My Diabetes My Way: Clinical Outcomes Impact and User Experiences of an Electronic Personal Health Record for Diabetes

SG Cunningham, B Allardice, M Brillante, L Wilson, DJ Wake

My Diabetes My Way (MDMW) is NHS Scotland's interactive website for people with diabetes and their carers, currently with over 30,000 registrants. It contains multimedia resources aimed at improving self-management, including information leaflets, interactive educational tools and videos. MDMW offers access to clinical data via a novel electronic personal health record, which sources data from primary care, secondary care, specialist screening services and laboratory systems. This merged record provides a more complete overview of diabetes than is available from any single data source. Patients set and record goals and receive automated highly-tailored advice and guidance based on the current status of their results.

Aim: We aimed to evaluate user experience of the records access service and assess impact of MDMW on routinely collected process outcomes.

Methods: In January 2015, an online evaluation survey was emailed to 3,979 active users to assess experiences and benefits. Survey Monkey was used to capture results, using a series of open and closed questions. In April 2017, clinical outcomes were assessed using time-series analysis by comparing the HbA1c recordings of the intervention cohort (active users) with those in the inactive background patient population, matched by age, duration of diabetes, socioeconomic status and gender.

Results

1,095 (27.5%) of active users contacted completed the survey. Key results regarding use and experience of MDMW records access were as follows:

- 92.1% - system contains all expected features
- 87% - access act as a reminder of information discussed at consultations
- 89.6% - helps make better use of consultation time
- 85.2% - don't need to phone doctor for results; 89.1% - system was easy to use
- 94.2% - supporting information helped to understand results better
- 93.7% - helped find information tailored to own diabetes
- 95.9% - graphs helped monitor changes over time
- 96.7% - confident the system was secure; 88.2% - helped manage diabetes better
- 90.3% - improved knowledge; 89.3% - improved motivation
- 89.8% - system helps patients to set their own goals

1,892 active users of MDMW had 3 or more year's follow-up data since first login. Patients with type 2 diabetes not treated with insulin ($n=943$) showed most significant and sustained changes ($p<0.001$). In this group, the intervention cohort reduced from 59 to 54 mmol/mol (females) and 58 to 53 mmol/mol (males) within 1 year, while the matched cohort reduced from 58 to 57 mmol/mol (females) and 58 to 57 mmol/mol (males) during the same period. Intervention patients remained between 4 mmol/mol (females) and 3 mmol/mol (males) below their matched counterparts at 56 mmol/mol after 3 years of follow-up, showing a significant ($p<0.001$) sustained reduction.

Discussion

History graphs and tables allow individuals to track changes over time from multiple electronic sources. Data items contain links to detailed descriptions, explaining reason for collection, and what 'normal' values are, providing education and context.

MDMW aims to provide highly tailored information for users allowing them to make best use of consultation time. These features allow people to take control of their diabetes and become more empowered to enhance their self-management and care. During October 2017, MDMW reached the milestone of 16,000 active users

Users demonstrate statistically significant Improvements in HbA1c when compared to a matched cohort of non-users

Conclusions

MDMW is an effective low-cost population-based self-management intervention. Patients report enhanced knowledge and understanding of diabetes and motivation to make positive changes following MDMW use. The service is acknowledged as a key resource to help achieve strategic aims for the diabetes population in Scotland. We are actively pursuing opportunities to extend the service into other parts of the NHS and overseas.

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Contact: scott.cunningham@nhs.net

www.mydiabetesmyway.scot.nhs.uk