



**Transforming Conversations  
about Type 2 Diabetes**

**July 2019**

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A collaboration between

**THE GLASGOW  
SCHOOL OF ART**



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NHS Lanarkshire / Digital Health and Care Institute  
Led by The Glasgow School of Art (GSA)

## Transforming Conversations about Type 2 Diabetes

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.

Participants:

4



People living  
with type 2  
diabetes

10



Practice  
Nurses

4



Diabetes  
Specialists  
nurse/  
dietitians/  
podiatrist

2



hospitals

1



health  
centre  
Clinic  
attendees

Methods:

Scoping workshop  
Pop-up engagement  
In-depth interview  
Co-design workshop

Fourteen Interviews  
+ Five Pop-ups  
+ One Co-Design Workshop  
+ One Scoping Workshop

Team:



» Sneha Raman  
» Gemma Teal  
» Ciarán Morrison  
» Cate Green  
» Miriam Fisher  
» Janette Hughes  
» Kara Mackenzie  
» Chaloner Chute

Locations:

- University Hospital  
Hairmyres  
- University Hospital  
Monklands  
- Hunter Health Centre  
- Carlisle Health Centre



\* Interview locations not included  
to maintain anonymity

2017-2019



15 Hours Interview  
time

12 Hours Pop-up engagement  
time

3 Hours Co-Design workshop  
time

3 Hours Scoping workshop  
time

Type 2 Diabetes

Diagnosis

Structured Education

Outputs:



x2



x1



x7



x1

- 2 Reports  
- 1 Video  
- 7 Current service maps  
- 1 prototype

Tools & Artefacts:



x23

- 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





## 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<sup>1</sup>. 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<sup>2</sup>. 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.

<sup>1</sup> [radar.gsa.ac.uk/6244/](http://radar.gsa.ac.uk/6244/)

<sup>2</sup> [www.futurehealthandwellbeing.org/modern-outpatients](http://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

<b>Sneha Raman</b>	Research Associate, The Glasgow School of Art
<b>Gemma Teal</b>	Research Fellow, The Glasgow School of Art
<b>Cate Green</b>	Production Manager, The Glasgow School of Art
<b>Louise Mather</b>	Photographer and Videographer, No Middle Name
<b>Ciarán Morrison</b>	Policy Review, Research and Knowledge Management Officer, University of Strathclyde
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<b>Janette Hughes</b>	Head of Planning and Performance, University of Strathclyde
<b>Kara Mackenzie</b>	Project Officer, University of Strathclyde
<b>Chaloner Chute</b>	Chief Technology Officer, University of Strathclyde

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]. In addition, approximately 500,000 people have an elevated risk of developing 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),



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

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 part of treatment for people with, or at risk of, type 2 diabetes.

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].

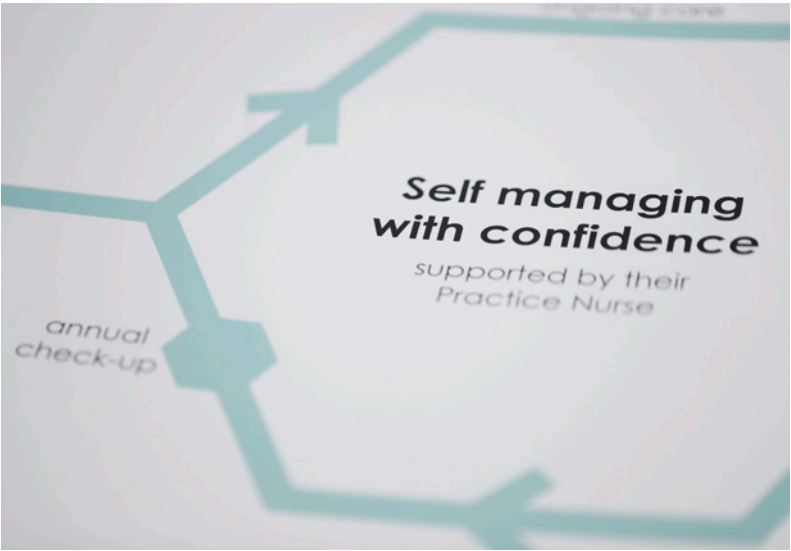
Digital technology is also being used as a means of delivering or supporting delivery of structured education for type 2 diabetes [20] and weight management [21]. It is used to provide ongoing support to those who have attended face-to-face sessions, or as an alternative to those for whom group education is not a first choice, for example offering videos of education sessions [22].

To enable the broadening scope of diabetes services to include those at risk, the Scottish Government has made a commitment to develop SCI-Diabetes to integrate those in the at risk and high-risk categories, and to investigate the use of decision support tools for this purpose [7]. They also aim to tackle some remaining interoperability issues by enabling SCI-Diabetes to pull information from Acute, Maternity and Community TRAK software used by all healthcare professionals and those delivering weight management interventions.

Diagnosis Experiences

Previous work undertaken by the DHI has identified the importance of a person’s experience when receiving a diagnosis of a long-term condition [23]. This experience impacts on how people feel about their condition, how they engage with health professionals and the time it takes for them to accept, learn and manage their condition. The early stages can be an anxious time, and we identified an opportunity to improve the information shared about what they can expect from both the condition and the health service.

These findings are supported by research which offers insight into effective diagnosis consultations. The provision of a clear action plan at diagnosis, supported by reassuring messages about how diabetes can be successfully managed, is associated with better self management and improved dietary behaviours



[24]. An earlier study found that most patients wanted more information about diabetes management at the time of diagnosis [25], and identified the importance of explaining the post-diagnosis process and clarifying 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 at hospital, and found hospital education sessions were more comprehensive [26]. Over 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’s 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 physician 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 within the diagnosis conversation to create the conditions for a ‘teachable moment’, to maximise the potential for any necessary behaviour change [29, 30].

*\*Please see the accompanying DHI ‘Policy and Market Analysis Report’ for a full discussion of relevant policy. This was used as a key reference for this report [31].*

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## 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 staff: 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.

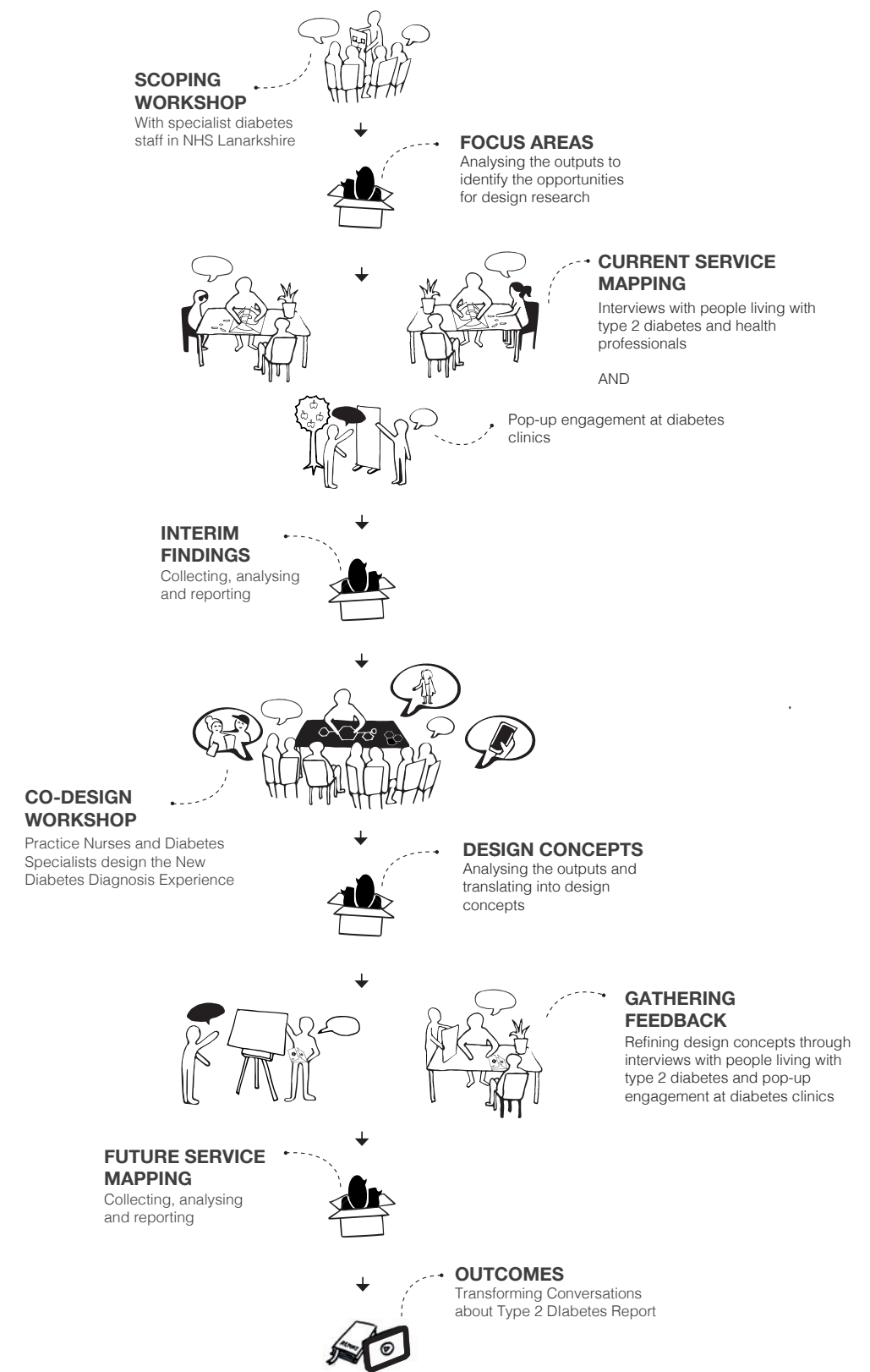
## Approach

A participatory design approach was used to iteratively explore and ideate with a diverse group of participants including people with lived experience of diagnosis, 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.



**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.**

## Methodology





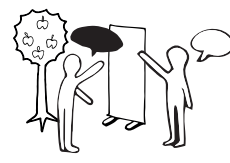
## Interviews with health professionals

We interviewed four specialist staff and two primary care staff working in NHS Lanarkshire. In these interviews, we used a visual tool (see bottom left image) based on the 'donut' model of care (see Figure 2) to capture their perspective of the primary and secondary care system, with the people they support who are living with type 2 diabetes in the centre. Participants were asked to place themselves on the map, and tell us about their role and the kinds of people they support. We also mapped all the staff they collaborate with, conversations, tools and challenges they experience in their role. The interviews lasted around one hour, and took place at the participant's workplace. In addition, we also interviewed staff who designed and deliver the current structured education programme in Lanarkshire.



## 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 relaxed and informal, lasted around one hour, and took place wherever was convenient for the participants. We also audio recorded and transcribed the interviews with the participant's consent.



## 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:

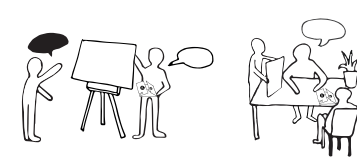
- What keeps you well?
- What was the most valuable information you received at diagnosis or something you now know that you wished you had been told at diagnosis?

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:



## 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 *why* they have the condition. Investing time early on to support people to understand 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.

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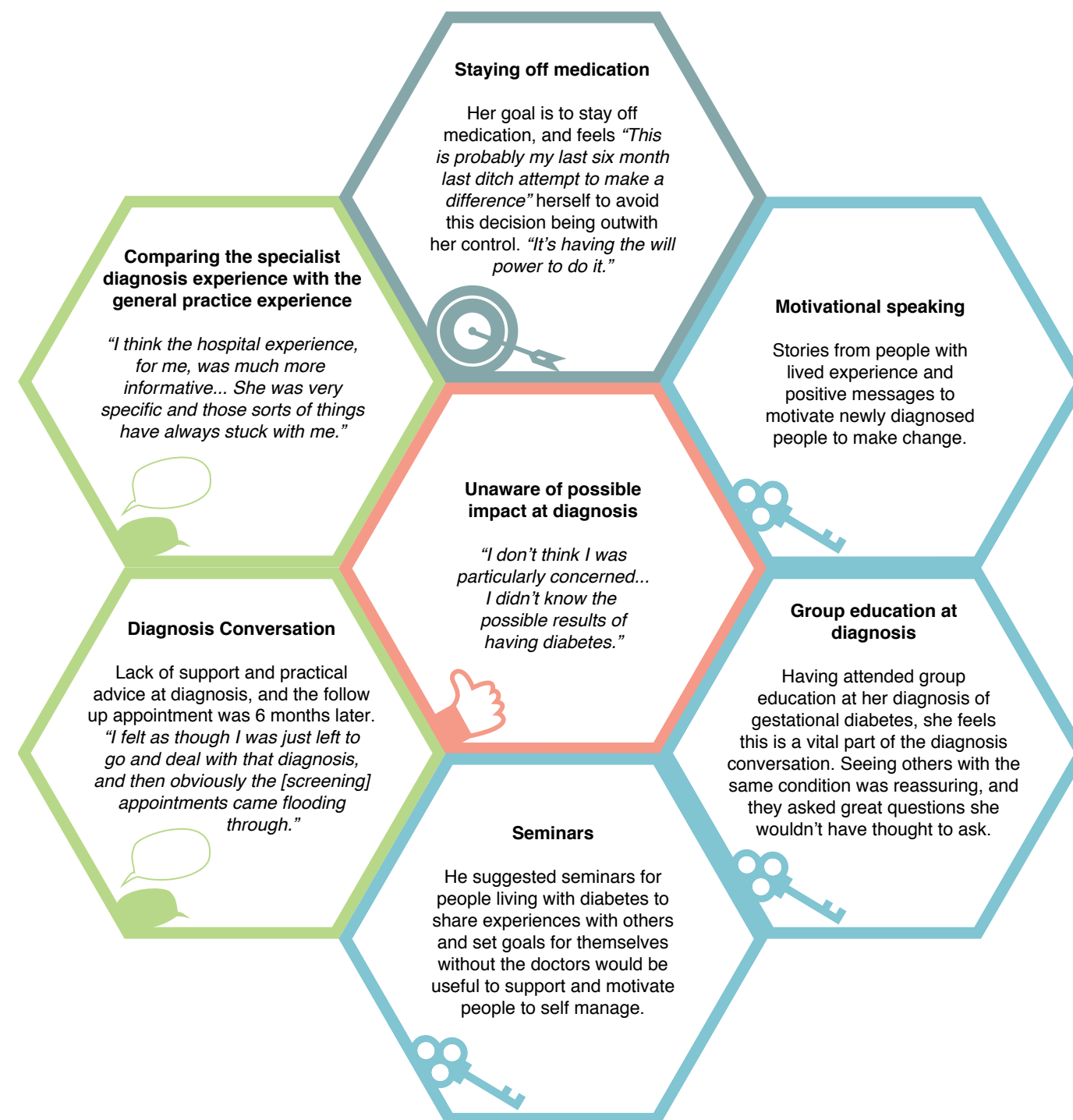


Figure 3: Insights from interviews and pop-up engagement with people living with type 2 diabetes.

## 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 from the conversation was seen as a way of ensuring the information is getting across.

Structured group education was seen to be a fantastic resource to support self management, but challenges were identified in encouraging people to attend, leading to poor uptake. We learned that the NHS Lanarkshire structured education programme for type

2 diabetes (STEP 2) is currently being prepared for accreditation 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.



Figure 4: Insights from interviews and pop-up engagement with health professionals.



## 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.

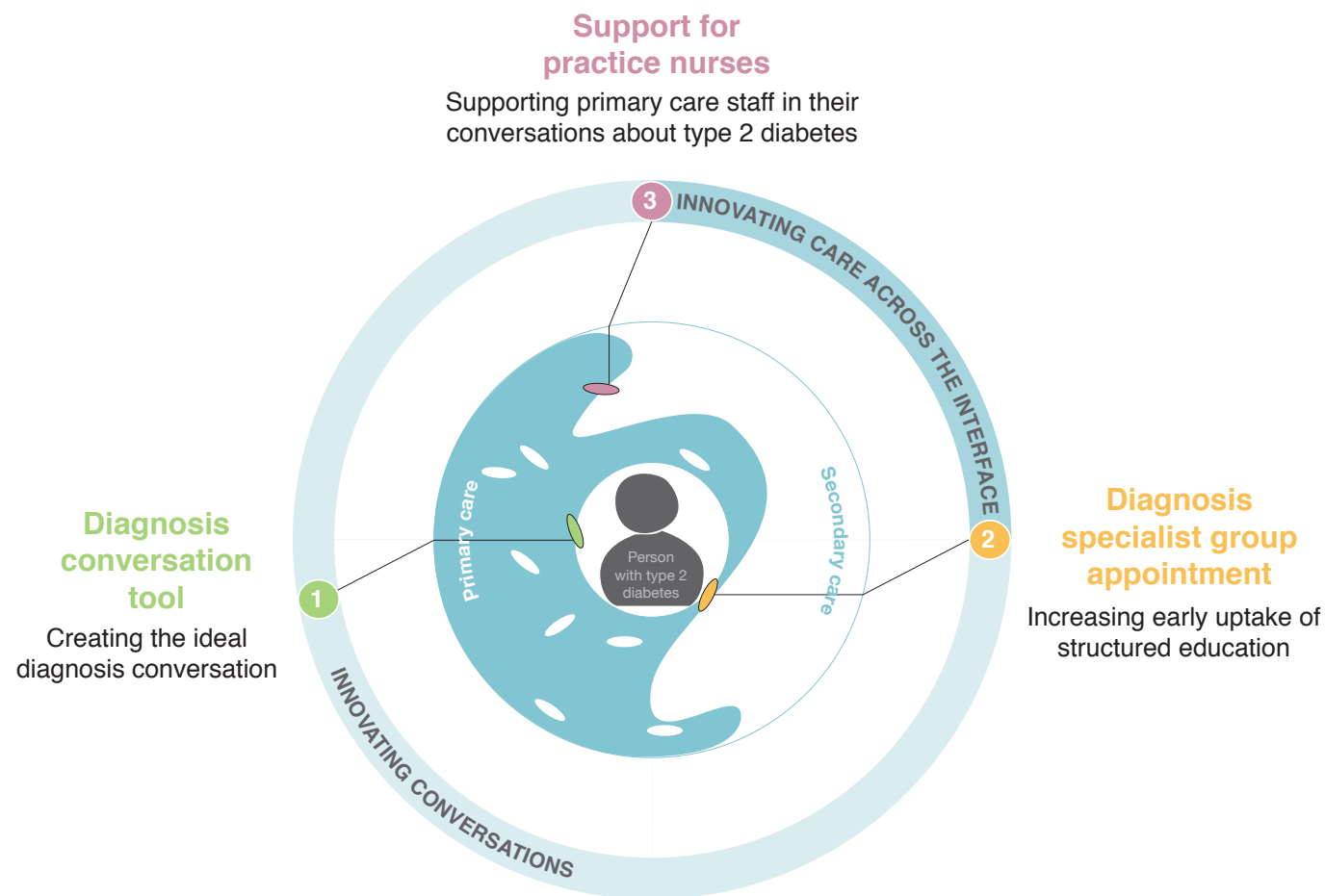


Figure 5: Overview of concepts for transforming conversations about type 2 diabetes

## Concept 1: Diagnosis Conversation Tool



### 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

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 care 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.

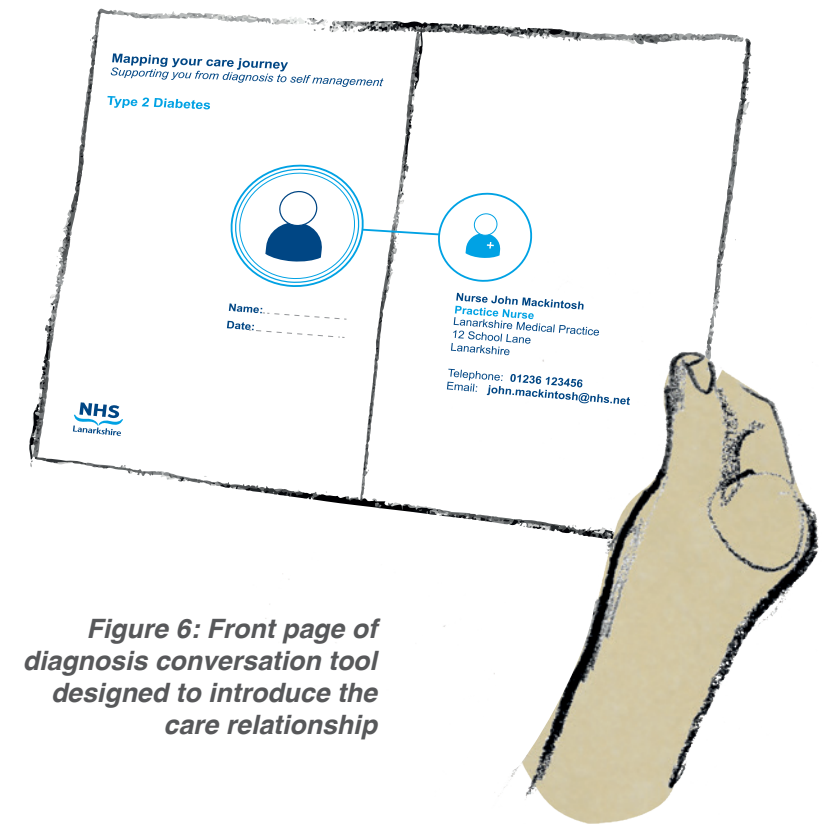
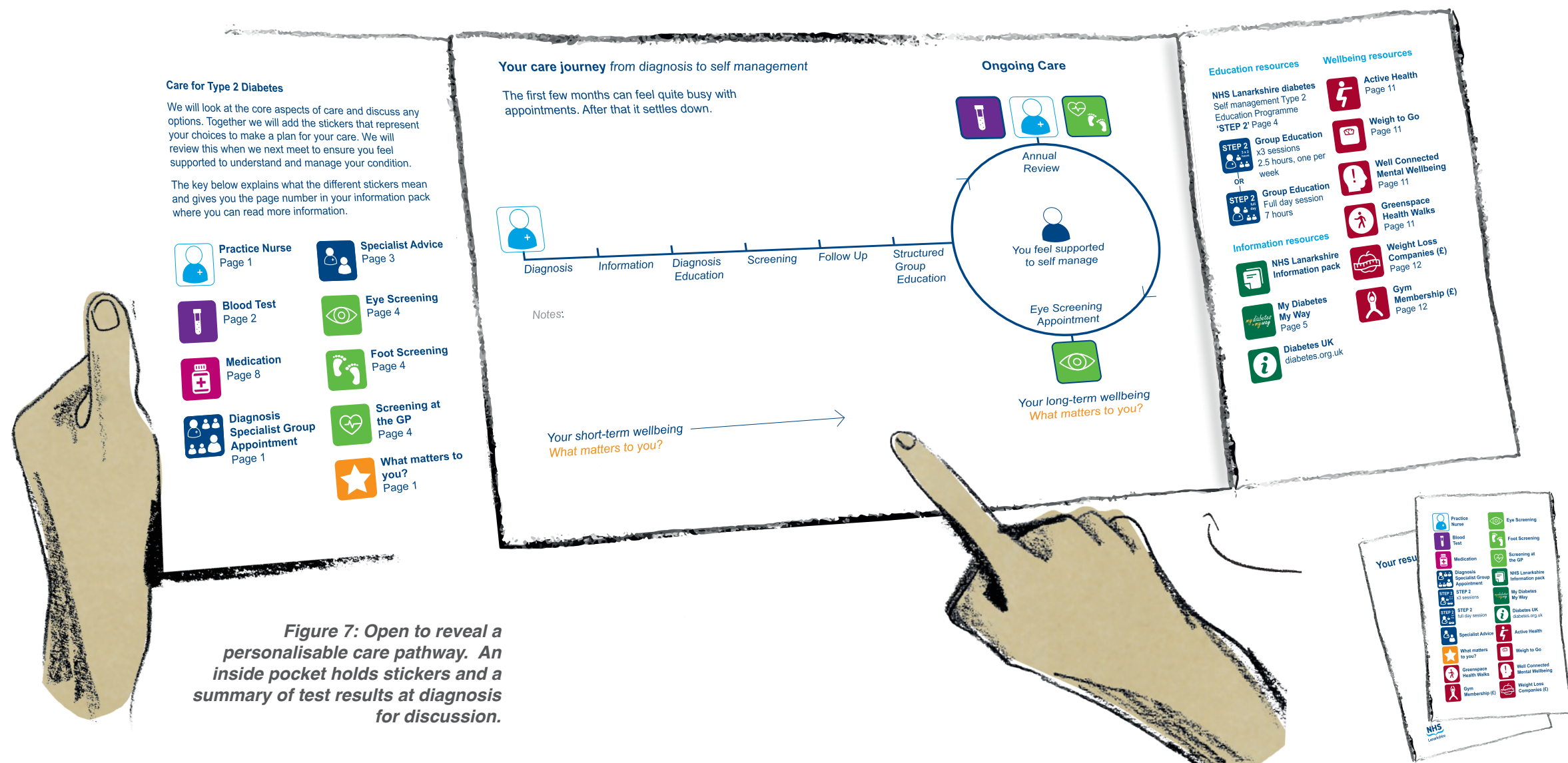


Figure 6: Front page of diagnosis conversation tool designed to introduce the care relationship



- **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



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

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.

*"It (the current guidance) is lengthy. (...) 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*

*"I think, going down the route of House of Care, we are trying to change our way of thinking and the way that we communicate with patients, by asking what they want. There is no point in saying that they have to do it. If they*

*come back in three months we can't say that they have to do things. It is about discussing what the importance is for them."*

*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



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 dietitian 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 with the specialist dietitian – by seeing patients in small groups the dietitians felt this would make a more efficient use of their time. The person would be referred for this appointment by the practice nurse during the diagnosis conversation using the same process they currently use to refer to the dietitian. Specialist diabetes educators advised that this session should last



**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 dietitian.**

around two hours, and include some interactive activities based on the principles of adult learning. The sessions could be scheduled for regular days and times in a range of different accessible community locations to increase availability and reduce waiting times for structured education. At the session, the person could choose to sign up for the full STEP 2 structured education or to receive a text message reminder to sign up at a later date.

### 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



**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.**

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

Person living with diabetes

Participants had mixed responses to the nature of the group, location and duration.

**“Group education is difficult. Also have other issues to consider - prolapsed disc, pain medications etc. Already have 3 appointments this week. No more appointments for me!”**

Person living with diabetes

**“It’s difficult to attend if you are working. I work for myself so it’s more difficult. Evening would be better, and I would prefer the hospital as I go there for other services.”**

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 mind-set. It doesn’t need to be hospital... need to let people know it is expected they will do this versus a choice.”**

Specialist staff

**“The session can take place anywhere – a place which is easy to get to, not seen as a threat (some may not like going to hospitals) but some people might not like being in a group.”**

Person living with diabetes

**“Two hours is too long. Individual appointments are only half an hour and more frequent. Individual needs are different. Going around and listening to everyone’s stories takes a long time. I wouldn’t want that.”**

Person living with diabetes

**“Need to be short, sharp sessions repeated to reinforce messages every 8-9 months.”**

Person living with diabetes



### 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



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

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**



**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.**

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

"I think, experience helps. Obviously the more experienced nurses become, then, you get better at it. **We have all to learn. It is about nurturing experience for the nurse.** Also, the patient wants to feel relaxed. So, before the patient comes into the room you want to feel 'in charge'. It is about preparation and

**you want to be prepared before the patient comes into the environment.** You want to make sure that you have got time."

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,  
Diabetes Specialist Nurse

**"I think peer support is crucial...** I think nurses are quite self-critical. You still have a responsibility to yourself as a nurse to know that you are confident before you sit a patient in front of you. You should know, although you need the support."

Workshop participant,  
Practice Nurse

"Protocols are useful and are there for a reason. I think, **what we really need to be doing is sitting down together and making them up, instead of us all having different protocols in each surgery.** I think, what is needed is for us all to sit around the table and get one that we can all use."

Workshop participant,  
Practice Nurse

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

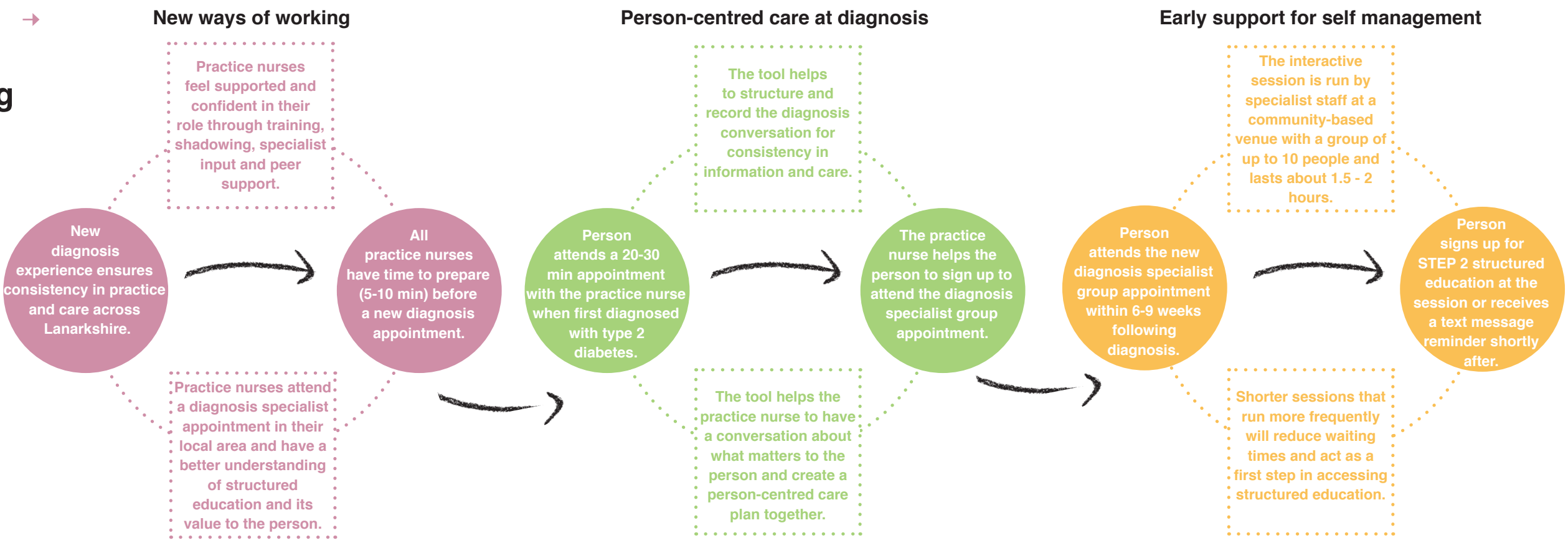


Diagnosis specialist group appointment

Providing information and support on  
diet, exercise and self management  
soon after diagnosis



Experiences  
of delivering  
and receiving  
care





# 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.

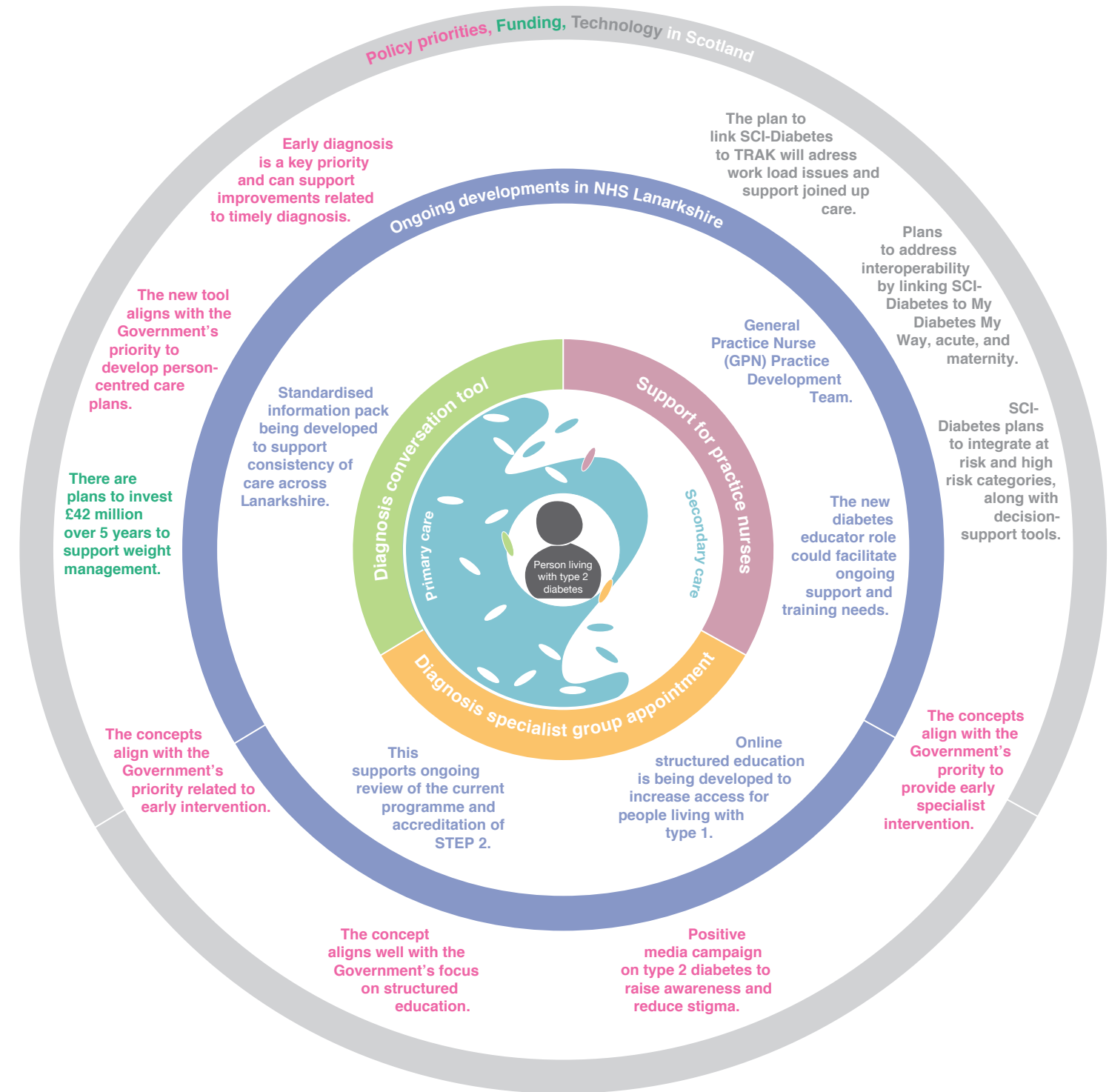


Figure 13: Alignment to Lanarkshire and National Developments.



# 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 the 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



## Diagnosis conversation tool



## Diagnosis specialist group appointment



## Next Steps

- 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.

- 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

- 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

## > Future Opportunities and National Developments

- Explore how digital tools could support new practice nurses to prepare for the diagnosis appointment, manage time and enable more confidence in delivering services.
- Work with senior decision makers at a national level to expedite interoperability between GP systems and SCI-Diabetes to enable joined-up care across primary and secondary care without duplication of effort from the practice nurse.

- 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.

- 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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[www.futurehealthandwellbeing.org/t2diabetes](http://www.futurehealthandwellbeing.org/t2diabetes)

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**Suggested citation:**

Raman, S and Teal, G. (2019). Transforming Conversations about Type 2 Diabetes: Final report. The Digital Health and Care Institute.

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