Focus Group Transcript

29.07.2014

## UCLRA01

Ok, well thank you very much for coming. So, what we’re doing. So as you know, we’re researchers from UCL, fortunately that’s why we're here. And um we, what we’re trying to do is trying to get the information from Black African and Caribbean about problem with memories. You know, what you should do if later in the age you get problems with your memory, where you should get help and what you should do. Now, as you know, the session is going to be recorded. It’s confidential, however we’d like you to say your name, this is just so that the typist can recognise you when they transcribe the information. I can start by myself, I’m UCLRA01.

## UCLRA02

Ok and I’m UCLRA02.

## G03BBM17

I’m G03BBM17.

## G03BAM18

G03BAM18.

## G03BBM16

G03BBM16.

## UCLRA01

Thank you, Thank you very much. Now to kick off the discussion what we’ll do, I’ll give you a case, you know, I’d just like you to think about a Mrs Abraham. She’s a 70 years old lady, her family members have noticed that she’s more forgetful lately, she cannot remember conversation with people and forget appointment with the doctors; she also misplaces important items like her keys, her glasses as well. She’s physically healthy but she’s concerned herself about her memory. So, if you knew somebody like that, would you think that she should look for help?

## G03BBM16

Absolutely.

## G03BAM18

Definitely.

## UCLRA01

Ok.

## G03BBM16

Would there be a no answer to that, do people say no to that? Really? Oh wow.

## UCLRA01

(1.47)

It’s possible. You tell me.

## G03BBM16

That’s supposed to happen. That’s normal

## UCLRA01

But you know, people usually forget that this is normal thing isn’t it, people forgetting things. So why would you think that she should look for help? I mean forgetfulness is everyday, you know you wake up and you can’t find where you’ve put your keys last night or you forget what you’re doing in the morning.

## G03BAM18

Well I am mean it depends, I mean if her usual pattern is that she doesn’t forget those things and she’s quite, she’s quite mem, what’s the word I’m looking for, she knows where everything is that would be extreme, I’d consider that extreme behaviour. In the sense that if she’s completely forgetting everything, ah well ok, well this is how you normally function, this is how you are at this current point in time. In relation to the old age as well, ok, there’s a level of forgetfulness that is expected, but at the same time, I suppose it’s from my personal point of view, I would want the relationship with the person that I remember; in a sense, do you see what I mean? (Inaudible) I relate with her and then you know, raise and reflect and then you know, propose that something be done, whether it’s, you know, maybe she just needs more minerals or you know something, but it’s either way, it’s alarm bells.

## UCLRA01

Ok, thank you.

## G03BBM16

I agree with that. I certainly think it is a matter of probably the body deteriorating or the brain deteriorating for whatever reason, but there are ways of (inaudible) helping her stimulate her mind (inaudible). Yes I would look for some help for her.

## UCLRA01

Ok, ok, thank you.

## G03BBM17

I mean, as both G03BAM18 and G03BBM16 said, it’s definitely, it’s definitely triggered off alarm bells. Because as G03BAM18 said, if it’s a change in her pattern where she used to remember things and now all of a sudden she’s starting to become forgetful you do become more alerted to that there may be a problem. So something that you would want to monitor, not necessarily just jump in and say right you’re going to need help, but you’ll monitor it and if it’s continuous and if there’s no improvement then you’ll want to step in and start to offer help, or talk to her on a personal level, see what the problem is because you never know, it could just be something where she’s probably stressing about something in her life and it could just be easily dealt with. But if it is something where there is no stress and it’s become a medical issue, mental health issue, then you want to step up the game, step up the help and provide the help for her.

## UCLRA01

(4.22)

Ok

## G03BBM16

I’m sure it happens to everyone though isn’t it, it’s not just old people.

## UCLRA01

Absolutely

## G03BBM16

I don’t remember reading that we were going to be recording this in any of the emails but here we are

## UCLRA01

Ah, well you forgot (laughter).

## G03BBM16

(Laughter) I’m just joking.

## UCLRA01

No no, that’s ok. Ah, well now, That’s a very good point that you’re making. So, my next question will be, because you were all very prompt in saying, yes she should look for help. If that happens to you, would you look for help?

## G03BBM16

Absolutely, definitely. There’s a few times…

## UCLRA01

Ok?

## G03BBM16

Yes, there’s a few times where I…, oh god, actually there’s been a time when I’ve forgotten my brother’s birthday or something along those lines and that was doing my head in for ages, my brother passed away, and I’ve got family members but it’s not something you want to ask your family members. Things of that nature, I do silly things, I forget silly things, well not silly things but small things…

## UCLRA01

Ok

## G03BBM16

…And there was a time where I thought I need to go to the doctors about this, reading books is not really helping at this stage

## UCLRA01

Ok

## G03BBM16

(5.24)

Um Like I say with looking for help, if it was me myself or younger people

## UCLRA01

So, did you actually look for help if I may ask?

## G03BBM16

I didn’t look for help at that stage, no.

## UCLRA01

Ok. So what would be the, what would make you take the leap to looking for help?

## G03BBM16

If it was severe. If it was affecting my performance, my ability for living a healthier life, if there is such a thing.

## UCLRA01

Ok, thank you.

## G03BAM18

I think one of the challenges with that, is that you know, I as a person, it’s about being on top of my game, that’s the most important thing. So, on one level, I think to a degree asking for help would be admitting, you know a form of weakness or whatever, I don’t know, in a sense, er I just have to be there for everybody. Asking for help, what I would do is I’d go and speak to a few people who I trust and maybe ask them for their personal opinions as to whether you know something is going on with me. It’s kind of like what happened with my mother, my mother we noticed it, she didn’t really notice it. She just didn’t accept it and everything like that and had, had it continued she would have, you know, obviously deteriorated more. First of, so once again it’s about help. You know, what is help exactly. Is it going to a doctor? You know, you’ve got these images, of you know going in to some sort of (inaudible), the treatment itself I am not clear about what the treatment is. Or is it a case of me going to get some ginko binko, or something like that (laughter) to improve my memory. Do you see what I mean, you know, but once again, it’s not something I’ve experienced before, so I’d be like don’t worry, I’ll get over it; you know, probably use a motivational tape or something like that.

(General laughter)

## UCLRA01

Ok

## G03BAM18

It’s true that though, it’s true though. This is what you do.

## UCLRA01

(07.13)

Thank you. So you said you’d look for help from close friends or somebody you trust. How about the GP?

## G03BBM16

Oh no, we don’t trust the GP. We never trust a GP, I’m joking I’m joking (laughter)

## UCLRA01

Oh no, that’s good, that’s fine. No go ahead, that’s ok

## G03BBM16

Of course, there may be a medication that the GP can offer me that will help me sort it out in short, temporarily or quickly

## UCLRA01

Ok, but would you go to the GP?

## G03BBM16

I think people go to the GP when they think it’s a serious reason to go to the GP, you know Black people, we don’t go to the GP until you feel that pain for about a month or so and erm, yeah so, we will go if it’s really necessary, you don’t, I don’t try to abuse going to the GP even though it’s a free service, I’m seeing even 5 minutes, until it is necessary.

## UCLRA01

Thank you, Ok

## G03BBM16

I’d go to my nan, she’s my GP, she’s my family GP

## UCLRA01

You’d go to your nan would you?

## G03BBM16

Yeah, my gran.

## G03BBM17

(Inaudible), I mean, I mean when it comes to the GP, you just don’t want, as G03BBM16 said, you just don’t want to go there when you think it could just be a mild problem or and you would just feel that you’re wasting the GP’s time. You’d be Just going there to say, oh I forgot this, erm could you help me out here. You just need to relax and something like that , cos like erm, there’re times when I’m writing, that I do a lot of writing, I do a lot of emails, and then when I’m proof reading emails I realise I missed out this word and I’ve never done that before and I’m not used to doing that but then…

## G03BBM16

Yeah I’ve read a few of your emails and I thought, no I’m just joking (laughter)

## G03BBM17

…Feel like I’ve missed out a word and like a couple of years ago that would never happen but it’s just, it’s just usually a case because I’m rushing; there’s nothing to worry about too much, it’s just a case of there’s a little issue there, a little catalyst in terms of erm taking out a word and it’s just a matter of, of just stepping back, just looking at the problem and then finding your own solution. But if as G03BBM16 said, if it becomes a problem, becomes to a point where I could be missing out a whole sentence, and I miss out probably I miss out a paragraph, then then then alarm bells are really ringing and then probably you could talk to someone in confidence, step it up and then you go to a GP just to get some advice from them, get some mental health advice as well.

## UCLRA01

OK

## G03BAM18

(09.30)

I mean my experience of the GP, because I spent a lot of time around GP’s because my mother’s a nurse, and um, one experience that I have with GP’s, sometimes it is quite hard to sort of open up in a sense you know and the simple reason being is that er there’s this quick, sort of like factory so like mentality where it’s like ok come in, ok you, ok this is the symptom, explain it to me etc, do you see what I mean and everything? I’ll give an example, it’s like um…Doctors back in the days they would touch, you know they would touch you etc etc, now it’s just a thing of consultancy, it’s like ok, tell me what the symptoms are, you’re expert on yourself if you like, do you see what I mean and everything, ok this is this and that is that, ok great, yeah I’ve got one for you, I’ve got another one for you, take this, if this doesn’t work then come back and we’ll try something else. It kind of feels like an experiment, kind of like in a sense to a certain degree, that’s that’s based on my experience. I’ve been in doctors surgeries like five, six, seven thousand times, something like that, because it’s going in to work, and going in to work with my mother. Um so, sometimes I don’t know if GP’s are ideally the best people at dealing with you know dealing with those kind of matters because first of all, do they give you the time? To to to basically explain what’s going on because if it’s, if you’re going through that kind of situation, have you got an hour for me? You know, for me to explain the whole entire thing, or is it a quick in and out, I walk home, I take out my medication which has got so so you know X amount of side effects and then which creates another problem for me, is that what that is? So, that’s it.

## G03BBM16

I think the older generation now in the back community, they do have a love-hate relationship with GP’s isn’t it. On one hand you know they appreciate what the GP is (agreement from others), they appreciate, do you know what I mean, they understand that this person has the knowledge, they’re specialists and they take almost everything they say for gospel, and on the other hand when they’ve been given a pack of pills, white pills and told to knock that back for a week or so and that will be able to health the pain you’ve being going through for X amount of time. No, I’m not really feeling that. So there is a lot of love-hate relationship with um yeah people of you know medicate… those Gp’s, basically like consultants, people of that status.

## UCLRA01

(11.51)

Why is that?

## G03BBM16

Love hate relationship? It’s either they understand them or they don’t understand them. They take what they say for gospel, because they you know they’re knowledgeable in their field; maybe even more than that actually, although yeah.

## UCLRA01

OK

## G03BAM18

It could be that…

## G03BBM16

You’ve never picked up on that? No, you don’t think so?

## UCLRA01

Personally, no but you know…(laughter)

## G03BBM16

May I ask why? What’s your view?

## UCLRA01

My view, oh, I could give you my view but later (laughter), we’d like your view first. This is the thing, because if I give you my view I might actually swerve the whole session and I’d rather get your view if you don’t mind, but I’ll give you my view after.

## G03BBM16

## Yes, that’s fine, that’s fine

## G03BAM18

Maybe it’s a connection, it’s a greater connection with natural things, do you know what I mean, because if we’re talking about the older generation, we’re talking about coming from the Caribbean or Africa and in a sense where perhaps a herb, or grandma’s herb, or something along those lines heals your cold or did something. Whereas, I say with the Western, with the Western Culture once again it’s about you know hey have this pill which from what I understand say like for instance if you had something as simple as a headache erm you’d take the Paracetamol and what it does is it shuts down the neurotransmitters if I’m using the right language erm that actually acknowledge the pain which means that I can have a continuous headache but it’s just that my body just doesn’t acknowledge it and what that does, that creates problems as well, where if I’m constantly straining, constantly straining my brain’s just unaware of it, obviously I’ll end up with dementia, memory loss and you know 10,000 other things. That’s why so it’s not really solving the problem, it’s just shutting down my acknowledgment of it if you like.

## UCLRA01

Yes, ok. Numbing the pain in this way?

## G03BAM18

(13.39)

Yes, numbing the pain, yeah.

## UCLRA01

OK. Thank you.

## UCLRA02

Can I jump in with a couple of other questions?

## UCLRA01

Please go ahead yes.

## UCLRA02

OK so, a couple of you have talked about how sort of seeing your GP might not be your sort of first port of call. One of you said about going to see your nan perhaps and you also said about how maybe the GP isn’t the best person to deal with some of these matters, so I just wondered if you could expand a little bit more around who you may seek help from you know maybe if you were noticing memory problems. Obviously you said your nan, is family your first port of call from communities such as your own or other Black African or Caribbean communities that you know of? I just wondered…

## G03BBM16

With me, my family would certainly be my first point of call because they’re more experienced than myself, they’re older so they’ve got more wisdom. So I would definitely go to them first. They may be able to solve it with a cup of tea or whatever; but erm, if they are incapable of understanding what it is that I’ m going through then of course, I would then go to the GP. It’s not that I don’t want to go to the GP because I just hate the GP but it’s more so, like I said before I use, utilise that service more efficiently/properly, to you know what I mean, rather than just pick up the phone, book an appointment and going. Erm, when I said I would go to my nan it wasn’t necessarily with me losing, being forgetful, forgetting things, it’s more so that if I had any form of illness or a cold, erm I would then speak to my older family members about that. But if it’s something I find more serious, then the GP it is.

## UCLRA02

Ok, thank you.

## G03BBM17

It’s also to do with time as well because as G03BAM18 was saying, Gp will have, they’ve got targets (interruption from another participant). Yea, so basically, I mean it’s all to do, it’s just to do with time in terms of, Gp’s they’ve got targets to meet, 15 minute slot here you go but you don’t get to talk enough to them, erm get that much out of yourself and explain yourself to them. So, for example, the first person I would probably go to would be my girlfriend because she’s a mental health practitioner. I would be able to talk to someone with the expertise, she’s very close to me and I can open up for a good two hour if that’d be the case. Go to a GP straight away then it’ll just be ok I’ve got this this and this; alright here’s the solution, this might work, if it doesn’t work, come back and see me in 6 weeks. Whereas if I was talking to my girlfriend I would be able to get it all out and then she could make some recommendations and then she could actually monitor me probably every day with a phone call, or a text. A GP you don’t get that sort of relationship, it’s you come and see me when you’ve got an appointment, make an appointment and check on me now and then.

## UCLRA02

(16.36)

Ok, thank you very much.

## G03BAM18

Family, I think family, I don’t know if I’d actually go to family. Erm one of the reasons why family is important, is because it also gives you a track record. You know as far as whether it’s genetic as well, so um being that’s the case, it may not be perceived as such a bad thing. I think to a certain degree, in our communities what’s happening is that there’s such a, erm, the link is severed in a sense that, you know, even if close together, there’s a lot of pride, as well er, where I can’t actually find out the simple basic things that my previous generations experienced and everything. Do you see what I mean? So I’m going through situations where I’m thinking that it’s me, you know, it’s actually me and me only, when in reality a simple explanation that no, that’s happened for generations that, so it’s ok (agreement from G03BBM16). Do you see what I mean, therefore why didn’t you come and tell us and everything you know? So part of the, 90% of the increased stress is as a result of believing you know, there’s something wrong with me (laughter). Kind of thing, do you see what I mean, you know and stuff like that. So, you know, putting it out once again, as far as the family connection is concerned to be able to relate with your own DNA, with your own genes. Your own familiar situation (general agreement).

## G03BBM16

(Inaudible) I agree with that totally.

## UCLRA02

Ok

## UCLRA01

Ok, so you think with even with a memory problem, because you were talking about you know your family line, DNA line, you know, what they have experienced before. So even for somebody with memory problem they should consult their family first? Would that be what you’re saying?

## G03BAM18

Erm, I think to a certain degree the people that’s closest to you will notice that’s the thing. So, I think that that, you know, the fact that they, your family well ideally should be closest to you and everything erm, they should notice something was… in your being. So they’d probably flag it, you know in comparison to you, having to speak to them, I mean you’re your speaking to them about it will just probably confirm what they’ve already seen (inaudible).

## UCLRA01

And would you believe that, well would you think that if your family noticed it and mentioned it to you and say maybe you should go and see a doctor? Would you go? Whatever they say, would that have an impact on your decision, whether you should go and see a doctor or not?

## G03BAM18

(19.15)

Definitely definitely. It definitely will, I think irrespective, I mean in the society going to see a GP is the first port of call, you know that’s what’s been introduced unless there’s other, I mean once again there’s other people like holistic, but once again there’s a price tag attached to that as well so you know, and plus perhaps the condition that I’ll be in is based on neglect of some sort, so um yes I’d go and see the GP, I’d go and see the GP, just to give them you know peace of mind, give myself peace of mind and plus if it’s coming from 5 family members that’s enough isn’t it to verify that what they’re saying.

## G03BBM16

I can see why somebody wouldn’t want to go to their family member for advice. You don’t necessarily need to be an expert of the matter, you don’t need a certificate, just some understanding. GPs they misdiagnose people from time to time as we already know, so um yeah there shouldn’t be a problem with going to so and so, they might have something (inaudible), they might a friend who’s a doctor, you get it for free.

## UCLRA01

Now, some people say to us, um because we’ve had a few discussions, and although I know you said you haven’t lived in, you’ve lived here you were born here, some people say that when you have memory problems or that kind of health problem it is so much better if you were back home in Africa or the Caribbean depending on your origin. What would you think? Other people have also said it’s better here, so

## G03BBM16

People say what?

## UCLRA01

If you have a mental issue or you have a memory issue

## G03BBM16

Then go back to your country?

## UCLRA01

No they say, it’s better to have, when you have that condition, you know it’s better to be back home for some reason. Whatever the reason, could be having family support etc but they believe it’s better to be ill back home than here. Other people have said it’s better to be ill here than back home.

## G03BBM16

I’ve never known anyone to say that

## UCLRA01

No? But what would you think about that?

## G03BBM16

I’ve always understood people to come here because, to be blunt, it’s NHS service.

## UCLRA01

Ok

## G03BBM16

(21.21)

So most people come here and get themselves, and again like I said to begin with they do trust in what most consultants and doctors are saying. They do take the information as gospel because they are specialised in that field. So hearing that is actually new to me, it is actually genuinely new to me. I suppose if they are going to go back home to their country, it would be because of the family support if they haven’t got family here. A lot of people have issues with the health system in the Caribbean and in part of Africa. People say that you need to pay for the service, you need to pay for the equipment, you don’t necessarily trust what the professionals are saying or what it is they even, they’re doing. So I’ve never heard that one before, I have always heard the other side of that.

## UCLRA01

OK. So you think it is better to be ill here. At least to have a memory issue here? If you do have a memory issue, it would be better to be in England?

## G03BBM16

That’s not what I’m saying. Um, do I think it’s better to be ill here? Personally, I’m from this country…

## UCLRA01

Well we’re talking about mental, you know memory issues. If you have a memory issue, is it better to be in London or UK, let’s say UK?

## G03BBM16

I think you would have to speak to somebody who’s actually from another country, that question, I certainly can’t answer that question. I would answer that question but I just can’t (laughter).

## UCLRA01

Ok, thank you.

## G03BAM18

I think there is um, I don’t know if it’s to do with specifically memory itself but it was a scientific experiment conducted amongst old people, what they’d done is that they asked each and every single old person or their relative, which is why the relative part is very important, about a particular object that they grew up with when they were youth or child. So, This, you’ve got this 80 year old looking at the wall paper that was in their house when they were 6. What happened is that it created an energy where they started to move around a lot and stuff so my belief therefore is that if they were surrounded by that, the environment which they grew up in it would create some form of, it would energise them in a sense. But in regards to the standard of health care, I think that the UK has got better standards of healthcare. But once again it depends on…yeah (laughter) certainly healthcare, but you know I mean It could take matters away. It could change things, or a balance of the two maybe or something.

## G03BBM17

(23.58)

Very new to me. I mean, I’ve never heard someone saying that they’d rather be have some sort of illness back where they come from rather than in another, their um their new new homeland. I mean, because the thing is that like for example, my grand uncle, he’s going through er stages of prostate cancer. Now he lived here for 40 years. He moved to Antigua, but he’s getting treatment back over here. Because when they picked it up (inaudible). When he came over here for a general health check-up. They picked it up over here. So now he’s constantly, well when he’s given the all clear then he will go back home. But then he is coming back here every 6 months to get the check-up over here as opposed to back in Antigua. So, It’s just a matter of where you get the best treatment, where you get the best consultancy, services, just a matter of where you could go to. Because for example, I’ve heard of like, I mean for example I can use like footballers. They get injured over here but they’re getting surgery in Germany. Because they’re the best consultant, best surgeons over there, to treat the injury, heal them faster and put them back on the pitch. A lot of footballers, they just go over there, they just have their injury, they got knee ligament injury and they’re having surgery in Sweden, Germany and elsewhere and then they come back here as opposed to staying here and getting their treatment here. It’s just a matter of where the services, where you go to. For example, us going shopping, we’re not just gonna go to the high street because it’s just close by. You’re gonna go somewhere where you get the best customer service you get the best deals. You just go for where the best service is.

## G03BBM16

So the best service is here (laughter).

## UCLRA01

Thank you very much.

## UCLRA02

Ok. So, just a couple of other things I’ve kinda picked up on whilst I’ve been listening to what you’ve been talking about. Two words, stuck out, a couple of you mentioned about pride, perhaps in terms of affecting why you may or may not seek help and I think one of you talked about being quite proud. I just wondered, two things really. One, proudness and pride-fullness, is that something specific to black African and Caribbean communities? Does that trait, do you think stand out in anyway? Or do you think that’s something kind of more across the board? Thinking about why people may not seek help when they first notice memory problems.

## G03BBM16

I think it’s across the board myself

## G03BAM18

I mean we’re currently seeing something at the moment which if you watch Eastenders, Patrick Truman, he had a stroke but he’s actually aware, he was aware from maybe two years ago about the problem. Now the thing with EastEnders is, the reason why I found that quite interesting is because they’re starting to tie into reality, you know if you notice at the end they say if you have a issue call this phone number. And that is a reality. Now why didn’t he tell anybody? I mean (inaudible) It’s probably headaches or something like that. Why didn’t he tell anybody? He walked up to the doctors surgery and then walked off again. That is so real. That is such a reality. (Inaudible)

## G03BBM16

(27.10)

People lose their morale isn’t it really, they feel as if they’re losing their self-esteem, I’m guessing why they wouldn’t want to go and see it through. They feel as if they’re, what’s the word I’m looking for guys? They notice… I don’t know, advanced…?

## G03BBM17

The strength that they used to have

## G03BBM16

Yeah. It’s coming to terms with that isn’t it. So it’s not necessarily Afro-Caribbean thing, I think, I’m sure it’s people of different cultures and races that go through the same emotions

(General agreement).

## G03BBM17

Seriously, that’s why they’ve got some many advertisement campaigns saying if you see these symptoms, act now (general agreement) and it’s not targeted at any specific demographic; it’s anybody, if it’s someone within your family, such as just a generalisation, if you see these symptoms act now. So wouldn’t be specifically just for black people within, saying that we’ve just got pride that we don’t want to go to the doctors, it’s just anybody really.

## G03BBM16

If they don’t want to go to the doctors, it’s probably because they feel intimidated by the doctors. You know, not being able to vocalise, or express their opinion or how they feel, maybe not even been able to understand what it is that the doctors are sharing with them. That could be a reason to why they wouldn’t want to go to the doctors. Um yeah, I think we’re more advanced now if we can be as bold and say, we’re more advanced, we’re encouraged to do a lot more reading, you know, a lot more um,

## G03BBM17

Focus on self?

## G03BBM16

I want to say that but I don’t want to say that but yes, you know, focus on self, exactly that. Whereas before, I am sure it was about making the money, look after the children, get on with it and not focus time on reading and so, I don’t know, it kind of prohibits they development, if I can be as bold to saying that. I’m looking at UCLRA01 and (inaudible)

## UCLRA01

No, every point is a good point. It’s your point.

## G03BBM16

OK, cool. Yeah, no, I think that could definitely happen to some degree where people don’t feel confident enough to talk to professionals because they’re intimidated due to their own abilities or their evaluation of self. But that’d probably…

## UCLRA02

(29.15)

Ok, do you think, just thinking about that, because all 3 of you are obviously male and I just wondered thinking about black African and Caribbean communities, do you think those kind of feelings are the same between men and women? Or do you think men and women feel differently about seeking help for problems such as memory issues?

## G03BBM16

My opinions, my opinions for myself?

## UCLRA02

Yes and you know, from communities you may be part of or are aware of. Or just for yourself, it’s absolutely fine, whatever…

## G03BBM16

If I had to answer that, I would say, I was raised by women, mainly women. I’ve got my father around me although none of my friends and family were raised mainly by their mothers and so I’m sure it was their parents, that would nurture ideas, their mothers that would nurture ideas that they, that they currently have now. Um so It wouldn’t just be a thing that men, I shouldn’t speak for women, but I don’t think it’s just my own opinion or just a man thing. I’m sure, you know, (laughter) we all go through the same thing. I think, they may have more to say women, you know but I’m, yeah, that’s it for me.

## UCLRA02

Ok, thank you.

## G03BAM18

I personally I was raised by my mother and I think that, well my mum she was a practice nurse anyway and the reality of it is so she spent a lot of time there, probably picked up a few prescriptions whilst in the process. Um, I think from a woman’s perspective. It’s important that they stay well. You see what I mean. With males I think to a certain degree. We have broad shoulders and you know, swollen chest to a degree. So, there’s a lot more to prove, ok you’ve got, you’ve got the mothers take care of the home etc ideally. I’m not saying that’s 100%, I say she takes care of the home, so her, you know, her role is pretty much (inaudible). A male is aspiring and once again if yeah, hold on I’m trying to word this properly. He’s aspiring, he’s got to have broad shoulder’s, he’s got to be king, the man of the house and everything like that. And he’s sick. Um, this it does, I mean I’ve seen it happen, even quite recently as well you know, um, the dementia came just like that. Yeah, and now, my thinking is well it couldn’t have just come just like that. It must have been, it must have built up to that stage. I’m taking about maybe even over a ten year period. But, swollen chests, you know I have to be the man, I have to progress forward. Yes, my knee’s broken but hey, I’ll go on crutches and I’ll do (general agreement). Do you see what I mean? So that kind ties in to that pride once again. But I think you know with a mother or a woman it’s just listen I need to be there for my children so I will do what’s necessary to you know, keep well, because even in the black community, I mean women are able to raise children in the absence of black males.

## G03BBM16

Single handily

## G03BAM18

Yes, single handily, successfully as well. So that’s probably a different way of looking at it as well.

## UCLRA02

(32.25)

Ok, thank you. That’s really interesting. I mean obviously nobody wants to be ill. But do you feel that getting a diagnosis of dementia is any different from getting a diagnosis of something like arthritis or diabetes for example?

## G03BBM17

For me, no. Just because Erm, it’s the fact that this is an illness that affects your everyday life. It’s gonna slow you down, from what you use to do. So for example, arthritis, if you’re used to going to the shops every day, that’s going to slow you down in terms of you’re having to, all that pain that you’re going to feel, I mean to actually, can you make the trip this day? There’s going to be a day when you say, well I can’t make it today. I’ll try tomorrow. Dementia, you’re using your mind a lot but now it’s going to be affected now because your memory is going so the fact that it is going to slow you down from your everyday process, there shouldn’t be a division or some sort or distinction in terms of it being different from another illness. Although it affects another part of your body, the fact that it affects what you’re doing or what you’ve done during your everyday life, then there’s going to still be a problem overall.

## G03BBM16

I think the question is, do people actually go to the GP to get themselves diagnosed with dementia? Like, I don’t know. Do you think mmm, yes, maybe I’m suffering with dementia, let me make an appointment and see. You have to kind of know, to know you have to think, er it could be that. I’m sure most people… am I being…I don’t know

## G03BAM18

I mean is there clear guidelines I mean, (general agreement, yeah) because I think the thing with dementia, dementia is really really blown up in my personal opinion over the last couple of years; you know it’s like it wasn’t there before kind of thing basically. Stroke was, arthritis was, high blood pressure etc. Is it that it wasn’t there or has it always been there or has the level of awareness increased? Because once again the question I would ask is how you would, remember the one about the stroke? Where it says FACE, I think it’s FACE (general agreement). Is there one for dementia? Is there enough focus where someone can actually, ok right, I’m going through dementia moment, let me just go and check (general agreement) just in case. Yea basically, (inaudible).

## UCLRA02

That’s really interesting and might be a good time to move on. UCLRA01, have you got any other questions before?

## UCLRA01

No, go ahead.

## UCLRA02

So, to just sort of build on what you’ve just said, about you know, how do you know. Building on what you’ve already been discussing, it would be really good now just to get your thoughts and opinions around what you feel could be done to help and encourage people from communities such as your own, or other black African and Caribbean communities, to seek help for memory problems earlier? So one of the things that we know is that obviously people who seek help for memory problems from their doctor earlier in the illness, generally speaking do better overall. These people are able to access support for themselves and also people around them, so friends, family and other caregivers are also able to get the support that they need. So if I could just start by asking you, if you or someone close to you had memory problems, what kind of information would make you more likely to seek help for these problems?

## G03BBM16

(35.49)

Information about symptoms maybe.

## UCLRA02

Yes, so I guess what I’m saying is that the kind of information, I’m thinking about what sort of form of information you know would you be interested in looking at, listening to or reading about, which would make you, or help and support and encourage you in seeking help? You know, whether it be from DVD’s, leaflets, whatever it is. That’s what I mean by what kinds of information do you think would help and encourage you.

## G03BAM18

I think it’s something that needs to be direct. DVD requires me to put it in to a machine and press the play button, so that’s an effort which I could probably do without. Reading is something I could do without you know, I’ve got a dementia leaflet, ok I’m going to open it but I’m probably not going to read it. So it’s something that needs to be thrown at you. You know…

## G03BBM16

Like that advert they use speaking about …(agreement). That was catchy, isn’t it?

## G03BAM18

Definitely,

## G03BBM16

Something like that. Oh maybe it affects me as well or maybe it affects my aunt or my nan. Yeah so advertisement. You know, billboards or something on the television, giving us a very precise and quick in depth understanding of what, yeah understanding of what it could be, how people go, the experiences people will go through. Just a nice clear example.

## G03BBM17

What to look out for

## G03BBM16

To look out for. Um yeah…

## UCLRA02

Ok. So all of you are sort of heading towards something kind of visual that you’d like to see or hear? Is that right?

(General agreement).

## G03BAM18

(37.19)

Best chance of making it socially acceptable as well because I think to a certain degree you’ve got someone with dementia, you’ve got a 1000 people surrounding that individual, and you’ve got (inaudible), but if it’s something that is once again socially acceptable, there’s a possibility that you have a you know just gone (in audible). Do you know what I mean, kind of thing, basically. (General agreement).

## UCLRA02

Ok.

## UCLRA01

I suppose it would be something like you said before, for stroke, you’d like something like FACE for dementia as well ?

## G03BBM16

(general agreement) Totally.

## UCLRA01

Just something where you can pinpoint on the symptoms and say, oh I should go and see the doctor.

## G03BBM16

Yes

## UCLRA01

Ok

## UCLRA02

Thinking about black African and Caribbean communities, in terms of the information that might be out there to help, support and encourage people to seek help, do you feel that there is any particular age group that this information should be targeted at?

## UCLRA02

So for everybody?

## G03BBM16

For me, for everybody, yes

## G03BBM17

For everybody, yes. Because you could be a young child that lives with his grandmother or grandparents. So something that he or she can understand, could read, read upon and he could take in consideration and then act upon rather than just having it aimed at solely at adults who could understand the information really.

## G03BBM16

(38.47)

So he could pick up, he could understand the information’s about and could help his grandparents out?

## G03BBM17

That’s right.

## G03BBM16

Is that what you’re saying?

## G03BBM17

Yeah.

## G03BBM16

We also suffer with dementia as well right? Do young people suffer with it is as well right? I’m asking.

## UCLRA02

Yes they can.

## G03BBM16

So, this is why the information would have to be pretty broad. It would be hard work for them to produce something, but no, it would have to be broad for all age groups, I’m sure.

## G03BBM17

And that’s where visuals will be helpful as well. Just pictures to explain, like simple, simple captions, saying if you see this, this is something, this is a symptom leading to that and so forth. To say something straightforward and something much easier for anybody to understand.

## UCLRA02

Ok

## G03BBM16

Would people take that advert serious if it did, if they used young people as an example? (laughter)

## UCLRA02

Yes, that’s a good question. I mean, in terms of how the information should be presented you know, how do you think it should be, what do you think people would…?

## G03BAM18

With children I mean, first of all you’re going to ask an 8 year old child, do you have dementia? Would they be able to break that down? It’s the same way that you can find that a child’s got emotional problems at 23, and you’re like, oh I didn’t know that, why didn’t you tell me that when you were 6!? (laughter) kind of like things so, yeah, in regards to young people…

## G03BBM16

(40.06)

For me you’d have to use a young adult (agreement) as an example. I think more people can relate to a young adult. Young people look up to adults and of course elderly people you know, they experienced being a young adult, so I think you would have to use people within their, I don’t know, twenties. Are we really going kind of to make this? Are we going to make this? (inaudible)

## UCLRA02

Well we will be making something as a result of this project.

## G03BBM16

Oh, really? Oh wow! Oh I see… Oh use me, use me…

## UCLRA02

Yes that is the idea, we can speak some more at the end about it. Yes, so that’s why we’re really interested to hear your views.

(inaudible response)

## G03BBM17

The thing is that, you have to be explicit. Like you, like you let the viewer’s know that it can affect anybody. Rather than, I mean you can use the young adults solely just to catch everybody, but the plan is that if you made it explicit and have statistics that back it up just saying X amount of young people have suffered from this. Then it will be taken more seriously (general agreement). Because up to now, I didn’t even know that young people, but I don’t know what the youngest person to have dementia is so, what we’re looking at… memory loss….?

## UCLRA01

On record the youngest patient is 39 I think. But dementia is actually an age related illness. The dementia which young people get is usually gene related, so it’s not an age, so much age related and depending on the description it’s not called dementia. It could be called something else.

**G03BBM17**

Oh ok.

## UCLRA01

It all depends on your age, you could have memory problems a certain age, but you might be diagnosed with something else just because of your age.

## G03BBM17

But it’s dementia (inaudible)…

## G03BBM16

mmmm

## UCLRA01

(41.48)

Because you do have to follow certain guidelines when you diagnose somebody with an illness

## G03BAM18

So I mean, would this increased, because I know children are becoming adults quite quickly as well. So I would imagine that the wear and tear, alright I mean, I’m 15, but I’m thinking like a 30 year old, because of the level of responsibility I have and you know my circumstances etc. So I mean, that does make sense in a sense that once again like I said a youngster is thinking like a 40 year old in a sense, yea (inaudible)

## G03BBM16

So (inaudible question) … memory loss?

## UCLRA01

Well if a young person suffers with memory loss, it’s very unlikely a doctor is going to say that he’s got dementia. They’re going to look for something else because on record this is, this is a way research and science work. So…

## G03BBM16

Right

## UCLRA01

You have to respond to a certain number of symptoms before they give you a diagnosis.

## G03BBM17

So it’s like, until the statistics go up for young people, say like 20 year olds displaying similar symptoms to dementia, that’s when we can consider dementia to affect young people as well? (General agreement). So for example, you’re saying that erm…

## G03BBM16

A group of young 20 year old people, if it wasn’t for the majority of young 20 year old people to go through dementia, memory loss, would it be, would it erm, sorry for interrupting you my brother…

## G03BBM17

No, no problem.

## G03BBM16

Would it be a matter, would it then be considered dementia if a whole load of young people was going through it, or would it still be a different….?

## UCLRA01

That will have, they will have to go through a whole process of changing the meaning of dementia in that case (general agreement). It’s the same as any illness before they give you, I don’t know, erm, the diagnosis of schizophrenia, you have to respond to a, you have to fit in a you know, a list of symptoms; so dementia falls into the same, if any illness falls in to the same kind of categorisation, so if you have a list of symptom, you’ll get dementia and age is just one of the criteria of this. So if you’re seven and you have memory problem they’ll think of a developmental issue but not dementia.

## G03BAM18

(44.05)

I see. A lot of the time, are they correct in that assessment or is it just something to be worked on?

## UCLRA01

Erm, it can be more difficult to diagnose somebody. But with this in mind, erm, the question I think was, who do you think should be in the presentation or ….

## UCLRA02

Yes, so, one things obviously you said about this information being aimed at all people, out in the community, not being age specific; but as UCLRA01 has just correctly said, in terms of how and who should be presenting this information, you know, we were talking about something visual for example. Do you think it’s important for people who are going to be watching this information to be able to relate to those people, and I’m thinking about black African and Caribbean communities in terms of the sort of content of information and how should that be presented to people? You talked about it being quite precise I think somebody said and direct, is there anything else that you think…

## G03BBM16

A 35 year old black woman.

## UCLRA02

Sorry?

## G03BBM16

A 35 year old black woman, a 35 year old as we said the common number is 39

## UCLRA01

I think that’s 39.

## G03BBM16

Let’s round that number, and I say a woman because, I don’t know, I think it’s more subtle isn’t it to see, we can relate, well yea, it’s more subtly, to see a lady on the TV and it comes more real, it’s more realistic. Not that it’s not realistic if a man do it, but I don’t know really (laughter). I think it will be more shocking, I can relate with it more if I saw a young lady on the advert.

## G03BAM18

You would, wouldn’t you?

## G03BBM16

Now now, it’s too early for that (laughter)

## G03BAM18

The thing that comes to mind for me is erm, you know I reflect on a film, I’ve forgotten which movie I saw where you had a whole bunch of children, different ages and they were getting up, uh Malcom X, that’s what it was, they were saying I’m Malcom X, I’m Malcom X, i’m Malcom X so you could relate with the different ages. Perceived that advert had like a voice there and then you had the images switching, so you’ve got a child one minute and then you’ve got a woman and then you’ve got a this, you got that (general agreement). You’ve got a chance of hitting all of the demographics. You know you’ve got a chance of hitting each and every single person because at the end of the day, I mean a child coming to me and breaking that scientific information to me is very inspiring. A woman coming to me and breaking it down is equally inspiring. A male coming to me is alright, do you see what I mean. So, but that’s just personally me. Now let’s talk about the other significant, million other people out there. In a sense you know, they’ve got their own preferences as to who they’d rather receive that information from (interrupted).

## G03BBM16

So, you’re right, an age range isn’t it. You’ve got the young person being very articulate, being able to deliver a presentation (agreement) and then we see a growth and then a deterioration in their memory, yeah, that sounds like an advert I would definitely pick up on and understand.

## UCLRA02

Ok. That’s interesting. Thinking about how we might get this information to people so erm, obviously you said that you might not have a DVD at home or bother to put it on or watch it, you know if it’s a 10 minute thing about memory problems. I’m just thinking, where should people be able to see this information or get hold of this information? What do you think? Again thinking about black African and Caribbean communities. Where do you think this information should be shown?

## G03BBM16

(47.23)

Mmmm..interesting question. Where’s place of gathering guys? (laughter)

## UCLRA02

That’s a good point.

## G03BBM16

Um, I think I’m having difficulty answering that question because… I think the answer would be television. It would be radio 5 or 10 years ago. It would be station FM, 10 years ago but erm I think there’s a lot more internet radio that’s going on, (agreement) people don’t really put on the computer and press the button, (inaudible) dialling to the frequency of a radio. (Inaudible) would have been able to digitally do it on, sorry on the internet, whereas you would have been able to digitally do it on the radio. So it would have to be television for me.

## UCLRA02

Ok, and the same for older generations do you think, on television?

## G03BAM18

Yeah, I think so, I think because it’s also influence erm, the level of influence, ok, I’ve got child, oh, daddy daddy, look, I oh I just saw this advert about dementia. Do you know what it is? So it’s about, you know, information being received by an individual and then they’ve got to do spread it around the household. Erm I mean, the reason I’ve chose to say that, I use Bond as an example, I mean Bond has got 50 years of history and what it’s done, there’s people who are 80 that can relate to it and then you’ve got a 6 year old who can relate with it as well. So, but, the formula doesn’t change much, it’s just the villain etc, do you see what I mean, but it’s just a cool Bond I, James Bond.

## G03BBM16

You watch a lot of TV, you do, you do know that, right? Three different movies in reference, I love that, I love that

## G03BAM18

(Laughter)

Yea, I’m into movies, I’m into movies. Er, but that is that’s the way that you know, like I said that information (inaudible) so I don’t know, it’s something that you can just take on.

## G03BBM16

(48.54)

The elderly they spend a lot more time indoors. Um, So, and I suppose they would have the TV on in the background, if they’re doing anything (inaudible) so having that information going through the air if not just visually, I think that would be beneficial for them as well.

## UCLRA02

Ok

## G03BBM16

I think that’s what you were asking…

## UCLRA02

Yes absolutely. Thank you very much indeed. Just out of interest, if a leaflet came through your door for example about memory problems, would that worry you?

## G03BBM16

If a leaflet came through my door?

## UCLRA02

Yeah, an information leaflet about memory problems would that worry you?

## G03BBM16

If I felt I was suffering with memory problems, possibly. Yeah because it’s made it real. But if it came through my door tomorrow morning, no, I’d be inclined to reading it (general agreement). Because we’ve just had the discussion today.

## UCLRA02

Ok.

## G03BBM16

And erm yeah, because I’m, to be honest with you, I thought we were going to have a more conversation, discussion with you guys telling us more about dementia because I don’t really know too much about it so I would read that leaflet if it came through my door so I had more understanding.

## UCLRA02

Ok

## G03BBM16

I would, sorry to cut you my brother, but would an older person pick up that leaflet and read it? I don’t know if they’d feel inclined to do it? Because myself, because it’s probably closer to reality for them. Probably a bit too sort of general statement to make but that’s the reality (laughter).

## G03BAM18

(50.23)

I mean personally I think it will be, I mean a leaflet come through the door I mean, I’m visualising leaflets. I’m thinking pizza, charities, so it may not have that level of effectiveness, it may not have that level of effectiveness, I think. And that’s probably the reason why the level of awareness you know in a lot of things, is as it is because I’m sure a lot of these organisations have been posting leaflets for years and things like that. But what people do is they get it, put it in the recycle bin or they do something with it. Erm, I mean they’re better off putting that calendar, 2015 calendar on it or something like that so people are encouraged to pin it up on the fridge or do something with it (agreement) in that kind of sense, do you see what I mean?

## G03BBM16

I think it would affect the majority, if there was an image of myself on the leaflet. I’d be more inclined to read that leaflet (agreement) if I saw, you know, a young black person, a man or a woman, I’d think ah that relates to me personally, let me (laughter) erm let me see what this is about. And yeah, I would take it more seriously then and I’m sure more older generation would do as well.

## UCLRA02

Ok, so having images with text you can relate to?

## G03BBM16

That they can relate to, absolutely.

## G03BBM17

Definitely something that’s eye catching, something I mean, if it’s just headline then you’ll think, er actually you’re just going to skim read it, but um, if it’s um an image and it could, I mean it could just …

## G03BBM16

Images shape our reality

## G03BBM17

Exactly, I mean it could be something, I mean it could just have somebody with similar features to me like, young black man, with glasses, just happens to be on the front cover of (inaudible)…

## G03BBM16

That is me.

## G03BBM17

That could be me (laughter), that could be me, let me read in to it and you see this and especially if it says oh ok, it affects black people and this and then you want to read more in to it and then you’ll put down the leaflet and then you probably might go on to the internet and

## G03BBM16

Absolutely

## G03BBM17

(52.18)

Further your research from there.

## UCLRA02

Do you think people would be more likely to read it if this letter or leaflet for example came from their GP or from the NHS? Or do you not think that matters?

## G03BBM16

If it resembles them, they could relate with it, yes

## UCLRA02

Ok, so that’s the key?

## G03BBM16

That’s the key for me.

## G03BBM17

Sometimes it could just be a generic leaflet from the GP, they’re just giving it out (inaudible), it doesn’t feel that personal, but…

## UCLRA02

So it being something that’s personal to you would make a difference to you reading it?

## G03BAM18

Yes, You know, I mean while we’re talking about personal and delivery of it as well I mean what’s to stop you from say like having a fair, you know a fair or something you know to engage the community. Because at this current point in time we have lack of community centres, we have you know, there’s so much things that are actually missing in the community, perhaps a way to build that awareness is to once again have a park, you’ve got, it’s something I saw yesterday in Croydon, not the actual what I’m talking about but I saw the park and I was like wow that’d be a good place to, for the family to gather. It’s not far from the local area, it’s a, yeah what is this all about

## G03BBM16

Putting an event

## G03BAM18

Yea, putting an event, presenting it with a level of enthusiasm, you know, hearing it from an enthusiastic persons voice rather than from a, their own voice (inaudible interruption).

## G03BBM16

The GP, the GP yea…, have the GP came to the park, isn’t it? With some shorts (inaudible)

## G03BAM18

Exactly, dressed up, whatever you know what I mean. Engaging, what does the community like? How can you get the information (Inaudible)

## G03BBM16

Could you guys make that happen? Get the GPs over in the park?

## UCLRA02

Ok, I’m not going to make any promises (laughter). OK that’s all really interesting.

## G03BAM18

Just like Madagascar or something, you know, (laughter).

## UCLRA02

(53.56)

Thank you very much indeed. Ok, I think that’s everything from my part. Have you got any other questions UCLRA01?

## UCLRA01

No. That’s fine.

## UCLRA02

Ok. Alright, so I think unless you guys have got anything else that you’d like to contribute…

## G03BBM16

Where could we find more information on dementia within the black community?

## UCLRA02

Well that’s a really good question, perhaps…

## UCLRA01

I could save you something if you like.

## UCLRA02

Yeah we could talk about that in a minute if you want? if I just wrap up this bit, we can turn the recorders off and then we can, you know, feel free to ask any other questions that you may want.