

# Understanding vaccine hesitancy through communities of place

Abridged report

Research conducted by Institute for Community Studies (ICS) UK, the Institute for Community Research (ICR), US, and Boston University, US.

# Introduction

# Why look at communities of place in the context of vaccine hesitancy?

This report presents a summary of the longer study 'Vaccine Hesitancy and Communities of Place'. Whilst the timeliness of this work reflects how COVID-19 has changed society, now and for the future (0), it is fair to suggest that consideration of the role of communities of place within the delivery of vaccine strategies is long overdue. Recent studies have highlighted explicitly that 'community engagement remains an underutilised approach' in the context of vaccine hesitancy and consequently, that there is a 'paucity of literature on community engagement's effectiveness on vaccination outcomes' (1). Yet it is what is happening on the ground: the observable and unmistakable role communities and their social, cultural and spatial conditions are playing in the race of the current COVID-19 vaccine roll-out, that has driven scientists, practitioners and politicians to pay greater attention to the need for an evidence base about how to improve vaccine acceptance that can truly take place-based and community considerations into account.

There are several, connected and primary reasons why community is important in relation to mass vaccination strategies, and to health engagement and public health strategies more broadly. Local communities are the sites of knowledge and action, as well as the physical locations, where interventions are introduced. To be effective, interventions must be consistent with community needs and mindful of community vulnerabilities; and community needs may be complex if communities consist of diverse groups with different cultural, socio-economic, and socio-historic backgrounds that mediate relationships with preventative health and immunisation. Research partnerships and open communication channels with policymakers to understand these needs and identify how to account for them, is essential.

Beyond this, community organisations know and can have the trust of local community residents, so should be part of community intervention efforts, particularly on a sensitive subject such as vaccination. History, previous studies of welfare system and policy implementation, a glance at the news or a brief look at voting behaviours, shows that local communities engage with or respond to national systems - policy, politics and messaging - whether invited or not. And the price when communities feel disenfranchised, excluded or discriminated against is high for those trying to drive positive and prosocial behaviours such as the acceptance of vaccination, in the intervention sphere. If they do not have good information; feel marginalised, just do not agree, or feel disrespected, communities have been shown to devise their own responses to policy and health strategies which may be more or less effective. Finally, longstanding reciprocal relationships between government, large institutions and other "official" entities and community organisations and residents have been shown to pave the way for better communication, preparation and action in other public health crises, indicating there may be much to learn that could support a mass public health strategy such as the roll-out of the COVID-19 vaccinations.

The research that has produced these reports examines the relationship between vaccine hesitancy and communities of place through a participatory approach to evidence prioritisation and examination. Alongside traditional search strings and terms of reference, community steering groups in the UK and the US, comprised of informed representatives of local systems, helped guide our rapid review of literature and evidence to where there were areas of weakness in understanding, and where there could be rich - even surprising - insights. They guided us from their experience of what has worked in vaccine strategies over the last six months since the COVID-19 vaccinations were available; and what has worked in previous crises to build confidence in public - particularly health - policy. This was accompanied by a community-based participatory research approach, based on in depth interviews and focused community conversations about vaccine hesitancy with diverse

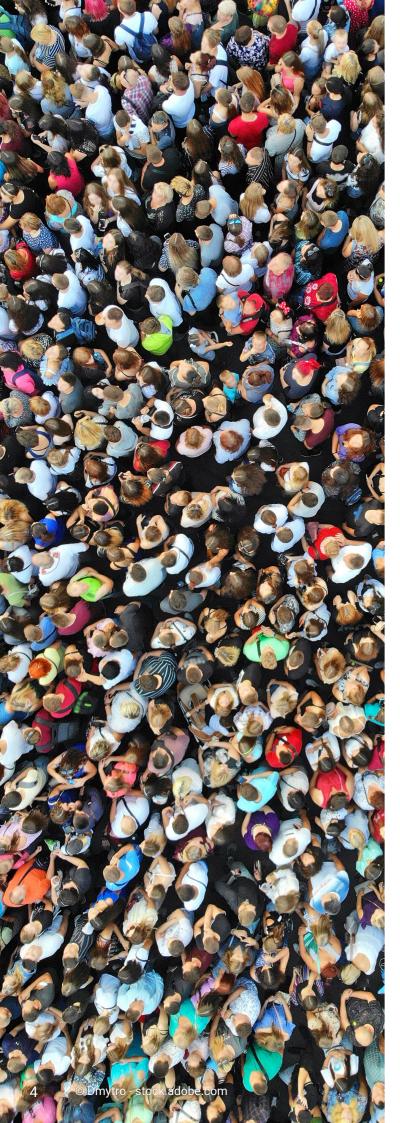
representatives of local community organisations, groups, institutions and systems, held in four case study locations: two in UK and two in US.

This report and each full-length case study explores how national and in the case of the U.S., State policies and practices for vaccine distribution, information, engagement and education have interacted with the sites of distribution, information, engagement and health response related to vaccine hesitancy at the local level. The report beyond this Introduction is structured as follows.

- Section A presents the key concepts, their definitions and terms, that interact and are considered in the study, alongside the research questions that informed both the evidence review and the focused community conversations.
- Section B presents a short account of the literature and evidence review, discussing medical distrust, different socio-economicpolitical contexts, different approaches to vaccine roll-out, community engagement, and the expanded SAGE 3-C Model, which informs much of the subsequent discussion.
- Section C presents the findings from the four case studies (two from the UK, Tower Hamlets and Oldham, and two from the US, Boston and Hartford). Findings are split into generalisable themes observed across all case studies, and context-specific findings, in which case studies diverge.
- Section D conclusion presents a synthesis of the findings of this study with consideration of the importance of Community in relation to the 3Cs model and the SAGE matrix of contextual factors that affect the 3Cs.
- Section E provides relevant policy recommendations for research and implementation.
- Appendix 1 details the research methodology and is followed by Appendix 2 - bibliography of references.

The full case studies are available as individual reports which present the in-depth context and findings from each case, for consideration alongside this summary report. Each presents a detailed account of a local ecosystem having to respond, innovate, and work during a time of national crisis.





# **Section A**

# Concepts, terms and definitions for researching communities of place in the context of vaccine hesitancy

Integral to understanding the relationship between vaccine hesitancy and communities of place is consideration of four key elements:

- Place conditions including socio-economic, political and historical context.
- Social relations including between communities, local ecosystems and authorities; and the connectivity, participation and engagement that occurs between these people, place and system dimensions.
- Community engagement, a term typically used to refer to involvement of national, State, and local governmental and private large institutions with local residential and CBO communities.
- Community mobilization, defined as the capacity of local communities of organisations and residents to organise the resources within their boundaries to address a local health issue.

These elements - place, social relations, community engagement and community mobilisation - are integral to how the COVID-19 pandemic has affected people, health systems and health outcomes. They have also proved integral to the mitigation, intervention and success or failure of policies, campaigns and health system responses to the spread and impact of the virus; to the health consequences of lockdowns and restricted health systems; and to the roll-out of the vaccine programme.

These elements are also integral to how people have experienced the pandemic: in their local neighbourhoods, through local media, local public services, local economies, and local points of contact to health and support systems. As the report The Covid Decade (0), shows, the local - and the hyperlocal - have been the first points of reference for people and communities over the last eighteen months since the pandemic first took hold in the UK and the US. The local shapes how the pandemic has affected peoples' health, wellbeing, and social security. This study builds on UK and US public health literature that recognises that people, place and powerbased factors mediate residents' experience of health and participation in accessing of health and health care (2). The context of communities of place, in the ways in which people interact with health care systems are also inextricably linked to their local geographical contexts—to their community.

#### A rights-based approach

The challenge of vaccine acceptance is often discussed in policy and research circles as a 'oneway' relationship: where sceptical, unreasonable or ill-informed communities must be converted to an 'informed' or reasonable position of being vaccinated. This study approaches the issue of vaccine hesitancy and acceptance through the lens of a rights-based approach, which recognises that those experiencing profound past and current structural inequalities will choose whether and when to engage with vaccination. It recognises that these choices are based on real and legitimate concerns held by communities, often rooted in distrust of government, medical and public health authorities that have been historically exploitative or unresponsive. Finally, it accepts that these concerns need to be responded to through immediate and longer-term strategies if vaccine acceptance is to be achieved.

Elements of the rights-based approach are consistent with the critical public health perspective that argues that disparities in how communities engage with health - or vaccination - are a consequence of inequities that derive from structural and social determinants of health. This includes inequalities of representation and participation - what is sometimes referred to as an "emic" perspective, or as representation. Anthropology and sociology are valuable disciplines for considering vaccine hesitancy alongside health and public policy, as they promote understanding of variations in people's beliefs, attitudes and behaviours and recognise that they are not irrational. This raises the value of community engagement in the importance of listening - and gaining insight from - diverse communities to navigate these behaviours, to identify how beliefs, attitudes and values are clashing or interacting with information, misinformation, power relations and authority, in delivery of vaccines.

Understanding and addressing the findings from rights-based, critical framings of why hesitancy exists is critical to shaping more inclusive and effective public health responses and to enhancing the ability of communities to take preventative steps to protect against and combat COVID-19. At the time of writing, the UK and to a greater extent the US are some distance from achieving so-called herd immunity<sup>1</sup> with vaccine engagement as the principal pathway. The risk of new variants that existing vaccines may not prevent, coupled with the challenge of a globalised society in which the inequalities of distribution and access to vaccination and health services interact with the vulnerabilities of different communities to COVID-19, means the threat of the pandemic and the need for collaborative insight is far from being over or diminished.

<sup>&</sup>lt;sup>1</sup> Herd immunity can be defined as the indirect protection from an infectious disease that happens when a population is immune either through vaccination or immunity developed through previous infection (World Health Organisation (WHO), 31st December 2020). WHO supports achieving 'herd immunity' through vaccination, not by allowing a disease to spread through any segment of the population, as this would result in unnecessary cases and deaths. The WHO estimates herd immunity as occurring between 80% and 95%, depending on the disease or virus. Double vaccination is seen as one route to achieving herd immunity, as initial studies indicate the vaccine provides strong protection against hospitalisation and serious after-effects of COVID-19. Other routes to herd immunity include natural immunity as a greater proportion of the population catch COVID-19 and/if they recover from it, but vaccination is regarded as a safer, ethical, and targeted approach.

#### **Glossary of terms**

Community	A psychosocial and spatial entity, with connections to belonging and memory as an imagined space, as well as to cultural or national origins. In the context of this study, it is also a local place where people live, and organise their lives, and where they organise to address health and other issues, where they experience inequities and disparities on the ground and the place where interventions are both developed and implemented, sometimes from inside and sometimes from outside and at times in interaction.
Place	Place is defined as a spatial entity with defined political, administrative, and environmental boundaries which mediate the application of health and social policies and the functioning of systems. These socio-political boundaries are not always consistent with a local sociocultural community's identity and perceived social, economic, political, and cultural histories.
Vaccine availability	Whether vaccine is available in a city, town or zone; the degree to which it is available to the entire population of a geosocial or sociocultural community; how availability is determined by national, State or local institutional health policies.
Vaccine accessibility	Whether vaccine is accessible once it is available to all people designated to receive it. Accessibility is defined by ease of accessing appointments for vaccination; adequate transportation to vaccine; and accessibility of vaccination sites to the populations they are designed to reach.
Vaccine hesitancy	Any delay in accepting vaccination even when a vaccine is available and accessible; reluctance to vaccinate even when vaccinated.
Vaccine refusal	Active refusal of vaccination when vaccines are available and accessible, due to a range of factors; often interacting with 'anti-vaccination' sentiments but not synonymous.
Vaccine resistance	Active promotion of vaccine refusal with others.
Vaccine engagement	Approaches and interaction between people, communities and authorities to negotiate decisions about receiving vaccination as and when it is available and accessible.
Vaccine acceptance	A decision making point where an individual or group agrees to receive (and promote) vaccination when it is available and accessible.



#### Research questions

The research questions for this study are as follows:

- What are the current, and lasting, health, social, economic, and political consequences of COVID-19 for different groups in each of the case study areas? Are there any place specific conditions or consequences?
- What are the historic and current dynamics of the relationship between different communities and a) health authorities; b) local authorities, and State authorities; c) organisations and groups? What incidences or services / provision are these founded on?
- How do issues of injustice, trust, cohesion and inequality interact with the dynamics around a) health inequalities in these areas, and b) health engagement, including the current vaccine program?
- What are the multiple efforts or approaches going on at the present time in the case study areas (Tower Hamlets and Oldham, UK, and Hartford and Boston, US) to improve vaccine engagement, health access and engagement and to reduce fears and concerns about health engagement with specific groups in each area? Who is leading them?
- What makes these initiatives work?
  What are the most critical elements in promoting success in the vaccination programs in each area?
- Where are the gaps in these efforts that need to be filled; who should fill them and how?
- What has been the interaction between State/national and local health department/system policies and strategies in the roll-out of the vaccination program? Where have the gaps been?



# **Section B**

# Literature and evidence review

This section provides a review of the main themes emerging from existing literature and evidence on vaccine hesitancy, taking in current and rapidly emerging studies and a historicist approach to understanding the issue of hesitancy or resistance to vaccination. It presents a network diagram of the peer reviewed and grey evidence found related to vaccine hesitancy and communities of place, in order to assess areas of strength and weakness in the knowledge base. It summarises the key themes and conclusions in the evidence base about why communities are hesitant; and what is known in the evidence about strategies for combatting hesitancy and building vaccine acceptance.

Our review focuses on the common themes for why communities are hesitant, sceptical or resistant to vaccination. It is important to note that where this study focused on evidence about strategies, attitudes and experiences of health engagement, and acceptance of medical intervention and medical care more broadly, we would expect to find different and more positive - themes, given that where individuals and communities seek treatment and support for illness or disadvantage, rather than receive preventative intervention, different dynamics between system, service and communities tend to be present. Therefore the following themes are the most prevalent and conclusive within the literature about vaccine hesitancy and communities specifically.

### Experience of medical distrust and health discrimination

Dimensions of vaccine hesitancy, which is sometimes called 'scepticism', can be understood from both historicism and contemporary perspectives within communities. In both Britain and North America, widespread scepticism about vaccination has guite often been a product of citizens' uneasy relationship with the State (3, 4). In the United States, State-sanctioned medical experiments often undermined the trust between doctor and patient - particularly when those patients were people of colour. The infamous Tuskegee Syphilis Study, for example, ran for 40 years before anyone thought to question whether intentionally withholding treatment from poor Black patients with syphilis (even after antibiotic therapy became available) in order to study the "natural history" of the disease was a reasonable thing for a State to do to its population. This all took place well within living memory. It was 1972 before the study ended (5, 6, 7, 8).

However, the history of this kind of medical mistrust dates back even further. In the late 19th century, when the English government tried to make smallpox vaccinations compulsory, they were met with protest (9). Vaccines in Victorian England often came with debilitating and even deadly side-effects (10). But compulsory vaccination was also understood as a tool of an increasingly interventionist government that had fallen into the habit of using its legal powers to target various vulnerable groups of people. including sex workers and migrants. Because vaccination was also closely linked to the Poor Law legislation that forced workers and their families into the brutalising regime of the workhouse, its new compulsory status seemed an attempt to extend this same punitive attention to the working classes (9). Early 20th century concerns over vaccination in both the UK and the US - where it is perhaps best known in terms of the 1905 Jacobson v Massachusetts ruling, which upheld the State's rights to

compel vaccination - are thus contextualised not by irrational unwillingness or anti-social tendencies but by real and compelling lessons in the misuse of vaccination as a weapon against the weak (11, 12, 13).

Thinking more broadly and globally about vaccine hesitancy offers a more tangible picture of how particularly complex the issue of vaccination has been over the centuries since its inception in 1790. In the 19th century, the British government enacted a series of coercive and punitive policies designed to vaccinate great swathes of the British Empire's colonised subjects (14). These interventions prompted immediate pushback, read as they were as the controlling, if not punitive, actions of a colonial government. In the 20th century, vaccination continued to be compromised by misuse in policy or through poor delivery, as well as being met with the rise of media, messaging and mass horizontal communication and information spreading within communities. Even the successful eradication campaigns of the WHO over the 1960s and 70s did not affirm, in the attitudes and belief systems of certain communities, an unambiguously beneficent role for vaccines. Additionally, though the smallpox eradication campaign was ultimately successful, it was also so costly, difficult, and labour-intensive that it was by no means a given that the WHO would continue with such campaigns in future.

More recently in the latter part of the 20th century and the advent of the 21st century, pharmaceutical companies have run afoul of critics for their pricing practices, which gouge patients and governments, including the very recent antics of Essential Pharmaceuticals, who threatened a 2600% increase in price for one bipolar medication as a bargaining chip in securing a more modest price hike for another. Controversy over pharmaceutical behaviour has fuelled scepticism over vaccines, as well as several notable scandals concerned with side-effects. What is certainly true is that vaccines have been, and remain, political objects that connect the historically problematic ethics of

pharmaceutical companies to the chequered history of institutional racism and sexism embedded in medicine's clinical and research practices, to the troubled politics of American and British healthcare, and even to the place of each of these countries in the world.

Debate, concerns and hesitancy about vaccination has never been restricted to the spaces ('sites') and the limited interactions between health practitioners and patients or population, but it has become an increasingly complex picture. Vaccine hesitancy in the 21st century can be seen to be heavily influenced by phenomena connected to group dynamics or what can be seen as 'communities of interest' or 'communities of experience' - such as parenting movements; wellbeing movements; and online communities around lifestyle choices and regimes, to name but a few. With many individuals seeking, receiving and being exposed to growing amounts of information including factual and non-factual information or 'fake news' about health and medicine - online, the sites and forms of community in which vaccine hesitant beliefs, resistant narratives and honest questions and concerns are raised and debated are multiplying - and certainly much faster than intervention and medical education strategies to combat them.

The issues of medical distrust are being found in rapidly emerging real time studies to interact heavily with hesitancy about the COVID-19 vaccine. As the scholars Shaun Danquah and Marcus Tayebwa have put it in their study of medical scepticism in the London borough of Lambeth:

"The sensitive nature of the COVID-19 vaccine programme, and the life-or-death situation that it is framed in can lead to very palpable fear across all communities. This fear may, in turn, ostracise those who are already medically sceptical - especially those within the BAME community - because they may be seen as the percentage of the population that are preventing progress." (15).

### Individual conditions: confidence, complacency, convenience

The SAGE 3Cs Model for Vaccine Hesitancy is the leading model for understanding vaccine hesitancy, emerging in the last decade. As well as synthesising the most conclusive evidence about the reasons individuals hold vaccine hesitancy, it is employed in this study to provide a framework for discussion of the findings of this study.

The 2014 report of the WHO working group on vaccine hesitancy developed the now-influential '3 Cs'—confidence, complacency, and convenience—model of vaccine hesitancy, emphasising the critical importance of trust in institutions, accuracy of information, and addressing mistrust of science (16). The SAGE Model of Vaccine Hesitancy (10) categorises the most common reasons for vaccine hesitancy or acceptance within three key terms:

- Confidence: Lack of trust in safety and utility of vaccine especially because of distrust in providers, medical system, government, vaccine producers; quality and safety of vaccine. Beliefs in detrimental aspects of vaccine.
- Complacency: Lack of concern about infection, serious consequences of COVID-19, concern about infecting others, perception of low risk delaying or preventing acceptance; belief that other health practices mitigate COVID-19 or prevent infection including healthy behaviours, foods, relaxation etc.
- Convenience: Lack of convenience in accessing available vaccine including long distances, inadequate hours, and days of service delivery, not available at worksite or school or places where people are comfortable to visit (like drugstores).

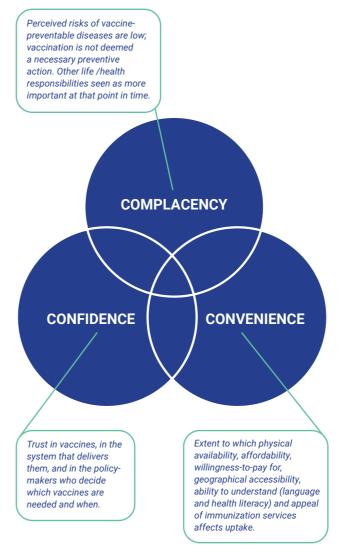


Fig.1 Sage 3Cs Model (SAGE, 2014:11)

These factors have been evidenced and discussed for how they operate at the individual level, explaining many of the reasons for vaccine hesitancy for different individuals and demographics. The SAGE model has not been tested at the 'local' or community level to understand how social relations and place dynamics interact with - and could offset or exacerbate - the hesitancy influences an individual may be experiencing. Group dynamics and organising by communities can have a powerful sway over individual choices. This study responds to this gap by testing elements of the SAGE model within the four case studies, asking about the applicability of the 3Cs to the way the COVID-19 vaccine was received by communities, in each case study.

#### **Emerging factors**

Over the course of the COVID-19 vaccine programme, several new factors affecting hesitancy have emerged prevalent in real-time scaled and individual, group and local case studies. We have summarised those particularly pertinent to community dynamics or to place. These can be described as:

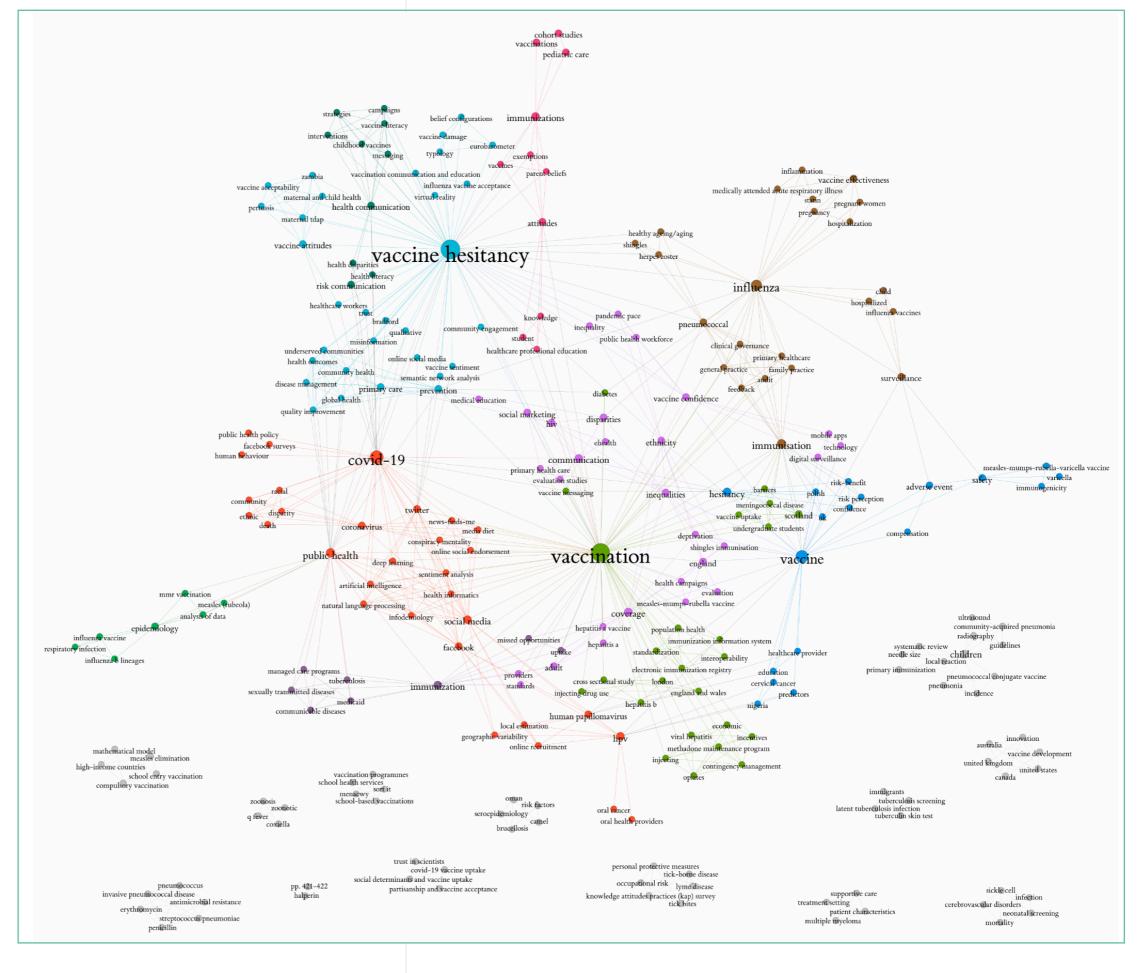
- Disbelief: it was developed too fast and is not sufficiently tested, or there is little, inconclusive localised information about it.
- Trauma: the impact of mass grief, shared by the community.
- Policy-based distrust: the distrust of the wider emergency response and lack of trust on traditional and authoritative sources (17).
- Scepticism related to the side effects: there are misconceptions related to the effects of vaccine on mental health, fertility or even a cause of other variants of the virus (18), which are shared and discussed in communities of identity and place, online and in person.
- Microchip vaccine conspiracy theory: it implants microchips to control individuals (19)<sup>2</sup>, which is discussed and shared via the same group dynamics as the above concerns about side effects.
- Relaxed attitudes towards personal health and well-being: this is more prevalent among younger groups who do not feel the need to feel concerned about getting affected (20). This often, not always, stems from poor health literacy among these groups.

An additional factor that is less well examined in peer reviewed studies, but has been discussed in journalistic studies and by communities themselves - is "fear", in this case defined as a primary emotion that weighs risks, heuristic or heard, far more heavily than benefits at a time when anxiety is widely prevalent and authoritative leadership is missing. This can also be understood as the 'risk/benefit' analysis, which has been

<sup>&</sup>lt;sup>2</sup> https://theconversation.com/reluctant-to-be-vaccinated-for-covid-19-here-are-six-myths-you-can-put-to-rest-165027

evidenced as a factor in vaccine hesitancy and acceptance by those working with communities around the development of vaccines for HIV, Ebola and Poliovirus. This third factor is dominant in hesitancy concerns for a third group, which also incorporates elements of the first two: those who have been racially or otherwise minoritised, persecuted and stigmatised by majority and dominant groups, and by systems and structural inequalities. Thus 'Fear' as a factor within vaccine hesitancy often incorporates elements of the other two factors for these groups.

Figure 2: Network Map of what is known from peer reviewed evidence about Vaccine Hesitancy. The network map was formed from collection of data from a Scopus literature review. The dataset included information about 112 distinct pieces of literature, including any author-selected keywords associated with each work. This data was transformed into a network diagram, with keywords as nodes and edges added given two keywords were included in the same work. This initial construction resulted in a network of 261 nodes and 846 edges, split between 1 large and 13 small components. This complete network had an average degree of 6.5, diameter of 7, graph density of 0.025, and average path length of 2.8. Network statistics were also run on the largest component (n = 193; e = 710) of the graph separately, resulting in a slightly higher average degree of 7.4, diameter of 7, graph density of 0.038, and average path length of 2.8.



# The knowledge base: strengths and gaps

It is important to consider the balance of *types* of available evidence and studies related to vaccine hesitancy and communities, in order to examine where there are evidence strengths and gaps. The network diagram above illustrates the field of published (peer and grey) evidence around vaccine hesitancy.

Within the network diagram, the vast majority of the 261 keywords included appear to relate to what can be called a 'top-down' approach to combatting vaccine hesitancy. The characteristics and practices of a top-down approach are discussed further below.

Towards the lower left of the diagram, the majority of the red neighbourhood (which contains, most notably, the large node for COVID-19) concerns the relationship between public health and the digital spread of vaccine information and misinformation. The cluster concerns especially the kind of large-scale quantitative study (including keywords such as natural language processing, artificial intelligence, deep learning, and sentiment analysis) which has become popular in the past decade for understanding general social trends, but which may elide local, placebased community contexts. Both the green vaccination and light blue vaccine clusters appear largely to concern the efforts of specific vaccination campaigns and the incentives, barriers, confidence, and safety of these measures. The brown influenza neighbourhood, to the top right of the diagram, likewise concerns the efforts surrounding vaccination against a specific virus. Other sub-clusters within the diagram (such as the dark green cluster to the top of the network), emphasise health communication, but these clusters are often isolated from nodes which appear more closely tied with concepts of community.

Gaps in knowledge are most significantly in the lack of studies that capture, understand, and evaluate the efficacy of local place-based

approaches to combatting vaccine hesitancy at both the system and the individual level. Just 1.3% of the peer-reviewed evidence focuses on place-based interventions or those with cross-community considerations, with a further a small number of case studies (15%) that consider how individual ethnic communities interact specifically with, and hold particular hesitancy towards, public health campaigns or vaccination. There is a particular lack of qualitative research that goes beyond surveys or attitudinal studies towards vaccination; which it is fair to say are typically limited to examining beliefs at the individual ('public') level and not how hesitancy and/or acceptance rationale play out within or across group dynamics, such as communities.

At the system level, gaps exist in the evidence understanding how and why coordination, partnership and delivery models that work, function, at local and regional level - and indeed how they are formed and work with or supersede national systems. At the individual level, gaps also exist in understanding how the 3Cs contribute to localized versions of vaccine hesitancy, interacting with the dynamics and belief systems shared in particular, place-based communities -; what elements of place interact with the 3Cs; and how consistent or distinctive these are to each different place or community.

The following sections discuss what is known from the evidence base that the diagram displays, focusing on particular fields (or 'neighbourhoods') of knowledge.

# Top-down approaches to addressing vaccine hesitancy

Traditionally, government-led approaches and structures to driving vaccine uptake and acceptance in the context of mass or targeted vaccination, tend to exhibit a 'top-down' approach. A top-down approach is more uniform and is centred on service provision and compliance, rather than specificity, adaptation and tailoring to local needs (21). This is often justified by the belief that centralised planning

and implementation leads to faster, efficient decision-making (19) and action. It is also typically the case that top-down approaches derive their measures from previous studies, rather than having a more exploratory outlook in new situations (22). Thus in the end, while decision making may be more efficient, delivery may be less effective. Community engagement approaches can improve the efficiency and effectiveness of top-down decision making while accommodating community voice, input and tailored action.

Top-down measures are designed to be uniform, streamlined, simple to implement and cost-effective, and very often achieve these aims with a majority part of a population or group (21). Unfortunately, this set of priorities, applied universally, may result in the efficacy of these measures being reduced among smaller, more marginal vaccine-hesitant populations largely due to barriers of the location, quality, specificity and types of communication and their relevance to different groups.

In the case of information-based campaigns, both the format and content may reduce the efficacy of a campaign. The format of the information shared is often not particularly useful, with leaflets noted as a particularly outdated form of communication. The content of information is not always available in multiple languages or in those locations where hesitant populations that need targeting will see it or engage with it. Moreover, public health communication content is often - and often necessarily - concerned with facts and figures, with content heavily reliant on statistics in order to provide factual evidence to support informed decision-making. However this approach takes in little consideration for the statistical interest or literacy of the target population. The evidence argues that for more tailored communication, there is a need for a narrative and relational approach that takes into account the fact that most vaccination decisions occur in the social sphere, through discussion, debate and, with communication driven not through solely statistics or impersonal measures such as leaflets.

The transmission, as well as content, of information—and its shadow *mis*information—has also proven key in understanding and combatting vaccine hesitancy. Social relations aspects of community are especially implicated here. Top-down approaches typically rely on one-directional 'broadcast' communication and standardised messaging, delivered through official channels and by official representatives, either from national or State public health bodies or national, devolved or State government.

In a recent overview of the evidence on effective vaccine rollouts. Razai et al. discuss the ways in which genuine dialogue with and within a community can enhance vaccine engagement, citing "lack of communication from trusted providers and community leaders" as one of a number of Stated reasons for low uptake of the COVID-19 vaccine, and suggesting that integrating communication with trusted, local, community sources is an essential avenue to increasing this uptake(6). Integrated measures of this type contrast with centrally distributed information campaigns, which make little use of trusted community sources and so may fail to fully engage or increase acceptance in vaccine-hesitant communities.

Conversely, but still with the potential for 'mass' communication, the diagram shows a growing body of evidence on the role of social media in vaccine information, education and hesitancy. Social media is a leading mode of information and opinion sharing and represented in a growing body of evidence, with research on influencers showing that they are emerging as key agents in behaviour change (19). There is still limited understanding of how the obstructive influence of negative media messaging affects group interactions with vaccination. Deep misbeliefs and false beliefs were held by people across the four sites studied in this research, as the case studies will demonstrate in Section C, below.

How these negative messages are diffused through social media networks and how they are challenged or cemented by relations in place, is a subject that would value further research and a significant gap in the evidence. Personal connections, too, with those an individual may know offline, can play a key role, and may aid in debunking some of the myths related to the effectiveness and side-effects of vaccination. As such, while study of social media dynamics is crucial for understanding the intra-community spread of misinformation, given the important limitations of supracommunity directed informational campaigns as described above, it is equally as important to understand the dynamics of this type of information once it begins to circulate within a given local community.

## Importance of place conditions and community engagement

In both the US and UK, histories of inequality, discrimination and prejudice, have combined to generate persistent inequities and disparities in health especially in populations of colour, or BIPOC in US identification, and low-income communities. Many of these disparities have structural causes. These structural factors are persistent and pervasive. They affect the conditions of daily living in marginalised local communities. In the early 2000s, a WHO commission on these 'social determinants of health'-or "the conditions in which people are born, grow, live, work, and age"(23)—drew attention to the ways in which health is more proximately socially determined. These may include such factors as the quality or location of an individual's housing, education, health, employment, social and community context, and the local neighbourhood and built environment.

The connection of the social determinants of health to the challenge and opportunity of *engaging* with communities of place, is on several levels. Firstly, the importance of gaining deep data and specific detail on group and individual hesitant cases, that goes

beyond 'mass' to 'bespoke' communication. Secondly, the potential for good community engagement to shift or counter past negative experiences that communities have had with authorities, for engagement to be 'dialogic' and for a testing of which messages are received and how. These negative experiences could include communities' experience of housing policy, gerrymandering or vote rigging, taxation and development policies, and accessibility or infrastructural gaps (such as closure of hospitals or health centres or transfer of health services online, excluded digitally marginalised groups). The implications of these experiences may not be immediately evident but may be cumulative shocks that have an impact on how far communities practice health engagement regularly, follow local and national government directives, and trust in health provision and guidance.

Beyond this, 'top-down' communication and engagement strategies often interact with discriminatory factors related to integration or assimilation practices and their impact in marginalising or 'othering' communities. Media-related strategies designed to prevent incorporation of marginalised populations into mainstream culture, economy, and politics, have implications in how, and how inclusively, messaging about vaccination or health engagement are a) disseminated and b) received by disadvantaged and discriminated against groups. This is highlighted in the evidence as important given part of successful health communication involves the right medium and the structures of transmission, as well as the right messaging.

# **Co-morbidities, social determinants and vaccine uptake**

In the COVID-19 context, the relationship between these structural and social factors and health is especially important. Social determinants of health have been particularly implicated in increasing the chances of COVID-19 infection, with key studies noting the ways in which historically disadvantaged populations have borne the brunt of the COVID-19 pandemic (22). Within both the US and UK, people of colour who have faced the acute burden of discrimination for centuries have also face disproportionate case and fatality rates throughout the pandemic (23, 24). Among unhoused or poorly housed populations, implementation of public health recommendations such as social distancing and isolation indoors becomes impossible (22). Among more impoverished populations too, with denser housing arrangements and a greater need to continue working in largely public-facing industries, the social distancing recommendations are less likely to function as intended (24, 25). Each of these populations also often faces increased comorbidities, such as asthma, which have been associated with an increased risk from COVID-19 (26). These structural and social determinants and others interact closely with, and are often most manifest within, geographic spatial inequalities (such as poorer areas with less access to public services) - which make place-based considerations a vital consideration of how to support communities through COVID-19 (0).

Yet despite ongoing vaccination efforts, many individuals, including among those most vulnerable as a result of the above factors and other social factors, have not yet received a single dose of the COVID-19 vaccine. Considering the place factors above, it is observable this may be the result of vaccine availability (whether a vaccine is available in close proximity in a State, town or zone related to inequalities of distribution). Equally, there are issues of accessibility (whether a vaccine is accessible once it is available to all people designated to receive it; e.g. if appointments can be made, if appointments can be readily found, if technology required to make appointments is available, if transportation to a vaccination site is easy to find). These factors align with Convenience if we consider the SAGE Model. However, where vaccines are both available and accessible in the UK and the US, low uptake may instead be the result of vaccine hesitancy.



# Bottom-up: an emerging community engagement model for addressing vaccine hesitancy

A limited but robust field of evidence, largely from vaccine programmes in the Global South, and Africa and South Asia in particular, discusses that unlike the popular top-down approaches, a community-engagement model of addressing vaccine hesitancy involves integrating local knowledge into a specific targeted intervention, designed to prioritise impact on a given local community (7). A small but specific body of literature proposes how interventions that incorporate community engagement may have transferrable applicability to vaccine hesitant contexts. This includes the field of participatory public health (27); patient and public involvement (28, 29), participatory research in health, applied research; and the less explored area of health preparedness (30).

Community engagement has also been found as essential to health promotion and to achieving global health goals: the WHO (2020) published a guide to community engagement in the context of global health coverage, citing as it's principle quote, "A strong primary health care platform with integrated community engagement within the health system is the backbone of universal health coverage (31, 32)". Within a growing field of community engagement methods, the - albeit limited - existing evidence highlights that in terms of efficacy, the approach of public and community dialogue (33) is the most important and effective within a bottom-up approach to combatting vaccine hesitancy.

A community engagement approach can be seen to have similarities to 'asset based' public health models which seek to understand and accentuate the capacity of communities to identify problems and activate solutions (34), particularly in addressing health inequalities (34). This is in opposition to so-called 'deficit based' public health approaches which frequently categorise communities as having needs and priorities that 'need solving' by

policymakers, often discussed in negative terms or in the context of seeking to shift their reliance on public service models. A consistent finding across all four of the case studies frequently highlights the importance of national public health devolving vaccination strategies and working in close alignment and partnership with a local ecosystem, recognising community relations, knowledge and insight as a strength or asset to building vaccine acceptance.

#### Summary

There are significant learnings to be drawn for how (and how not) to involve communities, community leaders and local stakeholders from the tried and tested models in the fields of participatory public health, priority-setting, and PPI. But the connection between these literatures and the issue of vaccine hesitancy is currently almost non-existent and it is evident from the network diagram and the evidence review that a disconnect exists between the different evidence, thematic and methodological fields that discuss community engagement in health contexts.

The emergency context of COVID-19 has started to produce an emerging literature on vaccine hesitancy and communities of place - but there is little indication that the models under study, nor the research approaches used, have actively learnt or sought comparison with the patient, public and community involvement in health literature. The field of evidence is currently limited in both case studies and comparative perspectives assessing community engagement methods at work in building vaccine acceptance. Given the interaction of the different spatial, social, historic and cultural conditions of communities with vaccination, this is a much needed gap for further research as it is hard to generalise what will work between and across cases without further testing of different bottom-up approaches in different case study sites. This study is an important start but very much only the beginning of a muchneeded evidence base to support future health engagement and health crises.

# Section C

# Case studies and findings

This section presents a brief account of the differences between the two country contexts, followed by the findings from the four case studies. We divide our findings from the case studies into generalisable findings that were significant across all the case studies, to start to build an evidence base for the factors that appear important within all communities of place and vaccine hesitancy; and case specific findings which were distinctive to one, or more, cases, but deserve particular attention. In the latter, case-specific, case, this is either because they presented a particularly striking reason for hesitancy that emerged within a place-based community; or because a case study demonstrated a particularly innovative or distinctive strategy to addressing hesitancy which may provide learning for other contexts.

## Differences between UK and US contexts

It is important to acknowledge, firstly, that within this comparative study are two very different health systems and histories of community. Despite historical relationships, continuity and similarities at nation State and local level, there are differences in the health structures of the two countries, which affects the dialogue between State/national and local communities around health. The greatest difference is the centralised versus decentralised US system, with centralisation only for those with lower incomes eligible for government insurance (Medicaid or Medicare, VA), those with specific disabilities (SSI). In the UK, primary health care is accessed through a place-based allocation system, whereby an individual's primary care physician, is selected by proximity. In the US, location is also a significant consideration in accessing health care, as people will choose local providers

However, the quality and accessibility of that care is influenced by ethnic/racial and linguistic identities, whether people are insured and by what carriers versus uninsured, whether they have complex health conditions, and whether they are documented or undocumented. Location is also important especially for specialised health care.

With regard to strategies for COVID-19 vaccination in both countries, access to vaccination was determined by age group. In the UK, the vaccine roll-out has largely followed three phases: first, all priority groups were offered the first dose by mid-April 2021this included over 50s, care home residents and care home workers, frontline health and social care workers, clinically extremely vulnerable groups, and those with underlying health conditions; the remaining adult population (aged 18-49) was offered their first dose by mid-July 2021. A booster programme is now underway administering a third vaccination shot to all those over 50 years; healthcare and keyworkers; and those with vulnerabilities or underlying health conditions. At each phase, delivery of the vaccine roll-out has been devolved via local health systems and local government, with distribution decided by the national system under Public Health and NHS England.

In the US, national governmental authorities, primarily the CDC, vaccinated in cohorts, recommending first older adults (75-65, and 50-65 first) and front-line medical providers, grocery store workers and some teachers. As more vaccine became available, different States prioritised in different ways. Connecticut mandated age cohorts, rather than priority exposure groups, which meant that older white residents were vaccinated first, and for the most part, younger urban residents of colour who were at high risk for COVID-19 were vaccinated later in spring 2021. This resulted in perceived racial bias and resentment. As in UK, in the US, the rollout was handled in collaboration with State health departments, but it also included local larger



medical establishments, then federally funded community health centres, followed by local health departments which had fewer resources, after which vaccine was distributed by many collaborating organisations, pharmacies and other local sites, including door to door and block to block delivery through mobile vans.

In both countries, the vaccine rollout depended on the ability to deliver vaccine to local sites and to make it available and accessible. In all four cases, the primary site of vaccine rollout, engagement, access, and delivery was the local setting, whether consisting of local departments and systems to promote vaccination, or local hospitals and clinics and CBOs. In all four instances, local communities (boroughs and cities) included similar groupings of types of stakeholders and institutions, a diversity of faiths and intersectional communities, and a shared sense, as articulated in the case studies, of belonging to, and recognising a commitment to act for and in that place.

A critical element in the vaccination roll-out was that decision making on availability, accessibility, information and resourcing (in terms of additional funding to support the rollout) was led from governance above the local level. The UK's approach to decisionmaking and allocation was top-down, with less connection to local organisations - leading to resistance and independent organising for delivery. The US approach to allocation was topdown led by State, but distribution depended on lateral collaboration of many different organisations at different levels. Significantly and conversely, once availability and accessibility (the distribution of the vaccine); eligibility (a principally age-led approach to who could receive the vaccine first); and resourcing were determined - the strategy in terms of how, where and by what approach the target of 95% coverage would be achieved was left very much to decision-making at the local governance level. This meant that effectively the strategies for vaccine acceptance were led primarily from place and local level and that the responsibility

for addressing hesitancy fell primarily to local authorities and local ecosystems. An additional but important macro finding that became obvious over time, is that the public health infrastructure in both countries is insufficiently resourced from the national and State level to enable efficient handling of a crisis like

COVID-19 - thus placing more onus on the innovation and collaboration of different types of organisation at local level.

In the box below, we briefly summarise the approach to each case study

#### **Tower Hamlets, UK**

This case study combined (1) primary research from two workshops held with a total of 43 individuals in Tower Hamlets to understand experiences of community leaders in promoting vaccine uptake and broader experiences of the pandemic, (2) a review of socio-economic-political history, informed by demographic data to understand the various loci of contention that have manifested across Tower Hamlets' history, and (3) wider literature and studies with available insight and data about the borough. We used these sources to construct a holistic narrative around vaccine uptake in Tower Hamlets. one which frames the vaccine hesitancy within the disproportionate impact of the pandemic on the Borough, which itself is nested in a broader substrate of socioeconomic-political marginalisation that has manifested in differing ways.

#### Hartford, US

This case study is informed by multiple sources of information. These include personal observations, newspaper and other media reports on Hartford's vaccination progress and response, State, city and other epidemiologic reports, resident surveys through community organisations representing diverse groups within the city and reports of CBOs serving Black women, Latinx, drug users, LGTBQ population, Black North Africans, and older adults about the concerns and needs of their clients. Most of the results and recommendations reported on here are heavily based on two, two-hour community workshops with over 40 representatives of local organisations, civil society, faith organisations and health

services, preceded and followed by a small number of in-depth interviews with people widely representative of the city's service, policy, and advocacy sectors. The primary research in workshops and interviews were informed, designed and co-ordinated by Hartford's Community Research Alliance.

#### Oldham, UK

This case study uses (1) workshop findings from two workshops with 35 representatives spanning health professionals, local government and councils, faith organisations, equality and diversity working groups, and community leaders in Oldham, seeking to explore experiences of encouraging vaccine uptake, challenges, and best practice, and (2) an exploration of literature and data, newspaper and grey articles and findings from previous policy reviews, charting antecedent and current conditions which set the backdrop to Oldham's COVID-19 experience.

#### **Boston, US**

In partnership with We Are Better Together Warren Daniel Hairston Project (WAB2G), we examined community perceptions of vaccine distribution efforts in Boston though conversations with Black women on a sides of community violence. WAB2G is a grassroots organization that connects and heals women and girls affected by homicide and incarceration to prevent the cycles of violence and victimization. WAB2G serves a diverse population of Black and Latinx women and their families. This includes incarcerated and formerly incarcerated individuals many of whom are experiencing or have experienced co-occurring mental health and substance use disorder (SUD).

#### Generalisable findings

The most significant finding is that, in every location, the successes of overcoming vaccine hesitancy in each community has been due to the emergence of a local delivery system and locally designed initiatives led from collaborative engagement between, or from multiple parts of, the local social and community ecosystem.

The membership, structure, practices, and ways of working of the local coordinating system varied in each location. Distinctive profiles of local systems emerged led by the make-up of the civil society, community and social sector; by historic alliances; and driven by local knowledge of both community *needs* and the risks of local reasons for hesitancy.

A significant finding is the membership and structure of the coordinating systems delivering the vaccine programme can be seen in each case to have been shaped by the *challenge* of hesitancy presented by the composition of the communities in that place. In other words, the system of vaccine delivery was shaped to respond to the community. This was explicitly discussed in the Oldham case, as a new way of working that was challenging, yet found to be more inclusive and effective in working with communities to deliver the vaccine.

"We were designing the system from the perspective of the community not of a system. And we had to drag the system kicking and screaming to the service of the community, not the convenience of the system and how it 'normally' works" (Clinical Commissioning Group

representative, Oldham)

Another key theme across all cases was the need for system adaptation towards integrated service delivery, and for blended (digital plus door to door or community and street level) outreach. For example, through emergency funding the City of Hartford and the United

Way partnered to form a consortium of larger and smaller organisations that met regularly to try to coordinate vaccination dates and times. Like most of the rest of the country, Hartford was not prepared to address a large-scale health crisis like COVID-19; but in a short period of time through this collaborative working group, organisations including schools and service organisations put into place structures to mitigate health providers' limitations in capacity.

Existing health service networks were able to respond and expand to stretch their outreach capacity and to create new coordinating structures (e.g. United Way), new roles (e.g. CHWs) funded by a combination of local foundation and federal COVID crisis funds. The health department shifted from online appointments which limited access and attracted predominantly suburban vaccine seekers, to direct outreach, face to face and onsite and mobile clinics to reach a more inclusive demographic. These are only two examples and the four case studies each elucidate in depth a distinctive system at work.

The emergence of each system and the areas of its success were frequently described as developing despite the national or State policy, resourcing, directives, and guidance for vaccination roll-out in each location. Tower Hamlets described the shock of the initial arrival of the pandemic followed by a new sense of solidarity and purpose, found in local collaboration.

"You know, it was a terrifying time I still, as I'm trying to remember it; inside, I'm kind of shaking because of the uncertainty of what we were facing...But what came through really quickly was that good, well, actually, you know what, we're all in it together. So we need to come together, and actually lower those barriers."

(Head of Research, Tower Hamlets Council)

The local stakeholders all expressed criticism about the challenge of working with top-down approaches designed and directed from State (US) or national (UK) governance. This included:

- criticism of the guidance on the content and style of messaging campaigns;
- the lack of specificity in vaccine information to support engagement with different communities with particular access needs;
- the lack of accessible research to support strategy development to engage the local population;
- the lack of data to support distribution, manage delivery and track demand (such as appointments).

Many representatives across the groups described having to translate and mediate at the local level and to 'make do' - or to innovate and heavily supplement - what guidance, resources and information tools that were made available.

"We were faced with a push, versus pull, model of encouraging people to get the vaccine. We would have done differently but there was no option to"

(Chair of the Vaccination Working Group, Oldham)

There were no conflicts mentioned between community groups in any case study, with many saying their 'emergency' context (the duress of the pandemic) had overcome bureaucratic or 'territorial' issues that had existed between different organisations and civic parties; but there were notes of tension recorded between community groups and local and national Government in every case study - largely on the basis of who led decision-making and who had ease of access to resources.





#### **Further common themes**

Several further, common themes can be observed across the case studies, which can be abstracted and contribute as being broadly applicable to understanding vaccine hesitancy in communities of place.

Addressing Social Determinants of Health (SDOH) is an important route to improving uptake

There were stark disparities in addressing SDOH outcomes in all the case studies, an example being minority ethnic groups in Tower Hamlets living in areas of overstretched GP and health coverage, which had an impact on their access to vaccines as well as general healthcare. Additionally, a strong finding was the role of competing stressors in building resistance and hesitancy to the vaccine in communities. In Oldham, the relationship between poverty and vaccine hesitancy was described as strong, with representatives discussing how the poorest households who felt neglected or invisible to welfare systems, refused the vaccine due to distrust and disenfranchisement. Similarly, participants in Boston cited the effects of struggles with social determinants of health in weakening their trust and confidence in getting the vaccine. They particularly cited social determinants such as financial loss due to unemployment, lack of in-person access to therapists and mental health services, food insecurity, inability to access adequate healthcare services, loss of social support system, restrictions on travel, having to relocate due to financial and employment seeking circumstances, lack of access to childcare and speciality care, and housing insecurity, as all interacting with whether accepting vaccination was a high priority or a service they felt confident in engaging with.

"A lot of people are getting services but so many people are struggling financially, homeless populations, people with no addresses as the result of COVID...offer people resources ...provide education and offer resources...people are not getting what they need so the last thing on their list is a COVID shot. we need to reach people with other issues...COVID is on the bottom it is not on the top."

(Participant, Boston)

Confidence in the context of vaccine hesitancy has been described as having trust in the safety of the vaccine as well as in government, science, and health care (33). Participants in all locations who were hesitant explicitly described having little to no trust in health care. It was recognised across all the cases that health care facilities have a long history of perceived or actual discriminatory practices, ranging from the digitalisation of appointments and services which excludes communities with limited digital access and literacy (Tower Hamlets; and Oldham) to racial-ethnic, gender or age biases discussed as inherent in treatment systems; as was particularly reflected within the US cases. As a result, it was important to address issues of structural discrimination while devising plans to outreach marginalised communities and integrate these social determinants to improve vaccine uptake.

"How do we overcome the long term, centuries of oppression? Which, for many, the pandemic of racism is still the pandemic? How do we talk about health care? And not just disease care, health management, and not just disease management? How do we teach people to become healthier? ... So these, again, are questions that are large, and take some deep dialogue and interaction with those who are most affected by these issues"

(Participant, Hartford)

These findings corroborate with the literature about vaccine disparities faced by minority ethnic groups (23). Slower vaccine uptake among ethnic minorities is deeply connected with broader structural inequalities. Confidence as a major factor behind driving vaccine uptake is supported by the results across all four case studies; with evidence that there was significantly higher trust by communities in civic and third sector organisations in comparison to a high distrust of officialdom. There were discrepancies in how explicit about issues relating to both discrimination and confidence it was helpful to be in addressing vaccine hesitancy, for example around acknowledging past relationships certain communities had had with health systems or authorities. Participants in the Hartford conversations generally agreed that this history of health-related trauma needs to be recognised directly in confronting distrust related to COVID-19 vaccinations; but in Oldham, it was found more valuable to use framings that avoided narratives of past trauma and conflict and instead prefigured more positive futures or the importance of personal choice.

# Devolved powers produce distinctive local systems of vaccine rollout that are appropriate to local needs

The top-down approach as the sole or principal strategy for vaccine engagement was deemed ineffective by all the studies. This particularly related to how information and education about the vaccine was provided and transmitted; how consistently, relevantly, accessibly and with bespoke consideration, for communities in local places.

"Most of what we've done in Hartford has been really big webinars. And I think those are successful in sharing information. And that's what they're about is trying to answer questions, but not as much yet of the one on one conversations that that people may need."

(City health department representative, Hartford)

There was a marked need to pay attention to place-based community factors and to codesigning the interventions and solutions for the communities, in enable greater accessibility to the vaccine. The rigid structures governing local health commissioning limited the first stages of rollout, with vaccination only led by local governments and health providers and only accessible in clinical sites. As the inequities in uptake of vaccination showed strong disparities between different communities, the need for commissioning local groups who held high trust and strong participation routes to marginalised and/or hesitant community residents and groups, became clear.

In Hartford, churches and mutual aid societies in the Black community promoted vaccination in their constituencies and congregations, as did grass roots CBOs and larger CBOs; beyond this, vaccines were distributed via mobile van to local neighbourhoods and within homes. Tower Hamlets Council and the Clinical Commissioning Group reported difficulties modifying their commissioning criteria due to overly complex due diligence structures, which prohibited the distribution of resources to smaller or informal community networks and groups who were gateways into disengaged and minority communities. This was also the case in Oldham. In both cases, those leading the vaccination efforts had to find workarounds in recognition that only by expanding who could be commissioned to deliver vaccine education, vaccine communication and vaccine rollout, would they reach the most marginalised and sceptic communities.

Critical to the success in each case was the recognition of the need to empower community groups closest to resident populations who were sceptic or hesitant. This often required new ways of working to devolve power and resource to local radio stations, messaging and education campaigns or the creation of local vaccination hubs in churches, mosques, youth centres and sports halls, in order to incorporate local knowledge of what engagement strategies would work best.

"We seeded control. We didn't do 'community engagement'. We seeded control, and speed gave freedom"

(Council representative, Oldham)

Of striking interest is that the national or State system was viewed as a direct contributor to hesitancy and resistance in each case study, though to varying degrees. The UK cases found the national policies, information and messaging structures and distribution system led by Public Health England to be particularly hard to navigate, unsupportive of local coordinators, and in certain cases a contributor to hesitancy. This was due often to patchy data availability and sparse resource, as well as overly simplistic educational materials and delays in providing guidance and tools about engaging hesitant groups.

Conversely, the distinctive local system that emerged in each of the four cases to coordinate the vaccine roll-out and consecutively combat vaccine hesitancy was found to have considerable strengths and impact in increasing uptake; though it was acknowledged in each location that standardising information and processes had been extremely complex, as a result of such a large number of delivery points and interventions combatting hesitancy that had emerged organically in response to different hesitancy narratives.

"We had 169 different reasons people were hesitant in Hartford and 160 different approaches to intervening."

(Foundation Representative, Hartford)

### Better support from a national level is needed to sustain local systems

Lessons learnt from the studies on COVID-19 responses in Boston and Hartford, demands continuous engagement and support from the national level to sustain local systems. Beyond the issues cited in the opening section of the findings about lack of resource and volatility of national and State distribution of vaccines, the gap between national and local messaging

and information was a critical finding. In Hartford, although messages and information were available on State websites and through State-wide messaging efforts in local communities, these messages were not in local languages and did not reach many community organisations that needed accurate information to provide to clients.

For better outreach, there was a need to engage with community influencers, who could represent unvaccinated youth and other reluctant sectors of the community and mobilise them; and for local sites to engage in interpretation of national messaging into other languages, and via localised channels. The role of local radio, particularly Mosque and Faithbased radio stations, was particularly cited in three of the four case studies as being a strong, trusted source of disseminating vaccine information.

In certain cases, the volatile release of national messaging or data, with no warning, exacerbated the challenge of overcoming hesitancy. In Oldham, a borough frequently associated with inter-ethnic tensions and conflicts, the regular release of data and messaging by national government identifying minority ethnic communities as being 'challenge' groups for vaccine uptake, led to racism towards the Asian and Black communities in local Facebook groups in Oldham. Equally, the short notice of the start of the UK vaccination programme and volatile decision-making by national government hampered the timely coordination and planning of local efforts.

"It is a journey not a sprint to vaccine uptake. It was a trickle - now it is a steadier stream, but trust and dialogue on risk-benefit takes time. That's what the national authorities didn't recognise or give us. We could have started earlier if resources and information had been available."

(Vaccination Coordination Lead, Tower Hamlets)





#### Role of bridging organizations and Structures

The importance of bridge building organisations as coordinators, of working groups, or alliances, as coordinators for local vaccine strategies, was found to be key across all four case studies.

The bridge building capital often existed in lieu of the disappearance of formalised community "organising" organisations. For example, Hartford was described as a city of alliances, working groups and task forces usually called together by a convening body to address a specific problem. While relationships may be forged in these temporary networks, they often are not sustained when the problem is solved or put simply, when the money runs out. Oldham's working group structure for coordinating the vaccine roll-out was described by many stakeholders as having been built from alliances forged during and in the aftermath of the Oldham Riots in 2001. But such relationships were described as having been dormant for over a decade with no ongoing cross-community activity prior to the pandemic. Conveners thus knew how to coalesce to deal with an issue or crisis due to past experience, but a gap exists in how to sustain their efforts over time.

Particularly in the US cases, certain networks arose because the conveners were also funders, with internal resources (such as foundations) or external resources (competing for State or federal grants) which plugged resourcing gaps in the State level provision. These funder-convenor relationships have some success in coalescing organisations around the funded issue, but also were described as typically unable to sustain these efforts once the funding is over. In addition, some have noted that organisations with specific missions do not always expand to see how their offer or service could align with a strategy such as the vaccine roll-out, despite the fact that the organisation itself is concerned about SDOH - and that certain organisations needed to be incentivised or supported to translate how their mission and skills could be brought to bear on the vaccine hesitancy issue.

"I was due to retire but feel that it has been one of the highlights of my career despite all the awfulness, getting COVID etc. I do think that there have been some incredible innovations but just from a PCN perspective progression and development has suffered."

(GP, Oldham)

### Lack of data and evidence at a local level inhibited a data-driven approach to engagement

This theme was spread across all the studies. There was a clear lack of locally specific data which made it difficult to strategise a data-driven approach to vaccine engagement, and data quality was poor. In the UK (particularly in Oldham), the representatives frequently discussed the lack of locally relevant and integrated data delays in the national data system meant it was not usable by local vaccine coordination teams. In Hartford, the lack of sufficient data at both the State and local level became apparent and made it difficult to ascertain which groups were being left out, and in what area.

All the case studies have indicated future areas of social research to improve the evidence base. Lack of data was a constant theme that data is not easily available at the local level, so it is not a simple exercise to see how SDOH and gaps in COVID-19 vaccination overlap - and what those working with communities at local level in health and community engagement could learn from this in terms of transferrable strategies for stronger welfare engagement with marginalised groups. There is also a need to consider how preventative health could be an entry point to services for those who have been systematically marginalised by racial oppression; and how systems set up to track eligibility and engagement with the vaccine could be adapted to support other forms of preventative health engagement. This was particularly remarked upon in the UK cases given the free access model of the welfare State, but it has relevance to the US cases,

even if mediated by the US's complex financial, insurance-related and distributed structures of health provision.

### Faith organisations have acted as an adhesive between different community groups

The role of faith groups in providing support during the pandemic and supporting vaccine rollout was a common theme. This is especially true in the UK, where faith groups acted as an adhesive between different community groups. Faith groups in Tower Hamlets had a unique overlap with ethnic minorities, providing inroads into isolated communities. In the US, Hartford in particular, faith organisations encouraged vaccine rollout, sponsored vaccination events, and provided other needed social and referral supports during COVID-19.

"How can we be there to provide Vaccine Education? We at that past Sunday meal, brought a community health worker, as well as a doctor to be able to answer questions, speak with people about the vaccine, and register folks to come in for vaccinations at Park Memorial, sort of on the spot. And so we're thinking about how we can further use those opportunities specifically at those churches, to connect with people and provide some of the educational gaps that seems to be missing."

(Pastor, Hartford group)

In several cases, faith organisations were seen to be working more cohesively with each other in bridging roles between specific, often minority ethnic, communities, alongside other faiths and denominations. This was described as providing routes to reach communities that would not previously have been easily engaged, particularly the smaller minority communities in Tower Hamlets or in Oldham. The impact *on* the prominence and role of faith organisations at local level was also a notable finding for the UK cases: in Tower Hamlets, the representatives of faith communities described how they felt

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previously disenfranchised from the civil society landscape, but how the pandemic had brought them into forums and working groups with secular and public service organisations, through the shared commitment to address the challenge to reaching hesitant communities. In the UK and the US, for reasons discussed above, hesitancy related factors often - but certainly not exclusively mapped onto faith groups, and many described the lack of interfaith structures within local UK communities in particular as a missed opportunity to inform and share relevant and accessible information and knowledge through faith structures and to integrate local faith networks and their members - some of whom would turn out to be hesitancy groups- in the vaccine engagement campaigns from early on, before hesitant-narratives had a chance to amplify and circulate.

"I've been involved in representing the faith communities in Tower Hamlets for a number of years and in attempting to relate them to, to secular bodies in the borough. And that's always been a bit of a struggle. At times we have been included and at times we've been overlooked or ignored. And I felt that that has changed dramatically for the better over the last 18 months."

(Christian Reverend, Tower Hamlets)

Given all the cases described the acceleration of vaccine uptake when faith organisations became involved in local vaccine rollout, the lack of interfaith structures and of connectivity between faith organisations and wider civil society and local ecosystems created delays to achieving a successful vaccine programme in the first instance; but were then transformative to each programme's progress

### The challenge of availability - and vaccination of - Health Workers

The role of community health workers in the US, and community nurses and health champions in the UK, who link residents to health and health related services, emerged as critical to

overcoming hesitancy in all four case study communities. These practitioners typically act as navigators hired by health care providers; or as community-based outreach educators connecting people, including potential patients, to health information and appropriate health care. They are usually from the communities they serve and share language, and lifestyle.

In the context of the COVID-19 vaccine engagement programme, community health practitioners frequently acted in broker roles between the communities they served and the vaccine programme, due to holding positions of trust, and through building messaging and accessibility to the vaccine into their 'business as usual' engagement with the community. However challenges in providing effective additional training for these practitioners about the vaccine; in recruiting and resourcing them to support the rollout, were prevalent in all locations. Despite being highlighted as a valuable, trusted and importantly - already existent - part of local health engagement infrastructure, their potential was underused due to lack of capacity and resource.

Vaccination rates remain low among front-line health service providers in all four of the case studies. Front-line health service providers, many of whom have intersectional concerns related to cultural considerations or the lived experience of health disparities, are ambivalent about or reject the idea of vaccination. For others, though certain cultural and belief-based concerns resonated, this was most frequently described as being due to health workers 'wanting to wait' to see if other side-effects of the vaccines emerged. The vaccination of health workers in hospitals and in the community was a key ongoing challenge for all the sites.

#### Distinctive local ecosystems featured trusted messengers who were effective in encouraging uptake

The frequently raised issue of local communities' distrust of government, in all four locations, underscored the importance of trusted interlocutors who could leverage

their legitimacy (built upon pre-existing relationships, or common identity) with communities to encourage vaccine uptake. The profile and identity of these interlocutors or 'trusted messengers' varied across all four locations due to the diverse profiles of the local communities in each location. Community groups rapidly took up the role of a trusted messenger in Boston and were eventually supported with approximately \$1.3 million of funding, given the strength of this model. A noteworthy example is the Black Boston COVID Coalition (BBCC) which was able to deliver vaccine education and outreach with 100s of volunteers based on a relationship of trust with Boston neighbourhoods. In Hartford trusted messengers included: barbers in Black and Latinx neighbourhoods, staff of drug harm reduction programs, housing programs, community staff in local Latinx service organisations, and local high school youth trained to deliver pro-vaccination messages to their peers.

These trusted messengers were related in all cases to findings about the efficacy of community sites of vaccine engagement and delivery, which were a strong contributor to building engagement and uptake. A popup clinic, organised with local mosques in Oldham at the Millennium Centre, proved a turning point in vaccine engagement with the local Muslim community, vaccinating over 1,000 people in a day after three months of low uptake via health services and GP site of vaccination. Community groups also played a more prominent role in vaccine educational initiatives, with notable examples such as East London Mosque's vaccination clinic in Tower Hamlets; or even private residences where local champions coordinated vaccine hubs in Boston to bring the vaccine to sceptic or vulnerable groups where they lived, in order to address the anxiety or resistance held by certain groups about engaging with officials and with health services.





"I work in the healthcare field. A lot of the patients had the vaccine, and they were coming, and they were proud of it. My hospital called me so much I had to block them. I heard about it on the news...I remember at first, I wasn't going to get it, but I have high blood pressure and am asthmatic. I live in a building with ppl who are elderly and people with disabilities. Our property manager set up an appointment with CVS and they came here...so we all got it..."

(Healthcare worker, Boston)

# Digital is a tool for distrust - unless highly localized and supplemented by local engagement

The role of social media was a prevalent theme for the transmission of vaccine information; both from official, top-down sources and by local authorities and coordinating groups. As is well documented and observable, social media is also the most prevalently cited transmitter of misinformation about vaccination between communities themselves. Across all the case studies, the role of social media was critical - particularly how misinformation spread through networked communities of identify or kinship via Whats app, and fake news campaigns via Facebook groups and YouTube videos.

All cases had used social media-led initiatives to seek to build vaccine confidence. In Oldham, the vaccination of 30 Imams was broadcast on TikTok, seeking to engage followers in their communities to get the vaccine. This proved effective in strengthening uptake in the Muslim community - but was said only to be so because it was coordinated with - and indeed broadcast from - the opening of a local vaccination site - the Millennium Centre - close to the main residential areas for these communities, which provided an accessible and non-clinical setting for the community to attend. Following this event, over 1,000 people from Muslim communities were vaccinated in a single day in Oldham.

Despite this, attempts to counter-message or to build vaccine engagement using social media advertising, Facebook groups or platforms was found to be fairly ineffective unless connected strongly to local, trusted institutions and to reallife, easily accessible examples of successful vaccination from the local area. Intersectional considerations meant messaging could not be uniformed but needed to be tailored to individual Whats app groups, Facebook groups or online forums to ensure relevance to each local group with a shared gender, faith, or intersectional identity. Furthermore, messaging on social media needed to appear distanced from government or local authority control or influence. Representatives in multiple case studies described the importance of trusted messengers to be seen as the sources of information, and for the need to double down on digitally transmitted information with real-life, consistent dialogue and messaging across local sites.

"They have trust in mosque leaders like the Sheikh. Also, because mostly the mosque leaders will speak Arabic and specifically women, they are pretty much mostly less fluent in English. There are people who are fluent in English and work or have their job or they go to school but the majority, especially those who go to the mosque are less fluent in English. Another factor, everyone trusts PCPs, so the group suggested providing Arabictranslated flyers to PCP practitioners and to support the school in providing Arabictranslated materials for awareness. And then the social media was a controversial aspect. The surveys highlighted that there is less trust in social media as a resource. However, the group mentioned that they relied tremendously on social media in their interpersonal communications. And I can attest to that because we recruited people via WhatsApp. This is the most used app in social media for this population. Even the mosques. Each mosque has a WhatsApp group for males, a WhatsApp group for females"

(Sudanese American House representative, Hartford)

### Rights-based deprivations should feed into health policies

Rights-based injustices were visible in the US and UK cases as long term challenges that were amplified or exacerbated - physically and in terms of visibility and claim-making - during the COVID-19 vaccination programme. However integration of minority rights approaches into health policies can allow us better opportunities for addressing social inequalities embedded in the current systems, and the COVID-19 vaccination programme can be seen as an - albeit underexplored and under-realised example - of how this could work in practice.

Vaccination was seen by all the case study sites as a way to engage communities around addressing the broader determinants of health, food and housing insecurity, transportation barriers and unemployment. In Hartford, advocacy organisations and foundations cooperated to prevail upon State legislators and policy makers to create a commission to examine racism's impact on health and expand data collection to include indicators of exclusion (race, ethnicity, language, age, gender identities) across State agencies and all health reporting. In Boston community health centres (CHCs) began to encourage holistic wellbeing of Black communities - in a bid to counter the experience many participants felt of being 'stigmatised' or as a 'problem' community through the use of clumsy interventions and messaging seeking to try to build engagement with Black communities.

"When then when we hear the phrase 'this population', it appears as though people are being targeted. As a matter of fact, the language sometimes comes across as the target population. I think that in the consideration of message and the consideration of messenger, it is about the dialogue with the community and helping them to understand not just about the vaccine, but about, overall health in their community, that people want to feel like they're being helped and not targeted."

(Participant, Hartford)

Corroborating the findings in the evidence review about the role of historical injustice in building vaccine hesitancy, communities in the US and the UK sites referenced past - and recent - injustices in health and broader policies around welfare in their reasons for distrust of the vaccine or scepticism. Specific examples of previous scandals; personal experiences of racism or poor medical experiences; or simply limited or compromised access to health services, all contributed to vaccine hesitancy and resistance. In Tower Hamlets, consistent issues with access to GPs over the last ten years was referenced frequently as a contributor to why communities were distrustful of medical intervention as they perceived the sudden engagement of local health services, trying to persuade them to get the vaccine, as a conspiracy or as 'one-sided', negating the benefit to them.

"Trust is a major factor just being able to trust the medical field. We know it is free today but in the long hall they will be making money...! just don't trust the medical field. I am a person who lost a child to medical malpractice. Tuskegee... the syphilis experiment...everything that has happened to our people I just pray for everyone. I feel like somehow through the pandemic the health system has been manipulating. Where are the numbers... I didn't get the information."

(Participant, Boston)

#### Trauma and fear - or risk/benefit narratives

Vaccinating young people was found to be challenging across all case studies for reasons that were connected with hesitancy among the broader population (distrust of Government, suspicion of motives and ingredients, fear of vaccination consequences including future death, fear of effect on reproductive health) - but also for specific reasons. A specific challenge for young people can be seen as an increased 'Complacency' factor through the lends of the SAGE model: the belief that they would not catch the virus, and that if they did, they would not be seriously affected.

In other communities, trauma, fear, and confusion were disenfranchising other communities from the vaccine, which was compounded by observations that health workers were also sceptic, and by inconclusive information from authorities.

"I almost lost a very close family member from COVID, and it traumatised me. I see people walking around without masks on, but I'm not ready for that. I'm not ready to eat in restaurants yet because I'm traumatised from it. I'm not ready to put my guard down yet. I am traumatised that something invisible almost killed one of my close family members. I don't know when or if I will put my guard down. It is going to take a day at a time for me to work through it. I was impacted work wise when it first started. I had to ask for assistance. That was new to me. I had not had to do that before. It gave me anxiety. I saw people on social media who had it. My daughter had it and I was worried. I did not get vaccinated. I work in a hospital and people who are vaccinated still get it, so I am not getting it. Maybe eventually but I am not there yet."

(Participant, Boston)

In every case study, the impact of structural inequalities and of poverty - including poverty of participation in health systems - was recognised as a reason for high hesitancy. Those who were coordinating engagement efforts in each location described one of the challenges of the vaccine rollout to be their negative perception of forced and instrumental engagement around the vaccine with communities, particularly impacting those who had struggled for years to gain access to other forms of primary health support or welfare. How vaccines have been delivered, which has been in both countries a fast-paced series of short appointments, often in large scale vaccination centres to rapidly administer vaccination at pace, has left certain communities frustrated and sceptical about the purpose of vaccines. Community

Health Workers in Oldham and Tower Hamlets particularly described how people rejected and mocked vaccine appointments, citing this was the 'only time officials had been interested in their health in decades' - so why should they be willing to engage now.

"What we were seeing in those that were resistant is what happens when poverty rubs up against a pandemic."

(Community Health Worker, Oldham)

A further issue arose not around resistance, but in terms of disengagement; in all locations, it was reported that poorer communities could not see the value of having a vaccine when they had more pressing issues they would still have to live with including co-vulnerabilities to COVID-19; again, it was cited that the messaging around vaccination led from the top, seemed blind to the complex lives and challenges many communities were facing, which were a higher priority to them than the risk of COVID-19.

"But it is we're talking about trauma that has been associated with systemic racism for centuries and delivering a message around an urgent issue like COVID-19, that that pandemic, without also talking about, the pandemic of racism is incomplete and may not ever be heard. So it's one thing to, to have the goal of everyone getting a vaccination, it's quite another to have everyone have a vaccination and be safe from the symptoms of COVID-19 or, you know, contracting the disease or having a very bad adverse reaction to disease, but then still having to live with not having access to great quality education, or to quality foods, or to adequate housing, into quality housing, and so forth."

(Participant, Hartford)





#### **Context-specific findings**

A number of important themes emerge in some case studies, but not all:

### Framing intervention from knowledge of underlying local challenges

The case study of Oldham paints a true picture of the uneasy relationship between citizens, the local governance system, and the national directive from Public Health England. The participants described the vaccine roll-out as sudden, and with limited support to local authorities and health systems. The national system was viewed as a direct contributor to hesitancy and resistance. In response to this, the distinctive local system that emerged to coordinate the vaccine roll-out and consecutively, combat vaccine hesitancy, was led by two principle anchor points: the Vaccine Working Group, comprised of the majority health system, GP, social care, primary care and community health representatives alongside local government and frontline social organisations; and the Equalities Group, comprised of multi-faith and multi-community representatives from faith organisations, civil society including charities and networks representing people with disabilities, community groups and those representing vulnerable communities.

Participants mentioned that the advantage of the hyper-localised model of vaccine rollout, meant they could develop a bespoke and flat hierarchy of governance in delivering the vaccine in Oldham. Power structures were largely equal between members of the working groups, leading to a unified interest in lessening the impact of the pandemic and encouraging vaccine uptake. Furthermore, the framing of 'equalities' in the aim of the working group itself, enabled bridging into communities that had felt excluded or disenfranchised by years of racial tension within Oldham, epitomised by the Oldham riots in 2001 and still manifest through 'siloed' and fractious community relations as

found in the Cantle review of 2017. Devolving power to community organisations built the confidence of people and combatted distrust built on histories of marginalisation or cross-community conflict. There were questions however, about how sustainable this sense of solidarity was and how far it extended to residents as opposed to the coordinating system of community leaders, civil society, and local authority representatives.

"I agree with Mike, where CCG, Trusts and Local Authorities are more together than we were, the population we serve are probably less convinced of improved integration"

(CCG lead, Oldham)

### Gentrification has exacerbated antecedent conditions to vaccine hesitancy

Gentrification has been a notable pattern in urban development in three of the case studies Tower Hamlets, Hartford and Boston, and was referenced frequently in relation to the emergence of social divides that intersected with other hesitancy or disenfranchisement narratives about the COVID-19 vaccine. Gentrification has deepened inequalities between different communities, particularly between white and minority ethnic communities, and strengthened oppositional activism towards local and national authorities due to the perception of its benefits only being felt for and by a privileged few. Oldham, as an area that has been characterised by longstanding deprivation, experienced higher vaccine hesitancy than neighbouring parts of Greater Manchester, for example.

As was found in the evidence review on the social implications of COVID-19 on communities of place, and summarised in the *Covid Decade* report (0), longstanding gentrification in parts of the UK - and the similar pattern experienced in the US cases of this study - has created poor housing conditions, limited access to green space and displacement or 'ghetto-isation' of poorer communities which creates conditions for greater vulnerability to COVID-19 itself as a

health threat - and a more challenging context for their recovery from it. Gentrification, insofar as it exists as a policy choice, can thus be viewed as an exclusionary policy that both exacerbates vulnerability to COVID-19 and entrenches vaccine hesitancy through a strained relationship with authorities.

### There are individual challenges around vaccine engagement for each ethnic group

There are overlaps between the different case studies in terms of the representation of different racialised minorities and the organisations that work with them. The US case studies there is a stronger inclusion of Black communities, notably in the Boston case, due to the specific demographics of this area. This has created a unique set of challenges that are couched in the historical context of the struggle against anti-Black racism, and more recently, Black Lives Matter, with the killing of George Floyd in 2020 raised as a political and violent issue that further compounded distrust by Black communities in authorities in the US, but also in the UK and across the world. The legacy of this injustice was frequently referenced as an incident that compounded the Black communities' distrust and thus - low engagement with the vaccine, as the COVID-19 vaccine was seen as another 'injustice' being forced upon these communities whilst they were seeking other rights-based claims elsewhere..

On a different basis, challenges were discussed in the US cases in terms of vaccine engagement for the different Latinx groups from different countries, whose needs are often unaligned with local social policy, hampered by their limited English ability (especially new arrivals/immigrants) -but have less visibility and political influence than majority racially minority groups, meaning strategies to adapt vaccine rollout to meet these needs or address these challenges are often not a high priority.

In the UK, South Asian communities comprise over 60% of the overall population in Tower Hamlets which creates separate and noncomparable challenges to the US cases. These

challenges have their own distinctive roots in the historic and current lived experience of the different South Asian communities which tend to stem from the UK's colonial legacy and historical and more recent Islamophobia. There is a need to distinguish between different racialised minorities in the development of vaccine engagement programmes and for research teams to ensure much finer granularity and representation in conducting research about the potential solutions to vaccine hesitancy, in order to account for the high specificity of lived experiences of discrimination or alienation. Through the lens of vaccine hesitancy the cases demonstrated the distinct political relationship of different racialised minority communities in different places to authority-led health agendas, which could not be accounted for through the limited number of largely 'top-down' approaches and required tailored, and locally informed, engagement.

### Differing healthcare systems present different vaccine hesitancy challenges

Alongside the distinctive factors considered above, the differences between the UK and US case studies were accounted for mainly by the mediating factor of the countries' differing healthcare systems. Due to the way the US system operates, a critical factor in the US was the impact of the lack of access to health insurance for those groups who were often the most affected by COVID-19 and health comorbidities; with heightened awareness of the inequalities the cost of healthcare presented and therefore the *distance* many of the most deprived groups have to regular health engagement, let alone vaccination.

The UK has free public healthcare but is still experiencing the impact of nearly a decade of austerity policies, which has created a heightened vulnerability for many communities to the impact of COVID-19, and a weakened health and community health infrastructure in the ten years prior to the pandemic. It is significant to some of the challenges to the vaccine rollout that much of the community health infrastructure, from social care to community nurses had been stripped out in the years prior to the pandemic

due to cuts in funding, meaning there was a heightened need discussed in the UK cases for cross-sector collaborative working to share budgets and achieve the rollout of the vaccine at the scale required. Austerity policies have created fragility on the part of local health systems, to the point where the necessary infrastructure in terms of staffing and expertise in particular was not present at the point the vaccine needed to be delivered: a significant number of those who took part in the UK cases (about eight in total) had come out of retirement to play their part in the local health response.

The report *The Covid Decade*, discusses these antecedent conditions in the UK and their impact on the health and social response to the pandemic in greater length. Despite the positive support for the NHS throughout the pandemic in the UK, the comparatively reduced choice of healthcare providers in the UK also makes the healthcare system a representation of officialdom in the eyes of those who are likely to be sceptic, removing it further from principles of 'individual choice' or bespoke (health)care against which sentiments of resistance can, and were, mounted in the UK cases.



# **Section D**

### Conclusions: Re-imagining communities

This study started from a critical position about the relationship of communities of place to the causes of vaccine hesitancy, and the intervention approaches designed in local ecosystems and communities to improve vaccine uptake. This section presents conclusions drawn from analysis of the findings across the four case studies, in discussion with the findings of the evidence and literature review.

The study has sought to answer the research questions set out at the beginning by looking at the issue of vaccine engagement with historical and sociological lenses. It has delved into the health, social, economic, and political consequences of COVID-19 for different groups in each of the case study areas and also examined the historic and current dynamics of the relationship between different communities and a) health authorities; b) local authorities and State authorities; c) organisations and groups.

It has asked critical how issues of injustice, trust, cohesion, and inequality interact with the dynamics around a) health inequalities in these areas, and b) health engagement, including with the current vaccine programme. It also explored the efficacy of vaccine engagement, health access and engagement, and examined strategies to reduce fears and concerns about the vaccine with specific groups in each area, in order to identify the gaps in policies and strategies and where practice and coordination can be captured and could be transferred, learned from and extended.

The study has found how the interaction of place with the social determinants of health has created antecedent conditions for vaccine hesitancy in certain communities. As the review of existing evidence demonstrates, known

factors can be grouped based on communities' access and participation - or rather, the lack thereof - in the local health system. The structural complexity and persistence of lack of access and routes to participation; alongside the lived experience of inequalities and injustice. were found in the literature to considerably mediate the readiness of communities to accept vaccination. This was born out across the four case studies, with each case contributing additional findings of how social determinants in a community affect vaccine messaging, who can and should be trusted messengers, and the existence of additional, complex needs that need to be taken into consideration to strengthen participation in vaccination.

Some critical lessons can be learnt from this report, namely:

- Addressing vaccine hesitancy requires the engagement of national, State and local institutions with local communities in an authentic manner over time to build trusting relationships. That engagement should include the diversity of people and groups within those communities.
- Messaging about COVID-19 should be straightforward and transparent, and grounded in pull - not push - reasons for accepting the vaccine, that may be locally specific. They should also be consistent with science) while clarifying that science is always work in progress and may change.
- Messages should be delivered in conversations between trusted "messengers" and local residents, and should consider their rationales, concerns and fears about vaccination, recognising that they are real regardless of the source; and that messengers should be able to address historical roots of resistance.
- Vaccine delivery should be associated with activities and materials that people want and need, including access to dialogue about their health, and health education - so it is viewed as responsive to communities and not simply an instrumental act. This must be balanced with managing expectations, but more can

- certainly be done than instrumental vaccine engagement, particularly in the context of emergency funding measures and even accounting for pace.
- Local organisations and convening efforts in communities as well as public health authorities should have reliable and accessible *local* and *hyperlocal* data able to be disaggregated by demographics and vaccine variables on an ongoing basis, that provide for agile planning in emergency and 'peace-time' public health approaches for different local communities.

A key contribution from this study is the importance of pre-existing local health and community infrastructure to overcoming vaccine hesitancy. The flexibility and *inclusivity* of the systems communities were being asked to engage with for the purposes of vaccination was a key dimension for how quickly these systems could mobilise and start to improve uptake. By far the most successful sites to administer vaccines for those groups who were hesitant,

were community sites - from faith buildings to sports centres, youth groups and housing associations. How to recognise, commission and ensure adequate equipping of these sites was a key challenge that each location had to find ways to respond to.

Equally where local systems had been asset stripped, lacked local, trusted practitioners or community infrastructure; or where civil society and community organisations had less honed collaborating structures, vaccine engagement was slower to coordinate and respond to. If certain groups were 'left out' of coordinating structures or had experienced long term alienation from the authorities leading the rollout, uptake was substantially harder.

The vaccination programme catalysed new bridging structures, whether working groups and alliances, which is important collateral to maintain in the face of future crisis - but the resource and sustained mobilisation of these structures is now a critical concern for those involved with them, and those dependent on their work.

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Iterating the SAGE Model: Community as the 4th 'C'

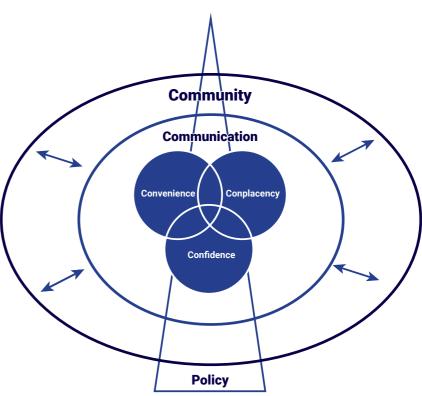


Figure 2: Adaptation of the SAGE model following the focused community engagement in this study. Community exists as the outer sphere, with Communication - defined as the different modes, strengths and types of engagement - as the mediating factor encompassed as the inner circle. The dialectical nature of the communication and community dimensions is expressed by arrows. Policies around vaccine delivery and education have the ability to mediate or shift the impact of the 5Cs, in various configurations depending on the design of the policy - as indicated by the sundial.

The evidence review for this study considered the SAGE model of vaccine hesitancy (the 3Cs) as the most established understanding of reasons for vaccine hesitancy to occur and employed it in considering the experience of the four case studies of delivering the vaccine programme. The case studies revealed gaps in the existing understanding of vaccine hesitancy, especially the lack of local community-level approaches - or robust 'bottom up approaches - to vaccine engagement, and an appraisal of the community and place dimensions that mediate vaccine uptake.

From analysis of the findings of this study against the SAGE model of the "3 C's" of vaccine hesitancy, a fourth "C" becomes essential: Community. Community is not a factor for vaccine hesitancy, but an interacting and mediating dimension epitomised in the historic, social, economic and governance conditions of a local setting. The case studies for this research have found Community to be a mobilising system of delivery, driven from a sense of communality or affiliation; it can also be described as a group of people who come together to solve a problem. These mobilising systems have been found to have distinctive profiles, operating approaches and characteristics in each case study which we have sought, humbly, to characterise.

The position that 'Community' enables the organising system to occupy is a catalytic one. Local communities are a place and space where people can and do organise and mobilise to address their own needs, and cooperate, compete, or oppose national and State-wide or provincial mandates or policies. In certain cases, the system can be described as operating from a 'rebellious' or 'outsider' stance driven from longstanding experience of marginalisation and spatial inequality for that local area within the regional and national geography, such as in the case of Oldham which is one of the poorest parts of the UK.

In the context of these findings, we propose a diagram of the interaction of **5 'C's of vaccine hesitancy** as an adaptation of the SAGE

model. 'Community' is the outer circle given its dual emergence as a mediating setting, a site for action and delivery, and its role which encompasses the opportunity of community involvement to mediate or mitigate the reasons for vaccine hesitancy. We now understand Communication - which also encompasses different forms and approaches of community engagement - as the inner circle; where messaging and mis-messaging about COVID-19 exists and interplays at different levels; but where community engagement acts as the route for intervention in the 3Cs and as the 'ladder' of participation in vaccine uptake.

The fifth C of communication is proposed by a study by McNamara (2021) proposing 'Communication' as crucial in the context of vaccine hesitancy. The evidence-base identifies communication - whether via top-, 'strategic communication' or 'mass campaign' approaches or via public health information and messaging, as critical to the immediate emergence of hesitancy narratives and the existence of demand or resistance to vaccination (35). Responding to this and recognising the dominance of informationbased campaigns in the most frequently employed policy approaches to addressing vaccine hesitancy- within the 'top-down' approach - we have proposed 'Communication' as a fourth C in our revised model, recognising its close linkages to national or regional policy and intervention approaches, as well as its importance in how communities engage and interact. This also corroborates the WHO report about the importance of communication.

A final, and untested consideration is whether the influence of what has been called 'community strength', or a shared sense of community, could emerge as a sixth factor. This could, though somewhat controversially, be also referred to as 'cohesion', which emerged in the Oldham and Tower Hamlets cases as a key element interacting with the speed and outcomes of vaccine acceptance by communities themselves. The lack of cohesion created racially based hesitancy and

resistance narratives; as well as conversely laying the groundwork for the partnership working that emerged to overcome these challenges which was built on previous cross-community collaboration structures designed to overcome local conflict. Measures of this exist in the psychology, sociology and community studies spheres, considering levels of identity, empowerment and cohesion and how they mediate group dynamics and system engagement, and could prove valuable in further research.

The model we propose is a developing model and would merit further testing and examination of its application to different contexts and under different national, State, and devolved systems.

It is important to recognise at this point that local communities are geospatial systems nested in larger entities. Communities, like all the sites in the UK and the US, are complex. Even communities seemingly united by identity or ethnicity, living together within a place, are differentiated by class, religion, country of origin, recency of arrival, or the segregation or integration of local geography; these associations drive and correspond to reasons for vaccine hesitancy and require specific intervention responses, which furthermore highlights the importance of research with and by residents and local stakeholders to understand these layers of specificity within the context of vaccination and broader public health. This research cannot and should not solely be done at the point of crisis; indeed, this study raises the question of how much value there could be to understanding the strength of community engagement in preventative health and public health strategies in different places; identifying more and different models that work well - and learning from them, in preparation for future challenges.

Similarly, community engagement has often been described by those who practice it as a 'muscle' which needs to be flexed, to be effective or agile when called upon. The

challenge of how to sustain these new positive ways of working beyond the pandemic, whether collaboration structures such as working groups and alliances, support structures such as hotlines and community health champions, or newly innovated local data systems, were at the forefront of the minds of those in Tower Hamlets, Hartford, and Oldham. Whilst many recognised that a stronger, and different, system had emerged in response to the challenge of the vaccination programme; all were realistic about its durability and the stark lack of resource to sustain and build on this integrated infrastructure once the 'urgency' of COVID-19 started to pass. Opportunities to capture learning from this, and strategies of how to sustain and think about the repurposing of local ecosystems to face the next challenges. are limited but much needed.

"And so I believe that while there is promise, that promise has to move into practice, and then that practice has to be set in for a period of time, and at least allows the allow those who have been the victims of or the recipients of this systemic conditioning, to somehow gain greater acceptance."

(Participant, Hartford)



# **Section E**

# Policy implications and recommendations for further research

#### 1. Policymakers:

- Should engage with local communities who are the people who are affected by their policies and resource allocations, and through forms of dialogue or power sharing, work together for the common good.
- Policy makers and service providers should understand and integrate recognition of historical trauma and discriminatory experiences into health and COVID-19 vaccination messaging - and strategies.
- Should inform themselves or be informed by local communities that are historically marginalised and experiencing bias and discrimination; and should receive training that promotes diversity and inclusivity in public health policies and practice.

#### 2. Public health Infrastructure

- Public health infrastructure consists of official and unofficial structures in both countries. Both are under-resourced and need further support from national and State governments to effectively form partnerships and alliances to meet the needs of future health crises.
- Public health infrastructure and emergency health campaigns should include resources that address social determinants of health; and which lay groundwork for collaborative development of matrix vaccination strategies. These strategies would be informed by a) a more expansive intersectional view of vulnerabilities in

communities, and b) analysis of propensity for hesitancy and with mitigating hesitancy at its core. This would mean vaccine strategies were founded on a weighting of place and community vulnerabilities and health risks, rather than being focused solely on those most at risk from a morbidity or co-morbidity perspective. The importance of this is as hesitancy tended to increase with delays to vaccination or perceived injustice or inequality in vaccine distribution.

- 3. Primary care providers, and other health care providers should recognise and assess and refer patients who need help in addressing social determinants of health.
- Health providers at all levels should integrate understanding of historical health trauma and discriminatory experiences with health care to provider training and continuing education.

#### 3. Communities

- Community agencies and representatives should be supported to work with providers to identify smaller homogeneous populations of hesitant or unvaccinated people, and their sources of influence.
- Should work with influencers to build their capacity to hold persuasive ongoing conversations with them and influence their social networks.
- Communities and other policy makers should advocate for more support for trusted smaller organisations with connections to community residents in marginalised areas, so that they have the resources to coordinate more sustainably with health care and other services.

### 4. Attention to specific groups and populations that are vaccine hesitant and lack services

1. More effective programs that target young adults, including young mothers

- with appropriate ongoing and sustainable programs that help them learn their histories, gain employable and social media and science literacy skills, and change their lives.
- 2. Programs and efforts that identify groups that are less visible (for example North African Arabic speakers in greater Hartford, caregivers of people with disabilities, LGTBQ and Trans populations, people released from prison and unintegrated into systems of service care and family, unstably housed youth) and co-create specific strategies to reach them in vaccination.

Further funded research is essential within this field to understand the social connections that knit different local communities together, and different strengths and weaknesses of different, highly place-specific local systems in the context of the multi-level factors of place and social relations.

#### Areas of need for further research

Further development of the 'Community' multilevel factors into a usable framework could enable more place-sensitive intervention, enabling areas to be anticipated which start from a more challenging position in terms of vaccine engagement due to 'community' factors (in the expanded SAGE Model of 4Cs). It would also enable different success measures to be applied; enabling local systems to be recognised for their innovation and coordination success in strengthening vaccine and health engagement via a weighting that takes into consideration the mountain they have to climb, rather than being seen as 'problem cases' based on ranking low compared to an arbitrary national, city or combined authority 'average' or 'ranking' based solely on % uptake of vaccinations. This could provide routes for greater recognition and transferable learning from local initiatives to combat vaccine hesitancy, as well as to support the efforts of local health and social systems.

In addition, and aligned with this priority, the following areas of further research would be beneficial.

- Mapping of the flows of information and coordination within local ecosystems that have built effective vaccine engagement.
  - This is identified by community representatives and by the research team as being the most valuable research needed at local level in three of the four local case studies. It is also an area almost entirely absent from the literature, particularly when framed around increasing participation and engagement of communities in public health campaigns and health interventions.
  - A network mapping approach within a case study model would be needed that could build on this study, engaging further local documentation review, interviews, and a participatory mapping workshop - to present a detailed view of the coordination system, connecting and engagement points, and flows of information, resources, responsibilities and powerr.
- 2. Development of a framework for preemptive analysis of communities - to inform responsive design of public health intervention.
  - A framework to measure the fourth 'C' of community within health participation could provide a means of:

     a) identifying and anticipating where there will be local areas with high risk of low participation in targeted and mass public health interventions, including vaccines and b) targeting and tailoring the design of systems, funding, and coordination mechanisms to address this risk, both in emergency contexts but also in terms of building stronger local systems.
     c) Understanding the efficacy and outcomes of community engagement within vaccination strategies.

 Understanding where there are viable mechanisms, models and best practices for communities of residents and CBOs who serve them to collect their own data as the basis for self-empowerment, improved involvement and voice in community leadership in health would be of huge benefit to ensure this framework is populated with lived experience and hyperlocal data - and better plan and service other areas of health delivery.

### 3. Understanding how to sustain and strengthen local systems

- Further understanding and mapping is needed of the role of public health infrastructure in connecting to multi-level partnerships and alliances in vulnerable communities, and in how to support and sustain infrastructure and partnerships. Is there sufficient infrastructure in placeand what should be done about it if not?
- Greater understanding is needed of what sustainable structures exist in local communities, that are able to plan for and execute plans to address a) ongoing health disparities and b) local and national/global health crises. Research needs to understand how local health structures function, what sustains them, are they effective and how could they be strengthened, given the clear role they play in national crisis.



# **Appendix 1**

### Methodology

The Institute for Community Studies (ICS) and the Institute for Community Research (ICR) teams sourced over 22,000 articles through searching of five key UK and US databases which produced a relevant field of consideration of 2,226 articles. Two search-strings were drawn from the research questions and an updated literature review of community and place determinants of health by ICR, provided focused search terms and Boolean operators. Grey literature and case studies produced by civil society, NGOs and independent research organisations were also included. Following a rapid review, 23 articles were selected for inclusion and in-depth review based on those that discussed place based, or community focused, vaccine engagement of any kind, to identify what was known about vaccine engagement in communities of place.

# Evidence network analysis

The network analysis began upon collection of data from a Scopus literature review. The dataset included information about 112 distinct pieces of literature, including any author-selected keywords associated with each work. This data was transformed into a network diagram, with keywords as nodes and edges added given two keywords were included in the same work. This initial construction resulted in a network of 261 nodes and 846 edges, split between 1 large and 13 small components. This complete network had an average degree of 6.5, diameter of 7, graph density of 0.025, and average path length of 2.8. Network statistics were also run on the largest component (n = 193; e = 710) of the graph separately, resulting in a slightly higher average degree of 7.4, diameter of 7, graph density of 0.038, and average path length of 2.8.

Analysis also identified 10 neighbourhoods within this large component. For analysis and presentation of data, these neighbourhoods were each uniquely coloured. Finally, node size was set according to the number of occurrences of each keyword in the dataset, with increased size indicating a greater number of appearances. Network analysis was undertaken in Gephi.

# Case study methodology

A rapid political economic analysis was conducted in each of the four case study locations to inform the context of the participatory research. Multi-sector and multilevel community representation was identified in four locations including Boston and Hartford (US) and Tower Hamlets and Oldham (UK). Sampling was purposive and inclusive of the diversity of communities and corresponding organisations and institutions in each location. In three of four cases it included representation of all major institutions of government, health, social welfare, education and faith institutions and community-based organisations. In the case of Boston, MA, the sampling was focused on understanding the systemic barriers to and possible interventions for greater vaccine engagement for a distinctive hesitant group of women affected by substance use and economic marginalisation.

The ICS and ICR team worked with already established relationships and added new relationships with local organising groups. Both utilised snowball sampling and referral. ICR worked through its own organisational networks established over many years, and

its Community Research Alliance composed of CBOs, rights advocacy organisations and committed faculty. ICS mapped the civil society and community organising fields via social media and online searches, which differed according to the location.

In Hartford, US, and Tower Hamlets, UK, a community steering/advisory committee agreed to co-design the research questions and guide. In Boston the research guestions and the workshop guide were co-designed by the site investigator at BU with the director of the collaborating service organisation. Participatory conversations/workshops (2) per location) were organised to promote intersectoral communication and gather data in Hartford and in Tower Hamlets and held through existing coordination structures in Oldham with boosted inclusion of representatives of community organisations who were not usual members. In Boston, two focused discussions were held with marginalised women. Over 120 community representatives were engaged across the four case study locations. This was supplemented with an online reflexive exercise in Tower Hamlets and Oldham with individual representatives via digital research engagement, where individuals shared written, brief accounts of their experience of the vaccination rollout and the initiatives they had found effective to enable asynchronous data collection and exchange to continue digitally.



# **Appendix 2**

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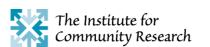
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#### **About the Institute for Community Studies**

The Institute for Community Studies is a new kind of research institute, with people and communities at its heart. We give increasing weight to the stories, experience and evidence created in communities, supported through our national network of community researchers. We provoke direct engagement with policy-makers, business and those holding power to change the experience of communities today through working with those who care about taking action. The Institute for Community Studies is powered by The Young Foundation.

#### **About the Institute for Community Research**

The Institute for Community Research founded in 1987 is dedicated to the conduct of research in collaboration with community partners to promote justice and equity in a diverse world. ICR supports innovative approaches to using research for social change by and with local communities locally and globally.

The Community Research Alliance, based at ICR, includes representatives of community based organizations, local community leaders and faculty of local universities committed to forging equitable and funded community conversations and research partnerships that collectively address inequities in health status and outcomes in the central Connecticut USA area.

#### **About the Boston Partnership**

In partnership with We Are Better Together Warren Daniel Hairston Project (WAB2G), researchers from Boston University examined community perceptions of vaccine distribution efforts in Boston though conversations with Black women on a sides of community violence.

WAB2G is a grassroots organization that connects and heals women and girls affected by homicide and incarceration to prevent the cycles of violence and victimization. WAB2G serves a diverse population of Black and Latinx women and their families. This includes incarcerated and formerly incarcerated individuals many of whom are experiencing or have experienced co-occurring mental health and substance use disorder (SUD). The majority of WAB2G clients live in the Boston neighborhoods of Roxbury, Dorchester, Mattapan and Hyde Park. Because of the ways in which systems impact women who experience SUD and/or violence, most of WAB2G woman are living in intergenerational families that include grandparents, adult children and grandchildren.

#### **Authorship**

**For ICS**: Emily Morrison, Caroline Stevens, Mikaela Springsteen, Sana Iqbal, Hamzah Zahid, Caitjan Gainty, Hazel Robertson and Alice Bell

For ICR: Jean Schensul, Joy Larson and the Community Research Alliance

For Boston: Linda Sprague Martinez, Samiya Hague, Sofia England, Ruth Rollins



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