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Case study: Developing resources to facilitate public conversations about the use of linked address-based data for research

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Abstract

Introduction

Unique Property Reference Numbers (UPRNs) provide every addressable location in the United Kingdom (UK) with an identifier up to 12-digits in length, which are persistently unique, and are a mandated standard across the public sector in the UK. This standardisation means they are suited to be pseudonymised for data linkage for research, innovation and public benefit. While there have been many consultations exploring public trust in, and attitudes to, using patient data for research, none have explicitly considered their use for address-based linkage using UPRNs.

Objectives

Our overarching aim is to build public trust in the uses of address-based data at household level. We set out to develop and test materials to facilitate conversations about the use of address-based data linkage at the household-level. In this case study, we describe the development of information materials and an initial dialogue to inform future public deliberation.

Methods

In collaboration with designers and researchers, we generated a prototype website and shared this with experienced public advisory groups. Feedback from these groups informed development of a suite of resources, including slides and a facilitator's script to guide workshop discussions. These were supplemented by interactive, tactile tools designed to promote understanding of key concepts, and to encourage participants to ask questions relevant to their interests and concerns. We hosted two workshops with residents in a multi-ethnic, disadvantaged inner city locality to test and refine these materials.

Results

Dialogue with residents emphasised the importance of accessibility, including clear descriptions of technical jargon, and the effectiveness of using less text-heavy materials and more interactive formats, particularly for participants for whom English is not their first language. Visual representations of people included in workshop materials need to reflect diversity in age, gender, ethnicity, and mobility to ensure resources are relatable. Adapting the approach to delivering information – whether through digital or physical formats – proved crucial in engaging with participants and meeting their diverse needs.

Conclusions

We have created and tested with different public groups a toolkit to support conversations with academic and public audiences about research using address-linked patient data. The toolkit has been disseminated and made freely available for use by the research community.

Keywords

Patient and public involvement; public engagement; administrative data linkage; unique property reference numbers; primary care research; households; electronic health records

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Introduction

Linking places to people is a core element of the United Kingdom (UK) government's geospatial strategy [1]. In 2019, the Public Sector Geospatial Agreement gave more than 5000 public sector organisations in Great Britain (GB) unlimited access to Ordnance Survey data, including Unique Property Reference Numbers (UPRNs) – the unique location identifier for every addressable location in GB. UPRNs provide every property with a consistent up to 12-digit identifier which is persistently unique throughout its lifecycle, from planning through to beyond demolition. UPRNs are described as the "golden thread" which links datasets together [2], with the potential "to underpin huge advances in our digital society, improving our lives and equipping the economy to recover from the effects of Coronavirus" [1]. UPRNs are now a mandated standard across the GB public sector, however challenges remain to implement this fully and to link data for research, innovation and public benefit. Address-based geography using UPRNs allow linkages of high-resolution geospatial data, reduce the impact of geostatistical fallacies, and allow the anonymised grouping of people into discreate address-based units of analysis allowing a richer understanding of the upstream determinants of health and social inequalities. Recent research has highlighted the important contribution made by household circumstances to physical and mental health [3–5], as well as the benefits of using information collected routinely by public services.

The importance of trustworthiness and transparency in using data collected about people in their interactions with public services for third party uses, including research, has received much attention. There have been numerous studies and consultations exploring public attitudes to using patient data for research [6–10]. These have been summarised by Understanding Patient Data (UPD), an organisation established to bring transparency, accountability and public involvement to the way patient data are used: support was found to be higher when people were more informed, their privacy respected, and the purpose was to deliver public benefit [11]. Beyond public attitudes, an increasing amount of literature now documents public involvement in data-intensive research, consolidating principles and offering practical methods. Key contributions include an international consensus statement setting out principles for involvement and engagement in data-intensive health research [12]; sustained accounts of embedding involvement within a national trusted research environment (e.g., SAIL Databank) [13]; and more recent reviews synthesising approaches across "big data" [14].

Deliberative and co-design methodologies are prominent: UK citizens' juries have tested conditions for acceptable data sharing and linkage, including during the pandemic [15, 16], while participatory data-stewardship work proposes governance mechanisms that bring publics 'upstream' into decisions about data access and use [17, 18].

It is reasonable to assume that the public considers their addresses to be identifiable and disclosive when linked to other information about them, especially given the opportunity to access addresses, postcodes and UPRNs publicly via internet browsers. A person's home address may have a deeper resonance than, for example, an NHS number, because it allows people to geographically locate an individual's place of residence, making it personally identifiable. While UPD has had considerable success in developing materials for communicating complicated concepts to the public in relation to health data and data linkage, despite advances in the involvement literature noted above, there are no similar materials available focused on address-based linkage using UPRNs. This underscores the need for resources to facilitate informed and meaningful public dialogue on using address-based linkage and data for research.

The Healthy Households project [19] was established as a three-nation collaboration between Swansea University, the University of Edinburgh, and the Clinical Effectiveness Group at Queen Mary University of London with the objective of developing methods for creating linked households using UPRNs from linked routine administrative and patient data. The overarching aim was to support trusted use of these data for household-level research at scale which would in turn enable a deeper understanding of the consequences of household level circumstances for a range of social, economic, environmental, educational, and health outcomes and their associated inequalities. We therefore situate our approach within this developing involvement literature while addressing a specific gap around address-based linkage using UPRNs.

We present a case study reporting our approach in developing resources to support public dialogues and our experience and reflections from working with existing public advisory groups who were experienced in contributing to research about data as well as groups of residents drawn from an ethnically diverse and disadvantaged urban community who were new to the topic.

Objectives

Our overarching aim is to build public trust in the uses of address-based data at household level. Our objective was not solely to inform but to actively engage individuals in the dialogue, emphasising the vital role of raising awareness about the nature of the research, the kinds of data collected about residents, and eliciting how the public understands and perceives this information. We aimed to develop and test information materials in an initial public dialogue to inform future public deliberation and to facilitate conversations about the use of address-based data at the household level. The challenge was to explain UPRNs, their pseudonymisation using encryption, and the potential benefits of linking to other data about households and the wider determinants of health.

This work was undertaken as a public involvement activity rather than as formal research and therefore did not require ethics committee approval. This distinction between public involvement and qualitative research is well established [17].

Methods

Stage 1: Identifying core content and prototype development with public advisory groups

We identified the core content of our materials and resources, prioritising the concepts that we wanted to convey through the resource. AT is a design researcher and member of the Healthy Households project team leading this work and worked with a team of designers to generate an initial prototype website (Figure 1). This was then presented to established and experienced public advisory groups affiliated with Edinburgh University and the Secure Anonymised Information Linkage (SAIL) Databank [20]. These groups, experienced in health data research consultations, provided verbal and written feedback. Public advisory group members possessed a deeper familiarity with this type of research than initially expected, resembling more 'expert' levels of knowledge rather than an audience unfamiliar with our resource. This reflects a well-documented challenge in patient and public involvement (PPI) literature, [21] where highly engaged patient and public contributors often bring a level of expertise that, while extremely valuable, may not fully mirror the broader, public audience perspective. However, early involvement of these more experienced groups was crucial, providing essential insights that helped us refine the public-facing materials designed to clearly explain UPRNs and their applications to those new to the topic. The website was developed further in discussion with the project leadership team who provided expertise in research using household linkage as well as examples of current or previous research uses to illustrate a range of public benefits.

Stage 2: Development of supporting resources

Informed by these insights, the design team created a suite of resources, including slides and a facilitator's script suitable to guide discussions with public participants with less prior knowledge of using data for research. Visual and design elements of these resources were developed to explain UPRNs, pseudonymisation, linkage of members of the same household, and linkage to data about the physical characteristics of the property (size and room number). These were supplemented by interactive, tactile tools designed to engage participants directly with the materials.

Stage 3: Community engagement in Tower Hamlets

We set out to gauge the clarity of these resources with a broader audience who were new to the topic, aiming to facilitate discussions on issues and concerns they find significant. We incorporated the outreach experience of colleagues at Queen Mary University of London to facilitate conversations with different local interest groups and residents in Tower Hamlets, an ethnically-diverse, disadvantaged local authority located in north-east London, UK [22]. These experienced researchers highlighted the importance of starting the conversation with a concept that the public could relate to, suggesting that we introduce a character consulting with their general practitioner (GP) as an experience likely to be familiar to all.

The Partnerships Manager (AR) of Tower Hamlets Council for Voluntary Service facilitated connections with local residents and hosted two workshops that brought together 23 public contributors, sparking conversations and gathering insights. The first workshop, advertised to members of the Women's Inclusive Team [23], was attended by 14 participants, all female, from different ethnic backgrounds. This workshop was held at the Women's Inclusive Team premises in Tower Hamlets, a space familiar to the participants. The second workshop was attended by nine participants: six women and three men and held at the Tower Hamlets Professional Development Centre.

Each session lasted between two and three hours, starting with a presentation using the facilitator's script and accompanying slides and physical resources, followed by an open discussion and lunch. Public contributors were financially reimbursed for their time following recognised standards [24]. Feedback from the advisory groups and public workshops was used directly to refine the design and content of the toolkit during this project.

Considerations in designing and delivering the workshops

The accompanying slides were designed with accessibility in mind: for example, they included minimal text to suit audiences with a range of literacy levels and where English may not be the first language. An example of this is shown in Figure 2 – the slide has no text and an illustration is used to depict the relatable encounter between a patient and their GP. All imagery in the slides and resources was designed to be culturally inclusive, reflecting the ethnic diversity of the UK population.

We also developed interactive, physical prompts to demonstrate the pseudonymisation process (Figure 3). Participants were encouraged to pick-up the medical record card and to pull the tab down to pseudonymise the data held in the record. We provided a series of medical record cards each containing fictitious information about different people so participants could talk to one another and identify fictitious characters who lived together, the characteristics of the household and the property they lived in, and their health status.

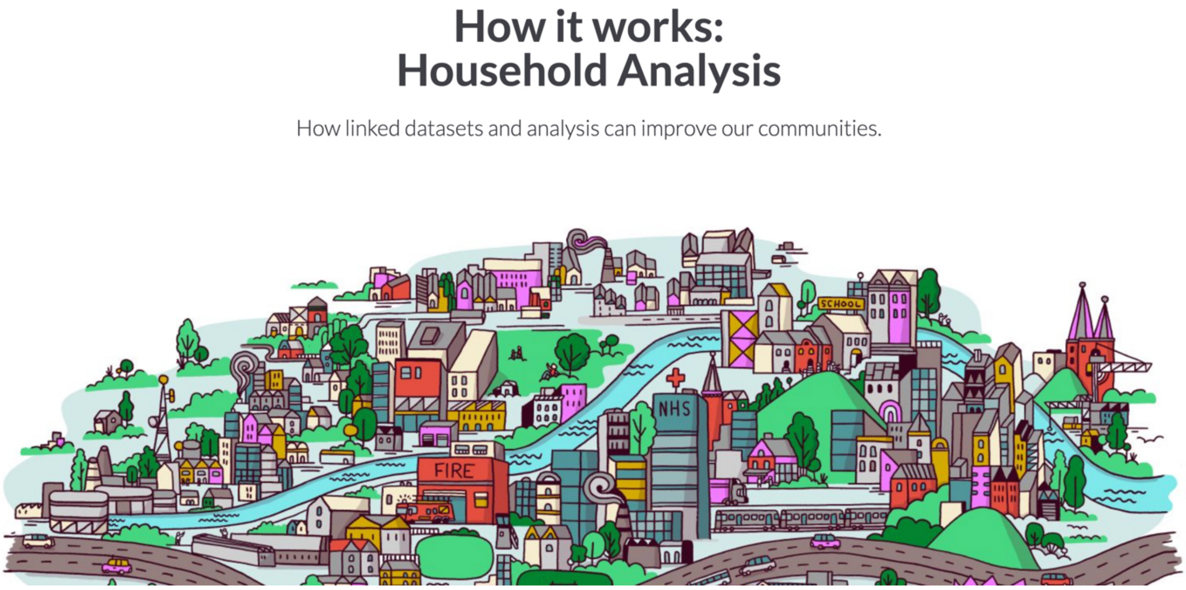
The workshop format was designed to be informal, encouraging the natural flow of discussion. This setup recognised that while the specific focus on household-level research might be new, the broader issues related to housing were already familiar to the participants. The goal was to create an environment that was not only informative but also welcoming of active participation, allowing attendees to share and elevate the issues most relevant to them.

The final resource, which includes a toolkit for workshops as the main product alongside these reflections and learning points, can be found in supplementary file 1.

Results

We learnt that accessibility of terminology is paramount – not just in terms of providing clear descriptions of technical jargon like 'UPRN' or 'pseudonymisation', but also in choosing words and phrases that resonate with people's experiences with health data and their locality. For example, we adapted our language to communicate more effectively by referring specifically to 'populations' or 'communities'. Lessons from the Tower Hamlets workshops revealed the effectiveness

Figure 1: Image of the website: https://healthyhouseholds.org.uk/



How it works:
Household Analysis

How linked datasets and analysis can improve our communities.

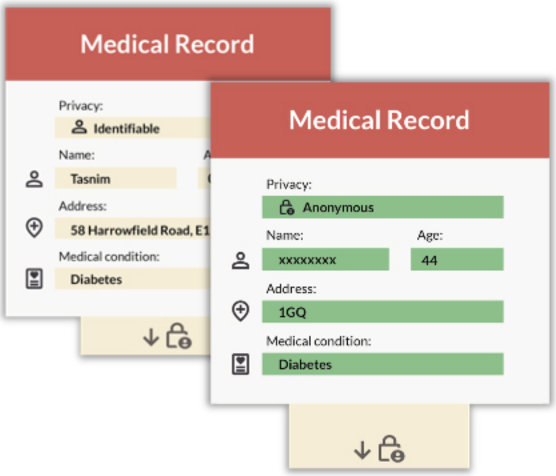
Figure 2: A slide from the workshop presentation supporting discussions about how a patient shares information with a general practitioner or primary health care professional

When talking to a doctor, you share your personal information.

of using less text-heavy materials and more visual and interactive formats, particularly for participants for whom English is not their first language. We found that the visual representation of people included in the graphics needed to reflect diversity in age, gender, ethnicity, and mobility to ensure the resources were relatable. Additionally, adapting the delivery methods of the information – whether through digital or physical formats – proved crucial in meeting the varied preferences of audiences. Building on the insights gained from these adaptations in material presentation and audience engagement, we explored pre-existing public familiarity with location-based data like the Census, What3words, or global positioning system (GPS) as a starting point to spark more conversations and deepen engagement. Incorporating illustrative case studies and addressing issues of trust and privacy also emerged as key elements. Public participants contributed their perspectives by sharing the kinds of data they regularly provide, like feedback to housing associations, activities in community gardens for mental well-being, and utilisation of local amenities, all of which offer a richer understanding of community-generated data.

The participants' questions and comments demonstrated their understanding of research using address-based data at the household level, its application in health research, and potential implications for population health. These discussions were made possible by the facilitator script which contained clear explanations of research using real-world address-linked data. We did not initially intend to use the term 'UPRN' in the public workshops, however, in both workshops, the group discussions naturally progressed such that participants asked questions which allowed use, and a more detailed description, of this term. This technical level of detail was enabled through

Figure 3: Participants pull the tab down on the medical record card. This shows how the data are pseudonymised (by covering the identifiable sections of data). No personally identifiable information can then be viewed



starting with a scenario familiar to all (of going to the doctor), and through the use of interactive tools to illustrate complex concepts effectively and simply.

Participants asked questions which highlighted their concerns and priorities for household-level research. Issues such as housing complaints, the therapeutic use of community gardens, and the participation in local wellness services were highlighted by participants as important aspects they would wish to see addressed in this kind of research. The participants wanted to understand the real-world impact of address-based research on their health, home, and local environment. Participants asked questions about who uses address-based data, and whether it could be used by the police, or housing developers, to better address the needs of local communities. Others were keen to share their experiences of housing in north-east London and highlighted potential questions that could be asked in address-based research, such as about the association between air pollution, housing conditions, and childhood asthma.

Discussion

The Healthy Households toolkit is designed to support open dialogue among and between varied groups, including local residents, interest groups, charitable organisations, researchers, health authorities, and local and national governmental staff. These interactions are critical in forming an environment conducive to meaningful conversation without overpromising the scope of research. With this in mind, it was important to include a slide in the facilitator script which outlined the objectives of the workshop, making clear the scope of the session and the professional capacity of the facilitator(s). Facilitation of these sessions is crucial and can be led by individuals from any of the participating sectors. It is beneficial to involve researchers who can provide in-depth data insights and discuss the possible implications of the research. This emphasis on scoped facilitation, role clarity and transparency is consistent with guidance across public involvement in data-intensive research [1, 2, 8]. Our contribution is to operationalise these principles in a place-based, address-linkage context through publicly tested, adaptable materials. In addition to the feedback gathered during development, the toolkit is intended to elicit further feedback when used by other researchers and practitioners in future engagement work. This second level of feedback will be valuable in adapting the materials to different contexts and publics.

The purpose of these resources is to aid dialogue on, and build trust in, address-based research, with the long-term goal of mitigating social inequalities in areas such as housing, healthcare, environmental quality, and food insecurity, recognising the real impact of such inequalities on people's lives. Availability of housing and the impact of poor housing conditions on health is of major importance to the public and a focus of research as well as policy [25]. For context, a 2020 consultation reported there was a shortage of social housing in Tower Hamlets, with 20,000 residents on the housing register [26]. It was therefore important for those leading the workshops to be mindful of this, being careful to make clear the objective of the workshop was to inform and discuss patient address-linked data for research, without dismissing individuals' personal experiences. This approach underscores the cultural competence essential to engagement work, ensuring that the discussions are not only informed but also respectful and responsive to the range of experiences and needs of the participants involved. Comparable deliberative and co-design studies show that locally salient examples and explicit attention to structural inequalities support fairer participation [4, 8]. While participants were ethnically diverse, we did not systematically record other demographic characteristics such as age, education, or employment. As such, the toolkit requires further testing with a wider range of underrepresented groups to ensure its applicability across different social contexts.

A particular strength of this approach was the use of design-led methods, which enabled the co-creation of resources that were visually engaging, culturally sensitive, and adaptable for use in different public settings. Bringing together experienced advisory groups with community participants also provided complementary perspectives that strengthened the refinement of the toolkit.

A limitation is that the project focused primarily on developing and piloting materials, rather than evaluating their impact systematically. We cannot yet assess how effectively the toolkit facilitates dialogue across diverse settings, or the extent to which it builds public trust in household-level data linkage. In addition, while case studies were used to illustrate potential benefits, the relatively early stage of research using UPRNs meant that few concrete, real-world examples were available to present to the public. Future work should include formal evaluation of the toolkit's effectiveness, alongside the incorporation of new case studies as the evidence base expands.

A particular challenge was how best to communicate a complex concept which may not have direct benefits for those participating. This is widely noted across the literature on involvement in data linkage and digital research, which highlights the difficulty of conveying abstract or collective benefits and the importance of articulating limits and safeguards. Many participants expressed frustration about times they had previously participated in research but did not see any tangible change or feedback. It is essential to reflect on how best to feedback to participants post-workshop, maintaining transparency and inclusivity about how their input contributes to the research process and outcomes. Participants of the workshop were provided with an accessible summary of the impact of their involvement (supplementary file 2). This also involves acknowledging the often slow pace of research against the immediate need for change expressed by participants. There should be a clear strategy for integrating the feedback received and for communicating subsequent actions effectively back to the contributors.

Identifying an engaging starting point for the public and deciding on the right level of complexity for explanations were crucial aspects of our reflection. There was a recognition that complex ideas can still be conveyed in an understandable manner, so long as adaptable materials are developed and facilitators listen and are responsive to the participants' interests and concerns.

Through building the resource there was a realisation of the importance of showing tangible benefits of address-based linkage using UPRNs. Initially, the team developing the resources struggled to identify case studies that clearly communicated the real-world benefits of household-level research using routine administrative data. The use of patient-address linked data and UPRNs for research is a relatively new field, particularly as applied to routinely -collected data and its impact is likely to take some time to emerge. As more research is undertaken using these methods, more case studies will be available to help illustrate the benefits. We recommend that researchers endeavour to articulate these benefits in publicly available and accessible ways, as urged across recent syntheses and involvement reports [3, 8].

Finally, we have reflected on the importance of developing long-term relationships with public voices, to build sustainable PPI networks. Others have already achieved this, for example the OneLondon Citizens summit has a longstanding relationship with a panel drawn from seldom heard communities which has deliberated on using health records for health and place-based research [6].

Next steps

We will disseminate the Healthy Households toolkit and make it available as an open-source resource for use by researchers and public health groups. This includes, for example, the newly funded National Institute of Health Research Health Determinants Research Collaborations which are aiming to link health and a wide range of local authority data to study the wider determinants of health [27]. It can be used with a range of audiences in mind, by a range of different organisations, to support and encourage conversations about research using address-linked patient data. In future iterations, we are considering the addition of audio explanations and providing multi-lingual translations of our materials. We recommend conducting wider public deliberations on the use of UPRNs to enhance our understanding of health in relation to households and places.

Conclusion

We have created and tested with diverse publics a Healthy Households toolkit and associated resources to support consultations and conversations with expert and non-expert audiences about research using address-linked patient data. The toolkit will be disseminated and made freely available for use by the research community.

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Statement on conflicts of interest

None declared.

Ethics statement

This study did not require ethical approval because it reports on patient and public involvement and engagement activities rather than research involving human participants. The work comprised consultation and co-design to inform and shape research, with public contributors acting as partners rather than research subjects. No intervention was delivered, no identifiable personal or health data were collected or analysed, and there was therefore no change to the care, rights, or privacy of individuals that would trigger formal research ethics review.

Data availability statement

The data supporting this article are included within the manuscript and its supplementary files. Any additional materials related to the public involvement and engagement activities reported in this study are available from the corresponding author, Alison Thomson, on reasonable request.

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Abbreviations

GB:	Great Britain
GP:	general practitioner
GPS:	global positioning system
PPI:	patient and public involvement
SAIL:	Secure Anonymised Information Linkage
UK:	United Kingdom
UPD:	Understanding Patient Data
UPRN:	unique property reference number