**GO1**

**Speaker key**

UCLRA01, Facilitator

UCLRA02, Facilitator

G01BAF01

G01BAF02

G01BAM03

G01BAF04

G01BAM05

G01BAF06

G01BAM07

G01BAF08

[00:00:14]

## UCLRA01

I’m hoping mine’s working. Is yours working?

## UCLRA02

Yes, we’re good.

## UCLRA01

Okay, welcome everybody, and thank you for taking part in our focus group, that’s excellent, thank you for coming. As we said, I’ve introduced myself already, I’m UCLRA01, and my colleague UCLRA02.

## UCLRA02

UCLRA02, yes.

[00:00:38]

## UCLRA01

UCLRA02, I always mispronounce her name I’m afraid. We’re researchers from UCL, University College London, and you’ve all seen the information sheet. What we’re trying to do is to get your belief, your point of view about the delays in looking for help when somebody notices they have memory issues among the Black and African Community. So we’d like to find out what you think about it.

As you know, the session will be recorded, but everything is confidential. However, what we need, we need your name. This is simply because the person who is going to transcribe the actual conversation will need to associate, you know, what comments you do, to your name, but later the name will be removed and an identification code will be put in place of the name. Okay, So, my name’s UCLRA01, what about you?

[00:01:36]

## G01BAF01

G01BAF01.

## UCLRA01

G01BAF01.

## G01BAF08

G01BAF08.

## UCLRA01

G01BAF08.

[00:01:40]

## UCLRA02

I’m UCLRA02.

## G01BAM03

I’m G01BAM03.

## G01BAM07

G01BAM07.

## UCLRA01

I beg your pardon, sorry, it’s G01BAM03, yes.

## G01BAM03

G01BAM03.

## G01BAM07

G01BAM07.

## UCLRA01

G01BAM07.

[00:01:50]

## G01BAM05

G01BAM05

## G01BAF06

G01BAF06

## G01BAF04

G01BAF04

## G01BAF02

G01BAF02

## UCLRA01

Thank you, thank you very much. Now, we’re going to start. To start the conversation, as I said, we need to find out your point of view about what would be your reaction, based on symptoms of memory problems.

So we’re going to start with the example of a lady, that’s a Mrs Abraham, and I’d like you to think about this lady. She’s 70 years old and she’s, well, just an old lady, but family members have noticed that she’s more forgetful lately, she cannot remember conversations with people, and she forgets also her appointments, like doctor appointments. She also often misplaces important items like her keys or glasses. She’s physically healthy though, but she’s concerned about her memory.

[00:02:49]

So she’s just somebody we made up. Obviously it’s not, you know, a real person, but you know, that happens to everyone. Everyone has, you know, moments where they forget something. They forget, you know, they have memory problems. She’s healthy, but she keeps forgetting important things like appointments, like keys, like conversations with people, and most people close to her have noticed that as well. So just to ask all of you, if you knew somebody like this, would you think that she could get help for her memory problems? If you knew somebody exactly like that lady. Yes, go ahead.

## G01BAM03

Yes, dementia people, and I think there’s a case for them, especially when they come to a home, relations, they’re normal, but when they are mixed with others who are non, they can’t know, because they’re foreign, and because of the care they have, they’re having at home, these are different things, and isolation as well, brings upon the dementia.

[00:04:02]

You see them, they forget they… you forget you are smoking, was wondering why. Only, between two and three months, you stop smoking, definitely you never smoke again. [Unclear] You know, it comes to so many things, like there isn’t enough of it, because the body is affected. They’re not eating well, they can’t feed themselves, they have to be fed, and I think, because… it becomes mental, it’s a mental case, because of that isolation and living in a different area, you know, before leaving their own houses, they’re put in a home, they become disconnected with the world. I think that that’s a isolation and mental. When you’re isolated it can come upon to anybody.

## UCLRA01

Okay, so you think if they’re isolated, they start getting more problems.

## G01BAM03

I think so, but it’s for me, not for everybody.

[00:05:01]

## UCLRA01

Okay. Before they get isolated, do you think that they will look for help?

## G01BAM03

They won’t look unless they were helped look for. They can’t remember in a group or anything. They forget everything. They are abnormal, totally abnormal, they are not themselves as before. Also it becomes a mental thing, because they don’t think about tomorrow or today, they don’t think about anything. They just sit there to be catered for.

## UCLRA01.

That’s interesting. Okay, so you’re saying since they’re having a memory problem, they can’t even remember, you know, looking for help…

## G01BAM03

No, they forget everything.

[00:05:36]

## UCLRA01

So they just stay, you know, where they are in the condition.

## G01BAM03

But when they start wandering around on their own, we have to offer them. If you care for three of them you’re a disaster, one goes this way, one this way, and this way and you offer this one, the others are gone, and you’re not supposed to keep them in the house.

## UCLRA01

Okay, thank you. Yes.

## G01BAF08

And what’s the thing that they cannot look for help, simply because they think it’s normal for everybody, and because everybody has that memory loss, everyone forgets, so they actually think that that phase is actually normal and it also depends on the age. So such people will never look for help. They won’t look for help.

[00:06:30]

## G01BAM07

I think she is not very old.

## UCLRA01

I beg your pardon?

## G01BAM07

Some, the lady, she’s not very old. She said 70.

## UCLRA01

70, yes.

## G01BAM07

So it’s not…

[00:06:39]

## UCLRA01

So, I mean, would you think she should look for help then?

## G01BAF01

She should look for help.

## G01BAF08

She should look for help.

## UCLRA01

Yes.

## G01BAF06

For me, to avoid to be alone, maybe with someone, because if there is reaosn leave alone, they will see as normal. It is good to be with people.

[00:07:04]

## UCLRA01

Would you say that if she has no one around her, that will be a cause of her not to look for help, but if she had family, she would? Is that what you’re saying?

## G01BAF01

Mm. That type of people, they should look for help, because they can’t do… there are some things that they can’t do by themselves and there are some they can do by themselves. So they definitely need help and they need people around them.

## UCLRA01

Carry on.

## G01BAF08

I’ve been… if such people also live with family… with somebody else in the family, the main reason why the black minority don’t look for help, is actually that it’s our background, sort of, because from Africa, we’ve never heard terms like dementia. We have never heard, you know, things that, you know, people who come abroad actually getting [unclear] technologies in certain diseases or sicknesses.

So for black minority people, they think it’s actually normal, so that is the reason why they’ve never… you’ve never heard it from Africa where you come from, therefore when you come here, then they just think, well, that’s the normal part of life. So if it is myself and if I’m living with somebody like that, still I would just think that it’s a phase that that person is going through, you know. So I wouldn’t seek for help for that person. Yes, I wouldn’t even, you know, think that, you know, that person needed help, and it is also, maybe, I might not even know that there is even help available for that person. So, you know, I just think it’s a normal thing.

[00:09:09]

## UCLRA01

So you wouldn’t see that as a problem.

## G01BAF08

Yes, I would not see that as a problem, and if it is a problem, as a family member, I can get the help. I can get the help, so I don’t ask… I don’t look for external help, but I will be… I would be thinking I am there to help that person, you know, to help, you know, asking the person, you have forgotten that thing, can you do this, can you do… because I am living with that person. So really, I would be thinking that the help is within the family, so I wouldn’t look for external help.

[00:09:49]

## UCLRA01

Thank you, that’s a very good point, yes.

## G01BAM03

What she’s saying, in Africa, we don’t have homes to take our elderly. Elderly people live in the houses, to be looked after by the family, which is very known in Africa. So when they’re sick, everybody knows they’re sick, the family knows. They can be located for the person so they, the person knows it is that way. They don’t have homes where you can take elderly people before they die. Here, because they see services and get after, and get old, it becomes more natural that they are taken to a home, to get out of the family for them to go to work.

Africa, we don’t have that. They have… they have to be there with you until they die. So it’s very different. Here we don’t even imagine… can’t even imagine Angela going to a home. She’s going to die at home where she is safe. Here, we are not... we don’t have… we don’t think about those services about home, no. When you die, you go back to Africa, which is true, for everybody here, you would go back where you came from.

## G01BAF06

[Unclear] strong family [unclear].

[00:11:15]

## G01BAM03

No, the bodies, it is too big, too tight, if you’ve got distant family and you… when we gather, you think it’s a meeting, because when you’re calling your people all of them… all of them, and when you go back home, you find that some friends coming from here, they are all there from regions, not even from where they live. Some live in Manchester, they are coming to see you, that’s how it is. Here, is only you and your family, finished.

## UCLRA01

So would you say that according to you, in Africa, external help, you wouldn’t look for external help, because you don’t need it, because you go to your family?

## G01BAM03

Because we don’t… we’re not, we wouldn’t get it.

## UCLRA01

You wouldn’t get it. So it’s not…

[00:12:03]

## G01BAM03

You cater for your own people, because even those have their own, so.

## UCLRA01

You wanted to say something?

## G01BAF01

Yes, because like as he said, in Africa, you can see they know each… everybody knows each and every one, even someone who’s lost. They would just take him in. They’d bring him back, we found him there… they bring him back. Everybody help each and every one.

And I remember a family, the mother was really sick, then she left to look after the parent, they couldn’t do anything, but I didn’t understand, because after they teach them and they know, they learnt very young, but here, at the time, you can’t do anything, they can’t do anything for you. They know that there is a service, but in Africa, the people even the community, they are already strong to do it, maybe for free, because it’s the culture, but here, it becomes difficult, because nobody will look after you, even your children they are busy, they have to do their things, everybody is busy, everybody has to look, it’s not like in Africa. Even the community, the neighbours, they help you, but here even your neighbour, they don’t know what is happening.

[00:13:16]

## UCLRA01

Yes please. Yes, thank you very much.

## G01BAM05

You were talking about a lady isn’t it? A woman of 70 years yes? There are a lot of factors, I believe the actual cause, the reason why she has issues and then as they said, it’s a stress of life that can cause her to forget the basic keys and that is, maybe she has other stress she’s going through. Maybe she’s just been diagnosed of having one or two problems, internal problems, so this might make her think enough, how am I going to survive in this issue that she can forget about her basic issues.

And if you’ve thought about her difficult situation, it is very difficult, for a lot of people that contribute to her forgetting those basic stuff. They want to take her drugs, maybe she’s been administered one or two drugs, to help herself and her memory, she tends to forget herself, and sometimes the availability of the information. Even if she’s decides to go for information, how is she going to get it? Who is there to actually give her that sort of information? It’s a communication issue.

There are people here, even from black communities, who aren’t speaking good English, so even if they go, who would be able to assist them, making sure the information is actually being conveyed to the people who actually… the government provide a service for them. So, like as I said, isolation is one of the biggest issues in this part of the world.

People living… you said the woman of 70 to 80 years, living in alone in a house, even the children don’t come to visit her, so such things can make them feel like they’re worthless. That nobody cares, they have nobody there to… even the kids, nobody is there to actually help them out actually one or two things, you know.

[00:15:19]

So those things can lead them, because I’ve been in a place where I have an aunty who had a problem, a very chronic problem. She was given drugs to be able to keep herself alive, but she couldn’t take those drugs because the family were trying to, you know, disassociate themselves from her, because she had a chronic illness. At the end of the day, she left, she said, if that is the case, I’m not going to take my drugs any more, you know. She said, I’m not going to have anything to do with the drugs anymore, you know, she had to stop taking the drugs, at the end of the day she died of that illness.

So the problem is not really if she goes for the information, the problem is even if she goes for the information, who is there to give it to… to support her in getting that information. The complication… how effective or efficient is she in terms of communicating.

The complex… the inferiority complex is another issue that might hinder her from going out. You know, when you stay alone from Monday to Sunday, you don’t have a friend to chat with, it’s a very big problem, I believe that the people who are there to provide those services are not doing enough.

Like if for example, she’s been given some medications for the memory loss, it’s an important part, if it’s from the GP or the nurses, they keep giving her a ring, from time to time, to remind her that look, do you… this is what you need. If they fail to do that, she might, because she has her memory loss, she might forget it, but if they have somebody outside, which I know would be an inconvenient situation nowadays, with cost cutting and so on and so forth, would not be able to give the government enough money to go to and change some of these issues, so this is basic things that should be addressed in order to make at least help that person to remember, even if an issue comes up.

[0017:28]

## UCLRA01

Okay, excellent, thank you, so you’re saying, there’s the complication from the first, so they might not want to go and see a GP or look for professional help, because…

## G01BAM07

They just forget.

## UCLRA01

Yes, either because they forget, or because they can’t [overtalking] properly.

## G01BAM03

Forgetful.

## UCLRA01

But you also mention a very important point, you’re saying that they may not get the help they need, so that might stop them from going to look for help. So you think she would stay at home saying, no one’s going to help me so I’m just going to stay here. Okay.

[00:18:02]

## G01BAF02

And they might also think that they will not get the help that they need, because they will think of the cultural values. They think that if I ask for help, right, and if I go, and if I’m taken away from my own home, then, which means I have go and stay somewhere and be given different type of food that I wouldn’t like. So really, that alone would make someone not to think to ask for help, because they think the setting will be totally different from what they want.

Therefore they’ll think it’s better to stay indoors and, you know, do my own things, according to my own culture, with my own people, like in [unclear]. Because if you seek for help, then it means that you actually, you know, everything will change when you get that help. Maybe if it’s a certain type of food, I might not get that type of food that the actually like. So that would actually stress you out instead. I’d rather stay and do what I want, you know, so that thinking, that if I seek help, but still I would, I wouldn’t get exactly what I want. It would make people think, no to asking for help, external help.

[00:19:30]

## UCLRA01

Okay, are you saying that they’re afraid of change?

## G01BAF02

The change, yes.

## UCLRA01

That’s what, you know, one of you to tell them that’s going to change.

## G01BAF02

Mm.

## UCLRA01

Okay.

[00:19:40]

## G01BAM03

I want to add to what she just said, because here, in this country, when you get old, they start bringing Meals on Wheels, Meals on Wheels. That’s putting one down, she has been cooking for herself, or he has been cooking for himself. For like these people here, I would say this isn’t good, but it happens.

Most people are not married, they stay alone. When they grow old, [unclear] everybody else. That thing causes a lot of disaster, when you get around 70, you can’t cook for yourself. Food start coming on wheels, you’re just lazy sitting in the house waiting for food, it doesn’t [unclear]. When you’re doing something you’re thinking. When you sitting down, you’re not thinking. Thinking about yourself and not what you can do. So it creates a lot of bad things to tell, because when food is brought to you, you just eat and sleep, you are not even washing your clothes.

[00:20:44]

In Africa, what you do now? You wash your clothes by hand. If I don’t wash by hand, it’s very bad. If you’re old, people do it for you. Here you put the machine. Things are very easy here, when you go back to Africa, it’s harder than here by far, because you live… we live… we struggle to live. We care for each other, I your family is old and I’m there, I wouldn’t let her forget all those things. I’ll be reminding her in the morning, wash and if she couldn’t, I’d find another lady to wash her.

That’s how it is, because there’s just this community thing in Africa [unclear]. As we view our age now, nobody was fathers and mothers, you are for the community. If you can render the stick, you’d be punished by anybody, not like here, anybody. So that things which makes one stronger.

When you’re in the community, and you’re part of the community, you don’t grow old and we usually meet most of the times, you are known all over. In your village everybody knows G01BAF08, where she lives, where she’s going there. When you’re not there for night, people will know she didn’t come to her house.

Here, if you go, you die in your house, and die, that’s the thing I don’t understand, months and months and you die and people find it, worms coming from your house, because nobody is looking after you. I find that people suffer, because for me, I want to know why I didn’t come for this meeting… the last meeting, oh, where is she, started by asking each other, oh I ask G01BAF01, have you seen G01BAF08? That’s our community. Here you don’t understand the system very well.

[00:22:39]

## UCLRA01.

Okay, well this…Oh, please go ahead.

## G01BAF01

Is she from Africa?

## UCLRA01

We… well, we don’t know, but we’ll assume she is.

## G01BAF01

Well if she’s from Africa, there are so many factors that affects her, that the Home Office.

## G01BAM07

Yes, that’s where the original issue stems from that issue, because if the person is having any memory loss, there’s no way he or she is going to be able to...

[00:23:12]

## G01BAM05

At 70 the fear alone, the fear alone will not allow her to approach any government officials, or any person in a better position to provide such services for her.

## G01BAM03

It’s affected everybody, even when you’re twenty. Home Office [unclear]. You don’t sleep, you hear voices at night, you know, it’s bad, because when you don’t have your papers here, you think any day you can go home, and you don’t know what to get, when you get home, what you see.

## UCLRA01

So we said that there are a lot of reasons why…

## G01BAM03

A lot.

[00:23:51]

## UCLRA01

Yes. What would prevent it, but what would make somebody like that look for help? I know you said there is communication issues, there is immigration, there is quite a few things you mentioned, but what would make the leap between her eventually saying, okay, now despite all these problems, all these barriers, I have to look for help. At which point do you think she will...?

## G01BAM03

I think when you get dementia, you can’t remember to ask for help. You never remember anything. You’re just a zombie. You don’t know what you’re doing on your own. You know, you can go to a person, care for her or him, he’ll ask you, who are you? You know that you were there yesterday, but today she is asking you, who are you, why are you coming to my house? They’ll even attack you, so you have to convince them you’ve been coming there every day. They usually forget… they can forget anything, anything, even eating. Food is there, she forgets, or he forgets.

## UCLRA01

Okay, and what if she’s actually noticing. She notices all this, that she’s actually forgetting, because, for example, we talked back to Mrs Abraham, she notices that she forgets things.

## [00:25:13]

## G01BAM03

No.

## UCLRA01

Oh yes, she…

## G01BAM03

They don’t notice anything.

## UCLRA01

In some cases that’s possibly true, but for example, in other cases people at the beginning of getting a problem, they realise that they forget their key.

## G01BAM05

So you mentioned looking for help, what if she wants to go for information.

[00:25:32]

## UCLRA01

Yes, I wanted to find out what would make her look for help? She may forget and say there’s too many problems.

## G01BAM05

I lot of factors can actually make her keep remembering, you know, we have national television, they should have a task, telling the nation of where to go for information so telling about the issue. Then you have radios, that the radio, leaflets, she can be like going around like through the door, they put it in, into their home. When they’re inside, they can go through it and read and say oh, this information and can act it out.

And another thing is, if most of them are registered with their GP, their GPs form the habit of at least regular phone contact, reminding them to always remember that being dementia, doesn’t mean they should... Even if the person is so, the brain work, the brain is the way you communicate with that person, in a friendly manner, you know, lovely way where the person would keep… some people have… they kind of, what do they call it, what they put on their neck?

## G01BAF01

Necklace?

[00:26:49]

## G01BAM05

Yes, every time the time comes to do something [overtalking]. So it is the responsibility of the government to provide food, so that all these dementia people, they would have something so they would remember any time they want to go out, the alarm beeps and they go straight to either for the medicine or the key or whatever.

## G01BAM07

I don’t think you understand what dementia is. Dementia is another… not about forgetting.

## UCLRA01

Yes, I totally understand what you mean. But for example in the case, in the case of that vignette, we’re actually analysing, She doesn’t know she has dementia yet.

## G01BAM07

Okay.

[00:27:36]

## UCLRA01

And she’s probably not advanced yet, she’s literally just started to…

## G01BAM07

Forgetfulness.

## UCLRA01

Yes.

## G01BAM07

Okay, I understand.

## UCLRA01

So, no, that’s fine, that’s great, very good point actually, what you said. So what we want to know is, from that beginning, you know, when somebody starts noticing, okay, I’m forgetting, which point you’ll say, okay, forget about it, it’s just part of life, or you go, okay, I should worry about it and I will see someone. What would make you say, okay yes, I need to go and talk to someone? Yes, sure.

[00:28:06]

## G01BAM07

It’s very difficult, you assume you are in a normal state. So unless you’re with somebody, who knows that you are really in that state of forgetfulness. To you it is normal. I have a neighbour and every time she goes out she starts talking to people in her house. Anyhow, her own people have given up, because every time she goes and she just talks with… I have no ten pound, I have no ten pound, I have no… And her people, inside the house, but they are not there, they are going for work, they are going for everything. I think they try to go to the normal people like the GP to work and everything to take care of this person, but I think nobody responded.

They think maybe it is a normal case. You see dementia is a new disease and maybe we talk about it, we don’t know what is… we don’t know what it is, why is there, maybe even researchers themselves have failed to come up with this, yes. So if somebody it just goes on like that. It is… I don’t think if you give people a bell to ring every time you take a medicine will be able to remember. He will just say this is a normal thing which is ringing.

So it needs a real human being to be near that person, even if they are [unclear] on TV, even if they are not bothered what is that? So it needss the human communication, someone who is noticing some abnormal symptom in that person, which is making him to act like that.

[00:30:00]

So the only way you can discover dementia, is to live with somebody for some time, especially if that person is 70 years, and especially in this country. A 70 year old is isolated and maybe living in alone somewhere, or she or he is living in a home… a home place, like a nursing home. So unless these social workers who visits them, can identify that, oh wait, she’s supposed to take her tablets, but she’s not taking them. So she needs that interaction. The other thing about it I suppose is there is no somebody who can remind it, keep… he will forget, even if it rings he will say, I forgot, I didn’t hear it or something like that. So the person in charge is very, very important.

## UCLRA01.

Excellent, thank you very much. Anybody else?

## G01BAF06

For me, I just suggest if an organisation like this, they can have a special project, because even me now I notice when old people, there’s a man, you see he’s talking to himself, I think I meet more than five people at this age, talking to themselves, talking to… doing [unclear] things. It’s a special project for me I think they should do like, an organisation like this, to find out they can help people, because sometimes they don’t know, sometimes they know, sometimes they are scared, some they are proud, afraid people will laugh at becomes like a stigma for some people. Maybe it’s a special project for those people because now people live longer at this age, like 70, maybe their children are very busy, their family have no time for the person that was my thinking.

[00:31:56]

## UCLRA01

Oh great, thank you, do keep that in mind. Please go ahead.

## G01BAF01

Okay, I agree with what they are saying. I went to a group, over 65, age concern but when reached there I say, ah these people they are not for me. I couldn’t cope with them, but if it, we have it here I know I will be… happy to be here. But they keep on ringing, what happened, when are you coming back? They are telling me so many things that [unclear] I just give up. I say I’m not going back there.

## UCLRA01

So if you don’t get the…

## G01BAF06

Help.

[00:32:39]

## G01BAF01

If we get it here, it’s better, because otherwise I have [unclear]. Because when you see this one is… the lady’s white, the other one’s white, the other one’s… nothing’s… what are you doing, what’s your mortgage? I can’t understand all these things.

## UCLRA01

Okay, that’s good.

## G01BAF01

That’s better.

## UCLRA01

Very good, yes.

[00:33:07]

## G01BAM07

I think, because she is the question, the 70 years, a woman, there are young people having dementia and there are a lot of people I know… I have a friend, I think he’s old, forgetfulness started as soon as he was diagnosed with a chronic illness, he started. What he does is go to colleges where they try to teach them on how to… he was very intelligent before he was diagnosed, but as soon as he was diagnosed, he started having memory loss. Then they had to, through the help of the doctor, the nurses, they had to take him into college where they teach them like, how they teach nursery school pupils. Do you get what I mean?

## UCLRA01

Yes absolutely.

[00:33:56]

## G01BAM07

So, there are a lot of issues, because what we’re talking about is… we’re talk about… if… because when you do your research it’s still going to be taking care of… the government will understand what is actually happening and what people need to get the information. Even if the information is there, who is able…? Because there are some doctors and nurses. I’ve been to a GP to assess what I should… when I get there the GP will try to hurry me to leave. The attitude of most of them who are actually giving us the [unclear] stop the person going for a diagnosis.

So this is my friend, he find it very difficult to remember test, the one I was talking to you now, but what the government have done and through the doctor and nurses, is they had him enrolled in the college where they teach them, try to [unclear] nursery school pupil, how to write A, B, C, you know what I mean, so from here… from there, his memory is trying to… he is trying to regain his memory back which is another issue.

## UCLRA01

Okay, so one last question from me, before I will ask UCLRA02 to help us. We all agree that Mrs Abraham or if we know someone like that, they should look for help. Where would they look for help first? According to you, where do you think that person should look for help first?

## G01BAM03

Citizen’s Advice.

## G01BAF06

[Overtalking].

## UCLRA01

If they’re having memory problems they’ll look to the Citizen’s Advice…? [interrupted]

[00:35:23]

## G01BAM05

Yes, because in this part of the world when we are talking about family, because we know that the issue of family is [2 percent?] nobody cares, even if you have children, they find it difficult to go visiting. So because we, we are not living in Africa anymore, because we’re here, so because we’re here, in this country, we have lived here for many, many years, therefore we should be accustomed to whatever is happening in North America. So we have citizens’ advice, you have a council, in the borough where you live, you go to the council, you seek advice and know the services they have for you and how to get it. So when you go to citizens’ advice bureau they should be able to tell you where the available services you need to be able to help yourself.

So if you are someone who’s on medication and you have your doctor, your doctor appointment, because my doctor gives me a lot of advice on how to go about all these issues. So I don’t get isolated and because even these things, I was registered for my doctor, you know, so the doctors have access to all these support groups where you can go, and they know, instead of being at home, and like I said, being alone. A lot of elderly women, in this country, they have this… the alarm stuff provided for them, it helps them, so it’s not going to set… it’s set at the time, you know, for you to remember what you’re going to do. As soon as it rings, it comes back to you. It’s like a memory reminder, you know what I mean? So it reminds you, you get a shock, you say, oh I have something to do. We all forget things, we all often forget things, I forget things so, but it’s now how we manage it. So we go to social housing in the borough where you live, and the citizens’ advice branch should be able to give out what advice….

[00:37:28]

## UCLRA01

So you think that she should go to the citizens’ advice bureau but you said you have good contact with your GP so you’ve been talking… if that happened to you, or someone in your family, would you be going to the GP or the citizens’ advice bureau?

## G01BAM05

I would go to the GP.

## UCLRA01

You would be going to the GP. How about everybody else? Yes.

## G01BAF01

From me, I think it depends. This… the origin of the people. People like from Africa, like me, I come from a country, if I’m French, because they speak French, it’s not their first language and after French there are new languages. Some of the people at the citizens’ advice and they do not get it because they do not understand properly. For me I think churches and organisations should not be forgotten, because in churches you find people from all the organisations, like this, they can come… interpreter. People come from the place they come. That’s very important for those kinds of people, regarding their origin as well.

## UCLRA01

Ok thank you.

[00:38:38]

***G01BAF08***

In support to what she said, really, because we have… we should according to different ethnics, we should have a certain point in order to create that chance for so many people from different ethnics to actually access those services. So if they actually get some charitable organisations which cater for, you know, different ethnics and with different people that they can actually get the help from, that would be help a lot, because that’s when people who doesn’t go and seek for that help at the first contact. And if they get that help from that first appointment, if they start from there, I know they will be helped so much that they can even go further to seek for more help for someone else, but that first… but that first contact is the most important thing.

Because really, for the person to admit that, you know, I have a problem, you really need to go to a place where you feel you are going to get the help that you need, and that one should be the first contact should be from your charitable organisation with a lot of ethnic groups like you, who are actually trying to help you.

And I think this, because I also have… I am a married person and my husband is, you know, above seventy and I can actually notice that he has a lot of problems. He is forgetting a lot of things. He’s going in that phase whereby he’s actually going into dementia, but how to help him? I wish I could, but I can’t get, because even if I say, we call the GP in, I know he will say no. Yes, so really, a first contact, like a charitable… someone with whom he actually trusts in order to meet, yes, because I can notice a lot of things on him, but honestly, I don’t know how best I can help him. You know, you seek for that help.

[00:41:05]

## UCLRA01

Excellent, thank you very much.

## G01BAM05

It comes with the first part of dementia, about how to get the information, so where to get information? If she knows how to do it… if the information is available, how she can get it. So she’s lacking the knowledge to get…

## G01BAF06

The knowledge.

## G01BAM05

To seek the information which is the first issue we discussed on how she can… she can get herself the information, because when you have access to the information, you will know how to go about it and solve your issues.

[00:41:38]

## UCLRA01

My colleague will actually talk to you about more of those things now, so UCLRA02.

## UCLRA02

Yes, I know, it’s a really good point. Before I move on to this bit,. I do have some questions just drawing upon what some of you have already said, and we can either come back to them at the end, or cover them now?

## UCLRA01

Now if you like.

## UCLRA02

Yeah, just a couple of points that I wanted to pick up on. One of the… you gave an example of your aunty, earlier on, in terms of not taking medication and I was just wondering, in terms of expanding on that a little bit, do you feel that other people’s opinions and views within the communities that you’re from is an important factor when somebody might be looking for help. What others around them, whether that would that be the family member or community think, because I just wondered.

[00:42:19]

## G01BAM05

Yes, it’s something where we come from, the black community, even in this part of the world and you have such sickness people tend to… there are certain sickness you have, people tend to walk away from you. People distance themselves from you, they don’t want to associate with you, so maybe… If you’re a young person, you have a dementia, people will say oh, maybe that’s what you caused for yourself. You get me? People will not see the other way round, they will not say, oh, it could happen to anybody as well. Especially in the black community, it is very common. So maybe he must have done something, that’s why he’s lost, he used to be… he used to be normal when he came to this country, but why has he changed? That must be because he’s done something bad. Maybe, he must have been smoking, or maybe they’ve been doing drug, that kind of thoughts. The attitude of people towards us [unclear] human being, [unclear] people who have dementia to withdraw from.

## UCLRA02

Okay, that’s really interesting, thank you. So, go on.

## G01BAF01

Most African people, you have the fear, the fear to seek help until they reach like a critical point. They fear to speak out and become… but you really need help.

[00:43:27]

## UCLRA02

Okay, that’s really interesting thank you. Sorry if I’m jumping around a bit, because I’m just picking up on points that you’ve previously said over the last half an hour. One of the other things that struck me was, you talked about getting a diagnosis of dementia, a couple of people, and I just wondered if you felt that getting a diagnosis of dementia is very different to getting a diagnosis of anything else, whether that be arthritis or diabetes, just for example. Is the diagnosis of dementia different?

## G01BAM05

Normally, what I mean by diagnosis was not really, but when he was diagnosed, the shock he had for two days, because he was put in the hospital for eight months in a coma. So the surgery and all the things the doctors did on his brain resulted in [unclear], even though nothing was found, resulted…, as soon as it came up he couldn’t remember. Even when I came to visit him in the hospital, he never remembered me. It took him months to recognise who I was. You know when you have a good friend, so it took him months to come back and now recognise me even when he saw me after some months, he couldn’t recognise me but now he can. So with the help… and the shock people get from diagnosis can cause a really big problem really.

## UCLRA02

Sure, no that’s really interesting, and thank you for sharing that.

[00:44:48]

## G01BAM07

I will give you an example of my partner. I was in UCL, I was in this coma, however many days it is, but see, when I recovered I had lost some of my memory, it took time for the doctor to investigate, but when they discharged me, I went to my family and they looked after me and now I can… I am myself now. So if you have an individual around you, you can fight dementia. I don’t believe in these… these funny techniques. If you have someone who identifies it and they identify it very well, you catch up. You’ll bring back the memory very well and start operating again.

## UCLRA02

Okay, thank you. Sorry, just to move over here, [unclear].

## G01BAF01

African people are embarrassed, they feel embarrassed and they are worried to lose their freedom. People are different, people come, social service, sometimes the police, immigration, all those fear to lose their freedom. They are not free, they can’t do things they used to do, nobody make them, bring them and the carer maybe, all that makes them fear to lose their freedom as well.

[00:46:18]

## UCLRA02

Okay, thank you.

***G01BAF04***

In addition to what my brother said, it is true, it is very easy to lose memory, because I can remember when I was at admitted at Kings. By the time I knew where I am, I don’t even know anybody, even the nurses. It was by force they give me the medicine, because I didn’t eat, because I don’t normally eat all the white people’s food, I don’t eat [unclear]. Tell me, [unclear] but it’s like, something like that, like, even my children, all of them run away. My children said, you were potty. I was nutty you know and in the hospital nobody came to see me.

It was like, that was then, I lost everything, but according to what the other brother said, my family, when they started coming to back then I was all right. When they started coming to me back, I was trying to regain, but not all, but gradually I’m regaining. You can see me, I dress up like normal person now, but that memory thing is still there. You can’t ask me some other bits. I will not remember. I will tell you I don’t remember; because for me to be [cracking?], even though the question is too much, I burst out crying. I’d be crying, because I… you know, at times, I lose my head, but the only thing they can do is to ask somebody around them or like carer, or, like, follow maybe voluntary services, just to go there. Even just to go there and say hello, how you are, they sit with people quietly and they talk to them, caring people, it can go.

That’s what needs to be, because when they wanted to discharge me, they didn’t give me easy like that. They brought some money for me to be adding, 1p, 3p, £2, 10p, for me to be…they… they go… have gone through something like that, which they would be saying, this, that, it was… so people will say, oh, what is your name? You see me, you ask me my name. I will tell them, but some of the times they will ask for me to tell them my name. I was waiting like two, three minutes before I could.

[00:49:02]

## UCLRA02

Thank you so much for sharing that. That’s really kind of you. Everything that you’ve been saying’s been really interesting, so thank you. If I could just move the conversation on slightly, if that’s all right, and by all means, at the end, if you’ve got any other bits you want to add, you know, we can come back to you.

What I’d like you to think about now, I mean, you know, you’ve all been discussing, you sort of touched on it a moment ago, about you know, people knowing where to go for help, and what, you know, what kind of information’s out there for people. So one of the things I’d like you to think about, if that’s okay, is what your thoughts and opinions are in relation to what could we do as part of this project and the work that we’re currently involved in at UCL. What could be done to help and encourage people from communities such as your own, to seek help for memory problems earlier?

[00:49:48]

So, you know, one of the things that we know from research is that people who get help for memory problems from their doctors, earlier in the illness, do better overall, generally speaking; because these people are able to plan for their future in a better way, their families or care givers around them can get better supported in their role as care giver.

So I’ll just start the discussion, if that’s okay, by asking you if you or someone close to you had memory problems, what kind of information would make you more likely to seek help for those problems? So what kind of format or form… I mean, earlier on in the discussion, you spoke a little bit… oops… about TV advertisements, you… someone mentioned leaflets and things like that, so I’m just trying to get you to think along those lines. What sort of information do you think would be able to help and support people to seek help earlier?

[00:50:47]

## G01BAM07

I think emotional support, emotional and peer support. You know, be there for him or her when she needs you and most of the time it’s when she needs it from you. If she has no memory, she needs someone close to her who she can… if she was normal, who she could confide too. They lack someone to talk to [unclear]. They lack ways to express what they’re feeling and [unclear] becomes that forgetfulness. You can’t even remember who she can consult or he can consult for help unless you organise going on and get it themselves.

They have no time to remember anything when they are forgetting, they forget everything. They can’t remember when to see someone and you forget your key… where your keys are when you go to your house. You don’t have the keys, so you have to know how he behaves or she behaves. know, when she’s not, when she can’t find the keys, let her know we keep the keys here. If they’re not there try to look for, and tell her this is where we keep our keys, because it can be a normal thing for a person if it is a routine. But sometimes you lose it because they have so many things going on around in your head.

We become disorganised, but I think you can be controlled by someone whom you visit every day, she knows that you are coming, on Sunday, she will remember you’re coming, it’s not, it’s stuck in her mind, someone’s coming to see me at this time, and make sure you come at the right time when she remembers you are already there, because if you miss her and then she forgets your coming, yes. So, to be in her head, said, someone is coming to visit me. Try to keep it up, to go there. She knows you’re coming, then when you’re starting with me I go to the shops, go around the back, start to get something for the person, otherwise even start walking the dog with other people. Even those who forget, they don’t forget to take the rubbish out, because it’s a routine.

## UCLRA02

Okay, thank you for that.

[00:53:13]

## G01BAM05

[Overtalking].

## UCLRA02

Just to repeat it?

## G01BAF06

Yeah.

## UCLRA02

Okay, sorry, just one second, I’ll repeat it for this gentleman and then we’ll come straight to you. So the question was, if you or someone close to you had memory problems, what kind of information do you think would make it more likely for that person or yourself to seek support, and when I say kind of information, you know, I’m talking about what form or format would that information take, whether it be leaflets, would a DVD be something that you think people… would be a good way of sharing information with people, those kind of things is what we’re really interested in.

[00:53:47]

## G01BAF08

According to my own thinking, in order to help such people, you said what kind of information, I don’t know what kind of information you can actually do to deal, work with charitable organisations like this one, to equip people like, you know, when most of the people like us go in order… I don’t know what equipment we really need to, you know, to support us, so that we can actually reach most of black minority and people like us. Like now, when I said to you about my husband, really I don’t know how best I can actually help him. So if I get something like people like you, you said, what can we do in order to be… to help, that information, like you said, to help, I don’t know how often you can actually help us in order to…

## UCLRA02

What would you like though? Using the example, if you don’t mind, of yourself and your husband, what kind of information do you think might be information that he might be interested in looking at, whether it be by himself or information he could look at with you. Do you have any ideas around, you know, what you think might be a good thing to have? If you don’t that’s fine, I just wondered.

[00:55:15]

## G01BAF08

Yes, I’m just trying to think, because, like, you know, the leaflets and whatever he has had with dementia, but that acceptance, so really I don’t know how we can be equipped in order to convince somebody to accept. That’s where the problem is.

## UCLRA02

Okay, thank you.

***G01BAF02***

Like for me, when I go through Bromley, Beckenham, there is a place there just for Dementia Support, but I never see it in Lewisham, normally if I see someone like that I will direct him to Beckenham, maybe myself, I would go there, because they’ve got all the services, they can help, but here I have to go, maybe citizens’ advice bureau or in the library to ask, because this person needs someone to go, maybe every day, they’ve got activities they do for them to help them, but I never see it in Lewisham. I don’t know how many Dementia Support in this area. I never see it in Lewisham.

## UCLRA02

Okay, thank you for that.

[00:56:24]

## G01BAM05

If you’re talking about information, we should… if you’re going to do like the research now, the research should come in a very persuasive way. Comic like way where people, if you’re going use television to do it, you make it like a comedy, where people, those who have dementia, when they see the star laughing on their own, even if [unclear] why are you laughing, they’re watching the TV, they have seen that comic like advert inviting them to go to such a place for information.

Then, if you’re going to use radio you give them something that, when they hear it, they will want to hear it all the time. When the kids, when they want to watch cartoon all the time, you ask if you have kids, you ask yourself, why is this kid so much attracted to this cartoon? They like it, they want to watch it, so you make it that way for them to be able to have that persuasiveness will be there.

So if they have a doctor because [unclear], she should have… the husband should be able to have a doctor who actually take some more information and should be provided at the doctors, making sure that the doctors have it available so that when people like that call, when people like that come, the doctors can give them more information on where to have access to this diagnosis. If they have diagnosis, you visit them at home, like me, I got a nurse who visit me at home, who tells me all the things. So, your nurse can tell you, look if you’re forgetting things, these are places where you should go. This is the situation. So your nurse will call you and remind you and say look, this is… Like she said the window display, people that go outside and see Alzheimer’s, you read them, I’m telling you, look if you go to Lewisham, social place in Lewisham, there is such a thing and I’m going to tell my friends, I saw a place where you have to go and seek help.

[00:58:19]

## UCLRA02

Okay, if I can just expand on what you’ve said a little bit. Do you, yourself, or anyone else, think people from communities such as your own have any preference in terms of information that’s given to you that you either hear or you see, you know, like something on the television for example, or a DVD, or information that’s more in paper format. A letter perhaps, or a leaflet, do you think people have any preferences in terms of how information’s given to them?

## G01BAM03

I don’t think so, because, like her husband, we were talking about. With her, they are so close, but she doesn’t know what he needs. Maybe he needs a man to talk to, a man to talk man to man. Sometimes it works like that, because you know, us African men are so, we regard the women as not being able to (unclear). She might not listen, he might not listen to her because she is the wife. If another person, a man calls to him, talk to him man to man, he will recover. They are talking as man to man. Women want to talk, they have women talk. Men do as well.

[00:59:26]

So what we need, like [unclear] we need training how we can talk to these people, help them before they get there, because you’re heading there as well. So, before we get there, let us save [unclear], because we could, if we got training like at AAF, if we got training, trained people to go to these people, we could [unclear]. Outreaching them, go and talk to them, sit with them, befriend them.

Befriending makes a lot of difference. [Unclear] you talk [unclear] and he sees you tomorrow, he remembers the rest of it, because you have shared jokes and drinking tea together… coffee together. Then you discuss things. You can watch tele together, comedy together and you are laughing. So we need this outreach to be one to one. Go to a person, support him in the way you know you can support, because being the support, if they have a person who is trained, not any person. Her, she can’t do [unclear]. We are stubborn, African men, we’re stubborn.

## Various

[Overtalking].

## G01BAM03

A woman would say [unclear] men say no.

## G01BAF02

Yes.

## G01BAM03

Medication? No! Are you eating? No! Then when she goes, he eats.

[Overtalking]

## G01BAF02

They think that we are patronizing, you know.

[01:01:12]

## G01BAF01

The men are very proud. I don’t know if it’s from Africa especially too. I agree something that was like you said… you said training… a special training people need for those who become old, like those old men, to agree, you need special training for that.

## UCLRA02

Okay, I mean that leads me nicely onto another question actually, which is about, you know, so there’s one issue around what kind of information you think people might like to receive, and what might help and support them to go forward and seek help, but also, we also interested in knowing where that… where you think it’s important that the information comes from. So obviously, is it G01BAM03? G01BAM03, you were just saying about how you feel it’s important for the information to come from someone like a GP or someone, you know, that knows something about that area. I mean, would you read a leaflet, for example, that came through your door, that wasn’t from your GP?

[01:02:08]

## G01BAM03

Okay, there are so many leaflets which come.

## UCLRA02

Okay, that’s a good point.

## G01BAF06

Pizza.

***G01BAM07***

It’s very difficult, okay, like in my case, I’m HIV positive, but they always have these pamphlets everywhere, go for test… for test, but rarely do you see people taking leaflets.

[01:02:27]

## UCLRA02

Okay, would you be more inclined to read a letter that came from your GP for example?

***G01BAM07***

Well, even letters from the GP. I feel it is a person to person talk… interaction like this, and you bring it as an awareness, okay. I think that would be good. Like the… those centres for dementia, something like that. The information was very fast, but leaflets are become like leaflets, you see, nobody will pick it and it would just… Some people say they want junk mail. They just throw it in the litter bin before even reading it, as long as it doesn’t concern their views, everything is useless to them. Such information is useless, apart from the bills.

## UCLRA02

Okay, thank you for that, that’s really interesting. Anyone else got any views on that? Sorry, in a minute we will come to you.

[01:03:17]

***G01BAM05***

Yes, I agree with what he’s saying, but sometimes there are a lot of people, you can’t always have one to one chats with a lot of people and the mail boxes have been kept for, to give out mails. We understand they are people who don’t want junk mails, there’s a lot of junk mails. Like I said earlier, most people of this country have access to doctors. Your doctors, actually challenge the doctors. Doctors, make sure you inform your patients. Let it be compulsory that your patients know where to get the available resources. Nurses should bear that in mind, GPs, because every human being in this country should have a GP. So GP should have access to what is vital information. Make sure, because your GP, we would say is the day to day management [unclear].

So your GP, even when your doctor in the hospital, but your GP, is your general practitioner who takes care of everything about you, so therefore the GP is… your information should go on to the GPs so that even if you don’t want letters to come to your house, you have a GP. As soon as you listen to your GP, definitely GP will, even if you don’t ask for that information, GP will definitely put it in front of you and say, look, take this leaflet, take it home and read it, you might need it, if not now, or somebody in your future.

## UCLRA02

Okay, thank you very much for that. I think we’ll come round here.

[01:04:46]

***G01BAF06***

For me, these people like dementia, they can’t concentrate. I feel they’ve got a problem to concentrate, they forget. How can they concentrate on reading? For me, I think the leaflet even the GP did…[interrupted].

## G01BAM05

That is you.

## UCLRA02

Can you hold on one second, sorry, we’ll work our way around, I’m sorry.

***G01BAF06***

This is myself, I’m thinking, it’s difficult for them to be concentrating and reading, the leaflet, they might well forget. They… for me it’s not… it’s a group place, people to visit them, organisation like this maybe in a workshop, that would be good, but the leaflet, they may bring the leaflet, but they will forget to read them, they not even finish, because they got a mental problem.

[01:05:31]

## UCLRA02

All right, thank you very much.

## G01BAF08

And in addition to what he has said about maybe from the GP or whatever, I think the government should make it compulsory that when a person reaches to such an age, like 70 and above, they should be actually, you know, be assessed for maybe dementia and get the help if they need. If it is like that, then I think everybody, because… will be given an appointment to be assessed and then if they’re trying to be, you know, diagnosed, then they get, you know the help, because right now, my husband is 70, 70 what, 79 and he has never been assessed. So really, if it is compulsory, it is coming from the government and it’s actually documented and, you know, put into whatever, then it will be, you know, it’ll… that’s the best way of, you know, helping and reaching people… a lot of people.

## UCLRA02

So you’re saying that you think that people are more likely to listen and take notice of information that comes from somewhere like the government. Is that…?

[01:06:45]

## G01BAF08

Yes, if it is put there, then it has been made compulsory, you know, just like, you know, the screening the breast cancer for women and whatever, it is compulsory that at a certain age, every woman needs… should actually be, you know, going for that assessment, and everything, and if you don’t you receive a letter to remind you and whatever. So it should be done even for dementia as well.

## UCLRA02

That’s really interesting, thank you. Just a couple of other things that I’ve been thinking about. A couple of people have mentioned about how you think that for yourselves and maybe other people from communities that you live within, receiving information, somewhere like here, you know a community centre that you all attend and where you know people and things like that, and you were saying as well, about people being similar to yourself here. I mean, would you as a group, do you think at a centre such as this, watch a DVD for example, you know, if that contained information about memory problems.

[01:07:48]

## G01BAM05

Yes, that would be good. [Overtalking]. It would help train us.

(general agreement)

## G01BAF08

Yes, that would be good.

## UCLRA02

That would be good.

***G01BAM07***

[Overtalking] It would help to train us. It would help a lot of people in fact, because everybody’s there and you will discuss the same DVD, though some of them wouldn’t be attentive, but at least if you are in a group, somebody would say, I saw this and this is what happened.

So, I think even for me, it is a personal thing, touch, if you are in a group, like what some people have talked about, a dementia centre, you talked about it, which is somewhere. That is the best way to pass on this information. That’s when somebody realised here, that he or she, has dementia, so groups like this one’s are very important, because here we don’t have so much of families around us… and everybody’s busy, but if you have somewhere where you can interact, like dancing groups, I’ve seen such things, the information can move very fast.

[01:08:56]

## UCLRA02

Okay, that’s really interesting, thank you.

## G01BAF04

A project for the elderly, like you said, so then they assess them.

## G01BAM07

Day centre.

## G01BAF01

A special project like at AAF, like a project for elderly people for around this age, so that they can assess them when they are talking, they understand.

[01:09:15]

## UCLRA02

Okay, that actually leads me to another good point. I am slightly conscious of the time, because we have run over our hour. Some of you might need to leave, so I will try to wrap it up fairly quickly. Just two points, kind of in relation to what you’ve said. One is, you’re talking about, you know, elderly people there, one of the other things we’d be interested to know is, who do you think, if we were going to be giving awareness raising information, you know information to be able to support people to seek help earlier, who should that information be targeted at in terms of age groups? Should that… should that information be targeted at everybody in these communities, or particular age groups?

## G01BAM07

Everyone, because [overtalking]

## G01BAF08

Everybody, so they can know.

## G01BAF06

Everybody, because some got a long [unclear] disease the side effect can get early dementia.

[01:10:08]

***G01BAF04***

I think it’s good for everybody.

## UCLRA02

That’s great, thank you.

## G01BAF08

And in addition, everybody, also because you also get, when you’re helping somebody else, so really, it’s very important that everybody, whether or not you’re (unclear), but you can also get information to help somebody, so really, everybody should be included.

## UCLRA02

Okay, that’s great thank you. Just one last thing, going back to the DVD that you know, just using it as an example, you said that you would watch somewhere like here. I was just wondering, you spoke earlier G01BAM03…

[01:10:37]

## G01BAM05

G01BAM05.

## UCLRA02

G01BAM05, sorry, about you thought that information that’s given to people in a kind of comical sort of fashion, you know, was something you thought people would be interested in seeing. I just wondered if other people had any thoughts around how the information should be presented on a DVD, you know, should it be information that’s given in a kind of drama or play type way, or should that… should it be more directive, coming from a doctor for example? Does anyone have any thoughts around how the information…?

## G01BAM03

Comical to know, I’ve seen some comical about blind people which don’t work, which feel we’re victimising them because of their disease. So we should be very careful when we go in that direction.

## UCLRA02

Okay, anyone else, any other thoughts?

[01:11:26]

## G01BAM05

And I think being comical stuff is, you know, there are things you watch, even if you’re dementia, even if you’re not, you don’t remember things, there’s something you watch, when you see it you smile or laugh it comes into your memory, it stays there, you want to see it on again, not in an abusive way, but in a way that will respect that person for some time; when the person sees it and that person wants to go back, you know, to go back and really watch, so I think in this part of the world, everything is done to respect the person, it’s an important issue. So in that way, definitely they receive joy in it and willing to actually go for a regular service.

## UCLRA02

Okay, thank you, anyone else, just finally [overtalking].

## G01BAM03

I think features of [unclear] was doing like a movie, this was really, like, it’s very easy to forget that movie, when you say [unclear]. Dr [unclear], he does whatever you see from him, [unclear] very keen at that, [unclear].

[01:12:48]

## UCLRA02

Okay, so you’re saying the information…

## G01BAM03

That’s right, yes, it goes wherever, because you see something that you never forget.

## UCLRA02

Sure, so you, just correct me if I’m wrong, you’re saying that the information needs to be, one, memorable.

## G01BAM03

Yes, memorable, even those that are forgetting, there might be something there to stick to their brains, because if I were to look at that picture and remember to place me [unclear], later, the one I hate most, to stick here so that’s something for you to remember. [Unclear] movies now, talks.

## UCLRA02

Okay, thank you.

[01:13:29]

## G01BAF02

And I think, for me, plays I think.

## UCLRA02

Sorry, say that again.

## G01BAF02

Do some plays I think, or drama.

## UCLRA02

Or drama, okay, so you feel that you’d rather watch that than a doctor or someone else just giving information on a video.

[01:13:46]

## G01BAF02

Change (unclear), that’s how I like to view like this (unclear). So you think you are like this, so someone you are watching, you go, oh, maybe I’m like that, [unclear], maybe I’m like that.

## UCLRA02

Okay, so it’s important for you to be able to relate to people in the video?

## G01BAM05

I think ask questions, you show them on the TV, in a comical way, where somebody, two people starts to try to demonstrate forgetting the key, you know, try to demonstrate she forgot her key, you know, that type of things, so, it makes the person thinks, oh that person forgets the key? And this person, you know, it keeps… it makes the person wants to watch that particular programme.

## UCLRA02

Okay, thank you ever so much. Is there anyone else that… you know, thank you so much for sharing all of that information, it’s really, really interesting. Just before we sort of wrap up with a few kind of house keeping things at the end, UCLRA01 may have some more questions that he wants to expand on.

## UCLRA01

Just one quick question from me, when we were talking about making assessment compulsory for dementia or something like that, you said make it compulsory, should come from the government, would you think a letter or anything coming, maybe not from the government as such, but the NHS, which is part of the government. Would you read the letter from the NHS?

[01:15:12]

## G01BAF02

Yes.

## G01BAF01

Yes.

## UCLRA01

If it said the NHS [general agreement]

## G01BAM07

I’d always know it was very important.

## G01BAF01

[Overtalking] something to do with health.

[01:15:21]

## UCLRA01

So the logo NHS would encourage you to read the papers and maybe do something about it.

## G01BAF06

Yes.

## UCLRA01

Okay.

## G01BAF08

And again, to pick that one, you know, even my husband’s so keen on that one. Everytime… [Overtalking].

## G01BAM05

[Overtalking].

[01:15:45]

## G01BAF06

Myself, if I forget an appointment, they will send me a text, they will send me a letter at my house and just where I have to go, because the GP and they text me from the hospital.

## UCLRA01

Thank you, thanks very much indeed, that’s good.

## UCLRA02

Thank you very much again for taking part to day. It’s been an absolute pleasure meeting you all and hearing all of what you’ve got to say, it’s been really wonderful. Just a couple of things, kind of, to finish up with now, is one of the things, we’ve brought some information with us, and if you know of anyone else, you know, from the communities that you’re part of, who you feel might be interested in taking part in the research that we’re conducting, we’ve got some information sheets with us, which we can certainly leave you some copies with.

[01:16:33]

We’ve got some envelopes and some stamps with us, so if you’ve got people who you’d like to post them to, you know, that’s fine, and you’d just like to give them in person, that’s equally okay. So that’s either other community groups and organisations that you may know of, or you might be part of, or individuals, you know, just individual people who you think might have an interest in this, as well as running the groups, we are also able to conduct some one on one interviews with people. So perhaps, you know, groups aren’t always a setting that everyone likes to be in, so if there were individuals that, you know, would like to do that outside of the group, then that’s certainly an option, and then, just a couple of other bits.

If you don’t mind waiting around just for a minute, when we finish, we have got some vouchers with us which we’d like to offer to each of you and that’s really just as a thank you for taking part in this today. We really do appreciate your time and everything that you contribute. Secondly, to that, I know some of you have travelled, you know, a distance to get here today. We are able to reimburse your travel expenses if you’d like to do so. We’ve got some stamped addressed envelopes with us, with a form in there that you need to complete and attach various receipts and things like that, but if you’d like to do that we can speak to about that individually at the end.

And last of all, it’s just about taking some contact details, some personal contact details from you. Now this is obviously entirely optional, you don’t have to, but one of the things that we’d be keen to do, if you were happy to do this, was to give us some feedback about any leaflets or any information videos that we might be producing as a result of the work that we’re doing on this project. And you know, we’re obviously wanted to develop these in the future, and we’d be keen for you individually, to take a look at these for us and give us your feedback and opinions as to what we’ve created. So if you’re interested in doing that, then we can write down your names and your details and we can get in touch in the future.

Okay, does that sound all right for everyone? Does anyone have any questions before we do, sort of, eventually finish?

[01:18:24]

## UCLRA01

I’d just like to add to this that if you do want to read the transcription of this meeting, you can after, because we can actually… we’re going to transcribe the entire group session and if you like, we’ll send it back to you. If you agree to make comments, if you like, with changes and send it back to us.

## G01BAF02

Yes

## G01BAF06

Okay, that’s fine.

## G01BAF02

How will you send it? By emails, or…?

[01:18:54]

## UCLRA01

We can do it by email or address [unclear], okay.

## UCLRA02

Yes, we’ll come round now and we can speak about those bits and pieces. Okay, thank you again.

## G01BAM05

Thank you very much.

## G01BAF01

Thank you.