

Policy Brief

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Cultural barriers to patient empowerment: Insights from the PatientsEngage digital health platform in India



Image from PatientsEngage digital platform

INTRODUCTION

Digital health platforms enable members of the public to access health information, monitor their conditions, and even receive online consultations or treatment. They also allow patients and carers to interact, sharing experiences that could otherwise be difficult to discuss. This is particularly important for patients with rare medical conditions, who might be physically dispersed or psychologically isolated.

Existing research has explored the role of digital health platforms in empowering patients in Western countries (Petrakaki et al, 2018). However, there is limited research about how such platforms interact with national cultures, and the implications for our understanding of patient empowerment in the Global South. To address these questions, researchers from the University of Sussex interviewed users, employees and directors of India's digital health platform PatientsEngage.

FINDINGS

PatientsEngage, a for-profit social enterprise, was established in 2013 with the purpose of informing and empowering patients. Although the platform was set up in Singapore, its users come primarily from India, where the health information gap is wider. PatientsEngage focuses mainly on providing information about the management of chronic conditions, such as diabetes, which often pertain to lifestyle choices. It also provides health information and advice on a wide range of medical conditions, and includes forums to enable interactions and information exchange. The health content is first reviewed by medical experts and then published by moderators with expertise in health journalism.

PatientsEngage fills a significant gap in Indian society (and perhaps across South and East Asia) by offering health information that is of relevance

Key findings and recommendations

- Digital health platforms should do more to empower patients, beyond simply providing information.
- The digital health platforms of the Global North have questionable relevance and significance to patients based in countries of the Global South.
- Patient empowerment has a fluid meaning that is conditioned by cultural factors including language, family relations, stigma and openness.
- Directors of digital health platforms should aim to make all content accessible, to embrace local cultures, to focus on education and capacity-building, and to keep content independent from any commercial interests.
- Health policymakers should recognise the value of digital health platforms in educating patients, helping them manage conditions, and addressing health illiteracy in the Global South. To enable this important work, and to ensure independence, governments should consider subsidising platforms.

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and significance to the users. Many other health platforms provide information from a Western perspective (Petrakaki et al, 2023). Dietary advice, for example, might not align with Indian lifestyles, and thus might be rendered irrelevant,

Our study found that PatientsEngage has succeeded in raising patients' and carers' awareness of health issues, helping them to ask questions, make effective choices and become empowered as they deal with their condition, and with carers and medical specialists. A single platform, however, cannot effect systemic changes. Our interviews identified several cultural barriers to patient empowerment, as described below.

LANGUAGE AND ACCESSIBILITY

India's population is one of the largest in the world, with 1.2 billion people speaking around 122 major languages, 22 of which are considered official languages (Census 2011). Platforms whose health content is solely in English may reach only 10-15% of the population, typically the most educated people with the highest socio-economic status. Some research participants argued that the choice of English language creates an elitist approach to health that exacerbates social issues and creates a digital divide. Lack of access to understandable content restricts patients' ability to be informed and thus empowered.

"The English-speaking population is a very small minority of the entire Indian population. This automatically restricts the audience to only the English-speaking audience from the cities. So the vast population is getting missed out - those who are in the rural, or those who are in other places who don't know English, and even Hindi."
(Interviewee 21).

To counter such problems, PatientsEngage presents content in Hindi as well as English, and offers an audio option for its articles. To reach people who are less educated, it aims to build health literacy through webinars and video interviews.

FAMILY RELATIONS

Western concepts of empowerment are attached to notions of individualism. They assume an active subject who seeks to be empowered through information. Yet in India, family relations constitute an inextricable part of an individual's identity and thus also their health. Families are places of care. Healthcare decisions and lifestyle choices are shaped by complex family relations within a patriarchal society. For example, decisions about medical treatments are taken by the breadwinner of the family – the father or the husband.

Our study found that interactions with the health platform were affected by this family approach to health. Some patients, for example, might see such platforms as redundant because socialisation takes place within the family space. Others might censor what and how much health information they share on the platform for fear of stigmatising their family members.

"So ultimately, you see, it is not a health platform that will support you later. It is the family. You have to live with them. You can't afford to offend them. And this will affect obviously the way the content is presented by the persons

giving first-hand stories...

If you look at a whole range of stories from any platform, including PatientsEngage, but any place where the stories are coming from India and are named stories, it is extremely rare to find someone talking against their family."
(Interviewee 7).

STIGMA AND OPENNESS

Patient empowerment also relates to a willingness to share information with peers about how a condition and its treatment is experienced. Such sharing presupposes a culture of openness, that is not characteristic of Indian society. Health information is not considered easy to share because of stigma. As Interviewee 10 stated: *"It is considered taboo to be sick."*

"Reaching out to somebody unknown is...not a done thing. You don't talk about your problems to people outside. That is the cultural context in which Indians, families, usually operate".
(Interviewee 10)

Information about certain medical conditions might be difficult to share on a public platform as this might create embarrassment for patients and their family members. For example, lung cancer might be perceived as a condition resulting from a patient's irresponsible behaviour, such as smoking. Experience of the treatment of cervical cancer might be embarrassing for a woman and damaging for her future marital prospects.

Nevertheless, interviewees argued that it is important to share patients' health experiences in order to create platform content that aligns with Indian culture, instead of relying on information shared on Western platforms, which reflects different values and traditions.

"The Western world sometimes is not always relevant to us. The issues are also not relevant. So there are a lot of support groups that are now online, you get a lot of stuff, but then those issues are not necessarily relevant to India. So our website is more India-specific. And we want to talk about issues that are pan-India now."
(Interviewee 6).

PatientsEngage aims to address these challenges by enabling patients to share experiences of managing chronic conditions, and by running patient advisory board meetings and health campaigns to challenge the stigmatisation of poor health.

RECOMMENDATIONS

The findings from this study are important for the directors of health platforms operating in the Global South and for health policymakers. Our key recommendations are as follows:

FOR THE DIRECTORS OF PLATFORMS

1. MAKE CONTENT ACCESSIBLE

Platforms could offer content in languages other than English and Hindi, in order to reach a wider population. Often linguistic translation of content might not work, and further curation of information might be needed.

Given the strong mobile infrastructure and high mobile phone penetration in Indian households, platforms could reach people in rural areas through brief videos presented in different languages. PatientsEngage has experience of communicating in this way: during the Covid-19 pandemic, it worked with local NGOs in 15 states of India to publish health information posters in local languages.

Even these interventions might still leave out a considerable proportion of the population. Working outside the platform and through in-person forums might be a way to inform and empower patients more widely. For example, PatientsEngage volunteers might continue acting as ambassadors, connecting people in non-digital ways.

2. EMBRACE LOCAL CULTURE

Research participants identified important differences between Western platforms and Indian culture and values. It is vital that platforms remain relevant by reflecting those values. In India, for example, it is important to incorporate what is unique about Indian culture, including the importance of family relations. Empowerment in this case is not confined to the individual patient, but also involves all family members.

There may also be lessons to learn from other digital platforms, for example, Zomato - the much acclaimed food delivery service.

This also relates to the local customization literature that firms regularly have to produce while doing business globally.

3. FOCUS ON EDUCATION AND CAPACITY-BUILDING

Health platforms can play an important educational role by helping patients and carers to better understand the impact of a condition on their lives. They can also work to raise awareness, especially about conditions that are stigmatised, such as mental health or cancer, and can help patients to become better prepared during consultations with doctors. Platforms should aim to improve and promote their educational value.

Creating clinical guidelines standards is also important. An example is the work of PatientsEngage with the Wellcome Trust India Alliance IHOPE center in Hyderabad, India (www.ihope2020.org) to upgrade local clinical guidelines.

4. MAINTAIN INDEPENDENCE

Interviewees expressed the importance of keeping the health content of PatientsEngage independent of any commercial interests and allowing individuals to participate without charge.

Independence is fundamental for establishing a trustworthy relationship with patients and for widening the user base. This is an important lesson for the business models of patient-centered digital health platforms.

FOR HEALTH POLICYMAKERS

- Digital health platforms have proven to be a valuable asset to educate patients, carers and families about medical conditions, their management and their impact on people's lives.
- To maintain independence, platforms need to be recognised and potentially also subsidised for undertaking this important but implicit duty of care.
- Digital health platforms constitute an important tool to address health illiteracy in countries of the Global South.

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ABOUT THE PROJECT

This briefing paper presents the findings from 21 in-depth semi-structured interviews with a range of stakeholders involved in the PatientsEngage platform. Interviewees included the platform's founders and Director; moderators; patients and carers who use the platform; and platform advisors.

The study was conducted between June and December 2022 by Professor Dimitra Petrakaki and Dr Chirantan Chatterjee at the University of Sussex with the support of the University of Sussex Business School and the ESRC-funded Digital Futures at Work Research Centre (Digit).

Dr. Hong Yu Liu was involved in data collection.

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