



Mobilisation Period

**February 2014**

**Patient Engagement**

**Events and Survey**

**Summary Report & Action Plan**

June 2014

## Contents Table

Executive Summary and Action Plan .....	3
Format and marketing of the events .....	10
Format.....	10
Marketing.....	10
Engagement and feedback .....	10
Locations, dates and numbers of attendees.....	11
Key facts about the events.....	11
Analysis of questionnaire responses.....	11
Analysis of ‘keeping in touch’ forms .....	12
Key themes from feedback sessions.....	12
Session 1 - the service model.....	13
Session 2 - patient education and involvement.....	13
Appendix A – Questionnaire responses.....	15
Appendix B – Keeping in touch forms.....	21
Appendix C – Feedback summary.....	23
Appendix D - Questions and answers .....	36

## Executive Summary and Action Plan

The local engagement events for NEEDS, which took place in February 2014, were a central part of the mobilisation plan for the new adult diabetes service. 151 diabetes patients attended the events and 74 questionnaires were returned. 118 'keep in touch' forms were also completed. 98% of those who attended the events rated them 'excellent', 'very good', or 'good'.

This was an opportunity to present the plan for the NEEDS service to groups of diabetes patients in five local areas. Round table feedback discussions focused on what patients would like to see in the service and sought their ideas on education, involvement and what would help them to manage their diabetes better.

86% felt either 'very confident' (14%), 'reasonably confident' (51%) or 'satisfied' (21%) that the new service will meet their needs and 14% said they felt 'concerned'.

Suffolk GP Federation, as the provider of the adult diabetes service in North East Essex, has always planned to use the feedback from these events and from the questionnaire responses to help shape the NEEDS service.

Below is a summary of the main messages in the feedback, divided according to the session topics. Alongside each point are the actions being taken to incorporate the feedback into the NEEDS service development plan. The timescales involved are also included.

What would you like to see in the service?	The NEEDS plan	Timescale
<p>"More local support groups – also for parents/family carers"</p>	<p>NEEDS is planning to establish patient-led support groups in Harwich, Jaywick and Walton-on-Naze. These are included in a Patient Engagement and Involvement Plan which will also support the further development and expansion of the Patient Forums in Clacton-on-Sea and Colchester.</p> <p>Family carers will be welcome to attend the local support groups and are also welcome at the Patient Forums.</p>	<p>June 2014 onwards</p>
<p>"More education and better access to courses"</p>	<p>NEEDS is introducing a big increase in education, including, for example, structured courses for Type 1 and Type 2 diabetes (including DAFNE and DESMOND) which patients can book themselves onto without a GP referral. There will also be refresher courses.</p> <p>More informal opportunities to learn</p>	<p>From May 2014</p>

	<p>are also part of the plan, including 'Buddies' who will be trained to help others by sharing their own experiences of living with diabetes. Patient 'Experts' will be trained to help deliver courses.</p> <p>For further information and to book a course:</p> <p>Tel: 0845 2413313</p> <p>Email: <a href="mailto:education@diabetesneeds.org.uk">education@diabetesneeds.org.uk</a></p> <p>See:</p> <p><a href="http://www.diabetesneeds.org.uk">www.diabetesneeds.org.uk</a></p>	
<p>"A helpline"</p> <p>"Knowing how to get my questions answered"</p>	<p>The NEEDS telephone helpline provides help and advice.</p> <p>Telephone 0845 2413313.</p> <p>Patients can also access information and advice via email:</p> <p><a href="mailto:info@diabetesneeds.org.uk">info@diabetesneeds.org.uk</a></p> <p><a href="mailto:education@diabetesneeds.org.uk">education@diabetesneeds.org.uk</a></p>	Available now
<p>"Easier access to GP/nurse at surgery with diabetes expertise"</p> <p>"Support and training for nurses and GPs"</p>	<p>Incentives, support and diabetes training are being provided to GPs and practice nurses, who are providing most of the NEEDS service care.</p>	On-going
<p>"Continuity of care and regime / consistency / regular check-ups"</p>	<p>NEEDS aims to improve the quality of care for ALL patients.</p> <p>The completion of annual reviews with each patient by their GP (with a review of all 8 care processes) is a key target for the NEEDS service and one of the performance indicators which the service provider, Suffolk GP Federation, will be paid for on results.</p>	On-going
<p>"More support for newly diagnosed"</p>	<p>One of the NEEDS targets is for all (98%) of newly diagnosed patients to attend a structured education course within 12 months of diagnosis.</p>	Available now

<p>“Better communication (including for those without English as 1<sup>st</sup> language)”</p> <p>“Printed information available, as website might not suit all”</p> <p>“Patient newsletter”</p>	<p>The NEEDS communications plan and ‘hard to reach’ patient strategy include providing leaflets in a range of languages for those without English as a 1<sup>st</sup> language. The website has a translate function.</p> <p>Patient newsletters will be distributed on a quarterly basis from June 2014</p>	<p>May/June 2014</p> <p>June 2014</p>
<p>“Home visits for the elderly and disabled”</p>	<p>The proposed approach for the ‘partially engaged’ patients, including the ‘hard to reach’, is currently being developed. ‘Partially engaged’ includes the housebound and care home residents.</p> <p>The objectives of the strategy will be to bring all of these patients into the health care system.</p> <p>The strategy will seek to identify these patients and all housebound and care home residents will receive a home visit for their annual review, which will be carried out by a trained GP practice nurse.</p> <p>A self-care and support scheme will also be piloted.</p>	<p>2014/15</p>
<p>“Better access to foot care”</p>	<p>Regular foot care checks will be provided by GPs who, where required, will refer patients to one of the podiatry clinics (delivered by Anglia Community Enterprise CIC (ACE) in community settings, closer to patient homes. The service plans to minimise unnecessary hospital visits.</p>	<p>On-going</p>
<p><b>What ideas do you have for education?</b></p>	<p><b>NEEDS Action Plan</b></p>	<p><b>Timescale</b></p>
<p>“Peer support / a buddy system”</p> <p>“After you have done an education course it would be good to then have an introduction to a local support group”</p>	<p>We know that the ‘one size fits all’ approach doesn’t work and that less formal education sessions will appeal to some people. This was clearly highlighted through the feedback we received at the events.</p>	<p>2014</p>

<p>“Variety - via support groups or online”</p> <p>“Mix of patient and HCP (Healthcare Professional) led”</p> <p>“Education on a ‘need’ basis and quicker access – newly diagnosed first etc.”</p> <p>“Education for close relatives, partners/carers”</p> <p>“Refresher courses”</p> <p>“Complications – raise awareness about what could happen if you lose control and what to do when unwell.”</p>	<p>We are therefore recruiting ‘Buddies’ who will be trained to help others by sharing their own experiences of living with diabetes.</p> <p>We are also planning to put in place a network of people interested in leading new local support groups in areas such as Harwich, Jaywick and Walton.</p> <p>The idea is for the groups to get together on an informal basis, supported by perhaps a Diabetes Specialist Nurse or Podiatrist or Dietician, as necessary, or just to spend time together as a group of patients to share experiences and support each other.</p> <p>We are going to start by running some local focus groups in Harwich, Jaywick and Walton, to test the level of interest and discuss ideas for these patient-led support groups.</p>	<p>From July 2014</p>
<p>“Weight management”</p> <p>“People need information on food – what are foodstuffs worth in carbs/sugars etc.”</p>	<p>How to manage your weight and how to develop a better understanding of food and a healthy diet are areas quite a few people highlighted they’d like support with.</p> <p>We are looking at running ‘Roadshows’ on particular topics e.g. weight management, foot care, with relevant expert speakers attending events in each local area. These could be hosted by the Patient Forums or local support groups.</p>	<p>From September 2014</p>
<p>Text/telephone reminders to attend courses</p>	<p>We will be looking at this suggestion, which we agree could be very useful in helping to reduce the numbers of people who book but who then do not attend a course (e.g. because they forget), which wastes the opportunity for others to take part as well as being an unnecessary waste of resources.</p>	<p>2014</p>

What help would you like to manage your diabetes?	NEEDS Action Plan	Timescale
<p>“A care plan &amp; management of results - regular follow ups”</p> <p>“Access to results prior to appointments so consultation is more meaningful”</p> <p>“Need to know what checks should be done at each review; more education needed”</p>	<p>These are very good suggestions and ones we are looking at addressing.</p> <p>Our plan is for the health care professional to send the patient the results of their tests (with an explanation) in advance of another appointment being arranged to discuss them.</p>	Ongoing
<p>“Health &amp; wellbeing help including weight management”</p> <p>“Dietician support specialist (information and advice)”</p> <p>“Knowledge about food”</p>	<p>We are looking at running ‘Roadshows’ on particular topics e.g. weight management, foot care, with relevant expert speakers attending events in each local area.</p> <p>These could be hosted by the Patient Forums or local support groups.</p>	From September
<p>“Special help line needed for advice and/or support from experts”</p>	<p>The NEEDS telephone helpline provides help and advice.</p> <p>Telephone 0845 2413313.</p> <p>Patients can also access information and advice via email:</p> <p><a href="mailto:info@diabetesneeds.org.uk">info@diabetesneeds.org.uk</a></p> <p><a href="mailto:education@diabetesneeds.org.uk">education@diabetesneeds.org.uk</a></p>	Available now
<p>Managing depression/anxiety – access to counselling</p>	<p>Access to counselling is available with a GP referral and is being provided by the charity Health in Mind.</p> <p>See <a href="http://www.healthmind.org.uk">www.healthmind.org.uk</a></p>	
How do you think patients should be involved?	NEEDS Action Plan	Timescale
<p>“A buddy system”</p> <p>“Role models for young people”</p>	<p>As part of our patient education and involvement plan we are recruiting ‘Buddies’ who will be trained to help others by sharing their own experiences of living with diabetes.</p> <p>We hope that prospective “Buddies” representing a variety of ages, male/female, Type 1 &amp; Type 2, will</p>	April 2014 onwards

	<p>come forward.</p> <p>PR and marketing will be used to support the recruitment of "Buddies".</p>	
<p>"Online chats and social media e.g. Facebook and using #NEEDS on Twitter"</p>	<p>A social media plan has been developed and launched and online chats will be piloted later in 2014.</p> <p><a href="http://www.facebook.com/NEEDDiabetesService">www.facebook.com/NEEDDiabetesService</a></p> <p>Follow @diabetesNEEDS on Twitter</p>	In place
<p>"Annual versions of this meeting (with feedback / reports on action and progress)"</p>	<p>The patient engagement events are to be repeated in early 2015, when progress on the service's plans against its objectives will be reported and patients will have the opportunity to provide feedback.</p>	February 2015
<p>"Putting an experienced patient on the Board (Type 1 / Type 2 representation)"</p>	<p>Patient representation on the Diabetes Services Board is very important and each of the Colchester and Tendring Diabetes Patient Forums has now elected their representatives for a 12 months term.</p> <p>Diabetes UK also has a local Patient Champion on the Board.</p>	In place
<p>"Patient Surveys/Feedback after appointments"</p>	<p>There will be regular patient surveys</p>	On-going
<p>"Other local groups, not just Clacton and Colchester"</p> <p>"Local support groups – better publicised and 'marketed' (more advertising/promotion)"</p>	<p>Patient-led support groups in Harwich, Jaywick and Walton-on-Naze are included in a Patient Engagement and Involvement Plan which will also support the further development and expansion of the Patient Forums in Clacton-on-Sea and Colchester.</p> <p>Better publicity for the Forums is part of the plan. This includes posting information on the new NEEDS website (<a href="http://www.diabetesneeds.org.uk">www.diabetesneeds.org.uk</a>) and providing flyer leaflets and posters for the Forums to use to publicise their meetings and events.</p>	From April 2014
<p>"Information/leaflets/posters at GP practices"</p> <p>"Suggestion boxes at GPs and nurses/clinics"</p>	<p>Leaflets and posters are being made available to GPs</p> <p>We will also look at whether suggestion boxes are viable</p>	On-going
<p>"Focus groups"</p>	<p>We are developing a database of</p>	On-going



	<p>patients who are interested in getting involved in a variety of ways, including taking part in Focus Groups.</p> <p>Our first Focus Groups will look at the viability of establishing local, patient-led support groups in Harwich, Clacton and Jaywick.</p> <p>Anyone interested in taking part in a Focus Group or becoming a Patient Ambassador should email:</p> <p><a href="mailto:info@diabetesneeds.org.uk">info@diabetesneeds.org.uk</a></p> <p>Telephone: 0845 2413313</p>	
<p>“Roadshow/ ‘diabetes bus’ in community setting”</p>	<p>We work closely with national charity Diabetes UK who often run this type of community event. We will be publicising any upcoming events in our patient newsletter which will be published quarterly from June 2014.</p>	<p>To be decided</p>

## **Format and marketing of the events**

The target numbers for the patient engagement events were 15-20 diabetes patients at each event (target of 100 people) and this target was far exceeded, with a total of 151 diabetes patients and guests attending. An additional 81 people who could not attend made requests for further information and were sent a pack with the questionnaire to give their feedback.

### **Format**

- Half Day interactive events
- Guests seated in small groups around a table with a facilitator
- Facilitators included representatives from national charity Diabetes UK, diabetes specialist nurses, North East Essex Clinical Commissioning Group and Suffolk GP Federation
- Session 1 was a presentation to introduce the new service model, followed by round table discussions and a feedback session
- Session 2 was a presentation about plans for patient education and involvement, followed by round table discussions and a feedback session
- There was plenty of opportunity for questions and answers throughout the events
- Attendees were encouraged to look at the logo ideas for the NEEDS brand, which were displayed on boards, and cast a vote for which one they'd like to see used

### **Marketing**

- An invitation letter and response form were created and a mail shot undertaken in association with Diabetes UK, who used their mailing list to direct mail 700-800 diabetes patients who lived in North East Essex
- PR –press releases were issued to all local media
- Posters were distributed to all GP surgeries
- Colchester and Tendring Patient Diabetes Forums helped publicise the events

### **Engagement and feedback**

Information Packs were provided to every attendee. These comprised:

- the agenda for the event and a service leaflet
- a copy of the presentation
- a questionnaire covering three key areas to be measured:
  - feedback about the event
  - feedback about the new diabetes service
  - experiences of the current diabetes service; responses to create a benchmark and questions to be repeated in annual surveys

Information gathering forms were also distributed on all tables, to encourage people to sign up to receive newsletters and information about getting involved.

The Response Form included with invites had invited people who were unable to attend to request a leaflet and a copy of the questionnaire so they could provide their feedback. 81 letters and packs were mailed, generating considerable additional feedback.

### Locations, dates and numbers of attendees

Dates and Locations	Venues	Diabetes patients & guests	NEEDS Team	Total attendees
<b>CLACTON-ON-SEA</b> Thursday 6 <sup>th</sup> February 5.30pm – 8.30pm	CVS Tendring 20-22 Rosemary Road Clacton-on-Sea CO15 1NZ	41	11	52
<b>COLCHESTER</b> Saturday 8 <sup>th</sup> February 10.30am – 2.30pm	Best Western Rose & Crown East Street Colchester CO1 2TZ	59	12	71
<b>WALTON-ON-NAZE</b> Monday 10 <sup>th</sup> February 10.30am – 2.30pm	St George's Community Ctr. 86 Hall Lane Walton-on-Naze CO14 8HZ	5	6	11
<b>HARWICH</b> Friday 21 <sup>st</sup> February 10.30am – 2.30pm	Long Meadows Dovercourt Harwich CO12 4US	29	14	43
<b>JAYWICK</b> Tuesday 25 <sup>th</sup> February 10.30am – 2.30pm	Community Resource Centre Brooklands Gardens Jaywick CO15 2JP	17	9	26
<b>Totals</b>		151	52	203

### Key facts about the events

Here are the topline figures about the events:

- 151 people living with diabetes in North East Essex, including some partners or carers, attended the five events. Between 6 and 14 people were on the organising and exhibiting team at each event (depending on its size) and this brings the overall attendance number across the five events up to 203.
- A further 81 people requested leaflets and questionnaires to be sent to them as they were unable to attend an event. Packs containing the leaflet, questionnaire, copy of the presentation and 'keeping in touch' form were sent to these people with a Freepost envelope.
- 13 people accepted but did not attend and they were sent the same pack and Freepost envelope.
- A total of 245 questionnaires were distributed (at the events and afterwards) and 74 questionnaires (30%) were returned completed - see analysis below
- A total of 118 'keeping in touch' forms were completed (48%) - see analysis below.

### Analysis of questionnaire responses

Here are the topline figures from the questionnaire responses:

- A total of 74 questionnaires were completed (80% of people who returned them have Type 2 and 20% have Type 1 diabetes)
- 100% of those who completed questionnaires would like to receive a newsletter and be kept informed
- 100% said the discussion and feedback sessions at the events were either 'excellent' (20%), 'very good' (55%) or 'good' (25%)
- 98% rated the events overall as either 'excellent' (28%), 'very good' (52%) or 'good' (19%)
- 86% felt either 'very confident' (14%), 'reasonably confident' (51%) or 'satisfied' (21%) that the new service will meet their needs and 14% said they felt 'concerned'.

See Appendix A for full analysis.

## Analysis of 'keeping in touch' forms

Here are the topline figures about the responses in the 'keeping in touch' forms:

- 118 forms were completed (92% are diabetes patients and 8% are relatives/carers)
- 59% (69 people) say they are happy to keep in touch via the post
- 48% (56) say they are happy to keep in touch via email communications
- Only 34 people answered the question 'do you use social media?'
  - 6 say they use Twitter
  - 33 say they use Facebook
- 88% of people (90) would like to receive updates about the service
- 80% would like more information (82 people)
  - 52% want more information about patient education
  - 56% want more information about self-management/care planning
  - 39% are interested in focus groups/surveys
  - 32% are interested in joining a Forum
  - 16% are interested in becoming a Patient Ambassador

See Appendix B for full analysis.

## Key themes from feedback sessions

Group facilitators wrote all the main points made by those around their table onto flip chart paper. If people had individual questions, they were asked to write these onto sticky notes.

The full feedback from each of the events is in **Appendix C** and below is a summary of the key themes which emerged.

## **Session 1 - the service model**

Groups were asked to consider three questions about the new service model and here are some of the main points which were made:

*Are the new plans what you expect?*

- Seems very ambitious to get the GPs to do more
- Plans look good
- No previous expectations
- Didn't know there was going to be a change
- They are well presented / make sense
- Good to encourage people to take more responsibility for their own care

*What would you like to see?*

The main themes emerging from answers to this question are:

- More support groups – also for parents/family carers
- More education and better access to courses
- Knowing how to get my questions answered
- Easier access to GP/nurse at surgery with diabetes expertise
- Support and education/training for nurses and GPs
- Continuity of care and regime / consistency / regular check ups
- More support for newly diagnosed
- Better communication (including for those without English as 1<sup>st</sup> language)
- Home visits for the elderly and disabled
- Better access to foot care
- A helpline
- Printed information available as website might not suit all!
- Patient newsletter

*What works well at the moment?*

Answers to 'What works well at the moment' were fairly consistent across all 5 events. In particular the retinal eye screening, podiatry and renal services were highlighted as working well. Good practice nurses and the charity Diabetes UK's helpline were also commended.

## **Session 2 - patient education and involvement**

After a presentation about the new service's plans for the increase in patient education and involvement, the round table groups were asked to give their feedback on three areas:

*What ideas do you have for education?*

The main themes emerging from answers to this question are:

- Peer support / a buddy system
- Weight management
- Refresher courses

- After courses – introduction to local support groups
- Variety – via support groups or online
- People need information on food – what are foodstuffs worth in carbs/sugars etc.
- Complications – raise awareness about what could happen if you lose control
- Education for close relatives, partners/carers
- Education on a ‘need’ basis and quicker access – newly diagnosed first etc.
- Mix of patient and HCP (Healthcare Professional) led
- Text/telephone reminders to attend courses
- Knowledge of the checks that have to be done

*What help would you like to manage your diabetes?*

The main themes emerging from answers to this question are:

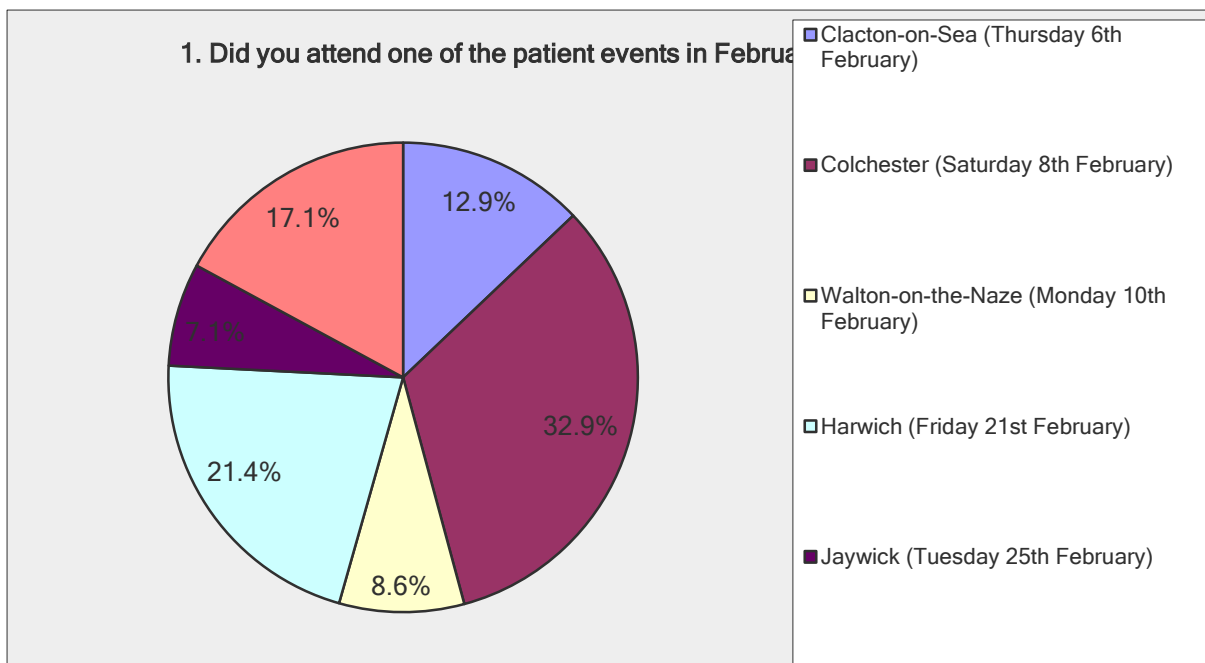
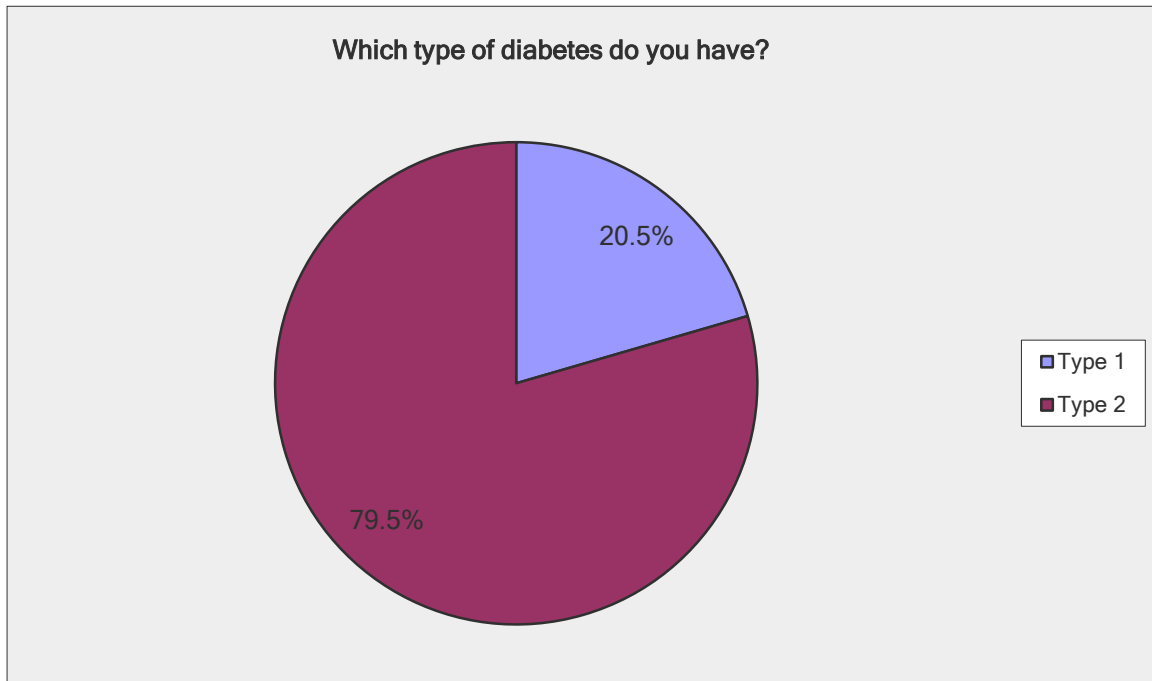
- A care plan & management of results - regular follow ups
- Access to results prior to appointments so consultation is more meaningful
- Health & wellbeing help including weight management
- Need to know what checks should be done at each review; more education needed
- Special help line needed for advice and/or support from experts
- Peer support and support groups
- Dietician support specialist (information and advice)
- Managing depression/anxiety – access to counselling
- Knowledge about food
- A buddy system
- Understanding what to do when unwell and in emergencies

*How do you think patients should be involved?*

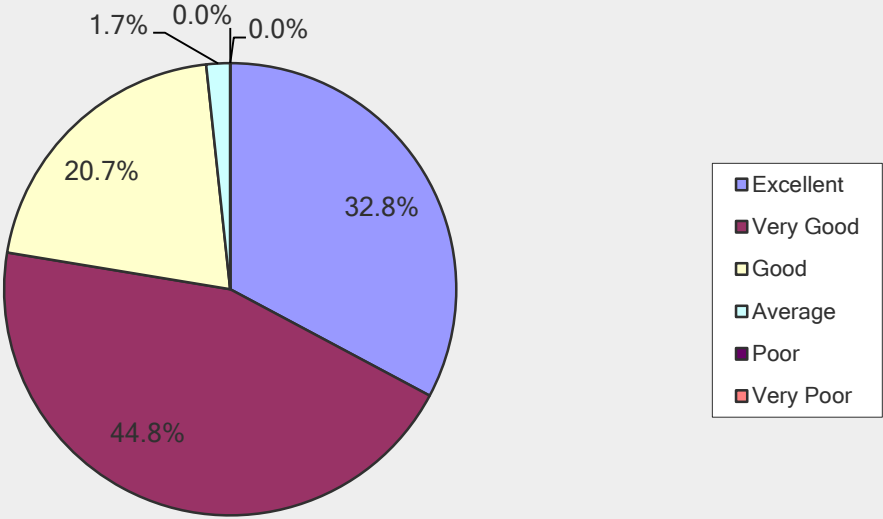
The main themes emerging from answers to this question are:

- A buddy system
- Role models for young people
- Online chats and social media e.g. Facebook and using #NEEDS on Twitter
- Events like this and with speakers
- Putting an experienced patient on the Board (Type 1 / Type 2 representation)
- Annual versions of this meeting (with feedback / reports on action and progress)
- Patient Surveys/Feedback after appointments
- Local support groups – better publicised and ‘marketed’ (more advertising/promotion)
- Other local groups, not just Clacton and Colchester
- ‘Forums’ – discussions need to be delivered in ‘plain English’ and with some context as to what is being discussed, especially if you want to attract new people
- Involvement of relatives/carers/partners/children in education
- Suggestion boxes at GPs, nurses/clinics
- Building patient confidence / empowerment
- Email feedback
- Forums/focus groups – Saturday/evening/daytime
- Information/leaflets/posters at GP practices
- Focus groups
- Roadshow/ ‘diabetes bus’ in community setting
- Stands at local events

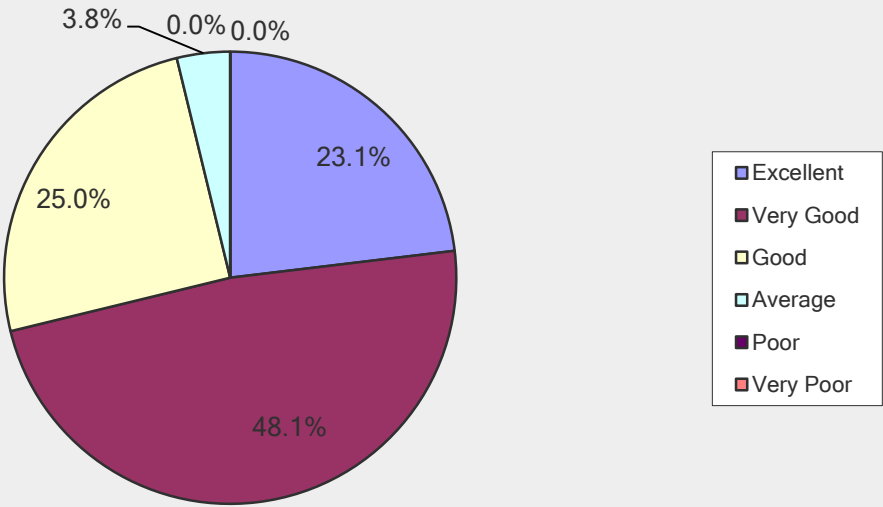
## Appendix A – Questionnaire responses



2. How did you rate the 1st session - the presentation about the new service?

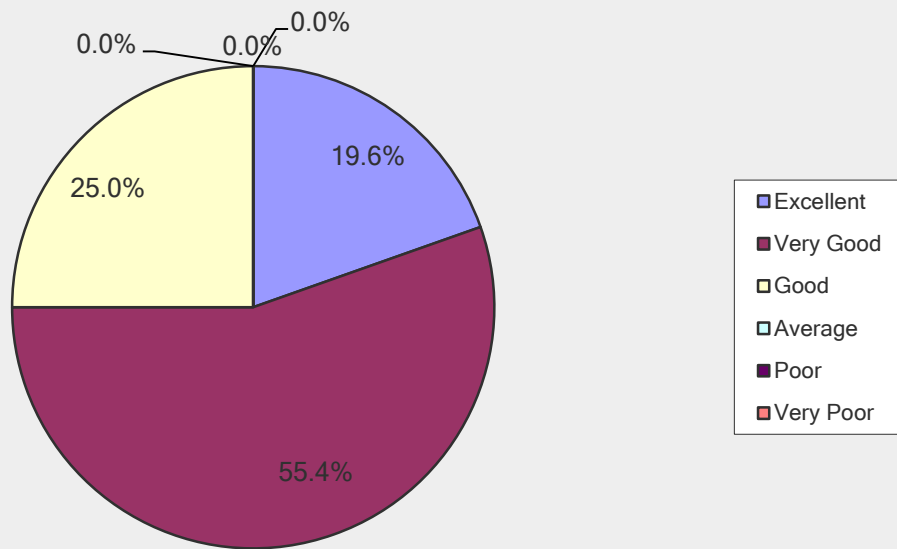


3. How did you rate the 2nd session - the presentation about patient involvement?

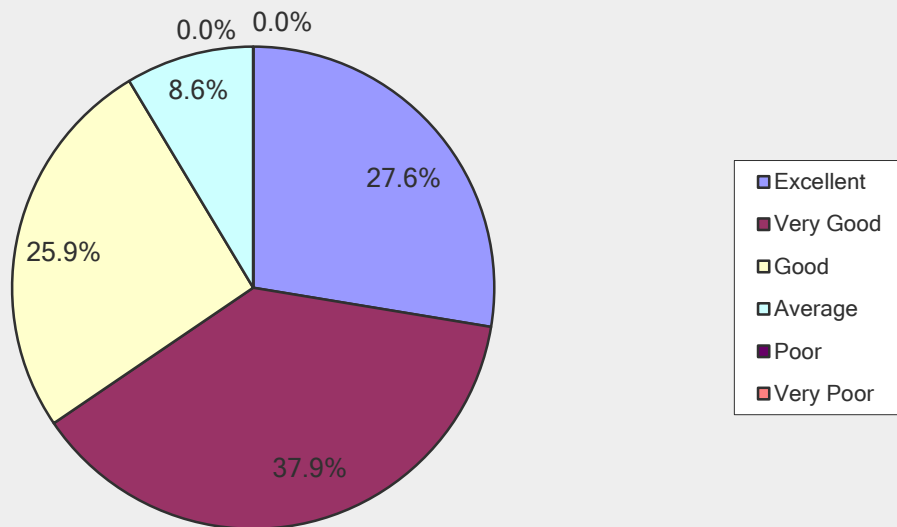




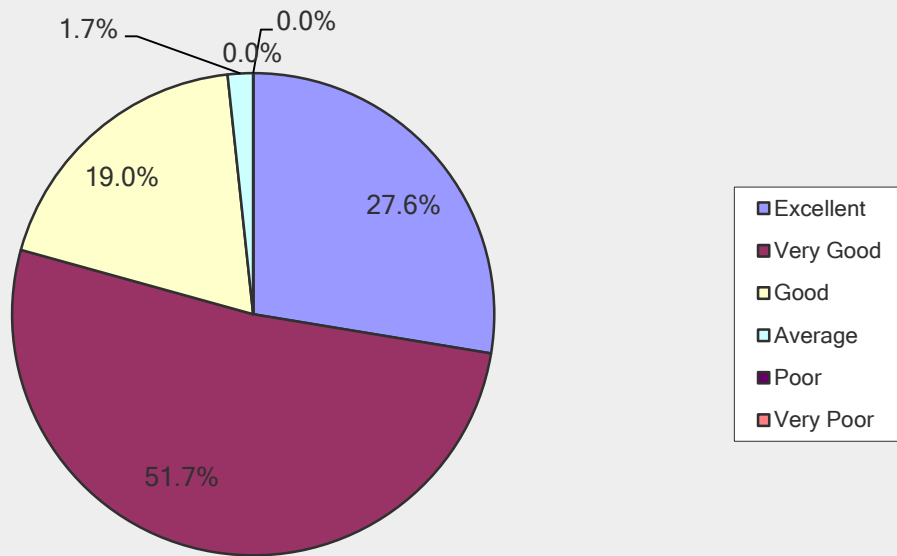
4. How did you rate the discussion and feedback sessions?



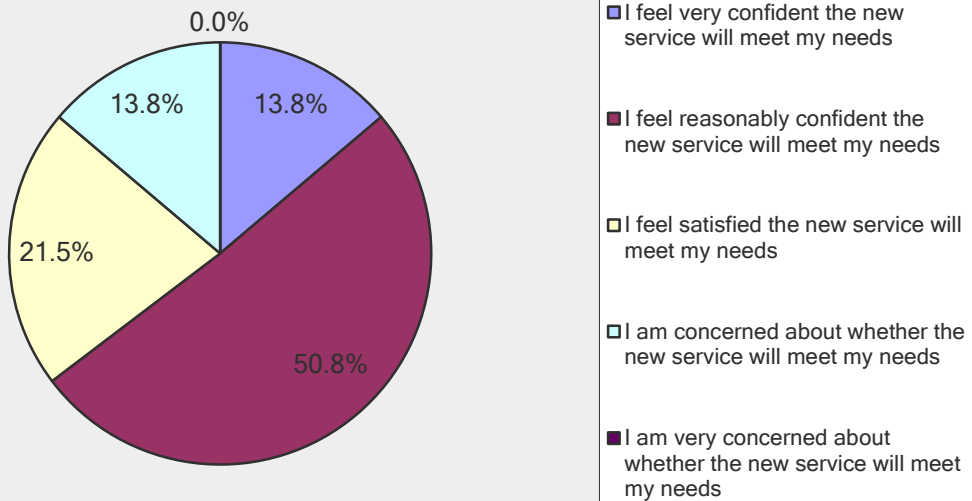
5. How did you rate the venue and catering?



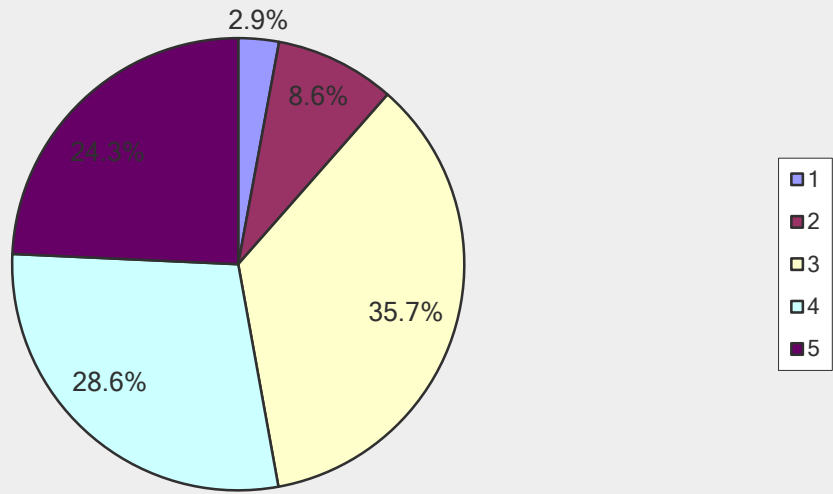
6. Overall how did you rate the event?



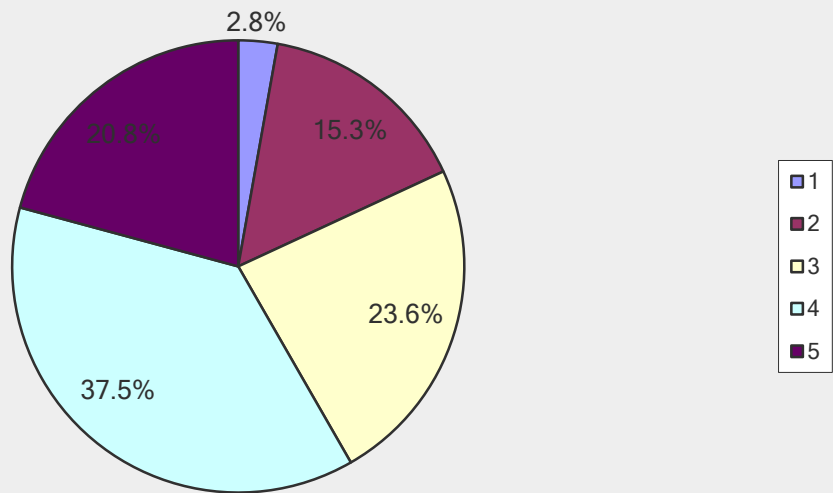
8. How confident do you feel that the plans for the new service from 1st April 2014 (as described in the leaflet and at the event) will meet your needs?



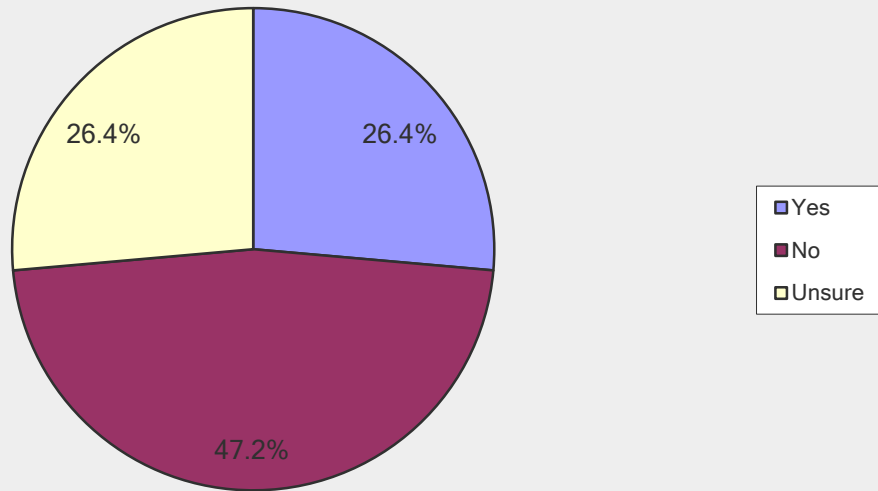
11. How well informed do you feel about diabetes on a scale of 1-5 (1 being 'not at all' and 5 being 'very well informed'):



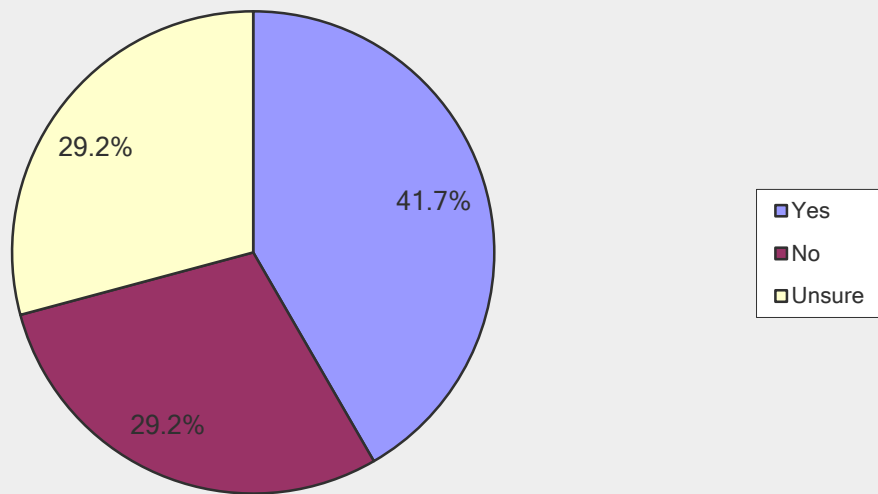
12. How in control do you feel of your diabetes on a scale of 1-5 (1 being 'not at all' and 5 being 'very in control'):



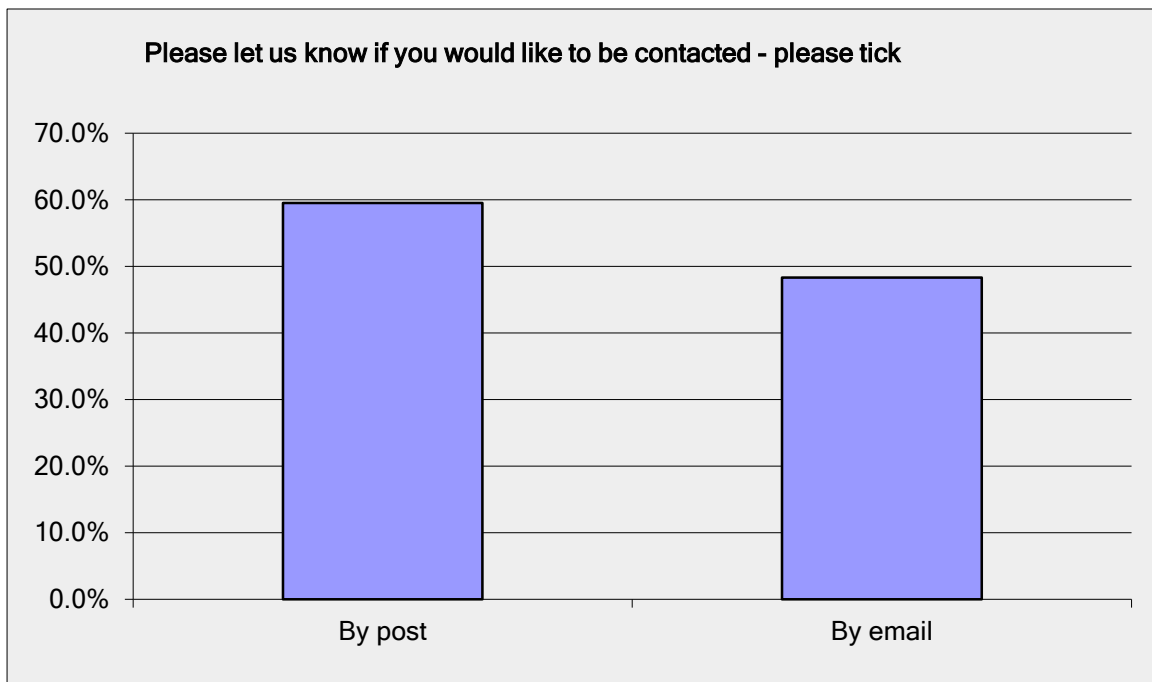
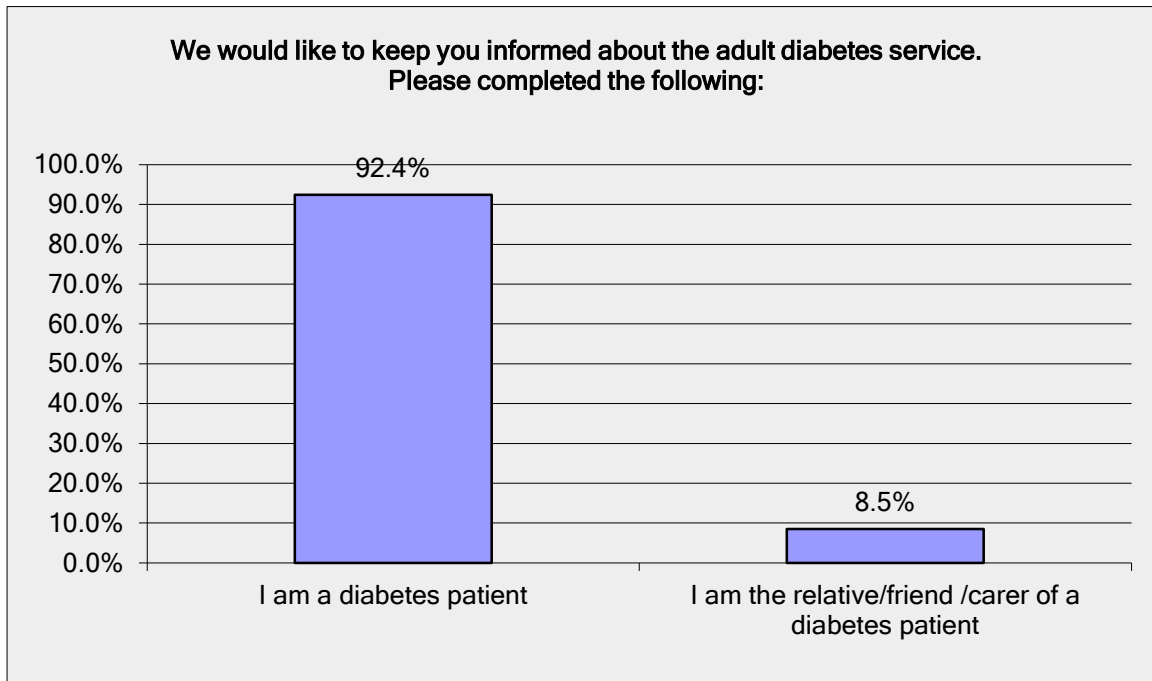
13. Do you have a Care Plan?

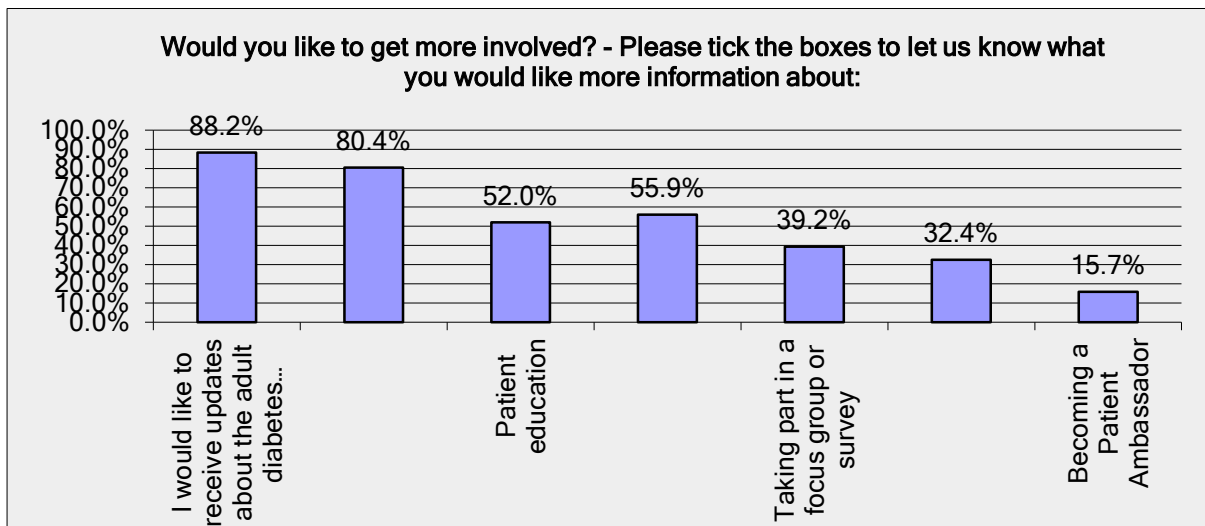
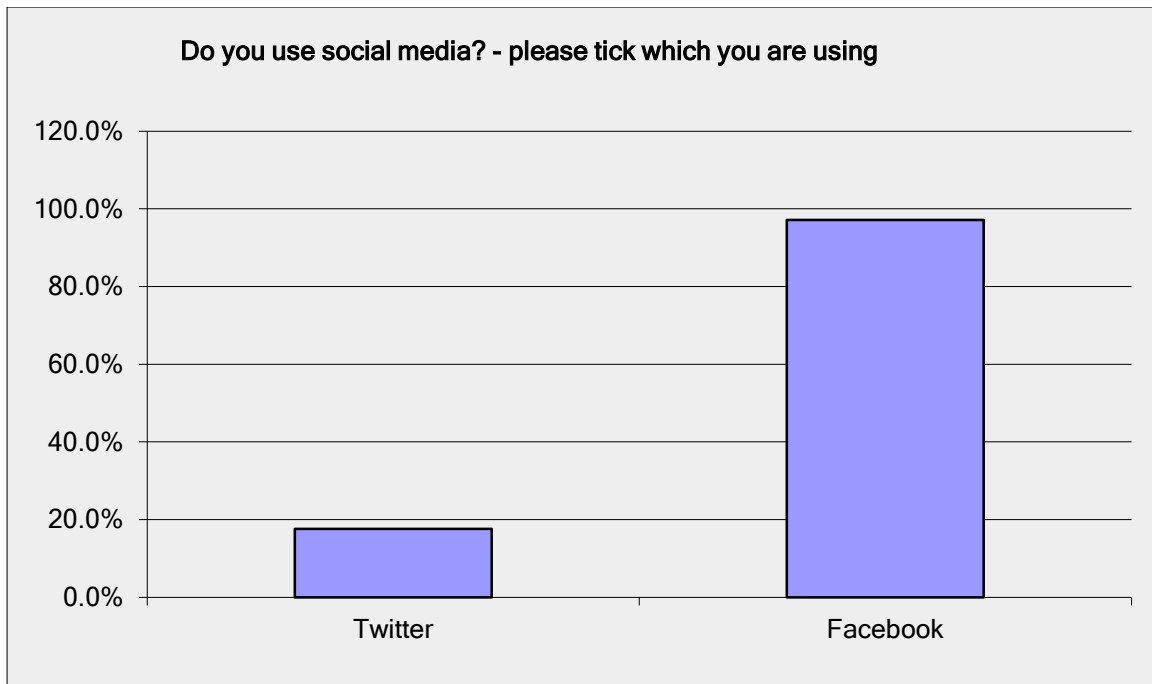


14. If you have a Care Plan, is it reviewed every year?



## Appendix B – Keeping in touch forms





**Would you like to get more involved? - Please tick the boxes to let us know what you would like more information about:**

Answer Options	Response Percent	Response Count
I would like to receive updates about the adult diabetes service	88.2%	90
I would like more information about: Patient education	80.4%	82
Self-management/care planning	55.9%	57
Taking part in a focus group or survey	39.2%	40
Joining a Patient Forum	32.4%	33
Becoming a Patient Ambassador	15.7%	16
<i>answered question</i>		<b>102</b>
<i>skipped question</i>		<b>16</b>

## Appendix C – Feedback summary

CLACTON-ON-SEA, THURSDAY 6 FEBRUARY 2014 Feedback summary				
Are the new plans what you expect?	What would you like to see?	What ideas do you have for education?	What help would you like to manage your diabetes?	How do you think patients should be involved?
<p>Didn't know much about the service/what to expect</p> <p>Plans make sense</p> <p>Wait to see what happens</p> <p>No one had heard about the change until the invite arrived</p> <p>Wasn't what we expected</p> <p>Hard to define – proof is in the pudding</p> <p>Don't see a lot of change</p> <p>Seems very ambitious to get the GPs to do more</p>	<p>More focus on Type 1 as all focus on Type 2</p> <p>Printed information available as website might not suit all!</p> <p>Regular appointment at GP, e.g. 6 months with reminder</p> <p>More information on the patient forums</p> <p>Patient newsletter</p> <p>Getting all I need from my GP practice</p> <p>More support groups – also</p>	<p>Refresher courses</p> <p>General awareness for non-diabetics; informed public message</p> <p>Preventative messages/education</p> <p>For all including people with disabilities</p> <p>Food labelling e.g. low fat but high sugar yoghurt</p> <p>Protein/fats/carbs – how they work; how to balance/eat sensibly; nutrition info/help</p>	<p>Help on weight management</p> <p>Alternative therapies</p> <p>More information about what to do when unwell</p> <p>Knowledge about food</p> <p>An email contact</p> <p>A diabetic nurse</p> <p>A proper care plan</p> <p>Help to build the confidence to increase dose if needed</p> <p>Someone to call 24hours</p>	<p>Forum – more advertising</p> <p>Diabetic services board – representation</p> <p>Staff to attend forums on a regular basis</p> <p>Free gym membership</p> <p>Online chat/Facebook/google and with video responses live/email help</p> <p>FAQ for newly diagnosed</p> <p>Tweet chats #NEEDS</p> <p>Public events –</p>

	<p>for parents/family carers</p> <p>Better distinction between Type 1 and Type 2 information</p> <p>More education and find out how to go on courses</p> <p>Same doctor and nurse every time</p> <p>Knowing how to get my questions answered</p> <p>Expertise in GP practices to understand complications</p>	<p>Transport to venues for education – access</p> <p>Advertise better and lots of promotion</p> <p>Group sessions – meet like-minded people</p> <p>Forums with speakers</p> <p>Apps for Smart Phones</p>	<p>a day, for security</p> <p>More education in general</p>	<p>stands/info; e.g. Clacton carnival, classic car show, art show</p>
	<p>GP appointment within 24 hours</p> <p>Better access at evenings/weekends</p> <p>Ability to book double appointment to deal with complex issues</p> <p>Easier access to GP/nurse at surgery with diabetes expertise</p>			



	<p>All Health Care Professionals (HCPs) and receptionists to have basic diabetes training</p> <p>Massive changes to all GP appointment services to ensure equality</p> <p>More groups for younger people</p>			
<p><b>COLCHESTER, SATURDAY 8 FEBRUARY 2014</b>  <b>Feedback summary</b></p>				
<p><b>Are the new plans what you expect?</b></p>	<p><b>What would you like to see?</b></p>	<p><b>What ideas do you have for education?</b></p>	<p><b>What help would you like to manage your diabetes?</b></p>	<p><b>How do you think patients should be involved?</b></p>
<p>Did not know what to expect</p> <p>Hard to tell what you would get</p> <p>No! Retinopathy still outside scope of the service, as is podiatry</p> <p>Hopeful – closer to home?</p> <p>One stop shop?</p>	<p>Better knowledge of Diabetes Specialist Nurses e.g. explain blood test results and interpret the data/results</p> <p>More expertise – even amongst ‘specialists’</p> <p>More frequent appointments if required –</p>	<p>Peer support / a buddy system</p> <p>Initially, basic training with a nurse which can lead onto a structured course</p> <p>Share experiences</p> <p>Classroom training</p> <p>Each practice could survey their patient population to</p>	<p>More info / dietary advice</p> <p>A buddy system</p> <p>Access to specialist dieticians; personalised care; long-enough appointments</p> <p>Telephone hotline with an expert avail. 24/7</p> <p>Understanding how to</p>	<p>Local support groups – better publicised and ‘marketed’</p> <p>Other local groups, not just Clacton and Colchester</p> <p>‘Forums’ – discussions need to be delivered in ‘plain English’ and with some context as to what is being discussed,</p>

Looks like a great idea	interactive	find out education needs	deal with illness	especially if you want to attract new people
Plans look good	More accessible – lower cost, e.g. parking – out of town or not in centre?, and bus service	Improve access to courses	Earlier diagnosis	Involvement of relatives/carers/partners/children in education
No previous expectations	Community clinics need to be in right places	Have alternative non-group education	More screening	Publicity material to be in bolder and bigger print if you want people to get involved
Didn't know there was going to be a change	Access to courses, e.g. Bertie, Dafne, Desmond	Provide training/education programs in practices	Regular checks post diagnosis, more support	More advertising and promotion e.g. Forum meeting dates / venues/ speakers etc.
Like the approach	GP contact in appropriate way to individual; reminder triggers; must be consistent	Ensure consistency in standard of education/quality	Hand book easily available, new pages for monitoring	A survey of people who attend both Clacton and Colchester Forums
Believe it's a better thing	Continuity of care and regime / consistency / regular check ups	Education for care homes	Care plan – with step/step advice/info to deal with potential emergency tailored to individual	Patient representation on Board should be from Type 1, Type 2 and from different age groups
Yes and more!	Better contact with eye screening	School nurses raising	Download results to compare/share with HCPs	Suggestion box at GPs, nurses/clinics
Nobody knew there would be changes	More support for newly diagnosed and for partners	Variety of days/times	Management of results care plan through joint access to records	Buddying
	TV – understanding and communication of different types of diabetes	Taster sessions are a good idea	Improve access to physiological support	Partnerships with Diabetes UK
	Better training for GPs and nurses	Quiz night for senior people	Regular updating	
		Knowing about complications and how to avoid them	Access to results prior to appointments so	
		Weight management		
		Refresher courses		
		Expert (Type 2) - make it		

	<p>Helpline for questions</p> <p>Location of podiatry clinics to be more accessible</p> <p>Lack of transfer of records/ information to be improved</p> <p>Back office support and education to GP practices – looking at PLWD records and advising</p> <p>More time to explain and in plain language</p> <p>Be aware of English not being 1<sup>st</sup> language for HCPs – improve communication</p> <p>Information in various formats – patient hand held record; website/ podcasts; DVDs</p> <p>Joined up processes planning from review to next review</p> <p>Better service and integration of care for elderly population,</p>	<p>longer/more detailed, especially on carbs.</p> <p>Knowing what info doctors want from me</p>	<p>consultation is more meaningful</p> <p>Health &amp; wellbeing help</p> <p>A care plan</p>	<p>Building patient confidence / empowerment</p> <p>GPs involving patients in their decisions</p> <p>Electronic method to feed-back</p> <p>Forums/focus groups – Saturday/evening/daytime</p> <p>Public meeting engagement events (across geographical area) 1, 2, 3 and 4 years on to give update/what's coming in 2nd year</p> <p>Feed-back reports from those events with what themes, what will be done, what won't and why (also as a section of website)</p> <p>Encourage PLWD to join Patient Participation Groups</p> <p>Forums, individual choice</p> <p>Information/leaflets/poster</p>
--	---	---	--	---

	<p>housebound/ dementia patients/ care homes</p> <p>Improvement in foot care provision</p> <p>Structured education and improve access to courses</p> <p>Weight management</p> <p>Rural patients not missing out versus living in town</p> <p>More support for patients – dieticians to services and help available</p> <p>Ensure that people know what they should be having regularly: eye check, feet</p> <p>Better trained practice nurses</p> <p>One stop shop; appointment bloods and eyes and if necessary see dietician, nurse and specialist</p>			<p>s at GP practices</p> <p>Focus groups</p> <p>Smaller groups in areas other than Clacton/ Colchester</p> <p>Roadshow/ 'diabetes bus' in community setting</p> <p>Stands at local event</p>

**WALTON-ON-NAZE, MONDAY 10 FEBRUARY 2014**  
**Feedback summary**

Are the new plans what you expect?	What would you like to see?	What ideas do you have for education?	What help would you like to manage your diabetes?	How do you think patients should be involved?
	<p>Less fragmentation of services</p> <p>Good diabetes nurses; Dr's not always informed on diabetes</p> <p>Advertising education courses – get to know each other. More local courses needed</p> <p>Review regularly to keep education up to date</p> <p>Feet are ignored – have to <b>request</b> podiatry services</p> <p>Phone annual reviews?</p>	<p>After courses – introduction to local support groups</p> <p>Need centres of excellence</p> <p>Variety of educational courses – via support groups or online</p> <p>People need information on food – what are foodstuffs worth in carbs/sugars</p>	<p>Need to know what checks should be done at each review; more education needed</p> <p>Special line needed for advice and/or support – can't get through to GPs</p> <p>Services that are out of hours</p>	<p>Buddy system</p> <p>People need to be taught how to access support/information online</p> <p>Role models for young people</p> <p>Use social media</p>

**HARWICH, FRIDAY 21<sup>ST</sup> FEBRUARY 2014**  
**Feedback summary**

Are the new plans what you expect?	What would you like to see?	What ideas do you have for education?	What help would you like to manage your	How do you think patients should be
------------------------------------	-----------------------------	---------------------------------------	---	-------------------------------------

			<b>diabetes?</b>	<b>involved?</b>
Like the ideas - they are needed to boot up the service	Communication needs addressing - social media for young people	More information re complications – raise awareness about what could happen if you lose control	To be listened to when in hospital	Involvement of patients in sharing info & advice
Didn't know the service was changing	Regular foot care	Education for close relatives, partners/carers	Greater education	Peer support is very important
No preconceived ideas	More access to home visits - elderly and disabled	Education placed on a 'need' basis and quicker access – newly diagnosed first etc.	Learn how to test blood properly	Local Harwich patient informal group or Forum
New model looks good	Access to info (paper and online)	Classroom based	Specialists to teach correct time for medication	Events like this and with speakers
Never had an issue with current service	Access to education / more education & training (for patients, GPs and Practice Nurses)	Online access/apps	Involvement of dieticians in courses	Leading education
They are well presented / make sense	GP patient participation groups in feedback	A mini-support group		Putting an experienced patient on the Board
	Continued access to specialists	Increase general public awareness		
	Diabetes to have a higher profile	Additional education when condition changes		
	A supportive approach	Refreshers		
	General awareness raised	Keep it local		
	Accessible foot clinics & nail clipping	Mix of patient and HCP		

	<p>Helpline / central number</p> <p>Annual reviews to take place on time / when due</p> <p>Better feedback/complaints administration</p>	(Healthcare Professional) led		
<p><b>JAYWICK, TUESDAY 25<sup>TH</sup> FEBRUARY 2014</b></p> <p><b>Feedback summary</b></p>				
<b>Are the new plans what you expect?</b>	<b>What would you like to see?</b>	<b>What ideas do you have for education?</b>	<b>What help would you like to manage your diabetes?</b>	<b>How do you think patients should be involved?</b>
<p>Like the ideas</p> <p>Didn't know what to expect</p> <p>Expected a separate clinic - not in the practice</p> <p>Good idea for GP practices/nurses to take more responsibility</p> <p>Good to encourage people to take more responsibility for their own care</p>	<p>Return of testing strips</p> <p>Education – not just for newly diagnosed</p> <p>Tailored care for the individual</p> <p>Support and education for practices and HCP</p> <p>Raise awareness of Diabetes in society generally, especially for type 1</p> <p>Raise awareness of the differences between type 1</p>	<p>Text/telephone reminders to attend courses</p> <p>Type 2 newly diagnosed education then followed up by someone after 2-3 months</p> <p>Type 1 – close contact every 3 days</p> <p>Buddy system</p> <p>Type 1 – system for parents and carers</p>	<p>Full access to own health records</p> <p>Access to information in other languages</p> <p>Culturally specific dietary advice</p> <p>More information</p> <p>Peer support and support groups</p> <p>Dietician support</p>	<p>Chance to participate in research</p> <p>Annual versions of this meeting</p> <p>Feedback after appointments</p> <p>Surveys</p> <p>Buddy system</p> <p>Education</p> <p>Support</p>

	<p>and type 2</p> <p>Communication between services</p> <p>Regular toe nail cutting</p> <p>Better care for the housebound</p> <p>Dietary advice</p>	<p>Media</p> <p>More access to better education for HCP</p> <p>Refresher courses</p> <ul style="list-style-type: none"> <li>o 6 monthly</li> <li>o Advertised locally</li> <li>o Flyers in surgeries/supermarkets/libraries</li> </ul> <p>Offering different types of education appropriate to the patient</p> <p>Knowledge of the checks that have to be done</p> <p>HCP training and on-going</p>	<p>Education</p> <p>Helpline (Freephone) – decent music</p> <p>Support from Diabetes UK</p> <p>HCP understanding everybody is different and levels may be different</p> <p>Forums – information from surgeries to discuss</p> <p>Better access to information – social media</p> <p>Managing depression/anxiety – access to counselling</p> <p>Regular follow ups and discussions with your surgery</p>	
--	---	---	---	--



## **‘What would you like to see in the new diabetes service? - written responses from questionnaires**

Many of the written responses in the questionnaire echoed the feedback and discussions of the local patient engagement events.

Here are some of the comments provided in the questionnaires in answer to the question ‘What would you like to see in the new diabetes service?’

- Psychological support. Help towards cost of new glasses. Being able to chat to others with Diabetes - forum sounds good. Better care in hospitals, when inpatient for other things / operations - regarding diet
- Better information about the condition. Better medical check ups
- I receive excellent eye care with the yearly testing. It would be nice to have something similar for feet. Also I have a weight problem and would love to have a group session (weekly / monthly) to encourage weight loss
- To be referred to diabetologist at start of diagnosis.
- More trained personnel in GP surgeries and hospitals
- Ease of contact i.e. no press button 1 etc. Also 1 to 1 contact, not passed from 1 department to another
- Information to improve self-help. e.g. I pay a podiatrist who will visit my home if I am not well enough to go out. Is there a similar service run through the NHS or NEEDS? I've only this year discovered that my GP is the diabetes person at our practice. Perhaps there should be a published / updated list
- More local events. Also helpline for advice preferably 24hr as 111 was no help at all - not worth the phone call.
- Access to podiatry on a regular basis e.g. at annual review, even if no obvious problem
- More frequent consultation
- Don't know at this time, maybe I will after it is up and running for a while
- More contact between the medical teams and the patient
- Personally as my diabetes is controlled by diet only all aspects of event seemed to cover all my needs. I found the book stall very helpful
- I would like to see some kind of walk in centre only because sometimes we have to wait so long to see a doctor
- More understanding of diabetes
- Like to see it run as it is being presented

- Further education for diabetics and general public education of what they should look out for before diagnosis
- Would like to see a drop in centre
- Foot clinic / drop in
- More people attending educational courses about diabetes and listening to advice that is given
- More communication with surgeries
- More advertising
- More 'Desmond' type teaching
- Better dietary advice
- A facility for one hospital to communicate with another
- More personal involvement
- Education offered to everybody who has diabetes!
- As diabetes is 24hr x 7 days a week I would like access to a person that I could talk to between 5pm & 9am weekdays and 5pm Friday to 9am Monday - not just office hours. I think that this is also essential for carers
- Ideally a 'one stop shop' where all services are available where needed.
- GP & nurse practices to be graded/rated & patients able to choose a surgery based on location & because they offer a good diabetes service - e.g. equivalent to choosing a school OFSTED grades. Ongoing feedback and consultation
- An improvement in the quality of care provided by local surgeries i.e. diabetic nurses & doctors with increased knowledge of the disease
- A good together organisation
- Improved access for podiatry. Better trained diabetes nurse specialist - more knowledgeable, access to senior person able to answer questions, explain laboratory results - I currently rely on google - DNs sometimes say "don't worry about it" then why do the test not referring to HBA1c etc.
- More personal support
- I think the new system could work if given a fair trial
- More uniformity in advice & treatment
- More communication about forums & education
- Provision of expert advice to back up my GP Practice Diabetes Nurse & GP
- Consistency of support available easily to all. Joined up thinking between service provider and GP's Surgeries. Provision of excellent service to diabetic patients across

the area, whatever their needs. To include all who need support, with those who have bodily or mental impairment or those who do not have English as their first language.

- Effective implementation. The proposed plans with appropriate monitoring, feedback & action to ensure that the needs of patients are being met
- Join up service & carer support
- Joined up service where communication is robust & effective
- Joined up services centred at the GP
- A more pro-active involvement by GP practice in relation to communication with patients
- Would like better foot care. More encouragement less depression
- More foot care
- Better long term support & multi-discipline access should be "built-in"
- More training for doctors and more diabetic nurses in surgeries and notification of annual reviews sent to patients
- More training for diabetic nurses in GP Surgery
- Training / course for newly diagnosed patients & their partners
- Psychiatry support.
- Online discussion groups
- Being able to go to one place and see the same person each time
- Helpline number & local events
- Emotional & psychological support help
- Mandatory education for newly diagnosed patients. Ongoing education opportunities for all patients. Information on alternative diets in addition to NHS recommendations. Emphasis on self-management and individual responsibility.

## Appendix D - Questions and answers

### NEEDS Patient Events - February 2014

#### CLACTON

**1. How will GPs cope when they are overloaded already?**

Answer: there will be incentives and training for GPs. The GPs will be supplemented by the Diabetes Specialist Team.

**2. What about amputees?**

Answer: Prosthetics and Physiotherapy services will continue to be delivered as they are currently.

**3. Will there be home visits?**

Answer: a plan for dealing with 'partially engaged' diabetes patients, which includes the housebound, home care residents and other groups, is being developed. This will include the identification of all of these patients and a plan for delivering their annual review, at their care home or home (if they are housebound), which will be carried out by a trained diabetes specialist nurse or GP practice nurse.

**4. There used to be monthly appointments with a diabetes nurse and now it's annual. Will we be seen more regularly?**

Answer: Our aim is for a big step up in patient education so you feel more confident in self-managing your diabetes alongside a healthcare professional. GPs will provide most of the care (including the annual review of 8 care processes) and will make referrals, where required, to the diabetes specialist team. Once stable, patients will be discharged back to the care of their GP practice.

**5. A lot of elderly are afraid to go to the Doctors - how will our concerns be addressed?**

Answer: you are advised to speak to your Patient Engagement Forum at your GP Practice and give feedback about your concerns.

**6. What happens if a GP won't refer me?**

Answer: GPs will provide most of the care (including the annual review of 8 care processes) and will only make referrals, where they are required, to the diabetes specialist team. Once stable, patients will be discharged back to the care of their GP practice.

**7. How will the new service be different?**

Answer: More services e.g. the clinics run by the diabetes specialist team will be available in a local community setting, reducing the need for hospital visits. There is a single brand (NEEDS) and a coordinated approach to make the service easier to understand and access, with a single telephone number for booking appointments with the diabetes specialist team (on referral).

**8. Will there be another patient meeting (like this one) in six months?**

Answer: Yes - although the events will be in 12 months (rather than six) and will take place in local venues in February 2014, when a report on the progress and an opportunity to provide your feedback again, will be available.

**9. Will N.E. Essex GPs sign-up to deliver this service?**

Answer: Yes - we are in the process of signing individual contracts with each of the 43 local GP practices in North East Essex.

**10. Will the podiatry service stay the same?**

Answer: Yes it will. Podiatry is being delivered by ACE (Anglia Community Enterprise CIC) as part of the new service with clinics at community venues alongside the diabetes clinics wherever possible.

**COLCHESTER**

**11. Why wasn't everyone aware of these events?**

Answer: at the moment there is no single mailing list of all people with diabetes in N.E. Essex but as we proceed we hope to build awareness and a better list of our own. We were fortunate to be able to work with national charity Diabetes UK for the patient engagement events and they undertook a mailing for us to invite people to these events.

**12. Who will run the administration of the service?**

Answer: the referral booking service team is based at Suffolk GP Federation's headquarters in Ipswich.

**13. How will feedback from a patient be managed?**

Answer: All patient feedback will be captured and recorded – this may be from patient forums, focus groups, during attendance in clinics or via patient surveys. Where appropriate responses will be given directly to those giving the feedback e.g. if there is a patient complaint. Feedback from surveys will be collated and reviewed quarterly and any actions arising will be included in an action plan and

if appropriate the service development plan. Outputs will be available on the NEEDS website.

**14. What sort of changes am I going to see if at the moment I see a diabetic nurse annually?**

Answer: GPs will give an annual check of 8 care processes (retinal screening is separate). One of the aims is to ensure everyone has an annual check - currently only 58% do.

**15. Will there all of a sudden be a difference?**

Answer: it will be a gradual change as we will be working with GPs to upskill them]

**16. There was originally talk (reference the Bexley Service) of integrating everything in one clinic - has this happened?**

Answer: there are still some things outside of the model: retinal screening/ophthalmology, renal, prosthetics, in-patients - these are not part of the model at the moment. We will work closely with other services for onward referrals. We will also aim to do as much as possible for everyone in one visit.

**17. How are GPs locally going to respond?**

Answer: there has already been very positive engagement. Each GP practice is a business in its own right and we will work with them and incentivise them as much as possible. We are also working with GP Primary Choice (the local GP Federation) to help with the engagement of local GPs.

**18. Where is the boundary for North East Essex?**

Answer: the boundary is along the Tendring coastline and then follows the boundary with Suffolk out to Tiptree (but not Kelvedon) and includes Mersea, Brightlingsea, Wivenhoe. Sibble Heddingham comes under Mid-Essex. There are 5 Clinical Commissioning Groups in Essex, each of which are individual statutory bodies.

**19. How many community clinics will there be in the new service?**

Answer: there are three and the locations are in Colchester, the Clacton area and Harwich.

**20. Will the ratio of nurses improve?**

Answer: the ratio of the number of patient to staff will stay the same. The aim is to have shorter waiting times and more choices.

**21. Will there be insulin pump clinics?**

Answer: Insulin pumps will be managed by the Diabetes Specialist Team.

**22. How was patient feedback used?**

Answer: it was used in developing the specification for the new service. We are going to actively encourage ongoing patient feedback. The feedback from the patient engagement events, for example, is being incorporated into our plan.

**23. What process for using data are you going to use?**

Answer: System 1 will be used for patient administration.

**24. Is the disposal of needles going to be an ongoing issue, because only selected chemists will take them?**

Answer: whoever prescribed the needles should dispose of them for you or provide places for their disposal.

**25. How do you join Diabetes UK?**

[There is a voluntary donation - not a subscription fee - see [www.diabetes.org.uk](http://www.diabetes.org.uk)

**JAYWICK**

**26. Does the service include chiropody/podiatry?**

Answer: Yes. Podiatry is being delivered by ACE (Anglia Community Enterprise CIC) as part of the new service with clinics at community venues alongside the diabetes clinics wherever possible

**27. Will I see the same doctor or nurse?**

Answer: if most or all of your care is currently being provided by your local GP practice then you will continue to see your own GP or practice nurse, who will refer you to the diabetes specialist team only when you need additional care in managing your diabetes.

**28. Who is funding the service?**

Answer: this is a National Health Service (NHS (Government funded)) adult diabetes service commissioned by the North East Essex Clinical Commissioning Group and provided by Suffolk GP Federation.

**29. Does it include retinal?**

Answer: No, retinal screening is being provided by Health Intelligence and is outside of the NEEDS service.

**30. Will education courses continue?**

Answer: Yes, there will be a big increase in structured and informal education.

**31. Why can't Colchester provide laser eye treatment?**

Answer: Colchester does provide proliferative retinopathy. Corrective lens laser eye treatment is not currently available on the NHS.

## **HARWICH**

**32. I have my Type 1 annual check-up at Harwich hospital. Will that continue?**

Answer: Your appointment will be with the diabetes specialist team and this will most probably continue to take place at Harwich Community Hospital.

**33. Will doctors still give prescriptions for test strips?**

Answer: Doctors will continue to prescribe test strips where clinically appropriate.

**34. Will you arrange referrals for other needs?**

Answer: Yes, there will be a single point of access for all referrals.

**35. Are you doing anything on the education side?**

Answer: Yes, there will be a big step up in education.

**36. How have you advertised the meetings as I didn't hear about them?**

Answer: through a mailing to those people on the Diabetes UK charity mailing list, through posters in GP surgeries and other places and through press releases issued to local media. No single database exists with all patient names but this is something we are hoping to develop.

## **WALTON**

The Walton event had 5 attendees and there was a more informal format rather than a question and answer session.