

# CLLNZ – Topline Summary of Research

December 2022

## Background, Objectives and Method

CLLNZ requested focus groups in order to help understand the needs and wants of patients and their support people who are attached to the organisation. Given limited time and resources this project was seen to be a critical step in the development of a plan focussing activities into areas that mattered most to people.

While initially planning on 3 focus groups, 2 eventually took place due to participant availability. Both groups were comprised of a mix of patients (in various stages of CLL), trustees of CLLANZ and supporters/carers/family members. Groups lasted 90 minutes and were held on the 3<sup>rd</sup> and 10<sup>th</sup> of December via Zoom to maximise the opportunity to participate for people across NZ.

The core task/objective of the groups was to:

- (a) Understand the needs and wants of patients and their supporters and
- (b) Understand what people might be willing to contribute to the organisation

## Key Findings

People's needs for the organisation depend on a number of factors including:

- Age of onset (younger people have different information and testing needs)
- Stage of disease (watch and wait is very different to those needing active treatment)
- Adequacy of medical people around them (some people are able to access good information from their health practitioners, others are less fortunate)
- Area lived in (different protocols in different parts of NZ)
- Connection to other cancer organisations or not
- Personal support system
- By implication: own ability to search out information and make connection with helpful others

Praise was given for the booklet provided by CLLANZ but access to this isn't consistent because referral to the organisation seems to be uncommon (from GPs, Specialists and other cancer organisations). Most feeling that they had to use overseas resources to get an understanding of what CLL is all about.

Connection with CLLANZ was largely for:

- Information – wanting to know more
- Support – wanting to connect with like others
- Access – advocacy for gold standard treatments

If FOCUS is the goal of CLLANZ, then participants are clear – **ADVOCACY is the primary need closely followed by INFORMATION** – other elements can be taken care of by other cancer organisations or third parties (e.g. pharmaceutical companies)

## Summarised Needs by Stage

General Awareness	Diagnosis	Watch and Wait	Active Treatment
<p>Sense that GPs need to have higher awareness of CLL and be better informed of both the disease and patient needs</p> <p><b>Wanting a wider GP education programme put in place regarding CLL</b></p>	<p>Everyone wanting information and struggling to find local sources. CLLANZ not typically referred to by health practitioners – discovering it through own search activities typically, questions about prognosis and prognostic testing a clear need for younger patients, but all wanting to be informed – praise for CLLANZ booklet noted, but its availability not consistently known about</p> <p>Hungry for information and personal stories, unsure of what makes a reliable source of information or not</p> <p><b>Wanting clear information about CLL and what to expect – booklet as a valued resource here but not always known about</b></p> <p><b>Younger participants wanting access to prognostic testing (advocacy)</b></p> <p><b>Wanting CLLANZ to be better known/have increased profile</b></p> <p><b>Wanting up-to-date information about gold standard treatments</b></p>	<p>Wanting to keep abreast of latest ‘gold standard’ treatment options and information – even if not at treatment stage this is a constant and present need and concern ‘just in case’ – aware that getting medication funded takes a long time hence being aware early means advocacy can start early too</p> <p>Wanting important information (e.g. avoid sun because of relationship to skin cancer) in order to live well and appropriately</p> <p>Wanting the excellent steps taken regarding medication funding via Pharmac is continued (part of the job done, more to go)</p> <p>Wanting to connection, sharing and support from like people</p> <p><b>Wanting clear information about living with CLL and what to do</b></p> <p><b>Wanting up-to-day information about gold standard treatments and advocacy for them to be available in NZ and/or funded</b></p>	<p>Wanting advocacy for testing and funding of treatments, wanting advocacy to ensure NZ patients have (funded) access to best-in-class treatments available overseas = equity to best practice options</p> <p>Wanting to keep abreast of latest ‘gold standard’ treatment options and information – aware that getting medication funded takes a long time hence being aware early means advocacy can start early too</p> <p>Wanting the excellent steps taken regarding medication funding via Pharmac is continued (part of the job done, more to go)</p> <p>Wanting to connection, sharing and support from like people</p> <p>Wanting ‘insider’ information (e.g. how to import cheaper meds from India legally) OR wanting advocacy to be able to do this</p> <p><b>Wanting up-to-day information about gold standard treatments and advocacy for them to be available in NZ</b></p> <p><b>Wanting work achieved to date with</b></p>

	<b>Wanting consistency of treatment across NZ</b>	<b>Wanting consistency of treatment across NZ</b>	<b>medication funding via Pharmac to be continued</b>
	<b>Wanting support/connection</b>	<b>Wanting support/connection</b>	<b>Wanting continued advocacy as treatment options evolve</b>
			<b>Wanting CLL community insights into work around/tips etc in order to import own medications</b>

### Suggestions:

1. Seek pharmaceutical company assistance in terms of GP education (e.g. rep sessions with practices) – this feels like a task for a third party rather than CLLANZ because it is time/labour intensive and not necessarily the best use of limited resources (despite its importance) – handing this off to someone else seems the most viable solution to meet people’s needs and be fiscally prudent
2. Increase awareness of CLLANZ and booklet – Search Engine Optimization on common search terms, website check regarding key terms for SEO seems important – if they can’t see you they can’t connect with you. Similarly, the use of an awareness building poster for use in haematologist’s waiting areas with a QR code that takes people directly to CLLANZ’s website may be useful – people sitting in waiting areas are a great captive audience. It may be possible to initiate a project (and obtain funding) to get these displayed. Ideally, you’d also continue to reach out to encourage other cancer organisations to refer to you however this seems problematic (competing in the same space) – regardless keeping these channels of communication open and encouraging referral seems like it’s the right thing to do
3. Creation of a platform where people can contribute interesting articles etc. (with a disclaimer of course) however this can’t just be a link – needs to have a templated executive summary section to be completed by the sender with the paper/information they think is important including the DATE of the article in question, WHO this article is appropriate for (audience), WHAT it covers and WHY it’s important to assist in terms of categorisation, management and search
4. Continued and focussed advocacy regarding testing, equity of treatment (across NZ and in comparison, to overseas) and funding of important medications (and access to cheaper medications through own resources if need be)
5. Newsletters ARE valued, but it could just as viably be an email update (to take off pressure) – it’s the connection and the sense of ‘something happening’ that people seem to want
6. There seems to be a need for some sort of support group or face to face meeting – with some suggestion that this be localised. Finding a ‘how’ to have this happen with minimal input from CLLANZ appears to be important – it is not a priority (as advocacy clearly is) but does meet a core need of people to connect and share with others. We suggest that this be a topic for further discussion.

## Contributing

Participants were asked directly if they felt they could give anything back to CLLANZ, revealing a variety of perceptions and suggestions.

Firstly, it was clear that people didn't really understand that CLLANZ isn't a sizeable and well-resourced organisation – they assume that there is a budget and a team of people. **Action point: consider re-wording your 'about us' on the website to make it clear that CLLANZ is small and largely unfunded – it's important that people have the right impression of the size and scale of the organisation.**

Secondly people that couldn't give time often wanted to give money, but needed a mechanism in order to do so. The donate button on the website assumes that people will visit the website (which they may once but not need to again). Several spoke of regular donations and one even spoke to bequests, but there needs to be a way that's easy for people to do this. **Action point: There needs to be a way to help encourage people to donate – one off, regularly and even in bequests. This needs to be part of regular communications so that the 'ask' is in front of people as often as possible (without being intrusive clearly).**

At least 1-2 people in each group (Catherine has their names) suggested they'd be keen to assist because they had time, or because they were passionate about advocacy. Notionally the idea of establishing a collective 'works' – a subset of people in groups impressed as being willing to engage if there was a reason, as long as the time commitment was manageable. Most were keen to contribute in simple ways (e.g. contribute articles), while others were willing to do more BUT finding out who can and will assist is an ongoing issue. **Action Point: Catherine has a list of about 80 people with very little idea about them. Briar has suggested that we survey this list to (a) build on the findings of focus groups and (b) seek willingness to engage in activities such as contributing patient stories through to being part of a committee or collective and/or helping with submissions. Briar suggests we conduct this later in January 2023 in order to make the most of the connections CLLANZ already has and to be certain about the potential scope of assistance and opportunities.**

Someone mentioned having contributed a patient story 'but nothing had been done with it' and another mentioned creating a blog – these types of resources are valuable but may need consideration. When it comes to the blog then it may simply be a push required through Facebook to support it/encourage connection with this type of activity, along with mentions in any activity updates/newsletters. Patient stories may need more active management – potentially needing a template so that stories are formatted in such a way to make use on the website more straightforward and consistent. **Action Point: Decisions regarding how to collect and support patient generated content need to be made, and a process put in place to ensure they are useful and able to be socialised.**

## Overall

It was clear that CLLANZ serves a useful and valued role in terms of advocacy however there are also clear opportunities in terms of ensuring that information is available to people in a timely way and transforming the organisation from a personal passion to a more collective or committee-based group where ideas can be generated and tasks assigned so that the burden is shared. At the moment it is too easy for people to assume that CLLANZ is a sizeable, connected and funded organisation that 'should' be able to deliver far more than it seems to, resulting in a mild sense of disappointment in the absence of Neil's personal connection and contributions (they're grateful for

successes but haven't seen 'much' lately). Increasing the volunteer base, re-focussing on core tasks around advocacy and information provision and finding ways to have regular meetings and define projects for funding or resourcing seems like a productive way to grow.