The Role of Value Concordance in Family Planning Care for Underserved Women

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Dedication

To women around the country who continue to face significant barriers to receiving high quality women's health care in an age when it should unequivocally be a basic human right. I dedicate this dissertation to you.

Acknowledgements

I cannot begin the introduction to this dissertation without first explaining its primary source of motivation. As the daughter of an immigrant mother, I grew up with stories about my *Abuelito* who was a physician during the era of political conflict and civil war in Colombia in the mid-20th century. After seeing dozens of patients in his clinical practice, my grandfather went home each night to his wife, his seven children, the two grandmothers, and the parrot that lived in their small apartment in Bogotá, Colombia. As if this wasn't enough, he traveled on the weekends to rural villages to deliver free essential health care in areas where clinical services were often scarce or non-existent and where many people had been displaced due to political violence. Most families had no money to pay for their services, but they often brought live chickens, hand-sewn tablecloths, or bags of corn that they offered in return for the care my *Abuelito* provided. Rarely, would he accept payment. His commitment, dedication, and passion to serve vulnerable populations stuck with me throughout my childhood and especially as I turned my professional interests toward public health. This dissertation, and my broader research portfolio are fundamentally driven by this very spirit of humanitarianism and social justice.

Among the next generation of grandchildren in our family, six of us have followed in *Abuelito's* footsteps as practicing physicians, medical students, other clinical providers and public health practitioners and scholars. I am sure each of us would count him as the leading source of inspiration for entering our respective fields, and it does me a profound honor to share in this legacy.

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I must recognize the invaluable partnership of the four community health center sites and their staff who served as primary research partners for the qualitative component of the study and the survey fielding procedures. The strength of this research study hinges strongly on your partnership and collaboration. I also thank the 12 participants of the technical expert panel that provided expert feedback on the development and definitions of the important domains of value concordance in a family planning context. I would like to thank the community health center patients who participated in the qualitative focus groups, interviews, and survey efforts. This work represents the voice of these remarkable participants in exploring elements of family planning care that are most important to underserved women in an attempt to realign health care systems in a truly value concordant and patient-centered way.

I also express my profound appreciation to my family and closest friends. To my parents Mike and Clarita for supporting me in each step to achieve my dreams. You have never stopped believing in me, even when I often lacked faith in myself. To my brother Nickolas Mattox for his unending support and reminding me to just “get it done.” To my in-laws, Dick and Robin Beeson, Nathaniel Beeson and Michael Beeson for their always kind and supportive encouragement. To my cousin, Dr. Tamara Grisales for offering equal parts technical consultation and personal inspiration when I needed it most. I thank my dearest friends, particularly Josh and Victoria Kennedy, Drs. Brad and Kasey Kasavana, Dr. Patsy Vargo, Megan DeLong, Andrea Croft, and many others who continued to offer support and insight from beginning to end. Many of them have shared

their own stories about patient preferences helping me ground my work in the collective experiences of women and families in my own community. To each of you, and to the countless others who are not named here, I thank you for making my work inspired and meaningful.

My deepest gratitude is saved for my husband and true partner, Aaron, who has granted me the strength of heart, courage of conviction, and peace of mind to carry this work out to completion. We have walked each step of this journey together, through the challenges and the victories. I share any achievement and all success with you.

Abstract of Dissertation

The Role of Value Concordance in Family Planning Care Among Underserved Women

Tailoring family planning care to patients' unique needs and preferences has been recognized as an effective approach to improving contraceptive and other family planning outcomes in both U.S. and international populations, but only limited knowledge exists on how health care providers incorporate patient values and preferences into their care delivery models (RamaRao & Mohanam, 2003). This dissertation attempts to explore the role of value concordance, defined as the degree to which patient experiences match or correspond with their expressed preferences, in the context of family planning services delivered to medically-underserved women. Through a mixed-methods approach, this study uses a grounded theory design to understand how underserved women form their preferences for family planning care and identifies the specific preferences that underserved women have for receiving family planning services by conducting patient focus groups and individual interviews with 53 women of childbearing age. The study also incorporates these qualitative findings with the input from a panel of nine technical experts to achieve consensus on the domains and items that comprise an original family planning value concordance (FPVC) measure. This FPVC instrument is used to pilot test the measure in a sample of 110 underserved women of childbearing age in two community health center (CHC) sites. Standard factor analyses and psychometric tests are performed to assess the reliability and validity of the FPVC measure in the target population of underserved women of childbearing age.

The most significant findings emerging from the grounded theory phase of the study included the development of an original conceptual framework to understand value concordance in the context of family planning services. This framework outlines six factors that influence how women form their preferences including life stage, health beliefs and culture, access to services, patient-provider interactions, information, and social support. These factors influence whether patient preferences and patient experiences can be aligned in a value concordant way, and were described by patients to strongly influence how they make family planning and reproductive health decisions. In the follow-up survey effort, an FPVC measure of 13-items was finalized through exploratory factor analysis and tested among the pilot sample. The average FPVC score was observed at 0.573 representing approximately 57 percent of patient experiences matching or corresponding to patient preferences. FPVC scores were modestly positively associated with patients' satisfaction with providers (p-value=0.068) and with clinical settings within which they received family planning care (p-value=0.093). It was also positively associated with family planning knowledge (p-value=0.096). However, no evidence of relationships between FPVC and either contraceptive use (p-value=0.634) or contraceptive discontinuation (p-value=0.530) was observed. The FPVC scale exhibited moderate reliability with an overall internal consistency of α=0.696.

This study offers a preliminary conceptual framework to apply value concordance to the delivery of family planning care and supports the proposition that improved quality and patient-centeredness can improve family planning decision-making among low-income and underserved women. With additional testing and refinement, the original FPVC measure serves as a promising early mechanism to both assess patient

preferences and evaluate the degree to which value concordant care can occur in health center settings. In light of the recent changes in the women's health policy landscape, offering these two tools is a critical step in ensuring that high quality family planning care is available to underserved women and delivered in a value concordant way to help them achieve the family planning and reproductive health goals they desire.

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Chapter 1: Overview of the Study

1.1 Background and Statement of the Problem

Despite advances in family planning technology and the widespread availability of contraceptive drugs and devices, low-income, uninsured, racial and ethnic minority, and other medically-underserved women continue to face barriers to high quality family planning care (Peipert, Madden, Allsworth, & Secura, 2012). Underserved women have reported experiencing unique barriers to accessing family planning and contraceptive services such as prohibitive costs of family planning care, difficulty obtaining and utilizing contraceptive methods, embarrassment or fear about acquiring a certain method, concerns about health and side effects, objection from partner, and lack of knowledge about acquiring and using certain methods (Peipert et al., 2012; Silverman, Torres, & Forrest, 1987; Sable & Libbus, 1998). We also know that low-income and minority women tend to use different contraceptive methods, are less likely to use contraception at all, and are more likely to experience contraceptive failure, than other women, putting them at higher risk of an unintended pregnancy (Dehlendorf, Rodriguez, Levy, Borrero, & Steinauer, 2010). It is no surprise then, that these same populations tend to experience higher rates of unwanted or unintended pregnancy and poorer perinatal and birth outcomes compared to the general population (Kramer, Según, Lyden, & Goulet, 2004; U.S. Census Bureau, 2012).

While the literature suggests that underserved women experience barriers in access to family planning care that may help them avoid or reduce these poor outcomes, other barriers may be directly associated with differential quality of family planning

services that underserved women experience (Becker, Koenig, Kim, Cardona, & Sonenstein, 2007; Dehlendorf et al., 2010b). In particular, recent attention has been focused on the notion that underserved populations may have differing values and preferences about family planning care which may influence their service utilization, their experience with those services, and their subsequent outcomes, although this relationship has yet to be substantiated through empirical testing in underserved settings. Tailoring family planning care to patients' unique needs and preferences has been recognized as an effective approach to improving contraceptive and other family planning outcomes in both U.S. and international populations, but only limited knowledge exists on how health care providers incorporate patient values and preferences into their care delivery models (RamaRao & Monaham, 2003).

Assessing and integrating patient values into the delivery of health care services is a core component of patient-centeredness, a concept that is central to many of the current conversations on health care quality in the United States (Epstein & Streeter, 2011). Patient-centered care has been defined by the Institute of Medicine (IOM) as "healthcare that establishes a partnership among practitioners, patients and their families (when appropriate) to ensure that decisions reflect patients' wants, needs, and preferences" (Institute of Medicine [IOM], 2001). One analogous application of patient-centeredness is the concept of *value concordance* which is defined as "the degree to which patients' experiences or treatments reflect their preferences," aligning closely with the IOM's definition of patient-centered care as responsive to individual preferences and values. This dissertation argues that value concordance is particularly important in the areas of family planning and reproductive health, as many of these care decisions may be

sensitive in nature and patients may have express values about how they prefer to receive care in a family planning setting that are different from their preferences for general health care (Dehlendorf, Diedrich, Drey, Postone, & Steinauer, 2010). These preferences may directly impact their care seeking behavior and utilization of family planning services, as well as their family planning outcomes (Knight, Latini, Studts, & Sands, 2010). For the purposes of this dissertation, the terms "preference" and "value" will be used interchangeably, as both have been used extensively in the literature to represent patients' preferred treatment or the utility associated with a particular treatment or care experience (Sepucha & Ozanne, 2010).

While value concordance has typically referred to the congruence between a patient's selected treatment and his or her preferred treatment in a particular medical decision, the concept may prove to be useful in broader contexts by representing the intersection between a patient's preference for the way family planning care is delivered and the experience she has in a family planning visit. Thus, value concordance may represent the correspondence of preferences and experiences on a number of elements of the overall patient visit, not simply those that reflect a particular medical decision. As the IOM report suggests, patient-centered care (and value concordance, as one dimension of patient-centered care) must engage patient involvement in all aspects of care design and implementation, not solely at the point at which treatment decisions are made. This involves taking into account the broader context of individual, social, and clinical factors that contribute to health care decisions. With this in mind, family planning value concordance (FPVC) may be a strategy to improve the patient-centeredness of family

planning services, thereby facilitating better decision making to achieve the family planning outcomes that underserved women desire.

Despite the IOM's call for health systems to deliver care that reflect patients' needs, preferences, values, and decisions, few resources and tools exist to fully understand how this type of care actually occurs, and even fewer focus on exploring the patient perspective (Sepucha & Ozanne, 2010; IOM, 2001; Agency for Healthcare Research and Quality, 2005; Shaller, 2007; Becker et al.,2007). Moreover, tailored family planning counseling and other services have long been considered an important element in the quality of family planning care, however no theory linking these important concepts and theoretical relationships has been offered to support tailoring care experiences to patient preferences in a family planning visit. Understanding the role of value concordance in family planning care and its impact on patient outcomes for underserved women will enhance the body of literature on family planning, especially among populations that have traditionally experienced inequalities in the quality of family planning care. The development of substantive theory to address FPVC may also hold promise in building the clinical tools and measures to then assess the degree to which value concordance occurs and offer insight into areas of improvement for providers and health care organizations looking to achieve higher levels of quality in family planning care.

1.2 Purpose of the Study

This study aims to define the role of value concordance in family planning care for underserved women by developing a preliminary conceptual framework through a grounded theory approach. Building on the grounded theory results, this study also

focuses on developing and pilot testing a measure of FPVC with underserved women of childbearing age. Preliminary empirical analysis using this measure of value concordance is also presented, in order to test the predictive validity of value concordant family planning care on select patient outcomes, such as contraception initiation and continuation, satisfaction with care, and other patient engagement outcomes, specifically for medically-underserved populations.

1.3 The Policy Landscape of Family Planning Care for Underserved Women

Underserved women face substantial barriers to accessing family planning services, many of which are due to the high cost of health care and lack of access to health insurance. In response to this need, several key public programs exist to support low-income and other underserved women in accessing family planning services.

In 1970, Congress enacted Title X of the Public Health Service Act to devote resources to delivering family planning and related preventive services to women, regardless of their income status. Administered by the Office of Population Affairs, Title X remains the sole federal grant program for family planning for low-income individuals and families. The program serves approximately 5 million clients annually through a network of over 4,400 providers including state and county health departments, community health centers, Planned Parenthood clinics, hospital-based clinics, school-based clinics, faith-based clinics and other free-standing family planning clinics (Fowler, Lloyd, Gale, Wang, & McClure, 2012). Since Title X funded clinics offer services on a sliding fee scale and are open to clients regardless of age, marital status, income or health insurance status, the program has long-been considered the lynchpin of family planning care for vulnerable populations (Cohen, 2011). Recent studies estimate that the program

averts 973,000 unplanned pregnancies in a single year and that the services provided by Title X clinics save $3.4 billion in health care costs that would otherwise be undertaken by federal and state governments for prenatal and infant care (Gold, Sonfield, Richards & Frost, 2009; Frost, Henshaw & Sonfield, 2010). The program's guidelines and standards for the delivery of family planning services also ensure that patients have access to high quality, confidential, and comprehensive family planning care.

Despite the landmark expansion of coverage through the Affordable Care Act (ACA) of 2010, a considerable number of women may not benefit from expanded coverage for a variety of reasons. These may include women who were unable to enroll in health insurance, who are undocumented or who are legal immigrants in their first five years of residency, who reside in states opting out of Medicaid expansions, or who are in need of confidential services (National Family Planning and Reproductive Health Association [NFPHRA], 2013). For many of these women, Title X clinics may be the only source of women's health and other preventive services available to them and represent an invaluable piece of the safety-net for underserved populations. Although Title X funding has been threatened in recent budgetary crises, this source of public funding for family planning care remains perhaps the most important program to provide family planning care for low-income women.

The Medicaid program also represents a crucial safety-net program offering coverage for essential health services, including family planning. However, adult women of childbearing age have typically faced difficulties qualifying for Medicaid due to limited eligibility in certain states. Several states have pursued Section 1115 family planning waivers to expand coverage for family planning services to individuals who

may not otherwise qualify for Medicaid. In 2009, twenty-four states had been granted a waiver, expanding access to over 3 million individuals (Ranji, Salganicoff, Stewart, Cox, & Doamekpor, 2009). The Affordable Care Act, in addition to expanding Medicaid eligibility, also provides a new option for states to expand family planning eligibility by submitting a State Plan Amendment. This option is a permanent change to the state's Medicaid program rather than a time-limited family planning waiver. As of April 2014, nineteen states opted to expand family planning eligibility through a waiver, while 11 states operate their program through a State Plan Amendment (Guttmacher Institute, 2014).

The ACA affords many other provisions related to women's health and family planning care. Perhaps most relevant to this study is the ACA's requirement of commercial insurance plans to cover women's preventive services including all FDA-approved contraceptive drugs and devices, family planning counseling, and an annual well-woman exam without cost-sharing ("Health Insurance Reform Requirements for the Group and Individual Health Insurance Markets, Exemption and Accommodations in Connection with Coverage of Preventive Health Services," 2010; "Women's preventive services: required health plan coverage guidelines," no date). In theory, this provision intends to ensure that women have the ability to select from the full complement of contraceptive methods, to find the method that best fits her lifestyle, values, and preferences. However some insurance practices continue to present barriers, such as "tiering" services (e.g. only generic or certain brands may be covered) which further limits women's access to the complete range of family planning options and services (NFPHRA, 2013).

Other challenges to the implementation of the ACA's contraceptive coverage requirement have been highlighted recently, with two legal cases appearing before the Supreme Court in March 2014: *Sebelius v. Hobby Lobby Stores, Inc.* and *Conestoga Wood Specialties v. Sebelius.* In both cases, these for-profit companies oppose the requirement to provide health insurance to their employees that covers emergency contraception, based on religious grounds. While the ACA provides for religious exemptions, these cases represent an enormous precedent for the interpretation of these exemptions going forward and have definite implications on the ability to fully implement the women's preventive services provisions as they were intended. A Supreme Court decision is expected in June 2014.

It is clear that low-income and underserved women have considerable support from indispensable safety-net programs and policies such as the Title X program, family planning expansions under Medicaid, and new provisions under the ACA; however, the implementation and sustainability of these important programs is challenged. Even with these challenges, the need for high quality family planning services is still great, especially among women who find difficulties in accessing high quality care. Although much of the movement on these issues has focused on policy-level interventions, it becomes clear that what is lacking from this picture is an understanding of women's perspectives on and experiences with family planning care, especially the experiences of low-income and underserved women who face barriers to accessing these essential services. An in-depth look into how women prefer to receive family planning care, how these preferences play into their experiences, and what role value concordance can play in improving the patient-centered design of family planning care may have important

implications for how providers deliver tailored services that help women achieve their family planning goals. This is particularly important at a time when the policy momentum swings in favor of improving both access and quality of these essential services for women.

1.4 Study Population

This study focuses on the population of women served in community health centers (CHCs), the largest primary care safety-net setting for medically-underserved patients, including women of childbearing age. From their inception as demonstration projects in the Office of Economic Opportunity in 1965, CHCs have grown into a substantial network of community-based delivery systems with nearly 1,200 centers serving over 21 million medically-underserved patients in every U.S. state and territory (Bureau of Primary Health Care [BPHC], 2012). CHC patients are overwhelmingly low-income and largely uninsured or covered through publicly financed health insurance. Compared with the general patient population, patients of CHCs are almost five times more likely to live below the poverty line (72 percent of health center patients vs. 15 percent of the total U.S. population), over twice as likely to be uninsured, and nearly 2.5 times more likely to receive Medicaid (Rosenbaum, Shin, & Paradise, 2012). Approximately half of health center patients self-report as either Latino or African American and 6-in-10 health center patients identify as members of racial/ethnic minority groups (BPHC, 2012).

Approximately 60 percent of health center patients are female, with women of childbearing age representing approximately 28 percent of patients who receive care in CHC settings -- making them one of the largest single groups of health center patients

(Wood et al., 2013). A recent analysis demonstrated that health centers served 20 percent of all low-income women of childbearing age in the U.S. in 2010, with a virtual doubling of the total number of women receiving care in health center settings over the past decade (5.7 million in 2000 and 11.4 million served in 2010) (Shin & Sharac, 2012). Furthermore, health centers' role as a primary care delivery system is expected to grow substantially in the coming years, largely as a response to two critical federal legislative efforts. The first is the Affordable Care Act's provisions to expand insurance coverage to low-income individuals and families through a substantial increase in Medicaid eligibility levels and the establishment of health insurance exchanges for the individual market (Kaiser Family Foundation, no date.). Secondly, a series of federal investments in the health center program, including $2 billion in American Recovery and Reinvestment (ARRA) dollars in 2009 and an $11 billion direct investment in health center expansion appropriated in the ACA have set health centers on the path to double the number of patients they serve by the year 2019 (Ku, Richard, Dor, Tan, Shin, & Rosenbaum, 2010; Rosenbaum, Shin, & Paradise, 2012). Family planning and contraceptive services are an essential women's health service in any care setting, however, health centers have an federal obligation to provide "voluntary family planning" as a part of the required primary health care services outlined in Section 330 of the Public Health Service Act, the authorizing legislation for the health center program (42 U.S.C. Section 254b(b)(1(A)(iii)(gg)). Despite this statutory obligation, there is observed variation in the scope of services provided at community health centers. Recent studies found that while 87 percent of health centers provide a typical package of family planning services (including STI testing and treatment, prescription and delivery of oral contraceptives and

at least one other contraceptive method), only one-in-five offers the full range of contraceptive methods that may be dispensed on-site. Furthermore, these studies found that the mechanisms for financing and delivery of such services widely vary across health center organizations and their respective clinical sites (Wood et al., 2014; Beeson et al, 2014). In particular, only 26 percent of respondents to a 2011 survey of community health center organizations reported that they participate in the Title X program, which provides federal funding for comprehensive family planning services for low-income patients (Office of Population Affairs [OPA], no date).

The role of CHCs in providing family planning services may begin to expand in the coming years, particularly as other sources of family planning care for underserved women continue to face challenges. Some states have restricted funding for STD testing, contraception, and other family planning services to qualified agencies, often limiting women's choice of providers. A prime example is the state of Texas where state funding for family planning (Women's Health Program, WHP) was slashed by nearly two-thirds in the 2012-2013 biennium and the number of recipient provider agencies was reduced to only 41 across the state. Most notable is the barring of all Planned Parenthood Federation of America (PPFA) clinics from participating in the Texas Women's Health Program, further limiting women's access to family planning providers "Texas Women's Health Program Provider Announcements," 2012). PPFA clinics accounted for nearly 49 percent of family planning care financed by WHP in 2010, serving almost 52,000 clients. The state's policy also prioritizes funding toward community health centers and other comprehensive health providers rather than clinics that only provide family planning services. While these women could theoretically get comparable family planning care in

a community health center setting, health centers would need to increase their capacity five times over in order to fill the gap for these patients. Recent analysis by Shin, Sharac & Rosenbaum (2012) states that this type of expansion is virtually impossible given the state's simultaneous reduction in funding for family planning across all providers. Although an additional $100 million was awarded in the 2014-2015 biennial budget, this funding continues to be directed toward CHCs and other similar providers, rather than family planning clinics. How CHCs will be able to respond to both the change in funding and the increased need as a result of limited provider capacity in Texas is a question that remains to be addressed, especially if other states follow suit in cutting family planning funding and limiting family planning providers. Even more concerning is how patient experience will change a result of facing these additional barriers to care, which underscores the significance and timeliness of this study.

As one of the largest primary care delivery systems for underserved patients – and one that is expected to grow considerably as a result of many complex factors, community health centers represent a unique context within which the quality of family planning care for underserved women may be assessed at the patient level. Exploring the delivery of family planning services from the patient perspective in community health centers provides the context for defining and measuring family planning value concordance, specifically for underserved women of childbearing age.

1.5 Former Research Efforts

In 2010, the Geiger Gibson Program in Community Health Policy[*] and the Jacobs Institute of Women's Health[†] at the George Washington University launched a joint effort to examine community health center performance in the area of family planning and reproductive health. The project included a nationwide study of over 420 health center organizations and in-depth case studies of health centers in six communities across the U.S. The purpose of this research effort was to understand the structure, scope, and delivery of family planning services in health center organizations, as well as explore the barriers and challenges to providing family planning services at the CHC organization level. Among other findings, the results of this study showed that while virtually all health centers provide some degree of family planning services as required by their federal designation, the scope of services and the organization and delivery of those services vary greatly from health center to health center. The study also found that health centers often face considerable barriers to providing the full range of family planning services, including lack of financial resources, staffing challenges, and minimal guidelines specific to the delivery of family planning services in health center settings.

Since this study primarily focused on the organizational perspective of health centers and the barriers and facilitators of the delivery of these services, the authors acknowledged the need for additional research focusing on the perspective of patients served in health center settings. They identified areas of promising research including

[*] Established in 2004, the Geiger Gibson Program in Community Health Policy is named in honor of Drs. H. Jack Geiger and Count Gibson, pioneers in community health practice and tireless advocates for civil and human rights. Through education and training and research and scholarship into community health centers and the patients and populations they serve, the Geiger Gibson Program shares the core mission of the community health centers program: to eliminate medical underservice and disparities in population health and health care and improve health and health care for all persons.

[†] The Jacobs Institute of Women's Health (JIWH) is a nonprofit organization working to improve health care for women through research, dialogue, and information dissemination.

studies to explore service utilization patterns, preferences for family planning service delivery, and patient experiences getting family planning care from community health centers. These research recommendations recognized the fact that the patient perspective is critical in order to present a complete analysis of the quality and delivery of family planning and reproductive health services to underserved women in health center settings (Wood et al., 2013). This dissertation research addresses some of these recommended areas through a subsequent inquiry into the patient preferences for family planning of underserved women in community health centers, as well as proposing a measure of value concordance as an indicator of patient-centered care. This study also provides the results of a pilot test of the measure to preliminarily explore whether value concordance in family planning care is associated with better family planning outcomes for underserved women.

1.6 Research Aims

This research project intends to address three specific research aims about the role of value concordance in family planning care delivery and outcomes.

Specific Aim 1: Develop theory to understand the role of value concordance in family planning care delivered to underserved women

This research aim focuses on using qualitative data at the patient level to explore the elements of a preliminary framework on value concordance in family planning care. Using a grounded theory approach for this research phase, this study will

achieve two separate sub-aims in the exploration of FPVC for underserved women.

Specific Aim 1A: Explore what factors influence the way women form their preferences about family planning care. The first sub-aim is to understand the factors that women consider when forming their family planning preferences. Virtually no theory currently exists to examine the drivers of patient preferences for family planning services, an inquiry that is even more complex for underserved populations who may face unique needs and circumstances that influence the way preferences are formed, assessed, and met in a clinical setting. By uncovering some of these elements in a grounded theory approach, this dissertation aims to reveal the factors that may be of most concern to underserved women and are most likely to drive their preferences for family planning care, thereby illuminating the pathway of family planning decision making among underserved women of childbearing age.

Specific Aim 1B: Identify women's specific preferences for aspects of family planning care delivered in community health center settings. Preceding literature has identified patient preferences for general primary care for populations at large, but very limited work has been done to uncover if there are parallel preferences in the context of family planning care. Even fewer studies have examined the family planning preferences of underserved women, who often face disproportionate barriers to getting the kind of family planning care they need and desire to achieve optimal family planning outcomes. By understanding what these family planning preferences are, we can better establish the measurement items that will comprise

a proposed FPVC instrument in subsequent research aims. Understanding the attributes of family planning care that patients tend to prefer, as well as the mechanisms by which patients form their preferences, is foundational for the development of targeted interventions to improve family planning care and outcomes for underserved women.

Specific Aim 2: Develop an original instrument to measure value concordance between patient preferences and the family planning care they receive

The second research aim utilizes the foundational grounded theory findings in concert with input from an expert consensus panel, and the literature to develop a measure of value concordance in family planning care. This value concordance measure consists of two components: (1) an assessment of patients' preferences, and (2) an evaluation of their care experience during a recent family planning visit. The standardized degree of agreement between these two sub-scales comprises the value concordance measure.

Specific Aim 3: Validate the proposed measure for family planning value concordance

This study presents standard measurement tests to demonstrate the reliability and validity of the proposed measure of value concordance in family planning care for underserved women. Standard psychometric properties of internal consistency and item scale correlations, as well as a discussion of the content, construct, and criterion-related validity of the measure are presented. Practical recommendations on the fielding and scoring of the value concordance measure are offered in the subsequent chapters.

1.7 Guiding Theories and Concepts

The notion that patient preferences may impact care decisions first emerged as an element of normative decision theory (NDT), which attempts to describe how rational decision-making occurs (Border, 1984). Brennan's 1995 seminal article on normative decision theory in health care applies the theory specifically to a patient's derived utility from a particular care experience, noting that it "reflects the degree to which an individual's actual experiences matches his or her preferences regarding the experience." She asserts that this appraisal process is essential to inform the care spectrum from initial treatment decisions through ongoing care, and as a summary judgment at the end of care (Brennan, 1985). Thus, value concordance can and should occur at multiple points throughout a patient's interaction with care delivery.

Knight's Individual Decision Making Model illustrates the relationship between patient preferences, experiences, and care outcomes. Her work highlights the importance of preferences and information, which directly impact a patient's health care decisions and outcomes. When patient preferences are adequately assessed and integrated into the care she receives, this is perceived to positively facilitate treatment decisions. Knight and other scholars of decision-making strongly focus on the necessity of either formal assessment or informal discussion between providers and patients to identify preferences, inform care delivery, and subsequently, guide treatment decisions (Knight, 2008; Knight, 2010; O'Connor et al., 1999). The concordance between preferences and care experiences then directly affect the outcomes of the received care – in our case, family planning outcomes.

Sepucha & Ozanne (2010) were the first to use the term value concordance to describe this construct, which they define as "documentation that the treatments received or the care delivered reflects patients' preferences." This dissertation uses this definition of the value concordance construct henceforth. Despite the illustrative conceptualization of value concordance in the literature, there is limited consensus on mechanisms by which to measure value concordance. Furthermore, value concordance has been traditionally considered important in medical decision-making around specific treatments such as surgical cancer interventions, hospice and palliative care, hormone replacement therapy for menopausal women, and prenatal genetic screening (Sepucha & Ozanne, 2010; Koedoot et al., 2003; Figuereido, Cullen, Hwang, Rowland, & Mandelblatt, 2004; Molenaar, et al., 2004; Temple et al., 2006; Caseratt, Van Ness, O'Leary, & Fried, 2006; Patrick et al., 1997; Lee, Smith, Fenn, & Ganzini, 1998; Schapira, Gilligan, McAuliffe, & Nattinger, 2004; Reynolds, Obermeyer, Walker, & Guilbert, 2002; Rothert et al., 2007; Heckerling, Verp, & Hadro, 1994; Kupperman et al., 2006; van den Berg, Timmermans, Ten Kate, van Vugt, & van der Wal, 2006). A more complete description of the prior literature on value concordance is provided in a subsequent chapter. This heavy focus on treatment decisions dominates most of the literature on value concordance, however, this research study refocuses the application of value concordance to more general service delivery in order to understand how closely one's care experiences reflect her preferences about the way family planning care is delivered, and is considered a precursor to family planning decision making. This dissertation applies the concept of value concordance more broadly to characterize a patient's experience with multiple aspects of the family planning visit, not solely the point at which family planning decisions are made (for

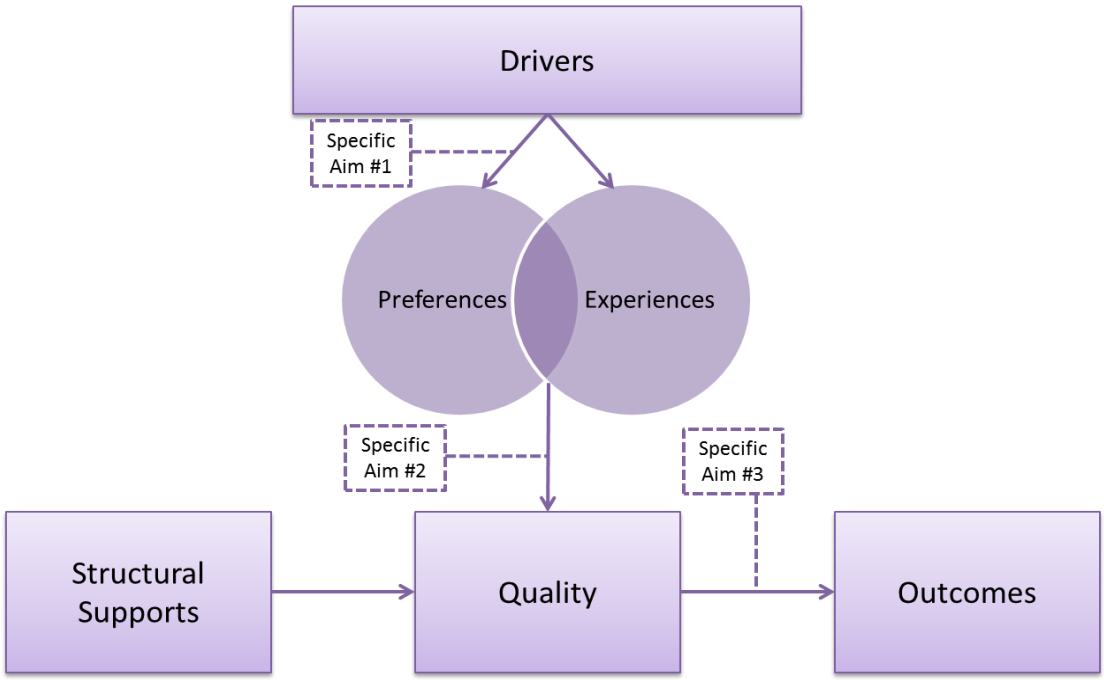
example, the choice to use contraception to prevent unwanted pregnancy or the selection of a contraceptive method). It is then a key assumption of this dissertation that value concordance can occur at any point in a patient's interaction with family planning care delivery and that it may play a critical role as an input into family planning decision making. Family planning experiences that are highly value concordant, are considered to be higher quality, are thought to facilitate better family planning decision making through patient engagement, and subsequently assist patients in achieving the family planning outcomes that they desire.

These propositions draw from the framework of family planning quality defined by Bruce (1990) and later adapted by Becker and colleagues (2007) The framework draws on Donabedian's structure-process-outcome quality model to highlight the relationship between the inputs into family planning quality (such as structural supports, policy, resources, access, and program management), the process of delivering high quality family planning care, and the resulting set of outcomes that are influenced by family planning quality: patient knowledge, patient satisfaction, contraceptive use (both initial and sustained) and overall patient health (Donabedian, 1988). Although this dissertation study does not aim to evaluate the structural component of the model, it is conceivable that a future research effort might use findings from the 2011 health center organizational survey to assess the relationship between structural components and outcomes, applying the model in its entirety to community health center settings.

In 2007, Becker and colleagues added the dimension of patient-centeredness to the quality framework, specifically referring to care that is tailored to the needs of individual clients (Becker et al., 2007). Additional literature on family planning quality

suggests that a patient-centered approach to delivering tailored family planning care is essential for improving the quality of family planning services (Kols & Sherman, 1998; Costello, Lacuesta, RamaRao, & Jain, 2003; Winter & Breckenmaker, 1991). Furthermore, the expressed assessment or collection of information on patient preferences has been identified as critical step in this patient-centered approach to delivering high quality family planning care and achieving better family planning outcomes for patients (Costello et al., 2003; Knight, 2008; O'Connor et al., 1999). Taking into account the theoretical concepts of many of the preceding frameworks on patient preferences and family planning quality, an adapted framework is presented in Figure 1 and will serve to guide the forthcoming research activities.

Figure 1. Adapted Framework for Family Planning Quality



This study expands current conceptual frameworks to include value concordance as the intersection between patient preferences and experiences, representing a measure of quality from the patient's perspective and linking it with family planning outcomes as expressed in the original framework for family planning quality (see Figure 1). The figure demonstrates that value concordance, as a dimension of patient-centeredness and family planning service quality, has an intermediate impact on family planning outcomes. These outcomes may include patient satisfaction, family planning knowledge, contraceptive use and continuation, and other outcomes that collectively impact a patient's reproductive health.

Because these outcomes rely heavily on a patient's behavior, it is imperative to draw upon theories of health behavior, recognizing that knowledge alone is insufficient in motivating patients to change or adopt a particular behavior such as the sustained use of contraception to prevent unintended pregnancy. The Theory of Planned Behavior (Ajzen, 1991), the Transtheoretical Model (Prochaka & DiClimente, 2005), and the Health Belief Model (Becker, 1974) all include constructs related to a patients' self-efficacy or perceived ability to successfully adopt the intended behavior. This sense of patient engagement in the family planning decision-making process, is thereby one set of potential outcomes that could be influenced by the receipt of value concordant family planning care. Weisman and colleagues (2002) operationalized this concept in their study on the effect of contraceptive counseling on family planning outcomes including satisfaction, self-efficacy to prevent unintended pregnancy and contraceptive use among a small Medicaid managed care population. This evidence substantiates the proposition that family planning value concordance may be a strategy to improve quality of care at

the visit level and facilitate family planning decision-making by elevating a patient's sense of engagement in family planning care.

In summary, the figure above illustrates the family planning quality framework driving this dissertation research, adapted from previously established frameworks. This dissertation research intends to address three specific aims that fall within this quality framework. First, Specific Aim 1 attempts to describe the factors influencing patient preferences and identify the specific family planning preferences of underserved women. This research phase also explores patients' perception on the importance of patient experiences that align with their preferences and what result this alignment (or misalignment) might have on their family planning outcomes. This will be achieved through a grounded theory approach to qualitative research with the purpose of generating new theory on the role of patient preferences in family planning care. Specific Aim 2 utilizes the data from qualitative focus groups, interviews, and a consensus panel of field experts, in addition to existing literature to develop an original scale of value concordance in family planning care. The purpose of this research aim is to develop a tool whereby patients' preferences can be assessed, while also evaluating the degree to which care experiences reflect those preferences, as a measurement of tailored and patient-centered family planning care. Specific Aim 3 focuses on testing and validating the measure in a small pilot test of the relationship between value concordant care and family planning outcomes, as proposed in the adapted family planning quality framework above. Among other measurement validity and reliability markers, this study will attempt to demonstrate the predictive validity of value concordance on those outcomes that may be most sensitive to patient preferences and experiences in a family planning context.

Chapter 2: Review of the Literature

2.1 The Burden of Unintended Pregnancy on Underserved Populations

Family planning, including contraception has been considered one of the crowning public health achievements of the 20th century in the United States by the Centers for Disease Control and Prevention (CDC) because of its effectiveness in preventing unwanted or unintended pregnancy (CDC, 1999). Contraception and family planning averts approximately 1.4 million unintended pregnancies every year, resulting in a savings to the health care system of $13.9 billion in direct medical expenditures (Trussell, 2007). Despite the effectiveness of contraception and family planning efforts, reducing the proportion of unintended pregnancies remains one of the priority objectives of the Healthy People 2020 effort, with a total of 15 national objectives referring to family planning and reproductive health.

One reason for this continued national priority to reduce unintended pregnancy is that a substantial amount of evidence has linked unintended pregnancy with negative health and wellbeing outcomes for both mothers and children across the lifespan. Specifically, women with an unintended pregnancy tend to delay entry to prenatal care, which has been linked with higher risk of complications during pregnancy, maternal morbidity, and low-birth weight (Kost, Landry & Darroch, 1998; D'Angelo, Gilbert, Rochat, Santelli & Harold, 2002; Klerman et al., 2001; CDC, 2000; Cheng, Schwarz, Douglas, & Horon, 2009). Women with unintended pregnancies are also less likely to initiate breastfeeding, a critical protective factor for infant health (David, 2006; D'Angelo et al., 2002; Dye, Wojtowycz, Aubry, Quade, & Kilburn, 1997). They are also more likely to report lower general psychological health during the pregnancy and after birth,

as well as higher risk of experiencing maternal depression following birth (Orr, 1997; Hardee, Eggleston, Wong, Irwanto, & Hull, 2004; Grussu, Quataro, & Nasta, 2005; Barber, Axinn, & Thornton, 1999).

Children born from unintended or unwanted pregnancies also tend to experience poorer physical and mental health outcomes than children from planned pregnancies. These include low-birth weight and preterm birth, being less likely to have excellent health during childhood, and higher risk of childhood obesity (CDC, 2007; Eggleston, Tsui, & Kotelchuck, 2001; Crissey, 2006; David, 2006). Similarly, children from unintended pregnancies report lower levels of psychological health, higher incidence of depression, and lower levels of self-esteem during childhood and adolescence (Axinn, Barber, & Thornton, 1999; David, 2006). They also tend to have lower educational attainment and achievement, including years of education completed and grades received (Myrhmam, Olsen, Rantakallio, & Laara, 1995).

Underserved populations such as low-income women, women of racial and ethnic minority groups, uninsured women, and otherwise medically-underserved patients experience a disproportionate burden of these poor outcomes, as rates of unintended pregnancies are higher among these populations. According to the National Survey of Family Growth (NSFG), a large majority of pregnancies among African American women (69 percent) and Hispanic women (54 percent) were unintended, compared to only 40 percent for non-Hispanic white women (Finer & Henshaw, 2006). Similarly, 62 percent of pregnancies to women living below the federal poverty level (FPL) were unintended, compared with only 38 percent among women earning > 200 percent FPL (Mosher, Martinez, Chandra, Abma, & Willson, 2004). In the last 20 years, the

unintended pregnancy rate of poor women has risen upwards of 56 percent, while the rate among higher income women fell by 24 percent (Finer & Zolna, 2014). While the unintended birth rate across the U.S. population rose considerably in the last decade, the increase in unintended births is most pronounced among women of low-SES and Black or Hispanic women, underscoring the disproportionate burden of unintended pregnancy on vulnerable populations (Finer & Zolna, 2014).

2.2 Family Planning Access and Quality for Underserved Women

Considering the established link between unintended pregnancy and poor health outcomes for women and children, the importance of family planning and contraception in preventing unwanted pregnancies and their respective consequences is wholly underscored. These services are particularly important for underserved women, among whom higher rates of unintended pregnancy are observed. However, barriers to access and quality of family planning care persist among medically-underserved women of childbearing age.

2.2.A Utilization of Family Planning and Contraceptive Services

Utilization of family planning and contraceptive services is less than optimal among underserved populations. In fact, the NSFG found that a higher proportion of Hispanic and Black women did not utilize contraception than white women, while low-income women tended to use contraception at significantly lower rates compared to higher income women (Mosher et al., 2004). Similarly, the disparity in contraceptive use between poor and non-poor women and minority and white women increased significantly between 1995 and 2002. Differences in the selection of contraceptive

methods also exist across underserved populations. Hispanic and Black women are significantly more likely to get a female sterilization (22 percent and 20 percent, respectively) compared to white women (16 percent). Black and Hispanic women are also more likely to use condoms as their primary method of contraception, while white women are more likely to use oral contraceptives. Black and Hispanic women are also less likely to use long-acting contraceptive methods such as an intrauterine device (IUD) and more likely to use less effective methods such as barrier methods and emergency contraception than their white counterparts (Dehlendorf et al., 2011). Several studies discuss the possible reasons for these differences in contraceptive method use, citing basic access to choice of methods, patient knowledge about certain methods (or lack thereof), misconceptions and fears about certain methods, patient preferences, as well as provider behavior in recommending particular methods over others for certain patient groups (Dehlendorf et al., 2010a; Ranjit, Bankole, Darroch, & Singh, 2001; Gilliam, Warden, Goldstein, & Tapia, 2004; Clark, Barnes-Harper, Ginsberg, Holmes, & Schwarz, 2006; Sangi-Haghpeykar, Ali, Posner, & Poindexter, 2006). While there is additional room for research attention around the reasons underserved women use different contraceptive methods and the impact on family planning outcomes, some studies demonstrate that even when controlling for method choice, low-income and minority women experience higher rates of both contraceptive failure and premature discontinuation (Ranjit et al., 2001; Trussell & Vaughan, 1999; Fu, Darroch, Haas, & Ranjit, 1999; Vaughan, Trussell, Kost, Singh & Jones, 2008). Another study found that lower-income and racial/ethnic minority patients were more likely to experience a

pregnancy within the first year of contraceptive use compared to women who were higher income and of white descent (Ranjit et al., 2001).

The affordability of family planning care and contraception is certainly a challenge that many underserved women face. In 2004, the average cost per pack for oral contraceptive pills was $14, however, uninsured and underinsured women paid significantly more in out-of-pocket costs for contraceptives than insured women (Phillips et al, 2004). Another recent study reported that removing the out-of-pocket cost barriers to reversible contraceptives actually improved both the use of such methods and reduced the rate of abortions and teenage birth rates in underserved communities in St. Louis, MO (Peipert et al., 2012). Meanwhile, recent economic conditions across the U.S. have exacerbated the cost constraints on family planning and contraceptive use. A 2009 Guttmacher Institute report found that nearly 1-in-3 low-income women reported having a harder time paying for birth control than in the past, while a similar proportion (30 percent) of low-income women reported delaying or forgoing a gynecological or birth control visit to save money in the past year. The study also found that women who were uninsured were more likely to delay getting family planning care. Additionally, 17 percent of low-income women reported switching to a less expensive provider for family planning and reproductive health compared with only 5 percent of higher-income women (Guttmacher Institute, 2009).

Access to insurance coverage mitigates some of these cost-barriers. Case studies of health reform in Massachusetts demonstrate that addressing the cost barrier to contraceptive use through insurance coverage is particularly promising. Decreased cost of contraception as well as improved access in getting oral contraceptive prescriptions filled

were cited as a key benefits of universal state coverage (McIntosh, Tsikitas, & Dennis, 2012). However, other access barriers persisted specifically for low-income women despite widespread coverage of contraception. These included the inability to get more than one month of contraception at a time, lack of coverage for over-the-counter methods, a poor understanding of coverage benefits, trouble obtaining a family planning visit with a provider, and inadequate time required for the visit (Dennis et al., 2012; Dennis & Grossman, 2012; McInstosh, Tsikitas, & Dennis, 2012). In 2011, the Department of Health and Human Services released a set of guidelines pursuant to the Affordable Care Act's provision on insurance coverage for preventive services, naming contraceptive methods as one of the required services health plans must cover with zero-cost sharing to patients (45 C.F.R. Part 147; Health Resources and Services Administration, 2011). Despite this advance in coverage, some gaps still persist for some women, including those that are covered by employers who are exempt from providing coverage for contraception due to religious accommodations. Furthermore, underserved women may still experience access-related barriers to contraceptive use including difficulty obtaining the method, embarrassment or fear about acquiring a certain method, concerns about health and side effects, objection from partner, and lack of knowledge about acquiring and using certain methods (Silverman, Torres, & Frost, 1987; Sable & Libbus, 1998).

2.2.B Underserved Women's Experience with the Quality of Family Planning Services

Even when underserved patients are able to access family planning services, the literature suggests they may experience differing levels of the quality of such care. Understanding these differences in quality is essential because of the influence of service

quality on family planning outcomes, as discussed by the original family planning quality frameworks (Becker et al., 2007). This is particularly important when considering that many family planning outcomes depend heavily on patient behavior and decision-making such as contraceptive initiation, prevalence, and continuation. Becker and colleagues (2007) argue that if family planning services are low quality, patients may not get the information and counseling they need to initiate and maintain effective contraceptive behavior and are therefore, more likely to experience a negative family planning or reproductive health outcome. Other studies indicate that family planning service quality may impact other family planning outcomes such as contraceptive continuation following a family planning visit, satisfaction with their contraceptive method, and incidence of unintended pregnancy (Herceg-Baron, Pickens, & Armstrong, 1985; Armstrong, Pickens & Herceg-Baron, 1985; Herceg-Baron, Furstenberg, Shea, & Harris, 1986; Rosenberg, Waugh, & Burnhill, 1998; Namerow, Weatherby, & Williams, 1989).

While the relationship between quality of family planning care and outcomes is clear for all women of childbearing age regardless of income or insurance status, certain underserved populations may be more at risk of experiencing lower quality of family planning. Forrest and Frost (1996) found empirical evidence that women who were satisfied with the quality of their care were more likely to consistently use contraception, but that Hispanic and Black women were less likely to have optimal satisfaction and were subsequently less likely to have consistent contraceptive use compared to non-Hispanic, white women. Similarly, low-income women, members of minority groups, and Spanish speakers have reported poorer quality ratings than higher income, white, and English-speaking patients (Bixby Center for Reproductive Health Research and Policy, 2005;

Forrest & Frost, 1996; Becker et al., 2007; Becker & Tsui, 2008; Downing, LaViest, & Bullock, 2007). Two recent studies explored the dimensions of quality ratings among underserved patients, providing important context for this dissertation. Becker and Tsui (2008) found that low-income minority women were less likely to report that their providers took the time to understand their needs and values related to family planning compared to more affluent non-minority women. In 40 interviews with low-income women in San Francisco, researchers found qualitative evidence that patients expressed the desire to have their preferences and decisions about family planning both considered and respected by their family planning providers. The authors of this study concluded that this particular dimension of family planning care requires more thoughtful research to understand how to reflect patient preferences and values in care delivery.

2.3 The Patient Perspective on Quality of Care

Much of the health services literature focuses on quality measurement through technical and clinical approaches; however, an emerging body of work focuses on patient-level measurements of quality of care. In fact, the patient perspective on quality has been increasingly considered a critical element of quality improvement efforts at both the practice and policy level (Sofaer & Firminger, 2005; AHRQ, 2011). The Institute of Medicine Report, *Crossing the Quality Chasm* endorses the six domains of quality of care for all health care organizations, among which patient-centeredness of care is key. The IOM specifically defines patient-centeredness as "providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions." The report provides further guidance on patient values, defining them as "the unique preferences, concerns, and expectations that are

brought by each patient to a clinical encounter and must be integrated into clinical decisions if the patient is to be served" (IOM, 2001).

While most definitions of family planning care have included some element that encourages services to be responsive and reflective of the needs and preferences of patients, no study to date has collected data on how health care organizations learn about their patients' values or preferences, nor proposed a mechanism for measuring whether health care organizations are delivering care that is responsive to patient preferences and values – what the literature characterizes as value concordance.

Although we know that patients' satisfaction with their care experiences have been linked with positive outcome factors such as treatment adherence, likelihood to return for care, and long-term health, limited research has specifically focused on the association between value concordant care and improved outcomes for patients, especially those who are underserved (Sofaer & Firminger, 2005; Becker & Tsui, 2008). Neither has any study specifically applied these concepts to the dimensions of family planning service quality or outcomes. A measure through which to operationalize value concordance in the larger framework of quality would provide an opportunity to achieve goals of patient-centeredness in family planning care and offer important insight to implement parallel measures for other service lines and conditions and for health care in general.

2.4 Value Concordance in Medical Decision Making

In medical decision making, the quality of a decision is measured by the "extent to which choices reflect the preferences of well-informed patients and are implemented" (Sepucha & Ozanne, 2010). The association between preferences and choices, in this

context, is what is considered value concordance and may be the closest measurement of the concept of patient-centered care presented in current literature. The measurement of value concordance, as it has been described in the literature, relies on three important assumptions. First, conceptually, value concordance assumes that patients are well-informed and are able to weigh the consequences and outcomes of any treatment decision. It does not consider any assumptions on the rationality or internal consistency of those decisions. Secondly, value concordance relies on the definition of patient preferences in its calculation or measurement. A recent systematic review of value concordance in medical decision making highlighted three types of preferences that could be used in measurement models: (1) patients' preferred treatment assessed through modeling; (2) patients preferred treatment assessed directly; or (3) patients' utilities or attitudes toward specific health outcomes and/or attributes of care. For the purposes of this dissertation, this latter definition is applied in the conceptualization of value concordance.

Value concordance also requires the definition of choice. Sepucha and Ozanne's review cited that the treatment undergone or treatment intention is often considered the resulting choice, upon which a value concordance measurement can be made. It is clear here, that the unit upon which value concordance focuses is the medical decision or treatment choice, however, this dissertation focuses on value concordance of the broader family planning visit, rather than an exclusive treatment decision. There are multiple attributes or elements of the patient's interaction in a family planning visit from which she may derive utility, therefore facilitating later decision-making. In this sense, we consider the evaluation of a patient's experience on multiple attributes of her family

planning visit to replace the “choice” or “treatment” variable on which so many previous value concordance measurement studies have focused.

Value concordance is then typically measured through two methods: (1) regression models; and (2) matching models (Sepucha & Ozanne, 2010). The majority of value concordance measurement studies use matching models, whereby investigators calculate a simple percent match between patients’ dichotomized preferences (preferring a treatment or not) and their dichotomized choice (preferred treatment received or not received). This dissertation adapts this simple percent match measurement model of value concordance to calculate a FPVC score for a patient’s most recent family planning visit (see Chapter 3: Methods for more details).

The simple percent match method has been used by several studies to measure value concordance in a variety of settings and conditions. Barry et al (1995) and Denberg et al (2006) first used value concordance measures to characterize decisions about prostate cancer treatments, highlighting the role of preferences and attitudes for specific treatments and their respective outcomes. Both studies highlighted that preferences for quality of life following treatment and preferences for avoiding prospective complications were important factors in decision-making. Denberg and colleagues found that patients’ treatment decisions were often justified using anecdotal evidence they had received from other patients with similar experiences, highlighting patients’ reliance on information from peers.

Value concordance using a simple percent match approach has been used in other cancer populations, including lung cancer, colorectal cancer, and early stage breast cancer (Brundage et al., 2001; Dolan & Frisina, 2002; Molenaar et al., 2004). Each of these

studies focused exclusively on treatment decisions following cancer diagnosis or on screening decisions for at-risk populations. The simple percent match technique has also been used to characterize end of life decisions for elderly and terminally ill patients and their caregivers. Danis and colleagues (1991) examined patients' previously expressed wishes for hospitalization, cardiopulmonary resuscitation, intensive care, artificial ventilation and other care directives when the patient was no longer conscious, finding that care was consistent with patients' preferences only 75 percent of the time. Srebnik & Russo (2007) found slightly lower rates (67 percent) of concordance with care preferences among community mental health patients who had an advance directive. A study of seriously ill patients in an ICU setting found that less than 40 percent of patients felt that they had adequate discussions with their providers about their preferences for life-sustaining care and other end-of-life decisions. Patients who did have these discussions on care preferences were 1.9 times more likely to believe that their treatment was concordant with those stated preferences (Teno et al., 2000).

Value concordance has also been used in primary care settings to describe decisions about counseling and treatment for depression. Dwight-Johnson and colleagues (2001) implemented a randomized control trial of a quality improvement program in 46 primary care clinics designed to accommodate patient preferences for depression treatment. Patients receiving the intervention program reported a higher likelihood of having received their preferred treatment and counseling compared to patients who received usual care. A later study found that only 72 percent of patients with depression reported receiving their preferred treatment but that those who did receive treatment matching their preferences demonstrated more rapid improvement in depression

symptoms compared to patients receiving treatment that did not reflect their preferences (Lin et al., 2005). The authors concluded that obtaining patients' preferred treatment contributed to the improvements in depression symptoms and that practitioners should attempt to assess and accommodate patient preferences as a mechanism to improve depression outcomes. This was substantiated in a more recent study by Mergl and colleagues (2011) who found that depressed patients receiving their preferred treatment reported significantly better outcomes (nearly 8 points on a standard depression rating scale) than those who did not receive their preferred treatment, irrespective of differences in depression severity. These findings emphasize the important role that value concordance could have in the primary care setting, as is suggested in this dissertation research.

Perhaps most closely related to this dissertation study, several articles used value concordance through a simple percent match protocol to measure decisions around prenatal care and genetic testing during pregnancy. Marteau, Dormandy & Michie (2001) found that only 27 percent of pregnant women made an informed choice on prenatal screening that was consistent with their values. A much larger study by van den Berg and colleagues (2005) found a higher rate of value concordance with 82 percent of women making a "value-consistent" decision to accept or decline prenatal screening. This was associated with more satisfaction with the decision and less decisional conflict experienced by patients. In a similar vein, pregnant women who were considering a vaginal birth after a cesarean section were less likely to experience decisional conflict if they received care that incorporated their preferences for birth modes than women in a control group. Women who received the intervention also demonstrated higher level of

knowledge on the risks and benefits of each birth mode than women in the control group, highlighting the potential impact of value concordance on other outcomes such as knowledge and information state (Shorten, Shorten, Keogh, West, & Morris, 2005).

Although value concordance using a simple percent match approach has not been used in the family planning context, a modified form of this measure has been used to characterize contraceptive decision-making in two studies. Wall (1985) evaluated the use of a decision aid to help women select a method of birth control using contingency table analysis of rated health states and health outcomes. The decision aid was found to be predictive of actual contraceptive use of the method(s) for which patient values were highest. Sixty-five percent of patients reported being satisfied with their selected method. Minnis and colleagues (2003) also used contingency table analysis to predict contraceptive choice and utilization of barrier methods, although no reliable predictive findings were reported. Satisfaction with the method was not significantly associated with subsequent use. The findings from these two small studies highlight the need for further investigation into the value concordance of contraceptive decisions, and perhaps more broadly to the value concordance of the counseling, information, and services that are provided during a family planning visit in order to help facilitate contraceptive decision-making.

Sepucha and Ozanne (2010) give some recommendations on the development of additional measurement models for assessing value concordance. First, they suggest that investigators use actual treatment (or care) received, rather than modeling or calculating treatment intention as the "choice" variable. This would require a measurement tool that incorporates patient reported decisions, treatments, or experiences, as is suggested in this

dissertation study. Secondly, they recommend that measurement tools compare patients preferences directly to the treatment or care received. This requires a direct inquiry into patient preferences for certain attributes of the treatment or the visit and the evaluation of whether those preferences were met in the clinical encounter. Finally, the authors call for rigorous evidence of the reliability and validity of any value concordance model, given that this data is often missing from prior literature. Sepucha and Ozanne assert that measures of value concordance can ultimately be used to understand the impact of educational or behavioral-change interventions on actual decision-making but also to understand the quality of medical decisions and thereby, more fully explore the quality of health care in general. This dissertation suggests that by focusing more broadly on the patients' experience in a family planning visit as the point at which value concordant care occurs, it provides a clearer picture of the quality and patient-centeredness of such care from the patient perspective. It also offers important insight into whether or not information, counseling, and support has been tailored to meet the preferences and needs of patients to best facilitate their family planning and reproductive decision making.

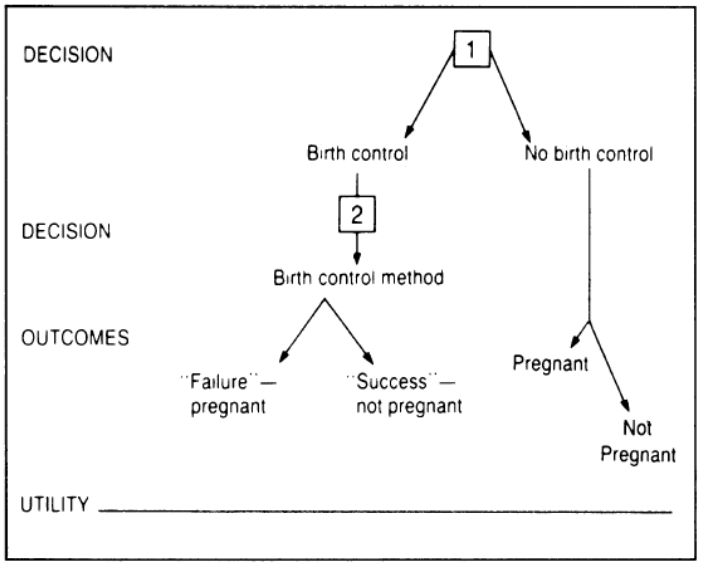
2.5 Family Planning and Contraceptive Decision-Making

The role of preferences in health care decisions has garnered a fair amount of attention in the decision sciences, especially with respect to utility theory and other efforts to model consumer preferences and decisions. Some studies have attempted to characterize decision- making styles in health care, with most studies focused on the role of the patient in decision-making about particular treatments. Degner and Sloan (1992) focused on newly-diagnosed cancer patients and found that treatment decisions were made by three different types of decision-making styles: the active role, where patients

have the final say; the collaborative shared-decision making role where physicians and patients make decisions together; and the passive role where the physician typically makes the decision independent of the patient. Latter studies corroborated these decision-making styles with other empirical evidence on patients' role in specific treatment decisions (Davison, Degner, & Morgan, 1995; Beaver et al., 1996; Charles, Gafni, & Whalen, 1997). In the family planning world, the active role has also been referred to as an *informed-decision model* or *autonomous decision-making*, while the passive role has been called a *paternalistic* or *provider-led model* (Kim, Kohl, & Mucheke, 1998). While terminology varies, the characterization of the three decision making styles remains fairly consistent. Generally, a shared decision-making style is preferred, both among patients in general health settings and among women receiving family planning care. This model of shared decision-making also underlies the principles of the patient-centeredness movement (Murray, Pollack, White, & Lo, 2007). However, as Dehlendorf and colleagues (2010b) found, many women prefer more autonomous decision-making in family planning and contraceptive choices, making these important decisions distinct from other health-related decisions. Their follow-up study in 2013 indicated that women want a fair degree of control over the contraceptive method they select, but they "also wanted their provider to participate in the decision-making process in a way that emphasized the women's values and preferences" (Dehlendorf et al., 2013). These findings indicate observed variation in women's preferences for making family planning and contraceptive decisions, which may underscore the need to tailor family planning services and information in a value concordant way to better facilitate patient decision-making.

While the literature highlights these styles of decision-making with substantial evidence, less attention has focused on characterizing the process of family planning decision-making among women of childbearing age. The few studies that focus on this area conclude that family planning decisions, including the selection of a contraceptive method can be considered a complex, individualized, and multifactorial process with a limited theoretical base for understanding family planning decision-making in a comprehensive way (Wall, 1984; Matteson & Hawkins, 1997). First, we must recognize what Wall (1984) calls the two-level model of contraceptive decision-making, highlighting two points where decisions are made: (1) the decision to use birth control; and (2) the selection of a birth control method (see Figure 2).

Figure 2. Two-order Contraceptive Decision Model



Women typically weight the value of pregnancy against the costs of contraception before making the decision to use contraceptive methods at all. Wall and others suggest that when the value of pregnancy and the perceived likelihood of becoming pregnant

without contraception is higher, women will likely choose to use birth control and move to the second order decision by weighing her options on birth control methods. The next decision on selecting a birth control method is particularly complex and women often have important issues, values, and preferences that are of high concern to them (Wall, 1984; Luker 1975). Wall's 1984 study identified some of these values, including moral/religious beliefs, interference with sexual activity, increased partner involvement, inconvenience of the method, risk of adverse side effects, fear or anxiety, risk of pregnancy, personal responsibility for the method, and negative advice of friends, family or one's physician. His study concluded that the complexity of contraceptive decision making lies in its value-laden nature and that further research on the clarification of values (preferences) in the decision-making process was needed.

The first to offer a theoretical model on this process was Joanne Noone, who characterized four factors that may influence women's contraceptive decisions. These include properties of the particular method in question, external influences, relationship dynamics, and personal characteristics and preferences. These are consistent with other models that focused on contraceptive decision-making such as Beckman and Harvey (1996) and Matteson and Hawkins (1997). The latter indicated that the contraceptive choice involves four sequential steps which involve personalizing pregnancy risk, exploring multiple options, using options, and "contending with ramifications of use." Both of these studies conclude that contraceptive decision-making must consider the individual and contextualized nature of such family planning decisions. Noone later developed grounded theory to further explore how contraceptive decisions are made from the woman's perspective. Her study concluded that women go through a complex process

of "finding the best fit," whereby a method(s) is chosen based on patient's current knowledge, experience, and their current life circumstances. Her findings displayed a more cyclical and dynamic decision process rather than the sequential process that had previously been presented in Matteson & Hawkins and Beckman & Harvey's studies. This grounded theory study supports the propositions made in this dissertation that value concordance can occur at multiple points throughout a woman's interaction with family planning care, and that family planning decisions, including the use of contraception may be made many times during a woman's childbearing years. Noone asserts that creating a practice environment that empowers women to make decisions about their chosen method is critical and requires providers to understand the individual and contextual factors that influence these decisions. In this regard, the role of value concordance is implied, but not fully conceptualized in Noone's grounded theory study. Neither is the role of preferences, or how preferences are formed, given more than a mention as a potential individual factor in the contraceptive decision-making process. Furthermore, her study sample reflected women with higher educational attainment than is generally indicative of medically-underserved populations. Thus, the need to understand this phenomenon from the perspective of underserved women is still a glaring gap in the literature (Noone, 2004).

While patient-centeredness principles dictate that patient preferences and values should be considered in all health care experiences, family planning and contraceptive services may require even more attention than typical medical decisions. First, medical decision-making often focuses on a specific point at which a treatment and potential alternatives to that treatment must be selected. These treatment decisions are nearly

always the result of a particular diagnosis or condition. In contrast, family planning services encompass the information and counseling about contraceptive methods, the provision of these methods, and reproductive health screening, testing, and potential treatment (such as STIs, cervical and breast cancer and genitourinary conditions) (Singh, Darroch, Ashford, Blassoff & the United Nations Population Fund, no date). In this regard, family planning focuses on the ability of women and their partners to plan, space, and achieve their desired number of children and the timing of their births, rather than a specific condition or diagnosis (World Health Organization, no date). Dehlendorf and colleagues found family planning to be unique from other health services, finding that women had different preferences for how they made family planning decisions compared to other health care decisions, and often preferred to have more control and autonomy over family planning choices than other medical decisions. This evidence underscores the need to assess patient preferences before such decisions are made in order to provide the information, support, and counseling services that facilitate effective decision-making (Dehlendorf et al., 2010b). Her work, among other studies suggest that understanding patient preferences and aligning care delivery in a way that facilitates patients' preferred decision making model may be effective at improving patient outcomes (Dehlendorf et all, 2010b; Murray et al., 2007; Kiesler & Auerbach, 2005).

2.6 The Role of Community Health Centers in Providing Family Planning Care

Very few studies have focused exclusively on health centers' provision of women's health services to underserved populations, and even fewer focus on the delivery of family planning care. A handful of studies present evidence that health center patients are more likely to receive preventive women's health screening like

mammograms, clinical breast exams, and Pap smears than underserved women not served in a health center (Shin & Sharac, 2012; Regan, Lefkowitz, & Gaston, 1999; Politzer et al., 2001; Shi & Stevens, 2007). Shi and colleagues (2004) also present findings that disparities in prenatal and birth outcomes such as low-birth weight among infants born to low-SES women are mitigated by the use of health center services.

More broadly, health centers have been recognized by the Institute of Medicine and the U.S. Government Accountability Office (GAO) as models for primary and preventive care including the management of chronic diseases such as diabetes, cardiovascular disease, asthma, mental illness, cancer, and HIV (U.S. General Accounting Office, 2003). Much of health centers efforts around chronic disease management has been linked with widespread rapid quality improvement efforts as a result of health centers' involvement in HRSA's Health Disparities Collaboratives (HDCs). Several studies indicate that health centers improved on indicators of clinical processes, quality of care, and composite measures of health outcomes and health status (Hicks et al., 2010; Chin 2010; Chin et al., 2004). Health centers' experiences with quality improvement initiatives specifically tailored to their respective communities of underserved patients substantiate their position as an important setting within which to research not only the delivery of primary care in general, but also the quality of family planning and reproductive health for women of childbearing age.

Health centers also play a key role as patient-centered medical homes (PCMH) for many underserved patients, including women of childbearing age. The PCMH model is an advanced primary care delivery model that focuses on providing care that is comprehensive, coordinated, and patient-centered. In this regard, health centers fulfill the

unique PCMH mission of "understanding and respecting each patient's unique needs, culture, values, and preferences (AHRQ, 2012)." As of 2011, about 6 percent of CHCs had achieved national PCMH recognition through the National Committee for Quality Assurance (NCQA) (Ku, Shin, Jones & Bruen, 2011). In 2010, the Commonwealth Fund released survey findings that demonstrated that about one-in-three health centers has capacity in all five NCQA-PCMH domains (regardless of whether they were seeking recognition or not). The majority (55 percent) had capacity on three or four out of the five domains for medical home recognition (Doty, Abrams, Hernandez, Stremikis & Beal, 2010). In 2013, the percent of health centers achieving PCMH recognition exceeded 40 percent, far exceeding the national target goal of 33 percent (Stevens, 2014). This level of PCMH activity indicates that most health centers already have the infrastructure and system processes in place to achieve the patient-centeredness goals of the PCMH model and continue to make significant growth in this area, making them a unique setting to study value concordance as an indicator of quality and patient-centeredness in family planning care.

In some of the first studies to ever investigate the delivery of family planning care in community health centers, two articles recently published in *Contraception* highlighted the high degree of variability in the scope of family planning services offered at health centers. This variation was largely observed at the clinic site level, indicating that very few health center sites were able to provide the full complement of contraceptive methods and other services on-site, and patients were often referred elsewhere for more advanced methods and services (such as IUDs and implants) (Wood et al., 2014; Beeson et al., 2014). This makes it more difficult for health centers to deliver family planning

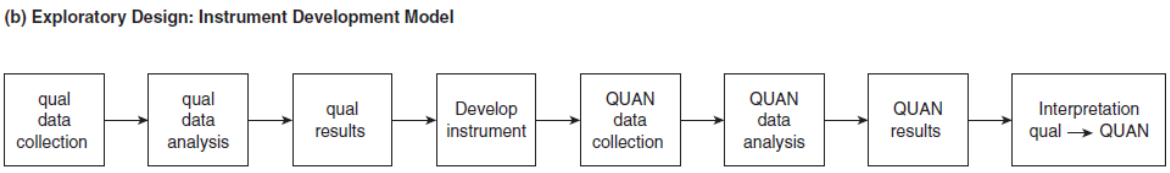
care that is concordant with patient preferences, if they continue to face barriers to delivering the methods and services that patients want most or perceive to be most important in making family planning decisions. Although health centers have regulatory obligations to provide voluntary family planning care, few guidelines or standards of quality specific to family planning care guide health centers provision of these services. Illuminating the state of quality of family planning and reproductive health care in health centers, at least from the patient perspective, may motivate the use of performance benchmarks or other quality improvement efforts in response to patients' unique needs, values, and preferences. For these reasons, health centers were selected as the ideal setting from which to investigate this particular area of inquiry into the value concordance of family planning care.

Chapter 3: Study Design and Methodology

3.1 Research Approach and Study Design

This research proposal follows a sequential exploratory mixed-methods approach, defined as the incorporation of findings from an initial qualitative methodology to develop or inform a quantitative research phase. Creswell writes that the exploratory approach is best suited for research that aims to develop and test a measure or instrument to explore an identified phenomenon (Creswell & Clark, 2011). Thus, the stages of the exploratory approach this study uses include (1) an exploration of patient preferences for family planning through a grounded theory qualitative approach; (2) the development of an instrument to measure value concordance in family planning care; and (3) the preliminary testing of this measure with 110 female patients of childbearing age (18-44 years) in community health center settings. This process is consistent with Creswell's instrument development model, presented in Figure 3 below.

Figure 3. Exploratory Instrument Development Model



The following chapter describes the data collection protocols and analytic processes employed during each phase of this research and correspond to each of the specific aims outlined in the previous chapters of the proposal.

3.2 Qualitative Research Strategy – A Grounded Theory Study

The grounded theory approach represents the form of research inquiry that systematically generates the theory of a process, action, or interaction experienced by a large number of participants (Strauss & Corbin, 1998). The strength of this approach lies in its inherent reliance on data from the field to develop and shape theory from the perspectives of the people who experience the phenomenon of inquiry rather than a set of predetermined concepts, theories, or propositions. This fulfills one of the identified gaps in the family planning literature, especially for underserved patients, as Becker and colleagues (2007) have indicated that many of the measures around family planning quality have been derived from researchers' and clinicians' impressions, priorities, and agendas, often lacking patient insight.

The grounded theory approach involves core principles that have been incorporated in this research study, including the constant comparative process, in which the interpretation of data moves forward through the continuous development and comparison across each source of data toward saturation (Glaser, 1965). Another key to the grounded theory approach is the importance of investigator memos in which the researcher documents the decision process around how to move beyond descriptive coding to generation of categories, themes, and relationships to build theory (Green & Thorogood, 2009). These memos have been included in Appendix A. Additionally, this grounded theory utilizes a three-stage coding process using open, axial, and selective

coding, and moving from an inductive analysis mode by which general properties of the theory may be generated in the early process, to a deductive approach by which theoretically-informed concepts are specified. This research study closely follows a modified grounded theory approach and its core principles to achieve the aims of developing theory around patient preferences for family planning care in underserved populations, and developing and testing a measure of value concordance in family planning care.

3.2.A Qualitative Data Collection

In order to understand the salient themes and key issues around family planning preferences and values for the development of the value concordance measure, I conducted a qualitative exploration of patient preferences for family planning care delivery. Six focus groups with women of childbearing age (18-44 years) in 4 different community health center settings were conducted between May and July 2013. The focus group guide followed domains of patient priorities for primary care and was adapted to reflect family planning service delivery (See Appendix B) (Jung, Baerveldt, Oleson, Grol, & Wensing, 2003; Cheraghi-Sohi et al., 2006). A copy of the full interview guide and accompanying materials is provided in the Appendix C. Participants were asked to discuss these domains and their perceptions on the key components of family planning care delivery from their own experiences.

At the midpoint of the focus group data collection effort, it became clear to me that a few participants preferred to discuss their family planning and reproductive health experiences in a private setting, rather than among peers in a focus group. Two participants specifically preferred this method because they had traumatic experiences

related to reproductive health that they did not want to discuss in front of others. Other patients indicated that the interview worked better for them because they could schedule it at a convenient time, compared with the set focus group date and time. At the request of participants and in line with the flexible approach afforded by a grounded theory qualitative design, I revised the data collection protocol to allow for individual semi-structured interviews with participants who preferred to disclose their family planning history privately. I made myself available to conduct one-on-one interviews in a private office in each health center setting and utilized the same interview guide as was used in the focus group efforts. Data collection and analysis procedures were identical across individual interviews and focus groups.

Research Partner Site Selection

Using a network of community health centers that have previously participated in GW-administered research on family planning in health centers, I identified and selected a set of 4 community health centers to partner in the research activities outlined in this study (Wood et al., 2013). Using a purposeful sampling approach, I implemented the following inclusion/exclusion criteria in order to achieve a typical group of health center settings:

1. Health center size: A former study of family planning services delivered in community health centers found that no significant differences in the range of services or other service characteristics existed between large or medium sized health centers but that small health centers were significantly more likely to have limited or reduced scope of family planning services (Wood et al., 2014; Beeson

et al., 2014). This meant that small health centers faced a different set of challenges or issues in providing family planning services to patients that may confound the value-concordance concept. Based on this evidence, I sampled from health centers that were characterized as either large health centers (patient volume > 20,000 patients per year) or medium health centers (patient volume between 10,000 – 19,999 patients per year) as they represent a homogenous group for the purposes of this study.

2. Title X Funding: I recruited sites from both recipients and non-recipients of the federal Title X Family Planning Program in order to determine if different themes emerged from one group over another. This strategy aligned with former analysis indicating that Title X funding is by and large, the strongest predictor of resources, staffing, and services dedicated to family planning and reproductive health in community health centers (Wood et al., 2013).
3. Urban/Rural: Although this was not an intentional inclusion criterion, by nature of the health center size (medium and large), I had the option to conduct focus groups and interviews in more than one site at each health center. This strategy was suggested by health center staff who indicated that there may be challenges and experiences accessing family planning care that are unique to the populations getting care in rural sites, compared to urban sites. I incorporated this selection criterion, in recognition of health center staff members' knowledge of their population and in line with the theoretical sampling approach that is consistent with grounded theory principles (Glaser & Strauss, 1967; Strauss & Corbin, 1990).

4. Geographic Region: A final selection criteria was to partner with health centers in different regions of the country, in order to explore differences in patient preferences for family planning care that may occur by nature of the community in which they live. We know from former efforts to understand family planning care delivery in community health centers, that community perception, political climates, and other factors unique to the regional location of the health center are known to be important factors in the delivery of family planning services, as perceived by health center staff (Goldberg et al., *forthcoming*). In this regard, I intended to sample from four different regional areas in order to understand if regional variation had any effect on these factors at the patient level.

Using this set of selection criteria, I reached out to a group of 13 health center organizations, among which four centers agreed to participate as research partners. Staff were responsible for scheduling focus groups and/or individual interviews, hosting the interviews on-site in a private location such as an office with a closed door, conference room or classroom, and recruiting participants that met the eligibility criteria (described below). Partnering health centers were provided with copies of the informed consent form, study protocols, and recruitment materials. The health center executive director or other executive level designee provided the researcher with a letter of support to indicate agreement to participate. Partnering community health centers were compensated with a $200 gift card for each focus group and/or day of individual interviews, for a total of $400 in recognition of their efforts as research partners in the qualitative phase of this study.

Participant Recruitment and Enrollment Strategy

Participants were eligible to participate in focus groups and individual interviews if they met the following eligibility criteria: (1) a patient of the respective community health center, or a friend/family member accompanying a patient of a community health center; (2) female, age 18-44 years; and (3) not pregnant or seeking to become pregnant. Because the purpose of the focus group and interview process is to gather broad patient perspectives on the most important aspects of family planning care, this study did not implement rigid exclusion criteria; that is, if a woman met the age range and either sought care at a community health center, or accompanied someone seeking care at a community health center, they were eligible to participate in the focus groups or interviews. The purpose of the pregnancy exclusion criterion was to gather information from women who were most likely to use contraceptive and family planning services at that time. Health centers also reported that most pregnant women using services at their clinical sites were enrolled in maternity services, typically delivered by a different set of providers and/or in different clinical settings, which may have confounded the findings on their experiences with health center services.

Staff and providers at the partner sites were asked to recruit patients by mentioning the focus group and handing recruitment flyers during appointment check-in and during clinical encounters with eligible women. Health center staff also posted recruitment flyers in public places (such as waiting rooms or health education rooms) at their clinical sites. At least two sites utilized special patient programs (such as prenatal education groups and post-partum support groups) to reach eligible participants. Each focus group participant was compensated with a $15 gift card to a major retailer and

provided a meal for participating. Individual interview participants were provided with a $25 gift card to a major retailer in recognition of their time (no meal was provided to individual interview participants).

Qualitative Data Collection

Focus groups with female patients in community health center sites lasted between 60 and 90 minutes, using the approved qualitative data collection instrument (Appendix C). In at least half of the focus groups, a team of two interviewers moderated the groups. The primary interviewer (Beeson) provided patients with study information, documented informed consent from each participant, and moderated the focus group discussion. The secondary interviewer was trained by the primary interviewer to take observational notes during the focus group and supported the primary interviewer in facilitating discussions and handing out participant incentives (gift cards). Interviews lasted between 30 and 45 minutes and were moderated by the primary investigator. All interviews and focus groups were audio recorded for the purpose of verifying accuracy of the content and for extracting illuminating participant quotes. Audio recordings were transcribed by either a professional transcription vendor or by the research team. The content of the patient focus groups and interviews drew upon the domains of patient preferences and values described in the literature around the delivery of family planning care and how women experienced this care in a health center setting (Jung et al., 2003). Revisions to the interview guide were made after the initial focus groups in order to account for necessary changes to phrasing or ordering of questions, however no changes in the scope of the proposed interview guide were implemented.

Focus group and interview participants were also asked to fill out a short demographic form to help the researcher describe the population of participants (see Appendix C) (Morgan, 1997). This form included questions on patient characteristics (such as age, income level, and insurance status) and typical use of family planning services. This data was aggregated for the purposes of describing focus group and interview participants and was not linked to the participants' responses in the qualitative discussions. Names or geographic identifiers were not requested of patients either on the demographic form or in focus group or interview discussions. Furthermore, no participant was required to give first or last names during the focus group or interview discussions, but could provide a pseudonym by which the interviewer referred to her. Participation in both focus group and interview discussions was completely voluntary and verbal consent to participate in the discussions was obtained for each participant. All qualitative protocols were reviewed and approved by the Institutional Review Board at the George Washington University.

3.2.B Qualitative Data Analysis

Drawing upon the principles of grounded theory, focus group and interview transcripts were analyzed in three distinct phases: (1) open coding, in which investigators inductively examined qualitative texts for salient characteristics, properties, themes, and concepts; (2) axial coding, in which linkages between emerging concepts were developed; and (3) selective coding, in which theoretical propositions are expanded to better describe the process by which women form their family planning preferences. These complex themes then informed the development of domains and items comprising the FPVC measure in later research phases. This analytic methodology is consistent with

the grounded theory approach to qualitative inquiry, research design, and analysis procedures (Creswell, 2007; Strauss & Corbin, 1990; Bernard & Ryan, 2010). A constant comparative method, whereby transcripts are analyzed line-by-line to identify codes and themes was implemented in all coding phases (Green & Thorogood, 2010). The primary investigator (Beeson) conducted all phases of qualitative coding. In order to address the inter-coder reliability of the qualitative data analysis, a second independent analyst coded a randomly-selected group of transcripts at an intermediate step in the coding process until consensus was achieved (Green & Thorogood, 2010; Bernard & Ryan, 2010). Inter-coder reliability was observed on major themes and met or exceeded standard measures of agreement ($k \geq 0.6$). All qualitative coding was conducted with QSR NVivo v.10 software. The final coding matrix presented in Appendix D was later used to inform the development of the proposed conceptual framework and to populate the list of items for the development of the value concordance measure. De-identified summary reports of the qualitative findings were also presented to each of the partnering health center sites to inform their future quality improvement efforts around family planning care delivery.

Challenges to Qualitative Methods and Researcher Credibility

According to Creswell (2007), one of the substantial challenges to conducting qualitative research from a grounded theory approach is that the investigator must set aside pre-conceived notions or former theoretical convictions to allow for substantive theory to emerge. In concert with the fluid nature of grounded theory work, the previously described systematic process for collecting and analyzing data was also utilized to maintain the rigor of this proposed study. Furthermore, grounding the value concordance construct in qualitative data ensured that the patient voice is represented in

the conceptualization and operationalization of the measure and lends to the external validity of the conceptual framework presented in this dissertation. Additional discussion of the limitations and challenges of this study are presented in chapter 5.

Additionally, grounded theory and other qualitative research designs must account for the investigator credibility in the study. Qualitative investigators often explicitly state their personal values and beliefs, their role as a researcher in the design, and any assumptions that may implicate the research findings, in an effort to elevate the transparency of their work. As a researcher with advocacy and participatory tendencies, my focus is often on research that contains an action agenda that may improve the conditions, experiences, and lives of participants. My research heavily favors traditionally marginalized populations, which is why this study and many others that I have worked on illuminate the barriers that underserved patients typically face in accessing high quality health care and offers recommendations and tools to improve the performance of the programs, systems, and policies that serve them. In this spirit, the research questions posed in this dissertation research, and the theoretical propositions I offer reflect my own values about what patients deserve in their health care experience. A more thorough description of the researcher background is provided in the Appendix A. As in any qualitative study, these personal values and beliefs create the lens through which the investigator views the problem or phenomenon, and intentionally noting this axiological perspective during the study process allows the research findings to be placed within their context.

One strategy intended to mitigate the investigator's bias on the theory development process is the use of *in vivo* codes, whereby initial open coding featured

verbatim words or phrases used by participants as part of the coding structure. While these codes may have later been adapted or re-categorized to reflect more complex themes, they were utilized to preserve the original meaning and context of the participants' voices in the initial stages of analysis (Given, 2008).

A second area where my philosophical paradigm influences this work is the way I perceive the role of the researcher in this study. Advocacy/participatory investigators often attempt to narrow the distance between them and the participants in qualitative research. They often spend time developing relationships and establishing strong credibility, and essentially perceive themselves as an "insider" to the participants' world. While I cannot say this is true with all certainty, I do feel a sense of rapport and trust was achieved between patients and myself. I often phrased questions in a way that reflected a sense of inclusion and collectivity (e.g. "What do you think is most important to women like yourselves about the way they get family planning care"). I also think that my presence as a woman of reproductive age may have advanced the feeling that I could relate or understand the experiences that my participants may have shared. In this sense, I suggest that participant reactivity was minimal in this study due to the fact that most participants shared openly about their family planning experiences, even those that were negative, unfavorable, or even traumatic in some cases. Another strategy used to mitigate the possibility of reactivity is that recruitment flyers and verbal announcements specifically referenced the purpose of the focus groups and interviews was to gather information on genuine opinions and experiences with family planning care, "both good and bad" and patients were also reminded of this during the consent process. Finally, periodic researcher memos debriefing each stage of the data collection process were

written in order to describe the investigator's experiences and document areas or instances in which researcher bias may be a concern (see Appendix A).

3.3 Quantitative Research Strategy

The second phase of this research study follows Robert DeVellis' (2012) well-accepted method for scale development to develop and pilot test a measure of value concordance in family planning care. Consistent with the sequential exploratory mixed-methods approach, the FPVC scale was developed following the collection and analysis of qualitative data generated by the patient focus groups and individual interviews. The measure of value concordance also drew upon guidance from an expert panel and was pilot tested using through a rigorous factor analysis procedure using data from a survey of women of childbearing age in two community health center settings.

3.3.A Developing a Measure of Value Concordance in Family Planning Care

The results of the grounded theory phase of this study heavily influenced the subsequent phases of instrument development and testing of the FPVC measure. In particular, careful attention was placed on developing domains and items that represented concepts parallel to those developed in the qualitative research phase. More descriptive discussion of the triangulation methods are discussed in subsequent sections of this chapter.

Following DeVellis' guidance on scale development, I generated a pool of potential items to comprise the FPVC scale through a set of distinct data generation mechanisms. First, I conducted a review of existing instruments and survey items related to patient preferences and values in family planning. Secondly, I convened a panel of

field experts in family planning to review these items and develop consensus on the conceptualization and measurement of value concordance in family planning care. Twelve members of the expert panel were selected and recruited to participate based on their experience with family planning quality, patient-centeredness research, and community health center practice. In 2010, a similar advisory panel was convened to discuss the development of the organizational survey of community health centers and family planning services and served as a preliminary list of potential expert panelists for this dissertation research (Wood et al., 2013).

Two rounds of expert panel feedback were conducted based on a modified Delphi-approach to building consensus (Fink, Kosecoff, Chassin & Brook, 1984). Panelists completed a self-administered web-based questionnaire asking them to provide insight on defining value concordance in family planning care and conceptualizing each domain of value concordance. The first round asked panelists to review domains from existing frameworks on primary care preferences, adapted to reflect the family planning care context and the data generated from our qualitative research phase. Panelists were encouraged to provide feedback on the elimination, revision, or addition of each domain and subcategories of items. They were then asked to rank each item on its importance to defining each domain and also rank each domain's importance to the overall conceptualization of value concordance in family planning care among underserved women. Items that consistently ranked in the bottom 10 percent of each domain were excluded from the second round of review.

The second round of review asked expert panelists to either "agree" or "disagree" that each domain and subcategory of items should be included in the conceptualization of

value concordance in family planning care. In order to achieve consensus, items for which less than 70 percent of panelists agreed were excluded from the final list of domains and items for survey instrumentation. A total of eleven panelists provided feedback in round one and at least partial feedback in round two, with nine panelists providing complete feedback in both rounds of consensus building. These nine panelists represented an average of 22.5 years of experience in their respective professions.

This consensus process confirmed the inclusion of 28 items for the purposes of measurement development through factor analysis. These 28 items were identical across two subscales: patient preferences and patient experience at last family planning visit. However, the question wording was phrased differently in order to measure the degree of concordance between the two. While one subscale measures a patient's preferences or expectations for a family planning visit, the other subscale is the assessment of the patient's most recent family planning visit and how closely the two correspond. A copy of the full instrument is presented in Appendix E.

The number of items generated for consideration in the final instrument is consistent with DeVellis' guidelines, which state that the universe of potential items should be at least twice that of the intended length of the final scale (DeVellis, 2012). As I originally proposed a final scale length of approximately 10 items, the pool of 28 items generated through a review of the literature, qualitative data collection, and consensus panel efforts was sufficient for the subsequent factor analysis techniques to finalize the instrument.

The instrument reflecting the 28 items on value concordance also included other items on patient demographics, service utilization, and family planning outcomes and

was later adapted to accurately reflect the most appropriate language, terminology, and literacy level (5th grade using the Flesch-Kincaid readability test) for the study population (Doak, Doak & Root, 1996; Microsoft Corporation, 2010). The instrument also included items from existing validated tools that are used to measure similar constructs, such as the Clinician and Group Consumer Assessment of Healthcare Providers and Systems (CG-CAHPS) to test for criterion validity of the proposed measure. Prior to fielding the preliminary instrument, I conducted cognitive testing with five participants meeting the eligibility criteria for study participation. Participants were asked to comment on the ease of survey administration, their comprehension of each section of questions, and any suggested changes to the survey instrument. Cognitive testing of survey instruments is a standard component of instrument development in order to ensure the questions are presented in a way that is valid, reliable, sensitive, unbiased, and complete (Collins, 2003). Cognitive testers also tracked the length of time it took to complete the survey. On average, participants took 21 minutes to complete the entire survey, including the 56 items on patient preferences and experiences (2-subscales of 28 items each) and the demographics, utilization, and outcomes items. Minor revisions were made to question wording and order based on comments from the cognitive interview participants. In recognition of cognitive testing participants' time and effort in completing the survey and providing feedback, they received a $30 gift card to a major retailer.

3.3.B Sampling, Recruitment, and Instrument Fielding

Following sample size recommendations by DeVellis (2012), approximately 110 patients were recruited at two health centers that previously partnered in the focus group and preliminary survey development phases of this research. This sample size was

approximated to achieve a power of 0.80, which is high enough to detect an effect size of 0.10 across the sample group (Hertzog, 2008). Based on existing literature on pilot studies in health services research, psychometric or instrument development studies involving a single group of participants utilized a median sample size of n=84, while descriptive or correlational studies of a single group had a median sample size of n=40. DeVellis (2012) suggests a sample size of 300 for testing a multiple-subscale instrument in order to eliminate subject variance, but also asserts that a sample size less than 300 is adequate, and in many cases more feasible for a single-scale instrument with less than 20-items. In addition, Tinsley & Tinsley (1987) recommend between 5 and 10 subjects per scale item in the intended instrument, which our final sample size of n=110 meets.

Two of the previously partnering health center sites agreed to field approximately 50 complete surveys at each site through clinic-based, mail, and web-based survey modes. A total of 175 paper surveys, self-addressed envelopes, postage, were provided to the two sites in September 2013. Each site was also provided with a locked drop-box in which participants could submit their confidential responses. Health centers also distributed flyers with the hyperlink to the web-based version of the survey, if patients preferred to participate online at their convenience. Participants were recruited primarily through the verbal communication with family planning providers or other staff members at each partnering site or through flyers posted in waiting rooms. The eligibility criteria for survey participation paralleled those that were used during the qualitative research phase focusing on women of childbearing age (18-44 years) receiving care at a community health center. Focusing on this population was intended to achieve a sample of patients that are (a) at risk of an unintended pregnancy and (b) more likely to use

family planning and contraceptive services (Guttmacher Institute, 2012). Due to resource constraints, surveys were only administered in English to English-speaking patients. Participants were offered a $20 gift card to a major retailer upon completion of the survey. A total of 110 surveys were completed during the survey fielding period of September – November 2013, representing a completion rate of approximately 63 percent.[‡]

3.3.C Survey Content and Variables of Interest

The instrument fielded among the 110 underserved women of childbearing age at community health centers represented the following topical areas. Table 1 identifies the categories of items that correspond to each topical area and the full instrument is presented in Appendix E. Standard language from the 2010 American Community Survey was used for items on general patient demographics such as age, marital status, and race/ethnicity (U.S. Census Bureau, 2010). Other demographic and service utilization items were adapted from existing surveys in similar topics, such as the National Survey of Family Growth, the Guttmacher Contraceptive Client Survey, and an original survey on family planning in community health centers (Centers for Disease Control and Prevention, 2002; Frost, Gold & Bucek, 2012; Wood et al, 2013). In addition, we asked participants to report how strongly they felt about preventing a pregnancy at this time in their lives, as an indicator of pregnancy ambivalence. Respondents that reported preventing pregnancy as "neither important nor unimportant", "somewhat unimportant"

[‡] The response rate reflects the number of complete surveys collected based on the total number of paper surveys distributed to participants at each site. This figure may over-represent the actual response rate because participants could submit responses through multiple modes of survey administration. Response rates were not collected for each survey mode.

or “not important at all” were considered “pregnancy ambivalent” and this variable was used to control for pregnancy ambivalence in later regression analyses.

Table 1. Survey Topics and Categories of Items	
Patient Demographics	Age Marital status Number of children Household size Race/ethnicity Employment status Distance traveled for primary care Health insurance status Pregnancy ambivalence
Family Planning Service Utilization	Last family planning visit Location of last family planning visit Distance traveled for family planning care Current contraceptive use Alternative contraceptive methods
Patient Preferences for Family Planning (subscale for FPVC measure)	Location of family planning care Family planning provider Dedicated family planning visits Specialty family planning providers Scheduling family planning visits (2 items) Family planning information source (2 items) Family planning information quantity Family planning counseling (2 items) On-site access to contraceptive methods Types of contraceptive methods (3 items) Affordability of contraceptive methods Family planning provider characteristics, gender, language, race/ethnicity (3 items) Family planning decision-making (7 items) Social support (2 items)
Patient Experiences in Last Family Planning Visit (subscale for FPVC measure)	Location of family planning care Family planning provider Dedicated family planning visits Specialty family planning providers Scheduling family planning visits (2 items) Family planning information source (2 items) Family planning information quantity Family planning counseling (2 items) On-site access to contraceptive methods Types of contraceptive methods (3 items) Affordability of contraceptive methods Family planning provider characteristics, gender, language, race/ethnicity (3 items) Family planning decision-making (7 items) Social support (2 items)
Other Patient Experience Measures (CG-CAHPS)	Questions answered to patient’s satisfaction Provider explained contraceptive method options Provider explained possible side effects of contraceptive method options Provider listened carefully Problems communicating with provider Patient rating of provider knowledge of patient’s family planning preferences, values, and beliefs
Patient Engagement and Satisfaction Outcomes	Satisfaction with family planning provider Satisfaction with source of family planning care
Family Planning Outcomes	Family planning knowledge Current contraceptive use Contraceptive discontinuation (switching or stopping a method)

As previously indicated, the two subscales of patient preferences and experiences at last family planning visit were developed as a result of the qualitative research phase and consensus panel efforts. Other patient experience items were included for the purposes of measuring concurrent validity of the scale, using measures from the CG-CAHPS provider communication subset (AHRQ, 2011). I also included items representing patient outcomes, as identified in the conceptual framework for value concordance in family planning care, in order to test the predictive validity of the instrument. Patient satisfaction was measured using existing CG-CAHPS measures adapted for the family planning context, including whether or not the patient would recommend her provider to a family member or friend, and whether or not the patient would return to the clinic location for family planning services in the future. We determined that responses indicating "yes, definitely" or "yes, somewhat" were indicative of patient satisfaction, and treated them as dichotomous variables. We gathered data on current contraceptive use and method satisfaction by asking patients if they were currently using a birth control method to prevent unwanted pregnancy and if that method was their first choice contraceptive method. Contraceptive satisfaction was considered a dichotomous variable for the purposes of analysis. Contraceptive discontinuation was measured by asking patients to indicate the number of times in the past year they had stopped using a birth control method or switched birth control methods for any reason. Contraceptive discontinuation was treated as a dichotomous variable by coding any incidence of switching or stopping a birth control method in the last year. We excluded responses that indicated reasons for stopping or switching birth control because of intent

to conceive or because the patient's provider recommended that they discontinue the method.

3.3 D Factor Analysis

The literature on patient preferences recommends that value concordance is best assessed by examining the agreement between patients' ratings of the most important attributes of care and the actual treatment or care received (Sepucha & Ozanne, 2010). In our case, this study aims to measure the degree of agreement between patient preferences for family planning and their actual family planning care experiences. The proposed approach for developing a measure of value concordance in family planning was to include two subscales in the overall survey instrument. The first corresponds to what patients prefer and value most in their family planning and reproductive health care, based on the domains generated from our formative qualitative work. Respondents were presented two options reflecting potential preferences on a given item and asked to report whether they preferred "Option A," "Option B," or had "No Preference." The second subscale corresponds to patients' experiences during their most recent family planning visit and whether the care they received reflected their preferences and values for family planning care. We defined most recent family planning visit as, "the last time you received family planning services such as a Pap smear, birth control services, STD testing or treatment, or other services related to women's reproductive health." Reflecting on their most recent family planning visit, respondents were presented two sets of statements on each item and asked to indicated whether "Statement A," "Statement B," or "Neither Statement/Not Sure," was most true.

An exploratory factor analysis procedure was conducted to determine which scale items may be eliminated due to duplicate representation and to show the shared variance around factors or domains supported by the survey data. While a higher number of scale items is generally considered more reliable, eliminating items that do not load properly onto the identified factors or that expresses multi-collinearity with other items (indicating duplication) may actually increase the overall reliability of the measure by removing weaker scale items (DeVellis, 2012). In a typical factor analysis, most datasets specify continuous variables, such as a 5- or 7-point Likert scale. Due to the categorical nature of our survey data, polychoric correlation matrices were used to complete the factor analysis procedure. The purpose of using a polychoric correlation matrix is to account for the fact that while our data represents categorical variables, there still exists a continuous nature underlying a given set of categorical response options and that variation across these continuous variables may be implied to identify unobserved latent variables in the measurement model (Bartholomew, 1980; Holgado-Tello, Chacón-Moscoso, Barbero-García, & Vila-Abad, 2008). The resulting matrix of residuals was then rotated obliquely to yield meaningful item groupings and produce the final factor loadings. Standard minimum thresholds of 0.3 factor loadings and three items loaded per factor were used to identify appropriate item groupings. Items not meeting these standards, or loading on more than one factor (thereby signifying poor measurement of a singular concept) were dropped from the final list of scale items.

3.3.E Psychometric Analysis

This study proposed to develop and pilot test an initial FPVC scale in community health center settings. In order to adequately determine whether the data supports our proposed measurement model, I employed a set of psychometric analytic procedures.

1. Inter-Item Correlation: According to classical test theory (CTT), item-test correlation demonstrates how correlated each item is with the overall scale, inclusive of all other items (DeVellis, 2006). This method also helps identify items that either do not correlate with the overall scale or that may not correspond to the same domain, factor or subscale. I used Cronbach's alpha to demonstrate item-test correlation for each of the variables included in the final proposed index measure resulting from the exploratory factor analysis. DeVellis (2012) indicates that for a 10-item scale, an alpha finding of less than 0.29 should indicate an item's elimination from the final scale measure.
2. Internal Consistency: In order to test the internal consistency of overall scale and the proportion of the variance explained by our measure, I also used Cronbach's alpha to assess item-scale correlations for each factor generated by the factor analysis, and the overall reliability of the proposed scale of all included items. Generally speaking, alpha measures above 0.6 are considered acceptable for the purposes of scale development (DeVellis, 2012).
3. Measurement Validity: As in any measure development effort, the value concordance measure must be tested for various types of measurement validity. Face and Content Validity were intended to be addressed in the study design by using data from qualitative patient input and from technical experts until

consensus was reached on the various domains of value concordance. A further discussion of these types of validity is presented in Chapter 4. This study also explored the concurrent validity of the scale by conducting Spearman correlations between the FPVC measure and similar scales, such as items from the CG-CAHPS questionnaire. Spearman correlations represent statistically-significant correlations between a set of variables when they exhibit p-values ≤ 0.05. I also employed tests of predictive validity by collecting patient outcomes that are assumed to be associated with value concordance in family planning and conducting multivariate regression modeling to determine if, in fact, value concordance performs as theory suggests. In this case, I hypothesized the value concordance would be positively correlated with a set of patient outcomes outlined in the final conceptual framework resulting from this research. These proposed outcomes included patient satisfaction and engagement, service utilization, and family planning outcomes. Logistic regression modeling was used to test the hypothesized relationship to these set of outcomes.

3.3.F Measurement Modeling

In order to adequately measure value concordance as the standardized degree of agreement between the two subscales (patient preferences and patient experience at most recent family planning visit), I utilized a simple percent match approach, or the percent of preference items that were met or reflected in the experience items. Incidents where patients expressed no preference were automatically coded as a match. Examples of the simple percent match approach are presented in Table 2 below. The sum of the percent match results on each of the final scale items comprises the FPVC measure. This simple

percent match approach has previously been used in a number of studies exploring the role of value concordance in other health services (Sepucha & Ozanne, 2010).

Table 2. Example of Percent Match Coding	**Expressed Preference**	**Reported Experience**	**Match**
Item: Location of family planning care	Option A: I prefer to get family planning care in the same place that I get my general health care	Option A: I received family planning care in the same place that I get my general health care	MATCH
	Option B: I prefer to get family planning in a different place than I get my general health care	Option A: I received family planning care in the same place that I get my general health care	NO MATCH
	No Preference	Option A: I received family planning care in the same place that I get my general health care	MATCH

3.3.G Descriptive Analyses

The pilot survey was used primarily to factor analytic and other validation procedures in the development of an original measure of family planning value concordance. However, we also used data from the pilot survey to explore the relationship between certain patient characteristics and their level of value concordance in their most recent family planning visit. We also tested the predictive validity of the measure by testing whether a relationship exists between value concordance and subsequent patient outcomes, according to theory. Descriptive statistics were used to characterize the sample of pilot study participants. We conducted bivariate statistics using Ordinary Least Squares (OLS) and unpaired t-tests to identify differences in value concordance by patient characteristics such as age, marital status, race/ethnicity, employment status, and insurance status. We considered statistical significance at the α=0.05 level indicating that less than five percent of the observed differences between

groups is due to chance, as a threshold for identifying statistically significant results. However, we also mention findings at a slightly elevated threshold (α=0.10) recognizing that the study represents a pilot effort with a small sample size. We would expect future studies testing these relationships would exhibit statistically significant differences at a higher confidence level.

Analyzing the Impact of Value Concordance on Patient Outcomes

We also conducted multivariate regression analyses to test whether value concordance is associated with family planning outcomes such as patient satisfaction with family planning provider, satisfaction with source of care, current contraceptive use, contraceptive discontinuation, and family planning knowledge. Multiple logistic regression models were constructed to test the probability of achieving the set of dichotomous outcome variables, controlling for covariates indicated in the literature as correlates with family planning quality as well as any salient variables that emerged as statistically significant in the preceding bivariate analysis (Becker et al., 2007).

1. **Patient satisfaction with family planning provider:** Patients' likelihood to recommend their provider to family and friends; dichotomous variable
2. **Patient satisfaction with source of care:** Patients' likelihood to return to their indicated clinical site for family planning services; dichotomous variable
3. **Current contraceptive use:** Whether or not the patient reports currently using any contraceptive method; dichotomous variable
4. **Contraceptive discontinuation:** Self- report of any lapse in contraceptive use during the past year that was not indicated by a clinician or planned by the

patient for purposes of trying to conceive. This outcome is reverse coded to account for the anticipated negative correlation with value concordance.

5. **Family Planning Knowledge**: Patient's self-rating of knowledge about family planning and contraception; continuous variable (Weisman, Macccannon, Henderson, Shortridge, & Orso, 2002).

The multiple logistic regression models report odds ratios (OR) to indicate the associative relationship between value concordance and each outcome measure in the model. In the two models for patient satisfaction, a positive odds ratio above 1.0 would indicate that patients with higher value concordance scores are more likely to be satisfied with either their family planning provider or their source of family planning care than patients with lower value concordance scores. A positive odds ratio above 1.0 for the model on contraceptive use would indicate that patients with higher value concordant care are more likely to be currently using a contraceptive method than patients with lower value concordance scores. Conversely, I anticipated that value concordance would be negatively correlated with contraceptive discontinuation, thus an odds ratio less than 1.0 would indicate that patients reporting higher value concordance scores are less likely to discontinue using contraception for reasons other than intent to conceive or provider recommended discontinuation, compared with patients reporting lower value concordance scores.

In conducting each multivariate regression model, I controlled for a set of covariate variables that are theorized to precede and potentially confound the relationship between value concordance and patient outcomes. First, we controlled for certain patient

demographics including age category, marital status, number of children, household size, race/ethnicity, employment status, insurance coverage, time since last family planning visit, and distance traveled for primary care. Some demographic variables were not able to be included in the model (or were transformed to fit the model) due to insufficient sample sizes. For example, we treated age as a dichotomous variable with patients being categorized as either under age 25 or over age 25. This allowed us enough statistical power to run the analyses as intended. We also accounted for the patient's level of family planning knowledge and information, as this is considered a major component of the value concordance assessment process (Sepucha & Ozanne, 2010). Family planning knowledge was measured by asking patients when they thought a woman was most likely to get pregnant during her menstrual cycle. Correct responses included "right before her period," "one week after her period," or "two weeks after her period" and incorrect if the response is "during period" or "no difference." This measure of family planning knowledge has been used in previous studies with underserved women by Gazmararian, Parker & Baker (1999). We also controlled for current contraceptive use and pregnancy ambivalence in order to control for how strongly a participant felt about preventing an unintended pregnancy. As previously indicated, respondents that reported preventing pregnancy as "neither important nor unimportant", "somewhat unimportant" or "not important at all" were considered "pregnancy ambivalent" for the purposes of this analysis.

3.4 Triangulation of Qualitative and Quantitative Data

The mixed-methods nature of this work relies, to some degree, on the notion that the data collected through both qualitative and quantitative mechanisms will converge,

based on the domains and assumptions presented in the adapted framework for value concordance in family planning care (Jick, 1979). However, each research method was chosen for distinct purposes in answering research questions that correspond best with the particular methodological procedure. For example, qualitative focus groups and interviews were selected to explore patient's general preferences and the factors influencing those preferences in a family planning context. The grounded theory portion of this study relies exclusively on this qualitative data. Focus group and interview data also informed the development of domains and items for the technical expert panel effort, which was intended to achieve consensus on the definition, key measurement items, and techniques for measuring value concordance in family planning care. Finally, the pilot survey tested the domains and items generated in the preceding research phases by conducting factor analysis to finalize a proposed scale and test the predictive validity of the FPVC measure through multivariate regression models. Given the contributions of each of the employed methodological strategies, this study engages triangulation in a number of ways. First, triangulation of methods was employed by using multiple techniques to help answer the research questions on the role of preferences and value concordance in family planning care for underserved women. Within each method, data triangulation was also achieved by using multiple sources of data (e.g. both focus groups and individual interviews) to investigate the same issues or questions around patient preferences for family planning. Similarly, both patients and field experts were consulted to develop domains of FPVC in order to offer diverse perspectives on the conceptualization of this concept and its measurement. Triangulation was also achieved through analysis by drawing from existing frameworks on patient priorities and

preferences in primary care to help guide latter stages of selective coding and informing the appropriate statistical tests for predictive validity, based on theorized relationships in prior conceptual models (Wensing, Grol, Van Montfort, & Smits, 1996). Finally, Denzin (1989) suggests that theoretical triangulation is the most challenging but useful form of triangulation, due to the nature of involving widened theoretical frameworks from multiple disciplines and traditions. This study draws from several theoretical assumptions including health behavior theory, medical decision-making, and quality of health services frameworks and attempts to bring them together in the proposed conceptual model.

3.5 Protection of Human Subjects

Approval and oversight by the George Washington University Office of Human Research Institutional Review Board (IRB) was obtained in 2013 before any data collection activities commenced (See Appendix G). Based on existing guidelines from the George Washington University Office of Human Research (2012) and in concordance with federal regulations, this study involves minimal risk to human subjects and qualified for expedited-review by the IRB. This study employed several human subjects protection strategies. First, participation in focus group, interview, consensus panel, and survey research was completely voluntary and participants could select to end their participation at any time without forfeit of any benefit that was owed them in the absence of the study. Participants were presented information on the risks, benefits, and contributions of their participation in the study and provided consent. Due to the nature of the focus groups, consensus panel, and pilot surveys, a waiver of consent documentation was obtained such that one's participation was implied by proceeding with the survey, interview, or focus group. No personal identifying information is reported in this study at any time and all

individual level data was kept in a password protected file. Individual participant demographic characteristics were kept separate from their responses in surveys or focus groups/interviews and only linked by an alphanumeric code accessible to members of the research team.

Chapter 4: Results

The key findings of this dissertation research are presented in the following chapter, following the distinct research phases. First, the grounded theory and framework development section highlights the findings from focus group discussions and individual interviews with patients. These qualitative findings are presented in a proposed framework for the role of value concordance in family planning care for underserved women. The second phase of this dissertation focuses on the development of the FPVC scale and describes the results of the item generation, consensus panel, and factor analysis to comprise the measure, as well as describing its psychometric properties. Finally, the results of the pilot test of the measure are presented, in an attempt to validate some of the theoretical relationships between value concordance and family planning outcomes.

4.1 Grounded Theory and Conceptual Framework Development

A total of 53 underserved women of childbearing age participated in the qualitative phase of this study. Thirteen women participated in individual interviews, while 40 women participated in focus group discussions across the four FQHC sites. Participants reflected variation across age categories with 26 percent being 25 years or younger, 43 percent between 26 and 35 years and 28 percent between age 36 and 44 years. The majority of participants (80 percent) reported a household income at or below $49,000 annually, although only 25 percent reported being uninsured at the time of the study. Among those who reporting having health insurance coverage, approximately 41 percent were on Medicaid or a state-sponsored health plan. The majority of participants

were white (68 percent), with a small proportion self-identifying as Hispanic/Latina (15 percent), American Indian/Alaska Native (8 percent), Black/African American (6 percent) or more than race (2 percent). Participants reported their health status as excellent (15 percent), very good (47 percent), good (28 percent), or poor (6 percent). A complete description of the qualitative sample is provided in Table 3.

Table 3. Characteristics of Qualitative Sample

	n = 53	%
Age Range		
18 - 25 years	14	26%
26 - 35 years	23	43%
36 - 44 years	15	28%
Income Level		
Less than $25,000	22	42%
Between $25,000 and $49,000	20	38%
Between $50,000 and $74,000	1	2%
Between $75,000 and $99,000	5	9%
More than $100,000	2	4%
Don't Know	1	2%
Race/Ethnicity		
White	36	68%
Asian	0	0%
Hispanic	8	15%
Black or African-American	3	6%
American Indian or Alaska Native	4	8%
More than one race	1	2%
Insurance Status		
Insured	39	74%
Uninsured	13	25%
Medicaid (percent of insured)	16	41%
Self-Rated Health Status		
Excellent	8	15%
Very Good	25	47%
Good	15	28%
Fair	3	6%
Poor	1	2%

4.1. A Factors that Influence Family Planning Preferences

The purpose of a grounded theory approach to qualitative research is to generate a general explanation or theory of a process, action, or interaction shaped by the views of its participants (Strauss & Corbin, 1998). In doing so, this dissertation highlights a number of key features in a new theoretical framework on how women come to form their preferences for family planning and the role that these preferences and experiences play in the delivery of patient-centered, high quality family planning care. The grounded theory framework presented in Figure 6 illustrates some of the factors that women consider when forming their preferences: life stage, health beliefs and culture, access, provider interaction, information, and social support.

Life Stage

The women in our study expressed that one's preferences for the types of family planning services a woman needs and how she prefers those services to be delivered are likely to change over time and that they are closely related to the stage of life she is in. This sentiment is highlighted by quotes from several participants:

> "As you grow older, and mature more, my decisions have changed based on my personal experiences, my personal growth and everything. Mostly time has changed where my values are."

> "At age 20 you're just looking at a method to keep you from getting pregnant and you're probably not thinking of other stuff. But as you get older you think about how those things are going to affect you long term."

> "When I was younger and everything was working the way that it should be working and all I needed was birth control, you know it was 'something I have to do to prevent my unwanted pregnancies.' And as you get older, I think especially for me, after having the abnormal Paps, and having one child and then a miscarriage, you gain a better appreciation for taking care of your body."

Characteristics about a woman's family, marital or cohabitating status may influence family planning preferences, needs and goals. Women with partners often referenced decisions about contraceptive methods or decisions about pregnancies and births in the context of their spouse or partners, while single women often thought more independently about selecting a contraceptive method.

> "My plan was to have two children and then we would adopt our other children because we want a large family. But we always very much decided together. Then we discussed that my husband would get a vasectomy later. I think we're still….I think that's the option we would like to pursue, but he just doesn't like to talk about it."

> "I would always discuss it with [ex-partner] first before I was going to go ahead and decide on something. But I've been single for two years now so I kind of get to make my own decisions. I think it's definitely something important to talk to your spouse or partner about family planning, because it's your family that you're planning."

Underserved women in our study indicated that the number of children or size of their household would also dictate their family planning preferences, particularly the contraceptive method she would select to use. Women with larger families tended to

prefer long-acting or permanent contraceptive methods, while this was not expressed among women with smaller families.

> "I think too depending on…like with me and my number of kids I have, I think that opportunity when I want it [tubal ligation]…if the opportunity was already open for me to be able to do that, I would do it."

> "I was…like I said, I was going get the IUD but they was like 'well, if you don't want any more then I don't think you need to get that 'cause sometimes it's 99.9%' and I was very fertile so I was like okay, tubes tied…it's like number one."

> "Let's get this done [tubal ligation]. I have enough children to know when I need to stop."

Other life stage factors such as pregnancy intention and level of ambivalence toward pregnancy were expressed by participants to be a factor that would influence their patient preferences for family planning care.

> "My family planning [preferences] definitely changed when I made a complete decision…I told myself that when I turned 38, if I wasn't pregnant by the age of 38, I wasn't going have any children and so that's why I made the decision to stick with the [injectable contraceptive]. It was like, the older I was getting, the less chance I wanted to take on having a baby, you know?"

> "I know the IUD has the longest lasting results and, you know, at the time I got pregnant with my daughter, I didn't have any indication that I would want another

one so I just kind of went with it. It's still, you know, I can always get it removed if I want another one"

Many women stated that their employment status (including school enrollment) reflected their life stage and would consequently influence their family planning preferences. These women often had strong feelings about preventing pregnancy because it would affect their ability to work or go to school.

"In my personal situation, I had to decide. Like right now I have taken the birth control pill because of my school situation. There's no getting pregnant again while I'm in school so that's a choice that [my provider] and I made for now. If it was a different time in my life, that may not have been a choice that we made."

"I was uninsured and paying $65 per month for birth control. And I was in school and working part time so it's like birth control or don't have sex or take a chance? What do I do?"

By and large, the women in our study placed a strong emphasis of the role of their current life stage in influencing their preferences. In general, they felt that their preferences for family planning care would change significantly over time, and that the major drivers of their preferences often reflected certain constraints that they were facing in their life at that time. As these constraints shifted, underserved women felt their preferences, as well as their perceived need for family planning also adapted and changed. One woman noted this process as one that all women consider over their lifespan, noting:

"Birth control is something that us women...have to think about every day from teenage to 30 something or whenever you get your tubes tied. That's how old I

was, but I mean that is a long span of your life and it's something that you have to remember every day and it's something you have to think about every day and the impact of not remembering or remembering impacts your life."

It is perhaps this dimension that sets family planning decisions apart from other health care decisions, especially those that require a choice of treatment, due to the fact that family planning decisions (including the choice to conceive or to prevent unwanted pregnancy through some form of contraception) reflects an active decision-making process that often requires daily attention and is not concentrated on the treatment of a specific condition or illness. In this sense, family planning decisions may be considered highly preference sensitive and can change invariably over a woman's different life stages.

Health Beliefs and Culture

A patient's cultural background can have a profound impact on her health and health care. One's culture can comprise the beliefs, attitudes, and values shared and perpetuated by members of the same social group, and often include elements such as shared traditions, language, customs, social norms, family and community roles and perceptions (Bussey Jones & Genao, 2003). The women in our study echoed the important role that one's values and beliefs play in determining their family planning preferences. They also expressed that at times, these health values and beliefs may contradict provider values or recommendations, proving to be challenging for patients to navigate in the family planning care experience and decision-making process.

> "For me, my family's history…I know it kind of sounds awkward, but it's like a commandment for us to have babies and not specifically to say how many. For my husband and I, we wanted four, but from there it followed our religion and background and stuff. There was also some disagreement with certain doctors because I'm [young] and they felt like, 'wow you have too many kids for your age,' and I always felt like that was part of my religion and family decision."

Women also considered their culture to play a role in determining family planning preferences, particularly with respect to the role of the provider, preferences about information and counseling, as well as the role of partners, spouses, or other family members in making reproductive health decisions.

> "It's hard for Native Americans, because we have, you know, our own medicine men or medicine people and to have to respect them, that does mean a lot. It's hard to talk to a lot of doctors about that who don't understand our culture. They're starting to understand now. More evidence is coming out that the old folk remedies and home remedies and American Indian remedies really work."

> "I get scolded by my mother-in-law too because I've been on the pill and that's why they think I can't [get pregnant]. They're Mexican Nationals and they say I shouldn't have ever done that [contraception], and that's why we don't have kids. So it's kind of hard."

These beliefs and values about family planning, contraception, and the role of one's culture on health may considerably impact the way a woman sees her family planning options, how she forms her preferences about them, and ultimately, how she makes

decisions that impact her family planning and reproductive health. These cultural, religious, and health belief facts are important factors that have been shown to influence patient adherence, utilization of services, patient satisfaction and health outcomes. Participants seemed to confirm that these factors are in fact important, at least to the formation of their preferences and the influence over their decision-making for family planning and reproductive health. In this sense, the role of value concordance may help women feel that their providers understand and respect their cultural and health beliefs that shape her preferences and decisions in family planning, thereby moving toward more patient-centered family planning care.

Provider Interactions

By and large, the role of the patient-provider relationship proved to be the most salient factor for focus group and interview participants in developing their family planning preferences. Many women expressed that the level of trust they have in their provider is essential to forming preferences for family planning services.

> "I think trusting your doctor it is really important. I want them to take in what I have to say and listen to me but I don't like it when they just try to leave it completely up to me. Because although I want to be informed and feel like I know what's going on, I'm still not the doctor, so I still want them to tell me what they really think we should do."

> "You're more comfortable talking to the person that you built the relationship with so you're more open to tell them so that they're able to help you because you're comfortable with them."

The majority of women reported that the recommendations on family planning services and contraceptive methods they received from their provider was the most important factor in making family planning decisions, particularly with respect to contraceptive method choice. However, patients wanted to have an established relationship with family planning providers to be able to trust their recommendations.

> "And then they have to know you to kind of recommend anything, you know? I might be a person that forgets to take my pill, you know, so you might recommend something, a shot or an IUD or something. So I think it's important for them to know you to even recommend something to you. You know, if you don't know me or know my life or what's going on in my life, you know, how can you really recommend something that will work well and fit me?"

> "The doctor we have now is kind of…she's already almost perfect. I mean, she already knows my history and she, you know, takes it into consideration with my daughters so that really helps and we just like her. We just trust her."

> "I've seen [my provider] forever now and me and her have an awesome rapport but I don't know how many doctors I went to see and I've actually looked at them at the end of the appointment and go do you even know my name? Do you even know who I am? You're giving me all these prescriptions and all these pills and you don't even know my name and it bothers me."

Other participants indicated less trust in providers when they felt that the providers' attitudes or beliefs limited their ability to openly communicate with patients or respect their family planning preferences:

> "My previous OB/GYN was affiliated with a Catholic group and I had to make a fake reason in order to get birth control. I couldn't say it was pure birth control. It had to be because I was menstruating heavily or I was having problems. Couldn't get it just for birth control."

> "Well, back when my ex and I first got married, I don't think they were as open. It wasn't…you know, when you went to the doctor and it was more of a hush-hush kind of thing. That was 27 years ago and now, you know, you can go into your doctor and you can talk to them and they're more open with you and I think, you know, people in general are more open than they were back then too. You know, I was a single unwed mother, I mean, even though we were living together and engaged but, you know…you know, that was oh, you're living together? Oh, you know, you're going to go to hell but, you know, I mean that was the attitude that they had back then and now that's not and you can go in there even if it's just your boyfriend and sit down and talk with your doctor"

Other women said they may desire to see a particular provider, but because they often experience long wait times for family planning visit, they would rather get care from an available provider than have to delay care any longer.

> "Yeah when I went to get a Pap smear, I had heard about a doctor that was great and I called the clinic and it was going to be like two months waiting. I wanted to get my appointment soon and it was a really long wait so I ended up going with a nurse practitioner because her schedule was more available. I guess it depends."

Still others indicated that they had such a strong relationship with their preferred provider that the wait time to schedule an appointment with him or her did not matter.

> *Participant:* **"**Not everyone understands the need for birth control or they want to push you toward a certain type and it's really important that you can go to your personal physician and get birth control instead of having to go to somebody you only see once every few months."
>
> *Interviewer:* "So you think if you see the person that is your regular provider, they're more likely to…"
>
> *Participant:* "Listen to you and they know you. They know whether or not you know your body and they're not going to give you something that is going to interfere with something you're already on. Yeah, I always double check when I make appointments. I'm like, 'Now that's with [provider name], right?' Now that I know about provider availability, I guess I just know that I have to call at least a month out if I'm shooting for [my provider]."

In some cases, women described situations where they had either moved residences or the provider had changed clinic locations. Despite often longer distances to travel and more complicated scheduling practices, their strong preference to remain a patient of their preferred family planning provider prevailed.

> "For me, I live further away from [my provider] now, but I like where I'm at here so I will come back over and over. I'm happy here so it doesn't matter how far I am. I'm still keeping my physician here. I guess as long as you have someone that you feel comfortable with, how far you have to drive doesn't really matter."

Along these lines, the way a patient perceives herself as a decision-maker in general health care choices may impact the way she forms preferences and values about family planning care and reproductive health. Existing decision-making frameworks suggest that general health care decisions remain fairly static over time (Degner, Sloan & Venkatesh, 1997). Our findings deviate slightly from prior theory, as participants suggested that reproductive health decisions may be fairly flexible and that their information seeking and decision-making patterns may be variable over time. However, general decision-making styles remain an important factor in considering how patients form their family planning preferences and whether there is a relationship between broader health care decisions and family planning decisions (Dehlendorf et al., 2010).

In particular, our work found that most underserved women perceived three styles of making family planning decisions, particularly with respect to contraceptive method selection. In general, these styles of decision-making always involved interactions between the patient and her provider at varying levels and the perceived roles of both the patient and her provider differ distinctively across styles. The first decision-making style was an informed choice model where the patient seeks information on a preferred contraceptive method and confirms that the selected method was a clinically-recommended option during a visit with a provider. While the provider often plays a role in providing or verifying information about contraceptive methods, he or she is not an active decision-maker. The informed choice model views the patient as the ultimate decision-maker and places value on a high degree of information in making care decisions. This was reflected in a number of participant quotes:

> "I tend to use the internet a lot of I'm unsure about something. I do my research first. And of course it's expensive to go see the doctor face to face…but once I've made my decision, narrowed it down to a few things, then I might want to have a visit and talk [to a provider] and they would prescribe it to me."

> "I like to do both. I like to do some research and then come in and ask questions, because you know, the internet is nice, but sometimes the information isn't very true. You never know if you're reading something false. I like to read the information to kind of absorb it because sometimes you can be talking to someone and think you're understanding it but then after I read it, I'll ask more questions if I have any."

> "I like the pamphlets or, you know, reliable sources from the internet. I find that more convenient for me instead of having to call or come in to talk to a provider. I just find it easier."

Women preferring an informed choice model viewed themselves as autonomous decision makers, but also recognized the importance of their provider's ability to understand and navigate their patients' needs and decision-making style.

> "You know, even body language and the tone of voice that [the provider] uses and the way she looks at you and just wants to know about your life in general and not just why you're there. Like who you are as a person and I just, you know, I think that's…some people just need the information and some people need hand holding. You know, like and they just have a good way of figuring out who needs what and being more understanding with like your decisions. Like sometimes

> they will persuade you. Sometimes it seems like they're going to veer you off to another path but when it comes around to it, whose decision really is it, you know?"

Another perception on the patient's role in health decision making is considered the "provider-led" or "paternalistic model" where patients rely on their provider to make recommendations to help them make family planning and contraceptive decisions. The provider is expected to filter and present information about a recommended contraceptive method and the patient often consults the provider's recommendation as their primary source of information and typically selects the provider's recommended method. While some of these women expressed that they later followed up with another source of information on their selected method in our study, many participants who preferred this decision-making approach reported being overwhelmed with too much information and preferred to rely on the insight of their provider to help them filter information to make family planning and contraceptive decisions. Often, the level of information offered to patients drove their preference or choice of contraceptive method.

> "There's a lot of different methods out there so it's really hard to decide. Sometimes I'm like, 'I don't even know what that means!' Lots of times I feel like the information is too much."

> "Holy moly, there's like everything…you just flip through the channels on the TV. I mean, I want to know…yeah…like I think like others, it's just too much."

> "If I want to know more information about the [contraceptive] methods, to narrow it down, I'd want my doctor to tell me what's good and then I'll go from there."

> "I usually get the Depo, but I wanted the [implant]. I guess there's this thing they insert now in your arm. My friend was telling me about it and it lasts for two years. So I went to talk to my family doctor and she's like, 'Oh I don't really know about that, but here's the name. Go look it up yourself on the internet.' I was really kind of shocked, so I just said never mind, I'll get the [Depo] shot."

The third approach, which was strongly preferred by the majority of underserved women surveyed in our study, was a shared decision-making style in which the patient and provider collaboratively discussed contraceptive method options during a clinical visit and shared the responsibility of deciding which contraceptive method would best suit the patient. This included considering the patients' demographic characteristics, lifestyle, health status and ability to afford or access the chosen contraceptive method.

> "When I first came in and [my provider] and I sat down and we talked about all the different types and everything, she was really….I think she had a lot of insight on what was going on, so she actually helped me in choosing the right kind of birth control."

> "My doctor sat down with me one on one and, you know, talked about my family history and everything and the way my body works…She didn't push one option over the other. She was really open to seeing what I wanted to do and that was really good and it was nice to be able to have options and know all of this stuff

> instead of, you know, going to somewhere else where it seems like there's only one option."

Another participant indicated that being in a collaborative partnership with her family planning provider made her feel more engaged as a patient.

> "If you feel like you've got a partner [in your provider], it's easier to put forth that extra effort or rearrange your schedule or whatever if you feel like you have a partner."

Ultimately, participants thought that the role of the provider in helping them form family planning preferences and make subsequent decisions about their family planning and reproductive health was extremely important to them, although they defined their providers' role differently, depending on their general decision-making styles. While most interactions with providers were positive, the few examples of negative experiences with providers also highlighted the importance of this factor in driving what women looked for in their family planning provider and care setting.

Access

A patient's ability to access certain family planning services and/or methods also plays a role in forming her preferences. For many underserved women, this was reflected in their ability to afford family planning services. Women highlighted the importance of their economic status on how they form family planning preferences, particularly on the selection of a preferred contraceptive method. In general, women discussed that they may prefer a particular contraceptive device or drug, but are limited to the method that they

can afford. In this regard, some women commented that having an affordable contraceptive method is better than having no method at all.

> "It really just depends on how much extra income I had and what I could afford at different times in my life."

> "I heard a lot of people say, 'well I got pregnant because I couldn't afford the birth control' and it's like, well, now you can't afford a kid. That's for sure. So it's one of those things that if you could just make it more accessible and cost less, I think fewer people would be in that situation."

Income level has been demonstrated to be a major predictor of patient preferences in a broader primary care context, but it is even more important for medically underserved women who face economic challenges to accessing family planning care and achieving optimal family planning outcomes (Cheraghi-Sohi et al., 2006).

Women also considered the role of insurance coverage in forming their patient preferences. Several participants indicated that lack of coverage and the prohibitive out-of-pocket cost of contraceptives is a challenge, making many women feel like they have few options.

> "I did birth control for a while, then just condoms, and now I'm not on anything at all. I'm on my own so it's hard to pay by myself now that I'm on my own. So I just stopped."

> "…I was uninsured so, yeah. I mean, before going to [provider name], I was paying $65 for a month's supply of birth control and that seems really high. I was

in school and working part time so it's like birth control or don't have sex or take a chance? What do I do?"

"When we lost our jobs, I called 'cause I needed my [contraceptive] shot and they said it's 250 dollars and I'm like, "there's no way." We don't have [insurance], you know, and they're like well, go try and find a free clinic or something."

Even women who were insured at the time experienced significant barriers that influenced their preferences, as some insurance carriers limited the range or brands of covered contraceptive methods. In this regard, participants expressed that they were often unable to access or obtain their preferred contraceptive method and consequently, they often changed their preferences accordingly.

Interviewer: "What would you recommend to improve family planning care in your community?

*Participant: "*Make it more affordable. I mean it goes back to you know, insurance. It might not cover certain ones that we might want, you know. I think making it more available insurance-wise would be helpful. You're kind of limited on what you can take sometimes."

"I was able to talk to, you know, [provider name] about it and there was like a couple different methods of it and it actually came down to what my insurance was going to cover. So I really didn't have a lot of choice."

"I went in and I had first originally asked for the [IUD brand name] but they said that it was going to cost more than $200 out of pocket, so they gave me another

option for the IUD. I went with that option so I didn't have to pay the larger out of pocket expense."

Without access to adequate health insurance that covers the full complement of family planning services, many underserved women are limited to the services and methods that are made available at health centers through subsidized programs or special funding. For many women, the support offered by health center staff proved to be essential in alleviating their access challenges.

> "My provider [name] like knew my insurance didn't cover [my birth control] but she was able to find other ways to get it covered for me so I thought that was really nice with her being informed and knowing different outlets and different things that would assist me with getting that service or getting it paid for."

> "I really like being at [health center name] because they really link you to resources even if you're uninsured. They helped me get services when no one else would take me."

Despite a health center's best efforts, underserved women continue to face other access-related challenges to getting optimal family planning services. Barriers like taking sick leave or unpaid time off for a family planning visit often influenced the way some women preferred to get family planning services, as did lack of transportation or childcare for other children. For example, some women who reported these barriers also reported a preference for getting their family planning in the same location and at the same time as their general health care, often because of employment, transportation or other constraints.

"That's the way it is. You know, especially for a teacher. You're busting your butt off for nothing, you know, and it's like…I don't have much time [for appointments]. I work three jobs."

"Yeah, my other kids are already covered, you know, daycare-wise. So to have the proper daycare when it's time for me to go back in again [for additional family planning care] so that's kind of another thing too, I need it to be all done at one time."

"I have three kids. I have three little babies…well, a four-year-old, a two-year-old, and a one-year-old and my husband works long shifts every day Monday through Saturday and so the only days off my mom has is on Mondays and that's when she can watch the kids for me and it's super hard to get like an appointment."

"Well you got two bus stops here. And you see the cane. I can't walk very far so…it makes it tough, you know, if [health center name] wasn't here, I don't know where I'd go."

"I don't understand why they have to run you around to four, five, six different places when one doctor can take care of it because a lot of women they can't afford the gas and then babysitters and husbands and boyfriends that work…it's just too extreme."

As another example, many women expressed challenges scheduling appointments for routine family planning services such as a Pap smear or an annual well woman visit due to long wait times for these services.

"Your Pap, you might wait three months, if you're lucky."

Participant 1: "If it's a routine thing, I know that it's going be a three-month wait. We can all sit here and say…we all know if you're coming in for a Pap, we're all going be waiting for three months."

Participant 2: "But let's say you think that you have a yeast infection but it's really, really bad and you're like this has to be more than that, you're not going to be able to be seen and you have to deal with the pain and agony, itching, and everything until you're seen and…

Participant 1: "Or if you're missing work, you have to miss work…"

Scheduling these visits three or four months in advance was a considerable barrier for underserved women because in that time span, many of their demographic or other life stage factors (such as insurance status, employment status, and even utilization of contraceptive methods) may change, either exacerbating their challenges with accessing family planning services or increasing their need for more acute care. One participant shared her struggle of trying to find a provider that would support her contraceptive choice:

"I wanted the Depo shot and [my provider] was like 'No, you can't because you're overweight so it won't work. You have to get the IUD.' So that was the only option they gave me. I didn't want to get it and so I was going to see somebody else but had to wait a long time for my appointment and within that time I had gotten pregnant again. And I was just so sad. I was just like, I didn't want another one. I had just had a baby."

Another patient indicated that she felt like a low-priority patient when trying to schedule family planning services compared to other services.

> "I know that OB patients are the number one priority here. When I was pregnant, I could get an appointment any time I needed it. But now if I just need to come in for like routine care, without my kids, they make me wait. Family planning patients end up waiting a long time."

Some women reported "saving up" all their questions or concerns for the scheduled visit because they did not feel they could access information or care in any other way.

> "It's kind of hard to come here, or really to any doctor's office so I just make sure I figure out all of my questions before I come, so that I can get everything done at one time. I just don't feel like I have time to get an appointment on my own."

As indicated through the participant quotes, these factors related to a patient's ability to access important family planning services were often expressed in stories or anecdotes of their experiences with family planning care, suggesting that although these service-level barriers are considerable for patients, eliminating these barriers could effectively reverse or at least change the way they negatively impact their family planning preferences and subsequently, their decisions. Understanding the elements of service delivery that patients experience as either positive or negative is essential to the goal of aligning family planning care with those preferences in order to achieve value concordant, patient-centered care.

Information

Women perceived that the information they received on family planning, contraception, and other reproductive health issues was a particularly important factor influencing their preferences. In general, women expressed a need for additional information on family planning and reproductive health, although the degree of information needs appeared to vary. Thinking about the types of information women wanted to receive, many women responded that they wanted to understand both their range of contraceptive options along with information about certain characteristics of particular methods that would aid in their decision making. These often included elements like the effectiveness of the method, the potential side effects, and length of time on the market.

> "I want to know what all the options are but I also want to know the side effects and how long it's been out on the market."

> "I want to know more about the IUD, like the statistics on how successful it is. Actually, I'd want to know that about all the methods."

> "I like to know how long it's been around. I mean, they give you the pamphlets, but they don't tell you specifics on any one birth control.

Two participants highlighted the need for more information on contraceptive options, also recognizing that women have different preferences on how information is presented to them.

> "We need more information. On all aspects of family planning. The more information you have, whether you use it or not…if you're the type of person who

likes to have limited options then you can just pick and choose what you want, but if the information's out there. You know, the more information we have, the better choices we can make and I think that's, to me, the most important thing."

"You know, not everyone reads pamphlets. I think they need to tailor to people who don't read information and maybe want to get it some other way. They don't always have time in the visit to go through everything, so there has to be another way for women to get educated."

In addition to the types of family planning information a woman receives, the source of information on family planning services and contraceptive methods was also perceived to influence patients' preferences. For many patients, the most trusted source of information came from providers or other clinicians.

"Now any time I've asked about any of it, they always give me…it felt like they were giving me all the information that they had to give me so I could make the best choice for myself."

"I just trust my provider, so whatever she tells me, I trust her opinion."

"I feel like my doctor gave me choices and let me ask questions. So I feel pretty good about what he tells me.

However, other participants shared that the information offered by providers was not sufficient in addressing concerns about efficacy and side effects of certain contraceptive methods.

"They don't explain side effects they don't explain methods, they just say 'there's this birth control and there's one percent chance you can get pregnant.' I think it's kind of manipulative because the woman is thinking, 'okay it's less than one percent so I probably won't get pregnant and that's my main goal.' Instead of also talking about what else you could be experiencing or you know, just being really open about what birth control is. It's not perfect and women need to know that."

"They don't actually tell you that it's possible for the set that they're actually giving you to make your hair fall out or that you actually gain weight because you sustain water and it just doesn't come out and so I went through about six different pills before I actually got to one that I was like, okay, I can deal with these side effects but I just thought they could've given a lot more information about the things that you were being subjected to and at first, if you haven't ever had them before, you don't really know what to ask and you don't know that you can actually go someplace else and get information. So that for me was upsetting."

"But I haven't found one [provider] that really would like sit down and talk to me about it. Like just last week I went to go…I usually get the [injectable contraceptive] but I wanted the insert. I guess there's an insert now my friend was telling me about that lasts for two years. I was like oh, cool. You know, I don't have to go back for an appointment. It'll be three years and so I went to go talk to my family doctor and she's like 'oh, I don't know. Here's the name. Go look it up on the internet.' I was like, really? I'll just get the shot then."

> "I asked my doctor about taking vitamin B and something else along with my birth control just for people who are exposed to breast cancer or whatever and he's like, 'No, I don't even know what you're talking about. I've never read that. I've never heard that.' Instead of saying, 'Oh, I'll look into that' or 'Let me talk to some of my associates,' he was like, 'Nope, never heard of it. Sorry, don't take it.'"

> "Yes, but I think sometimes…not with the OB section but the other general practitioners, they may not have as much information about all of the different options so they give you most of the benefits and hope that's what you're looking for and don't give you all of the negative side effects that may happen."

Other sources of family planning information also played a role in how well patients were informed of certain contraceptive methods, in particular mass media. Patients reported that the perception of certain contraceptive methods in the media influenced their preference for contraceptive choice. For example, the longer a method had been around (and advertised), the more they trusted the method and more negative attention on a method in the media (such as reports of bad side effects or lawsuits against the pharmaceutical manufacturer) would make them trust and desire the method less. These perceptions are highlighted by quotes from three participants below:

> "I guess I'm not as comfortable with all the new chemicals and things they're using. I know they're changing all the time but at least with the birth control pill there's some like familiarity with what they use and there's been studies for the

last 50, 60 years on that. And with the new things, they're telling you they're safe and then it comes out and well, maybe it's not so safe."

"I remember when I had the [contraceptive implant] and I heard you gained a lot of weight from it and there's a lot of stuff wrong with it. You see like the commercials and lawyers on TV and stuff."

"I think that's the biggest thing that's scary about it. Like I was on, [brand name oral contraceptive] and now they're say things like, 'oh file a lawsuit because you could have died.'

Other women indicated that they often consulted internet sources, including drug and device reviews, message boards and other web-sources to answer questions they had about symptoms or concerns related to their reproductive health.

"I Google everything. I look up everything on the internet and make my decision from, like you said, the reviews and that's how I knew I had an allergic reaction actually by looking at the other people reviews and their experiences."

Some women reported that they utilize written materials they receive at health centers however, some indicated that information presented in written form is not complete and requires additional effort to fill the information gap.

"I think most of the pamphlets they have is still very general information and you still have to go educate yourself on some of the material."

"They give you pamphlets. And you take them home and you're like, okay, I think that's a little bit shady. Let's go through all that. And you can't even get the

instructions on how they're going to put it [IUD] in and everything and so I ask a hundred and one questions before I leave."

While family planning information is surely a driving factor in the way women learn about and form their family planning preferences, this domain represents a number of complex dimensions. Women generally felt like they needed additional information on family planning, contraception, and other reproductive health services. Women expressed a desire to know more about the efficacy of contraceptive methods, the side effects that they could expect, and how much they could trust the method – given how long a particular method has been on the market. Women who needed more information often consulted both providers and mass media forms of communication, primarily web-based sources. The degree of trust in these types and sources of information appeared to vary across the women interviewed, but trust and credibility of family planning information was perceived to be an important influencing factor in family planning preferences formation.

Social Support

Another major driving force in women's family planning preferences was the support that she received from her social circles. Participants indicated that social support shaped their family planning preferences and decisions about reproductive health issues. Two sources of social support were described by participants: (1) a woman's partner or spouse, and (2) a woman's peer network. Many women indicated that they discussed most reproductive health decisions (such as planning a pregnancy or STI testing and treatment) with their partners/spouses and considered their opinions in making decisions.

> "They kind of make it a family…I mean, it's family planning, but about your family. Your husbands are included and they're kind of a big part of it too so I like how they make it…the way they present it, they're not just presenting to you. They're presenting to both of you."

> "They are a part of your relationship and they're a part of what you're doing so… they have to suffer to consequences right along with you if it's unplanned."

However, for other routine family planning care such as Pap smears or well-woman visits, they preferred not to involve their partner or spouse. Mixed preferences around contraceptive method selection were expressed, with some women indicating that they would like to highly involve their partner or spouse in their choice of a contraceptive method, particularly if it was a long-acting method or required partner awareness/use. Other women shared the perspective that the choice of contraceptive method belongs principally to the woman and only in rare instances (such as emergencies or complications) would a partner or spouse's opinions be considered.

> "I kind of don't think it's important [to involve my husband]. I mean, I think it's important to let him know but like, it's my body."

> "I mean, I'm not going to drag my boyfriend to my yearly woman visit, sometimes it just doesn't have anything to do with him at the time."

> "Like if there was an emergency situation and you maybe had to get a blood transfusion and something like that, I would want them to know."

Underserved women in our study also reported a strong reliance on their peers to help make family planning decisions. This social support from friends and family members proved to be important in validating family planning information that a patient had received elsewhere. For example, many patients reported consulting other women in their peer networks to hear about their experiences using a particular contraceptive method before they decided on a preferred method. Some women indicated that the information shared between trusted women in their social circles was more complete and unbiased, particularly information on contraceptive side effects.

> "Yeah, talking to my friends who might be on a certain thing just to see what the ups and downs are. You know you get these pamphlets and inserts and sometimes samples and you can read all that stuff you want or talk to the provider, but it doesn't always seem like you get the whole picture. Like the ups and downs to some of the different choices."

> "I mean don't all women do that, talk to each other? But yeah, that's something if I wanted the full information on birth control options; see what my friends are using."

Other women indicated that discussing their family planning experiences with their peers helped them feel more informed and prepared to ask their providers questions about certain contraceptive methods and other family planning services. Strong negative experiences, reports of side effects, or contraceptive failure were often reported as reasons to avoid a particular method, even if it was recommended by the patient's family planning provider.

> "I've always used the pill. I've tried lots of different types of pills, like the ones where you only have a period four times a year, but I've always used the pill. I'm terrified of other stuff because of horror stories I've heard. Especially the IUD. I would never ever do that. I have a friend whose baby was born, she got the IUD and it was terrible. Then she got pregnant on it."

Family planning information gathered from peers also serves as a sense of support for underserved women, in particular, those who are facing reproductive health needs or complications. One participant expressed this desire to connect with other women after receiving news of an abnormal Pap smear:

> "This is what I would like for me, to get a group of patients, who are experiencing the same thing that I am. Because when I first had abnormal Paps and this whole idea of cervical cancer is introduced to me, you feel very alone. And then so when you start talking about it, you realize that there are so many more women with the same experiences and you never knew it. So I think what I would like to see is… I would like to see groups of patients and clinicians getting together to discuss their experiences, to make you feel like you're not the only person there. Or that it's not just you and your clinician, but there's this sort of movement toward providing better care."

Another participant expressed the same sentiment, highlighting the importance of social support on information sharing and processing:

> *Interviewer: "*Thinking about your experiences, what would you recommend to improve family planning care in your community?"

> *Participant:* "Maybe to have support groups or even a women's get together just so they can discuss things or talk with someone who is going through something similar. And getting support from the community saying, 'yeah we support this, we think it is a good idea and it will help people come together.' But also, they are there to support together and their families. Just so they know it's been hard for this person because of fertility problems, or it's hard for this person because they're adopted, and this family over here wants to adopt. So some of the things certain families are going through they don't know or realize that there are other families out there that are going through the same thing. So just having support and turning to other people in your community. This way they have someone to turn to and ask questions and get information. There's a lot of people out there that don't understand about family planning and women need to be heard too, and that would help."

The number of different elements that women consider when forming preferences about their family planning highlights the fact that patient preferences are complex in nature. They are influenced by a number of different factors, from personal characteristics like one's life stage and culture, to interpersonal interactions with providers and other members of a woman's social circles. Other factors like a woman's access to services and the information she receives also plays an important part in how she forms her family planning preferences. What makes preference determination more complex is that these preferences can and often do change considerably over time and as one's lifestyle and personal circumstances change. Understanding how women form their preferences, what major factors influence them, and what role they play into their family planning care and

decisions is an important first step in conceptualizing family planning value concordance in an effort to achieve more patient-centered family planning care.

The Role of Patient Preferences in Value Concordance

This study inquired about the role of patient preferences by asking respondents to comment on the importance of incorporating patient preferences into their family planning care experiences and whether they believed it would change their care experience or their behavior. Generally, most patients commented that they expected their preferences to be incorporated into family planning care and that this was a basic part of good quality care.

> "Like, you know, if I come in to receive the service from you, I expect you to be able to give me the service in return. That's why I called and made an appointment to come in and see you so if like, if you don't respect me and my wishes, I probably wouldn't give that office another chance. Yeah, I think I'd feel mostly just like I had gone there for a service and it wasn't properly provided."

> "I think it makes me confident in the provider and in the overall practice. It really tells me about the quality of care I'm getting. I mean, the best practices out there know about their patients and what is important to them. And that's where I want to get my care."

However, women also expressed very specific key effects that value concordant family planning care had on their experiences as a patient. In addition to their general perception of the quality of and satisfaction with family planning care, many patients commented that having their preferences met and their values respected was one of the most

important factors in being able to trust their family planning provider and adhere to their recommendations:

> "I think it is incredibly important as a patient, potentially one of the most important things with that is just having a provider that is understanding and is willing to incorporate that. I think it would put me more at ease and make me feel a little more informed and comfortable, overall."

> "Nobody ever wants to feel just like a patient. They want to feel like a person. And that's the thing, they make me feel like a person, not just a body or a paycheck. If you don't know what I'm seeking when I come to ask for your help, then how are you ever going to help me in the way that I need it? It would make me feel more comfortable because they're tailoring their care to my needs and my wants. Why would I come in to someone who doesn't care to learn who I am and what I'm really looking for?"

> "Yeah, I think I would follow their recommendations, maybe not to a T, but if they knew my preferences, I think I would. I think also health wise, for my safety, I would listen to them. I would trust what they say."

Assessing and incorporating family planning preferences into care delivery also appeared to help facilitate patients' sense of empowerment and engagement in the decision-making process, particularly around contraceptive method selection.

> "I think that it would make it much more positive and it would make me feel like I was in control of my own health and it wasn't just, information or ideas passed to me or imposed upon me, it was my decision."

> "If you feel like you've got a partner [in your provider], it's easier to put forth that extra effort or rearrange your schedule or whatever if you feel like you have a partner."

In addition, many participants noted that having their preferences and values met would help them feel (1) more informed, (2) more supported, and (3) more confident in their ability to make family planning decisions as desired.

> "I would feel more confident in my decisions because I felt like we would have made it together, you know,"

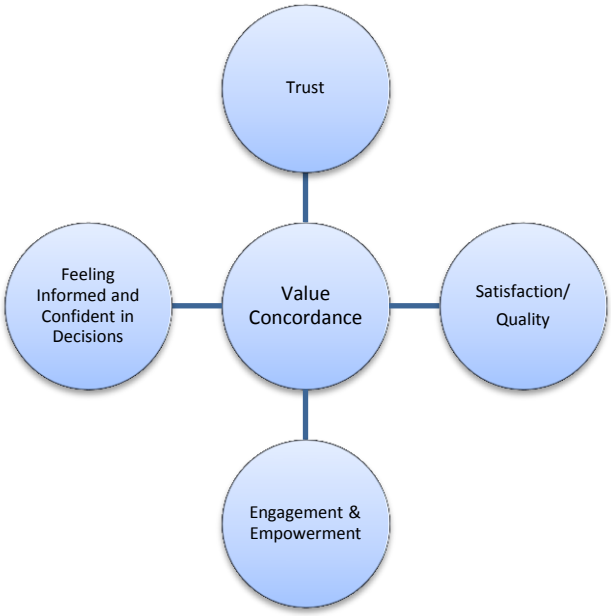
> "It would make it easier to know what method to pick and what to go in for. I wouldn't second guess myself after."

> "I would totally trust the [providers] way more and I would be more open to them. I think it is a good idea on their part. I would feel supported in what I was doing, so more confident in my decision."

> "I think maybe, it just makes us as a family more confident in what we're planning and how we're planning. It just makes us more confident to know that we have that same person to go to any time we need, if we have a question or something. We feel very supported."

These expressions of family planning value concordance are presented in Figure 4.

Figure 4. Expressions of Family Planning Value Concordance



Conversely, women who experienced family planning care that was discordant from their preferences or values expressed a sense of fear about what that would mean for them.

> "I think I would be really scared. I wouldn't want to get care from someone who didn't respect what I want. I mean this is a very personal thing, very personal decisions and to have someone not recognize that. That's scary."

> "I've got a lot of anxiety about it [family planning] already, I guess. That would just make it worse."

> "Family planning is a woman's body and to have that taken away from you, to have that like taken away from you, would be absolutely degrading and horrific. I can't even imagine; that would be horrible."

> *On a traumatic birth experience and follow-up care*, "My plans were not respected and I ended up with a separated pelvis and I've been in [physical therapy] for three

> months. I know that if [my family planning provider] had been there fighting for me, that wouldn't have happened. I feel like if I would've had someone that had been with me the whole time and knew me, the outcome would've been different. But all of a sudden, things got really bad and really scary. To have my people there that had been supporting me the whole time would have made the difference."

Women expressed similar severe negative reactions such as frustration with not having their family planning preferences met during a visit.

> "I would feel totally belittled and like they didn't think I was intelligent enough to make my own decisions. It would be really frustrating to me because I do have quite a bit of information on family planning already so if they made me feel like I didn't understand it, it would be offensive to me. It would be difficult."

> "I have experienced very hurtful things [from providers] because of my age and [number of children]. I felt like I was being judged instead of helped."

Another participant shared that women's preferences that were not met during a family planning visit would limit or hinder their ability to make contraceptive or other reproductive health decisions and potentially put them at risk for negative outcomes. This was perceived as a "lack of control" by participants.

> "It would impact it negatively 'cause then once you get there, you have to make a spur of the moment decision or, you know, they tell you six weeks [after delivery] but in reality, I'm not sure a lot of people wait that full six weeks [to have sex] so there's a window there that something can happen. You know? And so if you

don't know and haven't spoken to them about that, you're taking risks which you may not be prepared for."

"I've actually been very frustrated with [provider name] because I try to be responsible…but she doesn't seem to be aware of [my preferences]. It's like we have no control of our bodies. That was my frustration."

Women also expressed that they would quickly leave their respective provider or clinical setting, and that they might have to delay or forgo family planning care as a result of value discordant care. In this sense, value concordance may directly influence patient's care seeking behaviors and utilization of services. This perceived influence on care seeking behavior was true even for women who felt that they were well-informed about regular screening and preventive family planning care.

"I would switch to a different provider if I wasn't getting those needs met, and I feel like I need to trust them. I actually got to the point where I just kept pushing my Paps off and pushing my Paps off because I didn't have an opportunity to see a different [provider]. I just kept putting it off ... I just didn't come back in."

"I probably wouldn't follow-up and get my Paps like I know I'm supposed to."

Finally, women thought that a major component to value concordance was the ability to communicate with their providers and that poor communication was a reason to seek a different family planning provider.

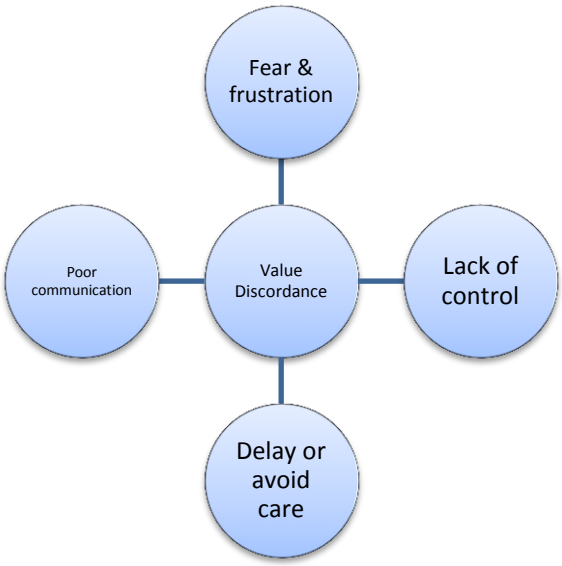
"If they can't communicate with you and you can't communicate with them and they can't try to figure out, you know, and help you decide what is best for you and

your situation and your body, and what kind of birth control that you need or don't need then there's a problem and you need to move on to somebody else who will communicate with you."

"I was looking for a little more discussion and I was really wanting to get birth control pills but she kept pushing that [vaginal ring] and it didn't feel like she gave me options or answered my questions. She just wasn't communicating with me or considering my preferences."

These expressions of what value discordance meant to women in our study are presented in Figure 5 below.

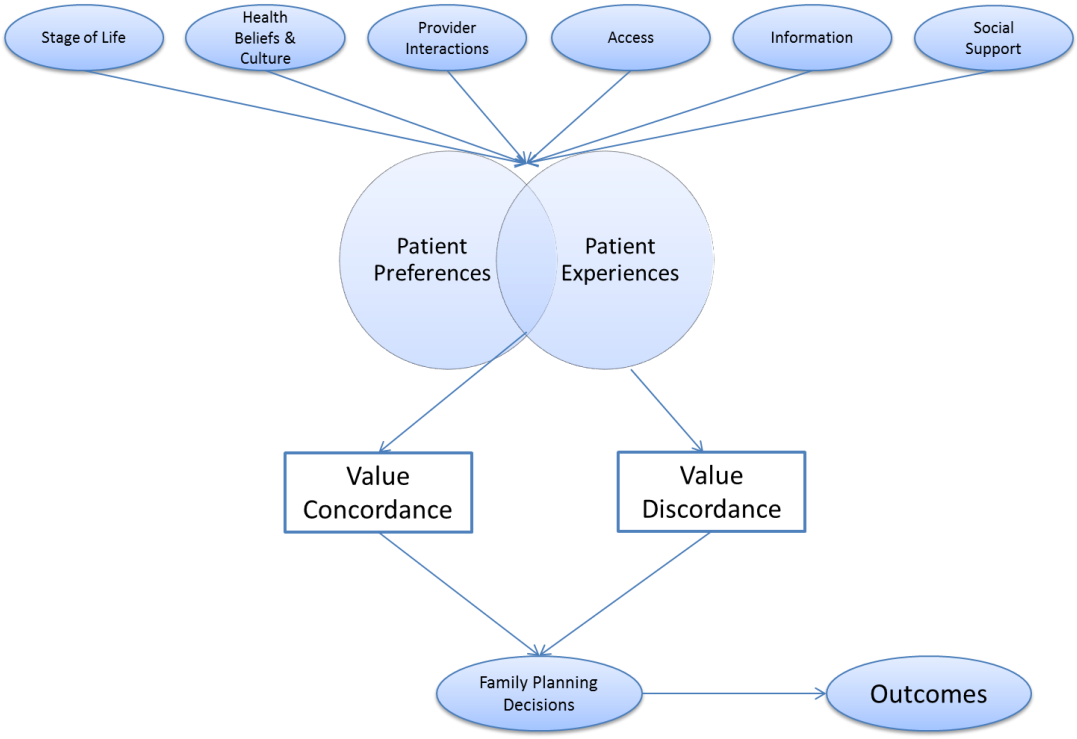
Figure 5. Expressions of Family Planning Value Discordance



4.1.B Grounded Theory on Family Planning Patient Preferences

A summary of the results from the grounded theory phase of this study are presented in Figure 6. This figure shows the six domains that inform our understanding of how women form their preferences about family planning, contraception, and reproductive health care. These include factors related to a woman's life stage, her health beliefs and culture, her interaction with providers, her access to services, information, and social support.

Figure 6. Grounded Theory on Family Planning Preferences



These categories of factors illustrate the process by which women come to formulate their preferences. These preferences then overlap or intersect with a woman's experience with family planning care; a larger intersection, where patient preferences and patient

experiences are very closely matched during a clinical visit illustrates family planning value concordance, while an experience that is incongruent with a woman's preferences would be considered value discordant. The level of value concordance that a patient experiences during a family planning visit then either facilitates or impedes a her ability to make family planning decisions and their subsequent outcomes, including where she receives family planning care, the decision to use contraception to prevent unwanted pregnancy, the selection of and adherence to a contraceptive method, and utilization of Pap smears and other family planning services.

Participants in the grounded theory section of this study vividly described what they would feel by experiencing either a value concordant or a value discordant family planning visit. In particular, patients expressed strong sentiments of feeling comfortable with and respected by providers, as well as a sense of trusting providers who offer value concordant care. Participants also described better communication during value concordant family planning visits, and a general sense of being more satisfied with their visit. In particular, women noted that receiving value concordant care allowed them to feel more informed about making decisions about their family planning care as well as feeling more confident in those decisions, once made. Finally, patients suggested an overwhelming sense of greater involvement, empowerment, and engagement in family planning decisions, as a result of experiencing family planning value concordance.

In contrast, many patients described negative reactions toward experiencing a value discordant family planning visit. Participants shared that they associated fear with value discordance, often feeling a lack of control in a family planning experience. They often felt that it led to poor communication with providers and a general sense that they

had been “let down” or disappointed by their care experience. Finally, many patients described that they would simply switch providers or even delay or avoid care that they knew was necessary and critical for their general health in the event of a value discordant family planning visit. As previously discussed, these expressions of what value concordance and value discordance means to patients in a family planning setting would impact the way a patient makes her family planning decisions – either positively or negatively, depending on the degree of value concordance. Achieving FPVC then improves the likelihood of better family planning decision-making, and improved outcomes associated with these decisions.

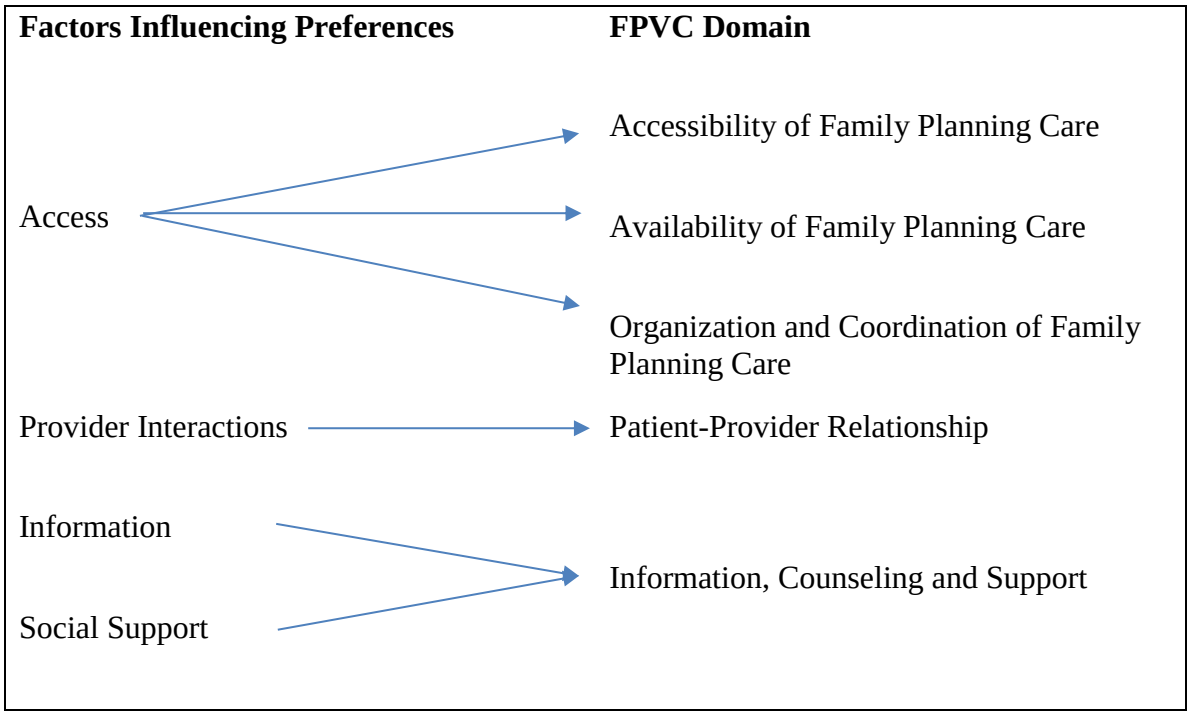
In order to appropriately determine how to achieve value concordance in family planning, one’s family planning preferences must be adequately identified and assessed by a provider or health care setting, and consequently incorporated into the delivery of family planning services. In forthcoming sections, these specific family planning preferences and a proposed mechanism by which to assess them will be identified, based largely on the results from this phase of grounded theory findings.

4.1.C Patient Preferences for Aspects of Family Planning Care

The results from our qualitative exploration of family planning preferences informed the expert panel consensus effort, in which nine technical experts provided repeated feedback to conceptualize the domains of patient preferences in family planning care. In many cases, domains of family planning preferences were analogous to those factors influencing patient preferences, as described in the grounded theory section by qualitative participants. With the exception of patient-level factors (such as life stage and health beliefs and culture), many of the domains exhibited parallel properties. For

example, the Access factor in the grounded theory model was expanded to reflect multiple characteristics of family planning care where patients may have specific preferences, such as Accessibility, Availability, Organization & Coordination of family planning. Provider Interactions was a major influencing factor of preferences as identified by qualitative participants, but it also informs the Patient-Provider Relationship domain which is a major attribute about family planning care that patients have expressed preferences. Figure 7 below shows the evolution of qualitative findings on factors influencing patient preferences that informed some parallel attributes of family planning care that patients may prefer.

Figure 7. Parallel Domains of Family Planning Value Concordance



This section begins by describing patients' qualitative responses when asked if they had certain preferences on these aspects of family planning care in order to provide

the grounded theory base from which the FPVC measurement tool was developed. It also presents the full list of FPVC domains and subcategories on these aspects that were finalized by building on prior frameworks of patient preferences and priorities in primary care and by the consensus review of technical experts in the field (Wensing et al., 1996; Jung et al., 2003). The results of both the patient qualitative phase and the consensus panel effort achieved triangulation with similar domains and aspects of family planning care emerging across both research activities, thus confirming their inclusion or exclusion in the final framework. Table 7 presents the results of this analysis, displaying each domain and its subcategories, as well as the percent agreement among consensus panelists.

Table 4. Domains and Subcategories of Patient Preferences

Domain	Subcategory	Consensus Panel Agreement
Accessibility of Family Planning Care		
	Geographic accessibility	100%
	Physical space accessibility	80%
	Financially accessibility	100%
	Linguistically accessibility	100%
	Wait time for appointments	100%
	Wait time during family planning visit	80%
	Access to provider through phone or other distance-mechanism	80%
Availability of Family Planning Care		
	Preferred provider	80%
	Provider continuity	90%
	Continuity with primary care	70%
	Appointment availability	70%
	Same day appointments	90%
Organization and Coordination of Family Planning Care		
	Coordination with general primary and behavioral health care	100%
	Coordination across providers	100%
	Co-location of family planning and primary care services	87.5%
	Privacy and confidentiality	100%
Clinical Care and Contraceptive Method Choice		
	On-site access to full range of contraceptive methods	75%
	Access to range of affordable contraceptive methods	80%
	Access to full scope of family planning services, including specialty care	100%
Patient-Provider Relationship		
	Provider shows respect and personal interest for patient as an individual	100%
	Provider demonstrates comfort working with sexual minority populations	100%
	Assessment of patient preferences before or during clinical visit	100%
	Provider offers a chaperone during clinical visit	100%
	Provider gender	75%
	Provider language	87.5%
Information, Counseling and Support		
	Adequate information about family planning and contraceptive methods	100%
	Language and literacy level of family planning information	100%
	Source of family planning counseling	75%
	Involvement of spouse or partner in family planning decisions	87.5%
	Involvement of other family members in family planning decisions	75%

Accessibility of Family Planning Care

The consensus panel findings and preceding qualitative work confirmed much of the work that has previously conceptualized patient preferences for care delivery and in some cases, expanded certain domains to reflect the family planning and reproductive health context (Wensing et al., 1996; Jung et al., 2003). The first among these is Accessibility of Care. This domain was principally conceived by patient participants to reflect the financial accessibility of family planning care (such as insurance coverage or out-of-pocket costs) but also the geographic accessibility of care, where health centers and other family planning providers are located in convenient areas. Not surprisingly, women preferred to get family planning care that was affordable or covered by their insurance, if they had it. Women specifically indicated that the ability to get free or low-cost care was a reason they came to a community health center for family planning care.

> "I think [health center name] is good, because we are low-income. We cannot pay to go somewhere else. It's too much money. I hear that if you go to some other clinics you have to pay like $100, it depends I know. And here, sometimes you don't have to pay anything for family planning. So I think it's great."

> "I don't know where I would be [without the health center] because I started out using birth control to regulate my period and I had really bad cramps and everything so it was more of a medical need than just, you know, avoiding pregnancies and everything so that would be really hard to, you know, have to decide whether you want to miss a week of school every month or pay the $50.

Women also preferred to get family planning care that was in a convenient location, although they recognized this was a barrier to some women.

> "I think accessibility can be really difficult in rural areas, but here at [health center name] it's really nice because the bus stops right in front."

> "I wouldn't be here if it wasn't convenient for me to get here."

> "The convenience is very important. I like that its right across from the bus stop. I am not personally a bus rider, but it's nice that it is right there for people who do ride … or especially somebody who's injured."

Patients also commented during focus groups and individual interviews that wait times for family planning visits often includes both a duration of time before appointments become available and can also reflect the time patients spend waiting at the clinic setting before their appointment. In some cases, these wait times were substantial and patients expressed frustration with showing up for scheduled appointments and being made to wait an extensive amount of time.

> "I would say that having the appointment starting on time is really important to me because there's been a lot of times where I can get the appointment scheduled when I want it, but it's like an hour later by the time you actually get in for the appointment. I showed up 30 minutes early so I was there for like two and half hours for something really quick and simple."

> "A long wait time, yes. I've spent up to two hours in that waiting room, just waiting for my appointment to start. It's extremely hard and very frustrating to sit out there that long."

Former studies confirm that the important elements identified by patients are essential to the conceptualization of the domain, accessibility of care (Wensing et al., 1996; Jung et al., 2003). Consensus panelists also supported these items, but also suggested the inclusion of items such as linguistic accessibility (does the clinic setting have the appropriate resources to provide linguistically accessible care and information?) and the ability to access a provider via distance mechanisms such as telephone or email encounters.

Availability of Family Planning Care

The availability of family planning care has previously been conceptualized as patients' opportunities to select appointment times with preferred providers (Wensing et al., 1996; Jung et al., 2003). Focus group and interview participants expressed that appointment availability was extremely important to them, particularly when they had other life factors (such as caring for children, transportation barriers, employment or school challenges) to consider when scheduling a family planning visit.

> "I think appointment availability is really important. You know, some weekend times would be really nice because a lot of people that are needing birth control are also working full time jobs and it seems to me like that would be a reason that people wouldn't be able to come in as easily."

> "Before [I got pregnant] I was working full time, 9 to 5, so I would always prefer to not take off work, you know, if I could do that. So if they offered maybe weekend or possibly early morning appointments or those sorts of things, at least the flexibility, that would be nice. I think they are pretty good at working with you. The easier you can make it on somebody, the better. And then you're more likely to get the care you need."

Other women recognized that health centers have more flexibility to offer same day or next day appointments, and this was perceived as an added value to women who may face difficulties getting in for family planning care.

> "[Health center name] is getting much better at this. I think the health center has more open appointments for walk in and day-of appointments than a private doctor. You do need an appointment that fits your schedule. That is definitely important."

Some women expressed that getting appointment times that worked for their schedule was essential for family planning care, because they viewed it as a routine and preventive visit for which they had more control, rather than urgent care. They placed a high utility on accessing care that was convenient for their schedule and that this facilitated their family planning decisions:

> "The access to care is really important. If [the schedule] isn't accessible, then it's not useful. It shouldn't be that hard to take care of yourself. You shouldn't have to rearrange your daily life to get these preventive maintenance visits."

Focus group and individual interview participants also strongly preferred to have continuity of providers for family planning. They often considered seeing the same provider for family planning to be more important than seeing the same provider for general health care.

> "It's very personal and sensitive. The fewer people I have checking that part of me out, the better."
>
> "My GP [general practitioner] could be Dr. Whoever, but for my womanly care, I really want to see the same person."
>
> "Seeing my own doctor [for family planning] feels more personal, like she knows me and is honest with me. That takes time, but I've been going to her for a decade, so it just makes sense."
>
> *Participant:* "For family planning, I'd say yes, I do want to see the same provider. If I'm just sick with strep throat, I don't really care who I see, I just need the meds."
> *Interviewer:* "And why is it different for family planning?"
> *Participant:* "Because it's a sensitive topic and you want it to be kept confidential."
>
> "When I've seen the primary care physician, he opened up [my medical record] and said, "oh you're taking the Depo birth control." But there was no concept or no discussion whatsoever when it came to birth control or family planning or female care you know what I'm saying? I mean nothing. He was cut and dry. It was all about my blood work. It was never about sexually transmitted diseases. It

> wasn't about pregnancies. It wasn't about any of that. It's about whether I was depressed, or put on weight or doing blood work. So I really like my family planning nurse because she's more complete."

The consensus panel respondents also considered the ability to see one's preferred provider, the ability to see the same provider in each visit, the ability to get family planning care in the context of general primary health care (when desired), and same day appointments to be additional elements of family planning care about which patients may have express preferences, further conceptualizing the domain of Availability of Care.

Organization and Coordination of Care

As indicated by many of our participants, the way family planning services are organized and delivered remains an area where they may have specific preferences. This domain was expanded to reflect the organization and coordination of family planning care. In particular, participants often desired a sense of coordination of family planning services within the context of both primary and behavioral health care. One patient in particular noted the importance of coordination between providers due to her mental health status:

> "I'm diagnosed bipolar and have depression so they've had to work real closely with like my psychiatrist, just making sure that I could be on birth control."

Another patient also indicated the role of providers in coordinating medication with contraceptive drugs or devices:

> "They know what medicine you're on, what medicine you're not on, and what goes with what and if you get [another method]… they don't always know and sometimes they can give you something that counteracts with your other medicine and that can be dangerous."

The co-location of family planning and primary care services in one health care setting also proved to be a benefit of the health center model that most participants preferred.

> "I like that there's so many doctors here and that it's a large facility. I actually really like it. And there's a pharmacy here too, and there's a dental section and I really like that the OB section is right next to the childcare section. That's the reason I was able to come here today is because I was here for my child's appointment, so it actually worked out really well. My birthing classes were all here, so I love that it's all inclusive. I like this sort of center where there is everything all together."

> "I think it's really important that not only one department or one section cares for you. Like it's important that they are aware of what, you know certain patients have expressed and what needs have to be met. I think that's really important. Not only within one certain area at any clinic."

> "I love it that [the providers] can all communicate and they're all under one building at least."

Another important factor is the level of privacy and confidentiality a patient can expect during a family planning visit. It should be noted that privacy is often considered a component of the patient-provider relationship or its own dimension of care in existing

conceptual frameworks, however our patient participants and consensus panelists both considered privacy and confidentiality to reflect mechanisms that may be employed at the organizational level, recognizing that providers and clinical staff play a large role in maintaining patient's privacy and confidentiality in a family planning context (Wensing et al., 1996; Jung et al., 2003; Cheraghi-Sohi et al., 2006; Anderson et al., 2001). This was originally proposed by some patients during focus groups who indicated confidentiality can be jeopardized by both interpersonal and structural barriers.

> "I find that [confidentiality] has been an issue for me. Not necessarily because they've gone outside of the clinic to speak about me, but because you're standing in front of a counter and the person that's taking care of you is telling the staff person behind her, 'Oh, no, she's here to get the [injectable contraceptive] or she's here to get these pills. She needs to get them changed or she wants the morning after pill' and it's like, 'Whoa! Everybody out here in the waiting room is hearing you. You could probably have waited until I left to actually say any of this stuff.'"

> "I think the lady nurse is too close to the window. I mean, the space is no bigger than this and there's three girls checking people in. It goes the other way too. I don't want to hear what everybody is checking in for. Sometimes I want to step back further because they say to wait behind the line to maintain confidentiality, but its only five feet away. You can still hear everything."

Clinical Care and Method Choice

Clinical care and contraceptive method choice involves the availability of a range of methods and family planning services from which a patient can choose. As demonstrated in early qualitative findings, underserved women expressed interest and desire in understanding both the range of contraceptive methods available to them, and certain characteristics about the nature of available methods. Many women felt strongly about the side effects they had either personally experienced or had heard of other women experiencing with certain birth control methods.

> "And I kind of feel that way too and when I take [injectable contraceptive] it does crazy things to me and I can't take the pill because of other health problems and so, you know, then I'm left without anything so…"

> "I always tell them don't get the shot because that's what made me [gain weight]…they look at me like I'm crazy but I was only 115 [pounds] and after I got that shot, I jumped from 115 to almost 200 pounds and my body didn't look like my body so after that experience, I didn't get it. It only took like four shots and then I even stopped having everything, you know, my menstruations and all that and I said, I'll never do it again."

Other women felt strongly about the use of non-hormonal methods for either personal reasons or due to a family history of a specific condition.

> "After being on the hormones and the way my body responded to it, I didn't like it. So as a personal choice, I decided not to put anything in my body where I could have a reaction. Or just not naturally occurring, I should say."

> "I don't even know how many types of birth control I've been on. At least five. And now I'm on another one. I just had a baby and I'm breastfeeding so it's like, I've had so many side effects from different ones over the years and my mom died of breast cancer so it's always been like I wanted to stay on the low estrogen pill for a while . I was on the ring. So I think I've just been kind of trying things out."

Patients also communicated their desire to have a method that was effective and that worked for them.

> "I had the [contraceptive ring] and I actually got pregnant on it. So that obviously didn't work for me and I couldn't use it anymore."

> "I actually got pregnant with my daughter on the birth control pill also. I was taking the…since I switched so many times, they ended up giving me the…I guess for when you're breastfeeding. It's like a weaker one but they didn't tell me it was possible for me to get pregnant and I got pregnant so yeah, the pill definitely is not a good option for me anymore."

Other considerations about the nature of a contraceptive method included the ease of using the method and the patient's ability to adhere.

> "Okay, I'm a big baby when it comes to pills. Like I have to hide them in food. It's ridiculous. [Laughter] So I knew I wasn't going to do the pill."

> "I wanted the [contraceptive] shot because I'm not good at taking pills…"

> "I'm not about to get an IUD because I know they're really painful even like a couple days after you have it put in. I like that it lasts a long time, but I don't know if I want to go through that pain."

> "I'm not good at taking pills, so I need something that is low-maintenance and effective."

Patients also described the importance of having access to contraceptive services on-site either through a pharmacy or direct delivery of the service. They also described some difficulty accessing certain methods or other women's health services at health centers.

> "My preferred method would be for my husband to get a vasectomy. I mean, we tried that, but unfortunately that's not an option [at this health center]. I know it's an option elsewhere but it would be nice if I could get it here. I know a lot of women have problems with birth control for hormonal reasons or other health problems so I think it would be nice if it was an option here and not have to go somewhere else."

> "Sometimes you get there and they ask you that question [about contraceptive preference] and it's like, 'well, what are my options?' You know you're asking them, but I feel like they probably only tell you the one that's quicker or easier for them."

> "The only issue I've had here is that I've been trying to get a mammogram for like two years. I get a referral from [health center] but I've been trying for two years and I have not received any phone calls back or anything. I can't blame [the health center] because they make the initial contact with [the specialist] but I've

> called them and left messages and I can't get through. I mean it's really hard. It's a little bit of a worry in the back of your mind that I've been trying to catch up with this for two years and it still hasn't followed through you know? There's a gap somewhere and you know, these are things that I wish I would be seeing [my family planning provider] for because I think that she would be a little more on top of these things – the referrals on the outside."

Some patients expressed negative experiences when they were referred out or had to come back for a separate visit:

> "The primary care provider has to give us permission, like the prescription for birth control. And then we have to see [another provider] who gives it to us. Like she administers it but we have to see someone different."

> "I think there is a disconnect when providers refer patients out [for family planning.] Closing that loop for a referral and getting that information back to my provider and actually get the right follow-up care. That's not easy."

Consensus panelists agreed that the ability to access selected contraceptive methods on-site during or directly following a family planning visit was an important element of this domain. They also suggested that patients should have access to a wide variety of other family planning services that support family planning and reproductive health, including specialty care.

In prior frameworks, this domain has also been conceptualized to include items on the quality and technical competence of providers; however no participants indicated differing preferences for the level of the quality and competence of their clinical

providers. This may suggest that all patients prefer high quality clinical care or simply that they are not equipped to assess the technical competence of their providers. Other studies have suggested that the technical quality of clinical care cannot sufficiently be assessed by patients and therefore may not correspond to the context of family planning quality from the patient perspective (Bruce, 1990). For these reasons, this item was eliminated from this domain of family planning value concordance.

Patient-Provider Relationship

The role of the patient-provider relationship remained a critical element of family planning care about which patients have substantial preferences, both expressed by qualitative participants and by consensus panelists. As women described in the focus group and individual interviews, these interactions both drive their preferences and impact their experiences, principally their perception of provider respect, their interest in patients as individuals, and their ability to adequately assess patient preferences and needs are core elements of the patient-provider relationship (Wensing et al., 1996; Anderson et al., 2001). The qualitative findings supported additional categories for measuring family planning value concordance, in particular, certain characteristics of one's family planning provider. Most women preferred to see a female provider for family planning because they felt more comfortable, perceived female providers to understand family planning and reproductive health better, and thought female providers could better relate to patients on family planning issues.

> "It's not that I don't think that males are competent. It feels so much easier to be with a female. They know the body better. A male doctor can be taught where a

woman doctor can know about the reproductive and you know their own parts. They're definitely more informed."

"You can talk better to the female, you know, we can relate more and I'm a little bit more open. I'm not so shy."

"Woman providers, they are going sympathize or know what the impact has on your life if you're having multiple periods in a month or too much bleeding or whatever the issue may be."

"And I think a woman, most likely they have some experience with different kinds of birth control or they kind of have a personal input about it. A man wouldn't really, besides his female patient experiences, he wouldn't really relate."

Participant: "I think for my GYN care, I'd prefer to have a woman but for my [primary care] stuff, I'd prefer a man. They're to the point, just real specific and that's kind of what I want to hear when I'm in a hurry and I don't want some small chat when, you know, I just need the facts, just lay it on me.
Interviewer: And why do you think it is different for gynecology or women's health?
Participant: "Because it's more of my private parts. My female parts and those are the parts that the woman understands."

However, other women either preferred male providers or had no preference on provider gender. Often, women described feeling comfortable with their provider as a more important characteristic of the patient-provider relationship than specific preferences about gender.

> "I actually found out that…I don't know about anybody else but men are a little bit more kinder because they don't know how it feels and they're a little bit more gentler."
>
> "See I always saw a man and I don't know, I've always felt comfortable and I've always chose my doctors wisely so I've always done my research."
>
> "I like my GP. I go to him for all birth control needs as well as regular health needs and I've been with this GP for over a year now and I'm really comfortable with him. I'm not saying that he understands the woman's body but I guess I just don't need that. You know, how they used to say, 'just the facts?' And that's all I want."

In some cases, women had changed their preference for provider gender after having children, as noted by this discussion among several participants:

> *Participant 1***:** "I'd prefer it was a woman. That's just my opinion."
>
> *Participant 2:* "I did too, prior to children. But after giving birth, I couldn't give a [expletive].
>
> *Participant 3:* "Yeah. Pretty much, that's true."
>
> *Participant2:* But before kids, yeah. As a young adult, I would've definitely said the same thing, that I would want a woman doctor."

Patients also supported the addition of having a chaperone during a family planning visit, if their provider was male.

> "I've had a male provider and when you have a male provider, when it comes down to the actual Pap and all that, you have a secondary female nurse standing by you, talking to you, you know, and I think it makes it more comfortable for both parties. You know, the doctor knows that he's not in any way shape or form going be accused of anything and I feel that she's there to make sure of that."

Patient participants did not indicate a strong preference for provider race/ethnicity or language, however, nearly all participants expressed that they needed to be able to communicate clearly with their provider.

> "As long as we can communicate and they understand me and I understand them then we're good to go."

> "As long as I can understand him, it doesn't matter what language he speaks. But since I only speak English, it better be in English!"

Although participants were asked to comment on their preferences for provider age and provider type (for example, mid-level providers vs. physicians) no strong preferences were expressed. In fact, most women noted that provider characteristics were less important to them than their ability to trust the provider and establish a positive relationship with their provider.

> "I think it's really okay to shop around. You know, we all have different personalities and providers do too. You really have to feel okay with them. Like if you tried [a male provider] first and you need to try something else, well then you should be able to. I should have that right."

> "I think it's so important. I like to meet people first. If I don't get a good vibe from them…that might make my decision to want to see somebody else."
>
> "It's such a personal thing, women's health care is so personal. I think it's important that you're comfortable with the person you're seeing. You develop such a personal relationship."
>
> "You know, when you asked me earlier about if I like men or women doctors and like if I want to see an OB or just a regular provider, I don't know that is really as important to me. I may have a personal connection with one that I just don't feel with the other. Even still when I make appointments here, I don't know who [I'm seeing] until I get in the room. I thought I was seeing this person and you know, then finding out, oh that person's not here. You want the personal experience that you had and sometimes it doesn't end up working out. My relationship with my provider is very important."

Consensus panelists supported the inclusion of several items within the patient-provider domain, in particular that the provider shows respect and interest for the patient as an individual and that certain preferences on provider characteristics (e.g. gender, language, chaperone) also be included. Expert panelists also felt very strongly that providers should express comfort working with sexual minority populations, although this was not referenced by qualitative participants.

Information, Counseling, and Support

Finally, the domain of Information, Counseling, and Support has been well-established in existing frameworks and focuses mostly on the quantity, adequacy, and

appropriateness of family planning information provided to patients. As previously described, qualitative participants often saw these items as inputs into their family planning preferences but they also described their specific preferences for family planning information. For example, many women preferred to seek information about family planning before or in lieu of a visit with a provider:

> "I think when I first was trying to decide what type of birth control method to use after my children, I talked to my family, my sisters first. Then I did my own internet research type of thing, and then I went into a family planning visit and made my own decision."

> *Participant:* "I research myself online."
> *Interviewer:* "Do you feel that usually answers most of your family planning questions?"
> *Participant:* "No, but it prepares me to ask the doctor more questions, like follow up stuff."

> "I think they should have a link for family planning online with some of their pamphlets in .pdf format or a phone number you could call. Or have a class where they describe your options and then we can pursue it. Because for me personally, I don't like calling to talk to [providers]. I like to find out as much information as I can on my own first. But that's just me. I do everything I can at home, and then I can branch out when I feel that I need to."

> "I like the pamphlets or, you know, reliable sources from the internet. I find it more convenient for me instead of having to call or come in to talk to a provider. I just find it easier."

Other preferences on contraceptive counseling also seemed to differ across qualitative participants. For example, some women preferred their provider to offer all contraceptive options regardless of how appropriate they perceived them to be for the patients.

> "I'd really like to know everything. Or at least have the options to go over all of your options and be able to tell your doctor what you want or don't want. But you don't know what you don't know."

Other women felt strongly that the provider should offer a more tailored list of options that he or she recommended based on patient characteristics. Often, this tailored counseling approach was described by patients in the context of a personal relationship with one's family planning provider.

> "That's what I like about having a personal relationship with a [provider]. I want them to follow my family planning goals and help me take care of my health, but I don't want all the extra stuff that doesn't really apply to me. If they know me, then they would know what I need."

> "I mean a lot of times they don't know what to tell you or what information you need. They are just guessing if you don't tell them what you're looking into. They have to know you to kind of recommend anything, you know? I might be a person that forgets to take my pill, so you might recommend like a shot or an IUD or something. I think it's important for them to know you to even recommend

something. If you don't know me or my life or what's going on for me, how can you really recommend something that will work well and fit me?"

"Every time I try to get on birth control, the doctors don't really like my questions. Like I've never found a doctor that's really sat and talked to me and said, 'well I think this is best for you.' Like they've only given me two or three options."

"Even the body language and the tone of voice that [the provider] uses and just wants to know about your life in general. Like who you are as a person and I just, I think that's important. Some people just need the information and they make their own decision. But some people need handling. Like they just have a good way of figuring out who needs what."

Participants also expressed specific preferences about spouse, partner, or family member involvement in family planning care decisions. The majority of women preferred being offered the opportunity to involve important members of their family (principally, spouses or partners) if they wished, but they often felt that this should be a choice offered to the woman during a visit.

"I don't really think [my husband] cares so much for the birth control part, but with the baby and pregnancy party, yes. I would at least like the option of having him there if I want. And if he wanted to, that would be good."

"I think including my partner would be great. The more people that understand women's health is going to be beneficial for whole families and society in general. I am totally fine with my partner coming to the visit. I know some people

aren't, but for me it's okay. Information is always good and I'm always up for that."

"I think that's something that we have to choose, if we want them there. We're the patients. We have to choose if we want our partners there or not, not the physician."

"I think I would mainly like to have my mom there. That's one thing I like a lot about [health center] because my mom can go in and she is able to talk to the providers without them hushing her and them telling her, 'excuse me but we're talking to your daughter.' That really bothers me and it really hurts me as a daughter to her. She knows a lot about me than I know about myself, so I think it's very important to me to be able to have family be there and say what they have witnessed."

"My daughter and I have the same doctor and she gives her the option of having me there if my daughter wants me there or not. I've been through both. Sometimes she doesn't want me there and sometimes she does. So I like having the option."

One area that was not explicitly expressed by qualitative participants was the importance of health literacy and linguistic appropriateness of the information provided to women. Consensus panelists indicated these items to be key to the definition of this domain, supporting their inclusion on the list of final domains and subcategories.

4.2 FPVC Scale Development and Validation

Following Creswell's instrument development model, this study used the results of the qualitative research to inform the development of the family planning value concordance (FPVC) scale. After careful review of the domains presented by the consensus panel, items representing each domain and subcategory were collected into the pool of 28 items to measure both the patient preference and patient experience subscales. As previously described, the measurement items are identical across both subscales, but are worded distinctly for the purposes of assessing the degree of correspondence between the two. An example of patient preference and patient experience items are presented in Tables 8-9 below with the full item pool and the finalized scale items presented in the survey instrument in Appendix E.

Table 5. Example of Patient Preference Item: Location of Care

Question Prompt: The next set of questions will ask you about some of your preferences about family planning care.

Please tell us if you prefer Option A, prefer Option B, or have no preference for each item below:

Option A	Option B	No preference
I prefer to get family planning care in the same place that I get my general health care	I prefer to get family planning in a different place than I get my general health care	I have no preference

Table 6. Example of Patient Experience Item: Location of Care

Question Prompt: The next set of questions will ask you to tell us about the last time you received family planning services (such as a Pap smear, birth control services, STD testing, or treatment, pregnancy test or other services related to women's reproductive health). We will refer to this as your "most recent family planning visit."

At your most recent family planning visit, tell us which of the following statements was most true for you:

Statement A	Statement B	Neither/Not Sure
I got family planning care in the same place that I get my general health care	I got family planning in a different place than I get my general health care	Neither/Not Sure

In accordance with general scale development guidance, we performed an exploratory factor analysis to reduce the final number of questions to a 13-item scale. The exploratory factor analysis procedure generated four factors with at least three items loading on each factor at a standard minimum factor loading of 0.3. A rotated factor loading matrix and item-scale reliability coefficients are provided in Table 10. We renamed each factor to correspond with its respective items, based on existing literature and patient-level qualitative data. The four factors represented in the scale include: (1) coordination of care, (2) accessibility of care, (3) contraceptive counseling and method choice, and (4) information and support for decision-making.

Table 7. Factor Loading Matrix				
Variable	Factor 1 "Coordination of Care"	Factor 2 "Accessibility of Care"	Factor 3 "Contraceptive Method and Counseling"	Factor 4 "Information and Support for Decision Making"
Location of care	0.7658			
Continuity with Family planning provider	0.6905			
Provider type	0.3068			
Access to preferred provider		0.6203		
Access to family planning information/questions		0.7193		
Family planning appointment scheduling		0.4977		
Family planning counseling source			0.6417	
Counseling on range of contraceptive methods			0.3376	
Contraceptive method type			0.7503	
Degree of involvement in family planning decision making				0.5222
Involving family members in family planning decision making				0.6024
Patient or provider responsibility to accept risks and benefits				0.8155
Patient or provider responsibility to select contraceptive method				0.9482
Scale reliability coefficient α	0.5136	0.4494	0.4639	0.6669

Generally, reliability coefficients on each factor should achieve a minimum threshold of α=0.6 (DeVellis, 2012). Only one factor (information and support for decision-making)

exhibited an adequate level of item-scale reliability, with the other factors demonstrating slightly lower reliability coefficients. However, inter-item correlations proved to be much higher on each of the individual items as well as the overall internal consistency of the FPVC scale, achieving an adequate level of reliability greater than α=0.29 (Table 11).

Table 8. Internal Consistency and Inter-item Reliability

Item	Inter-item correlation (α)
Location of care	0.233
Continuity with Family planning provider	0.513
Provider type	0.494
Access to preferred provider	0.422
Access to family planning information/questions	0.452
Family planning appointment scheduling	0.551
Family planning counseling source	0.475
Counseling on range of contraceptive methods	0.416
Contraceptive method type	0.332
Degree of involvement in family planning decision making	0.501
Involving family members in family planning decision making	0.545
Patient or provider responsibility to accept risks and benefits	0.539
Patient or provider responsibility to select contraceptive method	0.578
Overall Scale Internal Consistency	0.696

The first item on location of care exhibits a slightly lower inter-item correlation value than the typical threshold of α=0.29, however, it remains in the scale because of its high factor loading and because removing it proved to reduce the scale reliability coefficient of its factor.

4.2.A Pilot Survey Results

Over 100 women of childbearing age (18-44 years) getting their care in a health center setting participated in the pilot survey (n=110). Approximately 4-in-10 respondents were age 25 or younger, while the remaining 60 percent were between age 26 and 45. The respondents were fairly evenly distributed with respect to marital status, with 29 percent reporting they were single, 35 percent married, and 35 percent in a long-

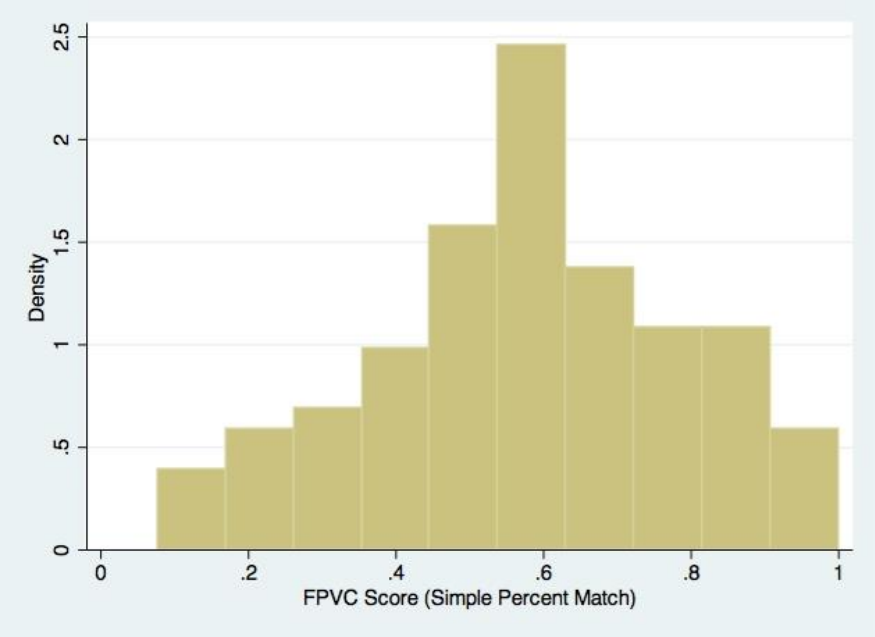
term relationship. Respondents were predominantly Caucasian, with Hispanic/Latina women and American Indian/Alaska Native women representing the next largest racial/ethnic groups. One third of participants were unemployed and 68 percent were uninsured, which was somewhat different from the participants in the qualitative phase, who were largely insured patients. The large majority of respondents reported that they were currently using a contraceptive method at the time of the survey. Additional descriptive statistics of the survey sample are presented in Table 12.

Table 9. Pilot Survey Sample Characteristics				
Age (n=110)	n	%	Mean	(St. Error)
Age 18-25	45	41%		
Age 26-30	38	35%		
Age 31-35	14	13%		
Age 36-40	11	10%		
Age 41-45	2	2%		
Marital Status (n=110)				
Single	32	29%		
Married	39	35%		
In a Long Term Relationship	11	10%		
In a Long Term Relationship and Cohabitating	27	25%		
Other	1	1%		
Household Characteristics (n=110)				
Number of children	--	--	1.18	(0.14)
Household size	--	--	3.61	(0.16)
Race/Ethnicity (n=110)*				
Caucasian	91	83%		
Black/African American	3	3%		
Asian	3	3%		
Native Hawaiian/Pacific Islander	2	2%		
American Indian/Alaska Native	7	6%		
Hispanic	14	13%		
Other	8	7%		
Employment Status (n=108)				
Unemployed	37	34%		
Employed PT	45	42%		
Employed FT	26	24%		
Insurance Status (n=108)				
Uninsured	73	68%		
Insured	35	32%		
Distance to Primary Care Source (n=109)				
Less than 5 miles	51	47%		
5-10 miles	36	33%		
11-15 miles	12	11%		
More than 15 miles	10	9%		
Last family planning visit (n=108)				
Within past 12 months	77	71%		
Between 1-3 years ago	16	15%		
Between 3-5 years ago	3	3%		
More than 5 years ago	12	11%		
Current Contraceptive Use (n=110)				
Currently use contraceptive method	78	71%		
Do not currently use contraceptive method	32	29%		

* Race/ethnicity proportions may not add up to 100% due to the fact that participants could select more than one race/ethnicity.

Following the exploratory factor analysis effort, value concordance was calculated using the percent match approach previously described. Respondents had a mean score on the value concordance index of 0.573, indicated that approximately 57 percent of their patient preferences were met in their most recent family planning experience. The value concordance measure was normally distributed with a standard deviation of 0.214.

Figure 8. Distribution of FPVC Score



Significant difference in the value concordance score were observed between certain groups of survey participants (Table 13). First, younger participants (under age 25) had marginally lower value concordance scores compared to women over age 25 (p-value=0.083). Additionally, women who reported not having a spouse or partner had significantly lower value concordance scores (p-value= 0.0134) while married women had significantly higher value concordance scores compared with women in any other

marital or cohabitating status (p-value=0.008). Value concordance scores did not differ by either household size (p-value=0.483) or number of children (0.193). It did, however differ by employment status with unemployed women reporting lower value concordance scores (p-value=0.018) than women who were employed either part-time or full-time. Similarly, women who reported having no health insurance coverage had lower value concordance scores on average, however this was not statistically significant in this sample (p=0.152). No differences in value concordance scores were observed by racial or ethnic minority status (p-value=0.569). Finally, women who reported traveling longer distances (over 10 miles to access primary health care had lower value concordance scores than women traveling less than 10 miles), although this was not a significant finding among the pilot sample (p-value=0.146). We also found that women who had a family planning visit more than 5 years ago had modestly significantly lower value concordance scores than women who received family planning services in the last 5 years (p-value=0.060).

Table 10. Value Concordance Scores by Patient Characteristic						
	Mean FPVC Score	St. Error	95% Confidence Interval		p-value	
Under age 25	0.528	(0.032)	[0.463	0.593]	0.083	**
Over age 25	0.600	(0.026)	[0.548	0.651]		
Single	0.495	(0.038)	[0.417	0.573]	0.013	*
Married or in a long term relationship	0.605	(0.023)	[0.559	0.652]		
Married	0.645	(0.031)	[0.582	0.708]	0.009	*
Not Married	0.534	(0.026)	[0.483	0.585]		
Unemployed	0.514	(0.036)	[0.439	0.588]	0.018	*
Employed (PT or FT)	0.614	(0.023)	[0.567	0.661]		
Uninsured	0.532	(0.033)	[0.464	0.599]	0.152	
Insured	0.594	(0.025)	[0.543	0.645]		
Racial/Ethnic minority	0.593	(0.041)	[0.519	0.614]	0.569	
Caucasian	0.567	(0.024)	[0.509	0.677]		
Travel less than 10 miles for primary care	0.588	(0.022)	[0.544	0.633]	0.146	
Travel more than 10 miles for primary care	0.514	(0.047)	[0.416	0.612]		
Last family planning visit less than 5 years ago	0.590	(0.021)	[0.549	0.631]	0.060	**
Last family planning visit more than 5 years ago	0.468	(0.074)	[0.306	0.630]		

* statistically significant (p-value <0.05)
** statistically significant (p-value <0.10)

Multivariate Regression Analysis

Following the bivariate analysis, multivariate regression models were constructed to determine if any relationship exists between the value concordance of a woman's family planning care (that is, how closely her preferences correspond with her care experience) and any intermediate patient outcomes. For the purposes of this analysis, I proposed a set of outcomes that are reasonably expected to be linked to value concordance, based on the qualitative findings. These intermediate outcomes include

patient satisfaction with one's family planning provider and family planning clinic setting, family planning knowledge, contraceptive use and contraceptive discontinuation. These outcomes are thought to be most directly influenced by a value concordant family planning visit and precede any effect on overall family planning and reproductive health outcomes for women. Regression tables for each of the family planning outcome models are presented in Table 14.

Patients with stronger value concordance scores were moderately significantly more likely to report being satisfied with their family planning provider (p-value=0.068), in the model accounting for other confounding variables that may influence patients' family planning experiences (such as the patient demographic characteristics explored in the previous statistical tests). Unemployed patients were marginally more likely to be satisfied with their provider (p-value=0.086), however patients who had a family planning visit more than five years ago were moderately less likely to be satisfied with their family planning provider (p-value=0.057). Patients who had a high level of family planning knowledge were 14 times more likely to be satisfied with their provider compared to patients who had poor family planning knowledge (p-value=0.010).

Similarly, patients with higher value concordant family planning scores were more likely to be satisfied with the clinical care setting in which they received family planning services (p-value=0.093), although this finding was only slightly significant among the survey sample. In addition, patients who had correct family planning knowledge were also more likely to be satisfied with their family planning care setting (p-value=0.045).

Table 11. Multivariate Regression Models A-B	Model A: Provider Satisfaction				Model B: Clinical Setting Satisfaction			
	OR	(SE)	p-value		OR	(SE)	p-value	
Value Concordance Score	86.337	211.194	0.068	**	224.021	931.639	0.093	**
Contraceptive Utilization	0.900	0.804	0.906		1.526	2.341	0.783	
Under Age 25	4.684	4.393	0.100		17.700	32.862	0.122	
Single	4.012	4.455	0.211		1.711	2.764	0.740	
Children	1.092	0.460	0.835		0.383	0.366	0.316	
Household Size	0.779	0.340	0.567		1.028	0.870	0.974	
Pregnancy Ambivalence	0.354	0.426	0.388		0.447	1.062	0.735	
Black/African American	0.459	1.172	0.760		0.846	4.055	0.972	
Hispanic	2.169	3.071	0.585		12.744	33.725	0.336	
Unemployed	7.480	8.754	0.086	**	8.588	20.178	0.360	
Employed Part Time	1.467	1.483	0.705		0.405	0.714	0.608	
Travel More Than 10 Miles	3.418	5.659	0.458		66.460	263.142	0.289	
Insured	2.801	2.733	0.291		0.003	0.020	0.335	
Last Family Planning Visit More than 5 years ago	0.055	0.084	0.057	**	0.015	0.044	0.159	
Family Planning Knowledge (Correct)	14.340	14.742	0.010	*	81.252	177.991	0.045	*
Constant	0.055	0.113	0.160		16.196	116.329	0.698	
R^2	0.408				0.673			

* statistically significant (p-value <0.05)
** statistically significant (p-value <0.10)

Both models demonstrate that family planning knowledge accounts for much of the effect on both satisfaction with family planning providers and satisfaction with the clinical setting within which family planning services are provided. However, even with accounting for the level of family planning knowledge a patient has, value concordance was positively correlated with these outcomes, at least marginally, indicating that value concordance may improve patient satisfaction. High goodness-of-fit measures were observed on both models with Model A exhibiting an R^2 of 0.408 and Model B carrying an R^2 of 0.673. This demonstrates that both models account for a substantial amount of the variation on the dependent variables, making them robust regression models to assess the relationship between value concordance and patient satisfaction.

In a similar model, the relationship between value concordance and patients' family planning knowledge was tested. Table 15 shows that patients reporting higher value concordance scores were more likely to correctly answer questions about family planning knowledge accounting for all other covariates, although this was only slightly significant at the α=0.10 level, which is acceptable for a small pilot sample. This demonstrates the positive correlation between value concordance and family planning knowledge, as an intermediate outcome, although the model accounts for a much smaller degree of variation in the dependent variable, indicating that there may some other factors contributing to family planning knowledge that are not accounted for in this model.

Table 12. Multivariate Regression Model C	Model C: Family Planning Knowledge			
	OR	(SE)	p-value	
Value Concordance Score	8.267	10.496	0.096	**
Contraceptive Utilization	2.236	1.166	0.123	
Under Age 25	0.616	0.328	0.363	
Single	2.551	1.487	0.108	
Children	0.773	0.187	0.288	
Household Size	1.296	0.265	0.204	
Pregnancy Ambivalence	2.467	1.930	0.248	
Black/African American	1.385	2.001	0.821	
Hispanic	0.551	0.384	0.392	
Unemployed	0.717	0.419	0.569	
Employed Part Time	0.963	0.611	0.952	
Travel More Than 10 Miles	1.197	1.028	0.834	
Insured	0.819	0.455	0.719	
Last Family Planning Visit More than 5 years ago	0.859	0.709	0.854	
Constant	0.237	0.262	0.192	
R^2	0.112			

** statistically significant (p-value <0.10)

Finally, this study also assessed the relationship between value concordance and two family planning outcomes: (1) current contraceptive use; and (2) contraceptive discontinuation, defined as stopping or switching birth control for any reason other than trying to conceive or for by provider directive. Model D demonstrated that while a positive correlation between value concordance scores and contraceptive use was observed, it was not statistically-significant among the pilot sample. Similarly, value concordance was negatively associated with contraceptive discontinuation, however this was also insignificant in Model E. Both models also demonstrated that younger women under age 25 were considerably more likely to both use a contraceptive method (p-value=0.038) and to report prematurely discontinuing contraception in the last 12 months (0.081) than women over age 25. Women who were considered ambivalent were over five times as likely to prematurely discontinue using a contraceptive method (p-value=0.026) compared to women who were highly motivated to prevent pregnancy. Unemployed women were about three-times more likely than women employed full-time to have prematurely discontinued using a contraceptive method, although this was only marginally significant in the model (p-value=0.077).

Table 13. Multivariate Regression Models D-E	Model D: Contraceptive Use				Model E: Contraceptive Discontinuation			
	OR	(SE)	p-value		OR	(SE)	p-value	
Value Concordance Score	1.939	2.695	0.634		0.419	0.581	0.530	
Under Age 25	3.254	1.851	0.038	*	2.579	1.400	0.081	**
Single	0.930	0.562	0.904		1.289	0.731	0.654	
Children	0.733	0.196	0.245		0.974	0.249	0.919	
Household Size	0.922	0.201	0.709		0.952	0.180	0.797	
Pregnancy Ambivalence	1.217	0.874	0.785		5.243	3.905	0.026	*
Black/African American	0.480	0.690	0.610		6.020	8.580	0.208	
Other Race	0.465	0.706	0.614		4.777	5.994	0.213	
Hispanic	3.581	4.406	0.300		1.467	1.491	0.706	
Unemployed	1.269	0.810	0.709		3.093	1.976	0.077	**
Employed Part Time	0.661	0.455	0.548		1.877	1.316	0.369	
Travel More Than 10 Miles	3.732	3.823	0.199		0.598	0.695	0.659	
Insured	0.647	0.413	0.495		1.125	0.647	0.838	
Last Family Planning Visit More than 5 years ago	0.259	0.256	0.171		0.388	0.402	0.361	
Family Planning Knowledge (Correct)	2.358	1.339	0.131		0.995	0.582	0.993	
Constant	1.590	1.865	0.693		0.160	0.186	0.114	
R^2	0.168				0.130			

* statistically significant (p-value <0.05)
** statistically significant (p-value <0.10)

4.2.B Psychometric Results

The development of an original scale instrument such as the proposed family planning value concordance scale requires careful consideration of the measure's reliability, validity and other psychometric properties.

First we found that the family planning value concordance scale exhibited moderate internal consistency as measured through item-scale reliability measures. While we expected the item-scale reliability to exceed $\alpha = 0.6$, the measure observed slightly lower reliability coefficients. As previously indicated, this could be addressed through increasing both the sample size and the number of response options to more accurately identify the shared variance on identified factors, thereby increasing reliability of the

measure. Additionally, our study design did not allow for the assessment of test-retest reliability, to determine the consistency from one survey administration to another. However, it is conceivable that future efforts to refine the measure build test-retest assessments into further measurement development and testing. This effort might also address the unanswered question about the stability of family planning preferences over time and how the identified determinants of family planning preferences influence or change preferences based on our conceptual framework. Lastly, our work does not address inter-rater reliability, as the value concordance scale is intended to measure the correspondence of family planning experiences to preferences exclusively from the patient perspective. Previous measurement work has attempted to evaluate the degree of agreement between patients and their providers on the elements of care that are most important to patients with poor inter-rater reliability, indicating that no external assessment of patient preferences beyond the patient herself is effective in a measurement sense (Kiesler & Auerbach, 2005).

With respect to the measure's validity, we must consider the various types of measurement validity including face validity, content validity, criterion validity and construct validity. First, one of this study's major strengths is its focus on underserved women and incorporating patient perspectives into theory and measurement development (Sofaer & Firminger, 2005). By engaging a grounded theory design and an instrument development process that draws directly from patients the elements of care that are most important to patients, we find strong face validity among the resulting measure. Similarly, the family planning value concordance scale was developed with a careful review of similar measures and items in the literature and the domains were identified by

consensus among a panel of technical experts. In this regard, I suggest that the measure has achieved a satisfactory level of content validity and covers the full range of possible items that could be used to measure value concordance in family planning care for underserved women. Thirdly, the criterion validity of the value concordance measure was addressed through two analytic mechanisms. First, we collected data on the outcomes we proposed would be most impacted by either value concordant or value discordant family planning care and used it to determine the predictive validity of the measure. That is, does the value concordance measure correctly predict the outcomes that are anticipated to be linked to the measure? Our findings illustrated that this was the case for many of the outcomes, in particular, patient satisfaction with family planning provider and setting. We found less statistically-significant relationships between value concordance and outcomes that are expected to be further downstream, such as contraceptive use and continuation, however these relationships could be tested in more robust sample sizes to better understand the complex predictive relationship. Similarly, the study analyzed the concurrent validity of the value concordance measure by collecting data on similar measures at the same time. Specifically, the survey collected a selected set of patient experience items of the CG-CAHPS instrument. The results of the concurrent validity test showed that the family planning value concordance scale achieved an appropriate level of concurrent validity with only one item (see Appendix F). It is possible that the sub-optimal correlation coefficients are due to the fact that we selected items measuring provider communication to assess concurrent validity, when there may be other more powerful measures that are better correlated with our measure of value concordance. For example, future efforts should attempt to capture additional items that are more relevant

to patient-centeredness and patient experience, such as the supplemental items of the CG-CAHPS Patient-Centered Medical Home Item Set. Additional criterion validity testing using more theoretically-related constructs in future efforts are suggested before widespread use of the family planning value concordance scale. Additionally, more robust survey efforts with larger sample sizes would address the limited psychometric performance of the measure, across the board.

Finally, the construct validity of this measure was principally assessed through the factor analysis procedure used to finalize the proposed scale. The factor analysis allowed us to identify sets of items that converged by measuring the shared variance among underlying latent variables. Further efforts to continue testing this measure should include more sophisticated approaches to examining the construct validity of the value concordance scale, principally through structural equation modeling (SEM), multitrait-multimethod matrices (MTMM) or other hierarchical modeling efforts. We also recommend the inclusion of discriminant validity tests in order to confirm that the value concordance scale does not measure constructs that are theoretically unrelated.

4.3 An Integrated Framework for Value Concordance in Family Planning Care

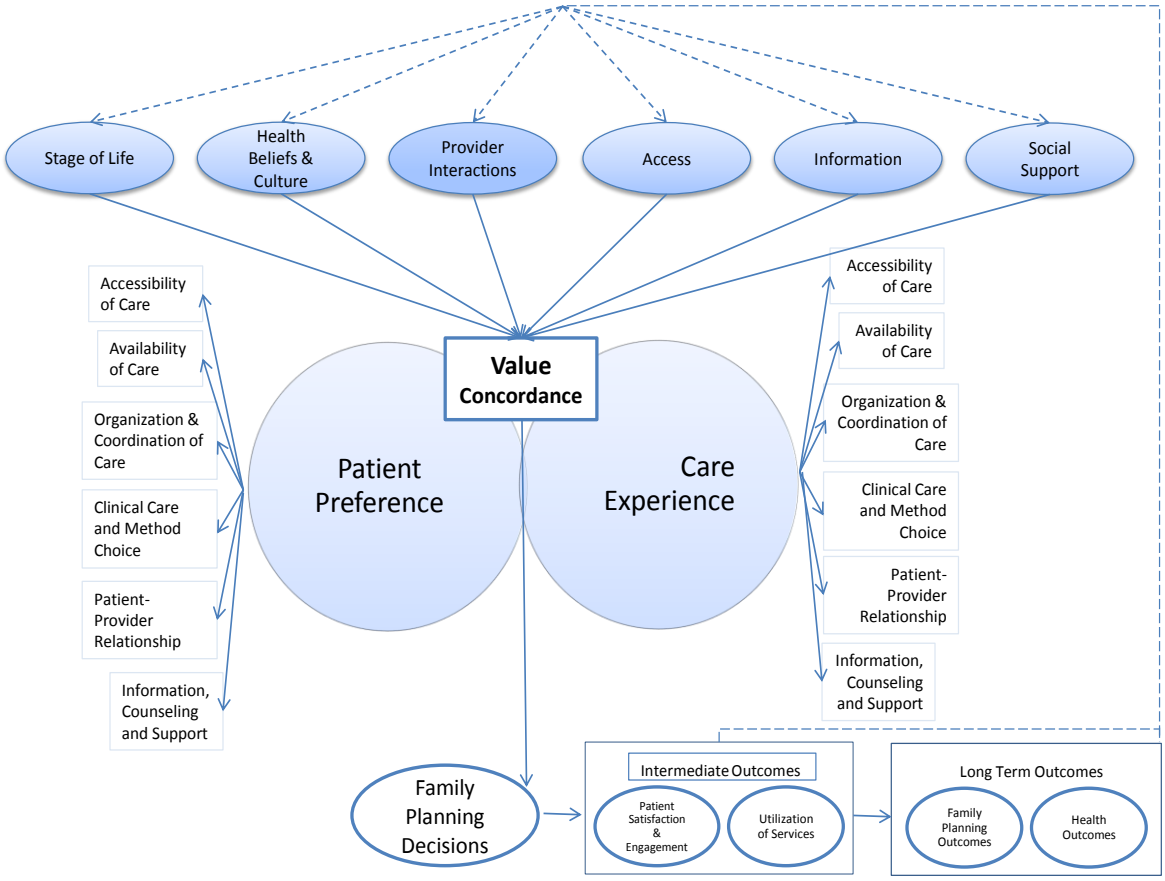
Value concordance, as it has been presented in former literature, represents the degree to which a patient's health care experience reflects or corresponds with their preferences and values about health care. With respect to family planning, value concordance represents the intersection between a patient's family planning preferences and her actual experiences with multiple attributes of family planning care. Thus, the more closely a patient' actual care experience during a family planning visit matches her expressed preferences, the more likely she is to experience the outcomes thought to be associated with value concordant family planning care.

Based on existing frameworks of patient preferences for primary care, qualitative findings, input from field experts, and a preliminary empirical analysis, this study presents an adapted conceptual framework of the role of value concordance in delivering family planning care (Figure 9). First, based on the early grounded theory work, this study identified the factors that drive patient preferences: (1) Stage of Life; (2) Health Beliefs and Culture; (3) Provider Interactions; (4) Access; (5) Information; and (6) Social Support. This framework proposes that these factors independently to influence both patients' formation of preferences, but also their evaluation of their family planning care experience; thereby also influencing value concordance as the intersection of the two.

The secondary phase of developing domains of value concordance used qualitative data on these factors to inform domains for the measurement of FPVC through consensus building with field experts. Through a modified Delphi approach and a review of the literature, six aspects of family planning care about which patients may have preferences were generated for consideration in the final FPVC measurement. The

concept of value concordance suggests that once these preferences are assessed, they can and should be incorporated into a patient's care experience and that the family planning visit should align with patient preferences on each of these aspects as much as possible. Assuming that patients generate greater utility from having their preferences met in a family planning care experience, the framework proposes that value concordance may help facilitate a patient's decision making process and the set of intermediate patient outcomes that may result from these family planning decisions (Brennan, 1995; Knight, 2008; O'Connor et al., 1999). These may include outcomes related to (1) patient engagement and satisfaction; (2) utilization of services; (3) family planning outcomes; and (4) broader health outcomes.

Figure 9. Conceptual Framework for Value Concordance in Family Planning Care



A preliminary predictive model showed a positive correlation between FPVC scores and the patients' level of satisfaction with both family planning providers and with family planning service delivery general. Although this study did not test the relationship between family planning value concordance and patient confidence or self-efficacy in making reproductive health decisions, qualitative participants indicated that these measures of patient engagement could represent outcomes linked with value concordance.

The model also hypothesizes a relationship between FPVC and utilization of family planning services. These services might include annual well-woman examinations,

cervical cancer screening, STI testing and treatment, contraceptive counseling and use of contraceptive methods, among others. Patients participating in the qualitative research phase also perceived that experiencing poor value concordance would make them avoid or delay important family planning services such as Pap smears. The pilot survey presented in this dissertation asked patients about the current contraceptive use and demonstrated that although a positive correlation between FPVC and contraceptive use was observed, it was not statistically-significant among the sample.

Other important variables that may be connected to family planning value concordance include patients' family planning outcomes. In this dissertation, two indicators of family planning outcomes were measured: family planning knowledge and contraceptive discontinuation. Patients qualitatively indicated that they often felt more informed as a result of value concordant family planning care. When patients' objective level of family planning knowledge was assessed in the regression model, a marginally significant relationship to FPVC was observed. Similarly, while more concordant FPVC scores were associated with lower likelihood of contraceptive discontinuation in the sample, this relationship was not highly significant in this pilot test. Although this study did not explicitly explore the potential long-term impact of FPVC on patient's overall family planning and general health outcomes, we can reasonably expect, based on prior theory on family planning service quality, that family planning value concordance as a measure of patient-centeredness, might also impact longer-term reproductive health outcomes such as the prevention of unintended pregnancy (Becker et al., 2007; Bruce, 1990; Kane, Maciejewski & Finch, 1997). A longitudinal empirical study might better

explore the long-range effects of value concordance in family planning care for this population.

Qualitative results from our study and others in the literature also suggest that patients' actual care experiences vary over time, with new information, and across care providers and settings (Sofaer & Firminger, 2005; Anderson et al., 2001; Frosch, Kaplan & Felitti, 2001; Peele, Siminoff, Zu & Ravdin, 2005). To incorporate this important consideration, the framework proposes that a feedback loop exists between the path from value concordance to family planning decisions (and subsequent outcomes) and the driving factors of patient preferences, to illustrate that patient preferences are not static, that they often change with a number of different factors, and that they are based on the reality of their experiences rather than on idealized values (Anderson et al., 2001).

Chapter 5: Discussion

This mixed methods study sought to achieve three specific research aims: 1) the development of a preliminary conceptual framework on value concordance – in order to understand both the drivers of patient preferences in the context of family planning care delivery for underserved women of childbearing age and the broader conceptualization of what value concordance means to this population of women; 2) the development of an original value concordance scale to measure patient preferences and experiences in family planning care; and 3) the testing and validation of the FPVC scale in a pilot survey of women of childbearing age receiving family planning care in community health center settings. This chapter summarizes the resulting contributions of this work, interprets its major findings, and considers implications for future research, policy, and practice.

5.1 Summary of Major Contributions

Grounded Theory on Patient Preferences in Family Planning Care

This sequential mixed-methods study utilized a grounded theory approach to explore how medically-underserved women form their preferences for family planning care and how important those preferences are in making family planning decisions. The qualitative findings were categorized into to better understand the factors that influence family planning preferences from the patient perspective. These included women's Stage of Life, Health Beliefs and Culture, Provider Interactions, Access, Information, and Social Support. These factors are well supported and consistent with other literature on family planning and decision-making, however the strength of this study's contribution to the literature is that these drivers of patient preferences were identified and expressed by

underserved women of childbearing age through an extensive grounded theory approach rather than through other researcher- or clinician-driven approaches (Sepucha & Ozanne, Kim, Kol & Mucheke, 1998).

The study participants also provided compelling descriptions of what family planning value concordance meant to them and how important receiving value concordant care would be in a family planning context. For many women, value concordance made them feel more satisfied with the quality of care they received. They felt they could often trust their provider more when their preferences and values were incorporated into their family planning care experience and that value concordance was often a catalyst toward a strong provider relationship. This patient-provider relationship was a strong value held by the majority of women in our study and they perceived this relationship to heavily influence their family planning decisions. Women also shared that they felt a general sense of empowerment and engagement in family planning decision making when their preferences were met, and that they felt more informed and confident in the decisions they were making as a result of value concordant family planning care. These expressions of FPVC also mirrored their expressions of value discordant care, where women often felt fear and frustration during a family planning visit that didn't incorporate their preferences. They also felt value discordance limited their ability to communicate with family planning providers, often feeling a general sense of a lack of control over decision making. Ultimately, many women stated that they would simply delay or avoid getting essential family planning services if they experienced value discordant care, even though they knew this care was important to their reproductive health.

Overall, the large majority of women indicated that value concordance was a general expectation they have during a family planning visit and when this occurs, they have a positive perception of the quality of such care. These findings confirm normative decision theory that states that a patient derives higher utility from an actual care experience that closely reflects her expected care experience or preferences (Brennan, 1995).

Evolution of the Grounded Theory Process

The purpose of using the grounded theory approach to qualitative research in this dissertation study was to discover the theoretical conceptualization of value concordance and its role in family planning care from the voice of patients. Rather than using a deductive approach where existing theories are fit to correspond to qualitative data, this approach was intentional in its inductive method of analysis, allowing theory to emerge directly from the patient perspective (Green & Thorogood, 2009). However, grounded theory studies often utilize preliminary theoretical propositions or frameworks to lay the foundation for later analysis. In this case, I used an adaptation of Bruce (1999) and Becker's (2007, 2009) frameworks on family planning service quality to help guide my decisions in the data collection and analysis phases. In these frameworks and others, quality is defined primarily through the lens of clinical quality and service delivery and therefore did not adequately reflect a framework that explored individual patient preferences and experiences. Although the data collection processes were set up to collect information on the domains identified in these frameworks, what emerged from the data was a much more individualized model tailored to patients' own values, experiences, and expressions of what family planning quality meant to them. This is critical to the

conceptualization of value concordance in family planning care because the premise underlying this concept is that patients' preferences must be adequately assessed, understood, and subsequently incorporated into care delivery in order to have the positive impact on family planning decision making and related outcomes that our theory proposes. As a result, the grounded theory approach moved from a preliminary conceptualization of value concordance as a measure of family planning service quality toward one of patient-centeredness in a family planning context, placing a strong emphasis on understanding what women's preferences and values are and what it means to incorporate them into their experiences with family planning care.

Consensus on Elements of Value Concordance

The findings of the qualitative phase of research on patient preferences in family planning care then informed a consensus building effort with field experts to define value concordance in the context of family planning care for underserved women. While prior studies have identified these attributes of patient preferences in primary care settings, our study exclusively focused on exploring these attributes in a family planning context (Wensing et al., 1996; Jung et al., 2003; Cheraghi-Sohi, 2009). For family planning, these attributes were adapted to include: (1) the accessibility of family planning care, (2) availability of family planning care, (3) organization and coordination of family planning care, (4) clinical care and contraceptive method choice, (5) the patient-provider relationship, and (6) information, counseling, and support. Each patient preference domain consists of a variety of subcategories, which are more thoroughly described in the preceding chapters. Data from qualitative focus groups and interviews drove the adaptation of these domains, and their inclusion in the overall framework for family

planning value concordance. These domains also formed the structure for the instrumentation process by which the FPVC scale was formed.

An Integrated Framework on the Role of Value Concordance in Family Planning Care

A broader conceptual framework is proposed in this dissertation, drawing from previous literature and utilizing qualitative data and insight from field experts to define the role of value concordance in the delivery of family planning care to underserved women. By defining value concordance as "the degree to which care experiences reflect or correspond with patient preferences," this study is the first to apply this construct to the domain of family planning and reproductive health, although in many ways, value concordance underlies the very principles of patient-centered care and is considered to be a major component of family planning service quality (Becker et al., 2007; RamaRao & Mohanam, 2003; Costello et al., 2003). In this regard, value concordance can be viewed as an indicator of patient-centeredness in family planning care and requires assessment tools to evaluate the degree to which value concordance can occur in a family planning context. While this construct has existed in other domains such as medical decision-making and decision quality, no previous theory has looked at value concordance in routine care nor has value concordance been examined through the lens of providing a patient-centered experience rather than simply facilitating a singular treatment decision. Even fewer empirical studies have discussed the potential impact of delivering value concordant (or discordant) care on subsequent decisions and the outcomes of those decisions (Sepucha & Ozanne, 2010). In this way, this dissertation study lends a different perspective on the unit of analysis of value concordance. Where value concordance has typically been measured at the decision level and often in the context of

a diagnosis or condition, this study proposes that value concordance can occur at the visit level, when a patient encounters the delivery of family planning care. Decisions about family planning and contraception may occur during or following a family planning visit. Thus, aligning care delivery with patient preferences in a routine family planning visit before any decision is made is crucial. The utility of FPVC is perhaps highest by facilitating a patient's decision-making process through elevating her level of trust in providers, patient engagement, and confidence in those decisions, as described by many of our qualitative participants. FPVC can then inform clinicians and health care organizations appropriately tailor their efforts at providing patient-centered family planning care that helps underserved women make decisions that achieve the reproductive health outcomes they desire.

This study also provides a preliminary look at some of the potential outcomes that could be linked to value concordant family planning care. Patient engagement and satisfaction, as well as family planning information and utilization of contraception were among the first outcomes to be tested in this study. Preliminary testing and validation of this model showed that value concordance was positively correlated with both provider satisfaction and satisfaction with family planning care setting, substantiating the relationship to patient satisfaction and engagement hypothesized in the conceptual framework and highlighting the predictive validity of the model. Patients also expressed that a visit that was discordant from one's preferences would be a reason to delay or forgo family planning services, more so than regular primary care services. This distinction between the sensitivity of family planning preferences compared to other health services or health care decisions remained present throughout our qualitative data

collection process and confirms other studies that present this complex distinction. Patient satisfaction and engagement, and utilization of services represent the initial set of intermediate outcomes thought to be most closely associated with value concordant family planning.

The model also demonstrates the potential impact on longer term outcomes such as specific outcomes related to a woman's family planning and reproductive health, and ultimately, long term health status (Bruce, 1990; Becker et al., 2007). While the design and purpose of this study was not to evaluate the impact of value concordance on long-term health status, some preliminary understanding of the impact on a select few family planning outcomes was developed. First, qualitative findings suggested that patients feel more informed when they receive family planning care that is concordant with their preferences and values, which was validated through regression models that found value concordance to be positively associated with family planning knowledge as an outcome. This was marginally significant, but remains a promising relationship to test in a larger study. Other family planning outcomes that are thought to be influenced by value concordant care include contraceptive use and continuation, as they represent decisions that a woman typically makes during or after a family planning visit. However, the preliminary regression analysis on these two variables did not prove to be sensitive enough to predict the influence of value concordance on contraceptive use and continuation. In fact, in these models, younger women were more likely to use contraception, but they were also more likely to have discontinued using a contraceptive method in the last 12 months, indicating that younger women may try out several methods before selecting a method that works best for them. This is consistent with what

Joanne Noone suggests in her contraceptive decision making theory on the iterative process by which women "find the best fit" in their contraceptive options.

Interestingly, women who reported being unemployed were three times more likely to discontinue using contraception than women who were employed full-time. This pilot test suggests that unemployed women may face limited resources, insurance instability, or other barriers to consistent use of a contraceptive method, potentially putting them at risk for unintended pregnancy. However, with nearly 40 percent of survey participants reporting having insurance coverage and yet no significant relationship between insurance status and FPVC scores or related outcomes, these findings suggest that providing health insurance alone cannot sufficiently improve the quality of family planning care or patient outcomes among underserved women.

Perhaps the most substantial contribution of this particular effort is the development of the first conceptual framework that considers patient preferences (and their influencing factors) as an input into family planning decision making, and presents value concordance as an indicator of patient-centered family planning services. In addition, this study undertook a grounded theory approach highlighting the importance of theory development that is grounded heavily in the data from the field. The fact that this study focused on engaging the voice of medically-underserved patients in helping to inform the development of theory on this topic lends particular strength to this study design and fills the gap identified by other family planning researchers (Becker et al., 2007). The conceptual framework presented in this dissertation also offers input from technical experts in women's health, research, and policy through a systematic mechanism to achieving consensus through a modified Delphi approach. Bridging both

data from patients and from field experts affords this study an enhanced sense of validity of the domains and relationships outlined in the conceptual model.

Measuring Value Concordance in Family Planning Care

Another major contribution of this study is the development of an original 13-item scale representing four factors of value concordance in family planning care. The scale can be used to: (1) identify the unique patient preferences underserved women may have on a set of family planning care aspects, (2) assess a patient's experience with those aspects of family planning care during her last family planning visit, and (3) evaluate the degree to which her care experience reflects her expressed patient preferences, achieving some level of value concordance measure by the percent match of actual experiences to preferences. While the value concordance measure is consistent with and draws from existing measurement tools to evaluate decision quality in other health services, the family planning value concordance measure is the first to be applied to a routine care experience and also the first to specifically consider a woman's family planning and reproductive health preferences, which some researchers have identified to be distinct from other health care preferences (Dehlendorf, et al., 2010b). It is also the first measurement tool that specifically considers the preferences and experiences of medically-underserved women of childbearing age who often experience barriers to access family planning care. Research findings on family planning or other health care preferences have not been fully explored among this population and remain a notable gap in the health services literature. Furthermore, our conceptual framework and other related literature hinges on the assumption that patient preferences must be assessed through some mechanism and that a patient's care experience must be optimally aligned with her

assessed preferences in order to achieve intended positive outcomes (Kiesler & Auerbach, 2005). Other proxies for direct assessment of patient preferences, such as asking providers to anticipate their patients' preferences have proven to be unsuccessful often because physicians have been found to poorly judge patients' actual preferences or because time constraints or poor patient-physician communication prevents them from doing so (Kiesler & Auerbach, 2005; Bruera, Sweeney, Calder, Palmer & Isch-Tolley, 2001; Rothenbacher, Lutz & Porzsolt, 1997; Coulter, Peto & Doll, 1994; Keating, Guadagnoli, Landrum, Borbas & Weeks, 2002). Other decision aids that attempt to evaluate patient preferences focus on patients' preferences and values about the desired level of involvement in treatment decisions, the role of the provider, or state of information in medical decision-making, but fail to measure preferences about the unique personal component of a woman's preferences about her family planning and reproductive health (Degner, Sloan & Venkatesh, 1997; Krupat, Yeager & Putnam, 2000; Krantz, Baum & Widesman, 1980). The proposed value concordance scale in this study is both informed by the prior work on patient preference assessment in medical decision-making and applies directly to the family planning care domain.

This study was able to examine factors that influence the level of value concordance a woman experiences in her family planning care. Not surprisingly, younger women and unemployed women had significantly lower value concordance scores than women over age 25 and women who had either part-time or full-time employment, perhaps for the same reasons previously suggested – that younger women have more flexible preferences and are still attempting to settle on a contraceptive method that works best for them, while unemployed women may face severe barriers to accessing

family planning that limits the degree to which family planning care can be tailored to meet their needs. Some literature has promoted the use of tailored family planning and contraceptive counseling for younger women, in particular, adolescents (Winter & Breckenmaker, 1991). Although this study did not include women under the age of 18, a similar conclusion could be made that women under age 25, including adolescents may benefit most from value concordant and tailored family planning care. Married women also reported significantly higher value concordance scores than their unmarried counterparts, which is consistent with literature that states that married women are more satisfied with family planning care and have a positive rating of their last family planning visit (Forrest & Frost, 1996). Ultimately, these findings suggest that while value concordance should be an indicator of quality for all women, certain sub-groups of underserved women may not be getting care that aligns with their preferences and values for family planning.

5.2 Limitations and Challenges

Methodological Challenges

Despite the strong contribution this dissertation makes to conceptualizing value concordance in family planning care for underserved women, some limitations to this work exist. First, it is generally accepted that qualitative methods allow investigators to achieve saturation of themes and key concepts that represent the shared, collective experience of a group of subjects (Creswell & Clark, 2011). And while this study's findings illuminate important information about the family planning preferences and experiences of a subset of medically underserved women of childbearing age, they may

be quite unique to this study's respondents and may limit the generalizability of our results to the larger population of underserved women. This challenge is even more complex when one considers the fact that preferences are specific and unique to an individual, making the characterization of these preferences on a population level difficult to achieve. Furthermore, the integrated conceptual framework proposes that a patient's preferences may change many times over the course of her lifetime, while the empirical data presented here have been gathered only at a singular point in time.

The original proposed methodology employed the use of focus groups to gather information from patients on their family planning experiences and preferences. The purpose of this approach was to gather a broad conceptualization of how preferences are formed and how patients perceive they are incorporated into their family planning visits. This approach focused largely on gathering breadth of information from patients to understand their collective experiences and develop preliminary theory, rather than probing deeply into the complexity of preferences and decision-making in family planning care. However, it became clear to the investigator during the data collection period, that some participants preferred the opportunity to discuss sensitive family planning and reproductive health experiences in an individual setting rather than a group discussion. To respect the nature of our participants' concerns and to protect their privacy and confidentiality, I amended the protocol to engage participants in semi-structured individual interviews at their request. In this case, it was noted that data emerging from individual interviews provided more depth to more fully understand the individual experiences and personal characteristics pertaining to their family planning care, even though the interview guide did not change in scope or nature. According to Morgan

(1997), this distinction between breadth and depth of qualitative data is evident among the focus group and individual interview approaches, and the investigator must often sacrifice one for the other to maintain a streamlined data collection methodology. This study, however, was able to leverage both breadth and depth by utilizing individual interviews and focus groups, although this was not originally sought out in the initial study design. In either case, the study achieves the sample size and level of saturation that is recommended by qualitative research guidelines. In this sense, what could have presented a substantial challenge in changing the qualitative design at the mid-point of data collection is considered a strength of the grounded theory qualitative approach. Grounded theory methodologies afford the investigator the flexibility in design and data collection protocols to gather additional perspectives from participants, and ultimately richer data as a result.

It is also unknown how feasible the FPVC tool is to implement in a health center setting or to adapt to other family planning care delivery settings. Although the study conducted cognitive testing of the overall instrument, the length of the survey was considerably longer than the final scale due to the fact that we had incorporated twice as many items as the finalized value concordance scale now contains, as well as additional demographic, utilization, and other questions that captured data on the measure's construct validity. Understanding the timing of instrument fielding as well as the burden on both clinic staff and patients to administer the instrument is an important consideration when thinking about scaling up or disseminating this tool in future research or practice. In this study, we found the greatest success with equipping a specific family planning provider or program manager in administering the survey and collecting confidential

responses on-site. We provided the health centers with a locked drop-box to collect completed surveys which was most highly utilized compared to self-addressed and stamped mailed surveys, or web-based surveys. The study purposefully employed three modes of survey administration in order to provide patients with multiple methods of providing confidential responses to patient preference and experience items. However, the higher response rate among surveys that were completed during clinical visits indicates a few important considerations. First, patients waiting before or after a clinical visit may represent a captive audience for completing a survey. In fact, many of our focus group participants indicated that it is not uncommon for them to wait up to an hour in the waiting room for a routine scheduled visit and that they could fill that time with answering a survey. It is anticipated that handing a patient a paper survey or directing them to a website to complete the survey at their convenience was less effective in the study sample because of the myriad of other competing challenges a patient faces once she leaves the health center (e.g. time constraints, limited access to internet or computers, change in living situation or mailing address, etc.) This may have led to the higher attrition rate among the mailed and web-based surveys compared to the clinic-based mode of survey administration. However, we maintain that employing three methods of gathering survey responses was important to this research effort for two reasons: (1) It gave patients the choice to submit responses through their preferred mechanism, thereby protecting their privacy and confidentiality of responses as they directed; and (2) it provided important insight for future patient-level survey efforts that have similar aims.

Any process that aims to develop an original instrument faces important analytical challenges and tradeoffs in order to achieve a proposed measurement tool. This proved to

be true in this study. In particular, the original methodology proposed to use a 5- or 7-point Likert scale to measure patient preference items during the scale development process. In consultation with technical experts, the large majority of panelists recommended that the response options be reduced to two options, reflecting discrete choices on each preference item (e.g. "Do you prefer Option A or Option B?") Panelists indicated that limiting the response options would clearly illustrate dichotomous preferences and would best inform the alignment of clinical practice with such preferences. In addition, panelists strongly recommended that fewer response options would prove to be more functional and easily understood by the population of underserved women. With these recommendations in mind, the study implemented three response options to reflect either Option A, Option B, or no preference between the two. While the increased feasibility of fewer response options proved to be essential to the completion of the survey fielding process, the categorical nature of the preference variables proved challenging during the factor analysis process. In particular, traditional factor analysis is generally conducted on continuous variables, such as the 5-point Likert scale that was originally proposed. However, I employed polychoric correlation matrices in order to account for the categorical nature of the variables and conduct the appropriate factor analytic procedures. The assumption of a polychoric correlation matrix technique is that variation across categorical variables still exists and can be implied using this technique. Thus, a polychoric correlation matrix assumes enough shared variance underlying the categorical variables upon which unobserved latent variables in the measurement model may be identified (Holgado-Tello, et al., 2008). Despite this adjustment technique, the sample size was not large enough to achieve a high degree of

variation on certain items, requiring the elimination of such items in the final model, and ultimately leading to less than optimal psychometric properties of the proposed value concordance scale. Another notable challenge is that the final measurement model accounts for only four unique factors, whereas the integrated conceptual framework of this research proposes six. It is not unusual for an original measurement tool such as the one proposed here to undergo several iterations of revision and testing and in particular, to test multiple variations of the proposed measurement model $\pm$ 2 factors (DeVellis, 2012). In this regard, this study could be considered a preliminary effort to construct the value concordance scale and will be critically valuable to the next steps toward the validation of the measure.

Conceptual Challenges

This study offers an untested, preliminary conceptual model highlighting some of the important relationships between patient preferences, experiences, and outcomes. Although it is grounded in field data and incorporates both expert analysis and prior evidence, the integrated model requires robust testing to more concretely define these relationships, more finely investigate the role of value concordance, and understand the strength of its predictive capability. It is also unclear if value concordance independently impacts the proposed outcomes in the model or if there are other confounding variables for which the model does not account. Although this dissertation did not focus exclusively on family planning decision-making, it became clear that patients perceived value concordance to be linked with their ability to make decisions and their confidence about their reproductive health decisions. Patients' tendencies toward general decision-making styles were not included in the empirical testing phase, although future work

should incorporate decision-making scales such as Degner's Control Preferences Scale or the Autonomy Preferences Index for comparison to understand the role of decision-making in the model (Degner, Sloan & Venkatesh, 1997; Ende, Kazis, Ash & Moskowitz, 1989). This omitted variable bias is perhaps a threat to validity for the pilot study model, however it could be addressed in future empirical modeling. The true contribution of this early conceptual model is that it allows us to build on these hypothesized relationships and construct measurement tools and analytical procedures that would gather empirical evidence to confirm or disconfirm the theoretical relationships proposed in the framework.

The resulting value concordance scale represents a promising measurement tool to gather baseline data to inform the collective effort of health centers, clinical providers, and policymakers in elevating the quality of family planning service delivery and improve family planning and reproductive health outcomes for underserved women. At this stage, it would be best used to develop a baseline understanding of value concordance in family planning care at community health centers and inform future efforts to support tailoring family planning care to patients' unique needs and preferences. We cannot, however make any normative judgments about the "value" of value concordance. It cannot be used to determine a "good" or "bad" level of value concordance nor can it be utilized to evaluate the performance or underperformance of health centers without first gathering baseline data. The results of the pilot test showed that the mean value concordance score reported by patients was 0.57, representing 57 percent of patient preferences that were acceptably met during a recent family planning visit. This figure is well within the range of value concordance scores reported in other

populations and settings (46 percent – 87 percent), suggesting that health centers provide tailored care that is concordant with patients' preferences about as well as other health settings who provide other types of treatment (Sepucha & Ozanne). While some researchers call this a "crude measure," it is comparable across organizations and contexts and it provides solid insight into future efforts to develop clinical interventions or other quality improvement activities to improve on patient-centeredness and value concordance in health center settings and assess the impact of those efforts on quality and other outcomes (Sepucha & Ozanne). The family planning value concordance scale provides a concrete measurement tool to support the use of tailored family planning services, which have long been a suggested strategy to better reach underserved patients, but without the reinforcement of strong theory or measurement efforts. This study serves to fill those gaps and equip researchers and practitioners in implementing tailored family planning interventions.

Finally, two questions about the consistency of the value concordance measure remain. First, this study used equal weightings of each item representing patient preferences in family planning care. However, it is conceivable that patients have a select set of family planning preferences that are most important to them and for which they would strongly desire their preferences to be incorporated into care, compared to other preferences or elements about care. The level of importance a patient places onto one preference item or another is not considered in this measurement model but could be explored further in future studies. Secondly, the integrated framework presented in this study recognizes that preferences for family planning care may change substantially over time. However, it remains unclear how these preferences may change, and subsequently,

how changes in preferences may affect patients' ability to get value concordant care. This concept is known as "value consistency" and represents a severe gap in the value concordance literature, which Sepucha & Ozanne (2010) suggest can be addressed by examining, "the stability of patients' preferred treatment and their preferences for outcomes and attributes across key points in the decision making process." Future studies may consider incorporating multiple preference assessments over time to determine the consistency of patients' preferences and their outcomes respective to any family planning or reproductive health decisions made during that time.

Application Challenges

As previously discussed, the value concordance scale resulting from this research study was the first to achieve two advances in the measurement of patient-centeredness and quality of family planning. First, the scale was developed to address value concordance in the context of routine family planning care compared with complex medical decision-making. Secondly, the scale was developed from and within the community of underserved women, incorporating their experiences, preferences, and opinions into both the conceptual framework and the generation of items represented in the value concordance scale. By focusing exclusively on patients receiving their care in community health centers, we highlight the preferences and experiences (and their subsequent impacts on patient outcomes) of the women who are most at risk of experiencing the disparities in family planning and reproductive health that continue to be most pervasive in this population. Generating a measure of value concordance through the incorporation of the patient perspective is an approach that grants this study additional face validity and represents inclusion of traditionally underrepresented

populations in health services research. However, as described in the preceding results section (Chapter 4) additional psychometric testing and validation of this measure would strengthen it and should be conducted before a full implementation is rolled out on a large scale. In particular, this study was unable to sufficiently test the construct validity of the FPVC measure in this early iteration, and it is recommend that more sophisticated hierarchical modeling be completed to achieve this in future research efforts.

5.3 Implications for Research, Policy, and Practice

This study aims to add several essential contributions to the existing evidence base for the quality of family planning services for underserved women. First, the development of the first theoretical framework to recognize the role of value concordance in family planning care is itself an asset to the existing literature. Much of the research around value concordance and quality of care, though seminal in conceptualization of this construct, focuses largely on surgical and medical treatment decisions and has not been adequately applied to routine primary care, including family planning. An important future research effort should follow the methods that have been traditionally used in these fields to test the relationship between value concordance and other health services outcomes, as they apply to a family planning context. Furthermore, the relationships between patient preferences, experiences, and outcomes has not been systematically tested or validated, especially for underserved populations. This study presents a conceptual framework whereby these proposed relationships – and their impact on decision-making, patient outcomes and health status – are hypothesized, an important next step is the development of a rigorous confirmatory measurement model,

incorporating structural equation modeling and hierarchical modeling to better understand these relationships.

Building on this integrated conceptual framework, a strong measure of value concordance could be utilized to help providers and payers assess their degree of patient-centeredness and family planning quality and inform them on appropriate mechanisms to better reach their underserved populations. This effort is especially important and timely, given the fact that the Office of Population Affairs (OPA) and the CDC jointly released guidelines on quality and performance of family planning providers (QFP guidelines) in April 2014. The guidelines provide recommendations for providing care to "clients of reproductive age who are in need of family planning services," and are intended to be applied for all providers of family planning services, inclusive of grantees of the Title X program (Gavin et al., 2014).

The work of this dissertation aligns with the priority areas of the QFP guidelines in many ways. First, the QFP guidelines are based on the similar assumption upon which this dissertation is centered: that improving the quality of family planning and women's health services will ultimately improve the reproductive health of women receiving them (Gavin et al, 2014). In doing so, the guidelines focus on quality improvement as a mechanism for addressing sub-optimal family planning outcomes in populations of need, as does the central premise of this dissertation. Furthermore, both this dissertation and QFP guidelines utilize the IOM's definition of quality, which includes patient- or client-centeredness as a dimension of health care quality (IOM, 2001). In this sense, the guidelines encourage the "availability of a broad range of contraceptive methods so that clients can make a selection based on their individual needs and preferences," engaging

the IOM definition of patient-centeredness as being responsive to individual needs, preferences, and values (Gavin et al., 2014). However, this dissertation suggests that patient-centeredness can and should reflect all elements of the care experience, not solely the point at which a contraceptive method is selected, as is described in the QFP guidelines. For this reason, among others, this dissertation extends the client-centered approach recommended by the guidelines to the patients' entire interaction with family planning and reproductive health services rather than the limited contraceptive decision point highlighted in the QFP guidelines.

Although the QFP guidelines make considerable headway in offering standards for quality improvement in family planning services, opportunities for strengthening the recommendations remain. The guidelines emphasize assessing patients' need as a principle component of delivering high quality family planning services. The report includes a comprehensive clinical pathway outlining the multiple points at which assessment may take place. For example, the report suggests that providers should first assess the patient's primary reason for the visit, followed by an assessment of the patient's need for services and reproductive life plan. It does not however make any mention of the role of patient preferences for aspects of family planning services and where preference assessment might fit in the recommended clinical pathway for family planning and reproductive health services. As this dissertation has stated, achieving value concordance (inclusive of patient preference assessment) during a family planning visit is an input into patient decision-making and therefore preference assessment should take place as early as possible, before any contraceptive or other family planning decisions are made. Perhaps the most parallel mention of this type of assessment is the

recommendation to assess clients' reproductive life plan and contraceptive experiences and preferences, whereby decisions about pregnancy intentions and contraceptive methods are clarified. However, as previously stated, the guidelines seem limited in highlighting only contraceptive preferences, whereas this dissertation expands the application of preference assessment to the broader care experience, which should be aligned with patient's values to appropriately help them achieve their goals over their reproductive lifespan.

Finally, the QFP guidelines also include a comprehensive list of performance measures and a strong statement on collecting data on the quality of family planning services, suggesting measures on eight dimensions of quality and one dimension of the value and cost of care. Among these is the dimension of client-centered family planning, which use CAHPS and other data sources to address "how clients perceive the care they receive" (Gavin et al., 2014). These measures include: (1) "proportion of clients who report the provider communicates well, shows respect, spends enough time with the client and is informed about the client's medical history; (2) proportion of clients who report that staff are helpful and treat clients with courtesy and respect; (3) proportion of clients who report that his or her privacy is respected; and (4) proportion of clients who report that she or he receives contraceptive method that is acceptable to her/him." Besides the relative imprecision with which these measures are defined, they are somewhat disconnected from the definition of client-centeredness on which the guidelines so heavily rely: "client-centered care is respectful of, and responsive to, individual client preferences, needs, and values; client values guide all clinical decisions" (Gavin et al., 2014). In this regard, this dissertation offers both the conceptual framework and the

measurement structure underlying FPVC as a mechanism for assessing patient preferences, and also in evaluating how truly client-centered family planning services are. In doing so, this dissertation offers a measurement tool that is perhaps more closely related to the dimension of quality that appears to be strongly emphasized in the QFP guidelines than those measures offered in the guidelines.

The performance measures offered by CDC and OPA in the QFP guidelines are a strong preliminary step in developing the first nation-wide standards for high quality family planning care. Although OPA has administered the Title X Family Planning Program for over 40 years, with its own set of guidelines and program requirements, the QFP guidelines represent the first work to unite quality improvement efforts for all providers of family planning services, including community health centers that do not receive Title X funds. Despite this tremendous advancement, some additional supporting efforts are needed to translate the QFP guidelines into practice for health centers. First, the report assumes that health centers and other family planning providers will utilize the QFP guidelines to develop their own respective protocols for the delivery of family planning care. As principal sources of primary care for underserved populations, community health centers represent an integrated setting whereby patients may receive not only family planning care, but other related and non-related preventive services, which is often very different from the model of care provided by other exclusively safety-net family planning providers, such as those focused primarily on providing reproductive health services. How health centers will incorporate the guidelines into their models of integrated care remains to be seen, and may require additional practice redesign efforts in order to maintain the level of integration that is often characteristic of health centers. In

other cases, health centers may prefer to contract or collaborate with reproductive health-focused providers that are better equipped to provide these services and focus more closely on delivering related services. Developing strong collaborative partnerships with other family planning providers located within their service area is another promising opportunity the deserves exploration in the health center community, especially at this time when attention is focused on this issue of high quality family planning services (Gold et al, 2011). Additionally, strengthening health center performance on family planning service delivery may require more substantial support in the form of funding for quality improvement and oversight by the Health Resources and Services Administration. For example, no current statement exists to define what CHC program expectations call "voluntary family planning services," leaving the exact package of family planning services that each individual health center chooses to deliver open to interpretation. In fact, previous studies on health centers and family planning care revealed that the scope of family planning services varies widely from health center to health center, and even more so across clinical sites. Program expectations that outline the minimum level of family planning counseling, education, and clinical services that must be available at health centers would serve health center staff and providers, and help patients be clear about what services they can count on receiving in health center settings. Furthermore, these practice level expectations should include a statement on the importance of delivering patient-centered, value concordant family planning including the assessment of patient preferences, which is in line with the health center mission to deliver community responsive care. Finally, and perhaps most substantially, any effort to elevate the quality of service delivery by community health centers and other providers will require a

financial investment to support practice redesign. This may come in the form of an upfront grant-based funding source to conduct quality improvement activities or in the form of a reimbursement mechanism, whereby providers receive an enhanced rate for family planning when they meet certain performance benchmarks (presumably aligned with the QFP guidelines). While other financial incentives may emerge as more appropriate models for supporting this effort, it is clear that a substantial investment in the health center system is necessary for fully implementing the QFP guidelines and strengthening health center performance in this area.

The results of the FPVC scale development process are an important first step in providing a baseline measure of value concordance that could be used to assess patient preferences and experience, and evaluate the degree to which patient-centered and value concordance family planning care is being delivered in health center settings. It is not, however, a finalized tool that can be implemented widely without further testing and validation. First, revising the response options to account for greater variation in respondents' preferences may prove to be a valuable next research effort. In particular, a survey effort that focuses exclusively on the value concordance scale would be shorter in length and more focused to address the potential for survey fatigue and non-response bias among the population, as was previously anticipated by technical experts. Secondly, expanding the survey sample would lend greater statistical power and improve the overall psychometrics of the scale. Lastly, testing and validating the scale among other segments of the medically underserved population is an essential future effort. This is particularly important because the data gathered from the sample of respondents in our study did not display some of the demographic representation that is characteristic of typical

community health center patients. Health center populations are comprised of 60 percent racial/ethnic minorities, while the composition of the study sample reflected only 32 percent minority patients in the qualitative phase and only 17 percent in the pilot survey phase. Targeting survey fielding efforts among women of racial/ethnic minority groups, women whose first language is not English, immigrant women, adolescent women, and other segments of the population who may be traditionally underserved, even in health center settings would be an important future consideration.

In addition to the implications for future research, the utility of a finalized scale of value concordance in family planning is particularly high given the efforts to restructure payment incentives for quality improvement among community health centers. The Bureau of Primary Health Care (BPHC), which administers the health center program, has not adopted or recommended any formal guidelines or quality standards respective to family planning or reproductive health. Rather, national standards specific to family planning have primarily existed within the confines of the Title X Family Planning Program, which provides funding to and oversight of federally-designated family planning clinics (Office of Population Affairs, no date). The CDC and OPA guidelines for quality family planning and reproductive health services are intended to provide evidence-based guidance for all clinicians and care delivery systems providing family planning services, but at this point, only grantees of the Title X Program are expected to be evaluated on the performance measures presented in these quality guidelines. Evidence from a recent study of health centers indicated that only 26 percent of CHCs report receiving funding from the Title X program, consequently requiring them to comply with the program's forthcoming quality standards and reporting requirements.

However, there is no comparable set of consistent family planning quality standards or performance measures for all community health centers (2 U.S.C. §300 and 42 C.F.R. §59.5). This lack of clinical practice expectations may indicate that health centers lack the degree of robust guidance that is necessary to achieve evidence-based practice (Wood et al., 2013). Thus, translating the QFP guidelines into practice in community health center settings may help health center organizations develop their own respective quality improvement strategies for family planning services and help patients achieve better levels of service quality and improved outcomes. Patient-centeredness and the tailoring of family planning services to patients' unique needs and preferences is supported as a critical component of overall quality of care, particularly for family planning and as previously described, the QFP guidelines prioritize these dimensions of patient-centered care (Becker et al., 2007). This study lends itself to this effort by presenting a measure of value concordance as an indicator of how health centers and other delivery systems tailor their care delivery to reflect patients' preferences and values about family planning. This measure will be a valuable marker of quality to include in a set of performance standards for patient-centeredness and family planning services delivered in community health centers.

While it is reasonable to expect that most clinical guidelines and performance benchmarks are traditionally developed by clinical and quality improvement experts who have the depth of knowledge to explore the complexity of performance measurement, maintaining a level of responsiveness to local community needs has been and will continue to be a hallmark of the community health center model. In this way, the construct of value concordance fits within the community-oriented model of health center

care delivery, by identifying and measuring the elements of care that are most important to family planning patients and providing a gauge on the performance of the health center delivery system in achieving patient-centered and value concordant care. The value concordance scale resulting from this dissertation work was developed with an intentional approach to bridge both knowledge and insight from technical experts with the experiences and values of patients, aligning well within the traditions of the community health center delivery system. This study may serve to till the ground for future efforts to develop similar metrics in performance improvement efforts across service lines and other community-based providers and settings.

Secondly, any set of quality improvement guidelines and standards of care should be linked with financing mechanisms that incentivize better performance from providers and health centers. The structure of the FQHC payment methodology lends itself to this approach by utilizing enhanced negotiated rates that could include payments for costs related to a minimum set of family planning services determined to represent high quality family planning care. The current FQHC payment structure requires state Medicaid agencies to pay FQHCs a prospective payment system (PPS) per-encounter rate equal to 100 percent of the health center's costs per Medicaid visit incurred during a baseline year (1999-2000) which are then adjusted annually by the Medicare Economic Index (MEI) inflation factor to take into account any fluctuation in the scope of services provided by the health center (Leifer & Freedus, 2011). Thus, for Medicaid beneficiaries which comprise approximately 40 percent of all health center patients – a proportion that is expected to grow as the result of the Medicaid expansion provisions in the Affordable Care Act -- CHCs receive the PPS rate (or an alternative rate agreed upon by the state and

its FQHCs) regardless of the number of services provided per visit, or the actual cost of providing those services (Wood et al., 2013). Critics of the FQHC payment methodology have often cited the improper calculations for health centers' reimbursement due to the fact that even with the MEI inflationary adjustment, health centers are not incentivized to expand their scope of services because their PPS rate was based on the average cost of services in the baseline years, which may not cover an expanded care delivery model (Leifer & Freedus, 2011).

The Affordable Care Act maintains the current FQHC payment system and also promotes opportunities for exploring payment innovations to achieve better coordination, comprehensiveness, and quality of care, both in community health center settings and beyond. One such example is the Advanced Primary Care Practice Demonstration project, which provides bundled payments through Medicare for eligible health centers' quality improvement efforts in achieving PCMH recognition (Centers for Medicare and Medicaid Services [CMS], 2012). A similar approach might prove promising for the delivery of family planning in health centers, by which enhanced family planning payments could account for health centers' efforts to upgrade the availability and quality of family planning services available at their clinical sites, with respect to the performance standards set forth in the QFP guidelines. While this level of payment reform would require a substantial effort to develop and test new innovative payment models, it is worthy of mention in the context of improving family planning quality, especially for underserved women. The findings from this research study may help inform future conversations around family planning quality improvement efforts that are necessarily linked with payment innovations. In a time where both federal and state

policy action have changed the dynamic of how family planning services are being delivered, in some cases limiting access to family planning care for underserved women, community health centers are an invaluable source of women's health care. For many low-income and underserved women, health centers may be the only place where they can receive essential family planning and other preventive services. It is therefore vital to ensure that the family planning care delivered in health center settings is of the highest quality, both in terms of the clinical care and contraceptive methods offered and with respect to a truly value concordant patient experience. These two approaches to elevating the quality of family planning services should be simultaneously addressed, considering both the clinical and patient experience aspect of service quality. This dissertation offers important findings that can support these efforts as health centers and other family planning providers respond to the changing policy environment for family planning and women's health care in the U.S.

Lastly, this research has the potential to impact family planning quality improvement interventions at the practice level. The results of this study present health centers and other family planning providers with both a conceptual model to identify the factors that influence patients' unique preferences and a measurement tool to explore value concordance and patient-centeredness in a quality improvement context. The proposed measure of value concordance may provide a useful assessment tool by which health centers and other delivery systems may collect data to understand their patients' preferences on how family planning services should be delivered and may help them better identify gaps for quality improvement efforts. The conceptual framework also supports efforts to tailor family planning counseling and other services in an effort to

facilitate better family planning decision-making, more patient engagement and satisfaction and other related family planning utilization and outcomes. This effort to tailor services is well-regarded in the family planning world, but it is not clear the extent to which tailored family planning occurs in health centers or other health care settings. The conceptual framework provides support for this effort, while the FPVC scale offers a preliminary measurement tool to assess the degree to which tailored, value concordant care is happening in a health center setting. In this regard, the measure of value concordance is intended to help health centers address family planning disparities in their own communities, through systematic local, targeted, and tailored intervention efforts.

5.4 Final Considerations

As experts in measurement development often state, the process of generating an original instrument such as the proposed family planning value concordance scale requires multiple iterations of rigorous testing and modeling to construct a finalized scale that may be used widely. As the first step in this effort, we recognize that continued testing and validation efforts should be undertaken to strengthen this measurement tool. Our study represents a comprehensive effort to (1) define the value concordance construct within a family planning context, (2) gather a preliminary measurement model of value concordance in family planning care, and (3) begin the assessment of the measure's reliability and validity among the targeted population of underserved women of childbearing age. Although much work is left to be done to present a finalized scale for widespread dissemination, this dissertation represents a strong grounding for future measurement work in this area. In light of the recently released QFP guidelines, the

family planning value concordance scale developed through this dissertation research offers a preliminary measure that incorporates a patient-driven measure of family planning quality and also provides insight to providers and clinic staff on their patients' preferences and experiences on specific aspects of family planning care that might help them align care delivery to better reach their underserved populations. Utilizing the FPVC scale could serve as an important patient-level assessment tool in cooperation with clinical quality measures to improve the overall delivery of family planning care, facilitate reproductive health decision-making and respective outcomes for medically-underserved women of childbearing age. This study goes a step further by presenting both a conceptual framework grounded it patient data and a concrete measurement model piloted in health center settings, both of which lend an important contribution toward achieving the patient-centeredness goals of high quality family planning care in community health centers and improving the reproductive health of the patients they serve.

References

2 U.S.C. §300

42 C.F.R. §59.5

42 U.S.C. §254b(b)(1(A)(iii)(gg)

45 C.F.R. Part 147

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Appendices

Appendix A: Researcher Memos

Researcher Memo – Background

The purpose of this memo is to explicitly state my own personal and philosophical values about this research topic in order to address the transparency of my research. As a researcher with advocacy and participatory tendencies, my focus is often on research that contains an action agenda that may improve the conditions, experiences, and lives of participants. My research heavily favors traditionally marginalized populations, which is why this study and many others that I have worked on illuminate the barriers that underserved patients typically face in accessing high quality health care and offers recommendations and tools to improve the performance of the programs, systems, and policies that serve them. In this spirit, the research questions posed in this dissertation research, and the theoretical propositions I offer reflect my own values about what patients deserve in their health care experience. First, I consider that patients (regardless of their socio-economic status or lack of resources) should have a fundamental right to health care, and that the health care experience should be of high quality. I also believe that health care experiences should incorporate the views and perspectives of its patients, and that quality assessment simply from a clinical or productivity lens is insufficient. Rather, health care organizations must adequately assess the patient experience in determining how to best respond to the needs of its community. In this same vein, I believe that value concordance reflects one approach to a quality improvement effort and that it is, by nature, a process. That is, value concordance may not necessarily be optimally "achieved" but instead offers insight into the level of responsiveness to patient preferences and desires that is expected by patients, and may change depending on patients' needs or conditions. I would also assert that value concordance, along with structural supports (like access, insurance coverage, method choice) could facilitate patient engagement and behavior in leading healthy lives. Despite the heavy emphasis on the role of providers and health care organizations as drivers of value concordance, I also respect the role of the individual in this type of health care decision-making and perceive it as a critical component of the equation. A second area where my philosophical paradigm influences this work is the way I perceive the role of the researcher in this study. Advocacy/participatory investigators often attempt to narrow the distance between them and the participants in qualitative research. They often spend time developing relationships and establishing strong credibility, and essentially perceive themselves as an "insider" to the participants' world. While I cannot say this is true with all certainty, I do feel a sense of rapport and trust was achieved between patients and myself. I often phrased questions in a way that reflected a sense of inclusion and collectivity (e.g. "What

do you think is most important to women like yourselves about the way they get family planning care"). I also think that my presence as a woman of reproductive age may have advanced the feeling that I could relate or understand the experiences that my participants may have shared. In this sense, I suggest that participant reactivity was minimal in this study due to the fact that most participants shared openly about their family planning experiences, even those that were negative, unfavorable, or even traumatic in some cases.

Researcher Memo for May 28 – 29 Focus Groups

Note: Geographic, organizational, and individual identifiers are removed to protect the confidentiality of patient and organizational data.

I conducted two focus groups with six women each on May 28th and 29th in [City Name], Washington. [City] is located in [County County], spanning the [Regional Area]. The current population is 36,648, of which 86 percent are Caucasian and nearly 10 percent are Hispanic/Latino. The remaining 4 percent are identified as a share of African American, Asian American, and American Indian/Alaska Native, as well as more than one race (Census Bureau, 2010). Manufacturing and lumber industries are the largest employers in the county however, the county employment rate remains at a high 12.8 percent. [County Name] also ranks 39th out of Washington's 39 counties in terms of health behaviors including adult smoking, adult obesity, sexually-transmitted infections and teen birth rates (County Health Rankings, 2012). [Health Center Name] serves 22,155 patients annually, over half of whom live below the federal poverty line (63 percent). The health center ranks in the second quartile among FQHCs for the number of women receiving pap smears within the last three years at nearly 53 percent (one of the HRSA performance measures). The health center does not currently provide OB or prenatal care.

The State of Washington currently provides Take Charge, a family planning program for women, men, and teens based on citizenship/legal residence and income eligibility (below 250% FPL). The program covers one annual exam for women, and frees birth control (including tubal ligation and vasectomy) for one full year. Many of the women who participated in the focus group indicated that they were Take Charge enrollees and may not have any additional medical coverage.

Six women participated in each focus group. The first focus group was conducted mostly with women at the upper end of the reproductive age range (35 years or older), although this was not intentional in the recruitment process. The second focus group was split with 3 women in their 20s and 3 women in their 30s and 40s. Preliminary impressions from this set of focus groups are included below:

1) **There is an overwhelmingly positive view of the health center and the family planning staff.** The majority of patients indicated that the health center had been their primary source of care for several years, with many indicating that their

family members and friends also seek care at the health center. They also shared that there are no other sources of care for uninsured or low-income patients in the area. Patients spoke at length about the relationship with their family planning provider (an RN) who administers Depo and provides counseling. Many indicated that she is the reason they keep coming back to the health center. Others indicated that the relationship with a family planning provider is one of the most important factors in their health care experience and that a poor relationship with a provider would be a reason to delay or forgo family planning care (including Pap smears, contraception, etc).

2) **Patients shared several things that they really liked about getting their family planning care at the health center.** These included
    - **a.** "Getting me in on time, even if I don't have insurance."
    - **b.** "The people. They really listen and treat me as a person."
    - **c.** "I feel comfortable here."
    - **d.** "It's easy to get an appointment when you need it."
    - **e.** "I got a lot of counseling and information the first time I came in."
    - **f.** "It's very convenient to get here when I need to."

3) **Patients also shared some of their challenges or barriers to getting family planning care, including:**
    - **a.** Getting through the phone lines to reach someone at the health center or make an appointment
    - **b.** Wait time for appointments (Pap smears – 3 months)
    - **c.** Wait time in waiting room
    - **d.** Privacy in waiting room and being asked "the reason for your visit" in front of other patients. Patients do not want to have to reveal family planning or reproductive health matters in public area.
    - **e.** Hard to get in anywhere else
    - **f.** Coordination with referrals and specialists, particularly for mammograms for uninsured women
    - **g.** Billing for Take Charge (family planning coverage) services

4) **Patients trust their providers for information about family planning and reproductive health.** Participants responded that their preferred method of getting family planning information was with their provider in a face to face visit, but that other methods of getting information (especially to teens and young adults) should be explored such as providing more information in schools, having an advice line, holding an education session or class, and having a family planning nurse at eligibility counter so that patients could get family planning

counseling at the same time they are signing up for insurance or other social services. Participants also referenced the health center website as a source of potential information and having flyers or pamphlets available in the waiting rooms.

5) **Patients reported very specific preferences for provider gender, provider language, and the involvement of partners and spouses in family planning decision making.** Patients prefer to have a female provider for family planning and reproductive-specific services (such as Pap smear, contraception, STD testing, etc.) Participants expressed that they feel more comfortable with a woman because they are more likely to relate to them and understand them. Although differing opinions were expressed, indicating a preference for male providers because they are "kinder and gentler." Others referenced the fact that they like having a female chaperone in the room with a male provider and that it makes it more comfortable for them to get the care they need. Nearly all participants preferred their provider to speak English well enough to understand the patient and for the patient to understand her provider. There was no clear preference indicated for race/ethnicity of the provider, provider type, or age of the provider, although at least one participant indicated that experience was important to her and that she preferred not to have medical students or very new doctors perform procedures on her (such as an IUD).
6) **Patients reported that their family planning preferences have changed over time.** Factors that contribute to preference formation include age, pregnancy intention (e.g. pre-conception, first time pregnancy, and post-partum), and family size (number of children). Older women and women with more children seemed to prefer longer term (or irreversible) methods such as an IUD or tubal ligation.

7) **Patients reported that they would like to be asked about their family planning preferences and offered several suggestions for ways to get this information.**
    - **a.** Host a forum or focus group
    - **b.** Conduct surveys (online or by mail)
    - **c.** Allow space for patients to communicate (e.g. online blogs, discussion forums)
    - **d.** Ask patients during their family planning appointment
    - **e.** Send an email or have outreach person call

8) **Patients reported a strong sense that having their preferences met would lead to better patient engagement.** Participants indicated "I would rearrange my schedule to be here if I knew they treated me like a partner." And conversely,

without respect for patient preferences, it would lead to disengagement, "I wouldn't follow up and get my Paps and I would probably stop getting care."

It is noteworthy that both focus groups were enthusiastic and willing to share their experiences without much probing. The interview guide served me well for this set of focus groups and I do not recommend any changes, other than minor rephrasing of questions such as asking both the affirmative question (If your provider knew about your family planning preferences, how would that change your experience) and the converse (If your provider didn't know or respect your family planning preferences, how would that change your experience).

Participants also shared a strong sense of gratitude and I received a lot of comments thanking me for asking them their opinions and that they wish they had more opportunities to share more about their experiences. They also appreciated the gift card and food and indicated that the food was enough to attract them to come to the focus group.

In terms of logistics and coordination, I learned that I should distribute the organizational gift card at the end of day 1 or the beginning of day two because at the end of the second focus group, my contacts had already left for the day and I was unable to get a signature on the audit form to confirm distribution of the gift card. I will now have to mail the gift card and verify receipt through email or mail (which causes delay in reimbursement).

Next Steps

I have planned the next six focus groups to take place in the month of June at three separate CHC sites. Recruitment is currently taking place and I will have an update on recruitment numbers in the days preceding the focus groups. I have considered theoretical sampling based on age in order to tease out any differences by age group or pregnancy intention, however it is not yet clear to me how strong this factor is in determining preferences and utilization and so will wait to determine if this is a sampling criteria I wish to employ in future focus groups. I will also consider it as a possible query in the analysis stage.

I also plan to comprise the analysis plan including phases of open, axial, and selective coding and begin the codebook in NVivo v. 10. Analysis will begin as soon as I receive the first transcript.

I am also planning to send out the first correspondence for the Expert Panel starting this month, and as such, will need to complete the literature review on family planning survey items and finalize the survey instrument for submission to IRB by the end of June. I plan to send out this instrument for the first round of review by the 10th of July.

Researcher Memo for June 5-6 Focus Groups

I conducted two focus groups with six women each on June 5th and 6th Western Michigan. The first focus group was conducted in a small rural town which is mostly an agricultural town located in [County Name]. The current population is 626, of which 82 percent are Caucasian and nearly 14 percent are Hispanic/Latino. Five percent are African American, 1.4 percent are Native American and 7.2 percent self-identify as some other race. (Census Bureau, 2010). I also conducted a focus group in an urban area of Western Michigan, in [City Name], also located in the same county. [Urban City 1] is located across the river from [Urban City 2] and the two cities starkly contrast in terms of resident demographics. [Urban City 1] is 89.2 percent Black/African American with a median household income of $17,301 while [Urban City 2] is 88.1 percent white/Caucasian with a median income of $49,982. [County Name] is ranked in the lowest quartile in the state of Michigan in terms of health outcomes, largely due to a significantly higher proportion of residents reporting poor or fair health status (17 percent). [Health Center Name] serves 44,533 patients annually, over 75 percent of whom live below the federal poverty line. Over 37 percent of [Health Center Name's] patients are uninsured, including 15 percent of children under the age of 19. Sixty-five percent of its patients are racial/ethnic minorities and nearly 1-in-3 are best served in a language other than English. The health center ranks in the second quartile among FQHCs for the number of women receiving pap smears within the last three years at 67 percent (one of the HRSA performance measures).

Six women participated in each of the focus groups, with the majority being 26 -35 years. Half were enrolled in Medicaid while one-quarter of the focus group participants were uninsured. The remaining 25 percent were privately insured. Ten participants indicated they receive birth control and contraceptive services from the health center but only 2 indicated that they had received counseling about contraceptive methods. Ten participants also received their prenatal care and post-partum care with the health center. Major findings include:

1) **There is an overwhelmingly positive view of the health center and the family planning staff.** The majority of patients indicated that the health center had been their primary source of care for several years and patients spoke at length about the relationship with their family planning provider. Many indicated that their provider is the reason they keep coming back to the health center. Others indicated that the relationship with a family planning provider is one of the most important factors in their health care experience and that a poor relationship with a provider would be a reason to delay or forgo family planning care (including Pap smears, contraception, etc).

2) **Patients shared several things that they really liked about getting their family planning care at the health center.** These included
    - **a.** "We're paying less."
    - **b.** "I know that when I come in and talk about the problems that he goes over everything very thoroughly and then refers me to, you know, a physician that can help me."
    - c. "Yeah, I like the fact that you can actually get family planning that doesn't have any hormones and that you can have it on without really even knowing that it's there."
    - **d.** "I wanted a closer relationship, I guess, with my caregivers and so that's why I came here."
    - **e.** "The relationship that you can develop with…because there's only the three midwives that are here so the relationship that you can have with them personally and then some of the other providers are the same way. They're very open and willing to listen to what you have to say and your concerns."
    - **f.** "I was getting everything done here so it was like, one stop shop."

3) **Patients also shared some of their challenges or barriers to getting family planning care, including:**
    - **a.** Making appointments
    - **b.** Getting through the call center
    - **c.** Staying with the same provider, if preferred
    - **d.** Problems with specific contraceptive methods
    - **e.** Out of pocket costs of contraceptives
    - f. Difficulty accessing specialty procedures (tubal ligations) at hospitals

4) **Patients trust their providers for information about family planning and reproductive health.** Participants responded that their preferred method of getting family planning information was with their provider in a face to face visit, but that other methods of getting information are also typically used, including prenatal information during visits, magazines, television, internet searches, and talking to other women about their experiences. Overall, women tended to trust the information from their provider over other sources of information. They also referenced the ability of providers to connect them with additional resources to improve their access to services and/or information about contraceptives and other services.

5) **Patients reported very specific preferences for provider gender, provider language, and the involvement of partners and spouses in family planning**

decision making. Patients prefer to have a female provider for family planning and reproductive-specific services (such as Pap smear, contraception, STD testing, etc.) Participants expressed that they feel more comfortable with a woman because they are more likely to relate to them and understand them. Nearly all participants preferred their provider to speak English well enough to understand the patient and for the patient to understand her provider. There was no clear preference indicated for race/ethnicity of the provider, provider type, or age of the provider, although several participants indicated that experience was important to them more than age.

6) **Patients reported that their family planning preferences have changed over time.** Factors that contribute to preference formation include age, pregnancy intention (e.g. pre-conception, first time pregnancy, and post-partum), marital status, family size (number of children), employment or education status, and life stage (e.g. attitudes have changed over time). Older women and women with more children seemed to prefer longer term (or irreversible) methods such as an IUD or tubal ligation.

7) **Patients reported that they would like to be asked about their family planning preferences and offered several suggestions for ways to get this information.**
    - **a.** Conduct surveys (online or by mail)
    - **b.** Ask patients during their family planning appointment
    - **c.** Send an email or have outreach person call

8) **Patients reported a strong sense that having their preferences met would lead to better patient engagement, more confidence in their decisions, and more trust in their providers.** Participants indicated it would "make it a lot easier. It would make it a better experience." Another patient indicated, "I would feel more confident in my decision." And "you know if something comes up, you can trust them. I would feel like the physician actually knows what he's doing." Conversely, without respect for patient preferences, it would lead to disengagement and delay or switching care, "I would find somebody else. That would absolutely be the last they saw of me."

9) **Patients also made recommendations on things that could be done to improve the family planning care that women in their community received:**
    a. Openness to natural family planning
    b. Affordability of care (less out of pocket costs and more coverage of contraceptive methods)

c. Engaging families and parents in family planning education for teens
d. Family planning education for all generations
e. More discussion of various contraceptive methods and their side effects

It is noteworthy that the focus groups differed slightly in terms of their experiences. The participants at the rural site were very positive toward and committed to their primary care provider. Several had experiences at the urban clinic and preferred to receive care at the rural site (despite distance) because they felt they were getting more personal care in a smaller clinic setting. The urban clinic participants spoke a lot about their birth experiences (many were first time moms) which has had an impact on their contraceptive and family planning decisions going forward. For example, some participants were breastfeeding, and were seeking a method that wouldn't interfere with breastfeeding their infant but anticipated switching methods in the future. All participants were largely positive about their family planning experiences, especially the relationship with their provider.

Participants also shared a strong sense of gratitude and I received a lot of comments thanking me for asking them their opinions and that they wish they had more opportunities to share more about their experiences. They also appreciated the gift card and food and indicated that the food was enough to attract them to come to the focus group. Health center staff members were warm, welcoming, and very accommodating both to the participants and to me as the facilitator. They took great sense of ownership over the focus group and provided linen table clothes, gourmet catering, and flowers for each of the participants, making it a very welcoming and special environment for patient participants.

Researcher Memo for June 11th Focus Group

The focus group effort in West Virginia was largely disappointing. Only two participants showed up for the first focus group, and at the suggestion of the health center site we canceled the second focus group due to lack of interest and high no-show rates. The focus group of two participants will be treated as individual interviews, since each participant had the opportunity to answer each question and the setting did not allow for group dynamics as a traditional focus group would. Therefore, we will not make any comparisons by site for this West Virginia group of participants, nor will we present any summary statistics for this particular site.

The difficulties with recruitment for this site could have been avoided with increased engagement from the health center partner. I found it difficult to communicate and coordinate with staff and had a hard time getting responses from the health center staff when needed. Several weeks went by from the point of agreement (and memorandum) to agree on a focus group date without any communication, despite several outreach emails

and phone calls. In the future, I will require health centers to have a pre-call with me at least one week prior, in order to verify recruitment efforts and get an estimated head count of participants.

Researcher Memo for June 17th -18th Focus Groups and Individual Interviews

I conducted one focus group of 9 participants in [City], AZ in mid-June 2013. Two days before the focus group, the site coordinator called to notify me that recruitment was particularly slow and that some patients expressed the desire to speak with me privately, rather than in a large group. At their request, I made myself available to conduct one-on-one interviews in a private office on both days of the site visit. This greatly increased recruitment. I have submitted a modification to the IRB protocols in order to accommodate patients who prefer to speak to me individually rather than in a group setting and will implement individual interviews in the future. Two participants specifically preferred this method because they had traumatic experiences related to reproductive health that they did not want to discuss in front of others. Other patients indicated that the interview worked better for them because they could schedule it at a convenient time, compared with the set focus group date and time.

It was clear to me that the dynamic between the group and individual interviews was very different. Focus group participants tend to pick up on the group dynamic and a sense of agreement or disagreement on certain topics is immediately observable. This is not the case in individual interviews, however I am able to probe on specific responses from individuals much better in a one-on-one case, rather than the group setting which limits the depth I can go with participants. I am confident that this adapted protocol will serve me well in the future and will capture a greater proportion of interested participants.

[Health Center Name] is a large health center located in [County Name], Arizona. The county has an uninsured rate nearly twice that of the state rate (21 percent vs. 11 percent) but it ranks first in terms of healthy behaviors among adults. The county population is 134,421 and is located proximally to several Native American tribal lands including Navajo, Havasupai, and Yavapai. Major industries include lumber, railroad, ranching, and distribution. The population is is 61.7 percent White/Caucasian with 27.3 percent self-identifying as Native American and 13.5 percent as Hispanic or Latino. Nearly 9 percent self-identify as other race or two or more races. The health center serves 47,756 patients annually, with 19 percent of them being uninsured and 31 percent enrolled in Medicaid or CHIP. Sixty-five percent of patients live at or below the federal poverty line and 28 percent self-identify as a racial or ethnic minority.

The vast majority of the focus group and interview participants were under age 35 (80 percent) with 20 percent over age 35. Sixty percent self-reported as white/Caucasian while 20 percent were Hispanic/Latina and 15 percent were American Indian/Alaska

Native. Only two participants said they were uninsured, with the majority having either Medicaid or private insurance. About half (56 percent) indicated they receive birth control services and 64 percent reported receiving STD testing or cervical cancer screening at the health center. One third reported receiving prenatal care at the health center.

At present, I have achieved focus group and interviews with 50 participants, well on the way to a minimum of 60 participants that I proposed in the original dissertation proposal. I plan to reach out to one additional health center for research partnership to explore the possibility of hosting a final focus group and/or set of individual interviews. Transcription and analysis of the focus group and interview data is planned for the month of July. I also plan to use this preliminary data to inform the expert panel survey, which is planned for distribution in the early weeks of July. The domains and items related to patient preferences will be informed by focus group data and by a review of the literature. I plan to engage the secondary coder to complete validity checks on the coding once selective coding is completed, likely by the first week in August.

Two rounds of consensus panel review will be conducted in the month of July, with a finalized survey instrument prepared by mid-August. After IRB approval (requiring modification), I plan to conduct cognitive testing with 5 patients and field the survey in the month of September in at least one CHC site with at least 50 patients. Survey modes are being discussed with the health center partner sites. Final stages of the research will include analysis of survey data (confirmatory factor analysis), reduction of survey items, and finalization of the survey tool. This is expected to be completed in the months of September and October. Additionally, the development of preliminary theoretical models on patient preferences will be conducted during the months of August – October, using the data from patient focus groups and interviews, as well as the review of the literature. Development of three manuscripts will begin in September, with a goal deadline of submission in early January. This will put me on target to complete the dissertation process and defend by early March 2014. Frequent contact with dissertation committee members will need to take place during this time to adhere to the aggressive schedule of deliverables.

Researcher Memo for Analysis

Individual interviews and participant focus group data was analyzed in an identical method. First, open coding was completed by the primary researcher by selecting key phrases and words that represented important concepts in the data. Using the constant comparative method of analyzing transcript text, a list of open codes was generated across all of the interview and focus group transcripts. Following open coding, a set of axial codes was generated by linking key concepts and relationships observed in the interview and focus group data. These axial codes were then compared with the existing

framework of patient preferences in primary care to create selective codes. The coding hierarchy was then used by a secondary analyst to code five randomly selected transcripts to assess the internal consistency and inter-rater reliability of the qualitative analysis. Any discrepancies between the coders was resolved through collaborative discussion until a consensus was reached. Kappa coefficients were generated for all selective codes and themes. All qualitative analysis was conducted using NVivo v. 10.

Concerns that have arisen for me during the analysis center around how to separate my prior knowledge of existing frameworks on primary care preferences to ensure that they do not influence my coding. One strategy I used is to use predominantly "in vivo" codes during open coding, where the phrasing of participants' responses was maintained to better represent their sentiments. When I noticed similarities around collective thoughts or experiences, I often grouped them into categories and renamed them based on my interpretation during the latter phases of axial and selective coding. Having the secondary coder conduct selective coding on random transcripts was very helpful and we found a fair degree of agreement on the majority of transcripts. One learned strategy is to make sure that both coders have the same protocol for coding (e.g. do you include the question prompt along with the response in the code?) to make sure that the percent agreement/Kappa figures accurately represent the actual degree of agreement.

As of July 31st, I have completed individual interviews and focus groups with 50 patients in community health centers. I plan to reach out to the existing health centers to see if any patients would like to schedule one-on-one interviews with me to attempt to get at least five more participants. I believe I have reached saturation, since no new concepts or themes were generated from the last focus group/interview, but I proposed a minimum of 60 participants in my proposal and would like to achieve a number very close to that. I hope to complete these in the month of August. In addition, I have submitted the draft survey instrument (assuming no radical changes from the final set of interviews) and accompanying documents to the IRB for approval to field the survey potentially in September. One health center has already agreed to partner with me as a survey site and I will need to recruit an additional health center for a total of 100 respondents. In addition, I have proposed three mechanisms for the survey instrument to be administered: on-site by hardcopy (mail or dropbox submissions) or online via surveymonkey where participants may take the survey at any time and any location convenient for them. I have also proposed that participants may submit mailing or email information to be able to receive their preferred gift card remuneration. I have not received IRB feedback on this voluntary mechanism for incentive payment at this time, but expect they will have additional guidance.

One element of concern for me is that I did not conduct true theoretical sampling for this population, which is a critical component of the grounded theory approach. At the onset of the focus groups, it appeared to me that one sampling criteria could be age, as older

and younger adult women had differing opinions and preferences around family planning. However, as additional focus groups were conducted, I felt that I had enough variation in my sample population to achieve saturation for both age groups. Another theoretical sampling criteria could be race/ethnicity, as this may also be a defining factor for the development of preferences and values in family planning. This may be an interesting approach for future studies testing the preliminary theory. In addition, I found employment status or school status as well as marital status to be defining characteristics of patient preferences and would be interested in conducting additional focus groups using these sampling frames for a future exploration of these issues. However, because the scope of this study was to examine a very narrow segment of the family planning user population (low-income, medically-underserved women of reproductive age) I do feel that I have recruited the appropriate population to answer the research questions and form a preliminary theory of patient preferences and value concordance in family planning care for underserved women.

Appendix B: Patient Preference Domains and Definitions

Domain	Definition
Availability	Ability to choose a physician and appointment times
Accessibility	Time before physician can be consulted, accessibility of physician by telephone, physical and geographic accessibility of care, financial accessibility of care
Organization and Coordination	Balance between input (money, means, time) and output of care, physical suitability of the organization, organization of treatment in the course of time, transfer of treatment in care of more providers of care, substitution or retirement, availability of special services such as preventive screening
Clinical Care and Method Choice	Actual improvement or stabilization of the state of health, accuracy in the use of knowledge and skills, attention for the consequences of care for the patient
Provider-Patient Relationship	Respect and personal interest for the patient as individual, exploring patients' wishes and needs, respect for personal privacy of the patient or desire for chaperone, time for paying attention to the patient, preference for certain age or sex of provider, patient involvement in decisions about care
Information, Counseling and Support	Provision of relevant information to the patient, attention for patients' psychosocial problems, stimulating patients' responsibility for treatment compliance and self-care, attention for needs of patients' partner and relatives

Appendix C: Focus Group Data Collection Materials

Consent Form for Participating in Patient Focus Groups
Research Study on Patient Preferences and Experiences in Family Planning Care

PI: Marsha Regenstein, PhD, MPP; Co-PI: Tishra Beeson, MPH
IRB #041309

INTRODUCTION

This consent form will give you information about the research study so that you can make an informed decision about participating in this research. You are invited to take part in focus group discussions with female patients ages 18 – 45 to talk about ways to improve a patient's experience in receiving family planning services. This study has been approved by the Institutional Review Board at the George Washington University. We encourage you to ask any questions you may have about this study now, or at any time following the study. A member of the research team will be available to answer your questions and provide further explanations.

Your decision to take part in the study is voluntary. You are free to choose whether or not you will take part in the study. You may refuse to answer any question or to stop participating in the discussion at any time. Your participation is confidential; we will not report your name, address, phone number, preferred language, diagnosis, or any information that could be used to identify you.

PURPOSE OF THE STUDY

The purpose of this study is to gather information on women's preferences and experiences in receiving family planning care at community health centers and other clinical settings. The results from this discussion group will help us better understand what women prefer and value in their family planning care and will help inform health care providers on ways to improve the quality of family planning services by tailoring them to patients' unique needs and preferences.

If you agree to participate in this study, you will be asked to respond to questions in a group setting regarding your preferences and experiences with family planning care. This will include questions about services for birth control and testing for sexually transmitted diseases. This discussion is expected to last between 60 and 90 minutes. You will also be asked to fill out a short demographic form that tells us some information about the patients who are talking to us in the discussion groups. This information will not be linked with your responses.

The discussion groups may be audio recorded and transcribed in order to check for accuracy. Only members of the research and transcription team will have access to these audio recordings. Audio recordings will be secured in a locked filing cabinet and will be destroyed within 30 days of transcription.

POSSIBLE RISKS

To the best of our knowledge, participating in this study poses no more risk of harm than you would experience in everyday life. We have made every attempt to minimize the harm or risk to you by making this study completely voluntary and avoiding questions that ask identifying information, such as your name or address. Possible risks or discomforts you could experience during this study include: a possibility of loss of confidentiality due to the group nature of the focus group or discomfort/stress in answering the questions.

POSSIBLE BENEFITS

The benefits to science and humankind that may result from this study are: a better understanding of the important values and preferences that patients have when they seek family planning services and increased physician knowledge of the patient experience in order to improve the quality of family planning services.

COMPENSATION

In appreciation of your time and effort in participating in the focus group discussion, we will provide you with a $15 gift card to a major retailer as well as a catered meal.

CONFIDENTIALITY

Although the researchers will take every precaution to maintain confidentiality of the data, the nature of focus groups prevents the researchers from guaranteeing confidentiality. We would like to remind participants to respect the privacy of fellow participants and not repeat what is said in the focus group to others. If results of this research study are reported in journals or at scientific meetings, the people who participated in this study will not be named or identified.

Further information regarding this study may be obtained by contacting:
Marsha Regenstein | marshar@gwu.edu | 202-994-8662
Tishra Beeson | tbeeson@gwu.edu | 202-994-4238.

For any questions about your rights as a research participant, please contact the George Washington University Office of Human Research at ohrirb@gwu.edu | 202-994-2715.

Your informed consent to participate in this research study is implied if you proceed with participating in the focus group.

*Please keep a copy of this document in case you want to read it again.

FOCUS GROUP PARTICIPANT DEMOGRAPHIC FORM

Date _____

DEMOGRAPHIC INFORMATION

We want to ask you a few questions about you and your family. Your answers are completely **anonymous**. We are not asking you more than your first name. We in no way will be able to identify you through your answers. These questions are for statistical purposes only, to help us better describe the people who participate in this focus group. Answering these questions is completely voluntary; it is not required that you answer them.

1. How old are you? _____ years

2. Are you male or female? _____Male _____Female

3. What is the highest grade or level that you have completed?

- ☐ 8th grade or less
- ☐ Some high school, but did not graduate
- ☐ High school graduate or GED
- ☐ Some college or 2-year degree
- ☐ 4-year college graduate
- ☐ More than 4-years of college

4. What was the combined income of everyone living in your house in the past year?

- ☐ Less than $25,000
- ☐ Between $25,000 and $49,000
- ☐ Between $50,000 and $74,000
- ☐ Between $75,000 and $99,000
- ☐ More than $100,000
- ☐ Don't know

5. What is your race/ethnicity?

☐ White ☐ Black or African-American
☐ Asian ☐ Native Hawaiian or Pacific Islander
☐ Hispanic ☐ American Indian or Alaska Native
☐ Others

7. Do you have health insurance? ☐ Yes ☐ No

7a. If you have it, what type of health insurance do you have?

☐ Private	☐ Medicare	☐ Medicaid	☐ Other, please specify

8. Have you been to this health center in the past year for family planning services? Family planning services would include services such as obtaining birth control, STD testing, pregnancy testing or pap tests?

☐ Yes ☐ No

9. How long have you received care at this health center? _____ months/years

10. What types of family planning services have you come to this clinic for?

☐ Birth control
☐ Counseling/info for birth control
☐ Pap tests
☐ STD testing
☐ HPV vaccine
☐ Pregnancy testing
☐ Prenatal care
☐ Postpartum care

11. Do you have a provider who you regularly see for your family planning care?

☐ Yes ☐ No

11a. If yes, is your provider a/an:

☐ Family Physician/General Practitioner

☐OB/GYN

☐ Nurse Practitioner

☐ Physician Assistant

☐ Certified Nurse Midwife

☐ Other, please specify

_____

☐ Don't know

12. How would you characterize your health?

□ Excellent	□ Very Good	□ Good	□ Fair	□ Poor

FOCUS GROUP INTERVIEW GUIDE

1. Welcome participants:

   Hello, my name is _____. I work at a health policy research center at The George Washington University in Washington, DC. We are working with [CLINIC NAME] to understand what women go through to get family planning care, such as birth control or STD testing. We're interested in what you have to say because your opinion and experiences matter. Thank you for participating in this focus group discussion.

2. Explain the project:

   The purpose of this project is to look at how easy or hard it is for women like you to get the family planning services you want. We are especially interested in what things are most important to you and what your preferences are when you get family planning services. For the purposes of this discussion, when we talk about family planning care we are talking about different types of birth control, education and counseling about birth control, STD testing and treatment, cancer screening, preconception (to prepare for pregnancy) care, pregnancy testing and post-natal (after birth) care. We do not include services you might get when you are pregnant. The information you share today will help your doctors provide better care around important issues such as family planning and reproductive health.

3. Ground rules:

   - There are no right or wrong answers. Feel free to speak openly and give your own opinions.
   - We need to hear from everyone. We want to give everyone an opportunity to talk about each topic, so each person needs to be somewhat brief.
   - I may sometimes need to stop you so that we can get back on focus and get through our topics
   - This discussion will be audio recorded for accuracy.
   - The discussion in this group is confidential and voluntary. That means that we will not be connecting your name with what you say and your personal information will not be available to anyone outside the study team.
   - We also want to respect the privacy of the other women in this group. Some of the questions might be sensitive to some people and we want everyone to feel comfortable sharing. That means that the responses that are shared here today need to be kept confidential.
   - This group is not connected with any specific health care facility, provider, or funder and will in no way impact your ability to get care.
   - We expect this meeting to last approximately one and one-half hours.
   - Usually people enjoy these groups as an opportunity to talk with others. Please relax and be as open as possible.

QUESTIONS ABOUT PATIENTS' FAMILY PLANNING PREFERENCES AND VALUES

Opening Questions

1. **First, I'd like to start by having everyone introduce themselves. Let's go around the room and have each person tell us the name you'd like us to call you and what kind of care you usually get from this clinic.**

   Probes:

   - Annual check-up with internist, family practice doc, NP
   - Ob/gyn care, midwife
   - Dental care
   - Other specialty care – cardiologist, endocrinologist, behavioral health
   - Child gets care from a pediatrician
   - Other family member gets care here

2. **Do you ever come to this health center for FP services like pap tests or getting birth control? Describe those services.**

Benefits and Challenges of Getting Family Planning at Health Centers

3. **What do you like about getting family planning services from this health center? What do you dislike?**

4. **Have you ever had any problems getting the family planning services you wanted at this health center? Please explain**
   Probes:

   - Cost
   - Confidentiality
   - Unavailable methods
   - Inconvenient or inaccessible

General Patient Preferences

5. **One of the things that we are really interested in hearing from you are the things that are most important to you when getting family planning services, like birth control, STD testing and treatment, pap smears? We will call these family planning preferences.**

   - **Some people have suggested that _____ may be really important to women in getting family planning care. What do you think?**

Accessibility of Care

6. **How do you think the availability of family planning services impacts your ability to get family planning care?**

- **For example, the ability to choose your own provider?**
- **Getting an appointment at the time you want it?**

7. **How do you think the accessibility of family planning services impacts your ability to get care?**
   - **For example, is the clinic located in a place that is convenient for you to get to?**
   - **Would you like to be able to talk to or get advice from your provider by phone or by email?**

Organization and Coordination

8. **Have you ever needed specialty care related to family planning that you couldn't get here at the health center?**
   - **How did that referral process work?**
   - **Do you feel like the providers worked together to coordinate your care?**
9. **Is the physical space of this clinic organized in a way that meets your needs regarding family planning?**

Information, Counseling, and Support

10. **How do you get information about birth control and family planning services?**
    - **Providers**
    - **Written materials**
    - **Counseling/health educator**
    - **Internet, television, other media**
    - **Friends and family members**
    - **Other?**

11. **Do you generally feel like you have enough information about birth control and family planning services?**

12. **If you feel like you need more information about birth control and family planning services, how would you prefer to receive information?**
    - **Providers**
    - **Written materials**
    - **Counseling/health educator**
    - **Internet, television, other media**
    - **Friends and family members**
    - **Other?**

Provider-Patient Relationship

13. **Does it matter to you if your family planning provider is a woman or man?**

14. **Does it matter to you what age your family planning provider is?**

15. **Does it matter to you what race/ethnicity your family planning provider is?**

16. **Does it matter to you what language your family planning provider speaks?**

17. **Does it matter to you whether or not your provider involves your partner/spouse in family planning decisions? How about other family members?**

Value and Preference Assessment

18. **Do you think your family planning preferences have changed over time? If so, how have they changed?**

19. **Have you ever stopped seeing a doctor or nurse because they didn't meet your preferences or values?**

20. **Do you think your doctor or nurse who provides family planning care knows about the things that are most important to you? (family planning preferences)**

21. **Do you think doctors and nurses providing family planning care <u>should</u> find out about their patients' family planning preferences?**
    - **How should they find out? Survey of patients, call on the phone, note in the chart, family planning counselor?**

22. **If your doctor or nurse providing family planning care knew about your family planning preferences, how would that change your experience getting family planning care from them?**

    - Information
    - Satisfaction
    - Accessibility
    - Utilization of services

23. **If you could recommend that your doctor change something about how he or she provides family planning care, what would you recommend?**

Appendix D: Qualitative Coding Matrix

Selective Codes		**Axial Codes**	**Open Codes**
Factors Influencing Preferences	Stage of Life	Age Marital Status Number of Children Household Size Pregnancy Intention/Ambivalence Health Status Family History	Younger women Older women More children "After having children" Family status Intent to conceive Mental illness Trauma Condition Abnormal Pap smear STD School Employment Taking time off Work/school Personal situation
Factors Influencing Preferences	Culture & Health Beliefs	Health beliefs Attitudes Culture Language Religion	Part of my faith Attitudes Cultural influence Religious influence Race/Ethnicity/Minority
Factors Influencing Preferences	Access	Socioeconomic status Insurance coverage Insurance benefits Contraceptive methods covered Accessibility of services	Insurance only covers certain methods Wait times Getting appointments Choice of provider Routine vs. urgent Limited options
Factors Influencing Preferences	Provider Interactions	Trust Provider recommendations/attitudes Provider relationship Informed choice Provider-led Shared-decision making	Trust Provider influence Bias/Attitudes Decision-making I decide what is best Provider decides what is best Share decisions
Factors Influencing Preferences	Information	Information type Information source Information adequacy	Range of methods Side effects Efficacy Written information Pamphlets Internet Provider as source of information TV commercials Advertisements or legal cases Ease of use/adherence Safety of method Familiarity with method Informational group or class Trusting information
Factors Influencing Preferences	Social Support	Spouse or Partner Support Peer Support	Spouse or partner involvement Parents Group or class Trust peers

			Social community
Expressions of FPVC	Positive Expressions	Trust Satisfaction/Quality Engagement and Empowerment Feeling Informed and Confident in Decisions	Satisfaction with experience Satisfaction with provider Satisfaction with method Being honest with provider/Trusting provider Feeling comfortable Feeling empowered Feeling informed Feeling confident in decision Feeling like a partner Feeling respected Feeling supported Feeling less stressed
Expressions of FPVC	Negative Expressions	Fear and frustration Lack of control Delay or avoid care Poor communication	Fear Feeling judged Feeling lack of control Feeling let down Feeling rushed Feeling dissatisfied Finding a new provider Delaying/changing method Delayed Pap Avoid coming in
Other Outcomes of FPVC	Utilization and Outcomes	Contraceptive Services Family Planning Services Contraceptive failure	Change or delay method Delayed Pap Prevent unwanted pregnancy "Got pregnant on it"
Aspects of FP Care (Preferences)	Accessibility	CHC takes uninsured patients Financially accessible Physical space/environment Convenience/geographic access Wait times Phone/distance mechanism	CHC takes uninsured patients Affordability Child-friendly space Preference for separate areas Updated equipment Waiting room space Problem getting care for uninsured Transportation Insurance coverage influences method choice Cost of FP Advice line Triage Wait times for appointments Wait times during visits Wait times for Pap smear or routine care
Aspects of FP Care (Preferences)	Availability	Appointment availability Continuity of care Preferred provider Visit type	Same day appointments Short window for Depo-provera Problem getting urgent appointments Want to see the same provider Want to see my own provider Face to face visits
Aspects of FP Care (Preferences)	Organization and Coordination of Care	Integrated Care Care Coordination Co-Location	Other sources of FP care/Primary care School based FP

		Privacy and Confidentiality	Shortage of providers Providers referring out for family planning Problems getting tubal ligation Problems with paperwork Privacy Confidentiality breach CHC is my health care home
Aspects of FP Care (Preferences)	Clinical Care and Method Choice	Care is high quality Referrals Limited method choice Range of methods	Quality Affordable or covered methods Problems with referrals for specialty care Unavailable methods Available methods Preference for long-acting method Preference for method not requiring daily use Preference for non-hormonal method Preference for non-invasive method
Aspects of FP Care (Preferences)	Patient-Provider Relationship	Provider influence on decision making Personal interest for patient Provider communication Provider responsibilities Provider gender Provider experience Provider continuity Provider type	Relationships "Knowing patient as a person" Provider relationship takes time Provider counseling about methods Provider asks about satisfaction with method Provider is respectful Provider is thorough Provider listens Provider makes recommendations Provider spends time Provider doesn't make assumptions Providers care Provider asks about preferences during visit Provider training Provider willing to learn Trust in provider Comfortable with females Comfortable with males Male with chaperone Female providers relate more Male providers are more/less gentle Experience matters Prefer to see same provider No difference in provider type OBGYN General practitioner
Aspects of FP Care	Information,	Mass Media information	Sources of information

(Preferences)	Counseling and Support	Interpersonal information Information quantity Information adequacy Support from partner/spouse Support from family Support from peers	Health center website Internet Other women Pharma Phone/Text Provider source TV commercials Written information Informational group or class Too much information Finding out information on my own Verifying information Trusting information Support from partner/spouse Support from friends, other women, family members
Family Planning Decisions	Decisions	Pregnancy Intention Contraceptive Use Contraceptive Method	It's a daily decision It's my body Methods to choose from Number of kids I want Prevent unwanted pregnancy

Appendix E: Pilot Survey Consent Form and Instrument

Consent Form for Participating in Pilot Survey
Research Study on Patient Preferences and Experiences in Family Planning Care

PI: Marsha Regenstein, PhD, MPP; Co-PI: Tishra Beeson, MPH
IRB #041309

INTRODUCTION

This consent form will give you information about the research study so that you can make an informed decision about participating in this research. You are invited to take part in a patient survey on your experience receiving family planning services. This study has been approved by the Institutional Review Board at the George Washington University. We encourage you to ask any questions you may have about this study now, or at any time following the study.

Your decision to take part in the study is voluntary. You are free to choose whether or not you will take part in the study. You may refuse to answer any question or to stop participating in the discussion at any time. Your participation is confidential; we will not report your name, address, phone number, preferred language, diagnosis, or any information that could be used to identify you.

PURPOSE OF THE STUDY

The purpose of this study is to gather information on women's preferences and experiences in receiving family planning care at community health centers and other clinical settings. The results from this survey will help us better understand what women prefer and value in their family planning care and will help inform health care providers on ways to improve the quality of family planning services by tailoring them to patients' unique needs and preferences.

If you agree to participate in this study, you will be asked to respond to a survey regarding your preferences and experiences with family planning care. This will include questions about services for birth control and testing for sexually transmitted diseases.

POSSIBLE RISKS

To the best of our knowledge, participating in this study poses no more risk of harm than you would experience in everyday life. We have made every attempt to minimize the harm or risk to you by making this study completely voluntary and avoiding questions that ask identifying information, such as your name. Possible risks or discomforts you could experience during this study include discomfort or anxiety due to the nature of some of the questions in the survey.

POSSIBLE BENEFITS

The benefits to science and humankind that may result from this study are: a better understanding of the important values and preferences that patients have when they seek family planning services and increased physician knowledge of the patient experience in order to improve the quality of family planning services.

COMPENSATION

In appreciation of your time and effort in participating in the survey, we will provide you with a $20 gift card to a major retailer. In order to send you this gift card, we may ask you to provide an email address or mailing address. This information will not be linked in any way to your survey responses and your contact information will be destroyed immediately upon distribution of the gift card.

CONFIDENTIALITY

The researchers will take every precaution to maintain the confidentiality of your survey responses. If results of this research study are reported in journals or at scientific meetings, the people who participated in this study will not be named or identified in any way.

Further information regarding this study may be obtained by contacting:
Marsha Regenstein | marshar@gwu.edu | 202-994-8662
Tishra Beeson | tbeeson@gwu.edu | 202-994-4238.

For any questions about your rights as a research participant, please contact the George Washington University Office of Human Research at ohrirb@gwu.edu | 202-994-2715.

Your informed consent to participate in this research study is implied if you proceed with participating in the survey.

*Please keep a copy of this document in case you want to read it again.

Instructions: *Please respond to each question in the sections below. If you are not sure, please mark "Not Sure." It may seem as though the questions are repeated throughout the survey, however there are slight changes to the questions and your responses to each question are very important. Thank you again for participating!*

1. What is your age?
   - ☐ 18 – 25 years
   - ☐ 26 – 30 years
   - ☐ 31 – 35 years
   - ☐ 36 – 40 years
   - ☐ 41 – 45 years
   - ☐ 45 years or older

2. What is your current marital or cohabitating status?
   - ☐ Single
   - ☐ Married
   - ☐ In a long term relationship, but not living together
   - ☐ In a long term relationship and living together
   - ☐ Other, please specify

3. How many children do you have?

   _____ children

4. How many people currently live in your house?

   _____ people

5. What is your race? Mark one or more.

   - ☐ White
   - ☐ Black or African American
   - ☐ Asian
   - ☐ Native Hawaiian or Other Pacific Islander
   - ☐ American Indian or Alaska Native
   - ☐ Other, please specify

6. Are you of Hispanic or Latino origin or descent?
   - ☐ Yes, Hispanic or Latino
   - ☐ No, not Hispanic or Latino

7. Are you currently employed?
   - ☐ Yes, I am employed full-time
   - ☐ Yes, I am employed part-time
   - ☐ No, I am not employed
   - ☐ Not sure

8. How far do you typically travel to get your general primary health care?
   - ☐ Less than 5 miles
   - ☐ 5 – 10 miles
   - ☐ 11 – 15 miles
   - ☐ More than 15 miles

9. Do you currently have health insurance?
   - ☐ Yes
   - ☐ No
   - ☐ Not sure

Throughout this survey, we will refer to "family planning care." Family planning care includes counseling and dispensing of birth control methods, testing and treatment for sexually-transmitted diseases, a Pap smear or pelvic exam and other care for women of reproductive age to help them plan and space their pregnancies.

10. When was the last time you saw a doctor or nurse for family planning care?
    - ☐ In the last 12 months
    - ☐ 1 – 3 years ago
    - ☐ 3 – 5 years ago
    - ☐ More than 5 years ago

11. Where did you last see a doctor or nurse for family planning care?
    - ☐ At a community health center
    - ☐ At a family planning clinic or Planned Parenthood clinic
    - ☐ At a county or state health department clinic
    - ☐ At a hospital or emergency room
    - ☐ At a private doctor's office or clinic
    - ☐ Other, please specify

12. How far do you typically travel to get your family planning care?
    - ☐ Less than 5 miles
    - ☐ 5 – 10 miles
    - ☐ 11 – 15 miles
    - ☐ More than 15 miles

13. Do you currently use a contraceptive or birth control method to prevent pregnancy?
    - ☐ Yes
    - ☐ No
    - ☐ Not sure

14. If yes, which of the following birth control methods do you currently use? Select all that apply.

- ☐ Oral contraceptive (birth control pills)
- ☐ IUD (Mirena, Paragard)
- ☐ Implant (Implanon)
- ☐ Injectable contraceptive (Depo-Provera, the Shot)
- ☐ Patch (Ortho Evra)
- ☐ Vaginal Ring (NuvaRing)
- ☐ Diaphragm or cervical cap (Lea's Shield, FemCap)
- ☐ Sponge (Today)
- ☐ Male condom
- ☐ Female condom
- ☐ Spermicides
- ☐ Natural family planning (rhythm method, withdrawing)
- ☐ Tubal ligation (tubes tied)
- ☐ Vasectomy
- ☐ Emergency contraceptive pills (ECP, Plan B)
- ☐ Not sure
- ☐ Other, please specify

15. How satisfied are you with the birth control method you are currently using?

- ☐ Very satisfied
- ☐ Somewhat satisfied
- ☐ Neither satisfied, nor dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Very dissatisfied

16. Is the birth control method you currently use your first choice method?

- ☐ Yes
- ☐ No
- ☐ Not sure

17. If no, what birth control method would you most prefer? Select all that apply

- ☐ Oral contraceptive (birth control pills)
- ☐ IUD (Mirena, Paragard)
- ☐ Implant (Implanon)
- ☐ Injectable contraceptive (Depo-Provera, the Shot)
- ☐ Patch (Ortho Evra)
- ☐ Vaginal Ring (NuvaRing)
- ☐ Diaphragm or cervical cap (Lea's Shield, FemCap)
- ☐ Sponge (Today)
- ☐ Male condom
- ☐ Female condom
- ☐ Spermicides
- ☐ Natural family planning (rhythm method, withdrawing)
- ☐ Emergency contraceptive pills (ECP, Plan B)
- ☐ Not sure
- ☐ Other, please specify _____

18. Why aren't you currently using your first choice birth control method? Select all that apply.

- ☐ My first choice birth control method is too expensive
- ☐ My first choice birth control method isn't covered by my health insurance
- ☐ My first choice birth control method isn't available at this clinic or doctor's office
- ☐ My doctor or nurse didn't tell me it was an option
- ☐ My doctor or nurse recommended something else
- ☐ Other, please specify

  _____

19. In the last 12 months, how many times have you switched birth control methods for any reason?

_____ times

20. In the last 12 months, how many times have you stopped using birth control for any period of time?

_____ times

21. Please mark any of the following reasons why you switched or stopped using a birth control method.

- ☐ It caused unwanted side effects
- ☐ It was too difficult to use
- ☐ It was too expensive
- ☐ It wasn't covered by my health insurance
- ☐ It wasn't my first choice of birth control
- ☐ I got pregnant while I was using it
- ☐ I wanted or planned to become pregnant
- ☐ I didn't think I needed birth control
- ☐ I wasn't able to get birth control at my clinic or doctor's office
- ☐ My doctor recommended I switch or stop birth control
- ☐ Other, please specify

_____

22. At this time in your life, how important is it to you to avoid or prevent pregnancy?

- ☐ Extremely important
- ☐ Somewhat important
- ☐ Neither important, nor unimportant
- ☐ Somewhat unimportant
- ☐ Not important at all

The next set of questions will ask you about some of your preferences about family planning care. Please tell us if you prefer A, prefer B, or have no preference for each item by marking the box below:

	A		B		NO PREFERENCE
	I prefer to get family planning care in the same place that I get my general health care		I prefer to get family planning in a different place than I get my general health care		I have no preference
	I prefer to see the same doctor or nurse for family planning that I usually see for general health care		I prefer to see a different doctor or nurse for family planning than I usually see for general health care		I have no preference
	I prefer to schedule a separate visit for family planning where I can get dedicated time with my doctor or nurse to talk about family planning		I prefer to get my family planning care at the same time I have a general health care visit		I have no preference
	I prefer to see a specialist in women's health, such as an OBGYN for family planning care		I prefer to see a general practitioner for family planning care		I have no preference
	I prefer to see my preferred doctor or nurse, regardless of how long it takes to get an appointment		I prefer to get an appointment as soon as possible, regardless of the doctor or nurse I have to see		I have no preference
	I prefer to primarily have my questions answered during an in-person family planning visit with my doctor or nurse		I prefer to primarily have my questions answered through any means, such as over the phone, by email, or looking it up online		In have no preference
	I prefer to schedule a family planning visit on either the same or next day		I prefer to schedule a family planning visit in advance, on my preferred day and time		I have no preference
	I prefer to get information about family planning and birth control from my doctor or nurse		I prefer to get information about family planning and birth control from another source, such as the internet, written materials, or television commercials		I have no preference
	I prefer to have too much information on family planning and birth control		I prefer to have too little information on family planning or birth control		I have no preference
	I prefer to receive family planning counseling on different birth control methods from a doctor or nurse		I prefer to receive family planning counseling on different birth control methods from someone I trust, even if they are not a clinician or medical provider		I have no preference
	I prefer to have my provider give me the full list of available birth control methods and let me decide, even if some methods may be too expensive or inappropriate for my health status or lifestyle		I prefer to have my provider offer me a smaller list of recommended birth control methods that I can choose from, based on my age, family history, health status, lifestyle, and income		I have no preference

	A		B		NO PREFERENCE
	I prefer to have access to my preferred birth control method as soon as I leave my appointment		I prefer to go to an outside pharmacy or other location to get my preferred birth control method		I have no preference
	I prefer to use a birth control method that is non-hormonal		I prefer to use a birth control method that uses hormones to prevent pregnancy		I have no preference
	I prefer to use a birth control method that doesn't require every-day use		I prefer to use a birth control method that requires every-day use		I have no preference
	I prefer to use a birth control method that is long-acting (such as an IUD or implant)		I prefer to use a birth control method that is not long-acting		I have no preference
	I prefer to use a birth control method that I can afford, even if it isn't my first choice method		I prefer to use my first-choice birth control method, even if it is unaffordable		I have no preference
	I prefer to see a doctor or nurse that speaks the same language as I do		I prefer to see a doctor or nurse that speaks any language		I have no preference
	I prefer to see a doctor or nurse that is my same race or ethnicity		I prefer to see a doctor or nurse that is a different race or ethnicity		I have no preference
	I prefer to make the final selection of my birth control after seriously considering my doctor or nurse's opinion		I prefer that my doctor or nurse makes the final decision about which birth control I will use but that he or she seriously considers my opinion		I have no preference
	I prefer to be highly involved in making my own family planning decisions, even if it is different than what my doctor or nurse recommends		I prefer to trust my doctor or nurse's recommendations for family planning and follow their guidance		I have no preference
	I prefer to involved my spouse or partner in family planning decisions		I prefer not to involve my spouse or partner in family planning decisions		I have no preference
	I prefer to involve other family members in family planning decisions		I prefer not to involve other family members in family planning decisions		I have no preference
	I prefer to be asked about my family planning preferences by my doctor or nurse during my appointment		I prefer to be asked about my family planning preferences in another way, such as a survey or a phone call before my appointment		I have no preference
	Given all the information about risks and benefits of the different types of birth control, I prefer my doctor or nurse to tell me how acceptable the risks and benefits are to me		Given all the information about risks and benefits of the different types of birth control, I prefer to make the decision about how acceptable the risks and benefits are to me		I have no preference

	A		B		NO PREFERENCE
	Given all the information about risks and benefits, I prefer my doctor or nurse to tell me which birth control method to use		Given all the information about risks and benefits, I prefer to make the decision myself about which birth control method to use.		I have no preference
	Given all the information about risks and benefits, I prefer to equally share the responsibility with my doctor or nurse in deciding which birth control method to use.		Given all the information about risks and benefits, I prefer to leave all decisions regarding which birth control method to use up to my doctor or nurse.		I have no preference

The next set of questions will ask you to tell us about the last time you received family planning services (such as a Pap smear, birth control services, STD testing, or treatment, pregnancy test or other services related to women's reproductive health). We will refer to this as your "most recent family planning visit."

23. At your most recent family planning visit, tell us which of the following situations was most true for you:

	A		B		NOT SURE
	I got family planning care in the same place that I get my general health care		I got family planning in a different place than I get my general health care		Not Sure
	I saw the same doctor or nurse for family planning that I usually see for general health care		I saw a different doctor or nurse for family planning than I usually see for general health care		Not Sure
	I scheduled a separate visit for family planning where I got dedicated time with my doctor or nurse to talk about family planning		I got my family planning care at the same time I had a general health care visit		Not Sure
	I saw a specialist in women's health, such as an OBGYN for family planning care		I saw a general practitioner for family planning care		Not Sure
	I saw my preferred doctor or nurse, regardless of how long it took to get an appointment		I got an appointment as soon as possible, regardless of the doctor or nurse I had to see		Not Sure
	I primarily got my questions answered during an in-person family planning visit with my doctor or nurse		I primarily got my questions answered through any means, such as over the phone, by email, or looking it up online		Not Sure
	I scheduled a same-day or next-day family planning visit		I scheduled my family planning visit in advance, on my preferred day and time		Not Sure
	I received family planning counseling on different birth control methods from a doctor or nurse		I received family planning counseling on different birth control methods from someone I trust, even though they are not a clinician or medical provider		Not Sure
	My provider gave me the full list of available birth control methods and let me decide, even if some methods are too expensive or inappropriate for my health status or lifestyle		My provider offered me a smaller list of recommended birth control methods that I can choose from, based on my age, family history, health status, lifestyle, and income		Not Sure
	I had access to my preferred birth control method as soon as I left my appointment		I had to go to an outside pharmacy or other location to get my preferred birth control method		Not Sure

	A		B		NOT SURE
	I am currently using a birth control method that is non-hormonal		I am currently using a birth control method that uses hormones to prevent pregnancy		Not Sure
	I am currently using a birth control method that doesn't require every-day use (such as the Pill)		I am currently using a birth control method that requires every-day use (such as the Pill)		Not Sure
	I am currently using a birth control method that is long-acting (such as an IUD or implant)		I am currently using a birth control method that is not long-acting (such as an IUD or implant)		Not Sure
	I am currently using a birth control method that I can afford, even if though it isn't my first choice method		I am currently using my first-choice birth control method, even though it may be expensive or unaffordable		Not Sure
	I saw a female doctor or nurse for family planning care		I saw a male doctor or nurse for family planning care		Not Sure
	I saw a doctor or nurse that speaks the same language as I do		I saw a doctor or nurse that primarily spoke a different language than me		Not Sure
	I made the final selection about which birth control I use		I left all decisions regarding my birth control up to my doctor or nurse.		Not Sure
	I feel like I am highly involved in making my own family planning decisions, even if it is different than what my doctor or nurse recommended		I feel like I trust my doctor or nurse's recommendations for family planning and followed their guidance		Not Sure
	I involved my spouse or partner in family planning decisions		I did not involve my spouse or partner in family planning decisions		Not Sure
	I involved other family members in family planning decisions		I did not to involve other family members in family planning decisions		Not Sure
	I was asked about my family planning preferences by my doctor or nurse during my appointment		I was asked about my family planning preferences in another way, such as a survey or a phone call before my appointment		Not Sure
	My doctor or nurse to told me how acceptable the risks and benefits of birth control are to me.		I made the decision about how acceptable the risks and benefits of birth control are to me.		Not Sure
	My doctor or nurse told me which birth control method to use.		I made the decision myself about which birth control method to use.		Not Sure
	I equally shared the responsibility with my doctor or nurse in deciding which birth control method to use.		I left all decisions regarding which birth control method to use up to my doctor or nurse.		Not Sure

The next set of questions will ask you to tell us about your interactions with a doctor or nurse in the last 12 months. To answer these questions, think about the doctor or nurse that you usually receive family planning care from.

24. In the last 12 months, how often did your doctor or nurse answer your questions about family planning to your satisfaction?
    - ☐ Never
    - ☐ Sometimes
    - ☐ Usually
    - ☐ Always

25. In the last 12 months, how often did your doctor or nurse clearly explain your birth control options?
    - ☐ Never
    - ☐ Sometimes
    - ☐ Usually
    - ☐ Always

26. In the last 12 months, how often did your doctor or nurse clearly explain the possible side effects of birth control methods?
    - ☐ Never
    - ☐ Sometimes
    - ☐ Usually
    - ☐ Always

27. In the last 12 months, how often did your doctor or nurse listen carefully to you?
    - ☐ Never
    - ☐ Sometimes
    - ☐ Usually
    - ☐ Always

28. In the last 12 months, how often did you have problems communicating with your doctor or nurse due to language issues?
    - ☐ Never
    - ☐ Sometimes
    - ☐ Usually
    - ☐ Always

29. How would you rate your doctor or nurse's knowledge of you as a person, including your preferences, values, and beliefs about family planning and birth control?
    - ☐ Very knowledgeable
    - ☐ Somewhat knowledgeable
    - ☐ Minimally knowledgeable
    - ☐ Not knowledgeable at all

30. When is a woman most likely to get pregnant, if she is not using a method of birth control to prevent pregnancy?
    - ☐ During her period
    - ☐ Right before her period
    - ☐ The week after her period
    - ☐ Two weeks after her period
    - ☐ No difference in her likelihood to get pregnant
    - ☐ Not sure

31. Do you currently have any family planning or reproductive health problems that you would like to talk to a doctor or nurse about?
    - ☐ Yes
    - ☐ No
    - ☐ Not sure
    - ☐ If yes, please explain

32. Would you recommend the doctor or nurse that you currently see for family planning care to your family and friends?
    - ☐ Yes, definitely
    - ☐ Yes, somewhat
    - ☐ No
    - ☐ Not sure

33. Do you plan to return to this clinic or provider's office for family planning care in the future?
    - ☐ Yes, definitely
    - ☐ Yes, somewhat
    - ☐ No
    - ☐ Not sure

Thank you for responding to this survey and providing your important opinions, preferences, and insight on family planning care. Please insert your completed survey in one of the attached self-addressed stamped envelopes and send it by mail at your earliest convenience. Your health center may also have a locked drop-box location where you can submit your completed survey.

If you wish to receive a $20 gift card for your time and effort in completing this survey, please fill out the information on the next page, detach it and send it in the second envelope. Your personal information will not be linked in any way to your survey responses.

Appendix F: Concurrent Validity of Pilot Survey

Correlation Coefficients of Family Planning Value Concordance and Adapted CG-CAHPS Measures	Spearman Correlation (*r*)	P-value
In the last 12 months, how often did your doctor or nurse answer your questions about family planning to your satisfaction?	0.0624	0.5534
In the last 12 months, how often did your doctor or nurse clearly explain your birth control options?	0.0248	0.8045
In the last 12 months, how often did your doctor or nurse clearly explain the possible side effects of birth control methods?	0.0647	0.5179
In the last 12 months, how often did your doctor or nurse listen carefully to you?	0.0932	0.3514
In the last 12 months, how often did you have problems communicating with your doctor or nurse?	0.2487	0.0117
How would you rate your doctor or nurse's knowledge of you as a person, including your preferences, values, and beliefs about family planning and birth control?	0.0132	0.8948

Appendix G: Human Subjects Approval

THE GEORGE WASHINGTON UNIVERSITY

WASHINGTON, DC

Date: April 18, 2013
To: Marsha Regenstein, Ph.D

From: The George Washington University Committee on Human Research, Institutional Review Board (IRB), FWA00005945

Re: Correspondence dated 03/11/2013
Subject: **IRB#041309** – *Developing a measure of value concordance in family planning care among underserved women*
Sponsor: None
Risk Level: **Minimal** **Status**: Active **Expiration date: 4/16/2014**

This is to certify that the Institutional Review Board has **fully approved** the above referenced protocol via expedited review procedure under categories # **6 & 7** of 45 CFR 46.110.
The IRB has also determined that this study meets the criteria for a waiver of the subjects' signature as documentation of consent under 45 CFR 46.117 (c).

The expiration date of this project is **4/16/2014.** HHS regulations at 45 CFR 46.109(e) require that **continuing review** of research be conducted by the IRB at intervals appropriate to the degree of risk and **not less than once per year**. The regulations make **no provision for any grace period extending the conduct of the research beyond the expiration date of IRB approval. When your protocol expires all research activities must stop.** Please mark your calendar now to insure that the IRB receives a renewal request 30 days before the anniversary date of the project, if this study is expected to extend beyond one year.

This protocol has been approved for **a maximum number of 115 subjects** to be enrolled under the auspices of George Washington University. If you wish to increase enrollment beyond this number, you must submit a modification request to the IRB and obtain approval before exceeding this number.

Please note that the IRB must be notified if the project is altered in any way (change in location, personnel, number of subjects, age of subjects, or any change in research protocol). If you have any questions, please do not hesitate to contact the Office of Human Research either by email at ohrirb@gwu.edu or via phone at 202-994-2715.

SJS/dba

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