Transforming Conversations about Type 2 Diabetes

Interim Findings

Sneha Raman and Gemma Teal
The Glasgow School of Art

Released: September 2018

Revised: January 2019



Background and aim



In this project, the Digital Health and Care Institute* (DHI) responded to a challenge set by NHS Lanarkshire, to identify opportunities to innovate care for people living with diabetes. Working in collaboration with senior stakeholders and staff in the diabetes team, design researchers from The Glasgow School of Art (GSA) are leading a programme of research with health professionals and people living with type 2 diabetes in Lanarkshire.

The aim is to develop a person-centred approach to diabetes care in Lanarkshire and create a roadmap for future care, working together with those delivering the services and those receiving care.

We want to understand how care can be improved for people living with type 2 diabetes. Following a scoping workshop with staff in NHS Lanarkshire, two focus areas were identified: conversations at diagnosis for type 2 diabetes; and ways of working collaboratively between staff in GP practices, hospitals and community to provide person-centred care. A core part of this work involves engaging clinical and citizen groups to co-create visions for a preferable future. This is achieved using a participatory design approach to integrate multiple perspectives to ensure that it meets the expectations and needs of all those who provide and receive care.

Current state of type 2 diabetes care

The interim findings present the key insights on current care experiences, opportunities and ideas emerging from our engagements with people living with type 2 and health professionals delivering care in Lanarkshire.

* The Digital Health and Care Institute (DHI) is a collaboration between the University of Strathclyde and The Glasgow School of Art 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.

Research questions

How might we:

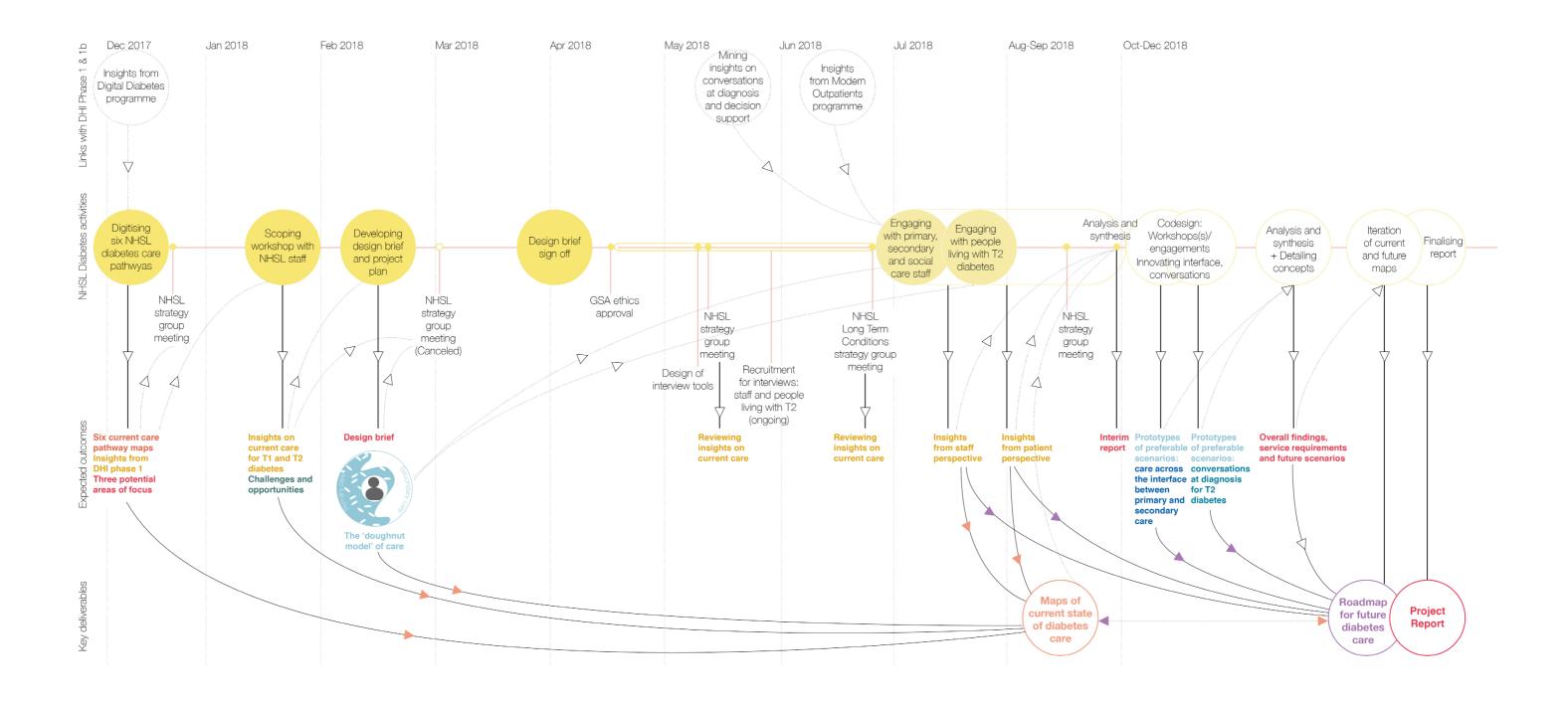
innovate conversations at diagnosis?

innovate care across the interface between primary and secondary care?

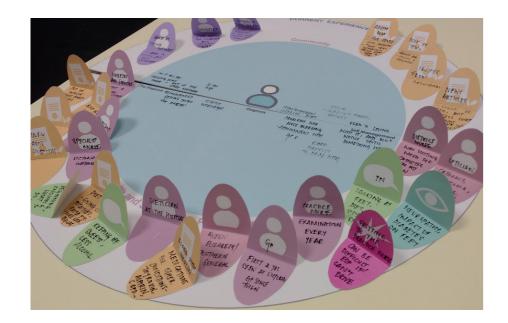


By focusing on one key moment in the care journey, i.e. the conversation between the primary care professional and the newly diagnosed T2 patient, we can understand how the secondary care team can work more collaboratively with primary care to improve self management in the community and prevent referral to secondary care.

Process



What we did



Interviews with people living with T2 diabetes

We interviewed four people living with type 2 diabetes in Lanarkshire. During the interview we used a visual tool to capture 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.



Interviews with staff

We interviewed four specialist staff and two primary care staff working in NHS Lanarkshire. In these interviews we used a similar visual tool, adapted to allow us to map 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. Through the interview 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.



Pop-up Engagement

We visited Monklands and Hairmyres diabetes clinics for two half-day 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 free-standing tree. These engagements gave us the opportunity to talk to people living with T2 diabetes who receive specialist care.

Introduction to the interim findings

The interim findings are intended to provide the current state of the T2 diagnosis conversation and care across the primary and secondary care interface in NHS Lanarkshire, from the perspective of people living with T2 diabetes and specialist and primary care staff. The key insights from each interview are presented in hexagons and categorised using colour coded icons (see adjacent key). Summaries of the insights from each interview is provided as an appendix to this document. The insights have been thematically analysed and are presented as follows:

The insights and ideas generated through engagement with people living with type 2 diabetes:

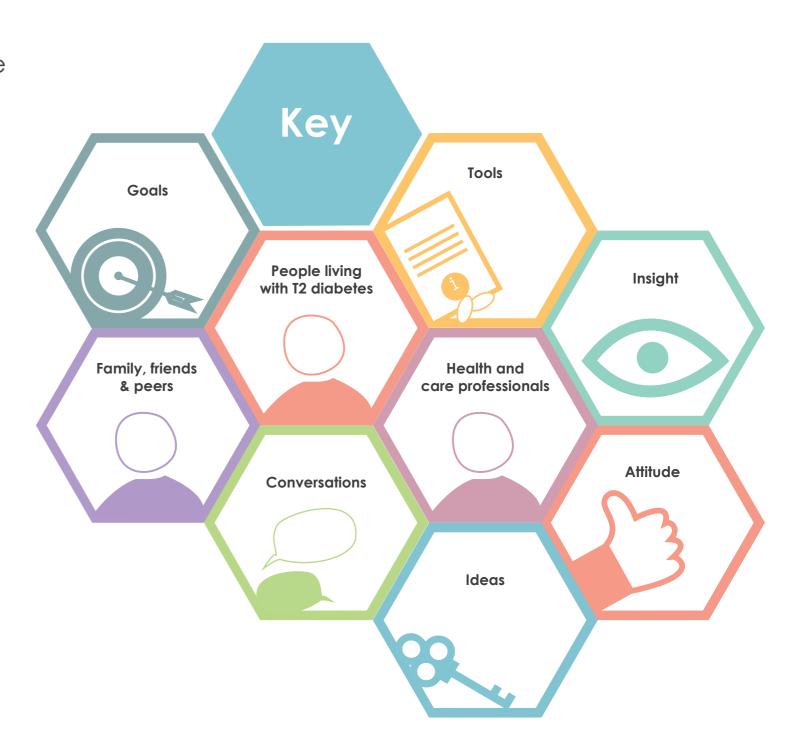
- a) Experiences of diagnosis;
- b) Attitudes to self management;
- c) Approaches to self management;
- d) Needs;
- e) Ideas.

The insights and ideas generated through interviews with specialist and primary care staff who support people living with type 2 diabetes:

- a) Attitudes and approaches to care;
- b) Attitudes and approaches to ways of working;
- c) Needs;
- d) Best practice and ideas.

Introducing the three questions identified as the focus for co-design workshops.

A summary of the insights mapped onto each of the key questions.



Who we engaged with

Practice Nurse

Sue has 20 years of experience as a practice nurse at the same health centre. She has a diploma in diabetes in addition to a professional degree and diplomas in other conditions such as respiratory and heart.

*Pseudonyms have been used to protect identity.

Mike

Mike is an 88 year old
widower with two grown up
daughters, one who lives around
the corner and is an ambulance
clinician. He enjoys reading,
crosswords and jigsaws. He self manages
well following diagnosis and early
treatment in secondary care. His
self management is complicated
by many other
conditions.

Primary care

Advanced Nurse Practitioner

Diana is one of the most experienced nurses at the practice, and organises nurse-led clinics on various topics. She runs clinics on long-term conditions two days a week.

Jane

Jane is 88 years old and lives on her own. She was diagnosed with diabetes 5 years ago. She does not notice any difference in her life following diagnosis, and has not had any complications. She is living with more than one long-term condition. "It's really all connected as far as I am

concerned."

y care. His mplicated

People living with T2 diabetes

People with T2 Diabetes attending specialist clinics

Two half-day pop-up engagements at Monklands and Hairmyres diabetes clinics gave us the opportunity to talk to people living with diabetes receiving specialist care.



Louise

Louise is a busy working mum and it is hard for her to prioritise her own wellbeing. Having used a meter in pregnancy, since being diagnosed with type 2 diabetes she feels she is being asked to manage "in the dark" and feels having short term feedback would help her make better decisions.

Community Diabetes Specialist Nurse

Amy is based in a community
health centre and all her patients
have T2 diabetes. She provides
specialist advice for people with T2
diabetes, carers, GPs, PNs and other HCPs.
She sees patients referred by GPs/PNs and
consultants to assess/make changes to
their diabetes treatment. Some are on
maximum oral agents and others
are existing patients on insulin

having problems managing their diabetes.

Gary

Gary is in his late fifties and lives with his wife. He was diagnosed with diabetes about 10-15 years ago. He has worked in multiple jobs and continues to do so, maintaining a busy life. He is proactive in learning about his condition and prioritises diabetes, but has had difficulty in the past managing weight and controlling his HbA1C.

Community Diabetes Dietitian

Julie is based in one of the community health centres, and sees patients who have chosen the option to be referred.

Secondary care

Podiatrist

Lucy is based at the Diabetes
Clinic and sees her role as that
of a care provider, motivator,
and educator. She chairs
the wound group, diabetes
specialist professional group,
attends the joint specialist
group and has built strong
links with other services such as
TVNs, dermatology, vascular
services etc.

Key themes, insights and ideas: People living with type 2 diabetes

Experience of diagnosis

Practice Nurse

May have been diagnosed by the practice nurse, when visiting the health centre for another condition (don't remember clearly).



Prompting diagnosis

One of his former work colleagues and friends recognised his constant feeling of thirst as a symptom for diabetes and prompted him to visit the GP.



Diagnosis conversation

He received his diagnosis from the GP, and remembers discussing his symptoms, medications, weight and diet.



Diagnosis conversation

Does not remember the details. Confused because of overlap with treatment for another condition.



general practice experience "I think the hospital experience,

Participants had different experiences of diagnosis.

Participants who had

a secondary care setting

valued the specialist input

received at diagnosis

and felt it shaped a better

understanding of their

for me, was much more informative... She was very specific and those sorts of things have always stuck with me."

Comparing the specialist

diagnosis experience with the



Diagnosis conversation for gestational diabetes

Attended a specialist clinic at her local hospital. Received her diagnosis in a 1:1 appointment, followed by group education. Felt confident and empowered to self manage using her meter and the tailored education and follow up care



received.

Diagnosis conversations

In the early stages he was full of questions about what changes he needed to make, but it quickly became his normal routine: "It was interesting in the hospital at first because it was all new but nowadays, you're living with it



and you're used to it so you don't think about it."

Diagnosis conversation

All training and initial treatment was in secondary care. Mike was admitted for a week for monitoring and to start insulin. He received training from a number of different specialists while in hospital, including the eye specialists



who were colocated with the ward.

Attitudes to self management

Insulin as a last resort

People want insulin to be a last resort as it has a big impact on their life, and more needs to be done to provide dietary advice early on.



Staying off medication

Her goal is to stay off medication, and feels "This is probably my last six month last ditch attempt to make a difference" herself to avoid this decision being out with her control. "It's having the will power to do it."



People have different motivations and triggers for engaging with their condition and self managing, including the 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 is a key reason to not engage.

Low priority

Diabetes is a lower priority as it does not impact day-today life as her other condition.



Engaged because it's life threatening

Finding out that diabetes can be life threatening, and the cost implications Type 2 diabetes has on the NHS prompted him to engage more with his condition.



Potential consequences/ complications

Is very pragmatic and uses humour when talking about long-term complications, but it is clear he is anxious about the impact this may have on his independence and interests.



Self management

Despite his many conditions, Mike has a very positive, proactive attitude towards self management:

"I think I've been quite fortunate in the treatment I've had and the outcome of it."

"You've got to keep going, as they say! You've got to have an interest in something."

Dietitian

He feels he is very knowledgeable on diet due to working in the food sector previously and his interest to proactively find more information. He does not feel the need to see a dietitian.



Group sessions

Does not think he will have time for group sessions due to a busy lifestyle, but trusts peer feedback.



People find value in

specialist advice and

peer support, but may

still choose not to

engage because of other

reasons.

Does not tend to engage as much with the condition unless a specific action or change may be required. No change in diet or lifestyle since diagnosis, and test results have been consistently within safe levels.

Self-management



Approaches to self management

Good relationship

He has a good relationship with all health professionals involved in his care - GP, consultant, practice nurses, DSN - and believes it is important for his care.



No judgement

People valued the friendly and helpful attitude of the staff with no judgement.



Having a good relationship, not feeling judged, being able to ask questions and access to specialist knowledge were important for people in their interactions with health professionals.

Motivated to know more

Wants to have as much information as possible and feels the way to do this is to ask lots of questions and also challenge them during interactions with health professionals. He also believes in sharing things he learns from other sources around diet etc. with his GP and consultant, as he feels sometimes they don't have all the information.

Specialist input

People valued the specialist input, direct practical advice and longer appointments. They contrasted this with their experience from primary care. "GP not specialised enough".

Investing time early on to support people to understand their condition, and ensuring they have all the required information specific to their needs can enable people to self manage and live well.

Self management

It took about a year to get his diabetes under control, and find the right insulin dose. Since then his diabetes self management has become a routine part of life, and he doesn't really have any practical issues or concerns.

Local services

Paid for a private podiatrist to come to her house, and found her advice more informative and personal.

"I'm serious about looking after my body so getting somebody out to look after my feet... I'm keen to do that and I'll pay for that myself."

Value of conversations

Feels it's not possible to have a relaxing conversation with the GP as they are under pressure. Recalls a good conversation with her consultant (for another condition) - more time, communicated well and engaging.



"It was the hospital that recommended 'carbs n cals' which is a brilliant app. It shows you on a plate portion sizes and takeaway food. That really worked for me."



Tools - Books

His first port of call when faced with a new challenge is to buy a book. He found a fantastic book about type 2 diabetes in the early stages following diagnosis, "In fact is was the best book I've ever had.".



Approaches to self management

Peer support

People valued the support and experience of others living with diabetes. This was seen to be a key benefit of group education.

Experience in the family

"My family all had it before me, so I knew a lot already".



Support from family

Many people attended their appointments with a family member, and highlighted that they played an important role in taking care of them, and supporting them in moments of weakness. "My good lady keeps me well. And hides the biscuits!"

Husband

Husband is supportive, and encourages her to eat healthily: "My husband is quite good. He'll say things like, 'Oh, do you think you should be eating that?', which is not very helpful when you really want it..."



Value of talking to peers

She has family and friends with type 1 diabetes, and she finds their practical advice and insight very useful. She finds it easier to ask questions and talk openly with peers.



Shared interests with son

Enjoys spending time with son who visits regularly, sharing their interests in reading, crosswords and Sudoku.



Family and peers were a big part of people's approaches to learning and self managing.

Life

Keeping busy. Keep travelling to see family. Loves gardening. Feels part of the community, and used to take an active part in community gardening events.



Progression to T2

Informed by her consultant that gestational diabetes increases the risk of developing type 2 diabetes, and that this would need to be monitored by her GP. She described seeing her numbers gradually rise at each check-up, and the almost inevitable eventual diagnosis.

Early, accurate diagnosis, and the need to prepare people on the possibility of progression to T2, as well as supporting them to understand and accept why they have the condition were found to be important at the beginning.

Early diagnosis

People who were diagnosed late or misdiagnosed felt that early, accurate, diagnosis would have prevented confusion and complications.

Diagnosis conversation for T2 diabetes

While it was not necessarily unexpected, it can still leave the person feeling "taken aback" and in need of reassurance, and advice about what it will mean for them.



"Why me?"

On top of the day-to-day management of diabetes, but would like to understand why he developed diabetes in the first place as he has never really been overweight and has a healthy diet and lifestyle.



Diagnosis conversation

Start with the basics and don't assume I know anything.



Diagnosis conversation

Lack of support and practical advice at diagnosis, and the follow up appointment was 6 months later. "I felt as though I was just left to go and deal with that diagnosis, and then obviously the [screening] appointments came flooding through."

Potential consequence/ complications

This was not discussed during the diagnosis conversation. Aware of annual screening for feet and eye, and the potential complications now.



Supporting people to understand the severity of the condition at diagnosis through realistic conversation about potential consequences and practical advice on how to avoid complications was considered very important.

Unaware of possible impact at diagnosis

"I don't think I was particularly concerned (...), I didn't know the possible results of having diabetes."



Underestimating the severity of the condition

Helping people to understand the severity of diabetes early with honest facts framed in a positive way.



More control through self management

Getting weight down and managing HbA1c levels, and cutting down medication. He feels he is making progress.

"I don't want my life to be shortened."

Understanding people's goals

(both related to their condition

and living well in general) is

key to understanding people's

motivations to self manage.

Living with multiple

It is difficult to know which condition a symptom or problem is related to, and medications for one condition

conditions

may make others worse.

Making time for self

management

Finds it hard to find time for

herself. She knows she needs

to make small changes like

ensuring she eats breakfast,

drinking more water and doing

regular exercise but it is hard to

prioritise herself.

Understanding people's personal circumstances, internal struggles, expectations and needs from their care are important factors in supporting them to overcome barriers and increase engagement.

More interaction and

reassurance

Would like the new practice

nurse to go beyond just

providing the test results and

provide the comparisons and

more explanation of what

this means in relation to safe

levels.

Value of conversations

Sees his Practice Nurse annually for a diabetes check up, but this tends to be for screening and questions about his lifestyle. He doesn't need to ask any questions.

"I probably know more about it than she does (laughing)..."

Coping with stigma

She is aware of the view of society that people living with type 2 diabetes have "done this to themself", and often jokes that her children are actually to blame. Her nurse has reassured her "You're fighting against bad genes, you're not my typical type 2... you're overweight but not hugely."

Being honest

She feels that she can't talk as freely and openly with health professionals as she does with peers, and wouldn't feel comfortable asking many questions.



Maintaining Independence

Mike's main goal is to retain his eyesight for as long as possible, so that he can continue to drive and get about, and to do his hobbies - reading, crosswords and jigsaws.



Being normal

Her main goal relates to her other condition, which has more of an impact on her day-to-day life.

"Longer period of being normal."



Sleep

Improving sleep pattern.



Leaflets

" (...) some sheets stapled together." Received at the group session, which she read at the time, but cannot remember the content now.

In general, leaflets were

thought be lacking in quality,

participants.

Leaflets

Received info leaflets from the practice, but does not find them useful. Instead values 1:1 face-to-face interactions for receiving information.

Use of technology

She uses the computer to check emails when her son visits every week. Has heard from her son that you can find information on diabetes on the computer, but does not use it herself.

Memory

Has difficulty remembering things.

Mulitple appointments

He has many different hospital appointments across different hospitals which he finds it difficult to manage, and takes a large number of medications per day.

Tools - Online

"The last thing I would do is look at the medical programmes and the web... You get so much worry (laughing)."

Group session

Remembers that the session was held with other women - cannot make a clear distinction between the group she met for the other condition and for diabetes.



There is a need for tools and resources to support people to retain/ recall information from the group sessions, as well as for engaging their family and children in these conversations.

With children

It is hard to know how to talk about the possible long-term complications with her young children when they ask.



Group education

Remembers discussion on diet, "Diet interested me". Exercise was probably discussed, but can't remember.



Diabetes in the family

Two of her sons have Type 1 diabetes. They don't talk much about diabetes with each other.



Screening

She can see the value of screening: "I think it's good that these things will be checked up yearly...", but she would like more information about why: "I think they need to explain why you're seeing that specialist and how the diabetes will affect that part of your body."

Be specific

Clear, directed and quantitative advice about diet, blood glucose targets and exercise. For example, pictures to see portion sizes and 'My fitness pal' to count carbs.

What to do when

Would prefer to know what to look out for if something went wrong, and information on 'what to do when ..'



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 blood glucose readings) can help people to prioritise these actions.

Short Term Feedback

Having experienced using a blood glucose meter during pregnancy, Louise feels that she is being asked to manage her condition "in the dark", without knowing the short term impact of her choices. "I felt as though she was asking me to be on top of my bloods and be on top of what I was eating but I didn't have any way to check that."

No short term consequences

"Well, yesterday I ate a whole bag of chocolate buttons because there's no number coming up on a screen to say, 'By the way, that's 14.9, horrendous, stop it' nothing. It is invisible and that, for me, is the difficult thing."

Healthy Eating

A very healthy diet generally, but learnt during pregnancy that her love of fruit is not suited to diabetes. She really enjoys food, and would love to be able to eat what she likes. She would like tailored and specific advice, e.g. only eat small bananas.

Underestimating the severity of the condition

Helping people to understand the severity of diabetes early with honest facts framed in a positive way.



Conversations about long-term complications and the actions required to prevent them should be honest and factual, but also realistic. 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.

Treatment at home

Given challenges with getting to his appointments, Mike wonders if it would be possible for his annual diabetes check-up to happen at his home, perhaps by the district nurse.

Potential complications and realistic advice

While she appreciates that it is important to know about feet problems, she felt she was being "lectured" and that the podiatrist was trying to frighten her with "the most horrendous story". She felt it didn't take her personal circumstances into account. As a young woman

she would not realistically wear flat, velcro shoes to work.

Unrealistic advice

During his visit to the podiatrist it was pointed out to him that the soles of his feet were hard and he needed to keep them moisturised. However, he feels this is unrealistic advice as this is a result of his years of doing karate.



Ideas

Use of visual aids in conversations and tangible information were suggested as key for engaging people in diagnosis conversations and self management.

Visual aids

He would like warning cards (as those used in football) to show how well a person is managing the condition or if they are at risk using visual tools (e.g. traffic light system).

Action cards

He would like every person to receive an action card stating targets to achieve within a specific time scale and actions to take at the end of each consultation.

Use of visual aids in

Having attended education at her

Use of visuals to engage people in the diagnosis conversation

Recounted an experience of a consultant explaining her son's kidney issue by drawing a diagram. "I would have loved her to draw a liver, and just talk to me about what that meant and [asked] 'How do you feel about it?,' Nobody has said to me, 'Are you alright?'."

Meter for first 6 months following diagnosis

While she acknowledges the high cost of meters and test strips, she feels they would prevent life-long reliance on medication. "I know it sounds really silly but if you've got your monitor and your diary to fill out, that's real."

Group education at diagnosis

Having attended group
education at her diagnosis of
gestational diabetes, she feels
this is a vital part of the diagnosis
conversation. Seeing others with the
same condition was reassuring, and
they asked great questions she
wouldn't have thought to ask.

Motivational speaking

Stories from people with lived experience and positive messages to motivate newly diagnosed people to make change.

Group education including positive stories from people with type 2 diabetes, and general public awareness were found to be important for engaging people.

Seminars

He suggested seminars for people living with diabetes to share experiences with others and set goals for themselves without the doctors would be useful to support and motivate people to self-manage.

Public education about the causes of diabetes

In order to reduce stigma and ignorance around type 2 diabetes, Louise thinks: "..there should be more out there about the causes."

Key themes, insights and ideas: Primary and secondary care staff

Attitudes and approaches to care

Patient responsibility

She feels people need to take more responsibility for their own care and to selfmanage.

While some staff talked

about their responsibility

to support the person

to self manage, others felt

people living with T2 need to

take more responsibility for their

that prevent engagement, being

realistic that people will relapse,

understanding the impact

of family and agreeing

personal goals are all

useful approaches.

Family approach to care

Believes it is important to

know a person's family

history and use this to tailor

their care. She may have

experience of caring for

other members of the family which she uses to build the care relationship.

Motivation

Feels responsible for the person's care, and is motivated to do as good a job as possible.



Family history

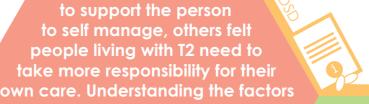
She asks if the person has anyone in their family who has diabetes, as this can have a psychological impact especially if they have had amputations. She reassures that the condition is different for each individual and



there have been significant advances in treatment.

Goal setting

She uses the goal setting tool in SCI Diabetes to agree goals for the person.



Change is a cycle

Non-compliance can be difficult to discuss. Some may not come back for a long time until they have a problem. You need to be realistic that relapses can happen, and make a holistic assessment to find the reason people aren't engaged.

Diagnosis conversation

Gives basic information in the first appointment, and schedules a follow-up appointment 2 weeks later to give the person time to absorb their diagnosis.



The diagnosis conversation and changes in their 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 to leverage these opportunities.

Time for change

The diagnosis is the best time for motivation to engage. It's also possible to re-engage using changes in their test results, e.g. protein in the urine.



Reassurance

"I am telling you today you have a chronic progressive condition, but it can be managed."



Diagnosis conversation

She feels that the diagnosis conversation is an opportunity to motivate and support people to make changes and sort things out.

Attitudes and approaches to care

Group education

Structured education is difficult for working patients to attend. She feels there are already too many appointments for them to go to. This leads to uptake issues. For some patients there is a long waiting period following diagnosis to attend STEP. She does not get any feedback from STEP about her patients.

Introducing group education

She encourages her patients to attend group education. "I would go to it". But she worries that it is too complicated for some of her patients.



Local services

She refers people to two programmes locally: 'Weigh to go' and 'Active health'. She feels they have a better uptake than the structured education programme.



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. Information and education from other sources were also seen as valuable and popular with people living with T2.

Group education

She has delivered structured education since 2007, and started delivering the STEP programme since 2016. STEP is run over 3 half-days, and are opt-in, and she feels it is difficult to get people in. Feedback from patients who have attended STEP often say 'they wish this was

available before'. She has only run one class this year.

Resources to give patients

She refers to My Diabetes My Way, Diabetes UK website, leaflets from medical reps, carb awareness leaflet and others printed from her computer. She mentions 'carbs & cals', which is a complex booklet.

She refers patients to the dietitian for this.



Group education

Tries to encourage all patients to attend STEP, as she feels in addition to education peer support is important. Some patients prefer 1:1 education, and even with the reduced number of session, it is demanding for some patients to attend the programme.



Diabetes UK booklet 'Everyday Life with T2 Diabetes' offered to all patients.

My Diabetes My Way is offered to all, but some engage with it more than others.

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 your conversation is a way

of ensuring the information is

getting across.



Take away

"What do you think is the main thing from what we have discussed today?"



Specific, practical and simple advice

Giving simple tips like "avoid 'cream of ..' soup", "cut out sugary drinks" and making the conversation relatable to them is important.



Being direct

Being direct can be difficult, but it is important to give the facts as they are, framed positively in terms of what they can do to stop complications. This includes explaining both the pros and cons of medication including possible side effects.

Attitudes and approaches to ways of working

Collaboration

Collaborates with the DSN for patients on insulin, counsellors, staff from the local gym. She makes referrals to DSN, consultant and dietician.



Collaboration

She believes that it is very positive to be co-located with the DSNs.



Collaboration

She has an open door policy for community staff to learn wound care.
Community staff can review their training needs using the core competencies form and request targeted learning.



Examples of collaborative working across the primary and secondary care interface were shared, but tended to be most evident in places where specialist and primary care staff were co-located. In addition to MDT meetings, some professionals had established their own approaches to support themselves and their colleagues.

Learning from the MDT

She attends a weekly MDT meeting, and feels well supported. The MDT (which involves the consultant) discuss new drugs, ideas and ways of supporting patients. MDT discuss complex patients and decide which treatment option would be best for the patient.

Medical illustrations

Photos of wounds are taken using an iPad and uploaded to a Lanarkshire-wide photo web. This provides a photographic record which charts progression of the wound. Photos can be shared between departments e.g. dermatology if any concern wound may be malignant. Photos can be motivating for patients and a training resource presenting case studies at inservice days or for publication etc.

Learning from colleagues

She organises a monthly support group for practice nurses in her area. They share learning, get peer support and occasionally have specialist staff attending to provide training.

SCI Diabetes

Uses it to find info on patients that she has referred to specialists. Enters info about foot screening, but not her notes from the consultations. (These are entered into Vision).



Advice from colleagues

She feels the hospital staff are an additional resource when needed. She occassionally phones the hospital dietitian or the consultant for advice, especially around interpreting complex diagnostics.



Supportive employer

She feels supported by the practice, and feels it is important for her to do her job well. They encourage her to continue learning and recognise her expertise.



Feels it's important to look care of herself.



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.



Attitudes and approaches to ways of working

Life long learning

Keeps up-to-date with the latest research and treatments.

Conferences

Attends conferences 2-3 times a year, for e.g. Primary Care Diabetes Network conference to keep up-to-date with the latest studies. She feels this is the best kind of education.

Guidelines

Using national and local guidelines and protocol to assesses patients before diagnosis. These are useful in her job.

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
or people living with T2. Having
sufficient time to make
changes was a barrier to
implementation

Guidelines

There are a significant amount of changes to guidelines sent out to the ANP regularly, and she feels there is no time provided to make changes.

Change takes time

New initiatives such a 'House of Care' need time to be successfully implemented and evaluated.



Seeing the right patient

All diabetic wounds should be referred into the podiatry service. Up skilling community podiatrists supports them to identify the complex patients and refer on to acute podiatry staff with the appropriate level of urgency. This allows diabetes specialist staff to maintain capacity to continue to provide rapid access to the acute multi disciplinary service.

Lack of admin support

A large part of time is spent managing referrals, making appointments and dealing with cancellations and DNAs.

Needs identified by staff included administrative support for record keeping and arranging appointments, and training and support for appropriate referrals. In some areas, opportunities for communication between primary and secondary care were very limited.

Patient records

She does not feel that the IT systems support her to do her job and to collaborate. She accesses SCI Diabetes usually only when she is with the patient and needs to. There is not always communication from secondary care when a patient has been seen. She feels things can then get missed unless a letter comes in. Changes are usually faxed. Updating records is

time consuming and adds to her workload.

Collaboration

She feels there are major communication issues between primary and secondary care and district nurses. There are no regular events or updates that bring



everyone together.

Joined up systems

It would be preferable for the SCI diabetes and VISION systems to be integrated. This would allow her consultation narrative to be included for joined up care.

Joined up care

Years ago the person saw the dietitian, specialist nurse and all specialist staff in a single appointment. She feels this allowed more joined up care for the person.

Waiting times

Inappropriate referral

Sometimes GPs/PNs refer

before they maximise oral

treatment. This involves

extra admin time to triage.

She is involved in updating

the referral criteria to

address this issue.

She refers all patients to the dietitian, but there is a long waiting period before they can be seen.

Training

There is a lack of training in chronic conditions tailored for primary care, for e.g. around changes in drugs.



Referral

Some patients prefer to see the practice nurse exclusively, rather than seeing specialist staff.

Patient fear of judgement

There is a perception among patients that the dietitian will make judgements on their dietary habits. This means that not all patients who can benefit from her support opt in for an appointment.

Psychological support

She feels people are often at their lowest ebb when they come to see her. Patients can be frightened and want her to fix their problems. They can be depressed about how long it can take their wound to heal and the impact this has on their lives.

Staff discussed some of the challenges and needs of people living with T2 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 disease and the need for psychological support.

Invisible

It is hard to change behaviour you can't measure. E.g. To the patient weight loss is visible but HbA1C is not.

Diagnosis conversation

She feels that there is a need for more information on the complications and the progressive nature of the condition at diagnosis. People are usually more motivated to make lifestyle changes at diagnosis.

Changing behaviour

People's perceptions of portion sizes can be variable, and altering diet in one go can be a problem.



Best practice and ideas

Collaboration

Collaborates with the DSN for patients on insulin, counsellors, staff from the local gym. She makes referrals to DSN, consultant and dietitian.



Collaboration

She believes that it is very positive to be co-located with the DSNs.



Learning from colleagues

She organises a monthly support group for practice nurses in her area. They share learning, get peer support and occasionally have specialist staff attending to provide training.

We heard many
examples of best
practice to support
collaboration that could
be shared with other parts of
Lanarkshire. In primary care, the
practice nurse had establised a
support group for others in her area
to share advice and information.
In secondary care, the
podiatrist is using photos

Collaboration

to share advice about

wound care.

She has an open door policy for community staff to learn wound care.
Community staff can review their training needs using the core competencies form and request targeted learning.

Joined up care

Years ago the person saw the dietitian, specialist nurse and all specialist staff in a single appointment. She feels this allowed more joined up care for the person.

New ideas for joining up care included the use of existing technologies, shadowing and more training opportunities.

Medical illustrations

Supportive employer

She feels supported by

the practice, and feels it is

important for her to do her

job well. They encourage

her to continue learning

and recognise her expertise.

Photos of wounds are taken using an iPad and uploaded to a Lanarkshire-wide photo web. This provides a photographic record which charts progression of the wound. Photos can be shared between departments e.g. dermatology if any concern wound may be malignant. Photos can be motivating for patients and a training resource presenting case studies at inservice days or

oresenting case studies at inservice days or for publication etc.

Joint working with community wound leads

Skilled wound leads within community podiatry provide an extension on the MDT, ensuring that all community staff are well trained and support skills development through shadowing at acute sites. Diabetes specialist podiatry service provide an outreach service providing a second opinion or joint review with community staff for patients unable to attend acute sites.

Outreach

Using technology to link community staff and nursing homes directly with diabetes specialist staff and/or diabetes consultant to provide specialist advice to ensure nobody is missed.

Attend anywhere

She feels that piloting Attend Anywhere could make a difference in attendance at her clinics, as it would be a good option for some people who find it difficult for example get time off work to attend appointments.

Best practice and ideas

Training family members

Training family members to check for symptoms and provide support for better foot care.

Motivational speaking

Stories from people with lived experience of diabetes using humour and positive messages can motivate newly diagnosed people to make change.

Signposting

She feels it is important for people to have choice on how information is accessed.
Libraries can enable this through access to printing, alongside additional digital resources, but patients have to be careful to ensure information is not out of date.

Ideas for involving
the wider community
in the circle of care
of people living with T2
diabetes included: training
family members, peer support
and involvement in educating
people who are newly diagnosed,
and collaborating with community
resources and services. New
ways of introducing and
advertising STEP were
suggested to improve
uptake.

Collaborating with local services

She suggested that STEP could be combined with local services such as 'Weigh to go' and 'Active health' for better uptake.

Introducing STEP

How STEP is introduced has an influence on uptake.
Advertising STEP in diverse locations and positively introducing the programme early on after diagnosis in primary care should motivate people to attend.

Referral to STEP

STEP is currently a self-referral programme. She feels STEP would be better attended if patients are referred in, thus giving it more importance.

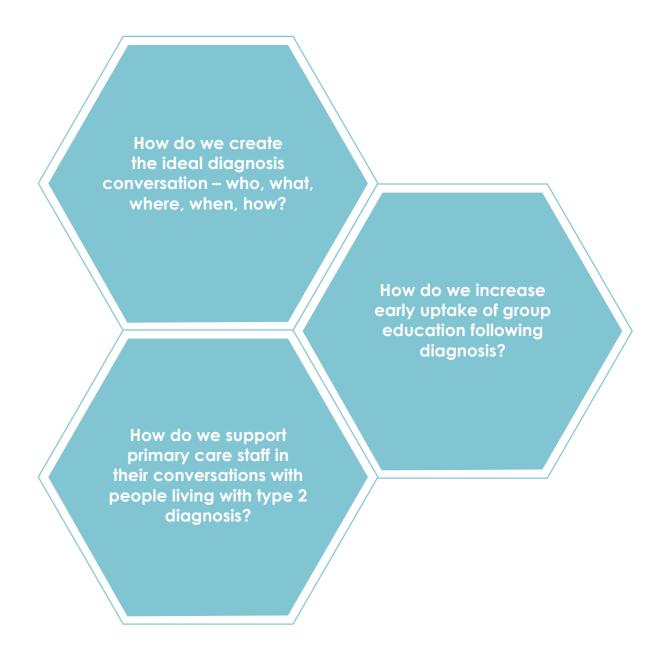
Focus for co-design workshops

Questions for the co-design workshops

Designing future state of type 2 diabetes care

Based on the key themes, insights and ideas emerging from the engagements, we have identified three focus areas for the co-design sessions. These are opportunities to innovate the experience of diagnosis and ways of working across the primary and secondary care interface.

Within these findings are the key ingredients to respond to these questions, and these will be used to inform and inspire participant in the co-design workshops.



Key ingredients for co-design workshops

Summary of the key ingredients: from the perspective of people living with T2

diabetes

More interaction and reassurance

Would like the new practice nurse to go beyond just providing the test results and provide the comparisons and more explanation of what this means in relation to safe levels.

Use of visual aids in conversations and tangible information were suggested as key for engaging people in diagnosis conversations and self management.

Participants had different experiences of diagnosis. 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

Investing time early on to support people to understand their condition, and ensuring they have all the required information specific to their needs can enable people to self manage and live well.

Diagnosis conversation for T2 diabetes

While it was not necessarily unexpected, it can still leave the person feeling "taken aback" and in need of reassurance, and advice about what it will mean for them.

> Diaanosis conversation

Start with the basics and don't assume I know anything.

Conversations about

long-term complications

and the actions required

to prevent them should be

honest and factual, but also

realistic. Tailoring the information

can help to ensure they

engage with the advice.

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

to the person's circumstances and appreciating that they may have There was an appetite for specific, practical other competing challenges instructions on the dietary changes people need to make. Providing the reasons why screening is necessary, through blood glucose

Supporting people to understand the severity of the condition at conversation about potential consequences and practical advice on how to avoid complications was considered very important.

What to do when

Would prefer to know what to look out for if something went wrong, and information on 'what to do when ..'

Summary of the key ingredients: from the perspective of staff

The diagnosis
conversation and
changes in their
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 to leverage
these opportunities.

Group education

Tries to encourage all patients to attend STEP, as she feels in addition to education peer support is important. Some patients prefer 1:1 education, and even with the reduced number of session, it is demanding for some patients to attend the programme.

Resources to give patients

Diabetes UK booklet 'Everyday

Life with T2 Diabetes' offered to all patients.

My Diabetes My Way is offered to all, but some engage with it more than others.



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

Signposting

She feels it is important for people to have choice on how information is accessed.

Libraries can enable this through access to printing, alongside additional digital resources, but patients have to be careful to ensure information is not out of date.

of ensuring the information is getting across.

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

Local services

She refers people to two programmes locally: 'Weigh to go' and 'Active health'. She feels they have a better uptake than the structured education programme.

Motivational speaking

Stories from people with lived experience of diabetes using humour and positive messages can motivate newly diagnosed people to make change.

Diagnosis conversation

She feels that there is a need for more information on the complications and the progressive nature of the condition at diagnosis. People are usually more motivated to make lifestyle changes at diagnosis.

Summary of the key ingredients: from the perspective of people living with T2

diabetes

Group education at diagnosis

Having attended group education at her diagnosis of gestational diabetes, she feels this is a vital part of the diagnosis conversation. Seeing others with the same condition was reassuring, and they asked great questions she wouldn't have thought to ask.

Group education including positive stories from people with type 2 diabetes, and general public awareness were found to be important for engaging people.

People find value in specialist advice and peer support, but may still choose not to engage because of other reasons.

How do we increase early uptake of group education following diagnosis?

Peer support

People valued the support and experience of others living with diabetes. This was seen to be a key benefit of group education. Having access to tools
and services that can offer
additional information
and support is important
to enable people to have
greater control in managing
their condition

There is a need for tools and resources to support people to retain/ recall information from the group sessions, as well as for engaging their family and children in these conversations.

Summary of the key ingredients: from the perspective of staff

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. Information and education from other sources were also seen as valuable and popular with people living with T2.

Group education

Tries to encourage all patients to attend STEP, as she feels in addition to education peer support is important. Some patients prefer 1:1 education, and even with the reduced number of session, it is demanding for some patients to attend the programme.

Introducing STEP

How STEP is introduced has an influence on uptake.
Advertising STEP in diverse locations and positively introducing the programme early on after diagnosis in primary care should motivate people to attend.

How do we increase early uptake of group education following diagnosis?

Joined up care

Years ago the person saw the dietitian, specialist nurse and all specialist staff in a single appointment. She feels this allowed more joined up care for the person.

Local services

She refers people to two programmes locally: 'Weigh to go' and 'Active health'. She feels they have a better uptake than the structured education programme.

Summary of the key ingredients: from the perspective of staff

We heard many
examples of best
practice to support
collaboration that could
be shared with other parts of
Lanarkshire. In primary care, the
practice nurse had establised a
support group for others in her area
to share advice and information.
In secondary care, the
podiatrist is using photos
to share advice about
wound 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 T2. Having
sufficient time to make
changes was a barrier to

Supportive employer

She feels supported by the practice, and feels it is important for her to do her job well. They encourage her to continue learning and recognise her expertise.



How do we support primary care staff in their conversations with people living with type 2 diagnosis?

Needs identified by staff included administrative support for record keeping and arranging appointments, and training and support for appropriate referrals. In some areas, opportunities for communication between primary and secondary care were very limited.

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.

Patient records

She does not feel that the IT systems support her to do her job and to collaborate. She accesses SCI Diabetes usually only when she is with the patient and needs to. There is not always communication from secondary care when a patient has been seen. She feels things can then get missed unless a letter comes in. Changes are usually faxed,

Changes are usually faxed Updating records is time consuming and adds to her workload.

Joined up systems

It would be preferable for the SCI diabetes and VISION systems to be integrated. This would allow her consultation narrative to be included for joined up care.

Training

There is a lack of training in chronic conditions tailored for primary care, for e.g. around changes in drugs.





ACKNOWLEDGEMENTS

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

We would also like to thank staff from NHS Lanarkshire diabetes team for attending the scoping workshop which identified the focus for this research, and for enabling our pop-up public engagement sessions outside their busy clinics, and to all the citizens and staff who engaged with us to share their views.

Finally, many thanks to June Currie for her fantastic support and encouragement!

Design research: Sneha Raman and Gemma Teal

Graphic design: Sneha Raman

Images courtesy: Louise Mather, No Middle Name; Gemma Teal

To cite this report or reference any material, please use the following reference: Raman, S and Teal, G. (2018). Transforming Conversations about Type 2 Diabetes: Interim Findings. The Digital Health and Care Institute.



DHI is a collaboration between The Glasgow School of Art and the University of Strathclyde





Transforming Conversations about Type 2 Diabetes

NHS Lanarkshire

Appendices

Sneha Raman and Gemma Teal

The Innovation School, The Glasgow School of Art

Released: September 2018 Revised: January 2019



Introduction

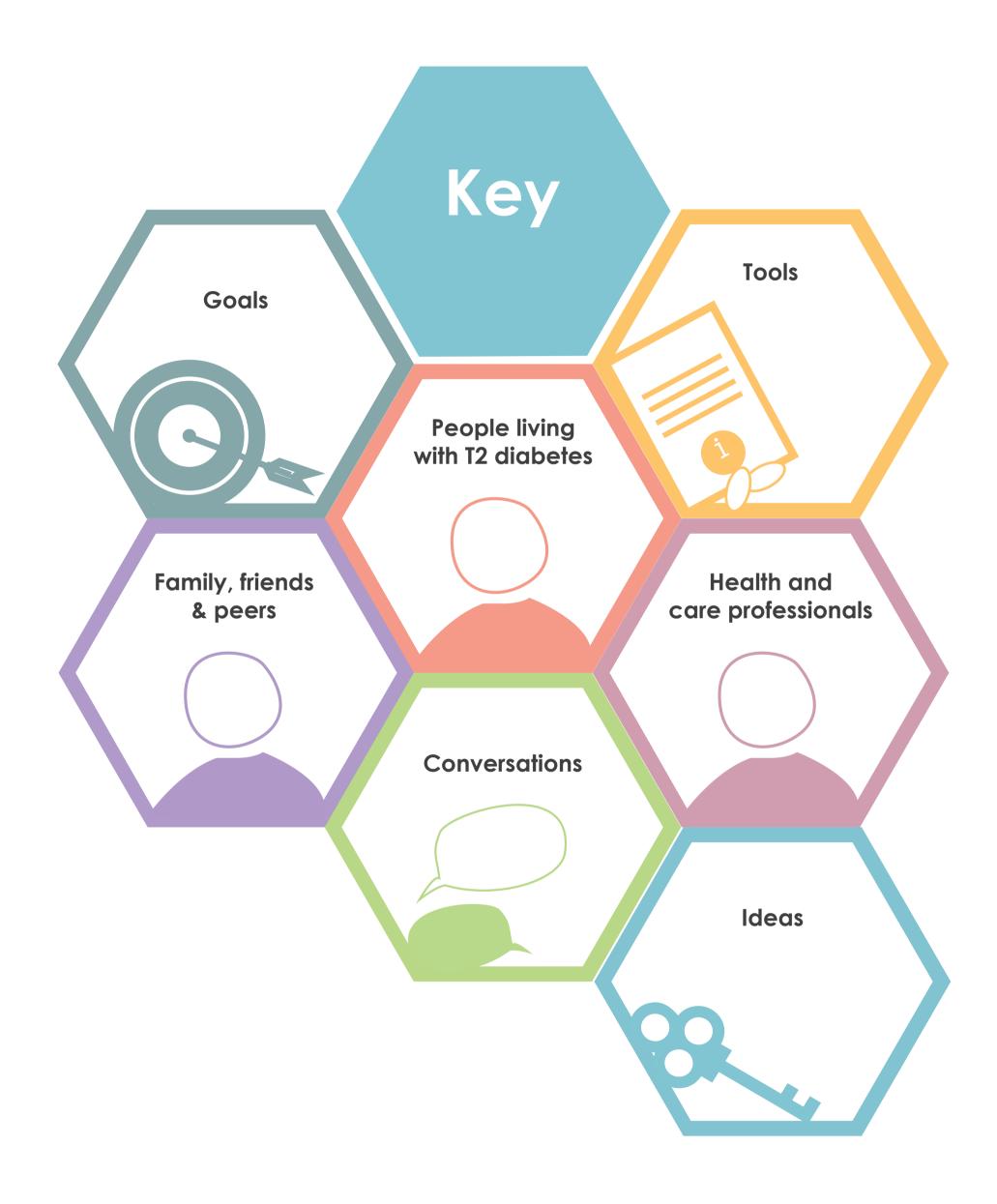
This document provides a full summary of the insights from each interview as an appendix to the Interim Report. These have been organised into two sections:

Appendix 1: Engagements with people with type 2 diabetes in Lanarkshire

- 1a. Mike (Interview)
- 1b. Louise (Interview)
- 1c. Jane (Interview)
- 1d. Gary (Interview)
- 1e. People with T2 diabetes attending specialist clinics (Pop-up engagement)

Appendix 2: Engagements with primary and secondary care staff in Lanarkshire

- 2a. Advanced Nurse Practitioner (Interview)
- 2b. Practice Nurse (Interview)
- 2c. Community Diabetes Specialist Dietitian (Interview)
- 2d. Podiatrist (Interview)
- 2e. Community Diabetes Specialist Nurse (Interview)



^{*}Pseudonyms have been used to protect identity.

Summaries of interviews and pop-up engagements with people living with type 2 diabetes

Tools - Books

His first port of call when faced with a new challenge is to buy a book. He found a fantastic book about type 2 diabetes in the early stages following diagnosis, "In fact is was the best book I've ever had.".



Diagnosis conversation

All training and initial treatment was in secondary care. Mike was admitted for a week for monitoring and to start insulin. He received training from a number of different specialists while in hospital, including the eye specialists

eye specialists who were colocated with the ward.

"Why me?"

On top of the day-to-day

management of diabetes, but

would like to understand why

he developed diabetes in the

first place as he has never really

been overweight and has a

healthy diet and lifestyle.

Diagnosis conversations

In the early stages he was full of questions about what changes he needed to make, but it quickly became his normal routine: "It was interesting in the hospital at first because it was all new but nowadays, you're living with it and you're used



Value of conversations

Sees his Practice Nurse annually for a diabetes check up, but this tends to be for screening and questions about his lifestyle. He doesn't need to ask any questions.

"I probably know more about it than she does (laughing)..."

Group sessions

"I quite like meeting people and things like that, [but] it was the sort of thing I couldn't really be bothered

Self management

active attitude towards self

management:

"I think I've been quite fortunate in the

treatment I've had and the outcome of

"You've got to keep going, as

to have an interest

Mike has a number

of different health

conditions, including: a four

graft heart bypass operation;

bladder cancer requiring

surgery, chemotherapy (pending)

and currently needs to use a cathetar;

COPD; cateracts, glaucoma and retinal

damage; lower spinal degeneration

causing problems with bending and

walking; neuropathy; stroke

leading to memory

and speech

problems.

in something."

they say! You've got

Self management

It took about a year to get his diabetes under control, and find the right insulin dose. Since then his diabetes self management has become a routine part of life, and he doesn't really have any

really have any practical issues or concerns. Despite his many conditions, Mike has a very positive, pro-

Mike

Mike is an 88 year old widower with two grown up daughters, one who lives around the corner and is an ambulance clinician. He enjoys reading, swords and jigsaws. He self manage well following diagnosis and early treatment in secondary care. His elf management is complicated by many other conditions.

Challenges

"Well, yes, the COPD is probably the worst of it all. I can't walk and can't converse at the same time...
You don't know whether your nose is going to bleed or you can't speak when you straighten up.
That's a really difficult part of my life at the moment."

Eye Specialists

Sees the eye specialist and optician as his eyesight is significantly declining to the extent that the optician told him he would likely only have his driving licence for one more year. The eye specialist won't operate on his cataracts due to his other complications.

Tools - Online

"The last thing I would do is look at the medical programmes and the web... You get so much worry (laughing."



Potential consequences/ complications

Feels fortunate that his diabetes hasn't progressed as he is aware there can be significant complications from stories in the media: "Well, you read about cases in the paper or things like that of people losing their toes and their feet and eventually their legs."



Mulitple appointments

He has many different hospital appointments across different hospitals which he finds it difficult to manage, and takes a large number of medications per day.

Potential consequences/ complications

Is very pragmatic and uses humour when talking about long-term complications, but it is clear he is anxious about the impact this may have on his independence and interests.



Treatment at home

Given challenges with getting to his appointments, Mike wonders if it would be possible for his annual diabetes check-up to happen at his home, perhaps by the district nurse.

Maintaining Independence

Mike's main goal is to retain his eyesight for as long as possible, so that he can continue to drive and get about, and to do his hobbies - reading, crosswords and jigsaws.





Being honest

She feels that she can't talk as freely and openly with health professionals as she does with peers, and wouldn't feel comfortable asking many questions.

Comparing the specialist diagnosis experience with the general practice experience

"I think the hospital experience, for me, was much more informative... She was very specific and those sorts of things have always stuck with me."

Diagnosis conversation

Lack of support and practical

up appointment was 6 months later.

go and deal with that diagnosis,

advice at diagnosis, and the follow

"I felt as though I was just left to

and then obviously the [screening]

appointments came flooding

through."

people in the diagnosis conversation

Recounted an experience of a consultant explaining her son's kidney issue by drawing a diagram. "I would have loved her to draw a liver, and just talk to me about what that meant and [asked] 'How do you feel about it?,' Nobody has said to me,) 'Are you alright?'."

Use of visuals to engage

Meter for first 6 months following diagnosis

While she acknowledges the high cost of meters and test strips, she feels they would prevent life-long reliance on medication."I know it sounds really silly but if you've got your monitor and your diary to fill out, that's real."

Inevitable progression

Informed by her consultant that gestational diabetes increases the risk of developing type 2 diabetes, and that this would need to be monitored by her GP. She described seeing her numbers gradually rise at each check-up, and the almost inevitable eventual diagnosis.

Diagnosis conversation for gestational diabetes

Attended a specialist clinic at her local hospital. Received her diagnosis in a 1:1 appointment, followed by group education. Felt confident and empowered to self manage using her meter and the tailored education and follow up care received.

Diagnosis conversation

Start with the basics and don't assume I know anything.

Staying off medication

Her goal is to stay off medication, and feels "This is probably my last six month last ditch attempt to make a difference" herself to avoid this decision being out with her control. "It's having the will power to do it."



Louise

Diagnosis conversation for T2 diabetes

While it was not necessarily unexpected, it can still leave the person feeling "taken aback" and in need of reassurance, and advice about what it will mean for



Screening

She can see the value of screening: "I think it's good that these things will be checked up yearly...", but she would like more information about why: "I think they need to explain why you're seeing that specialist and how the diabetes will affect that part of your body."



Local services

Paid for a private podiatrist to come to her house, and found her advice more informative and personal.

"I'm serious about looking after my body so getting somebody out to look after my feet... I'm keen to do that and I'll pay for that myself."

Public education about the causes of diabetes

In order to reduce stigma and ignorance around type 2 diabetes, Louise thinks: "..there should be more out there about the causes."



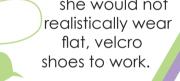
Coping with stigma

She is aware of the view of society that people living with type 2 diabetes have "done this to themself", and often jokes that her children are actually to blame. Her nurse has reassured her "You're fighting against bad genes, you're not my typical type 2... you're overweight but not hugely."



Potential complications and realistic advice

While she appreciates that it is important to know about feet problems, she felt she was being lectured" and that the podiatrist was trying to frighten her with "the most horrendous story". She felt it didn't take her personal circumstances into account. As a young woman she would not



No short term consequences

"Well, yesterday I ate a whole bag of chocolate buttons because there's no number coming up on a screen to say, 'By the way, that's 14.9, horrendous, stop it' nothing. It is invisible and that, for me, is the difficult thing."

Tools - carbs n cals

"It was the hospital that

recommended 'carbs n cals' which is a brilliant app. It shows you on a plate portion sizes and takeaway food. That really

worked for me."



top of my bloods and be on top of what I was eating but I didn't have any way to check that."



With children

It is hard to know how to talk about the possible long-term complications with her young children when they ask.



Husband

Husband is supportive, and encourages her to eat healthily: "My husband is quite good. He'll say things like, 'Oh, do you think you should be eating that?', which is not very helpful when you really want it..."



Short Term Feedback

Having experienced using a blood glucose meter during pregnancy, Louise feels that she is being asked to manage her condition "in the dark", without knowing the short term impact of her choices. "I felt as though she was asking me to be on



A very healthy diet generally, but learnt during pregnancy that her love of fruit is not suited to diabetes. She really enjoys food, and would love to be able to eat what she likes. She would like tailored and specific advice, e.g. only eat small bananas.



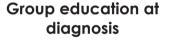
She has family and friends with type 1 diabetes, and she finds their practical advice and insight very useful. She finds it easier to ask questions and talk openly with peers.

Value of talking to peers



Making time for self management

Finds it hard to find time for herself. She knows she needs to make small changes like ensuring she eats breakfast, drinking more water and doing regular exercise but it is hard to prioritise herself.



Having attended group education at her diagnosis of gestational diabetes, she feels this is a vital part of the diagnosis conversation. Seeing others with the same condition was reassuring, and they asked great questions she wouldn't have thought to ask.



Appendix 1c: Jane

the group session, which she read at the time, but

Leaflets

" (...) some sheets stapled

together." Received at

cannot remember the

Diagnosis conversation

Does not remember

the details. Confused

because of overlap with

treatment for another

condition.

Practice Nurse

May have been diagnosed by the

practice nurse, when

visiting the health centre for another condition (don't remember clearly).

Don't ask questions

As long as nothing

is wrong don't feel

the need to ask

questions.

content now.

Group education

Remembers discussion on diet, "Diet interested me". Exercise was probably discussed, but can't remember.



Optician

For eye tests.

Practice Nurse

Meets twice a year annual review during "my birth month" and follow-up meeting after 6 months. Measures weight and blood pressure during the review, and checks feet.



The two practice nurses previously used to share outcomes and trends based on comparing the test results, but don't receive this information from the new practice nurse. "No explanation given."

Use of technology

She uses the computer to check emails when her son visits every week. Has heard from her son that you can find information on diabetes on the computer, but does not use it herself.

Group session

Remembers that the session

was held with other women

- cannot make a clear

distinction between the

group she met for the other

condition and for diabetes.

Memory

Has difficulty

remembering things.



Two of her sons have Type 1 diabetes. They don't talk much about diabetes with each other.





Does not tend to engage as much with the condition unless a specific action or change may be required. No change in diet or lifestyle since diagnosis, and test results have been consistently



Potential consequence/ complications

This was not discussed.



Value of conversations

Feels it's not possible to have a relaxing conversation with the GP as they are under pressure. Recalls a good conversation with her consultant (for another condition) - more time, communicated well and engaging.



What to do when

Would prefer to know what to look out for if something went wrong, and information on 'what to do when ..'



Self-management

within safe levels.



Improving sleep pattern.

Diabetes is a lower priority as it does not impact day-today life as her other condition.

Low priority

No significant impact

Don't remember or worry about diabetes if it doesn't have a direct impact or cause difficulty.



day-to-day life.

normal.''

Diabetes in the family



Family

Jane has four sons, one of whom lives near by and visits often, another one down South, and the two others live in a different country whom she visits every year. Her grand children also visit often.





Unaware of possible impact at diagnosis

"I don't think I was particularly concerned (...), I didn't know the possible results of having diabetes."



Long-term complications

Aware of annual screening for feet and eye, and the potential complications now.



Keep travelling to see her

Travel



Enjoys spending time with son who visits regularly, sharing their interests in reading, crosswords and Sudoku.

Shared interests with son



Keeping busy. Keep travelling to see family. Loves gardening. Feels part of the community, and used to take an active part in community gardening events.

Life



Sleep



Being normal

Her main goal relates to her other condition, which has more of an impact on her

"Longer period of being



Prefers to have comparison

with previous results and the reassurance that it is consistent, rather than receiving only current outcomes when receiving test results from the Practice Nurse.

Comparing results



Leaflets

Received info leaflets from the practice, but does not find them useful. Instead values 1:1 face-to-face interactions for receiving information.



Motivated to know more

Wants to have as much information as possible and feels the way to do this is to ask lots of questions and also challenge them during interactions with health professionals. He also believes in sharing things he learns from other sources around diet etc. with his GP and consultant, as he feels sometimes they don't have

Consultant

Twice a year until

now, but in the most

recent visit it has now

all the

information.

Diagnosis conversation

GP

For diagnosis, and for

annual reviews and to

review medications, or if

something is wrong with

He received his diagnosis from the GP, and remembers discussing his symptoms, medications, weight and diet.



been changed to once a year.

He has a good relationship with all health professionals involved in his care - GP, consultant, practice nurses, DSN - and believes it is important for his care.

Good relationship

Practice nurse

For tests, taking blood pressure, HbA1C etc.

the test results.

One of his former work colleagues and friends recognised his constant feeling of thirst as a symptom for diabetes and prompted him to visit the GP.

Prompting diagnosis

Gary

Engaged because it's life threatening

Finding out that diabetes can be life threatening, and the cost implications Type 2 diabetes has on the NHS prompted him to engage more with his condition.

Visual aids

He would like warning cards (as those used in football) to show how well a person is managing the condition or if they are at risk using visual tools (e.g. traffic light system).

Action cards

He would like every person to receive an action card stating targets to achieve within a specific time scale and actions to take at the end of each consultation.

Target driven

Needs to be given specific targets and finds it difficult to know how to make changes without targets.

More control through self management

Getting weight down and managing HbA1c levels, and cutting down medication. He feels he is making progress.

"I don't want my life to be shortened."



Takes meter readings once a day and keeps a food

Medications

Was taking a number of medications daily, reduced from 6 to 2 since his recent visit to the GP.

Seminars

He suggested seminars for people living with diabetes to share experiences with others and set goals for themselves without the doctors would be useful to support and motivate people to self-manage.

Fitness

Has started on a special diet recommended by a heart consultant to help with losing weight. He also takes karate lessons.

Group sessions

Does not think he will have time for group sessions due to a busy lifestyle, but trusts peer feedback.

Monitoring

diary.



Unrealistic advice

Dietitian

He feels he is very

knowledgeable on diet due

to working in the food sector

previously and his interest

to proactively find more

information. He does not feel

the need to see a dietitian.

Podiatrist

Had annual visits with

the podiatrist until 2

years ago when he

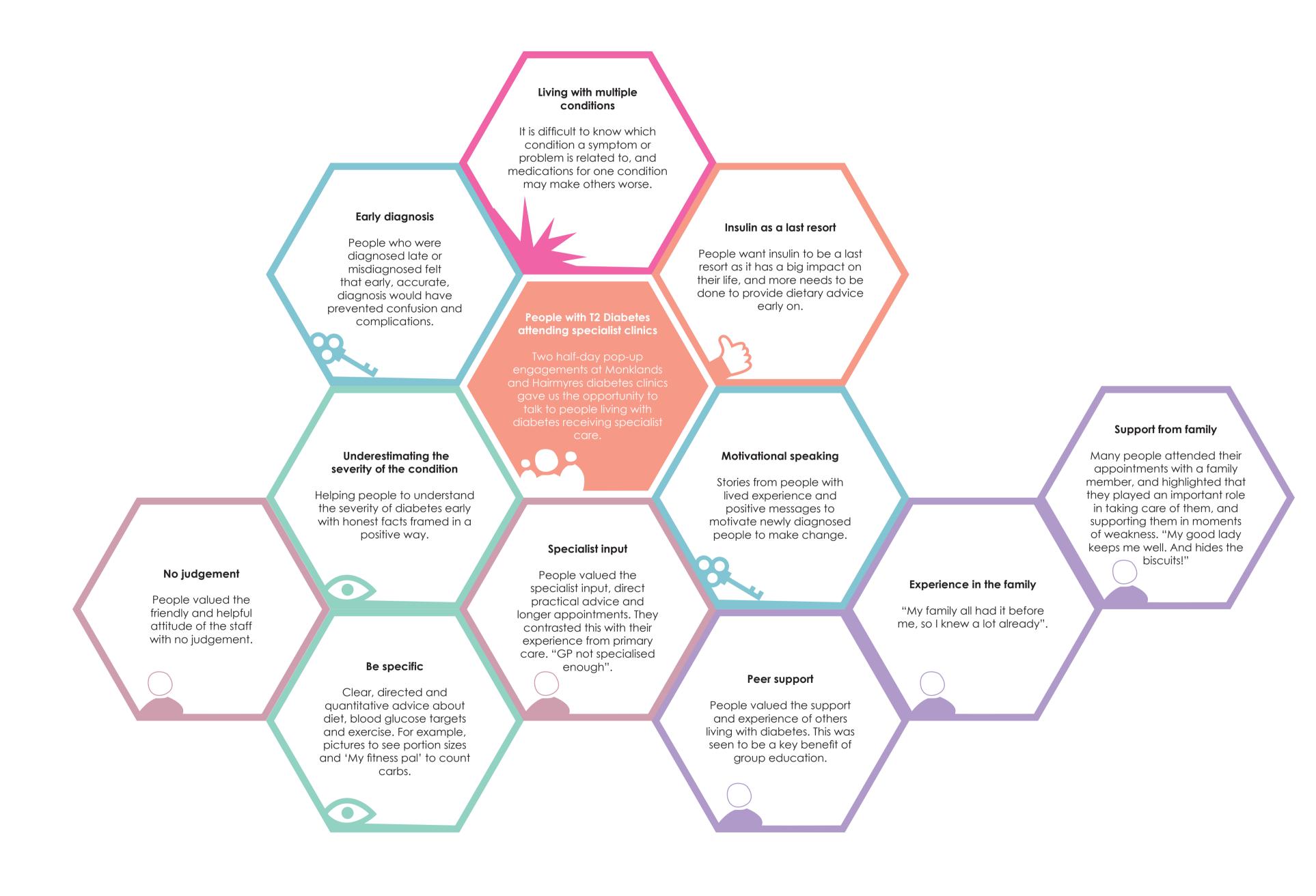
stopped receiving

appointment letters.

During his visit to the podiatrist it was pointed out to him that the soles of his feet were hard and he needed to keep them moisturised. However, he feels this is unrealistic advice as this is a result of his years of doing karate.







Summaries of interviews with staff in primary and secondary care

Appendix 2a: Advanced Nurse Practitioner

Local services

She refers people to two programmes locally: 'Weigh to go' and 'Active health'. She feels they have a better uptake than the structured education programme.



Introducing group education

She encourages her patients to attend group education. "I would go to it". But she worries that it is too complicated for some of her patients.



Medications

She speaks about doses, side effects, taking metformin with food, and impact of medications on driving. She uses Lanarkshire formulary for diabetes as a reference.



Joined up care

Years ago the person saw the dietitian, specialist nurse and all specialist staff in a single appointment. She feels this allowed more joined up care for the person.



Advanced Nurse Practitioner

Diana is one of the most experienced nurses at the practice, and organises nurse-led clinics on various topics. She runs clinics on long-term conditions two



She refers to My Diabetes My
Way, Diabetes UK website,
leaflets from medical reps, carb
awareness leaflet and others printed
from her computer. She mentions
'carbs & cals', which is a complex
booklet. She refers patients to the
dietitian for this.



Group education

Structured education is difficult for working patients

to attend. She feels there are

already too many appointments

for them to go to. This leads to

uptake issues. For some patients there

is a long waiting period following

diagnosis to attend STEP. She does

Specific, practical and

simple advice

Giving simple tips like "avoid

'cream of ..' soup", "cut out

sugary drinks" and making

the conversation relatable to

them is important.

not get any feedback

from STEP about her

patients.

New initiatives such a 'House of Care' need time to be successfully implemented and evaluated.

ed up

It is hard to change behaviour you can't measure. E.g. To the patient weight loss is visible but HbA1C is not.

Invisible



Guidelines

There are a significant amount of changes to guidelines sent out to the ANP regularly, and she feels there is no time provided to make changes.



Patient responsibility

She feels people need to take more responsibility for their own care and to selfmanage.

Training

There is a lack of training in chronic conditions tailored for primary care, for e.g. around changes in drugs.

W

Collaborating with local

She suggested that STEP could be combined with local services such as 'Weigh to go' and 'Active health' for better uptake.

services



Patient records

She does not feel that the IT systems support her to do her job and to collaborate. She accesses SCI Diabetes usually only when she is with the patient and needs to. There is not always communication from secondary care when a patient has been seen. She feels things can then get missed unless a letter comes in.

Changes are usually faxed.

Updating records is time consuming and adds to

her workload.

Collaboration

She feels there are major communication issues between primary and secondary care and district nurses. There are no regular events or updates that bring everyone together.



Changing behaviour

People's perceptions of portion sizes can be variable, and altering diet in one go can be a problem.





Take away

"What do you think is the main thing from what we have discussed today?"

She reflected on the importance of self management for the patients as they are the ones who will be looking after their condition. She feels patients need to be empowered to take ownership of their condition and manage it with support from resources such as My Diabetes My Way and preparation of an

Self management

individualised care plan.

Group education

Tries to encourage all patients to attend STEP, as she feels in addition to education peer support is important. Some patients prefer 1:1 education, and even with the reduced number of session, it is demanding for some patients to attend the programme.

Waiting times

She refers all patients to the dietitian, but there is a long waiting period before they can be seen.



Referral

Some patients prefer to see the practice nurse exclusively, rather than seeing specialist staff.



Resources to give patients

Diabetes UK booklet 'Everyday Life with T2 Diabetes' offered to all patients. My Diabetes My Way is offered to all, but some engage with it more than others.



Being direct

Being direct can be difficult, but it is important to give the facts as they are, framed positively in terms of what they can do to stop complications. This includes explaining both the pros and cons of medication including possible side effects.



Care responsibilities

Most of the workload of T2 diabetes is based in primary care. PNs are at the forefront of T2 diabetes care in the community (collaborating with the full paramedical team) and responsible for holistic care of the patient from diagnosis, formulating a care plan. Patients are referred only in few situations, e.g. some PNs do insulin initiation, but specialist nurses may see few patients who may need insulin if 🖊

the PN does not

initiate this.

Family history

She asks if the person has anyone in their family who has diabetes, as this can have a psychological impact especially if they have had amputations. She reassures that the condition is different for each individual and there have been significant

> advances in treatment.

Reassurance

"I am telling you today you

have a chronic progressive

condition, but it can be

managed."

Diagnosis conversation

Gives basic information

in the first appointment,

and schedules a follow-up

appointment 2 weeks later

to give the person time to

absorb their diagnosis.

Relationship and trust

Places emphasis on building

a good relationship with the

person, and understanding

their social and psychological

circumstances. This is a key part of

her approach to care, and this starts

with the diagnosis conversation as

throughout their

care journey.

this partnership with continue

Collaboration

Collaborates with the DSN for patients on insulin, counsellors, staff from the local gym. She makes referrals to DSN, consultant and dietitian.



Practice Nurse

nurse at the same healtl

Supportive employer

She feels supported by the practice, and feels it is important for her to do her job well. They encourage her to continue learning and recognise her expertise.



Self care

Feels it's important to look care of herself.

Change is a cycle

Non-compliance can

be difficult to discuss. Some

may not come back for a

long time until they have a

problem. You need to be realistic

that relapses can happen, and

make a holistic assessment to

find the reason

people aren't

engaged.



Feels responsible for the person's care, and is motivated to do as good a job as possible.

Motivation



Family approach to care

Believes it is important to know a person's family history and use this to tailor their care. She may have experience of caring for other members of the family which she uses to build the care relationship.



Learning from colleagues

She organises a monthly support group for practice nurses in her area. They share learning, get peer support and occasionally have specialist staff attending to provide training.



Life long learning

Keeps up-to-date with the latest research and treatments.



Using national and local guidelines and protocol to assesses patients before diagnosis. These are useful in her job.

Guidelines



Joined up systems

It would be preferable for joined up care.





Attends conferences 2-3 times a year, for e.g. Primary Care Diabetes Network conference to keep up-todate with the latest studies. She feels this is the best kind of education.

Conferences



SCI Diabetes

Uses it to find info on patients that she has referred to specialists. Enters info about foot screening, but not her notes from the consultations. (These are entered into Vision).



the SCI diabetes and VISION systems to be integrated. This would allow her consultation narrative to be included for



Time for change

The diagnosis is the best time for motivation to engage. It's also possible to re-engage using changes in their test results, e.g. protein in the urine.





Signposting to resources

She signposts to services and resources based on the individual's needs. This includes STEP, Weigh to go, Get active, Men's Sheds and Diabetes UK (local groups no longer exist). She also provides printed info sheets.

Appointments

All newly diagnosed T2 diabetes patients are offered an appointment with the dietitian, and other patients have the option to



Goal setting

She uses the goal setting tool in SCI Diabetes to agree goals for the person.



Getting people to act on

the information

She has a wealth of

information and insight to

offer, but feels that getting

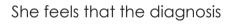
people to act on them is a

challenge.



Patient fear of judgement

There is a perception among patients that the dietitian will make judgements on their dietary habits. This means that not all patients who can benefit from her support opt in for an appointment.



conversation is an opportunity to motivate and support people to make changes and sort things out.

Diagnosis conversation

Signposting

She feels it is important for people to have choice on how information is accessed. Libraries can enable this through access to printing, alongside additional digital resources, but patients have to be careful to ensure information is not out of date. Appendix 2d: Podiatrist

Psychological support

She feels people are often at their lowest ebb when they come to see her. Patients can be frightened and want her to fix their problems. They can be depressed about how long it can take their wound to heal and the impact

lives.



Collaboration

She has an open door policy for community staff to shadow clinics and expand their knowledge on wound care. Community staff can review their training needs using the core competencies form and request targeted learning

Medical illustrations

Photos of wounds are taken using an iPad and uploaded to a Lanarkshire-wide photo web. This provides a photographic record which charts progression of the wound. Photos can be shared between departments e.g. dermatology if any concern wound may be malignant. Photos can be motivating for

patients and a training resource presenting case studies at inservice days or for publication etc.

Podiatrist

wound group, diabetes specialist professional group, attends the joint specialist group and has built strong links with other services such as TVNs, dermatology, vascular

Motivational speaking

Stories from people with lived experience of diabetes using humour and positive messages can motivate newly diagnosed people to make change.

Seeing the right patient

All diabetic wounds should be referred into the podiatry service. Up skilling community podiatrists supports them to identify the complex patients and refer on to acute podiatry staff with the appropriate level of urgency. This allows diabetes

specialist staff to maintain capacity to continue to provide rapid access to the acute multi

disciplinary service.

Outreach

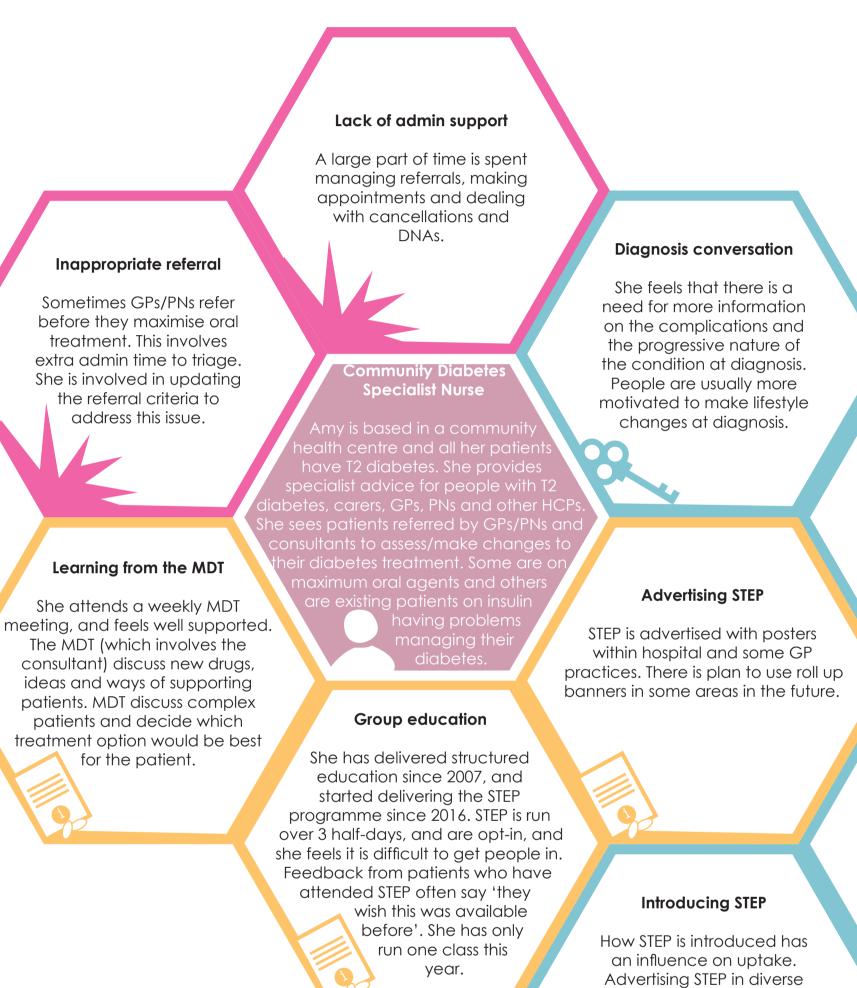
Using technology to link community staff and nursing homes directly with diabetes specialist staff and/or diabetes consultant to provide specialist advice to ensure nobody is missed.

Joint working with community wound leads

Skilled wound leads within community podiatry provide an extension on the MDT, ensuring that all community staff are well trained and support skills development through shadowing at acute sites. Diabetes specialist podiatry service provide an outreach service providing a second opinion or joint review with community staff for patients unable to attend acute sites.

Training family members

Training family members to check for symptoms and provide support for better foot care.



Attend anywhere

She feels that piloting Attend Anywhere could make a difference in attendance at her clinics, as it would be a good option for some people who find it difficult for

example get time off work to attend appointments.

Referral to STEP

STEP is currently a self-referral

programme. She feels STEP

would be better attended if

patients are referred in, thus

giving it more importance.

locations and positively introducing the programme early on after diagnosis in primary care should motivate people to attend.