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SCHOOL OF MEDICINE

DISSEMINATION OF RESEARCH FINDINGS TO PARTICIPANTS BY INVESTIGATORS AT THE AMPATH RESEARCH PROGRAM, ELDORET, KENYA.

BY

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A Thesis Submitted In Partial Fulfilment of The Requirement For An Award of The Degree of Master of Science In International Health Research Ethics, Department of Behavioural Sciences, School of Medicine, College of Health Sciences, Moi University.

Declaration

Declaration by candidate:

This thesis is my original work and has not been presented for a Degree in any other university. No part of this proposal may be reproduced without prior written permission of the author and/or Moi University.

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Dedication

The pursuit of this degree has not been without its fair share of challenges; but also joys and wins. I would therefore like to dedicate this thesis to friends and family who have been with me through it all. First, to the one who embodies both friendship and family in equal measure, my best friend, my support system and partner in life, Charity Wambui. Secondly, to my siblings and their spouses whom I am greatly indebted for the unyielding support in all matters. Last but not least, I dedicate this work to my dad, the good professor himself, Vincent Sudoi, the rock upon which all of our family stands. I salute you all.

Abstract

Researchers have a professional and ethical obligation to ensure that research findings are disseminated to research participants, as well as other stakeholders. In a climate of increasing distrust of research, dissemination of findings may help to foster trust in researchers and in research as an institution. Studies have shown that only 20% of investigators disseminate findings back to research participants. Investigators affiliated to the Academic Model Providing Access to Healthcare (AMPATH) have conducted research since 1989, with over 359 publications up to date and over 72 ongoing studies currently. No specific information on dissemination to research participants was available in this setting.

The broad objective was to describe the dissemination practices of investigators at the Academic Model Providing Access to Healthcare (AMPATH). The specific objectives were to determine the proportion of investigators who disseminate findings to research participants, describe the methods used by these investigators and assess the factors that influence dissemination to research participants.

This was a cross sectional, descriptive, quantitative study conducted at the AMPATH Research Program. An online semi-structured questionnaire was administered to 136 investigators between May and November 2015. Analysis was done using standard statistical package for analysis and computing (R Core, 2015). Association between categorical variables and the binary outcome variable (explicit dissemination to research participants) were assessed using Fisher's exact test. A p-value of less than 0.05 was considered significant in all analyses. The covariates that were significant in the bivariate level were included in a logistic regression model to assess their effect on the outcome. We reported the odds ratios and the corresponding 95% confidence limits.

In general, 113 AMPATH investigators (91.1%, 95% CI: 84.7, 95.5) disseminated their research findings. The most commonly used method of dissemination was through scientific conferences/workshops 61 (49.6%). Of all the participants that took the survey, 77 (62.1%, 95% CI: 53.4, 70.8) disseminated findings specifically to the research participants. The most commonly used method to participants was through community meetings/events 59 (48%). The factors that influence dissemination to research participants at AMPATH are allocation of budget to dissemination activities (p=0.032), presence of a dissemination plan (p=0.005), external study funding (p=0.047) and submission of dissemination related materials to IREC (p=0.008).

Investigators at AMPATH have a higher dissemination rate to research participants (62.1%) compared to investigators in Sudan and the United States that had a prevalence of 20%. Scientific conferences/workshops were the most commonly used dissemination method. Factors associated with dissemination to research participants were mostly found to be study related rather than individual investigator characteristics.

AMPATH should ensure investigators conducting research under the institution build dissemination to research participants into their protocols. IREC should check for the presence of a dissemination plan and adequate budgetary provision for dissemination during the review of protocols prior to approving them. AMPATH should strengthen their frameworks and provide support to investigators of self-sponsored studies to ensure dissemination to research participants.

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Abbreviations

AIDS	Acquired Immuno-Deficiency Syndrome
AMPATH	Academic Model Providing Access to Healthcare
ART	Anti-Retroviral Therapy
CBO	Community Based Organization
CBPR	Community-based participatory research
CFR	Code of Federal Regulations
CHS	College of health Sciences
DR.	Doctor
E.G.	*Exempli gratia* (for example)
E-mail	Electronic Mail
FGD	Focused Group Discussion
HIV	Human Immuno-deficiency Virus
IHRE	International Health Research Ethics
IRB	Institutional Review Board
IREC	Institutional Research and Ethics committee
IUPUI	Indiana University-Purdue University Indianapolis
KES	Kenyan Shilling
MA	Master of Arts
MBCHB	Bachelor of Medicine, Bachelor of Surgery
MD	Medical Doctor
MIHRE	Master of Science in International Health Research Ethics

MPH	Master of Public Health
MSC	Master of Science
MTRH	Moi Teaching and Referral Hospital
N/A	Not Applicable
NGO	Non-Governmental Organization
NO	Number
PG	Post Graduate
PHD	Doctor of Philosophy
PI	Principal Investigator
PROF	Professor
REC	Research Ethics Committee
REG	Registration
RPO	Research Program Office
SM	School of Medicine
SOP’s	Standard Operating Procedures
TB	Tuberculosis
US	United States
USA	United states of America
USD	United States Dollar

Operational Definitions

AMPATH research program: The research hub consisting of investigators from the Moi University College of Health Sciences (CHS), the Moi Teaching and Referral Hospital (MTRH) and investigators from a consortium of over 15 US and European universities led by the Indiana University.

Attitudes: The general and relatively enduring evaluations people have of other people, objects, or ideas and they can be positive, negative, or neutral, and can vary in their extremity

Author: An author is considered anyone involved with initial research design, data collection and analysis, manuscript drafting, and final approval of a research study.

Autonomy: Personal capacity to consider alternatives, make choices, and act without undue influence or interference of others.

Behavioural research: The systematic analysis and investigation of human and animal behaviour through controlled and naturalistic observation and disciplined scientific experimentation. It attempts to accomplish legitimate, objective conclusions through rigorous formulations and observation.

Biomedical research: In the context of this study, biomedical research involves clinical trials, which are phased studies using human volunteers, designed to answer safety and efficacy questions about biologics, devices, pharmaceuticals, new therapies or new ways of using known treatment

Chart Review: A research methodology in which the investigator does not interact directly with human subjects but rather gathers information from their medical records. This can be done retrospectively or prospectively.

Clinical Trial: A controlled study involving human subjects, designed to evaluate prospectively the safety and effectiveness of new drugs or devices or of behavioural interventions.

Dissemination: An active and planned process that involves the flow of research findings from a particular source to a targeted and intended audience. This can be individual or aggregate findings and can occur at any point in the research cycle.

Funded study/ Study grant: A study in which all the funds to carry out the research are provided by a third part party/sponsor.

Grant: Financial support provided for research study designed and proposed by the principal investigator(s). The granting agency exercises no direct control over the conduct of approved research supported by a grant.

Informed consent: A person's voluntary agreement, based upon adequate knowledge and understanding of relevant information, to participate in research or to undergo a diagnostic, therapeutic, or preventive procedure. In giving informed consent, subjects may not waive or appear to waive any of their legal rights, or release or appear to release the investigator, the sponsor, the institution or agents thereof from liability for negligence.

Investigator: An Investigator is the principal investigator, co-principal investigator or any other individual who is independently responsible for the design, conduct, or reporting of a research protocol.

Partially funded study: A study in which some of the funds for conducting the research are provided by a third party/sponsor while the rest are provided by the investigator

Primary Author: The individual who assumes responsibility for the publication, making sure that the data are accurate, that all deserving authors have been credited, that all authors have given their approval to the final draft; and handles responses to inquiries after the manuscript is published.

Protocol: The formal design or plan of an experiment or research activity; specifically, the plan submitted to an IRB for review and to an agency for research support. The protocol includes a description of the research design or methodology to be employed, the eligibility requirements for prospective subjects and controls, the treatment regimen(s), and the proposed methods of analysis that will be performed on the collected data.

Research Participant: A living individual about whom an investigator conducting research obtains data through intervention or interaction with the individual, or identifiable private information.

Research: The systematic collection, analysis interpretation and dissemination of data to generate new knowledge and answer a certain question or solve a problem.

Research Findings/ Results: The principal outcomes of a research project; what the project suggested, revealed or indicated.

Self-funded study: A research study in which all the funds for conducting the research are provided by the study investigator.

Surveys: Studies designed to obtain information from a large number of respondents through written questionnaires, telephone interviews, door-to-door canvassing, or similar procedures.

CHAPTER ONE: INTRODUCTION

1.0 Background Information

Health services research and health care research have the potential to improve people's health, the delivery of health care, and patients' outcomes in general (Tetroe et al., 2008). Numerous community based health research studies -both biomedical and social- have been carried out under the auspices of the AMPATH Research program since its inception in 2001.

Often a neglected afterthought in busy research schedules, the dissemination of key research findings is a crucial step in health research. A research activity involving human subjects is complete only when its results are released into the public domain(Song et al., 2010). In fact, researchers have a professional and ethical obligation to ensure that research findings are disseminated to research participants, as well as other individuals and institutions in the communities in which they work as objectively and as accurately as possible (Fernandez, Kodish, & Weijer, 2003; Miller, Christensen, Giacomini, & Robert, 2008; Song et al., 2010; Yale, 2001).

The standards of science extend beyond responsibilities that are internal to the scientific community. Researchers (including those at the AMPATH Research program) have a responsibility to reflect on how their work and the knowledge they are generating might be used in the broader society (Committee on Science, 2009). The first priority in any dissemination plan should be returning results to study participants and their communities. The research participants, whose enrolment made the research possible, are entitled to know the results of the research, and the implications for their health. Dissemination to any other stakeholder groups ought to take place following this first step (Sugarman et al., 1998; Yale, 2001).

For research to be considered ethical and adherent to the ethical principle of respect for persons, investigators have an obligation to disseminate research findings to research participants. This is further fortified by common rule which states that protecting participants from harms of research requires that research participants be informed of any new developments in research which may influence their choice to continue participation in a research study. This suggests dissemination to participants is a continuous process to be undertaken at various stages in the research effort.

The nature of information to be disseminated ought to be tailored to the needs of the audience. The language should be appropriate and the information adequate. Various dissemination methods need to be employed and existing relationships, resources and networks leveraged fully by those disseminating results (Yale, 2001).

Current processes tend not to recognize distinctions across audiences. Researchers get caught up in a “one-size-fits-all” process of dissemination, failing to tailor the content, timing, setting and format of dissemination to the audience.(Fullilove, Green, Hernández-Cordero, & Fullilove, 2007; Lomas, 1997)

For dissemination to research participants and their communities, investigators and their teams have to be culturally-competent and possess an acceptable understanding of the communities they are researching on (Skeete, 2009). Investigators also need to have a shared understanding of exactly what it is that needs to be disseminated to this community and why (Harmsworth, Turpin, & Team., 2000).

Initial efforts and the focus of dissemination has been assembling and disseminating the evidence on clinical practice (for clinicians) and are mainly for changing practitioner behaviour of clinicians, administrators and /or legislators (Lomas, 1997). Consumers (like research participants) do not normally actively participate in the design of the healthcare system or in their own process of care such as dissemination (Vigneault, 2007).

This study sought to establish whether and through what means investigators disseminate findings of research to research participants at the AMPATH Research Program. It also sought to establish some of the factors that influence dissemination practices and choice of dissemination methods.

The knowledge gained from this study will provide a foundation for future action by the leadership of academic/research programs like AMPATH to refine dissemination activities and conduct more ethical research that is cognizant of research participant needs.

1.1 Problem statement:

Literature suggests that researchers are most successful and confident when disseminating the results of their research studies to academic colleagues. Most are less successful in disseminating these results to other target audiences, even when they feel that their results are of considerable importance to these audiences such as the public and decision makers (Tetroe et al., 2008).

Writing dissemination materials for participants and for use in the community is much different from writing a research grant or an article for publication in a scientific or professional journal (Yale, 2001).

According to a study conducted in Sudan, only 51% of researchers publish their work in local and international journals. Approximately 20% of surveyed researchers provide feedback to the served communities (Elsayed & Kass, 2006).

Although clinicians are central to health services, pre-occupation with practitioner behaviour change has tended to obscure the relevance of other potential audiences for health research findings (Lomas, 1997). For this reason, researchers will have to make a conscious effort and have as a core objective, the need to disseminate the outcomes of their research to other stakeholders including the community (Harmsworth et al., 2000).

The problem of research dissemination becomes considerably more complex when other kinds of health research audiences, such as research participants are considered. Research participants are more diverse than clinical practitioners regarding their research information needs, and regarding barriers to and incentives for research dissemination and uptake (Waddell, 2001)

Awareness of research results potentially conveys risks as well as benefits which are important to research participants (Miller et al., 2008). Failure by investigators to disseminate results to research participants leaves them feeling that they were only used as a means to an end and denies them the feeling of self-worth gained through altruism and the pleasure in knowing that they contributed to an overall enrichment of scientific knowledge. This is true even when participants do not directly benefit from the research (Fernandez et al., 2003; Green & Mercer, 2001).

Many researchers face the challenge of how to disseminate to participants and their communities to maximum effect within the constraints of the resources allocated to their projects (Harmsworth et al., 2000).

Moreover, the dissemination profile of research findings is often determined by the interests of research sponsors, investigators, peer-reviewers and editors. These interests, particularly industry’s interests, can restrict the dissemination of the research findings to particular audiences (Song et al., 2010).

What this demonstrates is that there is a clear problem in the complete/successful transfer of health research findings in a timely manner to the required audiences (Vigneault, 2007) and suggests that research participants are likely to be left out of the dissemination process.

1.2 Justification

The risks or burdens that study participants accept through participation in research are justified, ethically, by the knowledge gained through research. If research is not disseminated, then knowledge cannot be gained and the entire premise of the research becomes ethically suspect (Elsayed & Kass, 2006). Researchers have responsibilities not only to minimize harm, engage in meaningful informed consent, and avoid exploitation of individual subjects, but also to disseminate their findings to research participants and their communities (Goldberg-Freeman et al., 2007; Strauss et al., 2001).

In a climate of increasing distrust of research, dissemination of findings may help to foster trust in researchers and in research as an institution. Sharing research results also signals the openness and accessibility of researchers. This could help in raising a positive profile of research in general and highlighting the impact of research on health outcomes which benefits society as a whole (Fernandez et al., 2003).

Decision makers in research institutions such as AMPATH have a role to ensure that structures are in place to actively disseminate research results (Waddell, 2001). The results from this study will form a platform for such future action.

1.3 Significance of the study:

The practice of dissemination of research results to study participants is intended to uphold the ethical principle of respect for persons and to ensure that participants are not treated merely as a means to an end (Fernandez et al., 2003; Miller et al., 2008)

All research is conducted within “cultural” contexts in which different ideologies (values, beliefs), institutional structures, interests and incentives apply. The AMPATH Research Program is not an exception and these social systems or contexts influence not just the way people think and work in general, but also the kinds of research (and other) evidence and the kinds of dissemination formats that are preferred, needed, or used (Waddell, 2001).

Like in all settings, the community within which AMPATH operates have to see the need for research, and researchers need to be able to disseminate research findings back to the community.

Dissemination exercises if well executed increase the interaction between researchers and the community. These interactions are often constructive and positively viewed as they help researchers understand the context in which research is done and helps them know the most appropriate avenues for dissemination (Goldberg-Freeman et al., 2007). The interactions will also better guide researchers to make sure research is most appropriate, ethical and meets the needs of the community.

Academic, care and research programs like AMPATH need to make greater effort to involve communities regularly in their community-based research and ensure that the research they conduct is ethical and in compliance with national and international ethical guidelines. These efforts may help to promote the shared goal of improved public health (Goldberg-Freeman et al., 2007).

1.4 Objectives

1.4.1 Broad Objective

To describe the dissemination of research findings to participants by investigators at the AMPATH research program.

1.4.2 Specific Objectives

1. To determine the proportion of investigators who disseminate research findings to participants

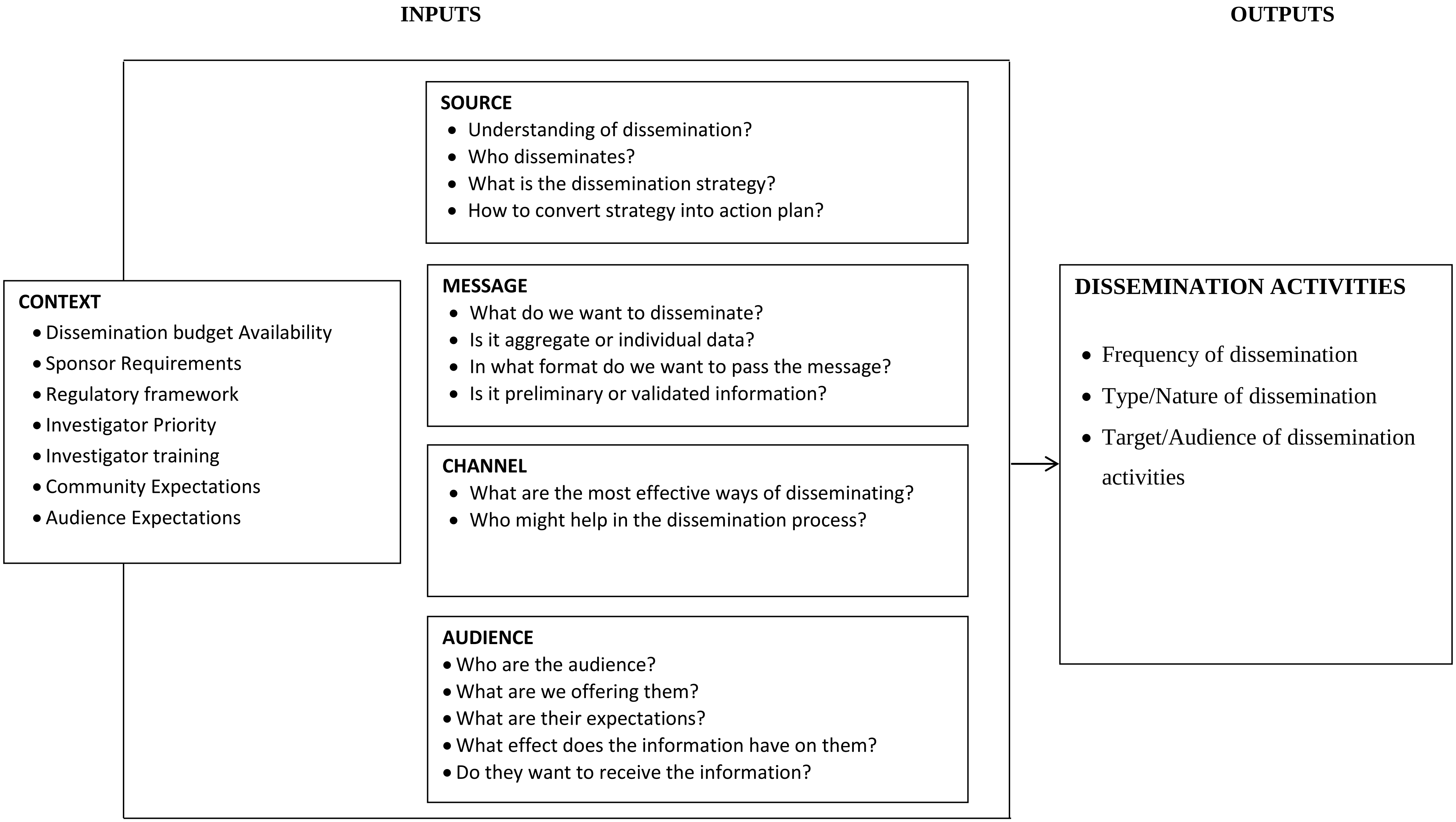
2. To describe the methods used by investigators at the AMPATH Research Program to disseminate research findings
3. To assess the factors that influence dissemination to research participants by investigators at the AMPATH Research Program.

1.5 Research Questions:

1. What is the proportion of investigators who disseminate research findings to participants?
2. What are the methods used by investigators to disseminate research findings to research participants at the AMPATH?
3. What are the factors that influence dissemination to research participants by investigators at the AMPATH Research Program?

1.6 Theoretical framework.

The dissemination process is a communication process. McGuire’s Theory of Persuasive Communication was adopted for this study. McGuire (2001) was one of the pioneers in trying to understand how mass media messages persuade people. His communication matrix is a step-based model which assumes that persuasion is the result of successfully transiting through several steps of inputs and outputs. Each step on the model is a move forward towards achieving the behaviour in question. This same matrix can be adopted in dissemination of health findings. The inputs are the different aspects that go into the dissemination attempt, and outputs are the resulting dissemination approaches/outcomes (Corcoran, 2007).



INPUTS

OUTPUTS

CONTEXT

- Dissemination budget Availability
- Sponsor Requirements
- Regulatory framework
- Investigator Priority
- Investigator training
- Community Expectations
- Audience Expectations

SOURCE

- Understanding of dissemination?
- Who disseminates?
- What is the dissemination strategy?
- How to convert strategy into action plan?

MESSAGE

- What do we want to disseminate?
- Is it aggregate or individual data?
- In what format do we want to pass the message?
- Is it preliminary or validated information?

CHANNEL

- What are the most effective ways of disseminating?
- Who might help in the dissemination process?

AUDIENCE

- Who are the audience?
- What are we offering them?
- What are their expectations?
- What effect does the information have on them?
- Do they want to receive the information?

DISSEMINATION ACTIVITIES

- Frequency of dissemination
- Type/Nature of dissemination
- Target/Audience of dissemination activities

Figure 1: Theoretical framework

Source: (Corcoran, 2007; Wilson, Mark Petticrew, Mike W. Calnan, & Irwin Nazareth, 2010)

CHAPTER TWO: LITERATURE REVIEW

2.0 Definition of dissemination

Various definitions to the term dissemination exist. There is however concurrence by many authors in that their definitions encompass the common elements of it being “an active concept” that involves the “flow of information” from a particular source to a “targeted” and “intended audience”. Many authors are also in agreement that information has to be “tailored” for that particular audience and that the audience has to be engaged in the process. (Harmsworth et al., 2000; Lomas, 1997). Wilson *et al.,* 2010 further adds that dissemination is a planned process that involves consideration of the settings in which research findings are to be received and that in needs to facilitate research uptake in decision-making processes and practice (Wilson et al., 2010).

For purposes of clarity, Lomas,1993 makes an important distinction between dissemination and diffusion. He writes that as opposed to dissemination, diffusion is passive and unplanned and requires the potential adopter to seek out the information (Lomas, 1993)

2.1 Reasons for dissemination

There are three broad reasons why researchers may want to disseminate their work; for awareness, for understanding and for action (Harmsworth et al., 2000). Dissemination for awareness is useful for those audiences that do not require a detailed knowledge of the research but for whom it is helpful to be aware of the research activities and outcomes. Dissemination for understanding is normally targeted at groups/audiences that the researcher believes can benefit from what the research has to offer; for example peers or professional colleagues. Lastly dissemination for action is aimed at prompting a change of practice resulting from the adoption of products, materials or approaches offered by the research in question and will be targeted at those people that are in a position to “influence” and “bring about change” within their settings for example policy makers (Harmsworth et al., 2000).

2.2 Obligation to disseminate

The principle of respect for persons, beneficence, and justice are widely recognized to shape the conduct of research with human subjects. Respect for persons requires that choices be made by individuals who are capable of making decisions for themselves and that these individuals be accorded high regard. The principle of respect for persons is embodied in the concept and practice of free and informed consent (Fernandez et al., 2003; Research, 1979). Respect for persons should however extend beyond informed consent and should encompass informing research participants of the results at the conclusion of the study. The act of offering research participants a summary of research results prevents treating persons solely as a means to an end. It also places the welfare of the participant in focus, as research results may have direct and significant implications for the participant’s health.

The Common Rule also requires that "significant new findings developed during the course of research which may relate to the subject's willingness to continue participation ... be provided to the subject" (45 CFR 46.116(b)(Fernandez et al., 2003).

Respect for the persons and the common rule therefore obligates the researcher to offer research results in a clear and understandable manner to research participants. However, respect demands that we recognize the right of every research participant, having been fully informed, to decline to be given the results of studies in which she or he was enrolled (Fernandez et al., 2003).

2.3 Benefits of dissemination to research participants

According to (Fernandez et al., 2003) there are several benefits to disseminating results to research participants. Firstly, disseminating results to research participants’ aids in demonstrating the on-going central nature of the participant's role in research. Secondly, it diminishes the chance that the participant may feel exploited by the researcher. Disseminating results to participants also provides information that may enhance quality of life or lead to interventions that may decrease the risk of future harm to participants. Dissemination also ensures that information learnt from research is shared beyond the traditional medical sphere and raises public awareness of the impact of research as well as helping in emphasizing the contribution of participants to the understanding of disease and therapy. All these enhance trust in the researchers and the research process in general. All these benefits notwithstanding, research results should be offered to all participants regardless whether or not they benefit directly or indirectly from the disclosure.

2.4 What should be disseminated

The type of information and level of detail to be disseminated will vary with the research question, the data available, and the needs of the participant (Fernandez et al., 2003). However, the nature of the information can be classified in broad categories in order to better understand what should and what should not be disseminated by investigators.

An investigator may choose to disseminate research results at several points of the research study: interim results may be disclosed while the study is on-going, for example, after completion of accrual, or after completion of data collection. Dissemination can also be done at the time an abstract is submitted to a scientific meeting or when the manuscript from the study undergoes peer review for publication. Lastly dissemination to research participants can be done after publication of the manuscript (Fernandez et al., 2003). The kind of information disseminated in each of the above stages is different. There is a school of thought that postulates that investigators should only disseminate definitive (validated) as opposed to preliminary (un-validated) results. They argue that premature disclosure of results, that is, before peer-review, may cause harm in many ways, including dissemination of inaccurate results, unnecessary anxiety among participants, and inability to complete a trial without bias.

For this reason they believe that disclosure of research results should, in general, be delayed until the results are published or until they have undergone peer review and been accepted for publication(Fernandez et al., 2003; Miller et al., 2008).

In light of the above, a mechanism should be developed to address the appropriate timing for disclosure of results from studies that are never peer-reviewed or published. Researchers should offer to provide a summary of results to participants at the completion of the study (Fernandez et al., 2003)

Investigators must also consider whether to disclose aggregate study results (findings representing the sample of participants) or individual results (findings regarding the person herself) (Miller et al., 2008). The general rule is to disseminate aggregate results. Individual-level research results should be disclosed only when data are valid and confirmed, have significant health implications, and a course of action to ameliorate or treat the problem is available. The information/results must also be clinically relevant or useful and have relevance for the health of the individual (Miller et al., 2008).

2.5 Role of audience in dissemination

It is important to identify and have a clear understanding about who the audience of a particular research project are in order to be able to map them to one of the categories outlined in the awareness, understanding, and action model above (Harmsworth et al., 2000). Separating potential users of research into community, legislative, administrative, clinical, and industrial audiences' highlights that each wishes to extract different things from research and each have different preferences for the format of dissemination. (Lomas, 1997). A consideration of each of the target audiences/groups and the level of dissemination required for each will help in planning for dissemination (Harmsworth et al., 2000; Yale, 2001).

Current dissemination processes tend not to recognize these distinctions across the different audiences. Researchers get caught in a “one-size-fits-all” process of dissemination, failing to tailor the content, timing, setting and format of dissemination to the audience.(Lomas, 1997)

It is important to tailor dissemination strategies to the audience and to apply innovative methods to help the them understand (Fullilove et al., 2007). In the African context, this can be by translating dissemination materials to a language best understood by the audience. (Skeete, 2009). Strategies that engage the end users of the findings and evaluate past efforts to inform future dissemination efforts have higher chances of success (Fullilove et al., 2007).

2.6 How to achieve quality dissemination

Investigators need to think about quality as opposed to just quantity dissemination (Harmsworth et al., 2000). Quality dissemination will be realized through the development and careful execution of a dissemination plan which seeks to answer several pertinent questions: At which points during the study and afterwards should information be disseminated? Who will be responsible for dissemination activities? Who are the users of the data? How applicable is the information? How useful is the information given and in what context are the findings being disseminated? (Lomas, 1997; Yale, 2001)

Achieving quality dissemination is an effort that will have to involve more than the researchers and the decision makers. It is a concerted effort in which the larger institutions in which researchers reside (usually academic settings), community members, research participants, sponsors of research, governmental and non-governmental organizations will need to be involved (Lomas, 1997)

2.7 Factors that influence dissemination

There are several factors that influence the dissemination effort. First, unless dissemination is built in from the beginning it normally does not happen. Adequately planning for it speeds up the process of research dissemination and uptake and leads to development of activities and processes to promote more effective research and dissemination of findings (Canadian Foundation for Health-care Improvement, 2014; Lomas, 1997). Dissemination activities need to be a part of the project plan and designed prior to the start of the project (Harmsworth et al., 2000; Yale, 2001). Leaving dissemination until the final year of the project fails to allow time for actively engaging users and finding ways of generating a feeling of ownership amongst those people and groups to whom the investigator wishes to disseminate and make an impact (Harmsworth et al., 2000).

Secondly, the most effective instances of health research being translated into practice is when stakeholders are involved in the study process from the very beginning (Lomas, 1997). The community also needs to be involved in the research from the design phase, to allow for the dissemination activities to be culturally-tuned (Skeete, 2009). Research findings ought to be reported to community leaders and residents early so that their feedback can be incorporated to improve the utility of the document(Yale, 2001).

Thirdly, it is important to decide and set out who the target audience for dissemination activities is. Dividing the audience into primary audience (more important) and secondary audiences(less important) will allow an investigator to allocate dissemination efforts according to audience importance. This ensures that with the limited resources, one is at least able to reach the primary audience (Canadian Foundation for Health-care Improvement, 2014).

Forth, time and budget requirements for dissemination are frequently underestimated by many researchers yet effective dissemination involves resources and planning. Allocating the correct budget, time and personnel is often an important determinant whether dissemination is eventually carried out(Canadian Foundation for Health-care Improvement, 2014).

All these factors though broad, summarise some of the factors that ultimately influence whether dissemination of research findings occurs.

2.8 Dissemination methods

Dissemination goes well beyond simply making research available through the traditional vehicles of journal publication and academic conference presentations. It involves a process of extracting the main messages or key implications derived from research results and communicating them to targeted groups in ways that encourages them to factor the research implications into their work." (Canadian Foundation for Health-care Improvement, 2014)

One of the most effective methods of identifying an effective dissemination method is Identifying existing, tried and tested channels through which to disseminate (Harmsworth et al., 2000).

Traditionally dissemination has been limited to scientific meetings and peer-reviewed publications and texts,' (Fernandez et al., 2003). There are however various ways in which knowledge gained from research can be disseminated to the public. The following specific dissemination methods have been proposed for use on research participants:

Letter of thanks to study participants:

The investigator can choose to write a letter to thank participants for their involvement in a particular study. These letters can be written either in the course of or at the end of the study. Investigators can use this opportunity to include information/findings about the study that he/she thinks are important for the participants to know.

Community meetings/Events:

Community meetings present a perfect opportunity for researches to disseminate important information about research. These meetings can either be convened by the researchers in collaboration with community leaders or can be existing community meetings in which researchers take advantage of to disseminate research findings (Skeete, 2009).

In a study conducted by (Vigneault, 2007), participants mentioned that there should be regular meetings in which investigators should share information/knowledge gained from research with key players in the community. They also suggested that community leaders should be involved in developing “quality” messages for their communities do be disseminated during these meetings. This approach is echoed in a report by (Skeete, 2009) in which he advocates for the need to recruit celebrities and role models (from involved communities) who have a good understanding of local culture, ethical values and who can champion cultural issues during dissemination in community meetings.

Study Newsletters:

These could be printed and circulated to research participants in the course of a research study or at the end of the study. Study newsletters can have useful information for research participants including presenting preliminary findings.

Opinion leaders:

Opinion leaders often act as important links between researchers and the communities from which research participants hail. This relationship can be leveraged upon in the organization and execution of dissemination activities.

Community Agency Publications:

This can be achieved by incorporating research findings in community publications e.g. CBO’s, NGO’s or community papers that are readily available to and easily accessed by community members(Skeete, 2009; Yale, 2001)

One-on-one Conversation:

Research participants could be invited back at the end of the research study where research team members could have one on one conversations with them. In a study conducted in England, research participants gave specific advice on how to reach out to the community.

Community representatives and residents suggested that researchers could walk around the community not only to listen to community priorities and needs but also to have face-to-face interactions or discussions with community members. This would give researchers an opportunity to share about their research studies.(Goldberg-Freeman et al., 2007)

Flyers, Posters, Brochures:

These can be used to reach numerous research participants and community members. They offer a concise and visually-appealing way to disseminate information to broad audiences.

Road shows:

These have the effect of drawing crowds that can then be given useful information including dissemination information.

Research Summary Document/Research Briefs/Policy Briefs:

Clearly and concisely summarizes the key conclusions from a research initiative. Research results are often utilized to advocate for legislative and policy change at local, and national levels. Policy makers and legislators look to current research trends and information to make decisions. The best way to present this information is through policy briefs which outline the rationale for choosing a particular policy alternative or course of action in a current policy debate. They should be brief and concise and should focus on how new evidence has implications for a particular policy.

Scientific Conferences/Workshops:

These are meetings of scientists of a certain research field, intended to bring them together to learn about recent developments, present new data to each other and discuss it critically, and to socialize and get to know new colleagues. These are often technical in nature and research participants may not benefit from such engagements.

Publication in Scientific journals:

This is the primary means by which scientists circulate detailed research results intended for other professionals. There are over 2million articles published annually in over 20 000 health related journals (Waddell, 2001). Because they report recent scientific findings and allow the data to be verified by others, they are an important part of the scientific dissemination.

Press Release:

Offer one of the most efficient and effective ways to disseminate information, particularly to the media and other organizations.(Yale, 2001)

E-mail /List-Serves/Mailing lists:

These are lists that are generated with contacts of persons to be reached /targeted by specific dissemination materials. These materials can be emailed or sent via mail to everybody on the list once information is available**.**

Media:

This is a catch-all term used to describe all forms of communication. Most often, it is used to refer to television, radio, books, and newspapers (often referred to as the "Mainstream Media") but now also refers to the internet. This is more of a channel through which researchers can reach various audiences and is not strictly speaking, a dissemination method in itself.

2.9 Dissemination of information at AMPATH

According to the AMPATH Standard Operating Procedures (SOP’s) for research grant and project budget development, research projects are required to provide a dissemination plan for their studies to the Research Program Office (RPO) at the development of the research proposal. The AMPATH RPO urges dissemination of research findings to the local communities that were engaged in research, the wider research community, as well as to policy-makers. The SOP also states that any planned publication and dissemination costs should be included as a line item in project budgets to ensure that sufficient funds are available to support the dissemination activities(AMPATH, 2014b)

Twice per year AMPATH investigators are asked report on their active research projects. These reports are compiled to produce semi-annual research reports. The reports include information about project objectives, investigators involved, research site locations, funding sources, research budget and progress to date. These reports are available for viewing at the AMPATH research network website (http://medicine.iu.edu/ampathresearch/what-we-do/reports/). Furthermore, all studies must submit a one page summary of the study findings to the Research Office when the study is completed (AMPATH, 2014a). Apart from the semi-annual reports, the Research program office (RPO) conducts work in progress presentations on Tuesdays to inform AMPATH staff and investigators of on-going research at AMPATH.

There also exists within the AMPATH research program, a publications committee that ensures that all investigators and students involved in AMPATH research, clinical, and administrative programs comply with AMPATH SOPs for dissemination prior to submission of findings to a publisher, conference, or external audience (Plater, Senior AMPATH Leaders, & consortium, 2014). As the investigators submit their work to the AMPATH publications committee, they are also required to submit a research results compendium. The research results compendium summarizes how findings from the research in question impacts organizational and national policy. The compendium is normally shared with different stakeholders including the AMPATH board of governors which has representation from the ministry of health.

There have been over 359 peer reviewed publications from the AMPATH research program since its inception in 2001. There is however information on publications made by investigators currently affiliated to AMPATH dating back to 1989. (IUPUI, 2014).

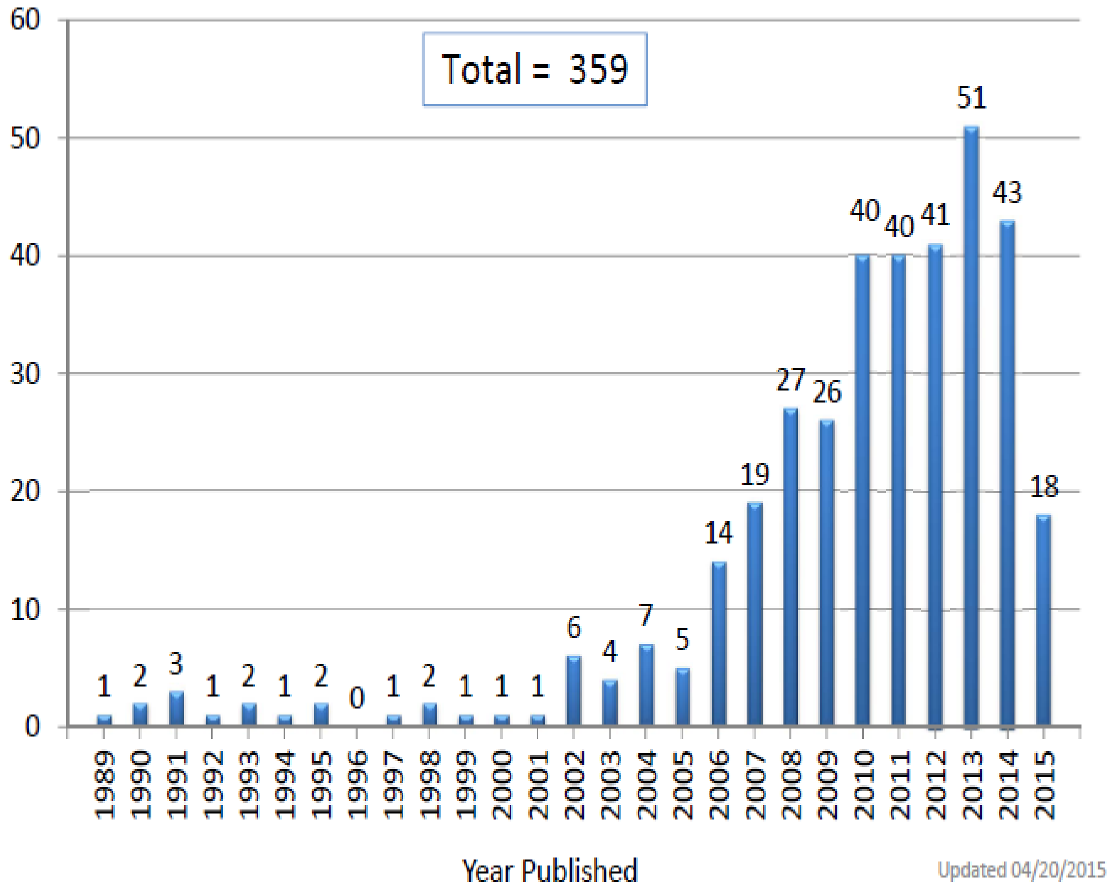


Figure 2: AMPATH Research Publications (1989-2015)

2.10 Conclusion

Literature suggests that dissemination is an important element of any research undertaking. Dissemination not only provides a means through which findings can be implemented/ translated into practice, but also accords an opportunity to investigators to inform and educate the general populace and colleagues on new developments in the field.

It has also been established that disseminating health research findings to research participants ensures that their rights and welfare are taken care of and that they are not used only a means to a research end. The practice of dissemination has been established to be in line with the core ethical principle of respect for persons as elucidated in the Belmont report (1979). It can be stated therefore, that dissemination to research participants is not only an ethical imperative but an ethical obligation on all researchers.

Literature also indicates that consideration of the audiences to whom one wishes to disseminate is a key consideration in the development of any dissemination strategy. Little is however known overall about which dissemination approaches work best with which audiences and neither in which kinds of settings nor the prevalence of dissemination to research participants by investigators. Clearly, a gap remains with respect to getting good quality research evidence not only summarised and published, but also disseminated to less traditional audiences.

From the literature, there is also a wide variation in opinion regarding what information should be disclosed and under what circumstances investigators should disclose such results. Moreover, consensus needs to be reached on the notion of ‘‘research results,’’ specifically regarding the choice between aggregate or individual results, amongst different types of research, and across different degrees of result veracity. This ambiguity regarding what is to be disclosed confounds ethical action.

This research study attempted to answer whether and through what means investigators at AMPATH disseminate research findings to research participants. It also attempted to establish what factors influence the dissemination of findings to research participants.

CHAPTER 3: METHODOLOGY

3.0 Introduction

This chapter elucidates the methodology that was used in this study. It includes the study area, study design, study population, sampling techniques, research tools, eligibility criteria, data collection, data analysis as well as ethical considerations.

3.1 Study area

This study was conducted at the Academic Model Providing Access to healthcare (AMPATH). AMPATH started as a collaboration between the Moi University School of Medicine, the Moi Teaching and Referral Hospital and the Indiana University School of Medicine back in 1990 when the Moi University School of Medicine(SM) had just been established (Einterz et al., 2007). By 2001, the partnership had evolved from a program of limited size and focus into one of the largest and most comprehensive HIV/AIDS control systems in sub-Saharan Africa, then called the Academic Model for the prevention & Treatment of HIV/AIDS (Einterz et al., 2007). Over time, the program grew to addresses health issues in a holistic approach to include primary care and management of chronic illnesses including cancer, diabetes and hypertension among others (Indiana Institute for Global Health, 2014).

AMPATH has a network of over 35 main clinics and more than 530 sub-locations spread throughout western Kenya (Refer to figure 3 below). Currently, AMPATH delivers care to more than 160,000 HIV-positive persons, with almost 2,000 new patients being enrolled each month at over 500 clinical sites throughout western Kenya (Indiana Institute for Global Health, 2014).

To the AMPATH program, care of patients is the most important and pressing obligation. The program however pursues a tri-partite mission of care, training, and research in order to address the short and long-term challenges of global health (Indiana Institute for Global

Health, 2014; Inui et al., 2007). In order to fulfil its research mission (to improve the health of the Kenyan people, through the identification, development and dissemination of relevant and timely information on health and health care systems for use by decision-makers in medical care, public health, and public policy makers in Kenya and elsewhere in resource-constrained settings), there exists an AMPATH research network/program within the broader AMPATH care program. The research studies conducted under the AMPATH research network aim to provide critical clinical research and bioethics training opportunities for Kenyan students, increase understanding of persistent health challenges like drug resistant HIV, TB, and malaria, and help improve clinical care for chronic diseases like cancer, diabetes, and heart disease while at the same time informing policy (Shawn Grinter, Jepchirchir Kiplagat-Kirui, David Plater, & Walumbe, 2013a).

The research network serves as a research hub for investigators from the Moi University College of Health Sciences (CHS), the Moi Teaching and Referral Hospital (MTRH) and investigators from a consortium of over 15 US and European universities (Appendix VII) led by the Indiana University. (IUPUI, 2014)

By December 2013, there were over 72 open research studies conducted all over Western Kenya under the AMPATH research network umbrella (Plater et al., 2014; Shawn Grinter, Jepchirchir Kiplagat-Kirui, David Plater, & Walumbe, 2013b) These have led to more than USD 85 million secured in extramural awards with about 60% of these resources flowing directly to Kenya (Plater et al., 2014).

This study was conducted at the AMPATH Centre situated at the Moi Teaching and Referral Hospital (MTRH) in Eldoret which is the largest and busiest of all AMPATH clinics.

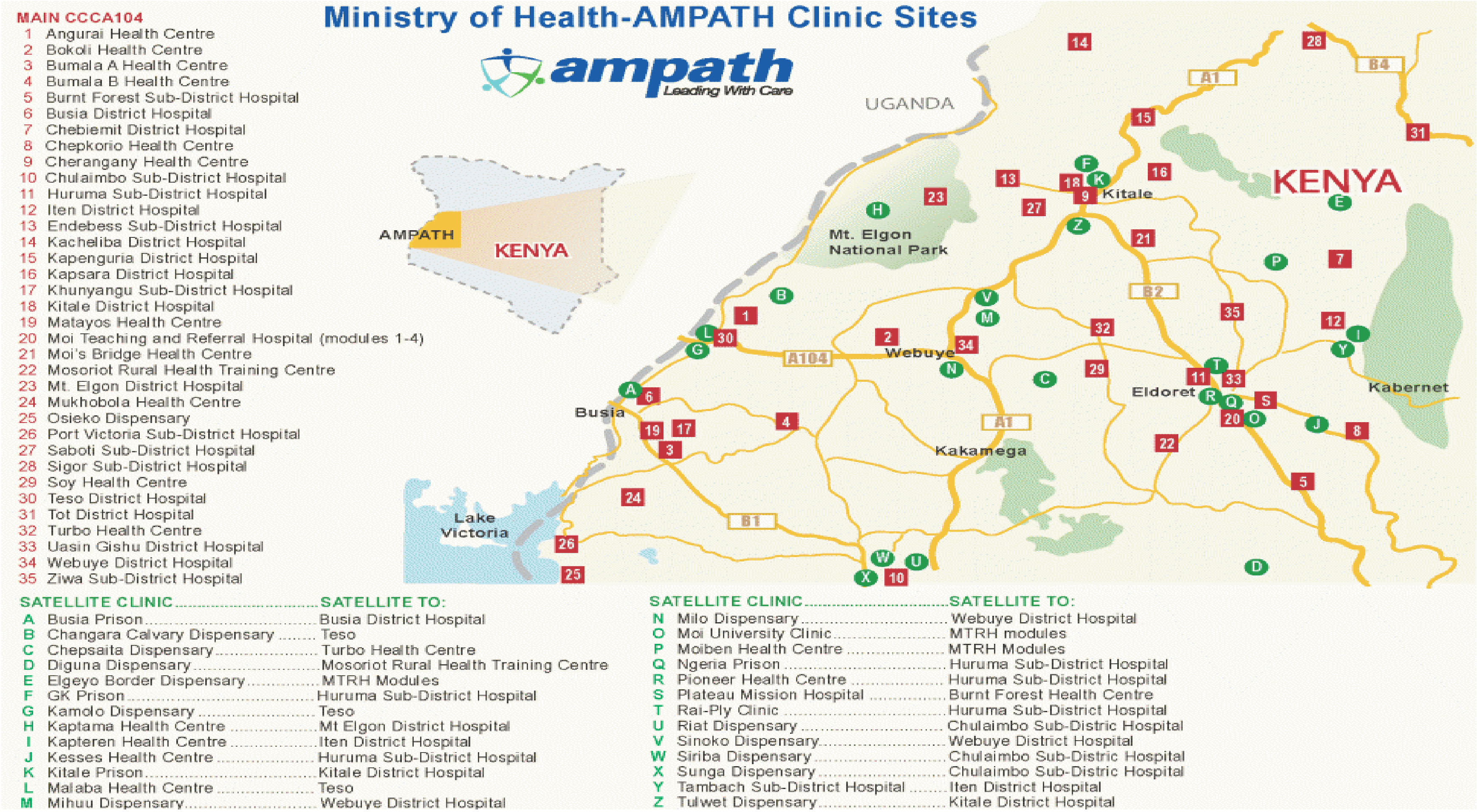


Figure 3: Ministry of Health-AMPATH Clinic Sites 2014

Source : http://medicine.iu.edu/ampathresearch/programs/sites (IUPUI, 2014)

3.2 Study design

This was a cross sectional, descriptive, quantitative study. Information was collected from each of the respondents only once (snapshot) over the course of the study to examine the relationship between dissemination to research participants and several variables of interest (see independent variables, section 3.10.1).

3.3 Study Population

The respondents comprised of investigators at the AMPATH research program. Individuals listed as investigators by the AMPATH Research Program Office or those listed as corresponding authors in publications for research conducted at AMPATH who met the inclusion criteria were included. The investigators were chosen because they hold ultimate responsibility dissemination activities.

3.4 Inclusion criteria

i. Must be an AMPATH investigator
ii. Must be involved in human subjects research

3.5 Exclusion criteria

i. Investigators from non-affiliated institutions
ii. Investigators who have not participated in any AMPATH research

3.6 Sample size determination

For this study, the sample size was estimated Using Fisher's formula (1973) $n = \frac{Z^2 \times p \times q}{d^2}$

From various sources (see section 3.7 below), there were a total of 251 distinct investigators conducting research at the AMPATH Research Program. This number constituted the finite study population (sampling frame) for this study. According to a study conducted in Sudan

(Elsayed & Kass, 2006), 20% of investigators disseminate research findings back to their research participants/communities. This formed the prevalence for this study.

Applying the Fisher's formula;

Z = 1.96 (Z score corresponding to 95% confidence interval).

P= 0.2 (Prevalence of dissemination to research participants in similar settings)

q =0.8 (1-p)

d= 0.05 (Sampling error /the margin of error (5%) that can be accepted in this study).

n = sample size

$$= \frac{1.96^2 \times 0.2 \text{ x } 0.8}{0.05^2} = 245$$

n= 245 investigators

This will then be corrected for a finite population: $n = \frac{N_0}{1 + \frac{(N_0 - 1)}{N}}$.

Where;

N= 251 (Finite target population)

$N_{0=}$ is the sample size calculated from the Fisher's formula

$$n = \frac{245}{1+(244/251)}$$

Adjusted sample size = 124 investigators

This number was adjusted upwards by 10% to account for non-responses. The sample size was therefore 136 investigators.

3.7 Sampling methods/techniques

The sampling frame consisting of all individuals considered to be AMPATH investigators was generated by the researcher in this study from various sources. These sources included the AMPATH publications bibliography, AMPATH Research Program Office (RPO) list of investigators, the AMPATH research compendium among others.

Over the years, the AMPATH Research Program Office has been compiling a list of publications made by investigators affiliated to the AMPATH program. This list is made into a bibliography that is distributed by the Research Program Office to the AMPATH research list serve and also uploaded onto the AMPATH research website (http://medicine.iu.edu/ampathresearch/what-we-do/publications/). This study utilised the latest bibliography published in April 2015 in which there were 359 publications listed. This was purposively selected as it was the most recent, publicly available bibliography and met the needs of this study. A list of all the investigators listed as first authors in the bibliography were first drawn up. Investigators who had more than one publication were considered only once. This was compared to the AMPATH RPO list of investigators that had 117 names and to a list derived from the AMPATH research compendium that had 216 names. All these sources were used to develop one master list containing all the available AMPATH investigators that formed the sampling frame. From all these lists, there was a total of 251 distinct names of investigators.

The names were first listed alphabetically by surname and numbered with the first name on the list being 1 and the last 251. A computer random number generator was then used to randomly select 136 investigators from the list. A random number generator is a computer software that produces customized sets of random numbers within a specified range. The numbers are generated with a uniform distribution - that is, no number within the specified range (1 and 251) is any more or less likely to appear than any other number.

The 136 respondents randomly selected were then sent the online questionnaire.

3.8 Recruitment Procedures

All investigators selected through the sampling process were sent an online form containing the informed consent form for the study. The consent form included details about the study, its purpose, duration, required procedures, and key contacts. Respondents who wished to participate showed their willingness by digitally signing the online form. Only after signing could they access the online questionnaire. Those who did not wish to participate also indicated this on the online form. Those investigators who preferred to fill paper questionnaires were given a chance to do so as well. There were 50 investigators who preferred paper questionnaires and these were provided to them. There was 1 investigator who preferred to print, fill in, scan and submit via email their responses. Investigators who indicated their willingness to participate but failed to respond within 1 week were sent weekly reminder emails. The total number of non-responses were recorded and this was taken into consideration during data analysis. Information on non-responses is presented under the results section of this thesis under the title "Response rate".

3.9 Data collection

The data collection questionnaire was programmed into an online form that was sent to all the selected investigators. The online questionnaire accepted 3 forms of input: 1) check boxes which allowed respondents to make multiple selections per question, 2) option boxes allowed investigators to choose only one of the options provided and 3) "other" which allowed respondents to enter free text. The checkboxes resulted in multiple responses per question which were taken into consideration during analysis as outlined in section 3.11 below. The responses were collected in a secure Microsoft Excel database. This system was piloted on 15 investigators from the sampling frame who were not selected during the sampling process. The pilot process was conducted in April 2015 and appropriate adjustments were made on the survey tool based on the responses from the pilot. This resulted in an amendment to the research protocol which was submitted to IREC on May 11, 2015 and approved on May 22, 2015.

3.10 Study variables

Both the independent and dependent variables in the study were picked from the theoretical framework and formed the basis of the research questions.

3.10.1 Independent variables

- Availability of budget for dissemination
- Sponsor requirements for dissemination
- IREC/IRB requirements for dissemination/ Regulatory framework
- Level of planning
- Investigator training
- Investigator priority
- Nature of research
- Nature of information to be disseminated
- Research stage

3.10.2 Dependent variables

- Frequency of dissemination
- Type /Nature of dissemination
- Target/Audience of dissemination activities
- Timing of dissemination activities

3.11 Statistical Analysis Methods

The data entered by the 78 investigators who completed the online questionnaire was automatically captured onto a Microsoft excel database. Data from the 50 paper questionnaires and 1 emailed response were entered by the research investigator into the same excel database. Data was then cleaned and coding done for the categorical variables.

Data analysis was done using standard statistical package for analysis and computing (R Core, 2015). Categorical variables were summarized as frequencies and the corresponding percentages. Continuous variables, age in this case, were assessed for Gaussian assumptions using Shapiro Wilks test. Since the Gaussian assumptions were violated, we reported the median and the corresponding inter quartile range. Multiple response variables were summarized as the total number of participants responding to one item divided by the total number of responses. Association between categorical variables and the binary outcome variable (explicit dissemination to research participants) were assessed using Fisher's exact test. The associated p-values were reported. The covariates that were significant in the bivariate level were included in a logistic regression model to assess their effect on the outcome. We reported the odds ratios and the corresponding 95% confidence limits. A p-value of less than 0.05 was considered significant in all analyses. Results were presented using tables and graphs.

3.12 Data presentation and dissemination.

Visual displays such as tables, and figures were used to condense information, present it in a clear format and highlight relationships and trends.

The findings from this study will be presented as a bound thesis to the Moi University School of Medicine. An oral presentation will also be made during the mock defence and the actual defence of the thesis. Key findings will be summarised and an email containing the summary will be sent to all participating investigators. A copy of the research results will also be submitted to the AMPATH research program. The findings from this study will be published in reputable journals in the field.

3.13 Scope and Limitation(s) of the study

This was a cross-sectional descriptive study that could not establish why (causal inference) the respondents (investigators) made the choices they did, rather only associations can be deduced.

Since this study was self-reported, we cannot entirely rule out the possibility of social desirability bias on the part of respondents, telling us what they thought we wanted to hear.

3.14 Ethical considerations

This study posed no physical risk to participants, though completing of the questionnaires took close to 25 minutes which might have been considered long by some research participants. Neither the participants name nor the studies that they participated in were revealed to persons not directly involved in the study. Personal identifiers were eliminated and each participant was assigned a unique identification number. Collected data was secured in password protected computers which only the study investigator had access to. Consent was obtained from each participant prior to commencement of the study.

The study was conducted following Institutional Research and Ethics Committee (IREC) approval (granted on January 16, 2015) and institutional approval by the AMPATH research program on February 11, 2015.

The findings from this study will be summarised and sent to the participants who made the research possible.

CHAPTER 4: RESULTS

4.0 Introduction

This section gives a detailed description of the findings from the study. Results will be presented in the form of tables, figures as well as continuous prose.

4.1 Response Rate

The survey was conducted between May and November 2015. A total of 136 participants accessed the data collection tool. Of this number, 7 (5.1%) did not respond while 5 (3.7%) indicated that they did not wish to participate. Data was therefore analysed for 124 (91.2%) participants. This number was sufficient to reach the power of analysis as it was the initial calculated sample size before adjusting for non-responses was made.

None of the questions were compulsory so there were different response rates for each of the questions. There were instances where respondents opted not to answer certain questions. This was taken into consideration during analysis and resulted in a different denominator (sample size) in the questions not answered by 100% of the respondents.

4.2 Characteristics of the respondents

The median age of the respondents was 37.0 years (IQR: 30.0, 44.0) with a minimum and a maximum age of 25.0 and 73.0 years respectively. There were 63 male and 61 female respondents. (Table 1).

Table 1: Respondent characteristics

Variable	Sample size	n (%)
Male	124	63 (50.8%)
Female		61 (49.2%)
Level of Education		
College certificate/Diploma		10 (8.1%)
Undergraduate degree e.g. B. Sc., BA.		42 (33.9%)
Graduate degree e.g. MMed, M.Sc. / MPH/MA.	124	43 (34.7%)
Medical degree e. g. MBChB		14 (11.3%)
Post Graduate Degree e.g. PhD		15 (12.1%)
Primary Employer		
AMPATH		50 (40.7%)
Brown University School of Medicine		2 (1.6%)
Columbia University		1 (0.8%)
Duke University Medical Center/Hubert-Yeargan Center for Global Health		2 (1.6%)
Indiana University – Purdue University in Indianapolis (IUPUI)		1 (0.8%)
Indiana University School of Medicine		11 (8.9%)
Maseno University		1 (0.8%)
Moi Teaching and Referral Hospital	123	22 (17.9%)
Moi University		26 (21.1%)
Purdue University		1 (0.8%)
St. Paul's University		1 (0.8%)
University of Bordeaux		1 (0.8%)
University of Massachusetts Medical School		1 (0.8%)
University of Toronto Dalla Lana School of Public Health		2 (1.6%)
Yale		1 (0.8%)
Role		
International PI		17 (14.2%)
International sub-investigator	120	4 (3.3%)
Local/Kenyan PI		29 (24.2%)
Local/Kenyan sub-investigator		18 (15.0%)
Program/Project staff member		51 (42.5%)
Advisor		1 (0.8%)

One third (33.9%) of the respondents had completed an undergraduate degree e.g B.Sc. or BA., and another one third (34.7%) had completed a graduate degree e.g. MMed, M. Sc. / MPH/MA.

Majority of the respondents, 50 (40.7%), were employed by AMPATH. One fifth, 26 (21.1%), were employed by Moi University, while 22 (17.9%) were employed by the Moi Teaching and Referral Hospital.

17 respondents (14.2%), were international PIs, 4 (3.3%) were international sub-investigators, 29 (24.2%) were local/Kenyan PIs, and 18 (15.0%) were local/Kenyan sub-investigators. In addition, there were 51 (40.5%) program/project staff members, and one advisor.

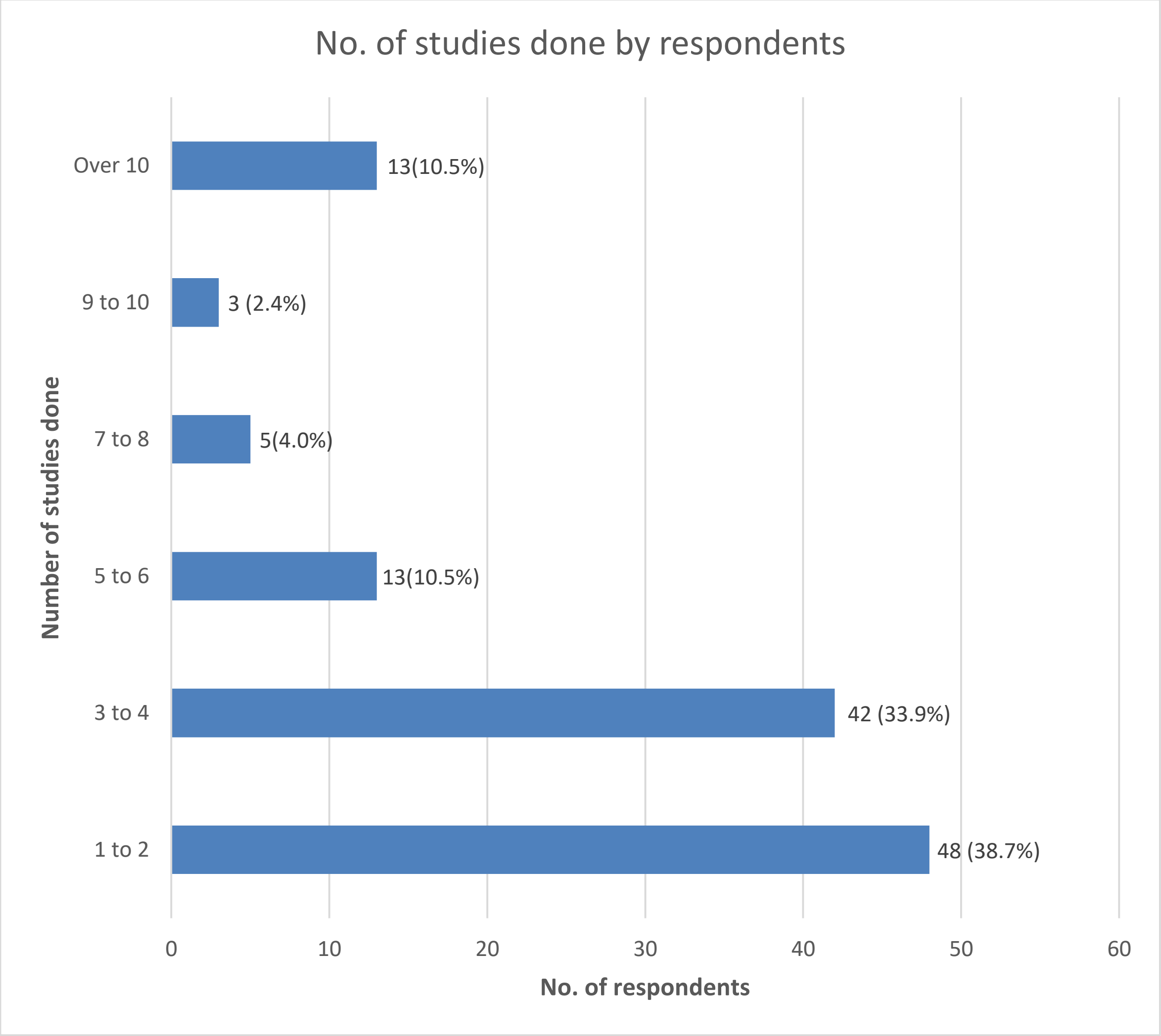


Figure 4: Number of studies undertaken by the respondents

Majority of the respondents 48 (38.7%) had participated in between one and two studies at the AMPATH research program. One third (33.9%) had undertaken between 3 and 4 studies. More than one quarter of the participants had done 5 or more studies.

4.3 Study Characteristics

Over half of the study participants 64 (52.0%) had completed their research projects/studies at the time of the survey. One fifth 26 (21.1%) said that their studies were at the data analysis stage, while a similar number 26 (21.1%) were still collecting data. Some 7 (5.7%) were still developing the proposals.

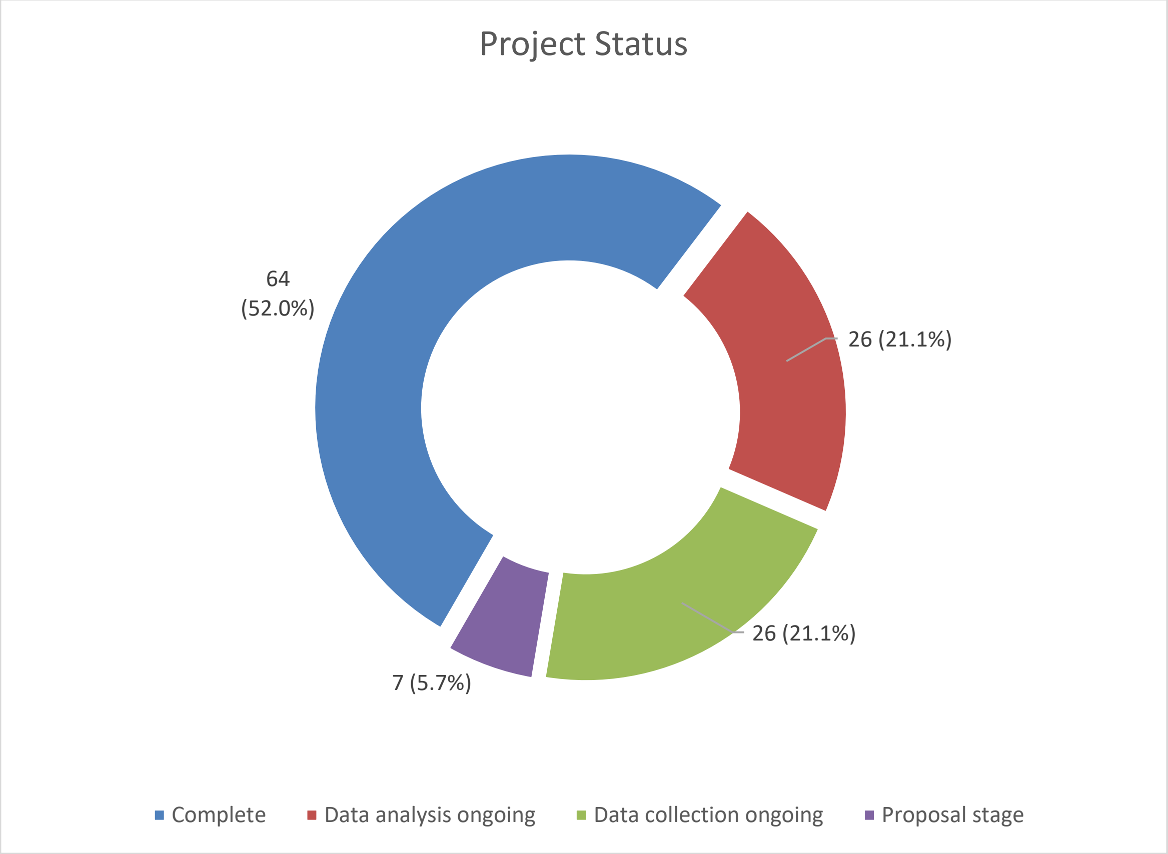


Figure 5: Project status

Table 2: Nature of research

Nature of the research (n=124)	**n (%)**
Behavioral	38 (30.6%)
Biomedical	79 (63.7%)
Others	7 (5.6%)

Close to one third of the respondents were doing behavioural studies while 79 (63.7%) were doing biomedical studies. The "others" category comprised of a dietary study, an environmental research, one health insurance financing research, one health systems research, one healthcare financing research, an implementation research, and a medical records related research.

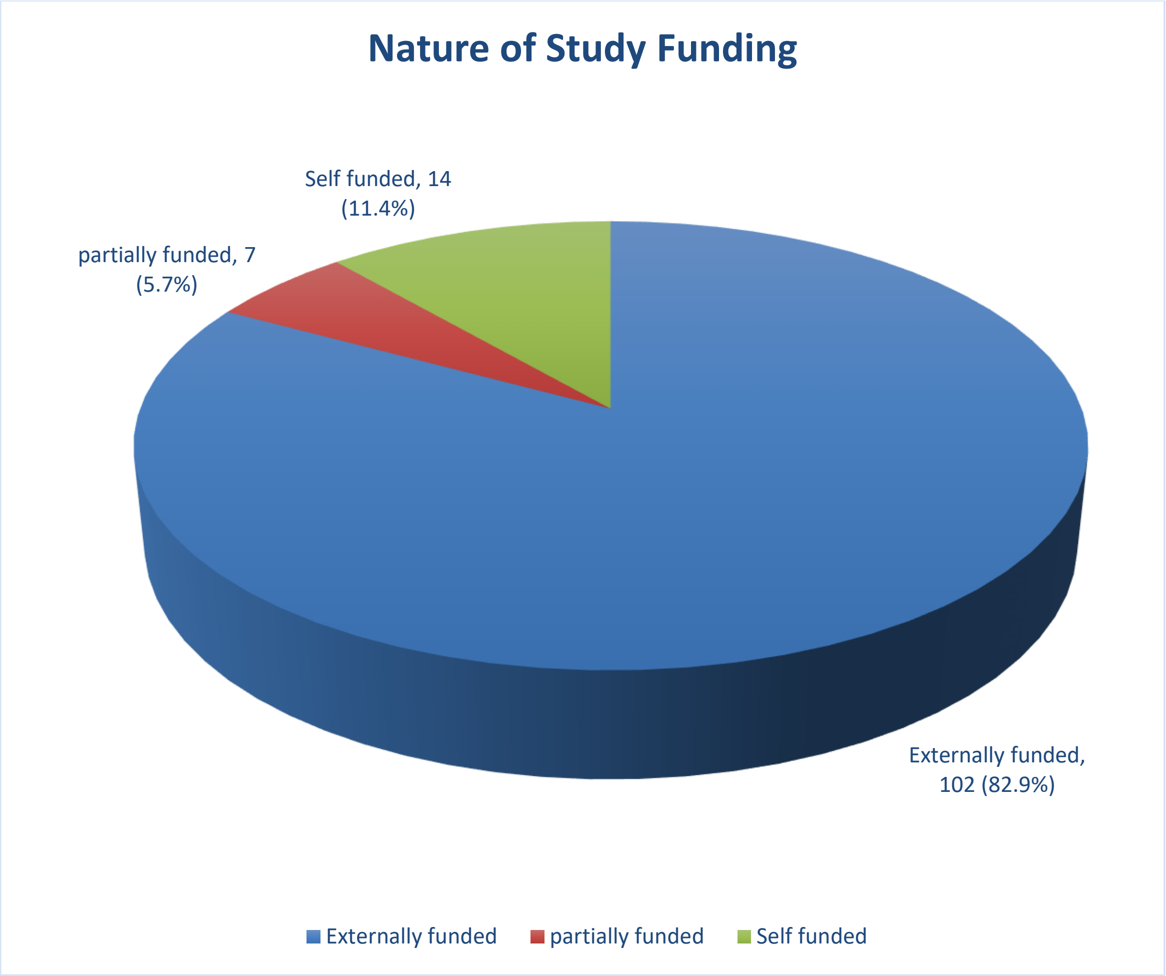


Figure 6: Nature of study funding

102 (82.9%) respondents said their studies were externally funded/study grants, while 7 (5.7%) said their studies were partially funded. Slightly above 10%, 14 (11.4%), had self-funded studies.

Table 3: Dissemination requirements explicitly stated by the funding agency

Responses (n=107)	Number of responses	Percent among the participants who responded
Requirements related to the method of dissemination	58	54.2
Requirements related to ownership of disseminated materials	43	40.2
Requirements related to intellectual property rights	41	38.3
Requirements related to the mode/media for dissemination	40	37.4
Requirements for dissemination of results to research participants	39	36.4
Requirements related to audience of dissemination activities	36	33.6
There were no requirements on dissemination in the contracts	28	26.2
Requirements related to review of dissemination materials by sponsor prior to dissemination	24	22.4
Requirements related to frequency of dissemination	11	10.3
Other	5	4.7
Total responses	**325**	

This was a multiple response question. Respondents who said their studies were funded or partially funded were asked if the funding agency had explicitly stated any of the listed dissemination requirements in their contracts with them or in the research protocols. There were a total of 325 responses from 107 participants for this question. Of all the requirements, the funding agencies mostly emphasized on the method of dissemination. The response rate for this requirement was 54.2%. The next on the list of requirements was related to ownership of the dissemination materials, followed by requirements related to intellectual property rights, mode or media of dissemination, and the need to disseminate to the research participants in that order with response rates of 40.2%, 38.3%, 37.4%, and 39.0% respectively. A requirement on the type of audience to be disseminated to was also stipulated with a response rate of 33.6% among all the respondents. A total of 28 (26.2%) said that there was no requirements stated by the funding agency. Respondents did not specify what the "other" sponsor requirements were.

Table 4: Study funding and dissemination budgeting

Variable	**Sample size**	**External funding/study grants** **n (%)**	**Partially funded** **n (%)**	**Self-funded** **n (%)**	**Overall** **n (%)**
Funder could have done more to help in dissemination of findings					
No	106	46 (46.5%)	6 (85.7%)	-	52 (49.1%)
Yes		53 (53.5%)	1 (14.3%)	-	54 (50.9%)
Proportion of the budget dedicated to dissemination related activities		N=101	N=6	N=14	
None		13 (12.9%)	1 (16.7%)	5 (35.7%)	19 (15.6%)
<5%		44 (43.6%)	3 (50.0%)	4 (28.6%)	51 (41.8%)
Between 5% and 10%	123	18 (17.8%)	1 (16.7%)	1 (7.1%)	21 (17.2%)
Between 11% and 20%		4 (4.0%)	0 (0.0%)	2 (14.3%)	6 (4.9%)
Between 21 and 30%		0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Between 31 and 40%		0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Between 41 and 50%		2 (2.0%)	0 (0.0%)	0 (0.0%)	2 (1.6%)
>50%		1 (1.0%)	0 (0.0%)	0 (0.0%)	1 (0.8%)
I don't know		19 (18.8%)	1 (16.7%)	2 (14.3%)	22 (18.0%)

Half of the participants believed that the funder could have done more to help in the dissemination of findings. Among those who had external funding/study grants, slightly above half (53.5%) of them believe that the funder could have done more to help in the dissemination of the study findings. Majority (85.7%) of those who received partial funding did not think there was more the funder could have done to aid their dissemination effort though the high proportion was not statistically significant, p=0.06.

Nineteen participants (15.6%) had not dedicated any part of their budget to dissemination related activities, and 22 (18.0%) did not know whether part of the budget had been dedicated to dissemination of the research findings. The highest proportion of those who did not set aside any money for dissemination (35.7%) were respondents of self-funded studies. Among those who received full funding or had study grants, majority (43.6%) set aside less than 5% of their budget for dissemination of the research findings.

Table 5: Methods of dissemination supported by the budget

Responses (n=81)	**Number of responses**	**Percent among the participants who responded**
Scientific conferences/workshops	55	67.9
Community meetings/events	45	55.6
Publication in scientific journals	41	50.6
Research summary document/briefs/policy briefs	37	45.7
Dissemination through opinion leaders	34	42.0
One-on-one	22	27.2
Letter of thanks to study participants	21	25.9
Flyers, posters, brochures	17	21.0
Community agency publications	15	18.5
E-mail /list-serves/mailing lists	14	17.3
Study newsletters	11	13.6
Press release	7	8.6
Road shows	6	7.4
Media	5	6.2
No particular method	1	1.2
Total number of responses	**331**	**100.0**

There were a total 331 responses from 81 participants on this multiple response question on the methods of dissemination supported by their budgets. More than half (67.9%) of the respondents set aside funds from their budget to support scientific conferences/workshops. The next most voted methods supported were community meetings and events (55.6%), publication in scientific journals (50.6%), and research summary documents/research and policy briefs (45.7%). The rest of the methods supported by the budget were as shown in Table 5 above.

4.4 Dissemination practices

One third of the participants 40 (32.5%) developed dissemination plans at the proposal development stage, and 37 (30.1%) developed dissemination plans at the final report stage of their studies. Fourteen respondents (11.4%) said they were cautious to plan dissemination related activities at all stages of the research.

Table 6: Dissemination planning and execution

Variable	**n (%)**
When was a dissemination plan developed for your study(n=123)	
At proposal stage	40 (32.5%)
After completion of the accrual	3 (2.4%)
After completion of data collection	8 (6.5%)
At the draft report stage	4 (3.3%)
At the final report stage	37 (30.1%)
After publication of the manuscript	5 (4.1%)
At the time of submission of the abstract to the scientific meeting	4 (3.3%)
At all stages of the process	14 (11.4%)
There was no dissemination plan	8 (6.5%)
When were dissemination activities executed/planned for execution (n=122)	
After completion of the accrual	3 (2.5%)
After completion of data collection	20 (16.4%)
At the draft report stage	10 (8.2%)
At the final report stage	47 (38.5%)
After publication of the manuscript	12 (9.8%)
At the time of submission of the abstract to the scientific meeting	2 (1.6%)
At all stages of the process	28 (23.0%)

There were 47 (38.5%) respondents who executed or planned to execute the research findings at the final stage of the report development, and another 28 (23.0%) who were keen to ensure that they disseminated at all stages of the study.

Table 7: Reasons for disseminating or planning to disseminate research findings

Responses (n=123)	**Number of responses**	**Percent among the participants who responded**
To raise awareness of the findings	102	82.9
To influence policy/practice	77	62.6
To promote public understanding of science	69	56.1
To stimulate discussion/ debate	58	47.2
To attract future funding	57	46.3
To justify funding	51	41.5
To raise your profile within the organization	48	39.0
To satisfy contractual obligations	39	31.7
Other	4	3.3
Total number of responses	**505**	

The respondents were asked why they disseminated/planned to disseminate their research findings. A total of 505 responses from 123 respondents were received on this item. Majority of the respondents (82.9%) responded that it was to raise awareness on the findings among different groups of audiences. Close to two thirds of the participants said it was to help influence policy and practice. 56.1% and 47.2% said it was to raise understanding on the science, and to stimulate discussion and debate respectively. Fifty seven (46.3%), and 51 (41.5%) of the respondents disseminated/planned to disseminated in order attract future funding, and to justify funding respectively. Less than 40.0% of the respondents did it to help raise their profiles within their organizations. The “other” respondents gave “the need to demonstrate ethical conduct of the research”, and “to show appreciation to the research participants” as the reasons for disseminating research findings. Two other respondents said that their researches were still ongoing and that they were therefore yet to disseminate.

Table 8: Investigator opinion on the most important reason for disseminating research findings

Most important reason (n=123)	n (%)
To raise awareness of the findings	41 (33.3%)
To influence policy and practice	39 (31.7%)
To attract future funding	13 (10.6%)
To promote public understanding of science	8 (6.5%)
To justify funding	6 (4.9%)
To stimulate discussion or debate	5 (4.1%)
To raise your profile within the organization	2 (1.6%)
Other	9 (7.3%)

One third of the participants (33.3%) thought that the most important reason for disseminating research findings is to raise awareness of the findings. Another 39 (31.7%) thought that doing so would influence policy and practice. Thirteen respondents representing 10.6%, thought that the most important reason for disseminating research findings is to help attract future funding while 4.9% thought that it was important in order to help justify funding already given. The respondents who indicated “other” did not specify what in their opinions were the most important reasons for dissemination.

4.5 Review of dissemination materials by IREC

There were 70 (57.4%) respondents who submitted multiple dissemination related documents to IREC for review, and 52 (42.6%) who did not submit any material to IREC. Table 9 below highlights what was submitted.

Table 9: Dissemination materials submitted to IREC for approval

Responses (n=70)	**Number of responses**	**Percent among the participants who responded**
Research summary document/research briefs/policy briefs	44	36.1
Community meetings/events guidelines	38	31.1
Content to be presented in scientific conferences & workshops	31	25.4
Content for publication in scientific journals	26	21.3
Flyers, posters, brochures	24	19.7
Letter of thanks to study participants	22	18.0
Study newsletters	19	15.6
Content for community agency publications	17	13.9
Request for approval to conduct road shows	14	11.5
Press releases	10	8.2
Content for release to the media	10	8.2
Total responses	**255**	

Of all the documents submitted to IREC, majority (36.1%) were research summary documents, research briefs and policy briefs. The others that were top in the list were community meetings and events guidelines (31.1%), content to be presented in scientific conference and workshops (25.4%) and content for publication in scientific journals (21.3%).

Table 10: Feedback from IREC on dissemination materials submitted to them

IREC feedback (n=70)	n (%)
Approval as it is/No comments	20 (28.8%)
Comments related to language/translation	17 (24.3%)
Comments related to language/translation, Comments related to appropriateness,	8 (11.4%)
Comments related to appropriateness	5 (7.1%)
Comments related to language/translation, Comments about dissemination method	5 (7.1%)
Comments about community engagement	4 (5.7%)
Comments related to language/translation, Comments related to appropriateness, Comments about dissemination method	4 (5.7%)
Comments about dissemination method	3 (4.3%)
Comments related to appropriateness, Comments about community engagement	1 (1.4%)
Comments related to language/translation, Comments about community engagement	1 (1.4%)
Comments related to language/translation, Comments related to appropriateness, Comments about community engagement	1 (1.4%)
Comments related to language/translation, Comments about dissemination method, Comments about community engagement	1 (1.4%)

The IREC responses were varied but 20 (28.8%) of the respondents received express approval without any comments on the dissemination materials they submitted to IREC. There were 17 (24.5%) respondents who received comments concerning the translation of the language.

4.6 Investigator opinions and practices on dissemination

Majority of the respondents, 52 (42.3 %) said that the main focus of their dissemination activities was the research participants while thirty four (27.6%) said that the main focus was the scientific community. There were 19 (15.4%) who said that the main focus was the local community. Up to 87.9% of the participants strongly agreed that it was important to disseminate research findings specifically to research participants.

Table 11: Dissemination practices of AMPATH investigators.

Variable	Sample size	n (%)
Main focus of the dissemination activities		
Scientific community		34 (27.6%)
Policy makers		16 (13.0%)
Research participants	123	52 (42.3%)
Local community		19 (15.4%)
Scientific community, research participants		1 (0.8%)
All of the above		1 (0.8%)
Importance of disseminating research findings to participants		
Extremely important		46 (37.1%)
Very important	124	63 (50.8%)
Fairly important		13 (10.5%)
Somewhat important		2 (1.6%)
Not important		0 (0.0%)
Frequency of producing dissemination materials targeted specifically at research participants		
Always		25 (20.3%)
Usually		23 (18.7%)
Sometimes	123	42 (34.1%)
Rarely		21 (17.1%)
Never		12 (9.8%)
Established mechanism to maintain contact with participants		
No		51 (41.8%)
Yes	122	71 (58.2%)
Received specific requests from individual participants		
No		61 (50%)
Yes	122	46 (37.7%)
Not sure		15 (12.3%)

One fifth of the respondents 25 (20.3%) always produce dissemination materials targeted specifically at the research participants. One third 42 (34.1%) sometimes produce materials tailored specifically for the research participants. There were 21 (17.1%) participants who rarely or have never produced materials for research participants. 71 (58.2%) established a mechanism to maintain contact with the participants with the intention of communicating results with them.

Slightly above one third (37.7%) of the respondents or members of their study teams had received specific requests from the research participants regarding results for studies they had participated in.

Table 12: Investigator opinions on dissemination methods with most impact to research participants

Variable	**n (%)**
Dissemination methods with the most impact to participants(n=122)	
Community meetings/events	36 (29.5%)
Research summary document/Research Briefs/Policy Briefs	28 (23.0%)
One-on-one	18 (14.8%)
Letter of thanks to the study participants	10 (8.2%)
Scientific conferences & workshops	7 (5.7%)
Other	7 (5.7%)
Publication in scientific journal	4 (3.3%)
Study newsletters	4 (3.3%)
Media	3 (2.5%)
Flyers posters, brochures	2 (1.6%)
Opinion leaders	2 (1.6%)
Road shows	1 (0.8%)
Community agency publication	0 (0.0%)
Press release	0 (0.0%)
E-mail/List-Serves/Mailing list	0 (0.0%)

A total of 36 (29.5%) respondents thought that community meetings and events are the dissemination methods that have the most impact to the research participants, while 28 (23.0%) thought that research summary documents, research briefs, and policy briefs have the most impact to the research participants.

A total of 113 respondents (91.1%, 95% CI: 84.7, 95.5) said they had disseminated research findings from their studies. The respondents used at least one of the methods in Table 13 (completed studies) and Table 14 (ongoing studies).

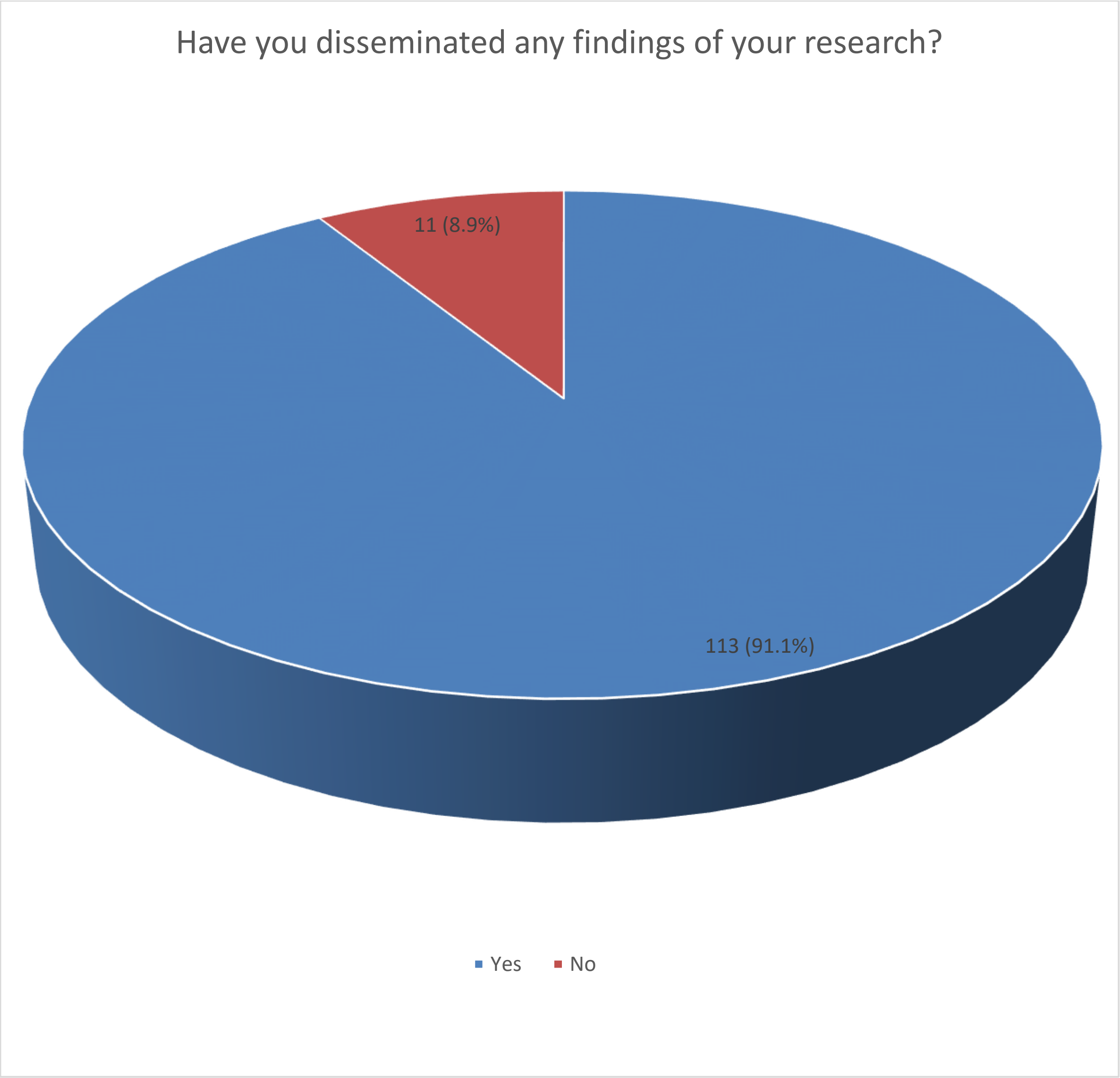


Figure 7: Overall dissemination of research findings

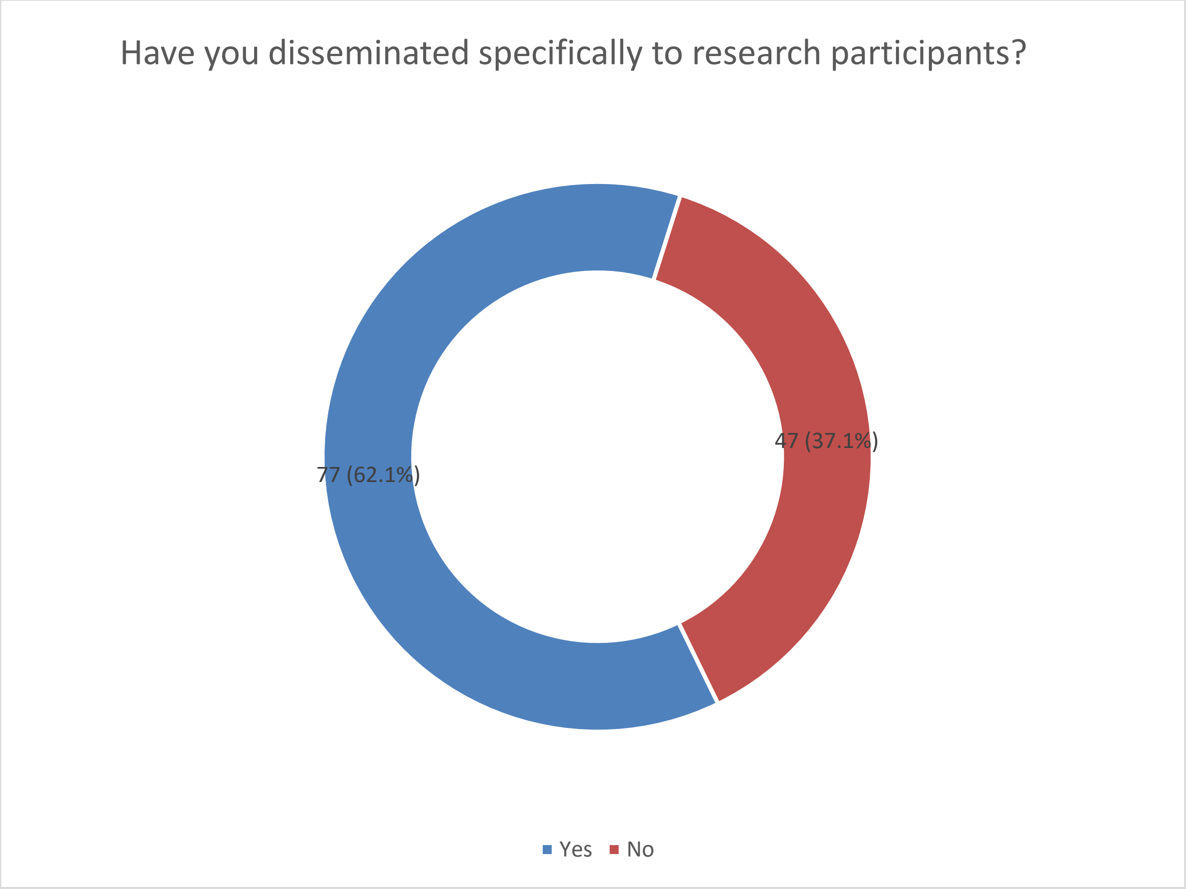


Figure 8: Dissemination specifically to research participants

Of all the participants that took the survey, 77 (62.1%, 95% CI: 53.4, 70.8) had disseminated their research findings specifically to the research participants.

Table 13: Methods used/planned to disseminate research findings

	Completed Studies: Responses (n=64)		Ongoing Studies: Responses (n=59)		All studies (n=123)	
Dissemination methods	**No. of responses**	**Percent among participants who responded**	**No. of responses**	**Percent among the participants who responded**	**No. of responses (Total)**	**Percent among the participants who responded (Total)**
Scientific conferences /workshops	36	56.2	25	42.4	61	49.6
Community meetings/events	27	42.2	32	54.2	59	48.0
Publication in scientific journals	27	42.2	21	35.6	48	39.0
Research summary document/research briefs/policy briefs	25	39.1	21	35.6	46	37.4
One-on-one	18	28.1	14	23.7	32	26.0
Opinion leaders	15	23.4	14	20.3	29	23.6
Letter of thanks to study participants	14	21.9	9	15.3	23	18.7
Flyers, posters, brochures	9	14.1	12	15.3	21	17.1
Press release	9	14.1	4	6.8	13	10.6
E-mail /list-serves/mailing lists	8	12.5	4	6.8	12	9.8
Study newsletters	8	12.5			8	6.5
Media	6	9.4	5	8.5	11	8.9
Other	4	6.2	7	11.9	11	8.9
Road shows	4	6.2	5	8.5	9	7.3
Community agency publications	3	4.7	6	10.2	9	7.3
Total responses	**214**		**188**		**402**	

The dissemination methods that were most commonly used/planned for use among respondents who had completed their studies were scientific conferences/workshops, community meetings/events, publications in scientific journals, and research summary documents/policy briefs accounting for 56.2%, 42.2%, 42.2%, and 39.1% of all the responses that were made by the participants respectively.

Majority of the participants (54.2%) who had ongoing studies used/planned to use community meetings/events to disseminate their findings. Another 42.4%, and 35.6% used/planned to use scientific conferences/workshops, publication in scientific journals respectively.

Overall, the most popular methods that were used/planned to be used by both groups (investigators of complete and ongoing studies) were scientific conferences/workshops accounting for 49.6% of all the responses. Community meetings/events represented 48% of the vote and was the second most popular method followed by publications in scientific journals (39%).The least commonly used/planned dissemination methods were road shows and community agency publications both accounting for only 7.3% of the responses.

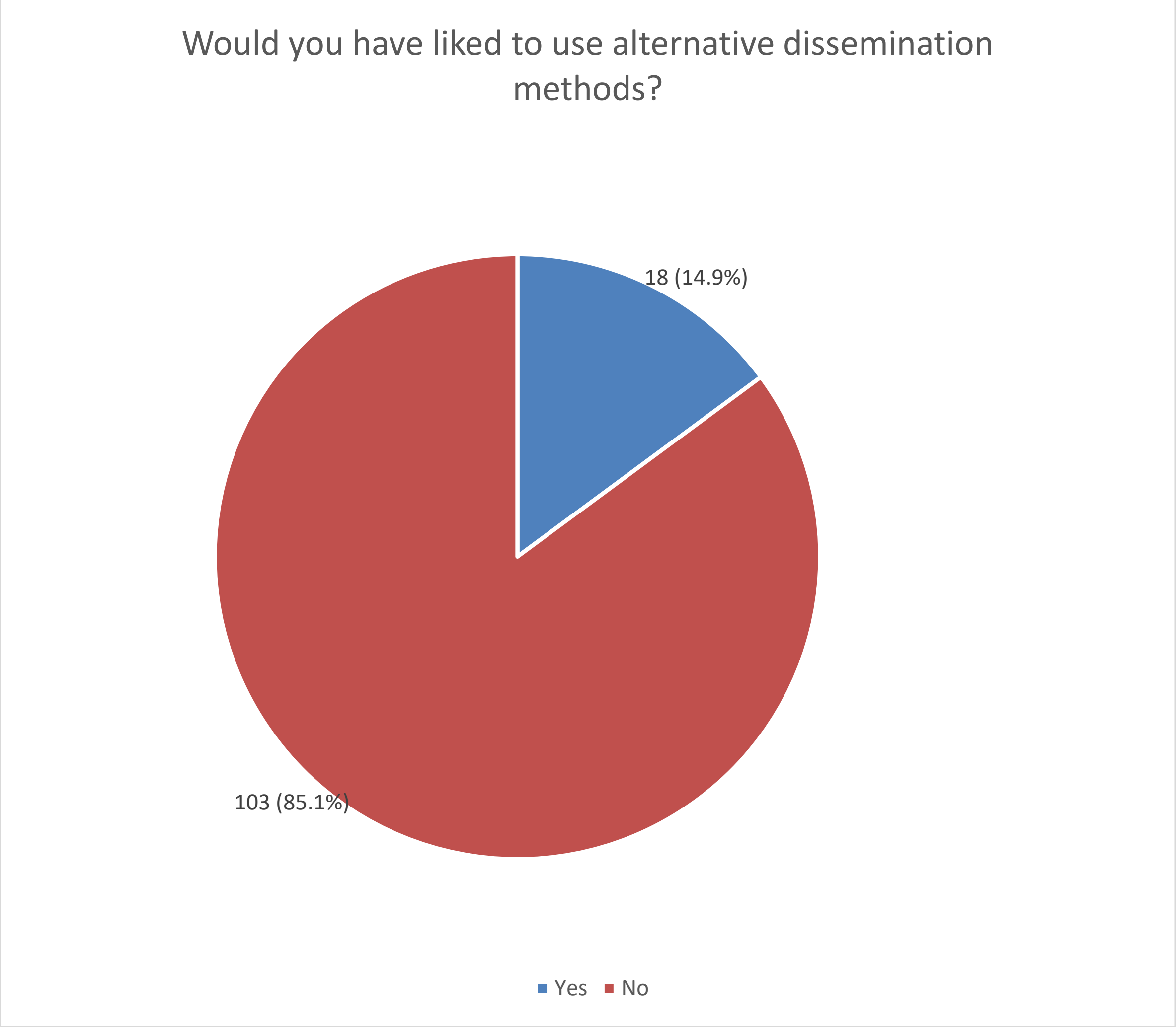


Figure 9: Alternative methods for dissemination

Eighteen of the participants (14.9%) said that they would have liked to use alternative dissemination methods not listed in the survey including: cell phones, home visits, using field counsellors with skills for counselling and disclosure of findings, phone/email contacts, through media, regular meetings with the communities and through the use of existing health systems e.g. health centres

4.6 Training on dissemination

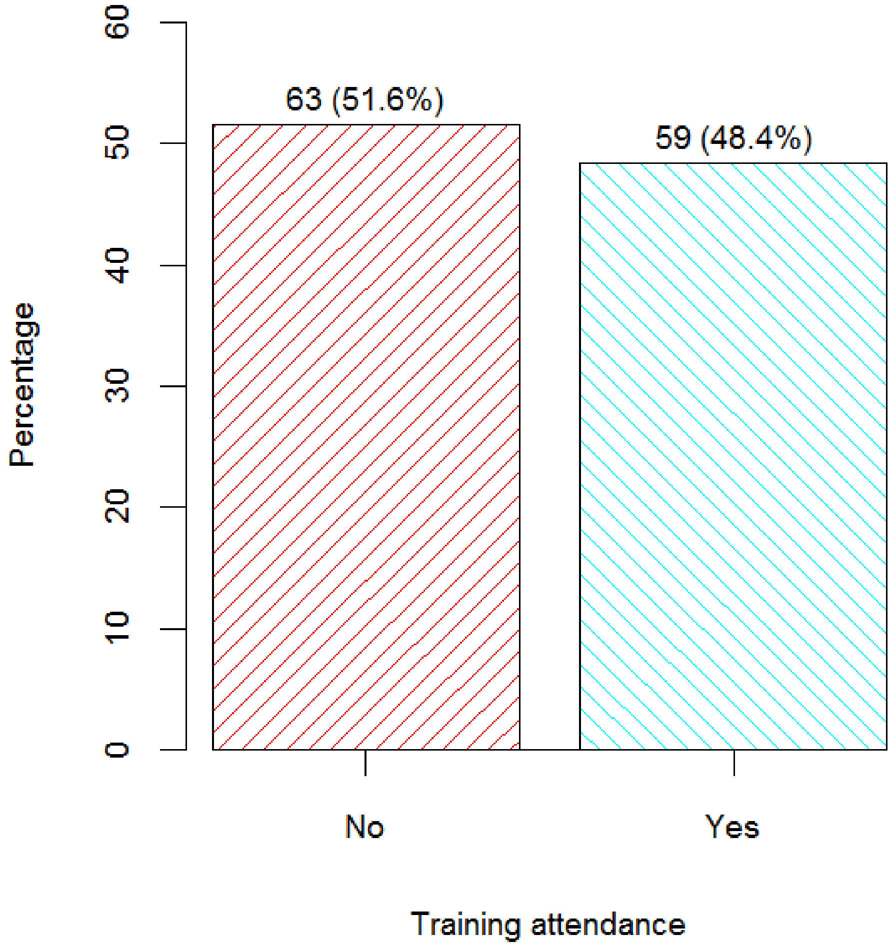


Figure 10: Training participation

Close to half of the participants 59 (48.4%) had attended training on dissemination of research findings. The methods they covered during the training were as shown in Table 14.

Table 14: Dissemination methods covered during the training

Responses (n=59)	**Number of responses**	**Percent among the participants who responded**
Scientific conferences/workshops	43	72.9
Research summary document/research briefs/policy briefs	39	66.1
Publication in scientific journals	36	61.0
Community meetings/events	33	55.9
Opinion leaders	26	44.1
Study newsletters	26	44.1
Flyers, posters, brochures	23	39.0
One-on-one	21	35.6
Letter of thanks to study participants	20	33.9
Media	19	32.2
Community agency publications	18	30.5
E-mail /list-serves/mailing lists	17	28.8
Press release	16	27.1
Road shows	15	25.4
All the above	3	5.1
Total responses	**355**	

Participants covered multiple methods. Of the total number of responses given on the methods covered, 43 (12.1%) were on how to use scientific conferences/workshops to disseminate research findings, 36 (9.3%) were on publication of the research findings in scientific journals, and 20 (5.6%) were on the need to send an appreciation letter to the research participants. Only 5.1% of the respondents covered all of the methods listed shown in Table 14.

Table 15: Audience/ group of focus during the trainings

Groups/Audience of focus (n=59)	n (%)
Scientific community	13 (22.0%)
Policy makers	2 (3.4%)
Research participants	23 (39.0%)
Local community	1 (1.7%)
No particular group	1 (1.7%)
Policy makers, Research participants, local community	1 (1.7%)
Research participants, Local community	2 (3.4%)
Research participants, Local community, No particular group	1 (1.7%)
Scientific community, policy makers	3 (5.1%)
Scientific community, policy makers, local community	2 (3.4%)
Scientific community, policy makers, Research participants	2 (3.4%)
Scientific community, policy makers, Research participants, local community	4 (6.8%)
Scientific community, Research participants	2 (3.4%)
Scientific community, Research participants, local community	2 (3.4%)

Of those who had attended any training, 38 (64.4%) said that the focus of their training was the research participants, 28 (47.5%) said it was the scientific community, 14 (23.7%) said it was the local community, and another 14 (23.7%) said that the focus of the training was on the policy makers. Two participants (3.4%) said that the training they attended was not focused on any particular group.

Thirty-two (54.2%) of those who were trained felt adequately prepared for dissemination activities.

4.7 Self-assessment on dissemination

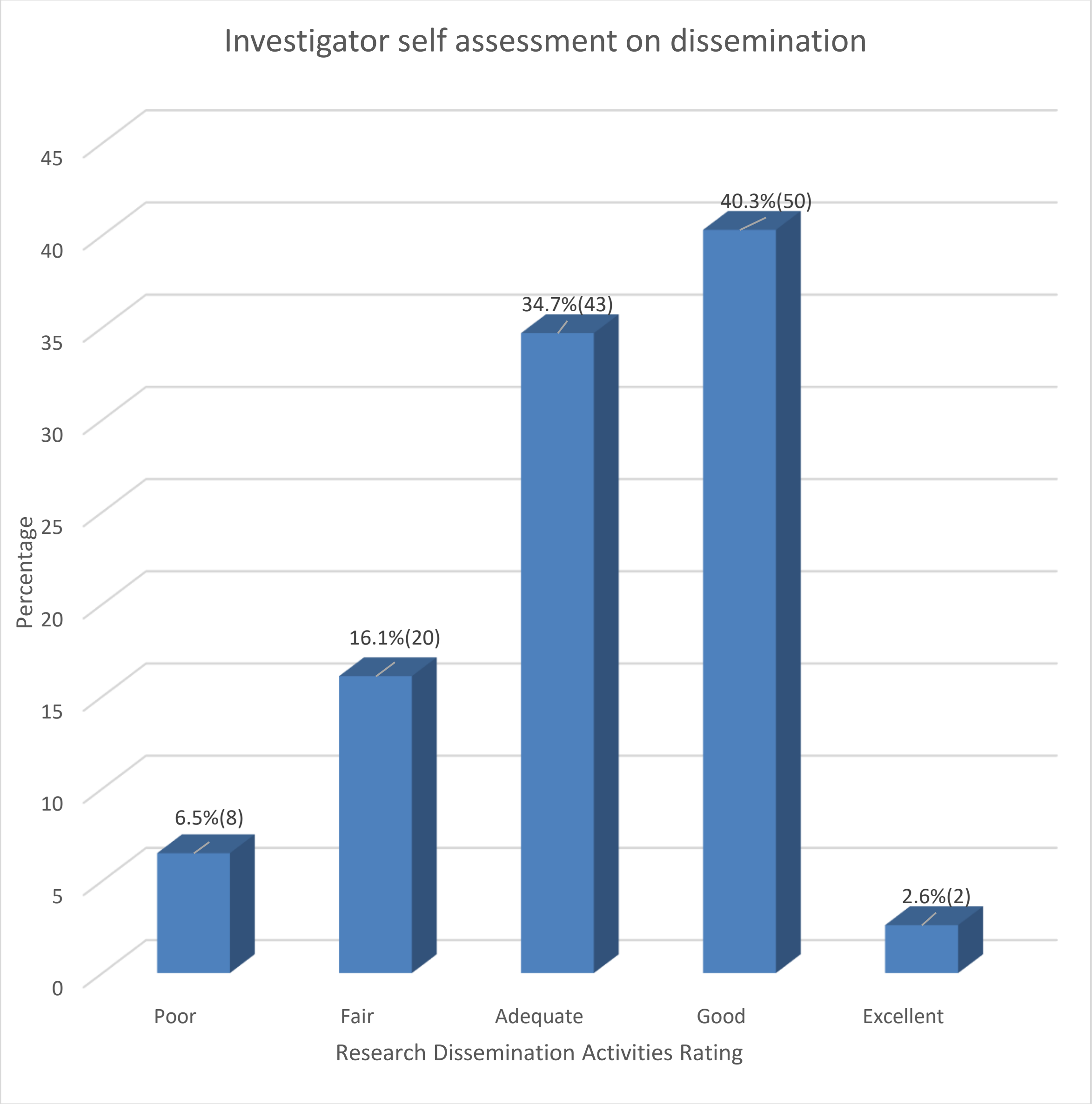


Figure 11: Rating of research dissemination activities

Over three quarter of the respondents, 95 (77.9%), were satisfied with the way they did their dissemination activities saying it was either adequate, good or excellent.

4.8 Association between key variables and dissemination

Table 16: Association between key variables and dissemination to research participants

Variable	Responses	Disseminated to study participants		Fisher's Exact P
		No	Yes	
Funding agency requirements explicitly stated (n = 107)	No	10 (35.7%)	18 (64.3%)	0.819
	Yes	26 (32.9%)	53 (67.1%)	
Nature of research (n = 123)	Behavioral	13 (34.2%)	25 (65.8%)	0.708
	Biomedical	31 (41.3%)	44 (58.7%)	
	Other	3 (30.0%)	7 (70.0%)	
Attended training (n = 122)	No	26 (41.3%)	37 (58.7%)	0.457
	Yes	20 (33.9%)	39 (66.1%)	
Allocated part of the budget for dissemination (n = 100)	No	11 (57.9%)	8 (42.1%)	0.032
	Yes	24 (29.6%)	57 (70.4%)	
Investigator experience (n = 124)	<5 studies	38 (42.2%)	52 (57.8%)	0.146
	≥5 studies	9 (26.5%)	25 (73.5%)	
Dissemination plan (n = 123)	No	7 (87.5%)	1 (12.5%)	0.005
	Yes	40 (34.8%)	75 (65.2%)	
Level of education (n = 124)	College	5 (50.0%)	5 (50.0%)	0.438
	Graduate Degree	22 (39.3%)	34 (60.7%)	
	Masters degree	17 (39.5%)	26 (60.5%)	
	PhD	3 (20.0%)	12 (80.0%)	
Nature of study funding (n = 123)	Externally funded	34 (33.3%)	68 (66.7%)	0.047
	Partially funded	4 (57.1%)	3 (42.9%)	
	Self-funded	9 (64.3%)	5 (35.7%)	
Submitted dissemination related materials to IREC (n = 122)	No	27 (51.9%)	25 (48.1%)	0.008
	Yes	19 (27.1%)	51 (72.9%)	

Respondents who had to meet the dissemination requirements from the funding agency had a higher probability to disseminate the research findings (67.1%) compared to those who did not have dissemination requirements explicitly stipulated (64.3%). However, there was no sufficient evidence from the data to link dissemination of research findings to explicit requirement to disseminate the research findings, p=0.819.

The nature of research conducted was not associated with explicit dissemination to the research participants, p=0.708. Similarly, those who attended training on dissemination of research findings were not associated with increased likelihood of dissemination to the research participants, p=0.457.

Respondents who had allocated part of their budget for dissemination of the research findings were more likely to disseminate the research findings (70.4%) compared to those who did not allocate their budget for dissemination of the research findings (42.1%), p=0.032.

Those who had dissemination plan in place were more likely to disseminate their findings to the research participants (65.2%) compared to those who did not have a plan (12.5%), p=0.005. Similarly, those who submitted dissemination related materials to IREC were more likely to disseminate their research findings to the research participants (72.9%)compared to those who did not submit (48.1%), p=0.008.

Table 17: Logistic regression model on joint effect of the factors associated with dissemination

Variable		**Unadjusted OR (95% CL)**	**Adjusted OR (95% CL)**
Allocated part of the budget for dissemination		3.27 (1.18, 9.43)	2.11 (0.67, 6.62)
Dissemination plan present		13.12 (2.23, 249.87)	-
Nature of study funding	Partially funded or self-funded vs. Externally funded/study grant	0.31 (0.11, 0.80)	0.3 (0.09, 0.96)
Submitted dissemination related materials		2.90 (1.37, 6.27)	2.81 (1.13, 7.13)
Sample size used:			98

OR – Odds Ratio; CL – Confidence limits; “-” Not included in the adjusted model due to small cell frequencies.

Adjusting for the nature of study funding and allocation of the budget for dissemination, the participants who submitted dissemination related materials had more than twofold increased odds of dissemination, OR: 2.81 (95% CL: 1.13, 7.13). On the other hand, adjusting for allocation of the budget for dissemination and submission of the dissemination related materials, the participants who w ere either self-funded or were partially funded had 70% reduced odds of dissemination findings compared to those who were externally funded of had study grants, OR: 0.30 (95% CL: 0.09, 0.96).

CHAPTER 5: DISCUSSION

5.0 Introduction

This chapter presents the interpretation of results in relation to the study objectives. The discussion was used to draw conclusions which will in turn informed the recommendations for the study.

5.1 Proportion of investigators who disseminate

This study found that majority of investigators at AMPATH disseminate findings of their research. 91% of the participants had disseminated their research findings to various audiences, through various means. The proportion of respondents that exclusively disseminated to research participants was 62.1% which is much higher than a study conducted in Sudan (Elsayed & Kass, 2006) where the prevalence of dissemination to research participants was 20%. In the US a study (Hood, Brewer, Jackson, & Wewers, 2010) found that 20% of investigators of NIH funded studies disseminated back to the communities through various community based initiatives. At AMPATH, this was 3 times the proportion who disseminated in these other settings. This could be attributed to AMPATH research program standard operating procedures that urges dissemination of findings to the local communities and research participants. The study can however not entirely rule out the possibility of social desirability bias on the part of respondents, telling us what they think we want to hear, since this study was self-reported.

In our study, 71 respondents had established mechanisms to maintain contact with study participants with the aim of disseminating findings to them. Although it’s not possible to create a direct link, establishing a mechanism to contact participants could be construed to indicate an intention to disseminate to research participants.

5.2 Dissemination methods utilized

Among investigators who had completed their studies, scientific conferences/workshops constituted the dissemination method most used .This was followed by community meetings and events. This was different from a study (Waddell, 2001) in which publication in scientific journals was found to be the most used method even though the dissemination methods in our study followed popular academic outputs as found in the similar study by Paul Wilson(Wilson et al., 2010). A South African study (Sibanda, Summers, & Meyer, 2016) found that 35% of clinical studies conducted had been published in peer reviewed journals. This was very close to the 42.2% (completed studies) and the 35.6% (ongoing studies) found in this study. Methods such as community agency publications, road shows, media and study newsletters were least used. Perhaps these methods have yet to be adopted in the scientific arena and within this context for dissemination of findings.

For ongoing studies, investigators said the method they would use most to disseminate findings was community meetings/events. This was followed by scientific conferences/workshops. Publications in scientific journals also came third amongst investigators whose studies were still ongoing.

5.3 Factors affecting dissemination

The study investigated how several variables impacted dissemination to research participants by investigators at AMPATH. First, the study looked at whether investigator experience (based on the number of studies undertaken by an investigator) had any impact on dissemination to participants. The study found that neither the level of education nor investigator experience was associated with dissemination of findings to research participants. This is probably because investigators with different levels of education and experience, all operate within the same institutional framework which grants them equal opportunity to disseminate.

Secondly, the study sought to determine if there was a relationship between the type of research an investigator conducted and the likelihood of them disseminating to research participants. The nature of research was not associated with dissemination to research participants with investigators of biomedical, behavioural and “other” studies all having similar dissemination patterns.

Under investigation also, was how the nature of funding, funding agency requirements and amount of budgetary allocation influenced dissemination to research participants.

Overall, close to three quarters of all the studies (funded and non-funded) dedicated less than 10% of their study budgets to dissemination related activities. This is in keeping with practice. A study in Denmark (Nielsen et al., 2009) found that only 0.6 % of research budgets had been allocated for dissemination related activities. Of the funded studies, sponsors had varied requirements related to dissemination with the most common being the method of dissemination and the least being concerns related to frequency of dissemination. We did not probe further to determine which methods were most emphasized by the sponsors. Scientific conferences/workshops received the lion’s share of the budgets. This could explain why it was the most used method of dissemination by investigators of completed studies as demonstrated above. Media received the least funding among the dissemination methods and this could also explain why it was among the least used dissemination method. The prohibitive costs associated with using the media could also explain the low uptake of the dissemination method.

Similar to a study done in the United Kingdom (Wilson et al., 2010) , there was a wide variation in funder expectations as to their requirements for dissemination. Participants who had to meet the dissemination requirements from the funding agency had a higher probability to disseminate the research findings compared to those who did not have dissemination requirements explicitly stipulated. However, there was no sufficient evidence from the data to link dissemination of research findings to explicit requirement to disseminate the research findings.

There was however a strong association between allocation of budget to dissemination activities and dissemination to research participants (P=0.032). Majority of the research studies covered in this study were externally funded/research grants. The nature of study funding was directly associated with dissemination to research participants with externally funded studies being more likely to disseminate (p=0.047).

Apart from budgeting, the study investigated what other measures taken by investigators prior to study completion had influences on dissemination activities. We looked at regulatory/ethical preparations including submission of dissemination materials to IREC and preparation of an elaborate dissemination plan by the investigators. We found that there was a direct association between having a dissemination plan and dissemination to research participants (p=0.005). According to the Canadian Health services (Canadian Foundation for Health-care Improvement, 2014), developing a dissemination plan helps research teams to be able to synthesize research findings more effectively, identify key audiences and therefore improve chances of dissemination. This seems to be what happened with the investigators at AMPATH and confirms the assertion by several authors that unless dissemination is built in from the beginning, it normally does not happen (Lomas, 1997; Yale, 2001).

This study found that investigators disseminated/planned to disseminate findings from their research studies primarily to raise awareness of findings and to influence policy. Their actions were in line with their beliefs as these very reasons are what they thought were the most important in the dissemination effort. This is in keeping with literature on beliefs leading to or influencing action (Fullilove et al., 2007).

Institutional review boards play an important role in determining the ethical merits of a study. Close to half of the participants submitted several dissemination materials to IREC for review.

Majority of the participants' submitted Research summary document/research briefs/policy briefs which are not targeted at research participants but rather to the scientific community and policy makers. Apart from community meetings/event guidelines, most of the other materials that would be targeted specifically at research participants' e.g. letter of thanks to study participants, content for community agency publications, press releases and content for media distribution were seldom submitted to IREC for review. These dissemination methods were also seldom used by the investigators. There was however a positive association between submitting dissemination materials to IREC and disseminating to research participants (p=0.008). Perhaps submitting dissemination materials to IREC was an indication that the investigator had made adequate plans for dissemination prior to study initiation.
Similar to a UK study that found that 93% of investigators considered dissemination to be an important activity (Wilson et al., 2010), there was general consensus on the importance of disseminating findings to research participants with over 87% of the respondents selecting either "extremely important" or "very important" when asked how important they thought it was to disseminate to research participants. This importance translates to focus as majority of the investigators focused their dissemination activities on research participants followed by the scientific community. The investigators perspectives on importance and focus of dissemination to research participants could be responsible to the high rate of dissemination to participants as indicated above.

Close to half the respondents had attended some form of training on dissemination. Scientific conferences/workshops again featured prominently as the methods of dissemination covered in the trainings according to most respondents. Research summary document/research briefs/policy briefs as well as publications in scientific journals were the next most covered methods of dissemination in the trainings. All these methods focus on the scientific community and policy makers. As much as most of the training methods covered had a focus on the scientific community and policy makers, research participants were considered the main focus of the trainings when it came to audience by the respondents. There was therefore a disconnect between the methods emphasized in the trainings and the focus of the trainings in the opinion of the respondents. This could have been a bias by the respondents since they understood that the survey was specifically targeting dissemination to research participants. This is perhaps why training was not found to be an important determinant whether investigators disseminate to research participants or not. There was no association (p=0.457) between training and dissemination to research participants. This differs from a study conducted South Africa (Kramer & Libhaber, 2016) that demonstrated that training investigators led to increased dissemination of scientific knowledge.

5.2 Conclusions

The proportion of investigators at AMPATH that disseminate findings from their researches to research participants is comparatively higher than investigators in other settings.

The most popular method of dissemination amongst AMPATH investigators is through scientific conferences/workshops.

The factors that influence dissemination to research participants at AMPATH are allocation of budget to dissemination activities, presence of a dissemination plan, nature of study funding and submission of dissemination related materials to IREC.

5.3. Recommendations

AMPATH to encourage Investigators to continue building dissemination to research participants into their overall dissemination plans.

Investigators of self-sponsored studies at AMPATH are encouraged to make efforts for dissemination to research participants like their funded counterparts

IREC to ensure that all proposals sent to them have a dissemination plan to research participants as well as adequate budgetary provision for dissemination.

5.4 Future research

As much as this study established that a high proportion of AMPATH investigators disseminate to research participants, more research still needs to be done to find out what kind of information is disseminated by these investigators. It still needs to be determined whether investigators disseminate individual or aggregate results and whether all information disseminated is peer reviewed prior to dissemination.

The study was also able to determine what methods the investigators use most but a more in depth qualitative study can be done to unearth the factors that influence their choices and their attitudes towards less conventional dissemination methods.

This study also focused on dissemination to research participants but from the investigators perspective. It will be interesting to do a research from the participant's perspective to gain more in depth understanding of their attitudes and opinions and also to corroborate findings from this study.

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APPENDIX I: BUDGET

Items	**Quantity**	**Unit Price (KES)**	**Total (KES)**
Stationery & Equipment			
Printing Papers	5 reams	500.00	2,500.00
Black Cartridges	2	2,000.00	4,000.00
Writing Pens	1 packet	500.00	500.00
Flash Discs	1	2,000.00	2,000.00
Box Files	2	200.00	400.00
Document Wallets	2	50.00	100.00
Sub total			**9,500.00**
Research Proposal Development			
Printing drafts & final proposal	10 copies	500.00	5,000.00
IREC Fees			1,000.00
Photocopies of final proposal	6 copies	100.00	600.00
Binding of copies of Proposal	5 copies	100.00	500.00
Sub total			**7,100.00**
Personnel			
Biostastician	1	10,000.00	10,000.00
Sub total			**10,000.00**
Thesis Development			
Printing of drafts and final thesis	10 copies	800.00	8,000.00
Photocopy of final thesis	6 copies	200.00	1,200.00
Binding of thesis	6 copies	300.00	1,800.00
Sub total			**11,000.00**
Grand Total			**37,600.00**

BUDGET JUSTIFICATION

Stationery and Equipment

Stationery and equipment constituted a total of nine thousand five hundred shillings of the total budget. Printing papers were required for printing draft proposals to supervisors, final proposal to IREC and printing necessary amendments. To facilitate safekeeping of the information a flash discs was required for data storage. The researcher also required ballpoint pens, notebooks and document wallets for his work.

Research Proposal Development

Research proposal development costs are incurred during the write-up of the proposal and summed up to seven thousand one hundred shillings. The bulk of these expenses were incurred during the printing of the drafts of the proposal before seeking approval and submission to the Institutional Research and Ethics Committee (IREC). Several copies had to be submitted to IREC.

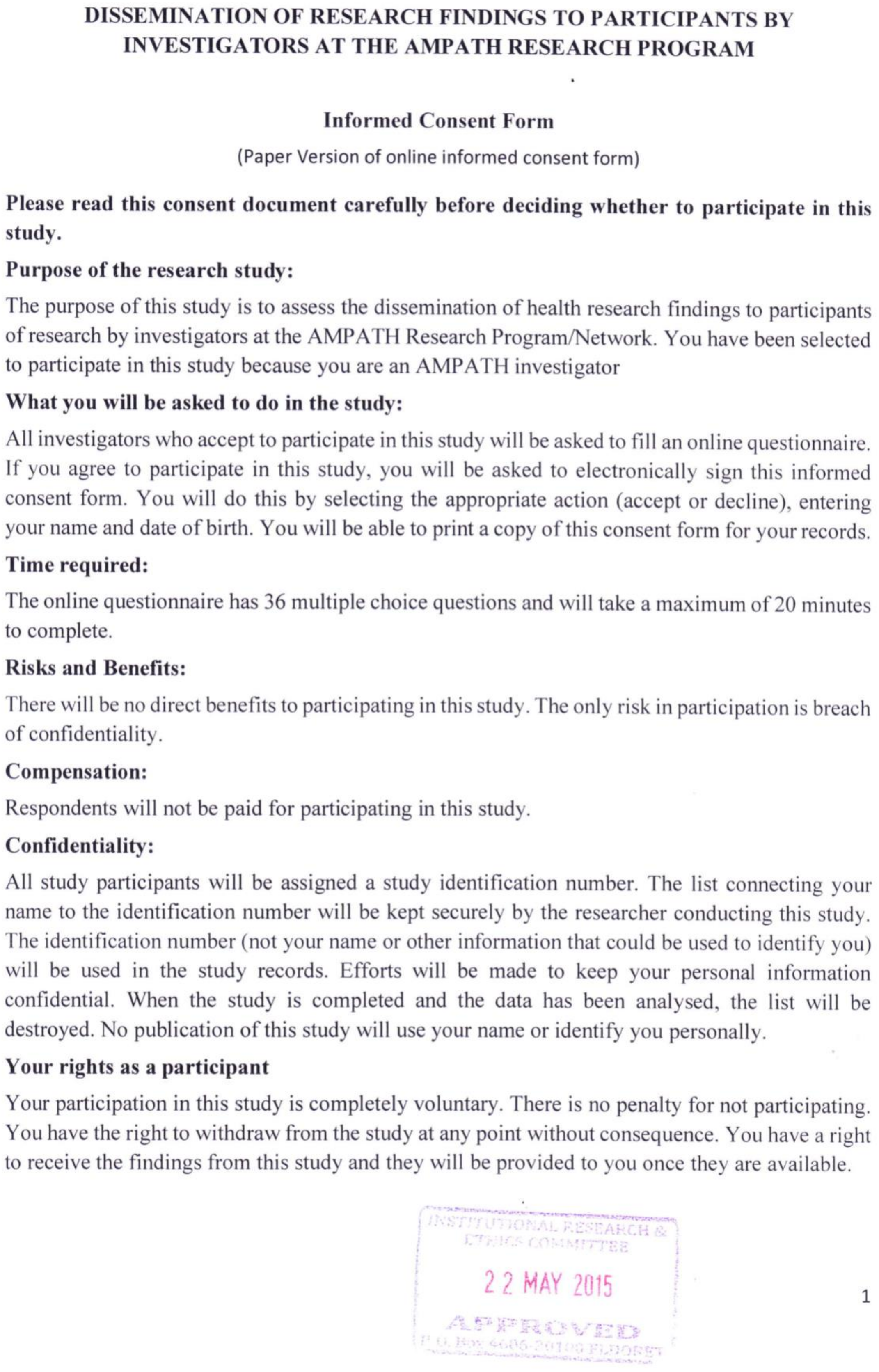
Personnel

A biostatician was required for a period of two (2) weeks to assist in data analysis. The Principal investigator was however responsible for the development of the research proposal, supervising data collection, writing of the final thesis and dissemination of information.

Thesis Development

Writing of the thesis commenced after data collection and analyses. Costs included printing of drafts, which had to be read and approved by the supervisors before being submitted to the School of Medicine for marking. After the thesis defence, copies of the thesis are to be submitted to the School. Dissemination costs will encompass providing the respondents and other interested parties with feedback, this involves publications in a peer reviewed journal and presentations in AMPATH work in progress presentations.

APPENDIX II: INFORMED CONSENT FORM



DISSEMINATION OF RESEARCH FINDINGS TO PARTICIPANTS BY INVESTIGATORS AT THE AMPATH RESEARCH PROGRAM

Informed Consent Form

(Paper Version of online informed consent form)

Please read this consent document carefully before deciding whether to participate in this study.

Purpose of the research study:

The purpose of this study is to assess the dissemination of health research findings to participants of research by investigators at the AMPATH Research Program/Network. You have been selected to participate in this study because you are an AMPATH investigator

What you will be asked to do in the study:

All investigators who accept to participate in this study will be asked to fill an online questionnaire. If you agree to participate in this study, you will be asked to electronically sign this informed consent form. You will do this by selecting the appropriate action (accept or decline), entering your name and date of birth. You will be able to print a copy of this consent form for your records.

Time required:

The online questionnaire has 36 multiple choice questions and will take a maximum of 20 minutes to complete.

Risks and Benefits:

There will be no direct benefits to participating in this study. The only risk in participation is breach of confidentiality.

Compensation:

Respondents will not be paid for participating in this study.

Confidentiality:

All study participants will be assigned a study identification number. The list connecting your name to the identification number will be kept securely by the researcher conducting this study. The identification number (not your name or other information that could be used to identify you) will be used in the study records. Efforts will be made to keep your personal information confidential. When the study is completed and the data has been analysed, the list will be destroyed. No publication of this study will use your name or identify you personally.

Your rights as a participant

Your participation in this study is completely voluntary. There is no penalty for not participating. You have the right to withdraw from the study at any point without consequence. You have a right to receive the findings from this study and they will be provided to you once they are available.

INSTITUTIONAL RESEARCH &
ETHICS COMMITTEE
22 MAY 2015
APPROVED
P.O. Box 4606-30100 ELDORET

Whom to contact if you have questions about the study:

If you have any questions or concerns about this study, you can reach the researcher through the following contacts:

Allan Sudoi – Reg No. SM/PG/IRE/01/12
Moi University School of Medicine,
P. O. Box 4606, Eldoret.
Cell phone: 0721821242.
Email: aksudoi@gmail.com

Whom to contact about your rights as a research participant in the study:

If you have any concerns about your rights as a research participant, you can contact:
The human subject's administrator,
Institutional Research and Ethics Committee,
P O Box 3-30100, Eldoret.
Phone: 0787 723 677.

Agreement:

I have read this consent form and all my questions have been answered.

- ☐ I voluntarily agree to participate in this study by signing below.
- ☐ I do not wish to participate in this study

Name (Print)	Email address	Date Of Birth	Today's Date

APPENDIX III: SEMI STRUCTURED QUESTIONNAIRE

(Paper version of online form)

Dissemination Of Findings To Research Participants By Investigators At The AMPATH Research Network.

You have been selected to participate in this study because you are an AMPATH investigatorYou are also receiving this online questionnaire because you have consented to participate in this study.

This study aims to describe the dissemination practices of investigators at the AMPATH research program, with a focus on dissemination to research participants.

This questionnaire contains 35 questions and can be completed within 15- 20 minutes.

Any information provided will be treated with utmost confidentiality . The investigator in this study is Mr. Allan Sudoi, a Masters student in International Health Research Ethics (IHRE), Moi University, School of Medicine, Eldoret, Kenya.

For questions or clarifications, contact Allan Sudoi (aksudoi@gmail.com).

A. Demographic information

1. What is your highest level of education?

(*Only select completed studies*)

☐ College Certificate/Diploma

☐ Undergraduate degree e.g BSc., BA

☐ Medical undergraduate degree e.g. MBChB/ MD

☐ Graduate degree e.g MMed, MSc./ MpH/ MA.

☐ Post graduate degree e.g Ph.D.

☐ other: ____________

2. Date of Birth ____________

3. Sex

☐ Male

☐ Female

4. Which of these institutions is your mother institution/ primary employer?

☐ AMPATH

☐ Brown University School of Medicine

☐ Columbia University

☐ Duke University Medical Center/Hubert-Yeargan Center for Global Health

☐ George Washington University

☐ Indiana University- Purdue University in Indianapolis(IUPUI)

☐ Indiana University School of Medicine

☐ Lehigh Valley Hospital

☐ Moi Teaching and Referral Hospital

☐ Moi University

☐ Mount Sinai School of Medicine

☐ New York University

☐ Providence Portland Medical Center

☐ Purdue University

☐ Syracuse University

☐ University of California San Francisco

☐ University of Massachusetts Medical School

☐ University of Missouri

☐ University of North Carolina

- ☐ University of Notre Dame/Eck Institute for Global Health
- ☐ University of Toronto Faculty of Medicine
- ☐ University of Utah School of Medicine
- ☐ other: ____________

5. **Investigator Status**

- ☐ Local/Kenyan P.I
- ☐ International P.I
- ☐ Local/Kenyan Sub-investigator
- ☐ International Sub-investigator
- ☐ Program/Project Staff member
- ☐ Other______________________

6. How many AMPATH research studies have you participated in/undertaken?

- ☐ 1-2
- ☐ 3-4
- ☐ 5-6
- ☐ 7-8
- ☐ 9-10
- ☐ >10

B. Study Details

7. **What is the status of the research project for which your responses to this questionnaire are based?**

(if you have more than one research project, please base your responses on only one)

- ☐ Proposal stage
- ☐ Proposal completed, yet to collect data
- ☐ Data collection ongoing

- ☐ Data-analysis on-going
- ☐ Complete

8. **Which option below best describes the nature of your research?**
    - ☐ Biomedical
    - ☐ Behavioural
9. **What was the nature of your study funding?**
    - ☐ Self funded
    - ☐ External funding/ Study Grant
    - ☐ Partial funding
    - ☐ Other___________
10. **Which of the following dissemination requirements were explicitly stated in your contracts with the funding agency?**
    - ☐ Requirements related to the method of dissemination
    - ☐ Requirements related to the mode/media for dissemination
    - ☐ Requirements related ownership of disseminated materials
    - ☐ Requirements for intellectual property rights
    - ☐ Requirements related to audience of dissemination activities
    - ☐ Requirements for dissemination to research participants
    - ☐ Requirements related to review of dissemination materials by sponsor prior to dissemination
    - ☐ Requirements related to frequency of dissemination
    - ☐ There were no requirements on dissemination in the contracts
    - ☐ Other_______________________________________
11. **Do you believe the funder could have done more to help in dissemination of research findings?**

☐ No

☐ Yes

If yes, please give details:

____

____

12. What proportion of your budget was dedicated to dissemination related activities?

☐ None

☐ Less than 5%

☐ Between 5 and 10%

☐ Between 11 and 20%

☐ Between 21 and 30%

☐ Between 31 and 40%

☐ Between 41 and 50%

☐ More than 50%

☐ Do not know

13. **What methods of dissemination listed below were supported in your budget?**

Please tick all that apply

☐ N/A

☐ Letter of thanks to study participants

☐ Community meetings/Events

☐ Study Newsletters

☐ Dissemination through opinion leaders

☐ Community Agency Publications

☐ One-on-one

- ☐ Flyers, Posters, Brochures
- ☐ Road shows
- ☐ Research Summary Document/Research Briefs/Policy Briefs
- ☐ Scientific conferences/workshops
- ☐ Publication in Scientific journals
- ☐ Press Release
- ☐ E-mail /List-Serves/Mailing lists
- ☐ Media
- ☐ Other (please give details)

14. Was a dissemination plan produced for the research project?

- ☐ Yes
- ☐ No
- ☐ Not sure

15. At what stage in the research process did you plan dissemination-related activities?

- ☐ At the proposal stage
- ☐ After completion of accrual
- ☐ After completion of data collection
- ☐ At the draft report stage
- ☐ At the final report stage
- ☐ After publication of the manuscript
- ☐ At the time of submission of the abstract to a scientific meeting At all stages of the process

16. At what stage in the research process did you execute/plan to execute dissemination-related activities?

☐ After completion of accrual

☐ After completion of data collection

☐ At the draft report stage

☐ At the final report stage

☐ After publication of the manuscript

☐ At the time an abstract is submitted to a scientific meeting

☐ At all stages of the process

17. Why did you disseminate/plan to disseminate the findings of your research?

Please tick all that apply

☐ To raise awareness of the findings

☐ To stimulate discussion/ debate

☐ To influence policy and practice

☐ To justify funding

☐ To attract future funding

☐ To raise your profile within the organisation

☐ To promote public understanding of science

☐ To satisfy contractual obligations

☐ Other (please give details)

____

____

18. In your opinion, which of the above reasons for disseminating the findings of your research is the most important?

Please choose one

☐ To raise awareness of the findings

☐ To stimulate discussion/ debate

☐ To influence policy and practice

☐ To justify funding

☐ To attract future funding

☐ To raise your profile within the organisation

☐ To promote public understanding of science

☐ To satisfy contractual obligations

☐ Other ___________________________

19. **Did you receive any comments about dissemination to research participants during the review of your research proposal at IREC?**

☐ Yes

☐ No

☐ Don't know

☐ If yes, please give details:

20. **Which of the following dissemination related materials did you submit to IREC for approval over the course of your study?**

Please tick all that apply

☐ Letter of thanks to study participants

☐ Community meetings/Events guidelines

☐ Study Newsletters

☐ Content for Community Agency Publications

☐ Flyers, Posters, Brochures

☐ Request for approval to conduct Road shows

☐ Research Summary Document/Research Briefs/Policy Briefs

☐ Content to be presented in scientific conferences/workshops

☐ Content for Publication in Scientific journals

☐ Press Releases

☐ Content for release to the media

☐ Did not submit any dissemination related materials

☐ Other (please give details)

21. What kind of feedback did you receive for your submissions?

☐ N/A

☐ Comments related to language/translation

☐ Comments related to appropriateness

☐ Comments related to dissemination method

☐ Comments about community engagement

☐ Approval as it is/ No comments received

☐ Other____________________________

22. As part of your research dissemination, how important do you think it is to consider how audiences or groups you would like to reach access, read, and use research findings?

☐ Extremely important

☐ Very important

☐ Fairly important

☐ Somewhat important

☐ Not important

23. Did/Do you tailor your dissemination materials to your audience?

☐ Never

☐ Rarely

☐ Sometimes

- ☐ Often
- ☐ Always

24. Who would you say is/was the main focus of your dissemination activities?

- ☐ Scientific community
- ☐ Policy makers
- ☐ Research participants
- ☐ Local community
- ☐ Other

25. How important is it to disseminate research findings/results to research participants?

- ☐ Extremely important
- ☐ Very important
- ☐ Fairly important
- ☐ Somewhat important
- ☐ Not important

26. **Did/Do you ever produce dissemination materials targeted specifically at research participants?**

- ☐ Always
- ☐ Usually
- ☐ Sometimes
- ☐ Rarely
- ☐ Never

27. Did you establish a mechanism to maintain contact with research participants with the express intent of facilitating disclosure of research results?

- ☐ No
- ☐ Yes

If yes, please give details:

28. Have you or a member of your research team received any specific requests by individual participants regarding findings from research they participated in?

☐ Yes

☐ No

☐ Not sure

If yes, please give details:

____

____

29. **Of the following dissemination methods, which do you think have the most impact to research participants?**

☐ Letter of thanks to study participants

☐ Community meetings/Events

☐ Study Newsletters

☐ Opinion leaders

☐ Community Agency Publications

☐ One-on-one

☐ Flyers, Posters, Brochures

☐ Road shows

☐ Research Summary Document/Research Briefs/Policy Briefs

☐ Scientific conferences/workshops

☐ Publication in Scientific journals

☐ Press Release

☐ E-mail /List-Serves/Mailing lists

☐ Media

☐ Other (please give details)

---

30. **Which of these methods did you use/plan to use to disseminate your research findings?**

Please tick all that apply

☐ Letter of thanks to study participants
☐ Community meetings/Events
☐ Study Newsletters
☐ Opinion leaders
☐ Community Agency Publications
☐ One-on-one
☐ Flyers, Posters, Brochures
☐ Road shows
☐ Research Summary Document/Research Briefs/Policy Briefs
☐ Scientific conferences/workshops
☐ Publication in Scientific journals
☐ Press Release
☐ E-mail /List-Serves/Mailing lists
☐ Media
☐ Other (please give details)

____

____

31. Are there any research dissemination methods that you would like to have used but were unable to do so?

☐ No
☐ Yes

If yes, please give details:

____

____

32. Have you ever attended a training on dissemination of research findings?

☐ Yes (jump to question 34)

☐ No

33. If yes to question 32 above, which dissemination methods below were covered in the training?

(Please tick all that apply)

☐ Letter of thanks to study participants

☐ Community meetings/Events

☐ Study Newsletters

☐ Opinion leaders

☐ Community Agency Publications

☐ One-on-one

☐ Flyers, Posters, Brochures

☐ Road shows

☐ Research Summary Document/Research Briefs/Policy Briefs

☐ Scientific conferences/workshops

☐ Publication in Scientific journals

☐ Press Release

☐ E-mail /List-Serves/Mailing lists

☐ Media

☐ Other (please give details)

____

____

34. Which of the following groups/audience did the training focus on?

- ☐ Scientific community
- ☐ Policy makers
- ☐ Research participants
- ☐ Local community
- ☐ No particular group
- ☐ Other

35. Do you feel adequately trained for dissemination activities?

- ☐ No
- ☐ Yes

If yes, please give details of your training:

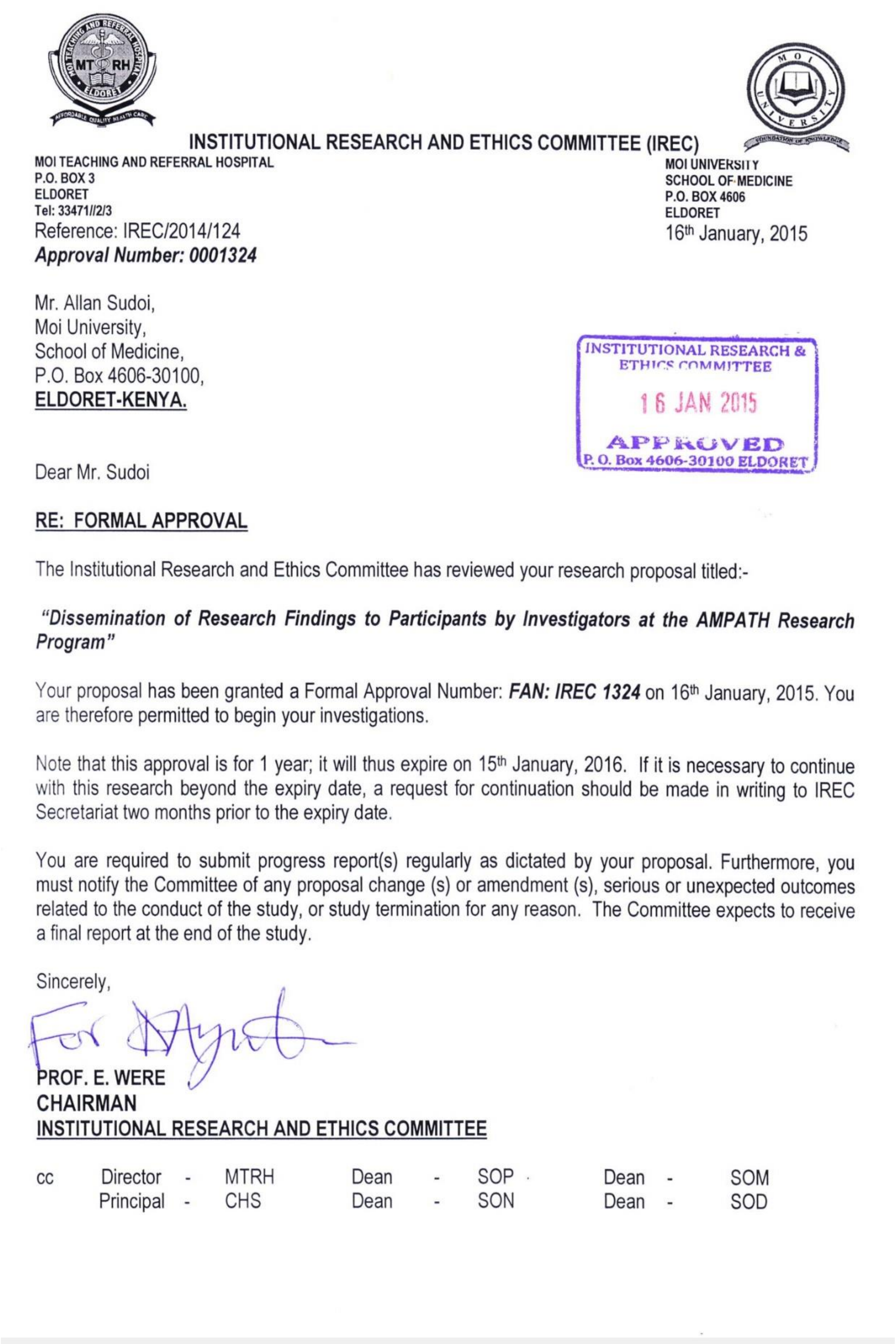
____

____

36. Overall, how do you rate your current research dissemination activities to research participants?

- ☐ Excellent
- ☐ Good
- ☐ Adequate
- ☐ Poor
- ☐ Not sure

APPENDIX IV: IREC FORMAL APPROVAL



INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE (IREC)

MOI TEACHING AND REFERRAL HOSPITAL
P.O. BOX 3
ELDORET
Tel: 33471//2/3

MOI UNIVERSITY
SCHOOL OF MEDICINE
P.O. BOX 4606
ELDORET

Reference: IREC/2014/124
Approval Number: 0001324

16th January, 2015

Mr. Allan Sudoi,
Moi University,
School of Medicine,
P.O. Box 4606-30100,
ELDORET-KENYA.

INSTITUTIONAL RESEARCH &
ETHICS COMMITTEE
16 JAN 2015
APPROVED
P. O. Box 4606-30100 ELDORET

Dear Mr. Sudoi

RE: FORMAL APPROVAL

The Institutional Research and Ethics Committee has reviewed your research proposal titled:-

"Dissemination of Research Findings to Participants by Investigators at the AMPATH Research Program"

Your proposal has been granted a Formal Approval Number: ***FAN: IREC 1324*** on 16th January, 2015. You are therefore permitted to begin your investigations.

Note that this approval is for 1 year; it will thus expire on 15th January, 2016. If it is necessary to continue with this research beyond the expiry date, a request for continuation should be made in writing to IREC Secretariat two months prior to the expiry date.

You are required to submit progress report(s) regularly as dictated by your proposal. Furthermore, you must notify the Committee of any proposal change (s) or amendment (s), serious or unexpected outcomes related to the conduct of the study, or study termination for any reason. The Committee expects to receive a final report at the end of the study.

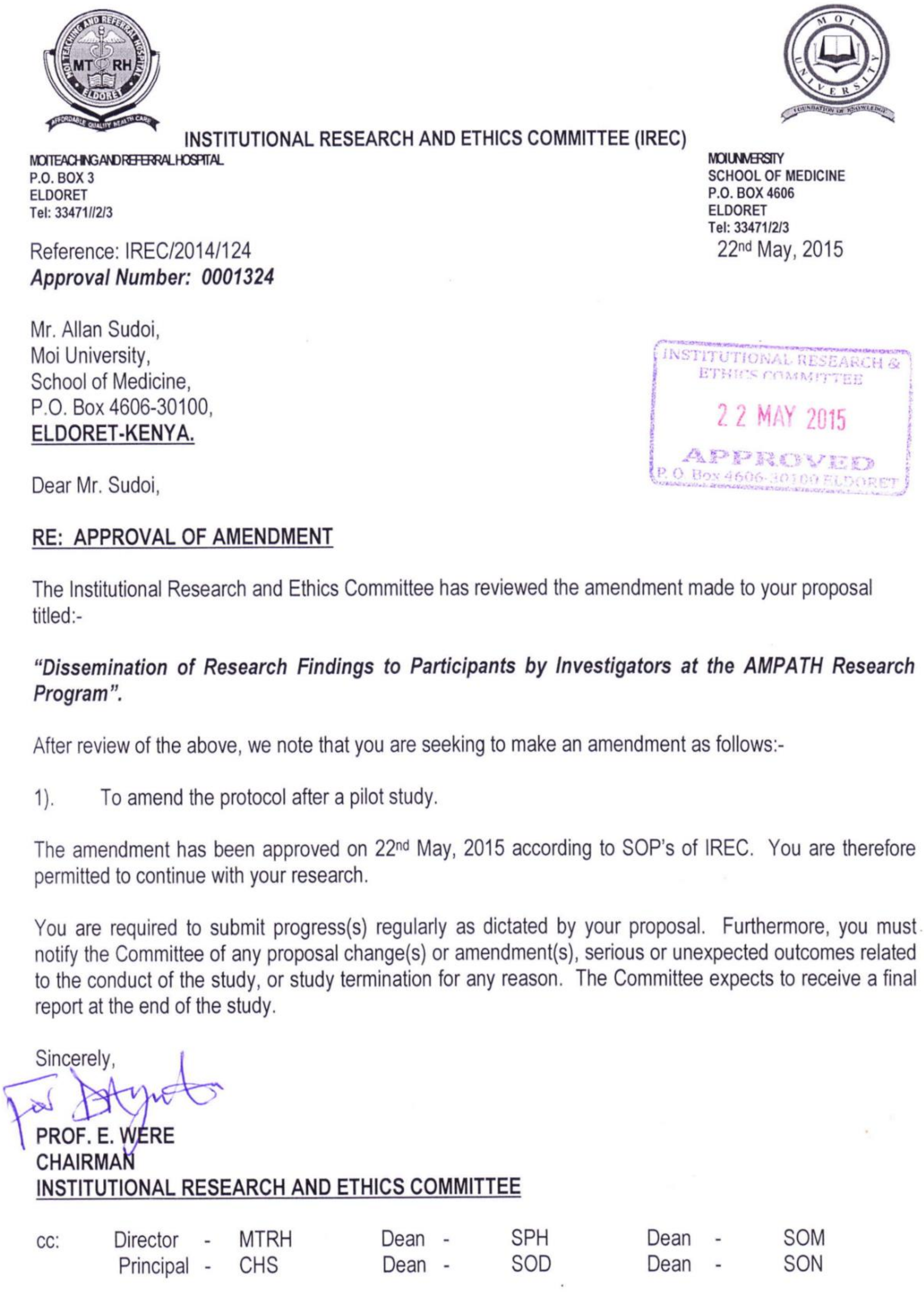
Sincerely,

For

PROF. E. WERE
CHAIRMAN
INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE

cc	Director	-	MTRH	Dean	-	SOP	Dean	-	SOM
	Principal	-	CHS	Dean	-	SON	Dean	-	SOD

APPENDIX V: IREC APPROVAL OF AMENDMENT



INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE (IREC)

MOI TEACHING AND REFERRAL HOSPITAL
P.O. BOX 3
ELDORET
Tel: 33471//2/3

MOI UNIVERSITY
SCHOOL OF MEDICINE
P.O. BOX 4606
ELDORET
Tel: 33471/2/3

22nd May, 2015

Reference: IREC/2014/124
Approval Number: 0001324

Mr. Allan Sudoi,
Moi University,
School of Medicine,
P.O. Box 4606-30100,
ELDORET-KENYA.

INSTITUTIONAL RESEARCH & ETHICS COMMITTEE
22 MAY 2015
APPROVED
P. O. Box 4606-30100 ELDORET

Dear Mr. Sudoi,

RE: APPROVAL OF AMENDMENT

The Institutional Research and Ethics Committee has reviewed the amendment made to your proposal titled:-

"Dissemination of Research Findings to Participants by Investigators at the AMPATH Research Program".

After review of the above, we note that you are seeking to make an amendment as follows:-

1). To amend the protocol after a pilot study.

The amendment has been approved on 22nd May, 2015 according to SOP's of IREC. You are therefore permitted to continue with your research.

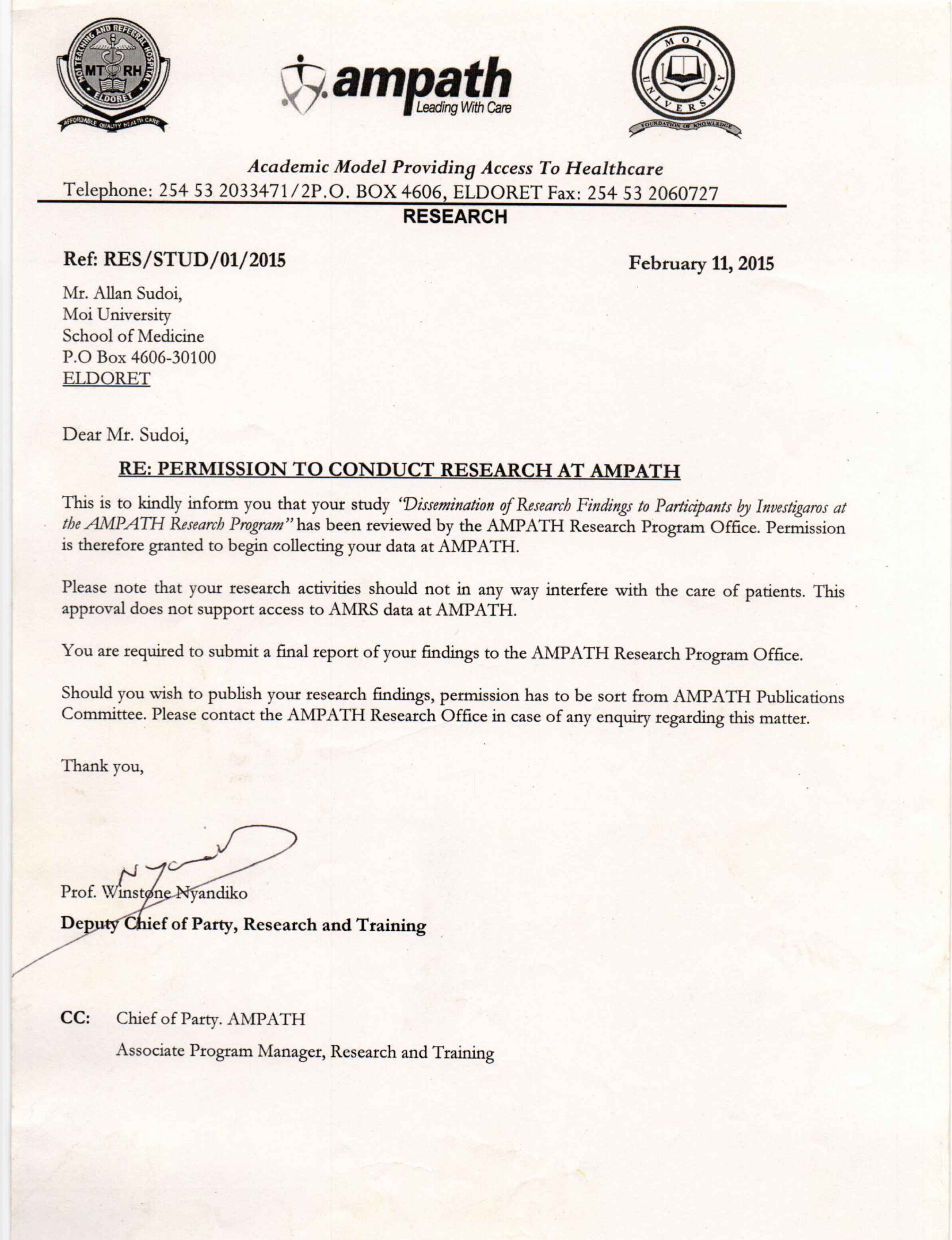
You are required to submit progress(s) regularly as dictated by your proposal. Furthermore, you must notify the Committee of any proposal change(s) or amendment(s), serious or unexpected outcomes related to the conduct of the study, or study termination for any reason. The Committee expects to receive a final report at the end of the study.

Sincerely,

PROF. E. WERE
CHAIRMAN
INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE

cc:					
Director -	MTRH	Dean -	SPH	Dean -	SOM
Principal -	CHS	Dean -	SOD	Dean -	SON

APPENDIX VI: AMPATH INSTITUTIONAL APPROVAL



ampath
Leading With Care

Academic Model Providing Access To Healthcare
Telephone: 254 53 2033471/2P.O. BOX 4606, ELDORET Fax: 254 53 2060727
RESEARCH

Ref: RES/STUD/01/2015 **February 11, 2015**

Mr. Allan Sudoi,
Moi University
School of Medicine
P.O Box 4606-30100
ELDORET

Dear Mr. Sudoi,

RE: PERMISSION TO CONDUCT RESEARCH AT AMPATH

This is to kindly inform you that your study *'Dissemination of Research Findings to Participants by Investigaros at the AMPATH Research Program"* has been reviewed by the AMPATH Research Program Office. Permission is therefore granted to begin collecting your data at AMPATH.

Please note that your research activities should not in any way interfere with the care of patients. This approval does not support access to AMRS data at AMPATH.

You are required to submit a final report of your findings to the AMPATH Research Program Office.

Should you wish to publish your research findings, permission has to be sort from AMPATH Publications Committee. Please contact the AMPATH Research Office in case of any enquiry regarding this matter.

Thank you,

Prof. Winstone Nyandiko
Deputy Chief of Party, Research and Training

CC: Chief of Party. AMPATH
Associate Program Manager, Research and Training

APPENDIX VII: AMPATH CONSORTIUM UNIVERSITIES (2015)

1. Brown University School of Medicine
2. Columbia University
3. Duke University Medical Center/Hubert-Yeargan Center for Global Health
4. George Washington University
5. Indiana University- Purdue University in Indianapolis(IUPUI)
6. Indiana University School of Medicine
7. Lehigh Valley Hospital
8. Moi University
9. Mount Sinai School of Medicine
10. New York University
11. Providence Portland Medical Center
12. Purdue University
13. Syracuse University
14. University of California San Francisco
15. University of Massachusetts Medical School
16. University of Missouri
17. University of North Carolina
18. University of Notre Dame/Eck Institute for Global Health
19. University of Toronto Faculty of Medicine
20. University of Utah School of Medicine

APPENDIX VIII: LIST OF AMPATH RESEARCH STUDIES AS AT DECEMBER 2013

1. A Formative Study to Develop Culturally Valid Psychosocial Assessment Tools and Interventions to Promote Family Well-Being in Kenya
2. A Population-wide Home-Based Study of Hypertension Prevalence in Western Kenya
3. A Stage 2 Cognitive Behavioral Trial, Reduce Alcohol First in Kenya Intervention (RAFIKI)
4. A5225/HiFLAC Protocol - A Phase I/II Dose-Finding Study of High-Dose Fluconazole Treatment in AIDS-Associated Cryptococcal Meningitis
5. A5263 'A Randomized Comparison of Three Regimens of Chemotherapy with Compatible Antiretroviral Therapy for Treatment of Advanced AIDS-KS in Resource-Limited Settings'
6. A5264/AMC067 A Randomized Evaluation of Antiretroviral Therapy Alone or with Delayed Chemotherapy versus Antiretroviral Therapy with Immediate Adjunctive Chemotherapy for Treatment of Limited Stage AIDS-KS in Resource-Limited Settings (REACT-KS)
7. A5265 A Phase III, Open-Label, Randomized, Assessment-Blinded Clinical Trial to Compare the Safety and Efficacy of Topical Gentian Violet to that of Nystatin Oral Suspension for the Treatment of Oropharyngeal Candidiasis in HIV-1 Infected Participants in Non-U.S. Settings
8. A5273 'Multicenter Study of Options for Second-Line Effective Combination Therapy (SELECT)'
9. A5274/REMEMBER Reducing Early Mortality and Early Morbidity by Empiric Tuberculosis Treatment Regimens '

10. A5288 'Management Using the Latest Technologies in Resource-limited Settings to Optimize Combination Therapy After Viral Failure (MULTI-OCTAVE)'
11. Accuracy of Oral HIV Self-tests in Kenya
12. Addressing the Fourth Delay: Improving Communitybased Accountability for Maternal and Newborn Health
13. Anticoagulation Project
14. Antiretroviral Treatment Failure and Drug Resistance in HIV-infected Patients on Second Line Regimens in Western Kenya
15. Assessment and Treatment of Pain in Hospitalized Patients at MTRH
16. Biomarkers of Vincristine Toxicity in Kenyan Children
17. Building Competencies through Bilateral International Exchanges-Using Qualitative Methods to Measure the Impact on Pediatric Residents from Host and Visiting Countries in Professionalism, Communication and Systems-Based Care
18. Cervical Cancer See and Treat: How Best to Follow-up
19. Childhood Leukemia in Kenya Identified Through Malaria Slide Review
20. Computerized Counseling to Promote Positive Prevention and HIV Health in Kenya (CARE+ Kenya)
21. Cross-Cultural Histories of Family Care-Giving to AIDS Orphans in Western Kenya
22. Descriptive Study of Patients Seeking Emergency Care in Western Kenya
23. Diabetes Mellitus and Glucose Intolerance in HIV Patients in Western Kenya
24. Drug Resistance in HIV Infected Children after Failure of Prevention of Mother to Child Transmission in Western Kenya
25. EARNEST: A Randomised Controlled Trial to Evaluate Options for Second-line Therapy in Patients Failing a First-line 2NRTI+ NNRTI Regimen in Africa
26. Enhancing Training for Implementation Research in Chronic Disease: CITE/Kenya

27. Evaluating Handheld Clinical Decision Support Tools to Improve Community-Based Delivery of Reproductive and Pediatric Health Services
28. Evaluation of A Comprehensive Strategy to Measure Pediatric Adherence to Antiretroviral Therapy (CAMP study)
29. Evaluation of HIV Drug Resistance Prevalence and Consequences in the Setting of the Recent Political Crisis in Kenya
30. Exploring factors that support a sustainable model for engaging and retaining CHWs in the PHC program of AMPATH (CHW Incentive Project)
31. Facilitators and Barriers to Initiation of Antiretroviral Treatment Among Pregnant Women Living with HIV Receiving Antenatal Care in Western Kenya: An Evaluation
32. Feasibility Intervention Trial of Two Types of Improved Cook Stoves in Three Developing Countries
33. Health Facility Incentives to Improve Adherence to Malaria Diagnostic Test Results
34. HIV Prevalence and Ante-natal Care Attendance Among Pregnant Women in a Large Home-Based HIV Counseling and Testing Program in Western Kenya
35. HIV Testing Uptake and Prevalence Among Adolescents and Adults in a Large Home-Based HIV Testing Program in Western Kenya
36. HIV-1 Drug Resistance in Different Subtypes
37. HIV-1 Genotypic Diversity and Drug Resistance in Western Kenya
38. Improving Diabetes Management and Cardiovascular Risk Factors Through Diabetes Peer Group Education in Western Kenya
39. Increasing Animal Source Foods in Diets of HIV Infected Kenyan Women and their Children
40. Indiana University-Moi University Academic Research Ethics Partnership
41. Inhalants and the Pathway to HIV Infection Among Street Youth in Western Kenya

42. International epidemiologic Databases to Evaluate AIDS (IeDEA)
43. IU Health Cardiovascular Research Biobanking Project
44. Linkage and Retention to Care in Western Kenya Following HIV Testing
45. MESA Malaria Prevention Study (MPS)
46. Modified Directly Observed Antiretroviral Therapy (M-DART): An Intensive, Nurse-Directed, Home-Centered, Treatment Strategy to Reduce Mortality and Loss to Follow-Up in High-Risk HIV-Infected Patients Initiating Antiretroviral Therapy
47. Mortality Among Street Connected Children and Youth in Eldoret, Kenya: a Retrospective Chart Review
48. National Cancer Institute Supplement to East African IeDEA: Improving Kaposi's Sarcoma, Lymphoma Diagnostics, and Assessing Kaposi's Sarcoma Incidence in Western Kenya
49. Nurse Management of Hypertension Care in Rural Western Kenya
50. Optimizing Linkage and Retention to Hypertension Care in Rural Kenya
51. Patient-Centered Disclosure Intervention for HIV-Infected Children, Helping AMPATH Disclose Information and Talk about HIV Infection (HADITHI)
52. Patient-Reported Outcomes of Cancer Care in Eldoret, Kenya
53. Pharmacovigilance in a Resource-Limited Setting: Approaches to Targeted Spontaneous Reporting for Suspected Adverse Drug Reactions to Antiretroviral Treatment
54. Physical and Sexual Abuse in Orphaned Compared to Non-Orphaned Children and Youth in Sub-Saharan Africa: A Systematic Review & Meta-Analysis
55. Prevalence and Impact of Alcohol Use in Patients Enrolling in HIV Care
56. REACH Informatics Center of Excellence
57. REALITY 'Reduction of EArly mortaLITY in HIV-infected adults and children starting antiretroviral therapy'

58. Reducing Early Mortality and Early Morbidity by Empiric Tuberculosis Treatment Regimens (REMEMBER)
59. Renal Study
60. SAFI (Stigma in AIDS Family Inventory) Validation Study
61. Sexual Health Risks and HIV and STI Prevalence Among Street Involved Youth in Western Kenya
62. STEPwise Approach to Cardiovscular Diseases Risk Factors Revalence Study in Webuye Adults
63. Street Youth's Perspectives on Sexual Health in Western Kenya
64. Survival Among HIV-infected Patients with Kaposi's Sarcoma in sub-Saharan Africa in the Era of Potent Antiretroviral Therapy
65. Taking a LEEP! Implementing a 'See and LEEP' strategy for women in Western Kenya with positive cervical cancer screening
66. Taking to the Streets: a Mixed-Methods Systematic Review of the Reasons Children and Youth Become Street-Involved
67. TB/HIV Integration Study
68. The Epidemiology of Substance use Amongst Street Children in Resource-constrained Settings: a systematic review and meta-analysis
69. The Implementation of a Neonatal Nurse Training Program at the Riley Mother Baby Hospital of Kenya
70. The IU Simon Cancer Center (IUSCC) AMPATH-Oncology Institute (AOI): An Exemplar of Care for the Developing World and a Population-Based Research Environment for IUSCC
71. Treatment Outcomes of Childhood Cancer in Western Kenya

72. Utility of Handheld Echocardiogram Among Clinical Officers in Patient Referred for Routine Echocardiography at Moi Teaching and Referral Hospital, Kenya