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"Valuing the quality of life of the mentally ill persons in France through the best available tools"

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LIST OF ACRONYMS

BDSP: Banque de Données en Santé Publique (French database on Public Health issues)

DALY: Disability-Adjusted Life Year

DSM-IV: Diagnostic and Statistical Manual for Mental Disorders, 4th edition

EURONHEED: European Network of Health Economics Evaluations Databases

EQ-5D: Euroqol 5 Dimensions

GDP: Gross Domestic Product

ICD-10: International Classification of Diseases, 10th edition

IHEA: International Health Economics Association

LQOLP: Lancashire Quality of Life Profile

MSQoL: Modular System for Quality of Life

QALY: Quality-Adjusted Life Year

QLDS: Quality of Life in Depression Scale

QLQ: Quality of Life Questionnaire

QLS: Quality of Life Scale

QoL: Quality of Life

QOLI: Quality Of Life Interview

QWB: Quality of Well-Being scale

RIM-Psy: Recueil d'Information Médicalisée en psychiatrie (national system to collect medical information in psychiatry)

RCT: Randomized Control Trial

SAS: Statistical Analysis System

SEIQOL-DW: Schedule for Evaluation of Individual Quality of Life - shorter Direct Weighting

SF-36: MOS 36 Items Short Form Survey

SFS: Social Functioning Scale

SIP: Sickness Impact Profile

S-QOL: Schizophrenia Quality Of Life scale

SWN: Scale to Measure Subjective Well-being under Neuroleptic Treatment

TTO: Time Trade-Off

URC Eco: Unité de Recherche Clinique en Economie de la santé (Clinical research unit specialised in health economics)

VAS: Visual Analogue Scale

WHO: World Health Organisation

WHOQOL: WHO quality of life assessment

I. Introduction

The present document falls within the scope of the validation of a Public Health Master for which I undertook an internship at the URC Eco, the clinical research unit specialised in health economics for the Ile de France region. During this practical experience, I was involved in a project aimed at evaluating the mental disease burden for the French population. Especially, I worked in close collaboration with Amélie Prigent who is responsible for the project follow up.

Indeed, mental disorders, due to their prevalence, represent a considerable part of all the diseases affecting the population worldwide, in Europe and more specifically in France. They result in significant deleterious consequences for those who suffered from them. Nevertheless, few studies are available establishing the economic impact of these disorders. Thus, the URC Eco decided to undertake a study to evaluate the costs of these diseases for the French population. In particular, the study goal is to measure the quality of life losses for patients care for in psychiatry settings in France. However, to perform the field study necessary to determine the quality of life from the perspective of the patients, it was essential to identify the best tool to use in order to obtain valid results pointing to conclusions adapted to the reality of the context. For this purpose, I undertook a systematic literature review to identify best available tool(s).

The object of the present document is to detail the literature review performed from its definition to the discussion of the results obtained based upon a selection of articles made in March 2010. I will firstly describe further the context of intervention in order to define the research question and objectives. Then, I will expand upon the conceptual framework upon which the research was based before establishing the methods to address the question and objectives. Finally, from the analysis of the results, I will discuss the general frame of the quality of life measurement tools utilisation and draw conclusions with respect to the instruments appropriate for a survey in psychiatry, in France, based upon the currently available information.

II. From context to problematic: justification of the project

II.1. Mental disorders: real but neglected epidemiologic and economic burden

Worldwide, the prevalence of psychiatric disorders and the resulting costs for the health systems are significant. Surveys conducted in developed as well as developing countries have shown that more than 25% of individuals develop one or more mental or behavioural disorders during their lifetimes [1]. The World Health Organisation (WHO) estimated that, in 2002, 154 million people were suffering from depression and 25 million people from schizophrenia [2].

At the **European level**, mental health is currently one of the biggest challenges facing each country. Thus, out of 870 million people living in the European Region of WHO, 100 million are estimated to suffer from anxiety and depression and 21 million from alcohol-related disorders, for example. Neuropsychiatric disorders account for 19.5 % of all disability-adjusted life-years (DALYs – years lost due to ill health and premature death). They also account for over 40% of chronic diseases [3].

Meanwhile, **in France**, the most recent statistics show that 5 to 7.8% of French people have suffered at least one diagnosed depressive episode. In 2007, 16.3 per 100.000 inhabitants committed suicide (representing around 2% of all causes of death). It is also estimated that 1% of the population suffers from schizophrenia [4]. Regarding persons who access services, the data from the national information system (RIM-PSY[1]) revealed that around 1.7 millions patients were followed in a public setting for psychiatric care during the year 2008. These data have to be considered cautiously due to the recent introduction of this monitoring system which remains incomplete. But it still gives and indication of the magnitude of the need for care in this area.

From a medico-economic perspective and based upon the need to rationalise the spending within health systems, some foreign studies estimated the economic and social costs of mental disorders, especially England [5] and Canada [6]. These studies measured direct costs to the health care system as well as costs related to productivity and quality of life losses. For this purpose, one year of life in perfect health, lost due to a mental disease, was valued at the level of the Gross Domestic Product (GDP) per capita. Consequently, the costs of quality of life losses were estimated at 54% of the overall mental disorders costs in England and 55% in Canada whereas, the costs for the health care systems accounted only for 16% and 10% of the overall costs, respectively. Thus, these studies suggested that investments in the health system may produce important benefits in terms of productivity and quality of life for patients.

In France, the health accounts per pathology estimated that mental illnesses represented 10.6% of medical care and services consumptions in 2002, making it the second most costly item of the overall health expenditure [7].

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[1] RIM-PSY : national information system for all public psychiatric institutions introduced in 2006 in order to allow the valuation of the activities undertake and to realised medico-economic evaluations

These pieces of evidence highlighted the existing burden due to mental illnesses for the health system, society and the individuals who suffered from them. Nevertheless, despite the crucial need to consider this aspect of health, the literature reveals a gap between this need and the level of involvement of the different related stakeholders.

II.2. From questioning to the definition of a study centred on the patient

In France, few data are available exploring in depth both direct and indirect costs of mental disorders as a whole. Such data are essential to better understand the economic consequences, to identify efficient strategies to fight these diseases and their consequences at individual and collective levels, and to determine fair and efficient financing mechanisms [7].

Thus, to evaluate the economic and social burden of mental disorders over a year in France, the URC Eco conducted a study in order to determine the costs of mental disorders among the general population. This study was undertaken in collaboration with the FondaMental foundation, created in France in 2007 to support research in the psychiatric field. The results showed that mental illness costs represented a total of **€109.2 billions** in 2007. The study considered four types of costs: medical costs (€13.4 billions), the costs borne by social services (€6.3 billions), productivity losses (€24.4 billions) and the quality of life losses (€65.1 billion). The costs related to quality of life losses represented 60% of the total costs and, on average, mentally-ill people have 30% lower quality of life comparing to persons without psychiatric disorders. Yet, this measure was performed with partial data from a study of the general population living in households which did not include patients receiving residential institutional care.

These results brought new insights regarding the economic burden of mental illnesses in France and the significant share of the indirect costs. But, due to the limitations of the previous study, the picture of the impact from the patient’s perspective was still incomplete. Moreover, the nature of the study and of the available data did not allow identification, within the global overview, of more precise information, such as the pathologies considered, the structures of follow up or other characteristics of the patients and type of care.

It seems important to get a precise measure of the quality of life in order to integrate the perspective and needs of patients when evaluating for example the benefit of an evolution of practices. For this reason, the URC Eco decided to undertake a field study including persons suffering from mental disorders followed either in hospitalisation, in a day care service or in an ambulatory setting. The goal of this study is to value the overall quality of life and the quality of life per group of pathologies in order to allow for some elements of comparison between these groups.

For this study, the research questions are:

- What is the impact of mental disorders on the quality of life of the adult population followed in psychiatry, in France?
- Is this impact linked to the characteristics of the pathology and/or with the setting of care?

The mental disorders examined were defined based upon the ICD-10[2] as this is the classification used for data collection within the RIM-Psy system. The pathologies included are detailed in *Annex 1*. Five main groups were determined after consultation with specialists, specifically:

- Mental and behavioural disorders due to psychoactive substance use,
- Schizophrenia, schizotypal and delusional disorders,
- Depressive disorders,
- Neurotic, stress-related and somatoform disorders,
- Other behavioural and mental disorders.

The design of this study includes the administration of quality of life measurement tools to patients. This in turn requires tools that are validated and adapted to the research questions.

During my internship, I participated to various steps from the conception to the practical organisation of this ecological descriptive survey. A summary of the study protocol with these steps is presented in *Annex 2*. Nevertheless, as the overall study is still in process and includes broad aspects that cannot be treated in the limits of this document, I choose to focus on one particular element which is the definition of the best available tools to measure the quality of life consistent with the criteria of the larger study. Indeed, for this specific part of the study, I was fully involved and was able to pursue it from the beginning to end.

II.3. The need to identify an appropriate tool for quality of life measurement

To measure the quality of life of the adults followed in psychiatry in France, the choice of an appropriate tool implies consideration of the following constraints related to the research questions:

- The instruments should be adapted to all pathologies included in the scope of the study.
- The study aims to evaluate the quality of life of patients cared in different kinds of settings. Thus, the tools should be usable in both hospital and ambulatory settings.
- The study is undertaken in France. The tools should be validated for this context meaning available in French and adapted to the socio-cultural context of this country.
- The study is from a medico-economic perspective. The scores obtained from the chosen instruments should then be transformable into utility[3] data.

After consulting reference books and articles on this topic, I quickly understood that the field of quality of life measurement tools was vast and complex. Thus, the need to undertake a literature review in order to bring a sufficient level of evidence for the choice of the best tool from which the results would be acceptable and fully recognised as representing the reality of the study population became obvious.

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[2] ICD-10: International Classification of Diseases, 10th edition

[3] The concept of utility will be defined in a subsequent part, page 13.

III. Objective

Considering the context described, the general objective of the literature review is:

- **To identify the quality of life measurement tools best adapted for a study whose goal is to evaluate the quality of life of adults followed in psychiatry, in France, in both public and private structures, including hospital and ambulatory settings.**

To bring a comprehensive answer to this objective, several secondary objectives were defined:

- To get a general overview of the range of applications of the quality of life instruments in psychiatry and of the evolution of the use of these tools.
- To identify the different tools used in the psychiatric field and their characteristics.
- To define the validity elements of the identified tools in light of the research criteria.

IV. Conceptual clarification

Before establishing the methodology to answer the objectives of the literature review, it is first necessary to define the concepts on which I based the research.

IV.1. Field of study: mental illness

The research unit is undertaking a study to measure the quality of life of patients suffering from mental disorders in order to evaluate a potential gap between this population and the population in *good health* regarding this indicator. Thus, some elements of definition are necessary to frame the field of study and then to bring results within the scope of this framework.

Thus, whereas it seems widely recognised that a ***good* mental health** is broader than the absence of clinically defined mental disorders, the debate is still open regarding the elements necessary and sufficient to define a state of positive mental health or well-being. According to the WHO, it is a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community. *“It includes subjective well-being, perceived self-efficacy, autonomy, competence, intergenerational dependence, and self-actualization of one’s intellectual and emotional potential, among others. [...] Mental functioning has a physiological underpinning, and is fundamentally interconnected with physical and social functioning and health outcomes”.* [1]. A French definition [4] summarizes these aspects by stating that mental health corresponds to a positive state of equilibrium and harmony between the structures of the individual and those of its environment to which he/she should adapt[4].

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[4] Full definition of mental health according to the French report mentioned : « *la* ***santé mentale positive*** *fait référence, soit à un état de bien-être, un sentiment de bonheur et/ou de réalisation de soi, soit à des caractéristiques de la personnalité (résilience, optimisme, capacité de faire face aux difficultés, impression de maîtriser sa vie, estime de soi). C’est un état positif, d'équilibre et d’harmonie entre les structures de l’individu et celles du milieu auquel il doit s’adapter. C’est la part de « santé » dans la santé mentale, qui ne se définit pas seulement par l'absence de troubles mais comme une capacité dynamique, voire comme « un effort permanent, une perpétuelle conquête de l'autonomie ».*

This health state should not be seen as the opposite of mental disease as, according to the literature, there exists an intermediary and usually transitory state of **psychological distress** or psychical suffering that does not necessary reveal a mental disease but that could be a reaction to a specific situation.

Regarding **mental and behavioural disorders**, they are "understood as clinically significant conditions characterized by alterations in thinking, mood (emotions) or behaviour associated with personal distress and/or impaired functioning. Mental and behavioural disorders are not just variations within the range of *normal*, but are clearly abnormal or pathological phenomena." [1] They refer to diagnostic classifications that meet specific criteria and require targeted therapeutic actions. Several international classifications exist, including:

- The International Classification of Diseases, 10th edition (ICD-10), [9]
- The Diagnostic and Statistical Manual for Mental Disorders, 4th edition (DSM-IV). [10]

These instruments distinguish different pathologies, as well as groups of pathologies, based upon precise and defined symptoms.

IV.2. Dimension studied: quality of life

Based upon the research question, the dimension of study is quality of life. But, the various philosophical, sociological, political and medical foundations underpinning quality of life lead to the construction of a heterogeneous concept for which it is difficult to set limits. Indeed, no consensus exists regarding a common definition of quality of life outside of the context of application and on the theoretical models to which it applies. [11] [12] In the literature, several theoretical models that may frame the quality of life concept were encountered: [13] [14] [15] [16]

- An objective point of view of quality of life taking into account criteria linked to people's resources and their integration in their physical and social environment;
- The health-related quality of life taking into account the functional capacities, the psychic symptoms and the perception of the individual regarding his/her health as well as his/her expectations for the future;
- The satisfaction of the individual in various domains of life.

Increasingly, authors conclude that it is important to combine these models and to consider both objective and subjective aspects of quality of life.

The first reference to the quality of life can be attributed to Aristotle (384-322 AC). Nevertheless, the term "quality of life" appeared in the language only in the 1950s in the economic and social sciences. Since then, the interest in this concept has grown to become an essential component of the evaluation as well as the health care process. This interest was accompanied by an evolution of the concept and its applications. For instance, its use in the field of psychiatry did not appear until the 1980s. The late introduction of the evaluation of the quality of life in psychiatry was due to the difficulty in dissociating it from the psychiatric symptoms and to give a value to the patient's opinion. However, today this difficulty seems to have evaporated as several works on this subject are published each year. [17] [18]

The quality of life concept is still in evolution, and several definitions exist. In order to consider a broad perspective, I chose to apply the global and relatively unrestricted definition of the WHO, which defined the concept of health-related quality of life by taking into account its objective and subjective aspects. [19]

Indeed, after 1948 definition of the health as "*a state of complete physical, mental and social well-being*" [20], the WHO defined quality of life as:

"Individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept incorporating in a complex way the persons' physical health, psychological state, level of independence, social relationships, personal beliefs and their relationships to salient features of the environment." [21]

With respect to the application of this concept, a review of literature [22] identified four different uses of quality of life measurement in the medical field:

- For health needs assessment of a population,
- For the planning of adapted clinical care at individual or collective level,
- As an outcome measure considering a treatment or an intervention,
- For health economic studies and resources allocation.

For these different uses of the quality of life measurement, specific tools are needed.

IV.3. Quality of life measurement tools

After defining the quality of life concept and its fields of application, it is necessary to focus on the instruments that allow understanding of quality of life quantitatively and sometimes qualitatively, within their specificities and their psychometric properties.

As the definition and theoretical models underlying the quality of life concept are diverse, tools to measure it are numerous and various. The spectrum of tools is wide ranging from a single question to assess quality of life to complex instruments measuring several items organised in several dimensions and requiring the use of algorithms to define one or several quality of life scores. Nevertheless, standards exist to validate within a population and a specific context the results obtained.

IV.3.1. Elements of classification

To define the instruments and understand their scope and differences, several characteristics have to be considered. [11] [22] [12] [23]

First, the quality of life measurement tools can be generic or specific to a disease. **Generic tools** aim to measure the quality of life of the general population whatever the health or illness status of the questioned individuals. Their advantage is to allow comparison between different groups of persons or different diseases. These tools are often built to be cross-cultural. The **specific instruments** are developed to measure the quality of life of patients suffering from a particular illness or group of illnesses (e.g. instruments used only with respect to mental disorders). They aim at considering the specific concerns of a particular condition. They are generally more sensible to changes related to a treatment or a medical intervention and thus are very useful in therapeutic trials.

Second, the tools' distinction can be analyzed based upon their objective or subjective evaluation. **Subjective** measures rely on the evaluation made by the patient himself of his/her own quality of life. **Objective** measures are performed by the relatives of the patient or by the medical staff. They rely on objective criteria evaluating the health state of the individual and its capacity to adapt to his/her environment in a *satisfactory* manner and in order to *satisfy* his/her needs. Recent works seem to agree that the perspective of the patient is essential in order to get a coherent picture of his/her quality of life. But, due to possible distortions of reality or potential cognitive deficiencies induced by the condition of the subject, the need to combine subjective and objective measures is often considered.

Third, we could distinguish one-dimensional versus multidimensional instruments. **One-dimensional** tools consist of a single question or of several items clustered in one dimension. These tools measure either the quality of life in a global perspective or, they are specific to one aspect of quality of life. On the other hand, **multidimensional** tools measure the different dimensions comprised in quality of life according to the definition adopted by the authors. They permit one to obtain several scores, one for each dimension. Some questionnaires accept, based upon the development of specific algorithms, the possibility to translate these different scores in one single quality of life index.

From a practical point of view, it is apparent that some instruments may be **self-administered,** while others are administered through an **interview**; certain tools may be used in either way.

IV.3.2. Psychometric characteristics

Regarding the tools' specificities, it is important to consider their psychometric characteristics that allow predicting the validity of the results. Validation of an instrument is the process of determining whether there are grounds sufficient to believe that an instrument measure what it is intended to measures. The validation is specific to a context or to a population. For example, a tool that is valid in Canada may not be valid in France for reasons of cultural adaptation.

The acceptance of a scale or questionnaire requires three main psychometric qualities: sensitivity, validity and reliability to which we may add harmlessness, low cost and rapidity of administration. [11] [24] [25]

- **Sensitivity**

Sensitivity is the ability of an instrument to detect small changes in the quality of life of an individual or to identify the variations between different states. Meanwhile, to be sensitive, an instrument should not vary or allow only small variations if several measurements are performed during a period in which the state of the individual or sample is stable.

- **Validity**

Validity refers to the pertinence and possibility of justifying statements made from the scores of a test. [26] Three validity criteria exist.

Content validity relates to the adequacy of the content of an instrument in terms of the number and scope of the questions it contains. It considers the conceptual definition of the constructs being assessed. It means, on the one hand, the credibility or face validity given to the tool related to a subjective judgement and its acceptance by the subjects. It depends on the way the questions are formulated and whether they can be understood without ambiguity. On the other hand, it means to evaluate the pertinence and exhaustiveness of the tool. This implies that the content was precisely defined through the consultation of the literature, experts and/or patients.

Structure validity allows evaluation if the items of a dimension are better correlated between them rather than with items of other dimensions, and then if they form a coherent whole.

Measurement tools evaluate *constructs* meaning abstract aspects not directly perceptible. The **discriminant validity** is usually judged on the degree of correlation between the tool and a gold standard. Nevertheless, this reference does not always exist. We may then use approximations such as the accumulation of convergence and divergence of the results obtained through different methods. Moreover, the stability of the factorial structure (sum of the conceptual dimensions included in the model) of the tool for different samples may indicate construct validity.

- **Reliability**

A tool should have temporal stability and internal consistency. Reliability refers then to the stability of the measure over the time and the capacity of a tool to illustrate precisely the underlying phenomena.

The **test-retest reliability** substantiates the stability of the results over time for a same sample for which the studied state is stable. The stability of the results is also tested on the evaluators in the case of interviews. The Pearson’s correlation coefficient is generally used when dealing with continuous variables. Otherwise, the Kappa’s concordance coefficient is used.

The reliability may also represents, when applicable, the level of inter-rater agreement. It consists of evaluating the agreement between the judgements of two different persons.

The **internal consistency** evaluates the homogeneity of different dimensions of the construct. It encompasses, for each dimension, the consistency of the items, which should represent the same concept with different wordings. The internal consistency can be measured using Cronbach’s alpha coefficient.

IV.4. Valuation of quality of life and the medico-economic perspective

After describing the general picture of the quality of life measurement tools and their characteristics, I will focus on a specific field of interest for the study which is the economical perspective associated with the quality of life concept.

IV.4.1. Quality of life from a medico-economic perspective

Nowadays, in a world of limited resources, economic analysis may facilitate physicians and decision makers' decisions regarding the best ways to use social and individual resources for clinical resources [27]. For instance, cost-effectiveness and cost-benefit analysis aim to compare the costs and effect of one or several interventions. [28] For this purpose, it might be necessary to express the outcomes of an intervention using a common scale, generally using the technique of utility analysis. The utility represents the weighted sum of the preferences associated to a health state for different domains of life and under situations of uncertainty. [29]

The results obtained with some quality of life measurement tools can be transformed into utility scores and more specifically into QALYs (quality adjusted life years). Thus, the concept of QALY measures the utility associated with a health state. It was developed in the 1960s in order to compare outcomes expressed through different indicators or units. Indeed, they allow translating these units based upon algorithms that value a health state, taking into consideration the preferences associated with this health state. The utility of a health state is then expressed on a scale from “0” to “1” where “0” corresponds to the utility of the state “death” and “1” to the utility of the state of “optimal health”. The more the quality of life associated to a health state is low, the more the utility score on the scale is low. Thus, QALYs provide a synthetic measure that takes into account the quantity and the quality associated with the health state.

QALYs are then used to compare different interventions by weighing their costs against the benefit obtained in terms of *good* quality years of life. They also permit evaluation of the burden associated with a specific condition for the individual or for society.

IV.4.1. Valuation methods

In order to establish utilities or QALYs from the quality of life tools, three methods to measure preferences associated with a health state are frequently used: visual analogue scales, time trade-off technique, and the standard gamble technique. [30] [31]

With the **Visual Analogue Scales (VAS)**, the value of a health state on a scale from 0 to 1 is obtained by asking the subjects to directly rate this state on a linear scale.

For the **time trade-off technique (TTO)**, two alternatives are proposed to the subject:

- To be in a state i for a time t followed by death or
- To be in an optimal health state for a time x.

We vary x until the answerer is indifferent between the two alternatives, which indicates the length of life in an altered health state the person is ready to give up in order to reach an optimal health state.

With the **standard gamble technique**, two possibilities are offered to the answerer:

- To take a treatment for which he has the probability x of going back to a normal life for a time t and a probability $(1 - x)$ of dying immediately or
- Not to take the treatment and live a certain number of years in a certain chronic condition.

We vary the probability of dying immediately $(1 - x)$ until the answerer is indifferent between the two alternatives.

These valuation methods are performed in the general population to associate preferences to a health state described by a quality of life instrument. These tools usually describe a significant number of distinct perceived health states (for example 243 for the EQ-5D scale). Then, only one sample of these health states is valued directly by the general population. The preferences associated to the other health states are derived from the preferences initially defined. These measures permit researchers to obtain value sets that aim to translate the answers from a questionnaire into utilities. Nevertheless, it is important to consider that these value sets are available for few instruments and were established from populations specific to a country and to a period of time.

V. Methodology of research

After defining the context and some key concepts with respect to the research, I elaborated the related methodology. Thus, in order to realise this systematic literature review, I based the findings on scientific articles from different databases as well as a few referent documents from the grey literature.

V.1. Selection criteria for the articles

V.1.1. Inclusion criteria

Articles from France, where the study was performed, were favoured, but the research was not limited to this context in order to obtain a broader overview. Nevertheless, the search was limited myself to countries where the societal and medical culture is similar to the context of interest.

- Period of inclusion: articles published between 1995 and February 2010. The search was limited to a fifteen years period for reasons of feasibility, and also to take into account the contexts evolution and the necessity to use tools that are currently valid.
- Publication languages of the documents: English or French.
- Articles that refer to the measure of quality of life through an identifiable instrument.
- Population of study: at least a part of the population studied should suffer from a mental disease as defined in the protocol of the ecological survey to be performed (*Annex 1*).

V.1.2. Exclusion criteria

- Country of study: outside Europe, North America and Australia.
- Population of study: exclusively under eighteen years old.
- Scientific articles without abstracts, editorials and correspondence.
- Articles referring to a similar study. In this case, when existing, the article studying the validity of the quality of life tool used was preferred. Otherwise, only the first article published was considered.

V.2. Sources of information used

The search engines selected to perform the literature review were the following [32]:

- **PubMed** (Medline database). Produced by the National Library of Medicine (United States), the database is one of the best worldwide and the most frequently used. It is freely available since 1997.
- **Embase**. Produced by Elsevier in the Netherlands, this biomedical anglophone database is equivalent to Medline, with an emphasis on European coverage.
- **Psydoc**. This database comes from a project led by the French psychiatric federation that aims to facilitate access to the literature, increasing the link between different disciplines and highlighting French scientific works in psychiatry. It includes the abstracts of articles published in French psychiatric journals since 1997. It was important to include this source of information in order to access articles related to mental health from the French literature.
- **EURONHEED (European Network of Health Economics Evaluation Databases)**. This network was initiated in 2001 from the International Health Economics Association (IHEA), with the goal of implementing databases with respect to economic evaluations of health interventions in various European countries. This allowed us to access articles with an economic perspective and related to the European context.

Moreover, a search on WHO, BDSP (Banque de Données en Santé Publique) and European Observatory on Health Systems and Policies websites was performed to complement the information gathered in the scientific literature with generic documents on mental health, quality of life and related measurement tools.

V.3. Identified keywords

To facilitate the search of the corresponding articles in the different databases the following keywords were identified:

- *Quality of life* AND
- *Mental health* OR *Mental disorders* OR *Psychiatry* OR *Schizophrenia* OR *Addiction* OR *Psychoactive substance* OR *Neurotic disorders* OR *Behavioural disorders* OR *Mood disorders* OR *Depression*. These keywords relate to the different diseases included in the scope of the research. AND
- *Measure* OR *Evaluation* OR *Cost* OR *Outcome*.

These keywords were defined after reading approximately fifty abstracts of articles on the subject in order to identify the appropriate terms related to the objective and to the scope of the review.

V.4. Definition of a reading grid

To establish a reading grid, I focused on the objectives of the literature review. A total of 37 variables were identified and pertain to the following categories (detailed in *Annex 3*):

- Characteristics of the article: title, author's name, year and journal of publication;
- Type, place, main objective and perspective of the study;
- Studied population: type (age, sex, disease), sample size, structure of care;
- Quality of life measurement tools used and their characteristics;
- Validity of the tools: psychometric characteristics, adaptation to the study context;
- Choice of the tool;
- Other measurement tools used.

V.5. Analysis performed

After identifying the articles considering the inclusion and exclusion criteria and completing the reading grid, the results were analysed through the following steps:

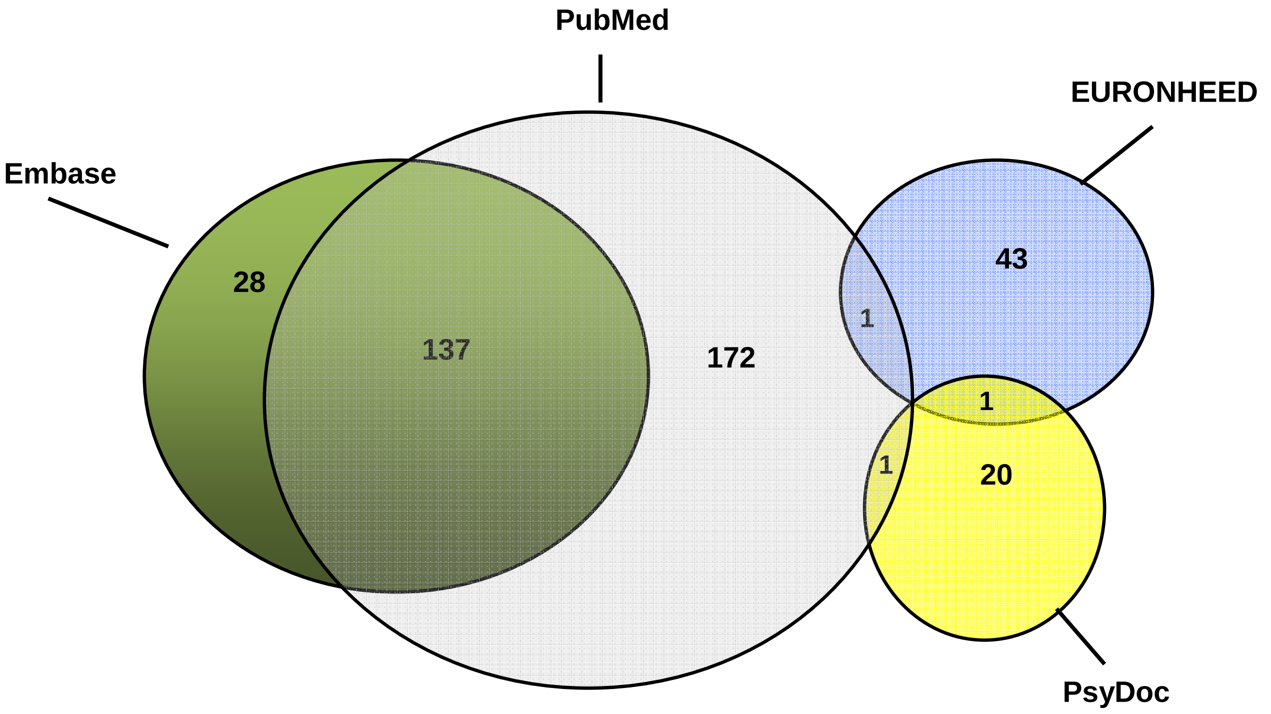
- Descriptive univariate analysis using Excel®.
- Listing of the different quality of life questionnaires used.
- In-depth research on the different identified tools regarding their characteristics (creation date, author, country and language of creation, number of items and dimensions, type of dimensions, duration and manner of administration, type of scoring system, type of quality of life measured, type of population studied, period of evaluation considered) and elements of validation (context of validation and psychometric characteristics validated). Indeed, the initial articles reviewed did not allow access to this full panoply of information.
- Establishment of a common database from the initial reading grid and the information gathered during the second phase of bibliographic research.
- Bivariate analysis to determine potential correlations using SAS®.
- Establishment of a decision tree from the criteria defined initially to identify the best adapted quality of life measurement tools.
- Discussion about the results and conclusions.

VI. Results

VI.1. The process for selection of articles

Using the defined keywords and then eliminating any duplicate articles, **401 articles** were identified from the four databases that fit the research. Moreover, while examining the articles, I identified **two** additional studies for which inclusion in the list seemed essential to me, for a total of **403** articles.

Figure 1: *Repartition of the articles in the different databases*

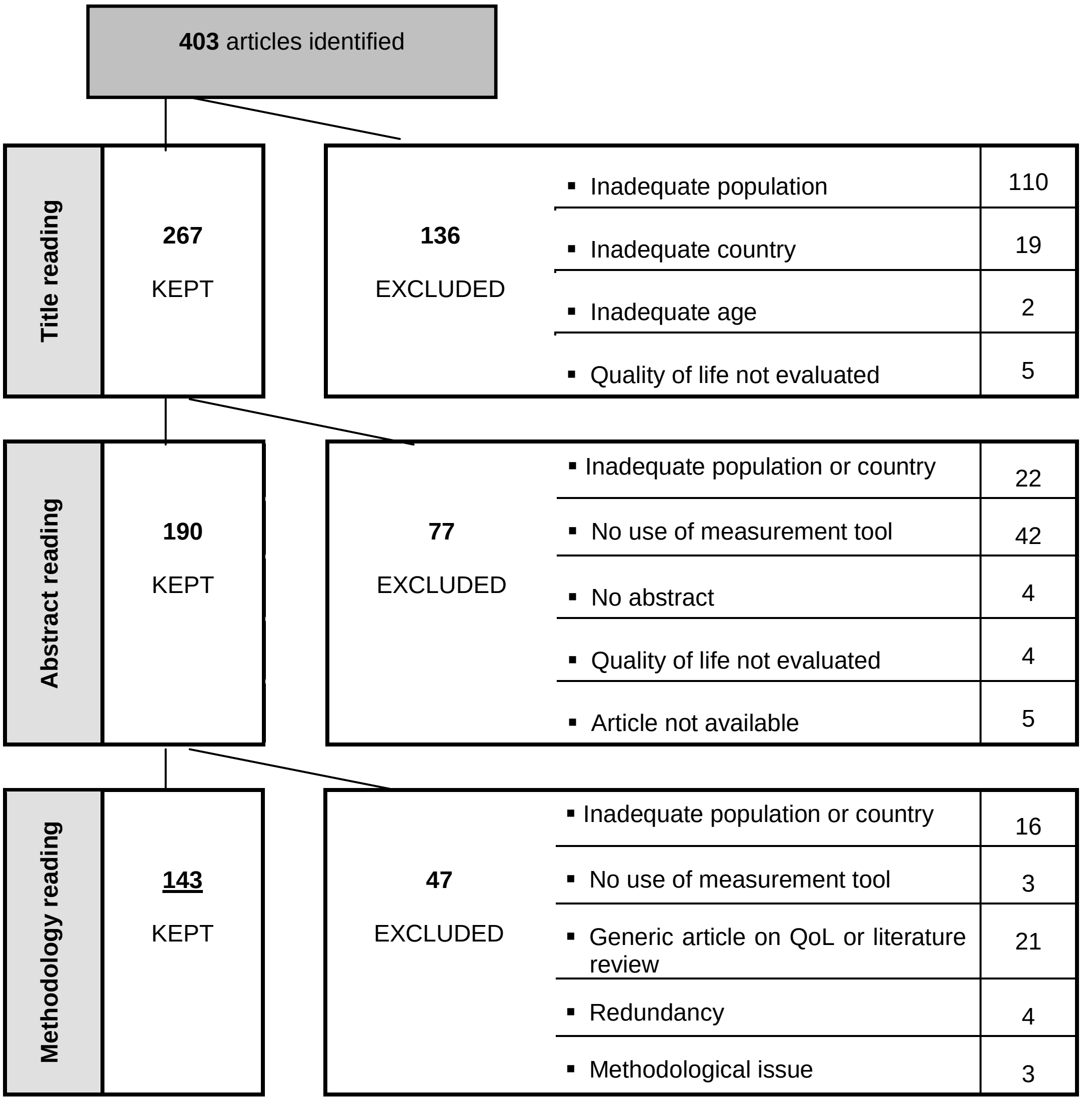


For the databases PubMed and Embase, the keywords had to be present within the title of the article except for "*Measure"* OR "*Evaluation"* OR "*Cost"* OR "*Outcome*" which could also appear in the abstract.

As the Psydoc database is specific to mental diseases and yielded a limited number of articles, I used only the keyword "*Quality of life". * Similarly, for EURONHEED, which is specialized in medico-economic studies, I opted for the selection "mental disorders" in the pull-down menu for the type of pathology. A posteriori, with the abstract, the articles not related to the field of study were eliminated.

Among the 403 articles, the selection was performed in several steps based upon defined inclusion and exclusion criteria. The figure below sums the selection process of the **143 articles** included in the literature review. The list of these articles is available in *Annex 4.*

Figure 2: *Selection steps of the articles*



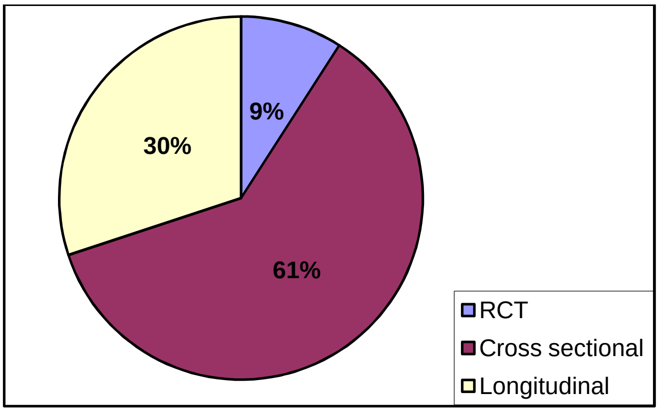
VI.2. General framework of the tools used

The selection focused on articles published in the past fifteen last years (1995-2010). As far as the number of publications is concerned, I could observe a positive evolution in succeeding five years periods (33 articles for the period 1995-99, 45 for 2000-04 and 63 for 2005-09). This constant growth highlights the greater attention of the scientific community and physicians to the importance of measuring quality of life in the mental health area. Indeed, measuring quality of life of patients with chronic diseases of a physical nature has become common in recent decades. Nevertheless, the introduction and development of this type of measure in psychiatry is more recent, as noted above. Quality of life slowly developed as an outcome to consider when evaluating treatments or interventions in the mental health field, and the growing number of validated measurement tools in various contexts supported this evolution. Several articles in the literature review emphasize this evolution [17] [33] [34] [35].

VI.2.1. Characteristics of the studies

Three main **methodological models** allow the inclusion of the quality of life measure as a study variable.

Graph 1: *Methodological type used in the studies (n=143)*



* *RCT: Randomized Control Trial*
*** Cross sectional: Punctual observational studies*
****Longitudinal: Longitudinal observational studies*

Thus, for the quality of life measure in mental health, most of the studies (91%) use observational methods and, often results are based on data collected at a particular time (cross sectional type) (61%). Randomized control trials are essentially used for the evaluation of interventions or treatments (33% of these studies), but for other types of studies only 5% used this type of method. As a consequence, most of the authors state as a limitation to their studies the difficulty of generalising the data obtained or concluding on a prognosis of the evolution of the quality of life of the studied population over time.

With respect to the **main study objectives**, five groups for consideration of the selected articles were defined. These groups were identified taking into account the perspective of the quality of life measurement tools used. Indeed, because of the literature review objective, the study objectives were evaluated based upon the quality of life measure even when it was not the primary focus.

Table 1*: Main objective of the studies (n=143)*

	Number of studies	**%**
Evaluation of correlation between quality of life and predictive factors	82	57.3%
Evaluation of an intervention/ treatment	21	14.7%
Validation/development of a measurement tool	17	11.9%
Evaluation of psychometric characteristics of tool(s)	10	7.0%
Comparison of measurement tools	9	6.3%
Others*	4	2.8%
TOTAL	**143**	**100.0%**

** **Others :** Conceptual development of a quality of life model OR comparison of the patients and caregivers point of view on quality of life OR picture of a population quality of life measure OR choice of a tool to measure neuro-cognitive disorders (quality of life used as a comparative variable)*

Most (**57.3%**) of the studies are related to the evaluation of factors that could explain or affect the quality of life of people suffering from mental disorders. The studied and/or identified factors are mainly socio-demographic factors (sex, age, living place, etc.) or factors associated with the disease (duration of symptoms, severity, co-morbidities, etc.) [36] [37] [38] [39] [34] [14]. Thus, some authors attempted to define an explicative quality of life model for specific diseases. This preponderance of studies focusing on the definition of predictive factors could be explained by the fact that the research on the quality of life concept is quite recent and that, today, a certain number of uncertainties remain regarding the definition of this concept and its field of application in the mental health area.

On the 143 selected articles, only **14** (9.8%) introduced an economical point of view in the presentation of the results or while discussing them:

- six articles calculated the costs associated to the evaluated intervention in order to compare them to the quality of life measures [40] [41] [42] [43] [44] [45],
- three articles calculated utilities from the quality of life results [46] [47] [48],
- five explained that it is possible to use quality of life measurement tools to calculate utilities. These five articles also mentioned possible calculation methods [37] [49] [50] [51] [52].

VI.2.2. Specificities of the studied populations

With respect to the **geographical origin** of the studied populations, regional discrepancies exist regarding the quality of life measurement tools. Keep in mind that the literature review is limited to Europe, North America and Australia.

<u>Table 2:</u> *Continent of origin of the studied population (n=143)*

	Number of studies	**%**
Europe	84	58.7%
North America	46	32.2%
Europe and North America	2	1.4%
Australia	9	6.3%
Not specified	2	1.4%
TOTAL	**143**	**100.0%**

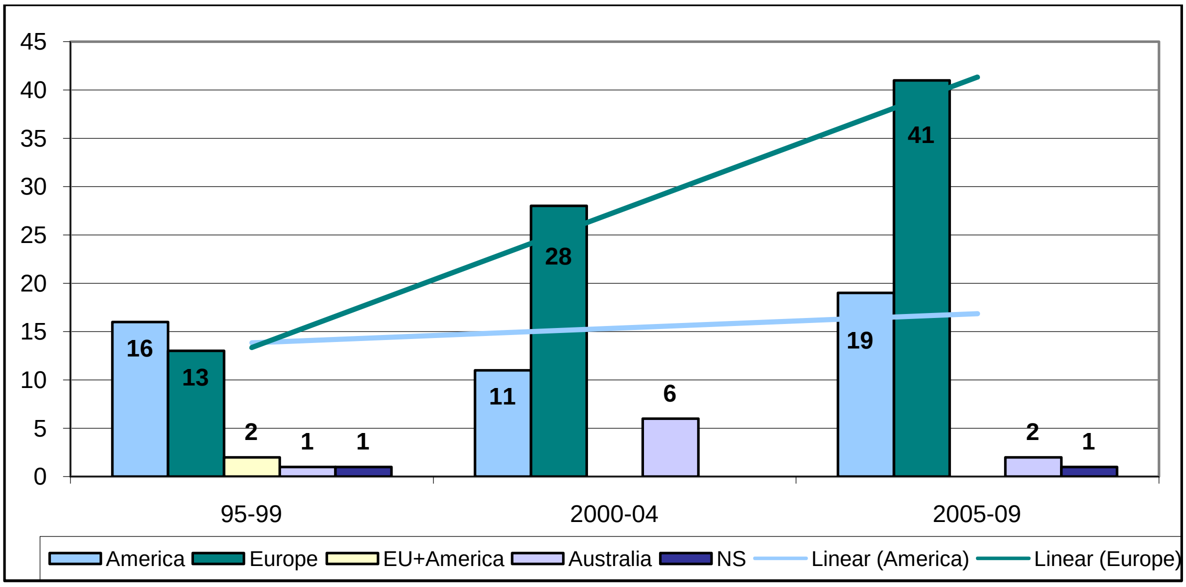
<u>Table 3:</u> *Country of origin of the studied population (n=143)*

	Number of studies	**%**
Study including France	17	11.9%
France not included	124	86.7%
Not specified	2	1.4%
TOTAL	**143**	**100.0%**

Regarding the geographical origin of the populations studied in the articles, I observe that most of the articles describe results related to the European population (**60.1%**) in comparison to the other regions included in the review. Seventeen studies (**11.9%**) included a French population. This relatively high percentage may be explained by the fact that apart from the English language, articles written in French were included.

To go further, I chose to study the temporal evolution of the number of studies related to the origin of the studied population:

Graph 2: *Studies repartition by continent of origin of studied populations and by five years periods, 1995-1999, 2000-2004, 2005-2009 (n=141)*



** Difference of the number of articles between continents statistically significant: p-value < 0.05 (exact test of Fisher)*
*** Evolution difference of the number of publications in America and in Europe between 1995-99 and 2000-04 statistically significant: p-value < 0.05 (T test of Student)*
**** Evolution difference of the number of publications in America and in Europe between 2004-09 and 2005-09 statistically significant: p-value < 0.05 (T test of Student)*
***** NS: Not specified*

It is interesting to notice that the evolution of the number of articles published is different for the European and North American continents. Thus, in North America, which was a pioneer in quality of life studies [17], the number of published studies remained stable over the three successive periods. Moreover, I observe that most of the tools created in the 1980s originate in the United States (e.g. *General Well-Being scale* – Dupuy and Ware, 1984, *Sickness Impact Profile* – Bergner et al., 1981). By contrast, the number of studies in Europe concerning quality of life measures in the mental health area significantly increased during the studied period, with three times more studies between the periods 1995-99 and 2005-09. This evolution is linked to the necessity of evaluating the introduction of new strategies in the different European countries (new psychotic treatments, de-institutionalization…) associated with the importance of cost-containment. Moreover, new tools adapted to various European contexts were validated over time, allowing the quality of life issues in these countries to be addressed more easily (e.g. *Schizophrenia quality of life scale* –S.QOL – Auqier et al., 2003, *EQ-5D* – Euroqol group, 1996) [33] [52].

In addition to the geographical distinctions, the **diseases affecting the studied populations** were analyzed. The diseases types were categorized following the classification described in the study protocol (*Annex 1*).

Table 4: *Diseases affecting the studied population (n=143 studies)*

	Number of studies	%
Schizophrenia, schizotypal and delusional disorders	104	**72.7%**
Depressive episode	31	**21.7%**
Neurotic, stress-related and somatoform disorders	7	4.9%
All types of mental disorders	5	3.5%
Bipolar affective disorder	5	3.5%
Mental and behavioural disorders due to psychoactive substance use	3	2.1%
Other or unspecified mood [affective] disorders	2	1.4%
Others mental or behavioural disorders*	1	0.7%
Undefined disorders	5	3.5%

** **Other mental and behavioural disorders**: Eating disorders*

The group of mental disorders most studied is “Schizophrenia, schizotypal and delusional disorders” (diagnoses F20 – F29 in the ICD-10), which is studied in **72.7%** of the articles.

This interest for schizophrenia could be explained by its epidemiological burden, as 1% of the worldwide population is estimated to be affected by this disease [18] [36], and also because of its chronic nature. Indeed, due to their burden, chronic diseases have increasingly become the focus of attention, and the measure of quality of life has become an essential indicator to evaluate and compare their consequences for individuals, health systems, societies. [53]

Similarly, depression is more and more considered a chronic disease given that in the absence of preventive treatment the recurrence of depression is estimated at 80% [54]. The burden of depressive episodes worldwide is huge, with a 1.9% prevalence for men and 3.2% prevalence for women. Depression represents the fourth largest cause for Disability-Adjusted Life Years (DALYs) [1].

Nonetheless, it is interesting to note that the percentage of studies per disease is not equally related to the epidemiological burden. Indeed, when considering schizophrenia and depression, an inverse rate was observed (depression is two to three times more prevalent but approximately three times fewer studies were observed).

Table 5: *Number of disease groups studied (n=143)*

	Number of studies	%
One single disease category, such as:	**121**	**84.6%**
# Schizophrenia, schizotypal and delusional disorders	95	78.5%
# Depressive episode	24	19.8%
# Neurotic, stress-related and somatoform disorders	2	1.7%
Comparison of several categories	**12**	**8.4%**
Type of disorders not defined / all types of disorders	**10**	**7.0%**
TOTAL	***143***	***100.0%***

I found that **84.6%** of the articles studied a single group of diseases. Few articles (**12**) explicitly compared several types of mental disorders between them while others (**10**) did not mention specifically the mental diseases studied or expressively studied the entire range of mental disorders.

Populations suffering from mental disorders are cared for in different settings. In order to study the **structures of care**, it was chosen to classify them in two categories (ambulatory care and hospitalisation).

Table 6: *Structure of care of the studied populations (n=143)*

	Number of studies	%
Ambulatory care	67	46.9%
Hospitalisation and ambulatory care	44	30.8%
Hospitalisation	14	9.8%
Not specified	18	12.6%
TOTAL	**143**	**100.0%**

Most of the studies focused on patients followed exclusively in ambulatory care (**46.9%**), while few studies followed exclusively hospitalised populations (**9.8%**). Nevertheless, a considerable number of studies included mixed population – cared for in either ambulatory care or in hospitalisation (3**0.8%**). From a qualitative point of view, the type of structure does not appear to be an obstacle to the administration of a quality of life measurement tool. The type of structure choice is generally linked to practical criteria (e.g. available population) or to the nature of the study (evaluation of an intervention performed in an ambulatory setting, for instance). The criteria of choice for the settings of the studies are rarely expressed explicitly in the articles.

With respect to the **size of the studied sample**, there is a wide variability (from 17 to 58,442). However, **44.8%** of the studies have a sample size under 100 subjects with a median of 104 when all articles are included. Studies with a large sample (over 1.000 subjects) are mostly international studies (5) or relate to the population of an overall region or country (2) or are multicentre studies (3).

VI.3. Applicability of the instruments for the planned medico-economic study

VI.3.1. Quality of life measurement tools identified and their characteristics

No fewer than **62 instruments to measure quality of life** were identified (*Annex 5*). In addition, two of the selected articles used questionnaires for which the name was not specified and two used simple visual analogue scales.

Among the selected articles, **one to five different tools** are used to measure quality of life. Most of the articles (**72.7%**) refer only to one tool. For the others, the justification for using more than one tool can be based upon the need to compare a tool of reference in order to validate or develop a new instrument. In considering the evaluation of predictive factors of quality of life, the use of several tools is often justified by the fact that the instruments are complementary, measuring different dimensions of quality of life. Sometimes the importance of using a generic tool together with a specific one in order to combine the advantages of both types is mentioned.

Among the 62 tools identified, **33** (53%) are used only in one article while only **five** are used more than ten times:

- the *MOS 36 Item Short-Form Health Survey (SF-36)*, used in 27 (19%) of the articles,
- the *Lancashire quality of life profile (LQOLP)*, used in 19 (13%) of the articles,
- the *Quality of Life Scale (QLS)*, used in 19 (13%) of the articles,
- the *Lehman Quality of life interview (QOLI)*, used in 15 (10%) of the articles,
- the *WHO quality of life assessment-BREF (WHOQOL-Bref)*, used in 13 (9%) of the articles.

With respect to the **frequency of use of the tools**, it is interesting to note that the tools cited above are encountered in articles across the full period of inclusion of the review with the exception of the WHOQOL-Bref used only since 2002. However, the WHOQOL-Bref was developed in 1992, whereas the other instruments were all created before the study period (between 1984 and 1992). Similarly, the *Euroqol 5 dimensions (EQ-5D)*, developed in 1996, appears less frequently than the above instruments, yet accounts for six articles from 2003 on. Thus, a certain amount of time seems necessary between the development of an instrument and its acceptance and use on a larger scale by researchers. Moreover, some tools have been used regularly since their creation, whereas others were used for a few years before being abandoned (e.g. *Quality of Life Self-Assessment Inventory* or *Tableau d’évaluation assistée de la qualité de vie*).

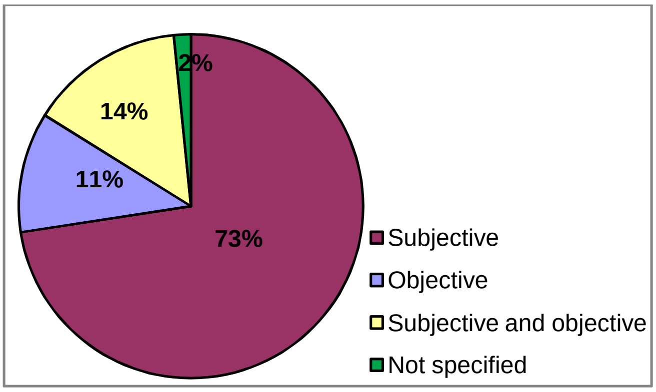
It was also notice that some instruments are used several times (3) but always by the same author(s):

- *Quality of Well-Being scale (QWB)*
- *Gurin's global quality of life question,*
- *Sickness Impact Profile (SIP) et*
- *Quality of life in depression scale (QLDS).*

Despite the large number of instruments, all the **validation** elements defined following the established standards were encountered at least once in the literature for only **five** tools: the *Quality of Life in Depression Scale (QLDS)*, the *Quality of life Interview (QOLI)*, the *Lancashire Quality of Life Profile (LQOLP)*, the *Schizophrenia Quality of Life (S-QOL)* and the *Social Functioning Scale (SFS)*. For eight tools, only one element of validation was missing: *Euroqol 5 dimensions (EQ-5D), Modular System for Quality of Life (MSQoL), MOS 36 Item Short-Form Health Survey (SF-36), Quality of Life Inventory (QOLI), Quality of Life Questionnaire (QLQ), Scale to Measure Subjective Well being under Neuroleptic Treatment (SWN), Schedule for Evaluation of Individual Quality of Life - shorter Direct Weighting (SEIQOL-DW), WHO Quality of Life Assessment-BREF (WHOQOL-Bref)*. For twelve tools (19%), no element of validation was found. Some of these tools (4) were developed specifically for the purpose of the study in which they were used and were not encountered subsequently.

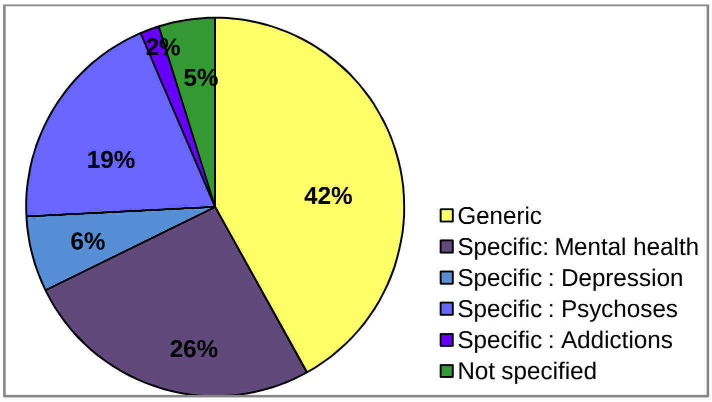
To detail further the specificities of the instruments, some of their characteristics were analyzed.

Graph 3: *Type of quality of life evaluated through the identified instruments (n=62)*



A large majority of the tools (54, 87%) measure the **subjective quality of life** that is the quality of life perceived by the subject, either exclusively (45, 73%) or associated to objective criteria of evaluation (9, 14%). This result is in line with the evolution of the quality of life concept for which the international community tends to consider the necessity of assessing the perception of the person for whom quality of life is measured.

Graph 4: *Domains of use of the identified instruments (n=62)*



With respect to the **populations for which the tools were created**, 26 (42%) tools used in mental health are adapted to all types of populations (generic tools) while 33 (53%) are specific either to a group of diseases (16 specific to mental health, 26%) or to a disease in particular (e.g. depression or psychosis).

The number of **items** comprising the instruments is extremely variable, ranging from one to 263 with a mean of 42 items (median: 30). These items are clustered in **dimensions** that each evaluates a particular concept. The number of dimensions for a tool varies from one to 22 with a mean of seven dimensions (median: 6). However, the number of items was not found for five tools or the number of dimensions for four instruments.

Linked to the number of dimensions and items included in an instrument, the **duration of administration** of tools is very different. Thus, the maximum time estimated for each tool varies from one minute to 120 minutes with a mean of 20 minutes. For the same instrument, the estimations vary from one article to another. For some tools, the time of administration may represent an obstacle to their use.

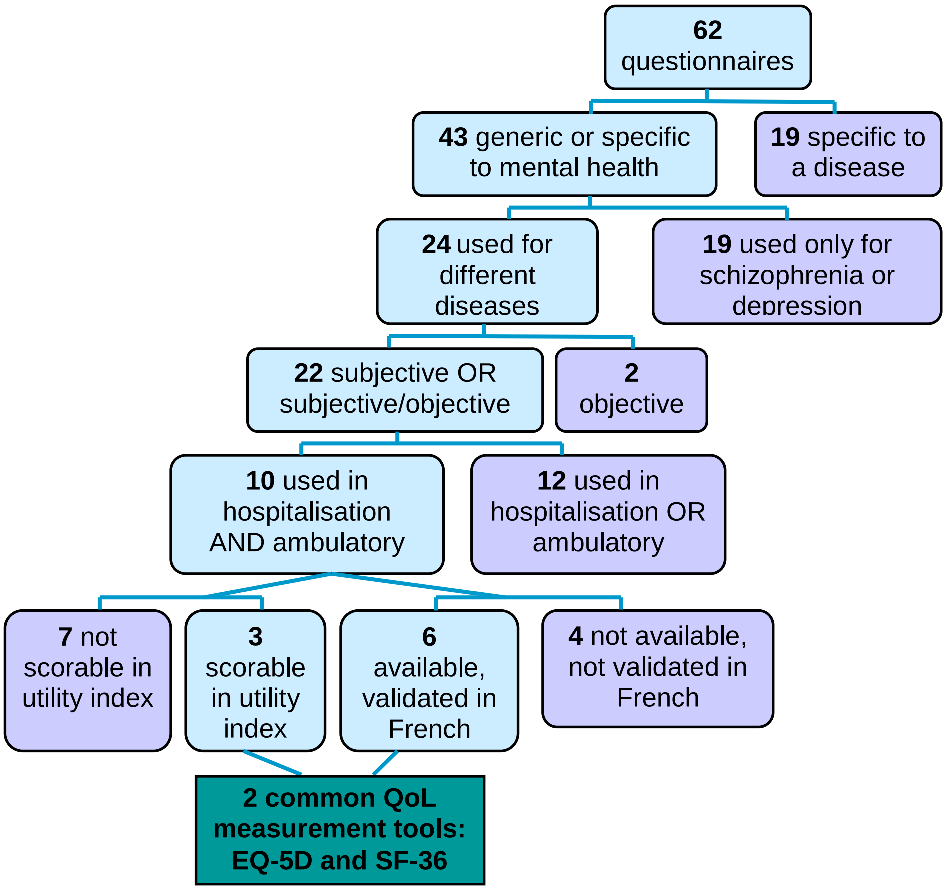
A summary of the quality of life measurement tools characteristics can be found in *Annex 6*.

A description of the quality of life measurement tools cited in this chapter is available in *Annex 7*.

VI.3.2. Choice of questionnaire(s) adapted to the measure of quality of life in patients with mental illnesses, in France

After the descriptive phase and through a **decision tree**, I could determine, based upon the criteria defined in the methodology, two tools that are usable with respect to a survey measuring the quality of life of psychiatric patients in France as it is described in the protocol in *Annex 2*.

Figure 3: *Selection tree of the quality of life measurement tools*



Step 1: Among the 62 instruments, twelve were developed specifically to measure the quality of life of persons suffering from psychoses and in particular schizophrenia, four are specific to depression and for three tools the disease of interest could not be specified. The **43** remaining instruments are either generic (26) or specific to the entire field of mental disorders (17).

Step 2: Among these 43 tools that are theoretically applicable to the measure of quality of life within a population suffering from different mental disorders, only **24** were effectively used for at least two distinct mental disorders while 19 were used only for schizophrenic patients or only for patients suffering from depression.

Step 3: Of the 24 instruments that are in fact used for people suffering from mental disorders regardless of the diagnosis, two are tools that measure only the objective quality of life. Thus, as the recent literature accepts that the measure of quality of life should include subjective indicators evaluated by the subjects, these two tools were excluded. The **22** remaining instruments measure either exclusively subjective quality of life (17) or are mixed tools (5).

Step 4: From these 22 instruments, only **10** that were used both for ambulatory care and hospitalisation settings were identified. The other 12 were used only in one of these two settings.

The ten identified instruments are presented in the table below with some of their characteristics:

Table 7: *Quality of life tools usable for different mental disorders, in hospitalisation and ambulatory care and that include at least one element of subjective quality of life (n=10)*

Tool name	Number of articles concerned	Generic / specific	Number of dimensions	Mean time of administration	Scorable in utility index	Available and validated in French
EQ-5D	6	Generic	5	5 minutes	YES	YES
SF-36	27	Generic	8	10 minutes	YES	YES
Quality of well-being scale	3	Generic	4	10 minutes	YES	NO
Lancashire quality of life profile	19	Specific	10	45 minutes	NO	YES
Quality of life Interview	15	Specific	8	45 minutes	NO	YES
WHOQOL-100	3	Generic	6	30 minutes	NO	YES
WHOQOL-bref	13	Generic	4	12 minutes	NO	YES
QoL-GAP	1	Specific	10	120 minutes	NO	NO
Five accomplishments	1	Specific	5	Not encountered	NO	NO

Step 5: Only the *Euroqol 5 dimensions (EQ-5D)* and the *MOS 36 Items Short Form Health Survey (SF-36)* are at the same time transformable in utility value and available in French with a validated translation.

The **EQ-5D** is a European quality of life scale developed by the EuroQol group. The “EQ-5D descriptive system” provides a simple descriptive profile and a single index value for health status. It includes five items corresponding to five dimensions (mobility, self-care, usual activities, pain/discomfort, anxiety/depression), which are evaluated through a 3-point Likert scale. It is complemented by a visual analogue scale (“EQ VAS”). It is designed for self-administration or for face-to-face administration. Combining the different levels of each dimension, it defines a total of 243 health states.

The **SF-36** (Medical Outcome Study Short Form 36 – Ware and Sherbourne, 1992) is a generic instrument that comprises 36 items exploring eight domains (physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, mental health). The items are either binary answers or rated on a 3 to 6-point Likert scale. It allows obtaining two distinct scores, one related to physical health, the other to psychological health.

The two questionnaires are available in *Annex 8* and *Annex 9* respectively.

VII. Discussion

The main objective of the literature review is to identify the most appropriate tool(s) in order to study the quality of life of the population suffering from mental disorders in France. However, the obtained results appear to be quite enlightening on the research on mental health in a broader sense. Thus, I will discuss the results from this general point of view before concluding on specific aspects of the quality of life measurement tools used in the mental health field.

VII.1. Mental health: more research needed

The number of articles directly linked to the quality of life measure in mental health and identified during the research remains limited compared to the evaluation of this indicator in other health domains, especially with respect to chronic diseases. By comparison, a search performed in PubMed in April 2010 including the terms “quality of life” and “cancer” in the title retrieves 3,082 articles published since 1995. When doing a similar search with the terms “quality of life” and “mental health”, 50 articles were found. With the terms “quality of life” and “mental health” or mental illness” or “mental disorder” or “psychiatry” or “schizophrenia” or “addiction” or psychoactive substance” or neurotic disorder” or “behavioural disorder” or “mood disorder” or “depression”, 959 articles were found. Comparatively, cancer represented, in 2000, 5.3% of the worldwide burden of diseases in terms of DALYs whereas neuropsychiatric disorders accounted for 12.3%, including 4.4% for depression [1]. These numbers underscore a gap between the epidemiological reality of mental disorders and the amount of research dedicated to the measure of the quality of life of persons suffering from mental disorders, especially when we compare the data to other types of pathologies, especially with chronic diseases. The controversial character of the quality of life measure in mental health is apparent from the review of the literature. Indeed, some professionals questioned the validity of measuring quality of life of persons presenting psychiatric symptoms due to the possibility of reality distortions or cognitive deficits. This questioning may be one explanatory factor for the relatively scarce number of studies in this domain. Nonetheless, in the recent literature, a consensus seems to have emerged arguing the validity of the subjective quality of life measure from patients suffering from a mental disease.

Further to the limited use of the quality of life specific indicator, a study [55] showed that, in 2007, in France, the portion of public spending for health research attributed to psychiatry represented only 2.05% in 2007. Meanwhile, in the same period, the mental disorders prevalence accounted for 18.5% of all the health problems in the country. This result reinforces the WHO perspective [1] [3] that underscores the lack of studies in the mental health field, especially evaluative or long-term studies. It also emphasizes a lack of an international strategic framework related to research on mental health issues.

Thus, despite an increase in the number of studies during the 1995-2010 period as selected through the literature review, it appears that the research directed toward persons suffering from mental disorders and taking into account their perspectives has room for growth. This reality can be partly explained through the limited amount of spending allocated to the mental health field in general. Thus, in a 2005 report, the WHO highlighted low and not inappropriate level of financing for a majority of European countries given the burden of mental diseases in these countries.

Moreover, only a limited number of generic studies on mental health or at least studies comparing two or more mental illnesses was found (15.4% of the articles). Thus, there is a specific evaluation gap for obtaining a general picture of the mental disorders burden from the perspective of patients, for any given country or region.

Finally, studies that consider a medico-economic perspective – evaluating, for example, the efficiency of interventions or programs in the mental health field – are scarce. This implies a lack of evidence with respect to the advantages, drawbacks and needs for improvement of the different policies undertaken for prevention or treatment for mental illnesses.

These few elements highlight several vast domains for research in order to develop strategies that aim to improve patients' well-being and to reduce the burden of mental disorders.

VII.2. Quality of life measurement tools

With respect to the literature review, I observed a large diversity of quality of life measurement tools used within the mental disorders field. This result is consistent with the conclusions of several authors who evaluated quality of life instruments [11] [56]. Some instruments are used more frequently than others, while others are specific to a study or to a particular context. Thus, given the elements described within this document, it can be concluded that there is no gold standard or perfect tool to measure the impact of mental disorders on the quality of life of those who suffer from them. This is in line with the fact that the quality of life concept remains difficult to define and that there is no international consensus regarding the dimensions included within this concept. Moreover, cultural and linguistic differences from one context to another are obstacles to the elaboration of tools that are valid and transposable to these various contexts.

In addition, quality of life measurement tools may be classified in different ways depending on the specific criteria: validity, adaptation to the study context, type of quality of life measured, considered perspective (patients, relatives, caregivers), duration of administration, type of score obtained... All these elements complicate the selection among the available tools. Then, to make any choice, it is necessary to define precisely the objectives of the particular study as well as the conceptual framework adopted to evaluate quality of life.

Furthermore, a methodological aspect should be considered. Indeed, through the results of the review, it is notable that psychometric characteristics of the instruments are, most of time, not fully documented. This raises questions about the validity of the results obtained through certain tools and must be considered when choosing an instrument as well as when writing a research protocol in order to compensate for some of gaps in the literature through potentially complementary measures.

More specifically about the planned study that will be undertaken, the present literature review allowed to identify two quality of life measurement tools usable in this context: the *Euroqol 5 dimensions (EQ-5D)* and the *MOS 36 Items Short Form Health Survey (SF-36).*

Indeed, these tools present several advantages considering the criteria of the planned study. They are widely used, in particular for mental illnesses. They are translated into French and validated for the French context [57] [58]. They are not specific to one mental disease and they were used in both ambulatory settings and in the hospitalisation context. Moreover, they measure subjective quality of life taking into account the subject's own perspective. Furthermore, the scores obtained from these tools are transformable into utility measures. For the EQ-5D, a single score is obtained directly whereas for the SF-36, it is necessary to calculate a global score from the ten distinct values related to the different quality of life dimensions measured. From a practical point of view, these instruments are administered in a relatively short time on average: five minutes for the EQ-5D and 10 minutes for the SF-36.

However, with respect to the psychometric properties of these tools and as far as mental disorders are concerned, it was not find in the literature any accreditation of content validity for the EQ-5D and of structure validity for the SF-36. For the EQ-5D, the absence of content validity can be compensated by the fact that we are considering using it in combination with the SF-36 for which this property was validated and then that appears as an exhaustive measure as explained in the conceptual chapter. What's more, several studies confirm the acceptance of the EQ-5D by the answerers which suggests, at least partly, its credibility. Regarding the structure validity of the SF-36, it has been validated in the general population, which is a first element in favor of its validity for the population affected by mental disorders.

It is important to add that these tools are generic measures of quality of life. This allows obtaining results that are comparable with, for instance, the general population. However, a tool specific to mental disorders would measure more precisely differences between two health states within a population suffering from the same disease or for one person whose health state changes over time. This type of tool can be used to complete data from a generic tool or in studies aimed at specifying different clinical stages of a disease or evaluating the evolution of the disease over time. However, the only specific tools available in France for the measure of quality of life in psychiatry regardless of the mental disorder are the *Lancashire Quality of Life Profile (Oliver, 1992)* and the *Quality of Life Interview (Lehman, 1998).* They do not allow obtaining utility value and they are time consuming with more or less 45 minutes of administration. It would be useful then to consider the development of a specific tool without these disadvantages and adapted to the French context.

VII.3. Limits of the review

In addition to the aspects discussed above, it is necessary to state that the present literature review suffers some limits. First, the keywords for the article search in the databases were identified from the reading of approximately 50 abstracts related to the subject of study. This allowed us to determine the terminology frequently used regarding the mental disorders included in the selection. However, this method remains partially susceptible to an author-induced subjectivity. Thus, it is then possible that some relevant articles were not included in the selection.

Furthermore, for feasibility reasons, the research was limited with respect to the country of origin of the studied populations, the language and period of publication. Thus, a selection bias may have artificially excluded certain tools from the review. However, apart from the practical aspect, regarding the geographical region and the period of publication, criteria of adaptability of the selection to the objectives of the review were considered. Indeed, the decision was taken in order to avoid the inclusion of instruments abandoned in the past that do not fit current use or instruments adapted only to regions culturally different from the context of study.

Finally, a lack of homogeneity of the selected articles due to large field of inclusion did not allow us to perform a deep qualitative analysis of these articles. This heterogeneity is also a result of the fact that the authors present in divergent ways their methodology or results related to quality of life. For instance, it is often difficult to uncover all the information regarding the standard characteristics of the measurement tool used. When the tool is frequently used, it is possible to discover these elements of information in different articles or works. But when it is a unique citation, it can be impossible to determine all of the characteristics of a given instrument.

VIII. Next steps and proposals

I did not uncover a worldwide consensus defining one or several tools as being instruments of reference to measure quality of life in the psychiatric area. Instead, numerous tools were developed, including questionnaires that did not follow any validation process as defined by established standards. In France, few instruments are available to evaluate quality of life of the mentally ill population. Some tools exist for specific diseases, especially for schizophrenia, and two allow the quality of life measurement for all mental disorders but have significant disadvantages. Moreover, mental disorders are not extensively studied, especially from the perspective of the patient and his/her well-being. The few studies identified are all specific to one disease, most often schizophrenia.

Consequently, an increased interest on the part of the different stakeholders concerned by the research in this field could bring an important added value with respect to the mental disorders care and the program planning process; this in turn has the potential to relieve suffering from the persons affected by mental disorders and to diminish the mental illnesses burden for society. To facilitate further such studies, the framework developed in the current work may be helpful in identifying tool(s) adapted to various contexts of interest. Moreover, it would be helpful to continue identifying areas that would benefit from new tools or improvement of existing tools through, for instance, validation process, reducing the administration time.

Considering the highlighted research gaps in France, the study that will follow this review aims at establishing a picture of the situation for the population suffering from mental disorders and taking into account the perspective of the patient. The anticipated results should facilitate the identification of sectors where positive outcomes have been achieved. It may also serve as a baseline for intervention planning or allocation of resources according to potential benefits in utility terms. To reach these goals, the next steps are to perform the field study in the public settings within one administrative area (Loiret district) and then to broaden the scope of the study to different kinds of public and private structures in order to get a sample representative of the population cared for in psychiatry settings in France.

ABSTRACT

To evaluate the burden from mental illnesses, estimating patients' quality of life seems essential. However, few data are available in France on the economic impact of mental disorders from the patients' perspective. To address this gap, a survey was planned in order to measure the quality of life of patients in France. To perform this study, it was first necessary to identify appropriate tool(s).

Thus, a systematic literature review was undertaken in order to identify appropriate tools with respect to the stated criteria of the survey: valuing quality of life with utility scores, in different psychiatric care settings, in France. Keywords ("quality of life" and diagnoses included in the planned study) and a reading grid were defined to frame the review. Selection criteria for articles including the following: publication between 1995 and February 2010; in English or French; European, North American or Australian areas; and population over 17 years old.

From the 143 articles selected, different evolutions were appointed in the number of publications in North America and Europe with a growing interest in the latter. Most of the articles address individual illnesses, with schizophrenia as a particular focus. Sixty-two quality of life measurement tools were identified. They are diverse in terms of characteristics (number of items, dimensions, target population…) and in terms of their validation processes. But, only two instruments (EQ-5D and SF-36) fit the planned survey.

When considering quality of life measurement, it is essential to define precisely the objective and conceptual framework to identify appropriate instruments. For the planned survey, both the EQ-5D and the SF-36 will be used. The results will serve as a baseline of the French burden of mental disease on patients, while enabling identification of areas where positive outputs are achieved and recommendation for specific interventions or resource allocation.

Keywords: Quality of life, Mental disorders, Measurement tools, France, Literature review

RESUME (en français)

« Mesure de la qualité de vie des personnes souffrant de troubles mentaux en France grâce aux outils les mieux adaptés. »

Pour estimer l’impact associé aux troubles mentaux, la mesure de la qualité de vie des patients est essentielle. Néanmoins, en France, peu de données existent concernant le poids économique de la pathologie psychiatrique notamment en considérant le point de vue du patient. Ainsi, une étude qui vise à mesurer la qualité de vie des patients est en cours. Pour mener à bien cette étude, il était d’abord nécessaire d’identifier des outils adaptés à cette mesure.

Ainsi, une revue systématique de la littérature a été réalisée dans le but d’obtenir un niveau d’évidences suffisant pour le choix d’outils adéquats c’est-à-dire permettant de mesurer la qualité de vie en valeur d’utilités, dans différentes structures psychiatriques, en France. Les mots-clés ont été définis (« qualité de vie » et diagnostics d’inclusion) ainsi qu’une grille de lecture pour encadrer la revue. Les articles étaient inclus lorsque publiés entre 1995 et Février 2010, en anglais ou français, étudiant une population européenne, nord américaine ou australienne et de plus de 17 ans.

A partir des 143 articles sélectionnés, une évolution divergente du nombre de publications entre l’Amérique du Nord (stable) et l’Europe (croissante) a été observée. La plupart des articles était relative à une pathologie spécifique et notamment à la schizophrénie. Soixante-deux outils de mesure de la qualité de vie très divers au regard de leurs caractéristiques et des éléments attestant de leur validité ont été identifiés. Cependant, seulement deux outils (EQ-5D, SF-36) répondent aux critères définis pour l’étude planifiée.

Ainsi, lorsque l’on considère la mesure de la qualité de vie, la définition précise de l’objectif d’étude et du cadre conceptuel est un préalable au choix d’un instrument adapté. Pour l’étude envisagée, l’EQ-5D et le SF-36 seront utilisés conjointement. Les résultats permettront un état des lieux de la situation en France. Ils devraient faciliter l’identification de domaines pour lesquels des résultats positifs ont été achevés et aider à l’allocation des ressources en fonction des besoins.

Mots-clés : Qualité de vie, Troubles mentaux, Instruments de mesure, France, Revue de littérature

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Annex 1: Diseases entering the chapter “Mental and behavioural disorders” of the ICD-10 and included in the ecological survey

Code	Description
F10-F19	**Mental and behavioural disorders due to psychoactive substance use**
- F10	- Mental and behavioural disorders due to use of alcohol
- F11	- Mental and behavioural disorders due to use of opioids
- F12	- Mental and behavioural disorders due to use of cannabinoids
- F13	- Mental and behavioural disorders due to use of sedatives or hypnotics
- F14	- Mental and behavioural disorders due to use of cocaine
- F15	- Mental and behavioural disorders due to use of other stimulants, including caffeine
- F16	- Mental and behavioural disorders due to use of hallucinogens
- F17	- Mental and behavioural disorders due to use of tobacco
- F18	- Mental and behavioural disorders due to use of volatile solvents
- F19	- Mental and behavioural disorders due to multiple drug use and use of other psychoactive substances
F20-F29	**Schizophrenia, schizotypal and delusional disorders**
- F20	- Schizophrenia
- F21	- Schizotypal disorder
- F22	- Persistent delusional disorders
- F23	- Acute and transient psychotic disorders
- F24	- Induced delusional disorder
- F25	- Schizoaffective disorders
- F28	- Other nonorganic psychotic disorders
- F29	- Unspecified nonorganic psychosis
F30-F39	**Mood [affective] disorders**
- F30	- Manic episode
- F31	- Bipolar affective disorder
- F32	- Depressive episode
- F33	- Recurrent depressive disorder
- F34	- Persistent mood [affective] disorders
- F38	- Other mood [affective] disorders
- F39	- Unspecified mood [affective] disorder
F40-F48	**Neurotic, stress-related and somatoform disorders**
- F40	- Phobic anxiety disorders
- F41	- Other anxiety disorders
- F42	- Obsessive-compulsive disorder
- F43	- Reaction to severe stress, and adjustment disorders
- F44	- Dissociative [conversion] disorders
- F45	- Somatoform disorders
- F48	- Other neurotic disorders

Code	Description
F50-F59	**Behavioural syndromes associated with physiological disturbances and physical factors**
- F50	- Eating disorders
- F51	- Nonorganic sleep disorders
- F52	- Sexual dysfunction, not caused by organic disorder or disease
- F53	- Mental and behavioural disorders associated with the puerperium, not elsewhere classified
- F54	- Psychological and behavioural factors associated with disorders or diseases classified elsewhere
- F55	- Abuse of non-dependence-producing substances
- F59	- Unspecified behavioural syndromes associated with physiological disturbances and physical factors
F60-F69	**Disorders of adult personality and behaviour**
- F60	- Specific personality disorders
- F61	- Mixed and other personality disorders
- F62	- Enduring personality changes, not attributable to brain damage and disease
- F63	- Habit and impulse disorders
- F64	- Gender identity disorders
- F65	- Disorders of sexual preference
- F66	- Psychological and behavioural disorders associated with sexual development and orientation
- F68	- Other disorders of adult personality and behaviour
- F69	- Unspecified disorder of adult personality and behaviour
F80-F89	**Disorders of psychological development**
- F84	- Pervasive developmental disorders (including Autism, Rett's syndrome, Asperger's syndrome …)
F90-F98	**Behavioural and emotional disorders with onset usually occurring in childhood and adolescence**
- F90	- Hyperkinetic disorders
- F91	- Conduct disorders
- F92	- Mixed disorders of conduct and emotions
- F93	- Emotional disorders with onset specific to childhood
- F94	- Disorders of social functioning with onset specific to childhood and adolescence
- F95	- Tic disorders
- F98	- Other behavioural and emotional disorders with onset usually occurring in childhood and adolescence
F99	**Unspecified mental disorder:** Mental disorder, not otherwise specified
R45	**Symptoms and signs involving emotional state:** Nervousness, unhappiness, agitation, hostility…
R63.0	**Symptoms and signs concerning food and fluid intake**: exclusively Anorexia

__Annex 2:__ Summary of the study protocol

Title	**Evaluation of the quality of life of patients care for in psychiatry settings, in France**
Objectives	To measure from an economic perspective the impact of mental disorders on the quality of life of the adult population followed in psychiatry, in ambulatory care, day care or hospitalisation settings, in France. To identify existing correlations between this impact and the characteristics of the pathology and/or with the setting of care.
Type of study	Cross sectional ecological study.
Methods	• Study of the patients followed within different services of the Gorges Daumézon hospital that covers the psychiatric sectors of the Loiret district. • Data collection including types of care, month and date of birth, sex, main diagnosis and evaluation of the disease severity (CGI-S scale) will be undertaken for each patient through interviews of the caregivers. • In a second step, two quality of life questionnaires will be administered to the patient. Collected data will be compared with the data of the RIM-Psy in order to obtain information about the disease history and socio-demographic characteristics of the patient. • The data collection will be made in each care unit, on a given time. To avoid selection bias each patient present in the care unit at the time of study will be proposed for participation.
Study population	Patients followed in the units, including patients under administrative constraints (tutelle, curatelle). The objective is to include all subjects corresponding to the selection criteria. Number of subjects expected: between 300 and 400.
Selection criteria	
Inclusion criteria	• Patient that has completed 18 years old. • Patient speaking and understanding French. • Patient that have one of the diagnosis included in the chapter « Mental and behavioural disorders » of the ICD-10 with exception of a mental retardation, a behavioural syndromes associated with physiological disturbances and physical factors or a disorder of psychological development (other than pervasive developmental disorder) as its main diagnosis. This diagnosis should have been defined by a physician of the structure where he/she receives treatment. • Beneficiaries of the social security or equivalent. • Patient accepting to undertake the interview.
Criteria of non-inclusion	• Patient under 18 years old and/or cared for in a paediatric unit. • Medical contraindication (therapeutic isolation…). • Patient under legal safety. • Opposition of the tutor for a patient under administrative constraint.
Exclusion criteria	• Impossibility for the patient to answer the questionnaire.
Main variable	Quality of life declared by the patients.
Statistical analysis method	• Scores from the quality of life questionnaire will be translated in utility data. • Utility data mean will be calculated per group of diseases. • Quality of life explanatory factors will be studied through linear regression model. • Representativeness of the sample regarding the factors identified in the previous steps will be studied, on the overall patients of the hospital and then at national level. • The global burden of mental illnesses in terms of quality of life will be calculated, after adjustments, for all the patients care for in the psychiatric sectors.
Anticipated results and steps forward	The anticipated data will serve as a baseline of the situation in France. Nevertheless to be representative to the overall French population, it is foreseen to then broaden the scope of the study to different public and private settings in France.

Steps of the study	***Steps***	***My implication***
	• Conceptual framework definition	• Done previous to my internship
	• Protocol definition	• Partial
	• Literature review to identify the appropriate tools	• Complete
	• Application for the CTTIRS authorization	• Complete
	• Application for the CNIL authorization	• Partial
	• Contact with the place of study: design of the practical aspects of the study and formal agreement	• Partial
	• Elaboration of the necessary documents for the survey: information letter for the patients...	• Complete
	• Data collection form elaboration	• Not
	• Elaboration of an automatic and electronic data form and base	• Complete
	• Field survey	• Will be performed after my internship
	• Analysis of data	• Will be performed after my internship
	• Conference presentation	• Participation to the elaboration of a poster on the literature review for the SMDM conference (May 2010)
	• Publications on the literature review and on the survey	

Annex 3: Reading grid of the articles included in the literature review

Article characteristics	Title	
	Author	
	Year of publication	
	Review of publication	
	Database of origin	
Study characteristics	Type	
	Scientific reliability (qualitative evaluation)	
	Main objective	
	Place of study	
	Economic reference	
	If yes, what?	
Studied population	Sex	
	Age	
	Type of disease	
	Sample size and eventually presence of a control group	
	Structure of care	
Quality of life measurement tool	Name	
	Number of items	
	Duration of administration	
	Quality of life dimensions studied	
	Way of administration	Type
		By whom?
	Language	
	If several tools used, is there a main tool? Which one?	
Psychometric properties of the quality of life measurement tools	Acceptability by the subjects	
	Validity	Discriminant
		Pertinence/ exhaustiveness
		Content
	Reliability	Internal consistency
		Test-retest reliability
	Sensibility	
Quality of life measurement tool choice	Evoked?	
	If yes, criteria of choice	
Other tools used (if yes, which one)	Diagnosis tool	
	Tool to characterize the disease	
	Tool to measure the severity	
	Other	

Annex 4: **List of the articles selected in the literature review**

1- Awad AG, Voruganti LN, Heslegrave RJ. **A conceptual model of quality of life in schizophrenia: description and preliminary clinical validation.** Quality of life research 1997; 6(1): 21-6.

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Annex 5: List of the 62 quality of life measurement tools identified

Name of the tool	Abbreviation	Author	Year	Country or organisation
Batelle Quality of Life Scale	BQOLS	Revicki, et al.	1992	USA[1]
Behaviour and Symptom Identification Scale	BASIS	Eisen, et al.	1986	USA[1]
Carers' and Users' Expectations of Service - User version	CUES - U	Lelliott, et al.	2001	UK[2]
Diagnostic Inventory for Depression (échelle de qualité de vie seulement)	DID	Zimmerman, et al.	2004	USA[1]
Echelle d'autoévaluation se composant de 8 visages		Geronimi-Ferret, et al.	1997	France
Echelle de qualité de vie de Retentissement fonctionnel et socio-affectif ou Functional Status Questionnaire	RFS ou FSQ	Jette, et al.	1986	USA[1]
EuroQol - 5 Dimensions	EQ-5D	Kind, et al.	1996	Europe
Everyday Life Questionnaire	EDLQ	Bullinger, et al.	1993	Germany
Five Accomplishments		Goodwin and Madell	2002	UK[2]
(Psychological) General Well-Being Scale	PGWBI	Dupuy and Ware	1984	USA[1]
General Well-Being Schedule	GWB	Dupuy, et al.	1977	USA[1]
Global Measure of Quality of Life	GQOL	Zimmerman, et al.	2006	USA[1]
Gurin's global quality of life question		Gurin, et al.	1960	USA[1]
Health Measurement Questionnaire	HMQ	Gudex, et al.	1988	UK[2]
MacMaster Health Utilities Index-Mark 3	HUI3	Feeny, et al.	1995 et 1996	Canada
Lancashire Quality of Life Profile	LQOLP	Oliver, et al.	1992	UK[2]
Lehman TL-30	TL-30	Bech, et al. et al.	2007	Denmark
Life Experiences Checklists - User	LEC-USER	Ager, et al.	1990	USA[1]
Manchester Short Assessment of Quality of Life	MANSA	Priebe, et al.	1999	UK[2]
Modular System for Quality of Life	MSQoL	Pukrop, et al.	2000	Germany
MOS 12 Item Short-Form Health Survey	SF-12	Ware, et al.	1996	USA[1]

Name of the tool	Abbreviation	Author	Year	Country or organisation
MOS 20 Item Short-Form Health Survey	SF-20	Ware, et al.	1992	USA[1]
MOS 36 Item Short-Form Health Survey	SF-36	Ware and Sherbourne	1992	USA[1]
Munich List of Life Dimensions	MLDL	Heinisch, et al.	1991	Germany
Nottingham Health profile	NHP	Hunt, et al.	1980	UK[2]
Personal Evaluation of transitions in Treatment	PETiT	Voruganti, et al.	2002	Canada
Physical, Cognitive, Affective, Social, Economic-social and Ego Functions	PCASEE	Joyce, et al.	1987	Sweden
Profil de la Qualité de Vie Subjective or Subjective Quality of Life Profile (SQLP)	PQVS	Gerin, et al.	1989	France
Psychiatric Symptoms You Currently Have	PSYCH-BASE and PSYCH-UP	Andreasen, et al.	1989	USA[1]
QoL-GAP	QoL-GAP	Welham, et al.	2001	Australia
Quality of Life Enjoyment and Satisfaction Questionnaire	Q-LES-Q	Endicott, et al.	1993	USA[1]
Quality of Life Enjoyment and Satisfaction Questionnaire - short form	Q-LES-Q - short form	Endicott, et al.	1993	USA[1]
Quality of life in depression scale	QLDS	Hunt and McKenna	1992	UK[2] and The Netherlands
Quality of Life Index	QLI	Spitzer, et al.	1981	Canada
Quality of Life Inventory	QOLI	Frisch, et al.	1992	USA[1]
Quality of Life Interview	QOLI	Lehman, et al.	1988	USA[1]
Quality of Life Measure for Persons with Schizophrenia	QOLM-S	Laliberte-Rudman, et al.	2000	Canada
Quality of Life Questionnaire - Interviewer rating version (Bigelow)	QLQ	Bigelow, et al.	1990	USA[1]
Quality of Life Scale	QLS	Heinrichs, et al.	1984	USA[1]
Quality of Life schedule	QLS	Zissi, et al.	1998	Greece
Quality of Life Self-Assessment Inventory (or scale) QLS-100	QLS-100	Skantze, et al.	1992	Sweden
Satisfaction with Life Domains Scale	SLDS	Baker and Intagliata	1981	USA[1]
Satisfaction with Life Scale	SWLS	Diener, et al.	1985	USA[1]

Name of the tool	Abbreviation	Author	Year	Country or organisation
Scale to Measure Subjective Well being under Neuroleptic Treatment	SWN	Naber, et al.	1995	Germany
Schedule for Evaluation of Individual Quality of Life - shorter Direct Weighting	SEIQoL-DW	Hickey, et al.	1996	Ireland
Schizophrenia Care Assessment Program Instrument	SCAP instrument	Fitzgerald, et al.	2003	Australia
Schizophrenia Quality of Life	S-QOL	Auquier, et al.	2003	France
Schizophrenia Quality of Life Scale	SQLS	Wilkinson, et al.	2000	UK[2]
Schizophrenia Quality of Life Scale	SOL	Martin, et al.	2003	France
Sickness Impact Profile	SIP	Bergner, et al. et al.	1975	USA[1]
Social Functioning Scale	SFS	Birchwood, et al.	1983	UK[2]
MRC Social Performance Schedule	SPS	Hurry and Sturt	1983	UK[2]
Standard of Living Questionnaire Interview	SOL-I	Skantze, et al.	1992	Sweden
Subjective Quality of Life Analysis	S.QUA.LA	Zannoti and Pringuey	1992-1994	France
Tableau d'évaluation assistée de la qualité de vie	TEAQV	Tignol, et al.	1996	France
Values Satisfaction		Hartley, et al.	1988	UK[2]
Wisconsin Quality of Life Index Client Questionnaire or Quality of Life Index for Mental Health	W-QLI	Becker, et al.	1993	USA[1]
WHO Quality of Life Assessment	WHOQOL-100	WHOQOL Group	1991	WHO[3]
WHO Quality of Life Assessment-BREF	WHOQOL-BREF	WHOQOL Group	1998	WHO[3]
Quality of Life for Proxies	QOL-P	Ruggeri, et al.	2002	Italia
Quality of Well-Being Scale	QWB	Kaplan, et al.	1988	USA[1]
Assessment of Quality of Life	AQOL	Hawthorn, et al.	2000	Australia

[1] United States of America

[2] United Kingdom

[3] World health organisation

Annex 6: Summary of the characteristics of the quality of life measurement tools used in mental health (n=62 instruments)

	Value	%
Frequency of use		
1 time	33	53 %
2-10 times	24	39 %
> 10 times	5	8 %
Date of creation		
1960-1979	3	5 %
1980-1989	17	27 %
1990-1999	27	44 %
2000-2010	15	24 %
Place of creation		
North America	28	45 %
Europe	29	47 %
Others	5	8 %
Tools validation		
No validation criteria encountered	12	19 %
All validation criteria or 1 missing	12	19 %
Others	38	62 %
Type of quality of life		
Subjective or subjective/objective	54	87 %
Objective	7	11 %
Not specified	1	2 %
Domains of use		
Generic	26	42 %
Specific	33	53 %
Not specified	3	5 %
Number of items		
Minimum	1	
Maximum	263	
Mean	42	
Number of dimensions		
Minimum	1	
Maximum	22	
Mean	7	
Administration duration*		
Minimum	1	
Maximum	120	
Mean	20	

** Expressed in minutes*

Annex 7: Brief description of the quality of life instruments cited in the document

The **EuroQol 5 dimensions** (Kind, 1996) is a self-administered questionnaire which measures subjective quality of life. It includes five dimensions and is usable in the general population. It evaluates mobility, self-care, usual activities, pain and discomfort, anxiety and depression.

The **General Well-Being Scale** (Dupuy and Ware, 1984) is a self-administered questionnaire which measures subjective quality of life. It includes 18 items and 7 dimensions. It evaluates general mood, stress and anxiety, feeling of control over one's behaviour and thoughts, level of interest in one's life, health concerns, energy level. It is usable in the general population.

The **Gurin's global quality of life question** (Gurin, 1960) is a single question which measures the global subjective feeling of an individual regarding his/her quality of life. It is usable in the general population.

The **Lancashire Quality of Life Profile** (Oliver, 1992) is an interview specific to mental disorders that measures subjective and objective quality of life. It includes 105 items clustered in 10 dimensions. It evaluates legal and safety matters, religion, leisure, living situation, health (physical and mental), family relationship, social relationship, work and education, finances.

The **Modular System for Quality of Life** (Pukrop et al., 2000) is a self-administered questionnaire which measures objective and subjective quality of life. It includes 47 items clustered in 7 dimensions. It evaluates physical health, vitality, psychosocial quality of life, affective quality of life, material satisfaction, spare time quality of life. It is usable in the general population.

The **MOS 36 Item Short-Form Health Survey** (Ware et Sherbourne, 1992) is a self-administered questionnaire which measures subjective quality of life. It includes 36 items clustered in 8 dimensions. It evaluates physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, mental health. It is usable in the general population as well as in various diseases.

The **Quality of Life in Depression Scale** (Hunt et McKenna, 1992) is a self-administered questionnaire specific to depression that measures subjective quality of life. It includes 34 items clustered in 2 dimensions. It evaluates physical and psychological needs.

The **Quality of Life Interview** (Lehman, 1998) is an interview specific to mental disorders which measures subjective and objective quality of life. It includes 143 items clustered in 8 dimensions. It evaluates living situations, daily activity and functioning, family relations, social relations, finances, work and school, legal and safety issues, mental and physical health.

The **Quality of Life Questionnaire** (Bigelow, 1990) is an interview specific to mental diseases which measures objective quality of life. It includes 263 items clustered in 14 dimensions. It evaluates physical condition of home, total satisfaction in home, responsibility for self and home, self and home maintenance, employment success, meaningful use of time, psychiatric distress, psychological well-being, interpersonal relations and received services.

The **Quality of Life Scale** (Heinrichs et al., 1984) is a self-administered questionnaire specific to schizophrenia which measures subjective quality of life. It includes 21 items clustered in 4 dimensions. It evaluates interpersonal relations and social network, instrumental role functioning, intrapsychic foundations, common objects and activities.

The **Quality of Life Self-Assessment Inventory** (Skantze et al., 1992) is a self-administered questionnaire specific to mental disorders which measures subjective quality of life. It includes 100 items clustered in 11 dimensions. It evaluates housing, environment, knowledge and education, contacts, dependence, inner experience, mental health, physical health, leisure, work and religion.

The **Quality of Well-Being scale** (Kaplan et al., 1988) is an interview which measures subjective quality of life. It includes 37 items clustered in 4 dimensions. It evaluates symptom or problem complex, mobility, physical activity, social activity. It is usable in the general population.

The **Scale to Measure Subjective Well being under Neuroleptic Treatment** (Naber, 1995) is a self-administered questionnaire specific to schizophrenia. It includes 38 items clustered in 5 dimensions. It evaluates emotional regulation, self-control, mental functioning, social integration, physical functioning.

The **Schizophrenia Quality of Life** (Auquier et al., 2003) is a self-administered questionnaire specific to schizophrenia which measures subjective quality of life. It includes 41 items clustered in 8 dimensions. It evaluates psychological well-being, self-esteem, family relationships, relationships with friends, resilience, physical well-being, autonomy, sentimental life.

The **Schedule for Evaluation of Individual Quality of Life - shorter Direct Weighting** (Hickey et al., 1996) is a self-administered questionnaire which measures subjective quality of life. It includes 5 items and 5 dimensions. It evaluates the 5 most important areas of their life chosen by the patient. It is usable in the general population.

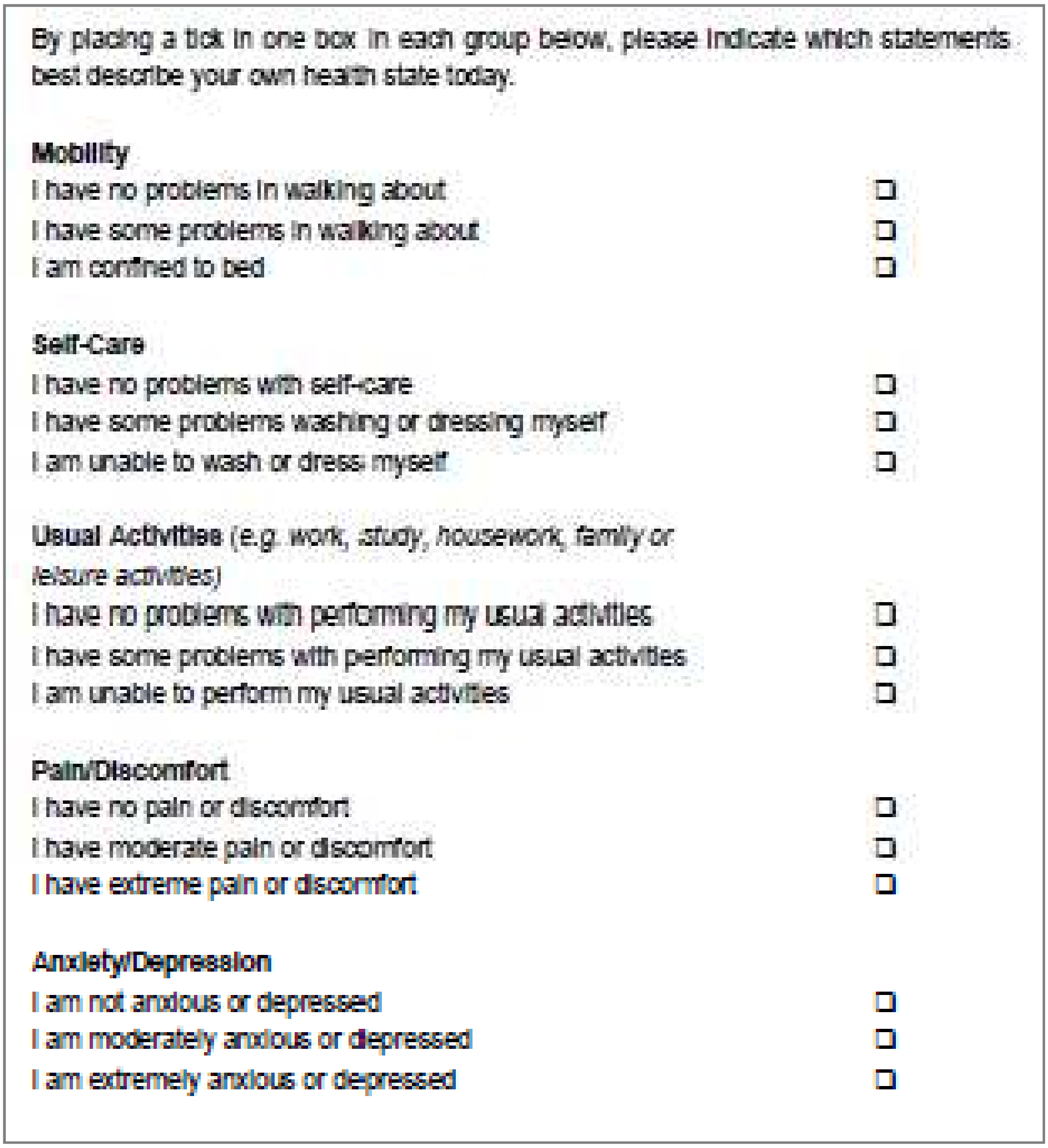
The **Sickness Impact Profile** (Bergner et al., 1975) is a self-administered questionnaire which measures a subjective quality of life profile. It includes 136 items clustered in 12 dimensions. It evaluates sleep and rest, eating, work, home management, recreation and pastimes, social interaction, alertness behaviour, emotional behaviour, communication, body care, mobility, ambulation. It is usable in the general population.

The **Social Functioning Scale** (Birchwood et al., 1983) is a self-administered questionnaire specific to schizophrenia which measures subjective quality of life. It includes 79 items clustered in 7 dimensions. It evaluates social involvement, social relationships, usual activities, leisure, social activities, autonomy, and work.

The **Tableau d’Evaluation Assistée de la Qualité de Vie** (Tignol, 1996) is a self-administered questionnaire which measures subjective quality of life. It includes 8 items clustered in 4 dimensions. It evaluates physical, psychological, family and professional domains. It is usable in the general population.

The **WHO quality of life assessment – Bref** (WHO, 1998) is a self-administered questionnaire which measures subjective quality of life. It includes 26 items clustered in 4 dimensions. It evaluates physical health, psychological, social relationships and environmental areas. It is usable in the general population as well as for various diseases.

Annex 8: The EuroQol 5 dimensions: "EQ-5D descriptive system"



By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility
I have no problems in walking about ☐
I have some problems in walking about ☐
I am confined to bed ☐

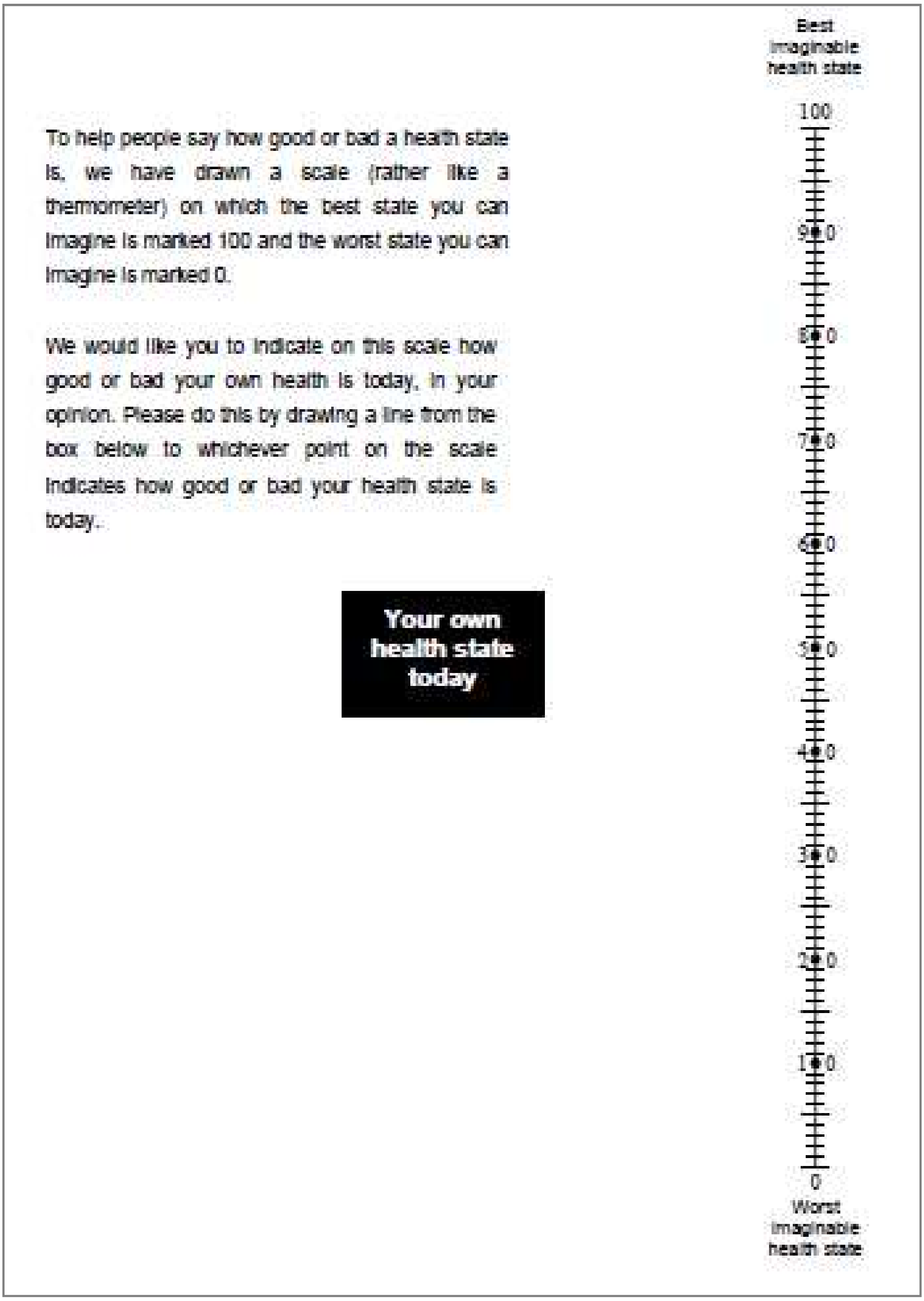
Self-Care
I have no problems with self-care ☐
I have some problems washing or dressing myself ☐
I am unable to wash or dress myself ☐

Usual Activities *(e.g. work, study, housework, family or leisure activities)*
I have no problems with performing my usual activities ☐
I have some problems with performing my usual activities ☐
I am unable to perform my usual activities ☐

Pain/Discomfort
I have no pain or discomfort ☐
I have moderate pain or discomfort ☐
I have extreme pain or discomfort ☐

Anxiety/Depression
I am not anxious or depressed ☐
I am moderately anxious or depressed ☐
I am extremely anxious or depressed ☐

Annex 9: The EuroQol 5 dimensions: "EQ-5D VAS"

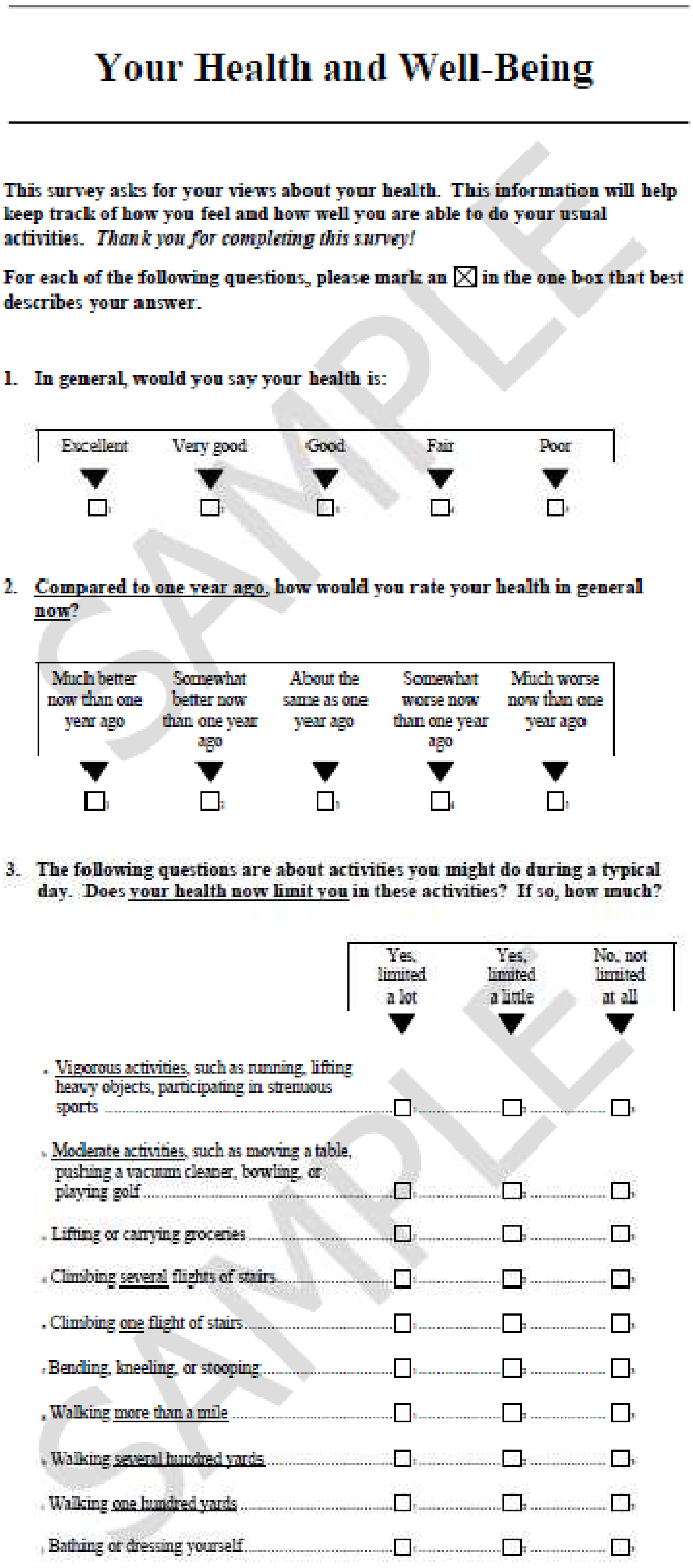


To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

Your own health state today

Annex 9: The MOS 36 Items Short Form Health Survey



Your Health and Well-Being

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. ***Thank you for completing this survey!***

For each of the following questions, please mark an ☒ in the one box that best describes your answer.

1. In general, would you say your health is:

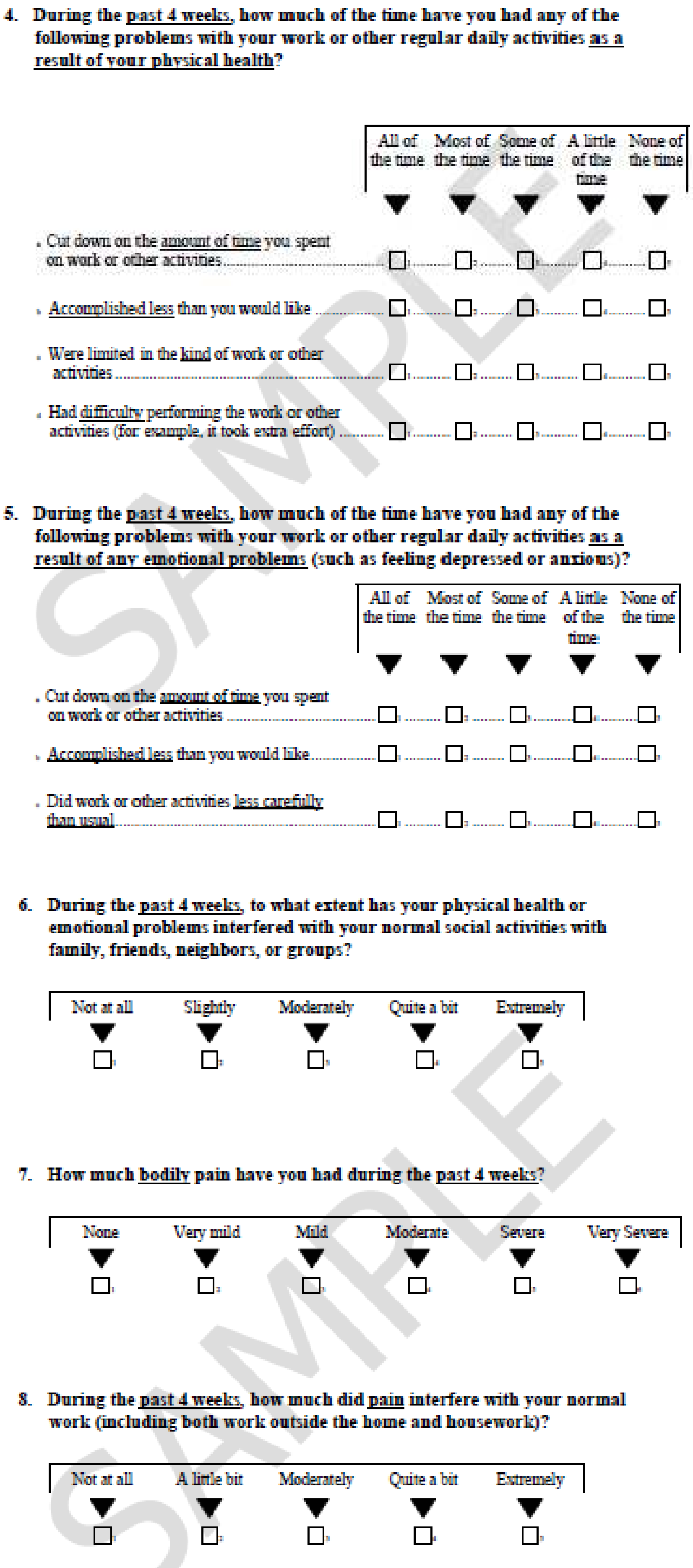
Excellent	Very good	Good	Fair	Poor
☐	☐	☐	☐	☐

2. Compared to one year ago, how would you rate your health in general now?

Much better now than one year ago	Somewhat better now than one year ago	About the same as one year ago	Somewhat worse now than one year ago	Much worse now than one year ago
☐	☐	☐	☐	☐

3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	☐	☐	☐
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐	☐	☐
Lifting or carrying groceries	☐	☐	☐
Climbing several flights of stairs	☐	☐	☐
Climbing one flight of stairs	☐	☐	☐
Bending, kneeling, or stooping	☐	☐	☐
Walking more than a mile	☐	☐	☐
Walking several hundred yards	☐	☐	☐
Walking one hundred yards	☐	☐	☐
Bathing or dressing yourself	☐	☐	☐



4. **During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?**

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Cut down on the amount of time you spent on work or other activities	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Accomplished less than you would like	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Were limited in the kind of work or other activities	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Had difficulty performing the work or other activities (for example, it took extra effort)	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

5. **During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?**

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Cut down on the amount of time you spent on work or other activities	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Accomplished less than you would like	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Did work or other activities less carefully than usual	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

6. **During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?**

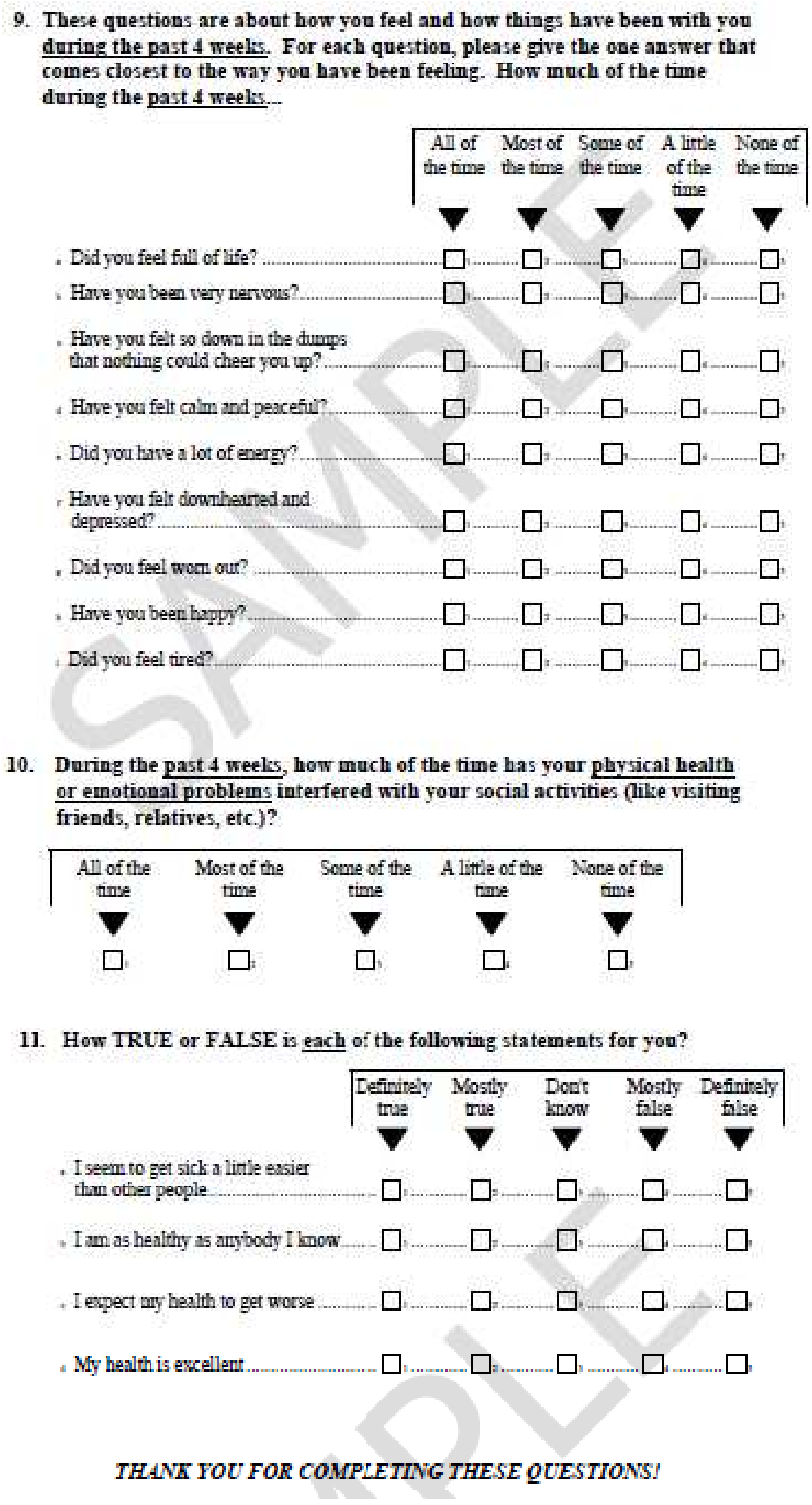
Not at all	Slightly	Moderately	Quite a bit	Extremely
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

7. **How much bodily pain have you had during the past 4 weeks?**

None	Very mild	Mild	Moderate	Severe	Very Severe
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

8. **During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?**

Not at all	A little bit	Moderately	Quite a bit	Extremely
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5



9. **These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...**

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Did you feel full of life?	☐	☐	☐	☐	☐
Have you been very nervous?	☐	☐	☐	☐	☐
Have you felt so down in the dumps that nothing could cheer you up?	☐	☐	☐	☐	☐
Have you felt calm and peaceful?	☐	☐	☐	☐	☐
Did you have a lot of energy?	☐	☐	☐	☐	☐
Have you felt downhearted and depressed?	☐	☐	☐	☐	☐
Did you feel worn out?	☐	☐	☐	☐	☐
Have you been happy?	☐	☐	☐	☐	☐
Did you feel tired?	☐	☐	☐	☐	☐

10. **During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?**

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐	☐	☐	☐	☐

11. **How TRUE or FALSE is each of the following statements for you?**

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
I seem to get sick a little easier than other people	☐	☐	☐	☐	☐
I am as healthy as anybody I know	☐	☐	☐	☐	☐
I expect my health to get worse	☐	☐	☐	☐	☐
My health is excellent	☐	☐	☐	☐	☐

THANK YOU FOR COMPLETING THESE QUESTIONS!