# Rössing Uranium Health Study – Uranium Mineworkers Participant Information Sheet

Rössing Uranium proposes to provide independent researchers with data for a health study relating to past and current Rössing employees. We are contacting you as we would like to include routinely collected data from your past or current employment records, including occupational health data, in this study. This information sheet is to explain the purpose of the health study and what it will involve. Please take time to read it carefully.

#### What is the purpose of the health study?

The health study focuses on the effect of exposure to dust, radiation and other substances on workers at the Rössing Uranium Mine. Specifically, it aims to determine whether there have been work-related cancer risks at the Rössing Uranium Mine from 1976 onwards.

#### Who will conduct the research?

An experienced research team from The University of Manchester in England will conduct the health study.

## Why have I been chosen?

The health study proposes to include all workers employed by Rössing Uranium at the Rössing Uranium Mine between 1976 and 2010, with at least one year's continual employment at the mine during this period. The study will focus on the exposures of workers known to have developed certain cancers as well as those of a sample of others who did not.

### What will I be asked to do if I participate?

If you decide to participate, you will not be asked to do anything at all. You will not be asked to provide any additional data. No medical examinations are required.

## What will the research involve?

A team from Rössing Uranium will collate your relevant data from its records and will set up an anonymised database for use by The University of Manchester research team. In the database, your name and other identifying information will be replaced with a unique 'Medical Research Number' that cannot be linked back to you by the researchers. This is intended to ensure your anonymity. Data in the database will be limited to information such as your age and working area (kept as part of the records of your past or current employer, Rössing Uranium), occupational exposure data (about radiation, dust, etc.), also collected by Rössing Uranium, as well as some of your existing occupational health data collected on behalf of Rössing Uranium by Medixx Occupational Health Services. However, as explained above, in the database this information will be linked to a 'Medical Research Number', not your name.

Rössing Uranium will also ask the Namibian Cancer Registry to advise the University's research team if you have been registered with a cancer under investigation. If you have been, the Namibian Cancer Registry will provide your unique 'Medical Research Number' (not your name) to the University so that the information is provided on an anonymous basis. Rössing Uranium will not be informed about who is and isn't registered with the Namibian Cancer Registry.

Once the database is established, statistical analyses will be carried out by the University of Manchester research team, using the aggregated and anonymised data. The research team's analysis of the data will take place exclusively at The University of Manchester in England and will be independent of Rössing Uranium.

If the data is sufficient, the results of these analyses will be published by the University research team in international medical and other scientific journals, conferences and research reports. Any such publications will be based on the anonymised data. No names of workers will be included, and the data that is published will not identify you (as the University team will not have access to such personal data, as explained above). You will be able to obtain copies of the publications if you wish.

The University of Manchester will retain the anonymous study data for a period of five years after completion of the health study, to respond to any queries that may be raised.

# How is confidentiality and privacy maintained?

Information retained by Rössing Uranium about employees is confidential and will only be disclosed to the research team on the basis that such confidentiality is protected, and personal data is anonymised. The same applies to any data that may be disclosed by the Namibian Cancer Registry to the University research team.

Anonymised employee information required for the purposes of the health study will be collated by

Rössing Uranium and uploaded and stored in a secure 'E-Room' (a type of database). It will be downloaded from there to be analysed in Manchester (England) by The University of Manchester's research team.

The University of Manchester's strict policy for data security and data custody will be applied to the handling of this data. As described above, data in any resulting records or documents will be anonymised and no individual workers will be identified. This is consistent with Rio Tinto's global Data Privacy Standard and The University of Manchester values.

#### When will the project be completed?

If there is sufficient data for the health study, it is proposed to be undertaken in the period up to April 2018.

## Will the outcomes of the research be published?

As stated above, the outcomes of the research will be published in peer-reviewed academic journals. A summary of the outcomes will also be discussed with the union representatives of the Rössing Uranium Mine before the study results are published and made public, and this summary will be made available for current and former workers.

The research team is based in the Centre for Occupational and Environmental Health, Institute of Population Health, Faculty of Medical and Human Sciences, The University of Manchester, Oxford Road, Manchester, M13 9PL, United Kingdom. The team has made a presentation of the study and publication proposals to union representatives at the Rössing Uranium Mine.

What if I have any questions or want to complain?

If there is anything that is not clear, or if you would like more information, please use the contact details at the beginning of this information sheet.

Should you decide that you DO NOT wish to take part in the health study, please do one of the following by 30 March 2016:

Return the Appendix A form in this advertisement to Rössing Uranium by placing the form in the drop box at the:

- Environmental Management building at Rössing mine, or
- · Rössing Foundation in Ondangwa, or
- Rössing Uranium Corporate Office in Windhoek, or
- Rössing Uranium Corporate Office in Swakopmund,

or

- send by email to RUL.healthstudy@ riotinto.com, or
- •send by post to Rössing Uranium, Private Bag 5005, Swakopmund

If we do not hear from you by 30 March 2016, we will understand that you agree to:

- the processing of your personal data (including your health information) by Rössing Uranium, and
- the processing of your anonymised data by the research team at The University of Manchester, and
- the provision of your anonymised data (if any and if relevant to the study) held by the Namibian Cancer Registry to the University of Manchester, for the purposes and in the manner described in this information sheet.

This Project has been approved by the University of Manchester's Research Ethics Committee. It has also been approved by the Namibian Ministry of Health, and the Namibian Cancer Registry has agreed to participate on the basis outlined in this letter.

If there are any issues regarding this research you should contact, in the first instance Prof Raymond Agius, Professor of Occupational and Environmental Medicine at The University of Manchester Tel: +44(0)161 275 5524, raymond.agius@manchester.ac.uk. You are also welcome to contact Rössing Uranium directly at RUL.healthstudy@riotinto.com, or by phone, 064-5202608.

If you wish to make a formal complaint about the conduct of the research you can contact a Research Governance and Integrity Manager, Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning +44 161 275 2674 or +44 161 275 8093. You can also complain to the Rössing Uranium data privacy co-ordinator (Zeka Alberto, by emailing zeka. alberto@riotinto.com or by telephoning +264 61 280 9025).

This Project has been submitted for approval by the University of Manchester's Research Ethics Committee. It has been approved by the Namibian Ministry of Health, and the Namibian Cancer Registry has agreed to participate on the basis outlined in this letter.

# APPENDIX A

**Project Title** 

Rössing Health Study – Uranium Mineworkers

An Epidemiological Study of Uranium Mineworkers

WITHDRAWAL OF CONSENT FORM

Note: If you are happy to participate in the health study and for your personal data to be processed by Rössing Uranium, and de-identified for analysis by the research team, you do not need to complete or return the form below.

However, if you DO NOT want to participate in the study and DO NOT want your personal data to be processed for the purposes of the study by Rössing Uranium, or for your anonymised data to be processed by the research team from the University of Manchester, you should complete the form below and return it to Rössing using the details below. You do not need to give a reason for the withdrawal of your consent.

Withdrawal of Consent

I do not agree to take part in the Rössing Health Study of Uranium Mineworkers, and do not want my anonymised data shared with the research team.

Name & surname of participant (print)

Date

Signature

Your company number(s) (provide all numbers if you had more than one)

RioTinto

Rössing Uranium Working for Namibia