“AS I WALK THE LAST MILE OF THE WAY”

This Report is a collection of interviews from families who have borne witness to and experienced the devastating impact that dementia has on their families.

African, African Caribbean, Asian and Minority Ethnic families living with Dementia

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FW Consultancy

diverse cymru
Promoting equality for all
Hyrwyddo cydraddoldeb i bawb

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Thank you so much for letting FW Consultancy be a small part of your journey.

Faith Walker and Aisha Jenkins

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Contents

Acknowledgement 0
Glossary of terms 3
What is Alzheimer's disease? 5
Dementia prevention 5
Some early signs of dementia 8
Introduction 7
Semi-Structured Interviews Faith Walker & Aisha Jenkins FW Consultancy 11
One to One Interviews Suzanne Duval BME Mental Health Manager (Policy) Diverse Cymru 54
Samira Salter, Mental Health Support Manager, Diverse Cymru who held the Focus Groups for the Yemeni women 65
Self-reflection by David Truswell Executive Director, Dementia Alliance for Culture and Ethnicity. 70
Dr Sofia Vougioukalou, Research Fellow, Y Lab – the Public Services Innovation Lab for Wales, Cardiff University 76
January 2021 76
Conclusion 81
Recommendations 85
APPENDIX 1 88
Biography 96
References 96

Glossary of terms

Public Sector Services – Companies and corporations that are government run.

Third Sector Services - Voluntary and community organisations (both registered charities and other organisations such as associations, self-help groups and community groups), social enterprises, mutual and co-operatives.

Private Sector – Comprised of organisations run by individuals and groups who seek to generate and return a profit back to its owners.

EPICC - Enhancing Nurses Competence in providing Spiritual Care through Innovative Education and Compassionate Care.

Diagnosis - The identification of the nature of an illness or other problem by examination of the symptoms.

Equality Act 2010 – It provides Britain with a discrimination law which protects individuals from unfair treatment and promotes a fair and more equal society. https://www.equalityhumanrights.com/en (T) 0161 829 8327.

Older People's Commissioner for Wales - Protects and promotes the rights of older people throughout Wales, scrutinising and influencing a wide range of policy and practice to improves their lives.

www.olderpeoplewales.com (T) 0344 264 0670

Social Services and Wellbeing (Wales) Act 2014 – Came into force on 6 April 2016. The Act provides the legal framework for improving the well-being of people who need care and support, and carers who need support, and for transforming social services in Wales

https://socialcare.wales (T) 0300 303 3444

Well-being of Future Generations (Wales) Act 2015 – requires public bodies in Wales to think about long-term impact of their decisions, to work better with people, communities and each other, and to prevent persistent problems such as poverty, health inequalities and climate change.
https://futuregenerations.wales/ (T) 029 20677400

Public Health Wales (PHW) - Is the national public health agency in Wales which

exists to protect and improve health and wellbeing and reduce health inequalities for people in Wales. PHW are a part of the NHS and report to the Cabinet Secretary for health, well-being and sport in the Welsh Government.
www.wales.nhs.uk/ (T) 0292 022 7744

Questions asked for this Black Minority Ethnic Dementia Project

1. What are the factors, if any, which stop people from the African Caribbean communities seeking early help/intervention and /or getting a diagnosis?
2. How can these factors be overcome?
3. How can we improve diagnostic tools and the diagnostic experience for people from African Caribbean communities?
4. How do African Caribbean individuals and families experience living with dementia?
5. What services might individuals and families be looking for?
6. What are the best ways to reach our communities?
7. What challenges might be encountered when developing and providing tailored services to people with dementia from minority groups?
8. How can these be overcome?
9. Which organisation and individuals, at local and national levels, are best placed to lead this work?

Questions were adapted to reflect the ethnicity of the participants and taken from the All-Party Parliamentary Group on Dementia: Dementia does not discriminate.

The experiences of Black, Asian and Minority Ethnic Communities. July 2013

What is Alzheimer's disease?

Dementia is the name for a set of symptoms that includes memory loss and difficulties with thinking, problem-solving or language. Dementia develops when the brain is damaged by diseases, including Alzheimer's disease. Alzheimer's disease is a physical disease that affects the brain. It is named after Alois Alzheimer, the doctor who first described it.

The brain is made up of billions of nerve cells that connect to each other. In Alzheimer's disease, connections between these cells are lost. This is because proteins build up and form abnormal structures called 'plaques' and 'tangles'. Eventually nerve cells die and brain tissue is lost.

The brain also contains important chemicals that help to send signals between cells. People with Alzheimer's have less of some of these 'chemical messengers' in their brain, so the signals are not passed on as well. There are some drug treatments for Alzheimer's disease that can help boost the levels of some chemical messengers in the brain. This can help with some of the symptoms.

Alzheimer's is a progressive disease. This means that gradually, over time, more parts of the brain are damaged. As this happens, more symptoms develop, and they also get worse.

More than 520,000 people in the UK have dementia caused by Alzheimer's disease and this figure is set to rise. (Alzheimer's Society)

Dementia Prevention

Diet/nutrition Research suggests that adopting a "brain-healthy" diet can reduce the risk of developing dementia. Focus on a diet which is low in cholesterol, saturated fat, sugar, and salt, and high in dietary fibres, fruits, vegetables, whole grains, other complex carbohydrates, potassium, calcium, and magnesium.

Exercise When it comes to brain health, starting and maintaining a regular exercise program is often the most difficult lifestyle change to implement. But physical activity doesn't have to be overly strenuous or involve a huge time

commitment to generate benefits. The most important thing is that it is done on a regular basis (e.g. 30 minutes a day can be sufficient for a preventive effect). Walking is a good example of something that we may do every day without going out of our way to do it. If you cannot manage this you may try arm and/or foot exercises whilst sitting in a chair.

Exercise is beneficial because it increases the blood flow to the brain and reduces the risk of cardiovascular conditions that are associated with vascular dementia. Regular physical exercise also helps maintain the hormonal balance and stimulates the release of chemicals required for brain cell survival. Thus, it can delay the onset of dementia.

Mental activity Mental exercise has been associated with a reduced risk of developing Alzheimer's disease. Keeping the brain active increases and strengthens connections between brain cells and builds up "cognitive reserve". Brain cells may die as we age, but research shows that mental and social activities promote new connections between cells.

To stay mentally active, it is important to commit to the idea of lifelong learning. The key is to add novelty to your experiences by learning and doing new things (rather than just repeating old activities). Variety and newness keep the mind sharp and promote a healthy brain.

Social engagement Elements such as active involvement with family and a wide network of friends are likely to lower your risk of dementia. Research suggests that social activities which combine physical and mental activity are most effective in preventing dementia. For instance, walking with a friend while talking about a topic that requires problem solving is better than just walking, just visiting a friend, or just problem solving. Good ways to stay socially active include being involved in work or volunteer activities, joining clubs, and/or participating in organised travels.

Some early signs of dementia

- Dementia is not a natural part of ageing
- It is not hereditary and isn’t contagious – you can’t catch it from anyone

- Don't ignore what is happening and put the signs down to 'old age' <u>always</u> tell your doctor
- Are these familiar things, listed below, happening more frequently?

  - ✓ Memory loss affecting day-to-day abilities that you, your family and friends are noticing
  - ✓ Getting lost easily in places that you would know
  - ✓ Difficulty performing familiar tasks – such as dressing, making a cup of tea
  - ✓ Problems with language – not always finding the right words
  - ✓ Uncertainty about time and space – when things happened and where they took place
  - ✓ Impaired/reduced judgment – not understanding that you mustn't wear shorts and a vest in very cold weather
  - ✓ Problems with trying to make sense of sentences or follow a film/programme
  - ✓ Misplacing things – maybe your keys, glasses, purse or wallet - are you putting them in the fridge or oven for example
  - ✓ Changes in mood and behaviour
  - ✓ Changes in personality
  - ✓ Loss of interest in things that you normally enjoy or love to do

If someone you know is becoming increasingly forgetful, encourage them to see a GP to talk about the possibility that they are exhibiting the early signs of dementia.

Introduction

This report is a collection of interviews from families who have borne witness to and experienced the devastating impact that dementia has on their families. The families were at different stages of their loved ones' dementia journey, either

recently diagnosed dementia, advanced dementia, at the end of their dementia journey or sadly passed away.

Dementia is one of the most challenging health issues we face and the number of African, African Caribbean, Asian and minority ethnic people affected by dementia is expected to rise significantly and at a more rapid rate than that of Caucasian people. (Let's talk about Dementia – End the Stigma 2019)

The All-Party Parliamentary Group on Dementia suggested that the current estimate of nearly 25,000 people with dementia from the African, African Caribbean, Asian and minority ethnic communities in England and Wales will grow to nearly 50, 000 by 2026 and over 172,000 people by 2051. This is nearly a 7-fold increase in 40 years. It compares to just over a 2-fold increase in the numbers of people with dementia across the whole UK population in the same time period. (The British Psychological Society 2016).

This collection of interviews is direct conversation with no analysis of the data, raw data, so is accessible for all to read and understand. The interviews give a voice to the voiceless, the seldom heard communities. They give an insight into their loved ones' dementia journey and how they navigate through their understanding of the complexities of dementia and contact with the Public Sector and Third Sector Services. Although these stories are a small sample, Alzheimer Europe's policy briefing on intercultural care (2020), draws on an extensive range of sources to assess:

"People with dementia from minority ethnic groups are not using support and services to the same extent as the general population as a whole and are notably absent in residential care home.

Those who do, often find services inappropriate or of poor quality. They encounter barriers at individual, societal and structural levels. Governments and other policy makers have a moral and legal obligation, based on the principles on non-discrimination, human rights, beneficence, non-maleficence and respect for human dignity and personhood, to ensure equity in the provision of dementia care and services. This obligation is based on governments having signed up to the provisions contained in a range of European and International documents such as

the European Convention on Human Rights, the Universal Declaration of Human Rights, the Convention of the Rights of Persons with Disabilities to name but a few."

This report provides new insight into the above, and explores, for the first time in Wales, the effects of dementia in our societies. For that reason, the information is presented in such a way as to facilitate, build and connect with both our communities and the policy makers. Too often African, African Caribbean, Asian and minority ethnic people are isolated within our pain, unable to share our stories in fear of being stigmatised and being judged. The 'Breaking the Circles of Fear' Report (2002), emphasises the fear within the Black communities and the inseparability between both racism and mental illness. The fear is real which stops African, African Caribbean, Asian and minority ethnic people from connecting with appropriate services and partaking in meaningful recreational activities, not utilising our own support mechanism, families, friends, church, community centres and bingo halls.

Two of the researchers have been on this dementia journey with their loved ones; therefore, they have gained a deeper understanding of the complexity of this terminal illness. We speak out, but is anyone listening or taking any action regarding our concerns? We reach out, however, too often we are told that the diverse communities are hard to reach. This dichotomy is echoed within these semi-structured interviews.

It has been a privilege to undertake this research with the families sharing their very intimate private and personal stories and memories of their loved ones. It has also been a very painful journey knowing that the bewilderment, isolation and frustration that we felt as we walked our own journey were resonated, within the families' stories.

Furthermore, what was interesting was the voice of the grandchildren in how they perceived the illness and the lack of resources for that age range 12 - 30 years old and how they felt excluded as they watched their parents trying to understand this mystery illness that devastates families.

Even though the African, African Caribbean, Asian and minority ethnic people are

reluctant to engage in services, key policy makers recognise that there is a lack of service for the minority ethnic communities. For example, Patel (2013) who was the Chair of Community and Adult Services Scrutiny Committee states:

"Almost one fifth of the population of Cardiff self-classifies as being from a minority ethnic group: at the same time, just over one tenth of Adult Services clients self- classify as being from a minority ethnic group."

For that reason, it is vital that service provision for the African, African Caribbean, Asian and minority ethnic people is made accessible, safe and culturally competent, to address the "layers of complexity to the already complex and life-changing challenges facing those living with dementia and their families and carers" (Truswell, 2020, p.15). Care dignity is so important for our elders (Saltus and Folkes, 2013; Saltus and Pithara, 2015; Yu, Saltus and Jarvis, 2020).

Within our diverse culture, our elders are deeply spiritual, religious or both. These attributes are their pillars, the essence of their being, their cornerstone. Enhancing Nurses' and Midwives' Competence In Providing Spiritual Care through Innovative Education and Compassionate Care (EPICC), have provided a new definition of spirituality, the adopted definition from the European Association for Palliative Care (EAPC), to reflect wellbeing as well as illness.

"Spirituality is: "*the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred*"."

This definition encapsulates who our parents and grandparents are, how they see and view the world, nevertheless, this aspect of the 'self' is too often ignored within our Public Sector and Third Sector Services.

Semi-Structured Interviews

Faith Walker & Aisha Jenkins
FWConsultancy

Daughter	Age 73

(Q1) What factors if any stop people of colour and their communities from seeking early help, intervention or getting a diagnosis?

Daughter

Probably stigma I think, stigma because if they know about dementia they think It's like, a mental health thing, so they don't want to go the doctors because they think, its stigma.... and not understanding.

(Q2) How can these factors be overcome?

Daughter

Well, I think they need better understanding of the disease, they don't understand it I don't think, I don't know if its ignorance or what, but yes probably and not seeking help, not discussing it with the family if, you know, if the family notice something, they're not going to think, oh my mum's got dementia, you know they probably think, oh mum is alright, she's just forgetful, something like that.

(Q3) So, how can we improve diagnostic tools and the diagnostic experience for people of colour?

I think to diagnose someone with dementia, you have to notice that there's something not quite right with your loved one and then you go to the GP and the GP will notice the change anyway in that person, so therefore the GP would refer that person to the memory clinic and then from the memory clinic they do the test and then they'd be diagnosed.

I found it really good because, the GP noticed the change in mum, the GP referred mum to the memory clinic in Llandough, I took her, they spoke to both of us and then I had to go to a separate room, mum did the evaluation, you know there's a special tool and then lots of questions and a clock face, they have to fill that in and mum didn't do it, she did the clock, you've got a round circle and then she had to do the hands and the numbers and then she did them on the outside, she didn't know how many children she had, she didn't know where she was, she said she was still in Jamaica and stuff like that...so that was diagnosed and then from

then she had medication from the professor at the memory clinic and they were quite good because if I was worried about her I'd ring them and the support was there .

She didn't have understanding because of her dementia, well it was questions like, who is the prime minister...oh I see what you mean... I don't know...I don't know because the questions they're just set for everyone, I don't know what questions they would be because it's no good asking her who's the prime minister of Jamaica, she wouldn't know, so I don't know what, if there could be a separate thing for ethnic people. I don't know if they would do that, I don't think they would.

Because if they were sort of like, in the community if there was somewhere that you could go where there would be Black people to talk to, say there's like Awetu, that's gone, if something like that was set up and then say it happens to me then, I could go to you because it's different isn't it, the culture is different. I think that would have been a help, because some people find it easy to talk to their own colour and they could explain because the stigma around it...my mum had friends and they didn't visit her because they probably thought it was catching or something, yes, it's lack of awareness because they don't understand it, they think it's a mental health...that person is mad or something like that. So that would be good if something was set up.

(Q4) So how do African Caribbean individuals and families experience living with dementia? How did you experience living with dementia?

Daughter

Oh it wasn't good, when she was diagnosed, I was angry and...I don't want to cry...I was sad....(crying)....and then it got worse and then she wasn't my mum.... yeah it was difficult...(crying)...and then as I said about that, then I had one family member saying she hasn't got dementia, I say she's got dementia and she hasn't....I didn't diagnose her....my family member said I said she's got dementia,

yeah it was hard, it was really difficult. I went to, Penylan, because I knew there was an Alzheimer's Society there and she was really good, Karen, she was really good...and all the leaflets are there and you know she was really good and the social worker, she was ok....I had to go...no one came to me, I had to it myself.

I wouldn't have had anything because even at the memory clinic there were no...I can't remember if there were any leaflets, probably leaflets were there but they wasn't handed out, yeah she was just diagnosed and then we left, I picked stuff up but..

I can't remember...I had to pick it up myself...I think there were leaflets there and I picked one up but then I made an appointment to go to Penylan myself and I took my family, so from there, Mary* (family member) didn't understand ...I had to explain to her because she even said it to me on Thursday she said, I didn't know what it was I didn't understand it until you explained to me , you told me about it... but there was support as well....the psychiatrist in St David's, he was good.

I don't remember what happened....they gave me the number and I phoned and when mum was getting worse I phoned them and I used to take her and they evaluated her...to see if she was getting worse, when she was hallucinating I phoned them, went down and they monitored her and her medication, see if she needed any different medication or whatever... and another thing is ...I don't know if you're going to go into that....places to go... there was the day centre but there's not Black people there, mum was the only Black person there, you see so if there was somewhere like that it would be good because it's a different culture....and there's Singing for the Brain in Splott and they do have a day centre at Penylan but there again I didn't see any Black person there so something like that would be good and then the family could get involved then and work with the family as well, because it is important that the family get support as well, I know there's respite and stuff like that but there could be teaching. I also went on the dementia course, it tells you about dementia...it was from Penylan but they had it down Llandaff...what's that place called, not on Llandaff Road by the lights, not a community centre....Chapter...it was held there for a month I think and they taught you what the patient is like with dementia, the services you can

get, about finance, you know how you can't take any money out without power of attorney and stuff like that...that was good. It was, I can't remember now, I can't remember if it was Penylan.....I'll ask Mary*...because the three of us went, it wasn't the social worker... Karen was there...yes...Karen ...she works at Penylan and I told them about it because I used to phone Karen when there was anything and she was quite good...she was quite helpful, because she was taking a session and then the other person took it as well, quite interesting, there was other people there and she was looking after both her mum and dad who had dementia... if you can push for something for Black people....somewhere to go and someone to educate them that would be good.

(Q5) What services might individuals and families be looking for?

Daughter

Somewhere they can go like a day centre.....like the singing because mum was going to singing for the brain but the songs they sang, it wasn't what mum could sing so that's why a community centre or something for ethnic people.

War songs...she used to sing along but she didn't know the words ... so something like that...what else...a day centre...yes because at the day centre if they're able they could help prepare food...you know sort of like help, cut up the food and stuff if they're able and they could bake, the ones who like to bake and stuff...my mum went every week....she went to singing for the brain that was one day a week and ....she used to go missing, she wouldn't get in the car half the time ...and when they brought her home she wouldn't get out.

(Q6) What are the best ways to reach our communities?

Daughter

I was thinking someone could do a talk on it at the community centre, someone could do talks, different people, a doctor, someone specialising in dementia, like Karen, people like them so they can have a better understanding to know what dementia is, how it affects the family and the help that's out there and stuff like that.

Before it happens...

(Q7) So what challenges might be encountered when providing tailored services to people from minority groups?

Daughter

I can only talk from experience, I didn't....I wouldn't say I had any challenges I think with mum apart from within the family....some people....well, didn't understand what mum was going through...up to before she passed, they didn't understand...we had to fight with her when we had to wash her and stuff and I tried to say to them if you go to give her medication and she refuses, leave her and then go back and even one family member didn't understand...the family needs to be more educated as well...you know. You're out against [people's] lack of understanding, their miseducation about it, their unwillingness to accept this is happening...for whatever reasons so it's, yeah… for our community, it's that...no she hasn't got that...no it's not that...you know because of the stigma they attach to it...they think the person is mad...they use that word don't they and not visiting...some Black people wouldn't want people interfering ....and some relatives wouldn't want to know that outsiders know their mum has got it...yeah.

(Q8) How can these be overcome?

Daughter

Educating...educating them but see like I don't know if you had anything down at the community centre if people would go...you'd have to tailor it...about food...like cakes and stuff and people to give talks because if you did leaflets where would you...there's church....the church people are the worst to be honest....mum had it and the pastor didn't visit or his wife but yet when she was well she was cooking for them every Sunday....but most Black people go to church...yeah...and one in five person has got dementia, it's probably one in three now...you know every person you talk to...my mum had dementia....oh my aunts got it my mum had it, it's really....but for some reason some Black people aren't willing to accept or be open about it....yeah , I go to Sainsbury's, there's a lady says, oh my mum's got dementia...I says, oh my mum had dementia...it's surprising. I don't know why they think it's...it's they're mad...it's from the West Indies isn't it, you're mad and they didn't have anything to do with people who

were mad, I think that's what it is, they need educating.

(Q9) Which organisations and individuals at local and national levels are best placed to lead this work?

Daughter

You (laughs) ...hahaha....you....yeah why not....put that in...yes you because you're already in the community and you've got experience with dementia...I don't see why not.

Someone who's experienced with a family member with dementia...

Which you have...I couldn't do it, nobody knows me, people respect you...because you've experienced it with a family member....it's like when we had Irene the Black health visitor you felt more comfortable with somebody Black...yeah...it's like Suzanne from Awetu... she gave advice...we rang her, that's another thing people could ring for advice if they notice ...a member of the family is acting ...out of the ordinary...that's not the word I want...yeah something like that.

Yeah...I could phone you and say, oh my sister she keeps leaving the saucepan on and she keeps walking outside without her slippers and I've noticed something totally different with her...yeah just say what you've noticed about your family....that person could give you the right advice....for support....because I didn't realise until I went to the dementia study days that if you and I are married, well you know anyway, if I pass away you couldn't use my account although it's joint , it's got to be closed and before they have dementia they have to have power of attorney otherwise if it's not registered it cannot be used...all that could be part of it....you wouldn't know...it's so complicated...the person's got dementia, they haven't got a power of attorney...well we know, we've been through that...it took a long time and if they're mismanaging the relative's money then there's a trust that can manage it....see, all that , it's a lot.

Because I didn't know about the trust until I did the power of attorney and it came back saying it couldn't be registered because I had it too late, the solicitor gave it to us too late to sign, I had all the forms, I did it all, I was still doing it, sent it back, it came back and then I phoned and they said to get the council to do it, I

phoned, they don't do it unless the person goes into a home...oh...and then I phoned ...what's it called?....safeguarding, I've got the form.... everything I've done for mum it's in a Black book, all the telephone numbers, everything that was said...phoned safeguarding, they said they don't do it but The Friendly Trust does it but it's going to cost and there's a waiting list, so I phoned The Friendly Trust explained to them what was happening so they said they could do it, it's £85 a month, I said just do it and that was it...and they did everything, they phoned the gas board, everything, they sorted it out, if it wasn't for them...they're down Canton, they're what's it called...what's the word I want...charity...it's called The Friendly Trust...they sort it out, they paid all the bills, sorted out everything, ...they paid for the funeral....it was mum's money, they looked after the finances but they're with the power of attorney....they're with the office of public guardian, they do an audit...so everything...not all the family trusted them , no they work at the office of public guardian, because they do an audit and everything that they spend, whatever came in, whatever went out had to be seen by the office of public guardian.....I wouldn't have known that...but that's something to remember as well if you come across anyone. Not many people know...if I hadn't phoned safeguarding I wouldn't have known or if the power of attorney was registered I wouldn't have known anything about that. I probably wouldn't have needed it but still...it's something.

Researcher

Is there anything else?

Daughter

Mum used to go to the home sometimes for respite and it's the food as well, yeah the food, it's different food, so that's a big thing as well I'm just remembering now what we went through.

Granddaughter	**Age 28**
Grandson	**Age 15**

(Q1) What are the factors, if any, which stop people from African Caribbean communities seeking early help/intervention and/or getting a diagnosis?

Granddaughter

No education around it, At one point I thought that only Caucasian people suffer from dementia, I didn't think it was a Black thing, until Aunty X nan suffered and then someone else had it, Mrs X, then Nanna its seems to be growing. There is no education around it.

Grandson

I also agree with my sister about education, because it's older people that suffer from it, maybe that they don't have access to tell people because a lot of older people are like isolated and they are not connected to the internet and all that stuff, so they might find it hard to find someone who can actually help and tell them they have dementia.

Granddaughter.

Well, our generation will go, 'oh my gosh I have this symptom and this symptom' and put it into google.

Grandson

Yeah

Granddaughter

Diagnosis? I would not know how that works.

Grandson

Me neither, no clue.

(Q2) How can these factors be overcome?

Grandson

I reckon you have to like teach children, as they get older, they will become more educated. I know that is going to be a very, very long term solution to it, which is still going to affect the older people, you need somehow to reach them. I don't

know how, but open communication with the older generations.

Granddaughter

The dementia society.. I don't know, find where people are really and have like afternoon tea. McMillan have coffee mornings like all the time. The dementia society don't really have them, not that I'm aware of. For older people who don't have a big family, maybe pamphlets through your door, reaching more. What's the word I'm looking for..

Grandson

Inclusive?

Granddaughter

Inclusive yeah, better advertising, looking at where the communities are, like Butetown community centre, a few pamphlets there, people will recognise it.

Grandson

Like dominoes club or something.

Granddaughter

Yeah, the older communities when they see a picture that looks like them and the tag of dementia society or like you know, a simple advertising that catches their eye would be more effective. Seeing Caucasian ladies sitting there and the tag of dementia and a forget-me-not it doesn't really apply to them does it?

(Q3) How can we improve diagnostic tools and the diagnostic experience for people from the African Caribbean communities?

Grandson

Well, not being aware of the process of diagnosis, I don't know how to answer that question.

Granddaughter

Yes, same really. From what was said about my nanna, you give them a list, pen, paper, where Nanna is like illiterate, it would make more sense if words like the

market, dutchie pot, hot comb, rather than things that don't apply to her, maybe she could remember that. Like a pen and pencil, Nanna wouldn't use a note pad, she would use a back of an envelope, wouldn't she. Like a list, shortbread biscuits, pot noodles, turkey neck, pig trotters, things that apply to them. My husband's family would respond to things like a flower chrysanthemum, Nanna wouldn't. It needs to be more inclusive and culturally sensitive

(Q 4) How do individuals and families' experience living with dementia?

Grandson

I can remember going down to Nanna's it was like the feelings were not the same anymore, like the person was slowly slipping away.

Granddaughter

She plays jokes on me anyway, so Nanna haven't change from yesterday she pretended and said "so mi catch you"

For my age group, I don't know about that. There is a big cohort of cousins that think, jeez dementia or Nanna is on one, you don't really think or she just forgetting, she doesn't know or "what's that's again", because she used to say it anyway, it's just a tag on it now.

But the books for my son, they were great for the children, they were helpful, from the doctors. The big cohort like my age group 16 – 24 it could be something more for them, maybe like a focus group, the siblings went in for the doctor's appointment, that could be done for the grandchildren, rather than them explain it, what is actually happening take you through the process rather than just say it's dementia, because of our age within the family, dementia wasn't explained to us.

Nanna got dementia, oh ok, the first thing that we did was the memory walk, we didn't know what to do, and that was it basically. Yes, Nanna got dementia and that was it, so we googled it.

Grandson

The same, just like dementia is here now, no one really explained what was going

on. No one said anything to us, no one really explained to us, just had to make our own mind up about it via Google and through what nanna would say.

Granddaughter

I'm not saying a full-on doctor's appointment or a dementia focus group I don't want to sit there with strangers. Maybe Nanna…siblings, because it's hard for the children of the parent, something for the grandkids as an option, some people may not want to. The book what my son had was helpful for adults, it was that simple it doesn't have to be hard work.

Grandson

It could be something like online that we can have access to that explains it.

Granddaughter

Something our age…there was something on CBBC ages ago. That was great "Me and My Granddad", that was enough that was, but obviously it was targeted at a younger age range, you wouldn't see people our age on TV. There is a gap for young people between the age of 12 and 29 years old.

(Q5) What are the best ways to reach African Caribbean communities?

Granddaughter

Go to local events, Butetown Community Centre, dominoes then like…

Grandson

The people, the elders go to dominoes and the elderly are more likely to have dementia, then surely they should be putting two and two together.

Granddaughter

Butetown, Tiger Bay they are very close knit aren't they, so that just word of mouth. But for the people who can't get down there, maybe it could be something in the different areas of Cardiff I guess or family days which is not necessarily like dominoes.

Grandson

You would have to have activities to bring people there though, you can't just have a dementia event because no one would just come. If you had like at the Rec, when you have these events and different people roaming around having something to say they would also have some activities to do, something like that.

Granddaughter

Colouring a forget-me-not, with like Jamaican colours little things that get the message across. I'm not saying a focus day, like at 12'o clock we're going to speak to this person, because that's way too formal for me. But, if you have people just there, "what you here for today, do you want to talk more about dementia?" and if you like a more in-depth conversation they got somewhere for you to talk about it I guess.

Advertising needs to be more inclusive, culturally aware and diverse and all that. Everything from dolls, having a more diverse family whatever that may be. I am more inclined to look at a picture these days if it's a mixed race couple because it captures your eyes straight away, because it's something that applies to you. Then having something like the Shreddies Nanas on a poster that doesn't really apply, that would apply to my husband. Advertising is a massive one.

(Q7) What challenges might be encountered when developing and providing tailored services to people with dementia?

Granddaughter

Denial I guess, if you're speaking to people from our communities they will have to get it on point as a package to deliver anyway. I guess someone who looks like you, if you're going to receive it better ... I know nanna would see it that way anyway she's friendly and polite to everybody but somehow you take it more on board if a doctor who looked like you… you're going to receive it in a way that is appreciated if you're nice, however it's received greater from someone who knows what's going on. Even if it's grandchildren trained to speak to other grandchildren and vice versa.

Dementia is a hard thing to take on board, like with anything that you're suffering

with, it's something hard to take in anyway, regardless of race or your background. I think it's something specific because it's African Caribbean people I think it's a lack of education in the mainstream.

Grandson

I think they are very proud people, like we will just get over it. Like my dad, we get over it just walk it off and wouldn't actually go and ask for help. My dad like… have a broken hip, its really obvious but he says, nah just walk it off, I don't need physio, I just like, go training or something, they're just stubborn I guess.

Granddaughter

I think so, if one organisation can get it right because Caribbean food is not meant to be good for you so if you looked if the British Heart Foundation were interested and you worked together to collaborate something that caters for all so when you got that down…. You know you don't have to fry something in whatever or don't be really heavy. If one gets it right, I think it should all just fit into a jigsaw that one community nailed really.

(Q8) How can these be overcome?

Granddaughter

People being open and honest, not being scared to approach somebody because of the colour of their skin, just finding more in-depth case studies really, where you can go in and say, "oh this is X family, she's the matriarch, she has 6 kids, 18 grandchildren, what can we do for them?.. Oh, we can have a cooking day or we can have a bingo day", something that is tailored to that person or family can come in and have rice and peas, because having fish fingers and boiled potatoes and peas is not something we eat, or beans on toast it's not something that applies. People are different, but I can only compare to my nanna. She's not going to have faggots when she should be having ackee and salt fish and dumplings and boiled potatoes. Because it's something more of a decline, because you're slowly losing your culture when you should be keeping it because that's your base at the end of the day, not what they've got at the moment.

Grandson

Especially how like the older generation, they have come over from Jamaica to come here, they're still like really tightly linked to their culture so they're not going to be like attracted into doing something if they're not going to be appreciated.

Granddaughter

It's pointless doing activities that you would never do, you can't have the memory skill and that's not your memory in the beginning and that could be the same for any care home. This is a group of people who like to knit, we're the knitting workshop, something that is a generic icebreaker. Like your skill would be like to make dumplings, you know the flour and the water, not the frying of the dumplings because that's health and safety, just like peeling a banana, peeling a yam, gutting a fish. I don't know whatever's normal to them, seasoning chicken, scaling a fish, bun and cheese, hard dough bread.

Grandson

Because they are not from here, so they are not going to be like submerged into a culture we are in, if you get me. They going to… because it's a memory thing and I'm guessing they are going to remember stuff from their childhood, stuff from the last 20 years – 30 years in Britain but 30 years in Jamaica they're still going to have memories of Jamaica. I can remember Nanna, she would always ask about her mother even though her mother has been dead for a couple of years… I'm going to see her soon, that shows that in her head she still thinks about Jamaica or just moving here, you need staff or someone almost speaking Patois to her, like almost.

Granddaughter

Inclusion days, but it shouldn't have to be inclusion days it should be inclusion all the time. Just being around predominantly like diverse…there is not much Black people in care homes, it's having to be next to, you know people who are always wary of Black people, you can see it in their faces and being around old white people who are wary like of Black people anyway, that's going to be an instant defence, wherever you are in your dementia journey it's got to be overbearing. It is kind of like, if you don't know about those White people, they might have a

thing against Black people, their dementia is going back as well.

They might start being abusive, their mind-set resets back to whenever they want to.

(Q 9) Which organisation and individuals, at local and national level, are best places to lead this work?

Grandson

I don't really know any organisation, Age UK, Dementia Society that's about it. Well, they are the most well-known they must be doing something good?

Granddaughter

I don't know much about Age UK or Dementia Society to talk about what they're doing now. Doing more field research really just even down to their magazines. I have seen their magazines there's nothing in there that Nanna's going to want. Even the simplest things like a dutchie pot or something similar in the Asian communities, I don't know what's in their household but I'm sure they'd appreciate something that will apply to them it's very one sided.

It is targeted at the Caucasian people, that's most advertising anyway. Dementia as an organisation can do more outreach things and take advice from people maybe a carer or someone who has experienced it. I think they'd be the best trained to talk to, rather than someone….. I'm not going to listen to somebody who has just learnt or studied dementia and the affects, I'm more inclined to listen to someone who has had proper experience of it. That applies to me and you. If we went in and there were two separate families you could talk about… my Nan's got vascular dementia almost like a story book. This is what happened. This is like how it affected the family, this is what we done to combat it, here are the struggles, and these are the…. this is what we done to overcome the struggles and then it would be like my personal opinion, how I felt like emotionally.

What questions have you got… I can't help you with that but however can pass you onto someone…train up families who have lived experience then they go into communities.

Well, I've done the memory walk three times and you have the emails to meet

Hannah. Hannah doesn't look like me, or meet Alex or meet Sharon and there is a picture of Sharon and there is a picture of Hannah and Alex and none of them look like me. They've all done amazing things...but there are more people than Sharon, Hannah and Alex really. I open the email and think, oh my gosh…. it would be nice to open up a page and Peter is actually Black with a dual heritage family and how that's affecting him. You can't be scared of it though, there's people seem to be scared, just ask me the question I will give you the answer. I haven't got a problem with you asking me, however I might have a problem with how you approach me. But if you're just nice about it, I've got no problem in answering your question in a positive way. I don't know why people are scared to approach it. It's just a bit ridiculous.

I feel like dementia is like a scary topic and you might be going through a lot of things in your head mentally. You need someone you can open up to and be comfortable and vulnerable with….British Heart Foundation don't have pictures that look like us in their brochures, health charities, even sickle cell there is never a picture when there's something wrong, the same with Save the Children.

Grandson	**Age 25**
Daughter	**Age 54**

(Q1) What are the factors if any which stop people from the African Caribbean communities seeking early help/intervention and/or getting a diagnosis?

Grandson

I think a big thing that affects a lot of people, because my nan has dementia on my mum's side and on my dad's side as well, so I've seen it from both of them and it's a reluctance to accept facts, like for a long time my nan, the both nans were saying, "people are stealing from me in the house, people have moved this, blah, blah", I knew straight away but because obviously when I speak to them about it they don't see me as someone who has got a bit of information they just see me as a grandchild. It's like, " ah ok, yeah, yeah, whatever, blah, blah, blah, don't talk back to me", etc, etc and then as it gets worse and worse, then it turns into "ok, stop telling me this and because you're saying I'm going crazy" etc, etc and they just don't want to accept it, so like I just think, a big thing stopping any sort of, like progression, is the people actually just accepting it themselves and accepting it from early.

Daughter

In the case of with my mum, I tried to tell her for maybe the seventh time or whatever, but it's not registering and I was having a conversation with her and it shocked me she said "oh, Christian people or whatever don't get it", that was I mean, that, absolutely blew my mind, saying that statement and I mean like I'm still in shock now that, that ever come out of her mouth and I thought, what, I'd never heard that before and I said, what you talking about.

Researcher

What did she mean by that, do you think?

Daughter

I don't know, I honestly don't know.

Grandson

She means that, she doesn't want to believe that anything bad can happen to her because she believes in God and I understand where she's coming from, but I

think that that is a big kind of… just puts a cloud over things as well, where both of my nans because of that, they kind of struggle to see objectively.

Yeah, I think, I think, maybe that and I think I also… maybe it's a little bit of well, because I'm a Christian, bad things won't happen to me, I'm protected.

Daughter

What I forgot is, his other grandmother has got dementia as well, he knows more about that because he's seen her and gone through the stages but one thing though John* for a number of years has been saying about my mum, and we relayed it to my eldest sister and like all she was saying was, "it's just mum getting old" or whatever so that's why you know, I tried to put things in place, you know before I got ill, there was this group and this, that and the other, to make sure that, people, the older generation had a day for themselves, some time for themselves, to go out, activities, at least I know they've had some laughs because like with my mum all I've ever known her to do was work and church, you know , never been cinema, never been here there and everywhere, never been to the theatre and this, you know all the things that's seen as ungodly you know, so I just made sure and now I think yeah well you know, even though she might not remember half of the things that she's done or places where she's been, I know that I've had time with her.

Yeah and also I think as well, embarrassment, you know, yeah I think embarrassment but I never, really for me, understood dementia and this, that and the other, until when I went with her and like she had brain scans and this, that and the other and they explained it, and I thought wow, that's when I thought oh, it's an actual illness, you know and I think there's a lot of misconception surrounding it, I think, a lot of misconception.

(Q2) How can these factors can be overcome?

Daughter

By more contact with the Black-led churches, I think that is a main thing, like I think it was back in May,2017, although you know, I've got this thing (illness), I still arranged for a lady called Ann to give a sort of dementia talk sort of thing,

you know, and she came and gave a talk and explained to whoever was there, and even the pastor at the church where we held it said that he would invite her back to talk to the congregation because there's an awful lot of things that we just don't understand... yeah, I think that is a real sort of thing that we have to put in because like my mum, what she's 79 nearly 80, you know, I don't know... it's like she's ...for all these years she's been so...not untouchable, but she's a person by the book, if the church says this, that…so I think you know, if more people with knowledge stood up one Sunday morning or whatever and explained or gave a talk then I think that people or a congregation would listen, would understand I think, that's how a lot of people will get through, it's like, if somebody from Alzheimer's, dementia care, was invited to the churches just to give a half hour talk and if people wanted, because at the end of the day like for my mum, I mean, church is her world, that's her club, and like if anybody who knows my mum, I mean like they tell my sister when they see her, because I've been able to say oh blah, blah, my mum has....people have been coming up to me saying, things, but then again nobody wants to say anything to me because of what I've been through and because I'm still recovering.

Researcher

Saying things like what?

Daughter

Oh, your mother said this, or you know calling me and saying this about...well it's not so much about behaviour, it's you know her getting frustrated, losing her keys things like that.

Grandson

Forgetting things she shouldn't be forgetting, it's just small things like that, which obviously, these things might happen once or twice but when these things happen on a regular basis it's like, ok is something going on, that's what she means. I think, that's a good way of approaching it, I also think people have to be a bit more responsible, like when I've told for instance about it, like my aunt, her instant thing was like, "oh it's just old age, it's her just forgetting things". I'm like, it's not normal to just forget things like in old age, like if she'd been a bit more

clued up and thought, oh actually I need to educate myself about this a bit more, then earlier interventions could have taken place but I don't know how you could influence someone to be a bit more responsible about themselves, but I think that is an issue as well.

Daughter

I think maybe the issue with you know, with your aunty is maybe not wanting to face it because she's always sort of known, but I suppose it's just wanting everything to stay the same until the call, you know, because I went with my mum for the scans and it's all been confirmed, she's leaving work September, so it's sort of something that she's known, didn't want to say anything to anybody in the family or whatever, just trying to maybe just let her carry on as normal.

Grandson

Yeah I would agree, but I don't think that's any justification for it because it's not something that's just going to get better if you don't talk about it, so like, it's actually made things worse, it's not actually helped.

Daughter

How has it made things worse?

Grandson

Because if she had accepted it a little bit earlier we could have seen doctors and made all of these changes earlier and you can slow it down earlier, but if it gets to so far along and then it's like, oh, ok it's just gonna speed up now and you can't do anything. So, it's not a case of, oh we'll all just wait to do something like it's a cold, it will only get worse and as it goes on it's just gonna get even worse, even faster.

(Q3) How can we improve diagnostic tools and the diagnostic experience for people from African Caribbean Communities?

Daughter

Well, my experience, like the women, they were very kind, sympathetic, it was the doctor or consultant and they had a junior or psychology student, who took

my mum into another room and was asking questions, this was down at the memory clinic, the consultant told me that you know, I said oh we have to tell her, are you gonna tell her and she said I have to and she come back in, sat down and everything else and was just talking and she did say, she broke it gently to me, told us that, there's medicine or whatever that she could take so then I seen my mum didn't quite get it so, when we come out of the doctors, just sat in a private thing just in two chairs, we were down in St David's and you know I explained and she was crying, she was sobbing and then, yeah and then I said let's go for something to eat, so we went for something to eat.

The way the woman told me and the way that she tried to break it down to my mum, it was excellent, but then…. I don't know, but me personally I thought it was fine. I thought that the attitude and everything as soon as I walked in because I've never been down there before, never seen these people, I was put at ease straight away, but unfortunately with the student he seemed, I wouldn't say frustrated or whatever but I think he seemed a bit scared, this is what I picked up from him, you know he seemed to be, a bit scared, a bit frustrated you know, it looked like he thought he didn't do his job properly. He didn't know, the vibe that I got, the interaction he had with my mum put him off guard, whatever, then when my mum come in, she was...oh...I know that whatever exchange, maybe he was asking her the questions or whatever…that didn't go well.

I think, if my mum had said to him, you know, she's a retired midwife, this that and the other, blah, blah, then maybe that's what put him off, you know, if she had been trying to tell him something and him not wanting to overstep the mark or something, do you know what I mean.... I think it was the memory clinic, they took her in one room and I think asked her some questions and then maybe asked her the same question five minutes later, that's how they check.

(Q4) How do African Caribbean individuals and families experience living with dementia?

Grandson

We don't know because the diagnosis came so late, a month ago.

Daughter

A month/six weeks ago but...

Grandson

But we've noticed for about three years.

Daughter

A long time.

Grandson

There's not been support, but that's not because support hasn't been offered or available it's because it's not been accepted that there's something wrong,

Daughter

Yeah, this has only come about really because of the intervention of my sister because when she come down here , she was looking for places or whatever, it's my sister that come down from Birmingham and done something about it that's why everything you know happened, she done it because when she was asking me different things from when I was doing a project before, I could tell her Diverse Cymru and I could tell her certain things but she ...Care and Repair...there was things,...oh something in my mum's house, a magnet and my sister phoned them and that's how everything came about.

Grandson

To be honest it doesn't really make a massive difference to me, it's just kinda like a lot of times I just find it funny because I'm just past the point of...because like I've just accepted it now, I accepted it a couple of years ago so like certain things that she does like putting brown rice in her tea and thinking it's sugar ,like I just think stuff like that's funny, so it's not had like any personal effect on me, the only thing I would say is ...yeah like I'm a bit concerned about when she's out and about on her own because if she like… I remember like years ago now I was in London and I'd phoned her just to like say hello and she had gone, "oh yeah it was nice when I saw you on the bus earlier" and I was thinking what… and so she had obviously seen someone on the bus and then thought it was me and I don't know if she tried to have a conversation with that person or like, I don't know but

obviously it wasn't me and that was a couple of years ago and there have been times as well that I think my mother has just put her in the back of a taxi or something and she has been back and forth arguing with the taxi driver, take me here and the drivers saying no I've got it here on my screen, I've got to take you here and she's there back and forth, "No I'm telling you do this, do this" ...that's the only thing that I'm concerned about but apart from that there's nothing really.

Daughter

Yeah, I get concerned because I don't know what, like when she goes to the shops and like she buys... you know I went to the bank with her, I don't try and get in with all of that business, but you know, like when she was here, I said oh how are you gonna go to prayer meeting and she was talking about you know, getting the number 8 bus...but the number 8 bus don't go down Bute St and all of that, like it used to and so we called her a taxi and I told them where to go and then I seen the taxi man come back and he said, "oh you know she's telling me to go to Canton so I brought her home" and then he said "because she's getting irate as I am" and then I said, she needs to go and then he said to me, "oh yeah I understand, my mum gets like that". I said, I'll give you the money just take her drop her off, you know where it is, so I had to go to the taxi, calm her down, I said, mum he's taking you to prayer meeting, you don't have to pay him or anything, I've done that already, you know so, that's ....

Daughter

Yeah, yeah, I mean, she's got so much clothes but she's lost so much weight but what I notice is she not eating, I said to her, "what have you eaten?" and she says "oh toast" and all these things, I said "no you haven't" because of such and such, you know, she forgets to eat it, she thinks she's eaten, I have to go through the fridge, throw things away so when I'm down her house we'll go out for dinner.... "oh I haven't been here before", she has, but never mind....so I like just take her out and although she's been to a place before I just ...but then I'm...I have to be careful as well because I get very frustrated so I you know I have to calm down.

Grandson

But again for me it's not really too much of a big deal anymore because I've known about it for a couple of years so when I was telling like my mum and stuff in the past and then it was like, yeah ok, we'll see, we'll see, I just accepted it from then and so, but like I'm ok, like I, obviously I'm here but it's not as if I'm always having to take care of her or I'm having to sort out like… like if it comes to care, it's really most likely my aunty first , my aunty and uncle and then my mum and then me, so it's not really any burden on me, it's not a big effect on my life, you know

Daughter

But no, I mean like, it's no problem really.

(Q5) What services might BME individuals and families be looking for?

Grandson

To be honest, I don't really know what services are out there, so I couldn't say that we need anything different because we're Black…. I think Black people and any sort of mental health or any illness that they can't see it's just like, it's just like not really talked about.

Daughter

It's not really talked about or anything like that.

Grandson

With my nan in London, I'm not really sure about that because I'm not really involved in her care and I don't really know her friends and stuff, but with my nan's friends here, to be honest, like I haven't noticed a change, because obviously all of her friends are from the church, they're always, just always about anyway.

Like as far as I can see and like whenever she goes to church or has like a church event or something, there's always someone picking her up, always someone dropping her off, like coming around to fix blah, blah, blah, when I'm at her house for any sort of reason, you can't sit down for fifteen minutes and the phone don't ring, literally, she's always on the phone or someone phoning her.

She's always on the phone, always.

Daughter

But one thing, though is like, because she's incontinent now, but she never said anything to me, I know she went up to the hospital or something, anyway, but it's my sister who told me, but you know, I go and I buy her incontinence pads sort of thing and this, that and the other, yeah.

I just buy them, my sister, I mean I didn't know anything about it, it was my sister who told me and it was my sister who told me where to get them because she knew, because I'm the youngest in the family and my sister is the eldest so she's spoken a lot with her that's how I knew and then she went up the hospital and had something fitted but it's not working, I don't know, I just buy them … yeah.

(Q6) What is the best way to reach our communities?

Daughter

Well, I mean from my perspective it's the church and I think that in all churches because they've got like such an aging population, I think on all churches' calendars they have to have one time or whatever, someone goes and speaks to them about dementia, Alzheimer's Society or whatever, because looking back, like in the Baptist church that I used to go to, I think about things now and I think oh that's what was wrong with that person, you know.

Grandson

I can't really think of much else than that, just maybe on the leaflets and stuff just like more Black people on the leaflets, I think that fact which you said earlier that more Black people by blah, blah, blah there'll be like this amount of people of colour with dementia, just let people know that, literally like because if they don't know they'll just think, oh that won't happen to me, just make sure that any of the marketing material or just information is directed at them.

Daughter

It's because, I thought dementia was a psychological thing and that's me! I honestly thought it was a psychological thing and like it's taken me all this time to

realise and to understand, so basically it's a physical thing, it's your brain cells have worn away, you know.

(Q7) What challenges might be encountered when developing and providing tailored services to people with dementia from our communities?

Grandson

People not seeing themselves reflected in healthcare professionals, so let's say there's like a community nurse who comes around, gives a talk even like my mum was saying, someone from a health organisation comes around and does a talk, if it's some old white guy there, you know just none of the old ladies who are Black and the men are just thinking, ah who's this guy now, I'm not really listening, I don't really care, but say it was like a Black person, they would take more notice, I honestly think that but obviously don't know how they're gonna do that but I think that would be good just to see someone that looks like them talking to them, they're gonna listen more.

Daughter

Yeah, I remember in ACE group, when they were showing a film, I remember there was an old Black guy in the film, it could even have been in a church setting and I remember they were saying "oh, love him", the film was a dementia film sort of thing, he wasn't aware of it and they were saying "oh love him", you know, it's just I can hear my mum and see my mum while watching the film and I'm thinking my goodness, whoever, you know is saying what's happening to her.

Grandson

I think that's the main thing.

Daughter

I mean, I don't know whether, well, I know I don't know the woman who come to talk and had that film but there's another lady, her names Anna with Alzheimer's association, she does the talks now, she's white. But they...you know, I think that since you're saying about how dementia is going to be you know coming to the forefront, I think the government or whatever have to put in place or have to have, a person of colour to be able to relate, you know, they need that.

Well they just have to train people, look for people, professionals or ...they have to look for people to represent…. or they need to have a person who's from that background, maybe Pentecostal backgrounds or grew up in that setting, same like if you're talking to African people, they're different, they've got a different perspective on things but you know… and like from a Pentecostal, Jamaican or Caribbean…you know that back home in Jamaica , how they were raised, under colonial rule sort of thing so they've still got you know…somebody who really understands, you know, that's how you get through…. even though you know, you know like, it can be like, if somebody like John*, only because he's seen it from an African and Caribbean, you know although he's sort of like Black sort of British, he's had a connection with the older sort of like community, you know like a lot of people in… a lot of children now they've got a disconnect.

Grandson

I haven't seen any difference…..

Daughter

The African one is in a home now isn't she...

Grandson

Yeah

(Q8) Which organisations at local level and international level are best place to lead this work?

Grandson

I don't know any organisations

Daughter

Ok, well, I would say ACES, (African Caribbean Elders Society) but ACES is no longer but the Pentecostal churches, there's got to be someone, because you think of it, the majority of the older generation were nurses, they come from a medical background, those sort of people… ACES was something that I just thought out one day and set it up, it wasn't, you know...I was just lying in my bed and thought, oh, you know, I sort of like… I know it sounds kind of freaky, I'm very

aware and conscious of government money, you know because back in the day, I seen so many organisations thrive and their funding's taken away and then I thought you know, I only set up ACES because I thought [It's] somewhere where the ladies don't have to cook, fry their fish on a Friday over a hot stove and this, that and the other, let them sit down ...yeah and just to sit, chat, have a laugh, that's what it was but then it grew and grew, you know what, I think there was one video where I said I want something for me, you know just somewhere to go and just talk.

I think it has to be a new organisation, it would have to be a new organisation, a kind of independent organisation because there's so many organisations, me, I'm all for everybody working together but then you hear this set of people, "me nah want to go down dere", "I don't go to dem places" , "me nah want to go dere", it just has to… you know what I use to like about ACES, all people, all different people from the Caribbean used to come, Seven Day Adventist, they all used to come, leave everything behind and just come, have their meal, if there's a speaker, listen to the speaker, you know and that's all, somewhere they can go and talk freely, because some of the older ones don't know political correctness and you can't put no bridle on them, some of them women, their mouth, but you know.....

Researcher

Is there anything you would like to add?

Grandson

I think we could have been more helpful if we were further along in the process, I think a lot of the things you asked like, we just don't know yet, about like services and stuff we just done, don't know yet but maybe in like six months, eight months' time, when there might have been a little bit of interaction from the council or I don't know, the health service etc, etc and then we can see how they interact with her and stuff or like, what sorts of processes are in place, that's when we could say, oh, actually we found this and this can be changed by this.

Daughter

Are there a specific group....a Christian group would be nice sort of thing, whereas people who meet have got that ideology from Pentecostal sort of thing, you know they can meet and talk about oh…back in the day, you know, they had wide brim hats or whatever, you know have a conversation about church now, church then, you know, something that they all, you know...when you first came over to this country and you know, people used to talk about, you know coming to Cardiff, and you know in a nice way, but like with people who you know go to the pub and stuff, they've got their own sort of like network sort of thing, this sort of people are used to more you know, white people sort of thing, but yeah it would be, I mean for someone like my mum it would be nice but yeah but I think she's, yeah I think she's alright at the moment so to speak but what concerns me is she's always complaining of her legs and I just don't want where she can't walk or whatever, I don't know, I've got some niggling thing in my head you know, yeah she's always complaining about her legs.

Daughter	**N/A**

(Q1) What are the factors, if any which stop people from African Caribbean communities seeking early help/intervention and/or getting a diagnosis?

I am worrying about what other people might think, I think that's one of the biggest things and maybe being concerned about how the issue will be misconstrued. Like will it be, will they just think like, you know, a typical obnoxious Black person or something, yes just concerned about perception of maybe the professionals and amongst friends and family or just community. Just a bit of a worry, but yeah for us, we just wanted to have answers but then perhaps there was a lot of denial first you know, in terms of like, you know not wanting maybe to think about what might be going on health-wise but, yeah I think that's it.

For us, it was just about, you know that there is an incident happened that made us realise, oh gosh this is like you know something more serious and… and I guess as soon as we realised that we started to ask for help…yeah, we started to ask for help because it's like a safety thing for us, you know what I mean.. when someone starts to become unsafe to be going around by themselves. So… but I think I can imagine for many people there will be those things that I've mentioned before yeah, it's getting that early help that could put you off. Like I said denial as well, yes denial, yeah, yeah, yeah and just you know when you think about people getting old and cantankerous as well and yeah you may be thinking in terms of that, it's a bit of old-age or whatever… until you could no longer accept that you know. So when it comes to diagnosis… once we got, you know…. we went to the GP, we were just pushing for a diagnosis as soon as possible.... we just wanted to know what's what and I guess hoping that it was obviously not dementia and it could be something else causing it you know, but unfortunately it wasn't and yeah it was dementia, Alzheimer's in Dad's case.

(Q2) How can these factors be overcome?

Having like more people talking about it and maybe like support groups for BME communities to get together and to talk about these things. Yeah I think that's… yeah awareness raising and trying to break down stereotypes about who these things happen to... yeah just raising the awareness, getting people together

getting more Black professionals to talk about it and to maybe deliver services themselves, specifically people who may have more of a understanding who older people could relate to you know, because especially with dementia you may be looking back to where you were at before and it'd be good to have people who could relate to … so people are more forward opening their [mouths'] about the issue….. and could talk about it more to break down that stigma.

There is a big mental health stigma with Black people and they don't talk about it as much as white people do at all. Like White people will openly say I've got depression, I've got anxiety, I've got personality disorders and all sorts of stuff really, when you just meet them, you know a couple of times, you know what I mean…and like you know with your relatives or your cousins and you've known them all your life they don't talk about their mental health. It would be wonderful but it's very rare unless they had to tell you. So yeah, the lack of openness I feel …like Black people can be really proud as well you know, very proud about themselves and what other people may think which is not at all helpful.

When it comes to resources, I guess if people knew that if my relative was to need support and care…if there was more specific or were more specific resources and places to go, visit residential homes etc, etc, that might open that can of worms more easier… because when you start to think what's going to happen and if you can manage, but you had that light at the end of the tunnel where there could be somewhere suitable for them, that it may just make it that bit easier. Rather than just like open the can of worms and thinking, oh my gosh what are we gonna do... there's so much horrible decisions that need to be made you know, there's not enough options.

(Q3) How can we improve diagnostic tools and the diagnostic experience for people from the African Caribbean communities?

The assessment it was okay, we had like support staff, the staff were good, I have to say they were, yeah, really good they were. They explained everything and they gave us a lot of information about coming back and what would happen next and I asked a lot of questions and they answered them all and they said you could ring up. So, the diagnostics bit, it took too much time, I would say it could be sped up a bit.

Researcher
What do you mean?

Daughter
The process, maybe the process could be maybe sped up a bit. If there was a way of doing it in people's homes that would be good that might be better in terms of the person being somewhere where they feel comfortable instead of being somewhere where they're not familiar, but quite often I think dad was more on the ball when he was out of the house…. but I don't know if that's good or bad at assessment do you know what I mean, because it could be good because he is more alert like you know, I am out and put a front on, but that's not necessarily how he is at home, but yeah I think that's all I can say on that. I think maybe doing something at home or having that kind of option…yeah, for some people it could be that that they might prefer to have services from their own community or someone that looks a bit like them, they can relate to that, my dad wasn't too much like that, if you know what I mean, in terms of terms of engaging. Dad engaged with lots of people really from different backgrounds and stuff. I can see how that can be beneficial if there was somebody who looked like them around, because there was nobody like that you know. If there was somebody to provide that support or just…or a friendly looking face then yeah, I could see how that could benefit some people… like, some people, my dad would think that he knew them.

(Q4) How do African Caribbean individuals and families experience living with dementia?

Well, it could be very up and down in terms of like, my father became very, very ill, it was the case of being told you know, being told to prepare for the worse. You know like then, being prepared all the time and then dad overcoming the illness that he had at the time, going up and down like that for about two years roughly. It was about two years… and… yeah. So being told that you have to be prepared for the worst, he hasn't got long left and one time we went into hospital, he had an infection and we were told he's not going to overcome it… so those ups and downs….

In the beginning it was very…. it was weird because obviously this person looks the same and… but yeah at times they could be the same person, but then other times they can be such a different person and just seeing how the person could pretend, and just try and style it out in terms of acting like everything is okay, but you could see in their eyes, they are panicking, because they have forgotten something. So very, very, very, upsetting. Like seeing him feeling frustrated and everything…and from our perspective it made him like… from when he was first diagnosed, bond more with my daughter, because he could just sit down and play with her and so she has a lot of positive memories about that. When maybe had he been well he maybe would have been watching the news or something, you know what I mean… he wouldn't have been sitting down, playing with her on her level on the floor, playing with her dolls and her toys, he may not have been interested. So…so yeah, it was very frustrating, at times just upsetting ….. (long pause).

When he was unwell, like you know…so the health service…getting the doctor to come out and when he had an emergency, often he used to collapse in bed and stuff, we would have to ring an ambulance… like the lack of continuity with the doctors. Like obviously with out of hours, doctors are different ones coming and sometimes they wouldn't know him and so they couldn't…. they didn't know his baseline, so they couldn't really know how unwell he was and they will ask us, is this how he normally is or whatever…but like always having different doctors because it was always like out of hours, things didn't usually happen in the day time Monday to Friday and so it would always be an out of hours doctor. They could be very good but they didn't know him and if there was like somebody that knew him...obviously I know it doesn't work like that does it, you can't have you know…. It was very difficult when just the doctor would ask questions and for us the hardest part for us was not knowing if he was in pain or not and trying to read the situation and trying to read you know like, is he in some kind of pain in his stomach, or you know, it was very, very upsetting when he couldn't communicate any more. Yeah, for us that was the worst time and very frustrating and upsetting yeah, just seeing him, yeah… it's so difficult like, seeing the person there but they are not really there, yeah, yeah, yeah, then…. (long pause)

It could be hard when people came to see him and then they are very upset because they haven't seen him for a very long time, so that can be very upsetting.

Then people also talking about him and not to him, when he's there, like you know…. I guess that's a learnt skill, but people talking about him and not very sensitively in front of him, but professionals were ok with that, on the whole they would talk to him, even though we would answer, you know they would look at him engage with him and hold his hand or something, so we always appreciated that.

So yeah, it was just like… it was a very difficult journey not knowing what was going to happen and like you know for us…it was like constantly being told to sign a DNR and like us resisting that… like you know. Whenever we'd go into hospital they would say to sign a DNR, or encouraging us that much towards the end you know, we got told that a DNR was put in place and like we had no choice in the matter and when dad went into hospital the final time and he was put on the ward the guy said, oh I've torn up the DNR, they shouldn't have done that you know. What I mean… the last time he went into hospital, we rang the ambulance, he sort of collapsed in bed…the hospital had said that, then two days later at the ward, he (a member of staff at the hospital) was like yeah they shouldn't have done that. So that was you know, it was positive for us, made us have a bit of hope, but then unfortunately that was the last time he was in hospital, so yeah very, very, very, very, upsetting journey. Fortunately, we had each other (referring to her mum) to support you know, we're close…but, yeah, we had each other and so we fear for somebody who wouldn't have anybody to talk to, anybody there. We could do what we had to do together, so for me it had an impact, reduced my hours at work, that had a financial impact, but you know, I was happy to have that time to be able to be home, to help Mum care for Dad. Yeah, the financial impact…we paid for the caring costs as well, so yeah that could be another financial impact, but it was, it was…yeah that's its really.

(Q5) What services might African Caribbean individuals and families be looking for?

Support from people that look like them. Support from people who've got cultural understanding, for us, especially in terms of the DNR, because so many people are not Christian in society, because dad has always believed, where there is life there is hope, Mum strongly believes that and you know it's like a complete kind of like, not grasping that at all. Yeah, support groups again…support groups, maybe BME

staff being involved in assessments, and maybe it happening in people's homes to see how they are in their normal environment. Yeah, there were some groups which you get booklets and those stuff to read, that we found out about, but mum never ended up going to those groups, you know. Yeah, there were at one time… mum was going to a group, but it got closed down or something…Penylan, there was something, I looked into it, so also when it came to day centre and stuff, we were a bit reluctant to send him off to a day centre, just in terms of just worrying about him, especially if he's been out of that environment for a short time and how he would be. If there was somewhere maybe where… yeah, there were, you know more likely to be ethnic minority people, then you know then it might not have been such a daunting prospect really, yeah, yeah. Mum wanted to do like everything by herself, well with me, but you know what I mean, it was hard to let go of that and knowing if he was with us, we would know what was happening kind of thing… yeah I think that.

(Q6) – What are the best ways to reach our communities?

Places where we are, you know whether it's like they got used to going to the ACE group and …. Mum used to go with dad, which was really good, before dad stopped walking, they used to go on a Friday and my friend X used to have my daughter when I was at work…and I remember it was good, you know. Dad, used to go to that it was lovely, he used to brighten up. He didn't get involved as much in conversation or anything like when he was there. Going to groups like that and going to churches and the community centre, like having maybe events down there, awareness raising events in the community, and there's people that don't live in Butetown, Grangetown or Cardiff, who don't have that or… coming together in anyway.

You know, maybe [GPs] having no services there really, sign posting BME people and … yeah, I think that's it, churches, community centres, dominoes club… I don't hear of any…not sure, I don't hear of any West Indian Cultural Association anymore. If that (dominoes club) was organised, in a way it would be good because that would reach a lot of men. You know Black men, in particular, are just less likely to seek medical help than anybody else. That would be a good way to reach them….reach them through their families as well, you know, or cricket clubs, do they have them anymore… times have changed, we don't seem to have

these things anymore, when you want to reach our communities.

I guess it's just making sure that everyone is aware in the communities, have as many people as possible, so they can sign post people to them, and there can be somebody to take them out.

(Q7) What challenges might be encountered when developing and providing tailored services to people with dementia from minority groups?

Maybe the lack of openness in some communities, if they are engaging with somebody who they may not think will understand their culture and then there will be communication barriers perhaps with regards to people speaking Patois and people think they are mentally ill… or that they're just not understanding… like our communication. People might go back to a time when they spoke more, you know Patios, than you know, than they did in later life… lack of communication.

Getting them to speak about it or getting them to go to support groups. Due to stigma, some might not want to go, but should at least be there. Stigma, lack of understanding, communication, lack of residential homes, where people would feel comfortable with them having their food and feeling at home…making it more homely, so having the lack of that…yeah… that's it.

Speaking to people and seeing what they want, like doing pieces of work, what changes would you like to see, what might make you engage, what might make you come forward to say that you're worried about yourself or a family member…. having people from their backgrounds, having places where they can have their own food and everything …. Food is such an important part of things and those people having to eat food that they are not accustomed to. As my father's dementia got worse, he became more flexible with his diet, you know he would eat anything, he wasn't always like that. He was very, very, very, particular, he was a really healthy person.

(Q8) How can these be overcome?

Getting BME Communities on board from the beginning and listening to them and

making them see that changes will happen. You know, like having a plan to say that, after we have done this, these things are going to happen or we've got this money to do this, or we're going to apply for this money and letting them see that, buying into the fact that there's going to be some changes and putting resources into it…putting money into it and… just thinking sometimes as well, Black peoples diet is not great and they do talk about links with dementia and diet and types of food and exercise…is that answering a different question?…

That can be an issue, a lot of people are set in their ways and they don't have, like you know, you won't find the older people saying they're going to the gym in their 70's, who are Black you know, but you might find some white people in the gym, no Black, more white, they're not doing that.

Yeah… education around prevention in terms of diet.. I think because of diet… I think because there are main things that we are predisposed to, like high blood pressure and lots of other things which could be linked to dementia. So just having these services led by people with proper cultural understanding.

(Q9) Which organisation and individual, at local and national level, are best placed to lead this work?

Which organisations.... I guess somewhere like Diverse Cymru then, who deal with mental health, yeah and there are mental health projects, just think now….

No… that's not the one that's been closed down…I was thinking the one that was closed down… something to do with advocacy…
Making sure that organisations such as Diverse Cymru have got the money to do these pieces of work, with people and people who know people on like, grassroots level and who are able to get in contact with people and who are in the community rather than people who are not in the community, people are not going to feel comfortable to talk to…because they can't relate to, but that can be good and bad as well… though some people might want to have people that they don't know to open up to and also maybe having ways of people to feed into things anonymously. For some people they may have other ideas but they're not going to stand up and say what they think should happen.

People like you know…like the ACES (African Caribbean Elders Society) group, I don't know what it's called now sorry. I think it's still called the Ace group or is it called something else now…

People who know people who are familiar…and also community nurses as well. We need to work together as wider services. In terms of… it's great to have specific details of services as well but also, everybody needs to buy in so that all these issues are mainstreamed… so everyone's thinking about how to cater for our people's needs and everyone's got responsibility, not just you know, people to just listen to what's being said and what's been found out… yeah they would be the only groups that I can think of.

Setting up something specifically would be ideal...

One-to-One Interviews

Suzanne Duval BEM

BME Mental Health Manager
Diverse Cymru

Answers for Dementia Project (Humie Webbe) Caribbean	Father aged 85 has dementia and lives with her
	Interviewed 14 January 2019

- **What are the factors, if any, which stop people from BAME communities seeking early help/intervention and/or getting a diagnosis?**

Not having the services out there. Shame and stigma and you need other support than your family. People trying to access services. Not like people knowing their business. Practitioners not sympathetic to their needs. Not culturally appropriate.

- **How can these factors be overcome?**

Training – practitioners and families. Access to local resources. People needing to know how to speak (advocating) and explain what it is they are experiencing/needing. Utilising community networks so that they can access their own groups (like the Barefoot project used to be).

- **How can we improve diagnostic tools and the diagnostic experience for people from BAME communities?**

Use activity based actions. People don't always want to respond to a questionnaire. Using tools that tell you about the person. Different types of diagnostic tools.

- **How do BAME individuals and families experience living with dementia?**

It can be a battle with professionals when you try and advocate on their behalf. You as the carer need to keep yourself well, whilst trying to look after an ill person. Information about respite not forthcoming. When I asked the social worker about it after looking after my father for one year, the social worker asked me why I wanted it.

- **What services might BAME individuals and families be looking for?**

Activities – music, dancing, singing, short films, reminiscent [reminiscence] groups. More involvement with voluntary groups. Sport related activities. Services that they can have in their homes. Foot and eye services whilst in respite

are not forthcoming. My father's hair was not washed for the 2 months that he was in the hospital (2 month's worth of dirty hair and dandruff).

- **What are the best ways to reach BAME communities?**

Have to make connections through GP's, places of worship, cultural activities, e.g., Chinese New Year, ethnic minority fayre and personal contacts. Look at range of things. Project related things.

- **What challenges might be encountered when developing and providing tailored services to people with dementia from minority groups?**

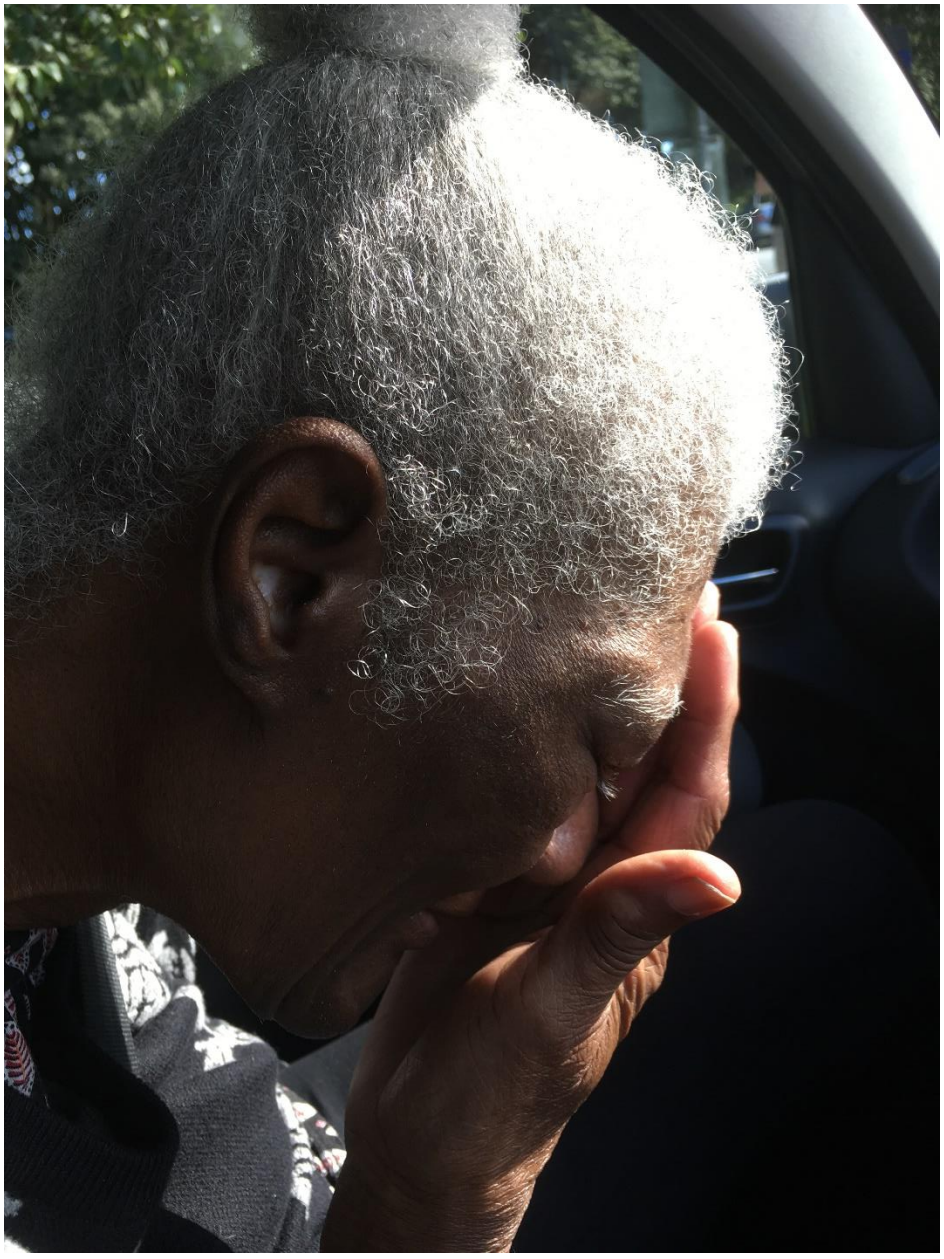
The challenges appear to come from the services not the people. Not enough time in projects to build relationships. Put on roadshow events, e.g. - not always being able to engage with people.

- **How can these be overcome?**

Having designated practitioners to work with people from their own communities. Welsh Government needs an understanding of being able to reach – how and when.

- **Which organisations and individuals, at local and national level, are best placed to lead this work?**

In terms of people responding to documents, people need to see what the outcome will be and something (a service) that doesn't have a time limit and closes. A BME focussed service to make sure BME people are catered for and it shouldn't be a crisis management approach.



Answers for Dementia Project, African Caribbean Carer	**Her mother who has mixed dementia, Alzheimer's disease and vascular dementia has been in hospital for 2**

	years.
	Interviewed 17 December 2018

Questions for BME Dementia Project

- **What are the factors, if any, which stop people from BAME communities seeking early help/intervention and/or getting a diagnosis?**

Because of racism and the barriers that exist within institutions. The fear. Not understanding/realising. Lack of awareness.

- **How can these factors be overcome?**

More education within institutions, not only front-line staff, but from Boardroom to managers. Raising awareness within the communities to empower them to take action. These are long-term solutions.

Staff to treat patients humanely and to be culturally sensitive/aware.

- **How can we improve diagnostic tools and the diagnostic experience for people from BAME communities?**

Questions need to be appropriate to the person, e.g., not Eurocentric. Questions need to be personal about the family. Questions can be audible and not in writing. Questions can be prepared by the family before the appointment and can either be sent in advance to the clinicians or taken on the day.

- **How do BAME individuals and families experience living with dementia?**

Lonely and isolating for both. When my friend's nana had dementia, her friends stopped visiting the nana. Stereotypical beliefs that if you're from a large family then everyone will help and look after the person. Families split up over it. Lack of awareness within families. It's challenging. Institutional racism. Hell. Fear.

- **What services might BAME individuals and families be looking for?**

A humane service with staff that take cultural sensitivity seriously. An equitable service.

- **What are the best ways to reach BAME communities?**

Through the media – adverts on TV, to have Black people featured in the adverts. Black helpline. To show diversity in dementia articles.
Black churches, community centres, schools, barbers, bookies, GP's, bingo halls, restaurants, post offices, banks – everywhere!

- **What challenges might be encountered when developing and providing tailored services to people with dementia from minority groups?**

The lack of understanding of minority groups by staff. Need support from the bigger institutions. Not just a Black issue, everyone must support everyone! Organisations need to meet the 5 ways of working from the Future Generations Act; Equalities Act 2010; Social Services and Well-being (Wales) Act 2014 to be followed. Equity and equalities not to be seen as an add-on.

- **How can these be overcome?**

Accountability, repercussions, consequence, counteraction. Education. Gatekeepers need to put you in touch with their groups. Needs to be a safe space where people can talk and not bottle it up and be able to disclose safely.

- **Which organisations and individuals, at local and national level, are best placed to lead this work?**

There isn't one and something needs to be set up.

Answers for BME Dementia Project Carer (Wife)	Husband has Dementia
	Interviewed 16 April 2019

Questions for BME Dementia Project

- **What are the factors, if any, which stop people from BAME communities seeking early help/intervention and/or getting a diagnosis?**

I suspect maybe embarrassment at this type of illness; dementia/mental illness taboo, a wish not to disclose this problem.
Lack of awareness of memory problems becoming an illness and of the availability of services.

James denied his problems from the time of diagnosis and became angry if one mentioned them. He said crossly "are you saying I am mentally ill?"

- **How can these factors be overcome?**

Target raising of dementia awareness among BAME communities e.g. in cafes, meeting places and places of worship

- **How can we improve diagnostic tools and the diagnostic experience for people from BAME communities?**

Avoid using family, relatives and close friends as interpreters who may share the view of dementia as a stigma.

- **How do BAME individuals and families experience living with dementia?**

Denial has been my response! Like the non BAME population? E.g. memory problems put down to old age and something to be lived with. Gradually increasing constraints on an ordinary life especially when incontinence kicks in. Carers' lives become more restricted.

There may be advantages from BAME cultures e.g. more frequent dropping to the house of friends which reduces the isolation felt by the carer/cared for person in the non BAME population. Some BAME who have been in Cardiff for generations, may have more family support than nuclear families.
Conversely, newly arrived BAME families may be even more isolated.

- **What services might BAME individuals and families be looking for?**

As with non BAME people, culturally sensitive advice and information.
Counselling and support for the carers.

Continence advice and, when applicable, continence supplies.

Medical, medication and social care assessments regularly reviewed.

Helplines with relevant languages. Audio services helpful if individuals are not literate.

- **What are the best ways to reach BAME communities?**

As above in point 2: BAME community groups, cafes, places of worship. Posters in relevant languages in GP surgeries and pharmacies.

- **What challenges might be encountered when developing and providing tailored services to people with dementia from minority groups?**

The key is in the question “tailored”. This applies equally to non BAME people. Care plans should take into account individual preferences, individual circumstances. Lack of staff and paid care workers with the appropriate skills in dementia care and with appropriate knowledge of language and culture.

- **How can these be overcome?**

Ask BAME individuals their perspective as you are doing here!

Research into the numbers of BAME affected by dementia. Statistics provide evidence of the scale of the issues in order to plan appropriate services. Publish widely the results. Training of staff in health and social care sectors, both statutory, private and third sector organisations.

- **Which organisations and individuals, at local and national level, are best placed to lead this work?**

Alzheimer's, Solace and other dementia organisations have the knowledge of the condition which probably needs supplementing by knowledge of factors significant to BAME populations.

Samira Salter

Mental Health Support Manager, Diverse Cymru

who held the Focus Groups for the Yemeni women

Dementia Workshops/Focus Group	Yemeni women in Cardiff
Workshops	December 2018 to February 2019

This initial workshop was to meet the Yemeni ladies and explain about having a

mental health illness. In order to gain their trust and to breakdown any stigmas and barriers towards mental ill health that they have, we talked about general health & wellbeing and touched on what it means to them when they feel sad and down. The ladies were able to explain that they have stresses in their lives due to family and physical ill health like diabetes, arthritis, high blood pressure etc.

Workshop 2

In this workshop we explored what you eat and drink and your brain. Research shows that diet plays an important role in reducing dementia. They were asked what they would eat and what they thought was a healthy diet. The ladies were given a sheet of information about dietary fats, bad fats good fats, and which dietary factors might affect dementia risk. We went through different diets eg Mediterranean diet, omega-3 fats, and what is the best diet for people with dementia. The information sheet was also given to the ladies in their own language, Arabic, so they could take it away and read at their own pace or have a family member read it to them as some could not read at all. They recognised how healthy eating can be beneficial to their mental health and wellbeing.

Workshop 3

I wanted to focus in this workshop on dementia and one of the ladies who attended opened up and said that her husband has dementia and she found it difficult to cope in the beginning and to find the right support. She explained that she noticed there was something not right with her husband and his behaviour had changed dramatically which prompted her to go to the doctors she said they had an interpreter and the doctor took some blood tests. A week later they were called to come back and see the doctor who confirmed it was dementia. The lady was very tearful explaining her situation. I asked whether she has any support, she replied '**only from my children and I am exhausted but what can I do?**'

The participants were shown 3 videos in Arabic about other people with dementia and doctors explaining the symptoms of dementia. We had a discussion

afterwards about if they had or have any concerns themselves or for a family member, and if they did, then they should go and see their doctor just to get checked; it may be that the illness could be something else, but it would be best for them to go to their GP if they had any concerns. The ladies were given a folder with information eg leaflets in English & Arabic about dementia and contact details on where to access support.

Workshop 4

In this workshop participants were asked a series of questions about dementia:

- What are the factors, if any, which stop people from BAME communities seeking early help/intervention and/or getting a diagnosis?
- How can these factors be overcome?
- How can we improve diagnostic tools and the diagnostic experience for people from BAME communities?
- How do BAME individuals and families experience living with dementia?
- What services might BAME individuals and families be looking for?
- What are the best ways to reach BAME communities?
- What challenges might be encountered when developing and providing tailored services to people with dementia from minority groups?
- How can these be overcome?
- Which organisations and individuals, at local and national level, are best placed to lead this work?

This took some time to go through and I will go through each question in detail.

Question 1 Answer

There needs to be education about dementia as, apart from one of the ladies who has a personal experience of a family member, the others did not know what the signs of dementia are, when to go and ask for help and most of all there was a lack of understanding due to language barriers.

Question 2 Answer

The factors can be overcome by having community champions raising awareness within the communities about dementia.

Question 3 Answer

You can improve diagnostic tools by having information –eg leaflets in different languages and making information more visual.

Question 4 Answer

From the experience of the lady with her husband having dementia she feels she would probably accept support if there was someone who spoke the same language and from her cultural and religious background. There is not enough support or information for the family.

Question 5 Answer

Respite service even if it was for an hour so this particular lady could get some sleep. More hands on support.

Question 6 Answer

The best way is to take it to the heart of the community, a leader or community champion. Word of mouth is the quickest way of communication. Build up trust with the community, this takes time.

Question 7 Answer

The challenges are language barriers, lack of trust with services. BAME communities need to feel valued and have culturally appropriate services tailored to their needs. It is always better to consult with the community first and listen to what they want, not what services think they need.

Question 8 Answer

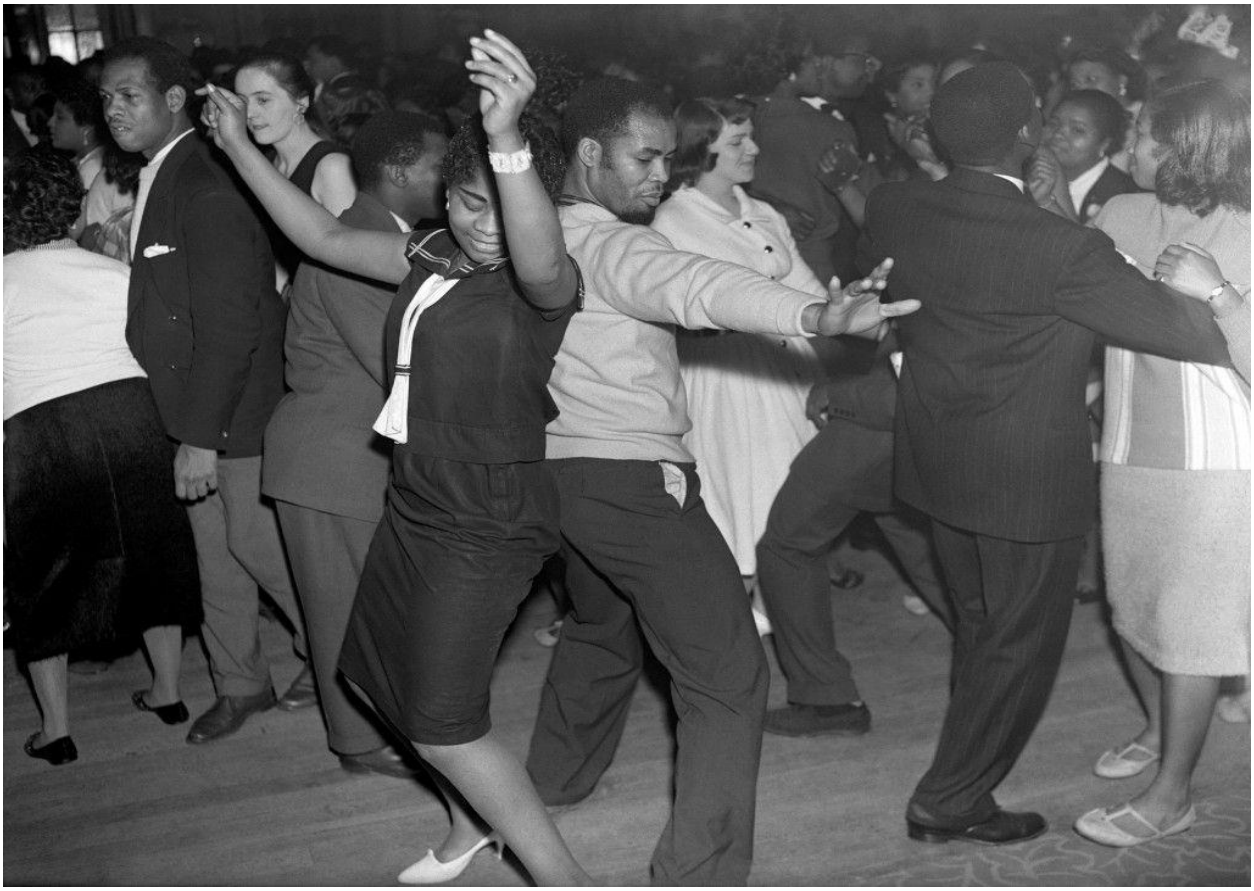
Building trust with seldom heard communities over a period of time, having a community champion within specific communities and most of all listen to their needs.

Question 9

At a local level there will be organisations that community leaders are already familiar with - organisations that understand and listen to BAME community needs and who can be culturally appropriate when delivering training sessions, information sharing etc.

Self-reflection by David Truswell Executive Director

Dementia Alliance for Culture and Ethnicity.



Questions for BME Dementia Project	David Truswell
	15 January 2019

- **What are the factors, if any, which stop people from BAME communities seeking early help/intervention and/or getting a diagnosis?**

There are a number of factors which I have explored in some detail in a book I'm about to get published and also in my Briefing for the Race Equality Foundation 'Black, Asian and minority ethnic communities and dementia, where are we now?' Which is on their website but also soon to be updated.

In brief:

1. People think dementia is a natural part of ageing so tend to dismiss early signs and symptoms.
2. People think BAME people are at less risk of dementia when the reverse is true for some BAME groups.
3. People feel that asking for help is a sign of weaknesses and they do not want to give up their independence and self-reliance
4. People expect services to be either ignorant of BAME cultures or actively discriminating.
5. People think that they should not let anyone outside the family know through fear of stigma within their own community.
6. People think they should provide the bulk of care within the family.

- **How can these factors be overcome?**

Community education that is targeted at the main oldest BAME communities and includes the whole community not just those directly affected. This needs to be sensitive to local population demographics but most likely would include the African-Caribbean, Asian and Irish. In some localities e.g. London, local populations may include a relative high number of ethnic seniors from other communities, e.g. Chinese. The aim would be to inform and create more understanding within the community so that not only people living with dementia in the community and their carers know more about dementia but that people in the community can be more supportive and understanding. People in services from primary care onward need to have a better understanding of the anxieties and risk of stigma that people from BAME communities feel. Good practice guide (**see Appendix 1**)

- **How can we improve diagnostic tools and the diagnostic experience for people from BAME communities?**

We need to look at what is being done internationally currently with creating better tools for BAME communities and also work closely with local BAME community groups to improve diagnosis and post diagnostic support locally.

- **How do BAME individuals and families experience living with dementia?**

I go into this in some detail in my book but it is often devastating as a result of people not understanding dementia and also the complexities involved, particularly in the latter stages, or how long people may live with their dementia and continue to be in need of high levels of support during the time. I've heard it variously described as 'a nightmare' and 'the most challenging thing I've ever had to do'. The high risk to the health and welfare of carers does not get enough attention. We actually know very little about how it affects BAME families because there is little research done and little to encourage the voices of BAME carers and people living with dementia in mainstream dementia promotion and information. I suspect some of the most vulnerable are also the least likely to get a hearing.

- **What services might BAME individuals and families be looking for?**

1. Information and advice
2. Ongoing support with activities of daily living and support for carers
3. More culturally informed personal care and support services e.g. personal grooming, diet, healthy activities, spirituality, leisure and social activities.
4. Culturally appropriate end of life care

- **What are the best ways to reach BAME communities?**

There are a variety of options and all should be used to carry a coordinated campaign to raise awareness and directly involve the participation of local community groups.

Options should include:

1. Local themed conferences and events.

2. Community media i.e. local community newspapers, community radio, social media.

3. Engaging with existing health or welfare education programmes for example there may be health education programmes run by local churches, mosques, synagogues, etc or local health. Information events already being delivered by community groups.

There should also be development of short film clips or interviews to give a platform to the 'voice from experience' from BAME people living with dementia and their carers in the mainstream media e.g. regional BBC or Independent local bulletins.

- **What challenges might be encountered when developing and providing tailored services to people with dementia from minority groups**?

People from BAME communities not understanding the risks of dementia or stigma towards the illness.
People in dementia services not understanding BAME communities.

- **How can these be overcome?**

I've already identified a number of ways of addressing the lack of community knowledge.
Better training and support for carers.
Training in cultural competency and how this affects the whole dementia pathway in the context of dementia has to be improved for dementia professionals.

- **Which organisations and individuals, at local and national level, are best placed to lead this work?**

It ought to be local commissioners leading this work but with a few exceptions they aren't and even local good practice has only short term funding. I think both the Race Equality Foundation and the Dementia Alliance for Culture and Ethnicity have tried to provide a clearer view and some specific recommendations on what in health and social care should be doing but at the end of the day the Department of Health's dementia programme is where the authority lies, to

provide credible and influential leadership. Where commissioners have worked with local community groups there have been some valuable if short lived initiatives, but this never gets built on or adapted at scale. There needs to be a National Programme of work supplemented by local delivery structures that also integrate the BAME dementia challenges into existing programmes of work such as dementia friendly communities, dementia champions, diabetes health, stroke health, community resilience, etc.

Dr Sofia Vougioukalou, Research Fellow, Y Lab – the Public Services Innovation Lab for Wales, Cardiff University

January 2021

Evidence submission on BAME dementia care experiences in Wales to Diverse Cymru

Dr Sofia Vougioukalou, Research Fellow, Y Lab – the Public Services Innovation Lab for Wales, Cardiff University
January 2021

Introduction

In this report I provide examples and lessons learnt from nine Welsh people of Somali, Bengali and Greek heritage that I interviewed for the project: **'Dementia care experiences – understanding diversity, implementing equality, creating shared learning'**. The project was funded by the HEFCW Enhancing Civic Mission and Community Engagement funding stream and we worked in collaboration with Diverse Cymru and Alzheimer's Society Cymru. The aim of this project was to address the significant gap in engaging and understanding the needs of diverse under-represented communities in relation to ethnicity, sexuality and disability who receive dementia care in Wales and develop new research projects and educational resources based on participant priorities.

Methods

Data was collected through interviews and engagement meetings in community settings between September 2019 and September 2020. The project did not seek to evaluate dementia care services per se but to understand the experiences of carers and whether they felt that the services were culturally appropriate. The analysis focused on identifying similarities and differences between the equality strands of ethnicity, sexuality and disability and subgroups within each strand. As a medical anthropologist and health services researcher, I sought to understand the impact of dementia on disrupting perceptions of the self, family and access to healthcare.

Results

Somali carers

Two women of Somali heritage who looked after their mothers with dementia reported being very satisfied with the dementia care services that they received. For example, Carer 1 from Grangetown mentioned that as her mother couldn't speak very good English, during a period of hospitalisation, staff allowed a carer to be by her mother's side around the clock and provide translation, company and care. The family carer was also allowed to stay overnight in hospital.
Carer 2 from Riverside could not speak very good English and was interviewed with an interpreter. She provided round the clock care for her elderly mother in her house and reported being very happy with the home visiting service. Her daughter spoke good English and helped with any translation needs.

Bengali carers

Three women of Bengali heritage who had parents and grandparents with dementia also reported being very satisfied with the dementia care services their family members had received. Similarly to the Somali carers, upon the onset of dementia, one of the children of the person with dementia took responsibility for managing care in the home and the whole family contributed to the care and its management. All three carers, from Roath, Riverside and Port Talbot, mentioned that 'looking after our own' was something they had always done as a family and their religion, Islam, placed a very high cultural importance on looking after one's elderly parents, and mothers in particular.

Greek carers

Four carers of Greek heritage from Barry took part in a detailed focus group about their mother's care. They had some negative experiences of dementia care in hospitals and care homes. More specifically, they felt that staff in the general medical ward did not have the knowledge to communicate with their mother who had dementia and there were regular breakdowns in communication as ward staff were not able to pick up on non-verbal communication cues. Also, in the general ward there was very limited staff capacity to provide enhanced supervision (1:1 care). They observed that people with dementia were left to their own devices without much to do during the day. Their mother was very sociable and tried to leave her bed to be able to socialise with others. Their mother was also very proud of her appearance but during the hospital stay her appearance was very unkempt. Mealtimes were difficult and their mother didn't eat much because there wasn't somebody to help her. For example, a meal and a drink were left on her tray but she didn't know what to do. One time she poured the cup of tea over the meal, perhaps thinking it was a jug of gravy. One of her daughters offered to come outside visiting hours and help with personal care and feeding and this request was refused. They also felt that staff in both the care home and the hospital tried to coerce them to accept the administration of antipsychotics with a view to chemically restraining their mother and limiting antisocial/disruptive behaviour.

Some of the points mentioned above have also been reported by White British carers within our broader research programme. Key points, specific to being a person with dementia from a minority ethnic background, are the ones relating to the use of Greek language as people with dementia often revert to their mother tongue. For example, their mother spoke in Greek but understood instructions in English. Because she did not speak Greek, staff thought that she didn't understand and therefore did not explain to her what procedures they were going to do to her i.e. take a blood sample, get her dressed, get her pulse. This lack of explanation and warning caused her to be aggressive towards staff as she felt that her personal space was being violated and she was under attack. Their mother speaking in Greek also caused confusion and delays in care as staff did not understand what she was saying. Staff in one of the care homes where she was admitted showed interest in learning basic words that she would understand. They asked her children to write down phonetically some basic questions such as 'are you hungry?' and 'do you need the toilet?' and answers. They made asking

her questions in the Greek language a fun part of the care they provided and their mother was much calmer and happier. They felt that this initial investment in very basic linguistic competence saved the care home a lot of resources in staff time dealing with antisocial and aggressive behaviour.

Recommendations for dementia care providers

We identified four key recommendations for health and social care providing organisations based on these testimonials:

• Improve capacity for the enhanced supervision of people with dementia in general medical wards in hospitals by decreasing the nurse-patient ratio, involving healthcare support workers and volunteers.

• Ensure staff, including nursing and medical students and healthcare support workers in general medical wards have a good knowledge of dementia and related communication skills.

• Understand and identify solutions for the psychosocial needs of people with dementia such as involving arts activities, family members and volunteers in a more targeted way to provide cognitive stimulation and prevent deconditioning.

• Engage in a more nuanced way with the mother tongue of the person with dementia. When it is not possible to use interpreting services over the phone or online, this can be achieved by producing an inventory of additional languages spoken by staff members and deploying them accordingly, involving carers in writing down basic words for staff to use or using google translate. This also applies to the Welsh language. This is recommended to prevent agitation and escalation into aggressive behaviour.

Next steps

We are developing a short play on dementia and ethnicity and a digital story to share learning from this project with the health and care workforce. Both resources will be available on the Cardiff University YouTube channel. We will be

piloting their use in medical and nursing dementia care education in Cardiff University during 2021.
We are developing three new research projects on dementia care and restrictive practices, social care use and personal payments, and Covid-19 messaging.

If you would like to find out more, please email Sofia at vougioukalous@cardiff.ac.uk

Conclusion

This report will serve as a base for future studies on African, African Caribbean, Asian and minority ethnic people living with Dementia. This report has demonstrated, for the first time what can be achieved by meaningful engagement with our communities. Taking a co-productive and systems approach to tap into the expertise of professionals and individuals with lived experiences who have a shared vision, mission and purpose that drives them toward change. A positive change that implements long term solutions that will have a constructive impact on our future generation, not a symptomatic solution, quick fit that only address the system. (Senge 2006).

The stories were collected by:

- Structured in-depth interviews - Faith Walker & Aisha Jenkins, FW Consultancy.
- One-to one-interviews, undertaken by facilitator Suzanne Duval BEM BME Mental Health Manager (Policy) Diverse Cymru.
- Focus groups with Yemeni women undertaken by Samira Salter BME Mental Health Support Manager, Diverse Cymru
- Self-reflection by David Truswell, Executive Director, Dementia Alliance for Culture and Ethnicity
- BAME dementia care experience, Dr Sofia Vougioukalou, Research Fellow Y Lab – the Public Services Innovation Lab for Wales, Cardiff University

The above process started in 2018 and was delayed due to the impact of Covid - 19. The events of 2020 have shone a light on the disparities that exist throughout the globe. The entrenched and individual racism that is woven within the fabric of our societies, was sadly our, the diverse community's reality. Therefore, we decided not to reach out to our communities during Covid 19 because we felt the injustice, the entrenched individual and structural racism that exists within our society was particularly magnified at this time.

From the cradle to the grave, socio-economic factors and the inequalities have a detrimental impact on our health and well-being. For example, educational attainment gaps, unemployment, mental health, stop and search, criminal injustice, comorbidities, also Black women are more likely to die in childbirth. African, African Caribbean, Asian and minority ethnic people are disproportionality impacted. McConnell and Hart (2019) notes that:

> "Cutting across all are insights from the non-decision, mobilisation of bias, agenda setting and policy stasis literature that 'doing nothing' happens in particular institutional context, where biases are reproduced and potentially critical issues are not considered worthy of attention."

The Race Equality Action Plan is a starting point to address the inequalities that exist in Wales. This plan is still in its embryonic stages, time will tell if cultural strategies will be used to avoid, marginalise and redefine issues, Cobb and Ross

(1997) define this as the concept of 'agenda denial'. This is now the time for action and to build back better, for fairness and justice in Wales. Race Alliance Wales 'From Rhetoric to Reality: our Manifestos for an Anti–Racist Wales, throws down the gauntlet for action. There have been numerous reports written before and since Covid 19 and the murder of George Floyd, the death of Christopher Kapessa, and the Black Lives Matter Movement. These reports echo the findings of the interviews of the person living with dementia's loved ones about being looked over. It is important to implement the recommendations from these reports for change for a fairer and anti-racist Wales.

Further information

- "Let's Talk about Dementia – End the Stigma", Diverse Cymru, September 2019.
- "Intercultural dementia care – a guide to raising awareness amongst health and social care workers" Alzheimer's Europe, 17 December 2020
- "Black people, racism and human rights", Eleventh Report of Session 2019 – 21 – House of Commons, House of Lords, Joint Committee on Human Rights, 4 November 2020.
- "Supporting People Living with Dementia in Black, Asian and Minority Ethnic Communities, Key Issues and Strategies for Change", Edited by David Truswell, 2020.
- "Better Health Briefing 45 – Dementia and end of life care for Black, Asian and minority ethnic communities", June 2018
- "The dementia experiences of people from Caribbean, Chinese and South Asian communities in Bristol". 2017
- "Is Britain Fairer?" Equality and Human Rights commission Report series 2020
- "The Impact of Covid-19 on BAME Community and Voluntary Sector Organisations in Wales: innovation, resilience and sustainability". Ubele 2020

- "From Rhetoric to Reality: Our Manifesto for an anti- Racist Wales", Race Alliance Wales, 2020
- "Race and Ethnic Disparities", Commission on Race and Ethnic Disparities,25 September 2020
- "All Wales BAME Engagement Programme" – research-publications. EYST 2020
- "First Minister Response to the BAME Covid-19 Health Advisory Sub-Group Socio-economic Report", June 2020
- "Do the Right thing: achieving equity in racialised representation in public and political life in Wales", January 2021

Although this report is based on a small sample of participants, the findings suggest that some African, African Caribbean, Asian, and minority ethnic people are reluctant to engage in services. some of the participants said they were happy with services. Key policymakers recognise that there is a lack of services for the minority ethnic communities. For example, Patel (2013), Chair of Community and Adult Services Scrutiny Committee, Cardiff, states:

> *Almost one fifth of the population of Cardiff self-classifies as being from a minority ethnic group: at the same time, just over one tenth of Adult Services' clients self-classify as being from a minority ethnic group.*

For that reason, it is vital that service provisions for the African, African Caribbean, Asian and minority ethnic people are made accessible, safe and culturally competent, to address the "layers of complexity to the already complex and life-changing challenges facing those living with dementia and their families and their carers" (Truswell, 2020, p. 15). Care dignity is so important for our elders, (Saltus and Folkes, 2013; Saltus and Pithara, 2015; Yu, Saltus and Jarvis, 2020).

This report reflects the challenges and the moving accounts that the loved ones shared. That is why it is imperative that these seldom heard voices are shared in the way that they told their stories, and the report is presented in this way.

The richness and depth to co–create with other professionals to capture the communication with the diverse communities, is invaluable.

Recommendations

At regional and local level, policy makers, and key stakeholders should work together with people with dementia and carers from African, African Caribbean, Asian and minority ethnic communities to address the following recommendations.

- Recognise the pervasiveness of structural institutional racism in Wales, and power structures which seek to reproduce themselves, as being contrary to the public-sector duties of equality of opportunity, equality of access and equality of outcome.

- Establish a multi-stakeholder response group to deal with allegations of individual and or institutional racism.

- Greater efforts are needed to ensure that services reflect the diversity of the African, African Caribbean, Asian, and minority ethnic communities. Recognise the intersectionality of the protected characteristics of age, disability, gender reassignment, race, religion or belief, sex, sexual orientation, marriage and civil partnership, and pregnancy and maternity as outlined in the Equality Act 2010.

- Continue to work with Public Health Wales and Health Boards (local health boards) to improve data collection on health and ethnicity, to inform understanding and to prevent future disproportionate health outcomes for ethnic minorities.

- Ensure all health and social care staff receive in depth anti-racism training, in order to prevent inequalities from persisting from the ground up.

- Improve support and complaint structures for health and social care staff experiencing racial/ethnic/religious discrimination.

- Invest in a comprehensive and multi-sectoral approach to address mental health promotion, prevention, treatment, discrimination, exclusion, care and recovery which is culturally sensitive and meets the needs of African, African Caribbean, Asian and minorities' communities.

- Further investigation and experimentation into a culturally sensitive diagnostic framework is strongly recommended.

- Continued efforts are needed to make diversity and multiculturalism more accessible in private, public sector and third sector organisations.

- Drive behaviour change in the private sector, for example, by requiring anyone tendering for a public sector contract to show what steps they are taking to make their workplaces more inclusive, as recommended by Baroness McGregor-Smith's review **'Race in the Workplace'**

- Greater efforts are needed to ensure health professionals and other professionals recognise and identify their own cultural bias and are mindful that not all minority ethnic people are the same because they are from the same cultural background.

- Service provision for the African, African Caribbean, Asian and minority ethnic people should be made accessible, safe and culturally competent, to address the "layers of complexity to the already complex and life-changing challenges facing those living with dementia and their families and carers".

- Implement culturally informed personal care and support services including culturally appropriate end of life care.

- Diversity needs to be shown in leaflets, posters, and communications to reflect the communities in which services operate.

- African, African Caribbean, Asian and minority ethnic communities need to see themselves reflected in services and healthcare.

- Develop culturally sensitive health and social care materials for awareness raising and information about health and social care and treatment options (i.e. which challenge negative stereotypes, are suited to different linguistic abilities and educational levels and portray people from a range of African, African Caribbean, Asian and minority ethnic communities).

- Use commissioning and procurement powers to require positive action amongst service deliverers to achieve more diverse and inclusive workplaces.

- Use appropriate channels of communication to reach, inform and engage in exchanges with people from African, African Caribbean, Asian and minority ethnic communities about available care and support (e.g. through community centres, places of worship, sheltered housing and day centres, community radio stations, bilingual support workers and dedicated roadshows).

- Promote health literacy amongst African, African Caribbean, Asian and minority ethnic communities.

- Create incentives for health and social care professionals and be prepared to take disciplinary measures when necessary.

- Further research is needed to explore and implement working practices to people from the Black, Asian and minority ethnic communities in Wales.

APPENDIX 1

David Truswell, Dementia Alliance for Culture & Ethnicity - A Call to Action Good practice guidance

Introduction

This document lists activities, actions and examples of good practice for working with Black, Asian and minority ethnic (BAME) people, families, communities and organisations affected by dementia. They were compiled at a workshop held in Sept 2015, with a number of BAME organisations represented, also including information sent by email. They are listed as bullet points under headings describing key areas of dementia policy and practice.
Contributing organisations included:

- Asian People's Disability Alliance
- Alzheimer's Society Waltham Forest & Connecting Communities Project
- Chinese National Health Living Centre – Dementia Project
- Community Action on Dementia – Brent
- Culture Dementia UK
- Mental Health Foundation
- Nubian Life
- Irish in Britain

1. Accessible information about dementia being generally available, e.g. in GP waiting rooms, including information about reducing the risk of developing dementia.

- Community radio talks + short inserts about dementia in health programmes – also 2 below
- Alzheimer's Society information translated on YouTube
- Importance of producing/providing information about dementia that is translated in audio/video/visual formats
- Irish in Britain has a whole community approach to addressing the dementia need within the Irish community. Our **Cuimhne** strategy and

campaign **(pronounced "qu'eevna" the Irish word for "memory")** is raising awareness, delivering training and supporting our Irish services to be inclusive of persons living with memory loss. We use the memory loss to include age related forgetfulness, dementia and Alzheimer's. However, like all BAME communities we do not receive funding or support to deliver this strategy and we are concerned for the lack of cultural awareness by mainstream provision of the needs of Irish who are not accessing mainstream services.

2. The person or their family identifying something is wrong e.g. memory problems.

- Community events that have a dementia focus but are also community social events with food, personal stories, music, and a range of ages in the audience e.g. young children – also 1 above
- More needs to be done to raise awareness to help Chinese elders with memory problems to access services/screenings

3. Seeking and being given a dementia diagnosis (in a timely, sensitive and helpful way). Usually via a GP and a specialist assessment but sometimes as a result of a hospital admission

- Bringing the memory clinic on site (i.e. to a community organisation) where the client feels safe and less fearful of meeting a healthcare professional – also 3 below
- Having a Chinese (and other culture/language specific) version of the mini mental state examination (MMSE)
- Services need to fulfil their duty of care, with appropriate risk and safety assessments

4. Being given good quality information about a dementia diagnosis – the effects, prognosis, care, support and treatment available for the person and their family

- Person-centred care where the next of kin (NOK) are able to speak to qualified staff openly. Developing relationships that encourage robust conversations in order to explore best activities/pathways for the client and enable the NOK to step back/have respite – also 4 below

- Lasting Power of Attorney (LPA) information sessions encourage people to have plans
- Partnership work among community groups, statutory and voluntary, and conversations to support the person and their carers

5. Being put in touch with a dementia "advisor", "Navigator", Admiral nurse, etc.

- BAME specific dementia support worker in Tower Hamlets for Bangladeshi community with Alzheimer's Society
- Meri Yaadain team (http://meriyaadain.co.uk/) is a social services led initiative in partnership with Bradford and Airedale Teaching Primary Care Trust, Age Concern Bradford and Alzheimer's Society Bradford. The team consists of a manager and two part-time staff who undertake a wide range of activities to reach out to and engage with older people who have dementia and their carer's and families who need educating about the condition as well as the services available to help them.

6. Having peer support available e.g. peer support groups, memory cafes, Alzheimer cafes, drop-ins, etc.

- Circles of Support approach – informal, unstructured approach within a wider structure of support. Circles of Support give space and allow the group to work as they wish within the moment – not having any other agenda apart from asking the person what they want to do, what they like, etc. right now. The Circle collects as much info as possible about the person and NOK to get a picture of the individual in order to design activities they enjoy
- Essential to have bilingual advocacy services and service navigators to help BAME people access services
- Café facilitated in Sylheti for Bangladeshi community in Tower Hamlets
- Information Programme for South Asian families project led by Alzheimer's Society in partnership with local South Asian organisations - nationwide

7. Other forms of support being made available (and 'dementia friendly') e.g. community groups, faith organisations, local Age UKs, etc.

- Circles of Support (see above), portfolios of pictures to enable people with dementia and their families to reflect, write poetry, music, dancing, etc.
- Finding out from the person how they want to be cared for – choice and control
- Information about diet – link between diabetes and dementia – provided by Seventh Day Adventists
- Dementia Friendly Gurudwara: http://dementiafriendlygurudwaras.com/
- Being aware of people with learning disabilities + dementia
- Life story work
- Methodist church, Roman Catholic Church and Church of England developing dementia friendly church work including "dementia Sunday" (see websites)
- Carers Information and Support Programme (CrISP) – Alzheimer's Society programme provides carers with excellent insight into dementia, coping strategies, support and support services
- Embedding clients with dementia into the general activity schedule of the service e.g. generic day centre, so they feel part of a great group, "normal" and included, rather than being treated differently e.g. one lady with dementia had often wandered from home and got lost, scared and angry when she first came to the day centre for older Asian people, as a result of using this approach the day centre had enhanced her wellbeing and engagement, and got her involved in helping out at the centre
- Difficulty of generic BAME day services having to provide specialist support to people with dementia but without sufficient resources, training etc.
- Many statutory, advocacy and national voluntary organisations not understanding the role of local BAME organisations
- Some faith organisations may have barriers to people with dementia accessing faith support
- Irish in Britain under, our Cuimhne campaign, approached Brent which has the highest population of Irish in England to become a dementia friendly Borough. We were confident that the Cuimhne model was broadly transferrable to all people with memory loss but especially those from various BAME groups. This has led to Community Action on Dementia – Brent a new Charity which aims to address the needs of BAME communities

and working with an ambition to make the Borough dementia friendly. We are about to launch the findings of an ethnographic research study and are using a system leadership approach to address needs identified from the research. The research findings highlight the need for peer support and one person living with dementia is being supported to fundraise to set up peer support in Brent.

Availability of social care – personal budgets, domiciliary care, personal assistants, etc.

- Telephone assessments by social services often not appropriate for BAME people with dementia
- Cuimhne and CAD – Brent are working with faith and community groups who are keen to have a role in raising awareness and addressing the needs of people with dementia and their carers. Again the progress is slow as we do not have funding to deliver the training required.

9. Ongoing support for family carers, including information about the respite breaks, the right to a carers assessment, etc.

- Chinese Carers Support is useful + support from Alzheimer's Society, Age UK, etc.
- Consultations that include NOK (next of kin) – developing a relationship with NOK and being able to signpost clients to relevant bodies for assessments, respite, housing, benefits, etc.
- Importance of translating information + interpretation/advocacy when in contact with health and social care, housing etc.
- An organisational strategy that is inclusive of families caring for a person with memory loss and works with member services to ensure they understand the specific needs of families caring for a person with memory loss.

10. Appropriate hospital care if the person needs to be admitted because of their dementia, or for other reasons

- Need to ensure awareness in mainstream health services of barriers faced by BAME people and how to work with BAME communities.

11. Appropriate intermediate care and reablement for people with dementia coming out of hospital

- Advice for Alzheimer's Society, Dementia UK, Admiral nurses, carers organisations, regarding help available + raising awareness of dementia, BAME groups in intermediate/reablement services.

12. Appropriate housing with care, telecare, assistive technology

- More bilingual staff.
- More befriending and volunteers recruited by mainstream statutory and voluntary sector services.
- Cuimhne are working with an Irish housing association who have undertaken memory loss awareness training and aims to develop more activities and support for their elders living with dementia.

13. Availability of good quality care homes and nursing homes

- Example of facilitating conversations involving a person with dementia having falls and not being able to cope with living in their own home any more. Negotiations involving social services, Alzheimer's Society and a care home for her to move into – now the person is very happy in the care home and has a new social life.

14. Good quality end of life care

- No examples.

15. Swift, appropriate responses to emergencies, crises, or safeguarding issues

- Example of services responding well to a fracture that a person with dementia incurred following a fall.
- Importance of identifying delirium among people with dementia.

16. Information for the person and carers about rights, entitlements, welfare benefits e.g. Care Act, Mental Capacity Act, Mental Health Act, Equality Act, etc.

- Example given of using an LPA (Lasting Power of Attorney) as a way of making important and appropriate decisions about a person's jewellery.
- Example of person with dementia getting the Blue Badge disable parking scheme.
- But staff themselves sometimes don't understand legislation etc.
- This will be included in the website that is being designed for Community Action on dementia – Brent. Under the Cuimhne strategy we send out information and articles to our members and are working on a series of Policy Advisory Group meetings to promote this further.

17. Communities becoming more 'dementia friendly' aware, supportive, inclusive

- EKTA organisation in Newham (charity working with South Asian families) just received international award for its drama "Dementia's Journey" to raise awareness of dementia.
- Dementia Friends materials have been adapted to be better suited for people who do not read and write English.
- Training for BAME community centres to become more dementia friendly.

18. Opportunities for people and carers to participate in research

- There are a number of research project underway regarding specific BAME issues by UCL partners and others. These should be ready to be reported on during 2016/17.
- Community Action on Dementia - Brent has carried out ethnographic research where we hear the voices of BAME communities and their needs. We have 4 videos as well as a full report.

19. Opportunities for people with dementia and carers to use their experiences to influence services, policies

- All Party Parliamentary Group report on "Dementia Does not discriminate"
- Dementia Engagement & Empowerment Project (DEEP)
- Supporting person(s) within the BAME communities to have a voice at a strategic level but also to utilise their skills and knowledge to help make the changes in the Borough.

20. Anything else?

- Training for BAME community organisation staff, volunteers and NOK.
- Importance of the advocacy role BAME organisations play – both representing communities and individuals.
- Example of an organisation (Culture Dementia UK) building links with local housing service so tenants can be referred to the organisation for social support.
- Importance of community groups co-ordinating the support they give to people.
- Example of the Chinese Healthy Living Centre (CHLC) acting as a "navigator" for 90 year old widow, cared for by her granddaughters, reverted to speaking Chinese, unwell with an infection and not coping at home – referred to Chinese Community Centre, Alzheimer's Society + statutory services involved – multi-disciplinary and multi-agency involvement provided information to granddaughters and negotiated with the lady that she was not coping – she happily agreed to go into a care home.
- Dementia Friends programme has now amended materials to include BAME specific ones and piloting materials with Chinese community.
- The Gypsy and Traveller communities have a high risk of dementia despite very poor longevity. They are largely forgotten and considering their limiting long term physical and psychological morbidity, social marginalisation and low access to services need to be considered as a distinct group with a high risk of dementia.

For more information on Race Against Dementia contact David Truswell at:
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Biography

David Truswell has worked in community based mental health services in the UK for over thirty years developing services for people with complex care needs and enduring mental health problems in a career spanning the voluntary sector, local authority services and the NHS. From 2009 – 2011, he was the Dementia Implementation Lead for Commissioning Support for London, working with commissioners across London to improve dementia services. He is an independent writer and researcher on dementia support and services for Black and minority ethnic communities, working with a number of projects and initiatives.

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