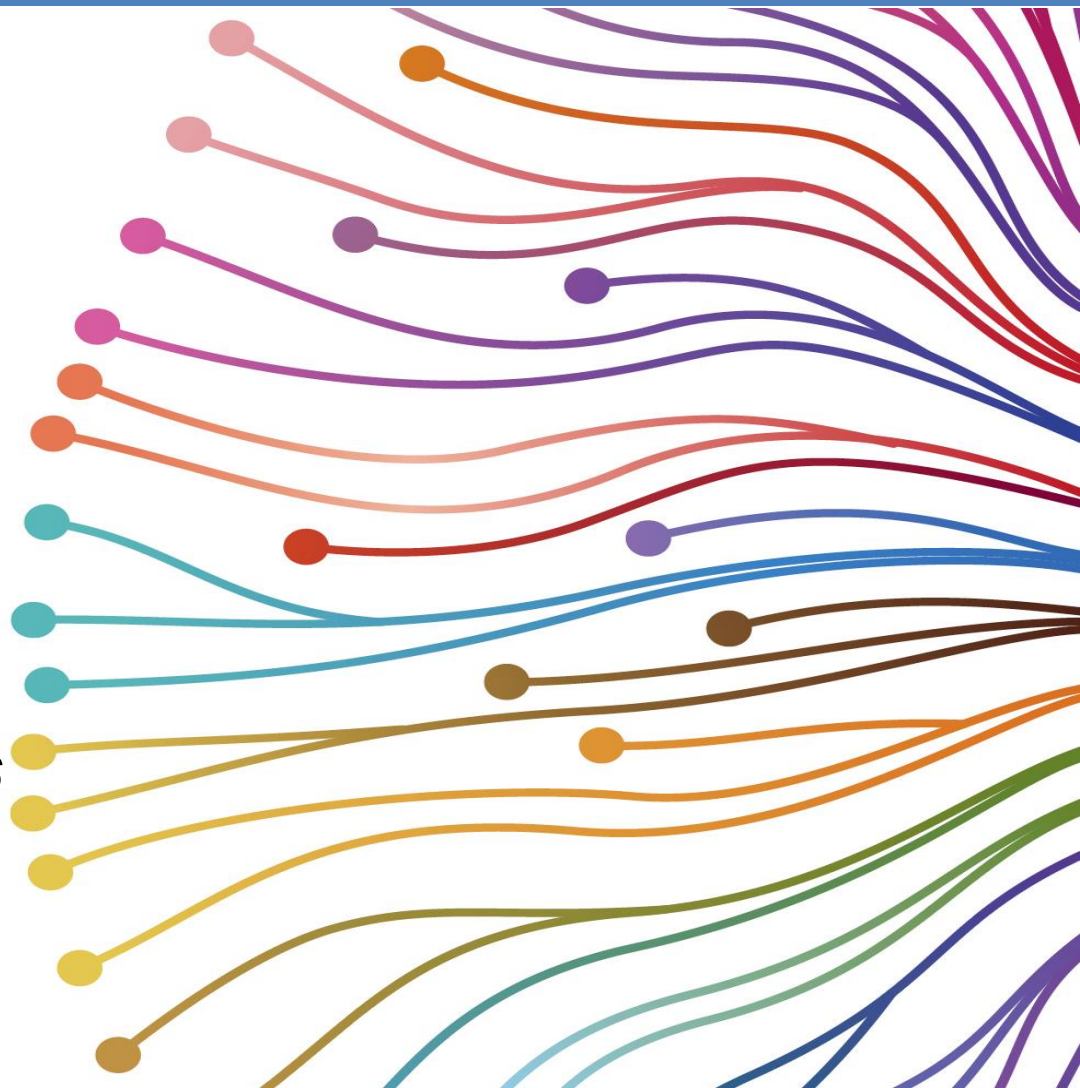




*Board Meeting  
& General Assembly  
30 November – 1 December 2016*



# **Value of Treatment for Brain Disorders Research Project**

# Brain – neuropsychiatric - disorders represent an enormous threat



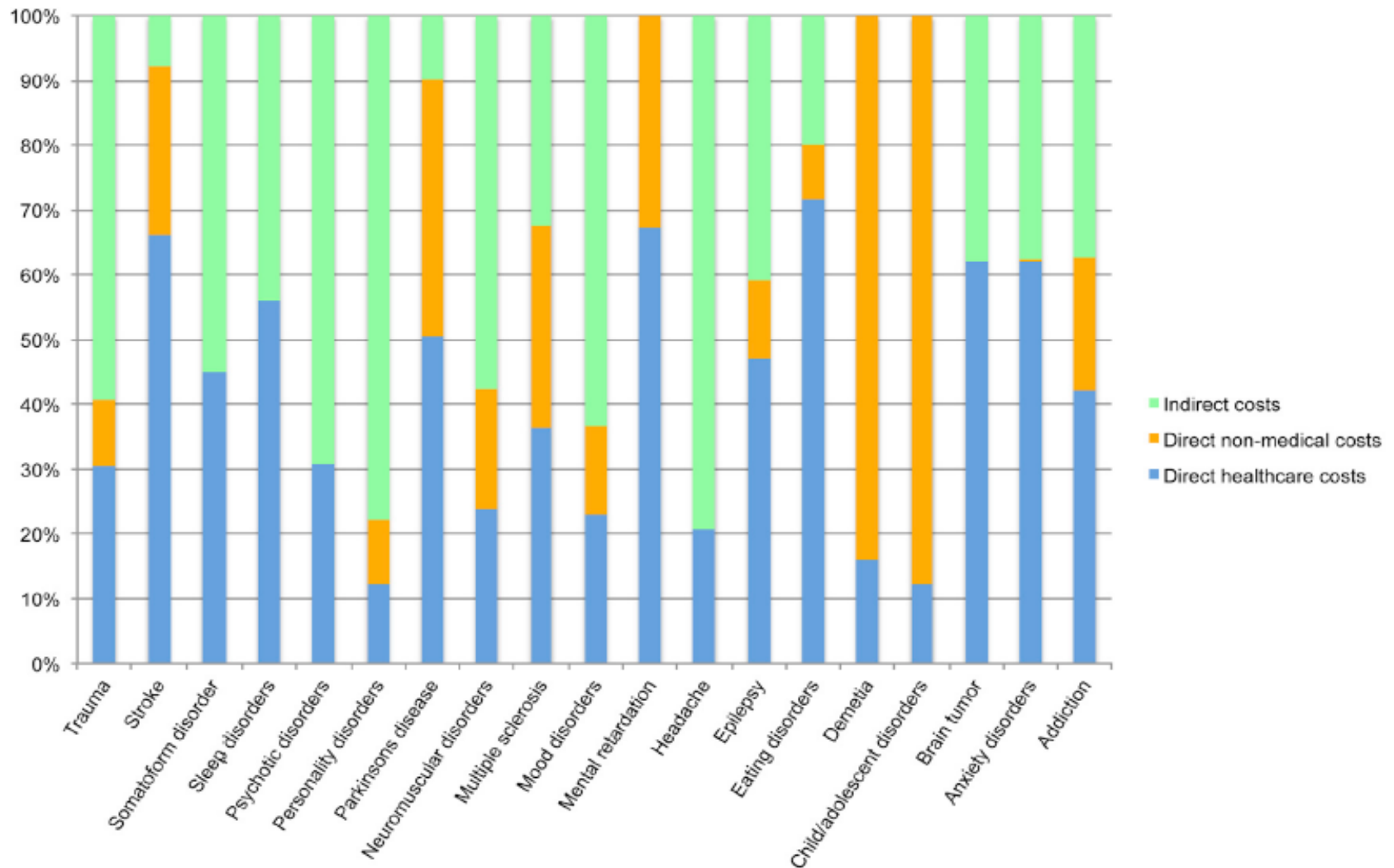
- ❑ Highly prevalent and disabling conditions: 165 million (38%) affected in EU across all life span <sup>(1)</sup>
- ❑ Contributing to 35% of the burden of all diseases in Europe, and the burden is increasing <sup>(2)</sup>
- ❑ Direct costs of brain disorders make up for 60% of the total costs – which EBC estimated at 800 bln€/year in Europe <sup>(1)</sup>
- ❑ Despite escalating costs, 3 to 8 out of 10 people living with brain disorders remain untreated although effective treatments exist <sup>(3)</sup>

(1) H.U. Witschen et al. The size and burden of mental disorders and other disorders of the brain in Europe, ECNP/EBC Report 2011

(2) M. Di Luigi et al. The Cost of Brain Diseases in Eur.: A Burden or a Challenge? NeuroView Vol. 82, Issue 6, p1205–1208, 2014

(3) EBC Poster “mind the gap” presented at EFNA annual conference, July 2016

# EBC Distribution of costs by disorder



# In the continuity of EBC Cost Study: policy relevance of VoT Project

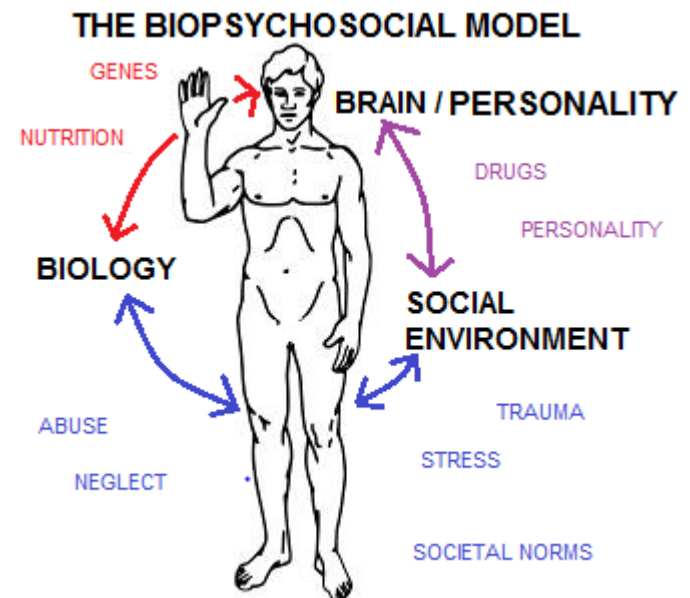
*« A coordinated policy covering all disorders of the brain is needed », « From evidence-based clinical and basic research to improved health outcomes » CBDE 2010 Policy Implications (1).*



(1) H.U. Witchen et al. The size and burden of mental disorders and other disorders of the brain in Europe, ECNP/EBC Report 2011

# Brain: the vision and EBC Call to Action

- **Mental and neurological disorders, or “disorders of the brain”** : complex and interlinked with hundreds of specific diagnosis, codified in diagnostic classifications systems (WHO International Classification of Diseases, ICD-10 and American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders, DSM-V ).
- **Biological evidences:** environmental and genetic influences
- Brain disorders have been until recently associated with **disciplinary fragmentation in research and practice using different concepts and approaches**: today greater awareness on their burden and challenges to manage them, and even to prevent some of them (modifiable risk factors reduction), emphasizing the need for developing an EU-wide Plan to address brain health in a comprehensive (combining research and public health), transversal and collaborative way.



THE **VALUE OF TREATMENT**  
FOR BRAIN DISORDERS

A NEW VISION IN PROGRESS



## 2015-2017 Value of Treatment Research Project: Bridging the Early Diagnosis and Treatment Gap



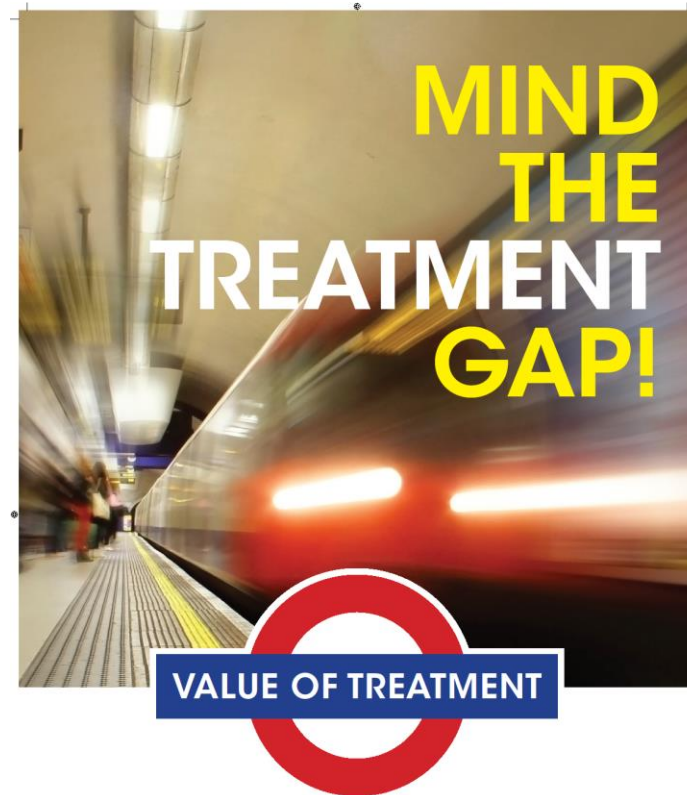
## Objectives: Case studies analysis will aim to

1. Assess, value the **socioeconomic impact and health gains** of best practices in specific healthcare interventions (clinical practice) *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;
2. Demonstrate the potentials **for early diagnosis and new treatment paradigm**, generating **evidence** on the socioeconomic benefits of healthcare (pharmacological, non pharmaco and psychosocial) interventions, and assessing optimal strategies such as **integrated, seamless care** to close the treatment gap in Europe.

=> **concrete outcomes**

The ultimate goal is to provide evidence-based and cost-effective policy recommendations for health care interventions addressing the treatment gap in brain disorders

TOWARDS POLICY WHITE PAPER



Out of 10 Europeans living with a brain disorder, between 3 and 8 are not receiving adequate treatment.  
More info: [braincouncil.eu](http://braincouncil.eu) [@EU\\_Brain](https://twitter.com/EU_Brain) #VoT

# Three Expected Deliverables

EBC Discussion Paper (Phase 1)  
« Conceptualization »

8 Jan. 2016

Presentation Outline for development of Discussion Paper. Discussions at EBC Experts Workshop on coordinated, integrated model for brain disorders as well as case studies presentation for consensus building and validation

Case Studies Analysis (Phase 2)  
« Qualitative and Quantitative Research, Consultation Process »

27 Jan. 2016 – Feb. 2017

EBC project Kick Off Meeting and Discussion Paper released. Start regular case study working groups meetings based on combined health care model and economic evaluation. Consultation around 2<sup>nd</sup> Discussion Paper

Consolidated Study (EBC White Paper) (Phase 3)  
« Policy recommendations »

March 2017 – Launch Mid June 2017

Consolidated results case studies and evidence-based policy recommendations

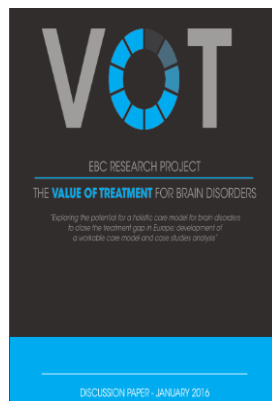
## Retroplanning – Phase 2



# Case studies research process and tools



**EBC Experts Workshop and consultative process, January 8th**



**EBC**

**ECONOMIC EVALUATION**  
(OF THE SPECIFIC CARE PATHWAY SERVICE TO BE EVALUATED)

OBJECTIVE OF THE ECONOMIC MODELLING: To compare the socio-economic impact of different healthcare scenarios. Please define the scenarios you would like to include, see below:

**1. APPROPRIATE TREATMENT(S):** they include (please select more than one option where appropriate):

**(a) Medical/Interventional treatment(s) already available in practice**  
If yes, please report here the three best practices you may want to evaluate (please rank them in order of priority).  
Note: Considering the time and budget constraints we may decide to focus our attention on a limited number of interventions.

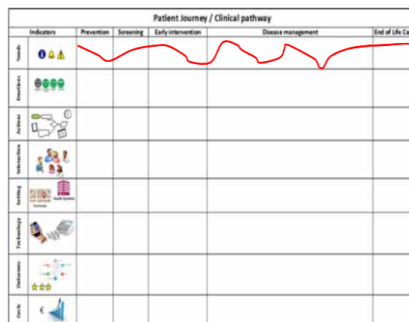
**(b) Coordinate care scenarios already available in practice**  
If yes, please report here the three best practices you may want to evaluate (please rank them in order of priority).  
Note: Considering the time and budget constraints we may decide to focus our attention on a limited number of interventions.

**(c) Hypothetical intervention(s) (not available in practice yet)**  
If yes, please specify:

**2. COMPARATORS:** they include (please select more than one option where appropriate):

Current care: If current care is your comparator, please specify in some paragraph(s), in which the development is far more ahead. This geographical disparity is one of the aims of the study.

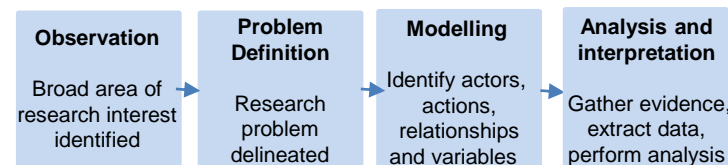
Non treatment: If non-treatment is your comparator, it would be defined as:  
Misled (or delays in diagnosis) ☐ Yes ☐ No  
Lack (or delays in treatment) ☐ Yes ☐ No  
Inappropriate treatment ☐ Yes ☐ No  
Non-referral to treatment ☐ Yes ☐ No  
Other, please specify: ☐ Yes ☐ No



**EBC VoT Project Kick Off meeting and 1st Plenary WG meeting, January 27th**

## Research process

**Joint WGs meetings**  
**April 22<sup>nd</sup>, May 25<sup>th</sup>**  
**& September 28th**



## Tools components

- 1. Practical Guidelines for Patient Journey Mapping and Designing Integrated Services for Brain Disorders**
- 2. Economic Evaluation Framework and Decision Analytic Modelling**

## State of Progress



# Value of Treatment | What is ....

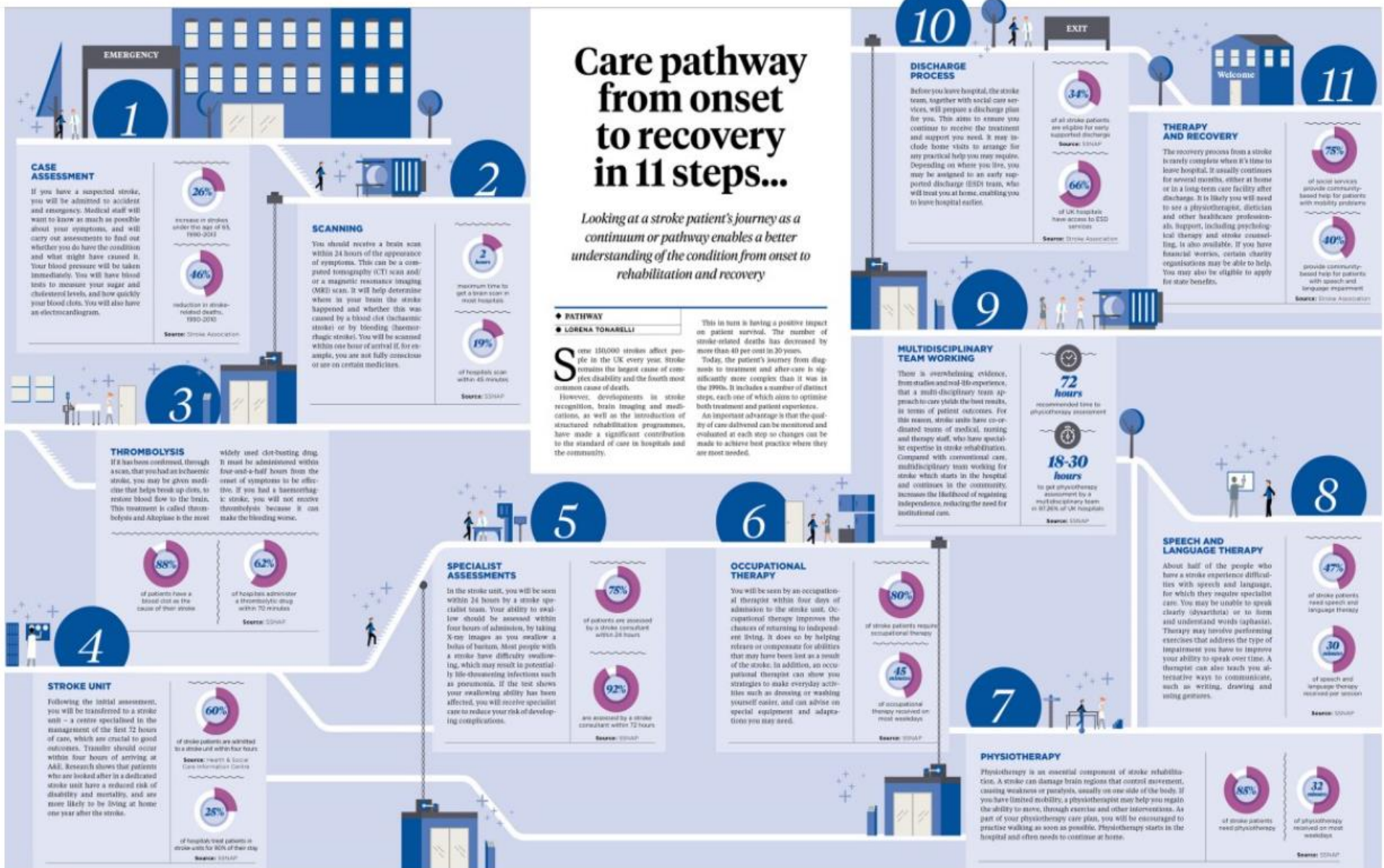
**Case study** will value the socio-economic impact and health gains of **healthcare interventions** in comparison with the cost-burden of current care/non treatment (misdiagnosis, non-treatment, non-adherence,...)

<u>Value of Treatment</u>	
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	
Policy White Paper and Scientific Publications of the Results in 2017	

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

- **Patient's care pathway analysis** to assess needs and identify gaps and opportunities for improvements in the current care pathway (patients and clinicians perspectives with a set of defined indicators)
- **Economic modelling** assessing the socio economic impact of specific clinical interventions targeted to close some of the gaps identified in the patient journey analysis

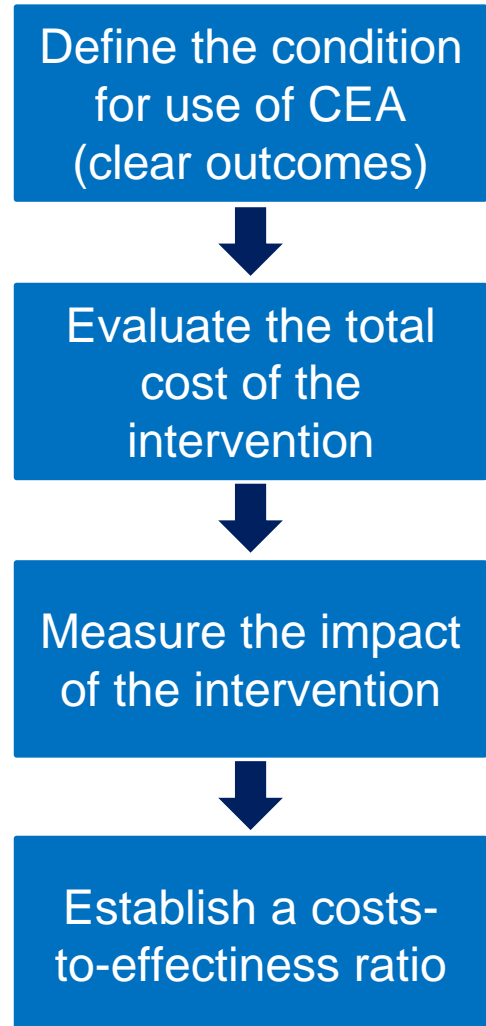
# Patient journey/care pathway: stroke



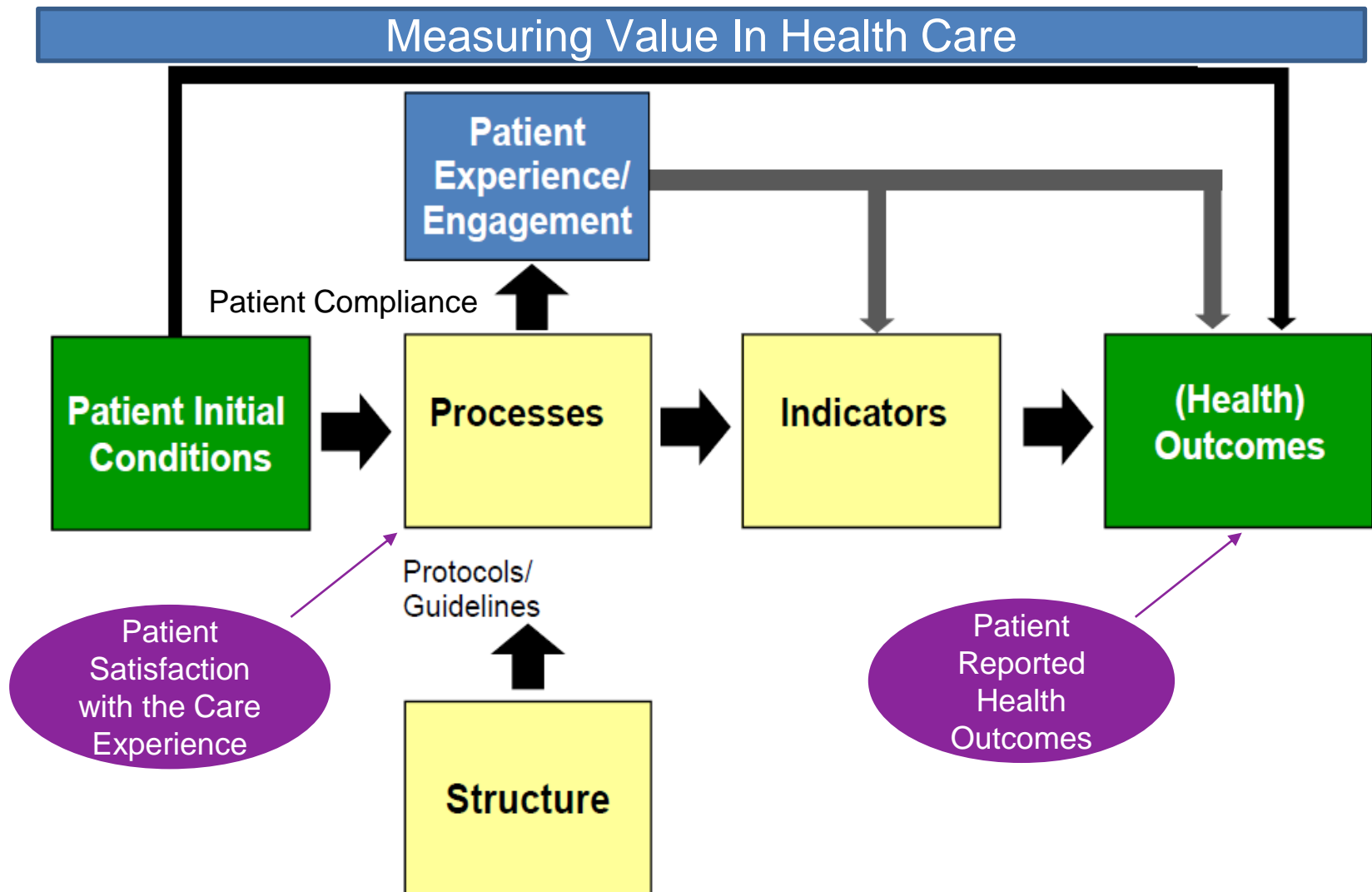
# Economic evaluation: cost-effectiveness analysis

The **economically most efficient way to fulfill an objective**

- Focusing on the key result of a specific healthcare intervention (*for instance intervention strategies in the early illness course of schizophrenia*)
- Assessing socioeconomic impact and health gains of best practices in specific healthcare interventions (clinical practice) in comparison with the cost burden of current care/non-treatment
- Identifying the option to achieve the best evidence-based result at least cost



# Value of Treatment | What is ....



# Illustrations: state of progress of VoT Case Studies



## Alzheimer's Disease

**Study objective:** to develop a model and estimate the impact of a hypothetical treatment for AD in terms of wellbeing and resource use costs in a population of people with memory complaints from a societal perspective

**Setting:** memory clinics and various care provider settings during the progression of Dementia (home setting, day care, hospital care and institutionalization)

## Headache

**Study objective:** to develop an interventional model for headache management and to value the socioeconomic impact and health gains of best practice in early detection (early intervention) compared with current care (/no treatment) in adult population

**Setting:** structured headache services primary care, specialist care, pharmacists

## Schizophrenia

**Study objective:** to provide evidence-based information on what is available and needed to overcome the treatment gap in schizophrenia in a cost-effective manner (intervention strategies in the early illness course of schizophrenia). Areas of focus: 1) indicated prevention, 2) reducing the duration of untreated psychosis (DUP), 3) relapse prevention

**Setting:** specialist care with primary care, community care settings)

# Illustrations: state of progress of VoT Case Studies



## Stroke

**Study objective:** to perform a systematic analysis of cost-effectiveness of the core acute and secondary treatment modalities in acute ischemic stroke: focus on Stroke Unit and capture LT benefits of secondary prevention

**Setting:** primary care, secondary care and tertiary care

## Parkinson's disease

**Study objective:** to identify issues and gaps in the treatment of Parkinson's Disease (PD) in Europe, to work on the gaps at least for the most relevant issues and assess qualitative but also economic value of treatment for the identified gaps

**Setting:** primary care and specialists care including rehabilitation specialists

## Epilepsy

**Study objective:** « new » antiepileptic drugs have had little impact on the proportion with refractory epilepsy. Only a minority is suitable for surgery. Best option to improve QoL and efficiency is to ensure services are resourced and configured to meet patients needs. The study will aim to 1) assess the health and economic outcomes of ideal *versus* existing services and 2) propose a care model starting with diagnosed epilepsy

**Setting:** specialist care

# Illustrations: state of progress of VoT Case Studies

WORK IN  
PROGRESS

## Multiple Sclerosis

**Study objective**: to value the socio-economic impact and health gains of primary prevention, early diagnosis (to slow down the progression rate) and treatment - Clinically Isolated Syndrome (CIS) and Relapsing-Remitting MS

**Setting**: primary care, secondary care including rehabilitation specialists

## Restless Legs Syndrome

**Study objective**: to assess the current burden of RLS (as whole) to healthcare and society in Europe and address specific patient journey gaps pending on data availability (early intervention, etc...)

**Setting**: primary care and specialists care

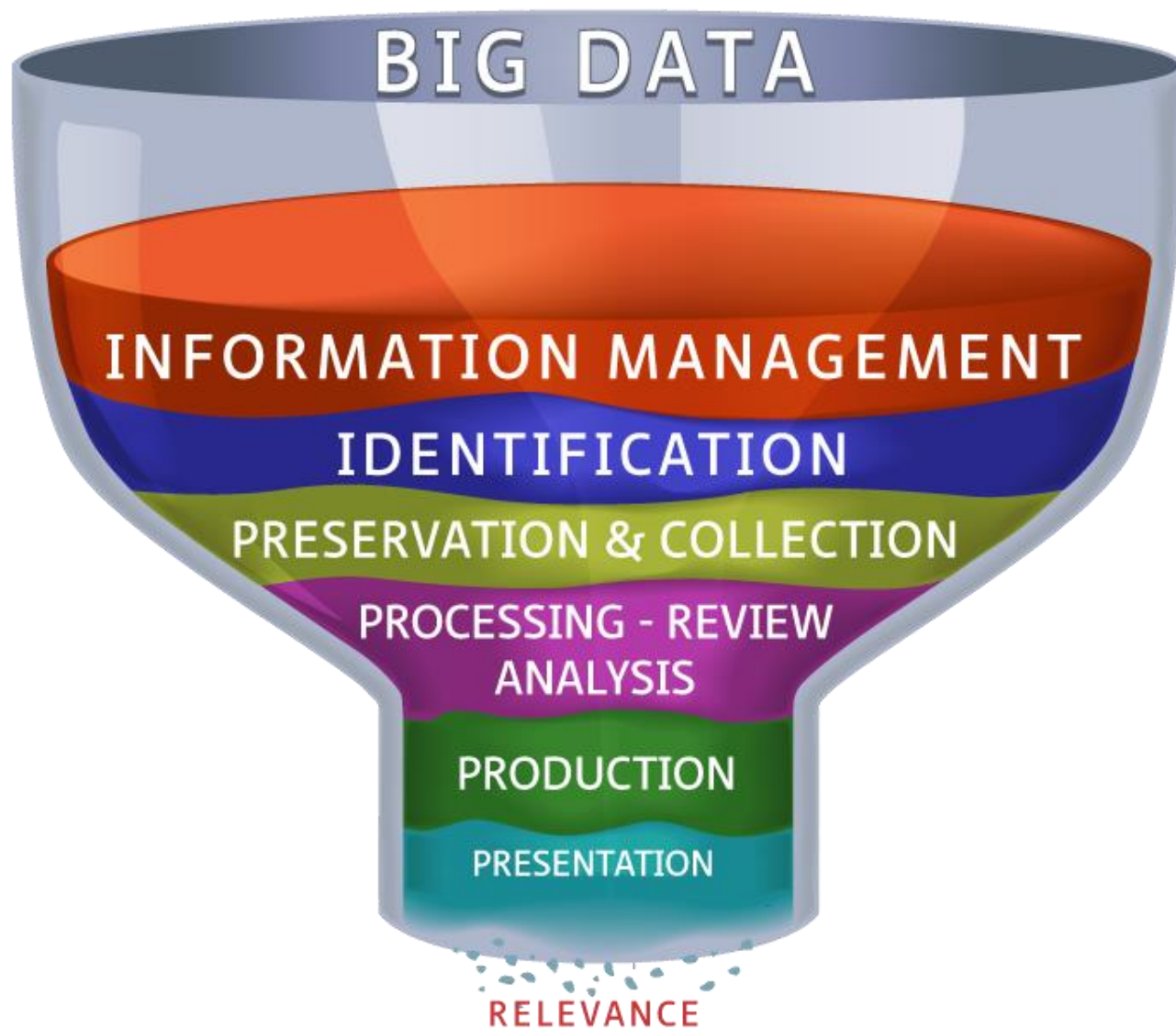
## Normal Pressure Hydrocephalus

**Study objective**: to assess the cost effectiveness of NPH treatment and to assess the socio-economic impact of NPH non-treatment (burden) and address unmet needs in order to: 1) increase awareness; 2) improve the possibilities for diagnosis and treatment of NPH

**Setting**: primary care and specialist care

# Overarching analysis

TOWARDS POLICY WHITE PAPER



# Overarching analysis: from case studies research to policy

To guide us, the following **questions are raised to examine options and optimal strategies** to improve patients' quality of life and reduce the socio-economic burden of mental and neurological disorders:

*What is the **amplitude of current unmet needs** (obstacles such as misdiagnosis, delayed treatment, non-adherence, unaffordable access to care and pricing,...) **in health care in Europe, not only within the provision of medicines but also within health care systems and services?** What is the **socio-economic impact of targeting these gaps** (e.g. avoidable costs,...)? What are the **potential benefits for integrated, coordinated care** combining effective team care and care planning? What are the **new research developments?***

# EBC 18th January 2017 Meeting

**EBC Value of Treatment Research Project**

**January 18th 2017**

**AGENDA (Draft)**

**University Foundation Rue D'Egmont 11, 1000 Brussels**

- |               |   |
|---------------|---|
| 9.00 – 13.00  | <b>Value of Treatment Plenary Working Groups Meeting with EBC Partners and External Experts:</b> presentation of case studies pre-results           |
| 13.00 – 14.00 | <b>Networking lunch</b>   |
| 14.00 – 15.45 | <b>Value of Treatment Experts <u>Round Table</u></b><br>Session moderated by <b>Prof. David Nutt</b> , EBC President<br>Speakers (External Experts) |
| 15.45 – 16.00 | <b>Wrap up</b>  |

# Discussion and consultation process

- **OUTLINE**
  - What should be **IN THE SCOPE**
  - What should be **OUT OF SCOPE**
- **HOLISTIC APPROACH (VS FRAGMENTATION AND RESULTS IN SILO)**
- **CANVAS/STRUCTURE**
- **PROPOSED CONTENT AS A START**



**Join our** discussion about the Value of Treatment for Brain Disorders

## EBC RESEARCH PROJECT – THE VALUE OF TREATMENT FOR BRAIN DISORDERS

*“Bridging the early diagnosis and treatment gap: exploring the potential clinical and socioeconomic impact of targeting unmet needs - reflections on new research developments including the benefits of alternative approaches such as seamless, integrated care in the prevention and treatment of brain disorders “*

DISCUSSION PAPER no 2 + outline

Setting the scene from case studies data analysis towards evidence-based policy recommendations

 Please send your comments to V. Quoidbach and G. Esposito by 6 January 2017



## Sustainability of VoT: Other case studies to come by 2017

1. Pain
2. European Reference Network (ERN) and Rare Neurological Disorders

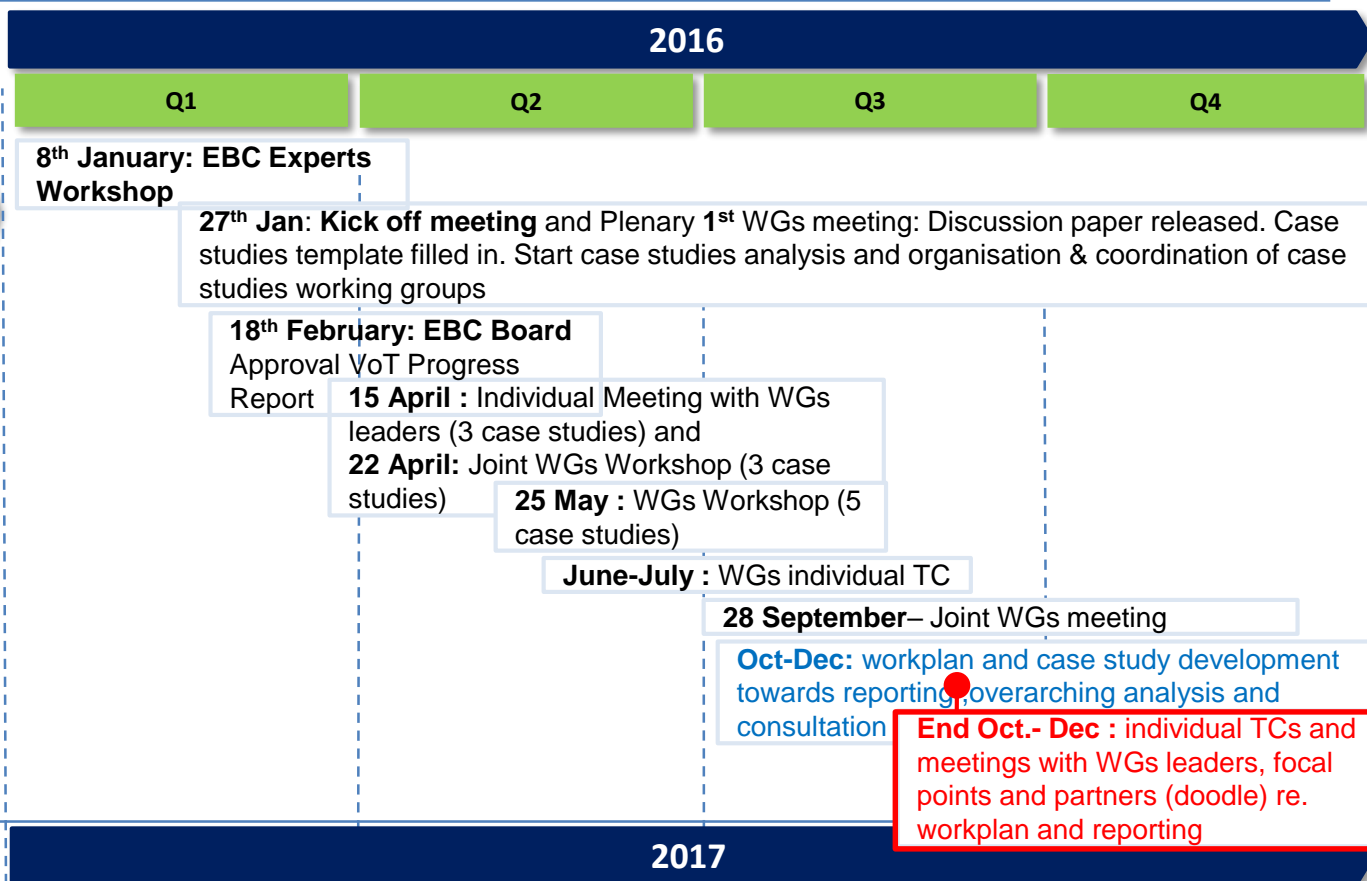
**MORE  
TO  
COME!**

# Project milestones: activity planning

With deadlines for deliverables

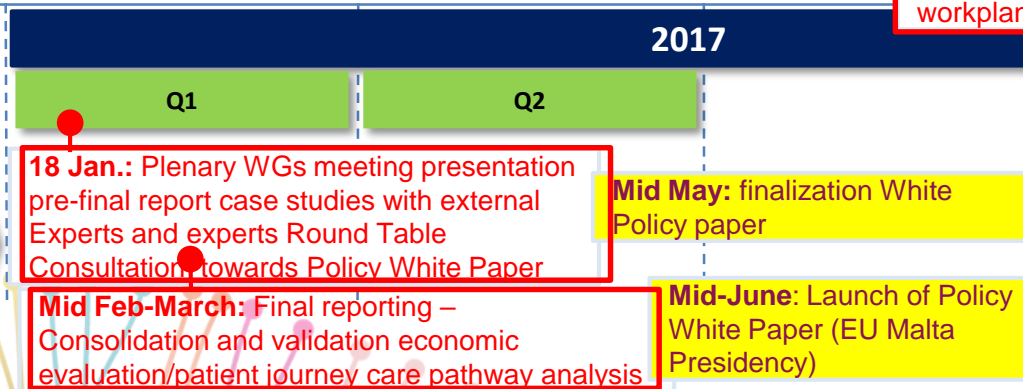
PHASE 2

Project development towards releasing final report



PHASE 3

Consolidation and dissemination highlighting major conclusions and policy recommendations



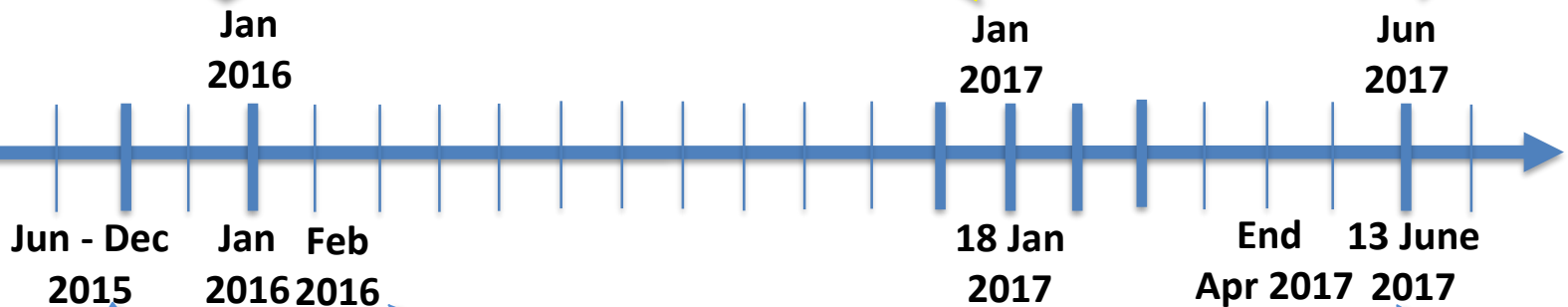
# Brain disorders Value of Treatment project: a tangible outcome



EU Joint Action on Mental Health and Well Being: final policy recommendations & best practices

EU Horizon 2020 Mid-Term Review

Malta EU Presidency



EBC Project devel. & design

EBC Project Kick off

Start case study analysis

Pre-results presentation of Study

Final Report

Launch Policy White Paper

