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## The Context of Collecting Family Health History: Examining Definitions of Family and Family Communication About Health Among African American Women

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### Abstract

Public health initiatives encourage the public to discuss and record family health history (FHH) information, which can inform prevention and screening for a variety of conditions. Most research on FHH discussion and collection, however, has involved predominantly White participants and has not considered lay definitions of family or family communication patterns about health. This qualitative study of 32 African American women, 16 with a history of cancer, analyzed participants' definitions of family, family communication about health, and collection of FHH information. "Family" was defined by biological relatedness, social ties, interactions, and proximity. Several participants noted using different definitions of family for different purposes (e.g. biomedical vs. social). Health discussions took place between and within generations and were influenced by structural relationships (e.g. sister) and characteristics of family members (e.g. trustworthiness). Participants described managing tensions between sharing health information and protecting privacy, especially related to generational differences in sharing information, fear of familial conflict or gossip, and denial (sometimes described as refusal to "own" or "claim" a disease). Few participants reported that anyone in their family kept formal FHH records. Results suggest FHH initiatives should address family tensions and communication patterns that affect discussion and collection of FHH information.

Public health initiatives have encouraged the public to discuss family health history (FHH) information with family members and create written records that can be shared with family and clinicians (Dunlop & Barlow-Stewart, 2010; Guttmacher, Collins, & Carmona, 2004). Such information can inform recommendations for disease screening and prevention (Guttmacher et al., 2004), including recommendations for several cancers (American Cancer Society, 2012). Although most Americans believe tracking FHH information is important for their health, most do not keep formal FHH records (Yoon et al., 2004). To achieve

Healthy People 2020 goals of increasing access to genetic counseling and realizing the potential of genomic information, the Department of Health and Human Services recommends studying disparities in the collection and use of FHH between different populations (U.S. Department of Health and Human Services, 2013).

Many FHH initiatives promote a FHH tool, an electronic or paper instrument that people complete on their own, often before a provider visit, to compile FHH information used to guide risk assessment or clinical interventions (Acheson, 2003; Fuller, Myers, Webb, Tabangin, & Prows, 2010; Rich et al., 2004; Yoon et al., 2002). Gathering information to complete FHH tools requires people to discuss health information with family members, but little is known about whether existing tools reflect how families discuss health information. Most FHH tools are predicated on a biological definition of family (e.g., U.S. Surgeon General's Office, 2011), which may not reflect the social or other lay definitions of family that people employ. To promote widespread use of FHH tools, it is important to understand whether current tools reflect the family definitions and communication patterns of diverse populations.

## Defining Family

In order to use FHH information to guide prevention and screening, more information is needed about how people in diverse populations conceptualize family and how they communicate with family members about health information. Most research on family structure and family communication has involved White families (Socha & Diggs, 1999) and, despite health disparities between African Americans and Whites in the U.S. (Adler & Rehkopf, 2008), most prior research on communication of health information within families has involved predominantly White samples (Acheson et al., 2010; Cohn et al., 2010; O'Neill et al., 2009; Wideroff et al., 2010). Family communication patterns and beliefs about family may differ by ethnic group (Gudykunst & Lee, 2001), which could affect family communication about health and collection of FHH information.

Scholarly and lay definitions of "family" vary widely. Scholarly definitions often focus on structure (e.g. biological or legal ties), function (e.g. caretaking or financial support), or transactions (e.g. creation of shared meaning through affective ties or symbolic communication such as stories and rituals) (Segrin & Flora, 2005). Research on how laypeople define family suggests that they often blend these kinds of definitions or shift back and forth between them (Baxter et al., 2009; Newman, Roberts, & Syré, 1993; Schmeckle, Giarrusso, Feng, & Bengtson, 2006; Weigel, 2008).

African Americans may be more likely than Whites to include extended family and fictive kinship when defining family (Coles, 2006; Segrin & Flora, 2005; Stewart, 2007), which may not reflect the structural/biological definition of family that underlies many FHH tools. It is unknown whether differing conceptions of family affect communication about health and collection of FHH information, but a mismatch between an individual's definition of family and the structural/biological definition underlying many FHH tools could affect patterns of communication about FHH or the use of tools (Petrucchio et al., 2008). For example, if certain populations often consider fictive kin family, a biologically based FHH

tool may not be appropriate. Little empirical research has addressed this issue, however. Prior work found that African American women generally rated an electronic version of the Surgeon General's FHH tool as a "good fit" for their families based on one close-ended Likert item, but those analyses did not address family communication patterns or participant definitions of family (Thompson et al., 2013). The current study explores family definitions and family communication patterns in the context of FHH collection.

## Family Communication Research

Family communication research has analyzed patterns of communication and social roles within families that may apply to communication about health information. For instance, one way of maintaining family closeness is through sharing stories (Adams, 1999; Mares, 1995; Segrin & Flora, 2005). Within families, women are often "kinkeepers" who maintain family ties (Adams, 1999; Williams, 2007). Adult sibling relationships may be an important source of emotional support (Adams, 1999), with sister-sister pairs having especially strong bonds (Riggio, 2000). Women, grandmothers in particular, play an important role in promoting health in African American families (Williams, 2007; Cherlin & Furstenberg, 1985; Hunter & Taylor, 1998). These family ties and family stories may be conduits for information about health.

Several factors influence family communication patterns specifically about FHH. There may be differences in discussion of FHH information depending on whether a family has a history of diseases such as cancer (Kaphingst et al., 2012). Most research on family communication about FHH has been in the context of specific diseases resulting from highly penetrant genes in families at high risk (e.g. Geelen, Van Hoyweghen, & Horstman, 2011; Koehly et al., 2009). In one study of White families at risk for hereditary breast and ovarian cancer, family of origin was important in communicating health information; women often served as gatherers and disseminators of such information (Koehly et al., 2009). Less is known, however, about the flow of health information within diverse families, or about the flow of health information about multiple diseases. This information is important for planning FHH collection initiatives aimed at the general population that involve collecting information about a range of diseases.

Theories of family communication are important because in order to develop a FHH, people must gather information from families or receive information from family members who have already collected it. Although poor relationships with family members and lack of health information may be barriers to collecting FHH information (Wallace et al., 2009), people may also enjoy discussing FHH topics with family members (Petruccio et al., 2008). Reeder et al. (2013) found that sharing health information within a family depended on relationship quality, type of information, and stage in the life course. Lindenmeyer et al. (2011) found that families—particularly sisters—create "collective health narratives" about FHH through "everyday health talk." Simply discussing FHH information, however, is not sufficient to ensure creation of a written FHH record that can be shared in a clinical context; prior work has found health discussions and formal FHH collection are distinct processes (Thompson et al., 2013).

Family communication theory suggests that discussing personal health information and collecting FHH information from family members are acts that require people to balance disclosure and privacy. The present analyses use a dialectical perspective, which “emphasizes the interplay of opposites” (Baxter & Montgomery, 1997, p. 328) and explores dialectic tensions in family relationships such as openness/protection or disclosure/privacy. These tensions are managed by employing strategies such as *denial* (affirming one pole of a dialectic and refusing to discuss the other, e.g., discussing only positive health information), *segmentation* (restriction to one pole or another depending on the topic, e.g., refusing to discuss sexual health but being open about other topics; see Reeder et al. 2013), and integration (an ideal, not often achieved, in which people satisfy both parts of a dialectical tension simultaneously) (Segrin & Flora, 2005). Given that most Americans think collecting FHH information is important and yet do not do so, a dialectical perspective may help researchers understand conflicting attitudes and behaviors regarding FHH collection.

Overall, research about FHH collection that examines lay conceptions of family and family communication about health is needed, especially in underrepresented populations. The current study addresses this gap by examining African American women’s definitions of family, family communication about health, and collection of FHH information.

## Methods

### Study Design

This qualitative study was conducted as part of a larger mixed methods study exploring African American women’s use of FHH tools. Between January and July 2011, we recruited a purposive sample of 32 African American women, 16 of whom had a personal history of cancer. Participants, who were told this was a study of family health history, were recruited via phone from two databases: one composed of people who had participated in prior studies at the research center and had requested to be contacted about future studies, and the second composed of people who had volunteered to be in a university-wide database of prospective participants. Participants were eligible if they were 21 years or older, said they could read and write in English, and had not seen a genetic counselor. The university institutional review board approved this study and all participants gave informed consent. Participants received a \$30 gift card.

Trained students conducted in-person interviews lasting approximately 90 minutes. Open-ended questions (see Table 1) in the semi-structured interview guide solicited participants’ views on family and information about health communication patterns within their family (Beatty & Willis, 2007; Willis, 2005). Interviewers were free to follow the flow of conversation and vary the question order, and they were encouraged to probe on brief responses. At the end of the interview, closed-ended items were administered verbally to collect demographic information.

### Analysis

SPSS 19.0 was used for descriptive analyses of closed-ended questions. Interviews were audio recorded and transcribed verbatim. Analysis of open-ended data, undertaken by a team

of faculty and students, was progressive and iterative (Coffey & Atkinson, 1996; Miles, 1983; Miles & Huberman, 1994; Sandelowski, 1995). A preliminary codebook, developed based on the literature, was supplemented by inductively derived codes after an initial reading of transcripts. Two trained, independent coders used Atlas.ti to code each transcript, with discrepancies resolved by consensus of the study team.

After coding, memos summarizing each theme were created and analyzed. Initially, analysis was stratified by participant cancer history, but because only one salient difference was noted between responses of participants with and without a history of cancer (described below), we collapsed these groups for the presentation of results below. Participant numbers in the 200s designate women with a personal cancer history, and numbers in the 100s designate women without a personal cancer history. Although we considered the interviews to be exploratory, as analysis progressed we considered several theoretical perspectives to determine which offered the best insight into participants' responses and corresponding themes. After discussions among the study team, we determined that a dialectical framework was most helpful in illuminating the way FHH information was discussed and collected among participants. Our inductive findings are thus interpreted in light of this framework.

## Results

We examined how participants defined family and how families communicated about health and collected FHH information. Participants described varied conceptions of family and noted different patterns of communication about their own health versus communication about FHH information within the family. Mean participant age was 55.0 ( $SD = 9.1$ , range 26-72). Most participants (71.9%) had a high school education or higher; 37.5% were married/partnered.

### Defining Family

Participants used a variety of family definitions. Structural and transactional definitions were most common; functional definitions (e.g. focusing on caretaking or financial responsibilities) were rarely used.

Structural definitions of family relying on biological or legal ties were used frequently. Many participants defined "family" by listing specific family members, most of whom were biologically related, although others listed spouses and in-laws. Some participants considered half- and step-siblings family, but others did not. Some participants defined family as exclusively people who are blood-related; Participant 210, for example, said, "Family is blood."

Other participants employed transactional definitions of family focusing on emotional or physical closeness. Many participants reported feeling emotionally close to family members through family communication and saw families as providing love and emotional support. According to Participant 103, "Family are people who come to you to share their thoughts, talk as a family, bond as a family. People who are pretty much close together, knit together." Participant 111 said a family is people "you could trust and be there for you when you need them. Someone that's going to love you unconditionally." A few participants, however,

reported they were not emotionally close to people they considered family; according to Participant 207, “I don’t talk to my sister, I don’t talk to my niece, and I live in the same house with my mama, and I have very little to say.... We’re not a close family.” Many participants saw physical proximity as another possible criterion for defining a family, but taken by itself they considered it neither necessary nor sufficient. Some participants acknowledged that immediate biological family members often live together but noted exceptions, such as blended families and adult children living alone.

Transactional definitions also allowed people to include in their families people to whom they felt emotionally close but who were not biologically or legally related. Participant 104 gave an example of such fictive kinship, saying, “I would say to me family is blood related and then also people that are very close I kinda consider them my family too.” Participant 211 said, “We have a large family which we’re all very close, but we also adopt other people in our family very often that are just friends that have been around forever and we just claim them.”

A few participants discussed using different definitions of family for different purposes and noted that the structural/biological definition of family used by doctors can differ from the transactional definition used in daily life. Participant 201, for example, explained that her personal definition of family was more complex than a biomedical definition: “For me, all family members are not blood-related, but for purposes of collecting family diseases and histories, yes.” Participant 107 said, “All family members related by blood?... In some cases it may not be, it could be because of an adoption involved or it could be someone took in someone else’s child because they were going through hard times and that child just became a part of the family but as far... as your DNA and things that may come, as far as diseases and health issues, that would definitely be related by blood.”

### **Family Communication about Health**

Participants discussed their family’s communication patterns around health, including whom they talked to, the topics they discussed, and barriers to discussing health information.

One theme involved family members with whom they discuss health information. Those discussions took place both within and between generations; participants discussed health with older relatives (often mothers), siblings (often sisters, but sometimes brothers to whom they felt emotionally close), spouses, and children. Family members were often chosen both due to their role and their personal characteristics, such as having a medical background, being easy to talk to, well informed about health, interested in health, or trustworthy. Participants reported discussing their own health with people of various ages. Sisters in particular were mentioned by more than half of participants, and were described as emotionally close, interested in discussing health, or sharing common health issues or concerns. Participant 105 said, “[My sister and I have] always been kind of two peas in a pod, you know. It’s always just been the two of us.” Many participants named their mothers, saying they felt emotionally close to them. Some participants also discussed health topics such as prevention or wellness with children, often to persuade them to improve their health. Although many participants identified female family members, some participants also mentioned discussing their health with brothers, often due to personality characteristics (e.g.



good listener) and willingness to communicate about health. Participant 214, for example, said, “I’m just closer to [my youngest brother]... I think because of his medical issues that he’s shared with me over the years. ... There’s no subject that’s off limits with him, nor does he get upset or defensive when I have questions or concerns.” Some participants also discussed health with partners, citing comfort, trust, and the partner’s interest in their health.

Another theme involved health topics discussed within families. A large number of participants reported being able to discuss “everything” with their families, including health topics they saw as potentially embarrassing, such as sexually transmitted diseases. Participant 111 said, “I talk to them about anything. Anything.” Participant 203 said, “[W]e communicate quite a bit, so there’s nothing that we don’t know about, and if somebody has something, everyone discusses it. It’s not hidden or taboo.” Some participants reported their families discussed only serious health topics, however, such as grave or terminal illness. A few people reported their families never or rarely discussed health. In addition, although many participants initially reported being able to discuss “everything” with their families, some later mentioned specific health topics that were not discussed in their families or with particular family members. Cancer and sexual problems were the most common topics that were not discussed (or not discussed with some family members); other avoided topics included addiction, mental health, diabetes, and kidney problems, often because they were considered shameful. According to Participant 209, “You just didn’t talk about things [related to sexual health]. The women didn’t talk to each other we didn’t talk ... about reproductive history and stuff like that.”

Many participants reported discussing prevention and wellness with their families, especially in relation to specific diseases or risk factors. These discussions could be a mutual exchange of information; for example, Participant 109 said, “[W]e’ll discuss what we’re doing as far as maybe buying more healthier foods or trying to be more active or something.... We might talk about what not to do. We don’t smoke, we don’t drink, we don’t do drugs.” Health discussion was also employed as a strategy to improve the health of particular family members. Participant 102 said, “I talk to my son about health. I’m on my son about taking his diet, getting some exercise. He’s got problems his mother doesn’t have real young.”

Another theme discussed by many participants was generational differences in the discussion of health information. Some people said that older family members were less likely to discuss health information than younger family members. Participant 105, for example, said, “[My grandparents] lived during a time where certain things were just not discussed, and that’s been the problem. You know, I know it’s more of an upbringing than just them being secretive.... Because this is a whole new generation. We talk about everything.” In contrast, a few participants thought that younger family members were less interested in health. Participant 213 said, “When you look at the generation today, I don’t think they’re too much interested in anything but hip hop. And that’s some of them, anyway. They could be more interested than I ever realized.”

Denial was another theme that many participants brought up as a barrier to discussing health information. In some cases, family members did not want to talk or think about illnesses they had or could potentially contract. Participant 213 said,

I don't know if it's a miseducation, or our people didn't go to the doctor, or if it's just blatantly, *If I'm sick I don't want to know it...[I]f I don't know it, it won't hurt me*. But then when I do find out, it's so bad that nothing can be done.... I think it's like, *I don't want to know and if I don't know, I'm better off by not knowing*.

A few participants described a specific form of denial: the desire not to “claim” or “own” a disease. Participant 109 said, “We don't talk about cancer.... Cause it's almost like, some people feel that when you talk about something, you're claiming it. So you've like accepted it. But if you don't talk about it, you don't claim it.” Participant 107 saw the desire not to “claim” or “own” a disease as linked to religion:

They say, *Don't claim that*...maybe if you don't talk about it, it won't happen... Say that you don't have it and you don't want to own it.... Even some of the ministers...will say, *Don't claim certain things*, you know, *just ask God for help to remove it or not let it be*.

Family members' refusal to “claim” or “own” a disease could make forthright discussion of health information difficult or impossible.

Privacy was another reason for not discussing health issues with family. Sometimes a desire for privacy was attributed to generational differences or the characteristics of a particular family member. While some participants thought that family members' privacy concerns could impede the sharing of important health information, others were reluctant to share their own health information with particular family members due to fear of gossip. Participant 106 said, “I wouldn't want to [discuss my health with my family] even if it wasn't anything major...Their level of discretion is not the same as mine and so... if it's something I wouldn't want the whole world to know...then no.”

Some participants reported family members did not discuss health information to protect others from stressful knowledge. This theme was the only instance in which the responses of cancer survivors were different than those who had not cancer; cancer survivors were more likely to describe themselves as protecting others, while participants who had not cancer were more likely to describe others as protecting them. Participant 116 (no cancer history) said, “I just think they just don't want you to worry about them.... Especially my grandmother. She says, *Oh, I'm fine, everything's okay*. Well, you know, she's getting older and everything's not okay.... I just think it's more of a protective mode.” In other cases, participants, including several cancer survivors, described withholding information from family members so as not to upset them. Participant 215, who had a cancer history, said, “When I found out I had breast cancer I called my girlfriend first because I knew my mom would be just hysterical.... I didn't want her to be upset.”

### Collection of FHH Information

In addition to discussing family health in general, participants identified people within their families from whom they could collect FHH information. Whereas women reported



discussing their own health with a wide variety of relatives, as discussed above, one theme in collecting FHH was the importance of older relatives, particularly women; many participants mentioned mothers, grandmothers, aunts, and older sisters as sources of FHH information. These women were sometimes seen as matriarchs who had extensive knowledge about the family. Older brothers, uncles, and fathers were mentioned less frequently. Some older participants stated that there was no one they could ask about FHH information because the people who had known that information had passed away; in some cases, those participants said *they* were the ones that other family members seek out for information.

Many participants described a lack of systematic FHH collection in their families or were uncertain about whether anyone collected FHH information. Fewer than half the participants were aware of a specific person in their family who tracks FHH information. Some people named themselves; Participant 214, for example, who has a chronic disease, said, “[T]he only reason why I did track my family history is because of my illness... I just wanted to know how did I get this disease? So in order to find that out, you have to track.” Other people mentioned older female relatives. Family members who tracked FHH information were often seen as doing so due to personality characteristics such as being organized, intellectual, or detail-oriented. Some participants specified that no one in their family tracks FHH information systematically: “No, nobody really does. Just everybody just knows it in their head. You know, nobody has it written or anything like that” (Participant 114).

## Discussion

This study addresses gaps in FHH research by examining lay conceptions of family, family communication about health, and FHH collection among African American women. Such in-depth knowledge of health communication patterns in diverse populations is essential for developing targeted tools and interventions that promote the creation of FHH records that can inform prevention and screening for multiple health conditions. We found that communication patterns differed depending on whether participants were collecting FHH information or discussing their own health more generally. Although some participants mentioned fictive kinship when defining family, they differentiated between a personal definition of family and the biomedical definition underlying FHH tools.

Participants defined “family” primarily in structural and transactional ways, with several participants acknowledging their definition depended on context. Functional definitions were rarely used; the age range of participants suggests that this may be because few of them had young children at home. Although many participants emphasized structural definitions of family such as biological or legal relatedness, transactional definitions involving proximity and emotional interactions were also important. The fact that several participants described using different definitions of family for different purposes—indicating an understanding that the biomedical view of family underlying FHH tools includes only blood relationships—suggests that varied family definitions among African American women may not lead to problems with using biologically based FHH tools. However, future quantitative research should examine how common it is to use different

family definitions for different purposes and how the definitions that women employ affect their experience with FHH tools.

Many of our findings were similar to prior research involving white women, which suggests that women from different groups may face similar challenges in collecting FHH information. Women in our study reported discussing their own health with a wider variety of people than those from whom they collected FHH information. Although female relatives were important for both communication tasks, when collecting FHH information participants were more likely to turn to older women, consistent with past findings that women serve as gatherers and disseminators of health information (Koehly et al., 2009) and that African American women serve as “kinkeepers” (Williams, 2007). Despite interest in collecting FHH information, most participants were either unsure whether someone in the family tracked FHH information or reported that no one did, consistent with past evidence that the majority of Americans do not keep a formal FHH record (Yoon et al., 2004). Similar to prior research, our results suggest that although discussion about health is a norm in many families (Lindenmeyer et al., 2011), keeping written FHH records is not (Thompson et al., 2013; Yoon et al., 2004). Future FHH interventions should explore ways to channel family discussions about health into creating more formal FHH records.

Both lack of information and lack of formal record keeping may lead to difficulty creating a complete and accurate FHH record. A dialectical perspective offers insight into these barriers because it illuminates how people balance tensions such as disclosure and privacy. Participants believed sharing health information was important, but, consistent with prior research (Lindenmeyer et al., 2011; Reeder et al., 2013), they also wanted to protect themselves and others by being selective about such sharing. They did not want to become the subject of gossip or cause conflict with family members. Limiting discussion about some health topics but not others constitutes *segmentation*, which allows family members to vary their degree of openness by specific topics (Segrin & Flora, 2005). Although clinicians and practitioners may assume collecting FHH information is always beneficial, our findings suggest that communication about health information can also cause conflict or disrupt family dynamics. Our results also suggest that certain health conditions, including cancer, sexual problems, and mental illness, can be particularly sensitive; developers of future FHH tools should be aware that people may need specific advice about discussing these topics with family members in order to collect FHH information. The fact that a minority of participants reported discussing limited or no health information with their families suggests these individuals may need targeted strategies for FHH collection.

Another strategy employed by some families was *denial*, which resulted in unwillingness to discuss negative health information, possibly in order to manage or avoid anxiety about potential health problems. Refusal to “own” or “claim” a disease, although only mentioned by a few participants, is an intriguing, rarely studied elaboration of the concept of denial that may significantly impede collection of FHH information in African American families. One study exploring African American women’s perceptions of heart disease suggested that “not claiming” a disease may affect risk perception (McKenzie & Skelly, 2010), but further research is needed to determine whether refusal to “own” or “claim” diseases affects health communication, collection of FHH, and use of FHH information in this population.

Public health practitioners and clinicians should acknowledge these dialectical tensions inherent in FHH collection and provide support to overcome family communication barriers. Tools that encourage FHH collection *and* suggest strategies for discussing health information with family members (e.g., Petruccio et al., 2008) have the potential to increase collection of FHH information.

### Limitations

Although our sample of African-American women from one urban area allowed us to conduct an in-depth exploration of participants' views, this sample does not allow comparison across sex or racial groups. Women were chosen as the study population because they are more likely to collect FHH information than men (Yoon et al., 2004), but this may have influenced our results; it is possible, for example, that participants considered women the keepers of FHH information because women are more likely to talk to other female family members. Further quantitative research should investigate differences in communication about health and collection of FHH information by age and sex, as well as whether employing structural, functional, or transactional definitions of family affects type or amount of communication about FHH.

### Conclusion

Collecting FHH information is a complex process that should be analyzed in the context of lay definitions of family and family communication about health. Drawing on family communication theory, this study adds to the literature about family communication about health and collection of FHH in an understudied population. Our findings suggest that differing definitions of family do not affect African American women's use of FHH tools based on a biological definition of family. Participants did, however, speak of difficulties negotiating dialectical tensions between sharing and privacy and between acknowledging and denying disease risk. Providing specific strategies for managing these tensions will allow practitioners planning FHH initiatives to support discussion of health and collection of FHH information in diverse populations.

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**Table 1**

Constructs and sample open-ended items used in interviews about family health history.

Construct	Sample items
Definition of family	How would you define family generally? Who do you think of as members of your family?
Relatives with whom participant discusses health	Who in your family would you be most likely to talk to about your health?
Health topics discussed in family	What types of health information does your family talk about? Would you say that there are health topics that people actively avoid?
Sources of family information about FHH	Who in your family would you be most likely to ask about diseases that run in your family? Is there someone in your family who keeps track of information about diseases that run in your family?