



The  
Queen's  
Nursing  
Institute

# Webinar:

Working with Underserved  
Communities

## SUMMARY

Wednesday 10 May 2023

2pm - 3.30pm, via Zoom

#QNIResearch  
#CNRf



Dr Ben Bowers QN, Community Nursing Research Consultant, The QNI, [ben.bowers@qni.org.uk](mailto:ben.bowers@qni.org.uk), @Ben\_Bowers\_\_ and Kumbi Kariwo, registered Learning Disability Nurse, Equality & Inclusion Project Lead, @KCK\_Brum

- Welcome to everyone.
- A brief overview of the forum: it's a national forum for community nurses who are undertaking or considering carrying out research and those keen to be more research aware.
- It aims to strengthen the capacity of community-based nursing research through peer support, mentorship, and supporting personal development and research opportunities.
- We offer monthly newsletters about research and research activities, webinars and masterclasses. There are website resources and we have a mentorship scheme, to help develop your research career.
- To sign up and/or find out more, go to: <https://qni.org.uk/nursing-in-the-community/community-nursing-research-forum/> or scan the QR code, below



## 1. An introduction to - in fair health? A pilot study of the health and wellbeing status of travelling showpeople in two locales

Margaret Greenfields, Professor of Social Policy from Anglia Ruskin University, Cambridge and Sheldon Chadwick, Showman's Mental Health Awareness Charity

- The purpose of the study was to explore the health status, needs, barriers and solutions to accessing, effective, culturally competent health care for Showmen communities and to provide information and advice on service needs to health professionals, commissioners and health policy advisors. We're currently writing up the study, it will come out next month.
- We spent more than 100 hours speaking with Showmen on Yards and Fairgrounds completing the survey, convening focus groups and learning about their experiences accessing healthcare.
- 80 surveys were completed and 10 individual interviews with Showmen; 2 focus groups with Showmen in Manchester and Cambridgeshire; 1 joint focus group with healthcare professionals and Showmen in Manchester and 1 focus group with Health Professionals in Manchester; individual interviews with Health Professionals in Cambridgeshire/East Anglia and 30 surveys completed by Healthcare Professionals.
- We engaged the local community by running photography exhibitions and stands in September 2022 and we will run it again soon. We spoke to 22 people including families in the Meadow Shopping Centre in Chelmsford.
- We interviewed 80 individuals from a range of ages with emphasis on 26 to 35, then 46-55 and 56-64. It was very interesting talking to the Showmen about physical and mental health and learning and listening. I could sit here as a



Showman and empathise saying my dad has back pain and my mum has candy floss wrists as we call it.

- A big emphasis is resilience, as Showmen have this resilience, they're very hard working, family orientated, close-knit community, very proud and have generations of passed-down knowledge.
- The Showmen's Guild was founded in Salford in 1889: it was a turning point of Showmen identifying their lifestyle as a culture rather than an occupation, leading to the idea of Travelling Showmen being a cultural group.
- It's a life based on manual labour so we uncovered a lot of stress, carpal tunnel, bad diet and of course fighting the elements.
- We did two surveys: one for health professionals and one for Showmen.
- The health professionals locations ranged from Surrey, to Suffolk and ranged from nurses to GPs.
- Health professionals described Showmen as peaceful, hardworking, out in all weathers, with no way of identifying them unless they tell us. "It's very simple for somebody who is not a Showman just to presume, 'A Traveller is a Traveller' - they don't understand there are different communities within that umbrella." Showman feedback
- It's very important to have that cultural awareness of the community. There is a huge lack of understanding about Showmen culture. Emphasising work is very important, Showmen will miss health appointments due to travel.
- Showmen do not show up as an ethnicity or separate category.



- Health conditions identified by participants showed that anxiety, depression, stress and diabetes were the main issues. Mental health is not talked about: 42.9% of health professional respondents spoke of the stigma amongst Showmen of mental health which precluded open discussions.
- We need to bring the voice from the community and healthcare/academia together.
- **Question:** As founder of charity, what made you step forward? **Sheldon:** We founded the charity after losing a number of showmen during covid to suicide. We tried to break stigma of talking about mental health. We've since had over 140 referrals. It was very much needed. We work promoting positive mental health. We have ambassadors from inside and outside the community. It's a collaboration in terms of everything we do. We know the importance of making great connections with healthcare professionals such as with Margaret, with Samaritans and Mind. We've been commissioned to do a video to raise cultural awareness within Greater Manchester area.
- **Question:** What's the take home message? **Sheldon:** I think it's all about really understanding the community first and foremost and having community members on board always helps. Leading with an open mind and through empathy. Even though I'm ingrained in the community, my voice is only one voice, to understand my community is to get on the ground floor with them, not sending emails, but going to visit people and listening non-judgementally. Having a good team, a varied team, younger and older members of the team to balance research and outreach team. Understanding your limitations, my limitations are my biases as well, making sure I'm offsetting them with someone like Margaret who's so knowledgeable.



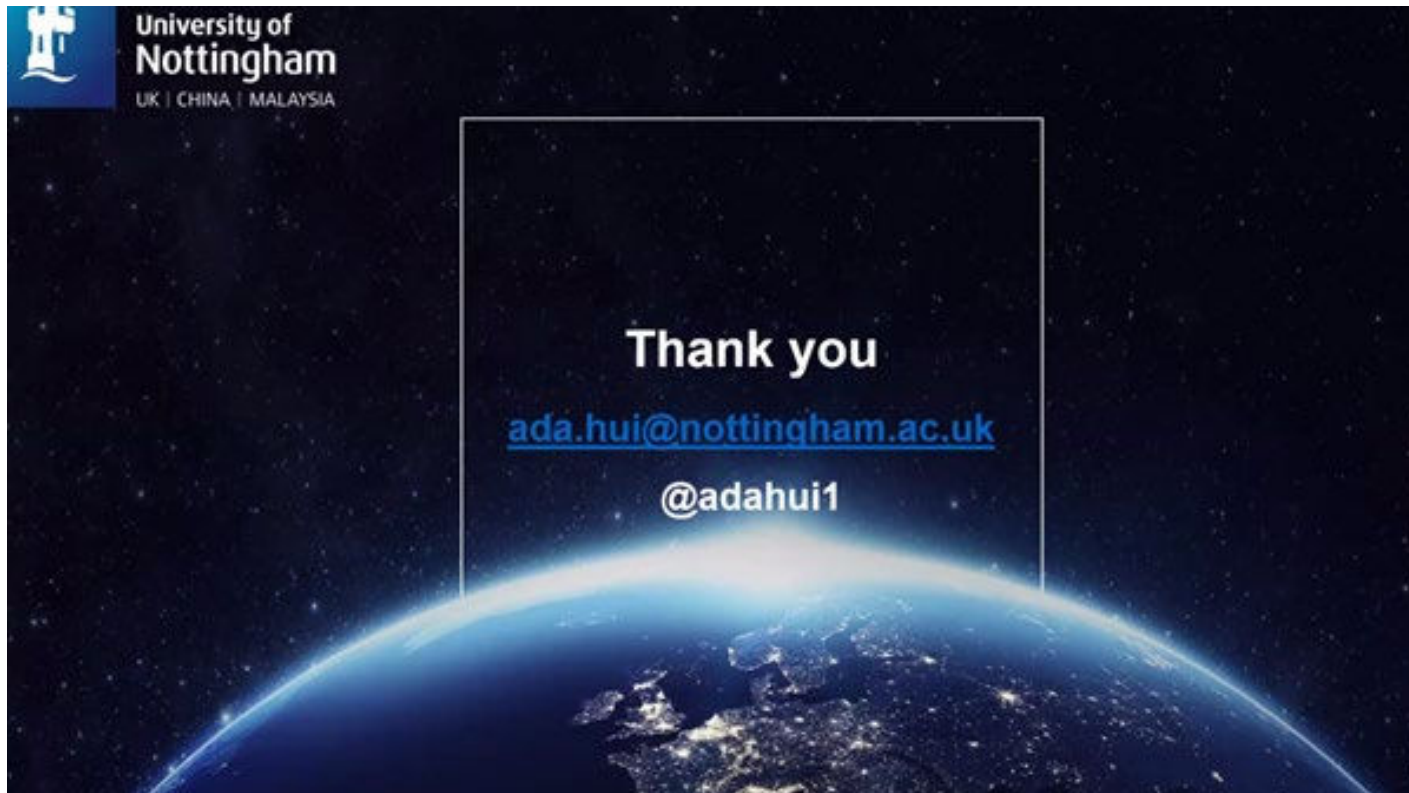


## 2. Legitimate dialogues *Dr Ada Hui, Assistant Professor in Mental Health, University of Nottingham, @adahui1*

- I am a mental health nurse and a sociologist. I'd like to start with a quote which has really stayed with me, 'There is something really rather sad and beautiful, which is that sometimes, society thinks we are lying because they can't really cope with how bad it gets.'
- We looked into Institutional Injustice and marginalisation around recovery, underserved or under-represented communities and undertook 77 interviews from people with mental health problems, Black, Asian and minority ethnic populations, and those with complex needs.
- The multiple challenges included not being believed; not being heard and not being acknowledged.
- Not being believed: being discredited by social status. One woman reminisced about how she disclosed as an 11 year old that she was being abused but she wasn't believed because her mother was a prostitute.
- Not being heard: talking about mental health but not using the 'professional language' and therefore being discredited, participants were denied a voice because of this.
- Not being acknowledged: discrediting your identity because of how people would like to see you rather than as you are. All facets of the person create the person.
- These discreditations created disengagement through fear and mistrust, tension and multiple oppression. This resulted in them choosing not to engage at all.



- What we need is system transformation: cultural competency: being open in new ways; co-production: how we share new knowledge and authentic expression: having the courage to speak up and speak out, being humble, being open to the fact you don't always have expert knowledge that might come from those we're trying to help.



- **Developing an inclusive health and care research system: a realist evaluation of participation in health research with people from Black African Diaspora Communities (BAFDC) in the UK**

Eleanor Howard, HEE/NIHR Clinical Doctoral Research Fellow, Research Lead, Policy & Strategy Unit, CNO Team, NHSE

- I've worked as a nurse for 23 years, started in Coventry and worked in that role until 2011 when I then moved into a research nurse role.
- Defining Black African Diaspora Communities: individuals who self-identify as Black African, African-Caribbean, West Indian, Black British and individuals with dual heritage and other groups who have Black African heritage and living in the UK. This is the preferred term of the co-production team.
- The problem: the UK goal of health and care research is to improve the health and wellbeing of our nation though those that face the greatest health challenges are less able to benefit from scientific discoveries. Black African Diaspora Communities experience the greatest disparities in infant and maternal mortality; cardiovascular disease; diabetes; cancer; covid-19.
- The lack of representation compromises clinical research findings. Effectiveness of studies is limited. This may prevent new discoveries and lack of access for potentially life-saving procedures.
- The definition of inclusion: 'NIHR goal to improve representation of groups who have been excluded, which can result in harm eg through lack of opportunity to benefit from new treatments.'





- Society is becoming more diverse and has transformed in the past 2 decades. Birmingham soon to be one of the first minority majority cities. Why is participation not improving? It feels like we are recycling information that is already known.
- Value driven approach: those affected by a service are best placed to design it. This allows involvement from experts by experience, researchers and all the insights and expertise make a huge difference.
- We meet every 6 to 8 weeks and engage in developing theoretical frameworks, recommending references, supporting realist reviews and protocols and dissemination strategy.
- The groups themselves benefit from connecting with each other, receiving training, and will be co-authors too. We also have a Patient Public Mentor: Tony Kelly. He champions the research as well as other things and his view is to restore trust and enable the community.



### Patient Public Mentor

**“Restore trust, raise awareness and enable the community”**. – Tony Kelly,  
Diabetes Ambassador, NIHR Public Research Champion





### Bringing the community to the table

**What is Co-Production?**



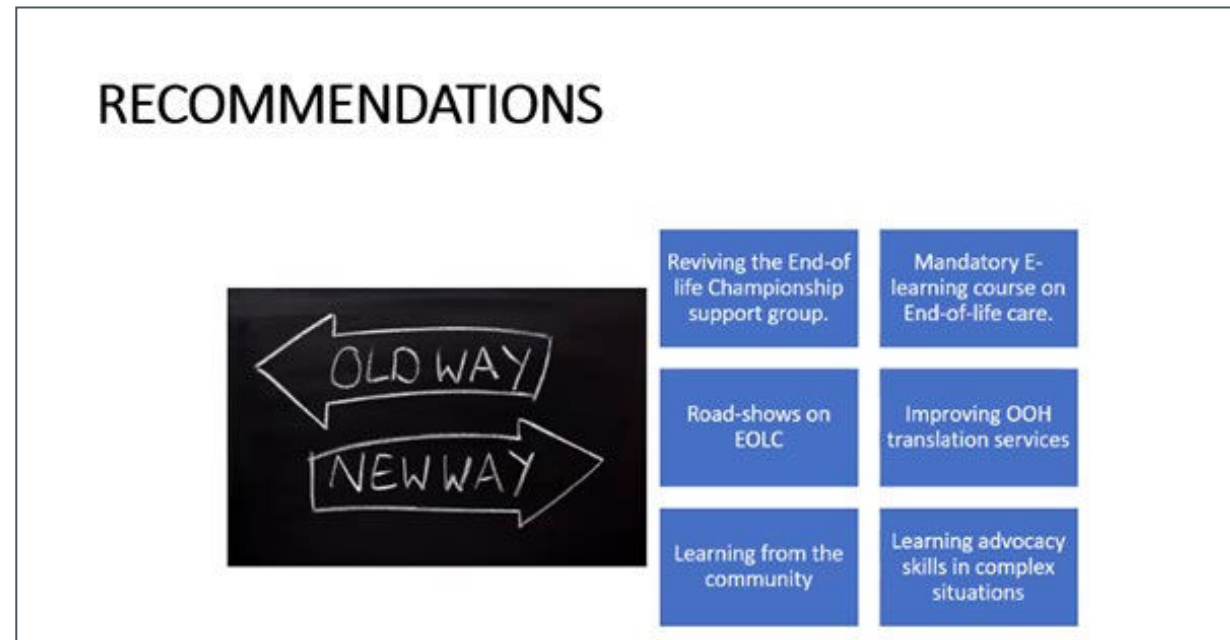
## End of life care in the patient's home: an exploration of experiences of nursing staff caring for patients from the Ethnic Minority Background *Pretty Manyimo, Specialist Palliative Care Nurse/PGR*

*Student, @Nyimoss*

- Aims of the project were to identify gaps in individualising end of life care and promote evidence-based practice to explore ways of improving end of life outcomes for all ethnic communities.
- People from ethnic minorities are most disadvantaged in end of life care, there is not much literature on this.
- We held interviews with 16 participants - initially planned face to face, but due to Covid we did it on Teams. The themes that emerged included: family hierarchy: facing tight knit families and paternalism; mistrust of western palliative medicine; building relationships with the family: influence of cultural and spiritual beliefs and language barriers and challenges and nurses' competencies and skills: gaps in race and equality training.



- Family hierarchy: in big families everyone gives their opinions. During Covid some of the nurses felt vulnerable if some families didn't observe social distancing for example.
- Distinct family hierarchy influenced end of life care delivery. Families preferred to give care and support. Some patients and families relied on family from their home country for health and medical advice.
- Western mistrust of palliative medicine: there were concerns the western medicine hastens death and so there was a low use of services.
- Building relationships with the family: with language barriers, poor English proficiency. Some nurses found it distressing when minors were used as translators.
- There were gaps in nurses' competencies and skills: in race and equality training; there were variable levels of spiritual and cultural competencies; varying specialist skills acquisition and training.
- There was poor recruitment from diverse ethnic minority staff and participants struggled to get time for the interview.



## **Question: how did you overcome challenges with stakeholder engagement?**

**Eleanor:** I got to know the champions, spent time working with them, and that's how I got to know Tony. I learnt from the community things like to be *in* the community, not be behind a laptop, it takes extra effort, takes a lot longer. You do have to be thoughtful. If you're passionate about your subject and those you're working with it makes a difference. Demonstrating you're there for the long distance not parachuting in and out. That all helps with barriers with engagement, you have to be prepared to put the effort in.

**Pretty:** engaging communities wasn't much of a problem as my stakeholders were my employer, and I was part of the team. My colleagues were stakeholders, so I didn't have many problems recruiting and getting stakeholders. Recruiting from outside was harder, generalist nurses, most of them didn't get time to come, possibly because of Covid and workloads.

**Ada:** a lot of patience and passion for the topic helped me, it's quite challenging to listen to those narratives. I think I've been fortunate to work with large teams of researchers, multi disciplinary with very different backgrounds. We've also got an experienced advisory panel.

## **Question: Where/how to start a research project?**

**Ada:** Talk to colleagues, peers, researchers. Think about the practicalities: how to design the study, whether funding is needed, whether your employer is supportive of the study, what is the passion or focus, who is going to help etc.



## Thank you to all delegates who attended this webinar.

Next masterclasses:

- **14 June, 1pm-2.15pm:**

**Introduction to quantitative data analysis** with Anthony Manning-Stanley

**To find out more or to book, please go to:**

<https://qni.org.uk/news-and-events/events/research-masterclass-14-06-23/>

- **13 July, 1pm-2pm:**

**Using quality improvement and audits to enhance care** with Dr Carolyn Lees

<https://qni.org.uk/news-and-events/events/research-masterclass-13-07-23/>





## COMMENTS

### A selection from delegates:

Ben/Lucy thank you for an excellent session highlighting these underserved research topics. It's definitely inspired me to undertake a research project and to also inspire my community nursing colleagues to as well.

Thank you for these fascinating presentations.

Really interesting meeting!

Fantastic session, thank you

Really interesting to see spiritual competencies identified.

Brilliant presentation - great to see research changing practice - well done.

It's been really interesting & great to see that nursing research is so active and breaking into new areas, otherwise little understood.

Great presentations, thought provoking.

That's was really interesting thank you.

