Stakeholder Perceptions on Ethical Aspects of Mobile Phone Surveys to Monitor Noncommunicable Diseases

STUDY OBJECTIVE
To identify stakeholder views related to ethical dimensions of mobile phone survey use for noncommunicable disease surveillance in low- and middle-income countries

BACKGROUND
The use of MPS to capture population data on NCD risk factors, such as tobacco use and harmful use of alcohol, can raise unique ethical and regulatory challenges. Global opinions regarding such challenges have been poorly documented.

METHODS
• A 47 item, English language, online survey (Qualtrics) was developed and pretested.
• The survey was distributed to individuals and groups with experience in mHealth, ethics, surveillance, MPS technology, and regulatory/policy oversight.
• Responses were collected from March–April 2017 and were organized into five domains: general attitudes and beliefs, nature of the activity, potential harms, potential benefits, and community engagement and sustainability.
KEY MESSAGES

• Survey respondents indicated strong support for MPS.
• Concise consent processes need to be developed to facilitate voluntary informed participation in MPS.
• Some groups may be systematically underrepresented in MPS due to inequalities in mobile phone access or use.
• Comprehensive ethics guidance for mobile phone-based public health surveillance is needed.

ATTITUDES TOWARD MOBILE PHONE SURVEYS

95% of participants agreed that MPS are likely help to improve public health.

58% believed that privacy-related risks are lower for MPS compared to face-to-face surveys.

76% agreed that data should be restricted only to uses that support public health.

Nearly three quarters thought that ethics and regulatory requirements for MPS were unclear or inadequate.

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ABOUT DATA FOR HEALTH

The Data for Health Initiative (D4HI) is a Bloomberg Philanthropies-funded project that seeks to improve vital registration systems, expand current NCD surveillance efforts, and provide data analysis training to governments in LMICs.