Barnsley Diabetes Survey 2017
Engagement Report

1. Background

NHS Barnsley Clinical Commissioning Group (CCG) has the responsibility for the commissioning (planning and buying) of local healthcare services for the benefit of the people of Barnsley.

The future of health and care in Barnsley is to create a more joined up health and care system, where you experience continuity of care. This is particularly important for people living with diabetes, who see a wide range of healthcare teams.

We are re-procuring *two elements* of Diabetes services in Barnsley and have recently undertaken a dedicated engagement phase between July and August 2017 with clinicians, partner organisations, patients and the public in order to feedback on proposals, and inform the final version of the new service specification and subsequent re-procurement process.

What developments have taken place in relation to local Diabetes services so far?

There are lots of positive things that we have already been able to put in place. This year for example we have:

- Invested in identifying and supporting people at higher risk of developing Type 2 diabetes.
- Invested in the DAFNE education support for people living with Type 1 diabetes, which will be available in early 2018.
- The diabetes services are working with young people and their families to get the best outcomes from any move from children's to adult services.

What have people told us before this engagement phase?

Over the past 18 months, we've talked to people about how the diabetes services and support works for them and how these services could meet people's needs in the future.

There was lots of positive feedback but one of the main things people told us was that they were seeing lots of different teams. This could sometimes feel like they were in a pinball machine - moving from one doctor or nurse to another. Sometimes this meant repeating conversations but it could also mean repeating tests.

What are the proposals for change?

We want people living with diabetes, and their families, to feel supported and empowered, so that when they do need these services, it feels like “one team”, each delivering their part, without duplication and designed around the individual. We also want to make the most of the skills of all the different teams.

To make this way of working together better happen, a range of diabetes specialists such as consultants, specialist nurses, GPs, dietitians and podiatrists, along with us as commissioners, have developed a service specification that describes the aims, outcomes and proposed way diabetes services will run in the future. This was informed by feedback from people with diabetes.

We have also looked at what other areas of the country are doing to lead the way in this type of diabetes care and support.

To make sure that the services can meet people's needs now and into the future based on those issues we described, we are putting out a service specification to re-procure *two elements* of the Diabetes services in Barnsley.

These are:

- The Community Diabetes Specialist Nursing service for adults aged 17+
- Outpatient services at the hospital, for adults aged 17+ relating to their diabetes

What did we want to find out?

We were keen to understand first- hand experiences and views of local services and thoughts on the proposals from patients, carers, family members and clinicians with the aim to share a summary of the all the feedback with organisations wishing to bid to provide this service, in order to find an organisation best placed to meet the needs of Barnsley people.

This information will also be used to develop some quality standards, which will accompany the new contract.

This summary report details all of the collective feedback that we received as part of the above engagement exercise.

2. Acknowledgements

We would like to take this opportunity to express our gratitude and to sincerely thank all of the individuals and organisations who have taken the time to share their extremely valuable views and feedback regarding their experiences of both accessing, using and referring into Diabetes services in Barnsley.

We would also like to thank South West Yorkshire Partnership NHS Foundation Trust (SWYPFT) for their assistance in helping to develop the engagement resources.

We would also like to acknowledge the assistance received from our local partners working across health and care in Barnsley who provided their help in promoting the opportunity for local people to have their say.

3. Our engagement approach

We set out with the aim to carry out engagement activity that would;

- Obtain views and feedback from professionals, patients and carers from across Barnsley in relation to Diabetes Services with our overall aim being that this feedback will directly help shape quality related aspects of the new service specification and future re-procurement of the following two elements of local Diabetes Services; The Community Diabetes Specialist Nursing service for adults aged 17+ and Outpatient services at the hospital, for adults aged 17+ relating to their diabetes

- Act in accordance with the NHS Constitution and meet the statutory duty to engage in line with the Health and Social Care Act 2012 which introduced amendments to the NHS Act 2006 highlighting two specific legal duties which require CCGs and commissioners to enable:

  1) Patients and carers to participate in planning, managing and making decisions about their care and treatment, through the services they commission and

  2) The effective participation of the public in the commissioning process itself, so that services provided reflect the needs of local people.

In order to help us to achieve the above, a survey was designed and undertaken in order to obtain views from local patients and carers and clinicians on their experiences of accessing, using and referring into Diabetes services in Barnsley.

Input regarding the development of the surveys was sought and received from the current service provider, South West Yorkshire Partnership NHS Foundation Trust (SWYPFT).

Information and links to both surveys were posted online on the 'Get involved' section of the NHS Barnsley CCG website (www.barnsleyccg.nhs.uk) and also kindly circulated by local partners working across the health and social care economy. The patient and carer survey was also circulated, to members of the NHS Barnsley CCG Patient Council and to members of the OPEN (Our Public Engagement Network) Database. Paper copies were also available on request and respondents were also able to feedback over the telephone.

In addition to the above, we also held a joint informal patient, public and carer drop in session on Thursday 10th August between 2:30pm and 8pm at the Core, County Way, Barnsley in order to discuss this work and also similar work that is being undertaken (in relation to Community Based Musculoskeletal (MSK) Services and Pain Management) in further detail and gain additional feedback via the surveys. 13 people attended throughout the day.

Notification of the engagement phase and workshop was circulated to the local media and the opportunity for people to have their say was promoted on social media via the CCG Facebook and twitter pages on a regular basis throughout the engagement period.

We also set up a closed group on Facebook to run some group chats on these topics. People were encouraged to search for NHS Barnsley CCG, like and follow us, then join the relevant group.

4. Summary overview of the feedback received from the Survey

Overall we received responses from 28 respondents in total to the survey by the closing date of Monday 28th August 2017

A summary of the feedback we received can be found below. Please note that not everyone answered every question.

Q1) Which option best describes you?

- I have type 2 diabetes = 19 people (68%)
- I have type 1 diabetes = 3 people (11%)
- I don't know = 1 person (3%)
- I am part of the community diabetes team = 3 people (11%)
- Other = 2 people (7%) (Community Podiatrist)

Q2) How long have you, or the person you care for been living with diabetes?

- Less than six months = 1 person (4%)
- Between six month and two years = 2 people (7%)
- Between two and five years = 4 people (14%)
- Between five and ten years = 7 people (25%)
- More than ten years = 10 people (36%)
- Does not apply = 4 people (14%)

Q3) Which of the following do you use?

- Insulin by injection = 7 people (17%)
- Insulin by pump = 2 people (5%)
- Metformin (or other tablets) = 16 people (39%)
- Diet and Exercise = 10 people (24%)
- Does not apply = 4 people (10%)
- No response given = 2 people (5%)

Q4) Thinking about your diabetes care in the past 18 months, how many times have you seen or had contact with the following teams? (not including standard prescription ordering, flu jab, or eye screening)

OPTIONS	0	1	2	3	4	5-12	13+	Does not apply	No answer
• GP	4	9	4	1	1	1	0	5	3
• Practice Nurse	3	9	4	3	1	0	0	5	3
• Diabetes Specialist Nurse(booked appointment)	6	4	5	0	2	0	0	6	5
• Diabetes Specialist Nurse(drop in)	10	2	0	0	0	0	0	6	10
• Diabetes Specialist Nurse(telephone call)	11	2	0	0	0	0	0	6	9
• Consultant (outpatient appointment)	5	7	4	0	0	0	0	6	6

Q5) What works well and why?

23 responses to the above question
Themes included the following;

- Local GP/ specialist nurse appointments. (continuity of care which is local) x 8
- Annual reminders – bloods, review, screening x 3
- Eye screening picked up problems early
- Practice nurse appointments for foot checks, advice re weight mgt. x 3
- Consultant appointments – very approachable, knowledgeable x 2
- Community specialist diabetes team x 6
- Online ordering of prescriptions
- ***No idea what works well, more or less left to my own devices*** x 3
- Access to right appointments/ advice when I need them x 5
- Access to the Ophthalmic Service x 1
- Community based clinics and appointments x 3
- Single point of access x 2
- Praise for individual staff members x 4

Q6) What doesn't work well and how would you improve it?

21 responses to the above question

Themes included the following;

- Lack of continuity of care (different consultants) x 3
- Nothing x 4
- Cancellation of appointments often at late/ short notice and waiting times for new appointments x 7
- Access over phone to Diabetes reception x 2
- Be good to have access to telephone/ skype appointments x 2
- Sync all annual check appointments into one day x 2
- Lack of communication between different services involved in my care x 2
- Difficult to get hold of specialist nursing team x 1
- Lack of communication regarding my appointments/ treatment/ care x 7
- 'Feel forgotten' and lack of support x 6
- Difficult to get appointments with GP x 2
- More positive advice and respect from professionals x 2
- Lack of regular reviews x 6
- Disengaged with services due to feeling ignored x 2
- Lack of support/ information re: equipment/ treatment/ medication x 3
- Support for different types of diabetes care e.g. T1/ T2 x 3

Q7) Do all of the services available to you, meet your needs? Please tell us why/ why not.

20 responses to the above question

Themes included the following;

- Too long between appointments
- Having to go to hospital for short appointments (inconvenient) x 1
- Happy with current services x 1
- Improve communication with patients and between services x 2
- Stop cancelling appointments at short notice x 2
- A peer support group in Barnsley would be useful/ f2f and virtual/ patient forum x 5
- Options about my appointments/ treatment x 1
- Lack of patient involvement in my own care x 2
- Feel unsupported x 4
- Good services x 5
- MDT approach to care around patient rather than lots of separate appointments x 4
- Regular appointments/ follow ups/ reviews with GP's x 2
- Diabetes dietician very helpful and encouraging x 2
- Lack of options around time for education sessions x 2

Sometimes you may have appointments with more than one healthcare person at a time. A specialist nurse and a consultant, or specialist nurse and a dietitian for example.

Q8) Have you had any of these types of appointments over the past 18 months?

- Yes x 3 (11%)
- No x 19 (70%)
- Does not apply x 5 (19%)

Additional comments made in reference to the above;

- ***I saw a consultant following an early diagnosis of retinopathy and asked to see a dietitian as my HBA1c had increased and I have put on a weight this year despite exercising more. Excellent advice only required 3 meetings, 1 for initial assessment, 1 for review and a final check before discharge.***

- ***Appointments after each other would be good but not at same time if dietitian was involved - don't want to talk about non- food stuff with them.***

- ***I had prior to 18 months ago and I absolutely hated it, patients MUST to be given the option of who they want to see in a consultation, it should never be assumed, otherwise it risks breaching patient and legal rights involving issues of consent and confidentiality.***

- ***It is high time people with type 2 diabetes were treated as an individual. We are not all idle couch potatoes. I have always had lots of exercise, had a fairly standard diet of veg. fruit meat fish etc… No-one ever considers the impact of years of shift working; irregular meals and lack of sleep might have in developing type 2. If someone is diagnosed type 2 it is always considered that they have brought it on themselves by a poor lifestyle. I may have had a poor lifestyle because of the shift work that I have done over my working life…Please look at changing attitudes towards people with type 2 diabetes.***

- ***Am not a number on a page...I am a real person.***

- ***I have only ever seen consultant only. No MDT has ever been involved.***

- ***That is why I have asked to complete this survey***.

Q9) Is there anything else about your current experience of, or suggestions for, services you would like to add?

15 comments (some included in full below)

- ***I feel very strongly that any revised diabetes services need to move away from being completely hospital based, especially in view of policies implemented by the Department of Health to encourage more community care and to move away from hospital-centric care.***

  There does need to be closer co-operation between the community and hospital sides... I believe that it is also important that health inequalities across the Barnsley area are taken into account, especially the marked difference between the western more affluent side compared to areas of deprivation, especially in the Dearne valley.

  More engagement with GPs and upskilling of practice nurses within the primary care environment needs to be a priority ….

  Some patients get better seamless diabetes care than others depending on which practice they belong to. Ideally it would be better to have more clinics and education sessions outside of the typical working hours…

- ***Give individual patients a choice in their healthcare at all levels, don't assume public consultation will result in all patient opinion covering all people. Diabetes in all its forms is complex to treat and requires immense time and effort by the person with diabetes if alienated this will be highly likely to result in bad clinical outcomes for all involved.***

- ***As far as my care and that of my husband is concerned the service is excellent.***

- ***There needs to be more support regarding diet and a follow up, and a change in attitude. If a user is finding out for themselves what works, stop with the mantra about carbs, it's very demoralizing.***

- ***Genuinely thought diabetes treatment would be more proactive.***

- ***I used to be allowed test strips to monitor my glucose levels but these were stopped years ago. My glucose levels are well controlled down to my lifestyle and following the advice given by my diabetes nurse. I know someone who takes little exercise, is a drinker and likes chocolate but is still allowed test strips because he does not have good glucose control. I have occasional low glucose levels that leave me feeling drained all day but cannot test to check my glucose level. But again I worked; payed into a system and look after myself unfortunately I have a condition that is considered purely to be caused through bad diet and idleness. Being treated as an individual and not being generalised with a condition might just might lead to a better understanding of the true cause of type 2 diabetes. After completing this questionnaire I will be going on my bike for***

some more exercise, I have already walked one hour this morning

- ***I have had 3 appointment letters for the same appointment, 2 on the same date***
- ***Only appointments at hospital***
- ***It was very useful that my wife was allowed to attend the "education" classes. I might be the patient with diabetes, but my illness is a joint responsibility, especially as she is the main person who cooks prepares the food we eat.***
- ***I would like to see someone to check up on my tablets/injection condition***

Q10) What do you think to the proposals and why?

22 responses

Themes included the following;

- More community care beneficial x 3
- More specialised services welcomed but can they be sustained (funded) x 1
- More integrated working between specialists and primary care (MDT approach) x 3
- Priority to improve communication and reduce waiting times x 3
- Additional training needed for GPs (not specialists) x 3
- Need to ensure consistency of care and effective support for model x 4
- Prefer specialist support in community x 5
- Depends on getting support when required and an appointment x 4
- ***Why is eye care not included? x 2***
- Joint clinics in community with consultants and specialist nurses to support primary care x 4
- Concern over type 1 care and pump management being in hospital only due to lack of expertise x 1

Q11) Do you have any other suggestions about improving diabetes care, support and self-management?

17 responses provided

Themes included the following;

- Improve the quality of care in GP services for people with Diabetes x 1
- Increase education and resources for patients x 4
- More joint working between community diabetes team and mental health team x 2
- Need to ensure that the computer systems used are compatible between different organisations involved x 3
- Listen to staff who work in the services and engage with them effectively x 2

- Set up a local peer group in Barnsley e.g. with Diabetes UK x 4
- More investment and resources required e.g. More specialist diabetic clinics in the community x 4
- Increase education and training in GP practice regarding Diabetes x 3
- Effective partnership working between patients and clinicians x 3
- Increase range and flexibility of appointments available out of working hours etc. x 4
- Consistency of level of service needs to be monitored across GP practices in relation to Diabetes services x 2
- More holistic services and appointments x 3
- Include eye care x 2
- Improved joint working, integration and better communication between staff working across Diabetes services whether in community or hospital setting x 4
- ***"Don't mend it unless it's broken". Why would you need/want to change things if everything is working smoothly x 2***

Q12) Any further comments

12 comments received

Themes included the following;

- Gratitude expressed for care received from specialist staff since diagnosis x 2
- Invest in community based diabetes services x 4
- Engage with staff as well as patients on how the service could be run better x 3
- Concern expressed over suggestion of glucose testing being removed x 1
- Concern expressed over repeated cancelled appointments x 1
- Praise for members of staff and public involvement in the development of services, new specification and subgroup development x 1
- Concern expressed over changes impacting on positive work undertaken by current provider x 2

Q13) Did we provide enough information for you to be able to comment on the questions we asked?

Yes x 21 (75%)
No x 5 (25%)

Keep in touch

14 people provided their contact details and asked to be kept updated

Equality Monitoring Section

Age of respondents
25-34 x 1 (4%) 35-44 x 6 (21%) 45-54 x 6 (21%) 55-64 x 4 (14%) 65-74 x 8 (29%) 75 plus x 2 (7%) Prefer not to say x 1 (4%)

Postal code areas indicated
HD8, WF4, S35, S36, S70, S71, S72, S73, S74, S75

Gender
Male x 13 (46%) Female x 15 (54%)

Transgender - Do you live and work permanently in a gender other than the one you were born into?
Yes x 1 (4%) No x 25 (89%) Prefer not say x 2 (7%)

Ethnicity
White (UK) x 26 (93%) Prefer not say x 2 (7%)

Sexual Orientation
Gay x 1 (4%) Bisexual x 1 (4%) Heterosexual x 23 (82%) Prefer not to say x 3 (10%)

Religion
No religion x 11 (39%) Christian x 11 (39%) Buddhist x 1 (4%) Pagan x 2 (7%) Prefer not to say x 3 (11%)

Disability
I don't have a disability x 9 (36%) Mental Health x 5 (19%) Physical Impairment x 6 (15%) Long standing illness x 8 (30%)

Carer
Yes x 5 (19%) No x 18 (67%) Prefer not to say x 4 (14%)

5. Summary overview of the feedback received from the Facebook Group

During this engagement phase we also set up a closed group on Facebook to run some group chats on these topics.

People were encouraged to search for NHS Barnsley CCG, like and follow us, then join the relevant group.

We also conducted a mini campaign via Facebook between the dates of 15 and 22 August 2017. 9,381 people were reached and where 147 took action (like/dislike/share/comment) 134 of those directly clicked through to the online survey.

We received a number of comments unrelated to this work and they have been responded to separately.

Of the couple of comments we received in direct relation to this survey, the respondents highlighted that they were in favour of appointments where appropriate in the community where they could be seen by their GP (who they see more regularly) thus freeing up hospital appointments for people whose care is more complex.

6. Summary of the key themes from the collective feedback we have received

The key themes taken from this engagement are as follows:

- The feedback received during this engagement activity confirmed that the current service is valued and appreciated by many of the patients, carers and clinicians who have direct experience/ knowledge of the service (and who responded to the survey) and the following elements were particularly praised;

  ✓ Acknowledgment of improvements/ developments made in community diabetes services to date
  ✓ Patient centred and tailored care
  ✓ Professionalism and knowledge of a number of the staff working in the current services
  ✓ Clear advice and information for patients
  ✓ Continuity of care

- However there were also suggestions highlighted where improvements could be made mainly in relation to the following areas;

  × Access to timely assessment treatment and appointments with less cancellations
  × Communication with patients and between services/ teams
  × Frustration over waiting times
  × Referral processes and correct information
  × Wider range of services and appointments 'out of normal working hours'
  × Support, training and education for patients and professionals
  × Concern over developments/ improvements being lost in any changes
  × Concern that decisions already made

- The respondents to the survey were almost fairly split between male and female (46%/ 54%) with the majority being between the ages of 35 and 54 (42%).

- Over 80% of respondents stated their ethnicity as White British and their sexuality as Heterosexual.

- 19% of respondents identified themselves to be an unpaid Carer for a friend or family member.

7. Next Steps

This engagement process has provided a brief snapshot of the views and experiences from a number of patients, carers, clinicians and other stakeholders regarding Diabetes services locally.

The collective feedback that we have gained as a result of this engagement will help us understand more about how Diabetes services work now - what respondents think works well and what doesn't in relation to the those points we described in the introduction to this report.

We will share the themes from the feedback with the organisations wishing to bid for this service, in order to find a provider best placed to meet the needs of Barnsley people and in line with the national guidance. We will also use this information to develop quality standards. This will only be done in ways that ensure that no individuals can be identified.

A further report will be compiled within the next few months in order to highlight how the feedback gained as part of the engagement process has shaped the specification and outcome of the re-procurement of the following two elements of local Diabetes services in Barnsley;

- The Community Diabetes Specialist Nursing service for adults aged 17+
- Outpatient services at the hospital, for adults aged 17+ relating to their diabetes

As a direct result of the above engagement we have already recruited two patient representatives to be involved in the procurement panel for the re-procurement of the two elements of local Diabetes services highlighted. Their role will be to help to set the relevant questions for potential bidders of this service relating specifically to accessibility and patient involvement and they will also help to score these questions in order to help determine the successful bidder to provide these services going forward.

The content from this report will be made publically available and feedback provided to those respondents who have requested it.

Again we would like to reiterate our thanks to all respondents who have given their time to share their views to help inform this process and to all partners who have helped us to gain their feedback.

V2 – 22/09/17