Challenges of implementing an integrated electronic health record system in the Breast and Endocrine Clinic at Tygerberg Hospital, Cape Town, South Africa

To the Editor: In low- to middle-income countries, the majority of patients with breast cancer are diagnosed with locally advanced disease. This remains a problem at the Tygerberg Hospital breast clinic in Cape Town, South Africa, with ~60% of all patients presenting with stage 3 or 4 disease at the time of diagnosis. The reasons cited are multiple and include fear, unawareness of disease severity, concerns surrounding losing a breast, unreliable transportation, referral difficulties and financial constraints.^[1]

Communication between the various stakeholders in healthcare is affected by how information is exchanged between the healthcare professional and the patient, different disciplines, caregivers and the community. Poor communication has far-reaching effects, including discontinuity of care, wasting finite resources, and compromising patient safety.^[2]

An initiative, Patients Know Best (PKB), was started in the UK in 2008 to address this issue. PKB serves as an integrated digital care record. It operates as an internet-based platform for sharing information with healthcare providers spanning diverse organisations. PKB is individualised through personal email addresses and gives patients the power to approve who can access and input information to their profile. A team is currently implementing PKB in the breast clinic at Tygerberg Hospital. This letter explores the challenges we have encountered during the early implementation phase.

Firstly, the patient requires a functioning email address to be invited to, and ensure continued access to, the PKB platform. We conducted an informal survey which revealed that a minority of patients attending the clinic have an individual email address. Patients without their own email addresses therefore have to use that of an immediate family member to sign up.

Secondly, accessibility is further obstructed by the absence of reliable internet connectivity. This problem has been rectified with the installation of a new internet connection in the clinic.

Another challenge that we have encountered is over-reliance on individual people. Consequently, when key players are unable to fulfil their duties, the entire process is halted. In our quest for technological advancement, a few enthusiastic individuals have championed progress, while the system has been slower to adapt to and accept change. The default response in challenging situations is returning to the pre-existing system. Going forward, we have committed to integrating change management principles into the implementation process to allow for sustainable change.

To improve patient buy-in and uptake, we created an informational video detailing the purpose, history, sign-up process and applications of PKB. It plays in the patient waiting area prior to consultations.

Navigating the linguistic diversity of our environment is crucial to ensure that all patients receive information in a form that they understand. Communication barriers due to language have been addressed by all interactions being translated into isiXhosa and Afrikaans.

So far, we have been pleased by the patient interest and enthusiasm surrounding PKB. Despite the barriers mentioned above, many patients were eager to interact with the digital platform and take a more active role in their healthcare.

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