September 10th 2014

3pm

Individual Interview

## UCLRA02

Ok. So as I said, I’m a researcher from University College London, my name is Sharne Berwald and we’ve obviously already discussed some of this, but just so that you are aware, everything that we talk about today will be confidential. It’s obviously being recorded and just for the purpose of the recording would you mind just saying your name just so the typist who’s transcribing this can identify you.

## I02BCM49

## Yes, no problem. My name is I02BCM49.

## UCLRA02

(00:31)

That’s brilliant. Ok so just again to re-emphasise really that there is absolutely nothing right or wrong in what I’m here for today, I would like to hear anything and everything that you’ve got to say. I’m really really am interested in your own perspective, your views, experiences, things like that. So, again as we’d already have said, we’re interested today in how people from the black African and Caribbean populations in particular think about aging and memory problems as they get older. So we’d like to discuss your opinions, views and experiences, if you would like to share those with us, as to why it is that often people from the Black African and Caribbean communities don’t always seek help for memory problems when they first notice those initial signs and symptoms and your views as to what you think we could do to try and help and encourage and support people to come forward at an earlier stage.

## I02BCM49

(01:23)

Ok.

## UCLRA02

(01:24)

So just really, I mean I’m sure you’ve got loads to say on it, I mean just to kind of open up the discussion I’ll just give you a very short kind of vignette of a lady who for the purpose of this she is called Mrs Abrahams, she’s 70 years old. Family members have noticed that she’s becoming more forgetful lately, she cannot always remember conversations with people and she’s often forgetting important appointments such as doctors’ appointments. She often misplaces items such as her glasses, her keys. She’s physically healthy but she has noticed that she is starting to have memory problems herself. So just to start us off really, if you were experiencing problems like this or you knew somebody experiencing problems like this, do you think they should seek help for their memory problems?

## I02BCM49

(2:07)

Well I, yes, I would, I would because I work in kind of the health and wellbeing er the sector, I would I would be able to, I would sign post somebody or I would you know alert somebody. One of the issues though is around aging, and I think aging is because, people don’t er take it seriously because when somebody is forgetful mindful and er, generally I mean people will say Ah it’s because they’re getting old and they would just stop it there, they’re getting old so it’s expected that they’re going to become a bit forgetful so that the idea that dementia being a debilitating illness is not really recognised, in terms of that that dementia because people say oh they’re getting old, it’s expected of them and we just have to be a bit more you know understanding of that rather than saying this could be you know a debilitating thing that has got serious implications further down the line. So, er, I mean that’s one of the kind of generally that, me I found that people don’t really take it seriously that see dementia’s an issue. More recently we’ve seen over the last couple of years the government has been putting in a lot of, trying to do a lot of work around, sensitising people to Dementia, so I think there’s a bit more awareness and people are understanding that you know that it’s not just forgetfulness and using that umbrella term but actually it is dementia and dementia is a serious issue and that there’s ways that people can be supported around dementia. But with aging, er, again I know with African and African-Caribbean I know with our community that we don’t put people in old people’s homes so therefore, because it would be seem as a shame if you said you’re old, to put them in a home. (inaudible) that would be a wider thing to look at and see how many people are actually, African or African-Caribbean are actually in old people’s homes, because they’re not; because generally it’s our responsibility to take care of our older generation and older folks and more, the majority of them would be living with er one of the children or a relative so they’re the ones really who have got to be made aware of their responsibility not just keeping Somebody fed and breakfasted and giving them somewhere to sleep but really about taking responsibility for their ongoing health, needs…

## UCLRA02

(04:48)

## It’s really interesting that you say that actually because I’ve heard on a couple of occasions now talking to people about how they’ve said very similar things about how you know we don’t put our mothers or father in homes etc, we care for them more within the community and at home if we possibly can and also, someone recently talked to me about the kind of fear of care homes (agreement I02BCM49) and things like that and I wondered, do you think within those communities because you know they see how you know often within kind of white UK communities we do put people in to care homes, do you think there’s a fear of coming forward to services with memory problems that that may happen to them and that’s where they have to go ?

## I02BCM49

(05:24)

Yeah. Maybe it seems a strange thing to say and it seems people might even perceive it as naïve when you vocalise it but people might think that people generally think that if you do put them in a home then they’ll get worse. There’s no, ‘cause once they’re in a home they’re on a slippery slope downwards as opposed to you know, an extended opportunity to care for the individual which is what the homes by right should be. It should be about you know giving respite to the carer and you know having much more focussed services that will meet the needs of the older person but generally you know it’s perceived… I mean I would never, I would never if it’s within my powers to be able to, I would never put my mother, my father if he was still alive in a care home. Not as, within my powers I mean, yeah you know even if I had to split off a bedroom to make an extra room if I didn’t have, but I would see it as a shame, other people or members of my community would say to me you know, they would look down at me to say ay you know, why have you sent your , and this is the mother who gave birth to you or your father who brought you in to this world and then you’re abandoning them like that. So er I would never I would never never think, it would never occur to me even though I know and I work in the care sector, I would never think to myself to put my, any of my relatives in a home. An uncle of mine passed away on Monday in fact and he was in a, he was in a warden controlled home, but in the warden controlled home that was a, a choice that he had made to go in to a home because he was starting to see that he was feeling a little bit isolated because his son wasn’t kind of visiting him and he was feeling a little bit lonely so he went in to a, he went in to , he put himself in to a, or really the council put him in a warden controlled flat er and as I said he passed away but still he would often come and he would eat at my sister’s place, er you know and then my mother would go and visit him and just check on him and then he would come and, when he was active he was er very active and er, but he died and this is, but he had melanoma and the melanoma just kind of got in to his legs and then it eventually got in to his lungs and even up to last week, even up to last week when he was in hospital, again I went in to the hospital and er you know I shaved him, even though I’m somebody with a beard but if I haven’t said it I’m the last person to be wielding a razor to his (inaudible) but I haven’t used one of these in so many years but to shave him, to take care of his needs er, and to encourage him because anyway the plan was that when he came out, instead of him being back in the home he would be you know in one of our, with one of my, in my younger sister’s place or the chance was there that maybe he wanted to come and stay with myself then he would do that because he did, not a lot of confidence in the NHS and even as somebody who works in the sector, still not a lot of confidence in the NHS. You were talking about you were being in Croydon, Thornton Heath, they’ve got a hospital there, Croydon University Hospital, before it was called Mayday but colloquially it was called Maydie. Because experiences I’ve had, I had my sister went in to that hospital and the level of care that she received I mean she had pancreatic cancer and er you know that in the hospital they allowed her to and say they allowed her because she ended up getting the legs became swollen, I think what I’m trying to remember what it was that she got, she got er just that the legs, her legs became swollen and really the last kind of just before she passed she was really that we really you know, my mother , I had to pay for my mother to come from the Caribbean to come and then she stayed and looked after her my sister in her last few days and then we took her out of hospital and then she was out of hospital for about, what was it, a week and then, after that she passed away but it was, she herself my sister wanted to leave the hospital because she herself was having, wasn’t having, well it didn’t really feel that she wasn’t getting the level of care so therefore the confidence generally and this is what I will try and illustrate, the confidence within the NHS, people don’t I mean, small things aren’t a problem but anything major…

## UCLRA02

(10:35)

Ok. Well just maybe expanding upon that and building upon the experiences that you’ve obviously had um, if you started noticing memory problems in yourself or somebody around you, where would you think it best to go and seek help?

## I02BCM49

(10:50)

Well I mean, well I mean because I know a little bit about that er there are I think there’s a carpal body syndrome, carpal some syndrome is one of the kind of the longer er, term effects of dementia that you can get it’s one of the serious, or Alzheimer’s; but er if I had dementia er or I was starting to notice memory problems, I know that I should go to my GP but I don’t have a very good experience of my GP because you know the GP’s they themselves are under pressure so you can’t really discuss with them and many people African, African-Caribbean and the majority of the time when we’re talking about our experience with the doctor, we’re saying like, why the doctor doesn’t just give you enough time, when you go there you’ve got seven or eight minutes and what he wants you to run and get straight to the point of why you’ve come to visit him. Whereas most of the time you want to go there you want to talk about some of the other things and I’m very much in er in favour of a much more bio-psycho-social approach to healthcare and docsten, doctors they still focus on that medicalised approach and because they’re still focussed on that medicalised approach it means then you don’t have very much, people don’t have much confidence in them dealing with serious issues. So if I had memory issues I would know I needed to go and speak to a doctor, but I’m more likely to exhaust er avenues within my own community before I go to, I don’t know if that is also because I’m a man and we as men, boy, ay to get us going to a surgery door is tough.

## UCLRA02

(12:38)

That’s interesting that you say that because I was going to ask you about gender as it’s something that has come up in some of the other groups that I’ve run and whether or not you think within the Black African and Caribbean communities there is, there could be differences between men and women seeking help and the dynamics around gender?

## I02BCM49

(12:53)

Definitely, definitely, definitely men, men we don’t, we don’t as much as we should be, we don’t I mean we, and I think again it might be a cultural stroke traditional thing whereby you know all the while it’s men you know, we we’ve got to be you know seen to be strong and firm in the community although can I just say that man flu is real! But, say so all the while we’ve got to just make sure that you know so all the time so it’s kind of not wanting to take the time out to go to the doctor or to be seen as er you know that you know you’re not able to stand up to the pressures of time or er, your experience that you have, having to be sitting in the doctors surgery as a man waiting for the doctor to come and tell you oh there’s nothing wrong, here’s two tablets. I mean my son, I’ve got an, I’ve got my son, which I think the doctor himself sometimes doesn’t realise, don’t realise what they say but my son is only 19 and he was feeling not so well so he booked himself an appointment with the doctors and when he went to the doctor the doctor examined him and basically told him, because when he came back and told me I was quite shocked, I laughed, I was quite shocked. The doctor said to him er, I don’t want to see you again because you’re a healthy fit young man er you know you’re coming here wasting my time and that’s what the doctor told him, you’re wasting my time, I was laughing, because the reason I was laughing was because I thought that I would look at my son and my son he keeps himself well, he’s in the gym, he’s in the gym like six out of seven days er so but that experience will stay with him and then that’s why black men present late because when they do go they’re told that you know why you’re coming to with your aches and your little twinges and things so therefore, that then puts off a lot of men from going because they would just feel that the doctor will come and tell them you know that it’s nothing, that you know it’s nothing. I went to the doctor about a couple of weeks ago because I was feeling a bit twinges in the back and I wasn’t feeling something. The doctor gave me a box of ibuprofen and said to me take these anti-inflammatories and what I really needed him to tell because I really felt that I was in, that I was in a lot of pain and I’m still feeling a little kind of the twinges there, but because of the experience of the doctor, you know, I would, I would just think to myself maybe let me not bother, let me just find somebody else, maybe go to a chiropractor or somebody like that, or go and have a massage somewhere that might be able to help rather than going to the doctor because then the experience that we have of the doctor . The doctors are not sympathetic to the issues that we’re talking about and maybe again I would say a lot of other ex… , people who I’ve spoken to and even in the work I’m doing now, have talked about the language that if you’re a White British you generally , have got an understanding of the language that you need to use when you go to the doctor. So therefore I think perhaps you know if people understood what language, what, how do you express to the doctor how you’re feeling because obviously we’re not saying it in the right way that the doctors are taking that the issues that we got, are quite serious to us because (interruption alarm) yeah so you know it’s a and that’s the experience that I have and I am quite, you know somebody who is schooled () and you know I’ve really been around, I’ve been to different I, the experience that I have here in the UK is (interruption alarm) is quite negative so therefore this is why you know many of us we wouldn’t be going. So if I had, To go back to question, this is why I wouldn’t really because the experience , I mean I know I should go to the doctor and I think if things reached a stage where you know I was seeing it was really becoming a problem to me then I would go for the memory loss or I was losing too many things, but generally you know we don’t have good experiences of the doctor, the doctor we don’t feel we’re supported when we go to our doctors, so really that’s the short answer.

## UCLRA02

(17:19)

That’s really, all really interesting stuff. I’ve got all sorts of questions now! One of them would be what do you think from your own experience of going to the GP and for other people in Black African and Caribbean communities, what do you think would make people feel like it’s worthwhile going to their GP to seek help for memory problems?

## I02BCM49

(17:37)

Well I think being able to have a er, be able to, feeling comfortable to have a conversation with the doctor. Er when I was much younger, much much younger er I had a, I used to have a very good experience with the doctor, in fact my mother was a nurse, my father we used to work at Kings College Hospital he was an intern there so er so we weren’t fearful I mean I because of the kind of medical background which my mother had, we rarely ever had any need to go to the doctor when I was younger; and then when we did our family doctor he was so good Doctor Foster you know we used to have a really he was, wanted to know everything about us, even when we got older, we went to him ourselves, he knew our record, our history so he would ask us relevant questions and, that was it. So there was a relationship, you felt that you had a relationship with the Doctor and I think that helps a lot and over the years that has been eroded, doctors don’t have as good a relationship with their patients they used to be. Maybe amongst the white community it might be that the doctors are familiar and they can be on first name terms but generally most of the people I know, only go to the doctor as a must and not because you know they want to pick up things early which is what we should be doing I mean, prostate cancer is a classic example, prostate cancer there’s two issues about that. First off all again just to, there’s what I’ve talked about in terms of relationship with the doctor and to have a prostate examination, boy, for a lot of, we as a black man Oh, that’s a bit invasive you have to know before you’re going to let them do that examination on you, your prostate, so therefore if you’ve not got confidence you don’t really go and this is why many of we again suffer with prostate issues because you know we just put off, it’s put off, it’s put off until we see that there’s an issue. Doctor, when I have the conversations with the doctor about prostate, er he even himself seemed reluctant to say we do a prostate examination; he told me these are the symptoms, when you start to see these symptoms come back to me. OK. No problem.

## UCLRA02

(20:04)

Ok. That’s really interesting stuff, all of it. Just moving on slightly, you’ve spoken a little bit about the community and shame amongst community, you used the example of you know deciding whether or not to put a family member in to a care home perhaps. I just wondered sort of thinking a step back from that, just around seeking help and going to the GP for memory problems. Do you think that other people influence people’s decision to seek help within the Black African and Caribbean community?

## I02BCM49

(20:30)

Yeah absolutely, absolutely, absolutely. I mean it it’s I mean before if I was feeling that a member of my family had a medical issue or might need medical attention my first point of call would be a friend or somebody who I knew who was in the medical profession before I would go and seek formal medical help. So, there is that and then people’s negative experiences that’s what shapes your own actions and as I said as somebody who works with you know GPs er with kind of working, understanding them, the health service, people then come and ask me, so people come and ask me, oh this is the problem with my mother, my son, my daughter, you know how can, so I would advise them, ok look this is what you can do, this is you know you should go and see your GP, possibly even people who had mental health support needs who are very fearful about antipsychotic medication and again that’s another issue why people access mental health services very late because there’s this kind of cycle of fear and that as I said going back to what I was saying before, predominantly in a lot of people who are either African or African-Caribbean people who’ve got dementia issues the majority them did have you know mental health issues prior to the onset of dementia and the psycho, their be er antipsychotic medication is what really many of them see as the route cause of their ill health because you know people who suddenly they’ve got diabetes, didn’t have diabetes before, before they started taking the medication Loranzapine, Rispiridone, they you know the people who are on lithium and er you know a lot of the IEDs people who I know who had ECT so therefore their experiences with the health service are very much shaped by other peoples experiences In the community and that kind of is the is the, the precursor to how people access health services in terms of what other people have told them about their experiences or advising them and sometimes it’s not always the right advice, but it’s the first port of call and it’s generally the first port of call without exception really. Very few people would get up and run straight to the doctor, first of all they’d go and they’d ask somebody, say, look I’m not feeling well, or this is how i’m feeling you know and then other people would give them advice and then if that advice was oh go and see your doctor then that would be the course that somebody would take, if somebody said oh no what you want to do is you want to do this or want to go to a Chinese you know chiropractor or you want to take these Chinese medication, people would take that route before they would go and…

## UCLRA02

(23:27)

Ok, that’s interesting that you say about more traditional modes of medicine again sort of building on some of the other things I have heard in some of the previous groups is about different kind of systems of knowledge around medicine and illness. Do, more traditional forms of medicine for people who are Black African or African Caribbean communities, do you think that influences their health seeking behaviours?

## I02BCM49

(23:52)

Yes, absolutely, absolutely. I mean I mean, I, in terms of food, in terms of medication, we’re very much within ourselves a more and more in fact and this is why I think the NHS need to be aware because more and more people are now looking at alternative sources of medication, sources of as I’ve said medication and er traditional healing around er, herbs especially around the herbs I mean I, you know we take bitters, we take our sorrel we take the meridiana, we take other natural plants which can help us cleansing you know and detoxing using er natural things in my household in the fridge I’ve got all the medicines and the natural foods which help the different aspects of the body so you know, that’s what we would do really. So you see it does shape, I mean as I’ve said there’s more and more, what you have to realise is that people are moving away from traditional medication, traditional forms in terms of accessing through the NHS or the GP and really looking at traditional healing and that ‘cause, that traditional healing it works better on us, we are you know, this environment is not ours we, in the UK here the life is very different from the life that we had in the Caribbean, in er in Africa. I’ve spent a lot of time in Africa and in Africa you know I think that when I went to the African continent in 1987 I think I used to take the antimalarial’s and the prophylactics and then since in the time that I’ve been there since about 1990 where we’re talking about 90 since about 1994, I haven’t taken any antimalarial’s but I go to Kenya all the while, I go to places and er it’s because I take natural medications to when I’ve got malaria or when i think I’m going to get malaria so I wouldn’t take the traditional medicines, the er what is it, they call er, they’ve got the, I’m trying to remember the name, but I couldn’t even tell you name of them..

## UCLRA02

Of the antimalarial’s?

## I02BCM49

(26:08)

Antimalarial yes, I mean there’s, oh er I’m trying to remember the name, the names have even gone from me but I know Chloroquine and the Fansidar and the Mefloquine and all those medications, people generally wouldn’t take those; you would only take medication that will er rather than taking antimalarial’s or the prophylactics you would take the medication when you have malaria rather than as a preventative because er you know having those, so therefore really er the traditional medication, the majority of people take traditional medication. People would come and ask me and recommend to me traditional medications for things, or even with dementia. Again dementia you have to see that people will take more homeopathic medications before they would want to go and be taking er medicalised, pharmaceutical products.

## UCLRA02

(27:11)

That’s interesting because I mean we’ve obviously spoken to a really diverse range of people throughout this study and we’ve heard a mixture of things, on the one hand people saying that if they were experiencing memory problems they’d feel that things would be better if they were back in their home country and on the other side of that you’ve got people that actually say no, I’d actually prefer to be here in the UK if I was experiencing those kinds of problems. What do you think about that?

## I02BCM49

(27:33)

I’d, I’d, if I was, I’d rather be back in, well in fact I’ve made my home in Kenya so er I would be back and my children are instructed that if I ever get too, so ill they must book me a flight and get me, because my biggest fear and it’s many of my age mates who are saying that their biggest fear is to die in this country. They’d rather go die in, back in the Caribbean or in Africa and more and more of my age mates are also, have set up home in different parts of Africa now and they’ve kind of left here because over the years we’ve just seen that you know we’ve seen this happen to our parents that they would, originally came here just to work, earn some money and then go back to the Caribbean and they got stuck here and many of them you know on their kind of death beds, and I’m going to put that in inverted commas, but when they’ve got you know regretted having got stuck here because when they go back then they’re seen as foreigners by their own communities back in the Caribbean you know er back in Africa and so, so many people would like to, many would like to make sure they’ve got that relationship already so that if, when they do go back there they’re gonna back and people there, become integral parts of the communities again.

## UCLRA02

(29:08)

Ok, interesting. So just moving on because I’m conscious of time and we’ve got lots of questions to fit in and everything you’re saying is really interesting. So obviously nobody wants to be ill and I wondered within communities such as your own and communities which you work with, do you think that for them, getting a diagnosis of dementia is any different to getting a diagnosis of arthritis for example?

## I02BCM49

(29:30)

Yeah, yeah I mean I think because of the understanding about dementia, dementia people will see that getting the diagnosis of what did you say arthritis, people recognise that.

## UCLRA02

Just as an example

## I02BCM49

People recognise that because arthritis is things that they feel it’s sort of Dementia, people would say ok I’ve got dementia that means I’m just getting a little bit forgetful and they wouldn’t take it as seriously.

## UCLRA02

Ok, do you think that’s around a lack of knowledge?

## I02BCM49

(29:57)

A lack of knowledge, definitely around a lack of knowledge yeah. Yeah, people don’t understand, it’s going back to what I was saying before, people don’t quite see that forgetfulness and you know er memory loss is as grave an illness as having arthritis, rheumatism or something like that, diabetes again. Those are the things, heart disease, those are the things that people really see and there are I suppose to some extent serious but dementia can also be just as debilitating so therefore people don’t see it at the same level of seriousness so if someone got a diagnosis of dementia they’d say ok, oh I’m glad it wasn’t anything worse than that.

## UCLRA02

(30:38)

Again that’s interesting because one of the other things we’re interested in is there’s kind of ideas around forgetfulness, being something that’s extremely common (agreement), you know we’re all forgetful at times so what is it that makes someone who’s forgetful, you know they can shrug it off, laugh about it, to the point where they actually think there’s a problem here and I need to seek help? What is it that kind of makes people have that transition from laughing if off to saying actually I need help?

## I02BCM49

(31:08)

Ok, when a serious incidence would occur, occurs, because of the forgetfulness. So for instance , er, you know somebody maybe getting lost because they’re forgotten where they live er you know being er you know perhaps even somebody when they’re at the extreme end, perhaps wandering the streets or forgetting you know you know you’re my son and I’ve forgotten you. That would then, that’s a wakeup call for individuals. But generally it will have to be and this is , again it seems so wrong that it needs to be so serious for people to take note, but that’s the reality of it that people wouldn’t see it… if somebody’s diagnosed with dementia unless it then a serious incident takes place. People wouldn’t you know take it that seriously and I know that many many people as I said you know when they see somebody’s forgetful or you know they’re dropping things or they’re saying mmm, er, you know I’ve got you know, my mind isn’t what it used to be people don’t take it, they say oh it’s because you’re getting old and that’s it.

## UCLRA02

(32:25)

Mm, that’s really interesting. Just two more things before we kind of move on to the second half really. I wondered what you thought about religious beliefs within the Black African and Caribbean communities and whether or not people’s religious beliefs influences whether or not they would seek help for memory problems?

## I02BCM49

(32:42)

Yeah, definitely definitely. Religion, I mean er and this has been a strange thing, and I just feel like i’m can’t illustrate without going in too much but amongst, within the African and African Caribbean community when it comes to faith, generally they see themselves much more serious or much more religious than the people who have brought the religion to them. So most African, African-Caribbean people, when they are part of a faith they are really in it. They’re not you know, we always say something about boy we’re not part time Christian yeah, because you’re Christian seven days a week so it’s not just on Sunday yeah so therefore every day, so therefore religion then and because of that especially among with an African community er yeah you would seek, you would go to your pastor first of all and the pastor would er say this is the issue; now the pastors and I did some work some time back with pastors because some of the pastors are very misleading and they’re not very helpful especially around mental health because you know I have people who have come in and told me that the pastors have told them that they’re possessed, that they’ve not been praying enough, that even some people before seeking medical help they’d given an awful lot of money to the pastor, to the church to pray for them before they’ve actually seen that you know they need medical assistance so religion does play a very important part, faith plays a very important part, again many people, many of my age mates , men who are very disillusioned with faith and with religions so therefore er they see that it’s all part of the kind of the general ruse to make us feel er inferior so this is why again you know, with diagnoses, with a diagnosis, health diagnosis even many men that I know take it with a pinch of salt because they think all this is part of again you know the, the er the kind of, kind of the criminalising of us, the down pressing of us as men because they’re trying to make us ill, they’re giving us diagnoses that aren’t really real diagnoses, you know the church is was is er you know the Engels thing about religion being the opium of the masses, so therefore people don’t really you know, those who are in the faith, deeply in the faith, those who aren’t of the faith you know burn everything to do with you know er the church and the kind of anything that will come out of that and er things that people would say, so diagnosis, diagnosis people who don’t have a faith would see that the diagnosis is another type of religion they’re trying to catch us inside in terms of giving us a diagnosis and then making us all you know be mental health service users, or being all diabetes sufferers when we don’t have to be because we’ve got our own medication that can heal us.

## UCLRA02

(35:50)

Ok, that’s really interesting. Really interesting stuff. Last question just before we move on to the other part is I mean you’ve spoken a lot about um relationships with GP’s affecting whether or not they’d be the person you might go and talk to about memory problems. You’ve talked about a lack of knowledge around dementia and memory problems within communities of your own and others that you’ve experienced. Do you think there’s, are there any other kind of main issues out there which might prevent somebody seeking help for memory problems within the communities that you know of?

## I02BCM49

(36:18)

Er, well I mean er let me see, that, I mean those are the key things in terms of relationships with the GP, lack of knowledge, er lack of the information in terms of, not just lack of knowledge, lack of information in terms of if I was thinking oh I’ve got memory problems and I wanted to take me myself, where would I go for to get the information about dementia? How will I know that it could possibly be dementia?

## UCLRA02

(36:54)

Ok, well that’s the perfect opportunity to move into the next bit of the discussion if that’s ok. (agreement). So really building on all the things that we’ve already been discussing um it would now be great for me to hear a little bit about your thoughts and opinions around what you feel could be done to help and encourage and support people from communities such as your own or the ones that you’ve got, have a lot of experience of working with to seek help for memory problems earlier on, so when people first start to notice those memory problems and as we discussed earlier, we know that generally speaking we know that people who do seek help for memory problems earlier on in the journey do better overall and with outcomes. They’re able to be better supported themselves, people around them er, family members, other caregivers are also able to be better supported. They can plan for their future etc etc. So just to ask really, if someone close to you had memory problems, or yourself perhaps, what kind of information do you think would make it more likely that for you or for them to seek help for those memory problems?

## I02BCM49

(37:50)

Well, first of all and I’m going to go with the information because the information that is given, then again and the information around dementia and one of the misnomers I think that that continues within the health service is that if I take this information and I translate it in to Kiswahili because I speak Kiswahili or Zulu or something like that, that I’ve came up half, I’ve got information that’s available to Zulu speakers, or Kiswahili speakers; well before I’ll pick up this paper, and actually read it, I need to be convinced that there’s a need for me to read this information. Even if it’s in my language. Because it’s the same as when you go anywhere and how many times has the cultural competence, the cultural competence is er, because even individuals when you see papers down you might glance at it but you wouldn’t read it even if it’s in English unless you know that there’s some benefit to you reading that information.

## UCLRA02

(39:00)

How shall we do it!? (laughter) What do you think?

## I02BCM49

And that’s what it is and it’s about letting people be aware so I definitely must be more culturally competent and this is going back to what I was saying. Culturally competent information, the information has got to be culturally competent so the example I want to give is the Time For Change because I work in mental health, so the Time For Change campaign and it’s something I did, I had to do, when Time For Change first came out, a lot of their information was they were using celebrities, they had Steven Fry there, Ruby Wax were kind of their headline people. They had another, I try to remember who it was; there was about 3 celebrities that they used to talk about mental health. Time For Change was, is a good campaign and it’s about helping people to change the stigma, address stigma around mental health. But Ruby Wax and Steven Fry, they don’t mean nothing, nothing to me. How I’m going relate to the message that Steven Fry is giving me, or Ruby Wax is giving me? So immediately it’s got no relevance to me. Even though the information is relevant to me. But because there’s no cultural competence around it, there’s you know, it’s considered irrelevant.

## UCLRA02

(40:26)

Can I just check, when you use the term information needing to be culturally competent. What exactly do you mean by that, just to check I’ve understood it?

## I02BCM49

(40:31)

OK. Er, Frank Bruno. There use, Time For Change is now moving towards Frank Bruno. Now they have to, and we used to use Frank Bruno to talk about mental health. Because Frank Bruno is who so many people can relate to; people from African, African-Caribbean can relate to Frank Bruno because they know the issue, but at the same time that’s also tainted by the fact that when Frank Bruno spoke about his mental health issue er he was lambasted, The Sun was, Big Black and Bad and all those negative connotations about Black people with mental health issues, so that coloured people’s view of accessing mental health services because they saw, wow you do and then what happens is they rip you apart. Catherine Zeta-Jones, recently she went in and she came out, she talked about how she was bi-polar and people were lording her and clapping, saying she was very brave, and she’s you know, but yet when it’s a Black individual it’s negative, whose got mental health problems. When it’s a white person, hey they’re lorded, you’re very brave, you come out like. So therefore when we talk about cultural competence, it’s about making sure that you’re actually putting positive images and positive information about black people and how they have overcome these issues. So when you talk about dementia, you don’t want to talk about dementia, because dementia’s always, again it’s cloaked in now this is a white, old white peoples disease, it’s not seen as a Black people have dementia. Because our dementia, as I said, people just say, oh it’s because he’s getting old, look he’s crotchety, so therefore cultural competence in terms of saying that how you’re portraying the information, it must be so that it seems appropriate to me.

## UCLRA02

(42:25)

## So if let’s say for example, we’re going to produce a leaflet. (I02BCM49: yes). What content should that leaflet have? What’s going to make you either see that leaflet somewhere and pick it up or if it came through your door for incidence, what’s going to make you not put it in the bin and pick it up and read it?

## I02BCM49

(42:42)

## OK. You’re going to like that. This is a good leaflet. (I02BCM49 handed UCLRA02 a leaflet).

## UCLRA02

Ok. Is it alright if I take that away?

## I02BCM49

Yeah, absolutely.

## UCLRA02

Thank-you.

## I02BCM49

(42:50)

That’s a good leaflet and that’s a good leaflet because it immediately and again, straight away when you look at that. Whose it aimed at?

## UCLRA02

Men

## I02BCM49

(43:00)

It’s aimed at men and again when you open up here and see, you don’t see Black people or white people in isolation. You see them together. So then the message that sends is that it’s all of us.

## UCLRA02

We’re in it together

## I02BCM49

Are in it together, we have the same issues, the issues that affect this one here, other ones that affect him here, that affect him here so therefore there is cultural competence in terms of saying it’s not about this is a black man’s disease or a white man’s disease, it’s something that is all of us and that’s cultural competence because it’s not about saying, making people or kind of portraying the extent that this is an issue for black people or this is an issue for white people, this is an issue for all of us and all men so therefore that’s where when I talk about cultural competence about that, it’s about you know having, making sure the, the context is a universal context. Again sometimes that type of change they’ve started to do adverts which show you know er black people discussing mental health that you know that one in four of us can have mental health issues and then you see black people discussing healthily black people, not black people who are disordered or anything like that but ordinary people to show that hey, this is, this is all of us, it’s even if you think you’re ordinary or everything is ok, then lets; so it’s sort of like that, cultural competent information.

## UCLRA02

(44:38)

Ok. I mean obviously with this project, were specifically targeting people from black African and Caribbean communities and it’s not gender specific. So if you were to receive a leaflet and there were images on that leaflet what would you like those, would you still like it to show images of everybody, could it be…?

## I02BCM49

No no it, because I’m trying to think of if I’ve got, if I’ve got, because most of the, most of the good information has got that (inaudible, laughter).

## UCLRA02

No no no, it’s absolutely fine… (Inaudible)

## I02BCM49

(45:07)

## Yeah but if it was a leaflet, I like this for instance. Yeah it would, if I would, if it was just for African and Caribbean, you would need to have yeah, just er a black individual, a black older person and a black older person on the leaflet er, yeah there was a, was a, I remember there something we did some years back, er that was through one of the, that was through er the Sutton and Merton primary care trust and that was, that was just images, big images about A3, images of black people, just the face, talking about er you know that I’m unwell and it was just an image you know, I’m unwell er and I need to make sure that I’m, I am looking after my mental health and it was so good because it, it’s clear like that (I02BCM49 showed UCLRA02 leaflet again), it’s not wordy, you don’t have to wade through so, information needs to be clear and concise. All the time we’re dancing around and trying to not offend people and trying to be politically correct, most of us, we talk, when we’re in our, in our own groups amongst black people or amongst, ey, we’re not dancing around words, our words are very particular and I don’t know if it’s because of the language thing because you know I always tell people about the language thing that in English you would say to somebody you know, can I have a cup of tea, or please, can I have a cup of tea? In African languages, you don’t have to say Taffadali, let please, Leterchai, GIVE ME tea so therefore the language is much more straight forward yeah er you know pure Swahili, num ba chai, I’m begging for tea. So therefore all the while language is, says what it is you know on, on the tin, does what it says on the tin really and that’s what the leaflets need to be. They need to be very clear. They need to be, you know when I send out material to people er one of the first things I do, is I tell them ey you know, last year 103% of the people who were admitted to Mill View Hospital that there was an increase of 103% on the number of men who had neurosis in and admitted to Mill View Hospital there was a 68% increase in women who were admitted to Mill View Hospital so therefore mental health is a big issue amongst us.

## UCLRA02

(47:42)

Ok, so I mean obviously you’ve talked about the imagery, people need to be able to relate to the imagery and we’ve talked about clear information and concise information. In terms of the actual information itself, I mean you spoke earlier about there being a lack of knowledge around dementia, so some information about dementia itself, what other information do you think people need to be able to come away from looking at that leaflet feeling encouraged and supported to go and seek help for their memory problems?

## I02BCM49

(48:06)

Well like that, just as you have said to go, go and speak to your GP, yeah, you have the right to speak to your GP

## UCLRA02

So just telling people that?

## I02BCM49

Yes, just telling people you have the right to speak to their GP. You have the right, your GP, because I think GP’s, I had a conversation some time back and again this is my experience er, but it’s for me it’s very relevant and it’s relevant because when I speak to other people about it, I spoke to a GP here in a workshop, phase one better care, they’re doing a kind of NHS are doing a programme, CCG are doing a programmer about looking after frail people er and I was sitting next to a GP and she was so condescending. So condescending, I mean I made a mention of it at the tea break and then but the workshop we were at was about frail and when I was talking to her about BME, she didn’t understand what BME was. Nah she didn’t understand what BME was. When I asked her about the number of people from BME communities or people who weren’t white British who came and attended her surgery, she says to me, maybe we have 1 or 2 people who you know, we have 1 or 2 a week. When I asked her about the number of people over 65 who attended her surgery, ey she gave me the full statistics. So that makes me already see that she is not really you know, when it comes to people who aren’t white British, not really got that much of an interest; but when it comes to her own people, ey she was able to give me the fullness. So it’s the perception is GP’s themselves engaging and GP’s themselves, I think the issue is with the GP’s themselves. They really need to be, move themselves out of that medical school approach and start understanding that they’ve got to be much more aware of the demographics of their communities and start responding to that and making themselves much more receptive because the perception that most people have about GP’s, except for let me see, we’ve got a lot of Asian GP’s but those Asian GP’s you know often many Asian people who study medicine, a fairly few of them unless they’re much older, operate at the GP level; many of them are going in to like cardiothoracic surgery, they want to do specialists rather than the GP’s. But the GP’s, generally people don’t have a lot of so, the GP’s themselves I think need to become much more involved and much more frontline and then it seems like a strange thing to say because GP’s are saying oh you know they’re far more removed, they want the practice nurses to be you know picking up a lot of the work. But yeah the information needs to be you know a, apart from the imagery and kind of the sentiment that they put across, really need to feel that er they’ve got an interest in what, in your illnesses, the experience that you have because, It’s no good the information saying look you can go, you’ve got to go to your GP and then the GP’s themselves then are an obstacle then that you have to come across. If I want to speak, go to my, and I don’t wanna, if I want to go, I make an appointment with my doctor. First of all I have to face the cross examination of the receptionist, now you’re not even medically qualified so what am I talking to you, I want to talk to a doctor. Ok the doctor will call you back. The doctor then calls you back to assess you, to triage you over the phone. People don’t want to be triaged over the phone I don’t know many people I know who like to be triaged over the phone. What they want to do is that they want you to say, come to my surgery, you this is your concern and then er, this is your appointment; and again that’s also the other area that I think needs to be, in terms of dementia, and people who are African, African-Caribbean communities, our things are responsive which means I tell you today I’m not feeling well, you can’t come and tell me next week, come and see me next week. I’m feeling unwell today. I’m feeling unwell now. You need to respond to me now, I need to get some sort of support now. Because if you tell me come to see me tomorrow or the day after tomorrow, you might not see me tomorrow or the day after tomorrow because I needed support now. So my experiences outside of here now you see for instance and I will tell you that in other countries, your engagement with the doctor I don’t know if it’s because you pay, but if you want to see your doctor, you go and see your doctor, you’ve got your fifty shillings I’m talking about in Kenya. You’ve got your fifty shillings you pay, you pay the consultation fee, you go see your doctor and the doctor will deal with you there and then and that’s the experience many people have when they were growing up in the Caribbean, when I was in the Caribbean and as I said, I knew my doctor, my doctor was intimately, doctor mine, my doctor was intimate with me. I had a friend of mine when I was living in Kenya, my children the doctor who delivered them is a friend of ours, a family friend of ours. My children know him er, again I used to, when the doctor I mean I know it’s ethics and all of the things but I used to (inaudible) with a friend of mine, the same doctor and then he’d, I’d be in the office with him and while he’s extracting someone’s tooth he’d be talking to me, I’m there and he’s, and, so therefore you feel much more confident so when the doctor, when your doctor tells you something you feel much more that they’re looking after your best interest; here generally you don’t get that sense.

## UCLRA02

(53:52)

Ok. Well that’s really interesting stuff certainly things for us to think about and stuff for me to take back. Just going back to the information a little bit. Do you think a leaflet is the best way of getting information across to people in the Black African and Caribbean communities?

## I02BCM49

(54:05)

No, no. you got to speak to us on the radio, you’ve got to get involved in our shows. Again you see, main stream radio you can’t be using main stream radio, we don’t listen to main stream radio. Regular main stream radio doesn’t play what we want to listen to. It doesn’t play our music. So you, the pirate radio stations and then that’s, because when I was working before, we wanted to do that, we wanted to do some promotions through, but the NHS told us that they can’t be seen to be advocating pirate radio stations; but that’s where the majority of people from African-Caribbean communities, that’s what they’re listening to. They’re either listening to highbrow radio 4 or LBC, or they’re listening to the pirate radio stations; they’re not listening to Capital radio or Radio ‘blun’ they’re listening to, like radio 1 I should have said or Capital or Kiss FM or all these things, or Choice FM. Choice FM used to be a good station but then they went mainstream, when they went mainstream, yea people just saw that they sold out. So we listen to Galaxy, Genesis, Vibes FM, er X FM, you know stations which, er Colourful radio, stations which are for us because the rest of it, the rest of the stations don’t speak to us so therefore on the radio stations, GP’s sitting and talking about health issues.

## UCLRA02

(55:34)

Ok, what do you think about things like people watching DVD’s or videos and things? Is that a very good medium for communicating this kind of information?

## I02BCM49

(55:40)

Well I used to, I did that but only in the workshop setting. So for instance I used to you know run workshops, do presentations, I used to do around mental health and then we, run a film and then we’d have a discussion about it. We used to do the Happy Soul festival where we used to get a black film and then, you know Black or Asian film and then we’d show the film and then after we’d have a discussion maybe sometimes with a director and then we’d look at some of the issues that were highlighted in the film. So, but not to say that DVD’s are given out and then people are supposed to take it and go home and watch it because, not not really.

## UCLRA02

(56:20)

Do you think that there’s more chance people would read a leaflet?

## I02BCM49

(56:22)

People would, a simple leaflet, more people would want a leaflet, again you know listen to something on the radio, maybe then you know information that’s circulated er via you know social media but it’s again that’s got to be really in a way like you see the Whatsapp for instance, err you tube and I’m gonna and I’m gonna and it’s the same thing with we’re discussing, but I want to just illustrate how our information is coming to us.

## UCLRA02

(57:04)

Ok, whilst you’re just finding that. I’ve only got a couple of questions left before the end, and then I’d absolutely love to have that.

## I02BCM49

Yea, that’s ok, that’s ok. Ok, The Black Fathers support group there’s a, we’ve got something called the black fathers support group and the black fathers support group and all I want to show you is, it’s sharing information. So all the while you can see…

## UCLRA02

This is Whatsapp is it?

## I02BCM49

(57:22)

Yeah, this is Whatsapp. So Whatsapp, its’ all, this is where information is coming, is how we would share information. So we share information, this person now, so a lot of the time, amongst African and Caribbean communities, this is what it is. So if somebody see’s something interesting, health related, send it via what’s app, the link is there and people will access it. And then you see this is then how people will see information so you know little You Tube video and then the link is sent out and then the link, people can click on the link and then they watch it on their phone. DVD’s as I say, I think the days of DVD’s unless you’re watching a film that you’re going to sit for an hour and a half or whatever, watching it like that, this is the way, if you want to catch people and if you want to inform people, do it like this, using as I said, Whatsapp er I don’t know if the other ones, because then again I’m, I’m somebody, I don’t use a lot, I don’t know many of my friends who use, my age mates, who use any other means. Generally Whatsapp is there, not really Facebooking, not really you know using any other, Whatsapp is good because you know, you’re in a group and then that group you know, everybody in the group gets the information. Even my kids, we’ve got our own group that then you know where’s the keys? Who’s at home now?

## UCLRA02

(58:53)

Absolutely. That’s interesting. Um, I think I’ll wrap this up because we are, we’ve only got a couple of minutes left really. Just going back to the leaflet and then I’m just going to come back to the social media if that’s ok. In terms of physically getting the leaflet to people, how do you think it’s best to do that? I mean, will people pick up leaflets that look relevant to them from their GP surgery or if leaflets are posted out to people?Do you think things that come through their letterbox are…?

## I02BCM49

(59:20)

I’m going to give you the inside track, normally I would charge people for it (laughter, Sharne: ok, thank you). Barber shop and hair salons. That’s where you will get information out to people er, that they will read. Barber shops, hair salons, because that’s where the font of all, when I, when I want to engage with communities, you go to a barber shop, go to the barber shop. You talk to people there. You’ve got a captive audience, people will stop and listen to you, they’ll ask questions, they’ll get the information, take it forward. We used to give, I used to give them little cards, the little kind of, like the, the dance, when we have a dance like dance and the music, a club playing, then normally got the kind of the embossed, you know when they emboss their card. See, then you put all of the information on the card, give it to somebody like that and…

## UCLRA02

(1:00.24)

Just out of interest do you think if something did come through your door, obviously a lot of things come through peoples doors and a lot of it goes in the rubbish bin. If an information leaflet was accompanied with a letter from your GP that was addressed to yourself, something personal. Do you think you’d be more inclined to have a look at the information?

## I02BCM49

(1:00.39)

Yes you would. But you’ve got issues around that because, a piece of what we’re doing now, around sharing information. So for instance if my GP sent me a health, a health check that was very good. Because the health check I was sent information from my GP, you’re turning 40, you should have er, a health check, go and have a free health check. Right, ok, I like that because it was addressed to me. It was specific saying to me these are the surgeries that you can go to visit to get your free health check so immediately I knew that it wasn’t just a mail out to everybody but it seemed more sort of specific to me because it was giving me my local practices that I could go and, and get a health check. So, you do, you say wow ok…

## UCLRA02

(1:01.33)

So if we targeted people who were perhaps over 65. Do you think it would worry people if they received a letter from the GP and an information leaflet about memory ?

## I02BCM49

(1:01.44)

No, because it’s the same thing that I’ve said, if over 65 the prevalence of dementia is highest amongst people who are over 65, from 50 almost but, over 65, so over 65 you know if you’re having, if you feel you’re having problems with forgetting things and you know you’re, you think your mind is not as sharp as it used to be, go and have a chat with your GP. Something like that would then encourage somebody and it’s from their GP you know, come and have a chat with the practice nurse or come and have a chat with the GP. People would respond to that because it’s specific and it’s and it’s targeted like that. If it’s er yeah, so I’m going to stop there because what I was going to say the wider was that sometimes people feel, if it’s targeted, the language, because if you say, if you say er you know, 35% of people from Black African, African-Caribbean communities have got dementia, people will feel a little bit offended by that. But if you’ve got something that says, you know if you’re over 65, you should go and have a chat with your GP if you feel your mind is, that’s more, because that’s a general thing and It’s all about the language and understanding that when you’d talk about things which are just specifically because you people are at more risk of it, people take a lot, a lot of people take offence at that because then they see that you’re labelling them and therefore if it’s specifically targeted at black people over 65, strange and naïve as it might sounds, people might say mm boy so what do they want to do? They want to inject us with something?

## UCLRA02

(1:03.30)

Ok. So that leads me to my final question, which is this information that we would like to get out to help um support and encourage people to seek help for memory problems, who should this information be aimed at in terms of an audience?

## I02BCM49

(1:03.44)

Yeah people, people who are over 50, people who are over 50, you then want to start letting people be aware of these things, not, over 50 because over 50 the prevalence from 55 onwards with dementia, dementia’s not just for 65’s 70, it is also people who are 55 years old so therefore that information goes out and also people who are over 50 who have got relatives will also transfer, there mind will really think oh ok well perhaps it’s not me yet, but let me think about this uncle of mine, this aunt of mine, it might be because yeah I recognise that may be they have been a bit forgetful, so therefore you spark the conversation there. Rather than younger guys, which younger guys I mean it’s not a silly, it’s not to say, I would say over 50’s would definitely, you’d get a much stronger pick up than if you targeted it at people who were 30 and, or 40 and then expecting them to transfer it to others. People who are over 50 generally would say Oo ok, that’s relevant to me, or it might be relevant to somebody who I know because that’s your age set who you’re, you’re engaging with or who you are more familiar with so therefore you’ll be more likely if it’s not relevant to you, knowing who it will be relevant for whereas somebody who’s younger might not see the relevance, they might say oh ok, I’ll give this to my father, he might box me and tell me ey, you didn’t say I’ve gone mad you know. So therefore people would look and see you know.

## UCLRA02

(1:05.15)

Ok, so people might, if people were going to be transferring information to others, you think that they might respect this coming from somebody’s who’s older?

## I02BCM49

(01:05.21)

Older that’s right, that’s right because I mean I was, when I was telling, talking about Jermaine (man in leaflet), who when I was starting to do the project with, Jermaine you can see is very young guy and even he used to have problems because even though he’s older, he’s a black young black man some of the people who he used to work with, say ey, boy you, you, you’re just a youth to me. Why you have to tell me more than, yeah I’m a big man to you, yeah. So forgive me for (inaudible). But, you know…

## UCLRA02

(1:05.48)

No I mean gosh, I could stay and chat to you about this for hours and hours but I think I will leave it there if that’s ok?

## I02BCM49

Yeah, yeah that’s fine.

## UCLRA02

I don’t want to take any more of your time.