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

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.

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

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

Discussion groups, made up of men and women of varying ethnicities and ages, 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.

The overriding barrier to access was a lack of awareness. Most people had never heard of Marie Curie. If they had, they knew about the end of life care provided and cancer care. The majority of participants did not know where the hospice was or had never been to the hospice. Many believed the services were not set up for people from Black, Asian and Minority Ethnic backgrounds and some had concerns over whether the hospice was culturally and religiously appropriate. Diagram 1 summarises participants’ responses.

Diagram 1: Participants’ perceived barriers to accessing hospice services
Part 2: How to help reduce the identified barriers to access

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.

The groups talked about the need to build awareness – predominantly through word of mouth – of the types of services Marie Curie provides, the conditions that are supported and how to access the services. They also suggested ways to promote the services in their communities and stressed that people from Black, Asian and Minority Ethnic backgrounds were keen to help fundraise and volunteer for the charity and not just be seen as service users. Diagram 2 summarises participants’ suggestions.

Diagram 2: Participants’ views on how to reduce barriers to services
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.

Marie Curie has carefully evaluated all of the feedback from the discussion groups. We have used participants’ key recommendations and our key learnings to help make improvements to services and facilities at the Marie Curie Hospice, Cardiff and the Vale and we have started to address the need for updated working practices. Diagram 3 summarises the changes that have been made or are being planned at our hospice.

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

Conclusion

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.

Visit mariecurie.org.uk/bmereportwales to download the full report.