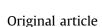
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# Data quality from a longitudinal study of adolescent health at schools near industrial livestock facilities



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#### ABSTRACT

*Purpose:* Longitudinal designs enable examination of temporal relationships between exposures and health outcomes, but extended participation can cause study fatigue. We present an approach for analyzing data quality and study fatigue in a participatory, longitudinal study of adolescents. *Methods:* Participants (n = 340) in the Rural Air Pollutants and Children's Health study completed daily diaries for 3 to 5 weeks in 2009 while we monitored outdoor pollutant concentrations. We used regression models to examine established associations between disease, symptoms, anthropometrics, and lung function as indicators of internal consistency and external validity. We modeled temporal trends in data completeness, lung function, environmental odors, and symptoms to assess study fatigue. *Results:* Of 5728 records, 94.2% were complete. Asthma and allergy status were associated with asthmarelated symptoms at baseline and during follow-up, for example, prevalence ratio = 8.77 (95% confidence interval: 4.33–17.80) for awakening with wheeze among diagnosed asthmatics versus nonasthmatics. Sex, height, and age predicted mean lung function. Plots depicting outcome reporting over time and associated linear trends showed time-dependent declines for most outcomes.

*Conclusions:* We achieved data completeness, internal consistency, and external validity, yet still observed study fatigue, despite efforts to maintain participant engagement. Future investigators should model time trends in reporting to monitor longitudinal data quality.

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#### Introduction

Although prospective studies can reduce recall bias, conditioning effects such as sensitization and fatigue may affect data quality in longitudinal studies [1–4]. Sensitization typically occurs at the beginning of the study when participants become more aware of their health and over-report behaviors or symptoms [1]. Fatigue in the later stages of participation leads to under-reporting [1]. Reliability and validity of data can be evaluated using internal consistency and criterion validity measures [2], in addition to missing data assessments.

Several studies have documented conditioning effects among adolescents using health diaries [2–4]. In the Asthma Daily Diary for Children study (ages 7–12 years), investigators noted that 64% of respondents reported fatigue with keeping a diary, and that missing data mostly occurred in the final week of follow-up [2].

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Strickland et al.[4] followed injury reports from youth aged 9 to 18 years for 13 weeks, and although there was no indication of study fatigue based on missing data, they observed a time-dependent decline in injury reporting.

Although the risk of bias in longitudinal studies is not necessarily greater for adolescents compared with adults, investigators conducting research with children can minimize errors by keeping children engaged [5]. Techniques include involving adolescent participants in questionnaire design [5–7]; offering encouragement and rewards [2]; sharing study progress [8]; and incorporating innovative research methods, including drawings, photographs, participatory techniques, diaries, and worksheets [6]. Punch [6] also suggests maintaining confidentiality; developing rapport between researchers and participants; giving comprehensive, unambiguous instructions; avoiding leading questions; and permitting "don't know" responses to avoid guesses. Ozer et al. [8] emphasize consideration for researcher-participant dynamics in research involving youth of color to avoid disengagement if the common dynamic of white teachers questioning students is replicated in research design.

The Rural Air Pollutants and Children's Health (RAPCH) study employed many of these approaches during participatory data



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collection with middle school students in eastern North Carolina (NC). The study was collaboratively designed by researchers from the University of North Carolina at Chapel Hill (UNC-CH) and community partners from the Rural Empowerment Association for Community Help (REACH), a community-based organization seeking to provide economic and environmental justice for residents of rural southeastern NC. We used a longitudinal design to assess acute health effects associated with daily air pollutant concentrations at three middle schools near large-scale livestock facilities that emit particles and gases that can affect respiratory health [9]. In NC, 99% of the nearly 10 million swine under production are raised in facilities with more than 1000 animals [10]. Cross-sectional studies have documented associations between home and school proximity to swine facilities and prevalence of asthma-related illness in children [11–13].

In the RAPCH study, adolescents completed their own diaries and recorded their own lung function values during science class. Here, we describe our data collection methods and engagement strategies, present an analysis of data quality, and discuss implications for our research aims to inform future longitudinal studies.

#### Materials and methods

#### Recruitment and data collection

REACH staff recruited three public middle schools for the study. Participating schools had 9 to 56 swine barns and 4 to 25 poultry barns within 2 miles. School staff selected science classes for the study based on class size, schedule, and student maturity. Teachers learned the study protocol and confidentiality procedures but did not collect data.

After a presentation about air pollution and health effects, we described the study to science classes. Students received a packet containing a letter of support from the principal and science teacher plus parental consent forms in English and Spanish. We obtained assent from students who returned forms indicating parental consent. The UNC-CH Institutional Review Board reviewed and approved study activities.

We collected data between February and November 2009 in five waves lasting 3 to 5 weeks each; three classes comprised each wave. Of 358 students, 340 (95%) from 15 science classes participated. At baseline, participants reported sociodemographic information, exposures to smoking, and exposures to livestock, and they answered questions about asthma-related diagnosis or symptoms drawn from a previous school-based study of adolescent asthma in NC, which included the International Study of Asthma and Allergies in Childhood (ISAAC) video questionnaire [14–17]. Participants then received binders containing a daily diary and a Mini-Wright Digital (MWD) peak flow meter (Clement Clarke International, Harlow, UK). Because of supply challenges, some participants received MWDs after they began daily diary completion. We trained participants to use the diaries and peak flow meters, emphasizing accurate and honest reporting. Last, we measured participant height as an indicator of expected pulmonary function values.

Participants took approximately 10 minutes each day to complete the following steps: (1) report the strength of 11 illness symptoms using a scale of none, barely there, present, strong, and very strong; (2) record 24-hour odor observations for engine exhaust, livestock, and smoke using the same scale; (3) report asthma and allergy medication use, respiratory-related physician visits, and respiratory-related school absences; (4) record time outside in the previous 24 hours; and (5) measure forced expiratory volume in one second (FEV<sub>1</sub>) and peak expiratory flow (PEF) three times with their MWD instruments, recording each measurement to supplement electronic data. REACH hired local community members to assist data collection and promote data quality. These community liaisons were former educators who trained in research ethics, learned the study protocol, and were approved by the UNC-CH Institutional Review Board. Typically, two liaisons were present daily to distribute and collect diaries, monitor use of MWDs, and check diaries for completion. Although participants maintained autonomy in their responses, liaisons briefly checked diary pages and alerted students to blank sections, for example, skipped pages. After a school absence, students were instructed not to complete missed diary entries. Liaisons also verified air pollution monitors measuring particulate matter less than 10  $\mu$ m in aerodynamic diameter and hydrogen sulfide inside and outside of schools.

We incorporated concepts of scientific inquiry, technological design, air pollution, and the human respiratory system into research activities to complement the NC Standard Course of Study [18]. We also demonstrated air monitoring instruments and MWD data downloading. Using preliminary results, students practiced interpreting summary statistics and generated graphs. To encourage participation, we provided incentives at the student, teacher, and school levels.

#### Analysis of data quality

We analyzed data for students who completed both a baseline survey and a diary (N = 340). We considered each diary entry a record with a maximum of 25 records per participant (5 d/wk for up to 5 weeks). Of 6249 records collected, we excluded 521 with more than 50% of items missing as presumed school absences; 77% of these excluded records were marked "absent" by community liaisons and may have been completed retrospectively by participants. We conducted analyses on the 5728 remaining records.

We examined data completeness by tallying missing items for each record. For lung function data, we tallied missing written values separately for records with and without stored electronic data because written values without electronic data may be fabricated. We then computed the number and percent of complete records overall and by diary section.

We defined five categories of asthma-related disease at baseline using established definitions from the ISAAC study and a previous school-based study conducted statewide in NC [19].

- (1) *Diagnosed asthma* is defined as responding "yes" to ever having an asthma diagnosis by a health professional.
- (2) *Diagnosed current asthma* is defined as responding "yes" to ever asthma diagnosis and "yes" to experiencing any of the following four ISAAC wheeze in the past year: wheeze at rest, wheeze after exercise, awakened by wheeze, or wheeze with intercostal contractions.
- (3) Current wheeze without asthma diagnosis is defined as responding "no" to ever asthma diagnosis but "yes" to experiencing any of the four ISAAC wheeze symptoms in the past year.
- (4) Frequent wheeze without asthma diagnosis is defined as responding "no" to ever asthma diagnosis but "yes" to any of the four ISAAC wheeze symptoms each month in the past year.
- (5) *Allergy* is defined as responding "yes" to having at least one of the following allergies: dogs, cats, dust, or grass or pollen.

We define *internal consistency* as the observation of expected relationships between variables within our data set that measure similar traits [2]. We used bivariable log-binomial models to estimate associations between (1) allergy status and the prevalence of two asthma outcomes (diagnosed asthma and diagnosed current asthma) and (2) asthma-related disease and the prevalence of ISAAC symptoms. We also used Poisson-distributed generalized

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