

Implementing standardised patient-reported outcomes measures into a population-based electronic personal health record for diabetes



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Background: Diabetes prevalence is rapidly increasing globally and effective interventions are required to mitigate the associated spiralling individual and health service costs. The need for well-structured information to support global monitoring and continuous quality improvement in diabetes has been addressed effectively by ICHOM, delivering a standard dataset in November 2018. The resulting data dictionary included a range of case-mix variables and clinical outcomes, plus three patient-reported outcome measures (PROMs): The World Health Organization-Well-Being Index (WHO-5), the Patient Health Questionnaire's depression module (PHQ-9) and the Problem Areas in Diabetes (PAID) Scale for diabetes distress.

My Diabetes My Way (MDMW) is Scotland's interactive website and mobile app for people with diabetes and their carers, with over 50,000 individuals registered. It contains multimedia resources for diabetes education, structured eLearning courses and offers access to electronic personal health records (ePHR). The aim of MDMW is to support diabetes self-management, enhance communications between people with diabetes, their carers and healthcare teams and to support shared decision-making. The MDMW ePHR is well established and has been available for use by all >310,000 people with diabetes in Scotland since late 2010.

Aims: We aimed to implement and assess the results and data collected through new functionality to support patient-reported outcomes measures (PROMs), based on the ICHOM standard diabetes dataset. PROMs had not previously been added to MDMW due to a lack of consensus regarding which questionnaires to use.

Methods: PHQ-9 and WHO-5 were implemented as part of the MDMW ePHR core functionality, adding to previous functionality allowing patients to directly record their home test results and personal goals. Both questionnaires were launched in August 2019 and awareness was raised to existing registrants through the MDMW monthly email newsletter and via social media channels. Users must log-in to the service to access the questionnaires so that results can be tracked and monitored. Once a form is completed, patients are given guidance and advice on further follow-up and actions, which in some cases may recommend that the patient contacts their healthcare team for further support.

Results: A total of 793 patients completed at least one PHQ-9 questionnaire with an average of 146 forms submitted per month since launch (total forms submitted=875). Based on the last observation for each patient, 344 subjects (43.4%) showed no signs of depression, 162 (20.4%) mild signs, 109 (13.8%) moderate, 88 (11.1%) moderately severe and 90 (11.4%) severe.

A total of 605 patients completed at least one WHO-5 questionnaire with an average of 111 forms submitted per month since launch (total forms submitted=666). 320 (52.9%) respondents indicated no signs of poor wellbeing, however 285 (47.1%) indicated reasons for follow-up, based on the criteria of a score below 13 or if the patient answers at least one question in the lowest 2 categories.

Discussion: This is the first time PROMs data have been analysed within the context of Scotland's national diabetes population. The application within MDMW showed that people with diabetes can remotely monitor their psychological wellbeing and depression status on a routine basis.

Conclusions

These positive results encourage further PROMs implementation plans in future. These developments can potentially apply the ICHOM standard dataset to the entire population of Scotland. This implementation would enhance further opportunities for broader adoption of PROMs into electronic health records and application of value-based care in chronic disease conditions.

Acknowledgements

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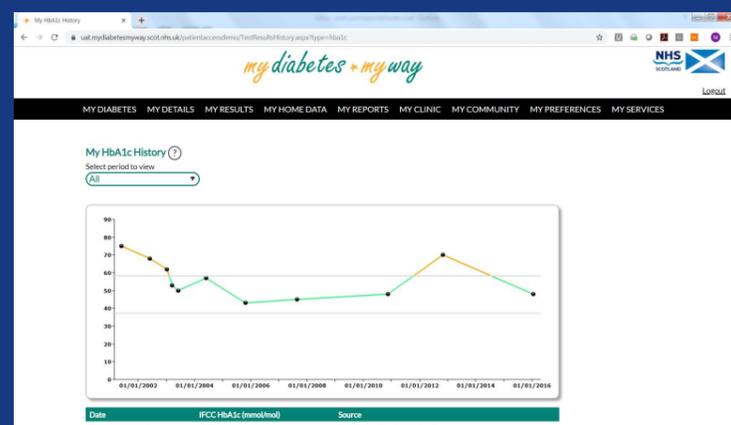


Figure 1: System screenshot from My Diabetes My Way

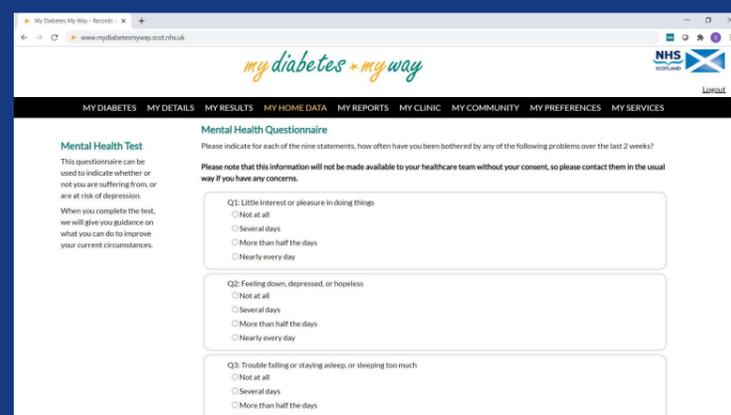


Figure 2: PHQ-9 Questionnaire

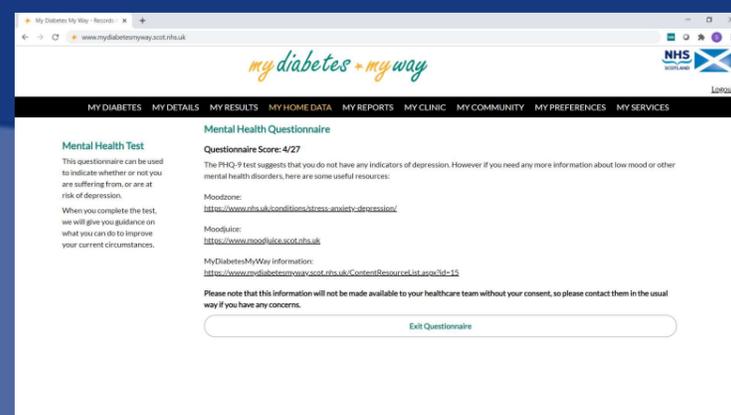


Figure 3: PHQ-9 summary results with guidance and signposting to further help and resources