



2016-2017 Beacon Bursary Awardees

Caroline Hilton – Lecturer, Department of Learning and Leadership, Institute of Education

Supporting children with Apert syndrome to become confident learners of mathematics

I recently completed my PhD on the mathematical development of children with Apert syndrome. Children with Apert syndrome are born with their fingers fused and only have use of them after several operations. As the use of fingers is very important in the development of early number skills, my findings suggest that children with Apert syndrome should be supported to develop their finger awareness and mobility as early as possible. This is the first study exploring the mathematical development of children with Apert syndrome, I would like to make links with the four craniofacial centres in the U.K. (in London, Oxford, Birmingham and Liverpool) in order to discuss my findings and to bring education into the conversation about care for these children and their families. I would also like to meet with Headlines, a family support group for children with craniofacial anomalies. I would like to run a workshop at the Headlines conference next year for parents and carers and other interested parties. I would also like to run workshops in schools for teachers and support staff working with children with Apert syndrome. Through these meetings and workshops I would like to engage in exchanges of ideas for implementing changes in practice.

Christian Nold – Research Associate, Civil, Environmental & Geomatic Engineering, BEAMS

Are you listening? Noise and its impact on well-being at Heathrow

The project is designed to compare a variety of ways of assessing noise in the area of Heathrow, London. Heathrow is the world's third largest airport and London the European city most affected by aircraft noise. While sound pressure is technically 'easy' to measure, commonly used assessments of 'noise' do not capture the complex subjective experiences of noise. This project aims to connect people who are 'researching' noise with those who 'monitor' noise and those who 'experience' noise such as residents and community groups. The project connects researchers from the Doing it Together Science (DITOs) project (www.togetherscience.eu), UCL students from the new MSc Health, Sustainability and Well-being in Buildings in the Bartlett (<https://www.ucl.ac.uk/bartlett/environmental-design/programmes/msc-health-wellbeing-sustainable-buildings>) with residents close to Heathrow airport and the Royal Borough of Windsor & Maidenhead council (RBWM) and HACAN – a community group for those under Heathrow flight paths (www.hacan.org.uk). Together they will collaborate to reimagine existing noise metrics that are used to define community annoyance and exposure. It is envisioned that working together will develop new approaches for creating evidence for the impact on health and well-being of noise. Heathrow is a pertinent place for this project, since local government, community groups and local residents' dispute current proposed metrics to assess noise, health and well-being.

Claire Shih – Lecturer, Centre for Translation Studies (CenTraS), SLASH

Promoting access to health information and services in the Chinese community in the U.K.: a translation/interpreting project and an app for medical terminologies

This project is designed to establish a new model of collaborative engagement between staff and students at the Centre for Translation Studies (CenTraS) and a charitable organisation, Chinese National Healthy Living Centre (CNHLC; <http://www.cnhlc.org.uk/>), in support of their (translation/interpreting) work to promote and facilitate access to health services and information for the Chinese community in the U.K.

Emma Matthews – Postgraduate Research Student, Institute of Neurology, SLMS

A family consultation day to discuss the development of a registry of sudden unexpected death in infancy and childhood

Sudden unexpected death in infancy and childhood is a devastating event that affects all community groups. Even after detailed investigation professionals are often unable to tell families why their child died. As part of a wider project involving clinicians, researchers and the Lullaby Trust charity who support families affected by the sudden and unexpected death of a child we propose creating a national registry of sudden unexpected deaths that occur before age 18. The registry would collect detailed clinical and family information along with tissue samples and will facilitate research and understanding of the risk factors for death. Our aim is that this information will be used to help families understand what has happened to their child and to help prevent such deaths in future.

We believe the success of such a registry depends upon close working relationships between professionals and families. To help us create a registry that is mutually beneficial to families, clinicians, researchers and charities we would like to host a public engagement event involving all these groups. We would like an inclusive and open forum for insights and ideas to be shared by all interested parties including but not limited to whether they would support a registry, what shape it should take, and how and when it should be discussed following bereavement.

Eve Mackinnon – Postgraduate Research Student, Civil Engineering and Geomatic Engineering, BEAMS

Co designing of faecal waste management options on canal boats

The funding will be used to publicise, organise and run a co-design 'waste to value' workshop in Hackney Wick, East London to respond directly to needs of canal boats users and the wider local community. It is to be co-hosted by Eve Mackinnon (2nd Year PhD CEGE student) and 'Gaia Gallery' - a carbon neutral sustainable touring canal boat organisation. The 3-hours evening workshop will explore options for the safe collection and treatment of human waste on board canal boats directly from inputs from a wide range of stakeholders. Canal boat users and organisations such as the Canal and River Trust (CRT) will lead the codesign process with inputs from toilet manufacturers (e.g. Kildwick, Airhead and Simploo). Community mapping of the canal geographies will support the potential location of collection points and treatment stations. Expert advice related to collection and potential treatment mechanisms (e.g. anaerobic digestion systems and composting) will support the co-design process. Potential re-use options will be also linked into the system with participation from interested stakeholders (e.g urban farming systems). As part of the co-design process, a short film (2-3 mins) will be made following the work of 'Poo-pioneers' who are taking on the management and re-use of human waste on board canal boats. Script development, and some scenes shot, before editing to produce a short 2-3 min film about re-use of human waste designed to engage with decision makers.

Tse-Hui Teh – Lecturer, Bartlett School of Architecture, BEAMS

Lena Ciric – Lecturer, Civil Engineering and Geomatic Engineering, BEAMS

Compost conversations

UCL are working with Spitalfields City Farm to install a new vacuum flush composting toilet. Our engagement project 'Compost Conversations' is the initial step for longitudinal research looking at how people change their behaviours and views with the introduction of a new toilet system and how the microbial communities in the compost change over time. The collaboration between UCL and Spitalfields City Farm originates from the misuse of the current flush toilet system at the Farm. The toilets are often blocked by nappies and sanitary products, therefore this project represents an opportunity to not only test more sustainable methods of recycling human waste, but also a chance to convey the limitations of current toilet systems. 'Compost Conversations' occurs before the toilet is installed. This initial step is a series of workshops that enables a conversation with four of the most disparate communities who regularly visit Spitalfields City Farm and are likely to use the toilet and compost in the future. The conversation centres on a project to create communication tools about toilet systems, the vacuum flush compost toilet and the long term research we intend undertake. Each workshop will be tailored to the relevant age group: primary school, high school, and adults. The workshops will be designed to be highly interactive combining quiet thoughtful exercises, with high speed games to draw out preferred communication tools and topics. Following the workshop, drafts of the communication tools will be displayed and feedback welcomed from other visitors to Spitalfields City Farm. This feedback will then be synthesised into the pilot communication tool for the vacuum flush toilet and UCL research. 'Compost Conversations' gives participants a forum to discuss the toilet installation; compost from the toilet and its potential use and hazards; refine our research questions; and build long term engagement with our research project. It is also a pilot study in which we learn more about the publics who are toilet users. We intend to apply for further funding from other sources for the long term engagement project.

Irene Petersen – Reader, Primary Care & Population Health, SLMS

Psychotropic medication in pregnancy – translation of evidence into practice

Every year 650 000 children are born in England. Nearly 10% of their mothers would have been on antidepressant treatment in the year before they become pregnant. However, only 1 in 5 individuals continue antidepressant treatment in pregnancy and many stop treatment because of fear of harming the unborn child. Our previous work with women using psychotropic medication demonstrated that women often find it difficult to identify reliable information on drug safety in pregnancy. The popular media tend to present drug safety issues in a black and white fashion with headlines such as "Women who take antidepressants during pregnancy have nearly double the risk of having an autistic child". In contrast, much scientific evidence is often difficult to understand, and healthcare professionals are often not well informed creating a barrier to translation of evidence.

In this project, we will work with women who have been pregnant recently (within the last 2 years) and had first-hand experience of making decisions on whether to continue or stop antidepressant medication in pregnancy. We will form a 'Lived Experienced Advisory Group' (LEAG) of 6-8 women who live near the Bromley-by-Bow community centre in east London <http://www.bbbc.org.uk/> (see details below). Meeting at the community centre, the members of the LEAG will participate in three workshops with the aim to co-produce information material on psychotropic medication in pregnancy based on existing evidence and their own experiences.

Katherine Twamley – Senior Lecturer, Social Science Institute of Education

Fathers and parental leave: An exhibition on Father's Day 2018

I propose to organise an interactive family photo exhibition on parental leave for fathers, launched on Father's Day in June 2018, at a local community arts centre in West Drayton, London. The exhibition launch

will be a fun day for families with a professional high quality photo exhibit, craft table and food stall. The exhibition will engage with families on parental leave availability, eligibility and its potential benefits / drawbacks. I will organise the exhibition in collaboration with families who have taken Shared Parental Leave, drawing primarily on study participants (around 48 families). The aim will be to engage with the fathers in how they and the study findings are presented, as well as future directions of the research (since some themes they take to be important may not have figured in the research and vice versa).

Katie Harron – Honorary Research Associate, GOSH Institute of Child Health

FNP turns 10

It has been 10 years since the Family Nurse Partnership (FNP) was introduced as an early home visiting service for first time teenage mothers in England. The anniversary is being marked by a number of events (<http://fnp.nhs.uk/fnp-turns-10>) aiming to share experiences of the programme and to think together about how to improve the service. To complement these events, we are planning to hold workshops to engage FNP participants and FNP nurses in ongoing research into the effectiveness of the programme. In particular, we will discuss the use of administrative data for research, which is increasingly being used within health and social research, but which involves concepts that the public may not be familiar with (such as de-identification and data linkage).

We will hold two workshops of 6-8 participants each (one for mothers and one for nurses). Workshops will last around 2 hours, including refreshment breaks, and will be recorded and transcribed.

Nerea Amoros Elorduy – Postgraduate Research Student, Bartlett School of Architecture, BEAMS

Engaging place-making: Architectural design and mural-making workshop with refugees, young architects and artists to improve young children learning in Kiziba refugee camp

How does the built environment of long-term refugee camps in East Africa affect young children's learning, and how can we communicate knowledge about this subject? This project will share the results of my doctoral research to help transform refugee camps in an innovative and locally rooted way, using art, design and architecture to transform them into stimulating learning settings. Through this project, I will help to boost collaboration between several groups: refugees in the Kiziba refugee camp in Rwanda; Rwandan mural artists and architectural students; relevant NGOs, UN agencies and local authorities; those involved in UCL's 'Refugee in a Moving World' initiative (RIMW); the Bartlett School of Architecture, the DPU and IoE research communities.

Patrick Glen – Research Associate, Social and Historical Sciences

Remembering 1960s British Lesbian, Bisexual and Queer Women's Cinema-going

Between 2013 and 2015, we ran a 3-year Arts and Humanities Research Council-funded project at University College London collecting memories of British 1960s cinema-going in the form of questionnaires (900+) and interviews (70+). These materials shed considerable light on how the decade of the 1960s is remembered in social, cultural and political terms and are now gathered together as an open-access Digital Collection in UCL Library.

We will begin a dialogue with LBQ women that will allow them to contribute their memories so that their reminiscences are remembered and respected. We will also provide an opportunity for them to learn about their histories in context by sharing our findings about 1960s and cinema-going and contrasting them with *their* experiences. Doing so will enable us to interrogate our results through the prism of an underrepresented

group. The Beacon Bursary will allow us to pilot innovative and original public engagement events in which we invite women to attend two participatory workshops.

Sara Ghorashian – GOSH Institute of Child Health

A focus for family participation: CAR T cell games that start a conversation

We have initiated a clinical trial of a cellular treatment for childhood blood cancer (acute lymphoblastic leukaemia). Immune cells called T cells are genetically-modified with a receptor called a CAR to kill cancer cells by recognising a molecule on their surface called CD19. Children on this study are often treated as a last resort, having reached the tolerable limits of chemotherapy and radiotherapy. The study offers great hope as similar US studies have shown unprecedented responses. Our early results are similar and 4 out of 6 patients treated have now survived to 6 months or more. However, we are keen to ensure our patients and their families contribute their experience of participating in the study and have a role in shaping future CAR studies through tailored engagement activities.

The project will therefore involve meeting with families and patients on our study during their routine hospital follow-up visits. As this will be a challenging environment with which to deliver successful engagement, we propose to create a computer game, accessible to both children and their parents which explains the main aims of our research programme. Such a game would act as a focus, for example to allow for deeper discussions with parents whilst another healthcare professional assists the child in playing the game; for sharing knowledge with both parents and children about our research programme, and consequently to enrich the conversations held with them around setting research priorities for the future.

Vicky Price – Special Collections Education Co-ordinator, Library Services

East London: Place, Memory, Life

East London: Place, Memory, Life is a collaborative project between UCL SCAR, Newham Libraries and Local Studies Library, and UCL East's future MA course in Public History and London Memory Archive.

At the heart of the project is the desire to share the research and interpretation that resulted in the current Main Library's exhibition (East Side Stories) and, as part of a two way conversation, to learn more of East London's felt significance with local residents and professionals in Newham's Library and Archive services. This will be achieved through a separate touring exhibition, featuring items from both UCL and Newham Archives' collections. The exhibition will tour all 10 libraries in Newham, acting as a centrepiece around which members of the public will be invited to participate in the acquisition of an oral history collection. Andrew Flinn (Reader in Archival Studies & Oral History, Deputy Vice-Dean of Research at the Faculty of Arts & Humanities and Departmental Graduate Tutor in the Department of Information Studies) will provide support and guidance, especially with creating opportunities for volunteer students to assist in the recording.