



EBC RESEARCH PROJECT

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## THE **VALUE OF TREATMENT** FOR BRAIN DISORDERS

*"Exploring the potential for a holistic care model for brain disorders  
to close the treatment gap in Europe: development of  
a workable care model and case studies analysis"*

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DISCUSSION PAPER - JANUARY 2016

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The European Brain Council (EBC) is a non-profit organisation gathering patient associations, major brain-related societies as well as industries. Established in March 2002, its mission is to improve the lives of those living with brain disorders by advancing the understanding of the healthy and diseased brain through bringing together science and society.

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BACKGROUND AND AKNOWLEDGEMENTS

The Discussion Paper on “*Exploring the potential for a holistic care model for brain disorders to close the treatment gap in Europe: development of a workable care model and case studies analysis*” is the result of a review of international literature & rapid appraisal supported by an EBC Experts Workshop which took place on 8 January 2016 (with case studies presentation related to multiple sclerosis, stroke, normal pressure hydrocephalus, mental illness co-morbidities, schizophrenia, Parkinson’s disease, restless legs syndrome, epilepsy, headache disorders, dementia).

The release of this Discussion Paper is ending the first phase of the EBC Value of Treatment 2015-2017 project, objectives of the overall project being: 1) develop a workable model of care for brain disorders with template for case studies analysis and methodological framework (theoretical approach around integrated/seamless care); 2) demonstrate through case studies what are (cost)-effective interventions (clinical practice) and conduct cost effectiveness analysis based on components of care model and use of calculation model to assess costs and outcomes; and 3) based on economic evidence, provide policy recommendations (policy development and multi-stakeholder engagement).

The purpose of this Discussion Paper is twofold:

- 1) To set the scene, capture issues and challenges related to current context (brain disorders and burden of diseases), rationale (value of treatment, paradigm shift from re-organisation of care towards coordinated care), proposed and structured care model framework to be adapted to brain disorders needs and to country healthcare systems specificities for further case studies analysis;
- 2) To generate a collective thinking on the concepts and evidence highlighted so far in this discussion paper, confront (test) hypotheses and examine options for optimal patient-centred care strategies to close the treatment gap.

The European Brain Council would like to thank sincerely its Academic Partners, Experts and Patients Associations’ Representatives for their constructive insights during the consultation process, specifically: Panos Kanavos (LSE), Martin Knapp (LSE), Michela Tinelli (LSE), Nick Guldemon (University medical Centre Utrecht), Steve Bazire (The College of Mental Health Pharmacy), Nicola Bedlington (European Patient’s Forum), Guy Dargent (Consumers, Health, Agriculture and Food Executive Agency, European Commission), Gianni Franco (Belgian Brain Council), Matilde Leonardi (Istituto Neurologico Carlo Besta) and Altinal Satylganova (WHO Regional Office for Europe)

## FOREWORD

Unprecedented innovation in technology and medical processes is rapidly revolutionising human life. Current health systems, however, have **not been able to adapt quickly enough to meet the needs of patients**. This is **particularly true for brain disorders, and particularly challenging for policy makers**.

Value-based healthcare is currently gaining traction in Europe **as the desired solution or path forward in improving health systems. This holistic approach** towards coordinated, integrated care models critically intertwines **wider patient and societal** outcomes with spending and in doing so could lead to both a **more sustainable framework for payers and improved care for patients**.

The European Brain Council (EBC) is carrying out a **new Study for 2015-2017** on the *"Value of Treatment: Exploring the potential for a holistic care model for brain disorders to close the treatment gap in Europe"*. This research project is building on the *EBC Report "The Economic Cost of Brain Disorders in Europe"* published in 2005 (Balak and Elmaci 2007) and updated in 2010 (Gustavsson et al. 2011) that provided a **solid estimation on the economic costs of brain disorders in Europe**.

With this new **"Cost Study"**, EBC will not only be **looking into the socio-economic impact and value of healthcare interventions**, but will also be able to **determine how timely treatment pathways are likely to need greater integration and how better collaboration can be set up in the future for the benefit of those living with a brain disorder**.

**Why an integrated care model?** In joint initiatives promoted by the European Commission such as in the area of cancer (e.g. the European Partnership Against Cancer and the development of care management guidelines, the Integrated Care for Breast Cancer Initiative), it has proved essential **to put scientific evidence into care standards, and to use case studies to make available evidence-based diagnostics and treatment guidelines as well as quality assurance norms covering all stages and aspects of care**. This leads us to the **integrated, coordinated care approach** with an expectation that it might support the achievement of the so-called **"Triple Aim"** in the respect of patient's needs: a simultaneous focus on **improving health outcomes, enhancing the quality of care and increasing cost-efficiency**. In order to realise this aim, the European Commission and the WHO are calling on policy makers to **initiate a process of reorganisation of care delivery, with the following priorities**: access to care, sustainability of healthcare system and cost efficiency interventions (human workforce, technologies including the potential of digital health,...).

We are at a **pivotal time of change**; our new Study couldn't be more opportune **in exploring the beginnings of a European paradigm shift toward a value-based model of healthcare for brain disorders**.

With the Project Kick Off taking place on 27 January 2016, **the case studies Working Groups** on specific mental and neurological disorders will provide a **platform for continued discussions around the opportunities patient-centric coordinated care models promise, potential solutions and challenges**.

This EBC Study is a **starting point**, we won't have all the solutions in once. However through building up evidence, EBC will provide the necessary policy recommendations to **address the treatment gap and its consequences**.

David NUTT  
President of EBC

## EXECUTIVE SUMMARY

Brain Disorders, including both mental and neurological disorders, represent **an enormous burden on both individuals and societies**. The **broad impact of brain disorders**, which in the future is likely to be even greater, is threatening the quality of life of millions of European citizens **with important consequences on the sustainability of health systems and implications for potential achievement of the Europe 2020 strategy on economic growth**.

To compound this public health major issue and beside brain disorders escalating costs, **many individuals with brain disorders remain untreated although effective treatments exist**.

The current healthcare system does not fully respond to the **needs of patients** living with brain disorders. **The current healthcare system, fragmented and essentially reactive** - responding mainly when a person is sick - has many **deficiencies** in the management of patients with brain disorders who need **a long-term care and treatment. The reorganisation of care delivery requires a paradigm shift and the adoption of three intertwined principles**, namely: **patient-centric integrated care, improved hospital efficiency, and interventions in an optimal settings, either in hospitals, at home or in communities**.

A **patient-centric coordinated care model** (combining effective team care and planned dynamic interactions with the patients, and considering the whole spectrum and continuum of care from early detection, diagnosis to care, treatment, rehabilitation) is seen as an interesting **solution** to overcome the deficiencies of the current model of care. **To translate this paradigm shift into concrete outcomes**, a certain number of **effective initiatives at country level** (in-hospital patient journeys, intra-extra muros care pathways, multidisciplinary care models based on the bio-psycho-social approach,...) have already been implemented with **promising health outcomes**. However, evidence on cost-effectiveness and sustainability is still lacking but increasingly researched.

This has been capitalized by the European Commission with the **"Investing in Health" 2013** policy framework linking health and social policy. Recent EU initiatives looking into greater integration were also put in place as cooperative efforts for better health in the areas of cancer, ageing, mental health and well-being, chronic diseases, digital health, innovation and research (Horizon 2020).

**More research evidence definitely appears to be necessary.** In this context, the **EBC Project on the Value of Treatment for Brain Disorders** will explore through case studies analysis the **potential for innovative patient-centric coordinated care models, generating evidence on the socioeconomic benefits of healthcare interventions, and assessing optimal options and strategies to close the treatment gap in Europe.**

A comprehensive **evaluation of treatment gaps and best practices** available will be conducted in selected EU countries, in order to identify commonalities and differences between various brain diseases **towards building an overarching holistic framework based on integrated care principles and economic analysis. A model of care will then be adopted based on well-defined indicators (government, clinical practice, patients) for further policy recommendations.**

**The concept of integrated care is to be seen as a process**, essential prior to a coordinated plan development and implementation by health authorities at national and decentralized levels, **to complement necessary quality assurance norms.**

## 1. INTRODUCTION

**Mental and neurological disorders, both comprehensively referred to "disorders of the brain"**<sup>1</sup> represent an enormous disease burden, in terms of human suffering and economic costs.

European countries have faced major gains in population health in past decades, resulting in an **increased life expectancy** coupled with major scientific breakthroughs in medicine and significantly improved chances of surviving diseases: for example, mortality rates relating to **stroke** have sharply decreased<sup>2</sup>. Notably, **there is a transition from 'acute patients' to 'chronic patients'**<sup>3</sup>. **Pressure** on health and social systems is therefore building up and is expected to further **increase** due to demographic changes and, particularly, the growing share of older people, high cost of technological progress and the rising burden of chronic diseases<sup>4</sup>. **Many brain disorders are chronic and incurable conditions** whose disabling effects may continue for years or even decades and requiring an ongoing management<sup>5</sup>.

Today, budgetary restrictions are challenging **the sustainability of the European social welfare model, as a whole, and making cost-effectiveness of health systems and its deliverables increasingly necessary**. In fact, the sizeable share of public money that is devoted to health and the ever-increasing cost pressures and demands to cut public expenditure, put health systems at the heart of the policy debate<sup>6</sup>. In particular, **chronic conditions sheer range, the multiplicity of determining factors** (health, socio-economic, genetic, environmental and behavioural), **the long-term nature of care and treatment** have all served to confound hospital traditional, fragmented and top-down led responses<sup>7</sup>.

These developments are calling **for organisational hospital and delivery systems changes**. According to WHO: "There is a widespread recognition that health care systems need to change to respond to the **long term trends in demography and epidemiology** as well as adapt to **changes in medical processes and technology that require very different delivery models from those currently in use**. In most of the European region the short term impact of the financial crisis and the long term challenge of rising costs and shaky funding streams give the need for change even greater urgency while at the same time limiting the options that are available to policy makers"<sup>8</sup>.

This leads us to the **"integrated, coordinated care" approach** with an expectation that it might support the achievement of the so-called **"Triple Aim"** in the respect of patient's **needs**: a simultaneous focus on **improving health outcomes, enhancing the quality of care and increasing cost-efficiency**<sup>10</sup>. In order to realise such aim, literature review suggests to **initiate a process of reorganisation of care, with the following priorities**: 1) access to care, 2) sustainability of healthcare system and 3) cost efficiency interventions (human workforce, technologies including the potential of digital health,...)<sup>11</sup>.



Therefore, the **following questions are raised to examine options and optimal strategies** to improve patients' quality of life and reduce the socio-economic burden of mental and neurological disorders: *could the approach of integrated care for brain disorders (e.g. comprehensive mental and somatic healthcare models, seamless care models to service the elderly, care pathways promoting the bio-psychosocial approach) 1) be considered as a response to the fragmented delivery of health and social services? 2) be considered as a relevant solution to close the diagnosis and treatment gap as well as improve the accessibility to care? Are interventions based on the components of the integrated care model cost-effective? Which quality strategies – complemented by and integrated with existent strategic initiatives – would have the greatest impact on the outcomes delivered by health systems?*

To address these questions, we need a comprehensive **evaluation of the existing literature and best practices available**, in order to **identify** the commonalities and differences between various brain diseases in an **overarching holistic framework based on integrated care principles and economic analysis**.

International literature commonly emphasizes that there is a need for a **thoughtful, multidisciplinary, holistic (patient, family and carers), bio-psychosocial approach to the practical implementation of a coordinated system based on patient-centred and continuous care**. In such a system, health promotion, disease prevention, detection and early diagnosis, treatment, rehabilitation, research as well as healthcare and social care are seen as one **continuous link of actions** across different healthcare professionals and areas (e.g. hospitals, psychiatric hospitals, specialist care, primary care, homecare, institutional care or nursing home, social care, pharmacies), **in order to deliver patient care and improve health outcomes**<sup>12</sup>. As the potential for integration are being explored –and case studies analysis will be the opportunity to value healthcare interventions (in comparison with the cost-burden of delayed, inadequate or non-treatment) and to come up with ideal approach around the integrated care concept, **solid evidence** needs to be built to assess and support the best option **for further policy development**.

In the following section, we elaborate on **brain disorders and burden of disease, reflecting on future challenges** and suggest **possible steps** towards the development of a workable coordinated care model.

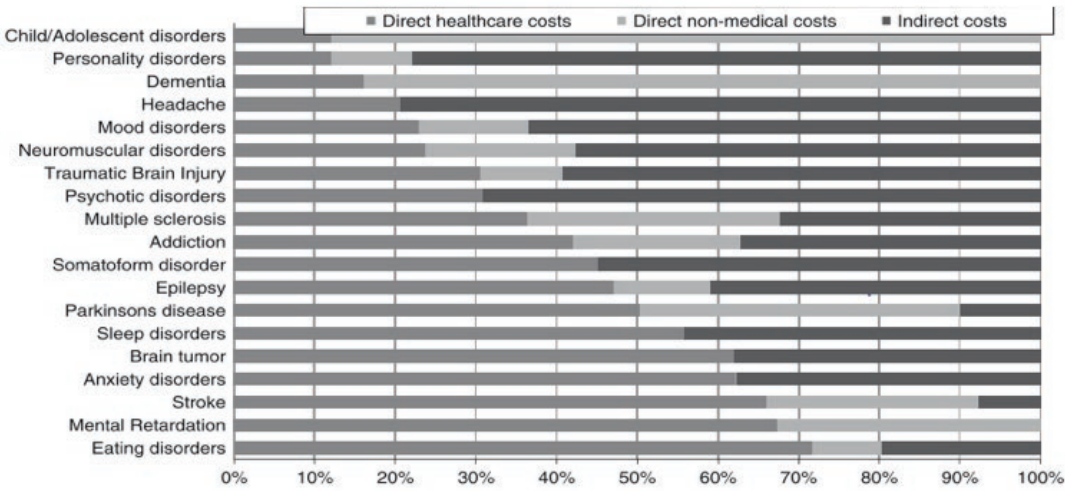
## 2. SETTING THE SCENE

### ■ 2.1. CONTEXT: BRAIN DISORDERS AND BURDEN OF DISEASE

In recent years, there has been a **growing awareness of the importance of brain disorders**<sup>13</sup>. Conditions such as depression, stroke, dementia, schizophrenia or anxiety will affect at least **one in three** European citizens during their lifetime – currently **165 million people in Europe**<sup>14</sup>. The profiles of these diseases raise particular challenges: lack of physical and visible symptoms, complex biological factors, and sometimes a lack of understanding of their cause(s)<sup>15</sup>.

Brain disorders are **not only highly prevalent medical conditions, they are also highly disabling**: today, mental disorders and other brain disorders **represent 26,6% of the burden of all diseases in Europe**<sup>16</sup> but also represent many **chronic conditions**<sup>17</sup>. **Major depression** is among the **top three causes** in the burden of disability in each EU-Member State<sup>18</sup>. The **consequences** extend **well beyond the healthcare system** from the loss of healthy life years and quality of life, to burdens on health and social welfare systems and implications for labour markets (loss of productivity, absenteeism, and early retirement). **The total cost of brain diseases** both in terms of financial and human resources (see table 1) is estimated to account for up to **€800 billion every year** in Europe, with an average cost per inhabitant of €5.550<sup>19</sup>. This cost far exceeds that of cardiovascular diseases, cancer and diabetes combined<sup>20</sup>. What is more, given that the elderly represent the largest portion of recipients of health and long-term care, the prevalence of brain disorders, and its related burden, is expected to increase even more<sup>21</sup> as the EU population ages. All this combined will put hard pressure on national healthcare and social welfare systems, which will need to be adapted in order to provide adequate care and remain financially sustainable<sup>22</sup>.

Table 1: Distribution of costs by disorder (EBC Cost of Brain Disorders in Europe Study, 2010)



Recent analyses demonstrate that, beside brain disorders' escalating costs, there is a **considerable gap in terms of diagnosis and treatment ("unmet needs")**. This is particularly blatant for mental illnesses in Europe, with only **about a third of all cases** receiving the therapy or medication needed (ranging from alcohol abuse and dependence with the widest treatment gap to schizophrenia)<sup>23</sup>. There are also no consistent indications of improvements with regard to delayed diagnosis and treatment provisions and grossly inadequate treatment, **with considerable differences in the treatment gap within and between countries** (health inequalities)<sup>24</sup>.

As **health budgets**, particularly those related to **prevention and health promotion**, have been dramatically cut during the past few years, particularly in South and South Eastern Europe<sup>25</sup>, institutions such as the European Commission, WHO, and OECD examined the impact of the crisis and reduced budgets on health outcomes and health systems in Europe in order to develop adequate frameworks for action<sup>26</sup>. Findings of such studies include, for example, a **correlation** between rises in unemployment and debt, and **significant short-term increases in mental health disorders such as depression and suicide**<sup>27</sup>. Moreover, it is likely that there will be negative effects on health in the longer term, particularly if the number of long-term unemployed people continues to increase, if social safety nets experience further cutbacks, and if there are changes in access to much needed healthcare and services<sup>28</sup>. In this respect, the WHO pointed out that "health systems and public health in general are not a drain on resources but an investment in health and wealth – that is in the health of the population and in economic growth"<sup>29</sup>.

This was further developed by the European Commission with the **"Investing in Health" 2013 policy framework<sup>30</sup> linking health and social policy**. Many initiatives looking into more integration were put in place as cooperative efforts for better health in the area of ageing, cancer, mental health and well-being, innovation and research (Horizon 2020). As an example of "health and social care become one", the "Smart Care" project<sup>31</sup> under the Digital Agenda for Europe, a Europe 2020 Initiative published a White Paper in July 2015 on Pathways for integrated eCare<sup>32</sup>. The project aims to define a common set of standard functional specifications for an open ICT platform enabling the delivery of integrated care to older European citizens.

## ■ 2.2. CHALLENGES DESERVING SPECIAL ATTENTION FOR THE FUTURE

**E-health practices and solutions** are powerful tools for integrated care and healthcare reform. Many EU countries, in the development of telemedicine, e-prescribing, e-referral and e-reimbursement capabilities, are making progress towards modern e-health infrastructures and implementations. Challenges remain to achieve wider implementation at country level and the implementation of a coherent EU approach for overall coordination. Large-scale deployment will occur once the pilot phases of current research projects end<sup>33</sup>. Commitment and leadership by health authorities, on issues related to finance and organisation, are essential elements for the successful deployment of e-health services in order to

improve the way healthcare is provided. **It needs to be combined with organisational changes and the development of new user skills<sup>34</sup>**. The EU supports various projects in the field of eHealth, and to ensure that policy making stays informed by the latest developments and information such as the Europe 2020 Initiative on Digital Agenda for Europe<sup>35</sup>. With the help of ICT, care can be offered in an integrated way; no longer in an institution, but in the own home environment.

**New treatments and technologies** are needed for a number of diseases including brain disorders. Various new technologies, therapies and treatments are emerging, including gene and cell therapy, regenerative medicine, the development of nanomedicines and medical technology (medical devices, assistive devices such as implantable brain stimulators e.g. for Parkinson's disease). These advanced therapies herald revolutionary treatments of a number of diseases such as neurological disorders – and therefore have a huge potential for patients as well as research and development, and industry.

In addition, **sustained work integration** for people with a severe mental illness (e.g. schizophrenia) is an important issue in the society today. Indeed, work is not only an essential factor in people's social integration but is also a stepping-stone towards recovery, it is also essential for the informal care giver. Health promotion in the workplace, as well as well-defined programs and services related to work integration are being developed and implemented<sup>36</sup>. The awareness of the impact of the workplace environment on the work integration of people with a severe mental illness increases the need to find solutions and develop environmentally sensitive clinical strategies to overcome during the work integration.

## ■ 2.3. RATIONALE: BRAIN DISORDERS AS CHRONIC CONDITIONS FROM COORDINATED CARE TO BUILDING A CONCEPTUAL FRAMEWORK

**Chronic diseases including brain disorders and long term conditions** can represent up to 70-80% of a country's total health expenditure<sup>37</sup>.

According to the OECD, among the biggest drivers of healthcare costs are the priorities that have governed the healthcare systems in their management and their financing since their inception, and which are proving resistant to change. European countries share a common problem, which is the lack of preventive care and inadequate coordination of care between health and social services. Based on past legacy healthcare structures, both the financing and delivery of healthcare remain highly fragmented, and oriented to providing acute, rather than chronic, care to face more intractable medical conditions than in the past such as chronic diseases. Many local communities retain their own full-service hospitals, resulting in system-wide duplication, medical education is oriented around hospitals. Payment systems are oriented around particular interventions and biomedical research is still based on the assumption that people have single diseases at a time, but already the biggest challenge is multiple

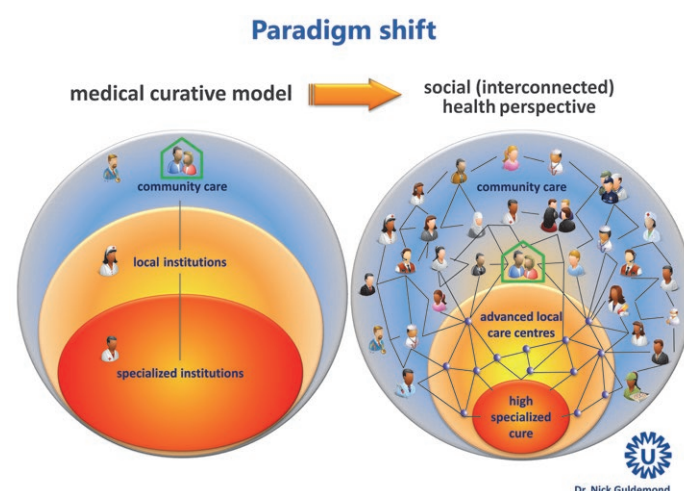


morbidities. These require a more **longitudinal or multidisciplinary network approach linking health and social care** (see figure 1: paradigm shift) and payment systems that can cope with care provided in more than one setting<sup>38</sup>.

In some cases, better health outcomes and reduced costs are associated with shifting certain types of care from hospitals to step-down, rehabilitation, and community care.

The concept of integrated care seems particularly important **to service provision to the elderly, as elderly patients are likely to be chronically ill and subjects to co-morbidities, and therefore in special need of continuous care**<sup>39</sup>. Almost half of all people with chronic illness have multiple conditions<sup>40</sup>. Prevalence of co-morbidity increases with age but is not just an issue for older adults<sup>41</sup>.

Figure 1: Paradigm shift

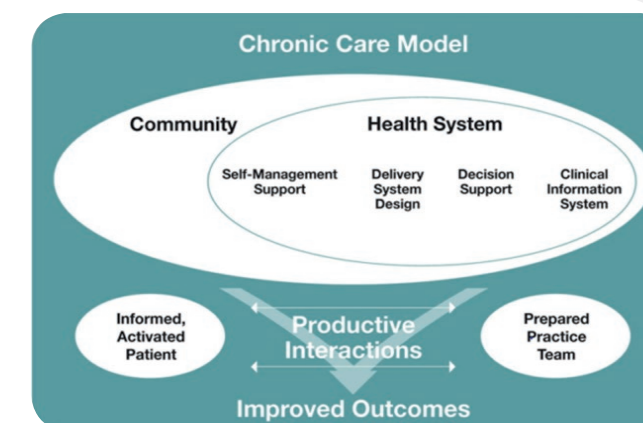


From an international perspective, **the paradigm shift** is leading to the **transformation of health care** and illustrates one or perhaps **the most applied strategy for improving the quality of care** for people with chronic conditions such as many brain disorders which is the **integrated Chronic Care Model**<sup>42</sup>.

The aim of the **Chronic Care Model** (see figure 2) is to meet **patient's needs** and transform **the daily care for patients** with chronic illnesses from a system that is essentially **reactive** - responding mainly when a person is sick - to one that is **proactive and focused on patient-oriented care**. It is designed to accomplish these goals through a **combination of effective team care and planned interactions with the patients; self-management support; patient registries and other supportive information technology such as digital solutions allowing better exchange of information**. These elements are designed to work together to strengthen the health care providers-patient relationship and improve health outcomes<sup>43</sup>.

This care model (with a possible expanded focus on prevention and social environment) could be of **particular interest for the management of mental and neurological disorders as it can be applied to a variety of chronic conditions, health care settings and target populations**. The Chronic Care Model identifies the essential elements of a health care system that encourage high-quality care. These elements are: **(1) community, (2) health system, (3) self-management support, (4) delivery system design, (5) decision support and (6) clinical information systems**. Evidence-based change concepts under each element, in combination, foster productive interactions between informed patients who take an active part in their care and providers with resources and expertise. The Chronic Care Model, summarizes the basic elements for improving care in health systems at the community, organization, practice and patient levels<sup>44</sup>.

Figure 2: Chronic Care Model



All across Europe, various forms of provider networks and interventions have been set up for instance **to close the gap between primary and hospital services or in advanced practice nurses (APNs), ...**

### 2.3.1 TRANSFORMATION OF HEALTH CARE AND "PARADIGM SHIFT": PATIENT-CENTRED CARE

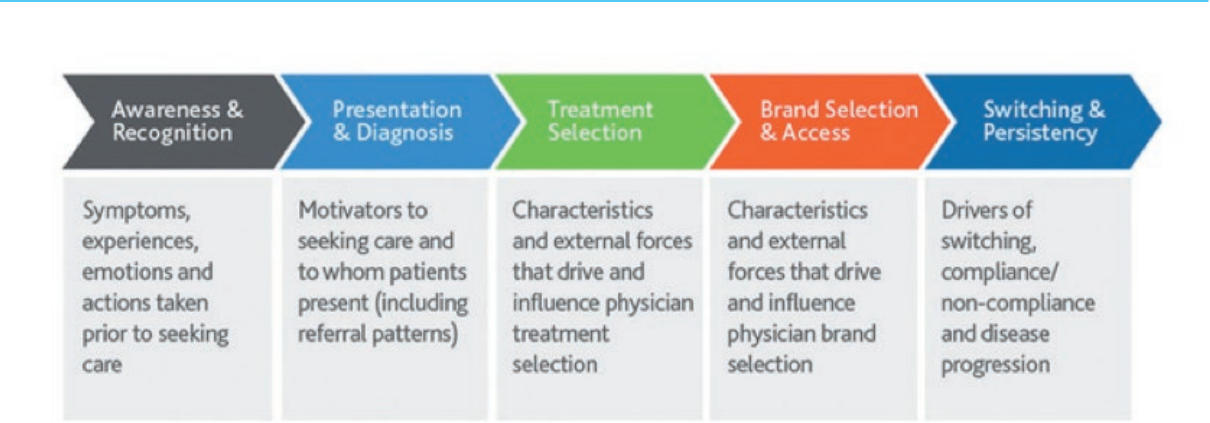
**Another important concept for the organisation of care is emerging with the principle of "patient-centred care"**: a person living with one or more chronic condition(s), including brain disorder(s), has needs that evolve according to the stage of his/her disease(s)<sup>45</sup>. For instance, home care services play a major role most of the time but acute services are necessary **in case of acute episodes whereas end-stage diseases call for accessible palliative care**. **The needs of the patient with long-term disease may be grouped along four main dimensions**<sup>46</sup>: **biological** needs (mainly the relief of the physical symptoms, as pain), **psychological** needs (need for tailored information e.g. on treatment options, evolution of the disease; and need for psychological support to deal with emotions such as fear, frustration, depression, distress)

related to chronic condition), **health care services** needs (coordination of care provision and integration between the different settings), and **social** needs: can be a major concern for chronic patients with mental and neurological disorders, in particular issues in relation to their autonomy and social isolation.

Efforts to **empower patients** to be engaged in responding to their health needs **may improve health outcomes, adherence to treatment**, and has the potential for patients **to make more informed decisions** with regard to their health<sup>47</sup>. Research shows that adherence among patients suffering from chronic conditions is only 50% on average<sup>48</sup>.

To ensure that health care is **centred on patients**, the **patient journey approach** aims at giving patients a “voice” through enhancing collaborative multidisciplinary teamwork, shared ownership and decision-making, providing evidence to substantiate change, and achieving results (see figure 3)<sup>49</sup>.

Figure 3: Patient journey phases

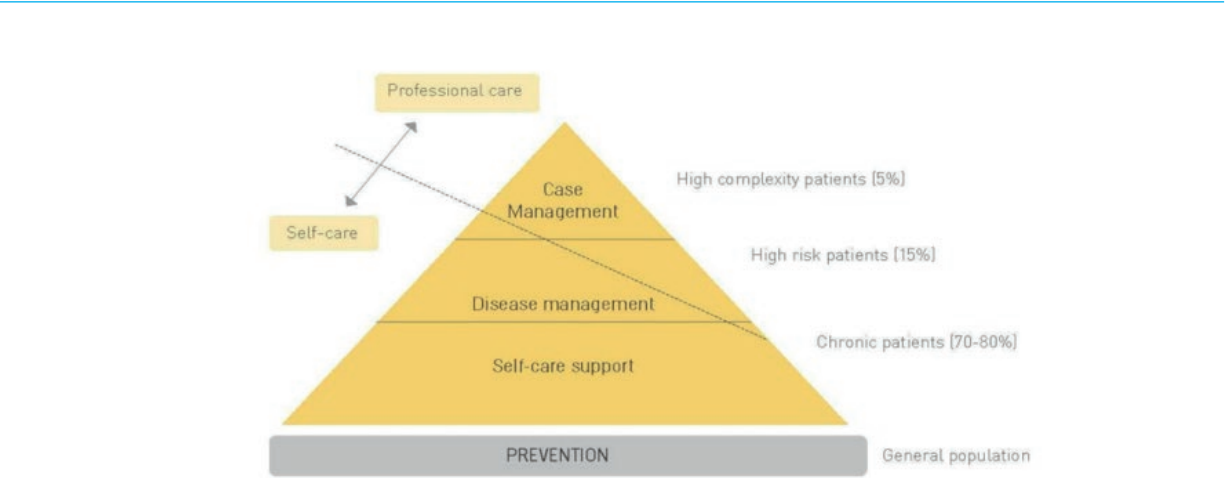


Nowadays, mental and neurological disorders are **diagnosed reliably and accurately**. Whilst **all can be successfully managed and treated, some disorders can even be prevented**<sup>50</sup>. As of today, there is currently no cure for Alzheimer’s disease, neither for schizophrenia, epilepsy or other brain disorders. In the case of schizophrenia for instance which is one of the most severe and disabling mental illnesses, the treatment success rate with antipsychotic medications and psycho-social therapies can be high<sup>51</sup>. The **treatment gap** including delayed diagnosis and treatment **applies for all brain disorders**, particularly for mental illness, **and it is a major issue**.

**Reducing the burden of mental and neurological disorders relies on both timely diagnosis and treatment of disorders** by health professionals through **pharmacological, non-pharmacological and psychosocial interventions**. In the meantime, the complex basis of these conditions (including co-morbidities) requires constantly assessing the situation and the level of risk for a patient (see figure 4), which may vary according to the severity of the pathology. Case management<sup>52</sup> by a healthcare provider being responsible for the assessment of

**need and implementation of care plans** may be an additional support to coordinate medical care, paramedical care and well being. It is usually required for individuals who have a **serious and persistent mental illness or severe neurodegenerative disease and need ongoing support** in areas such as housing, employment, social relationships, and community participation (e.g. patients with a major psychotic disorder or with a severe neurological condition, such as Parkinson’s disease).

Figure 4: Kaiser Permanent risk stratification pyramid



The reorganisation of care delivery requires a **paradigm shift** and the adoption of three intertwined principles, namely: **patient-centric care, improved hospital efficiency, and interventions in an optimal settings, either in hospitals, at home or in communities**. All these developments underpin the need to address **the integration between the different healthcare providers and the different settings**.

2.3.2 INTEGRATED, COORDINATED CARE CHALLENGES

Though **strategies to achieve better integration** may differ, the principal driving forces behind the system reform are similar in many countries. The strongest impetus for transforming care delivery processes is driven by:

- The rapidly increasing demand for chronic care for patients with mental illness or neurological disorder being exacerbated by the rising health care costs calls for the integration of services.
- On the supply side, the development of medical technology and information systems and the restrictions from economic pressures (such as shortening hospitals length of stay and the need to avoid unnecessary readmissions) call for reforms to contain costs. Whereas demand-side factors mainly force the integration of services, supply-side factors such as medical technology and information systems may facilitate it<sup>53</sup>.



There is consensus that new ways are required for delivering high quality healthcare, involving **integration** (in contrast with fragmentation) of care providers (e.g. specialists, general practitioners and other healthcare providers such as pharmacists, nurses, psychologists, physiotherapists) and much **closer coordination** (multidisciplinary care) of their activities across levels of care and multiple sites, all of which need to be optimally embedded within a system that promotes **patient empowerment**<sup>54</sup>.

Integrated care, disease management or care pathway for pathologies such as diabetes, heart disease, depression, schizophrenia and others can be characterized by the following key elements<sup>55</sup>:

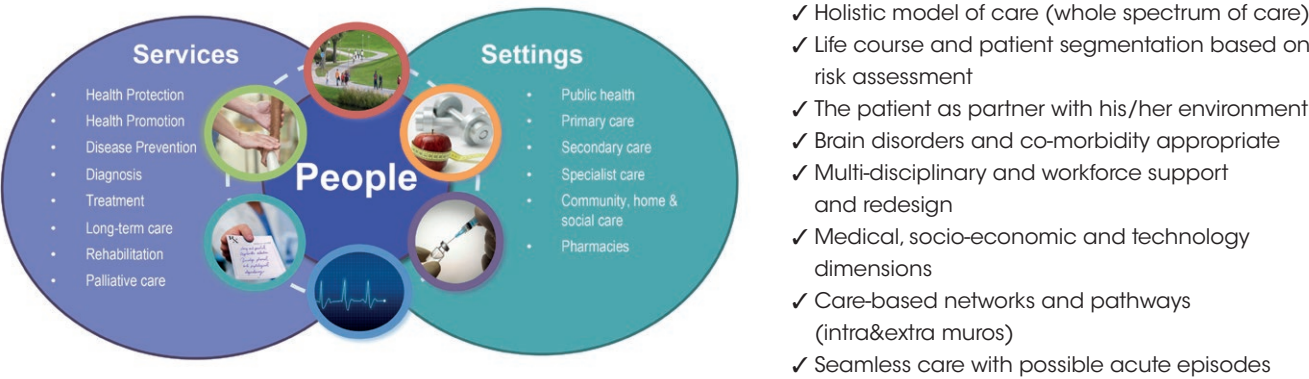
- Comprehensive care: multidisciplinary care for entire disease cycle;
- Integrated care, care continuum, coordination of the different components;
- Population orientation (defined by a specific condition);
- Active client-patient management tools (health education, empowerment, self-care);
- Evidence-based guidelines, protocols, care pathways;
- Information technology, system solutions; and
- Continuous quality improvement.

Disease management has traditionally targeted a **single disease or condition** but **what makes chronic conditions management complex including brain disorders** is that **co-morbidity** is increasingly recognized as a critical clinical issue in medical care, in part because it is an independent predictor of adverse outcomes, including quality of life (QOL), mortality, healthcare, disability, and complications of treatment beyond the effects of the individual conditions.

2.3.3 PROPOSED OPTIMAL FRAMEWORK: A HOLISTIC CARE MODEL FOR MENTAL AND NEUROLOGICAL DISORDERS

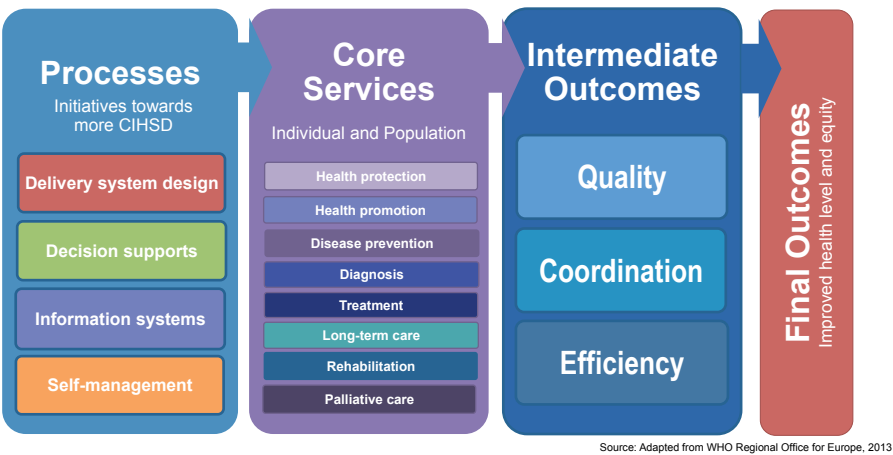
The Framework for Action towards integrated Health Services Delivery (FFA IHSD)<sup>56</sup> as defined by WHO Regional Office for Europe (2013) is proposed as a generic framework for coordinating care interventions. This model is currently being implemented by European Member States as part of the framework for action. This framework –adapted to consider the **full spectrum of care**– aims to ensure the delivery of these services, **across settings of care by removing gaps** in care or poor coordination that adversely affects care and, ultimately, health outcomes. A number of initiatives and approaches or processes (see figure 5) have been introduced to create needed linkages across settings and services, from delivery system redesign, the introduction of decision supports and modern information systems among a number of other approaches.

Figure 5: Coordinated/integrated health services delivery defined model (WHO Regional Office for Europe, 2013)



By overcoming fragmentation and by creating linkages between services along the full continuum of care **improved quality, continuity and efficiency** in the delivery of services may be realized, and ultimately improved health outcomes secured (see figure 6).

Figure 6: Improving health outcomes through the model on coordinated/integrated health service delivery



Integrated health care components of the Framework for Action towards Integrated Health Services Delivery are described here (see figure 7) as a suggestion for the defined template/check-list to be used for the case studies analysis: system (re-)design in the delivery of services; support and shared information among professionals; improved information integration through the use of modern technologies (e.g. clinical registries and patient records); and self-management or patient integrated care towards individual empowerment of their personal health needs<sup>57</sup>. A step-by-step guide for developing profiles on health services delivery transformations was released in January 2016<sup>58</sup>.

Figure 7: Examples of initiatives as model progresses towards the model on coordinated/integrated health service delivery

Delivery system design	Decision supports	Information systems	Self-management
<div>✓ Revision of professional roles</div> <div>✓ Case/care manager</div> <div>✓ Multidisciplinary teams</div> <div>✓ Nurse-led clinics</div> <div>✓ Follow-up by home visits</div> <div>✓ Continuous evaluation</div> <div>....</div>	<div>✓ Implementation of evidence-based guidelines, protocols, care plans</div> <div>✓ Standardized education/trainings</div> <div>✓ Distribution of educational materials among professionals</div> <div>....</div>	<div>✓ Reminder systems</div> <div>✓ Shared clinical records</div> <div>✓ Audit and feedback of provider performance</div> <div>✓ Register of health/social care service users</div> <div>....</div>	<div>✓ Patient education and training</div> <div>✓ Patient motivational counseling</div> <div>✓ Distribution of educational materials</div> <div>✓ Use of mHealth and eHealth tools</div> <div>....</div>

Source: Adapted from Nolte & McKee 2008, citing Zwar et al. 2006

There are effective interventions to be shared. As illustrations, initiatives such as the “RAI” (Resident Assessment Instruments) for home care, RAI for mental health (RAI MH), or the “hospitalization at home” can be referred to as current initiatives that are being implemented in Europe.

- **RAI MH** is a comprehensive, multidisciplinary mental health assessment system for use with adults in facilities providing acute, long-stay, forensic, and geriatric services. The Resident Assessment Instrument-Mental Health (RAI-MH) comprehensively assesses psychiatric, social, environmental, and medical issues at intake, emphasizing patient functioning. Data from the RAI-MH are intended to support care planning, quality improvement, outcome measurement, and case mix-based payment systems<sup>59</sup>.
- **RAI for home care** is the same instrument but used particularly for patients ranging from medically complex patients needing close attention to relatively older adults who receive and require less formal support.
- **Hospitalization at home** is defined as a service that provides active treatment by health care professionals, in the patient’s home, of a condition that otherwise would require acute hospital in-patient care, always for a limited period<sup>60</sup>.

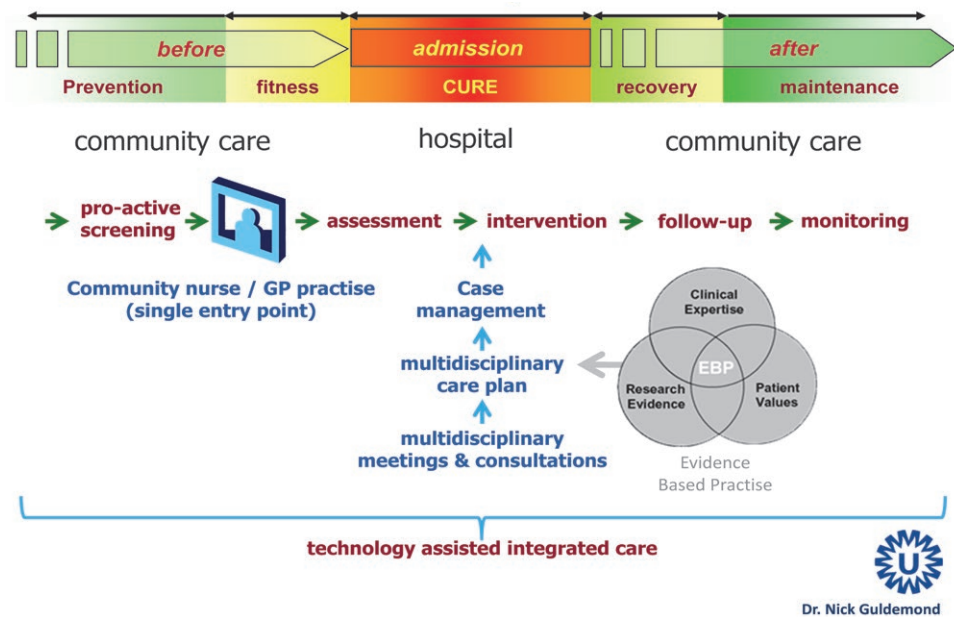
3. ELEMENTS TO BE RETAINED FROM LITERATURE REVIEW

No evidence suggests that one policy approach to chronic care management is necessarily superior to others. The key to success rather appears to be the joint development of solutions to meet patient needs and systematic implementation with regular monitoring build in<sup>61</sup>. In addition, an approach to policy development is recommended that involves all government departments, ensuring that public health issues receive an appropriate cross-sectoral response (health in all policies such as public health policy as well as labour policy and social security systems)<sup>62</sup>.

All across Europe, various forms of provider networks and interventions (case management, trans-mural care) have been set up to close the gap between primary and hospital services<sup>63</sup>. From the literature research, **experience of integrated care so far is limited but promising to improve care, several components of the model seem to be effective but there are still insufficient rigorously designed large-scale population-based evaluations**<sup>64,65</sup>. It is highlighted that information and communication technologies (ICT) are broadly perceived as facilitators for the implementation of integrated care to enable prospective follow-up of the patients. More user-friendly and efficient ICT platforms are needed that include shared decision-making, the process by which a healthcare choice is made jointly by the practitioner and the patient. Ideally, an innovative patient management program would combine ICT, shared decision-making and personalized education of the patient, together with his/her caregiver, about multidisciplinary approaches<sup>66</sup>.

**Coordinated (integrated) care can be a key strategy** in reforming health systems to **improve quality of care and access to care (including access to drugs), reduce costs and lead to better population health outcomes in the long run**. The changing nature of the demands made on hospitals means that it is particularly important for them to work closely with the different health and social care services. There is a **strong business case for investing in the early intervention and community-based interventions** proven to generate **savings** or value-for-money gains through **reduced inpatient admission, or through other routes**<sup>67</sup>. Research confirms that **patient’s’ perception** of the quality of care is largely determined by the success of this coordination<sup>68</sup>. Research also suggests **that better outcomes occur by addressing diseases** through an integrated approach in a **strong primary care system (see figure 8): hospitals have to be integrated with primary health care and the gatekeeping function of general practitioners (GPs) is to be fully effective**<sup>69</sup>.

Figure 8: Chain of (planned) care



**Initiatives to integrate care** are frequently driven by a need to contain cost; yet as mentioned, investing in integrated care **does not necessarily imply an economic gain**. This will depend on the part of the cost associated with the disease burden or level of need that can be averted or reduced through the intervention set against the cost of carrying out the initiative in question<sup>70</sup>.

Literature review highlights the **lack of evidence on cost-effectiveness** of selected integrated care interventions<sup>71</sup>. As such, indicators are needed to measure outcomes. This is the objective of the OECD with “delivering health care value by improving outcomes” (see Table 2). The OECD is expanding its activities on **consolidating and refining data and indicators**.

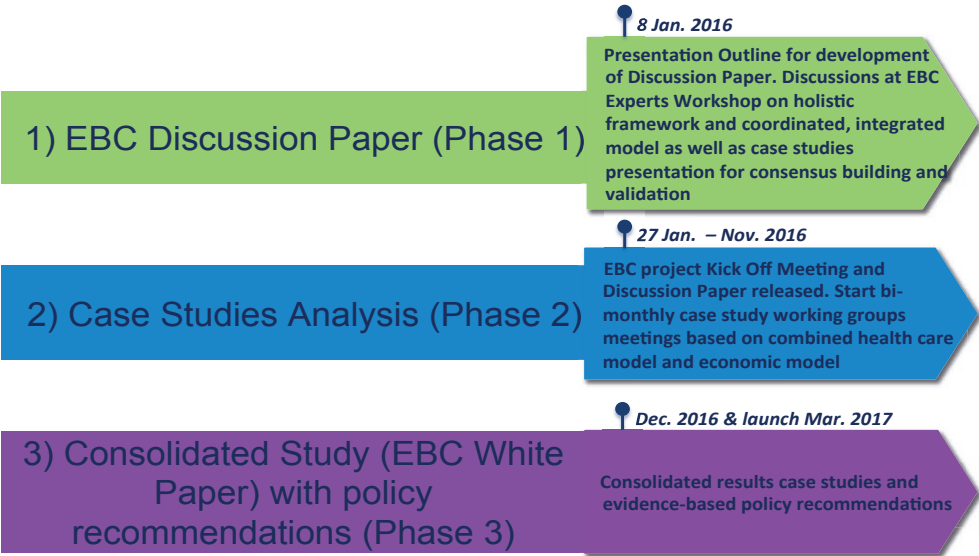
Table 2: OECD Delivering health care value by improving outcomes (2015)

An evolving view of outcomes	Rational of measures and data sources
From Deaths	<ul style="list-style-type: none"><li>- Mortality and life-expectancy</li><li>❖ Public health perspective</li><li>❖ Data source: death registries</li></ul>
To Diseases	<ul style="list-style-type: none"><li>- Prevalence and incidence of diseases</li><li>- Outcome measures to capture the reduction in morbidity and for specific diseases (e.g. QALYs, SF 36)</li><li>❖ Medical/clinical perspective</li><li>❖ Data source: clinical registries</li><li>- Linking to costs/value</li><li>❖ At system level: burden of diseases studies</li><li>❖ For specific services and interventions: cost-effectiveness studies</li></ul>
To Disability	<ul style="list-style-type: none"><li>- Outcomes to address the way a health system deals with disabilities</li><li>❖ At system level: DALY</li><li>❖ At health services: e.g. inter RAI initiative</li><li>❖ Data sources: administrative data-bases and surveys</li></ul>
To Discomfort and Dissatisfaction	<ul style="list-style-type: none"><li>- Outcomes experienced by citizens/patients</li><li>❖ PROMs (patient reported outcomes) including EQ5D</li><li>❖ PREMs (CAHPS, Picker)</li></ul>

4. CONCLUSIONS AND NEXT STEPS

As from the official EBC Kick Off meeting and first working groups meeting to be held on 27 January 2016, a combined template on health care services delivery model and economic model (or check list) will be developed (it will be used as a “standard or ideal approach” reference framework for the case studies analysis, this will help for the analysis and the reporting). This common template for all case studies analysis will enable to consolidate the research framework and together with this discussion paper, both documents will be released for **the start of project phase 2** (see figure 9).

Figure 9: EBC Project – Three expected deliverables





ENDNOTES

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