Using a Digital Solution to Create Survivorship Opportunities

Matt Eby, Consumer Engagement Coordinator



The Problem:

How do we safely identify survivors/'chronic phasers' and help them share their 'lived experience' with blood cancer?

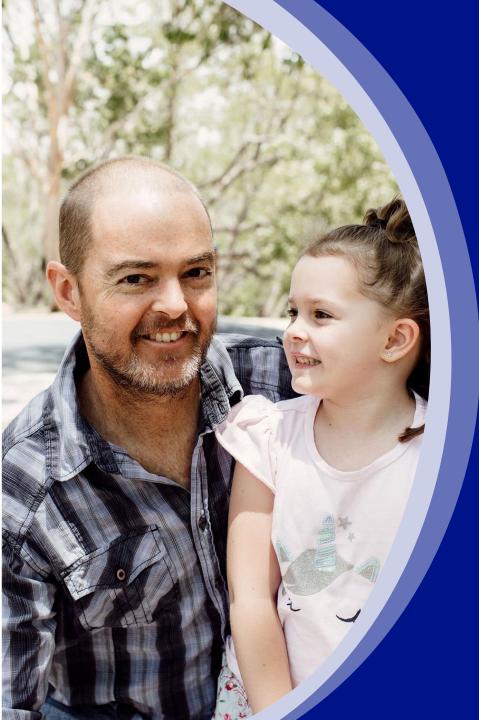




Background

- For the last few decades, our Health Services team are doing an excellent job supporting patients and caregivers during the acute phase of the patient journey.
- What offerings have we been able to offer those in survivorship/'chronic phase' of patient journey?





'Discovery moments'

- Strong motivation to 'give back' and have an impact on the blood cancer community.
- A need for LF to build a more streamlined and robust approach for participant engagement, incorporating a supportive care framework.
- A need to enhance quality assurance processes for participant engagement.
- Opportunity existed to provide a consumer program that met the need of survivors and an avenue to advocate change.

Leukaemia



Our aims from early 2022...

- **Provide** a new survivorship service addressing the unmet need to give back to their blood cancer community and create an impact.
- **Reach** existing and new audiences through a digital solution.
- **Embed** a consumer program that allows the patient, carer or bereaved to define their level of engagement and participation.
- Deliver a program within best practice aligned to national safety and quality standards, led by a healthcare-trained staff.



How are we doing it?

- **Consultation** with staff members to understand the many opportunities to engage with consumers.
- **Collaboration** with staff members from all parts of the Leukaemia Foundation.
- Enhancement and build-out of new elements into our existing resources.
- **Creation** of a new registry ('database within a database')



Questions for the Room

Leukaemia Foundation



Think of this Digital Solution in terms of a Mercedes or BMW Engine... with less expensive parts!



The Basic Parts

- 1. LF website CE Group recruitment landing page
- 2. Jotforms registration and profiler questionnaire
- 3. E-noticeboard
- 4. Welcome email journey
- 5. Quarterly Newsletter
- 6. Fortnightly Zoom calls
- 7. Monthly SMS with link to e-noticeboard
- 8. Record creation in our CRM database
- 9. Entry of information following consumer participation





 If you (or your loved one) have been retreated, this commenced 6 months ago or more

Recruitment methodology

- Email advertisement
- Social media advertisement
- Word of mouth from our Blood Cancer Support

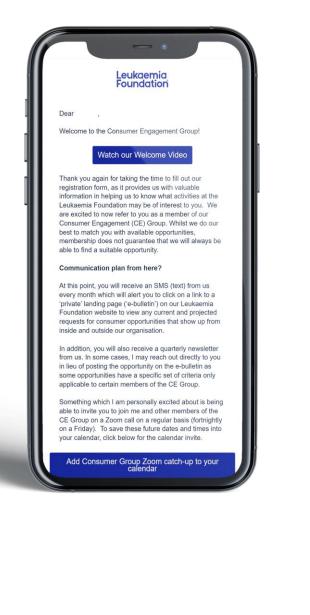
Coordinators





CE Group Registration





The digital journey commences...

- Welcome email and video
- Setting expectations
- Building awareness on communication strategy



Consumer Engagement Program CEP-000184		
come deceased?		
Relationship to PLWBC 🕚		
Relationship to PLWBC - 6	•	
Age of PLWBC 🚯	0	. Mart
Blood cancer diagnosis 🚯	Leukaemia	
Amyloidosis subtype 🚯		
Blood disorder subtype 🚯		/
Leukaemia subtype 🚯	Acute myeloid leukaemia (AML)	
Lymphoma subtype 🚯		<i>"</i>
MDS subtype 🚯		<i>"</i>
Myeloma subtype 🚯		. Mart
MPN subtype 🚯		. Mart
Blood Cancer Diagnosis - If 🛛 🕼	•	
What was their blood cancer diagnosis?	•	
First Diagnosed Date 🕚	27/08/2019	. Mart
Blood Cancer Stage 🚯	Survivorship (you have finished treatment or in maintenance, or you are in remission)	<i></i>
Initial Treatment Completion 🚯	More than 2 years ago	<i>"</i>
Commencement of relapsed & re-treated	Does not apply to my situation	
Engagement opportunities (Ambassadors / Advocates (i.e. community influencers) *;Campaign stories (e.g. featuring in fundraising appeal or newsletters);Committee participation *;Leukaemia Foundation Consumer Advisory Board *;Media requests *;Participating in blood cancer webinars or support groups as co-facilitators *;Podcasts *;Research participation (e.g. interviewed by researchers around the blood cancer journey;IV commercials of Leukaemia Foundation activities *	1

CRM Record generation

Leukaemia Foundation

Hi Mark, as a member of our Consumer Engagement Group, don't forget to check the latest opportunities to get involved with the Leukaemia Foundation.

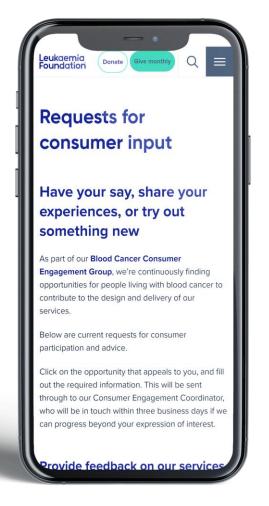
Follow the link for the full list <u>https://bit.ly/3EQTqHp</u>

Regards, Matt from Leukaemia Foundation

Reply STOP to opt out

SMS alerts reminders to check out emerging consumer opportunities





Noticeboard to advertise consumer opportunities





A game-changing test

Backed by your contributions, Dr Pagani is developing a test using biomarkers to predict which patients are most likely to be able to come off treatment and stay in remission.

"My vision is not only to identify patients who can safely cease their TKI, but also to offer new therapies for patients with a predicted worst outcome," explains Dr Pagani.

Importantly, your support will help accelerate the test development to become part of routine clinical practice in the next five years.



Annie Dunn was diagnosed with CML when she was 21 and has been on TKI treatment ever since. Some days are good; others are challenging.

"I have had side effects ranging from body aches, vomiting, diarrhoea, brain fog,

fatigue and nausea. I

Annie Dunn and her husband Matthew

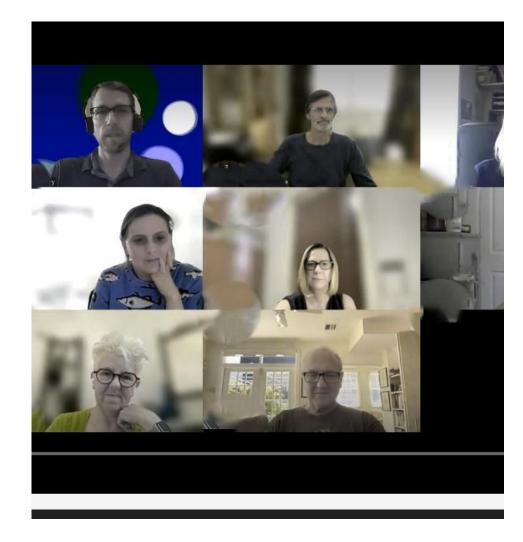
Case study example





Bonus features of being a member of the CE Group





Optional CE Group Zoom catch-up for members





Summary

This new approach of introducing a digital solution to the consumer engagement (CE) space allows us to move forward whilst mitigating risk in *3 different ways*.

- 1. Implementing a supportive care framework with health-trained staff member supporting the group
- 2. Survey approach delivers a 'customisation experience' by empowering consumers to build their 'consumer profile' which helps determine 'best fit' and suitability for future consumer involvements
- 3. Prioritising our recruitment for consumer opportunities to this pool of people who have expressed desire to share their experience as a part of their survivorship

Questions, Comments, Thoughts...

