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PATHWAYS OF PATIENTS WITH MENTAL DISORDERS

A Multi-Centre Collaborative Project

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## 1. The aims of the research

This brochure describes a four year programme of research activities consisting of two basic projects - the 'Pathway Study' and the '100 Patient Study' - and a range of optional studies that can be chosen depending upon the needs of each participating centre. These studies are intended to allow mental illness services to develop; to prepare the ground for intervention studies; to form a research basis for the development of new training courses for general and specialized staff; and to identify mental illness tasks which can be carried out by primary care physicians, nurses, native healers and mental health aides in order to help the mentally ill and their families.

The Pathway Study concentrates on new patients who come to services for the mentally ill. This study will increase awareness of the referral paths which patients take in the course of their illness, and document the use made by other care-givers in each setting. It will identify the symptoms which are thought by others to need attention from the services for the mentally ill, and measure the delays at various points in referral pathways.

The 100 Patient study will validate the screening questionnaire to be used in later phases of the research programme, and will take place in a primary care clinic. The study will allow a measure of unmet need to be made in each culture, and will allow optimal use of scarce resources. This study will allow the investigators to plan intervention studies in the 3rd and 4th years.

There are several optional studies that can easily follow on from the 100 Patient Study. These include assessing educational needs of primary care physicians and mental health aides and the design of training programmes to meet them; studying special groups of patients; in developing intervention studies suggested by the second year study (e.g., introducing changes of patterns of service delivery and measuring the impact of such changes); and studying the situation at different nodes on the referral pathway. It is a simple matter to use the first two studies to measure inception rates for mental illness in both primary care and specialist settings.

## 2. An outline plan

It is intended that participating centres will choose which projects they wish to carry out and meet costs from local resources: the role of WHO will be to coordinate the project and to arrange meetings of Principal Investigators.

In year one, all participating centres will carry out the Pathway Study, since this is inexpensive, can be completed with minimal resources, and it forms the basis of planning subsequent studies. There will be a meeting of Principal Investigators at the end of this year.

In year two, the 100 Patient Study will be carried out in an area of population group which uses the same primary care facilities. This study allows validation of the screening instrument to be used at other important points on the referral pathway (e.g., native healers, social services) and will provide information about the proportion of similar patients not passing that point on the pathway. We will assess the 'remedial need' (i.e., the numbers of patients who have untreated disorders which should respond to interventions available at that particular setting). This phase of the study will allow approximate estimates of inception rate to be made at each node; to assess the needs for educational intervention for health care workers; and to plan intervention studies. There will need to be a second meeting of investigators at the end of this year. The fact that broadly similar studies using similar assessment instruments are taking place in other parts of the world will permit trans-cultural comparisons to be made.

3. Requirements for participating Centres\*

1. There should be a principal investigator with some prior experience of research who would like to provide local supervision for the research activities. Resources should exist to cover the modest costs associated with the various projects.

2. There should be a list and description of all services that are likely to provide help to people with mental illness and their families. It would be advantageous to have an area or population group for which a single psychiatric service is the sole provider of care for the population at risk. (If this is impossible, the centres may still wish to carry out many of the studies in the brochure - such as the educational studies on the detection and treatment of various types of mental illness. However the epidemiological studies cannot be carried out).

3. It would also be highly desirable to identify within the area served by the psychiatric service a smaller population all using the same primary care facilities (general medical clinics). This will be the case when the health system is such that a Health Centre or Medical Clinic is serving a known population at risk; or where a small group of primary care physicians collectively represent the only source of medical care for a defined population at risk. It would be necessary to secure the agreement of these primary care physicians or the Medical Clinic to having a small survey carried out, including interviews with patients and observation of clinical encounters.

4. There should be a fair probability that research activities can be continued for 3 to 4 years.

5. There should be agreement with the relevant administrative authorities and ethical committees to the conduct of the programme; and an agreement that the results of the studies will be given full consideration by the authorities responsible for health care so as to facilitate the application of knowledge obtained.

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\* see page 15 for definitions of terms used

#### 4. PROTOCOLS

##### 4.1. Year One: THE PATHWAY STUDY

AIM This study aims to describe the pathways which patients with mental illness take in each centre. For a variety of practical reasons it begins with patients coming to mental illness services with new illnesses, and it aims to answer questions such as the following:

###### Pathways of care:

What paths do people with mental illnesses follow in the course of their search for help ?  
How long does it take to pass the various nodes in the path, and which symptoms hasten the process of referral to a specialist psychiatric service ?

###### The first decision to seek care:

Who makes the first decision to seek care ?  
How long do caregivers take to refer patients for first help ?  
What symptoms cause people to seek care in the first place ?  
Which symptoms are taken first to which caregiver ?

###### The referral to mental illness services:

Who decides on referral to mental illness services ?  
Which symptoms cause referral to mental illness services ?  
How long have symptoms lasted when various caregivers refer ?

###### Inception rates for treated mental illness:

What is the inception rate of mental illnesses under treatment ?

#### RESOURCES

This is a very easy and inexpensive study. It could be done by the mental illness caregivers themselves as a small addition to their normal work, or it could be carried out by graduate research workers.

#### METHOD

The mental illness services are asked to complete an encounter form for all patients who come to the service from a defined geographical area for a fixed period of time. It is essential that the population of this area is known, and that all mental illness services for that area participate in the study.

For example, for a period of two months, an encounter form is completed for every new patient seen by the service. Patients are eligible to be included if they are seen for a new episode of illness by anyone working on the mental illness service. Patients are included who are admitted to a psychiatric ward, are seen in an outpatient clinic for the first time, are seen in an accident room or medical ward, or are seen on a domiciliary visit.

The encounter form is attached as Annex 1, and is fairly short: if completed at the time that the mental health worker makes his or her usual assessment of each new patient it should take only about 5 minutes for each patient.

In centres where resources are scarce, the observations can therefore be made by the usual staff; where resources permit, however, research assistants can be hired for two months to carry out the observations.

4.2. Year two: THE 100 PATIENTS STUDY

- AIM
1. This study will produce an estimate of unmet needs in the primary care clinic(s). It will allow the investigators to make certain generalisations about unmet needs in their primary care clinics.
  2. This study will validate the psychiatric screening questionnaire which is to be used to study other nodes in the referral pathway in each participating centre.
  3. An approximate estimate of inception rate for new psychiatric illnesses in primary care settings can be made if the proportion of residents consulting primary care clinics in the course of a year is known in this setting.

## RESOURCES

This is a more expensive study to mount, since it needs a research assistant to administer the screening questionnaire, and a research worker (preferably a psychiatrist) to administer a research interview to approximately 150 patients selected for interview by the research assistant.

## METHOD

This study takes place in a primary care clinic. This clinic should be selected because it provides all primary health care to a defined population. It is essential that the patients selected for the study are a representative sample of patients seen in this setting. The way in which patients to be included in this study are selected will vary in different centres: the advice of a statistician should be sought on this point, and the sampling method must be described in detail. Depending on the statistician's advice and the availability of research workers the study can be done full-time for a short period, or part-time over a longer period.

During the study, primary care physicians are asked record in a 'daybook' their own ratings of any mental illness thought by them to be present. They are asked three questions about each patient included in the study:

- Does the patient have a psychiatric illness ? (either answer 'no' and ignore question 2 and 3, or write in diagnosis).
- Is the psychiatric illness new or established ? ('new' = no consultation during past 12 months).
- What treatment was offered ?

The research assistant will administer the screening questionnaire to all those included in the study, without knowing the primary health care worker's answers to the above questions. The research assistant divides the respondents into three groups: score zero; score above zero but below threshold; score above threshold. (We will use published data for the most comparable setting to predict the probable threshold). The research assistant sorts the questionnaires by score, and enters them onto three lists. Every fourth patient on the first list (zero scores); every second patient on the second list (sub-threshold); and every patient on the third list (threshold and above) are asked to see the research psychiatrist. The research assistant is responsible for recording all refusals to complete the screening questionnaire, and all refusals to the interview procedure. Whenever a patient refuses the interview, the research assistant is responsible for recording the assessment made by the primary care physician; the patient is replaced by the next person seen on that list.

The research psychiatrist administers a poly-diagnostic research interview (either the PAS or the SCAN) blind to the score on the screening questionnaire and the primary care physician's assessment. For each case of illness detected, the research psychiatrist is responsible for deciding what the best treatment would have been, bearing in mind the resources available in that setting. Treatments can be included that are not available as the services are organized at present, but could be available if different working arrangements existed.

The study continues until the research psychiatrist has identified 100 cases of psychiatric illness (data processing described in Annex 2).

4.3. Year Two: OPTIONAL STUDIES

Any of these studies can easily be combined with the "100 Patient Study". However, it is hoped that all centres will wish to carry out the described study under 4.3.3., dealing with the other nodes on the referral pathway, so as to obtain a full picture of the referral pathways.

Optional Studies 4.3.2, 4.3.3 and 4.3.4 are offered as examples of the sort of work which can easily be combined with the 100 Patient Study: but it is appreciated that some Centres may wish to combine the 100 Patient Study with one of the later studies - such as the effect of detecting hidden illnesses, or the best management of somatized psychiatric illnesses.

#### 4.3.1. Optional study 1 : ASSESSING EDUCATIONAL NEEDS

**AIM** This study aims to collect data for use in designing educational interventions. It is a fact-finding exercise, to enable teachers of health staff to plan training courses required for a particular centre. The observations made in it can be used as baseline observations in order to do a "before-after" evaluation of the effectiveness of the new training course.

#### **RESOURCES**

In high technology settings, use may be made of video-recordings. However, the same data may be obtained by two very much less expensive ways: first, by the research psychiatrist sitting in the primary care clinic and being given the screening questionnaire by the research assistant as each patient comes in; or second, by the primary care worker or GP audiotaping his interviews with patients.

#### **METHOD**

Consecutive patients complete the screening questionnaire and have their consultation with the GP either recorded or directly observed. The observing psychiatrist confines his or her attention to those interviews where the patient has a high score on the screening test. (If the GHQ-28 is used, it is especially important to examine interviews with patients with high scores on the depression subscale, since depressive illness is common, often undetected, and remediable). The psychiatrist (or a research assistant) must watch real interviews between caregivers and patients, without being blind to the score on the screening questionnaire.

#### **DATA PROCESSING**

1. The most important observations concern the interview behaviours of the GPs. Do they allow the patients to say what is on their minds? Do they ask too many closed questions, and not enough directive questions (see page 15 for definitions)? Do they only consider the possibility of psychiatric disorder either when the patient leaves them no alternative by insisting or telling them or when they have been unable to make a physical diagnosis? Do they know and use the correct probe questions for, say, depressive illness? Do they have skills in making supportive comments in problems definition; in problem definition; and in formulating treatment plans?

2. Further questions can be addressed in direct discussion with primary care workers: Do they have realistic concepts of minor psychiatric illness? Do they understand that psychiatric disorder commonly accompanies undoubted physical disease processes, rather than being something only to be diagnosed by exclusion?

3. If an intervention study in the form of an educational programme follows this study, the same data can be used to calculate base-line data about the doctors in two ways: (i) to calculate agreement between the primary care worker's ratings and the questionnaire; and (ii) to assess change in behaviours relevant to case detection during interviews (see references).

4.3.2. Optional study 2: SPECIAL GROUPS OF PATIENTS

AIM To obtain information necessary to improve services for patients with a particular conditions (such as alcoholism or for a high risk group, such as elderly).

RESOURCES

This depends on the precise aim of a particular study. If screening is to be extended to identify patients with alcohol problems for example, this can be done at a minimal extra cost by asking the research assistant in the "100 Patients Study" to include the CAGE questionnaire, and by ensuring that the second stage case-finding interview includes systematic ratings concerning alcohol-related problems (see King 1986).

A centre which wished to survey the mental health of elderly patients would need to include a short cognitive screening test, and would carry out a study similar to the "100 Patients Study" but confined to those over the age of 65. (It would be particularly important to include those under the care of primary care physicians who are confined to their homes or are in residential settings).

A centre which wished to survey particular illnesses such as depression would pay particular attention to instruments which can help in the identification of depressive disorder, such as the "D-Scale" of the GHQ, or the WHO's SADD Scale.

4.3.3. Optional study 3: THE STUDY OF OTHER POINTS ON THE PATHWAY  
(for example, social services, native healers)

AIM The pathway study is likely to have shown other nodes besides primary care clinics through which patients pass before reaching psychiatric services. How many conspicuous illnesses are not referred? What treatments are given to such illnesses? What is the rate of hidden illnesses in these settings?

RESOURCES

Centres that have carried out the "100 Patients Study" will have validated the screening procedure, which can now be used to investigate illnesses at non-medical locations without causing much disruption. The screening questionnaire will not identify which particular individuals are psychiatrically ill, but it will predict prevalence of mental health problems at each location, and this can be compared with recognition by the non-medical caregiver. The resources necessary will be those for the application of the questionnaire by a research assistant, and the collaboration of staff at the point of the pathway under study.

METHOD The location for care to be studied is selected as a result of the Pathway Study because it is clearly important in that culture (for example, social services, medical outpatients department in a hospital, a native healer, an osteopath, a faith-healer).

Consecutive attenders are given the screening questionnaire by a research assistant. The caregiver completes a daybook in a form similar to that described in the "100 Patients Study", or a research assistant sits with the healer and records his or her views. (The latter arrangement has the advantage that the research assistant can be given the task of making observations about the consultation itself, along the lines of Optional Study).

DATA PROCESSING

Total illness among attenders can be calculated from the percentage of subjects with scores above the threshold, using one of the conversion formulas given in the references at the end.

USES OF THESE DATA

These studies allow researchers to calculate how many patients with similar illnesses to those seen by psychiatric services are being seen by other caregivers. They also document the treatments being given to patients for mental disorders at each location.

Observations made during sessions with the caregiver allow an assessment to be made of the possible scope for intervention studies and educational studies.

4.3.4. Optional study 4: CALCULATING PREVALENCE & INCEPTION RATES  
BY DIAGNOSIS

AIM To compare rates for different mental illnesses seen in community settings with those seen by the specialist mental illness services.

RESOURCES

This study requires little further effort on the part of the psychiatrists, but imposes a heavier burden on the primary care physicians. In order to calculate approximate prevalence and inception rates it is essential that the proportion of residents served by the Health Centre who attend their doctor for any reason during the course of a year is known.

METHOD

Instead of rating patients only when the research psychiatrist is present, the primary care physicians will rate every patient seen for a calendar month. The method of calculation of the various rates is given in Annex 3.

4.4. Year three and four: OPTIONAL STUDIES

One of the main purposes of research in the first two years is to sharpen and define the precise questions which should be investigated in the third and fourth years. Here are some brief sketches of the sort of work which might form the content of these years:

4.4.1. First example: The optimal management of patients with somatic presentations of mental disorders.

It is probable that these patients make up the single commonest presentation of psychiatric illness across the world. Very little is known about how they should best be treated. It is not even known whether there are advantages in changing their attribution of their problems by making them aware of their psychological illness (although clinical experience suggests that this is the case). Nor is it known how various kinds of native healer or holistic schools of healing fare with these patients, compared with a conventional medical management consisting of detection and treatment of depressive illness. These questions could be investigated.

4.4.2. Second example: The effect of detecting hidden illness.

Here patients rated as non-cases with high scores on the screening questionnaire are randomly assigned to two groups: one where the caregiver is informed of the high score, another where no action is taken as a control. Outcome is assessed at three months, after initial contact, both in terms of care received, and psychological adjustment.

4.4.3. Third example: Social versus clinical intervention.

Here patients with affective illnesses are randomly assigned to simple counselling by a non-medical health care worker and treatment by the doctor with his usual treatment methods. Outcome assessed as above.

4.4.4. Fourth example: Native healer versus Medical healer.

Since patients cannot be randomised between the two conditions, only a crude matching can be done. Two groups of patients are selected in each setting with scores on the screening questionnaire well above the usual threshold (in order to minimise false positives, and so increase the 'positive predictive value' of the test). Samples would also be matched for presenting complaint and duration of presenting complaint. Outcome assessed as above.

4.4.5. Fifth example: Providing educational experience for non-medical caregivers in community settings.

It seems likely that depressive illness is quite common in all careseeking populations; that it responds to imipramine better than to placebo; and that imipramine is readily available in most parts of the world, and relatively inexpensive. Educational courses could be directed at the detection of depressive illness.

Other possible candidates for detection in developing countries might be psychotic illness and major epilepsy. Educational courses could also be offered in simple counselling techniques and the provision of social help by lay health care workers.

A study could be undertaken of the effects of training courses on the service providers, on the services delivered, and the satisfaction of the population served.

4.4.6. Sixth example: Educational courses for general practitioners

The optimal format for such teaching is the provision of feedback, either by audiotape or videotape, of actual sessions with high scoring patients. Teaching is carried out in small groups of six or so doctors, who join in a discussion of the clinical encounters. The psychiatrist providing the teaching chooses interviews between the participating doctors and patients with high scores on the screening questionnaire. Participating doctors suggest various ways of handling points in the interviews: the doctor who carried out the interview is encouraged to try out alternative ways of proceeding, with the teacher as the patient.

This teaching is popular with GPs, and quite straightforward for the teacher.

Doctors can be encouraged to attend a course and to bring recordings of sessions between themselves and patients with conspicuous psychiatric morbidity (CPM), supervision is given as above.

At the end of a course, doctors rate another series of consecutive attenders who have completed the screening questionnaire: studies can then be carried out to show changes in interview behaviour as a result of teaching, and improvements in accuracy of the caregivers ratings of patients.

4.4.7. Seventh example: Changing patterns of service delivery.

It is quite likely that the distribution of patients between primary and specialized mental illness services could be improved. Some patients with chronic disorders who mainly need regular medication could be moved from secondary to primary care; many patients with complex problems could perhaps be referred from primary care with advantage.

Detailed studies might address the question of which patients actually do better if referred, by randomly assigning patients with particular problems to care by mental illness service or by primary care worker.

Other studies might address the role of the specialized nurse, the social worker and the lay primary health care worker.

## 5. Glossary of Technical terms

CAGE Questionnaire - this is a 4 item screening questionnaire for alcohol related problems. (See King, 1986)

Closed Questions - are those which restrict the possible range of replies; usually to "yes" or "no".

Conspicuous psychiatric morbidity (CPM) - refers to mental illness about which the medical staff at the primary care clinic are aware; these are the patients seen as mentally ill.

D Scale - this is the fourth scale of the GHQ-28 and deals with severe depression.

Directive Questions - refers to questions which indicate the topic area in which the doctor is interested, but which do not limit the patients freedom of reply. (For example, "Tell me about your pain?" would be a directive question; while "Is the pain sharp?" would be a closed question.)

GHQ - this is the General Health Questionnaire described by Goldberg in 1972.

GHQ-28 - this is the 28 item version of the General Health Questionnaire. It consists of 4 scales, dealing with somatic symptoms, anxiety and insomnia, social dysfunction and severe depression.

Hidden psychiatric morbidity (HPM) - refers to mentally ill people attending the primary care clinic who have not been detected by the staff.

Inceptions of psychiatric illness refer to episodes of illness for which care has not been sought in the previous year. An annual inception rate refers to the number of new episodes of illness which occur in the course of a year in a defined population.

Minor Psychiatric Illness - refers to anxiety states and depressive illnesses which are common in primary care settings. They are commonly accompanied by somatic symptom formation. (Psychotic illness is by definition a "major" psychiatric illness).

Nodes in the Path - refers to the number of referral points between home and seeing the psychiatrist. For example, a patient who goes first of all to a family doctor, and is then referred to a general medical clinic in hospital, and only from there sees a psychiatrist will have passed two "nodes": the first being the family doctor and the second being the general medical clinic in the hospital.

PAS - this is an abbreviation for the Psychiatric Assessment Schedule, described by Dean et al 1983, which consists of the 40 item Present State Examination with 20 additional questions to enable it to make diagnoses using the "DSM-III" diagnostic system.

Pathway - refers to a referral path, see below.

Problem Definition - refers to the ability to focus on the particular problem which the patient brings at the consultation being studied.

Psychological Adjustment - this can be measured by any of the standardized psychiatric assessments: for example, the Psychiatric Assessment Schedule, or the Clinical Interview Schedule.

"Referral Path" refers to the sequence of events by which a patient enters psychiatric care. A patient who first consults a family doctor, and is then referred to a psychiatrist follows a referral pathway of "home, to family doctor, to psychiatrist".

Remediable Need - refers to disorders for which treatments or management are in fact available in a particular setting. It is a more restricted concept than "unmet needs" or hidden psychiatric morbidity (qv).

Supportive Comments - these are comments by the doctor aimed at showing sympathy with the patient's plight: for example: "You have obviously been going through a difficult time".

SCAN - Schedule for Comprehensive Assessment in Neuropsychiatry (in development).

SRQ - this is the Symptom Rating Questionnaire of the World Health Organization.

Threshold Score - this refers to the best threshold to use in order to obtain optimal discrimination between cases and non-cases on a particular screening questionnaire.

The pathway study:

ENCOUNTER FORM

The mental health worker will first carry out their usual full clinical assessment, with particular attention to the sequence in which symptoms were developed.

There will often be only one referral between home and mental illness services, in which case only sections 1,2 and 3 would be completed.

1. BASIC INFORMATION

- 1.1 Name of facility at which the form is filled in \_\_\_\_\_   1 - 2
- 1.2 Form filled in by: \_\_\_\_\_   3 - 4
- 1.3 Date: \_\_\_\_\_       5-10  
day month year
- 1.4 Patient's name or initial: \_\_\_\_\_ Number:    11 - 13
- 1.5 Date first seen by mental health service: \_\_\_\_\_       14-19  
day month year
- 1.a What was first symptom developed by the patient ? \_\_\_\_\_   20-21
- 1.b How long ago ? (number of months) \_\_\_\_\_   22-23
- State your diagnosis: \_\_\_\_\_ ICD-9     24-27  
    28-31

2. THE DECISION TO FIRST SEEK HELP

- 2.a Who was first seen ?  32
- 0 = native/religious healer  
 1 = police  
 2 = social worker  
 3 = community nurse  
 4 = osteopath  
 5 = medical practitioner  
 6 = general hospital  
 7 = psychiatric services  
 9 = not known
- 2.b How long ago ? (number of months): \_\_\_\_\_  33-34
- 2.c Who initiated first contact?  35
- 0 = patient himself/herself  
 1 = relatives/friends  
 2 = neighbours  
 3 = workmates/colleagues  
 4 = employer  
 5 = police  
 6 = medical practitioner  
 7 = other (specify)  
 9 = not known
- 2.d What symptoms caused  
 decision to seek care ? (specify): \_\_\_\_\_  36-37
- 38-39
- 2.e What treatment(s) was offered ? \_\_\_\_\_  40-41
- 42-43

3. THE FIRST REFERRAL

- 3.a Who was next seen ?  44
- 0 = native/religious healer
  - 1 = police
  - 2 = social worker
  - 3 = community nurse
  - 4 = osteopath
  - 5 = medical practitioner
  - 6 = general hospital
  - 7 = psychiatric services
  - 9 = not known
- 3.b How long ago ? (number of months): \_\_\_\_\_  45-46
- 3.c Decision taken by whom ?  47
- 0 = patient himself/herself
  - 1 = relatives/friends
  - 2 = neighbours
  - 3 = workmates/colleagues
  - 4 = employer
  - 5 = police
  - 6 = medical practitioner
  - 7 = other (specify)
  - 9 = not known
- 3.d What symptoms caused  
decision to seek 1st referral (specify) \_\_\_\_\_  48-49
- \_\_\_\_\_  50-51
- 3.e What treatment(s) was offered ? \_\_\_\_\_  52-53
- \_\_\_\_\_  54-55

4. THE SECOND REFERRAL

4.a Who was next seen ?

- 0 = native/religious healer
- 1 = police
- 2 = social worker
- 3 = community nurse
- 4 = osteopath
- 5 = medical practitioner
- 6 = general hospital
- 7 = psychiatric services
- 9 = not known

56

4.b How long ago ? (number of months): \_\_\_\_\_

57-58

4.c Decision taken by whom ?

- 0 = patient himself/herself
- 1 = relatives/friends
- 2 = neighbours
- 3 = workmates/colleagues
- 4 = employer
- 5 = police
- 6 = medical practitioner
- 7 = other (specify)
- 9 = not known

59

4.d What symptoms caused  
decision to seek 2nd referral (specify) \_\_\_\_\_

60-61

62-63

4.e What treatment(s) was offered ? \_\_\_\_\_

64-65

66-67

5. THE THIRD REFERRAL

5.a Who was next seen ?  68

- 0 = native/religious healer
- 1 = police
- 2 = social worker
- 3 = community nurse
- 4 = osteopath
- 5 = medical practitioner
- 6 = general hospital
- 7 = psychiatric services
- 9 = not known

5.b How long ago ? (number of months): \_\_\_\_\_  69-70

5.c Decision taken by whom?  71

- 0 = patient himself/herself
- 1 = relatives/friends
- 2 = neighbours
- 3 = workmates/colleagues
- 4 = employer
- 5 = police
- 6 = medical practitioner
- 7 = other (specify)
- 9 = not known

5.d What symptoms caused  
decision to seek 3rd referral (specify) \_\_\_\_\_  72-73

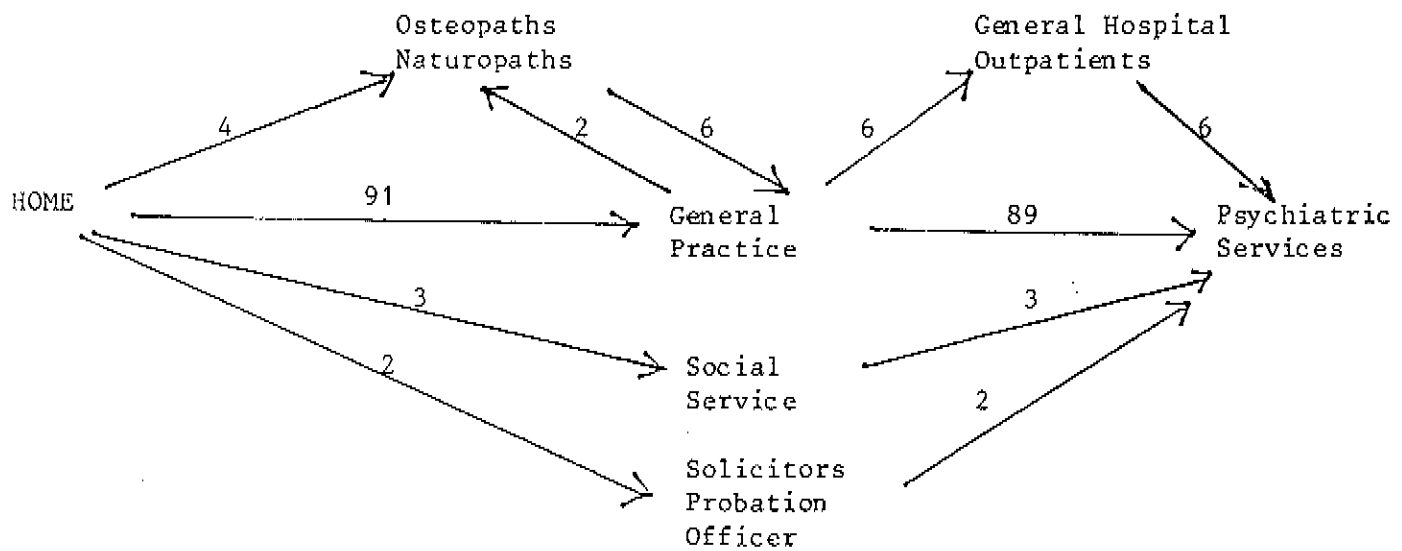
74-75

5.e What treatment(s) was offered ? \_\_\_\_\_  76-77

78-79

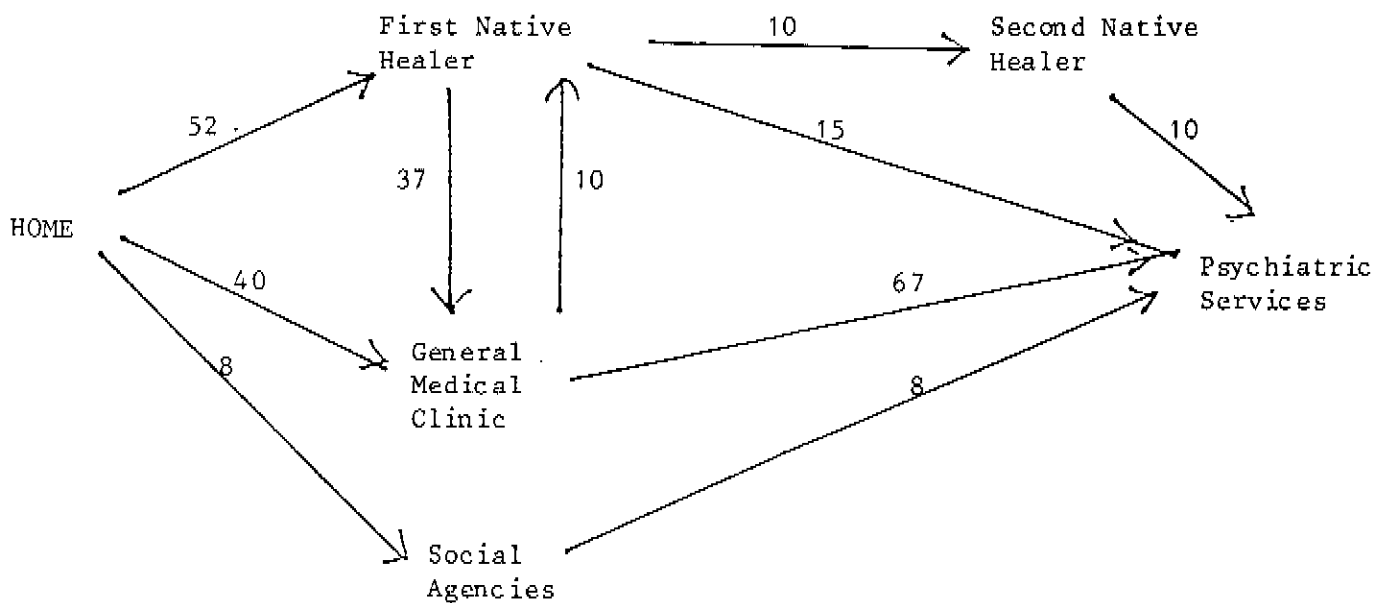
WHO Study : Pathways to Care

Some imaginary data for Manchester:



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Some imaginary data for a developing country:



Data processing for the 100 Patient Study

1. Validity coefficients and threshold scores.

For each score band of the screening questionnaire, draw up a count of cases and non-cases. For those scoring zero, multiply these figures by 4. For each of the score bands below the 'threshold' used, multiply the figures by 2. You have now corrected for the sampling fraction used by the research assistant to select the patients for second stage interview. You can now proceed to an 'ROC Curve' for the screening questionnaire, and select that point on the score range where there is an optimal trade-off between sensitivity and false-positive rate. This will be the threshold that is best in your cultural setting; it can be used to calculate validity coefficients for the screening questionnaire.

2. Measuring Unmet Need.

The conspicuous psychiatric morbidity (CPM) can be read off directly from question 1 in the doctors' daybook; measure the hidden psychiatric morbidity by counting those cases detected by the 2-stage screening procedure but not by the primary care physicians. (Remember to correct for the sampling strategy used: thus numbers with hidden illness in those with subthreshold scores must be doubled; while hidden illnesses among those scoring zero must be quadrupled).

The following question can then be answered:

To what extent were those with psychiatric illnesses getting the treatment thought best by yourself? (Divide the illnesses into conspicuous and hidden; then answer this from question 3 in the daybook).

3. Approximate estimates of inception rates.

In a series of consecutive attenders, we can tell from questions 1 and 2 in the daybook that the GPs thought that, say, 10 % had new psychiatric illnesses. If we know that, say, 75 % of the residents served by the GPs attend in the course of a year, then it follows that the annual inception rate for conspicuous psychiatric illness in this population is  $10 \times .75 \times 10 = 75/1000$  at risk/year. We can now use the research psychiatrists estimates to predict the prevalence of illness taking into account the hidden illnesses, and produce an inception rate for all psychiatric illnesses (hidden and conspicuous) in the same population.

USES OF THESE DATA

1. The validity coefficients and best threshold are essential for studies in other consulting settings, and for calculating predicted prevalence in this setting.
2. The estimates of unmet needs are essential for planning intervention studies.
3. The inception rates for CPM and total psychiatric morbidity in primary care settings may be compared with the inception rate for illnesses seen by the mental illness services, calculated in the first study. The figures may be compared since they have each been related to the population at risk; the resulting comparison will be a valuable consciousness-raising exercise for caregivers in both settings. Such a comparison should pave the way for intervention studies and educational studies in primary care, and for consideration of the optimal use of resources by workers in both settings.

If observations by the caregivers can be completed for a calendar month, it would be possible to calculate inception rates providing the proportion of the resident population in contact with each service over the course of a year were known. Once more, this knowledge is of interest, but by no means central to the studies described here.