



Q(h)ubeka Trust Research Policy

1. Introduction

The Trustees of Q(h)ubeka Trust (“the Trust”), wish to utilize Trust data to enable research that will contribute to scientific advancement, and the sharing of crucial knowledge of the challenges and lessons learnt in implementing the claims process.

The Trustees wish to engender an inclusive approach to research which recognises all individuals’ contributions to the subject matter.

The Trust Deed of the Trust allows for research to be undertaken. More specifically, clause 12 of the Trust Deed permits Trustees to:

1. determine and prescribe (subject to the provisions of this Deed) such research (including actuarial research) as may be reasonably required to achieve the Primary Object;
(Clause 12.2 (viii) (5))
2. prepare and publish information gathered by the Trust in an anonymised form for the purpose of advancing public health;
(Clause 12.2 (xiii))
3. use, publish or disseminate in an anonymised form and without profit or payment, the information and data gathered during the course of the operation of the Trust solely for the purpose of advancing public health.
(Clause 12.4)

The Trustees reaffirm their commitment to utilise Trust data to advance knowledge and deepen understanding and prevention of the adverse health effects of silica dust exposure, TB and silicosis, for the common good and for the advancement of public health.

2. Guiding Principles for Utilising Trust Data

1. Trust data will be utilised to facilitate the underlying spirit of the implementation of the complex Trust Deed and to engender participation, transparency, inclusiveness, scientific rigour, fairness and prevention.
2. Trust data belongs to the Trust.
3. Trust data cannot be used without the express written permission of the Trustees of the Trust and, where granted, only for the specified purposes.
4. Research projects shall allow all who participated on a regular and committed basis in the claims assessment process and the interpretation of the Trust data, to have the opportunity, by default, to be part of research projects unless they select to opt out.
5. The Trustees shall encourage collaboration with multiple stakeholders but especially, research undertaken must assist the process of transformation, including gender equity, and actively support improvement of research skills and scientific writing.
6. Research undertaken shall be inclusive and facilitate greater unity.

3. Applications for Using Trust Data for Research

1. All applications for using Trust data for research purposes must be made in writing to the Trust.
2. All applications shall be considered by the Trustees. Where an application is successful the Trustees may stipulate conditions for the use of the data and subsequent publication of the research.

4. Research Funding

Funding applications shall be considered having due regard to:

1. The funds available for research;
2. The importance and impact of the proposed research on the Primary Object of the Trust and the advancement of public health;
3. The provisions of the Trust Deed where applicable.