



Value-Based Healthcare

ICHOM meeting, 11 June 2019, Poland

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Value-based healthcare

- Why value is important for both health systems and patients?
- Why patients' needs should be at the centre of any discussions about value?

Introduction

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.



For an improved quality of life for Europeans living with brain conditions

<https://www.braincouncil.eu/>

Disorders of the Brain: the big picture



Brain disorders: Causes, Symptoms and Diagnosis

- Mental disorders: Depression, Schizophrenia,...
- Neurological disorders: Alzheimer's diseases, Epilepsy, Multiple Sclerosis, Parkinson's disease, Restless Legs Syndrome, Stroke,...

Disorders of the Brain: the big picture

- Highly prevalent and disabling conditions across all life span: worldwide and particularly Europe
- 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

[1] Di Luca, M. & Olessen, J. (2014) The cost of brain diseases: a burden or a challenge? *Neuron*, 82, 1205-1208.

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The Cost of Brain Diseases: A Burden or a Challenge?

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Brain diseases represent a considerable social and economic burden in Europe. With yearly costs of about 800 billion euros and an estimated 179 million people afflicted in 2010, brain diseases are an unquestionable emergency and a grand challenge for neuroscientists.

The Cost of Brain Disorders in Europe: The Grand Challenge

Brain research is at the forefront of science but extensive work is still needed to understand brain functioning at molecular, cellular, and system levels as well as to unravel the pathogenesis of complex brain diseases. Brain research and brain diseases are relatively new terms. The former covers neuroscience, neurological, and psychiatric research and the latter includes disorders that might be classified as neurological or psychiatric, even though they can be also cared for by other specialists and general physicians. Both terms are better understood by decision makers and the general public and were therefore proposed by the European Brain Council (EBC), an alliance of all major European organizations interested in the brain and its diseases. FENS, the Federation of European Neuroscience Societies, has been a major supporter and partner of EBC since its inception and has participated in a long and successful drive to increase the support of brain research in Europe.

There is no way to escape from the fact that brain disorders are a major public health problem in Europe and the rest of the world. The World Health Organization (WHO) global burden of disease study and two major pan-European studies on the cost of brain disorders were of seminal importance in disclosing this major challenge. They demonstrated that, beyond doubt, brain disorders are the major public health problem in Europe and all other high-income countries.

Brain diseases were included in the global burden of disease study by the WHO (World Health Organization, 2008;

Murray and Lopez, 1997), and the burden of brain disease was collected in a single article in 2003 (Olesen and Leonard, 2003). It showed that brain diseases are responsible for 35% of Europe's total disease burden. This figure was, however, calculated in terms of so-called DALYs, or disability-adjusted life years, which is difficult for politicians and other decision makers relate to and understand.

In 2003, the EBC decided to fill this knowledge gap by providing sound estimates of the cost of as many brain disorders as data would allow for all of Europe. Since data for each disease were only available in a few countries, a health economic model was developed using the imputation of missing values. The calculations were based on the cost of a given disorder in one single person for 1 year and the 1-year prevalence of the disorder. More than 100 epidemiology and health economic experts made the best-possible estimates from existing data. Prevalence and cost values were given as a European mean using all available national data since no global European information was available. Values were then calculated for all European countries and multiplied with their population to give the total cost in each single country; these values were added up to provide the total European cost. This first cost study (Andlin-Sobocki et al., 2005) was prevalence based and it estimated the cost of a given brain disease for a single year, namely 2004. It included 12 major brain disorders, some traditionally classified as psychiatric, some as neurologic. Because data were considered too weak for the inclusion of other brain diseases at the time, several major disorders were

left out. A major category excluded for lack of accurate data was represented by child and adolescent disorders as well as mental retardation. The document included both direct and indirect costs of diseases. Two types of direct costs were analyzed. All costs related to health care, such as hospital care, doctor's visits, and drugs, regardless of who pays—the individual, a private insurer, or the public through taxes and social insurance—were intended as the direct health care cost. Costs outside the medical sector, both private and public, such as nursing home costs and assistance given through the municipality to compensate for limitations in function caused by dementia, multiple sclerosis, or schizophrenia or private costs for adapting to the disorders, in terms of services or goods, formed the direct nonmedical costs. Indirect cost included the days that can be taken off work due to illness, no matter if this means a short-term absenteeism from work or early retirement. Presenteeism, intended as limitations in one's work capability while at work, was not evaluated as it was considered too uncertain.

Following this accurate methodology, the above study already pointed out that, in 2004, 127 million European citizens were living with a brain disorder, for a total annual cost of 385 billion euros. Psychiatric disorders accounted for 62% of the total cost, while the remaining 38% were caused by neurological diseases including dementia. These data highlighted that brain disorders were more costly than cardiovascular disorders or cancer. The results of this study were made available to the European

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Overview healthcare expenditures

Among the EU Member States, Germany, Sweden and France had the highest healthcare expenditure in % of GDP in 2015 (around 11 % each).

	Million EUR	EUR per inhabitant	PPS per inhabitant	% of GDP
Belgium	42 982	3 812	3 546	10.5
Bulgaria	3 715	518	1 224	8.2
Czech Republic	12 202	1 157	1 992	7.2
Denmark	28 065	4 938	3 623	10.3
Germany	338 207	4 140	4 113	11.2
Estonia	1 319	1 003	1 458	6.5
Ireland	19 855	4 273	3 489	7.8
Greece	14 732	1 361	1 639	8.4
Spain	98 586	2 123	2 320	9.2
France	241 366	3 623	3 505	11.0
Croatia	3 246	771	1 245	7.4
Italy	148 029	2 437	2 459	9.0
Cyprus	1 193	1 408	1 590	6.8
Latvia	1 389	702	1 090	5.7
Lithuania	2 432	837	1 483	6.5
Luxembourg	3 165	5 557	4 131	6.1
Hungary	7 936	806	1 532	7.2
Malta
Netherlands	72 323	4 269	3 857	10.6
Austria	35 077	4 063	3 765	10.3
Poland	27 280	718	1 396	6.3
Portugal	16 106	1 555	1 959	9.0
Romania	7 925	400	865	5.0
Slovenia	3 295	1 597	2 000	8.5
Slovakia	5 418	999	1 619	6.9
Finland	19 790	3 612	3 000	9.5
Sweden	49 225	5 023	3 835	11.0
United Kingdom	254 827	3 913	2 910	9.9
Iceland (*)	1 303	3 938	2 978	8.6
Liechtenstein	340	9 073	.	6.1
Norway	34 748	6 697	4 499	10.0
Switzerland (°)	60 276	7 361	4 710	11.4

Eurostat: Data extracted in March 2018. Planned article update: June 2019.

https://ec.europa.eu/eurostat/statistics-explained/index.php/Healthcare_expenditure_statistics#Curative_care_and_rehabilitative_care_services

Overview curative care and rehabilitative care services

Curative care and rehabilitative care services accounted for more than half of current healthcare expenditure in a majority of EU Member States - Healthcare expenditure by function, 2015 (% of current healthcare expenditure)

	Curative care and rehabilitative care	Long-term care (health)	Ancillary services (non-specified by function)	Medical goods (non-specified by function)	Preventive care	Governance and health system and financing administration	Other health care services
Belgium	49.4	24.3	5.0	16.2	1.7	3.4	:
Bulgaria	47.7	0.1	4.2	43.5	2.6	1.3	0.6
Czech Republic	53.7	12.8	5.2	20.4	2.7	2.6	2.7
Denmark	55.8	24.5	4.7	10.2	2.5	2.4	0.0
Germany	51.3	16.3	4.9	19.8	3.0	4.8	:
Estonia	57.7	5.7	10.8	20.9	3.2	1.9	0.0
Ireland	53.9	22.7	2.9	14.1	2.7	2.9	0.8
Greece	61.7	2.1	4.0	28.3	1.3	2.6	0.0
Spain	58.7	9.2	5.0	22.3	2.0	2.9	0.0
France	55.9	10.7	5.4	20.1	1.9	6.0	:
Croatia	53.5	2.8	9.1	28.5	2.8	2.7	0.6
Italy	55.1	10.1	8.2	20.7	4.0	1.9	0.0
Cyprus (*)	63.6	3.4	11.5	19.3	0.7	1.5	0.0
Latvia	49.3	5.2	10.9	30.5	2.0	2.0	0.0
Lithuania	52.1	8.6	5.2	30.1	1.9	2.0	0.0
Luxembourg	52.9	23.5	5.9	11.0	2.4	4.3	0.0
Hungary	53.6	3.9	5.2	32.1	2.7	2.1	0.4
Malta	:	:	:	:	:	:	:
Netherlands	51.9	24.8	1.8	12.7	3.6	3.9	1.3
Austria	59.3	14.9	3.0	16.9	2.2	3.8	:
Poland	61.3	5.9	4.7	23.4	2.7	1.7	0.4
Portugal	65.8	2.6	8.3	19.6	1.8	1.9	0.1
Romania	42.9	6.4	5.2	39.6	2.1	2.5	1.3
Slovenia	57.8	9.9	3.7	22.4	2.7	3.5	0.0
Slovakia	52.2	0.3	6.9	35.3	2.1	3.2	:
Finland	59.9	17.0	3.3	14.9	4.0	0.9	0.1
Sweden	52.2	26.3	3.7	12.3	3.1	1.7	0.7
United Kingdom	56.7	18.2	1.8	14.5	5.2	2.2	1.5
Iceland (?)	59.1	20.5	2.4	14.5	2.4	1.3	0.0
Liechtenstein	60.4	14.0	5.0	13.5	1.2	5.9	0.0
Norway (?)	50.0	27.9	7.8	10.9	2.9	0.6	0.0
Switzerland (*)	57.9	19.2	3.4	13.2	2.2	4.1	:

Eurostat: Data extracted in March 2018. Planned article update: June 2019.

https://ec.europa.eu/eurostat/statistics-explained/index.php/Healthcare_expenditure_statistics#Curative_care_and_rehabilitative_care_services

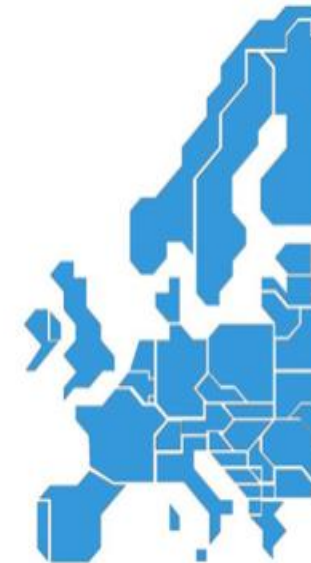
The Value of Treatment for Brain Disorders



EBC White Policy Paper released on 22 June 2017

https://www.braincouncil.eu/wp-content/uploads/2017/06/EBC_white_policy_paper_DEF26072017_Low.pdf

2015-2017 Pan-European Study



Value of Treatment
for Brain Disorders
**Case Study on
Multiple Sclerosis**



> 770.000 people
are living with MS
in Europe



Etiology

Immunologic



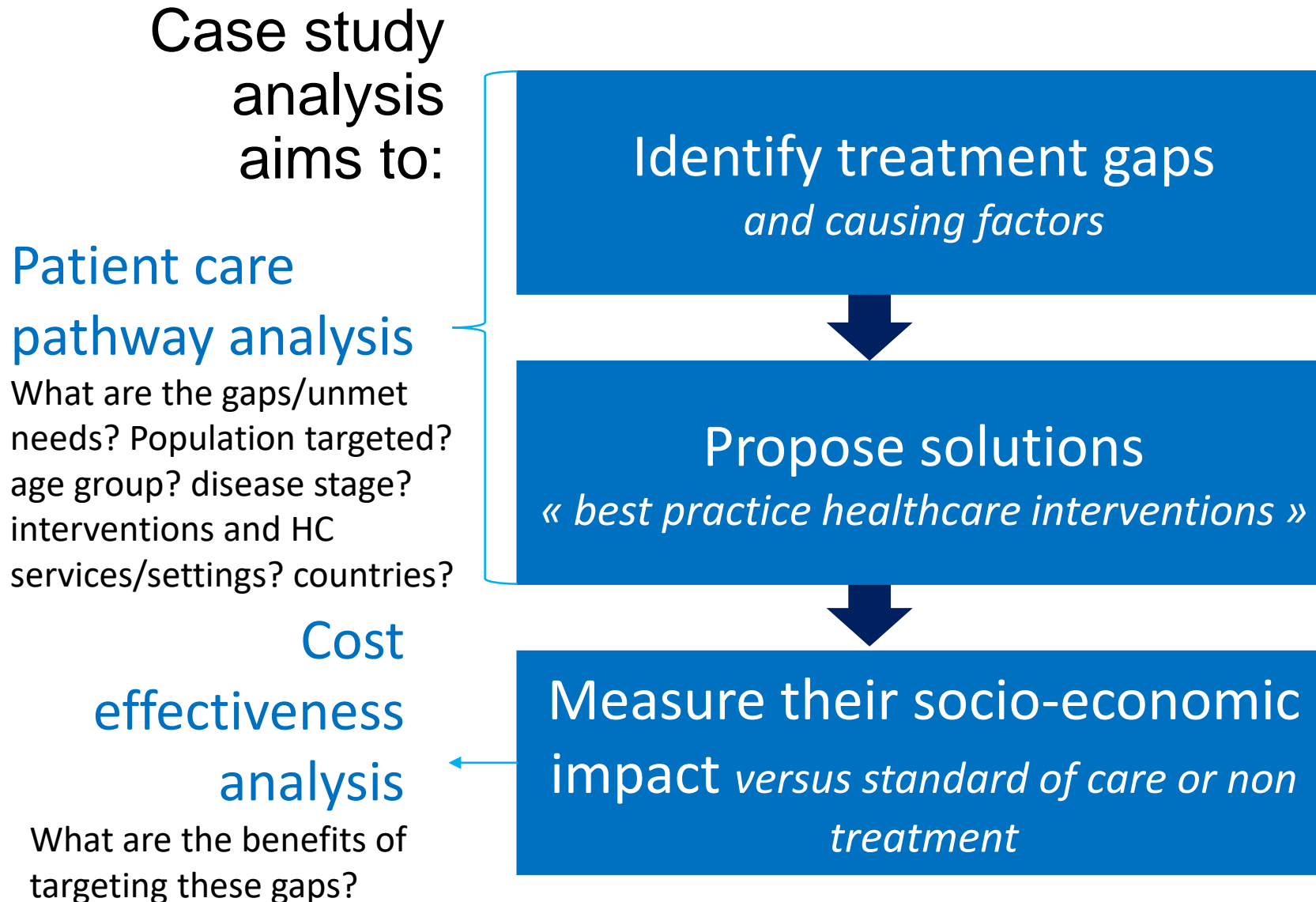
TREATMENT

**Disparity in access
to care & treatment**

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

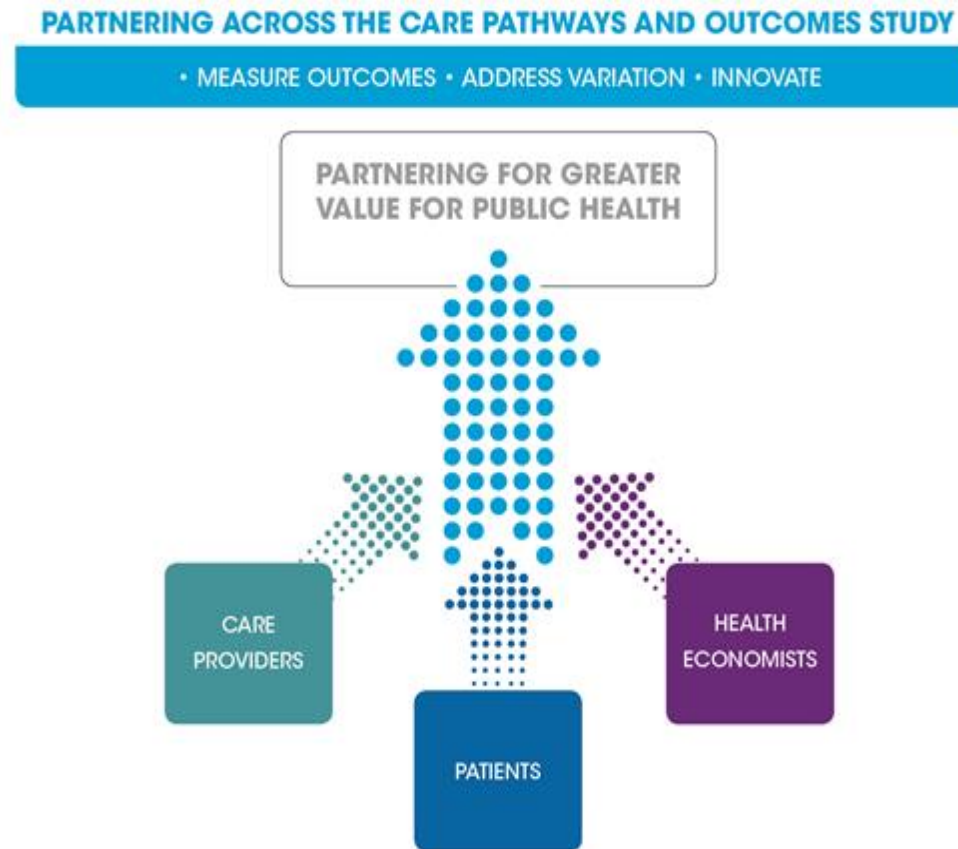
- From **issues** (patient care pathway analysis)
- To cost effective **solutions for the benefits of the patient** (economic evaluation study)

Study objectives



An innovative research

Fig. 1: EBC Value of Treatment research methodology framework



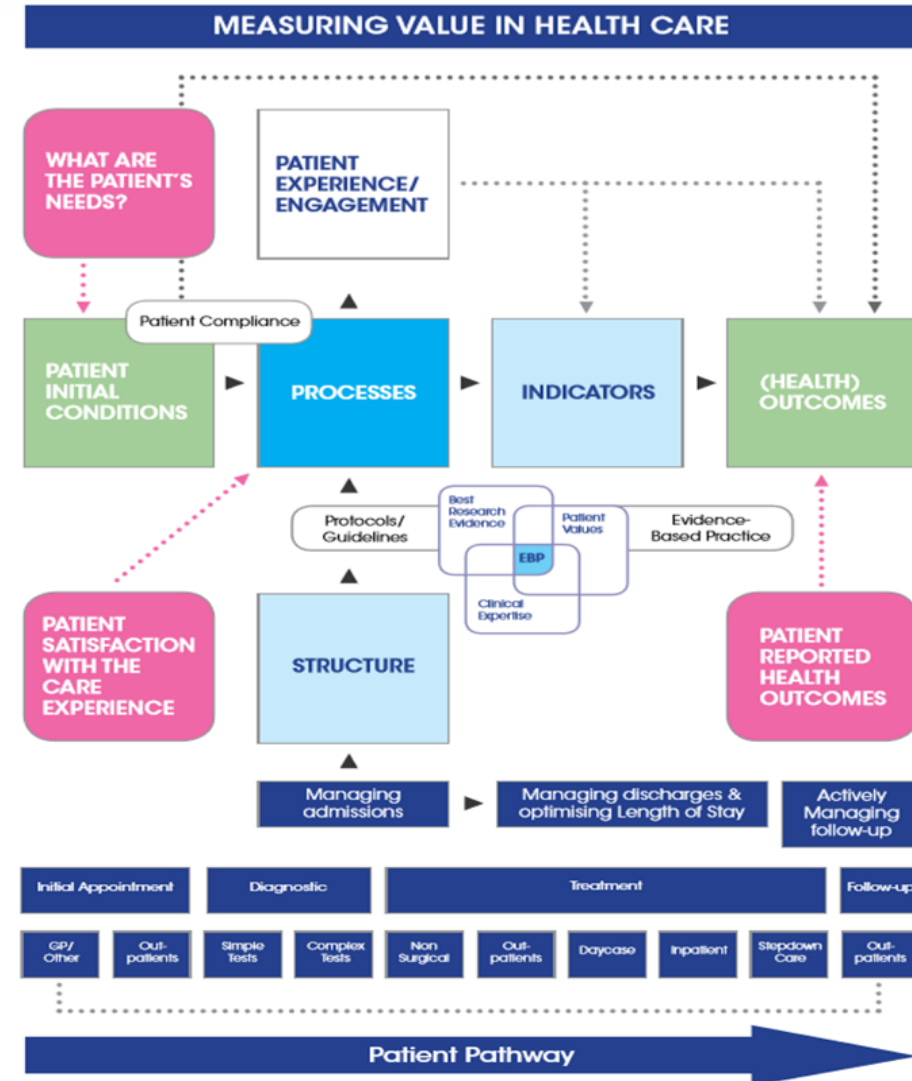
An innovative research

Patient-centred:

- Target **unmet needs** to achieve **high value for patients** (for the same pathology, different needs, different care pathways) – patient stratification
- Promote **early intervention and a biopsychosocial approach to care**
- Propose **solutions with societal impact** and reflect on **new research development**

The Care Pathway Approach

Optimizing healthcare processes with an outcomes-based approach: care pathways enable health systems (and other health care organizations) to make evidence-based decisions about where to focus improvement efforts for better outcomes.



Averting multiple sclerosis long-term societal and healthcare costs.

Early intervention and lifestyle choices as key to success



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Background

Multiple sclerosis (MS) is a chronic, inflammatory demyelinating and degenerative disease of the central nervous system (CNS) with typical onset between age 20-40 years. Over 2 million people have MS worldwide. MS is the commonest cause of non-traumatic neurological disability in young adults [1]. MS imposes a high burden on society, in terms of production losses as well as on families, with a very high need for informal care. All types of costs increase with increasing disease severity. MS is an acquired immune-mediated inflammatory and degenerative disease due to an abnormal immune response to environmental triggers in people who are genetically predisposed. The actual cause is unknown [2]. The MS course is unpredictable, with some people minimally affected and others rapidly accumulating disability. To date, there is no cure for MS, but a number of disease modifying treatments (DMTs). Early diagnosis and treatment may delay, or even prevent, the previously inevitable disability [3]. The course of MS implies different stages, from the clinical onset and clinically isolated syndrome (CIS), to later stages of life featuring severe cognitive decline and physical disability. Also economic and patient related outcomes (PROs) (eg., Patients' preferences), vary across these stages of the disease. We therefore aimed to define the MS 'patient journeys' capturing the main unmet needs on the different life domains.

Methods

In order to perform a 'MS patient journeys' analysis, scientific and lay literature was scrutinized for the disease relevant clinical features, disease course, prognostic factors, available DMTs, guidelines for the management of a person with MS, and implications for his/her quality of life and social functioning. Also the economic burden of the different stages of the disease was considered. The 'MS patient's voice' was listened to, through the wealth of material from the European MS Platform and its initiatives. In particular, semistructured interviews were conducted by EMSP with two MS patients advocates each representing a separate journey.

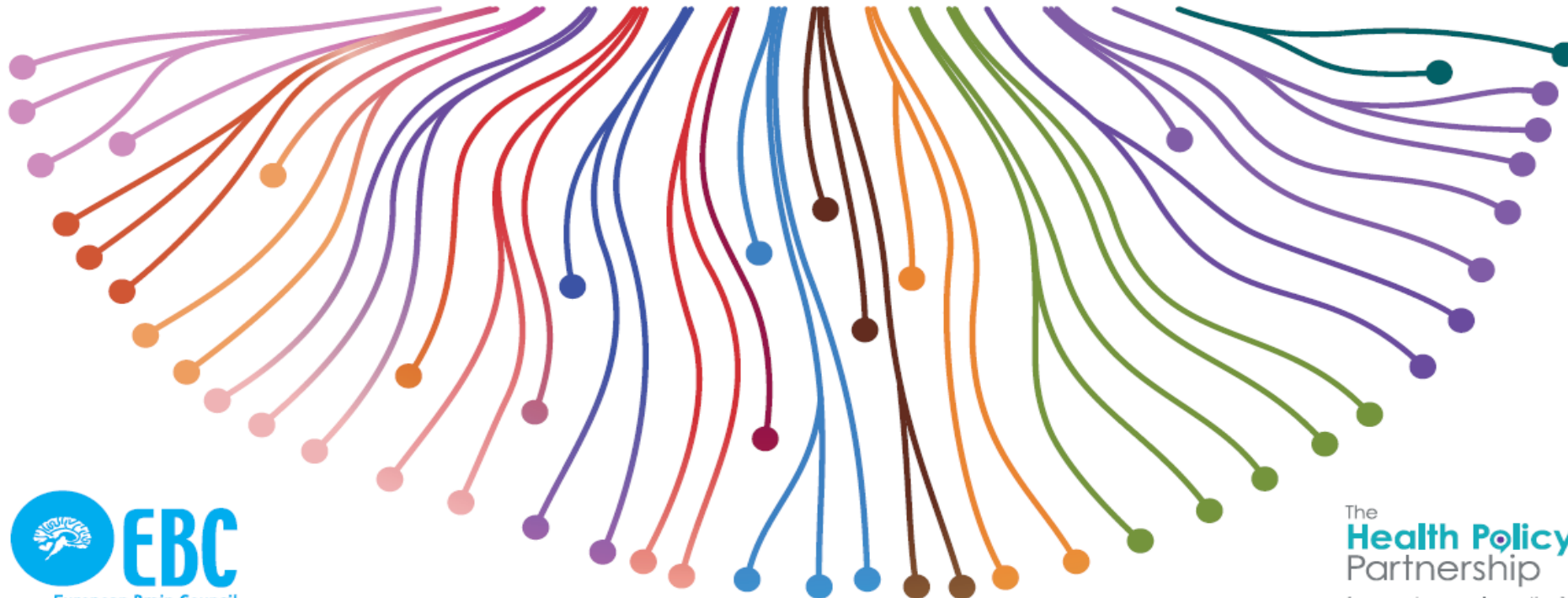


VoT study **conclusions**
and policy
recommendations at
health systems level to
improve the QoL of
PWMS and reduce the
burden of disease

- Early diagnosis and treatment, and brain healthier lifestyle interventions to slow MS progression
- Coordinated, multidisciplinary care approach
- Participation in daily life
- Framework for action at country level
 - ⇒ Epidemiological and public health relevance
 - ⇒ Coherence with major strategies
 - ⇒ Evidence driven targets and indicators
 - ⇒ Evidence of achievability at the country level
 - ⇒ Existence of surveillance instruments (national MS Registry)

A multiple sclerosis policy report with country health policy and systems assessment in support of the development of national brain health strategies - A European Brain Council & Health Policy Partnership 2018-2019 Joint Project

.....
The policy report will be launched on the 6th November 2019.
.....



Aim of the project is to *drive tangible policy and regulatory changes* in health and social care which can improve the lives of people living with multiple sclerosis (MS) across Europe.

2018/2019 EBC&HPP

Joint Project Health Policy and Systems Research with a focus on Multiple Sclerosis



1

Expert Advisory Group

Experts from Europe

Consultation with more than 25 neurologists, general practitioners, hospital pharmacists, clinical psychologists, physiotherapists, rehabilitation specialists, nurses, academic researchers and patients associations representatives



2

Care Indicators Analysis

Research methodology

- Desk research and grey literature review from international and national institutions (employment, health and social services research in relation with MS) across 11 European countries
- Experts semi-structured interviews



3

Country Profiles & Priorities

Research structure

Introduction

- Country context
- MS in numbers
- Top three unmet needs
- Policy and regulations landscape

Research scope

Organisation of care

- Diagnosis
- Pharmacological management
- Multidisciplinary management
- Monitoring and long-term follow-up

Support for people with MS in their daily lives

Further information

Case studies / best practice

Roundtable meetings in Denmark, Italy, Spain and Romania consultation on findings and validation.

By taking a holistic view of healthcare and social services, and identifying best practice and national priorities, we aim to create greater visibility for the unmet needs experienced by people with MS.



4

The MS Value of Treatment and Policy Report

Launch at the European Parliament on 6 November 2019

Building on the findings from the 2017 Value of Treatment report, EBC and HPP will develop a multidisciplinary consensus around practical and sustainable policy responses to MS at European level and specifically in four European countries.

HEALTH POLICY AND SYSTEMS RESEARCH

HPSR



Thank you!

For any questions or comments, please do not hesitate to reach out to:

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