Coastal Champions Collaboration

Building a collaboration to deliver a high-quality study to test a Liver Health Champions intervention in under-served populations living in deprived coastal areas

Background

Complications of liver cirrhosis represent the 3rd most common cause of premature mortality in the UK and in 2020, 2.5% of all deaths in England.(1,2) Deprivation is associated with increased mortality from liver cirrhosis(3) and in deprived populations the mortality rate is rising fastest.(4)

NHS England has recently commissioned a programme of work to identify liver cirrhosis in marginalised, deprived populations that are under-served by existing models of health service delivery. This builds on pilots of community liver cirrhosis case finding (e.g.,(5,6)) and reflects NICE guidelines that advise assessment for liver cirrhosis in people with risk factors.(7) However, following a diagnosis of liver cirrhosis it is important the care pathway continues to ensure the act of making the diagnosis leads to tangible clinical benefits. A feature of the ongoing pathway is sustained engagement with ultrasound scans to identify early-stage hepatocellular carcinoma (HCC).(8)

HCC is an important complication of liver cirrhosis. In England and Wales there were 5,445 deaths from liver cancer in 2020(9) and HCC is expected to become the 3rd most common cause of cancer death world-wide by 2030.(10) HCC has a very poor prognosis, however, if cases are identified at an early-stage curative treatments are available. Treatments include surgical resection, liver transplant, or tumour ablation.(8)

The incidence and outcomes for HCC follow a social gradient.(11,12) In Scotland (UK) the incidence of HCC is double in the most economically deprived populations compared to the least economically deprived and there has been a disproportionate increase in incidence in more deprived populations in England.(13) Notably, people from economically deprived areas are more likely to present as an emergency with HCC than more affluent individuals(14) and have worse overall survival once a diagnosis is made.(3,15)

A recent meta-analysis has shown that if HCC is detected in a patient with liver cirrhosis as part of cancer surveillance they have twice the chance of receiving curative treatment and almost half the chance of death.(16) Accordingly, international guidance recommends biannual surveillance with ultrasound for HCC in patients with liver cirrhosis.(8)

Notably, engagement with HCC surveillance in patients with a diagnosis of liver cirrhosis is poor in patients from socio-economically deprived populations.(17–19) This level of engagement contrasts with less deprived populations and is consistent with experience in other cancer screening programmes(20) and engagement with broader healthcare services.(21–23) As liver disease diagnostic community pathways develop and liver cirrhosis is increasingly identified in deprived, under-served populations this problem is likely to get worse.

These challenges have been highlighted to our group by our personal experience trying to engage people experiencing homelessness and people who inject drugs with liver health services. People who inject drugs (PWID) with Hepatitis C (HCV) have been historically under-served by conventional models of care(e.g.,(24)). In England, the Hepatitis C Trust charity has developed a successful peer support programme to bring PWID diagnosed with HCV into treatment services.(25,26) In the programme, people with a lived experience of HCV are employed to improve access to HCV treatment. This may involve talking through the treatment with a patient or even physically driving them to their appointments.

Co-applicant RB is currently working with the Hepatitis C Trust and has been awarded funding by NHS England to adapt the programme to support people with HCV cirrhosis to attend liver cancer surveillance scans. However, in the current programme the employment of people with a lived experience to provide peer support is expensive. It currently costs the NHS £80,000 to employ a single peer full-time (this cost covers all expenses to the charity and the peer). Therefore, before the model is expanded to support a wider range of patients to engage with other aspects of liver health care provision, it is essential its effectiveness is robustly assessed.

In Part 2 of this funding call, we aim to apply for funding to conduct a randomised control trial. The trial will test whether people with a lived experience of liver disease from under-served populations can work as ‘liver health champions’ and help people from under-served communities diagnosed with liver disease (due to any cause) sustainably engage with HCC surveillance. However, first we need to create a collaborative network that can reach people in deprived and underserved communities.

Overarching aim

To build a sustainable collaboration of researchers, healthcare professionals, community partners and members of the public to deliver a high-quality study to test a liver health champions intervention and form a strong platform for the next decade of liver disease research in deprived coastal areas of England.

Objectives

1. Build on existing, and establish new, research collaborations in deprived coastal areas to boost research implementation capacity, particularly in sites not currently research active. Sites to be ready to implement research for Part 2 of this call.
2. Build sustainable Patient and Public Involvement (PPI) networks in under-served communities currently not represented in research activity.
3. Develop a high-quality application/s for Part 2 of this funding call.

The Team (see attached collaborators map)

We are a diverse group with expertise in Public Health, Hepatology, PPI in Research, Health Psychology, complex behaviour change interventions, and the third sector. We are geographically spread across coastal communities in England.

There are some existing relationships within the team, with KGO working across Portsmouth and Southampton, JP with NG in Nottingham, and RB across Southampton and the Isle of Wight. New relationships with team members in Newcastle and Hull, and collaborators in Bristol, Liverpool, and Loughborough have been formed through national group meetings facilitated by the NIHR Clinical Research Network (CRN) and the Hepatitis C Trust. These relationships are very new and working on this application has been the first output from them.

The team includes researchers at different points on their career journeys. This range will ensure the sustainability of our work and partnerships over time, helping us to achieve our aim of conducting high-quality research over the next decade or more. By investing in us, the NIHR is investing in a collaboration with diverse experience and geography, who have the skills and passion to perform high-quality research in marginalised and under-served populations at high risk of liver disease.

The team are already embedded in NIHR CRNs, with LC the CRN National Specialty Lead for liver diseases, JP the Public Health Specialty Lead for the Wessex CRN, and RJA the liver specialty lead for the Wessex CRN.

We also have strong existing relationships with Wessex NIHR Research Design Service (RDS) team, for whom RB and KGO are clinical advisors, and Southampton City Council who have experience working with community health champions. We are supported by Dr Andrew Cook (Associate Director Southampton Clinical Trials Unit (CTU)) and implementation experts within the NIHR Applied Research collaboration (ARC) Wessex (see letters of support).

Programme setting (see attached collaborators map)

Coastal areas experience a ‘coastal excess’ of chronic disease and corresponding poorer health outcomes including life expectancy. Our project is focussed on five coastal areas - Newcastle, Hull, Southampton, the Isle of Wight (IOW), and Portsmouth. These represent large coastal communities with extensive areas of deprivation and high rates of liver disease.

According to the NIHR liver disease targeting tool, these five areas have some of the highest rates of mortality from chronic liver disease in England. Hull has a rate of premature and preventable death which is two-thirds higher than the England average.(27) Additionally, these areas have large populations (for example the conurbation stretching from the New Forest through Southampton and Portsmouth has a total population of over 1.5 million – making it the most populated part of South-East England outside of London) and therefore our work could reach a very large absolute number of people at risk of or already living with liver disease.

According to the NIHR research activity targeting tool available as part of the commissioning brief for this call, some of these areas rank relatively well in terms of participation in liver health related research.(28) However, we know that research activity is very patchy within each area. For example, collaborator Graham Halls (business intelligence officer at Wessex CRN) has told us that just seven people have been recruited into liver research on the IOW since 2017, and the last liver-related study run by St Mary’s (IOW) R&D department was led by co-applicants RB and JP and closed in 2016.

Project design

We will work over 12 months through three work packages which map to our three objectives (see attached Gantt chart for timelines).

Work package (WP) 1 – Build research collaborations to increase research capacity

We have reached out and made new connections with collaborators in response to this call (see collaborators map). In WP 1 we will meet with these collaborators, understand the research landscape in their area, and identify settings with poor research involvement. We will share our experiences from working in areas with poor research engagement, e.g., RB has conducted research on the IOW, and with people experiencing homelessness and people who inject drugs in deprived areas around Southampton. We will support and mentor these areas with a view to their becoming recruitment sites for our part 2 trial.

To do this we will use a hub and satellite site model. This approach has been shown to be effective at increasing the number of people accessing and engaging with treatment across geographical areas and in under-served populations.(29) The work will take place in two steps:

Step 1 – Using conversations with hub sites, existing satellite sites, and by continuing our work with business intelligence at the NIHR CRN, we will try to micro-geographically map hubs to new satellite sites with poor research activity and deprived local populations (already identified sites are shown on the attached collaborators map). We will then identify new collaborators in these sites who can facilitate the development of research capacity.

Step 2 – At least monthly online and face-to-face buddy and mentoring meetings between hub and satellite sites, which will identify needs of each satellite site to become research active and co-create a programme to address and support these needs.

Outcomes from WP 1

- A map of hub and satellite study locations for part 2 study with organisational commitment to hub-satellite relationships.
- Ongoing programme of research mentorship meetings with collaborators and stakeholders in these areas with this activity recorded as strategic priorities and protected personal professional development time at satellite sites.
- A completed needs assessment outlining requirements for part 2 recruitment in these areas.

Work Package 2 – Build PPI networks from within under-served communities
We have successfully formed and worked with PPI groups from under-served populations (e.g., RB has experience forming and working with PPI groups including people experiencing homelessness and people who inject drugs). We therefore know this requires resources and sustained effort. This has been confirmed in recent meetings by our PPI team:

“it's gonna be a difficult one and I think you're right to get some funding to do it, cause it's not the money around to do it without” – PPI contributor from strategic team, 18th August 2022

We will therefore address Objective 2 through a sequence of steps:

Step 1 – Appoint PPI lead/project coordinator
We have identified an excellent candidate for this role, who has already provided valuable input to our application. They have considerable PPI expertise, have worked as the RDS PPI officer and as an NHS Trust R&D PPI officer. They have recently attained distinction in a Masters programme which specifically included a module on engaging with under-served populations. Following appointment we will do a training needs assessment with the PPI lead and our PPI co-app SK and arrange appropriate training.

Step 2 – ‘Love your liver’ roadshows - trusted community stakeholder ‘engagement events’
To do this we are collaborating with the British Liver Trust (BLT), who run an existing national programme of public engagement events with their ‘Love Your Liver’ roadshow events held in towns and cities. including a recent event we supported in Portsmouth. These events are very successful and a recent event we supported in Portsmouth achieved high engagement from at-risk populations and trusted stakeholder organisations working with these populations

We will run three events, one each in Newcastle, Hull, and the Isle of Wight during April 2023 (the BLT roadshow programme for next year already includes events in Southampton and Portsmouth which they have given us permission to attend). The PPI lead and co-applicants will use existing contacts and chain-referral to engage local services with the roadshows.

Co-applicant KGO has experience working with community stakeholders to run these events and has success engaging them with PPI activity afterwards. At each event the PPI lead will use side-by-side conversations to begin planning PPI engagement for the rest of the project.

A key outcome of the roadshows will be the identification of trusted community stakeholders (TCSs) who can facilitate the attendance by members of the public at PPI events and help plan contributor activity days (see step 2). The TCSs will meet with the PPI lead online after the roadshows.

Step 3 – PPI contributor activity meetings
Activities will be co-designed by talking to people from local under-served communities at the roadshows and through the meetings afterwards with TCSs. As examples, our PPI co-applicant has suggested activities might be hairdressing, a clothes exchange, or a cookery workshop. During the activity meetings, a researcher and the PPI lead will facilitate activities and seek side-by-side conversations with attendees, as these are experienced as less threatening by participants.

At these activity meetings we will recruit PPI contributors. The PPI contributors will be invited to two follow-up meetings with the PPI lead to continue to build relationships, and assess their training needs to be able to contribute effectively in the part 2 study.

WP 2 Outcomes

1. A team of PPI contributors who sustain contact (measured by attendance at sequential events)
2. A more diverse resource of PPI contributors when measured against the demographics of existing local R&D PPI networks
3. A completed training Needs Assessment for PPI contributors (training will be planned and delivered as part of WP 3)

Work package 3 – Develop a high-quality part 2 application
A commissioning call for an effectiveness evaluation will be advertised by the NIHR in early 2024.(28) We anticipate our trial design to test the Liver Health Champion intervention will be an unblinded RCT where a patient diagnosed with liver cirrhosis who has ‘poor’ engagement with HCC surveillance is randomised to support by a liver health champion to encourage or support attendance. However, to ensure the trial is successfully implemented in diverse geographical settings it needs to be carefully designed using our PPI network, research partners, and our collective experiences from WPs 1 and 2.

The PPI lead/project coordinator will organise and facilitate two co-design workshops. It is our intention for these workshops to include regional PPI contributors, clinical and non-clinical stakeholders from each area and academic collaborators (we have support for this from the Southampton primary care research centre, Wessex ARC implementation science team, Southampton CTU, the Hepatitis C Trust (see supporting letters), Professor Matthew Hickman (University of Bristol), and Professor Neil Guha (University of Nottingham)). However, we know organising a workshop with diverse participants needs careful thought so this may change.(30) Attendance will be supported with travel costs and reimbursement.

The co-design workshops will start with a presentation summarising our collective experiences from the engagement events and a visual representation of how these experiences map to the provisional study design using a rough ‘PICO’ format. The workshop activity will focus on iteratively amending this visual representation using ‘post-it’ notes to ensure the final version is representative of an implementable study. This approach has been used effectively by others(30) to adapt study protocols, and co-applicant RB has experience facilitating workshops with professionally diverse participants at national Hepatitis C network stakeholder events.

After the workshop we will hold a ‘celebration lunch’ for the stakeholders and use the afternoon as an opportunity to deliver training (planned in WP 2) for the PPI contributors who will be supporting the part 2 study.

The day will be an opportunity for the outcomes from the project to be disseminated throughout the collaboration.

Outcomes from WP 3

- A team of diverse regional PPI contributors who report feeling prepared and supported in their roles for the part 2 study
- A submitted abstract summarising the work of the collaboration
- A finalised research team for the part 2 application
- A draft part 2 study proposal (including a clear participant identification strategy, the likely study recruitment rate, carefully selected outcomes etc)
- A clearly defined strategy to identify and employ community liver health champions
- Draft job specification and training materials for liver champions (adapted from Hepatitis C Trust material)

Project Impact

In the short-medium term the project will support the design and delivery of a trial to test whether liver health champions can increase engagement with liver cancer surveillance and other aspects of liver healthcare in under-served people diagnosed with liver cirrhosis. The programme will therefore help to address a significant health inequality in marginalised and deprived communities from coastal areas in England.

In the long-term the programme will foster a close and effective geographical network that connects enthusiastic early career researchers in Public Health and Hepatology with academic experts, clinicians, charities looking after marginalised populations, and importantly members of the public who represent these communities. This network will form a framework to deliver other studies that seek to address other causes of health inequality in liver disease over the next decade.