

# PROJECT PROPOSAL

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## 2023 Academic Entry Year – Cohort 2

### Supervisory Team

#### Primary Supervisor

Name: Prof Bibek Goptu

Input (%): 50

Email: [bg129@leicester.ac.uk](mailto:bg129@leicester.ac.uk)

Centre/Institute/School/University: University of Leicester Centre for Fibrosis Research/Institute for Precision Health, Department of Respiratory Sciences, School of Biological Sciences; NIHR Leicester BRC - Respiratory

Website: [Bibek Goptu \(0000-0002-5223-1121\) \(orcid.org\)](#); [\(87\) Leicester Institute of Structural & Chemical Biology - Professor Bibek Goptu - YouTube](#); [Professor Bibek Goptu | University of Leicester](#)

#### Secondary Supervisors

Name: Linzy Houchen-Wollof

Input (%): 25

Email: [lw326@leicester.ac.uk](mailto:lw326@leicester.ac.uk); [Linzy.Houchen@uhl-tr.nhs.uk](mailto:Linzy.Houchen@uhl-tr.nhs.uk)

Centre/Institute/School/University: University of Leicester Centre for Exercise and Rehabilitation Science/Institute for Precision Health, Department of Respiratory Medicine; NIHR Leicester BRC – Respiratory (lead for AHP training)

Website: <https://orcid.org/0000-0003-4940-8835>

Name: Dr Shamsa Naveed

Input (%): 25

Email: [Shamsa.Naveed@uhl-tr.nhs.uk](mailto:Shamsa.Naveed@uhl-tr.nhs.uk)

Centre/Institute/School/University: Department of Respiratory Medicine, Glenfield Hospital, University Hospitals of Leicester

## Project Details

### Project Summary

**Title:** Defining and Tackling the Barriers to Healthcare Equity in Women of South Asian Ethnicity with Chronic Lung Diseases

**Summary:** Women from ethnic minorities are under-represented in studies from research-active environments. Women of South Asian ethnicity are at increased risk of the lung disease chronic hypersensitivity pneumonitis (CHP) that limits quality and length of life. Identifying factors driving disease in individuals can help resolve or stabilise the disease, but the causes in this group are unknown. Local demographics mean that Leicester clinicians manage many such patients, and Respiratory researchers here are superbly-placed to investigate using multiple state-of-the-art approaches within the Centre for Fibrosis Research. However, appropriate engagement with patients/controls is critical for research ethics and excellence. We hypothesise that multiple intersecting factors limit research engagement. These include socio-economic/linguistic/gender issues, and mismatches between cultural perspectives informing patient and research paradigms (e.g. biopsychosocial models of disease, breathing, mechanistic/clinical research). The student will therefore interrogate these domains from a patient-centred perspective. They will establish appropriate fora to hear patient and community voices and experience, then explore the perceptions that may inform study design and patient engagement. After optimizing patient-related outcome measures (PROMs) and importance thresholds to cultural context, they will develop intervention strategies, aimed at improving research engagement to understand the underlying causes and best treatments for CHP in this population.

**Theme(s) the project most closely aligns to:** Health Inequalities, Respiratory Health, Patient Centring, Research Excellence, Applied Social Science, Local/National partnerships, Inclusive & Positive Culture, Experimental Medicine

**How the PhD project and training would be appropriate for NMAHPs or GPs:** The work is grounded in patient interactions, in which NMAHPs and GPs have highly-developed skills. The supervisory team and collaborators will maximise the value of these skills, their utilisation to produce high quality scientific data, and interpretation in the appropriate clinical and research contexts for outcomes that will inform, and potentially change, policy and practice.

**How the project addresses health inequalities:** The project addresses health inequalities based upon gender and/or ethnicity and their intersection. It aims to do so with a patient-focused approach, research and clinical expertise, and a wide remit to characterise areas of mis-alignment between patient and healthcare service perspectives.

**Aim:** To work with patients to assess the contributions of differing cultural perceptions, socio-economic status, linguistic challenges, and previously unrecognized factors that may limit healthcare equity in chronic respiratory disease, with particular reference to severe asthma and chronic hypersensitivity pneumonitis.

**Background:** Women of South Asian ethnicity are at increased risk of developing the respiratory disease chronic hypersensitivity pneumonitis (CHP). CHP causes inflammation of the airways and gas exchange membranes of the lungs, and typically progresses to scarring (fibrosis). These processes make breathing

harder work and less effective, and shorten life expectancy. It is classically considered as an abnormal reaction of the immune system to an inhaled organic trigger. Because of Leicester's demographics, the interstitial lung disease (ILD) service here looks after a large number of women of South Asian ethnicity with CHP. CHP is also the commonest ILD described in populations in India, however the putative atmospheric exposure triggers considered in that context do not apply in our clinic population. There is therefore an important translational research question that we are well-placed to address as to what causes CHP in women of South Asian ethnicity. However, this demographic is poorly represented in UK patient groups and previous research initiatives in this clinical area. We hypothesise that a patient-centred approach will better define key common factors that represent barriers to research engagement in these patient groups. We will compare findings in CHP with those in women of South Asian ethnicity with severe asthma, another chronic respiratory disease in which this demographic appears at increased risk of disease and suboptimal management, and is under-represented in research studies. Other control/comparator groups will include: people of South Asian ethnicity without respiratory disease, disease-specific controls (non-South Asian CHP), men of South Asian ethnicity with respiratory disease.