



VirtualBrainCloud

Personalized Recommendations for Neurodegenerative Disease



www.VirtualBrainCloud-2020.eu

Public deliverable report

Deliverable D2.6

Stakeholder conference: specific issues of neurodegenerative disease
- the patients' perspective

Date	November 2020
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Dissemination level	Public
Website	www.VirtualBrainCloud-2020.eu



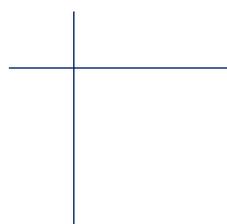


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1. Abbreviations

Acronym/abbreviation	Description/Definition
AD	Alzheimer's Disease
AE	Alzheimer Europe
CHARITE	Charité Universitätsmedizin Berlin
COVID-19	Coronavirus Disease
GA	Grant Agreement
GDPR	General Data Protection Regulation
TP 21	tp21 GMBH
TVB-Cloud	The VirtualBrainCloud Project
UNIVIE	University of Vienna





2. Background

The primary objective of the VirtualBrainCloud project (TVB-Cloud) is to create a decision support system for clinicians, structured around a cloud-based platform for personalized brain simulations. These simulations are constructed using high-quality, multidisciplinary clinical data, including EEG and MRI scans, genetic analyses and blood-based biomarker data. The goal of the decision support system is to enhance the early diagnosis, prognosis and personalized treatment of Alzheimer's disease (AD) and other neurodegenerative conditions.

One of the overarching goals of TVB-Cloud is to connect clinics, researchers and patients. To support the seamless and integrated connection of these diverse stakeholder groups, TVB-Cloud incorporates many measures to maximize impact, including outreach to stakeholders and dissemination of project results. This deliverable reports on the organization and delivery of a stakeholder event, held as part of the 2020 Alzheimer Europe Annual Conference.

3. Introduction

As part of Work Package 2 (WP2) under Task 2.6 of the Grant Agreement (GA)¹, Alzheimer Europe (AE) organized a stakeholder event provisionally entitled "Specific issues of neurodegenerative diseases: the patients' perspective", held as part of the AE Annual Conference. This conference brings together all types of people who are affected by dementia; those who are living with the disease, those who care for someone with the disease and those who work in the field of dementia, as well as policymakers, pharmaceutical company representatives and healthcare professionals. The 2019 AE Annual Conference took place in The Hague between 23-25 October. Held under the banner "Making valuable connections", this conference attracted 954 participants from 46 countries, and was supported by the European Union Health Programme. In total, the 2019 conference hosted 287 oral presenters and 241 poster presenters across 6 plenary sessions, 32 parallel sessions, 10 special symposia and 20 poster sessions, sharing their research, projects and experiences in an atmosphere of collaboration and exchange. For Task 2.6, AE sought to leverage this broad audience, by holding the TVB-Cloud event as part of the 2020 Annual Conference, the 30th conference to be hosted by AE.

4. Conference organization, format and platform

The 2020 AE Annual Conference was originally planned as a face-to-face event in Bucharest (Romania) during the month of October, with a similar format to the 2019 conference in The Hague. However, by the time of the TVB-Cloud general assembly meeting in June, there were strong indications that the COVID-19 pandemic would make it impossible to host a face-to-face conference. Instead, the conference plans were adapted to a virtual format, using a virtual conferencing platform and an online registration, abstract submission and review portal.

Two key aims for the virtual conference were: 1) to ensure that the platform was maximally interactive, replicating the atmosphere of collaboration of AE Annual Conferences, and; 2) to increase 'live'

¹ Grant Agreement (826421), 18.



engagement of attendees with conference sessions, retaining some of the dynamism and excitement that characterizes attendance at the AE in-person events. To achieve these goals, conference attendees were provided with various tools to engage with their peers and with conference speakers, including the option to leave comments and questions for speakers on a “question board”, the possibility of asking and polling questions live, the option to conduct teleconferences with fellow participants via the online platform, and the presence of a ‘social feed’ on the platform to enable wider communication to all participants. To encourage dynamic engagement of conference attendees, the communication agency Live Online Events (LOE) was employed to incorporate some live elements into the virtual conference, including live music interludes during breaks and online, live and moderated YouTube broadcasts during plenary sessions. LOE also supported the delivery of the parallel sessions, which used a Zoom platform that was integrated into the virtual conference platform. Finally, the virtual conference platform hosted a number of sponsor and exhibitor booths, which displayed materials relating to the sponsor/exhibitor and acted as a contact point for sponsor/exhibitor representatives, with the option to leave messages for these representatives and/or request one-to-one meetings using the internal teleconferencing facility.

Prior to the conference, the Alzheimer Europe communication channels (website, social media channels, magazine) were leveraged to increase awareness and visibility of the event, using the conference hashtag #30AEC to build a social media following. Conference attendees were encouraged to use this hashtag throughout the event when posting on social media. The conference was also advertised via the communication channels of our collaborating projects, including on the TVB-Cloud website and through the TVB-Cloud twitter account.

The conference was held between 20-22 October 2020, under the banner “Dementia in a Changing World”. A link to the virtual conferencing platform can be found here (<https://30aec.alzheimereuropevirtual.org/onboarding/welcome>) and a registration portal accessed via the Alzheimer Europe website (<https://www.alzheimer-europe.org/Conferences/30AEC-2020/Online-conference-registration>). Images showing the conference platform are presented in **Figure 1** below. Early-bird registration fees were set at EUR75 for professionals, rising to EUR125 after the early-bird deadline (15 September). Reduced fees were set for specific groups, including people with dementia and their caregivers, students and affiliates to our member organisations. Registration included access to the conference platform (and all associated content, e.g videos of oral presentations, posters and virtual booths) until December 31 2020; after the conference, access to the platform could be purchased for EUR25. The conference was structured around five live plenary sessions broadcast via YouTube and moderated by Kim Koppes, a LOE host; 24 parallel sessions with live oral presentations, delivered via Zoom; six special lunchtime symposia; five quick oral presentation sessions (5 minute presentations; available on-demand); and five poster sessions (available on-demand). In total, the conference hosted 260 oral presentations, over 100 posters and 25 booths, welcoming 719 attendees from 42 different countries.



Figure 1 – Alzheimer Europe virtual conference platform

My schedule: tab which presents a personalized schedule with session timings

Agenda: tab which presents a overview of the full conference schedule, in calendar or list format

Presenters: tab which displays the profiles of each presenter, in alphabetical order and showing the presenter's session(s)

Sponsors/Exhibitors: tab which lists the sponsors and booths of exhibitors, including TVB_Cloud

On demand presentations: tab which lists all presentations available 'on-demand', including links to recordings

Attendees: tab which displays a profile directory of all conference attendees, with links to contact/message them

5. TVB-Cloud at #30AEC

At #30AEC, TVB-Cloud hosted two parallel sessions (on Wednesday 21 and Thursday 22 October) and was also represented as an exhibitor, with a virtual conference booth hosted on the virtual conference platform. The schedule for the parallel sessions can be seen in **Figure 2** below, with an image of the virtual conference booth in **Figure 3**. TVB-Cloud also hosted a lunchtime webinar focused on the gaming rehabilitation system being developed by Eodyne (a TVB-Cloud partner) as part of WP6. As indicated in the previous section, all TVB-Cloud content on the virtual conference platform (including oral presentations and the booth) will remain available for registered conference participants until 31 December 2020. We also plan to make the presentations from the TVB-Cloud sessions available via the project website, for wider dissemination.

The first TVB-Cloud parallel session, entitled “AI approaches for dementia research, diagnosis and treatment”, was chaired by Katarina Stevanovic of TP21. During this session, project leader Petra Ritter (Charité Medical University Berlin) presented the TVB-Cloud approach to develop a cloud-based platform for personalized diagnosis and treatment of dementia. Martin Hofmann-Apitius of Fraunhofer SCAI outlined the knowledge graph approach to increase our mechanistic understanding of neurodegenerative disease, and to identify potentially druggable pathways. Viktor Jirsa (Aix-Marseille University) rounded off the session, illustrating how algorithms developed to analyze complex systems could help us understand brain networks in health and in disease.

The second TVB-Cloud session was entitled “Dementia research and AI: ethical, legal and social implications” and was chaired by Angela Bradshaw of AE. Bernd Stahl, Ethics Director of the Human Brain Project, outlined how some of the ethical issues raised by the use of AI in healthcare research could be mitigated at policy, organizational and project levels, to ensure that the benefits of AI do not outweigh the risks. Data protection is a major concern for big data research using AI, and Michael Copic



(University of Vienna) guided the audience through the General Data Protection Regulation, showing how it protects patient privacy whilst enabling health and care research. Rounding off the session, Richard Milne of the Wellcome Sanger Centre addressed the benefits and harms of risk disclosure when risk is detected using algorithm-based approaches, describing a potential route to mitigate harms whilst maximizing benefit.

From a communications perspective, each of the TVB-Cloud sessions was covered on twitter, using the #30AEC hashtag and including the @TVB_Cloud twitter handle. These tweets attracted over 44,000 tweet impressions in total, with some examples presented in Figure 4 below. For wider outreach, an overview of the TVB-Cloud sessions was also included in the final conference press release that was published by AE on 22 October and sent to all newsletter recipients and conference participants (>11,000 recipients), including many EU policymakers, Industry representatives, academic researchers and other key stakeholders. The AE press release was issued via the Newsweaver platform and taken up by many other news outlets, including the ScienceX platform and the EU Health Policy Platform, which forwarded the press release to its 7837 members, which include participants in the 83 EU health interest groups, EU Commission staff and other health stakeholders.

Figure 2. Schedule for TVB-Cloud sessions at #30AEC

30th Alzheimer Europe Conference
Dementia in a changing world
Virtual conference, 20-22 October 2020

#30AEC

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Wednesday, 21 October 10.45-12.00 **AI approaches for dementia research, diagnosis and treatment**

- **P11.1.** Petra Ritter (Charité Universitätsmedizin Berlin): Cloud-based simulation for personalised diagnosis and therapy
- **P11.2.** Martin Hofmann- Apitius (Fraunhofer SCAI): Mapping mechanisms in AD and PD
- **P11.3.** Viktor Jirsa (Aix Marseille University): Biomarkers of healthy ageing from brain imaging data and prospective applications in AD

Thursday, 22 October 10.45-12.00 **Dementia research and AI: ethical, legal and social implications**

- **P19.1.** Bernd Stahl (de Montfort University): Responsible AI: implications for brain research
- **P19.2.** Michael Cepic (University of Vienna): Legal considerations for data protection in AI-driven research
- **P19.3.** Richard Milne (University of Cambridge): Ethical challenges in the data driven detection of dementia

These sessions are held within the framework of *The VirtualBrainCloud project*, which receives funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 826421



Figure 3 TVB-Cloud virtual booth at #30AEC

Figure 4. Examples of social media coverage for TVB_Cloud sessions at #30AEC