The Value Of Treatment for brain disorders in Europe

Value of Treatment research (VoT12)
Case studies on Rare Neurological Disorders (RNDs): Ataxia, Dystonia, Phenylketonuria & Mental Disorders (MDs): Autism Spectrum Disorder, Eating Disorder, Major Depressive Disorder

PROJECT OVERVIEW

The European Brain Council (EBC), an organization promoting research on brain health and disorders in Europe, initiated a Pan-European study called the Value of Treatment (VoT) for Brain Disorders. The project (2015-2017) included case studies on disorders ranging from schizophrenia to Alzheimer’s disease, epilepsy, headaches, the normal pressure hydrocephalus, Parkinson’s disease, multiple sclerosis, restless legs syndrome and stroke. The Value of Treatment (VoT) for Brain Disorders policy white paper, published in June 2017, provided important new progress in the areas of pharmacology, the biopsychosocial approach and health-care service delivery.1

Conclusions of this first phase of the VoT project highlighted the need for more seamless management of brain diseases and led to a second phase of the project, “VoT2” (2018-2021), focusing on rare neurological diseases (Ataxia, Dystonia, Phenylketonuria) and on mental disorders (Autism Spectrum Disorder, Anorexia Nervosa, Major Depressive Disorder). This new phase was initiated by EBC mid-2018, with the case studies on Rare Neurological Disorders looking at the value of early diagnosis and intervention, with an aim to assess the benefits of coordinated care and multidisciplinary care patterns on patient outcomes. Following initial discussions to identify treatment needs for people affected by mental disorders, it was decided in early 2019 that the scope of the VoT2 case studies on mental disorders would focus on value of early intervention, additionally the role of transition or continuity of care and their impact on health service use and patient outcomes.

OBJECTIVE

The Value of Treatment (VoT) project aims to examine health gains and socio-economic impacts resulting from best practice healthcare interventions in comparison with current care or no treatment, and to converge evidence to policy.

OUTCOMES

The study on Ataxia together with Dystonia and Phenylketonuria will provide insight on the value of specialist centres in terms of diagnosis, management of patients with rare conditions and its cost implications in several European countries. For mental disorders, lack of seamless care between multiple services and between patients and services is commonly seen as a major problem for people affected by mental disorders. The issues associated with continuity are non-disease specific: they apply to all mental disorders. There are clear benefits from effective maintenance and continuity of care for patients with complex needs but there is strong evidence that optimal continuity of care does not occur in most cases. We will assess the patients’ needs and evaluate the costs and consequences of transition or continuity of care for mental disorders in several European countries.

Ultimately the EBC Value of Treatment project aims to examine the role of national policy and programs, including National Rare Diseases Plans on the effective implementation of coordinated and comprehensive services directed to Ataxia, Dystonia, and Phenylketonuria. It also aims to influence the policy towards better treatment and care for people with mental disorders across Europe. Results of the research are to be released by end 2020 (RNDs) and mid-2021 (MDs). During 2021, findings will be disseminated via newsletters, scientific publications and an overarching policy paper.

PROPOSED STRUCTURE

VINCIANE QUOIDBACH EBC RESEARCH PROJECT MANAGER

EUROPEAN BRAIN COUNCIL

WORKING GROUP

EBC EXPERT ADVISORY COMMITTEE

Data from Country A

Care Pathway Analysis

Academic Partner in close collaboration with Patient Ass.

Data from Country B


Research scope Selection of indicators depending on the specific intervention.

Data from Country C

Health Economics

Academic Partner

EBC Research collaboration team bimonthly project update

What is crucial is to harmonize datasets for the 3 case studies on RNDs based on a standardized approach, same for MDs.


VOT2 - PROJECT RESEARCH COLLABORATION

Study includes: Academic partners, clinicians, health economists, epidemiologists with the participation of patient associations (*).

Research collaboration with academic institutions for RNDs case studies:
• University College London Hospitals: Ataxia care pathway analysis
• University of Cambridge: Ataxia AND Phenylketonuria health economic studies
• University of Zagreb Medical School: Dystonia care pathway analysis AND economic evaluation
• University College Dublin: Phenylketonuria care pathway analysis

Research collaboration with academic institutions for MDs case studies:
• King’s College London and Greenwich College London: Major Depressive Disorder care pathway analysis AND health economic studies
• King’s College London and Greenwich College London: Major Depressive Disorder care pathway analysis AND health economic studies
• London School of Economics: Autism Spectrum Disorder care pathway analysis AND health economic studies

1 CONCEPTUALIZATION

(3 months) - Mapping and kick-off

Method
• Proposed template per case study completed with defined study protocol.

Workshop (integrating various stakeholder perspectives)

Economic evaluation pathways (prices/estimations)

2 FIELDWORK

(6 months)

Method
• Care pathway analysis (care gaps(patient unmet needs mapping)

Patient economic burden (from issues to cost effective structure for the benefits of the patient)

3 DATA ANALYSIS

(3 months)

Method
• Case study analysis (results of VoT2 meeting)

Evidence based assessment and quantitative research

4 PATIENT SUPPORT GROUPS

(2 months)

Method
• Consultation to formulate final report conveying case studies data analysis into evidence based policy recommendations (patient led paper)

Proposed template for case study publication

Three phases project:

CONCEPTUALIZATION

(3 months) - Mapping and kick-off

Mapping care consequences for both healthcare system and patient

Mapping cost-consequences for both healthcare system and patient

Patients

1. Identify best interventions and costs in healthcare delivery.
2. Targeted intervention that can be implemented to achieve optimal outcome with the greatest value to both patient and healthcare system (economic modeling)

1. Omitting patient economic burden to identify burden of disease and burden (treatment gaps) to achieving optimal outcome

3. Obtaining patient economic burden to identify burden of disease and burden (treatment gaps) to achieving optimal outcome

4. Identifying best interventions and costs in healthcare delivery.

1. Data from Country A
2. Data from Country B
3. Data from Country C

Three phases project:

 jsonify(EBC)$product = "brain"

Timeline: all case studies and relevant reports to be completed by December 2020 (rare neurological disorders) and by June 2021 (mental disorders). Publications will be released in 2021.

Milestones for 2019 and 2020:
• 15 May 2019: VoT2 Joint Meeting
• 27 November 2019 (afternoon meeting): VoT2 Researchers Meeting (with researchers and WG leaders only)
• 18 May 2020 (afternoon meeting): VoT2 Joint Meeting
• November 2020 (date tbc): last VoT2 Researchers Meeting
• December 2020 (RNDs case studies) and June 2021 (MDs case studies): all analyses completed and written up - reporting and recommendations: Submission to EBC

Note: scientific publications will be released in 2021.