

# Improving access to palliative care services for people from Black, Asian and Minority Ethnic backgrounds in South East Cardiff

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Caring for carers within revitalised communities in Wales is funded by the Big Lottery Fund Wales.





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Vaughan Gething, AM for Cardiff South & Penarth and Deputy Minister for Tackling Poverty

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## Foreword

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I am very pleased to have the opportunity to write the foreword for this important report.

In my role as an Assembly Member I represent the largest constituency in Wales by population size. It is also one of the most diverse, with a large number of people from Black, Asian and Minority Ethnic backgrounds. The richness and the mixing of cultures and people from across the globe in the ports of Cardiff and Penarth is part of our collective history and our shared future. It's a pattern repeated across a number of towns and cities in Wales and Britain. Despite the widespread acceptance and celebration of the diversity of modern Wales, there are still barriers to access and inequalities in provision that many Black, Asian and Minority Ethnic families face. We know all too well that if left unaddressed this inequality can cause significant problems for people throughout their lives. It should come as no surprise to see that those same challenges need to be addressed to ensure that high-quality end of life care services are available for all of our communities.

This Marie Curie project has already achieved much and I know it wants to achieve a great deal more. It is to Marie Curie's credit that the charity has recognised the reality of this challenge and is prepared to take practical steps to address it.

I hope that you find this report as interesting and informative as I have and that, like me, you wish this important project even greater success in the future.

A handwritten signature in black ink that reads "Vaughan Gething". The signature is written in a cursive style.

**Vaughan Gething**

AM for Cardiff South & Penarth

Deputy Minister for Tackling Poverty

## Introduction

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Wales has an ageing population. People are living with poor health and with more complex problems for longer. The subsequent pressure on the finite resources of the health and social care system has increased the need for alternative models of service provision.

Marie Curie is at the forefront of innovation in end of life care services in Wales. We work with NHS Wales and other partners to meet national and local strategic requirements and goals. We support people across Wales through our community nursing service and at our Marie Curie Hospice, Cardiff and the Vale, in Penarth.

Our hospice is located close to Riverside, Grangetown and Butetown; areas which have a high percentage of residents from Black, Asian and Minority Ethnic backgrounds. However take up of our hospice and community services among these groups has been very low.

In September 2012 we launched a three-year project, funded by the Big Lottery, entitled *Improving Access to Palliative Care Services for Minority Ethnic communities in South East Cardiff*.

The project was set up to meet three main objectives:

1. Improve links with Black, Asian and Minority Ethnic community leaders and community-based agencies (including GP practices).
2. Reduce barriers to service access for people from Black, Asian and Minority Ethnic backgrounds.
3. Increase support for patients from Black, Asian and Minority Ethnic backgrounds with life-limiting illnesses and their families.

The report outlines the main barriers to accessing hospice care from the perspective of people from Black, Asian and Minority Ethnic backgrounds living in Cardiff. It includes their suggested ways to break down these barriers, together with key learning messages for Marie Curie and other healthcare providers. It also highlights improvements made and planned at the Marie Curie Hospice, Cardiff and the Vale as a direct result of their recommendations.

## Methodology

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Seven discussion groups, made up of 67 people, were invited to the Marie Curie Hospice, Cardiff and the Vale between November 2012 and January 2014. The groups were given tours of the hospice and services were explained.

The groups included:

- men and women
- mixed ethnicities and faiths
- representatives from community organisations
- community members
- professionals
- local councillors
- other stakeholders

A further 64 people participated in discussion groups at an event at the Cardiff and Vale College in April 2014. The participants were all studying English for Speakers of Other Languages (ESOL) and were of varying ethnicities and ages.

All participants were asked a set list of discussion questions.

## Part 1: The main barriers to accessing hospice care for people from Black, Asian and Minority Ethnic backgrounds in South East Cardiff

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The Marie Curie Hospice, Cardiff and the Vale is located close to areas which have a high percentage of residents from Black, Asian and Minority Ethnic backgrounds. However take up of our hospice and community services among these groups has been very low.

The discussion groups were asked to outline what they thought were the main barriers to people from Black, Asian and Minority Ethnic backgrounds accessing the hospice's services.

Diagram 1 summarises their answers.

This chapter includes an assessment of each barrier, based on the participants' responses, together with a key learning message for Marie Curie and other healthcare providers.

**Diagram 1: Participants' perceived barriers to accessing hospice services**



## Barriers

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### Lack of awareness

All groups felt a lack of awareness of the hospice, its services and the range of conditions it supports was the overriding barrier to access.

Despite the fact that some participants had worked in Cardiff for many years (including in healthcare), most had never been to the hospice and most had never heard of the hospice or knew that it cares for patients with other terminal illnesses, and not just cancer.

Those that had heard of the hospice felt that there was still a stigma attached because of the assumption that being admitted to a hospice signalled the end of life.

Most were unaware that the hospice also helped families and carers and felt that healthcare services in general were only focused on the patient, while relatives and carers were largely ignored.

Participants who were refugees and/or asylum seekers had very little knowledge of healthcare services in general.

### Key learning

People from Black, Asian and Minority Ethnic backgrounds need to be informed and educated about palliative care. Palliative care services also need to connect more with relatives.

### Terminology

Words like 'hospice', 'palliative care' and 'symptoms' were not easily understood by participants.

### Key learning

Words like 'palliative care' and 'hospice' need to be explained. Even when translated there is often no comparable word/concept in community languages.

### Trust

There were anxieties and a general lack of trust and faith in healthcare services. Examples included anxieties around the purpose of medical tests and a fear that social services would take children away.

### Key learning

Healthcare services need to be aware that a lack of trust in services may be due to past experiences and that they need to gain the trust of the community.



## Diet

Appropriate food and food preparation was important to participants. They said it would play a part in their decision to use a service. Some felt that services were set up mainly to cater for white British diets while others didn't see this as a concern because they felt families would bring in food for their loved ones.

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"Food is good, makes people feel at home."

### Key learning

It is important to reassure patients and families that the hospice can cater for religious and culturally appropriate food.

## Language

Language was seen as a barrier, especially for older community members. Participants felt that it was important to have interpreters available to explain what was happening while patients were receiving care.

However, there were mixed feelings as to whether information translated into community languages was important. Some felt it was not cost effective because a family or community member could translate the information to patients and carers.

### Key learning

It is important to help patients understand medical procedures in a way that is clear to both the patient and the family.

## Culture and religion

Some participants felt that palliative care services were not set up for people from Black, Asian and Minority Ethnic backgrounds and had concerns over whether the hospice was culturally and religiously appropriate.

Most participants talked about the importance of prayer and washing facilities for patients and families. They were happy to share the hospice's quiet room (a room used for quiet reflection or multi-faith prayer) with different faiths but felt the room should have a peaceful ambience and be clear of furniture and clutter.

There were also discussions around the need for artefacts needed for prayer, including prayer mats, a sign for the direction to Mecca, Tassibee prayer beads, a Quran, pictures or statues of Hindu Gods and a copy of the Geeta holy book.

Participants felt staff needed to understand praying rituals and be able to help if needed. They also felt families should be assured of the hospice's links with religious organisations in order to ensure that it fully understood the importance of rituals after a patient has died and could support them.

### Key learning

It is important to assure patients and families that the hospice is culturally competent and respects and supports religious needs in a language that is understood by patients and families.

### **Gender issues**

Participants said that gender issues could prevent people from accessing services. They felt very strongly about the need for single gender wards and bays, but did not have an issue with mixed-gender clinical staff. They also felt that there should be separate male and female wellbeing groups.

#### **Key learning**

It is important for patients from Black, Asian and Minority Ethnic backgrounds to have gender-specific wards and bays.

### **Transport**

Some participants felt transport was a barrier to accessing hospice services and visiting people receiving care. The key factors were a combination of a lack of own transport, difficulties with public transport and the distance between the hospice and local communities.

#### **Key learning**

It is important for people to be aware of times and details of bus services to make hospice visiting easier.

### **Lack of staff diversity**

Participants felt there was a need for more staff from diverse backgrounds, including volunteers. If this was not possible, participants felt staff should have cultural awareness training around the needs of patients and families from Black, Asian and Minority Ethnic backgrounds.

#### **Key learning**

Having staff and volunteers from Black, Asian and Minority Ethnic backgrounds helps to break down barriers, build trust and gives a message of diversity.

## General Practitioners

Participants said misunderstandings about services were not always related to language and some were unsure if GPs were fully aware of Marie Curie's services.

They felt that GPs should refer more people from Black, Asian and Minority Ethnic backgrounds to Marie Curie and explain fully to patients and carers what services were available, including respite care. They also believed that some healthcare professionals held the preconception that members of their communities 'looked after their own'.

Furthermore they felt GPs should offer to refer patients to services at regular intervals and should find out why a patient might decline the service, to ensure they fully understood the services available to them.

### Key learning

GPs are held in high regard and people will do as they are advised. GPs play a very important role in providing information about the charity. There is a need to ensure that GPs understand Marie Curie's services and that they refer patients from Black, Asian and Minority Ethnic backgrounds.

## Attitudes

Participants were keen for Marie Curie to understand that, although people from Black, Asian and Minority Ethnic backgrounds would prefer to care for their loved ones, it wasn't always possible. Cultural changes such as family members moving away, financial and economic pressures and the adoption of western lifestyles now made caring for relatives challenging. However some said there was still a stigma attached to sending a relative to a hospice because it could be seen as a person not doing their job as a mum, daughter or carer.

Some participants felt families themselves could be a barrier to accessing services due to fears that the hospice was a care home that would take their loved one away from them and affect their benefits.

Participants also spoke of attitudes to illness that needed to be addressed, such as a fear of catching the illness, which caused families and patients to try to hide their illness or disability from others.

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"People want to look after their parents, 95% want to, but this will change... due to men and women having jobs."

### Key learning

It is important that people from Black, Asian and Minority Ethnic backgrounds know that Marie Curie can help them look after their loved ones at the end of life, as opposed to doing it alone.

## Part 2: How to help reduce the identified barriers to access

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Once they had identified the main barriers to accessing Marie Curie services, the discussion groups were then asked how they felt these barriers could be reduced for people from Black, Asian and Minority Ethnic backgrounds.

Diagram 2 summarises their answers to this question.

This chapter outlines some of the suggested solutions, based on the participants' responses and highlights key learning messages for Marie Curie and other healthcare providers.

**Diagram 2: Participants' views on how to reduce barriers to services**



## Suggested solutions

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### Building awareness of services

Participants felt that Marie Curie could raise awareness of its services and the quality of care available by giving out more details about the services offered, eg support for families and carers, complementary therapies, counselling, help to access benefits, occupational therapy, physiotherapy, support for children and specialist nurses who visit patients at home.

They also thought it was important to communicate the differences between a hospice and a hospital in relation to visiting times, visitors per bed etc.

Participants felt communities, GPs and healthcare workers needed to be clear on referral routes into Marie Curie services.

### Key learning

Participants felt strongly that people from Black, Asian and Minority Ethnic backgrounds would use services if they knew they existed. It is important to reach out to communities on an ongoing basis to inform people about the range of services offered and conditions supported by the hospice.

### Specific needs

Participants indicated that people from Black, Asian and Minority Ethnic backgrounds may have a preference for home care services – in line with their cultural background of looking after relatives at home. This included services such as being supported to be able to die at home, home visits for help with pain relief, occupational therapy and physiotherapy.

Day care services were viewed positively, including complementary therapies, bereavement support, counselling services, benefit and welfare rights, family services, relaxation and sleep management services.

Short stays in the hospice for pain control and symptom management were also viewed positively, as were short stays for respite.

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"We have respect for nurses and would welcome them into homes."

### Key learning

People from Black, Asian and Minority Ethnic backgrounds may have a preference for home care services – in line with their cultural background of looking after relatives at home. They may also favour short hospice stays for pain control, symptom management and respite care.

### **Promoting Marie Curie services within Black, Asian and Minority Ethnic communities**

Participants said that word of mouth was a powerful way to spread information about Marie Curie services in their communities and many offered to help spread the word in their own communities.

They suggested a number of places to promote the services including community groups, community centres, leisure centres, job centres, libraries, GP surgeries, hospitals, places of worship, social media sites, schools and colleges and English for Speakers of Other Languages (ESOL) classes.

They also recommended that the charity attend community events and organise special information days at the hospice.

Participants felt that having a regular presence (eg once a month) was advantageous as people would remember the charity and what it does and would feel more comfortable asking questions and asking for information.

They also felt a DVD, available in several community languages and shown to community groups and on monitors at GP surgeries, would be an excellent tool to showcase the hospice and its services.

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"In every Minority Ethnic community there are community leaders, both formal and informal, who can be used to share information about Marie Curie services. It is important to get to know who these people are by networking."

#### **Key learning**

Overall, participants felt the best way to raise awareness of Marie Curie is through word of mouth. Participants liked the idea of Marie Curie staff going to talk to them and more community members being invited into the hospice. This would give them the best opportunity to understand the services that Marie Curie provides and to ask relevant questions.

#### **Language**

Participants felt it was also important to provide information in a variety of community languages for patients and carers. They felt information should be short and clear, should include diverse images and should be aimed directly at their communities.

#### **Key learning**

Written information needs to be short, clear and concise with diverse images and if possible in community languages.

### Positive hospice environment

Participants felt that visiting the hospice was crucial in breaking down barriers and they were keen to take the message back to their communities that there was no need to be afraid of the hospice.

They supported regular hospice tours, arranged by the hospice, and also suggested that GPs could arrange visits to the hospice for their patients through referrals to special information/open sessions at the hospice.

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"Very pleasing, welcoming atmosphere, where families are welcome."

### Key learning

The hospice environment and services are very well received when people visit the hospice. This is a positive way to break down barriers and dispel myths.

### Volunteering and fundraising

Participants felt that it would be very beneficial to have Marie Curie volunteers in the hospice and in the community that spoke their languages and shared their cultural backgrounds.

They also supported the idea of training volunteers to share information about Marie Curie and the services it provides. They felt volunteers would have good access to their communities and could also help to put patients, carers and families at ease and help them to feel less isolated.

Participants also suggested that Marie Curie should do some work with communities around fundraising, such as asking community groups, shops and centres to take fundraising boxes.

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"If you speak another language, we want you!"

### Key learning

People from Black, Asian and Minority Ethnic backgrounds volunteer all the time in their day-to-day lives but do not see it, or name it, as volunteering. People are keen to help fundraise and volunteer and not just be seen as service users.

### Part 3: Changes made and planned at the Marie Curie Hospice, Cardiff and the Vale to improve access to people from Black, Asian and Minority Ethnic backgrounds.

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Marie Curie is extremely grateful to the discussion groups for their insights and for the sheer volume and quality of their feedback.

We have carefully evaluated all of their feedback and have used their key recommendations and our key learnings to help make improvements to services and facilities at the Marie Curie Hospice, Cardiff and the Vale. We have also started to address the need for updated working practices.

We will continue to seek advice on ways to remove barriers to access and improve services for patients, carers and families from Black, Asian and Minority Ethnic backgrounds in South East Cardiff.

Diagram 3 summarises the changes that have been made or are being planned at our hospice, following feedback from the discussion groups. This section also includes an assessment of each of the changes.

**Diagram 3: Changes made and planned at the Marie Curie Hospice, Cardiff and the Vale.**





## Changes made and planned at the Marie Curie Hospice, Cardiff and the Vale

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### Environmental

The hospice's quiet room, which is available to patients and families for multi-faith prayer, has been improved. It now includes artefacts that have been donated by religious groups.

We are also exploring the washing facilities, including installing a foot basin and bidet in the toilet close to the quiet room so people can wash before prayer.

Our hospice is establishing a routine to ensure celebratory food is available for all patients and staff on significant dates in the calendar such as Chinese New Year.

We have also begun to address issues that may affect families from Black, Asian and Minority Ethnic communities, such as drinks trolleys at the hospice and the health and safety risks involved if nursing staff are asked to take shoes off when in people's homes.

### Referral

We have introduced a pilot community signpost form so community organisations can refer community members to Marie Curie services.

### Communication

We have produced and distributed improved publicity information with diverse images to communicate the range of services provided and conditions supported. Information is now also available in community languages.

We are also producing a DVD to showcase our hospice and its services to people who are unable to visit the hospice personally.

We have communication cards to use with patients where language may be a barrier and we have informed all hospice staff that we now have access to interpreters 24 hours a day, every day of the year, should patients, families or carers require this service. This has also been highlighted in publicity materials.

We have added information about improving access to services for people from Black, Asian and Minority Ethnic backgrounds on our main charity website.

### Volunteers

We are working with community organisations to encourage volunteers from diverse backgrounds to get involved with our hospice.

## Working with staff

We have established a need to improve staff awareness of a number of issues and have begun to address them. These issues are:

- The diversity of cultural and religious practices.
- The cultural, religious and dietary needs of some patients.
- Key dates in the multi-faith calendar and other specific significant dates that may affect patients.
- Sensitivity around people's experiences of other services to ensure patients understand why they are asked certain questions.
- The diverse nature of family groups, including mixed White and Minority Ethnic families.

We have also established a need for improved patient monitoring information and the creation of a learning resource for all Marie Curie staff to promote good practice in regard to improving diversity.

## Gaps in healthcare services

Our discussions have identified the need for social support for young people with terminal illnesses from Black, Asian and Minority Ethnic backgrounds. There is also a general need for culturally appropriate counselling and befriending services for people of all ages from these communities.

## Links with external agencies

We are now on the referral database for the Stroke Association and Diabetes UK and we have contributed to a report for the Welsh Government rapid evidence review that looks into health inequalities experienced by people from Black, Asian and Minority Ethnic backgrounds and people with disabilities.

We are a named contact in Diverse Cymru's 'The Health & Well-being of Black & Minority Ethnic People - Selected Services & Resources' and we have developed a Black and Minority Ethnic Health and Wellbeing leaflet for GPs in conjunction with the mental health and wellbeing group at the hospice.

Cardiff and Vale UHB Local End of Life Delivery Plan 2013 – 2016 refers to our work with Black, Asian and Minority Ethnic communities and states that it would like to, "...expand links to and review the outcomes of the Marie Curie BME link post and utilise these to inform the development and delivery of services".

## Conclusion

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This project has given us a better understanding of the palliative care needs of people from Black, Asian and Minority Ethnic backgrounds in South East Cardiff. It has enabled us to identify barriers to access, examine possible solutions and make and plan improvements to services and facilities at the Marie Curie Hospice, Cardiff and the Vale.

Our work is ongoing and we will continue to seek advice on ways to remove barriers to access and improve services for patients, carers and families from these communities.

## About the Marie Curie Hospice, Cardiff and the Vale

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The Marie Curie Hospice, Cardiff and the Vale provides free specialist care and therapies to give people with serious illnesses such as cancer, heart failure, lung disease, kidney failure and motor neurone disease the best possible quality of life. It can also offer patients, families and carers free advice and support.

Our hospice is here to help people remain comfortable and feel as well as they can, for as long as possible.

Our team of doctors, nurses, social workers, counsellors and therapists work together to make sure people have the care and support they need.

Services are tailored to individual needs and may include:

- expert care to manage difficulties such as pain or tiredness
- physiotherapy to help people to move around and stay active
- advice and support to help people to live with their illness

People can receive these services by visiting the hospice during the day or, if they need to, by staying at our hospice for in-patient care. Our nurses can also visit people in their own homes.

All our services are completely free of charge to patients and their families and we always aim to provide services that are sensitive to people's different cultural and religious needs.

### How we can help

#### Day services

Many people come to our hospice day services for a few hours to help them cope with their illness, meet other patients and improve their sense of wellbeing.

We have a choice of services, activities and support for patients and their families. They include:

- exercise programmes and information about medicines to help people live more comfortably with their illness
- clinics led by our nurses for us to talk about, and address, patients' care needs and preferences
- complementary therapies such as aromatherapy and relaxation
- support groups so people can share their thoughts and feelings with others in a similar situation
- spiritual support from representatives of different faiths such as an imam, a rabbi or a vicar

We can arrange for groups or therapists specifically for men or women, if required. Our day services are open Monday to Friday from 9.30am to 4.30pm, with some evening sessions available.

## Care in the community

For patients who are unable to come into the hospice, we have specialist nurses who can visit people at home to provide advice and support.

## In-patient care

Patients with persistent pain or those who are very close to the end of their lives may come into our hospice for in-patient services. Usually patients with problems such as pain or breathlessness come in for a period of time so that we can help them feel more comfortable before they are able to return home.

At our in-patient facilities, we offer:

- a number of single rooms with en-suite bathrooms
- food that caters to the specific dietary requirements of our patients' cultures and faiths
- a quiet room that patients and families from any faith can use as a prayer room
- rooms where families can spend time together
- flexible visiting hours

## Contact us

Community Nursing Team  
Marie Curie Hospice, Cardiff and the Vale  
Bridgeman Road, Penarth CF64 3YR  
Phone: 029 2042 6000  
Email: [cardiff.hospice@mariecurie.org.uk](mailto:cardiff.hospice@mariecurie.org.uk)

Marie Curie Cancer Care gives people with all terminal illnesses the choice to die at home. Our nurses provide them and their families with free hands-on care and emotional support, in their own homes, right until the end.

[mariecurie.org.uk](http://mariecurie.org.uk)

