



Integrated care for brain disorders in Europe

*ICT 4 Life closing conference
Brussels – 18.10.2018*



1. EBC – who we are
2. The societal & economic impact of brain disorders: the need to act
3. The Value of Treatment for brain disorders in Europe
The example of acute stroke units
4. The need for a paradigm shift thanks to digital solutions

We stand together for the Brain

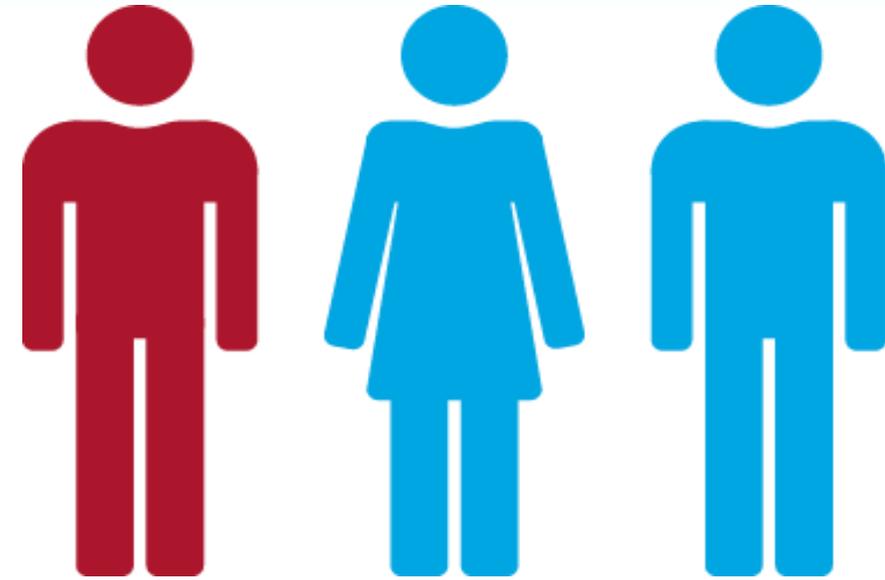


- National Brain Councils
- Industry partners

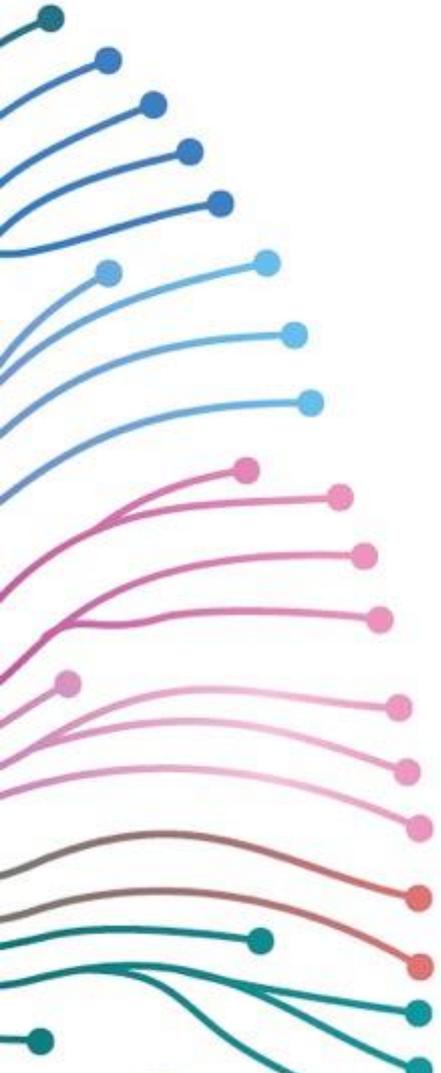
>1 in 3 Europeans is affected

EBC 2011 Cost Study:

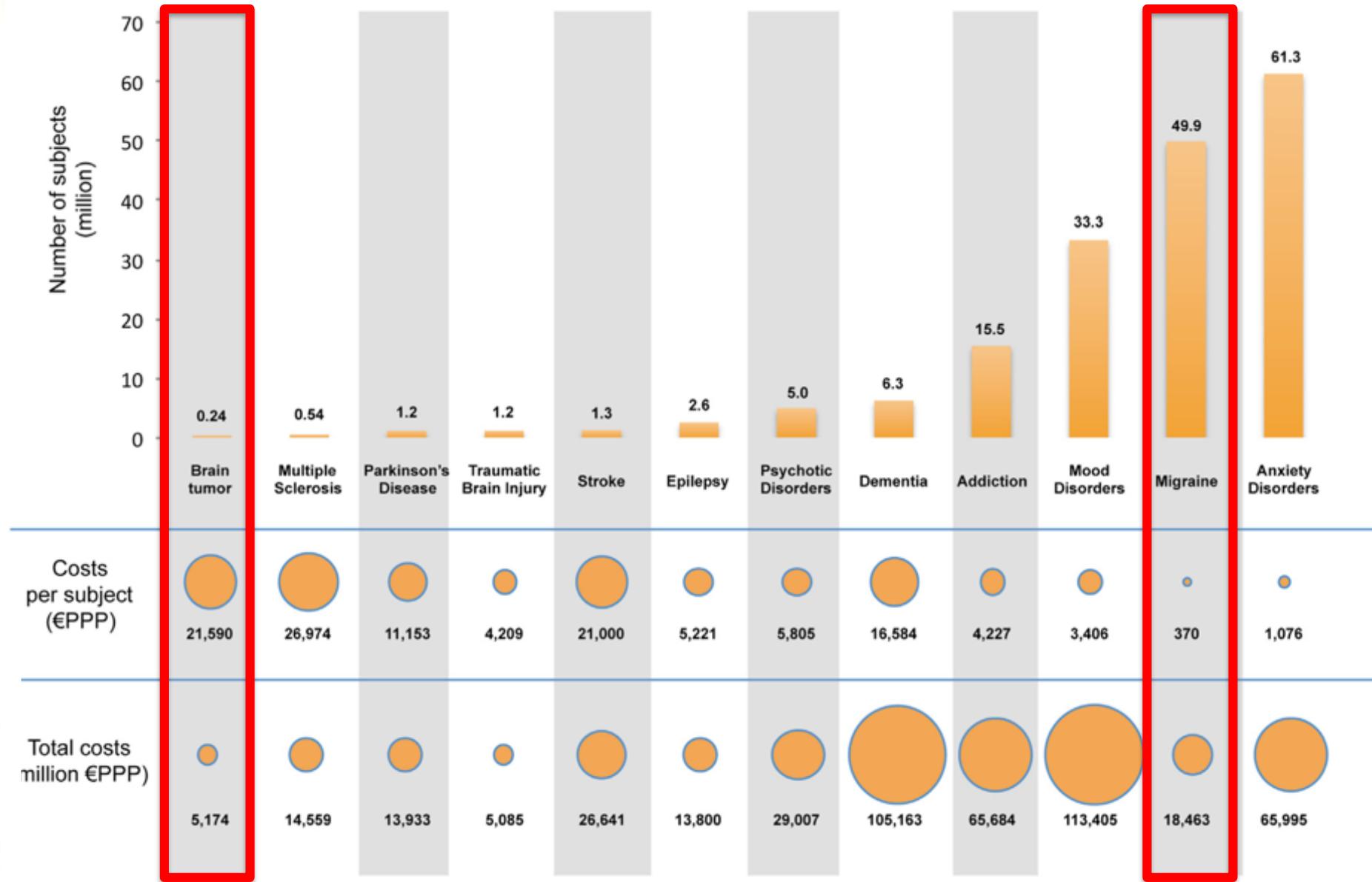
179 mlns citizens
in Europe (28+2)



€ 798 bln /year



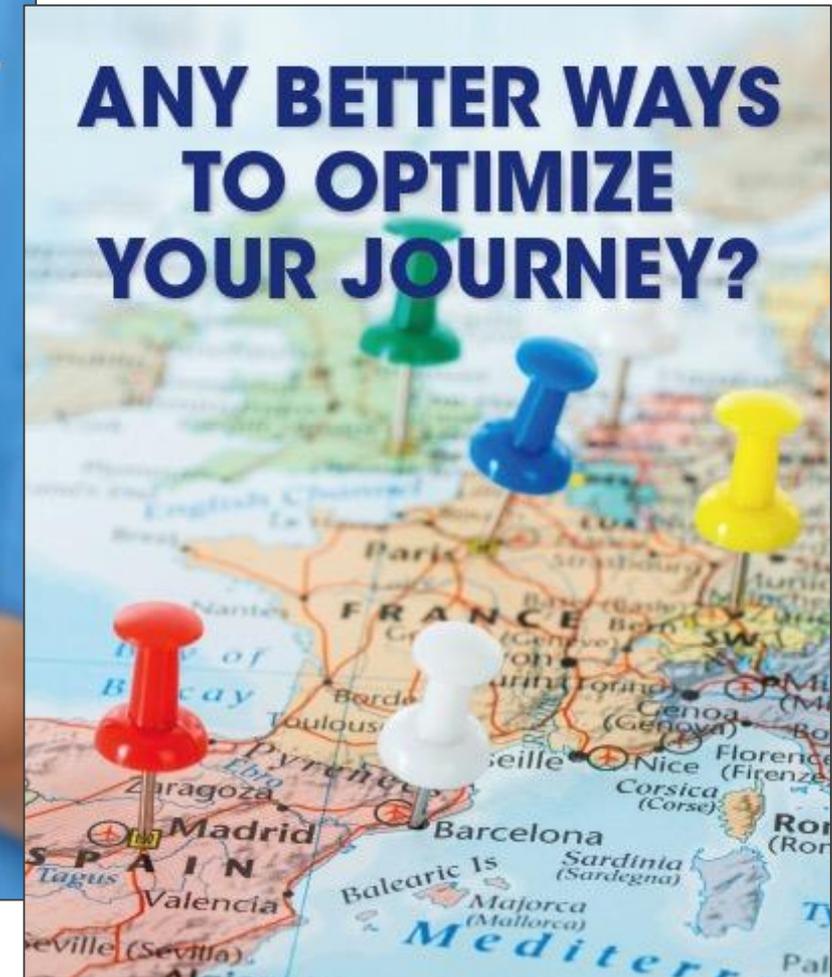
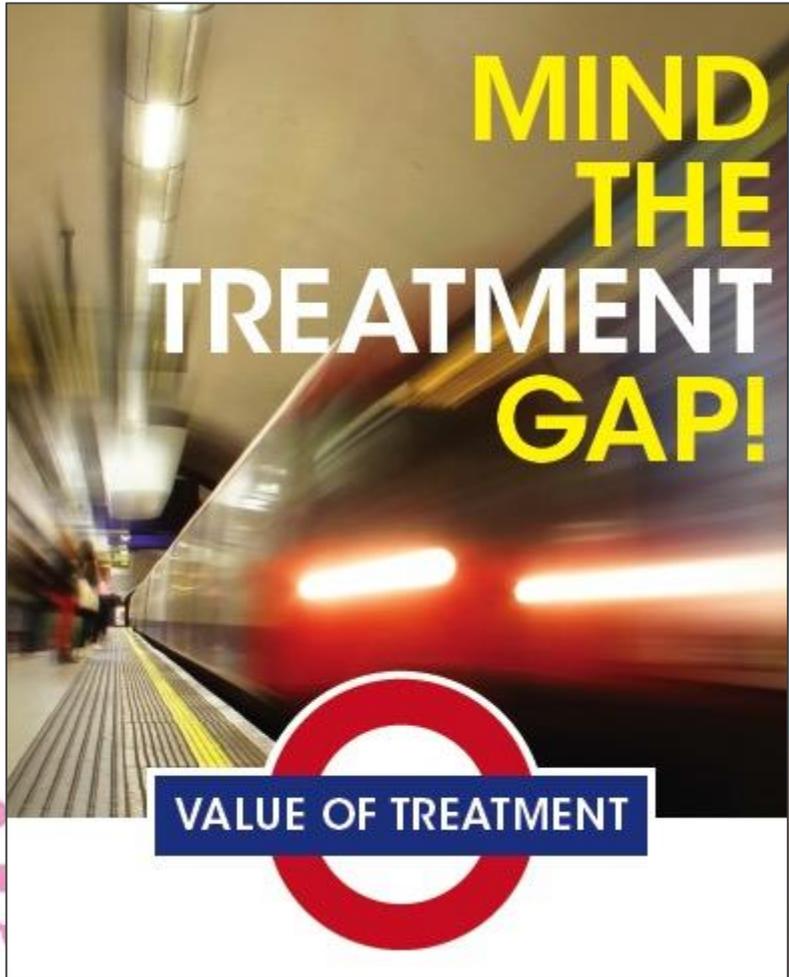
Uneven distribution of costs for each disorder



J. Olesen & M. Di Luca
Neuron 2014



Demonstrating the societal impact of the Brain



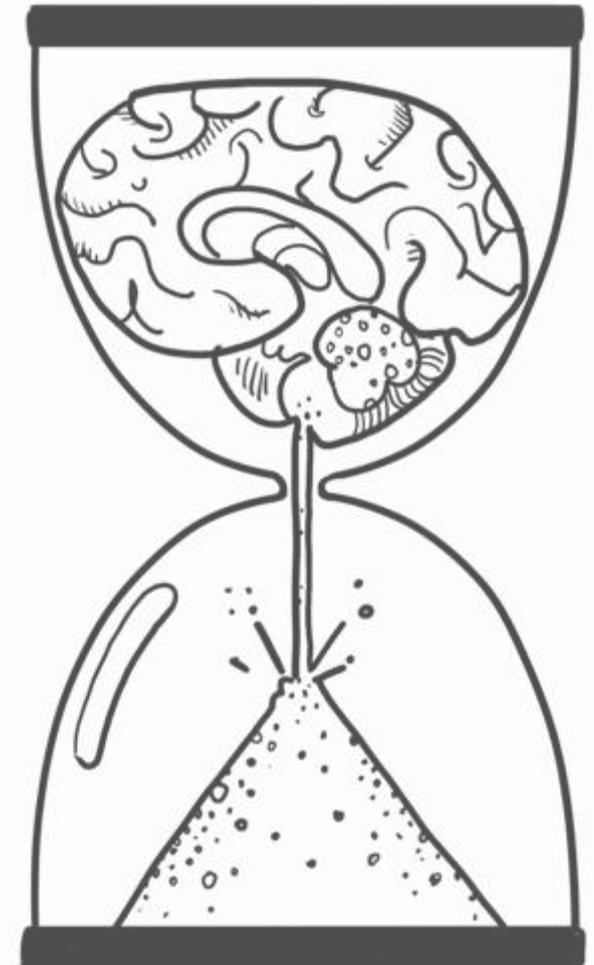
Gaps	Schizophrenia	Alzheimer's Disease	Headache	Stroke	Parkinson's Disease	Epilepsy	Multiple Sclerosis	Restless Legs Syndrome	Normal Pressure Hydrocephalus
Prevention 							Impact of modifiable lifestyle factors on MS Lifestyle factors prevention COST EFFECTIVE		
Screening 	Missed detection Early detection COST SAVING / COST EFFECTIVE								
Diagnosis/treatment 	Late intervention Early detection COST SAVING / COST EFFECTIVE	Late intervention / inadequate treatment Early intervention / adequate treatment COST EFFECTIVE	Lack of structured headache services and education Structured headache services and education COST EFFECTIVE	Lack of inpatient stroke unit In-patient stroke unit COST EFFECTIVE	Lack of early / timely treatment Lack of adequate treatment for advanced PD Lack of adherence to drug treatment Early / timely treatment COST EFFECTIVE Adequate treatment for advanced PD COST EFFECTIVE Adherence to drug treatment COST EFFECTIVE	Inadequate treatment & care Adequate treatment and care COST EFFECTIVE	Delays in treatment Early in treatment (DMTs) COST EFFECTIVE	Inadequate treatment (& Socio economic impact of RLS) Adequate treatment COST EFFECTIVE	Delayed and inadequate treatment Early and adequate treatment COST EFFECTIVE
Follow-up 				Lack of rehabilitation In-hospital rehabilitation COST EFFECTIVE					
(Case studies)									

Timely intervention is key!

Still no cure for most brain disorders, hence necessary to focus on:

- Risk reduction
- Timely intervention
- Prevention
- More research
- Address Stigma

Brain:
Time matters!



Stroke: the big picture



- 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 & improving care for ischemic stroke patients

The case for integrated Stroke Units



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

Recognize symptoms & call ems

Timely ems response

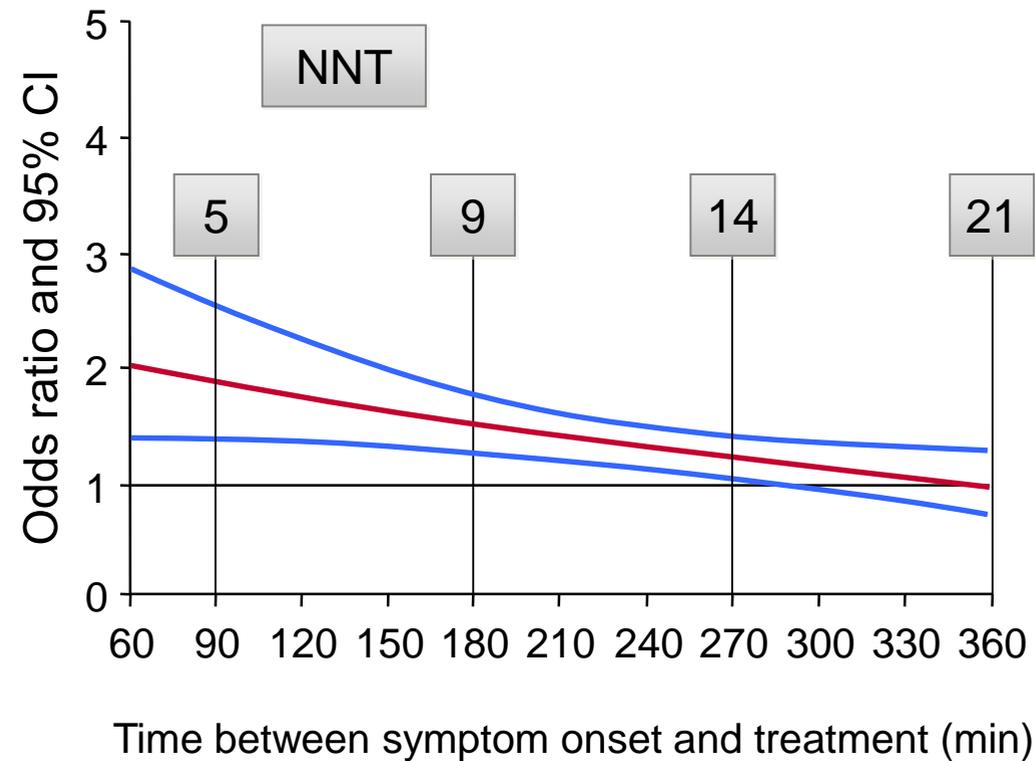
Transport & notify stroke center
guideline-based stroke care

Increasing survival rate
Improving patient QoL

Reducing the overall burden associated with stroke

Treatment gaps analysis: need for coordinated care

The successful example of stroke units



The need for an overall transformation of our healthcare systems

Promote a value-
based and patient
centred
research & care
for brain disorders



- **E-health** practices and solutions as the tools for integrated care and healthcare reform
- **New technologies, therapies and treatments** for brain disorders: translation into concrete outcomes accessible to patients



EBC

European Brain Council



A digital future for Brain Health?

Innovation Showcasing Session #1

Tallinn – 16.10.2017

Delivery system design

- Difficult access to primary and secondary care in some countries (even within regions)
- Delay in screening (late recognition of prodromal symptoms/early stage of disease) and diagnosis leading to late treatment
- Missed or inadequate diagnosis and treatment

Decision supports

- Lack of evidence-based guidelines
- Lack of educational materials/trainings among professionals at all levels of care (e.g. checklist for screening first symptoms)

Information systems

- No shared-clinical decision making
- No shared clinical records
- No disease registries

Self-management

- Lack of disease awareness and patient education
- Poor treatment adherence
- No patient empowerment
- Lack of information and support of family / caregivers

Macro health system governance

- Lack of prioritization, adequate budget and investment in health services delivery [diagnosis, therapy and care] and research
- Insufficient access to essential medical products and devices
- Lack of legislation and incentives (financial and human) for seamless care

VoT Identified Issues

Along The Care Pathway and Covering the Whole Life Course



Prevention



Screening



Diagnosis



Treatment



Follow-up & Rehabilitation

VoT Proposed Solutions

- Early detection and timely intervention are key
- Care/case manager with a clear referral and linkage system between primary care and secondary care
- Multidisciplinary teams
- Nurse-led clinics
- Follow-up by home visits
- Seamless and coordinated care: improving the patient flow (in-patient care or transmurals care)
- Continuous evaluation

- Implementation of evidence-based guidelines, protocols, care plans
- Harmonization of European postgraduate curriculum for psychiatry and neurology and distribution of quality educational materials among professionals

- Patient-centred care planning
- Shared clinical record and register of health/ social care service users
- Disease registries in place (public health surveillance)

- Patient education and empowerment to facilitate adherence/ compliance (e.g. electronic reminder systems)
- Patient biopsychosocial counselling and support
- Distribution of quality educational materials
- Use of mHealth and e-Health tools (**)

- At EU level, investing in basic&clinical research to better understand the heterogeneous causes of brain disorders (public-private partnerships) to improve treatment and primary or secondary prevention
- At national level, policy prioritization for brain disorders prevention and management: costs rationalization and optimization of healthcare processes and outcomes (seamless care). Cross-sectoral legislation (***) in place and incentives for more collaboration (human and financial) towards setting-up of care networks

Implementing digital technology for brain health

EBC believes policymakers need to prioritise action in a certain number of areas such as:

- health data sharing for research purposes [1]
- use of integrated health information systems (IT platforms) and potential of mobile interventions e.g. to reduce symptoms of mental disorders such as stress, depression and anxiety and need for further investigation [2]
- digital health literacy

[1] Marjanovic, S et al. (2017). Understanding value in health data ecosystems: a review of current evidence and ways forward. 1-40

[2] Rathbone, A et al. (2017). The use of mobile apps and SMS messaging as physical and mental health interventions: syst. Review. Journal of Medical Internet Research 19, e295



A few partnerships to support our endeavour



Impact at national level from 2018 onwards

- Outputs:**
- VoT national dissemination
 - Survey to National Brain Councils (NBCs)
 - Template for National Brain Plan (NBP)
 - Concept notes, series, policy papers
 - « Country mapping » countries health systems assessment (regulations, policies,...) and toolkit

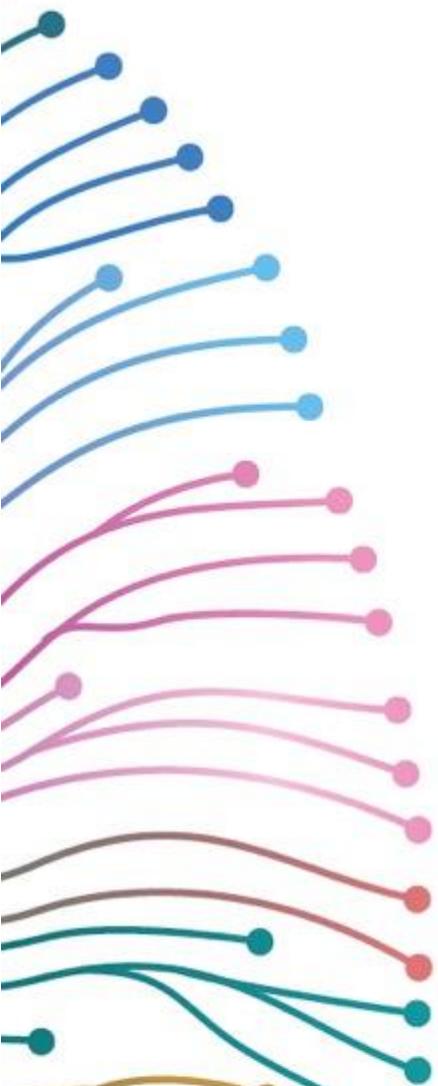
Timeline: 2018-2019



- National Brain Councils (NBCs) Academy meeting, Apr. 2018
- Roundtables, workshops with Policy Makers, Experts, KOLs,... throughout 2018

**National
Brain
Plan/Strategy**

- Priority topics:**
- 
- CNS drugs and innovation incl. review of treatment guidelines
 - VoT and organisation of care
 - E-health
 - HTA
 - Basic and clinical research, and translational research

- 
1. We need to transform our health & care systems to address the challenges posed by brain disorders
 2. Digital solutions hold the key to this shift
 3. This change must be done in a holistic fashion



THE EUROPEAN BRAIN COUNCIL PRESENTS

BRAIN MISSION

UNDERSTAND - FIX - ENHANCE

THE SPACE RACE OF THE 21ST CENTURY



European Brain Council

@EU_Brain

Abonné

We welcome the increased budget of [#HorizonEurope](#) but firmly believe the proposal's insufficient to address challenges, particularly for [#health](#). Join EBC in the call to revert the decline in [#health](#) [#research](#) funding & for a future without underfunded R&I: bit.ly/2usFbDj

Traduire le Tweet



15:42 - 16 juil. 2018

31 Retweets 41 J'aime



FENS Kavli Network, POLITICO Europe, Guardian Science et 7 autres



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