

PROJECT PROPOSAL

2023 Academic Entry Year – Cohort 2

Supervisory Team

Primary Supervisor

Name: Dr Linzy Houchen-Wolloff

Input (%): 50%

Email: Linzy.Houchen@uhl-tr.nhs.uk and lw326@leicester.ac.uk

Centre/Institute/School/University: 1. Senior Research Physiotherapist, Centre for Exercise and Rehabilitation Science (CERS), NIHR Biomedical Research Centre (BRC)- Respiratory and Research Lead for Therapy, Physiotherapy, University Hospitals of Leicester NHS Trust.2. Honorary Senior Lecturer, Department of Respiratory Sciences, University of Leicester.

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

Secondary Supervisors

Name: Dr Nicola Bateman

Input (%): 25%

Email: nab34@leicester.ac.uk

Centre/Institute/School/University: Associate Dean Marketing and Global Engagement ULSB Associate Professor Operations Management School of Business, Brookfield, 266 London Road, Leicester, LE2 1RQ .

Website: <https://le.ac.uk/people/nicola-bateman>

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Name: Dr Jennifer Creese

Input (%): 25%

Email: jlc60@leicester.ac.uk

Centre/Institute/School/University: Lecturer. Department of Population Health Sciences (SAPPHIRE Group), College of Life Sciences, University of Leicester, George Davies Centre, University Road, Leicester, LE1 7RH.

Website: <https://le.ac.uk/people/jennifer-creese>

Other collaborators/ informal mentors:

Dr Natalie Darko (School of Media, Communication and Sociology): Dr Natalie Darko is an Associate Professor specialising in research within Health Inequalities and is the incoming Director of Inclusion within the BRC.

Dr Mark Orme (Respiratory Sciences): Dr Orme is a Lecturer and currently supervises 5 UoL PhD students. His CV was one of the 10 example CVs provided to Wellcome, the only one from an Early Career Researcher (ECR). Dr Orme is a member of Department of Respiratory Sciences EDI Committee and, as Research Manager and Co-Investigator for a NIHR Global Health project (£2.4M), has significant experience of increasing research capacity of non-medical AHPs (e.g. Physiotherapists and Dieticians) and other medical professionals in the UK and low and middle income countries (LMICs).

Dr Molly Baldwin (CERS, UHL): Dr Baldwin is an exercise physiologist with expertise in delivering Covid-19 rehabilitation (online and face to face) from both a research and clinical perspective. Dr Baldwin will have support to build capacity as an early career researcher (ECR) from the supervisory team to enable her to take her own PhD students in the future. Molly has expertise in the Your Covid Recovery© website analytics and is a co-investigator on the PHOSP rehabilitation trial.

Project Details

Title: Adaptation and testing of the Your Covid Recovery© programme to address ethnicity, language and digital divide health inequalities.

Summary: A high proportion of individuals experience persistent COVID symptoms after their acute COVID infection [described as “Long COVID” (1)]. These symptoms have a profound effect on the individual’s quality of life as they impair their ability to perform activities of daily living. To support people throughout their COVID recovery, the Your COVID Recovery® programme was developed (2). In addition to traditional face-to-face rehabilitation, this programme includes a digital rehabilitation programme, paper-based rehabilitation manual, and an open access website with information on how to relieve and manage COVID symptoms. To date, over 2300 patients have enrolled onto the digital rehabilitation programme in the UK. However, despite minority ethnic groups being disproportionately affected by COVID, 88% of individuals using the digital rehabilitation programme self-report as White British (2). The aim of this project is to increase minority ethnic group participation in the Your COVID Recovery programme by designing a new culturally appropriate version. This may include the web, paper-based or face-to-face platforms to offer a menu of choices for patients. This programme will then be implemented in an underrepresented/ minority ethnic group to determine if it effectively improves COVID symptoms, exercise tolerance and health-related quality of life.

Theme(s) the project most closely aligns to: Respiratory and infectious disease.

How the PhD project and training would be appropriate for NMAHPs or GPs: This project will integrate several patient-centred methodologies relating to digital health and social science, thus providing high-quality PhD training. The supervisory team offers a mix of backgrounds/ skills, bringing in ECRs who have the time to commit to the student and those with experience of supporting NMAHPs. This project will collaborate with the PHOSP-COVID study (Rehabilitation/Data working groups), SAPPHIRE group (qualitative), Schools of Media, Communication, Sociology (Health Inequalities) and Business, Human Factors, Innovation (co-design and data analytics). The student will have access to a high-quality clinical data source which represents an excellent opportunity to address inequalities in this patient group.

How the project addresses health inequalities: The Your COVID Recovery© website has attracted more than 12 million users since July 2020 from 187 countries and >2300 patients from UK NHS Trusts have enrolled onto the digital rehabilitation programme (2). However, despite minority ethnic groups being disproportionately affected by COVID (3), including being at a greater risk of dying (4), 88% of individuals using the digital rehabilitation programme are White British (2). This is also at odds with the diverse population in Leicester, Leicestershire and Rutland [LLR (5)]. These inequalities have been further exacerbated by the pandemic, leading to ethnic minority groups being caught in a vicious spiral, with material inequalities contributing to an increased risk of poor COVID outcomes (6). This project will address inequalities highlighted by user feedback, addressing the discordance between COVID burden and reach of the Your COVID Recovery© programme. Users have expressed the need for culturally appropriate versions of the programme, in different languages and with culturally tailored components to increase programme appeal, accessibility and suitability. Moreover, this project will also tackle the digital divide by developing and testing offline versions of Your COVID Recovery© (e.g. manual/ face-to-face programmes), adapted to underrepresented and ethnic minority groups in LLR.

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Aims: 1. To examine existing data from the PHOSP-COVID study and Your Covid Recovery© programmes to identify the demographics of the post-COVID population in terms of the 9 protected characteristics (7), to identify health inequalities in access to rehabilitation. 2. To explore the barriers to the current Your Covid Recovery© programme platforms for patients and carers from minority groups. 3. To adapt the Your Covid Recovery© programme to address these inequalities. This may include culturally appropriate redesign of the web/ non-digital platforms adopting participatory design methodologies [co-design (8)]. We anticipate that ethnicity, language, digital access/ skill will represent some of the barriers from our previous work. 4. To evaluate the feasibility and acceptability of the adapted Your Covid Recovery© programmes offered to the patient using shared decision making methodology (9). Outcomes to include: uptake and completion of the chosen platform (menu of web, paper-based or face-to-face classes), symptoms, exercise tolerance, health-related quality of life, and lived experiences from patients, family members or carers and health care professional interviews and focus groups.

Background: “Long COVID” describes the persistence of symptoms or disability after the acute infection, not explained by an alternative diagnosis (10). In patients hospitalised with COVID-19, only three out of ten patients felt fully recovered at six/ 12 months post-discharge (1,11). With over half a million adults admitted to hospital with Covid-19 in the UK to date (12), symptomatic survivors of COVID-19 therefore represent a large and growing population. To support individuals throughout their COVID recovery the Your COVID Recovery© programme was created. Alongside a traditional face-to-face rehabilitation programme that improves clinical outcomes (13), this programme includes, a digital rehabilitation option and a paper-based manual is currently being developed. As described above, the web programme has been extensively used worldwide (1). However, the demographics of users are not reflective of those most at risk of COVID/ the LLR population. Feedback from users’ centres on the need for culturally appropriate versions of the programme in different languages to increase programme accessibility. We have experience in similar populations where we have taken existing programmes (e.g SPACEforCOPD©) and adapted this to other languages/ cultures in low/ middle-income countries (14-16).

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