UCLRA02: I just thought we’d start the discussion by asking all of you if you knew someone like this, do you think that she should get help for her memory problems

G04BCF21: I think first you need to ask whether or not it is memory problems, rather than something else, it could be related to an ailment rather than memory. So you need to really make sure it’s memory. Once you realise that it is memory, then one you could either inform the relatives, or two, have a discussion with this young lady or this per…this…. what’s her name, sorry?

UCLRA02: we just named, Mrs Abrahams…

G04BCF21: Mrs Abraham, have a discussion with Mrs Abraham and from the conversation you and her have, you could derive that there is a memory problem and then as I said, tell her that it’s, you know, why not going to see the doctor and find out what’s happening to her, but don’t tell her that is her memory because often they are proud people you know and they won’t accept the fact that “oh, I’m losing my memory”. So you really have to be careful how you word things and the way you go about it, I think.

UCLRA02: that’s really interesting. Other people

G04BAM19: yeah, I’m losing mine now. Who would I go to see?

UCLRA02: we can certainly talk about things like that, if you like, afterwards. I mean for the purpose of just this little bit of the discussion, if that’s ok, I mean it’s a good question, “who do you go and see, you know. May be we can move on to that. I mean, who do people feel you should go and see if you, yourself notice that you have memory problems or another family member, what do people think?

G04BCF21: Me personally, hmmm, sorry let’s someone else talk

UCLRA02: that’s ok. Anyone feel free to jump in at any point

G04BCF21: alright, me personally, I’ll go and see my doctor. Um, that’s my first port of call. Find out what’s happening. Find out what can be done to derive whether or not it’s a memory problem. What… what… what is there that they can do to help me to say yes its a memory problem. Once I’m certain that it is a memory problem then I have and I tell my family and say yep, I have a memory problem, sometime I misplace things, sometimes I’ll…., you know, but I think it’s best if you find out first rather than just jump the gun “oh, I got memory problem”. Well, it’s too easy to say that, it is. (05:24)

UCLRA02: thank you G04BCF21. Anyone else, does anyone else have any views on where you may go to seek help if you noticed that you have memory problems or someone around you?

G04BAF23: hmmm, for me personally, I may not go to my doctor because I just have something about these doctors’ people. I might actually go to my friend, probably a close friend of mine and just…probably just explain things to them and just hear their own view on things. That’s just me personally and then may be if I see that it’s becoming, you know, frequent of me, losing stuff or forgetting stuff. Then, I might decide to give it a go, depending on the doctor i’m going to see. So sometimes, I may take my time, but I will first phone maybe a friend, may be a very close friend of mine to discuss with her, her own view or what she has to say about it. And then may be later, I’ll progress to see a doctor. Actually, I wouldn’t even go to the doctor, may be a counsellor or something like that.

UCLRA02: ok

G04BAF23: yea I won’t go to like just medical centre now, just may have a one on one counselling with someone, just talk and then they may have alternative, you know, medication for what I might be going through.

UCLRA02: sure, ok. Thanks for that. Do you mind we asking just a little bit more about it. I’m just interested to know a bit more about, why it wouldn’t be the doctor to be your first point of call and why not the medical centre?

G04BAF23: because with the doctors nowadays, it’s like, to me, they’re just not reliable. I’ve had experiences with doctors and it’s like, is that all. For them it’s like just paperwork so they don’t take the time to literally hear your health and like give you what you really need. So instead of me wasting my time at my doctor’s place, because he’s looking at his time, he’s looking at his next patient. I’d rather go to a friend or go for counselling because I know with counselling or any other alternative medication, they would have more time.

UCLRA02: ok

G04BAF23: That’s one of the things I’ve noticed, because I’ve had, you know, one on one with doctors before so I know that, no, it’s a no go area.

UCLRA02: ok

G04BAF23: (inaudible) that kind of, you know, of discovery about myself with my health. When you talk about mental health, you know, it’s a tricky issue. It’s not like I had a fall or I’m going for an operation, you are talking about memory now. So it’s a very delicate issue to talk about to doctor.

UCLRA02: sure, ok, thank you for that. Does anyone else have any views or thoughts around their GP perhaps, as going there as a place for help.

G04BAM19: well, me, no I kinda google everything now.

UCLRA02: google everything?

G04BAM19: yea google everything

UCLRA02: ok

G04BAM19: to do with, what you call it, brain…memory loss?

UCLRA02: yea memory problems

G04BAM19: well, everyone have memory loss even young children forget certain things. So it’s not based in the older community. It starts from the babies, young children growing up. Like misled something (inaudible). So it’s not just based around older people from 50 upward. Young people, teenagers, everyone (inaudible) there’s too much things to occupy their mind and the older one them too, you know. Their brain cells… is wearing off. Sometimes too far too early, than our people. It’s to do with the climate… what they eat what they drink…. Things like that…

UCLRA02: ok… so…

G04BAF23: sorry

UCLRA02: after you G04BAF23…no? ok if you want to chip in…. Ok thank you for that. That’s really interesting….

G04BAM19: yea, I could go deeper but right now I just stop there… (laughter)

UCLRA02: ok, that’s fine. If you want to later, feel free. I mean, I guess drawing on what you’ve just said…and something G04BCF21 said; one of the things we’re interested in is about, you know, forgetfulness being extremely common, you know as you both rightly said. So one of the things we’d like to know a bit more about is, what makes that leap between having forgetfulness and may be laughing it off or ignoring it, and what, you know, and then what would actually make you go to the doctor, so along that spectrum, I guess of forgetfulness, what would make that transition to make you think, I need to seek some help. Is there any particular type of forgetfulness that might concern you?

G04BAM19: hmm, it’s kind of difficult, you know. Because saying that for start losing lots of stuff, we were told to rely on the GP, general practitioner. Then sometimes, they can’t tell the answer. So they probably send you onto someone else. But in reality, we should look at the cause of it, instead of trying to find out why this happening. It starts up from an early age. Even before the woman can see it’s been happening (laugh) more or less and transferred down to her unborn children. So even children, you know have mind problem. Things to do with where it’s all coming from, that could be… food, it could be anything.

UCLRA02: ok, alright, thank you very much for that

G04BCF21: can I quickly ask something, I hear what you’re saying and I’m not saying you are wrong, but then how do you separate…off forgetfulness and memory loss. That that’s It, that is it… there are, I mean I could be forgetful….

G04BAM19: yea but it’s the same, it’s the same…

G04BCF21: …but I also have memory loss

G04BAM19: that is the same thing, isn’t it?

G04BCF21: no no, I don’t think so…

G04BAM19: if you…well…

G04BCF21: I don’t think so…

G04BAM19: you see when…

G04BCF21: forgetfulness is, oh I forgot this, I’ve got to go back. Like I forgot your cake this morning, that’s it. Right, memory loss is where in heaven did I put that cake?

G04BAM19: (errr…sound of disbelief/disagreement)

G04BCF21: that’s mine, and you looking for looking for this cake, you can’t find it.

G04BCM22: mmm (sound of agreement)

G04BCF21: and perhaps, 2 or 3 weeks later you’re sitting down and all of the sudden, I know where the cake is…

G04BCM22: yeah…

G04BCF21: but the cake is no good, because… so that’s what I’m saying. With children, it’s forgetfulness. They are forgetful ‘cause they’re not using their brain cells to the… the best of their ability. Half of these children are too…hmm, electronic minded, it’s television and all these things. Which is not a bad thing, but read, read, read, read, it’s a lot more interesting than television, than the video games, laptop or tit tit whatever you call those things. Do you know what I mean?

UCLRA02: sure

G04BCF21: you know, so I want to know is, are you talking about forgetfulness or you talking about dementia, that’s what you need to look at G04BAM19.

G04BAM19: well, eventually they come under the same umbrella, right. So they …they are all the same whether you have got forget… mem… memory loss, they’re all the same. And but, what what happening with we afro-Caribbean…we’re not living in our own environment….

(unclear)

G04BAM19: we’re not we’re not eating our own food. We’re living in a cold climate which you have to set up…whoever, right, yea some winter. We’re taking in too much chemical. Not just afro-Caribbean people, the world is taking on too much chemical. We’re living in an age of IT, technology, that can destroy your brain cell, with the radiation and thing.. yea… so the system now is working against the human race. Some people can live with it, some can’t. Eventually, it’s gonna start messing about with your mind, mobile phone, tic tic (unclear) all the radiation… carry on the radiation, this bigger one, (pointing at the facilitator’s tablet) more radiation (laugh)…

UCLRA01: I totally understand what you both are saying which are very interesting points, because one thing I’ve noticed is for you forgetfulness and memory loss would be exactly the same. You would make a difference between the two, right? So do you say that, if you qualify something as memory loss you’ll go and see your doctor but if you qualify it as forgetfulness you would not?

G04BCF21: no, I think you would act on both of it, because you need to separate them. I think you would act… if I had a child and that child keeps on forgetting things, is it because the child is lazy and just don’t want to do it? Or is it something specifically that’s wrong? So yes I would, I personally go see my consultant, find out where I can go for support in the system to come to that conclusion, yes it is definitely laziness, no it’s not laziness, the brain cell is deteriorating. And then take it from there. So that’s what I’m saying to you. I’m not saying that, you know, I’m not flippant about it…

UCLRA01: oh no, absolutely…

G04BCF21: but there’s, there’s I think, there’s a line there, it can be crossed over in term, dementia, yeah, forgetfulness.

UCLRA01: and what would you make you take the leap to go and see your doctor?

G04BCF21: if I can’t, if I can’t… keep forgetting things…yes. .well, if I notice… say for instance my…right, my son, my….both sons, I don’t have no daughters, my sons go to school, and they got homework and everything else. I constantly notice their report and I’m seeing bad, poor efforts, everything else. I’ll go to the teacher, I’ll speak to the teacher. And she said, you know son A don’t remember this. You tell him now and he does remember this, and then I go home and I try to act with him in terms of giving him things to do and noticing him and more and more. Then I say yes I need to go and see someone else for help because obviously there is a problem whether in their brain or the brain cell is deficient, or vitamin or whatever, I don’t know, but I would have to definitely consider the doctor. Again with dementia, I’m not joking I think I’ve got some of that. I have got some of that, because I always forget things. And I laugh at things because I remember it weeks later and I’m killing myself with laughter because I just remembered what I was supposed to remember about 3 weeks ago (laughs). So for me, I personally I’m forgetfulness slash dementia.

UCLRA01: if I may ask, have you seen your doctor about it?

G04BCF21: I’ve told my doctor…

UCLRA01: right so you’ve actually taken…

G04BCF21: Now, I have… yes I spoke to my doctor. What they want me to do is keep a diary, and I keep a diary. Ermmm, you know, last week I went to the door, locked myself out, couldn’t find the key, knocked my neighbour’s door house, help help help… couldn’t get in. Where was the key? In my pocket! And I searched my pocket 4 times, it wasn’t there. But it was in my pocket. So to me, (laugh)… the brain…(inaudible – mixed with laughter) you have to laugh.

UCLRA01: thank you, thanks very much for sharing….

UCLRA02: thank you… (17:00) so just thinking perhaps about the other side of if, hmmm, about why people may not seek help, does anyone have any thoughts on what might be the reasons that would stop you going to seek help from somewhere, If you notice memory problems either in yourself or somebody else?

G04BAF23: I think for some people it’s just the fact that, you know, this pride… as to...what would people think… that… Oh I’m losing my memory. Especially for a young person…. A young person might actually be experiencing…let’s say even memory loss and then he knows he’s told, oh you’re too young to be experiencing that… like they discriminate you even on that note, oh you’re too young to be going through that… how can you say you….you’re too young…like… I see, it can affect everybody, you know… and then you just think to yourself, you know what, I’d better not say this out again, you know… not just for memory loss… even for other issues as well, you know… we’re just focusing on memory loss because of this….recording, you know… so for that, for some young people or just for people generally, it’s the fear of what would people say, you know.. the perception that they have of you as to, no you can’t be going through that or no no just brush it off. And also, as I said earlier on you know sometimes you consult your doctor or your GP and it’s like they are of no use to you and it’s like you can’t be bothered anymore, you can’t be bothered like, if the GP is of no use… I… I …I had an encounter with someone on the bus and we were just talking about medical, you know, things and she was like, you know I went to the GP…, this was actually two days ago, it’s like I don’t like that doctor because he doesn’t just give me what I want. I have to request for someone else, so now I’m thinking to myself, if you’re having that problem, at least you’ve taken the time to even request for someone else. Some people might not even give it another chance, you know what, that’s how they all are. So for some people is the experience they had before can actually prevent them from taking it further in the medical side and some people they would rather just prefer going the ethical way of things, the more traditional way of things. Say you know what, I‘m gonna try may be this herbal tea or go for this acupuncture, or try something different compared to the, let me say NHS form of going, you know what I mean. So I would, some people they would rather compare something that they’ve never tried before than go to the NHS. And also with all these things going on with the NHS changing and stuff like, it’s like how can you trust them. You know, can you trust them with your confidential information. Can I even trust you with this recording? That’s the question now. As much as you telling me, oh you’re gonna give me a number, at the end of the day, can I still trust you? This is so…for some people it’s the trust in the health side, and also, you know, what people would think of them. As so, dementia… you’re too young for that. If you’re not born in the era whereby the war, war was going on. And as one of our, you know, participants said, you know with the radioactivity going on now, it’s like you shouldn’t have a problem. So, that’s just my view on why people might not actually go to see the GP or the doctor, so.

UCLRA02: Thank you very much for that. Does anyone else have any views on, issues that might stop people seeking help perhaps if they were noticing memory problems?

G04BAM19: well, I think the damage is done already, you know. Even though people seek advice from the doctors, or wherever they go, the damage is already done. So, I don’t think doctor can help. They might…might… might prescribe medications. That’s not… that’s not…that’s not gonna help. It might make it get a bit worse… you know, you have to go back to the cause of it, from a younger age, with the food, the GM food they are introducing now. It’s not new, GM food is not new. It’s been around for a long long time.

UCLRA01: Can I ask you why you said the doctor cannot help? That’s a very good point but why would you say….?

G04BAM19: ok, I’m suffering with dementia, brain loss, whatever you want to call it… I go and see my GP, I tell him all that. What is he gonna do for me? Prescribe medications? We all know that medication don’t work. It depends, I know, how old that person is anyway. You see, nowadays we don’t get time to use our brain anymore. But rely on mobile phones, all kind of things electrical gadget now. So the youths them of today, they’re more or less burning out their brain with this new technology and they’re not eating properly, right. Most of the time you see them at the corner shop, they’re game talking, they’re McDonalds. I know it’s gonna cause a lot of things. The women them, they bleaching their skin, they straightening their hair… too much chemical…that’s one of the reasons why it’s happening all now. It’s mainly to do with money

UCLRA02: Ok

G04BCF21: Can I just pick-up on something G04BAM19 said. Also, you are right. The chemical they’re injecting in food to preserve it nowadays, that also contribute to our memory loss. Because we don’t know what chemical is going in these foods nowadays. Look at all these sweeteners, all these E’s and everything else. You know, G04BAM19 is right. We’re feeding these children with all these E’s (22:38), not knowing the side-effects as they get older. I’m not saying that it could contribute to dementia, but we have to look at the food, you know…. Are we stupid…

UCLRA01: ok, very good point, thank you

G04BAM19: (inaudible)…

G04BCF21: everything… with anything that’s been preserved with all these chemicals in them, we need to review them, we need to look at it, you know.

UCLRA02: Ok….alright… Thank you very much for sharing all those things. Do you want to say something else… about?

G04BCM22: heummm…no…

UCLRA02: Ok, no no that’s fine, don’t worry. I can move on to another question. That’s fine. I just wanted to pick-up on a couple of things that a few of you have said. G04BAF23 you spoke about not wanting to seek help perhaps as a young person, because of what other people may thing about you, yeah, if you were experiencing memory problems; and G04BCF21 you talked about people being very proud and having a lot of pride, and I just wondered if any of you could may be expand on that a little more, whether you think, hmm the opinions of others, whether that could be family and friends perhaps, and how that may influence your decision to seek help?

G04BAF23: hmmm, I think when it comes to seeking help, I would rather go privately. Because sometimes, it’s like you don’t want people to know your business. So you go privately… you do certain things private because you want to keep that integrity, you know the front. Especially for some black people, keeping the front is extremely important than even their life…

G04BCF21: hmm (affirmative sound)

UCLRA02: Ok

G04BAF23: that’s just the truth. Like, how people perceive them is just number one. Then, every other thing can come after. So in order to ensure that the front is being kept, certain thing has to be put in place. If I experienced that I wouldn’t even tell no one. I would go seeking help privately to ensure, you know…and that’s why I said… that is when your closest friend will come in…just, for plan B… you know, just in case anything happens tomorrow. You know, someone is aware that, ‘oh this person is actually experiencing dementia or this person is paranoid or this person is experiencing schizophrenia’. You understand? So, in that sense, you don’t want too much people to know your business. Because you don’t know how they’re gonna use it against you, as a black person. That’s just one. And secondly, as I said it’s just… when it comes to the pride stuff it’s about integrity. It’s not like you’re being pride like you’re being rude or anything. It’s just about how people…. how you carry yourself. You know, you want to maintain that standard. And as I said for a young person, I wouldn’t go to my GP anyways. So GPs are out of the equations because as my colleague said earlier on, they just google it. So there’s nothing the GP wanna tell me. I would google everything first, you know. And then, after I google it, then maybe go to alternative therapy to… I don’t know why I’m just saying alternative therapy because maybe I just think they’re even more trustworthy than the GP and the doctors of nowadays. And then, maybe progress from there… or it’ll only take me, maybe when I say that… the symptom is progressing at the faster rate and then maybe families and friends are getting aware of it and they like, maybe calling my attention to that: “Oh G04BAF23, I called you yesterday and you don’t remember some stuff”. Then, I might be prompted to like maybe say, “Oh, you know what, I have something I just need to tell you. You know pardon me if I forget things. Now, I’m just experiencing some things at the moment”. That might be my introduction to telling them about my memory loss. But I wouldn’t just go, “boom, oh I have memory loss, I consulted my doctor and all this no”.

UCLRA02: Ok

G04BCF21: So.. oh sorry… I was gonna say, is it because..hmmm…a trust issue with GP in general, hmm I’m talking about in general, not your GP…

G04BAF23: Oh yea…

G04BCF21: is it because of trust with GP in general or is it to do with the data… hmm…information. Which one it …

G04BAF23: would it be…?

G04BCF21: would it be for you not to go to your doctor?

G04BAF23: I think for me personally it’s the data. Because, now it’s like they’re more focused on data, statistics and stuff like that; compared to the actual treatment; compared to the one-on-one. To say, “ok, you know what, Miss L this is what you’re going through…”, you know, how… you know, have a one-on-one with me without thinking, “oh, in the next two minutes, I have another patient coming in, you know.. I need to put this…I…” No! I need you to have the time. That’s what they are paying for. But now it’s like the pay is to one side and data collection is more important.

UCLRA02: Ok

G04BAF23: You know, so if your data collection is more important, I might as well go somewhere else that they’re not keeping track of the data and more keeping….more aware of the treatment. And ensuring that six months down the line they gonna contact me again, even after I’ve forgotten about them. Contact me again, say “how are you faring?” My GP never called me back after three months. They just tell me you have another appointment. If I don’t go they don’t call me. The receptionist, they call me. Hmm, they might even charge me.

G04BCF21: Maybe you need to change your GP. I’ve got a good one, so I can’t complain…

(LAUGHTERS)

UCLRA02: Ok

G04BAF23: I’m just saying, I’m just saying, so…

UCLRA02: That’s really interesting..

UCLRA01: So, I just want to clarify, when you say going… earlier you were saying you would go privatlye, you meant you would go and see a private doctor or you would go and see a friend…?

G04BAF23: hmmm, privately…when I mean private, I mean like alternative to the, probably NHS.

UCLRA02: Ok

G04BAF23: that’s where I’m coming from..

UCLRA01:… a specialist…?...a private doctor that you would pay…?

G04BAF23: Exactly! You know, because you know that when you’re paying someone else…. You know, when you’re paying for certain things, you expect a good service. That is the thing. But when you’re not paying for things, it’s like they’re looking at you…like “oh, you’re on benefit anyway so…you know, next!” Or, “you’re getting this for free, so…”, you can’t really challenge them…

UCLRA01: Ok

G04BAF23: So when you’re paying for certain service when it comes to your health, they know you can sue them. Because, there’s declaration for you… you know you sign certain paperworks to say I need the best service from this hospital. So their own reputation as well is at hand…

G04BCF21: But they’re still collecting data of you…

G04BAF23: They’re still collecting data…

G04BCF21: So it’s still there in the system to be used….

G04BAF23: Yes, but at least….

G04BCF21: (inaudible)

G04BAF23: But at least they’re giving the service you want… do you see what I mean, they’re still giving you the service you want.

G04BCF21: But who is to say that the service is the right… not because you’re paying for it; could be another, excuse my French, quack doctor… that… “oh, we’ll give you this… we’ll do this.. we’ll do that… we’ll try this… Just to get the more money from you.

G04BAF23: Yea but then, you…you.. you know…nowadays you read on the news about how people go to the.. their GPs… they don’t discover certain things. They go to the doctor like from one doctor to the other, and until they take a private route before they actually discover that “oh, actually… oh, you have this”. And then, it might be too late because four GPs down the line didn’t discover that until they went to a private doctor…

G04BAM19: (Sounds of agreement) (30:03)

G04BAF23: …or until they seek alternative medication… and it’s a thing of how come my doctor didn’t recognise that or how come those under the NHS couldn’t detect that? Why do I have to pay thousands of pound for them to be able to discover that I have this?

G04BCF21: No, I agree with you but what I’m saying is you go to the doctor for your memory problem or forgetfulness either one and they say, ‘Ok, we’re gonna do this, we’re gonna do this investigation’. Three, four, five months later you’re no closer to finding out what’s the problem, right! What do you do, do you continue with him? Because, maybe he just wants more money? Maybe he just wants money? There are private doctors out there who’ll constantly say ‘come back’, ‘come back’, come back’… they just want money!

G04BAF23: yea but then, before you go to a private doctor, you’ll…one of the things I’ve noticed is before people go to private doctor they research because they know their money is at stake. So they make the research as to, you know, ‘have you been to this doctor before? Was is your recommendation of him? Have you been to this doctor before, what’s your recommendation of him?

(hmmm sounds of approval.. from G04BAM19)

G04BAF23: You know, they… they ensure that before I would put five thousands pound down to detect if I have a memory loss from this hospital, I need to find out that this hospital is gonna give me the service…

UCLRA02: Sure

G04BAF23: ..that is how it is..

UCLRA02: OK

G04BAF23: …and then you know most of this privately owned hospital now, they know what is going on out there; their reputation is extremely important. They get the best lawyers to ensure that no client who come in and sue them

(Sounds of approval)

G04BAF23: Because they don’t wanna lose no money

UCLRA02: OK

G04BCF21: But you are… you are aware that the same doctor you gonna see privately is the same doctor in the National Health… you you are aware of that, aren’t you?

G04BAF23: Yea but at least they gonna give me better service on the when… compared to when they are under the NHS

(Sounds of approval)

UCLRA02: OK, thank you ever so much

G04BCF21: Sorry

UCLRA02: No, absolutely fine they’re all really really interesting points and we really appreciate you discussing them amongst yourselves and sharing them with us. If I could just move the conversation on just a little bit if that’s ok. Just before I hand over to UCLRA01, I just wanted to ask one more question; which is what your thoughts were around… obviously nobody wants to be ill or to get ill, but I just wondered what you thought about, is getting a diagnosis of dementia any different to having a diagnosis of something like arthritis or diabetes for example. What people think about the diagnosis?

G04BCM22: Two different conditions tho’, ain’t it?

(mmm of consent)

UCLRA02: Sure, I mean in the literal sense absolutely, I guess I’m thinking… this question is kind of coming from ideas that maybe people might not be so concerned perhaps around getting a diagnosis of arthritis. People might be more accepting of that perhaps and I just wondered what your views and attitudes were around a diagnosis of dementia whether it be for somebody in your family, your community, yourself… what you think about that?

G04BCM22: Ermmm, I don’t know, what is it like (inaudible) I suppose it is a serious condition…(inaudible) at the end of the day it can affect you on the long run, can’t it? You know what I mean, like it could last for life. It could affect you on a long run, ain’t it? (inaudible) diagnosed condition (inaudible) suffering with, (inaudible) do you know what I mean?

UCLRA02: Sure. OK. Thank you.

G04BAF23: I think with the question you asked, for some people you know, accepting that if you’re diagnosed with cancer or arthritis something like that; that is something that people can easily accept. Because in a way it’s like, ‘oh yea she has cancer or she has this or she has that’, but when you’re talking about memory loss that is in a class of its own. Because that is your entire life … locked up somewhere….

G04BAM19: yeah (approval)

G04BAF23: … and you’re telling someone…

G04BCF21: You gonna lose that

G04BAF23: … you gonna lose that…

(Yeah of approval)

G04BAF23:.. that that is not even a funny issue you know…?!

G04BCF21: mmm

G04BAF23: It’s like…. you might as well shoot me… than tell me I will get to a stage I can’t remember you? No!

UCLRA02: OK. Thanks

G04BCF21: Ca-catering what G04BAF23 said and sorry, what’s your name?

G04BCM22: G04BCM22

G04BCF21: And what G04BCM22 said, I do agree because cancer is curable. Dementia, it’s prolonging. It’s not. And your whole life as G04BAF23 said, your whole life history, your family, your children, your grandchildren is there, is gone. So yes, might as well shoot me.

(mmm sound of agreement)

G04BCF21: Because you, it is, for me I love my grandkids. I cannot even ….dream that I would never remember who they are and what we’ve done. No… no…so you might as well take me away, you know. Whereas with cancer there is a possible that there is cure, there is everything else. But for dementia, there isn’t at the moment.

UCLRA02: OK

G04BCF21: I don’t know what the government’s doing. If they’re not focussing on treatment for dementia like they’re doing for cancer…

(mmm sound of agreement)

G04BCF21: The thing is, if they find the treatment, if they find that there is help…it’s like if you don’t have this *(gesture of rubbing thumb against index and middle fingers to denote ‘money’)*.. you’re not gonna get it

G04BAF23: Yea, the money

G04BCM22: Sound of approval

G04BAF23: Say it, if you don’t have the money, if you don’t have the money*… (directed at the recording device)*

(Laughs)

G04BCF21: If you don’t have the money, you don’t get this..*(short laugh)* if you don’t have the money you’re not gonna get it. And that gets me very frustrated because I lost a friend last night to cancer. Now, if they…. they found some sort of treatment for cancer

G04BAF23: (loud mmm mmmm of agreement)

G04BCF21: Why didn’t they give it to her to prolong her life?

G04BAF23: I think I was… (unclear) or something like that

G04BCF21: But it’s not being done. So if that’s not being done, if it comes along with the dementia, I … when they find the medical cure for that. What are they gonna do?

G04BAF23: It’s like they gonna select people to give it to

G04BCM22: Yea

G04BCF21: it’s so… it’s not fair

G04BAF23: A-a-as I said, you know, based on what G04BCF21 said regarding if they find a cure, one of the things I’ve noticed when it comes to health care… is like those that are in power, those that are in the high ranking, they detect who gets what. You see what I mean? And most of this research or most of the medications that they do get, when you trace it back down it comes from Africa. With cancer for instance, from one of the research I read or one of these illnesses is that marijuana, one of these weeds that people smoke was actually the cure, you see. It was conducted in America a couple of years back before this Professor or whatever it is found out that that was the cure, he destroyed the document because there was feeling there’s no way that this weed, you know of the *(unclear)* would cure cancer or something like that. And now, it’s like if people knew that that was the cure lots of people would not be dead by now. And now that they’re even bringing it back into the system, then they said “oh ensure that you don’t take…people don’t end up you know taking weed just because they find out, oh…” you know, they they…at the end of the day it’s about making money. Making money for the health care is more important than saving lives.

G04BCF21: mmm

UCLRA02: OK

G04BAF23: That is the honest truth. (37:17) So it’s the thing falling back down to memory loss… is the family or somebody in the family’s memory more important for you to waste on one person to be able to remember their children and grandchildren at the very low costs that the family can rally around and get five K compared to you selling to them fifty K just to get a treatment

UCLRA02: OK, thank you very much

G04BCF21: That’s exactly what G04BAM19 said going back.

G04BAF23: Yea…

G04BCF21: We have to go back because if you look at our foreparents, there’s a lots of herbs out there that can cure

G04BAF23: Go to Africa, please

G04BCF21: There’s a lot of herbs out there…

G04BAF23: Actually, don’t go to Africa *(laughter)*

G04BCF21: … that can cure. And as you get older, we don’t know, down the line we look at it, hmmm, but it’s a good cure.

G04BAF23: (mmm mmmm of agreement)

G04BCF21: It’s fantastic

G04BAF23: Yea

G04BCF21: What happened was somewhere along the line all this information

G04BAF23: Got lost

G04BCF21: It’s got lost

G04BAF23: It got lost. Yea!

G04BCF21: And we… I don’t remember all of the medica… all of the herbs that’s out there, on the street that you can use. I don’t remember all of them. I do know some of them. But I’ve got to pass that down to my grandchildren. Now, who is to say that my grandchildren are gonna pass it down to their children.

G04BAF23: To their children

G04BCF21: So they’re going to lose some of the…

G04BAF23: Information

G04BAM19: Yea

G04BCF21: … Information. There’s a lots of things out… there’s things out there you can actually go and drink. You’ve got lavender out there.

UCLRA01: It’s interesting what you’re saying. So that brings to mind a question which we’ve been asking to all the groups. Some people when we talking about memory looking after memory, some people said that dealing with memory problems is much better back home, whether it’s in Africa or the Caribbean country, while other people said they prefer it here. What are your feelings about that?

G04BCF21: No no I’d rather back home. Me personally, I’d rather back home ‘cause you know that there will be a treatment for it in terms of the herbs we’re - we’re drinking. You’ve got the old… hmmm…

G04BAF23: Traditionalist

UCLRA01: OK

G04BCF21:… generation over there. They are traditionalists.

G04BAF23: Yea, traditionalists….herbalists

G04BCF21: They’re herbalists.

G04BAF23: Herbalists

G04BCF21: Yes, they know, they know because they’ve b… this’s been passed out from generation to the next. So they know what to give you, to drink. They know what to give you to eat to help you…

G04BAF23: mmm mmm (sound of agreement)

G04BCF21: …over here… And the food is a lot fresher, over here unfortunately…

G04BAF23: Fertilized

G04BCF21: …even the tablets they give you is not even a hundred percent.

G04BAF23: Yea

G04BCF21: Whatever they said (40:00). It’s only like about two percent and the rest is mixed up with something else

G04BAF23: Something else, yea…you know based on what G04BCF21 said as well, yea… personally, you know I went… I had a wazzy? massage couple of weeks back and I was speaking to the lady and she said “oh, I’ve found this seed” and I said “what’s the seed”, she said “Moringa seed”. And, you know she said she’s begun to eat nowadays and stuff like that. And when you trace it back it’s from Africa. I called home, I called my people back home and I said “oh, there’s this seed, what’s it about?” and they’re like “oh, it’s…it’s Moringa seed, it’s been here ages, years”. And they have it freely. You know, they eat it they drink it they do whatever it is. That is why they’re healthy, because it’s natural. Nothing been mixed with it, nothing whatsoever. You see what I mean? It’s free. But when you bring it from back home Africa, here and they try to even put it in tablet form. They still gonna half it. Add something else to it. So it’s not gonna be one hundred percent Moringa seed. When they make it into the tea tablet it’s not gonna be one hundred percent Moringa seed. They still gonna add their own chemicals just to get money of you. Do you see what I mean?

UCLRA02: Absolutely. Thank you very much

G04BAF23: So, that’s just an example for them to know that you don’t add these to a natural stuff. You leave it natural, that’s it. Don’t add nothing else.

UCLRA02: Thank you. Just before I do pass over to UCLRA01. Any of the other three of you got any views in terms of UCLRA01’s question about…

G04BAM19: I got lots of views(41:35)

UCLRA02: We’d love hear some of them

G04BAM19: um where where do I begin? OK, you you said at the beginning this is mainly to do with Afro-Caribbean people. Ok and I did mention early that in in our own environment, right. You see we are children of the kidnapped people, the runaway slaves. She’s children of the colonised people, right, colonise the mind first and then they take your ancestors out. Now, the greatest power they have in their arsenal is the mind. The people minds have been conditioned whether they are from the Caribbean or from here. Your mind have been programmed now, conditioned to rely on what they give you. Not what is good for you. We Caribbean people we deal with the herbs, natural herbs. She mentioned marijuana, right. It’s a very, it’s one of the most important available plant on the planet. It “nurtricide?” the land. It bind together. The plant itself it can give you many thousands of different different product from it apart from just drinking it or smoke it. Now the powers to be, I know you’re taping this and it might get back to them. The powers to be don’t want we as Afro-Caribbean people to advance, right to rise up. So what they do, they using us as Guinea-pigs right, for the medicine, the medication. That’s why I said earlier, the GP not gonna help

UCLRA02: OK

G04BAM19: Because you not taking their their product, right. That’s all they want at the moment. Now, cancer been mentioned. They can cure cancer. For a matter of fact, most of the disease and germs, you know they can cure them. ‘Cause when they met creating those things they make the serum to do it.

UCLRA02: OK

G04BAM19: So, this thing about oh they still searching for cancer… even every moment they come on the TV said they, they got something will prolong your life for six months. What’s gonna cost one, ninety thousand a person? – Laughs -

G04BAF23: Yep

UCLRA02: It’s really interesting everything you’re saying and you know I’d love to hear more about it. I am just going to have to stop you there if that’s ok just because I’m conscious of the time. We said you wouldn’t run sort of much over an hour hopefully and I want to hand over to UCLRA01 because he’s got lots of other really interesting questions that he’d like to share with you if that’s ok.

G04BAF23: Yea, it’s fine.

UCLRA02: Thank you very much. OK UCLRA01.

UCLRA01: OK, I will try to make it quick. One thing that we know, we know that when people who’ve got problems with memory when they look for help soon near their GP or specialist, they do better. You know they have time to plan for the future. They have time to organise with their family. I know you said that, OK the conditions here are not right. But if you know that you have a condition you can probably do something about it. So if you had a problem with your memory what sort of information would actually make you look for that help? What kinds of information, let’s say um if I put something through the post to you would that help you to look for help, or if you see something on TV or if you receive something on a DVD what would actually make you look for help for your memory problems? I know the idea so far is, there’s actually no point trying to look for help but we know that if you do look for help early it’s gonna be good, so…

G04BAF23: It’s gotta be visual. I think a visual stuff leaves a lasting impression

UCLRA01: OK

G04BAF23: People, not that people like looking…you gave me the sheet now for… I’m young yea but it’s like reading all this is… it’s too long for me. I might as well see something visually or just explain it to me for me to hear. Those two things will last longer, nowadays. And I think it’s just because we don’t use enough of our brain cells to read and as he said being conditioned as well. So, to uncondition us is a thing of take away the visual, take away the hearing then I’ll be forced to read this. So with memory loss now, in order for you to get probably more awareness or read or stuff like that, is a thing of put more visual out there. Let there be more visual. It’s just like when there was mental health awareness week or month, in the bus you just see the posters, you know, your next friend might be suffering from this or something like that. It’s always in your face. So you can always relate to the picture. People can see, people can hear it. You understand? Compare to you send… If you were to send this for me by the post, I look at it, I put it in the bin. I don’t have time.

G04BCF21: Also, you have to remember that there are… unfortunately, there are people out there who cannot read….that, you know. So you have to you know…visual

G04BAF23: Yea

G04BCF21: Yea, you got this…

G04BAF23: Yea there’s lots of people they can’t read they can’t write, so…

UCLRA01: OK

G04BCM22: I feel like… I think part of it like, the scientology…

G04BAF23: The science, yea

G04BCM22: The scientology, the neurology, ain’t it… There could be like MRI scanning, ain’t it…

G04BAF23: Oh yea

G04BCM22: Scanned ain’t it, it can tell you what’s wrong with the person, you know what I mean. It might be something… but then again sometimes memory is just in the mind… if you query your brain, your brain can process all that…(inaudible) at some (inaudible) stage, later stages of someone life when they get older (inaudible) when they like…(inaudible) sometimes they can get to stage where they get memory problems, forget things, like that…

G04BAF23: Umh… Yea

UCLRA01: OK, they forget…absolutely… Umh, but what would help somebody like this? I mean, if we trying to, if you knew somebody like this, how would you try to reach them and make them look for help? Would you send them a letter? Would you send them a DVD? Would you…

G04BAF23: Do you mean for someone that has lost their memory or that’s at this stage?

UCLRA01: Yes, somebody who’s having problems with their memory. I mean, what would be the best way to reach them?

G04BAF23: I think it’s just talking you know and just trying to bring somethings back into memory, you see what I mean? If they’ve actually forgot something very very important like, oh maybe their granddaughter’s birthday or …

UCLRA01: Oh sorry, I don’t mean about what they forget, you know, the thing they forgot about. I’m talking about, you know somebody has memory problems and you believe that they should look for help, how would you make them look for help. Let’s say we know that umh, we think that there’s a community, a black community not looking you know, not looking for help when they should

G04BAF23: I’d talk to them one on one, one on one.

UCLRA01: So you think, one to one?

G04BAF23: One on one sometimes is good and then you might actually…Wait, before you talk to them, you make sure that you have enough information and research about… is there a community project going on that is quite intimate. You understand what I mean? Something that they can relate to. ‘Cause say, “OK, you know what mum this is going on. Recently you’ve been forgetting stuff, blah blah blah.. you know just go and try this out. You don’t have to but you know if it’s persistent, just try you know maybe going to this place or something like that”. But I would talk to them one on one. Make them realise what I’m seeing and what other people seeing as well. Give them the time to digest it, you know, not like force it on them like, you have to go to where we are now, or you have to go to a GP something like that. But, more “it’s getting persistent now, you know. What do you think you wanna do about it? Give them the option.

G04BCF21: But I’ve just lost that memory, you know that?

G04BAF23: What?

G04BCF21: I’ve just lost it because you’re telling me this but I’m not gonna remember

UCLRA02: OK. So, that’s a really good point G04BCF21 and I think one of the other things that we can build on from that is about saying, you know, if we were going to be giving information to people to try and help and encourage and support them in looking for help, who should that information be aimed at within the Black African and Caribbean community?

G04BAF23: Next of kin

UCLRA02: Next of kin

G04BAF23: Like (Short laugh) not really like next of kin but like someone that is…

G04BCF21: It should be aimed at the family. It should be not necessary next of kin because the next of kin may not be close. It should be aimed at…

G04BAF23: Close family

G04BCF21: …the family… it should be aimed at the family. For me the family is imp… for me family is important and if my memory is not um good um and you send the letter home, I say send it to not just to me but send it to every member of the family, letting them know that you’ve written to Tom, Dick, Harry, and this is what is happening and this is where we can go to get a bit of help and support. Because if you’re just going to write to G04BAF23 about me and G04BAF23’s gonna tell me “Yes, yes yes”, when G04BAF23 goes through the door, I don’t even remember what G04BAF23 is saying. And then I’ve got my son coming through and says “Oh mum, did so and so talk to you? No, no she didn’t say anything to me, no”. So for me, it is about the family.

UCLRA01: OK. So you’ll tell all the family including the person with the condition…

G04BCF21: I think yes, the immediate family

UCLRA01: Now, let’s say your GP sends you a letter. Just to let… you know with information about it saying umh if you’re that age and youreceive, have memory issues go and see your GP, would you read it?

G04BCF21: I would, so long as I know is from *my* GP, I would. But my GP tends to phone me up. I’m very fortunate, I’ve got a lovely GP. He does tend to phone me up

UCLRA01: OK.

G04BCF21: And if I miss an appointment, he will ring me and say “What happened?” Right, so I’m very fortunate. I’ve had some rotten GP and I finally got one that I .. thank you!

UCLRA01: So you would read that. Excellent!

G04BCF21: I would I would

UCLRA01: Anybody else?

G04BAF23: (Laughs) That’s because you’ve got a good GP (51:44)

G04BCF21: That’s what I’m saying (Laughs)

UCLRA01: OK. So… you? Would you read it?

G04BAF23: If it’s just from the GP like just addressing it, I might not really pay much attention to it. You understand? I might not pay… if it’s just the kind of general “If you’re between the ages of fifty too sixty, blah blah blah… I might just put it somewhere because I might be thinking, I’m not that age.

UCLRA01: OK.

G04BCF21: You think it’s circulars so you put it in the bin

UCLRA01: How about you guys? Would you…

G04BAF23: … read this…

UCLRA01:… if you have a letter from your GP giving you information about memory problems? Would you ready it?

G04BCM22: Umm, I don’t, that depends, ain’t it…

UCLRA01: Depends on?

G04BCM22: (inaudible) if you didn’t have it you wouldn’t read it ‘cause it wouldn’t apply to you, ain’t it

G04BAM19: Yea

G04BCM22: It depends, ain’t it, like so you have to aim at certain groups of people, ain’t it..

UCLRA01: OK

G04BCM22: Yea, who it apply to, ain’t it. So you could single out people properly (inaudible)

UCLRA01: So, you’re saying if you haven’t got any memory problems you wouldn’t read it

G04BAF23: No

UCLRA01: OK

UCLRA02: OK

UCLRA01: What if it comes in the form of a leaflet? It’s a leaflet, colourful leaflet with pictures on it?

G04BCF21: No…circular… in the bin

UCLRA01: Would it be more accessible? No, you wouldn’t, not for you..

G04BCF21: Circular… in the bin…no. That’s why I said aim at the family because there are some family, there are some family umh nowadays they still sit down and have family dinners together and that’s a topic, “Oh did you get a letter from so and so, Oh..” and it’ll go round the table. And it then become a subject where everybody’s talking about. “Oh, I noticed, mum, you you sometimes forget about things”, “Oh, do I? Oh…” , “Oh, what about if we go find out whether or not it’s a memory problem or not”. Whereas if you… if you…like this leaflet you sent me, if I didn’t know it was from you I would have thrown ‘em in the bin. But because I knew if was from you I took the time to read it (Laugh)

UCLRA02: Thank you

UCLRA01: Thank you

G04BCF21: So that’s the problem, you’ve got to make sure that you know that it is from who it is, rather than a circular. Because if not, there’s so much things come through my door, I throw them away

G04BAF23: Junk… Junk…Junk

G04BCF21: And lots of them is my bill and don’t even know. I throw them away.

(LAUGHS)

G04BCF21: My Sky bill, I threw it in the bin. I’ve no time to read it.

UCLRA01: Thank you. Excellent, and how about if the leaflet or the letter says NHS on the envelope in big letter

G04BCF21: I would definitely throw it away then

(LAUGHS)

UCLRA02: OK

UCLRA01: Interesting… and you guys?

Umh

G04BAM19: So you say this is run by NHS, yea?

(Umh Umh)

UCLRA01: Yea…

UCLRA02: Yea, if you received information that explicitly said that it came from the NHS would you be more or less inclined to read it?

G04BCF21: Less

G04BAM19: Well, I would… I wouldn’t…I would read it but I don’t think I would act on it.

UCLRA02: OK

G04BAM19: I see NHS they closing down most of their hospitals anyway…

G04BCF21: Ummh, thank you

G04BAM19: They gonna have one stop for…(Inaudible)

(INTERRUPTING NOISE)

G04BAM19: So I don’t see… I don’t see how this gonna… gonna help…

G04BAM19: HELLOO… HI… (Call directed at children noise playing outside)

G04BAF23: Shuttt...

G04BCF21: G04BAM19… G04BAM19…

UCLRA02: It’s ok (Laugh). Let’s… we can move on just while the others…

G04BAM19: They can … they can … erase that bit there…technology…

(LAUGHS)

UCLRA02: One really interesting question that leading from what you just said G04BAM19 I’d be interested to know is, if you were going to be given information in whatever form about memory problems trying to help and encourage you or someone you know to seek help for those problems, where should the information come from? Where would you… who would you like to be giving you that information?

G04BAM19: Listen, me personally, I need more black doctors who know about our condition. Only we alone right can feed ourselves. Only we alone can free our mind. No other group of people can do for we what we suppose to be doing for ourselves.

(UMMMH SOUND OF AGREEMENT)

G04BAM19: But the system does not allow that

(UMMMH SOUNDS OF AGREEMENT)

G04BAM19: Right. Whenever we have anyone in our group which is go to their school, their university, get their qualification they stay with them. They don’t come with us. We need to have our own doctors, our own lawyers. We need everything for ourselves. We don’t do nothing for ourselves. I’m fed up of we as a group of people relying on other group of people for everything, right. And it’s kinda, bringing us down. It’s killing us slowly, right. We need to come together as a group of people. Our young people need to know who they are. That’s why they’re suffering with brain problem now because they don’t read their stories. We always reading other people stories and not our own. We need to have our own story so our children can find out and know who they are so we can grow.

UCLRA01: Thank you

G04BCF21: That’s what I said to you about…about umh a generation of knowledge has gone, has absolutely gone through our hands because it’s been passed, passed down and somehow it seems to stop at somewhere and not come down the other end. As I said about all these things we got outside there, you know.

UCLRA01: That’s very interesting. Thank you very much. But what I’m trying to find out again umh we talked about te letter, leaflet…

G04BAF23: Yea, how to get the information…

UCLRA01: Now, what if you get a DVD through your post? Given to you with information… I’m trying to find out what type of media we’ll use to make you read the information?

G04BAF23: Oh… I think you should just have things like workshops and like open events that you know that would catch people

G04BCF21: Get people, yea

G04BAF23: You know, that that … because you wanna make awareness of something you know, don’t make it enclose like private things like “Oh it’s just for G04BAF23” or stuff like that. No, generalise it. Let people know that something is going on there. You know now, NHS can afford to make a… I don’t know what is called… like this big carnival about memory issue, you know. They can have that you know. People want to see what’s going on there. It’s summertime, so many activities are going on. (57:49). It’s just like having activities, outdoor activities for kids. After, you know… have memory loss day or dementia day or something like that whereby not just all the old nurses going there and looking down and everything. Have young people, get them involved in things like this you know. Let them be aware that you know this is what’s going.

G04BCF21: This is what’s gonna happen

(YEA YEA)

G04BAF23: You know this’s what’s gonna happen. You have people in universities now studying for nursing, how many of them are in mental health in nursing? What’s the percentage? All of them are going on to general health, or child health. How many are going under the mental health section? You know you have to look at that and they’re all under the NHS. This are young people… if I was to see a young person you know campaigning about memory loss, I would want to get interested, I would wanna know what’s it about. But when I see an older person there just looking as if “oh, I’ve been forced to do this… oh yea yea yea…” I’m like you know forget that… I can’t… I don’t have time for this.

UCLRA01: OK. Thank you. So…

G04BCF21: Another thing is… sorry…

UCLRA01: Sorry, go ahead

G04BCF21: Another thing is umh when you walk through Croydon ummh… I have to admit I hate Croydon… but when you walk through Croydon on a Saturday, you will see all these different…

G04BAF23: Stands

G04BCF21: …vans, like a reading umh umh is it a library or whatever…

G04BAF23: Yea

G04BCF21: What, why can’t you have…

G04BAF23: One stop

G04BCF21: … not you personally… what, why can’t the government have more of those umh. What they call it? Is it a van?

G04BAF23: Vans and (Unclear)

G04BCF21: Vans…there’s… because, the reason why I said that is years and years ago I was a very bad sm… I was A VERY bad smoker. And because of that van, I actually gave up smoking. Because I saw the van there and I thought “OK…no, I won’t go in”, but somebody actually said, “why don’t you come in and just listen to what we got to say”; and because that person said come in, I went in, I listened, and true to that person I don’t smoke. And I’m I’m talking about…what? Ten years ago… I haven’t smoked. So if you have things like that in…

G04BAF23: Strategic places

G04BCF21: …in the area, in the Thorton Heath area, in the Croydon area, whatever area… I think you will, the message will be sent home, because you’re speaking on a one to one… is eye contact.

(UMMMH SOUNDS OF AGREEMENT)

G04BCF21: You’re hearing what the person is saying. Yes you may leave the van and go down the road and you, you know you got memory problem you may forget but you can guarantee you will not forget your face! And somewhere along the line, even from a cup of tea, I will remember what you say somewhere along the line.

UCLRA01: OK. Thank you

G04BAF23: And also, based on what she said, those van stop… is not just gonna be a kind of seasonal thing whereby is just for…

G04BCF21: No

G04BAF23: … one month…

G04BCF21: No

G04BAF23:… or we’re having this campaign because that’s what…

G04BCF21: No

G04BAF23: …NHS tend to do. It’s like they just have this whole month…

G04BCF21: Yea

G04BCF21:… the van will be there and after that you don’t see them again. No, it has to be consistent. You know you must have…it’s like employ these people. Let that be their full time job. You know come rain, come sunshine, they will be there, that is their office, that is their station you know. You can’t just… because not everyone wants to go to the hospital.

G04BCF21: I think they’re more likely to go to that than the GP to be honest…

G04BAF23: than…exactly, I would go to that

G04BCF21: … especially if the GP is in there, they would more likely to go to that

G04BAF23: Yea, I would go to that

UCLRA01: Thank you. Thank you very much

G04BCF21: Even though with the data thing they would more likely go to that than anything else

UCLRA01: Thank you

G04BCF21: I… what…

G04BAF23: That’s what we think

UCLRA01: One final question

G04BAF23: Of course

UCLRA01: Do you think that this information should be directed at a specific age group?

G04BCF21: Specific…? Who’s … who’s…?

UCLRA01: We’re talking about memory problems, should we target a specific age group?

G04BCF21: Right, can I … can I… right, I hear what you’re saying but can I ask a question before I answer that?

UCLRA01: Sure

G04BCF21: It’s like… they are targeting women over fifty to go on a screening for breast cancer, yes? Because, what’s her name? Who she died the other day?

G04BAF23: eumm this girl, a celebrity lady.

G04BCF21: In big brother’s house. What’s her name? She died?

G04BAF23: um, that had two boys…?

UCLRA02: I don’t know, so… Oh Jade?

G04BCF21: Jade!

G04BAF23: Jade, yea

G04BCF21: So, because of Jade now developing this cancer…

G04BAF23: (Unclear)

G04BCF21: …they realised that fifty wasn’t the age. You need to…

G04BAF23: Bring it back down

G04BCF21: …bring it back.

G04BCM22: Yea

UCLRA01: OK

G04BCF21: So my answer to you is, why am I targeting just at a certain age group which is nearer to dementia. As G04BAM19 said, the youngsters… the youngsters could be having…not dementia but memory problems so focus on that so that later days they don’t end up with dementia. Find something for them to… to train because if we train their brain now, I think you can lead them out of dementia.

G04BAF23: Yea

G04BAM19: Yea

G04BCF21: I really have that belief me personally

UCLRA01: OK. So… anybody else?

G04BAM19: You see, what, what this system do, they pick out certain group of people at certain time…

G04BAF23: (Ummh sounds of agreement)

G04BAM19: …to go on their…

G04BAF23: Research

G04BAM19:… survey

G04BCF21: Yea research

G04BAM19: Yea....and they…they… you see, it’s no good jumping in the middle if you can’t swim don’t jump in the water, right? You gotta go back from where this all this things are coming from. I said it many times already.

UCLRA01: Absolutely, and we did get that….

G04BAM19: At the… at the beginning

UCLRA01: So what are you saying? If we’re sending information, who should we target?

G04BAM19: All group

UCLRA01: All group

G04BAM19: All group, all age group.

UCLRA01: Excellent. Thank you.

G04BAM19: From unborn baby (Laughs)

(LAUGHS)

UCLRA01: Yes, that would be a challenge but that’s a very good answer

G04BCF21: But, that is not, he’s not wrong there because I mean, years ago they used to say if a mother smokes so much they that they’re stopping the brain growth of a child

UCLRA01: Absolutely

G04BCF21: You know… umh, as I said me smoking…so it probably does start in the womb from us. Yea…

G04BAM19: Is… is to do with what we eat man. Few weeks ago, they said, no you shouldn’t wash your chicken before you cook it.

G04BCF21: That’s…(Laugh)

G04BAM19: Now they come on TV say you have to wash it…

G04BCF21: Please… please… please…

G04BAM19: … wash it good with lemon. We’ve been doing that for years..

G04BCF21: Please… (Laugh)

G04BAM19:… but we… we…(Laugh) black people we become so assimilated now with Western Culture that we lost our own way…

G04BCF21: (Ummh of agreement)

G04BAM19: We lost our (Unclear)

G04BCF21: Not all of us, some of us

UCLRA01: Excellent. You have a question? Go ahead

UCLRA02: Yea, just few very quick questions before UCLRA01 wraps it up for us because I know we have been going about an hour now. I really would try and make them brief. I just wanted to pick up on two things. One of which you said G04BAF23, you talked about being a young person if you saw a young person being engaged in mental health issues and things you know you’d want to get involved and you’d want to listen. I was just wondering what you all thought about umh the older generations of people with the black, within the black African and Caribbean communities. For the older generation, would they be more or less inclined to listen to young people who might be umh speaking about memory problems…

G04BAF23: Oh, don’t get me wrong…

UCLRA02: … or peop… contemporaries of theirs?

G04BAF23: … don’t get me wrong. When it comes to, you know, awareness… it’s good to have a blend of both the experienced and those that are just coming in. Do you see what I mean? Because at the end of the day you need someone to hand it back into.

G04BCF21: Yea

UCLRA02: OK

G04BAF23: You need someone to hand it back into. And that’s where G04BCF21 comes in to say, it’s been lost somewhere…information has not been passed down correctly. Or it has been passed down and it’s like the generation just stops it there. But when you have a younger generation coming up and they have an older generation to say “You know what, come on we’re cheering you up”. That would encourage more people you know. If an older generation passes and sees a younger person, you know, campaigning about memory loss and stuff like that, I’m sure the older person would be like “Wow, that girl is doing a very good thing”. Or, you know, they may not really… the younger person may not have detailed information but the fact that she has sufficient information for her age you know for that particular season, it’s enough for me. And as I said, I would go to somebody that is more like minded than myself. To get the information, G04BCF21 might as well go to maybe a more professional nurse because she’s more advanced in that. But there is… has to be a blend as well. And not just females as well, you need more males in this as well. Because it tends to be more female kind of oriented job kind of thing. You need more male people in this sector as well. Because men as well do experience dementia or memory loss or forgetfulness, so…

UCLRA02: OK. Thank you very much, that’s really interesting…

UCLRA02: Just one last question if that’s ok. G04BAM19, is actually something that you said earlier on. Umh, I hope I remember this correctly, you talked about how maybe some young black African and Caribbean people out there umh have kind of lost connections, you know with their kind of home place and you talked about stories and things that they maybe haven’t been hearing and haven’t been passed down to them. I’m just thinking about UCLRA01… you know, we talked about a DVD perhaps being a way of communicating information to people. And if we…do you think… it would be useful if that information was communicated to people such as yourself through using kind of umh traditional stories, umh ideas and things like that? People that you can absolutely relate to? Do you think that would help in any way?

G04BAM19: Yea… yea, yea there’s people out there but… or some of our older people, they’re suffering with what you call dementia, alright… memory loss. So they can’t pass on the information. Now there’s people out there who can pass it down. But some of our younger people them, to they haven’t heard it before, they don’t want to know. ‘Cause most of our story is based around slavery, colonisation… for a lot of them will say “Oh, that’s gone, that’s gone, forget about that, let’s move on”; but we cannot move on because we don’t know our past, our present, our future or all those kind of things. So, some of our older people they’ve been here so long and truly enough, they not very well now they can’t be bothered and their sibling, they younger people they can’t be bothered. So, that’s where the information is lost because we do it already. We have we have levels. The most two important levels it is in, in our community. It’s the older one and the younger one. We have the middle section where we pass down orally. But that’s, that’s gone now.

UCLRA02: OK. Alright, thank you ever so much for sharing that. I really appreciate it

G04BCF21: A.. a.. another thing is, you know if you tap in on the youngsters and listen to what they’re saying in terms of what they do in terms of their technology and their dancing and the whatever. Perhaps, it’s another way to get through to them, the younger ones. Because they, they always seem to got these “high…high” what is it call it? What you call them? Stuck in your ears?

G04BAM19: (Laugh)

G04BCM22: iPod, ain’t it

Multiples: Earphones… iphone…

G04BCF21: oh… oh…yes, so maybe you know that’s something you know, if they’re constantly hear that thing… yeah… they love their music, tap into that…

G04BAM19: I use it as well

UCLRA02: OK

G04BCF21: Yea… you do as well

G04BAM19: I… I use but not so much for the music, so much for the information that I can get…

G04BCF21: There you are

G04BAM19: I… I … I love… I love information. Things I didn’t know when I was a youth growing up. I can… I can hear them now and I can listen to them.

UCLRA02: So for you, hearing the information is really important?

G04BCF21: Yea, that’s what I’m saying

G04BAF23: Hearing or seeing

G04BAM19: Yea, that is me. I… my … my eyes is impaired so vision…

G04BCF21: It’s hearing

G04BAM19: It’s …so, I rather this…(Laugh)

UCLRA02: OK. Thank you so much…

G04BCF21: That… that’s… that’s something you can do. These young ones that’s coming up, give them the music, give…instead of… you know… computer…they’re very…very…give them all of that. They’ll take it in. Make it part of the school…

G04BAF23: Curriculum

G04BCF21: Curriculum

G04BCM22: Yea

UCLRA01: OK

G04BAM19: But really they’re in school. Right, the system they ain’t gonna… they ain’t gonna do that

UCLRA02: OK. I think we are gonna wrap up…up there if that’s ok

UCLRA01: Thank you very much

G04BCM22: They like their rap music, ain’t it?

(LAUGHS)

UCLRA01: Thank you very much for taking part; that was a very good discussion. Thanks again.

G04BAM19: There…there…there’s a data protection on my name, yea? (Laugh)

UCLRA01: Yes, absolutely. Your name will be…

UCLRA02: They will be removed

(LAUGHS)

G04BCF21: I just wanna say, thanks very much for coming. It was very informative. I didn’t expect it to be.

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