**G06**

**Speaker key**

UCLRA02

UCLRA01

G06BCF30

G06BCM31

G06BAF33

G06BCF32

G06BCF34

00:00:00

## UCLRA02

So firstly I’d just like to welcome you all today. Thank you ever so much for coming. We really do appreciate you giving up your time to come and speak to us. We’re both researchers from University College London and as I think you’re all aware from reading the information that you’ve been given prior to today the session today is going to be recorded.

00:00:28

Everything that you say will be confidential but one of the things we need you to do is just to go round the room and just say each of your names so that the typist who is going to be typing up today’s session knows… can identify, you know, the voice with a name. Later on this name will be taken out so anything you say will be anonymised and you’ll be given, like, a unique identification number. Okay, so I’ll start with myself and then perhaps we’ll work round the room this way. So I’m UCLRA02 from University College London.

## UCLRA01

I’m UCLRA01 from University College London.

## G06BCF30

I’m G06BCF30 from Brighton.

## G06BCM31

I’m G06BCM31 from Brighton.

00:01:07

## G06BAF33

I’m G06BAF33 from Brighton.

## G06BCF32

And I’m G06BCF32 from Hove.

## UCLRA02

Thank you very much indeed. Okay, so just before we get going I just want to reiterate a few things, really, that, you know… there are no right or wrong answers today; we’re interested in absolutely everything that you’ve got to say, your opinions and thoughts that you’re willing to share with us, and we’ll obviously ensure that everyone has an opportunity to speak and say their bit. So the reason that we’re here is that we’re interested in how people from black African and Caribbean populations think about memory problems as they get older, and what you think might be helpful in this area. So we’d like to discuss your opinions as to why people from the black African and Caribbean communities may not always seek help for memory problems when they first notice symptoms, and what you feel could be done to help and encourage these people to see problems earlier on in the journey.

00:02:01

So just to start the discussion off we’ve just got a hypothetical scenario, so this is a lady that’s made up. She’s called Mrs Abrahams. She’s 70 years old. Her family members have started to notice that she’s getting a little more forgetful lately. She’s starting to not be able to remember conversations with people and she’s forgetting appointments with the doctor, for example. She often also misplaces important items like her keys or her glasses. She’s physically healthy but she is concerned about her own memory. So, as I said, she’s just a person that we’ve made up but obviously there are people like that out there who have similar memory problems and, as we said, she’s forgetting things; she forgets sometimes where her glasses and her keys are, and people close to her have noticed these memory problems, and, as I said, again, she’s physically healthy but she has got concerns herself. So I’d just like to start by asking all of you, if you knew somebody like that, do you think that she should get help for her memory problems?

## G06BCM31

Isn’t that normal with age? You lose that at a certain point, don’t you?

## UCLRA02

Sure. Anybody else?

00:03:12

## G06BCF32

No, I don’t think it’s normal really. Age is just a number, isn’t it, really? And we know a few people out there like that.

## G06BAF33

Yes. I think, you know, people… we just feel that, you know, as you get older, you know, you’re, sort of… get a little bit forgetful which is… which, you know… maybe in Africa we don’t think it’s, sort of, like, normal, you know, process; that’s what they think so it’s, like, a bit embarrassing, you know, when you say, oh, you know, I forgot where my glasses are, you know, I can’t find my keys and that. People don’t, you know, take in… they just take it… as something normal so, you know… so I, you know… it’s better, maybe that’s why people don’t, sort of, seek help, you know, early enough, you know, because, I mean, sometimes I forget things and forget where my glasses are placed, you know. Even though, you know… when I think back or I trace my steps back and I can’t remember, you know, but I think it’s just one of those things that we associate with, you know, getting older.

00:04:25

## G06BCF32

And you’re frightened as well that folks are going to…

## G06BAF33

[Overtalking], yes.

## G06BCF32

…place you in a certain place, you know, thinking she’s gone loony and…

## G06BAF33

Yes. I think that’s why, you know, older people, you know, tend to, you know, sort of, place their things in certain places and when anybody moves it round you, sort of, forget. You… they say, okay, you’re set in your ways, you know. I’ve got to have my cup on that table there and if you put it somewhere else, you know, you tend to lose track.

## UCLRA02

Okay. G06BCM31, sorry, you had something…

00:04:58

## G06BCM31

I think it’s the problem in life as well, what people face, you know what I mean? Stress, all sorts of things.

## G06BCF30

Yes, I think family as well… I think probably lack of care. In Jamaica families are a lot closer whereas here we’re more segregated and so maybe it is more normalised abroad than it is in the UK because they have the support and help.

## G06BCM31

Yes. Back home you’ve got… we all come from big families so we all stick together so if there is a problem you notice it as well.

## UCLRA02

I’m certainly going to pick up on some of those points in a moment. I just wanted to ask one thing: you know we talked about… we’ve spoken about being forgetful being normal, perhaps, and one of the things that we’re interested in is that transition from, kind of, normal, everyday forgetfulness to, you know, maybe a more significant memory problem that you might feel that you need to seek help for externally.

00:06:05

And I just wondered if any of you have any experience of this, or if you’ve got any ideas around what makes that transition from just normal, everyday forgetfulness to actually, you know, alarm bells ringing and I think I’m, you know… maybe need to seek help for this.

## G06BCM31

I think… basically I think over the… I think it’s this country, really. I do believe that because there are so many problems and you’ve got to worry about so much. I… my grandmother was, like, 80 and she would remember everything basically, you know what I mean? You go out for the day or wherever you go but she would remember something about what you’re doing, you know what I mean? Over here you’ve got so many problems; you’ve got bills, you’ve got all sorts, right, and with your health, it doesn’t help, you know what I mean? So at the end of the day you’re going to feel all these things and you tend to forget about things because you want to lose it otherwise your worries… always worrying about something or another, isn’t it?

## G06BCF30

The exercise and food as well, I think in Jamaica and Africa, in the Caribbean and Africa, it’s more healthy, food… they exercise more, they’re more…

00:07:16

## G06BCM31

Fruit, you know as well.

## G06BCF30

Yes, they’re having fruit and veg. They… they’re more independent whereas here it’s more of an indoor lifestyle, convenience and, yes… and money.

## G06BCM31

That is a good point as well because back home you can pick any fruit off of the tree, yes, because you’ve got big land. Over here, if you haven’t got the money you can’t have it, can you?

## G06BCF32

No stress or not as much stress.

00:07:47

[General overtalking]

## G06BAF33

I think people will pick it up more, you know, if… I mean, like I said, you know, people will just feel, oh, well, losing your this and that, but when people start going out and then you forget how to get back or, you know, something then people… alarm bells will start ringing that, oh, okay, you’ve gone out somewhere, you’re not sure which way to get back to your house, then that’s, well, you know… but I think at that stage it’s probably…

## G06BCF32

Too late.

## G06BAF33

You know, getting a bit… so I think that’s probably one of the reasons; because people will tend to think it’s probably part of growing, which it’s not really, you know… you know, part of growing old, which it’s not.

## UCLRA02

Thank you very much for all that. That’s really interesting. I mean, lots of you have been speaking about, sort of, back home in parts of the Caribbean or Africa.

00:08:43

One of the things I’d like to ask is that, you know, throughout these groups that we’ve been running and speaking to people, we’ve heard a mixture of responses but some of the things people have said to us are that, you know, being in their home country and having to cope with memory problems for some people, you know, would be better; they’d rather be at home. And I just wondered what you thought about that; whether, if you were experiencing memory problems yourself or a member of your friends or family, you know, would you rather be in England or would you rather be back home?

## G06BCM31

I think family… well, in the West Indies it’s, like… if somebody died over here and they’d rather to ship the body back to Jamaica and take it back over there because they feel more like, it’s a home ground, isn’t it? You know, so… but now it’s getting so expensive people can’t afford to do that.

## UCLRA02

Sure. I mean, in terms of what you think’s available for you, perhaps, with memory problems, all the support around you, do you think being here in England or…?

00:09:42

## G06BCF32

You can look at it two ways; you can look at it in the sense that if you’ve got anything physically wrong with you this is probably the best place to be because you’ve got all your medicine and doctors and… well, [unclear] some of the doctors are not all that good anyway but at least you’ve got medication here and things at hand, whereas back home it’s… you might have to walk miles and miles to get treatment and you’ve… speciality is not there.

## G06BCM31

Yes, distance is a problem over there.

## G06BAF33

I think the important thing is, you know, having the family support no matter where you are, whether you’re abroad or you’re here. If you’ve got your family’s support and you know they’re there for you, you know, it doesn’t really matter, you know, where you are, you know, when you have a problem because you know the family will be there to support you. This is why you’ve got children. When you’ve got, you know, close family, relatives, you know, who are constantly in contact with you I think you feel, sort of, like, safer, you know, being there rather than, I mean, like… you’ve left Africa years ago; even though you’ve got some relatives there but, you know, when problem… you know, to go back, you know, to, you know… that it’s not the same as being in your own environment that you’ve really, sort of, got used to.

00:11:11

## G06BCF30

Yes. I think there’s a familiarity of home. It’s… I remember my mother always saying that she’d go back home and she still says it and I think it’s, sort of, like, that security. And I think here as well things like GP surgeries and receptionists… where I work I hear a lot that people say, oh, the receptionists talk to you differently, they know you’re not English, they have a… they’re quite rude to foreigners and GPs, sort of, brush things off, they don’t really investigate what’s wrong with you; they’ll just write a prescription and it’s always about drugs and… take that and, you know, go away, bye-bye, see you later. So, yes, the attitude maybe… that standoffish, rude attitude, maybe that has to change as well.

## G06BCM31

And then people hide what they want to say.

00:12:08

[General agreement]

## G06BCF32

Because you’ve got to get past the receptionist first; she’s like a Rottweiler or a door person. You’ve got to tell her your information and we’re not used to doing that before we get to the doctor.

## UCLRA02

That’s really interesting. Just thinking about the GP a bit more, then, I mean, if you were noticing memory problems either in yourself or a close friend or family member perhaps, would the GP be somewhere where you’d go to look for help? How do you feel about that?

## G06BCM31

I think some GPs are all right. Yes, you can get on with them but, like she said a minute ago, you’ve got to get past that first guy before you can go any further, and if you don’t go past him you’re not going anywhere, are you?

## UCLRA02

What do other people think?

00:12:56

## G06BCF32

Well, the GP… for example, my GP, when they changed surgery I went up there and she said… because I’ve got lots of problems with myself she said, don’t forget, what do you want to see the GP about? And I said, certain things, and she said, well, you’ve only got ten minutes, you know, so she shouldn’t really discuss that with you, you know… well, book me a double appointment then, please, you know. So they tend to talk it over with your friends first and if you know the connection you go that way first to see what they think and then you go off. Maybe one of your friends can help you, you know. I’m very lucky because I know… the circle of folks I know are all nurses so we know to… how to go in the back door, you know. You don’t… if you’ve got something wrong, the time the doctor refer you to go somewhere, you’re probably dead by then. So what we tend to do is… for example, one year I broke my leg and I had an appointment… I had three months before I saw the orthopaedic specialist so one of my friends said, just get up, you’ve had your X-ray, just go up to casualty. And normally casualty don’t allow you in unless you’ve been referred to you… from your GP or something like that, but that’s what I did and I was seen within… seen plus that day and then and I got in the system, so there are other ways of going in the system. It’s, like… say, for example, if I wanted something done, I would come along to you and I’d ask your advice and you’d probably give me someone that can help me, so… find us the best way round to go.

## UCLRA02

That’s all really interesting. Thank you very much. You’ve also spoken quite a lot about the closeness of family and, you know, networks amongst friends and things and I just wondered, within communities such as your own and perhaps other black African and Caribbean populations, do you think that the close network of family and friends is something that’s very important in terms of sharing information if you were to notice memory problems either in yourself or somebody else?

## G06BAF33

Yes, it is. It is because, I mean, like, we’re such a… so… close community, even with BME [unclear] community based if there’s something wrong with somebody, even if she doesn’t notice it, we pick it up…

## G06BCF32

Pick it up. Yes.

00:15:41

## G06BAF33

And then, you know… so, you know, either talk to her or, you know, sort of, give that person… say, look, you know, do you feel this? You know, which is a good thing, you know, because you’re looking out for, you know… we’re, sort of, like, looking out for each other. You know, you might not even notice that, oh, you know, something is happening; somebody says, oh, you know, this is, you know… do you feel this? They’ll say, oh, yes, you know, and, you know, it feels, sort of, comfortable, you know, because we’re, you know… to talk your problem, you know, with friends or close, you know… people who are there. So I think it’s a good thing really.

## UCLRA02

Thank you. Anyone else?

## G06BCF30

Yes. I think it’s more about community. I think … that’s what the doctor should be doing; he should be listening to you and taking the time to get to know what’s wrong with you and… but I suppose, yes, the community does that as well, and I probably… I probably wouldn’t go down that doctor, GP surgery route.

00:16:45

I’m more into natural therapy. I think, yes, doctors and medication, it’s all about the money and how many drugs they can get down your throat as quickly as possible and how many side effects you have due to… so I’d probably go more natural and more exercise and health and diet and maybe homeopathy or some… or acupuncture more than medication and…

## G06BCF32

And the amount of folks that actually come to the organisation and say, do you know any black counsellors, and things? Because you get referred to… out there to a counsellor and the fact that we’re sitting there talking to someone that doesn’t understand where we’re coming from or doesn’t want to know, because it’s… if you walk into a room, you get that vibe straight away, you know, and it just puts you off.

## UCLRA02

Do you think that’s an issue around going to see your GPs as well? Is that a similar problem [overtalking]?

[General agreement]

00:17:45

## G06BCF30

Yes, and they… yes, there are certain ailments that we could have that doctors and GPs don’t even know about, even senior doctors and GPs don’t know about. I could tell you a few stories about my son having sickle cell and he doesn’t even carry a gene for sickle cell and I’m a nurse and I… and this was a registrar, like, a highly qualified doctor who’s trying to diagnose my son with sickle cell and that doesn’t give me confidence to go back to see a doctor, especially here. Maybe I’d travel to London to see someone who has a wider… because it’s about culture as well; it’s not just about the body, it’s about culture and, yes, there are lots of different aspects [overtalking].

## G06BCF32

It’s the same… like G06BAF33; she… you took your son into hospital, didn’t you? And [overtalking].

## G06BAF33

Yes. You know, years and years ago, you know, my son was… I mean, I’ve been round to my GP several times with this boy and, you know, I keep saying, he had, you know, ear infection, you know, and they kept saying, oh, give you antibiotics [unclear] and I said, look, but I live with my son, I know exactly, you know, where I’m coming from; when you’re looking after, you’re not there with me.

00:18:59

And I’m saying, look, I don’t feel happy, you know, with this boy. And, you know, they kept saying, oh, there’s nothing wrong, we’ll just give you antibiotics. So one day I just decided, that’s it; I’m taking this boy to A&E because he was not improving. He was, sort of, being funny and I got there and the doctor there said, oh, you know, I’ll just give him some antibiotics and I’ll send you home, and I said, I’m sorry, I’m not going home, you know, with this boy. I said, I’ve been asking my GP for weeks and weeks to try and investigate and see, you know, why he’s like this but you’re just giving me antibiotics, I said, so I’m not going back home.

That was at the old Alex [?] and he said, okay, you know, I’ll tell my consultant and then, you know, went to tell the consultant that probably there was this very erratic lady who wants him, you know, who is insisting, and... because my instinct was telling me that this thing was not right so I waited and, you know, so he came back and said, okay, we’ll admit the boy. Then they did blood tests and everything, then they started running around and they couldn’t even talk to me, you know, about anything because they knew something definitely was wrong.

So… and, you know, ended up, you know, like, having… because he ended up, you know… he had leukaemia and they couldn’t, you know… and they couldn’t pick it up, you know, because he’s been ill and ill. But luckily because I insisted they started treatment and, you know, he got better, thank god, you know, but, I mean, that was just, you know… makes you think that if I hadn’t insisted then it would be another story.

00:20:47

## G06BCM31

I think you’ve been just really… the quickest way is… to fob you off is giving you antibiotics and just get rid of you, really and truly.

## G06BAF33

Yes, and they keep giving… repeated, repeated and not even investigating. That is one thing, you know, they just don’t really listen properly to what you’re, you know, trying to say. They feel, yes, we know it all and, you know, whatever you’re saying is irrelevant.

## UCLRA02

Thank you very much for sharing all of that with us. Just picking up on diagnosis and things - and you were talking about sickle cell and you were telling us about your son there - do you… I mean, obviously nobody likes to get ill but do you feel that having a diagnosis of dementia, for example, is any different to getting a diagnosis of something like arthritis or diabetes?

00:21:32

## G06BCF32

Well, because they can’t see it, you see. You know, they don’t think there’s anything wrong with you. If you’ve got a broken leg they’ll see it straight away but anything internal, you know...

## UCLRA02

Sure. So, I mean, obviously, you know, getting a diagnosis of dementia may be more difficult than somebody with a broken…

## G06BCF32

Well, it puts your mind at ease because you could say, I told you there was something wrong with me, you know, even if you don’t want anything to be wrong with you.

## UCLRA02

Yes, sure. I mean, I guess I was trying to get at, there, you know, how dementia is viewed within the black African and Caribbean communities in terms of someone receiving that as a diagnosis. What are the feelings around that diagnosis?

00:22:19

## G06BCM31

I don’t know. I think the doctor over there might know a bit more than the doctors over here in that respect because they probably know what you’re going through or go further with it more than the doctors here, because the doctors just want to give you antibiotics and think that it’s going to cure everything really.

## UCLRA02

When you say, over there, you mean in… back… in Jamaica [overtalking].

## G06BCM31

Yes.

## UCLRA02

Would you mind just expanding a bit more about that? About what would happen if you went to see a doctor there.

00:22:45

## G06BCM31

Well, one of my friends… one of my friends, I think he fell sick while he was over there and he was examined by a… by the hospital over there and they went further and further into it and they found out what the problem was, you know what I mean? And if they’re going to just give you antibiotics and just let you go obviously they’re not going to know what the problem is, are they, you know, until you follow it up?

## UCLRA02

Anybody else around… ideas around having dementia and things in the communities that you’re from?

## G06BCF30

I think you have to really investigate. I think it’s harder to diagnose dementia than it is diabetes or arthritis and so you really have to investigate the person and I don’t think doctors or the GP… maybe doctors in the hospitals do once you’re referred on, but the GP doesn’t seem to have the time or it’s more like a conveyor belt, like a factory site, one person in, next person out, so it must make it ten times harder to…

00:23:54

## G06BCF32

Yes. Not only that…

## G06BCM31

It’s… go on.

## G06BCF32

Not only that but once you’ve been diagnosed with dementia, especially if you’re a younger person, it follows you all the rest of your life; all your jobs, anywhere, so folks don’t… they leave it until the last minute and by that stage you’re in a system where… you can’t get out of.

## UCLRA02

So do you think that puts people off going forward to get [overtalking]…

[General agreement]

00:24:21

## UCLRA02

Diagnosis?

## G06BCM31

I think doctors as well… there’s a lot of pressure on doctors here because, one, they only have limited amount of time to see certain amount of people. You go to a surgery and sometimes you have to wait for an hour before you even see the doctor. Some people can’t wait that long, you know, so doctors have got a lot of pressure on them, you know, I mean, and if they do something wrong, boom, they’re going to be cut off of the list, aren’t they? Because, you know, I mean, the first thing… they’re going to say, right, we’re going to sue you for this because that and that and this, so they have got a lot of pressure on them.

## G06BCF32

And they don’t know what’s wrong with you, do they? They’re relying on us, you know. You go to your GP, he doesn’t know; he sees somebody sitting in front of him, he can’t tell until he starts getting blood tests or things like that and he doesn’t know what avenue to go down so…

00:25:15

## UCLRA02

Thank you very much for all of that. Do you have anything that [overtalking]?

## G06BCF32

Sorry, [inaudible].

## UCLRA02

That’s okay.

## G06BCF32

You’ve arrived, yes?

## UCLRA02

I was just going to ask one more question, if that’s okay, before I hand over to UCLRA01. I want to just pick up on what you said, G06BCF30 [?], about, kind of, natural therapies and, sort of, more maybe traditional modes of medicine.

00:25:41

Because that’s something that’s come up… that’s something that’s come up in another group, somebody talking about that and perhaps other ways of dealing with ailments back at home, and I just wondered what you felt about that within the black African and Caribbean communities; if, sort of, alternative systems of knowledge around medicine and illness and things exist and whether that’s something that’s perhaps popular within those communities and might be a reason why people don’t seek help from conventional medicine in the UK.

## G06BCF30

I think, yes, there are… I think there are certain… yes, I think it’s, like, everywhere in all cultures but I think it’s more herbal, it’s more…

## UCLRA02

Can we leave it closed because we’re recording?

## G06BCF30

Yes, I think in the Caribbean community it’s more… it’s more preventative as well, before it happens, and then there’s herbal medicine I think [inaudible] the fruit [unclear] and I think fruit and medicine… I think it was… was it Hippocrates who said, let food be their medicine and medicine thy food?

00:27:04

And so I think even though we might not know it but we are curing our… well, preventing ourselves from getting these ailments due to our lifestyle. It’s a different lifestyle; we’re probably out more than we’re inside more, we’re eating more fresh produce, we’re exercising to get the produce - we’re not going to the supermarket, we’re going to pick the food - and then there’s that community, the people around you, and I think… and the independence as well. I think being independent and looking after your… I think that’s all, like, brain gymnastics as well; it’s, like, exercising your brain as well, and herbs as well, I suppose we cook with fresh herbs and herbs are said to be, like, medicinal as well and…

## G06BAF33

Yes. We have a lot of herbals, yes. That’s true.

## G06BCF32

Yes, the family plays a very important part because over here, once you come to Britain and you’ve got a house which… you’ve got a house back home but back home you have a families are there, and where you’re locked in the house you can be a prisoner in your own home here because your family’s… they’ve got families to look after, they’ve got a busy life, it’s like a rat race, you know.

00:28:31

So it’s… lots of the folks we know, they are locked in and this is why we’ve… our communities [unclear] because it’s somewhere to go, it’s something to do and all we need to do is call each other and there’ll be… we… they’re here… we’re here for each other.

## UCLRA02

That’s really interesting. I mean, thinking about your communities, what do you think are the, sort of, levels of knowledge around illnesses such as dementia within your communities?

## G06BAF33

Oh, I think they’re very, you know, knowledgeable really. I mean, like, I mean, in Nigeria we, you know… we’re so used to our elderlies, you know, being very knowledgeable and, you know, they’re really, highly, knowledgeable enough in almost every area of… so when… and because, like, I mean, you say, [unclear] my grandmother, okay, once she starts getting older she’s living with the son or, you know, within the family so if they notice that, you know, anything is going, you know… she’s going downhill or something, you know, they quickly get her to the doctor’s and say, oh, no, my mum, you know, she’s… she used to be able to remember numbers, you know, so quickly but now she doesn’t.

00:29:52

So they will, you know, sort of, like address it, but I think it’s just the close community, you know, within, as you said… that makes all the difference in dementia. And, I mean, the majority of people are aware of what dementia is and when… it’s only, you know, when it starts to get bad… when it gets worse, that’s when people actually notice but, I mean, like, you say a few things like, oh, I’ve lost my… I don’t know where I put my glasses and things like that, people just take it like a normal day, everyday thing until something really significant happens, yes [?].

## G06BCF32

We notice things a lot quicker… we notice things a lot quicker if you’re in a family unit because here you’ve got nursing home and once you’re a certain age the older folks get put in the nursing home or put into… and this is what we’re trying to avoid, you see, because they’re not with the family [group?] whereas you would notice things a lot quicker if you’re… the women are the elders and folks take note of what they say, they’re respected, you know.

00:31:13

## G06BCM31

Yes. I think that a lot of the herbs as well, like Pauline [sic] mentioned… the grandmother will find something to dress whatever wound it is that you’ve got which… over here you don’t get that, you know what I mean? Somebody in the family is going to find something to put on a cut, a bruise or a pain, or whatever it is, and there is something there for that.

## G06BCF32

It is very difficult to find… here it’s very difficult to find a shoulder if you need but in the Caribbean or Africa you get more than that, you get more than a shoulder.

## G06BCM31

The older generation, they can see things far ahead of what we can see, you know.

## UCLRA02

That’s interesting. I mean, just touching on some of the things you’ve been saying about communities and families, for black African and Caribbean people living here in the UK, do you think having their family or friends around them will influence their decision as to whether or not to seek help if [inaudible] memory problems?

00:32:16

## G06BCM31

Yes, I do believe that.

## G06BAF33

Yes, so, you know… because they will be, sort of, like, encouraged, you know, to seek help early and if you notice something, you know, and you, sort of, say, oh, you know, you feel this, you know, I mean, if you’re… somebody that is so close to you, they will listen and say, okay, you know, we’ll seek help…[Noises]

## UCLRA02

All right. Well, thank you for all of that information. That’s really, really interesting. I’ll move up here, you can sit there. I’m going to hand over to UCLRA01 if that’s all right, just to, kind of, move the conversation on a little bit and to think about some other things, so I’ll start off and then I’ll hand over to UCLRA01.

00:33:07

So building on some of the things that you’ve already been discussing today, we’d like to move the discussion on to your thoughts and opinions around what you feel could be done to help and encourage people from communities such as your own here in the UK to seek help for memory problems earlier. So one of the things we know is that for… people who get help for memory problems from their doctors earlier on in the disease generally speaking do better overall; they’re able to get better support for themselves and their family, carers, friends, for example, are also able to become better supported as well. So, UCLRA01, shall I hand over to you?

## UCLRA01

[Unclear].

## UCLRA02

Oh, no, I’ll keep going. So we’ll start the discussion…

## UCLRA01

Oh, sorry, I beg your pardon [?] [overtalking].

## UCLRA02

No. We’ll start the discussion by asking you, if you or someone close to you had memory problems, what kind of information would make it more likely for you to… for you or for them to seek help for these memory problems? What kinds of information do you think might support and encourage people to make that step forward to getting help for the problems?

00:34:15

## G06BCF30

I think leaflets and… with images of black and BME community on would help… be, sort of… relate to the person who needs help and maybe even, like, a TV advertisement with a scene of a BME family having a problem, that would help as well I think [inaudible].

## UCLRA01

Thank you.

## G06BCF32

And also a befriender. Community groups where you’ve got… you can go and get someone to help you along, you know, because we’re doing it on certain levels because it’s not only [unclear] something to the person who needs help as well as it… we’re getting something in return.

00:35:08

## G06BCM31

I think what Pauline [sic] mentioned here is about leaflets or something like that because we’re keeping it, like… this in the family group basically but it’s not out there for somebody to pick up something and say, look, here, this is where I can go and get help or whatever it is, you know, so that is a good thing in a way.

## G06BCF34

If you’ve got an…

## UCLRA01

Can I just ask you to introduce yourself for the recording?

## G06BCF34

Okay.

## UCLRA01

Just give your name, yes.

00:35:38

## G06BCF34

Right. My name is G06BCF34.

## UCLRA01

Thank you, G06BCF34. Go ahead, please.

## G06BCF34

Okay. If you’ve got an elderly family member who has a carer come in, then if that carer knows of these facilities or if there was more training for the carers who came in, in recognising and talking to the family about ways to support that elderly person, that’s a good idea.

## G06BCF32

I had... sorry. I had somebody in a hospital and this person was part of our group and they’d been in hospital. Nobody knew this person was in hospital; the hospital provided visitors for BME folks and this guy kept refusing. He went and he had his legs amputated and he was getting visitors from the hospital but he refused and I heard that he was in [and I went up?] and his eyes… he lit up just to see somebody from his own community come to see him.

00:36:41

## UCLRA01

Excellent. Thank you very much. So you talk about leaflets, befriending and having someone with the knowledge of the condition as well. Now, one of the questions I have for you, it’s… oh, I was going to ask you if there’s… if you would get that information, would you like it in a different form? Let’s say a DVD or something like that, and if somebody hands you a DVD rather than a leaflet would you actually watch that DVD?

## G06BCF34

Well, if it’s an elderly person, maybe from the Caribbean or so and they, you know… they’re quite elderly, they weren’t educated, they can’t read a leaflet, you know, it might be embarrassing to talk about it with their families or… because they can’t even read the leaflet themselves, they may need it in a form where they can listen to it and think, oh, yes, that is for me. So you have to think of the people who maybe aren’t educated; they worked in the country for, you know, 20 years, 40 years, and they’ve done things like bought a house and done all these things, travel and… but they don’t actually read and write so they need… it’s their time now; they’re elderly, they need that support and that help in that area.

00:38:03

## G06BCM31

Because if that format is there then at least if they’re watching the DVD they can watch it with their family and they can have a different opinion from all sides, yes.

## G06BCF30

I think, like, a TV ad after Coronation Street or EastEnders… I think that’s how… if you really want to get that person that’s where those types… you have to get it in at that time where they… where that community are watching those things and I don’t… yes, are we important enough to put an ad of a black family on after EastEnders or Coronation Street?

## G06BCF32

But they’re going to get the funding to do that, aren’t they? Because you give somebody a DVD and it all depends on who you give it to. If you give it to G06BCF34, they might watch it; give it to somebody like myself, I’ll go in and I’ll put it in my bag and I’ll forget about it. With… the older the person now and whatever you’ll find, it’s a different kettle of fish.

00:39:04

## G06BCM31

Well, when you think about adverts, there’s nothing there to talk about us, really; it’s all about selling, isn’t it? It’s all about selling and buying, really; it’s about money. There’s nothing there for us or nothing there for anybody, really; it’s all about selling and buying.

## G06BCF30

Yes, and it’s not even selling and buying to us. The only thing that they want us to buy is McDonald’s. That’s the only time I see the BME families, in McDonald’s ads, but the majority of the ads are aimed at not the BME community.

## UCLRA01

And what type of information would actually make you seek help? Let’s say… well, you said DVD and leaflet but what would you like to read in the leaflet or hear from the DVD?

## G06BCF34

I think that when you’ve got an elderly person in the family they’ve got lots of grandchildren, they’ve got children, they’ve got, even, great-grandchildren who are past that age of ten, they’re great-grandchildren, then, you know, going to sit with grandma or old aunty and just doing, like, a little bit of colouring in with her or a little bit of looking back at photographs.

00:40:18

She may have been good at making a cake or she may have been a good dressmaker in her younger days and showing her back pictures of what she used to do and how she used to support the family brings her memory back into… so activities, teaching somebody in the family who is now the carer how to…

## G06BCM31

Continue it or care for him…

## G06BCF34

Bring this person’s memory back by small, little tasks, and especially ones who can’t read and write; they can’t do computers, they can’t do mobile phones, they can’t do all of this modern technology so they are just cut off, left sitting in a chair, when this person used to work, you know, shop, used to run a family, used to travel with all the children on holidays. Now they’re just sitting cramped in a chair.

00:41:11

## G06BCF32

Discarded.

## G06BCF34

Yes.

## UCLRA01

Thank you very much. [Unclear] anything else to add?

## G06BCF30

Yes, I agree. I think that could be aimed at anyone but just having the imagery of the BME person knitting or dressmaking or cooking, that’d probably encourage the family members to maybe go to a GP and seek help and...

## G06BCM31

I think what that lady said as well… because they’re old they’re more experienced and we’re not… they’re not passing enough on to us, you know what I mean? It’s just… they’re just put in one side like she said, yes. If it was passed round then we can continue to do that with our own children, yes, and then we’re just spreading the word or doing whatever they used to do.

00:42:02

## G06BCF34

As… nobody would like to be treated like that; when you get to that age all your skills are forgotten. You were the head of the family, you used to be the one everybody would look up to; now you’re… everybody’s going out or everybody’s in the garden having a barbecue and you’re in the front room, in the back room, in a chair. You’re not… because you… and if you ask this elderly person sometimes when you come in… you say, she might just remember who I am but she doesn’t remember who Natalie is because she doesn’t… since Natalie’s been born she hasn’t even been involved because she couldn’t make it to the hospital, she couldn’t go out and shop for the new baby that’s come into the family. So little things that, you know, start bringing their memory… making them feel alive again and involved before this dementia really sets in and they’re forgotten. Very sorry.

## G06BAF33

Also, I think you have, you know…

00:43:06

## UCLRA02

Can I pause you just one second? Only because we won’t pick it up. Thank you. Go on, carry on. Sorry.

## G06BAF33

Yes, and I think to have, you know, posters, you know, just to…

## G06BCM31

Direct people.

## G06BAF33

You know, either post the big ones all around the town, hospital, everywhere, you know. All this misconstrued conception that, okay, it’s normal for you to… I mean, I’m still picking up on normal for you to say, I’ve forgotten my glasses somewhere or whatever, that… because that… just, like, little, little tell-tale signs and, you know, if people can, you know, sort of, like… oh, question mark, you know. Are you forgetting your glasses or are you forgetting to put things or do this? And then people will start thinking more that, oh, you know, maybe this is not normal, you know, I need to seek help, you know, but, you know…

00:43:55

## G06BCM31

We’re not finding it [?].

## G06BAF33

We don’t… yes. Like, I mean, if people signpost things, you know, to jog people’s memory about it… say, oh, you know, it’s not normal for me to, you know, just put my glasses down somewhere, I don’t k now where it is, you know. This is a little tell-tale sign of the beginning of dementia so people need to seek help earlier rather than when they start getting lost somewhere or whatever so I think [overtalking].

## G06BCF32

Because, you see… it’s not something that you can [say?]…

## G06BAF33

[Overtalking] thing.

00:44:27

## G06BCF32

…is going to happen straight away.

[General overtalking]

## G06BAF33

It’s a gradual process

## G06BCF32

Any of us can leave this room and in two months’ time we could be away, don’t remember this meeting that we’re having here today. Dementia comes on so quickly, doesn’t it?

## G06BCF34

I have an aunt with this exact, you know, thing going on right now and when I go to visit her she knows that I’ve come to visit her. If I buy her something, on the day she knows I gave it to her; if I phone her the next day she says, god, I haven’t seen you for, like, how long? And she says, can you take my address so that you can come and visit? That’s how bad she’s got it now; she thinks I don’t know where she lives and she sits and frets that… well, if you don’t know where she lives you obviously can’t visit her and if…I could’ve seen her the day before so she’s gone fully into dementia now.

00:45:32

## UCLRA01

Thank you for sharing that. You said the… you said the information should depict maybe family scenes. But, who do you think that… what age group do you think that information should be aimed at? If we do a DVD or we do a leaflet or anything like that, who and what age group do you think we should be aiming at?

[General overtalking]

## G06BCF32

Younger.

## G06BCM31

Also the older people.

## G06BCF34

Young….The grandchildren, the nieces, the… all the children that they have in the family going… all the generations need to be the one who spot it and take that time to go and… not laugh about it - oh, grandma doesn’t remember who we are - it’s not a joke; it means that you need to visit her regularly, you need to care about her enough to still show interest in her because she’s, you know… she’s not gone. She’s even… could live another… she’s, like, about 80-odd so she could still be here when she’s 100. If she’s like this now, by the time she’s 100 is everybody just going to… really just [overtalking]?

00:46:44

## G06BCF32

And if you put lots of old people on a poster and put it out there they’re going to class it as an old people’s disease which is not what we want to do.

## UCLRA01

Thank you. So you were saying… you’re saying young people, you’re saying old. Could you tell me why you’re saying that?

## G06BCM31

Well, the older people are the ones who suffer like this lady said, right. When they get into this thing they’re pushed aside or put at one side, aren’t they? Nobody takes any notice of it so you’ve got to see where that is coming from, yes.

## G06BCF32

Education before it gets too set in.

00:47:22

## G06BCM31

Because… sorry. That lady’s right; once they reach a certain age they can’t remember… you could see them the day before or even the same day and that… they don’t remember about you because it’s gone, you know, so you’ve got to focus it on… all right, a lot of people said younger people but I’d say the older people because they’re the one who’s feeling it and they can bring out… whatever you ask them they will tell you and that way you’ve got more hope in hearing about it. You ask the younger people, some of them don’t even know what it is, you know, so it’s hard in a way but I’d go for the older people.

## UCLRA01

Thank you. Now, I know there was some concern about the GPs, going and seeing your GPs; some people think the GPs are not helping too much. Let’s say your GP sends you… sends you a letter about, you know, memory issues; would you read that information if you see a letter from your GP?

00:48:17

## G06BCF32

Not really.

## G06BCF34

But would you… what… when you say, if your GP sends out a letter, if a person in their late 40s, 50s, is now a full-time carer to their mum or my aunt then does that mean that the letter comes addressed to them, they need to read it on her behalf and act on it? Are they going to say, well, she’s just getting the letter because she’s old? Or are they going to say, this is a letter that we really need to address?

## UCLRA01

It may not be that specific. Let’s say that the GP doesn’t really know your age or… I wouldn’t say he doesn’t care but it doesn’t matter for him; for him, now, dementia is a big topic so he decides to send a letter to everyone.

## G06BCF34

Okay. A general letter that comes through the post to everyone.

## UCLRA01

Yes, to every one of his registered patients.

00:49:10

## G06BAF33

Is that with information of what we should be looking for or just a letter to say, oh, come…?

## UCLRA01

A letter saying that if you… let’s say… I’m just, you know, guessing or giving you an idea… saying, okay, if you noticed that you’re having memory problems you should see your GP, and if you noticed so-and-so types of symptom, go and see you GP and look for help. Would that make you look for help?

## G06BCM31

I don’t know. Some people don’t want to hear that help [?] because, one, that help could be leading off to a different road, isn’t it, you know what I mean? You go to a GP because you’ve got a problem but when your GP is calling you in, you’re saying, well, hang on a minute, why does he want to see me, you know what I mean? He wants to see me because something’s wrong or there’s something that he picked up or something that he didn’t know, you know what I mean?

00:50:03

## UCLRA02

So do you think… picking up on what you’ve just said, in terms of the content of what this letter might have or what this leaflet might include, do you think telling people what they can expect, you know, is really important? So UCLRA01 talked about giving people the signs and symptoms to look out for, what you can do if you notice, X, Y, and, Z. Do you think it’s important for people to know what to expect? If I do seek their help, what’s going to happen? What will be the journey? Do you think that’s a fear for people, not knowing?

## G06BCF32

I think the GP needs to have something in place to, like…

## G06BCM31

Explain to you.

## G06BCF32

Yes. To talk to folks, to give them counselling and, you know, explain what’s the next step. You can’t just send out a letter and expect you to, you know… because it’s, like… folks are… get a letter and they see trigger point, the big C, and you think about… oh, my god, I’ve got cancer, or something like that…

00:51:02

## G06BCF34

Yes, you do.

## G06BCF32

And with the… with the mental issue you think, I’m going mad, they’re going to shut me away in an asylum or something like that…

## G06BCM31

Yes. You hear alarm bells and when you hear that you don’t want to see another GP, mate, believe me.

## UCLRA01

So, I hear you say, if you get a letter like that, that might worry you. Is that correct?

00:51:23

## G06BCF32

Yes, yes…

## G06BCF34

In a way it might worry you but it might be the very letter that you were hoping your family would get because each day that your memory’s going you’re feeling helpless and you don’t want to trouble the family with, well, I’ve forgotten where I put my glasses or, you know… somebody’s got to take charge of your medication. If they ask you the simple question… they’ve been busy, they come back into the room and say, did I give you your medication an hour ago? And you don’t remember, this is very important that this gets addressed so it’s going to help the family who’s caring for you and it’s also going to help you. So you might have been waiting for them to get a letter, then they come and sit back beside you and say, well, look, we’ve got this letter and it just says that we can go along and talk to somebody about the fact that you are slowly not remembering things that, you know… a couple of years ago you could actually spell out the day; now you don’t know whether the news comes on or whether the, you know…

## G06BCF32

I think precaution as well is better, you know, rather than cure. Take precautions… 30 years ago in the 80s I went to my GP and I said, I’m getting dementia, I’m getting Alzheimer’s, and he turned round and said, you’ve got stress, you know, and that triggered things on… because I went to the hospital; they did a well woman’s check, MOT and found all these things wrong with me, you know, so that… I actually took this… the… went off to him to say, I’m forgetting this, I’m doing this, I’m doing that, should I be doing… and this is why I’m so active now when folk said, sit down, take it easy, because we need to take things up earlier on, do things, you know, even the crossword in the paper, start doing things that are going to help us

00:53:21

[General overtalking]

## G06BAF33

Keep exercising your brain…

## G06BCF34

Keep your brain…I’m very, like… with my aunt, when it was the Jubilee… she’s the age of the Queen’s mother or whoever it was in the Jubilee, I don’t know, but anyway, it was all going on so I went to Marks and Spencer and I bought her a little tin and it just had this Jubilee stuff on it and it had all these little symbols. I bought her a little bag, although she doesn’t go anywhere, but she’s got a little bag to put the little tin in, just to keep her feeling like she’s, you know… then I didn’t get to another shop because I had Natalie, I was rushing to go to see her where she could’ve had a magazine, so I said to one of her daughters, you know, you get her the magazine because I’ve spent a fair bit now, the magazine will show her pictures of the Queen because she… my aunt likes to be wearing what the Queen’s wearing.

00:54:11

She’s of that age and she feels whatever the Queen’s got she should… she likes to model herself off of the Queen. Like, my role model would be somebody… a pop star of my decade; the Queen’s of her decade so she likes to see what the Queen’s doing. So that’s a way she’s using her brain but my cousins are not interested in… they don’t think my logic makes sense.

## G06BCF32

It’s also with music and things; certain music for folks triggers things so that’s what… we’ve got to get the GP to get things out there.

## G06BCF30

Maybe putting leaflets in libraries and, like… where… places that a lot of the elderly meet. Just different places as well so that that information is out there and whenever you feel…

## G06BCF32

On the buses.

[General agreement]

00:55:07

## G06BCF30

Yes, on the buses, the train station.

## UCLRA01

So would you say that even if that information came from a totally different source which is not your GP, you get a leaflet through your box… your letterbox, would you read that?

## G06BCF34

I think they listen to their carer. The carer who comes in to give them a wash down and, you know…

## UCLRA02

Sorry to interrupt you there.

## UCLRA01

That’s okay.

00:55:32

## UCLRA02

I was just going to say, just to, kind of, pull it back slightly I… we’re thinking about people… perhaps they’ve even got to the point where they’ve got a carer so obviously they might have the carer if they’ve received the diagnosis or got problems, but if we could just think, kind of, pre the carer, so these are people that might be having memory problems in their home or in their families but they haven’t yet been to the GP to get the help and to even have got the care in place. So thinking, kind of, before… even before that. Does that make sense?

## G06BCF34

So who comes into contact with them, is what you’re saying. Who you’re going to give the letter to, to give to them. Or is it just the GP that you’re trying to…?

## UCLRA01

No. Just somebody living at home, hasn’t got a, you know, diagnosis of dementia; she has no idea she has dementia, because we are actually addressing memory problems. We don’t know yet if this is dementia; it could be something else. Somebody sitting at home… do you think if you knew somebody like that or if it was yourself and you get a letter through your box… your letterbox saying, if you do have memory problems go and see someone, seek help. Would that make you look for help?

[General overtalking]

## G06BCF32

It might trigger, it might trigger because you see, somebody says [?], oh, G06BAF33 did this, she didn’t used to do that, or you might say, why is G06BCF30 doing that? You know, or you say…

00:56:50

## G06BCF34

What about through the workplace? Because in my work I used to have a lot of problems with the type of work I was doing and I wasn’t up to scratch, and they kept having to call me down and talk to me about why I’m not, you know, complying… the… working the way which I should be, and they were trying to decide whether I should stop doing that particular area of the job and just do something a bit lighter because I’m not getting it. But if somebody at the time had said, look, it could be that you’re not remembering things or you’re not able to apply yourself because you need to go and have a check, so maybe through the workplace, like, your manager being given the information to pass on to the employees, that you’re not… because at that time, when they did that with me, it actually worked; somebody took me aside, she had to re-train me, she had to spend specific time teaching me that every mistake I’m making is being watched and until I get it to scratch then… so work is a good place where they can look at you and see if this is happening to you.

## G06BCF30

Digital imagery as well, like, in a train station and just on the corner here and I look at it and maybe something like that, something big and bold where someone can just, like… if you’re waiting for the train [overtalking].

00:58:16

## G06BAF33

Yes, even at the station, you know, they’ve got those, you know… if, like, sort of, something comes up you will actually look at it and [overtalking].

## G06BCF30

Yes. When I walk through the train station everybody’s, like, looking up at it so it’s something that captures everybody, like the TV and even, like, radio advertising [overtalking].

## G06BCF34

How about women’s magazines? Because women spend a lot of time buying magazines and reading magazines so rather than another advert for shampoo or cream maybe one… just a flyer put inside that… that’s been out from GPs.

## G06BCF32

They’ll kill it [?], the magazine, the commercial… the folks that are advertising the shampoo that… they won’t like that [?].

00:58:59

## UCLRA01

Thank you. So, we talk a lot about what would make you seek help. Now, what would prevent you from looking for help? I mean, what would you see out there that would stop you from going for help?

## G06BCF32

To know that they’re going to put you to a nursing home or they’re going to put you away in a home. You want to retain the family unit… you want to stay with your family.

## G06BCM31

When you go for a… when you go for a full MOT basically you don’t know what they’re going to find, do you? And nobody wants bad news, do they?

## G06BCF30

Fear of the unknown, isn’t it?

00:59:33

## G06BCF34

The fear of losing your job; if your memory is not being able to retain the information to do the job… if you’re asked to fill out forms, like I was asked to fill out things, and constantly being asked to remember how to do things in a certain, particular way that they wanted and I was cutting corners… what I was doing is I was… there was a certain way that you present the information and things I couldn’t be bothered to do, I just used to leave it out. So when they brought it to my attention that you are clearly leaving it out; if you carry on leaving it out then you might have to leave. So, you know, if it’s your memory that’s going and you know that you’re… this is out of your control then you’re going to be scared so you’re not going to want to go to your employer and say, oh, I have to take this afternoon off because I have to go and check my dementia status, because they’re going to say, well, then if you’re… if you’re giving out medication and you can’t remember… or if you’re, you know, cutting corners at work because your dementia’s setting in but you don’t even know that dementia’s what you’ve actually got then you might be scared.

## UCLRA01

Thank you very much. Anything else that might prevent you from [Interrupted]

01:00:48

## G06BCF32

And you’re also frightened what other folks are going to say, aren’t you? Because I’m not going to want to confide in folks if they think I’m losing it.

## G06BCM31

Yes. I think what this lady was saying… when you can’t do certain things or the way they’ve taught you to do something… like we were talking about the mobile phone and this and that, yes, because a lot of people don’t know how to get to this and that, yes, so they will go round corners and cut it off because they don’t know how to do it, and it’s the same with sickness. If you don’t know that you’ve got it, right, you… well, you want to know what is going to cure it but the easy way; you don’t want to go through the doctor and then he says, right, you’ve come in here for this but you’ve got that and that, and you’re starting to say to yourself, well, I didn’t go in there for that, I only go in there for one thing but now he’s telling me I’ve got this and I’ve got that, you know what I mean? So it is a frightening…

## G06BAF33

I think the most important thing is to have a good rapport with [?]… I mean, it’s not all GPs that don’t listen to, you know, people. There are some very concerned about… caring GPs who will actually listen no matter how many patients they’ve got, you know, and they’re concerned about you. It’s just having that, you know, confidence in your GP to say, oh, okay, if I say this, you know, to my GP who, you know, sort of… listen and act on it.

01:02:13

You know, but when you feel, you know, that, oh, you know, I haven’t got a GP who listens then you’re not likely to go and visit them and say, oh, you know, I feel… I’m… and just say, oh, you’re wasting my time, you know, and just writes you off on some Panadol or whatever, you know. But then if you’ve got caring GPs who… you go there and they listen and say, okay, look, let’s investigate this, let’s send you off to the hospital and do this, then you feel more confident in them. But when you don’t have confidence in your GP or, you know, system it makes it… and, you know, you just want to go to [unclear], yes.

## G06BCM31

I think there’s good and bad in everything that we do, all right, because with the GP as well, right, he hasn’t got the time to listen to an hour’s story or half hour story, right, of your lifestyle, right; he’s only there to treat a certain amount of patients and when you go in the queue or you’re going in to see him, there are about five or six people before you and then when you look at the time that you come out of there you say to yourself, did I… was it worth it, going in there? Because all he’s going to do is probably give me tablets or whatever it is.

01:03:22

## UCLRA01

I’ve got one final question. You did mention that the change of life… the idea that your life might change, that, you know, you might end up in a home away, you know, locked somewhere, would prevent you from looking for help. Let’s say they provide you with the information that that’s not going to happen. Let’s say in the letter or the leaflet that the GP or the hospital or anyone sends you through the post it says, look for help but you will maintain your, you know… your independent life, you know, your individuality, would that make you look for help? If they tell you the earlier you get help the better you’ll be?

## G06BCF34

What people like to hear is that whatever information they discuss with the GP at this stage is confidential, so the GP’s not obliged to call your workplace and say, well, you know… even if you are a doctor, then, and you think you could be having this but you don’t want to talk openly about what you’re going through, while the GP’s dealing with you he’s not going to… it’s not the law that he has to disclose this to anybody until he’s further gone through all of the investigation with you, so the early stages of approaching your GP to say that you’ve noticed these memory... or whatever problems you’re having, that’s just between you and the person, any information you talk about and… will be kept confidential. Then people will feel, oh, right, I’m just going to have a chat, no-one’s going to know, it’s just between me and my doctor.

01:05:09

## G06BCF32

No, but sometimes… I was going to say, sometimes it’s good that they’re not going to bring it back to your family as well and say… because you don’t want your family to know, oh, I might be losing it, I might be flipping. But you need a person… whenever I go to the hospital now I always take a friend with me. Because lots of the things they’re telling me about, as soon as you walk out of that room it’s all gone, you know. You don’t know what’s causing it so that’s why you need a befriender or someone like that that can help you to understand what’s going on.

## G06BCM31

I think… I think you have got a point there, where the GP has got something to do with it because he’s the one you’re going to go and see and discuss all your problems whenever you’re sick or whenever you’re feeling down or whatever it is, yes, and you can… you can use something from the GP to go out there and make us aware of what we can seek and what we can find.

## UCLRA01

Absolutely. Thank you very much.

01:06:15

## G06BCF32

But you’ve got to get to see a GP, haven’t you? You’ve got to get to that stage. Quite often you go there, you can’t get past the receptionist [overtalking].

## G06BCF30

Yes, maybe you should have someone who… or who’s trained, like a nurse or someone who’s got the time to sit down and talk to you and have, like, a pre diagnosis and can give you information and is… and can give you the time and listen before you go and see the GP. And maybe say that you’re in charge of your health as well; you don’t have to take whatever medication they’re going to give you, or you can just do the exercises or you can… you don’t have to take everything; it’s just there for you to… yes, like, give you that information for you [unclear].

## G06BCM31

Then, that means every GP would have to have somebody there to do that and that will [?]… it’s going to cost a lot…

[General overtalking]

01:07:15

## G06BAF33

I mean, that’s why the nurses, you know, are there in GP surgeries, you know, because, you know, I mean, apart from just treatment or whatever they’re doing they should be able to, you know, have a, kind of, system where, you know, rather than the GP, because there’s so much workload, as you say, on the GPs, you know… where someone, you know, can, sort of, walk in, you know, and I know they get busy, you know, maybe just have… I mean, this is, like, health’s[?] talking, I know, you know, the government are trying to cut costs and everything but then they should still invest in people, you know, so that it will not be a problem in the future. So, I mean, if they have these people there, you know… you go in and you say, oh, can I make an appointment to see my nurse or somebody, you know? I’d like to discuss this. She can take it on board, you know, what you are discussing and then, you know, like, sort of, say, okay, I’m really listening to… okay, I’ll discuss it with the GP and then we’ll make an appointment to see you. Because then you’ve got all that time to talk with the nurse rather than the GP because the GP’s not going to listen to you anyway [overtalking].

## G06BCM31

I think you’re right. You’ve got a point [overtalking].

01:08:25

## G06BAF33

So they need to invest… the government needs to, like, sort of, invest in people [overtalking]…

## G06BCM31

To help the doctors… to help the doctors.

## G06BAF33

[Overtalking] to help the doctors who will, you know, sort of, like…

## G06BCF32

Because later on down the line we’re the ones that are going to be clogging up the system because if they don’t treat us then, later on you’re going to be costing the NHS a lot of money, aren’t you?

## UCLRA01

I’ll take one last comment from you because I’m quite aware it’s almost one o’clock and we have to leave the room. You had your hand up.

01:08:54

## G06BCF34

My point is that when you go to the reception desk after receiving that letter that you’ve given out, the GP’s responsibility or the NHS’s responsibility should be that when somebody presents themselves with such a letter saying, I’ve received this, I’ve come to make an appointment about this sensitive subject, it’s not left for the untrained, a receptionist at the desk who is not sensitive who starts shouting out to you over the desk, well, what day can you be seen? What time? What is the reason you’re here? The GP’s very busy now, you’ve missed… you’re late for your appointment, or whatever they say… come up with, you know, talking to you. If you are suffering with some slight dementia, or think you may be, it could even be an agonising time for you to even make that appointment and dealing with an insensitive receptionist when you come and they see the heading on that letter that is coming… you’ve taken the attention to come because you have one of those letters then you should be put to one side to somebody who’s been trained. You know, they just take one receptionist out and train her; she knows, when you see that person coming in, to take them aside to deal with them because all this talking at the desk, it can… you… can make you just want to walk out because some of them are so not professional in what they’re doing and they get away with it because you’re in a panic and you need assistance so you take it from them.

01:10:25

## UCLRA01

Thank you very much. Thank you very much for taking part. So that’s the end of our discussion.