

# **MENTAL HEALTH IN THE GENERAL POPULATION : IMAGES AND REALITIES**

## **FINAL RESEARCH REPORT**

### **- FIRST SURVEY PHASE - 1998-2000**



The survey is realised by the Association Septentrionale d'Épidémiologie Psychiatrique (ASEP), the Department for Medical Information and Research (DIRM) of EPSM Lille-Métropole and the World Health Organisation Collaborating Centre for Research and Training in Mental Health - Paris (CCOMS). Financial support was given by the French Ministry of Foreign Affairs, the French Ministry of Health, the WHO – Geneva ("Nations for Mental Health" program), the WHO local office in Moroni (The Comoros), the WHO local office in Antananarivo (Madagascar), the "Health Systems Research for Reproductive Health and Health Care Reforms in the Eastern and Southern African Region" (Harare, Zimbabwe), the Nord Pas de Calais regional direction of health and social services (DRASS), the Ile de France and Réunion regional agencies of hospitalisation and the Synthelabo et SmithKline&Beecham companies.

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If the world population could be reduced to a village of exactly 100 individuals, maintaining all the human ratios, here is what it would look like :

57 Asians  
21 Europeans  
14 from the Western hemisphere from North to South  
8 Africans

52 women  
48 men

70 non-white  
30 white

70 non-Christians  
30 Christians

89 heterosexuals  
11 homosexuals

6 people would own 59% of the world's wealth,  
and all six would be in the USA

80 would be in poor quality housing

70 would be illiterate

50 would be suffering from malnutrition

1 would be close to dying  
1 would be about to be born

1 (yes, only 1) would have studied to university level  
1 would possess a computer

When we look at our world on this scale, there is an obvious need at once for acceptance, understanding and education



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## PART ONE : BACKGROUND AND METHODS

### I. INTRODUCTION

In the course of recent decades there has been a significant decrease in infant mortality and an increase in life expectancy. The physical health of populations generally has improved, but mental health problems have increased. Urbanisation, modernisation, the deterioration of rural structures, and forced displacements of populations have given rise to numerous psychiatric disorders. Yet, nowhere in the world, is priority given to mental health problems.

**Figures issued by the World Bank<sup>1</sup>** show that 8.1% of global morbidity burden can be attributed to mental illness. In low-income societies, neuro-psychiatric disorders account for as much as 12% of the total morbidity among adults between the ages of 15 and 44. Depressive disorders, Alzheimer's disease and alcoholism are the most frequent, followed by epilepsy, psychoses, substance addiction, and post traumatic stress disorders. According to World Health Organisation (WHO) forecasts for the year 2000, 24 million people suffering from schizophrenia can be expected (+ 45% in 15 years). Yet prevention methods and efficient treatment are available for these patients, whether pharmacological or psycho-social.

An international study conducted by WHO in the early nineties showed that 25% of patients consulting a general practitioner suffer from anxiety or depressive disorders<sup>2</sup>, but only a quarter actually receive appropriate treatment. Further to this, the level of disability involved for these patients is greater than that of patients suffering from certain chronic conditions such as diabetes.

In 1994 the National Co-morbidity Survey<sup>3</sup> evidenced that nearly 50% of the general population in the USA had, at some time in their life, suffered at least one psychiatric episode, and 30% of these in the year preceding the survey. Among these subjects, only one third had relevant professional help.

In France, on the basis of descriptive statistics derived from declared morbidity, over the decade 1980-1990, mental disturbances come third (17%) after cardio-vascular disease (32%) and malignant tumours (24%); they however take first place as reasons for declaring disability<sup>4</sup>.

As these few figures show, **mental health is a public health problem**. Yet access to adequate care falls short of both implicit and explicit needs. This can be explained in part by the fact that mental health is still not well understood, often ignored and taboo. The mentally ill, their families and relatives, as well as professionals providing specialised care, are still the object of very marked stigmatisation. Whatever the country, whatever the culture, representations of mental illness (madness, lunacy or insanity<sup>5</sup>) and the mentally ill (lunatics, the insane) have an influence on the priorities fixed for national mental health policies, the prevention of mental health problems, their recognition on the part of the general population and professionals, and the integration of the mentally ill in the community<sup>5-6-7-8</sup>.

**The aim of this Research-Action** is to give health professionals the means to gain a better acquaintance with the scale of mental health problems in the population in which they are working, and to identify the representations on which they can have an impact, for the purpose of prevention and treatment of such problems. They are problems that have no boundaries, and, for background reasons, this study started out in the Indian Ocean.

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\* Translator note : to cover the semantic field of "*fou*" (noun and adjective) and "*folie*" in French, several words are required in English, depending on the function of the word (person, condition, general category, adjective) as well as to reflect variations in common usage : *lunatic, insane, insanity, mad, madness* and, to a lesser degree *lunacy, madman*

## II. BACKGROUND

A regional seminar on mental health took place in **1995** in Antananarivo (Madagascar). The seminar was organised by the French Health Ministry and the World Health Organisation (WHO).

This seminar had a strong component of representatives from mental health teams from Reunion Island. The purpose was to develop plans and programmes for mental health in countries belonging to the zone : Madagascar, the Comoro Islands, Mauritius, the Seychelles, Mozambique and Djibouti. The representatives from Madagascar, joined in this by those from the Comoro islands and Mauritius, put in a request for assessment of mental health needs in the general population. The Seychelles and Mozambique, for reasons of local resources, did not follow suit.

The logistic support for this survey of needs was to be provided by the Association Septentrionale d'Epidémiologie Psychiatrique (ASEP), in which most of the parties were from the Etablissement Public de Santé Mentale (EPSM Lille Métropole), located in Armentières in northern France.

The issue of assessment of the needs of the population is just as important in Western countries, where psychiatric professionals, in the face of a growing demand, (populations in precarious situations, unemployment, stress of urban life, alteration of family structures and so on) feel they are not able to meet these needs adequately.

Thus EPSM Lille-Métropole agreed to provide support for the survey project, and to make certain means available for its implementation, the condition being that the survey should be a joint venture France/Indian Ocean, prepared jointly following procedures agreed upon by the persons in charge of each site.

On account of the methodology adopted (Research-Action) the involvement of agents in the field underpinned the whole project. Wherever the survey was involved, prior work was carried out to raise awareness with respect to mental health and care among partners in the fields of health, social work, public administration and politics. This made it possible for all parties to express opinions and also to realise that there was a need to compare theirs with those of others.

In **1996** the research project gained the financial support of the French Ministry of Foreign Affairs for the Indian Ocean sites. A network of the centres involved was established and enlarged to include centres in metropolitan France made up of teams in psychiatric sectors with an interest in the theme (Evry, Lille, Nantes and Tourcoing) and international co-operation in the field of mental health.

The pilot phase of the survey was implemented in **1997-1998** in 7 sites (749 subjects interviewed), followed by an international methodology seminar in Lille in 1998. The main phase of the survey was conducted in **1999**, in 16 sites (10 881 subjects), 12 in France and 4 outside. The results are being analysed in collaboration with DREES (Direction de la Recherche, des Etudes, de l'Evaluation et des Statistiques) a body belonging to the French Ministry of Health.

The dynamics of this research are strictly in line with French health ministry priorities : regional care planning, community psychiatry, definition of needs, analysis of pre-existing networks providing access to care, obstacles to access to care, raising awareness on the part of agents in the field with a view to re-deploying resources in the community. Thus numerous psychiatric sectors showed interest. The **second survey phase** will end in 2003 in France, aiming at reaching a national representative sample (40.000 subjects), using the same overall methodology. Several other sites are in preparation (Mauritania, Algeria, Greece...)

### III. BRIEF PRESENTATION OF DIFFERENT SITES

Resources in terms of structures and staff in the area of mental health are very restricted in Madagascar, and virtually absent in the Comoro islands. Mauritius is an exception, since it has inherited the British organisation system for psychiatric care until the 1980 reform; until 1998 access to care and psychiatric treatment was only provided in a context of compulsory internement.

In these Indian Ocean countries traditional practitioners are frequently resorted to by people suffering from mental disorders, and by those around them. The survival of an organised family structure makes it possible, up to a point, to integrate and maintain the patient in his/her family, but the cost to the family is not known. The Comoro Islands attempted to provide care for mental disturbances via a network of dispensaries less than one hour on foot away for any inhabitant. There is however no staff trained in psychiatric care, rather marabouts and traditional practitioners providing services locally. These three countries are facing an increase in the incidence of drug and alcohol related problems. Traditional society is changing, and a process of globalisation of issues is underway, accompanied by fast accelerating urbanisation and proliferation of poverty zones.

Despite a mental health policy based on sectorisation (co-ordination and continuity of care within the community) France also suffers from backwardness in this field. In addition, prejudice and the poor social image of mental illness and psychiatry are major obstacles in the field of care. Further to this, differences in resource allocation and the organisation of care are very great between metropolitan France and her overseas *départements*<sup>9</sup>.

### IV. OBJECTIVES

The two **main objectives** of this research work are as follow :

- **to describe representations** among the general population associated with "madness", "mental illness" and "depression", as well as with the different modes of assistance and care (psychiatric care, traditional approaches, alternative medicine). This can be termed **the socio-anthropological line** of study
- **to assess the prevalence of the main mental disorders** in the general population. This is the **epidemiological line** of study

The **secondary objectives** of this Research-Action are inherent in any implementation of a participative method involving field teams, that is to say :

- **training agents in the field** : training psychiatric teams in research methods, raising awareness among people working in primary health care with regard to recognising and taking account of mental disturbances, informing field agents of the importance mental illness prevention and of the need to take cultural factors into account in the provision of care.
- **raising awareness among social, administrative and political partners** on problems of mental health promotion, mental health prevention and care provision for the mentally ill, via their involvement and consultation at every stage in the research procedure.
- **fostering** the development of community based psychiatric practices.

## V. METHODOLOGY

### 1. GENERAL METHODOLOGICAL FRAMEWORK

The research option was to carry out a multi-centre survey in the general population. Essentially, in this survey, for feasibility reasons, this covers the population as a whole **with the exception** of marginalised and hospitalised populations. Indeed, sampling methods for the latter types of population are very specific and could not be incorporated into this research<sup>11-12</sup>.

Data was collected using questionnaires administered in the course of face to face interviews to a sample of subjects, by interviewers trained in the use of the particular instrument. For each subject interviewed these questionnaires enabled firstly exploration of individual representations of mental health and of modes of assistance and care available, and secondly an estimation of the existence of present or past psychiatric disturbances, and the therapeutic resources resorted to.

The pilot phase made it possible to test the feasibility and validity of this methodology in all the study sites on 100 subjects. In the course of the main phase, a representative sample of 900 subjects for each site were interviewed.

### 2. CULTURAL ANTHROPOLOGY AND PSYCHIATRIC EPIDEMIOLOGY : HOW THE TWO APPROACHES ARE HINGED

Given the two lines of study chosen, the main issue was to combine the two research methods rather distant one from the other at the outset. For this purpose, from the start the research team comprised professionals from the area of mental health as well as a sociologist and an anthropologist.

Anthropology has already taken an interest in psychiatry : Kraepelin, Freud and Devereux all felt the need to consider mental manifestations from indisputable non-variants, whether manifest of latent, visible or invisible. But this is in fact the first time in the field of research that the approach has been transverse, inter-disciplinary and inter-locality.

While sociology and epidemiology can be easily "instrumentalised" for large groups, psychiatry and anthropology start from case study and small groups. These disciplines are concerned with the more intimate, the impalpable; they are concerned with day to day observation where the subjective is the object of the science itself.

**This can be simplified by saying that sociology is to cultural anthropology what epidemiology is to psychiatry and even more so to psycho-analysis. The absorption of one discipline by another has led to all manner of confusion and lumping together.**

**Psychiatry** distinguishes the sign or symptom as belonging to the patient's history whether reported by him/herself or by others; it studies the social background, family history over three generations, it takes account of lineage and alliances, and what is said of them. It studies the material and libidinal patterns of the individual in its care, an individual who does not always recognise him/herself to be "ill". Lay psychiatry has taken little interest in political and religious beliefs, this area being curiously absent from questionings. It rarely mentions social class or money. It is these neglected areas that are brought to the fore in this study.

**The task for psychiatric epidemiology** is to describe the mental health status of a given population, to assess incidence of "mental illness", and theoretically to prevent epidemics. Yet figures regularly published in general population studies can but make one wonder : 50% of the population experiences at least one disorder in their lifetime according to one American study, and 30% in the 12 months preceding the survey<sup>13</sup>. Other figure to reflect upon are : 25% of subjects seeing a general practitioner are suffering from anxiety or depressive disorders. Only a quarter of these disturbances are "properly" cared for.

All of this puts a certain perspective on the very notion of "mental health", further underpinned by more subtle notions such as "quality of life" and "asymptomatic status" : can mental health be reduced to merely absence of disturbances ?

Epidemiology in psychiatry is only a poor image of the problems inherent in the discipline : either it is objective and simplistic, not reflecting the patient's history, or it is subjective and non-operational, allocating the signs to a multitude of interpretations that psychiatry and derived disciplines (psychoanalysis for instance), abound in, with the obvious attendant non-communicability, and inability to reason the issue in terms of public health. The ongoing debates in the philosophical field on the concepts of the universal and universality only compound these difficulties : globalisation perhaps requires a monstrous new tower of Babel for the psyche.

Epidemiological psychiatry, if it is to deserve its name, needs to integrate mental representations of the object it is to manipulate in disguised form (symptoms). These representations are translated in terms of insanity or lunacy yesterday, "mental illness" today and "depression" tomorrow.

This is a challenge that we have attempted to put into figures in this survey : beliefs, opinions, and care itineraries with respect to illnesses and social concepts that are very markedly "taboo" :

- defining cultural habits in naming insanity and "mental illness", and their symbolic or medical treatment;
- ascertaining whether cultural difference is operative at a time when individuals, commodities, ideas and care are in the throes of globalisation;
- setting representations of "mental illness" against "real" attitudes towards care;
- examining whether, and if so how, the megalith of mental alienation and that of alienness (alien and foreign) will co-exist, and whether their social and cultural processing will be identical or not;
- supposing that practices previous to or concurrent with official triumphant medicine may be merely vanishing species from cultures of the past, crushed by the rollers of all-efficient single-mindedness,
- or, in complete contradiction, thinking that the evils afflicting mankind, translated into psychiatric symptoms, can only be cured by the ritual of integration into a re- founded community "as it used to be". But this may be forgetting dominant individualism and its damaging lateral effects.

**In the face of these uncertainties, moving on beyond splits and divisions is essential for the mental health of researchers. Our studies will only be improved if we take into account other fields of research concerned with the same subject, and if we go on to build alliances with them. In this sense the work conducted in collaboration with anthropology makes it possible to avoid making over-mechanical interpretations of results from the survey, and to remain faithful to empirical observation. These challenges are also philosophical, and concern the place of the researcher or of so-called knowledge in the constitution (or destitution) of knowledge itself.**

## VI. INSTRUMENTS

### 1. SOCIO-ANTHROPOLOGICAL LINE OF STUDY : PRELIMINARY SEMANTIC ISSUES

This research, which from the outset was directed towards a set of very different societies, had to ask the question of the trans-cultural validity of its chosen approach. Hence great efforts have been made to take account of the cultural dimension of illness, of its perception, and of the behaviours arising from this dimension. However, the need to ensure adequate co-ordination with the epidemiological survey *per se* imposed certain limitations. Thus the choice made was to deal with questions relating to representations in the general population using a "socio-anthropological" questionnaire.

- **Representations linked to illness** : behaviours and responses, causes, responsibility and awareness, suffering, exclusion, role of the family and friends/acquaintances
- **Representations linked to assistance and care** : care, cure, knowing facilities available, referral of the subject and those close to him/her.

In view of these requirements, the term "socio-anthropological" could seem misleading : indeed this is neither an anthropological nor a sociological study, but a questionnaire included in an epidemiological survey, presented and then interpreted along the lines of this sort of survey ; yet it broaches themes connected with these representations, **and it is these themes that are anthropological, not the methods used.**

Aspects that might appear difficult to accept on the part of anthropologists, had the research work aimed solely to explore the anthropology of representations of illness, in fact take on a meaning here, since :

- **the homogeneity of the sample, essential for administration of questionnaires in a given site and from one site to another, was an overall requirement to ensure that it would be possible to obtain comparative data, and above all to ensure coherence with the strictly epidemiological questionnaire.**
- **the task was to obtain a general picture of these representations rather than to enter into the details of how they are structured and how they arise.**
- **it is rarely a case of exploring less well known facets of the societies under study, but rather an exploration of general categories, estimating the frequency of certain social and cultural characteristics and the links that emerge between them.**

**It is therefore within these clearly defined boundaries that results derived from the "socio-anthropological line of study" should be received and analysed, thus avoiding misplaced expectations. It is also beyond these boundaries that recommendations for future research can look.**

The spirit in which results are commented on here reflects what the health anthropologists were able to conceive when setting their work against that of epidemiologists. The results of this research are, in this instance, backed up by the conclusions of one researcher who did a lot of work on

relationships between the field of application of anthropology and that of epidemiology. After wondering if the logic of anthropology and that of epidemiology were identical or different, he reaches the conclusion that there is "more than one logic, but a lot less than two"<sup>14</sup>.

This leads him on to considerations that are directly applicable here : "The explicit objectives of these two disciplines differ widely. Anthropology attempts to conduct analyses that are rich on account of their context, showing how numerous particular details fit together to produce a unique configuration. Conversely, epidemiology aims to conduct analyses linking universal factors, freed from their context. Anthropology is "fat" and "soft" and epidemiology is "lean" and "hard". There is in fact a distribution of tasks : "the epidemiological procedure can cast light on the process of assessment of hypotheses underlying anthropological interpretation of beliefs and practices"

In contrast, anthropological methods can provide epidemiology with the perception of the meaning of events as seen by the subjects involved. If the epidemiologist has found that a certain behaviour is associated with certain illnesses, knowledge of the meaning of this behaviour for those adopting it can be a pre-requisite to understanding how the behaviour can be changed and what the consequence of this change are likely to be.

## 2. SOCIO-ANTHROPOLOGICAL LINE OF STUDY : QUESTIONNAIRE ON REPRESENTATIONS

### A. SOCIAL REPRESENTATIONS IN PSYCHIATRY

*"We need to know about the world around us. We have to adjust to it, to know how to behave in it, to control it physically or intellectually, and to identify and solve the problem it poses. This is why we manufacture representations. And just as, in the face of this world made up of objects, people, events and ideas, we are not (solely) concerned with automatism, in the same way we are not isolated in a social vacuum : we share this world with others, we rely on them to understand it, manage it or face up to it. That is why social representations are so important in day-to-day life. They guide us in our joint naming and defining of different aspects of everyday reality, in the way we interpret them, make judgements on them, and in some instances take up positions with respect to them and defend that position."*<sup>15</sup>

For Denise Jodelet a social representation "is a form of knowledge that is elaborated and shared socially, with a practical aim contributing to the construction of a reality shared by a social unit". It is also what can be called shared knowledge or "naïve" (non-expert) knowledge. Durkheim<sup>16</sup> was the first to put forward this concept under the term of collective representations. Moscovici, and later Jodelet, see social representations as being markedly interactive.

Other fields of medicine concern themselves with social representations of pathologies so as to assess their effect on care provision or recourse. Asthma, cancer and epilepsy have been the subject of different studies. The issues encountered are similar to those found in psychiatry in the article by F. Larra in 1996 : *Images and representations of cancer, from myth to reality*<sup>17</sup>.

The word cancer goes beyond the field of medicine. It is used pejoratively in expressions like a social cancer.... It has a considerable mythical load of incurability, reinforced by the idea of the association of cancer with death, while some patients recover without the word cancer ever being pronounced. Some general practitioners avoid hospitalisation in specialised cancer units, because they are wary of the impact of this sort of referral on the patient and family. The influence of representations can be seen in the way care is provided or sought. Professionals are concerned likewise. This pattern can be applied to numerous other pathologies, all the more so where they are chronic or life-threatening. **It is the weight of representations that alters care patterns.**

## B. FROM SOCIAL REPRESENTATIONS TO ATTITUDES

Attitudes are often conditioned by social representations, sometimes going as far as to eclipse scientific knowledge. In many areas of public health, it has quickly become clear that it is not sufficient to inform to bring about changes in behaviour. In anti-smoking campaigns, so long as the scientific establishment addressed the population to inform them about the risks of disease or to show them diseased lungs, the impact remained moderate. It is only by altering social representations of the smoker that it became possible to alter attitudes. An example would be the advert that used a revised version of the Marlboro cowboy image.

Work on behaviours in alcohol addiction have given special attention to the area of the relationship between social representations and attitudes. L. Gaussoit<sup>18</sup> states that social representations of alcohol addiction and alcoholics have a part in the construction of the social norm for "managing drink" or "drinking sensibly". These are the representations that fuel the way people talk and the way they behave. These negative stigmatised images contribute to the "managing drink" construct and help people to keep to a "reasonable" level of drink consumption.

In psychiatry the attitudes that can be studied are not just those of patients and those around him/her, (that is to say the way in which care is resorted to and used) but also those of society with regard to the mentally ill : what is their place in society ? how are they represented ?

## C. REVIEW OF THE LITERATURE ON THE ASSESSMENT OF REPRESENTATIONS OF INSANITY, MENTAL ILLNESS AND DEPRESSION

**In France**, there has been some theoretical work on insanity and its social representations, like that by Jodelet, and Boiral and Brouat<sup>19-20</sup>, and a group of professionals was recently commissioned by the French health ministry to analyse the image of psychiatry<sup>21-22</sup>. But no referenced French studies in the general population were found on large samples and using structured questionnaires.

Various authors have studied public attitudes towards the mentally ill<sup>23-24-25-26-27</sup>. Some studies describe the impact of establishing mental patients within the community<sup>28-29-30</sup>.

As assessment instrument, the Community Attitude to the Mentally Ill (CAMI) scale developed by Taylor and Dear<sup>31</sup> explores three domains : fear and exclusion, social control, and tolerance. It is regularly used by these authors as the basis of their work.

A semi-structured questionnaire was developed by Angermeyer and coll.<sup>32</sup> to assess representations with respect to treatment of mental illness, clinical vignettes were used in a national Australian survey on the systems of belief in the general public with respect to depression and schizophrenia and their treatment<sup>33-34-35</sup>. This survey showed up the limitations of the use of "preformatted" vignettes because the gender of the case described markedly influences the perception of risk factors.

These studies are intended to identify certain factors that foster rejection of the mentally ill, so as to better direct educational initiatives in the general population. Brockinton<sup>36</sup> (1993) found **a relationship between tolerance and age, educational status and proximity with respect to the mentally ill**. This proximity is widely recognised. The fact that a person knows a mental patient directly or indirectly leads to greater tolerance. Wolf (1996) notes that people who have the strongest tendency to reject are those with children to bring up and those with low educational status. No social determinant is identified.

Hayward and Bright<sup>37</sup> (1997) carried out a review of the literature on the stigmatisation of the mentally ill. **They are described in the population as being dangerous and unpredictable. It is difficult to talk to them, and it is they who are responsible for this. They could "shake it off" if they wanted to, and respond little to treatment.**

National studies were conducted in the USA on this subject in the 50s, 70s and 90s, following the same methodology<sup>38</sup>. In the 50s the American public attributed a dimension of shamefulness to "mental illness", and showed non-scientific understanding of the phenomenon. The subjects interviewed were not able to identify mentally ill cases from profile definitions offered. "Mental illness" was associated with great **social stigmatisation**, strongly connected with fear of unpredictable and violent behaviour. In 1996 the survey showed that Americans had progressed towards a better knowledge of "mental illness". But this progress had done nothing to alleviate the atmosphere of shame and rejection on the part of society. In fact, the general public attributed an overestimated frequency of violent behaviour to "mental illness". The general perception that the mentally ill are likely to be dangerous was more marked than before. Thus **stigmatisation has remained very strong despite better understanding of the disorders.**

Certain authors have taken an interest in one of the **supposed vehicles of these perceptions of the mentally ill** : the media. Day<sup>39</sup> (1986) in Canadian newspapers, Dudley<sup>40</sup> (1994) in Australian fiction and Wilson<sup>41-42</sup> (1999, 2000) who studied television representations of the mentally ill. All note a pejorative view in these representations. But little is known about what inspires or motivates such attitudes. Why is this sort of attitude widely held in the population ? Attitudes have frequently been studied without determining their origins.

Numerous subjects who develop depression do not admit it to themselves and are reluctant to seek help<sup>43</sup>. **Mental illness is experienced as something to be ashamed of, and this does nothing to promote access to appropriate care.** The image of psychiatry is hindered by representations of the pathologies it deals with, as well as by representations relating to the care it provides, which include both psychiatrists themselves and treatment. Thus nearly two thirds of the people needing psychiatric care for recognised mental disturbances do not seek it...<sup>44</sup>

Khon<sup>45</sup> (2000), in a study conducted in the San Domingo republic using clinical profile descriptions, notes **that out of depression, alcohol addiction, hyperactivity in children and psychosis, only psychosis is recognised as a mental illness.** A similar study in Nigeria conducted by Erinosh<sup>46</sup> (1978) shows **that only the description of paranoid schizophrenia is recognised as a mental illness**, while other clinical profiles (simple schizophrenia, anxiety, neurotic/depressive condition, alcohol addiction) are described as shy, nervous, odd, agitated or drunk. Any similar study in France would no doubt show up a certain degree of ignorance about psychiatric disorders.

**There are at least three factors that limit the initiation of care :**

- **the ability to recognise the fact that something is happening that bears some relationship with a disorder or an illness**
- **the ability to recognise this disorder as belonging to the psychiatric field, i.e. to recognise it as a mental pathology**
- **the stigmatisation of receiving care for this type of disorder**

Further to this, medical circles also need educating<sup>47-72</sup>. Indeed the medical profession is also weighed down by representations. There is reluctance on the part of certain general practitioners to refer patients to a psychiatrist. How can he announce it to the patient? And often it is eventually in an emergency that the patient is referred, when there are no longer any alternatives.

Social representations are tools for public health, since they concern the community. There is talk about "educating the population". But what should they be taught? Change. Yes, but what is it that needs changing? It is perhaps in these areas of mass communication, in communication strategies, and in health policies, that social representations can most readily be used.

Thus, as the recent American report on mental health<sup>48</sup> suggests, pejorative perceptions of mental pathology can be toned down via appropriate information. Only progress in public mentalities can make it possible to reduce the time lapse between the emergence of a state of distress and an appropriate response. "Overall approaches to reduce stigmatisation imply programmes involving representatives of users, public education, and contact with individuals with mental disturbances".

**The first aim of the study of social representations is to recognise and use these representations so as to improve therapeutic strategies and favour proper use of the care system. This "proper attitude" is the patient's, but also that of those around him/her, and above all that of professionals.**

#### **D. DEVELOPMENT METHODS FOR ASSESSMENT INSTRUMENTS**

In a preliminary study Crisp and coll.<sup>49</sup> note that they consider the terms severe depression, panic attack, schizophrenia, dementia and addiction were understood in a satisfactory manner by the general population. Their interviews were conducted in a direct manner.

We however contend that medical terminology is often not in line with that of the patient or those around him or her. We do not speak quite the same language. Kovess mentions this gap in a study on representations concerning depression<sup>50</sup>. There are indeed many patients who claim to be depressive ; how often have we not been confronted with delirious psychotics who talk about their " depression " ?

Hence the issue is how to question populations if we do not use the same language ? The main difficulty in any attempt to study representations in psychiatry is therefore to determine a way to approach these representations.

Various strategies have been suggested to get around this misfit of language. Some have suggested clinical profile descriptions (see Jorm and coll.). These are presented to determine the attitudes of people towards the mentally ill. In these studies the starting point is a particular case

servicing to move on to the general picture, shifting from a "photograph" of a particular psychiatric pathology as determined by professionals towards public attitudes with regard to the profile set out.

Wilson's<sup>40</sup> work on television representations of mental illness in children's programmes faced the same issue : how can meaningful terms be selected ? Should they be those referring to mental illness ? Should references to being insane be considered ? All too often the terms used reach beyond the field of mental illness.

Different social representations are to be found in the sphere of psychiatry. **The aim here is not to start out from psychiatry and move towards social representations, but the reverse.** Indeed, these representations are so numerous that they reach far beyond the field of mere psychiatry. Social representations are not solely rooted in medical matters. They are a very complex phenomenon, and are influenced by numerous factors culture, history, science, media coverage. Their origins are also numerous. Hence the design of the questionnaire is an attempt to follow along these paths.

## E. DEVELOPMENT OF THE "SOCIO-ANTHROPOLOGICAL" QUESTIONNAIRE

The questionnaire on representations needed to explore representations with regard to "insanity", "mental illness" and "depression", to the "insane" the "mentally ill" and the "depressive", and also to care provision, in different cultures. It also needed to be simple to administer and to exploit, and as far as possible suitable for administration in all the cultural contexts found among the study sites.

A review of the literature led to the observation that there was, to date, no French-language questionnaire, hence the decision to develop a **specific questionnaire for this survey**, following a multi-centre international development protocol tested by WHO<sup>51-52</sup>, the main steps of which are presented in **Table 1**.

The research quoted above contributed to general reflection leading up to the development of the questionnaire, as well as casting light on more specific considerations concerning the Indian Ocean cultures<sup>53-54-55</sup>. The development of the questionnaire was enriched by active multidisciplinary collaboration from anthropologists mainly Gilles Bibeau<sup>56</sup> and Jean Benoist. This consultation was conducted in several stages all through the research work :

- initiation of the project within work underway in the Indian Ocean islands ;
- interpretation of results from the first test questionnaires administered to small samples, and then development of final questionnaires ;
- examination of results from the various sites as they came in ;
- overview and comparison in the course of meetings.

These stages were sometimes rather difficult for the parties involved. The conceptual and methodological distance between anthropologists and psychiatric researchers often proved to be so wide that dissatisfaction and even tension sometimes developed. The anthropologists had great

difficulty in reconciling their approach with a questionnaire that fragmented issues which they generally tackle in a more global manner, via an in-depth clinical type procedure.

However it was clear that the procedure was necessary, on account of fact that the task also involved using the epidemiological questionnaire to explore prevalence. Hence the consultation of the anthropologists in no way concerned the opportuneness of this type of approach, but rather the way it was implemented, so as to obtain the best possible results : wording of questions, possible introduction of new questions, and at a later stage the interpretation of results.

The final questionnaire comprises some fifty open, semi-open and closed questions enabling exploration of representations relating to "insanity", "mental illness", and "depression", to types of assistance and care available (medical, religious, magic, and other), to tolerance on the part of society and to the role of the family.

## **F. VALIDATION**

The acceptability of the questions was assessed at each stage of the development procedure by administering them to about ten individuals from the general public. An inter-rater reliability test was conducted with all the interviewers who scored a video interview at the end of the training period. This test showed that more than 90% of the scores were identical from one interviewer to another. The differences in scoring could be attributed to the hierarchical ordering of coding in semi-open questions.

## TABLE 1 : INTERNATIONAL DEVELOPMENT OF THE QUESTIONNAIRE ON REPRESENTATIONS

1. **20 open questions** put forward by teams in each site (France and Indian Ocean) generated from the general population. The questions conformed to criteria of simple wording and syntax.
2. **Collation of questions** from all the sites (about 120 in all)
3. **Selection of 20 questions by the scientific committee** (elimination of redundancies, questions that were too long or too complex, double negatives, followed by classification by vote).
4. **PRE-TEST** : administration of preliminary questionnaire of 20 open questions to 15 subjects in each site (general population and administrative social and political partners,)
5. **Analysis of response content** leading to a first proposal for instrument construction (main domains explored, type of response pattern)
6. **Conversion of open questions into closed questions** (in international workshops according to themes : "insanity/the insane", knowledge of care facilities, recourse to care). The task was at the same time to take into account the responses provided in the pre-test (content analysis), and to reword the questions and draft corresponding response choices, observing the structure defined for the instrument (main domains) and cultural diversity
7. **Expert review** (psychiatrists, psychologists, anthropologists, and sociologists). The opinion of experts from RESAME was sought and their comments were taken into account in the drafting of the pilot questionnaire
8. **Pilot Questionnaire** : N closed questions (international core section) + n national questions + recording of spontaneous comments by interviewers and interviewees
9. **Translation and adaptation of the pilot questionnaire** for Comoro Island, Guadeloupe, Madagascar and Mauritius sites, with possible addition of specific national questions in individual sites.
10. **PILOT STUDY** : administration of pilot questionnaire to 100 subjects in each site (50% men, 50% women between 25 and 50 years of age) so as to test for acceptability. Recording of comments on the questionnaire made by interviewers and interviewees.
11. **Analysis of results**, test for psychometric properties (factorial analysis, multiple regression) validation of domains
12. **Drafting of final survey questionnaire** from the analysis of psychometric properties and comments from interviewers/interviewees during the pilot study. The choice of wording for each question was validated in international workshops
13. **Translation and adaptation** of the final questionnaire.
14. **Inter-rater reliability test** : simultaneous scoring by several interviewers from a single filmed interview.

### 3. THE EPIDEMIOLOGICAL LINE OF STUDY : THE DIAGNOSTIC QUESTIONNAIRE

#### A. CHOICE OF QUESTIONNAIRE

The psychiatric diagnosis questionnaire needed to be short, simple to administer, validated, and able to provide diagnostic assessments according to ICD-10 criteria, in the different sites.

Several instruments have been developed in the course of the last 20 years, mainly by English-language teams, to enable exploration of mental disturbances and collection of epidemiological data on a large scale. The common features of these questionnaires are firstly that they are **structured diagnostic questionnaires**, the construction of which is based on diagnostic criteria defined in the WHO international classification of disease<sup>57</sup> (ICD 9<sup>th</sup> or 10<sup>th</sup> edition) or in the DSM<sup>58</sup> (version III, III-R or IV), and secondly that they can be administered by non-clinical personnel trained in their administration. The diagnoses are obtained by using integrated algorithms.

The evolution has been towards greater simplification of exploration procedures, so as to reduce bias linked to administration procedures that may indeed be exhaustive, but too tedious for the subject interviewed. The first questionnaires developed could last as long as three hours, while today, with the latest generation of questionnaires, administration time is around 20 to 30 minutes. The main instruments in this family are presented below, and the final choice of the MINI is explained.

The **DIS**<sup>59</sup> (Diagnostic Interview Schedule) used by the ECA<sup>60</sup> survey in the early eighties covers the main diagnoses on DSM-III axis 1. Each symptom, when reported present by the subject, is checked by a series of complementary questions (physical or psychological origin, connection with alcohol or drug abuse, etc.) and then severity of the symptom is assessed (adverse effects experienced, therapeutic recourse). This instrument has been validated in the general population. A self-administered version, the **DISSA**<sup>61</sup> (Diagnostic Interview Schedule Self Administered) has been developed by a Canadian team and validated in the general population.

The **CIDI**<sup>62</sup> (Composite International Diagnostic Interview) developed by WHO is the result of the fusion of the DIS with the PSE<sup>63</sup> (Present State Examination). It has been validated in the general population and makes it possible to produce ICD-10 and DSM-III-R and IV diagnoses, but it is complicated to administer (flow chart for the exploration of aetiology of symptoms noted to be present, as for the DIS).

The **CIDIS**<sup>64</sup> (Composite International Diagnostic Interview Simplified) developed by Kovess made use of contributions from the DISSA and the CIDI, and after adaptation now enables DSM-IV and ICD-10 diagnoses. It was used in two general population studies, in the Enquête de Santé des Franciliens<sup>65</sup> (Paris region) survey and in the Enquête de Santé en Basse-Normandie<sup>66</sup> survey. The instrument is relatively simple compared with the other two since it has no aetiology decision tree, but it has not been validated in the general population. It has also been used in two studies on mental health among the homeless, with all the limitations of this type of instrument for such populations<sup>67</sup>.

The **MINI**<sup>68-69</sup> was developed by a French-American team (Lecrubier & Sheehan), and it belongs to the latest generation of standardised diagnostic instruments. Drawing inspiration from its predecessors, it is simple to administer (Yes/No responses) and short (20 minutes on average). It makes it possible to produce ICD-10 and DSM-IV diagnoses. Reliability and validity of the MINI have been explored in psychiatric patients and non-patients in comparison with the CIDI. Kappa coefficients proved to be good (between 0.43 and 0.68) or very good (>0.75) for most diagnoses except simple phobia and generalised anxiety. Further to this, a validation study was conducted among general practitioners, comparing the diagnoses generated by general practitioners and those produced by psychiatrists<sup>70</sup>. Finally, a general population study<sup>71</sup> enabled collation of elements of validity concerning the sections on mood disturbances. The section on mood disorders was used both in the European Study on depression (DEPRES<sup>70</sup>) and in a survey on health and social cover conducted in 1997 by the CREDES<sup>72</sup>.

**There is at present no reliable validated instrument to cover all psychiatric pathologies. Most are reasonably efficient in detecting depressive disorders and certain anxiety disturbances, but there are still numerous problems in particular for psychotic disturbances, panic attacks, and generalised anxiety.** In this context, the MINI was chosen because it is relatively simple to use while at the same time having acceptable validity. According to Lecrubier (one of the designers of the instrument), the gain in data quality derived from the CIDI in comparison with the MINI is around 5%, for an administration that last three times as long, and with a more complicated question system<sup>73</sup>. It remains that the result interpretation requires considerable care.

## B. PRESENTATION OF THE MINI

The version of the MINI chosen for the survey enables exploration of the following present disorders : **mood disorders** (major depressive episode, dysthymia, manic episodes (lifelong); **anxiety disorders** (agoraphobia, panic attacks, social phobia, obsessive compulsive disorders, generalised anxiety, post-traumatic stress disorder), **eating disorders** (anorexia, bulimia), **disorders related to alcohol and drugs abuse; psychotic symptoms.**

**It should be added that the version of the MINI chosen here does not make it possible to explore all the criteria required to diagnose schizophrenia and other psychotic disorders, giving merely some information on certain psychotic symptoms.**

Some complementary questions were added at the end of the MINI, aimed at exploring the impact of the disorders scored positively on everyday life, as well as to explore recourse to assistance or care (general practice, psychiatry, alternative medicines, religious and magic practices).

The pilot study made it possible to validate the use of the MINI by non-clinicians (in comparison with clinicians). The results will be presented elsewhere<sup>74</sup>.

### Methodological details

The question of the ability of standardised diagnostic questionnaires to detect psychotic disorders in a reliable and valid manner has been a recurrent one, ever since the first English-speaking teams began to take an interest in the possibility of standardising diagnostic assessments in psychiatry. Indeed, if reliable standardised assessment of the presence of neurotic type disorders is problematic, that of psychotic type disorders is virtually insoluble.

It can be recalled that the large American study, the Epidemiological Catchment Area Study (ECA)<sup>a</sup>, which made use of the DIS administered by non-clinician interviewers obtained an age-adjusted annual incidence for schizophrenia of 1 to 7.1/1000, **which is 25 times higher than the average rates obtained from other studies using the standard diagnosis approach**. A sub-sample of 810 subjects was submitted to a counter-assessment by psychiatrists (Anthony et al, 1985) and a high rate of false positives and false negatives was evidenced. Only 16% of the cases diagnosed by non-qualified interviewers using the DIS were confirmed by the psychiatrists, and conversely only 21% of the cases diagnosed by the psychiatrists had been detected by the DIS<sup>75</sup>.

The validity of the MINI, in a more general manner, raises the question of the validation of this type of instrument, which are often validated by setting one against the other (the CID compared with the DIS, the MINI with the CIDI) without there being any recognised "gold standard" as such. Further to this, the instruments have been validated on (small) samples drawn from populations in psychiatric care, or "cases", which renders their sensitivity doubtful when subjects from the general population are involved.

**Thus the MINI poses the same problems of reliability and validity as all the other structured diagnostic instruments used by non-clinicians with respect to evaluation of psychiatric disorders.**

In the pilot phase of the survey aberrant prevalence data were obtained for psychotic disorders. After analysis, several explanations were found :

- the questions are worded in such a way that they markedly lean towards over-inclusion; among the 7 screening questions, any individual can respond YES at least once. And a single YES is sufficient to qualify as positive in this section.
- many interviewers did not discriminate between true and false positives in an appropriate manner (hardly surprising as they were not clinicians)
- to these two reasons can be added the cultural interpretations of questions<sup>†</sup>. For instance, for a Moslem it appeared quite ordinary to feel that someone was "controlling his thought and acts" ; i.e. Allah, who decides how everything happens.

Therefore, to reduce the bias arising from the very design of the instrument and from the involvement of non-clinician interviewers, a **complementary procedure** was developed for this part of the questionnaire, which is as follows :

- whatever the relevance of the response, the interviewer systematically noted a **detailed example** provided by the subject in the case of positive response to one of the questions in the psychosis section,
- a series of **questions complementary** to the MINI concerning the psychosocial consequences of the disturbances and recourse to care was then asked for any disorder with a positive score,

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<sup>†</sup>Here we reach the limits of trans-cultural applicability of this type of instrument, based on "internationally" validated classifications

- from the detailed example and the complementary information, as well as the feeling of the interviewer with respect to the example recorded, a clinician (psychiatrist or psychologist) assessed true and false positives each evening in the presence of the interviewers.

This method was tested empirically in the course of the pilot phase in sites in the Comoro Islands and Mauritius, and showed its ability to reduce the number of false positives (estimations of presence of psychotic disorders fell from 35% to 5%).

A **reliability survey** was then conducted on 106 patients in a psychiatric sector team in France. This enabled comparison of presence of psychotic disorders (present or lifetime), as assessed by clinician A and by an interviewer using the MINI, checked in the case of positive score by clinician B (using the method described above).

**The Kappa coefficients obtained vary for the ICD-10 diagnosis from 0.79 (present isolated psychotic episode) to 0.83 (lifetime psychotic episode). These results are highly satisfactory.**

Thus care was taken as far as possible to reduce systematic error inherent in the type of instrument used and in the object of the assessment itself. However, if by way of this complementary procedure it is possible to control false positives and obtain reliable true positives, nothing covers against obtaining false negatives, i.e. subjects suffering from psychotic disorders who respond negatively to all the items in this section.

#### 4. SOCIO-DEMOGRAPHIC DATA

A final questionnaire was aimed at collecting socio-demographic data from subjects interviewed, these being : gender, age or year of birth (in some Indian Ocean countries this can be rather approximate), marital status, educational status, professional qualifications, professional situation, cultural reference group.

#### 5. ANONYMITY

The survey was anonymous. The subjects interviewed responded after receiving information on the aims and conditions of the survey, and after giving consent to take part. The research protocol was submitted to the consultative committee of the French CNIL (protection of individual privacy). This body did not consider it necessary to undertake a complete authorisation procedure from the CNIL.

#### 6. TRANSLATION METHODOLOGY

All the sites involved in the study are French-speaking countries; however the distribution and command of the French language can vary within a given country. At each stage in the work, the following **translation methodology** was used :

- **review of all the translated material available** in the field of mental health in the site taking part in the survey.

- **translation from French into the target language** by at least two independent translators (not involved in the survey, but with some knowledge in the field of health)
- **first consensus meeting** convening translators and research team, analysis of differences in translations produced question by question, agreement on wordings. At this stage resorting to outside expertise can prove useful (linguists, ethnologists, etc). Care is taken to use wordings accessible to a wide public.
- **test for acceptability and understanding** on **at least 5 subjects** of low to average socio-cultural status.
- **second consensus meeting** to analyse results of the test and develop a final version of the instrument.
- **translation report** delivered to the survey co-ordination.

## 7. INTERVIEWERS

Action- research is based on involvement of partners identified as potential relays for action in each stage of the research. Thus it appeared important to ensure agents or future agents involved in mental health should collaborate in the data collection phase. To achieve this, health personals in the different teams involved in the research (primary health care agents, nurses, doctors, hospital psychiatrists, psychologists, social workers) as well as students in nursing or sociology were called upon to participate.

- **for health personnel** (whether specialised or not) the survey constituted an opportunity to raise awareness on research work and methods in the field of psychiatry. It was also an opportunity for consideration of representations linked to mental illness that each person entertains, and their effects on professional practice<sup>76</sup>.
- **for the students**, the purpose was to initiate reflection on the place of mental health in society, and to provide better knowledge of the different pathologies and the patterns of therapeutic recourse. Here the issue is promotion and prevention work in the field of mental health. This work was carried out in close collaboration with the teaching staff in charge of the establishments approached.

**In each French site**, nursing schools, university departments of sociology, and colleges training social workers were applied to in the last quarter of 1997, so as to integrate the research into the 1998-99 curriculum for third year students. Courses on psychiatric nosology and on mental health and psychiatric research were put on offer. After a three day training course, the students collected data in the field. Some of them incorporated this experience into their final dissertations. In some sites, the DDASS structures (department of health and social services) supported and promoted formal existence of this collaboration at local level.

In the **Comoro Islands** the interviewers were recruited among individuals who had taken part in the Demography and Health survey (state registered nurses, demographers, statisticians) or any other similar survey. They were under the responsibility of the people in charge of the survey at local level, who had been through the National College of Health.

In **Madagascar** the interviewers were unemployed general practitioners, while in **Mauritius** the interviewers were the staff locally in charge of the survey and some twenty individuals recruited among the staff of the National Institute of Health and Brown Sequart Hospital.

## 8. TRAINING OF INTERVIEWERS

So as to harmonise the basic training of all the interviewers, training was provided by a representative from the WHO Collaborating Centre or by one of the six training officers trained by WHO CC. Each interviewer had a **guide for scoring the questionnaires** providing detailed recommendations for completing and coding the three survey questionnaires.

The training session ran over three days along the following agenda :

- raising awareness on problems of mental health
- presentation of the research (purpose and implementation)
- general rules of the survey (anonymity, confidentiality, observance of instructions)
- training in administration of the three survey questionnaires (theory and role play)
- completion of a test questionnaire by each interviewer with a subject from the general public
- assessment of the test questionnaire
- inter-rater reliability test (video)
- organisation of the field work

## 9. SAMPLING

### A. SAMPLE SIZE

Several aspects enter into the size of the sample : the expected prevalence rates for psychiatric disorders in the general population, the amount of detail required for the analysis of data, and the error (alpha) risk fixed.

Recent WHO figures<sup>77</sup> give worldwide prevalence in the general population of 9.4% for **major unipolar depressive disorders** (8.3% for men and 10.5% for women), of 0.5% for **schizophrenia**, and 2.7% for **generalised anxiety** (2.4% in men and 3% in women, prevalence reaching 4.4% for Africa).

At the start of the eighties in **the American survey Epidemiological Catchment Area (ECA)**<sup>78-79</sup> prevalences observed were as follows : major depression 4 to 7%, phobias 7 to 9%, anxiety disorders with panic attacks 1.5%, obsessional disorders 2% and schizophrenia 2%.

The **National Comorbidity Survey**<sup>80</sup>, a more recent study, found slightly higher prevalence rates for psychiatric disorders in the USA, which were as follows for the previous 12 months : major depressive episode 10.3%, disturbances related to alcohol and drugs abuse 11.3%, generalised anxiety 3.1%, phobic disorders 8% and schizophrenia 0.5%.

**In France**, in 1987, the study conducted by Lépine<sup>81</sup> and coll. in the Paris area, found for the year preceding the interview, an incidence rate for depression of 3.4% for men and 6% for women, for phobia respectively 7.9% and 16%, and for generalised anxiety 3.7% and 6.5%. Three years later the survey **Santé des franciliens**<sup>82</sup> noted similar rates, and for depression over the preceding 6 months 3.3% in men and 8.2% in women. Conversely rates for phobia and anxiety disorders are rather different, since they respectively reach "only" 3.5% and 6.2% over the whole lifespan. Two studies conducted on national samples in 1995 and 1997 with the MINI<sup>c</sup> find rather higher rates for depression : the survey DEPRESS<sup>84</sup> found 6.9% over the preceding 6 months, and the CREDES<sup>83</sup> survey 12% (depressive episode) over the previous year (see Table 2).

As the above data shows, the rates of prevalence for psychiatric disorders in the general population vary from one source to the other. This can be explained by numerous factors<sup>85</sup> :

- difficulty in finding a consensus in defining the disorder
- variations in classification of disorders between the various surveys (DSM-III, DSM-III-R, DSM-IV, CIM-9, then CIM-10)
- difficulty in defining a "case" in psychiatry (distinction between normal and pathological)
- variations in the methods of data collection
- varying complexity of questions asked
- psychometric validity of the instrument used
- the very nature of the disorder being explored
- the time frame selected (present, previous 6 months, lifetime).

With the above reservations, it can be said that prevalence in the previous 12 months for the disorders explored in this study would appear to vary from 0.5% (schizophrenia) to 20.2% (major depressive episode). In order to have a sufficient number of subjects for each type of pathology explored with a 5% alpha risk, a minimum of 900 subjects was required to ensure adequate accuracy in the analysis phase.

**TABLE 2 : ANXIETY AND DEPRESSION PREVALENCE IN FRENCH GENERAL POPULATION SURVEYS**

<b>SURVEY TITLE</b>	Anxiété et dépression en pop générale		Santé des franciliens	DEPRES	Santé des bas-normands	Enquête santé et protection sociale
<b>SURVEY TYPE</b>	Local (1town in Paris suburbs)		Regional (Ile de France)	European and National as for France	Regional (Basse Normandie)	National
<b>YEAR</b>	1987		1991	1995	1997	1996-1997
<b>AUTHORS</b>	Lépine, Lelouch		Kovess, Poinsard, Gysens	Lépine, Gastpar, Mendlewicz, Tylee	Kovess	CREDES : Le Pape, Lecomte
<b>INSTRUMENT</b>	CIDI (anx and dep)		CIDIS	MINI (depression)	CIDIS	MINI (depression)
<b>CLASSIFICATION</b>	DSM III-R		DSM III-R	DSM IV	DSM IV	CIM 10
<b>INTERVIEWERS PROFIL</b>	Psychologists clinicians		Non clinicians	Non-clinicians	Non clinicians	Self-administrated
<b>SAMPLE SIZE</b>	1746		2260	15000	1445	10000
<b>TIME FRAME</b>	One year		Six months	Six months	n.a.	current
	<b>M</b>	<b>F</b>				
<b>MAJOR DEPRESSION*</b>	3,4	6	3,1	9,1	6,9	12
<b>PHOBIC DISORDERS</b>	7,9	16	2	1,4	-	-
<b>PANIC ATTACKS</b>	0,5	1,9	0,4	0,4	-	-
<b>GENERALISED ANXIETY</b>	3,7	6,6	2,8	n.a.	-	-

\*CREDES survey : (depressive episode)

## 2. SAMPLING PROCEDURE

In the **Comoro Islands** (Grande Comore), **Mauritius**, **Guadeloupe** and **Réunion**, the survey concerned the whole island territories. In **Madagascar**, where the surface area is greater, a representative site on the high plateaus (Antananarivo area) and a representative coastal site (Mahajanga area) took part in the survey.

**For metropolitan France sites**, the geographical area chosen was that defined by the **psychiatric sectors** taking part in the survey. There are several reasons behind this choice : the care offer varies widely from one area to another and inside a given area, from one sector to another; the teams in the psychiatric sectors are strongly implicated in the follow-up and implementation of the survey; they have a part in the collection of data; one of the aims of the study is for the teams to gain better apprehension of the specific problems of the population they are likely to be treating; and descriptive data of care offer is available for each sector and enables comparisons between sectors.

**In order to form a sample representative of the geographical zone concerned, sampling methods suited to specific local features were chosen.**

**In Madagascar, Comoro Islands and Mauritius** the sample was formed by **two step cluster sampling**. This method has been validated in previous studies (demography and health surveys in the Comoro Islands<sup>86</sup>, Madagascar<sup>87</sup>, and Mauritius<sup>88</sup>). The method consists in forming geographical zones from population numbers, and then randomly selecting "n" zones and then "n" households within the zone. The interviewers then visit the households to interview one member chosen at random.

In the **French sites**, the two stage cluster sampling method was not suitable for reasons of feasibility and cost. Consequently the **quota method**<sup>89</sup> was used. This consists in **constructing a sample that is a model of the population under study**. The principle of this method is to choose several criteria for which distribution is known for the population under study and to give each interviewer a work plan which imposes observance of these different proportions. Hence :

- The composition of each psychiatric sector in terms of belonging to a particular *commune* (administrative district) was submitted to the **services of INSEE** (National Institute for Statistics) for calculation of quotas for each site.
- the quotas thus formed are based on the structure of the population in the area as per the 1990 population census, according to the following characteristics : gender, age, socio-professional status of subjects.
- for each site the sample is representative of the population in terms of the above criteria

- each interviewer has the appropriate quota sheet, which defines the proportions to be observed in the interviews conducted.
- the interviewers have the following briefs :
  - ✓ not more than one interview per street
  - ✓ change to a different block or area after each survey outing
  - ✓ vary the times at which interviews are sought (daytime, weekend, evening).
- In order to ensure that these instructions are observed, interviewers were systematically met at the end of each day by staff supervising the survey (nurses, psychologists, doctors) to report on progress.

The quota method also requires attention to be paid **to the characteristics of the subjects who refuse to respond**. Thus the interviewers recorded the number of refusals and as far as possible noted the age, gender and socio-professional status, as well as the reasons why they refused.

## VII. PRELIMINARY SURVEY (1995-1996)

### 1. AIMS OF THE PRELIMINARY SURVEY

The main task was to carry out preparatory work in each site to motivate the professional teams involved in the research, to establish contacts with the decision-makers at local level, to define a consensus on working procedures between metropolitan France and the Indian Ocean sites, to establish multi-centre co-ordination procedures, to make methodological choices and to test the instruments selected.

Bibliographical work was carried out on the existing socio-demographic data :

- Description of the socio-demographic characteristics of the populations concerned (age, gender, socio-professional criteria, place of residence, reference culture etc)<sup>90</sup>.
- Description of family structures, religious affiliations, and health system (traditional and medical/psychological)<sup>91</sup>.
- Specific bibliographical research on representations of "insanity" and the "insane" or "lunatics" in the different cultures<sup>92</sup>.

### 2. RESULTS

This first preliminary survey stage ended in 1996 with a 4-day co-ordination meeting which made it possible to cover the following agenda :

- Presentation of survey methodology.

- Interventions by anthropologists on the socio-cultural environment of the survey.
- For each site, presentation of the geographical sector (description – facilities - technical resources - expectations).
- Analysis of results from questionnaire administration in the preliminary survey stage (open questions, see Table 1).
- Joint drafting of a first version of the pilot questionnaire, for subsequent adjustment to particular local features in each site.
- Recommendations for translation work, so that each questionnaire should be accessible to the populations concerned.
- Training of interviewers in administration of the MINI.
- Drafting of a research calendar and practical arrangements for the pilot study.

This co-ordination meeting was hinged on the conference organised by APSMOI<sup>d</sup> (Association pour la Promotion de la Santé Mentale dans l'Océan Indien) entitled "Santé mentale, santé publique : cinquante ans de départementalisation"

## VIII. PILOT STUDY

### 1. AIMS OF THE PILOT STUDY

The pilot study was designed **to test the survey methodology** selected, in particular its general feasibility, the acceptability of the questionnaires, the internal validity of the questionnaire on representations, the content of interviewer training courses and the modes of organisation for the survey in each site.

### 2. METHODS

To achieve the above objectives, the three survey questionnaires were administered to **100 subjects in each of the 7 sites**, according to the following pattern :

- **Training** of interviewers in the administration of the questionnaires (students in sociology and psychology, specialised or non-specialised health personnel),
- **Supervision** of interviewers by a senior agent,
- Random **recruitment** of interviewees in public places (shopping centres, public offices, cultural centres, libraries, public parks) or in their homes
- **For each site** 50% men and 50% women between 25 and 50 years old,
- **systematic recording of spontaneous remarks** from interviewers and interviewees concerning the acceptability and comprehensibility of the questionnaires,

- **Quality control** of completed questionnaires by person locally responsible for the survey
- **Data entry** of responses
- **Data entry check** (double entry of one randomly selected questionnaire in ten)
- **Drafting of pilot study** report for each site
- **Overall and site by site analysis** data in DIRM (department for information and medical research), ESPM Lille-Métropole, on SPSS software.

### 3. RESULTS

The pilot study went satisfactorily in the 7 sites. 749 questionnaires were collected. The overall review of the pilot study took place in the course of an international co-ordination meeting in Lille.

This second co-ordination meeting was preceded by a conference organised by ASEP<sup>a</sup> on the theme "**Ethnopsychiatrie en questions**". The progress of the survey was presented by international participants in the course of a half day workshop on epidemiology.

As the sample was not representative, it is not possible to derive information from the results : the aim was basically to test methods<sup>93</sup>. The main lines for consideration that emerged from the pilot study and which orientated the adjustment of the different questionnaires can be noted :

- the place of the **concept of depression** in the domain of insanity and mental illness
- the part played by **religious beliefs** in representations of insanity and mental illness
- the part played by **recourse to religion** and magic alongside medical care.

The **methodology for the main survey** was revised, adapted and finalised in the light of the results of the pilot study (validation of sampling methods, adjustment of joint methodology for the translation of questionnaires, reinforcement of interviewer training programmes).

The **questionnaire on representations** was altered on the basis of a qualitative analysis of comments made by interviewers and interviewees, of the analysis of the psychometric properties of the pilot instrument, and of comments provided by experts. The structure of the questionnaire was validated and the wording of questions revised. Open questions (free response) were added at the start and the end of the questionnaire, and semi-open questions (pre-coding) were included alternately with closed questions.

The methods for assessing the **reliability** of results obtained by **non-clinical interviewers** were defined. Thus, to reduce bias caused by using non-clinical interviewers, a **complementary method** was devised : that consisted on the one hand in exploring psychosocial consequence for any disturbance scored positively (social and family relationships, work, daily activities) and recourse to care and any other form of assistance (western

medicine, alternative medicine, religious or magical practices) and on the other hand in having the MINI validated by a clinician at the end of each data collection day in the field.

In order to test the reliability of the complementary methodology, which was developed empirically, for a given subject the diagnostic assessment provided by the MINI administered by a non-clinician and validated by a clinician was compared with that provided by another clinician. The degree of agreement between the MINI diagnosis validated by a clinician and the diagnostic assessment by a clinician alone was calculated by Kappa coefficient.

The complete results are given elsewhere, but it can be noted that the inclusion of a clinical judgement enables a reduction in the number of false positives generated by the MINI.

## IX. MAIN SURVEY PHASE

The preliminary survey and pilot study carried out over a period of 18 months (October 96 to December 97) enabled the following :

- The **constitution of efficient research teams** (health and mental health professionals, statisticians, etc)
- **Genuine awareness** among local, regional and national partners (importance of the Research-Action concept)
- **Regularly reinforced collaboration** between statisticians (INSEE), directors of regional health and social services (DRASS), training staff (in the field of nursing, social work, special needs teaching), researchers in other disciplines (law, anthropology, sociology, etc).

Certain partnerships gained formal existence :

### **World Health Organisation :**

- **WHO Geneva** entered this survey into the "Nations for Mental Health" programme led by Dr. Benedetto SARACENO.
- The **WHO Collaborating Centre in Paris** ensures the methodological supervision of the survey.
- **In the Comoro Islands**, the local WHO office financed the pilot study and undertook to fund the whole of the main phase and provide logistic support.
- In Madagascar, **the local WHO office** undertook to give financial support to the main phase.

### **French Secrétariat d'Etat à la Coopération :**

Doctors on French co-operation missions in the three Indian Ocean sites concerned involved themselves in the work in a very concrete manner. Without their collaboration, the survey would have been impossible in these sites.

### **Department for Research, Study, Evaluation and Statistics, French Ministry of Health (DREES):**

Took a real part in the study computerising all the data of the main survey. A member of this Direction joined the co-ordination team. DREES has agreed to give its financial support for the constitution of a French representative sample (second study phase) A member of DREES staff has been appointed to the study and has joined the co-ordination group. DREES provides funding for co-ordination of the second survey phase what will enable a nationally representative French sample to be formed.

### **Hospitals**

The research was included in the official hospital agenda in EPSM Lille Métropole, EPS Léon Grégory in Thuir, EPS Paul Guiraud in Villejuif, CHU St. Jacques in Nantes, CHS in St Paul de la Réunion and CH Montéran, St. Claude in Guadeloupe.

### **Department of Ethnology, Lille 1 University**

Active participation on the part of students for the pilot phase and two students involved in supervision. One thesis student in sociology (under the supervision of Pr. Richard Pottier) has a close association with the survey which she is using as her field experience (Mauritius).

### **Anthropology department, Aix-Marseille University (Laboratory of human ecology and anthropology)**

Pr. Jean Benoist joined the survey scientific committee and has suggested the inclusion PhD students in qualitative anthropological work, complementary to the quantitative approach planned in the survey. This work is to take place in Guadeloupe in the course of the main survey phase<sup>94</sup>.

### **McGill University, Montreal :**

Pr. Gilles Bibeau has provided epistemological and methodological support by offering means of connecting the survey with international co-operation programmes in mental health which he co-ordinates (INECOM<sup>95</sup> programme).

In a complementary manner, exchanges among the different sites have developed :

### **Meetings convening all participants**

- in Réunion in December 1996 at the time of the conference entitled "50 ans de départementalisation à la Réunion"
- in Lille in January 1998 at the time of the conference "Ethnopsychiatrie en questions"
- in Réunion in May 1998 on the occasion of the conference "Psychiatrie et neurologie de langue française".

### **Special events :**

- lectures on mental health in Madagascar in Lille, Nantes and Paris.
- visits to psychiatric facilities in Madagascar, Réunion, Mauritius, Lille, Nantes.

- training personnel specialised in methodology took part in the pilot study in Madagascar in July 1997, Mauritius in November 97, in the Comoro Islands in October 97; they were made available in Lille, Nantes and Evry; in Réunion, consultation meetings were organised between international co-ordination and field agents.
- exchanges involving nurses, psychologists, doctors and ethnologists took place when the survey was initiated.
- a general practitioner from Madagascar had a period of 6 months work experience in EPSM Lille Métropole.
- student nurses from Réunion were in EPSM Lille Métropole in July 1998.
- a Malagasy psychiatrist had a period of work experience in Lille in 2000-2001.
- meetings aimed at raising awareness among ministries and decision-makers were organised in Madagascar (October 96, November 98), Mauritius (June 97) and the Comoro Islands (October 97, November 98).

The **main data collection phase** took place from September 1998 to December 1999 in the following sites : Comoro Islands, Madagascar (Antananarivo, Mahajanga), Mauritius, France (Nantes, Marseille-North, Southern part of the Hauts-de-Seine, Réunion, Guadeloupe, Lille, Pyrénées Orientales, Tourcoing, and Vallée de la Lys). In each site around 900 questionnaires were collected. Part two of this report presents a complete analysis of global data.

## X. DATA ANALYSIS

The DIRM, EPSM Lille-Métropole provided each site with data entry software EPI-INFO, accompanied by a coding guide for all the questionnaires. The questionnaires were checked and entered in duplicate by the sites themselves, and data were sent to DIRM for verification. The preliminary analyses were carried out on SPSS software.

The analysis of free responses to open questions was carried out using ALCESTE<sup>96-97</sup> software.

The analysis of the overall data is proceeding in the Direction de la Recherche, des Etudes, de l'Evaluation et des Statistiques in the French ministry of health using SAS software.