

Name of research project: Ambient Air Pollution in Oil-Gas situated Communities and the Risk for Kidney Disease: Integrating Citizen Science with a Mixed Method Study

Description of research project: The aim of this project is to investigate the impact of long-term exposure to ambient air pollution and urbanicity on the risk for chronic kidney disease (CKD) among adult residents of Oil and Gas situated communities. The study seeks to understand the perception of community members about their ambient air environment and related health impacts, if any. Secondly, to compare the prevalence of CKD and related diseases in four communities differentiated by urbanicity (rural vs. urban) and distance from an oil-refinery.

Data Controller	Edinburgh Napier University
Purposes for collection/processing	<p>To understand the communities’ perception of their ambient air quality, its relation to health outcomes, and the enablers and barriers to controlling air pollution.</p> <p>To determine the prevalence of kidney-related diseases and any associations between kidney-related health outcomes and ambient air quality in four selected communities.</p>
Legal basis	<p>Art 6(1)(e), performance of a task in the public interest/exercise of official duty vested in the Controller by Statutory Instrument No. 557 (S76) of 1993 as amended, e.g. for education and research purposes.</p> <p>Where sensitive personal data is being processed the additional bases from Article 9 is:</p> <p>Art 9(2)(j) for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes.</p> <ul style="list-style-type: none"> a) <i>The use of data is proportionate to the aim pursued as it is not possible to understand the outcomes using any other method.</i> b) <i>The measures in place to safeguard participants’ rights are that pseudonymisation and secure processing is used throughout.</i> <p>Please note that we are not relying on consent as a basis for processing under the GDPR, and our legal basis for processing is therefore distinct from the research ethics-related use of consent in this study.</p>
Whose information is being collected	Residents of four oil-gas communities in Warri, Delta State, Nigeria
What type/classes/fields of information are collected	<p>Information will be collected about your name, contact details, gender, age, ethnic origin, education level, employment status, health status, family history, behavioural and social history. If you take part in the focus group or interviews you will be asked about your views concerning your outdoor air environment and whether it relates to the communities’ health in any way.</p> <p>If you take part in the health survey, you will be requested to permit collection of 5mls of blood and 10mls urine respectively for laboratory tests. The test(s) will be repeated once after 3 months if any significant abnormalities are detected.</p>
Who is the information being collected from	Data is being collected directly from you.
How is the information being collected	Demographic and health information will be recorded on a paper by you or researcher for persons not able to write. This will then be

	<p>transferred to an electronic record. If you participate in a focus group or interview, this will be audio-recorded using an encrypted digital recording device and later transcribed verbatim to paper and transferred to a software for analysis.</p>
<p>Is personal data shared externally</p>	<p>No. Only the researcher will have access to personal data of participants, while de-identified data (identified only by ID number and date of birth) will be shared with the University, research assistants and Laboratory. The research assistants will have access to de-identified data during field data collection only.</p> <p>The laboratory will have access to de-identified data for the purpose of sample collection and biochemical analysis only; all data in the possession of the lab will be deleted after laboratory results have been transferred to the researcher</p>
<p>How secure is the information</p>	<p>All hard copy questionnaires and other documents used for data collection in this study will be in the possession of the researcher. All hard copy documents containing participant information will be locked in a file cabinet to be destroyed within 3 months after information is transferred to secure electronic files.</p> <p>Audio-recordings will be transcribed by the researcher with the assistance of one volunteer from the public relations unit of the State teaching hospital. All participants in focus groups and interviews will use pseudonyms any information that might identify the participant will be excluded from the transcript. There will be a password protected spreadsheet containing the names, contact details, and demographics of participants; pseudonym name/number and this will be used for all data collection instruments.</p> <p>Data will be stored in the researcher's secure computer in passworded files and on the University's secure data centres. The University data centres are resilient and feature access controls, environmental monitoring, backup power supplies and redundant hardware. Information on these servers is backed up regularly. The University has various data protection and information security policies and procedures to ensure that appropriate organisational and technical measures are in place to protect the privacy or your personal data.</p>
<p>Who keeps the information updated</p>	<p>The researcher (Ogochukwu Okoye) is responsible for keeping the study information updated. She will ensure that your data is destroyed if you request this.</p>
<p>How long is the information kept for</p>	<p>Most paper documents will be transferred to a passworded electronic record and then shredded as confidential waste within three months. However, some documents such as the informed consent, and contact information will be kept for as long as it is necessary for the purpose of the research project and until all verification of information has been completed. All documents will be confidentially destroyed using secure shredding standards.</p> <p>Audio-recordings will be transferred onto secure storage and the recording on the encrypted device destroyed within a week of the interview.</p> <p>At the end of the research, electronic data will be kept securely for ten years and then will be destroyed as per Edinburgh Napier University guidance on the safe disposal of confidential waste. All electronic</p>

	files containing data will be deleted from the secure university server where the data is held.
Will the data be used for any automated decision making	No