EXPERIENCES ACCESSING AND RECEIVING TUMOUR GENETIC PROFILING IN VICTORIA: A CONSUMER-LED CROSS-SECTIONAL SURVEY STUDY

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Supplementary file 6 . Consumer Reference Group and VCCC Alliance staff reflections regarding key take away points from the study

Consumer Reference Group Member Responses

It has been great to reinforce our assumptions with data from patients and carers. In addition to the health equity issues due to the cost of the tests, it also highlights the importance of educating the treating team about the importance of tumour genetic profiling (and the impending government ban in relation to life insurance concerns) as they are usually the primary source of trusted information and it promotes shared decision-making with the patient and/or carer, and the need for early tumour genetic profile testing to enable the medical team to provide a targeted treatment plan.
I agree with XXX on questions of Health Equity and cost of testing. In myeloid cancers, New Gene Sequencing can be up to $600 out of pocket, fortunately now covered by

Medicare. This is central to access for patients.
Having data that supports our perceptions, given our own experience, is important and will hopefully lead to action that will bring about changes that directly positively impact patients. There seems to be a clear need for education across the board on the use and benefit of tumour genetic profiling. Establishing clear processes and a common approach to the collection, use and application of treatment options as a result of testing is required.
I have always had the view that making key decisions requires access to critical information. Decision making relative to health, well-being and potentially survival in my view ranks right up there on the 'key decision' scale and as such, I have sought to contribute all I could to bring this about as a 'standard of care' consideration given my partners personal experience some 10 years ago and at the time, this was an entirely novel approach. Thankfully now there is a much stronger emphasis on the use and benefits of tumour genetic profiling but as this research shows there is indeed much more to be done.
• As consumers, we place a certain amount of trust and expectation on clinicians to provide a safe, well informed, non-biased explanation of all options available for our care. • Some of the survey responses about treating team's willingness to share and inform consumer on tumour genetic profiling as an option in their care plan is concerning as it suggests this may lead to uninformed decision making, minimising consumer choice and access inequities • It is evident from these findings that the lack of consumer awareness of tumour genetic profiling remains a limiting factor on consumer choice and therefore may impact health outcomes.

VCCC Alliance Staff

The aspects about potential changes in care are the key take-aways for me; better education for clinicians and the idea of a centralised service to answer questions is a great compromise,

given the demands on oncologists' time. And the aspect of the improved understanding through share-decision making, as mentioned before, is a really great finding and could be implemented through, again, education and training of clinical teams. Aside from the results, I think this being a consumer-led study, for me it meant that the questions were able to glean more information from the participants. I think a 93% completion rate (for those that started filling out the survey) shows that the consumers helped shape the survey into something that the participants would want to and find easy to complete. There are a few limitations to the study which we've all discussed before, but I did want to touch on the overrepresentation of breast cancer patients. These patients are typically a very well-informed group due to (unfortunately) the large number of those diagnosed and the subsequent amazing levels of information and resourcing being provided to them. We may need to touch on that in the discussion. (And yet, even still many of the breast cancer patients did not understand testing so yeh, could be discussed either way I guess).

The points that stand out for me from this study are:

- This survey indicated health care professionals remain the most important source of information for patients and carers of tumour genetic profiling. Clinicians' understanding and attitudes toward such testing plays a huge role in influencing access and patients' experience, like a gate keeper role if you like.
- Clinicians should be aware that patients may hold a different attitude when it comes to costs. Just that it's going to cost money, patients may still want to hear about testing as an option. Cite 'autonomy' as one of the key medical ethical principles (reference if you like https://pmc.ncbi.nlm.nih.gov/articles/PMC7923912/). Clinicians as facilitators to help patients and carers access and understand information, patients and carers to consider and make informed decisions.

• Responses from this survey provided further examples of 'personal utility' in testing decision making. Clinicians and policy makers should take note of how personal utility needs to be considered in the context of shared clinical decision making, as well as assessing new genomic testing technologies. • Figure 2 Box plot indicated a positive association between shared decision making and higher levels of understanding of testing information. It would be logical to argue that increasing health literacy levels would enable higher levels of patients and carers' understanding of testing information, and ultimately facilitate a shared decision-making approach.
• The outcomes of the testing were resoundingly positive. Even the drawbacks such as confusion and lack of support around interpretation, present a gap that could be filled through an educational intervention – for the patient, carer and clinician. Educating the treating clinical teams is paramount, given the reliance of patients and carers on them as information sources. • The most distressing result was the clinicians making an assumption about the patient's ability to pay for (what could potentially be) a life saving test. This will just exacerbate equity issues. Pathways for financial assistance, testing through research pathways, few panels etc. must be explored and communicated to clinicians and their patients. • I think the shared decision making finding makes sense to me. If a clinician is going to take the time and effort to ensure that the patient and carers are informed enough to make a decision with them, then there is an educational process occurring for that patient. This has got to be more empowering, educative, respectful, inclusive, and ultimately, lead to a more satisfying outcome for the patient regardless of the outcome. • Remarkable that one quarter of respondents didn't know if they had had testing or not.

Clearly we have a long way to go regarding informed consent!! and patient information processes. Particularly for such a well educated cohort, this was an interesting finding. • Also that completion rate is incredible so well done to all in following the respondents up to complete, or they may have been more responsive because it was consumer led? Who knows. • I am not sure if it is in here or not (I might have missed it) but did we hypothesise that the reason for the high level of satisfaction when they pursued testing was that they had done all that they could do for themselves and their family (if there were familial implications), regardless of the utilisation for personalised medical therapies?
• The importance of understanding patient preferences and shared decision-making as illustrated in the regression analysis • Place an emphasis on patient advocacy. The importance of involving patients in care, research, education and policy making. • I was surprised by the high score for the self-rated impact (Figure 3). Impact can be interpreted in many ways (relief, removing uncertainty, knowing the treatment team are doing all they can, or the individual is doing all that they can etc). The other comments raised suggest a greater differential in experience. • Findings emphasise the patient needs for developing a roadmap for molecular testing. Specifically, equity of access. The commentary from the survey suggests inconsistencies in the system where access to testing dependent on your specific treatment team, and finances. Important for policy makers. • The importance of communication and education for all stakeholders (clinicians, consumers) • The consumer-led development of the survey and dissemination strategies

- It is not uncommon for clinicians and researchers to make assumptions about key aspects of patient care that may not necessarily resonate from a consumer's perspective. It is therefore incredibly insightful to engage directly with consumers to better understand what their own lived experience has been around genomic testing and what is most important from their perspective.
- Bringing together a CRG to not only collaboratively work together but also to demonstrate collective leadership around this project has been so beneficial and has been a pleasure to witness and really showcases the importance of involving consumers in key research areas as early as possible and throughout the entire research and development pathway.
- The important challenge now is to take the important findings garnered from this research project and translate it into real world practice change via stakeholder engagement, patient and clinician education initiatives, robust policy decisions and continued advocacy efforts to ensure that patients access to genomic testing is optimised and equitable.