**G07**

**Speaker key**

## MR UCLRA01

## SB UCLRA02

## LB G07BCF35

## ML G07BAM36

## EO G07BAF37

## ET G07BBF38

## KD G07BCM39

## ET G07BBM40

## GD G07BCF41

## SW G07BAF42

00:00:11

## UCLRA02

Okay, so I think we’ll get going; I don’t think there’s anyone else that’s going to be showing up now.

## G07BAF37

No, I don’t think so.

## UCLRA02

No, this is, honestly, absolutely wonderful. This is more than enough people, it’s great. Thank you very much for your help, G07BAF37. Okay, so as I said, we shouldn’t take too much of your time. Hopefully we should be done within the hour but obviously you said you might need to leave early, that’s absolutely fine. If you just want to sneak out that’s no problem at all. So firstly I’d just like to welcome all of you for coming today and just to say thank you so much for giving up your time to come and speak to us; we really, really do appreciate it. We’re both researchers from University College London and one of the things that we would like to do before we get going is just remind all of you that everything that’s said today is confidential, but the session is recorded on these two recorders here and what we would like you to do, if that’s all right, starting with myself, is just to go round the room and just to introduce yourself by name so that the person who is transcribing today’s group when they’re typing it up can identify the voice with a name. These names will later be removed and you’ll be given, like, a unique identification number so your name won’t be revealed to anyone, okay?

So if I start with myself. My name’s UCLRA02 and I’m from UCL.

00:01:33

## G07BAM36

My name’s G07BAM36.

## G07BCF41

My name is G07BCF41.

## G07BAF42

My name is G07BAF42.

## G07BBF38

My name is G07BBF38.

## G07BBM40

My name is G07BBM40.

## G07BCF35

My name is G07BCF35.

## G07BCM39

My name is G07BCM39.

## G07BAF37

My name is G07BAF37.

## UCLRA01

And I’m UCLRA01.

00:01:56

## UCLRA02

Thank you very much, everybody. So as I said, there’s really no right or wrong answers today. We are interested in absolutely everything that you’ve got to share with us – your thoughts, your opinions, experiences – and we really will try and ensure that everyone gets an opportunity to speak because we are quite a large group, but we’ll do our best.

So we’re here today because we’re interested in how people from Black African and Caribbean groups think about memory problems as they get older and what you think might be helpful. So one of the things we’d like to discuss is your opinions as to why it is that some people from Black African and Caribbean groups don’t always seek help for memory problems very early when they maybe first start to notice symptoms. And we’d also like to know from you what you feel could be done to help and encourage and support those people to seek help at an earlier stage when they first do notice memory problems. So if we could start the discussion by thinking about a lady. Her name is Mrs Abrahams. She’s 70 years old. Family members have noticed that she’s started getting a little more forgetful lately. She’s not always remembering conversations that she’s having with people and she’s forgetting important appointments such as doctor’s appointments. She often misplaces important items like her keys and her glasses. She’s physically healthy but she does have concerns about her own memory. Now, she’s just a person that we’ve made up but obviously there are people out there like this who have similar memory problems and, as we said, she’s starting to forget things, she’s misplacing important items such as her glasses and her keys and people close to her have noticed these memory problems. She’s physically healthy but she does have concerns about her memory herself. And so what we’d like to start by asking you is, if you knew someone like this do you think that she should get help for her memory problems?

## G07BAF42

Yes, I think so.

## UCLRA02

Anybody else?

## G07BCF35

Yes, she should get help.

00:04:11

## G07BCM39

I think the first question should be if any of us here suffer with that problem.

## UCLRA02

Okay. So, yes, I guess we could think about… we don’t have to just think about Mrs Abrahams. You could be thinking about yourselves here, perhaps, or family members or friends of yours or other members of the church here perhaps. If you knew somebody who was experiencing these problems, you know, do you think that they should seek help for these problems?

## G07BBF38

To what extent would you first require help? Because right now I fall into that group, I don’t remember where I put my glasses or my keys, and I, I mean, I’m not sure if it needs attention right at the moment but I fall there.

## UCLRA02

Well, thank you for sharing that with us, and it’s a really interesting point that you’re making because, you know, forgetfulness is obviously extremely common. I’m sure we can all think of examples, you know, maybe where we can relate to the story of Mrs Abrahams, perhaps. But one of the things we’re interested in is what makes that link between being forgetful and perhaps laughing it off as some kind of everyday occurrence and ignoring it and what would actually make you perhaps seek help from the doctor, for example? What would that be to make you think, actually, this is the point that I need to seek help, does anyone have any thoughts around that?

00:05:40

## G07BCM39

I would put it this way, I remember Margaret Thatcher. They ask her, how many hours sleep at night she had, she say four hours. Somebody asked her another question and she said, if when you retire you just sit back, the brain becomes dormant. The thing is that most of us here, I am sure, don’t do a lot of reading. After they reach 30 here they are so busy you don’t take up a book and read like a youngster. Speaking for myself, I can remember names, like, from schooldays and places but something that happened last year or this year, especially names, it eventually comes back but in a discussion it just goes blank and then when you go outside you remember, my god that person’s name was and so on, that I was trying to remember. But then so much things is happening in your life as you grow older. Age is an important thing, as you grow older it’s like the brain gets clogged up thinking about this, thinking about that, and we all put down things and can’t find it. It’s annoying.

## G07BBF38

The other thing is I go to the doctor armed with the questions that I would like to ask and sometimes it’s when I get through the door, goodbye, that I say, oh, I didn’t say this or that to the doctor, you know. I mean, I’m just being honest.

## Shane Berwald

Sure, thank you very much for sharing that with us.

00:07:32

## G07BCM39

One thing I want to mention. There was a man named Mr Lindo, he was Jamaican High Commissioner here. He was head of the labour organisation in Washington. He wasn’t 60 yet. If his telephone rings, before he takes up the telephone he takes up his pen in order to make sure that whatever is said or discussed he don’t f… and this is a man who is active generally, you see. And you would say, but he should remember, but he don’t take a chance and say, I might forget, because it can be very important. But how many of us note things as a matter of fact? Put it another way, you make a note of the things you want in the supermarket…[Laughter]

## G07BCF35

And leave it at home!

## G07BCM39

Yes, when you’re ready to go home… you remember you had the note!

## UCLRA01

Just one thing from me, it’s very interesting what you’re saying. So you’re saying you forget things – you too – but did you ever talk to your doctor about it at all or did you just say, oh, you know, it’s forgetfulness…[Interrupted]

00:08:48

## G07BBF38

No, I haven’t spoken to my doctor about it.

## G07BCM39

I spoke to my doctor and I’ll tell you what he said to me. [Laughter]

## UCLRA01

Only if you want to.

00:09:00

## G07BCM39

He’s a Chinese doctor I have down Stanley Road. He says, my wife is… my mother is the same age as you and she was doing fine, no problem. Our daughter tell her to leave London and come and live with us and she went right down. Just the change of venue, I think, and, well, I don’t want to get too personal but the thing is that, change your situation where you live.. it’s the same thing with Tyrell, that’s why Tyrell won’t move from where he is. He says, I’m going in a new surrounding.

## UCLRA01

So what would make anyone take the leap? I mean, you talk to your doctors, some people would not. But what would make somebody decide, okay, I have to mention that to my doctor, that I keep forgetting stuff.

00:09:51

## G07BAM36

I think it may be depending on what it is you have forgotten, how serious it is. If it’s a pen you’ve forgotten it’s not as serious but if it’s something like a doctor’s appointment or your medication, that would make you think, okay, I forgot to take, that’s serious…

## G07BBM40

Excuse me, just caution here, is it about forgetfulness or dementia? Is it leading up to dementia, just forgetfulness or dementia? Is it found amongst Afro-Caribbeans or is it a worldwide thing?

## UCLRA02

Well, I guess there’s two separate questions there. One, in relation to Mrs Abrahams we’re talking about forgetfulness and I guess at the point at which I told you this story of this lady we don’t know whether it’s dementia or not, so what we’re interested in is whether if you were experiencing those problems or you knew somebody experiencing those problems do you think that they should get help?

## G07BBM40

I suppose it depends on the degree of forgetfulness. It is leading up to dementia because dementia is an illness, I presume, isn’t it?

00:10:52

## UCLRA02

Yes, absolutely, that’s correct. And so what we’d like to know is do people from black African and Caribbean populations seek help very early on when they first notice these memory problems.

## G07BCF35

Are they aware… are we aware…[GENERAL AGREEMENT] I don’t think I’m aware that there is anything anyone can do about it apart from you yourself if you think, okay, keep active. I remember some time ago where someone said if you played dominoes or word games or things like that to keep stimulating the brain, but what can the doctor do?

## UCLRA02

OK, that’s a really good question and we can certainly talk a little bit more about that. So one thing I’d like to put back out to you is do you… if you were to seek help for memory problems such as the forgetfulness that we’ve discussed, do you know what to expect if you went to see your GP?

[General disagreement]

## UCLRA02

Okay. And another question following on from that would be, where do you feel that you should seek help for these problems, where would you go if you noticed these problems in yourself or in somebody else?

00:11:58

## G07BCF35

The GP. That’s the only way really, isn’t it. It’s health, so it’s GP.

## G07BAM36

The first thing I think anyway you’d do is talk to somebody about it, somebody close.

## G07BAF37

Close relative, yes.

## G07BAM36

Yes, a close relative, I’m forgetting things, what do you think, kind of thing before you take any decision to go to your GP.

00:12:18

## G07BAF42

But sometimes you don’t think it’s anything of importance, you know … if you forget, like, once in a while you’re going to the supermarket and you forgot your list, you know, you’d think it’s just a normal thing. But if it continues then…

## G07BAF37

If it’s an ongoing thing then you’ve got to realise that there is a problem somewhere so you need to seek for help.

## G07BAF42

But if it’s a one-off thing people just…

00:12:42

## G07BCF41

But sometimes you go to the doctor, they don’t even have time for you. As you go in they write something, you haven’t got time. It’s only a few doctors will sit and listen to you, believe you me.

## G07BCF35

It is true, I believe it.

## G07BCF41

So you see, we are not… we’re not all that silly. We know what we are saying to the doctor but sometimes the doctor says, oh, it’s just a minor thing. It could be more than a minor thing but he don’t sit to say, well, we’ll do some research or do a test to see. So these are the things when you go to your doctor, you know. I have a nice doctor. When I go in there he sit and talk with me. I won’t complain. And I’ll ask questions. Because I went for these two fingers, when I hold things it shakes, and I went to my doctor. I said, I want to know if it’s Alzheimer’s or Parkinson’s. He sent me to this specialist and said, no, nothing like that. So I’m pleased, and I asked a question and I get an answer, which is good. But sometimes you go, if you find a different doctor he don’t have time for you.

00:13:50

## G07BAF42

Like my clinic. We have a main doctor who everybody wants to see but because she’s very busy you have other doctors, doctor this, doctor that. Some come three months there, here two months… you see them today, tomorrow you don’t see them. So if you want to see that doctor you have to make an appointment. But if it’s something that is very urgent how long will you wait?

## G07BCF35

Also, I believe there is an embarrassment, I don’t want to think that that is that way so therefore you’ll put a lid on it and hope that, you know, it’s not the truth, so that kind of denial.

## G07BAF42

But how long would you deny it?

## G07BCF35

Well, when you’re in that frame of mind you will deny it. My brother’s got MS and his memory is just rubbish, but to him it isn’t.

00:14:46

## G07BCM39

I would like to ask you something. Do you think that amongst the black African or Black Caribbean that ratio is higher than say the Italians or the Europeans or anyone else?

## UCLRA02

That what is higher, sorry?

## G07BCM39

Do you think the problem is higher amongst us than say the English man?

## UCLRA02

The problem of memory problems and dementia, yes? So, I mean, we can certainly speak more about this at the end, but this research has been designed and created following on from a number of different pieces of research and studies that are currently out there at the moment which is tending to show that there are higher rates of dementia amongst the black African and Caribbean populations. Now, there’s obviously questions as to why that is that we can certainly talk about afterwards.

For this piece of research we’re dealing with the fact that that is what’s being shown in terms of the research and this research is aiming to try and establish why it is that if there’s higher rates of it amongst these people, why it is that sometimes, not always, but on the whole people are not going to their doctor’s very early on when they first notice problems. They’re often presenting to services at crisis point. So this research is trying to establish why that is, why are people not going to their GP early on in the process, and also we want to try and help encourage and support people to seek help earlier on when they first notice these memory problems.

00:16:27

So off the back off this research we will be designing an intervention that will be being trialled, you know, I’m talking over the next year or so, to see if we can try to engage with the community a little bit better to maybe raise awareness or whatever it is, that’s what we’re here to talk to you about today. We’d like to know what could we do to try and help, encourage and support people from communities such as your own to seek help when they first notice memory problems.

## G07BAF37

I think the doctor… sorry. The doctor and patient or client relationship is not there. As she said earlier, people find it difficult speaking to them about their problems. If I come to you, for instance, I said, doctor, and confide in you that this is the problem I’m going through so can you help me out, and he’s not willing to help you. Sometimes they do shout at you as if you are a kid. They wouldn’t even want to look at the actual problem that is going on or happening. Rather they tell you, okay, why don’t you take this and we take it on from there. Even a phone call, a follow-up phone call to find out how things are with you regarding the previous problem is not happening. So I will rather coil in my shell, keep it to myself rather than going to the doctors to speak to him about the problem I’m facing currently. So I think that is a major issue why people are not really reporting or telling them the problems they’re facing in terms of memory loss.

00:18:06

## UCLRA02

Thank you very much for that, G07BAF37.

## G07BBM40

This lady in question, is she on medication?

## UCLRA02

Not that we’re aware of. I mean, it says that she’s physically healthy but she does have some concerns about her memory herself, as well as her family and friends. As I said, we’ve made this person up, this isn’t a real lady necessarily that we’re talking about, but we’re using it as an example of a situation and wanting to know your opinions around that.

00:18:44

## G07BBM40

So I think if we, as I already said, what we should do, memory loss, seek advice from the professionals or something like that before we reach further down with dementia. Has it got anything to do with age?

## UCLRA02

Quite possibly, in terms of there being higher levels of memory problems and dementia, you know, as people do increase in age, but not always.

## G07BBM40

Okay, thank you very much, to be continued.

00:19:06

## UCLRA02

Ok, thank you.

## G07BAM36

What I was going to add is, because what they are talking about, the client doctor relationship, most of these things go undiagnosed at an early stage. So if it’s undiagnosed there’s no real… people don’t know, okay, when this happens this is the cut-off point, I need to seek help. So therefore no one’s really going to be asking… going to a doctor. So it’s undiagnosed at an early stage so you can’t really detect when the problem’s occurring.

## G07BBF38

On the other hand too, we are a very secretive people.

## UCLRA02

Would you mind expanding on that a bit more? I’d be really interested to hear a bit more about that.

00:19:44

## G07BBF38

Well, it’s, in some cases, like say prostate cancer in men, you’d have in some cases the woman has to take over the rein completely and drag the man.

[General agreement]

## G07BBF38

To the doctor. He will not freely go. And even if he… when he goes, he wouldn’t tell anyone, you know. It’s this great big secret thing.

## G07BAM36

Embarrassment, yes.

## UCLRA02

Do you think those sort of views and attitudes are the same around dementia and memory problems, then?

00:20:29

## G07BBF38

It’s quite likely.

[Overtalking]

## G07BAM36

It actually is very true, we are very secretive. It’s very true.

## G07BCM39

Yes, but some countries do take a step forward with that. In Jamaica they are on TV quite regularly encouraging men once you reach 40 to go… you walked in church. My neighbour is the head of the urology department at the University of the West Indies, he was here a few weeks ago, I brought him to church. Every week they have programmes on the TV, once you reach 40 they are encouraging you to come out as men to test for prostate, not a lot of people have prostate cancer. You can have prostate and it’s not cancerous. When you reach cancerous stage, if your blood tests shows whether it’s a cancerous stage. But the thing is, as you were saying, most men will not go. And once you reach 40, just go and test. It’s not a big thing. But then our problem in Jamaica, we have the highest rate in the world of prostate, the highest rate in the world is established. And not even Jamaica, in Kingston. [Laughter]

00:21:59

## G07BAF37

And another thing is, I think people don’t want to know because if I don’t know I wouldn’t think about it. But as soon as I figure out that this is the exact problem I’m facing, that is the end of it. The stress level goes high and then everything just starts deteriorating. So people don’t want to know.

## G07BAM36

I’d like to see, like what you were talking about, there being some kind of education as to what to look for when things are going to the point where you need to see a GP, something like that. I don’t know, programmes, I don’t know what, some kind of education. Because most people don’t know and most people, as you said, are in denial, oh, it’s not that bad kind of thing. So some kind of education to show that when it reaches this point you need to see a GP, it’s getting to that stage.

00:22:46

## G07BCF41

Especially if you live alone too.

## G07BAF42

But where I come from we now have these Protestant churches, they’ve taken over the whole thing. When I went home I was suffering from diabetes and I have a very good friend, we spoke together and said to her, do you know they’ve detected that I’ve got diabetes. She said to me, claim it in Jesus’ name, you don’t have it. I’m like, what is this? Are you…[General laughter]. This is it. They’ve now taking over everything… you have ebola in Sierra Leone, they have to pray for it. They tell them it’s a dangerous illness, it will kill them and, everything claim it in Jesus’ name. Claim it. I claim I’m not, claim it, claim it. I’m like, what?

## UCLRA02

Thank you very much for sharing that with us.

## G07BAM36

The church system is now basically discouraging people to go for medical help because everything is spiritual now. So if you suffer from an illness pray for it and you’ll be healed rather than go and seek medical advice, and that happens a lot in black churches.

## G07BCF35

It’s been happening a long time because when I was working in psychiatry I remember having patients being taken away from the ward to go to wherever it is that prays and does the rituals and heals.

00:24:07

## UCLRA02

That’s really interesting.

## G07BAM36

It is a big problem.

## UCLRA01

So would you say that will be one of the first point of contacts when somebody has problems?

[General: Yes]

## G07BAF42

Yes, they don’t go to the doctor, they go to the spiritualist.

## G07BAM36

They won’t go to the doctor. Yes, they’ll talk to their pastor or whoever they know does miracle healing or whatever.

## G07BAF42

But these reverends are not always reverends, everybody is a bishop. Everybody is a this, that, you know. And in all…

00:24:32

## G07BCF41

It’s true.

## G07BAF42

Yes, it’s true. So he tells you, I’ll pray for you and god will…

## G07BCF41

It will go.

## G07BAF42

Yes. So you don’t go to the GP.

00:24:40

## G07BAM36

Yes, I would just say, like, the first point of contact is to go to a pastor or anybody you know who does that kind of miracle… there’s a lot of self-proclaimed miracle healers out there.

## G07BAF42

Churches even in England.

## G07BAM36

And they’re mainly protestant churches we’re talking [overtalking] Pentecost, kind of churches and they tell people, if you have an issue, I’ll pray for you, go heal it in Jesus’ name.

## G07BAF42

You give me £1000 and then I’ll pray for you. It’s not for free, hey. [Laughter]. Well, that’s what they do.

00:25:09

## G07BAM36

That is a big problem. You see it even on Sky TV. If you browse the gospel channels you’ll see a lot of those adverts coming up. If you have this, miracle healing, claim your healing, stuff like that.

## G07BCF41

But still you have to believe that you’re going to heal and if you can’t heal by them that means something wrong, so you can’t believe that they heal you.

## G07BCF35

But if the pastor says it then you believe.

## G07BAF42

That is it.

## G07BCF35

That is how it is. They’re brainwashed, really.

## G07BBF38

I don’t believe everything they says.

00:25:39

[Overtalking]

## UCLRA01

My next question… sorry, my next question to that will be then, if you… somebody goes and sees the pastor and do not get relief, you know, the illness carries on, you keep forgetting, what will be your next point of contact?

## G07BAF42

They’ll move from church to church.

## G07BCF35

It could be that they’re convinced that it’s because of something that they’ve done, probably because they’ve sinned or whatever, so you’re not going to get it, is it. I mean…

00:26:06

## G07BAM36

I think it’s down to the individual himself to know what to do. I mean, I’m a Christian, I believe in all kinds of healing that god can do but if I’m sick my first point of contact – although I pray – I still go to the doctor.

## G07BCF35

Yes.

## G07BBF38

Of course.

## G07BAM36

Because god can use a doctor to give me medicine, which can still do the same, do you see what I mean? So I think it’s down to the individual to say, okay, I’m going to seek medical advice. I will still pray and do all of that but medical advice as a first contact.

## G07BCF35

But that’s rational thinking, isn’t it. I mean, if you’re brainwashed, you’re brainwashed.

00:26:42

## UCLRA02

That’s really interesting. Just before I pass over to UCLRA01, and we’re going to go back to your point about information and education, just one last question I’d like to ask is, do you think that other people, whether that be your family, your friends or other people in your church community influence whether or not you would seek help from the doctor? Would you be influenced by others as to whether or not to see…?

## G07BCF35

My family, I would be influenced by my family. Probably you would not discuss necessarily with the church but your family would… say if it’s to do with memory loss, they would notice anyway if you are actually, you know…

00:27:17

## G07BAF42

There are some church members, if you tell them your secrets, tomorrow it’s all over. They start telling people, oh, look at her, she’s this. Do you understand?

[General agreement]

## G07BAM36

I think that’s part of why the whole secrecy thing. There’s a lot of people who are…

## G07BBF38

You tell something and it’s…

## G07BAM36

You tell something to and it’s circulated around. So most people tend to keep to themselves…

## G07BAF37

Keep to themselves…

## G07BAF42

The next day it’s all over the place so what’s the point?

## G07BAM36

But, as your family will definitely see, notice it first. Definitely talk to them about it first.

00:27:49

## G07BCF35

But the secretive thing is not necessarily to do with because somebody’s going to gossip. It is deep-rooted in our culture.

## UCLRA02

Do you mind expanding on that a bit more, I’ll be really interested.

## G07BCF35

From when I was a child it’s like, don’t tell people your business, don’t eat from this, don’t do that, don’t go there. It’s all a lot of don’t. Because they’re older people they’re not going to explain why. Just do as you’re told, don’t. And it carries... I mean, for example, say somebody might be travelling somewhere or they feel, oh, it’s best not to tell people. My sister was going to Jamaica a few years back and I did not know until the day she was going when she was going. I knew she was going but why she kept it from me I don’t know. So it’s a secrecy, unnecessary secrecy becomes a habit so it’s not, oh, they’ve got anything against you, just, like, best not to tell anyone. So it’s all of that. So you are not going to know unless you can see that somebody’s having a memory problem because they’re not going to be talking about it.

00:28:53

## UCLRA02

Thank you very much, that’s really interesting.

## G07BAM36

It’s very, very true as well.

## G07BCM39

The thing I would like to ask, will we get a feedback, and what?

## UCLRA02

Yes, that’s one of the things, you know, that we’ll absolutely make sure of. At the end of this we’ll take some contact details from you so that we can keep in contact and let you know how the study is going and some of the results of the study, absolutely.

At this point I can hand over to UCLRA01, he’s got some slightly different questions for you and just going to move the conversation on in a slightly different direction. But thank you very much for all of that, it’s really, really interesting.

## UCLRA01

But just before we move on I’d like to ask the question about, you know, some people say… we talk to quite a few different groups and some people say when they have memory problems in the community or the family they think it’s much better to be back home, whether it’s in Africa or in the Caribbean, or they said, no, I prefer being here if I have memory problems. What are your feelings about that?

00:29:56

## G07BAF42

Back home is better because if you have relatives there, you have friends, they take care of you. But here, if you are here, you live alone, they will give you a room all to yourself. Although it’s a room, you can be there the whole day. If you just continue nobody comes to see you. Back home people are inquisitive. Oh, you don’t come, hello, how are you? They will be interested in you. Even if it’s your money they want, but they come to see you. But here, nobody will come to see you.

I have a sister-in-law, she lives in… what do you call it now, Canning Town. She lives in a beautiful flat, a one bedroom flat, it’s all for her. But nobody.. . she’ll be there for the whole month, if you don’t call her… it’s sad. That’s the problem, people don’t want to be here. People say, even when I die, take my body home and bury me.

00:30:51

## G07BCF41

I don’t.

## G07BCM39

There was this man who died in his flat…

## G07BAF42

All by himself.

## G07BCM39

All by him.. and nobody… that wouldn’t happen in Jamaica because you and your neighbours, it is in contact.

## G07BAF42

Even if you’re not in contact, an inquisitiveness, [knocks], hello, how are you? Even we’re going by you, we’re going to the market, we’ll check on you to see what’s wrong with you. But here…

00:31:21

## G07BCF41

But if you have good neighbours among us here…

## G07BAF42

You have to make them yourself, G07BCF41.

## G07BCF41

Yes, but where I’m living if they don’t see me for a few days they knock on the door. So I’m not [unclear]

## G07BAF42

God forbid if you are dead before they knock for the few days…

## G07BCF35

I met a lady the other day walking in the street. I was actually coming from [mayday?] and I saw this lady who it turns out it was a carer and she was this lady who was from Jamaica, and this lady was going, you know, sort of not listening to what the carer said because she was having… she has dementia I gathered in the end. So she was trying to encourage the lady to go back to the house. They only went out for a walk. But the lady came here, her son brought her here because she’s in a nursing home in Jamaica, to spend six months here and then from here she’ll spend another six months in America. Well, I just felt very sorry for this lady because in the end I pretended I knew her and her sister and I said to her, come with me, of course I know where your sister is, come with me, and I said to the carer, where does she live? And she disregarded the carer and she came with me and she started talking. And I felt very sorry for her because this lady is totally lost and for me even if she’s got the tiniest bit of memory of her surroundings she’d be better off in Jamaica because she was… this carer, who she doesn’t know at all, and the son was off at work and this lady was in the house. The carer said, I sense that I should take her out. I said, but it is dangerous for you to take her out because she was about to walk out in the road. Before I intervened and said, do you know I do know, and she said, are you lying? I said, no, of course not, I’m not lying, come with me, I’ll tell you where your sister is. Now, I said to the carer, don’t take her out again on her own because, you know, the poor lady is so confused. So I don’t believe it’s a good idea unless, as you say, there’s a relative that can spend full-time, not having carers looking after them.

00:33:26

[Overtalking]

## G07BBF38

Sometimes they don’t recognise they’re a relative. They still don’t… they’ll look at the daughter and she said, mum, and she’ll say, I’m not your mother, you know. Where are you from then, go away. And the next minute there’s a flash of [unclear] speak to her. It’s the most awful disease.

## UCLRA02

Thank you very much for that.

## G07BAM36

Just saying, the culture back home, I mean, for example, my grandma was here, living for about ten years over here, and over here when she suffered health problems if she had suffered it when nobody was around nobody would be around, whereas back home she stays on a compound and about four or five of her own children who are elderly, I mean, much older with their own kids, they will stay in the same compound. So if anything happens to her somebody is always in the house or somebody is always around. So it’s better off… why I would say it’s better off is because most people have more of their family back home rather than over here, so if anything is… there’s an issue there’s always somebody around them to be there.

00:34:41

## UCLRA01

So the general feeling here is it’s better to be back home. Would that relate, you said, to the community? So let’s say if you had a community around here in England would that make the situation better?

[General agreement]

## G07BAF42

Yes, it’s good for the medication. Here the doctors… if you are ill you… in Africa it’s expensive, you understand. That’s why people go and come because here it’s difficult to stay when you are retired.

## G07BCF35

It’s got to be a caring community as well. Because there’s a lot of communities that so-called care homes and staff that do not understand this illness and those people are not looked after properly.

00:35:26

## UCLRA01

Now, we know that people when they look for help, you know, in going to the doctor look for help with a memory problem, they usually do better because they can prepare for the future and their family feel more supported and know what to do. So my question now is, if you or someone you know had that problem what kind of information would actually help you? What kind of information would make you more likely to look for help, so see a doctor rather than…?

## G07BAM36

I would say what… I mean, information as to where the cut-off point is. As in, okay, this is bad right now in terms of the whole memory thing. This is not in a place where it’s safe for you to go without seeing a doctor. Information as to when is best for you to see a doctor, I mean, how bad, how serious is the forgetfulness now. Things like that, that would probably make me think, okay, now this is a point where you need to see a doctor or you need to know what it is.

00:36:41

## UCLRA01

So clear information telling you, when this happens…

## G07BAM36

Yes.

## G07BAF37

I think they have to educate the people. Because just as we all met here this morning discussing this, it gives us a clear view or an idea of what it’s all about and when things set in, how you can deal with it. Whereas someone without that knowledge wouldn’t know where to start from. It would be best for there to be, sort of, leaflets, you know, or, sort of, information that would clearly explain things as to how this starts off, where are you supposed to seek the help from and how you can deal with situations like that.

## G07BAF42

In simple English. Because sometimes you take these leaflets from the GP, they’re so complicated you don’t know where to start.

## G07BBF38

Need to be plainer.

00:37:37

## UCLRA01

So clear, concise instructions on leaflets.

[General agreement]

## G07BAM36

That says, when it reaches this point, I need to see a GP.

## UCLRA01

Excellent, thank you. So you’re saying leaflets. Any other form that you might be more likely to..?

## G07BAM36:

TV…

## G07BCF35

On the TV. They do it for strokes and heart attacks and…

## G07BAM36

There’s lots of them. There’s different other stuff, yes strokes and yes… TV helps for this kind of thing.

[Overtalking]

00:38:02

## UCLRA01

So let’s say TV, DVDs and leaflets. But let’s say if you actually see that leaflet at your doctor would that actually make you look for help? If you see a leaflet at your doctor, your GP, saying, if you do have these kind of issues talk to your doctor, would you actually do it?

## G07BCF35

I would, yes.

## G07BCF41?

I would.

## UCLRA01

What if that gets, you know, that leaflet is sent through your door. It’s just a leaflet from, not from your GP, it’s just…

00:38:39

## G07BAM36

But it’s just a random… I mean, you’re going to look at it before you do anything… I mean, if you look at it and it’s very… I mean, obviously I think how the leaflet looks as well plays a part in how likely you are to look at it and actually have a read and see.

## G07BCF35

If it has a link with NHS I think people trust more that it’s something to do with the Health Service rather than a private person.

## UCLRA01

Excellent, thank you. So it has to have a link with the NHS.

[General agreement]

## UCLRA01

What if the link is only with your GP?

## G07BCF35

That’s okay.

[General agreement]

00:39:17

## UCLRA01

Okay, I like that reaction, thank you.

## G07BCF41

Because you get a lot of leaflets dropped through the door and some of them… [Overtalking & Laughter]

## G07BAF42

Sainsbury’s or this, shop advert, you just put them in… like the Sunday paper, you buy the newspaper, there’s so many other adverts, you just throw them away, you don’t look at them. But if a specially made one, NHS or whatever, you check.

00:39:46

## UCLRA01

Now, you want clear instruction on these leaflets or DVD. Now, what else in that…[interrupted]

## G07BCF35

Not DVD so much as the television. The television is at everybody’s home.

## UCLRA01

Ok, more the television. Maybe I should have asked, if you do receive a DVD would you actually watch it?

## G07BCF35

No.

## G07BAF42

I don’t have a player so how can I watch a DVD?

## G07BAM36

TV is something everybody watches. DVD is more like private time. TV is everywhere…

00:40:18

## G07BAF42

TV, African channel.

## G07BBF38

And it’s a source of conversation. Did you see that last night? Did you see that? And then the other person would say, and there’s a follow-up on Wednesday night, and you would be more motivated to watch it.

## UCLRA01

Good, thank you. Did you want to…?

## UCLRA02

Yes, just a quick question, just picking back up on the leaflet idea, thinking about it coming through your door. Obviously you were saying lots of leaflets do come through your door. Would it help in any way if alongside the leaflet there was a letter, a persona letter to you from your GP explaining, you know, what the leaflet is, why it’s been sent to you, etc.?

[General agreement]

00:41:02

## G07BBF38

That would help.

## G07BAF42

The problem is there are so many illnesses. If you can just save memory loss, there are many other illnesses…

## G07BCF41

But you wouldn’t just put memory loss

## G07BCF35

But this time we’re talking about memory loss, isn’t it.

## G07BAF42

Yes, but… people, sometimes you don’t look at things.

## G07BAM36

But I think if your GP is going to send a letter saying, okay, like, for example, I walked into my GP just because I’m a certain age I have to have a chlamydia test, just because I’m that age. So just because you’re elderly you get a memory loss leaflet. I think it would work.

00:41:37

## G07BCF35

Yes, the link… because I’ve had leaflets from other organisations about this, this, this and I have just binned it because I just think straight away, you’re after my money. But if it’s the NHS I think you’ll take it more seirously.

## UCLRA02

Would it worry you if you received a letter from your GP and a leaflet about memory problems through the post?

## G07BAM36

No, it’s not saying you have memory problems, it’s just saying have a look and see…

## G07BCF41

Yes, have a look and see.

00:42:10

## UCLRA01

And what would you like to see on that leaflet exactly? Would you like to see just information or a doctor saying something, you know?

## G07BAF42

The symptoms. What’s causing the thing. Medication if…

## UCLRA01

Any particular pictures or…?

## G07BAF42

I don’t think… memory loss, you don’t need pictures.

## G07BCF35

We’re aware of memory loss, we see it every day. So it’s like, the symptoms, yes, what can be done, how can it be helped.

00:42:43

## UCLRA01

Would it matter if the person on the leaflet is black or…?

## G07BAF42

Doesn’t matter.

## G07BCF35

Is it necessary to be black? Why can’t… you get this memory thing with any race, so put a combination of people, put three, four, different races.

## G07BBF38

Yes.

## G07BAM36

Could be a group picture.

00:43:02

## G07BCF35

Yes.

## UCLRA01

Okay, thank you.

## G07BAF42

Or don’t put a picture.

## UCLRA01

I beg your pardon?

## G07BAF42

Don’t put a picture, just leave it plain.

00:43:12

## G07BCF35

I think it’s more forceful when you see the picture, though. I think you think about it more, I think, if you see.

## G07BAM36

You need something to capture attention.

## G07BCF35

I think so. As long as it’s not my picture.

[Laughter]

## UCLRA01

Just as we were about to ask you!

## UCLRA02

One other question, then, as people in the room seem quite enthusiastic about the idea of a leaflet. In terms of who we’d be aiming this leaflet at, maybe thinking about an age group, is there a particular age group that you think the leaflet should be aimed at or should it be for all? We’re interested as to what…

00:43:58

## G07BCF41

For all but, I mean, different ages, different age, because it could be a young person going…

## G07BAF42

Suffering problems.

## G07BCF41

And then it’s just for the older they are age between, you know, they would have to do it, you know between age. Not just me, not just she, not just he, you know, that we understand and you’re looking at the thing and see how you feel.

## UCLRA02

Thank you. Anybody else, anything around that?

## G07BCF35

Yes, the age… because there was a problem on last night and this lady in America, some place in America, and she was 46, had a daughter of nine. So it can… it’s more with the older people but it could happen…

## G07BCF41

At younger age.

## G07BAM36

Of course the early signs would be younger. It starts off somewhere.

00:45:02

## UCLRA01

So my next question is, we talked about what would make you seek help but what would prevent you from seeking help? What might, you know, stop you from going to see the doctor if you know you have a memory problem, you are aware of it now, you have seen the information but something is stopping you.

## G07BCM39

Personal pride. Personal pride. People feel that nobody should know what I’m going through and they don’t seek help in many cases.

00:45:45

## UCLRA01

How about based on… if we go back thinking about the leaflet or the information a doctor will give you, if the doctor put some information in there what would stop you from actually going, okay, they sent that to me but…?

## G07BCF41

I’d still go.

## G07BAF42

I would go. I don’t have that pride in me. If I’m unwell, I’m unwell.

## G07BCF41

If I’m unwell I’m unwell. So if I’m going to the doctor and he’s going to give me something, so what. All I want to know, he tell me what the illness is and what I’m taking the tablet for.

## G07BCF35

That’s if there’s any tablets.

00:46:22

[Laughter]

## G07BCF41

Or whatever medication, whatever medication

## G07BCF35

What if there isn’t any.

## G07BCM39

And next thing again, it depends on your personal relationship with your doctor.

## G07BCF35

Yes, that’s the problem.

## G07BCM39

I have a Chinese doctor and I went to book an appointment and they’re telling me about three, four weeks ... I said no, I said Dr Chan told me when I come here if they don’t book me to phone him. I phone him and he said to me he’s a bit busy now he’ll phone me at home. He did phone me at home and we had a good talk. But he’s somebody that you can more or less communicate with. But a lot of these… well, first time you just go and see.

00:47:03

## G07BCF41

Yes, but now you have to phone and you’re on that phone, like they say I must phone at eight and you’re on that phone until quarter-to-nine and every time I phone it is engaged. I told the doctor the last time I go, I said, I could drop dead by the time you get that phone call. I could be dead. He said, don’t say that, Mrs G07BCF41. I say, yes, I’m telling you because it’s too long. I say, when we used to just come in there and make your appointment. And sometimes you go there, you’re sitting there and the phone’s ringing and they’re not answering. I’m sorry but I let…

## G07BCF35

Is this at the surgery?

## G07BCF41

Yes. I let the doctor know. I said, sometimes you’re on the phone for hours and I said I could drop dead before I get… and you have to wait for the doctor to ring you back.

## G07BAF42

Everybody wants just one doctor who’s so busy.

## G07BAM36

If you know you’re not going to get help from the person, it would probably why you might not end up going…

[Overtalking]

00:47:56

## G07BCF41

But then sometimes they give you a different doctor. You go to…

## G07BAF42

We have different doctors.

## G07BCF41

We have different doctors but if I want to see Dr Fernanda I probably have to wait a week, but I’d rather wait a week because when I go in there and I tell him how I feel and what I feel not right and he’ll take care of it. But some of these doctors, you don’t know them, they don’t know your sickness and they just write anything, give you, believe you me.

00:48:27

## UCLRA01

That’s a very good point, thank you. So relationship with the doctor…

## G07BCF41

Is very… it has to be good. [Overtalking]. Very important.

## G07BAM36

Yes, it follows on from that. If you know that if you go to a GP, specific GP, they’re not going to help you, you won’t bother going. [General agreement] You’re not going to bother with it.

## G07BBF38

And the age factor as well has a lot to do with it.

## G07BCF41

If you are old they say you are living too long!

[Overtalking]

## G07BBF38

Yes, you’ve passed your [unclear]…[interrupted]

## G07BAF42

Your sale-by-date…

[Laughter]

## G07BBF38

Yes

## G07BAF42?

We have to laugh

## G07BCF35

The press encourages that because they say every day, people are living too long. You’re feeling like, well, I might as well die. No, it’s the truth. So why are they going to be bothered about dementia? Okay, you’re closer to dying, really. So I think that’s why people won’t bother.

00:49:25

## G07BAM36

Following on from some doctors that don’t know you. In terms of GP, I’m actually talking about, like, hospital, so if you’ve been referred… I’ve been to hospital before and I’ve seen about four or five different doctors that have no clue about my history. They come in and write something and what they’ve written is wrong because that’s not… I remember I had a blood test and they told me that I’m not allergic to anything, that was the first thing. I went back three or four months… no, about six months later, the same blood test, different doctor, you’re allergic to this, this and that. The same blood test. So I’d been eating things which were giving me a reaction and I didn’t know for about six or seven months. So I don’t know, I think the whole system makes it difficult for you to…

00:50:13

## G07BCF35

Entrusting them,trust, trusting that they know and care enough to…

## G07BAM36

I wouldn’t bother going to, I mean, that particular hospital, then telling them I’ve got an issue because what they did to me, I’m thinking if you did that to me, you can’t even follow-up on the same results, I’m getting two conflicting opinions. It put me off.

## G07BAF37

To add to that, if I’m to see a doctor facing a problem and I’m given two options as to whether to go for medication A or medication B and I’m given a leaflet that I should read through and decide which one to choose, I come back to you the doctor and say to you, I’m a bit confused. This one is giving me this information that, but I need a bit further information on that so can you just brief me through that and then decide on which one to do or which one do you think is the best for me and the doctor says, well, I’ve given you the leaflet so it’s up to you to decide one what to do, I wouldn’t want to come back to you again. If I’m facing a problem I would rather keep it within rather than come to you and then get that sort of treatment from you. So these are some of the things that will deter me as an individual that will deter me as an individual from going to the doctor.

00:51:35

## UCLRA01

Thank you for that.

## G07BAM36

The whole trust thing, the whole relationship with not only the doctor, the system as well.

## UCLRA02

So previous experiences that you may have had that would affect that.

## G07BAF37

I’ve had such an experience before so I don’t even want to see the doctor because it’s the case whereby I’d never met the doctor before, I was seeing a locum doctor for quite a while and then suddenly he comes in, he takes over and the very day he sees me he goes, oh, have you made up your mind, are you going for this or are you going for that? And I’m stuck, I don’t really know what to do, and then he says to me, if you can’t make up your mind then I’m sorry, I can’t do anything about it. And you walk out of the hospital in tears and the nurse meets you and says to you, are you okay, and then you keep on wondering what is going on.

00:52:29

## G07BAM36

The GP, I don’t know, the GP I went to initially, sometimes the information they give you…

## G07BCF41

Is wrong.

## G07BAM36

It’s like I’ve been there, I’ve shown the doctor, this is what I’m suffering, he tells me one thing, two weeks later I end up in hospital and I’m going through biopsies and stuff. He’s told me, don’t worry about it. Two weeks later I’ve got a swollen ankles, I’ve gone to the A&E, they’ve admitted me in hospital. So if he knew what he was talking about the first time we could have prevented that whole situation when I was in hospital for about two or three weeks.

00:53:02

## G07BCF35

Yes, risking your life.

## G07BAM36

So the information they give you has to be clear.

## G07BCM39

If this meeting wasn’t done on a Wednesday I would bring a patient here and he would tell you if you have any feeling go straight to the accident and emergency. Because he had that… I’m talking about Cyril. Anytime anything happened he’d call the taxi and straight to [unclear] St George’s…[Overtalking]

00:53:28

## G07BCF35

But the hospitals now have… not the hospitals, the GP surgeries now have notices, I don’t know about your one but my one, not to go to A&E.

## G07BAF37

Yes, it’s everywhere.

## G07BCF35

They’re saying, we’re going to A&E unnecessarily, we should go to a GP

[Overtalking]

## G07BAM36

If I didn’t go to A&E that time, I would be in a different situation.

## G07BCF41

And if you go there and nothing wrong with you, you have to pay £10. It was on the news.

## G07BCF35

I don’t think that’s coming to [unclear]

## G07BAF42

She goes to St George’s. She doesn’t go to…

00:53:58

## G07BCM39

They have this place in Croydon, near the flyover.

## G07BCF41

It’s called, umh…I can’t remember what it’s called.

## G07BCM39

The leaflet, the project came round in the post a week ago say, say you just go there, at anytime.

## G07BCF41

Yes, it’s under the bridge. It used to be up Kettering Street but it moved under the bridge now.

## G07BCM39

[Overtalking] bypass your doctor.

## UCLRA01

That’s very interesting. It sounds like everyone wants to bypass their GP and go straight to A&E.

00:54:29

## G07BAM36

The GP sometimes they just don’t get it right

## G07BCF41

They have doctors and nurses there.

## G07BBF38

Are they run by the NHS?

## G07BCF41

Yes.

00:54:34

## UCLRA01

I’ll ask you one final question, which is slightly related, what would build your confidence in your GP, because it looks like no one has much confidence in their GP?

## G07BCF35

I like the GP. I have a good surgery

## G07BCF41

I have confidence in my GP.

## G07BAF42

I just went there yesterday, she’s a very nice lady.

## UCLRA01

So you are happy. Those who aren’t happy, what would build confidence in your GP?

00:54:55

## G07BCF41

You would have to explain to the GP that you are not comfortable or you are not…

## G07BAF42

She doesn’t see me all the time but when I see her I’m happy with what she tells me.

## G07BCF35

Building confidence is to believe that you are being listened to and advised or, you know, not leaving the surgery and thinking, what was the point of coming? Because sometimes you feel like that. Or the next thing is that the GP is not in a hurry to get you out of the surgery under ten minutes, because then you feel pressured. You feel, like, I apologise to my GP, sorry for taking up your time. He’s a very nice man but I’m getting in the habit of apologising and I shouldn’t have to, not after I’ve waited three weeks to see you.

00:55:41

## G07BCM39

My granddaughter went to her doctor and he’s giving her ten minutes. She said, I work for the council and I’m here for a purpose. He gave her half an hour because she don’t take no for an answer. The main thing is that stick up and challenge him. Mind you he might kick you out of the office at the same time you’re making your point.

## G07BAM36

Having more positive experiences will outweigh the previous bad experiences you’ve had

## G07BCM39

But mind you, some of these doctors are impatient that it’s like you don’t feel you should go and see him

## G07BCF41

They just…when you go in, can I help you? And they start writing. They don’t know what’s wrong with you.

## G07BAF42

Well, some patients are very aggressive.

00:56:32

## G07BCF41

I know that, we know that.

## G07BAF42

Sometimes they are and you feel sorry for the doctors.

## G07BAM36

Sometimes you have to be with them

## G07BCF41

Yes

## G07BCF35

Can I just ask, is there any medication or… that can slow down or help people with dementia?

## UCLRA02

Well, perhaps if we’re done in terms of the discussion what we might do is turn off the tape recorders now, tie a few loose ends up and then feel free, we’re around for a little bit and we can discuss things like that.

00:56:58

## G07BBF38

Please may I have a cup of tea now?

## UCLRA02

You certainly can.

## UCLRA01

Thank you very much, everyone.