Individual Interview

Community Base – Brighton

September 10th 2014 – 1pm

## UCLRA02

So as you know, my name is UCLRA02 and I’m a researcher from University College London. We have just discussed lots of this already but obviously the group today is going to be recorded and if you wouldn’t mind just introducing yourself just so that the typist when they come to transcribe what we’ve been saying today they can identify who you are. If that’s ok, so just your name would be great.

## I01BBF48

Ok, my name is I01BBF48.

## UCLRA02

That’s brilliant. And obviously again we have discussed this already but I have to say that everything is obviously confidential today. So if there was anything today which we wanted to later use, in terms of writing up a paper or anything, something you might have said, your name would always remain anonymous and you will be given like a unique identification number.

## I01BBF48

Right.

## UCLRA02

Ok. (agreement) There’s absolutely nothing right or wrong (laughter) in terms of what you want to say today (agreement). I’m here to listen to what you’ve got to say (acknowledgement). Your opinions, your experiences if you want to share them. I’m interested in all of it

## I01BBF48

OK

## UCLRA02

So please feel free to speak freely as you possibly can.

## I01BBF48

OK

## UCLRA02

(1:13)

Again, we’ve already talked about lots of this but we’re obviously interested in how people from Black African and Caribbean populations think about memory problems as they get older and what you think might be able to help. So we already said that we would like to discuss your opinions as to why it is that sometimes people from black African and Caribbean communities may not always seek help for memory problems when they first start to notice symptoms (acknowledgment). And we’d also like to hear about what you think we could do to help and encourage people to seek help at an earlier stage. So, the vignette that we were speaking about before is um, Mrs Abrahams who is 70, 70 years old. She’s a lady and family members have noticed that she’s started to become a little bit more forgetful lately. She can’t remember conversations with people and forgets appointments such as to see her doctor. She often misplaces important items like her keys or her glasses. She’s physically healthy but she does have some concerns about her own memory. So as I’ve said, she’s a hypothetical person but obviously there are people out there who have similar experiences to her (agreement). As I’ve said, she’s forgetting where she puts her glasses, her keys and people close to her have noticed that she’s got problems with her memory. She’s physically health but has concerns herself. So just to start to conversation off really, I’d just like to ask you, if you knew somebody like this, do you think she should get help for her memory problems?

## I01BBF48

(2:49)

Um, that’s a funny one because sometimes I mean like, we all tend to forget things. We all, sort of like have those kind of like moments you know (UCLRA02 agreement). Um, If I kind of like relay it back to my mum, like umm,

## UCLRA02

Sure

## I01BBF48

I suppose there were little signs like that, but we didn’t pick up on it. You know, we didn’t actually recognise it.

## UCLRA02

Ok

You know, we, you know cos er, Like in our, I can only speak for my, in my family right,

## UCLRA02

Ok

## I01BBF48

I can’t speak for the Black community as a whole I can only speak from my own experience right. Um, but like you know, er, I remember there were times when um, I remember one time she actually forget her handbag at mine, which is not something she would, she’s very possessive over her things you know. And um, we just kind of like laughed it off you know, we found it and went “Oh you forgot your bag”. I took it out to the car and off she went home. And we never really thought about it you know. I did notice that she was getting more snappy and irritable and you know, just kind of like being pessimistic and things like that you know. But we still didn’t really pick up on it.

## UCLRA02

OK

## I01BBF48

We didn’t actually think you know, oh no, she’s got a memory problem. Because, she was always saying, “Oh I keep forgetting things, or you know, I can’t get the words out of my mouth”. We never recognised it as an issue in inverted commas if you like, you know. We never saw it as an issue. It’s like yeah, you’re getting older, you start forgetting things. Fact of life you know.

## UCLRA02

(4:45)

Sure and that’s really interesting that you say that because one of the things we’re really interested in is, the fact that forgetfulness is extremely common as you say

## I01BBF48

(laughter) yeah

## UCLRA02

And so…

## I01BBF48

When do we actually…

## UCLRA02

Yeah so we’re interested to mow a little bit more about, you know, what makes you take that leap from maybe being a little bit forgetful and perhaps laughing it off, shrugging it off, and what would actually make you go to your doctor for example. At what point on the, kind of I guess spectrum of forgetfulness, would make you actually think, I think I need to go and see someone about this?

## I01BBF48

(5:15)

Well I’ll tell you from a personal point of you, that er when I was studying, like especially like um, this year, during the beginning before we had our exam and everything. I was kind of like, I started to notice it actually earlier on, right like I wasn’t, you see I just put it down to stress, I just put it down to having to juggle so many different things you know. But I did sort of like notice things like for example, I just couldn’t remember things you know. Some things I would remember and some things I wouldn’t. It would always take longer. But I just thought, well that’s because I am one of the eldest in the class (laughter). There’s always an excuse for everything you know. You excuse things away you know. And um, so you know, for example, I went to my doctor as it got closer to the exam, I started to really start to fret you know, because I was thinking to myself, I am just reading all of this stuff and it doesn’t feel like anything is cemented. So that’s when I went to my doctor and I said look, is it menopause or something? You know, what’s going on? Why kind I you know remember this or that, you know? They say it that time and then I’ve forgotten it by the end of the sentence you know like what’s going on there you know. So I kind of, because I know that I’m in like peri-menopause or whatever they call it. I just kind of like, likened it to that. See, there’s all these things, underlying things that you kind of like look at. You know, so you just think everything’s down to that, especially for the female you know. And er, but the same with my mum, when we really sort of like, something’s wrong, was when she was coming over to me and I said to her, ok when you come out of yours just you know, just go to the bus stop and get on the number 2. Just wait for the number 2. So I found out what time the number 2 was coming so she knew exactly when it was coming. Then I got a phone call from her like an hour and a half later, it shouldn’t have taken her that long to get there saying that she was down the other end of Portslade. What the heck are you doing down there you know? She’s like, you said number 1 didn’t you? No. I said number 2. And then there was other times when like she would like um, you know, just phone me up in the middle of the night and go, I’m at the bus top, what bus is it that I get to yours? I’m like, AH WHAT, why are you coming at that time and She had a car you know. Why are you coming at this time? So, it’s only when things got dramatic. Maybe she knew. Maybe she knew something wasn’t right. But she never let us know. She hid it.

## UCLRA02

(07.50)

Ok, so it was at that point that you

## I01BBF48

That we started to go, that’s not right. That’s not mum

## UCLRA02

And did she want to seek help herself or was it something you had to encourage her to do if you don’t mind me asking?

## I01BBF48

(08.03)

I suppose um, I suppose we had to sort of encourage her. I think I did say to her, er, I asked her whether she had been to the doctor and spoken to the doctor about it and she said, Oh they don’t listen to me, they just want me to leave; they don’t, they just fob me off with this that and the other. And that had actually been a complaint for a number of years.

## UCLRA02

OK…

## I01BBF48

That the doctor was just fobbing her off you know. So I said to her ok that’s it, I’m going to have to start coming to the appointments with you, you know, and actually one of the doctors insulted me when I went. Right?

## UCLRA02

Ok.

## I01BBF48

Because um one of the doctors when we turned up together he said, Oh I see you’ve brought your Rottweiler with you.

## UCLRA02

And he hadn’t, this isn’t someone you know I assume? No?

## I01BBF48

NO! This is one of the doctors in her doctor’s surgery.

## UCLRA02

OK

## I01BBF48

(08.58)

So I was like, what the heck. You know like, how do you turn…,you don’t know me. You don’t know what I’m capable of. You don’t know how I am. You know. You don’t know nothing about me. You have just looked at me and you’ve made this kind of assumption that you know what kind of person I am. How can you, how can you just say that to anybody. It’s just, it didn’t make sense. It showed complete disrespect to my mother, right, and a disrespect to me. Right, so, I said to her, right that’s it. You don’t see that doctor again you know. I don’t care. And do you know what, he works up at Sussex (laughter) that’s the biggest joke you know. So um, and then um, we started to see this other doctor and at first he seemed to be on the ball and then um you know things started to slip and then we started to notice that like one day mum came round in, it just looked like, oh where she’s gone, like, she’s lost a whole heap of weight. So we started to get concerned about that you know. She just started to look a bit haggard and things you know. And so, that’s when I kind of like, just after the, after my exams, right that’s it, I’ve got to focus on mum now. And that’s what we did. We started to, I started taking her to the doctors, talking to them about her what you think about all this weight she’s lost you know and that’s when the doctors like, (sigh) some of them are just ridiculous honestly. It’s not that people don’t go, I don’t think that it’s that people don’t go. People don’t like being fobbed off. People don’t like being told, Oh um, you know like, just making it out like it’s part of your make up you know, or, it happens, you’re old, it happens. You know, you loose your memory.

## UCLRA02

So that’s your experience of going to the Doctor?

## I01BBF48

(10:48)

YEAH. That’s the experience of going to the doctors. I mean now that we’ve um, I’m moved her from that surgery because as far as I was concerned, when I asked them to do the memory test, the doctor nearly freaked out on me you know, and that was just basically from me saying that she was having problems with constipations and things like that, that’s the thing she wanted to get sorted out. So when we spoke to him about that, um, he um, he was fine with you know doing all the kind of, the things they needed to do there, but um when I said to him about a memory test, he was like, oh god, I can’t do everything at once, blah blah blah, and just went off in to one. And I was just like, this is not right. So from then, I just said right that’s it, we’re out of here. These doctors are doing you more harm than good you know, and the doctor that we went and saw just actually yesterday is on it. So he’s going to do the blood tests because I’m wanting to see if there are vitamin deficiencies, he’s going to do the memory test, he did the small memory test and is going to refer her on for the full one. Um, she’s in denial as well. So she’s not coping very well with the whole thing. She’s going for a lot of issues. She’s concerning it and any, it’s almost like externalising it to *they, they* don’t let me sleep, *they* are watching me, *they* are this, *they* are that. And it’s, can’t have that conversation with her because you have to believe her that *they* are doing this. You know, so it’s she, so she, so exactly what you’ve said about going, you know, at that kind of moment when it becomes a big issue is exactly what’s happened. Because she’s hidden it and hidden it and hidden it and not said anything about it and now it’s just got to a point where you just can’t hide it. She can’t hide it. It’s in your face for all to see. You know, so.

## UCLRA02

(12:52)

Well thank you for sharing all that. It’s been really really interesting. I guess thinking about your experience with the GP, with your mum; if you were experiencing memory problems yourself or someone else close to you perhaps? Would the GP be the person that you would go to first of all to seek help for those problems?

## I01BBF48

(13:11)

It really much depends on the GP (UCLRA02: Sure). Really does depend. I mean like my, the GP that I’m actually registered with I don’t see her; because I’ve never had, (hesitation) yeah, I don’t see her right. So what I did, was I kind of, um made appointments with the other GPs to see if there was any others I could get on with, who understood where I was coming from and didn’t just want to force me in to their sort of like way of doing things you know. And I did find one you know, so I’d often go off and see her you know. and um yeah I would, and I have done and I’ve gone to her and I’ve said to her you know all this stuff with my mum it’s kind of, kind of freaking me about a bit you know and um you know because I know that I’ve had memory problems i.e. Like I said before about when I was studying I was noticing that I wasn’t retaining, but I’m dyslexic right. So there is always that you knows. So it’s always kind of like, oh it’s the dyslexia, short term memory, you know that’s all part of the diagnosis or whatever you know. So you know, it’s like you know, I just put it all down to that and then and I thought nooo, this is, it’s just, no it’s not right, so I went to my doctor and i said to her like I want to have, not the dementia test, because I don’t think it’s anything like that but um I just wanted to have the vitamin deficiency test to see if because you know, menopause brings on these things as well you know, you become depleted in all sorts of vitamins you know and those things have an effect. So I need to know, is this happening now and shall I get on it now you know; and she seems to be at the moment quite accommodating with that. Now if mum had had those kind of queries and gone to her doctor, and had they responded in the way that my doctor has, then maybe she wouldn’t be in the situation that she is in now. Well not so early on. She’s only 74, you know.

## UCLRA02

(15:12)

So in terms of looking for help with memory problems, obviously you’ve talked about the experience that your mum’s had with her GP and how that may you know, has affected you, and may or may not um, affect whether or not you’d go to your GP in the future? Do you think that for people within the Caribbean and Black African communities there are other reasons that would stop them going to seek help from their GP other than maybe their previous experience with their GP? Do you think there’s anything else that stops people seeking help?

## I01BBF48

(15:42)

Well for some people it could be um, some people may not want to sort of recognise that you know some people just want to push on you know. Just push on through life. I mean, (hesitation) from my perspective right, um as black people, people of colour, right have always had it hard in the world, right (laughter) plain and simple right. Anything that you’ve done from going to school when you were little, to trying to go to college, to go to university, to keep a job, flat, you know mortgage, bank loan, whatever it’s, there’s always a problem. There’s always a problem. So you’ve get double the stress of anybody else right. So, we get double the stress therefore blood pressure is primary around you know ethnic minorities, yeah, course, yeah, that makes perfect sense. Because you’re under a lot of stress, you’re holding a lot of things just to get through life you know. Whereas you know you might walk through a door and you won’t think twice about your circumstances, I can walk through a door and think I’ve been judged, initially in somebody’s mind, I’ve been judged, you know, on, on whatever you know. I mean I’m not saying it happens every time but it is a factor you know. It is a big factor and It’s a big factor that people feel that they don’t get the same, they don’t get the same treatment, like you go to a doctor, you don’t get the same treatment as your other friend, your English friends. You know, you English friends say, Oh, you know, my doctors done this that and the other, I had that, I’ve had this done, that done, that done and that done and then you go to the doctor thinking alright, you know, maybe that and then they go oh no. and they just kind of fob you off with something you know and it’s like there’s only so much, you’re not going to keep, if you keep getting pushed away, you’re not going to keep going to keep getting pushed away and there’s only certain, you have to be quite forceful, quite determined right, to keep pushing through to get what you want and then you get the stigma of being classed as aggressive, because that comes up in your notes, because that happened with me and my child when she had eczema, because I didn’t want to go down the lets just slap it with hydrocortisone, steroids, blah blah blah blah blah; I kind of wanted to take a bit of that and a bit of the alternative and find another way to sort of you know… and um, I found that in my notes, that I was a bit aggressive and that’s the other things it’s all preconceived ideas, it just makes it difficult, you don’t know, you know like sometimes you just don’t know, when you…if people… when I’ve spoken to other people about things, they’ve said to me, yes, don’t they just and then I’ve heard English people say exactly the same thing you know. I really am… I’m kind of like at a loss. I just know, I just know that in some places, because not everywhere is the same, but in say in Brighton, that maybe that is more um a reason why people tend not to bother to go to the doctors because either they don’t have a very good doctor so they don’t want to go there and feel like a nuisance which is something mum used to say a lot, they make me feel like a nuisance.

## UCLRA02

(19:18)

It’s interesting that you say that because some of the people that we have been speaking to who were perhaps born abroad, have told us that things are better in their home country with coping with memory problems (I01BBF48: yeah) and others, obviously have said that things are worse. Or what do you think about that?

## I01BBF48

I think that in um I think that back home right, I think that people are more the culture is more accepting that um that you’ll have, it’s more, not everywhere, see I can’t generalise, I’m scared of generalising, I don’t want to appear like I’m generalising, um but there’s a lot more acceptance of the elderly, of children, there’s a lot more acceptance of like you would help each other; there’s a lot more like, Oh what’s happened to Miss Brown down the road? I haven’t seen Miss Brown, did you see Miss Brown? No, I haven’t seen miss brown, go and knock on the door, see if she’s alright you know and if she’s not alright, oh when you cook up the food, take some food over for Miss Brown because you know she’s not cooking anymore. Do you know what I mean, and it’s such a matter of fact, like here everything’s all sort of like, you’ve got break through barriers, you’ve got to break through doors, you’ve got to find the right one person, you’ve got to say the right, you’ve got to use the right turn of phrase; all these things are barriers, they’re all barriers to help you know. If somebody needs help, they fall down you don’t know, ok what’s your registration number, what’s your house number, what’s your postcode before you give that person help, you just help them. And I think that, yea I think it’s a systemic thing and it’s a cultural thing you know. Country used to have that you know, but it’s not like that anymore you know, you used to have that, you know.

## UCLRA02

(21:08)

That’s really interesting, so you feel for some people from Black African and Caribbean groups being back at home might be a place where they’d more readily get help from the community…

## I01BBF48

They would get help from the community, the problem with that kind of is that sometimes what they don’t have is things like the NHS which is a godsend right. So they don’t have the NHS so the free care, when a person gets to that point when they need medical assistance or psychological assistance and things like that might be different, you know so they might not have access to that and to medication, those kind of things, those kind of like infrastructure kind of things you know that they may not have access to, that would be the problem you know, that side of things would be the problem, back home maybe you know where you have to pay for everything you know. So, that could be a big um, a big issue, that’s maybe that’s why some people believe that it’s better here. You know we, then you’ve got in some countries where they just don’t um, you know, when people are having problems or you know they’re just kind of cast aside, you’ve got that side of things as well so…

## UCLRA02

(22:20)

Ok, so a mixture. I mean thinking about community perhaps and other people around you, do you think others would influence your decision as to whether or not you would seek help for memory problems for yourself or?

## I01BBF48

For me personally?

## UCLRA02

Yeah, or for somebody around you or someone that you know, close to you perhaps. Would others influence whether or not somebody seeks help for memory problems? That could individuals or the community.

## I01BBF48

(22:43)

I think maybe. I think maybe that has an impact on the older generation, on the first generation, because they do come from abroad and they come with their own set of values and er cultural um traits you know which are also different from the second generation because we grew up here so, our culture is based in England with the background of the Caribbean or Africa or wherever you know. So um for us it would be I believe, my generation it would be easier, but I think for the older generation it’s a lot harder…

## UCLRA02

To seek help sorry?

## I01BBF48

Yeah, yeah I think it’s a lot harder you know for them and I think it’s got a lot to do with community

## UCLRA02

OK

## I01BBF48

(23:32)

Because um, I do believe that Isolation right, I know that this could happen across the board across spectrum, I do believe that isolation doesn‘t help. I mean I’ve been looking at since my mums like kind of had all these issues going on, we’re not quite sure what it is yet, but um I’ve been looking around at you know other places where they you know look after people from like um ethnic minorities and how they deal with it and what kind of facilities they have and you know and they do have a more, like the same like you would have like clubs for the over 50’s, and they have this that and the other they have similar things buts with a not a colour base but er an ethnicity base you know like um you know anyone whose from a another culture you know who wants to take part and can go you know. So it’s not a black thing you know what I mean, it’s not that, you don’t want to be segregated you know, it’s a universal thing where people from other cultures might just feel more comfortable within that environment; that’s not the exclusion of like any English person who wants to be involved in that as well, do you know what I mean, but you know they have buses that pick people up and take them to a community centre where they can have something to eat; they might have rice and peas or Daalpuree you know for the Indians, or do you know what I mean ,you know so things that um that stimulate them and games like dominos and things like that they remember from when they were younger and stuff you know and apparently those kind of things is what helps to keep their memory active you know, helps to stimulate you know, maybe, I don’t know, maybe that’s something else you could look at as well you know, like whether people within those areas are doing better than people without those facilities in other areas? It’s another um aspect of things because I think that that’s what’s really missing in Brighton.

## UCLRA02

(25:35)

Ok, that’s really interesting. Just moving on from that slightly (laughter and I01BBF48 apologising for going on)… it’s all really interesting stuff. I was just thinking I mean, obviously nobody wants to be ill.

## I01BBF48

NO

## UCLRA02

But do you feel within the Black African and Caribbean communities, getting a diagnosis of dementia is any different from getting a diagnosis of something like arthritis or diabetes for example? Is the diagnosis of dementia any different from anything else within those communities?

## I01BBF48

(26:08)

At the minute it’s hard to say because um I’m only just being thrown in to it, so to speak, but it would not surprise me if it was (laughter,) I wouldn’t be surprised if it was you know.

## UCLRA02

OK. Do you feel that there’s much knowledge about dementia within those community groups? What do you think the levels knowledge are around dementia?

## I01BBF48

(26:27)

Er, put it this way, when I’ve been asked a lot of like mum’s peers have asked me you know how’s your mother, this that and the other, then they’ve used words as doolally, and um a bit crazy or you know and it’s like, but that’s kind of ignorant talk from people who are supposed to be previous nurses (laughter) you know and it’s like well if you grew up with these kind of people as your friends, would you really want to say you’ve gone doolally? You know, would you really sort of you know, you would try and hide it wouldn’t you? Because it’s like whole kind of like crazy, she’s gone crazy you know. Um it’s that sort of impression that maybe they wouldn’t you know, maybe they wouldn’t tell each other, because she’s very, um when I talk to her about certain things and I say oh you know so and so is going to come…I don’t want her to come and see me like this. That’s a fear of hers.

## UCLRA02

Ok. So do you think she talks about her memory problems with her friends her peers?

## I01BBF48

I don’t. I don’t think she does. No, I don’t think she does. I think that maybe its part of the problem that she didn’t have anybody that she could talk to about that. Or maybe the only person, because there was one woman, an African lady who she was really close with and um she may have spoken to her about it but she died. She died.

## UCLRA02

I’m sorry to hear that.

## I01BBF48

(27:58)

So um that was quite a big er, quite a big knock for her you know so um I think she might have been one of the only people if anything, or maybe um, you see the thing is is, my aunty, she’s kind of, I think she’s got Alzheimer’s now you know. So she’s gone in to a home, so this…

## UCLRA02

Ok, So is this your mums sister?

## I01BBF48

Yeah, her older sister and um so that’s kind of constant thing for her. Because she went and saw her the other day and um and I think it might have frightened her. Yeah. The thought of being in a home you know. I think that really scared her; and not only that, we don’t get much help do we. I mean maybe there should be more, I mean I know that there’s a drive at the moment because they think that by the year 2020 or whenever it is there’s going to be so many million people with dementia, but um (pause) I don’t know, you know, I kind of like always feel like these things are sort of like hit and miss you know and nothing really gets um, really gets done you know. Studies fine but unless there’s something practical that comes at the end of it then it’s just paper work, it’s just more paper work.

## UCLRA02

Sure. Well that’s probably a really good time to actually move on to the sort of second half of what we’re going to discuss if that’s ok.

## I01BBF48

Fine.

## UCLRA02

(29:25)

Can I just ask you one more question before we move on? Obviously you were saying you think your mum’s perhaps not talking to other people about some of the problems she’s experiencing but obviously she speaks to you and the two of you have a relationship where you speak about it. I don’t know if your mum’s religious or not, but I just wondered if you thought that anyone’s religious beliefs would affect whether or not they might seek help for memory problems? Any religious groups that they might be part of. Would that influence whether they’d seek help for memory problems? Your mum may not be religious, I don’t know.

## I01BBF48

Er, no no, she is, but she’s not ultra ultra religious but um I can think of um some other people from um a different community, religious community, which are a lot more devoutly religious who had an elderly member of their family who had um dementia which turned in to Alzheimer’s and they looked after her at home for a long time and um then it got to a point where they couldn’t anymore you know and she had to go in to a home but she was on medication and always going to the doctors and things like that so I , the only thing I can really say on that one is no, I don’t think that, I think it really does depend on the individual and how (pause) what’s the word, I can’t think, devout, I don’t know um they are. But some people do become really obsessed by religion and kind of and a bit over the top with it you know so those kind of people may not but..

## UCLRA02

May not seek help sorry?

## I01BBF48

Yeah, they would say it’s up to the good lord you know to heal you know whatever but um for some people they would see it’s a medical problem not a religious issue kind of thing. It’s not a thing of faith you know. So it just depends on the level of you know understanding that they have of you know what is religion and what is just a medical function you know that needs addressing.

## UCLRA02

(31:35)

Yes. That’s really interesting. Thanks very much. So as I’ve said we’re just going to move on to kind of the second half of our discussion if that’s ok. It’s building on the things we have already been talking about. I’d like to really now hear about your thoughts and opinions around what you feel could be done to help and encourage people from communities such as your own or your mums for example to seek help for memory problems earlier on? So we discussed prior to meeting that we know that people who seek help for their memory problems earlier on in the illness do generally speaking better overall. Those people are better able to be supported themselves but also the people around them, family, other care givers, perhaps also best placed to get support and to plan for the future. So, just again to start the discussion off really…If you or someone close to you had memory problems what kind of information would make you more likely to get help for those problems? And when I say kinds of information I’m thinking about you know, would it be leaflets, DVD’s; what kind of information do you think you would take notice of I guess and would encourage you to seek help? What do you think would be useful to have out there?

## I01BBF48

(32:54)

Um, in the surgeries it might be good to have like some big posters right, not scary (laughter) but maybe slightly light heartedly humorous you know. Um, starting from the you know 50 plus you know, starting to forget a few things? How about having a check-up you know. Little things like that you know. Don’t you know, sort of like just aim it at like 70 plus or something like when you know things could have already gone downhill like start earlier you know start people thinking about maybe I could have a check-up and see you know, you know and you know things to sort of like not to say that’s it dementia, maybe it could be formed in a way, maybe you have a vitamin deficiency. People will be much more inclined to go if they just think it’s something a vitamin deficiency which it could actually be you know. So so, something when you’re sitting in a waiting room you’re just sitting around trying not to state at somebody else who’s staring back at you. You’re looking at the pictures and the things that are on the wall, you know so things like that would be good, right. Um, I can’t, from the Black community um organisations, organisations that are specifically geared towards families or you know um the elderly and not necessarily just in black organisations you know like in um in any kind of community centres you know. Um just to attract people’s attention to it you know and to suggest you know going to the doctors but then having like a mandate for the doctors that you know, not to fob people off when they come. You know it should be a necessary thing you know like the same like when a woman has to have a cervical smear every 3 years right, when you reach a certain age right maybe it’s good to have a blood test that specifically looks at vitamin deficiencies you know when people reach a certain age then you would flag up certain things and if it’s not due to that then you should be looking in to other things you know so you would strike at that time when the person can still think clearly enough to make a decisions for themselves.

## UCLRA02

(35:24)

Ok, so you talked there about having a sort of mandate for the doctors I think was your words. If you received a letter in the post perhaps or your mum received a letter in the post from her Doctor, giving her information about memory problems and perhaps inviting her in to the practice you know if she had any concerns. Do you think that’s information you’d take note of?

## I01BBF48

(35:36)

I think people might do. Because not only that it’s private isn’t it. Because if you have it coming through the door then you don’t have you know, because some people, I would just take a picture of the poster you know and then like go home and sort of like phone up the people, but some people wouldn’t like to do that you know. Some people might prefer that something just comes through the letterbox, they open it up, they read it in private and they can go in private ad see the doctor and don’t have to mention it to nobody else. Nobody else has to do. So something like that might actually be a good idea you know.

## UCLRA02

Do you think it might worry somebody, receiving something like that through the post?

## I01BBF48

(36:24)

There’s always, there’s always hypochondriacs, there’s always those people who are going to go’ Oh my god I’ve got a brain tumour’, there’s always going to be that. You know, you can’t escape it you know and but as far as is and that’s something that’s going to have to be dealt with, you know, have to know how to weed those kind of people out you know and allay their fears but um I think in general it’s just um (pause) you know it’s not something that people have to do. It’s a choice you know. Do it or not. It’s just like the cervical smear you know. I don’t go for it every year, every time I’m supposed to go for it no matter how many letters I get. I don’t go for it all the time. You know, so it’s a choice for people to do it you know. If it comes through the door you’re going to hit a lot more people that way, I know it’s the cost is going to go up, you’re probably going to say about the cost of doing that but you know, but I suppose it’s about weighing up that cost against the ongoing er cost of medicating or looking after somebody in a nursing home or something for X amount of years until they die. If you can have a person who’s more independent for more of those years and then they only need help towards the end of that time, that’s got to be a better situation for both.

## UCLRA02

(37:50)

That’s really interesting. Just going back to one of the things you said earlier on um when I first said about your mum and seeking help. One of the things you said to me was that you didn’t pick up on the signs, you just didn’t notice those early signs. You didn’t realise…

## I01BBF48

(38:02)

Yeah, I didn’t see it as a problem.

## UCLRA02

Yes. So I’m just thinking about in terms of what information people should have out there. Do you think it would be useful for people to know about what the signs and symptoms to look out for?

## I01BBF48

Yes, yes. The same way like they tell you how to look for breast cancer, for testicular cancer, for this for that and the other exactly yeah. There should be. There should be information out there leaflets, posters, something on the net that’s easily accessible for you know, for the geeky lot you know um in all aspects you know whether it’s like little, like adverts on the TV you know like um I don’t know how they would do it you know, um, but yeah, there should be, you know in newspapers, all sorts of places.

## UCLRA02

(38:59)

Ok. If we were to produce a leaflet for example, other than the signs and symptoms and things like that that people can keep and look out for, what other information do you think people might find useful in helping them and encouraging them to seek help if they were noticing those problems? Do you think people know where to go for help?

## I01BBF48

(39:18)

No. I don’t think so because I’m finding it a bit of a nightmare, and not only that when you go to places like um er. A lot of the time um services are stifled because of a lack of diagnosis. Right so they say, has she been diagnosed? Er, no. Oh we need a diagnosis before we can do this, before we can do that. Do you see what I mean? So a lot of help so to speak is hampered because the diagnosis isn’t there and then, I’ve been told that diagnosis can take a long time so it’s (laughter), you kind of hit a brick wall really in a way.

## UCLRA02

(40:02)

Sure. Do you think people who are seeking help from their GP for memory problems, do you think people such as your mum or yourself, know what to expect when you seek help from your GP?

## I01BBF48

(40:15)

No, no. Haven’t got a clue. You’re just thrown in at the deep end and you’re just splashing around hoping someone is going to fish you out of deep water you know, because you just feel completely lost and unless you’re in the health profession and you have some inside knowledge or some friend who’s had a previous situation who can tell you how to get round the mire of stuff, everybody’s got a horror story. Everybody’s got a horror story about trying to get the right kind of care, about there just being one type of care. It’s like a step ladder. It’s rigid sides and um you know, even when people have tried to say well you know like, I tried to do it like this and they seem to be happier like that you know and then you’ll have a health professional go NO, this is what you have to do, you have to do X, Y and Z and then you’re left with a person who’s not only angry because they feel like they, because they’re still in there. That’s the thing, what people forget, they’re still blimmin’ in there you know and it’s like you know, you’re treating this shell but there is somebody inside the shell you know; who has needs, who has an Ego, who has pride, do you know what I mean and that is not being addressed and that’s when you end up with these people apart from when they get to that, um the other end of things when they kind of just lash out and stuff, you know that’s when you end up with the confrontation you know and like maybe stubbornness, won’t take their medication you know because it’s the only thing they’ve got left you know. So this kind of, I know person centred might be a bit sort of corny you know, and it is, in some ways it is and in some ways it’s not but it has to be a little bit flexible you know in the treatment you know.

## UCLRA02

(42:08)

Sure. That’s really really interesting points that you’re making. I’m just thinking, obviously we’ve talked a little bit about what information might be useful for people to know about. How do you think is the best way of getting the information across to people? You know we talked about obviously a leaflet. How should the information be presented? What do you think people would take notice of?

## I01BBF48

(42:32)

Now what would I have taken notice of? (pause and laughter) One of the first things that I even knew about dementia, it wasn’t kind of, was a film. It was a film and I think it was with Robin Williams and somebody De Niro or something and they were, it was a, he tried this way, he found this drug or this something or other that he did with these patients who were like almost like comatose you know and um ere non-responsive and then he found this way to interact with them but it was, it was done in a way that was um, it’s visuals. I think visuals is what really stick in people’s minds you know; like whether it be mini vids or pictures or whatever, but I think visuals really stick in people’s minds you know.

## UCLRA02

So with the text to have visuals as well?

## I01BBF48

(43:33)

Yeah, yeah. Not just like sheets of writing and people kind of go uhh. You know, I mean I’ve had to do loads of research and I still don’t know, still don’t know enough. You know, I’m still just learning you know and it’s very time consuming if looking after somebody, where do you get the time to do the research you know so um, I think, kind of visuals, I’m not really sure about that one to tell you the truth.

## UCLRA02

That’s ok, we can move on.

## I01BBF48

(44:05)

Maybe even little plays, plays? You know um, anything that highlights it. It could be highlighted in a humorous way, but you get the message across and it makes people turn, makes people kind of like think well actually that was a really good play, it was really funny but do you know what (laughter) do you know what I mean, I don’t know.

## UCLRA02

(44:28)

Ok, um, perhaps another question or a good thing to talk about would be who do you think the information should be aimed at if we are going to be giving the information to people about memory problems? Do you think it should be pitched at any particular group?

## I01BBF48

When you say group, do you mean age group, or do you mean ethnicity?

## UCLRA02

(44:44)

Well I mean this study will obviously be just Black African and Caribbean groups, so in that sense yeah, I guess I mean age group or gender, it could be?

## I01BBF48

No, I think it should be pitched at everybody I don’t think there should be any race, gender or age group kind of thing because the problem with dementia unfortunately so I’m learning is that it can hit some people at a very young age you know, so just don’t know. You know who it’s going to hit and when you know. But um…

## UCLRA02

So it’s good to have everybody knowing about it is it?

## I01BBF48

(45:21)

Yeah, I think, I think it’s good to sort of like plant the seeds, maybe secondary school age is good you know, sort of like when you’re not in the first couple of years at secondary school but in the second half of like secondary school when they’re coming up to fifteen/sixteen kind of age group. It might be a good idea to just plant a few seeds, not make it heavy you know, just plant some seeds you know at that age, just gentle seeds at that age; but then you can like ratchet it up you know like I don’t know, for the 18’s and above I suppose and those people who are interested and working in that kind of field will sort of like be curious about it enough to go and do more research and those other people who just kind of like want to take the pointers and just stick with that and take that. But um, I think it is good to be pitched at everybody, because it’s not something, it might escape a few people but you’re always going to know someone who had someone you know so…

## UCLRA02

(46:22)

I’m just thinking, going back to receiving things in the post perhaps do you, I mean a lot of things come through the post, a lot of junk mail, lots of leaflets come through the door, so I just wondered what you felt about if you were to be sent something, what would make it more likely that someone might pick it up and actually take the time to read it if it came through the door?

## I01BBF48

(46:45)

Yea, that’s a good question actually. Hmm..Err…so long as it doesn’t come in like takeaway flyer, because that just goes straight in the bin for me, you see all them bright colours and I’m like (laughter) but um…

## UCLRA02

Does a logo of the NHS means anything to people do you think within communities such as your own?

## I01BBF48

(47:03)

Yeah, yeah. I think it would because it’s something to do with health, then automatically you’re going to think oh that’s a health something or other, let’s have a look, a quick look at that and see what that is. Because you just kind of like just open up envelopes don’t you, just open up envelopes and see oh what’s that, you just have a quick look you know, so the first, the first few lines are going to have to be the gripping ones (laughter) otherwise if you get to the punch line at the bottom, you’ve had it (laughter) because you’re only going to read the first few lines you know and see whether you want to keep that or not you know, so um…

## UCLRA02

(47:35)

Do you think people would be more inclined to look at a leaflet that perhaps came in an envelope with a letter from you GP?

## I01BBF48

(pause) Yeah. Because if you, if you’ve got a letter from your GP you are going to look at it aren’t you and um, I wonder how that would work? Maybe um (pause) you know like you have, like some places have um like banks and things you know, that they have letters that they send out to their customers and things like, something like that that could be like, a letter he just has to sign once and then you just print them off and they just go, I can’t remember what you call it, mail merge or something you know, off to each individual person you know but then some information about you know, dementia or if you’re coming to a certain age you know you should consider X, Y and Z, you know maybe there’s a little leaflet inside or for further information please contact or make an appointment or this that and the other but then you see, then again you’d come and the doctors going to say well we’ve got this influx of people coming in to find out if they’ve got the onset of dementia (laughter) and you’ve got a (inaudible), always something isn’t it, it’s like you’re going to, there’s always going to be something, someone’s going to have some sort of gripe with it you know, but it does need to be tested.

## UCLRA02

(49:07)

Yes, absolutely and I mean the part of this study is that we are going to do that in whatever it is that we develop, whether it be a leaflet or a DVD ,you know that is the next phase of the study, to do a randomised….

## I01BBF48

I’m not sure about the DVD, that’s the thing, the DVD it sounds like a good idea but I’m not sure how many people will actually get round to looking at it do you know what I mean because it’s like if you’re going to watch a DVD you’re planning to have a video night in and you kind of get your popcorn and your bottle of whatever you know and you sit down with your feet up to be entertained you know so, it will work for some people but I’m just, when I think about my neighbours (laughter) I can’t see my neighbours sticking one of those on the video and watching it at all. Not at all (laughter)

## UCLRA02

(50:00)

That’s ok. I mean time wise, we should probably think about coming to an end just one last question if that’s ok before we do wrap up. I just wondered, what would make you feel that it was worthwhile going to your GP to seek help for memory problems? What would make you feel that seeking help earlier on would make it worthwhile for you?

## I01BBF48

(50:20)

Knowing the effects that it has, seeing the effects, because that’s what has made me go oh my god, I don’t want to do this to my kids.

## UCLRA02

Ok, so knowing what dementia is and…

## I01BBF48

Yeah, the real side of it not the not a ponsed up fancy ideas of it you know, real, just make it real. It can be like this and for some people it’s like this and they can still lead their lives and for other people it’s like this. This is a serious thing you know. It’s like you said you know, the earlier people get you know screened for it, the earlier they get diagnosed, the earlier they get help, the better their outcomes are, the more independent, more sustainable even, you know their outcomes can be you know; but for those people like mum who didn’t get the help you know, who didn’t recognise it, we didn’t recognise it you know, dementia is just a word. It’s just a word you know. What does that actually mean you know? And then assuming all nurses know. Because they don’t! They don’t. You have to work in that field to know you know. So it’s still kind of limited knowledge out there on it, it’s only through personal experience you know and through your own research that you can really get to find out what it is and then understand the difference between vascular and some, I can’t even remember, there’s like three or four of them or something you know and what’s the difference and what does that mean, what does that mean and how does that come about and how does that work.

## UCLRA02

(51:56)

OK, thank you very much indeed, I’m going to turn this off now I that’s alright as we’ve come to an end.