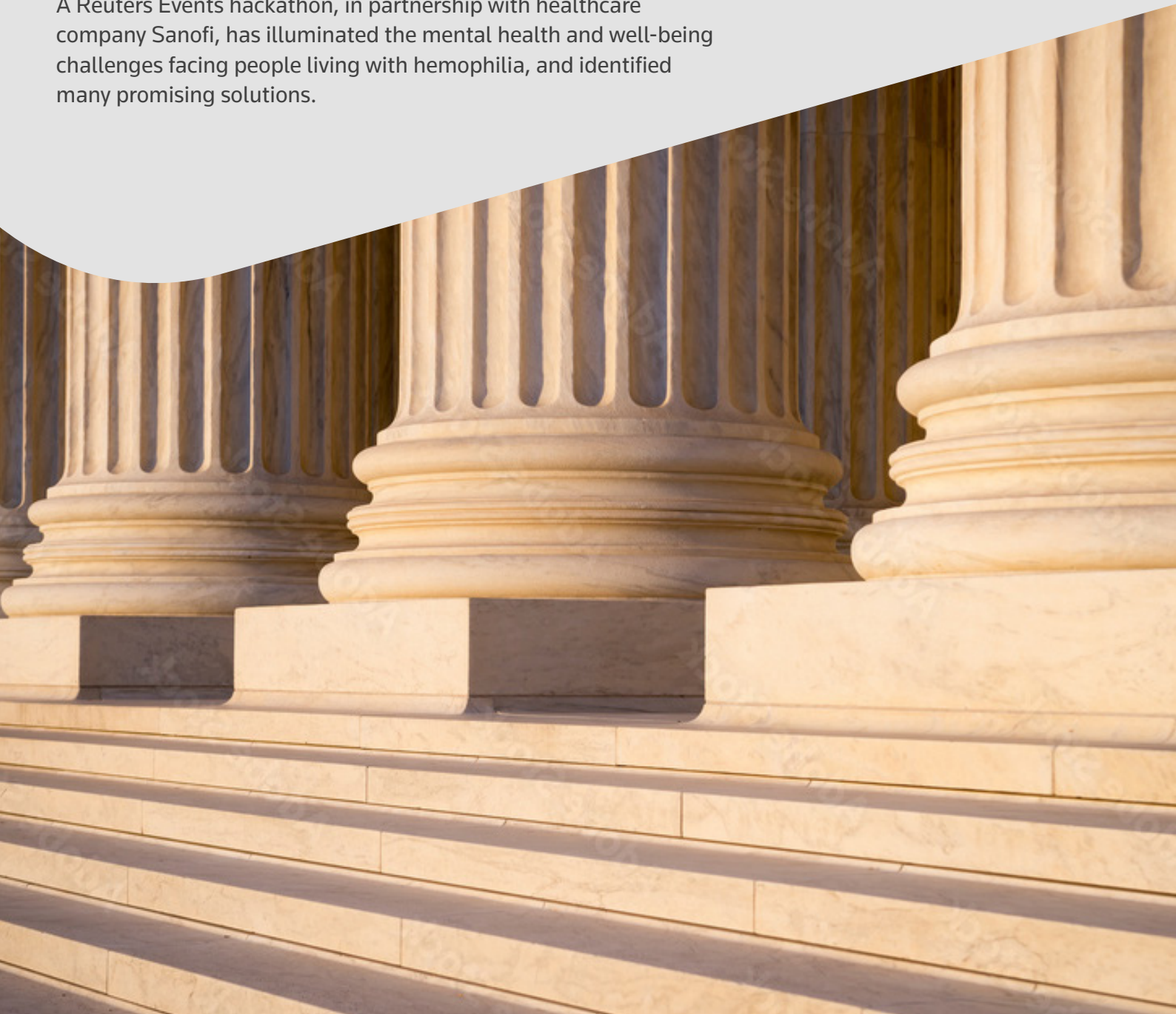


Why hemophilia mental well-being must be a core pillar of care

A Reuters Events hackathon, in partnership with healthcare company Sanofi, has illuminated the mental health and well-being challenges facing people living with hemophilia, and identified many promising solutions.



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INTRODUCTION

Every person is a complex interplay and ever-evolving sum of physical and mental parts. For the one million people living with hemophilia globally, however, it's an even more nuanced and multilayered equation. A rare, lifelong and often inherited condition that affects blood clotting, the medical and physical aspects of hemophilia are well-documented. But these impacts, everything from excessive bruising and bleeding to chronic pain and joint damage, can also have a profound impact on the quality of life of people living with hemophilia and their caregivers.

To better understand the life stages and changes through the hemophilia journey, in 2023 Sanofi partnered with market research and analytics firm The Harris Poll.¹ One of the key findings to emerge from this global survey of hemophilia patients, caregivers and providers was that the array of physical and mental burdens was not being fully or effectively communicated. More than half of patients living with hemophilia (54%) reported fair or poor mental health, yet 71% of those same people tell healthcare providers they are coping fine.

Recognizing the pressing need to normalize conversations around mental health, Reuters Events and Sanofi brought together representatives from across the hemophilia community to hack a solution. Over 20 countries and 25 organizations were involved with participants including healthcare providers, advocacy groups, academics and, most importantly, people living with bleeding disorders. Armed with relevant information, data and analysis, four teams were set loose to find tangible, targeted, and implementable solutions that could make a real difference in the lives of people living with hemophilia.

Outlining the vision, hackathon host Manon Degenaar-Dujardin, Former Vice-President Finance, European Haemophilia Consortium, said: "We are creating a global movement and a global platform for knowledge sharing, both of which could help us make huge strides in access to diagnosis, treatment and care."

All groups identified common themes and challenges – from addressing stigma, cultural differences and resourcing challenges to providing education and peer-to-peer support. However, it was Team 4's solution, The Power Within, which stood out as the most creative and globally adaptable model.

In the pages ahead, we explore the solutions that emerged from the hackathon and discuss how they aim to raise the bar for mental health care in the hemophilia community.

REUTERS EVENTS **sanofi**

VIRTUAL HACKATHON:
Breaking Down Stigmas to Improve Mental Health in the Hemophilia Community

HOSTED BY:

- Chris Bombardier (SAVEONELIFE)
- Manon Degenaar-Dujardin
- Mark Skinner (Institute for Policy Advancement Ltd)

JUDGING BY:

TEAMS LEAD BY:

- Patrick James Lynch (Believe.LIMITED)
- Tirsa Carcamo (Kenya Hemophilia Association)
- James Kago (Kenya Hemophilia Association)
- Tatiana Bathfield

Part of the Hemophilia Changemakers Series, in partnership with Sanofi

EXAMINING PATHS TO NORMALIZE CONVERSATIONS

Beyond the everyday physical adversity that people with hemophilia face, there are untold mental health burdens – from stigma, anxiety and depression to impacts on quality of life and issues with identity.

Stigma, and the disconnect between acknowledging mental health burdens while being unwilling to speak about it, is a significant one. Over half (51%) of patient respondents to the Sanofi-Harris poll self-reported that they hide their symptoms from others at least once a week, and 68% avoid telling friends about their condition.

Unable to share their mental health struggles outside their immediate community and family, sufferers are left feeling isolated. Speaking during the hackathon's opening address, Mark Skinner, President and CEO of the Institute for Policy Advancement at ICER, the Institute for Clinical and Economic Review, said: "This creates an emotional barrier". It could also indicate a "certain pre-conditioning to accept the status quo".

Yet, the poll data is clear on the burden that hemophilia places on mental health. At least once a week, 60% of patients report feeling anxious and over half (51%) are depressed. "Emotional impacts are not rare. They're frequent and...persistent in our community, and these feelings can impact how we are treated," Skinner said.

The reluctance to open up goes beyond the desire for privacy. Skinner believes it "can be rooted in fear" of being judged, viewed as weak or a burden, and this can lead to negative social, personal, professional and even financial consequences. Some six in 10 patients report low self-confidence and believe their hemophilia has negative consequences on their jobs, career aspirations and romantic relationships.

Neither fear nor anxiety are rare and this can and does impact quality of life. Indeed, an earlier study, the HemActive Project, found that 44% of patients limit their activities because they're afraid of the potential physical impacts, and 41% are afraid of pain. Past fears also drive anxiety with 47% reporting this as a reason for stopping an activity. Sadly, 43% of children stop participating in activities and 35% don't play a school sport because of their hemophilia.²

Not only do fear and anxiety-based avoidance limit participation in life, it can also further fuel isolation and impact treatment. "The significance of past pain certainly does weigh on how we adjust and adapt for the future," Skinner said.

Explaining the impact of pain on a BloodStream Media Podcast,³ Dr. Michelle Witkop, Consultant for Inherited Disorders, said: "Pain is very interrelated in the brain, and the connections and the connectivity in the brain is very organic. So, pain is not just a

"IT'S IMPORTANT TO NOTE THAT THIS TOOL (A NEW, CONTENT-VALIDATED, PATIENT-REPORTED OUTCOMES MEASURE) WASN'T DESIGNED TO PROVIDE A CLINICAL DIAGNOSIS OF ANXIETY OR DEPRESSION, BUT REALLY TO HELP UNDERSTAND HOW HEMOPHILIA IS ALWAYS IN THE BACK OF YOUR MIND OR ON YOUR MIND"

Mark Skinner

President and CEO of the Institute for Policy Advancement at ICER, the Institute for Clinical and Economic Review

Frequency of Hemophilia Patients' Emotional Experiences

Patient Perspective

About once a week
or more often

Caregiver Perspective

Experience feelings of anxiety



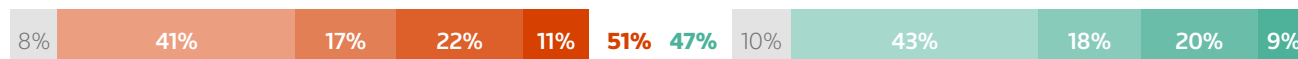
Worry about experiencing a sudden bleeding event



Worry about having to take medication



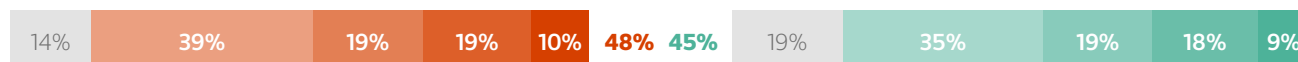
Experience feelings of depression



Experience feelings of guilt about how their hemophilia impacts their relationships with others



Worry about being able to afford their medical care



Never Several times a month or less often About once a week Several times a week Every day

matter of pulling yourself up by your bootstraps", or having a better outlook "it's a very organic change in your body that affects your mental health".

MOVING TOWARDS MEASUREMENT

Skinner pointed out that until recently, there has been no instrument, tool or patient-reported outcomes measure to assess the mental health outlook of individuals living with hemophilia or to track progress over time. To gain greater understanding, a team of researchers set about creating a new content-validated, patient reported outcomes measure (PROM). The process, documented in the World Federation of Haemophilia (WFH)⁴ journal, involved a systematic review of the literature and interviews of 53 patients in multiple countries, as well as healthcare provider engagement.

"It's important to note that this tool wasn't designed to provide a clinical diagnosis of anxiety or depression, but

really to help understand how hemophilia is always in the back of your mind or on your mind," Skinner explained in his keynote address. In the end, five key domains – stigma, anxiety, depression, life interference and identity – were identified as well as multiple sub-domains.

Implementing subtle shifts in language was one of the recommendations from patient interviews. When talking about stigma, for example, rather than pointing to "difficulty in forming relationships," it could be reframed to having an "impact on relationships". A patient's "future expectations" could be considered as a cause of anxiety, rather than their anxiety being attributed to a patient's "concern about the future, and concern about treatment".

In an interview after the hackathon, Team 4 participant Antonio Gomez Cavallini, General Coordinator of the Coalition of the Americas, stressed the importance of ensuring "that the literature on therapies, protocols, medical and scientific research, among others, is sifted into simple language".

THE ROLE OF COMMUNITY, CULTURE AND CONTEXT

The message that nothing compares to being with people who share and understand the lived experience could not have been clearer. There was recognition, too, that digitalization has made the ability to connect with others across borders easier. As health advocacy filmmaker Patrick James Lynch, the Founder & President of Believe Limited, sees it, this can “metaphorically and maybe literally” help someone to “take a step back from the ledge, wherever they are in the world”. While he acknowledged there were limitations to providing practical or medical support on the ground, in the moment, he said: “As a fellow blood brother, I can connect...I can reduce each of our feelings of loneliness by connecting globally as a community.”

**“AS A FELLOW BLOOD BROTHER,
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Patrick James Lynch
Founder & President of Believe Limited

Perhaps unsurprisingly, every solution recommended a strong peer-to-peer component, and there is already evidence of this working in various country approaches. Yet participants agreed that more can be done to build community and connections that promote healthy, open communication right at the outset of the hemophilia journey. Key to the success of any peer-to-peer network is trust. As Team 3 pointed out, privacy is crucial and should be community led rather than corporate. Peers could also receive professional training to ensure that they recognize and report red-flag behaviors.

Not all experiences are, however, the same and demographics such as race, age and gender can all play into the lived experience. According to the Global Hemophilia Report,⁵ women, girls and people with the potential to menstruate (WGPPM) who live with hemophilia have more difficulty getting a diagnosis and accessing adequate care than biological male counterparts. They also experience unique symptoms such as prolonged menstrual bleeding and childbirth-related complications. Acknowledging that more work is needed, the WFH has chosen ‘Access for All: Women & Girls Bleed too,’ as the theme for the 2025 World Hemophilia Day.⁶

The report also recognizes that more research is needed to better understand mental health in adolescents and young adults with hemophilia. Speaking on a BloodStream Media Podcast,⁷ Randy Curtis, a bleeding disorders advocate for the past 40 years, said adolescents have all the “normal coming of age,” challenges. But when the transition from pediatric to adult centers happens, it is at a time “when their hormones are raging and they’re discovering all the freedoms of this new life”. In trying to balance pain and bleeding, while also fitting in with friends, mental health challenges arise. Here there is a paucity of research, and a need for better diagnostic tools and interventions, in particular for early identification and support.

Data is emerging now which suggests that psychological trauma often originates in childhood. According to newest

data from International Society on Thrombosis and Hemostasis,⁸ 70% of respondents who identified a traumatic event specified that it occurred before age 18.

CARING FOR THE CAREGIVER

Team 4 Team Leader Tatiana Bathfield, Secretary of The Haemophilia Association of Mauritius, shared how her experience reveals how children and mothers can be particularly vulnerable. When she learned her daughter inherited a rare Factor VII deficiency, she was “plunged into a world of uncertainty, fear and isolation”. Feeling “enormous pressure to hold it all together”, she prioritized her daughter’s health at the expense of her own, which ultimately led to burnout and mental exhaustion. “I know now that seeking support for these mental health challenges would have been a life-saver for our entire family unit,” she says.

Bathfield’s experience underscores the role of caregivers and the importance of including them in peer-to-peer support networks. A high 80% of caregivers responding to the Sanofi-Harris Poll felt both physically and mentally drained, and over two-thirds (64%) experienced a negative impact on physical and/or mental health. By providing a safe and secure environment to share experiences will continue to help normalize the conversation. The earlier this happens in the hemophilia journey, the better - if families with new diagnoses can access support early on,

this could have an immediate impact on reducing anxiety.

While the importance of a global approach to mental health challenges is recognized, geographical divides, cultural differences and resource constraints remain key areas for consideration in the hemophilia journey.

In the US and Europe, the conversation around mental health in hemophilia is gathering momentum. For example, people with bleeding disorders in the U.S. have some, limited access to comprehensive mental health care and assessments through federally funded hemophilia treatment centers (HTCs). Across the pond, the European Hemophilia Consortium’s #ThisWay Campaign⁹ aims to promote physical and mental health and wellbeing through a range of initiatives, such as sharing patient stories, facilitating physical activity challenges, and hosting walking tours, among others.

However, mental health services are frequently under-resourced in low to middle income countries. In Africa, for example, only 0.4 to 5% of public money is spent on mental health, according to the Wellcome Trust.¹⁰ Since COVID-19, there has been a shift towards better understanding mental health, but progress remains slow.

Gomez Cavallini stressed that to “break the bubble” around mental health and well-being in hemophilia two key conditions must be met: access to treatment and support. It must also be a personal decision.

COUNTRY APPROACHES

With 25 countries represented, the hackathon also provided an opportunity to share communication and connection success stories.

Pakistan: The Hemophilia Foundation Pakistan organizes retreats for people with bleeding disorders in beautiful natural surroundings. In an informal setting, people are encouraged to open up and share stories, and a dedicated WhatsApp group has been established to ensure continued support.

Michigan, U.S.: The Hemophilia Foundation of Michigan (HFM) runs an annual conference for women and teens. One of the educational sessions at this year’s three-day event had a dedicated session to discuss mental health concerns, learn from national experts, healthcare providers, and other participants, and build community and connection.

Korea: Here patients are turning to a ChatGPT hemophilia helper,¹¹ that collects data from patients. Capable of generating human-like text, this expert AI delivers tailored treatment advice, tracks symptoms, provides the latest research and emergency guidelines.

India: In India, with the third-highest global burden of sickle cell disease (SCD), U.S. charity PATH¹² is working with the government in Maharashtra to enhance screening, diagnosis and care. Community engagement is a key part of this, not only to create more awareness about SCD, but also to counter stigma and discrimination. PATH is collaborating with community health platforms, local non-governmental organizations and village council members, and including them in the program activities to reduce stigma. Facilitating the formation of patient support groups is another key strategy, which “complements the ongoing efforts to improve compliance with care protocols, thereby enhancing the quality of life for SCD patients”.

BUILDING UNIVERSAL COLLABORATION AND MULTILAYERED SOLUTIONS



The complexities of bleeding disorders, combined with the diverse experiences of those affected worldwide, demand a comprehensive, multidisciplinary approach to mental health. For this approach to be truly effective, information must be democratized and made universally accessible. It should permeate the entire community – reaching patients, advocacy groups, caregivers, and healthcare providers alike.

“It is important that the patient not only feels supported by local professionals, family and friends, but also feels supported by resources of various kinds that encourage them,” Gomez Cavallini says.

On the one hand, this requires a global outlook. However, there is also a need for regional and country-specific action plans. Organizations like WFH are already working to provide valuable resources globally, while also connecting to regional and local bodies. Podcasts from BloodStream Media and the Global Hemophilia

Report, and social media platforms like Facebook, are helping to spread awareness globally. Meanwhile, local “influencers” can also play a role in garnering support and deeper understanding on the ground.

In the Latin American and Caribbean region, the Coalition of the Americas, is carrying out a Continental Mental Health program for patients with bleeding disorders. “This generates an umbrella of sustained work in the region where different implementation tools can be used,” Gomez Cavallini says. This includes everything from webinars to continental awareness campaigns and the creation of a virtual space with tools, as well as face-to-face meeting opportunities. Videos, readings, games, interviews, news and so on all help to “democratize information and help patients feel less isolated”.

Sarah Ford, Chief Executive Officer, Canadian Hemophilia Society, believes national patient organizations should play a role in helping community members access the support and tools they need. Prioritizing collaboration with other national mental health support organizations and, organizations like the Canadian Social Workers in Hemophilia Care association, can help to provide additional support.

FOUR HACKS, ONE SOLUTION

There were common threads running all four hacks – from addressing stigma, cultural differences and resourcing challenges to providing evidence-based education and peer-to-peer support.

Chris Bombardier, Executive Director of Save One Life, who judged the hackathon alongside Skinner, said the ideas and passion around making a difference in mental health “give me a lot of hope”.

Group 1 was the first to outline its solution – a multilayered approach that would use patient-led podcasts, open days, conferences and a structured toolkit for healthcare providers to dismantle stigmas. Group 2’s Get the Bloody Word Out, focused on creating resources, as well as translating and circulating existing ones, to increase awareness among families and healthcare providers. For Team 3, it was about creating a Safe Space Network, and buddy mentoring system, as well as training for healthcare providers to better understand mental health challenges.

In the end, however, there could only be one winner and that was Team 4’s global online forum, The Power Within. Skinner particularly liked Team 4’s “creativity” in tapping external resources to broaden what was currently available to the community. The solution would call on mental health professionals and foundations working with the Hemophilia Journal, as well as local networks and psychosocial services.

For Bombardier, the peer-to-peer component struck a meaningful chord. Connection, he recalled, is what helped him out of some of the “darker, darker places that I have been”.

HOW TEAM 4 PLANS TO UNLEASH THE POWER WITHIN

Team 4’s winning solution made numerous recommendations which included to:

- **Put community at the core.** A community hub, with a universal logo, will ensure that mental health and well-being are recognized as a core pillar of care across the hemophilia journey. Peer-to-peer networks were a cornerstone of the solution with mentorship recognized as especially important for more vulnerable groups.
- **Go global, stay local.** A global online forum will enable access to key resources and toolkits about mental health. For example, shareable patient videos for use online and across social media. The video chat feature of platforms, like Facebook, or even a written pen pal system, would help patients to share experiences and form relationships across the world. However, to ensure access, especially in countries with patchy internet access there should be boots on the ground.
- **Provide the evidence, educate.** More reliable, relatable, scientific data on the psychiatric implications of bleeding on mental health is needed - this is a gap. To ensure wide access to information, language should be kept simple and translated into various languages. A universal set of standardized tools could help drive more patient-centered language.
- **Power diverse partnerships.** In order to deliver the vastest range, knowledge, skillsets and resources should be harnessed at both local and global levels. This should go beyond the work already done by dedicated bodies like WFH and include garnering support from global strategic leaders while fusing efforts with broad-based mental health institutions.
- **Stay sensitive to differences.** Resources should be fully flexible and based on the needs of different communities. Locally customized toolkits, translated into different languages, could be presented online and in physical formats to be distributed in areas without internet access. With the right checks and balances, artificial intelligence could be leveraged for translation. In less developed countries, providing free access to mental health professionals and other resources will be vital.
- **Measure and evaluate.** Forum visits, clicks-per-view, downloads of resources must be measured. Through social listening and evaluating user engagement, the aim is to understand what is working and what isn’t, and customize and shift strategies when appropriate.

CONCLUSION

Addressing mental health and well-being within the hemophilia community is no longer an optional aspect of care; it is essential to the holistic treatment of individuals living with this lifelong condition. The findings from the Reuters Events hackathon, in partnership with Sanofi, underscore the urgency of normalizing conversations about the psychological and emotional burdens associated with hemophilia. The challenges, which stem from stigma, anxiety, depression and isolation, are as prevalent and impactful as the physical symptoms of the disorder.

The hackathon revealed that the issues are well-understood and there is a strong desire to make a difference. Team 4's winning solution represented the promising shift towards a more integrated approach to care. By creating a global online forum that connects patients, caregivers and mental health professionals, and emphasizes peer-to-peer support, these efforts aim to break down barriers to mental health access and provide ongoing, accessible resources. Equally important is the recognition that these solutions must be adaptable to diverse cultural, regional and socioeconomic contexts.

Undoubtedly, the journey to improving mental health care for those with hemophilia is complex. However, through continued collaboration, education and empathy, it is possible to foster a global community that supports both the mental and physical health of individuals with bleeding disorders. Looking to the future, work should focus on ensuring that mental health becomes an intrinsic part of care, providing individuals with the tools they need to live fuller, more empowered lives.



REFERENCES

- ¹ <https://www.sanofi.com/en/magazine/your-health/global-hemophilia-survey-captures-the-voice-of-patients-caregivers-and-providers>
- ² Skinner, M., Blamey, G., & Khair, K. (2020, February). Emotional impact of fear and anxiety on physical activity in persons with hemophilia A: Global findings from the HemACTIVE study. Poster session presented at the 13th Annual Congress of the European Association for Haemophilia and Allied Disorders (EAHAD), The Hague, Netherlands.
- ³ <https://www.bloodstreammedia.com/>
- ⁴ <https://onlinelibrary.wiley.com/doi/epdf/10.1111/hae.15085>
- ⁵ <https://static1.squarespace.com/static/60928e73d253a16512e0b2a2/t/64beb9c3239ce0576bd1bab5/1690221000573/Global+Hemophilia+Report+-+Season+01+Summary.pdf>
- ⁶ <https://wfh.org/world-hemophilia-day/>
- ⁷ <https://www.bloodstreammedia.com/>
- ⁸ <https://www.isth.org/>
- ⁹ <https://community.ehc.eu/ehcs-thisway-campaign/>
- ¹⁰ <https://wellcome.org/news/programme-shaping-future-mental-health-policy-africa>
- ¹¹ <https://chatgpt.com/auth/login?next=%2Fg%2Fg-lulnrP75p-hemophilia-helper-pro>
- ¹² <https://www.path.org/our-impact/articles/improving-screening-and-diagnostics-to-eliminate-sickle-cell-disease-in-india/#:~:text=Leveraging%20community%20platforms%20for%20awareness,of%20life%20for%20SCD%20patients>