The Value of Treatment

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The Brain, A New Approach to Brain Diseases
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European Brain Council

Mission:
Advance the understanding of the healthy and diseased brain to improve the lives of those living with brain disorders
The Cost of Brain Disorders (2005/2010)

➢ Value of Treatment Study Builds upon EBC report “The Economic Cost of Brain Disorders in Europe (2005, updated 2010)

➢ This report gave a solid estimate of cost of Brain Disorders in Europe

➢ Indirect Cost 40% of total cost of €800 billion / year in Europe
The Value of Treatment for Brain Disorders

The cost of non-treatment
Value of Treatment

Main objective

Assess the socio-economic impact of clinical interventions, or the lack thereof,

and provide evidence and tools that can assist policy makers and healthcare workers in shaping effective policy responses for some of the most prevalent brain disorders.
Disorders of the Brain: the big picture

- 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

Disorders of the Brain: VOT studies

- Mental disorders: Schizophrenia
- Neurological disorders: Alzheimer’s, Epilepsy, MS, Parkinson’s, RLS, Stroke, Headache and NPH.
## Value of Treatment: 9 case studies

<table>
<thead>
<tr>
<th>Etiology</th>
<th>Schizophrenia</th>
<th>Stroke</th>
<th>Epilepsy</th>
<th>Multiple Sclerosis</th>
<th>Headaches</th>
<th>Restless legs</th>
<th>Alzheimers' disease</th>
<th>Parkins ons' disease</th>
<th>Normal pressure hydrocephalus</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unknown</td>
<td>Neurovascular</td>
<td>Multiple etiologies</td>
<td>Immunologic</td>
<td>Unknown</td>
<td>Unknown</td>
<td>Degenerative</td>
<td>Degenerative</td>
<td>Degenerative, immunologic</td>
<td></td>
</tr>
<tr>
<td>No of subjects in Europe*</td>
<td>5 Mio</td>
<td>1.3 Mio</td>
<td>6 Mio</td>
<td>0.7 Mio</td>
<td>50 Mio</td>
<td>20 Mio.</td>
<td>8.7 Mio</td>
<td>1.3 Mio</td>
<td></td>
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</tbody>
</table>

~ 100 Mio European inhabitants affected by these diseases (*EU 28*)
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
Case study will value healthcare interventions in comparison with the cost-burden of misdiagnosis, non-treatment, non-adherence

<table>
<thead>
<tr>
<th>Value of Treatment</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost analysis</td>
<td>Value mapping (identification of current and potential values)</td>
</tr>
<tr>
<td>Cost impact analysis (with or without simulation)</td>
<td>Value optimizing healthcare initiatives</td>
</tr>
<tr>
<td>Model calculations (health economics) incl. QALY, ICER</td>
<td>New value creating initiatives (integrated care model)</td>
</tr>
</tbody>
</table>

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 (SWOT analysis patients and clinicians perspectives with a set of outcomes 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

Combined methodology

Policy White Paper and Scientific Publications of the Results in 2017
What do we mean by treatment gap? What is a patient care pathway?

Fig. 1: Possible cause of the treatment gaps

### Natural History of the Disease
- Asymptomatic phase of illnesses
- Illnesses usually with no symptoms
- Low understanding of the disease aetiology, symptoms, risk and preventive factors

### Deficiencies in Health Service Along the Care Process (Prevention, Screening, Diagnosis, Treatment, Follow-up and Rehabilitation)
- Not available services, systems or policies
- No health insurance
- Limited access to care (primary and secondary care)
- Fragmented, poorly organised or uncoordinated care
- Lack of primary and secondary prevention programs
- Delay in detection and diagnosis leading to late treatment
- Drugs not available for whatever reason
- Physician missing detection, diagnosis
- Inadequate treatment
- Low disease awareness in general public and lack of training, expertise from healthcare providers
- No patient empowerment to facilitate adherence, compliance – non-adherence to treatment being intentional or unintentional
- Absence of support for caregivers

### Economic Factors
- Costs of treatment
- Limited access to drugs and devices

### Social Factors
- Fear of disclosure
- Stigma discourages seeking treatment (e.g. epilepsy, mental illnesses)
- Isolation and vulnerability

### Other Factors (unknown because of lack of research)

Source: adapted from R. Kale. The treatment gap. BMJ. Epilepsia 43 supp 6):31-33, 2002
From issues (treatment gaps analysis) to cost effective solutions... for the benefits of the patient

Care pathway – addressing research and organisational needs for brain disorders
Benefits of targeting these gaps?

**Economic evaluation:**

cost effectiveness analysis/cost saving analysis of best practice healthcare intervention *versus* standard care or non-treatment
# VoT Scope

<table>
<thead>
<tr>
<th>Gaps</th>
<th>Schizophrenia</th>
<th>Alzheimer's Disease</th>
<th>Headache</th>
<th>Stroke</th>
<th>Parkinson's Disease</th>
<th>Epilepsy</th>
<th>Multiple Sclerosis</th>
<th>Restless Legs Syndrome</th>
<th>Normal Pressure Hydrocephalus</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevention</td>
<td>Missed detection</td>
<td>Early detection</td>
<td>Late intervention</td>
<td>Early intervention/ inadequate treatment</td>
<td>Lack of structured headache services and education</td>
<td>Lack of inpatient stroke unit</td>
<td>Lack of early/timely treatment</td>
<td>Inadequate treatment &amp; care</td>
<td>Inadequate treatment</td>
</tr>
<tr>
<td>Screening</td>
<td>Early detection</td>
<td>COST SAVING/COST EFFECTIVE</td>
<td>Early intervention/ adequate treatment</td>
<td>COST EFFECTIVE</td>
<td>Early intervention/ adequate treatment</td>
<td>COST EFFECTIVE</td>
<td>Lack of adequate treatment for advanced PD</td>
<td>Early in treatment (DMTs)</td>
<td>COST EFFECTIVE</td>
</tr>
<tr>
<td>Diagnosis/treatment</td>
<td>Early intervention</td>
<td>Structured headache services and education</td>
<td>Early intervention/ adequate treatment</td>
<td>COST EFFECTIVE</td>
<td>Early intervention</td>
<td>COST EFFECTIVE</td>
<td>Lack of adherence to drug treatment</td>
<td>Adequate treatment</td>
<td>COST EFFECTIVE</td>
</tr>
<tr>
<td>Follow-up</td>
<td>(Case studies)</td>
<td>-</td>
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</tr>
</tbody>
</table>

- Impact of modifiable lifestyle factors on MS
- Lifestyle factors prevention COST EFFECTIVE
- COST EFFECTIVE

- Early and inadequate treatment
- Early and adequate treatment COST EFFECTIVE
- COST EFFECTIVE
Two case studies

1. Stroke
2. Restless Legs Syndrome
A leading cause of disability and death among adults. 1.3 million people affected in Europe each year. One third will make a good recovery, but one third will not survive or will live with long-term disability. Strokes are more likely to occur with ageing [2].

Aetiology: Neurovascular

Identifying the treatment gap and improving care for ischemic stroke patients

In the Stroke case study, both approaches are analysed with recommendations on how to improve stroke care:

- The patient care pathway analysis: key issues and unmet needs for stroke patients are described along the care pathway from prodromal, diagnosis, disease management to patient empowerment;
- The delivery of evidence-based interventions within the stroke unit: the economic impact of a full implementation of stroke unit care is evaluated.
Identifying the treatment gap and improving care for ischemic stroke patients

The case for integrated Stroke Units

Fig. 1: Hospital intra-extra mural care pathways and seamless care

- Recognize symptoms & call ems
- Timely ems response
- Transport & notify stroke center guideline-based stroke care
- Increasing survival rate
- Improving patient QoL
- Reducing the overall burden associated with stroke
Conclusions VOT-Stroke

- Major treatment gaps need to be addressed:
  - Inadequate treatment of atrial fibrillation
  - Low number of stroke units
  - Low access to stroke units

- Full implementation of stroke services would be a cost-effective treatment for acute ischemic stroke. Although provision of comprehensive stroke services represents a significant logistical and financial challenge the ultimate benefits are likely to be extensive, both in terms of cost and burden of death and disability.
Restless Legs Syndrome: the big picture

- Highly prevalent brain disorder which is not commonly recognized and as a result is often not/too late diagnosed and/or treated
- Aetiology: Neurological
Treatment gaps and unmet needs

• There is a huge lack of awareness and knowledge of RLS. As a result patients are not taken seriously, wrong diagnoses are made and false treatments given.
• The knowledge among in particular primary care physicians leaves much to be desired, referrals to specialists are often not done, resulting in delayed or false diagnoses and no or wrong treatment.
• Medicines for RLS do exist. Treatment of first choice to date are the dopamine agonists. If applied incorrectly, adverse reactions to these drugs in RLS patients are frequent, the most severe adverse reaction being the paradoxical phenomenon called augmentation.
• The number of truly knowledgeable RLS specialists in Europe is very limited
• Due to lack of awareness medicines are not reimbursed in many European countries
• All available medicines were registered for other diseases in the first place, there is no pharmacological research for RLS per se.
Ranking Yearly total cost – NEUROLOGY

- **Epilepsy**: 6.682
- **MS**: 7.418
- **Parkinson’s Disease**: 8.028
- **Headache**: 19.931
- **Stroke**: 32.215
- **RLS**: 34.068
- **Dementia**: 45.399
It is safe to say

.......when translating RLS costs (and the impact of RLS inadequate treatment) to the general population we foresee substantial economic impacts. For example if we consider current epidemiological figures in the literature (2.7% with severe RLS) closing the treatment gaps in RLS may result in a few billions of euros saved annually by each of the EU country-specific healthcare systems.

LSE: July 2017
Case study
Restless Legs Syndrome

Conclusions:

1. Education about RLS is urgently needed to increase expertise of healthcare workers
2. The search into the cause(s) of RLS and for new treatment strategies has to be intensified in order to reduce the suffering of people with RLS and the high societal cost
Overall Conclusions VoT

1. Position brain research on the strategic research agenda
2. Ensure brain disorders prevention and management are part of policy prioritization, implementation and evaluation

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