

# VoT – General update, dissemination and future plans

Academy NBCs  
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By Prof. Patric Boyer, EBC Vice President




# Disorders of the Brain: the big picture



## Brain disorders: Causes, Symptoms and Diagnosis

- Mental disorders: Depression, Schizophrenia,...
- Neurological disorders: Alzheimer's diseases, Epilepsy, Multiple Sclerosis, Parkinson's disease, Restless Legs Syndrome, Stroke,...

# Disorders of the Brain: the big picture

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- Highly prevalent and disabling conditions across all life span
  - Growing burden of brain disorders: 35% of Europe's total disease burden with a yearly cost of 800 billion€ [1]
  - Major impact on health care (sustainability, quality, access) and society as a whole
  - Need for more basic, clinical and translational research

[1] Di Luca, M. & Olessen, J. (2014) The cost of brain diseases: a burden or a challenge? *Neuron*, 82, 1205-1208.



# Horizon 2020 Brain Research Proposals





European



1	<a href="#">PREDICTIVE MEMORY</a>	Multimodal neuroimaging of mechanisms supporting memory-based predictions in the human brain	2015
2	<a href="#">RESCUE THE HEART</a>	Understanding nervous mechanisms of cardioprotection to save the ischaemic and failing hearts	2016
3	<a href="#">THALAMODEL</a>	Multimodal, high-resolution modeling of the thalamus for neuroimaging studies: application to dyslexia	2015
4	<a href="#">APE</a>	An analyzer for preterm EEG	2015
5	<a href="#">SpikeControl</a>	Cerebellar Spiking Model For Real-time Closed-loop Sensorimotor Control	2015
6	<a href="#">Spinal cord fMRI</a>	Functional magnetic resonance imaging of the cervical spinal cord at 7 Tesla	2015
7	<a href="#">ProactionPerception</a>	From oculomotor action to perception	2015
8	<a href="#">PREDACTION</a>	Prediction and Anticipation of Actions: Modelling How We Foresee the Others	2016
9	<a href="#">NPA</a>	Neurodidactics of Performing Arts: The Impact of Drama Teaching on Second Language Acquisition	2015
10	<a href="#">BRAIN2MIND_NEUROCOMP</a>	Developing and delivering neurocomputational models to bridge between brain and mind.	2016

11	<a href="#">ETIC</a>	Encoding and Transmission of Information in the Mouse Somatosensory Cortex	2016
12	<a href="#">WideBrainImaging</a>	Development of high-speed microscopes to study wide-scale neural activity	2016
13	<a href="#">NeuralCon</a>	Connectivity in the neural control of muscles in stroke patients.	2016
14	<a href="#">INTERHYTHM</a>	Rhythms In Social Interaction	2016
15	<a href="#">SOCIAL ROBOTS</a>	Mechanisms and Consequences of Attributing Socialness to Artificial Agents	2016
16	<a href="#">MODEM</a>	Multipoint Optical DEvices for Minimally invasive neural circuits interface	2016
17	<a href="#">Farewell flashbacks</a>	Developing science-driven therapies after trauma: Neural mechanisms underlying the modification of intrusive emotional memories	2016
18	<a href="#">LUMINOUS</a>	Studying, Measuring and Altering Consciousness through information theory in the electrical brain	2016
19	<a href="#">GIANTSYN</a>	Biophysics and circuit function of a giant cortical glutamatergic synapse	2017
20	<a href="#">WhiteBox EEG</a>	Big Data EEG Recording and Analysis platform	2016
21	<a href="#">BUNGEE-TOOLS</a>	Building Next-Generation Computational Tools for High Resolution Neuroimaging Studies	2016

22	<a href="#">Detect and React</a>	Distracted drivers in autonomous cars: Do drivers safely detect and react to unexpected warning signals?	2016
23	<a href="#">SLAB</a>	Signal processing and Learning Applied to Brain data	2016
24	<a href="#">OPTOACOUSTOGENETICS</a>	Hybrid Volumetric Optoacoustic-Ultrasound Tomography for Noninvasive Large-Scale Recording of Brain Activity with High Spatiotemporal Resolution	2016
25	<a href="#">DNA</a>	Dendritic integration by nanoscale neuroanatomy	2016
26	<a href="#">HBP SGA1</a>	Human Brain Project Specific Grant Agreement 1	2016
27	<a href="#">TOPEX</a>	Philosophical Foundations of Topological Explanations	2016
28	<a href="#">CONNEXIO</a>	Physiologically relevant microfluidic neuro-engineering	2016
29	<a href="#">VISGEN</a>	Transcribing the processes of life: Visual Genetics	2017

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30	<a href="#">LISTEN</a>	Liaison in Scientific Training for European auditory Neuroscience	2016
31	<a href="#">Becoming Social</a>	Social Interaction Perception and the Social Brain Across Typical and Atypical Development	2017
32	<a href="#">MEME</a>	Memory Engram Maintenance and Expression	2017
33	<a href="#">Lightsheetelegans</a>	In-toto imaging of C. elegans larval development using adaptive optics light-sheet microscopy	2017
34	<a href="#">NETBIO-GE</a>	Quantitative brain network biomarkers for patient-specific diagnostics in idiopathic generalized epilepsy	2017
35	<a href="#">OptoFeedback</a>	Causal study of the role of feedback in the perceptual inference of figure location in the primate visual cortex using targeted optogenetics	2017
36	<a href="#">NEUROMICRONICA</a>	Neuromicronica: Modular behavioural neuroscience	2017
37	<a href="#">VALENCE-REPLAY</a>	Disentangling amygdala contributions to replay-mediated, hippocampal-dependent memory consolidation	2017
38	<a href="#">BrainPredictDynamics</a>	Temporal predictions in the auditory cortex: neural mechanisms and their specificity across species and stimulus domains	2018





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39	<a href="#">AGENT</a>	A neuroscience approach to investigating how hierarchy influences moral behaviour	2017
40	<a href="#">Motivageing</a>	Motivation–cognition interaction in healthy ageing and Parkinson’s disease	2018
41	<a href="#">GEOCOG</a>	Cognitive Geometry: Deciphering neural concept spaces and engineering knowledge to empower smart brains in a smart society	2017
42	<a href="#">MINDED</a>	MultIscale precision therapies for NeuroDEvelopmental Disorders	2018
43	<a href="#">EQIPD</a>	European Quality In Preclinical Data	2017
44	<a href="#">PurinesDX</a>	Interdisciplinary training network on the purinergic P2X7 receptor to control neuroinflammation and hyperexcitability in brain diseases.	2017

# VoT Research Framework

## □ Overall objective of the case study:

To provide **policy recommendations** on how to provide **optimal care** in the disease area under study by addressing the current treatment gaps.

## □ Specific Objectives:

- 1) Identify the **current treatment gaps and patient needs along the care pathway** and analyse the underlying causes & Identify/propose solutions addressing the them
- 2) Evaluate the **costs and burden associated with the treatment gaps** and the socio-economic impact of closing/reducing them by applying the solutions identified/proposed
- 3) Propose **policy recommendations** on how to **improve the care pathway**

# The Value of Treatment


































**2015-2017 Value of Treatment for  
Brain Disorders - Study findings  
and policy recommendations**



VOT  
EBC RESEARCH PROJECT  
THE VALUE OF TREATMENT FOR BRAIN DISORDERS

EBC White Policy Paper released on 22 June 2017

# Summary (Brain: time matters)

	Schizophrenia	Alzheimer's Disease	Headache	Stroke	Parkinson's Disease	Epilepsy	Multiple Sclerosis	Restless Legs Syndrome	Normal Pressure Hydrocephalus
<b>Gaps</b>									
<b>Prevention</b> 	Indicative prevention?	Risk factors?	Life-style	Risk factors		Life-style	Impact of modifiable lifestyle factors on MS Lifestyle factors prevention <b>COST EFFECTIVE</b>		
<b>Screening</b> 	Missed detection Early detection <b>COST SAVING / COST EFFECTIVE</b>								
<b>Diagnosis/treatment</b> 	Late intervention Early detection <b>COST SAVING / COST EFFECTIVE</b>	Late intervention / inadequate treatment Early intervention / adequate treatment <b>COST EFFECTIVE</b>	Lack of structured headache services and education Structured headache services and education <b>COST EFFECTIVE</b>	Lack of inpatient stroke unit In-patient stroke unit <b>COST EFFECTIVE</b>	Lack of early / timely treatment Lack of adequate treatment for advanced PD Lack of adherence to drug treatment Early / timely treatment <b>COST EFFECTIVE</b> Adequate treatment for advanced PD <b>COST EFFECTIVE</b> Adherence to drug treatment <b>COST EFFECTIVE</b>	Inadequate treatment & care Adequate treatment and care <b>COST EFFECTIVE</b>	Delays in treatment Early in treatment (DMTs) <b>COST EFFECTIVE</b>	Inadequate treatment (& Socio economic impact of RLS) Adequate treatment <b>COST EFFECTIVE</b>	Delayed and inadequate treatment Early and adequate treatment <b>COST EFFECTIVE</b>
<b>Follow-up</b> 	Relapse prevention			Lack of rehabilitation In-hospital rehabilitation <b>COST EFFECTIVE</b>					
(Case studies)	 	       	  		 		     	  	



# Findings and recommendations

**Our research has identified clear gaps for diagnosis and treatment**

**These gaps slightly differ from disease to disease, but the overarching requests are:**

- **Need for basic and clinical & translational research**
- **Need for measures of prevention**
- **Need for early diagnosis and treatment**
- **Need for training for healthcare providers**
- **Need for seamless, coordinated care**
- **Affordability of interventions**



# Risk reduction is the main focus. How to achieve it?

- **Primary prevention**
  - « Protective » prevention when risk factors are identified
  - « Indicated » prevention for population at high risk
- **Early detection and diagnosis**
- **Timely intervention**
- **To be followed on the long term by:**
  - Secondary and tertiary prevention
  - Seamless integrated and coordinated care**

## « Re-thinking » and restructuring health services

- **Implementation of early detection centers** and diagnostic services is the first challenge to be addressed
- Putting primary care assessments on first line
- **Primary care physicians should be trained by and work in collaboration with specialists** (the same for health care providers)
- Development of integrated and coordinated care, including
  - **Accesss to specialists (still problematic)**
  - **Referral and linkage system**
- Shared decision making with patient and families facilitating the process


# VoT: Impact thanks to targeted dissemination

1. Strategic Research Agenda
2. Health care delivery




AT MACRO HEALTH SYSTEM GOVERNANCE LEVEL, **OUR ROLE** IS TO ADVOCATE  
FOR THE TRANSLATION OF POLICY RECOMMENDATIONS  
INTO THE DEVELOPMENT OF RESEARCH AND PUBLIC HEALTH **BRAIN PLANS**

# VoT: Dissemination

- 
1. Overarching publications
  2. Individual publications
  3. Outreach

# Dissemination – overarching publications



Subject of the publication	Lead Writers	Target journal	Status
<b>The value of treatment: early intervention to reduce the burden of brain disorders”</b>	EBC (Vinciane Quoidbach)	<u>EuroHealth</u> (WHO European Observatory on Health Systems and Policy, and LSHTM)	Published, 29 December 2017. 2017 winter series
	EBC (Vinciane Quoidbach)	WHO Bulletin editorial	To be published, May 2018



# Dissemination – individual publications

Case Study	Subject of the publication	Lead Writers	Target journal	Status
RLS	One publication combining economic analysis and patient journey	Michela Tinelli Joke Jaarsma	Journal of European epidemiology	First Draft under revision of the WG
MS	One publication to cover the patient pathway, and the economic evaluations (Clinically Isolated Syndrome (CIS) Data CIS data and risk factors, in term of top results)	Michela <u>Tinelli</u> <u>Maura</u> Pugliatti	European journal of Neurology	First Draft in preparation
	One publication to cover the economic analysis for the risk factors (development of the models and full set of analyses)	Michela <u>Tinelli</u> <u>Maura</u> Pugliatti	Multiple Sclerosis Journal	First Draft in preparation
Dementia	Economic Evaluation	Ron Handel	TBD	Not Started yet
	Patient Journey	Sietske Sikkes <small>www.wur.nl</small>	TBD	Not Started yet

# Dissemination – individual publications

PD	One article to report on the <u>VoT</u> case studies analyses for UK and Germany looking at the three treatment gaps of interest 1) Lack of early/timely treatment; 2) Lack of adequate treatment for advanced PD; 3) Lack of treatment adherence	<u>Michela Tinelli</u> <u>Richard Dodel</u>	Pharmacoeconomics	Draft under revision of <u>Dodel</u>
NPH	One article on the economic analysis	Michela Tinelli	TBD	Draft under revision
Schizophrenia	CZ economic evaluation	Petr Winkler	European Psychiatry	In submission
	Patient Journey	Pavel Mohr	European Psychiatry	In submission
Epilepsy	Better management of epilepsy – an economic analysis	Liverpool Group	??	In submission
Stroke	Economic Evaluation	Alastair Webb Vincent Thijs	European Stroke Journal	Draft in preparation
	Patient Journey	Ana Catarina Fonseca	TBD	Not started yet

# Dissemination – individual publications

Headache	An editorial accompanying both patient journey and economic evaluation articles	TBD	Special issue, Journal of Headache and Pain (JHP)	Not started
	An article on the methodology including: background (patient journey, better interventions needed, proposal for intervention, need to assess cost-effectiveness); how to assess, development of methods including list of assumptions	Michela <u>Tinelli</u> <u>Tim</u> Steiner	Special issue, Journal of Headache and Pain (JHP)	Draft ready to be shared
	An article covering the results of the economic evaluation	Michela <u>Tinelli</u> <u>Tim</u> Steiner	Special issue, Journal of Headache and Pain (JHP)	Draft ready to be shared
	A literature review plus empirical data on Disability vs lost productivity.	Tim Steiner (Student)	Special issue, Journal of Headache and Pain (JHP)	Draft in preparation
	An article covering the patient journey	Matilde Leonardi, Alberto <u>Raggi</u> Elena Ruiz de la Torre	Special issue, Journal of Headache and Pain (JHP)	Draft in preparation



# EBC ANNUAL REPORT

IMPROVING  
BRAIN KNOWLEDGE  
AND ADVOCACY  
**2017**



## Dissemination - outreach



# Dissemination – outreach

## Value of Treatment Dissemination: The Value of Early Intervention event at the European Parliament

Joint EBC-EFNA event ,12 July 2017



The event was hosted by MEPs Jana Žitnanská, Marian Harkin, Michał Boni and Marek Plura.



# Dissemination – outreach



## **Value of Treatment Dissemination:**

EU Presidency Estonia - Joint Meeting of the Chief Medical, Chief Nursing and Chief Dental Officers

5-6 July 2017

## **Value of Treatment Dissemination:**

27<sup>th</sup> Alzheimer Europe Conference 2017

4 October 2017

## **Value of Treatment Dissemination:**

The European Alliance for Personalised Medicine (EAPM) Congress 2017

28 November 2017

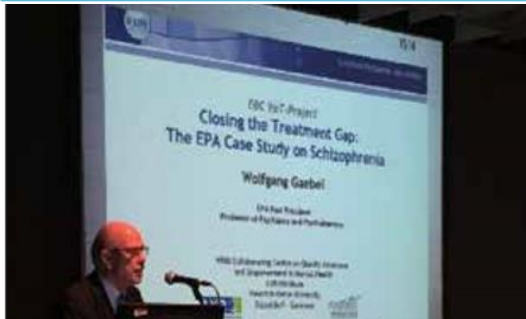
# Dissemination – outreach

## Value of Treatment Dissemination: 11<sup>th</sup> European Headache Federation Congress 2017

2 December 2017

## Value of Treatment Dissemination: VoT - Working Group's dissemination

And many other events...



Prof. Wolfgang Gaebel, Schizophrenia Working Group Leader, presents the case study during the "Value of Treatment: Schizophrenia" symposium at the 25<sup>th</sup> EPA Congress in Florence, Italy (1-4 April 2017)



MSParis2017 – Joint ECTRIMS-ACTRIMS Meeting, Presentation: "Promoting healthier lifestyle contributes to averting multiple sclerosis long-term societal and healthcare costs: results from the VoT Project"

# VoT 2: Sustaining it into a next phase

## Core Mission


Promote a value-based and patient centered research and care for brain disorders



**VoT**

EBC RESEARCH PROJECT  
THE **VALUE OF TREATMENT** FOR BRAIN DISORDERS

# Develop and expand further



**Focus:** Treatment  
/research gaps and  
patient unmet needs

**Scenario 1:** Existing case  
study/pathology looking at new  
topic along the care cycle

**Scenario 2:** New case study/pathology  
looking at value, early intervention and new  
topic



# VoT 2: Engagement – New case studies

## Transition Care

- Depression
- Autism
- ADHD
- Eating disorder

*Finance secured –  
Under discussion*

## Rare Diseases

- Dystonia
- Huntington
- Ataxia – *Started! (1st scoping meeting on 26/3)*
- Phenylketonuria (PKU)

*Under discussion*

*Under discussion*



# Phase 1: Defining the Working Group

WORKING GROUP COMPOSITION					
Name	Surname	Affiliation*	Capacity**	Expertise***	Email Address

\*If applicable, please indicate the EBC organization/industry partner you belong to

\*\* 1 leader, 1 secretary should be nominated. In addition, 1 industry representative, 1 patient representative and experts can be included. Preferably, the working group should not exceed 8 members.

\*\*\* Clinician, health economist, epidemiologist, etc.

**A bottom-up method with case study data analysis and convergence of evidence to policy**

# Phase 1: « Conceptualization: define scope, research questions and methodology»

VoT methodology template

THE **VALUE OF TREATMENT**  
FOR BRAIN DISORDERS  
A NEW VISION IN PROGRESS



EBC Value of Treatment project

Methodology: Proposed template for working group discussion, 2018 (Phase 1)

Case study: .....

**Note:**

As part of phase 1, this template will be discussed during a preliminary working group meeting coordinated by EBC.

- **Phase 1 - STEP1:** Please complete this template, once final it will be submitted to the EBC Board for validation.

- **Phase 1 - STEP2:** based on this template, a study protocol will then be drafted that will be used for end publication (e.g. The Lancet or any other peer review scientific journals). Once final, it will also be submitted to the EBC Board for validation.


# VoT methodology template



Case  
Study

## Approach:

- 1) Care Pathway analysis
- 2) Economic Evaluation
- 3) Consultation to formulate policy recommendations

- 
- ➔ The template provided can be used to define the scope of the analysis and to map the data already available
  - ➔ Standardized tools across case studies



**Thank you!**