

The Surge of Telemedicine. Is this a Good Thing? 26 May HAAB Webinar: Discussion Report

During the initial webinar of the *Responding to an Evolving Landscape* series, everyone was encouraged to share the strengths and weaknesses of the community at this time, as well as the threats and opportunities being created. It became clear that telemedicine is a hugely important topic during this time of forced experimentation. As such the Hemophilia Advocacy Advisors Board (HAAB) held a dedicated webinar to explore the benefits that telemedicine could bring for our different stakeholders, along with the various aspects we should all be cautious of.

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

What benefits could telemedicine bring for our different stakeholders?

For People with Hemophilia, Caregivers and Families

- More convenient than visiting clinics, with less time spent travelling and waiting
 - Supports those living in remote areas
 - Easier to incorporate hemophilia into everyday life (*e.g. taking day off work to go yourself, or take your child*)
 - Removes the costs associated with visits (*e.g. travel and parking*)
- People with mild hemophilia may not need to visit clinics as often
- Some avoid going to hospital to assess a bleed with significant time waiting around. With an initial telemedicine assessment, this can be avoided
- Some may find face-to-face contact with a full comprehensive care team intimidating. Virtual contact with just one person can alleviate this
- In some cases, they can prepare for telemedicine appointments by logging on before meeting clinicians to access their own records
- Helps equalize care across a country, with access to a Comprehensive Care Clinic even if their local hospital does not have a Hemophilia Treatment Center
- May feel more empowered to become an equal actor in their own care
- This forced experimentation may help push the advancement of point-of-care testing

For Comprehensive Care Teams

- Due to Covid-19, healthcare professionals must clean after each patient, which reduces time for face-to-face visits. Remote consultations can alleviate strain on healthcare resources and reduce risk for patients
- Teams can support patients remotely from wherever they are
- Frees up capacity in Hemophilia Treatment Centers
- Ability to see patients' entire medical histories
- Healthcare professionals can be more flexible about when they see patients (*e.g. fitting appointments around teaching schedules*)

Healthcare Systems, Payers & Governments

- If the routine use of telemedicine can demonstrate that expensive medicines are being used more efficiently, its use may help with their reimbursement

What aspects of telemedicine should we all be cautious of?

For People with Hemophilia, Caregivers and Families

- May marginalize those who have limited equipment or technology skills
- Not all have access to high-quality internet and mobile phone services required for video consultations
- Aspects of in-person consultations may be lost
 - May not prepare for appointments mentally in the same way, so do not remember to ask all questions needed
 - Can be a lack of privacy when conducting calls at home
 - If just being seen by one clinician, may lose out on access to wider comprehensive care team
- If virtual consultations are delayed, may be stuck waiting on hold
- May lose out on opportunity to be enrolled in clinical trials if levels of interaction with the wider comprehensive care team are reduced

For Comprehensive Care Teams

- Aspects of in-person consultations may be lost
 - Harder to explain to people how to treat themselves, and particularly difficult to support newly diagnosed patients
 - Inability to perform required parts of in-person consultations (*e.g. taking blood / assessing range of motion / conducting MRI scans*)
 - Difficult to read patient's body language or check the state of their mental health, especially if just a traditional phone call
- If only consultations with full comprehensive care teams are being paid for, teams may lose opportunity to connect with patients who prefer one-on-one consultations
- Over time could lead to a loss of healthcare professional expertise if only reviewing people virtually
- Due to data collection regulations, can be hard to gain consent for remote consultations, which can limit the care provided
- In the US, clinicians may only treat people who live in the same state they practice. This is not the case for in-person visits

Healthcare Systems, Payers & Governments

- Data privacy issues – overlooked during Covid-19 crisis, but must be considered moving forward
- May think the comprehensive care model is no longer needed, especially as budgets are already challenged
- As Covid-19 places pressure on services, may use to cut back certain resources

Additional considerations

- Robust data needs to be gathered to properly assess the direct and indirect cost savings, as well as the quality of care benefits that telemedicine has brought during this forced experimentation
- Telemedicine should augment care, but not replace it. It is not a case of either, or
- Patients and healthcare professionals need to prepare for their consultations in the same way they would when a face-to-face
- Telemedicine is the next step in providing personalized care for patients, so comprehensive care teams must adapt how they work based on how patients want their care, and support to be delivered
- Increased use of telemedicine is here to stay, so we need to learn how to best adapt, so as a community we can benefit from it and protect ourselves against the challenges it brings