Evaluation Brief

The Leukemia & Lymphoma Society Information Resource Center

The Leukemia & Lymphoma Society (LLS) Information Resource Center (IRC) strives to give blood cancer patients and their loved ones access to information, treatment, and support services throughout their cancer journey.

Evaluation Overview

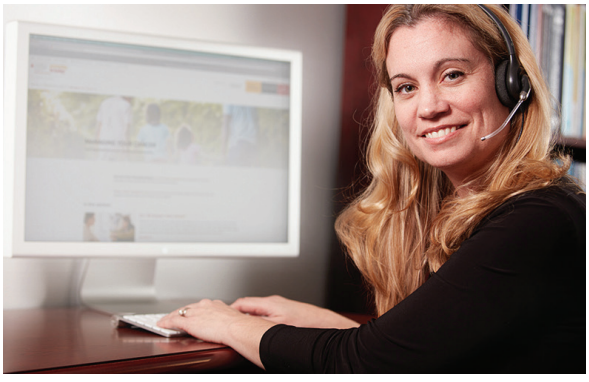
RTI International independently evaluated the IRC to understand patients' and caregivers' experiences with the IRC, the effects of their interactions, and how IRC services could be strengthened.

Online Survey

- Study involved 1,174 English-speaking patients and caregivers 18 or older who spoke with an IRC Information Specialist February–May 2018.
- Baseline survey was sent within 1 week of IRC contact; follow-up survey sent 6 months later.
- 515 patients and caregivers responded to baseline survey (44% response rate); 252 answered follow-up survey (51.2% response rate).

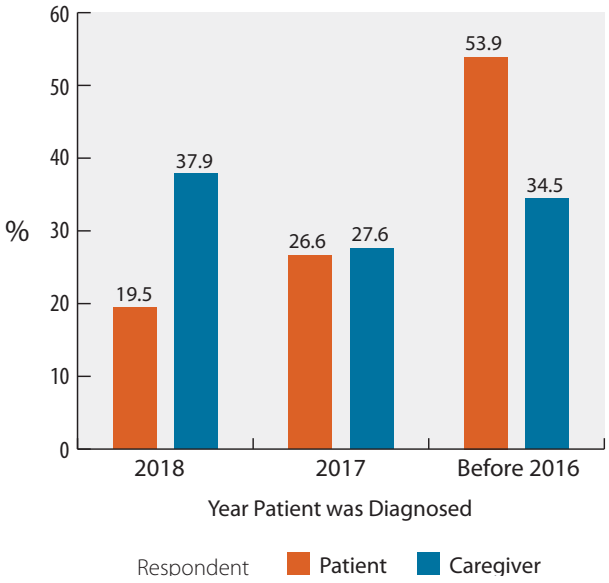
Qualitative Case Studies

- Telephone interviews were conducted with 18 survey respondents to learn more about their experiences.



Study Participant Characteristics

- At baseline, 64.1% of participants were patients and 32.0% were caregivers.
- Most were diagnosed with leukemia (32.2%) or lymphoma (28.3%), followed by myeloma (14.4%).
- About half were diagnosed in 2017 (23.1%) or 2018 (22.1%).
- Caregivers were more likely to report recent diagnosis ($p < 0.05$).



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Common Reasons for Contacting the Information Resource Center

Individuals affected by blood cancer contact the IRC with wide-ranging needs. The top reasons individuals initially contacted the IRC were as follows:

- Referrals to support programs that can help with coping (40.4%)
- Information on getting a second opinion (36.5%)
- Help with financial assistance (36.2%)
- Someone to talk to about experiences (21.8%)
- Information about blood cancer diagnosis and treatment (21.8%)
- A provider told them to call (18.9%)

Topic Discussed	Baseline (N=114)[a]	Follow-up (N=114)[b]
Financial assistance options	49.1%	48.3%
Taking advantage of LLS resources	44.7%	28.1%
Understanding blood cancer diagnosis	28.1%	26.3%
Clinical trial options	25.4%	21.9%
Information on treatment options	29.8%	21.1%
Insurance coverage information or issues	17.5%	16.7%
Getting second opinion	12.3%	7.9%
Talking with doctor or healthcare providers	9.7%	7.9%
Managing blood cancer day-to-day	7.0%	7.0%
Talking to loved ones about blood cancer	2.6%	4.4%
Other	7.9%	11.4%

[a] The baseline subsample is limited to individuals who responded to the follow-up survey.
[b] Among respondents who spoke with an Information Specialist since baseline survey.
Note: Totals may exceed 100% because participants could select more than one answer.

Experience with Information Specialists

Survey respondents rated their conversations with the Information Specialist very highly.

- Felt very comfortable (84.1%) or comfortable (7.6%) talking with Information Specialist.
- Information Specialist was very clear (83.4%) or clear (12.4%).
- Conversation was very helpful (77.6%) or helpful (13.3%).
- Information Specialist's ability to answer questions was excellent (79.4%) or good (14.7%).

> *"They never rushed me, never made me feel bad for taking their time. They wanted to make sure they understood. It made a huge difference: when people don't take the time to understand what the customer or the patient is saying, it becomes very frustrating."*
> — Case study participant—Patient

Almost all respondents said the Information Specialist seemed to care about them as a person (96.6%), treated them with courtesy and respect (99.4%), and spent enough time (98.5%). When asked what they valued most, respondents' most frequent responses related to information and resources provided (e.g., about diagnosis and treatment options) and that the Information Specialist was caring, supportive, knowledgeable, and a good listener.

How Calling the Information Resource Center Helped

Interview participants described how their conversations with Information Specialists helped them feel more hopeful about their or their loved one's situation, less stressed and anxious, and reassured. The information provided helped them deal with the uncertainties of the diagnosis, treatment, and prognosis.

"I'm definitely stronger and more confident from talking to LLS... I ask a lot more questions. I have information at my hand."
– Case study participant—Patient

"...It helped me think, 'Okay, people have this and they live.' You can find out what you need to know. There are survivors you can contact or you can read their stories. The information Specialist made me feel like it wasn't as hopeless as it felt at the time."
– Case study participant—Caregiver

Talking with Information Specialists also made them feel they were not alone. They appreciated that the Information Specialists were available to them and responsive, getting back to them quickly with answers and information.

Some interview participants said their conversation(s) with Information Specialists empowered them to advocate for themselves or their loved ones, for example, by asking healthcare providers more questions and seeking the information they need to make decisions.

After their first contact with an Information Specialist:

- 85.9% of participants said they felt more hopeful, and 82.9% said they felt more confident managing their or their loved one's care.
- About half (49.5%) said they felt more knowledgeable about blood cancer, and 63.5% were more knowledgeable about financial resources available to them (excludes those who did not need help in this area).

More than one-quarter (26.19%) of respondents said they had talked with a doctor or other healthcare providers about what they had learned from the Information Specialists.

Impact of Conversation(s) with an Information Specialist

- 22.6% said their conversation positively impacted how they advocate for themselves or their loved one.
- 18.2% said their conversation helped them receive financial assistance.
- 15.5% said their conversation positively impacted their ability to communicate with doctors and other healthcare providers.
- 13.9% said their conversation positively impacted their ability to communicate more effectively with family, friends, and other loved ones about blood cancer.
- 7.9% said their conversation impacted their decision to go to another doctor for a second opinion.

Differences in Findings by Diagnosis

Respondents diagnosed with leukemia were significantly more likely to say they or their loved one went to another doctor for a second opinion ($p<0.05$).

- **82%** for leukemia
- **54%** for lymphoma
- **40%** for myeloma
- **25%** for other blood cancers ($p<0.05$)

Differences in Findings by Year of Diagnosis

- Respondents diagnosed in 2017–2018 were most likely:
  - to get a second opinion ($p<0.05$).
  - to change how they communicate with doctors and other health professionals and the way they advocate for themselves or their loved one ($p<0.05$ for both).
- Respondents diagnosed before 2010 were most likely to say they spoke with a Clinical Trial Specialist ($p<0.05$).

Differences in Findings by Number of Contacts with the Information Resource Center

About half of participants had one or more additional contacts with an Information Specialist (by phone and/or online) after the first call. Those callers were more likely to have spoken with a Clinical Trial Specialist, changed the way they advocate for themselves and changed the way they communicate with doctors and other health professionals (all $p<0.05$).

Strengthening the IRC

Study participants suggested ways the Information Resource Center could be improved to meet patients' and caregivers' needs. About 12% said the Information Specialist could have done more to be more helpful, and about 19% said the Information Specialist could be more knowledgeable in certain areas.

Increase Awareness of IRC

Interview participants recommended increasing the visibility of LLS through promotion. Some said LLS should specifically publicize the different blood cancers covered (i.e., not limited to leukemia and lymphoma).

Follow-up from Information Specialist

Some interview participants wanted to receive follow-up from the Information Specialist (i.e., check in to see how things were going and if they needed anything else from the IRC).

> *"I had never heard of The Leukemia & Lymphoma Society prior to this... you always hear about American Cancer Society... I certainly want anyone who faces this to know that such a society exists."*
> – Case study participant—Caregiver

Option to Interact with Same Information Specialist

Participants split on whether they preferred to speak with the same Information Specialist each time (55.2%) or had no preference (44.8%). Some felt that speaking with the same person allowed them to develop trust and minimized the need to repeat information. Others felt they benefited from talking to different people.

Recommendations

- Increase awareness of the IRC through promotion efforts targeting healthcare providers, patients, and their loved ones.
- Offer the choice to reach the same Information Specialist again in the future if needed. Some patients and caregivers prefer to connect with the same individual again for continuity.
- Offer the option for a follow-up check-in call/ or email where the Information Specialist contacts the patient/or caregiver to check how they are doing, if they have questions about the information and resources provided, and if they need further assistance.
- Given the strong need for financial assistance, ensure that Information Specialists have up-to-date information about potential sources of financial support for individuals who are not eligible for LLS resources and can help callers navigate financial and insurance issues.