A collaboration between

Authored by:

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The Glasgow School of Art

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THE GLASGOW SCHOOL OF ART

University of Strathclyde
Glasgow
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The project employed a participatory design approach to redesign the diagnosis experience for people living with type 2 diabetes. Through scoping workshops, in-depth interviews with diabetes specialists, practice nurses and people living with type 2 diabetes we mapped the current experience. A co-design workshop with practice nurses and specialist staff generated a new model of care for diagnosis, which was developed with input from people living with type 2 diabetes.

**Outputs:**
- 2 Reports
- 1 Video
- 7 Current service maps
- 1 prototype

**Tools & Artefacts:**
- Interview mapping tools x 10
- Diagnosis experience design map x 1
- Current care mapping tool x 6
- New service concept boards x 3
- Prototype iterations x 3

**Team:**
- Sneha Raman
- Gemma Teal
- Ciarán Morrison
- Cate Green
- Miriam Fisher
- Janette Hughes
- Kara Mackenzie
- Chaloner Chute

**Participants:**
- People living with type 2 diabetes
- Practice Nurses
- Diabetes Specialists nurse / dietitians / podiatrist
- Hospitals / Health Centre
- Clinic attendees

**Locations:**
- University Hospital Hairmyres
- University Hospital Monklands
- Hunter Health Centre
- Carluke Health Centre

**Methods:**
- Scoping workshop
- Pop-up engagement
- In-depth interview
- Co-design workshop

**2017-2019**

- 15 Hours Interview time
- 12 Hours Pop-up engagement time
- 3 Hours Co-Design workshop time
- 3 Hours Scoping workshop time

*Interview locations not included to maintain anonymity*
Executive Summary

This document provides a description of the work undertaken by the Digital Health and Care Institute (DHI), led by The Glasgow School of Art (GSA) in partnership with NHS Lanarkshire, to innovate care for people living with type 2 diabetes. The project was undertaken between December 2017 and May 2019, with the purpose of informing the strategy for delivering person-centred care for diabetes type 2 in Lanarkshire. The report is accompanied by a short film illustrating the co-design process, and a policy review undertaken by DHI colleagues based at the University of Strathclyde.

As part of a programme of work commissioned by the Scottish Government, DHI formed a strategic partnership with NHS Lanarkshire to collaborate on health and care service transformation. In consultation with the Chief Executive and the South Lanarkshire Health and Care Partnership’s Long-Term Conditions Group, diabetes was identified as a key area of need. This project built on previous work undertaken by the DHI on the Digital Diabetes Programme (2016-2017), a series of projects working closely with people living with diabetes and health professionals to innovate care and services. It was also informed by our collaboration with the Modern Outpatient Programme (2017-2018), where we worked with people living with multiple long-term conditions and NHS staff to develop a vision for person-centred care. Following scoping activities in NHS Lanarkshire, services for people living with type 2 diabetes were identified as the focus for innovation and redesign activities.

The project employed a participatory process including pop-up engagement, interviews with people living with type 2 diabetes and primary care and specialist staff, a co-design workshop with practice nurses and specialist staff, and further engagements with people living with type 2 diabetes to refine the concepts. Rich insights were generated on how people would like to be supported at diagnosis, and how primary care staff can be supported by specialist staff to create person-centred diagnosis conversations.

The findings of the current state of care in NHS Lanarkshire are available in full in our ‘Interim Findings’ report, and summarised on pages 16-19. This provides the contextual basis for the future ideas presented in this document. Concepts are presented for a new visual tool to support the diagnosis conversation, a new diagnosis group appointment with a specialist, and new ways of working across primary and secondary care to support practice nurses to deliver person-centred care. These concepts together form the new diagnosis experience, which is discussed alongside recent developments in diabetes policy at a national level. In addition to this ‘near’ future map, we present opportunities for future care enabled by new digital services and a roadmap to support discussion and further development towards implementation.

Research activities with people living with type 2 diabetes received ethical approval from the GSA Research Ethics Committee. Activities involving NHS staff were reviewed and approved by the GSA Ethics Advisor.

1 radar.gsa.ac.uk/6244/
2 www.futurehealthandwellbeing.org/modern-outpatients
Design Innovation in Health and Wellbeing

Design researchers specialising in health and wellbeing within the Innovation School at The Glasgow School of Art apply design capability to innovate systems, pathways and experiences of care. We do this through three main activities: visualisation, strategic road-mapping and co-design.

The visual language of design enables communication and understanding of the current complex health and social care landscape. The visual exploration of a shared problem space generates an understandable system-level map which generates insights and immediate actions for improvement. With our partners and participants, we also create a map or vision of the preferable future that shows how things would be if the issues that have been identified were solved. Using this preferable future map as the agreed strategic direction, projects can be defined which translate the insights and ideas into tangible outputs, working with stakeholders to co-design and prototype solutions dynamically.

Researchers use current and emerging design research methods to engage with our partners and participants, who are encouraged to share their own experiences and ideas. Real-life practice is often replicated to allow new technology, services, processes and behaviour to be trialled rapidly.

The Digital Health & Care Institute

The DHI is a collaboration between the University of Strathclyde (UoS) and the Glasgow School of Art (GSA) and is part of the Scottish Funding Council's Innovation Centre Programme. It is part funded by Scottish Government. DHI support innovation between academia, the public and third sectors, and businesses in the area of health and care.

Project Team

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Acknowledgements

We would like to thank all of our interview participants for giving up their valuable time and for generously sharing their stories to inspire service redesign.

We would also like to thank the diabetes team across NHS Lanarkshire for supporting recruitment of interview participants and recruitment of NHS staff for co-design workshops.

Finally, many thanks to staff at University Hospital Monklands, University Hospital Hairmyres and Hunter Health Centre for permitting and facilitating our pop-up engagement sessions in their busy clinic foyers, and to all the citizens and staff who engaged with us to share their views.
Context

In Scotland, the number of people with diabetes has steadily grown over the last 15 years, rising from 103,835 in 2002 to approximately 298,504 people at the end of 2017, of which 88% live with type 2 diabetes [1]. These numbers only represent those who are registered as having diabetes: in 2015 it was estimated that a further 45,500 people in Scotland could be unaware they are living with type 2 diabetes [2]. It is estimated that by 2035 over 480,000 people will be living with diabetes in Scotland, an increase of 60.8% from 2016 [2]. Lanarkshire has seen a significant increase in the number of people with diabetes rising from 16,358 in 2002 to 38,671 in 2016, around 5.9% of Lanarkshire’s overall population of which 88.2% have type 2 diabetes and 10.5% have type 1 diabetes [1]. In 2012, it was estimated that 10% of Scotland’s NHS budget was being spent on diabetes [3], with social care spending at £23 million per year as of 2015 [4]. There are also significant personal costs when considering missed work hours, travel costs, loss of employment and early retirement due to poor health [3].

Diabetes Policy in Scotland*

The journey of diabetes policy in Scotland can be clearly traced from the ‘Scottish Diabetes Framework’ (2002), through the ‘Diabetes Improvement Plan’ (2014) to the most recent ‘A Healthier Future’ framework (2018) [5,6,7]. This recent framework aims to reduce health inequalities and take action to prevent diabetes by focusing on those at risk of, at high risk of, or newly diagnosed with type 2 diabetes. The actions set out are intended to provide comprehensive weight management services for the prevention, early detection and early intervention of type 2 diabetes. The framework recommends a tiered approach to these programmes that addresses the individual’s risk (see Figure 1, above). It is informed by recent research that has shown it is possible to delay, prevent and even reverse type 2 diabetes and its associated morbidity through changes in diet and lifestyle [8]. Structured weight management interventions in patients with type 2 diabetes have been shown to “reduce weight in the medium term, result in improved glycaemic control with fewer medications, and may be more effective than pharmacological alternatives” [9, page 879]. In order to achieve this, the framework commits an investment of £42 million over five years to establish supported weight management interventions as a core component of treatment for people with, or at risk of, type 2 diabetes.

Figure 1: Overview of the framework and proposed tiered approach to weight management programmes (adapted from [7]).

Structured Education

Structured education is identified as central to diabetes care and self-management, and it is a requirement that patients have timely and appropriate access to high quality education programmes and self management support [10]. Interactive learning within structured education has been found to be an active ingredient in behaviour change for people with type 2 diabetes [11]. Other key factors that contribute to successful education programmes are frequent contact and reinforcement of learning [12].

Improving equality, access and uptake of structured education is a key priority identified by the Scottish Government [7]. This strategic commitment is in light of challenges with uptake across Scotland, with only 3.7% of people living with type 2 diabetes attending structured education programmes in 2017 [1]. A 2015 study examined the reasons for non-attendance at structured education modules, postulating that shame and stigma of diabetes played a large role in non-attendance [13]. The Scottish Government has committed to running a positive media campaign about type 2 diabetes to raise awareness, challenge misconceptions and reduce stigma [7].

Person-centred Care

The wider policy agenda for care for people living with long-term conditions strives for value-based medicine and person-centred care [14]. This emphasises the need for health professionals to move from paternalistic to collaborative relationships with the people they care for, providing information and support to ensure shared decision making [14, centred on the goals of the person [15]. This is embedded as a key priority in the Diabetes Framework, which seeks to enable and empower people living with diabetes to safely and effectively self manage their condition. To achieve this goal, it mandates high-quality education and the creation of mutually agreed individualised care plans both for people living with diabetes and those identified as at risk of developing the condition.

“...the care pathway an individual follows must be decided upon by the individual with the healthcare professionals providing support and information about the possible options, the relative benefits, intensity and time commitment required so they can make an informed joint decision on their treatment pathway.” [7, page 12]

Digital Technology for Diabetes Care

The Scottish Government identifies digital technology as key to transforming health and social care services so that care can become more person-centred [16]. The Digital Health and Care Strategy highlights local service change and redesign as critical to achieving spread and adoption of digital technologies at scale [17]. This strategy places significant emphasis on the need for co-design approaches to ensure people are at the centre of the development process, and highlights the need to embrace and support new ways of working to embed these technologies in working practice.

Within the context of diabetes care, My Diabetes My Way (MDMW) platform is a national electronic personal health record for people living with diabetes in Scotland. Created in 2008, MDMW is a digital platform that has a direct link to the Scottish Care Information Diabetes Cloud (SCI-Diabetes), the statutory data store and shared electronic health record for all diabetes patients in Scotland [18]. In addition to viewing their personal health records for diabetes, MDMW gives patients access to diverse educational resources providing information on a range of topics such as diet and healthy lifestyle choices, medication, definitions of diabetes, information on possible complications and many other topics. Despite the benefits of the MDMW platform, in 2017 approximately 32,000 out of 298,504 diabetes patients were registered to access their diabetes information in Scotland [19]. Digital technology is also being used as a means of delivering or supporting delivery of structured educational for type 2 diabetes [20] and weight management [21]. It is used to provide ongoing support to those who have attended face-to-face sessions, or as an alternative to those for whom group education is not a first choice, for example offering videos of education sessions [22].
professionals and those Community TRAK software Diabetes to pull information issues by enabling SCI-remaining interoperability. They also aim to tackle some tools for this purpose [7].

Diabetes to integrate those a commitment to develop SCI-to include those at risk, the scope of diabetes services managed, is associated with diabetes can be successfully supported by reassuring a clear action plan at diagnosis, learning to accept more experience of living with recently diagnosed with type 2 diabetes, finding the diagnosis and explaining the post-diagnosis impact on how people feel.

Research that compared the stages of initial care to avoid misunderstandings [26]. Research that compared experiences of diagnosis in primary and secondary care settings found that people perceived that they received more appropriate attention and concern, and had found hospital education sessions were more comprehensive [26]. Review and above information about diabetes management at diagnosis, patients expressed the desire for emotional support from health professionals: “…right at the beginning you need somebody arms around you to explain it all”. [25, page 273]

More recently, conversations with clinicians at diagnosis of type 2 diabetes have been found to strongly influence patient self-care, and higher patient empathy resulted in fewer challenges during the diagnosis conversation [27].

In a study that contrasted the challenges faced by people recently diagnosed with type 2 diabetes and those with more experience of living with diabetes, learning to accept the diagnosis and finding the motivation to change habits were key challenges for the recently diagnosed group [28]. This highlights an opportunity to support clinician-patient interaction with the diagnosis to create the conditions for a ‘teachable moment’, to maximise the potential for any necessary behaviour change [29, 30].

References


Background

As part of a programme of work commissioned by the Scottish Government, DHI formed a strategic partnership with NHS Lanarkshire to collaborate on health and care service transformation. In consultation with the Chief Executive and the South Lanarkshire Health and Care Partnership’s Long-Term Conditions Group, diabetes was identified as a key area of need. Following early scoping work with the NHS Lanarkshire Diabetes Service, design researchers from The Innovation School at GSA designed a programme of work focusing on services for people living with type 2 diabetes in Lanarkshire.

The overall aim of this work was to explore person-centred approaches to diabetes care in Lanarkshire and create a roadmap for future care, working together with those delivering the services and those receiving care.

Our early scoping work with specialist staff within the diabetes service in Lanarkshire identified a number of specific challenges relating to care across the interface of secondary and primary care, including the need for more support for primary care staff to improve the consistency of care. This is in the context of challenges as a result of discontinuation of the Diabetes Managed Clinical Network (MCN) and changes in the way that outcomes are reported by primary care following the end of Quality Outcomes Framework (QOF). These insights were supported by the findings of previous GSA research with people living with long-term conditions, which pointed to the importance of the diagnosis conversation in engaging people in self-management. This supported us to identify two clear focus areas with associated research questions:

1. How might we innovate conversations at diagnosis?
2. How might we innovate care across the interface between primary and secondary care?

By focusing on one key moment in the care journey, i.e. the conversation between the primary care health professional and the newly diagnosed type 2 patient, we aimed to understand how secondary care and primary care staff could work more collaboratively to improve self-management in the community and prevent referral to secondary care. Through exploring and mapping current care experiences and identifying aspirations for future care, we aimed to identify opportunities to redesign the type 2 diabetes diagnosis conversation to support early engagement.

The ‘donut’ model used primary and secondary care settings as a basis of understanding the current system of care. The scoping work clarified that specialist care is provided in both primary and secondary care settings. In this report, we use the following terms:

- Primary care: practice nurses, GPs and other staff who are not solely focused on delivering care for diabetes.
- Specialist care: diabetes specialist staff, for example dietitians, nurses and podiatrists, who may be based in primary or secondary care settings.
- Secondary care: aspects of the system that are centrally managed rather than in primary care.

Approach

A participatory design approach was used to iteratively explore and ideate with a diverse group of participants including people with lived experience of diabetes, and health professionals across NHS Lanarkshire. This approach was used to integrate multiple perspectives to ensure that any innovation meets the expectations and needs of all those who provide and receive care.

Methodology

Figure 2: ‘Donut’ model of care showing the person living with type 2 diabetes at the centre, with the interface between primary and secondary care depicted by frosting, and individuals involved in care as sprinkles.
Interviews with people living with type 2 diabetes

We interviewed four people living with type 2 diabetes in Lanarkshire. During the interview, we used a similar visual tool to the one used in interviews with staff, adapted to map the participant’s experience of the current service, any challenges, and ideas for how things could be improved. Within the interviews we specifically asked participants to recall their experience of diagnosis. The interviews were recorded and transcribed. Responses were written on card apples that were added to a freestanding tree. These engagements gave us the opportunity to talk to people living with type 2 diabetes who receive specialist care to gather their feedback on how to improve the diagnosis experience based on critical reflections of their own care journey.

Co-Design workshop

The transcribed interviews and pop-up engagement responses were thematically analysed to identify insights to support redesign of the diagnosis experience, summarised on pages 16-19 (Interim Report with full findings available on request). Three focus areas were identified for a co-design workshop with practice nurses (n=8) and diabetes specialists (n=2). These represented opportunities to innovate the experience of diagnosis and ways of working across the primary and secondary care interface. The focus areas were introduced to the workshop participants using a specially designed tool which plotted the opportunities along a typical care journey of a person diagnosed with type 2 diabetes. The opportunities were framed as questions, supported by insights or ‘key ingredients’ from our interim findings to inform and inspire participants:

- How do we create the ideal diagnosis conversation – who, what, where, when, how?
- How do we increase early uptake of structured education following diagnosis?
- How do we support primary care staff in their conversations with people living with type 2 diabetes?

Through a facilitated group discussion we explored the questions and collaboratively developed concepts to innovate the service.

Pop-up engagement

We visited the diabetes clinics at University Hospital Hairmyres and University Hospital Monklands for two half-day pop-up engagement sessions. Stationing ourselves at the entrance to the clinics, we asked participants two questions:

- What keeps you well?
- What was the most valuable information you received at diagnosis or something you now know that you wished you had been told at diagnosis?

The opportunities were framed as questions, supported by insights or ‘key ingredients’ from our interim findings to inform and inspire participants:

- How do we support primary care staff in their conversations with people living with type 2 diabetes?
- How do we create the ideal diagnosis conversation – who, what, where, when, how?
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Pop-ups and interviews to test the emerging concepts

The concepts were translated into scenarios for future care, represented visually on large printed boards. Three pop-up events were undertaken across NHS Lanarkshire: University Hospital Hairmyres, University Hospital Monklands and Hunter Health Centre. The concept visualisations were displayed on easels, with space for researchers to note feedback and comments to refine the concepts with input from people attending appointments. A paper prototype of one of the concepts was used to gain specific feedback on the format and layout. The pop-ups were also opportunities to engage with health professionals, and gain feedback from a member of council staff responsible for physical activity and weight management referrals and a wayfinding volunteer.

We also took the concept visualisations to gather feedback from three of the interview participants living with type 2 diabetes who we engaged with earlier in the project. The interviews were audio recorded and transcribed, and the feedback was used to further refine the concepts.

Limitations

The key purpose of the study was to identify new opportunities for innovation to improve patient experience with a strong focus on the experiences of people living with type 2 diabetes, and is not intended to be a comprehensive service evaluation. The study engaged with a small number of people living with type 2 diabetes and staff in Lanarkshire using qualitative methods. This is a limitation of the approach and insights are therefore not generalisable.

The people interviewed were not newly diagnosed with type 2 diabetes, therefore their experiences do not reflect the current experience of diagnosis in primary care. These engagements focused on the ‘ideal experience’, asking people who have experience of living with diabetes to reflect on what might have supported them to engage in self management in the early stages following diagnosis. This limitation was also mitigated by engaging with primary care staff who currently deliver care to understand what is involved in the current conversation.

This is one of many initiatives undertaken by NHS Lanarkshire to innovate diabetes services continuing their focus on ensuring person-centred care. This project did not aim to redesign the whole service, but focused on one point in the care journey. The researchers worked closely with NHS Lanarkshire to ensure that the new opportunities identified build on other ongoing initiatives. Therefore, recommendations need to be seen as part of NHS Lanarkshire’s wider innovation landscape (see page 35).
Understanding the Current Experience

From the perspectives of people living with type 2 diabetes

Participants stressed the importance of early, accurate diagnosis, and support to understand and accept their condition, and ensuring they have all the required information specific to their needs were thought to be key to enabling people to self-manage and live well. Pop-up participants expressed the need to communicate the severity of the condition at diagnosis through realistic conversation about potential consequences and practical advice on how to avoid complications. Interview participants who had received their diagnosis in a secondary care setting valued the specialist input received at diagnosis and felt it shaped a better understanding of their condition. Despite this high value placed on specialist advice and peer support, it was clear that some may still choose not to engage because of other reasons.

Interview participants expressed different motivations and triggers for engaging with self-management, including the perceived severity of their condition, a fear of complications, or to avoid medications and insulin. For some, the lack of any short-term impacts or symptoms was a key reason not to engage. Understanding people's personal circumstances, internal struggles, expectations and needs from their care were important factors in supporting them to overcome barriers and increase engagement. Having a good relationship, not feeling judged and being able to ask questions were important for people in their interactions with health professionals. In addition, understanding people's goals (both related to their condition and living well in general) seemed to be key to understanding people's motivations to self-manage.

There was an appetite for specific, practical instructions on the dietary changes people need to make. Providing the reasons for these instructions, explaining why screening is necessary, and showing the impact (e.g., through test results) can help people to prioritise these actions. Tailoring the information to the person's circumstances and appreciating that they may have other competing challenges can help to ensure they engage with the advice. Use of visual aids in conversations and tangible information were suggested as useful for engaging and informing people in the diagnosis conversation.

Having access to tools and services that can offer additional information and support was seen to be important to enable people to have greater control in managing their condition. In general, leaflets were thought to be lacking in quality, and access to or motivation to use online resources was limited among some of the participants.

An interview participant who had attended group education found reassurance in meeting others with the same condition, and learned from other's questions. Other participants talked about how friends who were also living with diabetes had supported them, and suggested hearing stories of other's experiences would be useful for newly diagnosed people.

Figure 3: Insights from interviews and pop-up engagement with people living with type 2 diabetes.
Understanding the Current Experience

From the perspectives of health professionals

The diagnosis conversation and changes in the person’s condition were seen as key opportunities to motivate and encourage people to make lifestyle changes. The importance of offering reassurance, positive messages and time to digest the information were approaches used to leverage these opportunities. While some staff talked about their responsibility to support the person to self manage, others felt people living with type 2 diabetes need to take more responsibility for their own care.

Understanding the factors that prevent engagement, being realistic that people will relapse, understanding the impact of family and agreeing personal goals were all seen as useful approaches. Being honest and direct, and sharing practical and specific advice about diabetes was seen to be important. Checking the person has understood the key messages by the Scottish Government. Information and education from other sources were also seen as valuable and popular with people living with type 2 diabetes. We learned about successful initiatives that offer referral to community-based services (e.g. Weigh to Go) that are seen to be popular with people living with type 2 diabetes.

Staff discussed some of the challenges people living with type 2 diabetes experience in terms of: apprehension of going to see specialist staff, difficulties in discussing and understanding long-term complications when there are no short-term signs of the condition, and the lack of psychological support.

Collaboration between primary care and specialist staff

Examples of collaborative working across the primary and secondary care interface were shared, and tended to be most evident in places where specialist and primary care staff were co-located.

In some areas, opportunities for communication between primary and specialist staff were very limited. While some practice staff used parts of SCI-Diabetes to access information, the lack of integration with primary care systems meant that they did not use it to add information about their consultations to allow joined-up care. Keeping up-to-date with new guidelines, treatments and approaches through e.g. attendance at diabetes conferences was seen by some as part of ensuring they were delivering the best possible care for people living with type 2 diabetes. Not having sufficient time to get up to date with new practice and make changes was seen as a barrier to implementation. We learned about variation across primary care in Lanarkshire in terms of the time available for diagnosis appointments and follow ups, support from the wider GP team and awareness or use of the available resources for diabetes.

It was clear that staff who felt supported by their employers, and who made a concerted effort to look after their own health and wellbeing felt better able to cope with the demands of their job. In primary care, one practice nurse had established a support group with others in her area to share advice, information and peer support.

We also learned that there is an aspiration to work more closely with local community-based services and create stronger links between programmes such as Weigh to Go and STEP 2 structured education to ensure joined-up care and supported self management.

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We also learned that there is an aspiration to work more closely with local community-based services and create stronger links between programmes such as Weigh to Go and STEP 2 structured education to ensure joined-up care and supported self management.
Opportunities to Innovate

Three clear focus areas to innovate the experience of diagnosis and ways of working across the primary and secondary care interface emerged from the interim findings. These were framed as questions, to be explored with primary care and specialist staff in a co-design session:

• How do we create the ideal diagnosis conversation – who, what, where, when, how?

• How do we increase early uptake of structured education following diagnosis?

• How do we support primary care staff in their conversations with people living with type 2 diabetes?
Introduction to the Findings

Concepts are presented for a new visual tool to support the diagnosis conversation, a new diagnosis group education appointment with a specialist, and new ways of working across primary and secondary care to support practice nurses to deliver person-centred care. Each concept is prefaced by the insights that inspired them, a detailed description of the concept that emerged from the co-design workshop, and a discussion of the feedback received during pop-up engagement and interviews with people living with type 2 diabetes.

These concepts together form the new diagnosis experience, which is discussed alongside recent developments in diabetes policy at a national level. In addition to this ‘near’ future map, we present a future vision for care enabled by new digital services and a roadmap to support discussion and further development towards implementation.

Insight

Some participants living with type 2 diabetes told us that there was a lot to take in during their diagnosis conversation, making them feel overwhelmed. This can make it difficult to navigate and understand the different appointments in the period after diagnosis.

Experienced practice nurses told us they keep a ‘cheat sheet’ on their desk as a reminder of the many different things they need to cover in a new diagnosis appointment. They worried that some people were not able to take everything in during the first appointment, particularly when they were dealing with the stressful news that they had a long-term condition. Despite highlighting that the first few months following diagnosis was the best time to persuade the person to make changes to their lifestyle, many found it challenging to introduce structured education and other resources in the limited time available. There was variation in awareness of the wider support available in the community (e.g. exercise referral), meaning that not all practice nurses offered these resources to their patients at diagnosis.

Practice nurses also told us that they often work with the person to set a goal for the follow up appointment to “strike while the iron is hot”, and capitalise on their motivation at diagnosis to change their behaviour.

Both people living with diabetes and practice nurses told us that information about the long-term consequences of diabetes can be challenging to get across, but that it is vital that people understand the importance of managing their condition. In addition, both groups highlighted the power of visual aids in conversations to support people to engage and understand. They contrasted this with leaflets and information sheets that often contain a lot of text, which can be overwhelming.

Concept 1: Diagnosis Conversation Tool

Insight

Support for practice nurses
Supporting primary care staff in their conversations about type 2 diabetes

Introducing a new paper-based tool to support the diagnosis conversation. The tool structures and records the conversation between the practice nurse and the newly diagnosed person, and ensures consistency of experience and messages across practices. It has been designed to structure and prompt key aspects of the conversation:

- **Building a relationship:** the front page invites the practice nurse to explain their role and invite the person to contact them if they have any questions or issues.
- **Planning care:** inside, the booklet uses icons printed as stickers which can be added to the pathway visual to produce a personalised care plan. There is plenty of white space around the visual to permit the nurse to make notes. This can be reviewed and updated as required.
- **Shared-decision making:** the practice nurse can chat through the options before they decide on what is right for the person.
• Visual summary: the supporting information acts as a key for the care plan, explaining what each icon represents and referring to the page number of the new standardised NHS Lanarkshire type 2 diabetes information pack for more detailed information. It also functions as a memory aid to support the practice nurse to cover key information about the services and support available.

• Navigating the early stages post diagnosis: using the visual care pathway, the practice nurse can reassure the person that although the first few months can feel demanding with numerous appointments, this will settle down.

• Long-term complications: using the circular part of the pathway, the practice nurse can discuss the purpose of screening and relate it to the importance of managing their condition to avoid complications.

• Goal planning: discussing their personal goals can also be used as away to understand what is important to the person in the longer-term, and use this to help tailor their care and conversations about lifestyle changes they may need to make to achieve this, e.g., if they can reduce their HbA1c through lifestyle changes they can avoid starting medication.

• Documentation: the plan can be scanned to provide a short digital summary of what was discussed for the practice nurse’s records, with the hard copy given to the person to take away as a reminder of what was discussed.

Practice nurses stressed the importance of developing this new tool through engagement with all practices in Lanarkshire to ensure it addresses variation, achieves acceptance and becomes embedded in practice.

“...but we could break it down into a smaller pathway. I like to have my laminates beside me. I don’t know about you, but we do a lot of different areas and I think that is the complexity of it, because we are not only dealing with diabetes. We are dealing with different areas, but I often find my templates, laminated and sitting beside me are quite good.”

Workshop participant, Practice Nurse

“I think it is about building up a relationship because you are thinking about the patient sitting in front of you, who will probably be sitting in front of you for a number of years if you are not moving... You want to get off to a good start with your patient because you know that you want them to engage... It is the most important thing, I would say, on the first consultation when you are giving that diagnosis. It is about the relationship.”

Workshop participant, Practice Nurse

“We are the constant person right along that journey. The practice nurse is the person that is going to be along the whole line of the patient journey and are included all the way along that pathway. They want somebody like that.”

Workshop participant, Practice Nurse

Feedback

As a result of feedback from people living with type 2 diabetes, the prototype was reduced in size to make it more portable, and the textual content was reduced to simplify the design. A pocket was added to the tool to store the stickers and potentially a card with a print out.

Figure 7: Open to reveal a personalisable care pathway. An inside pocket holds stickers and a summary of test results at diagnosis for discussion.
of their results to support the discussion.

Both health professionals and people living with type 2 diabetes felt the tool could help to improve the overall diagnosis experience.

“Anything that educates you about diabetes is good as people can be in denial at the start, so this (the conversation tool) could help.”

Person living with diabetes

“Really like this. Need to make sure practice nurses are given time. And we need to end variation across practices.”

Specialist staff

Practice nurses noted that the tool would help them to create a record of their conversation, and people living with type 2 diabetes felt that seeing things written down would be helpful.

“Setting your own goals would be good.”

Person living with diabetes

“Being able to see and know the levels all the time can make a difference.”

Person living with diabetes

“Current blood pressure, HbA1c levels also should be on the card along with targets. It should be available to people as soon as these are taken (not six months later).”

Person living with diabetes

One of the participants felt that it would help to flag things if anything was missed (e.g. if they did not receive a screening appointment). Another participant noted that having the plan would help to join up the care and avoid overlaps (e.g. separate eye screening at the GP practice, hospital and ophthalmologist).

“It would be a way to show different things in place (for my care) so I could justify why I don’t need certain appointments if they are repeating.”

Person living with diabetes

The tool could also help to increase awareness of local services, most of which are free to access (e.g. healthy walking, managing stress).

“This would have been really useful (to know what is available). I didn’t know this (exercise referral) was available … I didn’t realise I could call the practice nurse with questions.”

Person living with diabetes

It was emphasised that for the tool to work, resources need to be in place to deliver the care plan. Both staff and people living with type 2 diabetes were concerned about capacity and how this could negatively impact the timelines on the plan.

Another issue that was highlighted was that it could be more difficult to make a clear plan for someone with multiple health conditions and the conversation tool might not be as relevant to them if it is only about diabetes. However, one of the participants felt that it is better to keep the discussion focussed on diabetes, while noting that the test results idea would be tricky as it would be hard to separate out if you had several conditions.

“Just stick to diabetes, the one thing.”

Person living with diabetes
Concept 2: Diagnosis Specialist Group Appointment

Insight

Some people living with type 2 diabetes told us they appreciated specialist input early on in their journey. Early education and peer support were found to be important for engaging people in self-management. Health professionals highlighted that some people are reluctant to attend a 1:1 appointment with the diettian due to stigma or fear of being judged on their eating habits. People who have attended the STEP programme highlighted its benefits and said that they wish they had been aware of the programme earlier.

Concept

Introducing a group education appointment within 6-9 weeks of diagnosis was suggested as a way to ensure early access to specialist input, and increase uptake of the full STEP 2 structured education programme. This would be an alternative to the current 1:1 appointment. Specialist group appointments will offer a one-on-one session with a diettian.

Feedback

Specialist staff and practice nurses felt that this could be an important step towards addressing the gap in access and uptake of structured education, and equip more people with the information and tools to self-manage early on to reduce the risk of complications. Some staff felt that it would be more feasible to organise the group appointment within 12 weeks of diagnosis. People living with type 2 diabetes agreed that early specialist input and education is important, and emphasised that it is only effective if it happens soon after diagnosis, again referring to capacity issues and off-putting waiting times. They also highlighted that the key messages should be positive and delivered in a way that is accessible to everyone, and family and carers need to be part of the change.

“Positive stories rather than scary (e.g. amputation), ‘Cure’ or the fact that it can be reversed needs to be emphasised more and people should be supported to swap foods or make changes.”

Person living with diabetes

“Motivation to attend or take action – the message about getting weight down and reversing needs to be emphasised.”

Person living with diabetes

“Cut barriers down so people don’t feel embarrassed to say they don’t understand.”

Person living with diabetes

“Useful for hearing how other people manage. You don’t know anything at the time … only what the health professionals tell you.”

Person living with diabetes

“Hearing about other people’s experiences or problems they may have faced as a result of diabetes ‘brings home the message’.”

Person living with diabetes

“Have someone who has had diabetes longer to be involved as well – not just newly diagnosed”

Person living with diabetes

“Community venues – we need to change the mindset. It doesn’t need to be hospital … need to let people know it is expected they will do this versus a choice.”

Specialist staff

Figure 8: The practice nurse discusses options for the next available diagnosis specialist group appointment in their area and they pick one that best suits the person. If the person feels a group session is not right for them, the practice nurse will offer a one-on-one session with a diettian.

Figure 9: Person attends the diagnosis specialist group appointment (up to 10 people) at a community venue.

Figure 10: STEP 2: sign up directly at diagnosis appointment or following new diagnosis specialist group appointment. A digital component can be developed in the future for those who cannot attend a group session, or as a refresher course.
Concept 3: Support for Practice Nurses

Insight
There are variations in patient pathways and the support available to practice nurses across Lanarkshire. This included variation in the time available to devote to diabetes diagnosis conversations. Some practice nurses are able to allocate 30 minutes and take time to review the person’s results and prepare prior to the appointment, while others are restricted to 10-15 minutes with no preparation time. Addressing these through enabling greater collaboration between primary care and specialist staff, offering more learning support for practice nurses and raising awareness of best practice throughout the wider GP team were highlighted as key to ensuring consistency of the new diagnosis experience.

Concept
During the co-design workshop, practice nurses shared many ideas for new forms of support. They suggested that attending the new diagnosis specialist group appointment (see concept 2) would be a great way to learn about new developments and the benefits of structured education so they can promote this to their patients. For new practice nurses, shadowing more experienced nurses and having specialists observe some of their diagnosis appointments and give feedback would ensure they felt confident in the quality of their care. In response to challenges in communication between primary and specialist care, they suggested creating a network and email list to disseminate messages and updates. They highlighted the need for more support sessions for practice nurses across Lanarkshire to share working practices and resources, and receive training and updates from specialist staff. They also saw this as an opportunity to involve practice nurses in any future developments (e.g. the development of the new conversation tool and the standardised information pack) to ensure they meet their varying needs. They highlighted the need for specialist staff to engage with the wider GP team to ensure consistency and support for the practice nurses at a local level. While there was a real appetite for input from specialist diabetes staff through training and development sessions, practice nurses cautioned that they have very limited time to spare and are often forced to do these kinds of activities in their own time.

“I think, a lot of it is time constraints. When people are diagnosed we have a fifteen-minute consultation when we are supposed to tell them everything about diabetes. Yes, I know it is all very well saying about bringing them back again, and we do, but then you have got to do your referral for the dietitian and for podiatry. So, I think we bombard them with so much information and it would be a good idea if we had some materials that we could use that they could follow through after diagnosis.”

Workshop participant, Practice Nurse

“We get referrals to the service, and our service is more for injectables. So, we see people who are referred to us, who have not been put on maximum tolerated oral medication. A lot of it is because of inexperience. So, it would be good to get some education out there for these nurses to give them some confidence. Some of the newer drugs are a little bit scary. So, giving people some confidence and some education and support. There has been a lack of support and education.”

Workshop participant, Practice Nurse

Figure 11: Support sessions for practice nurses across Lanarkshire to share best practice and resources, and bring specialist staff into the community.

Figure 12: Building confidence of new nurses through senior nurses or specialist staff sitting in on some diagnosis appointments to provide feedback and support. Using the new diagnosis conversation tool to structure the appointment and prompt the nurse to mention all the available options.
Overview of the New Service

Support for practice nurses
Trained practice nurses at the forefront of type 2 diabetes diagnosis and care in the community

Diagnosis conversation tool
Supporting consistent information and person-centred care plan at diagnosis

Diagnosis specialist group appointment
Providing information and support on diet, exercise and self management soon after diagnosis

Experiences of delivering and receiving care

New ways of working
Practice nurses feel supported and confident in their role through training, shadowing, specialist input and peer support.
All practice nurses have time to prepare (5-10 min) before a new diagnosis appointment.

Person-centred care at diagnosis
The tool helps to structure and record the diagnosis conversation for consistency in information and care.
Person attends a 20-30 min appointment with the practice nurse when first diagnosed with type 2 diabetes.
The practice nurse helps the person to sign up to attend the diagnosis specialist group appointment.
The tool helps the practice nurse to have a conversation about what matters to the person and create a person-centred care plan together.

Early support for self management
The interactive session is run by specialist staff at a community-based venue with a group of up to 10 people and lasts about 1.5 - 2 hours.
Person attends the new diagnosis specialist group appointment within 6-9 weeks following diagnosis.
Person signs up for STEP 2 structured education at the session or receives a text message reminder shortly after.

The practice nurse helps the person to sign up to attend the diagnosis specialist group appointment.

The tool helps the practice nurse to have a conversation about what matters to the person and create a person-centred care plan together.

The interactive session is run by specialist staff at a community-based venue with a group of up to 10 people and lasts about 1.5 - 2 hours.
Person attends the new diagnosis specialist group appointment within 6-9 weeks following diagnosis.
Person signs up for STEP 2 structured education at the session or receives a text message reminder shortly after.

New diagnosis experience ensures consistency in practice and care across Lanarkshire.
Practice nurses attend a diagnosis specialist appointment in their local area and have a better understanding of structured education and its value to the person.

Person attends the new diagnosis specialist group appointment within 6-9 weeks following diagnosis.
Person signs up for STEP 2 structured education at the session or receives a text message reminder shortly after.
Transforming the Diagnosis Experience

Support for practice nurses, the diagnosis conversation tool, and the diagnosis specialist group appointment – will improve the experience of delivering and receiving type 2 diabetes care in Lanarkshire through supporting new ways of working, by enhancing the person-centred diagnosis experience, and ensuring early specialist input and support for self-management.

New ways of working are geared towards ensuring consistency in practice across Lanarkshire by further developing the practice nurses, creating a shared care pathway and facilitating collaboration between primary care and specialist teams to deliver a joined-up care experience for each person newly diagnosed with type 2 diabetes.

With patient-centred care at its core, the new diagnosis experience is designed to build a relationship between the practice nurse and the person receiving care, offer clear information and reassuring messages, and support shared decision making and care planning aligned to the person’s motivations and goals. In this way, they can support the person to accept, learn and manage their condition.

The diagnosis specialist group appointment is geared towards supporting the person to learn to self-manage early in their journey. It also functions to introduce them to the benefits of group structured education to increase uptake for STEP 2 to support longer-term behaviour change.

By embracing the vision for person-centred and integrated care, the new services offer a promising platform to build on, towards transforming the overall experience of type 2 diabetes care in Lanarkshire.

These concepts together form the new diagnosis experience, which aligns with ongoing developments in NHS Lanarkshire and key priorities set out in diabetes policy at a national level, as detailed in the adjacent Figure 13.

The concepts align with the Government’s priority related to early intervention.

Figure 13: Alignment to Lanarkshire and National Developments.
### Roadmap to Future Services

The recommended next steps for NHS Lanarkshire to implement the new diabetes diagnosis experience are set out here, presenting a roadmap to the "near" future service, alongside a medium-term future vision of care enabled by new digital services. This roadmap is intended as a discussion tool to understand how DHI could support implementation of the new diagnosis experience, and to enable scoping of potential future opportunities for collaboration with NHS Lanarkshire and across Scotland.

### Support for practice nurses

- Organising type 2 diabetes training and education for practice nurses across central locations in Lanarkshire, preferably at lunch times.
- Facilitating and running peer support groups across multiple locations in Lanarkshire to share practice, support the wellbeing of practice nurses, and enable input from specialist staff.
- Implementing the new diagnosis experience and conversation tool.
- Extending this support to community teams including GPs and community district nurses, and promoting awareness about the diagnosis conversation tool.
- Introducing the Diabetes Educator role to act as a link between primary and secondary care.
- Consider how existing VC facilities could be used to further support practice nurses to access training and facilitate collaboration with specialist staff and peers by addressing issues related to time constraints owing to their busy schedules.

### Diagnosis conversation tool

- Developing the prototype through co-design with practice nurses across Lanarkshire, and implementing the paper conversation tool across all practices.
- Explore how a digital version of the tool could enable easier recording, editing and sharing of individual care plans to ensure that the documents are up-to-date.
- Explore how a digital version of the tool could support larger scale adoption by removing costs related to printing and updating the tool, and making it adaptable to the practices/local services.
- Explore how a digital version of the tool could be used to encourage people living with diabetes to use digital platforms for learning and self-management, by introducing the tool at the point of diagnosis.
- Work with senior decision makers at a national level to integrate with personal health records (e.g., My Diabetes My Way/SCI-Diabetes) to personalise options for care based on test results.
- Explore how a digital version of the tool could enable further personalisation to include co-morbidities, supporting joined-up care and making it more relevant to the person.

### Diagnosis specialist group appointment

- Developing and implementing the diagnosis specialist group appointment across Lanarkshire.
- Developing the sign-up process at diagnosis for the specialist group appointment and STEP 2.
- Consider using online event sign-up systems to make it easier to self-refer and sign-up to the most convenient STEP 2 course.
- Explore ways in which people who do not feel comfortable or able to access group sessions can be supported to access structured education using digital platforms.
- Work at a national level collaborating with other NHS Health Boards to develop online structured education for all of Scotland and consider using existing online education platforms.
- Explore how digital platforms for structured education could allow health professionals to customise and localise the education by including up-to-date information and local services to make it more relevant to people attending across different locations in Lanarkshire.
- Explore how online structured education could enable wider access to support the Scottish Government priority to open up diabetes education to those "at risk" (pre-diabetes) and support the prevention agenda.
- Share this model of new diagnosis education and structured education across NHS Lanarkshire and beyond to explore how it could be extended to support the redesign of diagnosis experience for other conditions.
“If we can strike while the iron is hot... the patients are more likely to be empowered and become an expert patient.”

Practice Nurse
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