NIH Public Access
Author Manuscript
Health Promot Pract. Author manuscript; available in PMC 2012 April 4.

Published in final edited form as:
Health Promot Pract. 2010 November ; 11(6): 798–806. doi:10.1177/1524839909334621.

Using Action Research to Implement an Integrated Pediatric Asthma Case Management and eHealth Intervention for Low-Income Families

Meg Wise, PhD[*], **Alice Pulvermacher, MS**, **Kathleen Kelly Shanovich, BSN, MS**, **David H. Gustafson, PhD**, **Christine Sorkness, PharmD**, and **Abhik Bhattacharya, PhD**
Center for Health Enhancement Support Systems, University of Wisconsin-Madison, 610 Walnut Street, Madison, WI 53726, USA

Abstract

Asthma case management and education programs improve pediatric asthma outcomes, but designing rigorous randomized controlled studies that accurately measure effects while encouraging parent participation is challenging. This is especially so for low-income African American families, who face significantly more severe asthma and social stress than their middle-class counterparts. Action research can help health education researchers negotiate between the elegant and complex designs favored by scientists with the real-life challenges of recruitment, implementation, and retention. This article discusses how a multidisciplinary team uses action research concepts to continuously adjust originally proposed protocols through the planning and implementation phases to encourage participation in a year-long randomized controlled trial of a program that combines telephone asthma case management and comprehensive online asthma education. As a result of these efforts, a higher proportion of low-income African American families are recruited into the study than originally proposed.

Introduction

Asthma case management and education programs improve pediatric asthma outcomes, but designing rigorous randomized control studies that accurately measure effects while encouraging parent participation is challenging (Lemaigre et al., 2005). This is especially so for low-income African American families, who face more severe asthma and socioeconomic stress than their middle class counterparts (Andrew, Auinger, Byrd & Weitzman, 2000; Centers for Disease Control, 2006). Action research can help health education research teams negotiate between the elegant and complex designs favored by scientists with the real-life challenges of recruitment, implementation, and retention familiar to clinical intervention researchers (Argyris & Schön, 1989). This article describes how we used action research concepts throughout the planning and enrollment phases of a five-year randomized control trial to evaluate the effects of integrating telephone case management with online asthma education on medication adherence and pediatric asthma control. By adjusting the research protocols, half of participants were low-income and non-white, compared to our original aim to recruit thirty percent from these underserved groups.

[*]Corresponding author: Meg Wise, PhD, Assistant Scientist, Center for Health Enhancement Systems Studies, University of Wisconsin, 610 Walnut Street, Room 1132, Madison, WI 53726, phone: (608) 263-1736, FAX (608) 263-4523, mewise@wisc.edu.

NIH-PA Author Manuscript
NIH-PA Author Manuscript
NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

Pediatric Asthma, Asthma Education, and Intervention Research

Asthma is the leading chronic pediatric illness in the US. It affects six million children under the age of eighteen and disproportionably affects low-income and minority children (CDC, 2006). African American children have a 20% higher rate of asthma, twice the rate of severe asthma, and greater use of asthma-related hospital and emergency department (ED) use than their Caucasian counterparts (Dey, Schiller & Tai, 2004). In addition to avoiding triggers, taking a daily asthma controller medication, monitoring symptoms, and adjusting medications as needed can control even severe asthma (National Asthma Education Prevention Program, 1997; Wolf, Guevera, Grum, Clark & Cates, 2002/2008), but the artifacts of poverty—low health literacy and lack of access to adequate healthcare —conspire against adopting these behaviors (Bauman et al., 2002; Mansor, Lanphear, and DeWitt, 2000).

Nurse case management and educational interventions improve medication adherence and pediatric asthma outcomes (Schulte, Musolf, Meurer, Cohn & Kelly, 2004; Wolf et. al., 2002/2008), but encouraging participation among low-income families is challenging (Lemaigre et al., 2005). Goss, Julian & Fogg (2001) found that motivated parents who believe in a program's efficacy were more likely to participate than their less motivated or more skeptical counterparts. To that end, Bonner (et al, 2002) and colleagues recruited 119 "pre-compliant" non-white families (28% of eligible candidates) into a three-month randomized trial to test effects of integrating a Family Coordinator with asthma education on pediatric asthma management and medication adherence; 85% of participants completed the intervention.

However, Bender, Milgrom & Apter (2003) argue that short-term interventions do not account for asthma's seasonal nature or help people sustain their newfound asthma management skills. They further note that most studies enroll relatively adherent participants and rely on self-reported data, which taken together may over-estimate intervention effects on improving medication adherence and asthma control. Finally, they (and others) note challenges of accurately measuring adherence—even with newer forms of objective data. Electronic medication dose measurement devices are expensive, and can malfunction and interfere with natural adherence routines and pharmacy claims data do not measure actual adherence or account for free samples (Riekert & Rand, 2002). In sum, asthma medication adherence research may benefit by using multiple data sources, enrolling less adherent participants, and extending the intervention time through all seasonal allergy phases (Bender et al., 2003).

The randomized trial, *Internet Telehealth for Pediatric Asthma Case Management*, addressed these limitations. It proposed frequent, multiple forms of measurement and strict enrollment criteria to evaluate whether a 12-month intervention that integrated monthly telephone case management with asthma eHealth could improve medication adherence and asthma control in children with persistent asthma. However, because the originally proposed, scientifically rigorous protocols posed challenges to real world implementation, we adjusted them continuously throughout the four-year planning and field implementation phases. Our challenge was to maintain rigor while reducing barriers for pre-adherent families who could most benefit from participating in the study.

Action Research

Action research (AR) is used in a variety of applied research fields like education, organizational quality improvement and social justice movements. AR provides a useful model to balance scientific rigor with the practical challenges of maximizing learner participation in health education research. In addressing this dilemma, Argyris & Schön

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

(1989 p. 612) suggest that if a choice must be made, the balance should aim for "standards of *appropriate* rigor without sacrificing relevance" to research participants.

Action research poses three models of collaboration with varying levels of control among scientists, practitioners, and participants to define the research aims, design the intervention, implementation protocols, and analyze and report the results (Brydon-Miller, Maguire, & Greenwood, 2003; Masters, 1995). The first model is the classic scientific approach, which guided our original study design. Here the scientist identifies theoretically informed hypotheses, designs the research and intervention, and reports the results. Skilled practitioners execute the protocols, and may suggest *minimal* implementation adjustments to ensure recruitment and data collection goes according to the protocol. Participants (or "subjects") have no input into the study design.

Second is the collaboration model, which we adopted. Compared to the classic scientific approach, it more closely follows Argyris & Schön's (1989) suggestion that rigor *may* yield to relevance as long as hypothesis testing is not compromised. Here, practitioners are *equal* partners in developing recruitment, data collection and implementation protocols—but not in defining the research hypotheses or measures. As in the scientific model, participants have no direct input into the study design. The third model is critical, or participatory, action research, which is often used in participant-centered research that aim to shift power relationships from experts to people who experience the problem (Patterson et al., 2007; Wang, 2004). Here, researchers and participants are *more equal* partners in framing research questions and hypotheses, evaluation criteria, implementation protocols, and data analysis and interpretation (Masters, 1995; Percy-Smith, 2007). Working within the critical action research paradigm was well beyond the mission of our hypothesis-driven study.

Rapid cycle testing is a common method used in action research. Based on Deming's (1982) quality improvement processes, it entails dialog, testing, analysis, and adjustment among stakeholders. It is operationalized as a continuous process, which entails planning a change to remedy an identified problem, doing it, studying the results using criteria of objective and the assessments of *appropriate* experts and taking action, accordingly (Moen, Nolan & Provost, 1999; Stringer, 2008). In our case, this entailed continuously adapting the complex protocols as problems were identified.

Action Research Case Study: Balancing Rigor and Relevance

Background

"Internet Telehealth for Pediatric Asthma Case Management" was a five-year randomized study funded by the National Institute for Nursing Research to determine whether integrating monthly nurse telephone case management into the Comprehensive Health Enhancement Support System's *Living with Asthma* program (CHESS) would improve adherence to controller medications and pediatric asthma control (Gustafson et al., 2001; 2004).

At each monthly call, the case manager (CM): (1) assessed the child's asthma, parent/child asthma management strategies, and quality of life; (2) provided appropriate education and encouragement; and (3) wrote a summary message in CHESS with links to recommended content, which followed the National Asthma Educational Prevention Program (1997) guidelines. In addition to expert information, CHESS provided interactive tools to assess asthma symptoms and asthma management strategies, share the results with the CM, and coach parents on how to address specific issues they reported). CHESS provided case managers with a toolbox to manage their caseload, including a scheduler, field notes, asthma

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

assessment results, internal email, and CHESS prescription pad of items to appear on the homepage. (See Wise et al., 2007 for more detail on CHESS and its development.).

Methods and Data

To conduct this study, we compared implementation protocols in the funded grant proposal with changes identified in notes from team meetings, emails between the project director and the research team, protocol modifications submitted to the Institutional Review Board, and recruitment tracking records that were generated over four years of the five-year randomized trial. We next describe protocols in the in the funded grant proposal and adjustments made during the planning, and early and late implementation phases.

Originally Proposed Protocols

Data collection protocols and measures—The proposed measures built in redundancy with frequent self-reports and objective data. Self reports were to include 1 two-week run-in diary, 12 monthly phone calls and 5 mailed surveys at 0, 3, 6, 9, 12 months. Objective data was to include managed care organization (MCO) claims data, and 5 readings of spirometry and electronic medication Doser (™), collected during nurse home visits.

Controller medication adherence (a primary outcome) was to be measured via the monthly phone calls, surveys, and MCO claims data. Asthma control was to be measured according to the following concepts: (1) symptom-free days (via 12 monthly phone calls); (2) Juniper's (1996) Asthma Control Questionnaire (ACQ®) (via 12 monthly phone calls); (3) 5 spirometry readings (home visits); (4) healthcare utilization (5 surveys and MCO claims data); and (5) rescue medication use (via 12 monthly phone calls, MCO claims data, and monitored Doser(™)). Demographics were to be collected during the intake interview (at a first home visit). Finally, mediators to explain the mechanisms of the intervention effects (e.g., knowledge, competence, self-efficacy, and quality of life) were to be measured via the 5 mailed surveys. In sum, this was a complex and demanding data collection schedule.

Target sample—Our target sample was parents and their children with poorly controlled asthma. According to our power analysis, three hundred parent/child dyads needed to complete the study to detect statistically significant intervention effects in medication adherence and asthma control—as well as to test the intervention's effects on the proposed mediators (e.g., self-efficacy, information competence). Based on prior CHESS studies, we assumed a 25% dropout rate. Target enrollment was thus 400 parents, including 33% (135) minorities.

Child eligibility criteria included: (1) age 4-12; (2) the same provider for at least four months; (3) a prescription for a daily asthma controller, filled at least once and missed at least once over the previous six months; and (4) evidence in the MCO claims database of poor adherence (i.e., missed refills of controller medications) and poorly controlled, moderate to severe asthma (i.e., oral steroids, over-use of rescue drugs, asthma-related emergency department visits (ED), urgent care, or inpatient visits).

Sample pool—The original study region (Region 1) was limited to Dane County, Wisconsin with an urban/suburban/ rural population of approximately 400,000 residents, including 40,000 with asthma, 4% African Americans (US Census Bureau, 2006), and 4% enrolled in Medicaid (Wisconsin Department of Health and Family Services, 2004). More than half of the population lived in Madison, home to the University of Wisconsin, which housed the study headquarters and a large allergy and asthma clinical research center. At the time of the proposal, almost 40% of children in the Madison Metropolitan School District qualified for reduced lunch. An attractive feature of this area was that 90% of the Medicaid

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

and nearly 60% of the privately insured residents were served four MCOs. The high penetration of managed care in this region allowed for the use of claims data to identify eligible participants, and to measure medication adherence and asthma-related healthcare utilization.

Original recruitment, run-in, and enrollment protocols—A letter with an opt-out card was to be mailed to the parent *from the physician responsible for the child's asthma care*, followed by a screening and recruitment phone call to non-opt-outs from the study nurse. Enrollment of those agreeing to be in the study required signed consent and assent forms, which were to be received and returned by mail. Participants would then complete two "gold-standard" pre- randomization "run-in" activities that are commonly used in pharmaceutical trials to ensure subjects' eligibility and ability to comply with data collection and medication-taking procedures. They included: (a) completing >70% of items on a two-week daily asthma diary, and (b) participating in the first of 12 monthly data collection telephone interviews. Those completing the run-in were then to be mailed the pre-test survey and scheduled by phone for the first home visit. Randomization status was to be announced just prior to the first (of 5) home visit to avoid biasing pre-test responses. Those randomized to CHESS would also receive a training (and a computer and internet access as needed).

Data collection—Protocols were designed to obtain multiple measures for key outcomes. In addition to the two run-in activities described above, participants were to complete: (1) twelve monthly phone calls to collect primary outcome data (symptom-free days, the Asthma Control Questionnaire (ACQ®); (2) five mailed survey (0, 3, 6, 9, and 12 months) with additional questions on asthma control, adherence, and mediators associated with chronic disease management (e.g., self-efficacy and barriers and facilitator to adherence); (3) five home visits to collect (a) intake information at the first visit (asthma history, demographics), (b) spirometry and home environmental assessment at all five visits; and (c) download Doser(™) data for rescue medication at visits 2-5.

Notably, this proposed protocol, while complex and scientifically elegant, was time-consuming and staff-intensive and thus posed considerable challenges to implementation.

Planning Phase Adaptations (first 18 months of the study)

The original multidisciplinary research team consisted of eHealth experts from the fields of systems engineering, medical and pharmacy asthma specialists, learning and mass communication theory, and eHealth development and evaluation. In the planning (and intervention development) phase, three community health and/or information professionals joined the team—including an advanced practice pediatric asthma nurse who would later lead the telephone nurse case managers. The new team then collaborated with MCO data managers and asthma clinicians. This influx of practice-based expertise led to significant protocol changes.

Changes in sample pool—The State Medicaid program (SMP) became a research partner and agreed to search its database for eligible participants in the target geographic area. However, the SMP IRB required that invitation letters be addressed, "To the parent of [child name]," and were accompanied by "opt-in" (rather than "opt-out" cards and the study recruiter's phone number rather than "opt-out" cards.

Changes in enrollment and run-in criteria—To streamline the MCOs' invitation process, letters were to be sent to the parent from the medical director or the chair of the asthma and allergy department, rather than the many physicians caring for pediatric asthma patients. We also added a nurse-run, clinic-based intake visit with the parent and child to

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

replace the mailings, phone calls and home visits to obtain consent/assent, child's asthma history and spirometry; administer the pre-test survey, and train people to do the run-in asthma diary. Intakes were scheduled after school; snacks, childcare, and transportation, as needed, were provided. This in-person visit not only expedited enrollment, but was also thought more likely to "seal" participants' commitment and encourage retention. The asthma run-in diary was still required, but criteria for >70% item completion and evidence of persistent asthma or poor control were dropped—as was the first monthly data phone call.

Changes in data collection measures and procedures—As shown in Table 1, three data collection procedures were eliminated: (1) Five home visits—spirometry would instead be measured twice (at intake and exit interviews). (2) Doser™, which was to be collected during the home visits, was cumbersome and expensive (and self-report and MCO claims data also measured rescue medication use). (3) Monthly telephone calls to collect ACQ®, symptom-free days, and adherence data. To compensate, we added the ACQ® into each of the five mailed surveys. We also added four more 2-week daily asthma diaries to measure symptom-free days and medication adherence to be mailed with each three-month survey. Despite a streamlined and less frequent data collection schedule, we believed these changes would maintained scientific rigor and could reduce extraneous intervention effects posed by our originally proposed phone and in-home data collection methods. Moreover, these changes cemented the buy-in of the experienced practitioners who would later implement the study protocols. In sum, in this process, we recognized that the "perfect" scientific design was simply impractical and too complex and expensive to implement with families already challenged by multiple stressors.

Early Implementation Phase Adjustments (Study Months 19-33)

According to the research protocol approved by the University of Wisconsin's Health Sciences Institutional Review Board at the beginning of the implementation phase, participants with poorly controlled moderate or severe persistent asthma and poor medication adherence were to be identified in claims databases, as they had originally been proposed: (1) filled >1 prescription for a daily controller in the past 6 months, *and* (2) poor asthma control: (a) visit to the emergency department or hospital with an ICD-9 code for asthma or wheezing, *or* (b) missed at least one month of refilling a controller medication, *or* (c) overuse (>2 canisters 6 months) of rescue medication, *or* (d) >1 oral steroid course. MCOs sent an IRB-approved invitation letter to parents with a card to opt-out. After purging "opt-outs," MCOs were to release names to the study recruiter. As noted, the State Medicaid used an opt-in invitation process to comply with their privacy regulations.

Patient identification procedure adaptations—The first data reports for the four MCOs claims data searches yielded vastly different numbers of study-eligible children, despite the same search algorithm, geographical reach, and covered population size and characteristics.

We analyzed de-identified data from one MCO of all children with an asthma diagnosis, and found that most asthma was mild. Moreover, the algorithm did not account for seasonal asthma, or for adherence to combined medication therapies or stepwise action plans. In response to these results, we expanded the window of controller medications from 6 to 24 months and standardized the selection process across recruitment sites. Thereafter, all four MCOs provided the project statistician with de-identified raw data (with temporary ID numbers) for all children, age 4-12 with an ICD-9 code for asthma or wheezing. He then identified *all possible* cases, conferring with an advanced practice asthma nurse, as needed. The MCOs then mailed opt-out invitation letters to parents of the selected patients.

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

Sample pool—Even with these adjustments, we recognized that the sample pool would not accommodate the 400-parent (and 135 minority) enrollment target. The search was expanded to the seven rural counties contiguous to Dane County that were also served by our MCO partners. However, even with these adjustments, the sample pool was still too small to meet our recruitment goals. Thus began the search for a partner serving a large population of children with poorly controlled asthma.

Run-in requirement adaptations—Because enrollment was slow—and especially for our targeted "pre-adherent" families—we randomized slightly more than 10% of families prior to their return of their two-week run-in diary. We encouraged them, however, to complete and return the diary as soon as possible.

Data collection—No changes were made during the early implementation phase.

Late Implementation Phase Adjustments: Region 2 Recruitment (Months 34-48)

After communicating with community and statewide asthma networks, the study team entered into a partnership with MCO 5, which joined the study in the last recruitment year, was located in Milwaukee County (Region 2), about an hour's drive from the study headquarters. With 100% of its members enrolled in the State Medicaid Program, MCO 5 had the State's highest rates of asthma ED and hospitalization use (Wisconsin Department of Health and Family Services, 2004). Fortuitously, at the time of initial contact, MCO 5 had just launched an initiative to reduce its high rates and costs of severe pediatric asthma. MCO funded staff time to recruit participants and assigned a dynamic African American caseworker to coordinate the recruitment. The study's project manager, four case managers and project assistant/trainer traveled to an inner-city community center after school two days per month to conduct the intake interviews, and to train participants that had been randomized to the CHESS group. This allowed for consistency across MCOs and continuity of collect data procedures. Nonetheless, some changes were made to accommodate MCO 5's IRB, staffing at a distance, and constraints on families.

Recruitment—Due to privacy constraints, MCO 5 could not share its de-identified data with the study statistician to pre-screen for eligibility, nor could it share names of non-consented/assented individuals with the study nurses (who had conducted the recruitment phone calls in Region 1). Therefore, all parents (or primary caregivers) of MCO 5 pediatric asthma patients (age 4-12) received an "opt-out" invitation letter and the caseworker screened for eligibility at the beginning of the recruitment phone call. She also scheduled intakes, organized needed transportation to the intake interviews for all interested study candidates, and welcomed families as they arrived for the intake interview.

Randomization and run-in requirement adaptations—In contrast to Region 1, randomization routinely occurred prior to the return of the run-in diary. Waiving adherence to the run-in diary not only accommodated the new CHESS training protocol (described below), but also reduced barriers to recruiting "pre-adherent" families. Shortly after the intake, the project director phoned the parent to share the random assignment (CHESS or Control); and to remind people to return their diary to CHESS and to contact MCO 5 to schedule a computer training session for those randomized to CHESS.

CHESS training protocol adaptations—Instead of individualized home or telephone training, MCO participants received group training at the community center where they had recently completed their intake interviews. The trainer traveled with the intake team and conducted the sessions while the researchers conducted intake interviews with new participants. He distributed laptops, trained people how to use them and how to use CHESS.

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

Unfortunately, most training occurred by CD and without Internet access, but it was in a familiar setting and provided an opportunity for more interaction and active learning among participants than the individualized sessions received by Region 1 participants.

Recruitment Results

As shown in Table 2, 305 parents (15.3% of the 1998 letters sent) enrolled in the study. However, recruitment numbers varied by MCO Region and by whether the letter contained an opt-in (MCO) or opt-out card (Region 1 State Medicaid Program).

Region 1 MCOs

172, nearly a quarter of the 694 parents who received letters with opt-out cards, enrolled in the study. Reasons for non-enrollment included parents' report of child ineligibility, lack of time or interest, or not showing up for the intake. Thirteen (7.5%) of those who enrolled did not return the run-in diary.

Region 1 State Medicaid

By contrast, only 23 (5.8%) of the 394 parents who were mailed opt-in (rather than opt-out) letters enrolled. Six (26%) did not return the run-in diary.

Region 1 totals

With planning and early implementation phase adaptations, 195 enrolled (19% of the sample pool); 19 (10%) did not return their first diary.

Region 2's MCO 5 recruited 110, accounting for 12.1% of the 910 sent letters with opt-outs to all parents of children with asthma. Despite waiving the run-in, 64% returned the diary.

Sample Characteristics

Data shown in Table 3 were analyzed from the intake interview. Of the 305 parent/child dyads, 15% dropped out; 51% were enrolled in Medicaid; 50% of parents and 57% of children were non-white. Including Region 2's MCO 5 was crucial not only for overall enrollment, but for reaching the underserved. All (100%) Region 2 participants were enrolled in Medicaid; 95% of children and 91% of parents were non-white (primarily African American). By contrast, of the 195 participants from Region 1, 23% were enrolled in Medicaid; 35 % of children and 27% of parents were non-white (including 23 from SMP, with 100% Medicaid, 83% of children and 52% of parents non-white). These between-region differences were all significant at $P < .001$.

However, regional differences in dropout rates were not significant ($P = .143$). Of the 46 dropouts (15% of the sample), 21 were from Region 2 (or 19% of that group), 25 were from Region 1 (or 13%) participants, including 6 (26%) of the 23 SMP participants.

Discussion

This article described how scientific and collaborative action research concepts were used to adjust the scientifically rigorous recruitment and intervention protocols of a randomized trial of integrating telephone case management with online asthma education. By so doing, we recruited 153 non-White participants (50% of 305). This exceeded our proposed minority target of 135 (33% of 400). Like other health interventions for low-income or minority populations, the recruitment was challenging. Its success required persistence of skilled nurses—and protocols that were adapting in the face of practical barriers (Bonner et al, 2002). We suspect that other researchers have streamlined their implementation protocols

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

while grappling to maintain scientific rigor, but to our knowledge such accounts have not been reported.

Action research and rapid cycle testing were used to identify problems, plan and test new solutions. These efforts resulted in simpler implementation protocols, a new research partner, and adapting protocols to new conditions. Adjustments to simplify data collection began as soon as practitioners with “on-the-ground” knowledge joined the research team. We adapted screening protocols after our early claims data analyses revealed that our theoretically-derived algorithms were too blunt for our complex eligibility criteria and the sample pool of poorly controlled asthma was smaller than our estimates from epidemiological data that did not account for advanced practice nurses managing asthma for MCO Medicaid patients in the Madison public schools; and a family-focused asthma intervention through area Head Start programs.

In following Argyris & Schön (1989), we gradually eliminated the rigorous run-in procedures used in pharmaceutical efficacy trials, because they were barriers to recruiting our target sample of pre-adherent parents. We waived the original 70% two-week diary item completion requirement in the planning phase, pre-enrollment return for 10% of Region 1 participants, and for all Region 2 participants. Losing 18% of the run-in diaries allowed us to enroll “non-adherent” parents who might most benefit from an intervention to improve medication adherence. In other words, we believed our “adherence” capital was better spent on supporting medication adherence than using diary non-adherence as a barrier to enrollment

In sum, the take home messages for the design and implementation of future patient education intervention research studies are few but cogent. First, mutual respect among scientists and practitioners in a multi-disciplinary team is critical to applying action research concepts—and overcomes potential barriers to negotiating and adopting change. Second, as Argyris & Schön (1989) suggest, the balance should tilt toward simplicity and reducing participant burden rather than toward complex and elegant designs. Finally, action research is about collaboration—between theory and practice-based researchers, between participants and researchers, and between different types of organizations. As such, health education researchers might consider incorporating critical action research methods. As described elsewhere, we involved participants in designing the intervention (Wise et al, 2007). However, we believe that a full collaboration in the proposal stage among participants, practitioners and researchers would result in simpler, more actionable, and scientifically rigorous protocols earlier in the research process.

Acknowledgments

National Institute for Nursing Research 5R01 NR007889-03 and the University of Wisconsin-Madison GCRC Grant # 3-1145-01 for supporting this research. Rhonda Christiansen, Sally Holman, Pam Richardson. Amy McCullough, and Elisha Terre for their efforts in recruiting patients; Daniel Causier and Seung-Hyan Lee for bibliographic, editorial and data assistance

References

Andrew A, Auinger P, Byrd R, Weitzman M. Risk factors for pediatric asthma: Contributions of poverty, race, and urban residence. American Journal of Respiratory and Critical Care Medicine. 2000; 162(3):873–877. [PubMed: 10988098]

Argyris C, Schön DA. Participatory action research and action science compared a commentary. The American Behavioral Scientist. 1989; 32(5):612–623.

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

Bauman LJ, Wright E, Leickly FE, Crain E, Kruszon-Moran D, Wade SL, Visness C. Relationship of adherence to pediatric asthma morbidity among inner-city children. Pediatrics. 2002; 110(1):1–7. [PubMed: 12093940]

Bender B, Milgrom H, Apter A. Adherence intervention research: What have we learned and what do we do next? Journal of Allergy and Clinical Immunology. 2003; 112(3):489–494. [PubMed: 13679805]

Bonner S, Zimmerman B, Evans D, Irigoyen M, Resnick D, Mellins R. An individualized intervention to improve asthma management among urban Latino and African-American families. Journal of Asthma. 2002; 39(2):167–179. [PubMed: 11990232]

Brydon-Miller M, Maguire P, Greenwood D. Why action research? Action Research. 2003; 1(1):9–28.

Centers for Disease Control. Access to health care, financial structural, and personal barriers. Healthy People 2010: Understanding and Improving Health. 2006

Demming, WE. Out of Crisis: Quality, Productivity and Competitive Position. Cambridge University Press; 1982.

Dey, A.; Schiller, J.; Tai, D. Summary Health Statistics for U S Children: National Health Interview Survey, 2002. Vol. 10. National Center for Health Statistics: Vital Health Statistics; 2004. p. 1-78.

Diette G, Markson L, Skinner E, Nguyen TTH, Algatt-Bergstrom P, Wu AW. Nocturnal asthma in children affects school attendance, school performance and parent's work attendance. Archives of Pediatric Adolescent Medicine. 2000; 15:923–928.

Freire, P. Pedagogy of the Oppressed. New York: Continuum; 1970.

Goss D, Julion W, Fogg L. What motivates participation and dropout among low-income urban families of color in a prevention intervention? Family Relations. 2001; 50(3):246–254.

Gustafson D, Johnson P, Molfenter T, Patton T, Shaw B, Owens B. Development and test of a model to predict adherence to a medical regimen. Journal of Pharmacy Technology. 2001; 17:198–208.

Gustafson, D.; Wise, M.; Meis, T.; Molfenter, T.; Staresinic, A.; Sorkness, C. Improving medication adherence through decision theory and the Internet. In: Dunbar-Jacobs, J.; Erlen, J.; Schlenk, E.; Stilley, C., editors. Methodological Issues in the Study of Adherence. Pittsburgh: University of Pittsburgh School of Nursing; 2004.

Juniper E, Guyatt D, Feeny P, Ferrie L, Griffith LE, Townsend M. Measuring quality of life in parents of children with asthma. Quality of Life Research. 1996; 5:27–34. [PubMed: 8901364]

Lemaigre V, Van den Bergh O, Van Hasselt K, De Peuter S, Victoir A, Verleden G. Understanding participation in an asthma self-management program. Chest. 2005; 128(5):3133–3139. [PubMed: 16304253]

Mansour ME, Lanphear BP, DeWitt TG. Barriers to asthma care in urban children: parent perspectives. Pediatrics. 2000; 106:512–519. [PubMed: 10969096]

Masters, J. The history of action research. In: Hughes, I., editor. Action Research Electronic Reader. The University of Sydney; 1995. Retrieved August 7, 2008 from http://www.scu.edu.au/schools/gcm/ar/arr/arow/rmasters.html

Moen, RD.; Nolan, TW.; Provost, LP. Quality Improvement Through Planned Experimentation. New York: McGraw-Hill; 1999.

National Asthma Education and Prevention Program. Expert Panel Report: Guidelines for the Diagnosis and Management of Asthma. National Heart, Lung and Blood Institute; 1997.

Patterson M, Jennifer M, Medves JM, Chapman C, Verma S, Broers T, Schroder C. Action Research as a qualitative research approach in inter-professional education: the QUIPPED approach. The Qualitative Report. 2007; 12(2):332–344.

Percy-Smith B. 'You think you know? … You have no idea': youth participation in health policy development. Health Education Research. 2007; 22(6):879–89. [PubMed: 17652346]

Riekert KA, Rand CS. Electronic monitoring of medication adherence: when is high-tech best? Journal of Clinical Psychology in Medical Settings. 2002; 9(1):25–34.

Schulte A, Musolf J, Meurer JR, Cohn JH, Kelly KJ. Pediatric asthma case management: A review of evidence and an experimental study design. Journal of Pediatric Nursing. 2004; 19(4):304–10. [PubMed: 15308981]

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

Stringer E, Guhathakurta M, Masaigana M, Waddell S. Guest editors' commentary: Action research and development. Action Research. 2008; 6(2):123–128.

Sung NS, Crowley WF, Genel M, Salber P, Sandy L, Sherwoood LM. Central Challenges facing the national clinical research enterprise. JAMA. 2003; 289(10):1278–1287. [PubMed: 12633190]

US Census Bureau, 2000 Census. Retrieved August 7, 2008 from www.census.gov

Wang M, Mannan H, Poston D, Turnbull AP, Summers JA. Parents' perceptions of advocacy activities and their impact on family quality of life. Research and Practice for Persons with Severe Disabilities. 2004; 29(2):144–155.

Warman KL, Silver EJ, Stein REK. Asthma symptoms, morbidity, and antiinflammatory use in inner-city children. Pediatrics. 2001; 108(2):277–282. [PubMed: 11483788]

Wisconsin Department of Health and Family Services. Burden of Asthma in Wisconsin. 2004. Retrieved August 7, 2008 from http://dhfs.wisconsin.gov/eh/asthma/pdf/boawi04.pdf

Wisconsin Department of Health and Family Services. Wisconsin Medicaid Recipients. Retrieved December 6. 2006 from http://dhfs.wisconsin.gov/medicaid8/caseload/481-caseload.html

Wise M, Gustafson D, Sorkness C, Molfenter T, Staresinic A, Meis T, et al. Internet telehealth for pediatric asthma case management: developing integrated computerized and case manager for tailoring a web-based asthma education program. Health Promotion Practice. 2007; 8(3):282–291. [PubMed: 16928987]

Wolf FM, Guevara JP, Grum CM, Clark NM, Cates CJ. Educational interventions for asthma in children. Cochrane Database of Systematic Reviews, 4, Cochrane Database of Systematic Reviews 2008. 2002/2008; (3) Status: Unchanged.

NIH-PA Author Manuscript
NIH-PA Author Manuscript
NIH-PA Author Manuscript

Table 1

Changes in Implementation and Data Collection Protocols by Study Phase

Protocols	Original	Planning	Early Implementation	Late Implementation
Region				
Region 1	x	x	x	x
Region 2				x
Reach: # of counties	1	1	8	9
Reach: large, urban underserved				x
Recruiting Agencies				
MCOs 1-4 (Region 1)	x	x	x	x
State Medicaid (Region 1)		x	x	
MCO 5 (Region 2)				x
Data Collection and Measures				
Home Visits	5			
Phone	12			
Clinic visits		2	2	2
Surveys	5	5	5	5
Doser(TM)	5			
Spirometry	5	2	2	2
Claims Data	x	x	x	x
Internet usage (CHESS group only)	x	x	x	x
Diaries (number)	1	5	5	5
Asthma Control Questionnaire (ACQ	12 [1]	5 [2]	5 [2]	5 [2]
Symptom-free days	12 [1]	5 [3]	5 [3]	5 [3]
Run-in/Pre-Enrollment Criteria				
Diary completed %	70%			
Diary Returned	x	x	Partial, as needed	No
Diary evidence of asthma severity	x			
Phone ACQ	x			
Subject Identification, Consent				
Claims data algorithm	Strict	Expanded	Expanded	Expanded
Statistician review [4]			x	x
Consent/assent	Mail	Clinic	Clinic	Clinic
CHESS training				
Home (individual)	x	x	x	x
Phone (individual)			x	x
Group [5]				x

[1] Phone call;

[2] Added to Survey;

[3] Added to Diary Region;

[4] MCOs only;

[5] Region 2 only

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript
NIH-PA Author Manuscript
NIH-PA Author Manuscript

Table 2

Recruitment and Enrollment by Region

	Region 1 4 MCOs *1, 2*	**Region 1 SMP** *1,3*	**Region 1 total** *1*	**Region 2 (MCO 5)** *4*	**Total**
Letters sent	694	394	1088	910	1998
Enrolled	172	23	195	110	305
% of letters sent	*24.7%*	*5.8%*	*17.9%*	*12.1%*	*15.3%*
No run-in diary (N)	13	6	19	36	55
No run-in (%)	*7.6%*	*26%*	*9.7%*	*32.7%*	*18%*

*1*Dane and 7 rural counties, prescreened;

*2*pre-screened for eligibility;

*3*Opt-ins;

*4*Milwaukee County (100% Medicaid), not screened 4

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

Table 3

Self-reported Sample Characteristics at Baseline

	Region 1	Region 2	Total sample	P-Value
Total N	172	110	305	
Medicaid (%)	13.9%	100%	51.5%	<.001
Child Non-White (%)	28.3%	93.6%	55.1%	<.001
Parent Non-White(%)	23.7%	90.8%	46.6%	<001
Parent Married (%)	67%	17%	50%	<001
Dropout (%)	13	19%	15%	.134