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Determining research priorities for young people with haematological cancer: A value-weighting approach

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ABSTRACT

Introduction: Haematological malignancies account for a third of all cancers affecting adolescents and young adults (AYAs). Funding agencies are regularly faced with the dilemma of how to deploy resources in order to provide the greatest possible benefit to this patient group. This study used a value-weighting approach to quantify the stakeholders' perceptions about how resources should be allocated to best improve outcomes for AYA patients and their families.

Methods: One hundred and fifty seven participants (112 health care providers, researchers and other professionals and 45 patients and carers) were invited to complete a web-based value-weighting questionnaire and indicate how they would allocate 100 units of funding among various research approaches, areas and populations.

Results: Eighty participants (51%) completed the questionnaire. Strategic research was allocated a significantly higher proportion of funding than investigator-driven research. For research areas, clinical medicine and psychosocial research were allocated the highest proportion of funding. Within research populations, AYAs who were newly diagnosed, relapsed or finished treatment were allocated the largest proportion of funds. Psychosocial research which focussed on identifying risk and resilience, developing psychosocial measures, translating research into practice and improving the treatment centre was allocated funding slightly above other items, however the difference was not significant.

Discussion: To improve potential congruence between the views of stakeholders and funding agencies, research funding for AYA haematological cancer patients and their families could be targeted towards newly diagnosed patients and those who have relapsed. Research in the areas of clinical medicine and psychosocial care is perceived to be of utmost value.

1. Introduction

Haematological malignancies account for a third of all cancers affecting adolescents and young adults (AYAs).[1] The five year survival rates vary from 47% to 95% depending on the type of malignancy diagnosed.[2] Psychosocial issues related to depression,[3] distress,[3] relationships,[4] fertility,[4] body image,[4] work[5] and education[5] are common. Family members

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have also reported feelings of helplessness, distress, loneliness and vulnerability.[6] Research may be able to identify strategies for improving these outcomes. Given limited funding and the time lag between research initiation and findings, it is imperative to establish research priorities.

1.1. *Decisions required to determine research and funding priorities*

Funding agencies are regularly faced with the dilemma of how to deploy resources to provide the greatest benefit to cancer survivors. The dilemmas include: which research approach to follow; which areas and populations to address and the relative time-frame within which particular types of research should occur in order to provide the greatest benefit.

1.1.1. *Approach*

Approaches to research have fallen into one of the two often opposing styles: investigator-driven and strategic. An investigator-driven approach allows researchers to determine the research questions to be examined, with proposals judged on their scientific quality.[7] A strategic research approach judges proposals on both research quality and how well they address a pre-defined topic.[7,8] Each of these approaches has its advantages: for example the opportunity for new ideas to emerge in an investigator-driven environment; versus harnessing the combined knowledge of experts towards a common goal in the case of a strategic approach.[7] If a strategic approach is used, then funding bodies need a mechanism by which research priorities can be determined.

1.1.2. *Areas*

Potential research areas which may improve outcomes for haematological cancer patients include: (1) basic science, focussed on biological causes or cure; (2) clinical medicine for better treatments; (3) psychosocial research to improve psychological, social and spiritual outcomes; (4) health services research to improve management and financing of care and (5) public health research regarding policies, laws or society-wide measures.[9]

1.1.3. *Populations*

The impact of a haematological cancer diagnosis is experienced not only by the patients themselves but also by those who care for them.[10,11] For AYAs, their support persons are most likely to be their parents and partners, however other family members, such as siblings, also experience poor psychosocial health.[12]

1.1.4. *Time-frames*

It has been estimated that the time between the discovery of an important therapy and its widespread application is approximately 17 years.[13] Therefore funding bodies need to consider where the balance lies between researches which can alleviate some patient morbidity in the near-term as well as long-term research studies.

1.2. *Who should be involved in decision making about research and funding priorities?*

The perspectives gained from various stakeholder groups may shed light on the appropriate balance between competing research priorities. Medical professionals have an insight into the effectiveness of the treatment, while allied health professionals may have a more precise understanding of the services.[14] The views of the researchers may reflect work already occurring in the field and time-frames needed to achieve the outcomes.[15] Consumers such as patients and their families can provide additional perspectives about the impact of the cancer and its treatment.[16]

1.3. *Techniques for determining research priorities*

As described by Paul and colleagues[17] combining a range of decision-making techniques, such as advocacy-based,[18] consensus-based (Delphi)[19] and health economic approaches (willingness to pay),[20] into a hybrid 'value-weighting' model may assist funding bodies to clarify research priorities in the midst of competing interests. Such a model should not lose the inherent validity of the individual techniques[20,21] and may provide a more rounded view regarding which areas of research should be prioritised.

The aims of this study were: (1) to use a value-weighting approach to quantify stakeholders' perceptions about resource allocation within the following research domains: approach, areas and populations; within the psychosocial sub-domain: (2) to determine research time-frames to best improve outcomes for haematological cancer patients and their families; (3) to compare the perceived research priorities of consumer and professional groups; (4) to assess stakeholder perceptions regarding the acceptability and usefulness of the value-weighting method.

2. Method

The value-weighting approach involved two stages[17]: (1) inviting an expert advisory group to take part in a modified Delphi approach to develop a list of potential priority research items and (2) undertaking a resource allocation exercise using a web-based questionnaire to gain stakeholder views regarding priority areas for research funding. Ethical approval for the study was granted by the University of Newcastle's Human Research Ethics Committee.

3. Stage 1

3.1. *Expert advisory group*

The Leukaemia Foundation Australia nominated ten opinion leaders in the field of haematological cancer. Experts were sought via a networking process in order to harness a range of expertise and represent a variety of viewpoints. The group included: a paediatric oncologist; paediatric haematologist; cancer care coordinator; cancer nurse coordinator; clinical psychologist; three researchers and two AYA haematological cancer survivors.

The advisory group created a list of potential areas of research which would have the greatest impact on improving outcomes for AYAs with haematological cancer and their families. The group met via telephone and provided two rounds of feedback via email to ensure that important themes, domains and items had been covered. This aspect of the value-weighting model allowed views about priorities to be expressed without requiring participants to reach a consensus.

4. Stage 2

4.1. *Web-based questionnaire*

The advisory group list formed the basis of a web-based questionnaire designed to quantify the perceived relative value of each listed item. The web-based questionnaire was piloted with 23 people including AYAs, parents of AYAs, researchers, health care professionals and members of the advisory group. Items were then refined and instructions on how to complete the value-weighting questions were clarified.

The final questionnaire consisted of items regarding priority research areas, the acceptability of the value-weighting method and participant demographics. The reading age of the value-weighting questionnaire had a Flesch–Kincaid Grade Level of 7.1 and a completion time of 15 min.

4.1.1. *Priority research value-weighting questions*

The value-weighting questions required participants to indicate how they would allocate 100 units of funding among various items within each of the following research domains: approach, areas and populations. As the list of potential areas identified by the expert advisory group had a strong focus on psychosocial research, the content of this sub-domain was explored in more depth.

Participants were asked to allocate 100 points of funding to the items they felt would best improve outcomes for AYAs with haematological cancer and their families. It was possible to allocate all the funding to one item, spread the funding across all the items or have some items without any funding allocation. A list of all research domains (approach, areas and populations), sub-domains (psychosocial) and items can be seen in Table 1. An example of a value-weighting question can be seen in Fig. 1.

4.1.2. *Time-frames*

Within the area of psychosocial research, participants were asked to indicate how soon they felt research in each area needed to start. For the eight items of psychosocial research, the participants indicated whether research should begin in the next 12 months; 1–2 years; 3–5 years or not at all.

4.1.3. *Acceptability of the value-weighting method*

Participants were asked to assess the acceptability of the value-weighting method using a 5 point Likert scale from 'Strongly Disagree' to 'Strongly Agree'.

Table 1 – Research domains, sub-domains and items listed in the questionnaire.

Research domain	Items
Approach	Investigator-driven Strategic
Areas	Basic science Clinical medicine and science Psychosocial Health services Public health
Psychosocial (sub-domain)	Developing measures to identify psychosocial concerns Identifying who is at risk of poor psychosocial health and who is resilient Testing the benefit of physical or psychological therapies Evaluating the effectiveness of peer support programs or social activities Examining the value of improving treatment centre environments or care delivery Determining the benefit of providing better information and education Exploring the value of online interventions and technology Incorporating existing research into practice
Populations	Newly diagnosed Receiving treatment Finished treatment Relapsed Receiving palliative care Parents and carers Siblings Partners and close friends

4.1.4. *Participant characteristics*

Demographic items included age and gender. Disease characteristics included: haematological cancer type; time since diagnosis; stage in cancer treatment and type of treatment received. The researchers and health care and other professionals were asked about their area of speciality.

4.2. *Web-survey participants*

4.2.1. *Young adult haematological cancer survivors and their carers*

AYAs with haematological cancer, and their parents, partners and siblings, were recruited from the client databases of either the Leukaemia Foundation, Australia or Canteen, Australia. These are the peak organisations providing services and support specifically for AYAs diagnosed with cancer and their families in Australia. AYAs were defined as being between the ages of 15 and 25 years, as used previously.[22] Eligible participants were Australian residents diagnosed, or related to someone, with haematological cancer; had an email address and were able to read English. A random sample was identified from each database, with the number selected in each state proportional to the number of individuals on the database.

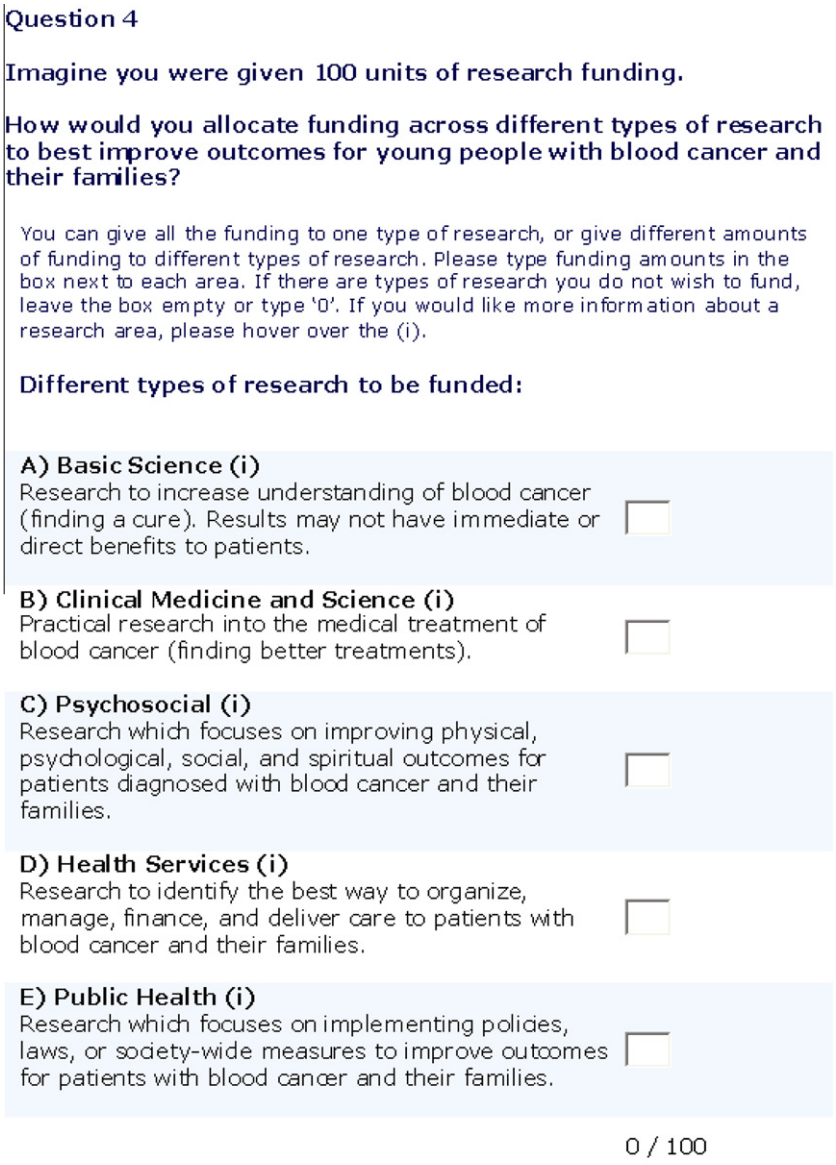

Fig. 1 – Example of a value-weighting question.

4.2.2. *Health care and other professionals working with young cancer survivors*

Health care and other professionals (e.g. oncologists, nurses, allied health and teachers) working with young haematological cancer survivors were recruited from the Leukaemia Foundation's Support Services Staff database or via peer nomination. Members of the advisory group also invited peers and colleagues in their field to take part in the study, although the advisory group members themselves did not participate. Eligible professionals had an email address and were able to read English. The number of health care professionals invited to participate was greater than that for the consumers to ensure that a wide range of specialties were represented. Likewise, as with the consumer sample, the sample identified from the databases in each state was proportional to the total number listed on the database.

4.3. *Procedure*

One hundred and fifty seven participants (112 health care and other professionals, and 45 consumers) were invited to take part in the study. The participants were sent an invitation by email from the Leukaemia Foundation which included a link to the questionnaire. Participants who had not completed the survey after 2 weeks were sent a reminder email.

4.4. *Statistical analysis*

Data was analysed using the Stata Statistical package. Descriptive statistics (proportions, means and confidence intervals) were used to identify priority research areas. Due to the multiple items within each domain and the constraints regarding the allocation of 100 funding units, confi-

Table 2 – Demographic characteristics of 80 study participants.

Participant demographics	$n = 80$	%
Gender		
Female	68	85
Male	12	15
Professionals		
Clinicians	7	8.8
Nurses	29	36
Allied health	17	21
Researchers/other professionals	7	8.8
Consumers		
Young people	10	13
Carers	10	13

dence intervals rather than *t*-tests were used. A non-preferential allocation was defined as the equal distribution of funding across all items within the domain (100 divided by the number of items within the domain). For example, in a domain with two items the non-preferential allocation would be 50. Within each domain, preferences were considered to be significantly higher or lower than non-proportional allocation if the 95% confidence interval did not include the non-preferential allocation. A sample of approximately 100 participants was required to provide mean allocations with 95% confidence intervals within ±0.2 standard deviations of the mean.

Mean funding allocations between consumer and professional groups were also compared. The ratio of professionals to consumers was 3:1 to allow for the variation of specialties within the professional group. Assuming a ratio of 3:1 for professionals relative to consumers, the 95% confidence intervals for these subgroups would be within 0.25 and 0.4 standard deviations of the mean, respectively.

5. Results

5.1. Participants

Eighty participants (Table 2) completed the value-weighting measure (response rate 51%). The 10 AYA participants were 19–23 years of age. Half of them had been diagnosed with Leukaemia and the other half with Lymphoma. Four were 2–5 years post-diagnosis and six were more than 5 years post-diagnosis.

5.2. Approach

Strategic research was allocated a higher proportion of the total research funding, compared with investigator-driven research (Table 3). The mean allocation and confidence interval for strategic research were significantly higher than the non-preferential allocation of 50 units, showing a clear preference for this approach.

5.3. Areas

Clinical medicine and psychosocial research were allocated the highest proportion of research areas funding (Table 3). These were the only items with mean funding allocations and confidence intervals greater than a non-preferential allocation of 20 units. Public health research was allocated less mean funding than all other areas. Within the area of psychosocial research there was a similar allocation of funding to all areas (Table 4).

5.4. Populations

AYAs who were newly diagnosed or had relapsed were allocated the greatest proportion of funding. Of the patient populations, only AYAs who were newly diagnosed, relapsed or finished treatment had confidence intervals above the non-preferential level of 12.5 (Table 5). None of the non-patient populations had mean funding allocations above the non-preferential allocation. Parents and carers had a higher mean allocation than the siblings, partners and close friends.

5.5. Time-frames

The perceived time-frames for commencing psychosocial research for each item are provided in Table 6. The development of psychosocial measures, identification of risk and resilience and translation of research into practice, were identified by

Table 3 – Mean, rank and 95% confidence intervals for funding allocation in the research approach and areas domains for all participant groups.

	Professionals ($n = 60$)			Consumers ($n = 20$)			Combined ($n = 80$)		
	Rank	Mean	95% CI	Rank	Mean	95% CI	Rank	Mean	95% CI
Approach									
Strategic	1	64	59–68**	1	69	61–77**	1	65	61–69**
Investigator-driven	2	37	32–41*	2	31	23–39*	2	35	31–39*
Areas									
Clinical medicine	1	27	22–31**	1	29	23–35**	1	27	24–31**
Psychosocial	2	25	22–29**	3	19	14–23	2	24	21–27**
Basic science	3	18	14–22	2	22	17–27	3	19	16–22
Health services	4	18	15–20	4	17	15–20	4	18	16–20
Public health	5	12	9.5–15*	5	13	9.1–16*	5	12	10–14*

* Significantly lower than a non-preferential allocation.
** Significantly higher than a non-preferential allocation.

Table 4 – Mean, rank and 95% confidence intervals for funding allocation in the psychosocial research sub-domain for all participant groups.

	Professionals (n = 60)			Consumers (n = 20)			Combined (n = 80)		
	Rank	Mean	95% CI	Rank	Mean	95% CI	Rank	Mean	95% CI
Psychosocial research									
Identify risk and resilience	1	14	11–17	5	13	10–15	1	14	12–16
Develop psychosocial measures	3	13	11–15	2	15	11–18	2	14	12–15
Translate research into practice	2	14	11–17	6	12	8.0–16	3	14	11–16
Treatment centre/care delivery	5	12	9.7–14	1	17	12–22	4	13	11–15
Peer support/social activities	4	12	9.7–14	3	13	10–16	5	12	10–14
Physical/psychological therapy	6	12	9.8–14	4	13	9.7–16	6	12	10–14
Online interventions/technology	7	11	8.9–14	8	9.0	6.1–12*	7	11	8.8–13
Information/education	8	11	8.5–14	7	9.0	6.4–11*	8	11	8.5–13

* Significantly lower than a non-preferential allocation.

Table 5 – Mean, rank and 95% confidence intervals (CI) for funding allocation in the research populations domain for all participants.

	Professionals n = 60			Consumers n = 20			Combined n = 80		
	Rank	Mean	95% CI	Rank	Mean	95% CI	Rank	Mean	95% CI
Populations									
Newly diagnosed	1	18	16–21**	2	17	15–20**	1	18	16–20**
Relapsed	2	16	14–18**	1	19	16–21**	2	17	15–19**
Finished treatment	3	15	13–17**	4	13	8.1–17	3	15	13–17**
Receiving treatment	4	13	11–16	3	17	14–20**	4	14	12–16
Receiving palliative care	5	12	9.9–14	6	10	7.6–13	5	12	9.9–13
Parents/carers	6	10	8.9–12*	5	11	8.3–15	6	11	9.3–12*
Siblings	7	7.7	6.2–9.1*	8	6.0	4.2–7.8*	7	7.3	6.1–8.4*
Partners/close friends	8	6.6	5.3–7.8	7	6.9	4.6–9.1*	8	6.7	5.6–7.7*

* Significantly lower than a non-preferential allocation.
** Significantly higher than a non-preferential allocation.

Table 6 – Participant views regarding time-frames for commencing research in each psychosocial research area (n = 80).

	12 months		1–2 years		3–5 years		Not at all	
	Rank	%	Rank	%	Rank	%	Rank	%
Psychosocial research area								
Develop psychosocial measures	1	69	6	21	8	6.3	1	3.8
Identify risk and resilience	2	66	5	24	7	7.5	2	2.5
Research into practice	3	63	5	24	5	13	3	1.3
Treatment centre/care delivery	4	44	4	33	2	20	1	3.8
Information/education	5	33	3	49	3	18	3	1.3
Peer support/social activities	6	31	1	58	6	10	3	1.3
Online interventions/technology	7	28	2	51	1	21	4	0
Physical/psychological therapy	8	26	1	58	4	15	3	1.3

the majority as areas which needed to be funded in the next 12 months in order to most quickly improve psychosocial outcomes. More than 77% of the participants indicated that research should commence within two years for all psychosocial research items.

5.6. *Comparison of research priorities between consumer and professional groups*

Tables 2–5 show the comparison of mean funding allocation between health, research and other professionals (n = 60) and consumers (n = 20). There were no significant differences in mean funding allocation between these groups for any of the domains, as the confidence intervals for all items overlapped.

5.7. *Acceptability of the value-weighting method*

More than 80% of the participants agreed or strongly agreed that the value-weighting method allowed them to indicate the areas of research they valued the most (88%) and were easy to understand (83%). The method was perceived as a good way to determine priority research areas (63%) and a process they would recommend (58%).

6. Discussion

To improve the outcomes for AYAs with haematological cancer and their families, the results show a preference for funding strategic research over investigator-driven research, with clinical medicine and psychosocial research perceived as the more valuable research areas. Within the psychosocial research domain, research regarding measure development, predictors of risk and resilience and translation of research into practice were identified areas which needed to be funded in the next 12 months in order to most quickly improve psychosocial outcomes. Research populations identified as having the greatest need for funding were patients who were newly diagnosed, relapsed or had finished treatment.

There were no significant differences between the mean funding allocations of professionals compared with those of consumers. This indicates that there are similar views in both groups about the types of research that are most needed and will provide the greatest improvement in outcomes for AYAs with haematological cancer and their families.

6.1. *Feasibility and acceptability of the value-weighting method*

The value-weighting method utilised in this study proved feasible and acceptable. Allocating proportions of research funding to items within previously determined domains provided details regarding the relative magnitude of preferences. This has an advantage over using advocacy, consensus or health economic approaches alone, as it provides funding agencies with the information concerning not only which areas to fund, but also the proportion of funding that should be allocated. The value-weighting approach also provides a mechanism by which a range of different views from various stakeholder groups can be consolidated.

6.2. *Limitations*

As a proportion of the sample was nominated by members of the advisory group, selection bias is possible in that the sample may not have been representative of the intended population. Given that members of the advisory group represented a wide range of expertise it is likely that a range of views across the professional and consumer groups was obtained.

Secondly, the sample size did not permit the detection of small differences between groups. Over-sampling to ensure adequate representation from a wide range of professional groups may have biased the results towards a clinical focus. However, no significant differences between the mean funding allocations of consumers and professionals were observed. Within the professional group, the higher proportion of the nursing professionals may have further biased the results. It is possible that the nurses are more likely to place higher importance on the psychosocial and survivorship aspects of patient care, given clinicians' work often focuses on acute cancer treatment.[23]

Thirdly, there may have been an order effect in the allocation of funding units, such as a trend towards less funding for items nearer to the end of the list in some domains. However, as, the rank order is different to the order in which items were listed for all domains, an order effect is unlikely to have had a major influence on the results.

Finally, it should be noted that AYAs with haematological cancer often experience more intensive treatment and report higher psychological distress than AYAs diagnosed with other cancer types,[3] therefore the research priorities of this group may not represent all AYA cancer survivors. The under-representation of newly diagnosed and relapsed patients in the consumer group may also impact the generalisability of the results.

6.3. *Comparison of findings to other funding organisations*

6.3.1. *Approach*

The preference for funding strategic research (65%) over investigator-driven research (35%) appears to contrast with the funding policies of most national health funding bodies. For example, in 2006, the National Institutes of Health (NIH) dedicated approximately 55% of their total budget to investigator-initiated research[24] and in 2008 the National Cancer Institute (NCI) allocated almost half of its cancer research funding to investigator-initiated research, a proportion which has remained constant for the past 15 years.[25]

6.3.2. *Areas*

The high proportion of funding allocated to clinical medicine and psychosocial research areas in this study is consistent with the previous findings. In the 2004 and 2008 Oncology Nursing Society Research Priorities Survey, quality of life was the top-ranked research priority across the spectrum of cancer care from prevention to palliative care.[23–26] Similarly, a Delphi study with haemato-oncology nurses identified chemotherapy and psychosocial issues as high priorities.[21] A study of patients attending cancer centres in the United Kingdom found that the psychosocial impact of cancer on daily life, and risk factors or causes of cancer, was their top research priorities.[27]

The priorities of patients and providers are in contrast to the way funding is currently allocated by national cancer research funding bodies. The National Cancer Research Institute (NCRI) reported that funding allocated to cancer control, survival and outcomes research was approximately 6% compared with 41% allocated to cancer biology.[28] The National Medical Health and Research Council (NHMRC) and other government and not for profit organisations in Australia also direct the majority of their cancer research funding towards basic research (65%) while clinical (23%), psychosocial (6%) and public health (6%) research share smaller proportions.[29] When research funding allocation is broken down by cancer type, such as for lymphohaematopoietic cancers, the proportions are basic research (82%), clinical (15%) and public health (3%), with nothing allocated to psychosocial.[29] This is despite consumer representatives often serving on the scientific review panels of these organisations.[30] Including representatives from funding bodies in future research allocation studies may be important for identifying where

possible differences in research priorities might exist between funders, and health professionals or consumers.

6.3.3. *Populations*

As reported in a previous study[17] targeting research funds towards patients in the early stages of their cancer journey is perceived to be the best way to improve psychosocial outcomes for both AYAs and older adults diagnosed with haematological cancer.

7. Conclusion/implications

Perceptions of research funding allocation in this study are in contrast to the current funding allocations of some organisations, suggesting that a review of research funding allocation may be warranted. The value-weighting approach represents an acceptable and feasible way to quantify stakeholders' perceptions about research resource allocation.

Conflict of interest statement

None declared.

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