

The organization of mental healthcare in laboratory

Life and death
of an assessment tool

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This report has been published thanks to the support of the European Commission, Directorate-General for Research, 6th Framework Programme for Research - Socio-economic Sciences and Humanities (contract nr 028848-2).

The information and views set out in this brief are those of the authors and do not necessarily reflect the official opinion of the European Union. Neither the European Union institutions and bodies nor any person acting on their behalf may be held responsible for the use which may be made of the information contained therein.

The KNOWandPOL project is co-funded by the European Community FP6 2002-2006, under the Socio-economic Sciences and Humanities programme.



Foreword

This report is a continuation of the research conducted by the European project « Know & Pol ». While the « Know & Pol » project is focusing on the interaction between all kinds of knowledge and politics, this report is rather integrated into the third orientation of the study which focuses on a tool used to mediatize the interaction process between knowledge and policy.

While the first orientation had the objective of presenting an overview of the main actors – many actors in Belgium due to its federal structure (see annex 1)-, of their knowledge and competencies, the second one was about the decision process as such. The first report of the second orientation focused on the process which led to the elaboration and implementation of a specific policy: therapeutic projects in mental health. The second report focused on the decision process that was deployed within this that was designed as a pilot experimentation expected to lead to the structural redesign of mental health in Belgium. Eventually, if the third orientation first dealt with a supranational tool of the WHO which had an impact on political processes in Belgium, the second part of the research orientation is about the study of an assessment tool for the decision process to be implemented in therapeutic projects: this is the topic of the present report.

We define « a regulatory instrument as a mechanism, object, tool or process which defines, specifies or structures the work of information gathering, planning, coordination, implementation, accounting or evaluation in a given domain of public action »¹ (Salamon, 2002). The selected methodology is a qualitative and inductive case-study (Glaser et Strauss, 1967). The empirical basis is three-fold and made of about twenty interviews, many documents (political notes, meeting minutes...) and some meetings observations.

¹ It is the common definition of the « Know & Pol » project. Based on the definition by Salomon, it is mentioned in the project specifications: <http://www.knowandpol.eu>.

Introduction

Under construction for about the last thirty years, mental health in Belgium started in the second half of the years 2000 a new reconversion phase. Aiming at de-institutionalizing the existing institutions by promoting network practices, the upcoming reform had to be preceded by an ambitious experimentation phase to test the new care model. This experimental policy, which was often called « therapeutic projects in mental health», was actually made of two large aspects. On the one hand, therapeutic projects² as such, or primary dialog, aimed at locally organizing care workers from different origins around a group of patients. On the other hand, transversal dialog was organized to draw conclusions from the experimentations to prepare the future care system reform. While the latter foresaw an « empirical » dialog process between the different stakeholders – analyzed in the second case study of the second orientation-, a scientific study of the experimentations was assigned to a specialized agency. In addition to a qualitative study about the different projects organizational processes, a quantitative assessment tool was built in order to collect the different types of data about the patients involved in projects. It is that tool that will be analyzed in this report.

If among all the existing mental health projects in Belgium, therapeutic projects have a significant place due to the importance of the perspective change they had to initiate, the quantitative study is worth talking about. Close to the « evidence-base » approach, this research is among the first to be conducted in mental health in Belgium. After it was announced, this tool quickly generated major controversies and the opposition of different actors more or less involved in projects. Initially planned to start right after the launch of therapeutic projects in the spring of 2006, this study will definitely be withdrawn in the fall of 2009 due to the many delays observed.

The strength of controversies about this tool reveals the significant issues crystallized by this assessment. Whether professional, managerial or clinic, these issues can reflect some of the main progresses of our care system and even go beyond the strict framework of mental healthcare.

We will start with a context overview in order to understand the tool's birth. This will enable us, after going through the history, to understand the meaning of the tool and the issues it brings for the different actors involved. *In fine*, we will see that the building and use of such tools based on scientific knowledge is not politically neutral but is in the center of many issues and power relationships for the different actors who have to work with it.

² This first aspect was particularly the object of our first research for the orientation 2 of the « Know & Pol » project.

1. A learning policy – a constantly changing area

Understanding this tool, its emergence, its construction and its critics bring us to focusing on the specific context to which it is constantly linked. Before presenting more in particular this tool and the policy which made it arise, we will first assess the mental health system in Belgium, its evolutions and the critics it has been facing for a couple of years.

1.1. Context: the hospital renegotiating its legitimacy

1.1.1. An area still dominated by the hospital

The mental healthcare system which has been prevailing in Belgium until today is still related to the history of the welfare state development. Based on the development of social rights, the hospital system will progressively arise with illness medicalization as preferred device.

Indeed, if we follow the historical reconstitution made by De Muck et al. (2003), it is at the end of second world war that the hospital started replacing the asylum as mental illness treatment institution. This progressive reconversion – as the asylum will only disappear completely in the 1970's with the end of distinctions between closed and open services – is translating the substitution of a security referential with a social rights referential.

By enforcing a principle that ensures access to care to as many people as possible, the hospital will quickly settle as a privileged device for somatic and mental illnesses treatment. Indeed, these years are also the years of mental health medicalization. Beyond the translation of these issues in medical terms, the development of medicine will progressively generate new specialties. In addition to an internal differentiation within the new medical sphere which was provided with care monopoly, the increase of state intervention areas will bring more specialization in related areas like social aid, training or labor.

At the intersection of sociopolitical and medical dynamics, several decades of welfare state development passed a complex administrative and institutional system of mental illness treatment on. Mutualistic organizations, hospital federations, medical associations or advisory body for hospital institutions, among others, will contribute to providing stability and legitimacy to the hospital as a treatment center for mental illnesses.

Many critics will be expressed in the 1960's but will not manage to challenge the hospital expansion. Indeed, this movement against patients' confinement and chronicization will lead to the creation of a hospital-related ambulatory area as from the 1970's.

It is only as of the 1980's, under financial pressure, that the decision will be made to bring hospital centrality and its underlying expansion logic to an end. The economic crisis provides then a political opportunity to use knowledge which puts into question the hospital as treatment center for mental illnesses. Ten years later, several policies will aim on the one hand at reconverting hospitals into different structures used to re-socialize stabilized patients, and on the other hand at implementing a better coordination of hospital and ambulatory areas which were so far in competition.

The reforms conducted in the 1980's until mid of the 1990's are not sufficient to stop the critics. At the beginning the years 2000, after a long reconversion process of the psychiatric hospital capacity, Belgium still had one of the highest numbers of psychiatric beds per head in the world. It was criticized by several international institutions like the WHO and the European Union, and therefore the hospital area is taking action as from 1996. That year, the National Council of Hospital Institutions (*Conseil National des Etablissements Hospitaliers* - CNEH), which is a body made of the different national hospital federations, published a note. In order to anticipate the end of the reconversion process initiated a couple of years earlier, this note proposes a complete reorganization frame for mental healthcare. An organization of care networks and circuits structure is suggested. The willingness to manage the organization based on target groups and not anymore according to the institutions is a significant change from perspective. However, by supporting existing institutions to looking at what happens outside, this proposal appears original compared to solutions supported abroad where the de-institutionalization process could lead to the replacement of existing structures by other external solutions.

	1997	1998	1999	2000	2001	2002	2003	2004	2005
UE(27 countries)	78.0	75.3	71.2	69.4	66.0	64.9	62.4	60.9	60.4
Belgium	259.4	259.6	259.4	259.5	252.8	249.0	248.0	248.5	250.8

Psychiatric care beds in hospitals (per 100 000 inhabitants)³

It is in 2005 that a project aiming at implementing the CNEH proposals appeared. That year, the Minister of Social Matters and Public Health, Rudy Demotte, published a « Note about mental health ». By addressing the mental health issue with the WHO terms, the note introduced a new policy that would lead to the organization of care networks and circuits: « therapeutic projects in mental health ». If the policy did not aim at reducing the number of hospital beds – which is though one of the main critics expressed to Belgium during many years-, it appears as an innovative and ambitious measure due to its global aspect. Indeed, these projects are primarily intended for patients with a « chronic and complex pathology », that is to say patients requiring a long-term support and the intervention of various specialists. In addition to the mandatory partners like psychiatric hospitals, ambulatory services and first line services, projects must be able to

³ Data collected on the Eurostat site :

<http://epp.eurostat.ec.europa.eu/tqm/table.do?tab=table&init=1&language=fr&pcode=tps00047&plugin=1>

Consulted on August 23rd, 2010.

involve when needed some related areas like education or social action which the welfare state development had so far deeply differentiated.

1.1.2. A stammering knowledge policy: attempts and reluctances

Another characteristic of the evolution of mental health during the last years is the building of a nationally-coordinated knowledge policy in mental health. It is useful to mention it for three reasons. First, this issue is the subject of our report through the study of therapeutic projects assessment scales. Also, because the development and critic about this development take place in a historical context in which it makes sense. Eventually, we must also note that the development of health indicators and of an evidence-based policy is a heavy international trend: for instance, the European Union wish to develop common health indicators (ESEMED project) or the WHO recommendations in favor of evidence-based policies.

If the lack of evidence-based policies in Belgium is not as intensively criticized by the international institutions as the Belgian hospitalization rate, the WHO relay in Belgium is highlighting the need to develop these policies. Indeed, the development of these practices is only starting. However, there seems to have been a shift of this movement during the last years. If we will analyze this evolution more in details later in the report, we must mention some experiences and milestones which occurred before the assessment tentative of therapeutic projects.

The first large experimentation in mental health evidence-based policy took place in the 1990's. Indeed, as from 1996, psychiatric hospitals had to communicate data collected with the « Minimum Psychiatric Summary » (RPM). This tool, which was mainly designed by a university team, was expected to build a data-based policy, mainly regarding the agreement standards and care institutions funding. Then, this tool was already presented as an innovation through the willingness to drive care policy towards patients and their needs rather than towards the institutions. Indeed, the RPM already used some indicators related to the patient's socio-demographical and epidemiological features as well as registration of care that was provided to the patient. At that time, the device was already strongly criticized by medical professionals who saw it as threat to the medical secrecy and the psychiatrist – patient relationship.

« After a profound analysis of this manual, the National Council feels that the Minimum Psychiatric Summary recordings are threatening the trust relationship between the psychiatrist and the patient. [...] It is surprising to see that the elaboration of a recording tool specific to the RPM is not taking into consideration the specific characteristics of the psychic illness and the trust relationship between the psychiatrist and the patient in hospital. » (Physicians order, 1996)

The RPM, which has been effective in the whole psychiatric residential area since 1997, underwent several redesign attempts which, as we will see and according to several speakers, are related to the therapeutic projects experimentation.

Another outstanding moment, which is more recent and more directly interesting us, was the creation in 2002 of the « Healthcare expertise federal center » (KCE). If we will also present it in more details in the analytical section, it seemed useful to present an overview of it in order to locate it from a historical perspective and illustrate the global healthcare movement towards the evidence-based policy. Indeed, this federal entity created by public authorities but which had a scientific autonomy, was created to produce recommendations for political authorities in order to definitely « promote an increased access to high quality care by taking into consideration the increased needs and the limitation of available funds. »⁴ As illustrated by the interview below, the creation of this center can definitely be related to the above-mentioned international trend.

« It is an international movement. And for Belgium, it is Vandembroucke⁵ who launched the movement and who created the KCE, but with the support of other institutions which requested an independent institution. Also, from an international viewpoint, it is evidence-based healthcare that was requested. There was a note written by the European Council to have one health technology assessment body in each country. It is for this reason that the KCE was created. »⁶

Indeed, in 2001, which was a particular year due the Belgian's Presidency of the European Union and the fact that it was declared year of mental health⁷, the Ministers of Health and Social Matters published a common note. The note had a chapter about the evidence-based question and was quite proactive at this regard. No doubt that this question kept on being part of the next government's political concerns as in 2005, the new Minister of Health repeated almost exactly this extract in his own general policy note : « The mental healthcare research must catch on the somatic healthcare research and should not be left aside. The constantly increasing literature about evidence-based mental health reveals that care providers and researchers are more and more effectively differentiating fact and fiction. It is possible, based on the qualitative and quantitative study data, to develop a treatment protocol that can help improving quality and efficiency. The study reveals that only 20 to 30% of the practice is evidence-based. The implementation study about evidence-based acts is needful » (Demotte, 2005 : 15, free translation)

Initially created to conduct studies about all healthcare types, the KCE quickly focused on mental health. So, a first report dedicated to this area was published in 2008 and announced in its introduction the KCE's willingness to develop its expertise in mental health: « This report is the first of a series of projects of the KCE in mental health. We hope that this series of reports will help feeding discussions which are often difficult concerning psychiatry objectives and reforms » (Verniest et al, 2008).

⁴ This extract is mentioned in many presentation documents of the KCE. It is for instance available on the center site : http://www.kce.fgov.be/index_fr.aspx?SGREF=3449

⁵ Franck Vandembroucke was then Minister of Social Matters and Pensions (1999 – 2003)

⁶ Extract of an interview of a KCE's researcher.

⁷ For more details about this, refer to our report about the reception of the WHO recommendations in Belgium (Vrancken et al., 2009).

1.1.3. Conclusion

From this historical overview, we will remind that the implementation of the therapeutic projects assessment tool by the KCE will take place in a two-fold context. On the one hand, the hospital system which is still dominant lost most of its legitimacy due to the policies conducted since the 1980's and in particular due to the recommendations at international level which were strongly opposed to the Belgian's mental healthcare system. As it had a significant position, in particular through the CNEH⁸, in the decision-making process in care policy, the mental health area itself will start preparing the reform. As it faced a request for de-institutionalization that could appear as a contradiction to its own survival, the hospital area will propose a reform project that would include these requirements and recommendations in its own functioning.

On the other hand, during the last fifteen years, different initiatives were progressively taken in order to develop a care policy that would be based on various scientific indicators and evidences. Since the beginning of the years 2000, the KCE creation and political priorities of the different ministers seem to indicate an acceleration of the process.

1.2. *An experimental device: therapeutic projects in mental health*

In May 2005, at the end of a political process that consecrated mental health leadership, the « Political note about mental health » of the Minister of Health provided a proposal for implementing a policy based on the main principles developed by the CNEH as from 1997⁹. The proposed solution is experimentation. Rather than an agreement about a collaboration protocol between the federal and federated institutions involved directly or indirectly in mental health, the different Ministers authorize the launch of projects and the participation of their tutorship departments. The participation to projects will be based on willingness. The call for candidates was made on November 16th, 2006, the different care providers who were candidates were invited to propose a project before year end in order to possibly start functioning in April 2007.

The learning objective seems essential in this policy. Therapeutic projects, which are expected to last a couple of years only, had to provide the experimentation and the data needed for generalization of the model in the subsequent policy. Either in their architecture or in their assigned objectives, therapeutic projects will definitely appear as a « social change learning device » (Chevalier, 2005 : 387, free translation) After a selection made by the National Institute for Illness-Disability (INAMI), some seventy projects were selected to make the experimentation that in the end will help « [...] the authorities as well as mental health acquiring useful expertise before these concepts are

⁸ The National Council of Hospital Institutions (CNEH) is made of the main interest groups involved in hospital policy, either from the administrative, medical or illness insurances areas. This dialog institution must mandatorily be consulted about all questions related to hospital policy.

⁹ The whole development process of therapeutic projects is detailed in the first report of the second orientation (Vrancken et al., 2008)

generalized as organization models for future mental healthcare » (CNEH, 1997: 8, free translation).

More practically, the architecture of the proposed device is two-fold. On the one hand, therapeutic projects as such, also called « primary dialog », involve the device part intended to organize an inter-professional and inter-institutional dialog regarding the patient. It is a clinic aspect as it is regarding the practical organization of care. The second aspect, called « transversal dialog », is about the whole device that was designed to produce and generalize the lessons learned from these experimentations. On the organizational side, the INAMI, which is funding healthcare, is responsible for « primary dialog » and expresses its own requirements to fund projects as care producers. Transversal dialog is organized by the Federal Public Service for Health (SPFS), which is the Ministry in charge of public health matters. Both parties are closely linked and therefore we will first present an overview of primary dialog prior to focusing on transversal dialog.

1.2.1. Primary dialog: experimenting new practices

In short, we can point three main characteristics to describe the public action device of therapeutic projects. First, the state action that is implemented is rather of an « involving power » (Kuty, 2004, free translation) as the State is rather involving a commitment of actors into the reform than mandatorily requiring them to get into it. Secondly, it is definitely part of a procedural policy and eventually it is implementing a « territory-based public management ». When they are combined, these characteristics make a specific public action mode that was described by Duran and Thoenig: « The State is involving other actors by naming a measure without defining it clearly, by building specific exchange places and opportunities, but without putting the old institutions into question, by involving third parties, but without imposing its own methodology as mandatory common denominator. » (Duran and Thoenig, 1996: 602, free translation).

Practically, care institutions from the same geographical area (whose boundaries must be defined by actors themselves) were invited to gather in order to propose a common network project. The projects had to be intended for a specific age category and a homogeneous epidemiological population that had to be defined with DSM and ICD codes¹⁰. Three mandatory partners had to make the project basis. According to the reform objective of the hospital area, therapeutic projects were required to have at least one psychiatric hospital, one mental health service and one first line service. Several additional partners could join a project based on the relevance of the specific issue that was dealt with. If projects had a significant liberty in defining their issues, objectives and methods, they were also required to integrate into their projects the issues brought by therapeutic projects: care network and circuits, custom care...

¹⁰ The « *Diagnostic and Statistical Manual* » (DSM) of the « *American Psychiatric Association* » (APA) and the « *International Classification of Diseases* » (ICD) of the WHO are two diagnosis and classification tools for illnesses. The first one is not dealing with psychiatric « disorders ».

Of course, the care convention that therapeutic projects had to sign with the INAMI and the administrative assessment methods that the INAMI was implementing had many characteristics of a traditional bureaucratic management of healthcare by the State. However, as we saw before, the importance of the interestment and involvement **creative** work (Callon, 1986) implemented by projects coordinators (see Vrancken et al., 2010, free translation) as well as the procedural and experimental architecture of this policy allow us to consider therapeutic projects as a translation device of new standards in care practices (Cerfontaine, Thunus, 2010).

1.2.2. Generalizing the experimentation: need for an assessment device

Overview of the device

Transversal dialog is a complex system built up to learn lessons from therapeutic projects for a future global reform of the mental healthcare system. It is the second essential aspect of therapeutic projects policy. A significant budget was released therefore. If the INAMI is responsible for the « care » aspect, this part of the device is managed by the SPF Health.

« The objective of the transversal dialog initiative is to identify orientations in terms of content and mental healthcare circuits and networks organization forms, based on the experimentations conducted in therapeutic projects, in order to produce an organization structural proposal of such care networks and circuits. » (CNEH 02/2007 : 4, free translation).

As stated in the above-mentioned note of the CNEH, transversal dialog, according to the therapeutic projects objectives, aims at producing recommendations for care **organization**. We must keep this element in mind because, as we will see later, the real objective of this device will be discussed and will be the subject of controversies between the different actors involved. Indeed, a second key point that will also be developed later but we have to mention right now is the existence of many actors involved in the different aspects of dialog.

Practically, transversal dialog on the whole is made of two main aspects: one « empirical » aspect and one « scientific » aspect. Both have the same overall **formal objective** of « elaborating standards or good practices in care circuits and networks » (Political note Demotte, May 2005). The consistency of the whole device and of the experimentation process had to be ensured by two additional « stages »: the « Accompaniment Committee » and the « Mixed Work Group ». Theoretically, if the second one had to prepare the papers for the first one which had to ensure the process follow-up and consistency, practically, except at projects launch, only the second one actually had meetings. In order to fulfill their mission, these two groups gathered the delegates of actors involved in the transversal dialog process.

More particularly, the empirical aspect of the device was itself split into two parts: « Transversal projects » and the « Participation project ». The latter was conducted by four users and relatives associations: two French-speaking and two Dutch-speaking. The

scientific follow-up was managed by two institutions: « LUCAS », research center of the « Katholieke Universiteit Leuven » (KUL) specialized in healthcare, on the Dutch-speaking part of the country, and the « Interregional Guidance and Health Association » (*Association Interrégionale de Guidance et de Santé - AIGS*) on the French-speaking side. Focused on the users' participation issue, the participation project had a two-fold objective. On the one hand, their mission was to compile « good practices » examples in users participation to mental healthcare and on the other hand, they had to train those users about the main mental health stakes in order to allow them to take part in « transversal projects » meetings. Although we do not dive into more details of the description and analysis of this part of transversal dialog, we must also note the users and users associations involvement in the process.

« Transversal projects », which are the specific objective of the second report of the « Know and Pol » project's second orientation, were mainly regarding practitioners involved in therapeutic projects. Theoretically, they had to « [...] enable therapeutic projects to exchange and think about their dialog practices and work methods they are implementing in order to produce in an empirical way 'efficient' organization methods of mental healthcare through care networks and circuits that are organized based on patients age categories. » (CNEH, 02/2007 : 4, free translation).

Actually, it took some time before transversal projects started producing political recommendations. Indeed, at first, these « stages » of all therapeutic projects delegates served as a « sound box » for the issues and disagreements expressed by projects. If they could be about administrative issues, transversal projects also played a key role in the critic expressed about another assessment: the assessment of the KCE. Either by writing reports, transmitting critics to the authorities, or on the contrary, by mediating information that would not always reach the different local projects, this « stage » played a significant role in the KCE's assessment progress.

Now let's focus on the scientific aspect, which we are more specifically addressing in this report. The KCE is the only responsible for this aspect. The request made by the Minister of Health and his tutorship department is also part of the therapeutic projects philosophy and objectives. This request must *in fine* lead to « relevant conclusions as far as the policy to be implemented is concerned. » (SPF, 2008 : 10, free translation)¹¹. In order to do so, the mission it must complete is two-fold. On the one hand, the KCE is also mandated to provide a methodological support to transversal projects. In this frame, the KCE will split therapeutic projects into different clusters related to their specific issues. On the other hand, the KCE is also, mandated to conduct a research on the organization and coordination models to achieve the objectives promoted by this policy like care sustainability. There is its main mission. In order to do so, the KCE will use an

¹¹ This document published online in 2008 was undoubtedly published earlier. The lack of date does not allow us to provide a clear date, however the existence of a calendar in annex enables us to be more or less sure that it must be from the spring of 2007.

international literature review as well as a study of the different specific experimentations conducted by therapeutic projects.

« In this new analytical approach, the objective, based on an analysis of the data collected by therapeutic projects, is to find coordination mechanisms that bring an added value in terms of sustainability of care provided to patients, in terms of customized care and in terms of a better harmonization of care services. In the empirical approach, the objective is that new collaborators would join transversal dialog by following a methodological framework of the KCE. » (Ibidem)

As stated in various documents, the KCE's work will focus on the organization processes – « The scientific research will be conducted through an approach that is described as a 'process assessment'. » (CNEH 02/2007 : 14, free translation) -, and not on a measurement of therapeutic projects efficiency as was done abroad like in France through a study conducted by the INSERM (INSERM, 2004).

The specifications reported by the ministry – of which an extract is provided below – describes at least six main missions that the KCE must perform about therapeutic projects policy. We can note that some characteristics of the scientific study made by the KCE were already observed then (at the beginning of 2007) : regarding the study object, it must be addressed to the care actors taking part to the projects coordination mechanisms as well as to the patients, in order to assess the added value of such integrated care system. From a methodological viewpoint, we will remind that the study had to implement qualitative as well as quantitative methods and rely on an international literature magazine. We also recognize the focus on evidence-based medicine: « available evidence in efficient integrated care » (see below).

« The KCE will

- assess therapeutic projects (TP) plans funded by the INAMI and will oppose them to the available relevant data;
- perform a literature study about available knowledge and evidence in efficient integrated care for the respective patients groups (including an international comparison);
- design a methodology intended to collect and assess the results criteria of therapeutic projects, and to ensure the prospective follow-up of clients within the TP ;
- design a methodology in order to analyze the organizational processes (barriers and enhancing factors) that will have to lead to integrated care implementation ;
- assess the therapeutic projects and transversal dialog process, based on qualitative and quantitative data;

- write conclusions about aid services and the organization of aid provided to the different psychiatric patients groups in therapeutic projects. » (SPF, 2008 : 10, free translation)

Despite a framed request, and as autonomous scientific institution, the KCE had the liberty to define its own research methodology to answer the specifications defined by the SPF Health. A first version of the methodology was presented to the Mixed group during the summer 2007. Beyond the action it performed for transversal projects and an important sociologic qualitative study that appeared to be quite consensual, it is the methodology of quantitative follow-up of patients that will draw the actors' attention.

A « user guide of scales descriptions » selected by the KCE was then presented. It reports a series of scales that have to be applied to all patients, included in therapeutic projects. It is the specific tool we will present in the next pages. Before presenting it more in detail, we will also highlight the fact that all therapeutic projects were contractually committed to applying them. Indeed, in addition to the convention signed with the INAMI for the « care » aspect, participation to a project required to sign a convention with the SPF Health. The convention included the obligation to take part in all transversal dialog aspects, including the studies conducted by the KCE, and the obligation to provide data needed for the process. We must clarify that the existence of this convention made any defection option quite expensive for a project as in this case the project would run the risk of having its funding suspended.

The assessment tool of the KCE

This part of the KCE's study was presented as a « lengthwise analysis of the patients / clients characteristics » (KCE, 2007: 1, free translation). As from the beginning, the KCE clarifies: « This research is not assessing the various clinic approaches in psychiatry or the pharmacological interventions. It is assessing the process and outcomes of the new collaboration models in mental healthcare for the people with chronic and complex mental health problems » (KCE, 2007 b : 6). This clarification is relevant because of the subject's sensitivity due to the French study of the INSERM in particular but also due to the ambiguousness that could be generated by the developed methodology. Indeed, the limit can seem thin. So, the KCE says it doesn't want to assess therapeutic projects efficiency, it wishes to measure the outcomes of the therapeutic collaboration on the patient... So one of its research questions is expressed as follows: « What is the impact of therapeutic projects on patients' symptoms, life quality and participation to social life? » (KCE, 2007 b : 7). The method used is clearly based on the evidence-based medicine as it is designed as a « before-after » study (Ibidem) that must be conducted through international diagnosis tools like the DSM 4 and the ICD-10.

The tool is based on a series of measurement scales taken from an international literature review and used as such. The research, well designed from a methodological viewpoint, was conducted with specialized browsers and the selection was made based on criteria like the scales validity, reliability and utilization frequency. At that time, they

were presented as « *top of the top* »¹². We will present here shortly the first version of the tool developed by the KCE. Indeed, the many controversies that will arise after its presentation will lead the expertise center to reviewing and adapting the first version.

As far as the adults group is concerned, the measurement tool was made of 7 + 2 scales. A first scale was intended to register the so-called static data of the patient. This scale mainly included socio-demographical and diagnosis data about the patient. Seven other scales were more dedicated to the measurement of therapeutic outcomes about the patient at different levels. Eventually, a last scale was dedicated to projects specialized in legal psychiatry.

The assessment was on four main aspects (Ibidem):

- The symptoms severity
- The needs as perceived by patients
- The use of services by patients
- The quality of life as perceived by patients

The KCE planned to register this data during three years. An appropriate software had to be developed by the SPF Health in order to register this data. In the meantime, the scales had to be written on paper. Practically, as we will see, the software was actually never used. Let's eventually mention that a budget was provided in order to hire people in charge of encoding data in each therapeutic project.

¹² Extract of an interview with a coordinator.

2. Historical overview: a permanent negotiation

2.1. Phase 1: the progressive appearance of a critic

On the 1st of April 2007, the clinic aspect of therapeutic projects was officially launched. Transversal dialog had not yet started. The KCE study specifications were known but the real methods of the study were not. The KCE was preparing its assessment method that had to be presented to the Mixed Group on July 27th 2007. However, the information heard by some privileged actors do already generate some concern. The main critics of the upcoming controversy are already appearing:

They are about the assessment objectives. The existence of a study in which funding methods are addressed is worrying people.

« The 2007/4¹³ is worrying us but apparently, it is not related to the TPs. It is clearly about costs control, and it is only an economic logic. And we clearly said that if they wanted to play that game, they would play it without us. The part about TPs is not yet available on the site. [...]

The questions raised are more particularly about consistency between therapeutic projects objectives. It is a common critic coming from actors involved in transversal dialog: « does the outcomes measurement bring anything to the therapeutic projects objective which was to experiment dialog? »

...] For the time being, we have a first draft. But personally, when I see the scales they select, I have big doubts. There are some psychometric values that are not to be discussed but we must see if it is consistent with the TPs objective and I have big doubts regarding this. At the beginning, we said to the KCE: we would like you to clarify the more efficient dialog mechanisms in order to organize care networks and circuits. » Then, we said that a « scientific » part was requested to quantify the « whole thing ». From a methodological viewpoint, they are out of the question but it has to be considered regarding the research question that they were asked to answer. And there, I have doubts. At the beginning, the question was about the more efficient dialog mechanisms? [...]

Another element that was also pointed was the bad communication made by the KCE and the partner, which was the SPF. The prevailing feeling was that decisions had already been taken outside of the follow-up committees.

...] But in the meantime, I have the feeling that the information management is still not very transparent. We learn things through rumors. [...]

¹³ Another study conducted by the KCE.
http://www.kce.fgov.be/index_fr.aspx?SGREF=3442&CREF=13891
Consulted in September 2010

Eventually, there are questions and doubts about the research objective itself: « would there be a hidden agenda? » Is the objective to go to a new « *managed care* »¹⁴ funding model as in anglo-saxon countries?

...] For the time being, scales seem to reflect a patients assessment or flow control through a central recording center as opposed to what we support for assessing care networks and circuits. This model type was already experimented in other countries (England, The Netherlands, Germany). The challenge of all that is efficiency, and services reimbursement. These models which failed. [...] I am a bit afraid that behind an attractive principle, some people try to pass this shit on to us. And when I see the scales selected by the KCE, we wouldn't have done it differently if we had wished to experiment this type of model. »¹⁵

During the summer of 2007, the KCE transmitted its definitive scales selection to the Mixed Group. The « mental healthcare platforms »¹⁶ (MHP) transmit it as well to the different therapeutic projects. The critic is arising and becomes generalized. Several therapeutic projects write to the SPF Health to express their critics. The MHP collect several critics to summarize them and transmit them to the SPF, which reacts by extending the Mixed Group to all MHP on the one hand, and by organizing an important information meeting intended for all therapeutic projects, on the other hand. However, this meeting will not satisfy the expectations and will not help stopping the critic : « *The KCE made a very technical presentation of its methodology so most of the people did not understand it [...] I think that the answers provided are not satisfactory and do not respond to the questions raised. They are systematic repetitions of what was said before.* »¹⁷

The critic is expressed by more and more actors, but is also fundamentally more diversified. So, if the critic of the consistency of the research made by the KCE with therapeutic projects objectives is strengthened and becomes more and more central, other sticking points appear as well. Due to their centrality, we will consider two of those:

First, there is an ethical and clinic critic. This critic which is expressed by many therapeutic projects, states that the questionnaires transmission could interfere with the therapeutic relationship between the doctor and his patient and would jeopardize a needful trust relationship.

¹⁴ « Managed care » in its generic meaning is a care organization system that can limit access to care in order to reduce costs.

¹⁵ Extract from an interview with a coordinator (July 2007).

¹⁶ Mental health dialog platforms are a system that was created at the end of the 1980's in order to coordinate care services in territories. As they are representing several care institutions, they are asked to play a role in therapeutic projects and in the « Transversal projects » process.

¹⁷ Extract of an interview with a coordinator (October 2007).

« For some projects, and there it is rather linked to specific therapeutic approaches, they say they almost reached their case load already. We must say that projects started in April-May and we are in October. So, they say they initiated a therapeutic relationship and you cannot say in the middle of the process: « I forgot something, we must also fill this in... ». It is not only a question of time, some people think it is definitely interfering with the therapeutic relationship that was established with the patient. The practitioner must fill in some files with the patient and that can interfere with the therapeutic process. It is not the same role, it is moving from being a therapist to being an investigator. And some psychiatry projects, in particular in Brussels, do not admit it. »¹⁸

Another central critic is about the fact that scales are not adapted to the Belgian context. Mentioned as such in the international scientific literature, they do not match the Belgian context. The absence of validation is presented as a blocking reason.

« There are some field critics regarding scales proposed by the KCE. They were written in English and French in the anglo-saxon world. The KCE proposes to register the patient's data from these scales that will be simply translated whereas they should be validated based on the socio-cultural context. We will collect data that do not match the condition of patients who will be analyzed. »¹⁹ « From a methodological viewpoint, and this seems weird for people who claim to be irreproachable in this matter, seventy-five percent of the scales are not translated nor validated for the Belgian context. These are anglo-saxon scales which have adaptations and translations in Dutch and in French but which come from Quebec for instance. Now, we know that the scales from Quebec must be customized for Belgium because they do not match. »²⁰

This last critic is definitely central. Indeed, it will lead to a pre-test phase conducted by therapeutic projects. Expected to start mid-December 2007 and to finish end January 2008, this phase had to be conducted by at least one therapeutic project in each cluster. During this period, other projects have the choice: either they do not fill in the scales as they are not obliged to do so before the end of the test phase, or they test them and transmit their remarks.

« It is one of our evolutions... One of the critics was about the validation of scales that were not customized. And what will be performed dis a pre-test phase. [...] But here, they at least admitted that until January 2008, there would be a mini pre-test phase at the end of which we will have to check if the scales can be filled in as they are, if that is working or not. The issue is that if we had imposed this, it would not have been filled in correctly and the data would not have been reliable. »²¹

¹⁸ Idem

¹⁹ Extract of an interview with a coordinator (October 2007)

²⁰ Extract of an interview with another coordinator (October 2007)

²¹ Idem

While waiting for the results of the pre-test phase, the critics are increasing. The first meetings of « transversal projects » are almost exclusively dedicated to these questions and the first dialog reports are mentioning the local actors concerns and critics : «... partners felt they were cheated by the assessment willingness of the KCE and therefore they were involved in a totally different process than what was supposed to be implemented at the beginning [...] the general feeling is that of a noose that is tightening, which reveals a lack of trust from the federal authorities towards TPs which are, we must remind, at experimental stage – « what did they do with us ? » is also what some partners are wondering »²². Some professional associations are also moving to relay the concerns of their members. So, in a letter of October 19th 2007, the « French-speaking association for health institutions » (AFIS) denounced the ethical issue raised by the KCE research (see argument above), the methodological inconsistency with the TPs objectives and asks « for a quick and complete review of the proposed approach, in collaboration with the primary involved parties, that is to say the structures in charge of transversal dialog. » The Federation of « psycho-socio-therapeutic structures » wrote on January 22nd that « due to the issues faced by field actors, that were relayed to the authorities through their various representation institutions and due to the fact that our mails were not answered, we fear that our psychosocial rehabilitation area will have to be withdrawn from Transversal dialog as it will not respond to the requirements ». Eventually, the « Professional association of French-speaking child and young psychiatrists » stated in a letter of December 19th 2007 that it supported the « all the discussions raised about these questions, as they go far beyond « therapeutic projects » and are related to the whole mental health area and more particularly the child and young area. »

A real turning point in the KCE assessment was came to an end and the first reports written by project pre-testers were transmitted to all actors. It mentions for each scale the details of practical issues generated by their transmission, and also some thoughts about the research basics. These last critics were often expressed before. However, the main difference is in the argumentation that is developed. Indeed, as it is often even more elaborated and detailed than usual, the critics use a scientific language: « the KCE is requesting « scientific » arguments about the scales and methodology validity, and many mails were written to denounce the non-scientific aspect of the KCE study. We will describe them in detail in the next section. These arguments are brought by partners who are working in universities...»²³. The argumentation that is developed there points out some methodological mistakes made by the KCE like the lack of scientific assumption to link the scales with the networking assessment or the lack of research protocol or test methodology. Finally, critics are also expressed about ethical questions for biomedical research involving human subjects ».

²² Extract of minutes from the first transversal dialog meeting of the « General psychiatry: adults » cluster, December 11th 2007.

²³ Critical synthesis written by the therapeutic project TEHOU-TEKI in collaboration with the Brussels PFCSM, page 4.

At the end of this pre-test phase, the different actors feel that even if the changes brought to the tool give them the impression that they were heard, at least to some extent, the KCE will not modify its fundamental methodology and as they are committed by their contract, they will have to encode the scales anyway. « *At the beginning, the position of [...] [TP X] was clear: if the scales were ok, we would stop. Now, they were implemented I have the feeling that we are trapped. But we need funding in order to proceed and everyone wants to proceed.* »²⁴ Despite this, some therapeutic projects which refused the principle of this assessment decided to resign rather than accepting the KCE constraint.

« Some verbal information, received through the Brussels platform, mentions a relaxation of the KCE requirements. But these are only superficial improvements. Two fundamental points are still not negotiable: the KCE willingness to monitor our patients through the same assessment tables, which are lighter but irrelevant and even harmful. We ignore the objectives of this monitoring. We denounce its scientific value. We do not want to instrumentalize our partners, our patients even less, for undefined purposes. We are not the only ones who denounce the KCE practices. Proceeding with this collaboration would mean that we validate these practices and take part in building incorrect databases that could be used later on. »²⁵

If the critics regarding the KCE work will keep on being strong and will be expressed in several documents transmitted by different field actors²⁶, most of therapeutic projects seem in the spring 2008 to be resigned to encoding the scales. While some projects started filling in the scales on paper, others wait for the dedicated software to be operational and for the SPF to give the green light for starting encoding. But the software will not come. If some technical issues were given as reason for the delay, the real reason was to be found elsewhere. While the « fight » seemed to be in favor of the KCE, another controversy seemed to be providing them more difficulties.

2.2. Phase 2: The involvement of medical issues

At the end of 2009 – almost two years after the TPs were started! - the dialog projects draw a status of the KCE assessment. The situation is quite unclear: some projects haven't started yet to encode and no one « knows [...] if the projects are invited to start or required to start. [Indeed,] as far as the data registration is concerned, the software is technically ready, but there would be an « ethical » issue, in particular with the general practitioners »²⁷.

²⁴ Extract of an interview with a therapeutic project coordinator.

²⁵ Extract from a resignation letter of the TEHOU-TEKI therapeutic project intended for therapeutic projects. March 2008

²⁶ This part was not exhaustive. If several other examples of critics were possible, we decided to make a choice. The objective was, on the one hand, to expose the main ideas of the controversy and on the other hand, to illustrate the power relationship between different actors.

²⁷ Extract of dialog meeting minutes (January 2009).

Indeed, on January 16th 2008, the Generalists Associations Forum (FAG)²⁸ publishes a note to denounce several projects conducted by the federal authorities, among which the TP study made by the KCE. If this document immediately denounces the fact that « such assessment tools do not improve patients' quality of life », it is mainly arguing on legal basis that allows requiring the « suspension of transversal dialog in mental health [...] while the procedures are in the process of complying with legal and deontological prescriptions... ». The FAG is also highlighting the need to erase all data that would allow to identify patients (according to a royal law (A.R.), the fact that only a doctor as physical person can transmit and receive medical data covered by medical secrecy... » (according to an advice from the National Council for the Physicians Order), and in particular the need to receive the approval from the Commission for Protection of Private Life (CPVP) (according to an AR).

On March 4th 2008, the sectorial Committee of the CPVP issued a note in favor of the data encoding. However, on June 24th, the FAG publishes again a communication against the project. If the first input could have been successful – « it is only after our intervention sensitive data encoding was suspended until the CPVP advise was provided »²⁹ - this time, it is against the data exchange infrastructure implemented for encoding.

Practically, the system designed to respond to the need to make the patient's data anonymous has a Third Trusted Party that must assign any number to each encoded person. This role should have practically been assigned to the « eHealth » platform. This project, which generated a lot of controversy, was ongoing for several years not only in mental health, aimed at allowing a generalized exchange of health data between mental health stakeholders, including the scientific institutions and public administrations.

The FAG raises then some issues, among which the first is the fact that the legal framework for implementing the platform had not yet been voted. However, beyond this formal issue, the FAG is opposed to the project at different levels. It is also expressing its concern about the real objective of the platform, about how the data will be used, about the under-representation of the medical world in the management committee and last but not least about the access provided by people who are not from the medical world and have no direct therapeutic relationship with the patient.

« We often had, with the patient's approval, to share data covered by medical secrecy with other health professionals who have a therapeutic relationship with him. [...] And this notion of therapeutic relationship seems essential to us to allow the sensitive data exchange. [...] The « eHealth » platform [...] which considers coded data sharing with Public Health, the KCE, the INAMI or health insurances, does not mention the

²⁸ The Generalists Associations Forum (FAG) is made of associations and generalists circles from the French and German speaking parts of the country. The Scientific Company of General Medicine (SSMG) is an effective member. The medical unions, the General Medicine University Centers are adherent members. Any association which is supporting and defending general medicine can be invited. <http://www.forumag.be/index2.php>
Consulted on : 2010-09-21

²⁹ Extract of the FAG communication (March 24th, 2008)

requirement to have a therapeutic relationship with the patient to access all or part his health data. »³⁰

Finally, the communication ended with a warning. While recognizing the benefits of dialog and its willingness to take part to therapeutic projects, the FAG clarifies : « this decision [to take part in it] is relying on the condition that the exchange of medical data does not go through the eHealth platform. »

On August 21st the platform law was voted. On December 9th, a Deputee, who is also a Physicians, raised a question to the Minister of Public Health during a session of the « Public Health Commission » of the Parliament. The deputee was concerned about the agreement to have eHealth data encoding based on willingness and therefore thought « *it would be unacceptable when creating a care circuit, to tell people it is not mandatory to register the data but if it is not done, the INAMI will not be involved anymore in care provided in that circuit.* »

The last turning point in the assessment process took place in the fall of 2009. It was then announced without any additional detail that due to technical issues, the data encoding was completely stopped. The projects which had started filling in questionnaires on paper were invited to destroy the documents. This news was considered as a victory by the TP delegates even though some of them regretted the financial mess. The announcement made by the SPF that due to the projects progress, that were planned to end a couple of months later, the data did not make sense anymore, was therefore not a surprise. Indeed, some projects had not yet started with the scales and one year and a half earlier, a SPF delegate said about the accumulated delays: *normally, we measure t0, t1,... but here we have lost the data of t0. And we definitely wish to measure the patient before, during and after the process. But we do not have the data from the start. [...] This can lead to distorted results.* »

³⁰ Idem

3. Analysis: a learning policy in training

The previous part, which provided details about the tool life, clearly revealed two different coalitions which are opposed on the assessment question. On the one hand, we have the KCE and the SPF Health, which support the assessment, and on the other hand, we have participants to the transversal process and the physicians who are opposed to it.

The analysis that we propose will be split into two parts. First, we will present the KCE and SPF « coalition ». We will explain their interests and action logics. So we will see how these actors have a common objective. Indeed, the interests and strategies of the KCE and SPF can be partially understood through their predefined institutional objectives. The empirical elements reveal an « emergent association » of these two actors which gathered about the question of therapeutic projects assessment rather than building a « historical coalition » which led to the initial definition of the tool.³¹

Later on, with the attempt to make the tool operational, other actors also joined the opposition. Their action logics³² and their respective and common interests regarding the assessment did not exist before assessment itself but were more contingent and were generated by the action. It is this particular mechanism of simultaneously building and putting into conflict the two « coalitions » that will be presented in the second part.

3.1. The KCE and the SPF: united by the evidence-based approach

3.1.1. The SPF Health

Its full name, which indicates the extent of its competencies that go beyond health, is Federal Public Service for Public Health, Food Chain Security and Environment.

This ministry, which depends on the Ministry of Health, was born in 2001 from the split into two parts of a more important Ministry which before made of the Ministry of health and the ministry of social matters. Its split in terms of competencies and implemented knowledge is related to the hygiene and public health areas. Indeed, this ministry is for instance not in charge of implementing healthcare insurance policy and medical services reimbursement, which are competencies of the INAMI.

³¹ The question of the assessment origin was as discussed as its real objective, and these two elements are obviously linked to each other. The paternity identification can vary based on the actors' version. We therefore cannot identify it clearly. However, our analysis rather reveals the idea that a quantitative assessment did not exist prior to transversal dialog but would have appeared when transversal dialog was organized. We must however add that the INAMI was mentioned several times as one of the actors supporting the idea to make an assessment. This version is accrediting the idea of confusion between the organizational objectives of transversal dialog and the financial challenges brought by the care reimbursement issue.

³² Indeed, we understand the « action logics » as in sociology of organized action (Friedberg, 1993), that is to say the rationality of an actor who is struggling to reach his objectives in a constraining action context.

Several scientific and consulting institutions are related to the SPF in order to provide support and advice about the health policy. There is, among others, the CNEH (see above), the Scientific Institute of Public Health (ISP) or the High Health Council (CSS).

The ministry is split into several General Directions (DG) among which the « Care Institutions Organization DG ». Its competency area is more particularly related to care standards, hospital programming, care quality through a data collection policy and medical practices (aimed at determining the agreement and funding criteria).

« With an efficient multi-disciplinary team, we are contributing to a healthcare policy based on specialists' data and advice to provide continuous quality care which can be accessed by everyone. »³³

The DG1 has a specialized department in psychic care: the « Psychosocial Healthcare Service ». The focus on a health policy based on scientific data is even stronger in this department than in the whole DG. Indeed, the department presents its activities as articulated on two directions: (a.) the implementation of an evidence-based policy in mental health and (b.) the preparation of the future policy through pilot projects. The focus is clearly on scientific and evidence-based policy .

« In addition to the current affairs follow-up, the launch of various accompaniment commissions of research projects in mental health, the drugs policy and the implementation of the RPM registration, our task is mainly about implementing an evidence-based policy (of factual medicine), through pilot projects and collaboration agreements in research and development (BOS). »³⁴

During the implementation of the therapeutic projects system, the person responsible of the department is a psychologist. He has a PhD and describes himself as an experimental and behaviorist psychologist. He was also the « National Counterpart » of Belgium at the WHO. He is defending the « evidence-based » approach: « *Developing an evidence-based policy for mental health is not an easy task because the mental health sector is not always supporting it. It is important to develop this kind of policy. It starts with the scientific literature and it is about telling what is working and what is not working. We must stimulate the area to implement it. There is a pilot project limited in duration: we assessed and compared it with a group with a classical framework. The institutions have the freedom to select the care program they wish to implement. The only requirement is that it has to be efficient. The actors keep some liberty in their activities. It is also related to the fact that in the law, there is therapeutic liberty. We do not have the choice to provide some liberty.* »

As a conclusion, the action logic of the SPF and in particular of its psychosocial care department is clearly the implementation of an evidence-based policy. In order to do so, they must face the

³³ Presentation page of the DG1

<http://www.patient-safety.be/eportal/Aboutus/ourorganisation/DGforHealthCareFacilitiesOrgan/index.htm>

Consulted on September 22nd, 2010

³⁴ Presentation page of the « psycho-social care » department.

<http://www.patient-safety.be/eportal/Healthcare/Specialisedcare/Mentalhealth/index.htm>

Consulted on September 22nd, 2010.

constraints of a sector that is reluctant to implementing it and of a law that is ensuring therapeutic liberty. If the law is limiting the ability to impose some medical practices to the therapists, it is not preventing the implementation of care organization that was successful according to the EBM criteria. The implementation of pilot projects is one of the action strategies supported by the department in the achievement of their objectives.

3.1.2. The KCE

The Federal center of expertise in mental health (KCE) is quite new in the Belgian healthcare landscape. It was indeed created in 2002. We will not come back on the context in which it was created (see above). We will however provide more details about its objectives, organization, philosophy and methods.

The main characteristic of the KCE is its scientific aspect. Indeed, this aspect is always highlighted when the center is presenting itself.

« The expertise center is a study service that will professionally promote the research, the curiosity and creativity in order to reach a high level of scientific expertise. Its activities must be conducted with severity, intellectual independence and objectivity. It will be underlain by information collected from the application of the most recent methods of evidence-based medicine and health economy » (KCE, 2003 : 6, free translation).

Indeed, the center is presenting itself with all the scientific attributes: independence, autonomy, transparent communication, deontology, strict methodology and peer review procedures. We will see them in action during the analysis we will present in the next section.

« *The KCE has a specific status in the public institutions, it is autonomous. It is managed by autonomous procedures, there are many complex scientific procedures coming from an autonomous academic research. We have management procedures and plans that ensure the scientific aspect of each report. We have peer review procedures with international actors. It is the same type of procedures as when we submit an article for review. If the report is not scientifically accepted, it is not accepted. What is clear is that there is a scientific dimension in each report that follows the « health technology assessment » principles.* »³⁵

The methods and disciplines implemented by the center clearly come from medicine and in particular from its evidence-based part, and from health economy on the other hand. They are implemented with a claimed objective : the implementation of a performing and efficient health system either regarding the care provided or care costs.

« Its permanent underlying concern will be to open tracks that will enable to ensure system performance and larger access to high quality care for all despite the increasing needs and the limitation of available budget. » (Ibidem)

Finally, at the global level of the KCE, we observe that it is clearly in favor of a scientifically-supported and evidence-based care policy. The production of a note to support the political decision is clearly one of its main objectives. The economic efficiency

³⁵ Extract of an interview with a delegate of the KCE.

has a significant place there. For instance, in a report made in 2008 (Cleemput, 2008), the KCE promotes the « ICER » (Incremental Cost-Effectiveness Ratio) – an index that is measuring the cost-efficiency difference between several therapies³⁶ - as supporting tool for making care decisions. It is recommending at the end of the report: « the cost-effectiveness ratio should be a criteria in the decision-making process as it is not ethical to ignore the economic efficiency. » (KCE, 2008 : 61). However, we must emphasize the fact that the KCE claims it is not willing to contribute to a reduction of the healthcare system costs but rather aims at improving the available resources assignment process.

« No, there is an incorrect interpretation of our missions. Our mission is not to reduce costs, it is to support policy within an efficient use of public means. In Belgium, we do not reduce the costs of the king. We often say so but if we analyze budgets, we see a 4,5 % increase every year. Actually, it is an effort to provide support on controlling the costs increase. Is something totally different than reducing costs »³⁷.

Eventually, let's finish with some remarks about the assessment made by the KCE within transversal dialog. The team that conducted it was managed by a sociologist and university teacher. As observed in several interviews³⁸, the assessment process implementation, based on a more sociological qualitative approach, generated a debate during the research methodology elaboration. Although it was not internally put into question, the outcomes assessment is clearly part of the culture of this center which is led by physicians and economists who are used to assessing somatic healthcare.

3.2. The various controversies: three opposition areas

3.2.1. The KCE assessment process: a closed and concurrent process

As we have explained in detail in the sections about therapeutic projects and transversal dialog description, the objective of this policy was to produce, from various field experimentations, some standards for therapeutic networking, in order to be able to propose a general model that would be applicable to the whole sector. Presented like this, the initiative proposed a philosophy that consecrated a bottom-up process based on which the experimentation conducted by « field actors » would be essential for the expression of future needs.

So, it is interesting to note, as we did in a previous report (Vrancken, et al., 2008), that one of the reasons given for their participation in TPs is that a reorganization of mental healthcare was inescapable and that the best way to face them was to actively take part to them : « It is for being up-to-date ! » ; « I prefer being on the train and complain rather than not being on it and then have to face this ! » ; « It is really to keep up with the changes. »³⁹

³⁶ ICER = Ca - Cb / Ea - Eb (CLEEMPUT, 2008)

³⁷ Idem

³⁸ Anonymous extracts.

³⁹ Extracts of interviews with different TP coordinators.

The existence of this policy and the participation to it is often seen as an opportunity to take part to the definition of a new care model that would not be imposed by mental health authorities. So, for instance, in December 2006, the Hospital Institutions Federation (FIH) publicly announced in the « Confluences » magazine of the Walloon Institute for Mental Health (IWSM) that it would advise its members to take part to the TPs for several reasons:

« Because they are an experimentation place, an opportunity for field actors to tell but also to demonstrate what mental health networking can be [...] Because through transversal dialog, field actors will themselves be involved in the assessment of their collaboration work, and extract orientations for the future [...] By supporting the initiative, the FIH hopes that therapeutic projects will avoid the issues of a rigid model that is imposed, [...] but also the abstract and theoretical analysis which ignores the field reality, like some scientific studies that were conducted previously. » (IWSM, 2006: 23, free translation).

Transversal projects were often a place where participants to therapeutic projects denounced some rules and procedures that were against the principles of experimentation and network practice. If it was often said that network practice could not by nature be formalized, the danger of a prior formalization of experimental projects was unanimously pointed out by TP participants. So, in January 2009, a consensus note was signed by all TPs and most of the resigning TPs. This note, which was called « Therapeutic projects. Experimentation *versus* formalization? Consensus note », attempted to summarize several lessons learned from the TP experience but also listed some dangers that, according to them, were jeopardizing the ongoing experimentation. The signing parties then reminded that the experimentation was just starting and would produce its recommendations only several months later. Even if a complete section is dedicated to the work of the KCE, the concerns are mainly related to some rules and requirements that would enclose them in an administrative collar and would threaten the experimentation principle.

« The rigidity of the dialog framework gives also the feeling that for contracting parties, *formalization precedes experimentation* ! And the issue is there : the space provided to experimentation and its avatars is narrow and the hiatus between the « designed system » and the « real world » that has been generating misunderstandings and tensions between the bottom and top of the hierarchy since the process was implemented, has increased in 2008. »

The previous paragraphs reveal some divergences between TPs that wished to conduct an experimentation within a rather free procedural framework and the authorities which through the implemented system were framing and constraining the process. However, in order to understand the nature of the conflict it can be useful to go back to the very start of the process. The arrival of the KCE and the announcement of its quantitative study is surprising some candidates who did not expect it. They feel it is announcing un

more framed process compared to what they were expecting in the beginning when they started the process.

« The partners feel they were cheated by the assessment willingness of the KCE and therefore involved in a totally different process than the one that was expected to be implemented at the beginning. They also feel deceived because the use of scales was absolutely not in scope when conventions with the INAMI were signed : they really feel like they signed a « blank cheque » [...] In any case, the enthusiasm and spirit in which these « pilot projects » were implemented and written by the partners : as the name is indicating, a pilot project is about trying something ; it is a test, daily reorganization of professional practices with the flexibility required by this type of challenge and process. [...] The dominant feeling is the a noose is tightening, which is a sign of the lack of trust of authorities toward TPs which are, we must remind it, at experimental stage – « what did they do with us ? » some partners are wondering.»⁴⁰

This feeling of a « stolen » experimentation process and the importance of the pre-test made by the KCE for participants raises the more fundamental question of the research process conducted by the KCE. There we reach a central assumption. This rather closed research process, from which participants felt excluded, seems to explain most of the oppositions that crystallized about the assessment. If PTs regularly criticized the bad communication about the assessment and the fact that the KCE did not listen to them, we must also remind the importance for some actors of the fact the KCE made a pre-test and slightly adapted these questionnaires, and for others, the fact that the KCE never gave the possibility to review the research basics.

« We have the feeling that if the KCE had not enclosed itself in its ivory tower and had not tested its scales in collaboration with the sector, everything would have happened with more flexibility. »⁴¹

This exclusion could have been considered as a feat of strength by the KCE. To face this situation, the only liberty of some projects holders was to negotiate their participation in this policy, and even to resign for some of them.

« The KCE presented its vision. After that, there had to be a debate. It is pretty much simple, there was no debate at all. And the KCE said they understand but if you do not go through the scales, you will not get the funding. »⁴²

Actually, the analysis of the research process logics of the KCE can be further developed and seen through its missions and philosophy as a scientific center. As such, the KCE attempted to maintain its scientific independence and tried to keep away from political influences that were threatening the scientific aspect of its work. This dynamic within which the mental health sector feared the KCE research and its objectives and kept away from any interested influence, seems to have generated a vicious circle of reciprocal fear.

⁴⁰ Extract of minutes of the first transversal projects meeting. December 2007.

⁴¹ Extract of an interview with a transversal coordinator.

⁴² Extract of an interview with a TP coordinator.

In this context, any opposition to the sector could be interpreted as an attempt to defend one's personal interests and the KCE's intransigence could be interpreted by the mental health sector as the sign of a hidden agenda.

« I think the KCE is working in a paranoid way. For them, it a guarantee of independence. They want to keep away from the influence of the political world. This is maybe an illusion as the political world is leading most of the research. But in this case, there is also a big fear toward the mental health. »

« We have the feeling that the KCE will come out of its ivory tower and say: « here is the truth ! »⁴³

Indeed, as we said above, the scientific aspect of the KCE can be considered as its main characteristic as it played a key role in the assessment process. The scientific aspect can be defined through several elements described by the sociology of sciences (Latour, 2005) and the KCE's work can be compared to other descriptions made this sociology. We will remember in particular the distance or, as called by Callon, Lascoumes and Barthes (2001), the « big confinement » of science which tends to keep away from the influence of society in order to produce a « truth » that is free from any social factor. Indeed, in order to proceed with this anthropological approach of the scientific process, we will also not the proximity between what Latour (1991) called the big split between nature and culture or, in other words, between science and policy, and the explicit way in which the KCE defined its role.⁴⁴

The KCE, which was conscious that public action in mental health was produced by a permanent negotiation on several political stakes, does not intend to be the basis for political decisions in mental health. It wishes to leave this responsibility to the appropriate and legitimate actors. However, it is explicitly describing itself as being part of a second area which is scientific and parallel to the political area. On behalf of this conception, the KCE's legitimacy is not in the democratic process of its research but rather in the severity of its independent and autonomous procedures that ensure the scientific aspect of its production.

However, as noted by several authors and in particular Bruno Latour (2005) or even Michel Callon (1986), science is also a political process as it contributes to redesigning the world or the « community ». The KCE is aware of the challenges brought by its activities and intends to leave the final decision to the political authorities. It is therefore proposing a method in order to create a link between the political world and the scientific area it is representing. We are clearly within the configuration described by Callon, Lascoumes and Barthes (2001) in which, after a « translation » phase of the « real » into scientific data in laboratory, we go back to the field. Raising initial questions was essential in this research process – which the KCE seemed to be aware of -, and these

⁴³ Extracts of interview with a transversal coordinator.

⁴⁴ Here, we will rely, among others, on interviews with actors who wished to stay anonymous.

authors had noted the importance to include stakeholders as from this first stage in order to ensure a good functioning of the process and to facilitate the use of results.

Indeed, the failure of the KCE assessment and the many controversies it generated can also be interpreted as an issue in the « intersement » phase (Callon, 1986). Due to the feat of strength that was observed by actors taking part to therapeutic projects, the translation process that was implemented in this study seems to imply an enrollment without any intersement (Callon) within a very challenging process. Indeed, beyond the suspicions that some actors opposed to the KCE and its real objectives, the research conducted by the KCE, like any other research, is a translation process through which the relationships, identities and interests of different stakeholders are redefined. Practically, this redefinition had an impact on two aspects at least which, in addition to the process, crystallized the oppositions to the KCE research. It is, on the one hand, therapy and the underlying subject conception, and on the other hand, the therapeutic relationship. We will provide more details in the next two sub-sections.

3.2.2. Assessment in mental health: scientific naturalization Vs therapeutic subjectification

As we mentioned from the beginning, the KCE always claimed it did not wish to measure the different therapies efficiency, although it is authorized to do so. Indeed, if this kind of assessment is usual in somatic care, the existence of different psychotherapies and paradigmatic approaches makes this exercise quite complex, delicate and controversial in mental health (Champion, 2008). The controversies (that were observed from Belgium) which took place in France after the assessment conducted by the INSERM (2004) are clear illustrations of this. However, assessment in mental health implies the use of some tools, in particular diagnosis tools, which are closer to in their logics or even directly inspired by some approaches, and this can generate controversy and position them in the middle of challenges that are part of the paradigmatic allegiance to the different therapists. Even if this critic was less spread and did not seem to be significant in the assessment controversy, it however appeared useful to present an overview of it. Indeed, it was supported by some therapeutic projects and interpreted by the SPF and the KCE as one of the reasons for the assessment issues.

So, the SPF and the KCE have several times invoked the « *reluctances of psychoanalytic therapies [for which] it [assessment] is still a big taboo* ». Despite this, as far as participants are concerned, the opposition was seldom expressed as such, sometimes by directly invoking different therapeutic approaches, but never by using the paradigmatic opposition.

It is true that some people could have been disappointed by the requirement to make a diagnosis through international codes and therefore were « reluctant to using this specialized clinic vocabulary which does not belong to them ; [and let's remind that] this people « labeling » according to medical/psychiatric reference codes does not go without

saying for everyone »⁴⁵. However, this opposition was rather expressed through ethical arguments about two aspects⁴⁶ which are closely related to each other and which we will shortly present. In the below extracts, we will indeed observe two interconnected dimensions : on the one hand, the status change of the therapist, who becomes an investigator, and on the other hand, the impact of this change on the therapeutic relationship (a question we will address more in detail and from another perspective in the next sub-section).

« On the one hand, the frame in which the KCE conducted its research, its foundations and theoretical references had been generating lots of questions since the start of the process – in particular among the many professional actors which could not find any of their questions there. On the other hand, although the KCE kept saying, as the only response to the questions, requests and concerns that had been expressed again and again by therapeutic projects, that the collection and registration of the « patient's data » were only intended for the monitoring scientific requirements and had no clinic purpose, therapeutic projects which started to implement the scales on paper could already observe the sensitive impact of this operation on the clinic work and the **transferential link** with some involved patients [...] To say it shortly, on the field – beyond the recurring theoretical oppositions expressed by some projects members about the KCE's research features – the scales implementation can modify the clinic practice itself along with the patients ; so, there is a specific impact about which many practitioners are concerned, and they are right. »⁴⁷

As suggested by the previous extract, beyond the basic theoretical opposition, the KCE's study generates a specific issue about the therapeutic relationship in particular – the « transfer » (see above) being a psychoanalytic concept – for projects with a theoretical psychoanalytic orientation. The below extract is confirming the relationship.

« For some projects for which it is rather related to specific therapeutic approaches, they say they almost already reached their case-load. [...] They [...] think it definitely that was built with the patient. The practitioner must fill in some files with the patient and that can interfere with the therapeutic process. It is not the same role, it is about moving from the role of therapist to the role of investigator. And some psychiatry projects, in particular in Brussels, do not admit it. »⁴⁸

These different critics could be, in particular during the pre-test, more deeply addressed by some projects. So, the « Tehou-Teki » project said during the pre-test phase : « Ethically speaking, we can agree to a project that would consider our patients as

⁴⁵ Extract from transversal projects meeting minutes. December 2007.

⁴⁶ We will not pretend to cover the whole controversy here. Our intent is rather to mention two sticking points we should not have addressed.

⁴⁷ Transversal projects, Status of therapeutic projects on September 1st, 2009, p. 14

⁴⁸ Extract of an interview with a coordinator. October 2007

research objects and not as care subjects anymore »⁴⁹ and recommended an assessment about the « objectivable and subjectivable » dimensions.»

These controversy directions do reflect some observations made (see Champion, 2008) about the mental health assessment or more in particular regarding one of its diagnosis tools – which we find back here - : the « *Diagnostic and Statistical Manual of Mental Disorders* » (DSM). Indeed, these tools developed for comparison and therefore research are « focusing [...] on pharmacological and epidemiological research, as well as on their conditions optimization (large homogeneous group, minimum of involved actors, trustworthiness between actors, and so on.) [...] rather than the individual clinic approach of the practitioner [...] who [is] more intuitive and based on the relationship and context » (Widlöcher, 2001 : 239, 240, free translation). By doing so, these tools use a naturalist approach which is specific of the behaviorist and cognitive approach they come from on a psychoanalytic practice which is rather focusing on subjectivity, meaning, individuality and the therapeutic relationship (Castel, 2008).

3.2.3. Medical and sectorial autonomy: a reconfiguration of powers?

Finally, one last big stake must be addressed. The interferences generated by the KCE's assessment on the therapeutic relationship cannot be considered only from the paradigmatic conflict perspective. More fundamentally, the question of professional autonomy seems also to be involved with the introduction of a third (state) actor in the therapeutic relationship.

If this stake can also be related to other professions involved in in mental health like psychologists for instance, it is more specifically addressing the medical profession. Indeed, we know from Freidson (1984) that the main characteristic of the medical profession is its autonomy to define a diagnosis and organize its own activities. This autonomy is settled by the peer review and the fact that the profession is organized by institutions it is managing itself.

We will address the issue of the KCE assessment regarding professional autonomy through two observations.

First, we should remember the reasons why the generalists associations (FAG) were opposed to the assessment. These reasons were in particular regarding medical secrecy. The requirements were about (a) the anonymous aspect of data and (b) the need to have a therapeutic relationship with patients in order to have access to the data.

« We often had, with the patient's approval, to share data covered by medical secrecy with other health professionals who have a therapeutic relationship with him. [...] And this notion of therapeutic relationship seems essential to us to allow the sensitive data exchange. [...] The « eHealth » platform [...] which considers coded data sharing with Public Health, the KCE, the INAMI or health insurances, does not mention the

⁴⁹ Overview made by the TEHOU-TEKI project in collaboration with the Brussels PFCSM, page 4.

requirement to have a therapeutic relationship with the patient to access all or part his health data. »⁵⁰

Secondly, throughout the assessment history, the different actors expressed suspicions regarding the real objectives of the KCE activities. These actors also regularly expressed assumptions relating the tool existence with other elements like care rationalization and the implementation of a new care model (see beginning of the historical section), or the review of the minimum psychiatric summary (RPM) (see point 2.2) : « What is the intention of the KCE and/or the SPF behind all this ? Is it about collecting data to redesign the RPM ? ».⁵¹

To finish, let's remember that data encoding was planned to be performed through the eHealth platform. This platform, which was highly controversial in the medical world, does not hide its objectives of exchanging medical data between all actors of the healthcare system.

« First of all, the eHealth platform is public institution, implemented by the law, which aims at promoting and supporting the electronic and secure data exchange between all healthcare actors (physicians, hospitals, pharmacists, patients...) while respecting private life protection and medical secrecy. The objective is to optimize healthcare quality and to reduce administration for all actors. »⁵²

Regarding this, the SPF is aware of the stakes of telematic tools implementation in healthcare :

« **The telematic approach applied to healthcare** is about to modify on long term the relationship between the patient citizens and care providers. And this happens independently from where each and every one is. These changes have many technical and legal implications but also ethical, social and organizational implications. »⁵³

However, the change is not limited to this patient – care provider relationship being registered on computer, it is rather more fundamentally about opening the singular colloquium and introducing additional actors like scientific agencies and care administration. This reconfiguration of therapeutic relationships can in some cases lead to a reduction of the doctor's autonomy event if it is still partially ensured: « *The actors keep some liberty in their activities. It is also related to the fact that in the law, there is therapeutic liberty. We do not have the choice to provide some liberty.* »⁵⁴

⁵⁰ Communication of the FAG, June 24th, 2008

⁵¹ Minutes of the first dialog meeting. December 2007

⁵² Presentation page of the eHealth platform :
<https://www.ehealth.fgov.be/fr/homepage/index.html>
Consulted on September 25th, 2010.

⁵³ Presentation page of the « Télématique » project of the SPF Health :
<http://www.health.fgov.be/eportal/Healthcare/Telematics/index.htm>
Consulted on September 25th, 2010

⁵⁴ Extract of an interview with the delegate of the psychosocial care department of the SPF Health at TP launch.

Finally, we would like to highlight one assumption – which still has to be explained – that has remained beneath the surface so far. The reconfiguration of mental health is not only involving the doctor's relationships. Indeed, as we explained when putting it into context, mental health on the whole – as it is made of many institutions like hospitals - in history in Belgium has always been autonomous. Apart from the experience of the KCE assessment, the therapeutic projects policy is the most recent example thereof. In the definition of its procedures and general principles as well as in its participative philosophy, it is the revealing the liberty left to mental health so that it can integrate new care organization standards. Our interviews⁵⁵ revealed that the KCE was aware that it was opening a window in this traditional autonomy of mental health. Indeed, to face a sector that was used to discussing and negotiating its future, the KCE intended to propose a dissident way based on a scientific method so as to gain legitimacy and which it wanted to be independent and protected from all what it perceived as the constituted interests of mental health. The history of this tool is therefore also the history of power relationships that go far beyond the strict framework of the therapeutic projects policy. The medical profession involvement of a network that is extended to politically committed colleagues is also illustrating this power relationship.

⁵⁵ Our speakers asked to remain anonymous.

4. Conclusion: towards a new care paradigm?

What does the KCE assessment teach us about mental health evolution in Belgium? The history of this tool can be seen, through the negotiations that were conducted about it, as a succession of framing made by the KCE that would limit the scope of its research to the organization of care networks and overflowing⁵⁶ by participants who related its existence to many stakes which are external to therapeutic projects policy. There were very different therapeutic projects: willingness to reduce costs or to impose a new care model, impact on the therapeutic relationship, medical secrecy, status of the patient or the practitioner...

What can we say about that at the end of this research about this tool? If the importance of controversy that went along with this assessment tool helped us identifying issues it generated for the involved actors, its early death and therefore the fact that its results were not used, doesn't allow us to definitely determine its real consequences on the issues that were raised.

This specific tool has however some original characteristics that must be emphasized so that the tool can be positioned among the other healthcare tools of the same type which were developed. So, the tool developed by the KCE seems to be positioned in a different configuration than those studied by Castel and Dalgarrondo (2005). Indeed, these authors demonstrated that if the development of evidence-based medicine had significant consequences on the medical area internal relationships, care managers were not ready to use the data collected to control the medical profession. However, unlike the works about the development of evidence-based studies with research purposes and the objective to rationalize practices through the profession itself, the assessment developed by the KCE aimed at supporting the political decision of external actors.

Replacing the work of the KCE into the context of mental health evolution in Belgium and based on its promoters objectives, allows shedding another light on it. By « imposing » a reconfiguration of mental health, its promoters wish to position this kind of tool in « a collective action aimed at change » (Setbon, 2000 : 65, free translation). However, the « powers redistribution » (Ibidem) that this kind of tool can potentially generate in favor of managers and patients is an issue. Indeed, the example developed in this report reveals that even in this case where the assessment is addressing care organization and not therapeutic actions of professionals, the involvement of

⁵⁶ We refer here to the works of Callon (1999) on the analysis of externalities and of Callon, Lascoumes and Barthes (2001) on the technical democracy. They developed the notion of « framing – overflowing » based on the works made by Goffman (1971). The frame is defining a border between the inside and outside and allows providing a meaning to the actions and interactions within the frame. If any « framing requires a violent effort to extract involved actors [...] and put them on a delimited and specifically prepared stage » (Callon, 1999 : 409, free translation), a research (or any other action) can have effects or externalities on « beings » or external challenges which have a predefined frame : these are the overflowing that were denounced by some actors.

professionals into the project is a very helpful. On the other hand, the fact that patients and their associations were not very concerned about the assessment is revealing that they could not find their « spokesman » (Callon, 1986) in a study that was intended to represent their interests.

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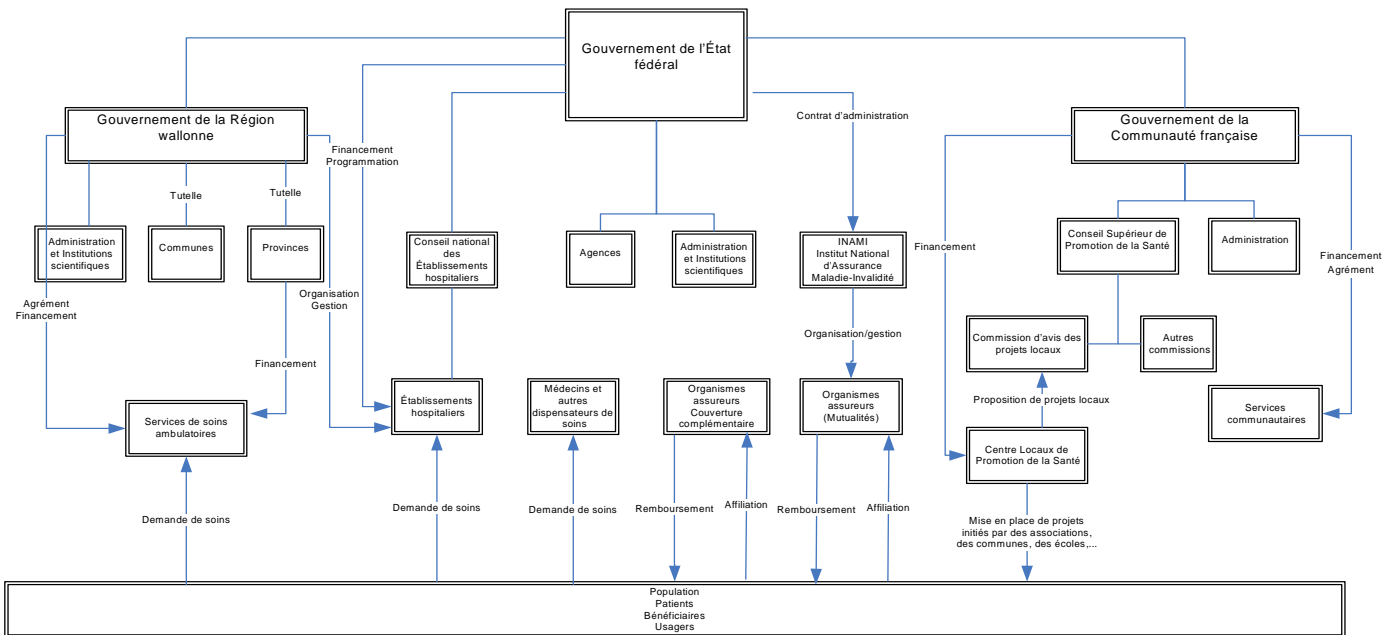
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Appendices

Appendix 1 Organization of mental health in Wallonia

Secteur de la Santé en Région wallonne



Appendix 2
Organization of transversal dialog

