

## **Knowledge is Power – Surveying Patients’ Understanding During HSE IT Shutdown**

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Dear Editor,

The shutdown of HSE IT systems in response to a ransomware attack brought our dependence on the electronic health record and online resources into sharp focus.

When faced with outpatient department (OPD) cancellations, our department contacted patients scheduled for review where a contact number could be obtained, to ascertain whether patients scheduled for OPD needed urgent review (before IT services could be expected to be restored).

Our hospital uses a “paper-light” system, in which most patients have had their paper records digitised and stored on an Electronic Health Record accessible throughout the hospital. As such, we did not have access to historic notes, correspondence, referral letters or investigations. We relied on patients to inform us of their reason for attending the dermatology OPD (in a tertiary referral centre), their diagnosis and current treatment. We took the opportunity to survey our patients’ understanding of their reason for attending OPD and their subsequent diagnosis and treatment.

Research has demonstrated that healthcare professionals’ understanding of their patients’ health beliefs differs from the patients’ actual beliefs<sup>1</sup>. Nineteen patients across two scheduled OPDs were contacted by phone in a two-day period. Patients were consented to take part in a survey regarding understanding of their condition. Sixteen patients (84%) were aware of reason for referral to OPD. With regards their subsequent diagnosis, four patients (21%) were awaiting results of investigations before a diagnosis was confirmed. Of the remaining patients, nine (60%) were unaware of their diagnosis. Regarding treatment, five (26%) of the patients were not currently being treated. Nine (64%) were aware of their treatment – medication name and frequency, though not always aware of doses. Five (36%) were unable to name the treatment prescribed for them.

Communication between healthcare professionals and patients is complex. A healthcare professional may leave an encounter with the impression that a diagnosis and treatment plan have been clearly explained. However, studies have revealed that patients often do not agree, and may not understand the plan going forward. This in turn affects outcomes, including adherence to treatment, recovery and future relationships with healthcare providers<sup>2</sup>.

Patient-held health records have been extensively studied but are not commonly employed in the Irish system – one notable exception being antenatal joint-care. Studies have shown that patient-held records can be of practical and psychological benefit to patients – giving patients an accessible record and empowering them to participate in discussions and decisions<sup>3</sup>. Patient-held records (used in conjunction with the current system of hospital-held records) would not only prove useful during an IT shutdown, but in situations where records created elsewhere are not accessible, by acting a point of reference for coordination of patient care - particularly given the fact that patients with complex health issues may be cared for in multiple hospitals, which in Ireland do not share a single electronic record.

This ransomware attack has highlighted wider issues in our healthcare system. Lessons need to be learned and acted upon going forward, notably the importance of effective communication, and of patient centred care.

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