

The University of Glasgow

School of Medical, Veterinary and Life Sciences

August 2016

An Analysis of the Opportunities and Challenges Involved in the Formal
Delivery of Self-Management Support in Diabetes using Digital Health
Initiatives

Author

Laura Rooney

2215566r

Supervisor

Dr Sanna Rimpiläinen

*A thesis submitted in partial fulfilment for the degree of Master of Science in
Stratified Medicine and Pharmacological Innovation.*

*I declare that none of the work detailed herein has been submitted for any other award at the
University of Glasgow or any other institution.*

*I declare that, except where specifically indicated, all the work presented in this thesis is my
own and I am the sole author of all parts.*

Contents

| | |
|---|----|
| 1. Acknowledgments..... | 3 |
| 2. Abbreviations..... | 4 |
| 3. Introduction..... | 5 |
| 4. Methods..... | 7 |
| 5. Issues within Self-Management Support of Diabetes in the Pre-Digital Era..... | 8 |
| 5.1. Reduced Access to Self-Management Support Services | 8 |
| 5.2. Digital Solutions Cannot Interact with the NHS System | 9 |
| 5.3. Social Barriers to Change | 10 |
| 6. Opportunities Available to Improve Self-Management Support Services through Digital Health Solutions | 12 |
| 6.1. What is Digital Health?..... | 12 |
| 6.2. The Digital Health and Care Institute | 12 |
| 6.2a. My Diabetes My way (MDMW)..... | 12 |
| 7. Challenges in Implementing Digital Health Solutions..... | 17 |
| 7.1. Uptake of Services | 17 |
| 7.2. Integration of Personal Data into the NHS Data Stores..... | 17 |
| 7.3. Data Protection Breaches | 18 |
| 8. Conclusion | 19 |
| 9. References..... | 20 |
| 10. Appendix..... | 22 |

1. Acknowledgments

I would like to thank my supervisor Dr Sanna Rimpiläinen for the taking the time to support and guide me throughout the course of my project and provide excellent feedback and leadership. I would also like to thank all the other people at the Digital Health and Care Institute who helped me with this report.

2. Abbreviations

| Abbreviation | Definition |
|---------------------|--|
| HCP | Health Care Professional |
| SM | Self-Management |
| LTC | Long-Term Condition |
| NHS | National Health Service |
| CVD | Cardiovascular Disease |
| EHR | Electronic Health Record |
| MDMW | MyDiabetesMyWay |
| SCI-DC | Scottish Care Information-Diabetes Cloud |

3. Introduction

This thesis will critically analyse self-management (SM) support services available in Scotland in the form of a gap analysis and demonstrate how digital solutions are required to increase the efficiency of health services nationally in order to fill these gaps. Firstly, the overall concept of self-management will be defined, including its importance in the treatment of long term conditions (LTC), using diabetes as an exemplary condition. This will be followed by an overview of the challenges involved in the delivery of self-management support in a ‘pre-digital’ era, where digital solutions have not been widely implemented. A review of the gaps present in the current provision of self-management support services will be demonstrated and an examination of appropriate digital solutions which could fill these gaps will be presented. Emphasis will be placed on projects run by the Digital Health and Care Institute and the challenges faced in implementing them.

There are various definitions of self-management but the executive summary of Alliance Scotland’s ‘Gaun Yerself’ strategy defines it as, “the successful outcome of the person and all appropriate individuals and services working together to support him or her to deal with the very real implications of living the rest of their life with one or more long term condition” (pg7)¹. Further to this, they state “successful self-management relies on people having access to the right information, education, support and services. It also depends on professionals understanding and embracing a person-centred, empowering approach in which the individual is the leading partner in managing their own life and condition(s) (pg10)¹.” There are various stages within the self-management journey of LTCs, each of which require different and varying levels of support (pg9)¹:

1. Diagnosis: SM support helps people come to terms with the diagnosis
2. Living for today: Challenges social exclusion and helps to navigate an often difficult time
3. Progression: Enables people to recognise early warning signs and react appropriately; supports changing needs.
4. Transitions: Provides person with control as they move between services.
5. End of life: supports people to maintain control during a complex time

There is a demographic shift occurring in Scotland which necessitates an evolution of the balance of health and care resources. With an ever increasing ageing population, chronic conditions are becoming significantly more prevalent. There is an estimated two million people living with long term conditions in Scotland. The economic argument for providing enhanced support for self-management that not only reduces the need for interventions by HCPs but also enables people to achieve greater continuity of work where possible is valid². Self-management as a concept is not new, however the current implementation of support strategies is not aligned across different service provisions. Moreover, individuals do not have the same ability to self-manage and some groups face greater or multiple

barriers to self-management. “Better Health Better Care” is an action plan setting out the Scottish government’s projections for health in Scotland. It entails a shift from viewing people as “patients” or “service users” towards a new ethos that sees people and the NHS staff as partners or co-owners in the NHS (pg5)³. LTCs and self-management of these conditions are key priorities within this agenda, giving way to the “Gaun Yerself: Self-management strategy for long term conditions in Scotland” (pg71)¹. These policies are driving towards a health service which is person-centred and therefore empower people to better self-manage their LTC. Achieving this will involve close collaboration from diverse services including agencies, carers and Healthcare Professionals (HCPs) however, these sectors need to become better integrated to allow for the evolution of a person-centred health care system which focuses on empowerment.

There is a plethora of LTCs in which SM is vital to the person’s survival, but for this thesis, the emphasis will be placed on the SM of diabetes. Diabetes Mellitus is a chronic condition of alarming prevalence with 5.1% of the Scottish population having some form of the condition. This poses a huge strain on the national health service and is estimated to account for 10% of the total NHS budget across the whole of the UK. Obesity is a major risk factor for type 2 diabetes and accounts for 80-85% of the diabetes cases in Britain and considering two thirds of the British population are overweight, rates of diabetes are expected to continue to rise. Cardiovascular complications are the major cause of mortality among those with diabetes meaning that one in five cardiac-related emergency admissions are by people with diabetes.⁴ Therefore, there is a need to adopt effective self-management support for diabetes nationally in an attempt to improve condition management and reduce the economic burden on the NHS⁵. Self-management of diabetes occurs in various different forms including the injection of insulin when required and correct healthy lifestyle choices being two major examples.

4. Methods

Documentary analysis was performed to allow for bodies of evidence to be collated and presented herein. Evidence to form the basis of the gap analysis was taken from appropriate policy documents, governmental strategies, NHS strategies, journal articles, websites and blog articles. Gap analyses are carried out in many industries in order to demonstrate which areas the industry excels at and which areas need more work. Carrying out a gap analysis in this area of the healthcare industry requires thorough investigation of the current state of self-management support services. Before writing the body of the text, it was imperative to look into what diabetes patients currently receive in way of support and what help is offered to them in order to self-manage (both at the point of diagnosis and for the rest of their lives). Then, an analysis of what is required to help to fill these gaps can be described. In this thesis, the emphasis is placed on the implementation of digital solutions to do this. This is then followed by the feasibility of the gaps being filled by these solutions-in this thesis that describes the challenges faced in implementing digital solutions in today's national health service.

5. Issues within Self-Management Support of Diabetes in the Pre-Digital Era

The term ‘pre-digital’ refers to the manner by which care is delivered in the absence of digital initiatives. In this section, a gap analysis will be performed to demonstrate the barriers to good self-management in the pre-digital era. These include reduced access to care or education on self-management, interoperability of digital solutions into the NHS and social barriers centred on expectations of the health service.

5.1. Reduced Access to Self-Management Support Services

Access to self-management support services plays a major part in the delivery of improved care for those with diabetes. Whether it be access to data, access to educational resources or access to care in general, access is an integral characteristic of a person-centred health service. The ability of a person to view their own health data is an essential part of the patient-empowerment ethos which is a core area of development in the national health service. However, despite this, the implementation of electronic health records has still not been verified. The opportunities which arise from employing an electronic health record are vast and in terms of self-management of diabetes, it would give the patient the ability to far better manage their condition with this new depth of knowledge at their disposal. Electronic health records (EHRs) have been implemented in several countries around the world with positive results. Estonia has utilized them since 2005 as part of their national health service and it has proven to be very successful. Estonia has a population of 1.4m people and like Scotland, offers free health care to all its inhabitants (pg2)⁵. Estonia is widely regarded as a leader in the field of electronic health records as it uses an open style exchange layer to allow for data from different databases to be integrated into one record so that all of the patient’s data is incorporated into one site. As well as the overall success of the actual system, the uptake of the EHR approach has also been excellent, with 44% of Estonians using the system by 2011 (pg19)⁵. Therefore, the scope for rolling out a system in Scotland similar to that in Estonia is possible and would allow for the data of patients to be accessed from one central hub instead of many distinct electronic medical records which is in use across the UK currently.

Educational resources are hugely important for people with diabetes to understand their condition and how to effectively self-manage at home. Valuable diabetes education has huge implications into the choices people with this LTC make. A study by Nicolucci et al reports on the effectiveness of self-care interventions in diabetes, demonstrating the benefits of education for better SM in diabetes. Although the study highlighted the inherent benefits of these programmes, it also emphasizes the lack of access or availability to the people who use these services. One startling statistic reveals that people with diabetes who have no such educational interventions are at a four-fold increased risk of developing complications⁶. Although there are educational resources provided by clinicians at the point of

diagnosis, there is a lack of engaging content to keep people motivated to continue self-managing properly for the rest of their life. This is particularly the case for young people and teenagers. Educating young diabetics is hugely important because they need the support to understand their condition and how to overcome hurdles they will face. Some of the content provided to newly diagnosed diabetics (for example lots of clinical terms) can be very bewildering and there is an expectation of these people to be able to properly self-manage right away. Therefore, people of all ages need simple and engaging content to educate themselves on their condition and what positive choices they can make to help control their diabetes.

Another huge access issue is the difficulties people endure as a result of their location. This is particularly the case for those that live in rural settings such as the Highlands and Islands of Scotland. Self-management for these people like any diabetic requires assistance and appropriate support to achieve good clinical outcomes and feel in control of their health. The Highland region covers a land mass equivalent in size to countries such as Belgium or Wales and while specialist staff can provide peripatetic clinics in community hospitals, coordinated by a small network of specialist diabetes nurses, face to face contact is limited and irregular. In addition, the travelling distances for patients and staff are long and may not be cost-effective. Therefore, by virtue of being remote, these people can often feel very isolated.⁷

5.2. Digital Solutions Cannot Interact with the NHS System

A major issue in digital health is to find a way to incorporate digital health innovations into the delivery of formal care so that patients and the health service can understand and make use of the information they provide. This integration of different digital interfaces and health services is called interoperability. People and service providers need rigorous interoperable health IT tools to ensure the right information is available at the right time to allow for better health and healthcare-related decisions to be made. An example of a device which is not interoperable with the health service is the 'FitBit' which feeds vital signs such as blood pressure and heart rate to the user. This kind of information tracking falls under the so-called 'Quantified Self' movement which has become hugely popular in recent times⁸. All quantified-self devices have a data store where the information collected about the individual is stored. These are called personal data stores. The information which is collected by HCPs and entered into an individual's health record is called statutory data and this data is trusted by the NHS because it is recorded by HCPs. The issue of interoperability becomes particularly critical in this context because the data generated and stored in one's personal data store cannot interact with the statutory data store. This leaves the personal health devices redundant in terms of functionality from a clinical perspective because the data cannot be used in decision-making. The aspiration in terms of digital health is to allow for the two types of data store to interact with one another in order to give an enhanced view of a

patient's overall health. This is particularly important in diabetes because it is a condition in which blood glucose recordings are being made constantly. If there was the possibility of sharing these recordings with a HCP, the self-management of the disease could be greatly improved because the HCP would be better able to support the patient in real-time⁹.

5.3. Social Barriers to Change

A national incentive to promote behaviour change within health and care service provision is required to allow for better self-management support services to evolve. However, in the pre-digital era, there are two major social barriers halting this behaviour change: the design of the services and lack of communication.

1. Firstly, the health care system was traditionally designed to deliver acute, symptom-driven care where the HCPs were in full control. Therefore, it is poorly configured to effectively treat chronic diseases such as diabetes that require the development of a co-operative, daily self-management plan. There is a requirement for strong collaboration between patients and health care professionals to properly deal with LTCs. However, clinicians struggle with the reality that the control lies with the patient. This paternalistic view which forms the basis of the NHS must evolve into a person-centred service where the control of the patient to self-manage is fully supported. Moreover, traditionally the success of patients managing diabetes has been evaluated by their ability to adhere to a prescribed therapeutic schedule and much research has been put into ways in which adherence to medication can be measured. However, a rigid model of care focussed on evidence-based medicine alone is not effective in achieving a sense of wellbeing for people faced with such complex challenges as those with diabetes. The needs of a diabetic patient are fluid and change considerably as their disease progresses. Therefore, interventions need to be tailored to suit the individual's needs, their lifestyle, culture, priorities and goals.¹⁰ The idea of a person-centred approach to healthcare will also enhance patient engagement to better self-manage. The patient will be better supported during their times of difficulty with personalised interventions tailored for different groups of people with diverse needs in order to keep them engaged in their self-management.
2. Secondly, the lack of communication holds back the evolution of better self-management support services because communication is integral to this process. Effective communication between patients and HCPs has been shown to improve patient satisfaction and engagement to self-manage their condition. A patient-centred health service requires frequent high-quality communication where the patient feels empowered to become involved in decision-making related to their care. However, there is limited infrastructure in place for patients to be able to communicate with HCPs when they need support to better self-manage. Doctors can empower patients by providing choices,

being responsive to patient preferences, and understanding, listening, and encouraging patients to ask questions. An approach that affirms the patient's capacity to identify and learn to solve their own problems relies on effective communication between doctor and patient. There needs to be a shift away from fully clinical checklists towards an agenda which also incorporates communication with the patient about how they are coping and what more can be done to support them. The main form of communication between the two is formal doctor appointments where the patient can discuss their issues face to face with the doctor. Although, it is the time period between these appointments where communication is lacking and therefore must be improved¹¹.

The modern delivery of care requires effective communication between HCPs in order to share best practices, knowledge and improve the standard of support within self-management services for all patients. Knowledge-management and knowledge-sharing is an ethos which the NHS wants to nourish in order to ensure the information on best-practice is well documented and shared across services. More needs to be done to allow for effective knowledge exchange within self-management support services to ensure each patient receives the best care¹².

There is also a lack of well-managed, high-quality communication between patients themselves. Patient to patient support is a huge part of effective self-management because it has the potential to enhance patient empowerment and provides the person with a sense of inclusion and positive reinforcement. It can allow them to discuss issues relevant to them and share knowledge on their experiences and advice to their peers. This can be especially useful for young people who may feel confused about how to effectively self-manage and are reticent to approach HCPs. However, there is limited patient to patient communication which can offer this level of support for diabetics in the health service at present. Specific services such as 'PatientsLikeMe' where patients with the same conditions can communicate are very beneficial and is something that the NHS should work towards to better support their patients.

6. Opportunities Available to Improve Self-Management Support Services through Digital Health Solutions

6.1. What is Digital Health?

In undertaking this analysis, it is valuable to provide a brief introduction to the concept of Digital Health. Nuviun describes health information technology as the application of processing data within digital health. They explain that “it involves both computer hardware and software, storage, retrieval, sharing and use of healthcare information data and knowledge for communication and decision-making”. Nuviun also postulates that the global health IT market is expected to reach \$56.7Bn by 2017. “Advances in technology, such as cloud computing, social networking, the emergence of ‘big data’ holdings and related analytics are anticipated by policy makers and the industry to improve healthcare systems by diminishing costs and ameliorating clinical outcomes”.¹³ Approximately 45% of the world’s population now have access to the internet and so the scope for rolling out digital health solutions is huge¹⁴. It is a well-known fact that technology can support individuals with better information; minimize face-to-face contact with health services where appropriate and embracing technology is key to the success of a person-centred healthcare system which is the goal for NHSScotland.

6.2. The Digital Health and Care Institute

In terms of digital self-management support for diabetes, there is a diverse range of opportunities to enhance and change the current delivery of care to empower people to make the best decisions for their health. The Digital Health and Care Institute Scotland is running many projects based on the improvement of self-management of diabetes through digital solutions. In this dissertation, focus will be placed on a specific digital platform called My Diabetes My Way¹⁵.

6.2a. My Diabetes My way (MDMW)

MDMW is a digital self-management platform created in 2008 to allow patients to have a more interactive role in their care. It is an award-winning national electronic personal health record linking multiple national institutional and patient recorded data sources to provide a unique resource for person-centred care and self-management. The platform is aligned with the Scottish Government’s ‘GauN Yerself’ self-management for long term conditions strategy and gives information on the key stages of support as outlined in the strategy. The resources encompassed in MDMW are:

1. An educational resource website

2. An e-Personal Health Record for all diabetic patients
3. Patient-decision support
4. Goal-setting functions
5. A linked, remote glucose monitoring system
6. Social media including peer-to-peer discussion groups

This platform poses various opportunities to fill the gaps in the current self-management support system discussed previously.

(i) Access to Educational Resources

In terms of access to education, MDMW gives patients access to an immense educational resources providing information on a range of topics such as diet and healthy lifestyle choices; medication categories; the definitions of diabetes varieties; information on possible complications and many other topics. The platform is incredibly easy to navigate and very interactive, allowing individuals to understand their condition more easily than through traditional educational resources provided by the NHS. It allows people with diabetes to explore their condition and their choices, as well as providing testimonials from other diabetic people who have shared their stories with the diabetic community. This allows newly diagnosed people to feel openly welcomed into the diabetic community and not to be afraid of the challenges ahead.¹⁶

(ii) Improved interoperability Allowing for Access to Personal Data

MDMW has tackled the issue of interoperability because it has a direct link to the Scottish Care Information-Diabetes Cloud (SCI-DC). The SCI-DC launched in 2002, is the statutory data store and shared electronic health record for all diabetes patients in Scotland. Since its launch, it has been successfully supporting the needs of the diabetes community in providing clinical information, support for diabetic screening services and the provision of data for local and national audit programs¹⁷. Therefore, MDMW also allows patients to access to their own health data as they can log into MDMW to view their clinical data. This is hugely empowering for diabetes patients as it allows them to see how their self-management regime is progressing and which elements of their care may require more support.

When a patient logs into the MDMW portal they are taken to their personal diabetes record which provides links to different subsets of information including ‘my results’ ‘my eyes’, ‘my feet’ and ‘my summaries’. Within the ‘my summaries’ page, the patient can view their results in a variety of different ways. For instance, the ‘clinical information summary’ gives a graphical representation of the patient’s

results and illustrates very clearly which aspects of their health are good and which need to be improved using red and green colouring respectively. This is depicted in Figure 1. However, on top of this functionality, the ‘my data trends’ link shows how the patient’s results have changed over time which is depicted in Figure 2. This gives the patient the ability to look at each individual aspect of their diabetes and view its changes since their diagnosis. This platform is an invaluable tool for diabetes self-management support because it gives a personalised account throughout a person’s lifetime and the opportunity to make changes in order to better manage their condition.

(iii) A Changing Paradigm for Health Management

As well as being an incredibly useful tool for diabetic patients to track their self-management, it is also breaking down social barriers towards new and improved health care. Patients can test their blood glucose levels at home and upload the results onto their MDMW profile. In addition, there is a food diary and a lifestyle diary-all of which their clinician can view if need be. Other inputs include a goal-setting function, giving patients the ability to have a say in their short and long term goals. The digital functionality has enabled the evolution of the new paradigm where patients take control over their health, and their clinician can actually have an up-to-date and trusted insight into the self-management of the patient’s diabetes. Since its launch in 2008, MDMW has had over 50,000 users take advantage of the resources available with 6000 accessing their medical records through the platform. It has also received positive feedback from users on its usefulness in supporting self-management¹⁸.

“The knowledge provided helps me understand the normal parameters and where I stand/can improve”

“More information available to me means I can play a more positive role in my treatment”

“Great site and I like having the long term history available to put current results in perspective”

“It is great to be able to view all of my results so that I can be more in charge of my diabetes”

Although this platform has proved popular in the diabetes community, it is not without its challenges. One of the main issues has been that uptake, although good, could be greatly increased. The reasons for this are varied and it is expected that the major cause of lowered uptake is the lack of knowledge of diabetic patients of the MDMW platform. Therefore, direct sign up of patients in primary and secondary care setting would greatly ameliorate this issue and is being investigated. Another issue is the incompleteness of the data provided or missing data which has caused discontent in the patients. In these instances, reports are sent back to the clinics for the healthcare teams to resolve the issue. In addition, the MDMW platform could greatly improve patient experience enabling peer to peer support as this is very beneficial for diabetics' learning- maintaining the ability to self-manage, as described earlier.

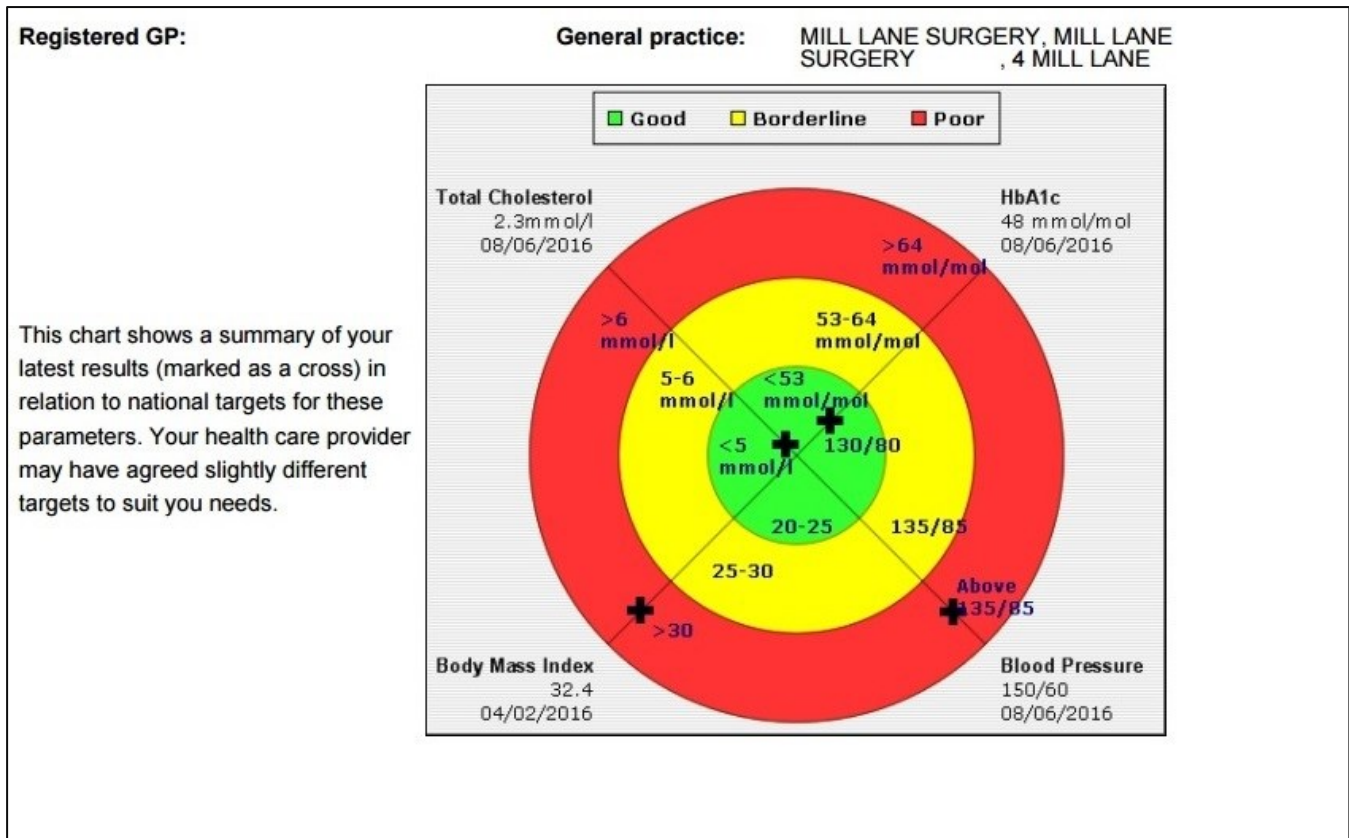


Figure1: MDMW Visual summary of patient's most recent clinical results

| My Data Trends | | | | | |
|--------------------------|--------------------------------------|---------------------------------------|---------|--|--------------|
| Result | Previous result | Current result | Change | Comment | Full history |
| HbA1c | 49 (6.6%) on 22/02/2016 | 48 (6.5%) on 08/06/2016 | -1 ↓ | Your HbA1c has decreased since your last measure, and is on target. Let your healthcare professional know if you are experiencing a lot of low blood sugar readings (hypoglycaemia) or reduced awareness of low blood sugars, as they may advise reducing your insulin dose - Click here to find out how to maintain your healthy level. | |
| Body Mass Index | 34.2 kg/m ² on 16/09/2015 | 32.42 kg/m ² on 04/02/2016 | -1.78 ↓ | Your weight is 83 Kg . Your ideal weight based on your height is between 47 Kg and 64 Kg . Your body mass index (BMI) is above target (in the obese range) but has improved from your previous measurement. Maintaining a healthy weight for your height will reduce risk of diabetes complications - Click here to find out how to maintain a healthy level. | |
| Waist Circumference | [no result] | [no result] | | Your waist measurement is an indicator of body fat which is linked to your risk of diabetes complications and heart disease. Click here | |
| Blood Pressure | 130/64 mmHg on 04/05/2016 | 150/60 mmHg on 08/06/2016 | 20 ↑ | Your blood pressure is significantly above target and is higher than your last result. Keeping your BP in target will reduce your risk of heart attack, stroke & kidney problems. If your blood pressure is regularly above target you should discuss your medication with your health care provider - Click here to find out how to maintain a healthy level. | |
| Total Cholesterol | 2.9 mmol/L on 07/09/2015 | 2.3 mmol/L on 08/06/2016 | -0.6 ↓ | Your Cholesterol is in target and is lower than your last measurement - Click here to find out how to maintain a healthy level. | |
| Albumin/Creatinine Ratio | 363 mg/mmol on 04/02/2016 | 295.7 mg/mmol on 08/06/2016 | -67.3 ↓ | Your urine protein level (ACR) is slightly above target but less than your last result. A persistently high ACR may be an early sign of diabetes affecting your kidneys. Your health care provider may wish to start you on medication to protect your kidneys - Click here to find out how to maintain a healthy level. | |
| eGFR | 18 ml/min on 11/05/2016 | 19 ml/min on 08/06/2016 | 1 ↑ | Your kidney function (eGFR) is significantly below normal but has improved - Click here to find out how to maintain a healthy level. | |

Figure2: MDMW table depicting trends in the clinical results of a patient over time.

7. Challenges in Implementing Digital Health Solutions

There is a diverse range of challenges involved in delivering a new and modernised health service which have varied levels of difficulty in overcoming them.

7.1. Uptake of Services

One key issue is the adoption of these solutions- by patients themselves and the NHS. The difficulties involved include low levels of digital participation across Scotland. For example, the fact that not enough people are digitally literate and therefore cannot make full use of digital health solutions. However, in order to achieve a digitally-literate nation, the Scottish Government has developed several strategies including the e-health strategy (2014)¹⁹ and the digital participation strategy (2014)²⁰. These strategies outline the requirement for digital participation in the roll out of e-health solutions to ensure high quality care is provided to all, no matter their condition or their location. The e-health strategy states that the “2020 eHealth Vision suggest that everyone’s health and wellbeing can be better supported through greater use of digital technology. eHealth is the key to how we access, use and share information within and across NHS Boards, and with partner organisations in order to deliver integrated health and social care; how we support patients and their carers to make informed decisions to manage their health and wellbeing; and how we use health data appropriately to improve the effectiveness of services and treatment and make significant advances in medical research”(pg2)¹⁹. Therefore, in order to achieve this integrated health service for a digitally literate nation, collaboration between the various important stakeholders must be improved. The digital participation strategy also sets out a plan to ensure digital skills are taught alongside numeracy and literacy in schools, providing children with a strong digital knowledge, early in life.

7.2. Integration of Personal Data into the NHS Data Stores

As discussed earlier, interoperability is a major issue within digital health. The integration of personal data stores and statutory health data stores is imperative to digital self-management because measurements recorded at specific, distinct time points may not accurately reflect the reality of the person’s day-to-day situation. Therefore, in order to solve this issue, data analytics companies have an opportunity to develop data exchange layers to allow for the personal data to be cleaned, analysed and fed into the statutory store efficiently. However, MDMW has achieved this by allowing for progress to be made by linking itself to the SCI-DC. This digital interaction could be used as an example of best practice within the NHS showing how personal data stores can be integrated with the statutory data stores, thus pushing forward the progression of more comprehensive real-time digital health records. In

addition, the Digital Health and Care Institute, create demonstrator environments that allow products to be tested in an environment similar to the system used within the NHS. Additionally, NHS England and the European Commission have released guidelines on the development of interoperability within healthcare systems and how it should be achieved thus further increasing the imperative for more sophisticated interoperable personal data systems ^{21,22}.

7.3. Data Protection Breaches

These changes mean the healthcare industry is moving towards ‘big data’ where large amounts of information about patients resides in different types of data stores that can be accessible quickly. The data held within these statutory and personal data stores is also incredibly sensitive with confidentiality and integrity being key attributes associated with the use of this data. This data is deemed to be of higher value to criminal organisations than banking details due to their unique characteristics²³. Therefore, security of big data is absolutely vital. According to an investigation by a privacy campaign group, the NHS has 2500 breaches of confidence each year²⁴. Despite the NHS having several data protection acts, more needs to be done to achieve safer, more secure data stores.

8. Conclusion

Digital Health has the potential to play a pivotal role in evolving the way in which care is delivered in Scotland, empowering both citizens and professionals through better digital services and information. This development will directly improve the outcomes of professional care, and simultaneously provide essential support for effective self-care and health improvement by people in Scotland. Self-management is an integral component of diabetes care and thus, support services must be aligned with policies set out by the Scottish Government to improve self-management services for patients. As discussed, the services currently provided for diabetes patients have greatly improved and the evolution of digital health solutions will be instrumental in further improvements. It has been demonstrated that digital diabetes solutions such as My Diabetes My Way are hugely beneficial for self-management of Diabetes because it provides patients with the ability to view their diabetes-related data and track their health as well as access important educational resources. By legislating for its development and enabling projects that move forward this field of innovation, there is a significant opportunity for Scotland to meaningfully improve the digital development of health and care systems and indeed create a leading position globally in its development. Digital solutions such as those used within the self-management of diabetes can be translated and expanded to improve the self-management of other LTCs. This will build greatly on the infrastructure that NHSScotland has created in its vision to create a person-centred health service for everyone in the very near future.

9. References

1. Long Term conditions Alliance Scotland (2008). *Gaun Yerself*. Edinburgh: The Scottish Government. 1-83.
2. Scottish Government, S. A. H. (2012, August 1). *Long Term Conditions*. Retrieved July 8, 2016, from <http://www.gov.scot/Topics/Health/Services/Long-Term-Conditions>
3. The Scottish Government (2007). *Better Health Better Care Action Plan*. Edinburgh: The Scottish Government. 1-86
4. Diabetes UK (2014). *Diabetes: Facts and Stats*. 3rd ed. England: Diabetes UK. 1-21.
5. Pro eHealth. (2014). *Estonian EHR Case Study*. Available: http://proehealth.eu/fileadmin/pro-ehealth/casestudies/proehealth_case_report_estonia_ehr.pdf. Last accessed 20/7/16.
6. Nicolucci, A., Cavaliere, D., Scorpiglione, N., Carinci, F., Capani, F., Tognoni, G., & Benedetti, M. M. (1996). A comprehensive assessment of the avoidability of long-term complications of diabetes. A case-control study. SID-AMD Italian Study Group for the Implementation of the St. Vincent Declaration. *Diabetes Care*, 19(9), 927–933.
7. Rushworth, GF. (2015). Access to medicines in remote and rural areas: a survey of residents in the Scottish Highlands & Western Isles. *Public Health*. 129 (3), 224-251.
8. Swan, M. (2009) *Emerging Patient-Driven Health Care Models: An Examination of Health Social Networks, Consumer Personalized Medicine and Quantified Self-Tracking*. Int. J. Environ. Res. Public Health, 6(2), 492-525
9. Diabetes UK (2015). *Taking Control: Supporting people to self-manage their diabetes*. England: All-Party Parliamentary Group for Diabetes. 1-24.
10. Funnell, M. M., & Anderson, R. M. (2004). Empowerment and Self-Management of Diabetes. *Clinical Diabetes*, 22(3), 123–127. <http://doi.org/10.2337/diaclin.22.3.123>
11. Jochen Gensichen, Michael Von Korff, Carolyn M Rutter, Michelle D Seelig, Evette J Ludman, Elizabeth HB Lin, Paul Ciechanowski, Bessie A Young, Edward H Wagner and Wayne J Katon. (2009). Physician support for diabetes patients and clinical outcomes. *BMC Public Health*. 9 (1), 367.
12. Milton, N. (2005). *Knowledge Sharing Culture*. Available: http://www.nhs.uk/media/2532512/nhs_iq_-_learning_handbook_-_knowledge_sharing_cultures.pdf. Last accessed 1/8/16.
13. Health IT - What is Health IT? Retrieved July 8, 2016, from <http://nuviun.com/digital-health/health-it>
14. Number of Internet Users (2016) - Internet Live Stats. Retrieved July 8, 2016, from <http://www.internetlivestats.com/internet-users/>

15. My Diabetes My way (<http://www.mydiabetesmyway.scot.nhs.uk/>)

10. Appendix

There are several other examples of digital solutions which are currently under work to be implemented into the NHS in order to improve self-management support services.

1. D.UDES or “Diabetes: Understanding Daily Events” is an interactive digital diabetes platform for young people to help them self-manage properly in a manner that is very engaging for this generation. This proposal aims to enhance the young person’s area that appears on the MDMW site. Working alongside Maverick TV and Diabetes UK, the team at D.UDES aim to give young people an education resource that is tailored to their age groups and needs. This is because lifestyle change and self-management are a huge part of the diabetes journey and so young people are a vulnerable group as they may not understand the implications of these aspects of diabetes to their health. Having all the relevant information laid out in an interactive and stimulating fashion instead of face-to-face contact will reach young people in a way that suits them more because they are a generation where the use of technology is second nature. Using this approach increases the engagement of young people to invest time into understanding their condition and achieving a sense of control over their health in an independent manner.
2. IDDEAS or “integrated diabetes data for external application services” is a project aiming to develop a data exchange layer to tackle the issue of interoperability from the profitable aspect of healthcare. It will be employed to link NHS Scotland services to commercial applications which have the potential to enhance self-management in diabetes. IDDEAS aims to define an interface to allow two-way communication with the NHS Scotland diabetes platforms (SCI-DC and MDMW) to improve communication and data transfer with third-party and commercial products, which have the capability to offer features and functionality not currently offered within NHS services. This project will allow for asynchronous communication through a standardized data integration interface. The model of having a functional integration layer will allow patients to continue to be given a high level of care but will also confer the ability for them to take control of their self-management by making use of reliable commercial applications. This will unite clinical and patient-recorded datasets to take full advantage of their reusability for the benefit of patients in terms of self-management and clinical guidance. In addition, patients will have the capability to select which applications they want to assimilate their data with through official patient consent, thus giving them the control over their health and the choices of support they which to take advantage from. This is hugely important for the development of a modernised healthcare whereby the economy can grow through it by the

exploitation of commercial applications which are fully interoperable with the healthcare infrastructure.

3. VSD or “Extending virtual support for people living with diabetes in Scotland” is a digital solution which aims to ameliorate the issues people living in remote locations of Scotland have when trying to receive support to self-manage their diabetes better. Therefore, the issue of access to services can be partly solved through this project. According to the Scottish Diabetes Survey in 2014, 5% of the population of the Highlands and Islands had diabetes and of this 5%, 10% were Type 1 diabetics and a staggering 39.3% of people with type 1 diabetes had poor glycaemic control. This is very alarming for any health board to have these kind of statistics but since the highlands and islands extend over such a vast area, the time it takes to reach people in an emergency is longer than average. Therefore, there needs to be more self-management support for these patients to try to lower the proportion of people with poor glycaemic control which will in turn lead to reduced complications associated with Diabetes. The VSD project aims to use video consultations to give diabetics with poor glycaemic control real-time support to get their blood sugar back to an appropriate level. This is to be achieved through the use of SMS, virtual platforms and email. The clinicians can view the appropriate signals which will prompt them to contact the person to give individual support and guidance to help return their blood glucose to a safe level. This is a hugely beneficial project because it has the capability to reduce travel costs for individuals and HCPs, promote engagement with support services, decrease hospital attendance and inpatient admission, ameliorate glycaemic control and lessen diabetes-related expenditures.

Additional References:

17. SCI-Diabetes. Retrieved July 8, 2016, from <http://www.sci-diabetes.scot.nhs.uk/>
18. Cunningham, S. G., Wake, D. J., Waller, A., Morris, A. D., & Walker, J. (2013). My Diabetes My Way: an electronic personal health record for diabetes. *The British Journal of Diabetes & Vascular Disease*, 13(3), 143–149. <http://doi.org/10.1177/1474651413493336>
19. Scottish Government. (2015). *eHealth Strategy 2014-2017*. Available: <http://www.gov.scot/Publications/2015/03/5705>. Last accessed 8/8/16
20. The Scottish Government. (2014). *Digital Participation: A National Framework for Local Action*. Available: <http://www.gov.scot/Resource/0047/00472754.pdf>. Last accessed 19/8/16.
21. The European Commission. (2010). *A Digital Agenda for Europe*. Available: [http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52010DC0245R\(01\)&from=EN](http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52010DC0245R(01)&from=EN). Last accessed 23/8/16.:

22. NHS England. (2015). *Interoperability Handbook*. Available:
<https://www.england.nhs.uk/digitaltechnology/wp-content/uploads/sites/31/2015/09/interoperabilty-handbk.pdf>. Last accessed 23/8/16.
23. Peterson, A. (2015). *Why hackers are targeting the medical sector*. Available:
<https://www.washingtonpost.com/news/the-switch/wp/2015/02/05/why-hackers-are-targeting-the-medical-sector/>. Last accessed 23/8/16.
24. BBC News. (2014). *NHS has repeated data breaches*. Available:
<http://www.bbc.co.uk/news/health-30037938>. Last accessed 9/8/16.