

Understanding diffusion of evidence-based community cancer care:  
A case study of network connections in an integrated health system

A Dissertation

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## ABSTRACT

Despite overall declines in cancer mortality in the U.S. over the past three decades, many patients in community settings fail to receive evidence-based, high-quality cancer care. Networks that connect community clinics and academic medical centers hold potential to address these disparities by creating avenues for knowledge diffusion and access to specialty care, but research on networks is mixed and understanding of the underlying diffusion and adoption processes is incomplete. A case study was conducted of a large integrated health system in the Midwest using electronic health record data for 20 patients with young-onset colorectal cancer (CRC) or risk-related conditions. Social network analysis was employed to describe the network and identify connections between providers. Process tracing of patient narratives provided detailed accounts of whether and how network functions led to evidence-based outcomes. Results indicate that the network addressed common barriers to evidence-based medicine (EBM) diffusion and adoption for some but not all patients. In fact, network failures offset benefits or delayed them for some patients, and access to EBM was often provider-dependent. Local specialists displayed higher levels of EBM knowledge and often brokered advice between community primary care providers and specialists in the academic medical center, but information diffusion was sometimes incomplete. Failures in documentation also led to fragmented care coordination and confusion about the best evidence course of care, especially when referrals circumvented local specialists and when patients brokered communication between providers. Full implementation of networks—informed by both network and interpersonal relationship theories—is necessary to leverage their potential to bring EBM information to community providers and increase access to specialty care. In the context of young-onset CRC, this includes increased awareness, opportunities for a mix of lean and rich communication between local providers and academic medical center specialists to determine evidence-based care, coordinated referrals, and systems to document information for all providers involved in care. Through in-depth understanding of how

and when this large integrated network operated to achieve EBM outcomes, the current study provides insight into factors that may support or inhibit the ability of networks to provide patient-centered, evidence-based, and coordinated care in community settings.

## Table of Contents

List of Tables .....	v
List of Figures .....	vi
Chapter 1: Introduction .....	1
Statement of the Problem.....	1
Purpose of the Study .....	8
Research Questions .....	15
Significance of the Research.....	18
Chapter 2: Review of Literature .....	20
Introduction.....	20
The Need for Primary Care Intervention for Rising Young Onset CRC .....	20
Connecting Community Settings to the Research Community .....	25
Professional Coordination across Time and Space.....	30
Theoretical Perspectives on EBM in Community Cancer Care .....	34
Diffusion of Innovations and Strength of Weak Ties .....	34
Relationship Centered Care .....	39
Distributed Cognition and Shared Mental Models .....	43
Limitations of Existing EBM Diffusion Research.....	47
Chapter 3: Methods.....	49
Research Design.....	49
Research Methods.....	51
Procedures.....	52
Step 1: Case Selection.....	53
Step 2: Case Unit Selection.....	55
Step 3: Data Collection and Transformation.....	58

Step 4: Data Analysis.....	61
Step 5: Data Integration and Interpretation.....	66
Chapter 4: Results.....	68
Results of SNA .....	68
Results of Process Tracing.....	77
Results of Mixed Methods Integration and Interpretation .....	89
Chapter 5: Discussion .....	109
Factors Related to Network Function .....	109
Meeting the IOM Call to Action.....	125
References.....	138
Appendix.....	153

## **List of Tables**

Table 3.1. Characteristics of Patients in Narrative Case Review .....	58
Table 3.2. Process Tracing Framework .....	61
Table 3.3. SNA Measures and Notations .....	65
Table 4.1. Centrality Measures for Network Actors .....	75
Table 4.2. Joint Display of SNA and Process Tracing Findings.....	89



## List of Figures

Figure 3.1. Research Questions, Case Study Approach, and Analysis Objectives .....	50
Figure 3.2. Study Design Flow .....	51
Figure 3.3. Embedded Single Case Study Design.....	54
Figure 3.4. Selection of Patients for Case Narratives .....	56
Figure 3.5. Sociogram Example.....	62
Figure 4.1. Sociogram of All Actors in the Case Study Network.....	69
Figure 4.2. Sociogram of Local Patient Care Providers and Advice: MCHS Patients .....	71
Figure 4.3. Sociogram of Local Patient Care Providers and Advice: ECH Patients.....	71
Figure 4.4. Sociogram of Local Patient Care Providers and Referrals: MCHS Patients. ....	73
Figure 4.5. Sociogram of All Relationships: MCHS Patients.....	93

## CHAPTER 1 INTRODUCTION

In many ways, oncology care is an extreme example of the best and worst in the health care system today—highly innovative targeted diagnostics and therapeutics alongside escalating costs that do not consistently relate to the clinical value of treatments, tremendous waste and inefficiencies due to poor coordination of care, and lack of adherence to evidence-based guidelines with frequent use of ineffective or inappropriate treatments.

—Institute of Medicine (IOM), 2013, p. xvi

### Statement of the Problem

The five-year cancer survival rate reached 69% in 2015—up from 50% when President Richard Nixon declared the “War on Cancer” and authorized increased spending for cancer research in 1971 (Howlader et al., 2015; National Cancer Institute [NCI], 2016a). Likewise, the overall cancer mortality rate in the U.S. has been steadily dropping for almost three decades. Between 1991 and 2012 alone, this drop amounted to more than 1.7 million cancer deaths averted (Siegel, Miller, & Jemal, 2016). These successes can be attributed in part to scientific discoveries that have led to better prevention, detection, and treatment (Byers et al., 2016). These include the identification of genetic mutations such as *BRCA1* and *BRCA2* that increase the risk of breast and ovarian cancer, the development of screening technologies such as mammography that identify cancers early, and new classes of cancer-fighting drugs (NCI, 2015). Some of the most groundbreaking work has been in precision medicine, which uses a patient’s genetic information to individualize treatment, and immunotherapies (biologic therapies that target, suppress, or activate the immune system), which have shown dramatic outcomes in cancer clinical trials (Burstein et al., 2017; Byers et al, 2016; Masters et al., 2015).

Despite these successes, the Institute of Medicine (IOM, 2013) has referred to cancer care in the U.S. as a system in crisis. The cost of cancer care has been rising rapidly and may soon outpace total health care inflation (IOM, 2013, p. 61). These costs are exacerbated by

demographic trends. By 2020, the expanding and aging U.S. population could lead to an increase of more than 20 percent in cancer cases (Weir, Thompson, Soman, Møller, & Leadbetter, 2015) and costs could reach \$173 billion—up 39 percent from 2010 (Mariotto, Yabroff, Shao, Feuer, & Brown, 2011).

Furthermore, advances in the fight against cancer are not evenly distributed across the U.S. patient population. Hispanic men and women are significantly less likely to meet screening guidelines for cervical, breast, and colorectal cancers than non-Hispanic people (Sabatino, White, Thompson, & Klabunde, 2015), and nearly every major cancer has a death rate that is higher for black men than for white men (Siegel, et al., 2016). NCI refers to these “adverse differences in cancer incidence (new cases), cancer prevalence (all existing cases), cancer death (mortality), cancer survivorship, and burden of cancer or related health conditions that exist among specific population groups in the United States” as cancer health disparities (NCI, 2016b).

Disparities are associated with unequal access to high-quality care (Siegel, et al., 2016), such that where patients live and where cancer care is available makes a difference. Patients in rural areas are less likely to receive recommended cancer screening like regular mammograms and Pap tests, and they are diagnosed later than their urban counterparts (Leung, McKenzie, Martin, & McLaughlin, 2014; Meilleur et al., 2013; Nguyen-Pham, Leung, & McLaughlin, 2014). Low levels of oncologic referrals and limited access to specialty care also result in inferior treatment regimens and outcomes for racial and ethnic minority patients and older patients (Bickell et al., 2006; Chatterjee, Gupta, Caputo, & Holcomb, 2016; Haider et al., 2013; Luo, Giordano, Freeman, Zhang, & Goodwin, 2006; Sheppard, et al., 2015).

Receiving cancer care from a facility that specializes in cancer can lead to better outcomes for patients. Facilities that are high volume, i.e., facilities that treat many cases, have been shown to have better patient outcomes including lower post-treatment mortality (Aquino et al., 2016; Hata et al., 2016; Go et al., 2017; Rogers, Wolf, Zaslavsky, Wright, & Ayanian, 2006),

and treatment at a comprehensive cancer center is associated with significantly better cancer-related outcomes (Wolfson, Sun, Wyatt, Hurria, & Bhatia, 2015). However, access to these facilities is lower among vulnerable and underserved populations (Wolfson et al., 2015). As much as 40 percent of the disparities in breast cancer diagnosis between non-Hispanic white and minority women may be explained by factors such as whether the facility is certified as a center of excellence in breast imaging (Molina, Silva, & Rauscher, 2015). Reducing cancer health disparities could have a significant impact not only on the lives of patients but on the costs burdening the health care system (Horwitz, 2016).

The field of oncology—like much of medicine—has turned to the development of evidence-based medicine (EBM) in order to standardize care decisions and reduce costly and inequitable variation in care. EBM refers to health care providers' systematic assessment of evidence, along with clinical expertise and patient preferences, to make the best clinical decisions (Grol & Grimshaw, 2003; Guyatt et al., 1992; Rosenberg & Donald, 1995; Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996). It rests in part on the hierarchy of evidence, which is arranged in order of strength based on likelihood of freedom from error, beginning with meta-analyses of large, high-quality randomized controlled trials (Prasad, 2013). The systematic nature of EBM can be contrasted with decision making rooted in anecdotal information or lower-quality evidence (Guyatt et al., 1992). EBM allows clinical expertise and patient values to play a role in decision making while providing guidance in terms of clinical evidence so that care does not “vary illogically from clinician to clinician or from place to place” (IOM, 2001, p. 62).

EBM is often codified in clinical practice guidelines (Agency for Healthcare Research and Quality [AHRQ], 2016). Between 2010 and 2015, nearly 2000 clinical practice guidelines were published in the National Guideline Clearinghouse, the publicly-sponsored U.S. database (AHRQ, 2016). Cancer guidelines outline best practices related to the prevention, detection, and treatment of cancer, as well as supportive care. They address specific questions, such as when

patients should receive preventive screening, when primary care providers should make referrals for suspected cancers, what first-line treatments should be recommended based on disease characteristics, and how pain and fatigue can be best managed (National Comprehensive Cancer Network [NCCN], 2016). The NCCN, a not-for-profit alliance of 27 world-leading cancer centers (including Mayo Clinic), regularly updates and publishes best-evidence guidelines that apply to 97 percent of cancers in the U.S. (NCCN, 2016).

Despite the logic of guideline-based care, EBM is not practiced consistently. According to the IOM, “less than half—perhaps well less than half—of all clinical decisions are supported by sufficient evidence” (IOM, 2007, p. 97). Furthermore, failures in EBM uptake are not evenly distributed across the U.S. patient population. Patients in community clinics in particular are less likely to receive cancer treatment that follows best practice or EBM guidelines (Bristow et al., 2015; Fleming et al., 2014; Monson et al., 2014), may have more difficulty accessing off-site specialty care (Aboagye, Kaiser, & Hayanga, 2014; Cook et al., 2007; Sequist, 2011), and may have more limited access to promising drugs or treatments (Panchal, Lairson, Chan, & Du, 2013).

Even clinics with designated cancer programs, if they are low-volume cancer centers, are less likely to provide guideline-adherent care for patients with less commonly treated cancers (Cliby et al., 2015; Cowan et al., 2016). Furthermore, residents of rural communities and patients receiving care outside a designated cancer center are also less likely to be recruited to clinical research studies, compared with individuals in urban communities or with access to cancer centers (Baquet, Commiskey, Daniel Mullins, & Mishra, 2006; Ford et al., 2008; Fouad et al., 2013; Murthy, Krumholz, & Gross, 2004; Vanderpool, Kornfeld, Mills, & Byrne; Wallington et al., 2016). This means that fewer of these patients have access to novel treatments—a situation that could translate into even larger cancer disparities for these populations (Chen, Lara, Dang, Paterniti, & Kelly, 2014; Oh et al., 2015). Low levels of inclusiveness in clinical trials also means guideline evidence may or may not be applicable to subgroups in the population. Strategies to

improve EBM uptake in community clinics may be one way to reduce costs and improve patient outcomes, thereby reducing cancer health disparities.

**A call to action: early onset colorectal cancer.** Colorectal cancer (CRC) is the second most common cancer among men and the third most common among women in the U.S (Siegel et al., 2016). Incidence and survival have steadily improved since the mid-1980s, along with increases in CRC screening uptake (Siegel et al., 2016). Still, disparities in CRC persist, including those between non-Hispanic whites and African Americans (Siegel et al., 2016). Barriers to CRC screening and care include living in a rural area, which is associated with a lower density of providers who perform colorectal cancer screening services and treatment, and insurance status (Aboagye, Kaiser, & Hayanga, 2014; Ojinnaka, Choi, Kum, & Bolin, 2015; Wheeler et al., 2014).

One of the most alarming trends in CRC is in incidence among those in younger age groups (young onset CRC). While overall CRC incidence is falling among those age 50 and older, owing in large part to increases in adherence to recommended guidelines for CRC screening beginning at age 50 (U.S. Preventive Services Task Force, 2016), CRC rates have been rising rapidly among those under age 50 (You, Xing, Feig, Chang, & Cormier, 2012), with the greatest increases among those age 20-29, where rates have been growing by more than 5% a year (Siegel, Jemal, & Ward, 2009).

Younger CRC patients also tend to have more delayed diagnoses and higher rates of advanced-stage diagnosis than patients age 50 and older (Chen, Sundaram, Chew, & Ladabaum, 2016). A general lack of symptoms may keep many younger patients from seeking care (Lowery et al., 2016), and the broad symptom signature of CRC (meaning that it is associated with a broad range of symptoms with varying predictive value) contributes to longer periods to both patient first presentation to primary care and subsequent referral to a specialist (Koo, Hamilton, Walter, Rubin, & Lyratzopoulos, 2017). Even patients with cancer “alarm symptoms” (e.g., rectal bleeding) may avoid seeing a generalist if they perceive they could be wasting generalists’ time

(Cromme et al., 2016). Late-stage diagnoses may also be related to tumor biology among young patients (Chen et al., 2016). There is almost no literature related to physician factors impacting delayed diagnosis of young adult CRC (O'Connell, Maggard, Livingston, & Yo, 2004), but experts suggest that providers—who may not be suspicious of CRC risk when young patients present with symptoms—must be increasingly vigilant (Ahn et al., 2014, You et al., 2012).

A large share of colon and rectal cancers among younger patients are related to genetic conditions, such as Lynch syndrome and familial adenomatous polyposis (FAP), which carry 80% and 100% lifetime risks respectively (Stigliano, Sanchez-Mete, Martayan, & Anti, 2014). Having a strong family history is also predictive of CRC among younger adults; having a first-degree relative with CRC or advanced adenomatous polyps (especially at a younger age) can increase risk of CRC up to four-fold, and even two second-degree relatives can increase risk 2- to 3-fold (Ahn et al., 2014)

Primary care providers play a pivotal role in increasing early detection of these cancers. Receiving a screening recommendation from a physician and discussing family history with a physician are both positively associated with increased rates of CRC screening among patients with familial risk factors for CRC (Lowery et al., 2016; Ait Ouakrim et al., 2013). The general population guidelines for CRC screening suggest most adults begin screening at age 50 (e.g., fecal occult blood test, sigmoidoscopy, or colonoscopy), but guidelines are also in place to help physicians give appropriate referral or diagnostic recommendations to patients under 50. These include guidelines that physicians speak with patients about family history of CRC by age 40, make referrals for those that meet criteria for a genetic disorder to a genetic counselor (Ahn et al., 2014), and screen for CRC when a patient presents with rectal bleeding, regardless of whether other symptoms are present (Astin, Griffin, Neal, Rose, & Hamilton, 2011). NCCN guidelines outline testing for Lynch syndrome and other genetic high-risk assessments (NCCN, 2016). Despite guidelines, though, research on primary care provider documentation suggests failures in

patient-provider conversations about CRC family history (Carney et al., 2013). Knowledge of hereditary colorectal cancer genetics is also low among primary care providers compared to specialists (Wideroff et al., 2005), and only 15% of community hospital cancer programs routinely test for Lynch syndrome, compared with 71% of NCI-designated Comprehensive Cancer Centers (Beamer et al., 2012).



## **Purpose of the Study**

### **The Problem with EBM Uptake**

Efforts to increase the use of EBM in community clinics could improve patient health outcomes and reduce variation in care that compounds health disparities. The central question is why providers fail to adopt EBM if those practices could ensure better care. A major problem is that the development of EBM guidelines is insufficient to ensure their use. Not all physicians are aware of the latest EBM guidelines, or they might not find them to be acceptable or applicable (Glasziou & Haynes, 2005). These attitudes reflect physician training or experience, as well as personal values or beliefs (Reschovsky, Rich, & Lake, 2015). Furthermore, some guidelines may not fit the structure or policies of the health care organization or system in which the provider practices (Glasziou & Haynes, 2005). Many of these barriers were outlined in a systematic review by Michael D. Cabana and colleagues (1999) more than 15 years ago, and many of these personal and organizational barriers persist in reviews in recent years (Lau et al, 2016; Murthy et al., 2012).

**Lack of awareness, familiarity, and self-efficacy.** Lack of awareness about guidelines is reported as an obstacle to EBM diffusion, despite an ever-expanding knowledge base, including rapid publication on the internet. The sheer volume of evidence can overwhelm physicians because much of it is not filtered or easily accessed (Glasziou & Haynes, 2005; Klerings, Weinhandl, & Thaler, 2015; Kosteniuk, Morgan, & D'Arcy, 2013; Larson, 1997; Reschovsky et al., 2015). These demands unfortunately coincide with increasing pressure on providers' time (Kosty, Acheson, & Tetzlaff, 2015), such that more information—albeit readily available to those who search for it—is not necessarily better if physicians lack the time to access and filter it. In the face of these challenges, physicians may fall back on heuristics, i.e., decision shortcuts, when making patient care decisions, resulting in decision making bias (Blumenthal-

Barby & Krieger, 2015; Reschovsky, et al., 2015). In the case of guidelines for CRC screening, providers may be more familiar with guidelines for those age 50 and older. Little is known about how often guidelines for patients under age 50 are followed by providers (Lowery et al. 2016). Another barrier to uptake is the level of knowledge, capacity, or skillset that is necessary to implement the guideline (Cabana et al., 1999). Some physicians may lack the skills to implement new procedures or practices (Lau et al., 2016); others may lack self-efficacy or confidence in their ability to do so (Cabana et al., 1999). Furthermore, cancer care is complex. The IOM report (2013) notes that “Advances in understanding the biology of cancer have increased the amount of information a clinician must master to treat cancer appropriately” (p. 2), and advances in complex fields like genomics and precision medicine, as well as complexities of treating cancer alongside multiple comorbid conditions, pose a challenge (American Society for Clinical Oncology [ASCO], 2016, p. 25). Already, studies of primary care providers’ attitudes show they may lack confidence in their cancer care competencies (Potosky et al., 2011), and primary care providers with low levels of training or knowledge may be reluctant to perform roles related to treatment and surveillance (Lawrence, McLoone, Wakefield, & Cohn, 2016).

These issues are critical in light of national efforts to create oncology medical homes (care models in which a single provider group is put in charge of on-going patient management across diseases, care needs, and settings) in order to improve care coordination and reduce health care costs (Abrahams, Foti, and Kean, 2015; ASCO, 2014; Cox, Ward, Hornberger, Temel, & McAneny, 2014; IOM, 2013). Providers in primary care settings have been shown to vary substantially in their competency in cancer care and their knowledge of emerging science in areas such as genetics testing (MacDonald, Blazer, & Weitzel, 2010).

**Low acceptability of existing EBM guidelines or practice inertia.** Physician attitudes are cited as a common reason for lack of adherence to guidelines or uptake of new evidence. Some providers cite lack of strong evidence that the guidelines will result in the suggested patient

outcomes or lack of transparency in developing guidelines (Cabana et al., 1999; Lau, 2016; Reames, Krell, Ponto, & Wong, 2013).

Lack of agreement with guidelines may also stem from feelings that guidelines are cookbook medicine or that they reduce physician autonomy and flexibility (Cabana et al., 1999). They may run counter to a “philosophy of care” or personal style (Broom, Adams, & Tovey, 2009; Lau et al., 2016), or they may be inconsistent with physicians’ values or beliefs (Ishibashi, Koopmans, Curlin, Alexander, & Ross, 2008; Kahn et al., 2005). Inertia of existing practice is also a barrier to guideline use (Cabana et al., 1999); once practice is firmly rooted, it is hard to change, and providers may look unfavorably especially on guidelines that are proscriptive (discouraging practice) when the guidelines appear to ration care (Carlsen, Glenton, & Pope, 2007). Inertia may relate to the individual physician’s practice, but it may also be organizational if the culture of the physician group is such that EBM is generally looked upon unfavorably (Lau et al., 2016). The tendency of individuals to associate primarily with similar individuals who share backgrounds and experiences is known as homophily. Physicians in a single clinic, for example, are highly homophilous with regard to education and training, and their experiences may also be very similar. Homophilous groups tend to have insular views, which may lead to inertia. Existing knowledge within similarly-minded groups tends to “get stuck” or be resistant to change if group members are isolated from outside views and experiences. This is known as “sticky knowledge” (Elwyn, Taubert, & Kowalczyk, 2007).

**Provider and patient system barriers.** While the focus is rightly on the decisions that providers make, i.e., whether or not to implement EBM when making clinical decisions, providers’ choices may also be constrained by system or contextual factors. These include lack of time for understanding new practices and discussing them with patients, lack of information infrastructure, disincentives when insurance reimbursement policies fail to recognize the latest EBM guidelines, and lack of resources including personnel support for EBM implementation

(Cabana et al, 1999; Lau et al., 2016). In community clinics, lack of access to specialty care can be a barrier to making referrals (Cook et al., 2007), even when evidence-based guidelines call for them (Stewart, Townsend, Puckett, & Rim, 2016). Furthermore, poor coordination between providers in different settings is a common source of errors and lower-quality care (Institute for Healthcare Improvement, 2017; Lyratzopoulos, Vedsted, & Singh, 2015; Tomaszewski et al., 2014; Thorne, Bultz, & Baile, 2005). Delayed diagnosis based on errors in the referral process also lead to considerable human harm and cost (Institute for Healthcare Improvement, 2017).

### **Potential Solutions to the EBM Problem**

**Improvements in information accessibility.** Promising strategies to improve access to information and reduce the use of heuristics include the development of decision support systems and other information technology solutions (Clarke et al., 2013). A primary aim of the IOM report involves the creation of an efficient, technology-based system to promote rapid adoption of EBM-driven cancer treatment guidelines (IOM, 2013). Such a system would provide rapid access to guidelines and information to inform care decisions when the evidence is less well developed.

Another avenue involves strategies that recognize the role of interpersonal relationships that influence information transfer. Research shows that providers tend to rely upon peer experts for information because they are accessible and trusted (Kosteniuk, et al., 2013). While technology can provide options for information dissemination, providers faced with time constraints and challenges in filtering information may prefer to rely on consultation with peers. This is especially true of colleagues in informal networks (Eisenberg, 1979; Larson, 1997). Health care industry leaders in the U.S. acknowledge the need to invest time in the development of informal relationships in order to diffuse knowledge across groups (Berwick, 2003) and encourage the spread of innovations (Dentzer, 2014).

**Changing attitudes toward EBM.** Research shows that peer influence can impact EBM uptake in several ways. Peers who have adopted a new practice can answer questions about it, and

their own experience with practice change can reduce uncertainty about its effects (Anderson & Jay, 1985; Gagnon et al., 2012). This type of peer-to-peer communication can shape physicians' judgments of new practices (Larson, 1997), and peer relationships can influence clinical decision making when providers seek to model their behaviors after peers (Reschovsky et al., 2015, p. S558). Strategies that simultaneously recognize the importance of peer influences, as well as the need to reduce cognitive overload, may be most effective at changing attitudes or "unsticking" existing knowledge in homophilous communities of practice (Ferlie, Fitzgerald, Wood, & Hawkins, 2005, p. 131). In particular, the promotion of social networks that link generalists with oncology specialists may serve to change attitudes toward EBM if specialists are considered to be influential peers.

**Improved access to resources.** Other factors that may influence clinical decision making relate to the system in which the physician practices and patients receive care. Increasingly, clinical recommendations based on EBM guidelines necessitate that community clinic patients have access to specialty care, including referral relationships with large-volume academic medical centers (Stewart et al., 2016), as well as timely appointments for patients and shared medical records between providers (Barnett, Keating, Christakis, O'Malley, & Landon, 2012). Creating preferred networks is one way to create administrative links between providers in different settings, and development of information technology solutions is one strategy for improving communication and care coordination across multidisciplinary teams (IOM, 2013).

### **The Potential of Care Networks to Improve EBM Uptake**

Potential solutions to the EBM problem are personal, organizational, and technical in nature. They may involve IT, administrative, and financial links, as well as interpersonal ones. Affiliated cancer networks are interorganizational networks created with the goal of connecting large academic medical centers performing cancer-related research with community providers, including those in underserved communities. The aim of one of the largest cancer networks, the

National Cancer Institute Community Oncology Research Program, is to “bring cancer clinical trials (cancer control, prevention, screening, treatment, and imaging), as well as cancer care delivery research (CCDR), to individuals in their own communities, thus generating a broadly applicable evidence base that contributes to improved patient outcomes and a reduction in cancer disparities” (NCI, 2016). Benefits to the research institution may be financial, and they may include expanded recruitment to clinical research studies. In turn, community partners gain access for their patients to high-quality specialist care and research opportunities.

Research suggests that affiliated providers and networks like these may be successful in promoting evidence-based practices. Community health centers that are affiliated with a hospital or medical school (Cook et al., 2007) and centers that are affiliated with cancer research networks (Carpenter et al., 2012; Penn, Stitzenberg, Cobran, & Godley, 2014; Penn et al., 2015) have been shown to provide better access to evidence-based care than non-affiliated centers. This includes better patient access to treatments and clinical trials (Carpenter et al., 2012; Fouad et al., 2013; McAlearney, Song, & Reiter, 2012). Likewise, integrated health care systems (i.e., networks of health care organizations under a parent company) tend to promote the use of evidence-based cancer care, resulting in fewer disparities in outcomes for minority patients (Rhoads, Patel, Ma, & Schmidt, 2015).

However, the underlying process through which EBM is diffused and adopted in integrated systems or practice networks is not well understood. Similarly, the research on the impact of networks is mixed; not all studies have found significantly better EBM uptake in networks. A recent study, for example, found no increase in uptake of an evidence-based practice by cancer network members when the practice was not related to a clinical trial, potentially suggesting uptake may hinge on particular types of links between groups (Tan et al., 2015). Similarly, a study of multigene testing in an integrated health system found wide variability among providers and practice groups (Lieu et al., 2017). It is possible that interpersonal links are

more important than organizational links in diffusion of EBM in cancer care, but again these mechanisms are unexplored.

## Research Questions

Researchers and policy makers have been studying innovation diffusion—including innovation and knowledge diffusion in health care—for decades (Greenhalgh, Robert, Macfarlane, Bate, & Kyriakidou, 2004). From sociology and psychology to communication and organizational management, several disciplines have tackled the question of how to spread innovations, considering individual, organizational, and system characteristics that support or impede diffusion (Greenhalgh et al., 2004). In recent years, the field of health care implementation science has also provided insights into why new practices are or are not adopted, stressing in particular the engagement of practitioners in developing the innovation and system-level barriers and facilitators to adoption such as organizational culture (Grol & Grimshaw, 2003). Strategies to address EBM uptake or guideline adherence include educational meetings, print materials, physician incentives, and policy or regulatory approaches (Gagliardi & Alhabib, 2015). They may also focus on creating conditions for innovation diffusion and a culture of change within organizations (Berwick, 2003; Parston et al., 2015).

The development of cancer networks over the past several years is aimed at improving access to high-quality cancer care in community settings, especially through increased patient access to clinical trials (Dimond et al., 2015). However, there is little research on EBM diffusion in networks, and while some research shows a positive association between network membership and evidence-based practices (Carpenter et al., 2012; Penn et al., 2014; Penn et al., 2015), the analyses rely on network membership as an independent variable without an understanding of why membership would positively impact uptake. A recent study of guideline care in colon cancer, for example, found better adherence to guideline care and more favorable outcomes for minority patients in an integrated health system relative to other settings (Rhoads et al., 2015). The authors surmise that improved care coordination among multidisciplinary providers in an integrated system leads to higher quality care but the mechanisms underlying greater guideline



adherence and care coordination are not specified. Studies show that interpersonal communication is critical for innovation and knowledge diffusion (Greenhalgh, Robert, Bate, Macfarlane, & Kyriakidou, 2005; Rogers, 2003), but it is unknown whether cancer networks promote those types of ties.

Likewise, technology-based strategies and interorganizational arrangements such as outreach clinics and telemedicine have been used to close geographic gaps in care (Charlton, Schlichting, Chioreso, Ward, & Vikas, 2015). However, the focus has been on providing access to specialty care in community settings, rather than on the potential of technology to impact innovation diffusion or the development of relationships and shared mental models over geographically dispersed organizational structures. Further research is needed to understand how and why institutional arrangements, such as networks that link geographically dispersed groups through administrative and technological ties, might lead to high-quality and evidence-based care in community settings.

Therefore, understanding the potential of networks to improve EBM uptake in community settings requires a multilevel approach with an emphasis on interpersonal relationships and communication, as well as the context within which the organizations in the network operate. The current research investigated these issues through a case study of network ties between CRC specialists at Mayo Clinic Rochester and community providers in the Mayo Clinic Health System. The objectives of the study were to: 1) Identify factors related to whether and how the network connections functioned to increase EBM in community settings; and 2) Understand the extent to which existing theory on innovation diffusion and interpersonal relations explain provider and patient outcomes. Three research questions guided data collection and analysis.

What **types of links** does the network create between generalists and specialists, e.g., referral or advice?

When and how do network links lead to **provider outcomes** related to EBM, e.g., awareness or attitudes?

When and how do networks function to impact **patient outcomes**, e.g., specialty access, evidence-based care, or care coordination?

**Question 1: What types of links does the network create between generalists and specialists?** The aim of this question is to identify links that connect specialists and generalists involved in the care of young adult patients with CRC or those at greatest risk for developing young onset CRC. This includes identifying interpersonal and technology-facilitated links. Understanding the types of links available to or accessed by providers can help identify potential conduits for different types of communication or collaboration. It can also highlight problems and opportunities for knowledge dissemination or patient access to EBM.

**Question 2: When and how do network links lead to provider outcomes related to EBM?** The literature on networks provides several hypotheses as to why networks may result in EBM uptake by providers in community settings. These include better access to information about best-evidence care and opportunities to communicate with others and influence attitudes. The aim of the second question is to identify when and how network connections lead to these types of provider outcomes. These findings can inform understanding of how and why different types of network links might achieve provider-level change in EBM delivery.

**Question 3: When and how do networks function to impact patient outcomes?** The aim of the third question is to understand the factors that support or inhibit the potential of networks to positively impact patient outcomes, such as access to specialty care, evidence-based care, and coordinated care. Networks lead to EBM in some but not all cases. Understanding the conditions under which they are effective is critical for capitalizing on their

potential. The development and sustainability of networks also depend on financial arrangements, administrative agreements, and shared infrastructure. An understanding of these arrangements can help to identify the structure of the network and improve understanding of the way in which context supports or inhibits the potential of network connections to impact patient outcomes. Some of these factors may be associated with persistent health disparities across patients served by community clinics. They may also highlight areas for potential intervention to improve network function.

### **Significance of the Research**

We all want the best care for our family members and friends, but our current cancer care delivery system falls short in terms of consistency in the delivery of care that is patient centered, evidence based, and coordinated. We are at an inflection point in terms of repairing the cancer care delivery system. If we ignore the signs of crisis around us, we will be forced to deal with an increasingly chaotic and costly care system, with exacerbation of existing disparities in the quality of cancer care.

– IOM, 2013, p. xiv

There is little argument against the notion that improved cancer care, especially the widespread adoption of evidence-based care, is good for patients and necessary to eliminate health disparities. Patients in community clinics currently face persistent health disparities (Siegel, et al., 2016), including lower likelihood of receiving evidence-based care (Bristow et al., 2015; Fleming et al., 2014; Monson et al., 2014). Consistency in best-practice care delivery is also needed in the face of escalating costs of cancer care; the delivery of evidence-based guideline cancer care can serve to manage costs and improve the cost-effectiveness of care in community settings (Neubauer et al., 2010).

The significance of the current research study is that it provides insight into mechanisms that may potentially increase EBM uptake in community clinics to levels more commonly seen in academic medical centers, thus lessening health disparities for patients in community settings. The development of networks is one way to increase access to high-quality care and ensure better

use of evidence-based practice in community settings. However, there are mixed findings on whether organizations that belong to networks are more likely to practice EBM than organizations that do not. The reasons for positive associations have been unclear. The current study contributes a better understanding of the characteristics that underpin successful networks and establishes a foundation to implement effective interventions to improve EBM uptake.

Thus the current research study is significant because it addresses issues of health disparities within the context of critical health system pressures, most notably efforts to shift more cancer care to community settings in order to improve care coordination and reduce health care costs (Abrahams et al., 2015; ASCO, 2014; Cox et al., 2014; IOM, 2013). Providers in primary care settings have been shown to vary substantially in their competency in cancer care and their comfort in delivering care to patients with cancer (Dossett et al., 2016). If these issues are not addressed, unequal access to EBM may continue to disproportionately and negatively affect health outcomes (e.g. stage of diagnosis, mortality, and quality of life) for patients in community settings.

## **CHAPTER 2**

### **REVIEW OF LITERATURE**

#### **Introduction**

The purpose of this chapter is to review the literature on young onset CRC, EBM in cancer care, and theoretical approaches that may assist in understanding how relationships in cancer networks can improve EBM uptake in community clinics. It also presents background on the development of networks that connect research or specialist expertise with providers in community settings.

#### **The Need for Primary Care Intervention for Rising Young Onset CRC**

CRC is a cancer that begins in the colon or the rectum. It is the second most common cancer among men and the third most common among women in the U.S, with an estimated 2180 new cases of CRC in Minnesota in 2016 (Siegel et al., 2016). The lifetime risk of developing CRC is about 4.4% in men and women in the U.S., and the rates of new cases have been falling by about 3% a year for more than a decade (NCI, 2017b). CRC risks include older age, inflammatory bowel disease, a personal or family history of CRC or colon polyps, and hereditary syndromes like Lynch syndrome or familial adenomatous polyposis. Lifestyle factors like diet and exercise can also increase risk (Centers for Disease Control and Prevention [CDC], 2018).

Cancer screening is especially important in CRC because it can identify precancerous polyps for removal; early detection can result in a cancer avoided. For this reason, public policy, health education, and health system measures have focused on increasing screening rates in accordance with recommendations from the U.S. Preventive Services Task Force (shown below).

“Regular screening, beginning at age 50, is the key to preventing colorectal cancer. The U.S. Preventive Services Task Force (USPSTF) recommends screening for colorectal cancer using high-sensitivity fecal occult blood testing, sigmoidoscopy, or colonoscopy beginning at age 50 years and continuing until age 75 years.

People at higher risk of developing colorectal cancer should begin screening at a younger age, and may need to be tested more frequently. The decision to be screened after age 75 should be made on an individual basis. If you are older than 75, ask your doctor if you should be screened.”  
*CDC, 2018*

The rate of patient adherence to recommended CRC screening guidelines in the U.S. has steadily increased for more than a decade. Between 2000 and 2010, annual percentage change in adults age 50-75 who had received screening based on the most recent recommended guidelines was 4.48% (CDC, 2018).

Still, about 1 in 3 adults age 50-75 are not adherent to recommended guidelines and about 28% (23 million people in the U.S. aged 50-75) have never been tested for CRC (CDC, 2018). Rates are even lower for some groups. Compared to an overall screening of 62.9% for adults 50-75 in 2015, the rate was only 49.1% for Hispanics, 50% for those below 200% of the federal poverty level, and 46.4% for those with less than a high school education (CDC, 2018).

The MN Community Measurement 2016 Health Care Quality Report tracks patient adherence to recommended guidelines among those age 51-75 in Minnesota using administrative data from health care providers. During the latest reporting period (July 1, 2015-June 30, 2016), *72% of patients who saw a doctor* [emphasis added] were up-to-date on CRC screening (MN Community Measurement, 2017). Rates for Mayo Clinic and Mayo Clinic Health System providers in Minnesota, Wisconsin, and Iowa ranged from 55% to 84% (MN Community Measurement, 2017).

In 2014, compared with CRC screening rates for Minnesota adults who identify as white (71%), rates were lower for Asian (62%), Black or African American (56%), and American

Indian or Alaska Native adults (55%), while screening among Hispanics was lower than non-Hispanics (58% vs 70%; MN Community Measurement, 2015). Trends by preferred language and country of origin show similar patterns; adults born in Somalia had the lowest screening rate of 22%. In the Southeast region of the state, the screening rate for the Black or African American adult population is 43% and the multiracial population is 56%, compared to 73% among the white population. The greatest disparities between Hispanic and non-Hispanic adults in the state are in Southwest Minnesota, where there is a 24 percentage point difference, followed by the Southeast region, which has a 21-point disparity (MN Community Measurement, 2015).

One of the most alarming trends in CRC is in incidence among those in younger age groups (known as young onset CRC). CRC rates have been rising rapidly among those under age 50 (You et al., 2012), which is the age where it is suggested that most patients begin CRC screening. Eleven percent of colon cancers and 18% of rectal cancers are diagnosed in patients under the age of 50 (Ahn et al., 2014). The greatest increases are among those aged 20-29, where rates have been growing by more than 5% a year (Siegel et al., 2009). Those born circa 1990 have double the risk of colon cancer and quadruple the risk of rectal cancer compared to those born circa 1950 (Siegel et al., 2017, p. 1).

Reasons for these increases are unclear. Increases in CRC may be related to increases in behavioral risk factors such as obesity, but those factors are similarly present for those aged 50 and older (Ahn et al., 2014). A large share of colon and rectal cancers among younger patients are related to genetic conditions, such as Lynch syndrome and familial adenomatous polyposis, which carry 80% and 100% lifetime risks respectively (Stigliano et al., 2014). Having a strong family history is also predictive of CRC among younger adults; having a first-degree relative with CRC or advanced adenomatous polyps (especially at a younger age) can increase risk of CRC up to four-fold, and even two second-degree relatives can increase risk 2- to 3-fold (Ahn et al., 2014). It is estimated that up to 30% of colorectal cancers have a hereditary component (Deen,

Silva, Deen, & Chandrasinghe, 2016). However, while family history is important, the majority of young onset CRC cases are sporadic (Siegel et al., 2017).

Younger CRC patients also tend to have more delayed diagnoses and higher rates of advanced-stage diagnosis (Stages III and IV) than patients age 50 and older (Chen et al., 2016). Reasons for this are also unclear. Late-stage diagnoses may be related in part to tumor biology among young patients that is more aggressive (Chen et al., 2016; Rho et al., 2017). A general lack of symptoms may also keep many younger patients from seeking care (Lowery et al., 2016). You and colleagues (2012) presented three factors that may contribute to trends in young onset CRC, including “(1) a reluctance on the part of young adults to seek medical care; (2) the large percentage of young adults without insurance or ready access to care (18.3%-29.2% for adults aged 18-44 years vs 1.3%-13.6% for adults older than 45 years); and (3) an under appreciation of the increasing risk for young-onset CRC, leading clinicians to overlook or dismiss symptoms that are nonspecific but may be consistent with CRC (ie, rectal bleeding, abdominal pain or cramping, change in bowel pattern)” (p. 288). In one large study, 86% of young onset CRC patients without known genetic predisposition presented with symptoms like these (Dozois et al., 2008). There is little evidence of how often young onset CRC cases are missed, but one review found that the average delay was estimated to be 6.2 months (O’Connell et al., 2004).

There is almost no literature related to physician factors impacting delayed diagnosis of young onset CRC (O’Connell et al., 2004), but experts suggest that providers must be increasingly vigilant (Ahnen et al., 2014, You et al., 2012). Primary care providers play a pivotal role in increasing early detection of these cancers because this is where most patients—and especially younger patients—interact with the health care system. There are guidelines in place to help physicians give appropriate referral or diagnostic recommendations to patients under 50. These include guidelines that physicians speak with patients about family history of CRC by age 40, make referrals for those that meet criteria for a genetic disorder to a genetic counselor (Ahnen



et al., 2014), and screen for CRC when a patient presents with rectal bleeding, regardless of whether other symptoms are present (Astin et al., 2011). NCCN guidelines outline testing for Lynch syndrome and other genetic high-risk assessments (NCCN, 2016).

Despite the NCCN guidelines, research on primary care provider documentation suggests failures in patient-provider conversations about CRC family history (Carney et al., 2013). Knowledge of hereditary colorectal cancer genetics is also low among primary care providers compared to specialists (Wideroff et al., 2005), and only 15% of community hospital cancer programs routinely test for Lynch syndrome, compared with 71% of NCI-designated Comprehensive Cancer Centers (Beamer et al., 2012). One study found that 77% of medical records for CRC patients had sufficient family history to assess risk for Lynch syndrome, but only 3% of patients were screened for Lynch syndrome (Cross et al., 2013).

Receiving a screening recommendation from a physician and discussing family history with a physician are both positively associated with increased rates of CRC screening among patients with familial risk factors for CRC (Lowery et al., 2016; Ait Ouakrim et al., 2013). Even though young onset CRC is more often diagnosed at a late stage, disease-specific survival is longer for these patients than older patients, likely because of more aggressive treatment (Abdelsattar et al., 2016). Providers who talk with patients about the risks for CRC at younger ages can counsel them about what symptoms to watch for and raise awareness that CRC is possible at young ages (Ahnen et al., 2014). Improvements in provider knowledge of guidelines and CRC risk and development of better systems for documenting family history in electronic health records may also help turn the tide on rising CRC rates among younger patients (Lowery et al., 2016). It is important to note that “although cancer screening is a required reporting metric in primary care, risk-appropriate screening based on familial risk is not” (Lowery et al., 2016, p. 2641). Guideline adherence to screening starting at age 50 has made a significant difference in CRC rates for those age groups. Absent consensus on reducing age requirements for population

screening, better vigilance at the primary care level may be the best strategy (Ahnen et al., 2014; Deen et al., 2016), including aggressively following patients who present with symptoms (Dozois et al., 2008) and timely referrals for diagnosis, genetic testing, and treatment as needed, as CRC outcomes continue to be better when CRC patients are treated at high-volume facilities (Rogers et al., 2006). This may be especially true for young onset CRC, which is less common and has a unique disease etiology and biology (Rho et al., 2017).

### **Connecting Community Settings to the Research Community**

There are several types of interorganizational arrangements that aim to connect community providers with academic medical centers or research institutions. Practice-based research networks (PBRNs) are partnerships of primary care practices “affiliated in their mission to investigate questions related to community-based practice and to improve the quality of primary care” (AHRQ, 2017). First established in the U.S. in the 1970s, today there are more than 100 PBRNs, almost all of them involving an academic partner (Green & Hickner, 2006). Several are located within NIH Clinical and Translational Science Award (CTSA) sites, leveraging the potential of PBRNs to engage community-level participation in research and of CTSA sites to provide research infrastructure (Davis, Keller, DeVoe, & Cohen, 2012; Fagnan, Davis, Deyo, Werner, & Stange, 2010). Many of these institutions are academic health centers. Academic health centers (AHCs) are organizations that play three roles: education (e.g., a medical school), research, and clinical service (Betancourt & Maina, 2004; IOM, 2004). They also hold missions to care for the poor and underserved, and as such they may be well situated to reduce health disparities by implementing evidence-based guidelines for all patients (Betancourt & Maina, 2004).

PBRNs originally focused on studies of single practice-based issues, but increasingly they are morphing into larger networks of multiple PBRNs—sometimes connected by a common electronic health record—and expanding their purview to more complex studies with a diverse group of health care providers (Davis et al., 2012). The National Cancer Institute Community

Oncology Research Program (NCORP), like its predecessor, the Community Clinical Oncology Program (CCOP), is a cancer-focused PBRN consisting of research bases and community sites. Research bases are organizational hubs (consisting in some cases of multiple institutions) that design and conduct clinical trials, while community sites include hospitals and clinics in urban and rural areas of the U.S. (NCORP, 2017). While NCORP's primary outcome of interest has traditionally been clinical trial enrollment in the community setting, it also develops research around cancer care delivery and cancer disparities (McCaskill-Stevens et al., 2013). According to NCORP, the structure of community-based research is aimed at EBM: "Engaging community oncologists in collaborative research can also facilitate the uptake of effective, evidence-based practices into routine care" (NCORP, 2017). Most cancer network-related EBM research to date has involved providers affiliated with NCORP or CCOP (Carpenter et al., 2012; Penn et al., 2014; Penn et al., 2015; Tan et al., 2015).

The role of AHCs may be critical in networks. The IOM (2004) recognized the growing importance in high-quality cancer care, and it suggested AHCs have three roles to play in the coming years. As educators, the IOM recommends that AHCs look for innovations in clinical, team-based education, including education in clinical informatics. The ability to use information technology to identify the evidence base and to communicate evidence to patients is a critical role for medical education. As care providers, the IOM suggests that AHCs should stress the role of processes; "AHCs should work across disciplines and, where appropriate, across settings of care in their communities to develop organizational structures and team approaches designed to improve health" (IOM, 2004, p. 10). The third role of AHCs—that of research—should expand into translational science, according to the IOM: "AHCs need to participate in developing solutions to society's most pressing health problems not only by creating knowledge, but also by developing more systematic approaches for using research to encourage evidence-based patterns of practice, in order to improve health for both patients and populations" (IOM, 2004, p. 81).

These three roles have been conceptualized as a learning health care system (Grumbach, Lucey, & Johnston, 2014), as described by the IOM (2013), with potential for AHCs to develop and scale up innovations. Specialty e-consultations and “novel care coordination approaches” are two strategies for achieving this diffusion (Grumbach et al., 2014). E-consultations in particular can open up timely and convenient access for patients needing specialty care (Vimalananda et al., 2015). However, availability of e-consultations does not ensure adoption of the technology. Uptake has been shown to vary based on factors described in diffusion of innovations theory, such as perceptions of benefit, compatibility, modifiability, trialability, and the presence of innovation champions, as well as contextual factors like administrative mandates (Afable et al., 2018).

Expansive NCORP networks have been shown to increase EBM uptake, especially when the practice is related to a clinical trial (Carpenter et al., 2012; Penn et al., 2015). However, local area networks—including those affiliated with AHCs—may provide unique mechanisms for EBM uptake. In recent years, AHCs have expanded their reach by acquiring community providers or creating relationships with community clinics and hospitals. This creates unique access to research and clinical expertise at the community level, and it does so with organizations that may be relatively close in terms of geographic proximity and access to common technology.

Mayo Clinic is one of the largest academic medical centers in the world, employing 3,300 physicians, scientists and researchers with major campuses in Rochester, Minn., Scottsdale and Phoenix, Ariz., and Jacksonville, Fla. Mayo Clinic is the hub of the Mayo Clinic Health System (MCHS), a network of clinics and hospitals in more than 60 locations across southern Minnesota, western Wisconsin, and northern Iowa. In 2017-2018, Mayo Clinic in Minnesota was ranked as the best hospital and its Gastroenterology and GI Surgery specialty was ranked No. 1 in the nation by U.S. News & World Report (Comarow, 2017).

Mayo Clinic has five NCI Specialized Programs of Research Excellence in specific cancers, 10 major cancer research programs, and more than 350 physicians and scientists affiliated with cancer research. It serves more than 120,000 cancer patients a year, and more than 3,000 colon cancer patients, making it a high-volume colon cancer practice. The Mayo Clinic Cancer Center is one of only 47 NCI-designated national comprehensive cancer centers in the U.S., which are institutions recognized for depth of leadership in basic, clinical, population, and transdisciplinary research (NCI, 2017a). The Mayo Clinic Cancer Center serves as a lead organization in the NCI National Clinical Trials Network, the NCI Experimental Therapeutics Clinical Trials Network, the Cancer Prevention Network, and other national consortiums and collaborative groups that are leading cancer clinical trial and cancer prevention research in the U.S. Mayo Clinic physicians and scientists also participate in guideline-authoring groups including ASCO and NCCN.

A goal of the MCHS is to expand access to Mayo Clinic expertise by making Mayo Clinic expert consultation available to community providers, staffing specialist outreach and telemedicine services in areas of the region, and promoting “seamless connections” to Mayo Clinic Rochester when needed (Mayo Clinic, 2018). MCHS providers also have remote access to e-tumor boards, which are video-assisted, multidisciplinary discussions of complex patient cases, and e-consultations (eConsults), which are electronic orders for specialist advice regarding a patient’s care or condition. The network seeks to provide world-class care closer to home. The MCHS website emphasizes the advantages of close connections with local care providers, combined with links to the world's leading medical experts.

MCHS primary care providers are charged with helping patients prevent and detect cancers early. Fifteen MCHS locations also offer local providers who specialize in the diagnosis and treatment of cancer. Community multidisciplinary teams include oncologists, radiation therapists, nurses, dietitians, and others who care for cancer patients and survivors. The Division

of Community Oncology oversees practices in the MCHS, and the Mayo Clinic Cancer Center oversees cancer care, education, and research across the three major Mayo Clinic campuses and the MCHS sites. The Office of Mayo Clinic Health System Research was established in 2016 with the goal of advancing research in the community practices.

## **Professional Coordination across Time and Space**

Care coordination is an especially critical concern in the domain of cancer care. The term “cancer continuum” is used to describe the multiple phases: prevention and risk reduction, screening, diagnosis, treatment, survivorship, and end-of-life care. The need to coordinate care across the various health care providers who might be involved concurrently during phases and at hand-offs between phases is immense, creating the potential for gaps.

Many of the issues in care coordination arise because of flaws in the interfaces between different parts of the process of care—parts often falling under the responsibility of different providers, sometimes in different settings (Taplin, Clauser, Ridgers, Breslau, & Rayson, 2010; Taplin & Rogers, 2010). “During the acute treatment phases (e.g., surgery or chemotherapies) and the chronic care phase (e.g., maintenance therapies or surveillance for patients in remission or with progression-free disease) multiple clinicians and primary care providers in different settings may need to coordinate care for cancer and other comorbid health conditions over the course of several years (IOM, 2013). Who is responsible for each step in care and how necessary information is communicated among providers and between providers is a concern at each phase of care” (Taplin et al., 2010, p. 106). The National Cancer Policy Board (2006) issued *From cancer patient to cancer survivor: Lost in transition* as a call to action for better care in the stage following active treatment.

Poor cancer care coordination can result in late diagnoses or treatment delays if referrals are missed or follow-up is mishandled (Lyratzopoulos et al., 2015; Tomaszewski et al., 2014). In addition to substandard care, failures in care coordination can also lead to additional costs related to substandard treatment, overtreatment, or surgeries or treatments where the risks are not appropriate for a particular patient’s condition (Thorne et al., 2005). Patients making important decisions about the best course of care may also face decision conflict if providers’ advice is incongruent, and this can leave patients feeling frustrated or confused and generate unnecessary

psychological distress (Thorne, et al., 2005). “Because cancer care is complex, requires frequent patient visits for treatment and monitoring, and involves providers from many disciplines, geographic access to care may be even more challenging for patients with cancer than for other rurally located patients” (ASCO, 2016, p. 25). It may also be of particular concern for older patients, who have seen widening age-related cancer disparities in almost all types of cancer over the last 20 years (Zeng et al., 2015). “Age is one of the strongest risk factors for cancer, and there are many important considerations to understanding the prognoses of older adults with cancer and formulating their care plans, such as altered physiology, functional and cognitive impairment, multiple coexisting morbidities, increased side effects of treatment, distinct goals of care, and the increased need for social support” (IOM, 2013, p. 3).

A systematic review of interventions found that cancer care coordination resulted in improvements among 81% of outcomes measured, including cancer detection, health care utilization, and treatment-related outcomes (Gorin et al., 2017). Current efforts to improve care coordination, reduce errors, and control costs related to fragmented care include the development of team-based care and patient-centered medical homes (Abrahams et al., 2015; ASCO, 2014; Cox et al., 2014; IOM, 2013). The aim of oncology medical homes is to put responsibility for care coordination on one team, which in turns serves as a single front door for patients with cancer and manages communication and treatment planning among primary care physicians, oncologists, surgeons, pharmacists, radiologists, and others involved in a cancer patient’s care. Consistent protocols for delivering evidence-based care and the ability to share information electronically are cited as facilitating medical home and shared care arrangements (Abrahams et al., 2015; ASCO, 2014; Waters et al., 2015). Similarly, multidisciplinary, team-based care is seen as a critical strategy for increasing the quality of cancer care delivery (Kosty, Hanley, Chollete, Bruinooge, & Taplin, 2016). Multidisciplinary oncology teams result in better treatment planning,



improved guideline adherence, and improved follow-up in some cases, but the reasons that teams achieve these outcomes is less clear (Taplin et al., 2015).

Getting providers to cooperate across the cancer continuum is difficult. Crosscutting problems, as described by Taplin and colleagues (2010, p. 106), include knowledge break downs, limitations around current electronic health records, limited information exchange on next steps or management of comorbid conditions, professional norms, and organizational structures. Some of these problems, including professional norms, may undercut collaborative efforts between generalists and specialists. A systematic review and meta-synthesis of primary care provider (PCP) and cancer specialist relationships found that PCPs favor a shared care model—where both providers are actively involved—while specialists largely prefer a model in which care during the treatment phase (broadly defined as diagnosis to five years post-treatment) is under the purview of the specialist (Dossett et al., 2016). Some generalists want to be more involved and informed during active treatment and the surveillance period following it, but there is concern that generalists in the primary care setting do not have sufficient knowledge or training to provide cancer care (Dossett et al., 2016; Jiwa, McManus, & Dadich, 2013; Lawrence et al., 2016). Primary care providers may be reluctant to answer patient questions related to cancer care and they may feel that they lack information about current protocols (Dossett et al., 2016). Even generalists with cancer-related training may feel like an underutilized member of a disconnected care team (Lizama et al., 2015).

Specialists may be even less likely than generalists to think that cancer care competencies are adequate in the primary care setting. One study showed that “A majority (59%) of PCPs but only 23% of oncologists strongly or somewhat agreed that PCPs have the necessary skills to provide follow-up care related to the effects of breast cancer or its treatment. Similarly, 75% of PCPs, but only 38% of oncologists, agreed that PCPs have the skills necessary to initiate appropriate screening or diagnostic work-up to detect recurrent breast cancer” (Potosky et al.,

2011, p. 1406). The current drive to increase the capacity to use primary care clinicians in oncology care coordination necessitate changing these attitudes (Potosky et al., 2011).

There is also a paucity of research related to the interface of oncologists in community settings, who treat a broad range of common cancers, and specialists in research settings, who have specialized knowledge of specific types of cancers and may be most knowledgeable about EBM and emerging science related to those cancers. Increasing EBM in community clinics requires a better picture of all of the health care providers included in the continuum of care, including providers in different settings.

## **Theoretical Perspectives on EBM in Community Cancer Care**

The hypothesis that EBM uptake in community clinics increases when personal relationships among providers in cancer networks are strengthened requires a theoretical perspective related to the manner in which new information moves across people, as well as how people make sense of it. Underlying constructs may include interpersonal communication, relationship building, and reciprocal influence or shared meaning.

### **Diffusion of Innovations and the Strength of Weak Ties**

Researchers in fields from anthropology to information technology have used diffusion theories to explain the spread of innovations—such as new technologies, practices, and public policies—from their initial development to widespread adoption. Rural sociology in particular and the work of Everett M. Rogers have advanced research on the phases of innovation adoption and the role of personal communication networks in determining the rate of adoption. In his seminal work in the 1960s, Rogers created and operationalized a new diffusion paradigm and published *The Diffusion of Innovations*, now in its fifth edition. Rogers' paradigm, which is based on the importance of interpersonal communication networks for innovation diffusion, originally drew heavily on studies of hybrid seed corn diffusion among Iowa farmers (Valente & Rogers, 1995). Since that time the paradigm has been used to provide insight into how medical innovations can spread between colleagues or peers, as well as how they might move from one professional group to another (Becker, 1970; Mascia, Cicchetti, & Damiani, 2013; Tasselli, 2015).

Interpersonal communication networks are central to several of the stages of innovation diffusion in Rogers' paradigm because innovation diffusion is largely understood to be a social process (Rogers, 2003). The diffusion paradigm offers the potential to address several barriers to EBM adoption, including lack of information access and negative attitudes related to EBM guidelines or their adoption.

**Networks as bridges to access new information.** Innovations by definition are new. Close colleagues and peers tend to be similar (homophilous on characteristics or in knowledge or experience) and thus possess redundant information. Therefore, gaining access to new information typically involves links to outsiders (heterophilous individuals who differ with regard to a key characteristics or knowledge; Rogers, 2003, p. 306). In the case of young onset CRC, physicians may be less familiar with the nuances of screening recommendations for patients under 50 (including knowledge of genetic or familial risk factors) than they are the U.S. Preventive Services Task Force recommendations for adults 50 and older.

“Strength of weak ties” theory, developed by sociologist Mark S. Granovetter, explains that weak ties (i.e., connections to people who are known but not a close peer) connect groups that might otherwise not interact, thus creating opportunities to access novel information (Granovetter, 1973). Outside sources are “most frequently consulted because they possess qualification credibility” (Rogers & Bhowmik, 1970, p. 534), where qualification means being experienced, trained, or informed (Berlo, Lemert, & Mertz, 1969). “It follows, then, that individuals with few weak ties will be deprived of information from distant parts of the social system and will be confined to the provincial news and views of their close friends” (Granovetter, 1983, p. 202).

However, creating connections for knowledge diffusion from one group to another (e.g., from a specialist group in an academic research setting to a generalist group in a community setting) can be difficult. Heterophilous groups may have little reason to connect, and because they have few things in common, communication may be more difficult. Furthermore, not all ties between groups act as information bridges (Granovetter, 1983), so even organizational or administrative ties between groups may not in and of themselves create opportunities for diffusion between individuals. Therefore the challenge is creating well-functioning communication between heterophilous groups. Cancer networks involve administrative

connections, but communication networks may be more reliant on other types of interpersonal connections. In fact, diffusion theory suggests that interpersonal ties may actually be more effective than organizational ones at spreading information.

A recent study of physician advice networks found that professional homophily (i.e., field of specialty), institutional homophily, and geographic proximity were all related to formation of advice networks (Mascia, Di Vincenzo, Iacopino, Fantini, & Cicchetti, 2015). While professional homophily had a stronger effect than organizational homophily, the authors suggest that new institutional arrangements that connect physicians in interdisciplinary groups may begin to blur the boundaries of professions and organizations. “The impact of such internal redesign on physicians’ identification and perception of homophily may eventually overshadow their traditional perception about homophilous colleagues (i.e., individuals holding the same clinical specialty)” (Mascia et al., 2015, p. 7).

**The potential of networks to influence attitudes.** Innovation diffusion is not limited to the simple transfer of knowledge; it also involves persuasion and ultimately an adoption decision (Rogers, 2003). According to Rogers (2003), adoption is based on the innovation’s “compatibility with the values, beliefs, and past experiences of individuals in the social system” (p. 4), and social connections have the potential to change attitudes and build consensus between parties (Rogers, 2003, p. 306; Rogers & Bhowmik, 1970). On-going communication between generalists and specialists who share patient care may help generalists make judgments about EBM, fostering more homophilous attitudes over time and reducing dissonance related to beliefs or understandings. This type of personal persuasion may be especially important when the innovation is ideological rather than material (Rogers, 2003). In the context of EBM diffusion, newly-developed best practices may compete with a long history of personal practice and strongly-held beliefs about what is best for patients. Without outside connections, generalists may

fall back on heuristics such as confirmation bias, using views of homophilous colleagues to support their existing ideas of best practice care.

Where weak ties connect people in different groups, diffusion theory also suggests a role for innovators among their peer groups. Innovators who venture outside their system to discover new knowledge, along with some peers who adopt the innovation soon after they learn about it, are labeled “early adopters.” Those who reject the innovation or take additional time to consider its merits before adopting it are labeled “late adopters” or “non-adopters.” Communication between potential innovation users and peers who are already adopters can be seen as a means of reducing the uncertainty that exists with something new—something that may be portrayed as better than the current practice but for which such a claim is less than completely known—as well as a means of creating mutual understanding about it. Near-peer networks can convey trusted evaluative information about personal experiences, and these experiences can influence attitudes among potential adopters. In the Columbia University Drug Diffusion Study, scientific reports of the effectiveness of tetracycline “were not sufficient to persuade the average doctor to adopt. Subjective evaluations of the new drug based on the personal experiences of each doctor’s peers were key in convincing the typical doctor to adopt the drug with his/her own patient” (case study as reported in Rogers, 2003). In the realm of EBM diffusion, the generalist who is connected to the specialist with knowledge of EBM can also serve as a local expert to his or her generalist peers.

This idea is consistent with Rogers’ conceptualization of the timing of innovation adoption (2003), whereby later adopters are more cautious and wait to adopt until the early adopters can demonstrate success. Rogers (2003) stressed that it may not be accurate to label later adopters as resistant or irrational (p. 121); in general they are less likely to have access to or value outside information sources. In the case of EBM, scientific review may indicate that the practice should be implemented, but some providers will not act as soon as the guideline is available

because it is disruptive to change practices, or they may eschew the results of emerging science (including strong evidence of best practices) while awaiting the judgment of trusted peers.

To speed diffusion and reduce variability in utilization of innovations, Anderson and Jay (1985) suggest identifying influential individuals and intermediaries in the network, as well as people on the periphery, and encouraging them to participate in external educational opportunities that expose them to new innovations. When they have adopted an innovation, they can provide information to others in their network. Opinion leaders are typically effective at communicating with peers because they are homophilous with them on almost all variables *except* “technical competence about the innovations promoted” (Rogers & Bhowmik, 1970, p. 531). Beamer and colleagues (2012) hypothesized that their study results showing better adoption of CRC genetic tumor testing in NCI-designated Comprehensive Cancer Centers than community hospital cancer programs might be explained by diffusion of innovations theory. They posit that the university might be an opinion leader that persuades peers to adopt by allowing “middle and late adopters of an innovation the opportunity to view benefits, risks, and costs of the innovation before implementation in their own programs” (p. 1062). They also note a “need for education regarding [tumor] testing among health care professionals who provide care to patients with CRCs so that these professionals may serve as local champions to promote the practice” (Beamer et al., 2012, p. 1062).

Rogers (2003) noted that diffusion theory tends to suffer from individual blame bias (i.e., individuals who are slow to adopt are blamed for not adopting quickly) and pro-innovation bias (i.e., assuming all innovations should be adopted). He suggests that organizational-level analyses and better attention to context and reasons for delayed adoption can offset these biases. Research on cancer networks may offer an opportunity for in-depth study of individuals, relationships, and organizations as units of analysis, potentially reducing these biases.

## **Relationship-centered Care**

We yearn for frictionless, technological solutions. But people talking to people is still the way norms and standards change.

–Gawande, 2013

Technology is an efficient avenue for storing, collating, filtering, and providing information to busy health care providers, and it has the potential to standardize and improve patient care. The Health Information Technology for Economic and Clinical Health Act of 2009 set aside \$27 million dollars for technology efforts including encouraging institutions to adopt electronic health records (EHRs), and widespread adoption of EHRs could potentially save the system more than \$80 billion through increased efficiency and safety (Hillestad et al., 2005).

Even the IOM (2013) has suggested that successes in the aviation industry, where “data have transformed the task of piloting an aircraft from one of eye-hand coordination and physical manipulation of controls into a task of selecting a destination, choosing an appropriate route, entering that plan into the systems that control the aircraft’s vertical and lateral movement, and then monitoring whether the flight is proceeding according to the plan” (p. 246), can be replicated in cancer care if adequate information technology infrastructure is in place. It also contends that technology can help improve coordination among diverse members of cancer patients’ care teams by improving information sharing. Still, EHR adoption on its own has shown mixed results on quality of care and utilization of practice guidelines in cancer care (Cole et al., 2015; Kern, Edwards, Pichardo, & Kaushal, 2015; Maroongroge, Dosoretz, Khullar, & Yu, 2014; Sprandio, Flounders, Lowry, & Tofani, 2013).

Diffusion theories claim that changing beliefs and norms to establish new, guideline-based care requires interpersonal communication. As such, they can help us understand failures in EBM diffusion, even as health information technology dispersion is at an all-time high. However, diffusion theory does not go far in explaining what conditions foster interpersonal communication between two individuals. A relationship-focused theory or framework is needed to help



researchers understand the quality or types of relationships that result in communication, trust, and influence. The care coordination relationship in particular requires a better understanding of whether connections in cancer networks move beyond administrative liaisons to foster relationships that lead to information access and persuasion. Gorin et al. (2017) found that only 3 of 52 articles in their systematic review of cancer care coordination employed theory, and they called for additional study using theoretical frameworks aimed at both patient, family, provider, and organizational factors.

**Relationships as a means to promote effective multidisciplinary teamwork.** In 1994, the Pew-Fetzer Task Force on Advancing Psychosocial Health Education put forth a model of care termed relationship-centered care (RCC) and called attention to the need for medical education to explicitly teach students how to develop effective relationships. According to the report, “The phrase relationship-centered care captures the importance of the interaction among people as the foundation of any therapeutic or healing activity” (Tresolini & The Pew-Fetzer Task Force, 1994, p. 11). *Patient-centered care* is defined as care that is “respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” (IOM, 2001, p. 40). In parsing out the difference between RCC and patient-centered care, Suchman (2011) described RCC as shifting the focus from the purpose of health care to the process of health care, calling attention to communication and relational aspects critical to any collaboration (p.37).

The Pew-Fetzer report highlighted the importance of patient-provider relationships, which are highly valued by patients and providers alike, but it also noted that the complexity of illness requires effective working relationships among multidisciplinary providers. RCC asserts that clinician-clinician relationships “require teamwork, shared values, learning from and making use of the expertise of others, helping others learn and develop, integrating services at individual and systems levels, and setting aside issues of specialism, hierarchy, and privilege” (Tresolini &

The Pew-Fetzer Task Force, 1994, p.27). Much of the RCC literature centers on medical education curriculum because it contends that coordinated care will be elusive unless health care providers acquire relationship building skills. In order to improve practitioner-practitioner relationship building, medical education should focus on self-awareness, knowledge of other professions, perspectives on team-building and group dynamics, effective communication, and trust, openness, and humility (Tesolini & The Pew-Fetzer Task Force, 1994).

Hierarchical relationships between specialists in academic medical centers and generalists in community clinics can create barriers, and cancer care coordination is plagued by fragmented care and poor communication. Strategies to improve care coordination and foster multidisciplinary communication must attend to relationships between clinicians, so that each feels that the other is a trusted source of knowledge and expertise about his or her given domain. The specialist has vast expertise in oncology care and science, but the generalist is the expert in treating overall patient health and well-being.

**Relationships as a means to influence and understanding.** The RCC focus on reflective practice may also lend itself to understanding how providers come to adopt new practices. Suchman (2006) extended the study of RCC by looking at the “self-organizing patterns of meaning and relating” that occur when two individuals interact. Understanding how professionals create trusted interprofessional relationships through small, repeated interactions, as well as how they reflect on their own practice, is central to the study of EBM knowledge diffusion and uptake. The clinician-clinician relationship may be especially important in the study of EBM diffusion between generalists and specialists because strong relationships underpin reciprocal communication and trust, which in turn foster diffusion. An example would be a specialist whose research activities gain greater appreciation for the needs of generalists and their patients. This would be a novel application of the RCC framework.

**The role of relationship-centered organizations.** Organizational norms can aid or inhibit EBM diffusion, as well as relationship building, and there is growing interest in organizational and administrative perspectives on RCC. Well-functioning teams have been shown to result in improved patient safety and organizational performance (Suchman, 2011), and some argue that the most important lessons learned from the aviation industry are lessons about the importance of high functioning teams, rather than lessons about the role of technology (Soklaridis, Ravitz, Adler Nevo, & Lieff, 2016).

A new model of relationship-centered organizations (Safran, Miller, & Beckman, 2006) proposes organizational qualities that support relationships, including several of the relational qualities relevant to the multidisciplinary interactions of generalists and specialists: diversity of mental models (capitalizing on different perspectives), trust that others are capable and committed, the use of a mix of rich and lean communication, and opportunities for both social and task-related interactions. In these types of organizations, clinical action (i.e., the work of a medical practice) is supplemented with ample time for reflection. “This is a time when teams can identify and solve problems, share knowledge, and fortify relationships” (Safran et al., 2006, p. S13). This model could help us understand how organizations can support interactions between colleagues that subsequently foster relationship building. An RCC organizational perspective may counteract conflicts that arise when existing hierarchies are upset or professional identities are threatened (Soklaridis et al., 2016). It may also address the individual blame bias of diffusion theory. It provides a framework for understanding the relationships that may emerge from connections in networks—the types of relationships that can foster not only communication but trust and influence. However, this model focuses on geographically proximal individuals who share an organizational culture. Further research is needed to understand how the RCC framework can be applied to interdisciplinary teams across settings, as in an affiliated cancer network.

## **Distributed Cognition and Shared Mental Models**

Where theories of innovation diffusion aim to explain the spread of knowledge, and RCC seeks to understand how individuals can enter the type of relationships that foster partnerships and information sharing, the theoretical framework known as distributed cognition (DCog) is positioned to explain the shared understanding that emerges when individuals collaborate. DCog extends diffusion theory's explanation of innovation persuasion and adoption by providing a theoretical framework for the creation of shared meaning. It also complements the RCC focus on reciprocal influence and competing professional hierarchies by providing a framework for the study of shared meaning making in care coordination.

**Appreciating expertise and shared aims in coordination relationships.** The division of cognitive labor is a core construct of DCog (Sellberg & Lindblom, 2014). DCog assumes knowledge crosses individual boundaries. Heterogeneous groups of individuals with varying but overlapping expertise “are more effective and innovative than groups with homogeneous expertise,” but along with individual expertise there must be “enough common ground to establish mutual understanding” (Palonen, Hakkarainen, Talvitie, & Lehtinen, 2004, p. 273). Within the subject of generalist-specialist care coordination, DCog is a useful theoretical framework for understanding the manner in which generalists and specialists maintain their expert positions (primary care of multimorbid conditions versus specific oncologic expertise) while developing shared understanding of the best care for the patient.

DCog could also frame the study of how shared meaning can counter weaknesses in individual decision making. Hutchins (1995) suggests that failures in cognitive processing, such as confirmation bias, which leads one to reaffirm what they know and discount new evidence, happen at the level of individual cognition. Shared understanding can offset these biased interpretations if members in the network hold different interpretations or have access to different evidence (Hutchins, 1995). Leaving open channels for new information from different

environments may be conducive to the development of shared understanding between different subgroups, as argued by the potential of weak ties to counteract sticky knowledge in homophilous groups. Therefore, networks that foster shared cognition may be most effective when they cross professional boundaries. DCog was used in this study to understand the conditions under which shared understanding is possible between professionally and geographically heterophilous network subgroups. These included specialists in different geographic settings, as well as providers with varying expertise in the same setting (e.g., in the academic medical center or in the community setting).

**Relationships that lead to shared meaning making.** Traditional views of decision making from the field of psychology suggest that cognition is isolated at the individual level, such that the process of two individuals working together to solve a problem is simply understood to be the sum of their individual cognition. In contrast, the DCog framework suggests that shared cognitive and affective schemas develop through repeated interactions and conversation. This group process can lead to information sharing, and once shared models are established, communication and decision making may become more cohesive (Roloff & Van Swol, 2007). Epstein (2013) described this as “shared mind” decision making and said that “the result of team communication should be not just that all opinions and views are voiced and heard, but also that new ideas and perspectives should emerge from within-team interactions that would not have necessarily resulted from the independent contemplation of the situation by any one individual” (p. 202). In the case of EBM diffusion and care coordination relationships, patients, generalists, and specialists each have specialized knowledge, whether it is related to oncology care, treatment of comorbidities, or patient values and preferences. The question is whether these parties build a shared understanding of the treatment options best suited for individual patients through repeated interactions.

There is an existing body of literature on shared cognition between clinicians and their patients, but the potential to understand shared cognition among generalists and specialists is still emerging. Some of the most recent work has been done as part of the NCI-ASCO Teams in Cancer Care Project, which was focused on “using team science to improve delivery of care to patients with cancer” (Kosty et al., 2016, p. 956). According to principles of team science, “Having a shared understanding of team objectives, roles, expertise, and the operating situation allows teams to preemptively avoid potential missteps and failures” (Salas, Shuffler, Thayer, Bedwell, & Lazzara, 2015, p. 609). In the oncology teams project, shared mental models were found to be necessary for creating common understanding of patient goals and avoiding failures in patient-centered care when multiple providers or teams were involved, including delays in treatment (D’Ambruso et al., 2016; Gerber et al., 2016; Noyes et al., 2016; Page, Lederman, Kelly, Barry, & James, 2016). However, development of shared mental models requires interaction, trust, and open communication. This is complicated when teams are assembled quickly for patient care or team members are dispersed across settings (Lazzara et al., 2016; Noyes et al., 2016; Page et al., 2016).

Understanding cognitive processes underlying EBM uptake is critical because it necessitates that clinicians come to see EBM as better than their existing knowledge or practice. In the case of EBM diffusion and care coordination relationships, generalists and specialists may build a shared understanding of the best evidence treatment options, as well as the treatments that best match individual patient needs, values and preferences over time. This values the expertise of both parties while building shared understanding through communication and negotiation. Interdisciplinary learning has been shown to emerge from “back and forth” engagement and self-reflection, with “the possibility for mutual expansion of understanding when team members deepen their dialogue” (Kane, 2016). Communication in this context is an interpersonal

transformational process rather than a transactional knowledge exchange (Manojlovich, Squires, Davies, & Graham, 2015).

### **Limitations of Existing EBM Diffusion Research**

The IOM, in 2013, signaled a call to action to ensure that all cancer patients receive care “that is patient centered, evidence based, and coordinated.” However, health care providers in community settings face many challenges related to the delivery of high-quality care, including difficulties in accessing and utilizing evidence-based guidelines. Likewise, there are barriers to coordinating care among the multidisciplinary providers involved in care across the cancer continuum (i.e., detection, diagnosis, treatment, surveillance, survivorship, and end-of-life). These challenges are compounded by growing demands on physician time and increasing complexity of cancer care.

Networks that create connections between generalists in community clinics and specialists in academic medical centers have potential to increase access to evidence-based practice and improve high-quality, coordinated care in community settings. However, existing research on the effectiveness of networks in increasing the use of evidence-based care is mixed, and it does not address reasons that some networks result in increased EBM uptake while others do not. Research is needed to elucidate the *types* of connections that could help networks address the major barriers to EBM uptake: providing generalists with access to knowledge regarding the best EBM practices; and persuading generalists to adopt EBM by developing relationships that can influence clinical decision making in otherwise homophilous groups. It is also necessary to generate understanding of cancer networks’ potential role in synchronizing the goals, actions, and objectives of patients and teams of multidisciplinary providers. Patients should not be faced with different information and recommendations related to EBM as they move through multidisciplinary systems. Furthermore, existing research does not address the effectiveness of networks in developing information technology solutions, including the impact information technology may have on communication, relationship building, and shared mental models across geographically dispersed settings. Finally, existing research falls short in its focus on individual-



level knowledge diffusion and adoption. Addressing disparities in care requires an understanding of both the personal and organizational barriers to diffusion. Research on cancer networks may offer an opportunity for in-depth study of individuals, relationships, and organizations as units of analysis, potentially reducing individual blame biases in EBM diffusion.

Research can also advance existing knowledge about EBM diffusion by combining diffusion of innovations and strength of weak ties theories—which have been employed in health care-related studies—with theoretical frameworks focused on relationships and shared meaning making. Without these frameworks, researchers are left with information about the association between network links and EBM uptake without an understanding of the underlying mechanisms (e.g., trust) that foster information access and changes in attitudes toward EBM. The application of the three theoretical frameworks outlined here to the study of geographically dispersed providers in cancer networks is novel in the EBM literature. Given increasing attention to the idea of oncology medical homes and using primary care settings to manage overall patient health and wellbeing, this research may inform investments in cancer networks and other efforts to build multidisciplinary teams across settings.

## **CHAPTER 3**

### **RESEARCH DESIGN AND METHODOLOGY**

The research questions outlined in Chapter 1 were addressed using a mixed methods case study approach. This chapter outlines the overall research design, the methodologies and methods employed, and the data collection and analysis strategies.

#### **Research Design**

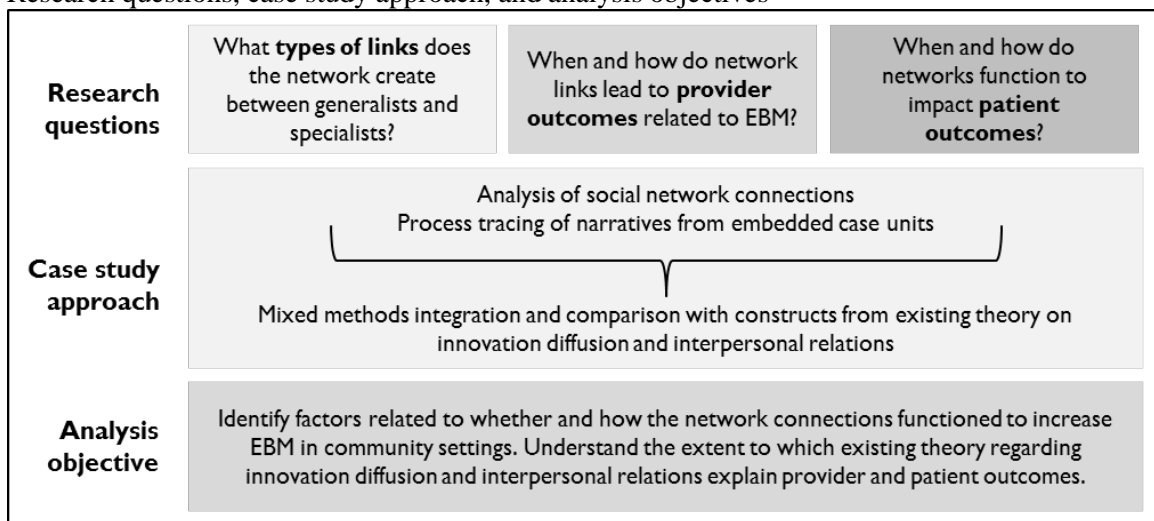
This study aimed to understand a complex, multilevel phenomenon: the flow of information in networks and the potential for relationships to improve quality of care in community settings. Case studies typically address “how” or “why” questions in real-life context (Bourgeault, Dingwall, & De Vries, 2010), often employing theory in iterative explanation building (Yin, 2014). They are especially useful when the lines between what is being studied and its context are blurred (Yin, 2014). This blurring is consistent with an investigation of EBM diffusion as it relates to the formal or informal connections in an integrated network.

This study employed methods of social network analysis, as well as process tracing of embedded case units and comparative analysis across case units. Social network analysis identified connections between individuals in the network. Process tracing was adopted for the purpose of understanding how the network operated within individual patient case units and the impact it had on provider and patient outcomes. Process tracing is a case study method that follows complex causal pathways of historical case narratives, including the analysis of variation in cases of equifinality (i.e., when different bundles of mechanisms and pathways may have similar outcomes; George & Bennett, 2005, p. 161). The theoretical perspectives outlined in Chapter 2 provided guidance for the framework used in process tracing. This framework outlined expected causal pathways as hypothesized in the literature, including pathways explained by these theoretical perspectives.

Comparative case analysis was adopted for the purpose of identifying variation in case unit outcomes and generating understanding at the case level (i.e., the overall network). This between-case analysis was used to further assess evidence of causal mechanisms even though case units were not narrowly selected in order to control for all variation except a single independent variable (George & Bennett, 2005). The benefit is thus less limited generalizability (George & Bennett, 2005).

Figure 3.1 illustrates how the case study approach aligns with the research questions and the objective of the analysis (i.e., to answer how and why questions about the network by subjecting the case to theory and further explicating when and under what circumstances networks operate successfully). Further details on the methods are described in the following sections.

Figure 3.1  
Research questions, case study approach, and analysis objectives



## Research Methods

The case study design guided methods of data collection and analysis. Data collection and analysis were iterative and recursive, but the general flow of the study design is shown in Figure 3.2 below.

Figure 3.2  
Study design flow

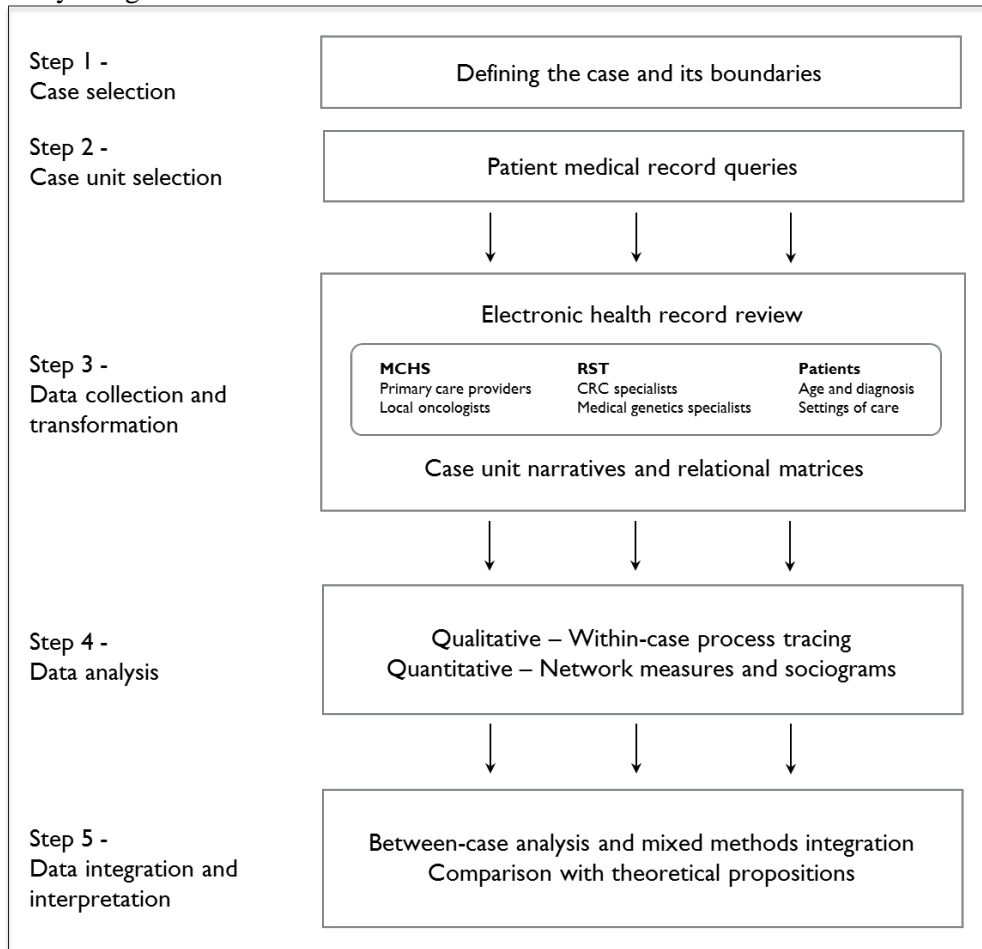


Figure 3.2. Study design flow from case selection to interpretation.  
Abbrev.: CRC = colorectal cancer; MCHS = Mayo Clinic Health System;  
RST = Mayo Clinic Rochester specialty.

## Procedures

In-depth descriptions of the steps of the research project—from case selection to data interpretation and case findings—are presented in the remaining sections of this chapter. The procedures are summarized below to provide an overall picture of the methods employed.

- The case was selected based on its potential to exemplify how a network might function to deploy best-evidence care in community settings. The integrated system includes a number of clinics in both large and small cities across a wide geographic area of southern Minnesota, western Wisconsin, and northeast Iowa. The academic medical center is a renowned institution for cancer research and care (see Step 1: Case Selection, pp. 53-54).
- Electronic health records were queried to identify patient units that met criteria related to age, settings of care, and diagnoses. Records meeting inclusion criteria were further reviewed in depth by the researcher in order to identify a subset of patients with ample data for written historical narratives (see Step 2: Case Unit Selection, pp. 55-58).
- For the selected subset of patients, the researcher developed historical narratives from clinical documentation in electronic health records. This included detailed notes from clinical visits, electronic messages between providers, and electronic communication between patients and providers (see Step 3: Data Collection and Transformation, pp. 58-60).
- Relational matrices of provider-provider and patient-provider interactions were developed from the case unit narratives. These included patient and provider identifiers, practice information, and identification of the type of relationship between any two actors, e.g., referred to, gave advice to, provided primary care for, etc. (see Step 3: Data Collection and Transformation, pp. 58-60).

- A process tracing framework was developed to correspond to hypothesized network benefits. Methods of process tracing were used to identify causal explanations for outcomes in each case unit (see Step 4: Data Analysis, pp. 61-65).
- Relational network matrices were used to generate sociograms showing visual representations of network and subgroup connections. Network centrality measures were used to identify actors in key positions of the network (see Step 4: Data Analysis, pp. 61-65).
- Results of the qualitative and quantitative analyses were combined to interpret when and how the network functioned to provide EBM and to challenge existing theoretical propositions related to EBM (see Step 5: Data Integration and Interpretation, pp. 66-67).

### **Step 1: Case Selection**

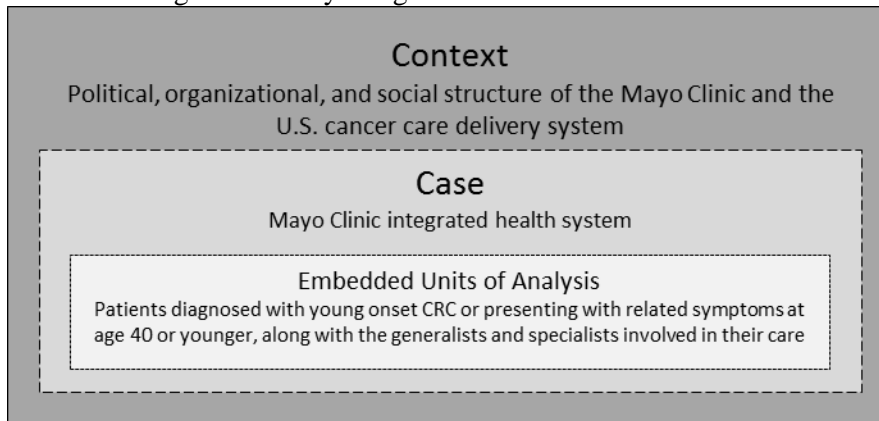
The first step was case selection. The case itself was the Mayo Clinic integrated health system. The Mayo Clinic integrated health system was an ideal site for a case study because it had potential to exemplify how a cancer network might function to diffuse EBM by connecting specialists at an academic medical center with health care providers at the community level. In the context of best-evidence cancer care, the Mayo Clinic integrated network serves to connect specialists leading groundbreaking cancer research and clinical trials (and who participate in guideline-authoring groups like ASCO and NCCN) with generalists in small and medium sized communities across the region. Shared infrastructure should aid in development of communication and information opportunities. However, while providers and patients in community clinics ostensibly have access to EBM, further study was needed to understand whether and how this network serves a role in delivering more evidence-based, coordinated and patient-centered care at the community level.

Bounding defines the scope of a case study. In this study, the case context included political, organizational, and social structures of the larger health care system (e.g., organizational

priorities related to patient care or research financing) and the U.S. cancer care delivery system. These factors exist outside the scope of the case, but they have potential to influence the case and actions by people within it. Information about context was collected as it came up in the course of the study, but it was not the focus of data collection.

The case analysis sought to understand how *interactions* in the network matter. Therefore this case study used what Yin (2014) called an embedded, single-case design, in which individual patient units were analyzed within the case. Outcomes that signal not only *if* the network improves care, but *how, when, or why* well-functioning networks interactions can be found within both the case and unit levels of analysis. The embedded units were selected based on *patient* characteristics, but they included information about both the *patients and the providers* involved in care, as shown in Figure 3.3. In this way, the case units were limited to those whose narratives could challenge and extend theory related to successful networks.

Figure 3.3  
Embedded single case study design



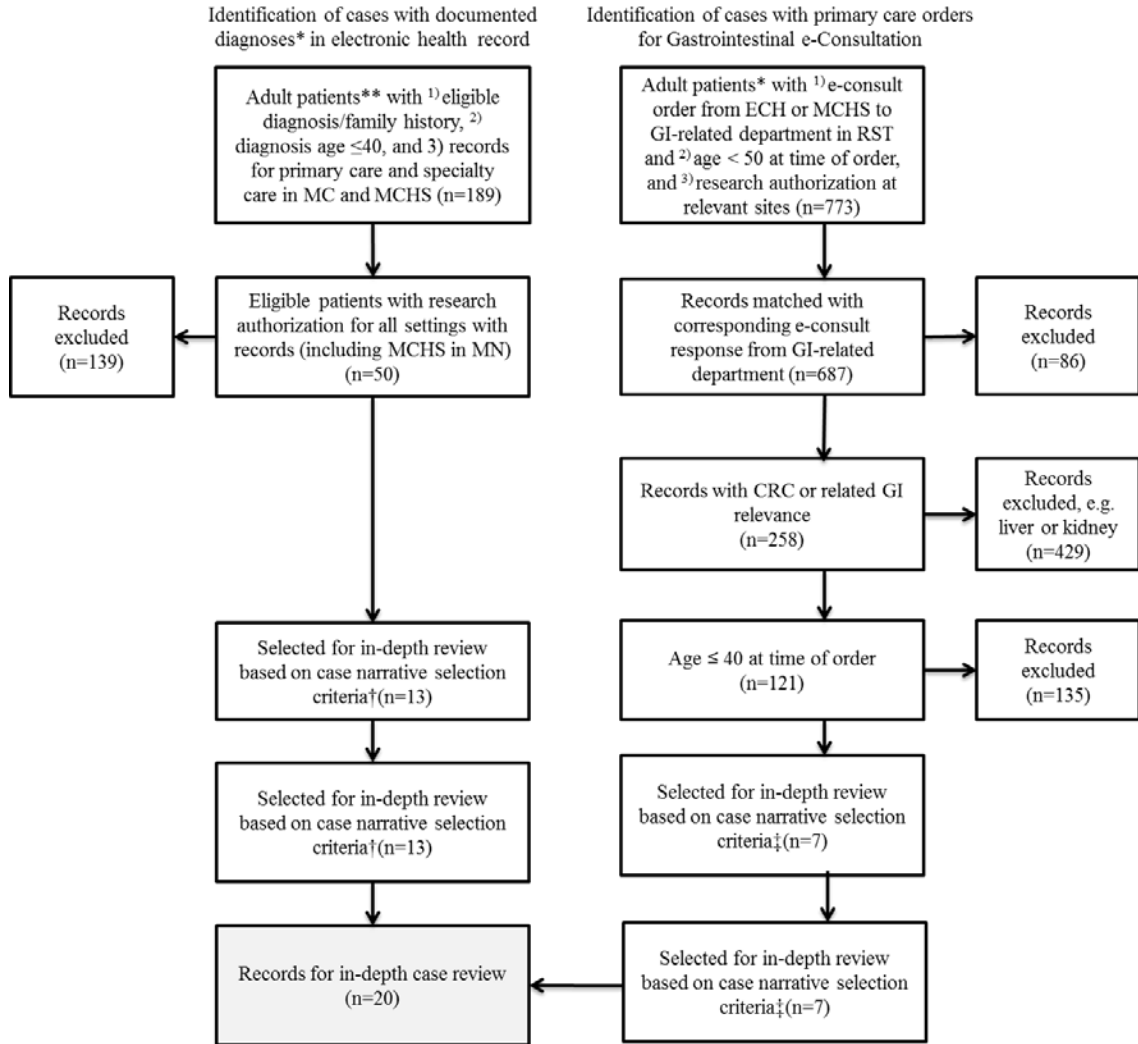
## **Step 2: Case Unit Selection**

The flowchart for selection of units to be the subject of historical narratives and process tracing is shown in Figure 3.4. Patients were identified in one of two searches of electronic health record (EHR) data. In the first search strategy, Mayo Clinic's Advanced Cohort Explorer (ACE), an institutional clinical data repository, was queried to identify patients meeting three criteria: 1) age 18 or older; 2) diagnosis at or before age 40 of colorectal cancer, hereditary colon cancer syndromes (FAP, Lynch, HNPCC), or other disease related to heightened risk of colorectal cancer; and 3) medical records for both primary care settings in the Mayo Clinic network and records related to specialty care or consultation in the network.

A second search of the same data sources was done to identify patients age 40 or younger whose primary care provider had submitted an eConsult order to the Gastroenterology department. Both search strategies were limited to records between January 1, 2000, and December 31, 2015. Research authorization policies differ between Mayo Clinic Rochester and the Mayo Clinic Health System, so patient records were excluded if they did not have Minnesota Research Authorization allowing use of records from all Mayo Clinic and Mayo Clinic Health System sites.



Figure 3.4  
Selection of patients for case narratives



\* Diagnoses included hereditary colon cancer syndromes (FAP, Lynch, HNPCC), colorectal cancer, or disease related to heightened risk of colorectal cancer

\*\* Adult patients age 18 years or older

† Criteria include: <sup>1)</sup> primary care records available before diagnosis and <sup>2)</sup>  $\geq 1$  years of records for review (excluding patients presenting only for second opinion or surveillance after outside diagnosis)

‡ Criteria include: <sup>1)</sup> primary care records available before diagnosis, <sup>2)</sup>  $\geq 1$  years of records for review (excluding patients presenting only for second opinion or surveillance after outside diagnosis), and <sup>3)</sup> subsequent diagnosis or GI-related plan of care (excludes orders that resulted in no finding related to GI diagnosis)

The subsequent decisions on which records to retain required that the researcher read the available clinical notes for the potential case units. Under the first search strategy, the researcher reviewed each of the remaining 50 records to identify a subset of cases with ample data for narratives. Patient units were excluded if: 1) there were no primary care records available before diagnosis and 2) there were less than one year of records for review. This excluded patients presenting only for a second opinion and those presenting for disease surveillance after being diagnosed at a facility outside the network. In the second search strategy, the same criteria were used, along with a third criteria that excluded records with eConsults if the symptoms or diagnosis was unrelated to colon or rectal diseases. These included records where the eConsult was primarily concerned with kidney or liver disease.

For both strategies, the dates for in-depth review were expanded to include any clinical notes documented between January 1, 1990, and December 30, 2018. This allowed for tracing histories prior to diagnosis so that documentation of earlier conversations about family history or genetic testing or counseling referrals could be identified. It also allowed for following some patients post-diagnosis, e.g., through the treatment phase and into the survivorship phase, which is a critical time for care coordination between primary and specialty care.

This process resulted in 20 units for in-depth analysis. Characteristics for patients in the units selected are displayed in Table 3.1 by search strategy. There were slightly more women than men in the review, and there was greater representation of cases from Southeast Minnesota than other regions of the health system. Notably, there were no cases of eConsults for patients residing in Wisconsin, although nearly a third of cases from the EHR review were for patients residing in Wisconsin. Furthermore, in the EHR review, almost all cases were from the MCHS, indicating large shares of phone calls, emails, or direct patient referrals to specialists in these cases. Almost all eConsult cases in the review were for patients in Employee and Community Health (ECH), which includes primary care practice locations within 15 miles of the academic medical center.

Table 3.1

Characteristics of patients in narrative case review by search strategy

Characteristic	EHR review of diagnoses n=13	eConsult order data n=7	Total
Gender			
Female	8 (61.5%)	3 (42.9%)	11 (55%)
Male	5 (38.5%)	4 (57.1%)	9 (45%)
Region and state of residence			
Southeast Minnesota	7	6	13
Southwest Minnesota	1	1	2
Northwest Wisconsin	2	0	2
Southwest Wisconsin	2	0	2
Other	1	0	1
Location of patient's PCP			
MCHS	10	1	11
ECH	3	6	9

*Table 3.1.* This table reports the characteristics of patients selected for in-depth case review through identification of diagnoses in the EHR or through identification of eConsult order data. Abbrev.: EHR = electronic health record; MCHS = Mayo Clinic Health System; ECH = Employee and Community Health (primary care practices in or near Rochester, Minn.); PCP = primary care provider.

### Step 3: Data Collection and Transformation

Records for the 20 case units were reviewed starting from the first entry after January 1, 1990, and on which the patient was at least 18 years of age. All primary care and emergency or urgent care records were reviewed, as were all records related to gastroenterology, medical oncology, medical genetics, surgery, or other departments related to gastrointestinal cancer diagnosis or care. The term “record” in this study refers to clinical documentation and notes, as well as patient forms. These included summaries of clinic and hospital visits, electronic correspondence between patients and providers in the secure, online health care portal (hereafter called portal messages), and notes that document eConsults between providers, wherein one provider submits a order for asynchronous consultation advice and the other responds with advice in an electronic note. Patient forms included standardized forms used to collect self-reported personal or family history of illness, including colon cancer and colon polyps. The median span of records for the units reviewed was 10 years (range 1.4, 21.1 years).

**Case unit narratives.** The histories were written as chronological narratives of the case unit. This process was similar to what has been termed journey mapping in some health-related research (Walter, Webster, Scott, & Emery, 2012). This is also similar to models of patient pathway to treatment, including the Anderson Model of Total Patient Delay (Anderson & Cacioppo, 1995) and a refinement of that model, which provided additional detail on interval of delay and contributing factors (Walter et al., 2012).

In this study, the researcher likewise created an historical account that broke the process down into discrete steps, primarily arranged chronologically and by the people involved in the interactions. However, in this study the focus was on patient and provider outcomes and theory-informed factors that could be used in EBM explanation building, including:

- Instances that described patient symptoms and diagnoses, as well as time from first symptoms to diagnosis or other indications of quality of care;
- Instances of communication—including advice seeking—between providers within and across settings and descriptions of those communications (e.g., mode of communication);
- Instances of evidence-based guidelines or care, including EBM communication;
- Instances where providers documented their own or other’s attitudes or beliefs related to cancer risk, diagnosis, or care;
- Instances of care coordination or handoffs between providers or settings; and
- Instances related to barriers to, or facilitators of, patient access or provider access in the network, including factors that are part of the practice environment (e.g., financial or structural).

**Relational matrices.** Social network analysis (SNA) is the study of connections between actors (people, organizations, etc.) in a network, and it begins with identifying network

membership. At its most basic level, SNA can be applied to essentially answer yes/no questions about whether actors are connected using a matrix. Information about connections can be collected through surveys, observation, or administrative data. For this study, the matrices were built using information in the case unit narratives (developed from information in the EHR) and functionality in NVivo 12 Plus (QSR International).

Case unit narratives were imported into the program, and the researcher coded each type of relationship to a relationship node: gave eConsult or notes advice to; gave personal advice to; made referral to; provided emergency care for; provided local specialty care for; provided primary care for; provided RST genetics advice to; provided RST specialty care for; and provided supervisory advice with. Supervisory advice was typical when a resident or fellow was supervised by a consultant provider. Patient and provider names were removed and replaced with study identifiers (patient identifiers began with PT and provider identifiers began with PA). Ties were directional (e.g., referred to or gave advice to) rather than binary (0 for not related and 1 for related).

The network presented in this study did not completely enumerate membership in the integrated health system, rather it identified relationships between patients and providers involved in the case unit narratives. As such it is unable to identify actors in the integrated network who were entirely disconnected from other network actors. However, the patient-provider social network diagrammed for this study shows relationships among physician specialists and generalists involved in care for patients with young-onset CRC or with conditions that put them at risk of it. These procedures for determining network membership are consistent with the aims of understanding network function in this case study.

#### Step 4: Data Analysis

Consistent with case study methodology, there were several types of data analysis in this study. Qualitative and quantitative data were first analyzed separately. Findings were subsequently brought together to describe and explain the case.

**Process tracing framework and methods.** The process tracing framework displayed below (Table 3.2) outlines four potential causal pathways leading to EBM, which correspond with the four hypothesized benefits of networks presented in Chapter 2: increased awareness or familiarity of EBM; improved EBM acceptability; increased ease of collaboration; and improved access to EBM. These outcomes may occur at different points along the care continuum: prevention and risk reduction, screening, diagnosis, treatment, survivorship, and end-of-life care.

Table 3.2  
Process tracing framework

<b>Network factor</b>	<b>Increased EBM awareness or familiarity</b>	<b>Improved EBM acceptability</b>	<b>Increased ease of collaboration</b>	<b>Improved EBM access</b>
<b>Causes</b>	Access to evidence based cancer knowledge	Potential for multidisciplinary interactions	Shared infrastructure including medical records	Access to specialty referrals or treatments
	↓	↓	↓	↓
<b>Causal mechanisms</b>	Providers can identify EBM for risk assessment, diagnosis, treatment, and surveillance	Opportunities to create shared understanding of best evidence care	Providers (and patients) have a common source of information / documentation	Providers (and patients) have access to novel best-evidence care and advice
	↓	↓	↓	↓
<b>Evidence based care outcomes</b>	Increases awareness of EBM across the cancer continuum	Changes in attitudes toward EBM and less practice inertia	Effective multidisciplinary communication and between providers	Increased EBM delivery in the local setting or access to specialty care

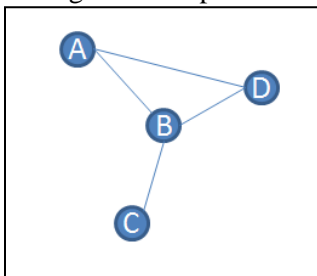
*Note: EBM = evidence based medicine.*

Process tracing of the 20 case unit narratives involved reviewing each narrative in light of the process tracing framework and other factors related to patient and provider outcomes or network function. Narratives were imported into NVivo 12 Plus (QSR International) and methods

of qualitative content analysis were used to identify passages in the text related to outcomes, including those informed by existing theory. Analytic memo writing was used to summarize findings from each case unit's narrative account (see Appendix). The aim was identification of factors related to hypothesized pathways and outcomes within each case unit. Not all case units had similar trajectories or outcomes, and this study did not aim to isolate the effects of a single independent factor on outcomes or a single causal chain. Rather, process tracing was selected because it can be used for within-case analysis in situations of equifinality, defined as situations whereby different causal patterns may have similar outcomes (George & Bennett, 2005, p. 161). The narratives illustrate how hypothesized factors did or did not explain outcomes.

**SNA sociograms.** SNA matrices of network interactions were analyzed first through the generation of sociograms. A sociogram is a visual representation of network relationship using nodes and lines, as seen in Figure 3.5, where it can be seen that, although C is not directly related to A or D, C is connected to them through actor B. The purpose of this visualization was to identify connections and subgroups in the network. In this study, the aim was to understand who was connected to whom in the context of the case units. While this was not a complete enumeration of all providers or patients in the network, it provided information about how generalists and specialists were connected with each other directly or through patients or providers.

Figure 3.5  
Sociogram example



The analysis began with the generation of a sociogram that showed how all members of the network were connected. This illustrated which actors were more centrally located and more connected, and which were on the periphery and therefore less connected. Next, the researcher generated sociograms displaying particular types of relationships. For example, sociograms of local care were generated to inform understanding of the extent to which patients received primary or specialty care in their community setting. Sociograms of referral patterns and advice networks informed understanding of whether patients received referrals to specialty expertise at the academic medical center or whether expertise was passed from specialists to generalists in such a way (e.g., through advice networks) that patients were able to maintain care in the community setting. Sociograms were generated using NVivo 12 Plus (QSR International), UCINET 6 (Analytic Technologies), and NetDraw 2 (Analytic Technologies).

Separate sociograms were also generated for ECH and MCHS settings. Both ECH and MCHS have primary care practices that were included in this study. There are four primary care practice locations in ECH, three of which are in the same city as the academic medical center. ECH and MCHS have different administrative leadership and there is variation in some policies between the two types of practices, although both have the same mission (To inspire hope and contribute to health and well-being by providing the best care to every patient through integrated clinical practice, education and research) and value statement (The needs of the patient come first). All of the ECH clinics were started by the Mayo Clinic. Some MCHS sites were acquired as the clinic expanded its reach in the region.

For this study, the two defining factors for analysis were distance and access to local specialty care. Distance from ECH clinics to the academic medical center is 15 miles or less for all sites. For the MCHS sites included in this case study, distance ranged from 40 to 108 miles. Thus distance traveled to specialty care in the academic medical center (herein referred to as RST



specialty) is greater for MCHS patients. This is consistent with the goals of the MCHS in creating opportunities for patients to get care close to home while being connected to a specialist network.

In addition to distance from RST specialty, the role of the local specialty practice was another factor for consideration in analysis. In the Rochester area, ECH patients get primary care in community settings, but specialist care in the local setting is synonymous with care from RST specialty. A primary care patient in ECH who received a referral to a GI specialist for consultation or care would receive a referral to a specialist in RST specialty. In contrast, a primary care patient in the MCHS may receive a referral to RST specialty or to a local MCHS hospital or clinic with GI specialty services onsite. Thus, the distinction between ECH and MCHS in this analysis highlights how the integrated network operates differently in the manner in which it provides patients with specialty care access based on whether their primary care is through an ECH or MCHS practice.

**SNA statistics.** Where sociograms provide an overview of the network and patterns within it, SNA statistics describe the overall structure of the network and identify key members of it. Statistics describing the whole network had limited applicability in this study, as not all actors in the integrated health system were enumerated. Density, for example, describes the network's total ties relative to its possible ties. In this study, we did not expect that all—or even most—actors were connected to each other. Of greater interest in this study was the position of actors, identified using SNA centrality measures. Centrality is the number of ties to or from a node, and it illustrates the concept of network “importance.” The most important vertices in the network can influence flow (e.g., of disease, information, or influence; Everett, 2014). Three centrality measures were computed for this study. First was in-degree centrality, which is the number of ties coming into or being received by a node. It is a measure of receptivity (Wasserman, 1994). Second was out-degree centrality, which may identify people who are sending out information or some other type of exchange. It is a measure of expansiveness (Wasserman, 1994). Third was

betweenness centrality. Betweenness centrality is a measure of a node’s importance, and it is related to the number of times a node falls between two others (Everett, 2014). The position of the node in the line between actors indicates the node’s control over information flow, or its strategic importance (Carolan, 2014). In considering a situation where deploying information is the aim, an actor’s betweenness centrality may be a measure of his or her ability to mobilize people or resources. Meltzer et al. (2010) suggest this concept could be used when thinking about key actors who serve as conduits in health care information dissemination, acquiring information on rare clinical topics from outside specialists and conveying it to members within the subgroup. This study focused on identifying influential or well-positioned members of the network, including those who have links outside their own group. While it is unlikely that all community generalists will have connections to specialists in Rochester, strength of weak ties theory would suggest that a single actor with ties to specialists could serve to bring information into his or her setting for use by other generalists. SNA measure descriptions and notations are displayed in Table 3.3. All network statistics were generated using UCINET 6 (Analytic Technologies).

Table 3.3  
SNA measures and notations

Measure	Description	Notation
In-degree centrality	The number of ties terminating at the node.	$c_i^i = \sum_{j:j \neq i} y_{j,i}$
Out-degree centrality	The number of ties originating at the node.	$c_i^o = \sum_{j:j \neq i} y_{i,j}$
Betweenness centrality	Number of shortest paths that pass through a node.	$c_i^b = \sum_{j < k} g_{j,k}$

Table 3.3. This table illustrates the notations for SNA measures that are generated by programs like UCINET, SNAP, or R. Adapted from Otte & Rousseau (2002) and Wasserman (1994).

### **Step 5: Data Integration and Interpretation**

This case study used a convergent mixed methods approach (Creswell, 2018) in which the SNA and process tracing were completed separately and then merged during data interpretation. This approach was selected because the different types of data each provided different information toward answering the research questions. The aim of interpretation was two-fold: 1) to describe when and how the network functioned to provide EBM, thus answering the three primary research questions; and 2) to assess existing theoretical propositions related to networks and EBM.

Joint displays that placed findings side-by-side provide structure for integration of mixed methods (Guetterman, Fetters, & Creswell, 2015). In this study, the datasets for SNA and process tracing both came from the same data source, and their results were placed side by side in answering the research questions. This approach was consistent with calls for the use of mixed methods in SNA in order to build better explanations of networks (Hollstein, 2014).

Subsequently, structured iteration between theoretical propositions and case findings were used to challenge explanations. Where process tracing was used to understand potential EBM mechanisms of individual case units (i.e., within-unit analysis), this data integration and between-case interpretation involved identifying more generalized pathways using existing theory as a guide. Further analysis involved explanation building for situations where similar units had different outcomes. In this way, equifinality (i.e., many paths to similar outcomes) was addressed through an iterative process of comparing instances to theory and identifying alternative pathways and outcomes. This step also included a return to process tracing to understand the explanation of individual units of analysis that diverged from expectations. The combination of individual unit explanation and generalized theoretical pathways is a strength of combining these methods. Analytic memos were written to summarize reflections. Memos were entered into NVivo 12 Plus (QSR International) to facilitate connections between data sources.

This final stage used all available data to make final recommendations for theory-based assessments of networks and EBM diffusion, especially on the issue of young-onset CRC, which is emblematic of a cancer that typically begins with presentation in community settings but which may require specialist knowledge and care. This step served to generate hypotheses for future work on intervention development and research, and to explore implications for practice change at the network level.

## CHAPTER 4

### RESULTS

The results are presented in three sections: Results of SNA; Results of Process Tracing; and Mixed Methods Integration. SNA described the network as a whole, the positions of actors in it, and ways in which generalists and specialists were connected directly or through patient care. Process tracing of individual case units provided detailed accounts of how providers interacted and whether hypothesized network functions successfully led to EBM outcomes. Mixed methods integration focused on how these two levels of detail—network structure and individual interactions—support or challenge theories of networks as strategies to improve patient-centered, coordinated, and evidence-based care. After presentation of these results, findings are subjected to explanation building using the theoretical perspectives outlined in Chapter 2.

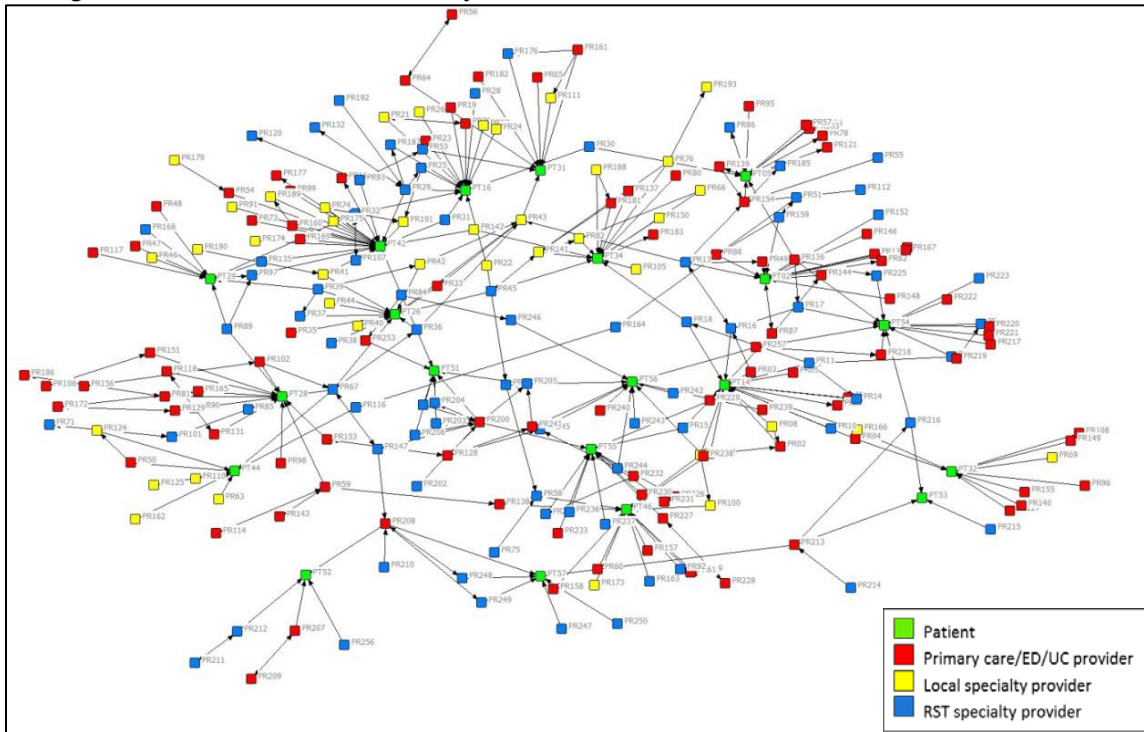
#### Results of SNA

- **SNA Finding 1:** The network diffused specialty expertise to community settings through personal and technology-mediated advice connections, sometimes through local specialty providers
- **SNA Finding 2:** The network opened up access to RST specialty referral for community patients, sometimes circumventing local specialty providers
- **SNA Finding 3:** Both patients and providers held central or mediating positions in specialty referral and advice connections

The network diagrammed for this study shows relationships among specialists and generalists involved in care for patients with young-onset CRC or with conditions that put them at risk of it. In total, the network assembled through chart review included 20 patients, 226 providers, and 346 relationships. Figure 4.1 displays the entire network, where green is a patient, red is a primary care or emergency/urgent care provider (i.e., generalist), yellow is a local specialist, and blue is a Rochester (RST) specialist at the academic medical center. This high-level display shows that the most centrally-located patients and providers had the greatest number of connections to all three types of providers, including more reachability to RST specialists

within one step (i.e., direct connection rather than mediated by another node). Centrally located actors may also play a role in brokering information or access. However, interpretation is limited at this level of analysis.

Figure 4.1  
Sociogram of all actors in the case study network



More detailed analysis of the *types of links* created between patients and providers was necessary to generate findings related to Research Question 1 (i.e., identifying the types of links the network created between generalists and specialists). *Referral links* may illustrate the potential of networks to give community patients access to specialized expertise if they travel to the academic medical center. In contrast, *advice links* have the potential to diffuse expertise to the community setting. These analyses also better highlighted the importance of actors' positions in the network. There were three major findings from the network analysis.

**SNA Finding 1: The network diffused specialty expertise to community settings through personal and technology-mediated advice connections, sometimes through local**

**specialty providers.** A primary goal of networks is to diffuse expertise to the community setting in order to allow patients to obtain evidence-based care close to home. The results suggest that the network diffused specialized expertise (e.g., knowledge and advice) to community settings though the use of synchronous and asynchronous communication strategies. However, how this diffusion happened varied between the MCHS and ECH. Figures 4.2 and 4.3 of *provider-to-provider* relationships (“gave eConsult or notes advice to” and “gave personal advice to”) illustrate how specialist expertise flowed to providers in the MCHS and ECH networks.

First, there were more advice connections in ECH than MCHS. Furthermore, ECH patients more often received advice from an RST specialist through their primary care provider. In contrast, advice giving was less common in the MCHS than in ECH. When advice was given, it typically flowed from a local specialist to a local primary care provider. In the handful of RST advice giving relationships shown in Figure 4.2, all but one included a local specialist who mediated advice-giving between an RST specialist and a primary care provider or between an RST specialist and the patient.

Figure 4.2  
Sociogram of local patient care providers and advice: MCHS patients

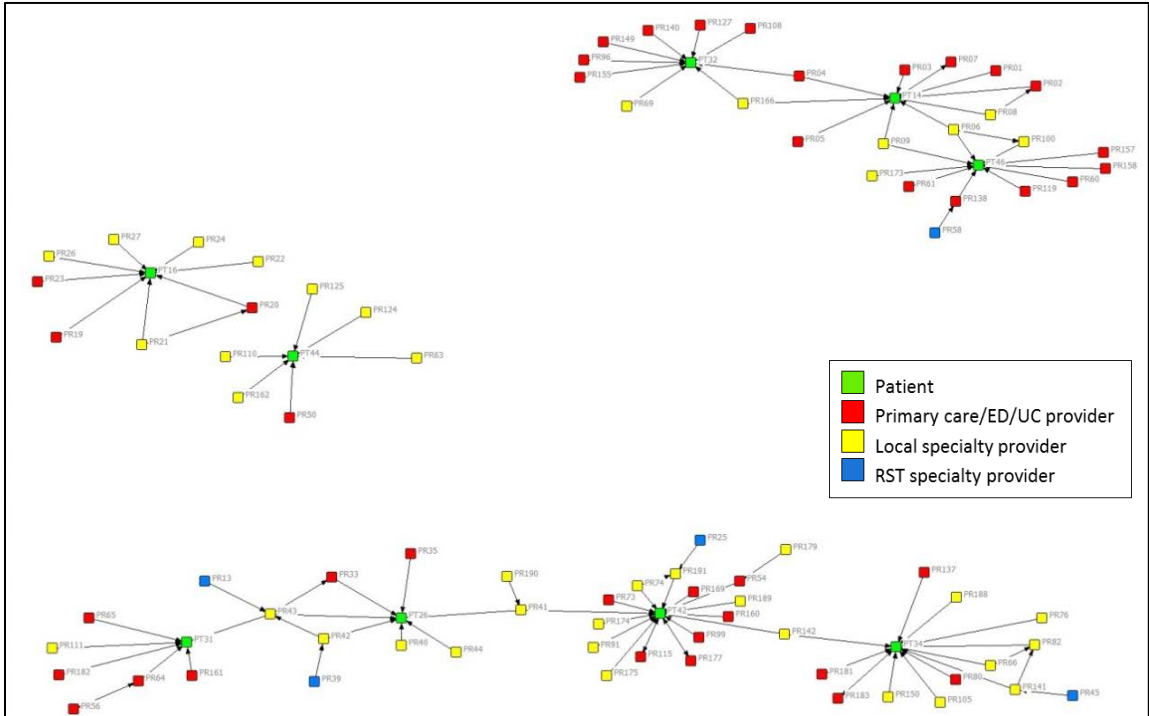
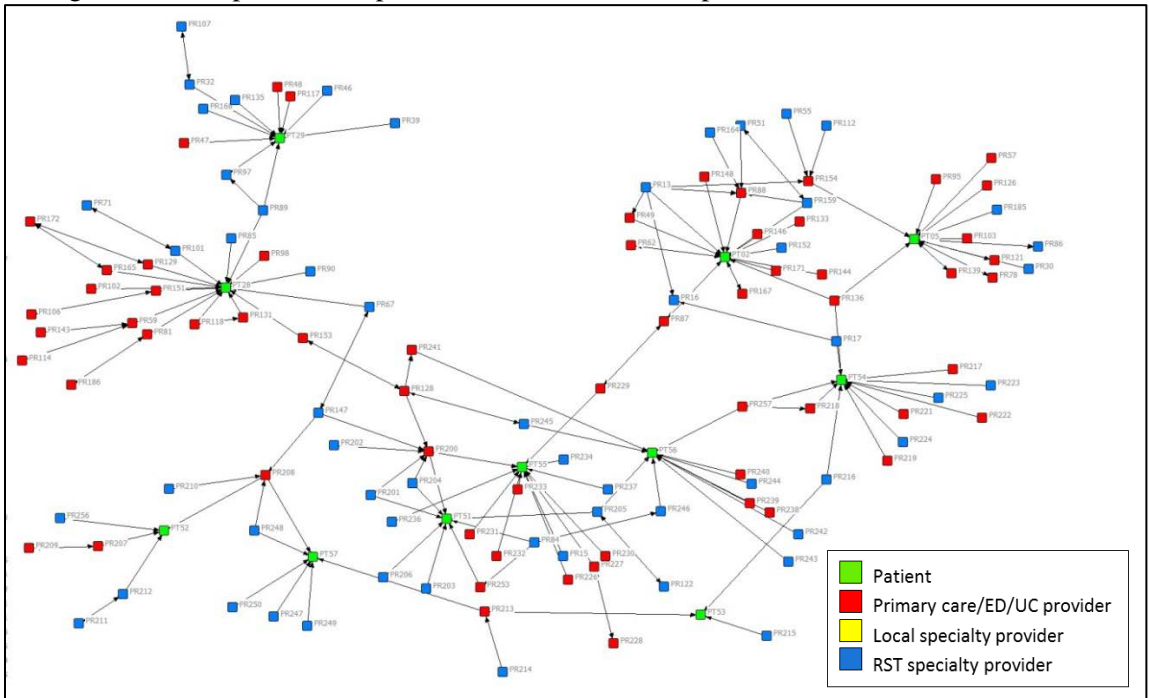


Figure 4.3  
Sociogram of local patient care providers and advice: ECH patients



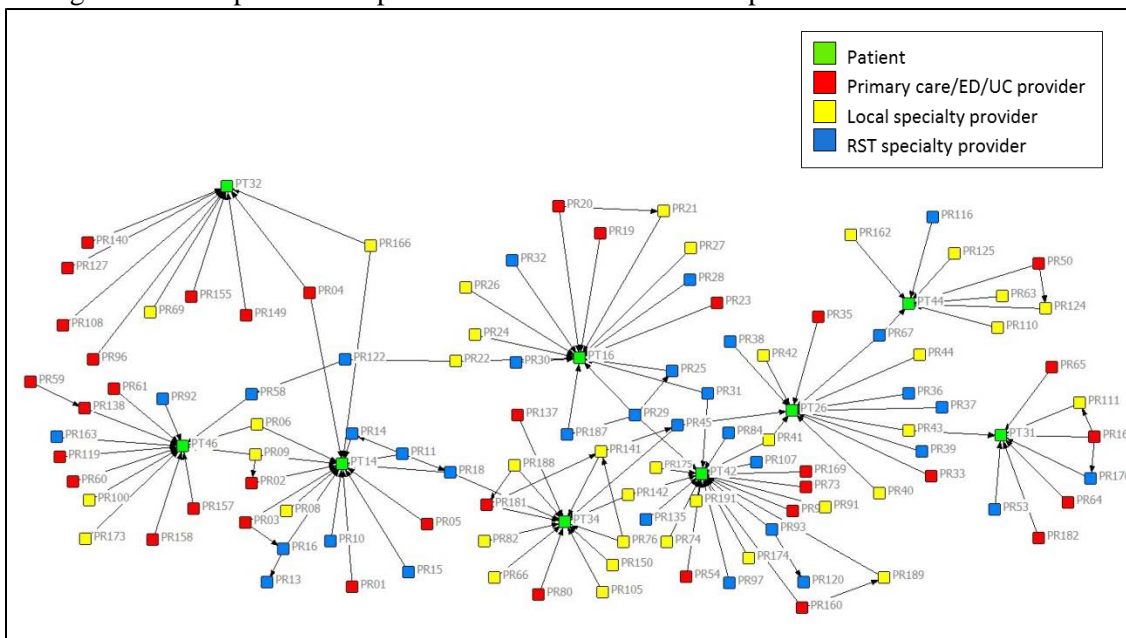


Second, analysis of asynchronous eConsult or notes advice versus synchronous personal advice (e.g., telephone calls) demonstrated differences between RST specialists and local providers. Primary care providers received advice from RST specialists using both electronic/asynchronous methods such as eConsults or notes in the EHR, as well as through personal means such as telephone calls. In the MCHS, asynchronous advice from RST specialists to MCHS primary care providers was rare. More common was personal advice from RST specialists to local specialists, followed by personal advice from local specialists to local primary care providers. There were also times when the RST specialist provided electronic advice to a local specialist, who in turn provided personal advice to a local primary care provider in the MCHS. This suggests that in some cases, knowledge dissemination from the academic medical center has a different path of dissemination, i.e., through local specialists who communicate directly with patients or through primary care providers. Understanding variation in how knowledge is diffused in the different network arrangements is critical in the case of young-onset CRC because patients typically present first to the primary care setting. Diffusing best-evidence risk assessment in particular may necessitate effective mediation by local specialists.

**SNA Finding 2: The network opened up access to RST specialty referral for community patients, sometimes circumventing local specialty providers.** While the goal of networks is to bolster and maintain knowledge and care in community settings, networks also create referral access to specialty care that is only available in the setting of an academic medical center or an institution designated as a comprehensive cancer center. The results suggest that the network increased access to specialty care for community patients. Where advice giving was more limited in the MCHS than in ECH, both ECH and MCHS providers utilized referrals to RST specialists. The ECH patients were largely referred to RST specialists through their primary care provider, consistent with how the network is arranged for those patients. Figure 4.4 shows how RST specialty care is available to MCHS patients once referrals are included. The MCHS

sociogram indicates that a significant number of RST specialty providers cared for patients without a referral path going through a local provider. These patients may have received a referral as part of an approval process, but the EHR notes did not indicate that the local provider listed referral as the recommended course of care. Some of these patients may have also self-referred to RST specialists. In terms of local provider engagement with referrals, the sociogram demonstrates that local primary care providers made direct referrals to RST as well as referrals to local specialists, some of whom went on to make an RST specialty referral. Likewise, local specialists made referrals among each other, as did RST specialists. This suggests that while local specialists played a key role in advice or knowledge diffusion, referrals sometimes circumvented the local specialists and went directly to RST specialists. This suggests that, although local specialists play a role in mediating advice giving, they do not always mediate referrals.

Figure 4.4  
Sociogram of local patient care providers and referrals: MCHS patients



**SNA Finding 3: Both patients and providers held central or mediating positions in specialty referral and advice connections.** Network centrality is important because actors with high in degree or out degree centrality may be influential or receptive to information flow, while those with high betweenness centrality can effectively mediate access and information flow or serve as gatekeepers to it. Identifying actors with high centrality represents a strategy for potential knowledge or innovation diffusion, especially when these actors sit on the path between heterophilous actors or groups. Table 4.1 lists the actors with the top betweenness centrality scores, along with their in-degree and out-degree. Patients with high in-degree had large numbers of providers involved in their care, especially those with long histories of disease or complex conditions.

Two patients in particular had high betweenness centrality scores: PT02 and PR05. Egocentric sociograms for those patients are also shown below. They are both typical of what is known as a star-shaped communication pattern. In a star-shaped communication network, the actor at the center is responsible for all communication with the other actors, who themselves have little or no interaction. Patients with high betweenness centrality may have been in charge of communication and coordination between the providers involved in their care. While patient-centered care places a high value on the role of the patient on the care team, putting patients in charge of coordinating communication between providers also puts burden on patients. By limiting provider-provider communication, it also diminishes the potential of networks to create knowledge diffusion links between providers.

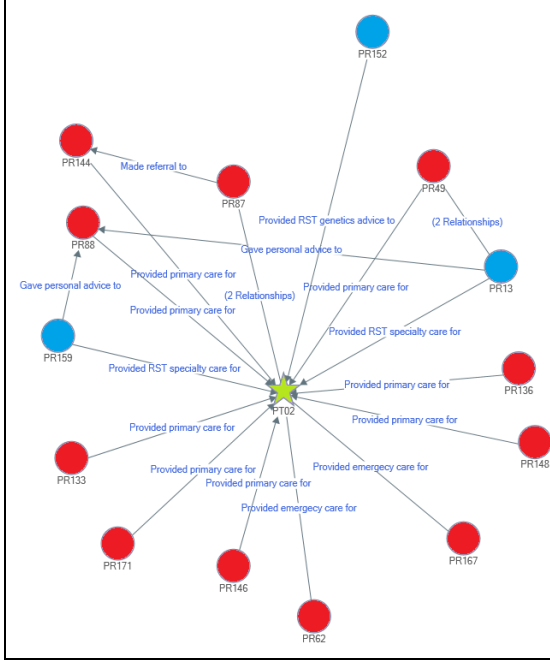
Table 4.1

Centrality measures for network actors with above average betweenness centrality scores

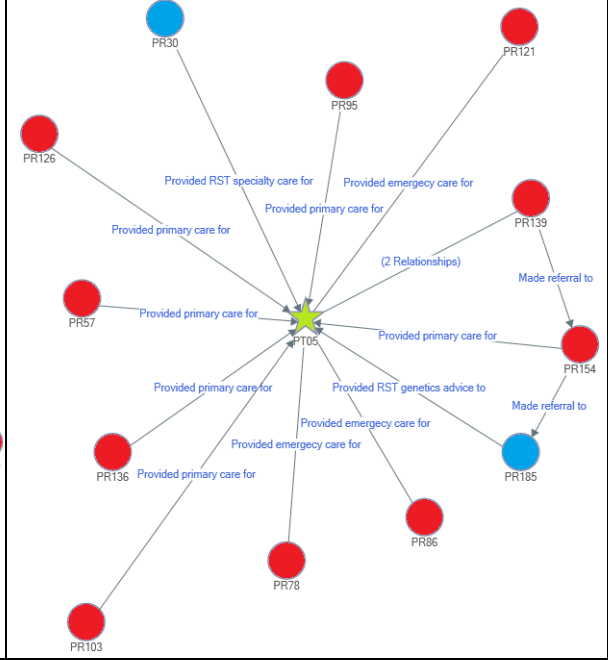
<b>Study ID and role</b>	<b>In Degree</b>	<b>Out Degree</b>	<b>Freeman Betweenness</b>
PR200: PCP in Rochester FM	5	6	115
PT02: Patient in ECH	15	4	109
PT05: Patient in ECH	13	5	91
PR13: Specialist in RST GI	2	6	81
PR67: Specialist in RST GI	3	5	75
PT42: Patient in MCHS	22	2	72
PR205: Specialist in RST GI	3	3	70
PR147: Specialist in RST GI	1	3	68
PR87: PCP in Rochester IM and ED	3	4	60
PR16: Specialist in RST GI	3	2	57
PR154: PCP in Rochester FM	4	2	53
PR122: Specialist in RST GI	2	2	51
PR128: PCP in Rochester IM	2	4	42
PR58: Specialist in RST Hematology	2	2	36
PR43: Local specialist in GI	3	3	32
PT29: Patient in ECH	11	1	27
PR208: PCP in Rochester IM	3	4	26
PR102: PCP in Rochester IM	1	3	26
PR97: Specialist in RST GI	2	3	24
PR139: Rochester ED provider	2	3	21
PR229: PCP in Rochester IM	1	2	20
PT14: Patient in MCHS	16	1	20
PR245: Specialist in RST GI	2	2	16
PR29: Specialist in RST Colon and Rectal Surgery	2	5	15
PT34: Patient in MCHS	14	1	15
PR36: Specialist in RST GI	1	3	12
PR241: PCP in Rochester IM	1	2	11
PR88: PCP in Rochester FM	4	1	10.5

Notes: FM = Family Medicine; IM = Internal Medicine; GI = Gastroenterology; PCP = primary care provider; RST = Rochester Mayo Clinic.

Egocentric sociogram: PT02



Egocentric sociogram: PT05



Most of the network members with high out degree are specialists, and these are the individuals with the highest betweenness centrality scores. There are also several primary care providers with high betweenness centrality. These providers may have been mediators or connectors of information flow between specialists and patients. High betweenness centrality among primary care providers may indicate effective coordination of care, especially when primary care providers relay information between specialists and patients and coordinate referrals to specialty and follow-up. On the other hand, it may signify gatekeeping.

## Results of Process Tracing

The results of process tracing are summarized relative to the process tracing framework (Table 3.2, Page 61), which outlined potential mechanisms based on the existing literature of networks and EBM. Summaries of process tracing for each of the patient narratives can be found in the Appendix.

- **Process Tracing Pathway 1 – Networks create access to and awareness of EBM**
  - **Finding 1:** Familiarity with EBM was inconsistent across the network, especially in primary care
- **Process Tracing Pathway 2 – Multidisciplinary interactions improve EBM acceptability**
  - **Finding 2:** There was evidence of changing attitudes among specialists across settings, but primary care providers had fewer interactions using rich communication
- **Process Tracing Pathway 3 – Shared network infrastructure increases collaboration**
  - **Finding 3:** Shared medical records provided lean means of asynchronous communication, but inconsistent use hampered care coordination and shared understanding
- **Process Tracing Pathway 4 – Networks provide access to specialty care and referral**
  - **Finding 4:** The network promoted access to specialty referrals and care, but not all referral patterns resulted in shared knowledge and coordinated care across settings

**Process Tracing Pathway 1: Networks create access to and awareness of EBM.** The literature suggests that effective networks create access to evidence-based knowledge when they connect providers in heterophilous groups. This access in turn may increase awareness of EBM among community clinicians who would otherwise have limited awareness of or access to the knowledge. Thus, in this study, the researcher looked to identify instances in the narratives where community providers demonstrated knowledge of EBM, especially those instances where a network connection provided the knowledge link.

In theory, all of the providers in the narratives were part of the integrated system and therefore had access to intranet databases and organizational process of care models (i.e., organizational consensus-based algorithms that illustrate evidence-based and expert knowledge on a disease or condition), as well as contact information for experts in the network. However, among the 20 patient narratives, the analysis identified only six instances where the first community primary care provider that saw his or her patient followed an evidence-based process for risk assessment, diagnosis, or care. In several cases, patients presented to primary care settings with symptoms with limited predictive value, such as abdominal pain. However, it was also the case that patients presented with alarm symptoms such as rectal bleeding, and they failed to receive advice consistent with EBM, including referral for further testing or specialty consultation.

Other narratives exhibited variability in primary care provider knowledge of family cancer risk assessment. Two cases exemplify the potential benefits and missed opportunities of networks to create EBM awareness related to risk assessment. In both instances, the primary care providers gave what they thought was an evidence-informed recommendation related to risk assessment and screening, but in both cases they had misinterpreted recommended screening guidelines. In the first case (PT31), the error was not caught until years later, when the patient returned to primary care and detailed his concerns about CRC and Lynch syndrome family history. In the second case (PT52), in contrast, the provider stated a recommendation that he thought followed published guidelines but he also queried advice from a specialist at the same time. The specialist was subsequently able to correct knowledge related to best-evidence risk assessment and screening. These examples also illustrate how network benefits may be dependent on the provider assigned and how delays in risk assessment or diagnosis can occur if the patient is assigned a provider who lacks knowledge and does not seek appropriate information.

In these case unit narratives, EBM recommendations in primary care often followed assignment to a new primary care provider. In cases where alarm symptoms had previously been dismissed or family history taking was incomplete, patients who subsequently saw a new provider for the purpose of establishing a new care relationship typically started with a visit that included an overview of the patients' social and medical history. These initial visits also included standard questions about family history of illness. In some cases, new provider assignment resulted in more comprehensive medical or family history taking than had previously taken place, and subsequently those led to appropriate follow-up care or referral.

Increased *patient awareness* was also a factor in 11 of the case units, where attention to EBM was prompted by patients who presented with concerns about family history, sometimes in combination with alarm symptoms like rectal bleeding. The narrative for case unit PT14 exemplifies patient dependent awareness of EBM. The provider's family history notes included text such as "Negative for young adult illnesses" and "No breast cancer" over the course of many years. When the patient eventually brought up her extensive family history of bile duct cancer and ovarian cancer at young ages, the primary care provider offered a GI consultation and CA-125 testing (for ovarian cancer) but did not follow up on it. He also used language in his notes suggesting a genetic disorder was unlikely and stated in his notes that the GI consult was to reassure the patient. As documented by the provider, even the patient, in one of these visits, noted that her abdominal pain and concerns about family history might be "just in her head." It was assignment to a new primary care provider that triggered a local specialty consult and subsequent referral to RST specialty care after a rectal mass was identified.

In contrast to variability among community primary care providers, awareness of EBM knowledge (related to young onset CRC and risk-related conditions) was consistently higher among community specialists, such that after patient referral from primary care to a local GI specialist, recommendations were generally evidence-based. Furthermore, when a local specialist



lacked personal knowledge or expertise, systems were often in place to consult with local colleagues or RST specialists. This suggests that even in an integrated network, local specialists have evidence-based knowledge or access to it, while primary care providers may lack access or may not be inclined to search for it. This is problematic in the case of young-onset CRC because primary care is the setting where patients receive preventive health care services. Local specialists can be local knowledge brokers but primary care providers may need not only connections to them but triggers to alert them to activate connections in clinically relevant situations (e.g., when a patient has a significant family history of CRC or symptoms suggestive of it).

**Process Tracing Pathway 2: Multidisciplinary interactions improve EBM acceptability.** Much of the focus of existing literature on EBM diffusion is concerned with changing attitudes toward EBM. In 14 of the 20 case unit narratives, there was at least some evidence of multidisciplinary interactions leading to improved EBM acceptability at some point in the patient trajectory. Most opportunities for multidisciplinary interactions to influence attitudes and provide opportunities for shared understanding of best-evidence care occurred later in the patient trajectories, for example, during treatment decision making for patients with a CRC diagnosis. They were also more likely to involve communication between specialists within settings. Within the RST specialty setting, there were multiple modes of communication available to multidisciplinary specialists, including curbside consultations, telephone calls, electronic notes, and e-tumor board meetings. However, these interactions did not always cross settings to community-based care. An example is PT16, whose GI specialist in RST outlined in her note the four multidisciplinary specialists whose expertise could help determine the best course of care. None of the RST specialty interactions involved providers in the community setting, though, even though the patient received much of his treatment there. Instead, the patient was the central actor in knowledge dissemination and understanding around best-evidence care across settings.

At the larger MCHS sites with local oncology practices, there was evidence of communication regarding the best-evidence course of care between local specialists, as in the example of PT44. In that case, the local specialist documented discussions with the patient and his local specialty colleagues about the NCCN guidelines and the best course of care given the complexity of the disease. However, there was less evidence of multidisciplinary discussions (i.e., those involving specialists with different clinical expertise). Rather, more common in the case unit narratives was for local specialists to consult with RST specialists of the same or different specialty. Those interactions included a variety of asynchronous and synchronous approaches with RST, including electronic notes, telephone conversations, and interactions with the e-tumor board.

There was some evidence of changing attitudes—in a handful of cases—based on communication between local and RST specialists. Evidence of this EBM pathway included both lean and rich opportunities for communication. Local specialists used phone conversations with colleagues to obtain input on a complicated treatment decision, for example, exhibiting rich communication. In these cases, specialist notes detailed conversations with other specialists. There was also documentation indicating that specialists read each other's notes, exhibiting effective lean communication strategies, even across specialty settings. An example is PT26, whose narrative indicated that conversations between local and RST specialists served as a way to arrive at a common understanding about the best course of care for a very complex patient, and those conversations changed some local specialists' attitudes about EBM for the patient.

However, at the primary care level, it was more common to see evidence of opportunities for *access to EBM knowledge* through the network (Finding #1) than evidence of *changes in attitudes about EBM* due to network connections. This is consistent with the fact that the current study found more cases of lean communication (e.g., eConsults or notes shared between providers) at the primary care level. These lean approaches may be more consistent with

knowledge dissemination, while richer interactions may be necessary to change attitudes. It is possible that primary care providers who accessed information about EBM subsequently put the information to use with patients, which may illustrate a change in attitude if providers subsequently also saw the evidence-based practice as more relevant than they had previously.

At the primary care level, the most relevant change in EBM attitudes may be family history taking and its value in risk assessment, along with attitudes toward recommended screening following alarm symptoms like rectal bleeding. These types of data analyses are outside the scope of research approvals for this study because they would have required sampling of patient case units using different selection criteria. Future studies could review family history taking practices for a broad cross-section of patients cared for by selected providers in this study, looking for trends before and after an encounter suspected of potentially changing the providers' attitudes toward history taking or alarm symptoms.

**Process Tracing Pathway 3: Shared network infrastructure increases collaboration.**

Networks are most effective when they include administrative or technical links that support communication and collaboration. In this study, the process tracing found several instances that provided evidence that the third pathway of the process tracing framework (i.e., shared infrastructure leads to a common source of information and documentation, which in turn leads to effective multidisciplinary communication and thus increased delivery of EBM) was an explanation for EBM outcomes. The pathway could be seen operating in two distinct but effective ways. First, eConsults were efficient ways for ECH primary care providers in particular to get access to best-evidence recommendations. Providers could submit questions, for example about screening recommendations, to a specialist and that specialist could respond with his or her advice—all without the time and travel associated with an office visit.

Second, effective lean communication between and across settings occurred when, as noted above, providers read each other's notes. Each specialist's documentation provided an

electronic paper trail for other specialists or the primary care provider. In the cases of PT31 and PT34, for example, there was no interaction between the local specialists and the genetics specialist in RST, but the local specialists documented awareness of the genetics consult findings via EHR clinical notes. In the case of PT56, interactions were typically limited to lean communication strategies, but the notes were so detailed in regard to evidence-based decision making that any provider with access to the records could understand how the best-evidence recommendation was formed. In at least one case, access to electronic records informed the eConsult response above and beyond what was included in the eConsult order. In that case, PT54's primary care provider omitted important details when she submitted for eConsult advice on colon screening. The specialist reviewed the records, even though there was likely sufficient information in the order to provide a response. His review brought important additional information to light and changed the recommendation he would have made based on the eConsult order information alone.

Lean and rich communication were not mutually exclusive. There were six cases of eConsults from ECH primary care providers to RST specialists in this study. Subsequent to the eConsult, the majority of those cases involved opportunities for personal advice using other modes of communication. For example, with case unit PT57, the ECH primary care provider first used an eConsult to get a screening recommendation, and he later sought personal advice to help interpret pathology results.

However, there is also evidence in nearly half of the case units that the existence of a shared medical record was not in and of itself cause for clear communication, shared understanding, or closed-loop referrals or follow-through. Many of these failures occurred when providers did not access documentation that could have informed care. In the case of PT02, RST specialists in GI family cancers and genetics documented clear screening recommendations, but notes from the subsequent primary care visit make evident that these recommendations were not

reviewed. The patient's and her family members' histories were also incorrectly documented in individual primary care notes over the next several years. Incorrect self-reports by the patient further obfuscated documentation in the record. In this instance, the patient may have been an ineffective information broker, raising the question of how to engage patients in their own care while maximizing the potential of shared electronic infrastructure.

Other failures were related to how information was stored in the record. For example, provider summaries of conversations with other providers were often stored in individual clinic notes from a patient encounter (e.g., an office visit or a portal message). In the case of PT14, the provider summarized extensive conversations with specialists in portal messages to the patient, rather than in clinical notes that could be more easily located for reference. Consequently, future providers would need to read through portal messages between the patient and the provider to obtain a summary understanding of the multidisciplinary discussions that informed care. This suggests that providers need easy access to electronic information, including personal and family history information and clinical actions or recommendations, which currently exist in separate notes tied to patient encounters. In the case of PT51, the narrative included more than 1000 records over the course of decades. These longer trajectories were common as patients presented with a broad range of symptoms with varying predictive value, which is typical of young-onset CRC, as described in Chapter 2.

These types of communication gaps are also the cause of "closed loop" failures. These occurred when a provider made a recommendation but no one was in charge of reviewing the recommendation in the record and ensuring that follow-up care or referral took place. This was the case for PT52, for whom a recommendation for a referral to a genetics consultation appeared in an eConsult but was not referenced again in later notes. Similar notes about the need for GI consultations without follow-up to arrange those consultations were also seen with PT05 and PT14. In the case of PT14, mention of the referral was described by the provider as being offered

to “reassure” the patient, rather than because it was a best-evidence step in her care. In the case of PT32, an outside genetics consultation resulted in a detailed screening recommendation, which the patient gave to her primary care provider. However, there is no indication that the provider was ensuring these screening recommendations were enacted. In fact, despite a wealth of information about the patient’s Lynch syndrome diagnosis and a recommendation for screening surveillance, the network did not function to improve EBM uptake for this patient.

There were also four other case units that involved providers in other health systems, unaffiliated with this integrated health system; even in an integrated network such as this, other providers may be involved in care, either because of geographic constraints or because of differences in insurance or access to care. For PT29, her RST oncology specialist provided a vast amount of evidence-based knowledge and knowledge on emerging science in GI cancer care; however, the patient’s outside oncologist, who provided some treatments closer to home, disagreed with the RST recommendation on a few occasions. In those cases, the patient was left to relay messages across systems. The EHR included scanned documentation of outside testing, but the only indication of documentation related to efforts to come to a shared understanding of best-evidence care was in portal messages between the RST specialist and the patient. In other case unit narratives, lack of access to records—including test results—also led to rework and thus additional costs.

**Process Tracing Pathway 4: Networks provide access to specialty care and referral.**

The process whereby a patient has access to specialty referral differs by health plan and organization, but it often requires coordination by the primary care provider. In this study, the referral relationship developed for SNA and process tracing analyses was reserved for instances in which the provider’s documentation stated that referral was the recommended course of care. Under this definition, the network provided access to specialty referral in 13 of the 20 patient

units. In two additional cases, the network opened up access to referrals in an unexpected way: it was the patients, rather than their providers, who were responsible for self-referral.

In most of these cases, the referral resulted in EBM delivery. This included consultation with GI specialists or medical genetics specialists who informed best-evidence screening recommendations. For those with a CRC diagnosis, it also included best-evidence treatment regimens not otherwise available and informed by multidisciplinary expertise in surgery, oncology, radiology, and other specialties. There were differences between ECH and MCHS patients. In ECH, specialty referral is akin to local specialty referral—there is no middle step, although use of eConsults were effective in determining when a referral for a face-to-face consultation was appropriate. In the MCHS, referrals could go directly to RST specialty from primary care, or they could go through the local specialist. Local specialist referral to RST specialty indicated that greater specialty or subspecialty advice was needed beyond the scope of local specialty expertise, such as in the case of RST medical genetics expertise. In some cases it also indicated that specialized treatment was only available in RST, e.g., certain types of chemotherapy or complex surgical techniques. In the case of medical genetics, there were examples of direct referrals from MCHS primary care providers to RST medical genetics, which suggests the primary care provider had the knowledge to determine which referral resources were appropriate in the situation. An example is PT31, where the primary care provider made separate referrals to the local GI specialist and the RST genetics specialist. While this may illustrate the most appropriate use of both local expertise and expertise in the academic medical center, the referral pattern may have also played a role in the fact that there was almost no communication between the local specialist and the RST specialist, although notes were available and documentation indicates that they were read.

There was evidence in the case unit narratives that the network did not open up access to specialty referrals for all patients, though. In the case of PT32, the fact that the local primary care

providers took the outside genetics report presented by the patient at face value without a referral to local specialists or RST specialists for screening guidance may have contributed to the lack of follow through in obtaining recommended screening. PT28 is another case where referral was limited by the primary care provider; it was the patient who advocated repeatedly for referral and eventually got one. Likewise, there is evidence that not all providers used the same threshold for referral. Some made a referral to GI or medical genetics consultation immediately upon presentation of an alarm symptom or report of significant family history of CRC. Others did not, indicating that for network benefits to be realized, both provider information about and their attitudes toward EBM may need to be addressed.

Process tracing also identified insights into situations when referrals did not promote shared knowledge or care coordination. When the link to RST specialty care did not involve a referral from the local setting, there was often evidence of failures in follow-up and confusion between providers. In the case of PT26, local specialists engaged RST specialists for advice, but they did not make referrals to them. Still, the patient sought care from several RST specialist providers, placing local specialists out of the communication loop and forcing them to subsequently track down information about RST encounters. There is also evidence in the narratives that the quality of care coordination and communication related to referrals between primary care, local specialty care, and RST specialty providers for patients with a CRC diagnosis may have been associated with efforts to move the patient's survivorship care back to the community settings. In the case of PT34, the majority of specialty care remained in the local area, with only RST genetics referral. In this case, there was greater local coordination of care and an easier transition back to primary care during survivorship. In contrast, PT42 received local and RST specialty care, but while the local specialists consulted with RST specialists for advice and they even brought the case to the multidisciplinary tumor board, they did not make referrals to RST specialty care. The involvement of multiple local and RST specialists without formal referral



links led to problematic communication loops among them and a difficult transition back to primary care.

## Results of Mixed Methods Integration and Interpretation

Mixed methods integration was aimed at using SNA and process tracing findings to answer the research questions, and in doing so, to assess whether the theories outlined in Chapter 2 explained EBM outcomes in community settings. The major findings from each type of analysis were first compared side-by-side, as shown in Table 4.2.

Table 4.2  
Joint display of SNA and process tracing findings by research question

Research question	SNA findings	Process tracing findings
What types of links does the network create between generalists and specialists, e.g., referral or advice?	<ul style="list-style-type: none"> <li>• Personal and technology-mediated advice links</li> <li>• Specialty referral links</li> <li>• Different paths for advice and referrals               <ul style="list-style-type: none"> <li>○ ECH: direct links between generalists and specialists</li> <li>○ MCHS: direct and indirect links between generalists and specialists</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Variability in activation of RST advice connections in local primary and specialty care</li> <li>• Varying provider decisions about use of referral links</li> <li>• Patient advocacy for referrals</li> </ul>
When and how do network links lead to provider outcomes related to EBM, e.g., awareness or attitudes?	<ul style="list-style-type: none"> <li>• How personal and technology-mediated advice flowed between providers</li> <li>• How referrals connected providers</li> <li>• How patients mediated information flow</li> </ul>	<ul style="list-style-type: none"> <li>• When providers were aware of EBM or activated the network</li> <li>• When opportunities were available for back-and-forth interactions between providers</li> <li>• When centrally-located providers effectively brokered information</li> <li>• When referrals had adequate information sharing and follow-through</li> </ul>
When and how do networks function to impact patient outcomes, e.g., specialty access, evidence-based care, or care coordination?	<ul style="list-style-type: none"> <li>• How providers' connections created advice or referral access for patients</li> <li>• How patients were included in advice or referral links</li> </ul>	<ul style="list-style-type: none"> <li>• When providers were aware of EBM or activated the network</li> <li>• When new providers or patients were engaged</li> <li>• When all providers were formally included in advice and referral links</li> <li>• When providers had time and gave attention to documentation</li> </ul>

The SNA and process tracing results provided unique but complementary insights into how the network functioned and whether or when it served to diffuse EBM to community settings. Both SNA and process tracing identified advice connections. Where sociograms highlighted network structure (including where actors did or did not have ties), the process tracing provided more nuanced understanding of conditions when knowledge connections were activated. Most notably, process tracing highlighted the variability of EBM awareness and actions providers took to find EBM information, especially at the primary care level. The sociograms showed connections and disconnections, but process tracing told a richer story of why providers did or did not search for information. Some providers did not recognize symptoms—others were unaware of guideline recommendations based on family history. New provider assignments and engaged patients—including patients whose family members had shared genetic information with them—were reasons for increased awareness or actions to search for EBM information.

SNA also identified differences in personal advice and technology-mediated advice between ECH and MCHS providers. ECH primary care providers used eConsults for advice, even though they were more geographically proximal to RST specialists, while MCHS primary care providers tended to use personal conversations with local specialists when they had EBM questions. Those local specialists mediated electronic or personal advice from RST specialists. This suggests an extra step for information search or advice giving in the MCHS, but the process tracing showed that local specialists had high awareness of EBM and systems to connect with RST specialists as needed, including using lean communication methods (e.g., creating and reading EHR notes).

There were also differences in referral patterns between ECH and the MCHS. SNA sociograms illustrated that most patients received access to specialty care in the network, but in the MCHS, there were instances when local specialists were circumvented in the referral process from community primary care to RST specialty. Process tracing further illustrated narratives in

which failure to formalize referral from the local providers to the RST providers resulted in fragmented care coordination and confusion about the best evidence course of care among the various providers. This suggests that there were differences in how the network operated when comparing advice giving and referrals for care.

Both EBM diffusion to community providers (in the form of advice) and access to care in the academic medical center are important means to keeping care in community settings and opening up specialty referral access. To better understand how providers mediate advice giving and referrals, the researcher performed additional analyses of the 773 eConsult orders to Gastroenterology and Hepatology identified in the unit selection process (Figure 3.4, Page 56). These data are limited to asynchronous advice (i.e., advice not given in real time), but they provide additional insights into how efficient, technology-enabled connections link providers across settings and answer the question of whether eConsults generate referrals to specialty care (which may take knowledge outside of the community setting) or whether knowledge is transferred to community providers.

First, the analyses found greater proliferation of eConsults in ECH (466 eConsults). While 10 providers accounted for a full third of these orders, each primary care location in ECH had multiple providers who submitted orders, demonstrating at least some level of adoption of eConsult orders in ECH settings. In the MCHS, there were a total of only 59 Gastroenterology and Hepatology eConsults identified using study criteria over the period.

Through review of the subset of 121 GI-related eConsult orders for patients under age 40 identified in the eConsults search strategy, the researcher found that 32 eConsults resulted in referral to specialist face-to-face visits, 22 resulted in recommendation for testing, and in 50 cases the specialist provided definitive advice that closed the loop on the generalist's question (e.g., making a recommendation for treatment or indicating that further follow-up was not needed). Seventeen cases did not have a follow-up note available for review.

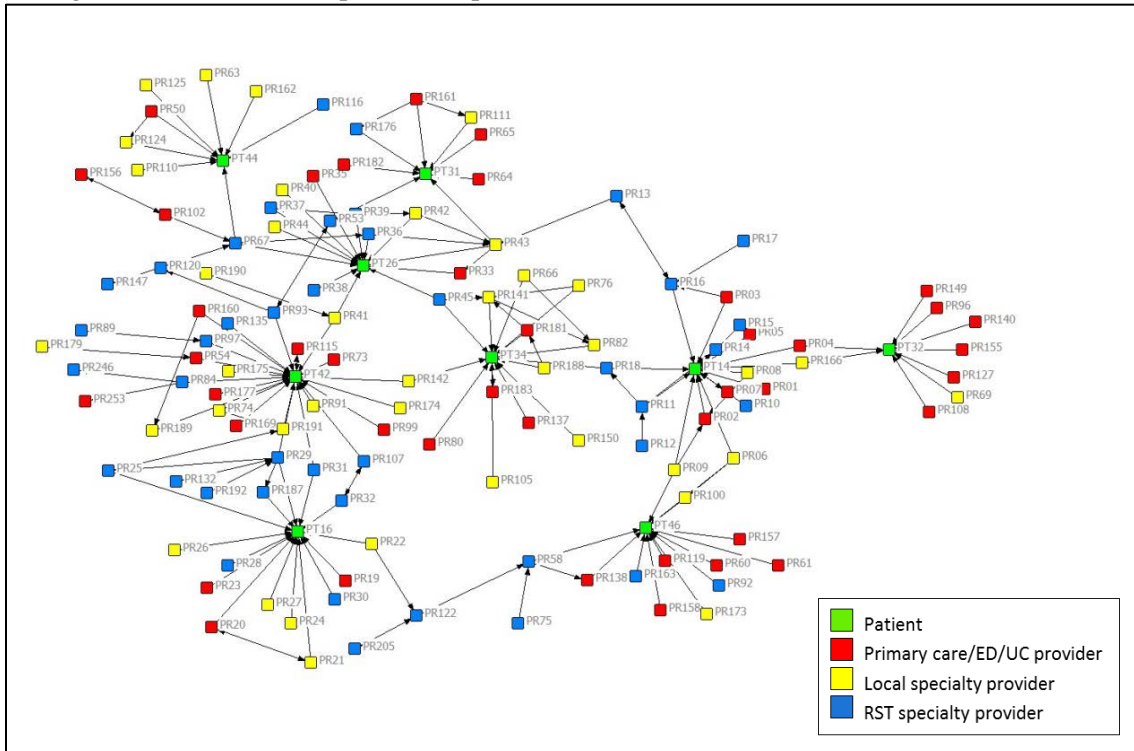
Although in a few instances a referral to a face-to-face consultation was made because it was difficult to make a definitive recommendation based on the electronic records available to the specialist making completing the eConsult, more often the referral indicated that a face-to-face visit was recommended because a review of the patient history suggested specialty consultation was appropriate. In these cases, an eConsult ensured proper use of referrals to specialty care. The same can be said for referrals to testing, which provided specialty oversight of when testing was warranted or what type of testing (e.g., colonoscopy or endoscopy) was recommended. In 13 of the 121 cases, the specialist was able to review the record—including notes on personal and family history of disease—and make a recommendation for surveillance. In those cases, appropriate future screening guidelines were suggested over immediate testing, per evidence-based guidelines. These findings suggest that in-depth analysis of advice and referral networks (e.g., using chart review) is necessary in interpreting results related to community-based and referral cancer care.

Process tracing also complemented SNA information on the positions of central actors in the network. SNA measures identified actors who were in a position between two other actors, but those measures alone did not provide information about whether actors with high centrality effectively mediated the flow of information or acted as gatekeepers to it. Process tracing found examples where actors with high betweenness centrality using SNA were either effective or ineffective brokers of knowledge between actors. Patients in particular were found to be less effective brokers of complex medical information, while local specialists more effectively mediated information between RST specialists and community primary care providers or patients in the MCHS.

Using the following MCHS sociogram in Figure 4.5 as an example, PR43 and PR141 are centrally located (i.e., located in the middle) local specialists, and they are also conduits for RST expertise. PR43 provided direct local specialty care to PT26, but he also received personal advice

from two specialists in RST, and he gave personal advice to the local primary care provider. The SNA in this case illustrates effective bridging of heterophilous groups, both in terms of profession and setting. The process tracing results for this patient likewise provide some evidence that persuasion also led to changes in attitudes. In the case of PR141, the local specialist was very involved in providing advice to colleagues involved in direct care related to PT34. The only RST expertise involved in this case unit was medical genetics, but it involved both a patient referral from PR141 and advice in the form of medical record notes back from RST medical genetics to PR141. This type of bridging was similarly effective in that patient case unit.

Figure 4.5  
Sociogram for all relationships: MCHS patients

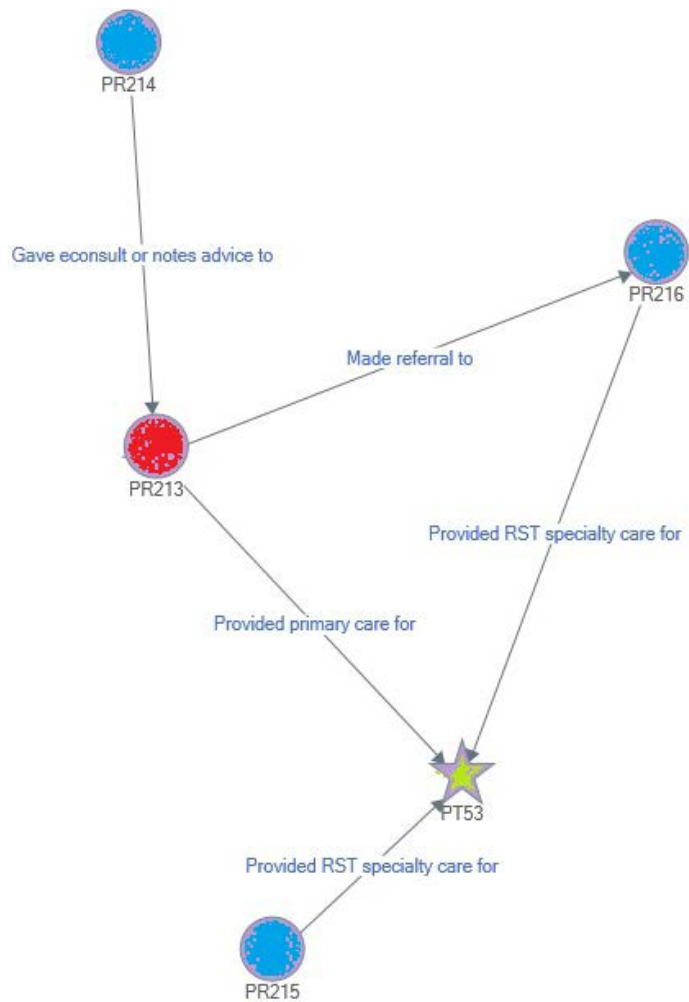


Central figures were not always effective information conduits. This was the case when providers acted as gatekeepers to information—most notably when specialist information was passed along through a local provider but there was little or no other interaction between the

specialist and the patient or other providers caring for the patient. In the ECH case units of this study, primary care providers consulted with RST specialists on several cases, but whether they acted as information conduits or gatekeepers was related to how specialist advice was documented and relayed to the patient or other members of the care team. Poor documentation and documentation errors were related to failures in EBM diffusion.

This situation was evidenced in the process tracing for PT53. This was a young male ECH patient whose primary care provider submitted an eConsult for advice on treatment (based on a particular lab value that was out of range) and colonoscopy screening recommendations. The response from the GI specialist responding to the eConsult order (PR214 in the sociogram below) outlined advice on three fronts. First, in regard to the lab value, the GI specialist corrected the primary care provider's interpretation and pointed out that another value was more important to watch. Second, the GI specialist made a recommendation for colonoscopy screening surveillance based on symptoms and increased risk for CRC. Finally, he suggested that there was some "newer data" on more effective medications, and he suggested the patient be seen in the GI specialty clinic for consultation. The primary care provider subsequently made that referral to a face-to-face consultation with a GI specialist (PR216). In an online portal message to the patient, though, the primary care provider did not pass along the screening recommendation from PR214. Instead, he told the patient that PR214 was deferring the recommendation to the person who would do the face-to-face consultation. Unfortunately, the subsequent face-to-face consultation did not include a documented screening recommendation, although it did suggest six-month follow-up for labs. In terms of shared understanding of the screening recommendation, the primary care provider potentially played an information brokerage role between PR214 and the patient, and the patient may not have ever had access to that knowledge. What is unknown is whether the second GI specialist read the eConsult screening recommendation and mentioned it

to the patient. That conversation is not documented, and the recommendation is not documented in a way that would be easy to find for future providers, even with access to the medical record.



Finally, this case unit example also shows how process tracing complemented the SNA findings by further describing whether, when, and how these connections resulted in the types of provider outcomes associated in the literature with EBM diffusion (i.e., access to information and opportunities for communication that could affect attitudes toward EBM or better care coordination). There were also a number of examples in the case unit narratives where the primary care provider was not included in RST-local specialty communications, which removes



opportunities for building shared understanding of best-evidence care and fractures patient care coordination at the primary care level.

### **Interpretation using Existing Theory**

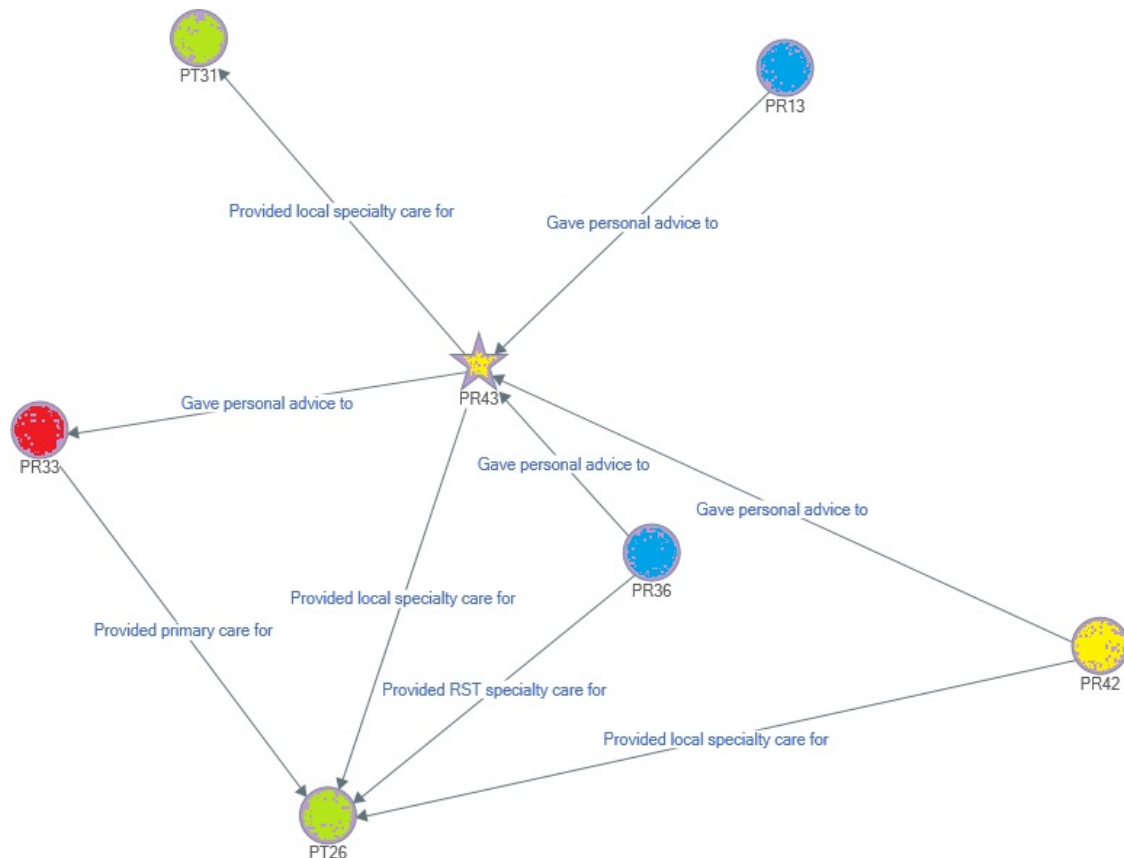
Another objective of mixed methods integration and interpretation was to understand the extent to which existing theory on innovation diffusion and interpersonal relationships explained provider and patient outcomes. Interpretation of mixed findings therefore included comparison to explanation building using the theories presented in Chapter 2.

**Diffusion of innovations and strength of weak ties.** The two primary theoretical explanations for effective networks under diffusion of innovations and strength of weak ties theories are 1) that networks act as bridges to new information between heterophilous groups, and 2) that networks have the potential to influence attitudes through personal persuasion or observing the experiences of peers. Therefore, this analysis involved assessing whether there were study findings that could be explained based on network connections of heterophilous providers that functioned to diffuse new knowledge or change attitudes.

First, in terms of bridges to new information, there was evidence in this case study that the network connected providers in heterophilous subgroups, including, those related to profession (e.g., type of specialty or primary care) and those related to geographic area (e.g., community setting or RST). These connections can be seen in sociograms that illustrate ties between primary care providers and cancer specialists. In ECH, these providers were geographically proximal but differed in terms of practice expertise. In the MCHS, cross-specialty ties were seen within setting when local primary care providers connected with local specialists, and there were also cases where local GI specialists connected to RST specialists across settings.

Many of these were direct connections between two providers, but there was also evidence of local specialists acting as brokers between local primary care providers and RST specialists. Local specialists who held this type of brokerage position were geographically

homophilous with local primary care providers and professionally homophilous with RST specialists, although RST specialists may have greater subspecialty expertise. An example of local specialist brokerage is seen with PR43, who was a local GI specialist with high betweenness centrality (see Table 4.1). As noted in the mixed methods results above, PR43 received personal advice from two specialists in RST, and he gave personal advice to a local primary care provider who was caring for a common patient. The egocentric sociogram for PR43 shows how the provider sits between PR13 (the RST specialist) and PT26, effectively brokering that advice relationship between them. He also gave advice to the local primary care provider caring for PT26 (PR33).



The study findings also demonstrated gaps in network knowledge diffusion. Network theories suggest that brokers may mediate information flow between heterophilous groups. An

example would be local specialists gathering information from RST specialists and sharing that information with primary care providers. However, failures in EBM knowledge and lack of EBM network activation at the local primary care level demonstrate that brokers did not necessarily bring information back to all members of the local subgroup. Rather, brokerage links appear to be provider-dependent, such that not all local providers shared the same level of knowledge about EBM or how to access it through network activation. This suggests that brokers between subgroups may need a more formalized role that engages all members of the local subgroup.

Regarding the proposition that networks serve to promote change in EBM attitudes, this study found fewer examples of persuasion than access to knowledge. The theoretical proposition that networks persuade actors to increase uptake of EBM may be best applied to two CRC practices: 1) family history taking, and 2) referrals to specialty advice or care. This case study did not allow for understanding of why providers did not consistently take comprehensive family history notes, or why they failed to make referrals for screening when patients presented with alarm symptoms or genetic counseling advice when patients exhibited characteristics potentially consistent with genetic predisposition to CRC. Lack of knowledge or lack of time may be two reasons, although there may also be providers who did not trust guidelines related to family history taking or referral.

What these analyses did demonstrate was that there was wide variability in how connected local primary care providers were to specialists and how experienced they were in caring for patients with these conditions. As shown in Figure 4.1 on Page 69, most primary care providers on the periphery of the network were only involved in one patient's care, and some of them were also relatively uninvolved with specialty care. For example, PT32 (in the lower right hand corner of the sociogram) is a patient from the MCHS who had several contacts with family medicine providers over the course of many years. However, she did not have connections to RST specialists, and her generalists were likewise relatively disconnected from specialists. These

may be providers with the least amount of experiential knowledge and for whom the network connections were less beneficial.

In contrast, there were a number of local specialists and some primary care providers who cared for multiple patients in this study, and they are more centrally located in Figure 4.1.

Providers who cared for multiple such patients may acquire additional experiential knowledge.

As such, if they are central actors in their community settings (e.g., acting as local sources of knowledge for peers), they would be ideal bridges for local knowledge diffusion and they could serve as exemplars for peers considering adoption of EBM practices. Identification of centrally located providers is also one way of indicating which providers have experience making network connections and potentially a cache of known specialist colleagues. This type of resource may benefit current and future patients of those providers. Providers on the periphery, in contrast, may represent those who lack information about network access or whose attitudes preclude access to it. In the MCHS, it may be especially critical to identify local generalists and specialists who have experience making those connections. Local specialists and MCHS generalists located nearer the center of the sociogram in Figure 4.5 have more varied and overlapping connections to others than those on the periphery.

Thus in terms of explanation building, diffusion of innovations and strength of weak ties were useful in guiding analysis of the *types of links* between providers, and especially between providers in different professions or settings. They also provided a framework for not only identifying central actors who bridged subgroups but also understanding the role that these individuals played in knowledge diffusion, e.g., information mediation versus gatekeeping. However, these theories may not adequately account for the types of EBM outcomes of interest in this case study, which represent a range of practices less precise than the single innovations studied in prior research, such as uptake of a new prescription or single treatment decisions. In this study, risk assessment, diagnosis, and care for patients with young-onset CRC or at risk for it

involved not only looking at if connections were present or absent, but under what circumstances providers activated potential network links over time. This involved nuanced understanding of different actions by providers in the same subgroups, as well as the role of patients in mediating information flow or advocating for EBM.

**Relationship centered care.** RCC in a multidisciplinary team involves making use of the expertise of others and setting aside issues of hierarchy. It also involves development of trust over time, often through small and repeated interactions. Thus, in this case study, the researcher looked for evidence of these types of interactions, especially for their potential to explain EBM diffusion or uptake. This included assessment of relationship qualities outlined by Safran and colleagues (2006). As a unique application of RCC, the researcher was also interested in assessing whether these types of relationships were possible across geographically dispersed teams.

Chart review methods may be more suitable for identifying relationships than assessing relationship qualities, but the researcher did find indications of RCC in the case study analysis, including relational qualities like mindfulness, diversity of mental models, a mix of rich and lean communication, mutual respect, and trust. Mindfulness involves awareness of other experts within the organization and willingness to see things from their perspective. This was illustrated when local providers reached out to specialists with different expertise, including more specialized GI expertise in family cancers or expertise in medical genetics. There were examples of primary care to local or RST connections, as well as connections between local specialists and RST specialists. An example of a primary care provider relying on the expertise of a GI specialist is documented in the narrative for PT56 when the primary care provider used an eConsult with a specialist because he was confused about how to interpret the results of colonoscopy, in light of information about family history. This interaction goes beyond information seeking and clearly documents the need for the specialist's expertise to assist the primary care provider in developing a care recommendation. Similarly, in the narrative for PT57, the provider submitted an eConsult

to the GI team, noting that he would “appreciate their input” on what he described as a challenging screening decision. In these situations, connections to experts within the organization led to evidence-informed recommendations for patients.

Diversity of mental models goes beyond consultation to include opportunities for group problem solving among individuals with varying expertise. There were fewer examples of this in the case study, but e-tumor board discussions among RST specialists were portrayed as opportunities for multidisciplinary debate and problem solving. There were few examples of these discussions involving people dispersed across the network, but the electronic nature of the e-tumor board discussions are meant to include the local specialist in the discussions via remote video access. This may have been the case for the local oncologist involved in care for PT42, who described in his note that he was preparing to present to the e-tumor board.

Organizational RCC refers to opportunities for rich and lean communication as important for fostering conditions for relationship building. The situations described above include examples of rich communication such as e-tumor board discussions and lean communication methods such as eConsults for advice on screening results. The network provided structure for these types of communications and knowledge diffusion, but whether these opportunities led to relationship building is less clear. Many of the connections between providers were for isolated questions, but there were a handful of narratives that involved repeat interactions between providers. Some of these were repeat lean communications, but there were also examples of provider dyads with repeat rich and lean interactions. In the case of PT51, the primary care provider had connections to eight RST specialists, either for referral or advice. Almost all of the interactions between the primary care provider and the specialists were one-time consultations or referrals, but there was one dyad that included multiple types of communication and repeat interactions over time.

These types of interactions also provide some means of assessing the RCC perspective on mutual trust and respect. Mutual trust in relationship theory assumes trust goes up and down the organization (Safran et al., 2006). Reaching out to access expertise as needed may be indicative of trust and respect, while failing to access expertise could reflect either lack of awareness (i.e., mindfulness) or lack of trust, as well as structural barriers like lack of time. One area in which achieving or failing to achieve mutual respect or trust may have impacted EBM outcomes was in care coordination during the treatment and survivorship phases. Care coordination represents an opportunity for repeated interactions and shared care management that leverages different expertise from different members of the care team at varying points along the cancer continuum. As such, these relationships may be ideal situations for fostering relationships between clinicians.

In the most successful process tracing case units, this involved a mix of rich and lean communication that looped in different members of the team to the extent that they needed to be involved at that point in the cancer continuum. An example is the case unit for PT34, where there was consistent communication between the local specialist and primary care provider during the treatment and survivorship phase. Communication with the RST specialist was limited to lean communication documented in clinical notes. In this situation, the network allowed local providers to leverage RST expertise, but development of relationships remained largely at the local level. In this case, this likely set the stage for a successful patient transition back to primary care after active treatment.

In contrast, the analysis also highlighted how failures in developing mutual trust and respect impacted outcomes like coordinated and patient-centered care. Two examples illustrate this issue. In the narrative for PT42, the patient saw high numbers of providers both locally and in RST. Distance to RST was described in EHR notes as being a challenge for the patient, but she continued to rely on RST specialists for specialty care, as well as medical concerns commonly treated in primary care. A local provider made note that some of the patient's care could likely be

handled in the local setting, but notes summarizing patient conversations also suggest the patient put her trust in RST specialists (more so than local providers at times). This may have been a missed opportunity for specialists to help increase patient trust in local provider expertise, thus demonstrating the up and down nature of mutual respect in RCC. Likewise, in other narratives, local providers redirected patients to RST specialists (e.g., PT16) or they were unsuccessful in attempts to engage RST specialists in shared care conversations (e.g., PT46). These examples demonstrate varying levels of respect, as well as missed opportunities for engaging in conversations across settings that might open up avenues for knowledge dissemination.

Finally, in terms of relationship characteristics such as mutual respect and diversity of mental models, this case study found several instances in which local providers deferred to a specialist. In the case unit narrative for PT44, the patient gave a paper report to his primary care provider that detailed the surveillance recommendation from an RST specialist. The primary care provider said in her note that she would “just follow him with recommendations made by” RST specialists. The paper note was not retained in the EHR, though, and there is no indication that any other communication took place across settings. In this case, deferral to the RST specialist may represent trust or respect, but it is not in the spirit of relationship-centered care. A similar deferral from primary care to RST specialist advice was found in the narrative for PT53. In that narrative, the specialist provided advice to the primary care provider, which could have brought the primary care provider into the communication loop. Instead, the primary care provider simply made a referral to a face-to-face GI consultation and told the patient he would defer to the specialist’s recommendations. These actions may indicate respect or trust, but they do not necessarily support knowledge dissemination to community settings.

In terms of RCC and its application to this case study, it appears that there were continued issues with hierarchy or lack of trust in some narratives, but the network did create opportunities for both lean and rich communication between multidisciplinary members who—at



the very least—were mindful of others’ expertise. In terms of geographically dispersed groups, there were more indications of lean communications and fewer instance of group problem solving, but repeat interactions evolved from lean to rich in some instances over time. In terms of the applicability of RCC in explanation building, these analyses suggest that RCC provided a useful means to understanding different types of relationships and identifying relationship characteristics related to EBM. Characteristics like mindfulness may be most applicable at risk assessment and diagnosis, which is a time when awareness of expertise and trust in recommendations from experts in other settings may be critical. In the time period following diagnosis and during treatment or survivorship, this study found that mutual trust and opportunities for rich and lean interactions explained outcomes like shared understanding of best evidence treatment. In terms of its applicability across settings, though, organizational RCC’s focus on group reflection and team problem solving may fall short. Distinct from the types of multimodal and collaborative problem solving evidenced in the RST specialty setting (e.g., e-tumor board discussions), this case study found that detailed notes and efforts to keep all parties involved in the communication loop were more effective EBM strategies across settings. This included the mediating role of local specialists, who spanned professional and geographic subgroups. Thus RCC may be more useful in explanation building if it is extended to consider connections between subgroups in a network (i.e., organization) more specifically, rather than considering all members as being involved on the same level.

**Distributed cognition and shared mental models.** The DCog framework is concerned with the shared understanding that emerges when individuals with varying expertise collaborate, such as with multidisciplinary members of a team. Thus, this case study assessed whether, when or how the network created opportunities for the types of interactions that fostered shared meaning—while maintaining professional boundaries—and led to evidence-based care. It also sought to assess whether DCog applied to teams that were not geographically collocated.

This case study found some evidence that the network engaged individuals in multidisciplinary conversations that led to shared understanding of EBM. These included a handful of cases in which generalist-specialist conversations informed common understanding of best-evidence risk assessment or screening. This was the case in the narrative for PT54—where there was back-and-forth lean communication and EHR review that led to shared understanding—and PT56, whose providers were similarly involved in a high degree of lean communication. DCOg refers to “varying but overlapping expertise” (Palonen et al., 2004), which may be analogous to the manner in which different subgroups are homophilous. For example, local specialists and RST specialists may share common training in GI care while varying in their subspecialty expertise or experience with community care. Both of the above examples were ECH patient narratives, meaning providers were heterophilous across profession but homophilous in setting. There were also instances where cross-setting conversations happened among providers homophilous in profession. An example is PT26, whose narrative indicated that conversations between local and RST specialists served as a way to arrive at a common understanding about the best course of care.

Similar to constructs like mutual respect under RCC, these analyses illustrated situations where efforts to access expertise could be seen as synonymous with appreciating and maintaining expertise. In the case of medical genetics or GI neoplasia clinic consultations (e.g., with subspecialists in GI family cancers), local specialists may have been asserting their expertise in GI diagnosis and care while appreciating the need for specialized GI-related genetic expertise from RST. Similarly, efforts by local specialists to secure second opinions, as was the case with the local oncologists for PT44 and PT46, may illustrate varying but overlapping expertise.

However, these types of multidisciplinary conversations were more common between specialists within a common setting. These interactions were also more often multimodal (e.g., in-person or telephone conversations, e-tumor board discussions, and EHR notes). Such was the case

for PT14. In this narrative, a new primary care provider assignment generated an advice relationship with a local GI specialist, but it was subsequent referral to RST specialty that led to multidisciplinary conversations—largely mediated by the RST GI specialist — and development of shared understanding between various parties. These conversations included RST GI specialists, RST medical genetics specialists, RST gynecology specialists, and the patient. A note from the GI specialist indicated that her initial thoughts on the best-evidence course of care were revised based on these conversations. Notably, most of the conversations between the patient and the RST GI specialist took place via portal messages, indicating the potential of lean communication across geographic distance between providers and patients. However, these conversations did not include the local primary care provider or the local specialist, and not all specialist input was documented in the EHR, limiting the availability of information to providers across settings. Similar gaps between settings were seen for PT16; multidisciplinary conversations informed decisions in RST, but the patient was largely put in charge of relaying information to local providers. In fact, information brokers often served to disrupt potential shared understanding across setting. This was similarly seen in the narrative for PT53, where the primary care provider relayed only part of the original specialist recommendation to the patient.

More common than multidisciplinary conversations were referrals across settings. This is a critical factor if communication across settings is necessary to change attitudes and come to shared understanding. Referral for medical genetics advice is an example; there were cases where local providers referred patients to RST for medical genetics consultation because that expertise was only available in RST. Patients attended those appointments in person because they involved detailed family history taking and counseling. In general, medical genetics consultations were documented in detailed clinical notes, which were then available to all parties, but medical genetics providers rarely gave personal advice to colleagues in this study. Subsequently, some local providers read and were familiar with advice given by the medical genetics provider and

some were not. The most successful interactions with medical genetics in this case study appear to be when a local specialist or other RST specialists were involved and engaged in using genetic information as one piece of a multidisciplinary strategy to determine best-evidence care, as was the case with PT42.

In addition to these challenges, the narrative for PT29 demonstrated the additional complications of shared mind conversations when providers from outside the network are involved in patient care. In this narrative, lack of a shared EHR may have limited communication opportunities, but there also appeared to be issues related to lack of a common mindset between the Mayo Clinic oncologist and the outside oncologist. Rather than personal negotiations between specialists about best-evidence care, the patient was left to relay messages between them, and her messages suggest she struggled to rectify their discrepant recommendations. The Mayo Clinic specialist outlined to the patient his impressions of the scientific evidence using a mix of in-person communication and electronic messages, but the patient and her different oncologists did not seem to achieve shared understanding. These interactions may have been further hampered by the time and emotional pressures of a late-stage diagnosis.

Thus in terms of explanation building in this case study, DCog and shared mind theories highlighted the role that shared understanding of evidence-based practice (or lack thereof) played in whether a patient received EBM. This included instances where providers appreciated the expertise of others, including expertise that overlapped in some ways with their own, such as between local and RST specialists. However, these theories focus most of their attention on transformational information sharing in settings with in-person interaction and open communication. This case study highlighted the potential of varying types of interactions and potential opportunities for both transactional and transformational information sharing in EBM diffusion. Prior research on shared mind suggests it is difficult to achieve when teams are assembled quickly for patient care or when team members were dispersed across settings

(Lazzara et al., 2016; Noyes et al., 2016; Page et al., 2016). Findings in this case study suggest shared understanding across settings may be possible using a mix of rich and lean interactions that leverage common infrastructure, if all members of the team have time to review notes and opportunities to connect for personal advice (including back and forth follow-up) as needed.

## Chapter 5: Discussion

Chapter 4 presented the results of SNA and process tracing, as well as the integrated findings, followed by interpretation with regard to the theories presented in Chapter 2. Chapter 5 revisits the analysis objectives of this study: to identify factors related to whether and how the network connections functioned to increase EBM in community settings; and to understand the extent to which existing theory regarding innovation diffusion and interpersonal relations explain provider and patient outcomes. The chapter then presents implications for clinical practice and directions for future research.

### Factors Related to Network Function

The results showed that the network made EBM available in community settings through information access and referrals, but they also showed that network connections alone did not ensure EBM delivery for all patients in this case study. In fact, network failures in some cases—especially in documentation and collaboration—either offset network benefits or delayed them. It is within this variation that the research began to identify factors whose presence or absence impacted outcomes. These factors can be summarized in seven related categories, which are personal, interpersonal, and structural in nature:

1. Awareness of young-onset CRC;
2. Activation of advice networks;
3. Access to specialty referral;
4. Role of information brokers;
5. Multidisciplinary interaction and culture of organizational teamwork;
6. Care coordination across settings; and
7. Efficient and effective documentation systems

**Awareness of young-onset CRC.** The current study investigated the potential of networks to address one of the most alarming trends in cancer incidence: the rising rate of CRC

among patients under age 50. However, this study's results suggest that personal knowledge of young-onset CRC risk assessment and diagnosis varied from provider to provider at the community primary care level in particular, which is the setting where most young adults interact with the health care system. This underscores the acute need to educate providers about young-onset CRC (Patel & Ahnen, 2018), so that access to EBM is not dependent on which provider a patient is assigned and whether that person is familiar with best-evidence risk assessment, diagnosis, or care.

Questioning patients about a family history of CRC before the age of 50 is an important strategy for addressing the growing number of young onset CRC cases. However, providers in this case study often failed to ask about family history of CRC, even if they did query family history on other cancers, e.g., breast cancer among young female patients. This suggests a need for provider education on the importance of comprehensive family history taking at early ages, including cancers typically not screened for until older ages. In addition to highlighting the need to take a comprehensive family history, this education should also aim to help providers better understand what family history details are relevant. Providers in this case study sometimes referred to first-degree relatives only or queried family history of CRC without attention to genetic risk factors, behavioral risk factors, or family history of colon polyps. Providers may also need to gain competencies to manage the increasing availability of patient genetic information (Rubin et al., 2015), including genetic information self-reported by patients. Specialists in the network may be one source of potential provider education, e.g., through in-person or technology-enabled webinars or training modules.

*Patient education* about the importance of family history is also critical. Patients in this study were often unaware of their own family history, or they reported limited detail about family history of CRC, colon polyps, or other indications of hereditary syndromes. At the same time, engaged patients were often the ones who reported family history concerns and advocated for

additional information or screening. Campaigns to help patients talk with family members about cancer family history may have promise for raising awareness in the community, including among those who do not seek regular health care. This includes the need for better understanding of what constitutes “family medical history” in the context of hereditary disease (Lim & Hewison, 2014). This is an important strategy for general awareness, but it is also important for risk assessment. This study found several instances where medical genetics or GI consultations were limited by the inability of patients to gather sufficient detail from family members with personal history of cancer or genetic disorders. Accuracy of family history reports—especially age at diagnosis or other details of a cancer diagnosis or diagnosis of polyps—was variable in the narratives included in this case study, but accuracy is critical to informing the personalized risk assessments that underpin screening recommendations. Providing patients with family history questionnaires to be completed outside the office visit may encourage family conversations and provide additional time for completion (Murff, Spigel, & Syngal, 2004). Welch and colleagues (2018) reviewed a number of patient-facing family history tools that may help patients organize information before a clinical visit.

Given that the majority of young-onset CRC cases are not hereditary, though, helping primary care providers understand other risk factors (e.g., obesity), as well as the signs and symptoms of CRC in the absence of family history (e.g., alarm symptoms like rectal bleeding), is also critical. This study found that providers did not all follow common EBM-informed steps for follow-up when patients presented with symptoms. This was especially true for symptoms with lower predictive value, such as abdominal pain or nausea, but it was also true for alarm symptoms. This was the case for PT42, whose referral for rectal bleeding did not happen with the first report of symptoms. In addition to education, primary care providers may also need new tools or awareness of existing tools for assessing CRC symptoms. These include process of care models or decision trees that help providers determine when a referral to screening or specialty



consultation is appropriate based on symptoms or risk factors. Similarly, this case study found examples of patients who delayed seeking care for alarm symptoms, suggesting the need for patient education. PT16 for example, reported a year or more history of blood in this stools, diarrhea, fatigue, and weight loss of more than 30 pounds when he finally sought help from the primary care provider. Timely care is critical given that most cases of young-onset CRC are diagnosed at late stages.

Furthermore, this study found few examples where providers utilized data in the EHR for risk assessment, thus providers may need triggers related to the application of EBM guidelines, particularly in the case of CRC risk assessment. Electronic algorithms could be used to alert the need for an assessment when patients present with symptoms (Murphy et al., 2014) or report family history that could be predictive of a hereditary disorder (Baer et al., 2013). These recommendations are in line with the IOM's call for creation of an efficient, technology-based system to promote rapid adoption of EBM-driven guidelines (IOM, 2013).

**Activation of advice networks.** One of the primary functions of networks is to diffuse evidence-based knowledge to community settings so patients can get the best available care close to home. Networks are hypothesized to increase EBM uptake by improving access to knowledge from experts, e.g., specialists in the academic medical center. This includes links to expert advice on risk assessment, diagnosis, and care, as well as advice on when additional services (e.g., screening or referral) are warranted. These various types of advice connections were found in this case study. Primary care providers sought expert advice on what type of screening was needed based on symptoms and family history, for example, and local specialists queried RST specialists when genetics advice or surgical expertise was needed to care for a patient with a diagnosis of cancer or a genetic disorder.

However, the case study results also identified variability in whether or when advice networks were activated, and in some patient narratives, this variability may have been associated

with failures or delays in EBM care. This can be seen in the narratives for PT31 and PT52, in which both primary care providers made a screening recommendation that was not aligned with the EBM recommendation, but in only one of those examples did the provider clarify the recommendation with a specialist. In the PT52 narrative, activation of the advice network resulted in a revised screening recommendation that was consistent with EBM.

Although the advice network should have been available to all providers, failure to activate it suggests there are remaining challenges to awareness of available links or related costs in the time and effort to activate links. Education related to the availability of expertise may be necessary to increase its utilization. This may be especially true given growth in the MCHS. Over the many years of patient data in this case study, MCHS clinics had varying levels of integration or years spent as part of the network. In contrast to ECH, which grew out of the academic medical center practice, many of the MCHS sites were purchased from other health systems or private practices. Those circumstances may have produced challenges in educating community providers about access to advice networks or challenges in identifying the proper channels for personal or electronic communication.

These issues may also be related to differences between ECH and the MCHS in *how advice networks were activated*. Primary care providers in ECH were more likely to use eConsults than MCHS providers, even though MCHS providers are more geographically dispersed. These eConsults were effective at providing advice about care and for making decisions on screening or referral, thus ensuring appropriate health care utilization. At the same time, those lean communication channels did not always foster the type of on-going connections between generalists and specialists that tend to foster changes in EBM attitudes and patient-centered, coordinated care.

In the MCHS, it was more common to activate personal advice networks at the local level, e.g., telephone conversations for advice from specialists in the same or nearby community

GI practices. This may leverage relationships that are built between primary care providers and specialists in local communities, but reliance on an interpersonal system of advice such as this also carries risks. Most importantly, development of these relationships requires time and effort that some primary care providers may lack, especially if staff turnover is high. Furthermore, systems may not be in place for new primary care providers to develop those links. Electronic communication may also be more efficient and more easily stored in the EHR for future reference.

Therefore, a multi-pronged system of education about the network, as well as a mix of rich and lean opportunities for advice from local and academic medical center experts may be needed. This may begin with education about what links are available, including systems for identifying the right expert for each question. Opportunities to bring specialist education into local settings for CRC awareness may also serve as a way to bolster awareness of advice networks, whether that be a connection to a specific expert (e.g., a specialist who could be emailed or telephoned with a question) or to a specialty group (e.g., the providers in the GI specialty group who respond to eConsult orders).

**Access to specialty referral.** Another primary aim of networks is to make access to specialty care available through referrals to expert care and treatment. High-volume specialty facilities, including NCI-designated comprehensive cancer centers, provide expertise and treatments unique to those settings, thus referrals provide benefits to community clinics that are in networks with these facilities. This study found that the network did indeed create access to referrals to RST specialty care. The benefits of access were clear in cases such as referral to medical genetics, which was otherwise not available in community settings. Examples of access to clinical trials and high-volume surgical capabilities were also identified in this case study.

Not all patients received referrals though, and the threshold for referral varied between patient narratives, as was the case for some medical genetics referrals. Provider knowledge or

attitudes may have limited referrals in these cases. For example, in the narrative for PT14, the eventual referral was made for the purpose of reassuring the patient, signaling that the provider may not have been of the opinion that a referral was necessary, absent the patient voicing a concern. Local specialists further played a role in determining when the patient required a level or type of expertise beyond what they could offer, as well as determining whether to activate an advice or referral network. Thus their opinions on what specialists or subspecialists could offer may have impacted when referrals were made. This is complicated by the fact that the threshold for referral may not be clearly defined in all situations. EBM involves clinical judgment using a variety of information; still, there was some evidence that differences in thresholds for genetic referrals, as an example, were the result of differences in provider knowledge or attitudes, rather than variation in clinical judgement of patient factors.

This case study also found instances where patients needed to advocate for referral. PT28, for example, repeatedly asked for referral to screening based on family genetic results, but his primary care provider played a gatekeeping role in access to referral. In at least two other narratives, the patients self-referred to specialty care. Furthermore, even when referral access was available to patients through the network, it was not necessarily the case that insurance coverage was adequate. Genetic testing was one example in this case study of a procedure that is not always fully covered by insurance. Similarly, colorectal screening before age 50 is not always covered, as documented in the narrative for PT31. Strategies to address referral access thus require multi-level intervention. At the system level, similar to the advice network, providers need to know what types of referrals are available and when they are appropriate. Efficient methods of advice, such as eConsults, may help providers triage complex clinical situations and decide when referral is warranted and to which specialist they should submit the referral. This type of triage could ensure that referrals are available but used appropriately, minimizing burden on the system and patients. Advice from co-located specialists (e.g., specialists who visit local

clinics on a rotating basis) may similarly reduce inappropriate referrals (Elrashidi et al., 2017). Providers and patients may also need additional guidance from the organization about the costs that referrals may incur. Failure to do so could result in financial or other burdens for patients and overwhelmed specialty practices.

**Role of information brokers.** Assessment of network links highlighted the role of brokers, including individuals who were located on the path between a provider and patient or between two providers. These individuals were sometimes effective and sometimes ineffective mediators of knowledge, information, and access. Local specialists in particular were advice brokers in the MCHS, where RST specialty advice more typically flowed *through* a local specialist, who only activated the RST link when additional *subspecialty* expertise was needed. As noted above, it was common for local specialists to get advice from RST and then translate that information to local primary care providers or patients.

Given the size of the MCHS, this method of knowledge diffusion from specialist to specialist may be efficient and lessen the burden on local primary care providers to keep up with growing number of EBM practices and sources of advice. Local specialists may also benefit from easier communication with RST specialists because they are more homophilous in their training, making local specialists effective bridges between subgroups. In fact, these different types of communication arrangements provide EBM access depending on whether or not the groups are homophilous with respect to specialty (e.g., GI specialists in the community and GI specialists in the academic medical center) or geographic location (e.g., all providers in the same community system or city). However, knowledge diffusion was incomplete in cases where the primary care provider was left out of the loop. In cases such as these, solutions may include personal or technology-mediated links. This study found examples where local specialists effectively relayed knowledge via personal conversations, but it also found examples where local providers appeared to have read specialist notes, thus obtaining access to information through lean communication.

Local primary care providers may not need to be involved in all care-related conversations between specialists, so development of effective documentation systems that summarize EBM decisions may be an efficient way to diffuse knowledge. However, primary care providers might benefit from alerts that documentation is available and access to specialists for follow-up questions. These are critical to eliminate closed-loop failures, for example when a specialist in this case study made a recommendation on screening but there was no provider in charge of reading those documented recommendations and ensuring that screening took place.

Unlike advice connections in the MCHS, referrals were more often directly made between primary care providers and RST specialists. This suggests that MCHS primary care providers viewed the network differently for advice and referrals, especially in terms of the role the local specialist might play. Taking local specialists out of the referral loop may fail to leverage their expertise to triage referrals appropriately. It also leaves them out of the communication loop, potentially resulting in misunderstandings about the best course of care and needed follow-up.

Social network theories such as diffusion of innovations and strength of weak ties refer to the role of brokers as connecting otherwise heterophilous groups and thus creating bridges to novel information. Brokers in this study, however, did not always represent a bridge between otherwise disconnected subgroups. Rather, they were often one of a few connections between subgroups, and they often connected individuals in more than one way. For example, some RST specialists provided advice to local providers and then subsequently provided direct care to their patients. They also varied in whether they served to mediate information or serve as a gatekeeper to it. Long, Cunningham, and Braithwaite (2013) refer to the different roles of actors who connect disparate groups of professionals, such as bridges, brokers, and boundary spanners. They suggest that brokers can work to effectively facilitate the appropriate level of information flow, including the flow of ideas in both directions. Therefore, to address the inconsistency in whether or not

brokers are effective in this network, organizational strategies must not only identify key network actors that link subgroups, but also clarify expectations for brokers; putting too much burden on brokers risks overwhelming them and taking away from the time needed to maintain expertise (Cross & Prusak, 2002), while leaving them out of the loop fails to leverage their potential to ease communication between subgroups. Regional organizational structures in cancer care may currently create structural links between providers who work in cancer-related disciplines, but the network may need to assess whether new structures are needed to further support the potential of local specialists to bridge RST specialists and local primary care providers.

**Multidisciplinary interactions and a culture of organizational teamwork.** Both network and relationship-focused theories posit the need for personal interactions, either to diffuse information or to come to agreement on the best course of care. This is especially true in an integrated network such as this, which connects community clinics to an academic medical center but which also brings together distal practices that are a part of the same organization. Two findings from this case study are important in considering how network organizations address challenges in multidisciplinary interactions. First, this study found that the most robust multidisciplinary interactions happened in the specialty setting, especially in the RST specialty setting, where in-person multidisciplinary e-tumor board discussions provide dedicated time for negotiation and information sharing among various experts. These interactions are consistent with the notion of building shared understanding of EBM for patients with a cancer diagnosis, and local providers can be included via remote video participation. Recordings of e-tumor board meetings are also increasingly being made available to patients whose cases were discussed.

Compared to these specialty setting e-tumor board discussions, multidisciplinary interactions *across settings* were leaner, but these conversations were often detailed in clinical notes, making them available to all members of the care team. Thus, the network may benefit from giving greater attention to creating opportunities for lean modes of communication between

multidisciplinary providers, especially on topics such as risk assessment or recommended screening, where asynchronous advice may be sufficient. In addition to electronic systems for connections, development of opportunities for in-person or real-time electronic interactions may begin to build a culture that showcases the diversity of available expertise to network members (including that of primary care providers). Examples might include educational seminars, networking sessions, or case review sessions with GI specialists and primary care providers. Opportunities for networking—in addition to more transactional information sharing—may be consistent with the organizational RCC emphasis on social and task-related interactions that foster information sharing and organizational culture. However, these types of personal connections are time and resource intensive, especially in a geographically dispersed and financially lean environment. Remote, real-time connections are efficient, but their potential to foster organizational culture may require further study. Local specialty groups—homophilous in setting with community providers and in profession with RST specialists—may have the greatest potential to bridge the organizational gap.

Second, research from the field of implementation science suggests that provider engagement in development of innovations (e.g., strategies to improve communication or information access) promotes their subsequent buy-in and uptake. Efforts to develop information and communication tools, as well as opportunities for social and professional interactions should be provider-driven. They should also be sensitive to contextual factors including payment structures that may or may not support time for fostering relationships (Reschovsky et al., 2015). Finally, the organization should consider the potential of strategies that foster unique but shared identity across settings or subgroups. While this network represents a single organization, it is still comprised of many local clinics, hospitals, and providers. Intentional decision making about teamwork can capitalize on the distributive potential of unique expertise while also teaching team members how and when to integrate knowledge and care—what Weaver (2016) called moving



“from a team of experts to expert teams that practice mindful teaming” (p. 976), including development of trust, shared mental models, and closed-loop processes.

**Care coordination across settings.** Networks that develop common understandings related to best-evidence patient care may also be able to overcome persistent problems related to care coordination and transitions between primary and specialty care. This case study found evidence of successful as well as less successful care coordination. The most successful cases occurred when there were formal referrals and advice connections between settings and effective communication and documentation, so that all providers (and the patient) were aware of clinical information and decisions.

In contrast, communication gaps often resulted in closed loop failures, as in when a provider made a recommendation but no one was in charge of ensuring that follow-up occurred. This was the case for PT05, PT14, and PT52, for whom a recommendation for a referral to a genetics consultation was referenced in an eConsult but never ordered. These gaps were further amplified when patients saw additional providers outside the health system who lacked both personal links and shared electronic records. In cases such as PT29, patients were put in charge of relaying information and coordinating care. For PT29, missed clinical trial opportunities were potentially associated with lack of coordination between the RST and outside oncologist.

Challenges also arose when referral took local providers out of the loop. Not only did such referrals leave some providers unaware of clinical decisions, they hindered the potential for local providers to gain additional expertise in risk assessment, diagnosis, or treatment. This is critical in light of research showing that many community providers feel unprepared to manage cancer-related care, even into survivorship, when patient care is optimally transferred back to the community setting. Reading EHR notes was a primary method for community providers gaining knowledge about a specialty visit, such that there was often limited personal interaction between providers. This type of knowledge sharing between local and RST specialists may be efficient

and effective given commonalities in training, but this may be less effective in raising primary care providers' comfort in managing complex care. In cases where patients self-referred, care coordination and knowledge sharing were especially fragmented. Likewise, in cases where providers noted “deferring” to RST specialists, they may simply have been transferring care decisions to RST specialists, rather than engaging in the type of back-and-forth communication and negotiation more indicative of shared understanding and effective care coordination. Strategies that involve local care providers in formal referrals also have potential to address another common failure viewed in this case study: lack of closed-loop referrals to specialty care.

Thus, the strategies related to care coordination are similar to those related to knowledge diffusion in advice and referral relationships: opportunities for efficient and effective rich and lean communication, effective documentation, and sufficient time. If the network is to simultaneously create referrals to specialty care and overcome barriers to EBM—including low awareness and lack of time—it will need to find the right balance of technology-driven and personal strategies. Furthermore, efforts to stem the tide of late-stage diagnosis of young-onset CRC are well-suited for intervention in primary care settings because that is where most patients present for preventive and acute care. Providing community clinicians with tools to assess when referral is appropriate—as was the case with several ECH providers in this case study who utilized eConsults for this purpose—could ensure appropriate use of referrals, but strategies for engaging community providers after the referral are needed to bolster knowledge diffusion and coordinated care, including closed-loop follow-up to determine whether the referral appointment was scheduled and completed. The organization could also consider how rich and lean communication strategies support the development of mutual respect and trust that underpin confidence in sharing patient care, especially when communication flows through a broker and may involve issues of professional hierarchy. This case study found more instances of trust in specialty expertise than respect for care in the community setting. Development of this trust is

necessary for successful transitions back to the primary care setting, a critical component of health care cost control, as well as patient satisfaction and safety.

Finally, engaging patients in their care is critical; this includes ensuring their preferences are taken into account and that they are engaged in conversations and decisions about their care. However, this study found challenges when patients were put in charge of communication and coordination between their providers. Systems that allow transparency of information flow between all parties—e.g., shared medical records that are available to patients through online patient portals—have potential to ensure all members of the team, including patients, have the same level of information. Remote video-enabled telemedicine consultations that include the patient and local provider in one setting and the specialist in another may have dual benefits of care coordination and relationship building (Kirsh, Ho, & Aron, 2014). Explicitly written shared care plans likewise identify which person on the team is responsible for care coordination or next steps at any given time. This case study found examples where a GI specialist was watching the EHR for test results or notes from other specialists and taking charge of communicating all of this information to the patient. These arrangements appeared to be ad hoc, though, rather than explicitly outlined in a shared care plan. Research on shared care plans to coordinate care during cancer survivorship (Loonen et al., 2018) may provide insights into how shared information could be structured during other phases, e.g., risk assessment. DCog and shared mind theory could provide a useful framework for development.

**Efficient and effective documentation systems.** Despite the emphasis in network research on the value of personal relationships, almost all of the above network factors are related in some way to efficient and effective documentation in the EHR. There was some variability in what records were available to providers across the network, with some providers able to access notes, for example, but not test results or radiology reports. Some of this variability is related to the fact that clinics often joined the network after previously being a member of a different health

system. Some ability to share information was consistent, though, and documentation was critical to lean methods of information sharing. In fact, this study found evidence that shared documentation supported EBM outcomes for several patients.

However, there was also evidence in nearly half of the case narratives that the existence of a shared medical record was not in and of itself cause for clear communication, shared understanding, or closed-loop referrals or follow-through. Many of these failures occurred when providers did not access documentation that could have informed care. In the case of PT02, RST specialists in GI family cancers and genetics documented clear screening recommendations, but notes from the subsequent primary care visit make evident that these recommendations were not reviewed. The patient's and her family members' histories were also incorrectly documented in individual primary care notes over the next several years. Incorrect reports by the patient further obfuscated documentation in the record. In this instance, the patient may have been an ineffective information broker, raising the question of how to engage patients in their own care while maximizing the potential of shared electronic infrastructure.

Other failures were related to how information was stored in the record. For example, provider summaries of conversations with other providers were often stored in individual clinic notes from a patient encounter (e.g., an office visit or a portal message). Providers also showed variability in family history documentation. Improvements in genetic family history taking may increase identification of high-risk patients (Harrison and Handley, 2017) but electronic systems must allow for adequate documentation of family history—and triggers to update information—so that all providers caring for a patient are aware of and have updated personal and family history. As noted earlier, algorithms that use personal and family history to identify high-risk patients and trigger conversations between patients and providers may also have promise, although integration of decision support tools at the point of care comes with challenges, such as over-triggering and inefficiencies (McGinn, 2016). This may be especially important in the

primary care setting, where changes in provider assignment is common; a new provider must be able to quickly identify prior history notes. This study found several examples where information on family history was buried in a clinical note for a specific patient visit rather than in a patient and family history form, making it time consuming or difficult to find in future visits.

Thus, if lean communication is an important strategy for network function across geographically dispersed settings, electronic systems must make it efficient for providers to access documentation, and providers must have ample time to create the detailed documentation that supports shared knowledge and diffusion of EBM information. For example, the oncologist in the narrative for PT29 wrote detailed notes about emerging science and recent clinical trial findings that supported his recommendations. Likewise, notes created from medical genetics consultations or consultations in the GI neoplasia clinic often gave very detailed accounts of family history and how different factors could be considered in making various clinical decisions. These detailed records are extremely valuable to future providers, but providers do not always receive financial (i.e., billable) support for time spent on this type of documentation.

## **Meeting the IOM Call to Action**

The aim of developing networks to improve EBM access in community settings is in direct response to the IOM call to action. In 2013, the IOM stated that the current cancer care delivery system fell “short in terms of consistency in the delivery of care that is patient centered, evidence based, and coordinated,” such that it created the potential to perpetuate disparities in care (IOM, 2013, p. xiv). This study found—in patient narratives that predated 2013 as well as those extending past 2013—that the network created many opportunities for community patients to receive EBM knowledge or care, but it did so inconsistently and EBM delivery was often provider-dependent. This variability suggests that the network did not create a structure whereby care did not, at least at times, “vary illogically from clinician to clinician or from place to place” (IOM, 2001, p. 62).

However, the significance of the current research study rests with this variability. High-level research on whether organizations affiliated with a network provide EBM at a higher rate than organizations not affiliated with one have shown mixed results. The design of this case study was advantageous because it allowed for identification of examples of successful and unsuccessful network function, and in doing so, it provided insights into factors that may potentially increase EBM uptake in community settings.

Indeed, because the patient narratives spanned many years, almost all of them included examples of both successful and unsuccessful network function. In the primary care setting, initial delays in EBM delivery related to individual provider knowledge or action were often followed by improved EBM delivery when a new provider was assigned to that patient. In the specialty setting, EBM delivery was more consistent, but there were sometimes inconsistencies in when or how local specialists communicated with or partnered with RST specialists, such that improved care coordination was not always realized. Coordination was further limited in cases where patients managed communication between providers and when patients self-referred to

specialty care. The significant use of portal messaging by some patients in this case study also shed light on how some patients engage in communication coordination with various providers, how they make sense of provider recommendations, and how they may feel that it is necessary to advocate for their own care.

Suboptimal collaboration across settings also resulted in incomplete knowledge diffusion at the local level, as well as patient burden in terms of time, travel, and clinical exams or testing rework. If networks (and networked organizations like integrated health systems) want to leverage their potential to improve cancer care in community settings, they need to be attentive to the factors outlined above, including opportunities for different types of lean and rich communication and interactions, clear roles for local specialty brokers, and systems that support awareness, activation, referral, and coordination across settings. Creating the network is only the first step in ensuring its successful operation.

This view of the potential for networks to improve EBM delivery is consistent with pushback against narrow definitions of EBM, especially by those who eschew the notion of it as formulaic, rule-based care (Greenhalgh, Howick, & Maskrey, 2014; Miles, 2018). EBM uses guidelines and best evidence to inform care so that it does not vary illogically, but it allows for variation that is responsive to patient values and preferences and leverages the knowledge and judgment of individual providers. This is also consistent with the call for clinician education that includes time for reflection, “discussion on how to interpret and apply evidence to real cases, and the sharing of collective knowledge and expertise” (Greenhalgh et al., 2014, p. 5). Efforts to measure network success with a single guideline-based outcome may miss the complexities of EBM care in community settings.

The combination of network and relationship-focused theories in this study further underpin the need to be attentive to both interpersonal and structural aspects of networks in crafting strategies that respond to the IOM critique. Diffusion of innovations theory and strength

of weak ties theory have guided much of the research on knowledge diffusion and EBM in health care over the past several decades. They are also the theories most closely associated with social network analysis, thus their perspectives are in line with efforts to identify links between network actors and consider questions related to how information or services flow between members or subgroups of a network. As noted in Chapter 4, network theories were able to explain EBM outcomes in situations where connections (or lack thereof) were related to EBM access. Network theories also framed understanding of how providers, especially local specialists, might bridge otherwise heterophilous groups of community primary care providers and RST specialists. However, they did not work as well to explain the nuances of communication between providers, although assessments of rich and lean communication ties in ECH and MCHS helped identify patterns.

Social network theories have also traditionally been used to study discrete network outcomes, such as uptake of a new clinical practice, rather than assessment—as in this case study—of the conditions that foster connections and a range of subsequent outcomes. Social network theories did challenge the researcher in this case study to identify outcomes that were most relevant in each of the process tracing case narratives, and to assess whether constructs from diffusion of innovations, such as persuasion to change attitudes, explained outcomes. Given their focus on network connections, they were also a useful lens for thinking about how the SNA and process tracing results might complement each other, for example when SNA identified advice connections and process tracing further explicated how advice took place or under what conditions it was, or was not, relayed to the patient.

In contrast, relationship-focused theories and frameworks such as RCC and DCoG have been used to study teams (including teams of patients and providers), but their application in knowledge or innovation diffusion research has been limited. They were used in this study because they have potential to supplement network theories with a view toward the types of



relationships and relationship characteristics that lead to effective network connections and subsequently outcomes like shared understanding of best-evidence care. As such they were chosen in order to fill gaps in network theory. They also provide a perspective more consistent with collaboration and shared, bidirectional knowledge diffusion, which may complement the more unidirectional knowledge diffusion seen in much of network theory. The challenge with these theories is that they have not been used as much for interactions that are not face-to-face, as is the case with networked teams. In fact, prior research using shared mind theory suggests the types of conversations needed to develop shared understanding are difficult to achieve across settings (Lazzara et al., 2016; Noyes et al., 2016; Page et al., 2016).

This case study found RCC and DCog theories to be useful for explaining how relationship characteristics led to the development of connections and resulted in provider and patient outcomes. However, these theories may need to be extended to provide insights to interactions across settings. There was some evidence of a mix of rich and lean interaction between providers in this study, but lean communication across settings in particular broadly included both electronic messages and notes in the EHR. Relatedly, the emphasis of these theories on repeated interactions only applied in some case narratives. This can be explained in part by the outcomes of interest during different phases. After patient diagnosis and during treatment, repeat interactions between geographically dispersed members of the care team would be ideal. This might include collaborative problem solving among specialists and lean communication with primary care providers to keep them in the loop. When EBM was related to risk assessment or diagnosis, though, single efficient interactions across settings had potential to inform best-evidence care. In situations like these, relationship characteristics such as diversity of mental models and trust or respect were possible despite lack of on-going interaction between two providers.

In fact, the RCC and DCog definitions of teams and organizations—while consistent with the conceptualization of networks in this case study—may not capture the fact that there are many types of subgroups within the networked organization, including homophilous professional subgroups and the professionally and geographically heterophilous teams assembled for patient care. Within settings such as the academic medical center, multidisciplinary teams were often employed to assess best evidence care using multimodal communication methods. Team actions were typically summarized in notes available to providers in the local setting, and there were some occasions for conversations across settings, especially between RST and local specialists. In situations like this, all members of the team were part of the same organization, which is joined by a network, but they were also aligned with other more homophilous subgroups. The key to knowledge diffusion and shared understanding is leveraging overlapping but distinct spheres of expertise.

These findings suggest that studies on networks that connect various types of providers in various settings of an organization (e.g., a small community clinic, a local specialty practice in a community setting, and a large academic medical center) may need to consider definitions of teams and even organizations, as well as what subgroups connect them. This is consistent with research showing that professional and organizational homophily impact advice network formation, but new institutional arrangements that connect physicians in interdisciplinary groups may also create new definitions of group or intergroup homophily (Mascia et al., 2015). Thus efforts to use relationship-focused theories to improve network advice-giving may need to consider how to best build new shared identities.

Another way in which these relationship theories may complement network theories is in their greater attention to shared understanding and mutual respect. They imply a two-way collaboration that holds promise for work in the domain of young-onset CRC, where both generalists and specialists have a role to play. However, their focus on on-going, two-way,

collaborative interactions may also fail to account for the potential of brief single interactions to benefit teams. An example is the system for eConsults. Several primary care providers in this study submitted more than one eConsult and did so for more than one patient. Likewise, while there are a limited number of specialists who respond to the eConsult requests, there were times where different specialists responded to a primary care provider's questions. Each of these limited interactions may build stronger connections between different providers from the subgroups, and if those primary care providers are champions in their clinics, they may also foster better connections between the subgroups. Thus, these relationship-focused theories may need to expand beyond descriptions of rich and lean conversations between individuals to appreciate different modes and levels of interactions among members of the subgroups such that information exchange is efficient and yet paves the way for future interactions. This may be especially important in the case of expert knowledge diffusion because these findings suggest that efforts to create systems that encourage generalists to reach out for specialist advice are at least as important as efforts to push information out from specialists to generalists. Thus, in contrast to knowledge dissemination, these strategies would be more attuned to creating conditions under which people seek out a mix of rich and lean connections. This also suggests the need to expand the focus of organizational RCC to appreciate lean opportunities for back-and-forth problem solving across settings or the role that local specialists may play in translating specialist-specialist problem solving to primary care providers on the team.

Finally, RCC considers patient-provider and provider-provider dyadic relationships, but this case study found that it should also consider the *provider-patient-provider* relationship. Some of the most challenging situations in this case study were when patients were tasked with mediating communication between providers. This includes the need to devote more attention to complex relationships and multiple modes of communication between the patients and various providers involved in care. This may be especially important given existing problems engaging

community primary care providers during the cancer treatment phase, thus paving the way for a successful return to primary care during the survivorship phase. This case study found few instances where the care coordination team leveraged the expertise of community primary care providers or engaged them meaningfully throughout the continuum. Research shows that patients are often concerned that returning to primary care during survivorship will result in missed signs of recurrence and poorer care, but development of shared mental models can be effective strategies to facilitate teamwork and continuity of care (Hebdon, Fahnestock, & McComb, 2015). Thus shared mind theory supports the notion of building relationships that value the different team roles.

The results of the current case study suggest that all of these theories (diffusion of innovations, strength of weak ties, RCC, and DCog) addressed complementary questions about network function by simultaneously addressing questions such as 1) what types of links the network created between members, and 2) how and when those links fostered the types of connections that resulted in outcomes like changes in provider attitudes toward EBM. They also suggest that existing network research may focus too narrowly on adoption (e.g., uptake of a single practice). Rather, the types of factors and outcomes addressed herein include aspects that maybe be more aptly called knowledge dissemination, knowledge diffusion, or practice implementation. The field of dissemination and implementation research presents a continuum from diffusion (passive spread) to dissemination (active spread) and eventually implementation (process of integration and use). In this case study, findings suggest that successful networks create opportunities for passive and active spread of knowledge. In terms of diffusion, networks create links that allow individuals to come into contact with each other (formally or informally) so that information and ideas can be spread. Knowledge dissemination may occur when experts actively share information about care for patients with young onset CRC or conditions that put them at risk.

Thus, these study findings suggest that the crux of developing networks that meet the IOM challenge may be in the implementation of the network itself, such that it creates conditions under which diffusion and dissemination (of knowledge and practices) is possible. Knowledge may move from person to person, but organizational or financial systems can be a barrier or facilitator in terms of time for reflection or shared negotiation, and documentation systems are particularly important for working across settings. A fully implemented network may be one in which all providers (and their patients) have equal access to resources and structures that support appropriate activation of those resources. Prior network research has hypothesized that access to knowledge, specialty referral access, and care coordination lead to better adoption of EBM practices, but case studies such as this one are needed to untangle the complexity of network implementation that includes both organizational and interpersonal aspects.

### **Future Directions for Research**

This case study utilized patient narratives to understand factors related to the potential of networks to impact EBM in an integrated health system. The author is planning future research that will incorporate two additional data sources: organizational documents describing the history, function, and goals of the network; and interviews with generalists, specialists, and administrators involved in patient care or network administration. Analysis will focus on a detailed description of the case study network and context, as well as assessment of provider views regarding the operation of the network in promoting EBM in community cancer care. This will assist with better understanding of variation among providers, including providers in the same setting. The analysis will also explore the role of local specialty practices in mediating information flow and evidence diffusion to community settings, especially with regard to rich versus lean strategies for communication and knowledge sharing with primary care providers. This research, focusing on the three key layers of an integrated network (community primary care providers, community specialists, and specialists in academic health centers) offers a novel view compared to existing

literature on EBM and networks, which tends to only focus on two types of settings, e.g., community oncology practices and academic medical centers. Future research on patient perspectives of network care may provide a more complete picture of how and when networks operate to improve EBM in community settings. Future SNA using fully-enumerated relational matrices may identify actors who are disconnected in the network, and primary data collection with those providers may result in information that informs strategies to ensure the network operates in all parts of the system and with all providers within it.

Further identification and testing of variables underpinning EBM uptake may also extend these findings, particularly after additional contextual data are explored through document analysis and stakeholder interviews. Such testing could utilize other case-based process tracing methods (George & Bennett, 2005) or qualitative comparative analysis (Cragun et al., 2016; Rihoux & Ragin, 2009) in order to specify causal pathways and isolate the independent effect of key variables that differ between the cases. Such testing may be an effective means of identifying causal chains for some of the discrete EBM practices in this case study, such as the use of eConsults or evidence-based referrals for alarm symptoms.

The current study also offers insights for future research measuring access to EBM in networks. Existing literature on EBM care in networks tends to focus on discrete actions after diagnosis, such as receipt of a particular cancer treatment or referral to a cancer center for surgery. However, EBM in young-onset CRC includes a range of outcomes from risk assessment through survivorship. The current study also highlights the need to expand beyond patient-level outcomes to include provider-level outcomes (e.g., change in knowledge or attitudes) if the aim of networks is knowledge diffusion. Take for example the case of PT14. If the outcome of interest was defined as patient access to specialty referral, this patient would be considered to have had a successful EBM patient outcome. However, the benefits of multidisciplinary communication and shared understanding did not extend to the local level, and failures in documentation likely made

access by local providers to that information difficult. If the success of networks to diffuse EBM is limited to referrals and ignores coordination and communication that engages providers at the local level, it may be difficult to overcome barriers such as familiarity with EBM and practice inertia.

These approaches may benefit from leveraging theoretical models and frameworks from the field of dissemination and implementation research. Dozens of models have been identified for the study of dissemination and/or implementation of evidence-based interventions or practices, many of which include a focus not only on individual but also organizational or systems levels of functioning (Rycroft-Malone & Bucknall, 2010; Tabak, Khoong, Chambers, & Brownson, 2012). Multidimensional frameworks such as this could help guide future case study research on the implementation of networks to achieve conditions for knowledge diffusion and dissemination, as well as outcomes such as the uptake of an evidence-based practice. These frameworks can also serve to unify theoretical perspectives by embedding theory within the framework constructs. Future work extending from this study could embed both network and relationship theories within a unifying implementation framework. Doing so would ensure attention to the personal, interpersonal, and structural factors identified in this study as necessary for network success.

### **Strengths and Limitations**

This case study went beyond prior research on the association between networks and specified EBM outcomes; it provided in-depth assessment of how and when an integrated network operated to increase EBM in a community setting. The case study design had several strengths. The use of multiple methods of analysis served to build a more complete picture than either method alone. SNA highlighted patterns that may have otherwise been difficult to identify in the dataset, while process tracing provided depth of understanding necessary to identify factors associated with successful network outcomes. Methods of triangulation also provided an

opportunity to assess the consistency of findings from the different methods (Patton, 1999). Validity, reliability, and credibility of study findings were bolstered by checking theoretical consistency (i.e., checking whether inferences were consistent with current theory). Furthermore, methods of explanation building using existing theory allowed for exploration of both hypothesized causal pathways and rival explanations. Dependability and confirmability (i.e., the degree to which the research could be replicated or the findings could be traced back to the data) were bolstered by the use of detailed procedures and an audit trail facilitated by the use of qualitative analysis software and analytic and administrative memo writing.

Use of existing EHR data for the SNA in particular minimized the respondent burden and recall bias that are typically associated with the use of questionnaires to identify relationships for SNA. This study was also novel in its use of NVivo 12 Plus (QSR International) to create SNA matrices from chart review narratives. This approach provided detailed insights into the types of relationships otherwise unavailable in administrative data, for example billing data that demonstrates care patterns alone and omits advice networks or referrals that do not result in a billable visit. It also retained the underlying qualitative narrative, so that the researcher could easily return to the narrative when exploring coded relationships, for example in a sociogram. Use of NVivo 12 Plus (QSR International), UCINET 6 (Analytic Technologies), and NetDraw 2 (Analytic Technologies) for SNA leveraged the unique capabilities of each software package.

There are limitations of this work, as well. First, the case study involved a single integrated health system, which limits the ability to generalize to other settings. Thick description may assist similar systems in determining whether these findings may transfer to their settings, but further research is needed to assess whether there are important contextual factors that impact network function. Second, the chart review methods did not allow the research to fully enumerate relationships in the network. This limited the ability to generate network statistics that could identify subgroups or cliques within the network, or to perform other statistical analyses of



network structure. This work also presents the social network as cross-sectional, although in fact actors joined the network at different times. Future longitudinal analysis of a fully enumerated network could provide important insights into how the network has changed over time. This could be especially important at the primary care level, where changes in providers were common.

Third, the selection of embedded case units for process tracing may have excluded case units that otherwise could have served to test rival explanations for EBM diffusion. In particular, the case unit selection procedures excluded patients who did not receive any care related to the academic health center. Therefore, while the selection procedures allowed in-depth study of network links, they did not allow for better understanding of situations in which no network links were activated. Future research in this area could provide additional insights into how or why some community patients remain unconnected to the available network.

## **Conclusion**

Cancer care in the U.S. is an example of extremes; precision medicine and scientific breakthroughs benefit many, but for others, care fails to be patient-centered, coordinated or evidence-based. This includes unequal access to high-quality, evidence-based care in many community settings, such that where patients live and where cancer care is available makes a difference. Networks that link community clinics and hospitals to academic medical centers hold promise for addressing barriers to EBM—including provider familiarity or attitudes toward EBM and lack of referral access to specialty care—by creating links for EBM information and expert advice, along with systems for referral access. The significance of the current research study is that it provided insight into mechanisms through which networks may potentially increase EBM uptake. Existing EBM literature has identified factors including limited provider awareness and lack of time as barriers to EBM diffusion. The current study expanded existing knowledge by contributing information about the conditions influencing the degree to which networks function

to overcome barriers and result in EBM delivery. When activated, advice and information links in the provider network that were the focus of the current study served to create access to EBM. However, links between primary care providers and specialists were utilized inconsistently, even within the same group of providers. Furthermore, not all providers had access to rich and lean methods of communication (e.g., electronic and personal conversations) or experienced the repeated interactions that may build relationships across settings, but local specialists were seen to effectively bridge subgroups in some instances. The current study highlighted the importance of adequate time to document notes in the EHR and time to read documentation, which may be an effective way to build shared understanding across geographically dispersed settings. Likewise, the current study found a mix of effective and ineffective care coordination across settings, some of which was dependent on referral practices. The provider network that was the focus of the current study created opportunities to reduce cancer disparities in community settings, but development of the network alone did not ensure EBM for all patients. A major lesson is that full implementation of the network, such that it consistently improves access to EBM for all providers and their patients, is necessary to leverage its full potential. These findings may help to inform the development of interventions to bolster network implementation. Interventions may include: provider education and triggers to activate network links; clearly specified roles for information brokers between subgroups; closed-loop referral systems; strategies for building shared identity, mutual respect, and mindfulness among teams; systems that support efficient IT-enabled and interpersonal connections and documentation across settings, and policies that address structural and financial barriers to collaboration and knowledge sharing.

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## Appendix

### Narrative summaries for process tracing

The following summaries present the within-case results of process tracing of each unit. Each case unit summary includes background information and historical narrative and is summarized in terms of constructs from the process tracing framework shown in Table 3.2 on Page 61.

**PT02:** This was a female ECH patient whose records go back roughly 20 years from the time of this study, when the patient was 18 years old. For this patient unit, the process tracing framework highlighted how different network factors alone did not lead to EBM delivery, and how failures in one area offset potential network advantages in others. Assessment of symptoms for this patient followed a very long trajectory, in part because her symptoms were also potentially psychosomatic in nature. Like several other young women in the study, queries on family history were primarily on breast and cervical cancer family history. These attitudinal factors and failures to proactively access best practice risk assessment may have contributed to the delayed identification of genetic CRC risk years after primary care visits for pain and nausea began.

Once an ER visit for abdominal pain uncovered polyps “potentially indicative of juvenile polyposis syndrome or attenuated FAP,” the connection to a GI expert in family cancers was made, demonstrating network access to EBM. That referral was for a face-to-face visit that included an extensive family history, which uncovered some additional information about family history of polyps not previously noted. The specialist also made a recommendation that a full colonoscopy was warranted, thus providing the knowledge on best evidence screening in this situation. From there, network factors alternately supported or obstructed evidence-based care. Access to the GI specialist, coupled with a genetics consultation and genetic testing at the academic medical center, outlined clear screening recommendations for the patient, however, failures in EHR documentation or review meant that the recommendation was not consistently known to all members of the care team. In the year after the consultation, the patient’s medical record indicated that she had never had a colon screening, and the report from the subsequent colonoscopy (at the academic medical center) said the patient had no family history of CRC or polyps, although a more distal relative may have had CRC “according to the patient.” This suggests that the RST specialists did not review the extensive family history documented in the specialist’s note and instead relied on patient report. This pattern continued over several years

with omissions in the notes related to prior screening, screening recommendations, and family history. The next colonoscopy was three years later, when a new primary care provider noticed the patient was overdue. He reengaged the GI specialists, but a series of miscommunications, including patient confusion when news was delivered by telephone, further obstructed shared understanding among all members of the team regarding best evidence surveillance.

In terms of multidisciplinary communication, there is evidence of the aforementioned referral to GI specialty for recommendation, one note indicating that a primary care provider had a phone consultation with a GI specialist, and one note detailing that a GI specialist left a phone message for a primary care provider indicating that a colonoscopy was warranted. Otherwise, recommendations were largely contained in individual notes that appear to have been unread, and the patient held a central (and sometimes problematic) role as a communication mediator.

**PT05:** This was a female ECH patient, whose records date back nearly 20 years from the time of this review. The process tracing framework for this patient unit highlights lack of awareness of EBM in the primary care setting (especially as it relates to cancer risk assessment), failure to utilize network connections to specialty advice or referral, issues related to closed-loop referrals or follow-up on recommendations, and problems when the patient is put almost solely in charge of information management. More than 15 years ago, a Patient and Family History form in the record listed first-degree family history of rectal and cervical cancer. However, the first recorded discussion of family history in a primary care visit was three years later and it was related to skin cancer, as the visit was for a dermatological concern. Less than two weeks after that visit, the patient returned for a follow-up visit and there is a self-initiated report that her father passed away from his cancer (age mid-50s). The provider at that time listed his screening recommendation 15 years younger than her father's age at diagnosis, which would be when the patient was in her late 30s. There are no other notes detailing other family history of CRC, and the screening recommendation is based on the age at death rather than the age at diagnosis (not detailed).

The next few years included a variety of primary care and ER visits, some for abdominal pain and nausea. Various tests were ordered to assess endometriosis and gallbladder issues, and dietary strategies and stool softeners were prescribed for GI symptoms. About six years after the patient's father passed away, there was a note suggesting that the primary care provider dictated a note to the GI specialists, but the note is not available and there is no follow-up correspondence in the record. Rather, it was two years later when the patient presented to primary care again and

reported that her sister, who was in her early 30s, had been diagnosed with CRC. This note also clarified that her father was diagnosed several years prior to his date of death.

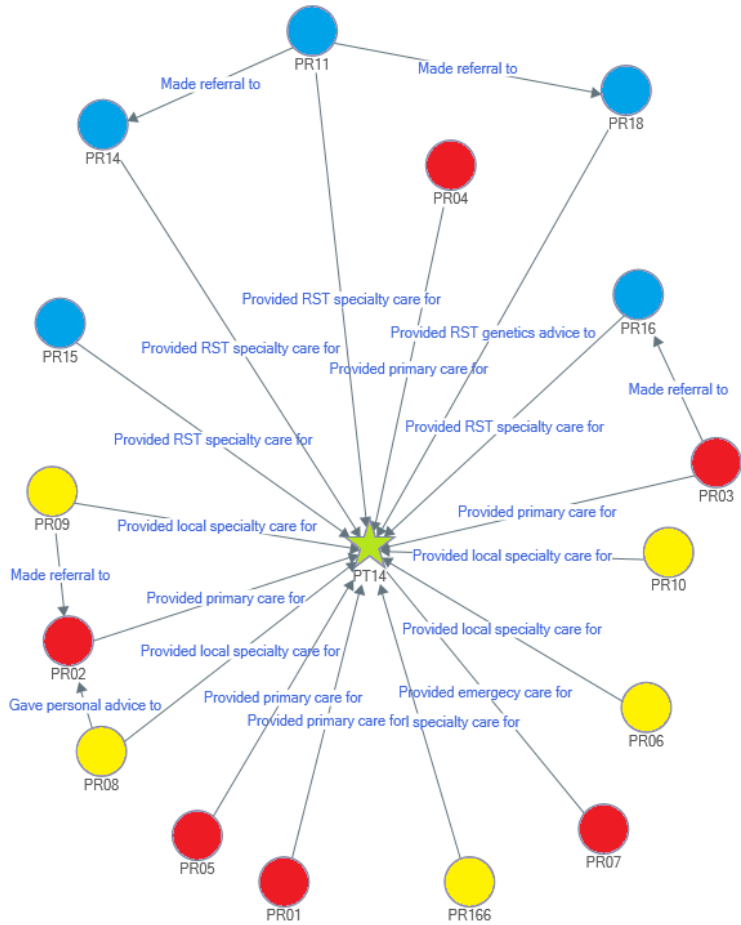
The patient's subsequent colonoscopy indicated a polyp and the provider ordered a genetics consultation. At that consultation, the geneticist noted that although her father's cancer was diagnosed in his early 50s, he likely had the disease earlier and it should be considered early onset. As in the early years of this patient's trajectory, there continued to be little evidence of rich or lean communication strategies between providers or any indication that shared attitudes about best-evidence surveillance were achieved. In fact, the relationships were largely mediated by the patient. With the exception of one unidirectional referral to genetics, there was no two-way communication between generalists and specialists indicated in these records. In the years that followed, family history of CRC continued to be incomplete in primary care notes. The genetics note said that the patient would try to get additional information from family members, but it does not appear that ever happened and there are no additional genetics notes. It was eight years after the initial colonoscopy and three-year recommendation that the next screening was completed.

**PT14:** This was a female MCHS patient who was in her early 20s at the start of the chart review records. For this case unit, the process tracing framework highlighted how patient access to EBM at the local level appears provider-dependent, and it illustrates that referral access to EBM falls short when there is no closed-loop between the referring and specialist provider.

During the early years of the case unit trajectory, the patient presented often with symptoms like abdominal pain and nausea, some potentially related to mood disorder. In terms of family history taking, her early notes were limited to statements like "Negative for young adult illnesses. No breast cancer." Despite tremendous continuity of care with the same primary care provider over a long period of time, symptoms did not trigger documented discussions of CRC or other family history. When the patient eventually brought up her extensive family history of bile duct cancer and ovarian cancer at young ages, the primary care provider offered a GI consultation and CA-125 testing (for ovarian cancer) but did not follow up on it. He also used language in his notes suggesting a genetic disorder was unlikely and stated in his notes that the GI consult was to reassure the patient. As documented by the provider, even the patient, in one of these visits, noted that her abdominal pain and concerns about family history might be "just in her head."

It was a new provider who ordered a local GI consult, and it was at that point in the narrative that consultations and referrals came into play, first with local specialists and then with specialists and subspecialists in the academic medical center. The following egocentric sociogram

shows some of the complexity of interactions. Referrals are both local and distal, while advice networks are local.



The first referral and colonoscopy resulted in identification and removal of a rectal mass. Various communications between specialists also led to referrals to a RST subspecialty clinic and a genetics consultation, at which point further surveillance recommendations were made as new family member information was documented. At that point, an RST GI specialist took over the role of coordination between RST specialties (GI, genetics, and gynecology), although the patient also telephoned the genetics counselor for further advice. Notably, over the course of 15 months between the first referral for colonoscopy and GI consult until the time of the chart review for this study, there were no documented communications with the local specialists or the primary care provider; all care and consultation was happening in RST.

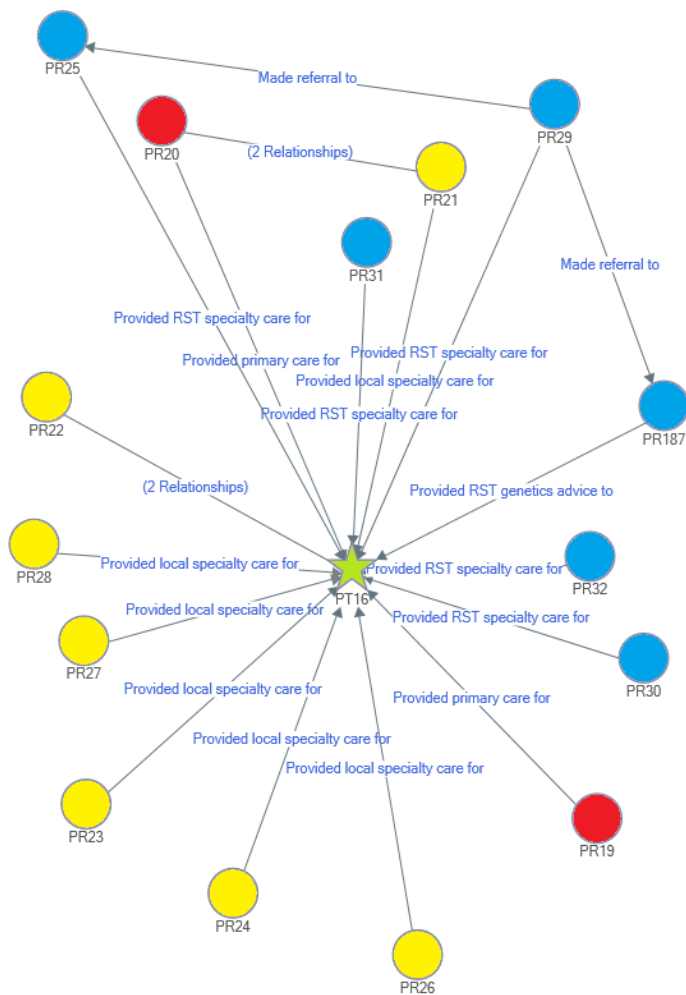
For this patient, referral to and consultation with specialty care occurred after she was assigned to a new provider. That provider appears to have had better familiarity of EBM care, and may have spent more time in the first visit establishing new care to review the patient's medical

history. She was also the one to order the local GI consult. At this point, the communication between specialists in RST also led to better diffusion of EBM. After a rectal polyp was found on colonoscopy, the initial specialist indicated that she would consult with a colleague but she was not sure that genetic testing would be warranted. Following there were extensive portal messages exchanged between the RST specialist and the patient, indicating which other specialists the provider had spoken with and querying the patient for additional information about her family's history of cancer. During this time, the specialist was the mediator of communication with the patient, unlike other cases where referrals took a provider out of the communication loop. The benefit of this type of exchange was that the specialist was increasingly refining and coming to a shared understanding of best evidence care based on communication with other specialists and the patient. In fact, her further consultation with colleagues changed her initial thoughts about the best-evidence course of care. The downfall was that those other specialists' recommendations were not included in the record; the record simply reflects her brief summaries of what she learned from them. They also did not include the primary care provider at any point. Efforts to find detailed information about recommendations in the future would require sorting through portal messages between the specialists and the patient. Even then, the recommendations were summaries by the provider and not verbatim recommendations from multidisciplinary specialists. This provider's position as a communication mediator is consistent with the fact that she (PR16) ranks quite high in terms of betweenness centrality. The role of mediating communication eventually moved on to another GI specialist. That specialist indicated in her notes that she was involved in referrals and watching for clinical notes from other specialties to review. Referrals resulted in visit notes, which better tracked the course of care and multidisciplinary recommendations in the EHR. This also made notes available to the patient via the online portal. Still, local specialists and the local primary care provider were not included in any of these communication loops, suggesting benefits to multidisciplinary communication and opportunities to develop shared understanding of EBM may not have extended to the local setting. In that event, the finding may be that networks provide patients with access to EBM at the academic medical center without changing local practices.

***PT16:*** This was a male MCHS patient. For this case unit, the process mapping framework highlighted how a network may increase access to EBM care across settings while only achieving a common understanding of best-evidence information within settings. For this patient, during the first three years of records for acute visits (e.g., rash or cough), there were no family history notes and no general medical exams (GMEs), which are regular preventive health

visits. Then the patient presented to his primary care provider, in his mid-30s, and reported a year or more history of blood in his stools, diarrhea, fatigue, and weight loss of more than 30 pounds. The provider noted that he suspected Inflammatory Bowel Disease (IBD) and made a referral to a local specialist, who took a family history (significant for lung cancer but not IBD or CRC) and ordered a colon screening. That local specialist found a rectal mass and signs of metastasis on colonoscopy. At that point, there was a referral to a colon and rectal surgery specialist in RST. There is no indication in the record that the patient had ever had a rectal exam, but the RST specialist determined that there was a palpable mass upon exam. She also took a family history, which at that point included some second- and third-degree relatives with CRC.

At the academic medical center, there were then various referrals and consultations between providers. In the specialist's first note, she described four multidisciplinary specialists that she thought would be beneficial for her or the patient to consult, and she outlined her reasoning on each. Notes from various specialists in RST, including radiology and medical oncology, together outlined what was believed to be the best course of care. They also indicated that a clinical trial was discussed and that Lynch testing would be done with surgery. In this case, surgery took place in RST but treatment was transferred back to the local specialty setting. Despite shared network infrastructure, communication was often mediated by the patient. For example, one note from a local specialist says the patient had a question about surgery, and the local specialist directed him to talk with the RST GI specialist rather than managing that communication. In another note, the patient's wife called the GI specialist in RST with a question about bowel symptoms. The RST specialist directed her to contact the local primary care provider and tell him to order a particular test, but the specialist did not otherwise communicate with the primary care provider (although her note detailed the type of test in the event the provider checked the record). Later the patient called his RST surgery team with a question about chemotherapy, and they directed him to talk with his local oncology team. The following egocentric sociogram illustrates how the provider-provider communication did not cross settings. The local primary care provider worked with the local specialist, and the RST specialists worked with each other.



There is some evidence that local specialists were aware of RST specialist recommendations, either through patient reports or reading records. In that case, EBM diffusion may have relied more on shared infrastructure than in the narratives reported above (e.g., PT02). Still, that sharing of information through record notes was largely at the specialist level. Whether attitudes related to diffusion of best-evidence risk assessment and diagnosis were affected in the primary care setting is unknown.

**PT26:** This was a female MCHS patient. The process tracing framework highlighted access to EBM knowledge locally and in the academic medical center, as well as communication that led to shared understanding of the care team across settings. There is even some documented evidence that attitudes were impacted by these conversations, which is a difficult thing to assess using chart review. Collaborative care led to EBM delivery at several points in the patient trajectory, but it was also occasionally disrupted by failures in shared infrastructure.



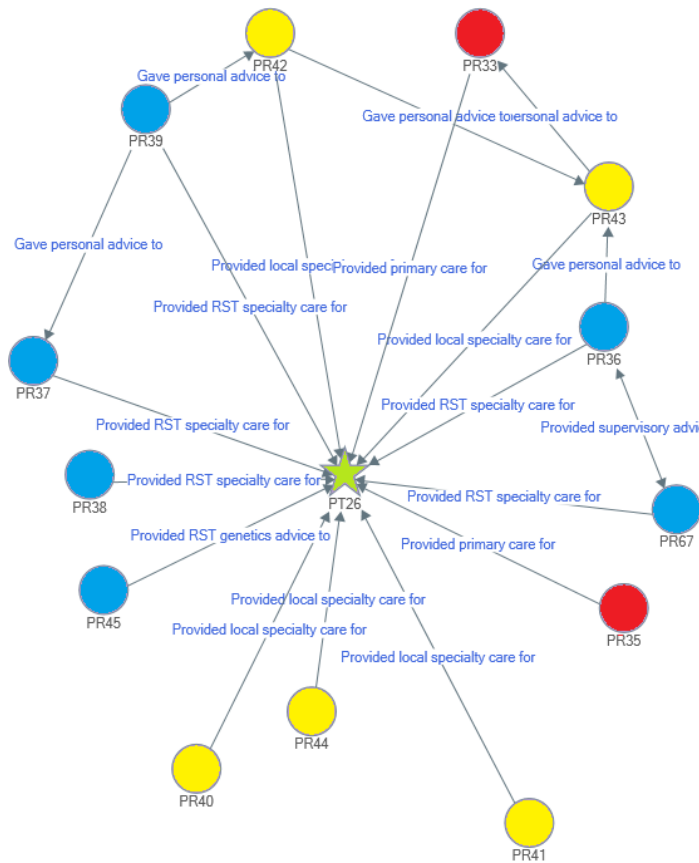
The notes for this patient unit begin around the time of diagnosis of Familial Adenomatous Polyposis (FAP). The initial EHR note was created by a GI specialist in RST who summarized the case, which started when the patient reported to the ER with abdominal pain. The scan was normal but suspicious of IBD, so a colonoscopy was done. That revealed extensive polyps consistent with FAP. FAP is a genetic condition that can cause more than 100 polyps in the colon at very young ages, and which has a very high likelihood of resulting in a CRC diagnosis, such that surgery is typically recommended by the time someone is in their teenage years or early 20s.

A note from a subsequent genetics consult suggested that the patient was aware that her father had CRC in his 30s or 40s and that her sister had CRC twice in her 20s. However, the note said “the concept of polyposis was not known to her.” The patient then saw a colorectal surgery expert in her local community, but he indicated in a note that the patient was to be referred to RST surgery due to complexities of her surgical situation. The next several years of post-surgical care show a complex back and forth between the patient, local specialists, RST GI specialists, and other RST specialists. Several of these exchanges were related to best-evidence treatment options for a patient with complex comorbid conditions, including diabetes and obesity, which limited the surgical options.

Notes from RST specialists outlined several conversations with a multidisciplinary team and efforts to come to consensus on best-evidence care. There were also several notes that report a local specialist consulted with an RST specialist. In one case, the provider wrote in his note that he spoke with the GI specialists in RST who told him what their practice is, and he commented that it seemed reasonable. However, involvement of multiple local GI specialists and specialists in RST seemed to lead to confusion on more than one occasion. In one instance, a local GI specialist described in his note how a colleague made a recommendation to the patient without knowing the history of care and prior recommendations from RST specialists that would have ruled out his colleague’s recommendation. He reported that he reviewed all of the historical notes and spoke personally with the RST specialists in making his recommendation. About a year later, the patient self-referred to RST for consultation, but the provider was unable to access scans and lab reports in the EHR in order to assess next steps. This resulted in rework of the test.

Patient self-referral also created some disconnections between specialists across settings, although collaboration was fairly consistent. One factor interrupting collaboration was failures in EHR infrastructure. Notes could be reviewed, but providers did not always have access to test results. This issue was further complicated by the fact that the patient also received primary and

specialty care from providers outside of the integrated health system. In those situations, she was in charge of relaying information between systems. This was a particular issue with primary care. There are almost no primary care notes in the EHR until recent years, and it appears that the bulk of her earlier primary care visits occurred outside of the integrated health system, in a safety net clinic. It is unknown if this disconnection in care contributed to the delayed diagnosis of FAP. The following sociogram shows that a primary care provider got advice from a local GI specialist (related to post-treatment symptoms), but otherwise the primary care providers included in these records have little interaction with specialists. It appears that the local primary care provider was aware of when the patient was due for colonoscopy, but a local GI specialist oversaw on-going FAP surveillance, including colonoscopy.



**PT28:** This was a male ECH patient. This narrative highlighted initial EBM failures at the primary care level, including failure to follow-up on referral recommendations, as well as situations in which the primary care provider controlled access to specialty care referrals. The patient's records began nearly 15 years ago when he was in his mid-20s. He saw 11 primary care physicians over the course of nearly 15 years, most of them supervised by one of nine other

consulting physicians. Up until the last couple of years, he did not see any of those providers more than once before being moved to a new primary care provider.

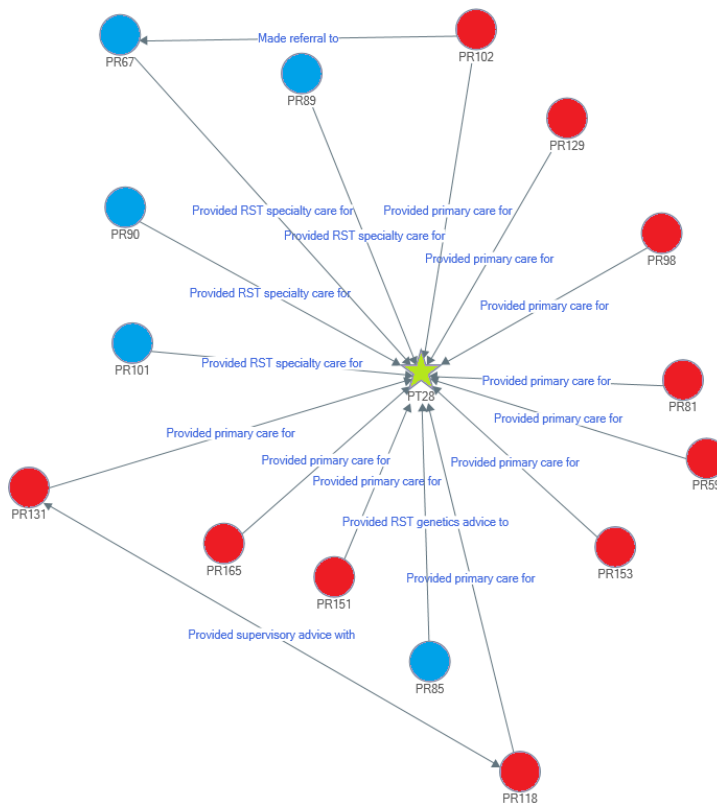
There are 78 primary-care related notes over the years. Some are for acute issues, including sports injuries, but a large number also mention abdominal pain or GI symptoms. Furthermore, his Patient and Family History form from nearly 15 years ago listed a mother with ovarian cancer and grandparents with other cancers, but there are no documented discussions of his family history of cancer indicated in the notes (except one mention that his mother died of ovarian cancer) until 12 years later.

At one point, the patient was referred to a general surgeon for repair of a hernia, but the specialist noted that the abdominal pain was unlikely to be due to the hernia. He suggested further evaluation with colonoscopy might be appropriate. His dismissal notes indicated that from a surgical standpoint he was cleared, and the notes indicated sending the patient back to primary care to pursue any other recommendations. There were no documented referrals from primary care to colonoscopy at that time, although a later primary care note listed dietary management strategies for GI symptoms like increased fiber. It was several years and many primary care providers later when the patient sent a portal message indicating that he would like to talk with someone about his family history of cancer and what preventive measures he should be taking. He mentioned his mother's death of ovarian cancer in her 40s, his brother's recent diagnosis of small intestine cancer and Lynch syndrome in his 30s, and a grandfather with CRC at age 40. A primary care provider he had not seen before responded that he should be tested for Lynch, but that he should be seen in primary care first. She was to be out of the office for several weeks, but she said he could call the appointment line to schedule with someone else if it is "stressing him out" in the meantime. The patient responded by sending his brother's genetics report and asking for a colonoscopy "ASAP." The provider pushed back, stating that she understood he was worried but that she wanted to "have things done right" and get him "the right screenings and the right specialists." There is no record of an eConsult, which may have been one option for timely advice on referral or testing.

Eventual colonoscopy found a sessile serrated adenoma, which was removed. The patient had to contact the provider after he saw the report in the patient portal but had not heard from her in more than a week. The provider response was by portal message. She noted in her message that the adenoma was not cancer and had been removed. She suggested follow-up colonoscopy in three years, but she also made referrals to the GI specialist clinic, medical genetics, and dermatology. A later note said she would defer to the GI screening recommendation, which ends

up being every 2-3 years. In terms of testing, the recommendation was that the brother, rather than the patient, should be the best candidate for further testing. This again differs from the original primary care recommendation.

This case unit highlights missed opportunities for conversations about family history, including ovarian cancer and its genetic link to colorectal and dermatologic cancers, which may have resulted in an earlier referral to GI or medical genetics specialists. Even when the patient explicitly asked for specialist referrals, there were delays in making them, in part because the primary care provider was trying to ensure coordinated primary-specialty care. However, eConsult may have been an appropriate mechanism for more timely care in this instance. Furthermore, there were some points where the primary care provider made a recommendation that did not quite align with the specialist recommendation, although she did defer to their expertise. It is unknown whether she changed her practice based on new knowledge from this experience.



**PT29:** This was a young female ECH patient. She is also one of the patients in this review who was diagnosed with young-onset CRC. Her narrative exemplifies access to EBM in the specialty setting, but there were virtually no interactions across primary and specialty care settings, thus limiting opportunities for EBM diffusion at the primary care level. In terms of the

process tracing framework, this narrative also highlighted barriers to shared understanding when providers in different networks are involved, especially when the patient is primarily in charge of communication flow.

The chart review started during the patient's 20s, when there was good history taking by her primary care provider at routine GMEs. At that time, the patient reported that the colon cancer in her family was among a second-degree over age 50. There was some mention of a family member with polyps, but there is no further detail on age of onset. One note detailed the following standard medical record language: "Reviewed blood pressure, diet, exercise, weight loss. Indications for screening tests including pap smear, gonorrhea/chlamydia, mammogram, lipids, glucose, thyroid, hemoglobin, bone mineral density, and colon screening reviewed and appropriate tests offered based on age and family history."

Throughout almost 10 years of PCP visits, there were no visits documented as being related to GI symptoms until the patient sent a portal message to her provider describing a two-week history of fever, achiness, and GI symptoms. The provider offered to make an appointment or observe to see if symptoms resolved. They appear to have resolved for a time, but then a month later the patient sent a message to the provider saying she had go to a primary care provider in her local area (outside the MCHS) because her fever recurred. That provider did a computed tomography (CT) scan, which found tumors on her liver. Subsequent testing provided the diagnosis of metastatic sigmoid cancer with extensive liver metastases. The remaining three years of records in this review detail the patient's various treatments considered and tried, as the patient worked with specialists at RST and oncologists who were closer to home and outside the integrated health system. Over those three years, though, the patient did not have any primary care visits in ECH. She did continue to communicate electronically with the primary care provider, though, as the provider reached out to see how she was doing and let her know that she is thinking of her. It appears that the patient did attend primary care visits closer to home as needed for acute issues, and at one point she told her ECH primary care provider in a message that it had been difficult to not have a regular PCP there. She also asked if her provider might know of anyone to recommend. The following sociogram shows a number of PCPs, but in fact, the patient saw three of those providers only one or two times each; the majority of the visits over several years were with one primary care provider. There was never any interaction between that PCP and specialists, though. It is likely that the patient self-referred to RST specialists after her diagnosis.



The process tracing framework highlights extensive EBM discussion and communication in the specialty setting, but it also highlights lack of interaction with the primary care setting. In terms of awareness at the primary care level, there is some mention of reviewing the patient’s personal and family history when making screening recommendations, but there is also potentially a lack of appreciation for asking for details on polyp history. Whether through referral by the PCP or self-referral though, this patient had access to specialty care, and there is extensive evidence in the review that those specialists made decisions in consideration of the best available evidence. The oncology specialist on several occasions detailed current research from institutions around the globe when noting which treatments he recommended for this patient. The patient also had consultations with radiation oncology and colon and rectal surgery specialists, and the patient’s case was presented to the multidisciplinary e-tumor board for review and recommendation.

In terms of the process tracing framework, though, there were consistent breakdowns in shared understanding of best evidence care between RST specialists and the specialists the patient saw closer to home. These are detailed in the oncology specialist’s notes. The release of information forms and outside testing records suggest written information was shared back and forth and stored in the medical record. However, on several occasions the patient contacted the RST specialist to say that the local specialist seemed to disagree or recommend a different course

of action. Several of the RST specialist's notes describe the evidence behind his recommendations and the "Mayo Clinic way" of doing things. The patient is often the go-between across settings in these cases. The outside specialists are not included in the network data as the researcher did not have approval to access the data, but this situation is one of the most difficult in terms of EBM diffusion. Failures in EBM access across systems were also seen in terms of clinical trial options when the patient had difficulty managing communication about criteria across settings. Having access to a designated cancer center should increase access to clinical trials (Fouad, et al., 2013). However, coordination failures may have resulted in missed trial opportunities for this patient.

The GI specialist does not appear to be a gatekeeper in the sociogram, but the review does suggest that he was away from the office on some occasions, and that care was disrupted during those times. In one instance, another RST specialist made a recommendation in his absence, and when he returned he disagreed with it. In another instance, the provider who took her message checked with colleagues and they determined that she should wait to talk with her usual provider when he returned. This caused a delay in care.

Overall, this narrative illustrated the benefits of EBM access in an integrated health system, and the benefits of communication between specialists in determining best evidence care. However, care delivery by additional providers outside the system caused confusion for the patient, who played a communication mediator role, as well as delayed care.

***PT31:*** This was a young male MCHS patient whose narrative highlighted a missed opportunity for early risk assessment. It also illustrated how local referrals and access to RST specialist knowledge can benefit EBM for the patient without necessarily yielding shared understanding between providers and the patient.

Records for this patient case unit date back about a decade, when he saw a local primary care provider and RST specialists for a non-GI-related condition. Subsequently, a primary care referral was made for smoking cessation assistance (in the primary care setting), and that primary care provider noted that the patient's mother had died of CRC at age 41. He recommended that the patient begin colon screening around age 30 (about in five years' time). There were no GMEs until five years later, when the patient presented to a new primary care provider with abdominal pain. This note expanded the family history to include the fact that his mother had a Lynch syndrome diagnosis and that his sister was also diagnosed with Lynch at a young age. At that point, the provider made local GI and RST genetics referrals, and the patient subsequently underwent genetic testing and colonoscopy.

The process tracing framework highlighted several points at which the outlined factors may explain outcomes. First, in terms of awareness or familiarity with EBM, the local primary care provider took a family history and made what he thought to be a recommendation based on family history, but it was based on the date of the mother's death rather than her diagnosis. It also did not indicate when his mother's tumor was tested for Lynch, but that information would have informed a different EBM guideline.

The patient did have access to referrals to specialists, though, which resulted in a diagnosis of Lynch syndrome. However, access was complicated by insurance issues. Originally, the testing was not approved by insurance, although that decision was later reversed. Still, on-going surveillance colonoscopies were often categorized as diagnostic instead of screening, which resulted in high deductibles for the patient. Notes in the record detailed telephone calls from the patient, describing his insurance difficulties and their impact on screening access.

Genetics consultation was the only interaction with RST, as shown below. There was no interaction between local and RST specialists, although a local specialist documented his knowledge of the genetics consult in his note. Thus, there was little opportunity for shared understanding of best-evidence care. In fact, the patient continued to present with abdominal symptoms and concerns that things may have been missed on colonoscopy; he failed to come to agreement that the surveillance recommended was sufficient to diagnose a cancer. The primary care provider ended up ordering a colonoscopy a year earlier than had been recommended based on the patient's request rather than the evidence-based guideline. Open communication between the primary care provider, the genetics specialist, and the patient may have better ensured shared understanding of recommended surveillance screening.





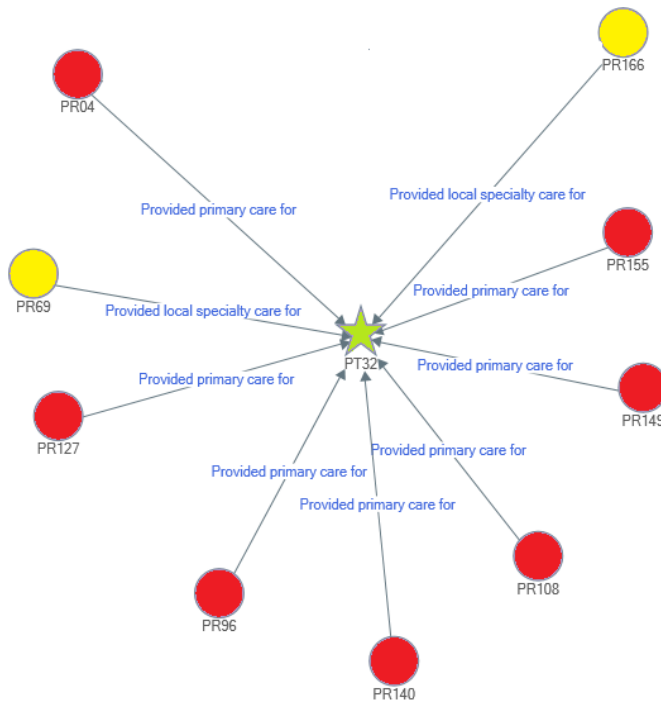
**PT32:** This case unit was the only one that did not indicate an activated connection to an RST specialist. Nor does it indicate that RST specialty advice or knowledge was accessed by providers at the local level, even though the notes suggest these network benefits were considered. It also illustrates lack of EBM awareness at the local level, although information brought forth by the patient from an outside provider had potential to inform best-evidence recommendations in the community setting.

This narrative centered on a female MCHS patient whose records date back more than a decade, and it is in large part associated with family history and genetic risk assessment. The patient’s family history was regularly documented in all of her early primary care visits: a first-degree relative with ovarian cancer, a second-degree relative with CRC, and a first-degree relative with testicular cancer. However, family history was not mentioned in notes when the patient presented with abdominal pain or a later visit when she presented with rectal bleeding, which was attributed to hemorrhoids. No testing was ordered in either of these situations. Over the first five years of records, the patient saw four primary care providers. The fourth provider did not follow up on the GI symptoms, but she did record the patient’s report that her mother had been diagnosed with breast cancer and was undergoing genetic testing. A subsequent note showed that the patient also underwent genetic testing, at the same outside health provider as her mother.

She was found to have a genetic mutation associated with increased risk for CRC, ovarian, breast, and other cancers. Given increased risk for a variety of cancers, the primary care note listed the outside genetic counselor's extensive recommendations for colonoscopy, upper endoscopy, endometrial biopsy and transvaginal ultrasound, mammography and breast MRI, and several screening lab tests. The primary care provider made a referral to the "Breast Clinic" and ordered colonoscopy and upper endoscopy, but there was no record that colon screening or referral to a Mayo Clinic breast clinic occurred. Rather, the only test was an abdominal CT when the patient presented to the ER with abdominal pain the next year. A follow-up visit with the same primary care provider the following year restated family history of illness but there was no mention of the genetic mutation or any follow-up on recommended screening. According to this record review, it was almost three years later when the patient underwent colonoscopy, and another three years later when the next one was completed. At that point, the local specialist recommended annual colon screening and hysterectomy.

One of the most notable things about this narrative was that there was no involvement of RST GI specialists, as can be seen in the sociogram below. Patient and Family History forms are attributed to Mayo Clinic Rochester in the medical record, and according to the medical record, the patient saw various RST specialists for other conditions, including endocrinology, and for emergency room visits. However, she never had referrals to the breast clinic or hereditary family cancer specialists at the academic medical center. Likewise, it looks like the screening recommendations made by the specialist outside of the network—as relayed by the patient to her primary care provider—were taken at face value by the primary care provider.

While this narrative did not illuminate interactions between settings, its inclusion added unique interpretation using the process tracing framework. First, in terms to awareness of EBM, it does not appear that local providers talked with the patient about risk assessment given her family history of cancers with genetic predisposition. Nor did they make referrals for genetic counseling. In terms of attitudes and acceptability, they took an outside specialist's report at face value, but they did not illustrate effective closed-loop referrals for screening or surveillance of recommended screening adherence. There was also almost no communication between local primary care providers and local specialists, and there are no notes detailing that the primary care provider talked with the patient after specialty results became available, e.g., with the results of colonoscopy. In terms of access, local providers did not make referrals to local or RST specialists. Further review of other specialty visits at the academic medical center, e.g., to endocrinology, show that the patient self-referred.



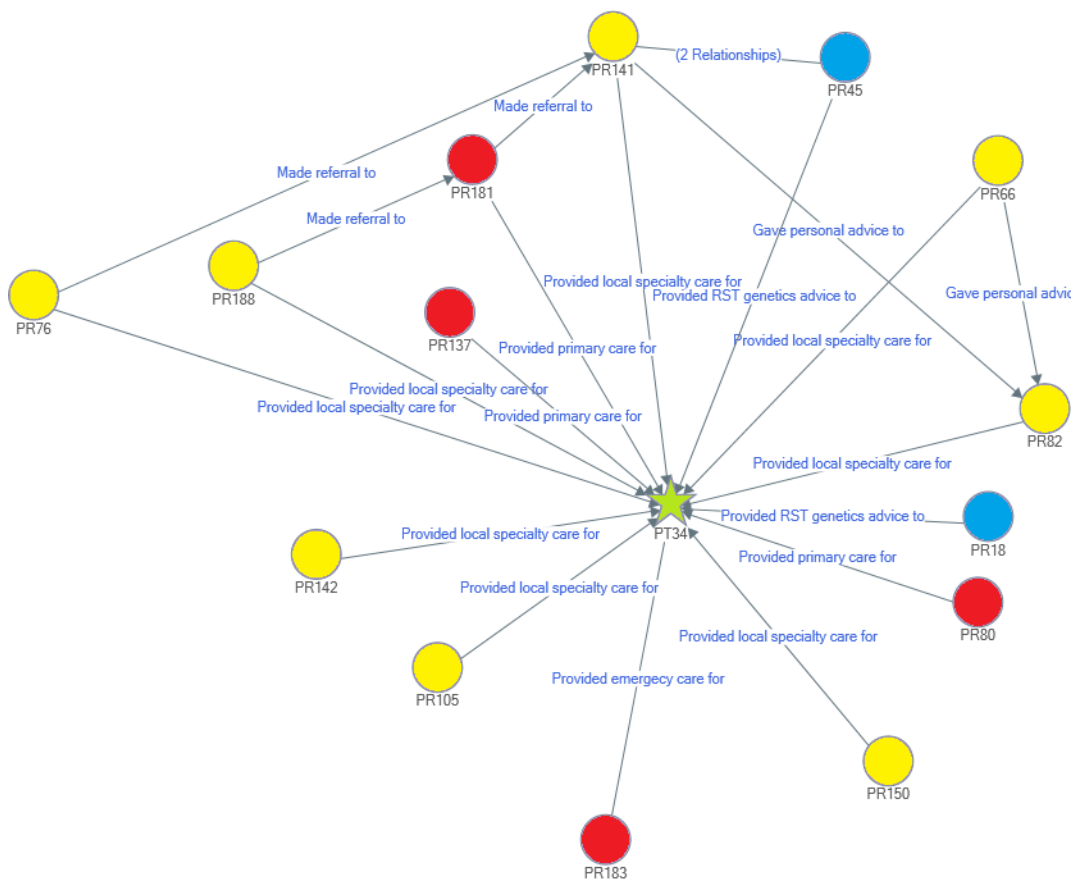
**PT34:** This was a male MCHS patient whose records date back more than 10 years. He had limited interaction with the integrated health system until he presented to primary care with rectal bleeding almost 10 years ago. The first primary care provider prescribed a diet regimen and told him to return for a colonoscopy and GI referral if symptoms did not resolve in two weeks. However, the patient did not return until six months later. At that point, he saw another primary care provider who noted that the patient did not have a family history of CRC but who ordered colon screening anyway. The local GI specialist completed the note detailing the subsequent CRC diagnosis. At that point, the local GI specialist also determined that there was one second-degree relative with CRC, but no first-degree relatives. Furthermore, those relatives had never had colonoscopies, which may be expected among young patients who potentially have parents under the age of 50.

The local oncologist suggested referral to an RST genetics specialist in order to recommend best evidence screening surveillance or even preventive surgical measures. The RST genetics specialist wrote in her note that screening guidelines should follow those for Lynch syndrome, and the local oncologist said in her subsequent note that screening should occur annually, suggesting lean communication of recommendations across settings at the specialty level. However, Lynch was not noted as a diagnosis in subsequent primary care notes, which is where future screening surveillance would occur after the active treatment phase. It was

mentioned in the text of a primary care note, though, and there was documentation of situations in which the primary care provider and local specialists worked together to assess a symptom or decide on the best course of care. This patient narrative was also long enough to illustrate an example of best-evidence procedures related to cancer surveillance. When the patient was five years beyond his diagnosis, the local oncologist wrote a clinical note in which he recommended that the patient see his primary care provider for future follow-ups. This is consistent with efforts to move patients back to primary care for surveillance after treatment, better utilizing specialty resources and creating improved continuity of care for cancer survivors.

The process tracing framework highlighted several key factors in EBM diffusion. First, the first primary care provider referral did not illustrate a closed loop, or a situation in which all steps were followed. The patient did not report back on symptoms, and the provider did not follow up to inquire about them, as far as the records show. The second primary care visit however did illustrate knowledge related to risk assessment and diagnosis, and the patient was able to access specialty knowledge and care both locally and in the academic medical center. Similar to PT31, the only RST specialty referral that was perceived as needed in this case was medical genetics—other specialists in the local area represented GI, surgery, and oncology—but the process of lean communication using medical record notes appears to have been effective. Richer personal communication was seen locally between specialists and with the primary care provider, which may have paved the way for better comfort around returning the patient to primary care for survivorship surveillance—a process that leverages the unique competencies of primary care providers in survivorship care coordination (Rubin et al., 2015).

In summary, once the patient accessed the right primary care provider (i.e., with the appropriate knowledge of risk assessment and diagnosis), he seems to have benefited from multidisciplinary communication and shared understanding of EBM that benefited care coordination. This case took limited advantage of expertise in the academic medical center, such as subspecialty care or GI expertise in Lynch syndrome, which is one benefit of networks, but genetics may have been the only perceived local gap in expertise.



**PT42:** This was a female MCHS patient whose records date back almost 10 years from the time of this review. Her narrative highlighted access to timely diagnosis once a referral to specialty care was made, but a delay in referral based on lack of EBM knowledge and follow-up in the primary care setting. It also highlighted a mix of effective and ineffective communication across settings. In terms of EBM in the primary care setting, the evidence-based practice of family history taking was consistently delivered with this patient (none for CRC), who received regular GMEs. EBM knowledge in the primary care setting was less obvious though when the patient reported with alarm symptoms. In that case, the patient’s rectal bleeding was described as only intermittent, and there was no documented plan for referral or follow-up. Some months later, the patient had a cardiac event, and the next couple years of notes were related to that. In the next GME, there was no mention of rectal bleeding.

The next primary care visit related to GI symptoms was more than four years later when the patient was establishing care with a new provider. This visit included extensive history taking. The visit note also said the patient reported struggling with diarrhea, bloody stools and weight loss of 30 pounds in less than a year. The patient reported trying to alter her diet but thinking she

may have IBD, based on research she did online about symptoms. The provider made a GI referral, and while the local GI specialist noted that she believed it was IBD, she still ordered a colonoscopy. A second local GI specialist performing the colonoscopy was able to identify a rectal mass upon exam (even before the colonoscopy). The resulting diagnosis was metastatic rectal carcinoma, and based on her young age (late 20s), the local GI specialist ordered genetic testing for evidence of Lynch. Subsequently the local oncologist noted that he planned to discuss her case with the e-tumor board and referred her to genetic counseling because of his strong suspicion that this was a genetically transmitted disorder. Less than a month later, the local GI specialist noted the results of the genetic testing that he ordered. It does not appear that the two local specialists were working together to assess the genetic etiology of the disease, although both of their notes were available in the EHR. The local surgeon detailed collaboration both locally and with RST in a subsequent note. He called the RST colorectal surgeon for advice, and he mentioned speaking with the local oncologist in preparation for the e-tumor board discussion. The following egocentric sociogram illustrates a sizable number of relationships between the patient and primary care, local specialty care, and RST specialty care providers. It also shows interactions at the local level, including between local specialists. However, it does not adequately capture e-tumor board interactions. As shown in the sociogram, there was some direct consultation and care between RST specialists and the patient, along with relatively robust communication between specialists across settings. In at least one case, the RST specialist made a redundant suggestion for referral – that to medical genetics. He also requested repeat scans.



The patient continued to get some primary care during this phase, but she also often telephoned or messaged RST cancer specialists to get their opinion before following her primary care provider's advice. In one case, her consultation with the RST medical oncologist resulted in canceling a procedure ordered by her primary care provider. In fact, the patient illustrated a high reliance on RST oncology for advice typically handled in primary care, e.g., ear pain, rash, hip pain. One of the notes indicated that the primary care provider thought some things could be monitored locally if the oncologist would like, but this was only documented in the note and there was no documented communication about this from the primary care provider to the RST team.

There were also notes from the RST team, indicating that they counseled the patient to contact her local primary care provider for some issues. The patient did occasionally talk over the years about the distance to Rochester as a barrier to care, as documented in notes.

The result was that there was a mix of effective and ineffective communication and sharing of knowledge across the network though. In the best instances, multidisciplinary discussions lead to shared understanding of best-evidence care, as in e-tumor board discussions. However, individual consultations were sometimes done in a vacuum, with providers ordering duplicate tests or offering redundant advice. Still, the patient in the end did have access to EBM and there seemed to be shared attitudes among specialists across settings. The disconnect may have been with primary care interactions. They were critical in making the initial referral to specialty care, but there were significant barriers to engaging primary care in appropriate surveillance, even though travel to RST was described as difficult for the patient. There was likewise no documented interaction between primary care and RST specialty, even after disagreements about care surfaced, suggesting little opportunity to change attitudes or come to shared understanding.

**PT44:** This was a male MCHS patient who was only seen in the integrated health system for a few years but whose narrative highlighted the manner in which provider attitudes—including assessment of how likely or unlikely a young patient may be to have CRC—may play a role in risk assessment and referral. It also highlighted how care across the network is not synonymous with multidisciplinary communication and coordination across the network. In the first couple of years of this review, the patient had a limited number of primary care and ER visits. In one of those primary care visits, the provider documented that it was the patient's first physical in more than five years. At that visit, meant to establish care with a new primary care provider, the patient noted a history of GI symptoms, including bloody stools, for the past year. The patient denied any history of GI cancers in his family. The provider outlined concern about the bloody stools in particular, and she ordered an upper endoscopy and colonoscopy. The local GI specialist met with the patient for a consultation before proceeding with the testing, though, and in her notes she described the potentially likely diagnoses and reassured the patient that these were unlikely to include malignancy. She further noted that colonoscopy in particular was something the patient was pushing for and the provider thought would offer some reassurance. The patient was required to go back to primary care for an exam to clear him for colonoscopy. There were no notes indicating that a rectal exam happened at the local GI or primary care appointments. The eventual diagnosis after testing was Stage I colon cancer.



The local oncologist documented that he “went over the NCCN guidelines with the patient,” but he also presented two options for treatment and described the complex factors to consider in making a decision. His note indicated that he sent the case to RST for a second opinion, but there was nothing formalized in the documentation about that consultation. The oncologist did state in his note that he consulted colleagues in his department as well as an oncologist from another state for advice (there is no detail on who was consulted or why), and both sources of advice suggested the patient have a surgery that would be done at the academic medical center. Therefore, a referral was made to RST colon and rectal surgery. Surgery took place with the RST colon and rectal surgery specialists, and the patient also had consultations with GI specialists there. There was no genetics consultation, although the local oncologist mentioned one might be needed. The following sociogram shows, rather, that most specialty care took place locally. What the sociogram does not reflect very well, are the interactions that are not clearly documented in the record. The local oncologist, for example, described talking with colleagues, but there was no formal advice in the notes nor electronic exchanges between local specialists. While this may be a limitation of the method—pointing out the weaknesses of using administrative data to identify network connections—failure to use the medical record to document advice giving means that it lived and died with the local oncologist who was the only one with knowledge of what that advice entailed.



The sociogram highlights the star-shaped pattern of communication between the settings. For example, in the first primary care note after surgery, the provider wrote that the patient gave her a paper with written recommendation for surveillance from the RST providers. The paper itself is not in the EHR, but her note lists out the various recommended screenings and their recommended intervals. The note ends “At this point of time, we will just follow him with recommendations made by the Colorectal Department in Mayo Clinic Rochester.” The next year or so of records illustrated on-going care from local specialists in GI and oncology, as well as on-going surveillance in primary care.

The process tracing framework highlighted the fact that primary care providers were assessing symptoms and risk and accessing advice from local specialists as appropriate. There may have been a small delay in diagnosis, but for the most part once a local specialty referral was made the patient went on to a speedy diagnosis. There were also opportunities for local specialists to talk about best-evidence options, although those discussions were not well documented. This is a MCHS site with a relatively large oncology practice, so the need for advice from RST specialists may have been minimal outside of the surgical expertise required. There were some noted differences in how local and RST specialists described the extent that the disease was removed during colonoscopy, which was a factor in surgical decisions, but for the most part surgical decisions were described as being deferred to RST by the local oncologist. There is no documentation of back-and-forth interactions between local and RST specialists, but it is possible that notes were providing adequate communication. In fact, the most notable factor of this case, in terms of EBM diffusion, may be access to specialty care and lean communication across settings, including electronic and paper notes. If it were possible with this data set, it would be worthwhile to consider why the local oncologist contacted a provider in another state for advice—whether it was because of a personal connection or because of knowledge that the person had expertise not available in the network.

**PT46:** This was a female MCHS patient whose process tracing illustrated care across settings without effective communication across settings, despite a common EHR. It also highlighted delayed access to EBM in the primary care setting and failures in care coordination after CRC diagnosis, even when local providers attempted to solicit information or advice from RST specialists. The patient had a relatively short history of records in this review (about 1.5 years). She was seen in primary care and the ER a few times at the start of the records, but there were no GI-related contacts until the patient called the nurse triage phone line about headaches and rectal bleeding. A CT scan was ordered for the headaches but the GI bleeding was described

as minor and deferred to a routine visit in 3 days. The notes suggest that the CT was completed but that the patient never attended a primary care visit. She subsequently called nurse triage again three months later with worsening bleeding, although the nurse documentation described it as minor and suggestive of hemorrhoids. The nurse scheduled an appointment for the following week.

In that primary care visit, the provider did a rectal exam and found some hemorrhoids that may have been contributing to the problem, but she wrote in her note that she was also unconvinced that they were responsible for the bleeding. The provider noted that the patient had no family history of CRC, IBD, or related diseases, but she still ordered a stool sample and said even if that came back negative, the symptoms had persisted long enough that they warranted further evaluation. The provider ordered colonoscopy, but the patient had significant GI problems with the colonoscopy prep (e.g., vomiting) so the local radiologist performed a CT scan. That CT showed “upper rectal mass compatible with carcinoma,” as well as suspicious lymph node activity.

As shown in the sociogram below, the local oncologist conferred with the local radiologist in determining a course of care, but the finding was that the disease was more involved than originally thought (i.e., dual diagnoses of rectal carcinoma and rectal lymphoma). The oncologist’s note says the patient requested a second opinion from RST, which is consistent with self-referral to RST specialty. A note from the same day shows the patient also met with the local surgeon about placing a chemotherapy port, but that local specialist indicated in his notes that he was not clear about the plan for treatment and that the patient told him a port might not be necessary under the plan with RST. There was no indication that the local specialist communicated with the local oncologist or any specialists in RST at that time; his note simply stated “Rochester apparently told her.”

The visit to RST was the first documentation in the record that the patient had a first-degree relative with colon polyps. The patient visited with GI specialists in RST, but they deferred her care to RST hematology colleagues. She was also enrolled in a clinical trial for chemotherapy. The following year of clinical notes showed a high volume of visits with many providers in both settings. Primary care notes often indicated that she needed advice from the RST oncologist (and in at least one case that she was still waiting for a response). At the same time, the hematology nurse in RST on several occasions sent a message to the patient redirecting care for a symptom to her local primary care provider. Care coordination was additionally complicated by patient visits to the ER and use of telephone calls to specialty to get emergent

care. These types of visits and phone conversations were with the provider on call, and not her usual providers, and this resulted in several situations in which the patient did not receive satisfactory care.



The process mapping framework might first and foremost highlight the fact that this patient did not have timely access to providers with EBM knowledge related to risk assessment and diagnosis in the primary care setting. Barriers to access may have been at the system level (e.g., the process of using telephone triage of patient problems), but they may have also been at the patient level. This patient did not always attend scheduled primary care appointments, and the notes indicated that on at least one early occasion, she preferred observation at home to coming into the office.

Second, process mapping highlighted the minimal real-time consultation within the network. There was only one indication of personal advice between an RST specialist and a primary care provider, and there were no interactions between RST specialists and local specialists. Instead, the patient was put in charge of relaying information between providers—a fact the providers seem aware of. There was some indication that the primary care provider reached out for information from the RST specialists in order to develop her care plans, but it seemed that specialty advice was not always available, which suggests a failure in opportunities to increase EBM knowledge at the local level. In the end, the patient received the best-evidence course of care, but it was not apparent that this fact should be attributed to the causal explanations for well-functioning networks as outlined in Table 3.2.

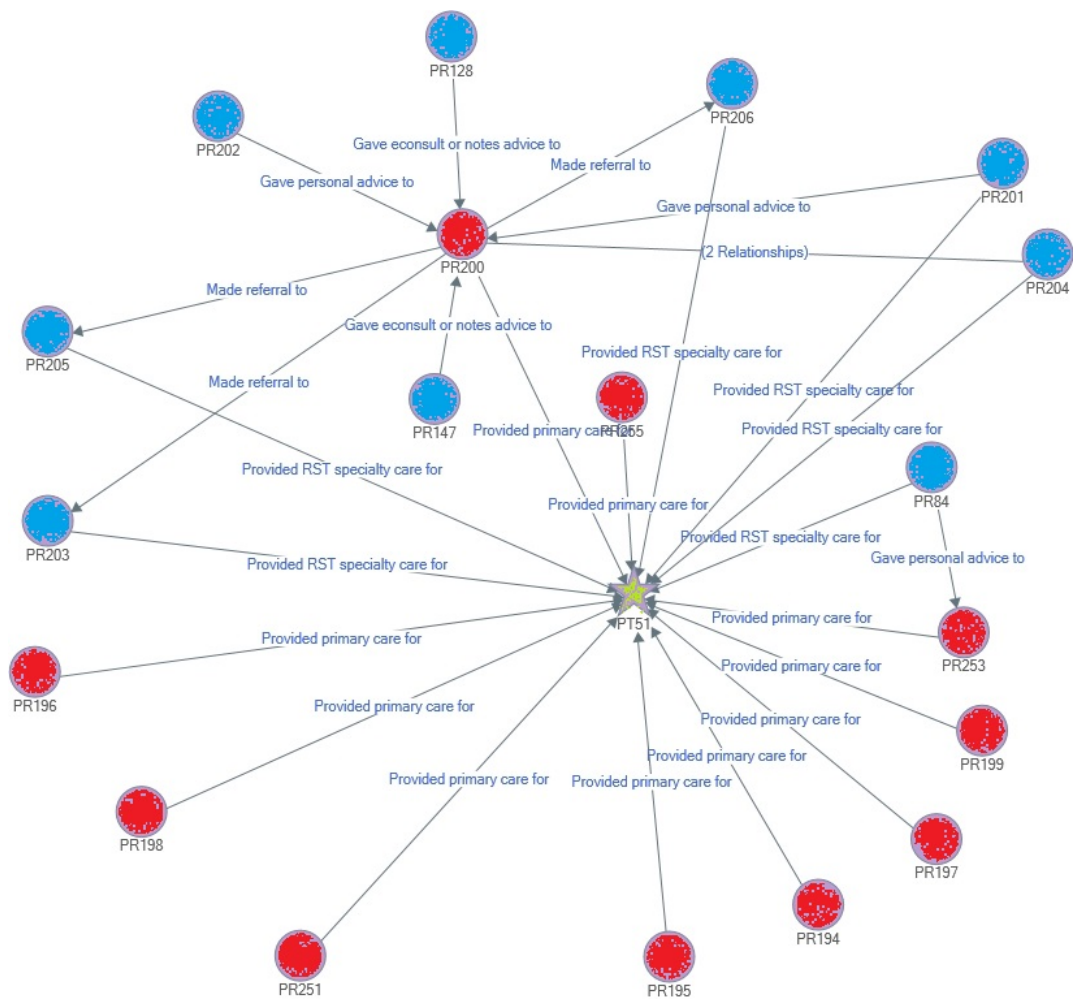
**PT51:** This was a female ECH patient with nearly 20 years of medical record history at the time of this review. She received a high level of specialty care access and consultation to determine the best-evidence course of care. However, access to large numbers of providers—sometimes directed by the patient and not her primary care providers—may have actually served to fracture the potential for multidisciplinary shared understanding and best-evidence recommendations. In fact, the primary care provider relied on the network to make best-evidence care recommendations, but these requests for information from network experts were often in reaction to individual concerns or isolated symptoms at given points in time. The narrative also exemplified a situation whereby the patient’s presenting symptoms were both physical and psychological in nature, which may have complicated the process of making a diagnosis.

During the first three years of records, the patient saw several primary care providers with GI symptoms including bleeding and abdominal pain. Repeat abdominal scans were typically reported as normal, although one mentioned colonic diverticula, which was then evaluated with colonoscopy, which was also normal. Subsequent primary care notes attributed pain to abdominal wall strain and mood disorder. Over the course of the next almost 10 years, there were a few abdominal scans for abdominal pain but there was no diagnosis of diverticulitis in the record. Then, almost 10 years after the first colonoscopy, the patient presented to primary care but was sent to the ER for severe pain. An abdominal CT showed “wall thickening and pericolonic inflammation in the sigmoid colon consistent with diverticulitis,” although there was no mention of prior diagnoses. A second flare led to a recommendation from an RST colon and rectal surgery specialist that a third flare in the next six months would be grounds for surgical removal of the bowel.

After the next primary care visit, the provider used an eConsult to get a recommendation on screening surveillance. The RST GI specialist who answered the request outlined the best evidence for screening, based on the patient's age and the type of polyp removed during colonoscopy. The detail of recommended surveillance extended to describe what the recommendation would be if the next colonoscopy was normal or if it was abnormal. In this way, the eConsult provided comprehensive and definitive advice to the primary care provider, which was also detailed in a clinical consultation note for future reference by any primary care provider in the network.

On-going symptoms resulted in a referral from the primary care provider to a face-to-face GI consultation a month later, which affirmed the eConsult recommendation. Over the next several years, there were a series of primary care and ER visits, as well as GI eConsult and face-to-face consultations. Some clinical notes mentioned the patient's strong family history of Crohn's disease, which is a risk factor for CRC, but this was not consistently noted as a personal risk factor and a CT scan five years before this review did not show evidence of Crohn's or IBD. Throughout the years, the primary care provider referred back at least once to the original eConsult recommendation in the file, although she also suggested face-to-face GI consultations because of on-going symptoms. Over the course of her care, the patient received some type of GI consultation or referral to GI specialty care from nine GI specialists in the academic medical center, almost always through the same primary care provider (PR200), as shown in the sociogram below. This was so much so, that the primary care provider has nearly as many connections as the patient and the second highest betweenness centrality score in this study.

Patient visits to primary care, the ER, and GI continued for several years of this review. Pain often resulted in testing, which came back normal. Pain and other GI symptoms were sometimes described in the record as psychosocial in nature, but providers were also reluctant to dismiss them without evaluation. Pain treated with opioids, which may cause constipation and related GI problems, also created a cycle of problems for this patient.



So, did all of these connections result in better evidence care? The answer to that was not immediately apparent. In regard to the process tracing framework, the patient and the providers certainly had access to specialty care and consultation, and it was used often. As this was an ECH patient, “local specialty” was the equivalent of “RST specialty,” which in this case opened the patient up to a vast array of subspecialists, directly from referral from primary care. Shared infrastructure captured specialist recommendations in the clinical notes, and there was both rich and lean communication between primary care providers and specialists. The two relationships indicated between PR201 and PR200 in the sociogram, for example, represent one relationship based on eConsult advice and one based on a personal conversation. The sheer number of providers—generalists and specialists—involved in this case, though, alongside the patient’s frequent changes in reported symptoms and new symptoms, may have contributed to failure to always reach consensus on evidence-based strategies. The sheer number of interactions may have

also made it difficult to piece together a full picture of the patient's history, even though she maintained the same primary care provider for many years. Over the course of almost 20 years of available records, there were more than 950 records related to primary care (mostly in-person office visits, but also portal messages and telephone consultations). There were also more than 60 records from GI-related specialists, and nearly 250 radiology-related records. In sum, EBM delivery occurred in many visits and consultations, but it may have increasingly happened in a piecemeal fashion as more and more providers were added to the network. At the time of this review, the patient and her providers were still searching for answers to explain symptoms; a diagnosis of CRC or conditions related to risk had not yet been determined.

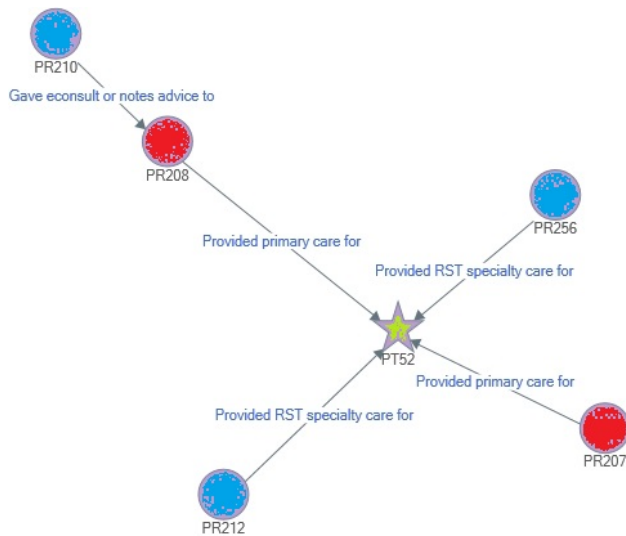
*PT52:* This was a male ECH patient. His records date back decades, but this review only included records after the age of 18 years, leaving more than 15 years of records available. Processing tracing of this case unit highlighted how network access to EBM can change knowledge held by primary care providers. However, it also illustrated the potential mediator or gatekeeper role of primary care providers between specialists and patients. Family history was again central to this case unit. An early primary care provider note listed a second-degree relative with CRC, but no other family history of CRC or related diagnoses. A primary care note a year later listed a long history of gastrointestinal reflux disease (GERD). Over the next several years the patient had several primary care and ER visits related to a number of conditions but most symptoms were not GI-related, although there was one GI consultation for an unrelated concern. Then a year later, the patient presented to primary care wanting to talk about his family history of colon cancer. He described a father diagnosed with adenomatous polyps in his early 40s, a second-degree relative diagnosed with CRC at age 30, and other second- and third-degree relatives diagnosed with CRC at older ages. The note said that the patient reported being told that he should begin screening colonoscopy by his mid-20s (which is the age of the patient at the time of the visit). The primary care provider detailed his recommendation in his clinical note: that the patient would be due for screening 10 years before the diagnosis for his first-degree family relative, which would not be for another nearly 10 years. He said he based this recommendation on a particular set of recommended guidelines. The patient was concerned that he had been told 25 years of age in the past, though, so they agreed to submit an eConsult for guidance.

The GI specialist responded to the request by clarifying the guidelines. In his note, he stated that the guidelines recommended by the primary care provider were relevant for sporadic cases, not those considered hereditary. For this patient, the specialist recommended screening at his current age, given the possibility of a hereditary cancer. The GI specialist also recommended



potential testing of the father in the Colorectal Neoplasia Clinic to help sort out some of the family history.

The patient did undergo colonoscopy and had two polyps removed. In his next note, the primary care provider said that, based on family history and poor prep for that colonoscopy, he would recommend the next colonoscopy in three years. This recommendation was not outlined in any GI notes and it does not appear to be based on a GI consultation. This provider (PT208) continued to be assigned primary care for this patient for the 10 or more years of records, and he consistently ordered colonoscopies every three years. The diagnosis in primary care notes was listed as “questionable family history of HNPCC” for several years, but the patient was not ever referred to or seen in the neoplasia clinic or medical genetics, so this diagnosis was likely based on family history taking. That diagnosis was later replaced with “history of adenomatous colon polyp” in primary care notes, as the patient did have a few removed over the years (he also had colonoscopies that were completely normal). However, in the latest colonoscopy report, a different GI specialist listed a diagnosis of “High risk colon cancer surveillance: Personal history of hereditary nonpolyposis colorectal cancer (Lynch Syndrome).” None of the various GI personnel who performed colonoscopy ever made a recommendation, so the only advice on screening was from the first eConsult. The patient subsequently saw two GI specialists in colon and rectal surgery for an unrelated diagnosis (shown in the below sociogram), but he never had a face-to-face GI consultation about hereditary CRC. The provider likewise never sought advice or made a referral for it. The last recorded colonoscopy was the second that was considered normal, so the primary care provider subsequently recommended screening reduce to every 3-5 years.



The process tracing framework for this patient highlighted that evidence-based care was somewhat familiar to the primary care provider, although he misinterpreted the guideline recommendations. However, guidelines are complex and subject to many variables, and in this case, it may have required a specialist to interpret them correctly. In this way, access to the network was the reason for evidence-based care delivery at that point in time. However, the provider did not follow up with the recommendation for a face-to-face consultation with a GI or medical genetics specialist. Again, ECH patients do not have local specialty connections per se—they are able go directly to RST specialty care, but that referral was never made. Likewise, the recommendations provided for repeat colonoscopies by the primary care provider are not sourced in the notes. They may be based on a recommendation that was never documented, but they may also be based on the primary care provider’s interpretation of guidelines. Using only the information available in this EHR review, it is thus not possible to assess whether the network went beyond providing access at one point in time to changing attitudes and increasing uptake of EBM delivery in the primary care setting going forward. Certainly there were limited opportunities for coming to shared understanding of best-evidence care.

**PT53:** This was a male ECH patient whose process tracing analysis highlighted the potential value in using lean communication with experts in the network to inform care. However, it also highlighted the importance of documentation to make that information available to all members of the team (including the patient) both at the time of the consultation and as reference for future providers.

The chart history available for this patient narrative was not very long. The patient only had intermittent records about a decade before this review, but then he had a number of visits over the course of a year and a half. The few notes from almost a decade ago detailed patient visits for a year or more history of rectal bleeding and an eventual “likely” diagnosis of ulcerative colitis. The notes indicated a possible diagnosis of ulcerative colitis in a second-degree relative, but no other family history. None of the notes indicated a discussion about increased CRC risk or the need for screening surveillance, but they did indicate that the provider (a GI specialist) would try to obtain outside records from a prior sigmoidoscopy. The outside results were scanned into the record, but there was no documentation indicating that the specialist had any follow-up communication with the patient after that.

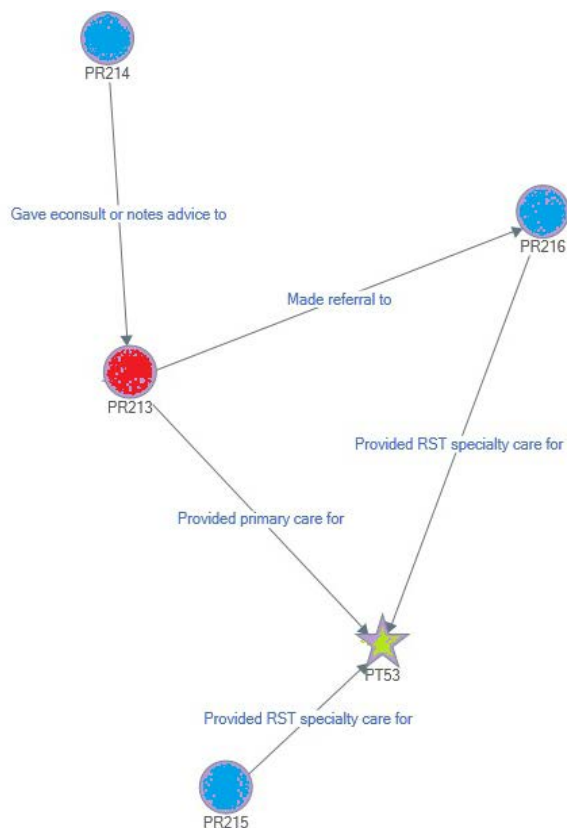
The patient came back for a GME in primary care several years later, and at that time, he reported that he had a likely diagnosis of Crohn’s disease. The primary care provider’s note indicated that he tried to reach the original GI specialist, but that he was no longer at Mayo

Clinic. He thus submitted an eConsult for advice on treatment (based on a particular lab value that was out of range) and colonoscopy screening recommendations. The eConsult response (PR214 in the sociogram below) outlined advice on three fronts. First, in regard to the lab value, the GI specialist corrected the primary care provider's interpretation and pointed out that another value was more important to watch. In fact, he said it should be monitored as much as every other month. Second, the GI specialist made a recommendation for colonoscopy screening surveillance based on symptoms and increased risk for CRC. Finally, he suggested that there was some "newer data" on more effective medications, and he suggested the patient be seen in the GI specialty clinic for consultation.

The primary care provider subsequently made a referral to a face-to-face consultation with a GI specialist (PR216). In an online portal message to the patient, though, the primary care provider did not pass along the screening recommendation from PR214. Instead, he told the patient that PR214 was deferring the recommendation to the person who would do the face-to-face consultation. Unfortunately, the subsequent face-to-face consultation did not include a screening recommendation, although it did suggest six-month follow-up for labs.

Shortly after that face-to-face consultation, the patient moved away, but he continued to travel back to the clinic to see the GI specialist. He eventually found a local provider—who regularly sent lab results to RST—and used the online portal to communicate with the specialist about medication adjustments. Records stopped in the next year, and there was no mention of colon screening recommendations.

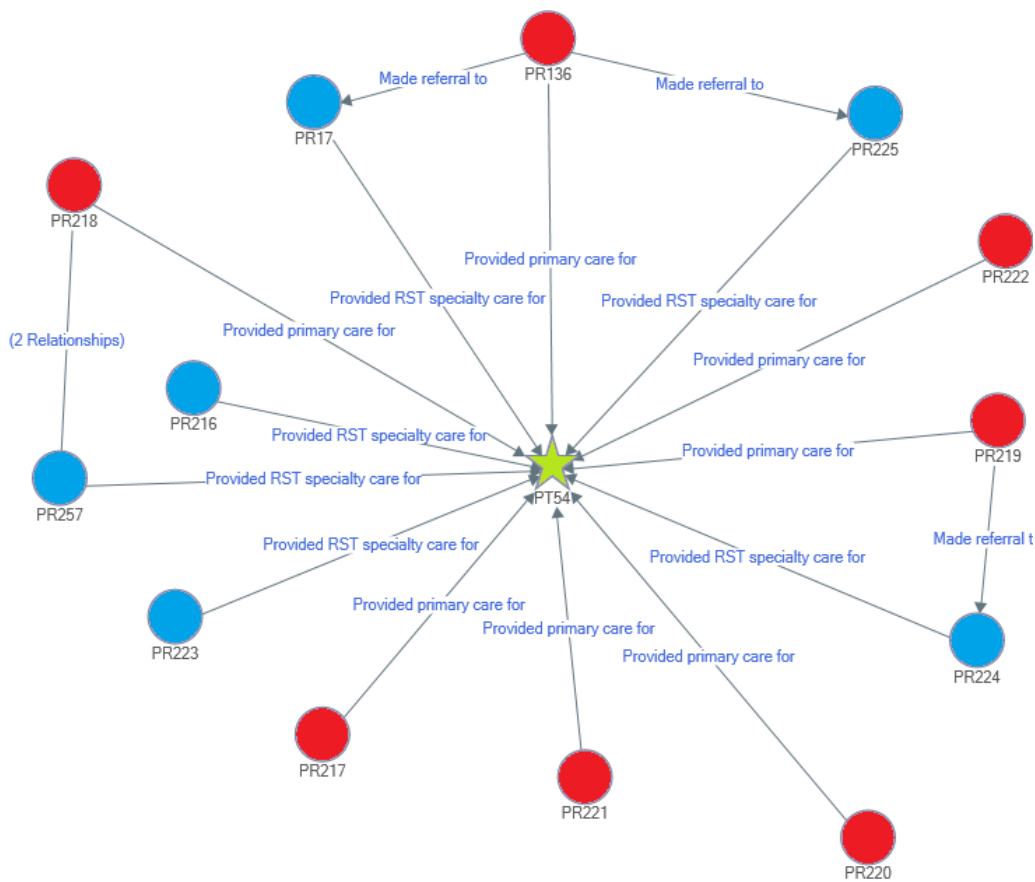
In comparison with other narratives, this patient's history is relatively short. That said, it is an example of a situation in which a generalist illustrated some level of knowledge related to GI specialty, but access to a GI specialist—even for a brief, asynchronous eConsult—was effective at correcting misinformation and offering knowledge about new or emerging science. In terms of shared understanding of the screening recommendation, though, the primary care provider potentially played an information gatekeeping role between PR214 and the patient, and the patient may not have ever had access to that knowledge. What is unknown is whether the second GI specialist had read the recommendation and whether she mentioned it to the patient. That conversation was not documented, though, and the recommendation was not documented in a way that would be easy to find for future providers, even with access to the medical record. In this case, the patient was a young adult who moved to different cities for school and employment opportunities, which further complicated access to information for the patient and his providers.



**PT54:** This was a female ECH patient whose records date back nearly 20 years before the time of this review. Process tracing of this case unit highlighted EBM knowledge at the primary care level but variable access to specialty care expertise. It also illustrated how referral to specialists may benefit local knowledge diffusion less than other relationships, such as advice or consultation relationships. To begin, this case unit provided examples of both family history taking and alarm symptoms in the primary care setting. One of the earliest primary care notes listed a family history of second-degree relatives with breast and bone cancers. More than 10 years before this chart review, the patient presented to primary care with a several week history of blood in her stools. The provider made a plan for follow-up if symptoms did not resolve. It listed no family history of IBD but a second-degree relative with CRC at age 40 (later updated to age in mid-30s). A colonoscopy showed signs of IBD, and subsequent clinical notes suggested that the primary care provider planned to email the specialist for further guidance on recommendations, although nothing else was documented in the record. The patient had another face-to-face consultation with a second GI specialist (PR257), and over the course of the next several years that specialist managed flares of her ulcerative proctitis.

Five years after her first colonoscopy, the patient asked her new primary care provider about colon screening, given her personal and family history. The text of the eConsult was included in the record. It asked the GI specialist for a screening surveillance recommendation based on the patient's personal history of proctitis. It did not mention that the patient had a family history of CRC, including a second degree relative with CRC at age mid-30s. The GI specialist (PR257) had provided direct care to the patient in the past and reviewed her chart, though, so his response to the eConsult said that the ulcerative proctitis alone did not increase risk of CRC but that her family history of CRC—especially at such a young age—was notable. Therefore screening at that time and every five years going forward was warranted. There was at least one more eConsult related to recommended screening in the next five years. In this case, the primary care provider mentioned in his note that he had reached out to the Integrated Community Specialist (ICS). ICS is a program that embeds GI specialists in ECH clinics or makes them available by pager or in-box messaging. There was also documentation of disease progression, and the patient received three screenings and had several polyps removed in the last year of records in this review.

The sociogram below shows various interactions between primary care providers and RST specialists. Over the course of these records, the patient had three primary care providers who sought advice from or made referrals to GI specialists, who subsequently provided care directly to the patient. The most notable aspects of this case, in terms of the process tracing framework were access to specialty care for the patient and access to advice for providers. Access to a common EHR and continuity of GI specialty care were critical to providing specialty advice that took advantage of patient information not included in the eConsult order.

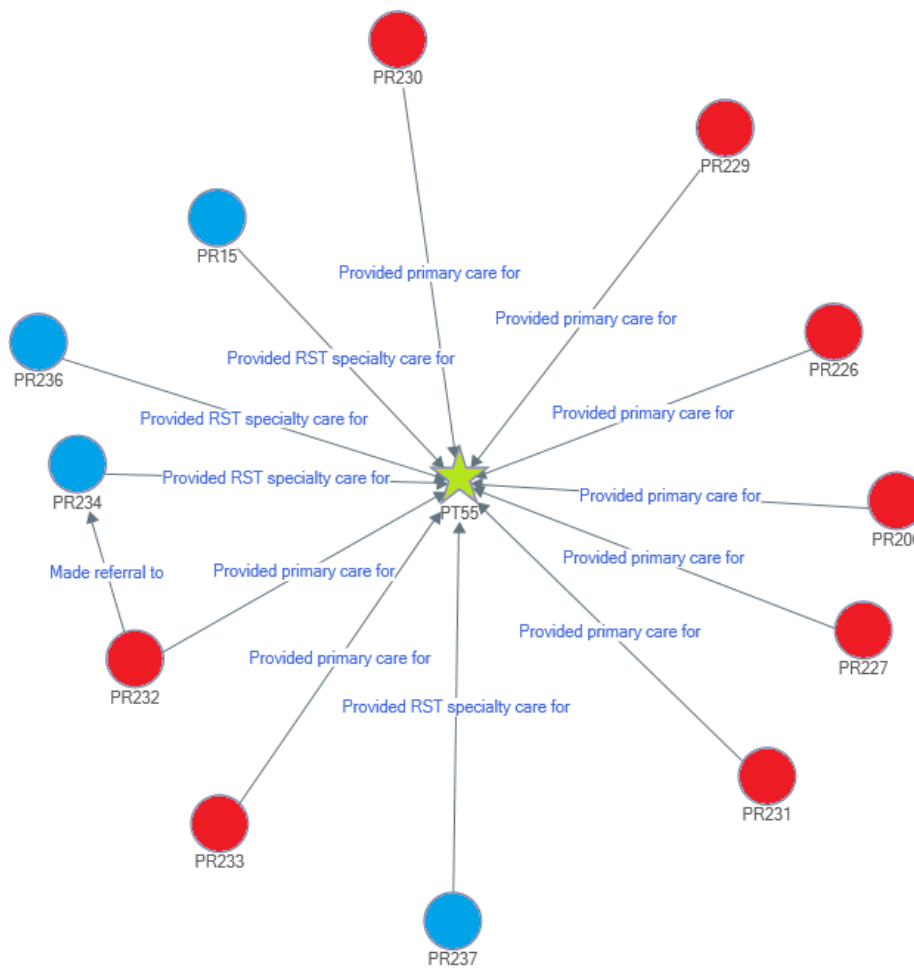


**PT55:** This was a male ECH patient with about 15 years of medical record history. His very first visit in the system included a Patient and Family History form, which listed a first-degree relative with colon polyps and a second-degree relative with CRC. Over the first seven years, there were three primary care visits for gastroenteritis or abdominal pain, but the symptoms resolved in all three cases. It was nine years after the first visit when the patient used a portal message to contact his provider, detailing his family history of CRC, which included two third-degree relatives with CRC in their 30s, two second-degree relatives with CRC at older ages, and four second-degree relatives with a history of colon polyps. In the message the patient stated that he had a colonoscopy scheduled but was wondering if he should also request an endoscopy. There was no documentation about how the colonoscopy was ordered, but the lack of any medical record notes related to it suggests the patient may have self-referred. The primary care provider gave his recommendation about appropriate screening, and the results of the colonoscopy were normal.

A subsequent portal message from the patient to the primary care provider asked for a recommendation on future surveillance screening and whether genetic testing would be

warranted. The patient reported that the GI specialist had mentioned genetic testing during the colonoscopy but that he was unable to ask follow-up questions at the time. The primary care provider attempted to submit an eConsult with these two questions, but in a note he said he was told that he needed to schedule an in-person primary care visit with the patient and then request an eConsult. Instead, he made a referral to a face-to-face GI consultation, which resulted in a screening recommendation and a decision that a genetics referral was not necessary. The specialist noted a “worrisome” family history but said lack of a first-degree relative with early-onset CRC was a reason not to pursue genetic counseling. The sociogram below shows the number of primary care providers who were involved in patient care over the years, including the one primary care provider who was eventually involved in GI referral. That GI specialist was not the same one who provided advice on genetic testing at the time of colonoscopy, and in fact the eventual recommendation on genetic testing differed between the specialists.

In terms of the process tracing framework, the primary care provider exhibited knowledge of CRC screening in his initial recommendation, but access to specialty advice was not as efficient as in other cases in which the primary care provider was able to seek advice without the requirement of an in-office patient visit. Use of a referral also took the primary care provider out of the loop; the patient got the benefit of in-person knowledge and counseling, but the primary care provider had a lesser opportunity to increase his understanding of best-evidence care. Concerning access to genetic advice, this case differs from others, in which genetic counseling referrals were made despite a lack of a first-degree relative with early-onset CRC.



**PT56:** This was a female ECH patient with about four years of medical records available for this review. As an ECH patient, all relationships were either local primary care or RST specialty care. The process tracing analysis highlighted a relatively high degree of interaction between the primary care provider and the specialists, even when communication was lean.

Although the patient consistently saw the same primary care provider for most of the records in this chart review (PR241), it was another specialist in obstetrics and gynecology who made the first referral to GI specialty consultation (as shown in the sociogram below, indicated as a blue to blue referral) after the obstetrics and gynecology specialist tried to refer the patient back to primary care without success. That specialist recommended full GI work-up after pregnancy to assess problems with constipation, but there was no mention of family history. The record did mention that the patient had a prior colonoscopy in her 20s with an outside provider, which found one polyp of unknown histology.

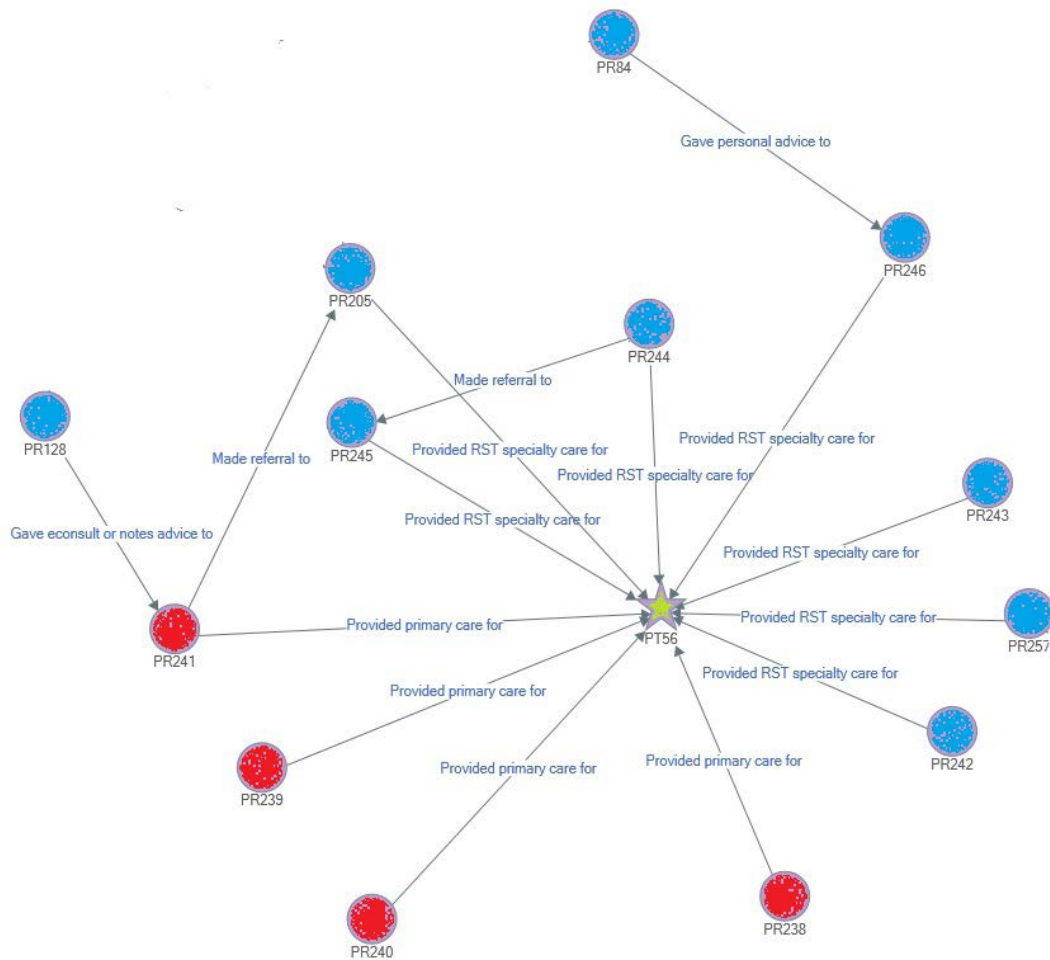


The patient subsequently returned to primary care (PR241) and spoke with that provider about rectal bleeding symptoms and CRC family history, including a first-degree relative with polyps, and second- and third-degree relatives with CRC in their 40s and 50s. Based on her personal and family history, as well as the fact that it had been five years since her last colonoscopy, the primary care provider ordered a colonoscopy, which found three polyps.

The primary care provider's note related to these findings portrayed his level of EBM knowledge and his strategy to access it: "I am confused concerning recommendations on what to do with her findings. I will submit an eConsult to GI asking for their assistance in interpreting the results and recommendations for further follow-up." Based on the patient's personal history of polyps and her family history, the GI specialist responding to the eConsult order recommended "that the patient be seen in the Colorectal Neoplasia Clinic for full evaluation regarding the possibility of a hereditary colon cancer syndrome." The patient subsequently was seen by GI specialists who recommended the patient gather additional detail on family history to inform a genetics referral.

The sociogram below shows a relatively high number of consultation relationships between the provider and specialists, as well as direct patient care by specialists. One of the primary care providers was consistently in the communication loop, and his notes suggest that he read the detailed notes from specialist visits. In terms of the process tracing framework, both the patient and primary care provider had access to EBM knowledge through notes or referrals. In fact, the threshold for referral was lower for this patient than the previous one, which involved a different GI specialist.

Specialist-generalist communication in this case was typically lean, i.e., through notes rather than documented phone calls or other personal conversations, but the notes included a high degree of detailed documentation, which made information about how specialists came to their recommendation available to all providers and the patient (through the online portal). This case also illustrated a high degree of multidisciplinary communication and collaboration on behalf of the patient, including GI specialists who got personal or supervisory advice from colleagues.

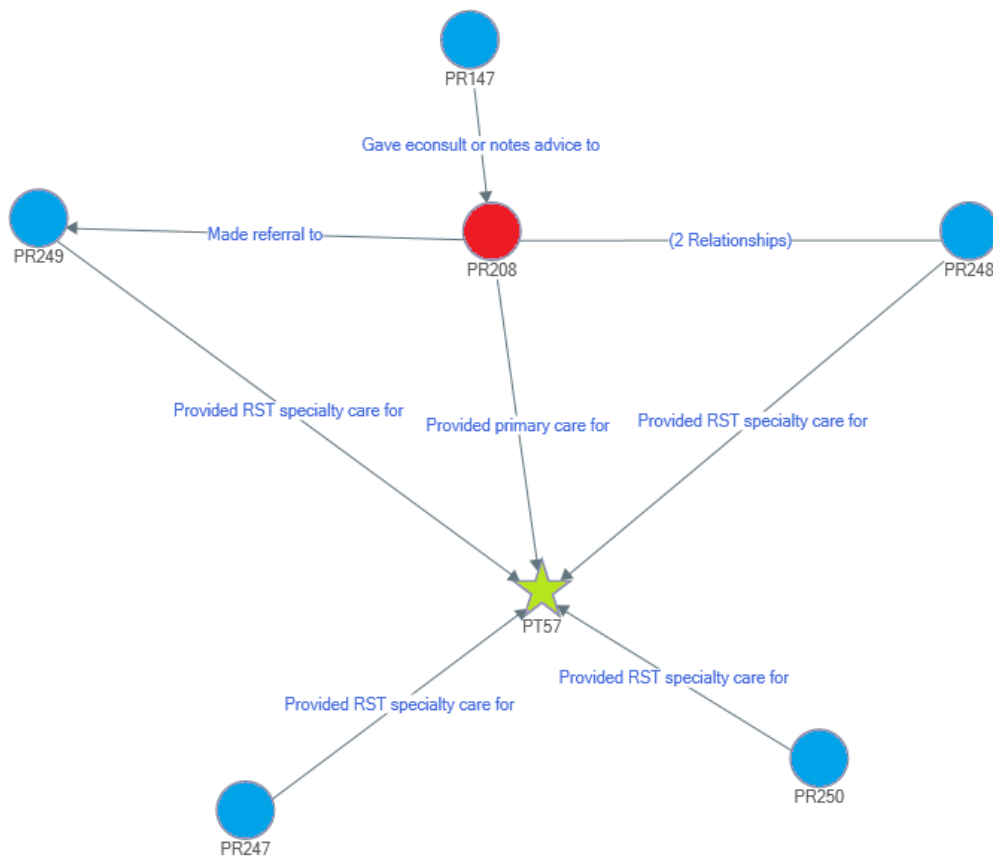


**PT57:** This final case unit narrative involved a male ECH patient with a three-year history of medical records. Process tracing illustrated that the network provided the patient with access to EBM knowledge and care, including access to specialists with knowledge of emerging science. However, the results of network benefits in the primary care setting were mixed.

The first primary care visit listed the chief complaints as “evaluate medical condition” and “family history of colon polyps.” The patient’s brother underwent colonoscopy for rectal bleeding and was found to have polyps. At that time, the brother’s provider suggested that siblings also be screened. The patient also reported two other first-degree relatives with polyps before age 50, and the patient himself was experiencing rectal bleeding at the time of the visit. The primary care provider outlined his thoughts on this case and the need for consultation: “This is a difficult situation as [patient] has been instructed by his family's endoscopist that everybody in his family needs to be screened; although, I cannot really fit him into a Lynch syndrome type of picture given that there has been no colorectal cancer in the family. Certainly his two siblings

with colon polyps at a young age is strange and does warrant some further thought. I discussed with [patient] our options which would include genetics consultation versus colonoscopy versus gastroenterology input. I think the challenge of proceeding with a colonoscopy at this point is I would be unclear as to what to do if it were normal. Instead we decided that we would ask for an eConsult from Gastroenterology for their input given his familial pedigree as to whether he warrants colorectal cancer screening at his young age. I would also appreciate their input as to if they feel he would benefit from genetics consultation.”

The GI specialist responding to the eConsult suggested that—despite lack of clarity of the family members’ polyp histology and no obvious signs of FAP—a colonoscopy would be warranted. Subsequent colonoscopy identified a carcinoid tumor, which was completely removed. These results were provided to the patient by the primary care provider, who also consulted with a GI specialist on the pathology findings—shown as two relationships (referral and personal advice) in the sociogram below. He subsequently made a referral to a GI specialty clinic for follow-up and guidance on surveillance screening.



Over the next nine months, all of the EHR notes were from specialists. They detailed family history and documented additional screening to assess metastasis. One GI note in particular outlined current guidelines and the state of the science on recommended surveillance. It included language such as “the two key features to keep in mind with [patient’s] specific case” and “the limitations in the available data, as well as current NCCN guidelines.” The specialist also documented “unpublished data from the Mayo Clinic, regarding our experience with sub cm rectal carcinoids over the past 12 years,” which he said was consistent with what others have found, the exception being a few studies “often limited by small sample size and other issues.” Additional testing was completed, which informed the recommendation for surveillance screening.

In terms of the process tracing framework, this patient’s case showed significant access to EBM knowledge from GI specialists aware not only of published guidelines but also with the nuances of guidance informed by emerging science. Furthermore, access to specialized testing provided additional guidance on treatment and surveillance.

The role of the primary care provider in this narrative was mixed, though. He provided access to specialist advice, which in fact led to colonoscopy screening that the primary care provider was initially unsure of recommending. Those advice relationships—which were both rich and lean (i.e., personal advice versus electronic notes)—created the potential to positively influence attitudes toward EBM going forward. However, during the active phase of diagnosing and assessing the patient’s tumor, the primary care provider was not actively engaged, although it is possible that he was reading the notes being created by specialists. This primary care provider (PR208) also cared for one other patient in this study. The specialists involved in the two patient cases were not the same, however, demonstrating that eConsults in particular and even referrals for face-to-face consultation may go to the specialist on-call or specialists with an open appointment, rather than to one where there is a personal relationship.