Dual Eligibles' Experience of Care in North Carolina's Patient-Centered Medical Home

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Dedication

The author wishes to dedicate this dissertation to:

Caroline Thompson who told me I could,

my two biggest cheerleaders, daughters Ellie and Natalie Selden,

and my husband, Tom Selden.

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The author wishes to acknowledge Donna Infeld, an expert, advocate and morale-booster, for her spirit and unflagging dedication to getting me across the finish line. The quality of this research was strengthened by her constructive criticism and that of my committee members; I am grateful for their input. This journey was made infinitely more pleasurable thanks to dear friends, extended family, neighbors Barbara and Sherman Robinson, child care providers, parents on the playground and cheerful Starbucks baristas, all of whom politely inquired about my progress and offered encouragement. Last but not least, many thanks to Heeth Grantham and Rachel Gross, who gave their assistance when I needed it most. For me, it has taken a large, loving and patient village…

Abstract of Dissertation

Dual Eligibles' Experience of Care in North Carolina's
Patient-Centered Medical Home

Individuals enrolled in both the Medicare and Medicaid programs, the "dually eligible," are generally vulnerable and face a wide range of health care needs; numerous studies have found that their health care is beset with problems of cost and quality. Health policy researchers find that these problems are directly associated with the inadequate coordination of benefits and services, but studies about care coordination have largely used quantitative approaches and focused on providers – they have not explored the critical perspective of patients receiving the care. To improve the complex processes of care coordination, this hybrid case study examines the experience of a sample of dual eligible enrollees served in North Carolina's patient-centered medical home, and care managers. The subjects were generally independently living, and at lower-risk that typical dual eligibles. Although some experienced some continuity of care issues within NC's PCMH, generally they described receiving the right care, at the right time, in the right care settings. However, some experienced barriers to accessing necessary care, especially in the areas of prescription drugs and navigating the health care delivery system. Some of these challenges could potentially be resolved by NC's PCMH, but many issues are outside the program's control. Care managers who were interviewed suggested modifications to the Agency for Healthcare Research and Quality's Care Coordination Ring, which represents care coordination for a more stable, middle-class population than the dual eligibles they serve.

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Chapter 1: Introduction

1. Background

This dissertation tells the implementation story of North Carolina's (NC's) patient centered medical home (PCMH) program. In the late 1980s and early 1990s, and faced with significant budgetary constraints, state leaders considered abandoning NC's fee-for-service (FFS) Medicaid payment model in favor of a capitated one. Although the state tried the latter approach on a limited basis, the strategy of buying Medicaid services from a private managed care company did not take hold in a significant way. Instead, the state decided to build its own infrastructure in order to enhance outcomes and reduce the costs of care for Medicaid-eligible and other vulnerable populations. One important factor was incentivizing the coordination of care for patients served through NC's PCMH through use of Medicaid's primary care case management (PCCM) model. This approach requires enrollees to select a PCP "who is responsible for coordinating the enrollee's care and is paid a monthly fee for doing so, on top of payment for providing medical services" (Robin & Cohen, 2009, para. 2). There is evidence of impressive results; numerous research articles have described the success of NC's PCMH program (Community Care of North Carolina [CCNC], n.d.g; CCNC, 2012a; Fillmore, DuBard, Grant & Jackson, 2013; Jackson, Trygstad, DeWalt, & DuBard, 2013; Steiner, et al., 2008).

Although there is evidence of numerous achievements associated with NC's strategy to build its own infrastructure to support NC's PCMH, how well does NC's PCMH coordinate care for one of the most vulnerable populations of patients: individuals who are dually enrolled in the Medicare and Medicaid programs ("the dual eligibles")? This group is one our nation's most vulnerable and highest-need. While the government-

funded health care of "the dual eligibles" is extremely expensive at $300 billion per year, it is also especially beset by quality problems (Adamy, 2011).

The dual eligibles are less likely than Medicare beneficiaries to report having a usual source of health care and they face a higher chance of needing emergency care and hospitalization (Centers for Medicare and Medicaid [CMS], 2003; McCall, Sauaia, Hamman, Reusch, & Barton, 2004; Miller & Weissert, 2004; O'Leary, Sloss, & Melnick, 2007). After such hospitalizations, certain dual eligibles face a longer average length of stay than their non-dually eligible counterparts (O'Leary et al., 2007). Further evidence shows that compared to Medicare enrollees, the dual eligibles are at greater risk of not receiving certain preventive care, chronic care management services, follow-up, and testing (Komisar, Feder, & Kasper, 2005; Makuc, Freid, & Parsons, 1994; McCall, et al., 2004; Merrell, Colby, & Hogan, 1997). Finally, the dual eligibles experience a higher chance of facing other unmet health care needs, such as assistance with activities of daily living (ADL), ambulatory and long-term care services (Grabowski, 2009; Niefeld & Kasper, 2005).

Health policy researchers find that these problems are directly associated with the inadequate coordination of benefits and services (Agency for Healthcare Research and Quality [AHRQ], 2011). For example, a dually eligible patient receiving care in an ordinary fee for service environment would likely have three identification cards, one for Medicare, one for Medicaid, and one for prescription drugs (Bella, & Palmer, 2009, p. 5). She would likely have three different sets of benefits that correspond to each one of the three cards (Bella & Palmer, 2009, p. 5). Further, she could have many providers who rarely communicate with each other, which increases the risk of uncoordinated health

care decision-making, and neglecting a patient-centered perspective (Bella & Palmer, 2009, p.5).

In response, researchers recommend better integrating the care that the dual eligibles receive (AHRQ, 2011). However, studies about care coordination have utilized quantitative methods, and have focused on providers and health systems representatives (AHRQ, 2011). They have not explored the critical perspective of the patients receiving the care (AHRQ, 2011). To improve the complex processes of care coordination, this dissertation uses a hybrid case study design that incorporates phenomenological techniques in order to better-understand the experience of dual eligibles receiving care through NC's PCMH.

2. Dually Eligible Individuals

About 9.6 million dual eligibles are enrolled in Medicare, the federally-funded health insurance program for beneficiaries age 65 and older and younger enrollees with permanent disabilities, and Medicaid, the mean-tested program for low-income individual eligibles (The Henry J. Kaiser Family Foundation [KFF], 2014). In the former program, the overwhelming majority (89 percent) are age 65 and older (AHRQ, 2011). Of the 11 percent of the Medicare population that is under 65 years old and permanently disabled, about 40 percent are dually eligible for Medicaid (AHRQ, 2011; The Henry J. Kaiser Family Foundation [KFF], 2010b). This group is entitled to Medicare program expansions including the treatment of end-stage renal disease and amyotrophic lateral sclerosis (ALS) (O'Leary et al., 2007).

While Medicare is a federal program, Medicaid is state-managed and jointly funded by both the state and federal governments. On average, the federal government pays about 57 percent of Medicaid costs, and the states pay the rest (Adamy, 2011; CMS, n.d.a; CMS, 2010a). For dual eligibles, Medicaid covers the premiums and cost sharing routinely imposed by the Medicare program (CMS, 2010a). (However, some states require certain Medicaid beneficiaries to pay nominal out of pocket expenses (CMS, n.d.a). The dual eligibles also obtain additional Medicaid benefits, such as dental coverage, based on their income and the Medicaid eligibility standards and coverage provisions of the states in which they reside (CMS, 2010a). Finally, a large proportion of Medicaid funds are dedicated to expensive long term care services for the dual eligibles. In 2007, while only about one in six Medicaid beneficiaries was dually eligible, about 70 percent of Medicaid spending was dedicated to their long-term care, including services provided in nursing home settings (KFF, 2010a).

3. Dual Eligibles' Health Care Needs

The dual eligibles' health care costs are disproportionately high because they tend to be in relatively poor health and have frequent and recurrent health care needs (Grabowski, 2009). Disparate levels of health are often correlated with socio-economic status (SES), and the dual eligibles are much more likely to be poor than other Medicare beneficiaries (Ward, et al., 2004). Only about one in 20 Medicare beneficiaries has an annual income of $10,000 or less, but this is the case for over half of the dual eligibles (Adamy, 2011). This financial status has a direct impact on health. A 2010 Medicare Payment Advisory Commission (MedPAC) report explains that for the dual eligibles,

> …poverty shapes their basic living needs. If they have inadequate housing or cannot afford heat and food, they cannot focus on and manage their health care needs. For example, a lack of adequate heating during the winter can delay recovery from illness… (Medicare Payment Advisory Commission [MedPAC], 2010, pp. 132-133).

Further, the dual eligibles are more culturally diverse than those enrolled in Medicare, and the evidence shows that this can be hazardous to one's health. The IOM's 2003 report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* indicates that even after controlling for factors such as insurance coverage and health status, racial and ethnic minorities are less likely than the population at large to receive routine medical procedures and are more likely to receive lower quality health services. While one of six Medicare beneficiaries represent an ethnic or racial minority, this is true of over one in two dual eligibles (Ryan, & Super, 2003). One in five dual eligibles is African American and just under one in six (15 percent) is Hispanic (Ryan, & Super, 2003).

For many dual eligibles, frequent health care needs are associated with the management of chronic conditions. Three in five dual eligibles have multiple chronic conditions, and they face higher rates of diabetes, cardiovascular and pulmonary disease, stroke and Alzheimer's disease than Medicare beneficiaries (Center for Health Care Strategies [CHCS], 2010a; Jacobson, Neuman, & Damico, 2010). Further, while about one in four Medicare beneficiaries has cognitive or mental impairment, this is true of about one in two dual eligibles (Adamy, 2010). These vulnerabilities lead to high health care usage. While close to one in two dual eligibles require emergency care, this is true for only about one in three Medicare (Adamy, 2010). The dual eligibles face more hospitalizations as well: about one in three need one or more in-patient stays, but this is

true of only about one in five Medicare beneficiaries (Adamy, 2010). The dual eligibles also need more home health care and expensive skilled nursing home services (Adamy, 2010). While about one in ten require the latter type of care, only about one in 20 Medicare beneficiaries need it (Adamy, 2010).

Within the dual-eligible population are dissimilar groups with divergent health care requirements. While two out of three dual eligibles are aged 65 or older, the remaining younger and disabled have unique health-related characteristics. Certain physical and cognitive impairments are more prevalent within the younger group than the aged. Over two-thirds of the disabled have been diagnosed with a mental illness, compared to just one of four of the aged (MedPAC, 2010, pp. 132-133). Further, while almost one in five of the younger group is developmentally disabled, this is true of only 2 percent of the aged (MedPAC, 2010, pp. 132-133). However, certain health issues are more rampant among aged dual eligibles. For example, about one in six aged has dementia, and only 3 percent of the disabled suffer from this problem (MedPAC, 2010, pp. 132-133).

4. Problematic Incentives

The dual eligibles' intense need for chronic disease therapy and nursing home services is responsible for much of the disproportionate cost of caring for this population (Adamy, 2011). However, another cost driver and obstacle to providing high quality care is the inadequate coordination of Medicare and Medicaid benefits and services (Grabowski, 2009). Programmatic payment incentives lead Medicaid and Medicare to attempt to push costs onto the other program instead of providing treatment in a

cooperative manner (MedPAC, 2010). This is apparent in nursing home care, where payment arrangements incentivize re-hospitalization (MedPAC, 2010). For example, Medicare has paid nursing homes about $422 per patient day for the first 100 days of care, but on the 101st day Medicaid has covered the dual eligibles' costs at an average of daily rate of just $172 (MedPAC, 2010, pp. 132-133). Since payments would rise back up to about $422 per day if the patient were readmitted into the nursing home, these incentives encouraged nursing homes to re-hospitalize their patients after 100 days of care (MedPAC, 2010). Researchers have estimated the annual cost to the government of these avoidable hospitalizations at $3 billion per year (MedPAC, 2010, pp. 132-133).

5. Medicare and Medicaid Integration Initiatives

Driven by significant cost and quality concerns, states have pioneered innovative approaches to integrate care for this group for decades (Korb & McCall, 2008). Health policy analysts have long-known that a more integrated delivery system could potentially address the cost and quality concerns associated with treating the dual eligibles (Korb & McCall, 2008). In 1979, one California community launched a non-profit to integrate care for the dual eligibles which would later become the foundation for the Program for All-inclusive Care for the Elderly (PACE). Since the late 1990s, Minnesota, Wisconsin, and Massachusetts have operated integrated Medicare and Medicaid managed care models, but this option required federal demonstration authority through CMS's tedious waiver process (Korb & McCall, 2008). Legislation passed in 2003 enabled states to avoid this by contracting with Special Needs Plans (SNPs), specially-designed Medicare Advantage managed care plans (Korb & McCall, 2008). In 2010, the Patient Protection

and Affordable Care Act (ACA) fostered the development of integrated and innovative care delivery systems; such programs have been implemented in Massachusetts and Washington state (Bella, 2013; "The Patient Protection and Affordable Care Act" [ACA], 2010). Nonetheless, the literature reveals that there are still no "easy answers" for states to coordinate high quality and low cost care for the dual eligibles（CHCS, 2010b). This is perhaps not surprising, given that care coordination is still an "emerging field" according to the federal Agency for Healthcare Quality and Research (AHRQ), making it difficult to design and implement effective care coordination programs (AHRQ, 2011, p.3). What is currently known about care coordination is almost completely informed by research that lacks the beneficiary perspective. This absence is also found in the literature about the provision of integrated care for the dual eligibles.

6. Purpose of Research

The researcher selected NC's PCMH as the case because this delivery system has been lauded in the health policy literature as a provider-driven model for reducing costs and improving health care quality (Community Care of North Carolina [CCNC], 2012a; CCNC, n.d.g.; Fillmore et al., 2013; Jackson, Trygstad, DeWalt, & DuBard, 2013; Steiner, et al., 2008). Although NC's PCMH does not integrate acute and long term care services, it represents an improvement over a straight FFS payment model, and an incremental step toward integration.

Central to NC's PCMH program is the patient's on-going relationship with a primary care provider (PCP) who leads a team that is accountable for patient care. The PCP is "responsible for coordination of services" and for addressing all the patient's

health care needs by either providing direct services or "appropriately arranging care with other qualified professionals" (Health Resources and Services Administration [HRSA], n.d.b, Principle 3; Reid, 2009). Through NC's PCMH, care is to be coordinated across elements of the health system and the patient's community, and it is improved through the engagement of participating practices in state-wide quality improvement (QI) initiatives (HRSA, n.d.b).

Relative to other care integration strategies for the dual eligibles, NC's PCMH seems a relatively inexpensive approach, especially compared to other options like PACE which has significant upfront and maintenance costs. It is important to study such a system in the face of rising health care costs; in the event that it represents a feasible policy option for other states that do not rely on private managed care companies to serve their dual eligible patients. Thus, this research strives to develop an in-depth understanding of how well NC's PCMH coordinates the care of dual eligibles by studying the experience of the patients themselves.

The use of a qualitative hybrid case study design is an appropriate way to study the complex and multi-faceted character of care coordination, which AHRQ has defined as:

> ...the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care (AHRQ, 2011).

As noted above, what little is known about care coordination has largely been informed by quantitative analyses (AHRQ, 2011). That approach is somewhat limited because, as Meyers (2000) explains, "reality is conceptualized as two-dimensional and explained by

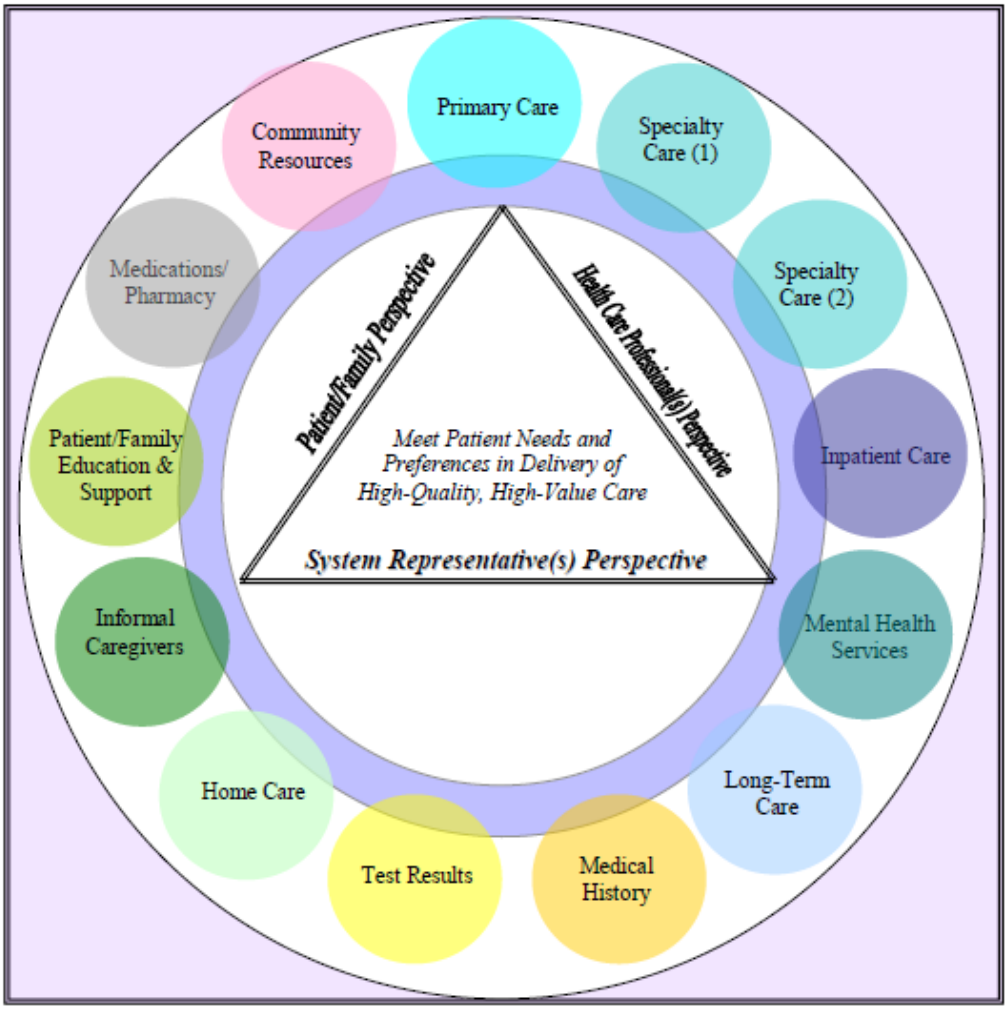
cause-and-effect relationships（Myers, 2000). Thus, greater access to qualitative data regarding the experience of care coordination is needed to gain "a more holistic account, and capture the complex problem under study. This work involves reporting on multiple perspectives, identifying the many factors involved in a situation, and generally sketching the larger picture that emerges" (Creswell, 2009, p. 176).

7. Conceptual Framework

A literature review revealed a number of theoretical models related to care coordination including Donabedian's Quality Framework, Wagner's Chronic Care Model and others. However, two models published by AHRQ were selected because they focus solely on care coordination.

Found in Figure 1, the first model is AHRQ's Care Coordination Ring, which connects all those who participate, (directly or indirectly) in patient care, and the tools they need in order to function effectively (AHRQ, 2011, p.7). This patient-centered framework represents care coordination as a band (or ring) that unites all possible participants, health settings and information involved.

Figure 1: AHRQ's Care Coordination Ring (AHRQ, 2011, p.7)

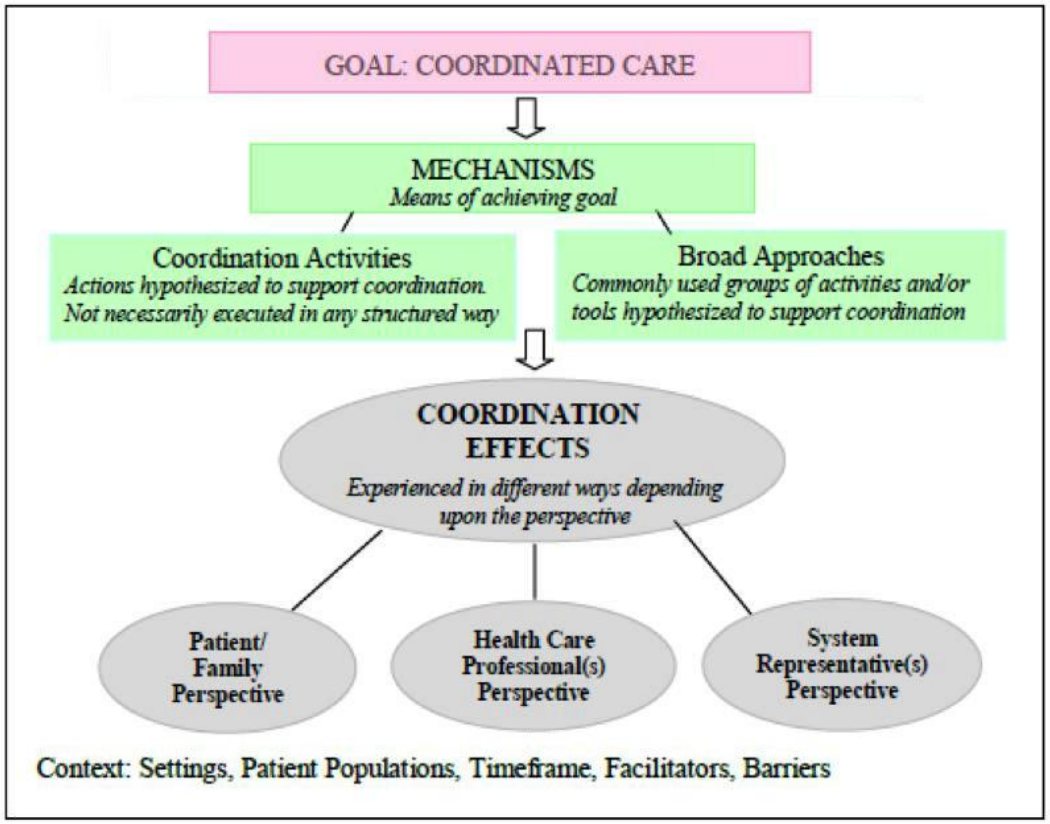


Found at Figure 2, the second model is the Care Coordination Mechanisms Framework, which represents the process by which care coordination is implemented (AHRQ, 2011, p.11).[1] The framework includes the goal of achieving effective

[1] For purposes of this research, the Care Coordination Mechanisms Framework was modified in three ways: 1) The name was changed from the "Care Coordination Measurement Framework" to the "Care Coordination Mechanisms Framework" in order to emphasize the two mechanisms that AHRQ hypothesizes are means to achieve effective care coordination, and to de-emphasize measurement, which is outside the scope of this research. 2) The original model says "See chapter 2" which refers to text in the AHRQ's Care Coordination Atlas but does not make sense for this research; thus, this language was removed. 3) The bottom of the original model referred to "coordination measures" Since measures are outside the scope of this research, this text was removed from the model.

coordinated care, and indicates that two mechanisms are the means of achieving the goal; *Coordination Activities* and *Broad Approaches*.

Figure 2: AHRQ's Care Coordination Mechanisms Framework (AHRQ, 2011, p.11)



For the purposes of this research, AHRQ's two conceptual frameworks were compared to the "real world" experiences of providing care coordination services for dual eligibles enrolled in NC's PCMH. This effort was designed to ascertain whether and how AHRQ's conceptual models "fit" these perspectives, or if it needs modification to accurately address the needs and concerns of the dual eligibles.

8. Conclusion

While health policy analysts and government leaders may focus on the high financial demands on taxpayers that are associated with caring for the dual eligibles, the care experience of these vulnerable and high-need individuals is little understood. Many could be considered at risk of poor health and health care disparities given their race/ethnicity and SES, and many dual eligibles have multiple chronic conditions that exacerbate their health care needs. Further, younger dual eligibles with permanent disabilities have a higher prevalence of certain physical and cognitive impairments than the aged dual eligibles.

Care coordination is an "emerging field" that may help improve care for the dual eligibles and reduce its costs (AHRQ, 2011, p.3). North Carolina's PCMH program represents an incremental step in the pursuit of enhancing care for the dual eligibles, and could perhaps represent a good policy option for states where a more fully integrated option is not otherwise possible (CHCS, 2010b). This approach is not only promising from the state perspective; enrollees are also expected to benefit from better care coordination in the NC's PCMH than in a straight FFS environment (CHCS, 2010b, p.4).

There is a need for a deeper understanding of the way NC's PCMH coordinates care for its dual eligibles because this approach has been studied only on a limited basis, and not from the perspective of the patients themselves. This hybrid case study research is an appropriate method to study their perceptions of how this complex and multi-faceted intervention is provided through NC's PCMH.

Chapter 2: Literature Review

1. Introduction

This literature review begins with an environmental scan of the U.S. health care system, finding it fraught with systemic fragmentation, poorly designed care delivery processes and inadequate HIT infrastructure. These gaps have led to wide-spread quality problems, as expenditures have grown rapidly and are expected to continue expanding (National Research Council, 2001). One group that is especially vulnerable to these quality of care problems is the dual eligibles, individuals who are dually enrolled in the Medicare and Medicaid programs. The cost of treatment for this group is disproportionally high, leading some health policy analysts to conclude that coordinating their care is of utmost importance (Center for Health Care Strategies [CHCS], 2010a). This is no easy task, considering the problematic incentives associated with the independent administration, supervision, and funding of the Medicare and Medicaid programs (Bella, & Palmer, 2009).

Nonetheless, for decades some pioneering states have been integrating the dual eligibles' care using different innovative approaches (Korb & McCall, 2008). More recently, the Affordable Care Act (ACA) has aimed to change health care delivery by encouraging innovative care provided through the medical home, the accountable care organization and the Financial Alignment Demonstrations (ACA, 2010; Bella, 2013). However, the literature review has revealed that there are no easy answers for states to increase quality and lower cost for dual eligibles' care.

One reason is that care coordination is but an "emerging field" which hampers the design and implementation of effective associated interventions (AHRQ, 2011, p.3;

McDonald et al., 2007). Although this literature review has considered numerous conceptual models related to care coordination activities, the Agency for Healthcare Research and Quality's (AHRQ's) Care Coordination Ring and Care Mechanisms Framework have been selected as the most appropriate foundation for this research because this intervention is their sole focus.

The literature review also indicates that there is a dearth of knowledge about the dual eligibles' own continuity of care experiences, and as the Center for Health Care Strategies suggests, this unique perspective may be of value in informing the development of innovative models of coordinated care (Lind, & Gore, 2010). North Carolina's (NC's) patient centered medical home (PCMH) is one such innovative approach, and the dual eligibles' experience of care coordination in that program has not yet been fully explored.

2. Today's Healthcare System

In 2001, the Institute of Medicine (IOM) published *Crossing the Quality Chasm: A New Health System for the 21st Century*. This report describes pockets of exceptional health care in our country, and extensive evidence of wide-spread and enduring quality of care problems (National Research Council, 2001, p. 3). The IOM notes that for the previous 50 years, our nation had experienced great advances in medical science and technology. The health care delivery system is extremely complex, and it is "characterized by more to know, more to manage, more to watch, and more people involved than at any time in the nation's history" (National Research Council, 2001, p. 25). It is challenging for health care providers to retain the vast array of clinical data now

available to them, and our system has not adequately translated scientific knowledge into real-world settings, and applied innovative technology in a proper and safe manner (National Research Council, 2001, p. 25). This deficit has led to quality problems.

Further, the needs of our nation have changed but our healthcare system has not transformed accordingly. Our aging population faces increases in the incidence and prevalence of chronic ailments like heart disease, diabetes, and asthma, but our health system still focuses on addressing acute, episodic care needs (National Research Council, 2001. pp. 4, 27). This lack of sophistication in chronic condition treatments is an important factor resulting in inconsistent quality of care. For individuals attempting to manage chronic conditions like the dual eligibles, our poorly organized delivery system is especially problematic because three features of this system lead to quality of care problems (National Research Council, 2001, p. 25).

The first is fragmentation between the medical services, health care providers, health care settings, medical equipment, and medications utilized to treat a patient, and the method used to pay for them ("Healthcare Delivery System," n.d.). This leads to medical system navigation challenges for patients. Another result is inadequate communications among providers, so decisions are made using incomplete medical information (National Research Council, 2001, p. 4). Further, there is no accountability among providers, so no single individual takes responsibility for the patient's overall health (Shih, et al., 2008, p. ix). This situation results in medical errors, waste, and duplication (Shih, et al., 2008, p. ix).

The second feature is poorly designed care delivery processes. These obstruct the collection of all relevant patient information which is required for proper diagnosis,

prognosis, and treatment. It is highly challenging to adequately complete these tasks given the complexity of care provided by various clinicians in multiple settings (Shih, et al., 2008, p. ix).

The third feature is inadequate health information technology (HIT) infrastructure. Without universal clinical information tools like the electronic health record (EHR), the U.S. health care system lacks a HIT infrastructure dedicated to quality improvement (Shih, et al., 2008). This represents a barrier to enhancing the quality of health care because HIT has the potential to improve safety, effectiveness, patient-centeredness, timeliness, efficiency and equity in the delivery of health care.

In sum, patients in the U.S. must navigate a highly fragmented delivery system, their clinicians rely upon poorly designed care delivery processes, and the current HIT infrastructure is inadequate. The literature indicates that quality of care and patient outcomes and experience are compromised as a result, and rising health care costs are another unfortunate consequence (Purington, Gauthier, Patel, & Miller, 2011).

3. U.S. Health Care Expenditures

The most recent estimates of private and public sector spending on health care in the U.S. suggest that expenditures reached about $2.7 trillion in 2011, or about 17.9 percent of the nation's Gross Domestic Product (GDP) (Centers for Medicare and Medicaid Services [CMS], 2011). Before addressing possible solutions to the problem of growing health care costs, it is important to understand who paid for them. The Kaiser Family Foundation reported that in 2009, public payers covered 47.4 percent of total health care costs, and the rest was funded by private payers (Kaiser Family Foundation

[KFF], n.d.a). The public programs Medicaid and Medicare financed 16.5 percent and 22.5 percent, respectively, and other government programs subsidized 8.3 percent of total health care expenditures (KFF, n.d.a). On the private side, private health insurance covered 34.1 percent of all health care spending, and consumers were responsible for 14.3 percent in out-of-pocket costs. Finally, other private payers (such as philanthropies or employers providing on-site health services) covered 4.2 percent of all health care spending in 2009 (KFF, n.d.a).

Where were our nation's health care dollars spent? CMS reported that in 2009, almost one-third of the funds (31 percent) went to hospitals. One fifth of the National Health Expenditures (NHEs) reimbursed physicians and clinics for services rendered (CMS, Office of the Actuary, National Health Statistics Group, n.d.). Ten percent of health care spending paid for prescription drugs (CMS, Office of the Actuary, National Health Statistics Group, 2010). Further, CMS predicts that the NHEs will continue to grow (CMS, 2010c). As a result of the ACA, by 2019 nearly 93 percent of the U.S. population will likely have health insurance; by that time Americans will spend nearly one-fifth of the GDP (19.6 percent) on health care (CMS, 2010c).

4. Dually Eligible Individuals

As the U.S. struggles to cover the growing costs of health care and insurance, policy experts focus special attention on one population of individuals which is among the most vulnerable and highest-need, and whose government-funded health care is especially expensive and beset by quality problems. This group is enrolled in both the Medicare and Medicaid programs and is therefore referred to as "dually-eligible."

Medicare is the federally-funded health insurance program for people over 65 years of age and for certain younger individuals with disabilities. In the Medicare-only population, 89 percent are age 65 and older but this is true of only 9 percent of Medicaid enrollees, a much younger population (Adamy, 2011). Medicaid is a mean-tested program for low-income individuals that is managed by the states and is jointly funded by both the state and federal governments. On average, the federal government pays about 57 percent of Medicaid costs, and the states pay the rest (Adamy, 2011).

For dually-eligible individuals, the Medicaid program not only covers Medicare premiums and cost sharing, it also offers additional benefits, (such as dental coverage), based on income and the Medicaid eligibility standards and coverage provisions of the state of residence (CMS, 2010a). (See Table 1.) Many of the dual eligibles become eligible for Medicaid because they utilize high-cost nursing home services and deplete their personal finances (CMS, 2010a).

Further, although the majority of the Medicare population is age 65 or over, 16 percent are under age 65 and permanently disabled (KFF, 2010b). Of these younger Medicare beneficiaries, about 40 percent are dually eligible for Medicaid benefits (KFF, 2010b). This younger and disabled subpopulation of Medicare beneficiaries became entitled to Medicare through a 1972 amendment to the Social Security Act (O'Leary, Sloss, & Melnick, 2007). This law also expanded Medicare to include those with end-stage renal disease (ESRD), and in 2001, Medicare eligibility was further enhanced to cover people with amyotrophic lateral sclerosis (ALS) (OLeary et al., 2007).

Table 1: Medicare and Medicaid Benefits Available to Dual Eligibles (National Health Policy Forum, 2003)

Medicare		Medicaid		
		Acute Care Services	Long-Term Care	Wrap-Around Services
Inpatient hospital Skilled nursing facility care Home health Physician services	+	Outpatient prescription drugs* Transportation Dental care* Vision & hearing* Medicare cost-sharing	Custodial nursing facility care Home- & community-based services* Personal care services*	Inpatient hospital Skilled nursing facility care Home health**

Key: *Benefits are provided at state option. **Home health services are mandatory for individuals who are entitled to nursing home care; the services are otherwise optional.

5. Dual Eligibles' Health Care Needs

The dual eligibles' costs are especially high because they tend to be in relatively poor health and have frequent and recurrent health care needs (Grabowski, 2009). While 22 percent of Medicare beneficiaries are in fair or poor health, this characterizes the health of 50 percent of the dual eligibles (Adamy, 2011). Moreover, a high proportion of dual eligibles are disabled but not elderly: in 2006 while only ten percent of Medicare beneficiaries were disabled but not elderly, this was true of about one third (33 percent) of the dual eligibles (Center for Health Care Strategies [CHCS], 2010a). The characteristics of this population of "young dual eligibles" will be discussed in greater detail below.

Furthermore, disparate levels of health are often correlated with socio-economic status (SES), and the dual eligibles are more likely to be poor than other Medicare beneficiaries (Adler, & Newman, 2002). Only six percent of Medicare beneficiaries have an annual income of $10,000 or less, but this is true of over half (55 percent) of the dual

eligibles (Adamy, 2011). A recent Medicare Payment Advisory Committee (MedPAC) report makes an obvious but important statement:

> "[The dual eligibles'] poverty shapes their basic living needs. If they have inadequate housing or cannot afford heat and food, they cannot focus on and manage their health care needs. For example, the lack of adequate heating can delay recovery from illness" (Medicare Payment Advisory Committee, 2010, pp. 132-133).

In addition to these financial challenges, the dual eligibles also tend to be less educated than the Medicare population at large. In 2006, about one in five Medicare enrollees (21 percent) had not received a high school diploma, but this was true for over half (55 percent) of the dual eligibles (CHCS, 2010a).

Moreover, in comparison to other Medicare beneficiaries, the dual eligibles are known to be more culturally diverse, with over 40 percent representing minority populations. While 84 percent of Medicare-only beneficiaries are white, just over half (58 percent) of the dual eligibles are white (National Health Policy Forum, 2003, p.3). Whereas seven percent of Medicare-only beneficiaries are African American, this is true of 20 percent of the dual eligibles (National Health Policy Forum, 2003, p.3). Although six percent of the former group is Hispanic, this group comprises 15 percent of the dual eligibles (National Health Policy Forum, 2003, p.3). As the groundbreaking IOM report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* suggests, being a racial or ethnic minority in American can be hazardous to one's health; these groups are less likely to receive routine medical procedures and more likely to receive lower quality health services (National Research Council, 2002). Thus, a large proportion of the dual eligibles could be considered "at risk," given their race/ethnicity and SES.

Table 2: Comparison of Medicare Beneficiaries by Dual Eligibility Status, 2000 (The Commonwealth Fund, 2007)

Characteristics	Dual Eligibles	Non Dual Eligibles
Total beneficiaries	$6.313 mil.	$34.315 mil.
Income less than $10,000	80.46%	14.55%
Age 85 or older	15.12%	10.69%
Under age 65 but disabled	35.78%	9.47%
Non-white (Hispanic, Black, Other)	42.33%	15.92%
Female	63.15%	55.09%
Unmarried	80.40%	42.89%
Institutionalized	21.60%	2.66%
Living alone if in community	31.77%	28.26%
Less than 12 years of education	62.95%	28.90%
Fair/poor self-reported health	55.35%	26.22%
1+IADL or ADL limitation	76.59%	44.06%
Upper extremity limitation	61.39%	40.76%
Mobility limitation	71.14%	46.81%
Urinary incontinence	36.90%	24.68%
Multiple chronic conditions	74.87%	70.46%
Hypertension	55.70%	55.25%
Diabetes	23.91%	16.93%
Arthritis	52.89%	55.97%
Osteoporosis/broken hip	17.09%	16.22%
Pulmonary disease	19.74%	13.86%
Stroke	14.49%	10.94%
Alzheimer's disease	12.09%	3.28%
Parkinson's disease	2.28%	1.32%
Skin Cancer	6.14%	17.14%
Other type of cancer	11.98%	17.63%

Source: 2000 Medicare Current Beneficiary Survey (Centers for Medicare and Medicaid Services, 2000).
Note: IADL= Instrumental activity of daily living; ADL= Activity of daily living.

For many dual eligibles, the frequent need for health care services is associated with the treatment of chronic conditions. The dual eligibles face higher rates of diabetes, cardiovascular and pulmonary disease, stroke, Alzheimer's disease and depression than other Medicare beneficiaries (CHCS, 2010a; KFF, 2010b). Three in five dual eligibles have multiple ailments. While about one in four (24 percent) of Medicare beneficiaries have cognitive or mental impairment, this is true of about one in two (54 percent) of the dual eligibles (Adamy, 2011). Table 2 offers a comparison between the characteristics of

the dual eligibles and other Medicare beneficiaries, highlighting the additional challenges that the dual eligibles are more likely to face.

Given these vulnerabilities, it is no surprise that the dual eligibles use more medical services than other Medicare beneficiaries. For example in the case of certain high-cost interventions, utilization by Medicare patients is significantly lower than that of the dual eligibles (Adamy, 2011). In 2006, while 44 percent of dual eligibles had one or more visits to the emergency room (ER), this was true of just 26 percent of Medicare-only beneficiaries (Adamy, 2011). Although 29 percent of dual eligibles had one or more in-patient stays, this could be said of just 19 percent of the Medicare-only population (Adamy, 2011). While 13 percent of dual eligibles had one or more home-health visits, this was true of just seven percent of Medicare-only beneficiaries (Adamy, 2011). Further, even though ten percent of dual eligibles had one or more skilled nursing home visits, this could be said of just four percent of the Medicare-only population (Adamy, 2011). There are high costs associated with the utilization of these nursing home services; seven out of every ten Medicaid dollars spent on the dual eligibles is dedicated to nursing home services (Adamy, 2011). In an effort to humanize these statistics, Box 1 describes the experience of Mattie, a dually eligible woman.

Box 1:Meet Mattie (Bella, & Palmer, 2009, p.5)

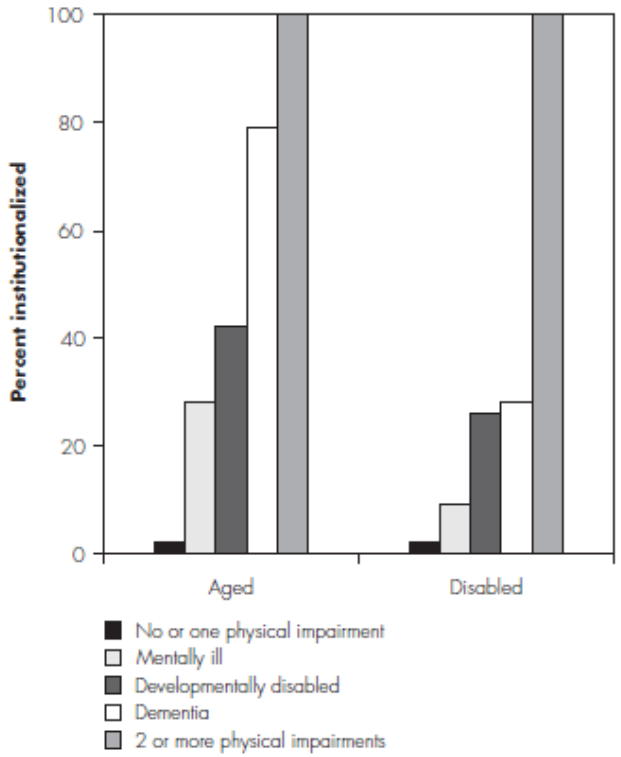
Mattie is a 77-year-old woman eligible for both Medicare and Medicaid. She has longstanding diabetes and hypertension, and has had several strokes, resulting in weakness on her left side. She needs care from many providers: a personal care attendant whose assistance allows her to live alone at home, a licensed social worker who helps address her depression, and a variety of specialists to whom she has trouble getting to because of her mobility problems.

6. Young and Disabled Dual Eligibles

Within the dual-eligible population are dissimilar groups with divergent health care requirements. While some dual eligibles are relatively healthy, others have chronic conditions, and/or physical and/or mental impairments, and a smaller number are institutionalized. While almost 66 percent of dual eligibles are aged 65 or older, this section covers the unique health-related characteristics of the approximately 34 percent who are disabled and under age 65 (Bella, & Palmer, 2009, p.5).

Certain physical and cognitive impairments are more prevalent within the disabled dual eligible population than the aged dual eligibles. Over two-thirds of the disabled (44 percent) have been diagnosed with a mental illness, while just over one-fourth (26 percent) of the aged have been diagnosed in this way (MedPAC, 2010, p. 133). Further, while almost 18 percent of young disabled dual eligibles are developmentally disabled, this is true of only 2 percent of the aged dual eligibles (MedPAC, 2010, p. 133). However, certain health issues are more rampant in the aged population; 16 percent have dementia, and only 3 percent of the disabled dual eligibles suffer from this problem (MedPAC, 2010, p. 133). Finally, for one category of physical impairment both groups are the same; only three percent of the aged and the disabled dual eligibles experience two or more physical impairments (MedPAC, 2010, p. 133).

Figure 3: MedPAC's Rate of Institutionalization Varies By Group of Dual-Eligible Beneficiaries (MedPAC, 2010, p. 134)



A 2010 MedPAC analysis reports that factors associated with institutionalization vary as well. Of the dual eligibles who are institutionalized, all of the aged and 100 percent of the disabled have two or more physical impairments (see Figure 3). However, more of the institutionalized aged tend to be developmentally disabled, suffer from dementia, or are diagnosed as mentally ill than the institutionalized disabled (MedPAC, 2010, p. 134). Within this institutionalized population, the aged and disabled are similar only with regard to the fraction of beneficiaries with no or one physical impairment, which is very small in both cases (MedPAC, 2010, p. 134).

There are also significant differences with regard to the frequency of chronic conditions between the disabled and aged; the latter group is more likely to be plagued by them than the former. As Table 3 indicates, for example, ischemic heart disease is a much greater problem within the aged population (with 43 percent affected) than the disabled (17 percent) (MedPAC, 2010, p. 134). However, depression tends to be a greater problem for the disabled; within this group, almost one in three (28 percent) receive this diagnosis. This is the case for fewer than one in five (18 percent) of the aged (MedPAC, 2010, p. 134).[2]

Table 3: Five Most Frequent Conditions Among the Aged and the Under 65 and Disabled Dual-eligible Beneficiaries (MedPAC, 2010, p. 134)

Chronic Condition	Aged	Under 65 & Disabled
Alzheimer's and related conditions	30%	5%
Chronic obstructive pulmonary disease	18%	10%
Depression	18%	28%
Diabetes	36%	23%
Heart Failure	33%	11%
Ischemic heart disease	43%	17%
Rheumatoid arthritis/osteoarthritis	31%	13%

This section has described many of the physical and cognitive impairments that aged and young disabled dual eligibles face. In an attempt to shed light on the way some of these statistics play out in the life of an individual younger person with disabilities, Box 2 describes the experience of dually-eligible Patricia.

[2] MedPAC indicates that it is likely that the disabled population may suffer from additional conditions that are not included in the relevant database, the Chronic Conditions Warehouse (MedPAC, 2010, p. 134). These omitted diagnoses include schizophrenia, other psychosis, serious neurosis, substance abuse, and other mental illnesses; the result is an understated prevalence of mental illness among the dual eligibles in MedPAC's report (MedPAC, 2010, p. 134).

Box 2: Meet Patricia

"Patricia" is a 44- year-old woman with cerebral palsy, a severe speech impediment, spastic quadriplegia, moderate mental retardation, a complex seizure disorder, and depression. She lives in a group home in the Boston area… Before [receiving enhanced care], Patricia had no consistent primary care and received care through multiple uncoordinated specialty clinics at a Boston teaching hospital. Her group home staff had no option but the emergency room for all clinical issues, minor or serious. As a result, she was hospitalized multiple times for seizures, aspiration pneumonia, and urinary tract infections. There was little attention paid to her psychosocial issues…(Community Catalyst, 2008)

7. Cost of Treating the Dual Eligibles

Not surprisingly, the average level of spending per dual beneficiary varies, depending on subgroup. For the average dually-eligible beneficiary, Medicare and Medicaid spent $26,185 in 2005 (MedPAC, 2010, p. 135). For the aged dual eligibles, per capita spending was three percent higher than average ($26,841), and for under 65 and disabled dual eligibles, this percentage was five percent less than average ($24,924) (MedPAC, 2010, p. 135).

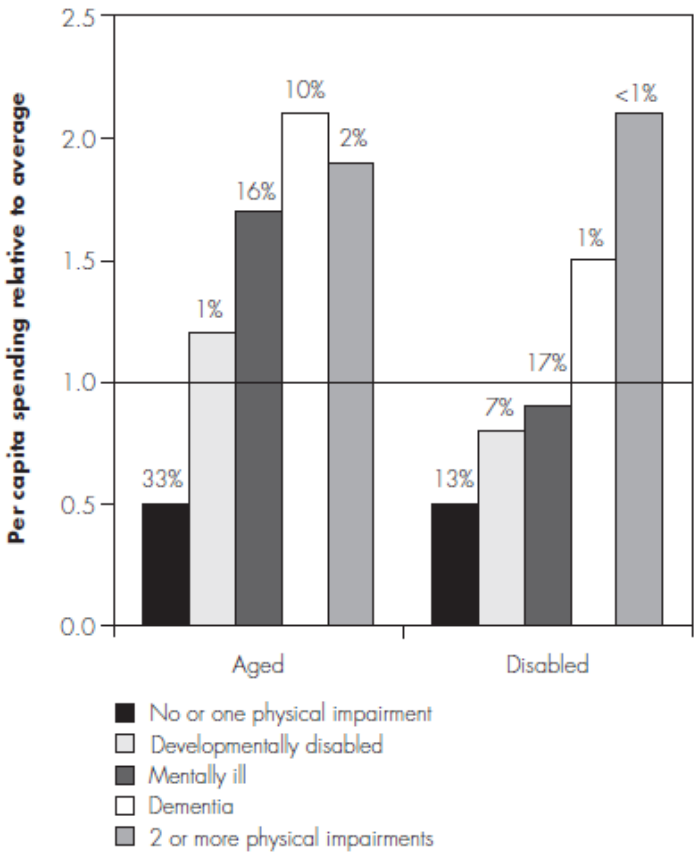
Table 4: Per Capita Spending for Under 65 and Disabled Dual eligibles Versus Aged, Controlling For Nursing Home Use, 2005 (MedPAC, 2010, p. 137)

	Total	Nursing home spending	Top nursing home spending
All dual eligibles	$26,185	$19,171	$75,469
Aged	$26,841	$16,916	$74,439
Under 65 & disabled	$24,924	$22,530	$84,339

These statistics are shown in Table 4, where the "Total" column shows the level of per capita spending for all dual eligibles, and for the two separate subpopulations (MedPAC, 2010, p. 135). The reason the aged have higher than average costs is because spending is strongly related to nursing home use, and the likelihood of nursing home use

is much greater among the aged than in the under-65 and disabled population. The cost differences by age reverse once one controls for nursing home use. For instance, among beneficiaries with no nursing home use, spending by the aged was $16,916 versus $22,530 for the under-65 and disabled, reflecting the health care costs of disability in that group. Among beneficiaries in the top quintile of nursing home spending, spending by the aged was $74,439 versus $84,339 for the under-65 and disabled (MedPAC, 2010, p. 135).

Figure 4: Per Capita Spending by Cognitive and Physical Impairment Group (MedPAC, 2010, p. 138)



MedPAC's analysis also covers the combination of services utilized by both groups of duals. As Figure 5 shows, for those aged and disabled who have been diagnosed as mentally ill or having two or more physical impairments, spending for both groups is only about half the Medicare per capita average (MedPAC, 2010, p. 138). However, spending levels on the two groups are quite dissimilar in other cases, such as dementia, where spending on the aged dual eligibles is over two times the Medicare per capita average, and for the disabled dual eligibles, about 1.5 times the per capita average (MedPAC, 2010, p. 138).

In conclusion, at 9.6 million people, the dual eligibles represent a relatively small group (KFF, 2014). Yet, taking responsibility for the costs of their care is risky because the level of health care funds required is disproportionally high (Adamy, 2011). In 2008, the dual eligibles represented about one in five Medicare enrollees (20 percent) and 15 percent of the Medicaid population (Jacobson, Neuman, & Damico, 2012). However, the share of Medicare funds spent on them was 31 percent, and this was true for 39 percent of Medicaid spending (Jacobsone, et al., 2012).

These percentages translate into expenditures of "about $300 billion of the roughly $900 billion spent annually on Medicare and Medicaid" (Adamy, 2011). Further, as the post World War II baby boom generation ages, spending is expected to grow larger over time as the health care needs of this population grow (Adamy, 2011).

8. Problematic Incentives

The dual eligibles' intense need for chronic disease therapy and nursing home services is responsible for much of the disproportionate cost of caring for this population (Adamy, 2011). However, another important cost driver and obstacle to providing efficiently-delivered high quality care for the dual eligibles is the inadequate coordination of Medicare and Medicaid benefits and services (Grabowski, 2009).

Responsibilities for program administration, supervision, and funding are split between the federal and state governments. Indeed, there are incentives associated with the payment methodologies of both programs which lead Medicaid and Medicare to attempt to push costs onto the other program instead of providing treatment in a cooperative manner (MedPAC, 2010, ch. 5). This is especially apparent when considering care provided in nursing homes, whose administrators are motivated to re-admit patients to the hospital due to payment arrangements (MedPAC, 2010, ch. 5).

This phenomenon is described in a 2001 report published by MedPAC. Medicare pays a nursing home about $422 per day for 100 days when an enrollee moves there from a hospital setting (MedPAC, 2010, ch. 5). However, on the 101st day, if the patient is dually-eligible, Medicaid reimburses the nursing home for services, at an average of daily rate of just $172 (MedPAC, 2010, ch. 5). This situation encourages the nursing home to transfer the patient back to the hospital, especially since the payment level will rise again to an average of $422 per day if the patient is readmitted into the nursing home (MedPAC, 2010, ch. 5).

Walsh et al. (2010) have suggested that this incentive leads to hundreds of thousands of preventable hospital readmissions each year (CMS, 2010a). The authors

show that in 2005 there were 382,846 hospital admissions that may have been prevented. This number represents 40 percent of all 958,837 Medicare hospital admissions of that year (CMS, 2010a). According to Walsh et al. (2010), $3.1 billion was the price tag of these avoidable hospitalizations, and the government, (most often the federal government), paid it (CMS, 2010a).

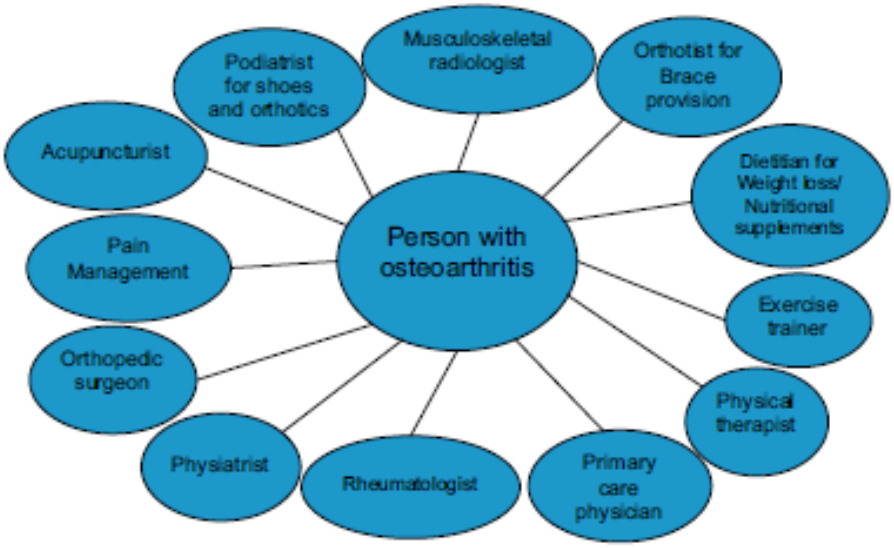
9. Quality of Care

Given the scenario described above, it is not difficult to understand how the incentives associated with the dual eligibles' care could result in serious quality of care deficiencies. Consider Gruber and Hunter's (2010) diagram at Figure 5, which illustrates the diverse array of providers required to deliver care for an individual with just one complex health condition, osteoarthritis. The beneficiary must discern which of the 12 providers is needed for each aspect of disease management, retain all the necessary contact information, and ensure that all the providers are apprised of her health status and osteoarthritis management strategy.

Now consider adding other complicated diseases *and* another health care delivery system. Dual eligible beneficiaries must navigate their own health care course across their providers, and across both the Medicare and Medicaid programs, which have different benefits and enrollment rules. Since governing the programs are separate "delivery, financing, and administrative policies and procedures," the results are the "misaligned benefit structures and opportunities for cost-shifting" discussed above (CHCS, 2010a). This has a direct impact on the quality of care that dually-eligible patients receive. Since a very small proportion of the dual eligibles receive care that is

especially tailored to meet their needs, some researchers have argued that nearly all of them receive fragmented and poorly coordinated care (CHCS, 2010a).

Figure 5: Array of Providers Participating in Osteoarthritis Management (Gruber & Hunter, 2010)



Early research indicating that the dual eligibles get poor quality care was published over a decade ago, when, in 1994, the Centers for Disease Control and Prevention (CDC) reported the rates of cancer screenings provided to women covered by different types of insurance (Makuc, Freid, & Parsons, 1994, p. 5). The evidence indicated that for women with Medicare and private insurance coverage, 43.9 percent received a mammography within the previous year; this was true of only 24.7 percent of dually eligible women (Makuc et al., 1994, p.5).

A similar phenomenon was observed in the case of the clinical breast exam (CBE); 54.7 percent of the former group received a CBE, compared to only 35.1 percent of the latter (Makuc et al., 1994, p.5). The difference between the two groups was found

to be somewhat smaller in the case of the Papanicolaou (Pap) test; 33.8 percent women with Medicare and private insurance got a Pap smear, while this was the case for 28.5 dually eligible women (Makuc et al., 1994, p.5). Although dually eligible patients consistently fared worse than women covered by Medicare and private insurance, they routinely fared better than women with Medicare coverage alone who had an even lower rate of receiving these cancer screenings (Makuc et al., 1994, p.5) .

Three years later, Merrell, Colby and Hogan (1997) showed that compared to Medicare enrollees, the dual eligibles were at greater risk of not receiving certain preventive care, follow-up therapy, or testing (Merrell, Colby, & Hogan, 1997). Their research showed that dual eligibles were more likely to require three or more ER visits for cardiovascular problems and faced a greater chance of needing hospitalization for congestive heart failure than their counterparts with Medicare (Merrell et al., 1997). Even with a history of breast cancer, dual eligibles were less likely to get a mammogram once a year, and without such a history, they were less likely than Medicare patients to get the test every two years (Merrell et al., 1997). After a diagnosis of breast cancer, dual eligibles remained less likely to get a mammogram, but they had a greater chance of getting a chest x-ray than Medicare enrollees (Merrell et al., 1997).

Biannual diabetes testing (glycosylated hemoglobin, or "HbA1c") was also less likely for dual eligibles and the same was true for the annual eye exam that is clinically appropriate with a diagnosis of diabetes (Merrell et al., 1997). Furthermore, Merrell, Colby and Hogan (1997) reported that in the event of hospitalization for gastrointestinal bleeding, dual eligibles were less likely to visit the doctor or have their hematocrit tested four weeks after discharge than Medicare beneficiaries (Merrell et al., 1997). Finally,

compared to Medicare patients, dual eligibles had less chance of having their gallstones surgically removed, and getting their eyes checked every two years (Merrell et al., 1997).

A thorough literature review indicated that the next article regarding the quality of care provided to dual eligible beneficiaries was not published until six years later, in 2003, when CMS indicated that dual eligibles are less likely than Medicare beneficiaries with other supplemental coverage to report having a usual source of care (Miller & Weissert, 2004). About 12 months after that, a quality of care study by McCall, et al. (2004) was published. This research contrasts the quality of diabetes care provided to dually eligible patients to that of comparable patients who are not eligible for both programs (McCall, Sauaia, Hamman, Reusch, & Barton, 2004). The study shows that a dual status is independently associated with not receiving diabetes care.

Moreover, this research showed that the chances of not receiving diabetes care are greater for beneficiaries living in urban areas, for enrollees of a minority race/ethnicity and for dual eligibles who utilize emergency department (ED) services. Further, although dually eligible patients have a greater chance of having more primary care visits, they also face an increased likelihood that they will require more trips to the ED, and will need more hospitalizations than their non-dually eligible counterparts (McCall et al., 2004). Finally, the dual eligibles have a lower chance of receiving certain tests and exams, (annual HbA1c and biennial lipid, and biennial ophthalmologic), and visiting endocrinologists. The latter factor is actually found to be associated with an *increased* likelihood of getting diabetes treatment.

A quality of care study was then published in 2005. In this article, Komisar, Feder and Kasper (2005) confirm findings from about 10 years earlier, indicating that

only about 25 percent of dually eligible women obtain a mammogram every two years. However, this is true of 40 percent of Medicare enrollees (Komisar et al., 2005). Furthermore, these authors find that 58 percent of elderly dual eligibles who live in the community and require assistance with activities of daily living (ADL) experience unaddressed needs (Grabowski, 2009).

During the same year, Niefeld and Kasper (2005) published an article regarding beneficiaries' access to care, finding that while 59 percent of elderly dual enrollees required ambulatory or long-term care service in a 12-month period, about 33 percent of them faced obstacles to accessing the services they need. Of particular relevance to this research is evidence that organizational and geographic barriers are more common than financial ones (Niefeld & Kasper, 2005). The factors associated with the organizational and geographical barriers include being of African American race, facing difficulties in paying essential living expenses, and having only poor or fair health (Niefeld & Kasper, 2005).

It took two more years for another related study to be published. O'Leary, Sloss and Melnick (2007) describe the quality of care provided to the dually-eligible young (less than 65 years old) and disabled population in California. They found that this group faced a greater likelihood of being hospitalized, and after hospitalization, had a longer average length of stay than their non-dually eligible counterparts (O'Leary et al., 2007). Furthermore, even when stratified by race, sex, age and system of care, the number of inpatient days continued to be greater among the dual eligibles (O'Leary et al., 2007). Finally, the rate of hospitalization varied by condition, but is higher for most diagnoses of

disabled dually eligible beneficiaries than for their counterparts with the same condition(s) (O'Leary et al., 2007).

There are two publications that provide some insights into the reasons why no additional literature regarding the quality of care provided to dual eligibles has been published. First, it may be extremely difficult for researchers to obtain the data required to conduct such studies. State Medicaid agencies face numerous problems while trying to develop tools that address the needs of the dual eligibles because it is very difficult to obtain the required Medicare data (Barnette, 2010).

States must go through a special process in order to access Medicare data from the Research Data Assistance Center (a CMS contractor); they must contract with CMS through a Coordination of Benefits Agreement to utilize Medicare claims data, and then they must learn how to link Medicare and Medicaid data (Barnette, 2010). Although this process has been made easier by the CMS' Federal Coordinated Health Care Office (the Medicare-Medicaid Coordination Office), researchers interested in studying the quality of the dual eligibles' care still face hurdles in accessing the data, a challenge when developing a feasible research design (CMS, n.d.b).

Further study by Lipson, et al. (2009) provides a second insight regarding why more dual eligibles' quality of care research has not been conducted (U.S. Dept. of Health and Human Services, Asst. Secretary for Planning and Evaluation, 2009). The problem may be tied to the incomplete development of quality measures. The authors write that although numerous measures have been have been endorsed by the National Quality Forum (NQF) and other bodies, many measures that are currently in use have not be endorsed or tested (U.S. Dept. of Health and Human Services, Asst. Secretary for

Planning and Evaluation, 2009). These may have been developed by states and private health plans, which craft their own measures for purposes of public reporting, quality enhancement initiatives, pay for performance programs, or other projects (U.S. Dept. of Health and Human Services, Asst. Secretary for Planning and Evaluation, 2009). An absence of a nation-wide uniform set of quality measures could act as a significant barrier to designing studies to assess the dual eligibles' quality of care. In response to these measurement issues and broader concerns about the quality of dual eligibles' care, the ACA includes strategies that seek to integrate care.

10. Integration Initiatives in the ACA

It seems that many ACA provisions that strive to improve quality through care integration for all populations (not just the dually eligible) were inspired by literature published in the mid 1990s, especially that of Shortell, Gillies and Anderson (1994). These researchers postulated that an integrated delivery system (IDS) aligned along two different planes, horizontal and vertical, was the most cost-effective way to provide high quality care for all patients (Shortell, et al, 1994). Conrad and Shortell (1996) expanded upon these concepts, explaining that that horizontal integration included a collection or network of similar organizations, like hospitals or nursing homes (Conrad & Shortell, 1996). In contrast, vertical (or virtual) integration referred to the relationships forged between providers at different levels of care Conrad and Shortell (1996).

Interestingly, by the time Conrad and Shortell's article was published in 1996, research about how IDS' actually performed was emerging and indicated that although IDS' were more financially successful than their competitors, integrated hospital systems

did not provide "added value" or create a true continuum of care (Idriss, 2003, p. 11). Further, noticeably absent from the model is the patient as an autonomous partner in health care decision-making. Indeed, Singer et al. (2011) argue that "integrated organizational structures and processes may fail to produce integrated patient care" (Singer, et al, 2011, p.112). The researchers argue for the utilization of measures based upon truly integrated patient care (Singer, et al, 2011).

The IOM also emphasizes more human aspects as critical to dramatically improving the health care system in *Crossing the Quality Chasm* which outlines six "redesign imperatives" required to provide higher quality care at a lower price (National Research Council, 2001, p.2). These include: 1) utilization of redesigned care processes, 2) effective information technology (IT) use, 3) clinical data and skills management, 4) teamwork, 5) care coordination, and 6) integration of performance and outcome measurement (National Research Council, 2001, p.2). Perhaps in response to these IOM recommendations, the ACA includes provisions to promote the delivery of more integrated care, through the medical home model and the accountable care organization (ACO). These are described in turn below and include discussions of whether, and how the dual eligibles would be served through each model.

10a) Medical Home Model

The ACA develops a new Medicaid option with a high federal matching rate (90 percent) to care for individuals with multiple chronic conditions. Considering that chronic conditions are a major health problem for the dual eligibles, these provisions may also help to improve their care. Pursuant to Section 2703 of the ACA, the beneficiary selects a "health home" which includes a designated provider or health team to provide

services that are high-quality, wide-ranging and inclusive. The ACA's "health home" is very similar to what is defined in the literature as a "medical home." The medical home is a philosophy with principals that support a primary care practice and bolster the efforts of a team of providers who deliver all-inclusive and synchronized care (Shih, et al., 2008, p. 22).

Payments to medical homes could be provided in a FFS environment, with additional fees assessed per-patient (Shih, et al., 2008). An alternative approach calls for all services provided through medical homes to be pre-paid (Shih, et al., 2008). Authors Shih et al. (2008) explain that such payment mechanisms incentivize care that is more patient-accessible, more coordinated and that utilizes all appropriate clinical information.

Further, Shih et al. (2008) argue that the potential result of these primary care enhancements is higher quality, lower cost care. The Geisinger Health System's "Advanced Medical Home program" assigns patients at "high risk for disease complications" to a particular physician practice that is accountable for all medical decisions (Shih, et al., 2008, p. 5). A nurse case manager embedded within that practice works with its physicians to create individualized patient plans of care that follow clinical guidelines and assure the provision of needed patient outreach and follow-up services (Shih, et al., 2008). For diabetes patient care, Geisinger achieves a savings of about $100 per member per month (PMPM) which is associated with reduced avoidable hospital use (Shih, et al., 2008). Further, some argue that the medical home may be an appropriate model for not only relatively healthy patients; the Kaiser Family Foundation notes that the "medical home could be a first step toward more integrated care for dual eligibles, a key goal of the ACA" (KFF, 2011).

However, other authors report that this strategy does not meet the complex and costly needs of the dual eligibles. Shortell and Casalino (2007) note that the medical home model may not bridge transitions between care settings because the model lacks sufficient incentives to encourage all providers to engage in care coordination. Further, Shih et al. (2008) argue that practice-level payments associated with the medical home do not help bolster the critical relationships among providers in the larger delivery system (Shih, et al., 2008). Finally, the medical home model does not address the outlays that are associated with a "duplicative and expensive medical infrastructure" (Shortell, & Casalino, (2007), p. 18).

10b) Accountable Care Organizations

As an alternative to the medical home model, Shortell and Casalino (2007) resurrect some themes discussed a decade earlier. They argue that the new ACO model that is embraced in the ACA utilizes cost and quality incentives that could serve to integrate clinicians across all care settings, minimizing fragmentation (Shortell & Casalino, 2007). Since these are some of the very problems experienced by the dual eligibles, ACOs are worth further consideration.

The authors state that an ACO must have an accountable care system (ACS) that utilizes organized processes to enhance care quality, reduce costs and achieve accountability (Shortell & Casalino, 2007). An ACS must have seven capabilities to improve quality and lower costs; six of these were outlined in *Crossing the Quality Chasm*. Shortell and Casalino (2008) added a seventh, adapting to change, because health care leaders and organizations must constantly shift with the changing health care landscape.

However, Shortell and Casalino (2007) argue that it is not enough for an ACO to simply employ an ACS with these seven capabilities, it must also include three additional features. First, an ACO must implement payment reform through a shared savings model (SSM) whereby savings that are realized are shared among contracted entities. While the ACO must rely upon global, prospective budgeting, it need not include full capitation (The Commonwealth Fund, 2011). Global budgeting identifies a target population and delivers services within a recognized system of care (The Commonwealth Fund, 2011). This system offers care within a continuum of settings, from robust primary care practices, to hospitals and specialists (The Commonwealth Fund, 2011).

Secondly, an ACO must utilize performance measures based on prompt and accurate data to assure quality and cost accountability that is based on value, not cost containment (Shortell & Casalino, 2007, p. 3). Thirdly, an ACO must modify its delivery system when necessary, using prearranged procedures designed to enhance quality, scrutinize utilization and minimize costs (Shortell & Casalino, 2007, p. 2).

Although there are many potential advantages associated with the ACO, there are drawbacks as well. Thus, it is appropriate to consider how the dual eligibles would fare in ACOs. Evidence by Shortell and Casalino (2007) suggests certain ACOs, (like Kaiser Permanente) have advantages in preventive care and long term treatment but patients may face difficulties negotiate its large bureaucracy, a potential obstacle for the dual eligibles. Further, the evidence suggests that ACOs are not easily scalable so it is unlikely that they would become widely-accessible to the dual eligibles (Goldsmith, 2009).

Even if ACOs were widespread, Rosenbaum (2011) argues that they could effectively bar enrollment of the dual eligibles because ACOs have wide discretion over

which providers may be invited to join. ACOs can cherry-pick the physicians with the healthiest group of patients, without consequence because CMS lacks monitoring plans to assess "whether health professionals and clinics that disproportionately treat more at-risk patients are under-represented in an ACO's network" (Rosenbaum, 2011, p. 6). Finally, the ACO model favors physicians over the clinics and nurse-led practices settings that disproportionally serve disadvantaged populations like the dual eligibles. Thus, the ACO may not be a viable option to serve many dual eligibles.

11. Integrated Care Policy Options for the Dual Eligibles

Given the significant quality of care concerns associated with services provided to the dual eligibles and the high costs of their treatment, states have been concerned about the delivery of services for this group for many years (Korb, & McCall, 2008). Health policy analysts argued that a more integrated delivery system could potentially address the cost and quality concerns associated with treating the dual eligibles (KFF, 2011, p 1). The sections that follow describe four policy options to integrate care for the dual eligible. Examples of each option are reviewed, as are the associated advantages and disadvantages. The source of accountability for care integration (state, county, health plan or health system) varies depending on the policy option.

11a) Program of All Inclusive Care for the Elderly

In 1979, the Chinatown-North Beach community of San Francisco identified the need of immigrant seniors for long-term care services. A nonprofit corporation called "On Lok Senior Health Services" integrated care and financing for dual eligible and was the foundation for the Program for All-inclusive Care for the Elderly (PACE), the first

policy option. Later, the Balanced Budget Act of 1997 enabled states to offer PACE to Medicaid beneficiaries as a state option (CMS, n.d.e). As of 2010, there were 75 PACE programs operating in 29 states and enrollment totaled about 20,000 in 2009 (Bella, 2010; National PACE Association, n.d.).

Eligible beneficiaries must be at least 55 years old and reside in an area offering PACE; the associated state must certify potential PACE enrollees as eligible for nursing home care (CMS, n.d.e). Through capitated financing, PACE providers accept full financial risk associated with delivering all the social and medical services that participants require, (such as adult day health center, in-home and referral services), as well as acute care and nursing facility services (CMS, n.d.e). Services are not restricted to those reimbursed under the Medicare and Medicaid FFS delivery system; there are no limits on quantity, duration of time or scope of services (CMS, n.d.e).

Table 5 shows the advantages of PACE: beneficiaries receive a complete arrangement of services with monitored quality measures, and they only need to understand and adhere to one set of administrative procedures (CHCS, 2010b). However, Table 5 also indicates that PACE may require beneficiaries to leave their previous providers, and adopt PACE providers instead.

Table 5: CHCS' Advantages and Disadvantages of PACE program (CHCS, 2010b)	
Pros	**Cons**
- Fully integrates Medicare and Medicaid funding streams - One set of comprehensive PACE services including non-medical supports designed to keep beneficiaries in their homes - One set of administrative processes -Established set of comprehensive quality measures that monitors/ensures consumer outcomes/satisfaction - Allows states to serve as the PACE organization - States have authority to provide PACE through their Medicaid state plans	- Inability for state to share in the savings that may result from integration - PACE organizations have limited scope in terms of their provider network so enrollees may be required to change providers in order to participate in PACE - Current age and level of care requirements may hinder wide-scale adoption of PACE

There are advantages and disadvantages for states, as well. While states have much authority and autonomy when Medicare and Medicaid funds are combined, a great deal of up-front funding is required to establish PACE. Even after securing initial funding, PACE is an expensive approach to satisfying the needs of a fairly small group (CHCS, 2010b). Moreover, although states bear all the financial risks of PACE, they do not reap potential savings associated with program integration; instead these accrue to federal Medicare and Medicaid budgets. Another disadvantage is that PACE's extensive enrollee requirements have barred extensive program replication; changes in regulations and statutes may be required to address these obstacles (CHCS, 2010b). Finally, although not identified in Table 5, another important disadvantage of PACE implementation is associated with payment. The ACA cuts the Medicare Advantage (MA) rates upon which PACE relies which could hamper program sustainability and scalability (Capretta, 2011).

11b) Special Needs Plans (SNPs)

The second policy option is that a state could contract with Special Needs Plans (SNPs). This strategy utilizes a capitation payment and one entity, the managed care company, bears the risk associated with the provision of all Medicare and Medicaid services (Korb & McCall, 2008). Beginning in the late 1990s, Minnesota, Wisconsin, and Massachusetts have utilized this integrated managed care model, but this could only be done by obtaining federal demonstration authority through CMS's tedious waiver process (Korb & McCall, 2008).

The viability of this approach improved with the passage of the Medicare Prescription Drug Improvement and Modernization Act (MMA) of 2003. The MMA enabled states to avoid the federal waiver process by contracting with SNPs. SNPs were a new type of MA managed care plan that was an alternative to receipt of Medicare parts A and B. Enrollment was limited to the dual eligibles or two other groups of Medicare beneficiaries.

Historically, MA payments have been higher than those in Medicare's FFS system, enabling plans to offer benefits comparable to original Medicare, plus supplemental benefits. However, the MMA does not require SNPs to offer fully integrated care for dual eligibles; only about half of states that contract with SNPs offer such care (Bella & Palmer, 2009). Thus, of the 1.5 million dual eligibles enrolled in SNPs and other MA plans, fewer than 120,000 actually receive fully integrated Medicare and Medicaid services (Bella & Palmer, 2009). To address potential gaps in care integration, the Medicare Improvements for Patients and Providers Act of 2008 (MIPPA) included more state oversight of certain SNPs and requirements that SNPs adhere to new

standards of care (CHCS, 2010b). Although the standards are uniformly required of all SNPs, there are four types of contracts that states may enter into with SNPs as shown in Table 6.

Table 6: Four State Special Needs Plan Contracting Options (CHCS, 2010b)

	Name	Description	Example
Least complex contract, least integrated care	Data-Sharing	A data and information exchange is established which enables all those engaged caring for the dual eligibles to receive the required information regarding that care (CHCS, 2010b).	Maryland
	Medicare Cost-Share Only	Contracts and/or agreements are signed by states and SNPs, whereby SNP covers its enrollees' Medicare premiums and cost sharing or covers the dual eligibles enrolled in the Medicare Savings Program (MSP).	Texas and Maryland
	Medicare Cost-Share & Medicaid Wrap-around Services	States contract to pay SNPs a capitated PMPM rate covering Medicare cost-sharing responsibilities; SNPs may also offer Medicaid acute care services that are either not covered, or are only partly covered by Medicare (CHCS, 2010b).	New York and Minnesota
Most complex contract, greatest level of integrated care	Medicaid Acute & Long-Term Supports & Services	Contracts and/or agreements are signed by states and SNPs, whereby the SNP provides the full complement of Medicare and Medicaid's acute and long-term supports and services (CHCS, 2010b).	Arizona, Minnesota, New Mexico, New York, Texas and Washington

Many of the advantages and disadvantages associated with state SNP contracts are outlined in Table 7. From the beneficiary perspective, SNPs offer enrollees a unique care plan and some may enroll regional and small-scale non-profits (like the Commonwealth Care Alliance) which customize care to address beneficiaries' needs and reinvest savings to "create medical/behavioral/long-term care homes" (Bella & Palmer, 2009, p.5).

However, there are quality of care concerns associated with SNPs that are not raised in the Table 7. The Kaiser Family Foundation notes that it is "still unclear if special needs plans provide coverage and care that is qualitatively better than that provided by other MA plans" (Neuman, 2007, p.11). Further, there are questions about whether "SNPs, many of which are large insurance companies, [are] uniquely qualified to provide care for high-needs populations" (Bella & Palmer, 2009, p. 5). An additional issue is when an SNP does not coordinate with Medicaid, the beneficiary may face unaffordable out-of-pocket costs and obstacles accessing "services covered by Medicaid but not Medicare or the plan" (Neuman, 2007, p. 10). These matters are especially problematic because it is difficult for potential enrollees to ascertain which plans are good ones, and which are not (Neuman, 2007).

Table 7: CHCS' Advantages and Disadvantages of Special Needs Plans (CHCS, 2010b)

Pros	Con
- Allows states to choose the locus and level of integration that meets their needs and goals - Capitated models provide states greater budget predictability (although consideration needs to be given to the degree of financial risk) - Allows for some streamlining of administrative processes (e.g., enrollment, marketing, quality measures and reports, etc.) - SNPs are required to have multidisciplinary care team that works together to develop individual care plans for beneficiaries	- Medicare and Medicaid funding not truly blended - Plans must comply with rules of two different purchasers i.e., different state and federal requirements about oversight of plans - If contract is not for full integration, consumers must continue to navigate two separate systems (e.g. enrollment, provider networks, evidence of benefits, marketing materials, etc.) - SNP model is not viable for all states (e.g., those without operating SNPs, those without Medicaid managed care, and those which may want to operate through an existing primary care case management infrastructure in which the state serves as the managed care entity) and/or in all areas of a state (e.g., rural areas) - States are unlikely to share in any savings on the acute care side that may result in service integration.

There are additional disadvantages associated with SNP contracting. While states are given a great deal of flexibility, authority and autonomy when offering SNP contracts, it is unlikely that they could share in accrued savings (CHCS, 2010b). Finally, a disadvantage for the SNPs themselves is that they must administer health care services while adhering to both Medicaid and Medicare rules and regulations which are quite different (CHCS, 2010b).

11c) Shared Savings Model (SSM)

The MMA of 2003 also authorized CMS to test shared savings models (SSMs), a third policy option for integrating the care of dual eligibles, through its Medicare Health Care Quality (MHCQ) Demonstrations (CMS, n.d.d). Although five year MHCQ Demonstrations using the SSM have been implemented in Indiana Wisconsin, Iowa, and Minnesota, the MHCQ Demonstration in North Carolina (NC) was described as "the best example of this [SSM] option" (CHSC, 2010).

In order to understand how NC's MHCQ has functioned, it is helpful to examine NC's evolving health care delivery system, upon which the SSM is built. In the late 1980s and early 1990s, NC's FFS Medicaid program faced increasing medical care costs (North Carolina Department of Health and Human Services [NCDHHS], 2013c). In response, in 1991, NC's DHHS contracted with primary care providers (PCPs) to control costs through a Medicaid's primary care case management (PCCM) payment model. This approach requires enrollees to select a PCP "who is responsible for coordinating the enrollee's care and is paid a monthly fee for doing so, on top of payment for providing medical services" (Robin & Cohen, 2009, para. 2). The PCCM model requires that care be available 24 hours a day, seven days a week (Robin & Cohen, 2009). This strategy is supported by evidence

indicating that "health care systems based on primary care have better quality, lower cost, less inequality in health care and health, and better population health" (Stange, et al., 2010, p.55).

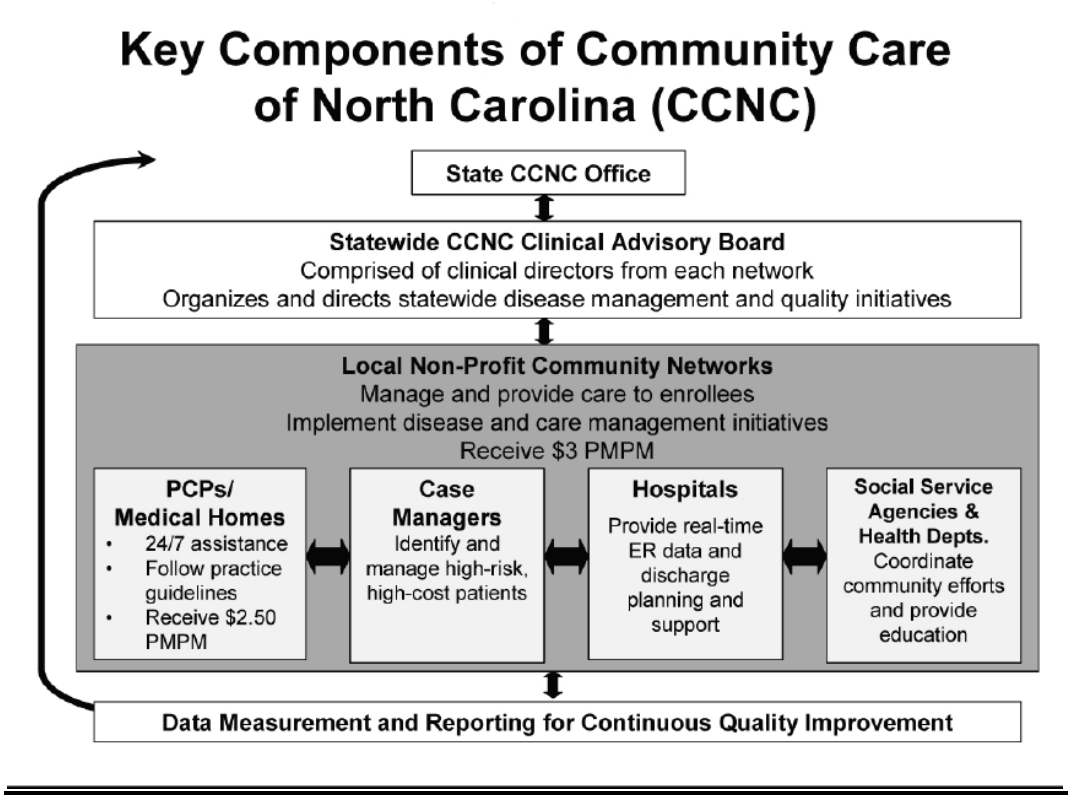
NC launched a pilot program in five counties. It explicitly tied each enrollee to a PCP and paid PCPs $3 per member per month (PMPM) to engage in certain care management activities, like authorizing ER and specialist visits (CHSC, 2009). Thus, participating PCPs acted as "gatekeeper to specialty services" and were responsible for associated with coordinating care for their women and children Medicaid patients (The Community Care of North Carolina [CCNC], 2009; Domino, Humble, Lawrence, & Wegner, 2009; KFF, 2009).

One year later, a 1915(b) waiver amendment allowed for statewide expansion of the waiver. PCPs in nine NC counties formed private non-profit community networks committed to an "enhanced" PCCM based on the previously-discussed medical home model (Academy Health, n.d.). Using NC's enhanced PCCM model, Medicaid enrollees are linked to a medical home through a PCP responsible for providing care coordination (Dube, 2008). In addition, "care coordination is provided by a system of community provider networks that also offer disease and care management and quality improvement [QI] initiatives" (Dube, 2008).

In 2001, under significant budgetary pressure, state officials decided to expand the program statewide and a non-profit organization of community provider networks called Community Care of North Carolina (CCNC) administered it (Partnership for Community Care, Community Care of North Carolina, n.d.). In 2007, CCNC's scope enlarged to serve NC's Medicaid-enrolled elderly and disabled populations as well as its

dually eligible and Medicare-only populations (CCNC, n.d.k). By 2011, all NC's 100 counties were enrolled in CCNC, serving over one million Medicaid recipients and 70,000 low-income uninsured residents (Partnership for Community Care, Community Care of North Carolina, n.d.). The Kaiser Family Foundation's representation of the current configuration is found in Figure 6 (KFF, 2009).

Figure 6: Kaiser Family Foundation's Key Components of CCNC



While the 14 CCNC networks contract with the state, CCNC's central office has a relatively small staff that administers the program. CCNC engages with the networks by identifying high-cost, high-risk, high-need patients, offering them care management services, and strategizing with participating PCPs about the best approaches to manage their care (CHCS & Oklahoma Health Care Authority, 2009). In addition, the networks

participate in statewide disease and care management initiatives that focus on specific diseases like diabetes, and broader efforts like reduced ED utilization (CHCS & Oklahoma Health Care Authority, 2009).

Throughout CCNC's transformative period from the late 1990s through today, its QI efforts and the state's Medicaid payment model adopted and become more committed to the patient-centered medical home (PCMH) model. Like the medical home model, the PCMH is not a place, it is a strategy to provide comprehensive primary care. Central to this work is an on-going relationship with a PCP who leads a team that takes responsibility for patient care. Indeed, the PCP is in charge of service coordination and addressing all the patient's health care needs, by either providing direct services or arranging needed care with other professionals" (Health Resources and Services Administration [HRSA], n.d.b; Reid, 2009). This care is coordinated across elements of the health system and the patient's community, and it is improved through the engagement of participating practices in safety and QI initiatives (HRSA, n.d.b). Finally, the model offers enhanced access to care through expanded appointment hours and it includes a payment methodology that recognizes the value of providing care through the medical home (HRSA, n.d.b).

While not all participating CCNC practices are PCMH-certified by the National Committee for Quality Assurance (NCQA), each CCNC patient has his or her own PCP and an associated medical practice that is intended to operate as a medical home. For certain high-cost, high-risk patients, CCNC care managers strengthen these links to medical and other services in the broader community through the provision of care coordination services (Steiner et al., 2008). Further, all CCNC patients have access to

24-hour on-call PCPs and practice-level continuous QI efforts; both of which are central to the PCMH model (Steiner et al., 2008). The payment methodology, which enhances the standard Medicaid fee schedule with a PMPM management fee, incentivizes the delivery of comprehensive primary care as well as specialty care, two other key components of the PCMH model (Steiner et al., 2008).

The MHCQ demonstration was launched in January 2010, with NC's PCMH program as its foundation. Enacted through Section 646 of the MMA, the MHCQ demonstration was referred to as "the 646," and aimed to integrate acute care for dual eligibles and Medicare-only beneficiaries served by participating providers (Wade, Ciesco, & Floyd, 2011). Further, the 646 strived to eradicate cost shifting between Medicare and Medicaid, and some of the resulting Medicare savings were to be either reinvested in the program or used to expand coverage (CHCS, 2010b). NC's 646 relied on eight of the state's 14 regionalized coalitions of PCPs to provide care within a partially-integrated delivery system and they received the PMPM fee discussed above as reimbursement for care management services.

Participation in the 646 enabled NC to utilize some previously-inaccessible Medicare data, which were to be used in care management efforts. CCNC tied these CMS Medicare claims data to other information from a variety of sources in order to produce reports about the quality of patient care and provider performance. Moreover, these data were used to develop provider alerts and reminders (CMS, 2010b). In addition, CCNC focused on four additional PCMH tactics to enhance care quality:

1. Designating a primary care provider (PCP) for each beneficiary

2. Connecting beneficiaries and their providers through community-based care coordination services
3. Broadening CCNC's case management information system to include the two new expansion populations (dual eligibles and Medicare-only beneficiaries)
4. Developing a SSM that includes QI incentives for participating providers (CHCS, 2010b).

As mentioned above, the 646 enabled NC to share any Medicare savings resulting from implementation with the federal government (Wade et al., 2011). At least 50 percent of shared saving payments to be made to CCNC were conditional upon the achievement of certain goals like diabetes management (CMS, 2010b). In order to ascertain whether CCNC received the savings, the 646 included out-of-state comparison groups with characteristics similar to those of participating NC counties (CCNC, n.d.d).

The advantages and disadvantages associated with the development and utilization of SSMs are described in Table 8. (The 646 Demonstration is but one such SSM model). The data imply that the SSM could be a good policy option for states in which a more fully integrated option (involving the acceptance of more risk, or the merging of funds) is not possible. Enrollees benefit from better care coordination in the SSM than in FFS, especially because in the SSM, Medicaid has a stake in care management. Although there are significant benefits associated the SSM model, there are disadvantages, too. As Table 8 suggests, while a state's SSM may defragment care to some extent, it does not reform the volume-based FFS delivery system, which includes incentives to provide more services instead of smarter ones. Furthermore, there are disadvantages for providers and beneficiaries, who face benefit constraints that are

associated with still-siloed Medicare and Medicaid funding. Moreover, a state's savings opportunities are narrow, and implementation requires an initial investment to fund care management. Finally, significant state staff time and expertise is required to design an SSM.

Table 8: CHCS' Advantages and Disadvantages of Shared Savings Models (CHSC, 2010b)

Pros	Cons
- Eliminates disincentives for Medicaid to provide better care management for its dual eligibles - Better coordination of care for beneficiaries than in FFS - Could be incremental step toward taking on more risk/blending of funds	- Maintains existing FFS, which does not reinforce purchasing for value and improved outcomes (e.g., quality over quantity) - Medicare and Medicaid funding is not fully blended, resulting in less flexibility for providers to tailor the benefits than with a global capitated payment - While there is limited risk for the state, there is also limited opportunity for the states to accrue savings - Requires upfront funding to support care management functions - May be designed anew for every set of purchaser/payer/provider circumstances

In the future, it is doubtful that other states will be able to implement a SSM model like NC's because it is unlikely that CMS will extend 646 demonstration authority to other states (A. Lind, personal communication December 26, 2013; CHCS, 2010b). However, NC's 646 demonstration is but one example of a particular type of SSM model, and other types are being launched through the CMS Financial Alignment Demonstration.

11d) Financial Alignment Demonstrations

The fourth policy option is the Financial Alignment Demonstrations, authorized through the ACA. Pursuant to Section 2602, CMS established the Federal Coordinated Health Care Office (the Medicare-Medicaid Coordination Office or "Coordination Office"), which was tasked with integrating the benefits of the two programs (CMS,

2013a). To do this, the Coordination Office strives to do away with the problematic and divergent regulations that are found under the Medicare and Medicaid programs (CMS, 2013a). Further, it seeks to abolish the highly problematic cost-shifting associated with the Medicare and Medicaid programs and related health care providers (CMS, 2013a). Finally, the Coordination Office strives to make the process associated with accessing the items and services to which the dual eligibles are entitled more straightforward (CMS, 2013a).

The Coordination Office also seeks "to align and coordinate benefits between the two programs effectively and efficiently" through an active dialogue with stakeholders from Medicaid, Medicare, relevant federal agencies, the states and other entities (CMS, 2013a, para.2). Another strategy is partnering with states to "develop new care models and improve the way dual eligibles get health care" (CMS, 2013a, para. 2). Finally, the Coordination Office focuses on the beneficiaries themselves, striving to enhance the dual eligibles' knowledge of, and contentment with, their coverage under the two programs (CMS, 2013a).

The ACA also establishes the Center for Medicare and Medicaid Innovation ("Innovation Center") to experiment with novel payment and delivery models crafted to reduce costs and enhance the quality of care provided to the dual eligibles (KFF, 2011). In pursuit of this goal, the Innovation Center and the Coordination Office offered up to $1 million each for 15 states to develop delivery systems that would integrate care for the dual eligibles" (Senate Rules Committee, 2011).

Through the State Demonstrations to Integrate Care for Medicare-Medicaid Enrollees, 15 states (including North Carolina) were selected in early 2011 (CMS,

2013b). They were given their funding and 12 months to further-develop their proposed models. CMS subsequently broadened the opportunity to all states through the "Financial Alignment Demonstrations," and most of the original 15 and several new states have pursued authority via that model. Of these capitated states, Massachusetts began serving enrollees in December 2013 (Bella, 2013). In addition, two other payment models have been approved. Washington's managed fee-for-service model (MFFS) was launched in July, 2013, and Minnesota was authorized to utilize an alternative payment strategy, through SNPs (Bella, 2013). (NC's plan has not been implemented.) It is too soon to describe the pros and cons of the Financial Alignment Demonstrations.

11e) Integrated Care Policy Options: Summary

This discussion of four policy options for integrating care for the dual eligibles indicates that there are currently no "easy answers" for states to ensure the provision of high quality and low cost care. PACE is an expensive program, and although it is a "widely cited as a model of well-integrated care, its effectiveness remains to be established" (Kane, Homyak, & Bershadsky, 2002, p.320). Further, only a relatively few SNPs are deemed by the CHCS to be "Model SNPs" (like the Commonwealth Care Alliance) and the level of care integration and quality at the others is decidedly mixed. The MHCQ Demonstration relied upon the SSM for the dual eligibles' care in NC required special authorization by CMS (which is no longer likely) and certain state-level conditions. Finally, it is too soon to determine if and how the Financial Alignment Demonstrations achieve their goals.

12. Research on Dual Eligibles' Perspective on Care

Although a great deal has been written on policy options to integrate care for dually eligible, little research has been conducted about the dual eligibles' own perspective on their care, and how to improve it; this topic is covered in this section. A literature review was conducted in order to begin to understand the dually eligibles' experience of care in an integrated care delivery system. First, the National Institutes of Health (NIH) grant website (called "Research Portfolio Online Reporting Tools") was searched for information regarding current NIH research projects involving the dual eligibles. Second was the conduct of a literature search; information regarding the interviewing of dual eligibles enrolled in PACE, social health maintenance organizations (SHMOs), and managed care organizations (MCOs) was found. However, there was no research on the patient experience and SNPs. The results of this work are described below.

The NIH grant website search showed six current research projects involving the dual eligibles but five of these lacked the dual eligibles' perspective on the experience. However, one multi-method study by Don Steinwachs included a qualitative component with interviews (conducted in 2010) with about 450 dually eligible individuals. This research examines the impact of the 2006 implementation of Medicare Part D on Marylanders with severe mental illnesses (SMI), ages 18-60, disabled, and the dually eligible and compares that experience with Marylanders with SMI who are enrolled only on Medicaid. (Unfortunately the NIH website and a recent literature review indicate that no publications have resulted from this research as of yet.)

However, the literature review identified research exploring the perspective of PACE enrollees. A 2002 study by Kane, Homyak and Bershadsky compared the consumer perspective of those enrolled in the Wisconsin Partnership Program (WPP), a modified PACE program that uses PCPs, with enrollees in two other PACE programs operated by two Wisconsin agencies. There were 215 WPP beneficiaries and 88 family or staff member proxies who were interviewed, as well as 200 PACE enrollees and 126 family or staff member proxies who were also interviewed. Beneficiaries were asked questions about their care and its quality, their satisfaction, and the decision-making process associated with their treatment, as well as unmet needs. The research found that although PACE participants tended to be less disabled than WPP clients, satisfaction levels were similar between the two groups. Further, while participants in both groups used advanced directives to a greater degree than the general population, usage rates were generally the same in the PACE and WPP groups (Kane, et al., 2002).

The literature search also identified a number of other recent studies on the dual eligibles' experience in innovative delivery systems in Wisconsin and/or Minnesota. In 2003, Kane et al. tested changes in the functional and satisfaction measures of dual eligibles enrolled in Minnesota Senior Health Options (MSHO), a managed care program for older dual eligibles. The dual eligibles themselves and their family members were interviewed for this study, which showed that MSHO enrollment did not seem to significantly improve in "outcomes across function, satisfaction, and caregiver burden" when compared with a comparable control group (Kane, Homyak, Bershadsky, Lum, & Siadaty, 2003, para.1).

In 2004, Kane and Homyak conducted a mixed-method evaluation of two dual eligibles demonstrations, MSHO and WPP, which had the common goals of improving the quality of dual eligibles' care while controlling costs or more appropriately allocating them. The results showed that although there were modest levels of improved participant satisfaction in the MSHO and WPP programs compared to control groups, neither program achieved significant reductions in utilization for community-dwelling persons. However, positive effects on quality were found for MSHO's nursing home group (CMS, 2004). Finally, the beneficiary perspective of enrollees in another innovative health care system in Minnesota, a SHMO, was studied by Fischer, Leutz, Miller, von Sternberg, and Ripley (1998). Case studies of the termination of the Group Health SHMO involved interviews with elderly who had previously received long-term care through the SHMO and switched to another HMO.

In conclusion, it seems that the dual beneficiary's perspective on care, and how to improve it, has been studied on a limited basis, with few studies conducted only in the states of Maryland, Wisconsin and Minnesota. This review suggests that there is more work to be done in this area, especially given CHCS' suggestion that additional information regarding the consumer perspective is required if the care of the dual eligibles is to be improved (Lind, & Gore, 2010).

13. Care Coordination for the Dual Eligibles

As described above, the dual eligibles tend to have disabilities and/or multiple chronic illnesses, and frequently need services delivered by many doctors and other clinicians in numerous settings. Coordinating the care provided

by these different entities is difficult for providers, the dual eligibles and the payors of health care (Palmer, Llanos, Bella, & Tobia, 2006). A great deal of effort is required for beneficiaries to navigate the health care system, and health insurers and other payors struggle with "the inefficiencies and redundancies that arise from such a fragmented care system" (Palmer et al., 2006, p.9).

This situation leads CHCS to conclude that the outcome of care coordination is "beneficiaries with the right care at the right time in the right places;" this result is a critical aspect of integrated care for the dual eligibles (CHCS, 2010b, p.1). However, care coordination means many different things to a variety of different stakeholders. The federal Agency for Healthcare Quality and Research's (AHRQ's) definition focuses on the need for cooperation between care providers in order to enable patients to access and receive suitable therapies:

> Care coordination is the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care. (AHRQ, 2011, p.4)

In this case, the provision of high-quality of care is implied, but is not specified. This is also the case in the definition by the Department of Veterans Affairs (VA), but the VA focuses on *tools*:

> Care coordination is the wider application of care and case management principles to the delivery of health care services using health informatics, disease management, and telehealth technologies to facilitate access to care and improve the health of designated individuals and populations with the intent of providing the right care in the right place at the right time (Wertenberger, 2006, p. 109).

Further, the nonprofit organization the National Quality Forum (NQF) offers another perspective, focusing on the patient and the explicit provision of high-quality care:

> Care coordination is a function that helps ensure that the patient's needs and preferences for health services and information sharing across people, functions, and sites are met over time. Coordination maximizes the value of services delivered to patients by facilitating beneficial, efficient, safe, and high-quality patient experiences and improved healthcare outcomes (National Quality Forum [NQF], 2010, p.1).

Moreover, as mentioned previously, Singer et al. (2011) also focuses on the patient, emphasizing that integrated coordinated care includes "patients' needs and preferences," and requires "shared responsibility between patient and caregivers for optimizing health" (Singer at al, 2011, p. 113).

While there are many different definitions of care coordination, AHRQ reports that performance measurement of this intervention only "represents early efforts in an emerging field" (Agency for Healthcare Research and Quality [AHRQ], 2011, p.3). An AHRQ synthesis of the evidence showed that while systematic reviews of interventions to enhance care coordination had been conducted using an extensive array of measures, almost none have focused on structure, process, or intermediate outcome measures that are especially relevant the intervention (AHRQ, 2011).

According to AHRQ, the cross-cutting nature of care coordination is one reason why it is so difficult to measure which factors lead to effectiveness. AHRQ explains that "care coordination is a complex concept, intertwined with many other concepts relating to quality, delivery, and organization of care" (AHRQ, 2011, p.3). This complexity lends itself well to qualitative research like that proposed in the Methodology in Chapter 3.

14. Theoretical Models of Care Coordination

Many theoretical models from a variety of disciplines have influenced the practice of care coordination including Donabedian's Quality Framework and Wagner's Chronic Care Model (AHRQ, 2011, p. 15; Wagner, 2007, slide 13). Although Wagner's and others' models are informative, this research focuses on two theoretical models of care coordination developed by AHRQ. The first is AHRQ's "Care Coordination Ring" (which is found at Figure 1, in Chapter 1). This model was selected because it focuses solely on this intervention and unites the "common elements from many definitions" of care coordination (AHRQ, 2011, p.4). Informed by a systematic literature review, this framework is intentionally broad because, in the past, care coordination models have had a limited usefulness due to their narrow focus.

Historically, other frameworks have focused a narrow population of patients, like those with chronic illness. Such groups were targeted for care coordination interventions because expensive interventions are often needed if these conditions are handled badly (McDonald et al., 2007). In contrast to the narrow scope of the other models, AHRQ's framework was designed to capture the care coordination experience of diverse patient populations, within many different health care settings and delivery systems.

At the center of the hypothetical framework (which represents an ideal situation), is the patient; this aspect of the model highlights the central importance of care coordination in the delivery of high quality patient care (AHRQ, 2011). The 13 colored circles that surround the triangle show that a broad continuum of possible participants, health settings, and information are critical to assuring high quality care. The large blue ring that ties the 13 colored circles together is care coordination which constitutes

"anything that bridges gaps (white spaces) along the care pathway" (AHRQ, 2011, p. 4). The Care Coordination Ring touches those who participate, directly or indirectly, in patient care: the triangle of the patient and her family, her providers, and system representative(s) (AHRQ, 2011). For the purposes of this research, one of the strengths of this model is its explicit inclusion of all three groups engaged in care coordination activities (AHRQ, 2011).

AHRQ identifies two mechanisms hypothesized as key to carrying out effective care coordination, which are shown in AHRQ's Care Coordination Mechanisms Framework, (in Figure 2 of Chapter 1). At the top of the framework is the goal, the achievement of effective coordinated care. The model's second level shows that certain mechanisms are vital to reaching the target of coordinated care. The third level indicates that there are two critical mechanisms that are the means of achieving the goal, and these are *Coordination Activities* and *Broad Approaches*. Table 9 includes a list of the tasks and structures that are associated with each of the two mechanisms (AHRQ, 2011). AHRQ reports that while *Coordination Activities* are "actions [that are] hypothesized to support coordination" they are not, however "necessarily executed in any structured way" (AHRQ, 2011, p.11). Thus, AHRQ seems to warn that these are emerging mechanisms, and their effectiveness is not guaranteed.

The Care Coordination Mechanisms Framework also includes the five *Broad Approaches* that represent the second mechanism that affects care coordination. These are the "structures of a system (whether a clinic, hospital, or integrated network) that will influence processes of care" (AHRQ, 2011 p.15). However, AHRQ seems to again caution that these are emerging mechanisms when stating that the implementation of

these *Broad Approaches* is not uniform, and is often not described in detail in the literature (AHRQ, 2011).

Table 9: AHRQ's Two Mechanisms of Coordinated Care (AHRQ, 2011)

Coordination Activities	Broad Approaches
Actions that help achieve coordination, whether employed in an improvised or systematic way including: • Establishing accountability or negotiating responsibility • Communicate • Facilitate transitions • Access needs and goals • Create a proactive plan of care • Monitor, follow up, and respond to change • Support self-management goals • Link to community resources • Align resources with patient and population needs	These structures of care are aimed at improving the delivery of health care, including improving or facilitating coordination, often incorporating a number of coordination activities including: • Teamwork focused on coordination • Health care home • Care management • Medication management • Health information technology-enabled coordination

The third and fourth levels of the Care Coordination Mechanism Framework relate to the discussion above, and focus on the different perceptions of care coordination efforts. The effects of care coordination are understood in different ways, depending on the point of view of the individual involved, be she a patient, family member, health care professional, or system representative. Finally, the text at the bottom of the framework reminds the reader that context matters; issues such as the relevant health care settings, patient populations and timeframe, as well as facilitators and barriers, affect the success or the failure of care coordination activities (AHRQ, 2011). This model enables the reader to consider both the actions that help achieve coordinated care, and the structures of care focus on enhancing the delivery of services.

In summary, care coordination is "an emerging field" which is nonetheless critical for ensuring that vulnerable groups like the dual eligibles receive high quality care

(AHRQ, 2011, p.3). There many perspectives about what care coordination entails, and how to achieve it, but all have numerous participants who are typically involved, and who are interdependent on each other because they need sufficient information about their own roles, the function of others, and the availability of resources (McDonald et al., 2007). Each of these participants relies on information exchange in order to play a part in ensuring that the patient receives "the right care at the right time in the right places" (McDonald et al., 2007).

Although other theoretical foundations of care coordination were covered in the literature review, it seems that AHRQ's Care Coordination Ring would best represent the experience of care coordination for the dual eligibles because it connects all those participate, directly or indirectly, in patient care, and the tools they need in order to function effectively. AHRQ Care Coordination Mechanisms Framework is also of value to this research because it pinpoints the two vital mechanisms hypothesized as critical to the implementation of effective care coordination. As has been previously noted, there is a dearth of knowledge about the dual eligibles' own continuity of care experiences, and as the CHCS suggests, this unique perspective is important when developing innovative models of coordinated care for this population (Lind, & Gore, 2010).

15. Conclusion

This literature review indicates that health care in the U.S. system is fraught with the systemic fragmentation, poorly designed care delivery processes and inadequate HIT infrastructure. These have led to wide-spread quality problems, as expenditures have grown rapidly and are expected to continue expanding. The dual eligibles are especially

vulnerable to quality of care problems, and the cost of their treatment is disproportionally high, leading some health policy analysts to conclude that coordinating their care is of utmost importance (Center for Health Care Strategies [CHCS], 2010a). This is no easy task, considering the problematic incentives associated with the independent administration, supervision, and funding of the Medicare and Medicaid programs.

Nonetheless, some pioneering states have integrated the dual eligibles' care by implementing PACE and/or 646 waivers, or by contracting with SNPs. More recently, the ACA aims to change health care delivery by encouraging innovative care provided through the medical home, the ACO and the Financial Alignment Demonstrations. The literature review has revealed that there are no "easy answers" for states to increase quality and lower cost for dual eligibles' care. One reason is that care coordination is but an "emerging field" which hampers the design and implementation of effective associated interventions (AHRQ, 2011, p.3; McDonald et al., 2007). Although this literature review has considered numerous conceptual models related to care coordination activities, AHRQ's Care Coordination Ring and Care Mechanisms Framework have been selected as the most appropriate foundation for this research because of their sole focus on this intervention and their application to a diverse array of patient populations.

Finally, there is a dearth of knowledge about the dual eligibles' own continuity of care experiences. As CHCS suggests, this unique perspective may be of value in informing the development of innovative models of coordinated care (Lind, & Gore, 2010). NC's PCMH is one such innovative model, and the dual eligibles' experience of care coordination in that PCMH has not yet been explored. Thus, this research topic will be discussed in more detail in the Methodology in Chapter 3.

Chapter 3: Methodology

1. Introduction

This chapter describes the research methodology, beginning with Section One, this introduction. Section Two introduces the problem statement and purpose of the research. Section Three describes the selection of a hybrid case study design, indicating why it is the appropriate approach to study how well North Carolina's (NC's) patient-centered medical home (PCMH) coordinates care for dually eligible patients. Section Four describes literature that suggests this to be true, since case study research has been conducted regarding the experience of other vulnerable populations.

Section Five covers the study framework; it details how NC's PCMH was selected as the case and outlines the sampling strategy. The two conceptual frameworks are highlighted in the sixth section, and the research questions covered in the seventh. The eighth and ninth parts of the chapter describe preparations for the focus groups and individual interviews. The logistics associated with data collection are described in the tenth section.

While Section 11 reviews the methods for organizing, categorizing, summarizing, and analyzing the data, Section 12 describes the qualitative research standards applied to this study and the approach to addressing the threats to the research and study limitations. Section 13 briefly defines the role of the researcher and Section 14 concludes the chapter.

2. Problem & Purpose Statement

As discussed in Chapter 2's Literature Review, our nation's health care system is characterized by systemic fragmentation, poorly designed delivery processes and an

inadequate health information technology (HIT) infrastructure, which have led to wide-spread quality problems, and rapid expenditure growth (National Research Council, 2001). Individuals enrolled in both Medicare and Medicaid, "the dual eligibles" comprise a population that is perhaps the most vulnerable and highest-need. Their government-funded health care is especially expensive and beset by quality problems (Medicare Payment Advisory Committee [MedPAC], 2010). The literature suggests that these problems are directly associated with the inadequate coordination of Medicare and Medicaid benefits and services, leading some health policy analysts to conclude that coordinating their care is of utmost importance (Center for Health Care Strategies [CHCS], 2010b). This is no easy task, considering the problematic incentives associated with the independent administration, supervision, and funding of the Medicare and Medicaid programs.

Driven by significant cost and quality concerns, states have pioneered innovative approaches to integrating care for this group. Today some dual eligibles are enrolled in completely integrated or somewhat integrated systems of care through the Program of All-inclusive Care for the Elderly (PACE) and Special Needs Plans (SNPs). More recently, the Patient Protection and Affordable Care Act of 2010 (ACA) has fostered the development of integrated and innovative care delivery systems (Henry J. Kaiser Family Foundation [KFF], 2012a). Nonetheless, the literature reveals that there are no easy solutions to coordinate high quality and low cost care for the dual eligibles (CHCS, 2010b). This is perhaps not surprising, given that one aspect of integrated care is care coordination, an "emerging field" according to the federal Agency for Healthcare Quality and Research (Agency for Healthcare Research and Quality [AHRQ], 2011, p.3). This

status renders the effective design and implementation of care coordination difficult (AHRQ, 2011).

What is currently known about care coordination is almost completely informed by research that lacks the beneficiary perspective, and this characteristic is also found in the literature about the provision of integrated care for dual eligibles. Much has been written from the perspective of health care providers and health systems representatives, but the critical perspectives of patients and their family members have been researched only on a limited basis. For example, while there have been numerous studies of PACE and SNPs, only a fraction of this literature has included the perspective of the dual eligibles themselves (Bella & Palmer, 2009; CHCS, 2010b; Centers for Medicare & Medicaid Services [CMS], n.d.e; CMS, 2004; Fischer, Leutz, Miller, von Sternberg, & Ripley, 1998; Kane, Homyak, & Bershadsky, 2002; Kane, Homyak, Bershadsky, Lum, & Siadaty, 2003; Kane, Weiner, Homyak, & Bershadsky, 2001; National PACE Association, n.d.; Neuman, 2007; Steinwachs, 2008-2011) . Further, although the Center for Healthcare Strategies, Inc. (2010) and the Medicare Payment Commission (2013) published research about the provision of integrated care for the dual eligibles, neither describe the patient experience of care in any detail (CHCS, 2010a). Only one study, published by AARP in 2011, focused on the dual eligibles' care experiences of care; however, since ten focus groups considered care models in five states, AARP's research offered a great deal of breadth but perhaps less depth regarding experience of care coordination (Slosar, Kolb, Flowers, & Lind, 2011).

The researcher selected NC's PCMH as the case because this delivery system has been lauded in the health policy literature as a provider-driven model for reducing costs

and improving health care quality (Community Care of North Carolina [CCNC], 2012a; CCNC, n.d.g; Fillmore et al., 2013; Jackson, Trygstad, DeWalt, & DuBard, 2013; Steiner, et al., 2008). Relative to other care integration strategies for the dual eligibles, NC's PCMH offers a relatively inexpensive approach, especially compared to other options like PACE which has significant upfront and maintenance costs. It is important to study NC's PCMH in the face of rising health care costs, in the event that it represents a feasible policy option for other states that do not rely on private managed care companies to serve their dual eligible patients. Thus, this research strives to develop an in-depth understanding of how well NC's PCMH coordinates the care of dually eligibles by studying the experience of the patients themselves.

3. Case Study Design

A hybrid case study design is an appropriate way to study the complex and multi-faceted question of how well NC's PCMH coordinates care for its dually eligible patients. This section discusses the advantages of quantitative research for tackling this query. As previously discussed, what little is known about care coordination has largely been informed by quantitative analyses. Qualitative research is needed to gain a more holistic perspective by investigating the phenomenon within its context, relying on a range of data sources (Baxter & Jack, 2008). The case study design assures that the subject is not considered through "just one lens, but rather a variety of lenses which allows for multiple facets of the phenomenon to be revealed and understood" (Baxter & Jack, 2008, p.544). The case study is widely used in health services research, and is featured in articles in prominent journals such as *Qualitative Health Research* (Sage Journals. n.d.).

Eminent qualitative researcher Robert Yin (2003) explains that this strategy is useful when it is not possible to control the behavior of study participants, and for answering "how" and "why" questions. Further, case study research is appropriate when context has an impact on the phenomenon of interest (Baxter & Jack, 2008). Context, especially the impact of low socio-economic status and the availability of community resources, is critical to understanding how well NC's PCMH coordinates care for the dual eligibles. Qualitative case study research is conducted in the world, not in a laboratory; it describes and represents the world using "field notes, interviews, conversations, photographs, [and] recordings" (Denizen, & Lincoln, 2005, pp. 3-4). This approach enables "researchers [to] study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them" (Denizen, & Lincoln, 2005, pp. 3-4).

Qualitative case study data analysis is inductive. The researcher recognizes themes "from the bottom up by organizing the data into increasingly more abstract units of information," and then moves back and forth from data to themes until a comprehensive picture of the phenomenon of interest has been described and interpreted (Creswell, 2009, p 175). This approach is useful when seeking to understand the dual eligibles' perceptions of care coordinated by NC's PCMH because it seeks to "learn the meaning that the participants hold about the problem or issue, not the meaning that the researchers bring to the research or writers express in the literature" (Creswell, 2009, p 175).

While NC's PCMH is "the case" for this case study design, a hybrid approach is utilized to incorporate phenomenological techniques and enrich the case data.[3] Patton (1990) writes:

> A phenomenological study…is one that focused on descriptions of what people experience and how it is that they experience what they experience. One can employ a general phenomenological perspective to elucidate the importance of using methods that capture people's experience of the world without conducting a phenomenological study that focuses on the essence of a shared experience (Patton, 1990, p.71).

Using Patton's recommended approach, this hybrid case study design aims to understand how well NC's PCMH coordinates care for dual eligibles, using the patient perspective to inform and enhance the findings. Thus, the phenomenological lens is an appropriate perspective to utilize when seeking these research objectives.

4. Case Studies of Other Vulnerable Populations

Previous case study research on vulnerable populations like the dual eligibles suggests that this strategy can effectively inform the design of targeted health care interventions. For example, a case study involved interviewing 20 residents in rural Appalachia was conducted in order to improve the design of management interventions for individuals with chronic conditions (Schoenberg, Bardach, Manchikanti, & Goodenow, 2011). Another case study informed the development of possible interventions to encourage mammography screening, through research involving focus groups of older women with no history of breast cancer (Wood, & Della-Monica, 2011). Finally, a case study of a group home for developmentally disabled adults in Atlanta has

[3] Additional detail about the temporal and geographic boundaries of the case will be described in Section 5, *Study and Sampling Frame*, and Section 10, *Data Collections: Logistics and Conduct.*

implications for community interventions aimed at bolstering the dwindling supply of such homes in the area (Perkins, Ball, Whittington, & Combs, 2004). These are but a few of many examples involving the use of case studies to improve health services delivery for vulnerable populations.

5. Study and Sampling Frame

While NC's PACE, SNPs and home- and community-based services (HCBS) have already been extensively studied, this research focuses on NC's PCMH (CMS, n.d.c). The selection of NC's PCMH was guided by deliberately identifying this model as important, rather than on generalizing, (as is done in quantitative research), through purposeful sampling (Patton, 1990). As Patton (1990) discusses, there are many different approaches to selecting critical, content-value cases. This dissertation uses "intensity sampling" which seeks "information-rich cases that manifest the phenomenon intensely" (Patton, 1990, p. 182). In this research, "the phenomenon" is NC's PCMH program, which aims to coordinate patient care, amid other goals. Among health policy analysts, NC's PCMH program is well-known for its results of lowering the costs and increasing the quality of enrollees' healthcare. Especially in the face of rising healthcare costs, NC's PCMH program is of special interest.

A brief history of NC's PCMH offers a better understanding of the study frame. As described in detail in Chapter 2's Literature Review, about 20 years ago, NC's fee-for-service (FFS) Medicaid program faced increasing costs. Although NC hired a for-profit managed care organization (MCO) to provide services in limited areas, the state was more committed to building its own infrastructure in order to lower costs and

improve quality. This effort was supported by the nonprofit Community Care of North Carolina (CCNC) which engages with state networks by identifying high-cost, high-need patients, offering them care management services, and strategizing with participating PCPs about the best approaches to manage their needs (CHCS & Oklahoma Health Care Authority, 2009) . Further, CCNC implements statewide disease and care management initiatives focusing on specific diseases like diabetes, and broader efforts, like reduced emergency department (ED) utilization. This work is supported by CCNC's extensive information technology (IT) system (CHCS & Oklahoma Health Care Authority, 2009).

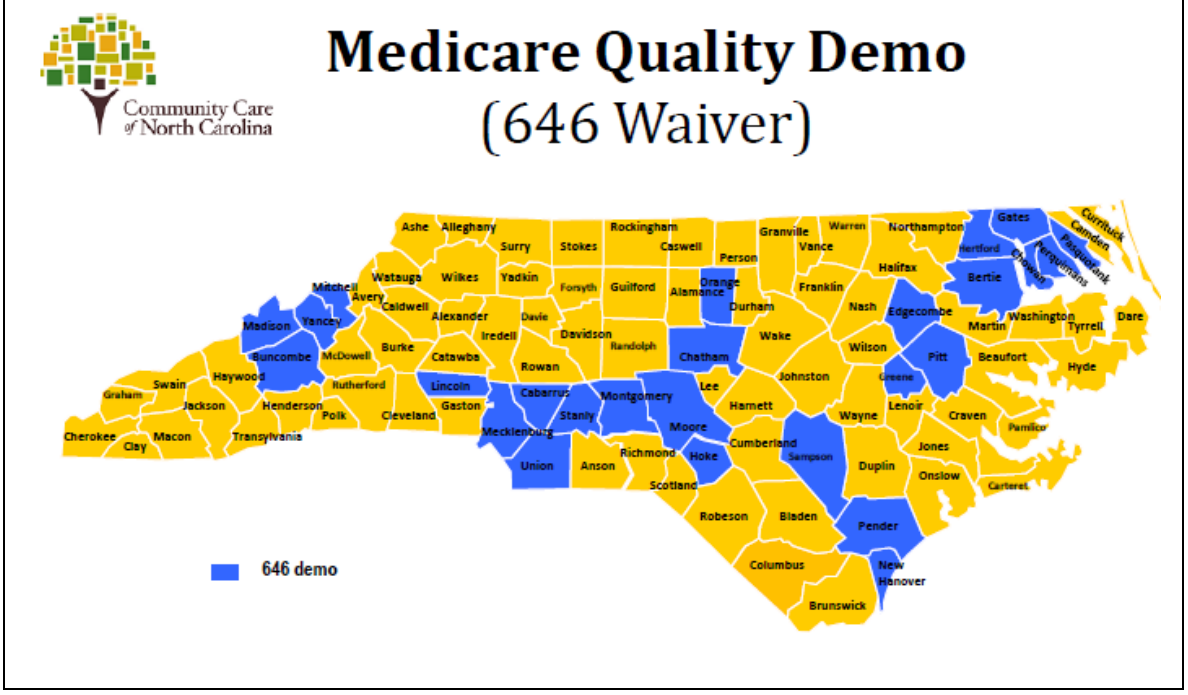
For the past two decades, CCNC has contracted with PCPs to control costs through a primary care case management (PCCM) system. Participating PCPs have been paid $3 per member per month (PMPM) to act as "gatekeeper to specialty services" and cover the costs associated with coordinating care for their women and children Medicaid patients (CCNC, n.d.l; Domino, Humble, Lawrence, & Wegner, 2009; KFF, 2009). Over time, the program has expanded statewide to include NC's Medicaid-enrolled elderly and disabled populations as well as its dually eligible and Medicare-only populations (Partnership for Community Care, Community Care of North Carolina, n.d.). By 2011, all NC's 100 counties were enrolled in CCNC, serving over one million Medicaid recipients (Partnership for Community Care, Community Care of North Carolina, n.d.). A representation of the current configuration is found in Chapter 2's Figure 6 (KKF, 2009).

Although PCCM has many advantages, CCNC and the state's Medicaid program have become increasingly committed to the PCMH model, which strives to connect enrollees to a medical home offering "accessible, comprehensive, coordinated, [and a]

family-centered form of care" (Domino et al., 2009, p. 1113). The PCCM payment methodology enhances the standard Medicaid fee schedule with the PMPM management fee, which incentivizes the delivery of comprehensive primary care and specialty care, two key components of the PCMH model (Steiner et al., 2008). The case, NC's PCMH, is a complex and interesting one because different care strategies aimed at integrating care for vulnerable populations have been implemented.

Of course one such strategy has been the reliance upon the PCCM, but another was the state's Medicare Health Care Quality (MHCQ) demonstration, which was launched in 2010. Referred to as "the 646" (after its enacting language), the MHCQ demonstration aimed to integrate acute care for dual eligibles and Medicare-only beneficiaries served by participating providers (Wade, Ciesco, & Floyd, 2011). Comprised of eight of CCNC's 14 local networks, the 646 aimed to address the myriad needs of a new subpopulation of patients, many who had multiple chronic conditions, through a greater emphasis on implementing PCMH model strategies such as better-managing transitions in care settings. Participation in the 646 was expected to enable NC to: 1) utilize some previously-inaccessible Medicare data to enhance care management efforts, and 2) benefit from a shared savings model (SSM) (Wade et al., 2011). A map of NC's PCCM and 646 counties is shown in Figure 7.

Figure 7: Medicare Quality Demo (646 Waiver)



The geographical bounds of the case, NC's PCMH, were chosen using purposeful sampling, selected in order to facilitate recruitment efforts for this study; four high population-density PCCM and 646 networks were selected. The four adjacent networks were located in the same region of the state in order to increase the likelihood that participants had similar characteristics and enable the researcher to focus on the provision of care coordination in NC's PCMH. Three maps of NC informed the selection of the four networks; these are found in Appendix A. The first shows state population density, the second indicates the locations of the state's PCCM networks, and the third shows the locations of the state's PCCM and 646 networks. An analysis of the maps indicated that the best place from which to draw the research sample of dual eligibles and care managers was the high population-density Raleigh-Durham region (in which more than 1,040 persons live per square mile) ("Southeast Region Population Density Map," n.d.).

Within that area, Johnston and Wake were the PCCM counties and Chatham and Orange were the "646 counties." State officials have noted that the dual eligibles who participated in this research received the same type of care, whether they received it through the PCCM or 646. (Additional information regarding this matter may be found in the Case Study Results, Chapter 4.)

This research utilizes the perspectives of eight different stakeholder groups in order to understand how well NC's PCMH coordinates the care of sampled dual eligibles. The first involved a medical practice in a PCCM county. In that location, two focus groups were conducted with dual eligibles age 65 plus, and 18-64. The second entailed a focus group carried out in a community-based center for senior citizens in a PCCM county. A third viewpoint was identified in a community-based setting for individuals with disabilities in a PCCM county; this focus group included dual eligibles age 18-64.

The fourth perspective was identified in focus groups conducted in a medical practice in a 646 county. Two group interviews were conducted there, with dual eligibles age 65 plus, and 18-64. The fifth point of view was noted in a community-based center for seniors in a 646 county. The sixth perspective was also gleaned in a 646 county, where two focus groups of dual eligibles age 18-64 were held in community-based settings for individuals with disabilities. The seventh and eighth perspectives were those of care managers. In the seventh, interviews with care managers from PCCM counties were conducted in a medical office and community-based settings. In the eighth, care managers were interviewed in a 646 county's medical practice. These eight perspectives on the functioning of NC's PCMH are arrayed in Table 10.

Table 10: Eight Stakeholder Perspectives of Care Coordination Provided through NC's PCMH

	Model		Setting		Interviewee		
#	PCCM	646	MP	CBS	DEs age 65+	Disabled DEs age 18-64	CMs
1	√		√		√	√	
2	√			√	√		
3	√			√		√	
4		√	√		√	√	
5		√		√	√		
6		√		√		√	
7	√		√	√			√
8		√	√				√

Key: PCCM= patient-centered care management model, 646= Medicare Health Care Quality demonstration shared savings model, MP= medical practice setting, CBS = community-based setting, DE= dual eligibles, CM= care manager

The key take-away from Table 10 is that the focus groups and interviews were deliberately conducted in a variety of locations and settings in order to assure a diversity of perspectives: this research aimed to not only identify areas where needs have been satisfied, but also recognize potential service gaps. Thus, it was critical that the research not rely too heavily on the experience of satisfied dual eligibles who could have been "cherry picked" by staff at the PCCM and 646 practices.

6. Conceptual Frameworks

This research uses two conceptual frameworks that represent the ideal care coordination experience, and are published in AHRQ's *Care Coordination Measures Atlas* (2011). As shown in Chapter 1's Figure 1, the first model is the Care Coordination Ring; this patient-centered framework represents effective care coordination as a band that unites all possible participants, health settings and information involved in a patient's

care. The second model is shown in Chapter 1's Figure 2 and indicates that there are two groups of mechanisms which are thought to be the means of achieving effective care coordination; these are *Coordination Activities* and *Broad Approaches*. For purposes of this research, the latter framework was slightly modified in the following ways:

1) The name was changed from the "Care Coordination Measurement Framework" to the "Care Coordination Mechanisms Framework" in order to de-emphasize measurement, which is outside the scope of this research, and to highlight the two mechanisms that AHRQ hypothesizes are means to achieving effective care coordination.

2) The revised model removes text from the top that says "See chapter 2" which does not apply to this research.

3) Text located at the bottom of the original model referred to "coordination measures". This was removed since measures are outside the scope of this research.

The original version of Care Coordination Measurement Framework may be found at Appendix B (AHRQ, 2011, p11).

7. Research Questions

Given that the research goal is to develop an in-depth understanding of how well NC's PCMH coordinates care for dual eligibles through an in-depth study of the intervention from the perspective of a sample of the dual eligibles themselves, the research questions are listed below. For a context on NC's PCMH, some of these questions focus on the experience of the CCNC care managers who provide care

coordination services to high-cost and high-need patients like the dual eligibles. There are also queries posed to this group regarding whether and how the two AHRQ conceptual frameworks actually represent the work of the care managers.

Question I.) How well does NC's PCMH program coordinate care for dual eligibles?

a.) From the perspective of sampled dual eligibles served by NC's PCMH, how well is their care coordinated by the program?

b.) From the perspective of sampled dual eligibles served by NC's PCMH, what are the necessary components of care?

c.) From the perspective of sampled dual eligibles served by NC's PCMH, what are the greatest barriers to accessing necessary care?

d.) What challenges does NC's PCMH program face in providing coordinated care for dual eligibles?

Question II.) What contextual information can be learned from NC's PCMH care managers?

a.) Upon which tools do sampled care managers rely upon most when providing services in NC's PCMH?

b.) From the perspective of sampled CCNC care managers, how is the experience of providing care coordination services to support NC's PCMH's similar or different for non-dual eligible patients versus dual eligible patients? For dual eligibles who are aged 65 and older versus those under age 65?

c.) From the perspective of sampled CCNC care managers, does AHRQ's Care Coordination Ring represent the experience of coordinating care for dual

eligibles in NC's PCMH? Why?

d.) From the perspective of sampled CCNC care managers, does AHRQ's Care Coordination Mechanisms Framework represent the experience of coordinating care for dual eligibles in NC's PCMH? Why?

The implications for practice, policy and theory that are associated with the coordination of care for dual eligibles enrolled in NC's PCMH program are explored in the Conclusion in Chapter 6.

8. Writing the Interview Guides & Conducting Pilots

This research required two interview guides, one for the dual eligibles and another for the care managers. The dual eligibles' interview guide was structured and open-ended. Short "yes or no" answer questions were excluded because the literature indicates that such queries are less productive than questions that offer many different ways to respond (AHRQ, 2011; McNamara, 1999). The questions were straight-forward and neutral to avoid leading the discussion in a certain direction; they were sequenced beginning with easy, general questions and following with more difficult or personal queries (Scheuren, (2004).

The researcher shared the first draft of the interview guides with dissertation committee members including one with significant experience with conducting focus groups comprised of individuals from vulnerable populations. After receiving feedback, the interview guides were revised accordingly and approved by the committee. The interview guides were then pilot-tested. There were seven participants of both genders, between the ages of 50 and 75 in the focus group pilot which was conducted on April 29,

2012, in the researcher's home in the District of Columbia. The individual interview pilot was conducted with a Kaiser Permanente care manager at her home in Beltsville, Maryland on June 7, 2012. The pilots went well, and the interview guides required no modification. (Both interview guides can be found in Appendix C).

9. Preparations for Data Collection

This section describes the preparations required for data collection including how the researcher gained access to the study sites and research participants. In order to understand the contextual landscape of NC's PCMH, a thorough document review relied upon content from the literature, the internet and emails with NC state officials and researchers. Moreover, the Commonwealth Fund's 2010 research on NC's PCMH program was an excellent source of contextual information, as was its internet-based "Community Care of North Carolina Toolkit," a guide to implement programs like CCNC (McCarthy, & and Mueller, 2009) (CCNC, n.d.h). The literature review informed the purposeful sampling described above.

9a) Focus groups

The literature suggests that focus groups are an appropriate data collection strategy when researching the experience of vulnerable populations like the dual eligibles, seeking insights into *what* interviewees believed and *why* they felt that way. In this research, the focus groups included the dual eligibles and any family members or other caregivers who accompanied them to the session. Since the literature indicates that dual eligibles over 65 years old have dissimilar needs than those of young, disabled dual

eligibles, separate focus groups were conducted for the two age groups. This strategy was employed to highlight differences between the two sub-populations.

The stratified sampling criteria for focus groups sampling were as follows: patients had to be enrolled in both Medicaid and Medicare and they needed to have no cognitive or mental impairments. Since nearly one in two dual eligibles struggles with these issues, it was unfortunate that dual eligibles with such issues were excluded from participating in the research. However, only dual eligibles with full decision-making capacity could be involved because the literature indicates that including interviewees with these impairments could undermine the quality of the data (Atkinson, Zibin, & Chuang, 1997; Kashner, Suppes, Rush, & Altshuler, 1999; Sainfort, Becker, & Diamond, 1996).

Although six to 12 participants is generally considered the ideal focus group size, a dissertation committee member recommended limiting the size to about six, in order to minimize the possibility of small group conversations, and participant frustration over a lack of opportunity to speak (Scheuren, F. 2004). However, during data collection, the researcher had less control over focus group size than expected because the staff members at the medical practices and community centers played a key role in the recruitment efforts.

Before commencement of the focus group discussions, each participant was asked to complete a brief demographic survey designed to capture interviewee characteristics. This survey was adapted from one developed by a George Washington University (GWU) researcher for focus groups comprised of another vulnerable population (Mead, Andres, Ramos, Siegel, & Regenstein, 2010). It is found in Appendix D.

The focus groups and interviews were conducted from June 7, 2013 through September 14, 2012. They began with moderator introductions and a brief description of the meeting's purpose. The researcher provided assurance that participation was voluntary, and she reviewed the ground rules that would facilitate participation by everyone, consistent with those specified by GW's Institutional Review Board (IRB). Group members were told how and why they had been invited to participate, and the reasons why the researcher would use two digital voice recording machines with omni-directional boundary microphones while taking notes. (The two devices were used in the event that one malfunctioned, the other would capture the voice data.) To enhance transcript quality, written notes identified which focus group participants said what and also highlighted the topics discussed at length or with great animation. Each focus group took between 90 and 120 minutes to conduct.

9b) Care manager interviews

Data were collected in one hour individual interviews with care managers. The goal was to understand the formal and informal care coordination tools upon which care managers rely in order to connect them with providers, link providers to each other and their patients, and to ascertain how well these processes work. Moreover, the interviews provided the opportunity to discuss the two AHRQ conceptual frameworks studied in this research. These in-depth discussions included many of the same processes used in the focus groups including the explanation of the interview's purpose and assurance of confidentiality (McNamara, 1999).

10. Data Collection: Logistics and Conduct

Serendipity and concerted effort played important roles in securing access to the medical practices and community centers willing to host focus groups and interviews, which were conducted from early June, 2012 through mid-September of that year. A colleague from the researcher's job at the Office of Health Care Quality in GWU's Department of Health Policy extended an invitation to join other researchers working on Robert Wood Johnson's Aligning Forces for Quality initiative on a trip to NC, to meet with officials at CCNC's central office and in one of their local network offices. Conducted on February 23-4, 2012, these meetings resulted in a deeper understanding of CCNC operations, and the opportunity to meet many individuals who would later play an instrumental role in the data collection efforts.

While in NC, the researcher met two high-level staff members at the Community Care of Wake and Johnston Counties who would help with the convenience sampling of participating medical practices. Over the coming months, these staff members helped to identify two willing medical practices with space available to conduct focus groups. The researcher contacted the designated individuals in the practices to explain the research project, its data collection methods and the protection of human subjects.

Although some practices engaged in the one-on-one recruitment of focus group participants, generally recruitment was conducted through the use of flyers posted in the waiting room of participating practices. The flyers stated that each participant would receive a $50 gift card and a meal in exchange for his/her time. The food was provided to engender a relaxed atmosphere that facilitates discussion. Efforts to assure confidentiality and frank discussion among the research participants were facilitated by

excluding the staff members of the practices from the focus groups. Interested dual eligibles signed up at the front desk or called a phone number at the practice to express their interest in participating.

In March 2012, the researcher began to identify community-based settings that might be willing to host focus groups for senior dual eligibles and younger dual eligibles. Contact was made with the Director of the "Triangle J Council of Governments," an organization covering seven counties (including the four research networks), that "promotes collaboration among local governments, stakeholders and partners, tackling challenges that cross jurisdictional lines" (Triangle J Council of Governments [TJCOG], n.d., para. 1). Through this contact, the researcher used the snowball method to identify other contacts who eventually lead to hosting agreements with three senior centers and two community-based centers for individuals with disabilities. The patient recruitment strategy noted above was repeated at these community-based centers.

It was more difficult to identify willing practices in Orange and Chatham Counties where the 646 demonstration was being conducted. Officials at the state level seemed uneasy about offering assistance for fear of conflicts with the Centers for Medicare and Medicaid Services (CMS). In April, 2012, a contact identified two health policy researchers at the University of North Carolina with information about which practices might be willing to participate. However, through another contact at CCNC, the researcher learned that CMS was conducting a 646 evaluation during the data collection period, and this may have hampered the willingness of 646 practices to participate in this research (T. Robinson, personal communication, November 5, 2012). Nonetheless, one 646 practice consented to host focus groups on September 13, 2012. Unfortunately, there

were problems recruiting for these focus groups; although at least five dual eligibles agreed to participate in each group, only two older dual eligibles arrived for the first, and only one joined the second. Thus, these sessions were more accurately described as "in-depth interviews."

Further, although the researcher diligently attempted to educate staff members at medical practices and community-based centers about the recruitment of only dually eligible patients, patient recruitment efforts were imperfect, and occasionally the researcher later learned that not all participants were dually eligible. In response, analysis excluded data from the few participants who were not dually eligible. (More detailed information is found in the footnote associated with Table 11).

Fortunately, there were fewer challenges and surprises conducting the individual interviews with care managers. Care managers associated with participating practices were asked if they would be willing to share their care coordination experiences in an individual interview and they agreed. The logistics associated with interviews were as follows:

- June 8, 2012: two individual interviews were conducted in a community setting with two care managers who worked with the Johnston County practice where focus groups had been conducted the previous day.
- August 7, 2012: an individual interview was conducted in a community setting with a care manager who worked with the Wake County practice where focus groups were conducted the following day.

- August 8, 2012: an individual interview was conducted in a community setting with a care manager who worked with the Wake practice where focus groups were conducted that day.
- September 13, 2012: two individual interviews were conducted in a medical practice with two care managers who worked with the Orange County practice where focus groups were conducted that day.

The logistics and conduct of the focus groups and interviews took over four months (from early June through mid-September, 2012) and approximately 150-200 emails and numerous phone calls were exchanged in an effort to recruit study participants. Table 11

Table 11: Data Collection Timetable

Date	County	Model	Setting	Interview Type	Interviewee Type	#participants
6/7/12	Johnston	PCCM	MP	FG	DEs age 65+	4[4]
6/7/12	Johnston	PCCM	MP	FG	DEs age 18-64	7
6/8/12	Johnston	PCCM	CBS	II	CM	1
6/8/12	Johnston	PCCM	CBS	II	CM	1
6/28/12	Chatham	646	CBS	FG	DEs age 65+	7
6/29/12	Wake	PCCM	CBS	FG	DEs age 18-64	5
6/29/12	Orange	646	CBS	FG	DEs age 18-64	7
7/19/12	Johnston	PCCM	CBS	FG	DEs age 65+	8
8/7/12	Wake	PCCM	CBS	II	CM	1
8/8/12	Wake	PCCM	MP	FG	DEs age 65+	6
8/8/12	Wake	PCCM	MP	FG	DEs age 18-64	3[5]
8/8/12	Wake	PCCM	CBS	II	CM	1
9/13/12	Orange	646	MP	IDI	DEs age 65+	2
9/13/12	Orange	646	MP	IDI	DEs age 18-64	1
9/13/12	Orange	646	MP	II	CM	1
9/13/12	Orange	646	MP	II	CM	1
9/14/12	Orange	646	CBS	FG	DEs age 65+	8[6]

Key: FG = focus group, DE= dual eligibles, IDI = in-depth interview, II= individual interview, CM= care manager, MP= medical practice, CBS = community-based setting

[4] Focus group (FG) also included one low-income individual (LII) who did not reveal non dually eligible (DE) status during meeting. While LII's participation facilitated a lively group dynamic, his/her content excluded from results and s/he excluded from tally of number of DE research participants.
[5] FG included two non-dual LIIs; their content was excluded from results and they were excluded from tally of number of DE research participants.
[6] FG included one non-dual LII; his/her content was excluded from results and s/he excluded from tally of number of DE research participants.

details the dates of the data collection effort, the settings where the data collection was conducted, and the geographical locations. The total number of dual eligibles interviewed was 61, and six care managers were interviewed. Many data were collected during these sessions. The number of discussions totaled 17, and there were 485 pages of transcribed data.

11. Organizing, Categorizing, Summarizing & Analyzing Data

Established qualitative data procedures were used for data management and analysis. Interviews and focus groups were audio recorded and transcribed; notes taken during these discussions facilitated this procedure. Through an iterative process, the data were synthesized into common themes in two phases. Phase one began in September 2012 after the data collection was complete. Preliminary research results were prepared through an immersion in the transcripts, using an old-fashioned tallying method, counting the themes that emerged the most often, and at the highest levels of intensity.

The same approach to theme identification was used during phase two, which commenced in the late fall of 2012 and continued through the summer of 2013. The management and analysis of data was facilitated by QSR International NVivo 9 qualitative analysis software; the researcher's GWU job provided valuable software training and use opportunities. For this research, Nvivo was employed to conduct a thematic content analysis, transforming the data into increasing levels of abstraction through "pattern coding." The pattern codes were used to pull large volumes of material together into distinct, meaningful overarching themes. Appendix E includes a matrix that shows the themes explored using the software and organized into nodes and sub-nodes.

This matrix explicitly shows how the data were transformed into increasingly higher conceptual levels. This coding process was applied consistently through phase two of the analysis.

After using Nvivo to organize, categorize, and consolidate the data into themes based on frequency and intensity of discussions, the data analysis was conducted. This effort was driven by the literature, which provided a lens through which to consider the data. For example, when considering the way the sampled dual eligibles felt that their care was coordinated through NC's PCHM, the Center for Health Care Strategies' (CHCS') definition of coordinated care, receipt of "the right care, delivered at the right time, and in the right setting*"* was utilized (CHCS, 2010b, p.1). Thus, the analysis focused on evidence indicating whether and why participating dual eligibles might agree or disagree with the concept that NC's PCMH offered the right care, delivered at the right time, and in the right setting. This is but one example of how the literature influenced the data analysis process. Further, the two AHRQ conceptual models grounded the data analysis. These were compared to the "real world" experiences of sampled care managers. Throughout the analysis process, the researcher considered the extent to which the sampled population was representative or atypical of the phenomenon being described; this rigor aimed to improve the quality of the analysis.

12. Qualitative Research Standards & Addressing Research Threats & Study Limitations

This section describes the researcher's adherence to Burns' five standards of qualitative study which include: 1) descriptive vividness, 2) methodological congruence and excellence, 3) analytic precision, 4) theoretical connectedness, and 5) heuristic

relevance. Also included is a discussion of the methods used to address threats to the validity of the research, as well as the study limitations.

12a) Descriptive vividness

In order to adhere to Burns' first standard of descriptive vividness, the researcher developed a contextual description of the data collection experience. To assure validity, detailed notes were drafted throughout the data collection, management and analysis process for clarity and descriptive credibility. In the summer of 2012, five trips were made to NC for data collection. A sufficient time was committed at each medical practice and community center in order to gain a familiarity with these settings. The researcher's previous experience with focus groups and interviews honed the required observational skills.

12b) Methodological congruence and excellence

Burns' second standard is methodological congruence, which required researcher knowledge of the appropriate meta-theoretical approach. The works of Yin, Patton, and Creswell informed the decision to use the hybrid case study design (Creswell, 2009; Patton, 1990, Patton, 1999; Yin, 2003). As described above, the selection of NC's PCMH as the case was guided purposefully through "intensity sampling," an approach that identifies "information-rich cases that manifest the phenomenon intensely" (Patton, 1990, p.183). The health policy literature indicates that NC's PCMH program has been shown to lower the costs and increase the quality of enrollees' healthcare, which makes the approach a topic of interest. Further, NC's PCMH program was chosen as the case because it was designed as a relatively inexpensive approach to coordinating care (which may possibly improve quality) for the dual eligibles, a population of interest because they

are one of the nation's most high-cost and vulnerable populations.

Further, this approach incorporates phenomenological techniques to enrich the case data by "captur[ing] people's experience of the world" (Patton, 1990, p.71). Thus, this hybrid case study design aims to understand how well NC's PCMH coordinates care for dual eligibles, using the patient perspective to inform and enhance the findings. It also strives to comprehend the care coordination challenges that care managers face in their support of NC's PCMH. Thus, the phenomenological lens is an appropriate perspective to utilize when seeking these research objectives.

In order to assure methodological congruence, this hybrid case study design is employed throughout the entire study. For example, the research questions seek to identify "Case Study" information about the program itself, by asking about the challenges that NC's PCMH faces in providing care for the dual eligibles. The research questions also address the phenomenological issues, asking about the experiences of the dual eligibles and care managers. The queries also ask care managers to reflect upon AHRQ's Care Coordination Ring and Care Coordination Mechanisms Framework in order to gain insight about the representativeness of these models vis-à-vis care managers' "on the ground" experiences supporting NC's PCMH.

The data collection methods follow both the case study methodology and phenomenological approach. In order to access the data needed to write the Case Study Results (of Chapter 4), an extensive literature review, a thorough internet search, and communications with state officials were required. Further, the focus groups and interviews with dual eligibles and care managers were conducted to access the phenomenological data required to answer the research questions.

The data analysis followed a similar approach. The Case Study aimed to understand the many facets of NC's PCMH program including: its history and evolution, its results, and the operations and finances of its supporting non-profit organization, Community Care of North Carolina. The care manager interviews provided contextual information regarding the functioning of NC's PCMH, but they also provided phenomenological insights regarding the challenges of coordinating dual eligibles' care.

Not surprisingly, the analysis of the phenomenological data was different from the Case Study information. Instead of focusing on facts and figures, it targeted the perceptions of care managers, who described the issues they faced when coordinating dual eligibles' care, and discussed how their experiences were the same or different as those represented in AHRQ's contextual frameworks. Further, dual eligibles expressed their feelings about the necessary components to care and barriers to that care. The phenomenological analysis was based on the frequency of topic discussions and the intensity of certain conversations with dual eligibles and care managers. For example, if a topic arose over and over again, and with passion, it was noted. The use of Nvivo software facilitated the data analysis.

Finally, the reporting of the findings followed the hybrid case study design. As will be discussed in greater detail in the chapter that follows, the reporting of the Case Study Results was guided by well-regarded examples of qualitative case study research identified in the health policy literature. These articles illustrated the contextual factors and details that must be reported in order to produce a high-quality Case Study.

The phenomenological reporting followed the same approach as the analysis, and was based on the frequency and intensity of topic discussions with dual eligibles and care managers. However, although certain issues were not frequently discussed, they were

noted because of their implications regarding the phenomenon of interest. For example, although only one dually eligible participant seemed to "fall through the cracks" because she did not receive needed care coordination services provided by a CCNC care manager, her experience was noted because it suggested an area of improvement for NC's PCMH.

In sum, methodological congruence requires the researcher to employ the same study design throughout the conduct of the research. This research utilized a hybrid case study design throughout the study, from the research questions, to the data collection methodologies, to the data analysis and the reporting of findings.

As mentioned above, in addition to methodological congruence, Burns also stresses the importance of methodological excellence, which is required for rigor in: i) documentation, ii) procedure, iii) ethics, and iv) an audit trail. Each of these topics is discussed in turn below.

12bi) Methodological excellence: documentation

While rigorous documentation involved clearly presenting the study elements, procedural rigor entailed assuring adequately-recorded data, and identifying the data that were representative of the data as a whole. The researcher identified no fully tested pre-existing interview guides regarding care coordination to use for this study's interviews and focus groups. Thus, the researcher worked closely with committee members to draft the interview guides in such a manner that would facilitate the gathering of valid patient-level data.

12bii) Methodological excellence: procedure

Methodological excellence also requires procedural rigor. One possible threat is selection bias in the data-gathering process, a concern because practices confident in their ability to provide high-quality care would be more likely to participate. However, this issue was mitigated somewhat by conducting community-based focus groups, where participating dual eligibles could discuss their experiences in a variety of different PCP practices. Further, there may have been a bias associated with the four high population-density networks that the researcher chose to study. These networks may not be typical of CCNC networks across the state, which has many rural areas. It is likely that the participating networks had more resources than other parts of the state, which could impact the degree to which care was coordinated. One way to address this bias is to acknowledge it, noting that since certain (but not all) networks were selected to participate in the research, the findings only apply to those sites.

There was another potential source of selection bias, which was associated with the sampled dual eligibles. As will be discussed in greater detail in Chapter 5, it is likely that high-need dual eligibles were unable to participate in the research, perhaps due to illness, transportation issues or other factors. Thus, dual eligibles who live independently (and not, say, in a nursing home), and who have lower health risks would be expected to participate; this subpopulation of sampled dual eligibles may not be representative of the population of dual eligibles as a whole.

Another potential source of patient-level selection bias is regarding mental health. Although about one in two dual eligibles have a mental or cognitive impairment, those with a mental disability or severe mental illness were excluded to protect data validity.

Given this, it seems likely that healthier dual eligibles would have agreed to participate. Further, it is probable that this group would require less intensive care coordination than patients with more complex medical needs. This patient-level selection bias was mitigated somewhat by gathering and analyzing demographic information regarding each participant so that the research sample could be accurately described, and reiterate that research results are *not generalizable* to dual eligibles as a whole. Further, it was not expected that this research would capture the experience of NC's highest-need dual eligibles, because NC's PCMH model does not integrate acute and long term care services.

Another procedural rigor threat is the Hawthorne effect, the impact of the researcher's presence on the individuals interviewed (Maxwell, 2008). There was an effort to reduce this threat by including language in the interview guides that informs interviewees that "there are no right and wrong" answers, to alleviate pressure to provide certain answers to the researcher's queries. This language may have also addressed another procedural rigor threat: study participants may lie to the researcher, or, in struggling to recall an event, may substitute their own ideas that may not reflect what actually happened. The exclusion of dual eligibles diagnosed with diminished decision-making capacity may have helped to reduce this threat. Further, the interview guides asked respondents to limit their responses to experiences that occurred in the past six months to improve recall. Moreover, the questions were designed to access subjects' experiences by avoiding theoretical jargon.

Another threat to procedural rigor involved researcher bias, which could have manifested as interpreting atypical events as typical. To address this problem, the

researcher routinely considered the different types of threats throughout the data collection and analysis process, and when atypical but highly problematic issues were identified, the situation was noted in the discussion of results. For example, one highly-problematic issue was the inability of two disabled dual eligibles to access services. In this case, the researcher noted that although such scenarios were highly uncommon within the sampled population, the situation was serious enough to require further attention.

Triangulation improved procedural rigor. A number of data collection and analysis strategies were used because "each method reveals different aspects of empirical reality, [and] multiple methods of data collection and analysis provides more grist for the research mill" (Patton, 1999, p. 1192). Focus group data, in-depth interview data, care manager interviews and a thorough document analysis were utilized to study the same issue from many perspectives. Another important data source for purposes of triangulation was Chapter 4's Case Study findings, which were reviewed and validated by CCNC's Director of Operations and Vice President for Communications (M. Benton & P.J. Mahoney, personal communication, October 15, 2013).

12biii) Methodological excellence: ethics

Of course methodological excellence also involves ethical rigor. To protect it, the researcher attempted to assure that the rights of study participants were protected by appropriately gaining their consent and informing them of their rights. The researcher followed all GWU's IRB procedures in gaining participant consent.

12biv) Methodological excellence: audit trail

Methodological excellence also involved a decision trail that allowed for "auditability," which enabled a second GWU graduate student to independently confirm the researcher's conclusions. GWU's Doctor of Public Health (Dr. PH) students must gain "real world" research experience in order to graduate. In mid-2012, Dr. PH student Kate Hohman agreed to participate as a research auditor, to assure that the data logically led to the themes and findings. This work was done by considering each theme that the researcher identified in the results in Chapter 5, and then reviewing the evidence in the transcripts. The researcher responded to each of the auditor's question, and on September 21, 2013 both researcher and auditor agreed that the process had been successfully completed.

12c) Analytic precision

This study also adhered to analytic precision, Burns' third standard, which required that decision-making processes be identified and recorded. Threats were mitigated through careful thematic development and the appropriate documentation of the related thought processes. Concrete data were made more abstract in order to develop a "theoretical schema" which gave meaning to the phenomena being researched. Further, analytic precision required that the decision-making processes were identified and recorded, and the theoretical scheme was cross-checked with the study's data and reported in detail. Moreover, analytic precision was enhanced by clearly documenting the inclusion and exclusion criteria for the research themes and through the appropriate assignment of data to the themes.

The work of the GWU research auditor also bolstered analytic validity through the review of relevant portions of transcripts, codes, and research findings in order to assess whether the auditor's conclusions were in congruence with those of the researcher. While often this was the case, sometimes it was not. In these situations, the researcher reviewed the original data and sometimes found that the auditor's conclusions were correct. When this was not the case, the researcher was required to show more clearly the evidence that was used to arrive at the findings. This lengthy iterative process ultimately served to improve the quality of the research.

12d) Theoretical connectedness

This research also adhered to Burns' fourth standard of theoretical connectedness, whereby the research's theoretical foundation had to fit the existing knowledge, be logically consistent, and reflect the research data. Although theoretical correctness may be threatened when concepts are not clarified, when there is no relationship between concepts, or when the proposed relationships between the concepts are not validated by the data, the use of clear concept-mapping in this research mitigated that threat. Further, although this standard may be at risk when theoretical statements are internally inconsistent, or the theoretical model does not adequately describe the phenomena under study, the use of the theory triangulation technique addressed these threats, by considering different perspectives or theories (like rival explanations) when interpreting the data (Patton, 1999).

The research auditor revealed two potential rival explanations including the possibility that NC's managed FFS delivery system encourages over-treatment; once this possibility was raised, the researcher became more aware of the potential problem and

was more receptive to evidence suggesting that this might be the case. Another rival perspective was regarding a strategy for coordinating care (conducting family conferences with medical teams) that did not seem to be implemented through NC's PCMH. However, the research auditor noted that while it may have *seemed* that this tactic was not utilized, (because it was not discussed in the focus groups), it would be unwise to make this assumption, because there was no question specifically addressing this issue in the questionnaire. Again, the quality of the research findings was advanced through the collaborative efforts of the research auditor and researcher.

12e) Heuristic relevance

Burns' fifth standard was heuristic relevance; the research findings had to be applicable to the larger world. The applied nature of this health policy research meant that heuristic threats that were less worrisome than other types of risks.

12f) Summary

In aiming for the development of excellent qualitative study, Burns' article was helpful because it identified criteria that must be met in the areas of: descriptive vividness, methodological congruence and excellence, analytic precision, theoretical connectedness and heuristic relevance. This section described how the researcher worked to meet each criteria, and the way the threats to these standards were addressed. Threats to procedural rigor were the most prominent of all the risks described and included selection bias associated with participating networks, PCP practices, and dual eligibles. Another concern was researcher bias, or interpreting atypical events as typical. The researcher aimed to resolve all the threats or minimize them through a number of different approaches including the: utilization of an audit trail for coding and theme

development, use of triangulated data sources where possible, and consideration of potential rival explanations.

13. Role of the Researcher

Due to the interpretive nature of the case study, the researcher is a central figure (Creswell, 2009, p.177). The researcher's prior experience has focused on health care for disadvantaged populations, such as women and children of low socio-economic status. As an undergraduate, the researcher conducted focus groups with women in Nigeria for a thesis on reproductive health choices. After receiving a Master in Health Science degree, the researcher was employed by a consulting firm and conducted extensive in-depth interviews with officials in Delaware, Maryland, New York, North Carolina and Virginia regarding the provision of Medicaid services. These efforts led to an interest in another disadvantaged group with whom the researcher had no previous experience, the dually-eligible. Although the researcher conducted an evaluation of NC's Department Health and Human Services in the late 1990s, she had no prior-existing connections with the individuals or settings involved in NC's PCMH.

14. Conclusion

This methodology has stated the research goals, and rationale for selecting the hybrid case study design. Further, the case was fully delineated. The case is NC's PCMH program and its geographical boundary is the Raleigh-Durham region. Further, the case is temporally bound, from early June, 2012 through mid-September, 2012. A stratified sampling strategy was employed to identify focus group and interview

participants: older dual eligibles, younger dual eligibles and care mangers. Purposeful sampling was utilized to identify high population-density counties, and convenience sampling to identify the sampled medical practices and community-based settings.

The methodology also described the two interview instruments that guided the data collection efforts, and the pilots which tested the two tools. While the use of triangulation and research audit were described as approaches to bolstering the validity of the research, the chapter also highlighted the limitations associated with this methodology. Finally, the data organization and analysis strategies were identified, as was the role of the researcher.

Chapter 4: Results- CCNC Case Study

1. Introduction

As noted in Chapter 2's Literature Review, consistent evidence indicates that the dual eligibles receive inferior care. However, few studies assess how care is perceived by dual eligibles themselves. Lind and Gore (2010) report that the design of innovative models of care for the dual eligibles should be informed by insights by the dual eligibles themselves about their unmet needs and how to meet them.

This chapter describes North Carolina's (NC's) patient-centered medical home (PCMH), a model lauded in the health policy literature as providing lower cost, higher quality provider-driven care. The broad goal of this research is to ascertain how well NC's PCMH coordinates the dual eligibles' care. Section Two describes the history and evolution of NC's PCMH, and Section Three focuses on the operations of the non-profit organization that supports NC's PCMH, Community Care of North Carolina (CCNC). A discussion of the estimated cost savings associated with NC's PCMH program are highlighted in Section Four, and Section Five focuses on CCNC from a financial point of view**.**

The structure and approach of these sections was guided by examples outlined in two articles. The first is by Lukas et al. (2007). The article describes a comparative study of 12 health care systems, illustrating which contextual factors are appropriate to consider in case study research. The second is Harrison and Kimani's (2009) description of Denver Health's system redesign, which exemplifies descriptive vividness and contextual detail in health policy case study research. Finally, Section Six concludes the chapter.

2. History and Evolution of NC's PCMH

The foundation of NC's PCMH is the American Academy of Pediatrics (AAP) medical home framework. Introduced in 1967, the model has expanded to include the principals of being accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective (American Academy of Pediatrics [AAP], 1992). Although the framework has changed over time, some researchers argue that it cannot meet the requirements of patients with complex and costly needs (like dual eligibles), because it lacks "explicit incentives for specialists and hospitals to coordinate care with the medical home" (Shortell, & Casalino, 2007, p.18). Perhaps in response to this criticism, AAP's model now includes care coordination, an explicit link to the broader health care system. This enhanced framework was termed the patient centered medical home (PCMH) (The Community Care of North Carolina [CCNC], n.d.l). In the PCMH, a primary care physician (PCP) is linked to a patient in an on-going relationship. While the PCP leads a team accountable for patient care, the PCP is also responsible for addressing all the patient's health care needs and coordinating care across the health system and broader community. Further, PCPs who provide care through a PCMH are engaged in safety and quality improvement (QI) initiatives (Health Resources and Services Administration [HRSA], n.d.b; Reid et al., 2009.

A similar evolution occurred in NC. In the late 1980s and early 1990s, NC's traditional Medicaid program faced increasing medical care costs, and state leaders considered abandoning the fee for service (FFS) payment model, in order to contract with commercial managed care organizations (MCOs) that would provide Medicaid services on a capitated basis. This approach was utilized on a very limited basis, with MCOs offering services in just

three counties for approximately 20 years (North Carolina Department of Health and Human Services, Division of Medical Assistance, 2013).

The focus of the state's cost control and QI efforts took a different direction when it began to build its own infrastructure to lower costs and improve quality. In 1991, NC's Department of Health and Human Services (DHHS) contracted with local PCPs to control Medicaid costs using Medicaid's primary care case management (PCCM) payment model. Enrollees must select a PCP "who is responsible for coordinating the enrollee's care and is paid a monthly fee for doing so, on top of payment for providing medical services" (Robin & Cohen, 2009, para. 2). Through the PCCM, care is available 24 hours a day, seven days a week" (Robin & Cohen, 2009). A 1915(b) Freedom of Choice Waiver enabled NC to mandate the enrollment of certain categories of Medicaid participants on a pilot basis in five counties (CCNC, n.d.l). Called "Carolina Access," the pilot enabled beneficiaries to access primary and preventive care while linking them to specialty care (CCNC, n.d.l). PCPs were paid $3 per member per month (PMPM) to act as "gatekeeper to specialty services" and cover the costs associated with coordinating their Medicaid patients' care (CCNC, n.d.l; Domino, Humble, Lawrence, & Wegner, 2009; The Henry J Kaiser Family Foundation [KKF], 2009).

In 1992, after achieving approval for a 1915(b) waiver amendment, Carolina Access began to expand statewide. Later, PCPs in nine counties formed private non-profit community networks committed to an "enhanced" PCCM model based on the medical home, and bolstered with care management and QI initiatives (CCNC, n.d.l; KKF, 2009. Further, 26 large practices, nearly all of them pediatric, agreed to participate in a private non-profit statewide physicians' network (Partnership for Community Care, Community Care of North Carolina, n.d.).

The network was supported by initiatives developed and coordinated through a central office, now a non-profit organization called Community Care of North Carolina (CCNC). The 14 provider networks contract with the state, which covers operating expenses for staff and health care initiatives. While CCNC's central office has a relatively small staff, it develops and implements QI initiatives across the state and engages with the local networks (North Carolina Department of Health and Human Services [NCDHHS], 2013c). The networks themselves employ clinical coordinators, case managers, and pharmacists to conduct external targeted care management and care coordination for enrollees to improve care quality while containing costs (Verdier, Byrd, & Stone, 2009). This is done by identifying high cost, high risk, high need patients, offering them care management services, and strategizing with their PCPs about the best approaches to meet their needs (Verdier, 2009).

Over time, CCNC's infrastructure grew as it implemented statewide disease and care management initiatives focusing on specific diseases like asthma, diabetes, and congestive heart failure, as well as broader efforts like improved medication management, dental screening and reduced Emergency Department (ED) utilization (Verdier, 2009). An important aspect of these tactics is the on-going submission of performance measurement data to CCNC by the networks (Verdier, 2009). These cooperative efforts have achieved success, as has been discussed in numerous research articles describing improved quality (Jackson, Trygstad, DeWalt, & DuBard, 2013; Partnership for Community Care, Community Care of North Carolina, n.d., para, 20; Community Care of North Carolina [CCNC], n.d.g; CCNC, 2012a; Fillmore, DuBard, Ritter, & Jackson, 2013; Steiner, et al., 2008). (Cost savings are described in Section 4: CCNC's Estimated Cost Savings.)

In 2001, under significant budgetary pressure associated with the economic downturn, state officials decided to expand the program statewide. From 2001 through 2005, nearly all of NC's 100 counties agreed to participate (Partnership for Community Care, Community Care of North Carolina, n.d.). In 2007, the NC Legislature mandated an expansion in CCNC's scope. Care would be managed not only for women and children, but also for NC's Medicaid-enrolled elderly and disabled, dually eligible and Medicare-only populations. This effort was funded by a Center for Medicare and Medicaid Services (CMS) demonstration (CCNC, n.d.k).

By 2011, all of NC's 100 counties were enrolled in CCNC. Providers included 14 physician-led, private non-profit networks comprised not only of PCP practices offering medical homes, but also of hospitals and local health and social services departments (Verdier, 2009). Over one million Medicaid recipients are now served, as are 70,000 low-income uninsured residents, (Partnership for Community Care, Community Care of North Carolina, n.d.). Most of these enrollees receive internal care coordination, through NC's PCMH, (as opposed to that provided externally, through a CCNC care manager). NC's PCMH providers are responsible for coordinating care and addressing all the patient's health care needs" (HRSA, n.d.b; Reid et al., 2009).

In exchange for their participation in these quality improvement and cost control efforts, NC pays care management fees to PCPs (between $2.50 to $5 PMPM) and the networks ($3 to $5 PMPM) (Verdier et al., 2009). Medicaid reimbursement for primary care services is relatively high at 95 percent of Medicare rates; this is an unusual feature of NC's Medicaid program, since few states pay Medicaid rates that are close to Medicare's. The literature indicates that this is a significant factor in obtaining provider

participation in the model (Verdier et al., 2009). Both the provider and the network receive a separate payment for the same patient.

Thus, from the late 1990s through today, NC's healthcare delivery system has transformed as it planned, launched and implemented its own infrastructure to conduct QI and cost-cutting strategies. During this time, the evolving philosophy, policies and payment model of NC Medicaid have reflected the changing PCMH program (Domino et al., 2009). Today, NC aims to connect enrollees to a PCMH that offers "accessible, comprehensive, coordinated, [and a] family-centered form of care" (Domino et al., 2009). Although not all participating individual CCNC practices have been certified as PCMH by the National Committee for Quality Assurance (NCQA), each CCNC patient has a PCP and a practice that is intended to operate as a PCMH. A CCNC PowerPoint presentation notes "Key Attributes of Our Medicaid Medical Home [include:]

- Provide 24 hour access
- Provide or arrange for hospitalization
- Coordinate and facilitate care for patients
- Collaborate with other community providers
- Participate in population management – care and disease management /prevention/quality improvement
- Serve as single access point for patients" (Hewson, 2010, slide 3)

The implication is that care coordination is provided internally, through NC's PCMH for all Medicaid and dually eligible patients.

Local hospitals and health/social services departments participate in each CCNC network and link participating CCNC PCPs and their patients to the community and to specialty services (Steiner et al., 2008). CCNC's payment methodology, which enhances the standard Medicaid fee schedule with the PMPM management fee, provides incentives

to deliver comprehensive primary care and to enable patients to access specialty care, two key components of the PCMH (Steiner et al., 2008).

Indeed, all CCNC patients benefit from another PCMH principal that has been operationalized in NC's PCMH: CCNC requires participating practices to improve access to services by providing 24-hour on-call coverage (Steiner et al., 2008). CCNC's continuous QI efforts are further evidence of adherence to the PCMH model (Steiner et al., 2008). Another characteristic of the PCMH is the provision of the care management services: for certain high cost, high risk patients, the intervention is provided by CCNC care managers. For lower cost, lower risk patients, care coordination services are provided internally through NC's PCMH (Tilson, 2013).

Another delivery system was built upon NC's PCMH and launched in January, 2010, a five-year Medicare Health Care Quality demonstration (or "the 646"). The 646 aimed to integrate acute care for dual eligibles and Medicare-only beneficiaries served by NC's PCMH (Wade, Ciesco, & Floyd, 2011). Eight of CCNC's 14 local networks have participated in the 646. (Chapter 3's Figure 7 shows the location of the 646 network). The demonstration aimed to improve the "quality of care and services delivered to Medicare beneficiaries through system redesign that fosters best practice..." by allowing NC to use previously-inaccessible Medicare A and B data files to identify patients in 646 regions needing care management interventions, track claims-derived performance measures, and establish outcomes for quality enhancements (Wade, Ciesco, & Floyd, 2011, p.245).

The 646 relied upon a shared savings model (SSM), payment reform seeking to change financial incentives (Wade, Ciesco, & Floyd, 2011). In the SSM, the state and

federal government agree to share any Medicare savings resulting from implementation (Coomer, et al. 2012). In year one, NC was slated to receive 50 percent of any savings if it met the quality-of-care objectives. Each year after that, the percentage of savings contingent on achieved goals was to increase by 10 percent. In year four, NC savings were to cap at 80 percent (Wade, Ciesco, & Floyd, 2011). In order to ascertain whether NC should receive the savings, the demonstration included out-of-state comparison groups with characteristics similar to those of participating NC counties (CCNC, n.d.d)

The new financial incentives and Medicare data would be required to address the myriad needs of the new patients served, many with multiple chronic conditions. To meet the additional demands, participating providers were required to sign contracts that involve the following QI strategies (Wade, 2009):

- Better management of patients transitioning from one care setting to another so that only 20 percent or fewer Medicare patients who were discharged from the hospital would be readmitted within 30 days.
- Enhance management of patients with multiple chronic illnesses (since nearly 70 percent of Medicare funds are spent providing care for patients with three or more chronic illnesses).
- Improve utilization of NC's PCMH program through the development of processes to enhance chronic illness care including adherence to the model's call for "care management support, information, and best practice," which would involve medication reconciliation and other interventions.

- Bolster community provider communications, encouraging more engagement of PCPs with the CCNC Informatics Center in order to assure the provision of timely and meaningful data and reports (Wade, 2009).

Beneficiaries were assigned to the 646 based on whether they had received a "qualifying service" from a medical practice participating in the 646 (Wade, 2009). CCNC officials reported that while providers and some staff members were aware of which individuals participated in the 646, the patients themselves did not have knowledge of it (N. Mendon, personal communication, December 10, 2012).

Unfortunately there is little available information regarding the actual program enhancements for patients enrolled in the 646. However, NC's 2012 Dual Eligibles Coordinated Care Demonstration proposal ("the Dual Eligibles Proposal") to CMS notes that bolstered services were geared to dual eligibles needing long-term care (LTC), those residing in nursing homes and adult care homes, and those with kidney insufficiency (NCDHHS Division of Medical Assistance, 2012, pp. 7, 20, 21). Thus, the 646 targeted special initiatives on its highest needs dual eligibles.

Finally, there is evidence that the 646 did not meet its goals. The Dual Eligibles Proposal suggests that although CCNC expected to receive Medicare A and B claims data on their dual patients early in the demonstration, these were delivered later than expected, and were reported to be less than complete which hindered expected efficiencies: "Hobbled by the absence of Medicare claims data for risk stratification and targeting until month 20, it is not surprising that these pilot efforts have yet to show evidence of anticipated cost-savings" (NCDHHS Division of Medical Assistance, 2012, p.7). In sum, the 646 could be described as less than successful and ended before the expected 5 year

demonstration period (CCNC, n.d.f; North Carolina Community Care Networks, Inc. [NCCCN, Inc.], 2012).

3. CCNC Operations

This section describes current-day CCNC operations, the basis for many care coordination services provided through NC's PCMH. This portion of the chapter is divided into the following subsections: Section 3a) describes CCNC's mission and vision, which guide system operations. Section 3b) discusses CCNC's operational functions, and Section 3c) covers the operational infrastructure that enables CCNC to do its work. CCNC's data security systems and legal considerations are the topics of Section 3d). CCNC's culture is described in Section 3e).

3a. CCNC's Mission & Vision

CCNC's website indicates that the organization's mission statement is "to improve the health and quality of life of all North Carolinians by building and supporting better community-based health care delivery systems" (Community Care of North Carolina, Northern Piedmont Community Care [CCNC, NPCC], n.d., para. 1). The site suggests that this goal is to be achieved through the following "key visions" (CCNC, NPCC, n.d.).

- "We will enhance and support advanced primary care for patients.
- We will focus on improving quality, value and resources available to the local healthcare system for the benefit of all North Carolinians.

- We will effectively manage the care provided funded by Medicaid and other public programs to provide the best care at the best value for North Carolinians.
- We will collaborate effectively with all North Carolina health care providers and serve as a nonproprietary representative of all providers and integrator in our communities.
- We will provide national leadership in health care reform" (CCNC, NPCC, n.d., para. 4).

As the repeated use of the word "we" suggests, the organization was envisioned by CCNC as a partnership, not like the hierarchical structure as shown in the Kaiser Family Foundation's representation of the non-profit in Chapter 2's Figure 6. Instead the researcher envisions the organizational structure more as a three-legged stool that includes the providers, their local CCNC networks, and the state-level CCNC office.

3b. CCNC's Operational Functions

CCNC's goal is to help participating providers manage patient care and its associated costs through the collaborative effort of CCNC's central office and the 14 local networks. The central office helps the local networks "to adopt shared performance goals and measures, create policies and provide training and reporting" (CCNC, n.d.i, para. 2). When CCNC began its work over two decades ago, two state agencies were responsible for program management. NC's Division of Medical Assistance (DMA), (which handles Medicaid and State Children's Health Insurance Programs), was responsible for CCNC's financing and policy (CCNC, n.d.i). NC's DHHS provided "technical assistance, training, data analytics, reporting and communications" through its Office of Rural Health and

Community Care (CCNC, n.d.i, para. 19). Under this structure, one senior employee at each of the two agencies was accountable for all program activities within the two organizations. This approach was utilized for over 10 years.

In 2006, when the state decided to participate in the 646 Demonstration, state agencies were not eligible to participate, so the 14 provider networks established an independent non-profit organization, North Carolina Community Care Networks, Inc. (NCCCN), to apply on their behalf. A board of directors governs NCCCN and includes representatives from each network, including hospitals and health/social service departments. The creation of an independent central organization has had two benefits. First, it helps achieve an important programmatic goal: to improve the care delivered to all NC patients, whether they are enrolled in Medicaid or private insurance. Moving the program out of state government had the potential to attract a greater diversity of providers, payers and insurers. Indeed, beginning in January, 2012, the private company GlaxoSmithKline contracted with CCNC to enable its employees to benefit from the CCNC's PCMH infrastructure (CCNC, n.d.e).

The second advantage of utilizing an independent central organization was that funding levels grew when care management was no longer provided by the state. When state staff and contractors provided care management, their efforts were reimbursed at 50 percent administrative-match rate. This rate is less than the service-match rate that can be paid to non-state workers at the 75 percent Federal Medical Assistance Percentages (FMAP) match rate (M. Benton & P.J. Mahoney, personal communication, December 15, 2013) (CCNC, n.d.e). This rate differential is perhaps one factor associated with the high level of provider participation (M. Benton & P.J. Mahoney personal communication,

December 15, 2013). In many states, the administrative match and service match rates are about the same, at a 50 percent reimbursement level (KFF, n.d.b).

However, concerns arose from the complete detachment of CCNC operations from the state because CCNC was perceived as an outside contractor instead of the state's Medicaid manager. In response, CCNC became a hybrid program; NC's DHHS continued its role of "financing, Medicaid policy, contracts, compliance and reporting to state officials," and CCNC becoming accountable for "training, information services, technical assistance, pilot program management and communications" (CCNC, n.d.e, para. 22).

Integral to this effort is the *Quality Measurement and Feedback Initiative*, whereby CCCN's board of clinical directors selects certain measures and standards to be used to assess the performance of individual practices and networks across the state (KKF, 2009). This effort involves mining the state's claims databases and the medical charts of participating patients for local data. These data are compared with national and local benchmarks and the resulting information is shared with participating practices in order to develop strategies to improve care quality. These data are also used for broader efforts to evaluate the program effects (KKF, 2009).

Provider engagement in these QI initiatives is key to achieving the goals of improved care provided at reduced cost. Through their participating PCPs, the 14 local networks are responsible for providing primary care as well as referral and service authorizations through the PCMH (Alabama Medicaid Agency, n.d.). In order to assure physician success, the local networks offer targeted provider education, endorse best practices, and engage in ongoing performance measurement efforts (KKF, 2009). They also utilize care coordination strategies, including collaborating with local agencies to link their patients with community resources

(Alabama Medicaid Agency, n.d.). Further, in order to meet budgetary, utilization and performance goals, the local networks engage in population management activities including developing care management systems, advancing disease management strategies, and executing state-wide QI strategies, as well implementing pharmacy, emergency department (ED) utilization, and other initiatives (Alabama Medicaid Agency, n.d., KKF, 2009). Finally, the local networks concentrate on high-cost, high-risk enrollees, including some dually eligible patients who meet these criteria. The heaviest utilizers of resources are eligible for care management services and the local networks are responsible for ensuring that care management funds are appropriately spent.

3c. CCNC's Operational Infrastructure

This subsection describes CCNC's operational infrastructure, its skilled personnel, and its information technology (IT) system. Since sensitive health care information is involved, IT security and a firm legal infrastructure are key components of CCNC's operational infrastructure. The management team of CCNC's central office includes a President/Chief Executive Officer, other high-level officers of finance, information, operations, and staff, as well as a general counsel. The team also includes functional positions related to: behavioral health care, clinical services, commercial operations, communications, data and informatics, finance, government relations, network relations, pharmacy and strategic planning (CCNC, n.d.b).

In order to manage and support target populations, each of the 14 local networks elects a physician who functions as its clinical director and collaborates with CCNC's statewide board of directors to assure the local implementation of statewide QI initiatives (KKF, 2009). To achieve broader CCNC quality and cost goals, each network is also required to hire one or

more pharmacists, QI specialists, nurses, and social workers (Alabama Medicaid Agency, n.d.). Finally, to manage the care of its target populations, the networks must set up and maintain linkages to local providers and community agencies, including behavioral health supports (Alabama Medicaid Agency, n.d.).

The networks' case managers are responsible for sustaining relationships with local PCPs and other providers. They cooperate and collaborate with participating PCPs in order to assist with identifying and assisting high-cost, high-risk patients. They supplement PCP efforts by providing care coordination, disease management education, and transitional support to willing patients (KKF, 2009). In addition to these patient-level efforts, care managers assist with broader population management efforts by participating in QI strategies requiring the collection and reporting of practice-level performance measures (KKF, 2009).

Each local CCNC network hires care managers based on its own QI needs. NC's literature notes that most networks employ a mix of nurses and social workers, including behavioral health social workers with masters' degrees (CCNC, n.d.m). However, this research revealed lower credentialing requirements in certain counties. While care managers were certified social workers and nurses in Johnston and Wake counties, those embedded in a practice in another county had only bachelor's degrees. Finally, there are diverse approaches regarding the location of care managers. While some care managers work from their homes and are shared across practices, there was evidence that is more consistent with CCNC literature indicating that some case managers are located in local health departments and community health centers (KFF, 2009). A CCNC care manager's average monthly caseload is one per 5,000 to 7,500 for average patients, but it

drops to 1,500 to 3,500 for higher risk patients, like those who are aged, blind and disabled (ABD) (CCNC, n.d.m). It is not expected that all patients require care management; these caseload assignments assume that just five to 10 percent of these populations will need services at any given time (CCNC, n.d.m). Thus, the care manager-high risk patient ratio would be expected to be somewhere between 1:75 and 1:175.

Care managers provide services at different levels of frequency and intensity (CCNC, n.d.m). For example, initially a care manager might contact a patient once a week, but this level of support could be scaled back over time. In terms of the intensity of care manager-patient contact, while most communications are telephonic, others have a higher degree of contact like face-to-face meetings and/or visits conducted in patient homes (CCNC, n.d.m).

As noted above, care managers and physicians are not the only providers who may participate in CCNC. In addition, family nurse practitioners, physician assistants, and nurse midwives play a part, and this is also the case for group practices and centers (Alabama Medicaid Agency, n.d.). No matter what their training, participating providers must satisfy specific obligations. They must adhere to evidence-based best practice guidelines in the provision of acute, chronic, and preventive care. If PCPs are unable to provide the required care, they refer enrollees to other appropriately-credentialed providers (KFF, 2009). Further, they must assure access to medical care for their patients by offering a phone number that patients can call 24 hours a day, seven days a week (KFF, 2009). In addition to these patient-level responsibilities, CCNC network providers must report clinical and other data to CCNC's central office to participate in broader QI initiatives (KFF, 2009).

Communications are a key element of the work that CCNC personnel and affiliated providers do, and IT enables the transfer of electronic healthcare data from numerous sources to many stakeholders (CCMC, n.d.). Since the late 1990s, CCNC has relied on Medicaid claims data as the main source of QI data. These claims are fed into the state's Medicaid agency and are updated on a weekly basis through a processing system, the Medicaid Management Information System (MMIS). The claims populate NC's data warehouse (called DRIVE), which contains at least six years of claims as well as "provider, eligibility, reference file, prior authorization and drug data" (CCNC, n.d.k, para. 3). These data are used for population management efforts, to assess the prevalence of disease, to recognize utilization patterns, and identify quality measures. The Medicaid data (and when available through the 646, Medicare data) are also used to detect high-cost and/or high-risk enrollees, such as those with diabetes and/or those who frequently use the ED (CCMC, n.d.).

Patient-level health records are found in CCNC's Case Management Information System (CMIS), a portal that CCNC care managers may access through the Web in order to facilitate patient management efforts and the fulfillment of documentation requirements. Further, the CMIS includes patient assessment and goal setting tools and health coaching strategies (CCMC, n.d.). The CMIS was developed by an outside contractor that populates the data each month. These data include patient demographic and PCP information as well as Medicaid enrollment and hospital claims, and ED and pharmacy claims (CCMC, n.d.).

The system has two main benefits. First, when using CMIS, care managers document their notes and actions so a history of their efforts is available for other care managers, if needed. Second, the continuity of patient records is maintained even as enrollees churn on and

off the Medicaid and Children's Health Insurance Program (CHIP) rolls, or during gaps in coverage.

CCNC's health IT infrastructure (called the Informatics Center) was bolstered after NC's Legislature mandated that CCNC serve Medicaid's ABD enrollees as well as its dually eligible and Medicare-only populations. The informatics system required improvements in order to better meet the complex needs of the new patients who had numerous co-morbidities, medications and providers. (CCNC, n.d.k) This decision was prompted by ongoing problems associated with Medicaid claims processing delays, and the clinical information gaps resulting from the lack of Medicare Parts A and B claims data (CCMC, n.d.). Further, an unintended consequence associated with Medicare Part D implementation was that the states lost access to pharmacy claims data (CCNC, n.d.k). This lack of information has diminished the value of CCNC's aggregated cost, utilization and quality reports as well as patient-level health records.

In response to the absence of Medicare Part D pharmacy claims data, CCNC has used three supplementary non-claims data sources to manage the care of dual eligibles:

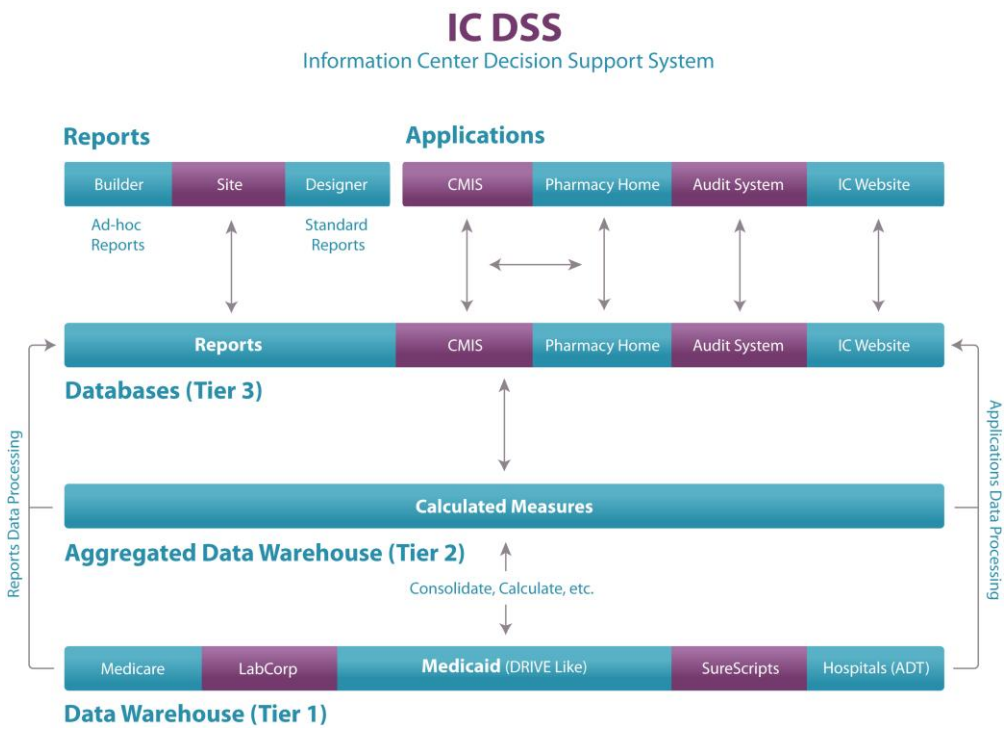
1. Surescripts: a company that enables CCNC to electronically access a 12-month prescription fill history from multiple pharmacies or prescription benefit plans (NCDHHS, Division of Medical Assistance, 2012).
2. LabCorp: sends CCNC's Informatics Center historical and monthly lab results when claims were billed to LabCorp (NCDHHS, Division of Medical Assistance, 2012).
3. Hospital admission, discharge and transfer (ADT) data, accessed through a Thompson-Reuters (now Turven) contract (NCDHHS, Division of Medical Assistance, 2012).

Thus, CCNC has attempted to identify creative solutions to data deficiencies that have hindered its QI initiatives.

Further, CCNC developed "a comprehensive, integrated database of healthcare information from multiple data sources" (CCNC, n.d.k, para. 18). One CCNC central office administrator describes the foundation of the IT system as similar to the i-Phone's mobile operating system, which has increased capabilities when installed with various applications that address the diverse requirements of various patient care teams across the state (T. Trygstad, personal communication, January 9, 2013). A visual representation of the Informatics Center is shown in Figure 8 (CCNC, n.d.k). As shown, CCNC's Informatics Center's offers six front-end applications, some of which are listed at the top of Figure 8.

First, it enables the previously mentioned CMIS system operations, which have been maintained through the Informatics Center since 2009. The second application supports the state's Pharmacy Home Project, which is utilized on a prospective basis to discover gaps in care and to generate reports of patients at risk of drug abuse (CCNC, n.d.k). It is also used on a retrospective basis in on-going QI and evaluation strategies. The third Informatics Center application is used for chart review, and it enables CCNC to appraise over 26,000 medical records. This effort included the 2009 transition from a paper chart abstraction tool to an electronic system that fully encrypts data offline and in transit. It enables skilled personnel to not only monitor the quality of care provided at the practice level, but also to engage in QI efforts at the county, network, and statewide level (CCNC, n.d.k). The fourth application is the web-based Reports Site, which allows appropriate users to create and utilize a series of different reports outlined in Table 12.

Figure 8: Information Center Decision Support System



The Informatics Center's fifth application is the Provider Portal, which was launched in 2010 to enable providers to access a Medicaid patient's health record, including services received from a variety of care settings (CCNC, n.d.k). Through the Provider Portal, a PCP can learn about patient visits to a hospital, a specialist's office, a laboratory or imaging center. This system includes functionality enabling the entry of contact information of members of the care team, so a PCP could potentially contact a patient's case manager, pharmacy, durable medical equipment supplier, mental health, home health, or personal care service provider. Through the Provider Portal, PCPs and other clinicians may access a patient's pharmacy claims history in order to discern whether prior prescriptions were filled, and which medications were prescribed by other providers.

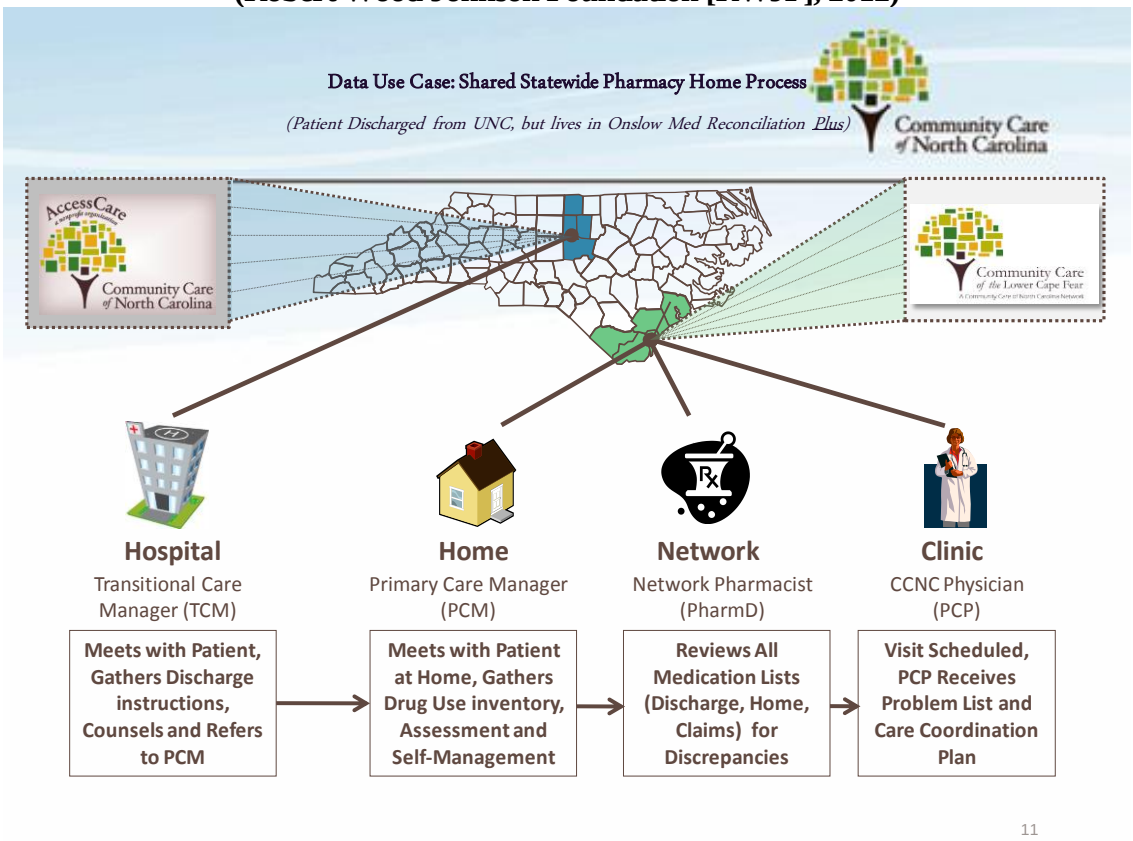
Table 12: CCNC Reports Generated through Informatics Center Reports Site (CCNC, n.d.k)		
Type of report	**Function**	**Purpose**
Quarterly population needs assessment	Identifies demographic, cost, utilization and disease prevalence patterns by service area to represent current ABD enrollees.	Report facilitates program planning and resource allocation, enables outlier identification and tracks utilization patterns.
Risk stratification, identification of high-opportunity patients, patient-level information	Reports generated using the quarterly-updated Chronic Care Patient Database, which includes cost, utilization, and diagnosis data for all ABD enrollees.	Identifies high-risk, high-cost patients for care management interventions (Hewson, 2012).[7]
Monitoring of ED and inpatient visits	Report parameters are hospital- or PCP-specific, or can highlight patient or visit characteristics. Report can tally visit counts by patient or practice.	This weekly-updated utilization report is used by care managers to identify which of their patients have used the ED or have been admitted to the hospital.
Tracking care quality indicators	Quarterly quality measures at the practice-, county-, network-, or statewide-level are tracked using claims data.	Reports offer providers a comprehensive practice-level perspective with trend information, and/or cross-practice comparison opportunities.
Program evaluation and tracking of key performance indicators	Updated on a monthly basis, key indicators include both process measures and outcome measures.	Program performance reports track cost savings and quality improvement metrics for the state Medicaid agency and state legislature.

The graphic in Figure 9 shows how this innovative approach is utilized: the medical records of a patient treated in one part of the state may be viewed by a variety of different providers in another. This multi-dimensional aspect of care delivery is an unusual and helpful

[7] Although it was not possible to ascertain exactly how sampled patients were identified for care management services, a June 28, 2012 PowerPoint by CCNC official Denise Levis Hewson and delivered to Illinois Health Connect indicated that the "priority criteria for flagging dually eligible enrollees" for transitional care management around transitional services include: "1 or more inpatient admits within the past 12 months; 3 or more ED visits within the past 6 months; 8 or more prescriptions over the past month or 24 [prescriptions]/3 months; 3 or more Outpatient Providers over 6 months; 0 PCP visits within the past year, 1 or more 30 day readmissions in the past 6 months; 3 or more chronic conditions, including Mental Health; [and] 1 or more key target conditions: CHF, DM, asthma or COPD." (http://www.illinoishealthconnect.com/files/downloads/Denise_Levis_Hewson_IHC_Quality_Conference_Presentation_June_2012_on_CCNC_Transitions.pdf)

aspect of NC's PCMH (A. Lind, personal communication, January 22, 2013). The system also includes clinical alerts that indicate whether a patient is overdue for recommended care like disease screenings. Finally, the Provider Portal offers provider tools to facilitate the provision of services such as educational materials especially geared to low-literacy patients.

Figure 9: Medical Record of Patient Treated in One Region May Be Viewed By Provider in Another (Robert Wood Johnson Foundation [RWJF], 2012)



(Despite this sophisticated system, for most dually eligible patients the extensive problems associated with the lack of access Medicare Parts A, B and D claims still persist.)

The Informatics Center's sixth application is the North Carolina Community Health Information Portal (NC-HIP). Launched in October, 2012, NC-HIP is used to geographically map data from a number of data bases including:

- U.S. Census Bureau,
- NC's DHHS Health Indicators Warehouse,
- CMS' Chronic Conditions Warehouse,
- the Institute of Medicine,
- Robert Wood Johnson Health Indicators, and
- North Carolina State Center for Health Statistics (CCNC, 2012b).

When these and other data are overlaid in a geographic format, this mapped information can uncover "the interaction between disease, public health, demographics and access to care" (CCNC, 2012b, para. 3). Most of these data are available through the internet, enabling researchers to "identify trends and aid the development of appropriate interventions" (CCNC, 2012b, para. 3). However, certain confidential databases are accessible only to authorized users (CCNC, 2012b).

3d. CCNC's Data Security & Legal Considerations

Since all Informatics Center efforts involve sensitive health care information, a key component of CCNC's operational infrastructure is data security. Data are secured on the macro level through the Informatics Centers' servers, which are located at Hosted Solutions, a SAS 70 Type II certified commercial data center in Raleigh. This company meets National Institute of Standards and Technology physical plant security standards (CCNC, n.d.k). CCNC determined that the use of a commercial data center would require fewer resources and offer more security and reliability than other alternatives (CCNC, n.d.k).

CCNC must comply with federal and state laws governing health care data sharing and protection. On the federal side, the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 are of special concern, as are regulations regarding the disclosure of substance abuse information (42 C.F.R. § 431.302) (CCNC, n.d.k). Further, CCNC must follow state confidentiality laws regarding mental health, developmental disabilities, substance abuse, the human immunodeficiency virus (HIV) and other communicable diseases (CCNC, n.d.k). In order to ensure compliance, CCNC's legal team has developed a provider agreement with NC's DHHS that protects personal health information exchange (CCNC, n.d.k). To support this and broader efforts, CCNC works with legal counsel from multiple stakeholder groups and contracts with a large NC firm that specializes in health-related issues (CCNC, n.d.k; CCNC, n.d.j).

3e. CCNC's Culture

CCNC's previously-discussed team-based philosophy is mirrored in the organization's culture. In a presentation describing its efforts, CCNC indicates that its work is inspired by a Culture of Teamwork with an emphasis on clinical integration (American Hospital Association [AHA], n.d.; CCNC, n.d.a). CCNC emphasizes collaborative efforts to provide patients with high-quality care across conditions, providers, settings, and time (AHA, n.d.). This culture is described by the National Academies Press as a "community-engaged, team-based approach to systems change on a statewide level" (Young, & Olsen, 2010, p. 285). The same publication describes CCNC's culture as a catalyst of change throughout NC since the late 1990s (Young, & Olsen, 2010, p. 285). Originally, the state's care paradigm was focused solely on "physicians in healthcare facilities," but now health care is provided through

"multidisciplinary partnerships involving community members, nonprofit organizations, governmental health and human services entities, hospitals, and medical practices" (Young, & Olsen, 2010, p. 281). This suggests that CCNC has responded to gaps in the PCMH model discussed in the literature review: the framework was too practice-centric. It appears that CCNC has focused on connecting its participating practices to the broader community, and engaging its PCPs in care coordination efforts within the PCMH in order to improve all patients' access to needed services.

4. CCNC's Estimated Cost Savings

The evidence suggests that CCNC's collaborative relationships with providers across the state have led to significant results. CCNC's webpage indicates that over the past decade or so, the state's care management strategies resulted in significant Medicaid cost savings (CCNC, n.d.g). In 2012, the firm Treo Solutions published a utilization study that estimated $1.5B in savings over three years (2007-2009) (CCNC, 2012a). The year before, the firm Milliman, Inc. found that from fiscal years 2007-2010, $984M in costs were avoided as result of serving 1.1 million Medicaid enrollees in NC's PCMH program. In an earlier study, the firm Mercer estimated $708M in cost savings over five years, from 2005 through 2009 (CCNC, n.d.g).

Although these impressive results have garnered wide-spread attention across the nation, the research on CCNC's savings have not been embraced by all (KFF, 2009; McCarthy & Mueller, 2009; RWJF, 2013). One reason is that the three pieces of research reach widely dissimilar results. Though the three reports have one year in common (2007), the level of savings identified in each varies widely for that year (Berra, 2012).

For example, while Treo calculates a savings of $273M for that year, Mercer's approximation is much lower, between $135M and $149M. Milliman's figure is even lower, at $103M.

A fourth firm, the Advisory Board, explains that these wide gaps exist because it is difficult to calculate savings associated with the medical home model (Berra, 2012). These computations are challenging, because the medical home model avoids costs by reducing ED and acute care use and because "savings figures are always modeled out compared to a control group or what *would* have been spent—they are almost never an absolute decline in spending compared to the past" (Berra, 2012, para. 6).

Further, while medical homes generally follow certain principles to reach reduced ED and acute care utilization, there are a variety of approaches taken to implement those principles (Berra, 2012). Care coordination is one such strategy, but as the federal government's Agency for Healthcare Research and Quality (AHRQ) reports, the current status of measuring the performance of this intervention only "represents early efforts in an emerging field" (AHRQ, 2011, p.3). Further, the cross-cutting nature of care coordination makes it quite difficult to measure which factors lead to effectiveness (Berra, 2012). In addition to these challenges, the 14 local networks may emphasize one PCMH strategy over others. For example, one network may focus on medication management, while another concentrates on maintaining or improving the health of individuals with chronic conditions via follow up care. The Advisory Board notes:

> Though the services [of CCNC] are centralized and uniform across each network, different networks have evolved different internal structures based on who/what is in the network. For example, depending on whether the region includes a dominant health system or many fragmented providers, the case managers may be deployed differently based on the delivery context. The networks also develop and

> disseminate best practices internally, leading to the formation of slightly different delivery models (Berra, 2012, para. 11).

This lack of uniformity makes it extremely difficult to study which factors matter most, and to determine the level of costs that have been avoided through NC's PCMH model.

Another researcher has expressed concerns about the quality of the research conducted by Mercer, Milliman, and Treo Solutions. Al Lewis, the President of the Disease Management Purchasing Consortium, suggests that the consultants neglected to utilize data from AHRQ's Healthcare Cost and Utilization Project (HCUP) and a June 2011 Medicaid and CHIP Payment and Access Commission (MACPAC) Report to the Congress. He claims that those sources indicate that CCNC's efforts do not result in reduced utilization or cost savings, and the state's Medicaid program actually costs more than comparable states (Lewis, 2012). In a September 2012 response to this criticism, the state argued that the methods utilized by the three consulting firms were sound, and Lewis' analysis was not well-researched (CCNC, 2012c). Since that time, NC's DHHS issued a Request for Information, for a state-funded research study on whether its PCMH model reduces costs and improves outcomes (NCDHHS, 2012c).

Thus, it seems that "time will tell" when it comes to accurate assessments of the cost savings associated with NC's PCMH program. In 2013, articles published in *Health Affairs* and *Population Health Management* show that NC's PCMH continues to show improvements in quality and lowered costs (Jackson et al., 2013, Fillmore et al., 2013). However, the science about what factors make a difference and can lead to cost savings is still emerging. It seems that these issues will not become clear until it is better-understood which interventions work best and why.

5. CCNC Financial Information

CCNC would not be able to pursue its mission without sound financials. Unfortunately, the researcher's request to CCNC for complete audited financial information was not honored: the researcher was informed that as a private company, CCNC's budget information is considered "competitively sensitive" (P. Mahoney, personal communication on January 14, 2013). However, the researcher was encouraged to use publicly-available tax information, specifically the IRS Form 990 ("the 990"), which is accessible to the public. The 990 provides information regarding the expenses and revenues of non-profit organizations, and the way they are governed. It offers insight into the organization's ability to earn financial support in the future and continue operating (Swords, 2011).

The following section analyzes the non-profit organization, North Carolina Community Care Networks, Inc. ("NCCCN") which does business as "Community Care of North Carolina." NCCNC has filed 990s since 2007 (National Center for Charitable Statistics [NCCS], n.d.).[8] As shown in Table 13, total assets have increased dramatically since the organization was formed in 2006, and CCCN's ability to seek and retain funding has increased since its inception. The focus of the rest of this section is on the tax years ending in June of 2011 and 2012. Assets exceeded $10 million in both years, and the 990s for 2011 and 2012 indicate that revenue exceeded expenses in both years (North Carolina Community Care Networks, Inc. [NCCCN], 2011, Part I, Line 20). In 2011, revenues less expenses netted $4.4M, and, in 2012, the net result was nearly $2.7M (NCCCN, 2011, Part I, Line 19). Thus, for both years, NCCCN had a healthy surplus that could be used to support future activities.

[8] North Carolina Community Care Networks, Inc's IRS 990 forms were obtained by going to the following website (http://nccsdataweb.urban.org/orgs/profile/205408367#forms). Once there, NCCCN's Employer Identification Number (EIN) was entered (205408367) and the website offers free links to the Portable Document Format (PDF) of the forms.

Form 990 for 2011 (which shows 2011 tax year beginning July 1, 2011 and ending June 30, 2012) indicates that NCCCN might be referred to as a "donative nonprofit" because the vast majority of its income is from contributions and grants (Swords, 2011). In 2011, 98 percent of all revenues (or $13.9M of $14M) were received from this source (NCCCN, 2011, Part I, Line 8). In 2012, this portion dropped to 93 percent of all revenues ($19.6M of $21M) (NCCCN, 2011, Part I, Line 8). Of these revenues, $2.3M were funded through "government grants" and $17.3M through "all other contributions, gifts, grants and similar amounts not included above" (NCCCN, 2011, Part VII, Lines 1e-1f).

Table 13: Total Assets as Reported in NCCCN's 990 Forms

Year	Total Assets	Data Source
2007	$347K	NCCCN, 2007, Part IV, Line 59
2008	$426K	NCCCN, 2008, Part I, Line 20
2009	$2.7M	NCCCN, 2009, Part I, Line 20
2010	$5.6M	NCCCN, 2010, Part I, Line 20
2011	$10.6M	NCCCN, 2011, Part I, Line 20
2012	$14.6M	NCCCN, 2011, Part I, Line 20

Based on this information, it appears that only about one-eighth of CCNC's revenues were associated with government funding, while the others were from non-governmental sources. A very small percentage of NCCCN revenue was generated from fees for services, called "program service revenue." However, program service revenue grew over 800 percent from $154K to in 2011 (NCCCN, 2010, Part VII, Line 2a, Column A) to $1.4M in 2012 (NCCCN, 2011, Part VIII, Line 2a, Column A) and was attributable to "service fees." Unfortunately, no additional information was available about the new revenue source.

On the expense side of the ledger, NCCCN's expenses totaled $9.6M in 2011, and rose dramatically to nearly $18.3M in 2012 (NCCCN, 2011, Part I, Line 18). This increase was in part associated with organizational growth. In 2011, NCCCN employed 35 individuals

(NCCCN, 2010, Part I, Line 5); and that number jumped to 87 in 2012 (NCCCN, 2011, Part I, Line 5). In 2011, NCCCN's total functional expenses were nearly $9.6M (NCCCN, 2010, Part IX, Line 25, Column B), of which over 87 percent were spent on program services sustained to carry out the organization's mission (NCCCN, 2010, Part IX, Line 25, Column A). Organizational administration comprised nearly 15 percent of all expenses, and less than 1 percent of all expenses covered fundraising efforts (NCCCN, 2010, Part IX, Column D).

Even though total expenses nearly doubled in 2012, there was little change in these percentages. Of NCCCN's total functional expenses of nearly $18.4M (NCCCN, 2011, Part IX, Line 25, Column A), program services accounted for over 84 percent (NCCCN, Part IX, Line 25, Column B). Administration comprised 11.5 percent of all expenses (NCCCN, 2011, Part IX, Line 25, Column C), and approximately 4 percent of all expenses covered fundraising efforts (NCCCN, 2011, Part IX, Column D).

Two significant expenses were noted in the 990s and merit additional discussion. First, one component of the program service expenses included payment to five independent contracting firms reported as providing the following services at a total cost of over $2.6M in 2012 (NCCCN, 2011, Part VII, Section B1,Column B):

- data analytics and advisory services ($800K)
- chart audit services ($629K)
- legal services ($507K)
- establishing e-prescribe infrastructure ($406K)
- program support services in medication management ($299K)

The second significant expense was a total of nearly $370K in travel and conferences in 2012 (NCCCN, 2011, Part IX, Line 17 and 19, Column A). The researcher spoke with two CCNC

officials regarding this matter, and they noted that these funds covered the travel, meals and overnight accommodations (if needed) associated with monthly meetings of representatives of NC's 14 far-flung networks, as well as new-hire care manager trainings (M. Benton & P. J. Mahoney, personal communication, October 15, 2013).

The 990s also offer a snapshot of NCCCN's largest programs and the amount spent on each. Table 14 shows NCCCN's largest expenditures (of $100,000 or greater) in 2011 and 2012. It suggests that that IT investment is NCCCN's major expense, with clinical, pharmacy and mental health programs as other areas of large outlays. Particularly in 2012, NCCCN also invested significant funding ($745K) in the grants that it awarded to the 14 networks (NCCCN, 2011, Schedule O, p.2). Somewhat surprising was the large amount spent in 2012 ($121K) on promoting CCCNC and the PCMH within and outside the state (NCCCN, 2011, Schedule O, p.2).

The individuals who govern NCCCN have engaged in decisions regarding how the corporation's funds are spent. In 2011 and 2012, the Board of Directors totaled 34 members (NCCCN, 2010, Part VI, Section A, Line 1a; NCCCN, 2011, Part VI, Section A, Line 1a). As would be expected for a nonprofit organization, none of this group was reported to have been compensated for their duties. However, there were three noteworthy pieces of information regarding governance in 2012's 990. First, NCCCN's Chief Operating Officer and Director of Clinical Programs and Quality Improvement are independent contractors, not NCCCN employees (NCCCN, 2011, Section O, p.2).

Table 14: IRS Form 990 Data: Top NCCCN Expenditures Over $100K				
NCCCN Initiative	**2011**	**2011 Data Source**	**2012**	**2012 data source**
Informatics center	**$911K ($19K grant)**	NCCCN, 2010, Part III Section 4c	**$6.4M**	NCCCN, 2011, Part III, Section 4a
Clinical programs[9]	**$406K**	NCCCN, 2010, Schedule O, p.2	**$4.9M ($14K grant)**	NCCCN, 2011, Part III, Section 4b
Pharmacy programs	**$394K ($389K grant)**	NCCCN, 2010, Schedule O, p. 2	**$2.1M**	NCCCN, 2011, Part III, Section 4c
Mental health integration	**$228K**	NCCCN, 2010, Schedule O, p.2	**$670K**	NCCCN, 2011, Schedule O, p.2
Grants for 14 networks	**N/A**	N/A	**$745K ($472K grant)**	NCCCN, 2011, Schedule O, p.2
CHIP enhancement including HER	**$197K**	NCCCN, 2010, Schedule O, p.2	**N/A**	N/A
646 demonstration	**N/A**		**$205K**	NCCCN, 2011, Schedule O, p.2
Public/private multi-payer demo	**$120K**	NCCCN, 2010, Schedule O, p.2	**N/A**	N/A
Call center for proactive outreach	**N/A**		**$183K**	NCCCN, 2011, Schedule O, p.2
Maternity care for high-risk Medicaid patients	**$911K ($19K grant)**	NCCCN, 2010, Part 3 Section 4c	**$145K**	NCCCN, 2011, Schedule O, p.2
Promotion of CCNC	**$406K**	NCCCN, 2010, Schedule O, p.2	**$121K (Revenue $21K)**	NCCCN, 2011, Schedule O, p.2

Second, NCCCN's President and Chief Executive Officer was paid nearly $190.5K by another unrelated organization for the services he rendered for NCCCN (NCCCN, 2011, Schedule J, Part II, Line 1). The official name of that organization is *Carolinas Physicians Network Inc*, but the organization does business as *Cararrus Family Medicine* (NCCCN, 2011, Part III, p.3). The 990 for 2012 indicated that the level of compensation for the President was reviewed and vetted by the Executive Committee ("EC") of the Board of

[9] This large increase in investment in clinical programs from 2012 is perhaps misleading, and reflects an accounting change. Several programs that were listed separately in the 2011 Form 990 were listed under "clinical programs" in 2012, including the CHIP enhancements and the three-year multi-payer demonstration.

Directors ("BODs") (NCCCN, 2011, Schedule O, p.2). CCNC officials report that this type of arrangement is common practice when hiring clinicians and was the same type of contractual relationship that the state agreed to when the current President was the Secretary of Health from 2005-2007 (M. Benton & P.J Mahoney, personal communication, October 15, 2013). The 990 for 2012 also notes that the EC and legal counsel reviewed the lease agreement of the President's previous employer in order to determine his current salary and benefits (NCCCN, 2011, Schedule O, p.2). Further, the EC and the full BODs approved the President's lease agreement and terms (NCCN, 2011, Section O, p. 2). (An "employee leasing agreement" is a contract whereby the leasing company provides a person to perform ongoing services to a client company ["Leased Employees", n.d.].)

The third interesting aspect of governance revealed in 2012's 990 is that changes to the governing body of each of the 14 CCNC networks were approved in April 2012 (NCCCN, 2011, Schedule O, p2). The 990 Form from 2012 indicates that NCCCN made significant changes to its governance documents and bylaws. These modifications included the establishment of a corporate membership in June 2012 and the election of a BOD in September, 2012 (NCCCN, 2011, Schedule O, p2). Changes such as these suggest an important shift in the nature of the organization or potential internal conflict (Swords, 2011). A web search regarding these matters suggested potential attitudinal swings about CCNC within the NC legislature, as well. As was previously mentioned, an appropriations bill from the 2013 legislative session called for "a scientifically valid study" to ascertain whether CCNC actually saves the state money (General Assembly of North Carolina, 2013).

This analysis of NCCCN's 990s provided some useful insights about the organization's growth, priorities and governance. Since its 2006 inception, this donative

nonprofit has shown a significant ability to seek and retain contributions and grant funding; in recent years, assets have exceeded $10 million. The research shows that NCCCN's top expenses include HIT, as well as clinical, pharmacy and mental health programs.

6. Conclusion

The goal of this Case Study Results Chapter was to provide the contextual information required in order to understand how NC's PCMH coordinates the care of dual eligibles. This chapter was informed by a thorough literature review, an online document review and the data collected through interviews and focus groups. Finally, efforts to verify the accuracy of this case study research involved the review and validation of these results by CCNC's Director of Operations and Vice President for Communications (M. Benton & P.J Mahoney, personal communication, October 15, 2013).

Chapter 5: Results –Patient and Care Manager Experience in NC's PCMH

1. Introduction

This chapter describes the research results regarding how well the care of dual eligibles is coordinated in North Carolina's (NC's) patient centered medical home (PCMH) program. Section Two discusses the sample of dual eligibles and Section Three, sampled care managers. Section Four covers the research results, answering Research Questions 1 and 2, and associated sub-queries, using evidence from the Case Study Results, focus groups and interviews. Section Five summarizes the findings.

2. Sample of Dual Eligibles

This research included 61 dually eligible individuals who participated in seven focus groups conducted in two doctors' practices, three senior centers, and two community-based centers for individuals with disabilities. Further, two in-depth interviews with dual eligibles were conducted in a practice setting. Table 15 shows the demographic composition of the dually eligible participants. These data were gleaned from a brief demographic survey that participants completed just prior to the interview; it is found in Appendix D.

Table 15: Demographics of the 61 Focus Group Participants

Age	M/F	Education	Inc.	Race	Hospital-ization?	Health Characteri-zation	Alcoholic drinks/ day	Cigar ettes/ day
30	M	Some coll./2 yr.	<$25K	White	No	Fair	0	0
31	F	Some coll./2 yr.	<$25K	Black	ϕ	ϕ	ϕ	ϕ
31	F	Some coll./2 yr.	<$25K	Black	No	Good	0	0
32	F	HS grad/GED	<$25K	White	No	Fair	0	30
32	M	4 yr. college	<$25K	Black	Yes	Excellent	0	0
33	F	ϕ	$?	White	No	Good	0	0
34	M	HS grad/GED	<$25K	White	No	Good	0	0
34	F	>4 yr. college	<$25K	White	Yes	Good	0	0
35	F	Some coll. /2 yr	<$25K	White	No	Fair	0	0
39	F	ϕ	ϕ	ϕ	ϕ	ϕ	ϕ	ϕ
42	F	Some coll./2 yr.	<$25K	Black	No	Fair	0	0
45	F	Some coll./2 yr.	<$25K	Black	Yes	Fair	0	0
46	F	Some coll./2 yr.	<$25K	Black	Yes	Fair	0	1
48	F	HS grad/GED	<$25K	White	No	Poor	0	?
53	M	HS grad/GED	<$25K	White	No	Good	0	0
53	F	HS grad/GED	<$25K	White	No	Good	0	0
53	M	>4 yr. college	<$25K	White	No	Very Good	0	0
55	M	HS grad/GED	<$25K	Black	Yes	Very Good	0	1
59	F	Some coll./2 yr.	<$25K	White	ϕ	ϕ	ϕ	ϕ
59	F	HS grad/GED	<$25K	White	Yes	Poor	0	5
60	F	Some coll./2 yr.	<$25K	White	No	Good	0	0
62	F	HS grad/GED	<$25K	White	Yes	Fair	0	0
63	F	Some HS	$?	Black	No	Very Good	0	0
65	F	Some HS	<$25K	White	Yes	Good	0	0
65	F	HS grad/GED	<$25K	Black	Yes	Good	0	0
65	M	Some coll./2 yr.	<$25K	Black	Yes	Very Good	0	0
65	F	Some coll./2 yr.	<$25K	➢	No	Fair	0	0
65	M	8th grade/less	<$25K	Black	No	Fair	0	0
65	F	>4 yr. college	<$25K	White	Yes	ϕ	0	10-15
65	F	Some coll./2 yr.	<$25K	Black	No	Good	0	0
67	F	8th grade/less	<$25K	Black	No	Poor	0	0
67	M	8th grade/less	<$25K	Black	No	Good	0	0
68	F	Some HS	<$25K	Black	Yes	Good	0	10
69	F	Some HS	<$25K	ϕ	ϕ	ϕ	ϕ	ϕ
70	F	Some coll./2 yr.	<$25K	White	Yes	Very Good	0-2	0
70	F	Some coll./2 yr.	<$25K	White	No	Excellent	0	0
71	F	Some HS	<$25K	Black	No	Fair	0	0
71	M	>4 yr. college	<$25K	White	No	Fair	0	0
71	F	Some HS	<$25K	Black	No	Fair	0	0
72	F	Some HS	<$25K	White	Yes	Good	0	0
72	F	Some coll./2 yr.	<$25K	White	Yes	Poor	0	4.5
73	M	Some HS	<$25K	Black	Yes	Fair	0	0
73	F	Some HS	<$25K	Black	No	Fair	0	0
73	F	Some HS	<$25K	Black	No	Fair	0	0
75	F	HS grad/GED	<$25K	Black	No	Good	0	0
75	F	Some HS	<$25K	White	No	Fair	0	0
76	F	HS grad/GED	<$25K	White	Yes	Poor	0	0
76	M	>4 yr. college	<$25K	White	Yes	Excellent	0	0

Table 15: Demographics of the 61 Focus Group Participants (cont.)

Age	M/F	Education	Inc.	Race	Hospital-ization?	Health Characteri-zation	Alcoholic drinks/ day	Cigar ettes/ day
76	F	>4 yr. college	<$25K	White	Yes	Good	0	0
78	F	HS grad/GED	<$25K	White	No	Fair	0	0
80	F	Some HS	$?	Black	Yes	Very Good	0	0
81	F	HS grad/GED	<$25K	Black	No	Good	0	0
82	F	Some HS	<$25K	White	No	Fair	0	0
82	F	HS grad/GED	<$25K	Black	No	Good	ϕ	0
83	F	HS grad/GED	<$25K	White	No	Good	0	0
83	F	Some HS	ϕ	Black	No	ϕ	0	0
84	F	ϕ	ϕ	Black	ϕ	ϕ	ϕ	ϕ
84	F	8th grade/less	$?	Asian	No	Fair	0	0
84	F	HS grad/GED	<$25K	Black	Yes	Good	0	0
86	F	Some coll./2 yr.	$?	White	ϕ	ϕ	ϕ	ϕ
97	F	8th grade/less	<$25K	Black	No	Good	0	0

Key: *ϕ* = Did not provide this information on the demographic form. ***8th grade/less*** = Individual received up to an 8th grade education. ***Some HS*** = Individual received some high school education but did not earn a diploma. ***HS grad/GED*** = Individual graduated from high school or received a *General Educational Development* (*GED*) degree. ***Some coll./2 yr.*** = Individual attended a 4 year college but did not graduate, or received a 2 year Associates degree. ***4 yr. college*** = Individual earned a degree at a 4 year college. ***>4 yr. college***= Individual received post college education. ***<$25K*** = Individual receives less than $25,000 in income each year. ***$?***= Individual does not know how much income he/she receives in income each year. ➢=Racially white and Cherokee Indian. ***?***=unknown number of cigarettes smoked per day.

The average age of all sampled dual eligibles was 63. Nearly 38 percent of all participants were less than 65 years old, and the mean age of this younger group was nearly 45 years old. Of the participants who were 65 or older, the average age was just over 74 years old. Only about 20 percent (or 12 individuals) of the 61 participants were men.

While the literature review indicates that generally dually eligible individuals have relatively low levels of educational attainment, higher levels of education were achieved by sampled dual eligibles. Nearly 41 percent of the group (25 individuals) had attended some college; of this sub-group, 32 percent had received a four year degree or an advanced degree. As noted, this high level of patient education is atypical of the dually eligible population as a whole; it represents a limitation of this study. Nearly 23 percent of the 61 research

participants had received a high school diploma or General Educational Development (GED) degree. Another 23 percent of all focus group participants had received some high school education but had neither graduated with a high school diploma nor achieved a GED. Finally, eight percent of participants reported the receipt of an eighth grade education or less, and about five percent did not report educational attainment.

While most participants (87 percent) reported an annual income of less than $25K per year, about five percent did not report annual income and another eight percent stated that they did not know this information. However, the dialogue within the focus groups and in-depth interviews either confirmed Medicaid and Medicare enrollment or validated their low qualifying income. Generally the racial mix of participants was evenly distributed between white and black, with the former at 49 percent, and the latter at 46 percent. Two participants (or about 3 percent) reported other racial backgrounds, and two did not to report this information.

In order to generally ascertain participants' use of acute, hospital-based services, sampled dual eligibles were asked whether they had experienced a planned or unplanned hospitalization over the past year. Given that the literature indicates high hospitalization rates for dual eligibles, it is not surprising that over one in three (34 percent) participants had been hospitalized during the past 12 months. It is possible that this number could be as high as 44 percent, given that nearly 10 percent of focus group participants did not answer this question.

Participants were also asked to rate their health on a scale of poor, fair, good, very good, or excellent. Only eight percent of participants (5 individuals) reported the lowest level of health status. Nearly one in three (31 percent) indicated that they were fair health, and 33 percent reported good health. About 15 percent reported either very good or excellent health.

Although these self-reported health status indicators were not compared to an external source, the evidence suggests that it is unlikely that dual eligibles in poor health participated in this research. The absence of individuals who described themselves as such represents a potential limitation of this study.

The last two columns of Table 15 show self-reported alcoholic beverage consumption and cigarette smoking. Although just over 11 percent of participants did not report a daily number of alcoholic beverages consumed, almost 87 percent said they consumed no alcohol each day. Over one in five (21 percent) participants did not answer the question about the number of cigarettes smoked per day. State-specific information by the Centers for Disease Control (2011), suggests the possibility that those who did not answer may have been smokers, given that NC's smoking rate is higher than that identified in this group. The participants were asked demographic, hospitalization and health status questions so that the researcher could better-understand the characteristics of the research sample. It is important to comprehend whether and how sampled dual eligibles are typical or atypical of the general population of dual eligibles described in the literature. As noted above, the sampled group was more educated and healthier than the population of dual eligibles at large.

Further, the sampled dual eligibles could be described as *lower risk,* and *independent-living* compared with those who live in nursing homes and adult care homes; the sampled dual eligibles had not received long-term services and supports (LTSS). Further, there is evidence that Community Care of North Carolina (CCNC) treated sampled dual eligibles as relatively low-risk, low-cost patients. CCNC notes that patients who receive services provided by a care manager tend to be those at highest risk of

incurring the highest healthcare costs. Since none of 61 research participants received such services, this research suggests that sampled dual eligibles were not designated as highest risk, which is not surprising given that most reported fair health or better. However, within NC's PCMH, the primary care provider (PCP) is responsible for internal care coordination efforts, and this work is supported by CCNC which offer disease and care management and quality improvement (QI) initiatives (Dube, 2008).

For the sampled dual eligibles who required less support, the care delivered during the data collection period (June 7, 2012-September 14, 2012) was very similar regardless of whether it was received through primary care case management (PCCM) or the Medicare 646 demonstration. One reason was described in the previous chapter: the Centers for Medicare and Medicaid Services (CMS) did not share the Medicare Part A and B data files with the networks that participated in the 646 until 20 months after the demonstration's launch. Since CCNC had limited access to needed Medicare data, the targeted QI efforts of the 646 were hindered (Centers for Medicare and Medicaid Services (CMS), 2012b, p. 7). Thus, the health promotion initiatives for the relatively low-risk sample were based on NC's PCMH program, whether sampled dual eligibles received care in a PCCM or a 646 network. Sampled dual eligibles did not receive additional 646 service enhancements that were targeted at those with higher-level needs.

3. Sample of Care Managers

Six individual interviews were conducted with CCNC care managers for context regarding the functioning of NC's PCMH and information about the real-life application of the two theoretical Agency for Healthcare Research and Quality (AHRQ) care coordination

models described in previous chapters. The researcher planned to sample care managers from four high-population density counties in the Raleigh-Durham region: Johnston and Wake counties, which utilize the PCCM model, and Chatham and Orange counties, which participated in the Medicare 646 demonstration. However, as Table 16 indicates, the researcher had more success accessing care managers located in PCCM counties than 646 counties. Nonetheless, although it was not possible to gain access to a medical practice in Chatham, care manager interviews were held in Orange.

Table 16 shows that the credentialing of the sampled care managers varied, depending on the network. While care managers in Johnston and Wake counties were registered nurses (RNs), this was not the case in Orange County where the sampled care managers generally lacked advanced degrees. Previous related experience also varied; while one care manager reported none, four had hospital-based experience and one had coordinated a medical program for vulnerable, high-risk individuals. There were also contrasts in the amount of time spent working in the current position, from six weeks on the job to nine years; the median duration was five years. Monthly caseloads were reported as between 43-100 patients, with a median load of 60. Moreover, three of the six indicated that they were bi-lingual in English and in Spanish.

The interviewed care managers described a diversity of work locations. Two worked from home, two in a medical practice, one in an administrative office, and one did not disclose work location. The interviews took place in a variety of settings; three were conducted in the community, two in medical practices, and one in an administrative office. Further, a diversity

of work responsibilities were reported; while four of the six care managers conducted home visits and engaged in medication reconciliation ("med rec"), two did not.[10]

Table 16: Selected Care Manager Characteristics

Trait	T3[∇]	T4	T9	T12	T14	T15
PCCM network versus 646 network	PCCM	PCCM	PCCM	PCCM	646	646
County of Employment	Johnston	Johnston	Wake	Wake	Orange	Orange
Credentialed as RN	Yes	Yes	Yes	Yes	No	No
Previous related experience	Hospital case manager for 5 yrs	None	HIV case manager & ED RN	Hospital staff nurse	Coordinated medical program for homeless	Organ transplant coordinator at hospital
Amount of time in current position	5 yrs	9 yrs	5 yrs	5 yrs	6 weeks	2.5 yrs
Monthly Caseload	50-60	50	43	60-70	100[□]	70-100
Percentage Dual Eligibles Served	~25%	~75%	~30%	~15%	0%[┼]	~30%
Conduct home visits?	Yes	Yes	Yes	Yes	No	No
Conduct med rec?	Yes	Yes	Yes	Yes	No	No
Language spoken	English	English	English	Bilingual[⊥]	Bilingual[⊥]	Bilingual[⊥]
Work location	Home	Home*	Admini-strative office	Unclear	Medical practice	Medical practice

Key: [∇] **=** "T" refers to the interview transcript number. *** =** Although work location was not discussed in the interview, the care manager from transcript 4 worked in the same network as the care manager from Transcript 3, suggesting both worked from home, and in the field, conducting home visits. [□] **=** Considering the inexperience of this care manager, it seems possible that the monthly caseload was over-estimated, given that of other care managers, and the monthly caseload of a colleague, from T15. [┼] **=** This care manager did not work with dually eligible patients (yet) due to inexperience in the job. However, the interview offered valuable contextual information about training and network-level priorities. [⊥] **=** English and Spanish-speaker

Now that the reader has a sense of the characteristics of the research participants, it is appropriate to turn to the interviews and focus groups themselves.

[10] However, one Orange County care manager revealed that other RN care managers in Orange County's network did this type of work.

4. Research Results

This section answers the research questions in turn. The first part answers Research Question I; it describes how well NC's PCMH coordinates care for dual eligibles, the necessary components of care, and the greatest barriers associated with accessing that care. The second part of this section answers Research Question II regarding the perceptions of the sampled of care managers who provide services to high-risk, high-cost patients in NC's PCMH. Research Question II asks about the tools upon which sampled care managers most rely and about care coordination efforts for older versus younger dual eligibles. It also covers the real-life application of two theoretical care coordination models developed by AHRQ, the previously-described Care Coordination Ring and the Care Coordination Mechanisms Framework.

Question I): How well does NC's PCMH program coordinate care for dual eligibles?

Research Question I broadly asks about how well NC's PCMH coordinates care from the perspective of sampled dual eligibles. The sub-queries focus on the necessary components of care and the barriers to that care from sampled dual eligibles' perspectives, and the challenges coordinating care from a programmatic point of view.

Question Ia) From the perspective of sampled dual eligibles enrolled in NC's PCMH, how well is care coordinated by the program?

Given that the dual eligibles are one of the nation's most vulnerable and costly populations, and the heavy emphasis on care management on CCNC's website, it was expected that at least a few research participants would have received care coordination

services provided by a CCNC care manager supporting NC's PCMH. Yet, none of the 61 sampled dual eligibles reported the receipt of care coordination services provided by a CCNC care manager, a potential limitation of this research. It is likely that a higher-need subpopulation of dual eligibles was unable to participate in the research due to illness, transportation problems or other factors.

As previously mentioned, the demographic findings suggest that most research participants could be described as *lower risk, independent-living dual eligibles,* so this population apparently did not fit the profile of CCNC's highest-cost and highest-risk patients. However, the evidence suggests that at least one high-need dual eligible who required care coordination services provided by a care manager "fell through the cracks." While it was not clear why she did not receive these services, this research suggests that she needed this intervention after suffering a devastating accident when her wheel chair was hit by a car, and a six-month hospitalization was required.

It is unlikely that high care manager-patient ratios were the reason why sampled dual eligibles did not receive this care manager-provided intervention. CCNC's care manager-patient ratio follows that recommended in the literature. As was discussed in the Case Study Results, for most CCNC care managers, the monthly caseload is between 75 and 175 patients. This is well within the range recommended by the Agency for Healthcare Research and Quality (AHRQ) (2008), which is 1:500 for telephone patients and as low as 1:25 for those offering in-person services.

Although sampled dual eligibles did not receive care coordination services provided by a CCNC care manager, research participants were linked to NC's PCMH through a PCP responsible for internally coordinating care. As discussed in the Case Study results, CCNC

offers extensive disease and care management programs and quality improvement (QI) initiatives that bolster the efforts of PCPs participating in NC's PCMH (Community Care of North Carolina, [CCNC], n.d.n; Dube, 2008; Henry J. Kaiser Family Foundation (KKF), 2009). Integral to CCNC's work is the Informatics Center, which:

1) provides PCPs with patient-level information;

2) monitors patient emergency department (ED) and inpatient visits;

3) tracks care quality indicators; and

4) identifies the previously-discussed high-risk, high-medical cost patients for care management interventions (CCNC, n.d.k).

Although sampled dual eligibles were perhaps unaware that they were receiving care coordination services, the Case Study results indicate that CCNC's information technology (IT) infrastructure is the backbone of the NC's PCMH program's care coordination for sampled lower-risk independent-living dual eligibles. While this group did not receive "visible" care coordination services provided by a CCNC care manager, Chapter 4's Case Study Results indicate that they benefitted from the "invisible" ones bolstered by CCNC's Informatics Center and QI initiatives.

Given that sampled dual eligibles were perhaps unaware of the "invisible" care coordination efforts of NC's PCMH, how did they perceive well-coordinated care? Since the Center for Health Care Strategies (CHCS) argues that the outcome of care coordination is "beneficiaries with the right care at the right time in the right places" the research findings are considered using these three criteria (Center for Health Care Strategies [CHCS], 2010b, p.1). A fourth criterion for assessing effective care coordination from the patient perspective was identified by AHRQ, which argues that "Continuity of care

represents an individual patient's experience of [care] coordination over time with either a single clinician or with multiple clinicians" (McDonald , 2007, p. 43).

i. Right Care

From the patient perspective, one aspect of the "right care" is related to access to care. Most sampled dual eligibles participants reported that they received a sufficient amount of medical equipment, services and tests through NC's PCMH. For example, a 48 year-old man reported: "… if it's something you need, the doctors here will try their best to find out some way for you to get it." This evidence closely matched that reported during the state's nine "conversations" in eight communities with dual eligibles; these discussions were part of the state's data-gathering efforts to inform NC's Dual Eligibles Coordinated Care Demonstration proposal (CMS, 2012b). The state conversations were conducted from October, 2011 and February 2, 2012 and revealed that most participants were satisfied with their current level of care.

Further, most sampled dual eligibles reported that the "right care" provided relief of symptoms and/or disease resolution. Examples included resolution of breathing problems associated with a pollen allergy, bronchitis, and life-threatening pneumonia, as well as mental health improvements after taking prescribed antidepressants. Other examples included relief from arthritis pain, and control of diabetes and high blood pressure. Thus, most sampled dual eligibles reported that the "right care" had provided relief from symptoms and illnesses.

Although many participants had satisfactory experiences accessing sufficient levels of care, this was not the case for some who had to lobby their PCP in order to get the care they needed. For example, a 45 year-old with an amputated leg reported problems getting needed medication and tests explained:

> At one point, I told my doctor about pain in my knees. And I had told her on several visits, because I visit her like every month, and I had told her on several occasions that I was having pains and she even gave me some, some stuff to rub down on it. I said, 'but, we don't know what it is.' So she was telling me to put warm compresses on and all this stuff. So, I kept asking, can you please send me to have it x-rayed or something… to somebody that can tell me what exactly is the problem? So, finally, she did, because I kept asking her, and she did send me, and we found out that I have arthritis in my knees.

A 53 year-old man explained that he tried to address his own medical issues when he could not access sufficient medical care through his PCP:

> I usually just play doctor and try to find homeopathic remedies. If it's something I can make a brace, like a back brace or something, I made one because I couldn't get one. I made splints of different sorts. Or I do without, and suffer through it, and hopefully it will go away.

Although insufficient access to tests and medical devices is not a wide-spread theme, it is worthy of attention given that the evidence suggests that the insufficiency may lead to emotional distress and extraordinary measures (like a homemade back brace) that may not benefit the patient's health, or could even harm it. Further, in a couple of cases, inadequate PCP access was reported. Again, although not representative of the experience described by most focus group members, it is important because: 1) unless alerted by dually eligible patients, the PCP at the PCMH may be unaware of treatment elsewhere since the IT system does not track Medicare claims; and 2) by adding another provider, care coordination activities are potentially made more complex.

While most participants noted that they had received the "right care" with sufficient access to care, most were satisfied that that their PCP would refer them to a specialist if need be, or upon their request. Participants reported referrals to variety of specialists including heart, hand, sinus, and back. The evidence revealed that access to specialists was wide and appreciated by participants in most cases.

However, one important exception was regarding access to mental health specialists. This concern was identified in this research and in NC's nine "conversations" with dual eligibles. The state has reported: "Considerable difficulty was identified in finding mental health services in private practice (psychologists and counselors) who take Medicaid/Medicare" (CMS, 2012b, pp. 28-29). For example, a 60 year-old woman reported difficulty identifying a mental health therapist willing to accept patients with both forms of coverage:

> I had to find a psychologist or a social worker, something for therapy. And I spent two weeks on the phone talking with different therapists who would take both Medicaid and Medicare, who was willing to see me just once a month. And it's not easy to find a caregiver in the mental health system.

It was somewhat surprising that some sampled dual eligibles faced this problem, given that a critical role of the PCP within NC's PCMH is the coordinator of patient care, including making needed referrals to qualified professionals.

Other sampled dual eligibles reported issues of mental health provider discontinuity. For example, a 67 year-old woman suggested that in NC's PCMH, it was easier to access the medications to treat mental illness than the talk therapy that is also generally prescribed. A 53 year-old man expressed a similar sentiment:

> I know for mental health care and stuff its very…You are lucky if you get any counseling at all… You get them to prescribe you medication. But to… I think everybody that knows anything about mental health, having to go and get their medication, they have talk therapy and some other kind of therapy with that. [But in NC's PCMH], they are just hitting you with pills.

The broader literature suggests that these gaps in needed services could be addressed through the PCMH. Stange (2010) indicates that patients receive comprehensive care through the PCMH where there is "accountability for addressing a large majority of personal health care needs" (Stange et al., 2010, p.55). Further, coordinating care is an important PCMH activity

which includes the "integration and coordination of care in different settings, and across different domains that include acute and (often comorbid) chronic illnesses, mental health, disease prevention, and health promotion—guiding access to more narrowly focused care when needed" (Stange et al., 2010, p.55).

A CCNC PowerPoint presentation about NC's PCMH echoes the content found in the broader PCMH literature. Although the slides do not name care coordination as a goal, they say that the aims of NC's PCMH are to:

- "de-fragment care,"
- "improve quality,"
- engage in "outreach to patients with gaps in care" and
- "managing patients with multiple co-morbidities" (Hewson, 2011, slides 7-9).

Thus, the slides suggest that NC's PCMH strives to coordinate care even if not identified as an objective, per se.

In addition, there were mixed reports regarding receipt of sufficient levels of preventive care. While some sampled dual eligibles reported the receipt of annual screenings, mammograms, and colonoscopy through the PCMH, others noted that unless they specifically requested preventive services (such as an annual physical and a mammogram referral), they would not receive them, which may indicate that they had to proactively seek out needed medical care.

ii. Right Time

From the patient perspective, coordinated care also involves the receipt of care within an appropriate timeframe. This subsection focuses on the prompt receipt of appointments or services, and sufficient "face time" with the PCP. Most sampled dual eligibles reported that it

was easy to get appointments when they were sick and needed to be seen promptly. Further, some dual eligibles expressed their appreciation for Saturday and weekday evening appointments noting their importance in situations when all the day time appointment slots are filled or patients need to work until 5 pm. This easy access to care is a characteristic of a sound PCMH (Reid et al., 2009).

While many participants reported the ability to promptly get a PCP when sick, the same was generally true of participants' experiences with scheduling regular wellness or preventive appointments. However, some reported difficulty scheduling the latter types of appointments. Although most research participants were happy with their ability to get primary care appointments through NC's PCMH, some were less content with the multi-step scheduling process. A few reported that their calls were not promptly returned, the automated office telephone systems were aggravating, or they were unable to schedule an appointment three months in advance, as they had in the past. Finally, while the data suggests that the most positive appointment-making experiences focused on getting "sick" instead of preventive or follow up appointments, the questions in the interview guide emphasized access to acute rather than wellness care, which potentially skewed the results.

As previously discussed, the vast majority of sampled dual eligibles lacked experience with "visible" care coordination services, those provided by a CCNC case manager. However, two participants from separate focus groups described positive and negative experiences with accessing such services. An 80 year-old woman seemed glad to report that after a hospitalization, staff there arranged temporary home health services. Although these care coordination services were not provided through the PCMH but were instead delivered by the hospital, the patient experienced the right care, provided at the right time.

There was one notable exception which was noted above. It is important because the woman seemed to urgently need coordinated care but did not receive assistance. This 34 year-old woman was hit by a car while riding in her wheelchair and reported that during the six month hospitalization that followed, she missed an appointment with her PCP who:

> …did not find out I had been in the hospital until I went to her and said I was not at this appointment because of my broken leg. Excuse me, I was in the emergency room with tons of medication with me, I could not remember that I had an appointment with you. So, and then I told her what was going on, and she understood that. I gave her the names of the doctors to have her talk to them, so if she had any questions about any of their medications they had given me, because those medications would affect the medications I was going to go on, because of the pain medication that I was prescribed at the time. Now I am not taking that medication anymore thank God, because it's mostly healed. But if I was that would have affected anything else. Because that pain medication was so strong I was not even a regular human being, basically. I was just taking to go to sleep.

Of all the individuals needing care coordination and transitional care services at the "right time," this woman would seem like an ideal candidate. Since she needed help with keeping track of her appointments, it seems likely that she may have needed help with organizing other aspects of her care, like her medications, and the contact names, numbers and functions of the providers who participated in her recovery. It is not clear why she did not receive care coordination services through her PCHM or provided by a CCNC care manager, but it seems clear that she could have benefitted from this intervention.

Another aspect of care provided at "the right time" is sufficient "face time" spent with the PCP. In most focus groups and in-depth interviews, participating dual eligibles were satisfied with this aspect of their care. There was a great deal of variation in the amount of time reported as sufficient: one 32 year-old sight-impaired man was satisfied with spending just five or six minutes with his PCP, while a seventy-five year-old woman reported that 15

minutes was not enough. Other participants reported that their visits with their PCPs lasted between 20 minutes and an hour.

iii. Right Place

The site of services is the third aspect of receiving coordinated care from the patient perspective. Most participating dual eligibles who discussed this topic said travel distances were relatively short (seven-30 minutes), but they would be willing to drive further because they valued the care they received. However, those who relied upon public transportation had problematic experiences. This research indicated that transportation issues (including the cost of parking, as well as public transportation delays and fees) were a significant source of stress for affected dual eligibles and these barriers constrained their efforts to get needed care. This research verifies widespread evidence gathered in NC's nine state-wide meetings with dual eligibles in 2011 and 2012 (to inform the Dual Eligibles Coordinated Care Demonstration proposal). These sessions also revealed significant transportation barriers that inhibited patients' ability to keep appointments.

Nonetheless, once sampled dual eligibles had arrived at their PCP's office, most were pleased with the care setting and said that the wait to see the PCP was not too long. However, a few were concerned about the spread of children's infections and the sounds of crying babies. Two incidents that were not representative of participating dual eligibles bear reporting because they seemed egregious. A highly sight-impaired 53 year-old woman reported that her PCP's office was not at all "blind-friendly." When entering the building, a series of turns were required to navigate heavy-duty retractable queue poles in order to reach the check-in window. She reported:

> You got ta go all the way over to the right hand side to the receptionist. If you go straight ahead to the window, they won't talk to you, they will motion you to the

right... Even if there is no line. They will do nothing for you if you go to the right.

Another participant from the same group, a 45 year-old amputee who was also vision-impaired, noted that she'd had similar experiences at the same practice when she had to wait in line for such a long time that the office staff sent her home, saying she had missed her appointment.

Another care setting discussed at length was the hospital; the reports were mixed. Some participants were happy to note that their PCP visited them in the hospital, and others reported robust provider communications between hospital and primary care settings. This is a good example of a highly-functioning care coordination system. However, other participants were less content, with some older dual eligibles concerned that their PCPs had discontinued hospital visiting. These group members may be unaware of the trend toward the use of hospitalists that began in the late 1990s. Evidence from this research suggests that patients who are unaware of this change may feel abandoned or neglected by their PCPs, and that they must advocate for their interests in the hospital. The daughter of an 82 year-old participant noted:

> …not many doctors' offices today has doctors that work at the hospital. Usually when you at the hospital, you are on your own. They feed in orders and the hospital does what they need, what you need at that time. Then when you go home, you go back to your doctor. So, some doctors in some hospitals don't want to even talk to your doctor, because they are the doctor on call, and that's what they get paid for.

This quote highlights the problem of provider discontinuity between care settings and about a lack of PCP access to patients' hospital-based medical information. This is an example of poorly functioning care coordination within the NC's PCMH.

iv. Continuity of Care

AHRQ suggests that patients perceive long-term care coordination through an

experience of provider continuity, with either a single or multiple clinicians (McDonald, 2007, p. 43). In this research, with regard to the patient's relationship with a single PCP, the experience of sampled dual eligibles varied widely. About 50 percent reported that they had worked with the same PCP or practice for a long time, for five or more years. About one of five participants reported a relationship with their current PCP for a year to five years but about 30 percent of sampled dual eligibles had been served by their current PCP for about a year or less. Thus, it is possible that about one in three participants experienced usual source of care issues.

Further provider discontinuity was associated with the receipt of care at an area teaching hospital; this was reported by eight percent of participants. In the primary care clinics in these settings, a resident trains for three years and then his/her patients receive their care from a different resident (Policy Prescriptions, n.d.). Although infrequently discussed among research participants, the data suggest that the results of this discontinuity could be so problematic that they warrant further examination. One 53 year-old man who had developed epilepsy as a result of a serious car accident explained the importance of addressing the problem of PCP discontinuity:

> You go in there and tell them everything that's wrong with you. They should video tape it or put it on disk or something. Seriously… When dealing psychological issues and stuff, that are not really pleasant. Every single time that they have to go in and talk to these doctors, they have to… And you, dealing with a car wreck… every time I have to relive it… And the rest of the day I am just depressed because I've had to relive it and re-explain it… And "oh my God, you are alive from it," this stuff. So, I say, [at] first I said it off the cuff, they ought to be recording this things. But they really should, because then they could add to your file after that, but they are not going to have to make you go through… They can update it every two or three years or something. It's really tragic to go through.

For this man, the retelling of the medical history seemed to have a profoundly negative psychological effect. A second participant from that focus group, (the 34 year-old woman who required the six-month hospitalization after a car accident) responded:

> I would like to add something to what he just said. I think I have no problem talking about what happened to me six months ago, but I also feel like I would like to reiterate what he said about it. Because I don't like, there are some people, some providers I have gone to, and said I was in this accident and this is what happened to my leg. Then they want me to go through every single detail of the accident. And why was I outside at the time? I was outside because I wanted to take my recycling out. That was the only reason. You know I was not outside because I wanted to get hit by a car! I did not like go outside wanting to get hit by a car, thank you very much. I did not wake up and say I want to go in the hospital for six months. So, I think that's what he is trying to say, too, about having to go through the whole thing all over again. Because it just feels like we are not a person. It just feels like… It feels like we are a number.

Thus, this woman suggested that the retelling of the medical history had a dehumanizing effect. Although these two experiences did not represent the perspective of all participating dual eligibles, they are important because they highlight the possible psychological effects of provider discontinuity and the need to mitigate the problem.

These issues are related to the exchange of medical information among providers, a critical aspect of coordinated care which could be provided through the PCMH. When asked whether sampled dual eligibles believed their providers communicated with each other regarding their health, the response was mixed. There were many reports of participants directing their providers to communicate with each other and expressing confidence that they did. One woman, age 72 seemed glad that her PCP and hospital specialists exchanged medical reports using health IT:

> They puts it on the computer. So when I go to my heart doctor, my heart doctor goes on the computer and see [what] my… the Coumadin [blood thinner medication] man, the blood man, is doing. And then when I go to the um, primary doctor, she goes on the computer. Everybody sees what the other one is doing. They know what I am taking for what I am taking it for… So I'm almost sure there has never been a problem

there.

This is an example of care that is well-coordinated. However, several participants described breakdowns in communications between providers at different settings. Some patients lacked confidence that their PCPs had received reports when they had been hospitalized, or had received care through an outpatient clinic or from a mental health provider.

Although the subject of communication breakdowns between PCPs and mental health providers was not universally discussed by participants, some explained that the problem stemmed from NC's carved out mental health delivery system. NC's Division of Mental Health, Developmental Disabilities and Substance Abuse Services (MH/DD/SAS) contracts with ValueOptions Inc., (a private for-profit managed care company), for the provision of mental health services ("Mental Health Reform in North Carolina," n.d.). Given this contractual relationship between the state and the private company, one might not expect patients to express problems with accessing mental health providers because the company would assign providers to patients.

v. Summary of Results for Question Ia)

Question Ia asks how well care is coordinated by NC's PCMH. The research results indicate that none of the sampled dual eligibles reported the receipt of "visible" care coordination services by a CCNC care manager. However, the Case Study Results of Chapter 4 indicate that they benefitted by the "invisible" ones which were bolstered by CCNC's Informatics Center and QI initiatives.

Given that sampled dual eligibles were perhaps unaware that their care was being coordinated through NC's PCMH, this research aimed to understand whether they

experienced the "right care, at the right time, in the right place," and whether they perceived continuity of care (CHCS, 2010b, p.1). Regarding receipt of the right care, most sampled dual eligibles reported that a sufficient amount medical equipment, services and tests had been provided through NC's PCMH, and they had received relief of symptoms and/or disease resolution. However, a few had to lobby their PCP to access needed care, which was notable because of the potential for emotional distress and patient improvisation that could potentially harm their health. Further, in a few cases, inadequate PCP access was reported, which is notable because of the potential for hindered care coordination efforts. Nonetheless, most sampled dual eligibles reported robust access to specialist referrals, except where mental health was concerned. Reports were mixed regarding receipt of sufficient levels of preventive care.

The evidence shows that most sampled dual eligibles reported easy access to appointments, although some reported difficulty with the scheduling process. While one received needed transitional care services at the right time, another seemed to truly need them but they were not provided after her six month hospitalization. Finally, most reported that visits with PCPs were of an appropriate duration.

Generally the sampled dual eligibles who did not need to rely on public transportation reported that they were able to receive care in the "right place." But those who relied on these services suggested that a scarcity of public transportation represented a barrier to needed care. Most reported satisfaction once they arrived at the PCP's office, although two severely sight-impaired individuals seemed to have egregiously poor experiences navigating the office setting. Finally, reports regarding hospital experiences were mixed.

Sampled dual eligibles' accounts of continuity of care were also varied. While many sampled dual eligibles reported that they had worked with their PCPs for many years, it is possible that about one in three participants experienced usual source of care problems. Further, for a few sampled dual eligibles, provider discontinuity was associated with the receipt of care at an area teaching hospital, which was noteworthy because of the possible problematic psychological effects associated with repeatedly retelling the medical history. Finally, reports were mixed regarding whether patients' various providers communicated with each other, an example of care that is well-coordinated.

Question Ib) Necessary Components of Care

Research Question Ib asks: "From the perspective of sampled dual eligibles served by NC's PCMH, what are the necessary components of care?" Sudeh et al. (2008) indicate that patients want prompt access to professionals as well has high quality clinical and interpersonal care (Cheraghi-Sohi et al., 2008). Wensing, Jung, Mainz, Olesen, and Grol's, (1998) literature review on patient priorities for general practice care identified seven characteristics as important to patients; found in Table 17, these attributes were used to organize the findings (Wensing, 2007).

i. Necessary Care Components: Prompt Access to Professionals

As mentioned above, most research participants reported that they were able to promptly get PCP appointments and specialist referrals through NC's PCMH. Further, access to ED services was identified in the literature as a necessary component of care, and this research suggests that most participants were satisfied in this regard. Moreover, the research findings suggest good news for NC's PCMH: most sampled dual eligibles reported a desire to

avoid the ED and would choose it only in true emergency situations or when the PCP's office was closed.

Table 17: Wensing et al. (1998): Necessary Components Of Care, From Patients' Perspective

Themes	Subthemes
Theme I: Prompt access to professionals	1) Urgent or emergency care 2) Sufficient provider *face time* for care
Theme II: High quality clinical care	3) Competence 4) Availability of special services: preventive screening. regular health checks, and alternative preventive routines
Theme III: Skilled interpersonal care	5) Humaneness, empathy 6) Exploring patients needs & patient involvement in decisions 7) Informativeness

ii. Necessary Care Components: High Quality Clinical Care

Wensing et al. (1998) identify high quality clinical care as a necessary component of care from the patient perspective. But how did sampled dual eligibles discern that the care they receive is competent? How did they know that their PCPs are capable, knowledgeable and skillful enough to effectively treat them? Although sampled dual eligibles recognized clinical competence in many different ways, the two most frequently discussed themes were when PCPs carried out a thorough exam, and promptly and properly addresses medication issues.

Given research by Oboler, Prochazka, Gonzales, Xu, and Anderson, (2002), Boiko and Lacas (2004), Romm (1984), as well as Wensing et al. (1998), it is not surprising that focus group participants valued a thorough, comprehensive examination. Some discussed the importance of physical touch in the exam and a few expressed concern that their exams lacked this element. One 70 year-old woman reported:

> You know what the doctors don't do anymore, if you have noticed, is what they call palpitations, where they feel… They don't do that anymore. They used to tap. They don't do that anymore, and that was what doctors used for years.

Others expressed similar sentiments. The literature describes the importance of palpation (Bruhn, 1978; Cocksedge, George, Renwick, & Chew-Graham, 2013), strategies for training doctors in these matters (Arroyo-Moralesa et al., 2012; Rose, 1999; Saywitz, Goodman, Nicholas, &, Moan, 1991; Subha, 2008), and the need for sensitivity when touching individuals who may have been the victims of sexual abuse (Holtz, 1994; Siwe, Wijma, Silén, & Berterö, 2007). However, the literature review identified no research about patients' need for physical touch during routine exams.

Another wide-spread theme associated with competent high-quality clinical care was a PCP's ability to appropriately and promptly address medication issues. A literature review revealed that a great deal of research has focused on providing patients with information about side-effects in order to improve adherence (Bloom & McHorney, n.d.; Center for Health Transformation, 2010; Krueger & Hermansen-Kobulnicky, 2011). However, the issue of provider-responsiveness to medication side effects was not identified in the literature and warrants further attention because it was a wide-spread topic of interest, discussed by many participants and adjust medications when needed. Sampled dual eligibles described the following medication side-effects: cough, dizziness, general weakness, flu-like symptoms, lack of appetite and rapid heartbeat. Many reported that they were pleased when their PCPs adjusted their medication so they could be relieved of these problems. A 31 year-old woman noted:

> I was on Lexapro, blood pressure medicine, and I didn't know that, you know, one of the side effects was a hacking cough. And I would come just thinking I was getting a cold or something like that. Come to find out it was a side effect of

> that medication that was creating the hacking cough or whatever. And it was good that they are so knowledgeable…

Similar sentiments were expressed by many sampled dual eligibles.

Finally, Wensing et al. (1998) indicate that from the patient perspective, the necessary components of high quality clinical care involve access to special services including like preventive screening, regular health checks, family conferences and alternative medicine. Although these themes arose among sampled dual eligibles, they did not surface with enough frequency or intensity to warrant further attention.

iii. Necessary Care Components: Skilled Interpersonal Care

Wensing et al. (1998) recognize skilled interpersonal care as a third necessary component of care from the patients' perspective, identifying three subthemes including: 1) humaneness and empathy, 2) exploring patients' needs and involving them in medical decisions, and 3) informativeness. These topics will be explored in turn.

Given the extensive literature regarding the importance of the amount of time spent with one's doctor, it is not surprising that many sampled dual eligibles reported that not feeling rushed by the PCP is critical (David, Epstein, & Pantilat, 1999; Gross, Zyzanski, Borawski, Cebul, Stange,1998; Lin et al., 2001; Zyzanski, Stange, Langa, Flocke, 1998). Humaneness and empathy were perceived through the active listening of the PCP, a topic mentioned so frequently in connection with having a good doctor that it emerged as a crucial indicator of skilled PCP interpersonal care. Related quotes are provided in Table 18. This finding regarding the importance of PCP listening skills is not unique; it is described extensively in the literature (Anderson, Barbara, & Feldman, 2007; Anderson, Camacho, & Balkrishnan, 2007; Camacho, Anderson, Safrit, Jones, & Hoffmann, 2006; Uhas, Camacho, Feldman, & Balkrishnan, 2008).

Table 18: Research Participants' Quotes on the Importance of PCP Listening Skills

- "He listens. He takes time to listen and ah.. If I call the office, ah, he will call me back… I just think that he's a good doctor, because he just takes his time. And umm, examines me, and don't rush. And he's not impatient." (67 year-old woman)
- "He don't rush you out that door. He sit down and listen to you." (65 year-old man)
- "And you know if I tell him things, and you know, and he listens and he is a good doctor." (54 year-old woman)
- "She never seems rushed. She's always willing to stay as long as you need her…She never seems to be rushed. She's always willing to listen to things." (65 year-old woman)
- "I like her because she ahm she is a good. She listens to you, she take the time. She's not one of those doctors that you know gotta be in and out a certain amount of time. She's willing to listen." (45 year-old woman)
- "I ask my doctor questions, and she will, she will listen to what I have to say about the symptoms or things I'm going through…" (53 year-old woman)
- "Well my doctor, I think she's great. She's a good listener, the way she listens. And she seems to be interested in what you are saying in your condition." (75 year-old woman)

Another facet of skilled interpersonal care that Wensing et al. (1998), Kravitz and Melnikow (2001), Légaré et al. (2010) and Fotaki et al. (2008) describe involves exploring patients' needs and involving them in medical decisions. Indeed, Edgman-Levitan and Cleary (1996) suggest that patient needs are perhaps more extensive than previously thought, and the authors identified "access and coordination of care, information, communication, appropriate education, support and alleviation of fear and anxiety as needs of ambulatory patients" (National Committee for Quality Assurance [NCQA], 2008, p.4). Of course, investigating this diversity of patient requirements is a first step to satisfying them. This research indicates that these tasks are integral to medication management, a widespread topic discussed amongst sampled dual eligibles. Many participating dual eligibles reported that they wanted their PCPs to understand their medicine-related concerns, and use their input to inform prescription choices. For

example, a 70 year-old woman suggested that dialogue and negotiation regarding medication are important features of understanding her needs and collaborating on her care. Although she had resisted allergy medications, she and her PCP reached a resolution:

> She wanted to give me something, and I did not want it. And she said you really, really need it. And so the dosage she wanted to give me was way more than I could handle. So she brought it down to the lowest dose… I appreciated that.

These findings are not unique to this research. The broader literature describes the importance of provider-patient communications in medication management efforts (Chewning, & Sleath, 1996; Martin, Williams, Haskard, & DiMatteo, 2005).

Wensing et al. (1998) identify informativeness as another aspect of skilled interpersonal care. In this research, many dual eligibles discussed this topic and the issue has also been covered in the literature in the context of physicians' perceptions of patient ability to comprehend medical information (Arora, 2003; Street et al., 2010; Street, Gordon, & Haidet, 2007; Street, Richardson, Cox, & Suarez-Almazor, 2009). Generally, sampled dual eligibles recognized informativeness expressed when a PCP or nurse delivered medical information verbally, and many had had positive experiences in this regard. For example, a 46 year-old reported that while she had worked with other doctors who were incomprehensible, her current PCP was willing to "break it down" for her, to ensure she could grasp his meaning. Other sampled dual eligibles reported similar experiences.

Most reported that the medical information that they received through their PCPs was sufficient, and written materials were not required. However, in the cases when written information was given, it was most commonly accompanied prescription medication. For some, the content of the written materials was reportedly incomprehensible. This is not a surprising finding; the literature discusses patient misunderstanding of printed drug

instructions especially for patients with low levels of literacy (Davis et al., 2006; Davis et al., 2009; Shrank, & Avorn, 2007; Wolf et al., 2007). When confused, some sampled dual eligibles reported that they turned to the internet for clarification. Thus, this research suggests that patients no longer depend solely on a PCP's interpersonal skills when seeking information; they now have other sources to which they can turn. Similar findings have also been identified in the broader literature that describes extensive patient use of the internet for medical information (Baker, Wagner, Singer, & Bundorf, 2003; de Boer, Versteegen, G.& van Wijhe, 2007; Diaz et al., 2002; Gordon, Capell, Madhok, 2002; Jadad, & Gagliardi, 1998; McMullan,2006; Schwartz et al., 2006).

iv. Necessary Care Components: Summary

The first the necessary component of care from the perspective of sampled dual eligibles served by NC's PCMH was prompt access to professionals. Most sampled dual eligibles reported promptly access professional care through NC's PCMH, and their preference was to avoid the ED when possible. Most also noted the receipt of sufficient PCP "face time." The second necessary component was access to high quality clinical care, and the evidence showed that sampled dual eligibles recognized PCP competence especially when their PCPs conducted a thorough exam that included physical touch, and made needed medication adjustments (two findings not identified in the literature).

The third component was skilled interpersonal care, which included patients feeling unhurried during their office visit and good PCP listening skills. Exploring patients' needs and involving them in medical decisions was another important aspect of PCP social skills, especially where medication management was concerned. Person-focused care is a key component of the PCMH; the evidence shows that for many sampled dual eligibles, this

element of NC's PCMH was well-functioning. Finally, informativeness was another aspect of skilled interpersonal care. Most participants reported the receipt of a sufficient level of information communicated verbally by the PCP. However, some had problems understanding written content related to their medications and sought clarification on the internet.

Question Ic) Greatest Barriers To Accessing Necessary Care

This section answers Research Question Ic, which asks: "From the perspective of sampled dual eligibles served by NC's PCMH, what are the greatest barriers associated with accessing necessary care?" The literature review identified barriers at the system-, population-, and at the care-setting-levels; this section includes a brief overview of that literature and then summarizes relevant data from this research.

i. System-Level Barriers

The Institute of Medicine's (IOM's) *Crossing the Quality Chasm: A New Health System for the 21st Century* describes system-level barriers to care, reporting that the poorly organized delivery system leads to 1) health care fragmentation, 2) an inadequate health information technology (HIT) infrastructure, and 3) poorly designed care delivery processes (National Research Council, 2001). While this research found examples of all of these obstacles, we begin with the first two. As noted above, sampled dual eligibles experienced fragmentation as provider discontinuity between the hospital and the PCP, and resulting gaps in provider communications. However, it is not clear if participants would label the state's PCMH's HIT infrastructure as "inadequate." As mentioned above, efforts to coordinate the care of most sampled dual eligibles have been bolstered "invisibly," through CCNC's Informatics Center and QI initiatives. However, some participants seemed impressed that

their medical records were automatically exchanged electronically between PCPs and affiliated hospitals. Unfortunately others seemed anxious that this was not the case. The unsuccessful electronic exchange of medical information between providers suggests a lack of enabling functionality within NC's PCMH's (through CCNC's Informatics Center), or an IT malfunction.

Regarding the IOM's third system-level barrier to care, poorly designed care delivery processes, the research indicates that sampled dual eligibles experienced this problem most acutely in regard to the prescription drug delivery system. However, the reports were mixed; some appreciated of the delivery system and others did not. On the positive side, some seemed to have a sound understanding of the way Medicare Part D works, and others were happy that their medications were either mailed or delivered to their homes.

Yet, this was not the case for many sampled dual eligibles who described financial barriers to accessing needed medications. Federal- and state-level policies are at least partially responsible for this situation. National-level Medicaid policy prohibits pharmacies from denying prescriptions to enrollees who are unable to cover co-payments. However, these requirements do not apply to dual eligibles enrolled in Part D plans, so they can be denied the prescription until the co-payment is paid (KFF, 2004).

As noted in Chapter 2's Literature Review, Medicaid covers Medicare's copays for dual eligibles. Yet, NC's Medicaid program charges its enrollees copayments. State literature dated March 2012 says that copays are $3.00 per prescription and "providers may open an account for the patient and collect the amount owed as co-payments at a later date" (NCDHHS Division of Medical Assistance, n.d., p.17). At least in theory, this

policy should not be problematic for NC's dual eligible population because Medicaid prohibits providers from denying prescriptions to enrollees unable to cover co-payments.

However, this research tells a different story, indicating that these competing federal and state policies could be problematic for some participants, especially those who take many medications each day. For example, a 35 year-old suggested that financial stress limited her access to medication to treat a nervous system disorder: "I was like, I'm not paying $14 for one of my meds every month. I refused. I let me neurologist take me off that medication. I was not going to pay 14 dollars a month." A 76 year-old woman expressed surprise that the copayments for her prescriptions would total $146; she was unable to purchase them because the cost was prohibitive. Moreover, the 34 year-old woman who was hospitalized for six months after being hit by a car reflected upon the stress associated with costs:

> I'm just happy to have them [Medicare and Medicaid] pay my hospital bills, and at least they are paying that part so I don't have to worry about that. I have other bills I have to worry about, but not… It's the medication I have to worry about, it's not the hospital bills.

Further, during all of NC's nine "conversations" with dual eligbles in 2011 and 2012, there were discussions of co-payment obligations as a barrier to accessing prescriptions (CMS, 2012b). The evidence from this research (and that of the state) suggests that while participants were not *technically* required to cover prescription copays, they perceived payment as obligatory. The result of this poorly designed prescription drug delivery system is stress and reduced access. This situation is somewhat surprising, given that NC's Department of Health and Human Services' website notes that the dual eligibles may "join or switch drug plans at any time (effective the first of the following month)" if drug costs are too high (NCDHHS, 2013a).

In addition, this research found that financial issues had the potential to confuse some older sampled dual eligibles and limit their access to needed vaccinations. While one 76 year-old woman reported that she received a free shingles vaccine at her pharmacy, a 73 year-old woman was told that the pharmacy would charge $75 for it. Further, the 76 year-old was informed that she must pay $150 for the first in a series of hepatitis B shots received in the hospital; she never accepted the last ones due to financial constraints. The literature indicates that this should not be. Stange (2010) notes that through the PCMH, patients receive comprehensive care that is coordinated across different domains including disease prevention. Thus, the PCP's role would be to assure that patients receive the appropriate preventive care, including needed immunizations (Stange et al., 2010).

Nonetheless, this research shows that there have been two potential sources of confusion for these sampled dual eligibles. First, with regard to vaccinations for seniors, the ACA is confusing because it authorized some vaccines (flu, pneumonia and hepatitis B) be provided free of charge, but for all other recommended vaccines, Medicare recipients must pay copayments. Further, although vaccines are covered by Medicare Part D drug plans, the level of cost-sharing varies widely across plans (Andrews, 2012). This research suggests that the rules allowing for variation in copayments led to confusion and may result in obstructed access to preventive care for sampled dual eligibles, a group that tends to have multiple chronic conditions and would be well-served to receive preventive measures in order to avoid future interventions.

In addition to financial barriers to accessing prescriptions, this research found other obstacles to obtaining needed medications in a timely manner. Research participants indicated that untimely care was a problem when PCPs and/or their office staff did not promptly

transmit prescriptions to the pharmacy or improperly filled out the script. For example, one 83 year old woman reported:

> The doc, they [sic] don't get the prescription [refill order] back to the druggist. Maybe next day, you know, or something. And I try, my daughter, she tells me, don't let your medicine get out before you call it in. So that's what I try to do, get it in before it runs clean out so I won't have to do without. Especially without my sugar pill, I don't want that to run out. But the blood pressure and the cholesterol, I can do without that for a day. I don't like to, but I can, if I have to. But I most of the time, try to get it in before they give out… because my daughter she will lay me down if I let my medicine give out. She says 'Ma don't let your medicine give out. You call before so you can have it in time, on time.'

This quote indicates that the participant could not depend on NC's PCHM to assure that her prescription refill order was transmitted to the pharmacy in a timely manner and suggests that both daughter and mother found the situation stressful and potentially dangerous. Similar experiences were described by many others.

Further, some sampled dual eligibles reported that one source of delay in accessing prescription drugs is a NC Medicaid policy that prohibits payment for certain brand-name medications. In such cases, the PCP must write Medicaid a prior authorization note explaining why that particular drug is needed and noting which alternative (generic) medications have been tried and failed. Once NC's Medicaid program approves the brand-name medication, the pharmacy will override the Medicaid policy and supply the requested prescription.

Untimely care and frustration associated with prior authorizations and overrides was the topic of many lengthy and animated discussions amongst sampled dual eligibles. This process not only results in care delays and patient frustration. A 53 year-old participant explained that PCP effort and time are not the only squandered resources:

> That's what was happening with some of the dermatology medicine that I was getting. They would give me maybe one refill and then when I go get the second one and stuff,

> Medicaid would not approve it… So my doctor would have to convince Medicaid that this is the only medicine she's been able to find that will work. And we've tried six others, so she has to convince them, so she's trying to convince Medicaid that this is the only medicine that has worked and it's what I need. And then they'll said okay, we'll agree, we'll do it… I've got a closet full of… I've got thousands and thousands of dollars worth of medicines that never worked, just to find the one that did. But yeah, you have to prove to them that this is the only thing that will work. And sometimes they make you try other ones to prove that this is the one that will work. It's just, it's pretty sad, but that's what you got.

While the system strives to save financial resources by incentivizing the use of lower-cost generic medications, these prior authorization policies can result to unused and wasted medications, as well as a great deal of wasted provider and pharmacist time.

Further, policy and programmatic changes at the state-level represented problems for providers. Although this issue was addressed by few focus group participants, it is worthy of attention given the complexity of issues that emerged. A 53 year-old man reported that he wanted to quit smoking and his PCP wrote a prescription for a pill that was not covered by Medicaid:

> In the past year or two, Medicaid or Medicare, one of them I always get them confused, has changed so much, that they don't even really know. They don't know how to answer the question, and it can take several days for them to call you back, if they do. Because there seems to be this, no one seems to know what's going on. The pharmacist doesn't seem to know. There's this disconnect with the new rules or something, and a lot of times you're denied medications and things because they're trying to figure it out themselves because they don't even know. They're writing prescriptions for drugs that when you go to the pharmacy to get, they'll tell you that Medicaid will not approve this. Doctors don't even know that the prescriptions they're writing these drugs for aren't accepted by Medicaid. So, they're wasting your time. I've gone in with as many as four prescriptions and only one of them that Medicaid approved. So, it's a waste of time and money.

This quote highlights many issues of concern. The patient 1) describes confusion about which program (Medicare versus Medicaid) covers his prescription drugs, and 2) notes that his doctors do not know which will be approved and which will be denied. The former issue is problematic because in the face of a denial, the path to resolution is unclear since the two

programs "each have their own appeals process with distinct rules and protections related to notice, levels of appeal, review entities, timelines for filing appeals and making decisions," which makes it difficult to assess the correct course of action (National Senior Citizens Law Center [NSCLC], 2011).

The patient's second concern, a lack of provider knowledge about which drugs would be approved and which would be denied, stem not from his dual eligibility but rather a disconnect between two components of the Medicare program: Part A, which is responsible for the doctors, and covering their fees and Part D, which requires private insurance companies to cover the prescription drug costs. Since these issues are caused by service delivery gaps within the Medicare program, they impact not only the dual eligibles but also the much larger Medicare population. In the case of sampled dual eligibles however, NC's PCMH could facilitate the resolution of these issues.

In addition to the medication-related concerns described above, the deleterious impact of medication errors was another topic of concern. Although this topic was discussed by a few sampled dual eligibles, there are serious ramifications of such errors which make them worthy of attention. For example, a 97 year-old woman was treated by a new or different doctor who lacked information about the other medications that she was taking, and the consequences could have been fatal. Further, a 33 year-old woman with special needs explained that a medication error could have been avoided if a new PCP had appropriately responded when she informed him of her drug allergy. She reported that in speaking to the provider:

> I was like don't give me that shot. Give me something that I am not allergic to… I said what are you giving me? He said giving me amoxicillin. I said don't give me that shot, I am allergic to it.

Not long after the improper medication was administered, the woman required urgent medical attention in the ED to treat the allergic reaction. These are examples of poor PCMH program functioning.

ii. Population-Specific Barriers

In addition to the systems-level barriers to needed care that are described by the IOM, the literature indicates that the dual-eligibles face obstacles that are population-specific. Generally the dual eligibles receive lower quality care than other Medicare beneficiaries including lower rates of preventive screenings, treatment, follow-up therapy, or testing (Komisar, Feder, & Kasper, 2005; Makuc, 1994; McCall, Sauaia, Hamman, Reusch, & Barton, 2004; Merrell, Colby, & Hogan,1997). Further, the dual eligibles are less likely to report having a usual source of care and face an increased likelihood of needing more hospitalizations and ED visits than their non-dually eligible counterparts (McCall , 2004; Miller & Weissert, 2004; O'Leary, Sloss, & Melnick, 2007). Finally, the literature notes that dual eligibles face a greater likelihood that they will experience unaddressed needs with activities of daily living (ADL) (Grabowski, 2009).

Sampled dual eligibles echoed the literature; some were unable to access certain preventive screenings, treatments, follow-up therapies and testing. While research participants did not complain about lack of a usual source of care, about 30 percent were served by their current PCP for just one year or less, so it is possible that some encountered problems associated with PCP discontinuity. Further, while this qualitative research did not examine the likelihood of hospitalization and ED visits for sampled dual eligibles, it identified previously-discussed hospital issues. Finally, although the literature indicates that dual eligibles have a

greater chance of unaddressed ADL needs, this was not the case for the majority of research participants who could be characterized as *lower risk and independent-living.* [11]

iii. Individual-Level Navigation Barriers

This research also identified individual-level barriers to navigating the health care system that are described in an Academy Health brief (2007) explaining the four main issues of concern for individual patients including:

1) making coverage decisions, if patients have a choice of coverage;
2) understanding what is covered, getting referrals, and addressing reimbursement disputes;
3) selecting a health care provider who is covered by the patient's health care plan; and
4) care management for a major clinical event, and the associated emotional burden.

With regard to the first, regarding making coverage decisions, since research participants are enrolled in Medicare and Medicaid, they do not have a choice of insurance plan for their primary coverage. Although a few sampled eligibles expressed gratitude for Medicaid and Medicare, a few others expressed concerns about the quality of care that these programs offer. Further, while some participants seemed aware of Medicare Part D insurance policy choices, many others seemed unaware that alternative insurance options might be available that could result in lower co-pays and improved coverage for vaccinations.

With regard to understanding what is covered, getting referrals, and addressing reimbursement disputes, some sampled dual eligibles expressed confusion about which

[11] Only one participant, a 34 year-old who required a wheelchair received a few hours of home health a week. Home health care includes three different types of care: 1) assistance with ADLs, 2) instrumental ADL which is tasks like shopping and laundry, and 3) skilled care (which is more closely associated with nursing care). See: http://www.henrycohd.org/homehealth.htm

services were covered by Medicare, and which were paid by Medicaid, and about coverage for preventive services and vaccinations (as mentioned above). Yet, most sampled dual eligibles reported success in obtaining specialist referrals through NC's PCMH, with the notable exception of mental health providers who accept Medicare and Medicaid.

Another coverage-related issue involves reimbursement disputes. Although national-level dual eligibles' advocacy groups describe "balance billing" problems, the research indicates that generally, reimbursement disputes (other than Part D prescription drug co-pay concerns) were not an issue for sampled dual eligibles (Gupta, 2009; Center for Medicare Advocacy [CMA], n.d.; CMS, 2012a). Balance billing describes a situation when a provider illegally charges a patient for the difference between the Medicaid or Medicare reimbursement rate versus the doctor's fee ("Balance Billing," n.d.). NC's Medicaid agency, the Division of Medical Assistance, is legally required to pay Medicare cost sharing for most dually eligible individuals; NC's providers are not permitted to engage in this practice (Arden, 2008). While participants did not complain about balance billing per se, as noted above, there were concerns about the cost of some preventive vaccinations.

With regard to selecting PCPs covered by the plan, most sampled dual eligibles reported robust access. However, given that the Raleigh-Durham region is densely populated and contains two major research universities, it is possible that this easy PCP access by is not enjoyed by dual eligibles in lower-population areas of the state.

Another navigational challenge is problems managing care in the face of a major clinical event and/or any associated emotional burden. Generally sampled dual eligibles did not describe issues in these areas but one notable exception was the young woman hit by a car who could not function while taking high doses of strong pain medication. Given widespread

evidence in the literature about navigation problems, the lack of support from this research suggests that it would have been prudent to have included a question in the interview guide specifically addressing this important matter.

iv. Summary: Greatest Barriers To Accessing Necessary Care

This section has considered sampled dual eligible's greatest barriers to accessing necessary care at the system-, population- and individual-level. Many seemed especially concerned with the most-pressing system-level barrier to care, poorly designed prescription drug delivery processes, and faced financial barriers to accessing needed medications that were caused at least in part by competing federal and state policies on prescription drug copays. Further, federal rules allowing for variation in vaccine copayments led to confusion and resulted in obstructed access to preventive care for sampled dual eligibles. Many also reported obstacles to obtaining needed medications in a timely manner caused by PCPs and/or their office staff or delays associated with the prior authorization process. Finally, a few sampled dual eligibles suggested that poorly designed prescription drug delivery processes resulted in medication errors that could have had grave results.

With regard to the population-specific barriers to accessing necessary care, the research results generally echoed those of the literature, finding similar quality of care concerns. However, at the individual-level, there were numerous navigation barriers. Although sampled dual eligibles could not select their primary insurance provider, many others seemed unaware that alternative Medicare Part D insurance options might be available that could result in lower co-pays and improved coverage for vaccinations.

Regarding patient ability to understand coverage issues, some sampled dual eligibles expressed confusion about which services were covered by Medicare, and which were paid by

Medicaid, and about coverage for preventive services and vaccinations (as mentioned above). An ability to obtain specialists referrals through NC's PCMH is another issue related to coverage; most sampled dual eligibles were satisfied except where mental health providers were concerned. Coverage is also involved in addressing reimbursement disputes; while participants did not complain about balance billing per se, some had concerns about the cost of some preventive vaccinations.

Another navigational issue requires selecting a PCP covered by the plan, and most sampled dual eligibles reported robust access in this regard. However, given that the research was conducted in a densely-populated region, these findings might not stand up in lower-population areas of the state. The final navigational challenge is related to problems managing care in the face of a major clinical event and/or any associated emotional burden. The findings would have been more robust if a question had been included in the interview guide that specifically addressed this important topic.

Question 1d) Challenges Facing NC's PCMH's Program

This section answers Research Question Id, which asks: *"What challenges does NC's PCMH's program face in providing coordinated care for dual eligibles? Why?"* Chapter 4's Case Study Results and the findings from sampled dual eligibles revealed five primary issues for NC's PCMH in its efforts to provide coordinated care for this group of patients.

The first challenge is showing cost savings associated with NC's PCMH. Such savings are difficult to calculate because NC's PCMH seeks to *avoid* costs by reducing ED and acute care use (Berra, 2012). Further, while medical homes generally follow

certain principles to reach reduce ED and acute care utilization, there are a variety of approaches taken to reach those targets and the 14 local networks may emphasize one PCMH strategy over others. This makes the identification of factors associated with cost-savings difficult.

Another related issue not discussed in the literature but which emerged from the Case Study Results is regarding CCNC's cost of supporting NC's PCMH. The cost of NC's PCMH may seem relatively inexpensive because PCCM costs are about $3 per member per month (PMPM) for PCPs and the networks (CHCS, 2009). However, as the analysis of CCNC's IRS 990 Forms revealed that in 2011, CCNC expenses totaled $9.6M in 2011, and nearly $18.3M in 2012. With these CCNC expenses taken into account, is it possible that the care provided through NC's PCMH may not be as inexpensive as it seems? This question will be addressed in Chapter 6, the Conclusion.

A second challenge for NC's PCMH is although the federal government has recently made real-time Medicare claims data available, NC has not yet identified and implemented a strategy to utilize those data. As noted in the Case Study Results, the lack of data has hindered CCNC's efforts to coordinate care for the dual eligibles served through NC's PCMH. In the past, the federal government represented a barrier to accessing needed data but today, state-level obstacles still hobble CCNC's use of these data for QI initiatives in NC's PCMH.

Third, as previously discussed, federal and state policies regarding copayments for prescription drugs have resulted in significant financial barriers to accessing needed medications for some sampled dual eligibles served through NC's PCMH. At the federal-level, Medicaid policy prohibits pharmacies from denying prescriptions to enrollees unable to

cover co-payments, but these rules do not apply to those enrolled in Medicare Part D plans (KFF, 2004). For the dual eligibles, Medicaid is responsible for covering those Medicare copays but NC Medicaid policy enables enrollees to be charged copayments. Although federal Medicaid policy should shield the dual eligibles from these problems, the research findings show that sampled participants perceived payment as obligatory and the result has been obstructed access to needed medications. These competing policies represent a significant challenge in the provision of coordinated care for the dual eligibles because NC's PCMH program is responsible for the delivery of all resources (including prescription drugs) that are needed for patient care activities.

A fourth challenge for NC's PCMH is competing philosophies at the state-level about whether to strive to lower Medicaid costs and improve quality by contracting with private managed care organizations (MCOs) or developing a "home grown" infrastructure to meet these goals. As discussed in the Case Study results, this issue was addressed by the ambulatory care system in the late 1980s and early 1990s, when NC's state leaders considered abandoning the fee-for-service (FFS) Medicaid payment model to contract with commercial MCOs. While this approach was utilized on a very limited basis, the state began to building its own QI infrastructure in earnest in the 1990s.

This was not the path taken in the mental health system, however. Beginning in the early 2000s, NC's Division MH/DD/SAS carved-out the delivery of mental health services, by contracting with a private MCO. The evidence that emerged in the literature and from some sampled dual eligibles was that this policy resulted in fragmented care, mental health provider shortages and breakdowns in communication between PCPs and mental health professionals (Swartz & Morrissey, 2012). The resulting divisions in the

two systems represent a challenge for NC's PCMH, which strives to integrate all needed patient care through its coordination efforts.

Another related challenge is associated with NC's Governor McCrory's recommendation that the state's Medicaid program transition away from a managed FFS payment model toward a managed care one. Faced with a 2013 Medicaid budget shortfall of $248 million, the Governor planned to integrate physical, behavioral, and dental services, provided by a private MCO paid on a capitated basis. While the non-profit CCNC could enter the competitive bidding process, the Governor's proposal suggests that three or four for-profit MCOs would assume full risk for the state's $13 billion Medicaid program. Although NC's General Assembly did not approve the Governor's plan in its 2013 session, it could arise again; this pivot away from NC's current managed FFS model toward capitation would have a significant impact on the functioning of NC's PCMH program. Although CCNC and its participating providers could influence state policymakers regarding this matter, they do not have the authority to make decisions about the fate of the Medicaid program.

The fifth challenge for NC's PCMH in its efforts to provide coordinated care for the dual eligibles is regarding the availability of community services (or lack thereof). As noted above, evidence from this research and that conducted by the state to inform its Dual Eligibles Proposal indicates that for some dual eligibles, transportation barriers have inhibited patients' ability to keep appointments. This lack of public transportation represents a challenge to NC's PCMH because it constrains dual eligibles' efforts to access needed care. Further, as will be discussed later in this chapter, sampled care managers identified additional community resources necessary to their care coordination efforts including low-income housing, language interpretation services and financial

counseling. Although the care managers considered these factors to be crucial to improved health outcomes for the dual eligibles served through NC's PCMH, the availability of such services is outside CCNC's control and that of NC's PCMH. The main theme associated with all these challenges for NC's PCMH is that they are largely outside of CCNC's control, which makes their resolution more difficult.

Question II: Contextual Information from NC's PCMH Care Managers

Question II asks about the contextual information that can be learned by sampled care managers who provide care coordination services to support NC's PCMH. This broad inquiry is broken into granular sub-questions regarding the tools that sampled care managers rely upon most, the experience of providing care coordination services to different patient populations, and care mangers' perceptions of two AHRQ theoretical models of care coordination.

While many care managers' efforts result in coordinated care in NC's PCMH, CCNC's website makes it clear that coordinated care is *not* CCNC's primary aim. CCNC's webpage includes few references to care coordination per se (CCNC, n.d.c). Instead, CCNC's goal is to "achieve quality, utilization, and cost objectives in the management of care for Medicaid recipients across North Carolina" (Steiner et al., 2008, p. 361). As was discussed in the literature review, care management is but one of many components of care coordination. Nonetheless, Question II focuses on the efforts of CCNC care managers because they provided important contextual information about NC's PCMH program and the high-risk and high-cost patients (including some dual eligibles) whom they serve.

Question IIa: Tools Upon Which NC's PCMH Care Managers Most Rely

Research Question IIa asks: "*Upon which tools do sampled care managers rely upon most when providing services in NC's PCMH?"* In order to answer the question, this section contrasts the US Department of Veterans Affairs' (the VA's) description of care coordination with the real-life experience of CCNC care managers. This definition was selected because it emphasizes certain tools that CCNC's website also identifies as critical. The VA's definition is as follows:

> Care coordination is the wider application of care and case management principles to the delivery of health care services using health informatics, disease management, and telehealth technologies to facilitate access to care and improve the health of designated individuals and populations with the intent of providing the right care in the right place at the right time (Wertenberger, 2006, p. 109).

What is meant by health informatics, disease management, and telehealth technologies?

- Health informatics is another expression for health information technology (HIT), a familiar term used a great deal in this dissertation.
- A disease management program aims to bolster the relationship between patient and provider, while working to avoid complications by empowering patients and facilitating the utilization of clinical guidelines (Care Continuum Alliance [CCA], n.d.). This work is done by developing a patient care plan, engaging in monitoring and follow up, and appropriately responding to patient changes (CCA, n.d.).
- Telehealth technologies include electronic information and telecommunication tools to support the provision of long-distance clinical health care, and activities (Health Resources and Services Administration [HRSA], n.d.a).

CCNC's website focuses on the first two terms, but not the third, telehealth technologies. Rather than focus on the provision of long-distance care, CCNC focuses on telemedicine,

which emphasizes the exchange of medical information from one site to another via electronic communications. Tools include email, fax, smart phones and other forms of telecommunications technology (American Telemedicine Association [ATA], 2012).

Of course CCNC's website was not the only source of information regarding the tools that care managers rely upon most; the sampled group was also queried about this matter. This research indicates that health informatics is a key tool for sampled care managers: HIT was noted in nearly all the care manager interviews. Care managers reported reliance upon the Care Management Informatics System (CMIS) to track patients' care and to conduct an electronic comprehensive health assessment that facilitate transitional care. They reported that HIT also improved provider-care manager communications. In a patient's electronic medical record (EMR), PCPs are able to indicate that care management services are required, and the care manager generates patient-specific reports informing the PCP which services have been provided. Moreover, HIT is used to identify patients requiring specific interventions, like a cholesterol check, or who are "frequent flyers" to the ED. Finally, sampled care managers reported that in some cases, HIT enabled them to access the patient medical records of local hospitals and allowed staff at those settings to access care managers' records.

The second tool is disease management, which CCNC indicates is a vital part of NC's PCMH program, especially for patients with chronic conditions such as asthma, diabetes, congestive heart failure, and chronic obstructive pulmonary disease (COPD). On-site "disease management 101" meetings are hosted by CCNC clinical staff for area PCPs and include discussions of current disease management research. Surprisingly, "disease management" per se was referenced in just one care manager interview, but the management of targeted diseases, (especially diabetes), was discussed by all care

managers. The third and final set of tools upon which CCNC care managers rely upon most are the telemedicine devices of phone, fax and email; these tools were deemed critical by all sampled care managers.

Question IIb: Coordinating Care for Different Patient Populations in NC's PCMH

Research Question IIb asks: *"From the perspective of sampled CCNC care managers, how is the experience of providing care coordination services to support NC's PCMH similar or different for non-dual eligibles versus dual eligibles? For dual eligibles who are aged 65 and older compared with those under age 65?"* These questions are posed because the literature describes the health differences between these groups and this research aimed to understand if sampled care managers also experienced this variation in their work.

As was discussed in Chapter 2's Literature Review, three in five dual eligibles have multiple chronic conditions; they face higher rates of diabetes, cardiovascular and pulmonary disease, stroke, and Alzheimer's disease than Medicare beneficiaries (CHCS, 2010a); KFF, 2012b). Some sampled care managers noted that the dual eligibles they serve indeed have more chronic conditions than other patients. The literature also says that about one in three dual eligibles has cognitive or mental impairment (MedPAC, 2010). This finding was echoed in the research. One care manager reported special challenges associated with engaging younger dual eligibles with mental illness in their own care:

> [Mental health,] it's not as important to them, right? And then the mental health again, the understanding of the reason why they are being provided these services, and that again goes back to the lack of, or the level of education that these patients have around their medication, around their medical history or overall. Right? If it's someone with

> a history of mental health, if even it is just a minor history of mental health, or anything new, pretty much. I think those patients, especially if they are younger, don't take it as seriously. And with mental health, they may not have that support system outside of the clinic that gives them that push, or that understanding that no, [you can't disregard your need for treatment,] this appointment is in fact important for you.

This quote highlights the unique challenges associated with coordinating care for this sub-population, especially if patients lack the needed social support to reinforce the message that mental health issues are too serious to be ignored. Further, another care manager reported a different challenge when working with this group. She noted that one patient with special needs had a strong preference for working with a narrow set of providers in just a few care settings, which limited her care options.

The literature also notes that about one in 10 dual eligibles need home health care and expensive skilled nursing home services (Adamy, 2011). Two sampled care managers described these needs and one reported:

> Older [dual eligibles] in general, you know, they are needing… generally, more care. And it's you know, a lot of them get to a point where family is either taking care of them at the house, or they have to decide whether it's time to get more help. A lot of them get home health, PCS [personal care services] or aid services in their homes, three to four hours a day. Some don't qualify or some do, and they [the aides] come and help with house stuff. You know, like getting them bathed, or getting the house a little clean, and laundry and stuff like that. They tend to be needing more care as far as outside help than the youngers [dual eligibles] do and family is, or is not always available… They need more, they need more family, or home health, or equipment, or consideration of rest homes or assisted living or skilled nursing as they get older.

The need for family support of older dual eligibles arose in two care manager interviews. A few care mangers reported that younger, disabled dual eligibles tend to have more support from family members than their older counterparts. Without it, care managers explained that older dual eligibles face transportation and other barriers to care. Ciechanowski et. al (2004) presented similar findings about the need for support for older adults facing social isolation.

Question IIc) AHRQ's Care Coordination Ring

Question IIc asks *"From the perspective of CCNC's care managers, does AHRQ's Care Coordination Ring represent the experience of coordinating care for dual eligibles in NC's PCMH? Why?"* As previously discussed, the Care Coordination Ring represents the way care is ideally coordinated for a diverse array of patients, across many different health care settings. As shown in Chapter 1's Figure 1, the framework is patient-centered, and the 13 colored circles that surround the patient represent the continuum of care, participants, health settings and information that are critical to assuring high quality care. The large blue ring that ties the 13 circles together represents care coordination, and it touches all those who participate, directly or indirectly, in patient care. While this ideal representation of care coordination is interesting from a theoretical perspective, this research strives to understand its application to the real life care coordination efforts of sampled case managers in their efforts to serve dual eligibles in NC's PCMH.

All six care managers appeared to be impressed by the model and reported that it included many, if not all the most important elements of care coordination. However, care managers identified other components of care coordination that they felt should be added to the model including public transportation and language interpretation services, because these supports are crucial for low-income populations like the dual eligibles to access care. Another care manager noted that although "community resources" were included in the framework, insufficient attention was paid to low-income housing and other basic needs, which should have their own place in the model's ring:

> It kind of almost goes back to Maslow's Hierarchy of Needs, your basic needs are first. And then, for a patient they have to be secure. They have to have clothing, food,

> shelter, 'cause that's what they have to have to live. Then, they start thinking about the other things.

Another care manager described the challenge of trying to help patients with health needs in the midst of more urgent requirements:

> If you go to a family, like, a... You know, a family, a patient, and family members are out of work, there's no food, they can't pay for their electricity, they can't pay for this. No matter how, how much you go in to teach them, your intentions are to teach them about the diabetes or the congestive heart fail... It's not going, it's not gonna go... You, we need to take care of those social issues first, before we can even educate the patients how to take care of their chronic conditions…That's like major… It's not gonna happen…

Given that food security and a lack of electrical power are tied to financial insecurity, it is perhaps not surprising that another case manager reported that financial counseling was a critical feature of care coordination that was nonetheless excluded from the model:

> The one thing I don't see is financial… And I think we as a care manager everywhere see that quite a bit… If there's dually eligible patients, they are just, one reason or another, struggling with their finances. And we are trying to help them… So I think it's the one thing that's left out of here, and that… This is care management anywhere that probably works a lot with the patient and their financial needs.

In addition to noting that community supports should have been included in the model's framework, another care manager reported that although mental health services were included in the framework, they are largely inaccessible in reality:

> I'm glad mental health [services are included in AHRQ Care Coordination Ring because]... mental health services is major thing. And also, just even, like, I feel we have…We just have a lack of, providers that accept that accept Medicaid, Medicare… We're really poor in that area…especially in the much-needed neighborhoods… where, you would have a lot of concentration of patients there, and there are no clinics. They have to travel so far, and the clinics are overcrowded. So it's really hard to find good providers, now... that are not overflowing with patients.

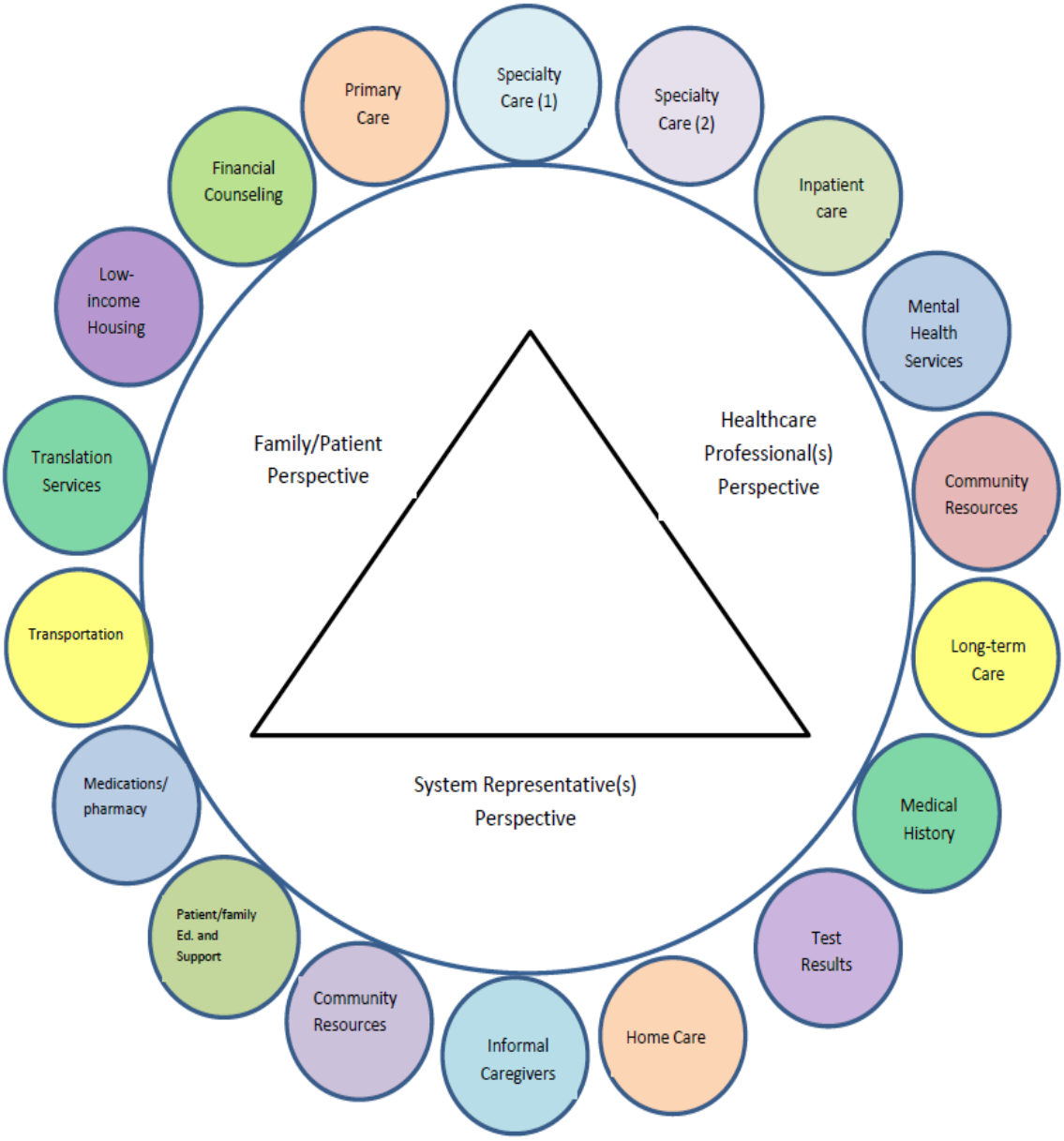
For this care manager, AHRQ's ideal theoretical represents a more robust mental health system than exists for dual eligibles served in NC's PCMH. In response to these care

managers' suggestions, AHRQ's Care Coordination Ring has been revised in Figure 10 to more adequately fit their "real world" experience.

The revised Care Coordination Ring includes low-income housing, transportation, language interpretation services and financial counseling because sampled care managers considered these factors to be so crucial to coordinating care for high risk and high cost dual eligibles and other low-income patients served through NC's PCMH.

Another aspect of care coordination is not represented in the model, but it was discussed by the sampled care managers and described in Chapter 4's Case Study Results nonetheless. Care coordination is provided with varying levels of frequency and intensity, but this variation is not shown in the model. For example, a care manager may initially have high-intensity contact with a dually eligible patient through a home visit. For a time, this level of intensity may be maintained through frequent in-person meetings, say, before or after medical appointments. However, as a patient's situation improves, a care manager may determine that less frequent telephonic contact is needed. Careful consideration was dedicated to potentially modifying the model to include the variance in frequency and intensity of contact by the CCNC care manager providing the intervention. Nonetheless, the model did not lend itself to show this level of detail.

Figure 10: Revised Care Coordination Ring



Question IId) AHRQ's Care Coordination Mechanisms Framework

Question IId asks *"From the perspective of CCNC's care managers, does AHRQ's Care Coordination Mechanisms Framework represent the experience of*

coordinating care for dual eligibles in NC's PCMH? Why?" As can be seen in Figure 2 of Chapter 1, this AHRQ model strives to explain *how* care coordination is achieved.[12] AHRQ identified two mechanisms hypothesized as key to carrying out effective care coordination, these are *Coordination Activities* and *Broad Approaches*. Certain activities and structures are associated with each of the two mechanisms and these are found in Table 19 (AHRQ, 2011). The two subsections that follow highlight the *Coordination Activities* and *Broad Approaches* that sampled care managers identified as vital to their efforts to coordinate care for dual eligibles served in NC's PCMH program.

Table 19: AHRQ's Two Mechanisms of Coordinated Care (AHRQ, 2011, p. 12)

Coordination Activities	Broad Approaches
Actions that help achieve coordination, whether employed in an improvised or systematic way including: 1. Negotiating responsibility and/or establishing accountability 2. Communicate 3. Facilitate transitions 4. Access needs and goals 5. Create a proactive plan of care 6. Monitor, follow up, and respond to change 7. Support self-management goals 8. Link to community resources 9. Align resources with patient and population needs	Structures of care aimed at improving health care delivery, including improving or facilitating coordination, and often incorporating a number of coordination activities including: 1. Health information technology (HIT)-enabled coordination 2. Teamwork focused on coordination 3. Health care home 4. Care management 5. Medication management

i. Coordination Activities

The Framework shows that nine activities are involved in effective care coordination. Sampled care managers indicated that two of these are key to coordinating care for dually eligible patients. The first is *negotiating responsibility and/or establishing accountability*, and

[12] For purposes of this research, this framework was modified in three ways: 1) The name was changed from the "Care Coordination Measurement Framework" to the "Care Coordination Mechanisms Framework" in order to emphasize the two mechanisms that AHRQ hypothesizes are means to achieve effective care coordination, and to de-emphasize measurement, which is outside the scope of this research.[12] 2) The original model says "See chapter 2" which refers to text in the AHRQ's Care Coordination Atlas but does not make sense for this research; thus, this language was removed. 3) The bottom of the original model referred to "coordination measures" Since measures are outside the scope of this research, this text was removed from the model.

the second is *linking the patient to community resources*. Many of the sampled care managers emphasized the importance of accountability and negotiating responsibility. Interestingly, their interpretation of these efforts differed from that described by AHRQ, which says that the health care professional, larger care team, or broad health care organization is responsible for patient care (AHRQ, 2011). Thus, AHRQ concentrates on accountability *within* the health care team.

In contrast, sampled case managers focused on negotiating responsibility and establishing a sense of accountability *with their patients,* noting that enabling patients to take responsibility for themselves is an important aspect of care coordination. One care manager reviewed the list of *Coordination Activities* and commented:

> I like this one, the establishment of accountability and initiative... I like to make sure that my patients are onboard. … You have to figure out where they are, ready for change or ready to be healthier, or at least take responsibility for their health care. So, if they're not even wanting to schedule their own appointments, they don't make their own appointments, they're not taking their medicines... I have to go back [and say to myself] 'Wait, I can't work harder than them because it's not going to help…' That's important, you have to start to figure out where they are... where to start because you can't go in there and go, 'Okay, we're going to do all this.' And they're like, 'What? You know, I haven't seen a doctor in five years, I don't want to go to the doctor…' Figuring out where they're at, the plan care and the goals should be focused on... initiated… should be per the patient. Not my goals, their goals… My goal can't be for them to go exercise five times a week when they don't even want to…Maybe they can walk to the mailbox once a week and they're fine with that and we'll start there, and see how they go. So, yeah, it has got to be their goals…

The quote highlights the importance of patient activation, and engaging the patient with the health care team in order to develop a meaningful plan of care (Hibbard, Stockard, Mahoney, & Tusler, 2004). Moreover, the quote suggests that a care plan lacks value if completed without patient collaboration and "buy-in." Another care manager described the development of this plan as a means of assuring patient accountability:

> Create a proactive plan of care, I think that's hugely important…at their new office visit… the first time a patient comes to a clinic… Because with our most vulnerable patients if they're not involved in the planning and they don't think it's feasible the care, the provider, the medications they're prescribing, different activities, different referrals…. If they're not up for it, it's not gonna happen.

This quote emphasizes timing, suggesting that establishing a meaningful, accountable rapport with a patient from the start is key to the patient's implementation of the care plan. One care manager implied that this work can be difficult because:

> Most of our patients don't really like the word "responsibility." So it kind of does, we do a lot of Motivational Interviewing and it come to mind when I was lookin' at that [model] to get them, to motivate them to accept responsibility of making their own appointments to ensure accountability that they're gonna be there [at their appointments]...

The quote suggests that CCNC care managers are trained in Motivational Interviewing to encourage self-care, a topic also found in the literature (Hettema, Steele, & Miller, 2005). Further, the themes of negotiating responsibility and establishing accountability that emerged from the research are echoed in the health care industry: the National Committee for Quality Assurance (NCQA) has identified Self-Management Support as one of six key PCMH standards (National Committee for Quality Assurance [NCQA], n.d.).

The need to link the patient to community resources also emerged in conversations regarding the Care Coordination Mechanism Framework. Sampled care managers described the needs for Spanish-speaking providers and translators, public transportation services, and free English proficiency classes (which would enable patients to identify other valuable community or health resources). As noted above, the Revised Care Coordination Ring in Figure 10 above reflects most of these suggestions.

ii. Broad Approaches

The Care Coordination Mechanism Framework indicates that the second mechanism hypothesized as crucial to effective care coordination is the utilization of five *Broad Approaches*. Given the previously-described evidence regarding the tools that sampled care managers rely upon most when providing care coordination services for dual eligibles in NC's PCMH, it is no surprise that the *Broad Approach* of *HIT-enabled coordination* was described at length in all the care manager interviews.

Further *teamwork focused on coordination* and *medication management* were described in detail by some care managers. Interestingly, these two approaches were discussed as they relate to each other, not as two separate approaches. One care manager reported: "Teamwork, that is just huge, with the providers and the patient and us, we all work together to get their needs met. The pharmacy – all of us." Another care manager indicated that teamwork is an essential part of medication management:

> The med management is huge for us. Making sure that their medicines are correct, and that they're taking them. Give them the pill box, making sure they know how to use it, and hopefully that is one of the tools they can use. And the team work, I couldn't do it without my pharmacists, or my social workers, or management.

These quotes suggest that medication management is such a complex and important activity that care must be carefully coordinated between members of the health care team with different types of expertise in order to effectively complete the task.

5. Conclusion

This chapter covers the experience of a sample of dual eligibles served by NC's PCMH and a sample of CCNC care managers who support the program. It describes the data collection efforts, as well as the data analysis and reporting process. It also

identifies the characteristics of sampled of dual eligibles and care managers. The research results are summarized in two brief tables; Table 20 covers the findings of the dual eligibles, and Table 21 shows those of care managers.

TABLE 20: Summary of Findings of Sampled Dual Eligibles (SDEs)	
Theme:	**Receipt of Coordinated Care through NC's PCMH?**
"Visible" versus "invisible" care coordination	• None of the 61 SDEs reported receipt of "visible" care coordination services provided by a CCNC care manager (CM). • CCNC CMs apparently serve higher-risk, higher-cost patients. • SDEs could be characterized as *lower-risk and independent living.* • SDEs receive "invisible" care coordination services through NC's PCMH which are bolstered by CCNC's Informatics Center and QI initiatives.
Theme:	**Right Care?**
Access to sufficient levels of care	• Many SDEs reported sufficient amount medical equipment, services and tests provided through NC's PCMH. • Many reported that PCP's treatment relieved illness symptoms and/or resolved disease. • A few SDEs had to lobby their PCP to access needed care; notable because of potential for emotional distress and patient improvisation that could potentially harm health. • Most SDEs reported adequate access to their PCPs. • A few SDEs reported inadequate access to their PCPs which is notable because of its potential to hinder care coordination efforts. • Most SDEs reported robust access to specialist referrals, except for mental health. • Mixed reports regarding receipt of sufficient levels of preventive care.
Theme:	**NCC: Right Time? (A necessary care component)**
Prompt Access	• Most SDEs reported easy access to PCP appointments. • Most SDEs reported their preference to avoid the emergency department. • One SDE received needed transitional care services (TCS) at the right time. • Another SDE seemed to truly need TCS after a devastating car accident but they were not provided.
"Face time" with PCP	• Most SDEs reported that PCP visit was an appropriate duration.
Scheduling process	• Some SDEs reported difficulties with the multi-step scheduling process required to get a PCP appointment.

TABLE 20: Summary of Findings of Sampled Dual Eligibles (SDEs) (cont.)	
Theme:	**Right Place?**
Transportation	• Most SDEs who did not rely on public transportation reported that care located in the "right place." • But SDEs who relied on these services reported that a scarcity of public transportation represented a barrier to needed care.
Experiences With Different Care Settings	• Most SDEs reported satisfaction with PCP's office but 2 severely sight-impaired women reported egregiously poor experiences navigating PCP offices. • Mixed reports regarding hospital experiences.
Theme:	**Care Continuity?**
Long-term relationship with PCP	• Many SDEs worked with the same PCP for many years. • However, it is possible that 1 in 3 SDEs experienced usual source of care problems because they'd worked with their PCP for 1 year or less. • Access to PCPs may not be as easy in lower-population areas of NC.
Psychological effects	• 2 SDEs reported provider discontinuity associated with the receipt of care at an area teaching hospital; this is noteworthy because of possible negative psychological effects associated with repeatedly retelling medical history.
Provider communica-tions	• Mixed reports regarding whether patients' various providers of different settings communicated with each other.
Theme:	**High Quality Clinical Care (HQCC)**
Recognizing HQCC	• Several SDEs perceived the delivery of HQCC when PCP carried out thorough exam that included lacked physical touch. • HQCC recognized when PCP promptly and appropriately addressed the side-effects of medications.
Recognizing PCP's skilled interpersonal care (SIC)	• Many SDEs recognized SIC when they felt unhurried during their office visit. • Most SDEs perceived SIC in the form of humaneness and empathy through the active listening of PCPs. • Many SDEs identified SIC when their PCPs explored their needs and involved them in medical decisions, especially those involving medication management. • Most SDEs satisfied with PCP informativeness but a few reported the receipt of incomprehensible information provided with prescription drugs; some relied on the internet for clarification.
Theme:	**Greatest Barriers to Accessing Necessary Care**
System-level: poor design of prescription drug (Rx) delivery processes	• Many reported financial barriers to accessing needed Rx; obstacles were caused at least in part by competing federal & NC Rx copay policies. • Some expressed confusion regarding variation in vaccine copayments which led to obstructed access to preventive care. • Many reported obstacles to obtaining Rx in timely manner caused by PCPs/office staff or delays associated with NC's prior authorization (PA) process. • A few SDEs reported medication errors that could have had grave results.
Population-specific	• Research results generally echoed those in the literature, finding similar quality of care concerns.

TABLE 20: Summary of Findings of Sampled Dual Eligibles (SDEs) (cont.)	
Theme:	**Greatest Barriers to Accessing Necessary Care**
Individual-level issues navigating health care delivery system	• Many SDEs were unaware that alternative Medicare Part D insurance options could result in lower co-pays and improved vaccine coverage. • Some SDEs were puzzled about which services covered by Medicare and which were paid by Medicaid. • Some SDEs were confused about coverage for preventive services and vaccinations. • While SDEs did not complain about balance billing per se, some had concerns about cost of some preventive vaccinations. • No SDEs described problems when in the midst of a major clinical event and/or any associated emotional burden. But findings would have been more robust if questions were included in interview guide that specifically addressed these important topics.
Theme:	**Programmatic Challenges of NC's PCMH**
Challenges outside of the control of NC's PCMH	• Difficult to calculate cost savings associated with implementation of NC's PCMH. With annual CCNC expenses taken into account, is it possible that the care provided through NC's PCMH may not be as inexpensive as it may seem? • CCNC needs real-time Medicare claims data in order to better-coordinate care for the dual eligibles of NC's PCMH, but the state is responsible for implementing a system that would enable CCNC to utilize these data. • CCNC lacks the authority to resolve conflicting state and federal policies regarding medication copays. • NC's decision to reimburse Medicaid mental health services on a capitated basis seems to have hindered NC's PCMH care coordination efforts. The functioning of NC's PCMH program would likely be more disrupted if NC capitates Medicaid ambulatory services. Although CCNC can influence policy makers, it is unable to make state-wide policy decisions. • Although community-based resources are key to coordinating care for SDEs, the direct provision of such services is outside of CCNC's mission supporting NC's PCMH, so scarcity of community services is problematic.

Table 20 shows that from the perspective of sampled dual eligibles, there are many areas of high functionality within NC's PCMH. However, there are also numerous opportunities to improve the program. Similar insights drawn from the experience of sampled care managers are revealed in Table 21, below.

TABLE 21: Summary of Findings of Sampled Care managers	
Theme:	**Tools Upon Which NC's PCMH Care Managers (CMs) Most Rely**
Three vital tools	• Health information technology (HIT) is essential to identifying patients needing certain interventions, conducting health assessments and PCP communications. • Disease management strategies are crucial. • The most frequently reported telemedicine technologies were phone, fax and email.
Theme:	**Comparing Dual Eligibles (DEs) to Other Patients**
DEs vs. other Patients	• DE patients have more chronic conditions than non-DE patients.
Heterogeneous DE Population	• Younger DEs have higher rates of mental illness than older DEs. • Denial of mental illness is problematic especially when younger DEs lack social support reinforcing message that mental health issues must not be ignored. • Older DEs have more home health care needs than younger DEs. • Older DEs face greater social isolation than younger DEs.
Theme:	***AHRQ's Care Coordination Ring***
Observations and CM Suggestions	• Model represents care coordination for a more stable, middle-class population than the DEs served by sampled CMs. • Model should include transportation, language interpretation services, financial counseling and low-income housing. • Model represents an ideal situation, but does not mesh with CM's real world experience, especially where the availability of mental health services are concerned. • Model does not include details regarding the variance in frequency and intensity of CM contact with patients.
Theme:	***AHRQ's Care Coordination Mechanisms***
Coordination Activities	• Beginning at very first appointment, establishing a rapport with patient that includes accountability is key to patient engagement on implementing a care plan. • Linking the patient to community resources (like public transportation and interpretation services for non-English speakers) is critical.
Broad Approaches (BAs)	• All sampled CMs reported *HIT-enabled coordination* as key to their work. • *Teamwork focused on coordination* and *medication management* were 2 other BAs that sampled CMs highlighted as crucial. • These 2 BAs were described in relationship to one another, suggesting that medication management is such a complex activity that care must be carefully coordinated between health care team members with different types of expertise in order to effectively complete the task.

As Table 21 suggests, the interviews with the six sampled care managers provided:

1) context regarding the implementation of QI initiatives for NC's PCMH;

2) insight regarding the different care needs of different patient populations; and

3) an understanding of how the real life care coordination experiences supporting NC's PCMH compare to those represented in AHRQ's two theoretical models.

Of course all the research results highlighted in Tables 20 and 21 have practice-level implications, as well as broader inferences for theory and for policy. These topics and suggestions for further research will be examined in Chapter 6, the Conclusion.

Chapter 6: Conclusion

This dissertation tells the implementation story of North Carolina's (NC's) patient centered medical home (PCMH) program. In the late 1980s and early 1990s, and faced with significant budgetary constraints, state leaders considered abandoning NC's fee-for-service Medicaid payment model in favor of a capitated one achieved through managed care contracting. Although the state decided to try the latter approach, this strategy never took hold in a significant way. Instead, the state began building its primary care infrastructure in earnest in the 1990s, in order to enhance health outcomes and reduce the costs of providing care through NC's PCMH. Although there have been some who question the results of NC's PCMH, the achievement of these goals has been described in numerous research articles (Community Care of North Carolina [CCNC], n.d.g., Grumbach, & Grundy, 2010; Fillmore, DuBard, Ritter, & Jackson, 2013; Jackson, Trygstad, DeWalt, & DuBard, Steiner, et al., 2008).

But how well does NC's PCMH coordinate care for one of the most vulnerable populations of patients, the dual eligibles? What challenges does NC's PCMH face when coordinating care for this population? What contextual information can be learned from Community Care of North Carolina (CCNC) care managers who support the care coordination efforts of NC's PCMH, and how does their real life experience compare to the models of ideal care coordination proposed by the Agency for Healthcare Quality and Research (AHRQ)? This chapter summarizes the research findings that answer these questions and then considers the implications for policy, practice, research, and theory that can be derived from the results.

1. NC's Patient-Centered Medical Home

As discussed in the Case Study Results, since the late 1990s, NC's quality improvement (QI) efforts for its Medicaid program have grown increasingly reliant on the PCMH philosophy and related strategies while remaining true to its managed fee for service (MFFS) and primary care case management (PCCM) payment models.

The PCMH program aims to provide comprehensive primary care and is built on an on-going relationship with a PCP who leads a team that takes responsibility for all patient care. Indeed, the PCP is accountable for coordinating services and addressing all the patient's health care needs by either providing direct services or "appropriately arranging care with other qualified professionals" (Health Resources and Services Administration [HRSA], n.d.b, para. 4). The team internally coordinates care across elements of the health system and the patient's community, and engages in safety and QI initiatives (HRSA, n.d.b).

By 2011, nearly all of NC's 100 counties were participating in CCNC's QI strategies, which were implemented in collaboration with the 14 state-wide provider networks. While not all participating CCNC practices are PCMH-certified by the National Committee for Quality Assurance (NCQA), each patient in NC's PCMH has his or her own primary care provider (PCP) and an associated medical practice that is intended to operate as a PCMH. For certain high-cost, high-risk patients, CCNC care managers strengthen links to medical and other services in the community through the provision of care coordination services (Steiner et al., 2008). Further, all CCNC patients have access to 24-hour on-call PCPs and the previously-mentioned practice-level continuous QI efforts; both of these strategies are central to the PCMH model (Steiner et al., 2008). Finally, NC's PCMH relies on the standard Medicaid fee which is enhanced by PMPM management fees that incentivize the delivery of comprehensive primary care as well as specialty

care. Enhanced funding and an emphasis on comprehensive primary care are two other key components of the PCMH model (Steiner et al., 2008).

As described in the Case Study Results, in 2010 NC launched a shared savings model (SSM) through the Medicare Health Care Quality Demonstration ("the 646") which integrated acute care for dual eligibles and Medicare-only beneficiaries served by participating providers in eight of the state's 14 local networks. Although the PCCM and 646 had different financial incentives, the foundation of both delivery systems is the same, NC's PCMH program. As confirmed by a NC state official, the *lower risk, independent-living* dual eligibles who participated in this research would have experienced the two care provided in the systems in the same manner, because the same type of care coordination interventions were used, no matter how the care was financed.

2. Study Participants

Sixty-one dual eligibles, ages 30 through 97, participated in the research, and six care managers provided contextual information about their provision of care coordination services to support NC's PCMH. The research sample was drawn from four high-population density counties in the Raleigh-Durham region including Johnston and Wake counties, where practices were reimbursed through the PCCM payment model, and Chatham and Orange, which were 646 demonstration counties, reimbursed through the SSM.

3. Research Question 1 Summary: Care Coordination in NC's PCMH

The first research question asked how well NC's PCMH coordinates care for the dual eligibles, from their perspective. Sampled dual eligibles reported that a CCNC care manager

had not provided this intervention for them; apparently they were not identified by CCNC algorithms as high enough cost or risk patients. The demographic information collected regarding this group indicated that this group could be characterized as *lower risk and independent-living*, so sampled dual eligibles did not receive "visible" care coordination services provided by a CCNC care managers. For most, the lack of care manager assistance seemed appropriate; they received "invisible" care coordination services (supports they did not necessarily perceive) through NC's PCMH which were bolstered by CCNC's Informatics Center. However it seems that one woman needed care coordination services from a care manager after a devastating car accident and the six-month hospitalization that followed. For her, the "invisible" care coordination services through NC's PCMH seemed insufficient.

Nonetheless, given that sampled dual eligibles were perhaps unaware of the "invisible" care coordination efforts within NC's PCMH, how do they perceive well-coordinated care? The literature says that patients define coordinated care as the "right care provided at the right time and in the right place" (Center for Health Care Strategies [CHCS], 2010b, p. 1). Further, AHRQ reports that patients perceive long-term care coordination through an experience of provider continuity. These topics will be discussed in turn.

3a) Right Care

In terms of receiving "the right care," the research found that most sampled dual eligibles had received a sufficient amount of medical equipment, services and tests. However, a few sampled dual eligibles had to lobby their PCP to access needed care. This finding was notable because of the possibility of resulting emotional distress and the potential that patients could independently attempt to independently address their own medical problems, which could potentially harm their health.

Some sampled dual eligibles recognized the "right care" when they experienced relief from certain symptoms, and others when cured of disease. Most reported sufficient access to PCP appointments, which enabled them to avoid the emergency department (ED), which was their preference. Nonetheless, a few sampled dual eligibles noted inadequate access to their PCPs, a noteworthy finding because the PCP is a key figure in the PCMH program, and care coordination efforts could be hindered without the PCP's crucial participation. Further, most sampled dual eligibles also reported adequate referrals to specialists when needed. However, for some, cost and other barriers blocked access to some preventive therapies, medications, and mental health services.

3b) Right Time

In terms of receipt of care at "the right time," one sampled dual eligible received needed transitional care services at the appropriate time, but another, who had experienced a devastating care accident, did not. This situation was notable because coordinating transitional care services is a primary tenant of the PCMH program. The "right time" also entailed the duration of the PCP visit and the scheduling process. While most sampled dual eligibles were satisfied with the amount of "face time" spent with their PCPs, reports were mixed on the multi-step scheduling processes.

3c) Right Place

Where receipt of care in the "right place" was concerned, most participants who had their own transportation expressed satisfaction that their care was not located too far away. However, some dual eligibles and care managers described scarce public transportation resources as a barrier to needed care. In terms of care settings, office experiences were generally positive except for two individuals with disabilities who struggled with navigating

their PCP's offices. Further, some older dual eligibles had concerns about hospital care and there were mixed reports about whether providers of different settings communicated with each other regarding patient medical history and status.

3d) Continuity of Care

Other continuity of care issues involved a long-term relationship with a PCP. While many enjoyed such a relationship, this was not the case for about one out of three sampled dual eligibles who had worked with their current PCP for 12 months or less. Further, this research was conducted in a high population-density region; it is possible that PCP discontinuity issues could be more significant in other regions of NC. Moreover, two sampled dual eligibles reported a psychological impact of PCP discontinuity that was associated with the need to repeatedly retell their traumatic medical histories. This finding was noteworthy because the negative effect seemed significant.

3e) Necessary Components of Care

In addition to asking sampled dual eligibles how well their care is coordinated through NC's PCMH, the research also explored the necessary components of care from sampled dual eligibles' perspectives. Participants recognized the provision of high quality clinical care through the conduct of a thorough exam that included physical touch, and when their PCP promptly and appropriately made needed medication adjustments.

Skilled interpersonal care was another necessary component of care. For many sampled dual eligibles, a PCP was perceived as humane and empathetic when participants felt unhurried during their office visit, and when the PCP engaged in active listening. Further, many sampled dual eligibles recognized skilled interpersonal care when their PCPs explored their needs and involved them in medical decisions, especially in the area of medication

management. Finally, this research identified informativeness as another necessary component of skilled interpersonal care. While most sampled dual eligibles reported that a sufficient level of medical information was communicated orally by their PCP, a few faced problems understanding written content provided with their medications and sought clarification on the internet.

3f) Greatest Barriers to Necessary Care

The research also examined the greatest barriers associated with accessing necessary care from dual eligible participants' perspectives. Many sampled dual eligibles faced poorly designed prescription drug delivery processes at the system-level. For example, many reported financial barriers preventing access to needed prescription drugs. These were caused at least in part by competing federal and state prescription drug copay policies. Further, some sampled dual eligibles expressed confusion regarding variation in vaccine copayments which led to obstructed access to preventive care. Moreover, many research participants reported obstacles to obtaining prescription drugs in timely manner. They noted that these were caused by slow PCP or office staff response, or by delays associated with NC's prior authorization (PA) process. A few SDEs also reported medication errors; these were noteworthy since they could have had grave results and because better-coordinated care may have helped to prevent them.

Sampled dual eligibles also faced barriers to accessing necessary care at the population- and individual-level. At the population-level, the research results generally echoed the literature's quality of care concerns for dual eligibles: inadequate preventive screenings, follow up therapies and testing (Koroukian, Xu, Dor, & Cooper, 2006; Zingmond, Wilber, MacLean, & Wenger, 2007)

At the individual-level, sampled dual eligibles face challenges navigating the health care delivery system. Many were unaware that alternative Medicare Part D insurance options could require lower co-pays and offer improved coverage of vaccines. Further, some sampled dual eligibles were confused about which services were covered by Medicare and which were paid by Medicaid. Moreover, others were confused about coverage for preventive services and vaccinations. In addition, while SDEs did not complain about balance billing per se, some had concerns about cost of some preventive vaccinations. Finally, while none of the sampled dual eligibles described problems during a major clinical event and/or any associated emotional burden, the research findings would have been more robust if questions were included in the interview guide that specifically addressed these important topics.

3g) Programmatic Challenges Facing NC's PCMH

Finally, the first research question asked about the programmatic challenges facing NC's PCMH in its efforts to coordinate care for dual eligibles. The first issue is regarding the financial justification of CCNC's efforts to support of NC's PCMH. As was discussed in the Case Study results, it is difficult to calculate the cost savings associated with implementation of NC's PCMH, because the process involves estimating the level of funds that would have been spent, since health care spending almost never goes down in absolute terms (Berra, 2012). Further, a new finding associated with this research is with annual CCNC expenses taken into account, the care provided through NC's PCMH is perhaps not as inexpensive as it may seem.

The second key challenge is that CCNC needs real-time Medicare claims data in order to better coordinate care for the dual eligibles, but the state is responsible for implementing a

system that would enable CCNC to utilize these data. Third, CCNC lacks the authority to resolve conflicting state and federal policies regarding Medicaid copays. Fourth, although CCNC's efforts supporting the coordination of care in NC's PCMH are made more difficult by state-level decisions to potentially abandon the current MFFS model and use a capitated one (as was done with the carve-out of mental health services), policy decisions such as these are not CCNC's to make. Fifth, although CCNC care managers identified an adequate supply of community-based resources (like public transportation and low-income housing) as key to improved care coordination and better health outcomes, the adequacy of such resources is outside of CCNC's control. Finally, the main theme associated with all these challenges for NC's PCMH is that they are largely outside of CCNC's control, which makes their resolution more difficult.

4. Research Question 2 Summary: Care Managers' Insights

The second research question queried the sample of six CCNC care managers who coordinate care for NC's PCMH. While these professionals did not directly serve the sampled dual eligibles who participated in the research (since none of the 61 received such services), the care managers provided important contextual information about NC's PCMH program and the dual eligibles it serves.

4a) Tools Upon Which Care Managers Most Rely

The three tools upon which the sampled CMs relied most were health informatics (or health information technology), disease management strategies, and telemedicine devices. All care managers identified the first tool as key to identifying patients needing certain interventions, conducting health assessments, and communicating with area PCPs. Further, all

care managers identified disease management strategies as another vital tool for coordinating patient care. Finally, the telemedicine devices of phone, fax and email were noted as critical to conducting the work of sampled care managers.

4b) Dual Eligibles vs. Other Patients & Heterogeneity in Dual Eligible Population

The second research question also examined whether and how the needs of dually eligible patients are different from non-dually eligible patients. Not surprisingly, care managers reported that the former group has more chronic conditions than the latter. The research also compares the needs of older and younger dual eligibles. Sampled care managers reported that older patients have more home health care needs and may face greater social isolation than younger dual eligibles. However, younger dual eligibles face higher rates of mental illness and may be in denial about the severity of that illness, which is a challenge when coordinating this subpopulation's care.

4c) AHRQ's Care Coordination Ring

The second research question also sought insight into how care managers would apply an ideal model of care coordination, AHRQ's theoretical Care Coordination Ring, to their work with high-risk, high-cost patients (including the dual eligibles). The model is shown in Figure 1, Chapter 1. All sampled care managers agreed that AHRQ's Care Coordination Ring represents their care coordination efforts. Their patient-centered services strive to bring together participants, health settings, and information to assure high quality care. However, some care managers noted that the model represents the provision of care coordination services for a more stable, middle-class population than the dual eligibles they serve. These care managers identified gaps in the model. Public transportation, translation services, low-income housing, and financial counseling were so critical to their work with the dual eligibles

that they could not be collapsed into the catch-all category "community resources." Some care managers noted that until those basic needs are met, patients could not concentrate on health education and the other tools that care managers provide.

Further, for some care managers, the model represented an ideal patient-centered care coordination experience that does not exist in NC's PCMH, especially where mental health services are concerned. In response to these care manager suggestions, AHRQ's Care Coordination Ring was revised to include the omitted services and may be found in Chapter 5's Figure 14. However, there were additional details described in many of the care manager interviews which could not be included in the modified model, and these include the variance in frequency and intensity of care manager contact with patients when coordinating their care.

4d) AHRQ's Care Coordination Mechanisms Framework

The second research question also considered the Care Coordination Mechanisms Framework. All the sampled care managers reported that the model is well-suited to represent their experience of coordinating the dual eligible's care. The framework, which is shown in Figure 2, Chapter 1, includes two mechanisms thought vital to effective care coordination: *Coordination Activities* and *Broad Approaches*. The factors associated with robust care coordination are not well-understood. AHRQ *hypothesizes* that the following nine *coordination activities* help achieve coordinated care, whether employed in an improvised or systematic way: 1) negotiate responsibility and/or establish accountability, 2) communicate, 3) facilitate transitions, 4) access needs and goals, 5) create a proactive plan of care, 6) monitor, follow up, and respond to change, 7) support self-management goals, 8) link to community resources, and 9) align resources with patient and population needs.

The sampled care managers reported the *Coordination Activities* they perceived as the most important. They noted that *negotiating responsibility* is key; beginning at the very first appointment, establishing rapport with patient that establishes accountability is key to patient engagement on implementing an effective care plan. In addition, many sampled care managers identified *linking the patient to community resources* as critical, especially to public transportation and interpretation services for non-English speakers.

AHRQ's Care Coordination Mechanisms Framework also includes *Broad Approaches*, which are five structures of care that improve health care delivery by improving or facilitating coordination. These include: 1) health information technology (HIT)-enabled coordination; 2) teamwork focused on coordination; 3) health care home; 4) care management; and 5) medication management. All sampled care managers identified *HIT-enabled coordination* as key to their work. Further, some care managers highlighted *teamwork focused on coordination* and *medication management* as especially important. Interestingly, these latter two strategies were discussed as they relate to each other, not as two distinct broad approaches. This suggests that medication management is such a complex and important activity that care must be carefully coordinated between different members of the health care team with various types of expertise in order to effectively complete the task.

5. Implications & Recommendations

This research has shown that from the perspective of sampled dual eligibles and care managers, there are many areas of high functionality within NC's PCMH and also numerous opportunities to improve the program. This section offers four broad

recommendations based on lessons learned from the research that could result in a stronger PCMH program in NC. These include: 1) "stay the course," 2) enhance NC's PCMH, 3) don't steal from Peter to pay Paul, and 4) improve prescription drug delivery policies and processes. Finally, there is one recommendation regarding the theoretical implications associated with this research, and the need to revise AHRQ's Care Coordination Ring. The five suggestions will be discussed in turn below. At the end of the chapter, Table 22 summarizes all the suggestions.

5a) "Stay the Course"

In many ways, the evidence suggests that sampled dual eligibles have been well-served by NC's PCMH program. Many noted that they had received "the right care" and had sufficient access to medical equipment, services and tests provided through NC's PCMH program. Further, numerous sampled dual eligibles reported that they received care at the "right time," with prompt access to needed services and sufficient face time with their PCPs. Many also stated that their care is provided in the "right place," and they have had positive experiences in a number of different care settings. Moreover, numerous sampled dual eligibles have had positive continuity of care experiences: many have enjoyed a long-term relationship with their PCP and a large fraction reported that providers from different settings exchange their medical information (with their permission, of course). Certainly these positive experiences were not uniform amongst all sampled dual eligibles, and there is room for improvement in NC's PCMH program. But the positive results of NC's PCMH from the perspective of the research participants should not be discounted.

Given this, there are concerns about the Governor's plans to transition the state's Medicaid program from a MFFS payment model to a capitated one by contracting with private managed care organizations (MCOs). Considering 2013's Medicaid budget shortfall of $248, it is perhaps no surprise that the Governor sought to cut publicly-funded health care costs. Indeed, this study has posed the question of whether the care provided by NC's PCMH is as inexpensive as it seems, given the budget of its supporting organization, CCNC. Thus, further research is required in order to conduct an "apples to apples" cost comparison of the care provided by NC's PCMH program (and supported by CCNC) versus that which could be provided by private MCOs.

There are other important issues to be deliberated when considering the Governor's proposal. NC's policy makers should recall NC's previous mental health reform efforts which resulted in fragmented care, mental health provider shortages, and breakdowns in communication between PCPs and mental health professionals. This research suggests that rapid and dramatic payment policy and service delivery changes did not seem to benefit the state or sampled dual eligibles. Thus, instead of transitioning Medicaid's ambulatory services from MFFS to a capitated model, the recommendation is to follow the advice of the Commissioner of Mental Health in New York, to anticipate problems, address them and "stay the course" (Rash, 2012).

In summary, NC's provider-driven approach and payment model have generally served a small sample of one of its most vulnerable populations, dually-eligible research participants, well. However, further research is needed to conduct a cost comparison of the care provided through NC's PCMH (and supported by CCNC) versus that provided by private MCOs.

5b) Enhance NC's PCMH

Although many sampled dual eligibles reported positive experiences with NC's PCMH program, the evidence indicates that certain aspects of NC's PCMH could be enhanced in order to provide higher quality, more coordinated care. None of the 61 sampled dual eligibles reported receipt of care coordination services provided by a CCNC care manager. In many cases, this seemed appropriate from the patient perspective. However, one sampled dual eligible seemed to truly need care coordination (transitional services) after a devastating car accident that required a six month hospitalization. In order to assure that *lower-risk and independent living* dual eligibles in similar circumstances do not experience the same service gaps, CCNC should conduct research designed to assess the costs and benefits of assigning similar dual eligibles to a CCNC care manager, especially those who receive care in multiple care settings.

The efforts of NC's PCMH to identify dual eligibles in need of care coordination services rely heavily on CCNC's patient-targeting algorithms. However, an algorithm's results are only as good as the data upon which they are built. CCNC has struggled for years to access Medicare Parts A, B and D claims data, and has attempted to use supplementary data sources to access the complete claims history of their dual eligible patients. Nonetheless, the result of these absent data has been the diminished value of CCNC's aggregated cost, utilization, and quality reports, as well as patient-level health records. Even though the federal government has recently made these data available to states, CCNC still does not have access to them. In response, NC should identify and implement a strategy to integrate newly-available Medicare data into the data warehouse.

In addition, some sampled dual eligibles had concerns about whether their different providers of various settings shared their medical information with each other. Given the importance of making medical decisions based on complete medical information, and given that inter-provider communications are a key aspect of a well-functioning PCMH, it is recommended that NC's PCMH program consider ways to improve system functionality in this area.

5c) Don't Steal From Peter To Pay Paul

One predominant theme noted in discussions with many sampled dual eligibles and care managers is the crucial role of robust community services in improving the health of low-income individuals. The Medicare Payment Advisory Commission perhaps said it best when it reported that for the dual eligibles,

> …poverty shapes their basic living needs. If they have inadequate housing or cannot afford heat and food, they cannot focus on and manage their health care needs. For example, a lack of adequate heating during the winter can delay recovery from illness…" (Medicare Payment Advisory Commission [MedPAC], 2010, pp. 132-133)

This sentiment was echoed in the research. Sampled dual eligibles and care managers spoke of the need for robust public transportation, language interpretation services, low-income housing and financial counseling because without them, patients faced significant barriers to needed care.

This issue represents a significant challenge for NC's PCMH and for its supporting organization, CCNC. Although sampled care managers and dual eligibles noted that community-based resources are crucial to maintaining and/or improving patient health and coordinating care, the availability of such services is outside of the control of CCNC and NC's PCMH. Nonetheless, it is important for state and federal

policy makers to realize that it would be misguided to say, eliminate a food program serving dual eligibles, funnel those dollars into a health initiative, and expect improved health outcomes.

5d) Improve Prescription Drug Delivery Policies & Processes

Numerous sampled dual eligibles implied that the greatest barriers to accessing necessary care stemmed from prescription drug policy and delivery processes. Many reported that financial obstacles prohibited them from obtaining needed prescription drugs. The evidence from this research indicates that while sampled dual eligibles were not *technically* required to cover prescription copays, (because this practice is prohibited by federal law), they perceived payment as obligatory, (since NC law allows copays to be charged for individuals enrolled in Medicare Part D plans). This issue is a significant one from the perspective of NC's PCMH because its supporting organization, CCNC, lacks the power to resolve these conflicting policies. However, the problem could be addressed by state and federal policymakers. This is suggested because improved access to needed prescription drugs makes sense not only for patient health, it is also wise from a budget perspective--when patients cannot get required medications, they may face more intensive health needs, which have financial implications for the state and federal government.

In addition, some sampled dual eligibles expressed confusion about variation in vaccine copayment requirements. The evidence from this research suggests that with regard to vaccinations for seniors, the ACA is confusing because it authorized some vaccines (such as flu, pneumonia and hepatitis B) to be provided free of charge, but Medicare recipients must pay copayments for all other recommended vaccines. Further, although vaccines are covered by Medicare Part D drug plans, the level of cost-sharing

varies widely across plans (Andrews, 2012). This research shows that the ACA's rules allowing for variation in vaccine copayments has led to confusion and has resulted in obstructed access to preventive care for sampled dual eligibles, a group that tends to have multiple chronic conditions and would be well-served to receive preventive measures in order to avoid future interventions. Thus, further research is needed to better-understand the breadth and depth of potential enrollee confusion and attempt to address it.

Another related concern associated with prescription drug policy is regarding Medicare Part D insurance options. NC's Department of Health and Human Services' website notes that dual eligibles are able to enroll in, or switch prescription drug plans at any time if they find that medication costs are too high. However, many sampled dual eligibles seemed unaware of this option, which could result in lower copays and improved vaccine coverage. Additional research is required in order to better understand and consider options that would address it.

Further, many sampled dual eligibles reported obstacles to obtaining needed prescription drugs in timely manner. This research shows that one cause is delays associated with the state's prior authorization (PA) process. NC Medicaid policy prohibits payment for a certain brand-name medication. When a brand-name drug is required, the PCP must write Medicaid a prior authorization note explaining why a particular drug is needed, and reporting which alternative (generic) medications have been tried and failed. Once NC's Medicaid program approves the brand-name medication, the pharmacy overrides the Medicaid policy and supplies the requested prescription. This research indicates that the PA process leads to care delays, patient frustration and a great deal of PCP effort. It is ironic that while the PA process strives to save financial resources by incentivizing the use of lower-

cost generic medications, it can result to unused and wasted medications, as well as a great deal of wasted PCP and pharmacist time.

Another irony is that NC has already implemented a cost-effective alternative to the PA process but it has not been used on a widespread basis. In June 2007, NC, CCNC, and a physician group collaborated to develop modifications to the PA process in order to allow for instant approval of proton pump inhibitors (Wegener, Trygstad, Dobson, Lawrence, & Steiner, 2009). Further study is recommended to determine the feasibility of implementing an instant approval process across all of NC's PCHMH.

5e) Revise AHRQ's Care Coordination Ring

Finally, this research has theoretical implications and recommendations. As described above, AHRQ's Care Coordination Ring represents the ideal care coordination experience. It shows the intervention as a band that unites all possible participants, health settings and information involved in a patient's care. However, sampled care managers reported that it does not mesh with their real world experience of coordinating care for high-risk, high-cost patients (including the dual eligibles).

The care managers identified gaps in the model, and noted that public transportation, translation services for non-English speakers, low-income housing, and financial counseling were so critical to their work with low-income populations that they could not be collapsed into the catch-all category "community resources." Some care managers reported that until those basic needs are met, patients could not concentrate on health education and the other tools that they provide. Thus, for purposes of this research, the model was revised and may be found in Figure 10. It is recommended that AHRQ consider the possibility of modifying the

framework in order to better-represent the care coordination experience of the dual eligibles and other low-income populations.

Table 22: Summary of Recommendations

Theme	Associated Suggestions
1) "Stay the Course"	• Sampled dual eligibles have been well-served by NC's PCMH program. Avoiding rapid and dramatic payment policy and service delivery changes is recommended. • Further research is needed to conduct an "apples to apples" comparison of the costs of care provided through NC's PCMH program (and supported by CCNC) versus those provided by private MCOs. In the meantime, anticipate problems, address them and "stay the course" using NC's PCMH program.
2) Enhance NC's PCMH	• Further research is recommended on the costs and benefits of targeting certain *lower-risk and independent living* dual eligibles for care coordination services provided by a CCNC care manager, especially those who receive care in multiple care settings. • NC should identify and implement a strategy to integrate newly-available Medicare A, C and D data into the data warehouse. This would likely improve the value of CCNC's aggregated cost, utilization, and quality reports as well as patient-level health records. Such enhancements could result in better-targeting of dual eligibles in need of care manager-provided care coordination services. • Given the importance of making medical decisions based on complete medical information, it is recommended that NC's PCMH program consider ways to improve system functionality around inter-provider communications, in order to facilitate the exchange of medical records.
3) Don't Steal From Peter To Pay Paul	• Robust community services are key to improving the health of sampled dual eligibles, so state and federal policy makers should realize that budgetary decisions that reduce or eliminate community services in favor of health initiatives may not result in improved health outcomes.
4) Revise AHRQ's Care Coordination Ring	• Public transportation, translation services for non-English speakers, low-income housing, and financial counseling are crucial to care coordination efforts for dual eligibles and other low-income groups so they should be included in AHRQ's Care Coordination Ring.

Table 22: Summary of Recommendations (cont.)	
Theme	**Associated Suggestions**
5) Improve Prescription Drug Delivery Policies & Processes	• State and federal policymakers should resolve conflicting Medicaid prescription drug policy regarding copayment requirements because the result of such policies has been barriers to needed medications for sampled dual eligibles. • Further research is needed to better-understand the breadth and depth of dual eligible's confusion about variation in vaccine copayment requirements which stem from the ACA and Medicare Part D plan policies. • Additional research is suggested in order to better understand the extent to which dually-eligible Medicare Part D enrollees' lack of awareness about a policy enabling them to switch prescription drug plans at any time if the costs of their medications are too high. • Further study is recommended to determine the feasibility of modifying NC PCMH's prior authorization process to include instant approval. •

6. Wrap Up

This extensive research on North Carolina's PCMH began in the spring of 2011. The researcher was skeptical that the delivery system was as special as it was hyped to be, which is why the question was asked "…but what do its most vulnerable patients think about it?" However, over time the researcher's respect for NC's delivery system has grown because: 1) sampled dual eligibles generally reported a positive experience of care for their complex needs, and 2) when striving to identify solutions to respondents' problems, it seemed that in many cases, the answer could be found in NC.

For example, the researched noticed the angst of participating dual eligibles regarding medication issues and considered ways to improve the prior authorization processes. The literature suggested that across the nation, Medicaid programs aim to save money using prior authorization processes that result in inefficiencies. In searching for resolution, the researcher found one, in NC, where an instant approval process has been piloted and found to improve

quality and lower cost. Thus, the state has already laid the groundwork in this regard, and should build upon its own success in order to improve patient access to needed drugs. This is but one example of the many innovations launched in NC.

Is NC's delivery model perfect? Of course not! The research indicates that there are numerous issues that need to be addressed, many of which could be resolved through improved care coordination provided through NC's PCMH. Given the expertise and dedication of CCNC's providers, care managers, pharmacists, administrators, information technology specialists and researchers, there is little doubt that NC's PCMH can continue to be enhanced. However, political support is critical for this program and other innovative initiatives implemented in the state to support that health of its most vulnerable citizens, the dual eligibles.

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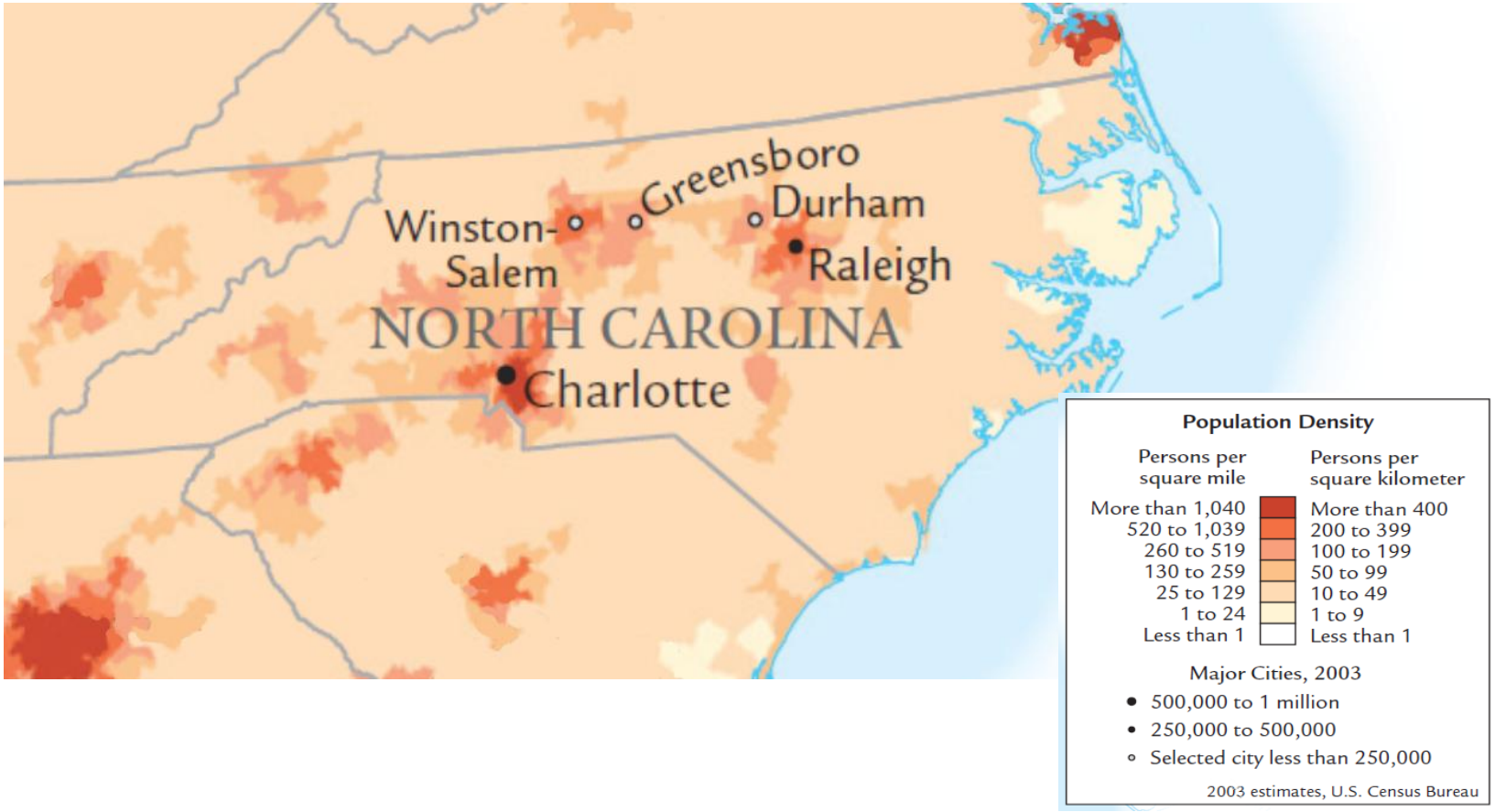
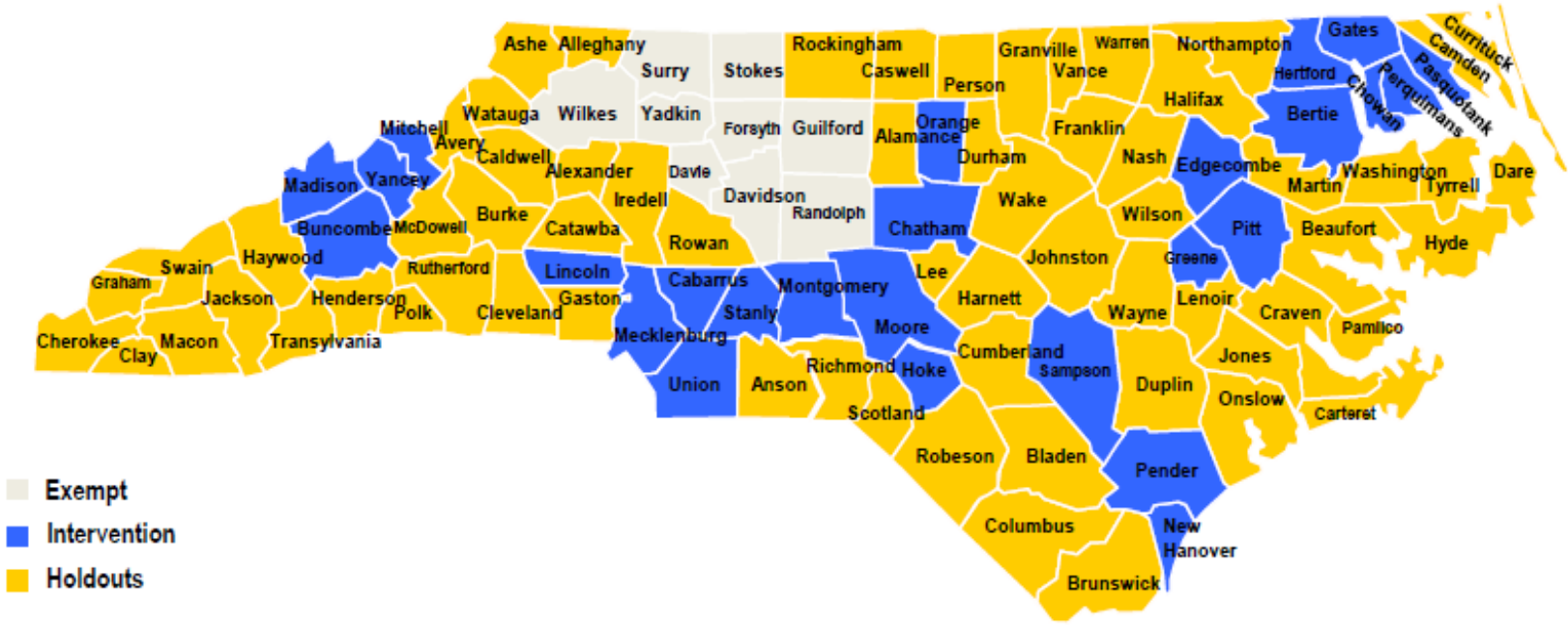
Appendix A: Three NC Maps that Informed the Identification Network Case Selection

North Carolina Population Density Map

Source: "Southeast Region Population Density Map," n.d.



646 Counties



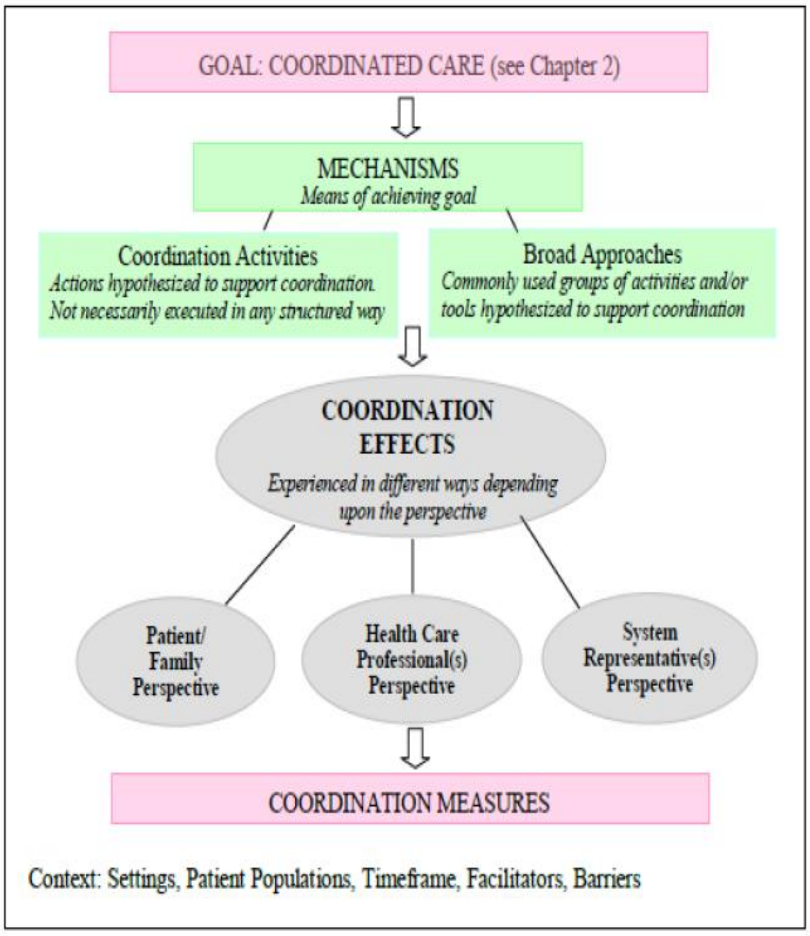
Updated October 1, 2009.

Source: (CCNC, n.d.d)

This map informed case selection and includes: 1) population data from the North Carolina Population Density Map, and 2) information from the 646 Counties Map about which Community Care of North Carolina (CCNC) networks participated in the Medicare Health Care Quality demonstration("the 646") and which simply continued their primary care case management (PCCM) work. This map was developed by laying the population density data on top of the 646 data, to identify two high population 646 networks that were adjacent to two high population PCCM networks. The red curvy shape indicates the high-density region selected for research which includes Orange and Chatham (646 counties) as well as Wake and Johnston (PCCM counties).

Source: (Community Care of North Carolina [CCNC], 2013)

Appendix B: Original Version of "Care Coordination Measurement Framework"



Source: (Agency for Healthcare Research and Quality [AHRQ], 2011, p.11)

Appendix C: Interview guides for Dual Eligibles and Care Managers

Interview guide for focus groups with dual eligibles

Welcome participants:

- Hi, I'm Sarah Grantham. I am a student at The George Washington University in Washington, DC.
- I am studying the experience of individuals who are enrolled in both Medicare and Medicaid, and are getting care through North Carolina's Community Care Networks. I am particularly interested in your thoughts about whether you get the right care at the right time, in the right setting.

Explain the project:

- I am meeting with you today to get your thoughts about a number of issues related to North Carolina's Community Care Networks, including:
    - Your doctor or another type of clinician and your relationship with him or her.
    - And other types of care you have gotten, like seeing specialists, hospital care, ER services or medical equipment.
    - And finally, I am interested in the different types of support you might be receiving to help you manage your care

Ground rules:

- Before we get started, I need to go over what we will be doing here today.
- There are no right or wrong answers. Feel free to speak openly and give your own opinions.
- I need to hear from everyone. I 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 tape recorded and student (*name*) will help take notes.
- Everything you say in this group is confidential. You should know that I am not connected with any health care facility, provider, or funder, so your personal information will not be available to anyone outside the study team. Anything discussed here will not affect your ability to get care. Also, I will not be connecting your name or your personal information with anything you say.
- We expect this meeting to last approximately 1 to 1 ½ hours.
- Usually people enjoy these groups as an opportunity to talk with others. Please relax and be as open as possible.
- At the end of this session you will receive a gift card as a thank you for participating, if you need to leave early they can see the student (*name*) and s/he will give it to you before you leave.

Does anyone have any questions before we get started?

Let's start with a few general introductions so we can begin to know each other better.

Could you please share your first name? Could you also please tell me how long you have been using the services in this office, and how you found out about it?

PATIENT EXPERIENCE OF CARE COORDINATION

Now I am going to ask you to talk about your feelings about your health care. In particular, I would like to know whether you feel you are able to get the right care, in the right place, and at the right time. Let's start with the first part of this question.

1) Could you please tell me one thing you are really happy about in receiving your care here?
    - Probe: Why do you feel this way?
    - Could you please provide examples of times when you have gotten services that actually satisfy your needs?

2) Could you please tell me if there is one thing you are unhappy about in receiving your care here?
    - Probes: Why do you feel this way?
    - Could you please provide examples?

3) How do you feel about the amount of services or tests that you get? Too many or too few?
    - Probe: Could you please give some examples?

4) Do you feel you are able to get all of the care that you need?
    - Probe: How do you deal with a situation when you can't get a service, or test, or medical device that you feel you need?

5) Now I want to ask you a question about the places where you get your care. Are the places where you get your health care convenient or do you have to travel far distances to reach them? Probes:
    - How would you describe these settings? How is the noise level? Are they crowded?
    - Could you please provide some examples?

6) Now I would like to ask you some questions about the time that it takes to get you the care that you need. Are your calls answered promptly?

    - Probes: Did you have to leave a phone message and someone called you back, or did you get your question answered right away?
    - How long does it take for you to travel to see your provider?
    - What is the wait time at the office?
    - How much time do you get to spend with your health care provider?
    - Could you please provide some other examples?

YOUR PRIMARY CARE PROVIDER AND YOUR RELATIONSHIP WITH HIM/HER

Now I have a few questions about your relationship with your main health care provider, which could be the doctor, nurse practitioner or physician assistant who you see for your routine health care concerns.

7) Are you satisfied with your relationships with that person?

    - Probe: If you could, what would you do to change your relationship with your doctor, or primary provider?

8) How would you describe the way your provider communicates with you?

    - Probe: Could you please provide some examples?

9) How do you feel about the amount of time your provider spends with you?

    - Probes: Could you please give examples of when your provider did or did not have time to hear about your health care concerns?
    - Do you feel like you have a say in health care decision-making with your provider?
    - Does your provider give you instructions about how to care for your health? If so, are they verbal or written? Are they helpful?

10) How well do you feel like all your health care providers communicate with each other?

YOUR HEALTH CARE TEAM

Now let's talk a bit more broadly about who helps you with your health care needs. Some of these questions will be about family and friends who give you assistance with your health. As you will see, I also have questions about whether you have a health care team that helps you. This team is a group of *health care* workers like doctors and nurses and care managers with different types of skills who work together to get you the care that you need.

11) Let's start with this question, is there anyone who helps you make sure that you get the health care that you need?

    - Probes: Who is that person, a parent, guardian, other family member, friend, nurse, therapist, social worker, hospital discharge planner, care manager, or someone else?
    - Are you working with a care manager now, or have you done so in the past?
    - Could you please share an example of how this helper person assists you with managing your health care?

12) Who helps you to make sure you get all the right medications at the right times?

- Probe: Could you please give examples of special tools or special ways that you manage your medications?

13) Does a person on your care team (or someone else like a relative or another caregiver) call to talk to you about how your health is doing even when you are not sick?

- Probe: Can you provide an example of this?

14) If and when you are feeling sad or stressed, is there someone in your health care team (or someone else, like a relative or another caregiver) that you can speak with about it

- Probe: Can you provide an example of this?

WRAP-AROUND NETWORKED SERVICES

Now I have one final question about your need for other types of services.

15) Do you have any concerns that you wish the health care providers would help you with?

- Probes: For instance, have you gotten needed help with issues like housing or food?
- Can you please provide any examples?

Interview guide for individual interviews with care managers

Greeting:

- Hi, I'm Sarah Grantham. I am a student at The George Washington University in Washington, DC.
- I am studying the care coordination experience of individuals who are enrolled in both Medicare and Medicaid, and are getting care through North Carolina's Community Care Networks.

Explain the project:

- I am meeting with you today to get your thoughts about a number of issues related to North Carolina's Community Care Networks, like
    - The way contact is maintained with your dually eligible patients
    - The way that you assist them as they transition from one care setting to another
    - And finally, I am interested in the network infrastructure that enable the doctors and nurses to act as a team

Ground rules:

Before we get started, I would like to explain what we are doing here today.

- There are no right or wrong answers. Feel free to speak openly and give your own opinions.
- This discussion will be tape recorded and student (*name*) will help take notes.
- Everything you say is confidential. My research is not connected with any health care facility, provider, or funder. That means that I will not be connecting your name with what you say, and your personal information will not be available to anyone except me.
- I expect this discussion to last about 1 hour.
- At the end of this session you will receive a gift card as a thank you for participating,

Do you have any questions before we get started?

First I would like to begin with some general questions about the work that you do, and about your clients.

1) How long have you been working with the North Carolina Community Care Network?

2) Could you please describe any other experience you have in care management?

3) Are you a nurse, or a social worker, or do you have another type of certification?

4) How many patients do you routinely serve in a month?

5) Could you please estimate what percentage of those patients are dually eligible?

    - Probes: Do you think you develop new skills when dealing with lots of duals?
    - Could you please share some examples?
    - How do you compare your work with dually eligible individuals to your efforts with individuals who are not eligible for Medicare and Medicaid?
    - Would you say that your dual patients tend to be particularly healthy or unhealthy, relative to your other patients? Could you provide examples?

6) Can you please tell me a little bit about the network in which you work?

    - Probe: What are the resources upon which you rely most in order to address your patient's needs?

7) Would you say that your older duals, (age 65 and above) tend to have different health and care management needs than your younger duals, who are less than 65?

    - Probe: Could you please provide some examples?

Now I would like to ask you a few questions about how you maintain contact with your patients.

8) How and when do you make contact with your dual patients?

    - Probes: How do you handle the situation if they miss an appointment?
    - Could you please tell me a bit about what is running through your mind when patients miss an appointment?
    - What are other red flags that alert you that there might be a problem with a patient?

Now I would like to ask you some questions about the things you do to help your patients move from one care setting to another.

9) How do you handle a dual's transition from a hospital setting back into the community?

    - Probes: Does anyone reconcile medication when moving from one care setting to another?
    - More broadly, how is medication management addressed?

10) The duals have many coexisting problems, and it's obviously not feasible for staff to address all of the problems of every patient. Could you please tell me about how you prioritize the patient's needs?

11) Could you please tell me a bit about referral procedures?

The literature includes different representations of care coordination. The Agency for Health Care Quality and Research has developed two theoretical frameworks that I would like to discuss with you. (*I will send interviewee these figures and the table ahead of time so CM has time to consider them ahead of time*). The first one is called the care coordination ring. (*Show care manager Figure 1, below.*) As you can see, this is a patient-centered framework that represents care coordination as a band (or ring) that unites all possible participants, health settings and information involved in a patient's care.

12) Does this representation of care coordination fit your experience as a care manager?
    - Probes: When you consider the unique health needs of the duals, is there anything that you would change about this model to make it more accurately fit your experience working with this population?
    - Are there any aspects of care coordination that are omitted which should not be?

Here is the second model, AHRQ's *Care Coordination Measurement Framework Diagram.* It represents the process by which care coordination is implemented. The framework includes the goal of achieving effective coordinated care, which must consider patient preferences and needs. The model also indicates that two groups of mechanisms are the means of achieving the goal. These are coordination activities and broad approaches. (*Show care manager Figure 2, below)*

13) Could you please tell me if this representation of the mechanisms that enable the implementation of care coordination fits your experience as a care manager?
    - Probes: When you consider the unique health needs of the duals, is there anything that you would change about this model to make it more accurately fit your experience working with this population?
    - Are there any aspects of care coordination that are omitted which should not be?

14) As you can see from the table below (*show Table 1, below*), AHRQ has described the actions and approaches that they believe make a difference when implementing care coordination.

- Probes: When you consider the unique health needs of the duals, what are the most important actions or approaches that make your work more effective?
    - Are there any aspects of care coordination that are omitted which should be added to this list?

Thank you so much for your time today. I am almost done asking my questions. But before we go, I wonder if you could tell me:

15) Do you feel satisfied with the care coordination that is provided to patients under this system?
    - Probes: Could you please tell me why you feel this way, and provide examples?

16) If there were one thing you could change about your job, what would it be?
    - Probes: Could you please tell me why you feel this way, and provide examples?

Figure 1: AHRQ Care Coordination Ring

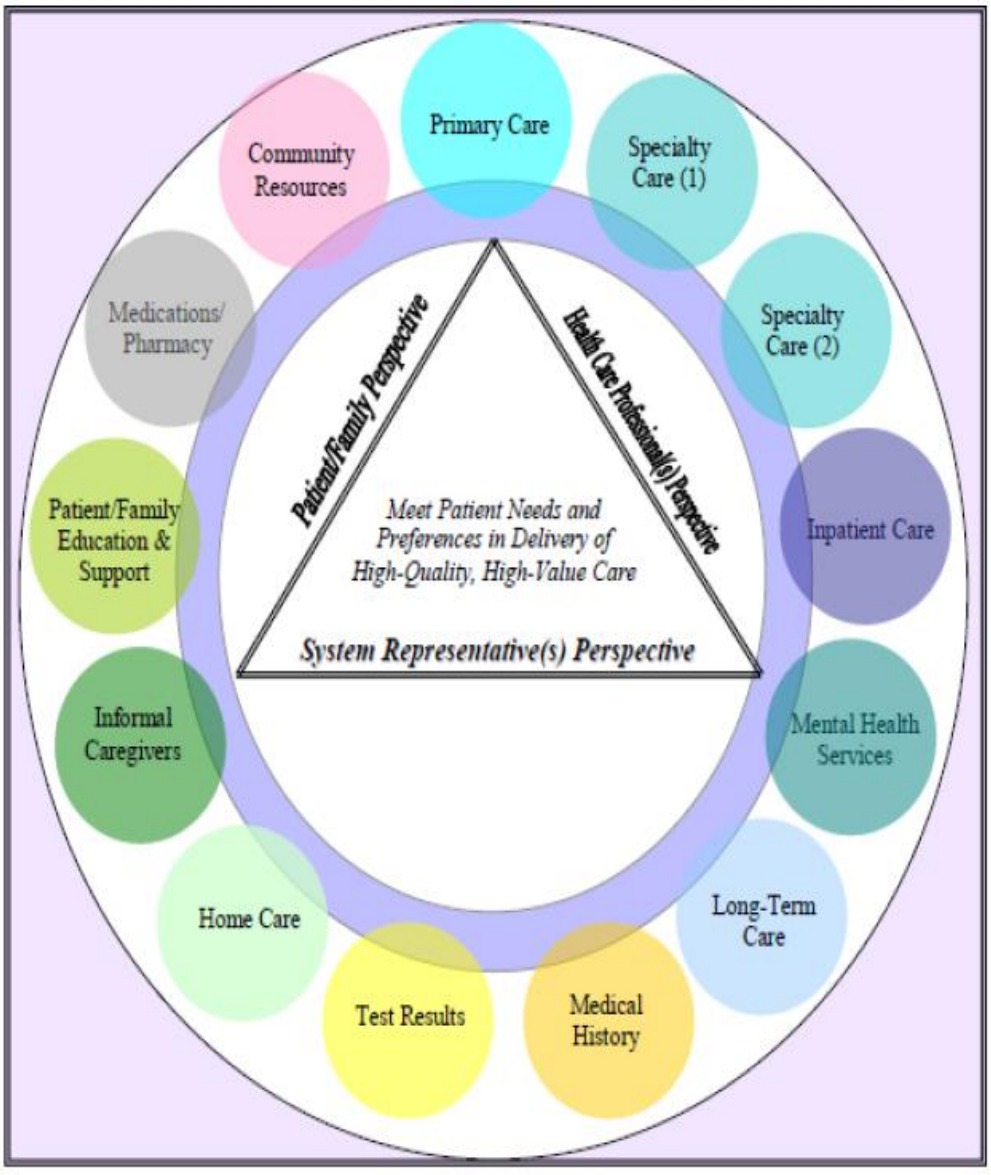


Figure 2:AHRQ's Care Coordination Measurement Framework Diagram

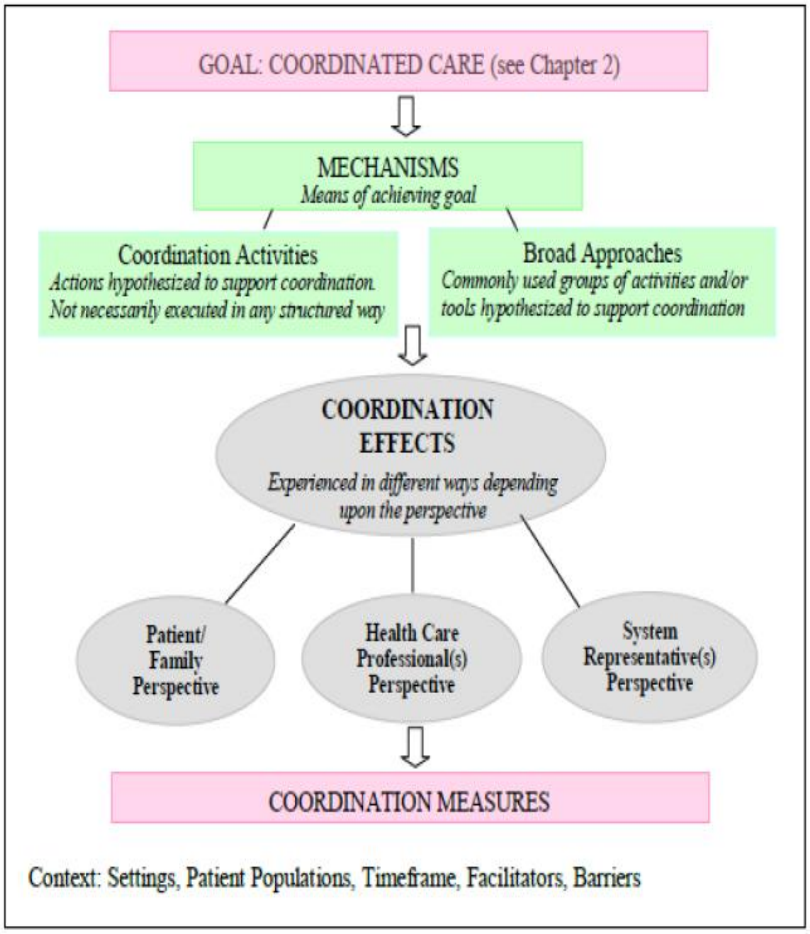


Table 1: AHRQ's Two Mechanisms of Coordinated Care	
Coordination Activities: Actions that help achieve coordination, whether employed in an improvised or systematic way. These include: • Establishing accountability or negotiating responsibility • Communicate • Facilitate transitions • Access needs and goals • Create a proactive plan of care • Monitor, follow up, and respond to change • Support self-management goals • Link to community resources • Align resources with patient & population needs	**Broad Approaches:** These structures of care are aimed at improving the delivery of health care, including improving or facilitating coordination, often incorporating a number of coordination activities. These include: • Teamwork focused on coordination • Health care home • Care management • Medication management • Health information technology-enabled coordination

Appendix D: Demographic survey for dual eligible interviewees

Only First Name _____

DEMOGRAPHIC INFORMATION

We want to ask you a few questions about you. Your answers are completely **anonymous and confidential**. We are not asking that you provide more than your first name. We in no way will be able to identify you through your answers. These questions are 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? _____

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

- ☐ More than $25,000 but less than $50,000
- ☐ More than $50,000 but less than $75,000
- ☐ More than $75,000 but less than $100,000
- ☐ 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
- ☐ Other

7. Have you been to the hospital in the past year?
_____Yes _____No

If yes, please briefly note the reason why you needed to go to the hospital:

_____

8. How would you characterize your health?
□ Excellent □ Very Good □ Good □ Fair □ Poor

9. Do you drink alcohol or smoke cigarettes?

_____Yes _____No

If so, how many alcoholic beverages per day, and how many cigarettes per day? _____

Appendix E: Matrix of Themes Organized into Nodes and Sub-nodes

Node	Subnode	Sub-sub node	Sub-sub-sub node	Description/Definition
Access				Content regarding patient access to services.
Access	Appointment times		.	Content regarding access to appointments and time-related issues around appointments.
Access	Appointment times	Getting appointment		Amount of time required to get an appointment. EG: Prompt sick/emergency care or phone issues associated with getting an appointment.
Access	Appointment times	PCP enough time		Patient feels doctor takes sufficient amount of time with him/her during office visit.
Access	Appointment times	PCP lacks time		Patient feels doctor takes insufficient amount of time with him/her during office visit.
Access	Appointment times	PCP time concerns		Patients express concern regarding doctors' time constraints. EG: doctor does not seem to have time to read medical history.
Access	Dental			Patients express concern or happiness with regard to access to dental services.
Access	Distance from care setting			Maximum distance from residence to care setting. Also includes patients' willingness to drive more miles in order to access care from preferred doctors.
Access	Medicine			Description of barriers to obtaining needed medications.
Access	Medicine	Override		Description of required override as a barrier to obtaining needed medication.
Access	Medicine	Part D		Description of experiences particularly associated with Medicare Part D. EG: care manager describing lack of information re: Part D or patient describing a number s/he called to access information re: Part D.
Access	Medicine	Reauthorization		Description of required reauthorization as a barrier to obtaining needed medications.
Access	Medicine	Refill		Description of inability to get a refill a barrier to obtaining needed medications.
Access	Mental health			Patients express concern or happiness with regard to access to mental or behavioral health services.
Access	Non-office hours			Patient experiences when PCP office is closed. EG: Appreciate or use doctor on call.
Access	Office			Patient feelings about care setting offices.
Access	Office	Office Experience		Patient reports about experiences around care setting offices. EG: Certain practices perceived as unwelcoming to individuals with disabilities.
Access	Office	Office Experience	Crowd	When patients say waiting room or practice is crowded.

Node	Subnode	Sub-sub node	Sub-sub-sub node	Description/Definition
Access	Office	Office Experience	Long wait	When patients say wait time is too long.
Access	Office	Office Experience	WaitFine	Patients say wait time is appropriate and acceptable.
Access	Office	Office Hours		Patient Description of PCP office hours. EG: hours too limited, or appreciate office hours after 5 pm weekdays and/or Saturday mornings.
Access	Prevention			Experiences related to beneficiary access to preventive services.
Access	Screening			Patient Experiences related to beneficiary access to screenings. EG: Screening for clinical depression or BMI screening.
Access	Sufficiency			Patients feel they receive sufficient or insufficient amount of tests, services or medical devices.
Access	Sufficiency	Insufficient number		Patients feel they receive insufficient amount of tests, services, devices.
Access	Sufficiency	Sufficient number		Patients feel they receive sufficient amount of tests, services or medical devices.
Access	Transpor-tation			Experiences regarding general transportation issues facilitating or creating barriers to access services.
Access	Travel times			Experiences regarding travel time as an issue facilitating or creating barriers to access.
AHRQ				Care manger reports on how and whether AHRQ's definition of care coordination activities generally fit experience of providing care coordination.
AHRQ	Disparities			Care manager discussions regarding AHRQ model suggests that all individuals have equal access to equal number of resources and this is not the case.
Coordin-ation of care				Experience with coordinated care (or lack thereof) with multiple providers and facilities, and transitions from one care setting to another.
Coordin-ation of care	CC among providers			Description of coordinated care among multiple providers.
Coordin-ation of care	CC among providers	Behavioral health		Experiences regarding how PCP and behavioral health providers communicate and coordinate care.

Node	Subnode	Sub-sub node	Sub-sub-sub node	Description/Definition
Coordination of care	CC among providers	No reports		Patients report that specialists do not automatically send reports to PCPs, or communicate with them (or vice versa). Or patients don't know if this is done.
Coordination of care	CC among providers	Pharmacy		Care coordination issues associated with pharmacy. EG: PCP and pharmacist interactions; coordination and communication between Medicare and pharmacists; appreciate doctor/staff assistance with refilling and ensuring meds do not run out; delays in getting required Rx
Coordination of care	CC among providers	Reports		Patients report that specialists automatically send reports to PCPs, or communicate with them, or vice versa.
Coordination of care	CC multiple facilities			Description of coordinated of care among multiple facilities.
Coordination of care	CM Broad Approaches (AHRQ)			Description of Broad Approaches (described by AHRQ) which are used in care coordination efforts and are aimed at improving the delivery of health care, including enhancing or facilitating coordination and often incorporating a number of coordination activities.
Coordination of care	CM Broad Approaches (AHRQ)	Care management		Description of care management services to achieve an optimal level of wellness and improve coordination of care while providing cost effective, non-duplicative services.
Coordination of care	CM Broad Approaches (AHRQ)	Health care home		Description of the health care home, which uses an interdisciplinary clinician-led team approach to delivering and coordinating care that puts patients, their families, and caregivers at the center of all decisions concerning the patient's health and wellness. HCH provides enhanced access to physical health, behavioral health, and supportive community and social services, ensuring patients receive the right care in the right setting at the right time.
Coordination of care	CM Broad Approaches (AHRQ)	Health information technology-enabled coordination		Description of health information technology-enabled coordination. EG: care manager reports that some PCPs use HIT and others do not.

Node	Subnode	Sub-sub node	Sub-sub-sub node	Description/Definition
Coordination of care	CM Broad Approaches (AHRQ)	Medication management		Description of medication management: the prescribing and/or administering and reviewing of medications and their side effects.
Coordination of care	CM Broad Approaches (AHRQ)	Teamwork		Description of teamwork focused on coordination. EG: PCPs and their nurses appreciate role of care manger (CM) because they know CM provide support services that PCP and PCP staff cannot provide.
Coordination of care	CM Coordination activities (AHRQ)			Coordination activities described by care managers. AHRQ states that these are actions that help achieve coordination, whether employed in an improvised or systematic way.
Coordination of care	CM Coordination activities (AHRQ)	Access needs/goals		Description of care manager's unique ability to satisfy patient needs or help patients to realize their goals. EG: CMs conduct home visit and PCPs know this is a service they cannot provide.
Coordination of care	CM Coordination activities (AHRQ)	Accountability		Description of CM establishing accountability or negotiates responsibility with patient.
Coordination of care	CM Coordination activities (AHRQ)	Align resources with patient and population needs		CMs are engaged in assessing population needs to identify and address service gaps. EG: identifying clusters of patients who smoke and offering smoking cessation programs.
Coordination of care	CM Coordination activities (AHRQ)	Care plan		Description of a written, proactive plan of care.
Coordination of care	CM Coordination activities (AHRQ)	Communicate		Description of CM communications with PCPs or other providers. EG: CM sends PCP a case management report describing a home visit.
Coordination of care	CM Coordination activities (AHRQ)	Link to community resources		Description of community resources that meet patient needs, or CM may connect community resources on behalf of patient, or provides patient with information so s/he may follow up.
Coordination of care	CM Coordination activities (AHRQ)	Monitor, follow up, and respond to change		Description of CM activities that are responsive to dynamic life of patients. EG: CM calls patient to talk about diabetes control, but when patient describes symptoms of coronary heart failure, CM rapidly switches priorities.

Node	Subnode	Sub-sub node	Sub-sub-sub node	Description/Definition
Coordination of care	CM Coordination activities (AHRQ)	Support self-management goals		CM conducts "patient activation" strategies in engage patient in own health. EG: Help a grandmother responsible for taking care of her grandchildren to brainstorm about arranging other childcare so she is able to get to her PCP appointment.
Coordination of care	CM Coordination activities (AHRQ)	Transitions		Description of when CMs help patients move from one care setting to another. EG: helping a patient to transition from an inpatient hospital stay back home, or getting patients a PCP appointment when they are sick instead of sending them to Emergency Department.
Coordination of care	Continuity of care			NSCLC says examples of continuity of care include: 1) maintaining access to current services like prescription drugs, during a defined transition period; and 2) continued access to a current provider who is not part of the integrated model's network during a defined transition period.
Coordination of care	Continuity of care	Provider continuity		Description of issues associated with the ability to continue using the same provider over an extended period of time. EG: As a result of physician discontinuity, some patients required to routinely re-explain painful traumatic incidents.
Coordination of care	Continuity of care	Services continuity		Description of services continuity when patients continue maintaining access to current services like prescription drugs, during a defined transition period.
Data collection descriptors				Node to code the location and type of settings where data was collected, in focus groups and interviews.
Data collection descriptors	Chatham County			Focus group or individual interview was conducted in Chatham County, NC.
Data collection descriptors	Community-based setting			Focus group or individual interview was conducted in a community-based setting, not in a medical practice.
Data collection descriptors	Focus group 18-64			Focus group included dually eligible individuals who were 18-64 years old.
Data collection descriptors	Focus group 65			Focus group included dually eligible individuals who were 65 years old and older.

Node	Subnode	Sub-sub node	Sub-sub-sub node	Description/Definition
Data collection descript-tors	Johnston County			Focus group or individual interview was conducted in Johnston County, NC.
Data collection descript-tors	Medical practice			Focus group or individual interview was conducted in a medical practice.
Data collection descript-tors	Orange County			Focus group or individual interview was conducted in Orange County, NC.
Data collection descript-tors	Wake County			Focus group or individual interview was conducted in Wake County, NC.
FG character				General Description of focus group patient characteristics (abbreviated FG character).
FG character	Financial stress			Description of financial stresses of all kinds
FG character	Financial stress	Food stress		Description of financial constraints associated with paying for food.
FG character	Financial stress	Food stress	Food stamp-food bank use	Description of experiences of patients relying on food stamps or food bank
FG character	Financial stress	Housing financial stress		Description of trouble with paying house-related bills, taxes, etc.
FG character	Financial stress	Medicine financial stress		Description of trouble with paying for medicine. EG: Issues with balanced billing--being charged inappropriately for cost sharing.
FG character	Individual-emphasis			Node focuses on issues regarding the individual patient perspective including individuals' preferences, individual experience of care, and individual engagement in decisions about care.
FG character	Individual-emphasis	Engagement in care decisions		Description of sense of control and autonomy and self-determination. EG: Experiences of some individuals who want to be engaged in their care and others who want to simply follow doctor's orders.
FG character	Individual-emphasis	Engagement in care decisions	Compli-ance	Description of patients who follow provider instructions, or not. EG: Patient says s/he does not follow doctor's orders or CM who complains about non- compliance
FG character	Individual-emphasis	Engagement in care decisions	Goals, treatment and recovery	Description of progress or lack thereof regarding treatment and recovery goals.

Node	Subnode	Sub-sub node	Sub-sub-sub node	Description/Definition
FG character	Individual-emphasis	HIT preference		Description of health information technology at point of care.
FG character	Individual-emphasis	HIT preference	Computers dislike	Description of physician computer use acts as communication or relationship obstacle.
FG character	Individual-emphasis	HIT preference	Computers like	Description of how provider's, healthcare system's or personal computer facilitates healthcare experience or quality.
FG character	Individual-emphasis	Individual choice plan provider		Description of how patients choose their providers, and when and how they choose to leave them.
FG character	Individual-emphasis	Individual experience of care		General node focused on how and why individual patients experience care in a certain manner.
FG character	Individual-emphasis	Individual experience of care	Bad PCP	Description of bad primary care provider experiences. EG: negative physician characteristics or provider's provision of insufficient medical information.
FG character	Individual-emphasis	Individual experience of care	Change PCP relationship	Description of aspects of relationship with PCP that patients would want to change.
FG character	Individual-emphasis	Individual experience of care	No change PCP relationship	Description of patient desire for no change in relationship with PCP.
FG character	Individual-emphasis	Individual experience of care	No change PCP relationship	Description of a good PCP. EG: Characteristics patients like in a doctor or the provision of sufficient medical information.
FG character	Individual-emphasis	Individual experience of care	Hospitalist	Description of receiving care from hospitalist while in a hospital setting.
FG character	Individual-emphasis	Person-centered care		Description of person-centered care (PCC) in use. EG: understanding the strengths, abilities, needs and challenges of individual patient, understanding patient goals and helping him/her achieve them. EG: patient reports that s/he will lose access to housing today, and that becomes the most important priority.
FG character	Maslow			Description regarding Maslow's hierarchy of needs.
FG character	Multiple chronic conditions			Description of patient(s) with one or more chronic conditions
FG character	Quality of life			Description of patient quality of life.

Node	Subnode	Sub-sub node	Sub-sub-sub node	Description/Definition
FG character	Quality of life	Functional status		Description regarding what makes for a life well-lived. EG: being productive, when living with a disability, or providers properly calibrating dosages and drug-taking schedules to improve functional status, or improving/maintaining mental health.
FG character	Quality of life	Psychosocial		Description of patient's ability to adjust and relate the body to its social environment. EG: level of engagement in community activities or feel a lack of information regarding available social services.
FG character	Quality of life	Psychosocial	Health illiterate	Description suggests low health literacy. EG: Patient says she ignores information about when to take medication.
FG character	Quality of life	Psychosocial	Health literate	Description suggests high level of health literacy. EG: Patient tells specialists to send medical reports to PCP.
FG character	Quality of life	Symptom control		Description of symptom control. EG: providers properly calibrated dosages and drug-taking schedules to improve their symptoms.
FG character	Quality of life	Unsafe home		Description of violence at home, or otherwise unsafe living conditions.
Follow up care				Descriptions of needing or providing follow up care.
Follow up care	Emergency Department			Description of emergency department visits for ambulatory sensitive conditions (ASCs) or other conditions.
Follow up care	Ongoing management of chronic conditions and CC risks			Description of management of chronic conditions and the risks for chronic conditions. EG: providers properly calibrated dosages and drug-taking schedules to improve chronic conditions and risks of chronic conditions, or patient control of blood pressure.
Follow up care	Re-admission			Description of hospital readmission shortly after acute event. EG: follow up after hospitalization for mental or other serious illness.
Medica-tion stress				Description of stress regarding barriers to obtaining needed medications.
Support				General category of sources and types of assistance for patients.
Support	Caretakers			Descriptions of different types of caretakers who help a patient manage care and health.
Support	Caretakers	Family		Descriptions of family members acting as care takers and care managers. EG: Family helps patient get needed care or checks on the patient even when s/he is not sick.

Node	Subnode	Sub-sub node	Sub-sub-sub node	Description/Definition
Support	Caretakers	Friends		Descriptions of friends acting as care takers and care managers. EG: Friends helps patient get needed care or checks on the patient even when s/he is not sick.
Support	Caretakers	Self		Description of patient him/herself as responsible for getting needed care.
Support	Caretakers	Self	Self care taker	Description of patient taking care of him or herself and caring for others.
Support	Caretakers	Spouse		Description of spouses taking care of patient and spouses take care of each other.
Support	Community support			Availability (or lack thereof) of community support services and systems.
Support	Doctor link			Description of PCP as a source of information (or not) about needed community-based resources and support.
Support	Doctor link	PCP link no		Description of PCP not facilitating access to needed wrap around social services.
Support	Doctor link	PCP link yes		Description of PCP facilitating access to needed wrap around social services.
Support	Educate each other			Observations or descriptions of patients educating each other.
Support	Educate each other	Educate health strategies		Observations or descriptions of patients educating each other re: health care strategies.
Support	Educate each other	Educate health strategies	Educate medication	Observations or descriptions of patients educating each other re: medication-related strategies.
Support	Educate each other	Educate health strategies	Educate reports	Observations or descriptions of patients educating each other about need to direct specialists to send health reports to their PCP and vice versa.
Support	Educate each other	Educate health strategies	Educate social services	Observations or descriptions of patients educating each other about social service resources. EG: Where and how to access needed food and other essentials.
Support	Enrollment assistance and options counseling			Description of getting or providing enrollment or information regarding different providers or approaches to care.
Support	Medication			Broad category regarding different types of sources of support for medication adherence.
Support	Medication	Medication helpers		Description of different individuals who assist with taking prescriptions properly.
Support	Medication	Medication helpers	Medication care taker	Description of non-professional assister who helps with medication adherence. EG: assister arranges pills, or picks up medications from pharmacy.

Node	Subnode	Sub-sub node	Sub-sub-sub node	Description/Definition
Support	Medication	Medication helpers	Medication pro-fessional	Description of professional assister who helps with medication adherence. EG: Professional arranges pills, or helps to pick up medications from pharmacy.
Support	Medication	Medication helpers	Medication self	Description of patient who is responsible for his/her own medication adherence. EG: Arranges pills, and/or picks up own medications from pharmacy.
Support	Medication	Medication strategy		Description of different strategies employed to assure medication adherence.
Support	Medication	Medication strategy	Medication alternative strategy	Description of using alternative (non-pill box) strategy to assure medication adherence.
Support	Medication	Medication strategy	Medication manage-ment	Description of the use of medication management by provider and patient/caregiver to optimize appropriate use of medication and minimize negative drug interactions.
Support	Medication	Medication strategy	Medication pill box	Description of pill box use to assure medication adherence.
Support	Medication	Medication strategy	Medication reconcilia-tion	Description of the conduct of medication reconciliation.
Support	Nurse			Description of nurse or other non-PCP clinician identified as a source of support. EG: Close working relationship with individual nurse and/or other staff assistance, in response to PCP time constraints.
Support	Sad/Stress			Descriptions of issues regarding sad or stressed feelings.
Support	Sad/Stress	Deny sad stress		Descriptions of denying feelings of stress and/or sadness.
Support	Sad/Stress	Don't tell sad stress		Description of patient who does not want to tell anyone when sad or stressed.
Support	Sad/Stress	Family sad		Description of patient calling sibling or other family member when sad and/or stressed.
Support	Sad/Stress	Friend sad		Description of patient calling a friend when sad and/or stressed.
Support	Support access issues			Description about ability to access wrap around supports. EG: Patient feels she lacks in information regarding how to obtain needed social services.