

Challenges in Patient Engagement during the COVID-19 Pandemic



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Capturing the minority patient voice

The current landscape

Healthcare in the UK and other developed countries has had to adapt to novel ways of engaging with patients during the COVID-19 pandemic. Healthcare professionals (HCPs) are increasingly reliant on reaching patients via digital channels and have been able to pivot and switch to telehealth offering where possible.¹ The UK has seen GPs offering a triage system of screening patients over the phone or via an app, with an in-person follow-up offered only to those that need it.² There are also online portals where patients can ask for repeat prescriptions or to even check test results. Similarly, in the US, direct to consumer medicine has seen exponential growth especially since the pandemic.³

This does place a spotlight on disproportionate care for certain patient groups. The health inequality gap existed well before the COVID-19 pandemic, driven by a lack of trust with HCPs, cultural factors (e.g., religious belief), stigma around certain health issues, linguistic barriers, and misinformation.^{4,5} It appears the pandemic is further widening this health inequality gap.⁶

Patients from black and minority ethnic (BAME) groups have already been affected by the pandemic significantly more so, with COVID-related deaths estimated to be 10-50% higher amongst BAME groups compared to White British.⁷ As the pandemic changes how healthcare is delivered, this could further disadvantage those from minority backgrounds, even if they do not contract COVID-19.

And what of those who have a relatively low digital literacy or those from lower socio-economic backgrounds? Patients need to have the necessary hardware to access some of these digital systems, as well as the inclination and ability to engage with HCPs using technology. It is clear that there are many barriers still to be addressed in order to connect effectively with all patients.

The importance of capturing the minority patient voice

To adopt a truly patient centric strategy, healthcare companies and health systems need to understand the voice of the harder to reach patient. These patient cohorts often have the greatest unmet needs, and it is important that any future innovations, communications, services or support structures truly understand the perspectives of these communities and lower socio-economic groups. Furthermore, these minority groups are not a homogenous monolith, each patient journey is unique, and it is the researcher's responsibility to capture this. Healthcare services and pharma companies have already adopted novel approaches when attempting to connect effectively with niche patient groups. Community outreach (via primary

¹ <https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-020-09301-4>

² <https://www.theguardian.com/world/2020/mar/06/gps-told-to-switch-to-remote-consultations-to-combat-covid-19>

³ <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2773813>

⁴ <https://www.thelancet.com/journals/lancet/article/PIIS0140-67361632312-1/fulltext>

⁵ <https://blogs.bmj.com/bmj/2020/10/08/covid-19-and-ethnicity-how-the-information-gap-exacerbates-inequality/>

⁶ Macaninch E, Martyn K, Lima do Vale M. Exploring the implications of COVID-19 on widening health inequalities and the emergence of nutrition insecurity through the lens of organisations involved with the emergency food responseBMJ Nutrition, Prevention & Health 2020;bmjnph-2020-000120. doi: 10.1136/bmjnph-2020-000120

⁷ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/908434/Disparities_in_the_risk_and_outcomes_of_COVID_August_2020_update.pdf

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care facilities, PCPs or even at places of worship⁸), bilingual services, education and training for HCPs and social media outreach are just a few approaches that can help engage patients. The success of these innovations and engagement strategies can only be enhanced by digging deeper into the attitudes, behaviours, and unmet needs of these harder-to-reach patient populations.



The challenge of capturing the minority patient voice

Like the challenge's healthcare professionals encounter whilst recruiting patients for clinical trials, researchers also face barriers and challenges to accessing harder-to-reach patients for qualitative and quantitative insights. Typical recruitment mechanisms rely on social media campaigns (e.g., through Facebook or Twitter), via patient advisory groups or potentially through HCP referrals. Whilst these channels are useful with identifying patients, are we biasing the sample and omitting the voice of important patient minority groups or those from lower socio-economic backgrounds who might not have access to internet enabled devices?

To capture insights which are more reflective of the whole patient population, mechanisms need to be in place to connect successfully with the right people. By understanding the nuances in the difficulty of engaging with patient groups, researchers can apply these learnings to patient recruitment. For example, expanding recruitment methods further to find different routes to engage with minority patients. Advertisements on non-health related websites or social media sites or even engaging directly with prominent members of a community may help encourage recruitment further. Adapting materials such as recruitment screeners or research invitations to make them more culturally appropriate or even providing it in more than one language will certainly help increase outreach. Perhaps establishment of strong relationships with minority-

⁸ <https://www.england.nhs.uk/2021/01/nhs-delivers-covid-jobs-from-cinema-and-mosque/>

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serving physicians might increase outreach further and at the very least, yield minority patient referrals.⁹

By adopting some of these practices in a recent rare disease study across the US and EU5, 7i Group and their fieldwork partners not only reached rare disease patients, but also ensured fair representation of the patient population within the given markets.

Conclusions

Capturing patient insights can drive strategy and create tactics to improve patient experience, quality of life and health outcomes. Patient insights can help inform many aspects of care e.g., clinical trial set-up, engagement/activation in a certain indication, patient treatment preference, and patient journey. Healthcare services and pharmaceutical companies can use this information to improve patient services/care, patient support programmes and tailor treatments to help suit patient needs.¹⁰ Health Technology Assessment bodies such as NICE require patient insights to be included in a submission, but this movement has been seen across the industry as well e.g., ISPOR Special Task Force, Patient Council.^{11,12} Therefore, as researchers it is paramount that we can continue to reach patients so that their voices can continue to be heard and their knowledge and expertise are valued and harnessed for better research but ultimately for better health outcomes.

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⁹ Amorrortu RP, Arevalo M, Vernon SW, et al. Recruitment of racial and ethnic minorities to clinical trials conducted within specialty clinics: an intervention mapping approach. *Trials*. 2018;19(1):115. Published 2018 Feb 17. doi:10.1186/s13063-018-2507-9

¹⁰ The UK Rare Diseases Framework. Department of Health & Social Care. Published 9 January 2021.

¹¹ <https://www.ispor.org/strategic-initiatives/patient-initiatives>

¹² Bouvy JC, Cowie L, Lovett R, Morrison D, Livingstone H, Crabb N. Use of Patient Preference Studies in HTA Decision Making: A NICE Perspective. *Patient*. 2020 Apr;13(2):145-149. doi: 10.1007/s40271-019-00408-4. PMID: 31942698.