

What do blood cancer patients want? (And what do we need and expect too?)

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5 things that patients want:

1. “I want my disease to be picked up early and treatment started.”
2. “I want to fully understand my diagnosis and treatment options.”
3. “I want to be cared for as a person not an NHS patient number.”
4. “I want to live with the same quality of life.”
5. “I want support after my treatment is finished as well.”



These “wants” are becoming expectations and/or needs.



The sources and evidence:

- Patient views – the NCPES 2013 (and 2014)
- Patient needs and expectations – anecdotal and preliminary qualitative findings – LLR PPN



NCPES Report



*National Institute for
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Cancer

The report gives analyses by:

- Type of cancer
- Patient Demographics
- Individual Trust
- Region

It is openly accessible and available online at:

<http://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey>

Respondents by Cancer Type

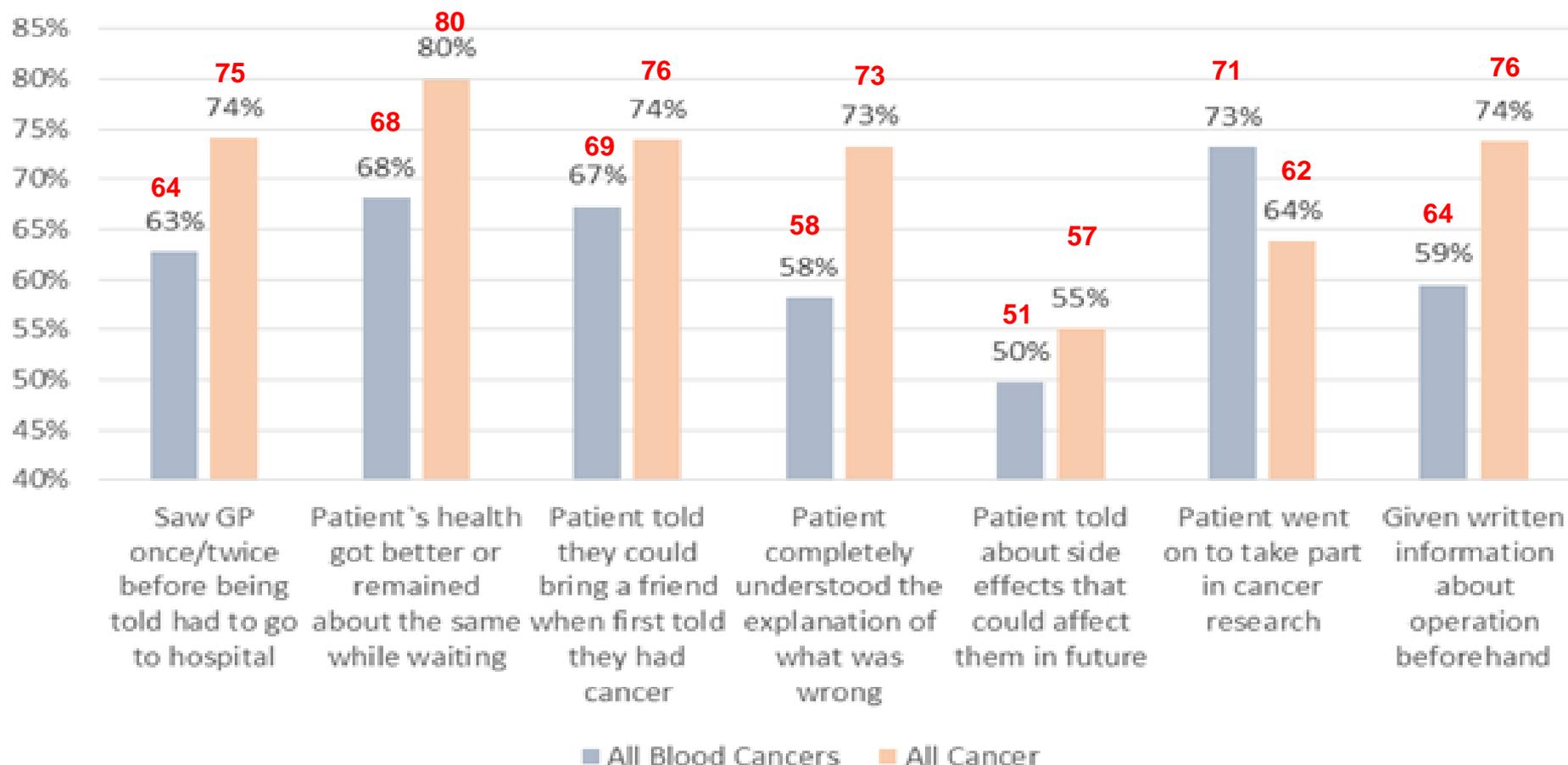
Tumour Group	Number of Respondents	Percentage
Breast	13916	20.2%
Colorectal / Lower Gastrointestinal	8899	12.9%
Lung	5018	7.3%
Prostate	5585	8.1%
'Big 4' Combined	33418	49%
Brain / Central nervous system	730	1.1%
Gynaecological	3896	5.7%
Haematological	11602	16.9%
Head and neck	2437	3.5%
Sarcoma	720	1.0%
Skin	1854	2.7%
Upper Gastrointestinal	4283	6.2%
Urological (excluding Prostate)	7058	10.3%
Other Cancers	2739	4.0%

Breakdown of disease types

Category 1	Identifying ICD10 Codes	Number of patients
Acute lymphoblastic leukaemia (ALL)	C910	153
Acute myeloid leukaemia (AML) 2	C920, C924, C925, C930, C940, C942	682
Chronic lymphocytic leukaemia (CLL)	C911	1194
Chronic myeloid leukaemia (CML)	C921	233
Hodgkin lymphoma (HL)	C81	497
Non-Hodgkin lymphoma (NHL) 3	C82-C85	4506
Myeloma (MM)	C90	3748
Other haematological malignancies (Other)	C912-9, C922-3, C927-9, C931-9, C943-9, C95, C96	295

Experience of Blood Cancer Patients vs experience of all cancer patients – NCPES 2013 (2014 in red)

Comparison of Scored Findings for All Eligible Blood Cancers compared to All Eligible Cancers





Research Participation and Quality of Care

Patients are asked to rate their care overall.

- Of those who did not have a discussion about research:
87.2% Rated Their Care Excellent or Very Good
- Of those who did have a discussion and *did not* go on to participate:
90.2% Rated Their Care Excellent or Very Good
- Of those who did have a discussion and *did* go on to participate:
91.9% Rated Their Care Excellent or Very Good



Patient needs and expectations

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1. Blood cancer patients think and feel they are different. They often have greater need to understand treatment options, symptoms, side effects.
2. Improving survival rates is the most important priority for patients, but as more and more survive their blood cancer, issues related to quality of life, and psycho-social factors are becoming more important.
3. Access to a CNS is especially important to blood cancer patients and to their carers.
4. There is a clear and proven positive association between participation in research and perceived quality of care.
5. As the number of long-term survivors increases, so do the (ex-)patient concerns and queries about late effects, recurrence and second cancers.

Patient queries (from real patients)

What's the best treatment for this disease for survival? Or for side-effects? Or for giving me an extra few months of decent quality life? And what's the next best treatment if the best one fails?

What's the best treatment for ME in view of my other health problems? Do my chances depend on me doing exactly as I'm told or is it all in the DNA anyway?

I have found lots of information about age, ethnicity, socio-economic backgrounds. Surely it is more useful to compare and contrast medical histories, treatment regimes, care packages, MDTs, or early discharge vs "keep them in another day"?

Is there a difference between "chances" and "risks" – apart from one sounding positive and the other scary? And are they the same as "predisposition"?

Why do they quote "average" survival times when the truth is often that you need to get through the first year or you need to respond to the first treatment, and if you don't that's when things look bad?



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NIHR CRN:Cancer NCPES Working Group:

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