

Research Series

Development of a Practice-based Patient Cohort for Primary Care Research

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Background and Objectives: Efforts to develop “laboratories” for primary care research have largely focused on the development of networks that recruit subjects on a project-specific basis. We sought to develop an alternative model—a representative cohort of adult primary care patients maintained for use in multiple projects. **Methods:** In 2001, research assistants in waiting areas of a representative sample of 16 family medicine practices in North Carolina approached all adult patients during a 4-week period. Follow-up has been maintained for 3 years. In 2004 and 2005, the cohort was refreshed by adding eight new practices. Each consenting subject was administered a four-page self-report questionnaire that included items on demographics, risk factors, health status, and quality of life. **Results:** Of 10,649 eligible patients approached in 2001, 6,811 (64%) completed the enrollment questionnaire, of whom 5,575 (81.9%) consented to be included in the cohort. African Americans, Latinos, and older persons were enrolled at rates paralleling the state’s adult population. Poor general health, chronic illness, and risk factors for chronic disease were more prevalent in the cohort than in the general population. Over 3 years, cohort members were included in multiple studies, and 77% of the original cohort remained active. The per-subject enrollment cost varied between \$27 and \$45; annual program maintenance costs were estimated at approximately \$35,000. **Conclusions:** The research cohort has these advantages over traditional practice-based research networks: patient focus rather than physician focus, a structure that places few demands on practices, ability to target racial and ethnic minorities, and a better-defined patient population. As is true of all aspects of research infrastructure, the cost of development and maintenance is significant.

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Although the vast majority of health care is rendered in primary care practices,¹ most research is carried out in subspecialty settings, largely in tertiary care centers.² To help alleviate this disparity between research and practice settings, it has been increasingly recommended that “various types of practice laboratories, or centers of excellence” in primary care research be established.^{3,4} To date, efforts to develop a primary care research infrastructure have largely focused on establishing practice-based research networks (PBRNs)—groups of practices that affiliate to carry out practice-relevant research.

The growth of PBRNs has served a valuable role in promoting and carrying out primary care research. However, PBRNs have several limitations. Membership has largely been solicited through personal networks, leading to selection bias and underrepresentation of racial and ethnic minorities in PBRN-sponsored studies.^{5,6} Further, because PBRNs are physician and practice centered, their research has tended to focus more on physicians and physician services (eg, office function, quality of care, and health services research) than on patients and health behavior.⁷ Finally, PBRNs have tended to be costly, inefficient, and demanding of participating practitioners, factors that have become particularly problematic in the increasingly stressful primary care environment.⁵

This paper describes the development of a different type of primary care research laboratory—a cohort of adult patients recruited from a representative sample of primary care offices and maintained for use on mul-

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multiple projects. The cohort, the North Carolina Health Project (NCHP) research cohort, was developed by faculty of the University of North Carolina (UNC), in collaboration with the North Carolina Academy of Family Physicians, for the purpose of facilitating research on chronic disease and related health care problems commonly addressed in primary care settings. As such, it may represent a new model of primary care research infrastructure development—different from, and complementary to, traditional PBRNs.

Methods

Under a grant from the Centers for Disease Control and Prevention (CDC) to study complementary and alternative medicine use in arthritis, funds were obtained to screen primary care patients for arthritis symptoms. Since all adult patients were to be screened, the enrollment process was tailored to establish a general adult cohort that could be used for multiple studies. Pilot studies in two primary care practices developed and refined a data collection method that worked in the high-volume primary care office setting.

Selection of Practices

A purposive sampling method was used to develop a sample of family medicine practices that would represent the geographic regions and the ethnic diversity of the state of North Carolina. An initial list of practices was developed from a survey of the North Carolina Academy of Family Physicians membership and recommendations of our family medicine departmental faculty from around the state. Each identified practice was telephoned to obtain contact information, identify the county in which the practice was located, and estimate the daily patient volume and percentage of patients who were racial or ethnic minorities. Practices that could not be contacted were deleted from the list, yielding 28 sites eligible for selection.

The 28 eligible practices were divided into six strata by location in the state (west/central/east) and rural/urban status. Within each stratum, all practices reporting more than 40% of their visits from racial/ethnic minorities were selected for recruitment. One additional practice from each stratum was randomly selected; of these, one had four sites, each of which was included. One or both of the study's principal investigators then visited each of the 16 selected practices to solicit their inclusion in the project; all 16 were successfully recruited and participated in study data collection. The participating practices were designated the North Carolina Family Medicine Research Network (NC-FM-RN).

Initial Enrollment of Cohort Subjects

In each participating practice, all patients ages 18 and older presenting for a scheduled office visit during a 4-week period in 2001 were approached for participation

in a baseline enrollment survey. Depending on practice size, one or two trained research assistants were placed in the waiting room during the data collection period to approach potential subjects about participation in the survey, obtain written consent, assist subjects with survey completion, and gather completed surveys. The study research assistants were mostly students on summer break; Spanish-speaking data collectors were placed in the two study practices with relatively large Latino populations. Since functional literacy, visual impairment, and other problems are common and difficult to screen for, the data collectors were instructed to offer to help all subjects with questionnaire completion; approximately 10% of the study enrollees received assistance filling out the survey.

All subjects who agreed to participate were given a four-page self-report questionnaire, which was available in English or Spanish and contained standardized questions aimed at: (1) describing the demographics, common diseases, risk factors, and health habits of the subjects and (2) providing data by which the subjects could be compared to other populations, such as all North Carolina or US adults. The questionnaire included demographic items, self-reported chronic conditions, questions on health habits (eg, smoking and physical activity), self-rated health, the American Diabetes Association risk factor survey,⁸ the Medical Outcomes Study 12-item Short Form Survey (SF-12),⁹ and selected questions on health status and behaviors from the CDC Behavioral Risk Factor Surveillance System (BRFSS).¹⁰ Each practice was given the opportunity to insert one or more individualized questions. One practice inserted a satisfaction survey, and another added several questions on race and perceptions of health care.

The accompanying consent form, approved by the UNC Committee on the Protection of the Rights of Human Subjects, contained two separate consent requests: one for use of the information in the questionnaire for research and the other for permission to contact the subject later about participation in future research. Completed questionnaires and recruitment reports were mailed weekly to the coordinating center at UNC. At the coordinating center, the data were reviewed and edited and double entered, and the data set was cleaned. When the data collection was complete, each practice was provided with descriptive data on its enrollees and, for comparison purposes, data from the entire cohort. The cohort was designated the NCHP cohort.

To determine the correspondence of self-reported diagnoses to the medical record, an audit of 100 consecutive medical records of cohort subjects was performed in each practice site. Concordance varied widely among conditions, from nearly 100% for diabetes to approximately 50% for depression (patients self-identifying more frequently than indicated in medical records).

Maintenance, Attrition, and Refreshment of the Cohort

Maintenance and updating of contact information on cohort members requires ongoing effort. A newsletter is sent annually to all cohort members (and physicians in the participating practices). The newsletter provides results of selected studies and asks for updated contact information. Each time a survey is conducted on all or (more commonly) a portion of the cohort, project staff monitor returns, change address lists, and delete individuals who are known to have died or who ask to no longer be contacted. The following approaches are used to minimize loss to follow-up: all questionnaires are mailed in three waves; nonrespondents to mailed questionnaires are contacted by telephone (a minimum of seven attempts are made); and the enrollment form includes space for a relative or friend, and that individual is contacted if the subject has no telephone or the line is disconnected. Cohort membership is not dependent on continuing to visit the practice from which a member has been recruited. Incentives to help maintain cohort membership include the newsletter (which contains health information and study results) and the provision of small honoraria (generally between \$2 and \$10, often as a gift card to a discount food store) on completion of additional questionnaires.

In keeping with the low-physician-burden philosophy of the project, regular meetings of the network are not held. Instead, ongoing communication consists largely of newsletters and informational mailings about studies that are about to begin. Visits to individual practices occur on enrollment and approximately every 2 years. A steering committee of three particularly involved practice physicians has met about once a year. In addition, project staff annually attend the winter meeting of the North Carolina Academy of Family Physicians, at which they hold a reception and/or present research posters and to which all physicians in participating practices are invited.

To maintain the size of the cohort, it became clear that new members would need to periodically be enrolled. In the summers of 2004 and 2005, grant funding from the Agency for Healthcare Research and Quality (AHRQ) supported the recruitment of eight additional practice sites. As with the original enrollment, practices were selected that contained a mix of rural/urban populations with relatively high levels of minority enrollment. The new study questionnaire included all key demographic and health status indicators that would allow merging of the new cohort with the original enrollees. In addition, new subsections were added that gathered data on topics of investigator interest. With experience, enrollment rates increased; in 2005, the response rate was 75%.

Results

Characteristics of Cohort Members

During the initial cohort enrollment (16 practice sites, 2001), 7,687 adult patients had appointments at the study practices. Of these, 2,921 were not enrolled, largely because they refused study participation. The remaining 4,766 (62%) completed the enrollment questionnaire, of whom 4,054 (85% of those completing the questionnaire, 53% of eligible subjects) consented to be included in the cohort that would be approached for additional studies.

Selected demographic characteristics of the initial cohort are presented in Table 1, along with comparison data on North Carolina adults sampled as part of the CDC's 2001 BRFSS. Note the similarity between the populations, other than the higher enrollment rates for women and middle-aged persons, which are reflective of primary care practice in general. Also note that efforts to oversample minorities yielded enrollment rates of African Americans and Latinos that were similar to the state population. Refusal rates were not calculated by race/ethnicity, but data collectors reported higher refusal rates among Latinos. According to physicians

Table 1

Selected Demographic Data on Initial NC-FM-RN Cohort Enrollees,* With Comparison Data for All Noninstitutionalized NC Adults from the CDC 2001 Behavioral Risk Factor Surveillance System

Characteristic	NC-FP-RN Cohort Enrollees (%)	All NC Adults (%)
Gender: Female	70.8	52.2
Marital status: Married	58.4	60.7
Age: 18–40	36.5	44.6
41–64	45.9	38.4
65+	17.6	17.1
Education: < 8th grade	7.4	4.6
Some high school	12.3	12.0
High school graduate	30.4	31.9
Some college or more	49.9	51.5
Race/ethnicity: White	76.0	75.4
African-American	19.7	19.0
Latino	2.1	2.5
Other	2.3	3.1

* n=4,766

NC—North Carolina
 NC-FM-RN—North Carolina Family Medicine Research Network
 CDC—Centers for Disease Control

in the study practices, this was likely due to patient concerns about immigration and/or insurance status.

Table 2 presents data on the health status of the cohort enrollees who consented for follow-up, including scores on the physical and mental health components of the SF-12 and the BRFSS health-related quality of life (HRQOL) items. The SF-12 uses norm-based scor-

ing with a mean of 50 and a standard deviation of 10. Scores on both measures indicate poorer HRQOL in this sample compared to population-based estimates. Hypertension, osteoarthritis, depression, and low back pain were the most frequently reported chronic conditions. Figure 1 compares data from the cohort with data from the US National Health Interview Survey for the general US adult population;¹¹ it shows that the NCHP cohort contains a higher proportion of persons who report not being in good health.

In the second wave of cohort recruitment (five practice sites, 2004), 1,935 new subjects were successfully enrolled (65.3% of eligible patients). Of these, 1,411 (72.9% of enrollees and 47.6% of all eligible subjects) agreed to be contacted for further studies. The racial/ethnic distribution of the new enrollees was 58.1% white, 30.0% African American, 9.2% Latino, and 2.7% other.

Three-year Follow-up

The NCHP cohort has now been in existence for more than 3 years. During that time, a variety of studies have been conducted using enrollment data and/or additional efforts targeted at specific subgroups, such as prediabetics.¹²⁻¹⁹ Funding support for maintenance of the cohort has been pieced together through research grants and institutional funds. Research grants that have supported the cohort have been obtained from the AHRQ, the CDC, and the National Institutes of Health (NIH). Oversight and maintenance of the cohort databases has been conducted on a part-time basis by faculty and research staff who are largely assigned to and funded on research grants that utilize the cohort.

Figure 2 provides data on the status of cohort members 3 years after enrollment. Of the original 4,054 cohort members, 3,128 (77%) remained active 3 years later, 31 (1%) were known to have died, 306 (8%) to have withdrawn from the cohort, and 589 (14%) to have been lost to follow-up.

The cohort has been particularly valuable for post-doctoral research fellows and junior research faculty, because it provides a source population for studies that have limited funding. Studies involving the cohort have been conducted by three postdoctoral fellows, and the cohort has been written into two CDC applications (both funded), five NIH career award applications (three funded, two pending) two NIH R01s (one funded, one unfunded), and one AHRQ R03 (pending).

Cost of Development and Maintenance of the Cohort

Table 3 provides estimates for the costs of establishment, maintenance, and refreshment of the cohort. The estimated cost of cohort establishment was \$126,750; this represents a per-subject enrollment cost of \$26.59. Annual maintenance costs were approximately \$35,000; these included oversight, subject tracking,

Table 2

Health Status of Enrollees in the NC-FM-RN Cohort Who Consented for Follow-up (3,925)

Measure		#	%*
Selected chronic conditions	Heart disease	400	11.4
	High blood pressure	1,307	36.1
	Osteoarthritis	859	24.5
	Diabetes	553	15.6
	Depression	1,022	29.2
	Low back pain	911	25.9
Selected risk factors for chronic disease	Obesity (BMI >30) ^a	1,319	39.2
	Current smoker	813	20.7
	Nondiabetic with high risk for diabetes ^b	1,281	32.6
	Not physically active ^c	1,644	45.0
Self-rated health status	Poor	243	6.4
	Fair	827	21.6
	Good	1,530	40.0
	Very good	969	25.4
	Excellent	252	6.6

	Potential Range	Mean	SD
SF-12 Physical Component Score ^d	0–100	43.9	11.9
SF-12 Mental Component Score ^d	0–100	46.3	12.2
BRFSS HRQOL physical ^e	0–30	8.8	10.7
BRFSS HRQOL mental health ^e	0–30	7.3	10.0
BRFSS HRQOL limited activity ^e	0–30	6.0	9.6

* Actual number of subjects differed depending on missing items.

^a BMI=body mass index

^b Score of 10 or greater on the American Diabetes Association Risk Factor Survey

^c A positive response to “Do you get little or no exercise during a usual day?”

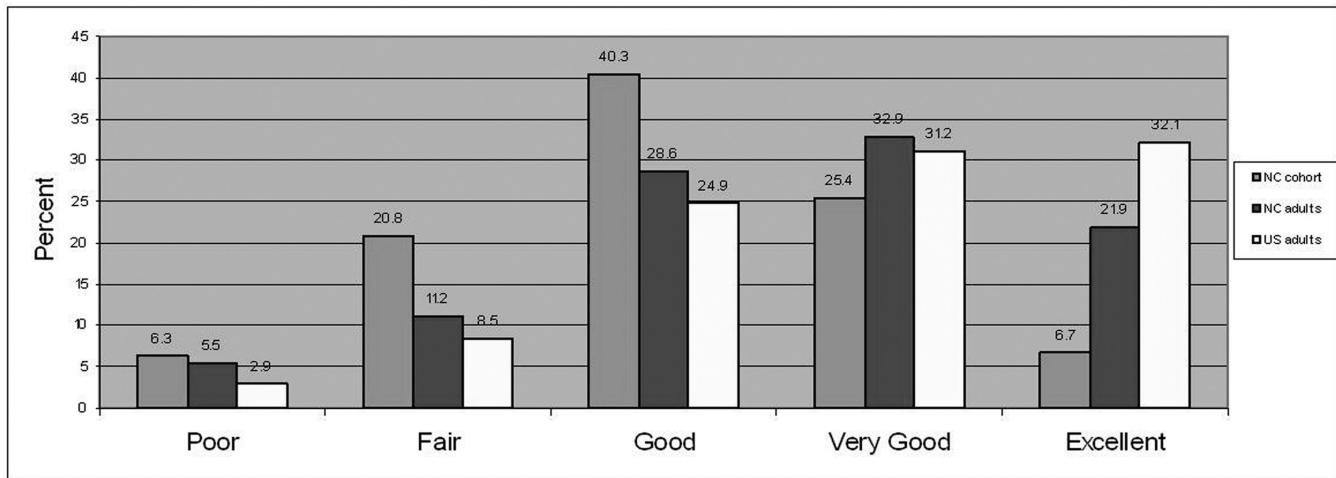
^d Higher scores indicate better health. Population mean=50, SD=10

^e Represents number of days per month not in good health or with activity limitation due to poor health. Higher scores indicate poorer health.

NC-FM-RN—North Carolina Family Medicine Research Network
 SF-12—Medical Outcomes Study 12-item Short Form Survey
 BRFSS—Behavioral Risk Factor Surveillance System
 HRQOL—health-related quality of life

Figure 1

Self-reported Health Status of the NC-FM-RN Cohort,
Compared to the General NC¹⁰ and US Adult¹¹ Populations



NC-FM-RN—North Carolina Family Medicine Research Network

database management, periodic communications with practices (usually by letter), and an annual newsletter to cohort members. Refreshment of the cohort added approximately \$60,000 of costs over and above cohort maintenance, representing a per-subject recruitment cost of approximately \$45.

Discussion

This paper describes a novel approach to developing a primary care research laboratory—a research cohort of patients recruited from a statewide sample of family medicine practices. In its first 3 years of operation, the NCHP cohort has proven valuable as an “incubator” for new investigators, as a means of facilitating the inclusion of primary care subjects in research proposals, and as a source of patients for research involving chronic illness and its risk factors. This research cohort has the following advantages over traditional PBRNs: a patient-focused rather than physician-focused structure; a loose, “top down” administration that places little demand on practices;²⁰ the ability to gather a representative sample through targeting of practices that serve racial and ethnic minorities; and a better-defined and better-described patient population. Further, case-control studies can be nested within such a cohort, and cohorts can be used to recruit for randomized trials.

In 1996, Stange called for the establishment of “primary care research centers” that included expertise in research methods.⁴ The NCHP cohort, by virtue of its sponsorship by established university investigators with

affiliations in multiple research entities on campus, has been able to employ on a part-time or consulting basis a variety of highly experienced research staff, psychometricians, health services researchers, medical subspecialists, and biostatisticians who were linked to the investigators on project teams. Thus, the program we have developed, building a cohort within established interdisciplinary research programs, but anchored in family medicine, may provide a new model for a researcher-driven primary care research laboratory.

There are, however, challenges involved in this type of infrastructure development. They include involvement of practitioners, minimization of selection bias, and maintenance of funding to support the network and cohort infrastructure.

Clinician Involvement

The literature on PBRNs has repeatedly emphasized the value and importance of the involvement of practitioners in research.^{2,5,7} While we believe that faculty in an academic department that is clinically active and well networked within its geographic region are in touch with issues of importance to primary care, we also believe that some kind of ongoing communication with the practices from which the cohort has been recruited is essential. Thus far, this has taken the form of in-person visits to the practices, an annual newsletter, an informational letter to all practices whenever any new data collection is to be conducted on some or all cohort members, presentations at the annual meeting

Figure 2

Enrollment and Retention Data for the North Carolina Family Medicine Cohort

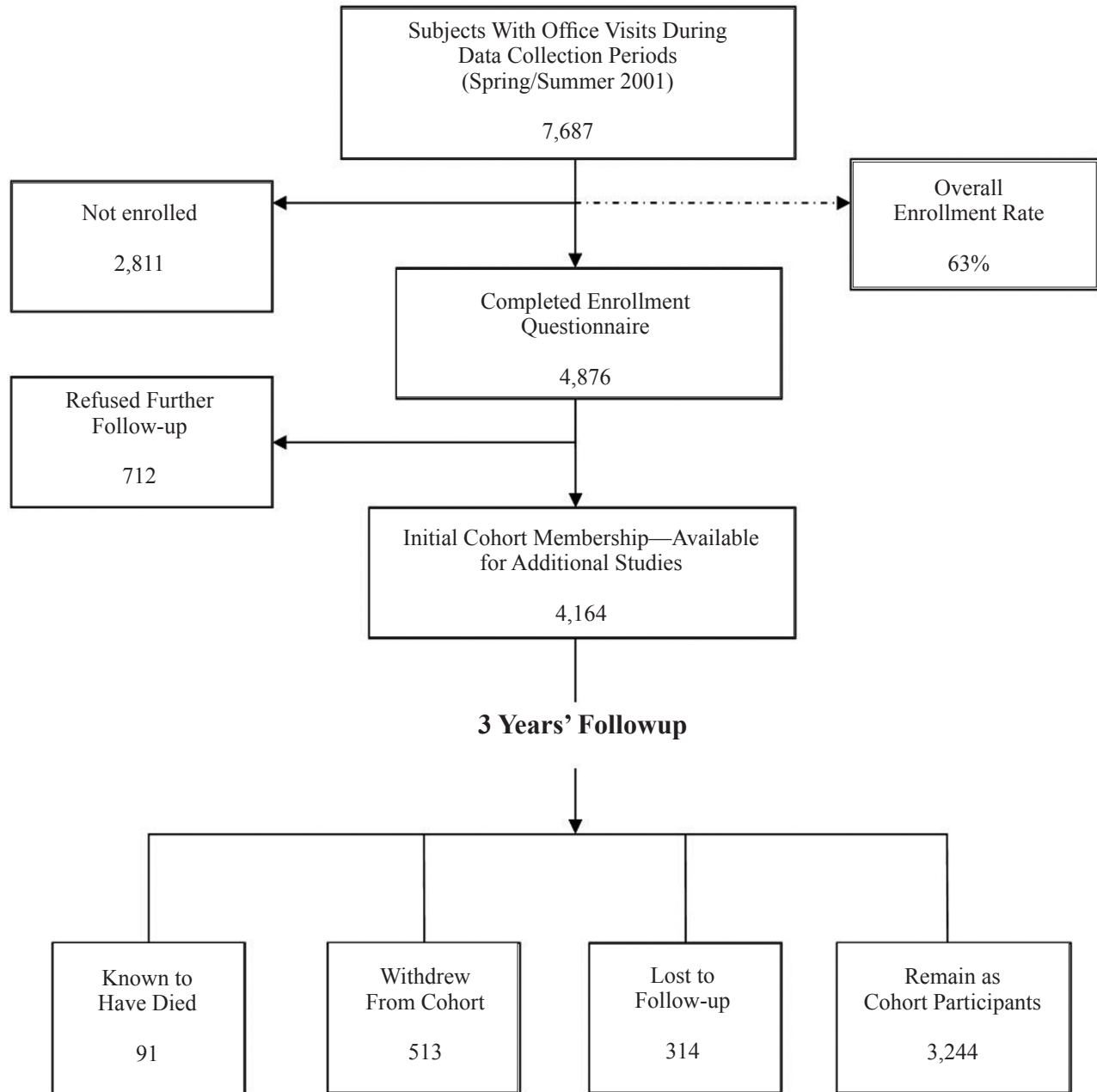


Table 3

Estimated Cost of Developing and Maintaining the UNC Family Medicine Research Cohort

	<i>Estimated Cost, by Calendar Year</i>			
	<i>2001</i>	<i>2002</i>	<i>2003</i>	<i>2004</i>
<i>Major Expenses, by Category</i>	<i>Cohort Development</i>	<i>Cohort Maintenance and Research Support</i>	<i>Cohort Maintenance and Research Support</i>	<i>New Subject Enrollment and Research Support</i>
Personnel				
Directors (salaries of co-PIs)	.20 FTE	.10 FTE	.10 FTE	.15 FTE
Project coordinator(s)*	.60 FTE	.15 FTE	.15 FTE	.40 FTE
Part-time research assistants (data collectors)	1.4 FTE	0	0	.7 FTE
Database management	.15 FTE	.10 FTE	.10 FTE	.20 FTE
Data entry	\$6,000	0	0	\$4100
Travel				
To practices for coordination	\$1,000	0	\$400	\$600
To statewide meetings for communication with practices	0	\$700	\$1,000**	\$500
Communication				
Telephone calls to obtain key missing data and/or follow-up lost/missing subjects	\$250	\$500	\$500	\$250
Design, printing, and mailing of newsletter to practices and subjects	0	\$4,000	\$4,000	\$5,000
Other costs				
Incentives/reimbursements to practices	\$15,000	0	0	\$1,000
Steering Committee	0	0	\$3,000	\$2,000
Estimated total cost	\$126,750	\$34,100	\$37,800	\$93,950

UNC—University of North Carolina

PI—principal investigator

FTE—full-time equivalent

* Includes Institutional Review Board work, organizing data collection, maintenance of tracking system, designing of questionnaires, coordinating data editing and entry, communication with family medicine offices, setting up meetings, training data collectors, site visits to monitor data collection, maintenance of ongoing contact lists of subjects, drafting of newsletters, and assistance with grant preparation/reporting. At times, these activities were shared on a part-time basis by two individuals (a project manager and a research assistant).

** Includes fee for display space

of the North Carolina Academy of Family Physicians, and involvement of a few physicians from the practices on an advisory panel.

What we have not done as part of our looser affiliation with practices, but what is common among PBRNs, is bring the practice physicians together for regular meetings and/or routinely involve practice members in proposal development. In our discussions with practice physicians, the vast majority preferred

not to have regular meetings. Whether this reflects a unique nature of our network (ie, where practices were selected primarily because of location and population served rather than on interest in research), or whether it reflects the increased time pressures of clinical practice, is unclear. The first network-wide meeting was successfully held in 2005 and was attended by representatives from more than 60% of network practices.

Selection Bias

As was pointed out by Lindbloom et al⁵ and Woolf et al,²¹ selection bias is a potential problem whenever sampling is nonrandom, such as in selection of practices or when patients refuse to enroll. While our initial data indicate that enrollees were demographically similar to North Carolina adults (Table 1), it is possible that our estimates are not representative of primary care patients, and this likelihood increases as subjects are lost to follow-up. Further, over time, selective attrition may further diminish the representativeness of the cohort. However, the issue of potential selection bias is present in all research, and it remains likely that selection bias by our method is no greater (and probably less) than that used in other, specialty-based clinical studies.

Maintenance of Funding

As is true of all attempts to develop laboratories for primary care research, maintenance of the NCHP cohort will depend on a combination of committed leadership, funding success, and thrift. During the past 3 years, research grants from the CDC and a practice network infrastructure grant from AHRQ have helped maintain the cohort. For the immediate future, modest support for network infrastructure is assured by two 5-year grants—an NIH grant to the Thurston Arthritis Center (within which a study of social and community determinants of health will be conducted using the cohort) and an NIH career mentorship award (that includes maintenance of the cohort for use by junior faculty as one of its specific aims). Additional support will continue to be sought through inclusion of the cohort in research grant proposals. Several additional potential sources of funding, which we have not explored but that could be valuable in maintaining cohorts, include industry funding for pharmaceutical trials involving chronic illness, partnerships with the state Academy of Family Physicians, and donations and/or an endowment from individuals interested in fostering research.

Conclusions

This paper describes a new model for development of a university-based primary care research infrastructure—a practice-based research cohort. It describes the development, characteristics, and 3-year experience with a cohort that was developed in North Carolina. Such a cohort may be more appealing to funding agencies than traditional PBRNs, because it can better characterize its patient population and can more clearly demonstrate access to subjects. Involvement of practitioners, minimization of selection bias, and maintenance of infrastructure funding are continuing challenges. As a method of facilitating primary care research, the development of practice-based cohorts may be useful as an alternative, or complement to, more-traditional PBRNs.

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The North Carolina Health Project (NCHP) is a program of ongoing research aimed at improving the health and primary medical care of persons with chronic illness. NCHP research is conducted in a practice-based research network consisting of a representative sample of family medicine practices in North Carolina, from which a cohort of patients has been enrolled and is maintained longitudinally. The network is called the North Carolina Family Medicine Research Network (NC-FM-RN), and the cohort is called the NCHP cohort. NCHP research studies are jointly sponsored by the Department of Family Medicine, the Thurston Arthritis Research Center, and the Cecil G. Sheps Center for Health Services Research at the University of North Carolina (UNC), in collaboration with the North Carolina Academy of Family Physicians. The project codirectors are Leigh Callahan, PhD, and Philip Sloane, MD, MPH. Participating family medicine practices have included: Biddle Point Health Center, Charlotte; Bladen Medical Associates, Elizabethtown; Black River Health Services, Atkinson and Burgaw; Blair Family Medicine, Wallace; Chatham Primary Care, Siler City; Community Family Practice, Asheville; Cornerstone Medical Center, Burlington; Day-spring Family Medicine, Eden; Goldsboro Family Physicians, Goldsboro; Henderson Family Health Center, Hendersonville; North Park Medical Center, Charlotte; Orange Family Medical Center, Hillsborough (pilot site); Person Family Medical Center, Roxboro; Pittsboro Family Medicine, Pittsboro; Prospect Hill Community Health Center, Prospect Hill; Robbins Family Practice, Robbins; South Cabarrus Family Physicians, Harrisburg, Concord, Mt Pleasant, and Kannapolis; Summerfield Family Practice, Summerfield; and Village Family Medicine, Chapel Hill. Support for the NCHP has been provided by the Centers for Disease Control and Prevention, the Agency for Healthcare Research and Quality, the National Institutes of Health, the Department of Family Medicine at UNC, and the Program on Health Outcomes at UNC. In addition, we would like to acknowledge Shannon Currey, PhD; Jennifer Milan Polinski, MPH; and Thelma Mielenz, PhD, PT, for their critical roles in development and maintenance of the NCHP cohort.

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