Notice of Research Fellowship Award

NATIONAL RESEARCH SERVICE AWARD

Department of Health and Human Services
National Institutes of Health
NATIONAL INSTITUTE OF NURSING RESEARCH

Issue Date: 04/03/2014

Grant Number: 1F31NR014952-01
FAIN: F31NR014952

Principal Investigator(s):
Jennifer Mammen, MSN

Project Title: Teens Experiences of Asthma Self Management Across Life Contexts

Corriveau, Anne, JD
University of Rochester
ORPA
518 Hylan Building
Rochester, NY 146270140

Award e-mailed to: urnihawards@orpa.rochester.edu

Latest Activation Date: 09/30/2014

Dear Business Official:

The National Institutes of Health hereby awards a grant in the amount of $32,581 (see "Award Calculation" in Section I and "Terms and Conditions" in Section III) to UNIVERSITY OF ROCHESTER in support of the above referenced project. This award is pursuant to the authority of 42 USC 288. 42 CFR 66 and is subject to the requirements of this statute and regulation and of other referenced, incorporated or attached terms and conditions.

Acceptance of this award including the "Terms and Conditions" is acknowledged by the grantee when funds are drawn down or otherwise obtained from the grant payment system.

Each publication, press release, or other document about research supported by an NIH award must include an acknowledgment of NIH award support and a disclaimer such as "Research reported in this publication was supported by the National Institute Of Nursing Research of the National Institutes of Health under Award Number F31NR014952. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health." Prior to issuing a press release concerning the outcome of this research, please notify the NIH awarding IC in advance to allow for coordination.

Award recipients must promote objectivity in research by establishing standards that provide a reasonable expectation that the design, conduct and reporting of research funded under NIH awards will be free from bias resulting from an Investigator's Financial Conflict of Interest (FCOI), in accordance with 42 CFR Part 50 Subpart F. Subsequent to the compliance date of the 2011 revised FCOI regulation (i.e., on or before August 24, 2012), Awardees must be in compliance with all aspects of the 2011 revised regulation; until then, Awardees must comply with the 1995 regulation. The Institution shall submit all FCOI reports to the NIH through the eRA Commons FCOI Module. The regulation does not apply to Phase I Small Business Innovative Research (SBIR) and Small Business Technology Transfer (STTR) awards. Consult the NIH website http://grants.nih.gov/grants/policy/coi/ for a link to the regulation and additional important information.

If you have any questions about this award, please contact the individual(s) referenced in Section IV.

Sincerely yours,
Kelli Oster
Grants Management Officer
NATIONAL INSTITUTE OF NURSING RESEARCH

Additional information follows
SECTION I – AWARD DATA – 1F31NR014952-01

Award Calculation (U.S. Dollars)
Other Fellowship Expenses $5,905
Institutional Allowance $4,200
Stipends $22,476

Federal Direct Costs $32,581
Total Award $32,581
Federal Share $32,581
TOTAL FEDERAL AWARD AMOUNT $32,581

AMOUNT OF THIS ACTION (FEDERAL SHARE) $32,581

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Recommended future year total cost support, subject to the availability of funds and satisfactory progress of the project.

Fiscal Information:
CFDA Number: 93.361
EIN: 1160743209A1
Document Number: FNR014952A
PMS Account Type: P (Subaccount)
Fiscal Year: 2014

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Recommended future year total cost support, subject to the availability of funds and satisfactory progress of the project.

NIH Administrative Data:
PCC: DTRLU / OC: 412L / Released: OSTERK 03/28/2014
Award Processed: 12/26/2013 14:35:08 PM

Fellow’s e-mail:
Jennifer Mammen jennifer_mammen@urmc.rochester.edu

SECTION II – PAYMENT/HOTLINE INFORMATION – 1F31NR014952-01


SECTION III – TERMS AND CONDITIONS – 1F31NR014952-01

This award is based on the application submitted to, and as approved by, NIH on the above-titled project and is subject to the terms and conditions incorporated either directly or by reference in the following:
a. The grant program legislation and program regulation cited in this Notice of Research Fellowship Award.

b. Conditions on activities and expenditure of funds in other statutory requirements, such as those included in appropriations acts.

c. The NIH Grants Policy Statement, including addenda in effect as of the beginning date of the budget period.

d. This award notice, INCLUDING THE TERMS AND CONDITIONS CITED BELOW.

(see NIH Home Page at http://grants.nih.gov/grants/policy/awardconditions.htm for certain references cited above.)

This award is subject to the requirements of 2 CFR Part 25 for institutions to receive a Dun & Bradstreet Universal Numbering System (DUNS) number and maintain an active registration in the Central Contractor Registration. Should a consortium/subaward be issued under this award, a DUNS requirement must be included. See http://grants.nih.gov/grants/policy/awardconditions.htm for the full NIH award term implementing this requirement and other additional information.

This award has been assigned the Federal Award Identification Number (FAIN) F31NR014952. Recipients must document the assigned FAIN on each consortium/subaward issued under this award.

Based on the project period start date of this project, this award is likely subject to the Transparency Act subaward and executive compensation reporting requirement of 2 CFR Part 170. There are conditions that may exclude this award; see http://grants.nih.gov/grants/policy/awardconditions.htm for additional award applicability information.

In accordance with P.L. 110-161, compliance with the NIH Public Access Policy is now mandatory. For more information, see NOT-OD-08-033 and the Public Access website: http://publicaccess.nih.gov/.

An Activation Notice (PHS 416-5) must be submitted to the NIH awarding office as of the day the fellow begins training. Submission of a Payback Agreement form is also required for postdoctoral fellows in their first 12 months of Kirschstein-NRSA postdoctoral support. A payback agreement does not apply to predoctoral support. The applicable forms should be submitted to the awarding component at the following address:

National Institute of Nursing Research
6701 DEMOCRACY BLVD, RM 710
One Democracy Plaza
Bethesda, MD 20892-4870
Bethesda, MD: Maryland 20892

The Activation Notice and Payback Agreement forms are available at the following websites:
http://grants1.nih.gov/grants/funding/416/PHS416-5.pdf and

No funds can be disbursed until an activation notice and a payback agreement, if applicable, are submitted to the NIH. This award should be activated within six months, in accordance with the latest activation date.

Fellows are required to notify the awarding unit as soon as they are aware of any possible change in plans regarding their fellowship support.
SECTION IV – NR Special Terms and Conditions – 1F31NR014952-01

INFORMATION: FELLOWSHIP ACTIVATION NOTICE
This award may not be activated from October 1 through November 15 or prior to the issue date of this Notice of Fellowship Award.

REQUIREMENT: The awardee is required to follow the data and safety monitoring plan dated 03/17/2014 and may not implement any changes in the plan without the written prior approval of the National Institute of Nursing Research.

INFORMATION: This award is issued in the absence of a Certificate of Confidentiality (COC), which protects against the involuntary release of personally identified research information of a sensitive nature sought through any federal, state, or local civil, criminal, administrative, legislative, or other proceedings. The NIH policy associated with COCs can be found at http://grants.nih.gov/grants/policy/coc/.

INFORMATION: STIPENDS

INFORMATION: TUITION AND FEES ADJUSTMENT
The Tuition and Fees Category for competing awards is calculated in accordance with the NIH Guide Notice NOT-OD-14-046, (http://grants.nih.gov/grants/guide/notice-files/NOT-OD-14-046.html). No future year escalation is provided.

INFORMATION: STIPEND SUPPLEMENTATION
Stipend supplementation and compensation policies must be followed as described in the NIH Grants Policy Statement, dated October 2013. National Institute of Nursing Research considers limited part-time to be no more than ten hours per week in addition to the full-time fellowship training.

INFORMATION: EMPLOYMENT
Since NRSA awards are not provided as a condition of employment with either the Federal Government or the grantee institution, it is inappropriate and unallowable for institutions to seek funds for or to charge individual fellowship grant awards for costs that would normally be associated with employee benefits (for example: FICA, worker’s compensation, and unemployment insurance.)

INFORMATION: INSTITUTIONAL ALLOWANCE
The institutional allowance is provided to help defray expenses as research supplies, equipment, travel to scientific meetings, and health insurance. Funds are paid directly to and administered by the sponsoring institution.

INFORMATION: FELLOWSHIP EXPENSES
"Other fellowship expenses" are provided to help cover a portion of tuition and fees.

INFORMATION: DOCTORAL DEGREE
This award may not continue beyond the completion of all doctoral degree requirements.

INFORMATION: PAYBACK
Section 1602 of the NIH Revitalization Act eliminated the payback obligation for pre-doctoral individuals. Therefore, it is not necessary for a Payback Agreement to be completed, and most of the terms discussed in the NRSA Assurance contained in the application that you submitted are
no longer relevant. However, Item V. Program Evaluation is still applicable, i.e., "I understand that I may also be contacted from time to time, but no more frequently than once every two years, after the termination of this award to determine how the training obtained has influenced my career. Any information thus obtained would be used only for statistical purposes and would not identify me individually."

INFORMATION: FELLOWSHIP EARLY TERMINATION
Should this fellowship terminate before the reflected budget/project period end date, a Termination Notice (PHS 416-7) must be submitted in xTrain in accordance with http://grants.nih.gov/grants/guide/notice-files/NOT-OD-11-026.html

INFORMATION: HUMAN SUBJECTS EDUCATION CERTIFICATION
This award reflects the National Institute of Nursing Research acceptance of the certification that all key personnel as defined in the February 29, 2008 NIH Guide announcement (http://grants.nih.gov/grants/guide/notice-files/NOT-OD-08-054.html) have completed education on the protection of human subjects, in accordance with NIH policy requirements. Any key personnel, as defined in that announcement, must satisfy this requirement prior to participating in the project. Failure to comply can result in suspension and/or termination of this award or withholding of support of the continuation award.

STAFF CONTACTS
The Grants Management Specialist is responsible for the negotiation, award and administration of this project and for interpretation of Grants Administration policies and provisions. The Program Official is responsible for the scientific, programmatic and technical aspects of this project. These individuals work together in overall project administration. Prior approval requests (signed by an Authorized Organizational Representative) should be submitted in writing to the Grants Management Specialist. Requests may be made via e-mail.

Grants Management Specialist: Lawrence R. Haller
Email: hallerr@email.nih.gov  Phone: 301-402-1878 Fax: 301-451-5652

Program Official: David Banks
Email: banksdh@email.nih.gov  Phone: 301-496-9558 Fax: 301-480-8260

SPREADSHEET SUMMARY
GRANT NUMBER: 1F31NR014952-01

INSTITUTION: UNIVERSITY OF ROCHESTER

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<td>Hyekyun Rhee</td>
<td>Other (Specify)-Sponsor</td>
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<td>Sally Norton</td>
<td>Other (Specify)-Co-Sponsor</td>
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**Appendices**

Appendi

**Reference Letters**

Mary Dombeck University of Rochester School of Nursing 07/25/2013

Bethel Powers University of Rochester 07/25/2013

JAMES MOMAHON University of Rochester 07/25/2013

Hugh Crean University of Rochester School of Nursing 08/05/2013
APPLICATION FOR FEDERAL ASSISTANCE
SF 424 (R&R)

1. *TYPE OF SUBMISSION
Pre-application □ Application X Changed/Corrected Application □

2. DATE SUBMITTED
Applicant Identifier

5. APPLICANT INFORMATION
* Legal Name: University of Rochester
Department: ORPA
Street1: 618 Hylan Building
Street2:
* City: Rochester County / Parish:
* State: NY: New York Province:
* Country: USA: UNITED STATES * ZIP / Postal Code: 146270140

Person to be contacted on matters involving this application
Prefix: * First Name: Anne Middle Name:
* Last Name: Corrieveu Suffix: JD
* Phone Number: 585-273-2137 Fax Number: 585-275-9492
Email: anne.corrieveu@rochester.edu

6. *EMPLOYER IDENTIFICATION (EIN) or (TIN):
1160743209A1

7. *TYPE OF APPLICANT:
Other (Specify):
Small Business Organization Type □ Women Owned □ Socially and Economically Disadvantaged

8. *TYPE OF APPLICATION:
New X Resubmission
□ Renewal □ Continuation □ Revision
If Revision, mark appropriate box(es).
□ A. Increase Award □ B. Decrease Award □ C. Increase Duration □ D. Decrease Duration
□ E. Other (specify):

* Is this application being submitted to other agencies? Yes □ No X What other Agencies?

9. *NAME OF FEDERAL AGENCY:
National Institutes of Health
10. CATALOG OF FEDERAL DOMESTIC ASSISTANCE NUMBER: 93.361
TITLE: Nursing Research

11. *DESCRIPTIVE TITLE OF APPLICANT'S PROJECT:
Teens' Experiences of Asthma Self-Management Across Life Contexts

12. PROPOSED PROJECT:
* Start Date: 04/01/2014 Ending Date: 03/31/2016 NY-025

13. CONGRESSIONAL DISTRICT OF APPLICANT

14. PROJECT DIRECTOR/PRINCIPAL INVESTIGATOR CONTACT INFORMATION
Prefix: * First Name: Jennifer Middle Name:
* Last Name: Mammen Suffix:
Position/Title: Doctoral Student
* Organization Name: University of Rochester
Department: School of Nursing Division:
* Street: 601 Elmwood Avenue
Street2:
* City: Rochester County / Parish:
* State: NY: New York Province:
* Country: USA: UNITED STATES * ZIP / Postal Code: 14620001
* Phone Number: 585-275-5121 Fax Number: 585-275-2176
* Email: jennifer.mammen@urmc.rochester.edu

Tracking Number: GRANTI1455545 Funding Opportunity Number: PAR-11-117 Received Date: 2013-07-25T15:44:01-0400
15. ESTIMATED PROJECT FUNDING

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16. * IS APPLICATION SUBJECT TO REVIEW BY STATE EXECUTIVE ORDER 12372 PROCESS?

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<td>PROGRAM IS NOT COVERED BY E.O. 12372; OR PROGRAM HAS NOT BEEN SELECTED BY STATE FOR REVIEW</td>
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Date: ____________

17. By signing this application, I certify (1) to the statements contained in the list of certifications* and (2) that the statements herein are true, complete and accurate to the best of my knowledge. I also provide the required assurances * and agree to comply with any resulting terms if I accept an award. I am aware that any false, fictitious, or fraudulent statements or claims may subject me to criminal, civil, or administrative penalties. (U.S. Code, Title 18, Section 1001)

* I agree

* The list of certifications and assurances, or an Internet site where you may obtain this list, is contained in the announcement or agency specific instructions.

18. SFLLL or other Explanatory Documentation

Add Attachment | Delete Attachment | View Attachment

19. Authorized Representative

Prefix: ____________ * First Name: Anne * Last Name: Corriveau

Middle Name: ____________ Suffix: ____________

* Position/Title: Research Administrator II

* Organization: University of Rochester

Department: ORPA Division: ____________

* Street1: 518 Wylan Building

Street2: ____________

City: Rochester County / Parish: ____________

* State: NY: New York Province: ____________

* Country: USA: UNITED STATES * ZIP / Postal Code: 146270140

* Phone Number: 585-273-2137 Fax Number: 585-275-9492

* Email: anne.corriveau@rochester.edu

* Signature of Authorized Representative Anne Corriveau

* Date Signed 07/25/2013

20. Pre-application Add Attachment | Delete Attachment | View Attachment
424 R&R and PHS-398 Specific Table Of Contents

SF 424 R&R Face Page............................................................... 1
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Appendix

Number of Attachments in Appendix: 1
Project/Performance Site Location(s)

Project/Performance Site Primary Location

☐ I am submitting an application as an individual, and not on behalf of a company, state, local or tribal government, academia, or other type of organization.

Organization Name: University of Rochester

DUNS Number: 0412941090000

* Street1: 601 Elmwood Avenue

Street2:

* City: Rochester

County:

* State: NY: New York

Province:

* Country: USA: UNITED STATES

* ZIP / Postal Code: 146420001

Project/Performance Site Congressional District: NY-025

Project/Performance Site Location 1

☐ I am submitting an application as an individual, and not on behalf of a company, state, local or tribal government, academia, or other type of organization.

Organization Name:

DUNS Number:

* Street1:

Street2:

* City:

County:

* State:

Province:

* Country: USA: UNITED STATES

* ZIP / Postal Code:

Project/Performance Site Congressional District:

Additional Location(s)
1. Are Human Subjects Involved?  □ Yes  □ No
   1.a. If YES to Human Subjects
      Is the Project Exempt from Federal regulations?  □ Yes  □ No
         If yes, check appropriate exemption number.  □ 1 □ 2 □ 3 □ 4 □ 5 □ 6
      If no, is the IRB review Pending?  □ Yes  □ No
      IRB Approval Date: ___________________________
      Human Subject Assurance Number: 0000009386

2. Are Vertebrate Animals Used?  □ Yes  □ No
   2.a. If YES to Vertebrate Animals
      Is the IACUC review Pending?  □ Yes  □ No
      IACUC Approval Date: ___________________________
      Animal Welfare Assurance Number: ___________________________

3. Is proprietary/privileged information included in the application?  □ Yes  □ No
4. a. Does this Project Have an Actual or Potential Impact - positive or negative - on the environment?  □ Yes  □ No
   4.b. If yes, please explain: ___________________________
   4.c. If this project has an actual or potential impact on the environment, has an exemption been authorized or an environmental assessment (EA) or environmental impact statement (EIS) been performed?  □ Yes  □ No
   4.d. If yes, please explain: ___________________________

5. Is the research performance site designated, or eligible to be designated, as a historic place?  □ Yes  □ No
5.a. If yes, please explain: ___________________________

6. Does this project involve activities outside of the United States or partnerships with international collaborators?  □ Yes  □ No
6.a. If yes, identify countries: ___________________________
6.b. Optional Explanation: ___________________________

7. Project Summary/Abstract
   ProjectSummaryAbstract.pdf

8. Project Narrative
   ProjectNarrative.pdf

9. Bibliography & References Cited
   BibliographyReferencesCited.pdf

10. Facilities & Other Resources
    FacilitiesandOtherResources.pdf

11. Equipment
    Equipment.pdf

12. Other Attachments
    □ Add Attachments  □ Delete Attachments  □ View Attachments

Other Information

Page 5
Project Summary/Abstract

Asthma is the most common chronic disease in teens. This age group has higher risk of asthma morbidity and mortality than other groups, which has been attributed to poor asthma self-management. Most research in this population has focused on the ways in which teen asthma self-management is inadequate to achieve asthma control. However, very little is known about the process of asthma self-management from teens’ perspectives. In order to promote better asthma self-management, it is imperative to understand teens’ perspectives of managing their asthma, including what they do to self-manage, what their rationales are for their choices, and how self-management behaviors may vary across life-contexts. This type of contextually specific knowledge of teen-self-management will facilitate the development of effective self-management interventions, and assist clinicians in shaping and delivering health information in a way that is both developmentally appropriate and meaningful to teen patients.

Therefore, the purpose of this study is to explore teens’ experiences of asthma self-management across their different life-contexts through use of asthma self-management diaries and in-depth qualitative interviews with teens and their parents. The aims of this study are to (1) describe how teens manage their asthma and what is important from the perspective of teens and their parents; (2) compare the asthma self-management of minority versus non-minority teens having well-controlled and not-well-controlled asthma.

The study design is case-based qualitative description, focusing on teen-parent dyads. Each case will comprise: (1) a primary interview with the teen; (2) an interview with the parent; (3) a two-week digitally recorded self-management voice-diary; and (4) a follow up interview with the teen. Thus, the estimated sample size of 14 to 18 cases will provide a minimum of 56 sources of data. Teens will be recruited through the Emergency Department, Pediatric Pulmonary Department, and from previous study databases to increase between subject variability. Purposeful and criterion-based sampling will be used to select for dyads best able to contribute to a broader understanding of the phenomena of teen asthma self-management. The in-depth interviews, in conjunction with digitally recorded daily voice diaries, will be used to capture both retrospective and contemporaneous data on teen asthma self-management. Four domains of self-management (symptom prevention, symptom monitoring, acute symptom management, and communication) will be explored across four primary contexts (home, school, community, and healthcare settings). Directed content analysis of transcribed interviews and diaries will be used to critically evaluate and extend the existing conceptualization of teen asthma self-management while highlighting teen perspectives and goals. Analysis will also include comparison of self-management between minority and non-minority teens, as well as teens with well-controlled and not-well-controlled asthma.
Project Narrative

Teens often have poorly controlled asthma, which is associated with increased asthma-related illness, poorer quality of life, and increased use of costly health care services. Improving asthma self-management is critical to helping teens achieve good asthma control and preventing negative health outcomes. Understanding asthma self-management from the perspectives of teens and their parents is a crucial first step towards this goal, and will help to increase the effectiveness of teen asthma education and interventions.
References

25. Wamboldt FS, Bender BG, Rankin AE. Adolescent decision-making about use of inhaled asthma controller medication: results from focus groups with participants from a prior longitudinal study. J Asthma 2011;48(7):741-50.
82. Oliver S, Lumley J, Waters E, Oakley L. Observational and qualitative research: increasing a review's relevance to practitioners and consumers. Cochrane Colloquium Abstracts Journal 1999 (7th Cochrane Colloquium, Rome).


FACILITIES & RESOURCES

The scientific environment of the University of Rochester School of Nursing, and the University of Rochester Medical Center provides multiple resources to early stage research investigators to ensure success. Full description of available resources to this applicant are provided below.

Laboratory: N/A
Animal: N/A
Computer: N/A

UNIVERSITY OF ROCHESTER AND MEDICAL CENTER

The University of Rochester
One of the nation's top academic medical centers, the University of Rochester Medical Center forms the centerpiece of the University's health research, teaching, patient care, and community outreach missions. With more than $145 million in federal research funding, UR School of Medicine research funding ranks in the top one-quarter of U.S. medical centers, while the School of Nursing ranks 12th highest in funding. The University's health care delivery network is anchored by Strong Memorial Hospital—a 750-bed, University-owned teaching hospital.

SCHOOL OF NURSING

History and Organization
The School of Nursing was established in 1925 as a diploma program administered by Strong Memorial Hospital with a baccalaureate degree offered to those enrolled who met the requirements of the university. In 1960, the diploma program was discontinued and the baccalaureate program became the only offering for entry into the profession. The graduate programs were developed beginning in the 1950s, with the PhD program added in 1979. The University’s commitment to nursing education was demonstrated by the establishment of an autonomous School of Nursing in 1972. A unification model was established that assisted the School of Nursing in assuming accountability and responsibility in nursing practice, nursing education, and nursing research. The activities of the Dean and Director are those of academic leadership, administrative responsibilities in the university and medical center, and top level policy-formulation for programs of education, research, and practice. In 1999, the school underwent a strategic planning process to position the school for the future. This resulted in a renewed commitment to unification of practice, education, and research for the 21st century and to a structure that would support it.

General administrative leadership for the school is provided by the Dean, Associate Deans (Associate Dean for Academic Affairs, Associate Dean for Research, and Associate Dean for Finance and Administration), and Education Program Coordinators for the Accelerated program for non-nurses, BS completion for RNs, Master's, PhD, and most recently a Doctorate of Nursing Practice (DNP) program. The roles are to promote the School’s mission: academic excellence, high-quality practice, and research. Each faculty member focuses on at least two of the missions: practice, education, and research.

School of Nursing Facilities and Building
The context for supporting research productivity is extensive within the University and extends into the surrounding community. This context consists of: health care facilities; the interaction among research, practice and education; and specific resources in the form of space, talented practitioners and researchers who are cross-discipline collaborators, and extensive sources for conducting research including library resources, available data sets, and financial resources to provide funds for seeding pilot studies.
The School of Nursing occupies space on the Medical Center Campus in Helen Wood Hall. In addition to classroom, seminar rooms, research space, and faculty offices for the School of Nursing, Helen Wood Hall also houses the Department of Pediatric, the Department of Family Medicine, and the Center for Developmental Disabilities.

Predoctoral and postdoctoral trainees have shared office space in Helen Wood Hall, providing easy access to nursing faculty, administration, the Center for Research & Evidence Based Practice, and The Elaine C. Hubbard Center for Nursing Research on Aging as well as to interdisciplinary colleagues. Predoctoral trainees will be housed in space shared with other doctoral students while postdoctoral trainees will have offices adjacent to their faculty advisors.

**School of Nursing and University of Rochester Information Technology Services**

Faculty, staff, and doctoral students are provided, at a minimum, Dell Core 2-class workstations running Windows XP SP 3 with Office 2007, SPSS, Internet Explorer, and other productivity related applications as a standard configuration. The SON's resources include two student computer labs, a small video studio for creation of materials for online and distance learning. There are five smart classrooms, a smart auditorium with video conferencing and mobile video conferencing available in most locations.

Each departmental workstation is running Sophos Anti-Virus to protect against computer viruses. The virus software is updated on a daily basis on each workstation. In addition, all email messages on URMC Email Servers are scanned for viruses. All hard drives of departmental workstations are encrypted by PointSec Full Disk Encryption.

All SON servers receive Nessus and other security scans and audits quarterly. The SONITS staff are actively involved in University-wide information security teams to ensure safety of SON information assets. All SON file servers are backed up to tape nightly with a three-month retention.

The School of Nursing is a member of the URMC's private ethernet "Enterprise" local area network (LAN). The LAN facilitates instruction, research, and professional activities. The Ethernet LAN interconnects all office and resource centers in the School with all University of Rochester Medical Center and Strong Memorial Hospital electronic resources, including Miner Library’s online biomedical knowledge bases, electronic order entry, human resources, medical billing, and student records computing systems. The LAN has complete access to the University of Rochester's redundant 500 MBps Internet connection, the 250 MBps Internet2 connection, and all faculty, staff, and students are provided with unlimited access from their desktops. Additionally, the URMC provides remote access using VPN to data files and email.

The URMC is protected by a Checkpoint Firewall-1, which limits the source and type of traffic coming into the institution. The University imposes some restrictions on network protocols to reduce the risk of various common vulnerabilities. The University utilizes SonicWALL and Checkpoint VPN-1 endpoints to provide secure permanent IPSec-secured VPN tunnel connections to remote sites. The URMC offers Virtual Private Network services for secure remote access, secure Web Servers, and Automated Security Scanning to ensure high levels of security. URMC has deployed an automated Intrusion Detection System, in order to assist in the detection of certain well-known attacks and prevent the attacks from being completed successfully. The SON is a member of the University of Rochester Medical Center (URMC) and uses its Voltage SecureMail service. This allows encrypted email to be exchanged between medical providers and patients. The Voltage technology is used by members of the financial industry such as Wells Fargo to provide secure financial information exchange with business customers.

The University has a wide range of centralized and dispersed computer resources, including the University Computer Center and the Division of Medical Informatics. The University's Academic Technology Services Division is extensive and available to all faculty, staff and students.

To augment classroom instruction, online instruction and for distance learning the University of Rochester runs the Blackboard Learning Management System, providing connectivity for all curricular materials, discussions, blogs, wikis, etc.
Mainframe computing uses an MVS operating system and an extensive network of VAX computers is also available. The Department of Biostatistics has a network of SPARC, SUN and VAX workstations with extensive specialized software for problems in health services research.

The University of Rochester's Center for Research Computing (CRC) manages two supercomputers including IBM Blue Gene and BlueHive systems. The CRC actively reaches out to help researchers take advantage of these resources. In addition to the shared mainframe computer resources, the University is a member of the Consortium for Scientific Computing which provides access to the supercomputer facilities at Cornell University and Princeton. The University also maintains connections to Internet, Bitnet, and the National Scientific Foundations NSFnet.

School of Nursing Research Centers
Center for Research and Evidence-Based Practice
The Center for Research and Evidence-Based Practice serves as the central resource for all research Centers and individuals (faculty, trainees and their interdisciplinary collaborators) within the School of Nursing. It is organized into three divisions: Pre- and Post Award; Research Facilitation; and Training, Education. The services of the Divisions are designed to complement and integrate with those of the University's CTSI. The Center includes experienced, highly trained staff that provides accessible, consistent, high quality services in an active academic research environment where collaboration, training and mentorship form the cornerstones and where the process of transitioning from junior investigator to an independent NIH-funded scientist is seamless.

Pre- and Post-Award Division: In this Division, an experienced staff consisting of a senior administrator, senior accountants and bookkeepers, and grants administration personnel dedicated to the support of intra- and extramural funding activities provides services and supports the training of investigators in Federal, University, and other regulations relevant to funding for research. During the Pre-award period, they work with the investigator to plan the application and submission process. After the plan is developed they provide information on application requirements, develop and review the budget, format the biographical sketch, complete routine documentation, provide graphic support for tables, charts, and models, orchestrate the internal approval process including ORPA and complete the electronic submission in coordination with the investigator. This Division also provides extensive Post-Award management which includes: financial management; interpreting of federal regulations and guidelines; acting as liaison with external agencies and internal departments; assisting with non-competing renewal preparation; and providing certified grant administrative services. The staff provides education and services in a supportive environment geared to the experience and needs of the investigators and Focus-Specific Centers.

Research Facilitation Division: The Research Facilitation Division provides key support services for research and scholarly activities. The group's goals include, but are not limited to providing services for preliminary and pilot studies, functioning as a training ground for graduate students, and training junior researchers in project oversight and management of their own project support staff. Specific structures exist to provide faculty and research trainees with direct access to timely assistance with both developing and carrying out ongoing projects. Requests for service begin with a Faculty Research Service Grant (FRSG), which is peer-reviewed. Following peer scientific review and development of a work plan cost estimate, projects are approved and assignments made for assistance with specific staff, work plan development, data analysis supports as needed, and ongoing monitoring and updates of research activity. With a staff of 3 senior nurse clinical research coordinators, 3 senior information analysts and programmers, and support staff, the group provides a broad range of services and training, including: recruitment strategies and services; MIS design and maintenance for tracking study subjects; instrument design; data and observation coding systems use; interviewing – including self-administered and interviewer-administered, web-based, and QDS; data processing; establishing/structuring analysis files, and providing descriptive analyses. The overall orientation of this Division is towards training and efficient completion of preliminary and pilot studies necessary for the production of publications and major research proposals.
Training and Education Division: Coordinated with the School of Nursing and University formal course offerings and the consultation and training services of the CTSI, the group’s activities are designed to enhance the training of researchers by direct provision of training and communicating announcements of pending research presentations, methods seminars, and conferences across the Medical Center and University. Among the multiple modalities for training are: 1) Senior School of Nursing Statistician, Professor Din Chen, and 3 senior methodologists conduct a weekly seminar/workshop where individual faculty bring their work along with their design and statistical question for consultation. Junior faculty/trainees who attend have ample opportunity to participate, and gain increased exposure to the challenges and strategies of design and analyses. Approaches to a specific project are discussed, along with the more general questions in that area of the field. 2) Weekly Brown Bag Research Hour Sessions are available and focus on individual research, development of new methods, and new developments in the field. Faculty and staff are invited to attend and encouraged to ask questions and provide suggestions. 3) A structured Research Proposal Development Plan is in place and provides guidance to investigators and mentors for the steps in the proposal development and evaluation process. These steps, which take place over a 4 month period, end with internal and external proposal critiques by senior investigators in the field. 4) Individual consultation is available for all steps in the research proposal generation and research implementation processes, including but not limited to biostatistics, sample size determination, design and methods, preliminary identification and design of instruments, and IRB requirements, including IRB submission and reporting. 5) Among the many software programs supported are: Access, DBMS copy; Endnote; Excel; Filemaker Pro; HLM; Lisrel; M Plus; Amos; Atlas-T; Nudist; QDS-ASCAI; Sample Power: SAS; SPSS; SUDAN; STATA. 6) Staff assists with the development of presentations, posters, and manuscript drafts, and colleagues in the field and an experienced editor provide review/critiques.

PhD program
Established in 1979, the aims of this research-focused doctoral program are to produce scholars able to critique, synthesize, and apply theory and research evidence on clinically relevant issues and problems; articulate the contributions of the graduate’s own research and that of his/her discipline; design, execute, and disseminate clinical research that is rigorous, ethical, theoretically congruent, and clinically and socially significant; demonstrate progression toward a leadership role in health science research, education, and policy; recognize importance of mentoring students and facilitating professional advancement of colleagues in clinical and educational settings; and disseminate information through scholarly presentations and publications to promote the growth of the profession. The program is open to licensed masters-prepared health professionals including nurses, physical therapists, social workers, and others. Applications are considered on a case-by-case basis. Students complete 60 credits of study beyond the masters degree, including rigorous training in epistemology, theory, research design and methods, and responsible conduct of research and scholarship. All students participate in required research assistant work and go on to complete and defend dissertation research projects that advance knowledge in their disciplines.

Curriculum structure mandating interdisciplinary involvement
All PhD dissertation committees in the University include a member from outside the originating school or department. Each defense is chaired by an additional outside member named by the University, again often a member of a non-nursing health profession. In turn, nursing faculty are equally likely to serve on doctoral committees and chair dissertation defenses for other schools. In this way, research training is structured as interdisciplinary, enabling nursing research trainees to develop a sophisticated awareness of health issues beyond their own discipline.

Instruction in Responsible Conduct of Research
URSON courses address ethical conduct of research throughout the doctoral level. Ethical considerations are discussed in courses focused on qualitative and quantitative research design. In addition, a 1-credit course, “Ethics and Professional Integrity for the Clinical Researcher” (IND 503) is required for all researchers at the University of Rochester. This course consists of seven modules related to the protection of human and animal subjects, plagiarism and copyright laws, intellectual property and responsible authorship, data management and sharing, and the reporting of ethical misconduct. Course content delineates the many responsibilities of individual researchers, teams, and institutions in valuing, maintaining and promoting scientific integrity. The course consists of weekly guest presentations followed by small group discussions in which interdisciplinary participants analyze various case studies.
Small group facilitators includes diverse faculty from several departments at the University of Rochester who have additional roles within the Office of Human Subject Protection. The combination of didactic and interactive learning activities for this course highlights the requirements of responsible conduct of research and expands knowledge and critical thinking on this topic, research programs, concept analysis, theory development, epistemology, and statistical data analysis.

As a pre-requisite to any research involvement, researchers including doctoral students must complete the self-study process and pass the test for the Human Subjects Protection Program (HSPP), which is administered by the University’s Office of Human Subject Protection. This level of certification is for participation in studies that involve greater than minimal risk, and must be renewed every two years. Seminars and/or classes offered by the Office of Human Subject Protection aim to further enhance responsible conduct of research at the University. Grand rounds, ethics rounds, and monthly interdisciplinary meetings regarding ethics and medical humanities, and lecture series are open to the research and clinical community at the University of Rochester.

The University Library System
River Campus Library: Standing 186 feet high, the tower of Rush Rhees Library on Rochester’s River Campus has been a symbol of the University since the building opened in 1930. Today, Rush Rhees Library offers a mix of quiet study places, collaborative work spaces, computer labs, and close to 42 miles of shelving and stacks. Sibley Music Library/ Eastman School: Founded in 1904, today the Sibley Music Library is the largest academic music library in North America. Miner Library Medical Center: The Edward G. Miner Library provides the University of Rochester Medical Center and the greater Rochester community with resources, expertise, and an inviting space to support health, discovery, teaching, and learning. Allen Library Memorial Art Gallery: The Charlotte Allen Whitney Library and Teacher Resource Center are open to the public for general research and to help teachers integrate art into classroom instruction.

www.rochester.edu/libraries

UR Research
UR Research is an institutional repository system with collaborative authoring and versioning capabilities. It is a fully featured digital repository management solution designed to be easy for users to understand and manage. Unlike Sharepoint, it enables collaboration with researchers at other institutions. Support for researchers and collaborators: UR Research provides a password protected private workspace that allows University of Rochester users to upload and store up to 2 gigabytes of files of any type. UR Research has been able to handle file uploads of over two hundred megabytes. UR Research allows for the storage and retrieval of multiple versions of any given file. Registered users may share files with collaborators (either within or outside the University) for co-authoring purposes. Collaborators must create an account in UR Research and always log in to access materials being shared with them. A publication area is also provided and can be used to disseminate material to larger groups. Published content can be restricted to a given set of users when necessary; contact the UR Research system administrators to discuss restricting access.

Information useful for grant applications: Encryption and security: the system is run over a secure connection and uses a signed certificate. The current certificate is supplied by Verisign and is encrypted at 128 AES; on 1/15/2012 this certificate will be replaced by one from Entrust, encrypted at 256 AES. Data preservation: the UR Research system is backed up nightly. Thirty days of backups are maintained locally on disk; after 30 days the disks are written to tape, and tapes are rotated so there are always 12 months' worth kept off-site, in a fire and water proof rated safe.

Server environment: The server holding the UR Research data is located in the University of Rochester River Campus Libraries’ server room, which is temperature and humidity HVAC controlled. The server room is equipped with an alarm system that is wired to central university support for immediate notification of changes in prescribed temperature or humidity levels. The Libraries’ server room is a secure, purpose-built room, accessible by keypad only by the libraries’ systems administrators.

www.urmc.rochester.urresearch.rochester.edu
Mary Parkes Asthma Center
There are currently over 15 million Americans with asthma—thousands of them right here in the Rochester community. At the Mary M. Parkes Center for Asthma, Allergy, and Pulmonary Care, we’re dedicated to the highest level of diagnosis, treatment and support.

www.urmc.rochester.edu/mary-parkes

There is an asthma epidemic underway in the United States and most other developed countries. Although the cause of the asthma epidemic is not known, current thinking is that environmental exposures (for example to air pollution or respiratory viral infections) in genetically susceptible individuals play a major role. An active asthma research program is underway at the University of Rochester Medical Center, with the goal of identifying the causes of asthma and discovering new therapies.

With the support of the Parkes family foundation, we started an Asthma Registry at the Mary Parkes Center in 2007. Patients enrolled in the Asthma Registry are followed closely by asthma experts who use non-invasive methods to monitor airway inflammation. This includes simple breathing tests that measure exhaled nitric oxide (eNO), and collect exhaled breath condensate (EBC). Other ongoing asthma studies involve obtaining a blood sample from subjects who have allergies to cats or other allergens. All asthma research conducted at the Mary Parkes Center has been approved by the Research Subjects Review Board at the University of Rochester Medical Center.

www.urmc.rochester.edu/mary-parkes/research.cfm
Equipment

This project requires no major equipment, with the exception of general office equipment.
**Graduate Institution Report of Scores**

**Last Name:** Mammen  
**First Name:** Jennifer  
**School Code:** 2360  
**Department Code:** 5199

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List of Referees

1. Hugh Crean, PhD
   Research Associate
   University of Rochester, School of Nursing

2. Mary-Therese Behar Dombeck, PhD, DMin, APRN
   Professor
   University of Rochester, School of Nursing

3. James McMahon, PhD
   Associate Professor
   University of Rochester, School of Nursing

4. Bethel Powers, PhD, RN, FSAA, FGSA
   Professor
   Director of the Evaluation Office
   University of Rochester, School of Nursing
July 6, 2013

Jennifer R Mammen, RN MSN NP-C
Department of Emergency Medicine, Box 655-A
University of Rochester Medical Center
601 Elmwood Avenue
Rochester NY

Dear Jennifer,

I am pleased to be writing this letter in support of your dissertation study entitled “Teen’s Experiences of Asthma Self-Management Across Life-Contexts. Self-management is an important part of asthma care for teen patients....

You are welcome to recruit patients from the Pediatric Pulmonary Practice at Strong Memorial Hospital for this project once it is approved by the RSRB. Our clinic sees many children and adolescents who have been referred from community practices for the evaluation and treatment of asthma. This letter affirms my commitment for the successful completion of your proposed project.

Sincerely yours,

Clement L. Ren, MD
Associate Professor of Pediatrics
Cystic Fibrosis Center Co-Director
Chief, Division of Pediatric Pulmonology
July 9, 2013

To: Jennifer Mammen, RN MS NP-C

Dear Jennifer,

This letter confirms the support of the Emergency Department at Strong Memorial Hospital for your study entitled “Teen’s Experiences of Asthma Self-Management Across Life-Context.” Many teens with asthma are treated in the Pediatric Emergency Department for acute asthma exacerbations. Understanding asthma self-management has the potential to help teens manage their asthma more effectively.

We are happy to support recruiting subjects for this study.

Sincerely,

[Signature]

Manish N. Shah MD MPH
Associate Professor
Department of Emergency Medicine
Department of Public Health Sciences
Department of Medicine, Division of Aging and Geriatrics
### RESEARCH & RELATED Senior/Key Person Profile (Expanded)

#### PROFILE - Project Director/Principal Investigator

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#### Profile Image

*Attach Biographical Sketch |
Attach Current & Pending Support

#### PROFILE - Senior/Key Person 1

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#### Profile Image

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Attach Current & Pending Support
**RESEARCH & RELATED Senior/Key Person Profile (Expanded)**

**PROFILE - Senior/Key Person 2**

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FELLOWSHIP APPLICANT BIOGRAPHICAL SKETCH
USE ONLY FOR INDIVIDUAL PREDOCCTORAL AND POSTDOCTORAL FELLOWSHIPS. DO NOT EXCEED FOUR PAGES.

NAME OF FELLOWSHIP APPLICANT:
Mammen, Jennifer R

POSITION TITLE:
Doctoral Student

EDUCATION/TRAINING (Begin with baccalaureate or other initial professional education, such as nursing, and include postdoctoral training.)

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<tr>
<td>University of Rochester, Rochester, NY</td>
<td>PhD</td>
<td>In progress</td>
<td>Health Practice Research</td>
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A. Personal Statement

I am a second year doctoral student in the University of Rochester School of Nursing Health Practice Research program. I am a Family Nurse Practitioner, and my area of research is asthma self-management in adolescents. I am working with Dr. Hyekyun Rhee, a well-established nurse-researcher in this area who is serving as my mentor. My long-term goal is to develop effective asthma self-management interventions to improve asthma outcomes in high-risk populations, specifically urban adolescents. I chose this area because of the prevalence of the problem, the preventable nature of asthma-related morbidity, and limited research in this population. Asthma is a common problem in teens, and morbidity is highly preventable through effective self-management. Currently, however, little is known about teen asthma self-management from the perspectives of teens and parents—most research in teens has been conducted from the ‘etic’ perspective. I believe that developing effective asthma self-management interventions rests upon: (1) understanding the phenomena from the perspectives of all stakeholders (particularly teens and parents), (2) using these perspectives to inform the development of asthma interventions; and (3) measuring actual self-management behaviors pre and post-intervention to assess intervention effectiveness. I am planning to address these gaps by first conducting a qualitative descriptive study (present proposal) of teen-parent dyads, exploring teen’s experiences of asthma self-management across life-contexts. I then plan to integrate the knowledge gained from the qualitative exploration with my previously published concept analysis of teen asthma self-management (Mammen & Rhee 2012), in which I delineated four specific domains of self-management behaviors. The proposed study, together with my previous concept analysis, will provide the necessary qualitative grounding to design more effective asthma interventions, as well as to develop a psychometrically sound instrument to measure self-management behaviors, combining understanding of the phenomena derived from providers, researchers, teens, and parents.

Recognizing that specific skills are needed to develop a program of research, I have selected academic courses that will assist me to gain necessary expertise to carry out my research goals. Specifically, I have taken three courses in basic and advanced qualitative methods, one in qualitative analysis techniques, two in quantitative methods and measurement, two in survey design, and three in epistemology and theory. Cumulatively, this course work will supply the methodological foundation and skills needed to implement the present study, as well as prepare me for continued work in instrument development and intervention research. The excellent grades that I received in these classes, in addition to publications within my chosen area, demonstrate my ability and commitment to excellent scholarship. In conclusion, the qualitative study proposed as my doctoral dissertation will not only make a significant contribution to the field on its own merit, but will assist in building my program of research. Overall, this fellowship opportunity will provide valuable experience that will help me grow as an independent researcher.
B. Positions

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<td>Kathy Backart</td>
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<td>Staff Nurse</td>
<td>1995</td>
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<td>Nursing/Cardiac, Medical-Surgical</td>
<td>Falmouth Hospital, Falmouth, MA</td>
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<td>1996</td>
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<td>Nurse Practitioner</td>
<td>1999</td>
<td>2006</td>
<td>Advanced Practice Nursing/ Family Practice</td>
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<td>Meghan Collyer, MD</td>
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<td>Nurse Practitioner</td>
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Academic and Professional Honors
- Valedictorian, Sandwich High School, 1992
- White House Advanced Placement Scholarship (Full scholarship) 1992-1994
- Friends of Nursing Scholarship, 1992
- A.D., Honors, Cape Cod Community College, 1994
- BSN, MSN, Honors, University of Massachusetts, Boston, 1999
- Sigma Theta Tau International Nursing Honor Society, 2009
- University of Rochester Doctoral Studies Nursing Tuition Award (Full scholarship) 2011-2015
- Graduate Assistance in Areas of National Need Doctoral Fellowship 2011-2013
- Doctoral Qualifying Exam; pass with commendation, 2012
- President, Doctoral Forum, University of Rochester School of Nursing, 2012-2013
- Sigma Theta Tau Research Award. Study Title: Teens' Experiences of Asthma Self-Management Across Life-Contexts, 2013

Memberships in Professional Societies
- American Academy of Nurse Practitioners
- Sigma Theta Tau, Epsilon XI
- Eastern Nursing Research Society

C. Publications

Peer Reviewed Publications:

Abstracts/Poster Presentation:

Educational Manuals:
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A. Personal Statement

Over the past 10 years, I have established a program of research on asthma in adolescents. Having recognized the seriousness of asthma morbidity in adolescents and their developmental uniqueness, I have focused on designing and evaluating asthma self-management strategies that exclusively target adolescents to ameliorate the burdens of the disease. Currently, I am leading a large NIH-funded study (R01NR011169) to develop and evaluate an innovative asthma symptom monitoring device for adolescents by applying a cutting-edge technology. Prior to the grant, I successfully completed a randomized controlled study (R21NR009837) that evaluated a peer-led asthma self-management program for adolescents (PLASMA). As such, I have demonstrated my sufficient expertise and extensive research experience on asthma self-management in adolescents that Ms. Mammen proposes to study in her fellowship application. I have been mentoring Ms. Mammen since her enrollment in the doctoral program, and the mentoring relationship has been proven effective and productive. I believe that Ms. Mammen's proposed study would no doubt address the critical research gaps in the literature concerning adolescents' asthma self-management. Generated information from her study will expand the current knowledge base and have significant implications for designing and evaluating asthma self-management programs targeting adolescents. As a sponsor, I am committed to facilitate and maximize her learning experience throughout her fellowship period by providing necessary knowledge and skills. I will work closely and systematically with her to ensure the successful implementation of the study protocol while maintaining scientific integrity.

B. Positions and Honor

**Employment**

1991-1992 Staff Nurse GY Oncology & Anesthesiology Unit, Kangnam St. Mary's Hospital, Seoul, Korea.
1993 Staff Nurse, Pediatric Oncology Unit, Seoul National University Hospital, Seoul, Korea.
1998-2001 Teaching Assistant, University of North Carolina at Chapel Hill, NC
1997-2002 Research Assistant, University of North Carolina at Chapel Hill, NC
2002-2006 Assistant Professor, University of Virginia School of Nursing, Charlottesville, VA.
2007-present Associate Professor, University of Rochester School of Nursing, Rochester, NY

**Awards and Honors**

2001-2003 Sigma Theta Tau, Alpha Alpha
2003-2007 Sigma Theta Tau, Beta Kappa
2003 Lanford Memorial Award, University of Virginia School of Nursing
2003-2004 Excellence in Diversity Fellow, Teaching Resource Center, University of Virginia
2004 Nightingale Award, University of Virginia School of Nursing
2005-2006 University Teaching Fellow, University of Virginia
2009 Dean's Award for Excellence in Teaching
2011 Provost's Multidisciplinary Award
C. Selected Peer-review Publications (out of 26 refereed publications since 2000)


D. Research Projects Ongoing or Completed in the Past 3 years

**Ongoing Research Support**

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<td>1 R01 NR011169-01A1 (Rhee)</td>
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NIH/NINR

Developing an Automated Symptom Monitoring Device for Adolescence with Asthma

This study is to develop and evaluate an innovative biomedical device that automatically monitors asthma symptoms using sound detection and analysis technology. Parameters of asthma symptoms including wheezing and coughing will be established using breathing samples provided by adolescents with asthma. Subsequently, these parameters will be programmed in the asthma monitoring system that captures, analyzes, and stores symptom data. Data from the device will be validated using a case-control study design comparing the asthma group and the non-asthma group. Sensitivity, specificity, reliability and validity of the device will be established. 

...
Role: PI

**Completed Research Support**
(Rhee, H.)

Mobile Phone-Based Asthma Self-Management Aid (ASMA) System for Adolescents
The purpose of this study is (1) to develop a mobile phone-based asthma self-management aid (ASMA) system and (2) to evaluate the feasibility and acceptability of the technology based on user (adolescents and parents) feedback.

R21 NR09837 (Rhee H) 9/1/2006-7/31/2009
NIH/NINR
Peer-Assisted Asthma Self-Management Program for Adolescents with Asthma
This study was to evaluate the feasibility and effectiveness of the peer-led asthma self-management program for adolescents.
Role: PI
BIOGRAPHICAL SKETCH

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<td>Norton, Sally A., Ph.D., RN, FNAP, FPCN, FAAN</td>
<td>Associate Professor of Nursing, Medical Humanities (secondary), and Family Medicine (secondary) Co-Director for Research in Palliative Care</td>
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EDUCATION/TRAINING (Begin with baccalaureate or other initial professional education, such as)

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<td>University of Wisconsin, Madison, WI</td>
<td>MS</td>
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<td>Oregon Health &amp; Science University, Portland, OR</td>
<td>Post Doc Fellow</td>
<td>2001</td>
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A. Personal Statement

My program of research focuses on palliative care and end-of-life decision-making with emphases on the communication processes and practice patterns of care delivery across settings especially among adults with advanced life-limiting illness and their family members. The proposed dissertation study builds on my extensive research experience in qualitative and mixed-method study designs and in interviewing and analyzing case-based data. There are some content overlaps (i.e., communication and decision making about treatments) however, my primary contribution to Ms. Mammen’s training award is to provide her with qualitative methods expertise. I worked with Ms. Mammen last semester when she took the Advanced Qualitative Methods course for doctoral students engaged in qualitative or mixed-method research that I teach. In addition to meeting with Ms. Mammen in group settings, Ms. Mammen and I will meet individually at least every two weeks as she works through the phases of her dissertation study.

I have served as a committee member or chair for 4 graduated PhD students. All of my past students have assumed faculty or postdoctoral positions. Among them they have 5 first authored dissertation publications and two additional manuscripts in review. Dr. Rhee and I serve together on 2 dissertation committees.

B. Positions and Honors

Positions

1983-1987 Registered Nurse, The University of Iowa Hospitals and Clinics, Medical Intensive Care Unit, Iowa City, IA
1987-1989 Critical Care Registered/Charge Nurse, The Royal Adelaide Hospital Intensive Care Unit, Adelaide, Australia
1989-1994 Nurse Clinician III, University of Wisconsin Hospitals and Clinics, Trauma Life Support Center
1993-1997 Clinical Instructor/Teaching Assistant, School of Nursing, University of Wisconsin-Madison
1994-1997 Registered Nurse, University of Wisconsin Hospitals and Clinics, Per Diem, Critical Care Division including adult ICU, CCU, Burn Unit and Emergency Room
1999-2001 Clinical ethics consultant and member of the clinical ethics service at Oregon Health Sciences University’s Center for Ethics in Health Care, Portland, OR
2001-2008 Assistant Professor, Center for Clinical Research on Aging, School of Nursing, University of Rochester
2003-2008 Secondary appointment as Assistant Professor of Medical Humanities, School of Medicine and Dentistry, University of Rochester
2003-present Co-Director for Research, Center for Ethics, Humanities, and Palliative Care, University of Rochester Medical Center
2008-present Associate Professor (with tenure) Center for Clinical Research on Aging, School of Nursing, University of Rochester
2008-present Associate Professor of Medical Humanities (secondary appointment), School of Medicine and Dentistry, University of Rochester
2010-present  Associate Professor of Family Medicine (secondary appointment), School of Medicine and Dentistry, University of Rochester.

Selected Honors and Awards (since 1998)
1998  Midwest Nursing Research Society, Qualitative Section Dissertation Proposal Award of Excellence.
1999  Vilas Professional Development Award, University of Wisconsin
2000  The Ada Sue Hinshaw Nurse Scholar Award, Friends of the National Institute of Nursing Research
2002  Hartford Institute Gerontological Research Scholar
2002  Promising New Investigator Award, University of Rochester School of Nursing
2002  Eastern Nursing Research Society John A. Hartford Geriatric Nursing Research Award
2006  Distinguished Practitioner, National Academies of Practice
2009  Fellow, Palliative Care Nursing
2012  Fellow, American Academy of Nursing

C. Selected Peer-Reviewed Publications (underlined —chair/committee member of past PhD students)


**D. Research Support.**

**Ongoing Research Support**

| Private Source | Gammel, R.E. University of Rochester Family Medicine | 07/01/13-06/30/17 |

**Communication and Race in Advanced Cancer Care.**

The overall goal of this mixed method study is to determine how communication about prognosis impact patient decisions about patient care and to determine how this process is influenced by race.

Role: Co-Investigator

1R01CA168387 (MPI, P. Duberstein-URMC Psychiatry and H. Prigerson-Harvard) 03/13-09/17

**NIH/NCI**

**Impact of a Novel Cancer Communication Intervention on Caregiver Bereavement.**

The goal of this mixed method study is to examine whether a novel health communication intervention designed for oncologists, patients, and caregivers can lead to better mental health and physical health outcomes in bereaved caregivers.

Role: Co-Investigator

1R01CA168387 (MPI, P. Duberstein-URMC Psychiatry and H. Prigerson-Harvard) 03/13-09/17

**NIH/NCI**

**Improving Palliative and End-of-Life Care in Nursing Homes.**

The objective of this study is to demonstrate, using a randomized controlled trial design and a difference in difference analytic approach, that nursing home-based palliative care practice guidelines implemented through PCTeams will improve quality of care processes and outcomes for residents at the end of life.

Role: Co-Investigator

1R01 NR010727 (Temkin-Greener, H., University of Rochester Public Health Sciences) 1/1/09-12/31/13

**NIH/NINR**

**End-of-Life Quality of Care in Nursing Homes.**

The objective of the proposed study is to develop and validate individual indicators and a composite measure for assessing EOL quality of care in nursing homes, and to identify characteristics of facilities associated with superior EOL quality of care.

Role: Co-Investigator

1R01 NR010727 (Temkin-Greener, H., University of Rochester Public Health Sciences) 1/1/09-12/31/13

**NIH/NINR**

**RNHELP Registered Nurses Helping Hospitalized Elderly Patients.**

The need for educational programs devoted to caring for older adults has been emphasized by the number of experts, including the Institute of Medicine in its report on geriatrics. It stresses the critical need for health professionals to understand how older adults and their families come into contact with health professionals along a continuum of care and how they make decisions about that care. The report cites the dramatic aging of the population as one factor that will transform practice requirements and create a need for better educated nurses and support personnel. The proposed program is designed to address this need.
**Completed Research Support**

**End-of-Life Decision Making in ICUs: Roles and Relationships of Key Players**

This study is secondary analysis of data collected from an RO1 study of end-of-life decision making (EOLDM) in intensive care units (ICUs). The purpose of this study is to focus in depth on the roles of the key persons in EOLDM in ICUs (patients, family members, physicians, nurses) and the inter-relationships of those persons.

Role: Site Principal Investigator

(Ragmling, R., University of Rochester School of Medicine)  
7/01/10-6/30/11

**Prognostic Communication in Palliative Care**

This research will advance our current understanding of whether clinician strategies for communicating prognoses with severely ill patients affect their end-of-life treatment decisions.

Role: Co-Investigator

R01 NR008790 (Norton, S. Principal Investigator)  
NIH/NINR  
4/01/05-3/31/10
A. Application Type:
From SF424 (R&R) Cover Page. The response provided on that page, regarding the type of application being submitted, is repeated here for your reference as you provide the responses that are appropriate for this Fellowship application.

- New  [□] Resubmission  [□] Renewal  [□] Continuation  [□] Revision

B. Research Training Plan
1. Introduction to Application (for RESUBMISSION applications only)
2. * Specific Aims
   - SpecificAims.pdf
3. * Research Strategy
   - ResearchStrategy.pdf
4. Inclusion Enrollment Report (for RENEWAL applications only)
5. Progress Report Publication List (for RENEWAL applications only)

Human Subjects
Please note. The following item is taken from the Research & Related Other Project Information form. The response provided on that page, regarding the involvement of human subjects, is repeated here for your reference as you provide related responses for this Fellowship application. If you wish to change the answer to the item shown below, please do so on the Research & Related Other Project Information form; you will not be able to edit the responses here.

Are Human Subjects Involved?  [X] Yes  [□] No
6. Human Subjects Involvement Indefinite?  [X] Yes  [□] No
7. Clinical Trial?  [□] Yes  [X] No
8. Agency-Defined Phase III Clinical Trial?  [□] Yes  [□] No
9. Protection of Human Subjects
   - ProtectionofHumanSubjects.pdf
10. Inclusion of Women and Minorities
    - InclusionofWomenandMinorities.pdf
11. Targeted/Planned Enrollment
    - TargetedPlannedEnrollment.pdf
12. Inclusion of Children
    - InclusionofChildren.pdf

Other Research Training Plan Sections
Please note. The following item is taken from the Research & Related Other Project Information form. The response provided on that page, regarding the use of vertebrate animals, is repeated here for your reference as you provide related responses for this Fellowship application. If you wish to change the answer to the item shown below, please do so on the Research & Related Other Project Information form; you will not be able to edit the responses here.

Are Vertebrate Animals Used?  [□] Yes  [X] No
13. Vertebrate Animals Use Indefinite?  [□] Yes  [□] No
14. Vertebrate Animals
   - Add Attachment  Delete Attachment  View Attachment
15. Select Agent Research
   - Add Attachment  Delete Attachment  View Attachment
16. Resource Sharing Plan
   - Add Attachment  Delete Attachment  View Attachment
17. * Respective Contributions
    - RespectiveContributions.pdf
18. * Selection of Sponsor and Institution
    - SelectionofSponsorandInstitution.pdf
19. * Responsible Conduct of Research
    - ResponsibleConductofResearch71813.pdf
C. Additional Information

Human Embryonic Stem Cells

1. * Does the proposed project involve human embryonic stem cells? [ ] Yes [ ] No

   If the proposed project involves human embryonic stem cells, list below the registration number of the specific cell line(s) from the following list: http://stemcells.nih.gov/research/registry/. Or, if a specific stem cell line cannot be referenced at this time, please check the box indicating that one from the registry will be used:

   [ ] Specific stem cell line cannot be referenced at this time. One from the registry will be used.

   Cell Line(s):

Fellowship Applicant

2. Alternate Phone Number:

3. Degree Sought During Proposed Award:
   Degree: [ ] PHD: Doctor of Philosophy
   If "other", please indicate degree type: [ ]
   Expected Completion Date (month/year): [ ]

4. * Field of Training for Current Proposal: [ ] 7500: NURSING

5. * Current or Prior Kirschstein-NRSA Support? [ ] Yes [ ] No

   If yes, please identify current and prior Kirschstein-NRSA support below:

   * Level: [ ]
   * Type: [ ]
   Start Date (if known): [ ]
   End Date (if known): [ ]
   Grant Number (if known): [ ]

6. * Applications for Concurrent Support? [ ] Yes [ ] No

   If yes, please describe in an attached file:

   ApplicationsForConcurrentSupport

7. * Goals for Fellowship Training and Career:

   GoalsForFellowshipAndTraining716

8. * Activities Planned Under This Award:

   ActivitiesPlannedUnderThisAward

9. Doctoral Dissertation and Other Research Experience:

   DoctoralDissertationAndResearch

10. * Citizenship: [ ] U.S. Citizen or noncitizen national [ ] Permanent Resident of U.S. Pending [ ] Non-U.S. Citizen with temporary U.S. visa

   (If permanent resident of the U.S., a notarized statement must be provided by the time of award)
C. Additional Information (continued)

Institution

11. □ Change of Sponsoring Institution

Name of Former Institution:

D. Sponsor(s) and Co-Sponsor(s)

* Sponsor(s) and Co-Sponsor(s) Information

SponsorAndCoSponsor.pdf

[Attach/Unattach/Delete]

E. Budget

All Fellowship Applicants:

1. * Tuition and Fees:

□ None Requested

☒ Funds Requested:

Year 1

Year 2

Year 3

Year 4

Year 5

Year 6 (when applicable)

Total Funds Requested: 25,239.00

Senior Fellowship Applicants Only:

2. Present Institutional Base Salary:

Amount

Academic Period

Number of Months

[Reset Entry]

3. Stipends/Salary During First Year of Proposed Fellowship:

a. Federal Stipend Requested:

Amount

Number of Months

b. Supplementation from other sources:

Amount

Number of Months

Type (sabbatical leave, salary, etc.)

Source

F. Appendix

[Add Attachment/Unattach/Delete View]
Specific Aims

Asthma is the most common chronic disease in adolescence. In the U.S., asthma affects nearly 11% of teenagers. Prevalence is as high as 44% in some geographic areas, with disproportionately high disease burden in urban, poor, and minority groups. Compared to other age groups, teens have poorer disease management and higher risk of asthma-related morbidity and mortality. Minority youth are 4.5 times as likely to be hospitalized, and 5.6 times as likely to die from asthma complications as compared to Caucasians.

In addition, teens with asthma have greater psychosocial difficulties, including social isolation, anxiety, and depression. Compared to peers without asthma, teens with asthma experience significantly poorer quality of life. They are more likely to be absent from school and engage in risk-taking behaviors such as smoking and substance abuse. Teens with asthma are a high-risk population, and there is an urgent need to reduce the burden of disease in these vulnerable youth.

Airway inflammation, obstruction, and bronchial hyper-reactivity occur as a result of poorly controlled asthma. These physiologic changes produce the symptoms of cough, chest tightness, wheezing, and difficulty breathing that is associated with asthma exacerbations. Acute exacerbations not only affect quality of life, but are also linked to increased emergency visits, hospitalization, and death. Preventing asthma-related physiologic changes circumvents the negative sequela associated with uncontrolled asthma, thereby reducing the overall burden of disease.

Asthma self-management (i.e., the behaviors used to prevent and manage asthma symptoms) is central to this process, and is considered to be a key component in achieving optimal asthma control. However, teen asthma self-management is frequently inadequate and is generally worse in high-risk urban and minority groups.

Increased emphasis on self-management research in teen populations has been fueled in part by the disproportionate burden of disease in vulnerable populations and by the highly preventable nature of asthma-related morbidity. The majority of research in this area has been conducted predominantly from a clinician and researcher perspective and does not account for the perspectives of teens. Although terminology may vary (e.g., compliance, adherence, responsibility), the dominant trend in teen asthma research has been to assess whether, and to what extent, teen self-management aligns with clinical recommendations. To date, most researchers have focused on examining behaviors such as adherence and trigger avoidance, or personal and interpersonal factors that affect specific self-management choices. Yet, little is known about processes of self-management from teen perspectives. In order for clinicians and researchers to promote better asthma self-management, it is imperative to understand teens' perspectives of managing their asthma, including what they do to self-manage, the rationales for their choices, and how self-management behaviors may vary in different life-contexts. Better understanding of teens' perspectives will enable clinicians to present health information more effectively, and will promote the development of asthma interventions tailored to the unique needs of teens with asthma. Incorporation of teen perspectives into clinical decision-making will facilitate development of mutual goals, teen-parent-provider partnerships, and ultimately improve health outcomes.

Therefore, the purpose of this study is to explore teens' experiences of asthma self-management across the life-contexts of home, school, community, and healthcare environments. The specific aims of the study are:

Aim 1: To describe how teens manage their asthma and what is important from the perspective of teens and their parents.

- Previously identified domains of self-management (prevention, monitoring, acute symptom management, communication) will serve as a sensitizing framework (i.e., a theoretical orientation based on prior research) from which to explore asthma self-management across the contexts of home, school, community, and healthcare settings using a qualitative descriptive approach.
- Data will be collected from teen-parent dyads through a series of semi-structured in-depth interviews and a two-week self-management diary.

Aim 2: To compare asthma self-management between teens with well-controlled and not-well-controlled asthma, and between minority and non-minority teens.

- Criterion-based sampling will be used to select teens who manage well, and teens who do not manage well, in order to explore similarities and differences in self-management between these groups.
- Within criterion sampling will be used to select for minority and non-minority teens in order to facilitate comparison of self-management processes between the two groups.
Significance

Asthma related morbidity is preventable through effective self-management. Asthma is characterized by airway inflammation, bronchial hyper-responsiveness, and airflow obstruction. Uncontrolled and chronic inflammation leads to progressively worsening disease and poor health outcomes through pulmonary scar tissue accumulation and structural changes associated with airway remodeling. However, these processes can typically be prevented through consistent use of control medications, avoidance of specific triggers, careful monitoring, and timely response to symptoms. Avoiding irritants and inflammatory triggers, in addition to consistent adherence to prescribed medication, is effective in preventing inflammation, bronchospasm, airway obstruction, and permanent damage to the lungs.

It is widely recognized that self-management is a major determinant of asthma outcomes. When performed effectively, self-management improves asthma control, prevents exacerbations, reduces healthcare utilization, and minimizes the personal and economic burden of disease. For these reasons, the 2007 Asthma National Guidelines suggest that self-management training be included in all asthma interventions.

There are four common domains of asthma self-management behaviors: (1) symptom prevention; (2) symptom monitoring; (3) acute-symptom management; and (4) communication. While healthcare providers play an important role in helping patients manage their asthma, the burden is mostly on the individual to engage in the daily activities of self-care including being able to identify and respond to asthma triggers, remembering to take medications in the manner prescribed, recognizing early signs of worsening asthma, and seeking appropriate medical care before symptoms become acute or life-threatening.

Teen asthma self-management is frequently considered inadequate. Adolescence is a unique developmental period, during which the responsibility for asthma self-management is transferred from parent to child. However, many teens are unable to effectively handle the complexities of daily asthma care. Most teens do not manage in a way that is considered to be medically effective. They often do not take medication as prescribed, ignore or fail to recognize symptoms of asthma, and delay treating until symptoms become acute or life-threatening. Desire for normalcy can make teens less willing to recognize, report, and treat symptoms while peer influences may encourage risky behaviors that place teens at high risk for acute exacerbation. Cumulatively, these factors translate into diminished asthma control, increased risk, and increased asthma related morbidity and mortality. Minority teens, who have a much higher incidence of asthma than non-minority peers, often have poorer self-management, and significantly worse asthma outcomes, including increase in symptoms and asthma morbidity, more frequent use of emergency care, and decreased quality of life. Worse asthma outcomes in these groups have been attributed to disparity in environmental exposure, sub-standard housing, frequency and quality of health care, health literacy, parental involvement, and cultural differences in asthma management.

Asthma interventions in teens have produced minimal improvement in asthma outcomes. Interventions targeting self-management skills, personal factors (e.g. self-efficacy, motivation, attitude, acceptance of asthma) and interpersonal mediators (e.g. cultural norms, social support), have had only modest or short-lived effects on asthma outcomes. It may be that limited intervention efficacy is due in part to limited understanding of teen self-management. Lack of knowledge about what teens consider important in self-management reduces researchers' ability to tailor programs to the unique needs of young people. In order to promote the development of effective self-management interventions, it is of paramount importance to understand the process of asthma self-management from teen and parent perspective, as well as the underlying forces that shape teen self-management behaviors in various contexts.

Little is known about the process of asthma self-management from the perspective of teens. Most of what is known about teen asthma self-management is what teens are not doing. Quantifying behavioral, intrapersonal, and interpersonal factors can help to define the scope of the problem, but does not address the issue of why teens manage in a given manner. Furthermore, it does not explain how teens understand their own self-management, or how this understanding compares to that of clinicians or parents. While it is recognized that effective self-management correlates with better asthma outcomes, little is known about the processes of self-management from teen or parent perspectives. It is well known that intrapersonal and interpersonal factors impact the quality and frequency of asthma self-management, yet how teens process these influences and make self-management decisions remains unknown. Similarly, it is
generally accepted that the goals of self-management are to improve asthma control and health outcomes, but little is known about teens' goals and priorities for self-management choices, or how these priorities relate to asthma outcomes. In order to promote better asthma self-management, it is necessary to understand what teens do to self-manage, what motivates their choices, and how self-management varies across different life-contexts. (Example: self-management of asthma symptoms at home may be different than at school).

Self-management varies according to the context in which it occurs

Chronic disease self-management research provides support that self-management behaviors, motivations, quality, and frequency vary according to the context in which they occur. While variation across context has not been specifically studied in teens with asthma, it is likely that contextual variation occurs in this population as well. (Example: a teen may modify her responses to an acute asthma exacerbation based upon whether she is at a home, school, or party.)

Qualitative description can help increase understanding of teen self-management behaviors and goals

Qualitative description is useful for exploring areas in which relatively little is known; it is inherently flexible in design and permits adaptation to developments that arise during the course of a study. It is particularly well suited to exploring variations in responses across individuals and diverse life-contexts. Self-management is a contextually dependent phenomena—it is the response of a specific individual to a specific situation at a specific moment in time. Since asthma self-management behaviors may vary both from individual to individual and from context to context (e.g. setting and time), developing an in-depth understanding of the phenomena of self-management requires considering both individual and contextual variations. Therefore, the purpose of this study is to explore teens' experiences of asthma self-management across different life-contexts. The knowledge gained through this study will increase understanding, facilitate the design of effective interventions, and ultimately promote better health outcomes.

Approach

Study Design

This study will use a case-based qualitative descriptive approach, focusing on the teen-parent dyad. For the purposes of this proposal, the parent is a teen-identified caregiver who lives with the teen and is most involved in the teen's asthma care. A case will consist of an initial interview with the teen, an interview with the parent, a two-week self-management diary, and a follow up interview with the teen. This approach will allow for a more holistic and multifaceted approach to understanding teen asthma self-management by incorporating contemporaneous and retrospective data gathered from multiple sources.

Setting

Teen-parent dyads will be recruited through the Pediatric Emergency Department and Pediatric Pulmonary Department at the University of Rochester Medical Center (URMC), a 750-bed tertiary academic health-center in the Northeast. Last year these two departments treated approximately 20 individual teens with asthma per month. Teen subjects from the sponsor's (Dr. Rhee) previous studies who have given permission to contact for future study will also be eligible. Additional recruiting as needed to increase between-subject variation in self-management experiences will be done via word-of-mouth and snowball sampling.

Sampling Strategy

A case-based purposeful sampling strategy will be used. I will purposefully sample adolescents with mild to severe persistent asthma, as self-management is expected to occur more frequently in these groups. This study will focus on high-school aged teens (ages 13 to 17), as this group is given greater responsibility for self-management than younger adolescents. The sampling strategy is displayed in Figure 1...

Inclusion/Exclusion Criteria. Inclusion criteria for teens are (a) source teen age 13 to 17; (b) with diagnosis of asthma (c) classified as persistent (mild, moderate or severe) according to the National Guidelines (Fig. 1, Box 2); (d) able to communicate in English; and (e) no other major medical or psychiatric conditions by self-report. The inclusion criteria for the parent include: a) ability to communicate in English and b) lives with the source teen. Eligibility screening and the sampling plan are presented in Figure 1. Teens who are unable to communicate in English or who have other major medical and psychiatric diagnoses (e.g. cystic fibrosis, cardiac conditions, bipolar disorder) are excluded from the present study. The added complexity of assessing language and cultural issues, or additional health related challenges are beyond the scope of this study.

Sample Size. The estimated sample size for the proposed study is between 14 to 18 teen-parent dyads, with each case including 3 interviews plus one diary. The minimum sample size would yield 56 sources of data (42 interviews and 14 diaries). This number is consistent with previous research and
recommendations from qualitative experts, and may be adjusted in order to achieve data saturation (i.e. the point beyond which no substantive changes to coding occur with the addition of new cases).52, 53, 55, 60

**Purposeful Sampling.** This study will use purposeful sampling to select for cases that can best contribute to a broader understanding of the process of asthma self-management.61 Teens will be selected for the diverse perspectives that they can bring to understanding the process of teen asthma self-management.

This study will also use **criterion-based sampling.** Criterion-based sampling is a specific sub-type of purposeful sampling that is used to select for participants who vary on certain aspects of a phenomenon.37 This type of between-group comparison will help to identify processes and individual attributes that may contribute to effective asthma management. For this study, two purposeful comparisons are sought to explore similarities and differences in asthma self-management: (1) between teens with well-controlled versus not-well-controlled asthma; and (2) between minority and non-minority teens.

**Figure 1. Eligibility Screening and Criterion Sampling**

**Box 1: ELIGIBILITY CRITERIA**
1. Are both teen and parent English speaking?
2. Is teen high-school aged (13 to 17 years)?
3. Does teen have asthma with no other major medical/psychiatric diagnosis?
4. Do teen and parent live together?

**Box 2: Does teen have persistent asthma?**
- Daily use of control medication, OR
- Symptoms AT LEAST 2 x week, OR
- Night Awakening AT LEAST 2 x month, OR
- Rescue inhaler use AT LEAST 2 x week, OR
- ANY Activity limitations due to asthma

**Box 3: Is asthma well-controlled?**
- Symptoms LESS THAN 2 x week, AND
- Night awakening LESS THAN 2 x month, AND
- Rescue inhaler use LESS THAN 2 x week, AND
- NO Activity limitations due to asthma

Cases will be sampled using **asthma control** as the primary criterion. In asthma management, asthma control is considered to range from well-controlled asthma to not-well and very-poorely-controlled asthma, as defined by the National Guidelines.14 Well-controlled asthma is defined as having symptoms less than two times per week, rescue inhaler use less than 2 times per week, nighttime wakening less than two times per month, and no activity limitations due to asthma in the past 4 weeks.62 Not-well-controlled and very-poorly-controlled asthma comprise symptoms that exceed the criteria for well-controlled asthma, and which fall along a continuum of progressively increasing symptoms, impairment, and asthma morbidity. This study will dichotomize between the concept of well-controlled and not-well-controlled asthma, and will sample participants to represent these categories. The sampling strategy is displayed in Figure 1. Sampling along the axis of control will facilitate exploration of differences between teens who manage their asthma well and those who do not manage well. Sub-cases will be sampled by the secondary criterion of minority and non-minority status. Minority teens have a significantly greater risk of asthma morbidity and mortality than non-minority teens, which has been at least partially attributed to poor asthma management.17 Exploring differences between the asthma management styles of minority and non-minority teens may help increase understanding of this disparity. This sampling approach will facilitate identification of common themes in asthma self-management that occur across cases, as well as highlighting differences in self-management behaviors that occur between cases.

**Data Collection Plan**

Data collection will be accomplished through semi-structured in-depth interviews and symptom diaries. Interviews conducted with the teen and a parent will be used to explore how teens manage their asthma across different life-contexts (see Appendix for interview guidelines). Interviews will be conducted at a time and place preferred by the participants.59 For a teen, the majority of self-management occurs within four primary contexts: (a) home; (b) school; (c) community; and (d) healthcare settings (e.g. routine check-ups and interpersonal negotiations with healthcare providers). In these settings, a teen may interact with family, peers, community members, teachers, coaches, a school nurse, or other healthcare providers. This study will explore
self-management across these four contexts using the four
domains of asthma self-management\textsuperscript{29} derived in my prior work
as a sensitizing theoretical framework from which to explore teens' experiences of self-management.\textsuperscript{29} The data collection plan and
recruitment timeline are presented in Table 1.

The data collection timeline is based on the estimated
sample size of 14 to 18 teen-parent dyads. Anticipated data
collection time for the maximum estimated number of cases
(N=18), is 20 weeks at a recruitment rate of 1 case per week.

**Interview with Teen.** Teens and parents will be interviewed separately, as teens may not feel
comfortable discussing medically undesirable management choices with the parent present. The first
interview will be used to gather data on the teen's perceptions of asthma symptoms, severity,
self-management behaviors, daily routines, motivating factors, and personal goals for self-management. These
perceptions and behaviors will be explored across the contexts of home, school, community and healthcare
setting. Care will be taken to help teens recall both positive and negative self-management experiences.
Verbal probing techniques will be used to assist teens to recall specific situations in which they had asthma
symptoms, and to delineate the process by which they made specific behavioral choices.\textsuperscript{31, 63, 64} Teens will be
couraged to describe their processes of self-management in various settings, and to consider how their
responses might be the same or differ across these contexts. The interview protocol will be flexible, allowing
for modification of questions based on analysis of prior interviews and genesis of new data.

**Interview with Parent.** Parents play an important role in teen asthma self-management. How a teen
manages is often directly related to parental beliefs about asthma and support, such as reminders to take daily
medications and assistance with acute symptom management.\textsuperscript{67} Furthermore, because parents live in close
proximity to the teen, they are ideally situated to observe how the teen manages asthma symptoms on a day-
to-day basis. Interviews with parents will be used to explore parents' perceptions of how the teen prevents,
monitors, manages, and communicates about their asthma needs. The interview will also be used to explore
areas of perceived strengths and weaknesses in asthma self-management, as well as the parent's perception
of the underlying motivations and goals for the teen's self-management choices. Information gathered from the
caregiver interview will also be used to inform the follow-up interview with the teen.

**Self-management Diary.** In addition to the interview, teens will be asked to maintain a voice diary
(Figure 2) for two weeks, to report on symptom management as well as episodic and routine medication use.
This will entail a brief verbal entry into a voice recorder whenever the teen experiences asthma symptoms,
uses asthma medications, or is aware of making asthma related decisions. Verbal diary methods are an
established alternative to written forms, and may be more acceptable to teens, who are increasingly
technologically oriented.\textsuperscript{65, 66} For teens with any degree of persistent asthma, a two-week period will provide
sufficient opportunity to capture either a minimum of four symptom episodes (not well-controlled teens), or
routine use of daily control medication (well controlled teens).\textsuperscript{14} Participants will be asked to use the "think-
 aloud" method to capture the reasoning and thought-process behind management choices, as well as specific
actions. These data will provide contemporaneous examples of self-management that can be further explored
in the follow up interview. Inducing heightened awareness of self-management may facilitate in-depth
exploration of self-management processes.

**Figure 2: Asthma Self-Management Diary Guide**
This guide is to help you use the daily voice recorder to tell me about your asthma. Please feel free to tell me about anything that you
think is important or that you think I should know. Below are some specific things that I would like to know about. You only need to
choose ONE box to talk about each day, but you can always say more if you would like to.

<table>
<thead>
<tr>
<th>ANY asthma symptoms:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Tell me about your asthma symptoms. Describe as much as you can.</td>
</tr>
<tr>
<td>2. What do you think is causing what you are experiencing?</td>
</tr>
<tr>
<td>3. What do you feel or think about it?</td>
</tr>
<tr>
<td>4. How are you handling it?</td>
</tr>
<tr>
<td>5. How did you decide what to do or not do?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ANY asthma medication use (with or without symptoms)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Tell me about the medication you are taking: Medication name, what it does, what you are taking it for today. Be as specific as possible.</td>
</tr>
<tr>
<td>2. How do you think this medication is going to help you?</td>
</tr>
<tr>
<td>3. What are the things that made you decide to take medication today (now)? Describe your thinking as much as possible.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ANY asthma related actions, choices, or decisions:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What did you do or not do to handle your asthma?</td>
</tr>
<tr>
<td>2. How did you decide what to do? Describe as much as you can.</td>
</tr>
</tbody>
</table>
A second interview with the teen will be conducted after completion of the voice diary and parent interview. Recent examples of self-management identified through review of the voice diary will be explored. Additionally, the follow-up interview may be used to explore ideas arising from the interview with the parent, or from the first teen interview that were overlooked or not investigated thoroughly.

**Subject Payment.** Participants will be paid $15 per interview and $30 for a completed voice diary.

**Data Analysis and Management Procedures**

**Data Transcription.** Audio-recorded interviews and diaries will be transcribed verbatim using a modified Jefferson Transcription method. Specifically, this will include notations for emphasized speech, pauses greater than 2 seconds, increased or decreased speech volume, prolongation of sound, audible exhalation, and use of parenthesis for text that is unclear. I will transcribe the majority of interviews myself. Where transcriptionist services are used, I will compare transcripts to the original audio file.

**Qualitative Data-Analysis Software.** Verified data will be entered into ATLAS.ti, a computer assisted data management software used for data management and to facilitate analysis. ATLAS.ti allows for storage, coding, retrieval, and analytical comparison of audio and transcribed data, and increases the overall manageability of qualitative analysis.

**Analytic Overview.** Data from teen interviews, parent interviews, and voice diaries will be incorporated in the analysis for both Aims. The unit of analysis will be sentences. Analysis of data will be contiguous with data collection. Aim 1. Analysis for Aim 1 will include looking at patterns of self-management within specified contexts, rationales, perceptions, and goals across combined data sources. Aim 2. Analysis for Aim 2 will focus on comparison of coding patterns within specified groups/subgroups (i.e. well-controlled/not-well-controlled; minority/non-minority). Specifics of analysis are detailed subsequently.

**First-cycle Coding.** For this study, I will use directed content analysis techniques with a preliminary a priori coding schema using the operational definition and conceptual domains of asthma self-management identified in my previous work (see Appendices). These domains include symptom prevention, symptom management, acute symptom monitoring, and communication behaviors. Initial coding steps will include highlighting all text that pertains to self-management processes. Highlighted text will then be coded using the a priori schema. Residual text (highlighted but not fitting with preexisting schema) will be carefully analyzed to determine how this data can serve to revise or extend our present understanding of asthma self-management. Highlighting all text in advance will help to minimize oversight of data that do not fit with the preexisting framework.

**Second-cycle Coding.** In addition to directed content analysis, first cycle coding will also include process coding techniques as described by Saldana. Process coding uses gerunds (words ending in “ing”) to identify actions and sequences within the data that are indicative of response pathways. While process coding is often used with grounded theory, it is not exclusive to this methodology. It is considered appropriate for any qualitative analysis that seeks to identify processes of human response to situations, and which typically occur for the purpose of reaching a goal or resolving a problem. Process coding will be used to reveal contextually embedded sequences of perceived stimuli, reasoning, and self-management responses. For example, a sequence such as entering a friend’s house, perceiving a known asthma trigger, reasoning that the trigger will induce asthma symptoms, and deciding to remain in the house, could be coded as “ignoring triggers.” Similarly, recognizing signs of uncontrolled asthma, reasoning that taking an inhaler might increase the risk of future osteoporosis, and choosing not to take daily control medications might be coded as “managing future health.”

**Third-cycle Coding.** The goal of second-cycle coding will be data reduction and reorganization into a more intuitive and parsimonious logical structure. In particular, pattern coding will be used to develop a metacoding schema that synthesizes coding categories representing similar concepts. For example, codes such as “adhering to control medication” and “avoiding triggers” could be recoded into super code “preventing symptoms.” Pattern coding is useful for organizational, explanatory, and inferential analysis, and will help to develop themes within the data.

**Other Considerations.** Although less developmentally broad than the entire adolescent spectrum, teens aged 13 to 17 still comprise a developmentally broad age group. Analysis will remain open to age differences in self-management, but will not impose a priori groupings.
Maintaining Rigor

**Validity.** The following steps will be taken to assure the quality and validity of the study: (1) member checking will be incorporated into the interview process to refine and extend the analysis by asking participants in later interviews to reflect on findings and interpretations derived from earlier interviews; (2) field notes will be written after each interview that includes observations, personal thoughts, and possibilities for follow-up; (3) coding decisions and results of analyses will be discussed with other experienced qualitative and teen asthma researchers; and (4) analytic memos will be used to keep track of my own perspectives and thoughts as they evolve during the data analysis process; and (5) careful search for and analysis of discrepant evidence will help to increase the validity of conclusions. The systematic recording of these processes will serve as an audit trail to demonstrate transparency and rigorosity.

**Generalizability/Transferability.** Findings are not expected to be generalizable to all teens, but will serve to broaden understanding of the similarities and differences between teen and healthcare providers understanding of the processes of asthma self-management, as well as similarities and differences between teens who manage their asthma well, and those who do not.

**Impact.** Knowledge gained from this study can be useful in several ways. First, it can be instrumentally useful to clinicians wishing to discuss self-management goals with teens in clinic situations, and may serve as a basis for anticipatory guidance. Identifying goals that are important to teens may help healthcare providers to present health information in a developmentally appropriate and meaningful manner, thereby helping to promote adherence and improve clinical outcomes. Second, knowledge of asthma self-management from the teen and parent perspective can contribute to the development and appraisal of existing and future asthma self-management instruments, and can serve as a referent to establish the psychometric validity of these tools. Lastly, findings may have implications for the design and evaluation of future self-management interventions, and may facilitate tailoring interventions to the unique needs of teens with asthma.

Feasibility

**Methods.** My sponsors, Drs. Rhee and Norton, are experienced faculty-researchers with expertise in content area and qualitative methodology respectively, and can facilitate the successful implementation of this study. Dr. Norton will be working closely with me on integrating analysis of diary and interview data; support for qualitative analysis is also available through the weekly qualitative group led by Dr. Margaret Kearney at the School of Nursing. This group provides access to experienced qualitative researchers, and allows students the opportunity to discussed methods and analytical techniques. **Recruitment.** Estimated time for recruitment and data collection is between 14 and 20 weeks at a recruitment rate of one case per week. Allowing for a 50% margin of error, the maximum estimated data collection time is 30 weeks. I am using several avenues of recruitment, and will therefore have adequate access to the target population. Letters of support from the recruitment settings are included in the Other Attachments. Teens from the sponsor's (Dr. Rhee) contact database will also be approached for recruitment. **Time.** Total time commitment for this study is projected at less than 5 hours for teens, and less than 1 ½ hours for parents. **Attrition.** Although the interval between data collection points is brief (3 weeks), it is possible that some subjects may drop out or become unreachable during the course of the study. Text and email reminders will be provided to remind teens to complete the diary and facilitate follow-up interviews. **Financial Feasibility.** I have been awarded a local Sigma Theta Tau research grant for this project ($2,500), which will cover subject payment ($15 per interview; $30 for 2 week diary), travel expenses, and cost of recording equipment. **Timeframe:** As shown in Table 2 below, the estimated date of completion for this project is 2 years from the start of the training grant (Spring 2014 - 2016).

| Table 2. Timeframe for study "Teen's Experiences of Asthma Self-Management Across Life-Contexts" |
|-----------------------------------------------|---------------|---------------|---------------|---------------|---------------|---------------|
| Consultation with Sponsors/Committee          | X             | X             | X             | X             | X             | X             |
| Proposal Defense                             | X             |               |               |               |               |               |
| IRB Approval                                  |               |               |               |               |               |               |
| Recruitment                                   | X             | X             | X             | X             |               |               |
| Data Collection and Analysis                  |               | X             | X             | X             |               |               |
| Writing                                       |               | Pre-          | X             | X             | X             |               |
| Dissertation Defense                         |               |               |               |               |               | Award         |
| Dissemination of Study Results                |               |               |               |               |               | X             | X             | X             |
4.1.1 Risks to Human Subjects

This study will be reviewed by the University of Rochester Research Subjects Review Board (RSRB). The voluntary nature of participation will be carefully relayed to potential subjects. Subjects may decline, or withdraw from participating at any point during the study. Measures to ensure the safety and confidentiality of subjects are detailed below under section 4.1.2.

a. Human Subjects Involvement and Characteristics, and Design

The study design incorporates collection of data over a period of 3 weeks. Each teen will participate in a maximum of 2 interviews, and one diary collection period. Each parent will participate in 1 interview. The anticipated interview length is 1 to 1 ½ hours. Maximum time required for participation in two interviews by a teen is 3 hours. It is anticipated that diaries will entail no more than 10 minutes per day over a two-week period. Therefore, maximum anticipated time for collection of diary data is approximately 2 hours. Total time commitment for each teen is projected at less than 5 hours for this study. Total estimated time for each parent is projected to be less than 1 ½ hours. The interview process and voice diary are unlikely to cause emotional distress or place subjects at risk in any way.

Approximately 50% of the subjects in this study will be minority group members, as purposeful comparison of differences in asthma self-management between minority and non-minority teens is one of the aims of this study. Additionally, 50% of subjects will be selected for not-well-controlled asthma to facilitate comparison between the self-management practices of teens who manage well, and teens who do not manage well. Rationale for selecting these two comparisons is to maximize understanding of the self-management practices of at-risk teens while simultaneously identifying between-group differences that could be targeted for intervention. Deliberate comparison between these groups can help to identify factors that contribute to racial and ethnic disparities in asthma outcomes.

b. Sources of Materials

The sources of data are individual interviews and voice diaries. All data will be by self-report.

c. Potential Risks

This is a minimal risk study as defined in the Code of Federal Regulations 46.303. Possible risks to participants include breach of confidentiality, interview fatigue, fatigue from maintaining daily diary for two weeks, and embarrassment. It is also likely that many teens will reveal non-compliance with medical recommendation, or even deception of their parents in regards to self-management practices. Methods for addressing these risks are addressed in section 4.1.2.b. While interviews are not expected to be emotionally disturbing, or contain content that would pose physical or psychological risk to subjects if inadvertently disclosed, it is possible that some adolescents would reveal self-damaging behaviors (e.g. illicit substance use, cigarette smoking).

Risks to Researcher. Interviews will likely be conducted in participants' homes. Survey of interview surroundings will be conducted prior to interview to assess the safety of the environment. Subjects living in an environment deemed unsafe for in-home interview will be rescheduled for an alternative safe location.

4.1.2 Adequacy of Protection Against Risks

a. Recruitment and Informed Consents

Approval for recruitment, screening, data collection and handling will be obtained from the University of Rochester Research Subject Review board prior to screening and data collection. I will obtain teen assent along with parental permission for collection of data through the teen interview and self-management diary. Additionally, I will obtain parent consent for participation in the parent interview.

Pediatric Emergency Department. I am employed as a nurse practitioner in the adult side of the emergency department, and have routine access to the electronic medical record for all areas within the ED. I plan to screen potential subjects during my off shift hours. As I do not provide care to adolescent patients who are on the pediatric side, there will be no risk of coercive recruitment of my own patients. Only a small number of subjects (less than 10) will need to be recruited from the ED, therefore identification of potential subjects in the Pediatric ED will be through ED providers' referrals, as discussed with ED administration. Permission to approach the patient will be obtained from the provider prior to patient contact in order to assure that recruitment does not interrupt the regular ED flow. Potential subjects will be approached during periods in which they are waiting for procedures, diagnostic results, or disposition. The study purpose, methods, and
subject payment will be briefly reviewed with potential subjects, and a one-page explanation of the study provided along with study contact information. Eligibility of interested teen/parent dyads will be determined using the screening criteria displayed in Figure 1. Contact information for interested subjects will be obtained. After discharge, a follow-up phone-call will be made to confirm subject interest and schedule the first appointment. This plan has been discussed with the Associate Director of Research for the ED, the Director of the Pediatric ED, and the RSRB pediatric representative, and was deemed acceptable, subject to final approval by the RSRB. A letter of support for recruitment is included in the Appendix.

If my involvement in the recruitment process is not allowed by the IRB, I would plan to employ ED research associates using similar procedures as described above.

Pediatric Pulmonary Department. Subject recruitment departments would be the same as for the ED, and has been discussed with the Director of the Department. A letter of support for recruitment is included in the Appendix.

Prior study subjects. Teen and Parent subjects from previous asthma research on which I served as a research assistant have consented to future contact for study participation.

Study Flyers. Additional subjects, as needed, will be recruited using an approved study flyer containing a lay description of the study purpose, methods, subject payment, and contact information. This has been reviewed with the pediatric RSRB representative and verbally approved, subject to final RSRB approval.

Snowball sampling. Word-of-mouth referrals through current study subjects, clinicians, or community members may also be used to locate additional subjects as needed to increase between subject variability. Referees will be provided with study flyers to give to interested acquaintances. The referent may then contact me via phone, text, or email at the study number/email provided for this purpose.

Process of Consent. I will obtain assent from teens and permission/consent from parents for study participation. A printed form clearly explaining the nature of the project, purpose, methods of data collection, and subject reimbursement in layman’s term will be used to obtain assent/consent permission. All forms will be written at or below a sixth grade reading level to facilitate comprehension, and will be approved by RSRB. As both teens and parents are subjects in the study and will participate in data collection, forms will include: (a) Information Sheet; (b) Assent form for 13-17 year olds (teen); (c) Permission/Consent Form (parent). Forms are based on the standardized URMCC RSRB templates, and will be reviewed with subjects in the order listed. The consent process will help to ensure that individual participation is informed, understood, and voluntary. In accordance with Federal and University requirements, consent will include: (a) that the project is research; (b) the purpose of the research; (c) description of study procedures; (d) expected duration of the study; (e) foreseeable risks as reviewed above; (f) benefits of participation; (g) alternatives to participation; (h) confidentiality; (i) contact information for the PI and RSRB; (j) statement that participation is voluntary; (k) right to withdraw at any time without consequence; and (l) a statement that subjects will receive a copy of the signed consent.

b. Protections Against Risk

Confidentiality. Confidentiality will be assured by de-identification of transcripts. Each transcript will be given an ID number. All identifying information will be removed and stored in a separate computer file, which will be kept in a double-password locked personal desktop computer. Sensitive files will be protected with FileVault encryption, a government-approved encryption standard using the Advanced Encryption Standard with 128-bit keys (AES-128). Use of demographic descriptions of the sample population, and quotations included in the final report, will be done in a manner that does not place subjects at risk for identification. After transcription and data analysis procedures are completed, audio-recorded interviews will be destroyed to prevent possibility of future voice identification. These confidentiality measures will be relayed to participants during the consent process.

Interview Fatigue. Potential fatigue during interviews will be addressed by making subjects aware at the start of the interview that fatigue may occur, and that it is common to take breaks during the interview process. Additionally, halfway through the interview, I plan to ask subjects if they would like to stop and take a break.

Self-Damaging or Deceptive Teen Behaviors. Information revealed by teens in private interviews, including non-compliance with asthma medications, parental deception, and substance abuse, will be treated as privileged information, and not subject to disclosure, with the exception of suicidal ideation or behaviors with immediate potential for harm to self or others. Information that would be subject to parental disclosure without consent of the teen subject include present or intended: thoughts of suicide; self-mutilation; risk-taking
behaviors associated with high risk of sudden death, injection, ingestion, or inhalation of harmful substances associated with risk of sudden death; and bodily harm to self or others. In particular, because of the risk of death associated with severely undertreated asthma, parents will be notified if their teen has asthma qualifying as "very-poorly controlled" according to the National Guidelines. Behaviors that would not be subject to disclosure without teen permission would include cigarette smoking, alcohol use, marijuana use, past (not current) self-harming behaviors, not-well controlled asthma, medication non-compliance, risk-taking behaviors not associated with risk of sudden death. During the consent process, and also prior to interviews, both parent and teen will be made aware that information obtained during the interview process will not be shared with other parties without explicit permission of the subject from whom the information derived. At the end of the interview, teens and parents will be asked if it is acceptable to discuss what was learned in the interview with their teen or parent. Furthermore, teens and parents will be encouraged to discuss relevant details of asthma self-management with the primary care doctor or asthma specialist. Any potentially sensitive information revealed by teens that I feel the parent should know will be carefully reviewed with the teen at the end of the interview. I will not disclose confidential information unless the teen agrees that the parent can be notified, with the exceptions noted above. Care will be taken during subsequent interviews to avoid disclosing confidential information and to respect subjects' right to privacy. These precautions are necessary not only to respect the rights of individuals, but also to ensure that teens will have maximum confidence discussing socially unacceptable self-management behaviors with the interviewer, and to minimize social desirability biases. These procedures will be conveyed to all subjects during the initial consent process.

4.1.3 Potential Benefits of the Proposed Research to the Subjects and Others

Benefits of this research will not accrue directly to participants, with the possible exception that increased self-awareness caused by the interview and diary process may encourage better self-management. Potential future benefit may result from increased provider understanding of the teen perspective, and may therefore lead to more effective asthma care.

Reciprocity. At the end of the study period, subjects will be given the opportunity to ask questions and receive information about asthma self-management. If asked, discrepancies between medically recommended and actual self-management behaviors and perceptions will be discussed, and teens will be encouraged to talk about these differences with their medical provider. This will be conveyed to subjects during the consent process and again after the completion of interviews.

4.1.4 Importance of the Knowledge to be Gained

Understanding generated through this study will help to increase healthcare providers' understanding of how teens manage their asthma, as well as the goals and rationale for their self-management choices. Such knowledge can assist clinicians wishing to discuss self-management goals with teens, and may serve as a basis for anticipatory guidance. Furthermore, defining common, mutually acceptable goals may help to promote adherence and improve clinical outcomes. Understanding goals that are important to teens may assist healthcare providers to present health information in a developmentally appropriate and meaningful manner.

In addition to anticipatory guidance, findings may have implications for future research, and may facilitate the development of interventions tailored to the unique psychosocial needs of teens with asthma. Rigorous qualitative research has been shown to improve intervention design and effectiveness, and enhance meta-synthesis of findings. Additionally, it is useful for evaluating the applicability, appropriateness, and effectiveness of interventions.

Finally, I am planning to use the knowledge gained in this study in conjunction with my previous research to develop a theoretically grounded, valid, and reliable instrument with which to measure teen asthma self-management behaviors; this is contingent upon solid qualitative understanding of the phenomena.

4.1.5 Data and Safety Monitoring Plan

Not applicable.

4.1.6 ClinicalTrials.gov Requirements

Not applicable.
4.2 Inclusion of Women and Minorities

I am planning to recruit 50% minority teens, and 50% non-minority teens as one of my goals is to examine differences in self-management behaviors between these groups, based on strong evidence of racial disparities in asthma health outcomes. While gender is not a purposeful comparison in the present analysis, it is anticipated that equal numbers of male and female teens will be recruited, as this will increase the usefulness of subsequent findings for other research and clinical situations. These goals are readily obtainable through purposeful and criterion-based sampling, which are the primary methods of subject selection in this qualitative descriptive study.
Targeted/Planned Enrollment Table

This report format should NOT be used for data collection from study participants.

**Study Title:**  Teens' Experiences of Asthma Self-management across Life-Contexts

**Total Planned Enrollment:**  Based on median estimated sample size of 16 teen-parent dyads (32 Subjects)

<table>
<thead>
<tr>
<th>TARGETED/PLANNED ENROLLMENT: Number of Subjects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnic Category</td>
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<tr>
<td></td>
</tr>
<tr>
<td>Hispanic or Latino</td>
</tr>
<tr>
<td>Not Hispanic or Latino</td>
</tr>
<tr>
<td><strong>Ethnic Category: Total of All Subjects</strong></td>
</tr>
<tr>
<td><strong>Racial Categories</strong></td>
</tr>
<tr>
<td>American Indian/Alaska Native</td>
</tr>
<tr>
<td>Asian</td>
</tr>
<tr>
<td>Native Hawaiian or Other Pacific Islander</td>
</tr>
<tr>
<td>Black or African American</td>
</tr>
<tr>
<td>White</td>
</tr>
<tr>
<td><strong>Racial Categories: Total of All Subjects</strong></td>
</tr>
</tbody>
</table>

* The "Ethnic Category: Total of All Subjects" must be equal to the "Racial Categories: Total of All Subjects."

**Note.** Priority will be given to the sampling teens, based on gender, ethnic, and racial categories. The teen will identify the parent most involved with their asthma care. Therefore it is likely that women may comprise a higher proportion of the parent group, as mothers are typically more involved with the health needs of the child than fathers.
4.4 Inclusion of Children

The unit of study is teen parent dyads; subjects will include equal numbers of teen and adult participants. For the purposes of this analysis, teen age ranges have been limited to 13 to 17 years of age, as including the entire adolescent age spectrum was considered unfeasible for a dissertation study. Younger teens are likely to experience asthma self-management differently than older teens, due to evolving maturity and increased expectations for self-care in older groups.

Additional Protections for Children Involved as Subjects in Research. As with younger children, teens are persons who have not attained the legal age of decision making to consent for participation in research. For this reason, it is necessary to obtain parental permission for teens to participate in this study. However, the autonomy and individuality of teens should be respected; therefore, it is also necessary to obtain teen assent for participation. This study will obtain both teen assent and the parent’s or the legal guardian’s permission for study participation. This is a minimal risk study and does not exceed the ordinary risks encountered in daily living. The benefit to teens with asthma (section 4.1.3), and to society in general (section 4.1.4), exceeds potential risks to subjects (sections 4.1.1 and 4.1.2). The voluntary nature of participation will be emphasized and excessive subject payments avoided in order to assure that recruitment of subjects is not coercive in any way.
Respective Contributions

Dr. Rhee’s (sponsor) research is in the area of adolescent asthma self-management; I have been assisting her in various projects since the Fall of 2011. I began work on the current research proposal in the Spring of 2012, in the Basic Qualitative Methods class taught by Dr. Bethel Powers, the PhD Program Director at the University of Rochester School of Nursing. My interest in exploring teen’s experiences and perceptions of asthma self-management was triggered by the absence of the teen perspective in the self-management literature. Based upon my many years of clinical experience in working with teens with asthma, I felt that a better understanding of how and why teens self-manage in a given manner would improve the effectiveness of self-management training in this population. I conducted preliminary interviews with teens as part of the proposal development for the basic qualitative methods class, which revealed interesting perspectives on self-management that are not presently represented in the literature. After discussing my interests and preliminary work with Dr. Rhee, Dr. David Banks, and other experience qualitative researchers we determined that pursuing a qualitative exploration of teen’s experiences of asthma self-management would be a feasible dissertation study, and would contribute a valuable and currently missing perspective to teen self-management research.

As Dr. Rhee has predominantly used quantitative methods in her teen asthma research, we both agreed that enlisting the support of a qualitative expert would greatly enhance my learning experience, as well as the overall quality of the proposed study. We subsequently solicited Dr. Norton, an experienced qualitative researcher, as a second committee member and co-sponsor. I enrolled in Dr. Norton’s Advanced Qualitative Methods class in Spring 2013, which allowed me to devote a significant portion of my time to continued proposal development under the combined topical and methodological expertise of Drs. Rhee and Norton.

After completing the first draft of the proposal, Drs. Rhee, Norton, and I began revising the proposal sequentially. Suggestions for revision by one of my sponsors were returned to me for review. After assessing the input and making appropriate changes, I would then email the next draft to the second sponsor to review and comment on. Disagreements in methodological approach were negotiated either in person or through email discussions, and were resolved to the satisfaction of all parties. Where differences of opinion existed, clear explanations of the underlying conceptual reasons for methodological choices resolved these differences easily. Overall, the process of revising the proposed study flowed seamlessly. Face-to-face and email discussions resulting in revision to the research plan have been preserved as methods memos, along with written suggestions for revision and sequential drafts of the proposal, and constitute part of the audit trail for this study.

It is our plan, in pursuing the proposed study, that Dr. Rhee will continue to provide the topical expertise, and Dr. Norton will contribute methodological expertise. In combination with my extensive clinical experience, my sponsors’ areas of expertise will provide a well-balanced guidance for the successful implementation of the proposed study.
Selection of Sponsor and Institution

Institution: University of Rochester School of Nursing

I am pursuing my Doctorate in Nursing at The University of Rochester School of Nursing (URSON). This institution is one of the top nursing research institutions in the country, and is oriented towards the development of outstanding nurse researchers. The Health Practice Research program at URSON is recognized for a rigorous program of study, emphasizing high quality science with solid theoretical underpinnings.

Sponsor 1: Hyekyun Rhee, PhD PNP

I have elected to work with Dr. Rhee, a tenured faculty member, as my mentor and primary sponsor during the period of my doctoral studies. Dr. Rhee’s research in adolescent asthma, with an emphasis on developing and evaluating self-management programs, aligns closely with my interest in asthma self-management in adolescent populations. She currently has over twenty first-author peer-reviewed publications, and is recognized as a leading expert in her field. Prior to electing to work with Dr. Rhee, I interviewed several of her previous students to learn what their experiences had been, and was told that Dr. Rhee was not only extremely talented, but that she worked closely with her students to help them grow in their own research. This has certainly been my experience: In my first year in the doctoral program here, Dr. Rhee diligently worked with me to publish a concept analysis of asthma self-management that I wrote during my first semester, and which now serves as the foundation of my proposed study. Considering her topical expertise and professional dedication to developing student researchers, I believe that working with Dr. Rhee here at the URSON will provide me with the best possible environment in which to continue developing my program of research.

Sponsor 2: Sally Norton, PhD RN

Dr. Norton is an experienced qualitative researcher and is also a senior tenured faculty member here at the URSON. Her area of research is in communication and end-of-life issues in Palliative Care. She has successfully sponsored two NRSA fellows in the past five years. This spring, I took the Advanced Qualitative Methods class that Dr. Norton teaches, which was instrumental in helping to develop my thinking about the proposed study. I will be continuing to work with Dr. Norton as a co-sponsor for my study on “Teens’ Experiences of Asthma Self-Management Across Life-Contexts” as I feel that her expertise in qualitative research, particularly in areas of pertaining to communication, will facilitate the development of a methodologically rigorous qualitative study. The majority of research in the field of adolescent asthma has been conducted quantitatively; there are very few adolescent asthma researchers who use qualitative methods. As I am pursuing a qualitative dissertation, I believe that it is critical to have the guidance of an experienced qualitative researcher in addition to the topical expertise provided by Dr. Rhee.

Jointly, the diverse but complementary expertise of Drs. Rhee and Norton will provide optimal guidance for the successful accomplishment of training goals and implementation of the proposed study exploring teens’ experiences of asthma self-management.
Responsible Conduct of Research

The University of Rochester School of Nursing places high priority on the responsible and ethical conduct of research. During the past three years at the University of Rochester, I have been educated about the responsible conduct of research through several methods. These methods include: (1) a multidisciplinary ethics course; (2) a formal self-study module for IRB Human Subjects Protection certification; (3) PhD coursework and seminars pertaining to ethical conduct of research; and (4) active participation in ethical conduct of research in collaboration with senior faculty. These four training methods are detailed below.

1. Ethics and Professional Integrity in Clinical Research/Multidisciplinary (IND 503): In the fall of 2012, I completed this one credit multidisciplinary course required for all researchers at the University of Rochester. This course fulfills the requirements for ethics training for NIH-funded research trainees, and consists of lectures related to the protection of human and animal subjects, plagiarism, copyright laws, intellectual property and responsible authorship, data management and sharing, and the reporting of ethical misconduct. The course curriculum includes a format of weekly guest presentations followed by guided group discussions. Content of these discussions focuses on the responsibilities of individual and team researchers, and the importance of maintaining and promoting scientific integrity.

2. Human Subjects Protection Certification: The completion of a formal self-study module is required by all students involved in any capacity with human research and must be completed for IRB certification. This self-study module consists of a 383 page book, “Protecting Study Volunteers in Research” (Dunn & Chadwick, 2004), which is regarded nationally as a comprehensive guide for human subject protection and was authored by two University of Rochester researchers. Content of this book includes: Historical Perspectives on Human Subject Research, Ethics and Federal Regulations, Definitions of Misconduct, and Roles and Responsibilities of Institutions and of the Investigator, FDA-regulated Research, Behavioral Research Issues, Publication of Results, Conflicts of Interest, Informed Consent, Community-based Qualitative Research, Genetic Research, Data and Safety Monitoring, Recruitment and Retention, Use of Tissue Samples and Record Reviews, and HIPAA. The study of this book was followed by the successful completion (score of 85% or higher) of a 52-question examination, required to obtain Human Subjects Protection Program (HSPP) certification through the Office of Human Subjects Protection Program (OHSP). My current certificate is valid through January of 2015. I will continue to keep my certification up-to-date, and when appropriate will participate in available resources through the OHSP including various seminars, grand rounds, ethics rounds and monthly interdisciplinary meetings to promote responsible conduct of research within the university.

3. PhD Coursework and Seminars/School of Nursing: In the fall semester of 2011, I participated in a weekly non-credit course entitled “Role of the Clinical Researcher”, in which faculty actively participating in research discussed their programs of research. During these sessions, I was able to ask questions pertaining to potential ethical dilemmas that may arise during the research process and resources available to help solve these dilemmas. This course enhanced my knowledge about the responsible conduct of research and its importance during the research process. In the spring semester of 2013 I participated in NUR 514 Research Integration and Synthesis, which includes a major unit on the preparation of a full IRB application for this proposed study. I am currently working on my IRB application and in preparation.

In Preparation I also took Dr. Norton’s (Sponsor 2) Advanced Qualitative Methods class this past spring semester, in which we discussed ethical issues common to qualitative research (e.g. interview distress, revelation of illegal behaviors during private interview, certificates of confidentiality, protection of subject identities when reporting qualitative results). Further education on the responsible conduct of research will continue next semester (Fall 2013) when I take NUR 590 Dissertation Workshop, which allows students to discuss ethical issues that arise during the dissertation process with experienced research faculty.

4. Active Participation in Ethical Conduct of Research: I was able to gain hands-on experience in the ethical issues related to the conduct of research during training as a research (RA) and teaching assistant (TA) under the supervision of Dr. Hyekyun Rhee. All students in the doctoral program are required to complete 360 hours of RA and TA experience with specific individualized objectives developed under faculty supervision. During my RA hours I received specialized training from Dr. Rhee on how to request informed consent from potential participants, how to apply for IRB approval, and how to ethically gain access to potential participants.

Lastly, I will obtain full IRB approval for this proposed study and my dissertation committee will closely monitor adherence to ethical conduct standards. Both my sponsors, Drs. Rhee and Norton, place a high priority on the responsible conduct of research in their own funded research programs, and are equally committed to training me as a responsible researcher. I will be meeting with Dr. Rhee and/or Dr. Norton on a bi-weekly basis, or more often as needed, to discuss strategies for maintaining scientific integrity, and to monitor human subject concerns throughout the course of my dissertation.
Applications for Concurrent Support

I have been awarded a small local research award ($2,500) from [Private Source] to conduct this study. This money is solely to be used for costs of conducting research, and will cover the following: payment to subjects for participation in research; transportation cost to and from interview site; recording equipment; and cost of transcription for a limited number of recorded interviews. I will be transcribing interviews remaining interviews myself. This award is complementary to the NINR Fellowship training grant, as it will ensure that there are sufficient funds for me to successfully complete the proposed study. The Fellowship training grant will meet expenses not covered by the research award from [Private Source], including: tuition, living expenses while conducting study, and costs of attending regional and international conferences. The research budget submitted to [Private Source] is displayed below.

Table I.
Budget proposal for study "Teens' Experiences of Asthma Self-Management"

<table>
<thead>
<tr>
<th>Expense Type</th>
<th>Estimated cost</th>
<th>Quantity</th>
<th>Total</th>
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</thead>
<tbody>
<tr>
<td>Private Source</td>
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Goals for Fellowship Training and Career

I am applying for support for a period of two years to complete the proposed qualitative study of teens' experiences of asthma self-management. My goals for the period of training covered by the Fellowship, are as follows:

1. **To gain hands-on experience in all phases of planning and implementing a qualitative research study**, including the following skills:
   - Preparing a study protocol for IRB review;
   - Experience in conducting ethical research in human subjects;
   - Obtaining site access;
   - Recruiting subjects;
   - Obtaining informed consent;
   - Collecting data (interview and journal);
   - Managing and storing qualitative data;
   - Analyzing data (e.g. practice using different data analysis techniques, writing analytic memos, developing codes and themes);
   - Practice using computer-assisted qualitative data analysis (QDA) software (Atlas.ti);
   - Writing up findings.

   My sponsors, the Pediatric IRB representative, and Grant Management personnel will be working closely with me to ensure the successful implementation of the proposed project. Additionally, the School of Nursing has a Qualitative Research support group that meets weekly to help researchers through all phases of a qualitative study. Computer support for QDA software (Atlas.ti) is also available.

2. **To gain experience in disseminating study results** (e.g. posters presentations, preparing manuscripts for peer-review journal). My sponsor, Dr. Rhee, emphasizes timely dissemination of research findings. During my two years in the PhD program, we have published one paper together (see Appendix), with a second currently in review.

3. **To build professional relationships with other researchers**, and to learn about different research strategies, challenges, and outcomes. Weekly attendance at Research Hour and Qualitative Group meetings will enhance my learning experience and facilitate meeting and developing relationships with other researchers. Structured classroom settings will also provide exposure to both experienced and developing researchers.

4. **To lay the foundation for the next phase of my program of research: Intervention research and Instrument development.** This will entail combining findings from my previous concept analysis of asthma self-management with the findings of the presently proposed qualitative study on teen's experiences of asthma self-management. Jointly, these findings will be used as a foundation for future asthma self-management interventions in teen populations, as well as to develop a psychometric instrument to measure asthma self-management behaviors. The instrument will be used to identify at-risk teens and serve as a measure of intervention effectiveness. First iterations of this survey have been developed using REDCap, which is available free of charge through the CTSI, University of Rochester. Dr. Rhee (sponsor) and I will be continuing work on this instrument after completion of the proposed study. We have also developed an asthma self-management manual for adolescents (see Appendix) for use in future interventions. We anticipate that the present study will contribute to modifying and refining the manual reflecting adolescents' perspectives and will help to inform subsequent self-management interventions.
## Activities Planned Under This Award

**NRSA Individual Fellowship: Summary of Activities Planned Under Fellowship by Year/Semester**

<table>
<thead>
<tr>
<th>Academic Year</th>
<th>Fall 2013 (Pre-Award)</th>
<th>Spring 2014 (Award Begins April)</th>
<th>Summer 2014</th>
</tr>
</thead>
</table>
| 2013 - 2014   | I. Coursework: 50% time  
- NUR517 Teaching & Learning  
- NUR 590 Dissertation Workshop  
- NUR 595/999 PhD Research  
II. Research 50% time  
- Complete Ch. 1 & 2.3  
- Weekly Qualitative Group meeting  
- Bi-weekly meeting with Sponsors  
- Proposal Defense          | I. Research: 100% time  
- NUR 595/999 PhD Research  
- Obtain IRB approval  
- Begin subject recruitment  
(Letters of support from recruitment sites obtained)  
- Weekly Qualitative Group meeting  
- Bi-weekly meeting with Sponsors  
- Attend conferences          | I. Research 100% time  
- Data collection (recruit and interview 8 dyads)  
- Begin data analysis (concurrent with data collection)  
- Weekly Qualitative Group meeting  
- Bi-weekly meeting with Sponsors |
| Fall 2014      | I. Research: 100% of time  
- NUR 595/999 PhD Research  
- Data collection (recruit 8 dyads)  
- Continue data analysis  
- Dissertation writing  
- Weekly Qualitative Group meeting  
- Bi-weekly meeting with Sponsors  
- Submit abstract to ENRS          | Spring 2015  
- NUR 595/999 PhD Research  
- Data collection (as needed to achieve saturation)  
- Continue data analysis  
- Dissertation writing  
- Weekly Qualitative Group meeting  
- Bi-weekly meeting with Sponsors  
- Attend Conferences          | Summer 2015  
- NUR 595/999 PhD Research  
- Continue data analysis  
- Dissertation writing  
- Weekly Qualitative Group meeting  
- Bi-weekly meeting with Sponsors |
| 2014 - 2015    | Fall 2015  
- NUR 595/999 PhD Research  
- Complete dissertation writing  
- Weekly Qualitative Group meeting  
- Bi-weekly meeting with Sponsors  
**Dissemination:** Submit abstract to ENRS; begin manuscript preparation for peer-review journal | Spring 2015  
- NUR 595/999 PhD Research  
- Complete dissertation writing  
- Weekly Qualitative Group meeting  
- Bi-weekly meeting with Sponsors  
- Dissertation defense  
**Dissemination:** continue working on manuscript preparation for peer-review journal | Summer 2015  
- NUR 595/999 PhD Research  
- Complete dissertation writing  
- Weekly Qualitative Group meeting  
- Bi-weekly meeting with Sponsors  
- Dissertation defense |
| 2015 - 2016    |                                    |                                  |              |

**NUR 590 - Dissertation Workshop**  
The purpose of the Dissertation Workshop is to help students who have completed their coursework to sustain momentum toward proposal defense and completion of the doctoral program requirements. It provides a regular, organized opportunity to present work in progress on the dissertation proposal and to receive feedback from faculty and fellow doctoral students. Research topics relevant to students’ ongoing research are discussed, e.g., examining issues of research ethics, research design, responding to evaluations of funding applications, and working with an interdisciplinary research team.

**Other Research-Related Activities Planned**  
1. Attend weekly University Research Hour meetings and weekly Qualitative Group meetings.  
2. Attend and present posters at annual Eastern Nursing Research Society (ENRS) conferences.  
3. Attend one conference in the field of asthma (American Thoracic Society, annual meeting).

**Objectives of Research-Related Activities**  
1. **Qualitative Group:** To gain experience in qualitative data analysis and presenting research findings, refine analysis through peer critique, explore approaches to disseminating results, and form relationships with other researchers engaged in qualitative research.  
2. **Bi-weekly meeting with Sponsors:** To review on-going issues related to research with human subjects, monitor study progress and data collection, discuss findings of data analysis, and give feedback on dissertation writing.  
3. **School of Nursing Research Hour:** To build and extend existing relationships with other researchers within the University, and learn about past and present study approaches, challenges, outcomes, and resources.
# Doctoral Dissertation and Research Experience

I enrolled in the University of Rochester School of Nursing PhD program in Fall, 2011. My research and dissertation experiences to date are as follows:

<table>
<thead>
<tr>
<th>Research Experience</th>
<th>Dissertation Development</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Fall 2011</strong></td>
<td></td>
</tr>
<tr>
<td>- Began working with Dr. Rhee doing literature reviews for pending grant proposals.</td>
<td>- Comprehensive <strong>review of the literature</strong>, synthesizing of existing asthma self-management interventions in teen populations to determine current state of the science.</td>
</tr>
<tr>
<td>- Subject recruitment for ADAM study.</td>
<td>- <strong>Identified research problem</strong>: No clear definition of asthma self-management. Conducted a <strong>concept analysis</strong> of adolescent asthma self-management to derive an operational definition and conceptual model.</td>
</tr>
<tr>
<td>- Data collection for ADAM study: Informed consent; Data collection and entry, Subject payment.</td>
<td></td>
</tr>
<tr>
<td><strong>Spring 2012</strong></td>
<td></td>
</tr>
<tr>
<td>- Continued subject recruitment and data collection for the ADAM study.</td>
<td>- Began working on revision of concept analysis with Dr. Rhee for publication.</td>
</tr>
<tr>
<td>- Began work on ASMA©: subject recruitment</td>
<td>- Submitted concept analysis to peer review journal.</td>
</tr>
<tr>
<td>- Facilitator for parent focus groups, ASMA study.</td>
<td>- Began building on concept analysis to derive theory of adolescent asthma self-management with theoretical model.</td>
</tr>
<tr>
<td>- Qualitative data analysis: coding focus group interviews; peer debriefing,</td>
<td>- <strong>Identified research problem</strong>: (1) teen perspective on self-management not represented in literature; (2) no psychometric instruments to measure teen asthma self-management behaviors.</td>
</tr>
<tr>
<td>- Began work developing an asthma self-management manual for teens (“Let's Talk About Asthma!”) based on the four domains of self-management derived in the concept analysis</td>
<td>- Developed <strong>preliminary proposal</strong> for qualitative study to examine teen’s perceptions and experiences of asthma self-management.</td>
</tr>
<tr>
<td>- Completed drafting asthma manual “Let's Talk About Asthma” (Appendix)</td>
<td>- Conducted <strong>preliminary interviews</strong> to inform proposal development.</td>
</tr>
<tr>
<td>- Pretested manual with teen reviewers; manual revised.</td>
<td>- <strong>Qualifying examination</strong>: Pass with commendation.</td>
</tr>
<tr>
<td><strong>Summer 2012</strong></td>
<td></td>
</tr>
<tr>
<td>- Begin TA work: NLX446 Epidemiology (role: facilitator for problem based learning)</td>
<td>- <strong>Publication</strong>: “Adolescent Asthma Self-Management: A Concept Analysis and Operational Definition” in PubMed Central, <em>Pediatric Allergy Immunology &amp; Pulmonology</em>.</td>
</tr>
<tr>
<td>- “Let's Talk About Asthma!” manual submitted to NIH as part of grant review for Dr. Rhee's planned intervention study.</td>
<td>- Developed a preliminary psychometric instrument (web-based version) to measure teen self-management behaviors.</td>
</tr>
<tr>
<td><strong>Fall 2012</strong></td>
<td></td>
</tr>
<tr>
<td>- Contribute to writing up results of the ASMA study. Manuscript currently in review.</td>
<td>- Began exploring qualitative data analysis software.</td>
</tr>
<tr>
<td>- TA for NUR512 Advanced General Linear Approaches (role: assist students with all stages of quantitative data analysis under the GLM; grading of laboratory assignments and examinations)</td>
<td>- Finalized plans for qualitative dissertation study on teen’s experiences of asthma self-management.</td>
</tr>
<tr>
<td><strong>Spring 2013</strong></td>
<td></td>
</tr>
<tr>
<td>- Finalized plans for qualitative dissertation study on teen’s experiences of asthma self-management.</td>
<td>- Began revising qualitative research proposal (present proposal).</td>
</tr>
<tr>
<td>- Began revising qualitative research proposal (present proposal)</td>
<td>- Solicited Dr. Norton as a qualitative methods expert, second committee member, and co-sponsor for training grant.</td>
</tr>
<tr>
<td>- Explored techniques for coding qualitative data.</td>
<td>- Explored techniques for coding qualitative data.</td>
</tr>
<tr>
<td>- Began process of grant application for F31</td>
<td>- Began process of grant application for F31.</td>
</tr>
<tr>
<td>- Applied for local research award from <a href="http://example.com">Private Source</a> ($2,500 awarded April, 2013)</td>
<td>- Preparation of preliminary protocol for IRB review.</td>
</tr>
<tr>
<td>- Made site contact and obtained administrative support from recruitment sites</td>
<td>- Made site contact and obtained administrative support from recruitment sites.</td>
</tr>
</tbody>
</table>
**STUDY DESCRIPTIONS:**

**1ADAM:** The overall objective of the proposed study was to develop and evaluate an Automated Device for Asthma Monitoring (ADAM). Specific aims were: (1) To develop a biomedical device system, ADAM, that facilitated non-intrusive, valid and reliable monitoring of asthma symptoms based on the parameters of asthma symptoms including wheeze and cough; (2) To evaluate measurement accuracy and validity of ADAM; and (3) To evaluate the acceptability of ADAM by the study population. This study consisted of two phases, a Development Phase and a Validation Phase. During the Development Phase, parameters of wheezes and cough were identified from the breath sound samples collected from adolescents with active asthma symptoms (N=24). A purpose-built device was designed for continuous symptom monitoring in real-life environments, applying technology that enables selective capturing of wheeze and cough based on the identified parameters as well as activity levels. The device employed a mobile phone as a platform where raw data inputted from a microphone and a wireless accelerometer were automatically processed, analyzed and stored. Participants were able to review the summary of data displayed on the screen of the mobile phone. Measurement Theory and Signal Detection Theory guided the research design and analytic approaches of the Validation Phase. For the Validation Phase, data were collected from an asthma group (n=42) and a non-asthma group (n=42). Accuracy and validity of ADAM will be evaluated using multiple statistical methods including Receiver Operating Characteristic (ROC) curve and correlational analyses, multilevel modeling, and the growth model. Data from ADAM will be compared with Forced Expiratory Volume at 1 second, exhaled fractional nitric oxide, and data from questionnaires including the Asthma Control Test, asthma daily diary, visual analogue scale of symptom perception, and quality of life. User acceptability of the device was assessed using both research-devised questionnaire and semi-structured qualitative interview.

**2ASMA:** Mobile Phone-Based Asthma Self-Management Aid (ASMA) System for Adolescents.

The purpose of this study was (1) to develop a mobile phone-based asthma self-management aid (ASMA) system and (2) to evaluate the feasibility and acceptability of the technology based on user (adolescents and parents) feedback. We used an automated agent (ASMA) that interacted with adolescents in a language that adolescents often use in “texting.” The adolescents used instant messaging systems or Twitter on their cell phones to communicate their current status and the system provided helpful responses. The interactions were prompted by the system based on preprogrammed personalized management plans (e.g., medication) or initiated by the users who wished to address their changing situations and needs. The collected information in the system was shared with the parents. This will exploit technology developed over the past two decades at the University of Rochester that provide generic capability to carry on natural conversations between humans and machines. The challenges faced in this project included adapting the system to understand the specific dialect of English that has emerged as messaging has evolved, and to encode key knowledge about the management of asthma to drive the system’s interaction. The ASMA system was pilot tested with 15 adolescent-parent dyads who used the system for two weeks and participated in focus groups. The participants provided feedback on the feasibility, functionality, and usefulness of the system.
Section II - Sponsor and Co-sponsor Information

a. Research Support

COMPLETED FUNDED RESEARCH

**Sponsor: Hyekyung Rhee, PhD PNP**

1. **Private Source** (PI)
   Living with Asthma: Focus Group Study of Adolescents.
   2003—2005

2. **Private Source** (Co-I)
   Protective Factors and Youth Nonsmoking Behavior.
   2003—2005

3. **Private Source** (PI)
   School of Nursing, University of Virginia
   Decision-Making in Understanding the Psycho-Behavioral Adjustments of Adolescents with Asthma.
   2003—2004

4. **Private Source** (PI)
   P20 NR009009-01 (pilot PI)
   Rural Health Care Research Center
   Decision-Making Program for Adolescents with Asthma
   2004—2006

5. **Private Source** (Co-I)
   Protective Factors and Adolescent Female Nonsmoking in Rural Virginia
   2006—2007

6. **Private Source** (PI)
   2006

7. **Private Source** (PI)
   R21 Grant (PI)
   R21NR09837-02
   Peer-Assisted Asthma Self-Management Program for Adolescents with Asthma.
   2006—2009

8. **Private Source** (PI)
   Faculty Research Support Grant (PI)
   Quantification of asthma symptoms through automated monitoring device: A pilot Study.
   2008—2009

9. **Private Source** (PI)
   Provost Multidisciplinary Award (PI)
   Mobile phone-based asthma self-management aid (ASMA) system for adolescents.
   2011—2012

**Co-Sponsor: Sally Norton, PhD RN**

1. **Private Source** (PI)
   1R01 NR010727 (Temkin-Greener, H., URMCF)
   NIH/NINR
   End-of-Life Quality of Care in Nursing Homes
   The objective of the proposed study is to develop and validate individual indicators and a composite measure for assessing EOL quality of care in nursing homes, and to identify characteristics of facilities associated with superior EOL quality of care.
   Role: Co-Investigator
   10/1/08—9/31/12

2. **Private Source** (PI)
   1R15NR012147 (Baggs, J.G., Oregon Health Sciences University)
   NIH/NINR
   End-of-Life Decision Making in ICUs: Roles and Relationships of Key Players
   This study is secondary analysis of data collected from an RO1 study of end-of-life decision making (EOLDM) in intensive care units (ICUs). The purpose of this study is to focus in depth on the roles of the key persons in EOLDM in ICUs (patients, family members, physicians, nurses) and the inter-relationships of those persons.
   Role: Site Principal Investigator
   7/01/10—6/30/13

3. **Private Source** (PI)
   (Gramling, R., URMCF)
   Prognostic Communication in Palliative Care
   Role: Co-Investigator
   7/01/10—6/30/11

4. **Private Source** (PI)
   R01 NR008790 (Norton, S. Principal Investigator)
   4/01/05—3/31/10
NIH/NINR
Palliative Care in the Acute Care Setting
Role: Principal Investigator
5. Private Source
(Temkin-Greener, H. PI and Norton, S. Co-PI)
Understanding End-of-Life Practice Patterns in NYS Nursing Homes.

CURRENTLY FUNDED RESEARCH

Sponsor: Hyekyun Rhee, PhD PNP
1. R01 (PI) 2009—2013, 2013-2014 NCE
   R01NR011169-01A1
   Developing an Automated Symptom Monitoring Device for Adolescents with Asthma.

Co-Sponsor: Sally Norton, PhD RN
1. Private Source (Gramling, R.E. URMC).
   Private Source 07/01/13—06/30/17
   Communication and Race in Advanced Cancer Care.
   Role: Co-Investigator.
2. 1R01CA168387 (MPI, P. Duberstein-URMC Psychiatry and H. Prigerson-Harvard) 03/13—09/17
   NIH/NCI
   Impact of a Novel Cancer Communication Intervention on Caregiver Bereavement.
   Role: Co-Investigator.
3. Private Source (PI, H. Temkin-Greener, URMC) 03/13—03/17
   Private Source
   Improving Palliative and End-of-Life Care in Nursing Homes.
   Role: Co-Investigator.
4. NYS HWRG
   New York State Department of Health (Norton, S. Principal Investigator) 1/01/12—12/31/13
   RNHHHELP: Registered Nurses Helping Hospitalized Elderly Patients...

STUDIES UNDER REVIEW

Pending Support

Pending Support

b. Previous Fellow Trainees

Sponsor: Hyekyun Rhee, PhD PNP
Previously, I had served as a committee member for three students’ doctoral dissertations. In addition, I had supervised and mentored seven doctoral students who were involved in several of previous projects as research assistants. I have not only provided the students with first-hand research experience but also strategically included them in my publications and conference presentations. To date, nine of my 26 peer-reviewed data-based publications include these students as co-authors.

Co-Sponsor: Sally Norton, PhD RN
I have chaired 3 completed doctoral dissertations and served as a committee member for a fourth student. To
date, 13 of my data-based publications have included students as the primary or co-author. All three of the students who’s committee I have chaired have received NIH/NRSA support though the first, Dr. Craig Sellers, was awarded his NRSA prior to my assuming the role of Chair on his committee. I was the sponsor for Dr. Susan Lowey on her dissertation study “Perspectives of people with non-cancer illness about care at the end of life.” NIH/NINR Lowey, 1F31NR011125-01 (01/09-05/11). Upon completion of the PhD program Dr. Lowey wrote and was awarded a [Private Source] She has just accepted a position on the tenure track at the University of Rochester, School of Nursing. I was the sponsor for Dr. Maureen Metzger on her dissertation study, “Patients’ Perceptions of the Role of Palliative Care in Late-Stage Heart Failure.” NIH/NINR Metzger, 1F31NR012084-01 (04/10-04/12). Dr. Metzger is currently a post doctoral fellow working with Dr. MiKyung Song at the UNC-Chapel Hill.

c. Training Plan, Environment, and Research Facilities

DETAILED COMPLETED COURSEWORK DESCRIPTIONS

Over the last two years, Ms. Mammen has successfully completed the following courses in the doctoral program:

NUR 560 - Role of the Clinical Researcher (Non-credit) is a seminar that draws on presentations from researchers in the School of Nursing, students are provided with the opportunity to consider their future career trajectories. Presenters will discuss the interplay between clinical practice questions and the research approaches being used to address these knowledge needs. Presentations are designed to help students to conceptualize their own research questions, driven by their “need to know” in order to provide evidence-based care.

NUR 507 - Research Programs (3 credits) is designed to review existing programs of research among faculty and in the research literature, and to provide practice in collecting, appraising, and synthesizing published research evidence in an area of student interest. In both activities, students consider the relationships between theory and research and between research questions and study designs. In this class, Ms. Mammen conducted a literature synthesis of existing adolescent asthma self-management interventions.

NUR 510 - General Linear Approaches I (3 credits) provides students education on the application of descriptive and inferential statistics, analysis of variance, correlation and regression, non-parametric and distribution free statistics. This class also provides the student with a thorough understanding of data types, file construction, descriptive statistics, estimation, and hypothesis testing.

NUR 555 - Basic Qualitative Methods (3 credits) introduces the student to the field of qualitative research and covers basic principles of research design with an emphasis on the appropriate use of methods. The primary focus is on approaches that are common to the design, conduct, and reporting of qualitative research across genres. Attention also will be given to the different purposes and approaches of specific genres through readings and examples of work representing the three major traditions of ethnography, grounded theory, and phenomenology. Ms. Mammen began preliminary work on a qualitative proposal entitled “Teens Goals and Perceptions of Asthma Self-Management,” which was later expanded into the current proposal. Ms. Mammen conducted pilot interviews with teens in the process of developing her proposal.

NUR 512 - General Linear Approaches II (3 credits) presents advanced techniques for the statistical analysis of multiple quantitative variables. These techniques are particularly applicable to the complex research designs characteristic of studies of nursing problems and other behavioral science questions. Building on General Linear Analysis I, topics include multiple regression, structural equations, logistic analysis, and multivariate techniques.

NUR 505 - Epistemology & Concept Development (3 credits) examines various the epistemological debates about science in current nursing and health care literature. These debates reflect different ways of knowing and arise out of different philosophical traditions, such as rationalism, empiricism, and historicism, and organicism. An understanding of these debates informs the discussion about the nature of science and theory. Different approaches to concept development are explored in the context of their philosophical foundations. Students will apply the process of concept development to a specific area of interest. Ms. Mammen conducted
a concept analysis entitled, "Adolescent Asthma Self-Management: a Concept Analysis and Operational Definition," which she subsequently published in *Pediatric Allergy Immunology and Pulmonology*. This paper serves as the conceptual foundation for the present proposal.

**NUR 511 – Research Design** (3 credits) covers basic principles of research design primarily, but not exclusively, from the standpoint of evaluating planned interventions with human subjects. The topics covered include the analysis of causal relationships; threats to validity; experimental, quasi-experimental, relational and descriptive designs. Considerable attention is given to hypothesis formulation, sampling design, statistical power, control and comparison groups, stratification and factorial designs, measurement design, and the analysis of data and interpretation of results.

**NUR 506 – Epistemology & Theory Construction** (3 credits) examines epistemology debates about science in current nursing and health care literature. The debates reflect different ways of knowing and arise out of different philosophical traditions such as pragmatism, phenomenology, hermeneutics, post-structuralism and critical theory. An understanding about these debates informs the discussion about the nature of science and methodological approaches to generating knowledge in nursing. The process of theory construction is examined from logical, inductive and deductive approaches. The interrelationship between concepts, constructs and variables are explicated for considering how study designs are generated. Students will apply knowledge gained about the process of theory construction to a specific area of interest. In this course, Ms. Mammen developed a paper entitled “Theory of Adolescent Asthma Self-Management,” which further built upon her prior concept analysis.

**PhD Qualifying Examination** (Non-credit) purpose to assess students’ ability to understand and interpret key concepts from first year courses foundational to the various methodologies for doing nursing research, synthesize and integrate this content in application to research problems, and use both oral and written forms of expression to present ideas both logically and succinctly. Ms. Mammen did extremely well on this exam, and was passed with commendation in August 2012.

**NUR 591 – High Risk Children and Youth** (3 credits) This class provides in-depth exploration of bio-behavioral and intervention research in high-risk children and adolescents. Established and emerging theoretical perspectives on development and intervention are explored. Students read extensively from a wide range of literature and explore concepts such as health and illness, family and social structure, nature versus nurture, and poverty, through in-class discussion with diverse faculty and analytical writing.

**ED 524 Survey Design** (1 credit) provides the student with an introduction to survey research and instrument design. Students learn the basic principles of survey research and design a preliminary survey.

**ED 525 Interview and Focus Group Techniques** (1 credit) introduces students to different approaches to qualitative data collection, with a focus on interviews and focus groups. Emphasis is laid on practicing interview techniques, preliminary data analysis and coding, and writing up findings.

**ED 529 Qualitative Data Analysis Software** (1 credit) introduces the student to computer assisted qualitative data analysis (CAQDA) using NVivo. Students learn the skills needed to import, enter, manage, annotate, analyze, and run reports on textual, audio, and visual data. Basic coding techniques are also introduced.

**NUR 513 – Research Measurement** (3 credits) introduces students to the principles of measurement and their application to problems in nursing research. Major emphasis of this course is placed on instrument development, reliability and validity, and factor analysis. Ms. Mammen wrote a measurement critique on the Illness Management Scale (Logan, Zelkovich, Labay, & Spergel, 2003). She further developed a web-based instrument to measure adolescent asthma self-management behaviors. This instrument was grounded in the conceptual framework developed in her previously published concept analysis. Ms. Mammen also conducted pre-testing with this instrument, including preliminary factor analysis with a small sample to estimate possible factor structure and identify problematic items.

**PM 412 Survey Research** (3 credits) provides in-depth instruction on methodological approaches to the development and testing of surveys. Students have the opportunity to design a survey from the ground up as part of a research team. Students conduct key informant interviews, pretest each survey iteration with experts, and pilot test the finished product. Students also run preliminary statistical analysis on data collected, report on, and present survey findings.

**IND 503 – Ethics and Professional Integrity in Research** (1 credit) provides a basic framework of guidelines, rules, and regulations, which exist to assess ethical issues arising in biomedical research and to apply ethical
principles to the conduct of biomedical research. This course fulfills the National Institute of Health requirements for training in the responsible conduct of research. Topics include scientific misconduct and plagiarism, human and animal experimentation, copyright, fair use, intellectual property, and conflict of interest related to research.

NUR 556 – Qualitative Description (3 credits) is an advanced qualitative methods course that prepares students to conduct a qualitative descriptive or interpretive descriptive study. Extensive readings and classroom discussions explore topics related to qualitative research, including: sampling, sample size in qualitative research, reflexivity, memoing, data transcription, data analysis, validation, rigor, validity, and generalizability. Students have the opportunity to practice various data analysis techniques including different coding strategies and methods for identifying themes in data.

NUR 514 - Research Integration and Proposal Development (3 credits) provides students an opportunity to integrate material from courses in cognate areas, research methods, statistics, and clinical nursing research against the context of environmental, professional, and ethical realities. Issues examined include protection of and access to human participants for research, collaborative roles, research funding, and publication. Learning experiences include examination of published research and reviews of research in the student’s area of interest, presentations of preliminary plans for a research project, preparation of a formal written research proposal, and peer review of a student colleague’s research proposal. Ms. Mammen developed the current proposal during this course, and has since then been working on revising it for this grant submission.

DESCRIPTIONS OF COURSEWORK TO BE COMPLETED

NUR 590 – Dissertation Workshop (Non-credit) is to facilitate students who have completed their coursework toward proposal defense and completion of the doctoral program requirements. Research topics relevant to students’ ongoing research are identified and discussed, e.g., examining issues of research ethics, research design, responding to evaluations of applications for funding, and working with an interdisciplinary research team.

NUR 595 – Dissertation Research (20 credits over remaining semesters in program) includes activities to complete doctoral degree like preparing and defending the dissertation proposal, conducting dissertation research, and completing the dissertation.

OPPORTUNITIES FOR INTERACTION WITH OTHER GROUPS AND SCIENTISTS

University of Rochester, Research Hour Group: This weekly interdisciplinary meeting is comprised of faculty members, clinicians, and students from across the university, who are interested in health practice research topics. Faculty and other guests from across the university present each week throughout the Fall and Spring semesters, either on their own research or on topics related to research design and methods, grant writing, and other relevant topics. Ms. Mammen regularly attends these meetings and will be encouraged to continue to her involvement in this beneficial group.

University of Rochester, Qualitative Analysis Group: This weekly interdisciplinary group is convened by Dr. Margaret Kearney at the School of Nursing and is comprised of faculty members and students who are conducting qualitative research studies. Dr. Norton is a regular attendee of this group. A member of the group is assigned to present at each session. This provides members with the opportunity to critique and evaluate methodological and analytic strategies related to qualitative study design, data collection, and analysis techniques. Additionally, the group provides a forum for peer-debriefing and consultation with experienced and developing qualitative researchers. Ms. Mammen will be a regular member of this group.

Eastern Nursing Research Society: The purpose of ENRS is to create a community for nurses interested in fostering, promoting, utilizing, and advancing research in the Eastern region of the United States. I have encouraged Ms. Mammen to attend annual conferences and meetings and to utilize this group as a networking and supportive opportunity for the advancement of her knowledge base as well as her personal program of interest. Ms. Mammen has submitted and presented a poster from her doctoral coursework in the past. She will be encouraged to continue her participation in the coming years.

American Thoracic Society: This annual interdisciplinary meeting and conference includes a Nursing Assembly that includes many members who are national and international leaders in the field of respiratory care including
asthma. Ms. Mammen will have the opportunity to network with experts in her field of research interest. She will also be encouraged to submit and present papers at this prestigious conference.

**d. Number of Fellows/Trainees to be Supervised During the Fellowship**

**Sponsor: Hyekyun Rhee, PhD PNP**

I currently chair three PhD students’ dissertation committees including Ms. Mammen’s. Mentoring and supervision of other doctoral students will not interfere with my availability to mentor Ms. Mammen and support her successful completion of doctoral studies as planned under this grant. I have been her advisor since she began her program at the University of Rochester and will continue to provide her mentoring and support.

**Co-Sponsor: Sally Norton, PhD RN**

I am the primary advisor for 3 PhD or MS-PhD students who are early in their programs. In addition, I am a committee member for 2 student dissertations with Dr. Rhee including Ms. Mammen. I meet every two weeks as a group with my doctoral students and every two weeks with each individual student.

**e. Applicant's Qualifications and Potential for a Research Career**

Ms. Mammen is an outstanding applicant and well qualified to pursue a successful research career. She was accepted at the UR SON for admission to the PhD program. She has been awarded the **Private Source** and has excelled in all of her academic coursework and received high accolades from the doctoral course faculty. Ms. Mammen has demonstrated exception intellect, talent and ingenuity as a student, research assistant and teaching assistant. As a first-year student, she worked with me to publish a concept analysis and operational definition of adolescent asthma self-management, based upon a paper she wrote for one of her courses in the program. This paper has been published in a peer-reviewed journal and is available through PubMed Central Open Access. This was a remarkable accomplishment for a first-year PhD student, and the paper can potentially make a great impact on asthma research by providing a standardized definition of asthma self-management along with a conceptual model for future research. She also presented the model at the regional nursing conference, Eastern Nursing Research Society (ENRS).

Ms. Mammen is exceptionally intelligent, talented and ingenious and has demonstrated solid beginning research skills as a Research Assistant (RA) on my two research projects. As an RA, she has been involved in subject recruitment, obtaining informed consent, data collection, moderating focus groups, data analysis, and manuscript preparation. Ms. Mammen’s ingenuity and dedication has led to the development of asthma self-management training manual for adolescent, which will be adopted for my **Pending Support**

As a Teaching Assistant (TA), she assisted the course faculty and masters and doctoral students in the Epidemiology and Advanced Statistics courses. The TA experience has contributed to not only extending her pedagogical knowledge and skills but also strengthening her foundation for quantitative and population-based research.

Ms. Mammen’s in-depth knowledge and strong commitment to science and adolescent health have been translated into a development of a research proposal of high quality and importance. She has already competed successfully in securing a small local grant to fund a portion of her study. Her proposed study is poised to make a significant impact on the methodological approaches by which asthma self-management in adolescents can be studied and evaluated. In addition, her study findings will extend clinicians’ understanding about adolescents’ asthma self-management beliefs and behaviors, which will enhance effective communication between providers and adolescents, leading to mutually agreeable management plans to which adolescents are more likely to adhere.

Ms. Mammen and I plan to meet regularly, at a minimum of every 2 weeks, and whenever necessary. I am committed to providing Ms. Mammen with structured guidance and supervision to ensure the successful implementation of the proposed project and to maximize her learning experience. I will facilitate her access to adolescents with asthma through my contact database and connections with clinical sites, and continue to mentor this extremely motivated and capable student on her journey to complete her dissertation research and defense in a timely manner.