



Promoting Epistemic Justice through Community-Based Participatory Health Research with the Traveller Community

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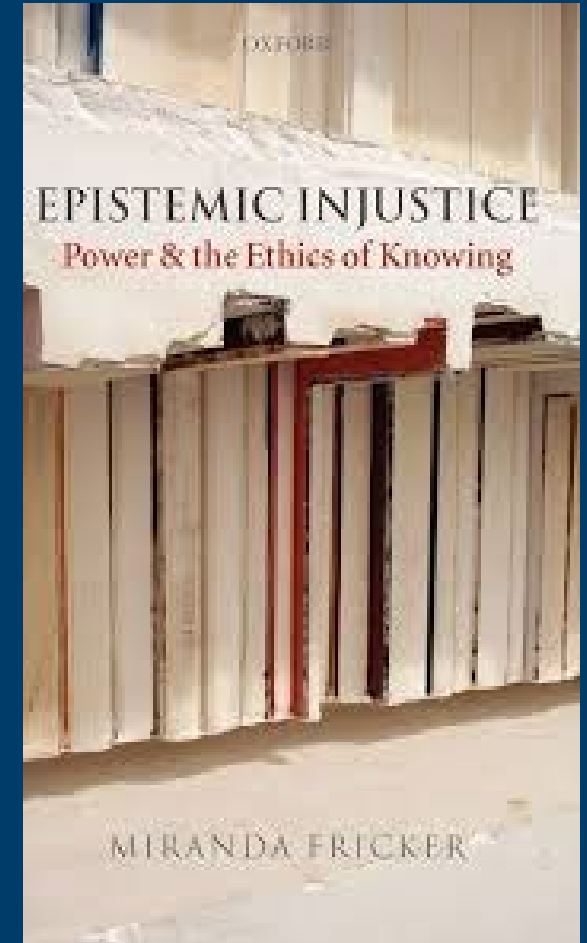


Presentation overview

- Traditional and Alternative Knowledge Production Approaches
- Study Background: Traveller Visibility Group – UCC Research Partnership
- Introduction to Community-Based Participatory Health Research Study
- Our Survey Co-Production Process
- Outcomes of Co-Production
- Promoting Epistemic Justice through CBPR

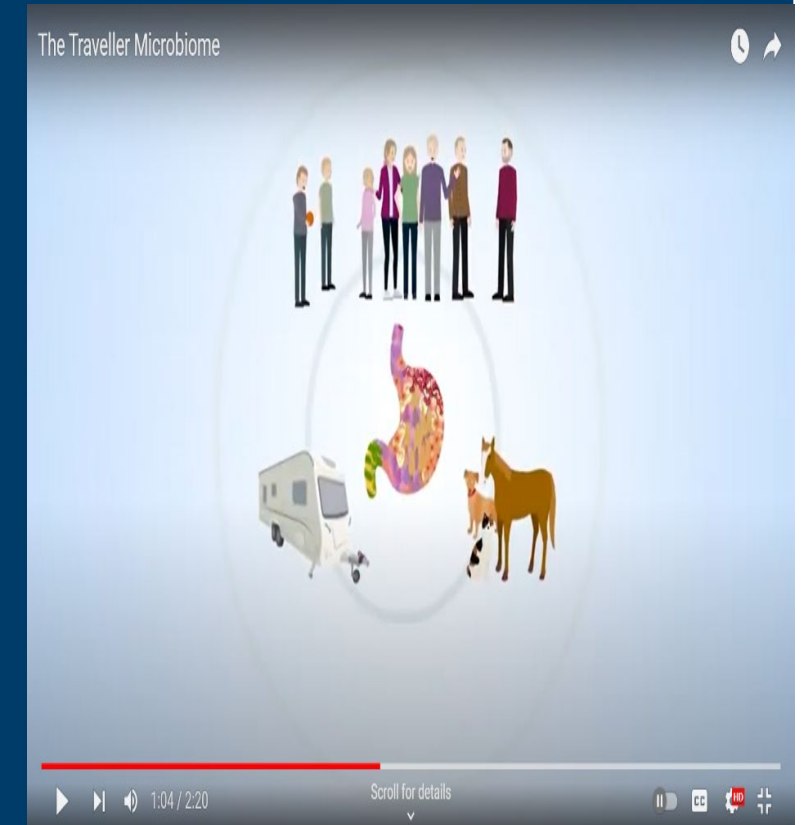
Who Produces Knowledge?

- Producing knowledge through research – traditionally preserve of academics / privilege of an ‘elite’
- Certain groups in society, especially most marginalised, excluded from knowledge production
- Research often exploited or abused these communities; commonly ignored their knowledge
- Has led to epistemic injustice (Fricker, 2007)
- Epistemic justice seeks to disrupt research traditions which exclude or exploit, and
- Promotes alternative research approaches such as community-led / driven research, participatory research & research partnerships



2017-2020 Traveller Gut Microbiome Study

- Traveller Visibility Group (Cork) worked with Prof. Fergus Shanahan & APC Microbiome Ireland scientists
- Unexpectedly discovered Travellers retain a unique, 'non-industrialised' gut microbiome - very rare, protective against serious inflammatory bowel diseases (IBD)
- Unique microbiome linked to cultural traditions - large family, living closely with extended family, & animal ownership - these cultural norms undermined by assimilationist & neglectful statutory policies & practices
- Unique microbiome diminishing among Travellers who lack opportunities to live in traditional ways (Keohane et al., 2020)
- Travellers' knowledge central to scientists understanding these unexpected results
- Planned follow-up research to investigate if Travellers' unique gut microbiome protecting against IBDs



Traveller Microbiome Animated Video

Community-Based Participatory Research (CBPR)

- CBPR is a research approach which equitably involves community members and researchers throughout all stages of the research cycle, in a manner which facilitates mutual exchange of knowledge, skills and resources, and through which all contributors share control, ownership and responsibility.

(Ref: Israel et al., 1998)

Engaged Research Framework



Ref: Irish Universities Association, 2022

Co-Production - Knowledge-Exchange Process: 2023-26

- Prevalence research – epidemiologist said data on 3,000 members of community needed
- Added social questions to inform advocacy work
- TVG recommended a ‘family unit’ survey ~ 600 families
- TVG members proposed digital data collection
- Assessed feasibility & agreed to go ahead - IT analyst joined design team
- Co-designed digital survey on MS Forms platform – accessible via QR using smart phone
- Agreed Peer Researcher best approach to introduce survey to community & manage data collection

Traveller Health & Accommodation
Study 2024



Data Collection Planning: Knowledge-Exchange Process

- Briefed other Traveller organisations – 3 offered help
- Recruited 14 peer researchers Cork city & county – TVG (6); Cork Traveller Women's Network (3), Travellers of North Cork (2) & West Cork Travellers Centre (3) – community development or health workers
- Data collection planning – knowledge-exchange; areas mapped
- Decisions on who / where / when of data collection led by peer researchers
- NB ensured shared understanding of research questions & research process
- NB Attention paid to Cultural Safety, Cultural Humility & Peer Researcher safety

Traveller Health & Accommodation
Study 2024



Survey Design: Focused, Relevant Questions & Culturally Safe

Anonymous, self-administered survey introduced by peer researchers; questions on:

- Social determinants relevant to Travellers' non-industrialised microbiome
 - Family size, accommodation type (10 choices), animal ownership, sanitation facilities
- IBD diagnosis
 - Didn't include common epidemiology questions – could reduce participation / create research fatigue
- Participants answered 21-30 questions & could complete in less than 5 mins - unless assistance required
- Likert scale on 'ease of use' of survey



The poster features logos for APC Microbiome Ireland, TVG, UCC, and the School of Public Health. The title is 'Traveller Health & Accommodation Study 2024' with a small icon. The text explains the purpose of the survey, mentions recent research findings, and asks for participation to improve policies. It specifies that a senior family member should complete the survey and that it will take 5 minutes. A confidentiality statement is at the bottom.

Traveller Health & Accommodation Study 2024

Why take this questionnaire.

Recent research carried out by UCC, in co-operation with 2 Traveller organisations, found that several features of the traditional culture of Irish Travellers may be good for their gut health and may protect them against certain diseases.

To try to improve policies in relation to Traveller health and culture, UCC in partnership with the Traveller Visibility Group, Cork, now want to research if there's a link between Travellers traditional ways of living and how rare or common certain diseases are in Irish Travellers. We need large numbers of Travellers to take part to give us a clear picture and you can help by completing this short questionnaire on behalf of all living members of your family.

We ask that one senior member of a family unit completes this survey on behalf of the members of that family unit.

It will take 5 minutes to fill out.

Your answers to the questions will be kept confidential: you don't need to give your name or address and your identity

Survey Outcomes & Findings

- 590 surveys completed – only 6 invalid = 99% compliance with protocol
- Data on 2645 members of community = achieved 88% of sample sought
- Ease of Use of Survey – 91% completed without PR assistance
- Have new Social & Health knowledge for Advocacy Work
- Evidence that Traveller IBD prevalence rates significantly lower
- Demonstrated importance and value of Traveller knowledge / insights, and Traveller organisations' access to the community
- Demonstrated feasibility of digital survey in community with low levels of literacy – based on Traveller knowledge and careful co-production

Promoting Epistemic Justice through CBPR

- Traveller knowledge central to co-production and success of research
- TVG an equal partner in whole study
- 3 additional Traveller organisations collaborated
- TVG as partner in dissemination
 - 2 presentations in UCC
 - Webinar
 - Invitation to present to Traveller Integrated Agencies Group (TIG)
 - Co-authoring conference papers / articles
- CBPR approach enhanced our research and our partnership
- Relevant to other communities
- Endorse CBPR to other Health Promotion researchers & practitioners



Thank You – Any Questions?

Traveller Visibility Group Co-Researchers

- Liz McGrath, John O’Sullivan & Patrick McDonagh (co-researchers & peer researchers)
- Breda O’Donoghue, Tehmina Kazi & Eileen O’Shea (co-researchers & project management, TVG)

UCC Co-Researchers

- APC Microbiome Ireland - Prof. F Shanahan & Marc McCarthy (IT analyst)
- School of Public Health – Mary Cronin (Research Lead) & Dr. Peter Barrett (Epidemiologist & Public Health consultant)



L to R: Patrick Mc Donagh, John O’Sullivan, Tehmina Kazi, Liz McGrath, Marc McCarthy, Breda O’Donoghue, Mary Cronin, Fergus Shanahan & Eileen O’Shea

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- Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (1998). Review of community-based research: assessing partnership approaches to improve public health. Annual review of public health, 19(1), 173-202.
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