecting recurrence	Side effects	Response to treatment
6	Detecting recurrence	Palliative treatment	Response to treatment	Detecting recurrence

- Younger patients ranked palliative treatment and detecting recurrence higher than older patients.
- Gender did not influence the ranking of the research themes.

- 264 patients also wrote free-text comments. These included:
  - Suggestions for other areas of research (e.g. alternative therapies, 11 patients)
  - Research into specific tumour types (13 patients)
  - Specific research proposals (e.g. impact of cancer on patients with dementia, treatment options for cancer in pregnancy)

Figure 4: Impact of treatment aim on ranking of palliative treatment



## CONCLUSION

- This 780 patient survey is the largest survey to date of patients views on priorities for cancer research. Patients' views should be considered when devising research proposals and strategies.
- Patients' top priority for cancer research was "Detection and prevention of cancer." The top research priorities for patients were remarkably consistent across age, gender and a variety of tumour types.
- The survey will be expanded to other institutions to investigate if these results are applicable to a wider population. This will require a researcher to distribute the questionnaires at each site as this greatly increased the response rates.