

# Meet the changemakers... and get involved

## Diabetes

### Questions and answers

Tuesday 13 March 2018 18.00-20.30

Jurys Inn, Wellesley Road, Croydon

In association with



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**Prad Solanki, Clinical Lead, Diabetes, Croydon Health Services NHS Trust**

## Session 1

**Ros:** Deborah and Prad will talk about the model and I'm here as the facilitator.

**Deborah:** So, what we've got here in this info graphics is some of the data about diabetes in Croydon. Over 22,000 in Croydon now have a diagnosis of diabetes. There are 10,000 estimated to have undiagnosed diabetes in Croydon. In the next 20 years, at least 45,000 people in Croydon will have diabetes. That will be more if obesity levels rise at the current rates. If we don't design services to focus on prevention of diabetes or early diagnosis, as well as helping people to look after themselves to manage their diabetes, the consequences will not be very nice. Diabetes is the leading cause of sight loss. We know it's one of the leading causes of stroke and renal failure. We don't want that happening to people. We're working together with prevention care, so building on some of things you've heard about this evening that are going on in Croydon. We recognise that together we can do this. The health service can't do this on their own. It's about making the services for diabetes a bit less fragmented than they are at the moment, so it feels more joined up. So, you don't have to navigate yourselves around the system. The main thing today is to listen to your ideas and experiences, so we can get this right.

**Prad:** If I said 'Beckham boot' what would you say?

**Croydon resident 1:** Football.

**Prad:** The metatarsal. Diabetes is the leading cause of lower limb amputation in the world. Diabetes, smoking and obesity don't mix. Limbs are at risk. If limbs are at risk, lives are at risk. A person with a foot ulcer, their five-year mortality is higher than someone with cancer. The length of stay for someone in hospital with diabetes is longer than other people. If you have a foot ulcer and diabetes you will be in hospital longer. In the UK, we spend £750 million to £1.2 billion a year on lower limb foot care. Croydon has the oldest population for a London borough. When you see children who are obese, it's a time bomb. These people are patients for life. Modern medicine is brilliant, but we need to better our health now. In America, it's crippling their health system. In the UK, it's getting that way. That doesn't count the social costs, such as being wheelchair-bound, and needing work in your house. If you lose both limbs, you need a bungalow, you need your kitchen lowered. The antibiotic time bomb is about to go off where we don't have suitable antibiotics for what we're treating. If we can catch ulcers and treat foot patients, the amount of people in hospital will be lower.

**Croydon resident 1:** I'm an ex-school governor and I wasn't aware of the diabetes problem with young children. It was never on the agenda, but I now understand it's on the agenda.

**Prad:** It's on the agenda, it's a time bomb.

**Croydon resident 1:** It's for head teachers to give to governors to say what the schools are doing.

**Prad:** That's a good idea.

**Croydon resident 1:** I'm diabetic. I suffer from foot problems. I have to put my feet into a bowl of cold water to calm down the nerve endings so I can try and get a good night's sleep. I don't want to have my feet off. I try to protect my feet.

**Prad:** Foot care, it's a team game. No one person does it all. I don't do it by myself. There is the vascular team, the GP. You have to be re-assessed.

**Croydon resident 1:** Can you take my name and speak to me outside.

**Croydon resident 2:** You always talk about prevention, but where are the resources. I've been a diabetic type 1 for 37 years. I was referred to a foot person to look after hard skin. It was 2 years ago and I'm still waiting for the appointment, I was told nearly 3 months. I've never rung them to enquire, as I get fed up with being told there are people more in need than others.

**Prad:** Just get your GP to re-refer you.

**Croydon resident 2:** You need to put resources into preventing.

**Prad:** Can I talk about resources? In 2016, the government in December said in London there is £8 million up for diabetes. Now credit to my vascular consultant, she worked over Christmas to do this. We're now employing a podiatrist in Croydon to reduce our waiting list. I'm sorry you haven't got your appointment.

**Croydon resident 2:** I go to a nail shop.

**Prad:** Don't do that. Get a referral.

**Croydon resident 3:** My GP is great, but they don't do foot care. I didn't know there was a podiatrist.

**Croydon resident 4:** He checks the foot, the blood pressure, all the things, it's satisfactory.

**Croydon resident 5:** The diabetic nurse isn't looking for pre-existing conditions. Calluses and corns can be as bad as anything else.

**Ros:** Are you at the same practice?

**Croydon resident 5:** No.

**Ros:** There is a lot of variation in Croydon.

**Croydon resident 4:** We do have a diabetic nurse who is employed by the Bromley.

**Deborah:** We are continuing this for another year, it will run until the end of April 2019. One of the things that myself and Prad are doing is we're working together on the specification and what it looks like for an integrated service. So, it looks at what Bromley does. It helps to enable the integration, so we can get more consistency. We're working with the GP practices and networks to think with them about which practices want to take the lead on diabetes. They may not all have the staff, but together, they may think that together, three out of six practices want to do that to make sure you get the care in the local area.

**Croydon resident 6:** What are you doing to think about prevention of issues in the long term? Particularly I'm thinking with technology. Graham has got it.

**Croydon resident 7:** I don't take blood well from my fingers. I went to FreeStyle Libre last year, the first time I had control. I have a sensor in my arm that works for 2 weeks, I go like that and it give me my blood reading. It does a graph and it takes the trends over 7, 30 and 90 days. You can feel it.

**Croydon resident 4:** Does it go into you?

**Croydon resident 7:** (Shows the group his arm). It's not on the NHS, but it's up to each individual CCG.

**Prad:** Can I take a photo? It's my work phone.

**Croydon resident 7:** For me it's been invaluable. It will prevent all these things in the future. There is the initial cost.

**Deborah:** It was put in the drug tariff in November. We have been working quite furiously across London with the London procurement partnership to work out commissioning criteria. I think it was going to the committee this week. I can update you this week.

**Croydon resident 7:** It takes away the painful finger pricking.

**Ros:** It's like a self check out.

**Croydon resident 1:** What kind of reading does it give?

**Croydon resident 2:** How do you put it on?

**Croydon resident 7:** It's got a tiny wire, like a needle. I hate needles, I don't even feel it.

**Croydon resident 4:** Do you take it off in the shower?

**Croydon resident 7:** Yes.

**Croydon resident 2:** The whole system broke down when it went from Croydon to the Bromley. Bromley took about 6 months to get it up to speed. Will it happen next time?

**Deborah:** We're conscious of that and we're thinking and planning about it now. One of the things that we are doing is thinking about better relationships between the different commissioned providers and services. Sometimes it's about knowing someone and picking up the phone with them. We're having a clinical forum, with lots of people from the GPs and hospitals to think about building those relationships. Then when it comes to the service translation, if it's the same people, people will still know each other as people have been talking together. We hope it will be more smooth.

**Croydon resident 2:** There are a lot of people that haven't been diagnosed formally. When they are diagnosed it's essential to get them educated quickly. I've got the materials that go with Expert, it's infinitely better than the Desmond stuff.

**Deborah:** We will look at that as the Diabetes education will be in the remit of the procurement.

**Croydon resident 2:** If you don't get these people educated quickly. You will have problems quickly.

**Deborah:** An aspiration is to have broader options, so there are things you can do on apps on phones and backing up with calls from dieticians, that might not suit everyone. You can take photos of your food and then they call you with feedback. That could be something that could be effective. There is research looking at how effective it is. So hopefully there will be something to suit everyone.

**Ros:** Is there anyone who needs to say something before they go?

**Croydon resident 1:** I've given him my email address.

**Ros:** If you want to be in touch with the CCG we need your details.

## Session 2

**Ros:** I'm the facilitator. Deborah is the commissioner and Prad is the podiatrist. They are going to talk and then it's over to you for questions, comments and thoughts.

**Deborah:** We've been looking at some of the data with diabetes care in Croydon and we've been coming to events like this that tells us what it feels like. What we know is 22,000 people in Croydon are diagnosed with diabetes. Another 10,000 are undiagnosed, that figure will jump to 45,000 people in the borough with diabetes in next 20 years. If we don't help people to stay well and encourage them to get that diagnosis early and to look after themselves, some of the complications can be very serious and we want to prevent that from happening. Diabetic retinopathy is the leading cause of sight loss. Prad will talk about ulcers and amputations. There is scope in Croydon to reduce the amount of heart attacks and strokes. The health service can't do this alone. It's helping people like you to get this right first time. We're working across the system, myself from the CCG, Prad and his colleagues at the hospitals and the primary care sector. We're looking at making things less fragmented. We want to make education easier to access with a wider range of options. Some people may prefer to do something online. As we were saying in the last group, helping people at diagnosis or pre-diagnosis so we can prevent some of those complications, we can help people to stay well.

**Croydon resident 8:** Do you do any awareness in schools?

**Deborah:** This comes up a lot. I've recently been talking to colleagues in the local authority about this, people who look after the child's healthy weight strategy. It would be good to talk to teachers and others so they can understand how important it is to keep healthy. So for those who have diabetes or have family member with diabetes, so we can help people. There was a lady who recently lost her father who had foot ulcers, she said, 'If I'd known he couldn't go into the garden in slippers, I would have done something.'

**Croydon resident 8:** In national eye health week, do you tag along with national campaigns?

**Ros:** We do. A lot of it is tweeting, sending messages and quite often it will say, 'If you want to have your eyes checked,' or whatever, 'Then contact your GP.' Information is put out about the different weeks. We could do more, we can always do more. We're happy to be told what we're doing wrong and what we could do right.

**Prad:** If I say 'Beckham boot', what does that mean?

**Croydon resident 10:** The football player.

**Croydon resident 11:** He broke a metatarsal.

**Croydon resident 10:** We found out what a metatarsal is.

**Prad:** Foot care is a team game, it's not just the podiatrist, it's the person combined with everyone they see. Diabetes is the biggest cause of lower limb amputation in Europe, more than shark attacks, industrial accidents, car accidents etc. Sue Townsend, the author Adrian Mole, she lost her sight to diabetes. The length of stay with people in hospital with foot ulcers is longer. If you have a foot ulcer, your life outcome is worse than some cancers. Up to 75% will die in 5 years. The outcome is worse than HIV/Aids, cervical cancer or prostate cancer. If we can educate earlier, it can help. In Scotland, they looked at those people and changed their care and treated them and the quality of life improved dramatically. It's a team game. It's working with the resources you have. In the UK we spend between £750 million - £1.2 billion a year on lower limb diabetes care. That doesn't include the social costs. It doesn't include the changing of your house, changing doorways if you've lost a leg. If you lose two limbs it doesn't include changing to a bungalow, moving your kitchen, changing from working to non-working. We need to catch and educate people about looking at their feet. Men are the worst affected.

**Croydon resident 12:** A friend of mine, he had problem with his toe and had it amputated. I had a text this morning saying he had 8 hours in hospital to have antibiotics pumped into him to have his wound opened as it's not healing.

**Croydon resident 10:** A friend had an amputation, it went up and up and she died in the end. When we did the interim views at the care homes, in the last few months, I've been asking if the people are getting a podiatrist at these homes. I'm actually thinking that this is down the low end of the list, looking after their feet. I'm getting old and a year ago I managed. I was in the GP surgery, the symptoms came out that I had a sepsis. It was due to getting a sting on the ankle that's only gone away this year. So I know that infections at the lower end of the body are lethal. The other thing is my dad was type 1 diabetic for 50 years, I can tell you about that.

**Croydon resident 8:** What about people who can't see their feet?

**Prad:** If people go to their GP for a referral. We have people who have poor sight that can do their foot care and then those who can't.

**Croydon resident 8:** Do they get it on a regular basis?

**Prad:** Yes. Depending on the care plan some come every four weeks or every four months. They're re-assessed to be looking at their feet. We would like people with diabetes to look at their feet as well. If you're isolated you need to know who to go to. Corns, calluses, bad shoes, these are the essential basics that need to be stamped out.

**Croydon resident 13:** How will you communicate this? Is there a way of accessing the information?

**Prad:** Diabetes UK website.

**Croydon resident 8:** Diabetes UK don't have it in an accessible format. There is a leaflet on foot care.

**Ros:** If you're visually impaired, you won't see it. They are accommodating.

**Deborah:** We're working with the local branch and the London team.

**Croydon resident 8:** I went to the Wimbledon meeting and that's when I asked. Another thing that would be good would be to send information to the talking news.

**Prad:** When you go to your GP practice, they're paid to do it. If they're not looking at your feet, tell them to, it's really important.

**Ros:** Who gets their feet looked at?

**Croydon resident 12:** I do.

**Croydon resident 14:** It's what they're looking for, they didn't look at calluses and corns.



**Croydon resident 15:** We were talking about when people have been diagnosed, how they get taught about the different aspects. About 20 years ago, all I had was a 2-hour talk and it gave me enough confidence that I've not been to a course since. These courses where you get 12 people talking for a week, there are too many people to tell. To have the resources tied up for 12 people, I don't think that's where we should be going. Maybe half a day or 1 day.

**Ros:** Deborah was saying different people need different things.

**Deborah:** DAFNE is the education for people with type 1 diabetes, that's 5 days.

**Croydon resident 8:** Is there a diabetic group that meets in Croydon?

**Ros:** This gentleman belongs to it.

**Croydon resident 16:** I should have brought my leaflets with you.

**Croydon resident 11:** Where are the DESMOND courses held, are they in practice?

**Deborah:** We'd like to see DESMOND, if not then, in community settings, maybe in different languages, to make sure it looks at different diets. Now it's in 2 GP practices, but I'm going to confirm that.

**Croydon resident 14:** I think it's Parchmore and Selsdon Park.

**Croydon resident 11:** I find Diabetes UK on diet information very useful.

**Croydon resident 12:** What are the signs of diabetes?

**Croydon resident 14:** You pee a lot.

**Prad:** You can be a type 2 diabetic for 10 years before you know about when you have a heart attack. I kid you not. So the work that Deborah is doing around pre-diabetes is really important. Some of the symptoms, blurry vision, feeling sleepy after a meal, you can get an itch between your toes, groin, arm pits, then you can get skin rashes, dry skin, loss of libido.

**Croydon resident 10:** I lost that years ago!

## Session 3

**Ros:** I'm the facilitator. Deborah is the commissioner and Prad is the podiatrist. They are going to talk and then it's over to you for questions, comments and thoughts.

**Deborah:** I would like to hear what's going well in diabetes care and what your thoughts on how we can make sure we commission a service that's integrated and also focuses on preventing diabetes and in reducing complications from Diabetes.

**Prad:** Foot care is important, if I say 'Beckham boot', what does that mean? David Beckham, he broke his metatarsal, Rooney did the same thing but 'Rooney boot' doesn't sound as good. Foot care is a team thing, all the patient healthcare, and people you are in contact with, it should encourage people to make sure they know what good foot care is. People need their feet looking at if they have diabetes. Diabetes is the biggest cause of lower limb amputation, we spend £750 million to £1.2 billion a year on lower limb care in England and Wales. We could prevent lower limb amputation. Essential basic foot care is really important. Corns, calluses, bad shoes, they are the precursor to the break in the skin, the foot ulcer. That's how it starts.

**Ros:** Any questions, thoughts or experiences?

**Croydon resident 17:** I'm a director of a charity in Croydon with elderly people and the issue of diabetes is an issue. They go to a workshop and hear about it, and they don't do anything about it. We have people from the Asian community who when their children move away, they stop taking their medication. I don't think there's much point in translating in many many languages, they don't get read. It should be a one-to-one basis. We can have that conversation in a one-to-one. For an organisation like us, it's about being linked to more so we can refer on if we need to and we can have that information so people that can read the information. We have mentors we work with and someone may need someone to go along with people to the doctor. Elderly people say, 'We don't go to the doctor as we don't want to worry them as they're busy.' I see suffering in silence. So I think the voluntary sector has a role to play. There is a misnomer that all elderly people go to Age UK, Age UK is great, but it only goes so far.

**Deborah:** Absolutely, we recognise the health service can't solve this alone. We're looking at the diabetes mentor programme based on something they do in North West London.

**Croydon resident 17:** Diabetes UK did work in Croydon a few years ago but it didn't work out with people volunteering. I think the idea of health activities and health champions who are non-professionals and can do in house training over a cup of tea or coffee is good. It's important as they won't go along to something wherever it's held.

**Deborah:** We're looking to resurrect the champions

**Croydon resident 19:** I was a champion.

**Deborah:** It could help us with community screening.

**Ros:** We could contact you via Healthwatch.

**Croydon resident 20:** My observation is that what you're saying ties in with the other table we were on, but I'm very struck by the way you describe the matters of being the same as the One Care Alliance, it could be a way you deal with people with diabetes.

**Deborah:** We're looking to try and complement and learn from what they're doing. For example, whether we could get a diabetes nurse to come to the meetings. So if we can get the specialist help supporting the GPs and the other coordinators, it helps them to understand and manage diabetes.

**Croydon resident 19:** Looking at preventative things, I'm known in this borough, but the thing that is highlighted from my move from Lewisham, the amount of people that come under your umbrella (points at Croydon resident 17). He works with volunteers, what I'm saying is the amount of people we meet together, we have places at the tables, we do jewellery making, it's using people's brains again, instead of having dementia.

**Croydon resident 17:** It's also the tools of getting the message across in a non-scary way.

**Ros:** It's more of a discussion.

**Croydon resident 17:** We would love everyone to go their GP but they won't, so we need to find other ways.

**Deborah:** Looking at social prescribing, so things like exercise classes and cooking classes.

**Croydon resident 21:** I was wondering about communities, for people who don't speak English as a first language, if you get that person involved and get them to take it back to the community.

**Deborah:** We're looking to do that with the mentors and looking at other boroughs, like Tower Hamlets, who have peer educators. They work with everyone and feed it back and can educate in the community.

**Croydon resident 21:** How can I be aware of that?

**Deborah:** Give me your contact details.

**Croydon resident 19:** It's very good people are talking.