my diabetes my way

...the interactive diabetes website

SCI-DC

SCOTTISH CARE INFORMATION
DIABETES COLLABORATION

My Diabetes My Way
Patient Access
Year 1 Evaluation

v1.1
August 2012

Contents

Amendments

Name	Description of amendment	Date	Version
Scott Cunningham	Initial draft	June/July 2012	v0.1
Scott Cunningham	Completion of Executive Summary	July 2012	v0.2
Scott Cunningham	First release following project board review	July 2012	v1.0
Scott Cunningham	Final release following further feedback	August 2012	v1.1

Executive Summary

Introduction

My Diabetes My Way (MDMW – www.mydiabetesmyway.scot.nhs.uk) launched its web-based records access module in December 2010. This module allows every person with diabetes in Scotland access to their electronic 'shared diabetes record'. It contains information captured from primary, secondary and tertiary care, laboratories and specialist screening services, therefore comprising a comprehensive overview of diabetes healthcare.

After the first year of use, we surveyed registrants in order to gauge their opinions of the system and the processes involved in gaining access. We also analysed system audit trails to better understand how the system was used.

Results

At the end of the first year, 361 individuals had registered, 216 (59.8%) had completed the enrolment process and of these, 160 (44.3% registrants; 74.1% enrolled) had logged in to access their diabetes information. 59% were male and 31% of all registrants had type 1 diabetes, compared to a background population prevalence of 12%. The age distribution of the respondents showed that those signing up for records access were, in general, younger than the overall diabetes population in Scotland.

During the first year, 160 users accessed the system (most logins=164), with 1425 logins in total (average=9/patient; median=4). Audit trails show 17745 page views (111/patient), with 'test results' proving the most popular (3216 accesses, 20/patient). The most utilised history graph was, unsurprisingly, HbA1c (792 accesses, 5/patient).

We analysed user experiences of the system using an electronic survey containing a combination of closed and open-ended questions. There were 55 respondents, of which 53 (33.1% of active users at this time) had successfully logged in to access their diabetes information at least once.

- 89% believed the system contained all the features they expected.
- 83% said that the system helped to remind them of information discussed during consultations.
- 98% believed the system would help them make better use of their consultation time.
- 73% said that the system means that they do not need to keep paper records.
- 73% said the system means that they do not need to phone their doctor for new results.
- 77% said the system was up-to-date.

- 96% said the system was easy to use.
- 89% said that the explanatory information helped them to understand their results better.
- 90% said the tailored links helped them to find further information relevant to their diabetes.
- 93% said that the graphs of information were helpful to monitor changes over time.
- 100% were confident that their information was secure when using the system.
- 81% said that the system has helped them manage their diabetes better.
- 79% said that accessing their information has helped to improve their knowledge of diabetes.
- 89% said that accessing their information has made them more motivated about their diabetes.
- 79% said that accessing their information has helped them to meet their diabetes goals.
- 89% said the system would help them to set their own diabetes goals.
- 96% said that online access to diabetes information will significantly improve diabetes self-care across Scotland.

In open-ended questions, the following points were mentioned most often:

- The current user name format is not easy to read or remember.
- Clinic letters, which were originally available when the project launched, must be reinstated.

Discussion

While the system was well received and is clearly providing significant support for patient self-management, there are some areas that can be improved and enhanced further.

MDMW are currently working with the Citizen Account team to streamline the registration and enrolment process to reduce the number of manual processing steps, leading to a significantly faster turnaround than the present situation where, in some cases, it can take several weeks from initial registration to final access. Automated interfacing is due to be implemented from August 2012. The Citizen Account will also allow users to change their username to their email address as part of this upgrade.

To further enhance the enrolment and registration process, and to enhance user support, MDMW are to employ a project administrator. The remit of this role will be to ensure that all steps of patient enrolment are continually progressing and to ensure that registrations are completed in a timely manner. Furthermore, the role will involve support and issue tracking to ensure that any feedback raised by users are acknowledged and tackled faster than they are presently.

A process has been defined to allow hospital diabetes clinics to sign off to allow the sharing of clinical letters. This ensures that staff' have the opportunity to be trained on what is, and what is not acceptable content for these letters. One clinic has already approved the reintroduction of letters, back-dating those available to 01/01/2000 and the objective is now to encourage the remaining clinics across Scotland to follow suit.

Conclusion

The overall conclusion of the evaluation is that the system is now a useful additional component for the self-management of diabetes in Scotland. Users report that it helps them in their self-management, with 98% also indicating that it leads to a more productive consultation with healthcare professionals.

Despite these important benefits, it is acknowledged that the project is currently only reaching a small proportion of the wider diabetic population (~250,000), many of whom are likely to benefit from this initiative. To this end, an awareness campaign has been devised in order to reach a target of at least 5000 registrants by the end of 2013.

Background

The My Diabetes My Way (MDMW – www.mydiabetesmyway.scot.nhs.uk) website (Scottish Diabetes Group, 2012) was launched in October 2008. It is the official NHS Scotland patient and carer information portal, containing validated educational materials in a variety of formats (leaflets, videos, interactive tools), for people with diabetes. The aims of this information resource are to improve patients' knowledge of the disease, their self-management and ultimately to improve their health outcomes.

The 2006 Scottish Diabetes Framework Action Plan (Scottish Government, 2006) stated that it would "*Support initiatives to improve patient access to their own electronic medical records*". Funding was received from the Scottish Diabetes Group in 2007 to develop a new module within the MDMW website where people from across Scotland could access their own information online. This originally began on December 15th 2010 as a three month pilot, which was subsequently extended after the feedback indicated acceptance of the website design and its functionality. The project then began to roll out more widely, potentially allowing all people with diabetes in Scotland access to their own information.

The 2010 Scottish Diabetes Survey (Scottish Diabetes Group, 2011) reported that at the beginning of 2011 that there were 237,468 people with diabetes in Scotland. The revised Scottish Diabetes Action plan in 2010 (Scottish Government, 2010) stated the aim to "maximise the use of the diabetes care system by patients to enhance self management and improve patient/professional communication" by increasing "the number of patients directly accessing their own data electronically." At this time, MDMW stated its aim to reach 5000 patients by the end of 2013. The project was subsequently referenced in the Scottish Government 'digital participation' strategy "Scotland's Digital Future: A Strategy for Scotland" (Scottish Government, 2011).

A project 'Editorial Group' consisting of patients, healthcare professionals and IT professionals oversees the development and management of the services provided by MDMW. During development and rollout, the multidisciplinary project board defined:

- What was to be achieved
- Choice of functions
- What data was to be used and how it was to be presented
- Thoughts on expected usage and benefits
- Implementation approach
- Awareness strategy

This evaluation of the first year of usage aims to report to what extent the system has met the expectations of the Scottish Diabetes Action Plan in assisting patients to more effectively manage their diabetes.

System Design

The MDMW record access module is available due to the fact that NHS Scotland has invested considerable resource since 2002 in the development of the Scottish Care Information – Diabetes Collaboration (SCI-DC) programme (NHS Scotland, 2012). SCI-DC is Scotland's national suite of information technology products designed to underpin Managed Clinical Networks for diabetes. It is used daily by healthcare professionals across the country to support the management of patients directly under their care. SCI-DC provides a shared electronic record for diabetes, with data captures from primary, secondary and tertiary care, national screening systems and laboratory systems. Without this information resource, the MDMW record access portal would not be possible across the whole of Scotland.

MDMW has engaged with the Scottish Government Improvement Service to utilise its Citizen Account System (CAS – (Improvement Service, 2012)) portal. The CAS has been designed to integrate with various public service infrastructures to provide a portal from which any Scottish citizen will be able to access their public services information. MDMW is the first initiative in which CAS has engaged with the NHS, but in future it will possible for an individual to log in once to access their council, NHS and social care records. CAS provides the authentication methodology for MDMW, meaning that that once a user has logged in to the CAS portal, they can immediately access their diabetes records. MDMW does not need to know the username or password of their users, ensuring that these details are fully delegated and managed by the CAS team, saving further development and considerable maintenance resource.

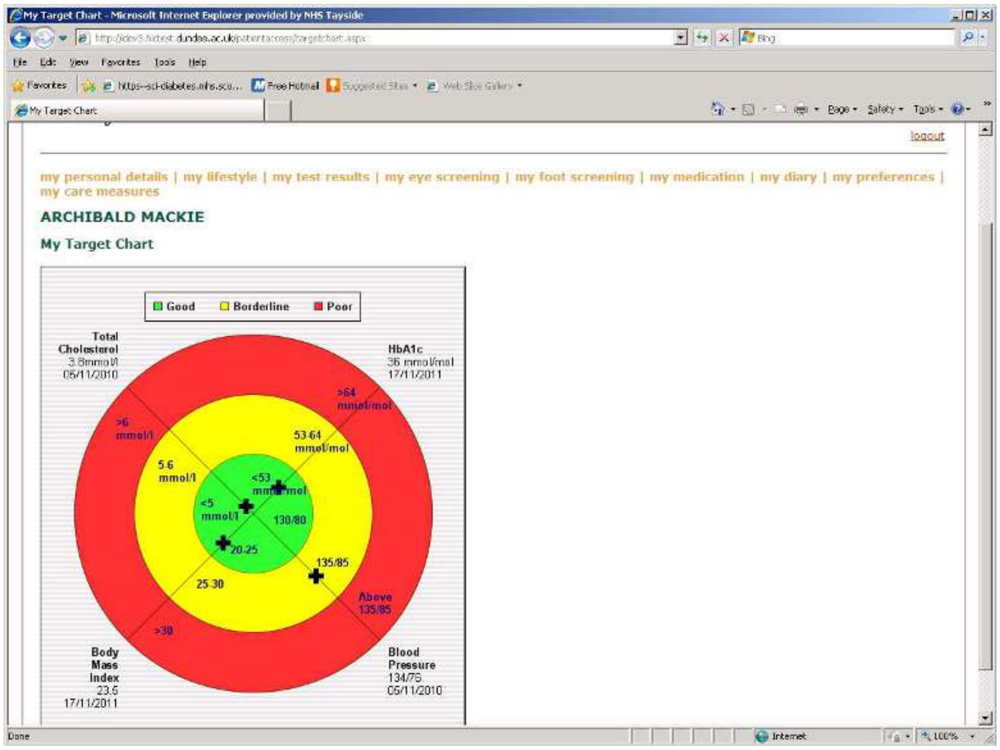
SCI-DC and CAS are two fundamental building blocks upon which the MDMW record access portal is built. The following paragraph describes how MDMW makes use of the SCI-DC data and how it designed the system to provide maximum benefit to its users.

There are a large number of clinical indicators that are relevant for the care of people with diabetes. While it would be feasible to include all of these in the record access module, a decision was made by the Editorial Group to only include the core, key clinical data items relevant to the management of diabetes. This is a similar approach to that used in implementing the original DARTS clinical information system for healthcare professionals (Morris et al., 1997). This defined the initial system based on SIGN25 (Scottish Intercollegiate Guidelines Network, 1998) minimum dataset for diabetes. A similar approach for patients ensured that only the most reliable data were used and that there was no possibility of overloading the patient with too much information. As the project evolves, the plan was to gradually incorporate new data as appropriate.

Data within the system were broken down into clearly defined sections. Once the user logs in, they are presented with a series of options which they can interrogate further:

- my personal details: contains basic demographics, diabetes type, diagnosis year and registered GP and surgery
- my lifestyle: factors such as weight, height, body mass index, smoking status and last influenza vaccination
- my test results: blood pressure and blood tests recorded at the laboratory such as HbA1c, cholesterol, creatinine and eGFR
- my eye screening: visual acuity and results from diabetic retinopathy screening such as retinal status, maculopathy status and last retinal screening date
- my foot screening: foot pulses, foot sensation and foot risk category
- my medication: all medication prescribed by primary care, with links to further information on diabetes-related drugs
- my diary: a summary of appointments in primary and secondary care and retinopathy screening
- my correspondence: letters dictated by secondary care clinicians and sent to the patient's GP

In addition to these screens which provide an overview of the patients' latest results, many data items provide an option to drill down further into historical results. As appropriate, these data are presented as tables and/or line graphs. As some users in the initial review group found line graphs difficult to interpret, the system also provides alternative presentations of data, such as the target chart to show how results relate to national guidelines and targets.



my personal details | my lifestyle | my test results | my eye screening | my foot screening | my medication | my diary | my preferences | my care measures

ARCHIBALD MACKIE

My Target Chart

Each clinical data item presented on MDMW contains a lay description, outlining why the data are recorded and what ‘normal’ values are. In order to tailor the system to each patient, links of the right of each screen are relevant to the patient’s condition. For example, if the patient has Type 2 diabetes, links will be shown describing how the condition is diagnosed and managed. If the patient has a specific stage of diabetic retinopathy, they can view a film describing that stage. If the patient has a particular foot risk category, they will be pointed towards the relevant leaflet describing the care they should expect and how they can best look after their feet. Finally, all diabetes-related drugs provide links to www.patient.co.uk (Egton Medical Information Systems Ltd, 2012) which explains why drugs are prescribed, what they are used for and what potential side-effects they may have. The ultimate objective of this functionality is the belief that the more information the patient has about their condition, the better they can manage their disease.

All of the sections of the MDMW website aim to present ownership of data to the patient so they can take control of their condition. This is done by labelling each section with the prefix ‘my…’. We aim to allow each individual to use it as their main reference point and ultimately contribute their own home-recorded results.

MDMW encourages feedback from its users regarding all elements of the system. If there are problems logging in, during the first year the patient could submit details via the feedback section of the public area of the MDMW website or contact the core team directly using the MDMW email address. Once logged in, direct comments regarding data errors or any other technical issues could be submitted using the secure feedback form within the secure, private area. If users had specific questions regarding their clinical data, they were encouraged to contact their usual healthcare provider to discuss their results. MDMW is not currently sufficiently resourced to manage these types of clinical queries, although work is continuing towards this objective.

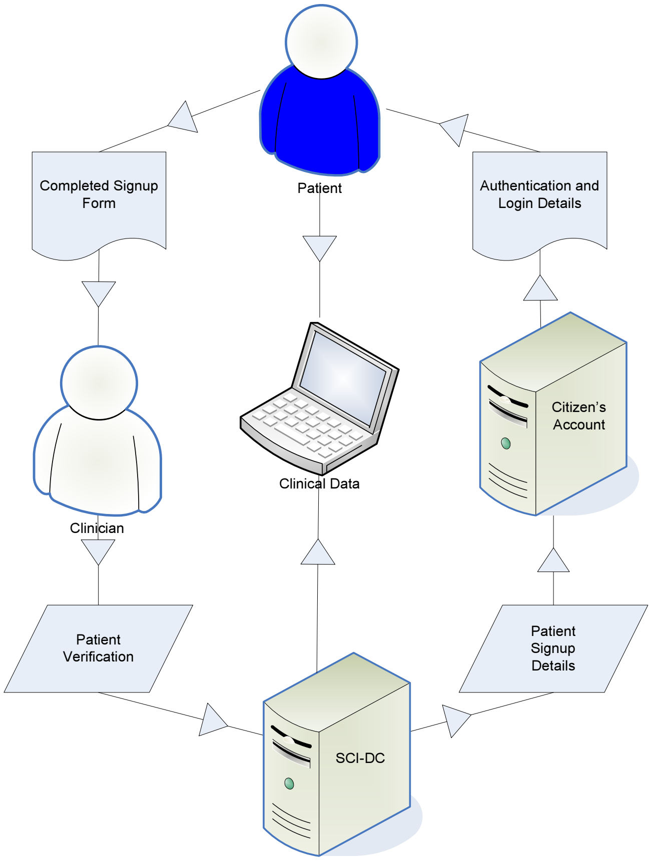
MDMW presents sensitive clinic data, so it is essential to ensure that this is processed and managed securely. In addition to the information governance obligations described later in this document, MDMW has followed methodologies used in internet banking to ensure the security of data and the access component. For example, all user interface interactions are managed using Secure Sockets Layer (SSL) encryption to guarantee that data are transferred without risk of interception. Many of the workflow processes used by MDMW follow the examples developed by Renal PatientView (Renal Information Exchange Group, 2012), a pioneering NHS system providing record access to patients with chronic kidney complications.

In addition to these standard approaches, the integrity and security of data have been validated via an independent ‘penetration testing’ exercise and a threat modelling review with representatives from Microsoft. The ultimate aim of MDMW is to provide access to diabetes data safely and securely at a place and time that is convenient to the patient.

Registration and Enrolment Process

The following section describes the registration and enrolment process:

Step 1: Patient registers an interest in participating using a secure form where they enter basic demographics for matching purposes on the MDMW website.
Step 2: An enrolment pack is sent to the patients containing further information materials and an enrolment form which they must complete and sign, consenting for their data to be made available to them and permitting the project team to contact them further.
Step 3: Their healthcare professional (GP, Clinician, Practice Nurse, Retinal Screener, etc) verifies the patient's identity and countersigns the enrolment form before it is returned to MDMW.
Step 4: MDMW passes details of patients requesting data access securely to the Citizen Account for login credentials to be generated.
Step 5: Citizen Account create user accounts and authentication details as appropriate and send securely directly to the patient.
Step 6: Patient uses authentication details received to access personal information from SCI-DC via MDMW.



MDMW provides patient demographics to the Citizen Account team so that a manual mapping of the CAS Unique Citizen Reference Number (UCRN) can be made to the patients CHI number to create a valid association. This information will be transferred securely on a one-off basis, with relevant mappings returned as part of this process.

The Citizen Account Governance Board will address all aspects of confidentiality and data security for all projects consuming its services. These include:

- Secure Printing
- User ID/Password transfer
- Password reset process
- Letter customisation/branding
- Signoff of Information security/governance papers

MDMW does not need to know details of the patients’ login credentials, therefore fully delegating this part of the process to the Citizen Account team and centralising the user provision workflow. This can therefore be seen to eliminate any NHS costs.

Analysis Methodology

Prior to the project going live on 15th December 2010, information governance arrangements were defined and implemented. The data controller was designated as the University of Dundee, who control the secure servers upon which the MDMW infrastructure is hosted. Caldicott approval was received individually from all 14 health boards. All except NHS Grampian had signed off by the start date, with their approval received during January 2011. Prior to any analysis and research publication, ethical approval was received in January 2012.

Qualitative and quantitative data were analysed. Statistics regarding usage patterns were derived from the system audit trail which logs when users log in to the system and each page that they access while they are actively using it. Qualitative data came from results obtained from a user survey (Appendix 1).

The survey was emailed as a Microsoft Word document to participants who had engaged with the system during the first year. This included patients who had submitted their initial registration but had not completed the enrolment process, those who had completed the enrolment process and who had not logged on and those who had used the system. We aimed to identify any steps in the process that caused potential users to disengage with the project.

The first page of the survey aimed to capture experiences of the registration process, before moving on to gauge opinions on experiences while using the system. Those who submitted feedback or comments when using the system were asked to describe their experiences regarding speed of response and the final outcomes to their enquiries and the final page aimed to summarise the best and worst parts of the system and allow suggestions for new functionality in free text.

The main objectives were to capture:

- User experiences
- Thoughts on current processes and suggestions for improvement
- Key successes and reasons for using system
- Barriers to use
- Recommendations for the future

Analysis of the user audit trail aimed to profile users and their activity patterns after login. For example, we wanted to know how often users were logging in and which data items were the most popular. We also wanted to determine whether the tailored components and lay descriptions were regularly referenced. Finally, we aimed to analyse when users were logging in to the system in relation to their appointments with their healthcare teams.

Usability was assessed as part of the initial MDMW website design and the record access component conforms to the design and styles validated by the University of Dundee Digital Media Access Group in discussion with focus groups consisting of lay reviewers. The system supports accessibility by providing support for screen readers, enlarged text and the layout conforms to W3C standards.

The initial MDMW development costs obtained from the Scottish Diabetes Group were £40,000 in 2007. Since that time, additional funding (currently ~£30,000) has supported additional management, development and enhancements. These figures do not cover the ongoing development and maintenance costs of SCI-DC, NHS Scotland's national diabetes system. At present, it is too early to report a return on investment in terms of clinical outcomes, but the evaluation results describe the social and patient satisfaction return on investment based on user feedback.

Results

The next sections outline the results of an analysis of the system user audit trail and evaluation survey following the first year of usage from 15/12/2010.

User Metrics at Year 1

After the first year of system usage, 361 individuals had registered, 216 (59.8%) had completed the enrolment process and 160 (44.3% registrants; 74.1% enrolled) had logged in to access their diabetes information. In comparison, the Ayrshire and Arran record access pilot reported that 49.6% registrants (194 of 391) went on to use their system.

The following table shows the breakdown of registrants by NHS Health Board.

Region	Patients
Ayrshire & Arran	15
Borders	0
Dumfries & Galloway	5
Fife	48
Forth Valley	11
Grampian	45
Greater Glasgow & Clyde	51
Highland	20
Lanarkshire	21
Lothian	88
Orkney	2
Shetland	12
Tayside	39
Western Isles	4
Total	**361**

At the time of writing this evaluation, all NHS Health Boards were represented.

The following table shows the breakdown of registrants by gender:

Gender	n	%
Male	213	59.00%
Female	148	41.00%
Total	**361**	**100.00%**

These figures are consistent with the general diabetic population, where a greater proportion of those with diagnosed diabetes are men.

The following table shows the breakdown of registrants by type of diabetes:

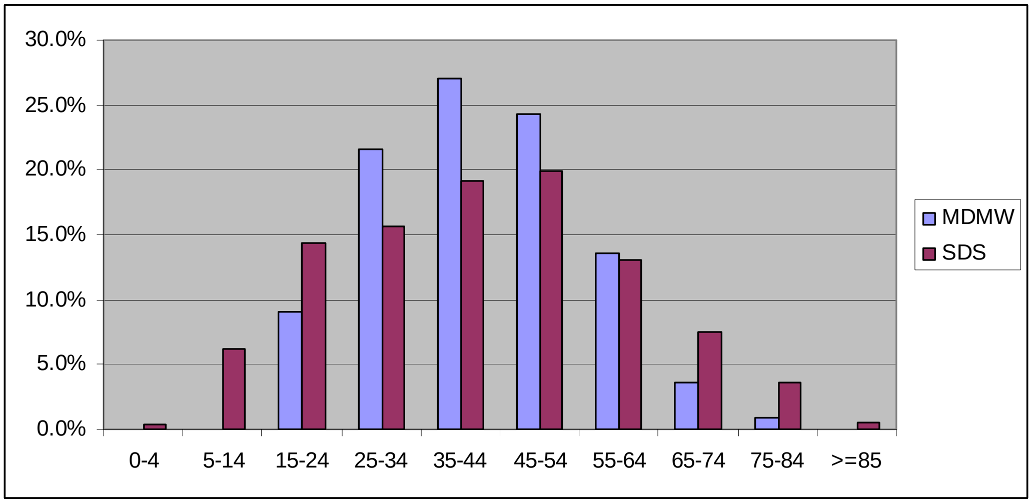
Diabetes Type	n	%
Type 1	111	30.75%
Type 2	250	69.25%
Total	**361**	**100.00%**

The figures above show a higher proportion of people with type 1 diabetes in the project group, compared to the diabetic population of Scotland where type 1's account for only 11.8% of the total number.

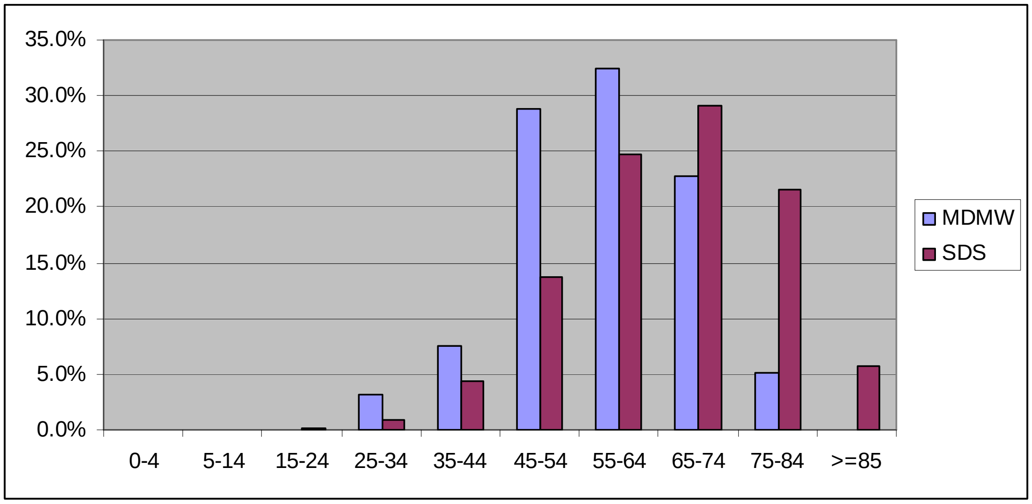
The following table shows the age distribution of registrants:

Age	Type 1	%	Type 2	%	All	%
0-4	0	0.0%	0	0.0%	0	0.0%
5-9	0	0.0%	0	0.0%	0	0.0%
10-14	0	0.0%	0	0.0%	0	0.0%
15-19	5	4.5%	0	0.0%	5	1.4%
20-24	5	4.5%	0	0.0%	5	1.4%
25-29	8	7.2%	2	0.8%	10	2.8%
30-34	16	14.4%	6	2.4%	22	6.1%
35-39	14	12.6%	6	2.4%	20	5.5%
40-44	16	14.4%	13	5.2%	29	8.0%
45-49	15	13.5%	27	10.8%	42	11.6%
50-54	12	10.8%	45	18.0%	57	15.8%
55-59	9	8.1%	37	14.8%	46	12.7%
60-64	6	5.4%	44	17.6%	50	13.9%
65-69	4	3.6%	33	13.2%	37	10.2%
70-74	0	0.0%	24	9.6%	24	6.6%
75-79	1	0.9%	7	2.8%	8	2.2%
80-84	0	0.0%	6	2.4%	6	1.7%
>=85	0	0.0%	0	0.0%	0	0.0%
Total	**111**	**100.0%**	**250**	**100.0%**	**361**	**100.0%**

The graphs below show how the age distribution compares with the overall diabetes population for both type 1 and type 2 diabetes. Firstly type 1:



The following graph shows the same distribution for type 2 diabetes:



The age distribution of the respondents showed that those signing up for patient access were, in general, younger than the overall diabetes population in Scotland, although the age range is still wide with even those between the ages of 75 and 84 using the system.

The table below shows the duration of diabetes of registrants by diabetes type:

Duration (Years)	Type 1	%	Type 2	%	All	%
<1	1	0.9%	36	14.4%	37	10.2%
1-4	22	19.8%	76	30.4%	98	27.1%
5-9	10	9.0%	62	24.8%	72	19.9%
10-14	13	11.7%	41	16.4%	54	15.0%
15-19	13	11.7%	20	8.0%	33	9.1%
20-24	12	10.8%	3	1.2%	15	4.2%
25-29	12	10.8%	5	2.0%	17	4.7%
30-34	7	6.3%	3	1.2%	10	2.8%
35-39	6	5.4%	0	0.0%	6	1.7%
40-44	8	7.2%	0	0.0%	8	2.2%
45-49	4	3.6%	0	0.0%	4	1.1%
>=50	3	2.7%	0	0.0%	3	0.8%
Unknown	0	0.0%	4	1.6%	4	1.1%
Total	**111**	**100.0%**	**250**	**100.0%**	**361**	**100.0%**

There was a clear spread of registrants by duration of diabetes but, significantly there were a considerable number of people with type 2 diabetes within their first 10 years of diagnosis.

Analysis of System Usage

During the first year, 160 users accessed the system (most logins=164), with 1425 logins in total (average=9/patient; median=4). Audit trails show 17745 page views (111/patient), with 'test results' proving the most popular (3216 accesses, 20/patient). The most utilised history graph was, unsurprisingly, HbA1c (792 accesses, 5/patient). History line graphs allow individuals to track changes over time for the full duration of their clinical record from multiple electronic data sources.

Page	Distinct Users	%	Total Accesses	Total / User
Personal Details Overview	160	100.0%	1890	11.8
Test Results Overview	158	98.8%	3216	20.1
Medication Overview	151	94.4%	873	5.5
Eye Screening Overview	150	93.8%	1230	7.7
Foot Screening Overview	150	93.8%	1147	7.2
Patient Diary	148	92.5%	814	5.1
HbA1c History	148	92.5%	792	5.0
Lifestyle Overview	147	91.9%	1402	8.8
Blood Pressure History	136	85.0%	500	3.1
Cholesterol History	132	82.5%	483	3.0
Creatinine History	131	81.9%	494	3.1
Weight History	122	76.3%	369	2.3
External, Tailored Links	116	72.5%	557	3.5
BMI History	113	70.6%	283	1.8
Target Chart	108	67.5%	329	2.1
Correspondence Page (withdrawn)	106	66.3%	793	5.0
Visual Acuity History	97	60.6%	214	1.3
Retinopathy History	91	56.9%	240	1.5
Maculopathy History	84	52.5%	182	1.1
Any Data Item Definition	83	51.9%	647	4.0
Foot Pulses History	77	48.1%	168	1.1
User Feedback	61	38.1%	176	1.1
Foot Sensation History	56	35.0%	114	0.7
Monofilament Testing History	50	31.3%	101	0.6
Foot Risk History	49	30.6%	117	0.7
Vibration Testing History	45	28.1%	90	0.6
Medication Information Links	43	26.9%	121	0.8
Correspondence Item (withdrawn)	37	23.1%	333	2.1
HDL Cholesterol History	28	17.5%	39	0.2
Triglycerides History	15	9.4%	21	0.1
LDL Cholesterol History	7	4.4%	10	0.1

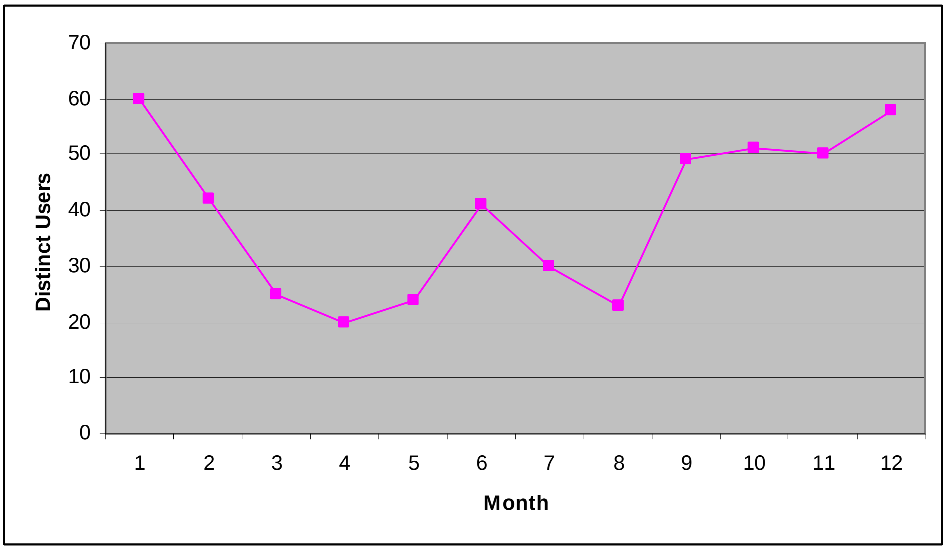
The personal details page is the first page shown when the user logs on, so as expected, every activated user had seen this. Interestingly, no other pages were viewed by 100% of users which indicates a potential training need.

The following table shows the number of distinct users and total page accesses by month during the first year:

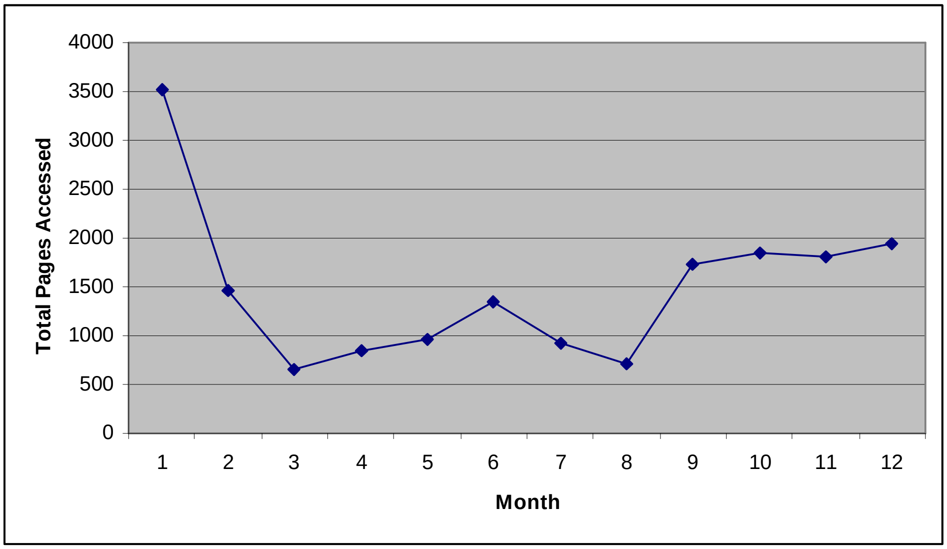
Month	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**Overall**
Distinct Users	60	42	25	20	24	41	30	23	49	51	50	58	**160**
Total Pages	3525	1455	656	851	966	1340	921	703	1737	1843	1806	1942	**17745**

This table shows in the last month of the first year that 36.3% of active users and 26.9% of those who had completed the enrolment process (and had therefore been sent login details) had logged in.

The graph below plots the number of distinct users by month over the course of the year:



The next graph shows the total number of pages accessed each month over the course of the year:



Qualitative Analysis Discussion

The tables and graphs above present some interesting data. At the beginning of the project there was a clear spike as user accounts were activated and those involved were interested in what the system offered and the data it presented. Since that initial flurry of activity, usage and user numbers clearly dipped before increasing towards the end of the year. Although new users were continually being added throughout the course of the year, there is a clear change in the way that users are now using the system. The number of monthly users recovered to the same level at initial launch, but the total page accesses remain at around a half of that first month. There may be several reasons for this:

- On first login, users are likely to want to see every feature offered
- Once a user has read supporting material on a particular data item, they may be unlikely to read it again
- Users are more familiar with the system and now have more focused activity after logging in. e.g. looking for test results after an appointment

Analysis of Patient Experiences

There were 55 respondents to the survey, 53 (33.1% of active users at this time) had successfully logged in to access their diabetes information at least once. We aimed to analyse their experiences and also to identify factors which enhanced the process, as well as those that caused barriers that could be addressed when moving forward. These analyses were based on groupings of the most common feedback.

Enrolment Process

Participants were asked if they had any comments about the enrolment process, or if they experienced difficulties in obtaining a signature to verify their identity from a member of their healthcare team.

Enablers

- The staff information leaflet was very useful to educate uninformed healthcare professionals

Barriers

Although most users experienced no problems, the three main issues raised are highlighted below:

- Doctor refused to sign the form
- Doctor requested a fee for signature
- HCP did not feel authorised to countersign the enrolment form.

Solutions Implemented

As a result of occasional difficulties in obtaining verification signatures, MDMW now encourages users not to give up and approach another member of their healthcare team in these situations. The form is not to provide ‘permission’ for access, but is purely to confirm that the patient is who they say they are. As a result, MDMW has engaged with the national Diabetic Retinopathy Screening Programme which has issued guidance to eye screeners to participate in the process. The patient should not be expected to pay a fee for this service.

Login Process

Users were asked to provide information regarding any problems they had experienced while attempting to access their data.

Barriers

The main issues are highlighted below:

- Username and password
    - Font size and type difficult to interpret (1 or l, 0 or O, etc)
    - The username is far too large and complicated
    - Username cannot be remembered unless written down.
    - Most other systems you access comprise your name/initials as a user id and a password of 8 characters or more
- Password updates
    - Obtaining a password was difficult
    - Password took a long time to arrive
    - ‘Captcha’ used when updating password difficult to read and interpret for those with visual impairment
- Length of time from enrolment to gaining access
- Consent for data sharing with other agencies
    - Uncertainty over who get access, what information they have access to and how they secure the information
    - Actual enrolment should just be via a single form containing all authorisations required
- General feedback
    - Login process is cumbersome, particularly for the elderly

Solutions Implemented

The feedback raised via the survey and from other feedback highlighted that the ‘Password Reset’ option on the Citizen Account System portal does not generate or send out new details. This is now routinely checked to ensure that no users are left in limbo.

Length of time for access is dependent on the time taken to obtain a signature from a member of the healthcare team. MDMW currently processes new registrations and marks enrolled patients for activation every 2 weeks. This time period will be considerably reduced once automated processes are in place.

Discussion

There are many benefits in using the Citizen Account portal as the authentication component for MDMW. Firstly, the ultimate aim is to have everyone in Scotland accessing all of their public services using this one system, rather than having to remember numerous usernames and passwords for each. Secondly, MDMW have been able to delegate responsibility for user account provisioning, relieving the core team of a considerable administrative overhead which would have been difficult to maintain otherwise.

Some solutions to the issues raised have already been implemented and the record matching and user detail provisioning is now much smoother, completing in around 1 week. The project team will continue to improve this and other areas via a Change Request which is currently in development and due for release by autumn-2012. This contains a change to the username format, which will allow users to update this to their email address. A password reset can then be automatically sent to their email if this is forgotten in future. In order to aid the login process, users can now contact the CAS team directly using the telephone number and email address provided on the MDMW website.

Opinions of My Diabetes My Way

Section B of the survey questionnaire contained 17 structured questions which aimed to capture the opinions of those who logged in and accessed their data. The results are shown below:

1. The system contained all the features that I expected

Section_B_1	n	%
No Response	1	
Agree Strongly	25	48.1%
Agree	21	40.4%
Disagree	6	11.5%
Disagree Strongly	0	0.0%
Total	**52**	**100.0%**

88.5% of respondents believed the system contained all the features they expected.

2. The system helped to remind me of information discussed during consultations

Section_B_2	n	%
No Response	1	
Agree Strongly	18	34.6%
Agree	25	48.1%
Disagree	9	17.3%
Disagree Strongly	0	0.0%
Total	**52**	**100.0%**

82.7% of respondents said that the system helped to remind them of information discussed during consultations.

3. The system will help me make better use of my consultation time

Section_B_3	n	%
No Response	1	
Agree Strongly	22	42.3%
Agree	29	55.8%
Disagree	1	1.9%
Disagree Strongly	0	0.0%
Total	**52**	**100.0%**

98.1% of respondents believed the system would help them make better use of their consultation time.

4. The system means I do not need to keep my own paper records

Section_B_4	n	%
No Response	1	
Agree Strongly	24	46.2%
Agree	14	26.9%
Disagree	14	26.9%
Disagree Strongly	0	0.0%
Total	**52**	**100.0%**

73.1% of respondents said that the system means that they do not need to keep paper records.

5. The system means I do not need to phone my doctor for new results

Section_B_5	N	%
No Response	2	
Agree Strongly	22	43.1%
Agree	15	29.4%
Disagree	14	27.5%
Disagree Strongly	0	0.0%
Total	**51**	**100.0%**

72.5% of respondents said the system means that they do not need to phone their doctor for new results.

6. The system was up-to-date

Section_B_6	n	%
No Response	0	
Agree Strongly	22	41.5%
Agree	19	35.8%
Disagree	7	13.2%
Disagree Strongly	5	9.4%
Total	**53**	**100.0%**

77.3% of respondents said the system was up-to-date.

7. The system was easy to use

Section_B_7	n	%
No Response	0	
Agree Strongly	26	49.1%
Agree	24	45.3%
Disagree	2	3.8%
Disagree Strongly	1	1.9%
Total	**53**	**100.0%**

94.4% of respondents said the system was easy to use.

8. The explanatory information helped me understand my results better

Section_B_8	n	%
No Response	0	
Agree Strongly	21	39.6%
Agree	26	49.1%
Disagree	6	11.3%
Disagree Strongly	0	0.0%
Total	**53**	**100.0%**

88.7% of respondents said that the explanatory information helped them to understand their results better.

9. The links helped me to find further information relevant to my diabetes

Section_B_9	n	%
No Response	2	
Agree Strongly	19	37.3%
Agree	27	52.9%
Disagree	5	9.8%
Disagree Strongly	0	0.0%
Total	**51**	**100.0%**

90.2% of respondents said the tailored links helped them to find further information relevant to their diabetes.

10. The graphs of information were helpful to monitor changes over time

Section_B_10	n	%
No Response	0	
Agree Strongly	30	56.6%
Agree	20	37.7%
Disagree	3	5.7%
Disagree Strongly	0	0.0%
Total	**53**	**100.0%**

93.3% of respondents said that the graphs of information were helpful to monitor changes over time.

11. I was confident that my information was secure when using the system

Section_B_11	n	%
No Response	0	
Agree Strongly	24	45.3%
Agree	29	54.7%
Disagree	0	0.0%
Disagree Strongly	0	0.0%
Total	**53**	**100.0%**

100% of respondents were confident that their information was secure when using the system.

12. The system has helped me manage my diabetes better

Section_B_12	n	%
No Response	0	
Agree Strongly	18	34.0%
Agree	25	47.2%
Disagree	10	18.9%
Disagree Strongly	0	0.0%
Total	**53**	**100.0%**

81.2% of respondents said that the system has helped them manage their diabetes better.

13. Accessing my information has helped to improve my knowledge of diabetes

Section_B_13	n	%
No Response	0	
Agree Strongly	23	43.4%
Agree	19	35.8%
Disagree	11	20.8%
Disagree Strongly	0	0.0%
Total	**53**	**100.0%**

79.2% of users said that accessing their information has helped to improve their knowledge of diabetes.

14. Accessing my information has made me more motivated about my diabetes

Section_B_14	n	%
No Response	0	
Agree Strongly	27	50.9%
Agree	20	37.7%
Disagree	6	11.3%
Disagree Strongly	0	0.0%
Total	**53**	**100.0%**

88.6% of respondents said that accessing their information has made them more motivated about their diabetes.

15. Accessing my information has helped me to meet my diabetes goals

Section_B_15	n	%
No Response	0	
Agree Strongly	11	20.8%
Agree	31	58.5%
Disagree	11	20.8%
Disagree Strongly	0	0.0%
Total	**53**	**100.0%**

79.3% of respondents said that accessing their information has helped them to meet their diabetes goals.

16. The system will help me to set my own diabetes goals

Section_B_16	n	%
No Response	0	
Agree Strongly	17	32.1%
Agree	30	56.6%
Disagree	6	11.3%
Disagree Strongly	0	0.0%
Total	**53**	**100.0%**

88.7% of respondents said the system would help them to set their own diabetes goals.

17. Online access to diabetes information will significantly improve diabetes self-care across Scotland

Section_B_17	n	%
No Response	0	0.0%
Agree Strongly	28	52.8%
Agree	23	43.4%
Disagree	2	3.8%
Disagree Strongly	0	0.0%
Total	**53**	**100.0%**

96.2% of respondents said that online access to diabetes information will significantly improve diabetes self-care across Scotland.

At the end of the structured section, a free-text box was available to allow the patient to explain any of the statements they agreed or disagreed with.

Enablers

Patients expressed an improvement in self-management outcomes, such as awareness, better information and satisfaction.

Described as "*a great resource for the newly diagnosed*", with resources "*of a very good quality and easy to understand.*"

Barriers

Some patients indicated that although they had access to a subset of their diabetes data, they didn't have access to all, or a sufficient amount of it. This includes information on more complex biochemistry tests and clinical outcomes.

One particular area of concern was from those who, during the initial three month pilot, had access to the letters sent from hospital clinicians to the patient's GP. These were withdrawn due to concerns expressed regarding the potential content. Particularly:

- Possible third-party references
- Possible information that may cause concern or harm to the patient
- Information written in a way that is not appropriate for patient review

Patients, however, expressed the importance for this information:

“Needs to have the written notes available as this is where ‘objectives’ are detailed”

Some patients indicated that they have other long-term conditions where additional tests are required and it would be useful to make these available.

Some members of the clinical community are still to be convinced that records access will provide any benefit. One patient’s response was:

“My DM consultant does not see the need for patient access, a shortsighted view in my opinion.”

Although in most cases, patient data was current and correct, several users expressed problems with data completeness for recent tests and data accuracy for others. In particular, some of the graphs were initially skewed by out-of range results and in many cases, smoking status was inaccurate.

‘Tailored’ information resources were provided to the patient as external links, and while users indicated that this information was useful, some indicated that the links did not contain sufficient detail.

Solutions Implemented

The available dataset has been expanded to include an extended lipid profile including HDL and LDL cholesterol and triglycerides. Latest Flu Vaccination status, eGFR, registered GP and surgery details have also been added. We will continue to add relevant data items as the project progresses,

A process has been defined to allow hospital diabetes clinics to sign off clinical letters en-masse from a date that they specify. This ensures that they have the opportunity to train staff on what is, and what is not acceptable content for these letters. St. John’s Hospital in Livingston approved the reintroduction of letters in May 2012, back-dating those available to 01/01/2000. The objective is now to encourage the remaining clinics to follow suit.

The system was originally designed to be read-only, with a view to implementing direct data entry at a future stage. Not only are patients recording their own weight, body mass index, blood pressure and some biochemistry tests using home recording devices, but when patients obtain results from their healthcare team, patients require the facility to enter the results. Implementing data entry was always planned for future phases, but this is likely to be prioritised based on this feedback.

While data accuracy is of critical importance in a record access system, some issues were raised as detailed above. To combat the effects of out-of-range values skewing historical graphs of data, MDMW has implemented a boundary value check, where obviously wrong values are filtered out. These results are also logged in the user audit trail so that they can be investigated by a member of the technical team. In addition, there were several reports of inaccurate smoking status, particularly those who proudly expressed the fact that they had given up smoking for several years. On investigation, it became clear that the date shown next to “Ex-smoker” was in fact the date on which this status had last been recorded. The date was corrected and users now have the opportunity to update the information themselves, the first of many data entry sections planned for MDMW.

Data currency is also an issue as some patients may still obtain results from their healthcare provider before it reaches the system. Due to the complex interfacing and batch processing implemented, it may take up to three days from the point a result is entered in a GP or hospital system before it appears on MDMW. SCI-DC and MDMW are looking at ways to speed up this process and incorporate more ‘real-time’ processing. Unfortunately, there is always likely to be some delay due to technical and data entry factors.

We received several reports from users who indicated that their registered GP was incorrect. After investigating this further, it has become clear that some practices allocate patients equally between all of their registered doctors. This means that the GP associated on the system may not necessarily be the GP that the patient regularly sees. As GP registration details are provided to us by the national master patient index (CHI) there is, unfortunately, nothing we can do to change this. To change the ‘official’ registration, the patient must raise this with their doctor during their next visit to their health centre or surgery.

While the tailored links were designed to be most appropriate for general information on relevant diagnoses, the project team acknowledge that they may not be suitable for all and this section of the resource will be reviewed to provide more dynamic and detailed links based on usage and duration of diabetes. Target charts will be tailored to patients’ current condition based on their process outcomes, rather than potentially unachievable ‘gold-standard’ target.

Discussion

Some patients expressed the opinion that they still need more help managing their medications and weight, particularly when starting new drugs. This is entirely understandable as MDMW is not intended, or expected to provide the complete solution for diabetes management. There will always be the need for clinical discussion, although MDMW can provide considerable assistance during the time periods between appointments and lead to more productive consultations.

We are currently investigating ways in which personalised goals can be included in the system and if this proves successful it may help to support successful weight management, amongst other metrics.

MDMW only presently provides data on diabetes, but it can effectively be viewed as a proof of concept for other long-term conditions, along with Renal

PatientView. Other conditions are however currently out of the remit of the project, as acknowledged by those who raised the possibility of including non-diabetes results.

User Guide

The next question aimed to identify what proportion of users reviewed the user guide before their period of access.

Did you review the user guide before you accessed your personal information?

Section_B_19	n	%
No	11	20.8%
Yes	42	79.2%
Total	**53**	**100.0%**

Discussion

Around 4/5 of users indicated that they had reviewed the user guide before they used the system, indicating that it was a worthwhile training resource. No other training resources are currently planned in addition to this guide.

User Feedback and Issue Reporting

The following three questions aimed to identify what proportion of users submitted feedback and whether or not this was responded to quickly enough and to the patient’s satisfaction.

Did you raise feedback about any problems you had when using the system?

Section_B_20	n	%
No	17	32.1%
Yes	36	67.9%
Total	**53**	**100.0%**

If so, was your issue responded to quickly enough?

Section_B_21	n	%
Slow Response	7	19.4%
Quick Response	29	80.6%
Total	**36**	**100.0%**

Did you receive a resolution to your issue that was to your satisfaction?

Section_B_22	n	%
Unsatisfactory	7	19.4%
Satisfactory	29	80.6%
Total	**36**	**100.0%**

Discussion

While a large proportion (roughly 2/3) of patients' submitted feedback either via the website or email, feedback indicates that this was responded to, in the main (over 4/5) quickly, and to the satisfaction of the individual. The project team acknowledges that there is scope for improvements to be made and this will be alleviated with the appointment of a new administrative resource to triage and manage any feedback. To date, the core project team has dealt with all feedback and as the project rolls out towards its target of 5000 registrants by the end of 2013, continuing the current approach is not sustainable.

Most issues highlighted were in relation to login problems and some users indicated that as the system has evolved, issues have been resolved more quickly and efficiently. Mid-way through the project, the Citizen Account team appointed a dedicated administrative resource to deal with these issues and provided a contact phone number. These developments have clearly made a considerable improvement.

Most indicated that issues were resolved quickly although feedback indicates that some issues remain unresolved. The project team will investigate these issues as a priority to ensure all users are provided with a suitable response.

Best Features

The remaining four questions in the survey were open-ended and allowed the patient to express their opinions in their own words. The first of these aimed to identify what the users felt were the best features of the system.

The presentation of clinical results not only provides traditional line graphs, but also the target chart described earlier. Patients report that they have taken this to appointments and have received favourable feedback from the healthcare team. The ability to track progress against guidelines is seen as an essential reminder of the history of the diabetes journey.

The full prescribing record containing all drugs going back several years was described as helpful to track progress and useful to identify when other illnesses were being treated.

Many users particularly liked the monthly email updates. These provide an update on the project status, detailing known issues and new developments. System usage around these mailings has proven interesting to observe as usage spikes significantly around these times. It is now seen as an essential awareness tool in encouraging repeat usage.

Patients appreciate the ability to have instant, hassle-free access to the data, where the traditional approach to diabetes care has been dictated by the healthcare team. The development has broken down barriers to access where there is often reluctance to share data. This has led to fewer phone calls to

NHS establishments, indicating a reduction in time and financial costs to both the patient and the NHS. Users preferred access to "hard data" rather than hearing terms such as "within acceptable limits". There is a strong belief that efficient and secure access leads to more involved and responsible patients aiming to benefit from improved outcomes.

> *"I firmly believe that I am part of the system that manages my healthcare. This facility encourages – and reinforces – that belief."*

> *"The doctor has told me that patients don't have the knowledge to interpret their results and it "only causes them to worry". The exact opposite is true. This service solves this problem."*

Patients like having the results at hand alongside easy to understand information so that they can discuss them with their healthcare providers. It also means that patients no longer need to write down their results and keep paper records. Users like being able to spend time interrogating their data, without any pressure. This led to reports of "less worry" and greater understanding, which will ultimately lead to a reduction in diabetes complications and inpatient admissions.

> *"…this has had a positive influence on my control/results already."*

Discussion

Many of the positive features highlighted were expected by the project team, but there were notable exceptions. While the process outcome histories were expected to be useful to track changes over time, the ability to track conditions using the medication history was not anticipated.

There was an expectation that the system would break down some traditional barriers to record access from clinical staff, but there were more reports of reluctance to share by data the healthcare teams than were anticipated.

The project team were interested in how patients deal with record access and that it may cause "harm" in some cases. Clearly, this is not the case for the majority, with reports of less worry and a positive impact on control and outcomes.

While the site was described as easy to navigate, suggestions have been made to improve the layout to make it less text-based and incorporating more graphical displays. This is an area that the project team are already investigating.

Worst Features

The next question aimed to identify what the users felt were the worst features of the system.

As described previously, some issues with the login process and username format remain, but these are currently in the process of resolution so that the user details are more memorable. Some would like the ability for the site to remember login credentials so that they do not have to be entered each time. Unfortunately, this would be in breach of security protocol so this suggestion cannot be progressed,

Data issues were mentioned by several respondents who said that some results were either missing, out of date, wrong or duplicated. Due to the nature of the system collecting information from all diabetes-related sources, duplication is likely.

One user indicated that the significance of the tests not explained well enough. This is believed to be a training issue as all clinical tests are displayed alongside “?” links which, when clicked, provide more information on the test, why it is recorded and what normal ranges are.

Finally, the time taken from original registration to initial access is in some cases too long. While the improvements described earlier will enhance the process, the time taken for doctors to sign forms is outwith our control.

Solutions Implemented

Data issues have been addressed where possible to do so. One significant area of “missing” data is eye data after patients are referred to the ophthalmology clinic with diabetes-related complications. This is a failing of the healthcare infrastructure generally as these results are not currently shared electronically outwith these silos. This is an area the project team is actively pursuing to obtain these results and provide a more complete, integrated record. Any obviously erroneous results outwith defined ranges are now filtered from display on the history graphs and table.

Those involved in the early stages of the project who had access to the clinical correspondence expressed their dismay at the fact they were removed. The solution to this problem is described earlier in this report, but correspondence will remain inactive until a hospital clinic explicitly opts-in to data sharing.

Early in the project, there were reports of system failures and downtime. While the system is now far more resilient, exception logs are also maintained and monitored daily.

The signup process clearly has scope for improvement in order to speed it up. One amendment is to allow diabetes clinics anywhere in the health service to provide information and enrolment forms directly to the patient while they are in the waiting area. This means that the patient can sign up immediately without the current paper trail, therefore reducing costs and improving the user experience.

Discussion

All issues raised were deemed to be manageable within the scope of the project and several improvements have already been implemented, with others in development. The system is far more resilient that when it was first implemented and more centralised resources are in place to deal with problems.

New Features

The next question aimed to identify what new features the project group wished to see implemented to assist in their self-management. We have divided these into two sections to distinguish between those we anticipated, and those we were not expecting.

Anticipated Requests

Many patients expressed their desire to enter their own home recorded results. In particular weight, blood glucose and blood pressure. They also asked to record related medical conditions, family history and any other issues. They also want to record details of their next appointments, all of these data cumulating as an aide memoir. This is already part of the plan for the next stage of development. Patients will also be given the option to decide whether or not they want to share self-recorded data with health care team electronically via SCI-DC, ensuring they remain in full control *their* data.

Users expressed their interest in additional results and data. The system was designed with a “minimum dataset” with the scope to expand as required. Results explicitly mentioned that are yet to be added include ACR, HDL:LDL ratio and dates of future appointments. Patients also want to know about how certain drugs can affect their diabetes. While the medication section shows external links explaining diabetes-related drugs, this section will be expanded to include other relevant medications such as steroids. Some asked for results not directly related to their diabetes, but this is currently outwith the scope of the system. There is no reason why, in future, other NHS system could not expand on the MDMW infrastructure, and this approach would be actively encouraged. Furthermore, patients want to be able to edit obviously erroneous results and become active participants in their data validation.

Users would like the ability print their own results to take for discussion at appointments. While the web pages are printable individually, the project team plan to provide focused PDF files for download and printing. These will include latest results and charts as appropriate and will be available in a variety of options including a complete summary and patient-recorded “my home results” to pass to the healthcare team. These can then be interpreted and discussed appropriately with the healthcare team.

Some respondents wished to have the ability to book appointments using the system. This has been discussed previously with the Diabetic Retinopathy Screening service and may be possible in future. Existing record access systems provide “appointment request” functionality due to the difficulty in directly interrogating hospital and GP systems. It should be possible to do the same for MDMW.

Enhanced online communication with the healthcare team is seen as being essential. The system is currently only resourced to deal with technical and non-urgent queries. Patients with urgent queries are advised to contact a member of their diabetes team directly. In future, the project plans to incorporate a real-time communication ‘hub’ where patients can ask questions during defined “surgery” hours to a helpdesk manned by a trained specialist nurse or consultant. We expect that this will cut down on phone calls and non-emergency appointments.

Patients said it would be nice have a goals section for discussion with the healthcare team describing objectives for the next review. The patients could then go on to the system to review and amend accurately what has, or has not gone well.

Finally, the project team are developing an alert system to advise when results are updated. This will avoid users having to go in and out of the system frequently as they await new reading. The project team will be implementing this functionality using SMS and email. Further consideration will be given to how patients are advised to act upon new results once they appear.

Unexpected Requests

Some patients expressed the desire to see all of their results since diagnosis, some even going as far back as 1966. Unfortunately, the system is restricted to data recorded electronically in NHS systems, so unless retrospective data is entered, this will not be possible until the patients can directly add information they may have recovered from previous personal notes.

Some patients wish to have the ability to view their eye photographs on screen. While this is possible, the project team are interested in knowing how these will be interpreted. It is likely that this will be taken forward in pilot to assess the implications prior to a wider rollout.

In addition to the presentation of results, patients would also like to see what in effect constitutes decision-support functionality. Respondents asked for a summary page showing “alerts” for out-of-range values for prioritisation.

Discussion

The requests listed above provide considerable food for thought for expanding the scope of the project. While many requests are already part of the plan, those that were not anticipated will be reviewed and prioritised appropriately. The user group will be informed as these developments progress.

Any Final Comments?

The final section of the survey allowed the respondents a final opportunity to express any opinions not previously articulated.

Generally, final comments were very positive, complimenting the team on developing the resource and indicating that several users were doing their best to promote it amongst their peers. Despite that, it is acknowledged that the project is currently only scratching the surface of the wider diabetic population, many of whom would benefit greatly from the initiative. The awareness campaign is discussed in the final sections of this report.

> *"I cannot tell you how much of a psychological boost this system has given me. I am suffering great pain and every day is a struggle to exist. This site and the information on it is like a lifeline for me. Thank you so much."*

There seemed to be general understanding that this was a new system and the 'odd difficulty' is difficult to avoid, although these are now known to be fewer and further between. The final request was to include links to more relevant websites such as NHS Inform. Closer collaboration with other NHS websites are currently under discussion.

Next Steps

In order to reach the target of 5000 registrants by the end of 2013, MDMW has devised a campaign to raise awareness of the record access system and the wider information resource. In 2011, posters were sent to all 14 diabetes managed clinical network managers to disseminate within their health boards. These have been displayed at hospital diabetes clinics and GP surgeries. From March 2012, all letters sent to patients regarding Diabetic Retinopathy Screening appointments contained links to the MDMW website. In the first 6 months of 2012. ~15,000 MDMW business cards have been sent to regional representatives, at their request, to disseminate as appropriate within their health board.

MDMW are now targeting specific groups of health care professionals to raise awareness within their patient populations. A pilot in NHS Lanarkshire has seen a rapid increase in uptake via the Diabetes Specialist Nurse clinic at Monklands Hospital. A highly significant development will begin in August 2012, where the Scottish Government have arranged a 6 week campaign to include MDMW literature in the prescription packs of people with diabetes collecting medication. It is expected that during this time, registration and enrolment will increase dramatically. Further activities include the project team delivering further presentations at patient and MCN events and circulating advertising presentations to all hospital clinics for display in their waiting rooms.

The project currently has funding to continue developing and rolling out the system until the end of 2013. Key requirements are to incorporate user data entry, encouraging further ownership of the clinical record. The ability to generate custom reports is seen as a complimentary development so that home results can be printed and taken along to the consultation. The project team also aims to reduce the number of manual steps in the enrolment process, with new developments due for release in August 2012. For the benefit of the patient, notifications via email and/or text message will let the user know when new data is available for them to review.

The project has a strong research agenda and in addition to the activities completed to date, further analyses and evaluation are proposed in the following areas:

- What do patients do with access to their electronic diabetes record?
- Clinician perspectives and evaluation of experiences
- Survey of patient awareness before and after advertising campaign
- Patient satisfaction analysis
- System usability and accessibility
- Economic analysis
- Impact on process, long-term outcomes and acute admissions

Conclusion

The feedback provided from the analysis of the surveys and the interrogation of the system audit trail has provided some essential insights into the current usage of the system, its benefits and where it can be improved.

The overall conclusion of the evaluation is that the system is now a useful additional component for the self-management of diabetes in Scotland. Users report that it helps them in their self-management, with 98% also indicating that it leads to a more productive consultation with healthcare professionals.

The project will continue to evolve until the end of 2013, providing new resources to further enhance self-management. The project team are due to employ a new administrative resource to deal with user feedback, further enhancing the sustainability of the system. The fact that it is centrally managed means that there is minimal impact on front-line services. Work will continue to evaluate and report on the system both via the MDMW website and via peer-reviewed literature.

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Appendix 1: User Survey

mydiabetes myway

… the interactive diabetes website

NHS
SCOTLAND

We will soon be writing our project evaluation which we will make available for you to review on the My Diabetes My Way website. In order to do this thoroughly we would very much appreciate your help. In order to gain your feedback on this service, we need to ask you a few questions about your experiences so far. It should only take about 5 minutes to do this.

We would like to know what you liked about the system and what could be improved. Please answer the questions as honestly as you can. There are no right or wrong answers. All responses will be stored securely and our analysis will conceal the identity of respondents. Please mark one answer for each question with a cross and return the completed form to mydiabetesmyway@nhs.net

Section A. The following questions aim to identify how you found the enrolment process.

Did you receive information leaflets and an enrolment form to sign through the post?

Yes	No

Did you complete and return your enrolment form, signed by a member of your health care team to verify your identity?

Yes	No

Did you gain access to your personal diabetes information?

Yes	No

If you have any comments about any part of the enrolment process or experienced any difficulties in obtaining a signature from a member of your health care team, please explain below:

Continued overleaf…

Section B: Please only answer this section if you were able to get online and access your information. The following questions are about your opinions of the My Diabetes My Way system.

Please mark one answer for each of the following statements with a cross, depending on how much you agree or disagree with them:

	Agree strongly	Agree	Disagree	Disagree strongly
1. The system contained all the features that I expected				
2. The system helped to remind me of information discussed during consultations				
3. The system will help me make better use of my consultation time				
4. The system means I do not need to keep my own paper records				
5. The system means I do not need to phone my doctor for new results				
6. The system was up-to-date				
7. The system was easy to use				
8. The explanatory information helped me understand my results better				
9. The links helped me to find further information relevant to my diabetes				
10. The graphs of information were helpful to monitor changes over time				
11. I was confident that my information was secure when using the system				
12. The system has helped me manage my diabetes better				
13. Accessing my information has helped to improve my knowledge of diabetes				
14. Accessing my information has made me more motivated about my diabetes				

Continued overleaf…

	Agree strongly	Agree	Disagree	Disagree strongly
15. Accessing my information has helped me to meet my diabetes goals				
16. The system will help me to set my own diabetes goals				
17. Online access to diabetes information will significantly improve diabetes self-care across Scotland				

If you disagree with any of the statements above, explain why below:

Did you review the user guide before you accessed your personal information?

Yes	No

Did you raise feedback about any problems you had when using the system?

Yes	No

If so, was your issue responded to quickly enough?

Yes	No

Did you receive a resolution to your issue that was to your satisfaction?

Yes	No

If you have any comments to make about any feedback you submitted and responses you received, please enter them below:

Continued overleaf…

Please answer the final questions in your own words:

What was the best part of the system, and why?

What was the worst part of the system, and why?

What new features would you like to see added to the system?

If you would like to add anything that has not been covered so far in the questionnaire, please use the space below:

Thank you for taking the time to complete this questionnaire. Please return the completed form to mydiabetesmyway@nhs.net

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