**G05**

**Speaker key**

UCLRA01

UCLRA02

G05BAF26

G05BAF27

G05BAM24

G05BAF29

G05BAF25

G05BAM28

## UCLRA01

Yes, well, thank you very much for coming, very kind of you, and giving us some of your time for our focus group. So, as you know, we are researchers from University College London and we’re going to record the group today. So, everything you say is confidential but for the purpose of the typist who’s going to transcribe the discussion, we would like you to say your name first. So, I’ll start with myself, I’m UCLRA01, working for UCL.

0:00:36.2

## G05BAF26

And I’m G05BAF26 and I work here at AF.

## G05BAF27

I’m G05BAF27 and I work for AF.

## G05BAM24

G05BAM24, working here at AF.

## G05BAF29

G05BAF29.

0:00:44.3

## G05BAF25

G05BAF25, working at AF.

## G05BAM28

G05BAM28, a service user.

## UCLRA01

Thank you very much.

## UCLRA02

I’m UCLRA02, I work at UCL.

## UCLRA01

Excellent, thank you very much. Now, as you know, we are interested in how people from the black African and Caribbean, in particular, think about memory. Particularly when they’re getting old and what we can do to help. So, to start the discussion, what we’ll do… I’ll give you the case of a lady. Now, it’s a lady called Mrs Abraham, she’s 70 years old, and her family members have noticed that she’s more forgetful lately. She cannot remember conversations with people and forgets appointments with doctors. She often misplaces important items like her keys and glasses. She’s physically healthy but is concerned about her memory. Now, obviously people usually forget things; that happens to everyone, but if you knew somebody like Mrs Abraham, you know, she’s healthy… she’s in good health, but she keeps forgetting things, she forgets important things like her keys, appointment with doctors. Do you think that she should look for help for her memory problem?

0:02:12.4

## G05BAM24

It depends on how severe the forgetting is or how frequent it occurs.

## G05BAM28

How frequent it’s coming.

## G05BAM24

I think you might have to understand… I mean, obviously for somebody to be able to comment or to take action on that would depend on how long they have known her and how severe they think her situation has gotten.

## G05BAF29

Well, you said see the doctor isn’t it?

## G05BAM24

What, help…?

## G05BAF29

Seek help or she needs to see…

## 0:02:47.2

## UCLRA01

Well, do you think she should look for help and… what first? Or should you…?

## G05BAF29

I think so; it’s good to rule out anything. It would be nice to seek for help, it could be just stress, it could be managed by you know, supported, something like that. I mean, seeking support is key; however, as the condition might be just too large that, you know, it is just part of life, and then an illness… or a real sort of an illness.

## UCLRA01

Okay, yes, sure.

## G05BAM28

I don’t know, we… your research… your researcher is… you are saying that you’re researching amongst black people, African… Afro Caribbean’s, but…

0:03:30.3

## UCLRA01

Yes.

## G05BAM28

If I go back to where I was born, you see, dementia, we don’t do dementia in our communities. Whereas, people live here a lot…

## G05BAF27

They’re around families.

## G05BAM28

It’s a friendly place, you don’t find an old man living on his own like what you find lives here. So, I mean, if someone develops this, kind of, maybe… Should it happen, usually there’s people around to seek remedial. Him or herself cannot go and seek help on his own… or themself. People are there and they find, oh and he seems to be forgetting, what should we do in order to help him? He cannot help himself or herself maybe at an age of 70, he’s always looked after. People, they don’t send you into a home, they look after… African people, they look after their own, they don’t send people to a home. You see, so it becomes a remedial in a friendly context.

## G05BAF29

So, should they seek help on [unclear]?

0:04:37.1

## G05BAM28

They can seek help if they cannot… if they cannot assist.

## G05BAF29

Yes, assist anymore.

## G05BAM28

They can seek help.

## UCLRA01

Okay, but you are talking about whether… if they had dementia, right?

## G05BAM28

If they are developing dementia or forgetting things.

0:04:53.0

## UCLRA01

Okay, what if somebody’s just forgetting things? Because usually you get a diagnostic of dementia only when you go and see the doctor. And, like I say, you do not know that you have dementia, you’re at home, or somebody you know and they’re frequently forgetting important matters. Do you think they should actually look for help?

## G05BAM24

Well, my question is… I mean, it’s also a challenge in that it depends on what kind of medical profession they seek. Of course there’s this tendency to, kind of, push… you go through the door and just… you go to a doctor with a concern and they, kind of, play it down and say, oh maybe you just need to do this. Actually, you find that the people who might actually take interest in such patients would be churches that are working among dementia because then they, kind of, take it as a priority. But the way the pressures of the healthcare services are having… I mean, experiencing now, with the GPs who are quite… you know, have this mind set that won’t be [overtalking], old people have nothing, I mean, well, they have too much time on their hands and that’s your problem. You find that, you know, the question is how useful would that be if it’s not already diagnosed? Because if I say I’m just forgetting… I mean, if I go to the doctor and I say, you know, I keep forgetting things, they’ll say, oh it will get better, you know, maybe just… you need to keep [overtalking].

## G05BAF29

Stress.

## G05BAM24

Yes, but, you know, so that’s the question, that’s what I was saying, that it needs to know, initially, how serious it is because there is a tendency for the healthcare professionals to play the issue down and say, you know, you’ll be all right, unless it becomes very serious.

0:06:25.0

## G05BAM28

But definitely help; you should seek help if you’ve got a problem. If something is happening that you never used to do, and you’ve started doing it, you need help. And the earlier you… even people with their own illness, or my illness that I have, if I don’t seek help early enough, it’s detrimental to me. If I seek earlier treatment, it’s better for me. You see the earlier you pick up a problem… it’s just like a headache, if you’re headache’s hurting you would start taking your painkillers.

## G05BAF27

When it persists.

## G05BAM28

But if you’re if you’re waiting for until you really feel the pain, to bring that pain down, it takes longer.

0:07:07.1

## G05BAM24

Certainly, I mean, but, again, my original point… it just depends on what you know, because not this… not this [unclear] here, but right now people are very empowered to actually maybe go on the Internet and try to research, why am I forgetting? No, but the thing is, to be able to take action about something like that, you need to know what to expect. So, if there’s no awareness or if you don’t know at all that forgetting things actually isn’t… is not normal. You know, if, for example, you’ve started forgetting frequently and it wasn’t happening before. For you to come to the realisation that that in itself is an actual problem, you need to have some levels of awareness. Or else, you know, you just, kind of, take it as one of those issues of growing old, because from where I come from there’s no definition of dementia, you know, it’s not there. So, if, for example, an old person is starting to forget, they take that as part of growing old.

## G05BAM28

He’s getting old.

## G05BAM24

And what Obe was saying about, I mean, a, kind of, setting of family and a family kind of set up, is that, you know, some of those issues are addressed within that context of an extended family. So, for example, if an old person is forgetting a lot, then they have to remind them, oh you were supposed to do this, oh you were supposed to do that. Because that help is readily there, the impact is not fair. So, what I was trying to say, in short, is just that the most important thing obviously for someone to know that they need to see a doctor is for them to go, my father has a problem and I expect that might be an issue. But if you don’t even know that that problem is there, you probably might not be able to make it a… see it as a priority.

0:08:45.6

## UCLRA01

Okay, thank you very much, one question though. So, what kind of forgetfulness would actually make you go and see someone? Because you’re saying you’re not too sure, it depends on the severity, and you say, we should go. But what kind of forgetfulness would actually make you take the decision to go and see someone?

## G05BAM24

Personally, I think it would… and I still go with this… obviously because you’re talking about this issue being specific. I mean, the, kind of, research you’re doing is with regards to the African and African Caribbean. I’m talking like an African…

## UCLRA01

Absolutely.

0:09:17.5

## G05BAM24

Yes, who’d say that there are so many problems that they already face… people face here, whether it’s in Africa or here, even if they migrated here. And it tends to be issues to do with poverty, poor housing, you know, lack of proper services. And something as little as forgetting is not going to be a priority for somebody. So, I would be concerned about whether they are going to sleep hungry, whether they have heating in their house. So, it has to be really serious forgetting, and for them to comment that they’re forgetting, that must be some… I mean, in most cases the African and black people tend to have the extended family, so it, kind of, plays down the impact. I suppose to a white person who’s living alone in their house, who is quite [unclear] with their health, or has been in this system for long, who’s had heard about dementia ever since they were young, their reactions would be different to somebody who has come from a completely different background [overtalking].

## G05BAM28

But most of things that you forget… most things that you tend to forget you start to forget even for a normal, healthy person, yes. Keys: home keys, car keys, these were some [unclear and overtalking] where are the keys? Where’s my keys? Where is your phone? Your phone… this is… These are basic things, that’s the way it starts the day, every time I leave; where’s my keys? Next time… but not when it gets to you forget your home address passing through where you live, it’s getting serious, isn’t it? Even eating habits, forgetting to eat until you collapse and… The people that don’t even think about… I mean, eating, forgetting to eat at the right times.

## G05BAM24

The question… the question is, what kind of level of severity would a… I mean, sort of, kind of…

0:11:06.3

## G05BAF29

What he’s describing is that if you pass your address, you’ve gone past your home, then you need to seek help really.

## G05BAF25

That’s what he’s saying. Every time you…

## G05BAF29

Not like, if you forget keys, it’s normal, you can forget keys.

## G05BAM28

Keys, yes.

0:11:19.1

## G05BAF29

But if you forget where you’re living then it’s severe, isn’t it?

## G05BAM28

Yes.

## G05BAM24

Yes.

## G05BAF29

But then maybe it’s…

## G05BAM28

Appointments… doctors appointments.

## G05BAF29

That could be because of a busy schedule. I forget appointments.

## G05BAM28

What your prescription? How about prescription?

## G05BAM24

Forgetting…

## G05BAF26

Forgetting people’s names [overtalking].

0:11:43.2

## G05BAF25

Not recognising family members.

## G05BAF26

Names, yes.

## G05BAF29

Do you remember people’s names every time?

## G05BAF26

No, but your close members, like nothing…

## G05BAF29

Okay.

## G05BAF26

If I come one day and I don’t know who you mean, or forgot maybe, that would be…

0:11:58.7

## G05BAM28

Certain people. You’re not forgetting…

## G05BAF26

Something is wrong. Close people, relatives, and you forget their names.

## G05BAF29

You’re right.

## G05BAM24

But in your society and the kind of areas that you work in, for example, [unclear] what would you term a situation about somebody’s forgetting? Because they’re taking something… Is there awareness as to… that it might actually be a specific problem or condition, or do they just take is as one of those things?

## G05BAF27

It depends on the age of the person. If it’s an old person I don’t think many people would recognise these issues or any memory problems.

## G05BAM28

But don’t [unclear] age.

## G05BAF27

That’s an old age issue but if the person is young and under 60…

0:12:39.7

## G05BAM28

Young.

## G05BAF29

Then I think, yes, I think they might think that something is wrong here and seek help.

## UCLRA01

Thank you.

## UCLRA02

Do you…? Sorry, I’ll just jump in. Would you say then there is a lack of awareness around memory problems and dementia per se within the black African and Caribbean community?

(overtalking)

0:12:54.5

## G05BAM28

We don’t know, it’s not so there in our communities.

## G05BAF29

Because you have to understand what is it? Like they’re saying it could repeated that… it’s just, ah he’s old, but if even people who support [inaudible]. Sorry my throat.

## UCLRA02

We can come back to that [unclear].

## UCLRA01

We…

## G05BAF25

I could give you one example.

## UCLRA01

Yes.

0:13:36.1

## G05BAF25

Since I’ve come here I’ve learned a lot about dementia. Like, my mother, she was starting to get forgetful. She would leave something on the stove, it would burn or it would [unclear] or the stove would go over all the… little things like that. And my sisters were telling me, oh I think mother… my mum… your mum is, kind of, so forgetful. I told them, why don’t you go and take her to the doctor to check if she has dementia. And they were, like, what, no, she’s just old. And I think that’s what you’re trying to say, like, if you’re from certain communities, if you’re age… If you’re an old person we don’t know that much about dementia, we just know this person is old and needs extra support, and that’s it. And that’s the way we sort it out, we don’t…

## G05BAM28

You definitely need to… big awareness for the…

## G05BAF25

Yes.

## G05BAM28

What we’re trying to say is that the way we understand it in this set up.

## G05BAF25

And every community has a different meaning.

0:14:24.9

## G05BAM28

Yes, we need to pick awareness... pick an awareness programme.

## UCLRA01

Well, the thing is you guys are thinking about dementia but I’m not particularly thinking about dementia itself…

## G05BAF29

You’re thinking about forgetfulness.

## G05BAM28

Forgetfulness.

## UCLRA01

That’s correct. The later we’re talking about because before you get diagnosed with dementia you would need to go and see a doctor. So, whether you’re not aware or not, we’re trying to find out at which point somebody’s forgetting things that would make them actually start to go and see anyone else. Whether they’re going to see their family or their doctors, and who they would go and see. I mean, you don’t know yet… let’s say you don’t know about dementia and you don’t know that you have dementia when you’re forgetting things. What would actually make you decide, okay, at this point, I need to go and see someone?

0:15:17.9

## G05BAM28

No, I don’t think there’s anything that would… that would…

## G05BAF29

They’ve just lost…

## G05BAM28

Yes, that’s just normal, it’s [overtalking].

## G05BAF29

This is the discussion, if you’re young and you’re forgetting… people around you are noticing you’re forgetting, then, you’d think, maybe. But if an old person living here within the communities that we live in… we just say, you’re getting old; you just need extra support. But for you to go in and see a doctor because you’re forgetting, it’s not… it’s not in our system, I don’t know how it gets [overtalking].

## G05BAM28

I’ve never heard an African boy or an African girl saying, I’m going to see the doctor because I’m forgetting things.

0:15:50.8

## G05BAF29

Forgetting things, yes.

## G05BAM28

I’ve never… I’ve never heard of it.

## UCLRA01

Good to know, really. That’s good, okay. Now, let’s say that… I mean, you said you might not go and see the doctor, let’s say you decide, okay, at this point it is really bad and I forgot to pick up my daughter, or, you know, I forgot the cooking on the fire… cooking and burning the house down. Who would you go and see first? Would you go and see, I don’t know, your GP, a family member, a friend?

## G05BAM28

I’d go and see…

## G05BAF27

I would say a family member.

0:16:25.6

## G05BAF27

Confide in the relevant person, yes. For me it’s… I can speak English so it’s easy, but for a person who doesn’t speak English I think it would be hard for them to talk. Instead of going to the doctors, I think they’d find it more easier to talk to a family member and then take it from there.

## UCLRA01

Thank you.

## G05BAF27

Some people prefer to be prayed for.

## UCLRA01

Okay.

## G05BAF27

Those who believe in, prayer can heal.

0:16:54.6

## G05BAF29

That’s a good act for… prayers are good, for example you might find a group of friends fasting on their behalf to pray for something to go away or for, of course, to heal the person. So, literally, they know there’s something wrong but the steps taken are different to address that particular issue. And also the belief that the person will get better can also override the fact that I need to go and see the doctor. So, you know, there are different ways of approaching and you… because, for example, I can use myself as an example now. I used to have a lot of telephone numbers in my mind. Somebody gave me their mobile number, I read it and tomorrow I know it all. I could meet people that I know today, you know, this is UCLRA01. You know, because now that I’ve seen you more than once I get your name quite well, but if I see a person once then the person meeting me they remember me quite well. And in my head I’m scratching, who is this? You have to try your best and be very nice but you don’t remember. And you’re afraid of asking, where did you…? Who are you? Where did I meet you? Because a person is only turning around and I think sometimes you need, you know, to get that. And you’ve forgotten them. So… and it starts to worry you, so where is this going? Is it stress? Is it another indication of something? You know, it’s… I think… I don’t know, it’s… but I have never thought of saying maybe go and see my GP about it; maybe I should.

## G05BAM24

Now, what are you reaching out for?

(laughter and overtalking)

## G05BAM28

Maybe I’ll start from… I’ll start with my partner… I’ll start with my partner. It’s a long question; maybe I spend most of my time with my partner. So, I tell him, ay, make sure that I don’t forget everything… I’m forgetting things. Then, you find that because the doctors, here GP, maybe because of who I am, I’ve got no faith in GPs here, but, I guess, if I need Paracetemol or…

## G05BAF29

Painkiller.

0:19:00.4

## G05BAM28

Or painkiller, it ought to be… it ought to be… Because when I visit my GP, he’s on the laptop, he’s not looking at me, he cannot… he doesn’t ask me any questions, and then he says, I’ll give you these tablets… these tablets, give it a try. But the more I… explain more this to the GP, he’ll say, first you must try that and then after two weeks…

## G05BAF29

You come back.

## G05BAM28

You come back.

0:19:26.4

## G05BAM24

There’s a feeling… there’s always that feeling that going to a GP is a waste of time.

## G05BAM28

It’s a waste of time.

## G05BAM24

Really.

## G05BAM28

Instead of a GP, you can go to the psychologist if it’s really… if it’s really concerning them, or to someone who deals with the use of mind. You know, behaviour is… there are principals, you know, what I mean. But GPs are useless persons here. Highly paid but very useless, honestly.

## G05BAM24

Oh, yes, we can often find out who is there to [overtalking] just, like, make them forget.

## G05BAM28

Which one of the girls for you [unclear].

0:19:52.8

## G05BAF29

I don’t imagine there’s any competition.

## G05BAF25

I think with the African communities, if you look at the African communities in Africa, for example, the healthcare system is not free. So, for us it’s like, you wait until you’re almost dying to go and see a doctor. So, I think that counts, you’re old…

## G05BAF29

Mentality.

## G05BAF25

I don’t need to see the doctor until I have to, I’ll wait, maybe when I’m properly sick and dying, then that’s when I’ll go. I think it’s followed us even here, so we don’t have that urgency of going to see the doctor unless you’re really really sick. And I think that’s why there’s delay… we delay in finding out so many issues about… yes, health issues about… you know, it can be anything, diabetes or whatever. We take longer to respond to it because of where we’ve come from. We have easy access to the doctor, so is this really an important issue? Is this something really important to me to go and see the GP? It’s going to take time to…

0:20:52.3

## G05BAM28

I’ll still go back to your question where you say we need more awareness, because in this age of digital ways there are other means. Education plays a big part. In most of the older people… older generation, they’re not as likely to go to Google what their problem is and find a solution to that. Unless, if we had a community programme that brings awareness to black people, you know, because my father cannot go and type in Google that he’s forgetting all the… you know. So, awareness programmes will play a big part in…

## UCLRA01

Will play a big part?

## G05BAM28

Yes.

## UCLRA01

Thank you. So, you said that… you mentioned the health system in Africa.

## G05BAF25

Mm hmm.

## UCLRA01

We discussed with some people and some people said, if you do have a memory problem to deal with, it’s usually better to be back home whether in Africa or in the Caribbean, only because they know it’s actually [unclear] being here. What do you think about that?

0:21:58.5

## G05BAM24

You mean like older people going back if they’re having…?

## UCLRA01

No, some people said, having to deal with a memory problem, it’s better if you’re at home… back home, you know, in Africa. Other said, no, they prefer being in this country for whatever reason. What are your feelings?

## G05BAF25

No, I personally… I think it’s much better if you having memory problems - severe ones - it would be better back home. As you said, there’s support back home… family support networks back home, because, like, there is always somebody who is going to take care of that elderly person, always somebody assigned. But here, everybody is for yourself. I mean, if your children… like, for example, if I had children and they’ve all grown up, gone from their own homes and…

0:22:39.0

## G05BAF29

They’ve got their own lives.

## G05BAF25

Old people live by themselves in their homes.

## G05BAF27

Exactly.

## G05BAF25

So, if you have a memory problem and you don’t have… Unless you have an assigned support or [unclear], which I don’t think they do it for hours, maybe two or three hours a day or something, you will have a very rough time if you’re here in the UK.

## G05BAM28

It’s a shame really because most of these community centres, they’re being closed for other places, you see. Old people they used to go out and play bingo and everything, practice their memory now. But all these centres now, they’re getting closed. So, if you live on your own you’re bound to suffer. So, it’s, sort of, a matter of, are we better off living in Africa or here? But it depends… it depends whether… am I connected with this society for me to… Because forgetfulness also depends with society behaviour that surrounds you, you see, social behaviour. Also, if you remain too secluded… individualistic most of the time, you will tend… you might tend to be your own mind, you become secluded from many things in life.

0:23:38.7

## UCLRA01

Thank you.

## G05BAF26

But I think another reason why people are…

## G05BAF27

You were speaking, sorry.

## UCLRA01

No, that’s okay, thank you.

0:23:44.4

## G05BAF26

Yes, the other reason why people would recommend for someone to go back is the atmosphere because… I don’t know why but I do think the environment, not just the people but the climate and so on, has a way that also affects our thinking. For example if you’re in Switzerland and it’s winter, you are more likely to deteriorate, but, whereas when they, say, go back to Africa, it’s always, oh the Caribbean is always sunny. And I go with the thinking that the sun also contributes to the make up of the person and how they respond to particular elements in their bodies; I would think so as well.

## G05BAM28

Vitamin D… vitamin D

## G05BAF27

I think it depends on the age of the person. If it’s a younger person they’ll probably want to stay here, but if it’s an old person they would say, I would like to go back home and for that, I’m basing it on my family. The younger generation would want to live here because of their knowledge of the system in the UK and what they can access. But all those people that came here after they were 50, so all they’ve know all their life is back home and they don’t fit in here well. So, if anything happens they’ll think it’s better to do it back home rather than live here. But that also brings understanding of memory problems to people who they are with and how they… the support that they can give you. So, if a person with a memory issue was to go back home, their relatives… what do they know about memory problems, almost less than zero. So, that person would face maybe stigmatisation or things like that, yes.

0:25:41.7

## G05BAF29

Well, I think it’s a double-edged sword really; it’s a double-edged sword.

## G05BAF27

Yes.

## G05BAF29

Because you’re a visitor there and you’re a visitor here.

## G05BAF26

Yes, certainly, yes.

## G05BAF29

It’s very complicated.

## G05BAF26

It is.

## UCLRA01

Could you expand a little bit more on that?

0:25:53.2

## G05BAF29

What I’m saying, when we… in this country when you come as an adult here you always feel you don’t belong. I guess, you dream about wherever you came from, and you’re always calling and seeing how they are. But when you reach there, they hear that you’re calling here your home. When you’re here, you’re calling Africa your home, but when you reach Africa you’re calling Britain your home. So, it’s… (laughter) yes, it’s…

## G05BAF27

Mixed up.

## G05BAF29

Yes, it’s a real mixed up generation of people and especially when there are things like war in their country of origin. Again, going back is more hazardous than remaining, but I still believe that a warmer climate is a benefit for us, especially as we age. I think so, yes.

## UCLRA01

Thank you, excellent.

0:26:52.0

## G05BAM28

And at the same time, I think this research is for you to really make a meaning… or to find the geographical set up of the city itself. Because, I guess, then, these are two worlds; Africa and here are two different worlds. Even the climate, like what you’re saying, it’s a different world. But here… forgetfulness here… the impact of forgetfulness here, how it would impact on African men would be different from the way it would… it would occur in Africa. You see, so we’d have to identify exactly… or try to particularly just say that forgetfulness in the UK, if it affects us then it affects that. And then maybe make a comparison with if I was the same person living in Africa.

## UCLRA02

I think I know what you’re saying. Do you mind just giving an example, if possible, please?

## G05BAM28

Yes, if I’m giving… As an African man, yes, when I came here since 2001 what I did, the first thing was to find a job. And my routine… my routine is go to work, come home, cook, sleep, and eat. In Africa when I knock off I’ve got to meet my friends, maybe [unclear] we share, we talk music, until about nine o’clock then it’s… and then at night we sit, like, talk what we’re doing as a family. We discuss our problems and everything and then everyone goes to sleep. There’s time for… in Africa there’s time for everything.

## G05BAF26

Social, yes.

0:28:23.8

## G05BAM28

You see here, it’s… my time is my time. I’ve got time to wake up, go to work shift, come from shift, cook, eat and sleep. If I’ve got maybe a little bit of time I can watch a bit of news.

## G05BAF26

Because when you look at some issues, like, mental health… now dementia is a big one, of course, and dementia is also part of that. If you look at mental health, people who have lost their jobs for example, with mental (unclear). They are prone to developing mental health issues. But it wasn’t as you were waking up and going to work because there is something you’re looking towards and then you’re also meeting other people. But the isolation system here, and also… sometimes also if his theories are tied to something that we’re doing. So, here, you’re really knocked by many angles and not very many people listen to others here; people don’t, they don’t have the time to do that. Whereas in other countries, and not only in Africa, you know, and when you go to Italy, for example, there is communal settings, people sit and talk, whereas the system here, that is very…

## G05BAF25

It’s just you.

0:29:33.5

## G05BAF26

Yes.

## G05BAM28

I think psychologists… like the sociologists, like, maybe… that did conditioning, people like Pavlov, I mean, like [unclear] conditioning. We, we’re conditioned, we’re so [unclear]. We don’t have time to use our psycho; we’re conditioned, you know.

## UCLRA02

In England?

## G05BAM28

In England, yes, we’re conditioned. Wake up, go to work, come home, yes. You know, the system is very conditioned, as I said, what we do.

0:30:02.3

## G05BAM24

But I think it’s also one of the most unfriendly societies in the world,

## G05BAM28

England, yes.

## G05BAM24

Because, you know, the good thing… community, kind of, factor, is not there. I mean, it’s quite strange because you find if ever you go to churches, for example, where the whole population are… they are quite…

## G05BAF26

Friendly.

## G05BAM24

Friendly. As long as they know you in that type of setting, but if you go out there it’s quite risky because they are very scared of, you know, the way it is. So, I mean, you wouldn’t find an older person feeling very confident on the street and…

## G05BAM28

[Unclear].

0:30:02.3

## G05BAM24

Yes, [unclear]. So, people here are very unfriendly and I think some of the effects of mental health, depression, you know, unhappiness in life, is just the way this society is. People… I mean, there is a theory that Britain is multicultural, I don’t think that is really true, because multicultural means the opportunity for people being able to share characters, being happy to be… I think it’s quite a turnaround of society in that, you know, anyone can exist but I don’t think it’s…

## G05BAF26

A community.

## G05BAM24

It isn’t that kind of…

## G05BAM28

Yes, compared to the Netherlands.

## G05BAM24

I mean, it’s very sad.

## G05BAM28

As a black man, I enjoyed being in the Netherlands than being here. Do you understand?

0:31:12.5

## G05BAM24

But (unclear) the issue of awareness, because I know you’re talking about, you know, the various… I mean, the way, you know, that dementia here… I mean, forgetting the impact on somebody’s life here or elsewhere. I think the problem we have in this place is that regardless of powers in the services, if you cannot create awareness about the problem it’s very difficult. Because the only time somebody just talks about dementia is maybe when a relative has been diagnosed with dementia. Or there’s, you know, something about dementia, you know, maybe a programme on TV or some campaign. But in the real communities that you’re looking at, the African community and the Caribbean communities, we never get any sustained, kind of, programmes. Not even sustained but no initiatives within the communities that we work in or that we exist in that actually looks at just creating awareness around some of these long-term conditions.

Now, we… what normally has happened with mainstream charities is that they said, oh we want to run this programme for the Caribbean… African or African Caribbean communities. And then they employ a black person and then they expect that that black person in charge of that programme is going to, you know, deliver. So, you know, really that’s, sort of, looking to just tick boxes, and I think that the power… I mean, the most important thing is empowering people. So, if you have a programme like dementia, that’s a person with dementia. You need to find out first of all where are the right areas to go. So, there are charities, you know, [unclear] who could actually talk about dementia there. Charities that are for these communities that can talk, and the mistake people make is that they look at Africa as a homogenous, kind of, society, and if we have Africans who speak Portuguese...

0:33:09.6

## G05BAF27

And the Caribbean’s, it’s the same thing.

## G05BAM24

And Caribbean’s, we’ve got Caribbean’s who speak French, who speak English and they’re from different places. So, when they talk about services for the African and Caribbean communities, they look very much as one with very same behaviours, but people are different.

## UCLRA01

A very good point, which she’s probably going to touch on in a minute. UCLRA02, keep that in mind. One question, which I’m going to ask you, one final question, we talked about… lets see, we talked about not going to see the GP, but going to see a family member when you have a memory problem. How…? Let’s say, which… let’s say… how do I ask that question? If you discuss, let’s say, your memory problem with a family member and they advise you to go and see someone. Would that stimulate you to go and see your GP? I mean, if you discussed your memory problem with a close friend, a family… a partner, would that make you look for help… external help? I’m talking about GPs or a specialist or hospital.

0:34:26.5

## G05BAM28

In a fair world… in a fair world, if someone tells you that you’ve got a problem, please try and look for help, it’s good advice, you know. But, also… we also suffer from, you know, what you call self-denial. If someone tends to forget… they’re forgetting things, you really… you might say, no no no, I’m not forgetting things. You know, they’ll say, he’s picking on me about me something, you know, and can get angry. I could get angry for someone telling me that I forget things, you know so I can… denial will be a great thing. But if someone that you trust, that said if I trust my partner, if I trust my brother or my sister telling me that I’m forgetting things, it’s going to… and see… so, maybe they might help you. You know, in a world like this… in a western world like this where education and everything is at a high level, it should be possible for you to seek help. But in Africa they think they’re problems.

## G05BAF26

Even here… even here, because I remember my thirty-year-old son then, he told me what I was forgetting, when I go out. So, just as I’ve forgotten my keys [unclear] he said, old age. He said, oh you have old age, so I said… and I said, are you calling me old? He said, yes. So, it’s the same thing, yes, if you start on a person usually they are going to be. Yes, you know.

## G05BAM28

But when I’m forgetting to [overtalking]

0:35:59.0

## G05BAF26

But when it was my own son, I didn’t take it very seriously, but if a man on the street told me, you know, it’s because of old age.

## G05BAM24

So, we should stop this joke of old age then?

## G05BAF26

No, it’s not that, but what we are saying in this context is…

## G05BAM28

I wonder if we should forget it and throw it away.

## G05BAF26

No, the thing is if you just start on a person, unless they’re very close to you, if they explain, because I’ve seen it with the other studies that we have done. Is it better to say, would you like to someone to accompany you?

0:36:26.5

## G05BAF27

Exactly.

## G05BAF26

You know, to go and see and doctor. Yes, for how long has it been happening? Can I come with you? Do you mind? Then they feel supported, but at the same time they are this close to you and then you’ve understood. But, yes, to say, I think it’s high time you went to see a doctor, sometimes they can help, the professionals, is the wrong approach.

## G05BAM28

You’ve got to approach your present issue.

## G05BAF26

Yes, and then they can say, oh don’t worry; I’ll go myself. Yes, so, you know, it’s the way we approach things.

## G05BAM28

For people like us it’s easier because we also do… we deal with advocacy.

## G05BAF26

Yes.

0:37:03.0

## G05BAM28

Like, you see, it’s part of advocacy. I can advise someone without making a choice for him, that’s the job of an advocate, and I can give him opportunities and tell him, you know, wait and go and everything but the choice is yours. But in a normal set up where people don’t do what we do, volunteer work and everything and help other people could be a bit more difficult. You have to start from somewhere because if there’s no awareness…

## G05BAF26

Well, that’s why if you have information in front of you it’s good.

## UCLRA01

Okay, so…

## G05BAF26

If you present it in a generalised way.

0:37:34.3

## UCLRA01

If you do have the information and a family member… one of your family members tells you, you should go and see a doctor. So, would you or would you not go?

## G05BAM24

Yes, I think I would, personally I would.

## G05BAF26

You would?

## G05BAM24

If I confided in my family member and they thought that I have… I mean, I might have a problem or they thought that I might have a problem. And I feel that… I mean, I’m just talking from… my own perspective obviously, but the first thing I would do is to research, but if no problem… if somebody recognise that I have this problem I would actually be [unclear] I would try and do some bit of research on the Internet or, I don’t know, what are they talking about?

## UCLRA01

That’s good, that’s your point of view, sure.

## G05BAM24

Yes, but I know that, you know, generally speaking, the people tend to have… the way that we’re set up, we tend to trust more somebody who actually is closer to you than someone who’s not. And it’s maybe better… it might be nice if there was a piece of… a leaflet or something to say, what I, kind of, think, you know, you might need to read this, but I think you have a problem and you might need to go and see the doctor. Then, yes, I would do that.

0:38:41.8

## G05BAF29

And also if you speak similar language, for example, you’re coming from the social perspective person other than… and also maybe a GP would still… you know, sometimes when you explain something to a GP, if they’re in their good days so they can listen, whereas [unclear] your friend at least you can listen.

## G05BAM24

I’d find it frustrating.

## G05BAF29

Yes, so…

## G05BAM28

In [unclear] we’re forgetting it can be a health hazard. As I said, you can kill people if you forget… if you forget to do things. You’re not even allowed to forget, if you’re forgetting… very disciplinarian [unclear], you get fired. Forgetting is usually a problem… it’s not allowed.

0:39:28.3

## G05BAF29

So, they take it more easy?

## G05BAM28

So, yes, I want to take you back to Dennis… what Dennis was saying, that there’s no awareness that comes with it. You see if you take a… let’s take, like, a cancer… cancer. How many adverts do you see on television about cancer in a single day?

## G05BAF27

Every day.

## G05BAM28

I think every hour there’s a cancer advert, but there’s no advert about forgetting.

## UCLRA02

That’s really interesting; thank you very much for sharing that. I’m just going to pause it there for a minute if that’s okay, just to move the conversation on a bit and then, you know, we can certainly pick that point back up again. So, building on what you’ve already been discussing and some of the questions that UCLRA01 has already posed, what we’d also like to find a little bit out about is your views and opinions as to what you think could be done to help, encourage and support people from communities… you know, from the black African and Caribbean communities, to seek help earlier on for memory problems. So, one of the things that we know is that, generally speaking, people who seek help earlier on in the disease generally do better. You know, they’re able to be diagnosed perhaps, if it is something… you know, if it dementia they’re able to get support for themselves and also their family members, and care givers around them, can also be properly supported. So, perhaps starting with the idea that, you know, if someone close to you had memory problems, what kind of information do you think would be… would make it more likely for them to go and seek help? So, when I’m saying, sort of, kind of information, we’re talking about things like, leaflets, DVDs perhaps, information, things like that. What kind of information do you think would help and support people in seeking help?

0:41:14.6

## G05BAM24

If I’m to respond to that, I think the problem has always been that… of assuming that, you know, information developed at a certain level by some people pretending to know… to be experts, will work. I mean, I think, personally, that people don’t really read leaflets or publications unless they have an interest in that subject. And I think leaflets may be a very good compliment to reinforce messages, but the most important thing is to find out whether people have an interest in the subject. And the only way we can find that is to, first of all, involve the communities. So, for example if you realise that forgetting might be a problem, then the first thing is to have it normalised and people recognising it is a problem and talking about it within their communities. And the best way to, kind of, do that is to understand the various communities you’re dealing with. The others and so working with faith leaders so the pastor or the imam, you know, kind of, would be involved. There is some good work with communities and charities, they, kind of, trained community champions that can work with people in their normal, kind of, setting… social setting and then those leaflets would work. But I think adverts are very good, like you said, if they had adverts, then I think that would also work. I mean, that’s my feeling, but the leaflets… this assumption that the leaflets that are printed and, you know, posted or distributed, or, you know, dumped somewhere. Will then people understand or appreciate the point? I think that’s one assumption that’s not good.

## UCLRA02

Okay.

## G05BAF29

We should not forget that we also have people speaking in different languages. Some people who do not... especially the age that we are looking for. If you are doing work on advancing age with dementia, the majority of... some people, the first generation that are coming into this country, maybe as refugees or students, and then they remain, not many of them do speak English.

## UCLRA02

Speak English, yes.

[00:43:20]

## G05BAF29

Yes, so, information must reach them in the language they understand. It’s key, whether it is in the form of a classroom speaking event, or it takes place in their language [unclear], so, it’s really key. But, also, for them to trust and have ownership over the... over that information, has to come from the source they believe, and have used, maybe, before.

## UCLRA02

Do you mind if I ask, you said about, like a source that you can trust or believe in, where do you think that source is? I mean, is that source coming from somewhere like the GP, for example, or will it be from somewhere else?

## G05BAM28

GPs are... I don’t think’s going to... GPs do little... I don’t know whether [?] to welcome GPs, but what I think... what I want to suggest, is to create an application, an app. An app like... there was the time when we designed an app for people that go to the GP, to prepare them when they visit to the GP, that this will be like a small video on there, indicating how they can behave, or how they prepare themselves, through actors, people that act, people showing people how to go and ask for help. Someone that can teach people to go and develop ways to go and ask for help.

G05BAF29   
Well the source also could be... for example, cultural centres that they’re used to, where they go. Charities in their community where they have accessed services before.

## G05BAM28

Churches.

[00:44:58]

G05BAF29Or where they have received volunteers in their houses, through those community organisations.

## G05BAM28

In churches as well.

## G05BAF29

So it’s a source that they trust. It’s not... they don’t feel like somebody is... it’s demanding on them to go and do something. They would understand it is support, coming from a particular individual that they have worked with. I think it’s...

[00:45:22]

## G05BAM24

The problem that most experience is that, and I’m always, really, you know, I’m reinforcing this each time I’m meeting it, is this assumption that Africans, or African Caribbean’s, do not have the ability, or the capacity, to do things for themselves. You can see that in terms of HIV, because it has disproportionately affected African people, and in the same days, you know, that tendency to, kind of, involve Africans in the delivery, so you find that they easily appreciate the role Africans can play, in terms of preventing HIV, or getting people to test. But, as when you look at some of the conditions like cancer, which was the first African with breast cancer or prostate, or whatever it is, they have those traditional charities, mainstream charities, and the clinical services that do not even bother to carry out any needs assessment, or do not even bother to involve people, find out what would be the best messages. So, I give an example of, for example, a mainstream charity, that may be securing funding to work with black Africans and Caribbean’s, and what they do is simply employ, you know, a black person, and expect that if they employ that black person, then, you know, that person will be able to do the work, and this has happened in mental health...

[00:46:43]

## G05BAF29 [?]

Everywhere.

## G05BAM24

In cancer, and now that’s a problem, so I think that, first of all, the realisation has to be that people are out of way ticking boxes. By that I mean that most of the researchers, or most of the studies that are taking, have these tendencies to try and entrust GPs with services, so, for example, if you want to roll out a service or you or you want to (unclear) a service, the first thing they do is see a GP. A GP, first of all, is a business. They are over-burdened as of now, but you’re talking about... I mean, information, you know, being accessible in GPs, they actually don’t even know how many leaflets they display there. They don’t know. So, and... let alone encourage people to take them, so the assumption is that they will put the leaflets on the rack. The person in the waiting, who has gone to the GP, will, kind of, pick them from there, and it’s quite difficult for there are thousands of leaflets, there are hundreds, and if somebody has a particular interest, how will they know if they have them on the rack.

So, there is a tendency for tick boxes and to get however many, you know, very easily, so [unclear], but I think that the most important thing is that if there’s a genuine interest, as you say, this service or whatever the research is targeted at, finding out really how African and African Caribbeans feel, I think it should be followed up with, and I think, probably, it’s out of... outside the scope of this research. But I think there should be a serious advocacy. A movement to try and say, if you are going... if you have an interest in a particular sub-group of people, whom you want to get involved, who don’t realise that it’s a problem with a condition or a disease, or, you know, who are nameless in that particular community, there should be genuine input to engage people, not only in consultations to find out their needs, but also in developing some of the things like resources.

## G05BAF29 [?]

And services to [overtalking] need.

[00:48:22]

## G05BAM24

Try to see what are the best training... what are the best, you know, what are the best methods for employing training people, and in terms of them working there, and I think that we underplay it, or we don’t play the role of small charities, like Air (?) for example, or the churches where people go, because frankly that see’s over 200 Africans every single Saturday.

## Unknown

Every Saturday, yes.

## G05BAM28

New Cross [?], I think. New Cross. If you go in New Cross [unclear] goes there. Churches all the way.

00:48:50

## Unknown

If they were nearer I should agree, but...

## G05BAM28

Just churches.

## G05BAM24

Not even once have they ever done a survey and said, okay, now, why don’t we have a programme involving the churches. Nobody’s ever said that. So there’s always this tendency that, you know, we can... service can be designed for us, and then people come and tell us how it should be done, and that will be it. Whereas we are capable of actually... you know the community set up networks. What we don’t know about community networks. You know, something like just putting [unclear], or just starting a conversation about it. You don’t need money and you don’t need tools. It’s just about empowering people to be able to...

## G05BAM28

Group networks.

G05BAM24  
To Talk.

## G05BAM28

Instead of a GP. Group networks instead of a GP.

[00:49:31]

## G05BAF26

So, there’s something... one thing I wanted to touch on, what G05BAF29 said about language interpreters. Interpreters, if we use interpreters who are trained on memory problems, they might get the message across better, because, for example, Somali community, there’s no word or... that addresses dementia or the other memory problems, so when the person is doing the translation, or the interpreting, they will do it how they understand it, rather than the actual message that you want to get across, and that, I have seen it with the Alzheimer’s Society website, where they have a fact on dementia and it refers to dementia, in Somali language, the person who’s done the translation, referred it as a crazy illness, so.

00:50:25

## UCLRA02

That’s a [unclear].

G05BAF27  
Even that’s a difference in [overtalking].

## G05BAM28

You won’t get anywhere.

## G05BAF26

If someone was diagnosed with dementia and they read it, they will think they are going crazy.

[General Agreement]

## UCLRA02

Okay

## G05BAF26

So that can be...

***Unknown***  
Tough for sure

[00:50:37]

## UCLRA02

Thank you for sharing that. One second, just...

## G05BAF25

For me, individually, I think that there’s an information overload. There’s too much information out there. I think, sometimes, like Obe was saying, we go from work, we go home, eat, sleep. You don’t have that time to assess all this information, or read all these leaflets about dementia, or whatever health problem that you might be having. So, I think, for us, the best would be to have those community events, you know, like the workshops, and seminars, and trainings. Get the information. Get people to come for this event. Ask them, what do you know about this? What are you doing here? What do you know about this? What information would you like about this? From those people, create those leaflets, that they understand. Not from, I don’t know. Create the information that they would understand, simply. So that it’s involving the users in developing the resources that you want to develop. It’s just not a matter of getting resources from somewhere, and distribute. They’ve got to understand those resources.

## UCLRA02

Sure.

## G05BAF25

So they should be specifically targeted at those people. But those people are the ones that are supposed to be involved in developing the resources.

[00:51:43]

## UCLRA02

Sure, and I mean up to a certain extent that is, you know, partly what this research is trying to do, and that’s why, you know, we’re here today talking to you, you know, we really want to find out, you know, all of your views and opinions on it. One thing, I mean, you’ve said about perhaps people not being that inclined to read leaflets and things like that. You’ve talked about an information overload. What do you think about people being inclined to watch DVDs, for example, as a way of getting information across to people? Do you think people would do that?

## G05BAM28

Yes, people, they will do that because, I mean, if you see anything today, anything that makes, even if you are marketing anything, or you are doing anything, business, whatever, anything, if you don’t have something [unclear] on Google, search engines, you won’t get anywhere. If you want [unclear] on Google, you must be on YouTube, you see. Most people... even if I want to... if I want to, I can get a YouTube video of how to peel... how to peel, like, orange. I can get any video that I want.

[00:52:48]

## G05BAF29

And because you can...*You* can, so...

## G05BAM28

But it’s obvious, this, isn’t it, as well

## G05BAF29

But what are we... but we are talking about...

## G05BAM28

Video works.

## G05BAF29

But when we say DVDs... I remember when we are doing the sickle cells, for example, they produced DVD that we were supposed to educate the community who have sickle cells, and when you are calling for people to come, unless you are going to distribute them door to door with the families, and ensure they have the DVD system to watch it...

[00:53:23]

## G05BAM28

That is their thing.

## G05BAF29

But, otherwise, if you are coming to a place like different, then say, I’ve got a DVD I want people to watch, without mobilising people first, to sit down, and maybe an hour or so to watch that DVD, and that would mean giving them, even, incentives to sit down and watch that DVD. You get what I’m saying. It’s going to be much easier, like all to get same. Have community events, and then wait for them to come and participate. About having the DVD, regards it, people... we ended up, all the sickle cell [unclear]. They closed down, didn’t they?

## G05BAM24

In fact they were a nuisance, for looking at the DVDs, they were... they were... they were not the VHS things, I think.

## UCLRA02

Yes.

## G05BAF29

Yes

G05BAM24   
And the systems are changing. People want iPads and tablets, not always having DVD players anymore.

## [00:54:10]

G05BAM28  
People... every phone... [unlear] their phone, then they’ve got YouTube so... and I know that YouTube works, and I know YouTube would work, but it would be a complete waste, but if it goes on television, everyone has got a television in their house.

## Unknown

Yes, and at least that... that would...

## G05BAM28

But I know Peak Challenge, and Action, and people that are... not only... in fact why not a short play that shows forgetfulness. I remember... when was that last year would... where one of our presenters showed us a ... showed us a, like, an iron man who was forgetful?

[00:54:43]

## G05BAF26

Oh, that’s mental health.

Unknown  
Mental health.

## G05BAM28

No, he had dementia. The one that had dementia.

G05BAM24  
[Overtalking] when the Alzheimer’s Society [overtalking].

## G05BAF29 [?]

Oh, okay, yes

## G05BAM24

So it’s kind of a... so it’s kind of a, you know, a short clip of... showing [overtalking] someone explaining himself.

G05BAF26 [?] But then they pass on the tape, when the pastor came for an event isn’t it? Yes, we had over a hundred people there.

## G05BAM28

Exactly.

## G05BAF26

So you had a chance of presenting it.

[00:55:05]

## Unknown

Of presenting it.

## G05BAF26

Yes.

## G05BAM28

But it was my last entry about dementia or forgetfulness, up until now.

## G05BAM24

And it was... it was [overtalking] when it was the first time.

[00:55:09]

## G05BAM28

Yes.

## UCLRA02

Okay.

## G05BAM28

It was since that, I’ve never heard anyone talking about forgetfulness or dementia, as you want to understand. But, as I say, you can have an application as well, when people will have to go to the doctor’s, they can app it. You know, it’s a place they’d like, to understand their composition [unclear].

## UCLRA01

That’s very interesting. Sorry, I’ll just jump in here. You mentioning DVD, download, YouTube, how about with someone which is 70? Let’s say like Mrs Abraham here. She is 70.

## G05BAM24

Television.

[00:55:47]

## UCLRA01

What I’m saying is...

## G05BAF27

Community television

## UCLRA01

What I said is

## G05BAF27

If it’s working.

## UCLRA01

Yes, go ahead

## G05BAM24

Community channels.

[00:55:52]

## G05BAF26

So that was Somali channels, Somali TV, here we have six channels that speak Somali language, and it’s on 24 hours a day, and they do address different issues, health issues, police, young people, so if an awareness session is done through the TV, I think people will understand what dementia is, or what memory problem, perhaps, when they go on that.

## UCLRA02

Okay, thank you.

G05BAF27  
We have had several approaches [unclear]

## G05BAM28

But I believe in group activities.

## G05BAF26

But also, but also I would say, a 70 year old person, when they’ve been diagnosed with dementia, or any other memory problem, maybe have a system where the GP can refer to a community centre to that person, so they can have access a person that speaks their language and also understands their issues.

## G05BAF29

Yes, links with the proper GPs and the community is important for referral purposes, yes.

[00:56:55]

## UCLRA02

Thank you for that, it’s all really interesting. Just picking up again on what a number of you have said. Earlier on someone talked about not having any faith in GPs and things like that, and I’m just thinking about, you know, terms of what intervention, as a result of this research project, is going to be designed as a way of helping and encourage people to seek help. You know, currently, the way the system is set up, is that to access memory services you go through your GP, you know, it’s the GP that makes the referral. So we’ve spoken a lot about, you know, the GP, maybe being a place where you maybe don’t want to go, and things like that. What I’m thinking is, what do you think would make you feel that it’s worthwhile going to see your GP for memory problems?

[00:57:38]

## G05BAM28

If they’ve got... it was like... if they’ve got enough time, because if you... for talking about forgetfulness, it’s not, like, five, ten minutes, you’ve finished. You need about 30 or 40 minutes

## G05BAM24

You haven’t got [overtalking].

## G05BAM28

To explain exactly what problems are you having, forgetting.

[00:57:51]

## UCLRA02

Okay.

## G05BAM28

How long... you need time to really explain yourself.

## UCLRA02

Okay, so...

## G05BAM28

You can... it’s more serious than a headache. It’s like a long job that you’ve got, trying to say doc, I forget things. I do things this way. Then she has to... she has to explain to you what’s... people, they don’t know what... what causes it anyway.

[00:58:12]

## G05BAF29

But as it is now...

## G05BAM28

It has never been explained.

G05BAF29There is no treatment for dementia, am I right? Yes, so seeing a GP, I would expect that they would actually refer me to appropriate services in the community, and some of the services that they have are not culturally appropriate to people’s understanding. So how am I sure that after seeing the GP, my issue’s going to get better not worse, because there are no links between the GP, mostly, with the community. So GPs are the first services commissioned by the NHS, but not usually in the community, because they don’t have that information of what is going on, so there needs to be a link, because not everybody can benefit from the majority of services. For example, like now, we work on the women who have undergone female genital mutilation, and when they go to their GPs, because they have psychological issues, they are referred to generic counselling services which do not help that person at all. So we end up getting women who have gone through the system for years, and when they come to us, and we do understand what they have gone through, then they wonder, why wasn’t I sent here? You see that? So we need to have certain services that limit risk, certain issues, in certain individual, because we are not all the same.

## UCLRA02

Sure, thank you very much.

## G05BAM28

Your question...

## G05BAF27

Can I say something?

[00:59:53]

## UCLRA02

Yes.

## G05BAF27

When you... like, for me personally, when I used to go to the GP, I have this problem, I have this problem, she would always tell me, oh it’s nothing, it’s nothing. I went so many times, like, six or seven times, and then I told a friend of mine. My friend said, let’s research into it on the internet, and we did get a problem, and had to print out that thing, and go with it to the GP to see what it is, and that’s the only time that the GP looked at it. So, I think before releasing, providing information, make people aware about the condition that they have, and then giving them, empowering them. Give... take them this leaflet that you’ve seen, either an app or a leaflet, go and address that with your GP, otherwise the GPs don’t listen to you. So even if you see a [unclear] with the GP they will just ignore that issue.

[01:00:38]

## G05BAM24

I think...

## G05BAF27

So I think its empowering people, to have something before going to the GP, otherwise they just don’t listen to you.

## UCLRA02

Okay, so they take something with them to the GP, to say, look at what I’m experiencing.

[01:00:50]

## G05BAF27

Yes. All these and... because it’s like no connection, sequence. They just [unclear] but once I connected all those symptoms I could see this is the problem that I have, and it’s through a friend that I was able to do that, otherwise the GP, there’s nothing wrong, this tick, this tick, small tick, they don’t have the time.

## UCLRA02

Thank you, that’s really interesting.

## G05BAM24

My concern is, you know, the way the question is asked. The interest is in, I believe, is in trying to get people to recognise, you know, memory problems. I know you asked, what would make us access... go to the GP? I think, this obsession with GPs, which is not only for dementia [unclear], everything, and I think this of course is the way the healthcare system is set up, but I believe that there must be recognition that healthcare, or, you know, public health, is not the responsibility of the GPs only. The GPs can do only so much, but we need a lot of complementary, you know, services, and there has been recognition that, you know, the community-based services contribute as much as clinical services, so, you know, public health services. So I think the question should not be what would make... what should be done to make people go to the GP. I mean, that’s fine, that’s fine in terms of training people. I mean, the GP staff, for example, to be aware of the various issues, and I’m saying this because of HIV, for example. If you go to a GP right now, I’m sure I can guarantee, to 80% of the GP surgeries in London, you will, almost definitely, encounter a Stealth member of a receptionist who has never known anything to do with HIV, and who does not understand the confidentiality issues, and yet does not want to touch it, and yet they want to more people to go to the GPs to do screening for HIV. So, first of all, training is very important.

[01:02:48]

## G05BAF29

For the GPs.

## G05BAM24

Yes, but I think the question, actually, should be, [unclear] talk [?] away from, I mean, should be geared at maximising opportunities for people to recognise and address memory problems, rather than this obsession with that... making sure that everyone goes to a GP. Because then, it seems like this research has been designed in such a way to justify or to try and get people to change their perceptions, or to have more confidence in GPs, as opposed to trying to get people to…

## 01:03:19

## G05BAF29

Building community services.

## G05BAM24

Yes, to recognise that their health is most important, try and look for solutions. And, you know, what… you know, G05BAF27 and G05BAF29, they’re saying about, you know, GPs actually not being as [unclear] as people think they are. They do not have time for people, they have abandoned, they are not well-trained on… well, they must be trained as GPs, but the stuff [overtalking].

## 01:03:45

## Unidentified Female Speaker

Most definitely.

## G05BAM24

Well, yes, so my issue is I think… and I think it’s the mistake that most GPs services do, and I’ve seen this thing with hepatitis, you know, because we’ve done work with hepatitis and HIV… because of cost-cutting measures, there’s this obsession to get everything going through GPs, and I think it’s doing a disservice to the public health service, because there is a lot of expertise within communities, there are people who know… but also, there are a lot of issues and barriers that the GPs alone cannot address. And as long as we… as long as we continue this obsession with GPs, GPs, GPs, all the time, I think that will get worse. So we need to recognise the various resources within the community, we need to be able to be flexible to design services to complement the existing structures, as opposed to insisting that all the files are to be done through GPs, that everyone recognises that they have a problem and see the GP (unclear).

01:04:42

## UCLRA02

Really interesting, thank you. Go on, go first, and then I’ll…

## G05BAF26

Okay. My uncle was diagnosed with Parkinson’s disease, a few years ago. When he first got diagnosed at the hospital, he was given a pack of information, how Parkinson’s can affect later on his life. But they never considered his language problems, they didn’t involve the family who were caring for him. Everything we had to do ourselves, to find the services, to find support, and now he’s at a stage where it’s affecting his mobility. Up to now, there’s no services in Somali community who address Parkinson’s. So the effect does… has caused him… not only the Parkinson’s disease has changed his life, but also socially he can’t go out and have a social life. So basically, what I’m saying is this… from when he was first diagnosed up to here, the care that he was given, no community language was involved, no understanding of how community takes… understands Parkinson’s, and all the other the problems that it can cause to him. But now he’s at a stage where his memory is going, and the impact that it’s having on my auntie is… she’s also having the time to care for him 24-7, so in terms of understanding dementia, we are seeing it in our own home, and how it impacts on the community and [unclear].  
  
01:06:36

## G05BAF25

Let me say something, in terms of GP they… everybody goes to see their GP. GPs, they have a lot of information, resources displayed in their offices, but when somebody comes to see them, they should be the ones to be able to refer people to those community places, because you see them for five minutes and then what do you do after the five minutes? You go back into isolation. Yet they have… they don’t even want to allow other charities or organisations to display their resources there. So I think there needs to be much, much more training for GPs, to understand that…when you assess somebody for five minutes, but what does the person do after they leave your office? They need to access this dementia charity, they need to access this… you know, this… they have the power to do that, yet they don’t want to interact and network with the community-based organisations that are within their own locations. I think that they are the ones who are creating a bigger problem, in terms… in terms of health, any kind of health problems. They should be the ones who tell people, here’s a leaflet on HIV, go and see these organisations. They have the power, but they don’t use it, so people just get worse and worse and worse, because you can’t go and keep seeing your GP, they don’t want you to go there. So why don’t they empower people by giving them those informational contacts? [Overtalking]  
  
01:07:52

## UCLRA02

So in terms of the information that we might be providing… Sorry, we… what time are we on? Yes, we have just run over. We will wrap it up in the next couple of minutes. I’m just thinking, in terms of the information that we might be providing people with, to try and support and encourage them to seek help, do you think that information, then… you know, again, talking about not having faith in the GPs, perhaps…

## G05BAF27

I think only Obi wanted to first, before we go on the next one, isn’t it?

## UCLRA02

Yes, do you want…?  
  
01:08:17

## G05BAM28

Yes, I wanted to give an example of a certain set up, HIV set-up. When you get diagnosed with HIV, you go to a GUM clinic, it’s in the hospital, most clinics [unclear]. And what happens then is you get counselled first, to understand your illness, what it… what it means to you, how it’s going to change your life and the routine that you’ve got to go through. When you come out of there, you accept everything, your pharmacist says… said, okay, we are starting your prescription, we are starting it on this day. Then, after that, there are two or three offices that you can choose. If you have a problem with your housing, if you have a problem… if you have a problem looking for friends or people that suffer the same… the same illness as yourself, you’ve got someone to tell you where to go. The other one is for just general upkeep of who you are. You know, from the… from the [unclear], from the hospital. The [unclear] it’s your consultant, that’s the consultant, that’s the person I will deal with. So if I compare, myself, a GP and a consultant, the time I spent with my consultant, every time I go and see my consultant I spend almost, like, an hour. I can say whatever I want, they’ll never chase me out of that office. But if I go to the GP, it’s not worth… it’s not worth it.

## UCLRA02

Do you mind me asking…? It maybe too personal, you don’t have to share it. To have got to the point of being able to see your consultant for the hour, did you not have to go through the GP to get… to access the consultant?

## G05BAM28

No.  
  
01:09:58

## UCLRA02

[Overtalking], so what was [overtalking]?

## G05BAM28

The comparison to say, the doctor is properly useless; consultant… the consultant is a doctor… is a doctor as well, but he gives me more time than what you get from a GP.

## G05BAF29

Well, the… also ,the consultants have expertise in a certain area, of course.

## UCLRA02

Sure, I’m just wondering about how you get to access them in the first place.  
  
01:10:25

## G05BAF29

Usually, what happens is, if a person is diagnosed to be positive, from hospitals, and then in those hospitals you are referred to a consultant of the hospital that deals with that particular issue. Many will have a lot of services who do not have GPs, but they have hospital consultants. Yes, so it happens. But they’re… now, of course, the system is they’re trying to train GPs to understand HIV issues, how they affect people, so like we said, you know, GPs are also humans. I [unclear] comes up and then they are trained on… they do not have every knowledge in every subject, and that’s why you find that many positive people will not have GPs, because the GPs do not understand HIV issues. But also, at the same time, GPs also exhibited signs of stigma. The way people went there and said I need to see my GP, and when they learn about their positive status, they were treated differently, you know, from other patients. So the patient felt better with people who understand their needs than the GP.

## G05BAM28

It could be the same with dementia. Stigma is there in dementia.

## G05BAF29

Yes, there’s no confidentiality. When a person reaches the receptionists, or sometimes when they ring to book up an appointment, the receptionist would ask, what is the problem? You know they are un [unclear], but they do that.

## G05BAM24

They ask you very loudly, where everyone is sitting [overtalking].  
  
01:12:02

## G05BAF29

Yes, what’s the… what’s the problem. So you realise that the people… some illnesses are very stigmatised. At one point, we did say, [unclear] to London… it was the London School of Osteopathy. They came here and said they have a clinic that supports people with long-term conditions, including HIV, so we went there and then, at the, right at the reception, there said, oh, you’re in the HIV issues. It’s called the Chapman Clinic and it’s not on today, you see.

## Unidentified Female Speaker

In the reception. In front of all those people.

## G05BAF29

Everybody turned and looked and said, yes, it was a man [?]. So that alone, it’s training and…

## G05BAM28

Someone needs to educate the GPs, before we send people to them. Remember these GPs, they don’t deal with it.   
  
01:12:59

## G05BAF25

Yes, and they may not understand issues of stigma in the community, for a particular illness. So, for example, dementia, within the African Caribbean communities, it is either witchcraft or old age. There are two things, only. Old age or witchcraft, nothing else, they say. So if a person says, I’m forgetting, then they went to the (unclear), all the African’s would say Oo..[overtalking and laugher].

## G05BAM24

Go to my witchdoctor, find out who is… who is trying to [overtalking].

## G05BAF25

Yes, and that’s why churches are making money, because they’re afraid, for people to break their curse.

## UCLRA02

Okay, it’s all really interesting stuff, and I could stay talking about it for a lot longer, but I’m sure you’re all need to get off.  
  
01:13:38

## G05BAM24

Can we have the last question [laughter], the last question…

## UCLRA02

Have you got time? Have you got… okay, we really only have two more minutes. I was just thinking about what you were… you know, you’ve all been talking about, perhaps, kind of, needing to deal with issues around the GP, before people might be inclined to go and seek help from a GP, so I’m just thinking about the intervention which will be designed, you know, as a result of this research project, about how… you know, there’s obviously issues around increasing knowledge, reducing stigma and things like that, but do you think it’s also the case that people need to be made aware of what other services are out there, other than the GP?

[General agreement]

You know, the Alzheimer’s Society, for example. Is it about signposting people to all different mediums, for lack of a better word?

## G05BAF29

I think so.  
  
01:14:25

## G05BAM24

I don’t know what kind of policy or strategy, currently, what the NICE guidelines are, or what responsibility the CCGs are towards, you know, dementia, but what I would think is that, for all health services, I think there should be a serious look at how they’re designed, and, you know, clinical services are very good, and people need to accept that, but I think that is… especially on issues that… where you need to raise awareness, you need to change attitudes and stigma, it cannot be done within a clinical setting. They must see community-based services, whether they are churches or charities or just community health workers or community social workers, they must see those functions, all those sectors of the community, all those stakeholders, as serious, you know, individuals, or a serious service, that, can actually compliment [unclear]. So if I was, you know, in one of the CCGs and I was trying to design services to get… to increase awareness on dementia, especially among black and ethnic minorities, I would, first of all, discount anything to do with GPs. It would be there as a service that you can access, say, I mean, if you need to, but I think, you know, [overtalking].

## G05BAF26

I think the GP have to [unclear] you first [overtalking].  
  
01:15:48

## G05BAM24

Yes, of course, well, the GPs are the ones who are commissioning services [unclear], but I’m saying in terms of raising awareness, the GP’s not going to give the time to go to the community and talk about dementia, so you actually are going to encounter [unclear] problem. But before you even recognise that that is a problem, you need someone to talk to you about it, and there needs to be [unclear] saying, there’s no point talking about government, because people have different priorities. If it’s a campaign that’s considered important at a national level, then that would be something to do with a media campaign on dementia. If it’s a local service, and CCGs have a decision to make, then probably the interest of… the interest of the [unclear], but I would imagine that they would have an element of a community-based... So the responsibility is on you guys to find out if there can be a pilot project, for example, that looks at effectiveness of community-based awareness, to get people to recognise… and that can be used as best practice. So for… so that’s my only, sort of, [overtalking].

## G05BAF29

Mmm. I think overall, as G05BAM24 is saying, if you have… if you’re intending to promote [unclear] the services, you need to find out how to best involve communities, directly. I think that’s the only way that the uptake can happen.

## Unidentified Male Speaker

Yes, [unclear].

## 01:17:09

## UCLRA02

Shall we, wrap it up? Can I finish on one question?

## G05BAM24

Yes.

## UCLRA02

If you received a letter, personally addressed to you, from you GP, would you be inclined to read it, if it was personally addressed to you?

## Unidentified Female Speaker

Yes, [overtalking] open it. What does it say?

## UCLRA02

If it was a letter, perhaps, accompanying a leaflet, or within the letter itself, had information about dementia and memory problems, what they are, what you can do if you think you’re experiencing problems, as an example. Would you read that, if it was personally addressed to you?  
  
01:17:42

## G05BAM28

Again, maybe I’ll read that, but not for the purpose of promoting the GP to be the main actor in my… in my forgetfulness and… I know he won’t do the right job. But if something is really wrong with my health, I’ll definitely pay attention to it. [Overtalking] to do that. So I don’t know for someone who doesn’t [unclear], what they do. But me, anything medical about myself, I take it seriously, no matter what it is.

## UCLRA02

Okay, thank you very much.

## G05BAF25

Can I [unclear]?

## UCLRA02

Yes.

## G05BAF25

Like this letter they normally send form NHS that we want… sometimes, they send a letter saying that we want to include your details or information on a computer base.  
  
01:18:24

## Unidentified Male Speaker

[Unclear]

## G05BAF25

Yes, I just read that and I just threw it in the bin, because it’s not relevant to me. So if I got a letter about dementia, is it relevant to me? Addressed in my name, dementia, go see a GP. So I think generic kind of letters, just in my name, with a health condition that I think that I don’t have, it may get a few people, but a big majority might just say it’s not relevant to them, you know?

## UCLRA01

Would it worry you though?  
  
01:18:51

## G05BAF25

No, it’s just not relevant to me, so I just throw it in the bin.

## UCLRA01

That wouldn’t … that wouldn’t matter, even if your name was on it?

## G05BAF25

No, it wouldn’t because how many letters do you receive that have your name on it, talking to you about so many different issues, I don’t know, retail, I don’t know what, but remember it’s not…

## G05BAF26

I think what I will say is, I’ve done some work with hepatitis and sending out letters to communities, and we also did a telephone interview, on the phone, in Somali language, so when the letters… when people receive the letters, it just introduced what the research was about, but when we… when I did the telephone interviewing, the first question people asked is: do I have hepatitis? So they didn’t read the… they actually read the letter, but they didn’t understand it was a general letter regarding the research. So the people automatically jumped to that: do I have hepatitis, or do I… [overtalking].

## G05BAM28

[Overtalking] hepatitis [overtalking] worried about it and…  
  
01:19:59

## G05BAF26

Yes, and also if, for example… if my mum was sent that letter, she would never read it because she doesn’t speak English at all, so she’d probably say, G05BAF26 can you… I’ve received a letter today, can you read it for me? If a person who doesn’t have somebody they can contact, they probably won’t read it.

## G05BAM24

My question would be: why would you write that letter through a GP, why would the GP write such a letter to their patients, for example, what would be the motivation? Is it because they recognise it’s a problem within that demographic group, or is it because they want to promote awareness? If it is meant to create awareness, then it’s a complete waste of money. [Overtalking]. No one would take it seriously, because they don’t have any relevance to it. But if you come back to what we were talking about when we say we have community health workshop, invite people to come to it. Everyone comes with an open mind, they’re going to have three presentations on dementia, HIV, mental health. People attend it as something as an activity and they’re speaking/thinking(?) about [unclear] something. So when they talk about dementia, they listen to the (unclear) talking about dementia, then they can talk about it, they can easily recognise it, because someone would have given some information about it. Or there’s a video where they [unclear], because then they have an interest. So, I think, you know, you need to think seriously, what is [unclear]? Is it meant to complete an exercise to show that [unclear] dementia? Is it going to work? Is it applicable, in terms of the religion, in terms of language? You cannot make these general assumptions, so in terms of resources and professionals and making sure that they are effectively used, I think we’ve come up with the same thing of consulting to find out what actually works.  
  
01:21:39

## UCLRA01

And on this topic, what would make it more likely for somebody to look for help, if they get information through the community rather than a GP?

## G05BAM24

Well, then they trust that [overtalking]. People have negative experiences to the GPs, they don’t have time for you, they can’t make appointments, when they finally give you that appointment you miss work and go to that appointment, you can’t even sit with him for ten minutes, they give you [unclear] medication which you can easily buy from a pharmacist.

## G05BAM28

[Unclear] letters [?], like a doctor, you [unclear], contact with my GP, this [unclear] [overtalking].  
  
01:22:15

## G05BAM24

I will trust information from my community organisation or my [unclear], for example, they say everyone has to go and check your blood pressure, it’s very important to check. So, you know, those kind of negative associations… because people, they have [unclear] if you go to a [unclear] based on a lot of negativity associated with GPs, and that’s something that people should understand. It should not be underestimated. People really feel negative about most of the GPs.

## UCLRA01

[Overtalking] final question.

## G05BAF25

I don’t think… I don’t [overtalking] they should be also involved in… our local GPs, they need to be more involved in our community, to know what we, the community, feel about them.

## UCLRA01

And a very final question from me, so, I get the feeling that the GP is not the best route. What if the letter comes from the NHS or hospital?  
  
01:22:15

## G05BAM24

[Unclear] people take letters [unclear] seriously, I….

## G05BAF26

[Overtalking] [unclear] letters to… certain community background, don’t use letter from Alzheimer’s Society regarding dementia, and MIND and Rethink, they’re all the same, all the wrong information about dementia.

## UCLRA02

Okay, thank you so much guys.

## UCLRA01

Thank you very much.