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The UK Silicosis Registry

Submission date 19/03/2026	**Recruitment status** Not yet recruiting	☒ Prospectively registered ☐ Protocol
Registration date 19/03/2026	**Overall study status** Ongoing	☐ Statistical analysis plan ☐ Results
Last Edited 01/05/2026	**Condition category** Respiratory	☐ Individual participant data ☒ Record updated in last year

Plain English summary of protocol

Background and study aims

Silicosis is a serious and irreversible lung disease caused by breathing in fine particles of silica dust. There is no good treatment. This dust is commonly found in jobs like mining, quarrying, and construction. Once inhaled, the dust can cause lung scarring and breathlessness. There is currently no cure. In recent years, a new cause of silicosis has emerged: working with artificial stone, a popular material used for kitchen worktops. Compared with natural stones such as granite and marble, artificial stone contains much higher levels of silica which can be higher than 90%. Cutting and polishing it, especially without water to suppress the dust, creates dangerously high levels of airborne silica dust. This puts workers at serious risk. The first UK cases of this type of silicosis associated with artificial stone were identified in 2023. These were mainly young men in their 30s, with some having worked with artificial stone for less than 10 years. It is associated with a particulary severe and progressive form of silicosis.

This project aims to establish the first UK Registry of patients with silicosis. The registry will collect vital information on all UK patients with silicosis. This will include information about their ages, where they worked, what jobs they did, and how severe their disease is. This will help doctors understand how best to monitor and treat these patients and ultimately prevent more people from getting sick.

The Registry will improve knowledge about patients living with silicosis in the UK and could lead to better protective measures at work and support medical research to find effective treatments.

Who can participate?

We are inviting everyone in the UK who has a diagnosis of silicosis made since 2020 and who attends a specialist occupational lung disease clinic to take part in this study

What does the study involve?

This is an observational study which means we are not testing any new treatments in this study. We will collect information recorded during your usual clinic visits from your normal clinical team. This may include:

- Height and weight
- Breathing tests
- CT scan results
- Other test results (for example, blood and urine tests)
- A list of companies you have worked for
- What you did in each of those jobs
- Your symptoms
- What treatment you take
- Any other medical conditions you have
- If you have ever smoked

We will also ask you to complete a short questionnaire which should take around 15 minutes to complete about your health and how you are feeling when you attend your usual clinic appointments. This will be on paper or online. Your usual clinical team will then enter this information, and your clinical information into the Registry after your clinic visits on an annual basis.

You will not need to attend any extra hospital appointments. If you decide not to take part it will not affect your clinical care. You are free to withdraw from the Registry at any time and should contact your usual clinical team if you would like to do so. If you decide to withdraw from the study, no further information about you will be entered into the Registry.

What are the possible benefits and risks of participating?

We cannot promise the study will help you, but the information we get might help improve the treatment of people with silicosis and improve our understanding of how silicosis may be prevented.

Analysing Registry information from hospitals across the UK should help to improve patient care by supporting us and the NHS in understanding:

- How many people are living with silicosis and if this changes over time.
- How well people’s lungs work once they have silicosis, if their disease is getting worse and how it is being treated.
- National trends in silicosis
- If there are differences in how people are treated (for example depending on where in the country they live)
- Where more support is needed for services like your clinic.

The main disadvantage to taking part is you will be asked to complete an additional questionnaire when you come to clinic which will take up to 15 minutes.

Where is the study run from?

The study is lead by researchers at Imperial College London.

When is the study starting and how long is it expected to run for?

The study will start in April 2026 and run for 5 years.

Who is funding the study?

Royal Brompton and Harefield Hospitals Charity for the first year

Who is the main contact?
Dr Johanna Feary, j.feary@imperial.ac.uk

Contact information

Type(s)
Principal investigator, Scientific, Public

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Additional identifiers

Integrated Research Application System (IRAS)
359280

Study information

Scientific Title
The UK Silicosis Registry

Acronym
UK-SR

Study objectives
1. To establish a Registry of cases of Silicosis in the UK
2. To describe the demographics and clinical characteristics including exposure history of cases of silicosis in the UK
3. To carry out geospatial mapping of the workplaces where cases have been identified
4. To collect longitudinal data on cases of silicosis to describe disease trajectory progression and identify relevant risk factors.
5. To build a resource that can be used for future work to describe the UK landscape of silicosis

Ethics approval required
Ethics approval required

Ethics approval(s)
approved 23/03/2026, North East - York Research Ethics Committee (2 Redman Place, London, E20 1JQ, United Kingdom; no telephone number provided; york.rec@hra.nhs.uk), ref: 26/NE/0013

Primary study design
Observational

Secondary study design
National registry

Study type(s)

Health condition(s) or problem(s) studied
Silicosis or silica associated lymphadenopathy

Interventions
This is an observational study. The aim is to recruit all patients with silicosis from the UK diagnosed since 2020.
The UK Silicosis Registry will be hosted at Imperial College London using the REDCap platform. Data from clinical health care visits, and from specific questionnaires, will be entered on currently known and all new cases of silicosis from GORDS centres. GORDS is a well-established UK-wide network of specialist occupational lung disease centres (at Royal Brompton Hospital in London and in Birmingham, Manchester, Liverpool, Sheffield and Newcastle). In the future, cases may be included from specialist interstitial lung disease clinics at other centres if appropriate.
Data will be collected on the following domains.
• Demographics
• Clinical assessment including (but not limited to)
o smoking history
o current employment status
o comorbidities
o measure of breathlessness using modified Medical Research Council dyspnoea scale
• Pulmonary function test results
• Chest CT (computed tomography) scan results
• Blood test results including serum angiotensin converting enzyme, connective tissue screen and QuantiFERON
• Occupational history
• Quality of Life data using the WHO-QOL BREF questionnaire
The lead clinician at each contributing site will enter data into the Registry using REDCap at the time of their appointment. Data will be entered into Reigstry at baseline and at subsequent appointments again by their local lead clinician to allow longitudinal analyses.

Patients with silicosis will be approached by their usual clinical care team and invited to take part in the Registry. They will be provided with participant information sheets and consent forms ahead of their clinic visit. Informed consent and completion of the Quality-of-Life questionnaire will take place at their routine appointment. Pseudoanonymised data will be added to the Registry following the clinic visit by the local clinical team. Data analyses will then be carried out by the Cheif Investigator.

Intervention Type
Not Specified

Primary outcome(s)

1. Description of clinical characteristics of patients in the UK with silicosis measured using review of patient notes at annually

2. Quality of life of patients in the UK with silicosis measured using WHOQOL-BREF questionnaire at annually

Key secondary outcome(s))

Completion date

20/04/2031

Eligibility

Key inclusion criteria

1. Patient reviewed in a specialist occupational lung disease service
2. Diagnosis of silicosis due to occupational exposure with diagnosis based on:
2.1. History of occupational exposure to respirable crystalline silica
2.2. CT changes consistent with silicosis or silica-associated lymphadenopathy

Healthy volunteers allowed

No

Age group

Mixed

Lower age limit

18 years

Upper age limit

100 years

Sex

All

Total final enrolment

0

Key exclusion criteria

1. Patients under the age of 18 years
2. Radiological changes of silicosis without appropriate exposure history
3. Patients where there is diagnostic uncertanty
4. Patients who do not give or are unable to give consent

Date of first enrolment

15/06/2026

Date of final enrolment

31/12/2030

Locations

Countries of recruitment
United Kingdom

England

Study participating centre
Royal Brompton Hospital
Sydney Street
London
England
SW3 6NP

Study participating centre
University Hospitals Birmingham NHS Foundation Trust
Queen Elizabeth Hospital
Mindelsohn Way
Edgbaston
Birmingham
England
B15 2GW

Study participating centre
Manchester University NHS Foundation Trust
Cobbett House
Oxford Road
Manchester
England
M13 9WL

Study participating centre
Sheffield Teaching Hospitals NHS Foundation Trust
Northern General Hospital
Herries Road
Sheffield
England
S5 7AU

Study participating centre

Liverpool University Hospitals NHS Foundation Trust
Royal Liverpool University Hospital
Prescot Street
Liverpool
England
L7 8XP

Study participating centre
The Newcastle upon Tyne Hospitals NHS Foundation Trust
Freeman Hospital
Freeman Road
High Heaton
Newcastle upon Tyne
England
NE7 7DN

Sponsor information

Organisation
Imperial College London

ROR
https://ror.org/041kmwe10

Funder(s)

Funder type

Funder Name
Royal Brompton and Harefield Hospitals Charity

Results and Publications

Individual participant data (IPD) sharing plan

IPD sharing plan summary
Not expected to be made available

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Participant information sheet	version 1.2	20/01/2026	19/03/2026	No	Yes
Study website			19/03/2026	No	No