

MANUAL FOR THE FIGS
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PURPOSE

The Family Interview for Genetic Studies (FIGS) is a guide for gathering diagnostic information about relatives in the pedigrees being studied. This diagnostic information becomes part of a pool of data on each individual relative, to be added to data from the completed Diagnostic Interview for Genetic Studies (DIGS) and from medical records.

The FIGS becomes particularly important when reliance on direct information from a subject becomes impossible. There are always relatives who are deceased or unavailable, and some who do not provide true or adequate information about themselves or who are too ill to be interviewed directly.

WHO PROVIDES FIGS DATA

Generally, the FIGS is done as the second part of the interview package, the first part being the Diagnostic Interview for Genetic Studies (DIGS). FIGS data should be collected from everyone interviewed about all known members of the extended family. This recommendation is backed by extensive experience, confirmed in a study by Gershon and Guroff (Information from relatives. Arch Gen Psychiatry, Vol. 41, February 1984) which states:

"Only 15% of the (1,093) interview-diagnosed relatives were identified as having a major affective disorder by one informant alone, going up to 64% agreement with four or more informants."

Another reason for collecting FIGS data from everybody interviewed about all known family members is that you never know in advance which relative has information that will enable you to determine bilineality or extenders or pointers.

COMPARISON OF TECHNIQUES BETWEEN FIGS AND DIGS

Whereas the DIGS is designed to be used verbatim (with relatively few item exceptions), the FIGS is meant to be only a guide for the interviewer. For example, the Face Sheet Question One requires a probe as to whether or not the subject has ever had any psychiatric or personality problems. The interviewer is free to word the probe in a way that will best elicit the information. The

interviewer may say, "Tell me about him. What was he like? Was he a moody person?" With practice and with clinical judgment the interviewer knows what to ask, how to ask it, how much to ask, when to push, and when to use restraint. It is the interviewer's responsibility to obtain as much data relevant to the study as possible, with the minimum number of questions. Because each individual and his/her family are unique, no interview instrument could cover the range of possible questions to be asked.

THE PEDIGREE DRAWING

A pedigree is usually drawn as part of the initial ascertainment to determine whether a particular family is suitable for study. If the proband cannot provide the information to draw the pedigree, another family member can provide the data. If it has not been drawn prior to the interview it should be done as part of the interview before beginning the FIGS.

At a minimum the pedigree includes the proband and his/her parents, grandparents, siblings, aunts, uncles, offspring, and spouse.

The pedigree may indicate the presence of bilineality. When a proband's relatives include affected individuals on both the mother's and the father's side, the family is said to be bilineal. In such a family the relationship of the affected relatives to the proband might be parents, grandparents, aunts or uncles. The limits of degree of relationship that would mark a family as bilineal are determined by the study design.

Bilineality may also be in a sibship other than the proband's, perhaps making that sibship ineligible for the study.

With regard to screening for bilineality, a general rule is that in any generation, when there are one or more affected offspring, the parent relative's spouse and the spouse's first degree relatives should be screened by the FIGS.

The pedigree may also indicate extenders. Extenders are any of the proband's second degree relatives (grandparent, uncle or aunt, half-sib, niece or nephew, or grandchild) who are affected. An extender expands the pedigree insofar as the first degree relatives of an extender are included in the pedigree for study. For example, if the proband's uncle is affected, the uncle's sibship and offspring are studied and if one of the offspring is found to be affected, the uncle's spouse and her family will be checked for bilineality. The interviewer should ask for information regarding pathology in any of them.

The pedigree may also indicate pointers. Pointers are relatives who are not affected but who have offspring who are affected. For example, if the proband's aunt is not affected but she has a daughter who is affected, the daughter's sibship is studied, and the aunt's spouse and his family will be checked for bilineality. The interviewer should ask for information regarding pathology in any of them.

THE THREE PARTS OF THE FIGS

There are three parts of the FIGS: the General Screening Questions, the Face Sheet, and the symptom checklists.

The most general information is gathered by using the General Screening Questions about all known relatives in the pedigree, regardless of how distantly related. The Face Sheet is for each of the informant's first degree relatives, and also for any affected relatives about whom the informant can provide information. The various symptom checklists are used to ferret out the diagnostic details that help make possible a best estimate diagnosis. There are checklists for these disorders: depression, mania, alcohol/drug abuse, psychosis, and paranoid/schizoid/schizotypal personality.

HOW TO USE THE FIGS

There are three steps to using the FIGS: 1) review the pedigree with the informant; 2) ask the General Screening Questions; and 3) complete a Face Sheet and symptom checklists with selected relatives.

1) Review the Pedigree

Before you begin the FIGS you will need a clean copy of the pedigree diagram without diagnostic information. (The pedigree diagram is drawn at the time of the first FIGS interview, and a clean copy should go to each subsequent interviewer.) A completed, clean pedigree provides the following for each person: name, number within the family, sex, age at the time of pedigree drawing, marital status, role in the family, whether living or dead, and if dead, age at the time of death. Persons about whom there is already sufficient information on a major diagnosis, such as schizophrenia or bipolar I, should be indicated so that unnecessary repetition can be avoided. The clean pedigree itself is identified by family name, number, date of the FIGS interview, and the name and number of the informant.

Show the pedigree to the informant and ask if anyone is missing, or if he/she can supply missing pieces of information (names, ages, and so on). At a minimum the pedigree includes the proband's parents, grandparents, siblings, aunts, uncles, cousins, offspring, spouse (and parents and siblings of the married-in spouse if there are affected offspring). If the informant's first degree relatives are not on the pedigree, expand the pedigree to include them.

2) Ask the General Screening Questions.

Ask the informant to keep in mind all of the relatives on the pedigree as he/she listens to the questions you will read.

When you get a positive response to one of the questions, record it directly on the pedigree by the name of the person being described. At this point you are receiving overall, general information and writing notes on the pedigree, being careful to pick up any hints of pathology. Probing for more detail can come later with the Face Sheets and symptom checklists.

- 3) Ask about individual relatives, using a Face Sheet and symptom checklists.

Having completed the General Screening Questions and having noted the responses directly on the pedigree, complete a Face Sheet for each of the informant's first degree relatives, e.g., the informant's parents, siblings, and offspring, as well as the informant's spouse. Ask about each one, using a separate Face Sheet for each, whether or not there is any hint of pathology reported by the informant. In addition, complete a Face Sheet as follow up on any hints from the informant of pathology anywhere in the pedigree, even if the person is not someone in the group described above. Otherwise, extenders and pointers may be missed.

The birthdate need not be asked if it is already in the data.

Write on the Face Sheet any narrative that may have significance for diagnosis, including that of "normal". The narrative can be one or two sentences describing what the person was like, and if there were any psychiatric or personality problems. If the informant offers nothing and you feel it would help, you could do some prompting from the General Screening Questions to refresh his/her memory on what information is being sought, at your own discretion.

If there is any known pathology, you should have detected it while going through the General Screening Questions with the pedigree. As you do a Face Sheet, immediately examine those hints and explore them further by asking questions on the pertinent checklists. The checklists ask details of symptoms, number of episodes, duration, age of onset, treatment, and impairment rating.

Complete a symptom checklist for any suspected depression, mania, alcohol or drug abuse, psychosis, or paranoid/schizoid/schizotypal personality. Symptom checklists for depression, mania or psychosis may be omitted for persons already assigned a major diagnosis such as schizophrenia or bipolar I.

Should you learn of a disorder other than those for which there are checklists, go to question five on the Face Sheet, which allows space for a description and has questions on the age of onset, treatment and impairment.

Use a checklist only if you have reason to believe that the informant can tell you something. You will know this either by responses to the General Screening Questions or by the narrative you get when doing the Face Sheet. If you start a checklist and find the informant cannot provide details stop using the checklist. If you find that the informant knows only about

treatment and onset but nothing else, get whatever information you can. If the informant may have "heard about" a problem, or may have rarely seen the subject, or for any reason simply doesn't have any knowledge, there is no point in even beginning a checklist. Use your own discretion, but note as narrative on the Face Sheet your observations regarding the reasons for the dearth of information.

If you already have enough information in a subject's data pool for a positive diagnosis, there is no need to use a checklist. For example, suppose you are doing the FIGS and you are beginning the Face Sheet on a proband with schizophrenia. The study already has confirming information from two other informants for the core diagnosis of schizophrenia. On the pedigree diagram it is indicated that two confirming FIGS reports would be sufficient evidence in this case to warrant omission of the psychosis checklist. Nonetheless you will still want to complete a Face Sheet narrative giving that informant's unique perspective, even though you do not need to complete a checklist on psychosis. On the other hand, if the informant gives information not previously revealed in the data, you will want to record it as fully as possible. Examples might be evidence of depression or alcoholism not disclosed previously by other relatives or in the DIGS.

To avoid the problem of a false negative, however, you may go ahead and collect information from at least four or five informants or until you get a report of a core diagnosis when pathology is suspected.

Even if a DIGS has been completed on the subject you can never be certain of its reliability, and the FIGS can help corroborate or expand the information. Notes jotted down as the informant speaks about the subject may turn out to be important pieces of the diagnostic picture as a whole.

Suppose the informant knows something significant about a family member on the pedigree who is not someone on whom you would normally do a Face Sheet (that is, not a first degree relative). In each case such as this, complete a Face Sheet and relevant checklists, the same as you would for a first degree relative.

DATA COLLECTION

As each informant completes a FIGS, the body of data about a single relative is increased with each FIGS completed. There may be many pages of data from various informants about a single subject.

Each completed FIGS page (whether General Screening Questions, Face Sheet or symptom checklist page carries identification: family name and number, informant name and number, subject name and number, and the date the information was obtained. Without this identification the page has little value. Thus, each page must stand on its own. This is necessary because for the best estimate diagnosis each page will be part of the subject's data pool entry, combined with FIGS pages from other relatives about the subject, the

subject's DIGS if completed, and the subject's medical records, if any. (The above does not apply to coded information.)

Additional FIGS pages will be needed during the course of the study as new information is acquired. Relatives who were not ill before may become ill, relatives in remission may have a relapse, or a previously not located relative may be found who can provide information. New information is recorded on a FIGS Face Sheet (with checklists as needed and as possible) and added to the pool of information about that subject.

TYPES OF PEDIGREE DRAWINGS

Hand-drawn pedigrees

1. Clean pedigree

A clean pedigree has everything but diagnostic information. It is essential for doing the FIGS. (Make several copies of this clean pedigree for use in interviews. Information from each informant should be recorded on a separate copy of the clean pedigree.)

2. Pedigree with FIGS information

This copy has new information from the informant, written onto the clean pedigree. The new information may be in terms of filling in missing persons, names, and so on, or of expanding the pedigree to include additional beginning. Write the responses to the General Screening Questions on this copy. Be sure to write the date and the name and number of the informant on the pedigree used when doing a FIGS. With each FIGS done there will be a pedigree with input from a single informant.

3. Master pedigree

A single pedigree with cumulative information from each of the FIGS informants. If it is kept up-to-date throughout the study by recording new information as it is collected, it provides detailed information at a glance. Used as a basis for the computer-drawn pedigree, the master pedigree is hand-drawn and gives the following information:

a) who has been interviewed, as each interview is completed; who has refused or is unable or deceased;

b) diagnostic highlights (in abbreviations) as each relative reveals details of family history (extracted from their FIGS);

c) diagnostic status, whether provisional (DIGS only), and then final best estimate diagnoses; or revised after new information;

- d) who has given a blood sample, and whether that sample is in culture;
- e) new marriages, births, deaths, and
- f) the master record of numbers assigned (no two relatives will have the same number).

Computer-drawn Pedigree

Drawn by means of a computer program, this can provide information on the final diagnosis of all affected beginning as well as the status of cell lines. The computer may draw pedigrees with or without diagnoses, with or without a record of cell line status, and with or without genotypes.

ADDRESSES AND TELEPHONE NUMBERS

In general the best time to ask for addresses and telephone numbers is not during the scheduled interview time. The information can be forwarded by telephone or by mail.

Probands and relatives who are well disposed to the study will generally provide addresses and telephone numbers of other relatives, but sometimes they may wish to contact a relative for permission before giving you access.

An ongoing record of current addresses and telephone numbers is conveniently kept in numerical or alphabetical order in a loose leaf binder so that additional pages of relatives or new families can be added to the study.

Continuing contacts, with probands and relatives as well as changes in name/address/telephone number are recorded on these pages in such a way that any of the research staff will be able to pick up the work at any point, knowing what has been done.