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Co-producing Public involvement and Engagement Guidance in Health Data Research Involving Unique Property Reference Numbers

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Objectives

Unique Property Reference Numbers (UPRNs) encode publicly available address data, which can be linked to confidential and sensitive health or personal data. We brought together researchers and members of the public to create specific guidance for conducting public involvement and engagement (PIE) regarding health data research using UPRNs.

Conclusions

The process of co-production created a partnership between the PAB and researchers that has amplified the public voice within researcher training materials. The discussions shaped how researchers will plan, manage and communicate research that uses UPRNs, positioning PIE at the heart of the research process and governance.

Methods

Researchers first consolidated findings from the HDR UK Social and Environmental Determinants of Health Driver Programme to draft learning content on privacy-preserving methods. They then formed a working group with six volunteers from HDR UK's Public Advisory Board (PAB) to develop top tips on UPRN-related PIE for researchers. This group met four times (each session lasting 60-90 minutes), facilitated by HDR UK's PIE Team, who contributed to the conversations and provided reimbursement for involvement in line with national guidance. Throughout the process, PAB members played a critical role as advisors and content contributors, also offering additional feedback via email.

Results

This project created an effective partnership for knowledge exchange to overcome the complexity of UPRNs-related research and embed PIE in research projects. Through the working group, the PAB and the research team explored how UPRNs are used in research, the associated risks, and ways to manage them, alongside other insights from the Driver Programme. We also benefited from the PAB's knowledge and experience in conducting PIE. Key outputs included a learning module in which both researchers and PAB volunteers are being filmed and featured, and a summary guidance document describing "Top Tips" for PIE related to UPRNs-related research.

