Electronic Data Collection in Health Research: Shared Experiences from the Field, South Africa

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Citation: Singh Y, Jackson D, Gevers A, Mahlangu P, Shamu S, et al. (2021) Electronic Data Collection in Health Research: Shared Experiences from the Field, South Africa. J Community Med Public Health 5: 204. DOI: 10.29011/2577-2228.100204

Received Date: January 20, 2021; Accepted Date: February 15, 2021; Published Date: February 19, 2021

Abstract

Background: mHealth and electronic data collection (EDC) systems have rapidly expanded in developing countries. A synthesis of the experiences of the researchers in resource limited African settings who have used electronic (mobile) systems to facilitate data collection in large-scale research was conducted.

Methods: We synthesise the experiences of researchers and users engaged in studies using electronic data collection conducted by the South African Medical Research Council (SAMRC): (1) A cross sectional national survey of 9679 mother-infant pairs measuring the effectiveness of Prevention of Mother to Child Transmission (PMTCT) programme using low cost Nokia mobile phones; (2) A school-based randomised control trial to prevent gender based violence with teenagers (N=3755) using iPod Touch; (3) A longitudinal community-based study on International Alcohol Control using LA V A tablets on 2000 adults and 1000 adolescents; (4) A retrospective descriptive survey on injury mortality using entry-level Nokia phones to interview 22,733 participants using questionnaires.

Results: Electronic Data Collection (EDC) necessitates systematic set-up and testing of the system, training and daily support of data collectors with appropriate matching between data collector age, ability, the tools complexity and size. Some of the risks noted in four research studies conducted in resource-limited settings were delayed uploading of data due to no or limited network coverage, loss of devices (e.g., cell phone or iPod touch), increased training time for older aged users, typing errors, and challenge of keeping batteries charged while conducting fieldwork. The benefits noted included the use of automated skip patterns and mandatory fields which reduced errors and early detection of potential errors, user-friendly interfaces, access to real time data for monitoring of field work enabling simultaneous feedback to staff and management, negated the need for data capturers, reduced printing and storage costs and reduction in time from completion of data collection to the generation of a cleaned final data set for analysis.

Conclusion: The benefits of using electronic (mobile) systems for data collection appear to outweigh the risks in resource limited settings. Given the continuously changing information and technology age, electronic mobile technologies are becoming a popular data collection tool. Like any other technological tool, electronic systems can be improved to overcome some of the risks highlighted in this paper.
Background

The use of Electronic Data Collection (EDC) methods in health research has grown rapidly in recent years. Whilst conventional methods of data collection are printed forms, there is a body of literature on the use of various types of electronic data collection systems used in the field of health care. The major advantages of EDC include the ability to enter, review and monitor data collection, evaluate study status and analyse data in real-time. There are a variety of suitable devices for electronic data collection, the most popular being mobile phones, Personal Digital Assistants (PDAs), iPod Touch, and tablets. In the past 20 years, electronic methods of data collection have been developed on handheld devices such as PDAs and more recently on mobile phones [1]. A study evaluating PDA and paper-based data collection reported that sixty-two percent of the participants perceived that the PDA-based questionnaire took less time to complete and participants preferred using PDA instead of paper for data collection [2]. Literature findings further suggest that smartphones may be more suitable than low-end mobile phones for data collection, as smartphones have larger screens and can more easily accommodate complex functions (such as wireless uploading and downloading, screen touch typing, and photo or video capturing) [1]. In a health behaviour assessment study, participants were asked to provide feedback on their experiences using iPod Touch. Ninety-nine percent of the participants reported an overall positive experience and majority of the patients did not believe the iPod Touch negatively affected their interactions with their doctor [3]. They further stated that iPod Touch was a promising device to assist behaviour change in a diverse population of varying age groups, genders, ethnicities and health status. Whilst literature findings indicate a positive approach towards electronic data collection systems, there is limited literature on the shared experiences, benefits, risk and challenges from researchers and users of electronic methods for data collection.

This paper aims to synthesise the experiences of researchers at the South African Medical Research Council who have used mobile/electronic systems to facilitate data collection in studies of varying designs, conducted in resource limited settings, in an attempt to provide contextual guidance for future users of mobile technology for data collection.

Methods

Project PI/Project managers (n=10) were invited to a discussion forum on electronic data collection users. Attendees were requested to share their experiences (benefits, risks, challenges) with mHealth in their respective research projects. These included four large scale studies using electronic data collection conducted by the South African Medical Research Council (SAMRC): (1) A cross sectional national survey of 9679 mother-infant pairs measuring the effectiveness of Prevention of Mother to Child Transmission (PMTCT) programme using low cost Nokia mobile phones; (2) A school-based randomised control trial to prevent gender based violence with teenagers (N=3780), parents (N=1000) and educators (N=800) using iPod Touch; (3) A longitudinal community-based study on International Alcohol Control using LA V A tablets on 2000 adults and 1000 adolescents; (4) A retrospective descriptive survey on injury mortality using entry-level Nokia phones to interview 22,733 participants using questionnaires.

Results

The results are presented by research project. Table 1 summarises the key elements of the systems presented in this report.
Project I: South African Prevention of Mother-to-Child Transmission of HIV Programme Evaluation

The SAMRC Health Systems Research Unit conducted large-scale Prevention of Mother To Child Transmission (PMTCT) national surveys. The aim of the survey was to assess the impact of a programme to prevent Mother To Child Transmission of HIV (MTCT), measured at 4-8 weeks of age, in three sequential, annual, nationally representative surveys in all nine South African provinces (2010, 2011-12 and 2012-13) [4]. In partnership with a South African company that specializes in designing and implementing mobile technologies for different mobile data collection systems (http://www.mobenzi.com/researcher/home), platforms were developed for the data collection and management of these surveys, conducted between (2010-2013) and one national prospective observational cohort study (2012-14) derived from the third survey. The mobile data collection system managed data collection from over 10,000 mother-infant pairs in each of the three-national facility-based surveys. Mobenzi developed two platforms to support the (2012-2013) survey with the added longitudinal cohort. Mobenzi Researcher supported the data collection component of the study and Mobenzi Outreach supported the operational workflow of the project.

The system was designed with internal quality control checks and restrictions e.g. limits were placed on certain fields to avoid ‘out of range’ values, compulsory questions could not automatically be skipped, extremely important information was double entered, and the system recognised discrepancies immediately, prompting for re-entry. Electronic skip patterns or loops were set in place based on maternal responses. The system was used by mainly retired nurses (employed as data collectors) who received one day of training on how to use the technology, and 5 days additional training on other aspects of the study protocol. Real-time telephonic support was needed to manage field-based crises and to ensure appropriate functioning of the technology. Many of the challenges arose when data collectors removed the mobile phone sim card or did not check for daily updates. To manage contingencies, data collectors carried a limited number of hard copy questionnaires. These were used if the cell phone malfunctioned in the field i.e. software application errors, inability to retrieve survey questionnaire, survey questionnaire freezing while data collection is in progress and completed surveys partially uploading onto the web base console [5]. The web-based interface created a platform for trained data collectors to undertake real time data entry during the interview. Additionally, real-time review of submitted data enabled supervisors to monitor field work progress, to track the quality of data collected and to perform manage the data collectors. Raw data reports were also readily available for feedback to stakeholders’ and program managers. Table 1 presents more detail about this use, lessons learnt, benefits and risks of using electronic (mobile) technology for data collection in large national surveys.

Project II: Randomised Controlled Trial on Teen Violence Prevention

The SAMRC Gender and Health Research Unit conducted a randomised controlled trial in (2014-2015) with teenagers in Grade 8, to develop and test a multi-faceted school-based intervention to prevent Intimate Partner Violence (IPV) among teenagers [6,7].

A standard self-complete questionnaire was loaded on to an iPod Touch. The iPod Touch allowed for confidentiality as data were entered anonymously and findings were reported with anonymity. They allowed a person completing a questionnaire to go back one screen but once a questionnaire was completed it could not be viewed again on the device. Thus, it was impossible for someone who viewed the iPod Touch to determine the information stored in its files even if multiple interviews were done on one day on the same device. Data were uploaded via a wireless network from the iPod Touch and sent to a web-based, password-protected system. The study team were able to easily attract their target group. Teenagers were fascinated by the use of mobile technology and were keen to participate in the study. The study team could reach many participants and administer the questionnaires in groups with only a few data collectors responsible for guiding and monitoring the process. Table 1 provides more details including lessons learnt, benefits and risks. The use of iPod Touch was also attractive to parents who were acquainted with use of mobile technology using smart phones, but a challenge to those who were not familiar with such devices and it took the latter group more time to complete the survey.

Project III: International Alcohol Control Household Survey

The Alcohol Tobacco and Other Drug Research Unit used LAVA tablets in a community-based survey aimed at (i) measuring alcohol consumption among populations in Tshwane, South Africa; (ii) documenting alcohol policy relevant behaviours, including place and time of purchase, prices paid, and exposure to and salience of alcohol marketing; and (iii) determining the impact of restrictions in alcohol marketing on alcohol consumption and policy-related mediating variables [8].

LAVA tablets were used to collect household survey data from two samples; adolescents (aged 16 and 17 yrs.) and adults (aged 18-65 yrs.). The use of tablets was prompted by the fact that the questionnaire was extremely complex consisting mostly of ‘loops within loops’. Participants had 17 different options regarding alcohol consumption locations (including ‘other’) and researchers asked them to report on 13 different types of alcohol consumed at these 17 different locations. This resulted in a vast number of variables due to the complexity of the questionnaire and therefore a pen and paper survey was not considered feasible.

Development of the software was an expensive exercise and it was extremely difficult to find a software developer due to
the complexity of the questionnaire. This resulted in challenges such as delays in the development of the software and delays in the commencement of the actual fieldwork. Problems that were experienced in the field with data collection using the tablet included broken or lost tablets, system failures at data collection points and the challenge of keeping tablet batteries charged in the field. However, despite these challenges, the use of tablets during data collection was advantageous. In addition to confidentiality and anonymity, the use of tablets prevented loss of data since data was uploaded in real time and sent to a central server immediately where it was stored within a protected database. The data collectors were trained in the use of the tablet as well as data collection processes and reported that the use of tablets was less cumbersome than traditional approaches. Benefits cited included that they were not required to carry papers and stationery around and electronic use of questionnaires eased concerns of not being able to account for all questionnaires. While concerns in respect of fieldworker safety were taken into consideration at study conception, the data collectors reported that they did not feel threatened in the field while carrying the tablets. Table 1 summarises the lessons learnt, benefits and risks whilst using mobile-based systems as a data collection tool.

**Project IV: Injury Mortality Survey**

The SAMRC Burden of Disease Research Unit conducted an Injury Mortality survey aimed to establish the cause-specific incidence of fatal injury for the year 2009. The specific objectives were: (i) to describe the incidence of fatal injury rates in South Africa for 2009 by age, sex and cause (ii) to describe the metro and non-metro profiles of fatal injuries (iii) to compare the provincial profiles of fatal injuries [9]. The study was designed as a retrospective descriptive study, utilising routine data collected through the post-mortem reports, and ancillary documentation including police reports and hospital records that appear in case folders. All folders and registers for patients who died an unnatural death during 2009 were reviewed across South Africa. Mobile phones were used to collect data via a web-based service provider Mobenzi. The Mobenzi team converted the questionnaire into a mobile phone application incorporating the screening logic, skips and control flow capabilities offered by Mobenzi Researcher for entry-level handsets. The unit conducted a survey of more than 22000 non-natural deaths that presented to mortuaries. The mobile phone-based questionnaire was used to collect demographic information from post-mortem reports, including age, sex and race of the deceased. The primary source of the data was entered on site via the custom-designed software for mobile telephones and submitted to a central web-based data platform, which enabled ongoing monitoring of data collection activities, quality control and data cleaning by the national coordinator and project manager. Mobenzi provided airtime monitoring and recharge services, which included both scheduled recharges as well as ad hoc recharge requests. Table 1 summarises the lessons learnt, benefits and risks whilst using this mode of EDC system.

**Discussion**

The use of EDC systems in research affords researchers new opportunities to enhance survey and questionnaire-based research. Collecting data through structured surveys with structured response options, coupled with the ability to view data in real time makes EDC system a desirable option for data collection. Analogous to all technological devices, the use of electronic devices like mobile phones, tablets, PDAs and iPod Touch for data collection has its risks and benefits.

The users who contributed to this paper shared their experiences, lessons, benefits and risks when using technology for data collection. They highlighted cost saving benefits including less paper, printing, and storage needs and no employment of data capturers. In addition, other benefits included a reduction in data entry time and data capturing errors, real time data viewing, real time and automated data quality checks, mandatory fields and skip patterns that reduce incomplete surveys and missing data, and enhanced data security. In terms of risks, they highlighted software development costs, initial hardware acquisition costs and potential replacement costs especially for desirable devices like iPod Touch and tablets if stolen, and lack of source data as survey responses are either verbal or responses entered directly onto device by participant. The benefits however appear to outweigh the risks.

The benefits highlighted by iPod Touch users are consistent with findings of a feasibility study using iPod Touch for a health behaviour assessment survey where majority of the participants found the iPod Touch easy to use, questions were easily understood, a clear recording of responses and minimising response error rate were reported [3]. Other benefits of a reduction in paper and storage costs were also consistent with reported findings in studies that used mobile phones to collect data in a household survey [10,11] and a study that reviewed challenges in mobile phone based data collection systems highlighted cost reduction as a benefit [1,2,12].

The availability of real time data and data quality control are also highlighted in various literature sources as a major advantage of using EDC for data collection [1,2,5,10-14]. A study comparing EDC with standard paper based data capture have found that regardless of the type of device, the major advantage of EDC is that data becomes available after collection in the field without delay [1].

The potential risks of EDC highlighted in Table 1 are consistent with findings in a household survey that reported the drawback of using a paperless system is that there is no paper questionnaires to review in the event of problems detected in the field [10]. Further studies that compared mobile phone technology
and paper based questionnaires in Nigeria and Benin-Republic reported the absence of source information which one can revert to in the event of a problem or errors detected and identified this as a limitation [15]. They found that it was not possible to ascertain the source of the differences for the variables which showed a weaker agreement, whether it came from the information given by the study participants during the interview or the entry of the information by the interviewers.

Mobile phones, iPod Touch and tablets are relatively high cost bearing devices. They are desirable items and their compact size means they can be easily stolen. In research settings, replacement costs can be escalated especially for iPod Touch and tablets which are relatively costlier to replace than some mobile phones, particularly if they are lower end non-smart phones. The risks of these replacement costs highlighted in Table 1 are consistent with findings in a study in China that compared two methods for a Maternal and Child health (MNCH) household survey. They report that the use of smartphones had some drawbacks, including that data can become corrupted when the device is damaged and replacement costs are relatively high when the device is lost or damaged [1].

Whilst there is a growing trend in the use of EDC systems, ongoing advancement in mobile technology make mobile phones a popular data collection tool. The synthesis of the experiences of researchers in this paper highlight the potential gaps, possible limitations, benefits and risks that will assist other researchers when engaging in EDC systems for data collection. This will also assist researchers to make informed decisions based on lessons, benefits, and risks when selecting appropriate tools that will facilitate data collection.

Conclusion

Mobile based systems as a data collection tool are less time consuming and more user friendly as they provide access to real time data, facilitate early detection of potential errors, can have a built-in error detection component, reduce the need for large and heavy data collector field-based bags and reduce printing and storage costs. Electronic systems can also be used to manage and monitor the day-to-day operations of a study, provide simultaneous feedback to staff and management as well as almost instantaneous reporting. Data are aggregated on a web based central database enabling a quicker processing, analysing and dissemination of data.

The benefits of use of electronic (mobile) systems for data collection appear to outweigh the risks involved. Given the continuously changing information and technology, mobile phones and other portable electronic devices are becoming a preferred data collection tool. Like any other technological tool, electronic systems can be improved to overcome some of the risks highlighted in this report.

Declarations

Ethics and consent to participate

This paper is a review synthesis; thus, no patients were recruited. All authors willingly contributed insights and perspectives.

Consent to publish

All authors have granted consent to publish. No patient-level data are included. Thus, no consent to publish is needed from patients. Thus, this section is ‘not applicable’.

Authors’ Contributions

YS: She had taken a major role in drafting the first version of the paper. She has taken a major role in reviewing the contributions in this paper, writing the submitted paper and approved the final version.

DJ: She has taken a major role in reviewing this paper and made substantial contributions in writing the submitted paper and approved the final version.

AG: She has contributed in writing the submitted paper and approved final version.

PM: She has contributed in writing the submitted paper and approved final version.

EN: She has contributed in writing the submitted paper and approved final version.

SS: He has contributed in writing the submitted paper and approved final version.

NHB: She has contributed in writing the submitted paper and approved final version.

AEG: She has taken a major role in reviewing this paper and made substantial contributions in writing the submitted paper and approved the final version.

Availability of Data and Materials

All data arise from the documented experiences of the authors and data collectors. No patient data were used for this paper. No raw data/materials are used for this paper. Thus, this is not applicable.

Acknowledgements

Contributions came from co-authors-acknowledged as stated above.

Data Deposition

This paper is a synthesis of experiences using mobile
technology for research. No raw data are used. Thus, this is not applicable.

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| Study          | Size and complexity | Service provider | Data platform | Features | Data collection instrument | Lessons | Benefits | Risks                                                                 |
|---------------|---------------------|------------------|---------------|----------|---------------------------|---------|----------|-----------------------------------------------------------------------|
| Project I     | A cross sectional  | Clyral            | service provider developed two platforms, Mbenzi Researcher that stored raw data and Mbenzi Outreach to view data and make necessary edits. | once the interview was completed, the data was automatically uploaded onto a web-based platform enabling real time viewing of data. | base low-cost Nokia 2330 mobile phone | during the data collection period the mobile platform was continually enhanced to cater for study needs. | paper saving, no further capturing. | most data captured directly onto phone and is the only source. Thus, difficult to correct errors thereafter. |
|               | national survey     |                  |               | 'strict access control limited to few personnel with assigned login codes. | 'the mobile phones were installed with application software and customised electronic data collection questionnaires. | 'However, this sometimes took time and had additional cost implications. | 'cost saving - no need to employ data capturers. | unable to verify certain responses |
|               | measuring the       |                  |               | 'data can be viewed and imported into excel. Data was accessed via a link sent to the email address of the requestor. | 'at the end of the day the system generated automated daily summary reports sent via email to supervisors and data manager. | 'Many errors identified in dataset may have been attributed | 'raw data is available for review in real time thus facilitating timeous availability of study statistics | the design of two platforms can create a problem as edits done on one platform is fed into the system to update the other platform. |
|               | effectiveness of    |                  |               | 'the study design was complex as confidential participant characteristics were sent to a password protected database that could only be accessed by the data collector. | 'this feature allowed for close monitoring of data collected for the day, eg. date, time, name of data collector, facility where data was collected, the province and the visit type that was completed. | 'advantage of the generation of daily reports and weekly summary reports for monitoring purposes | 'platforms were customised to suit study needs | 'one platform is more user friendly and easier to manage |
|               | prevention of mother|                  |               | 'additionally, unique identifiers of eligible participants based on their self-reported status were automatically sent to a 3mth follow up folder on the mobile application. | | 'parameters were set to limit responses | 'parameters were set to limit responses | depending on the users (age), a mobile phone with large screen and keyboard may have been more appropriate |
|               | to child transmission|                  |               | 'once the first follow up visit was completed, the unique identifier automatically moved to the next folder if the participant was eligible for the next interview. | | 'automated skip patterns and mandatory fields reduced errors of missing data. | 'despite customised platforms, adequate training for web-based users is essential. | |
|               |                      |                  |               | Follow up questionnaire: 220 questions | | | | |

Notes:
- N - no. of interviews conducted
- 2010  -  10820
- 2011/12  -  10473
- 2012/13  -  9679
- 580 clinics nationally
- 150 data collectors
- 160 handsets
- Recruitment and enrolment at 6wks questionnaire: 223 questions
- Follow up questionnaire: 220 questions
| Study | Size and complexity | Service provider | Data platform | Features | Data collection instrument | Lessons | Benefits | Risks |
|-------|---------------------|------------------|---------------|----------|----------------------------|---------|----------|-------|
| Project II | A randomised control trial to prevent intimate partner violence among teens | N=3780 teens (grade 8s) surveyed 4 times over 2 years; survey in 3 languages (text and audio); 271 item survey with 7 skip patterns (excluding instruction screens); self-administered; multiple choice and answer entry options | Scott Johnson (consultant based at University of Kentucky) | used "kiosk" mode to prevent participants exiting survey to use other functions | iPod Touch, 3rd Gen, 16GB | *building the app is time-consuming* | *data quality check can be done early.* | iPods are desirable items and relatively easily stolen if strict vigilance and procedures are not in place |
| | | N - +1000 parents surveyed 5 times over 2 years; survey in 3 languages (text and audio); 222 item survey with 2 skip patterns (excluding instruction screens); self-administered; multiple choice and answer entry options | | ability to track stolen iPods through Apple tech (if connected to internet) and to disable use of stolen devices | | *important to have a very detailed oriented person set up the survey in correct format for application developers;* | *save on data entry time, costs, and inaccuracies* | *
| | | N - ± 800 educators surveyed 3 times over 2 years; survey in 1 language (text only); 66 items survey no skips (excluding instruction screens); self-administered; multiple choice and answer entry options | | *parents, when compared to teens, are less comfortable with the technology and need a lot of help and coaching to complete the survey* | | *Participants' responses are clearly recorded (no deciphering of handwriting or unclear markings)* | *
| | | | | *teens are amazing at playing with devices and creating problems with the app (solved with kiosk mode)* | | *easier to manage 100 iPods than +5000 x 4 questionnaires over the life of the study (all three surveys are loaded on each device)* | *
| | | | | *parents, when compared to teens, are less comfortable with the technology and need a lot of help and coaching to complete the survey* | | *skip patterns are managed automatically thus minimising errors* | *
| | | | | *need monitoring and safety protocols to prevent theft of devices.* | | *data is backed up daily* | *
| | | | | *devices could be tracked through iCloud application only if the device is switched on and connected to Wi-Fi AND the tracking has been enabled on the device.* | | *teens and educators enjoy the novelty of the iPod Touch and their concentration and excitement about participating is increased* | *
| | | | | *having a mobile Wi-Fi station in the field would help with real time data uploads instead of waiting to get to the office for Wi-Fi access to upload data.* | | *can have options to have interactive consent/intro video on the device* | *
| | | | | *need protocols for supervisors to charge and store devices properly with good security* | | *unmonitored devices could be tracked through iCloud application only if the device is switched on and connected to Wi-Fi AND the tracking has been enabled on the device.* | *Data collectors had to closely monitor the devices when in use by the learner and to make sure that the iPods are returned safely.* |
| Study | Size and complexity | Service provider | Data platform | Features | Data collection instrument | Lessons | Benefits | Risks |
|-------|---------------------|------------------|---------------|----------|----------------------------|---------|----------|-------|
| Project III | N= 2000 adults 1000 adolescents | Aptronics | provided by Aptronics. | all functions on tablet were disabled with only the questionnaire function enabled to prevent abuse of tablets (eg. data collectors going onto non-work related websites eg. Facebook). | software development took 4 months due to the length and complexity of the questionnaire. | 'data is uploaded in 'real-time'. | Application is more efficient and easy to use. | 'strict protocols need to be in place in respect of checking in/ checking out of tablets to those who have access to the tablets. |
|        | '48-page questionnaire with more than 2000 loops and skip patterns | 'for system development | 'data downloaded by researcher in excel. | 'size was good, and no real problems were encountered. | 'data collectors had one-week training and several refresher training courses as there was a delay between training and actual commencement of fieldwork. | 'once a questionnaire is completed (and the tablet has 3G connection), data is immediately dispatched to the central administrator and database. | 'tablets are attractive and easily stolen. | |
|        | *Aptronics outsourced the software development component. | 'system maintenance | | | | | |
|        | *Software developer used a combination of odk, xform and surveycto to host the data. | *Aptronics provided tablets, *3G connectivity | | | | | |
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| Study | Size and complexity | Service provider | Data platform | Features | Data collection instrument | Lessons | Benefits | Risks |
|-------|---------------------|------------------|---------------|----------|---------------------------|---------|----------|-------|
| Project IV | N=22733 | Clyral using their Mobenzi Research Platform. | questionnaire was converted into a mobile phone application with screen logic, skips and control flow capabilities for entry level handsets. | each team supervisor had a cell phone with GPS capability. | entry-level Nokia C1 cell phones and Nokia C5’s for team supervisors | competency tests on the use of mobile phones prior to appointment clearly indicated who was capable of conducting the fieldwork properly. | automated checks during data capture allows for more accurate data capture. | there were few instances of technical difficulties with the cell phone. |
| A retrospective descriptive survey on Injury mortality | 2-page questionnaire including skips and collection of repeated data for reliability test | | | | | | |
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Table 1: Summary of Mobile Technologies for Data Collection in Health Research at the South African Medical Research Council.