

NHS West Kent Clinical Commissioning Group (WK CCG)

Engagement Report – Diabetes Services

Report Produced by:

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2 Introduction

NHS West Kent CCG is working with partners to review Diabetes services in the area and the Participation and Insights team (P&I), South East Commissioning Support Unit (SECSU) were asked to gather insights in order to help inform the business case.

An engagement plan was developed and agreed with WK CCG to ensure people with diabetes were asked to provide feedback using an online and paper survey, discussion groups and 1-2-1 discussions.

A total of 210 responses were received to the survey and 39 individuals took part in both the groups and individual discussions.

3 Background

Diabetes services are being actively re-commissioned by many CCGs in the country. There are various models in place or being planned. Local factors and CCG priorities have resulted in different models being implemented in different areas but each following a common underlying principle of moving the bulk of diabetes services into the community.

NHS West Kent CCG is working intensively with partners and the local Health and Wellbeing Board in the development of an obesity strategy that strategically aligns with the diabetic service; the same alignment is being sought with Public Health in strengthening the vascular check services for early detection.

The commissioning proposal is to decommission the current secondary diabetic services for West Kent CCG and re-commission a service fit for purpose in the community under level 2 & 3 services. Secondary care services could be re-contracted for level 4 only which will be a significantly smaller service than is currently provided. Further it is proposed that the level 2 LES with individual Practices should be decommissioned. Both level 2 & 3 could be procured under a single MSCP (Multisystem community provider) contractual model where federations will need collaborative arrangements with specialist services, preferably from the local Foundation Trust.

4 Methodology

The overarching aim for this engagement activity is to provide the CCG with feedback from patients and carers, primarily, and other members of the public on the current status and proposed re-design of diabetes services in order to ensure any changes reflect patient views. Specific objectives for the engagement and insights work, as agreed with the CCG, are to obtain feedback on the following areas:

- Awareness of condition & symptoms - current and projected epidemiology of Diabetes
- Quality implications of proposed vertical integration of primary and secondary Diabetes services
- Access to diagnosis/treatment
 - Location
 - Accessibility
 - Waiting time etc.
- Perceptions of current level of care – primary and secondary
- Education on condition and signposting

- Awareness and use of educational courses (DAFNE and DESMOND)
- Other self-help groups
- Preferences for re-design
 - Location of services
 - Timings/frequency
 - Specialist staff available
- Possible improvements
- Patient experience

A survey was developed in consultation with CCG commissioners to address these objectives. The survey was provided online and as a paper version where required. In addition, a short discussion guide was developed (based on key questions from the survey) in order to undertake a small number of focus groups with existing diabetes support groups. Furthermore, those individuals that agreed to be involved in further work around diabetes were also contacted by telephone and email to provide more in-depth feedback around key issues.

The survey and discussion guide can be found in Appendix A.

The table below describes the channels used to distribute the survey including the groups and individual discussions undertaken:

Target Group/Channel	Methodology	Dates
PPG Chairs Meeting	Discussion and Feedback	13.5.15
West Kent CCG Database	Email and paper	19.5.15
Healthwatch	Email for distribution	19.5.15
WKCCG Website	Website with link to survey	19.5.15
WKCCG Practice Bulletin	Insertion with link	19.5.15
WK Voluntary Action	Distribution to all diabetics on list	19.5.15
Bearsted Diabetes Support Group	Discussion and Feedback	21.5.15
Wateringbury Diabetes Support Group	Discussion and Feedback	25.5.15
KCC Community Liaison Officers in each of the boroughs	Email for distribution	10.6.15
Independent Diabetes & Renal Support Working with South East Strategic Clinical Networks and Senate	Email for distribution	1.05.15
Diabetes UK	Email for groups and distribution	1.05.15
One to One Interviews	Email, Telephone	23.6.15
One to one Interviews	Email, Telephone	24.6.15
One to one interviews	Email, Telephone	26.6.15
One to one interviews	Email, Telephone	28.6.15

A total of 38 respondents wish to be added to the West Kent CCG Health network and 71 respondents are interested in being further involved in the continuing work relating to diabetes.

5 Summary of Findings

- The majority of respondents were not aware that they were at risk before they were diagnosed.
- Whilst most respondents feel well informed and confident in managing their diabetes, there is mixed feedback as to whether information has been provided. Most answering the online survey indicate information was provided whilst the focus groups and individual discussions highlight a lack of recent and up to date information.
- The “location of appointments at the GP” and “quality of care at GP”, both receive the highest ratings with a mean score of 3.49 out of 4.
- The “waiting time to get an appointment in community” is rated lowest (a mean score of 2.61 out of 4) as well as “waiting time to get an appointment at hospital” (2.79 out of 4)
- Most respondents had not experienced any problems getting to appointments and the main issue for the remaining respondents included the waiting time for appointments with nurses.
- Whilst two thirds of respondents believe that the proposal would improve their experience of diabetic services either a little or a lot, the remainder indicates no improvement, although this is mainly due to respondents indicating they already receive good quality of care, often already delivered in a community setting.
- Respondents highlighted:
 - a need to improve podiatry and dietary services for patients
 - importance of psychological support for new diabetic patients
 - a need for more education on diabetes – possibly in community settings
- The main areas that would help respondents to manage their diabetes more effectively include:
 - More support and help with diet including losing weight, information and education on food groups and support with exercise
 - More regular appointments with diabetic nurses to ensure their levels were stable.

5.1 Recommended Next Steps

Given that ethnic groups are at higher risk of diabetes and whilst they are represented according to overall population, it is recognised that further more targeted engagement is required with these population groups within west Kent. The existing ethnic minority organisations and groups were contacted by email and paper as appropriate with the survey link and a request to complete and disseminate however given the relatively low response rate, further targeted work will be undertaken as follows:

- Work with Public Health, District Council contacts and Equality & Diversity Manager at the CSU to cross reference and identify relevant contacts.
- Distribute emails and conduct telephone calls to known ethnic minority organisations, voluntary groups and social groups to encourage involvement in engagement around diabetes services.
- Undertake telephone depths and discussion groups where possible.
- Incorporate feedback in final engagement report.

This work will be undertaken during late August and September 2015.

Online Survey - Detailed Analysis of Findings

The responses were analysed in a number of ways to check for any significant differences according to demographics as well as responses to other questions within the survey. However no differences were identified and responses were similar across age groups, gender and in relation to time with diabetes.

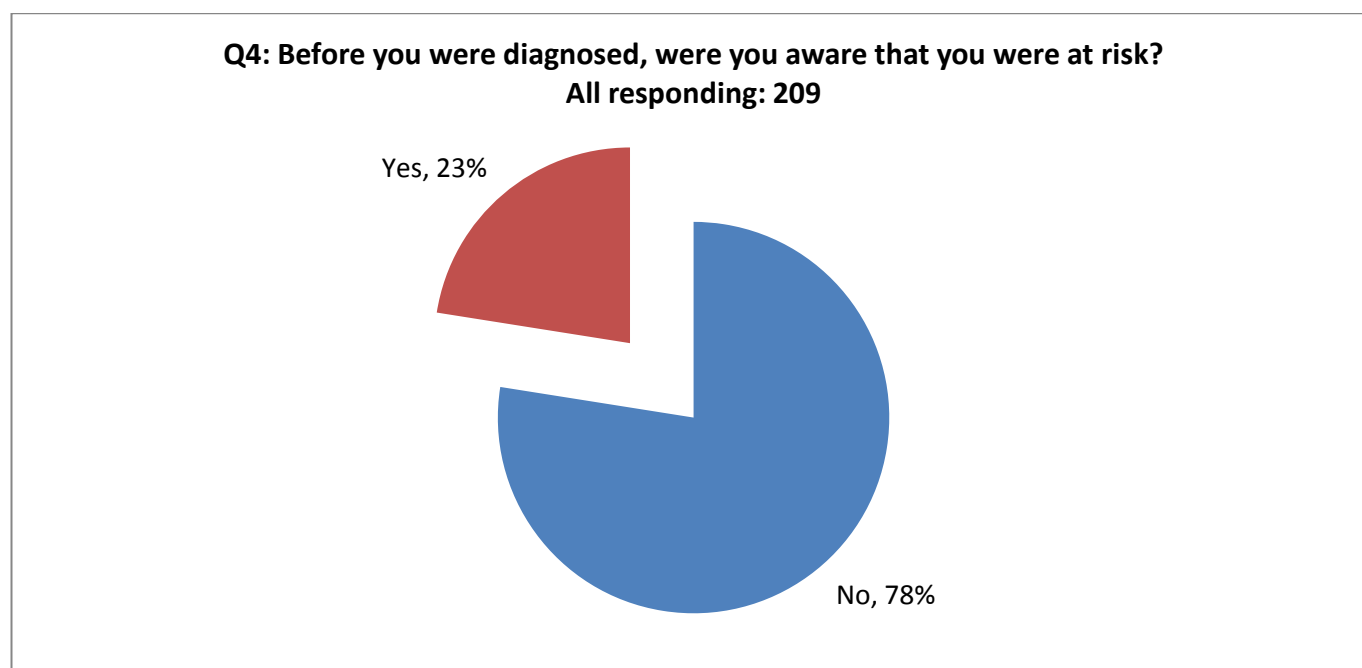
5.2 Respondent Condition

In order to put responses into context, respondents were asked to provide details of the type of diabetes they have and how long they have had diabetes.

	Total	Up to 1 year	2-4 years	5-7 years	8-9 years	10 years or more	Number of Respondents
Type 1	20%	5%	10%	10%	7%	68%	41
Type 2 (no medication)	19%	10%	28%	23%	10%	28%	39
Type 2 (medication only)	47%	7%	33%	21%	9%	30%	98
Type 2 (medication and insulin)	15%	0%	0%	13%	6%	81%	31
All responding	209	13	47	38	18	93	209

As shown in the table, almost half the respondents overall indicate that they have Type 2 diabetes and are on medication only (47%). Of those with Type 1 diabetes, two thirds have had it for 10 years or more (68%).

Over three-quarters of respondents were not aware that they were at risk before they were diagnosed (78%) as shown below. In fact of those responding 88% indicated that they were not provided with any information to prevent or delay onset. Where information was provided, this mostly related to dietary advice.

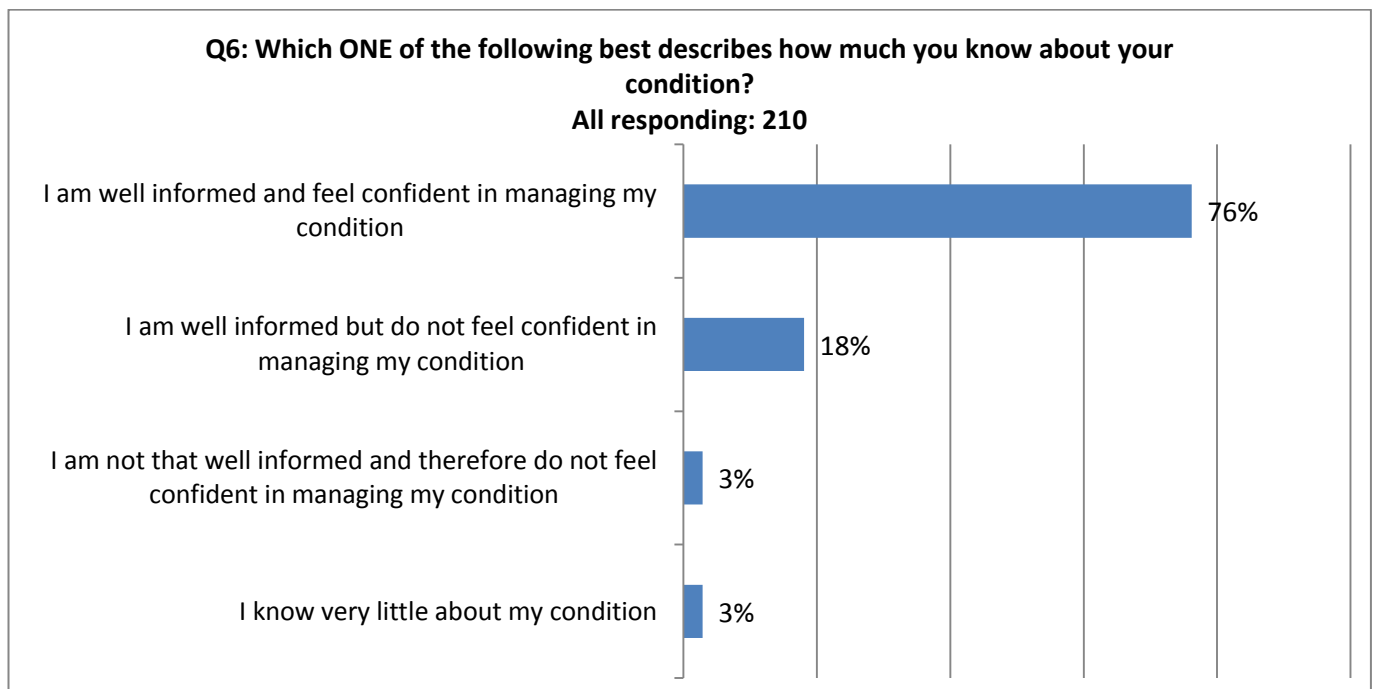


"Lose weight, exercise more. But not explained could result in Diabetes."

"Diet and weight control."

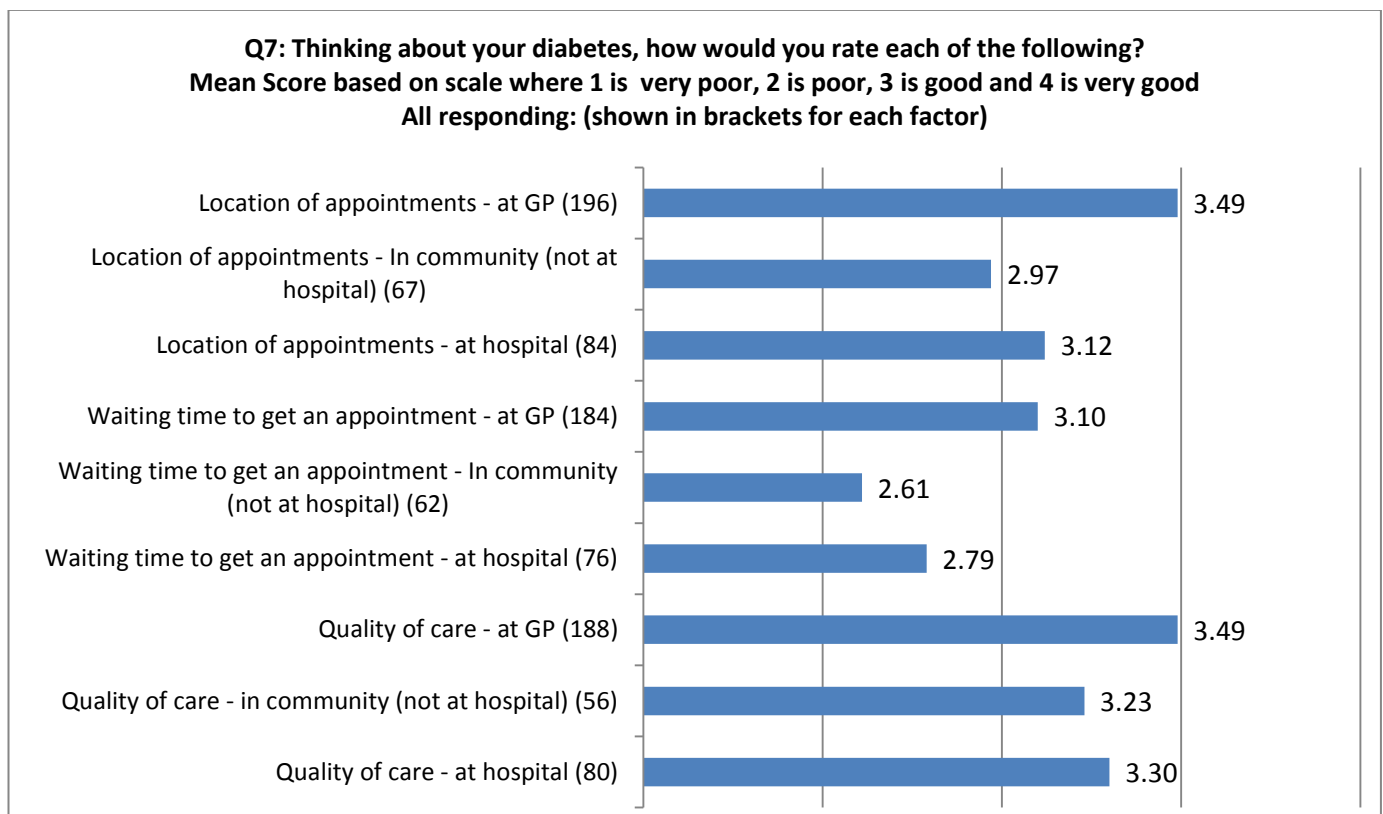
"Weight control and healthy diet."

Three-quarters of respondents indicate that they feel well informed and confident in managing their diabetes (76%). A further fifth (18%) feel well informed but not confident in managing their diabetes.



5.3 Current Experience of Services

Highest rated factors are “location of appointments at the GP” and “quality of care at GP”, both with a mean score of 3.49 out of 4.



Lowest rated factors are “waiting to get an appointment (in community)” with a mean score of 2.61 out of 4 and “waiting to get an appointment at hospital” with a score of 2.79 out of 4.

5.3.1 Problems Getting To Appointments

When asked if they had experienced any problems getting to appointments related to their diabetes, 57 responded and the main themes were as follows:

- 18 indicated that they had no problem getting to appointments
- 13 respondents stated that there were delays getting nurses appointments. Most felt that the nurses were very busy and waiting lists could be up to several months and clinics were only held on a couple of days a week, which causes further delay.
- 4 respondents reflected that getting to hospitals with parking problems and public transport issues proved problematic in getting to appointments
- 2 people stated that it was almost impossible to get a podiatry appointment.

“Diabetic nurses are busy - appointments can take several months”

“Delay in getting appointment as “clinics” only held two days a week”

“Surgery under resourced (One Health Care practitioner for diabetes) so difficult to get appointments.”

“Appointments at Podiatry Clinic hardly ever happen!”

“Parking at the Diabetes centre in Tunbridge Wells (Abbey Court) is appalling. I had to find a space on the road which made me late for my appointment even though I had allowed myself 20 minutes to find a space.”

“Travelling to the hospital for eye outpatients is quite difficult as bus services are quite infrequent.”

5.3.2 Information Received about Condition

When asked if they had received any information related to their diabetes (written or online), 62% indicated that they had (38% said no) and the main themes were as follows:

- 41 respondents stated that they had received general information in the form of leaflets and pamphlets. These ranged from guidance leaflets when first diagnosed, information on pregnancy and their condition.
- 33 respondents reflected that they received information from the health care professionals when they went to appointments/reviews, this included test results and diet advice.
- 14 respondents indicated that they found information from the Diabetes UK website or other sources on the internet. One person mentioned that he liked to look up information himself.
- 11 respondents had received copies of information passing between consultants and their GP
- 9 respondents had received education and information by attending educational courses (DAFNE)

“Guidance leaflets when first diagnosed”

“I was given some information at diagnosis”

“Got the NHS booklet”

“With every appointment, what are key areas etc.”

“From the diabetic nurse”

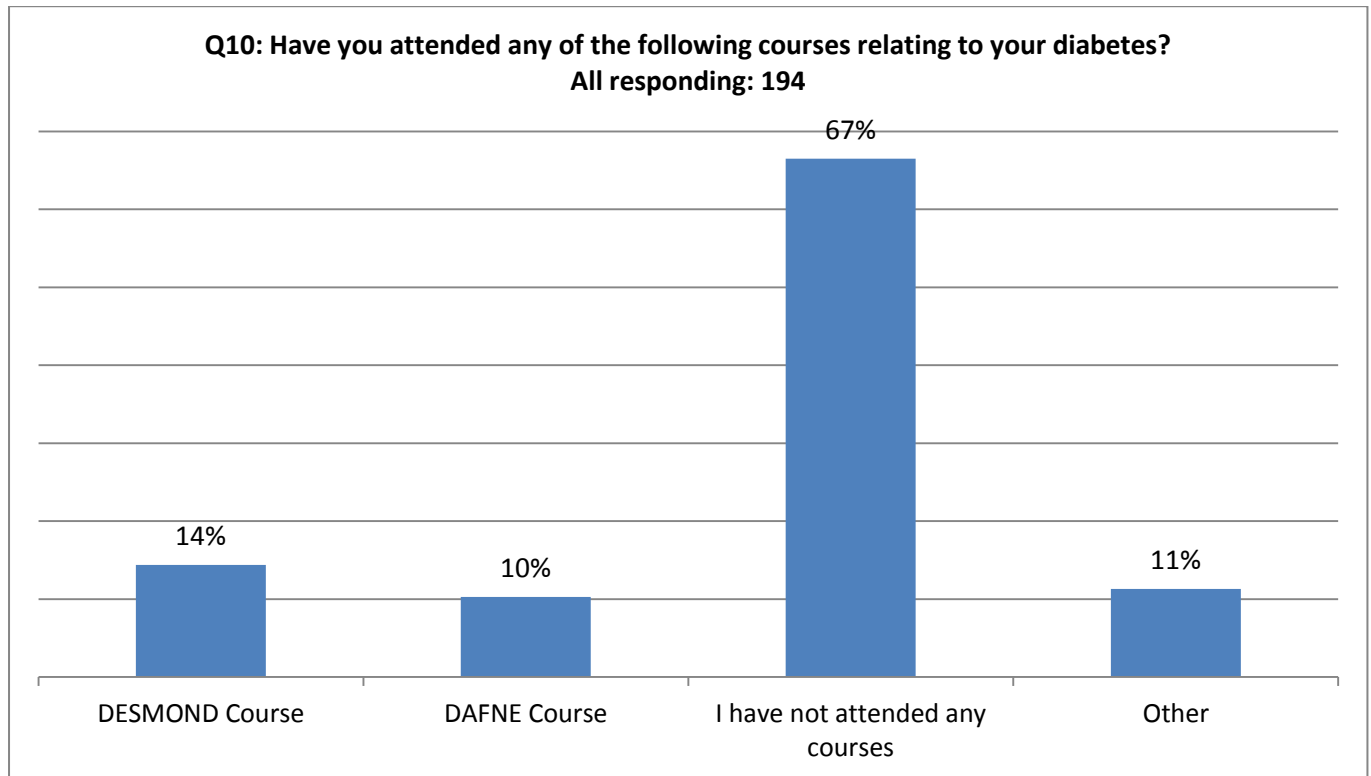
“Regular Handouts by my GP on test results and other information as required”

“What I found myself”

“Annual letter from consultant following appointment”

5.3.3 Courses Attended

Two thirds of the respondents have not attended any courses relating to their diabetes (67%)



Other courses mentioned include:

- 5 respondents said that they had had one to one interviews with their clinicians about diabetes, including dieticians and doctors
- 3 respondents had attended day courses, including the ‘Living with Diabetes Day’
- 2 respondents had attended different courses, Pitstop and Xpert
- 2 respondents had attended meetings put together by their surgeries
- 3 respondents are awaiting attendance to the DAFNE course.

“Living with Diabetes Day -excellent seminar”

“Initial General Course when first diagnosed + Diet course +dietician detailed guidance.”

“Health talk at surgery”

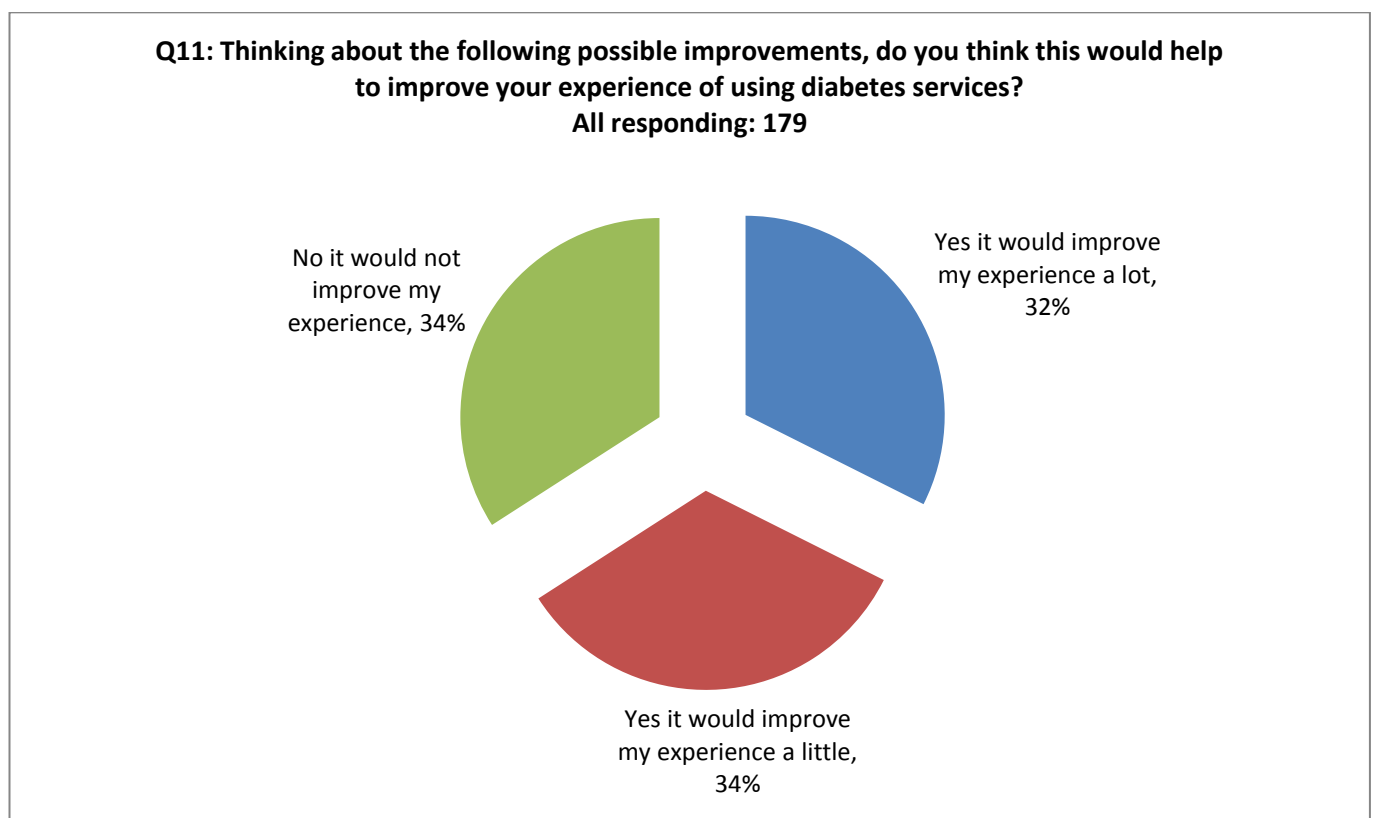
5.4 Feedback on Proposal

The following possible improvements were presented to respondents:

Possible improvements identified by NHS West Kent CCG include:

- Move services typically provided at hospital to community settings
- Provide a more local, specialist led service to include:
 - Access to community specialist services for housebound diabetics
 - Specialist dietetics including psychological support
 - Specialist podiatry
 - Insulin pump service
 - Education and support for patients
 - Multidisciplinary assessment and case management (specialist, nurse, dietician and podiatry)
 - Education, training and closer communication between this new service and GPs/Practice Nurses
- Services provided face-to-face as well as via email and telephone as appropriate.

Respondents were then asked to indicate to what extent, if any, these possible changes would improve their experience of using diabetes services.



Opinions are fairly evenly divided, although two thirds indicate that the possible improvements would improve their experience to some extent (32% a lot and 34% a little).

Of those indicating the proposal would **“improve their experience a lot”** a variety of comments were made (45 respondents) with few common themes emerging.

- 7 respondents felt the need to improve podiatry and/or dietary services for patients. The need to access and have regular podiatry check-ups is not available at present. Also advice and education on diet would be helpful.
- 5 respondents expressed a view that psychological support was very important to new diabetic patients
- 4 respondents indicated that local services would have the benefit of specialist care and help overstretched surgeries.
- 3 respondents would like to see improved communication between health care professional and patient as well as clinician to clinician
- Other comments included:
 - Personal care plans for diabetic patients
 - Not everyone is on a computer
 - More appointments being available
 - Proposals would provide a more holistic service

“Feels more like an holistic service”

“Psychological support is very important as I had a real chock and was in denial. Also I don't have symptoms so I tend to forget that I'm diabetic. Dietician & podiatry help will be good support too.”

“I have received specialist psychological support in another area and it was vital to improving my ability to control the diabetes. This must be offered quickly to whoever requests it if better control is to be achieved.”

“I do not feel that access to dieticians or podiatry is good at present. Maybe it is because of cost”.

“Having a more local specialist led service would be much better than using my overstretched GP surgery facilities”

“I am not fully aware of what services are available. More regular communication. Reminders when I should be having blood tests etc.”

“Having no computer I find myself isolated from receiving much relevant information, this must be remembered when planning services. Many of the older patients have this problem.”

“I would like the service to be tailored to the individual by means of an agreed (patient & carer) annual care plan”

Of those indicating the proposal would **“improve their experience a little”** a variety of comments were made (44 respondents) with the following themes emerging:

- 7 respondents indicated that an improvement in the podiatry service would be welcome. One person had been waiting since November 2014 for an appointment.
- 6 respondents felt that more education on the condition should be available with 2 saying dietary help would be beneficial
- Services closer to home would be welcome to 3 respondents with education available

- 5 respondents felt that they were getting sufficient care for diabetes but would welcome improvements as they could see that this could only improve patient experience
- Other comments included:
 - More check-ups being made available
 - Having greater flexibility on appointments within primary care
 - Improved face to face appointments

"I live close to my Practice so have no problems with travel. Podiatry care needs urgent improve I am still waiting to attend a Nov 2014 appointment due to lack of slots available"

"Regular podiatry would make a difference"

"I received podiatry service monthly for 1 year and was then told that I should seek private podiatry. I have had a replacement hip and find it extremely difficult to trim my toe nails."

"The more education and support, the better the chances of patients understanding and acting to improve their health."

"Explain personal diet and support face to face"

"There is always room for improvement but I am happy with my standard of care"

"I guess because I'm already pretty confident it would not affect me personally dramatically, but I think it would improve most patients' experience a great deal."

"Services provided face-to-face as well as via email and telephone as appropriate."

"Better location/time of day flexibility"

Of those indicating the proposal would "**not improve their experience**" a variety of comments were made (48 respondents) with the following themes emerging:

- 23 respondents stated that the care they receive from the surgery could not be improved. 6 referred to their GP, 6 specified the Nurse.
- 16 respondents felt that the care they receive already was good and could not be improved. 5 out of the 16 also felt they were in control of their condition that they did not need any further intervention.
- 2 respondents felt that they were very borderline in their condition and could not offer any comment
- 2 other respondents highlighted that they were happy with the care they received from the hospital and felt that their experience could not be improved.

"The person to person care given by my local surgery would be hard to improve"

"I feel very well served by the specialist nurse at my GP surgery."

"I am very aware of my situation and I try to manage my life by a good balanced diet and exercise."

"I have my condition under control and know what I should be doing and what I should be eating."

"I am satisfied with the care I receive."

"Provision of services related to my condition are excellent."

"My daughter has type 1 diabetes. She is incredibly well supported by both the consultant and ds nurse at Maidstone hospital. She receives regular 3-monthly check-ups. These cover psychological support if required, podiatry check-ups, discussions about the management of her diabetes via the pump. She feels well supported. However, I do feel that GPs could be more well-informed."

"I can access the hospital easily for my appointments. The nurse at the GP surgery does the annual checks for their records."

The full list of responses can be found in Appendix B.

5.5 One Big Thing to help Manage Condition More Effectively

When asked what one big thing would help them to manage their diabetes more effectively, 136 people responded and the following are the most frequently mentioned themes:

- 34 respondents felt they are managing their diabetes at the moment with about half saying they are happy with the care they receive.
- 22 respondents would like more help with their diet. 4 specifically wanted help losing weight and a couple felt exercise would help. Although several people mentioned that they could self-manage themselves better with their diet, most felt they needed help knowing those foods that were high in sugar and could affect their diabetes.
- 13 respondents stated that they would like to be seen more regularly by the diabetic nurses to ensure their levels were stable. Not everyone said how often they attended but a couple stated that 6 monthly and even 1 year appointments were not regular enough.
- 7 respondents reflected that they required more information around their condition and accessing the nurse for this was difficult, one person saying that they had to wait over 24 hrs for the nurse to come back to them on a question.
- Smaller numbers reflected on:
 - Access to podiatry (4)
 - Having better education around diabetes (4)
 - Access to psychological services (CBT) (3)
 - Group support (2)
 - Local services (3)
 - Pharmacies (2) difficulty getting diabetic essentials

"Finding more variety of food that is low in both sugar & fat together with cheaper options for nice and not boring exercise to help the reduction of the weight "

"Having a regular 3/4 month blood check automatically" "Regular compulsory blood testing by GP practices for all diabetics. i have experienced a GP's refusal to do just this."

"Treatment and discussion about my condition as an intelligent individual; the 'lowest common denominator' approach is condescending and rude. Explanation of the roles of both Consultant and Diabetic Nurse at the onset for a new patient (new diabetic or new patient moving into the area)."

“Help, either on line or at a call centre that is manned extended hours and weekends.”

“Improve access to podiatry service”

“Diabetic support groups locally e.g. Doctors surgery”

“Being able to have blood tests at my GP Clinic rather than at the local hospital. It would be far more convenient, time efficient and would mean that I would be more likely to have my blood tests more regularly than I do at present. Pressures of work mean that I do not find it easy to visit the hospital during their opening hours for a blood test.”

“We have regular problems with the local chemist and their supply of diabetic necessities. They constantly run out of stock. This would not be an issue if they called us once the repeat prescription has been submitted and they knew there was nothing in stock. We could then instantly go to another chemist”

“My medication is on a 28 day batch system for some of the items. All the items should be on a batch system and the Pharmacy should not demand 3 days advance notice for the next batch - they have all the information that they need to prepare the next batch needed in 28 days time.”

6 Discussion Groups and One to Ones- Detailed Analysis of Findings

6.1 Respondent Background

There were two support groups that agreed to run focus groups as follows:

- Bearsted: 21 patients attended – 1 Type 1, 20 Type 2
- Watlingbury: 6 patients attended – 1 Type 1, 5 Type 2

A further 12 respondents to the online survey agreed to some follow up questions relating to prevention and education.

It appears from the focus groups that most respondents were **not advised that they were at risk** before developing diabetes (around 6 out of 27 were advised). Two respondents also highlighted the lack of information of genetic risk. It became evident from the individual discussions that no specific advice was provided to patients other than to lose weight and without any clarification of the importance of doing so. The individuals highlighted the fact that they often feel fine at the point of diagnosis and that more should be done to promote the risks and early signs of diabetes.

In terms of **information provided** to respondents this is an area that needs to be improved. There needs to be more information provided at time when advised an individual is at risk as well as at the time of diagnosis. Respondents indicate that this information should be about managing the condition rather than clinical. Other respondents also highlight the need for information to be updated regularly as medical advice and available treatments change.

Few respondents had heard of DAFNE and DESMOND courses although they were all very positive about them and felt they should be offered to all patients with diabetes stating the benefits of education as well as sharing experiences with other patients. When education was discussed, individuals raised the

question of making courses available within primary care or within a community setting rather than at hospital.

6.2 Location and Quality of Care

Virtually all respondents **attend their GP surgery for check-ups** relating to their diabetes (1 attends hospital). The quality of care at the GP practice is considered good and those attending Watlingbury practice specifically highlighted the good communication and continuity of care.

6.3 Feedback on Proposal

Whilst on the whole respondents were positive about the proposal to provide more diabetic care in community settings with specialists, some gaps were identified in general:

- Difficulty obtaining podiatry appointments
- Lack of choice of hospital appointments
- Lack of flexibility of appointments especially for working people and parents

6.4 One Big Thing

When asked what one big thing would help them to manage their diabetes more effectively the following comments were made:

- Easy to understand list of symptoms you get when you get a 6 month check-up. If you want anything you have to ask, this should be made available.
- More information and for all information to be kept simple and clear especially information relating to diet and nutrition as patients can get confused over proteins, fats etc.
- Information on self-management - some patients use sticks, others don't and there is contradictory advice from clinicians.
- Better knowledge and help with support groups.
- Exercise classes for all – not just told to exercise and sent away but advice given on what exercise is good.
- Buddy Schemes and walking groups in surgeries

6.5 Respondent Profile

In order to put the responses into context the following provides a demographic profile of respondents.

Ethnicity	Total
White - English/Welsh/Scottish/Northern Irish/British	89%
White – Irish	1%
White - Gypsy or Irish Traveller	-
Any other White background	4%
Mixed / Multiple ethnic groups - White and Black Caribbean	-
Mixed / Multiple ethnic groups - White and Black African	-
Mixed / Multiple ethnic groups - White and Asian	1%
Any other Mixed / Multiple ethnic background	1%
Asian / Asian British - Indian	-
Asian / Asian British - Pakistani	-
Asian / Asian British - Bangladeshi	-
Asian / Asian British - Chinese	1%
Any other Asian background	1%
Black / African / Caribbean / Black British - African	1%
Black / African / Caribbean / Black British - Caribbean	-
Any other Black / African / Caribbean background	-
Other Ethnic Group - Arab	1%
Prefer not to answer	2%
Number of Respondents	179

Age	Total
16-24 years	1%
25-34 years	2%
35-44 years	4%
45-54 years	10%
55-64 years	22%
65-74 years	37%
75 years or more	23%
Prefer not to answer	1%
Number of Respondents	182

Gender	Total
Male	59%
Female	40%
Prefer not to answer	1%
Number of Respondents	177

Appendix A – Questionnaire – see attached document

Appendix B – Detailed Responses – see attached document