



VirtualBrainCloud

Personalized Recommendations for Neurodegenerative Disease



www.VirtualBrainCloud-2020.eu

Public deliverable report

Deliverable D2.4

Stakeholder conference on GDPR-impact

Date	September 2020
Authors	Michael Cepic, Nikolaus Forgó, Emily Johnson, Mariana Risetto (UNIVIE) Petra Ritter (CHARITÉ) © VirtualBrainCloud consortium
Dissemination level	public
Website	www.VirtualBrainCloud-2020.eu



This project has received funding from the **European Union's Horizon 2020** research and innovation programme under **grant agreement No 826421**



Table of content

1. Abbreviations	3
2. Background.....	4
3. Introduction.....	4
4. Organisation	4
5. Conference report	5
6. Some results and Takeaways.....	6
ANNEX	7

1. Abbreviations

#	Acronym/ abbreviation	Description/Definition
	AE	Alzheimer Europe
	CHARITE	Charité Universitätsmedizin Berlin
	GA	Grant Agreement
	GDPR	General Data Protection Regulation
	TP 21	TP21 GMBH
	TVB-Cloud	The VirtualBrainCloud Project
	UNIVIE	University of Vienna



2. Background

The overarching goal of The VirtualBrainCloud (TVB-Cloud) is personalized prevention and treatment of dementia. To achieve generalizable results that help individual patients, the VirtualBrainCloud integrates the data of large cohorts of patients and healthy controls through multi-scale brain simulation using The Virtual Brain (or TVB) simulator. There is a need for infrastructures for sharing and processing health data at a large scale that comply with the EU general data protection regulations (or GDPR). The VirtualBrainCloud consortium closes this gap, making health data actionable. Elaborated data protection concepts minimize the risks for data subjects and allow scientists to use sensitive data for research.

3. Introduction

As part of Work Package 2 (WP2) under Task 2.4 of the Grant Agreement (GA) ¹ UNIVIE was required to organise a stakeholder conference on GDPR-impact. The timeline was set out as Month 0 until Month 24. The conference was to be organised in order to foster exchange of opinions/strategies with other projects in the domain, regulatory authorities, data protection officers, patient organisations and other stakeholders. Through this conference the VBC project wanted to show and discuss the interdisciplinary nature of data driven research projects in the healthcare sector. Furthermore the conference aimed to specifically address GDPR-related issues, when it comes to the use of personal data in such research projects. Lastly, by bringing together people from different disciplines the conference was able to highlight the many dimensions the use and protection of personal data concern.

At the same time UNIVIE was required to deliver this conference as Milestone MS13 of TVB-Cloud. As outlined in the GA the means of verification for this Milestone was that the conference had taken place.²

4. Organisation

Around one year ahead of the conference, in September 2019, UNIVIE started with its preparations for the GDPR-impact conference. At this time the conference was planned to be hosted physically on the premises of UNIVIE. In contemplation of the GA we conducted research on potentially matching speakers from other projects, regulatory authorities, etc. In doing this we aimed to gather speakers from various disciplines to reflect the multi-disciplined nature of the project. Meanwhile UNIVIE also drafted a concept paper of the conference structure that was submitted to AE and CHARITE, and accepted by both. Furthermore, UNIVIE consulted with TP21 with regard to potential conference requirements set out by the EU and subsequently incorporated their suggestions. It needs to be noted that because of the development of the COVID-19 pandemic, UNIVIE monitored the legal situation with regard to the hosting of events as well as travel restrictions and ultimately decided to host the conference virtually. With regard to the speakers we collaborated with AE and CHARITE and sent out invitations in January 2020. For communication purposes we mainly used the VBC legal helpdesk and consulted with the Data Protection Officer of UNIVIE for data protection compliance of our web-based registration platform. To host the conference online, UNIVIE used Zoom Webinar, which allowed it to separate between the

¹ Grant Agreement (826421), 18.

² Grant Agreement (826421), 20.



speakers and the audience, while still enabling UNIVIE to promote discussion through a Q&A option as well as the technical possibility to enable the audience to verbally contribute. For the final conference structure as well as the speakers and their topics please review the conference agenda in the Annex.

The conference was announced on TVB-Cloud website (<https://virtualbraincloud-2020.eu/>) before and during the live event:

<p>Sep 2020</p>	<p>GDPR Impact Conference 18 September 2020 Online</p> <p>Join us for a free conference on the impact of GDPR on digitization of biomedical research and clinical applications, including those using AI. VirtualBrainCloud will act as a case study, providing insight into the challenges and practical solutions of working with patient data.</p> <p>» Info & Registration</p>
<p>Oct 2020</p>	<p>GDPR Impact in Health and Research conference recordings</p> <p>The videos of the recent GDPR Impact in Health and Research Conference held by Virtual Brain Cloud are now online.</p> <p>» Watch the Conference Now</p>

The conference was also announced on the TVB_cloud Twitter account:

VirtualBrainCloud
@TVB_cloud

Learn about the impact of GDPR on biomedical technologies including AI, through a case study of VirtualBrainCloud, at the GDPR Impact Conference. All are welcome to join! 🗣️💻🧠

id.univie.ac.at/aktivitaeten/t...

TVB-Cloud Conference
id.univie.ac.at

12:10pm · 31 Aug 2020 · Twitter Web App

VirtualBrainCloud Retweeted

Department of Innovation a... Sep 18

@TVB_cloud CONFERENCE: The session on the GDPR and Artificial Intelligence related challenges in healthcare research projects has just started with a talk by Heidi Bentzen on "Bias and discrimination, misuse, and ethics vs law as a way to regulate AI" (University of Oslo) #GDPR

VirtualBrainCloud Retweeted

Angela Bradshaw @AngeBra... Sep 18

.@TVB_cloud #GDPR impact meeting is underway, with @DipakKalra of @iHD_HealthData, discussing the use of health data and citizen's attitudes to #datasharing #datasaveslives

5. Conference report

The conference bore the title: **Bridging the Gap Between New Technologies, Health Research and the Protection of Personal Data: GDPR Impact** and was hosted online on 18 September 2020 from 9:00 am until 5:15 pm.



The conference had 156 registrations at the time of the conference. At the day of the conference around 70 registrees were monitoring the conference at any given time. In total, the conference had 18 speakers divided into 4 panels. The Annex attached to this document is the agenda of the conference.

The conference was recorded and based on written consent we were able to publish the recorded material on YouTube (<https://www.youtube.com/watch?v=LcTCF8veshc>) with the exception of one presentation, whose presenter did not consent to it being published. Furthermore, CHARITE published the conference on YouTube (<https://www.youtube.com/playlist?list=PLVtBlERyzDeJEtwweIwo2FEBYSXTfbL8n>) as well.

The publication of the videos has been announced on TVB-Cloud website:

The screenshot shows a dark blue banner with white and pink text. On the left, it says 'Oct 2020'. The main text reads: 'Videos: GDPR Impact in Health Research', 'Individual talk videos now online', and 'You can now watch the GDPR Impact in Health Research 2020 conference videos online, organized in a chronological playlist that covers all sessions.' Below this is a pink button with the text '> Watch the videos here'.

The lecture series will be posted shortly at the INCF Training space The Virtual Brain Simulation Platform Collection to reach even higher visibility and impact: <https://training.incf.org/collection/virtual-brain-simulation-platform>.

6. Some results and Takeaways

- The use of personal data for research purposes should appreciate the data subjects' contribution with their providing of personal data. This could include informing them about the research projects and their progress or expressing gratitude through means of public information like newspapers.
- Especially when using AI in research, focus should be given to transparency. This is to preserve human agency, the freedom and autonomy of individuals and to diminish the risks of misuse and abuse
- When concretising legal provisions for data processing and security under the GDPR there is room for ethical decision making
- Concerning digital doctors AI cannot replace natural people but it can support them
- The morale among researchers should include trust and reliability as these are fundamental when processing health data
- The diversity of legal systems and the jurisdictional framework could have an impact on a project's legal assessment
- Remote conferences in the format chosen can be an appropriate alternative to physical conferences if technical implementation is properly prepared
- Remote conferences can guarantee worse than traditional conferences that all audience is present all the time which should be taken into account when planning the content and the length of such a conference



ANNEX



**universität
wien**

Department of Innovation
and Digitalisation in Law



VirtualBrainCloud

AGENDA

Online Conference (18 September 2020, 9:00 am – 5:10 pm)

Bridging the Gap Between New Technologies, Health Research and the Protection of Personal Data: GDPR Impact

Welcome remarks & Opening statement (09:00 – 09:15)

Nikolaus Forgo/Michael Cepic

Session 1 (09:15 – 10:45): Privacy, data protection and ethics: The rise of new technologies in the healthcare sector

Introductory Moderation (Michael Cepic)

Dipak Kalra (i~HD) (09:20 – 09:35)	Catalysing innovations through health data: is GDPR a blunt enough instrument?
Sabine Fehringer & Stefan Panic (DLA Piper) (09:35 – 09:50)	AI Doctor – use of artificial intelligence in medical diagnosis
Jan Bjaalie (EBRAINS – HBP) (09:50 – 10:05)	Sharing and publishing human brain data through the EBRAINS research infrastructure
Tanja Sinozic-Martinez (ITA) (10:05 – 10:20)	Technology governance of the electronic patient records system (ELGA) in Austria: secret and exclusive, or transparent and inclusive?

Discussion Session 1: 10:20 – 10:45

-- 20 min break --

Session 2 (11:05 – 12:35): GDPR and Artificial Intelligence related challenges in healthcare research projects

Introductory Moderation (Emily Johnson)

Heidi Bentzen (University of Oslo) (11:10 – 11:25)	Bias and discrimination, misuse, and ethics vs law as a way to regulate AI
Gauthier Chassang (INSERM) (11:25-11:40)	Legal challenges of AI regarding the respect of transparency obligations imposed by GDPR in the use of AI devices in health, including in research.



Katerina Polychronopoulos (UNIVIE) (11:40 – 11:55)	Should governments apply different regulatory standards to the use of AI in diagnosis and research?
Edgar Weippl (UNIVIE) (11:55 – 12:10)	GDPR and Artificial Intelligence: Challenges in healthcare research projects

Discussion Session 2: 12:10 – 12:35

-- 60 min Lunch break --

Session 3 (13:35 – 15:05): Data security and Artificial Intelligence in the healthcare sector

Introductory Moderation (Emily Johnson)

Cecilia Magnusson Sjöberg (U. Stockholm) (13:40 – 13:55)	A structured approach to AI-based health research - seldom asked questions
Athena Bourka (ENISA) (13:55 – 14:10)	Security as a data protection principle in AI
Dara Hallinan (FIZ Karlsruhe) (14:10 – 14:25)	Clarifying the relationship between informational self-determination and data security.
Jan Schallaböck (iRights Law) (14:25-14:40)	Corona App vs. Electronic Medical Files in Germany - a tale of two different approaches
Fruzsina Molnár-Gábor (U. Heidelberg) (14:40-14:55)	Concretising provisions for data processing and security for ML-based medical applications

Discussion Session 3: 14:55-15:15

-- 10 min break --

Session 4 (15:25 – 16:55): Artificial Intelligence and the applied law: TVB– Cloud project on prevention, detection and treatment of NDDs – Technical, legal and ethical challenges

Introductory Moderation (Michael Cepic)

Petra Ritter (CHARITÉ) (15:30 – 15:45)	The Virtual Brain Cloud: Building a reference cloud architecture for integrating health data
Nathan Lea (i~HD) (15:45 – 16:00)	'I'd like a second opinion...' How do we regulate digital doctors?
André Gemünd (Fraunhofer SCAI) (16:00 – 16:15)	TVB-Cloud secure infrastructure: from theory to practice
Angela Bradshaw (Alzheimer Europe) (16:15 – 16:30)	TVB-Cloud: ethics and the patient perspective

Discussion Session 4: 16:30 – 16:55

Closing remarks & Farewell (16:55 – 17:10)

Nikolaus Forgo/Emily Johnson