

NEW METHODS OF COMMUNICATION IN A CHANGING WORLD

28 July HAAB Webinar: Discussion Report

The Hemophilia Advocacy Advisors Board (HAAB) held a dedicated webinar to reflect on what the new 'virtual methods of communication' means for the hemophilia advocacy community and to explore how it can best adapt. In addition to informative presentations from Pam Wilton (Canadian Hemophilia Society), Deon York and Alain Baumann (World Federation of Hemophilia), an open discussion took place to identify the key considerations for when organizing a virtual event.

Below is a summary of the key points raised as part of the open discussion.

Planning

Workload

- It takes a lot of effort to organize a virtual event (especially the first time).
 - Maintaining peoples' engagement on screen is an important consideration.
 - From a facilitation perspective, a greater level of preparation may be required, with a pre-event rehearsal also recommended (so everyone is comfortable with the technology).
 - Guest speakers still need to be identified and approached, even if not travelling to an event.
 - Need to plan for all technical issues. You cannot always tell why they are caused, but they are often due to bandwidth and internet speed.

Shorter days

Days cannot be as long, as people quickly suffer from digital fatigue and you may need to accommodate multiple time zones. Either events can be spread over more days or the amount of content that you look to cover can be reduced.

Content longevity

Making content and session recordings available online afterwards means people can access
if they couldn't attend the session. However, some people will always want the live
experience, even if means joining in the middle of the night.

Live or pre-recorded

 While live content is more authentic, pre-recorded is effective too. You can pre-record talks and bring people together for Q&As.

Industry regulations

• Industry partners face significant struggles with the regulatory and legal issues that different regions and countries pose when holding face-to-face events. Virtual events alleviate some of these complexities, providing new opportunities for collaboration.

Budget

- The business model of free virtual events may not be sustainable long-term.
- Difficult to drive people to virtual exhibit halls, so need to consider alternative ways of showcasing sponsors to ensure they still want to invest.
- Depending on their capabilities, virtual platforms can vary hugely in their cost. If planning an event with multiple requirements, don't assume it will be cheap (even if cheaper than face-to-face).



Attendance

Greater numbers

- Those who could not attend previous events due to the cost or time involved can now join. For example, 70% of attendees at the WFH Virtual Summit were first-time attendees.
 - Virtual events are borderless: no visas are required, so they may receive a broader global reach.
 - Healthcare providers or people with milder forms of hemophilia may now be encouraged to engage in events.

Speakers' availability

- Potentially increased access to key speakers who are difficult to book for in-person attendance due to high demand for their time.
 - Whilst they may not have time to travel (within country or abroad), they may have time to pre-record a session that can be shared.

Technology access

• Whilst some countries have technology access, not everyone has access to a phone or the bandwidth to dial into events. Consequently, we need to ensure steps are taken to accommodate their needs, even if means attendees traveling to a local hub with others to join.

Social media

- Social media can be used to boost engagement; for example, it can encourage attendance at sessions, highlight outcomes to those who couldn't attend, or drive people to archived content.
 - Need to identify people willing to post about event in advance.

Interactivity

Missing the face-to-face

- Face-to-face events are a vital engagement opportunity and help bring national and global communities together. Virtual events can generate aspects of connectivity but cannot replace the human connections.
 - Without established contacts in the global hemophilia community, face-to-face interaction is even more important for young and aspiring leaders. Networking helps them in learning how the global community works.
 - Limited spontaneity: you miss the chance to bump into people and gain learnings.
 - More difficult to debate ideas with others.

Attendee participation

- Virtual breakout spaces allow people with common interests to convene or for workshopping sessions to happen. To capture discussions, you need to nominate people willing to take notes and lead the conversation.
- Technology can be used to enhance interactivity, e.g. whiteboard tools, live audience polling tools (such as Sli.do or Mentimeter) or gaming tools (Kahoot) that run alongside event to boost interaction.

Translation

- As events can be recorded, it is easier to produce more accurate translations with translators re-listening to what speakers said.
- Alternatively, you can translate live with a translator or use an automated tool.

Ongoing engagement

- As it is less expensive to attend a virtual event than to travel large distances, with accommodation needs, you can increase their volume.
- Technology allows the global community to connect in between set events, increasing interactions and benefiting patients (i.e. gives patients and carers the chance to interact and ask questions on more regular basis).