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ORIGINAL RESEARCH ARTICLE

Genomic Testing for Relapsed and Refractory Lymphoid Cancers: Understanding Patient Values

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Abstract

Background New clinical genomic assays for lymphoid cancers allow for improved disease stratification and prognostication. At present, clinical implementation has been appropriately limited, owing to a paucity of evidence to support clinical and cost effectiveness. Understanding patients' values for precision oncology under conditions of uncertainty can be used to inform priority-setting decisions.

Objectives Our objective was to ascertain patients' qualitative preferences and attitudes for prognostic-based genomic testing.

Methods Individuals who were diagnosed with lymphoid cancer between 2000 and 2018 in British Columbia, Canada, were recruited to participate in one of three focus groups. A maximum variation sampling technique was used to capture a diversity of perspectives. A patient partner was involved in the development of the focus group topic guide and presentation materials. All sessions were audio recorded and analyzed using NVivo qualitative analysis software, version 12.

Results In total, 26 participants took part in focus groups held between November 2018 and February 2019. Results illustrate qualitative preference heterogeneity for situations under which individuals would be willing to undergo genomic testing for relapsed lymphoid cancers. Preferences were highly contextualized within personal experiences with disease and treatment protocols. Hypothetical willingness to pay for testing was contingent on invasiveness, the potential for treatment de-escalation, and personal health benefit.

Conclusions Patients are supportive and accepting of evidentiary uncertainty up until the point at which they are required to trade-off the potential for improved quality and length of life. Demand for precision medicine is contingent on expectations for benefit alongside an acknowledgment of the opportunity cost required for implementation. The clinical implementation of precision medicine will be required to address evidentiary uncertainty surrounding personal benefit while ensuring equitable access to emerging innovations.

1 Introduction

Lymphoid cancers are the fifth most commonly diagnosed group of cancers in Canada, with approximately 11,000 people expected to have been diagnosed in 2019 [1, 2]. Mortality is largely attributable to relapsed disease, with approximately 50–90% dying from relapse depending on cancer subtype [3–6]. High probability of relapse in combination with complex tumor biology lends lymphoid cancers to the application of genomics to provide information about prognosis and treatment options [7–9]. Recent advancements in gene expression profiling can be found in Hodgkin's lymphomas (HL). The newly developed prognostic assay RHL30 can stratify patients according to disease subtypes,

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Key Points for Decision Makers

Development of clinical assays is an important goal in the management of lymphoid cancers, yet evidence of patient and public preferences for genomic testing is limited.

Understanding of patient preferences will support informed decision making and alignment of reimbursement decisions that reflect health system stakeholder values.

Focus groups with patients revealed high tolerance for uncertainty and a belief that accuracy and affordability would improve over time.

There is a need to support patients with decision making for genomics-guided care, particularly to help navigate how uncertainty bears on decisions.

which can inform decisions about potential treatment response within specific patient populations [8]. For example, accurate subtyping allows for the estimation of benefit following autologous stem-cell transplantation, an aggressive treatment used for relapsed or refractory HL [8]. Within non-Hodgkin's lymphoma, patients with diffuse large B-cell lymphoma aged < 60 years with activated B-cell subtype may experience survival benefit from ibrutinib, although there is uncertainty around this result [10].

The reimbursement of both predictive and prognostic genomic assays has been appropriately limited [11]. This is partly because of a lack of evidence on population-level clinical and cost effectiveness [12, 13]. To date, much of the evidence informing clinical-effectiveness estimates has been generated through single-arm trials that used limited sample sizes [13, 14]. Given uncertainties related to patient outcomes following sequencing, identifying patient and public willingness to engage with precision medicine is necessary to inform health technology reimbursement decisions. The extent to which patients and the public value the highly complex and uncertain information generated through precision medicine will help decision makers predict uptake and value for money [13]. While national decision-making bodies such as the Canadian Agency for Drugs and Health Technologies (CADTH) aim to incorporate patient values into reimbursement recommendations, integration at the stage of evidence development is limited [15]. Patient and public values for precision medicine are characterized by substantial preference heterogeneity and preference-sensitive trade-offs [11, 14, 16–19]. Incorporating the spectrum of potential impacts of a policy decision directly into the economic evaluation of precision medicine allows decision making to align with stakeholder preferences [20, 21]. Failing to do so may result in resource allocation decisions that do not reflect valued outcomes and priorities [12]. To date, integration of patient and public values into reimbursement decisions for precision medicine has been limited. Alongside the development of precision medicine innovations, there is an unmet need to generate a robust evidence base for patient values that will inform resource-allocation decision making.

The application of qualitative methods to inform preference-based values has gained popularity in recent years [22–24]. To elicit preferences, both quantitative and qualitative methods are used [19, 25–28]. Discrete-choice experiments (DCEs) have been applied widely to quantify stakeholder preferences for healthcare interventions, including genomic technologies [28–31]. DCE surveys ask respondents to trade-off between different attributes of a decision, often using hypothetical scenarios. Studies investigating the value of genomic information have shown that patient preferences for this information vary considerably and may be a function of individual-level factors such as personal history of disease, expectations for personal benefit, and comfort with evidentiary uncertainty [32–34]. The objective of this investigation was to apply qualitative methods to comprehensively characterize values that inform hypothetical decisions to undergo genomic testing for relapsed lymphoid cancers. Our findings will be used to develop a DCE to estimate preference-based utilities for biomarker-informed relapsed lymphoid cancer care to inform health technology assessment and resource allocation.

2 Methods

2.1 Participant Recruitment

Focus group participants were recruited via email. Individuals approached for participation had consented to be notified about research at the Centre for Lymphoid Cancer at BC Cancer. BC Cancer is responsible for the delivery of cancer care in the province of British Columbia (BC) in Canada. We applied a maximum variation sampling technique to capture a diversity of perspectives [35]. We sought variation on lymphoid cancer type, age, sex, and years since diagnosis. Individuals were invited to participate if they were diagnosed with lymphoid cancer between 2000 and 2018, were ≥ 18 years at the time of diagnosis, and had received treatment in British Columbia, Canada.

2.2 Focus Group Sessions

Focus groups were selected as they allow patients to come together in an environment where shared experiences are encouraged, and discussion is generated through a process

of listening and responding to other participants' viewpoints [13, 32]. A semistructured focus group guide was developed for this study (see Table 1). We engaged the clinical research team and a patient partner to ensure that key concepts were included and communicated effectively. An informational slide deck was developed to introduce participants to key concepts. The slide deck was piloted with the research team and patient partner and was presented to participants at the outset of each focus group (see the Electronic Supplementary Material [ESM] 1).

Focus groups were audio recorded and professionally transcribed following written informed consent. Two researchers (SC and SP) facilitated and led the focus group sessions, and one researcher took notes (AJNR). SC and SP are trained masters- and PhD-level health researchers, respectively, with extensive experience leading focus groups and interviews and conducting qualitative analysis. To the best of the authors' knowledge, participants had no prior familiarity with either facilitator prior to the focus group session. At the outset of each session, the facilitators' occupation and role in the study was briefly summarized to participants. Facilitators made detailed field notes after each session. Each participant was provided with a $100 CAD honorarium. Following the session, participants completed a brief demographic survey online using Research Electronic Data Capture (REDCap) electronic data-capture tools hosted at BC Children's Hospital. REDCap is a secure, web-based software platform designed to support data capture for research studies, providing (1) an intuitive interface for validated data entry; (2) audit trails for tracking data manipulation and export procedures; (3) automated export procedures for seamless data downloads to common statistical packages; and (4) procedures for importing data from external sources [36].

2.3 Qualitative Analysis

De-identified transcripts were uploaded onto NVivo qualitative analysis software in preparation for analysis (QSR International Pty Ltd., version 12, 2018). Analysis was conducted by two reviewers (SC and SP) using both inductive and deductive coding methods [37]. In deductive coding, preestablished codes are used to categorize the data. Codes were based on the questions and topics from the topic guide, and an initial code book was developed. Inductive coding was used to capture additional discussions and ideas that emerged from the data. Both researchers (SC, SP) independently coded the same 50% of transcripts to determine the degree of agreement regarding code definition and to assist with development of the final code book (see ESM 2). Concepts were discussed between researchers, allowing for new codes to be established and refining definitions of current ones. Any discrepancies in coding between researchers were resolved through an iterative process of refinement, discussion, and consensus. Following this process, one researcher (SC) coded the remaining transcripts. After coding each focus group transcript, the analysts discussed emergent themes and how those themes mapped to the existing code book. Following the completion of the final focus group, analysts came to the consensus that thematic saturation was reached. Transcripts were not returned to participants, and participants were not asked to provide feedback on study findings.

This study received ethics approval from the University of British Columbia—BC Cancer Research Ethics Board (H18-00490). All participants were required to sign a consent form prior to participation in the study. Our work follows the COREQ guidelines for reporting of qualitative studies [38].

Table 1 Topics used to guide focus groups, including prompts

Topic	Prompt
Introduction	I would like to start off by getting a sense of whether you think these genomic tests are worthwhile
Expectations/return of results and willingness to pay	Do you have any concerns about genomics-guided strategies? What types of benefits would you expect or require? Under which circumstances would you consider paying for genomic testing (if any)? Would the amount that you would be willing to pay depend on the type of information you could receive from the test? If you had to pay for the test, what would you expect to receive from it (e.g., accuracy of results, speed of test results, ability to predict outcomes)? What impact would timing of the test have on your decision?
Decision making and informational needs	Who would you want to be involved in the decision to undergo genetic decision? What information would you like to receive before making the decision to undergo testing? What types of information would you want to be given after having the test? What types of procedures would you be willing to undergo? How should the information be presented?

3 Results

Three focus groups took place between November 2018 and February 2019. Each session was approximately 90 min in length, with sessions taking place at BC Cancer in Vancouver, British Columbia, Canada. A total of 486 invitational emails were sent, yielding 41 responses. Among the 41 potential participants approached, 26 individuals participated. In total, 15 eligible potential participants were unable to join because of availability, travel requirements, or personal preference. We ceased recruitment once reviewers determined that thematic saturation had been reached.

The mean age of participants was 64 years (range 30–83 years); 13 (50%) participants were female, and nine (35%) had self-reported having experienced lymphoid cancer relapse (Table 2). In total, 46% of participants had been diagnosed with indolent lymphoid cancer.

Table 2 Participant characteristics

Characteristic	Number, *n* (% all)[a]
Participants, *n*	26
Female sex	13 (50)
Mean age ± SD	64 ± 12
Personal experience with relapsed lymphoma	9 (35)
Age group, years	
25–34	1 (4)
35–49	2 (8)
50–64	11 (42)
65–79	10 (38)
≥ 80	2 (8)
Cancer type	
Chronic lymphocytic leukemia/small lymphocytic lymphoma	4 (15)
Follicular	8 (31)
Diffuse large B-cell lymphoma	4 (15)
Primary mediastinal large B-cell lymphoma	2 (8)
Hodgkin's lymphoma	3 (12)
Other[b]	5 (19)
Year of cancer diagnosis	
2000–2005	4 (15)
2006–2011	5 (19)
2012–2018	17 (65)

SD standard deviation

[a]Not all values add to 100 because of rounding

[b]Includes mucosa-associated lymphoid tissue and mantle cell lymphoma

3.1 Summary of Analytic Themes and Optimism for Benefit from Innovation

After coding was complete, the codes were organized into four major categories with related subcategories: decision-making process for testing; expectations and attitudes (of test/genomic information); concerns (about testing/genomic information); and preferences for return of genomic information. After reviewing and comparing categories and subcategories, two qualitative researchers identified commonalities with what was being discussed in each category. Major themes related to factors about the decision-making process, relationships with healthcare providers, preferences for the return of genomic information, and the complex nature of decision making on the basis of sequencing results. Through an iterative process of theme identification and refinement, four major themes were established: (1) decision making in context to evidentiary uncertainty, (2) preferences for returning of genomic information, (3) support for shared decision making, and (4) trade-offs related to paying for genomic testing. Participants framed each of these themes around strong support for implementation. Participants voiced confidence and hope for precision medicine to advance lymphoid cancer prevention and care, to the extent that at times it was challenging to generate critical discussion. These attitudes were influenced by the belief that genomic testing would provide more reliable information that could be used to inform prognosis and improve survival.

> Well, I see, for me, the genetic testing as a critical part of treatment plan. Like absolutely critical. (G3-P22)

Optimism was discussed in reference to individuals' lived experience with lymphoid cancers. Participants frequently referenced their personal experiences with lymphoid cancer when discussing concerns and expectations related to precision medicine:

> It takes a long time to get that sort of, you know, unwelcome guest out of the house where cancer isn't part of every single conversation. And I don't know, but I am really excited about this research without a doubt. (G1-P4)

Participants expected genomic information to establish disease etiology and offer ways in which the disease could be prevented or treated or progression delayed. Although there was a strongly articulated expectation of future benefit, participants acknowledged evidentiary uncertainty related to this emerging field. Crucially, they also expressed an expectation that uncertainty would decrease as additional data were collected:

> … in the infancy, I would be willing to put up with lots of vague kind of answers as the data sets get built with the understanding that over time they are going to get better. (G2-P15)

Support for research and clinical implementation of precision medicine to advance prevention and treatment efforts

for lymphoid cancers was prevalent across all three focus groups. Participants offered a strong desire to advance research, even if efforts were unlikely to provide them with personal benefit.

3.2 Decision Making in Context to Evidentiary Uncertainty

Decision making in context to uncertainty framed much of the discussions related to expectations, perceived benefits, preferences for the return of results, and concerns. Uncertainty was considered a necessary feature of genomic testing that should be tolerated in the short term:

> It just seems like the gene information is not an all-seeing killer app, it's just another tool. So it really doesn't allow you to get as far to a cure as you would like it to be. (G1-P5)

Alongside the expectation of future population-level benefit, participants were tolerant of the potential for test inaccuracies, uncertainty in results, and the potential to have non-actionable information generated through the testing process. The potential to make life choices and plan for one's future in a more informed way was perceived as valuable by some participants:

> … that is true, it's [genomic testing] not 100 percent. But it does give you some additional information to make maybe better choices as opposed to having to make some choices completely blind. (G3-P22)

Participants were willing to receive uncertain results rather than forego or delay testing, with the notion that risks, scientific probabilities, and information on survival in light of uncertainties are communicated in advance of testing.

> Facilitator: … what would you want to have, want to receive from the test?
>
> G2-P11: All the answers.
>
> G2-P17: Well, I think a clear sense of the probabilities of, you know, how – what the margin of error is, because it's not going to be 100 percent. So a sense of it. And, I mean, I think we all live with some sense of what our risks are … you live knowing you have some risks, so we all do that. But I would just like to get a sense, a scientific assessment of the probabilities …
>
> G2-P13: A more refined prognosis.

Where participants demonstrated lower tolerance for uncertainty was with respect to assignment of treatments. Participants voiced preferences in light of the treatments that they had received, with a motivation to develop interventions that would reduce the deployment of ineffective or harmful treatments:

> … this gene information … can be target specific … so that, you know, I'm not being loaded up with all these chemicals … a scatter gun approach in hopes that it gets the one that we're after. (G1-P7)

Our participants frequently referenced their own experiences with difficult treatment protocols as a rationale for valuing treatment de-escalation:

> Well, if getting the gene testing would influence the type of treatment that you're getting, then I think you would go through any lengths to have it done … [—] I actually had to go through it [chemotherapy] three times, then followed by the stem-cell transplant. So if gene testing would've more finely tuned the course of action then I think it would be really, really a good thing. (G3-P24)

Participants articulated a strong preference to avoid interventions that would not result in personal benefit, such as chemotherapy or stem-cell transplantation. Evidence-informed treatment de-escalation was prioritized across the three focus groups.

3.3 Preferences for the Return of Genomic Information

Discussions related to preferences for receiving genomic information centered on information used to inform prevention or treatment decisions, information unrelated to cancer, uncertain findings, and prognosis. Participants varied in terms of the extent to which they valued the return of different forms of genomic information. For example, some saw a danger in having all results returned without being equipped to interpret the findings or understand what it means for one's care:

> I think I want to just know about how [information from genomic test] relates to the cancer … I don't think I'd want to know my entire genetic profile because then you're just going to be terrified all the time … [—] I don't think I'd want to know everything. I think that's a little bit too much information. (G1-P9)

Others preferred access to all of their information, regardless of whether it was directly related to their current diagnosis:

> I'm still like one of these that I would like to have information. I don't know, I just do. And not all information is good, but then I know what I'm dealing with and how I'm going to deal with it. (G1-P1)

> I'd just like to have all the information I could. I'm not really that worried about the results. (G2-16)

Conversely, other participants preferred only information that could be used to inform prevention, treatment, or management decisions:

> It depends on whether the finding has a treatment. So say you found that you had Parkinson's disease, the risk for it, but there's no treatment that you can do in advance to prevent it from happening. There's no advantage to early treatment, so why know it? (G2-P12)

Participants acknowledged the potential for a negative psychological impact to knowing one's prognosis in the absence of targetable treatment options, even if they themselves did not subscribe to that personal opinion ("… a downside, psychological downside" G3-P22). The return of various forms of genomic information was met with considerable preference heterogeneity. While our participants were willing to undergo testing under conditions of uncertainty, they felt strongly about respecting the autonomy of tested individuals as it related to the return of genomic information. Individuals differed substantially in terms of the kinds of information that they would be willing to receive and the rationale for holding these opinions. Expectations, comfort with evidentiary uncertainty, and perceived ability to comprehend complex genomic information informed stated values and preferences.

3.4 Support for Shared Decision Making

In light of discussions surrounding informational complexity and uncertainty, participants described a balance between seeking advice from their oncologist while still having the autonomy to make decisions that affected their care. They saw their oncologist as a key partner in their decision-making process and as someone who was able to outline the potential benefits and drawbacks of genomic testing:

> I have a really great oncologist because he explains everything totally and pulls on his experience with other patients … [—] But at the end of the day it was my decision. (G2-P11)

Discussions about options for genomic testing were similarly contextualized, with participants wanting a broader understanding of the recommendation from the perspective of their oncologist but then being trusted with making the final decision on their own:

> But I think you were asking about how do you want to be informed if there's a possibility of test, right? So it would have to be something more than what they do with the mammogram thing. You know, which is just, you're over 45 here's the number for [the clinic]. [—] I want to see more information on the potential benefits and side effects … (G2-P17)

Closely tied in with discussions about how involved the oncologist should be in decisions about their care was suggestions for how information can be made more accessible and easy to understand. Many participants described striking a balance between high-level summaries of facts with more detailed descriptions. Participants described a preference for straightforward communication of test outcomes in terms of impact on care as well as treatment trajectories, usually in written format that allowed them time to review it at home. Further, stated preferences supported the receipt of information related to genetic risk and potential testing outcomes in lay terms, given the complex nature of the information being communicated:

> You know how you go get your car looked at and they give you a car inspection report and they say you need to get this done and here's why and you need to get this done and here's why. Something like that in plain English I think would be really awesome for most people. For everyone actually. I mean you can throw in charts and graphs at the back end for those nerdy types [—]. (G2-P15)

> … not just written results with a lot of numbers and percentages and plus and minuses and graphs because that would be too hard to interpret for most people. (G2-P17)

Across the focus groups, individuals articulated a strong sense of trust towards their oncologists, balanced with a desire for autonomous decision making. For this reason, there was consistent support for a shared approach to decisions for cancer treatment and genetic testing. While a common desire for involvement in testing and treatment decisions emerged through focus group sessions, they sought the active engagement of healthcare providers throughout the decision-making process.

3.5 Willingness to Pay

As stated previously, hope and optimism tended to dominate much of the discussions across focus groups. To identify aspects of genetic testing wherein trade-offs may be required, participants were asked to consider potentially harmful or unintended aspects of testing. Trade-offs included, but were not limited to, test invasiveness, cost, inaccurate results, and ineffective treatments. Trade-offs were frequently framed according to varying scenarios under which participants would consider paying for a genetic test given the potential for personal benefit. In general, paying for a genetic test

was a source of debate, with some participants appealing to equity of healthcare access.

> … whatever the cost might be, it would depend what it is and it would be prohibitive to lots of people, right? The disease knows no socio-economic boundaries. Just takes people out and there you go. (G2-P15)

Referencing previous experience with cancer treatment and care, participants expressed concern that paying for testing would increase the potential for inequity in access and prevent certain patients from being able to incur potential benefit. Further, the prospect of paying for a test caused some participants to impose expectations of what they would be willing to pay for and what their expectations were for the test. In these conversations, treatment-related information was often an expectation:

> I'd pay more for information that would lead to a better treatment as long as that treatment was available. (G2-P13)

Participants did not wish to pay for testing that was painful or would require significant recovery time, especially if the test exclusively provided prognostic information.

> If I'm not getting anything out of it at all, I'll leave it to more braver people for more invasive testing. (G2-P14)

> … it really depends on how invasive is your testing, that's what my concern would be. If you're saying I have to be cut up to do the thing, then I'll be second thought. But if you were to say a simple maybe a little bit of a needle poking in, then by all means, I'll be very interested. (G1-P3)

Willingness to pay for testing was an area of persistent debate and discussion across the three focus groups, with opinions differing regarding the conditions under which trading-off aspects of personal versus population-level benefit would be acceptable.

4 Discussion

Our analysis identified a high tolerance for scientific uncertainty alongside an appreciation for the complex nature of genomic information. Throughout discussions, participants valued a shared approach to decision making for genomic testing. Consistent with the existing literature, while participants consistently valued information with the potential to alter disease trajectory, preferences for the return of non-actionable genomic information varied [39–41]. Participants emphasized the importance of enhanced communication with healthcare providers and the development of supportive resources for patients to assist decision making. This finding is consistent with other research showing that heterogeneous preferences for genomic interventions is consistent with preferences for a shared and supported approach to decision making [32]. Similarly, healthcare provider involvement in decision making and trust in their ability to communicate results was important for our participants. Existing evidence supports this finding, in that patients frequently voice trust in their providers to interpret test results and tailor decisions accordingly [42, 43].

Individuals selected for inclusion in the focus groups each had a personal history of lymphoid cancers. Participants spoke at length about the extent to which concerns over relapse played an active role in their lives. For example, personal experiences with chemotherapy and stem-cell transplantation often framed discussions regarding what personal benefit might look like. Avoiding harmful, toxic, and ineffective treatments was prioritized throughout. Engaging individuals with lived experiences with the disease is likely to provide insights that differ from those of the general population [33, 34]. Alongside this conceptualization of benefit, there was a consistent and clearly articulated optimism for the promise of precision medicine and the hope that clinical implementation would provide both personal and population-level value to future patients.

Across focus groups, participants voiced comfort with evidentiary uncertainty and willingness to engage with precision medicine. Similar to published literature, our participants were hopeful that precision medicine would generate improved patient outcomes [44]. When discussing willingness to engage with precision medicine for the management of relapsed disease, discussions about budget constraints imposed trade-offs and impacted individuals' tolerance for uncertainty. Willingness to pay out of pocket for testing varied according to the potential for personal versus public benefit and test invasiveness. This finding supports the claim that demand for precision medicine is contingent on expectations for benefit, particularly related to changes in treatment or survival [45].

This research provides valuable insights into patients' perspectives for prognostic-based genomic testing. Obtaining this information from patients – not just patient advocates—is a key component to a reimbursement submission and priority-setting process to health technology assessment agencies. The patient-level information serves as a valuable complement to clinical and economic evidence and provides the ability to capture issues that fall outside these largely quantitative analyses. Our findings will inform a DCE to generate preference-based utility values for biomarker-informed relapsed lymphoid cancer care, with a view to guide reimbursement decision making [13].

4.1 Limitations

The results of our focus group investigation should be interpreted in context to its limitations. First, patients drawn from a single cancer center may not reflect the views of lymphoma patients more broadly. It is possible that we may have identified different emergent themes if we had sampled from a broader geographic range. Additionally, the majority of our population had been recently diagnosed with their cancer, which may have had an impact on perceptions and knowledge about genetic testing options and informed their expectations about testing. By applying a maximum variation sampling strategy, we sought to capture a diversity of patient perspectives rather than to generalize our findings beyond our sampling frame.

Our results should be interpreted alongside the hypothetical nature of the questions and situations posed to participants. The hypothetical nature of the discussions has the potential to overestimate individual's willingness to accept testing and may not reflect actual uptake [46, 47]. Hypothetical bias may play a role in the value individuals place on genetic information as they are not obligated to commit to their decision. Emerging evidence demonstrates the external validation of hypothetical stated preferences against actual decision making [13, 48]. Despite the potential for bias, the use of focus groups in this context allows investigators to characterize the spectrum of values that are important to groups of individuals when making decisions about biomarker-informed care.

5 Conclusion

Publicly funded health systems have a responsibility to ensure that reimbursed technologies provide value for money. The concept of value should correspondingly consider the spectrum of values related to both health and non-health consequences of reimbursed interventions. This is especially true regarding precision medicine, where there has been limited integration of patient and public values into reimbursement decisions. Our study sheds light on how individuals who have experience with lymphoid cancer come to value different aspects of genomic testing. We found that individuals expressed high tolerance for uncertainty and believed that accuracy of testing and its ability to become affordable would change over time. Willingness to pay for testing was also more strongly tied to the ability of the test to change treatment and improve outcomes. Participants also wanted the involvement of their oncologist in decision making but felt they could be better supported with resources and framing of test information to support their decisions.

The clinical application of precision medicine is characterized by complex and highly uncertain information. For this reason, efforts to acknowledge, address, and navigate uncertainty at both the system level and through the patient–physician clinical encounter will be necessary. In particular, as this work shows, individual preferences and values differ, making it important that it be consistently and thoughtfully integrated into reimbursement decisions. The evidence we present can help support the evaluation of precision medicine innovations and its integration into the health system.

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Declarations

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Conflicts of Interest Adam JN Raymakers (AJNR) has received compensation from CADTH, specifically from the pan-Canadian Oncology Drug Review (pCODR), for providing economic guidance about oncology drug submissions.

Availability of Data and Material The datasets generated and/or analyzed during the current study are not publicly available to protect the confidentiality of participants. De-identified data may be available from the corresponding author on reasonable request.

Ethics Approval This study received ethics approval from the University of British Columbia – BC Cancer Research Ethics Board (H18-00490).

Consent All participants were required to sign a consent form prior to participation in the study.

Author Contributions SC, DAR, AJNR, and SP contributed to the design of the research study. SC and SP conducted all participant recruitment and led the focus group sessions, supported by AJNR who took notes. SP and SC conducted the qualitative analysis. All authors were involved in the interpretation of the results and manuscript development. All authors read, reviewed, and approved the final manuscript.

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