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MyDiabetesMyWay: An Evolving National Data Driven Diabetes Self Management Platform

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Abbreviations: MyDiabetesMyWay (MDMW), Scottish Diabetes Research Network (SDRN), electronic personal health record (ePHR), Telemedicine (TM), Blood Pressure (BP), Body Mass Index (BMI), estimated glomerular filtration rate (eGFR), Haemoglobin A1c (HbA1c)

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ABSTRACT

MyDiabetesMyWay (MDMW) is an award winning national electronic personal health record and self-management platform for **diabetes** patients in Scotland. This platform links multiple national institutional and patient-recorded data sources to provide a unique resource for patient care and self-management. This review considers the current evidence for online interventions in diabetes and discusses these in the context of current and ongoing developments for MDMW.

Evaluation of MDMW through patient reported outcomes demonstrates a positive impact on self-management. User feedback has highlighted barriers to uptake and has guided platform evolution from an education resource website to an electronic personal health record now encompassing remote monitoring, communication tools and personalised education links.

Challenges in delivering digital interventions for long-term conditions include i) integration of data between institutional and personal recorded sources to perform big data analytics, and ii) facilitating technology use in those with disabilities, low digital literacy, low socioeconomic status and minority groups. The potential for technology supported health improvement is great, but awareness and adoption by health workers and patients remains a significant barrier.

Introduction

The use of online interventions for diabetes care is increasing, alongside a political drive towards e-health initiatives (1), despite limited robust evidence relating to clinical outcomes. E-health is a term coined in the late 1990s to encompass convergence of the internet and health care. The definition is constantly changing but generally covers user interaction with health data through online systems, cross transfer of data (often between institutions or systems) and user to user communication. Traditional users of e-health are health institution staff, but a new wave of e-health initiatives directed at patients brings exciting possibilities (2).

More cost-effective diabetes management is needed, and technology could be key to care delivery and diabetes prevention. Around 8-9% of the global population has diabetes (3). Health expenditure for diabetes is increasing dramatically. The total health care costs of a person with diabetes in the USA are twice to three times those for people without the condition (4). In the UK, annual spending on diabetes is expected to reach 17% of the entire NHS budget over the next 20 years (5).

Around 40% of the world population is now internet-connected (6) rising to around 84% in higher economic countries, like the UK (2015)(7).

Mobile phone and tablet use in the UK has increased from 30% in 2013 to 41% in 2014 (7) associated with increased use of apps, remote monitors,

fitness devices and environmental sensors (8,9). Healthcare system data quantity is also increasing exponentially, although it often remains in silos and its true potential thus never realised. Good data linkage and timely data availability to front line health staff has the potential to transform care delivery (10–12). This vision is highlighted in key political reports (13,14) making data and technology use in diabetes care a key priority. As informatics systems mature in their ability to connect and transform data, their outputs can become increasingly personalised, driving individualised support, advice and real-time decision making.

This will become more apparent with the advent of the “Internet of Things” (15) opening up further linkages to community devices containing sensors and electronics. This forthcoming tsunami of health related data will move into the realm of genuine ‘Big Data’, requiring ‘Data Science’ approaches to extract meaning and useful knowledge (16). Artificial intelligence techniques will increasingly be used to predict future events from data patterns, allowing early intervention. This level of informatics maturity could have particular benefits for self-management and complications prevention in long-term conditions (17,18).

Aims

In this article, we discuss

- i) the evidence for e-interventions in the management of diabetes, and

- ii) the development and evaluation of MyDiabetesMyWay (MDMW): Scotland's national electronic personal health record (ePHR) and self-management platform for diabetes.

Background Literature; Diabetes Web based Interventions

Web based interventions for people with diabetes are further categorised here, however in reality many interventions are complex utilising multiple technology approaches:

- **m-health** (abbreviation for mobile health) has increased the reach of e-health and describes use of mobile and wireless technologies to support the achievement of health objectives (19). m-health uptake is largely dictated by mobile phone and wireless signal availability. In diabetes care, interventions range from simple SMS texting to more sophisticated app based products.
- **Social media** (computer- mediated tools that facilitate the sharing of information) has transformed the way people live, work, shop and socialise and is an emerging aspect of e-health (20). There is a very active online diabetes social media community utilising global and local networks(21).
- **Telemedicine** utilises remote video consultation/ monitoring increasingly provided through software based tools
- **Remote glucose monitoring** utilises data sharing from internet linked blood glucose meters with or without external feedback.
- **Electronic personal health records** (ePHRs) are data repositories used to securely store and manage personal medical

information for tracking and monitoring purposes. ePHRs come in three main categories:

- Stand-alone: unconnected to any external system, containing solely patient-recorded health information
- Tethered: a view into an electronic medical record or a subset of its data, in some cases containing functionality to request medication and appointments and to communicate with physicians (22)
- Interconnected/integrated: collecting data from multiple data sources while incorporating bi-directional communications and functionality (such as MyDiabetesMyWay (23)).

Evaluation of Internet Tools

Systematic reviews and meta-analyses of e-interventions in the management of diabetes have demonstrated acceptability and improvement in glycaemic control of participants, although the effects are often modest and variable across studies (24–27). These reviews contain heterogeneous interventions, which are often outdated by the time of publication, but suggest that goal setting, personalised coaching, interactive feedback, mobile use and online peer support may predict success when applied to management of type 2 diabetes mellitus.

Evaluation of different categories of e-interventions is discussed below:

m-health

Self management interventions delivered through mobile technology tend to be more successful than browser based systems (24,26). Systematic reviews suggest m-health interventions can improve HbA1c (28), although impact is variable (29). A systematic review (2014) of available diabetes applications, of which 656 were reviewed in full, showed apps to be feasible with moderate to good usability in patients over age 50 (30). Apps can support self-management of patients with diabetes mellitus type 1 or 2 (31,32) and aid glycaemic improvements (33).

Social Media

Gilbert et al found that online communities are a valued resource by Type I diabetes patients for peer support (34). Story telling, sharing of experiences and tips for self management are common themes. Whilst healthcare staff are often concerned about sharing of personal data online, patients are generally happy to share with peers for mutual benefit (32). Little research has been conducted evaluating impact on glycaemic outcomes (21,31,35).

Telemedicine/Virtual Clinics

Freeman et al (36) found low-cost online video services such as “Skype”, to be feasible for providing online virtual clinics (37), allowing more flexible communication, whilst maintaining the patient-provider relationship, a strong predictor of medical adherence (36). Since January 2011, clinics in Newham (England, UK) have been trialing Skype

consultations (38). Early indications reported reduced HbA1c levels, uptake across a spectrum of ages and ethnic groups, fewer accident and emergency attendances and modest efficiency savings. Those in employment or education or with carer responsibilities reporting greatest benefits (38). **Robust quantitative clinical outcome evidence is, to date, lacking.**

Remote Glucose Monitoring

Improved clinical outcomes (including reductions in HbA1c, LDL cholesterol and triglyceride levels) have been **demonstrated** in studies delivering remote health care recommendations based on daily or weekly (31) or biweekly (39) online review of uploaded blood glucose readings (23). Furthermore, there is evidence that such interventions may be feasible even amongst low income diabetic patients with a high risk for poor diabetes outcomes (39). A meta-analysis revealed that using self-monitoring blood glucose data, stored in and/or shared through a personal data assistant, logbook, the internet and other technologies - worked well alongside consistent feedback from a healthcare professional. This resulted in enhanced glycaemic improvements and reduced hospitalisations (40).

Electronic Personal Health Record (ePHR)

A Nuffield Trust report (41) summarised a debate from key stakeholders involved in implementation of early ePHR systems, stating “ePHRs have the potential to improve communication between providers and patients

by sharing information, to enhance the quality of records by highlighting inaccuracies, and to reduce the burden of care by engaging patients in managing their own health and illness". A recent systematic review of electronic patient record access reported improved patient satisfaction, improved self-care and better communication and engagement with clinicians but did not evaluate clinical outcomes. "ePHR services positively impacted on patient safety, although there were variations in record access and use by specific ethnic and socioeconomic groups. Professional concerns about privacy were unrealised and those about workload were only partly so" (42).

MyDiabetesMyWay. a National Online Self Management Platform

Against this background of emerging online interventions, MyDiabetesMyWay (MDMW) was developed as a national self management portal for diabetes patients in Scotland. It now encompasses i) an education resource website ii) an ePHR for diabetes patients, iii) patient decision support (with data-driven information tailoring) iv) goal setting functions, v) social media including user peer-peer discussion groups v) a linked remote glucose monitoring system, and can be accessed on mobile devices.

MDMW was launched in October 2008 as an open access web site with patient educational materials, which were, and continue to be, curated, digitised and updated by the MDMW team. These include traditional information leaflets, interactive educational tools, videos, animations.

Some of these resources originated from the Scottish Diabetes Community (e.g. Scottish Diabetes Group/ NHS trusts across Scotland), while others have been commissioned.

Since December 2010, an ePHR has been available, allowing patients access to their own clinical information through a secure login (via the Scottish Government 'my account' citizen portal (43)). Data for MDMW is extracted from SCI-Diabetes, a national disease registry for Scotland, functioning as a comprehensive national diabetes electronic health record. It collates information from multiple sources including laboratories, primary care records, pharmacy/prescribing sources, screening services, and secondary care information systems. Data derived from SCI-Diabetes is used for regular regional and national audit and epidemiological research (44).

Patients use MDMW to access information about their condition including weight, blood pressure, blood results (HbA1c, creatinine, eGFR, cholesterol), eye and foot screening results, medication, clinical letters and appointment records. Information is displayed with patient-friendly data visualisations and explanations (see figures 1-4) e.g.

- Data item definitions and explanation of normal ranges
- Target charts and graphs for HbA1c, cholesterol, blood pressure (BP), Body Mass Index (BMI)

- Care standard visualisations to map personal care against national targets e.g. Diabetes UK 15 Health Care Essentials (45)

Patients can contribute to their care record through the addition of data such as weight, smoking status, blood pressure and upload blood glucose readings (either manually or through integration with a third party product DIASEND (46)).

Personalised Tailored Education

Individual patient data drives tailored links to specific educational resources to aid personal self-management. Examples include foot care information tailored to a persons foot risk, drug administration guidance dependent on personal prescribing records, and links to specific sections of a retinopathy educational video based on individual retinal screening results. In addition patients can view tailored lifestyle advice dependent on dynamic changes in anthropometric and biochemical readings.

MyDiabetesMyWay. Use, Effectiveness and Future Developments

Usage

From January to September 2015, the main MDMW website has averaged 60,792 page accesses per month, with a peak of 69,841 in July 2015. Up to the end of September 2015, 15,877 people have registered with MDMW electronic record access system and 6,482 people with diabetes

have accessed their records (figure 5). This represents a 108% increase since September 2014 (n=3,119) and a 296% increase since September 2013 (n=1,636).

Usage analysis (data from all MDMW registrants at the end of 2014) demonstrates that those registering to access MDMW are generally younger and more recently diagnosed. 35.7% have type 1 diabetes, compared to the NHS Scotland prevalence of 10.9%. A high proportion of registrants have a reported ethnicity of 'White' and its sub-categories. A significant proportion of registrants come from least deprived areas, whereas most of the background population come from the most deprived areas. The 'test results' screen was the most popular summary section of the website. The most utilised longitudinal history graph was, unsurprisingly, HbA1c (47)

MDMW Patient Reported Outcomes and Feedback

Regular feedback is received from users through targeted qualitative and quantitative evaluation questionnaires. These cover patient experiences, usability issues, reported benefits and concerns, and invite suggestions for future developments. Anecdotal feedback received through the website and social media has demonstrated high levels of satisfaction.

Examples include:

- *"I wish there were systems like this for other conditions as it would save me having to see doctors regularly"*

- *“I can see when my diabetes was poor and when it improved, a constant battle”*
- *“Immensely satisfied with the system. Really amazing to see my results online. Real motivator”*
- *“I don't have to make appointments to see GP or nurse which is good as I work and don't like taking time off work”*

Key findings from a recent evaluation survey of 1,098 MDMW users who had logged in at least once prior to January 2015 (27.5% response rate) include; 89.6% felt it helped them make better use of their consultation, 88.2% felt it helped them manage their diabetes better and 90.3% and 89.3% respectively felt it improved their knowledge and motivation.

Clinical Improvements and Cost Effectiveness

Unpublished observational data (from users up to end Sept 2015 with complete data) suggests modest improvements in most clinical parameters including HbA1C (n=2611), weight (n=2297), diastolic BP (n=2552) and cholesterol (n=2026) (all p<0.01) one year after first login for the MDMW platform. However confounders, including lifestyle and metabolic changes around time of diagnosis, which may coincide with platform registration, need to be taken into account. More detailed analysis is planned.

Costs to run the MDMW platform are very low. 2015 costs are around £5.40 per registrant per year, and could drop under 85p per person per year if 50% of the Scottish diabetes population enrolled. Full cost

effectiveness analysis has not been carried out, but considering the low running costs is expected to be positive.

Funding and Recognition

The funding for this project is predominantly from the Scottish Government and the platform supports key national strategies improving information availability, supporting health and wellbeing and the needs of people with long term conditions (48) MDMW has received many quality and innovation awards including the 2015 Diabetes UK Annual Self Care Award Winner, and UK Quality in Care Diabetes 2013 award for best initiative supporting patient care

Barriers to uptake

Despite positive feedback, uptake and usage remains very low, with only 5.7% of patients with diabetes in Scotland having registered (end Sept 2015). A survey of 175 diabetes patients across primary and secondary care (Sept 2015) (a) 106 paper surveys (48% response) completed in clinic, and b) 69 online surveys (25% response) completed by a cohort registered with the Scottish Diabetes Research Network (SDRN) registry (email invitation) was performed. Barriers to using MDMW included lack of awareness (48.9%), difficulties using computers (28.0%), not owning a computer (24.7%), remembering passwords (16.6%), concerns about Privacy (14.3%), no interest (13%), and having other priorities (11%). Difficulties with the registration process was also raised as a concern. Work by M Ronda and colleagues reported similar difficulties

with recruiting and retaining patients onto a diabetes patient web portal in the Netherlands (49–51)

User Guidance and Future Developments

In Aug 2015, preferences for features in a future mobile application was assessed through user questionnaires (52) and readiness for further online communication tools was assessed in the MDMW patient user group (n= 206), and SDRN registry (n=73), using online (MDMW) and paper based (SDRN) questionnaires. In the later group, which is more representative of the wider diabetes community, 50% would like to access their health records online, 47% would be willing to engage in online forums and only 37% are willing to consider online consultations despite 74% having internet access (53). Whilst there is support for digital tools amongst some diabetes patients, this is not uniform across the diabetes community.

Discussion

There is increasing evidence that digital interventions may have the potential to improve diabetes care. This evidence base, combined with user feedback has driven changes in the MyDiabetesMyWay platform from a web based information website to an ePHR now encompassing a broader diabetes self management platform with communication tools, remote monitoring, peer support and tailored self management advice. Whilst the platform is unique in providing a national data driven resource, there remains significant challenges and barriers. MDMW

platform usage is low, with disproportionately lower use in older populations, lower socioeconomic groups and minority ethnic groups, and there **remains** a risk that digital innovations may contribute to health inequalities. **D**espite one national advertising campaign and good national clinical networks, awareness of MDMW remains sub-optimal. More proactive promotion by healthcare teams particularly in primary care may reap results. One GP was able to recruit 23.4% of their caseload within 2 weeks of writing to them individually (54). Further developments such as increasing use of remote communication tools was welcomed by some by not all patients (53), suggesting that traditional models of care are still likely to be required for the foreseeable future.

Proving clinical benefit and cost effectiveness for any digital intervention is difficult, but increasingly necessary for funding justification and wider adoption. Whilst MDMW is **a low cost intervention** and has extensive evidence of perceived benefit from user feedback, it has not yet demonstrated definitive clinical outcome improvements or cost-effectiveness.

MDMW Current and Future Developments

The MyDiabetesMyWay platform evolution has been driven by patient preference and **the wider published evidence base. Further** planned functionality includes:

- an associated m-health app

- enhanced automatic data collection and integration from environmental and activity sensors.
- algorithm development and machine learning to enable timely tailored “push” decision support to mobile devices and timely warnings of acute deterioration to patients and clinicians.

These later developments would align with a high level of health informatics maturity with potential for personalised, real-time medical support systems. There is huge potential to deliver online self-management to empower and increase knowledge and self-management capabilities of patients..

The market place is flooded with standalone tools to support diabetes management ranging from mobile apps to remote monitoring and information prescription systems. Most do not integrate with institutional records and work is required to break down barriers in support of big-data analytics. Computers are capable of delivering sophisticated data-driven advice, however, for many people with long-term conditions, health management competes with other priorities.

Widespread, low-cost web access is lessening the economic, geographic and demographic barriers for use. Technology approaches however will only work if patients are willing, motivated and able to use them. Technology must be intuitive, and include automaticity where possible, and must ease rather than add to daily care activities. Further

understanding of user requirements and motivation is required. Unless technology is accessible across the range of socioeconomic, ethnic, disability and age spectrums then it will continue to be the pursuit of limited numbers of motivated patients, and will fail to greatly impact on population health outcomes.

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