



# “What we wanted was what we needed” - rebuilding a community of memories and inclusive advocacy for emerging hepatitis C research via a community-led multilingual documentary production

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## Introduction/Summary

- The EATG produced “What We Wanted was What We Needed - Rebuilding a Community of Memories and Inclusive Advocacy”, a documentary on the Sitges Meetings.
- The Sitges Meetings were a series of EATG international community-owned and community-led multi-stakeholder meetings (2007-2017 in Sitges, Spain) that promoted the inclusion of people with HIV/ viral hepatitis C coinfection in clinical trials for emerging HCV treatments, and advocate for rapid access to them.
- The film documents stories, experiences, results and lessons learned from the perspective of key stakeholders involved.

## Methods

- Filmed between September 30th and October 2nd, 2023 in Sitges, Spain, the documentary featured nine key testimonials from the original Sitges Meetings, including six community activists and three representatives from a pharmaceutical company, a regulatory agency and the clinical society and academia.
- Interviews were conducted without scripts, opting instead for an interactive approach for participants to share their experiences of the Sitges Meetings in their preferred language, resulting in a multilingual production (English, Italian and Spanish) that enhanced the authenticity and relatability of a creative storytelling.
- The filming production was concluded with a roundtable discussion with all participants, reflecting on learnings and future applications of the Sitges Meetings model.

Figure 1 An excerpt from the documentary



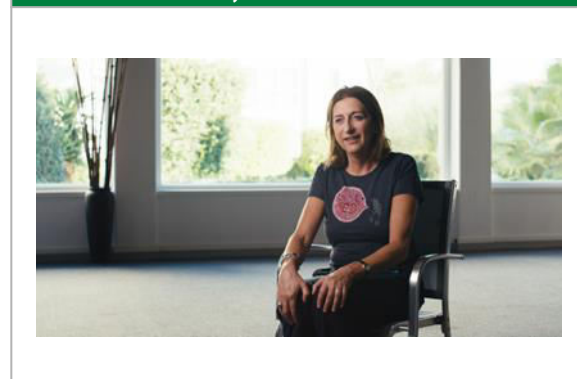
Figure 2 A Poster of the Documentary Promotion



## Results

- With the filming of this documentary, EATG captured and preserved an important moment in the organisation's advocacy history, while reflecting on community needs and drawing lessons from effective community advocacy that can influence policies and clinical trials at a broader level.
- The Sitges meetings employed a collaborative approach to find concrete solutions, raise awareness about the HIV/HCV co-infections and set the ground for building meaningful connections between all the relevant stakeholders, involving community activists from the HIV and viral hepatitis field, regulators, physicians, researchers and the pharmaceutical industry. This led to changes in exclusion criteria for clinical trials and revisions to the European Medicine Agency (EMA) guidelines.
- The documentary demonstrates the significant impact of community-led advocacy, showcasing the importance of a collaborative multistakeholder approach as a powerful model for addressing inclusion barriers that create positive change when community is at the centre of the planning, organisation, and implementation of such initiatives.

Figure 2 An excerpt from the interview with Alessandra Cerioli, EATG Member



## Conclusion

- Community-led productions can be a useful approach in sharing experiences of effective patient advocacy by giving community space and time to talk about their success stories via creative means and increase visibility for community-led initiatives.
- The reflections on the Sitges Meetings model can be repurposed to raise awareness and plan advocacy for the inclusion of people living with HIV in other non-HIV clinical trials.
- Community-led documentaries and similar productions should be further considered to promote networking and dialogue around community-centric approaches in clinical research.

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TO WATCH THE  
DOCUMENTARY



## Affiliation