

# D10.9 Liaison and coordination activities report









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#### **LIST OF ABBREVIATIONS**

AD	Alzheimer's Disease	
Al	Artificial Intelligence	
ALS	Amyotrophic Lateral Sclerosis	
BIDays	Brain Innovation Days	
BRAINTEASER	Bringing Artificial Intelligence home for a better care of amyotrophic lateral sclerosis and multiple sclerosis	
EBC	European Brain Council	
EMA	European Medicines Agency	
EU	European Union	
HaDEA	European Health and Digital Executive Agency	
IHI	Innovative Health Initiative	
MS	Multiple Sclerosis	



#### **EXECUTIVE SUMMARY**

This document outlines the activities of alignment of BRAINTEASER with other EU and non-EU initiatives with similar or complementary objectives carried out by EBC between month 1 and month 48 in the framework of the Task 10.4 (Liaison with related projects and initiatives) under Work Package 10 (Exploitation, Innovation, Communication, Dissemination). Through the participation in events relevant to the project scope, joint sessions and podcasts based on projects' focus areas and priorities, BRAINTEASER liaison activities aim to promote coordination and collaboration among related EU and global initiatives and stakeholders by:

- Generating synergies between EU research networks
- Identifying and addressing mutual drivers and barriers
- Accelerating the information flow and the exchange of experience and knowledge

As lead of BRAINTEASER liaison activities, EBC has facilitated relations with relevant EU and global players and fostered the translation of research breakthroughs into innovation and health interventions. Task 10.4 has successfully mapped, prioritized, and liaised with 32 related projects and initiatives, facilitating knowledge exchange and cooperation.

#### Key achievements include:

- Conducting surveys and organizing virtual meetings to identify and address overlapping challenges such as regulatory hurdles and data-sharing limitations.
- Promoting collaboration through events like Brain Innovation Days, podcasts, and policy-focused workshops at the European Parliament.
- Highlighting BRAINTEASER's advancements in addressing ALS and MS care while contributing to the broader discussion on the responsible development of neurotechnologies.
- Developing tools and solutions with scalability, regulatory compliance, and patientcentric design, resulting in enhanced visibility and impact in the global brain health community.

The liaison efforts have reduced fragmentation, fostering an ecosystem where research findings translate into impactful healthcare innovations. The consortium plans to sustain these connections to inspire future projects, inform policy, and unlock further funding opportunities in Al-driven personalized medicine for brain health.



#### 1 INTRODUCTION

The European Union (EU) and its Member States have made considerable investments in brain research leading to a significant increase of initiatives in this area. Although these initiatives have generated considerable amounts of knowledge and innovative approaches, the translation of research breakthroughs into innovations and health interventions is hindered by the complexity of the challenge and excessive fragmentation of the efforts. Effective and efficient collaboration and cooperation between projects and initiatives advancing brain health, research and innovation prove key success factor to achieve full impact.

Running from January 2021 to June 2025, BRAINTEASER (Bringing Artificial Intelligence home for a better care of amyotrophic lateral sclerosis and multiple sclerosis) is an EU-funded research project seeking to exploit the value of big data (large clinical datasets, patient-generated data from wearables and air pollution data from sensors in Madrid, Turin, Lisbon and Pavia) to advance remote monitoring and clinical decision making in Multiple Sclerosis (MS) and Amyotrophic Lateral Sclerosis (ALS). As illustrated in Figure 1, BRAINTEASER aims to promote fast, accurate feedback between patients and clinicians for a better (self-)management of MS and ALS through an Artificial Intelligence (AI)-based model enabling personalised early detection of patient complications and prediction of disease progression over time.

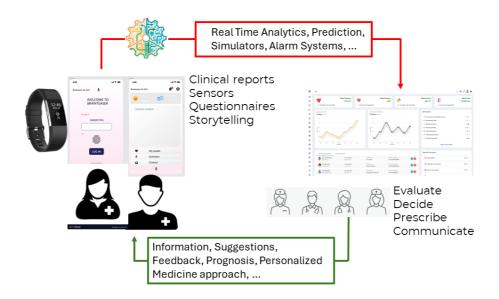


Figure 1. BRAINTEASER visual abstract

In the framework of the BRAINTEASER Work Package 10 (Exploitation, Innovation, Communication, Dissemination), Task 10.4 (Liaison with related projects and initiatives) meets the need for strengthening the information flow and accelerating the exchange of experience and knowledge as well as maintaining continuous dialogue between all relevant stakeholder groups. As Task Leader, the European Brain Council (EBC) has been leveraging its extensive network of key players in the EU brain space (encompassing patient organisations, scientific and professional societies as well as industry partners) to

#### BRAINTEASER - D10.9



enhance synergies in addressing mutual drivers and barriers and keep BRAINTEASER aligned with EU and non-EU projects and initiatives with similar or complementary objectives.



#### 2 METHODOLOGY

BRAINTEASER liaison with related projects and initiatives follows a stepwise approach:

- 1. Mapping of neuromotor-related initiatives with a focus on AI both at EU and international level
- 2. Identification of relevant priority initiatives, areas of coordination and coordination activities
- 3. Identifying relevant projects and initiatives based on the set consortium strategic objectives
- 4. Designing and implementing a liaison plan based on common interest points and focus areas

## 2.1 Mapping of neuromotor-related initiatives with a focus on Al both at EU and international level

MS and ALS have a huge societal burden and heavily impact the lives of those affected and their loved ones. Through the development of computer programs and systems able to emulate tasks normally requiring human intelligence such as recognizing patterns, taking decisions, evaluating and predicting, Al in healthcare is a booming field set to revolutionise early risk prediction, prevention and care of brain conditions.

In the early stages of the project, EBC put together and provided the consortium with a comprehensive list of potentially relevant Al-powered EU and non-EU projects and initiatives with a focus on neuromuscular disorders, including but not limited to:

- Projects funded under the same topic as BRAINTEASER: SC1-DTH-02-2020 -Personalised early risk prediction, prevention and intervention based on Artificial Intelligence and Big Data technologies
- Projects funded under the same main programme:
- H2020-EU.3.1. SOCIETAL CHALLENGES Health, demographic change and wellbeing
  - H2020-EU.3.1.4.2. Individual awareness and empowerment for selfmanagement of health
  - o H2020-EU.3.1.5. Methods and data

Aiming to inform the consortium decision making on projects and initiatives to prioritise, the list grew longer as time passed, and new contacts were made. Table 1 provides an overview of relevant projects and initiatives identified so far (32), including but not limited to both EU-funded and Innovative Health Initiative-funded projects.



Table 1. Overview of BRAINTEASER-related projects and initiatives

AP	Alameda

#### **ALAMEDA**

Treatment Gap of Brain Diseases via Smart, Connected, Proactive and Evidence-based Technological Interventions



<u>LETHE</u> (λήθη) - A personalized prediction and intervention model for early detection and reduction of risk factors causing dementia, based on AI and distributed Machine Learning



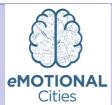
<u>Al-Mind</u> - Intelligent digital tools for screening of brain connectivity and dementia risk estimation in people affected by mild cognitive impairment



<u>Back-UP</u> - Personalised Prognostic Models to Improve Wellbeing and Return to Work After Neck and Low Back Pain



<u>eCARE</u> - Digital solutions supporting continuum of care for frailty prevention in old adults



<u>eMOTIONAL Cities</u> - Mapping the cities through the senses of those who make them



FEMale - Finding Endometriosis using Machine Learning



<u>IDIH</u> - International Digital Health Collaboration for Preventive, Integrated, Independent and Inclusive Living



<u>i-PROGNOSIS</u> - Intelligent Parkinson eaRly detectiOn Guiding NOvel Supportive InterventionS



<u>iHelp</u> - Personalised Health Monitoring and Decision Support Based on Artificial Intelligence and Holistic Health Records



<u>PRECISE4Q</u> - Personalised Medicine by Predictive Modeling in Stroke for better Quality of Life



RADAR-AD - Remote Assessment of Disease and Relapse – Alzheimer's Disease



<u>TIMELY</u> - A patient-centered early risk prediction, prevention, and intervention platform to support the continuum of care in coronary artery disease (CAD) using eHealth and artificial intelligence



	WARIFA - Watching the risk factors: Artificial intelligence
WATCHING THE RISK FACTORS	and the prevention of chronic conditions
premodi <b>ALS</b>	PremodiALS - A premotor disease signature for ALS
EDEN	EDEN - Embracing Dementia
SMiLe	<u>SMILE</u> - Strenghtening primary Medical care in Isolated and deprived cross-border arEas
<b>⊗INSILICO</b> WORLD	<u>In Silico World</u> - Lowering the barriers to a universal adoption of In Silico Trials
SIMCor	<u>SIMCor</u> - In-Silico testing and validation of Cardiovascular IMplantable devices
Better Health	<u>BETTEReHEALTH</u> - Human, technical and political factors for better coordination and support of e-health in Africa
ORIGENT SCIENCES	<u>Origent</u> - Managing Drug Development Risks through Better Foresight
connectinghealth	CONNECTINGHEALTH - CONNECTing the dots withIN diGItal HEALTH Innovation Ecosystems
XpanDH  Expanding Digital Health through a part-despised Digital Analoth Congression	<u>XpanDH</u> - Expanding Digital Health through a pan- European EHRxF-based Ecosystem
Digital Health Uptake	<u>Digital Health Uptake</u> - Uptake of Digital Solutions in Health and Care
HEALTHYCLOUD Health Research & Innovation Cloud	HealthyCloud - Health Research & Innovation Cloud
Mobilise-D	MOBILISE-D - Connecting digital mobility assessment to clinical outcomes for regulatory and clinical endorsement
K-HEALTHINAIR Manager to represent years afficially according to	<u>K-HEALTHinAIR</u> - Knowledge for improving indoor AIR quality and HEALTH
CLAIMS	CLAIMS - Clinical impact through AI-assisted MS care
PRIMS A Joint Global Initiative	PROMS - Patient Reported Outcomes for Multiple Sclerosis
<b>ZEH</b>	TEHDAS2 - Joint Action Towards the European Health Data Space





<u>HEREDITARY</u> - HetERogeneous sEmantic Data integration for the guT-bRain interplay

## 2.2 Identification of relevant priority initiatives, areas of coordination and coordination activities

To evaluate BRAINTEASER's strategic objectives, gather coordination requirements, and identify key projects to engage with from the initial mapping of 13 initiatives, EBC conducted a survey. Consortium partners were invited to indicate their areas of interest from the following focus areas:

- Bringing AI in actual clinical practice, clinical trials and real patient life
- Designing useful and understandable AI tools
- Including and empowering patients and clinicians
- Devising open science solutions (including data fairification)
- Other, please specify.

Consortium partners have been also asked to identify potentially relevant projects from the following:

- ALAMEDA Bridging the Early Diagnosis and Treatment Gap of Brain Diseases via Smart, Connected, Proactive and Evidence-based Technological Interventions
- LETHE  $(\lambda \hat{\eta} \theta \eta)$  A personalized prediction and intervention model for early detection and reduction of risk factors causing dementia, based on Al and distributed Machine Learning
- Al-Mind Intelligent digital tools for screening of brain connectivity and dementia risk estimation in people affected by mild cognitive impairment.
- Back-UP Personalised Prognostic Models to Improve Well-being and Return to Work After Neck and Low Back Pain
- eCARE Digital solutions supporting continuum of care for frailty prevention in old adults
- eMOTIONAL Cities Mapping the cities through the senses of those who make them
- FEMaLe Finding Endometriosis using Machine Learning
- IDIH International Digital Health Collaboration for Preventive, Integrated, Independent and Inclusive Living
- iHelp Personalised Health Monitoring and Decision Support Based on Artificial Intelligence and Holistic Health Records
- PRECISE4Q Personalised Medicine by Predictive Modeling in Stroke for better Quality of Life



- TIMELY A patient-centered early risk prediction, prevention, and intervention platform to support the continuum of care in coronary artery disease (CAD) using eHealth and artificial intelligence
- WARIFA Watching the risk factors: Artificial intelligence and the prevention of chronic conditions
- RADAR-AD Remote Assessment of Disease and Relapse Alzheimer's Disease
- Other (please specify)

Table 2 and Table 3 below summarise the results from the survey.

Table 2. Overview of responses to the first question of the consortium consultation

Q1: Here below, you find the strategic objectives to which projects relevant to BRAINTEASER should relate. Please, select max. 3 topics and/or add another one (N = 16)		
Bringing AI in actual clinical practice, clinical trials and real patient life	16	
Designing useful and understandable Al tools	13	
Including and empowering patients and clinicians	11	
Devising open science solutions (including data fairification)	2	
Other, please specify	1: Understanding the evolution and prognosis of the diseases	

Table 3. Overview of responses to the second question of the consortium consultation

Q2: Please select all relevant and/or interesting projects for BRAINTEASER (EU projects) (N = 16)		
eMOTIONAL Cities - Mapping the cities	62.50%	
through the senses of those who make them	10	
illala Danasalia dilladh Maribaria	56.25%	
iHelp - Personalised Health Monitoring and Decision Support Based on Artificial Intelligence and Holistic Health Records	9	
ALAMEDA Dridging the Farly Diagnosis	50.00%	
ALAMEDA - Bridging the Early Diagnosis and Treatment Gap of Brain Diseases via Smart, Connected, Proactive and Evidence-based Technological Interventions	8	



Q2: Please select all relevant and/or interesting projects for BRAINTEASER (EU projects) (N = 16)	
RADAR-AD - Remote Assessment of Disease and Relapse – Alzheimer's Disease	43.75% 7
LETHE (λήθη) – A personalized prediction and intervention model for early detection and reduction of risk factors causing dementia, based on Al and distributed Machine Learning	37.50% 6
Al-Mind - Intelligent digital tools for screening of brain connectivity and dementia risk estimation in people affected by mild cognitive impairment	37.50% 6
WARIFA - Watching the risk factors: Artificial intelligence and the prevention of chronic conditions	37.50% 6
TIMELY - A patient-centered early risk prediction, prevention, and intervention platform to support the continuum of care in coronary artery disease (CAD) using eHealth and artificial intelligence	31.25% 5
Back-UP - Personalised Prognostic Models to Improve Well-being and Return to Work After Neck and Low Back Pain	18.75% 3
IDIH - International Digital Health Collaboration for Preventive, Integrated, Independent and Inclusive Living	18.75% 3
PRECISE4Q - Personalised Medicine by Predictive Modeling in Stroke for better Quality of Life	18.75% 3
eCARE - Digital solutions supporting continuum of care for frailty prevention in old adults	12.50%
Other (please specify)	12.50% 2
FEMaLe - Finding Endometriosis using Machine Learning	0



Based on the survey results, bilateral meetings with the coordinators of the top 8 ranked projects were set up.

## 2.3 Development and implementation of a programme of coordination activities

Based on 1:1 meetings and discussions on potential points of collaboration, EBC designed a programme consisting of a set of joint activities addressing the overlapping needs of relevant projects and initiatives and being regularly updated based on new connections and priorities' reassessment. Encompassing 12 networking and visibility opportunities that actively involved a total of 12 EU and non-EU projects and initiatives, the plan was implemented as outlined below.

#### 2.3.1 October 2021: 1st virtual meeting

With the aim to identify similarities in terms of objectives, assess value and areas for further exchanges and cooperation, in October 2021 EBC brought together 11 projects' representatives. During the meeting, participants were given the chance to introduce themselves and their project objectives as well as to outline challenges and views on potential areas of collaboration, as outlined in Table 4, which presents the meeting agenda.

Table 4. Agenda of the 1st virtual meeting with other EU projects

1st virtual meeting with other EU projects – 4 October 2021. Participants include:

- BRAINTEASER: Maria Fernanda Cabrera, Barbara Di Camillo, Roberta Bursi,
   Natalia Allegretti, Françoise Van Hemelryck
- RADAR-AD: Dag Aarsland, Vera Nies
- LETHE: Sten Hanke
- Al-Mind: Ira Haraldsen, Lina Plataniti, Vebjørn Andersson

13.00 - 13.05 CET	Welcome
13.05 - 13.30 CET	Round of introductions
13.30 - 14.00 CET	Open discussion on potential areas of collaboration

On that occasion, participants discussed projects' approaches to multimodal data collection and agreed on the potential added value of sharing developed solutions and collected data to enable trustworthy databanks and algorithms. When it comes to data sharing, the assessment of cognitive decline, transversal to the four projects, was identified as potential area to tackle in a collaborative way. On a similar note, <a href="mailto:BRAINTEASER Open Evaluation Challenges">BRAINTEASER Open Evaluation Challenges</a>, which adopt an open-science paradigm making scientific research results accessible while respecting patient data confidentiality and ownership, were identified as potential framework and enabler.

With regards to developed solutions, BRAINTEASER showed a particular interest in the solutions developed by RADAR-AD in the context of Alzheimer's Disease (AD), their potential application to MS and ALS as well as joint activities fostering the sustainability of developed solutions.

Participants also addressed data security, ethics and the need for smoother regulatory processes – which inspired the idea of developing guidance on working with regulatory agencies.



#### 2.3.2 January 2022: 2nd virtual meeting

After the initial virtual meeting, BRAINTEASER and the other three projects met again in January 2022 to focus on RADAR-AD, the most advanced among the four initiatives. Discussions centred on RADAR-AD's approach to remote monitoring and assistance for AD patients and explored the potential for applying its developed solutions to other disease areas, including those addressed by BRAINTEASER.

As summarised in Table 5, the meeting fostered further discussions on RADAR-AD technology, which is based on the collection of both active and passive data from wearables, combines machine learning approaches and functional scales and includes tracking functional domains.

Table 5. Agenda of the 2nd virtual meeting with other EU projects

2<sup>nd</sup> virtual meeting with other EU projects – 11 January 2022. Participants include:

- BRAINTEASER: Maria Fernanda Cabrera, Barbara Di Camillo, Roberta Bursi, Manuel Ottaviano, Chiara Nicolo, Natalia Allegretti, Elke De Witte, Françoise Van Hemelryck
- RADAR-AD: Dag Aarsland, Vera Nies, Andrew Owens
- LETHE: Sten Hanke
- Al-Mind: Lina Plataniti

7 William Geather	
13.00 - 13.05 CET	Welcome
13.05 - 13.45 CET	Q&A on RADAR-AD solutions
13.45 - 14.00 CET	Consensus building on next steps

On that occasion, participants were also introduced to some best practices for cost-effective, user-friendly solutions including:

- Data collection through apps (less expensive than gait wearables)
- Workshops to better understand patients' needs in terms of wearable devices as well as constant dialogue to foster compliance and active data collection
- Co-design with patients and clinicians for increased acceptability of the Information and Communications Technology

With regards to regulatory affairs, RADAR-AD features a workstream focused on interactions with the European Medicines Agency (EMA), which includes an Innovation Task Force and provides advice not only on clinical trials but also on primary and secondary end points. A RADAR-AD Review of <a href="EMA Regulatory Scientific Advices">EMA Regulatory Scientific Advices</a>, <a href="Qualification Opinions">Qualification Opinions</a>, and <a href="Qualification Advices">Qualification Advices</a> was made available to participants.

#### 2.3.3 June 2022: 3rd virtual meeting

Between January 2022 and June 2022, EBC connected with new relevant projects and initiatives. As a result, the 3rd virtual meeting held in June 2022 saw the participation of a higher number of stakeholders – as shown in Table 6 below. Building on the focus on regulatory issues during previous virtual meetings, this session deepened discussions on the pressing regulatory challenges faced by the projects and the actions taken to address them.



#### Table 6. Agenda of the 3rd virtual meeting with other EU projects

#### 3<sup>rd</sup> virtual meeting with other EU projects – 21 June 2022. Participants include:

- BRAINTEASER: Barbara Di Camillo, Maria Fernanda Cabrera, Roberta Bursi, Dorina Stanculescu, Natalia Allegretti, Anthony Armenta, Elke De Witte, Kristien Aarts
- RADAR-AD: Katy Brem
- LETHE: Sten Hanke
- Al-Mind: Ira Haraldsen
- WARIFA: Chiara Zocchi, Manuela Guiducci, Thomas Schopf
- Neurodegenerative Disease Atlas: Ming Chen
- ROCK-ALS trial, MAXOMOD, premodiALS: Lingor Paul

14.00 - 14.10 CET	Welcome & Introduction
14.10 - 14.55 CET	Round of contributions on regulatory challenges + open discussion
14.55 - 15.00 CET	Consensus building on next steps

Based on the meeting outcomes, the BRAINTEASER consortium identified 3 priority regulatory challenges as follows:

- 1. dealing with different regulations in different countries;
- 2. linking the regulatory challenges with the commercialisation plan;
- 3. accuracy, transparency, generalizability, reliability and inclusiveness with regards to the use of AI to support healthcare.

#### 2.3.4 March – August 2023: bilateral meetings with related projects

Between March 2023 and August 2023, EBC relinked with some of the projects initially approached and built new connections through a series of 1:1 meetings with coordinators of the following projects (9): LETHE, RADAR-AD, eMOTIONAL Cities, ALAMEDA, WARIFA, FEMaLe, iHELP, TIMELY and CLAIMS.

Based on the discussions on potential areas of collaboration and given the complexity of addressing broad regulatory issues specific to each project, EBC put together a new programme of coordination activities. This programme prioritised communication and the dissemination of project results, with a focus on participating in relevant events, coorganising joint sessions, and contributing to podcast episodes.

## 2.3.5 September 2023: Time to improve the life of people living with ALS: policy recommendations for improved diagnosis, care and treatment. Event in the European Parliament, Brussels

BRAINTEASER disease areas include ALS, a rare brain disease facing major unmet needs – notably in terms of research funding, medical education and access to care. As network of multi-disciplinary experts in the ALS space including but not limited to people living with ALS, academic researchers, payers, healthcare professionals and industry representatives, the EU ALS Coalition advocates for a positive policy environment to support access to optimal diagnosis and care for people living with ALS.





Figure 2. Agenda of the launch of the EU ALS Coalition policy paper in the European Parliament

On the occasion of the launch of the EU ALS Coalition policy paper titled "Amyotrophic Lateral Sclerosis, a rare neurodegenerative disease: European landscape assessment and policy recommendations for improved diagnosis, care, and treatment" in the European Parliament, the EBC Executive Director highlighted BRAINTEASER as a relevant initiative aimed at deepening understanding of ALS, promoting knowledge sharing and advancing ALS treatments. In that context, BRAINTEASER was praised by Hélène Le Borgne, Policy Officer at the Directorate-General for Research and Innovation, European Commission, for offering a pathway to improve disease management and foresee the adjustments needed in management to ultimately enhance patient outcomes. As illustrated in Figure 2 above, the event brought together a diverse range of stakeholders.



2.3.6 October 2023: Personalised early risk prediction, prevention and intervention in brain diseases: challenges and opportunities of AI and Big Data technologies. Event at Brain Innovation Days, Brussels



## **Brain Innovation Days**

26-27 October 2023, Brussels

Personalised early risk prediction, prevention and intervention in brain diseases:
Challenges and opportunities of AI and Big Data technologies





Figure 3. Speakers of the BRAINTEASER Roundtable Discussion at BIDays

EBC-led, <u>Brain Innovation Days</u> (BIDays) bring every year the brain ecosystem together to foster dialogue, exchange knowledge, accelerate investment in research & innovation and facilitate business development. As part of the latest liaison activities plan, a roundtable discussion was held at 2023 BIDays with the aim of promoting collaboration among related projects and initiative and foster the translation of research breakthroughs into innovation. Featuring 3 EU-funded projects (BRAINTEASER, LETHE and eMOTIONAL Cities), 2 projects co-funded by the European Commission (TEHDAS2 and RADAR-AD) and a global initiative (PROMS), the event addressed personalised early risk prediction, prevention and intervention and benefited from patient perspective and regulatory experts' insights. Figure 3 offers an overview of the invited speakers.

Moderated by Usman Khan, Chair of the Motor Neurone Disease (MND) Association, the meeting kicked off with an address from Carl Mörch, Co-Director of FARI – AI for the Common Good Institute, on bridging the gap between medical technologies and society. In particular, the presentation stressed the importance of adapting the tools to the audience so that AI doesn't make inequalities even greater.

Session 1 brought together representatives from 3 EU-funded research project on brain diseases, who introduced their work to the audience.

 Barbara DI Camillo, BRAINTEASER Scientific Coordinator, showcased the BRAINTEASER project – highlighting the cost-effectiveness of BRAINTEASER



solutions and the fact that the app (translated in three languages to be accessible) is personalised depending on the patient status. The presentation also highlighted some of the challenges researchers in the field are meeting (notably different regulations across the countries and the need for data to be able to register the tools as medical devices) and called the entire scientific community and patient organisations to unite forces in a co-design approach.

- Hannes Hilberger, LETHE Representative, then took the floor illustrating the LETHE project which focuses on the prevention of dementia with Big Data and Machine Learning. As for BRAINTEASER, the project is implemented in different countries and data collected from different sources notably through cognitive games. In particular, LETHE consortium developed an app providing patients with feedback on a variety of interventions including nutrition and physical activity.
- Bruno Miranda, Co-Coordinator of the eMOTIONAL Cities project, sent a video message briefly illustrating how the consortium is exploring the notion of neurourbanism and using Data Science & Technology to make cities mentally healthier.

Session 2 turned focus to the patient perspective and the crucial role patients play as key partners in brain research, with an intervention from Orla Galvin, Executive Director of the European Federation of Neurological Associations (EFNA), and Paola Zaratin, PROMS Initiative SSC Co-Chair and Director of Scientific Research of the Italian MS Society – Italian MS Foundation.

- Paola Zaratin used the example of the PROMS global initiative to stress the importance of a renewed humanism in medicine: in the context of AI and new technologies, there's a need to find new ways to engage patients. Digital approaches could contribute to make patient engagement an even more successful partnership.
- Orla Galvin addressed the integration of Patient Reported Outcome Measures (PROMS) in healthcare policy, research and practice.

Session 3 invited regulatory experts to address the identified challenges researchers meet along the way for translating brain research into innovation. Panellists included Florence Butlen-Ducuing, Scientific Senior Specialist at the European Medicines Agency and former psychiatrist; Vera Nies, RADAR-AD Programme Manager; and Elina Drakvik – TEHDAS2 Representative, who highlighted the importance of fostering the collaboration of key players in the field including companies and players and engaging the society as a whole in the debate (notably through the implementation of patient advisory boards).

## 2.3.7 January 2024: How the environment influences brain health. Brain Talks Podcast

Available on all major platforms, <u>Brain Talks</u> is the podcast produced by BIDays. Within liaison activities with related projects and initiatives, a <u>Brain Talks episode on Urban Environment and Brain Health</u> was recorded and released in January 2024.

While evidence shows that environmental factors may influence both the aetiology and the progression of a number of brain conditions including MS and ALS, urban living is associated to an increase in mood and anxiety disorders, drugs addiction and risk of schizophrenia and psychosis. Addressing the concept of neurourbanism, a new interdisciplinary approach that brings together neuroscientists, urban researchers and



architects to investigate the prerequisites for mental health in cities, and environmental influences on MS, ALS and mental health, the episode featured Arianna Dagliati (BRAINTEASER) and Bruno Miranda (eMOTIONAL Cities).

## 2.3.8 February 2024: Towards a Rare Brain Disease Ecosystem. Event at the University Foundation, Brussels

On the occasion of Rare Disease Day, 29 February 2024, EBC hosted an event at the University Foundation, Brussels, to raise awareness on rare brain diseases and their societal impact. The event brought together researchers, clinicians, people living with a rare brain disease and industry representatives to address gaps and priorities in the field and brainstorm together on new ways to tackle them. The <u>programme</u> addressed the need for a rare brain disease ecosystem, patient and caregiver priorities, industry innovation trends as well as clinical care pathways and unmet needs. On that occasion, the EBC Executive Director stressed the need to join forces in the rare brain disease space shading light on BRAINTEASER and its liaison activities as example of best practices in the ALS space.

## 2.3.9 March 2024: Towards a European Charter for the Responsible Development of Neurotechnologies. Session, Institute of Earth Physics of Paris

Ranging from Magnetic Resonance Imaging and Electroencephalography to Deep Brain Stimulation, neurotechnologies have great potential to foster brain health and have proved effective both in the diagnosis and management of neurological and psychiatric diseases. Although existing regulations already provide general standards, the European Union still lacks specific regulations and directives in this regard, which led to the creation of an EBC-led group of relevant stakeholders to design comprehensive, non-binding guidelines for the development of medical and non-medical neurotechnologies at the European level.

At the invitation of the French Ministry of Higher Education and Research, the EBC Executive Director took the floor in a session on the upcoming European Charter for the Responsible Development of Neurotechnologies to shed light on BRAINTEASER technology and AI potential for brain health.

#### 2.3.10 June 2024: 10th Congress of the European Academy of Neurology, Helsinki

In June 2024, the 10th Congress of the European Academy of Neurology was held in Helsinki, Finland. On that occasion, BRAINTEASER strategy to keep BRAINTEASER aligned with other EU and global initiatives with similar objectives, increase visibility of this research field and facilitate relations with key stakeholders including policymakers for evidence-based policymaking was featured in the e-poster illustrated in Figure 4.



# MULTIPLE SCLEROSIS (MS) AND AMYOTROPHIC LATERAL SCLEROSIS (ALS): ADVANCING CLINICAL DECISION MAKING THROUGH WEARABLES



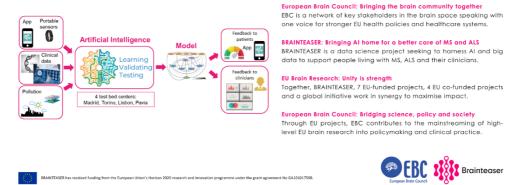


Figure 4. e-poster at the 10th Congress of the European Academy of Neurology

Congress participants were introduced to the BRAINTEASER clinical app during a scientific theatre session focused on uniting MS and ALS research innovation through collaborative efforts.

## 2.3.11 September 2024: HEREDITARY virtual Strategic Workshop on Multimodal Health Data Integration

HEREDITARY is an EU-funded project which started in January 2024 and leverages AI and big data to deepen the understanding of the gut-brain axis with regards to neurodegenerative disorders (ALS and MS, but also Alzheimer Disease, Parkinson Disease and Frontotemporal Dementia). As BRAINTEASER, HEREDITARY aims to harness the potential of multimodal health data integration for a better care of MS and ALS. In the framework of HEREDITARY liaison activities, the BRAINTEASER Coordinator was invited to share BRAINTEASER vast experience and best practices with regards to multimodal health data integration, challenges faced, and solutions envisioned so far – as illustrated in Table 7.

Table 7. Agenda of the virtual Strategic Workshop on Multimodal Health Data Integration

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14:30 CET	Introduction and roll call	
14:45 CET	<ul> <li>Project presentation on their approach to multimodal health data integration</li> <li>Al-Mind - Intelligent digital tools for screening of brain connectivity and dementia risk estimation in people affected by mild cognitive impairment,</li> <li>BRAINTEASER - Bringing Artificial Intelligence home for a better care of amyotrophic lateral sclerosis and multiple sclerosis,</li> <li>Next-Gen - NEXT GENERATION TOOLS FOR GENOME-CENTRIC MULTIMODAL DATA INTEGRATION IN PERSONALISED CARDIOVASCULAR MEDICINE.</li> </ul>	
15:15 CET	Open discussion on potential touchpoints and synergies related to data integration	
15:45 CET	Open discussion on other areas for potential synergies	



The event saw the participation of 49 project representatives.

#### 2.3.12 October 2024: Unlocking AI Potential in Brain Health. Brain Talks Podcast

BRAINTEASER and AI-Mind address the burden of neurodegenerative disorders from different perspectives: prevention (maintaining brain health) and care (brain disease monitoring and management). Featuring Alessandro Guazzo (BRAINTEASER) and Ira Haraldsen (AI-Mind), the <u>Brain Talks episode on Unlocking AI Potential in Brain Health</u> addressed the risks to be mitigated, the barriers to overcome as well as the importance of patient involvement in this research field.

## 2.3.13 November 2024: Harnessing AI for Brain Health: Lab to Market to Society. Event at Brain Innovation Days, Brussels



#### Harnessing AI for Brain Health: Lab to Market to Society

Bringing Artificial Intelligence Home for a Better Care of Amyotrophic Lateral Sclerosis and Multiple Sclerosis

13 November 2024, 16:05-17:50







The BRAINTEASER project has received funding from the European Union's Horizon 2020 research and innovation programme under the grant agreement No GA10101755

Figure 5. Speakers of the BRAINTEASER Impact & Exploitation Workshop at BIDays

As part of BRAINTEASER's liaison efforts to foster synergies in the brain research space and maximise impact, an Impact & Exploitation workshop was organised during the 2024 BIDays. The workshop showcased the BRAINTEASER clinical app, highlighting the role of AI in translating innovation from the lab to the market to benefit individuals living with brain conditions. On this occasion, EBC brought together a very diverse range of stakeholders to foster dialogue across disciplines. Figure 5 provides an overview of invited speakers.

The event kicked off with a keynote from Claudia Prettner, Project Advisor and BRAINTEASER Project Officer at the European Health and Digital Executive Agency (HaDEA), who introduced the audience to HaDEA and its portfolio of health research projects – with a focus on current and future brain health research. The presentation also stressed the role of EU Research & Innovation in contributing to effective prevention strategies and improved care of brain disorders as well as the role of the EU brain community in enabling evidence-based policymaking to counter today's brain health challenges. The keynote was followed by a short presentation given by Barbara Di Camillo, BRAINTEASER Scientific Coordinator, on BRAINTEASER most significant results and key exploitation challenges including data accuracy and reliability, interoperability



with clinical systems, standardisation of measurements as well as regulatory and compliance challenges.

As the project comes to an end, the democratisation of BRAINTEASER solutions – ensuring they are widely accessible, user-friendly, and beneficial to a broad range of stakeholders – is an urgent priority. Moderated by Gianmaria Silvello, HEREDITARY Coordinator, and featuring Elisabetta Vaudano, Principal Scientific Manager, Innovative Health Initiative (IHI); Mats Sundgren, Senior Industry Scientific Director, European Institute for Innovation through Health Data (i~HD); and Liesbet Geris, Professor, University of Liège, KU Leuven, VPHi; Research & Technology Working Group Leader, Avicenna Alliance, Session 1 brought together key actors on the way from lab to the market to stress the power of collaboration to accelerate the translation of research into innovation. In particular, public-private partnerships, which bring academia, industry, end-users as well as regulatory bodies together, were highlighted as key enablers. On that occasion, panellists also addressed main challenges to overcome to ultimately harness unstructured data in a meaningful way: insufficient funding, bureaucracy and healthcare unreadiness.

BRAINTEASER leverages AI to improve the quality of life of people living with MS and ALS and their caregivers. Moderated by Natalia Allegretti, BRAINTEASER Dissemination and Communication Manager, Session 2 provided a patient perspective (Elisabeth Kasilingam, CEO, European Multiple Sclerosis Platform (EMSP)), clinical perspective (Umberto Manera, BRAINTEASER Clinical Partner) and industry perspective (Leon Brudy, Business Development Manager EMEA, Garmin Health) on innovative solutions contributing to remote, value-based and patient-centred care. On that occasion, panelists highlighted the codesign with patients as an opportunity of mutual learning resulting in more user-friendly solutions: today, AI and data altruism participate in improving patients' quality of life and enabling better quality of care and clinical decision making. The panel also addressed resource allocation, the hardship of making successful research commerciable and highly fragmented market and healthcare systems across the EU as major obstacles to the translation of research into health interventions.

In session 3, moderated by Vincenzo Carbone, BRAINTEASER Exploitation Manager, BRAINTEASER clinical partners (Umberto Manera and Carlos de Miguel Sánchez) introduced the audience to BRAINTEASER clinical app for MS and ALS, which consists in a webpage designed for imputing and collecting patients' clinical data – including but not limited to pharmacological treatments and different instrumental evaluations. Through this tool, over 300 MS and ALS patients can also report symptoms. The session also featured Vebjørn Andersson, Research Coordinator, Oslo University Hospital and Project Coordinator, Al-Mind Project, who provided perspective on predicting dementia and advancing clinical decision making in mild cognitive impairment with the aim to foster the exchange of experience and knowledge for a better care of these conditions and increased access to care.

Led by Vincenzo Carbone, Session 4 aims to address the outcomes of a series of Focus Group meetings gathering BRAINTEASER community to enlarge the project's vision on users and market needs and obtain additional requirements to accompany the go-to market strategy towards the most suitable exploitation routes. Key takeaways include:



#### **BRAINTEASER - D10.9**

- Involvement of key stakeholders including patients (to increase trust), wearable manufacturers and biopharmaceutical companies (to reduce clinical trial fails and refine placebo studies)
- Explainability, to support both patients and clinicians
- Scalability, to face different healthcare systems
- Data reliability, validity and compatibility, to satisfy regulatory requirements
- Compliance with the newly adopted EU AI Act for regulated digital medical products



#### 3 CONCLUSION

Over the past few years, BRAINTEASER liaison activities have constantly adapted to the needs of both the BRAINTEASER consortium and related projects, managing to stay in step with the times and everyone's priorities. This flexibility led to a good engagement in the activities designed so far. For liaison activities not to be perceived as an additional workload but as a concrete added value, they need to be framed as opportunities of growth for the projects, and opportunities of networking and learning for the projects' partners. To this end, liaison activities need to merge into and support daily technical activities of each consortium.

To foster the translation from research into innovation and healthcare interventions, an active dialogue with regulators and policymakers is key. Over the past few years, EBC has managed not only to create opportunities for BRAINTEASER partners to exchange with such stakeholders but also to convince BRAINTEASER researchers of the importance of policy research and advocacy to achieve a greater impact.

BRAINTEASER liaison activities ultimately contributed to increase the visibility of this research field. In particular, through podcast episodes and sessions at Brain Innovation Days, the project benefited from a public and international exposure, which facilitated relations with relevant EU and global players including people with brain conditions, clinicians (especially neurologists), basic and translational neuroscientists, regulators and industry representatives. Gathering projects both virtually and in person has contributed to decrease fragmentation and increase cooperation in the field.

The BRAINTEASER consortium will leverage the connections built so far in the framework of relevant projects and initiatives, including but not limited to:

- The Rare Brain Disease Ecosystem, an EBC-led knowledge hub in which BRAINTEASER findings on ALS management and care could inspire new projects
- Ongoing and future projects on AI in brain health, which could benefit from BRAINTEASER multi-year experience in MS and ALS remote monitoring
- Future funding opportunities in the field of AI and big data-powered personalised medicine in brain health for which established connections could unite forces