

THE 10<sup>th</sup> EUROPEAN CONFERENCE ON  
RARE DISEASES & ORPHAN PRODUCTS



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THE JOURNEY OF LIVING WITH  
a RARE DISEASE in

2030

## Moving face-to-face events to interactive online events: Learnings from EURORDIS' recent ECRD 2020

### ECRD 2020 in figures

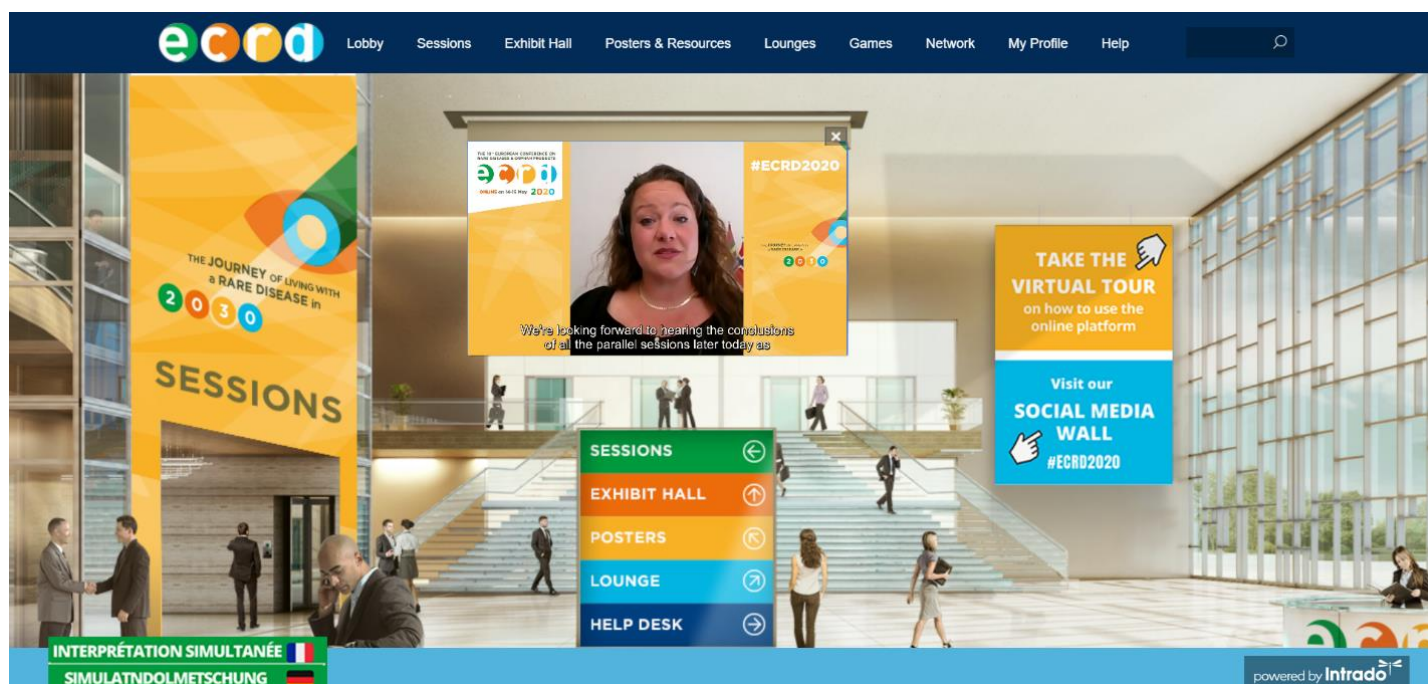


# First steps

## Identify the type of IT solution adapted to your event needs

- **Map out** what type of event you are planning to hold and the expected number of attendees. The IT solutions are very different for an event with 10, 20, 100 or 500 or more people.
- **Decide** whether or not registration will be charged. This also changes the IT solutions whether entry is open or closed.
- **Determine** your budget range. Having interactive elements, games, virtual exhibition and networking options change the type of solution needed and its cost.
- **Adapt** your programme to an online audience, try to limit the number of parallel sessions and duration of the sessions. Scheduling regular breaks is important as is interactivity every 10 – 15 minutes to keep the audience engaged. Your online event provider should be able to advise you on how to optimize viewing.
- **Determine** the number of speakers, which countries and time zones they'll be calling from, if any will be gathering together in one place (creating a hub) or all connecting remotely.

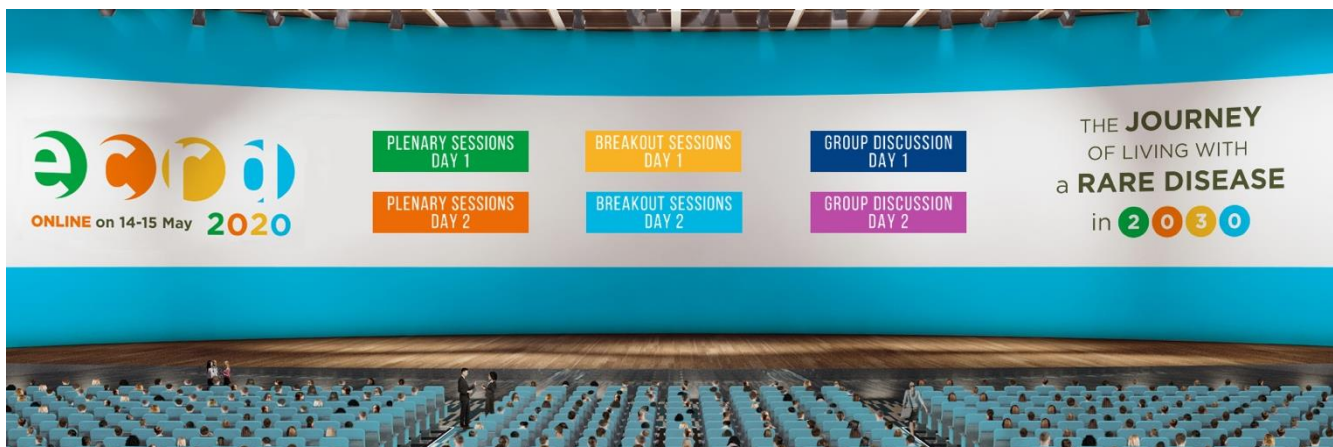
**Our example with ECRD:** 1500 attendees, paid registration, networking options were an important feature expressed by past attendees, plenaries and 6 parallel sessions over 2 days, funders who need visibility, posters that need visibility and easy search options, exhibitors who need visibility and options to display information to users and interact directly with participants. Our over 100 speakers were from across the world, all working remotely and therefore needed extensive technical training and assistance in order to ensure audio and visual connections were optimal on the event days.



## Do your research and request several quotes

- When considering which online tool/platform to use for your event, take the time to do your research and request several quotes. We discovered that providers have very different technical options and price offerings. It is important to find a provider which best fits your event needs.

**Our example with ECRD:** We selected the fully immersive virtual conference platform proposed by Intrado for our conference. We chose LiveOnlineEvents as our online expert consultant with the mission to rework our programme to better fit the online audience, to make suggestions about the interactive offer online, to lead interactive networking sessions and to train speakers and moderators how to adapt their talks and debates to an online audience.



## Some important points to consider before choosing the provider

- Platform
  - Ask to test the back-end of the platform prior to signing, is it **intuitive and user friendly**? Is it difficult for speakers to connect, carry out the tests and feel comfortable using the software?
- Technical back-up during the event
  - Depending on your needs, determine how much online technical support is included and what you will need on the day. This can vary in the options and can be expensive as it requires paid staff time from the provider.

**Our example for ECRD:** We had the following external paid support during the event: 1 virtual event design consultant (providing general advice and training speakers/moderators/virtual hosts) (external), 1 virtual event platform project manager (provided by platform), 1 IT engineer per session (provided by the virtual event platform to test speaker connections/sound, launch sessions, place speakers in and out of the 'scene' and respond to participants' technical questions), 1 front-end technical support person manning the help desk to respond to technical questions from participants (provided by platform)

- Chat boxes:
  - Depending on the speakers and the sessions, options should be available to make the chat boxes private or public / adaptable. Consider having technical issues separated from content related questions for the speakers.

**Our example with ECRD:** The interface provided several options which the hosts of the sessions could adapt ahead of the event. We learned that the public act differently and participate potentially more in a chat box with questions than raising their hand with a question. There is need to be able to sort questions and prioritize them to help the moderator manage incoming information while moderating the debate or speaking.

- Individual speaker connectivity issues:
  - Even with the best preparation, anything can happen. We highly recommend having each speaker send pre-recorded videos of their presentations in advance. These proved to be precious during the event, as some people at the last minute could not present live. Instead, we played their pre-recorded presentation as a video.
  - With the provider, talk about speaker training and technical set-up and invest time and potentially more budget in this training. Be sure technical issues are investigated and that you are in the loop to see that all issues can be resolved.

**Our example with ECRD:** Speakers were willing to provide the pre-recorded videos of their presentation (recorded in zoom) and were patient for the most part with the speaker training provided by Intrado. However, we were disappointed with this service, so in the future, we would increase our attention to the full completion and follow-up of the provider with our speakers. Pre-recording videos have the added advantage of checking the duration of speakers' presentations!

- Accessibility:
  - Consider closed captioning (live subtitles). There is an additional cost associated with this service.
  - Consider language apps which can provide your visually impaired attendees the possibility to hear the sessions.
  - Most of the providers we contacted did not have experience working with the visually impaired and specific voice software (screen reader). Speak about this from the beginning if this is important for your audience and be prepared to test voice software.

**Our example with ECRD:** The closed captioning option was highly appreciated and also for non-native English speakers. It worked very well.

We used an app called Interprefy which worked very well for both simultaneous translation but also allowed the visually impaired to hear sessions. Smart phones are compatible with voice software.

We learned 2 weeks before our event that although promised, Intrado was unable to guarantee access to the platform for people using voice software (screen readers). As a result, we contacted all of our visually impaired attendees ahead of the event to work out individual solutions for each of them which resulted most times in offering a registration to a caregiver to help them navigate the platform. Intrado also provided single webex links per attendee, per session as needed and at our request. But these solutions are not ideal and we will need to improve this service in the future.



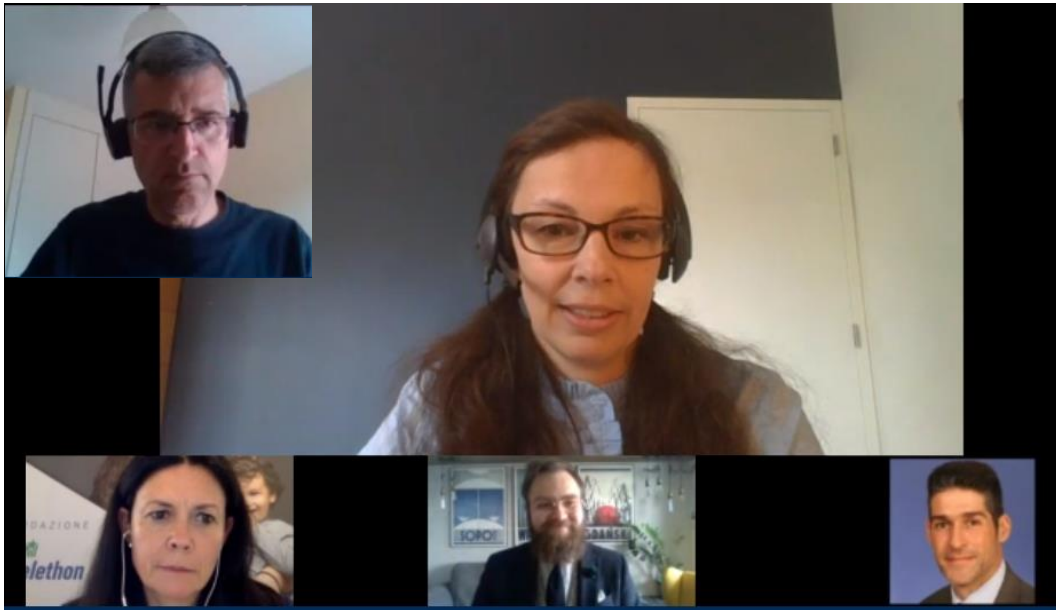


- **Check if the provider can integrate other systems into its platform.** Integrating zoom into the platform was a real bonus as it gave us more control and flexibility/agility – we were able to add a new networking session on Day 2 that was not planned in advance.
- **Does the platform provide gamification** elements (quizzes and interactivity leader board)? These options were new for us but helped encourage the participants to explore the platform more thoroughly, view/download documents in the resource centre, visit the exhibition and interact in sessions.
- If you have presentation booths, posters, exhibitors, funder visibility, check both the process for uploading materials to these booths but also ask the platform how they intend to encourage visitors to check out the booths and what types of push notifications exist. Finally, for posters, a search engine to easily browse is advisable.



## Organising speakers and sessions

- Best practice: Scripts (run of show/play) for each session were produced by each session moderator
- Good practice: Encourage all speakers to leave their contact details on the last slide of their presentation
- Issue calendar invites for each session to moderators/speakers etc. with clear instructions on how to connect on the day of the event – issue the invites for the time of the pre-session tests (30 / 45 mins before the actual session start time).
- We requested that every session chair designate a co-chair as a back-up in case there were any technical or health issues on the day.
- We asked all keynote speakers (and other speakers where possible) to pre-record their presentations in zoom – this proved very useful in the opening plenary session when our President couldn't connect to give his speech! This also helps to identify when a speaker's presentation is too long!
- We had 'virtual room hosts' for every session who helped to chat and prompt answers and act as models if needed – and we developed a special handbook/guidelines document for them along with training on the platform.



## Ideas for sessions/interactivity which were successful

- We will not hesitate to contract an external expert consultant again to help train moderators and speakers for both online / hybrid or on-site events in future, focusing on both interactivity and delivery. These training sessions were vital!
- The importance of interactivity during the sessions heightens significantly in an online setting (our consultant provided specific training to our moderators on how to do this e.g. by giving assignments to the audience throughout the sessions, using the chat function and polling features, giving the audience time for reflection and the power of music!).
- Opening the platform the day before the event helped participants to familiarise themselves with it prior to the official start and answer initial technical questions.
- The live virtual tour of the platform (run the day before the conference) was excellent in content and execution – resulted in fewer technical questions from participants during the conference (it was also available to re-view within the platform) and increased last minute registrations as the tour was transmitted live via our conference website and FB live.
- Speed networking sessions and meet the speakers sessions were very well received (vary the times and propose as many as possible!) – we ran 2 x COVID-19 discussion sessions to allow people the space to discuss the pandemic's impact on the community and to mitigate the possibility that this topic take over the rest of the discussions. These sessions were run via zoom which was integrated within the platform.
- For each session we suggest assigning the following roles: 1 virtual host, 1 note taker per session, 1 session chair/moderator accompanied by the individual speakers, 1 co-chair/moderator as back-up (in case of technical difficulties).
- **Participants really missed the face to face networking. Propose more networking sessions, get creative and don't forget to assign a virtual host to each session!**



## Changes in communications

- Pre-registered participants need more regular updates between the time they register and the actual event to provide useful content updates.
- Keep the main focus of your communications on the content of the event, not on the features of the platform.
- Know your target audience(s) and what parts of the content will be of most interest – tailor the messages to your different audiences to boost registrations.
- We created a welcome video for the homepage of the platform for each day: Day 1 = EURORDIS CEO and Day 2 = Co-Chair of the PC. Videos are important to animate the platform.
- Important to assign someone to design the graphics for the platform and produce videos – the time needed for these should not be underestimated.
- We increased communications to registered participants by sending out a reminder for the virtual tour the day before, a reminder to connect to the platform on Day 1, a highlights email from Day 1 with reminder to connect at the beginning of Day 2 and a post-conference thank you email.
- During our promotional campaign (1 month prior to the event), we reinforced the message that registered participants can get access to the content (all recorded sessions) for up to one year after the event. This was very much appreciated by participants.
- Encourage social media participation e.g. by asking participants to post photos of themselves tuning into the event from their home/office - since we couldn't see each other on the platform.
- Take advantage of the integrated push notification system and marquee announcements (rolling text at the bottom of the screen) throughout the conference to remind participants of what is coming up / where to go – if this feature is proposed by your platform.
- When advertising the times, it is imperative to point out which time zone applies. It is not possible to remind people of the time zone too many times!



## Overall conclusions

- Feedback from the conference was - for the majority - very positive, the major drawbacks of being online were the **connectivity issues** faced by speakers and participants at certain times during the conference and **no face-to-face networking**.

## Recommendations for roles and tasks to be assigned

- 1 overall project manager
- Committed, supportive and agile Programme Committee members / Theme leaders / theme supporters (external and internal)
- Social media relayer/community manager (in our case also responsible for community communications in our newsletters, press relations and producing videos)
- Registration staff (in our case also responsible for designing platform graphics, promoting the event and liaising with conference partners)
- Exhibition and poster coordination
- Corporate donor relations
- Technical liaison with platform, integration of zoom, management of interpretation app, technical accessibility for persons with visual/hearing impairments
- Contact for people with visual/hearing impairments in advance of and during the conference to ensure they are prepared and have a good experience, also able to troubleshoot during the event in an agile manner
- Answering questions and guiding attendees in the virtual lounges
- Platform champions to answer internal questions on their area of expertise





## Overall Positives

- It was helpful to have a robust, dedicated programme committee, theme leaders and session chairs with a willingness to jump in with both feet, and pilot and try things out.
- Maintaining the original dates of the conference – even online – **sent a strong message of solidarity** to the rare disease community that we are strong together and that we will not let rare diseases disappear into the COVID-19 'black hole'. A good sense of community was felt by many despite not being physically together. All stakeholders coming together was important.
- **Increased participation and inclusivity:** Record registration figures (+1500 online vs. 900 for on-site)! More participants and more inclusive than ever before. Going online provided the opportunity for more patient representatives to join the conference who would not otherwise have travelled to Stockholm due to financial or health reasons. Moving online also allowed more people from outside of Europe to participate (travel expensive and possibility to view all sessions on-demand almost instantly after they had taken place so no issue with different time zones). Reduced registration fees also enabled more patient representatives and other stakeholders to participate. Closed captioning (subtitles) made the conference **accessible/inclusive** to those with hearing impairments.
- No negative effect on the **quality of the programme** (no speakers cancelled) – on the contrary, new ones confirmed who were not previously available to travel to Stockholm!
- All registered participants able to **access the recordings of all sessions for up to one year** via the platform (until May 2021) - not limited to only participating in one session at a time as would have been the case on-site.
- **Post-conference registrations** possible for the first time to access all content recordings on-demand.
- We own copyright on all recordings so can re-use them to help leverage other projects.
- **Data, data, data!** We have access to a wealth of data that can be used internally to analyse traffic/trends/comments/chats and also share with exhibitors and poster presenters.
- A truly **immersive experience** for participants.
- Participants **more active on social media** during the event online than at a face-to-face event.
- This experience forced moderators and speakers to think more **about interactivity in their sessions** = polling / staying on time / reducing length of talks.
- **Impact on the environment / reduction of the event's carbon footprint** – while this was not originally the main driver, reducing travel, particularly by air, was a collateral benefit!



## Final Considerations

- Pivoting online significantly **increased administrative time** spent reimbursing pre-registered participants and responding to confused registrants.
- Huge pressure on administrative staff to handle **high volumes of late and last minute registrations** (one result of pivoting online is that registration remained open even during the conference and remains open now to access session recordings on-demand).
- Very time consuming to **re-confirm all speakers' availability** and to schedule the speaker training sessions. They received a lot of information/emails and requests in a short time period which was overwhelming.

Special note - **Enjoy the ride!** It will be challenging and new to everyone the first time but if your speakers and moderators don't enjoy it and exude confidence and enthusiasm, then the participants will not enjoy it either!