



# Diabetes and IT

## My Diabetes My Way: Providing online support for diabetes self-care in Scotland

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**My Diabetes My Way (MDMW) is NHS Scotland's information portal for people with diabetes, containing resources aimed at improving self-care. MDMW comprises validated educational materials, videos, interactive tools and social media. It also allows people with diabetes across Scotland access to their electronic record, presenting diagnostic information, demographics, clinical results, prescribed medication and correspondence. Tailored information refers individuals to knowledge related to their specific condition. In this article, the authors describe the main MDMW resources and provide an analysis of usage and uptake.**

**M**y Diabetes My Way (MDMW) (University of Dundee, 2014a) is the NHS Scotland interactive website for people with diabetes and their carers. It contains a variety of validated multimedia resources aimed at improving self-care. These include traditional information leaflets, interactive educational tools, videos, and social media access via Facebook and Twitter. A key component of the system is its novel electronic personal health record (ePHR), allowing everyone with diabetes in Scotland online access to their medical records. The aims of all MDMW resources are to support national self-management objectives (Long Term Conditions Alliance Scotland, 2008) and diabetes action plan priorities (Scottish Government, 2010).

### Background

In 2008, a report by Diabetes UK estimated that diabetes accounted for around 10% of all NHS expenditure (Diabetes UK, 2008), equating to £9 billion per year, or £1 million every hour. This was double the 2001 estimate by the Department of Health (Department of Health, 2001), showing the impact of a

rising prevalence across the UK. A subsequent report in *Diabetic Medicine* (Hex et al, 2012) predicts that NHS annual spending on diabetes will increase from £9.8 to £16.9 billion over the next 25 years, reaching 17% of the entire NHS budget.

The prevalent national diabetes population of Scotland has increased from 103 835 (2%) in 2002 to 268 154 in 2013 (Scottish Diabetes Group, 2014), representing 5% of the Scottish population. Breaking this figure down, 10.9% have type 1 diabetes, 88.2% have type 2 diabetes and 0.9% other types of diabetes. One in ten people in hospital have diabetes and 60% of people with diabetes admitted as inpatients have been admitted as emergencies (National Diabetes Support Team, 2008). A recent study using data between 2005 and 2007 estimates that admission for people with diabetes account for 12% of Scotland's hospital inpatient costs of £2.4 billion (Information and Statistics Division, 2009; Govan et al, 2011). The financial costs associated this figure were £26 million for type 1 diabetes and £275 million for type 2 diabetes. A focus on early management, education, self-monitoring and complication

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### Article points

1. Self-management approaches allow patients to educate themselves and take more responsibility for their healthcare conditions.
2. My Diabetes My Way (MDMW) is the NHS Scotland information website for people with diabetes and their carers.
3. MDMW contains general information, social media and a module allowing patients to access their healthcare data online.
4. Electronic personal health records allow patients to access and share their health information and contribute to their healthcare records.

### Key words

- Electronic personal health records
- Electronic records access
- Online support
- Self-management
- Social media

### Authors

Author details can be found at the end of the article.

### Page points

1. In its report *Delivering for Health*, NHS Scotland set out a fundamental shift in its health delivery strategy, focusing on providing care that is quicker, more personal and delivered closer to home.
2. The clinical need to improve figures related to diabetes can be assisted using appropriate technology.
3. The My Diabetes My Way website (University of Dundee, 2014a) was launched in October 2008 as the official NHS Scotland online portal for people with diabetes and their carers.

prevention can have a huge economic impact (Department of Health, 2002):

“for every £100 spent on encouraging self-care, around £150 worth of benefits can be delivered.”

In its report *Delivering for Health* (Scottish Executive, 2005), NHS Scotland set out a fundamental shift in its health delivery strategy, focusing on providing care that is quicker, more personal and delivered closer to home. The Scottish Government launched a strategy for self-management with the aim of empowering patients to become partners in the decisions that affect their own care (Long Term Conditions Alliance Scotland, 2008). It states that “people need information and skills to maintain optimum wellbeing.”

The clinical need to improve figures related to diabetes can be assisted using appropriate technology. For example, this can be achieved by improving learning and education, much of which can be facilitated electronically (Nicholas et al, 2012). The Scottish Diabetes Action Plan (Scottish Government, 2010) focused the self-management objectives for the diabetes community, as it aimed to increase “the number of patients directly accessing their own data electronically.” The Department of Health Information Strategy (Department of Health, 2012) aims to allow access to GP records for patients by the end of 2015. Most existing ePHR systems focus on single silos of data such as these, or population subsets. Until now, there have been no systems worldwide offering a fully population-based, focused, shared ePHR for diabetes.

### Methods

The MDMW website (University of Dundee, 2014a) was launched in October 2008 as the official NHS Scotland online portal for people with diabetes and their carers. MDMW is overseen by a multidisciplinary project board which meets approximately every 3 months and functions to prioritise developments and review content. The website contains a variety of educational materials which aim to assist people with diabetes in their self-management, in addition to supporting strategic self-care

objectives. MDMW offers three main routes of engagement:

- 1 A general information website.
- 2 An online ePHR.
- 3 Social media engagement via Facebook and Twitter.

### MDMW information website

The general information content contained within MDMW has been formally verified and validated by both clinicians and patients. The review process begins with the selection or creation of resources by a diabetes specialist nurse, who is also a trained DAFNE (Dose Adjustment For Normal Eating) facilitator. These materials are then reviewed for comment by a diabetes consultant and a national patient group prior to publication online. The resources available include traditional information leaflets and a variety of interactive resources, such as videos, games and educational tools covering all aspects of diabetes. While much of the content has been developed within NHS Scotland, some external resources are also referenced where appropriate, to prevent duplication. These features help users learn more about diabetes and how the condition can be managed effectively.

The website main page (*Figure 1*) is based on six main sections:

- 1 **My Diabetes:** allows users to sign up and gain access to their electronic data, including test results, clinic letters and treatment plans.
- 2 **What is Diabetes:** explains the different types of diabetes and how they are managed. Includes blood glucose monitoring guidance.
- 3 **My Complications:** discusses how poor diabetes control affects the body, how risk can be reduced and how complications are treated.
- 4 **My Medication:** describes the various diabetes treatments available and how they are administered.
- 5 **My Lifestyle:** examines how diabetes affects daily life, including topics such as driving, employment, travel and exercise.
- 6 **My Family:** provides information to help support patients and families. It covers diabetes and pregnancy and resources for children and their parents.



Figure 1. A screenshot of the homepage of the My Diabetes My Way website (on 08.05.14).

### MDMW electronic personal health record

In December 2010, MDMW launched its novel ePHR for diabetes care, available to those aged 14 and above. Data are sourced from primary, secondary and tertiary care via the national shared electronic record Scottish Care Information – Diabetes Collaboration (SCI-DC; <http://www.sci-diabetes.scot.nhs.uk> [accessed 08.05.14]). This ensures that it is possible to make the service available to anyone with diabetes in Scotland.

MDMW presents diagnostic information, demographics, lifestyle factors, laboratory test results, clinical assessments including foot and eye screenings, prescribed medication and clinical correspondence. Explanations are given for “normal” values and the reasons for assessments. Tailored information refers individuals to facts related to their specific condition.

In order to investigate ways in which awareness and engagement can be improved in primary care, a small project in one urban NHS Highland GP surgery explored the effect of inviting patients to sign up to access their records using MDMW. People with diabetes were sent a registration form together with a colour leaflet and a simple explanatory letter. Two weeks later, the non-responders were contacted by phone as a follow-up.

Further activities to increase recruitment and uptake have involved a campaign launched in collaboration with the Scottish Government and Diabetes UK (Diabetes UK, 2012). Posters signposting people with diabetes towards MDMW were displayed in all of Scotland’s community pharmacies for a 6-week period commencing in August 2012. In addition, all letters sent to patients across Scotland inviting them to attend for retinopathy screening now contain the MDMW website address, encouraging individuals to make use of the resources offered.

### MDMW social media

In July 2013, MDMW launched its social media presence via Facebook (University of Dundee, 2014b) and Twitter (University of Dundee, 2014c). The aims of these websites are to encourage moderated discussion amongst subscribers and to provide an outlet where targeted motivational and educational messages can be transmitted to users. Messages are sent out to subscribers up to three times each week and cover all aspects of diabetes management, education and relevant news articles covered in the media, or related to MDMW developments.

### Page points

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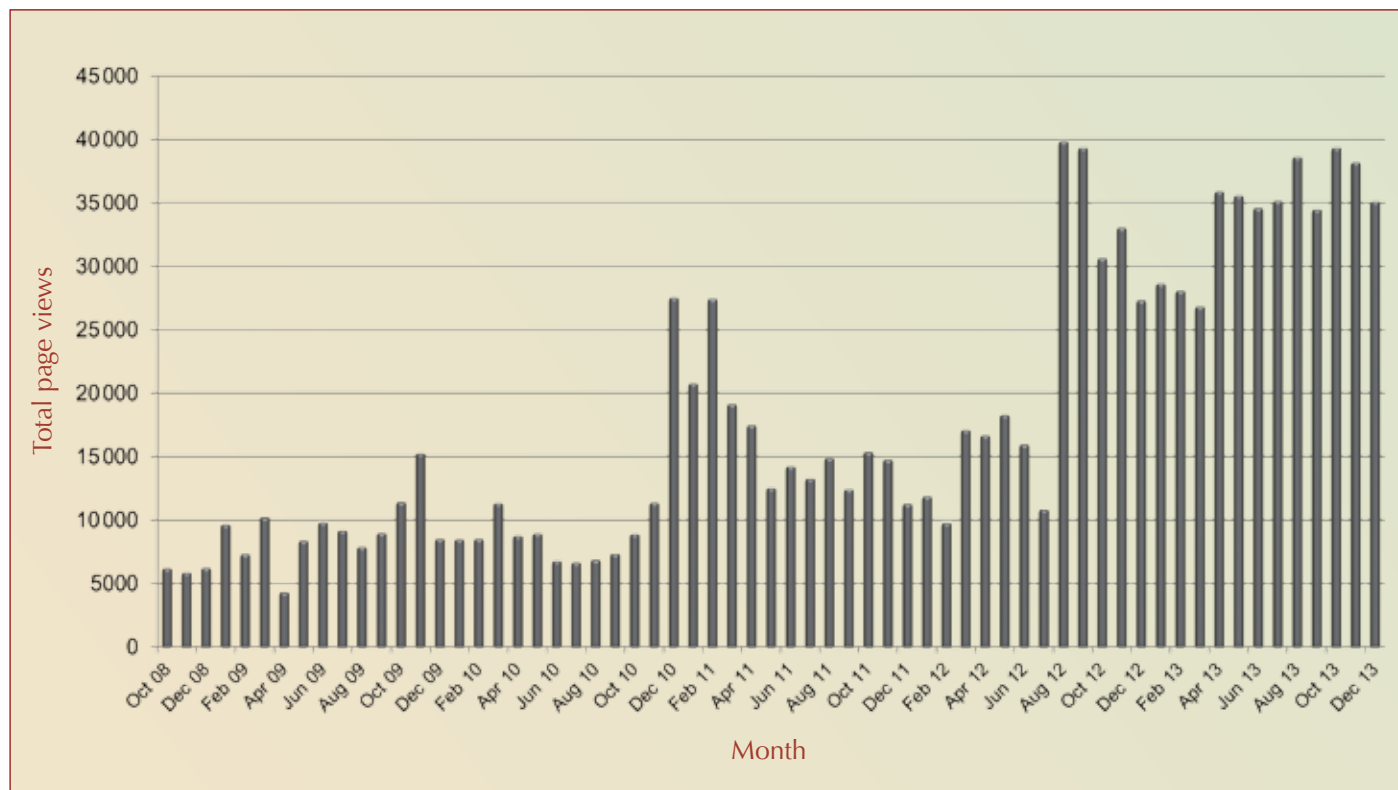


Figure 2. My Diabetes My Way monthly usage figures from the project launch till the end of 2013.

**Results**

**MDMW information website**

The website activity graph (Figure 2) provides evidence of a steady increase in user activity since it was launched in October 2008, through to December 2013. Two notable spikes in activity are also evident during this period. The first is between December 2010 and March 2011, during which time the records access service was launched. The second spike occurs during August and September 2012, when the Scottish Government and Diabetes UK awareness campaign was launched. During 2013, the information website averaged 34 151 page accesses per month. Users were tracked as arriving from around the world, although the vast majority of users came from the UK (95.3%).

Table 1 shows the most popular pages on MDMW, with users most frequently looking up information on diet and diabetes, foot care, causes of diabetes, insulin pumps and health and lifestyle.

**MDMW electronic personal health record**

Following the third full year of use in December 2013, 6528 individuals had registered to access their data (2.4% of the population with diabetes; 59% male; 33% with type 1 diabetes). In all, 4716 had completed the enrolment process (Cunningham et al,

**Table 1. Top 10 pages visited on My Diabetes My Way (October 2008 to January 2014).**

| Page topic          | Number of page visits |
|---------------------|-----------------------|
| Diet                | 10 010                |
| Foot care           | 6556                  |
| Causes              | 5386                  |
| Pumps               | 5199                  |
| Healthier lifestyle | 4592                  |
| Body piercing       | 4162                  |
| Eye disease         | 3861                  |
| Type 2              | 3602                  |
| Keeping well        | 3595                  |
| Sick day rules      | 3493                  |



2013), which requires the completion and return of a signed consent form. Of those who had been sent their login credentials, 1898 had accessed the system (total log-ins, 14 545; average, 7.7 per patient; median, 3; most log-ins, 485). Audit trails show 170 473 page views (89.9 per patient) during the initial 3 years of use, where laboratory results proved the most popular (34 463 accesses; 18.2 per patient). The most accessed history graph (i.e. containing longitudinal data) was that for HbA<sub>1c</sub> (7516 accesses; 4 per patient). *Figure 3* provides an example of this type of graph.

Patient feedback includes the following:

“Excellent resource for anyone actively managing their diabetes. I’d be lost without it.”

“Thank you so much for continuing to make life that little bit easier.”

The primary care pilot in NHS Highland was based on a caseload of 135 individuals and resulted in uptake by 32 (23.7%) following postal intervention and telephone follow-up. Of those, 16 (50%) signed up after the initial mailing and a further 16 (50%) following the phone reminder. Forty-one people gave a reason for not signing up. Seventeen (41.5%) described technical barriers including having “no computer” or “no broadband”, or being “no good with computers”. Twenty-four (58.5%) said that they were simply “not interested” or they felt they already had the information and support that they needed.

#### MDMW social media

By January 2014, MDMW had gained 132 Twitter followers and 314 Facebook likes following the first 6 months of availability. Despite the relatively small numbers at present, social media is proving to be a popular method of providing education while communicating with the target audience. Topics that have prompted most discussion so far have been healthy eating, carbohydrate awareness, diabetes and heart disease, and blood glucose monitoring.



Figure 3. An example of longitudinal data reporting (HbA<sub>1c</sub>) on My Diabetes My Way.

#### Discussion

The MDMW website has now established a strong branding and is widely advertised through all diabetes Managed Clinical Networks across NHS Scotland. Despite this, it is believed that users accessing MDMW services are likely to be a more motivated, self-selecting cohort. It is therefore essential to ensure that individuals are signposted towards these services in equal measures in both primary and secondary care. At present, there are pockets of proactive support and reference in some local diabetes structured educational courses, but awareness activities are not consistent across all of Scotland.

All hospital diabetes clinics are now encouraged to sign patients up for records access as they attend routine appointments or group education events and many now take advantage of this approach. This may provide an insight into the higher proportion of people with type 1 diabetes who have registered, as compared with the whole population (Scottish Diabetes Group, 2014).

However, those health boards that have actively recruited patients during secondary care appointments have the lowest percentage of active users following completion of the enrolment process. This may be due to motivational factors, where patients feel obliged to fill in the enrolment form when presented with it, without any real intent to actually go on to use the service. Another reason why just over 40% of enrolled users have accessed the system may be down to the usability of the log-in process, which was until recently supplied as a third-party component. Based on user feedback and reported loss of engagement, MDMW replaced this with a new and improved service that has been evaluated for accessibility and usability.

#### Page points

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**“My Diabetes My Way services allow users to engage at a pace with which they are comfortable, whether that be by searching for areas of interest via the website, receiving relevant messages via social media, or understanding and interacting with their clinical data to obtain tailored information.”**

Further engagement is required within primary care to encourage more practices to raise awareness with the people on their records with diabetes, whether they are newly diagnosed or have established diabetes. The primary care intervention shows that proactively contacting individuals can result in considerable increases in interest. It is clear, therefore, that many patients are still not aware that they can access their clinical data online. Feedback suggests that there will also always be individuals who have neither the technical skills nor the motivation to access their information online. These individuals may be encouraged to attend computing classes or be swayed by evidence provided by the healthcare team or by other patient advocates. Those unaffected by these barriers must be signposted towards the information required to engage. If the methods used in this small intervention were applied across all primary care sites in Scotland and it achieved the same level of uptake, 63 562 people would be recruited, based on the current diabetes population.

Analysis has begun on the impact on clinical outcomes following the first 3 years of use. Provisional data have shown that those who have accessed the system show improvements in process outcomes including blood pressure, weight, cholesterol, creatinine and HbA<sub>1c</sub> one year after first log-in. Work will continue to formalise and expand on these data for peer-reviewed publication.

### Conclusion

MDMW services are now a useful aid to diabetes self-management in Scotland. They allow users to engage at a pace with which they are comfortable, whether that be by searching for areas of interest via the website, receiving relevant messages via social media, or understanding and interacting with their clinical data to obtain tailored information.

The MDMW ePHR is unique in offering records access to an entire national population, providing information from many diabetes-related sources. Work will continue to raise levels of awareness and engagement, particularly targeting primary care involvement, with the aim to reach 15 000 people by the end of 2014. Parent and carer access is soon to be added, primarily to support the parents of young children. The automated upload of home monitoring results will also be available

in MDMW, and to the wider clinical community via SCI-DC by mid-2014. Despite its development for NHS Scotland, the MDMW ePHR has the potential to connect to any electronic medical record in the UK and beyond.

Further planned developments include the creation of a smartphone app and online communication tools, such as secure messaging, virtual consultations and e-learning courses to improve the flexibility of care delivery. Analyses will continue to stratify demographic characteristics of those registering, enrolling and actively using the service, along with their corresponding clinical outcomes, before and after use. MDMW services positively impact diabetes in primary care by contributing to the education of more knowledgeable and empowered patients. ■

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