APPENDIX F: PARTICIPANT INFORMATION SHEET

RESEARCH TITLE: Data Quality Evaluation Framework For Health Information Systems (His) In Developing Countries: A Case Of Botswana

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PROGRAMME STUDY: Doctor of Philosophy in Information Systems
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GENERAL INFORMATION

I would like to invite you to take part in this research study. Before you decide, you need to Understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Ask questions if anything you read is unclear or if you want more information. Take time to decide whether or not to take part.

INTRODUCTION

I am Onalenna Phambuka, a PhD candidate at Botswana International University of Science and Technology (BIUST) pursuing a Doctor of Philosophy in Information Systems. This study leads to a Dissertation in Partial Fulfilment of the Requirements for the Doctor of Philosophy in Information Systems Award by BIUST. Rest assured that any information you provide will be confidential and strictly used for academic purposes.

OBJECTIVES OF THE STUDY

This study aims to develop a data quality framework applicable to any Health Information Systems (HIS) database in Botswana and other developing countries.

This general objective is divided into specific objectives so that they will eventually lead to achieving the study's general objective. The specific objectives are as follows:

1. To determine the gaps and perceptions of policymakers and data managers relating to better data quality in Health Information Systems in developing countries
2. To establish the unique challenges and barriers to data quality in Health Information Systems in developing countries
3. To establish the impact of data quality in health information systems on healthcare outcomes and decision-making processes in developing countries.
4. Identify the available data quality framework on Health Information Systems that could help to guide the development of a data quality framework for Health Information Systems in Botswana.
5. To develop and validate the data quality framework by applying it to one of Botswana's Health Information Systems/databases, namely, the Botswana Pediatric Oncology Database (BPOD).

WHAT WILL THE STUDY HOPE TO ATTAIN?

The expected outcomes of the proposed study are two-fold. Those will include contributions to the body of knowledge of Health Informatics and society.

Expected academic contributions expected are as follows.

Firstly, developing the proposed data quality evaluation framework will set explicit knowledge in data quality dimensions and attributes used by scholars and researchers to improve data quality assessment within any HIS in developing countries and local Botswana Health Information systems.

Secondly, the developed data quality evaluation framework, with its dimensions, precise terminology, and guidelines validation to a local database, will establish reasonable control and practices on data quality in data collection, monitoring, and management in health systems for informed decision-making and interventions not only for the BPOD and surveillance of paediatric cancer. The data quality evaluation process is crucial as it determines the overall data quality.

Finally, the developed data quality evaluation framework applies to any local database, thus providing researchers with an excellent foundation to expand and adapt the same framework to any local dataset. The expansion and adaptability of the new framework will establish future development and scope of data quality assessment frameworks tailored for Botswana health systems; hence this being a novel foundation for future data quality evaluation frameworks in HIS in Botswana.

Contributions to society are as follows.

Results from the research will formulate recommendations that will benefit all stakeholders in understanding key data quality dimensions in collecting quality data that can help all patients create the necessary awareness and interventions using quality data. Given the dearth of research and intervention on paediatric cancer in Botswana and developing countries, the results and recommendations will benefit policymakers for informed decision-making.

WHAT WILL TAKING PART IN THE RESEARCH STUDY INVOLVE?

1. A consent form will be signed before any study assessments are performed.
2. Screening for eligibility would be conducted to ensure participants are selected based on their expertise, roles, and experience in data management, policy-making, and healthcare provision within the HIS context.

- This ensures that insights come from individuals with relevant knowledge. Different stakeholder groups, including Data Managers, Policy Makers, and Health Service Providers, will be purposefully selected to capture diverse perspectives and experiences.

3. Procedures and Activities involved in this study will encompass questionnaires which each individual would complete on their own time within the specified duration of two weeks within the four-week schedule for data collection.

- Data managers will participate in in-depth interviews to provide insights into their experiences and perspectives on data quality within HIS
- Healthcare providers will be involved through a combination of focus group discussions and individual interviews, allowing for a dynamic exploration of their viewpoints
- policymakers will also partake in in-depth interviews to gather their valuable perspectives on data quality in HIS, thus providing a holistic understanding of the subject matter

Approximately a maximum of 10 participants from each stakeholder group will be selected for interviews, and three focus group discussions (one for each stakeholder group) will be conducted with 10 participants in each group.

Completed questionnaire transcripts of unidentifiable and unidentified recorded focus group discussions will be collected as part of data collection.

DO YOU HAVE TO TAKE PARTICIPATE IN THE RESEARCH STUDY?

Participation is entirely voluntary, and you have the right to refuse participation, refuse any question and withdraw at any time without any consequence whatsoever.

WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF PARTICIPATION?

It is not anticipated that there are any risks to participation in this study. Whilst all care will be taken to maintain privacy and confidentiality, the researcher cannot guarantee anonymity and confidentiality for focus group discussions. All group participants will be asked to maintain the confidentiality of group discussions and the identity of participants. There will be no clear and direct benefit to you from participating in this research.

WHAT ARE ANTICIPATED DISCOMFORTS OR INCONVENIENCES TO WHICH PARTICIPANTS MAY BE SUBJECTED?

The research participants include Health Care Providers, Health Policy Makers and Datacenter Managers.

Health Care Providers divulge sensitive information concerning data in custody and how it is managed. The researcher will be sensitive to such situations, exercise caution, and protect the participant.

Health Policy Makers: The same issue of information disclosure on procedures and standards of operation, which are privy to various offices of the Health Policy Makers.

WILL PARTICIPATION BE CONFIDENTIAL?

By signing the consent form, you consent to participate in the research, collecting and using information about or from you for the research project. Any information obtained concerning this research project that can identify you will remain confidential. Information collected or used will be stored as individually non-identifiable. Only the researcher will have access to the raw data collected.

The researcher collects and uses information from questionnaires, interviews, focus groups and documentation reviews. Signed consent forms and original audio recordings will be retained in cloud storage and computer-based protected platform security arrangements. Only the researcher will have access to data until after two years of graduation, after which data will be destroyed. A transcript of interviews in which all identifying information has been removed will be retained for two years after this.

Your information will only be used for this research project and the future research described. It will only be disclosed with your written consent, except as law requires.

WHO HAS REVIEWED THE RESEARCH STUDY

Relevant ethical aspects of this research project approval have been sorted out by the University's Ethical clearance committee, and the necessary Research Approval from the appropriate IRB's done to protect the interests of people who agree to participate in such research studies.

WHAT WILL HAPPEN TO THE RESULTS OF THE STUDY

A summary of project results will be available after the final publication and completion of the dissertation from the researcher. Results and Publication copies will be provided to the participants and their institutions. Moreover, the results will be shared with the Ministry of Health archives library and stakeholders of the research study (Health Care Providers, Health Policy Makers and Datacenter Managers). The results will also be published online in academic papers for easy access.

FOR FURTHER INFORMATION, WHO CAN BE CONTACTED

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I have read and understood the information contained in this document.

Signature or Initials of Participant _____ **Date_____**