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Digital interactive patient reported outcome measures for long term conditions

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There are more than 15 million people with a long term condition in England alone.[1] Healthcare providers around the globe are facing the challenge of providing high quality services for these individuals and constantly evaluating whether these services are effective and offer value for money. There is a need to make the evaluation easier, in real time, and interactive between individuals, clinicians, and care providers. Digital Patient Reported Outcome Measures (PROMs) enable individuals' outcomes to be captured on their smart devices, relaying the information to their clinicians, and linking the outcomes directly to the healthcare records. In our view, there is a need to adopt this approach within all services for long term conditions.

Long term conditions for which this would be helpful include cardiovascular problems, chronic respiratory conditions, arthritis, neurological conditions or long covid. Countries spend up to 70% of their health and social care expenditure on caring for individuals with long term conditions.[1] PROMs are questionnaire tools to ascertain individuals' views of their symptoms, their functional status, and their quality of life.[2] The use of PROMs in the routine clinical management of long term conditions engages individuals in their care; allows healthcare professionals to monitor condition progression and tailor care to individuals' needs; and enables healthcare providers to assess the cost-effectiveness of services to treat long term conditions.[3][4] A nationally agreed standardised core set of PROMs enables the comparison of outcomes between different interventions and different service providers.

The use of digital PROMs is gaining acceptance and popularity due to their ease of administration. Individuals can complete the questionnaire tools on their smart devices in their own time thereby reducing the burden of the conventional practice of filling paper forms and services manually uploading these onto healthcare records. There is substantial evidence on the use of digital PROMs in research studies involving long term conditions such as diabetes, cancer, arthritis, COPD and mental health problems.[5 -7] There is a compelling case for the use of digital PROMs at a national level to gather uniform routine PROM data from services for treating long term conditions.

Digital PROMs allow individuals to self monitor and have a record of their assessments at various time points, to understand the trajectories of conditions, and to monitor responses to any treatment they receive. Real time assessment of symptoms allows clinicians to understand patients' changing needs better and direct appropriate treatments (sometimes even remotely). The collected information can be viewed by multiple teams saving the patient time and energy and avoiding duplication of work. The PROM data allow services to self evaluate their programmes and healthcare providers to justify the allocation of resources to improve services. Most digital platforms will also auto analyse the collected data and provide individual level or service level summary reports, reducing the resources needed for traditional data collection and analysis methods.[8]

There are however some limitations to this approach. The effective and timely rollout of any digital platform or registry requires complex regulatory hurdles around governance and procurement to be met within the healthcare system. The service information governance around the handling of data will need non-standardised Data Protection Impact Assessments (DPIA) approvals. Conformity to various data and healthcare-related national standards and certifications, such as the Data Security Protection Toolkit and CyberEssentials, is essential for all parties involved in the handling of patient data to prevent data breaches and meet standards to protect patient data from falling into the wrong hands. Response rate and completeness of digital PROM data can be limited by responders' digital accessibility and engagement issues, potentially increasing healthcare inequality.[9]

Modern healthcare systems need to invest in digital PROM platforms to empower individuals with long term conditions and their families and carers; personalise treatments and make the gathering of standardised PROMs across services easier and less burdensome. Such a uniform approach also helps evaluate and compare services, benchmark standards of care, and foster research to improve care and outcomes for individuals with long term conditions.

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