EBC Research Project

The Value Of Treatment for brain disorders in Europe

Value of Treatment research (VoT2)

Case studies on Rare Neurological Disorders (RNDs): Ataxia, Dystonia, Phenylketonuria **& Mental Disorders (MDs):** Autism Spectrum Disorder, Eating Disorder, Major Depressive Disorder

VOT

2nd ROUND 2018-2021

BRIDGING THE GAPS & ACHIEVING SEAMLESS, COORDINATED CARE

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, headache, 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[1], provided important new insight into recent progress in the areas of pharmacology, the biopsychosocial approach and health-care service delivery[2].

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 will 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.

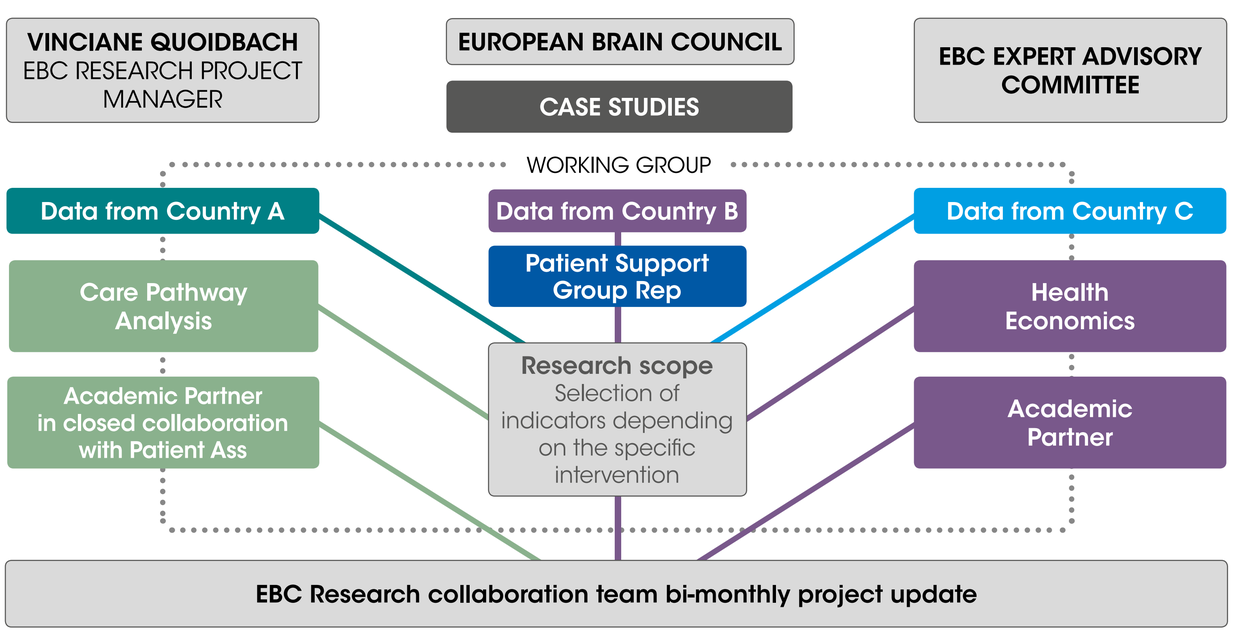
OUTCOMES

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 health 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 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.

Accessible online: VoT2 – rare neurological disorders article (CMJ 2019) on "Toward earlier diagnosis and treatment of rare neurological disorders: the value of coordinated care and specialist centers". Link to PubMed: https://www.ncbi.nlm.nih.gov/m/pubmed/31044588/?i=6&from=croat%20med%20j

PROPOSED STRUCTURE



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

[1] The value of treatment policy white paper: towards optimizing research and care for brain disorders. Brussels: European Brain Council; 2017. Available at: https://www.braincouncil.eu/wp-content/uploads/2017/06/EBC_white_policy_paper_DEF26072017_Low.pdf

[2] Bulletin of the World Health Organization 2018;96:298-298A. doi: http://dx.doi.org/10.2471/BLT.17.206599

VOT2 - PROJECT RESEARCH COLLABORATION

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

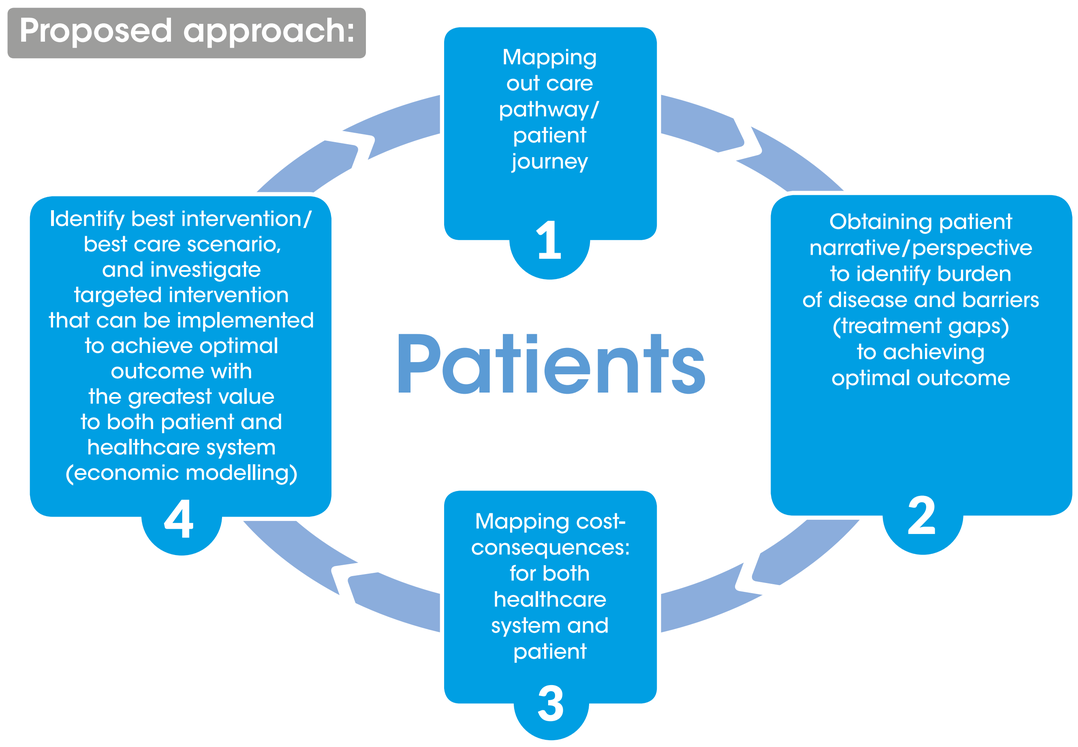
Research collaboration with academic institutions for RNDs case studies:

- 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**

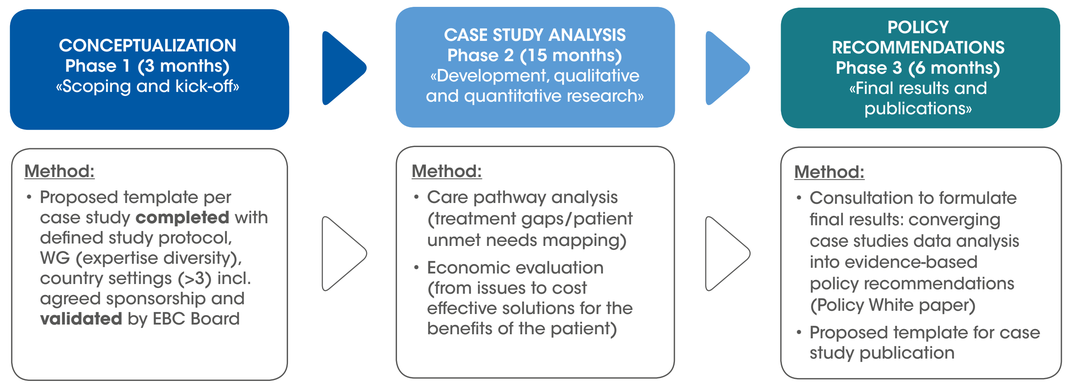
Research collaboration with academic institutions for MDs case studies:

- King's College London and London School of Economics: **Anorexia Nervosa 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**

Proposed approach:



Three phases project:



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)
- **6 May 2020 (date tbc):** VoT2 Joint Meeting
- **November 2020 (date tbc):** last VoT Researchers Meeting
- **December 2020:** all analyses completed and written up - reporting and recommendations: Submission to EBC

Note: scientific publications, reporting and policy recommendations will be released during the first semester of 2021.

(*) The European Brain Council (EBC) is a network of key players in the "Brain Area", with a membership encompassing scientific societies, patient organisations, professional societies and industry partners.

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