Université de Montréal
Département de médecine sociale et préventive
École de Santé Publique

**Information and Consent Form**

| | |
|---|---|
| **Title of the research project :** | **Workshop discussion to understand the needs and expectations of potential users of an One-Health data portal/dashboard (Project# 2023-3999)** |
| **Who is conducting this research?** | I, **Kamal Raj Acharya.** I am a postdoctoral fellow at the Department of Social and Preventive Medicine, the University of Montreal. The Principal Investigator of this study is **Prof. Bouchra Nasri**, School of Public Health, Department of Social and Preventive Medicine, the University of Montreal. |
| **Funding of the research project :** | This study is funded through the **One Health Modelling Network for Emerging Infections (OMNI-RÉUNIS)** which is funded by the Natural Sciences and Engineering Research Council of Canada (**NSERC**) and Public Health Agency of Canada (**PHAC**). |

## 1. Introduction

You are invited to participate in a qualitative research entitled: `**Workshop discussion to understand the needs and expectations of potential users of an One-Health data portal/dashboard**`(REB# 2023-3999).
Please read the information about the study presented in this document. The document includes details on the study, including the study's risks and benefits, that you should know before you decide if you would like to take part. You should take as much time as you need to make your decision. This document might have some words that you are unfamiliar with. If you are not clear on the content of this document, you should ask the study investigator or study staff to explain anything that you do not understand and make sure that all your questions have been answered before providing your consent to participate in this study. Before you make your decision, feel free to talk about this study with anyone you wish. You are also encouraged to print this Introduction and Consent document for your reference.

## 2. Nature and objectives of the research project

A brief survey conducted among researchers within the OMNI/RÉUNIS network identified their various data access and use needs. The major issues identified were difficulty in locating, accessing, and pre-processing data before they can be used for their One Health research. A data portal is being developed to be used by One Health researchers to address some of these issues. However, for the long-term sustainability and usability of the data portal, we need to understand the needs and expectations of potential users. Apart from these higher-level ideas gathered from the survey, having a richer in-depth knowledge of participants' needs and expectations regarding data access and use would help us address the data access issue and implement specific functionalities into the data portal.

So, this study is being conducted with the following objectives :

- To understand the data access and use experiences of researchers working on the One Health issues.
- To understand the needs and expectations of One Health researchers regarding the functionality and sustainability of data portal that is being built.

To achieve these objectives, we intend to enroll One Health researchers that access/generate and use data for their One Health research. Predominantly, the participants will be the researchers working in various themes of the OMNI/RÉUNIS : Data Management, Risk for Emergence and Spillovers, Early Warning Systems of Emerging Infectious Diseases, and Intervention and Control.

## 3. Details of the research project

### 3.1 Location of the research project, duration and number of visits

This study will not require any direct visits from you. If you agree to participate, you are required to submit an electronic survey as a consent to participate in this study. This research will take place online using a secure meeting platform for a duration of about 2 hours. Additionally, about 20 minutes of your time will be required to read this document and provide an electronic consent.

A total of 40 participants will be recruited for this project. The participants will be divided into two equal groups. Attempt will be made to ensure that each group has representation from each of the following group of participants:

1.Researchers working on different themes of OMNI-REUNIS project.
2.Representatives of funding agencies.
3.Government agency representatives known to host data.
4.Researchers independent of OMNI-REUNIS project.
5.Subject matter specialists: Computer engineers, Data scientists, Librarians, etc.

**3.2 Nature of your participation**

By participating in this study you will perform the following activities

| **Procedures** | **Instance** |
|---|---|
| You will read the information/consent document and fill in the electronic consent form. While filling this form, you will provide us some of your demographic information such as how long you have been working, your educational qualification, research area, etc. | 1 |
| The researchers will contact you electronically about the date and time of the online meeting. Instead, if you do not qualify for the study due to sample size fulfillment or other reasons, the researchers will notify you. | 1 |
| You will participate in an online meeting hosted over a secure platform. | 1 |

The total duration of time required for all the above mentioned activities will be around 2.5 hours.

**4. Incidental discovery**

This research does not expect to have any incidental findings during the study.

**5. Benefits associated with the research project**

While we can not guarantee it, you may benefit personally from your participation in this research project as the findings from this study will be implemented in the data portal that is being developed. Additionally, the results obtained will contribute to the advancement of scientific knowledge in this field of research and can motivate data providers to improve the access and use of data.

**6. Inconvenience associated with the research project**

The only disadvantage we can think of is the loss of your time as you should allocate some time to the research. The consent process will take about 20 minutes to read the research information and fill in the questionnaire, and the workshop discussion will require around 120 minutes of your time. Both of the steps will be online and you can perform it in the time and place convenient to you.

**7. Risks associated with the research project**

Taking part in this study may have minimal risks. Potential risks include : that some people might feel uncomfortable answering some of the questions related to data access and use. In such instances, you may stop answering a question or skip a question without any negative consequences. Likewise, while we will adhere to industry standards for conducting a survey and online workshop discussion, data storage, and security, it is possible this data could be illegally accessed which may result in social risk (loss of privacy).
There is also a possibility of risks that we do not know about. Please call the study investigator or study personnel if there are any concerns regarding possible issues related to the study.

**8. Voluntary participation and right of withdrawal**

Participation in this study is entirely voluntary and you can withdraw at any time without any negative consequences. You will not be required to provide any reasons for your withdrawal from this study.

During the study, you are free to skip any questions during the workshop discussion and only answer questions you are comfortable with. If at any point during your involvement in the research study you decide you would no longer like to participate, feel free to let researchers know this. In this case, any data collected to that point will be securely deleted. However, once we have recorded the discussion, your data could not be identified and hence cannot be excluded from the study.

**9. Confidentiality**

Any information you share with us will be used solely for this research and your privacy will be protected.

Your demographic data (name and affiliation) collected while obtaining consent from you will be stored encrypted on the dedicated servers of Qualtrics. The access to this data will be restricted to the research team. The survey data will be downloaded to an encrypted computer. Once downloaded, your personal identifiers will be removed, and the data will be stored under unique anonymous participant ID. The master list that can link the anonymous participant ID to you will be stored in an encrypted fashion in a password protected computer. The access to the master list will be restricted to the principal investigator. The master list will be used for data validation purpose only. Your email address will only be used to communicate regarding the date and time of the study. After this, the personal identifiers will be deleted from our computers.

The audio recording of the interview will be made on the Zoom platform. The audio recordings will be downloaded to the encrypted computer of the researchers and the recording in the server will be deleted. Your identity will be kept confidential by using a pseudonym instead of your real name during the interview. The audio recordings will be transcribed using a feature of the Zoom, reviewed and validated by the researchers for accuracy and completeness, and deidentified. The transcripts will be encrypted and stored in an encrypted computer/laptop in a locked room and will also be backed up in the encrypted USB drive. In the rare event that the computer is stolen, the data cannot be accessed as the data on the computer are un-readable. The deidentified audio recordings will be stored in an encrypted computer/laptop in a locked room for seven years after the completion of the project, after which the audio recordings will be deleted from the researchers' computer.

Data analysis will be performed on an encrypted University of Montreal computer. Linkage of the transcript with some simple demographic information, will only occur on secure computers during data analysis and validation of the data. The demographic information that can identify the participants will be securely deleted from our servers and hard drives after seven (7) years of the completion of the project.

Following completion of the study, anonymized transcripts will be stored in an encrypted manner on a password protected computer at the University of Montreal. This transcripts will not contain any information that can identify the participants.This data will be kept by the principal investigator. The access to this data however will be limited to researchers in the primary investigator's lab for academic purposes.

However, please note that full confidentiality cannot be guaranteed while data are in transit over the internet. It is recommended that the participant fill in the consent form and attend the interview using their personal devices over a secure internet.

**10. Secondary use of research data**

We do not envision any secondary use of this research data. The data generated in this research will only be used to fulfill the objective of this study.

**11. Potential for commercialization**

We do not intend to commercialize the findings of this research.

**12. Compensation**

We are grateful to your time commitment but will not be able to provide any compensation for your time.

**13. In case of harm**

We do not expect any harm to you due to your participation in this project. However, should you suffer any injury as a result of your participation in this research project, please contact your nearest health care provider.

By agreeing to participate in this research project, you do not waive any of your rights and you do not release the researcher in charge of this research project, the granting agency and the Université de Montréal from their civil and professional liability.

**14. Communication of the results of the study**

The study findings will be uploaded to the website of the OMNI-RÉUNIS (https://omni-reunis.ca/) as a webpage summary, and published in the OMNI-RÉUNIS newsletters. The participants will be sent the link to this. Likewise, the study findings will also be disseminated via seminars, conferences, and publication in a scientific journal. Likewise, participants will also be provided an opportunity to contact the Principal Investigator Dr. Bouchra Nasri at bouchra.nasri@umontreal.ca , after the research is complete, to obtain a web link or a copy of the study findings, or study presentation.

**15. Contacts**

If you have any questions about the research project or wish to withdraw from the research project, you may contact the principal researcher in charge of this research project at the following contact information:
**Prof. Bouchra Nasri**
Professeure Adjointe/Assistant Professor
École de Santé Publique, Département de médecine sociale et préventive, the Université de Montréal
**Téléphone** : (514) 343-7973 and **Courriel** : bouchra.nasri@umontreal.ca).

This project **(Project# 2023-3999)** has been approved by the Health and Science Research Ethics Board of the Université de Montréal. If you have any concerns about your rights or the responsibilities of the researchers regarding your participation in this project, you can contact the committee by phone at 514 343-6111, ext. 2604 or by e-mail at cerses@umontreal.ca
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Any complaint concerning this research project can be addressed to the Ombudsman of the Université de Montréal, at the following telephone number: (514) 343-2100 or at the following e-mail address: ombudsman@umontreal.ca. The ombudsman can speak in French and English and accepts calls between 9:00 a.m. and 5:00 p.m.

# Consent

**Title of the research project :** **Workshop discussion to understand the needs and expectations of users of an One-Health data portal/dashboard (Project# 2023-3999)**

**Commitment of the researchers**

- I have provided a detailed information on the conditions of participation in this research project.
- I have answered the questions asked to the best of my knowledge and have ensured the participant's understanding.
- I, on behalf of the research team, agree to follow what has been agreed in this information and consent form.

Signature of researcher: _____

Full name: _____

Date: _____

**Participant's statement**

- I have read the information provided for the study.
- I have been given a copy of this information.
- This study has been explained to me and any questions I had have been answered.
- I confirm that I fulfill the inclusion criteria of this study.
- I understand that by participating in this research project, I am not waiving any of my rights or releasing the researchers from their responsibilities.
- I know that participation in this study is voluntary and I may leave the study at any time.
- I agree with the use of my information as described in this form and agree to take part in this study as outlined above.
- I consent to the recording of the discussion.
- I agree to maintain confidentiality of what is said during the discussion.
- I agree to maintain confidentiality of the identity of other participants in the workshop discussion.
- I agree with the use of any quotation from my interview without my name in the final report.

By signing below, I provide my consent to participate in this study.

Your signature (Please type your initials): _____

Your full name: _____

Your email address: _____

Date (mm/dd/yyyy): _____