

# **Dementia Dekh Bhaal Scotland**

## Programme Evaluation

**PREPARED BY:**  
Susan Brackenborough

**PREPARED FOR:**  
Together in Dementia Everyday

**JANUARY 2022**





# Contents

<b>Dementia Dekh Bhaal Scotland</b>	<b>3</b>
<b>Introduction</b>	<b>4</b>
<b>Evaluation</b>	<b>5</b>
<b>Getting started</b>	<b>7</b>
<b>Data</b>	<b>8</b>
<b>Significant Findings</b>	<b>12</b>
<b>Consultation &amp; Engagement</b>	<b>12</b>
Evidence	
Challenges	
Solutions	
<b>Dementia awareness and coping strategies</b>	<b>14</b>
Evidence	
Challenges	
Solutions	
<b>Establishing Trust with communities</b>	<b>17</b>
Evidence	
Challenges	
Solutions	
<b>Legacy materials</b>	<b>19</b>
<b>Conclusion</b>	<b>20</b>
<b>Recommendations</b>	<b>21</b>

We wish to take this opportunity to thank everyone who contributed to this evaluation.

Credit for images: Images used in the report are from Pixabay and Pexels



# Dementia Dekh Bhaal Scotland



## Dementia Dekh Bhaal Scotland

Tide (together in dementia every day) is a UK-wide charity for carers and former carers of people living with dementia. Tide connects, mobilises, and supports carers of people with dementia to recognise their value and contribution to society. One of tide's values is to be 'inclusive': 'We will always value the diversity of perspectives, experiences, knowledge, skills, cultures, and beliefs that people have to share and contribute in the pursuit of our social mission. We will ensure that all voices will be welcomed and all contributions recognised.\* In 2017, tide established a dedicated network of carers and former carers of people with dementia in Scotland, funded by Life Changes Trust.

Tide approached Meri Yadaain CiC to work in partnership building on tide's niche branding of Dekh Bhaal to reach out to more ethnically diverse communities in Scotland. A report on tide's work commissioned in Scotland noted that: 'tide may benefit from monitoring the social and demographic profile of its growing membership in Scotland, in accordance with its ongoing efforts to ensure the network provides a safe and inclusive space within which carers from a diverse range of backgrounds can connect with each other.\*\*

Tide wants to 'invite member carers from diverse communities (e.g. BAME)...to lead the development of special interest groups and themed working groups within the overall network.\*\*\*

The evaluation provides evidence of the positive impact of the innovative tide-led Dekh Bhaal Scotland (DDBS) project, the challenges faced, and areas for further development.

\* [tide.uk.net/about-us/our-vision-mission](http://tide.uk.net/about-us/our-vision-mission)

\*\* [tide.uk.net/tide-scotland-evaluation-report/](http://tide.uk.net/tide-scotland-evaluation-report/)

\*\*\* *ibid*

## Challenges and opportunities

Given the restrictions associated with Covid-19, there was a risk that lockdowns and limitations of accessing community venues may hinder the work. Nevertheless, tide and Meri Yaadain CiC set out to engage with ethnically diverse communities with the intention of adapting strategies where needed to retain the focus of engagement, improving awareness and creating a legacy beyond the four-month period of work.

**Awareness of dementia** is limited in ethnically diverse communities as there is no word in most minority languages to identify the symptoms. With a lack of awareness, carers struggle to cope with the complexities of dementia care and the need to access appropriate services. Dementia Dekh Bhaal Scotland sought to improve awareness of dementia by initiating foundation steps that would enable the development of work to increase understanding of the issues impacting ethnically diverse communities in Scotland. A series of webinars - recorded for further sharing beyond the project, were delivered to raise awareness. Together with radio adverts and a radio programme, awareness was taken to be a long-term strategy and not just a quick win.

**Engagement** with ethnically diverse communities, people living with dementia or caring for a relative were key aspects of the purpose of this work. However, being mindful of covid-related restrictions and the need to build trust with communities, the project sought connections with frontline services, secondary services - including professionals and practitioners. This approach was taken to develop grassroots strategies of understanding community needs before developing or commissioning appropriate support.

**Creating a legacy** was the third area of interest for this work. Tide and Meri Yaadain CiC were in no doubt that it takes quite a while to develop trust with minoritised communities before they can and will engage in a way that is meaningful rather than short-term. So the project has developed information via postcards with artwork designed and hand-painted by a popular 'truck-art' artist in Pakistan. These postcards form a pack with information on the reverse relating to dementia and dementia care for and about ethnically diverse communities in Scotland. Together with the reminiscence booklet, the postcards provide a visual format to connect and grow the support for minoritised communities as well as working professionals trying to support ethnically diverse communities.

Note: Whilst the ongoing work is potentially Scotland wide, initial work focused on Glasgow and related more to South Asian communities. Meri Yaadain CiC and tide acknowledge that a more inclusive approach is needed going forward that is built on this excellent and much-needed starting point.

# Introduction



## Introduction to the evaluation

The evaluation took a phenomenological qualitative approach, and the focus was to understand the why and how of human behaviour in situations surrounding dementia care – looking at communities, cultures, and individuals within BAME (Black Asian Minority Ethnic\*) primarily in Scotland. Dementia is the loss of cognitive functioning such as thinking, remembering, and reasoning. It can impede and interfere with a person's daily life and activities. Some people with dementia cannot control their emotions, and their personalities may change.

Methods were designed to understand the lives of participants and people living with dementia (PlwD), carers, and organisations (BAME, foremost, and non BAME) during the series of webinars. The individual responses were treated in a non-judgmental manner. The research method taken was to look at the effectiveness of the Dementia Dekh Bhaal Scotland (Dekh Bhaal meaning to 'look after') project in Scotland, using evaluations of webinars, interview responses, surveys, and support material produced such as information postcards. Perspectives and insights from the participants themselves meant that experience, how they see something as lived / perception, could be analysed, and so the evaluation is not biased or based on opinions.

\* BAME will be referred to as ethnically diverse for the purposes of this evaluation - though they are interchangeable

## Dementia in ethnically diverse communities

According to the 2013 APPG report on BAME Dementia, there is an expected seven to eight-fold increase expected in ethnically diverse communities in the UK over the next few decades. Academic evidence also highlights there to be inequalities in regards to access, support and awareness of the needs of dementia carers from ethnically diverse communities. They are known to have a lack of awareness of dementia - in fact no recognised name for dementia in most languages spoken by minoritised communities in the UK.

Family carers of a relative living with dementia are facing increasing pressures, not only from a lack of access to information and support services, but the Covid-19 pandemic has shown there to be a greater impact on minority ethnic communities across the

UK. Influences of faith, gender, relationship dynamics in the home and social constructs arising from migratory history and experiences provide an altogether very challenging situation for such carers

The need to understand the given situation for dementia carers from these ethnically diverse communities and the need for institutional changes to meet the support needs of these communities has been essential in this project. The project has therefore attempted to undertake a number of aspects to:

- Reach out to grassroots community organisations in Scotland working with ethnically diverse communities
- Reach out to professionals and practitioners in Scotland working with or interested in a better understanding of the needs of ethnically diverse family carers of a relative living with dementia
- Initiate conversations regarding the barriers and opportunities for engagement between organisations as well as with carers from ethnically diverse communities
- Create awareness of issues affecting people living with or caring for a relative with dementia in Scotland
- Create resources that would act as a legacy for the time limited work in Scotland - ensuring these small steps act as opportunities for progression and growth in learning as well as supporting ethnically diverse communities

# Project evaluation



## Purpose of evaluation

Tide (together in dementia every day) is a UK-wide charity for carers and former carers of people living with dementia. Tide connects, mobilises, and supports carers of people with dementia to recognise their own value and contribution to society. One of tide's values is to be 'inclusive': 'We will always value the diversity of perspectives, experiences, knowledge, skills, cultures, and beliefs that people have to share and contribute in the pursuit of our social mission. We will ensure that all voices will be welcomed and all contributions recognised [1]. In 2017, tide established a dedicated network of carers and former carers of people with dementia in Scotland, funded by Life Changes Trust.

Tide approached Meri Yadaain CiC to work in partnership building on tide's niche branding of Dekh Bhaal to reach out to more ethnically diverse communities in Scotland. A report on tide's work commissioned in Scotland noted that: 'tide may benefit from monitoring the social and demographic profile of its growing membership in Scotland, in accordance with its ongoing efforts to ensure the network provides a safe and inclusive space within which carers from a diverse range of backgrounds can connect with each other [2].

Tide wants to 'invite member carers from diverse communities (e.g. BAME)...to lead the development of special interest groups and themed working groups within the overall network [3]. The evaluation provides evidence of the positive impact of the innovative tide-led Dekh Bhaal Scotland (DDBS) project, the challenges faced, and areas for further development.

[1] [tide.uk.net/about-us/our-vision-mission](https://tide.uk.net/about-us/our-vision-mission)  
[2] [tide.uk.net/tide-scotland-evaluation-report/](https://tide.uk.net/tide-scotland-evaluation-report/)  
[3] *ibid*

## Evaluation Process

This section summarises the main activities that were conducted as part of the evaluation and provides an overview of each activity. The data used for this evaluation include a survey, telephone interviews, and feedback during webinars.

## Webinars

Three webinars, advertised on Twitter, were initially proposed to cover 'BAME Dementia Awareness', the 'perspectives of carers' and the 'perspectives of organisations'. The purpose was to raise awareness, educate, share knowledge and have a ripple effect whereby participants would then go and share what they learned with their organisations, co-workers, and policy. This learning would support them to reach out to carers and people who need help – trying to make a better world for all.

The webinars were professionally facilitated, and knowledgeable support was given to generate lively conversations and written chats and to get participants to think 'out of the box'. The demand for more of these webinars meant that a series of six was put out during November and December 2021:

- Webinar 1: Ethnicity and Culture (presentation and discussion-based)
- Webinar 2: Stigma and Dementia (presentation and discussion-based)
- Webinar 3: Faith/Spirituality and BAME Dementia (presentation and discussion-based)
- Webinar 4: Carers Perspectives. Focused on carers of people living with dementia (three carers shared their stories)
- Webinar 5: The importance of research (two Bradford-based participants working with BAME communities, where their role is predominantly in research, gave an insight)
- Webinar 6: Building on the foundation (discussion-based)

The webinars were free and open to anyone, and several Scottish organisations were represented by some participants each week – including Alzheimer's Scotland, Alzheimer's Society, Glasgow Life, Scottish Fire and Rescue, tide, BOLD, MECOPP, Glasgow Museums, Queen Margaret University, Glasgow VCS, Glasgow City Health and Social Care Partnership, Gartnavel Royal Hospital and Sporting Memories.

## Interviews

Webinar participants were asked to take part in an interview once the series of six had been completed. A simple survey was sent out in advance to four participants based in Scotland and was used as a basis to have an open telephone



discussion with them a week later. One participant directly works with the ethnically diverse communities and the other three directly/indirectly work with PlwD. These interviews aimed to explore stakeholders' views, experiences and explore their ideas and suggestions for how the network can develop in Scotland.

Significantly, all had attended several webinars, and all expressed a strong wish for them to continue into 2022.

Their awareness of dementia organisations primarily in Scotland was literally mentioned as: Alzheimer's Scotland, Age Scotland, tide, Meri Yadaain CiC, Life Changes Trust, Dementia UK, and Dementia Friends.

Unanimously the webinars were appreciated, Mohammed Akhlak Rauf MBE of Meri Yadaain CiC was highly praised for his professional and friendly approach and experience-led content that was educational and interesting.

### Surveys

A monkey survey was sent out at the end of webinar one, which received 14 participants' responses. Participants were from various backgrounds, and many were Scotland-based. one former carer, four health practitioners, and 9 'others' representing various organisations. They joined the webinars to learn more about barriers faced by BAME communities and their elderly, how to support themselves in their work and develop their practice, raise awareness for personal and occupational benefits, and network. The webinar was given a scoring of 5/5 for usefulness and interest.

### Survey responses

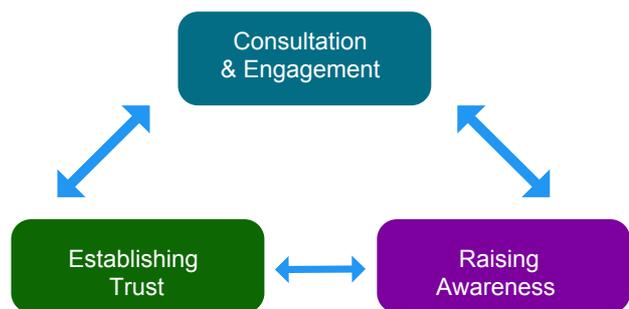
Data is shared on page 8. The webinars were informative, thought-provoking, and interactive, a forum for sharing challenges and ideas about supporting BAME communities to live well with dementia and develop their own best practices. The webinars will be posted on the tide website, and survey responses gave an average of 9/10 that they would recommend to people to view. Over half said they would approach their work differently after attending the webinar.

At the start of the webinar, over 75% of the survey participants responded that they knew little or nothing about matters affecting South Asian people living with dementia or caring for a relative with dementia, and after attending over 70% said they knew a moderate amount or more. In general, can be concluded that webinar 1 succeeded in raising awareness, and survey participants were shocked at the lack of support and services available for BAME even though it is clear they are needed.

There is a need for local councils and health organisations to support established smaller organisations working with dementia. Recognition of the work to be done in improving services and for services to be more inclusive and easier to access.

### Focus

The evaluation focused on the main points and is structured around three main interrelated overarching outcomes that the Dementia Dekh Bhaal Scotland project has brought out.



# Getting started



## Choosing Meri Yaadain CiC as a delivery partner

Meri Yaadain CiC was recruited by tide to make inroads into Scottish PlwD in the BAME communities. The outstanding reputation of Mohammed Akhlak Rauf MBE made his organisation ideal to be selected to carry out this project. Akhlak would understand and know what to do. He works from the heart. The project was undertaken during less than favourable circumstances - the pandemic - and the scope was ambitious. The project has only been running for three months and the time is very short to make any real progress, however, there has been potential for good outcomes and to lay the foundations of future work, both of which have been achieved. Ideally, it would have been good to employ someone who has the skills and expertise to work with the BAME communities in Scotland but lack of funding and time has meant that this could not be a short-term achievement. A formal job description would be required, time to recruit and the potential employee may have to give notice.

The DDBS project has been guided well by Akhlak through his knowledge, energy, and leadership. The webinars have been well attended by organisations in Scotland. If a roadshow is to go ahead it has to be well planned and not just ad hoc but to continue with network support so it is sustainable. A workable network needs to be formalised now and raising awareness needs to be well publicised.

Tide have allocated resources to continue with the project through a dedicated team member.

Tide  
Together in dementia everyday

## Working to make a difference

Tide is an incredible organisation with a reputation for making a meaningful difference to, and for, carers of people living with dementia. When approached by tide, we saw this as an opportunity to consolidate our mutual respect and recognition of the passion that both our organisations have in challenging the status quo and to bring to the fore the needs, challenges as well as opportunities for carers - especially from minoritised communities. We work to raise awareness of dementia amongst communities who generally do not have a word for dementia, they access information and support very late - often at the point of crisis.

At Meri Yaadain CiC we have a wealth of experience in understanding the cultural and faith-based influences that hinder access to support for ethnically diverse communities. They are often pressurised to care at home with caring duties, as a result of stigma, cultural obligations and expectations. We also have good connections with academic, research and practical experience of working with minoritised or what we sometimes refer to as under-served populations. There is a strong need to encapsulate good practice, challenge unconscious bias amongst practitioners and undertake practical steps in reaching out to communities. Professionals/service providers sometimes think that minority communities 'look after their own' - we sought to challenge that through this work we undertook in partnership with tide.

Overall, our expectations have been met in terms of raising awareness and reaching out to professionals as well as creating informational material that can be accessed well beyond the scope of this limited project. However, we feel that the project could have offered much more had there not been the time restrictions alongside physical restrictions imposed by the Covid-19 situation.

Meri Yaadain CiC



## Some feedback from participants

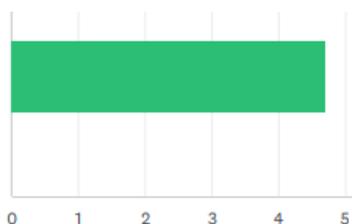
The evaluation process analysed the data from the feedback. Therefore, we felt it helpful to share some of the quantitative and qualitative data here - although qualitative data is shared within the findings sections of this report.

### Motivations for attending the webinars:

- To learn more about the barriers different communities face when access support
- Interested in getting a better understanding of the BAME communities perception towards
- Dementia, and I am also wanting to raise awareness around Dementia with regards to clinical health research
- To find out more and to network
- For more awareness
- Currently developing a Dementia Friendly weekly activity group that would be suitable for those living with Dementia, their family/friends as well as their carers.
- To be better informed re BME elderly
- To understand how to include and support BAME communities
- To be better informed and to see if we can develop our practice
- Personal and professional interest
- I think our concerts should be much more community based and led by the needs/wants of that community and not by me programming what I think people would like to hear. Attending the event to be better equipped to do this
- Interested to hear a bit more about what was being discussed and to learn about resources and models of support
- To gain insight into best practices.

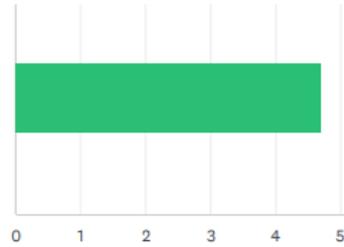
### How worthwhile did you find the webinars?

(scored out of 5)



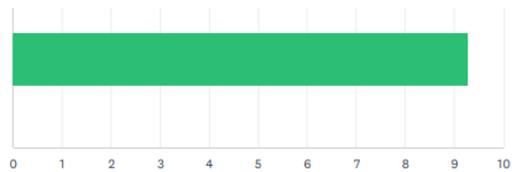
### How interesting were the webinars?

(scored out of 5)

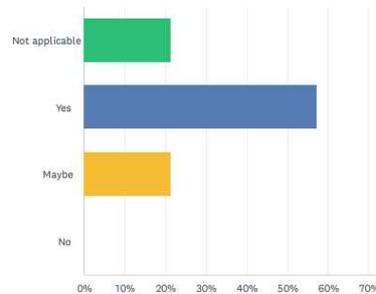


### If the webinars were recorded, how likely would you be to recommend them to other colleagues?

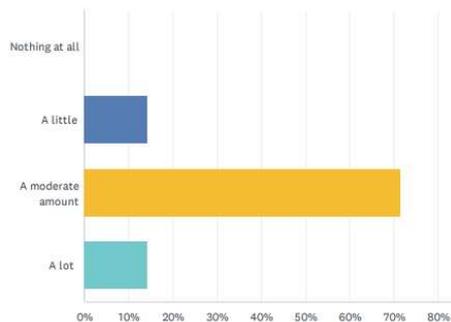
(scored out of 10)



### Will you be approaching your work any different as a result of participation in the webinars?



### Having attended the webinars, how much has your knowledge or awareness of BAME dementia / dementia carer improved?





## Having participated in the webinar(s), what would you say you have learnt from your attendance?

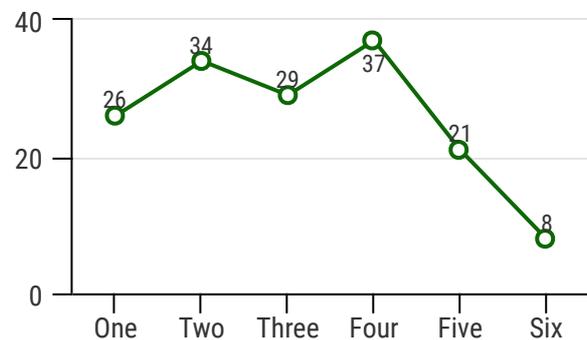
- The lack of support and services available for BAME for dementia is shocking. The little BAME services that are available like Meri Yaadian are not being commissioned by CCG's or local councils to deliver work at a bigger scale. So it makes you think that dementia in itself is something people don't want to know exists
- There is a lot of work to do to make a difference in improving people's sense of inclusion and access
- The lack of services available in certain parts of the UK, even though there is clearly a need to have these services.
- That there is support out there
- I learned more about South Asian people living with Dementia and how I could approach them with my new group
- A person-centred approach isn't always appropriate and consideration should be given to the relationship-centred approach re BME dementia
- Always be aware of your own bias as we all have them
- To be open, honest and to listen
- An opportunity to discuss/share and learn from everyone present
- Thinking about the differences between equality and equity
- Thinking about how I can make an effort to relate more to building opportunities and to understand that due to the complexity of peoples lives and cultures and heritage we might not always be able to assume anything and need to ask - not clump communities or groups together.
- Being clear about culture and identity. How diverse, complex questions of language can make understanding challenging and how to approach them

## Any other comments about the webinar(s)?

- The webinar was informative and interactive. It was great to hear from people from around the UK about dementia and their challenges to finding support for people from the BAME community.
- The webinar was interactive which was good, I would recommend breaking down the presentation into chunks, having some discussion around the subject and then continuing the presentation (I know this is easier said than done).
- Some notes that we can print out
- I think this webinar was very useful and wouldn't change or add anything
- What kind of support do BAME communities would need to live well with dementia
- Very interesting and informative
- Really useful and thought-provoking
- There were pictures of some resources used in the content and I am not sure if they are widely available - I would be interested if so
- Excellent thought-provoking and crucially helpful in developing approaches to best practice.

**Attendee numbers** for each of the webinars (note session six was a conversation about next steps rather than educational information relating to BAME dementia/dementia care. Session six was also two days before Christmas - so we had a lot of apologies

**Number of participants in each webinar at webinars**



# Feedback from the interviews



## Interviewee 1

C joined the webinars to *build knowledge and capacity so [she] can support colleagues and decision-makers with continuous service improvement.*

*The webinars would be good to continue for those who want to gain knowledge, skills, and insights into BME PlwD and not just a 'talking shop' for those who attended.*

It was also suggested that a *separate group should be formed from the webinars for action for real change for BME PlwD in statutory provision.*

Other topics suggested were: *How to plan for the end-of-life care for BME PlwD. What can I expect from statutory/public section provision in UK and Scotland?*

C felt that *BAME communities are not hard to reach out to.*

## Interviewee 2

M *joined the webinars as they looked interesting and educational. The webinars were excellent and produced a working group that found them educating and interesting.*

Further topics suggested were *Coping strategies for carers, Educating others about different cultural needs, Barriers to diagnosis: GP and cultural issues, Aftercare – end-of-life wishes.*

*BAME communities can be hard to reach out to where there is a language barrier. Even with a translator, it is very challenging.*

The only dementia group M wasn't aware of before the webinars was Meri Yaadain CiC, and now, *[she is] well acquainted with it.* She mentioned DEEP as another dementia organisation that tries to *promote voices for dementia carers and patients.*

*The webinars were excellent, and all went very well. The timings were fine and the length just right.*

M was very willing to be involved in any future plans.

## Interviewee 3

J joined the webinars as he *received an invitation from tide and became interested in attending.*

*The webinars were excellent and led by an amazing man who was able to keep the interest of the people every week. The series got more interactive as they went along as more people were confident to join in the discussions. The pot is boiling, and there is a need for more as they are interesting and beneficial.*

J was open to any topic for further webinars and had no particular agenda as he found them all insightful.

*BAME communities are hard to reach out to, as proven by the difficulty in involving groups in Scotland.* J's organisation does not have any BAME members, but it is *not for want of trying, and there is scope for it with sports such as cricket and hockey where some ethnically diverse may have more interest.*

The only dementia organisation J was *unaware of before the webinars was Meri Yaadain CiC, and after them [he] can never forget it.*

J expressed *great thanks to Mohammed and will always remember 'Mrs. Begum'* and it was a *shame to have a break from them [webinars].* He is *more than happy to help (not lead as he feels it has to come from someone with a BAME background) in any future plans and a coordinated network is needed now or at least a semi-formal network of email addresses/contact details shared amongst interested parties.*

## Interviewee 4

P *joined the webinars to learn more, to develop [her own] work practice and that of her colleagues. The webinars were very helpful and the discussion and information given were all very interesting.*

P was very keen for the webinars to continue. She suggested sessions on *communication and interpretation as translating has issues and the 'back translating' solution sounds interesting.*

*Taking a person-centred approach as working with the patient on their own is important as the family may say something else and take their right away (without any wrong intentions).*

She felt *BAME communities are hard to reach out to. Organisations have to be acceptable to be*

# Feedback from the interviews



*approachable. BAME organisations don't talk enough to each other and to other organisations. Often it is due to lack of funding that links can't continue as funding someone with BAME language skills doesn't last.*

The only dementia organisation P was not aware of before the webinars was Meri Yaadain CiC and after the sessions, she was well aware of it. P mentioned the Scottish dementia working group and National Dementia Care as other operational organisations.

*P enjoyed the webinars and [would] want to attend anymore if they become available. She was happy that it was not just a one-off and they continued each week. She has a great willingness to be involved in any future network plans and [her] Head of Policy also was keen to be involved.*

She strongly feels that the Scottish government wants to make Scotland inclusive for everyone and is wanting to make changes. Making it happen is the difficult part but if a coordinated network was to happen it could make a start.

The DDBS project needs to be well publicised and future plans could include contacting BBC Radio Scotland to help with this. It would be helpful to have more carers talking and if they were from the BAME communities in Scotland much more could be learned.

# Significant Findings 1



## Consultation and Community Engagement

The Dementia Dekh Bhaal Scotland project was identified after recognising that there was a gap in reaching out to ethnically diverse communities. It has proven to be very difficult to make a breakthrough in Scotland. There is no doubt that members of the forum are wanting to make a difference in Scotland. However, what is apparent is the difficulty of getting statutory bodies, dementia organisations, the ethnically diverse PlwD and their family carers in Scotland engaged with. The so-called 'hard to reach' are not necessarily that, but rather need to be consulted and involved so that culturally appropriate services are provided. Reaching out to these communities also requires a recognition by institutions and the people that work within them, that they too can be hard to reach, especially given the fact that everyone can be unconsciously biased in how we work and make decisions.

Trying to connect to organisations is difficult and service providers do not talk to one another resulting in difficulty in accessing the correct support required on a timely basis. One carer commented that the (CCG), couldn't provide anything '*tangible*', and, '*we are working towards*', became the standard response. A lot of comforting words but no action to back it up. GPs are so busy, especially with COVID, and '*don't want to know unless it is an emergency*'. If the patient could say their name and where they lived, no further action was taken. Link workers may be available, but it was felt that their role is '*limited*.' PlwD and carers struggle to get the help they need at the time of need as the support tends to be slow coming which leads to looking for a workable solution themselves. One adult carer support worker in Glasgow commented that '*they have no dementia-related services for BAME*', and that '*service providers don't respond appropriately to requests for help*.'

Statutory bodies/Commissioners make judgments / decisions on what they feel is happening rather than what is actually going on and so believe that the ethnically diverse '*communities look after their own and don't require their services*'. "*If people don't return or come for help in the first place, how can a budget be justified to provide services?*"

## Evidence from participants

- The services currently provided are disjointed and not culturally appropriate.
- Organisations fighting their own corners but need to join forces as "together we are stronger."
- No dementia awareness/support network is present in Scotland for the ethnically diverse.
- The Racial Equality 2015 report was more successful in acquiring data as it was done: 'through peer-led focus groups with trained community facilitators nominated by grassroots community groups [5]. It follows from this evidence and the DDBS work that Community Champion(s) are required in Scotland.
- Services are not being accessed and decisions made do not favour the ethnically diverse.

[5] Coalition for Racial Equality and Rights – ant-racist policy-making: review published 14 September 2021 (Scotland)

## Challenges

- There is a vacuum to be filled – organisations have tried to reach out to ethnically diverse communities in the past, but have not succeeded.
- Who will take responsibility to change the balance?
- Creating a sustainable network.
- Changing the mindset of those who make the decisions.
- Finding committed grassroots leaders in Scotland.
- Improvement of services practical/pragmatics so are culturally appropriate.
- Social services don't provide consistent care and often it is the 'luck of the draw' who you get to help or to answer your call whatever background you come from – so the quality of care comes into question.
- Cultural training needs to be given so organisations can provide culturally appropriate services – funding and provision.
- Ethnically diverse articulate carers are facing barriers which suggest it's the system that has problems and further training is required
- Obtaining funding for ethnically diverse groups.

# Significant Findings 1



- Carer – ‘scared – tried to reach out to organisations but not really got anywhere.
- Gatekeepers are seen as a spokesperson to represent communities even if don’t want the role – they may select info that suits them and their call – may not include lived experiences and help may get refused.
- Need to consider laws and culture pertaining to Scotland when producing resources – terminology/authorities may be different.
- BAME communities tend to go to the voluntary sector rather than statutory but what training do they have?
- Organisations should be coordinated so go through one door and get passed where you need to go immediately. Changes in the system need to be made.
- Recommended a ‘one-stop shop’ where everything can be found out – tips / ideas / how-to / advice, etc with possible development of a specific mobile application that has working and viable links.
- Following up procedures in place – if a letter is not responded to or an appointment not met, phone calls should be used as a follow-up – a personal touch.

## Solutions

- The formation of a sustainable working network with a firm belief that “together we are stronger,” with members competent in speaking English and/or Urdu and help to translate where required.
- Involvement of the non-voluntary sector.
- Education, training, and information for practitioners who provide services.
- Take a person-centred and a community or family-centred approach so that individual needs can be met.
- Need to work with local communities and not for them. Champion(s) in the community at grassroots giving them empowerment in their engagement with the ethnically diverse to who would contribute also not just participate.
- There are many ways to engage people– through resources, face-to-face engagement with the communities – visiting local schools, shops, barbers etc people will pick up the information and take it home and information gets spread. Engagement needs to reach into communities and organisations and be consistent and diverse.
- Meri Yadaain CiC is a strong anchor of support and can share culturally appropriate information and resources. Resources are being prepared to be ready and distributed appropriately across Scotland.
- Some Scottish organisations agreed to facilitate roadshows and pledged interest in creating a network.





## Dementia Awareness and Coping Strategies

Data on the ethnically diverse PlwD, especially the elderly, is lacking in Scotland. Scotland is mainly a rural/semi-rural area and has an ageing population so the impact on the NHS will naturally increase over time. Evidence from these webinars suggests that many ethnically diverse people living with dementia are not accounted for as many are not in care homes or access services. Organisations are starting to capture ethnicity in Scotland, however, a participant working in a dementia trust commented that 'not so many are coming through'.

Dementia is not a word that has been around for centuries and isn't even a word recognised in many of the ethnically diverse communities but in some religions, it has been alluded to for example in the Quran, '*and there are some who are sent back to a feeble age so that they know nothing after having known (much)*,' (Surah An Nahl, 16:70) and in the Bible, '*Biblical text indicates that King David forgot that he appointed his son Solomon to reign after him (1 Kings 1:17,18) [7]. Thus, it is a possible indication that the King suffered from dementia, even Alzheimer's type,*' (Ben-Noun, 2002). With this in mind, acceptance can be made easier for those who practice their religion as references can be made to their belief.

Religions nowadays recognise memory loss as a condition and contemporaries talk about the strength and faith that their religion gives them if they have dementia or care for someone with dementia and the spiritual reward for doing so.

An example of a dementia-friendly town was discussed, Prestwick in Scotland. Success in dementia awareness is huge in Prestwick and lessons can be learned from their success. However, it can be considered less ethnically diverse than the UK average, 'as a whole, the UK population claims itself as approximately 86% white, with residents of this area being exclusively so [6].

[6] <https://www.streetcheck.co.uk/postcode/ka92yd>

[7] Was the Biblical King David Affected by Hypothermia? Liubov Ben-Noun, The Journals of Gerontology: Series A, Volume 57, Issue 6, 1 June 2002,

## Evidence from participants

- There is no word for dementia in most of the ethnically diverse community languages. If people don't know what they are dealing with as they don't recognise dementia, how can they respond to it well or understand it?
- There is a lack of awareness of what dementia is and where support can be found especially amongst the ethnically diverse population.
- Awareness is something that has to stretch not only across communities but to service providers and statutory bodies as well.
- Some PlwD prefer to stay behind closed doors and rely on faith or because of stigma which tends to be more prevalent in the ethnically diverse communities.
- There is no winning formula for all towns/communities and whereas it may work for one group it may not for others. Caution has to be taken when making policies and conducting blanket awareness campaigns as it is vital to understand different language and cultural needs. This is exemplified in the CRER in Scotland report [8].

[8] Coalition for Racial Equality and Rights – anti-racist policy-making: review published 14 Sept 2021

A real-life example of the consequences of blanket approaches to race equality can be seen in the positive action programme carried out by one of Scotland's national agencies. After considerable investment in this programme, the results were deemed to be a great success. However, a disproportionate number of those completing the programme and moving into work were from various white minority ethnic backgrounds for whom no evidence of barriers to entry had been gathered. BME people did not benefit from the programme in the way intended and were still disadvantaged despite the high level of investment.

Replicating this type of approach, rather than taking evidence-based, anti-racist action, is an inefficient use of resources and could actively widen gaps if disproportionate numbers of people who do not face barriers benefit...UK-based research has found previously that social care services are failing to meet the needs and wants of minority ethnic older people, despite efforts at improvements. Research published in 2000, 'Researching Social Care for

# Significant Findings 2



Minority Ethnic Older People: Implications of Some Scottish Research', focussed on the Pakistani community in Glasgow and their relationship, or lack of, to formal social care. This concluded that, despite efforts of the staff to make social care 'user friendly' for this group, there remained considerable issues, with the very real needs of older Pakistani people often being left unmet.

- Research has shown that carers are wanting to talk about their experiences but need to be aware of platforms where they can talk openly and honestly and more importantly, make a difference. Tide promotes carers to find their voice and this empowers others to do the same.
- Carers as much as patients are requiring support and availability of coping strategies are not apparent and rest bite may not be possible.

## Challenges

- Got to recognise the condition first. Some BAME families do not know anything, or enough about dementia or even accept it (willingly or not) and not enough awareness of the help that is out there.
- Awareness of dementia comes too late or not at all. Advance care planning can't always happen in BAME communities – already passed the crisis point due to not recognising/ accepting wanting to cope alone so better to talk about decisions to be made. Helping them to manage rather than to live well with dementia has gone too far.
- A lack of awareness of support services available and reluctance to seek medical help due to social stigma and whereas 'memory problems' is acceptable 'dementia' is a taboo.
- Carers can be aware of services but still be struggling. One biggest challenge was knowing how to manage their own sanity and get support as a carer.
- Obligation to care on religious grounds – family grounds – could be very difficult to the willingness to care and therefore quality
- Technology is not always the best solution for all as a platform to spread awareness. The elderly are alone and don't use technology well – how do you reach out to them? People don't always have the confidence to use technology, websites are not always easy to navigate.

- Accessibility to services and awareness needs improving where the language used is mainly the English language.

## Solutions

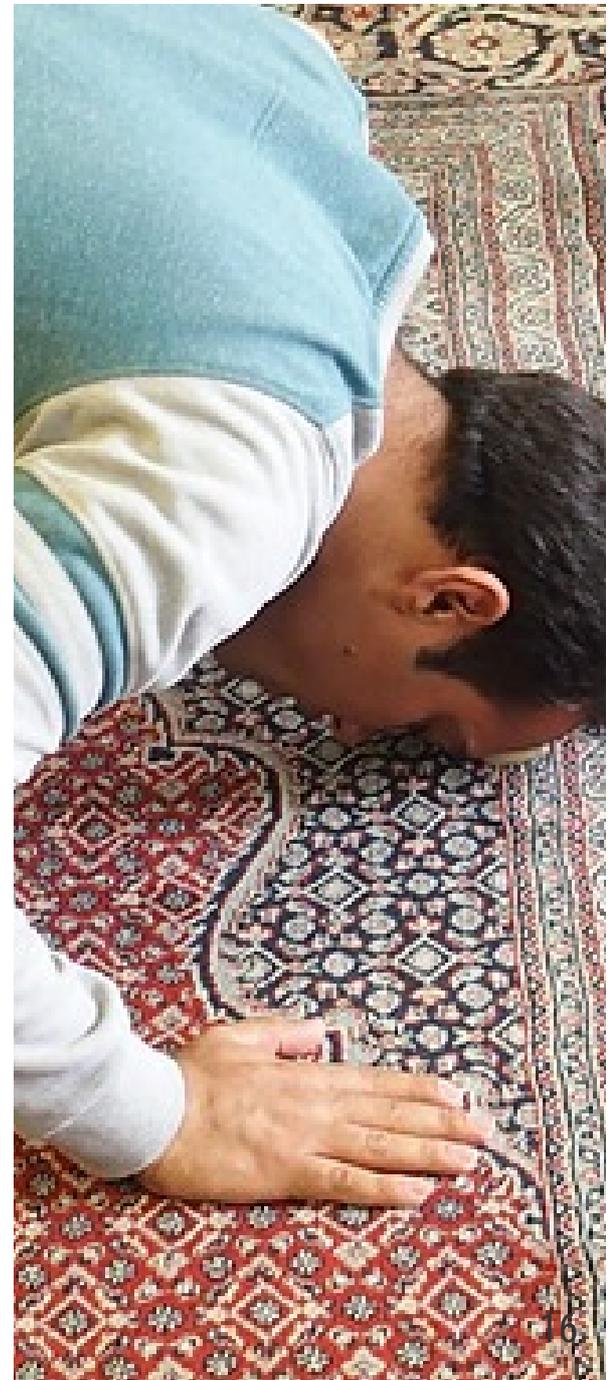
A well-publicised, effective, and sustainable awareness campaign needs to be launched.

- One Bradford-based organisation participant suggested that the responsibility lay at the door of the professionals to raise awareness and to not expect people to 'come knocking'.
- Families and carers need educating and to be aware so to help to 'live well' with dementia.
- Resource work has been prepared for the DDBS project. Truck art posters with information
- Health care professionals in all sectors need to be more culturally aware of different needs through education and training and gaining experience of working with people from different minority ethnic communities to create a reminiscence with culture and the ethnically diverse can relate to. Leaflets in different languages. Distribution alongside the campaign at grassroots.
- Traditional face-to-face and grassroots campaigning are vital as mentioned in findings 1.
- Comprehensive health service data needs to be recorded on the ethnically diverse to effectively promote and protect their health and well-being in Scotland. A clear baseline is needed so that any change can be measured. It is already recognised by the Scottish Government. 'The creation of a system that ensures consistent ethnic coding within Scotland's health information systems has to be a key priority for the Scottish Government [9].
- The idea of a 'kite mark' for dementia-friendly so people are aware and know that the organisation has people aware and trained to deal with dementia – a possible niche that would encourage more to take up the awareness training.
- Carers are determined to leave a legacy even if they don't benefit themselves.

[9] Op Cite

## Significant Findings 2

- Accessibility of services should be improved. Where language is an issue, there should be wider availability of interpreters and interpreting services. Increase the awareness of interpreting services amongst the ethnically diverse and health staff and train the interpreters to interpret medical and sensitive information. Telephone helplines should be available with trained staff available and able to speak the minority ethnic languages.





## Establishing Trust within the Scottish Ethnically Diverse Communities

Trust extends from within the community to outside including organisations and GPs. One carer stated that 'one main challenge was the GP' and the competency of the NHS services who 'got things wrong'- such as 'ethnicity' and 'assumptions' were being made and 'out of date information' passed on. Misdiagnosis can also lead to mistrust. If health services are dealing with people in such a manner, then their reputation as service providers is severely tarnished and there will be little or no trust in the services that they provide. Trust issues extend to other organisations such as 'councils (who) are not flexible for different cultures.'

Research has an important place in planning and development surrounding dementia awareness and racial equality and should be inclusive where qualitative and quantitative data are essential. People often don't take part for fear of being judged, their info /data is not safe (confidentiality) and therefore there is no trust in the process. Often participants feel like 'guinea pigs' and need convincing of the benefits for themselves or their community and not just a tick box or experiment exercise. This led to the question of 'whose responsibility is it to ensure the reciprocal benefits?' It was suggested that there should be engagement from community leaders but will need to be 'convinced of the benefits' of research to initially be involved and likewise to convince their members. So again trust and awareness go hand in hand and there is a need to raise awareness around the benefits of research. Trust takes time to build relationships and understanding. Once you have the trust it can be a sustainable working partnership.

Racial equality in health is crucial for improving the standard of life and life expectancy to better meet the needs of the ethnically diverse. A question mark hangs over institutional racism that prevents service providers to respond to ethnically diverse communities. If needs remain unmet through racism or unconscious bias, racism will always remain to some degree, and some don't want to understand other communities/faiths but organisations need to be educated to become more dementia-friendly to remove the unconscious bias and start to reduce the inequalities. Fear of unconscious bias works both

ways and the ethnically diverse members have a fear of prejudice and believe they won't be welcomed. So they end up 'managing' on their own until crisis point, due to the isolation factor caused by this two-way unconscious bias.

## Evidence from participants

- The more ethnically diverse communities tend to be the poorest, when they have jobs they are not usually in senior positions, they can be discriminated against and racism is prevalent. Research has shown this, but nothing much has changed after years of talking. So, if decision-makers minds cannot be changed, funding often cannot be received.
- Organisations like Meri Yadaain CiC are attractive to the more ethnically diverse as they 'will understand' and they feel more on 'familiar ground' with regards to language and culture and the personal service given.
- Research in Scotland shows that records relating to health and ethnicity are inadequate.
- 'The Expert Reference Group on Ethnicity and Covid-19 stated that data on ethnicity has been recorded in many NHS Scotland administrative systems for some time, but levels of recording and data quality have often been too poor to allow meaningful analysis (and) the incomplete recording of ethnicity in routine health data remains an issue...CRER research in 2020 highlighted that for the Health outcome of the Scottish Government's National Performance Framework, no ethnicity data is currently published on Equality Evidence Finder.' [10]
- Research is continuously taking place, but it appears to have a negative impact with regards to the ethnically diverse. When they are involved, there is a lack of trust around the research for several reasons. Some of these are lack of transparency and trust – why do you want this information, what are you going to do with it.

[10] Op Cite

# Significant Findings 3



## Challenges

- How do we know about the awareness if research also is failing to achieve meaningful results?
- Researchers make assumptions that community capacity has been built to the point that they can comfortably take part in studies - this is not always the case.
- Mistrust in 'solutions': 'It is evident throughout both reports that the solutions proposed are aiming to deal with the same entrenched racial inequalities, and in some cases, those solutions are almost identical.' So not much advancement. Specifically mentioned was: 'Improving culturally responsive approaches to healthcare and access to interpretation in healthcare settings... despite the clear continuing issues raised by both groups, the focus does shift in terms of where the groups believe solutions lie over time.'
- Who is responsible to change the balance? Universities, care trusts, etc? Research is continuously taking place, but it appears to have a negative impact with regards to the ethnically diverse, there is a lack of trust in the research process.
- Results are not used as the sample size of ethnically diverse is not big enough nor credible to show the changes that are needed and ends up being a waste of time and resources. Need more to take part.
- When the targeted people are involved in research, they often find that carers have 'survey fatigue' and don't have the time to take part due to their caring responsibilities. Gatekeepers turn researchers away to protect their members.
- The more ethnically diverse tend to be migratory/fluid – move around – so some people not there to continue research with and not around to get results.
- Research tends not to yield immediate benefits as it can take a long time and sometimes years to implement before results can be seen. 'It's one of the challenges of explicating the benefits of participating in research to potential participants and they may not even benefit from the findings.'

- Dissemination of results is often not given back to those who took part.
- Without knowledge of recommendations and implementations – people are not encouraged to take part.
- Unconscious bias, how to provide services and have equitable provision? Equality versus Equity.

## Solutions

- Research awareness within the communities and organisations.
- Need to build trust and relationships first and then do the research.
- Research needs to be designed better as it has flaws and expectations need to be managed – greater transparency is required.
- Responsibility is two-way – communities have to take responsibility and public organisations also have to say – both have to convince why it is being done and why research has benefits. Need for community group leaders to be involved.
- Can get people to sign up and they can choose what research they have time for and/or are interested in. Won't give immediate results and will take time to build the register but a starting point must be made. Personal feedback is required.
- A plan to address the unmet needs and persistent ethnic inequalities. The key to avoiding missed opportunities or making ineffective proposals is to specify the inequality to be addressed, identify reasonable assumptions about what will work to address it, begin to develop appropriate actions, and identify with certainty where these fit into the policy landscape without hesitation.
- Getting rid of assumptions and unconscious bias, not labelling people or communities and being confident to expose wrongdoing and prejudice.



## Legacy of the pilot work in Scotland

The Dementia Dekh Bhaal Scotland project set out to reach into Scotland to raise awareness of the issues impacting ethnically diverse carers looking after a relative living with dementia.

Taking into account the limiting conditions associated with Covid-19, the project changed direction from running community roadshows to organising radio adverts, postcards with hand-painted designs encouraging reminiscence for South Asian families where someone is living with dementia. The project also created an activity booklet that would encourage conversations within the home.

## Radio Adverts and a radio programme

Three radio adverts were created in English, Urdu and Punjabi, in line with the main languages most likely to make an impact on reaching out to ethnically diverse communities who tune into Glasgow's only Asian radio station - Awaz FM. The adverts ran for four weeks, with each of the language adverts being played four times a day.

Following the radio adverts, a two-hour radio programme was commissioned, which allowed for a discussion on dementia in ethnically diverse communities. It was also designed to run at the end of the four weeks of the radio adverts so that many of the listeners would have been introduced to the concept of dementia after having heard the radio adverts.

## Postcards

Postcards designed by a truck artist in Pakistan meant that the brightly coloured postcards were not only attractive to look at but that the South Asian communities would see them and want to pick them up. Each has a different colour-coded set of information on the reverse. These include:

- Dementia in ethnically diverse communities
- Caring for a relative with dementia
- BAME Dementia carers
- Dementia and faith
- Managing finances
- Living with dementia

## Activity booklet

Given that many families struggle with initiating conversations about dementia, the Dementia Dekh Bhaal Scotland project set about putting together an activity booklet that would allow the carer and the cared for to work through some simple colouring-in activities. This could then lead to conversations whilst the activity is being undertaken.



# Conclusion



## Conclusion

The three main overarching interrelated issues have been discussed above in detail, and the key points that have come out from the findings are noted below.

The main overall challenges are:

- Raising awareness and removal of stigma within the ethnically diverse communities.
- Getting organisations to work together.
- Allocation of responsibility to do the fieldwork, raise awareness and conduct the research so that positive changes can be made in practice and policy.
- Creating a sustainable and viable network.
- Changing the mindset of organisations and ethnically diverse – for improvement in services, decision making, and cultural perception.
- Finding reliable and competent Community Champions.
- Funding for the much-required training, education, and resources for service providers, carers, and families.
- Coping strategies for carers.
- Language barriers – services/resource material/support.
- Unconscious bias/racism/inequality.
- There is a lack of qualitative and quantitative research and data on the ethnically diverse elderly. ‘Some specific health conditions are more likely to be experienced by people in particular minority ethnic groups, but data on these issues for Scotland is patchy.’<sup>10</sup>
- Raising awareness of the benefits of research and gaining the trust, acceptance, and involvement of ethnically diverse communities.

While the challenges are great and there is a steep mountain to climb, the DDBS project has already planted the seed and members of the forum are talking to their colleagues, passing information on, questioning why there are few referrals from BAME, thinking about having a service that is appropriate for the ethnically diverse, and wanting to continue the work. The free webinars saw a good depth and diversity of attendees and most people came back each week to further their awareness which is testimony to how useful they were. Feedback and comments have been very positive. A great deal of

passion and activism has been generated, and a plea for ‘such conversations (to) continue’ with the extension to a series of 6 webinars was highly appreciated. All comments were very positive, and great thanks were given to the insight and engaging webinars facilitated by Mohammed Rauf, facilitator of the webinars. His enthusiasm was quoted as being “infectious” for everyone.

The limitations of the webinars were that no carer from Scotland presented their case, so no insight was given to how they are coping with Scottish organisations/authorities. However, a carer and two former carers joined the radio programme. Only six members attended the final webinar that was to discuss further recommendations. This was an important session and needed some members closer to the ethnically diverse communities to be involved, as the current members preferred to help rather than lead due to cultural differences. Insider/Outsider issue – is seen as ‘one of us’ is easier but outsider not trusted.

Cultural competency training is suggested as a solution but will take time. Some members wanted to have pdfs of the presentations. Data has been limited to the webinars, only one survey monkey and interviews. The measurable impact of the radio advertisements that went out in three languages – English, Urdu, and Punjabi, four times a day for four weeks to raise awareness on Awaz was difficult to capture. FM radio Glasgow, the resource materials to raise awareness (including truck art style information postcards, an activity booklet, and leaflets) and the impact of the webinars to be used as materials available to individuals and organisations, beyond the scope of this project.

# Recommendations



## Recommendations

The DDBS forum proved to be very effective but now needs to be more than just a forum. The challenges must be overcome. There is a real appetite in Scotland and the forum members want to play an active role in spreading dementia awareness so that the ethnically diverse members affected can live better. The DDBS project has only been functional for two months and so it is the start of a legacy and now the groundwork must be done to focus on the achievable within the short run and build up to greater achievements in the longer run.

Solutions also need to be focussed on creating meaningful change in the lives of people impacted by racism and racial inequalities. The questions "Will it work?", "How will it work?" and "How will we know if it worked?" should be omnipresent in the process of putting into practice any solutions to ensure they are meaningful measures taken.

- A strong and meaningful publicity awareness campaign is required to improve dementia awareness and coping strategies and to recruit members in Scotland.
- There is a large interest in forming a network and action has to be taken now to form a working viable network involving voluntary and non-voluntary members. To form community groups and involve and empower grassroots members to be actively and consistently engaged in promoting awareness and establishing trust.
- Scottish organisations have mentioned that they would like to partake in any roadshows to raise the BAME dementia/dementia care agenda.
- Continuation of webinars with more involvement from the voluntary and non-voluntary sectors involved with the ethnically diverse.
- More live radio programmes to go out on Awaz FM
- Dissemination and coordination of resources in Scotland that have been produced by Meri Yaadain CiC - possibly through a launch including some higher profile person such as an MSP.
- Develop a 'one-stop shop' where organisations come together, and all current sources of information can be accessed.

- Participatory research needs to be carried out within Scottish communities around dementia awareness and accessing of services. Data is only rich if they are willing to share and therefore trust has to be established.
- Training and education are required on race equality and provision of guidance resources - (include unconscious bias, white privilege, social constructs and migratory histories and their impact.
- The Scottish government recorded that policymakers are aware of the racial inequalities that need to be tackled 'provided they know where to look and how to interpret it.' Tide tries to work with members to influence politics and develop services. There is the scope and potential to work alongside the Scottish government as they have recently reviewed inequalities and racism relating to various subject areas including health.

The CRER [11] report noted that the 'challenges haven't changed that much over time, but a more challenging aspect of policymaking is gathering the evidence on what works to create change in these inequalities. Work on race equality, whether in terms of national policy or local interventions, is notoriously under-evaluated. This means that policymakers are often setting actions without the ability to firmly assert that the actions will make a difference.'

'Practice over the years has not always reflected this well. Instead of developing specific, race-focused mechanisms to create change, there is a tendency for policymakers to 'bolt on' race equality to current priorities and policy drivers, sometimes not specifying any action beyond considering race in these areas.'

'Mainstreaming is a key aspect of race equality work, and no reasonable argument can be made for approaches to race equality work that are divorced from the wider policy arena, but the key question must always be how to mainstream effectively. Care has to be taken to ensure that race equality is addressed in the most robust way possible, through both targeted and mainstream policy.'

We would also recommend the use of 'Theory of Change' to progress with this work so as to embed inputs, intervention, outcomes and achieve outputs.

[11] Coalition for Racial Equality and Rights – ant-racist policy-making: review published 14 September 2021 (Scotland)

