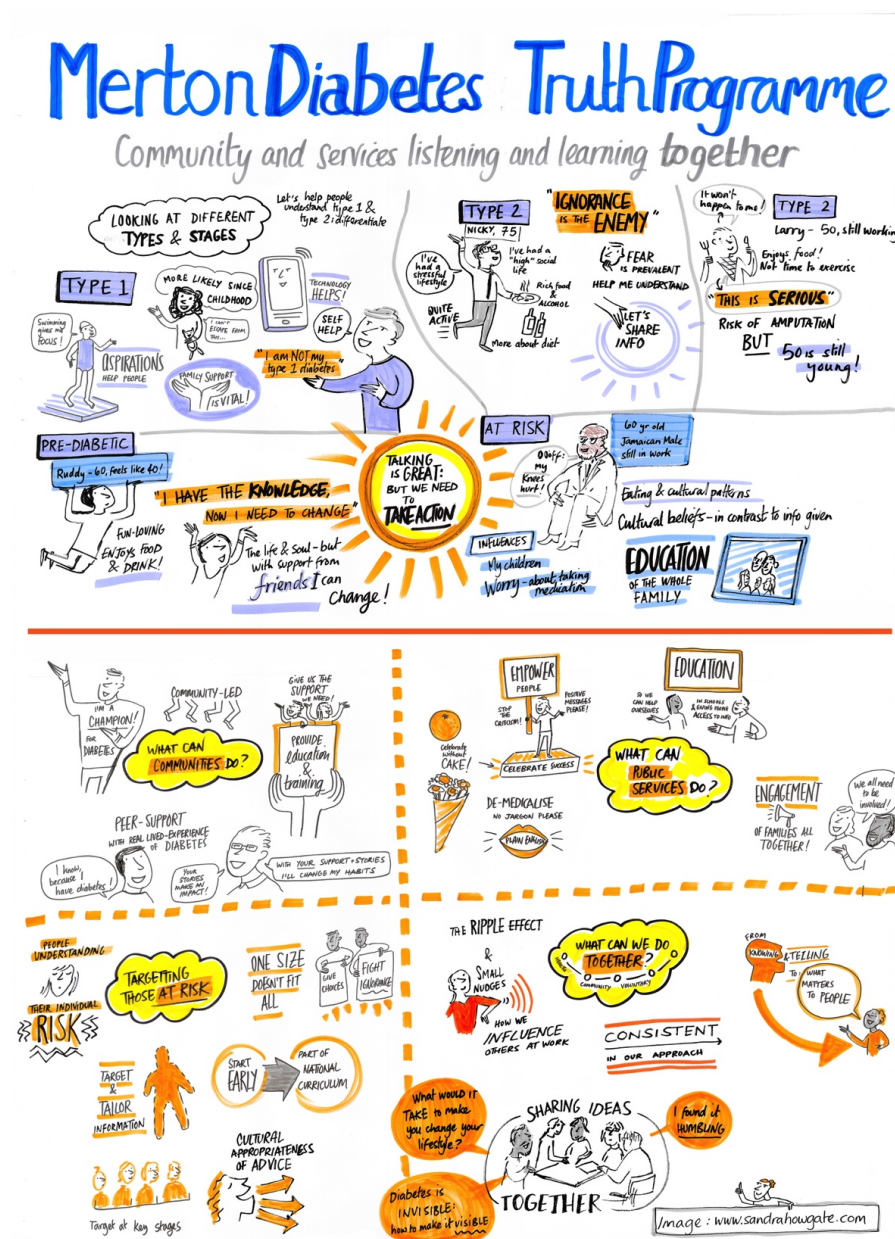


# Merton Health and Wellbeing Board and Expert Witnesses listening and learning together about diabetes



January - March 2018

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# Foreword

In 2017, members of the Merton Health and Wellbeing Board connected with the many communities in east Merton through a series of community conversations. The purpose of these was to find out how people wanted to develop the Wilson Campus and other health and wellbeing services in the east of the borough, ensuring that the services we provide are co-designed by the people who will be using them.



We were both moved and inspired by what we heard, so much so that when we made tackling diabetes a priority late last year, we decided to start by listening to the voices of Expert Witnesses from right across the borough - people with Type 1 or Type 2 diabetes, people diagnosed as a pre-diabetic, at risk of developing diabetes, and people caring for someone with diabetes. We have called this the 'Diabetes Truth Programme' because, quite simply, we wanted to deepen our understanding about diabetes by hearing people's stories; surfacing some of the root causes; identifying some of the barriers and influencers of change; thinking about the support needed to prevent diabetes; finding out how best to support those living with it; and ultimately identifying ways people can support themselves.

As Health and Wellbeing Board members we came to these conversations as people who genuinely wanted to listen to the experience of people who understand and have experienced diabetes first hand. We know we cannot find solutions on our own, and the content and ideas within this document have been greatly enriched by the experience of all of our Expert Witnesses. This write up of our work together is just the start. We now have to work together to tackle some of the issues that have been raised. We hope to use our shared ideas to build a sustainable approach to diabetes in Merton and beyond.

I would like to thank the Leadership Centre which has provided the funding for this work, and Mari Davis who has guided us through it. I would also like to thank Dr Dagmar Zeuner, the Director of Public Health, and her team, as well as all of the other board members past and present who have contributed to this process. Most of all, I want to thank our Expert Witnesses for their time, energy, ideas, enthusiasm, comments, and for sharing their hopes and fears. I hope that they will recognise some of the content within this document and look forward to working together as we begin to implement the ideas we developed.

Councillor Tobin Byers  
**Chair of Merton Health and Wellbeing Board**

# Summary

## – Diabetes truth programme

### What did we do?

Each Health and Wellbeing Board member paired up with an expert witness, a 'buddy' who was living with, at risk of, or caring for someone with Type 1 or Type 2 diabetes. We had conversations together and then shared what we had found out at a workshop.

### Why did we do this?

We chose the complex problem of diabetes as an exemplar; to find out the true day-to-day issues and choices that people living with diabetes face and to see how we as a Health and Wellbeing Board can work with our community to help identify solutions, rather than impose preconceived ideas.

### What did we find out?

- Type 1 diabetes is really different to Type 2 and when focussing on 'diabetes' we need to be clear on this.
- Type 1 and Type 2 diabetes are not just physical illnesses; they also require a focus on emotional and mental health resilience and support.
- We need to communicate and educate better about food and recognise that our food choices are often influenced by factors in our environment such as advertising and availability of fast food.
- There is plenty of information out there about diabetes but people do not always engage with it. We need to work on this – making better connections between those who produce the information and those who need to use it.
- Physical activity is important to help prevent and manage Type 2 diabetes. It can bring people together, which can help with adherence but it can be difficult to make the time. We need to promote the assets we have such as parks and open spaces and include activity in our every day lives.
- Peer and community support has a huge role to play; we need to learn from those who have experience, face to face and on line.
- Pressures relating to lifestyle, working hours and lack of sleep mean that just knowing the causes and risks of diabetes, is not enough to change behaviour. Instead healthier choices need to become easier choices through the right cues and support in our environment and everyday life.

## What will we do next?

Whilst some of the findings of this report are specific to diabetes, by exploring our approaches to this complex challenge we have created a new way of working as a Health and Wellbeing Board which we can use when addressing other conditions and wider work. This includes:

- Merton Health and Wellbeing Strategy, which sets the overall ambition for health and wellbeing in Merton, is being refreshed this year. The learning from the Diabetes Truth conversations will help to inform this Strategy and to shape the way we and our partners engage with our community.
- We are now working as partners on an action plan to tackle diabetes. The Diabetes Framework will be informed by the Diabetes Truth conversations, be based on a joint approach across all our partners and will be launched later this year.

The conversations have also helped mobilise our community and some of the expert witnesses have already expressed an interest in becoming health champions and working together with us to tackle diabetes.

# Tackling diabetes in Merton together

The facts around diabetes are stark in Merton and the causes are complex. We worked together as public services, with people and communities, to try to tackle this.



The Diabetes Truth Programme has helped us as a Health and Wellbeing Board build relationships with our community and develop a new approach to our ways of working.

## The facts about diabetes speak for themselves

- Type 2 diabetes affects 3.8 million people in England, with a further 5 million at high risk.
- The condition gives rise to complications such as cardiovascular disease, blindness, kidney failure and amputations.
- It accounts for 9% of the annual NHS budget.
- 6.1% of adults in Merton were diagnosed with Type 1 and Type 2 diabetes in 2016/17, almost 10,950 people.
- By 2020 that number is projected to rise to almost 12,550.

Type 2 diabetes is an issue where traditional medical models have been unable to curb the rise in

cases, serious complications and spiralling costs. The impact of Type 2 is falling particularly heavily on specific ethnic groups and people living in some of our more deprived communities.

In the autumn of 2017 we as a Health and Wellbeing Board agreed an approach to tackle diabetes. In setting out this approach we considered that where standard complicated problems require expert analysis and a logical choice of solutions, truly complex problems, such as tackling diabetes, need more experimental approaches.

Using the Diabetes Truth conversations as an exemplar we can now start to apply our learning to other long term conditions and health and care issues; adopting an iterative development of plans rather than a more straightforward clinical approach. The Diabetes Truth Programme is the start of developing this new approach in Merton.



# Developing the Diabetes Truth Programme

**Our approach was to pair a Health and Wellbeing Board member with an Expert Witness – someone with a lived experience of Type 1 or 2 diabetes and then to have conversations about what mattered to us. No more complicated than that.**

## **Health and Wellbeing Board 28<sup>th</sup> November 2017**

We agreed as a Board that tackling diabetes was a priority. We worked through the facts and figures and what we knew about effective services as our evidence base. We began conversations about how we might approach this differently and really understand what the lived experience of diabetes was and then base next steps and actions around this. We used each other's contacts and our teams to find people who might be willing to get involved.

## **Planning with Expert Witnesses 16<sup>th</sup> January 2018**

We met with our Expert Witnesses to explain the thinking behind the programme, hear people's stories and begin to plan what might be possible together. Hearing stories was very powerful right from the start. Two hours of just listening intently.

## **Workshop 1 30<sup>th</sup> January 2018**

Health and Wellbeing Board members and Expert Witnesses met for the first time. Each shared their

story in a group about why diabetes mattered to them. We paired up as 'buddies' and agreed when to meet each other. See appendix 1 for a list of who paired with who.

## **Expert Witnesses meet their HWBB buddies**

We met our buddies a couple of times between January 30<sup>th</sup> and March 25<sup>th</sup> in an open place and had focussed conversations.

We wrote, drew and recorded in our journals over the two months as a record of our thinking.

We had a crib sheet of ideas and questions in case we were stuck for words. Actually we weren't! The focus of our conversation was:

- Asking focussed questions
- Hearing each others stories

See appendix 2 for these questions.



## **Workshop 2 27<sup>th</sup> March 2018**

We came back together again as Expert Witnesses and Board members to review our conversations and learning. We used our shared buddy conversations to create typical diabetic characters and looked at what life was like for them. We then action planned what we could do together.

# Expert Witnesses' Stories

**Our Expert Witnesses' stories speak for themselves. It was very humbling to listen to such inspiring people. Some have generously agreed to share their stories here too.**

## Angie Martin's story

It was Easter 1993. I spent a week lying around drinking Lucozade, eating chocolate (lots of it) and rapidly losing weight. I went to see my GP and was immediately referred to the hospital. I was instantly diagnosed with Insulin Dependent Diabetes (IDD) and my life changed forever! But not in the way I thought?

I spent some time in shock – more so as there was no history of diabetes in my family, Type 1 or Type 2. I was afraid. Where had it come from? Why me? How would I cope with all those injections? What would happen to me now? A period of adjustment and intensive learning followed. The learning actually never stops as medicine advances so rapidly but the most important lesson I learnt is to manage the diabetes not let it manage you.

The biggest change was subsequently losing my job in the City – related to a huge lack of understanding about diabetes (and legislation) back then. However, this presented me with a huge opportunity and led to me going to University and ultimately the job I have now, which I have loved for the last 17 years.

So you could say it was one of the best things that ever happened to me. Twenty five years on, I have still done all the things I have wanted to; going to University, sports and activities, travelling the world and following my dreams.

## Annette Wiles' story



I'm Mum to Sam now aged 14 who was diagnosed with Type 1 Diabetes aged 9. I've always thought it was lucky that his symptoms came to the fore during half term when I was with him more. It meant that he wasn't as ill as he might have been at diagnosis and we only spent three days in hospital where they literally taught us how to keep him alive. Since then we've been on the diabetes rollercoaster, battling high and low blood glucose readings as we've learnt about the multitude of factors that can have an impact; obviously what he eats but also how much he exercises, how hot it is, whether or not he is anxious, if he is ill etc. Type 1 is an autoimmune disease where the



body produces no insulin at all. Sam can eat what he wants but we have to know exactly how much carbohydrate he consumes so we can give him insulin to match. Our life is full of maths! There are no hard and fast rules with how much insulin he needs. We've had to learn this by experience and sometimes we've got it very wrong. Parents with a Type 1 child live with a huge responsibility. We still get up every night to make sure he's okay as we won't let him go overnight without checking his blood glucose. Giving him his independence now as he gets older is difficult and something we work on constantly. Like lots of kids with Type 1, Sam has another autoimmune disease which causes him to have an underactive thyroid (more drugs) and he was born with a genetic condition that can affect his mobility. However, he is a big, tough kid who is currently seeking national qualification with his swimming. To look at him, you'd never know that he is battling with three life changing conditions daily. Like every Type 1 parent, I'd do anything to take away this burden from him.

### David Chung's story

Paradigm shift: The guiding principle regarding my health and wellbeing moves away from the medical model which is in the control of the medical staff and towards my control.

On reflection it is regrettable that action was not taken at the pre-diabetic stage of my diabetes. I could have started to treat my diabetes. This should be implemented for all diabetic

individuals. I would propose that a consultation takes place with a member of the medical team. It has taken a while but I am now engaging in life style changes which should impact positively on my diabetes. This includes: at the personal level: sleep (Why We Sleep – Matthew Walker); diet; exercise, including swimming; and, meditation to refine my self control. This is the most demanding aspect of my action plan for addressing my diabetes. It requires a high degree of self discipline. I must not punish myself when I don't get it right but keep on working toward my goal.

At the group level: joining a diabetic group which I see as very beneficial in terms of knowledge and support [www.diabetes.co.uk](http://www.diabetes.co.uk)

Support from family and friends

At the level of organisation:

participating where possible in groups dealing with diabetes at the strategic level.

I do believe that with my strategy I could control my diabetes and possibly reverse it.

Thanks to the Diabetes Truth Programme.



## Joan Henry's story



I am not diabetic myself but really wanted to get involved with this programme so I can work with my communities as a local Councillor and also my church so that I can ensure people have all the information they need to prevent the onset of diabetes. My father was diagnosed with diabetes at the age of 77. He is now 89. He had a very sudden onset of confusion and was found to be diabetic. I had to learn a lot very quickly and was his carer for many years. A lot of the information out there was very confusing. He has now returned to the Caribbean and is doing just fine. We will all be getting together as a family this year, which will be amazing. My dad will be with us. I am concerned I may be at increased risk myself due to my family history and so I do take regular check ups.

## Nicky Winter's story



I am now in my eighties and was diagnosed with Type 2 diabetes 10 years ago after suffering a fall and having a blood test.

I was commissioned in the Life Guards during the Suez crisis in 1956 and saw active service fighting terrorists in Cyprus in the same year and because of this experience in the Army suffered from what is now recognised as PTSD. I treated this with alcohol for many years becoming a full blown alcoholic. Champagne and Guinness, black velvet, earned me the nickname of "Champagne Nicky."

25 years ago, given just 6 months to live, I stopped drinking on August Bank Holiday and have not had a drink since. The drinking may or may not have been the cause of my eventual problem with diabetes - a still unanswered question.

I am using my own experience to help ex-military Veterans with mental health issues, in particular alcoholism to get back into a meaningful life style and maintain long term sobriety, by sharing the help and advice that gave me the support I needed.

## Mr S Saleem Ullah's Story



My understanding of diabetes is that it is in part inherited and my South Asian background possibly makes it more likely. Certainly my mother had it and I have had it for nearly 40 years. My first symptoms were starting to feel tired and needing to lie down and sleep at lunchtime. I carried on for 3 years and then when I was tested at St Gregory's hospital found out the inevitable. Yes, I had Type 2 diabetes. I have a very sweet tooth. My heart specialist said to me 'you love sweets but you are going to have to cut down'. I did change my diet and have tried my best to control it but in the end you succumb to insulin. It hasn't stopped me doing anything so far – I did football and I ran – and my life has been and is incredibly fulfilling and active in so many ways with family a big part of this.

## Wendy Tchilingirian's story



I have been in the pre-diabetic range for about 4 years or so found by a routine blood test, yearly MOT. No advice was given to me by GP or any suggestions made in life style changes. Maybe because I said I was aware of what I should be doing situation I was left. I had a blood test in early 2017, still in pre-diabetic range.

In summer of 2017 I was contacted by Healthier You, the NHS Diabetes Prevention Programme. I was invited to take part in a 9-month course giving advice on how to manage my pre-diabetic status and to prevent it developing to being classed as diabetic. I decided to accept the offer, had a HbA1c blood test on 11<sup>th</sup> September and started a course on 16<sup>th</sup> October. The course starts on a weekly basis, becoming fortnightly then monthly. I have managed to attend all but one session. I have found them very worthwhile reinforcing things I already knew and teaching me new facts to manage my pre-diabetic state and stop it developing into full blown diabetes.



I am more aware of what I am eating, know in theory what to avoid but do not find it easy. When buying food, I am now looking at labels and the traffic light system, avoiding high fat and salt etc.

### Steve Bowman's story



I now know my early life sowed the seeds of my Type 2 diabetes. Classic case! A sedentary job, where I could have taken more exercise, but I didn't at the time. That coupled with a high milk consumption and cream, which is pretty high fat. Lunches were always the big problem. All that changed 10 years ago when I sadly lost a family member to diabetes. I found out I had it too. I tried diet and exercise for 3 years and then had to start on Metformin so I could get my blood glucose levels down. It's shock treatment that makes you change. If I was told that I would lose a leg, that would be it. At the moment I am ok and doing my best to exercise and eat the foods my doctor tells me are ok.

A typical day for Steve living with Type 2 diabetes	
Time	What I have to do..
04:45	Wake up. Usually aware if glucose is low but not so much if it's high. Shower and dress.
05:15	Test. Prick finger then use machine for blood test. Get reading – should be below 10 mmo (10 when going to bed). Take 35 units of insulin. If reading below 6, take 30 units. If reading 6.5 or more take 40 units.
05:30	Breakfast. Cup of tea with sweeteners. Small fruit juice. Maybe a couple of biscuits – digestive or rich tea. Cereal – Fruit and Fibre, Just Right or Cornflakes – all with full fat milk.
11:00	If active, maybe packet of crisps and coffee and sweeteners. Lunchtime – Egg on toast, cheese on toast, maybe marmalade, white bread. May take blood test.
14:30	Cup of tea and "sin of the day" – cake or Belgian bun or apple Danish.
	Evening meal – cooked meal at mothers – walks for 8/9 minutes. Casserole or shoulder of pork or liver and bacon. Strawberries in summer. Cup of tea.
18:00	Walk home.
21:30	Bedtime. Statin and blood pressure tablets. Blood test and injection. 10 or above – insulin injected.

## Frederick Springer's Story



In early March 2017 I attended my doctor's surgery to get my usual yearly over 70s check up - as I call it human Medical Overall Test (M O T). I went back after about three weeks and the doctor told me that I was in good health but my blood count was high at 41 and that 47 is at diabetic level. He suggested that I go along to the Pre-Diabetic program which is twenty-six weeks and at Wimbledon YMCA Centre and I am very pleased I did. It's been very useful indeed. It started with 22 of us and is now down to 10. Some thought it was monotonous but I have been very grateful for the learning. Many of us have improved over the time and it spurs you on when the doctor recognises this. I found out recently my dad had diabetes and now my older brother has it. Exercise is the key for me in keeping my count down and especially cricket. My grandad was very fit and died at 96 and I still plan to overtake him!

## Edward Abu Maliki's Story



I am Edward Abu Maliki, Senior Pastor of the Power Centre Church located in central Mitcham. We are a ministry committed to ministering to the whole person as opposed to just addressing spiritual needs. We are a predominantly black majority church with a majority of members originating from Africa. We as a leadership recognise that the people we minister to are more susceptible to developing certain illnesses such as diabetes mellitus, particularly maturity onset Type 2 diabetes, according to epidemiological data. The reasons for these have been well documented in the literature, including dietary habits which include use of excess salt and seasonings. A contributory causal factor not often acknowledged and addressed is the spiritual dimension. Beliefs which include the impact of generational and family curses, which explain the perpetuating of diabetes within the same family



from generation to generation. People who believe in a strong and powerful spiritual causal link will inevitably present a challenge when required to consider more significant causal links such as dietary habits. They come eventually to an entrenched position that the cause of the diabetes is spiritual and therefore the significant and only therapeutic modality to be employed is prayer and deliverance. Here at the Power Centre Church we are committed to providing teaching that will enable our members to accept that physical and socio-cultural causal factors must also be considered alongside their spiritual beliefs. We have set up a Wellbeing and Wholeness in Christ Strategy group and facilitated seminars on diabetes mellitus to reinforce understanding of causal factors, prevention and management of diabetes, in particular the maturity onset/Type 2 form of diabetes. The impact of the workshop has led to considerable shifts in mind set which we believe would yield in the long term, positive health benefits for the community God has privileged us to serve.

### **Shaun Dallison's story**

My Type 2 diabetes started when I lived at Commonsides East, Wandle Housing and I have had it for more than 8 years now.



My support worker went to the doctor with me, as I was starting to feel sick and the doctor told me to cut out all sugar and fats and do more exercise. I was really surprised when I was told I had diabetes. My eyesight was blurring and I couldn't read by this time. I used to go shopping with my sister and never gave my diet a thought especially around cakes and sweets. I used to love bread and butter with sugar. I didn't immediately listen to the doctor but my other sister dying had a big impact on me. Also knowing I might lose my limbs – no one wants that.

I am now more active and have a better diet. I have cut out smoking. My other sister often tells me what to eat but doesn't listen to her own advice. I enjoy diabetic biscuits, grapes, bananas and Weetabix. The gym is very expensive so that's a problem and I wouldn't mind more help with exercise. I used to work in a charity shop in Morden and now work in two charity shops in Mitcham and Wimbledon. I have 3 lots of tablets and take my blood sugar reading twice a day. I do still drink Pepsi but not nearly as much – that's what I miss the most.

# Why diabetes matters to Health and Wellbeing Board members

Two Health and Wellbeing Board members tell us why understanding diabetes is important to them.

## Chris Lee - Director of Environment and Regeneration



*An extract from Chris' recent Merton Council blog.*

As a member of the Health and Wellbeing Board I am involved in a very interesting initiative. Diabetes has been selected as the Board's priority for this year and all Board members are taking part in a "Diabetes Truth Programme." I have been paired up with a Diabetes "buddy" who suffers from Diabetes and with whom I meet every couple of weeks until the end of March for a cup of coffee and a chat. The intention is to provide a real life insight into the cause and effect of diabetes. Whilst diabetes is a medical condition increasingly the solution is seen as a social one rather than purely

clinical. The roots of diabetes are often genetic but also linked to exercise, diet and lifestyle. That's why this matter is so relevant to our Department where we have responsibility for leisure, parks, licensing, town planning and many other services and functions that can contribute positively to supporting healthy lives and helping people make the best choices.

As a GP – diabetes is part of my everyday caseload. I have been a GP in East Merton for 27 years and have met very many diabetic patients. The current practice I work in is in Morden and has the highest prevalence of diabetes in Merton approx. 12%. It concerns me when I see patients with poorly controlled diabetes who are at increased risk of complication and I want to discover if there are any new tips or ideas that might help me to motivate patients to better look after their diabetes.

As a parent my daughter was diagnosed with Type 1 diabetes aged 9 years. So it has been a big part of my family life – she is now 25 and all grown up. In my Clinical Commissioning Group role – I am aware of variation in outcomes in relation to diabetes care and one of my aims in my role is to try to understand and help colleagues reduce unwanted variations in care.

## Karen Worthington GP Rowans Surgery



# Root causes of diabetes

**Understanding causes is vital to identifying solutions! We have identified many causes from our shared perspectives.**

Understanding root causes from the perspective of the Expert Witnesses helped us to understand the choices they face and what they believe might make a difference.

## Causes of type 1 diabetes

There is no clear cause and there can be a sudden onset. Conversations showed potential confusion, particularly with Type 2, and sometimes a lack of understanding, from friends, families and even from medical professionals.

## Causes of type 2 diabetes

A number of themes emerged from the conversations about the causes of Type 2 diabetes including:

### 1. Taking action too late

#### With our children

Many children with obesity are at risk of developing diabetes. We are not recognising this link and miss the opportunity to start education early. Much is being done to encourage children to live healthy lives. But more can be done and how much of this recognises the link with diabetes?

Talking to parents about the eating habits their children develop is difficult as parents can feel they are being blamed. Displays of sweets and chocolate at supermarket tills don't help.

Having opportunities for children to be active in and around the school day are important, but also to find opportunities for them to play safely outside.

#### As adults

We were interested in what stops people from changing their lifestyle when they are at risk of diabetes or have a diagnosis of being pre-diabetic. In part, it seems to be about denial and fear – human nature basically. In many cases, diabetes is not accepted as an illness until it's too late.

#### Conversation on diagnosis..

*"We suspect they know but don't want to know if that makes sense. There is a 'fear of finding out' - people don't want to know even when they have symptoms.*

*An attitude of 'this isn't going to happen to me'. It's far easier not to think about it until you become diabetic although when you do find out you then regret that you didn't do something earlier.*

*We have heard those people who are diabetic but don't do anything about it say 'it's no big deal. Family members have diabetes and are 'well'".*

## 2. Lifestyle

### The food we eat

Not eating the 'right' food or eating too much food and therefore carrying excess weight was seen by everyone as a cause of diabetes.

#### **Conversation on healthy eating..**

*"The way life is lived now often makes healthy eating difficult with irregular meal times and making do with 'fast food on the go'. The availability of any type of food day or night makes it more difficult to make the right choice. Eating outside the home has become so popular and normal food and drink at social outlets is top of so many people's lives (me included). A very different life style from only 30 years ago or even more recently".*

What we eat is influenced by the food industry, supermarkets and how food is labelled and packaged. It is often the least healthy foods which are advertised the most widely with prominent discount offers, cartoon characters to attract children and easy availability. The choice of what we eat is down to us but the environment we live in doesn't help us make healthy choices.

#### **Conversation on food..**

*"The pre diabetic classes at Wimbledon YMCA helped me to understand some of the food dilemmas. Starches fat and sugar are in almost every food we eat. Reading labels on processed food and drinks packaging can give you*

*a good sense of calories intake in each meal..*

*I have spoken to some of my friends who were quite surprised to find out all of this. We all know friends with diabetes but we didn't know this basic stuff".*

### What we drink - Alcohol and fizzy drinks

Similar to food there was confusion about the impact of what we drink as a cause of diabetes. Some of us thought alcohol consumption had a link to diabetes because of the sugar content. Most of us identified fizzy drinks as a potential cause.

#### **Conversation on drinks..**

*One of our expert witnesses bought a bottle of flavoured water to our first meeting. Wow, did that cause us confusion. He had been told by some people he shouldn't have it, by others that it was ok.*

### Exercise

Many of us cited not taking enough exercise as a contributory cause. We gave all sorts of reasons for this - no time for exercise with work and families; cycling is harder due to heavy traffic; not safe for children to play outside.

#### **Conversation on exercise..**

*"When I got my blood sugar results from the doctor he told me it was high. I then waited over 3 months to get into a local diabetic group where my count was tested again at Cheam Sports Centre and it had improved. I can only put this change of my health condition, down to the fact that it was in the*



*middle of my cricket season, where I was playing cricket two days a week. This taught me that exercise is a vital part of managing diabetes”.*

### **Stress**

Often we saw that our current lifestyles are not conducive to good health. Poor sleep quality was cited as a cause of diabetes. Stress was also mentioned – stress of work, of juggling with family life.

### **3. Cultural factors**

We listened to our expert witnesses and they told us about the influence of cultural factors which can serve to heighten the impact of genetic factors. Cultural beliefs and practices can also make it more difficult to talk about diabetes and can lead to increased resistance to change.

The voices of the Asian community told us about the added significance of food in their cultural life. We also heard the voices of the African community.

#### **Conversation on beliefs..**

*“In some communities many problems are thought to be spiritual and are only solved by prayer. These cultural beliefs can lead to a belief that there is nothing the person can do to impact on their health as it is God's will. There is a lack of understandable information about diabetes, often it is not intelligible and if it conflicts with existing beliefs it is disregarded anyway. Past experience of health, services*

*and ‘the system’ mean people are cynical and sceptical of authority and advice by nature so will not seek out information or help. Time pressure is a big factor and often means people eat at the wrong times, don't make time for exercise and find organising their time difficult”.*

#### **Conversation on overcoming cultural differences ..**

*“Engaging people / helping them understand and choose to change People don't want to feel foolish Spending TIME – with the person and realising it takes TIME to change.*

*Understand person's health beliefs – what they think has caused problem.*

*Slowly step by step challenge beliefs. People feel safer where they are than to consider moving into an unknown world. Encourage them to believe the truth of what you are saying.*

*Best by someone they can trust and who they feel has their best interests at heart such as a GP who can give messages like:*

- You only need to make minor changes to be healthy*
- Live longer and you can serve God better*
- Give clear information and help them think it through.”*



## 4. Information

There is a lot of information on websites, forums, support groups and diabetic specific websites about the causes and ways to deal with diabetes. Often this can be conflicting and in itself becomes overwhelming with people not knowing what to believe.

## 5. Genetics

There was a perspective from some people that diabetes was hereditary - 'my family has it therefore I might get it'. We didn't explore whether this was seen as being through inherited genes or inherited lifestyles.

### Conversation on reactions ..

*"Diabetes is such a hidden disease and not talked about enough.*

*Significant damage has already been caused before you know you have it. I have noticed that:-*

- *There are issues for those delivering services knowing the difference between Type 1 and Type 2.*
- *A lack of understanding about the impact of diabetes on other health issues such as exacerbating pressure sores for someone who is not mobile.*
- *Parents often react with shock and grief when their child is diagnosed with type 1. This is the same reaction as for other more visible illnesses. This surprised me".*

# Impact and behaviour change

People told us repeatedly about the links between food choices, exercise and the development and severity of their diabetes. We wanted to hear from our Expert Witnesses about what helps them to change behaviour and what gets in the way. Listening to each other and learning from each other at our March workshop seemed a powerful way of exploring change and how we make it more likely that we will change our behaviour and improve our health.

## Type 1 diabetes – what the workshop told us:



### Impact

There is no way to escape; every aspect of my life has an effect on my blood glucose.

I have to be smart – managing drugs, maths, knowing about food and technology and I need support!

Technology presents opportunities, especially online and digital.

### The big opportunity is

Differentiating messages more effectively between Type 1 and Type 2 diabetes.

Better understanding of Type 1.

### Barriers to change

The complexity of every day life.

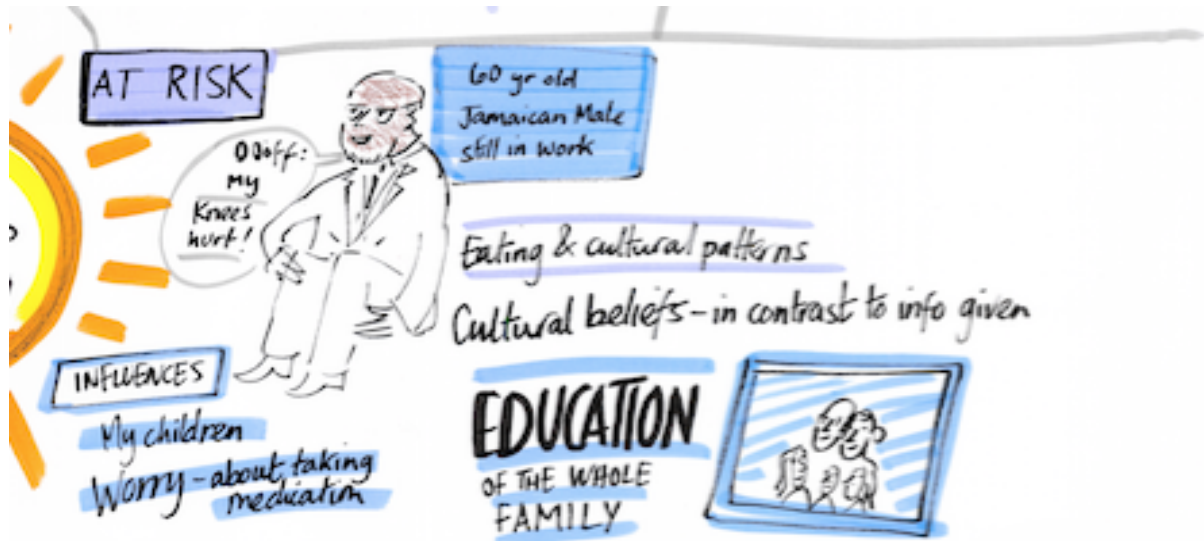
### Influences to change

Aspiration keeps me well.

Using self help in Type 1 communities.

*Type 1 diabetes is about managing a whole range of factors that affect your blood glucose. This can be overwhelming and oppressive. I see this typically in incidents of teenage type 1s who pretend they don't have diabetes and as a result their health can spiral dangerously out of control.*

## Type 2 At risk of diabetes – what the workshop told us:



### Impact

I worry that I will become a burden and my family will have to help me. I might have to give up drinking, and sweet things and have to take medicines.

My worries are all future tense.

I may or may not decide to do these things. At the moment I have no symptoms.

### Barriers to change

Time pressures leading to a lack of sleep and no time or enthusiasm for exercise.

My understanding of the risk and difficulty of taking medication regularly without lifestyle changes. Some confusion about what I should do for the best.

### Influences to change

My children and fears about losing my independence.

### Choice points

The impact of medical advice.

### The big opportunity is

Reaching the whole family with information and education we all can relate to.

## Type 2 Pre Diabetic – what the workshop told us:



### Impact

No physical impact yet but concern for future health. I feel observant but I don't have to act yet.

### Barriers to change

Family and friends, work, peer pressure and established habits from culture and upbringing. 'Fear of finding out'. People not wanting to know even when they have symptoms.

### Influences to change

GP check ups and flagging warnings, feeling tired and slower recovery, peers and family being diagnosed and having problems, meeting new people and taking up new hobbies and sports.

More education, if necessary graphic and disturbing to show what can happen if I don't change.

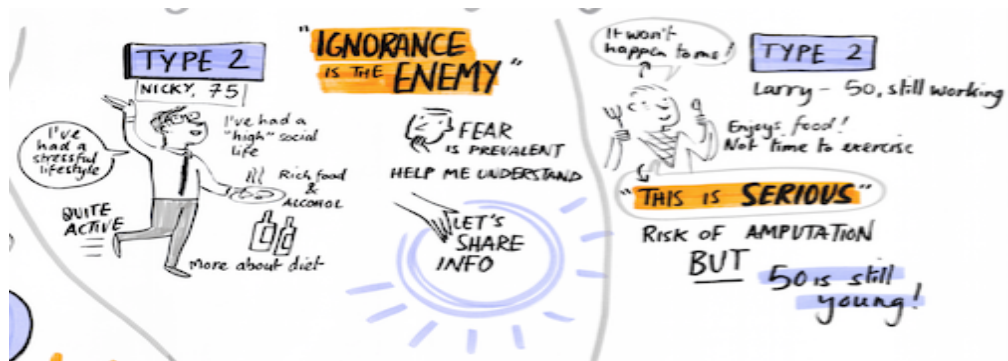
### Choice points

Change requires awareness of what needs to change and acceptance of it. This can relate to diet, exercise, reduced consumption of alcohol, even changed relationships.

### The big opportunity is

Making the decision to change and then embracing the new challenges and opportunities with gusto. Peer support and pre-diabetic clinics help.

## Type 2 diabetes – what the workshop told us:



### Impact

Watching my diet and being more careful about food and drink choices.

Having to lose weight and taking up exercise in a busy schedule.

Living with fear and the psychological impact of diagnosis.

Having to take lots of medication, some with side effects.

My condition affecting my family dynamic.

### Barriers to change

Conflicting information, the current environment, having to give up things you like and balancing this with work.

My family: not being in full control of what is in the fridge, finances, understanding nutrition and cooking.

### Influences to change

Fear is an influence. The knowledge that "this is serious".

The threat and risk of amputations. Emerging medical evidence.

### Choice points

From initial diagnosis: knowing what changes to make and making them OR living with the consequences.

### The big opportunity is

Understanding the problem and sharing information.

Finding out how to access help and self-help.

Creating better choices and start at an early age – not 50!

*"Please see people have more than one thing to contend with.. One of our service users is going blind and has been undergoing laser surgery to try to correct this. They had previously been homeless for a short period and had struggled to keep their insulin correctly. This person is also looking after several children and experiencing a range of financial and other challenges, which make day-to-day management of their diabetes quite difficult".*



be like if we tackled diabetes differently and together and what some of our suggested ways forward might be like.

## 1. Personal – what can the individual do?

- Use online support forums and advice

### **Online is a big opportunity**

*There is a massive online diabetic community for Type 1 and 2 available to offer support. There are always concerns about the accuracy of the information provided but typically if there are sufficient numbers of contributors and the site is active enough any incorrect information is quickly corrected. I have found the Type 1 parental community endlessly supportive and informative. There is something reassuring about knowing others who are going through the same as you and really are walking in your shoes.*

- Challenge expectation that diabetes is a fixed health problem

### **Mental health and diabetes**

*We identified issues around mental health and diabetes management (which equally apply to Type 1 and Type 2). Diabetes management isn't simply about taking your medicine or doing certain exercises. It's about how you live your life all day every day. For those with Type 2 this is very much about what you eat and weight management and for those with Type 1 it's about managing a whole range of factors that affect your blood glucose. This can be overwhelming and oppressive.*

## 2. Social – what can a group of people or community do together?



- Empowering people with diabetes to share their experiences if they want to, especially those who have got their diabetes under control.
- Recognising the value of sharing experiences through peer support from people with a 'lived experience' (this could build on the Expert Patient Programme).
- Identifying community champions and training them in movement building approaches.
- Creating healthy places, i.e. healthy streets, healthy schools, healthy homes – so that the whole environment makes healthy choices easy and normal for everybody instead of a daily battle.
- Workplaces, large and small, supporting their workforce to connect with each other, be it through exercise, food or something like a choir or book club.

### **Creating hope that change is possible**

We talked about the need to give those seeking to avoid type 2 and those that are pre-diabetic or already diagnosed with type 2 hope and belief that they can change their health. It is likely that many may have struggled with their weight for a period of time (possibly their whole life). Seeking to change this later in life may seem overwhelming and simply impossible. Could the stories of those that have managed this or mentoring by those that have been successful be used as a potential approach?

### **The Family Centre**

*The Family Centre runs a group for people with mental health problems. I asked if they would be interested to talk to me. They said 'yes' so I paid them a visit. I noticed that there is a higher proportion of people with diabetes in this group than the wider population. It was quite an eye opener listening to their questions and comments.*

*This session gave me an insight into how it really is to have mental health problems and be diabetic. Some of my insights are:*

- *There was a lot of misunderstanding and misconceptions and little or no understanding about the difference between Types 1 and .2*
- *People asking how do you know if you have diabetes?*
- *Little awareness of what a balanced diet is. What are carbs?*
- *No understanding of the importance of exercise.*

### **Better support to Type 1 diabetes**

*If Merton does want to consider how it better supports Type 1s, I would suggest the following:*

- *Better diagnosis pathways (too many young children are diagnosed too late by GP services and using the wrong procedures).*
- *Doing more to raise awareness of the symptoms of Type 1 amongst parents, teachers and school support staff.*
- *Providing help for admin support staff who are often those in primary schools that oversee day-to-day type 1 management.*
- *Ensuring that secondary schools are correctly reflecting the difference between Type 1 and Type 2 in their curriculum.*

### **Health Champions**

*Champions are ordinary people who are influencers in their own community. If their knowledge and skills are developed they help people to learn through ordinary conversations. They offer a real opportunity to bring a lived experience. Their skills include:*

- *Relationship building.*
- *Happy to share their life experience.*
- *Communication skills.*
- *Mobility to befriend and support others.*
- *Mentoring skills, motivation of others.*
- *Knowledge they can use to educate.*
- *Nurturing and training skills.*

### 3. Institutional – how can organisations work together differently and better to support and enable people with diabetes?



#### Our approach

- Listen.
- Actively engage with communities and help them to help themselves.
- Connecting services, working together and putting people with diabetes at the heart of what we do.
- Starting with education at all levels, involving families, so everyone understands what diabetes is and the different types.
- Ensuring all our different plans and strategies fit and work together.
- Improving the support to health professionals so they better understand and work with people with diabetes.

#### Retailers

Working with retailers to avoid pushing sweets at tills, encouraging healthy food options, reducing prominence of fizzy drinks; a healthy high street food offer.

#### Schools

Starting healthy life approaches early as part of the national curriculum including school meals and the 'daily puddings' culture.

#### Community

Enabling the community to take action to support itself, working with the community and voluntary sector locally and nationally to co-deliver new ways of working.

#### Information, advice and messaging

Targeting and tailoring information to the individual, ensuring messages are culturally sensitive.

#### Empowering

Being positive - not telling people to stop things. Considering a borough website, MVSC newsletter thread.

# Impact of the programme for the Expert Witnesses

*I enjoyed talking and having lunch with my buddy. I am afraid I did most of the talking. I told her about my childhood; growing up in Barbados; also a very short sketch of my working life here in England. .. she did not seem to be bored and listened gracefully to my story.*

*It would be great for some of us to have further training so that we can become diabetic friends and support other people. I am really keen to set up a support group at church and am taking the idea to our parish council meeting.*

*Between my meetings with my buddy, I thought more about how I am as a 'diabetic' and the importance of framing it positively and not asking for special treatment. Many people don't know they have diabetes so I am going to talk about it and how to take action before you get it. Thanks to my buddy.*

*I am pleased that Merton is leading on this work and glad to be part of it.*

*I feel strongly that an initiative like the Diabetes Truth Programme will help to give people the advice and guidance they need and whilst they still have a choice to give them the opportunity to take it. I would certainly be willing to be involved in a continuation of this programme. Sharing the problem with others who have it, provides help just by talking!*



# Impact of the experience for Health and Wellbeing Board members

Health and Wellbeing board members tell us what they have learned and the impact of being part of the Diabetes Truth Programme.

*I can see how much good work is already going on in our communities. A better awareness of the barriers for some communities in accessing and benefiting from existing health care. It was nice to get to know my buddy who was very wise and insightful and to learn from him.*

*I knew very little about diabetes – now I know something it has helped me realise the impact on people's lives and the opportunities to get in early and change this. I found it really humbling to have a buddy and to get to know what it was like and how it affected him.*

*I never appreciated the complexity of living with Type 1 diabetes*

*It is important to the board to reconnect with its purpose and the energy and focus of the Diabetes Truth Programme did that.*

*My elderly next door neighbour – who has Type 2 – also pointed out that we are often looking at multiple morbidities with Type 2 which (can) require complex medication regimes.*

*People have only a limited understanding of the implications of Type 2: they think it is caused by gluttony and sedentary lifestyles and can be successfully treated by strict dietary regimes. A little simplistic.*

*Sharing the buddy between two board members was an unexpected opportunity to develop closer relationships; our buddy was a strong and very impressive example of the role and importance of a carer, a resource that as a system we could use much more effectively and should look after much more systematically; our buddy really exemplified the power of self-help and self-determination and the fundamental importance of a true partnership approach between professionals, carer and patient in management of long term conditions.*

*It was very humbling to work with my buddy since it made me realise how much a person with diabetes is affected in every aspect of their life. It has made me realise that much needs to be done in terms of educating people how, where possible, to avoid becoming diabetic. It has raised a passion in me to want to move this project forward.*

*What was clear from across the sharing of experiences and stories is that, whilst there are commonalities, diabetes is something that needs to be looked at on an individual basis. People do not want to lose themselves and the way that they live and we need to find ways that enable them to make the right health choices but retain who they are.*

*I think what struck me most was the impact that living with diabetes has on people's lives, and how it affects so much more than just what you can eat. It was striking to hear how it had caused people to change their lifestyles in ways that extended far beyond merely diet and exercise. I was also struck by how varied the information on diabetes is, and how difficult it can be for a diabetic to know how best to control their diabetes, when they are presented with apparently conflicting recommendations on an almost daily basis.*

*In my particular conversation it was good to focus on the role of families and carers as part of the solution in long term condition management.*

*It was a good reminder to think about in the workplace and the way that we often use food as rewards and treats which can of course be an issue for people trying to live with diabetes – it is a challenge to me to think of other options instead.*

*I found the experience very humbling, both working with my buddy but also some of the wider conversations with others in the group. The willingness of people to give up their time and share their stories with a room of strangers in a bid to help others, either not develop diabetes in the first place, or to manage it once they have developed it was quite remarkable, and far more powerful than testimony from medical practitioners alone.*

# Conclusion

The Diabetes Truth conversations have allowed us as a Health and Wellbeing Board to reconnect with our purpose and focus our energy.

We have opened ourselves to a humbling level of insight from the expert witnesses. The richness and nuance of what they have shared has helped illuminate, not just our understanding of diabetes, but of what it might be like to live with other long term conditions.

Type 1 and Type 2 diabetes have been well researched and much work is in place to support the conditions. However, by sharing the day-to-day experience of people living with diabetes, we can begin to understand how that support might respond more directly to people's needs. Through working with the Expert Witnesses we have developed an approach to diabetes as an 'exemplar' – a way of engaging and understanding a condition which can apply in other areas.

Whilst some of the findings of this report are specific to diabetes, by exploring our approaches to this complex challenge we have created a new way of working as a Health and Wellbeing Board which we can use when addressing other conditions and wider work.

Specifically in working to tackle diabetes we have learned:

- Type 1 diabetes is really different to Type 2 – when focussing on 'diabetes' we need to be aware of, and do justice to, both types; making sure we connect the communities of each to share learning as there is a lot of expertise and self-help available.
- Type 1 and Type 2 Diabetes are not just physical illnesses – they require an explicit focus on emotional and mental health resilience and support.
- We need to communicate and educate better about food. This is both culturally and socially important. Food's purpose is fuel but it is also pleasure and there are confusing messages and uncertain science about what is good and bad, healthy and unhealthy.
- Our food choices are often influenced by factors in our environment such as advertising and availability of fast food, and there are also issues around blame, labels and discrimination.
- There is plenty of information out there about diabetes but people do not always engage with it. People feel the plethora of advice can be confusing. We need to make better connection between those who produce the information and those who need to use it.
- Physical activity is good for us in many ways and brings people together, but it can be difficult to make the time. We need to promote

our assets such as parks and open spaces and build activity into everyday lives.

- Peer and community support has a huge role to play; we need to learn from those who have experience, face to face and online.
- Pressures relating to lifestyle, working hours, lack of sleep mean that just knowing the causes and risks of diabetes is not enough to change behaviour. Instead healthier choices need to become easier choices through the right cues and support in our environment and day to day life.

## Next steps

The Diabetes Truth work will help inform the way we work as a Health and Wellbeing Board in future and also the plans we are making and actions we take to tackle diabetes.

Merton Health and Wellbeing Strategy, which sets the overall ambition for health and wellbeing, is being refreshed this year. The learning from the Diabetes Truth conversations will help to inform this Strategy and to shape the way we engage with our community.

We are now working as partners on an action plan to tackle diabetes. This Diabetes Framework will be informed by the Diabetes Truth conversations, be based on a joint approach across all our partners and will be launched later this year. It will reflect on, and respond to, what our expert witnesses have told us and focus on four areas:

- **Prevention for the individual** – helping us to take action ourselves, for example, through a Merton offer including participation in the National Diabetes Prevention Programme.
- **Prevention for the population and community** – improving the environment in which we live, for example, creating healthier streets, homes and schools and through work to tackle childhood obesity.
- **Clinical diagnosis and treatment** – improving early diagnosis of diabetes and encouraging people to take part in education programmes.
- **Holistic integrated care** – providing physical and mental health care, health and social care, clinical and non-clinical support and promoting self care, for example, giving mental health support to people with diabetes.

As well as responding to what the Expert Witnesses have told us, we also want to learn from the experience of listening to our buddies. We have arranged a Health and Wellbeing Board development session later this year to help us explore our future role and working. This will be an opportunity to consider and build on the experience from the Diabetes Truth conversations and plan how we can continue to work closely with the communities we serve.

Work is also underway to help health and social care link more closely. The prevention of diabetes and other long term conditions are central to this and will be included in the work of the new Merton Health and Care Together partnership. The Diabetes Truth work can bring an insight to this and will also feed into other work in East Merton specifically plans to deliver a new health and wellbeing campus on the old Wilson Hospital site. More broadly, learning from the conversations can help inform the health and wellbeing policy of Merton's new Local Plan, which provides a vision for Merton's future environment.

Some of our Expert Witnesses or buddies have already expressed an interest in becoming health champions and we look forward to working with them in taking this forward. As champions they will be the most valuable assets in our continuing work to tackle diabetes.



## Appendix 1: Who was involved in the Diabetes Truth Programme

Expert Witness		Health and Wellbeing Board Member	
Angela Martin		Brian Dillon	Chair Healthwatch Merton
Annette Wiles		Dr Dagmar Zeuner and Lyla Adwan Kamara	Director of Public Health, London Borough of Merton Chief Executive Merton CiL
David Chung		Dr Doug Hing	GP and Merton CCG Clinical Director
Edward Abu Maliki		Dr Andrew Murray	Chair Merton Clinical Commissioning Group
Frederick Springer		Hannah Doody	Director of Community and Housing, London Borough of Merton
Joan Henry		Dr Karen Worthington	GP and Merton CCG Clinical Director
Nicky Winter		Cllr Gilli Lewis Lavender	Councillor London Borough of Merton
Saleem Ullah Sheik		Cllr Katy Neep and Yvette Stanley	Cabinet Member for Children's Services Director of Children Schools and Families, London Borough of Merton
Shaun Dallison		Cllr Tobin Byers	Cabinet Member for Adult Social Care and Health, London Borough of Merton
Steve Bowman	PAIRED WITH	Chris Lee	Director of Environment and Regeneration, London Borough of Merton
Tamil Community		James Blythe	Managing Director, Merton and Wandsworth Clinical Commissioning Group
Wendy Tchilingirian		Khadiru Madhi	Chief Executive Merton Voluntary Service Council

## Appendix 2: The focus of our conversations

### Hearing stories

First and foremost the Diabetes Truth Programme was about hearing each other's stories. We heard:-

- What makes being part of the Diabetes Truth Programme important to us?
- What is our lived experience of diabetes?
- What is it like being part of the Health and Wellbeing Board?

### Asking questions

The sort of questions we asked were:-

- What do we each think are some of the real causes of diabetes?
- What do we hear other people say about these causes?
- What are the choice points for people with diabetes?
- What pressures do we each live with?
- What are the barriers that stop us changing?
- What do we think actually influences people to change?
- How do we think health and care services might do better in supporting people with diabetes?
- What are the ways we might pick up people at risk of diabetes earlier and help stop them getting it?
- What do we think a truly connected approach might look like between health, community, schools, emotional support, voluntary services, and advice services?
- How might we involve people as 'champions' to help communities support themselves in tackling diabetes?

