

Conceptualizing a Comprehensive Resource for Families Facing Blood Disorders

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Background

- Patients and families often use the internet to find information about their diagnosis, treatment, and care.
- St. Jude Children's Research Hospital launched the **Together by St. Jude™** online resource in 2018 to serve as a reliable source for families facing pediatric cancer.
- There is an unmet need for families facing sickle cell disease (SCD) and other blood disorders.
- The purpose of this quality improvement project was to explore informational needs and preferences of families with children who have a blood disorder.

Methods

- **Landscape analysis:** Content audit of 49 websites of peer institutions and disease-specific organizations
- **Social listening:** Analysis of social posts on blood disorders, focusing on posts from family members of children with blood disorders
- **Internal content audit:** Inventory of SJCRH patient education resources
- **Keyword and SEO analysis:** Evaluation of relevant website analytics and search data
- **Survey:** Electronic questionnaire to gather insights from family caregivers (n=117) and patients (n=18)
- **Stakeholder interviews:** Structured, one-on-one phone interviews with 4 family caregivers and 25 health care providers

Families want to hear from other families that have been through this. That is probably one of the biggest gaps that we have.
— *Clinical social worker*



I think if everyone would just share their experience more, then we can just say, 'OK that's what my daughter is experiencing. Let me see how they handled it.'
— *Father and mother of two patients with SCD*

If families have questions about getting help for their students in school or what they should be asking for or, 'If I asked for this, how long should it take for me to get it?' ... things like that would be helpful for families.
— *Academic coordinator*

Results

There is no one online resource that:

- Covers a wide range of blood disorders
- Is tailored to pediatric patients and families
- Offers a community of support

The top online content features were:

- Easy-to-understand medical information
- Information for specific blood disorders
- Research updates
- Credible information from trusted sources
- In-depth and complete medical information

Patients and families need:

- Advocacy tools, especially for school and emergency situations
- Information about transition to adult care
- Personal stories from patients and families

Application and Next Steps

- Patient families need a comprehensive, credible, user-friendly resource on pediatric blood disorders.
- In addition to information, patient families are seeking connection; they want to learn and get support from others who have been on the same journey.
- This feedback will inform the development of a **Together by St. Jude™** online resource for patients and families facing blood disorders, with the goal to launch in late 2023.