

INTRODUCTION

Disease surveillance in rural regions of many countries is poor, such that prolonged delays (months) may intervene between appearance of disease and its recognition by public health authorities. For infectious disorders, delayed recognition and intervention enables uncontrolled disease spread. We tested the feasibility in northern Uganda of developing real-time, village-based health surveillance of an epidemic of Nodding syndrome (NS, a childhood epileptic encephalopathy in East Africa) using software-programmed smartphones operated by minimally trained lay mHealth reporters.

SUMMARY

Eight young lay adults from remote rural regions of northern Uganda were trained to administer questions and transmit answers using pre-programmed mobile phones. Weekly, over a 3-month period, each lay reporter monitored an average of 40 children suffering from an epileptic disorder known as Nodding Syndrome (NS). For each child, episodes of head nodding, convulsions, injuries, deaths and availability of anti-seizure medication were reported weekly and the data instantaneously assembled by customized *Magpi*^R software (<https://home.magpi.com/>). Data submitted for analysis in USA and Uganda remotely pinpointed the household location and number of NS deaths, injuries, newly reported cases of head nodding (n=22), and the presence or absence of anti-seizure medication. A medical diagnostician physically examined a sample of households reporting existing and newly reported NS cases, the large majority of which had longstanding but unregistered NS.

TAKE-HOME MESSAGES

- Minimally trained lay mhealth reporters can reliably collect and transmit health data.
- Multiple electronic health data inputs are reliably integrated using *Magpi*^R software.
- Longitudinal real-time population health surveillance is challenging but feasible.
- Village-based mHealth surveillance detects unknown cases and new cases in real time.



CONCLUSIONS

mHealth-based surveillance not only provided a real-time map of the health status of children with established Nodding Syndrome but also revealed previously unknown children with head nodding. While logistical hurdles had to be overcome, the study demonstrates the feasibility of using lay reporters to build a current and continuously updatable medical geography of the rural populations in which they reside. Additionally, the lay mHealth reporters were incented to seek future local healthcare opportunities. Wide application of this type of real-time health surveillance could result in the early detection and control of disease in remote populations.

FIGURE LEGENDS

Figure 1: A, B, C. Geo-localized visualization of the surveillance area in northern Uganda. D. Close-up of a surveillance area section. E, F. Real-time electronic map of child health, injury and illness relating to NS in Paikat Akidi village (Angole parish, Awere sub-county, Pader district) and Bolo Lapeta village (Bolo parish, Awere sub-county, Pader district) at week 6 of data collection. Color coding: Red- Households with at least 1 child with NS; Green- Households with at least 1 child with NS who did not have medication (E1 and F1); was injured (E2 and F2); or died (E3 and F3) that week.

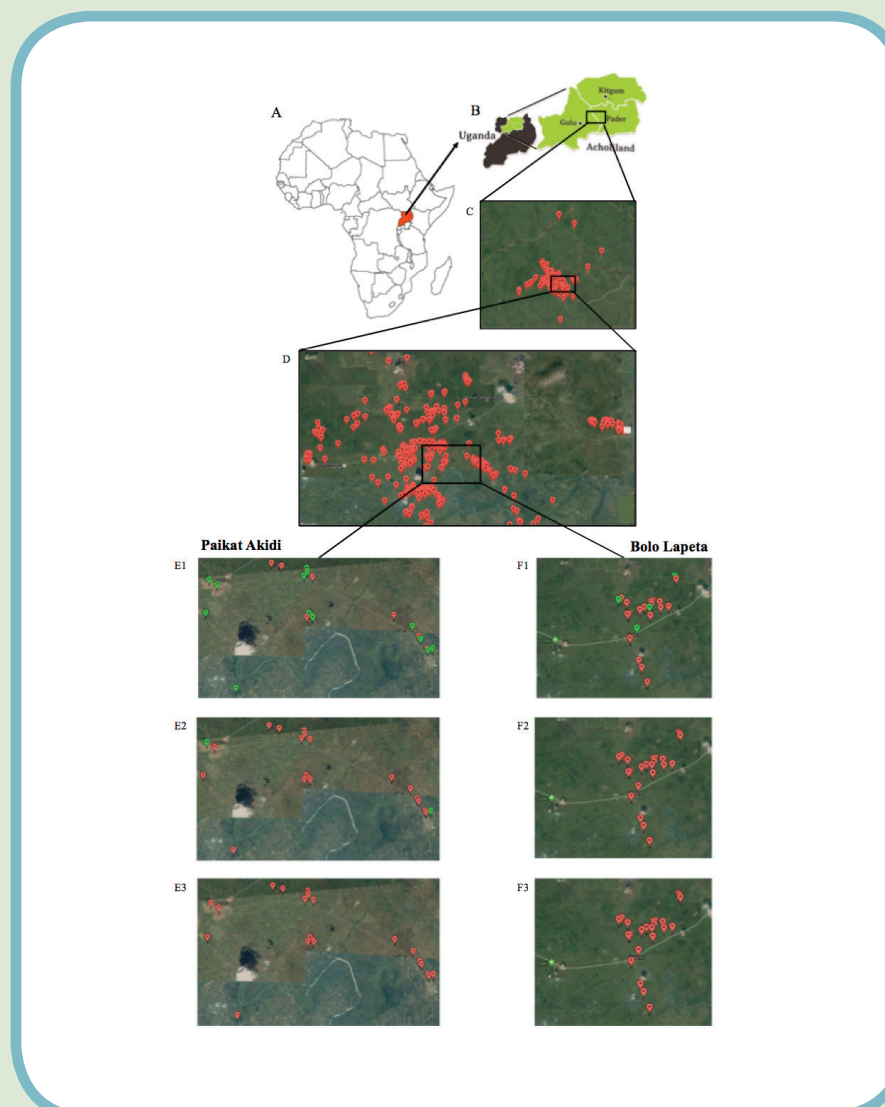


Fig. 1

Figure 3: Pie charts, one for each village of study, displaying different NS health-related data across the 12-week study period. Color coding: Red- Proportion of children with NS; Black- Proportion of children with nodding spells reported for the first time; Yellow- Proportion of children with NS who were injured; Green- Proportion of children with NS who died; Blue- Proportion of children with NS who did not have anti-seizure medication. For comparison purposes, the number of children with NS monitored per village was normalized to 100%. Percentages above 100% are indicative of repeated outcomes. The pie chart corresponding to Ludok and Olam villages (bottom right) should be taken only for reader orientation because values summarize data collected for only 4 weeks.

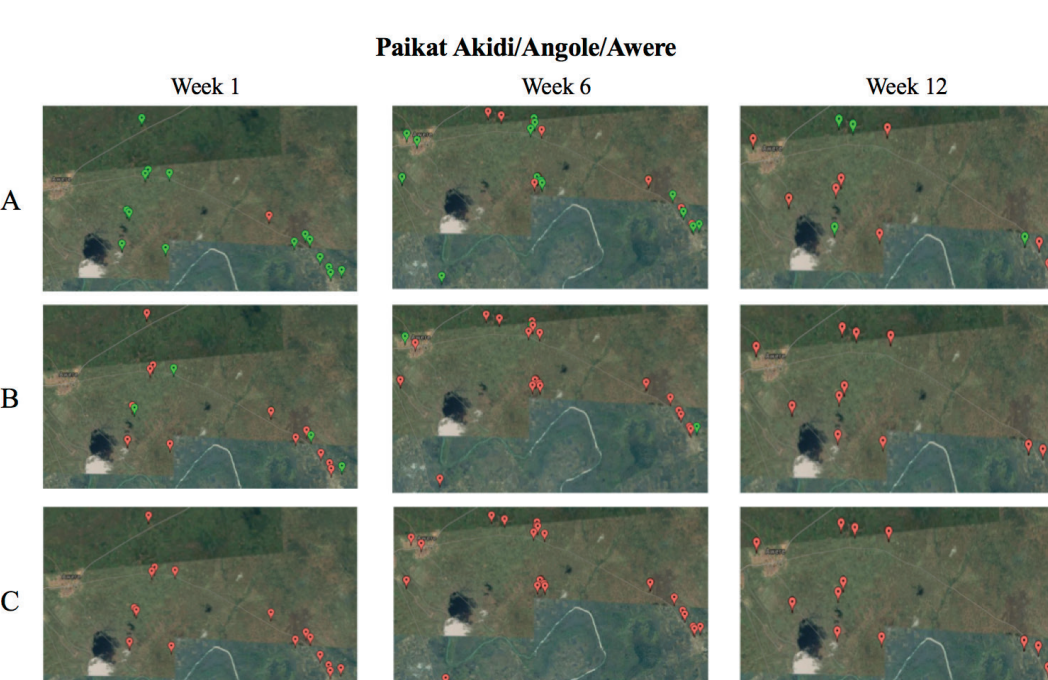


Fig. 2

Figure 2: Temporal monitoring of NS health data in Paikat Akidi village, Angole parish, Awere sub-county, pader District. A. Real-time electronic map for weeks 1, 6, and 12 of data collection. Color coding: Red- Households with at least 1 child with NS; Green- Households with at least 1 child with NS who did not have medication (A); was injured (B); or died (C) that particular week.

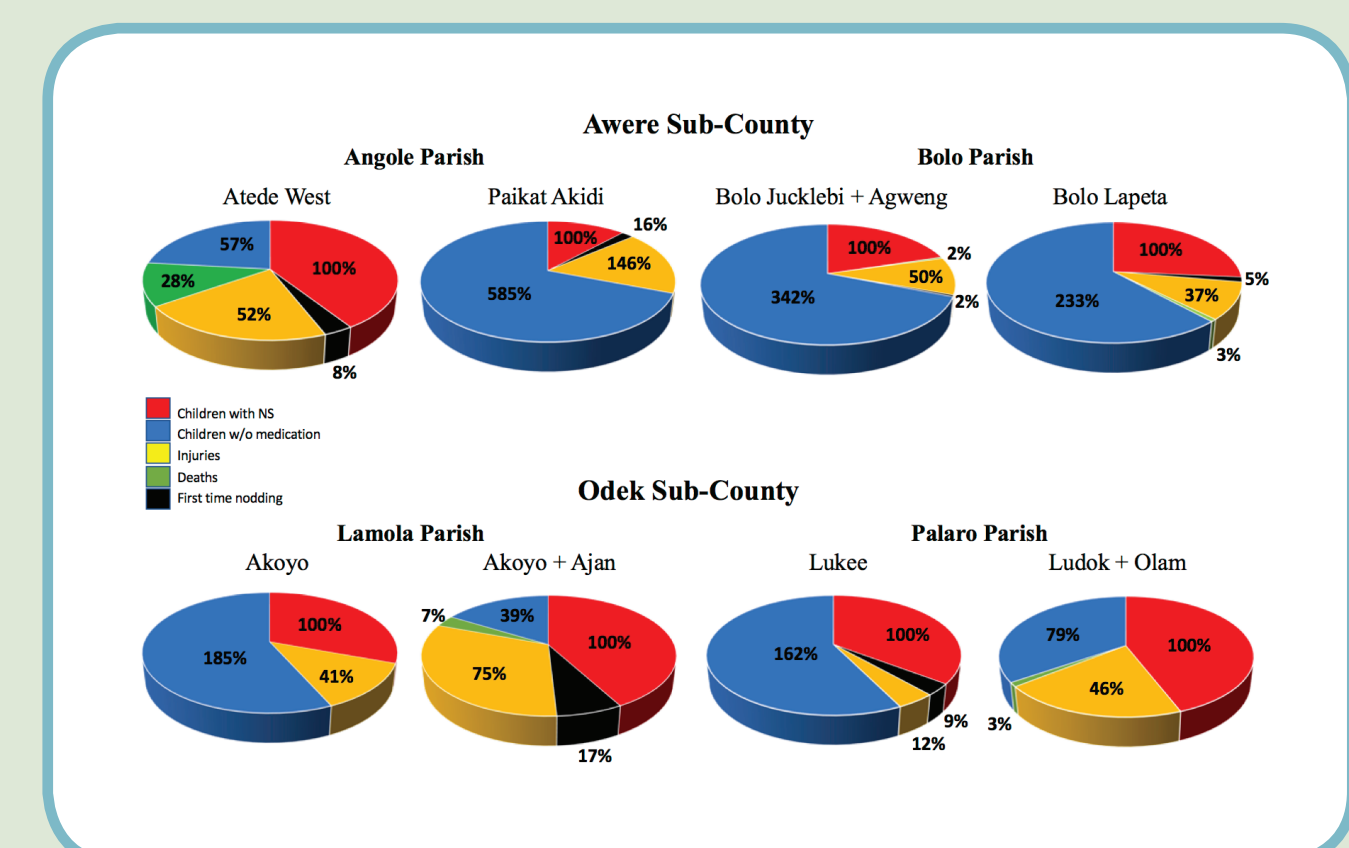


Fig. 3

FULL TITLE AND RESEARCH TEAM

Full Title: Village-based Lay mHealth Reporter Data Populate a Real-time Medical Cartography of Epidemic Disease (Nodding Syndrome)

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