Family history taking in pediatric practice: a qualitative interview study using the Theoretical Domains Framework

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Abstract

Family history (FH) is a risk factor for many conditions that can affect pediatric patients. While there is no evidence of the clinical utility of FH taking in pediatrics and there is no standard of care as to FH taking, many suggestions were made as to what conditions should be covered in a pediatric FH assessment. There is also no evidence of the current practice. In this study the Theoretical Domains Framework was applied to FH taking and used to conduct semi-structured interviews with pediatricians to explore their FH taking practice. The pediatricians reported similar FH taking habits. Their FH taking was reported to include a wide range of conditions and determinants of health, and they used this information for a broad range of clinical tasks. FH taking in pediatric practice was reported to be complex and embedded with other aspects of practice.

Résumé

Les antécédents familiaux (AF) sont des facteurs de risque pour plusieurs maladies affectant les patients pédiatriques. Alors qu'il n'y a ni données probantes concernant l'utilité des AF en pédiatrie ni normes pour la prise d'AF, plusieurs ont fait des suggestions quant à ce qui devrait être couvert par la prise d'AF. Il n'y a pas de données probantes décrivant la pratique actuelle de prise d'AF en pédiatrie. Dans cette étude, le *Theoretical Domains Framework* a été appliqué à la prise d'AF et utilisé afin de diriger des entrevues semi-structurées avec des pédiatres, dans le but de décrire leur pratique actuelle. Les pédiatres ont dit avoir des habitudes semblables quant à la prise d'AF. Cette dernière inclut plusieurs maladies et déterminants de la santé, et ils utilisent cette information pour plusieurs tâches. La prise d'AF en pédiatrie a été décrite comme étant complexe et très intégrée à leur pratique entière.

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« Maman, pourquoi est-ce que mon pédiatre me parle autant de choses qui n'ont pas rapport avec la santé? Comme l'école, et mes amis… Des fois je me dis qu'il n'est pas juste médecin, il est psychologue aussi. Il joue plein de rôles en même temps. »

-Laure Tessier, âgée de dix ans

« C'est cette curiosité qui aida à déclencher l'élément déclencheur du changement. »

-Nadia Seccareccia

Vitam impendere vero

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FH: Family history
NCBDDD: National Center on Birth Defects and Developmental Disabilities
ASD: Autism spectrum disorder
TDF: Theoretical Domains Framework
FH-TDF: Theoretical Domains Framework applied to family history taking
TAC: Thesis Advisory Committee

Chapter 1: Introduction

1.1 Family history as a tool in medicine

With the Human Genome Project, the usefulness of FH information as a public health and clinical tool has received renewed attention.[1] Taking a patient's family history (FH) has always been an important element of clinical care.[1] FH is defined as "the description of the genetic relationships and medical history of a family" [2], and is the core tool in clinical genetics. Geneticists and genetic counselors collect and represent FH information in the form of a diagram called a pedigree,[2] the construction of which requires medical information for at least three generations. A full genetic pedigree usually contains, at least, the age or year of birth of each relative, all conditions with which relatives were diagnosed and age at diagnosis, age and cause of death (of those deceased), ethnicity, and pregnancy and consanguinity information.[2] Patients are often encouraged to contact their relatives in order to obtain complete and accurate medical history, and permission is sought by physicians to contact relatives and review their medical charts to confirm reported illnesses.[2] While there is no standard operational definition of "positive family history", having one or more first or second-degree relatives affected with the condition is often considered positive.[3]

As described above, FH information is used to identify patients who may require genetic testing, but it may also have a place in common chronic disease risk assessment (in the absence of a clear genetic etiology).[2,4] Studies have shown that, for many conditions (e.g., colorectal, prostate, breast, lung, and ovarian cancers, stroke, type 2 diabetes, and cardiovascular diseases), the incidence is doubled for individuals with at least one affected first-degree relative (parent, sibling, or child), compared with the general population.[2,5] For most of these, this risk nearly doubles again when at least two first-degree relatives are

affected.[5] In general, risk increases with the closeness of affected relatives (i.e., how much genetic information is shared - first degree relatives share 50% of their genes), with increasing numbers of relatives affected, and with earlier age of disease onset in these relatives.[5]

FH can allow healthcare providers to have an insight of their patient's susceptibility to inherited disorders even if there is no complete understanding of the disease's etiology. FH information can include risk factors that go beyond genetic components of a disease or a condition. It can capture potential environmental causes of diseases, for instance in cases of coronary heart diseases, type 2 diabetes, and many cancers, because family members share environmental and cultural behavioural factors.[6–8] For instance, if a patient's father had lung cancer, it might not be only because of genetic predisposition - it might be because of exposition to second hand smoke in the family. The patient shares this environmental factor with all the relatives living in the same household, and this can be captured with family health history information.

Although FH appears to offer useful risk information in many medical settings, there are no standardised approaches to collecting and using it in settings other than genetic clinics. [2,9] Diagnostic texts currently used in medical education are inconsistent and incomplete regarding medical conditions that should be investigated and approaches for FH taking.[2,9]

FH as a way of improving risk assessment in primary care has been the subject of several recent reviews, examining the kinds of tools which are used, the likely accuracy of the information captured, the impact of using it in disease risk assessment, and also as a way

to personalize risk and encourage patient behaviour change.[1,2,9] In general, these reviews suggest a wide variation in practice and the quality of FH information collected. For example, of five studies reviewed by Rich and colleagues,[2] four concluded that FH information was poorly assessed in primary care. It was observed that, in general, a rather low proportion of family physicians routinely collected FH, the frequency of visits in which family history was discussed varying considerably between physicians. In another example, in a direct observation study of 4,054 patient visits involving 138 community-based physicians,[10] it was noted that FH was discussed in only half of new patient visits. Younger physicians were more inclined to take their patients' FH than older colleagues, the authors suggesting that this might reflect the inclusion of genetic advances in more recent medical education programs.[10]

There are a number of issues relevant to assessing the validity and usefulness of FH assessment in practice, including a scant evidence base on the accuracy of data collection, its quantitative impact on disease risk assessment, whether it is an effective motivator for patient behaviour change, and how often FH information needs to be updated. A recent paper[1] attempted to clarify this research field by identifying the different uses to which FH information could be put, and emphasising the need to account for this in developing, implementing, and evaluating diverse types of FH tools[1]. The authors proposed a framework to guide future research efforts in this area (Table 1).

Table 1: Family history tools development and evaluation framework (Table 1 from Wilson et al., 2012)

Attribute	Purpose				
	FHH medical database	genetic case finding	complex disease risk assessment	health promotion	family systems genogram
Target population	All	Clinical suspicion, patient concern	Large patient groups	All, related to life course?	All?
FHH information	Core data set	Depends on target condition	Simpler?	Sufficient for risk stratification?	Variable
Other information	Available through EHR/PHR?	Generally less important	Other clinical information important	Other health information important	Family, relationships, social, emotional, etc.
Timing of use	Any. Suited to new patient intake, PHE	Responsive to conerns, life stage?	PHE, clinical suspicion, patient concerns	PHE, oppotunistic	Reponse to concerns, life stage?
Need for updating	Yes	Less important	Yes. Linked to PHE?	Less important?	Unclear. Continuing evolution over time?
Linkage with other tools	EHR/PHR, CDSS	Referral/testing guidelines, CDSS	Clinical practice guidelines	Effective behaviour - change interventions	-
Resources required	Valid data capture tools, efficiency important	Valid risk criteria, time efficiency important	Valid risk criteria, time efficiency important	Unclear, related to behaviour change intervention?	Time, training

PHE= Periodic health examination; EHR = electronic health record; PHR= personal health record; CDSS=clinical decision support system(s)

1.2 Family history as a tool in pediatric primary care

The debate about the utility of routine FH assessment has focused largely on adult medicine, and, to a lesser extent, on prenatal health care.[4] A third area to which very little attention has been paid is child health. Primary care physicians who have pediatric patients (family physicians and primary care pediatricians) often see them through adolescence into early adulthood, and most genetic disorders will manifest during that period.[4] These clinicians are thus well positioned to use FH to identify children who might require formal genetics assessment.[9] As well as potentially benefiting the patients themselves, prompt identification of a genetic disorder allows fuller family assessment and intervention if necessary.[9] Even though most families do not have genetic disease risks, the focus on a child's health in the context of a family may offer opportunities for broader health promotion discussions with parents, and motivate parents to explore, and record, their FH more extensively than they would if acting on their own behalf.[9] However, reviews of recommendations on FH collection in pediatric and adolescent medicine textbooks found that the information varied considerably.[4,9]

These reviews suggested that the conditions addressed during FH taking could change depending on the developmental stage of the child.[4,9] As an example, they suggested that during the infant stage the focus of FH information could be on developmental delays, while during adolescence a FH of depression would be of importance. Another review[3] examined the use of FH as a public health strategy for birth defects. Birth defects are considered relevant in FH assessment, because they may indicate an underlying syndromic genetic disorder.[3] A review of the usefulness of FH for detecting children at risk for type 2 diabetes and cardiovascular diseases (CVD), [11] noticed that this might offer the opportunity for early prevention.[11] Although it found evidence that risk factors in high risk groups of children can be modified, it is too early to tell whether this translates to lower disease incidence.[11] However, in light of these findings, the American Diabetes Association, the American Heart Association, and the US National Cholesterol Education Program recommended the use of FH information in pediatric patients to assess risk and make decisions about treatment.[11]

Dolan and Moore's work[8] emphasises the importance of full FH information for children, extending beyond obvious "childhood" disorders. For example, a history of multiple miscarriages or early infant death in the family might indicate the presence of inherited birth defects or chromosomal abnormalities that could have been transmitted to the child. A FH of premature ovarian failure in parental or grandparental generations could be related to genetic diseases such as fragile X syndrome. FH of intellectual disabilities is also relevant to both chromosomal abnormalities and fragile X syndrome. With the help of this FH information, affected children could benefit from earlier diagnosis and treatment.

A 2006 meeting of the Center for Disease Control's National Center on Birth Defects and Developmental Disabilities (NCBDDD) identified conditions that could act as models for the use of FH in pediatrics.[6] Just as in adult patients, the workgroup could not identify any standard on how to collect FH information, or what conditions to investigate. On the basis of expert consensus, they created a list of conditions that should be included in a pediatric FH tool using the following criteria: whether the condition constituted a substantial health burden, whether the condition had a well-defined case definition, a high likelihood of awareness of the disease among relatives, a high likelihood of sufficient accuracy of reporting by family members, available interventions or prevention, and FH being an established risk factor. They identified three single-gene disorders (cystic fibrosis, polycystic kidney disease, and fragile X syndrome) and a number of common complex conditions (birth defects, dyslipidemia, atherosclerosis and coronary heart diseases) as relevant. Pediatric FH assessment for the three last conditions would be especially important since the disease process begins in childhood and adolescence.[6] Children considered at risk could benefit from early prevention, such as healthy lifestyle promotion and, in some cases, medication.[6]

There are many other pediatric disorders for which FH is known or strongly suspected to be a risk factor. For example, children have an increased risk of juvenile osteoarthritis if they have a positive FH, especially if they also have an FH of obesity.[12,13] Some studies also demonstrated a link between autism spectrum disorders (ASD) and FH of autoimmune diseases: children's risk of ASD would be higher if they have a FH of type 1 diabetes and/or maternal history of rheumatoid arthritis.[14] A cohort study also confirmed an elevated ASD risk with maternal history of celiac disease and general FH of ASD, and other studies have shown an increased risk of ASD with a positive FH of various autoimmune

diseases. [14] A cross-sectional study found a significant association between pediatric cases of genetic thrombophilia and FH of thromboembolism.[15] FH of skin cancer is also a significant risk in first-degree relatives, and physicians may place greater emphasis on the use of sunscreen and avoidance of tanning beds in children and adolescent patients with a positive FH as a form of prevention.[16] Positive FH was found to be a risk factor for hypercholesterolemia in children and adolescent patients.[17] Children with a FH of celiac disease are more at risk of developing the disease.[18–21] A study also found that children with celiac disease tend to have a positive FH of various autoimmune diseases.[22] Type 1 diabetes is also a condition for which some FH seem to be a risk factor: a case-control study of children and adolescents aged less than 16 years old has identify FH of type 1 and type 2 diabetes, allergic diseases, celiac disease, and Crohn's disease as risk factors.[23] Parental history of asthma or allergic diseases was found to be a risk factor for asthma in children.[24,25] Several studies have also shown that parental history can indicate how children cope with pain in families affected by either migraines, fibromyalgia, limb pain, or rheumatoid arthritis.[26] Children with parents that report higher ratings of pain are more at risk of reporting high pain ratings themselves.[26] In addition, one study suggests that children whose parents report high pain ratings are more at risk of using catastrophizing to cope with their own pain.[26] Taken together, these results illustrate that FH goes beyond biological aspects of health: while the children's higher pain ratings could be explained by genetic predispositions, they could also be explained by how their parents react to pain.

While there is evidence that FH is a risk factor for many diseases and conditions, whether collecting and using FH leads to better outcomes is still unclear, as there is a lack of evidence on this topic. However, many researchers have suggested using FH for screening

purposes or to identify patients who could benefit from early prevention. For example, Grodzinsky *et al.* suggested that FH could help identify children at risk of celiac disease and could be used to seek diagnosis in the early stages of the disease.[19] In another example, a study about genetic thrombophilia in children suggested that FH could be used to alert physicians as to which patients are at risk and could benefit from biochemical testing.[15] Many emphasised the need of standardizing FH taking, and the need to update the information regularly.[13,16,17,19]

Review articles have identified the potential utility of FH for various conditions in pediatrics, and none have identified any FH taking tools or guidelines.[4,6,8,9,11,27] However, the American Academy of Pediatrics recently developed an electronic pediatric FH tool that aims at 1) supporting the provider in FH risk assessment and genetic evaluation and 2) identifying additional evaluations, preventative services, and personalized management for patients at risk based on FH.[28]

1.3 Family history in pediatric primary care –research issues

As mentioned earlier, in theory primary care physicians working in pediatric settings have the advantage of seeing their patients regularly through well-child visits, especially in the first two years of life, providing multiple opportunities to collect and discuss FH.[4] Also, the 2006 NCBDDD meeting emphasised that placing the FH discussion in the context of family health may make patients and parents more inclined to participate[6] and promote more reliable FH information.[6] On the other hand, it also identified multiple barriers to FH taking, lack of time during well-child visits and lack of training being the most important, a finding which is concordant with studies in adult health care.[6,9] Just as in the adult context, pediatric

primary care physicians may not be able to confidently interpret pedigrees, to determine risk level, or to recognize "red flags" (such as early age of onset or death).[6] They also might not consider assessing FH for common complex conditions if they do not appreciate its applicability to the young patient.[6] While there is no consensus as to how to assess FH risk in adults, clinicians might be even more unsure how to do the assessment in young, presymptomatic patients.[6] The NCBDDD workgroup also identified many potential limitations to the FH information itself, which could affect the use of FH information in pediatric care: information on the patient's relatives can be unobtainable or inaccurate, smaller size and single-parent families may make the pedigrees less informative, many health problems may not have manifested yet in younger parents, and there might be a discrepancy in conditions reported in paternal versus maternal relatives (women tend to be more aware of their FH than men).

Lack of time has been identified in other reviews[6,9] as an important barrier to collecting a complete and up to date FH. It was found that the average visit duration for a pediatrician is 15.2 minutes, and for a family physician it is 17.9 minutes, leaving little time for discussion of issues beyond the primary clinical reason for a visit.[4] Parents who work full-time might not have enough time, support or motivation to obtain medical information from their relatives.[4] Pedigree construction could also be difficult for a parent who has suffered the loss of a child or a miscarriage.[4]

While the published research on FH in pediatric settings appears to make a plausible case for its potential utility in child and family health care, the evidence on current practice and attitudes of primary care professionals in pediatrics is incomplete. In fact, only one empirical study dedicated to the subject in pediatric populations was found.[29] This online

survey of primary care providers associated with the American Academy of Pediatrics' Quality Improvement Innovation Networks aimed at identifying primary care providers' current practices regarding genetic medical care and their choices regarding FH taking with pediatric patients. All respondents stated that taking FH with their pediatric patients was important.[29] Thirty one percent reported gathering a minimum of a three-generation FH for all their patients, and 98% reported that collecting this information was impeded by patients unable to provide accurate or complete information.[29] More than half of the sample of primary care providers (51%) stated they usually ask for FH using general questions about diseases that run in the family and about the health of specific family members.[29] Forty one percent reported using a standardized checklist of diseases to aid in obtaining FH.[29] Most respondents (87%) reported always or most of the time collecting FH during a first visit, but 56% reported always or most of the time updating this information in well-care visits.[29] Many (66%) reported updating the FH when a specific medical problem arose.[29] The investigators noted an appreciable variation between the primary care providers and the content of the FH information they collected.[29]

Despite the lack of evidence, some conclusions may also be drawn from more general studies that included some pediatric-related analyses as a secondary outcome.

The Direct Observation of Primary Care study found in 138 primary care practices in Northeastern Ohio that FH was discussed with approximately half of new pediatric patients (or their parents).[10] This proportion fell to around one fifth for repeat visits of established patients up to the age of 14, and a quarter for patients aged 15 to 44.[10] In a cross-sectional chart review study of 5485 overweight or obese and 744 hypertensive children and adolescents in Northeastern Ohio, Benson and colleagues found that FH of obesity and/or

hypertension was only entered in the chart before the diagnosis in 13% of hypertensive patients with a family history of hypertension, and in 35% of overweight/obese patients with a family history of obesity or a related condition.[7] The authors concluded that pediatric primary care providers did not use FH as a screening tool to assess future risk of obesity and hypertension, rather they usually gathered such information only once the diagnosis had been made, reducing its utility as a screening and prevention strategy. [7]

1.4 Family history taking as a clinical behaviour

The last fifteen years have witnessed a trend towards using psychological theories to understand more deeply how health professional behaviour is driven.[30] There are many psychological theories that may apply, which makes it very challenging for health researchers without expertise in psychology to gain traction on choosing an appropriate framework. In part because of this, the Theoretical Domains Framework (TDF)[31] was developed; it draws together a wide range of theories thought to be related to behaviour change in a way that could be used to inform the design of qualitative studies, surveys, and complex intervention studies. It seeks to be comprehensive about the determinants of behaviour change, rather than requiring investigators to choose a single theory from the outset, and possibly ignoring others that are relevant. This approach seeks to touch on all elements of behaviour, and it may be useful for this project because there is very little knowledge available about FH taking in pediatrics. Using other approaches, such as starting with a preconceived list of barriers and facilitators to FH taking, would run the risk of missing important issues about the behaviour.

1.5 Conclusion

Overall, there is clear evidence that FH is a risk factor for many conditions that can affect pediatric patients. It has been suggested that children and adolescents could benefit in identifying familial disease risks, through referral for specialist genetics assessment where single gene disorders are suspected, or (possibly) through early, enhanced prevention efforts for complex conditions such as cardiovascular disease. More research regarding FH in pediatric care would be useful in informing evidence-based practice. Even though some of the findings in adult care may be applicable to pediatric situations, pediatrics has unique characteristics and needs.[6,9] FH information may increase in importance as the genetic components of disease etiology become better understood.[8] There is no standard of care regarding what conditions should be covered in a FH assessment, while only a few studies of current practices in this area were conducted. They suggest that physicians do not enquire about FH consistently in their new pediatric patients.

1.6 Rationale

Understanding current patterns of practice, and attitudes of practitioners towards the utility of FH would provide a useful foundation for further research in this area, with the intent of promoting evidence-based practice – for example, defining and measuring 'clinical utility' as it relates to pediatric FH taking, designing usable and valid FH tools for pediatric settings, and understanding the most important factors which promote or impede the use of FH information in routine settings.

1.7 Thesis objectives

1. Apply an existing conceptual model, the Theoretical Domains Framework (TDF) to the new clinical context that is FH taking (Chapter 2)
2. Use semi-structured interviews to explore pediatricians' perceptions, attitudes, beliefs, and practices of FH taking (Chapter 3)

Chapter 2: A conceptual framework of family history taking using the Theoretical Domains Framework

2.1 Introduction

The Theoretical Domains Framework (TDF) was originally developed by a multidisciplinary group of psychology and health services researchers[31] and subsequently validated and revised by an independent expert group.[32] The current version of the TDF draws together 94 constructs (component concepts) into 14 theoretical domains (groups of related constructs).[32] To date, the TDF has been applied in research across several healthcare systems, with different healthcare professional groups, addressing a wide range of clinical behaviours.[30,32–39] The TDF was developed to inform interventions. Before its development, researchers were left to choose among a wide range of theories, with little guidance on which ones to choose, and little assurance that the chosen one addressed all factors relevant to a particular context. It seeks to be comprehensive about the determinants of behaviour change; rather than requiring investigators to choose a behaviour theory and possibly ignore other relevant theories. This approach seeks a way to touch on all elements of behaviour. The TDF is useful in our situation even though we will not use it to inform an intervention study: because there is very little knowledge available about FH taking in pediatrics, using it as a tool for behaviour description ensures every aspect that could influence behaviour will be considered. While a standard survey about potential barriers and facilitators would have to be designed based on what little knowledge we currently have and the investigators' preconceived ideas of the sorts of barriers and facilitators exist to FH, a TDF-based approach forces stakeholders to consider all domains, ensuring a complete comprehension of the behaviour under study.

Chapter 2 addresses our first objective: to use the Theoretical Domains Framework (TDF) to develop a conceptual framework of FH taking as a clinical behaviour (FH-TDF).

2.2 Approach

The overall approach comprised consultation with an expert group to assist with the interpretation and initial mapping of domains, and literature review to populate the domains of the 'FH-TDF' with illustrative examples to refine understanding and facilitate its application to later components of the thesis research.

2.2.1 Expert group

With the guidance of my supervisors, I convened an expert group, which became my Thesis Advisory Committee (TAC) with representation from pediatrics, psychology, epidemiology, family medicine, and public health. With guidance from Dr. Jamie Brehaut, co-supervisor, I developed a draft document identifying FH taking as the behaviour, and tentatively identifying examples of the TDF domains relevant to the target behaviour (the draft 'FH-TDF'). This draft document was circulated to the TAC. At a dedicated meeting, the group discussed each domain in detail, clarified the differences and overlaps between domains, and discussed how each might relate to potential barriers and facilitators of FH taking in primary care in general. The clinicians in the group then identified potential differences between FH taking applied in adult and pediatric clinical contexts and proposed further clinical examples.

I took detailed notes of this meeting and used them to redraft the FH-TDF in order to focus it on FH in pediatric settings specifically.

2.2.2 Development and population of the FH-TDF

In order to capture as full a range of examples as possible, I developed a search strategy to locate published literature describing FH taking in primary care and pediatric settings (see Appendix 1). The strategy was based on search terms originally developed for an extensive systematic review on FH taking in primary care[40]. I removed elements of this published strategy that were irrelevant to the current project, and added in search terms specific to pediatrics and child health. I also invited the expert group to identify examples from the literature with which they were familiar.

I reviewed the titles and abstracts generated by the search results, and kept those which did appear to relate in any way to the practice or behaviour of FH taking by health professionals, and/or to FH taking in primary care or pediatric practice. I retrieved the full text of remaining articles and retained those which offered accounts of FH taking apparently mapping to one or more of the domains of the draft FH-TDF. I aimed to identify at least one article mapping to each FH-TDF domain relating (a) to the primary care/family medicine context, and (b) the pediatric context.

After identifying an initial set of examples as described above, I shared the findings with the expert group in an iterative fashion and invited comment and feedback, which I used to develop a final 'populated' version of the FH-TDF.

2.3 The FH-TDF

The initial version of the FH-TDF, as developed by the expert group, is presented in Table 2. It shows the domains of the TDF, and indicates how they map on to FH taking as a clinical behaviour. Of note is that because we will use the FH-TDF in semi-structured interviews, results will look into perceptions by practitioners rather than necessarily 'observable' facts about the behaviour, which is the original intention of the TDF.

The literature search generated 3615 citations, which were reduced to 170 on initial title and abstract review (see flowchart in Figure 1). Of the 170 papers which were reviewed as full text, 31 were considered to report data relevant to considering FH taking as a behaviour. These articles comprised the set from which examples were drawn to illustrate the FH-TDF (in general and pediatric contexts). The FH-TDF will enable us to conceptualize FH taking as a behaviour and will enable us to develop a comprehensive interview scheme.

Figure 1: Flowchart of literature review

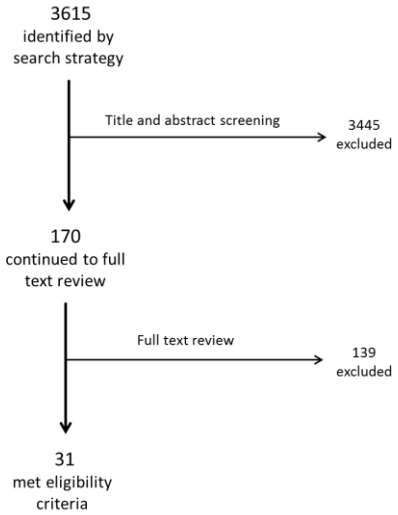

Table 2. TDF domains interpretation to FH taking

DOMAIN AND DEFINITION[32]	APPLICATION TO FAMILY HISTORY TAKING AS A CLINICAL BEHAVIOUR
Knowledge An awareness of the existence of something	Awareness that FH taking is or can be an accepted part of clinical care
Skills An ability or proficiency acquired through practice	Procedural knowledge of FH taking, e.g., • standard ways in which a practitioner takes FH • experience in taking FH built up over a period of time and how FH taking approach has evolved as a result of practice
Social/professional role and identity A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting	Perception of the extent to which FH taking is seen as consistent with professional role, and/or part of professional identity
Beliefs about capabilities Acceptance of the truth, reality, or validity about an ability, talent or facility that a person can put to constructive use	Self-assessed confidence and competence in FH taking
Optimism The confidence that things will happen for the best or that desired goals will be attained	General sense that FH taking can impact patients' health
Beliefs about consequences Acceptance of truth, reality, or validity about outcomes of a behaviour in a given situation	Beliefs about the clinical utility of FH taking, and/or the effects on practice, remuneration, relationships, etc., that might ensue if it is implemented as a routine activity
Reinforcement Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus	Perception of factors that trigger or reinforce taking FH, incentives or disincentives

Table 2 continued

Intentions A conscious decision to perform a behaviour or a resolve to act in a certain way	The extent to which individuals do, or are willing to, engage in FH taking in their practice
Goals Mental representations of outcomes or end states that an individual wants to achieve	Sense of what practitioners want to achieve when it comes to their own FH taking practices
Memory, attention and decision processes The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives	Cognitive factors and processes that make it easier or harder to take FH
Environmental Context and Resources Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour.	Perception of factors in the physical, organizational environment or circumstances that promote or hinder FH taking as a routine practice
Social influences Those interpersonal processes that can cause individuals to change their thoughts, feelings, or behaviours	Perception of pressure or expectations from peers, professional bodies, patients, etc., about FH taking
Emotions A complex reaction pattern, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant matter or event	Emotional responses that are (or could be) elicited by FH taking as a clinical behaviour
Behavioural regulation Anything aimed at managing or changing objectively observed or measured actions	Perception of factors or interventions that would help change FH taking behaviour

2.3.1 Description of FH-TDF domains

Within the 31 articles identified, we were not able to identify examples for all domains – which was somehow expected. Given the little evidence available on FH taking, some domains could not have been covered by previous studies. Where necessary, we offer a hypothetical example to illustrate the domain. FH taking as a practice is not necessarily a discrete 'behaviour', for example it may include the following (non-exhaustive) list of ideas or activities:

- Collecting standardised FH information routinely from every new patient
- Taking a targeted FH in response to 'red flags' in a clinical consultation
- Using a specific FH tool

At this developmental stage of the research, we decided not to narrow the focus onto one specific behaviour in order to conceptualize FH taking in a most comprehensive way. For each domain, several constructs could apply. Based on the team's expertise and the literature search, we chose the constructs that we thought would be the most relevant to FH taking.

Knowledge

This domain is defined as *an awareness of the existence of something*[32]. Knowledge is considered a potential component of behaviour change since it can act as a justification for actions.

Application to FH taking in general

This domain may be thought of as some level of awareness or knowledge of FH taking as a practice, and recognition that it could be applied in the area of clinical care in

question. For example, in a survey of UK nurse practitioners, their knowledge regarding the importance of FH in a range of conditions was assessed as good by the investigators: they knew that FH is a risk factor for breast, ovarian, and colorectal cancer, as well as chronic diseases. However, they were less certain about the role of FH in determining the risk of lung and cervical cancer.[41]

Specific application to the pediatric context

It might be expected through training and experience that with pediatric patients physicians would have a high level of awareness of the relevance of FH information in the identification and diagnosis of congenital and childhood disorders. How far they would consider the relevance of FH taking in relation to susceptibility to adult onset disorders (and by extension, case finding of susceptibility in adult relatives of pediatric patients) is unclear. For instance, in a survey assessing how pediatricians identify overweight in children and evaluate potential complications, most participants reported taking FH of overweight, hypertension, cardiovascular disease.[42] This suggests knowledge of the relevance of FH in managing overweight in children, and awareness of this as a recommended practice.[42]

Skills

This domain is defined as *an ability or proficiency acquired through practice*[32].

Application to FH taking in general

In relation to FH taking, this domain relates to procedural knowledge of the behaviour: the skills and qualities required to adequately take FH, how FH should be

collected, and the role of experience in these skills (how FH taking has evolved in an individuals' practice). If individuals perceive themselves to have the required skills, and/or are very experienced, they might be more likely to engage in FH taking. As an example, a review of 27 articles about the use of comprehensive FH taking for common, multifactorial diseases in primary health care showed that in general, family physicians expressed perceived lack of skills in taking detailed FH.[43]

Specific application to the pediatric context

Because the informants are likely to be adults, it might be expected that professionals might see FH taking for children and adults to require similar skills. Also, physicians who have been training in pediatrics might have been taught to take FH in a different way, and their experience in pediatrics might lead to a different FH taking practice. In a survey of FH taking for hypertrophic cardiomyopathy risk assessment in children, pediatricians who trained in foreign medical schools took more thorough FH than pediatricians who trained in the United States,[44] and were more likely to regularly update it.[44] This variation in practice appears to reflect specific training, which influences FH taking habits in practice.

Social/professional role and identity

This domain is defined as *a coherent set of behaviours and displayed personal qualities of an individual in a social or work setting*[32]: whether or not an individual perceives it to be his or her role to engage in the given behaviour will affect their decision to do so.

Application to FH taking in general

Some clinical professionals might feel that FH taking is an activity which is not 'their job' and 'belongs' to other professional groups (e.g., geneticists); conversely, some may identify FH taking as a central part of a clinical professional identity. Feeling that it is part of their professional role to take FH might increase the probability that they take FH routinely and/or in situations in which it is relevant. A review of 27 articles about the use of comprehensive FH taking for common, multifactorial diseases in primary health care suggested that, in general, family physicians thought it was their role to collect a detailed FH routinely. [43] This domain has been explored in a survey of general practitioners in Scotland about roles and current practice of cancer genetics services: participants identified FH taking as one of their roles.[45]

Specific application to the pediatric context

We found no published studies to illustrate the pediatric context. We anticipate that some pediatricians might identify using FH to assess the risk of childhood genetic conditions as being part of their professional role, but not exploring FH of conditions which are considered typically 'adult', such as cardiovascular disease or cancer.

Beliefs about capabilities

This domain is defined as *acceptance of the truth, reality, or validity about an ability, talent or facility that a person can put to constructive use*.[32] This relates essentially to self-confidence in performing a behaviour.

Application to FH taking in general

This would clearly relate to self-confidence about competence in FH taking. On the face of it, professionals who feel more confident about FH capabilities would be more likely to carry out this behaviour than those who feel less confident. This domain interpretation has been investigated in a survey of nurse practitioners in the UK, where 60% felt confident about collecting the relevant details of breast cancer FH, but they felt less confident in collecting colorectal FH.[41]

Specific application to the pediatric context

We found no published studies to illustrate the pediatric context. We anticipate that pediatricians might feel that the higher prevalence of rare genetic disorders in children make FH more complicated, and hence they might feel less confident in their FH taking capabilities.

Optimism

This domain is defined as *confidence that things will happen for the best or that desired goals will be attained*.[32] In psychological terms, it can be thought of as reflecting a person's general disposition, therefore is distinct from beliefs about abilities or consequences related to the specific behaviour.

Application to FH taking in general, and in a pediatric context

The interpretation of this domain is made difficult because it relates more to an individual's personality or disposition than it does to a specific behaviour. The literature we

identified focused on the behaviour, and hence we could locate no articles of relevance to this domain. By way of example, we suggest a hypothesis, in which the physicians' willingness to comply to new FH taking guidelines or to try a new FH taking tool might be dependent on their level of optimism towards FH, its use in medicine, and FH-related patient outcomes.

Beliefs about Consequences

This is defined as *acceptance of truth, reality, or validity about outcomes of a behaviour in a given situation*.[32] Beliefs about the outcome of a behaviour can relate to good and bad outcomes, and not only health outcomes but anything that might change if the behavior is implemented (e.g., change in work-flow, longer consultations, extra paperwork, etc.). Also relevant to this domain is the relative weighting of the different kinds of outcomes that would be expected to be related to the behaviour.

Application to FH taking in general

In relation to FH taking, this would reflect beliefs about the clinical utility of FH, and also how FH taking could affect practice – e.g., time required, change in treatments or referral patterns, altered relationship with the patient or parents. Taking all of these possible outcomes together, a feeling that FH taking has more advantages than disadvantages might reinforce physicians' collection and use of the information, and vice versa. The studies identified addressed specific outcomes rather than taking a broader perspective on consequences 'as a whole'. A UK focus group study with general practitioners [46] found that participants were positive about their role in relation to FH and could identify clinical

benefits, but were concerned about negative consequences, such as an obligation to disclose their patients' FH to insurance companies, causing difficulties in obtaining insurance. [46]

Specific application to the pediatric context

It is possible that pediatricians might believe that FH taking with children and adolescents might be more likely to reveal rare genetic disorders than with adult patients, thus affecting the balance of positive and negative outcomes. For example, identifying a genetic disorder in a child on the basis of FH might lead not only to effective treatments for the patient, but also lead to useful genetic counselling for the parents about the risk in future pregnancies.

Reinforcement

This domain is defined as *increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus*.[32] Reinforcement is about rewards, incentives, punishment, reinforcement, consequences, and sanctions that influence compliance with a recommended behaviour.[32]

Application to FH taking in general, and in a pediatric context

This domain relates to incentives or disincentives which could be brought to shift the frequency of FH taking, what conditions it covers, and the clinical situations in which it is undertaken. A review describing how FH is practiced in adult primary care found a relationship with reimbursement issues,[2] suggesting that adjusting these might alter FH

taking behaviours. It seems likely that, in general, those factors that appear to prompt FH taking with adult patients might also apply in pediatrics.

Intentions

This domain is defined as *a conscious decision to perform a behaviour or a resolve to act in a certain way*.[32] It can be thought of simply as any intention to change the behaviour under study.[32]

Application to FH taking in general, and in a pediatric context

This would be interpreted as a practitioner's stated intention to engage in or change aspects of FH taking in their practice (irrespective of their actual behaviour), indicating how likely they would be to comply with future guidelines or suggested changes to FH taking in pediatrics.

Goals

This domain is defined as *mental representations of outcomes or end states that an individual wants to achieve*[32]. Goals is defined as specific benchmarks, priority in relation to the behaviour,[32] and encompasses constructs such as planning and target setting.

Application to FH taking in general, and in a pediatric context

This maps to what practitioners want to achieve when it comes to their own FH taking practice. We could find no published studies to illustrate this. A hypothetical example

might involve exploration with practitioners on their 'ideal' FH taking practice, and development of individual plans to help them move towards implementing it.

Memory, Attention and Decision Processes

This domain is defined as *the ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives*.[32] It consists of the cognitive factors that affect individuals' decision making, including memory, attention control, and cognitive overload.

Application to FH taking in general, and in a pediatric context

This domain relates to those cognitive processes which act to promote or hinder FH taking as a behaviour carried out in an effective way, e.g., tendency to forgetfulness, ability to develop FH taking as a consistent habit, resistance to distraction during a consultation, etc. A chart review study involving hypertensive children and adolescents[7] found that the relevant FH was most often recorded in charts after the diagnosis was made, suggesting that the diagnosis in a child was triggering a review of the family's health rather than the other way round.

Environmental Context and Resources

This is defined as *any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour*.[32] This domain is related to aspects of practice

environment that are conducive (or not) to going ahead with a given action, such as sufficient time, access to adequate resources, having the adequate staff in place, etc.

Application to FH taking in general, and in pediatrics

In relation to FH taking, this could relate particularly to the availability of enough time to build FH taking into practice, availability of qualified support staff (e.g., nurses) who could facilitate FH taking, levels of illness/disability of typical patients, etc. Lack of time has been particularly documented as a barrier to FH taking in two reviews.[2,47]

Social Influences

This domain is defined as *those interpersonal processes that can cause individuals to change their thoughts, feelings, or behaviours*.[32] It is about the pressure from any group of individuals (peers, supervisors, patients, etc.) that could influence the decision to carry out, or not carry out, the behaviour.

Application to FH taking in general

In an FH taking context, this domain would relate to whether an individual subjectively felt pressure or expectations by their clinical colleagues, patients, or professional bodies to adopt certain FH taking habits, irrespective of whether they felt them to be useful. A review of 27 articles about the use of comprehensive FH taking for common, multifactorial diseases in primary health care (we assume a mostly adult patient population) showed that in general, family physicians reported that FH taking was a routine activity for

them, but they admitted it was often limited in detail and often done reactive to a patient's request. [43]

Specific application to the pediatric context

Specific published examples could not be located. However, the development of statements by NIH and CDC[5,40] as described in Chapter 1, or endorsement of FH taking by specialty opinion leaders[4,6] might conceivably lead to a sense by some pediatricians that this is becoming an expected practice.

Emotions

This domain is defined as *a complex reaction pattern, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant matter or event*.[32] This domain relates to emotions on the part of the practitioners, patients, or others involved in the behaviour.

Application to FH taking in general

FH taking might elicit emotional responses on the part of patients, for example as they recall the death of a close relative, and perhaps also on the part of the professional. In either case, this might alter FH taking practice if a physician wishes to avoid triggering negative emotions. For example, a study of primary care physicians in Ohio[10] suggested that having another family member present decreased the likelihood that FH would be discussed, [10] because of discomfort felt by physicians in initiating a discussion about FH in the presence of another family member and because of privacy issues.

Specific application to the pediatric context

With pediatric patients, FH is not asked of the patient himself or herself, but of the parents. Parents may feel uncomfortable talking about serious health issues affecting beloved relatives in front of a child. Also, when both parents are present, talking about their respective FH in front of each other might promote discomfort, for example, if there are family 'secrets' on one side, or if the parents are not inclined to share information equally.

Behavioral Regulation

This domain is defined as *anything aimed at managing or changing objectively observed or measured actions*.[32] It relates to factors that would help in changing or maintaining the behaviour.

Application to FH taking in general

In FH taking, this most obviously relates to FH tools and other interventions that are designed to facilitate FH taking as a routine practice. For instance, in a UK focus group study with general practitioners about genetics in primary care, participants expressed they would find guidelines very helpful for assessing which patient should be referred based on FH, but they did not think computer programs would help.[46]

Specific application to the pediatric context

A tool developed to help physicians discuss obesity with parents of preschoolers included a section to help physicians gather FH of obesity and obesity-related illnesses.[48] In a study of

its feasibility and acceptability, a large majority of physicians found this section somewhat or very useful[48].

2.4 Conclusion

We applied an existing framework, the TDF, to a new area: FH taking in primary care (FH-TDF). This application, the FH-TDF, may be useful in application to FH taking in both adult and pediatric primary care. We were able to establish that an agreement can be reached on how to interpret the TDF domains as they applied to the clinical context of FH taking, and that all constructs seemed to be relevant. Nearly all of the constructs seem to have some face validity in terms of being able to imagine how they would apply in the FH taking context. Furthermore, we identified through the literature scan some constructs for which there is already evidence that they come into play in this clinical context. Not finding a literature example for a given domain does not necessarily mean it is not relevant to the behaviour of study: it might indicate this domain and/or construct (the domain interpretation) has not been explored by previous studies. The TDF domains are groupings of constructs. The domain interpretations we developed for the FH-TDF, as well as their corresponding examples, are not clear and complete operationalizations of a given domain, but they are examples of a construct we think is the most applicable to FH taking. The development of the FH-TDF has shown that all domains have some potential applicability to FH taking, and thus it can serve as a starting point to developing an interview guide and collecting data.

FH taking is expected to be relatively similar in both adult and pediatric patient populations, but differences might be observed in some TDF domains due to the particular settings and needs of pediatric patients and practice. The focus of primary care providers

when caring for pediatric patients and their education specific to pediatrics may influence their FH taking, as they may be more likely to concentrate on childhood disorders, and less on adult onset diseases (Knowledge, Skills). Because pediatric visits are most often done with one or both parents present, the social and inter-personal aspect of FH taking might be very different (Emotions).

Chapter 3: Semi-structured interviews with pediatricians

3.1 Introduction

This chapter describes the semi-structured interview study designed to address objective 2: Use semi-structured interviews to explore pediatricians' perceptions, attitudes, beliefs, and practices of FH taking. Briefly, the work reported in Chapter 2 provided the foundation for developing the approach to the interviews; in particular, the FH-TDF provided the starting point for identifying the areas to be explored in the interviews with community pediatricians. Details are provided in the Methods section below. Ethics approval was obtained from the Ottawa Health Science Network Research Ethics Board and the Children's Hospital of Eastern Ontario Research Ethics Board (Appendix 2).

3.2 Methods

3.2.1 Development of the interview scheme

In Chapter 2, we developed the domain interpretations for the FH-TDF. I used this to develop a draft set of corresponding questions which could be used in the interview study. Following this, and concerned that these draft questions appeared very theory- driven but rather artificial, I consulted with the expert group to review and modify them to ensure they reflected clinical reality. The panel suggested that the distinction between the two distinct behaviours "FH taking" and "using FH information" needed to be made, as the preliminary questions tended to conflate them. For clarity, we agreed the focus would be "FH taking" as this more closely reflected the original goal of the project. In addition, logically "FH taking" comes before "using FH information". However, we appreciated that the distinction might be difficult to maintain, and would need to be explored in the analysis, so a few questions about

using FH information were retained. Table 3 presents the final interview scheme with questions that appeared to be both correct from a theoretical point of view and relatable to clinical settings.

Noting that there are no requirements for the TDF domains to be examined in any particular order, I worked with the expert group to assemble questions together in a way that would make sense to clinicians, and to order them as naturally as possible. Since there is so little in the literature about FH taking in this area of practice, we decided to include all the domains to begin, and decide whether some could be given less emphasis as the interviews progressed.

Table 3. Interview scheme questions derived from the FH-TDF

Interview scheme questions	Corresponding TDF domain[1]
• What family history information do you collect? • For what purpose do you collect family history information? • For what conditions do you ask for? • What do you think about the evidence to support using family history information in pediatric practice?	Knowledge
• How did you learn to take a family history? • What skills do you think are needed to take a family history?	Skills
• Who does family history taking in your practice? • Do you think that it is the right person who takes family history in your practice?	Social/Professional Role and Identity
• How confident do you feel about your ability to take family history? • How confident do you feel about your ability to use family history you collect?	Beliefs about Capabilities
• What do you think are the benefits of taking and/or using family history in your practice? • What do you think are the disadvantages of taking and/or using family history in your practice? • Do you think the potential benefits of family history taking and/or the use of family history information outweigh potential harms?	Beliefs about Consequences
• What triggers you to take family history? • Is taking family history something that you normally do when seeing already established patients? • Do you ask for FH when a patient comes in with specific symptoms?	Memory, Attention and Decision Processes
• Do you feel like you have enough resources in your work environment to adequately collect family history?	Environmental Context and Resources
• Do other physicians influence how you go about taking family history?	Social Influences

[1] See Table 2 (p. 24) for domains definitions and interpretations

Table 3 continued

• What about other physicians outside the department/clinic/office? • Do you sometimes sense that family history is important to your patients' parents? (Do they sometimes raise family history with you? How do you respond is FH is a concerned?)	
• In your practice, do you experience any affective or emotional aspects of family history taking? Please explain your answer. • Do your patients' (or parents'/guardians') emotions ever affect your decision to take a family history?	Emotions
• In your practice, are there any incentives to take family history taking? In your practice, are there any disincentives to take family history taking? • What triggers you to take family history?	Reinforcement
• Overall, do you think family history taking can impact your patients' health?	Optimism
• How important is family history information in managing most of your patients?	Goals
• Is it your intention to change your family history taking habits?	Intentions
• If you were to change your family history taking habits, what would need to happen?	Behavioural Regulation

3.2.2 Piloting

A practice interview was conducted with a volunteer pediatrician to test the flow of the interview scheme, after which I slightly modified the wording of a few questions to make them clearer and more precise.

3.2.3 Recruitment

Using a purposive sampling strategy, a list of potential participants was drawn from the community pediatricians affiliated with the University of Ottawa Department of Pediatrics.

Invitations to participate were sent by email (see Appendix 3). The initial contact was established by Dr Pranesh Chakraborty and included a letter of endorsement by Dr Ciáran Duffy, Department Chair (see Appendix 4). The information sheet and consent form were also attached to the initial invitation (see Appendix 5). A follow-up email was sent a week later to non-respondents. To ensure adequate recruitment, a second sample was drawn and invited.

3.2.4 Data collection

I conducted in-person semi-structured interviews at the pediatrician's time and location of choice, which was in most cases their workplace. Interviews were audio-recorded. The general approach was to explore as far as possible to pursue all areas represented in the interview scheme, and to foster discussion of other themes related to FH taking that emerged. As I moved from one interview to the next, I used the constant comparison method to review the data relating to FH-TDF themes, and also to identify those

emerging themes which fell outside that framework. I then attempted to explore those additional emerging themes in subsequent interviews, time permitting. Probing questions were used to verify my interpretation of the respondent's answers. The duration of interviews varied between 30 and 60 minutes. Consent for participation and audio-recording of the interview was obtained beforehand.

3.2.5 Data analysis

Immediately after each interview, I wrote a detailed descriptive account of the interview which included main themes, how the participant responded, reflections on my own input as interviewer, or any other aspect relevant to informing subsequent interviews and possibly relevant to analysis. The report also contained a short summary of the interview and a memo containing my various thoughts as the interviewer.

I transcribed interviews within 24 hours. Each transcript was available both to my primary supervisor, Dr Brenda Wilson, and me. She reviewed the first three transcripts and offered suggestions relevant to subsequent interviews, for example the kinds of phrases that could be used to probe, and how to encourage further discussion when a participant offered very brief or closed responses. The interview scheme was slightly modified to include questions about emerging themes that I identified along the way.

For the full qualitative data analysis, Dr Wilson and I reviewed each transcript separately. We based our approach on the FH-TDF. I developed a coding scheme, with several codes created for each TDF domain in addition to emerging themes I identified while conducting the interviews (see Appendix 6 for an example of a qualitative analysis table). Codes were created both before and during analysis. Dr Wilson conducted a simpler content

analysis in which she mapped text to the domains of the FH-TDF, and highlighted statements which did not fit directly but which appeared to her to relate to the research question.

We each mapped respondents' accounts of FH taking in pediatrics to each FH-TDF domain, and identified other emerging themes from the data. We then compared their results, discussed similarities and differences, and reached a consensus where interpretations appeared to differ or were unclear.

3.3 Results

3.3.1 Demographics

I contacted 71 pediatricians to invite them to participate in the study, and 11 accepted and consented to participate. Of these, four were male and seven were female, and all worked in Ottawa, Ontario or Gatineau, Quebec. One worked exclusively in a hospital, five did some hospital work in addition to their community practice, and five were entirely community-based. Five reported primary care as their only role, the remainder also doing some consults. There was a wide range of experience: from two to 46 years of practice. Ten interviews were conducted in English, and one in French.

The interviews were analysed using pre-determined codes referring to the FH-TDF, and codes from emerging themes. Once the analysis was done, both Dr Wilson and I independently reached a similar conclusion, that the emerging themes (not FH-TDF-associated) gave an account of FH taking as a practice that called into question the initial approach of 'isolating' FH taking as a discrete clinical behaviour. After fully reviewing the data, we concluded this was evident across all interviews and pointed to the need to reconsider the emergent themes as representing a more meaningful, and perhaps helpful,

approach to the topic. Over several sessions, we discussed the findings and agreed on a new set of categories which described the participants' accounts of FH taking in pediatric practice:

- Description of current FH taking practice
- "Embeddedness" of FH taking in personal practice
- Holistic nature of FH taking
- FH taking serving a range of purposes
- Evolution of FH taking skills and confidence in their application
- Perceptions of evidence and new tools
- The broader context of pediatric consultations

3.3.2 Description of current family history taking practice

The interviews revealed generally similar patterns of FH taking practice. The simplest approach reported related to the 'consult', i.e., when a pediatrician receives a patient referral from another health professional. In this situation, the interviews were consistent in describing a focused approach, in which participants would take a FH specifically (somewhat narrowly) relevant to the reason for referral.

Quote 1:

It will depend on what the clinical condition is the child presenting with, and what the setting is. …Well again it depends. If the child is presenting with seizures I am going to make sure I ask more about seizures in the family, developmental disorders, those sorts of things. If the child is presenting with a cardiac problem I am going to make sure that I ask about sudden death, rhythm disturbances or congenital heart

disease. So my FH will be definitely targeted to the problem that the child is presenting with. – participant 15

Quote 2:

So FH, hum... It really depends on the patient. So if it's a patient that I am initially seeing, for instance in a consult I will take FH depending on what the issue is. So if I get a consult for concerns about immune deficiency, then I ask for an extensive FH targeting for what they're presentation is. … This is what I usually ask, but yeah, it really depends on the presentation. – participant 21

In contrast, in their primary care role, participants' accounts indicated a common goal related to the first visit by a patient – to capture broad based FH information from parents or guardians - using a range of methods or tools. Three general approaches were described. The first was asking parents to complete a structured questionnaire in advance, which the respondent would then use to identify areas to be explored with further questions during the actual consultation. The second approach was the respondent having a checklist in front of himself or herself which would be worked through systematically as part of the consultation, with further probing to clarify or expand the information. The final approach, which seemed to be the dominant practice, was simply to ask parents in an open-ended way – either whether there was anything 'running in the family' or whether the family was healthy.

In terms of the extent of information gathered, the universal practice appeared to be enquiring at least about the child's parents, siblings, and grandparents. In some cases, the standard practice extended to routinely ask about the child's cousins, aunts and uncles.

After the first visit, for subsequent consultations, the most common practice appeared to be to follow a looser approach to enquiring of parents whether there was ‘anything new’ rather than repeated systematic enquiry.

Each participant was able to describe his or her own particular, specific, routine style of questioning – universally reported as combining open and closed questions – and of having a way of navigating through FH information gathering to their own satisfaction for each child.

Quotes 3, 4 and 5 illustrate typical approaches reported by participants.

Quote 3:

Starting with the parents and starting with physical issues, any physical medicine issues, and branching out from there to mental health concerns. And then, moving away from the parents, their siblings, their parents, and the extended family. In particular a question which provides an indicator whether we need to explore this any further is: are there conditions that are shared by two or more people in the family? - participant 2

Quote 4:

No, I don’t have a specific questionnaire, but in my chart I have a little paragraph that says FH. It’s one of the three paragraphs I follow. The child’s medical history, FH, and then I start my story, my problem. – participant 9

Quote 5:

When someone comes in as a new patient we collect issues of... we have a standard form that goes on the chart. ... It asks basic information. Asthma issues, GI issues, allergies issues.... It asks about seizures, eczema, deafness, blindness, tuberculosis, cystic fibrosis, cerebral palsy. From there we will ask any other health concerns that would be important for us to be aware of. Specifically when parents are new to the practice I will ask each parent their age, ask if they're married or common law, do they have other children... that aspect. That tends to be where we start from a more general point of view. Then if I am seeing them for a specific problem, then my FH will often be more geared towards the issues that might be a problem. - participant 6

A frequent observation was that FH taking appeared not to be narrowly targeted to ascertaining specific conditions diagnosed in family members, rather respondents reported enquiring about (presumably undiagnosed) symptoms, and about parents' perceptions of the consequences or impact of a condition diagnosed in a relative. The reasoning offered was that sometimes relevant conditions go undiagnosed, or the parents reporting the FH simply do not know their relative's diagnosis. It would also give insight into the parents' experiences or perceptions about what life is like with a given condition.

Quote 6:

Kind of like if I am still trying to kind of what is the diagnosis for this patient I might go back a little bit. … People don't always know if there's somebody who had neurofibromatosis... So you can ask questions like deafness or

cardiac issues, because they may not know the association when you ask those things. … You know it's like the questions about sudden deaths. You don't just ask if anybody has died. You asked if anybody drowned for unexplained reasons, or has been in a single car accident. You have to ask the questions about how would sudden death, or cardiac death present. – participant 8

Quote 7:

Exactly because they have never been diagnosed, but it's not normal in a family to have two of them with a splenectomy – the spleen was removed – and 3 of them to have gallstones at a young age. – participant 1

Quote 8:

And sometimes you have to be careful to ask what the diagnosis was but also what the impact was and what the treatment was. Because people might not have the diagnosis, so they just think "oh yeah, they just had irritable bowel syndrome", but they needed surgery four times... You kind of need to tease out what they mean. – participant 6

3.3.3 "Embeddedness" of family history taking in personal practice

As reported by participants, FH taking appeared to be a part of everyday practice, hard to isolate from other routine behaviours, and they could not imagine practising without it. They indicated FH as an aspect of medical information always on the back of their mind, as opposed to, for example, a check list of blood tests could be set aside once the results had

all come back as negative. They reported that if they knew a child had a positive FH for a given condition, they would keep an eye open for particular kinds of symptoms, and knowing this would affect every aspect of patient management. If they were not aware of any FH, they knew they could re-visit it at any time with the parents. Overall, FH taking appeared to be an ongoing process for which pediatricians had to pay constant attention.

In the interviews, participants often slipped into talking about non-FH information almost unconsciously. Several illustrated their thoughts with examples or anecdotes which could paint a picture of a part of practice that was woven into their medical culture, hard to isolate, articulate, or explicitly justify.

Quote 9:

So I think using the FH just gets incorporated with everything else. It's not one aspect all the time. And I don't take the FH and forget everything else and plug it in an algorithm and say: ok, we now do this. I process it in a way that it becomes one element of significant information that I get from the interview and I will weight it accordingly. But I don't have a decision-making tool that says to do this. That's how I do it: I process the information quickly, and we move on and it's stored in your brain. … FH is like using a pen, or a stethoscope. ... And considering it's also been so entrenched in the way we practice. I mean that is the single most identifiable icon of the physician, besides the white coat maybe. - participant 36

In all interviews, participants used language which suggested they valued FH taking very highly, as very important in their practice and something that helped them manage their patients. A common sentiment was not being able to imagine practising without FH.

Quote 10:

You will not be able to practice medicine correctly if you don't take this. Without FH you will be groping in the dark. - participant 16

Quote 11:

And the source of understanding of my patients' issues is so dependent on FH that it's even hard to articulate how I could hope to have a grasp of what's going on with my patient if I don't understand the context in which they are growing. And you know sometimes I have kids in care, or kids that have been adopted at birth, or taken into the care of the CAS at birth and there's very limited FH available. And it's very different trying to work in that environment. It makes it much clearer how huge a contribution FH makes to my understanding of the patient, when I have to work without it. - participant 2

Quote 12:

I don't think you can practice medicine in a primary care setting or in a consulting setting without asking FH. I just don't think you are... doing your job. - participant 6

It was universally reported that it was important for the physician himself or herself (rather than, for instance, a nurse) to personally take the FH, because they would be the ones processing the information. A picture of an iterative process between FH information gathering and processing emerged: as soon as a piece of information is obtained, it would be 'processed' right away, with the next question determined by the answer to the previous one. Some participants suggested that taking the FH themselves enabled them to better remember the information, and ensured that it is gathered in a comprehensive and complete way.

Quote 13:

I guess it has to be a physician, because we are not machines. Because according to the answer they tell you… So you start with open questions. But as a physician, it's up to you to decide what are the specific questions that you need to ask. - participant 1

Quote 14:

I worked in a clinic where a nurse would often take the history of the presenting illness and any sort of background information and such. That can be done as a clear cut screen but I find that the more detached it becomes, the less you get a feel for things. (...) I think it's often best that the physician gets himself or herself a feel for the FH. You get a good sense. And in my case, I know I certainly retain it better. When I see a patient next time, I have a better sense of the FH because I took it myself. Yeah. So by the mere fact of having your own inputting of this information through different senses, so not just

visually but also auditorily, non-verbally also it gets stored a lot more efficiently. - participant 28

3.3.4 Holistic nature of family history taking

In all interviews, participants appeared to indicate that 'FH information' included questions about psycho-social aspects of the child's life and family, which appeared to be very important for the quality of care they would offer their patients. A prominent observation was the difficulty in separating social and medical FH in practice, and for several, this actually seemed to be the most important aspect of FH information.

Quote 15:

So that's where I lump in FH and social history together. Because I think that in pediatric practice it's sometimes hard to differentiate between the two. - participant 36

Quote 16:

You know, I do not divide physical ailments from financial ailments from psychological ailments. Because they are all… the common word is ailment. They're all suffering. Because they're all suffering, my job is to alleviate that suffering. So whether I approach this cup from here, or here, or here... my job is to get that coffee out from there. And if this child comes to me with this thing, I have to make sure all that these things are covered. And if they're not, it's going to be leaking from somewhere, it's going to be a problem. - participant 16

In this context, ‘social FH’ appeared to include the education and occupation of the parents, how many siblings the child had, who was living at home, who was the caregiver, who fed the child, any housing or financial concerns, problems with the law, difficulties with relationships, and ease or difficulty of access to healthcare and other services.

Quote 17:

And the content of the FH would typically start with more generic data, like where are people [parents] *at in their lives – are they working, are they not working? What do they do, what’s their educational background? Often it’s relevant: whether they had difficulties in school, or interrupting school history. If they are employed, how did they go, where they are employed now? And then we talk about medical history.* - participant 2

3.3.5 Family history taking serves a range of purposes

It was impossible in the interviews to separate the ‘behaviour’ of FH taking from how the FH information was used in practice. Under this theme, we report how participants related the way in which they used FH information (holistically defined, as above) in their clinical practice. We separate the findings into several broad sub-themes.

FH information as a guide to diagnosis

Perhaps the most commonly reported use of FH information by participants was providing insight which guided their medical investigation strategy towards a suspected diagnosis, or at least to get a sense of what the child appeared to be most at risk, whether

from hereditary or environmental factors. FH information might affect the diagnostic process by changing the participant's threshold for ordering specific tests or investigations.

Quote 18:

So the FH can help on an epidemiological basis to say… You always think that common things are more common but if you have a context of a particular FH it is definitely going to alter how you view the possibilities for that child. - participant 15

Quote 19:

Because the mother had a thyroid condition, it changed the direction and tone of the conversation. (...)So it didn't change anything yesterday [first visit]*, but it set up a different dynamic for the second visit. We'll have a much different threshold for ordering investigation to rule out thyroid problems in this young girl next time, because of that FH.* - participant 36

Quote 20:

It helps guide. Especially in my practice, it definitely helps guide the diagnosis. It helps to inform on the social factors that influence, the social determinants of health. (...) So it definitely guides my diagnosis. If I say, and especially with ADHD, I am so reluctant, it is so overdiagnosed. And underdiagnosed too, but so overly diagnosed that unless I see a FH that is strongly of ADHD I am very reluctant. - participant 28

FH information in selecting medications

In some interviews, participants indicated that FH information helped them choose the medication for their patient – predicting which medication they thought would work best for the patient. This was most evident in the examples provided in behavioural and mental health situations, such as children affected by attention deficit and hyperactivity disorder (ADHD) or depression. The reasoning was offered that, if relatives had apparently responded well to a certain medication, then they would be likely to prescribe the same one for the child, in the first instance.

Quote 21:

FH for mental health can be very important when you are guiding a child towards starting medication. You want to know if there is a history in the family of somebody who did really well with that medication, or someone in the family who did really badly, for certain medication. ... Because, you know, certain things like ADHD... we got 6 or 7 options in front of us. And FH may be a significant impact on what we might choose as our starting medication. Because we know medication response is inheritable." - participant 6

FH information for tailoring overall management approaches

A prominent theme was the importance of FH (considered holistically) in gaining insight into the family situation, parental reactions, parental capacity, etc in order to tailor overall management choices and approaches. Respondents emphasised the importance of

knowing the environment in which the child was developing. A repeated comment related to understanding whether the child's environment allows for proper delivery of a treatment. For instance, parents with a low reading level might not understand how to give their children some medication because they cannot read properly the information on the bottles and labels.

Quote 22:

So for instance the other day I had an example of mental health. So I see a lot of kids with ADHD, depression, anxiety... So there is a FH component to that too as well. In terms of counselling and prevention... So I had a mom that came in the other day, she was worried. Her child was about 4 and she was concerned that he was depressed, amorphous, low mood, had problems with self-esteem. Her bringing that up, it helps me counselling her in terms of what to do, helping making sure he is in a proper environment at home and in school, to help with self-confidence and esteem. - participant 21

Quote 23:

Because, again, if a family member has a chronic illness, I think that impacts the dynamic and the ability to care for that child appropriately and seek out care appropriately ... And it's not just the FH that's relevant to the patient's particular concern. If the mom has a thyroid disease, could it also affect the child, yes. But if the mom has another chronic illness, it's going to affect the child's ability to be healthy if the mom cannot care for this child. So indirectly, there's a psycho-social component to the FH. - participant 36

Quote 24:

And it helps me to identify the vulnerabilities in terms of social support that my patient may have. So if there's a heavy FH, for example, of anxiety, parental anxiety, I know my patient doesn't have the same type of support as opposed to somebody not anxious. If there is a parental history of ADHD, a lot of challenges will come with that. So totally, totally, it's totally informative. - participant 28

Support for parents

Participants commonly communicated the idea that promoting the best treatment for their patient – the child – had to be seen to include meeting parents' emotional needs. It was suggested that FH sometimes offered insight into why parents might sometimes react unexpectedly to certain symptoms or complaints.

Quote 25:

In the sense that, you know, if they've had something close to them being very, very significant, sad, or complex or whatever... If I am not aware of that, it may make it difficult for me to understand why they are responding to a certain situation in a certain way. If they come in and I think their responses is a little bit out of keeping to the complaint... You know, if they come in and the child's got a spot. And I don't think it looks like anything serious, but the parent looks quite upset about it. I'll ask is there a reason within a family, or

something like that, that this would be more concerning to you. You know, you've had three people recently diagnosed with cancer, you've had two people die of skin cancer... That parent may respond to a funny looking spot differently than another parent that comes in without that. - participant 6

Building relationships

The process of taking a FH, especially exploring social aspects, was reported by many participants as something that enabled them to build a relationship with the parents. They indicated that they felt that, not only did this facilitate provision of appropriate care, but also that it helped make the parents feel more comfortable.

Quote 26:

Yeah, it's also an opportunity to get to know the family better. Until that point I may not have asked about siblings. Then I get to know how many siblings there are... And for me it sort of flows into social history. - participant 8

3.3.6 Evolution of family history taking skills and confidence in their application

Evolution of FH taking skills

Section 3.3.1 provides a description of how pediatricians, as represented by the participants in this study, appeared to have well-developed routines for taking FH in their day to day practice. When discussing how they developed their skills in the first place, we

noted variation in reports of how exactly they were taught to do this, with some respondents being unable to recall exactly how or whether they received formal instruction.

The most common observation was of remembering being taught how to take a FH at some point during their medical training. In general, they seem to recall being taught generally what to ask about, and sometimes specifically how to ask FH questions. In their pediatric training, the focus was mainly on topics relevant to child development such as heart, kidney and developmental issues, and consanguinity. Participants talked about this in a very basic and general way, and gave the impression that learning to take a FH was spread across various topics and occasions rather than specific lessons on FH.

Quote 27:

They were five major things: surgery, medicine, ophthalmology, preventative medicine, and ob-gyn. And each one of them had a course in history taking. - participant 16

Quote 28:

I think that each subspecialty rotation in pediatrics contributes its own templates of questions for common conditions, so that we should know, you know... - participant 2

The interviews gave a clear sense that experience seemed to have a bigger impact on their FH taking approaches and habits than their formal training, with most apparently developing their own FH taking method by observing others and honing it as they gained

experience. What did not come across in the interviews was any clear description of how they came to add in the larger set of conditions that most appear to enquire about.

Quote 29:

Of course we learn with experience, on the ground. - participant 9

Quote 30:

It probably didn't become relevant until later on, when we started putting two and two together and we started having clinical experience, to recognize where FH is important. - participant 36

Respondents are confident in their FH taking skills

Universally, participants indicated very clearly that they felt confident taking FH and using it in their practice. While the interviews as a whole contained a strand in which participants reflected on the possibility of room for improvement, this was not expressed in terms that indicated lack of confidence.

Quote 31:

Again it will probably depend on the specific disorder in terms of knowing what the importance is for the hereditary factors. But I feel pretty comfortable with that, with using the information and applying it to my interpretation of the child in front of me. - participant 15

Perceptions of evidence and new tools

In general, the interviews suggested that respondents did not concern themselves about the evidence surrounding FH taking and use in medicine. This went as far, in some cases, as statements that they didn't really need evidence, or that, if anyone were to start looking into the evidence around the use of FH, it would definitely become clear that it was essential to pediatric practice.

Quote 32:

Because I don't think it was ever discussed that "here's the evidence". When I was studying in medicine, the concept of evidence-based medicine was still in its infancy, I think. In terms of being applied to how we teach medical students... basic history taking. It was just done by... Here's a generational teaching tool, here's how your predecessors did it, here's why we think it's important. And it was probably based on some studies, but that evidence was never presented to us. I don't think it was ever clear, to me, that we were given the background and the evidence for why we need to do it. It just seemed intuitive to most of us that in order to know... … So it was very intuitive and it wasn't hard to make that leap. Nowadays the first question out of our mouth is: well what is the evidence? That was never the case back then. For most of us, when I was studying, it wasn't even an issue. So I don't even know what the evidence is. – participant 36

Quote 33:

I think the proof of the pudding is in the eating. … So to me, every time I see a new patient and I meet the family, it reinforces that to me. So that is good clinical evidence. Now, if you guys want to test it, I think you need to look at about… so many different charts or something, chart reviews, and see what the problem was, what the FH was and how it related to the diagnosis. And what contribution it made, if you can quantify that. Then you'll go into find that it becomes useful. – participant 4

The interviews explored whether participants might anticipate changing their FH taking habits. When asked directly about what would need to happen for them to change their practice, many participants indicated that it would take 'a good reason' or compelling evidence would make them revisit their FH taking habits. Overall, the impression was given that participants reported would make their own judgements about whether tools or guidelines would be useful in their own practice.

Quote 34:

But I think the evidence would have to be very, very, very compelling if I was going to change my practice. Now, after practising for a number of years, I see the value of it, more than ever. I can't see me changing the way I practice. I may evolve it, but I'm not going to stop taking it. (...) Oh, I would definitely consider them [guidelines]. *But unless it's really going to change my practice, I don't know that... I don't know right now...* – participant 36

Quote 35:

Well it depends on the guideline. I mean, if it's helpful I would use them. I think it'd be good for the initial assessment, so when I see a patient first. If there are guidelines in terms of checkmarks I think that is something that easily we could do. And when I come in to see the patient I can kind of tie it in together. - participant 21

Quote 36:

There must be a reason to want to change first. - participant 4

3.3.7 The broader context of pediatric consultations

Uncertainty around the accuracy of FH information collected

Despite communicating confidence in collecting and using FH information, it was evident in a number of interviews that participants also had reservations about the accuracy of information they collected from parents. It was reported that, in their experience, parents were not always sure about relatives' illnesses – parents might suggest, for instance, that they know something wasn't quite right, but they didn't know the specific diagnosis. They reported that parents might not remember things really well, or sometimes could simply not be expected to know about all relatives' medical conditions. Sometimes, it appeared, parents could not be definite about their own medical history.

Quote 37:

There are times where I am confident in what the family is telling me and there are times where what they are telling you is so vague and obscure that

it's hard to make a conclusion based on it. ... Most are fairly open but some may just not know. They may just say "well so and so just wasn't so bright and didn't do so well in school, but I don't really know what was wrong". - participant 6

Quote 38:

A patient was telling me about his sensitivities to different antibiotics, or like an allergy. He had a reaction, whether he had a type 1 hypersensitive reaction or he had an actual allergic reaction. So the parent tells me: oh I am allergic to penicillin, when I was a kid. And I ask him what the reaction was, and you know, they don't know. Depending on what the reaction is, it's an indication that could affect the treatment of the child. For instance if the child is coming in with… I don't know, a resistant organism or a suspected allergy to an antibiotic that is considered first line, the best treatment, then it makes it difficult to treat the child when it's not confirmed in the parents, in terms of like an increased suspicion. When the parent says they have an allergy, what does that mean? Is it a delayed hypersensitivity reaction? - participant 21

Deliberate omission of information

In some interviews, respondents indicated that they clearly understood that a parent was not disclosing FH information. It was explained that it was understood by them (respondents) that there were situations where they appreciated that one parent would not want to reveal some information in front of the other parent. In this context, they indicated that it was important for them to understand what was perhaps not being said and why, and

finding other ways of eliciting the information in a sensitive and appropriate way. One example offered was that a parent might have a child from a previous marriage, never mentioned to the current partner. A central issue is the appreciation that the child's FH includes the parents' personal medical history; the pediatrician, as a physician, has ethical obligations to the child as his or her physician, but also cannot ignore the parents in terms of their individual privacy.

Quote 39:

You know, if there's situations for example where I know that mom has a [history] *of genital warts, you know, but she's with a new partner, I'm not going to raise that in the context of both parents being present because I don't know what they've discussed. So I think you have to be very careful about one person's confidential health information even in the context of multiple caregivers for the child. Even asking about things like HIV or hepatitis, I mean there are lots of sensitive issues I think you just have to be careful and you have to know that sometimes if you ask those FH questions with both parents there, one may absolutely not choose to give you that information, and there's nothing you can do about that.* - participant 15

Distinct from this was the appreciation that parents might not want to mention some details of FH in front of the child, because it would be sensitive or disturbing. For example, it was suggested that sometimes a child is too young to understand or they might be unaware of illness in a beloved relative.

Quote 40:

Sometimes it's important, especially in pediatrics, it's important to get a scope of what the family have made the children aware of, how they have possibly introduced ideas to the kids. Especially around mental health, or cancer - stuff like that - maybe the kids just aren't aware grandma's sick. Or they don't know what the issue is. So just being a bit sensitive to that. So understanding parents aren't always comfortable with kids knowing everything. Although I do think it's important for kids to know most stuff. ... I do try to tell parents not to lie at the kids about FH. I think it is important that they have some knowledge. But it doesn't mean they need to know every detail. But I wouldn't lie to them. Maybe just letting them know what they need to know at that time." - participant 6

Cultural background can affect FH taking

A factor that many participants raised about FH taking in pediatrics was the cultural background of the patient and family. This is not specific to pediatrics. One issue raised was that even the definition of 'family' might vary according to culture.

Quote 41:

And the other thing, of course, because I grew up in [country] *and... The definition of a family is not a nuclear family there. The definition is: everybody... It's funny: everybody here says people living under one roof is a*

family. There the definition is a family is - that is true, that everybody who lives together is there - but everybody who eats out of the same stovetop. – participant 16

Another observation was that family dynamics could be different across cultures, leading to a pediatrician to ask different questions, or ask questions in a different way, and to have to tease out the information differently.

Quote 42:

Grandparents pay huge roles in aboriginal children's lives. In Inuit populations they do a lot of custom adoptions. So you always have to ask when you see a patient: are you the baby's birth mother? Because probably a third of the time they are going to say no. …. So the history taking is actually usually a little more complicated, in terms of the social structure. … So I find history taking just takes longer. They tend to have more kids, they tend to have them earlier, they tend to have more complex social structures sometimes than, you know… Kids may spend more time with grandparents, half time with the parents – half time with grandparents. … We know there are major issues with things like diabetes, hypertension and obesity, and poor nutrition… So taking detailed FH around those conditions takes maybe a bit more time. – participant 15

Finally, it was indicated that interpretation of diagnoses or symptoms might also be dependent on culture. For some parents, certain diseases might not be recognized in their

culture so they don't even think about mentioning them; symptoms might be considered part of everyday life and not considered problematic or needing reporting.

Quote 43:

I had a [particular nationality] *dad who was a highly successful professor, a Ph. D. in sciences, whose son definitely had a diagnosis of ADHD. That dad looking back also had a diagnosis of ADHD. But it was not as obvious. And I'm sure if I had asked his relatives they would not have though he had ADHD, but he had unstructured time, he could eat whenever he wanted to in* [country], *he played soccer whenever he wanted to. … So I'm sure if I had asked this family's relative, they wouldn't have thought he had any difficulties, because look at this man! He has a Ph.D.! He's teaching now in a high institution in a different country. They don't understand that there are other factors that are protective, or even very positive factors that will help overcome that distractibility and so on. Then they make presumptions and that affects how they answer to a FH. So again, the ethno-cultural background definitely plays a role.* - participant 28

3.4 Overview

With the help of the FH-TDF as a starting point, this qualitative study provided a lengthy description of FH taking in pediatrics in a Canadian sample.

The semi-structured interviews with 11 pediatricians showed that FH taking in pediatrics is a complex aspect of practice that can be assessed using a TDF-based framework.

At the end of each interview, pediatricians were asked if there was any aspect of FH taking we haven't talked about, and only a few had additional comments, which reinforces the view that the FH-TDF usefully covered most aspects of FH taking in pediatrics and was a good framework to use to begin to explore this practise.

However, during the analysis process, we realized it was easier to describe and appreciate all the aspects of FH taking when it was not isolated as discrete clinical behaviour. The FH-TDF approach was set aside and we re-framed the overall analysis using a more grounded approach to FH taking as part of pediatric practice.

Pediatricians in this study reported similar patterns of FH taking: for consults, FH taking was targeted to the complaint, and for primary care, they would capture broad basic information of the family's health. Three approaches were reported for the latter, the most popular being asking of the family was healthy or if there is any disease running in the family. For subsequent visits, most reported updating FH by asking of there was anything new. Pediatricians reported to use FH information for a wide range of purposes: to orient diagnosis, to select medications, to tailor the overall management of their patients, to provide psychosocial support for parents, and to build relationships.

FH taking also appeared to be embedded in the pediatric practice. FH was something that was reported to always be on the back of the pediatricians' minds. The way they illustrated their thoughts showed how much FH taking is woven into their specialty culture. FH was reported to be very important in pediatric practice: it was valued very highly, and it was said to be very important in managing their patients. The collection and usage/processing of FH information was reported to be an iterative process.

How pediatricians reported being taught to take FH varied, but overall, it seemed to have been done in a general way. Experience was said to have more impact on their practice than formal training. Universally, pediatricians felt confident in their FH taking and FH using skills. Most reported not being concerned about the evidence surrounding FH in medicine. Most also said they would be inclined to use new FH taking tools or guidelines, but overall, they would need a "good reason" or evidence to change their FH taking practice.

The context of pediatric consultations is such that pediatricians reported some challenges in obtaining accurate FH information: parents not being sure about their relatives' illnesses, parents who do not remember well their FH, parents omitting deliberately some information, and cultural background that could affect the definition of family, family dynamics, and interpretation of diagnoses and symptoms.

This interview study painted a picture of FH in pediatric practice which was quite different from what was anticipated at the onset. The FH-TDF was useful in that developing it in the first place required considerable thinking about FH as a behaviour, and it provided a comprehensive way of developing a set of questions. However, to understand FH taking from the perspective of pediatricians, it was necessary to step outside the framework completely and interpret the data in a more grounded way.

Chapter 4: Discussion

In relation to FH information in general, in some areas we are witnessing the "technological imperative" at work: particularly in the US, FH tools and systems are being embedded within developing electronic medical records systems without clear evidence of the benefits, costs, or implications.[1] This seems like the opposite of an evidence-based approach, but it means that FH systems will become increasingly available to all health practitioners, including those in pediatric practice. While there is no evidence surrounding the use of FH, both in general and specifically in pediatrics, there has been recommendations to use FH in primary care.[6,49]

This study was designed to explore FH taking in pediatric practice in order to understand factors influencing the implementation of future evidence-based guidelines and/or tools. Understanding pediatricians' current practice, particularly their attitudes towards FH taking as a practice, and their evaluation of the utility of FH information, will help inform the evidence-based use of FH information in this specialty in the future. Given the lack of published evidence about FH taking in medicine, especially in pediatrics, we chose a qualitative approach to this project. Originally considering quantitative designs, such as a survey, we realised that we need to understand more about the practitioners' perspectives before confirming the objectives of a survey or selecting appropriate areas of enquiry or specific items.

As a starting point, we sought to develop a framework to guide our approach to the qualitative study. Although we were not anticipating an intervention study, we were aware of the evidence that studies which use a theoretical framework appear to promote a broader and

deeper understanding of clinical practice than those which are completely atheoretical.[32] It has been argued that interventions developed without theory are less likely to be generalizable when successful, and provide little information about what went wrong when they are not successful.[30] This general philosophy led us to seek out a framework which might be applicable.

We noted current interest in the Theoretical Domains Framework (TDF) in implementation research.[30,32–39] Since its development, the TDF has been used to assess different behavioural problems in multiple healthcare professional groups, and it appeared to have value in identifying elements of behaviours to be targeted in implementation interventions.[30,32–39] Although our study was more exploratory, it still revolved around a set of behaviours, and we realised that the TDF might be useful as a way to organize our data collection and initial analysis and were attracted to its theoretical coverage and comprehensive approach.[50] We noted that studies suggest that qualitative studies using the TDF appear to elicit a greater number of beliefs than studies not based on any theory,[50] and that barriers and facilitators to a behaviour may be identified that would not otherwise be mentioned. [36] Gathering together 33 behavioral theories, it covers the full range of current scientific explanations of human behaviour.[33] We judged that this would help ensure that this initial exploration of an area of practice would cover a broad range of aspects as opposed to starting with a too grounded approach.

The most striking finding of the interview study was that, in this clinical professional population, it would have been inappropriate to approach FH taking as a discrete clinical behaviour, of addressing specifically biomedical aspects of history, and of being directed principally towards disease risk assessment. Pediatricians appeared to conceive of FH very

broadly, and considered information including social history and environmental factors as inseparable from medical information. FH appeared to be useful in clinical diagnostic and management activities, but was also a way to understand what parents needed to foster towards the well-being and effective care of their child, and to build relationships with patients and their family. FH taking was hard to isolate from other aspects of pediatric practice and came across as a rather personal activity, tailored to each pediatrician's preference and reflecting their own approach to practice. Most notably, pediatricians in our study very clearly communicated the feeling that taking FH is part of their professional role, tied to their professional identity. We concluded from these interviews that there is no apparent 'problem' with pediatricians failing to take a FH, rather there seems to be a disconnect with emerging disease-oriented recommendations.[6,49] The latter would imply some kind of a deficit model – professionals are not doing something they should do – whereas our findings imply that professionals have a well-developed approach into which one specific goal (disease-specific case finding) would need to fit. This is a complex implementation challenge. For example, our findings seem to indicate that FH relevant to the conditions recommended by the NCBDDD document[6] are probably covered by pediatricians, but the questions are not necessarily asked in as direct or systematic a way as might be recommended.

Based on implementation research in general, simply instructing a professional group about a desirable activity is unlikely to make them comply, especially in the absence of clear evidence behind such recommendations. Assuming evidence was forthcoming about FH-based disease specific case finding, what would be needed is a much narrower definition of the discrete behaviour to be targeted, careful studies to quantify the extent to which the

behaviour was 'lacking', and then explorations using tools such as the TDF to identify specific targets for intervention.

We noted that the literature on FH taking in pediatrics is extremely limited. We found many similarities between our findings and other published studies, for example that FH was important in pediatricians' practice[9,29], that they were systematic in collecting FH at new patient intake but not necessarily at follow up visits[2,10,29,44], that they used the same general approaches to FH taking (e.g., general questions)[29], and that contextual factors altered the quality of FH information.[29] We also found some differences, for example, in our findings pediatricians reported that time requires to take FH was not an issue in their practice, whereas in other studies, time was reported as a barrier to FH taking.[4,9] Also, previous studies have reported that physicians have very different approaches to FH taking[1,2,9], as opposed to our findings were pediatricians reported to take FH in a similar way. The findings of our study also contrasted with the literature on FH taking in primary care practice generally, for example pediatricians appear to collect and assess FH information to a much greater extent[2], and do not see time as so much of a barrier.[6,29]

Strengths and limitations

The first strength of this study was the decision to use a qualitative approach to explore an area of practice in depth. The original idea for this thesis had been to develop an instrument for use in a self-completion survey by pediatricians, and it is evident that such an approach would have been misguided and premature. The semi-structured interviews brought to the surface a way of looking at FH taking which was quite different to what we expected,

have enriched our own understanding and will contribute an original perspective to the published literature.

Secondly, as we argue above, we also consider the explicit use of a theory-based framework to be a strength. While it was challenging to 'decode' and interpret some of the domains, the exercise undoubtedly led to a deeper discussion about FH taking as a 'behaviour'. We also firmly believe that using the TDF to develop the interview schedule meant that the latter was broader than it would have been had we started with a set of 'common sense' questions.

The limitations of this study relate to the challenges of qualitative interview studies. Serious recruitment challenges meant that the sample size was constrained to eleven participants. Ideally, we would have preferred to base sample size on a judgement about whether the interviews had reached saturation, particularly as we were aware of the difficulty of covering all of the TDF-based items in the schedule in the time available for each interview. The eventual approach to the data which led to the themes presented in Chapter 3 only emerged after all interviews had been completed. This did not allow us to deliberately pursue these themes in further interviews, to test for saturation and seek out disconfirming statement.

Conclusions

The findings of this thesis project suggest that FH taking is a complex aspect of the clinical practice of pediatricians. Pediatricians appear to develop their own particular approaches to collecting and using FH information, take a holistic view of what constitutes 'family' history, use the activity and the information for purposes beyond clinical risk

assessment or diagnosis, and identify with it as a badge of their specialty, as much as the white coat or stethoscope.

This suggests that the implementation of recommendations for systematic enquiry about specific diseases or conditions cannot be seen as a simple additional activity. Efforts to modify FH taking behaviour may be more likely to succeed if they take pediatricians' attitudes, perspectives, and practices into account.

We suggest that future studies should seek to replicate and extend the work reported here. Further qualitative studies should explore and seek to confirm our observations, and are probably necessary to inform quantitative survey approaches. While the TDF was very useful, its place in future research requires further thought. A prerequisite for its use in implementation development is a very clear definition of the discrete behaviour of 'FH taking', and this is not yet settled in the literature.

The approach adopted here should be considered for other health professional groups where systematic FH taking is being advocated, particularly those working in primary care populations: nurses, family physicians, (low risk) obstetricians, and internists.

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Appendix 1: Search strategy – sensitive search for examples of TDF domains

interpretations

Database: Ovid MEDLINE(R) without Revisions <1996 to February Week 3 2014>
Search Strategy:
---

1 Primary health care/ (37897)
2 Physicians, family/ (9064)
3 Family practice/ (31856)
4 primary health care.tw. (8316)
5 primary healthcare.tw. (1837)
6 primary care.tw. (51985)
7 general practi*.tw. (34447)
8 family practic*.tw. (3238)
9 (family adj2 (physician? or doctor? or clinic?)).tw. (11180)
10 family medical care.tw. (9)
11 gp.ti,ab. (20139)
12 Community health services/ (11121)
13 or/1-12 (143364)
14 child health/ (12272)
15 child health.tw. (8081)
16 pediatrics/ (21132)
17 p*ediatric$.tw. (143832)
18 or/14-17 (164840)
19 exp Pedigree/ (38394)
20 limit 19 to humans (35704)
21 ((family or familial) adj3 (histor$ or history-taking or risk$)).ti. (3805)
22 (human adj2 pedigree).ti,ab. (23)
23 Family Health/ (16613)
24 (family history adj3 (taking or collect$ or tool? or questionnaire? or form? or algorith?m or assessment)).ti,ab. (522)
25 (family adj2 history).tw. (29053)
26 or/19-25 (77958)
27 13 and 26 (1897)
28 18 and 26 (2385)
29 27 or 28 (4127)
30 (note or comment or editorial or letter or congresses).pt. (871898)
31 29 not 30 (4027)
32 animals/ not (humans/ and animals/) (1733866)
33 31 not 32 (4023)
34 limit 33 to english language (3666)
35 limit 34 to yr="1996 - 2013" (3615)
36 from 35 keep 1-3,14,28-29,51,60,75-76,126,143,173,177,193,222,226,233,252,269,290,294,302,327,343,353,369,372-373,392,405-406,409,412,434,446,456,476,491,506,524,530-531,547-

548,564,579,582,584,613,620,625,656,671,701,707-708,723,741,767,789,799,813,831,843,861,874,878,890,900,923,929,947,956,979,989-990,995,1005,1012-1013,1016,1026,1031,1040,1042,1047,1064,1081,1090,1101,1107-1108,1150,1162,1188-1189,1215,1245,1247,1258,1280,1291,1298,1300,1342,1388,1395-1396,1401,1403,1424,1442,1444,1458-1459,1465,1483,1495,1498-1499,1506,1521,1531,1541-1542, 1551,1573,1580-1582,1591,1615,1625-1628,1633,1744,1759,1768,1800-1801,1819,1824,1845,1854-1855,1928,1983,2043,2056,2071,2099-2100,2154-2155,2187,2219,2227,2237,2245,2268-2272,2276,2347,2361 (170)

Appendix 2: Ottawa Health Science Network Research Ethics Board and Children's Hospital of Eastern Ontario Research Ethics Board approval letters

Ottawa Hospital Research Institute
Institut de recherche de l'Hôpital d'Ottawa

uOttawa

University of Ottawa Heart Institute
Institut de cardiologie de l'Université d'Ottawa

Ottawa Health Science Network Research Ethics Board/ **Réseau des sciences de la santé d'Ottawa Conseil d'éthique de la recherche**

Civic Box 411 725 Parkdale Avenue, Ottawa, Ontario K1Y 4E9 613-798-5555 ext. 14902 Fax: 613-761-4311
http://www.ohri.ca/ohsn-reb

Friday, September 13, 2013

Dr. Brenda Wilson
University of Ottawa
Epidemiology & Community Medicine
451 Smyth Road
Ottawa, ON
K1H 8M5

Dear Dr. Wilson:

Re: Protocol # 20130491-01H **Family history taking in pediatric practice: a questionnaire development and pilot study**

Protocol approval valid until - Wednesday, November 13, 2013

Thank you for the email from Laure Tessier dated September 13, 2013. I am pleased to inform you that this protocol underwent delegated review by the Ottawa Health Science Network Research Ethics Board (OHSN-REB) and is approved for two months to begin recruiting English-speaking participants. No changes, amendments or addenda may be made to the protocol or the consent form without the OHSN-REB's review and approval.

Approval is conditional upon receipt of the Children's Hospital of Eastern Ontario (CHEO) Research Ethics Board approval letter. Please submit a copy to our office to complete the file.
Approval is for the following:
- Electronic Application
- Protocol dated May 15, 2013
- English Recruitment Email from Investigators dated July 31, 2013
- English Reminder Recruitment Email from Investigators dated July 31, 2013
- English Semi-Structured Interview Scheme uploaded July 10, 2013
- English Participant Information Sheet and Consent Form (version 3) dated September 13, 2013
- French Recruitment Email from Investigators dated July 31, 2013
- French Reminder Recruitment Email from Investigators dated July 31, 2013

Once you have completed the development of the questionnaire, it must be submitted to the OHSN-REB for review and approval prior to implementing.

Upon receipt, review and approval of the French consent form and French interview script, approval may be extended for up to one year and the recruitment of French-speaking participants may then begin. When submitting the French documentation to the OHREB, confirm that it has been translated by Eric Lepine (elepine@ohri.ca) or an external certified translator. If the latter, provide a copy of their translation certificate. Refer to the OHRI standard operating procedure (SOP # OH 1000, v3) when submitting French documents to the OHREB for approval. Please note that there is a fee for Mr. Lepine's services.

.../2

The REB no longer requires a 'valid until' date at the bottom of all approved informed consent forms. The consent forms currently approved for use by the REB are listed above.

The Ottawa Health Science Network Research Ethics Board (OHSN-REB) was created by the merger of both the Ottawa Hospital Research Ethics Board (OHREB) and the Human Research Ethics Board (HREB) for meetings held at the University of Ottawa Heart Institute.

OHSN-REB complies with the membership requirements and operates in compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans; the International Conference on Harmonization - Good Clinical Practice: Consolidated Guideline; and the provisions of the Personal Health Information Protection Act 2004.

[redacted]

Raphael Saginur, M.D.
Chairperson
Ottawa Health Science Network Research Ethics Board

RS/ll

Ottawa Hospital Research Institute
Institut de recherche de l'Hôpital d'Ottawa

uOttawa

UNIVERSITY OF OTTAWA HEART INSTITUTE
INSTITUT DE CARDIOLOGIE DE L'UNIVERSITÉ D'OTTAWA

Ottawa Health Science Network Research Ethics Board/ **Réseau des sciences de la santé d'Ottawa Conseil d'éthique de la recherche**
Civic Box 411 725 Parkdale Avenue, Ottawa, Ontario K1Y 4E9 613-798-5555 ext. 14902 Fax : 613-761-4311
http://www.ohri.ca/ohsn-reb

Tuesday, October 08, 2013

Dr. Brenda Wilson
University of Ottawa
Epidemiology & Community Medicine
451 Smyth Road
Ottawa, ON
K1H 8M5

Dear Dr. Wilson:

Re: Protocol # 20130491-01H Family history taking in pediatric practice: a questionnaire development and pilot study

Thank you for the letter dated September 16, 2013.

The following documents are approved:
- French Semi- Structured Interview Scheme received September 17, 2013
- French Participant Information Sheet and Consent Form (version 3) dated September 16, 2013

Approval has been extended to September 12, 2014 to include the recruitment of French speaking participants.

The Ottawa Health Science Network Research Ethics Board (OHSN-REB) was created by the merger of both the Ottawa Hospital Research Ethics Board (OHREB) and the Human Research Ethics Board (HREB) for meetings held at the University of Ottawa Heart Institute.

OHSN-REB complies with the membership requirements and operates in compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans; the International Conference on Harmonization - Good Clinical Practice: Consolidated Guideline and the provisions of the Personal Health Information Protection Act 2004.

Yours sincerely,

[redacted]

Raph[redacted]
Chairperson
Ottawa Health Science Network Research Ethics Board

/kd

CHEO Research Ethics Board
Approval - Delegated Review

Principal Investigator: Dr. Pranesh Chakraborty
REB Protocol No: 13/97X
Romeo File No: 20130265
Project Title: CHEOREB#13/97X - Family History taking in Pediatric Practice: A Questionnaire Development and Pilot Study
Primary Affiliation: Other\Newborn Screening
Approval Date: October 31, 2013
Valid Until: October 15, 2014
Annual Renewal Submission Deadline: September 15, 2014

Documents Reviewed & Approved:

Document Name	Comments	Version Date
Protocol		2013/05/15
Consent Form	Version 3	2013/09/13
French Consent Form	Version 3	2013/09/16
Other Document	Letter of Support from Dr. Ciaran Duffy	2013/07/05
Other Document	OHSN-REB Approval Letter	2013/09/13
Other Document	Semi-Structured Interview Scheme (English and French versions)	
Other Document	Initial contact email for recruitment (English and French)	2013/07/31
Other Document	Followup email for recruitment (English and French Versions)	2013/07/31
Other Document	Recruitment Plan from OHSN-REB	

This is to notify you that the Children's Hospital of Eastern Ontario Research Ethics Board has granted approval to the above named research study on the date noted above. Your project was reviewed under the delegated review stream, which is reserved for projects that involve no more than minimal risk to human subjects.

Final approval is granted for the above noted study, with the understanding that the investigator agrees to comply with the following requirements:

1. The investigator must conduct the study in compliance with the protocol and any additional conditions set out by the Board.
2. The investigator must not implement any deviation from, or changes to, the protocol without the approval of the REB, or when the change involves only logistical or administrative aspects of the study (e.g., change of telephone number or research staff).

3. The investigator must, prior to use, submit to the Board changes to the study documentation, e.g., changes to the informed consent letters, recruitment materials.
4. For all other research studies, investigators must promptly report to the REB all unexpected and untoward occurrences (including the loss or theft of study data and other such privacy breaches).
5. Investigators must submit an annual renewal report to the REB 30 days prior to the expiration date stated above.
6. Investigators must submit a final report at the conclusion of the study.
7. Investigators must provide the Board with French versions of the consent form, unless a waiver has been granted.

For complete procedures relating to REB procedures, please refer to the REB website at http://www.cheori.org/en/researchethicsboard or contact Sharon Haig, Ethics Coordinator at [redacted] or [redacted]

Regards,

[redacted]

Dr. Carole Gentile
Chair, Research Ethics Board
Présidente, Comité d'éthique de la recherche
401 Smyth Road, Ottawa, ON K1H 8L1
Tel: [redacted] | Fax/Téléc: [redacted] | [redacted]

Appendix 3: Semi-structured interviews recruitment emails

Initial contact:

(La version française suit.)

Dear Dr. [name]

We would like to invite you to participate in a graduate research project being run jointly between the Departments of Pediatrics and Epidemiology and Community Medicine.

The topic is family history taking in pediatric practice. The student is Ms. Laure Tessier, who is a candidate in the MSc Epidemiology program. We (Dr. Pranesh Chakraborty and Dr. Brenda Wilson) are on her supervisory team, along with Dr. Beth Potter. The project has the support of Dr. Ciáran Duffy (see attached letter), and is part of a larger program of work on evidence to support the appropriate integration of genomics into health care.

If you agree to participate, Ms. Tessier will arrange to interview you at your convenience to explore your views about taking family history as part of your pediatric clinical practice. For information, the participant information form is attached. We identified you as potentially eligible through the contact details held with the Department of Pediatrics. We hope you will consider participating, although of course we respect your right to decline.

At this stage, we are seeking only an indication that you may be interested, by way of reply to this email (at [redacted]). If so, we will provide full details of the procedures and answer any questions you may have. If you do not wish to participate, you may let us know by way of reply to this email (at [redacted]). Alternatively, you may ignore this message. If we don't receive a response, we will send no more than one further email, after which we will assume recipients do not wish to participate.

We would both be happy to answer any questions, by email or phone. Our contact details are provided below

Kind regards,

[redacted]

Pranesh Chakraborty, MD, FRCPC, FCCMG
Associate Professor, University of Ottawa
Director, Newborn Screening Ontario
Metabolic Physician, Department of Pediatrics
Children's Hospital of Eastern Ontario

[redacted]

Dr. Brenda J. Wilson, MB MSc MRCP(UK) FFPH
Professor
Department of Epidemiology and Community Medicine
Faculty of Medicine
University of Ottawa

Email: [redacted]
Telephone: [redacted]

Cher/Chère Dr. [nom]

Nous aimerions vous inviter à participer à un projet de recherche de maîtrise mené par le Département de pédiatrie et le Département d'épidémiologie et de médecine sociale.

Cette étude porte sur la prise d'antécédents familiaux en pédiatrie. L'étudiante en question est Mme Laure Tessier, étudiante à la maîtrise en épidémiologie. Nous, Dr. Pranesh Chakraborty et Dr. Brenda Wilson, faisons partie de son comité de superviseurs, de même que Dr Beth Potter. Ce projet est appuyé par Dr. Ciáran Duffy (voir lettre en pièce-jointe) et fait partie d'un programme d'études visant à en apprendre plus sur le sujet afin de bien intégrer la génomique dans les soins de santé.

Si vous acceptez de participer, Mme Laure Tessier planifiera une entrevue selon vos préférences pour explorer vos opinions à propos de la prise d'antécédents familiaux dans votre pratique en pédiatrie. Afin de vous fournir de plus amples informations, vous trouverez en pièce-jointe la lettre d'information aux participants. Nous vous avons identifié comme étant un participant potentiel via nos contacts avec le Département de pédiatrie. Nous espérons que vous considérerez participer à cette étude, mais notez bien que nous respections entièrement votre choix de refuser, s'il y a lieu.

Si vous êtes intéressé à participer, vous pouvez répondre à ce courriel (à [redacted]). Nous vous fournirons ensuite les détails des procédures et nous répondrons à vos questions. Si vous ne souhaitez pas participer, vous pouvez également nous en aviser en répondant à ce courriel (à [redacted]). Vous pouvez aussi tout simplement ignorer ce message. Si nous ne recevons pas de réponse de votre part, nous ne vous enverrons qu'un seul autre courriel. Par la suite, nous présumerons que vous ne souhaitez pas participer.

Nous serions heureux de répondre à vos questions par courriel ou par téléphone. Vous trouverez nos coordonnées ci-dessous.

Cordialement,

[redacted]
Pranesh Chakraborty, MD, FRCPC, FCCMG
Professeur associé, Université d'Ottawa
Directeur, Dépistage néonatal Ontario
Spécialiste en médecine métabolique, Département de pédiatrie
Centre hospitalier pour enfants de l'est de l'Ontario

[redacted]
Dr. Brenda J. Wilson, MB MSc MRCP(UK) FFPH
Professeure
Département d'épidémiologie et médecine sociale
Faculté de médecine
Université d'Ottawa

Courriel: [redacted]
Téléphone: [redacted]

Follow-up contact

(La version française suit.)

Dear [name]

We would like to remind you that you are invited to participate in a graduate research project being run jointly between the Departments of Pediatrics and Epidemiology and Community Medicine.

The topic is family history taking in pediatric practice. The student is Ms Laure Tessier, who is a candidate in the MSc Epidemiology program. We (Dr Pranesh Chakraborty and Dr Brenda Wilson) are on her supervisory team, along with Dr Beth Potter. The project has the support of Dr Ciáran Duffy (see attached letter), and is part of a larger program of work on evidence to support the appropriate integration of genomics into health care.

If you agree to participate, Ms Tessier will arrange to interview you at your convenience to explore your views about taking family history as part of your pediatric clinical practice. For information, the participant information form is attached. We identified you as potentially eligible through the contact details held with the Department of Pediatrics. We hope you will consider participating, although of course we respect your right to decline.

At this stage, we are seeking only an indication that you may be interested, by way of reply to this email (at [redacted]). If so, we will provide full details of the procedures and answer any questions you may have.

If you do not wish to participate, you may ignore this message.

We would both be happy to answer any questions, by email or phone. Our contact details are provided below.

Kind regards,

[redacted]

Pranesh Chakraborty, MD, FRCPC, FCCMG
Associate Professor, University of Ottawa
Director, Newborn Screening Ontario
Metabolic Physician, Department of Pediatrics
Children's Hospital of Eastern Ontario

[redacted]

Dr. Brenda J. Wilson, MB MSc MRCP(UK) FFPH
Professor
Department of Epidemiology and Community Medicine
Faculty of Medicine
University of Ottawa

Email: [redacted]
Telephone: [redacted]

Cher/chère [nom]

Nous aimerions vous rappeler que vous êtes invité(e) à participer à un projet de recherche de maîtrise mené par le Département de pédiatrie et le Département d'épidémiologie et de médecine sociale.

Cette étude porte sur la prise d'antécédents familiaux en pédiatrie. L'étudiante en question est Mme Laure Tessier, étudiante à la maîtrise en épidémiologie. Nous, Dr Pranesh Chakraborty et Dr Brenda Wilson, faisons partie de son comité de superviseurs, de même que Dr Beth Potter. Ce projet est appuyé par Dr Ciáran Duffy (voir lettre en pièce-jointe) et fait partie d'un programme d'études visant à en apprendre plus sur le sujet afin de bien intégrer la génomique dans les soins de santé.

Si vous acceptez de participer, Mme Laure Tessier planifiera une entrevue selon vos préférences pour explorer vos opinions à propos de la prise d'antécédents familiaux dans votre pratique en pédiatrie. Afin de vous fournir de plus amples informations, vous trouverez en pièce-jointe la lettre d'information aux participants. Nous vous avons identifié comme étant un participant potentiel via nos contacts avec le Département de pédiatrie. Nous espérons que vous considérerez participer à cette étude, mais notez bien que nous respections entièrement votre choix de refuser, s'il y a lieu.

Si vous êtes intéressé à participer, vous pouvez répondre à ce courriel (à [redacted]). Nous vous fournirons ensuite les détails des procédures et nous répondrons à vos questions.

Si vous ne souhaitez pas participer, vous pouvez simplement ignorer ce message.

Nous serions heureux de répondre à vos questions par courriel ou par téléphone. Vous trouverez nos coordonnées ci-dessous.

Cordialement,

[redacted]

Pranesh Chakraborty, MD, FRCPC, FCCMG
Professeur associé, Université d'Ottawa
Directeur, Dépistage néonatal Ontario
Spécialiste en médecine métabolique, Département de pédiatrie
Centre hospitalier pour enfants de l'est de l'Ontario

[redacted]

Dr. Brenda J. Wilson, MB MSc MRCP(UK) FFPH
Professeure
Département d'épidémiologie et médecine sociale
Faculté de médecine
Université d'Ottawa

Courriel: [redacted]
Téléphone: [redacted]

Appendix 4: Letter of support from Dr Ciarán Duffy for the semi-structured interview recruitment

uOttawa

August 1, 2013

Dear Community Pediatricians:

I would like to draw your attention to a graduate student research project involving the Department of Paediatrics in which I hope you will be interested. It has my full support. To be clear, I am not personally involved as an investigator, and do not have an interest in authorship when the work is written up.

Dr Pranesh Chakraborty is the CHEO lead for this project, which also involves two colleagues from the University of Ottawa (Drs Brenda Wilson and Beth Potter, Department of Epidemiology and Community Medicine). This student project is on the practice of family history taking. It is part of a larger program of work designed to understand the shifting world of genomics from the perspective of different health professional groups.

Personally, I agree that it's important to ask practitioners on the front line what they think about some of the proposed ideas to build genomics into routine health care. I hope you will consider participating in this graduate student research project.

Yours sincerely,

[redacted]

Ciarán M. Duffy MB, BCh, MSc, FRCPC, FRCPI
Chief of Pediatrics, Children's Hospital of Eastern Ontario
Professor and Chairman, Department of Pediatrics
Faculty of Medicine, University of Ottawa

Children's Hospital of Eastern Ontario
401 Smyth Road, Ottawa, ON K1H 8L1
Tel: (613) 737-7600 · www.cheo.on.ca
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Le 1 août 2013

Cher pédiatres communautaires:

J'aimerais vous faire part d'un projet de recherche de maîtrise en collaboration avec le Département de pédiatrie, et j'espère que vous y serez intéressé. J'appuie entièrement ce projet de recherche. Il est important de noter que je ne suis pas impliqué dans cette étude en tant que chercheur, et que je ne ferai pas partie des auteurs lorsque les résultats seront publiés.

Dr Pranesh Chakraborty est le chercheur affilié à CHEO pour ce projet, qui est aussi mené par deux collègues de l'Université d'Ottawa (Drs Brenda Wilson et Beth Potter, Département d'épidémiologie et de médecine sociale). Ce projet de recherche étudiant porte sur la prise d'antécédents familiaux. Il fait partie d'un programme d'études visant à comprendre les perspectives de différents groupes de professionnels de la santé concernant l'application de la génomique en médecine.

Je suis d'avis qu'il est important de savoir ce que pensent les professionnels de la santé à propos de ces idées afin de bien intégrer la génomique dans les soins de santé. J'espère que vous considérerez participer au projet de recherche de cette étudiante à la maîtrise.

Cordialement,

[redacted]

Ciarán M. Duffy MB, BCh, MSc, FRCPC, FRCPI
Chief of Pediatrics, Children's Hospital of Eastern Ontario
Professor and Chairman, Department of Pediatrics
Faculty of Medicine, University of Ottawa

Appendix 5: Semi-structured interviews information sheet and consent form

Participant Information Sheet and Consent Form

Family history taking in pediatric practice: a questionnaire development and pilot study

Principal Investigators: Ms. Laure Tessier at [redacted]

Dr. Brenda Wilson at [redacted]

Dr. Beth Potter at [redacted]

Dr. Pranesh Chakraborty at [redacted]

Sponsor: **Canadian Institutes of Health Research**

Introduction

You are being asked to participate in this research project because you are currently working as a pediatrician affiliated with CHEO. Please read this Participant Information Sheet and Consent Form carefully and ask as many questions as you like before deciding whether to participate in this research study.

Background, Purpose and Design of the Study

We would like to describe the current practice of family history (FH) taking in pediatrics, as well as to develop a survey questionnaire to explore it on a larger scale. Understanding current patterns of practice, and attitudes of practitioners towards the utility of FH, would provide useful information for more definitive research in this area, with the intent of promoting evidence-based practice. The description produced from this project will be a useful addition to the research literature in general, and the instrument will be available for formal validation and subsequent application in a projected future Canada-wide survey. Community pediatricians affiliated with the CHEO are asked to participate in this study. You are being asked to participate in the first phase of the study, which consists of a semi-structured interview to explore the aspects of pediatric FH with pediatricians.

Study Procedures and or Description of Treatment
You will be asked to participate in an interview about FH taking in pediatrics. The interview should take up to one hour of your time and will be audio recorded. You will also be asked for your permission for the researchers to follow up afterwards to find out if you wish to participate in the second phase of this study (cognitive interviews with a questionnaire draft). You may choose not to take part in this follow up but still participate in the first phase of this study.

Study Duration
This study will take about six months to complete. You will be asked to participate in the semi-structured interview only once.

Possible Side Effects and/or Risks
There is no physical risk to you from participating in this study, and no medical information will be collected. The only personal information that will be collected will be about professional demographics.

Benefits of the Study
Your participation in this research will allow the researchers to understand the aspects of the current practice of family history taking in the pediatric setting. This information will be used to develop a questionnaire to be used in a later survey of pediatricians and other health professionals working in child health settings.

Voluntary participation & Withdrawal from the Study
Your participation in this study is voluntary. If you choose not to participate, you will not have any penalty or loss of benefits to which you are otherwise entitled. You have the right to withdraw from the study at any time. The decision to participate and/or to withdraw will have no impact on your current or future employment/affiliation with CHEO.

Study Costs
You will not be paid to participate in this research study, nor will you be required to pay to participate.

Confidentiality
Confidentiality will be respected and no information that would directly identify you will be communicated to any third parties. Representatives of the CHEO Research Ethics Board, The Ottawa Health Science Network Research Ethics Board and The Ottawa Hospital Research Institute may review your research data files for audit and quality control purposes. This will be done under the supervision of Dr. Pranesh Chakraborty or their delegates.

Your interview will be recorded, and the audio file will be password protected and will be only accessible by Laure Tessier (M. Sc. Candidate and research coordinator, University of Ottawa). The audio file will be deleted immediately upon transcription. The interview transcripts will be identified with a study number. The link between your name and the study number will only be accessible by Laure Tessier. In cases where a name was mentioned during the interview, a pseudonym will be used in the transcript. All study records will be kept for 10 years following the completion of the study. After that, paper records will be shredded or disposed of in confidential waste and electronic files will be deleted.

Questions about the Study

If you have any questions about this study, please contact the research coordinator, Laure Tessier, by phone at [redacted] or by email at [redacted].

The CHEO Research Ethics Board (CHEO REB) and The Ottawa Health Science Network Research Ethics Board (OHSN-REB) has reviewed this protocol. The CHEO REB and OHSN-REB consider the ethical aspects of all research studies involving human participants at the CHEO and The Ottawa Hospital, respectively. If you have any questions about your rights as a research participant, you may contact the Chairperson of the CHEO Research Ethics Board at [redacted] or the Chairperson of The Ottawa Health Science Network Research Ethics Board at [redacted].

Consent Form

Family history taking in pediatric practice: a questionnaire development and pilot study

Consent to Participate in Research

I understand that I am being asked to participate in a research study pediatric family history taking. This study has been explained to me by a study team member.

I have read each page of this Information Sheet and Consent Form (or have had this document read to me). All my questions have been answered to my satisfaction. If I decide at a later stage in the study that I would like to withdraw my consent, I may do so at any time.

I also understand that I am being asked for my permission for the study researchers to follow-up for another set of interviews (cognitive interviews). This has been explained to me by the study team.

□ _____ (initials) I agree to be contacted for the second set of interviews (cognitive interviews).

□ _____ (initials) I do not agree to be contacted for the second set of interviews (cognitive interviews).

A copy of the signed Information Sheet and/or Consent Form will be provided to me.

Signatures

__
Participant's Name (Please Print)

_____ _____
Participant's Signature Date

Investigator Statement (or Person Explaining the Consent)

I have carefully explained to the research participant the nature of the above research study. To the best of my knowledge, the research participant signing this consent form understands the nature, demands, risks and benefits involved in participating in this study

_____
Name of Investigator/Delegate (Please Print)

_____ _____
Signature of Investigator/Delegate Date

Lettre d'information et formulaire de consentement

Les antécédents familiaux en pédiatrie: développement d'un questionnaire et étude pilote

Chercheurs principaux: Mme Laure Tessier au [redacted]

Brenda Wilson au [redacted]

Beth Potter au [redacted]

Pranesh Chakraborty au [redacted]

Commanditaire: **Instituts de recherche en santé du Canada**

Introduction

Vous êtes invité à participer à ce projet de recherche parce que vous pratiquez présentement en tant que pédiatre affilié au Centre hospitalier pour enfants de l'est de l'Ontario (CHEO). Veuillez s'il vous plait lire cette lettre d'information et ce formulaire de consentement attentivement, et n'hésitez pas à poser autant de questions que vous voulez avant de décider de participer à ce projet de recherche.

Description et objectifs du projet de recherche

Notre but est de décrire l'aspect de la pratique médicale qu'est la prise d'antécédents familiaux (AF) en pédiatrie. Nous voulons également produire un questionnaire de sondage qui pourra être utilisé à plus grande échelle afin de mieux décrire cet aspect de la pratique. Comprendre la pratique actuelle entourant la prise d'AF et les opinions des médecins concernant l'utilité des AF sera un apport considérable aux connaissances actuelles. De plus, cela permettra de mieux orienter les futures recherches, et permettra éventuellement d'établir des lignes directrices selon des données probantes. Le questionnaire produit pourra être évalué et validé afin d'obtenir des données sur cet aspect de la pratique médicale à plus grande échelle dans un sondage. Nous invitons des pédiatres affiliés au CHEO à participer à la première étape de ce projet de recherche, qui consiste d'entrevues visant à explorer les aspects de la prise d'AF en pédiatrie.

Description des procédures
Vous serez invité à une entrevue à propos de la prise d'AF en pédiatrie par rendez-vous. L'entrevue durera environ une heure. Les chercheurs vous demanderont la permission de vous contacter une deuxième fois afin de savoir si vous voudriez participer à la seconde étape de cette étude (entrevues cognitives afin d'évaluer la première version du questionnaire). Vous pouvez refuser d'être contacté une deuxième fois tout en participant à la première étape de cette étude.

Durée de l'étude
Cette étude durera environ six mois. Vous serez invité à participer à cette entrevue une fois seulement.

Risques possibles
Votre participation à cette étude ne comporte aucun risque physique ni aucun autre risque. Aucune information médicale ne sera collectée. Les seules informations personnelles qui vous seront demandées sont vos caractéristiques démographiques en tant que professionnel.

Avantages à participer
Votre participation à cette étude permettra aux chercheurs de comprendre les divers aspects de la pratique médicale concernant la prise d'AF en milieu pédiatrique. Cette information sera par la suite utilisée afin de développer un questionnaire de sondage pouvant être utilisé à plus grande échelle avec des médecins et autres professionnels de la santé qui travaillent avec des patients pédiatriques.

Participation volontaire et comment se retirer du projet de recherche
La participation à cette étude est volontaire. Si vous choisissez de ne pas participer, vous ne recevrez aucune pénalité et vous ne perdrez aucun bénéfice auquel vous avez présentement droit. Vous avez le droit de vous retirer de l'étude à tout moment. La décision de participer et/ou de vous retirer de l'étude n'aura aucun impact sur votre emploi et votre affiliation actuels ou sur vos futurs emplois et affiliations au CHEO.

Coûts associés à l'étude
Vous ne serez pas payé pour participer à cette étude, et vous n'aurez pas à débourser de frais pour participer.

Confidentialité
Vos informations personnelles et vos réponses à l'entrevue seront traitées de façon confidentielles, et aucune information ne sera partagée avec une autre institution. Des représentants du Comité d'éthique en recherche du CHEO (CHEO Research Ethics Board), du Conseil d'éthique de la recherche du Réseau de science de la santé d'Ottawa et de l'Institut de recherche de l'Hôpital d'Ottawa pourraient réviser votre dossier à des fins de vérification et de contrôle de la qualité. Ceci sera fait sous la supervision de Dr Pranesh Chakraborty, ou ses délégués.

Votre entrevue sera enregistrée, et le fichier audio sera protégé par un mot de passe et ne sera accessible que par Laure Tessier (candidate à la maîtrise et coordonnatrice de recherche, Université d'Ottawa). Les entrevues seront transcrites par écrit, et ne comporteront qu'un numéro de participant (et non votre nom). Le fichier audio de votre entrevue sera effacé immédiatement après sa transcription. Le document liant votre nom et votre numéro de participant sera protégé par un mot de passe et seule Laure Tessier pourra y avoir accès. Dans le cas où le nom d'une personne sera mentionné dans une entrevue, il sera remplacé par un pseudonyme dans la version écrite. Les documents comportant les transcriptions des entrevues seront conservés durant 10 ans après la fin de l'étude. Par la suite, les documents papiers seront déchiquetés ou jetés de façon confidentielle et tous les fichiers électroniques seront effacés.

Questions à propos de l'étude

Si vous avez des questions à propos de cette étude, veuillez s'il vous plaît contacter la coordonnatrice de recherche, Laure Tessier, par téléphone au [redacted] ou par courriel au[redacted]

Le Comité d'éthique en recherche du CHEO ainsi que le Conseil d'éthique de la recherche du Réseau de science de la santé d'Ottawa ont approuvé ce protocole. Le Comité d'éthique en recherche du CHEO et le Conseil d'éthique de la recherche du Réseau de science de la santé d'Ottawa évaluent l'aspect éthique de tous les projets de recherche incluant des sujets humains au CHEO et à l'Hôpital d'Ottawa, respectivement. Si vous avez des questions concernant vos droits en tant que participant à une étude, vous pouvez contacter le directeur du Comité d'éthique en recherche du CHEO au [redacted] ou le directeur du Conseil d'éthique de la recherche du Réseau de science de la santé d'Ottawa au [redacted].

Formulaire de consentement
Les antécédents familiaux en pédiatrie: développement d'un questionnaire et étude pilote

Consentement à participer à cette étude

Je comprends qu'on m'invite à participer à une étude sur la prise d'antécédents familiaux en pédiatrie. Cette étude m'a été expliquée par un chercheur membre de l'équipe responsable de cette étude. J'ai lu les trois (3) pages d'information concernant l'étude, ou on m'a lu ce document. Toutes mes questions ont été répondues de façon satisfaisante. Si je décide plus tard que j'aimerais me retirer de cette étude, je peux le faire à tout moment. Je comprends qu'on me demande la permission de me contacter pour une deuxième entrevue (entrevue cognitive). Ceci m'a été expliqué par l'équipe de recherche.

□ _____ (initiales) J'accepte de participer à cette étude.

□ _____ (initiales) Je n'accepte pas d'être contacter pour la deuxième entrevue (entrevue cognitive).

Une copie de la lettre d'information et du formulaire de consentement me sera remise.

Signatures

_____

Nom du participant (en caractères d'imprimerie)

_____ _____

Signature du participant Date

Énoncé du chercheur (ou de la personne chargée d'obtenir le consentement)

J'ai expliqué soigneusement au participant la nature de l'étude susmentionnée. Pour autant que je sache, le participant apposant sa signature à ce consentement reconnaît la nature, les exigences, les risques et les avantages que comporte sa participation à l'étude. Je reconnais ma responsabilité envers le soin et le bien-être du participant susmentionné, le respect des droits et des désirs de ce dernier, et le déroulement de cette étude conformément aux lignes directrices et aux règlements en matière de bonne pratique clinique.

_____

Nom du chercheur/délégué (en caractères d'imprimerie)

_____ _____

Signature du chercheur/délégué Date

Appendix 6: Example of qualitative analysis table

PARTICIPANT 36 – Laure Tessier

Participant thumbnail	• Very enthusiast about FH, its role in pediatrics, and his role in pediatrics in general • Psycho-social history ties into medical FH • FH is definitely important • When asked about something regarding FH, will often respond talking about his practice in general - FH is embedded • Often explained things with examples or anecdotes - can't separate it, embedded, haven't thought of it before...	
Descriptive: Current practice of FH taking	40 to 51: For news patients, before they even come into the room, or before I see them, rather, I have a small intake form. It's a very basic form where I ask them/the family to describe what are the reasons for the visit, and a little bit about the medical background of their child. That includes their immunization status, allergies to medication, allergies in general, medication that they may be on. And I do ask specifically about FH but I leave it very vague. I let them fill it out. I ask about the family demographics. Are there any siblings? What do the parents do? Are there any smokers at home? Do they have any pets? Things like that. About half the time, that gets under-populated, that sheet. And that's not a bad thing. It give me an idea about the functionality of the family. Maybe they are busy, maybe they didn't understand it, sometimes there is a language barrier... And the other thing that's really helpful is that I have that form and they tell me why they think they are coming. And then I have the referral from the physician, and the reason why they were referred in the first place, and sometimes there is a disconnect. It tells me what the relative priorities are for that family, what their understanding is. 284 to 289: So you do collect FH about mental health issues? P: Everything, yeah. Where it's relevant. So	For new patients, give an intake form to fill that includes FH questions, but he lets them very vague. Are there any sibling, occupation of parents, any smokers at home, any pets at home, for instance. But half the time, that sheet gets under-populated. Tells him about the functionality of the family - they might be busy, or they don't care, or there's a language barrier. Will also ask in person who is the daycare provider, who is working, who picks him up from school - if relevant. Ask about mental health FH when relevant. Can also ask about that FH in parents even when their child has an organic problem, as to how they are coping. Ex: baby has an intake problem, not growing, how are you coping with all this? Anyone helping you? Social and family history are

	if the child is coming in with something that looks very organic, anything that's below the brain, then I'll stay on point with that. Like, infants who are not growing well, and it's clearly an intake issue, I may want to ask "How are you coping with all this? Is anyone else helping you?" to get a sense of the family… I may not ask specifically "Do you have a mental health disorder?" 301 to 303: So that's where I lump in FH and social history together. Because I think that in pediatric practice it's sometimes hard to differentiate between the two. 350 to 354: And for ADHD, behavioural issues, educational issues and mental health issues in general, I find there is a much stronger component of FH or genetic link, in terms of the phenotype. So if I see a child with anxiety – and sometimes it's obvious that a child has anxiety – then I won't even ask the FH in open terms. I'll say: "Who else has anxiety in the family?" 483 to 495: So I may just I may just ask quickly at the beginning, because we are really focused, when their babies are first born, on how did it go with the pregnancy, how was the delivery, what happened at the hospital, how was the weight gain, how are you coping… So basic primary care aspects. And I will add to it as we seem them further on: ok we didn't talk about this last time, but just so I can have a complete file here is there anything in the family I need to know about? Do you guys have any chronic illnesses? Are you sick? Are you taking any medication? What's happening? So we sort of build it. And because everybody is evolving, if there is something relevant, I do expect them to tell me periodically. If there is anything new going on in their lives… Because it will impact the health of their child, potentially. So I do ask, but I don't ask regularly. Because, again, most primary care patients I have are healthy. I am seeing them just for routine visits. And it's because they are coming regularly that they stay healthy. 496 to 497: So, yeah, I do ask a little bit, but that's not… *pauses* It's not something I spend a lot of	lumped in together. When a phenotype is evident, for example anxiety, he will not even ask about FH in open terms. He'll say: who else has this? See a stronger link with FH and mental health issues. If a child has it, he knows there are other cases in the family. With primary care patients, will ask about FH gradually. First visit is about how was the birth, what happened in the hospital, how parents are coping. Will add info on further app about anything in the family he needs to be aware of, are you healthy, are you taking any medication. He them expects them to tell him if there is something new in the future. With primary care patients, does not spend a lot of time on FH.

	time on.	
Descriptive: Current practice of FH information usage	135 to 144: I gave you an example of this child yesterday who was coming in with constipation and was probably still a bit early in the treatment but we would have expected somewhat of a better outcome with the treatment regiment she had been put on. So we started talking about other possible causes. Because the mother had a thyroid condition, it changed the direction and tone of the conversation, because she was concerned a little bit about her daughter possibly having a thyroid condition. Which absolutely can be an underlining cause of constipation. So it didn't change anything yesterday, but it set up a different dynamic for the second visit. We'll have a much different threshold for ordering investigation to rule out thyroid problems in this young girl next time, because of that FH. I'm not going to just look at the FH, but it's one of these extra pieces of evidence that might help. 180 to 187: For me FH is definitely important, but I think it's more relevant in terms of how it demonstrates what the whole psycho-social environment is in that family. Because, again, if a family member has a chronic illness, I think that impacts the dynamic and the ability to care for that child appropriately and seek out care appropriately. But if you are talking pure FH, in terms of if we need to go down a certain route for clinical decision making, yes it's helpful. I would have to say that it doesn't often change what my direction is, because usually by the time I get to discussing FH I have pretty much already figured out what direction I'm going on, because of the history surrounding the complaint. 370 to 382: P:A child is having headaches. And it depends, because headaches in a 4 year old it's not something… Or even in a 2 year old: why would a 2 year old complain of a headache? They don't even know what a headache is… Versus a child about to go to school, versus a child who's entering puberty, versus a teenager who is having trouble in school. You know, it's a very	FH can change the patient management. Will change his threshold for ordering investigation. FH doesn't often change his direction, because by the time he gets to discuss it he pretty much already have figured it out because of the history surrounding the complaint. The way he uses FH information changes depending on the age of the child – pathologies changes depending on their development. Headaches and hip pain mean different things in a baby vs a toddler vs an older child. Idem. Can order some exams given the FH.

	different pathology (...) So the way you use the information changes a bit depending on how old the child is, right? P: Absolutely, yeah 395 to 396: FH might be more or less relevant depending on where they're at in their development? P: Oh yeah. Absolutely, yeah, yeah… 430 to 433: One person in the family with a brain tumour is serious enough. Having multiple people in the family with a brain tumour? There's no way I can ignore that. So I'm going to do an exam. I will spend a lot more time doing a focused neurologic exam.	
Descriptive: General attitudes to routine FH taking		
Descriptive: Opinions on factors that influence the quality of FH obtained / Validity of FH information	155 to 177: Does it sometimes make you concerned about the accuracy of the information you are collecting? P: Yes, yes, absolutely. (...)I see this a lot when I have medical students residents working with me. They'll ask particular questions that report the history to me - I always ask about FH, and I get them to report it too. (...) But often what happens is that the information is not always consistent. It's very common for residents and trainees to get a different history that we'll get. So for example they'll say: well I went to talk to the mom and here's the story. And sometimes we'll take the time to go and chat with them because there's something we want to know about the history, and they'll give us a different answer. Then you'll look at the trainee or the resident and they scowl because they'll say: I asked this question, and they gave me a very different answer! It's not that the family is trying to hide it, it's often that they'll get confused. Sometimes they didn't think about it, they just gave us an answer, and afterwards they'll have a moment to reflect and think: why did that trainee or resident ask me that question? Oh I said this but I do remember now, there was another episode of this... They'll bring that information back. So I came up with the term: *Me*'s law of FH. The idea there is that	Sometimes is concerned about validity of FH info because some parents may not remember of certain episodes/things. When you ask the questions, it makes them think about it. This is why when he has residents, the resident gets a different answer than him, when he asks the same question a little later. Because the parents thought about it in the meanwhile.

	the more often you ask the question, the more often it's going to change.	
TDF **KNOWLEDGE** Awareness that FH taking is or can be an accepted part of clinical care (Awareness of potential application of FH in pediatrics)	See current practice, optimism, goals… 62 to 74: You know, that's interesting. Because I don't think it was ever discussed that "here's the evidence". When I was studying in medicine, the concept of evidence-based medicine was still in its infancy, I think. In terms of being applied to how we teach medical students... basic history taking. It was just done by... Here's a generational teaching tool, here's how your predecessors did it, here's why we think it's important. And it was probably based on some studies, but that evidence was never presented to us. I don't think it was ever clear, to me, that we were given the background and the evidence for why we need to do it. It just seemed intuitive to most of us that in order to know... We know we are the product of several things: not just genetics, but also our environment. One of the key issues in pediatrics, in your environment, is who you are living with. From a developmental and psycho-social point of view, the influence of a family, in terms of being a role model... So it's always helpful to know what else is going on in the household. So it was very intuitive and it wasn't hard to make that leap. Nowadays the first question out of our mouth is: well what is the evidence? That was never the case back then. For most of us, when I was studying, it wasn't even an issue. So I don't even know what the evidence is. 282 to 283: Actually, when we are talking about the area of mental health, that's when a FH is more important. I think there may be less evidence and it's less directing, but it's much more relevant. 329 to 331: So if you're speaking specifically from a clinical perspective, if I know there is a FH of atopic disease, asthma, allergies, eczema, and that child is coming in that may fall under the same umbrella it does help guide the diagnosis a little bit. 588 to 594: But at the same time, now we are doing this	Not sure what is the evidence around FH, it was never taught to him in med school. It seemed intuitive that FH is important, because we are a product of genes + env. FH of mental health is important. Although he thinks there is less evidence around mental health FH. FH of allergies, asthma, and eczema are relevant. Does not know how different mutations can affect outcomes and health - and feels like he should.

	panel and I can tell you all the different problems in different genes, but I cannot tell you the relevance of that. If I see there is some sort of deletion somewhere or some alteration of a gene, I don't know what it means. This is a problem: we are able to do so much and we don't know what it means, the outcome. So I think knowing how it's going to affect care and how it's going to change care is a piece that is important to identify. And I don't know that there's a good answer to that.	
TDF **SKILLS** Procedural knowledge of FH taking, e.g., • standard ways in which a practitioner takes FH • experience in taking FH built up over a period of time how FH taking approach has evolved as a result of practice (Training/experience in FH taking Opinions on what skills are needed)	82 to 101: How did you learn to take a FH? Before the interview you were telling me you learned that in medical school... P: That's right. There is a whole section on history taking, and they break that down into understanding the complaint, understanding the particular areas of concern. Of somebody presents which a certain condition, there is a list of certain mnemonics associated with the condition. You would also ask about past medical history, past surgical history. Where relevant, we would get into an early childhood and pregnancy/obstetric history. And then we would want to know about FH. So it was just one of the areas that we just covered. And it was very basic at the time. It was just: find out of there is any relevant issues, look for about the big ones first. But it has to be relevant. If someone comes in with, for example, asthma, do I care that the mother had her appendix out when she was 20? Probably not. Is it relevant? Probably not. But there's no harm in getting that data, except for the extra time it takes. And sometimes it's a jumping off point... But anyways, we would be looking for the major pathologies, and anything that would be relevant. So we would ask if there is a FH of anything like that. Sometimes we would start with close-ended questions, and then ask open-ended, or vice-versa: tell me about your FH... But some people don't understand what that means. So a lot of it was just: ask these questions. It was very black and white. Was it about asking for specific conditions? P: We were taught: ask about FH. And I remember, we were taught to ask about the big things: cardiovascular disease, stroke, diabetes, hypertension, arthritis, chronic diseases, medication use, hospitalisation, things like that. And they basically said "ask those things".	Learned how to take FH in medical school. Says it was very basic. They were told to ask for FH for certain conditions. They were also taught to ask about the big things including: stroke, hypertension, diabetes, arthritis, chronic diseases, medication use, hospitalisation. Importance of FH got more recognizable with experience. Skills = patience – a lot feel like they have a story to tell, maybe they don<t get to talk to a specialist very often. Skills = know what is relevant,

	101 to 106: It probably didn`t become relevant until later on, when we started putting two and two together and we started having clinical experience, to recognize where FH is important... And it's not just about the parents, it's also the siblings. "Oh well, my other 2 children also had this." Well ok, hold on, that changes everything now. We see a pattern here, we need to switch directions. So then it became relevant, and it reinforces the important aspect of FH taking. 110 to 135: I think it's patience. People that come into my office, I make them fill out a form, why do they think they are here... A lot of them feel like they want to tell a story. Maybe they don't have the opportunity to talk to a specialist very often. Most of my referrals are 45 to 60 minutes. So if they can capture somebody like me for 60 minutes, they are going to ask everything. They may come in for problem A, but before they leave, they are going to tackle B,C, D and E, F and G as well. So it's a little bit of patience to get through it. I think a skill that comes with experience is how to direct an interview. Because some people will take you off on a tangent. It's important to bring them back where relevant. (...)So you have to be patient, and know what's relevant. They may come in with a particular agenda, and you do have to address that, because I have to write back to the physician who did the referral and say: I did evaluate this and I don't think it's serious, but I also spend time on these other things which I think are important, but may not have come up before. So I think it's patience, and controlling the interview and the pace. And being respectful and I think being able to have a dialog is very important. One other reason why parents like to come to these visits is that they don't often have that long to speak with a specialist, and to be able to go through it. I will also spend a lot of time explaining what it means. Here's the reason why we are doing this test, here's the relevance of this result, here's what you should do next, here's a safety profile of this medication - why we use this one instead of that one. So I think education of the family is really important. And then, obviously you really have to have a good basic understanding of the medicine:	be able to re-direct the conversation/controlling the interview and its pace. Skills = being respectful and being able to have a dialog. Educating the parents about the “why” of things, sees it as part of this role. But talked generally, not necessarily only about FH. Skills = need to understand why it is important to take FH and how it is going to affect your clinical decision. His practice changed with experience, his approach to FH. With experience, he get more comfortable with mental health FH.

	why is it important to get a FH, how is it going to affect your clinical decision. 341 to 342: And I have to be honest: I probably have changed my approach a lot since I was a resident. 544 to 553: There are no tests for a lot of conditions that are in that sphere, in that element, in that domain of mental health. So that's where the experience comes in. It's taken me a long time enough, but still… You feel like you are still learning about this? P: Oh of course, yeah, yeah. It took me several years to get comfortable with it. Then fortunately you get to a point where you are making and you're getting lucky sometimes, and your patients to better, so it reinforces the way you practice. And then no matter how long the practice, no matter how good you are, at some point I think it is realistic to say you're going to come across with a situation where you made a mistake. And you better hope you are in the right frame of mind because the best you can do is learn from that. So you make sure the patient is covered but you are not going to let that happen again.	
TDF **SOCIAL/PROFESSIONAL ROLE AND IDENTITY** Perception of how far FH taking is seen as consistent with professional role, and/or part of professional identity (Relationship of FH taking practice to professional/group identity, role, boundaries)	423 to 425: So you really feel that it is your professional role to take FH, right? P: Like I said, if I had to forgo something... *thinks for a moment* I don't know, I don't even think I could forgo FH, because it's so easy and quick to get FH. 438 to 439: So they come to me and worry about this. I don't think I've done my job unless I address that. 559 to 567: So that's from personal experience, and they're never going to make that same mistake again. And if it means that you are more careful with the rest of the patients for the rest of your life… So to that person, that practitioner, maybe it's worth it because the feeling of doing that, of failing – because we're intrust with a huge amount of responsibility. You go to see so many people and at some point my name is the name at	Feels like it is his role to take FH. Feels like it is his role to address parent's concerns regarding FH. Adequate FH taking is part of his role, both in regards to the objective of helping the family than in regards to staying accountable

	the bottom. And if I don't sign it off properly and I don't take care of it, I may be responsible, but more importantly that patient is not being cared for adequately. That is the primary objective. Yes, I want to make sure my credibility is intact. Yes I want to make sure that my practice is surviving and doing well. But it means nothing if I'm not helping the families, right?	
TDF **BELIEFS ABOUT CAPABILITIES** Self-assessed confidence and competence in FH taking (Self-confidence, self-efficacy about FH taking in personal clinical practice)	189 to 195: You know what, I never really thought about it so I'll have to say yes. *laughs* Because I have never had reasons to go back and look at it. And even if I did, even if I missed something, it hasn't really impacted. It may just add to the story. Because the reality is: there is a limited amount of time that I have with the family, I need to focus on certain things. I hasn't become a problem where I missed something on the FH that has really changed what I do or has affected the care that I can give for that child. So I feel pretty confident in what I do. But again, it's just based on experience more than anything. So maybe there is an opportunity to have a better tool... 197 to 198: Yes I think so. Getting the history is one of these things where when you get the information, you process it right away.	Never thought about it before, but would say he feels confident in ability to take FH, because he never had reasons to go back to and look at it, he never missed something on the FH that has affected care. But feels open to the opportunity of having a better tool. Thinks he does feel confident using FH information.
TDF **OPTIMISM** General sense that FH taking can impact the patients' health (Extent of confidence that routine FH taking will make things happen for the best or not)	52 to 60: So it seems like to you, FH goes beyond diseases that run in the family: it's very bio-psycho-social, about the dynamics. P: Absolutely. There's no way you can do pediatrics unless you consider those factors. (...) But the psycho-social aspect, the dynamics, the functionality of a household are very very important. They may not be necessarily relevant to the particular situation, but they are always important. 74 to 77: But I think the evidence would have to be very very very compelling if I was going to change my practice. Now, after practising for a number of years, I see the value of it, more than ever. I can't see me changing the way I practice. I may evolve it, but I'm not going to stop taking it. 145 to 149: So overall, you really think that FH taking	H is absolutely important in pediatrics. Can't do it without considering those factors. Sees the value of FH as he gains experience. Can't imagine not using it. May evolve the way he is using it, but won't stop taking it. FH can absolutely impact his patient's health. FH is important. FH doesn't often change his direction,

	can impact your patient's health, correct? P: No question, yes. And it's not just the FH that's relevant to the patient's particular concern. Of the mom has a thyroid diseases, could it also affect the child, yes. But if the mom has another chronic illness, it's going to affect the child's ability to be healthy if the mom cannot care for this child. So indirectly, there's a psycho-social component to the FH. 180 to 187: For me FH is definitely important, but I think it's more relevant in terms of how it demonstrates what the whole psycho-social environment is in that family. Because, again, if a family member has a chronic illness, I think that impacts the dynamic and the ability to care for that child appropriately and seek out care appropriately. But if you are talking pure FH, in terms of if we need to go down a certain route for clinical decision making, yes it's helpful. I would have to say that it doesn't often change what my direction is, because usually by the time I get to discussing FH I have pretty much already figured out what direction I'm going on, because of the history surrounding the complaint. 339 to 341: So the thing is that FH is just so critical, I can't imagine ever not doing it. It just depends on the context of the patient. Sometimes it's more relevant and I need to spend time, sometimes sort of an aside, and I'll ask it for completeness. 402 to 404: So FH is interesting, it can be very relevant, and when it is relevant it's very relevant at that time. A lot of times it's not relevant but I still consider it an important aspect of the evaluation.	because by the time he gets to discuss it he pretty much already have figured it out because of the history surrounding the complaint. FH is critical, can't imagine not doing it. FH is important when relevant, but always an important aspect of evualuation.
TDF **BELIEFS ABOUT CONSEQUENCES** Beliefs about the clinical utility of FH taking, and/or the effects on practice, remuneration, relationships, etc., that might ensue as a result (What person thinks will	328 to 333: Well it gives… Like I said, I do lump it in with the social history, but it definitely give a broader context of what that family may be at risk for. So if you're speaking specifically from a clinical perspective, if I know there is a FH of atopic disease, asthma, allergies, eczema, and that child is coming in that may fall under the same umbrella it does help	Advantages = gives a broader context of what the family might be at risk for, helps guide diagnosis, helps guide the management, gives opportunities to educate the parents.

happen as a result of routine FH taking)	guide the diagnosis a little bit. It does help guide the management plan, absolutely. And there's a lot of opportunities for education because there is some misinformation out there and depending on the topics there's even some disinformation. 363 to 367: It definitely helps set the tone. And sometimes it's just an extra piece of the puzzle. Especially when it's not clear what's going on, that's another time it's helpful. They're telling me their child presents with problem A, B, C, the investigations have kind of ruled out those things, so all the ones I would have thought about are not so obvious. But if I get a FH now, it's another piece of the puzzle that could really change the way we approach that, the problem. 368 to 370: Do you think there are any disadvantages of FH? P: Yeah well… You know, the flip side of the same coin is: could it lead you off on the wrong direction. You don't want to miss the forest for the trees. 405 to 407: Overall, would you say that the advantages outweigh the disadvantages? P: Oh, no question! I don`t know if I ever came across with a situation where I've been mislead or it was a problem.	Advantage: FH is a piece of the puzzle that might change his approach. Disadvantage = FH could lead you in the wrong direction – you don't want to miss the forest for the trees. Benefits outweigh disadvantages – oh, no question
TDF **REINFORCEMENT** Factors that trigger or reinforce taking FH, incentives or disincentives ((Potential) rewards, reinforcements, incentives, disincentives, sanctions related to implementing/maintaining routine FH taking)	101 to 106: It probably didn`t become relevant until later on, when we started putting two and two together and we started having clinical experience, to recognize where FH is important... And it's not just about the parents, it's also the siblings. "Oh well, my other 2 children also had this." Well ok, hold on, that changes everything now. We see a pattern here, we need to switch directions. So then it became relevant, and it reinforces the important aspect of FH taking. 544 to 553: There are no tests for a lot of conditions that are in that sphere, in that element, in that domain of mental health. So that's where the experience comes in. It's taken me a long time enough, but still… You feel like you are still learning about this? P: Oh of course, yeah, yeah. It took me	Seeing when FH becomes relevant reinforces FH taking. With FH of mental health, he gets better with experience, and seeing his patients getting better reinforce his practice. Mistakes can make him change his practice, even if it goes beyond the guidelines. It is important not to let it happen again. Need to learn from it.

	several years to get comfortable with it. Then fortunately you get to a point where you are making and you're getting lucky sometimes, and your patients to better, so it reinforces the way you practice. And then no matter how long the practice, no matter how good you are, at some point I think it is realistic to say you're going to come across with a situation where you made a mistake. And you better hope you are in the right frame of mind because the best you can do is learn from that. So you make sure the patient is covered but you are not going to let that happen again.	
TDF **INTENTIONS** The extent to which individuals do, or are willing to, engage in FH taking in their practice (Conscious decisions or resolve to implement/maintain routine FH taking)	74 to 77: But I think the evidence would have to be very very very compelling if I was going to change my practice. Now, after practising for a number of years, I see the value of it, more than ever. I can't see me changing the way I practice. I may evolve it, but I'm not going to stop taking it.	Doesn't see him changing the way he practices, but may evolve it.
TDF **GOALS** Sense of what practitioners want to achieve when it comes to their own FH taking practices (Is FH important in managing your patients?) (Explicit descriptions of outcomes that routine FH taking is intended to achieve)	135 to 144: I gave you an example of this child yesterday who was coming in with constipation and was probably still a bit early in the treatment but we would have expected somewhat of a better outcome with the treatment regiment she had been put on. So we started talking about other possible causes. Because the mother had a thyroid condition, it changed the direction and tone of the conversation, because she was concerned a little bit about her daughter possibly having a thyroid condition. Which absolutely can be an underlining cause of constipation. So it didn't change anything yesterday, but it set up a different dynamic for the second visit. We'll have a much different threshold for ordering investigation to rule out thyroid problems in this young girl next time, because of that FH. I'm not going to just look at the FH, but it's one of these extra pieces of evidence that might help.	FH can change the patient management. Will change his threshold for ordering investigation.
TDF **MEMORY, ATTENTION, DECISION PROCESSES** Cognitive factors and processes that make it easier or harder to take FH Note: when they ask FH (new patient, return, when symptoms…)	40 to 60: For news patients, before they even come into the room, or before I see them, rather, I have a small intake form. It's a very basic form where I ask them/the family to describe what are the reasons for the visit, and a little bit about the medical background of their child. That includes their immunization status, allergies to medication, allergies in	For new patients, give an intake form to fill that includes FH questions, but he lets them very vague.

(Ability to retain information, focus as required, make decisions, etc in relation to implementing/maintaining routine FH taking)	general, medication that they may be on. And I do ask specifically about FH but I leave it very vague. I let them fill it out. I ask about the family demographics. Are there any siblings? What do the parents do? Are there any smokers at home? Do they have any pets? Things like that. About half the time, that gets under-populated, that sheet. And that's not a bad thing. It give me an idea about the functionality of the family. Maybe they are busy, maybe they didn't understand it, sometimes there is a language barrier... And the other thing that's really helpful is that I have that form and they tell me why they think they are coming. And then I have the referral from the physician, and the reason why they were referred in the first place, and sometimes there is a disconnect. It tells me what the relative priorities are for that family, what their understanding is. So it seems like to you, FH goes beyond diseases that run in the family: it's very bio-psycho-social, about the dynamics. P: Absolutely. There's no way you can do pediatrics unless you consider those factors. I spend a lot of time talking about, obviously, the presenting complaint, how it evolved., how long it's been there, what did they do. If they did see it, or who was looking after the child, who did see it. Who is the daycare provider? Who is working right now? And then I really get into the social aspect quite a bit. Who are the extended family? Are the grandparents involved? Who picks them up from school? If it's relevant... But the psycho-social aspect, the dynamics, the functionality of a household are very very important. They may not be necessarily relevant to the particular situation, but they are always important. 197 to 198: Yes I think so. Getting the history is one of these things where when you get the information, you process it right away. 483 to 495: So I may just I may just ask quickly at the beginning, because we are really focused, when their babies are first born, on how did it go with the pregnancy, how was the delivery, what happened at the hospital, how was the weight gain, how are you coping… So basic primary care aspects. And I will	When you get FH info, you process it right away. With primary care patients, doe s not actively update FH info. Waits for parents to bring something new. He doesn't ask regularly because those patients are healthy.

	add to it as we seem them further on: ok we didn't talk about this last time, but just so I can have a complete file here is there anything in the family I need to know about? Do you guys have any chronic illnesses? Are you sick? Are you taking any medication? What's happening? So we sort of build it. And because everybody is evolving, if there is something relevant, I do expect them to tell me periodically. If there is anything new going on in their lives… Because it will impact the health of their child, potentially. So I do ask, but I don't ask regularly. Because, again, most primary care patients I have are healthy. I am seeing them just for routine visits. And it's because they are coming regularly that they stay healthy.	
TDF **ENVIRONMENTAL CONTEXT AND RESOURCES** Factors in the physical, organizational environment or circumstances that promote or hinder FH taking as a routine practice (Circumstances of situation or environment that encourage or discourage, development of skills relating to routine FH taking)	423 to 425: So you really feel that it is your professional role to take FH, right? P: Like I said, if I had to forgo something... *thinks for a moment* I don't know, I don't even think I could forgo FH, because it's so easy and quick to get FH. 498 to 510: You mentioned earlier that FH can take time, but on the other hand, on some occasions it's only 8 seconds. Would you say that time is a barrier in your work environment? P: *thinks for a moment* No as a consultant I will often, the way that the triage is… There's a lot of complex patients: behavioural issues, problems at school, lots of social issues… I will often leave those referrals at the end of the day. It's not uncommon for me to go 90 minutes or longer. Some parents are very concerned and I'll just talk them into the ground, until they're deaf. Sometimes it's what you have to do it. Sometimes we'll just say: do you have any other questions? And I'll just wait for them to say: no, thank you, we're good, we can leave now. I would rather then feel that they leave on their terms instead of being ushered out. If it's relevant, I'll spend more time. If it's not then… It's not an issue for me, I think, because I don't do a lot of primary care. (...) I don't think I've ever come across any situations where I had to worry about not getting the information, or that time was a barrier, no. 511 to 516: Other than time, do you feel that in your	FH is easy and quick to get. Time is not a barrier. With his consults, he takes the time he needs, it`s important. Sees no other barriers to FH taking in his practice.

	practice, in your office, you have enough resources to adequately collect FH? P: I think so. Again, because it's not something is traditionally thought of as requiring extra tools to do, it's based on a history, it hasn't been a barrier because… *pauses for a moment* I don't know what other tools really I would use, that would be better than others I am using now, which is just sitting with families and talking…	
TDF **SOCIAL INFLUENCES** Perception of pressure or expectations from peers, professional bodies, patients, etc., about FH taking (Interpersonal processes that encourage or discourage routine FH taking)	211 to 215: Often just for comfort's sake of the family, I'll arrange a follow up. I'll say: "Look, I don't think this is a big deal, here's why.. But you know what? Jus to be on the safe side, because you had this concern, because somebody in your family had this, because we haven't been able to rule it out, why don't you come back and see me." 425 to 430: It's not something I say right from the outset, I don't ask right at the outset unless the family brings it up. "My daughter has headaches. And I'm really concerned because I had headaches, my mother had headaches, and I just found out my sister has been diagnosed with a brain tumour." You know, those kind of things. So will say: "Well, ok, it's unlikely that your 10 year old daughter has a brain tumour because she has no other physical symptom. But we don't know yet, so let's evaluate." 442 to 451: You just mentioned that sometimes, it's not just you: CHEO thinks it's a good idea to take FH, and there's other institutions who think that's a good idea... Do your colleagues or institution or any external body influence the way you take FH? P: Yeah. I mentioned it to you because I trained at CHEO. I know when the residents and trainees are coming out of there and I see them, how they approach their history taking, and there's a component where they always ask about FH. In that sense there is some consistency in the way we are trained. When I meet colleagues who have trained in other places we say the same thing, you know. They ask about FH. And again when we read in journals, when we read in articles and what not, there's almost always a component about a FH.	Parents that are worried about FH can change threshold for ordering investigations, even if he thinks it's ok. Can re-evaluate because parents worry about some FH. Feels influenced by where he trained, and he can see residents who trained at the same institution take FH similarly. Feels also somehow influences by the literature – although he says he doesn't know much about the evidence, he sees that in articles there's almost always a FH component.

TDF **EMOTION** Emotional responses that are (or could be) elicited by FH taking as a clinical behaviour (Emotional responses (by doctor or patient) to any aspect of FH taking, within or external to the clinical encounter)	238 to 243: Of course, yeah. If a family says: "Hey listen, my uncle died from cancer and now my father just got diagnosed. The doctor said that I should get tested now too." They brought in their child for another reason but she ends up talking more about her FH. So again, from a psycho-social perspective, it is a vulnerable family. I don't want them leaving with more on their plate. You have got to put things in context. If there is something concerning I need to tell them, I need to be honest and transparent with them. But it's not just what you tell them: it's how you tell them. There's a way do to it… 253 to 262: Most families I've talked to said something like: "If I had to sacrifice something, I would sacrifice something of my own if it meant helping my child." So I think when they are engaging with me and pediatricians in general, they recognized we are there to help – we are there to help children, arguably the most vulnerable part of society. Children are vulnerable, right? They can't advocate for themselves. We created this society where they can't do it. We've created barriers. Children are dependent. So we are helping these dependents when they can't help themselves. So I think it's really important that we advocate for them along with the parents. The emotional idea is: I want parents on board. I need to know that they are on the same page as me, or I'm on the same page as them, because we'll be able to tackle the problem better if we are working together. So that's really important… But in doing so I have to understand the dynamics of the family. 272 to 280: So, you know, it's very rewarding. I mean, I consider my job among medicine as one of the most important ones. I mean, I'm not fixing bones or doing brain surgery and doing lifesaving operations for adults, and I don't, to be honest, do that for children in the office, not lifesaving issues. But I don't I don't think it's any less important when I help a family identify that their child has depression. And if you don't treat this depression the possible followed effect can be very significant. If you don't identify that your 9 year old had depression, then when they are 10 or 11 and they're having	Some FH might makes the parents worried, even if it's their FH and not the child's – it makes them vulnerable. Ex: parent whose uncle died of cancer, his doctor told him he should get tested too. He feels he absolutely needs to help children because they are vulnerable, and he needs parents to be on board, to engage. FH taking can elicit some emotions in him because helping the child and the family is important and rewarding. He looks forward to see certain kids. It's encouraging to see children get better. Some FH can make parents worried, and he has to reassure them.

	problems or being bullied. Those things happen… And unfortunately we hear about that, we hear it in the news. We have the opportunity to stop that. It is a scenario which is really difficult because it stigmatizes, most people don't think about it as an issue. 303 to 304: But yeah from a personal/professional point of view, I look forward to see certain kids, to be honest. 425 to 430: It's not something I say right from the outset, I don't ask right at the outset unless the family brings it up. "My daughter has headaches. And I'm really concerned because I had headaches, my mother had headaches, and I just found out my sister has been diagnosed with a brain tumour." You know, those kind of things. So will say: "Well, ok, it's unlikely that your 10 year old daughter has a brain tumour because she has no other physical symptom. But we don't know yet, so let's evaluate." 522 to 524: I'm asking people to open up and give details they really wouldn't give to anybody else. And they're not even my patients! They're the parents of my patients. But I still ask because sometimes I still think it is relevant.	What he is asking could be very intimate details.
TDF **BEHAVIOURAL REGULATION** Factors or interventions that would help change FH taking behaviour (Behaviours/systems aimed at managing/changing personal intentions about routine FH taking)	74 to 77: But I think the evidence would have to be very very very compelling if I was going to change my practice. Now, after practising for a number of years, I see the value of it, more than ever. I can't see me changing the way I practice. I may evolve it, but I'm not going to stop taking it. 455 to 459: I honestly don't know what the evidence is except to say, like I said in the beginning, it would have to be very very compelling to me, and you'd have to prove to me that it's not relevant before I would change whatever in my practice. I would have a hard time changing my practice because really no downside. I really don't see a downside. 460 to 462: So even if there were guidelines out there, or tools that would be recently developed...	To change his habits, would need very compelling evidence. Compelling evidence would make him change his practice, but he would have a really hard time changing it. Would consider guidelines or tools, but does not see himself really changing his practice.

	P: Oh, I would definitely consider them. But unless it's really going to change my practice, I don't know that... I don't know right now... 544 to 553: There are no tests for a lot of conditions that are in that sphere, in that element, in that domain of mental health. So that's where the experience comes in. It's taken me a long time enough, but still… You feel like you are still learning about this? P: Oh of course, yeah, yeah. It took me several years to get comfortable with it. Then fortunately you get to a point where you are making and you're getting lucky sometimes, and your patients to better, so it reinforces the way you practice. And then no matter how long the practice, no matter how good you are, at some point I think it is realistic to say you're going to come across with a situation where you made a mistake. And you better hope you are in the right frame of mind because the best you can do is learn from that. So you make sure the patient is covered but you are not going to let that happen again.	Mistakes can make him change his practice, even if it goes beyond the guidelines. It is important not to let it happen again. Need to learn from it.
Can FH taking be isolated in the practice?	214 to 219: So I think using the FH just gets incorporated with everything else. It's not one aspect all the time. And I don't take the FH and forget everything else and plug it in an algorithm and say: ok, we now do this. I process it in a way that it becomes one element of significant information that I get from the interview and I will weight it accordingly. But I don't have a decision-making tool that says to do this. That's how I do it: I process the information quickly, and we move one and it's stored in your brain. You recorded it. 263 to 265: I lump in the FH and the social history together. When I ask about FH I also want to know, like: what are the finances like? I never see the dad, so is everything ok at home? Oh yeah it's fine, ok… 300 to 303: So again, a FH is important, but they may not even know that they are suffering from a condition. So that's where I lump in FH and social history together. Because I think that	FH taking embedded, incorporated with all aspects of practice. Embedded… Social and FH lumped in, hard to differentiate between the two. FH is like using a pen or a stethoscope. It's something very basic in his practice, something that defines being a

	in pediatric practice it's sometimes hard to differentiate between the two. 462 to 466: But again it's one of these areas, like the example I gave you earlier... If somebody would come up to me and say: "You know what, you should no longer use a stethoscope to check for murmurs and heart sounds. Now you should be doing Dopplers." Most of us would say:" Are you crazy?" I don't know what that means, I haven't trained in that, so I don't know what the relevance of that is. I don't know if it's been validated appropriately. FH is like using a pen, or a stethoscope. 467 to 470: So it would be very very difficult to change your FH habits and it would need very solid evidence? P: Yeah. And considering it's also been so entrenched in the way we practice. I mean that is the single most identifiable icon of the physician, besides the white coat maybe. Actually it has to be the stethoscope because you don't need a white coat. A white coat could just mean you work in a lab.	doctor (more like the stethoscope). FH is entrenched in the way he practises.
Science vs art	220 to 234: Medicine, especially in pediatrics is as much as an art as it is a science. You do need to know the science well. You have to understand why the heart makes this particular sound, what it means when the child is unwell, what is the caloric intake and how it's relevant. But I need to know how to get that information and identify areas that are very gray. (...) So there's the art aspect which in pediatrics, I think, is very relevant and difficult to measure. I think it distinguishes between the people who are going to be really good at their job and everybody else. 452 to 455: But we just know it's one of the elements that is part of the evaluation, and it's up to us to... This is where the art comes in - how much do you focus on it. Sometimes I feel it's a little, sometimes I feel it's a lot. But I do think that we all probably have some understanding that FH is important.	Medicine (and FH) is an art and a science - need to interpret the info and determine when it is relevant. Art vs science: The focus you put on FH is part of the art aspect.
Ask about symptoms and not diagnosis	298 to 300: So I'm asking her: "How are things going?	Can ask questions in a different way because parents

	Are you getting help? What do you do to get any time for yourself? Have you been able to see your doctor just to make sure you are staying healthy?" Because you need to be healthy yourself in order to take care of your children. So again, a FH is important, but they may not even know that they are suffering from a condition. 358 to 360: I think you see dispositions that way and I think it's largely genetic , but it's going to be obviously influenced by environmental factors. But I think when you ask the family, most of them are pretty honest. And I'll say: "Well, did you ever get told that from your family, from your parents, that when you were young …" Some of them will disclose that. I do think it's valuable, it's just highly dependent on this, the context. 370 to 380: If a family comes in, again, another example… A child is having headaches. And it depends, because headaches in a 4 year old it's not something… Or even in a 2 year old: why would a 2 year old complain of a headache? They don't even know what a headache is… Versus a child about to go to school, versus a child who's entering puberty, versus a teenager who is having trouble in school. You know, it's a very different pathology. But, you know, for example if the family says: " I have a history of migraines." Ok… If the child has migraines too, if it's very obviously a migraine, again, I'm going to pretty much ask: "Who else has migraines?" And invariably I'll get an answer. "Well you know what, my grandmother used to have a lot of headaches. She used to have migraines all the time. She would have to lie down. That's what I remember from when I was a kid. Too much noise, too much sound, she would go upstairs lie down in the bedrooms and no one would see her for 2 hours." So I said ok, that makes sense.	may not know they have some mental health condition. Example of when can ask about signs and not diagnosis. Can also ask about symptoms and consequences, not diagnosis, because parents may just not know for sure.
Heredity vs familial setting	So overall, you really think that FH taking can impact your patient's health, correct? P: No question, yes. And it's not just the FH that's relevant to the patient's particular concern. Of the mom has a thyroid diseases, could it also affect the child, yes. But if the mom has another chronic illness, it's going to affect the child's ability to be healthy if	FH, even medical FH of parents that is not necessarily genetic, can show how are things are at home and if the parent can appropriately care for the child.

	the mom cannot care for this child. So indirectly, there's a psycho-social component to the FH. 291 to 300: I may ask in open-ended questions, like: How are you coping? I have a mom who comes in regularly. She has babies who were only slightly prematured, maybe about 4 weeks, but they were twins and one of them was really not growing well. And this mom is very pleasant, very nice. She's got a very slightly different demeanour in the sense that she doesn't necessarily always smile right away when I talk to her for a start but she's very pleasant, very capable, she's doing a good job. But she is caring for twins, plus she has 2 other children under the age of 5. So it's a very busy household… And her partner is always working, the dad is always working. I'm always in the back of my mind thinking: I wonder how she's coping. So I'm asking her: "How are things going? Are you getting help? What do you do to get any time for yourself? Have you been able to see your doctor just to make sure you are staying healthy?" Because you need to be healthy yourself in order to take care of your children.	Again – health of the parent can affect the health of children, it's not just about hereditary things. A healthy parent can take care of the child.
Pharmacogenomics		
Awareness		
Privacy		
Cultural background can affect FH taking		
More data is better	90 to 92: If someone comes in with, for example, asthma, do I care that the mother had her appendix out when she was 20? Probably not. Is it relevant? Probably not. But there's no harm in getting that data, except for the extra time it takes.	
	160 to 167: I see this a lot when I have medical students residents working with me. They'll ask particular questions that report the history to me - I always ask about FH, and I get them to report it too. And I want to make sure they ask the questions that I think they should ask. Most of the time there's consistency, and they ask the kind of questions I would expect them to ask. So it reinforces the fact that people are being taught similar, certainly in the pediatric stream. But most of the people that I work with are coming from	Not much practice variation, all seem to get taught to ask the same questions about FH. When he has residents, they tend to ask all the questions he wants them to ask.

	CHEO, where I trained as well. There is not much practice variation because we train in a similar stream with similar people.	
	607 to 610: But I think… Medicine it going to evolve and we're getting further and further down and understanding more and more. So the FH will be… I don't want to see it's irrelevant, it's just that the nature of how we will identify the FH will change. As we get more information of how our genetics is and how we are a product of our environment.	Future views...

PARTICIPANT 36 – Dr Brenda Wilson

Participant thumbnail	• FH is core part of professional practice • Holistic view where FH is seen as encompassing broader insight into family circumstances, beliefs, dynamics, etc • FH taking is extremely embedded in personal practice and not separated out from 'non-FH' issues when being discussed in the interview • Confident in skills	
Descriptive: Current practice	*So about FH... What FH information do you collect?* [41] For new patients, before they even come into the room, or before I see them, rather, I have a small intake form. It's a very basic form where I ask them/the family to describe what are the reasons for the visit, and a little bit about the medical background of their child. … And I do ask specifically about FH but I leave it very vague. I let them fill it out. I ask about the family demographics. Are there any siblings? What do the parents do? Are there any smokers at home? Do they have any pets? Things like that. About half the time, that gets under-populated, that sheet. And that's not a bad thing. It gives me an idea about the functionality of the family.	Social perspective as well as clinical/health
Descriptive: General attitudes to routine FH taking	[58] Who are the extended family? Are the grandparents involved? Who picks them up from school? If it's relevant... But the psycho-social aspect, the dynamics, the functionality of a household are very, very important. They may not be necessarily relevant to the particular situation, but they are always important.	Social perspective
Descriptive: Opinions on what skills are needed		
Descriptive: Opinions on factors that influence the quality of FH obtained		
TDF **KNOWLEDGE** Awareness of potential application of FH in pediatrics		
TDF **SKILLS** Training/experience in FH	[100] We were taught: ask about FH. And I remember, we were taught to ask about the	How taught to take FH in the first place, how understanding

taking	big things: cardiovascular disease, stroke, diabetes, hypertension, arthritis, chronic diseases, medication use, hospitalisation, things like that. And they basically said "ask those things". It probably didn`t become relevant until later on, when we started putting two and two together and we started having clinical experience, to recognize where FH is important... And it's not just about the parents, it's also the siblings. "Oh well, my other 2 children also had this." [162] They'll ask particular questions that report the history to me - I always ask about FH, and I get them to report it too. And I want to make sure they ask the questions that I think they should ask. [215] So I think using the FH just gets incorporated with everything else. It's not one aspect all the time. And I don't take the FH and forget everything else and plug it in an algorithm and say: ok, we now do this. I process it in a way that it becomes one element of significant information that I get from the interview and I will weight it accordingly. But I don't have a decision-making tool that says to do this. That's how I do it: I process the information quickly, and we move one and it's stored in your brain. You recorded it. [342] And I have to be honest: I probably have changed my approach a lot since I was a resident. Because I have less time and just with experience… [353] So if I see a child with anxiety – and sometimes it's obvious that a child has anxiety – then I won't even ask the FH in open terms. I'll say: "Who else has anxiety in the family?"	developed with experience Skills revealed through approach to training students/residents Reflection on how he/she adapts FH taking approach depending on context
TDF **SOCIAL/PROFESSIONAL ROLE AND IDENTITY** Relationship of FH taking practice to professional/group identity, role, boundaries	[55] There's no way you can do pediatrics unless you consider those factors. [66] Here's a generational teaching tool, here's how your predecessors did it, here's why we think it's important. [302] So that's where I lump in FH and social history together. Because I think that in pediatric practice it's sometimes hard to differentiate between the two. [444] *You just mentioned that sometimes,*	Professional ownership Relates to pediatric practice specifically

	it's not just you: CHEO thinks it's a good idea to take FH, and there's other institutions who think that's a good idea... Do your colleagues or institution or any external body influence the way you take FH? Yeah. I mentioned it to you because I trained at CHEO. I know when the residents and trainees are coming out of there and I see them, how they approach their history taking, and there's a component where they always ask about FH. In that sense there is some consistency in the way we are trained. When I meet colleagues who have trained in other places we say the same thing, you know. They ask about FH. And again when we read in journals, when we read in articles and what not, there's almost always a component about a FH.	
TDF **BELIEFS ABOUT CAPABILITIES** Self-confidence, self-efficacy about FH taking in personal clinical practice	[189] *Overall do you feel confident in your ability to take FH?* You know what, I never really thought about it so I'll have to say yes. *laughs* Because I have never had reasons to go back and look at it. And even if I did, even if I missed something, it hasn't really impacted. It may just add to the story. [193] It hasn't become a problem where I missed something on the FH that has really changed what I do or has affected the care that I can give for that child. So I feel pretty confident in what I do. But again, it's just based on experience more than anything. [467] FH is like using a pen, or a stethoscope. [548] *You feel like you are still learning about this?* Oh of course, yeah, yeah. It took me several years to get comfortable with it. Then fortunately you get to a point where you are making and you're getting lucky sometimes, and your patients to better, so it reinforces the way you practice.	Basic clinical competence
TDF **OPTIMISM** Extent of confidence that routine FH taking will make things happen for the best or not	[77] I see the value of it, more than ever	Or perhaps beliefs about consequences?
TDF **BELIEFS ABOUT CONSEQUENCES**	[48] It gives me an idea about the functionality of the family.	Understanding family dynamics

What person thinks will happen as a result of routine FH taking	[136] why is it important to get a FH, how is it going to affect your clinical decision	Influencing clinical decision-making
	[139] Because the mother had a thyroid condition, it changed the direction and tone of the conversation, because she was concerned a little bit about her daughter possibly having a thyroid condition. Which absolutely can be an underlining cause of constipation. So it didn't change anything yesterday, but it set up a different dynamic for the second visit. We'll have a much different threshold for ordering investigation to rule out thyroid problems in this young girl next time, because of that FH.	Influencing clinical decision-making Holistic perspective on care of child Influencing clinical decision-making
	[147] If the mom has a thyroid diseases, could it also affect the child, yes. But if the mom has another chronic illness, it's going to affect the child's ability to be healthy if the mom cannot care for this child. So indirectly, there's a psycho-social component to the FH.	Influencing clinical decision-making Diagnostic clarity
	[201] But if the mom says: "well, I was diagnosed with inflammatory bowel disease just a few years ago and I started off exactly like my child", I will have a much lower threshold for ordering investigations. So it does definitely dictate things, but when I look back, I think: you know what? That's something I should have on my differential anyway.	
	[330] So if you're speaking specifically from a clinical perspective, if I know there is a FH of atopic disease, asthma, allergies, eczema, and that child is coming in that may fall under the same umbrella it does help guide the diagnosis a little bit. It does help guide the management plan, absolutely.	
	[364] And sometimes it's just an extra piece of the puzzle. Especially when it's not clear what's going on, that's another time it's helpful. They're telling me their child presents with problem A, B, C, the investigations have kind of ruled out those things, so all the ones I would have thought about are not so obvious. But if I get a FH now, it's another piece of the puzzle that could really change the way we approach that, the problem.	

TDF **REINFORCEMENT** (Potential) rewards, reinforcements, incentives, disincentives, sanctions related to implementing/maintaining routine FH taking		
TDF **INTENTIONS** Conscious decisions or resolve to implement/maintain routine FH taking		
TDF **GOALS** Explicit descriptions of outcomes that routine FH taking is intended to achieve		
TDF **MEMORY, ATTENTION, DECISION PROCESSES** Ability to retain information, focus as required, make decisions, etc in relation to implementing/maintaining routine FH taking		
TDF **ENVIRONMENTAL CONTEXT AND RESOURCES** Circumstances of situation or environment that encourage or discourage, development of skills relating to routine FH taking	[93] …except for the extra time it takes [409] "Ok, that's really interesting and I'd love to talk about that more. Let's talk about your child, here, right now. Because we've only got 15 minutes left." Let's redirect... So it may not be relevant. If it was, I may engage with them a little bit more. Everybody's style is different. Some people spend a lot of time, much more time on FH.	
TDF **SOCIAL INFLUENCES** Interpersonal processes that encourage or discourage routine FH taking	[213] I'll say: "Look, I don't think this is a big deal, here's why. But you know what? Just to be on the safe side, because you had this concern, because somebody in your family had this, because we haven't been able to rule it out, why don't you come back and see me."	Perhaps should be in beliefs about consequences?
TDF **EMOTION** Emotional responses (by doctor or patient) to any aspect of FH taking, within or external to the clinical encounter	[237] *That makes me think there might be an emotional aspect to family history taking… Do you think so?* Of course, yeah. If a family says: "Hey listen, my uncle died from cancer and now my father just got diagnosed. The doctor said that I should get tested now too." They brought in their child for another reason but she ends up talking more about her FH. So	Not sure this is emotion; relates also to professional role, beliefs about consequences?

	again, from a psycho-social perspective, it is a vulnerable family. I don't want them leaving with more on their plate. [257] Children are vulnerable, right? They can't advocate for themselves. We created this society where they can't do it. We've created barriers. Children are dependent. So we are helping these dependents when they can't help themselves. So I think it's really important that we advocate for them along with the parents. The emotional idea is: I want parents on board. I need to know that they are on the same page as me, or I'm on the same page as them, because we'll be able to tackle the problem better if we are working together. So that's really important… But in doing so I have to understand the dynamics of the family. Are they part of a blended family? Are they split? What are the relationships? Who's looking after them? What are the other issues going on with this family? I lump in the FH and the social history together. When I ask about FH I also want to know, like: what are the finances like? I never see the dad, so is everything ok at home? Oh yeah it's fine, ok… And they don't have to reveal it, they're not obligated to reveal it. It's helpful if they do, but… So I do think there is an emotional component, absolutely.	
TDF **BEHAVIOURAL REGULATION** Behaviours/systems aimed at managing/changing personal intentions about routine FH taking	[468] *So it would be very, very difficult to change your FH habits and it would need very solid evidence?* Yeah. And considering it's also been so entrenched in the way we practice.	Embeddedness of FH taking