Policy guidelines to ensure equitable use of Information and Communication Technologies for health surveys focussing on urban poor populations, Peru

Authors. This document was written prepared by all members of the Innovation for Health and Development group (www.IFHAD.org).

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Conflict of interest. All of the authors declare that they have no conflict of interest.

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Funding is gratefully acknowledged from:

- This research was principally co-financed by CONCYTEC, Peru, through its executing unit: FONDECYT (award code E067-2020-02-01 agreement number 083-2020);
- the United Kingdom (UK) Research and Innovation Quality-Related Strategic Priorities Fund grant to Imperial College London;
- the charity IFHAD: Innovation For Health And Development research and fellowship funding;
- the UK Research and Innovation Medical Research Council Skills Development Fellowship (award MR/T040165/1)
- The Wellcome Trust Institutional Strategic Support Fund to Imperial College London (award 204834/Z/16/Z);
- The Wellcome Trust Clinical Research Training Fellowship (award 105788/Z/14/Z);
- the Joint Global Health Trials Scheme funding from the Wellcome Trust, UK Foreign, Commonwealth and Development Office, the UK Medical Research Council, and the UK Department of Health and Social Care through the National Institute of Health Research (award MR/K007467/1=WT099951).

The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

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EXECUTIVE SUMMARY

Data collection for research, monitoring and advocacy is now an integral part of our society. Collecting and analysing data have become easier as access to Information and Communications Technologies (ICT) have increased, including internet, mobile telephones, and digital platforms. ICT has also become a useful tool in healthcare such as telemedicine. During the COVID-19 pandemic, ICT were fundamental in healthcare and research globally, including many telesurveys, internet surveys and data collecting applications.

Peru has also undergone a digital revolution, especially in its urban population. The Peruvian national statistical and information institute (Instituto Nacional de Estadistica e Informatica, INEI) report in 2021 stated that 95% of the Peruvian population had access to at least one ICT.

The current document provides a:

- comparison of the current available data collection tools for community research;
- summary of the international and national guidelines available for the adoption of ICT in healthcare versus health research;
- review of the national Peruvian INEI data regarding ICT access;
- and presents study findings comparing ICT access pre- versus during the COVID-19 pandemic and explores ICT logistical barriers against equitable data collection.

This evidence synthesis supports the following recommendations:

- 1. We recommend that health research groups undergo a gradual digital transition in their data collection system in which they reduce face-to-face contact to instead offer both face-to-face and also ICT-based interviews. The sole use of ICT and especially telesurveys is not recommended for data collection in the Peruvian context, as this may worsen inequality by neglecting the data and needs of marginalized households
- The INEI and other data collecting bodies should not only focus on access to a functioning mobile device as a marker of community development. We recommend that data also be collected on the long-term connectivity of households as a marker of development and focus for community need.
- 3. We recommend incentives, social programmes and laws that promote and ensure adequate permanent communication and connectivity to households, facilitating ongoing contact with them over time.
- 4. We recommend increased awareness of data protection laws and guidelines to ensure the privacy of contact details in order to improve confidence that contact details are not being shared inappropriately.
- 5. We recommend that there are guidelines and more support from research bodies and funders supporting long-term access to and training to use recommended digital platforms for secure data collection.

i. BACKGROUND

The use of Information and Communication Technologies (ICT) has become increasingly important globally and its role of connecting people has been emphasized during the COVID-19 pandemic. Organizations have had to adapt to changes caused by the COVID-19 pandemic, with the health sector being one of the most prominently affected including widespread ICT use, especially in primary care. This involved the promotion of digital platforms such as teleconsultations for patients, identification of risk factors and continuity of essential services for chronic conditions (1).

During the COVID-19 pandemic, research had a key role in the search for evidence to prevent, diagnose, treat and cure COVID-19 (2). These investigations provided a scientific foundation for evidence-based public policies (3). Pandemic-related infection prevention challenges caused research data collection to transition from face-to-face interviews towards digital or telephone interviews. Digital and telephone surveys are important tools especially during the COVID-19 pandemic because they reduce the time and frequency of contact between interviewer and patient, potentially reducing COVID-19 contagion (4). The increasing availability of digital platforms to collect data including telephone calls, text messages and emails have facilitated surveys and follow-up to be carried out remotely (5). **Table 1** compares some widely used digital platforms for research data collection, in which researchers may digitise information during face-to-face or telephone, or research participants may themselves enter their research data e.g. using WhatsApp or short-message-service (SMS) systems.

Participant enrolment and follow-up rates for community-based research have been reported to increase with the use of mobile technologies. (6,7) Potential reasons include the use of ICT facilitating flexible contact with participants that may improve contact with marginalised groups (6,7). Additionally, the use of ICT may involve a lower investment in time, mobility and personnel, potentially improving research cost-effectiveness (8).

Table 1. Comparison of current data collection platforms used for community research.

| | Free | Operating | Open | Data security | Maximum | Participant self | Offline entry | Geo |
|---------------|--------------------|---------------|--------|----------------------------|-----------------|------------------|---------------|----------|
| | | system | source | | capacity | fill | | location |
| CommCare | Free/ professional | Web/ Android | Yes | SOC 2 / HIPAA / GDPR | Unlimited | SMS, Platform | Yes | Yes |
| | | | | | | CommCare | | |
| Google suites | Free/ professional | Web/ Android/ | Yes | ISO/ IEC 27001 | Unlimited | WhatsApp Link | No | Yes |
| | | iOS | | | | | | |
| Jotforms | Basic free/ | Web/ Android/ | No | 256 Bit SSL / HIPAA / CCPA | 1 Terabyte (TB) | Voice, Web, | Yes | Yes |
| | professional | iOS | | / GDPR / CPI | | Platform | | |
| Kobo toolbox | Yes | Web/ Android | Yes | HIPAA/ AWS | Unlimited | Platform Kobo | Yes | Yes |
| | | | | | | Web App | | |
| Magpie | Basic free/ | Android/ Ios | Yes | HIPAA / SSL /AES-256 bit | Unlimited | SMS, Voice, | Yes | Yes |
| | professional | | | | | Platform | | |
| Microsoft | Free/ professional | Web/ Android/ | Yes | HIPAA, GDPR, FedRAMP, | 1TB-6TB | Platform, Link | Yes | Yes |
| teams | | iOS | | SOC, FERPA | | | | |
| Open data kit | Yes | Android | Yes | AES Cipher Feedback (CFB) | 100 Gigabytes | Platform Open | Yes | Yes |
| | | | | de 256 bits | | Data App | | |
| RedCap | Yes to NGO | Web/ Android/ | No | 21 CFR parte 11/FISMA / | Unlimited | Platform RedCap | Yes | Yes |
| | | iOS | | HIPAA / GDPR | | | | |
| Survey CTO | Trial free/ | Web/ Android | Yes | GDRP / SAFE PEOPLE + | Unlimited | SMS, Call, Web | Yes | Yes |
| | professional | | | DATA | | | | |
| Survey | Yes | Web/ Android/ | Yes | HIPAA/ AWS | Unlimited | WhatsApp Link, | Yes | Yes |
| monkey | | iOS | | | | Web | | |
| Teamscope | Trial free/ | Web/ Android/ | Yes | GDPR, HIPAA and 21 CFR | Unlimited | Multiplatform | Yes | No |
| | professional | iOS | | Part 11 | | | | |

Footnote. NGO=non-governmental organization, OS=operating system, SMS=short message system, HIPAA= Health Insurance Portability and Accountability Act, ISO=International Organization for Standardization, and GDPR=General Data Protection Regulation

ii. CURRENT POLICIES FOR ICT USE IN HEALTHCARE VERSUS HEALTH RESEARCH

Since 2005, Peru has had an evolving Telehealth Plan focused on the role of telemedicine including teleconsultation, teleorientation, telemonitoring and interoperability for health care. Due to the COVID-19 health emergency, the Peruvian Ministry of Health have implemented a resolution (resolucion ministerial 146-2020-MINSA) that approves the widespread development and implementation of teleorientation and telemonitoring services. This document defines teleorientation as the "set of actions carried out by a health professional through the use of ICT, to provide the healthcare user with counselling and advice for the purposes of health promotion, prevention, recovery or rehabilitation from diseases (9)."

Internationally, there are few guidelines and policies to inform data collection using ICT for community health research. Similarly in Peru, except for general data protection laws there is little guidance for researchers regarding appropriate data collection platforms and methods using ICT (10). The development of scientific research in the country is regulated by law number 30309, which promotes scientific research, technological development and technological innovation, SUPREME DECREE No. 188-2015-EF and law number 30948, which promotes, guides and regulates research (11,12). Most research studies are regulated by ethics committees, which must be multidisciplinary and independent. These committees are composed of professionals from different areas whose function is to preserve the physical and/or emotional integrity of research participants through supervision and to comply with the ethical principles of research studies. Since 2002, these committees are overseen by international standards according to the guidelines of the World Health Organization (WHO) and the Council for International Organizations of Medical Sciences (CIOMS) (13). Peru is also governed by these international standards. Since 2003, the United States of America (USA) National Institutes of Health (NIH) has determined that clinical trials must be registered with a research ethics committee registered with the USA Office for Human Research Protection (OHRP)(12).

iii. HOUSEHOLD ACCESS TO ICT: NATIONAL INEI FINDINGS FOR PERU

In Peru, data published by the INEI in its report from July to September 2021 report that 96% of households that have at least one of the ICT. This percentage decreased from the last year 2020 in 2% (See Table 2). (13).

Considering and analysing the population that have access to a mobile phone during July to September 2021 were 95%. This percentage is 1% less than the previous year 2020. Otherwise, during 2021, the access to mobiles phone was increasing quietly over the months (See Table 2).(13)

Table 2. Proportion of households in Peru that had access to at least one ICT and proportion of households in Peru that had access to at least one mobile phone. INEI data.

| | Jan- Mar | | April - June | | Jul-Sep | | Oct-Dec | |
|--------------|----------|--------------|--------------|--------------|---------|--------------|---------|-----------------|
| | Any ICT | Mobile phone | Any ICT | Mobile phone | Any ICT | Mobile phone | Any ICT | Mobile phone |
| Year 2020 | 95% | 93% | 98% | 97% | 98% | 97% | 94% | 96% |
| Year 2021 | 95% | 94% | 95.40% | 95% | 96% | 95% | * | * |

^{*}Pending report from INEI

iv. HOUSEHOLD ACCESS TO ICT: LOCAL FINDINGS FOR URBAN POOR IN CALLAO, PERU

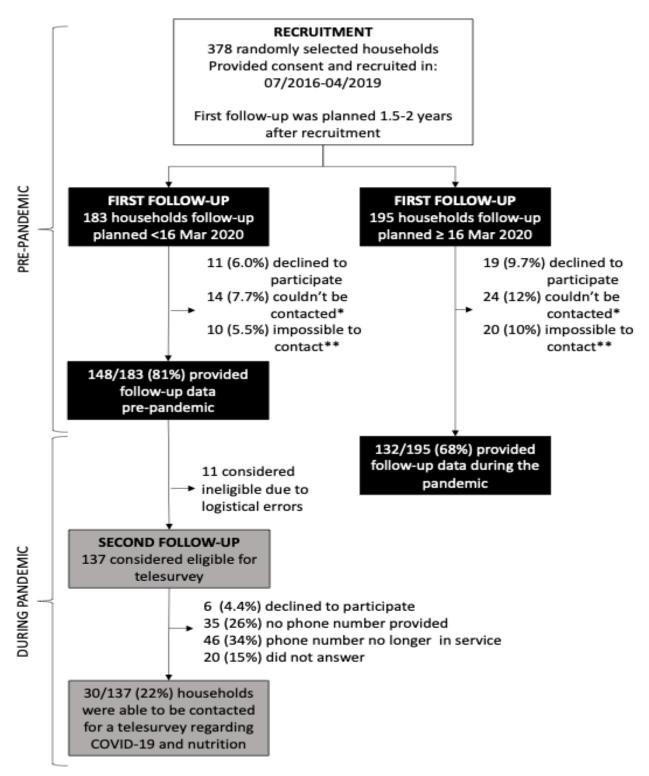
Study setting. This cohort study was carried out in the Province of Callao, Peru. Our research group has worked with 32 of 45 of the communities for over 6 years in community-based research regarding tuberculosis (TB) prevention and cure. These communities were selected for their high levels of poverty, population density and tuberculosis case notification rates.

Ethics. Data was collected as part of a larger ongoing cohort study and ethics approval was given by the following committees: the Peruvian Ministry of Health DIRESA Callao, Peru; Asociación Benéfica Prisma, Peru; and Imperial College London, UK.

Household selection method. Between 07/2016 and 04/2019, community control households were randomly selected and recruited as a comparison for other research (14). The random selection process used detailed maps of each community, in which residential "blocks" were allocated numbers; then with random number tables "blocks" were selected and then located; using another random number table a residential property within the block was selected. If the selected "block" did not have a cardinal numbering system of properties, then the North-West corner of the selected "block" was located and from there residential properties were counted in a clockwise direction, and the corresponding household approached. If no adults (defined as a person ≥18 years old) were available to provide informed written consent, then another randomly selected household in the selected block was visited.

We aimed to do face-to-face follow-up interviews with the members of each recruited household in order to evaluate any changes since the baseline data was collected. Recruited households were intended to be revisited 18-24 months after the time of the recruitment interview, and this occurred for 137 of the 378 households from September 2019 until mid-March 2020. Due to the COVID-19 pandemic restrictions that started in Peru 16th March 2020, the later-recruited households that had not had their follow-up by 16th March 2020 (see Figure 1) had follow-up delayed until the pandemic restrictions were eased in 2021.

Figure 1. Flow chart demonstrating the number of households that participated in each survey.



Footnote. *= "couldn't be contacted" indicated that there was no answer when the household was visited at least 3 times and their phone number(s) was(were) called at least 3 times. **= "impossible to contact" indicated that we determined that follow-up was impossible because the household had all died or moved outside the region without leaving contact details with their neighbours and without maintaining their previous phone number

Recruitment versus first follow-up survey results. As shown in Table 3, at recruitment 92%, 95% confidence interval (CI)=88-94% of households reported access to at least one functioning mobile phone. The proportion of households that had access to a mobile phone was similar during follow-up regardless of whether follow-up was pre-pandemic or during the pandemic.

In contrast to mobile phone access, at recruitment households were less likely to have access to a functioning landline (38%, 95% CI=34-44%). In paired analysis, households followed-up during the pandemic were 28% less likely (relative risk=0.78, 95%CI=0.62-0.99 times, p=0.04) to report having access to a fixed landlines at the follow-up interview, so that only 27% of households (95%CI=20%, 35%) had access to a fixed landline during the pandemic.

Despite almost all households reporting access to a functioning telephone (mobile or landline), at recruitment only 74% (95%CI=69-78%) were willing to provide a phone number to research staff (Table 3).

Table 3. Comparison of household ICT access at recruitment pre-pandemic versus first follow-up pre-pandemic versus first follow-up during the pandemic. Bold values indicate a statistically significant difference (p<0.05) between those who were followed-up pre-pandemic versus during the pandemic. Within the rounded parenthesis are 95% confidence intervals for percentages. Within the square brackets are interquartile ranges for median values. Note: "NA" indicates not applicable.

| | Recruitment | Follow-up pre-pandemic | Follow-up during pandemic | |
|----------------------|--------------|---------------------------|------------------------------|--|
| | N=378 | N=148 | N=132 | |
| Mobile phone access | 92% (88-94%) | 95% (92-99%) | 91% (86-96%) | |
| landline access | 38% (34-44%) | 41% (33-49%) | 27% (20-35%) | |
| Telephone access | 93% (90-96%) | 95% (92-99%) | 92% (87-96%) | |
| (mobile or landline) | | | | |
| Provided research | 74% (69-78%) | NA | NA | |
| staff a phone number | | | | |
| Median hours/week | 1 [0, 1] | 1 [0, 1] | 1 [0, 1] | |
| with internet access | | | | |

Household participation in second follow-up: 2021 telesurvey. As shown in Figure 1, households that had participated in the recruitment and first follow-up surveys pre-pandemic were invited to participate in a second follow-up interview by telephone survey (telesurvey) in December 2021. This second follow-up included a survey of baseline risk factors of COVID-19 and nutritional impacts of the COVID-19 pandemic restrictions (15).

Out of 137 households that were eligible for this telephone survey, only 22% (30/137) of households were contactable via telephone to be interviewed. The reason that 78% (107/137) households were uncontactable via telephone were because: 26% (35/137) had no telephone number recorded (3 of them because they had no access to a landline or mobile telephone);

34% (46/137 provided numbers that were no longer in service; and 15% (20/137) did not answer the phone during any of the five times that we tried to contact them.

Figure 2 demonstrates that compared to the recruited population and those who went on to have first follow-up pre-pandemic, the subset of 30 households that had a successful second follow-up telephone survey had more educated heads of household (p=0.006 for male head of households telesurvey households versus the recruited population), which is a surrogate marker indicating less chronic poverty.

Household income was asked for all households during the first follow-up and the median monthly income was 1450 Peruvian Soles (interquartile range(IQR)=930, 2000). At that first follow-up interview, the subset of 30 households that later had a successful telesurvey reported a higher monthly income (median 1860 soles, IQR=1200, 2400 Peruvian Soles, p=0.05, Figure 2).

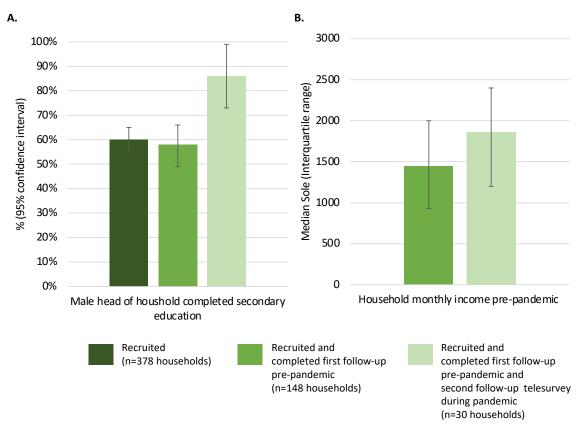


Figure 2. Comparison of (A.) educational attainment of the male head of the household and (B.) monthly household income of the 378 household that were randomly selected from the communities and recruited into the cohort (darkest green bar) versus the subset of 148 households that went on the participate in the face-to-face follow-up survey pre-pandemic (green bar) versus the subset of 30 households that participated in telesurvey (bar green bar).

v. RESEARCH SUMMARY

• In keeping with the INEI data, the great majority of households have access to a functioning mobile phone. However, it was very common in these urban poor populations for people

- and/or families to change their "pay-as-you-go" mobile phone number frequently, which made it difficult to contact them during subsequent years of follow-up.
- A fixed landline connection, which would facilitate contacting households using a more permanent number, was uncommon in this urban poor population. This is most likely due to landlines requiring documentation, regular payment and a fixed contract which many may not want to do, or be able to afford to do, or have the necessary documentation to allow. During the pandemic maintaining a fixed landline number significantly less common. A reason for this has been demonstrated in our other research that showed the majority of households in this population had to sell their household assets and defaulted on bills due to the economic strain of the pandemic.
- Many households did not wish to share their telephone contact details with research nurses.
- The use of telephone surveys led to a selection bias towards less poor households, thus data did not represent the most vulnerable households. We did not study other potential poverty markers such as a score of assets or a score of household services. However, our 20 years experience of socioeconomic research in these communities indicated *a priori* that schooling completion of the head of the household and household monthly income were the most meaningful poverty markers in this setting. (16,17).

vi. **POLICY MESSAGES**

- 1. We recommend that health research groups do not attempt an immediate change from face-to-face to ICT-based data collection. Instead, we recommend a gradual digital transition in their data collection system in which they reduce face-to-face contact to use more mixed interviews (home visits with telephone calls). Although ICT can be used to reduce social and health inequalities, when conducting community-based health surveys, there is a risk that only using telephone or other ICT to contact or interview households will underrepresent poorer households in the data generated. Thus, sole use of ICT and especially telesurveys is not recommended for data collection in the Peruvian context, as could lead to widening inequality by neglecting the data and needs of marginalized households
- 2. The INEI and other data collecting bodies should not only focus on determining whether households have a functioning mobile device as a marker of community development. Previous data from this study setting showed that having a functioning mobile phone was less likely in poorer and more vulnerable households (18). However socioeconomic development in this setting and the simultaneous digital revolution means that markers for adequate ICT access also need to transition to reflect the barriers faced by poorer households, especially as health care and health research embrace ICT into their routine systems. In urban poor population where the majority of household income is from the informal economy, it is very uncommon that contracts for more permanent or fixed communication lines will be provided or wanted. We recommend data also be collected on the permanent and long-term connectivity of households as a marker of development and focus for community need.

- 3. We recommend incentives, social programmes and laws that promote fair and competitive pricing for fixed contracts, auditing of communication company practice, ensuring that continuity of the same phone number is available and perhaps even the default when telephone contracts change, and availability of support if payments are defaulted for the short-term. This will facilitate adequate permanent communication and connectivity to these households, including ongoing contact with households over time.
- 4. We recommend that increased awareness of data protection laws and development of guidelines to ensure the privacy of contact details are maintained by all stakeholders that have access to individuals' phone number. This will improve the confidence of this population to provide their contact details to health care providers and researchers without fear of it being shared inappropriately.
- 5. We recommend that there are guidelines and more support from research bodies and funders supporting long-term access to and training to use recommended digital platforms for secure data collection.

vii. CONCLUSION

The use of ICT is generally increasing and technology has become a ubiquitous part of society despite the COVID-19 pandemic. Consequently, strategies must be sought to take advantage of these resources and optimally integrate them with healthcare and health research. However, this transition must be gradual to ensure equity in data collection, with safeguards in place to ensure that the most vulnerable households are fully represented in health research.

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