THE VALUE OF TREATMENT FOR BRAIN DISORDERS

A NEW VISION IN PROGRESS

VOT

# ”Bridging the treatment gap for Brain Disorders:

# EBC Value of Treatment Research Project”

June 2016

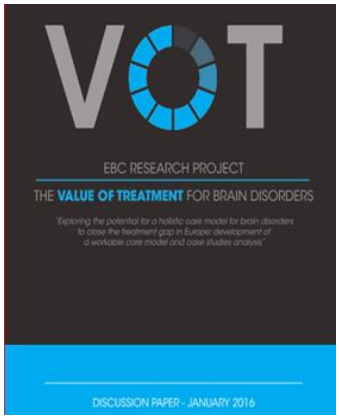
This January – June 2016 newsletter is providing the state of progress on **EBC Value of Treatment Research Project for internal and external outreach purposes.**

## FOREWORD

Unprecedented innovation in technology and medical processes is rapidly revolutionizing human life. Current health systems, however, have not been able to adapt quickly enough to meet the needs of patients. This is particularly true for brain disorders, and particularly challenging for policy makers.

Value-based healthcare is currently gaining traction in Europe as the desired solution or path forward in improving health systems.

This holistic approach towards coordinated, integrated care models critically intertwines wider patient and societal outcomes with spending and in doing so could lead to both a more sustainable framework for payers and improved care for patients.




The European Brain Council (EBC) is carrying out a new Study for 2015-2017 on the "**Value of Treatment: Bridging the Early Diagnosis and Treatment Gap for Brain Disorders**". With the project Kick Off meeting and the release of the first **EBC Discussion Paper** on 27th January 2016 "Exploring the potential for a holistic care model for brain disorders to close the treatment gap in Europe", we have now developed a strong research framework for the case studies analysis.

The Value of Treatment research project is building on the EBC Report "The Economic Cost of Brain Disorders in Europe" published in 2005 (Balak and Elmaci 2007) and updated in 2010 (Gustavsson et al. 2011) that provided a solid estimation on the economic costs of brain disorders in Europe. The indirect costs of brain disorders make up for 40 percent of the total costs – which EBC estimated at around 800 billion euros per year in Europe.

**With this new "Cost Study", EBC will not only be looking into the socio-economic impact and value of healthcare interventions, but will also be able to determine how timely treatment pathways are likely to need greater integration and how better collaboration can be set up in the future for the benefit of those living with a brain disorder.**

Why an integrated care model? In joint initiatives promoted by the European Commission such as in the area of cancer (e.g. the European Partnership Against Cancer and the development of care management guidelines, the Integrated Care for Breast Cancer Initiative), it has proved essential to put scientific evidence into care standards, and to use case studies to make available evidence-based diagnostics and treatment guidelines as well as quality assurance norms covering all stages and aspects of care. This leads us to the integrated, coordinated care approach with an expectation that it might support the achievement of the so-called "Triple Aim" in the respect of patient's needs: a simultaneous focus on improving health outcomes, enhancing the quality of care and increasing cost-efficiency. In order to realize this aim, the European Commission and the WHO are calling on policy makers to initiate a process of reorganization, transformation of care delivery, with the following priorities: access to care, sustainability of healthcare system and cost efficiency interventions (human workforce, technologies including the potential of digital health,…).

**We are at a pivotal time of change; our new Study couldn't be more opportune in exploring the beginnings of a European paradigm shift toward a value-based model of healthcare for brain disorders.**

With the Experts Workshop and the Project Kick Off which took place respectively on 8 and 27 January 2016, the case studies Working Groups on specific mental and neurological disorders are now providing a platform for continued discussions around cost effective analysis and the opportunities patient-centric coordinated care models promise, potential solutions and challenges.

**This EBC Study is a starting point; we won't have all the solutions in once. However, through building up evidence, EBC will provide the necessary policy recommendations to address the treatment gap and its consequences.**

David Nutt,
President of EBC

## BACKGROUND

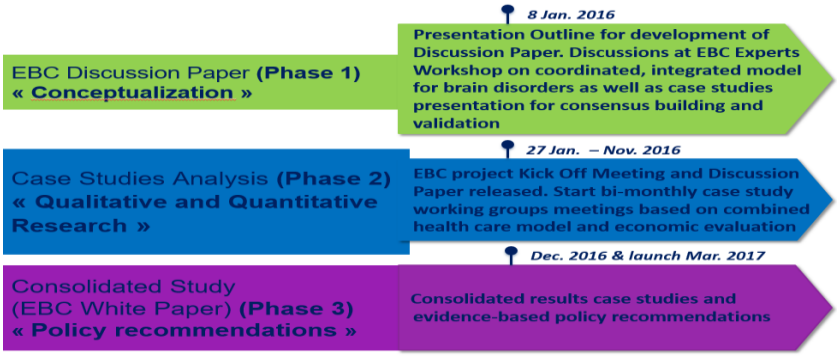
In recent years, there has been a **growing awareness of the importance of mental and neurological disorders**. Depression, stroke, dementia, schizophrenia or anxiety affect at least **one in three** people during their lifetime – currently 165 million people in Europe[1]. The profiles of these diseases raise particular challenges: lack of physical and visible symptoms, complex biological factors, and an incomplete understanding of cause. At the same time, **the global burden of brain disorders is rising (accounting for 35% of the burden of all diseases in Europe)[2]**, being the seat of many chronic disabling diseases. According to WHO estimates, major depression is projected to be the leading cause of disease burden worldwide by 2030[3]. Analyses show that there is a **considerable treatment gap**, particularly blatant for mental illness, with only **about a third of cases** receiving the therapy or medication needed[4]. **Reducing the burden of mental and neurological disorders** relies on **both timely diagnosis and treatment of disorders** by health professionals through **pharmacological and psychosocial interventions.**

[1] A.Gustavsson et al. The economic cost of brain disorders in Europe, Journal of Neurology 2012.
[2] J. Olesen et al. European Journal of Neurology 2003.
[3] World Health Organization Global Burden of Disease (GBD) 2004.
[4] R. Kohn et al. World Health Organization Bulletin, (82) 2004.

Considering health systems reforms taking place all over Europe and the challenges related to the management of chronic conditions including co-morbidities and ageing, **new models of care including a societal benefits approach are being examined for a better coordination of care.** Hence, healthcare is an information-driven process and is seen as a continuity of actions. In the provision of care intra and extra muros, multidisciplinary healthcare providers across different areas (primary care, general hospitals, psychiatry hospitals, specialists care, homecare, social care, nursing home, pharmacies, disability and rehabilitation centres, networks of excellence centres at national and European level, …) and services (health promotion, disease prevention, diagnosis, treatment, rehabilitation, research,…) will share in **synergy** information, decisions, instructions, planning (key components of a coordinated, integrated care approach) with **carers**. So, essentially the information flow drives and supports the care process within and across organizations with **the patient as partner** (patient-centred care based on needs) and her/his environment for **better health outcomes.**

The EBC Value of Treatment project for 2015-2017 (see figure 1: EBC project milestones and expected deliverables) will aim to **1)** Demonstrating through case studies what are (cost)-effective interventions (clinical practice) based on the combined patient journey mapping & care model components analysis as well as conduct cost-effectiveness analysis (CEA) and use of calculations modelling to assess costs and outcomes; **2)** Developing and validating an overarching model of care for brain disorders and **3)** Based on economic evidence, providing policy recommendations (consolidated study) for the adoption and implementation of a more patient centred and sustainable coordinated care model for brain disorders

Figure 1: EBC project milestones and expected deliverables




We have now entered into the dynamic **phase 2 of the project** with the case studies analysis.

Case studies analysis will aim **to value the socioeconomic impact and health gains of best practice in specific healthcare interventions in comparison with the cost burden of current care/non-treatment** by carrying out combined economic evaluation of specific care pathway services and patient journey/care modelling (see Table 1: Value of Treatment analysis).

Table 1: Value of Treatment analysis

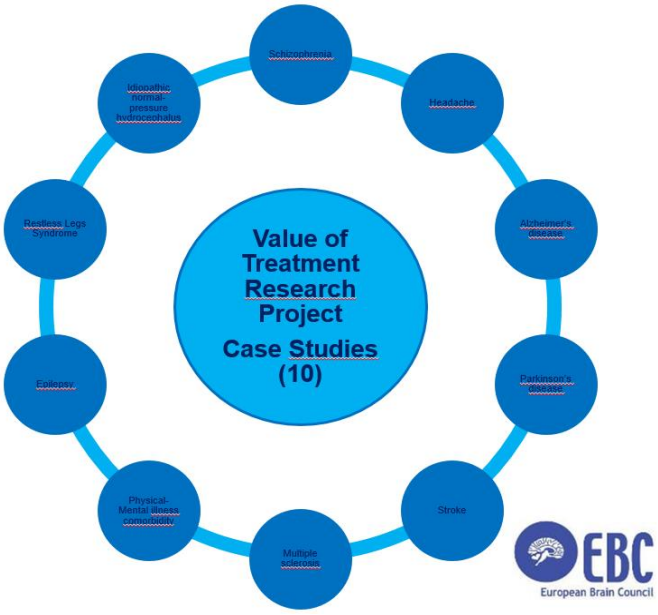
| Value of Treatment | |
|---|---|
| Cost analysis | Value mapping (identification of current and potential values) |
| Cost impact analysis (with or without simulation) | Value optimizing healthcare initiatives |
| Model calculations (health economics) incl. QALY, ICER | New value creating initiatives (integrated care model) |
| Combined methodology<br><br>Policy White Paper and Scientific Publications of the Results in 2017 | |

## CASE STUDIES ANALYSIS - 22 APRIL AND 25 MAY 2016 EBC JOINT WORKING GROUP WORKSHOPS: FINE-TUNING THE RESEARCH FRAMEWORK WITH COMBINED CARE MODELLING AND ECONOMIC EVALUATION METHODOLOGY

**EBC 2015-2017 Value of Treatment Research Project** will ultimately provide **evidence-based and cost-effective policy recommendations for the adoption and implementation of a more patient-centred and sustainable coordinated care model for brain disorders**.

In order to use the data to inform the policy document, **case studies analysis** will be conducted for the following disorders: **schizophrenia, dementia, idiopathic normal-pressure hydrocephalus, AF stroke, Parkinson's disease, epilepsy, headache, multiple sclerosis, restless legs syndrome and mental illness comorbidity** (see figure 2: case studies).

Figure 2: case studies as per 25 May 2016



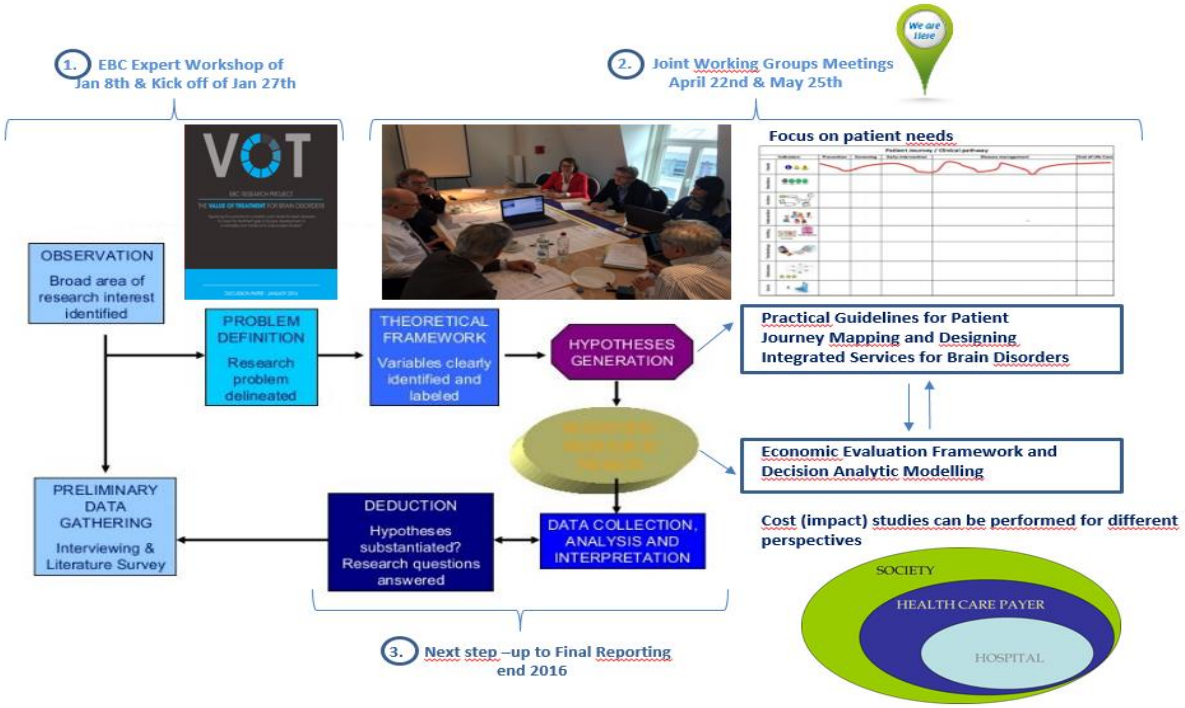

At this stage of the project (**phase 2 "qualitative and quantitative research"**), **two Joint Working Group Workshops took place respectively on 22 April and 25 May 2016** and enabled to dig deeper in the field of the **research methodology** for each case study (based on study template provided during the first phase of conceptualization "observation and problem definition"). Evaluation will be carried out through case studies analysis, in particular **1) the mapping of the patient's care pathway and 2) the economic evaluation of specific clinical interventions across different brain disorders (see figure 3: research process).**

As a stepwise approach and based on selection criteria (such as completed composition of the working group, filled in study template on care modelling and economic evaluation, and covered funding), we proceeded on **22 April** with the **case studies on Dementia and Schizophrenia and the research framework.** For the **case studies on Headache, Multiple Sclerosis and Parkinson's disease,** discussions were only focusing on the patients perspectives. The **second Joint Working Workshop of 25th May** went through the same process with five case studies on Epilepsy, Restless Legs Syndrome, Multiple Sclerosis, Parkinson's Disease and AF Stroke to elaborate further the outline going more into details of the focus and methodological aspects of the case study. Both meetings were fruitful and dedicated to the work progress achieved.

Objectives of **the combined case studies methodology** are twofold:

- **Patient's care pathway analysis** to identify gaps and opportunities for improvements in the current care pathway (SWOT analysis with stakeholders)
- **Economic modelling** assessing the socio economic impact of specific clinical interventions targeted to close some of the gaps identified in the patient journey analysis

Figure 3: Case studies - Research process




To conduct these analyses, we are **partnering with the Utrecht University Medical Centre** (Nick Guldemond)) **for the patient journey and with the London School of Economics** (Michela Tinelli and Martin Knapp) **for the economic evaluation**.

## PARTICIPATORY RESEARCH ANLYSIS

The working groups are formed with **experts within the network of EBC member organizations** (e.g. European Academy of Neurology, …) **as well as other industry and patient associations representatives.**

The setting up of the groups has been **a building process** to ensure a **high level of expertise** (participation of clinicians, health economists, epidemiologists,…).

We are taking the opportunity of this newsletter to thank all members of the Working Groups for their involvement and commitment, please see the list of participants in annex.

If you have any question, please don't hesitate to contact us.

EBC Project Management Team

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***More details on data research and analysis per case study in the next Semester Newsletter 2016!***

**2nd Semester Meetings dates & planned events**

Next VoT Joint Working Groups meeting: 28 September 2016

## List of participants per WG

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