



OPEN LETTER

# Lessons learnt in recruiting schoolchildren into a large asthma case-control study in urban Uganda [version 1; peer review: awaiting peer review]

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## Abstract

Schools present an excellent opportunity for research among children and adolescents. We share our experiences and lessons learnt in enrolling schoolchildren into a large asthma case-control study from schools in urban Uganda, and make recommendations for best practices.

Our key lessons were as follows: working closely with the school administration and teachers was vital in gaining timely access to parents of the schoolchildren; having a meeting with parents, within their children's school premises, was a cost-effective way of reaching a wide audience of potential research participants with our message and an opportunity to seek their participation; allowing flexibility within our processes enabled us to fit our research activities within the school schedule, and with minimal disruptions; however, obtaining informed written consent from parents of children in the boarding section of school remained a challenge.

In conclusion, conducting research in schools in Uganda is feasible and may be a cost-effective way to make the most of limited resources to remedy the research and data deficiencies among school-age children in sub-Saharan Africa.

## Keywords

Recruitment, schoolchildren, best practices, lessons learnt, Uganda, Africa

## Open Peer Review

**Reviewer Status** *AWAITING PEER REVIEW*

Any reports and responses or comments on the article can be found at the end of the article.

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## Introduction

Children are an important population for the achievement of the 2030 global sustainable development goals (SDG)<sup>1</sup>. There is urgent need for accessible, timely and disaggregated data for assessing children's positions relative to the SDGs and data on child health in general. Although the value of investing in the first 1000 days of life is a recognised high priority area, investment in health and research in the next 7000 days has been largely neglected<sup>2</sup>. For sub-Saharan Africa, we need data initiatives that make the most of limited resources so as to remedy the data and research deficiencies, such as collecting data on children from schools.

Taking Uganda as a case study, children aged 17 years and below make up 52.6% of the total population<sup>3</sup>. Moreover, 89% of children aged 5–17 years are in school, according to the Uganda Statistical Bureau statistical datasets published in 2018<sup>4</sup>. Schools present an excellent setting for data collection among children aged 5–17 years for research purposes and for assessing progress on SDG targets. Therefore, a good understanding of the best approaches for participant recruitment, enrolment and data collection from schoolchildren attending schools in sub-Saharan Africa is essential.

In this paper, we share our experiences and lessons learnt in recruiting and enrolling schoolchildren into a large asthma case-control study from schools in urban Uganda, and make recommendations for best practices.

## Summary of the asthma case-control study

We conducted a case-control study to investigate the risk factors for asthma among schoolchildren in urban Uganda, and have published three key results: asthma risk factors<sup>5</sup>; asthma control and management at enrolment<sup>6</sup>; and atopic sensitisation<sup>7</sup>. Briefly, this study was conducted in 55 schools (primary and secondary) in Entebbe Municipality and Katabi sub-county, Wakiso district, an urban area in central Uganda. The study field activities were conducted between May 2015 and July 2017.

The detailed participant flow diagram with detailed numbers has been published<sup>5</sup>. We identified 6,385 schoolchildren as

potential study participants and provided them with invitation letters (later changed to invitation cards) to deliver to their parents or legal guardians, inviting them to a meeting at school. The majority of the parents (4,550) did not make it for the meeting due to various reasons. Of the 1,835 who did, 1,786 provided informed written consent for their children to participate in the study. Children older than eight years provided informed assent. We enrolled a total of 1,702 schoolchildren, aged 5–17 years.

All study procedures were conducted within the school premises, including interviewer-led questionnaires to parents or guardians and to adolescents themselves, general medical examinations, lung function tests (spirometry), skin prick tests for allergy, tuberculin skin test, collection of blood and stool samples. We provided laboratory tests results for asymptomatic malaria, HIV, and helminth infections, as well as the appropriate treatment (only 12 children were HIV positive and all were already receiving antiretroviral therapy). For children with asthma, we provided the appropriate inhaled medication<sup>8</sup>, and referred them for further management and follow-up in one of the two hospitals that had an asthma clinic. At the end of the study, we held a large dissemination meeting with all relevant stakeholders.

This study was approved by the Uganda Virus Research Institute Research and Ethics Committee (reference number: GC/127/14/09/481), and the Uganda National Council for Science and Technology (reference number: HS 1707).

## Key lessons learnt

We provide the details of the steps taken from the time we obtained ethics approval from the relevant regulatory authorities, through study enrolment to results dissemination. We present our experiences in three key phases of the study: pre-enrolment, enrolment and study procedures, and post-study. We end with the lessons we learnt and recommendations for researchers planning to conduct research within schools in Uganda and possibly other sub-Saharan countries.

### Pre-enrolment phase

The key activities for the planning phase and lessons learnt are summarised in [Table 1](#).

**Table 1. Summary of key persons and activities in the pre-enrolment phase.**

	Key persons	Key lessons
1.	District and Municipality Education and Health Officials	Provided a formal letter of authorisation and introduction to schools, a list of all schools in the area, and an opportunity for a face-to-face meeting with the school heads during a meeting. This made it easy for the study team to approach individual schools
2.	School Head Teachers	They designated a specific teacher or school nurse to support the study team to implement the study activities within the school
3.	Teachers designated to support the research team	Provided practical tips on how to work within the school schedule, organised the space for the team, and introduced the team to the class teachers
4.	Class teachers	Supported the pre-screening study activities, and distributed invitation cards for a parents' meeting to eligible pupils

**Authorisation and support from the local Education and Health Offices.** We met and presented our study protocol to the Wakiso district and Entebbe Municipality Education and Health Offices once we obtained ethical approval from the two main ethics regulation offices (Uganda Virus Research Institute Research Ethics Committee and the Uganda National Council for Science and Technology). We explained to them what the study was about, and sought their permission to conduct this study within the schools under their jurisdiction. The Education Office provided us with a list of all schools in the study area, an introductory letter to the schools, and gave us the opportunity to speak to the school head teachers during their scheduled meeting. This made it much easier for our study team to approach the individual school administration.

**Introduction and support from school administration.** The study team met the school head teachers for each school and provided the introductory letter from the local Education Office, copies of the ethics approval letters and the study protocol. We specifically sought for permission to work in the school, to identify eligible schoolchildren and a space for our activities. Most schools designated either a specific teacher or school nurse to work with us, who were very helpful identifying space for the study team, advised appropriate ways of working within the school schedule and introduced the team to class teachers.

The class teachers worked with the study team on pre-screening activities which involved the identification of eligible pupils by asking broad questions regarding breathing problems. The class teachers then distributed the invitation cards to eligible pupils to take to their parents inviting them to come to school for a parents' meeting. The invitation cards contained phone numbers of the study team, which were very useful for parents to call and seek further clarification regarding the meeting.

### Enrolment and study procedures phase

The key activities in the enrolment and study procedures phase and lessons learnt are summarised in [Table 2](#).

**Parents' meetings.** Parents' meetings were held at each school, on the day and time suggested by the school administration. These meetings were a great opportunity for the study team to fully explain the details of the study to parents or guardians of eligible pupils and to respond to any concerns. At the start of the meetings, the schoolteachers introduced the study team to the parents. The study team used information, education and communication materials in very simplified terms (charts, power point presentations and videos), to provide clear explanations of the study protocol and general information on asthma. We also displayed the materials to be used in the study, such as biological sample collection containers and the equipment for lung function testing. The meetings were conducted in both Luganda (the main local language) and English. We allowed plenty of time for questions, which we responded to comprehensively, as we provided refreshments and transport reimbursement to participants. For large gatherings, we used a public address system.

The main challenge was that many parents were not able to attend the meeting for various reasons, including tight work schedules; forgetting the date or time of the meeting; and inability for some to stay until the end of the meeting. This challenge was compounded by the fact that some parents' phone contacts were not available and the pupils in the boarding section of the school were unable to deliver the invitation cards. We mitigated these challenges by holding additional parents' meetings at our study clinic (in Entebbe town) during the weekends, public holidays or school holidays. We reminded all invited parents and guardians several days before the meeting, by phone calls and text messages, and the community radio.

At the end of the parents' meetings, we invited all parents and guardians interested to have their children participate in the study to stay a little longer, to provide written informed consent.

**Informed consent and assent process.** The informed consent process involved reading with individual parents the study information sheet line by line, and making sure, they understood

**Table 2.** Summary of key persons and activities during the enrolment and study procedures phase.

	Key persons	Key activities and lessons
1.	Pupils and parents (or guardians)	<ul style="list-style-type: none"> <li>Parents' meeting was a great opportunity for the study team to meet a large number of potential participants and obtain informed written consent</li> <li>A large study team was required to obtain informed consent from several parents in a timely manner</li> <li>Obtaining consent from parents who could not attend the meeting remained a challenge</li> </ul>
3.	Pupils and teachers	<ul style="list-style-type: none"> <li>Having a good working relationship with the teachers was key to ensure timely access to the pupils and complete data and sample collection</li> <li>Friendly and honest communication with the pupils was vital</li> </ul>
4.	Study team	<ul style="list-style-type: none"> <li>It was important to be flexible and work within the school schedule, and to minimise disruption of the pupils' studies</li> <li>Respect of the schools rules included maintaining an appropriate dress code</li> </ul>

it. Those interested and literate signed the informed consent form, while those not able to read or write used the thumb print in the presence of an impartial witness.

Parents not able to make the decision on that day were provided with a copy of the study information sheet to take home and read with their spouses. They were free to come back to the school, usually within a week, to provide informed written consent.

We held a separate session for children whose parents or guardians had provided informed written consent, to explain the study information sheet, show them the materials to be used in the study (as we did for the parents), and respond to their questions. Children eight years and above provided informed written assent. The children's only meeting was very important for them to open up, in the presence of their teachers, and ask their own questions.

It was challenging to have large numbers of parents to individually consent at the end of the parents' meeting. Our mitigation measures included recruiting and training additional study staff so that the team was comprised of ten members or more during the parents' meetings (including colleagues working on other research projects, but also trained in our study protocol). For about 30 parents, we obtained informed written consent from either their offices or homes.

**Conduct of study procedures.** Data collection began immediately after the informed consent procedure, when the parents either answered a few questions regarding their own and children's health or provided us with phone contacts so that these few questions could be answered at a later time point.

We worked very closely with the teachers or school nurses assigned to work with us to identify the most appropriate dates and times for us to conduct the study procedures. These teachers brought the study team small groups of children at a time, for the study procedures and collected the early morning stool samples from the participating children. Therefore, it was very important to establish a good working relationship with the school staff, and at the end our study activities, we offered them a small financial token of appreciation.

Appropriate communication with children and adolescents was very important to win their trust and cooperation. This included being friendly, genuinely responding to their questions and concerns, and showing respect to them and their teachers. We provided children with simple refreshments after the blood draw, and they generally liked that.

It was very important to be flexible and work within the limited time allocated to us, in order to minimise disruptions to the pupils' learning. This meant streamlining our process to efficiently work during the lunch break, lesson breaks, and over the weekends (particularly for pupils in the boarding section). However, there were scheduled school activities during which we could not do any work, such as sporting activities, study trips, absenteeism due to school fees defaulting,

music festivals and during annual National Examinations (when non-candidates required to stay home).

We also had to be flexible and innovative with working space. In some schools, we worked from the school library, chapel, free classrooms, and even the school compound (thus important to have a tent). Most schools were able to provide storage space for our locked cargo boxes containing our equipment, but if this was not available, we transported this back and forth from our study clinic located in Entebbe town. It was also important to have a long power extension cable (>30metres; because the power source was sometimes far from our work space) and battery-operated or equipment with long battery life (public address system) because of an irregular power supply which is common in this setting.

We used paper based questionnaires and case report forms, these had to be checked daily for completeness by the team, and regularly by the internal study monitor. This was important in order to correct any errors before the study team moved to another school. Once complete, the data manager batched the forms and sent them for electronic double data entry.

**Appropriate code of conduct.** Working within schools requires respecting the schools' rules and regulations. For instance, some schools do not allow any females to wear trousers of any kind. As a general rule, the study team adhered to a strict dress code which included uniform shirts, T-shirts and aprons with the organisation's logo, and wore the organisation identity card on the neck when in the school premises.

#### Post-study phase

The main post-study activity was public engagement and results dissemination at the end of the study. We held a large meeting involving all relevant stakeholders such as study participants (pupils and their parents or guardians); school administration (head teachers, school nurses and teachers who participated in study recruitment); hospital staff from Entebbe hospital (the only Government-funded hospital in the study area); the Wakiso district and Entebbe Municipality health and education officials and political leaders; Ministry of Health officials from the Non-Communicable Diseases office; the media fraternity; and the general public.

The aims of the dissemination meeting were to create general awareness about asthma and to communicate our research findings. The meeting was held during the World Asthma Day celebrations in May 2018, at Kisubi hospital (the only hospital in the study area with an asthma clinic). Stakeholders were invited using appropriate means including official invitation cards, phone calls (and text message reminders), and radio announcements.

During the meeting we presented our findings in simplified terms; worked with Kisubi hospital physicians to talk about asthma and to demonstrate the use of inhalers; listened to speeches from various stakeholders, had a long question and answer session with the general public. We ended the function with refreshments, a celebratory cake and music and dancing

(the expected way to celebrate in this setting). This function attracted a lot of attention online<sup>9</sup>, radio and in newspapers.

Some schools requested a summary of the results, for their file. A simplified summary of results was distributed to the participating schools. Another simplified format of the main study results is also available online<sup>10</sup>.

## Recommendations

1. Working closely with the school administration is vital to the success of the entire project. It is therefore paramount to invest in a good working relationship, based on respect and clear communication. Respect is for the individuals, the school schedule and culture (including dress code), as well as seeking and following advice from the administration with regards to how to approach the children and their parents. Stakeholder meetings with local education authorities and school administration help in establishing rapport.
2. Parents' meetings are a cost-effective way to achieve several goals including promptly reaching a wide audience with your message before you seek their participation, obtaining informed consent from a large number of participants, initiating data collection, and obtaining immediate feedback regarding their thoughts and ideas on a proposed project.
3. Allow for flexibility within your processes because working within the school schedule requires constant re-adjustments. This also requires taking time and effort to obtain enough information on schedules and mandatory curricula to avoid major conflicts with school activities. For instance, avoid recruiting from candidate classes which have prohibitively complex schedules.
4. Seek for support from the different stakeholders and in doing that be precise with the nature of support you

need, why it is needed and how this may benefit their own mission (if appropriate). At the end of the study, have a stakeholders' meeting and highlight how each one's contribution led to the success of the entire project, as well as share the results.

5. We did not resolve the challenge of obtaining consent from parents whose children were in the boarding section of the school. It was possible to contact most of these parents on phone, so future options might include obtaining informed consent digitally or electronically for the urban participants, as pioneered by some studies<sup>11</sup>.

## Conclusion

Conducting research in schools is feasible and may be a cost-effective way to make the most of limited resources to remedy the data deficiencies in sub-Saharan Africa with regards to research and SDG targets involving school-age children. It is imperative for researchers to conduct careful planning, understand the operational aspects of the schools and maintain a collaborative working relationship with the school administration and the parents, who have the trust of the children.

## Data availability

### Underlying data

No data associated with this article.

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