

GIFD AIM 1 CODE BOOK

Categories Consolidated List for Round One Coding Draft 4 (Gordon/Koenig) 12-4-12
(most relevant interview questions are in red, but content may be anywhere in interview and numbers will vary a bit on different versions of the interview guides as they evolved over time; numbers in red below are from the “final” version of the guide)

Underlined word is suggested as coding category name.

0) Demographics

- 0.1 Pedigree discussion/Family Composition (1.1, 1.3)
- 0.2 Occupation or life history details (if provided)
- 0.3 Pancreas Disease Registry Participation (+/-)
- 0.4 Family history of disease in biological family; include any disease
- 0.5 Includes cancers and other diseases mentioned in social vs. biological/genetic family (e.g. in spouse)

1) Experience of Illness (1.1)

Family illness narrative: includes narrative of family experience with cancer (‘it was a terrible end’); Illness narrative of proband, e.g., process of diagnosis, treatment

2) Genetic Knowledge (introduction, 2.1)

Content describing understanding of genetics and overall “genetic literacy”
Response to written materials on BRCA2 sent earlier, etc.
Genetic thinking or etiological explanations invoking genetics (+/-)
Doing personal genetics-related research on the internet

3) Family Communication (& dynamics) (1.2, 5.6)

Contact and sharing of information regarding all aspects of illness: diagnosis, research participation, treatment strategies, etc. (Treatment may overlap with Code 6 below)

4) Research Orientation (of self, proband, or family) (1.4)

Discussions or expressions of Technological/Scientific/Medical Optimism vs. Fatalism (+/-); Motives for registry participation (if relevant); Research-philic / research-phobic

5) Disease Worry/Concern (about disease risk for family/self) (2.1)

Discussions of “Being at Risk” or not being at risk.
“Burden of Worry” or opposite, “I’m not worried because the information is so uncertain”
(n.b. action re the worry is Code #6; n.b. eventually we will code differences by high risk families vs sporadic cases)

6) Genetic Testing Experience or other Clinical Actions/Tests (2.2)

Examples include seeking out testing, having regular screening/scans, or other clinical actions, e.g. “My mother insisted that we all get MRI’s”;

“I spoke to my MD”

7) Factors that Matter (3.8, 3.9, 4.1 through 4.6)

Discussions of characteristics that matter when considering genetic results: actionability, uncertainty, lethality, treatment availability, legitimacy (e.g. government approval), preventability, treatability, cost, etc. Includes statements such as “I only want to know if...or I would never want to know if.”

7.1. Reproductive concerns/issues—code separately for prenatal context, abortion/choice, etc.

8) Communication Preferences for Offering Unexpected Findings (for self & family) (3.1, 3.2, 3.3, 3.4, 5.1, 5.3, 5.4, 5.5)

All statements re preferences & shoulds (e.g., whether the informant would want self and/or family to be offered results; should testing be offered, accepted, declined, under what circumstances?) Imaginings of what proband or other family members would do if they were in charge of the information. Includes preferred or suggested means of communication, e.g., letter vs phone, content of communication, who should be notified (self, family, others).

9) Policy Preferences for Offering Unexpected Findings (3.1, 6.3, 8.2, 8.4)

Focus on “third person” statements, includes answers to policy questions about return of results, both general and specific. Code all suggestions about practice and policy throughout interview, e.g. how to handle the conflict with Mr. Jones (“the law needs to change”). Include the role of researchers/institutions in offering results and the role of primary care physicians in the process of offering results. (n.b. Preferences for self or family should be code 8).

10) Reasons/Rationale for Knowing/Not Knowing (3.2, 3.4, 5.1, 5.2, 8.3)

Pragmatic reasons, such as “to prepare, to get more checkups” and moral reasons, such as a “right not to know,” “right to know.”

Discussions of the value of not knowing, or why this is not a valid concern.

Includes orientations toward knowing, such as being an “Information Seeker” (+/-) or the opposite.

11) Provenance/“Ownership” of Genetic Information (5.4, 7.4)

Boundaries of sharing genetic information, who “owns” it and who may share it or who does not have a right to share it/withhold it. Mrs. Jones scenario responses may be coded here. Statements of rights and distinctions about who in family is entitled to information.

12) Locus of Decision-Making Authority (6.3.1)

Discussions of who should decide. Direct (individual) vs mediated (by next of kin, physician). Discussion of control of information and decisions. Discussion of responsibility-“it’s the individual’s responsibility to decide what to do with that information (and only he/she must decide).”

13) Genetic Privacy/Confidentiality (7.1., 7.4)

Discussion of privacy/confidentiality of information
Trust (who to trust, who not to trust) (+/-)
Relevance/helpfulness of GINA or similar laws; privacy within and outside the family.
13.1 Code separately discussions about privacy after death of proband

14) Government Role (4.2, 7.2, 7.3, 8.5)

Trust (+/-) Views of government role in genetic testing oversight, research or clinical care regulation.

15) Faith/Fate (1.4, throughout)

Discussions of higher authority (related to code 4 faith in science)
Role of religion, destiny, prayer, etc., or lack thereof.

16) Research/Clinical Boundary or Distinction (3.1, 8.5, throughout)

Note where interviewee does or doesn't make distinctions between research genetic testing vs clinical testing, or role of clinician vs. researcher
(This is a theoretical code which we may want to flesh out later, but it is a theme emerging nationally so we want to look for it.)

17) Impact of Return of Results on Research Participation (9.1.through 9.3)

Discussion of whether offering results affects willingness to be in research.

18) Process (10.2)

All discussions about the interview process itself, or its implications, etc. such as, "this interview really made me think....."

Coding Summary Template for Interviews, Aim 1.

Coder of NVivo:

Summarized By:

Demographics:

ID:

Interviewer:

Sex:

Age:

Category of informant:

Relationship to pancreas cancer proband(s):

Education:

Occupation:

Duration of interview:

Date of interview:

Interview Content:

Genetic literacy:

Global desire to be informed/“information seeker”:

Pancreatic cancer is genetic/inherited in their family:

Actions taken related to worry about pancreatic cancer:

BRCA2 results to self:

BRCA2 results to biological family:

Melanoma same/diff:

CF same/diff:

Reproductive concerns:

Who should control whether information is offered:

Does it matter or not

4.1 New discovery:

4.2 FDA or government approved:

4.3 Treatability:

4.4 Cognitive decline:

4.5 Preventability/Early detection:

4.6 Conditions would not want to know:

What to do with results from deceased probands? (general):

Mrs. Jones Scenario - Biological relatives have right:

How extensive:

Role of the next of kin (can they trump):

Deceased research participants:

To whom should researchers offer results?:

Communication preferences, from whom and content:

Comes via primary care doc:

Who should pay for testing:

Importance of privacy within family:

Importance of privacy post death (general):

Employment concerns:

GINA concerns:

Summary of views of general policy:

Impact of universal return of results policy on research participation: