

## Project

Is your project funded?

Yes

Is the project funded internally or externally?

Externally

How would you categorise your source of funding?

UK Research and Innovation (UKRI)

### Project aims and research questions

As one of the most diverse cities in Europe, Leicester constitutes an ideal empirical crucible within which to explore the complex interdependencies between diversity, place, power, inequality, identity and health/wellbeing issues, concerns and outcomes. Both University Hospitals of Leicester NHS Trust (UHL) and the University of Leicester (UoL) are seeking to better explore these interdependencies through instituting a strategic shift towards consultation on health research priorities and practice that is properly community-centric, locally responsive, and co-productive in the development of expertise in the issues affecting the different health populations of a place. Moreover, UHL and UoL are looking to develop a sustained collaborative, citizen-centric engagement with local communities to co-develop policies and practices that effectively target structural inequalities and disadvantages in health as these play out at local levels. UHL/UoL are exploring how best to work with existing partners to foster new modes of engagement that empower local citizens to become involved in/with research as active agents/experts in their own lives. This forms part of a wider UHL/UoL drive to change institutional cultures of engagement, building upon several areas of existing excellent practice, and supporting others at earlier stages of implementation, including the recent development of a Public Engagement Unit. Partnership working between UoL, UHL (Leicester Diabetes Centre and Centre for BME Health) and Aakash Odedra Dance Company (AODC) has begun exploring culturally popular arts as a medium to engage seldom heard groups, with particular consideration of intersectional exclusion targeting deprived Asian women, and as a means of dismantling both real and perceived power. This has had the further advantage of engaging wider groups by creating wider appeal.

This project will establish the first phase of a longer-term consultation on health research priorities to inform the health research objectives of UHL and UoL co-developing place-based insights, primarily through digital and phone consultations during the Covid-19 pandemic, but ordinarily through developing and utilising innovative modes of community engagement facilitated by Leicester Citizens and community arts partners notably including AODC.

Leicester Citizens has an excellent track-record of utilising action-learning techniques to train local citizens to work as community brokers in the co-creation of research-based knowledge. Likewise, since April 2017 UoL and UHL have worked with AODC to use arts-based approaches to engage women from BME backgrounds with health science.

Through employing a combination of these participatory/engagement methodologies, in addition to other community engagement methods identified by the community researchers facilitating data collection, the project will seek to achieve three inter-related objectives:

1. Identify how UoL/UHL can better engage citizens from different backgrounds and places in the co-production of knowledge in ways attuned to the power dynamics involved in this engagement.
2. Building on the above, co-develop place-based priorities for research into health and wellbeing in key disadvantaged areas in Leicester.
3. Lay the foundations for a longer-term programme of UHL/UoL engagement with local communities in health/inequalities research and targeted policy development.

The project will focus on the areas of Belgrave, Spinney Hill, Oadby and Braunstone in addition to other areas that community researchers target digitally during social-distancing measures. Belgrave and Spinney Hill are LSOAs predominantly in the first and second quintile of deprivation (with one exception each); high populations of people from BME backgrounds; population dense innercity

areas. Oadby is ostensibly more varied LSOAs from 19, however these areas exhibit some of the risks affecting diasporic populations in less deprived places, such as high incidences of COPD, lung disease and diabetes (Leicestershire Joint Strategic Needs Assessment 2018).

This project will comprise three phases:

1. Training Community Researchers in action learning/knowledge co-production roles.
2. Action-learning health and wellbeing research consultation on health research priorities through meetings facilitated by Leicester Citizens and Community Researchers with UHL/UoL health researchers, via phone calls and digital media platforms.
3. Review of consultations and collation of research priorities based on themes raised in consultations which will facilitate dialogue between UoL/UHL and communities.

This project is supported by the community and engagement networks of all listed organisations, further expansion will be supported and brokered by Local Authority colleagues (Philippa Fisher for the County and Cllr Kirk Master for the City). All listed partners have been involved in the development of this proposal and it has been reviewed by the several public involvement groups in UHL infrastructure.

### Proposed methods/protocol

Interviews (details would include whether these are face-to-face, online or group interviews, e.g. focus groups)

Mixed Methods

### Who are the 'human participants' in this research?

The human participants in this project are all the individuals that will contribute towards co-production: the researchers in the core team, the community researchers, and the individuals we encounter through digital consultations, events we hold, or events that are already being held, in the outlined communities.

### Clearly describe how you intend to identify, approach and recruit participants.

Participants will be identified from the pool of people community researchers (who are trusted members of and organisers within their communities) reach out to via phone or digital platforms, people attending the events we hold, or already-established events being held within the outlined communities.

### Enter the number of participants

100

### Start date

11/05/2020

### End date

31/07/2020

### Where will the study take place?

The study will focus on the Leicestershire areas of Belgrave, Spinney Hill, Oadby and Braunstone in addition to other areas that community researchers target digitally during social-distancing measures.

If the study is to be conducted outside the researcher's home country/place of permanent domicile, what steps are being taken to ensure that the necessary research/ethical/other permissions are secured, and that the researcher is aware of and respectful of any political and cultural sensitivities in that place?

The Project Officer and core team will attend community organising training programmes with the community representatives, during which there is time allocated towards smoothing out any concerns. Further, all community representatives have an already-established working relationship with the co-investigators. The core research group will also conduct ourselves to the standards of research ethics, integrity and propriety to ensure we do not perpetuate any social injustices.

## Permissions

Are there any legal, cultural, religious or other implications to conducting the study and if so, how will these issues be addressed?

This project will form a key part of a UoL/UHL push to build a much longer-term (multi-year) engagement with disadvantaged communities in Leicester laying the foundations for a nexus of dialogue and support, empowering citizens to provide genuine and meaningful input into the research agenda. A core aim is to develop and establish a set of processes, protocols and practices through which members of disadvantaged communities can be engaged as co-creators in the development of expertise about the complex intersection of locality, space and place, identity and inequalities, particularly those pertaining to health.

The engagement is predicated on a recognition of the fundamentally relational and processual character of health and wellbeing, a position which in turn owes much to the figurational (processual/relational) sociology of Norbert Elias. Elias, now regarded as one of the most important thinkers of the Twentieth Century, helped establish the Sociology Department at Leicester in the 1950s during which time he undertook a study of intra-community relations in the region (South Wigston) (Elias and Scotson 1965). Today counted among the most significant texts within community studies, *The Established and the Outsiders* elucidated the complex interplay of power, family, length of association relations invisible to standard logics of social inequality such as class and ethnicity which had a profound bearing on a range of social and economic outcomes, including those relating to health and wellbeing. While a great academic success, it later came to light that the community in South Wigston felt somewhat side-lined with regard to their involvement in shaping the depictions of place and the findings the study reached. This project provides a key opportunity to implement a far more community-centric approach, one which draws upon the lessons of the past, but also lays a pathway for a responsive and adaptive programme of engagement in the future.

How will you gain permission to carry out this research (e.g. obtain data, access to sites etc)?

For identifying participants in the community, we will work closely with individuals employed as researchers in those community groups. These community researchers have long established links within their communities. It is via these individuals that we would hope to recruit research participants on digital platforms, via phone calls, at different community engagement events, such as dancing sessions, coffee mornings, and other social gatherings. All community researchers will receive training, and be fully informed about research protocol. They will be given project information sheets and consent forms for dissemination to potential participants. The interviews will be led by the community researchers in consultation with the project team. An interview guide is attached to the Community Researcher Brief: Community Researchers also have the flexibility to adapt this guide as they see fit, especially given that they know their community best. The topic covered in the guide generally focus on issues relating to community health priorities, but cognate areas may arise in the interviews. We do not anticipate any particularly ethically sensitive topics in the course of these interviews. However, given that these will be conversations that may flow organically, we cannot fully discount this possibility. We will provide guidance to community researchers on how to deal with such topics, of their responsibilities in such cases, including the point at which to refer such cases to the project team to ensure they are dealt with in a manner consistent with the University's ethical safeguarding policies.

What is the evidence you will provide to gain the necessary permissions?

The final UKRI bid, showing approval from research collaborators, is provided in the attachments.

Will the study require the co-operation of a gatekeeper for initial access to the groups or individuals to be recruited? (e.g. students at school, members of self-help group, residents of nursing home). Yes

Does the research involve administrative or secure data that requires permission from the appropriate authorities before use? No

## Informed Consent / Data Protection

Will all participants be provided with a participant information sheet and an informed consent form?

Yes

Is consent being sought for the data collected to be used for future research projects and/or with a view to archiving data and making it available and re-usable by other researchers?

Yes

How will you ensure ethical procedures if data is being made re-usable? Remember to include appropriate information in the participant information sheet and consent form.

We anticipate that the anonymised notes from consultations with participants, and reflections from researchers, will be made available for secondary analysis. This will only be the case where participants and researchers have consented to do so.

Will you be accessing non-anonymised data without consent?

No

Will the study involve participants who are vulnerable? (e.g. people under the age of 18, people who may lack mental capacity or people who are in institutional settings, such as prisons)

No

Does the research activity proposed require a criminal record check?

No

Does the research involve observing participants without their knowledge?

No

How will the confidentiality and privacy of participants be maintained?

The interview phase of the project does not require a name or personal details of the participants to be noted and therefore the entire data set will be completely anonymous from the outset.

Will the study involve discussion of sensitive topics (e.g. victimisations, sexual activity, drug use)?

No

Will research involve the use of the internet or other visual/vocal methods where respondents may be identified?

Yes

Give details about particular issues this raises and the decisions taken as a result.

Due to Covid-19 considerations, this project will have to be carried out respecting social (or corporeal) distancing. This means that digital consultations using mediums such as video conferences, social media platforms, as well as phone calls, will be used for data gathering. Video conferences and phone calls involving community participants will NOT be recorded. Researchers facilitating these meetings will only take notes. This is explicitly stated on the PIS and consent forms, so all individuals will be fully aware of the methods being used.

Are there financial inducements (other than reasonable expenses and compensation for time) to be offered to participants?

No

Are you processing personally identifiable data? (i.e. anything that would identify an individual such as date of birth, gender, contact information, ethnicity etc)

No

Please complete the checklist below to indicate any supporting documents included with this application:

Permissions

Participant information sheet(s)

Consent form(s)

Interview topic guides/schedules

## Attachments

UKRI EPPE Researcher Brief.pdf

PISICF Consultations 1.0 CLEAN.pdf

UKRI\_EPPE\_Final.pdf

Consent Process for UKRI Project.pdf

PISICF Covering Letter.pdf

UKRI EPPE Consent Form\_Researchers.pdf

Text for Invite.pdf

Webpage Text.pdf