

Mapping vaccine experiences to expose systemic issues in vaccine availability

RESEARCH INSIGHT

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SUMMARY

We used human-centered design to understand COVID-19 vaccine uptake challenges. Journey mapping revealed that systemic barriers, such as confusing distribution systems and lack of access to trusted healthcare providers, led to delays in vaccination among willing individuals. Difficulties in accessing vaccines can inadvertently contribute to what appears as hesitancy, highlighting the need for systems that support seamless vaccine delivery and clear communication. This approach highlights the importance of designing health systems that meet user needs effectively, fostering trust, and improving public health outcomes through responsive service design.

Key Words: Human-centred design; vaccine hesitancy; public health; equity; primary care

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INTRODUCTION

Although a highly efficacious and safe vaccine for COVID-19 reached the market in record time, only about 67 per cent of Americans were fully vaccinated one year after its arrival,¹ significantly fewer than the public health target towards herd immunity. Understanding this gap has been largely guided by the concept of vaccine hesitancy, defined as “the delay or refusal by individuals to accept vaccination despite availability”.² Over time the label of “vaccine hesitant” has been placed on all those who remain unvaccinated as vaccine hesitancy has become conflated with suboptimal vaccine rates.

When vaccine hesitancy is employed as the explanation for under-vaccination, it neglects causes related to access, the failure of services, or policies in some communities.³ Twenty-five per cent of people surveyed by Ratzan et al. reported being unvaccinated yet also receptive to the COVID-19 vaccine.⁴ In reality, there may be a host of reasons people may not be vaccinated that are not captured by the term vaccine hesitancy. Human-centred design (HCD) can interrogate the vaccine hesitancy narrative by framing vaccination as an experience, one that requires several steps including decision-making (eg, Is this vaccine right for me?) and navigation into possibly unfamiliar venues outside of primary care (eg, pharmacies or school gymnasiums). HCD activities are uniquely suited to identify the specific pain points in the entire vaccine experience, thereby illuminating the nature of needed interventions.

SUMMARY

Our Community Our Health St Louis (OCOH) is a pop-up vaccine clinic designed to provide vaccine services in neighbourhoods prioritised for vaccine outreach, and to those most disconnected from mainstream health care. Vaccine recipients and neighbours are regularly asked to participate in activities designed to learn about their vaccine needs and preferences, which directly inform clinic operations.

This embedded design work promotes continuous and bi-directional learning about how vaccination fits into people's lives.

We report here on our first design activity, which aimed to capture the entire COVID-19 vaccination experience of vaccine recipients at OCOH through journey mapping. We documented participants' experiences beginning with the moment they first heard about the vaccine up to when they received their first dose. Seven recipients spanning multiple demographic variables—including age, gender, and race—participated in journey mapping. Two of the seven participants were community health workers/outreach workers at the OCOH clinic. Staff trained in human-centred design conducted interviews that were audio-recorded, transcribed, and analysed using rapid assessment procedures for qualitative data.⁵ Washington University IRB (202304147) approved this research activity.

Four examples demonstrate the diversity of vaccine journeys and highlight the role of systemic barriers:

1. **Participant 1 (P1):** P1 did not fear getting sick with COVID-19 but was contacted by a primary care provider and encouraged to make a vaccine appointment, which led to vaccination. P1 had transportation and a flexible schedule to be able to make appointments, and consistently expressed the most positive feelings and feedback about the vaccine journey of all the participants interviewed.
2. **Participant 5 (P5):** P5 made a visit to their primary care provider (PCP) to inquire about the vaccine, and although the doctor recommended it, there was no vaccine supply at the office. This was very confusing and frustrating to P5, who attempted to follow PCP recommendations but was unsuccessful due to supply outages at pharmacies and difficulty navigating online appointment systems. P5 received the first dose, despite actively seeking it out, more than 18 months after it was first available, and noted this vaccine journey was worse than struggles living with a chronic medical condition.
3. **Participant 7 (P7):** P7 actively searched for the vaccine in response to strong recommendations from public health authorities in 2021 but struggled to find it despite having a flexible schedule and transportation. P7 compared their vaccine journey to “finding a needle in a haystack” and shared that their journey made them question the validity of the vaccine itself.
4. **Participant 4 (P4):** P4 was offered and accepted their first dose of the vaccine from their obstetrician while pregnant, but they struggled to get their second shot and complete their primary series due to, they said, “Things always getting in my way.”

LESSONS LEARNED

These illustrative examples from our findings show that despite a willingness and desire for the COVID-19 vaccine, some participants struggled to navigate the vaccine distribution system, thereby delaying their vaccination. Within the vaccine hesitancy framework, however, these participants are labelled as vaccine hesitant. Notably, the struggle to get vaccinated also produced frustration that could fuel genuine vaccine hesitancy. When participants received strong recommendations for vaccination and then experienced difficulty finding the vaccine, they felt significant frustration and began to question whether the vaccine was good for them.

We also found an important trend regarding the desired access point for vaccination. Of the three participants whose vaccinations were delayed more than one year after the vaccine became available, each would have taken the vaccine had their primary care doctor recommended it and had it available. Participants expressed willingness to accept a recommendation to get vaccinated from a healthcare provider with whom they had an established relationship, even while simultaneously expressing some doubts about the vaccine and its efficacy. Identifying people for whom this recommendation matters is an opportunity for primary care providers and designers to collaborate, as it is not solely related to any demographic factor.

HCD methods problematise system design, not patients, to frame health challenges and capture the entire experience of accessing health care. Journey maps expose where and how the system is unable to provide a complete service, from start to finish. Our findings show that counter to traditional narratives that centre vaccine hesitancy with individuals, system gaps in the vaccine distribution landscape generate confusion and doubt. When complicated and limited access to vaccination followed urgent public health recommendations, disinvestment and doubt in the value of vaccination ensued and concern already circulating in communities increased.

CLINICIAN INSIGHT

Improving vaccine uptake globally: we know what to do, we just need to do it together.

There is no doubt that a lack of uptake of vaccines across the world is a major public health issue.^{1,2} There are several very good publications supporting the authors' view that journey mapping of individuals, groups, and populations can assist in developing effective interventions tailored to improved vaccine uptake.^{3–5} (The comprehensive review of mapping across 149 countries by de Figueiredo et al. is particularly good.³) One of the main barriers noted was vaccine hesitancy.

Vaccine hesitancy (or vaccine refusal) is not new, dating back to the first smallpox vaccinations in the early 18th century.^{6–7} However, the pervasive nature of misinformation, myths, and uninformed influencers flooding social media, has led to significantly lower vaccination rates globally, which is now “threatening historical achievements in reducing the burden of infectious diseases”.^{6–8} Evidence shows that a lack of trust in the healthcare system, cultural and religious beliefs, social and political influences, access issues, and past negative vaccine experiences also impact vaccine uptake.^{6,9,10}

Research has also provided some insight into how to improve the uptake of vaccines. For example, there is strong evidence that physicians who have (or gain) the trust of patients are more likely to be successful in vaccine uptake.^{11,12} Other facilitators noted were positive attitudes and information-seeking behaviours, approaches tailored to local needs, culturally and socially sensitive approaches, and proactively promoting the benefits of vaccines via social media platforms using trusted sources.^{3,9,11}

Clearly, much work is still to be done in reversing the growing trend of lower vaccine uptake. Fortunately, there is a plethora of excellent research being conducted across the globe, with encouraging results. The authors are adding to that important research. The key now is open and effective collaboration on a local, country, and global scale.

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The coauthors made the following contributions:

- AT conceptualised, planned, and conducted the study, took part in analysis, and drafted the manuscript;
- AM undertook data cleaning, took part in analysis, and reviewed the manuscript;
- AG conceptualised and conducted a portion of the study, and reviewed the manuscript;
- HB, AB, and EG advised on the study, took part in analysis, and reviewed the manuscript; and
- BM conceptualised, planned, and conducted the study, took part in analysis, and drafted the manuscript.

PEER REVIEW

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CONFLICTS OF INTEREST

The authors declare that they have no competing interests.

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ETHICS COMMITTEE APPROVAL

None