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BREAKING DOWN BARRIERS: EVALUATING A MARIE CURIE HOSPICE PROJECT AIMED AT IMPROVING ACCESS TO PALLIATIVE CARE BY MINORITY ETHNIC GROUPS

FINAL REPORT: DECEMBER 2015

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December,2015

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1 SUMMARY

The need to ensure access to high quality palliative care for all individuals in all settings is recognised in UK policy. However, people from minority ethnic communities are underrepresented in their utilisation of, and access to, palliative care services, with growing evidence that their palliative care needs are not being met. In September 2012, with funding from the Big Lottery Fund (BLF), the Marie Curie Hospice, Cardiff and the Vale, appointed a key worker to engage with local black and minority ethnic (BAME) groups, hospice staff and healthcare providers to improve access to palliative care. The aims of this study have been to inform project development and evaluate its impact over a three year period.

Semi-structured interviews have been undertaken with the keyworker, hospice staff (n=17), and members of community organisations (n=6) at baseline and 30 month follow up. Two focus groups have been conducted with the project steering group (made up of representatives from local voluntary and statutory organisations) and one with the project board (made up of internal Marie Curie staff). Interview and focus group data have been analysed for key themes. Project documents have been analysed to corroborate and complement findings from stakeholder interviews.

Results in brief

Barriers to access for BAME communities

The most common factors preventing BAME communities from accessing palliative care included:

- Lack of awareness of what palliative care is and knowledge of what services are available locally, including the variety of services offered by Marie Curie;

- False assumptions of health professionals that families 'look after their own';

- Language barriers and difficulties accessing and using interpreters;

- Uncertainty over whether the hospice can cater for religious needs and provide culturally appropriate care.

Project approach and activities of the keyworker

A number of community based strategies were developed to raise awareness of Marie Curie services amongst local communities, and to identify and respond to the needs and concerns

of these groups. These included:

- The development of a large network amongst community organisations which helped to share information and support closer working between stakeholder groups;

- Extensive community consultations, hospice tours and representation of Marie Curie at important local events;

- The development of multi-lingual, culturally representative promotional material, including a DVD.

Educational and information giving approaches were undertaken by the keyworker to increase staff awareness of the potentially different needs of religious and cultural groups, and how to respond to these needs with cultural sensitivity and person-centred approaches. These included:

- Formal teaching sessions and informal discussions at staff meetings;

- Development of learning packages based on case scenarios;

- E mails sharing information on upcoming cultural and religious events;

- Acting as a point of contact and advice for staff with regards to individual patient needs.

The project has implemented several changes to hospice facilities and services to help create a more inclusive environment which meets the needs of different religious and cultural groups. These included:

- The re-development of a multi-faith quiet room and a more responsive catering policy;

- Improvements in how facilities are communicated and signposted;

- Increased volunteering opportunities for BAME groups;

- Acting as a 'familiar face' and source of communication and information support for some BAME families.

Project impacts

The project has achieved a number of different impacts. These include:

- Increased knowledge of Marie Curie services amongst BAME communities, including how to access these services and a growing confidence that religious and cultural needs will be met;

- Increased staff awareness and adoption of more 'person centered' approaches;

- A welcoming and accommodating environment which is positive towards change;

- A large increase in the actual and relative size of the BAME patient population in the project period.

Strengths and challenges

- Key strengths identified for the project included: a multi-faceted approach involving a wide range of stakeholders, intensive community engagement, building positive and supportive relationships with hospice staff, and determination and dedication on the part of the keyworker.

- Identified challenges experienced by the project included: some initial staff resistance, engaging with GP practices, on-going issues with the recording and monitoring of patient ethnicity data and ensuring a lasting legacy for the project

Legacy and the future

Resources and strategies developed to help ensure a sustainable legacy for the project have included:

- Physical resources such as the quiet room and the information and learning resources developed by the project;

- A 'community champions' project using volunteers from BAME communities to continue to raise awareness about Marie Curie within their communities;

- A continued commitment to diversity and awareness training for staff;

- Efforts made to embed and foster staff ownership of these different areas of work.

Conclusion

The project has achieved significant positive impacts and improvements in terms of community awareness and confidence in hospice services; staff awareness and approaches and hospice facilities, resources and services. Crucially these changes have also been matched by a large increase in service use by BAME groups and a corresponding reduction in the inequity of access between White British and BAME populations.

2   INTRODUCTION

The Marie Curie Palliative Care Research Centre (MCPCRC), based in Cardiff University School of Medicine, was invited by the Marie Curie Hospice, Cardiff and the Vale, to evaluate a project aimed at improving access to palliative care for black and minority ethnic (BAME) groups.

The Marie Curie Hospice, Cardiff and the Vale provides in-patient, out-patient/day centre and community nursing services to patients and families with advanced illness and palliative care needs across Cardiff and the Vale of Glamorgan. While the predominantly rural districts in the Vale of Glamorgan are overwhelmingly made up of people identifying as White British, Cardiff is a diverse, multicultural city with people from many different ethnic groups living there, concentrated in particular in the inner city areas of Butetown, Grangetown and Riverside. Within the catchment area as a whole, 84 % of the population are White British, with the remaining 16% identifying with many different ethnic backgrounds, the most common of these being Asian British (6.3%), Other White (3%) and Black African/Carribean/British (1.7%) (2011 Census data). A full breakdown of the different ethnic groups living in the hospice catchment areas of Cardiff and the Vale of Glamorgan is provided in appendix one.

The Marie Curie Hospice was funded by BLF to appoint two key workers to work with minority ethnic groups and healthcare providers in Cardiff and the Vale. However, the hospice were unable to fill these two posts. One key worker started in post in September 2012, and worked alone for three years, with administrative support brought in during the second half of the project. The core objectives and outcomes of the project were as follows:

- improved links with BAME community leaders and community based agencies (including GP practices);

- Reduce barriers to service access for people from the local BME community;

- Increased support for BME patients with life-limiting illnesses and their families.

This report presents the final findings of the project evaluation which has been running since September 2012.

3   BACKGROUND

The need to support patient choice in terms of preferred place of care and to ensure access to high quality palliative care for all individuals in all settings is recognised in UK and Welsh government policy (Department of Health 2010; Welsh Assembly Government 2007; 2008), whilst the need to ensure equal access and opportunity in all services is a statutory requirement for all public bodies under the Equalities Act (2010). However, people from minority ethnic communities are underrepresented in their utilisation of, and access to, palliative care services, with growing evidence that their palliative care needs are not being met (Bosma et al. 2010; Coupland et al. 2011; Evans et al 2012; Worth et al. 2009).

In part, this may be explained by the younger age structure of minority ethnic populations, their lower rates of cancer and higher rates of non-malignant disease (Evans 2012; Gunaratnam 2007). However, other factors that contribute to poor access to palliative care services have also been identified. These include: low numbers of referrals of patients from minority ethnic communities to palliative care (Evans 2012; Gunaratnam 2007); limited knowledge of local services among ethnic minority groups (Elkan et al. 2007; Evans 2012; Gunaratnam 2007; Koffman et al. 2007; Randhawa et al. 2003) and communication difficulties between service providers and users, including lack of appropriate translation, interpreting and advocacy facilities (Elkan et al. 2007; Evans 2012; Randhawa et al. 2003; Worth et al. 2009). Factors such as mistrust and dissatisfaction with services, lack of cultural competence amongst service providers, perceptions that religious needs will not be catered for (Elkan et al. 2007; Gunaratnam 2007), health beliefs, stigma and culturally determined preferences in end of life care (Elkan et al. 2007; Firth 2004; Randhawa et al. 2004) have also been identified. There are further concerns that when people from minority ethnic groups do access palliative care they do not benefit from holistic palliative care, in particular psycho-social support (Gunaratnam 2007).

There are examples in the literature of ways in which barriers can be addressed and how access to palliative care can be improved. Randhawa and Owens (2004) found that the South Asian women in their study were enthusiastic about the palliative care service once they had visited their local hospice and recommended that information should be made available via community networks to raise awareness (Randhawa and Owens 2004). Several awareness raising initiatives, including multi-lingual, multi-media resources have also been usefully developed (see Gunaratnam 2007), and a Bradford hospice has recently adopted a community engagement approach aimed at building relationships and involving individuals from BAME communities in the delivery of services (Phillips and Taylor 2012). Other initiatives aimed at improving access and referral to palliative care have included GP facilitator teams incorporating Macmillan liaison officers, bilingual health advocates and Nurse leads in Bradford primary care settings, and referral tools such as the SPARC (Sheffield Profile for Assessment and Referral to Care) developed for use by patients and carers (Gunuratnam 2007).

4 METHODOLOGY

4.1 STUDY DESIGN

The evaluation was designed in partnership with the Marie Curie Hospice, with an aim of evaluating and informing the development of the keyworker project. The specific objectives of the evaluation were:

- To explore, at baseline and follow up interviews, the understandings of members of minority ethnic community groups on end-of-life and palliative care, the barriers to the use of palliative care in their communities and how palliative care could be made more accessible to their communities;
- To explore, at baseline and follow up, the views of healthcare professionals (GPs, district nurses, hospice staff) on access to, and provision of, palliative care for local minority ethnic communities and how this could be improved;
- To gather the views of these stakeholder groups on the impacts of the project and suggestions for future development;

- To report ongoing findings to the keyworker(s) to help inform the development of the project;
- To identify changes over time in minority ethnic groups' access to palliative care services via analysis of ethnicity data collected by Marie Curie Hospice, Cardiff and the Vale.

Three methods of collecting data were proposed over the 30 month evaluation period: semi-structured interviews, documentary analysis and analysis of ethnicity data. Phase one of the evaluation aimed to gather baseline data and information on project activities. Phase two focused mainly on mapping project activities and experiences connected to these, and the final phase of the evaluation concentrated on gathering views on project impacts and recommendations for future work in this area.

4.2   DATA COLLECTION AND ANALYSIS

4.2.1 BASELINE INTERVIEWS WITH HOSPICE STAFF

Semi-structured interviews were undertaken with eight staff from the hospice (HCP1 1-8) between November 2012 and April 2013, which explored participants':

- Perceptions of the barriers to people from minority ethnic backgrounds accessing palliative care services;
- Educational needs in relation to minority ethnic communities' health, illness and death practices;
- Views on how these barriers could be addressed and palliative care could be made more accessible for people from minority ethnic communities.

Interviews lasted between 13 and 45 minutes, with an average interview length of 24 minutes. The views of a variety of hospice staff were sought which included; three clinical nurse specialists (covering different geographical areas); three doctors (with different clinical duties, including one junior doctor); one social worker and one long-term hospice volunteer.

4.2.2 KEYWORKER INTERVIEWS

The project keyworker has been interviewed 6 times, on a six monthly basis. The reflective, semi-structured interviews lasted approximately an hour and explored:

- What action the keyworker has taken in the last six months to promote minority ethnic communities' access to palliative care and how successful they perceive this to have been;
- Their perceived barriers/enablers to minority ethnic groups' access to palliative care and to their project work to date;
- Priorities for the coming months to promote minority ethnic groups' access to palliative care.

4.2.3 INTERRIM AND FINAL INTERVIEWS WITH HOSPICE STAFF AND COMMUNITY MEMBERS

An initial focus group was held with the project Steering Group in January 2014 (SG1). The steering group was made up of representatives of a number of local community organisations and functioned to provide guidance and direction to the project. Five of these members were present for the focus group and the discussion explored:

- Perceptions of barriers to people from minority ethnic backgrounds accessing palliative care;

- Views on how these barriers could be addressed and palliative care could be made more accessible for people from minority ethnic communities;

- Perceptions of the Marie Curie keyworker role and project.

In spring and summer 2015, end of project interviews were carried out with a mix of hospice staff (n=9; 3 Consultants, 2 Social Workers, 1 CNS, 3 Coordinators/Managers) (HCP2 1-9) and community stakeholders (n=6) (CM1-6), with whom the key worker had worked over the course of the project. Two focus groups were also held in this period; with the steering group (n=2) and project board (n=3). These interviews and discussions explored:

- Understandings of the project, its core activities and relevance to own role;
- Involvement and partnership working with the project;

- Perceived impacts of the project on; local BAME groups and community organisations; hospice staff, facilities and services; wider impacts;
- Project achievements, strengths and success factors;
- Challenges, weaknesses or gaps in the project;
- Views on the legacy of the project, sustainability and future work in this area.

Interview and focus group data were managed using a computer software package (NVivo 8, Nvivo 10). Data analysis was undertaken by two researchers who shared the analysis of transcripts, following an in depth thematic approach (Braun and Clarke 2006). Group results were analysed for consistent themes using techniques of coding and comparison. A coding framework for emergent themes was developed by the researcher. This was an iterative process, moving between the data and the analytical concepts to develop codes and concepts grounded in the data. Higher level abstractions of codes were decided and results were verified by the research team by independent review of a selection of transcripts. The key themes are explored in the next section.

4.2.4 ANALYSIS OF PROJECT DOCUMENTS

Key project documents have been reviewed. These included notes from some of the community discussion groups facilitated by the keyworker which informed our baseline findings on the barriers to accessing palliative care. Project outcome reports and minutes of management meetings were also reviewed and used to corroborate and sometimes supplement the findings from the interview and focus group data.

See appendix two for table of documents reviewed.

4.2.5 SERVICE USER QUESTIONNAIRE

In January 2015 agreement was obtained from the University Ethics Committee[1] to evaluate BAME patient and family experiences of Marie Curie services, with the following objectives:

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[1] The Ethics Committee agreed that this questionnaire study could be considered 'service evaluation', and did not therefore require ethical review.

- To identify which services these participants are using, how they have accessed and used these services, as well as which services they have not accessed;
- To consider how far the needs of participants are being met, and any unmet palliative or end of life care needs or concerns that they might still have;
- To consider how the role and project work of the hospice outreach worker has impacted on patient and family experiences;
- To identify ways of better incorporating diversity and improving access to local palliative care services for BAME groups.

A short survey comprised of open and closed questions was designed to gather the following information (see appendix 3 for copy of the survey):

- Demographics;
- Services accessed and for how long;
- How and why these services were accessed;
- Satisfaction with services, including any unmet needs and areas for improvement.

It was intended that the survey would be given out to patients and families from BAME groups who have used or are using hospice services by the project key worker and community nursing staff. Participants were also to be offered the option of completing the questionnaire with the assistance of the researcher either over the phone or in person at the hospice. Regrettably none of these questionnaires were returned to the research team.

5   RESULTS

This section is split into the following sub-sections, which reflect the key thematic areas identified in the interview data collected at the different stages of the evaluation. These are: barriers to accessing palliative care; engaging local communities; staff education and awareness; the hospice environment; practice sharing and wider impacts; strengths and challenges of the project; and finally legacy and the future.

5.1   BARRIERS TO ACCESSING PALLIATIVE CARE

We identified multiple themes relating to why individuals from minority ethnic communities may be less likely to access palliative care services, and potential difficulties that may be experienced when they do use these services. These included: lack of awareness of palliative care as a concept and misperceptions about the services offered by Marie Curie; the assumption of healthcare professionals that families will care for individuals with palliative diagnoses; language barriers and the use of interpreters and finally whether the hospice is able to meet the cultural and religious needs of patients and their families

5.1.1 AWARENESS

Participants agreed that 'palliative care' was a term misunderstood by the general population.

> "palliative care amongst non-minority groups is still a bit of woolly term… and then certainly people who whose first language is not English, might not know what is what the term that encompasses and what it actually means" (HCP1 3)

There were also some negative associations with the name of the hospice. For example, whilst members of the African Caribbean community who attended a community discussion session had heard of the hospice, they perceived it as somewhere people go to die.

This lack of awareness made it difficult for people to be aware of and access palliative care services offered by the hospice, with additional misperception that they would be required to pay for the service:

> "Generally people are not aware that this service is here and available to them and often people think that there's financial implications for this service as well, that they have to pay for it" (HCP1 6)

In terms of access to palliative care services provided by the hospice, participants reported that the main route of referral was from community healthcare professionals such as GPs. Suggested reasons for non-referrals included community services not engaging minority ethnic groups and patients' diagnoses. Participants suggested that people with cancer were more likely to be referred for palliative care than people with other long-term conditions, such as heart disease.

"patients who have cancer that have better access to the services than people who have got uh non-cancer palliative diagnoses, um and in my experience there's not been the same number of people from minority ethnic groups that have got cancers" (HCP1 1)

In terms of addressing this limited awareness, individuals who took part in the community discussions felt that the hospice should highlight the variety of services available, such as respite, home care and complementary therapies. They suggested that awareness could be raised through establishing stronger formal and informal links with organisations or leaders within the relevant communities and events such as:

- Question and answer sessions in community venues;
- Open days at the hospice;
- Attending community events such as Mela (multicultural festival);
- Holding fundraising events.

Participants also felt that it was important that relatives are invited to hospice events and the day centre, as well as ensuring that relatives are aware of bereavement services.

In terms of communicating the information, suggestions included:

- Explaining what "palliative care" means;
- Written information in a variety of languages, adopting a simple format, and available through health centres, religious places, community organisations (charities) and community venues;
- Multiple mediums, including posters, leaflets and advertisements (e.g. radio) and use of social media;
- Emphasising Marie Curie's understanding of individual needs (e.g., cultural, religious sensitivity).

To ensure that the message reaches communities, staff and community participants stressed the importance of promoting hospice services with GP practices, as GPs are respected by communities. Furthermore, the importance of training for staff in residential and nursing homes about palliative care was highlighted.

5.1.2 FAMILY CARERS

Several members of hospice staff assumed that individuals from minority ethnic communities would be cared for by their families and would therefore not necessarily require, or want, support from healthcare professionals.

> "a lot of the ethnic minority patients who I know about…they have a very close knit community and very close knit families and I wonder whether they tend to help each other out a bit more have a bit more of a close community, look after themselves" (HCP1 4)

There was however concern from some staff that patients may not be getting the medical care that they need. Furthermore, the discussion groups with individuals from minority ethnic communities revealed that communities are changing, making it more challenging for families to care for relatives.

> "People want to look after their parents… this will change in 15 years due to men and women having jobs, the relationship between the couple, and they can't do it" (Community Discussion November 2012)

5.1.3 LANGUAGE

Hospice staff spoke almost uniformly about the barrier that language caused when caring for individuals from minority ethnic backgrounds, in terms of verbal and written communication.

> "language seems to be a big barrier for people… I found that obviously on our first visit we do an initial assessment and we talk about patient symptoms and if they either aren't able to speak English or their English is broken it's very difficult to get an accurate assessment of their symptoms and therefore provide an appropriate treatment" (HCP1 6)

Although staff recognised the challenges of using relatives as interpreters, such as information being filtered, some participants admitted that in reality they used them.

> "What happens the patients I've looked after in terms of ethnic groups um at the end of life have been older and practically what happens on the ward is that we'd probably use family for much of the communication needs if there are communication difficulties" (HCP1 3)

Interpretation services were widely employed by staff at the hospice and participants preferred the presence of a person rather than using a telephone translation line. There were however challenges to using interpreters, in particular building the level of trust required for a patient to openly discuss their problems and needs.

> "even if you can introduce translators, who are from a, you know, not the relatives somebody who's um, you know, employed to do that, you still there's a difficulty in actually getting information from somebody if you don't talk to them directly. A lot of understanding what a person's needs rely on building a relationship with them for them to trust you and tell you everything that's wrong with them, um and it's very difficult to build that trust when you're going through a third person in talking to them" (HCP 1)

5.1.4 HOSPICE SERVICES: MEETING PATIENTS' NEEDS

Individuals who took part in the community discussions were concerned that the hospice may not be "culturally and religiously appropriate" (Community Discussion, December 2012). Hospice staff recognised that patients from minority ethnic groups may have specific religious and cultural needs, and they were anxious to meet them.

> "we need to be very mindful that when people come in to this, the building that we you know that we do have the facilities you know for people as such you know, if people do need to have time for their culture to pray" (HCP1 7)

Participants felt that the hospice was able to meet individuals' needs, such as providing prayer facilities and serving appropriate food.

> "I think we would be able to adapt whatever their needs, because they do have a different menu and the chef cooks on site, so I don't think that's a huge problem" (HCP1 5)

While hospice staff suggested that the quiet room could be used for prayer, the community discussion group highlighted that specific facilities are required and were anxious about whether these could be provided.

> "Washing facilities within the bathroom, separate to the prayer room. Cubicle within the bathroom for washing. People who are immobile do not need to leave their rooms to wash and pray – the cleric can offer advice in this situation. Staff need to understand praying rituals and be able to help if needed. The hospice can then advertise that the hospice has the resources for prayers" (Community Discussion November 2012)

There was also concern from some staff that they may not be providing culturally appropriate care for patients.

> "there's a lack of understanding of different cultures and their needs and their dynamics of sort of family support and grief, and dealing with grief, and perceptions" (HCP1 1)

However, others felt that it was more important to ask patients or their families about their needs, rather than making assumptions based on religion.

> "I tend to go about it completely from the other direction. I wouldn't necessarily I would never think 'oh this person is a Muslim or a Sikh or a Christian and therefore we must do this', I would just completely take the patient's lead if possible, if they're too unwell take the family's lead on what they would want" (HCP1 2)

Two key recommendations were made for how the hospice facilities could be altered to meet minority ethnic communities' needs:

- Completing the multi-faith room at the hospice, with appropriate prayer facilities;

- Flexibility with regard to visiting times and the number of visitors.

There were also practical suggestions made for the training and development of hospice staff so that their knowledge could be expanded and in turn the quality of care that they provide improved for minority groups. These included:

- Cultural awareness training for hospice staff to help them understand the needs of individuals from minority ethnic communities (Community Discussion);
- Talks with the opportunity for questions from representatives of different religious groups (hospice staff);
- A written document summarising major considerations and core beliefs for different religions – to be used while ensuring that the individual patient's needs are assessed (hospice staff);
- More creative ways of relaying information about different religions (hospice staff);
- The keyworker to engage in reflection with healthcare professionals about how they have cared for patients and how they could in the future (hospice staff).

Individuals who took part in the community discussion were also motivated to take part in a volunteering project with the hospice, which would: promote diversity within the hospice workforce, raise the profile of the hospice within minority ethnic communities, and provide work experience for the volunteers. A variety of placements were suggested, for example working on reception, in the kitchen, or with patients.

5.2 ENGAGING LOCAL COMMUNITIES

The core work of the keyworker can be categorized into three thematic domains; community engagement; staff education and awareness and building an inclusive hospice environment.

5.2.1 NETWORK BUILDING AND CONSULTATION

Community engagement has been at the core of the keyworker role. In the early stages of the project this involved building relationships with community groups, arranging tours of the hospice and running group discussion sessions. The key worker held seven discussion sessions with a total of 131 people which included; a mix of people from different

community groups (November 2012); interpreters and health link workers (December 2012) Apna Carers Centre (January 2013); Hindu Community Centre (July 2013); Oasis Project (November 2013); a mixed group (December 2013); the African Caribbean Elders Society (January 2014); and with English as Second Language students (April 2014). These sessions served the dual purpose of improving awareness of hospice services amongst these communities, but also finding out about local needs and barriers to the use of palliative care services within these communities, which could then inform and help direct the project.

> "they have indeed been in um the community leaders and I've met them in here as well and we've had little tours and chats and I think once they come in through the doors and they see what's on offer and they see the lovely surroundings and the friendly staff and it's not that taboo place that a lot of people think it is" (Volunteer)

> "There were a lot of assumptions being made and it was good to have clarity from them (local groups)." (Project board)

These sessions were valued by many of our community member and staff participants, several of whom had been involved in the discussions, as either attendees or gatekeepers (community members) or facilitators and hosts (hospice staff). They were seen to be particularly important for engaging at 'grassroots' level, and providing a useful and informative introduction to hospice services to people whose knowledge and awareness of the services had previously been limited.

> "the smaller focus groups for the more very grass roots level community based people and sometimes even in their own language Punjabi or Urdu cos I know that she speaks those two languages" (CM3)

> "she invited really key people who were connected to the community so yeah so that worked so yeah I think it was kind of beneficial because for me I didn't really know a lot about (names hospice)..I was kind of um what's the word ignorant myself" (CM5)

> "I think very effective because I think introducing the topic um having um the relationship in the first place and then being able to explore and for people to feel valued in er in the comments they were saying"(HCP2 4)

Several community member and hospice staff participants reported positive feedback from attendees at these events, including an increased likeliness to use the service if needed. Requests were also made for further information and talks for other groups in the community.

> "They definitely said they'd you know if they were in that circumstance they would speak to their GP about it they would mention that they would request it..and people like 'ah we didn't know this was here this sounds great' and 'it's really nice that these people do this'" (SG2)

> "They were quite happy and um when they left they were quite pleased to have been there and they were saying oh we've had a nice time thank you very much we didn't know this existed" (HCP2 5)

> "They enjoyed it we had a lot of fun it's quite um a relaxed it as a fun time with the dancers were all dancing people were just very kind of relaxed and that was nice um but people quite open and chatty with each other as well" (HCP2 8)

Following the last of these discussion sessions (April 2014) the key worker considered that she had reached 'saturation', meaning that no new themes were emerging from the discussions. She thus felt confident that she had acquired a comprehensive insight into local barriers to accessing palliative care amongst minority ethnic groups, and published these findings in a report which was presented at the project launch event in June 2014.

> "so we've already had sixty seven people come through the hospice to talk about barriers to and now we had sixty four more in this event so um and some of them so I think there's time to stop doing this because the same messages are coming over, nothing new is coming up I think we've reached saturation on that really so we're not going to do anymore on them." (KW4, July 2014)

The key worker also promoted hospice services by engaging with religious leaders and visiting places of worship. For example, collaborating with the Sikh temple, a local Rabbi and the Jewish Care Committee (March 2014); local imams and speaking at Friday lunchtime and evening prayers at a local mosque during Ramadan (July 2014).

"I'd gone to do a talk to the congregation at lunchtime they invited me to come back the same evening…they were really insistent that I come that night because that was the most important night of the year for them." (KW4, July 2014)

As well as engaging community groups the keyworker built links with other stakeholder organisations, including a carer's programme, organisations concerned with mental health, chronic conditions, old age, race equality and a local higher education college. By building relationships with these local organisations the keyworker was able to share information and access multiple networks with a shared interest in broadening access and reducing inequalities amongst BAME groups. Information on Marie Curie was also incorporated into the information leaflets of other organisations which were given out to service users and GP practices and a talk organized at a local higher education college, thus further helping to 'spread the word'.

"We worked together in terms of you've got access to all the different organisation … so we'd link through {our} minority ethnic networks and {then} through the broader range of communities in order to engage them in terms of accessing the project (CM1)

"I arranged for her to come into the college and do a presentation erm about the (names palliative care charity) project as I said there's a lot of people in the communities who don't understand English and er so giving information to young people who are conversant in English and them taking that information back to their homes would be a good idea (CM6)"

In February 2013 a project Steering Group was formed, which was made up of a mix of representatives from some of these community based organisations. The steering group would meet bi-monthly and functioned to provide guidance and direction to the project. Its members valued the group not only as a vehicle for supporting and influencing the project but also for facilitating their own work and organizational remit, for example by learning lessons, sharing information and contacts across their respective networks and client groups.

"So from our point of view it's about improving our services or approving the information we have that we can then give back to different communities to get them to access the service. From (names keyworker)'s and Marie Curie's point of view it's about making sure that um the services are and that accessible and people are accessing the services that need the services regardless of anything else (SG1)"

" We have access to community groups and um and you know we're planning to do more um visits to community organisations and er you know social and faith centres to make them aware of Marie Curie services...but that's that's the idea in terms of bringing the message to the communities" (SG1)

"I work in the NHS myself it's a cancer hospital so we have similar issues so I'm learning lessons that I can hopefully take back to improve access to the services" (SG1)

"So it's definitely relevant to us and cos we cover the whole of the equality...you know and um selfishly the research that she's done and the groups that she's identified can be helpful to us you know it's a two way thing really" (SG2)

The keyworker also did some work with EDF energy, who fundraises for Marie Curie and has a large BAME staff network, to recruit volunteers from the network who could help to spread the message of the services and support offered by Marie Curie within BAME communities across the UK. This relationship is now being managed centrally by Marie Curie, reflecting the national focus of the initiative.

5.2.2 PUBLICITY: EVENTS AND PROMOTIONAL MATERIAL

Representation at local events and the distribution of promotional material has been central to the community engagement approach of the project. The keyworker represented Marie Curie and the project at events such as; Cardiff Council and Vale Councils Carers Event (2013), Wales City of Sanctuary conference (2013), Gypsy, Roma and Traveller Symposium, Cardiff (2014), ISSA 50+ event (2014), with stands at International Women's day, Cardiff Mela 30th June 2013 and 14th September 2014; and Cardiff Minority Ethnic Health Fairs (2013, 2014 and 2015). Such events were seen to provide excellent publicity for Marie Curie, in particular the health fair which they sponsored and were on the planning

committee for the most recent 2015 event. This enabled them to secure an oral presentation and a stall with maximum exposure, a high number of visitors to the stall including those interested in volunteering, and a renewed political interest in the project. The newly produced DVD was also played on a loop at the stand and in the main seating area.

> "(at the health fair) we took around 7 contact numbers of people who are interested in the volunteer role…Vaughan Gething, Deputy Health Minister, launched the event….In his speech he made a special mention of Marie Curie saying how positive it was that a mainstream organisation such as Marie Curie identified a need to engage with Minority Ethnic communities and then worked hard to meet this need…After the speech he came to our stand and specifically asked me to make an appointment with him so he could come and meet the new hospice manager and myself and talk about progress and update on the project." (Project Report)

Several hospice staff and a community member were directly involved in some of these events and commented on the apparent success of the stands in terms of the level of public interest and information being given out about the hospice.

> "I also attended the one of the health fairs…so from a point of view from being on a stand …and noticing how people felt very easy about coming up to the stand to get information and more interested in learning more about it." (HCP2 4)

> "(The stand) was in a prominent place she had a number of volunteers on that stand she also had another um video …running and there was quite good feedback about that and we put that in the area where people sat down for tea's and coffee's so they could watch that if needed so it was very focused on trying to draw people towards her stand." (CM4).

As part of this awareness raising approach, the project also produced multi-lingual promotional postcards containing information about Marie Curie services, and which were made available on event stands and in different areas of the hospice. The importance of

achieving a fairer representation of different communities in the literature was discussed by several hospice staff and community members.

"She gathered feedback around representation in literature and so making sure that all different people from different communities were represented in literature which would make it more appealing maybe to different communities" (HCP2 2)

"People were really interested in the leaflets in different languages and quite interested in taking them. I think it just gives a really good message…we had two hundred printed and I think the Urdu ones have gone." (KW4, July 2014)

Following recommendations coming out of the community discussion groups the project has also produced a promotional DVD which is now available in six community languages and Welsh, and with English subtitles. This was played at the 2015 health fair and has been disseminated across staff teams at the hospice, the stakeholder network, at events and is available on-line and in the hospice.

"When we looked at barriers to access in our services we also asked communities what would help to reduce those barriers, one of those things they said was a DVD to promote the service in different languages …because not everybody will be willing to come to the hospice on one of the tours so this would take the hospice to them and the community" (KW 4)

Not all interviewees had seen the DVD at the time of interview but those community members and hospice staff that had seen, or had been involved in the making of the DVD, spoke very positively about the content, in particular the involvement of "well known" members of the community as case studies, which were felt to have effective "resonance" with the target audiences.

"It (DVD) featured two key members of the community and those people are very well known, one of them is a youth worker …and the other young lady has been around in Cardiff for the last forty years very active within the community…so these people once you see them featured on a video which was the idea people relate to

them and therefore they relate to the information and know that it's solid and that something they need to sit up and take note" (CM6)

"One of the ladies that features in the DVD she was quite known to some of the community members and quite trusted as well and her sister was and her sister still like talks about how amazing Marie Curie were… that really resonates when someone that is trusted in the community has a really good experience they won't stop talking about it" (SG2)

With the support of the media team at the hospice, several case study stories of BAME patients and families with positive experiences of using the hospice have also been developed and featured in local media. [2,3] The keyworker has also used twitter to publicize the project and has 'followed' a number of different community organisations in Cardiff to raise the profile of her work.

5.2.3 REFERAL PATHWAYS: SELF-REFERRAL AND GP AWARENESS

In order to try and facilitate the referral of BAME patients into the hospice, a simplified self-referral form was introduced which could be used by community groups to identify and pass on details of people who might be appropriate for palliative care.

"I've also done a really short referral form… the hospice referral forms, the purple forms, they're really long and they're medical and they're quite complicated, cause the GP fills them out… so I said that if we if I could change that and just do a very basic one with name, address, doctor's um details, you know some basic

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[2] Good Morning Wales & Wales today (08/04/15) (http://www.bbc.co.uk/programmes/b05px56n#auto).

[3] Western Mail (09/04/15) http://www.walesonline.co.uk/news/health/thousands-terminally-ill-people-wales-9000911

> information, um if I could send that to community groups and they could use that if they have a referral" (KW1)

Although a few people were identified via community organisations using these forms, most referrals of BAME patients came through more traditional GP pathways. Whilst the project did not manage to engage systematically with GPs as originally intended, promotional material was included in GP post bags and sent to pharmacies for dissemination, resulting in a few invitations to speak at GP meetings, and further engagement with a group of Muslim GPs. It was thus felt that many local GPs would have at least known about the project and have been encouraged to refer BAME patients.

> "So the only ways I've managed to access GPs is through the GP post bags and through these meetings and the one off kind of GPs that have been interested I had a Muslim GP who's a locum approach me about the he'd heard about the work that I'd been doing" (KW5, January 2015)

> "Even though there was not a lot of direct contact with GPs it certainly seems to have made an impact on people's understanding that Marie Curie are working to improve access for Minority Ethnic communities and therefore it's alright to make a referral." (KW5, January 2015)

A member of the Steering Group who worked for the NHS also explained how they have incorporated information on the project into their training programme, thus also helping to spread awareness amongst NHS staff locally.

> "We've kind of built it into the training so within the training we make people aware of this service and um I was at a meeting the other day looking at outpatient services and I discovered that there's a mini project that's going on so I wanna try and link those up as well." (SG1)

5.3   STAFF EDUCATION AND AWARENESS

5.3.1 TRAINING AND INFORMATION GIVING

Engaging with hospice staff and raising cultural awareness within the hospice has been a core feature of the project, involving different kinds of information giving and educational approaches. At one level, the keyworker sought to make staff aware of different religious and cultural events as they occur in the calendar year, and what these might mean for patients in their care. For example, internal e-mails were distributed providing information on Eid, Diwali, Chanukah, and Easter and multi faith calendars were given out within the hospice. Information was also disseminated on relevant cultural practices, such as a link to a short film by Dying Matters aimed at improving understanding Muslim traditions related to dying and death. This approach was welcomed and felt to be useful by most hospice staff, who found the information interesting and effectively targeted across the spectrum of hospice staff.

"she did a quiz round about Christmas time with the Christmas dinner all about different religions, Beliefs, that was quite nice, quite interesting, she I think she's given us a calendar with all the different religious events and cultural things that come up as well, so she tends to email us every now and again with different things and it's useful then that we know she's there as a resource" (HCP2 5)

"So she worked hard to try and um raise awareness of different cultural events .. you know things like Chinese New Year …and I remember some of the lines in uh that that they wouldn't want to have their rooms cleaned because it sweeps away their good luck and um so she made it interesting for all members of a team so you're talking about housekeeping, catering, nursing staff you know" (HCP2 2)

In addition to sending out information, the keyworker also organized teaching sessions and developed learning resources for staff based on real and fictional case scenarios at the hospice, for example issues with alcohol based drugs and use in cooking. More informally, she would also attend internal team meetings to offer advice, answer questions and encourage staff to record patient ethnicity information for monitoring purposes on the Patient Assessment Form which she had also amended to better capture this information. The diversity and cultural awareness training developed by the keyworker has been

delivered to all staff teams and new doctors and the case scenarios have been taken up by Marie Curie and will be available shortly as an on-line learning resource.

In addition to providing in house training, the key worker also used the hospice newsletter to promote free relevant training opportunities for hospice staff provided by other organisations such as the older people's commissioner, Tenovus, South Wales Police and Cardiff University Interpreters.

5.3.2 KEYWORKER AS POINT OF CONTACT AND ADVICE

In response to specific requests and discussions concerning individual patients the keyworker would also provide information for hospice staff on the cultural and religious needs of different groups, and attended staff meetings and some MDTs so that she could be on hand to provide such advice where needed. When providing this information on group beliefs and practices, however, the keyworker took care to emphasise the need for staff to find out about the personal needs and beliefs of the individual and avoid making assumptions.

> "they also asked me to um to put some basic information in this lady's file about um Sikh families at the end of life…So I'm really guarded about doing stuff like that because I don't want to say 'oh Sikh women don't like to be touched'… it's really really important that the hospice ask them what they want, how it works for them" (KW1, January 2013)

A number of staff described the benefits of being able (and feeling comfortable enough) to approach the keyworker for advice and support with the specific cultural or religious needs of particular patients.

> "it was quite difficult to get her to talk about planning for her death and the fact that she was dying because she didn't want to face that and would find every way possible not to and I think it just being able to talk about some of the difficulties that we had in managing that patient and just and a sounding board I suppose really yeah …and just understand some of the cultural beliefs and why those conversations were

you know so challenging at times" (HCP2 7)

"If we had a patient and we needed to find out or we would go to her generally if we wanted to know about how Ramadan might work if you were ill and had a really poor appetite for example and that sort of thing.she's always very very informative but also by saying you need to go and ask people for what they would want" (HCP2 9)

5.4   THE HOSPICE ENVIRONMENT

Creating a more inclusive hospice environment, which better supports the needs of people from different ethnic groups, has been a further core concern of the project. Following the recommendations made in community discussion events and sometimes requests and feedback from staff, several changes have been introduced in the hospice.

5.4.1 CHANGES TO FACILITIES AND SERVICES

The most widely noted change to hospice facilities was the new quiet room, which following the community consultations, was identified as a key action for the hospice to implement. Although previously there had been a chapel at the hospice, this was not easily accessible and was not appropriately resourced for some religious groups, with no washing facilities available for Muslim visitors. Over the course of the project the keyworker engaged with religious and community groups to identify and source resources for the room, and worked with senior management in the hospice to establish the new, multi-faith 'quiet room.' With input from the Steering Group, and the support of the project board, the new room now situated next to the family room, opened in early 2015, and includes a variety of religious materials, prayer mats, wash facilities and a sign pointing to Mecca. Directional signage will also be put in place around the hospice shortly to direct people to the facility.

"we talked quite a lot …about the washing facilities for people who might want to use [them] the quiet room for prayer …I need the hospice manager to be involved, day

centre manager to be involved you know everybody needs to be involved to agree on how these issues are going to be resolved" (KW4, July 2014)

"We were looking at you know about the things that you would put in there, and one of the faith groups said to me oh you know well um we'd be quite happy to donate some of the you know some of the things that we had for our ceremonies and religious items and things like that um so there is a I think um you know a learning on both parts in the sense that oh right ok that's good and they were open to that…" (SG1)

The keyworker also worked with the catering team to provide guidance on restricted foods and develop multicultural menus, some of which were included in the lunches provided for the groups visiting the hospice. At the time of writing this report diverse menu cards for patients were also being produced and made available in different languages.

"The chef cooked some sample plates in terms of demonstrating how the hospice could meet their dietary needs as well." (Project board)

Other changes to hospice facilities and resources have included multi-language leaflets on the wards, the Day Therapy Unit and reception and the installation of new directional signs to the quiet room following a patient feedback exercise on temporary signage. IPads and CD players were purchased and made available on the wards to enable patients to listen to religious CDs donated to the hospice, and to communicate with family members who may live abroad. Changes were also made to the bedside information so that the quiet room is better publicized and patients are encouraged to discuss their dietary requirements with a member of ward staff.

"they were reviewing the bedside information so we've been able to input into that around making the quite room much more prominent on it… but also about food and saying that…people to ask for what their dietary needs are because it's hard to say um it's hard to write list all the different menus" (KW5, January 15)

Following a meeting with senior ward staff to review current policy on visitor numbers it was agreed that future decisions would be made on a case by case basis, rather than implement a formal and prescriptive change of policy.

5.4.2 KEYWORKER SUPPORTING BAME PATIENTS AND FAMILIES

On occasions the keyworker would also provide direct support to patients and their families, including those being cared for in the community as well as on the wards.

> "I try to spend time on the inpatient unit and I try to spend time in the community with our nurses just so people see me out and about and I meet some of the families and then I can always ask them things about how is it for them and is there anything else we could do they might more likely to open up" (KW4, July 2014)

> "she came on ward rounds sort of sat down with um the family when we had difficult conversations" (HCP1 2)

This contact enabled families to communicate some of the issues they were experiencing, which enabled the keyworker to feedback to hospice staff to improve the care of these individuals and also ensure better care in the future more generally.

> "the patient's wife beckoned me so I went in and I was just um and I just said 'hello' I I think people really feel comfortable when there's somebody else like them and they seem to want to talk to you… then I was asking them how the stay had been and is there anything different we can do and they had some good points actually they said that they weren't getting Halal meat…they were saying that what he's having isn't filling him up so she was ending up having to go out and buy him take outs." (KW4, July 2014)

> "she was saying that he's finding it difficult to communicate…so what I asked them to do was use the communication cards with him because then if he wants water he can just point to water." (KW4, July 2014)

This aspect of the keyworker role was recognised and valued by a number of hospice staff, who similarly explained the benefits to families in terms of easier communication and cultural familiarity.

> "we did have a an older lady who was an inpatient and I went and got (Names KW) and said you know come and meet this family um the lady patient didn't speak English or just understand sort of a few words and the non-verbal's and her face was lighting up when she saw (KW) and (KW) started engaging with her…you just knew that she felt a lot more comfortable in the care setting because she saw someone and had met someone with whom she had some familiarity she'd never met her before but she had enough familiarity with cultural systems or that she was put at more ease" (HCP2 2)

> She would meet patients and talk about needs if we asked her to yeah…they found that very helpful um from a from what they have said to me yeah ..and she's also been supportive of their families as well (HCP2 9)

The keyworker also helped to signpost people that she met at community discussion sessions who had unfulfilled needs around loneliness, need for counseling and help with caring responsibilities. These people were referred internally, for bereavement support by the Therapies Manager and to the Marie Curie Helper service which matched the person with a fellow Urdu speaker. Examples of external sign posting included advocacy support for a minority ethnic patient attending a benefits tribunal, information on funding available for help with heating costs and emotional support via the ISSA. The keyworker also received and responded to requests from other local organisations for support for their BAME patients and families.

5.4.3 DIVERSITY IN THE WORKFORCE: VOLUNTEERING OPPORTUNITIES

The project has also looked at facilitating volunteering opportunities for BAME groups. A volunteering project was set up in partnership with a local volunteering charity, following a community discussion session, with the aim of increasing diversity in the staff team as well

as spreading the message about Marie Curie. Although a couple of volunteers were recruited via their placement project, unfortunately this partnership did not continue as hoped due to funding cuts in the partner organization. The key worker also became involved with the new 'Helper' project, which matches local volunteers with patients and families, to ensure that the volunteers they recruit are from as diverse a pool as possible and the service is sensitive to the needs of diverse communities. Following talks by the keyworker, a number of volunteers have come forward from a local mosque and Hindu community centre. This is important for enabling patients to be matched with someone of a similar cultural background should they so wish, and generally just raising awareness in those communities.

> "There was one gentleman that came along and suggested he felt he had a readymade group of volunteers who'd be really interested and it turned out they were a group of individuals from mosque so I worked with (Names PL) to make sure that we were running a um training that was uh because we did an almost bespoke kind of session we've got one coming up in a couple of weeks so that's great … we just needed to make sure you know everything was you know relevant I suppose" (HCP2 1)

> "we always then have a one to one with each of the volunteers to understand what they're looking for what they're wanting to get out of the volunteer experience and one of those questions is sometimes about you know would they rather be matched with someone from their own community or of similar religious background so what I might do is try and work with sort of these groups to try and understand how we can um reach them in the communities really and um you know so they can advocate .. to those communities to uh increase awareness of what we're doing" (HCP2 1)

As well as encouraging and facilitating volunteering for the Helper service, in the last year of the project the Keyworker has also developed a Community Champions role. These volunteers are trained to promote and represent Marie Curie services in their local communities, thus continuing to engage local BAME communities after the project finishes. To date, three volunteers have completed their training.

> "They're going to be community champions so they're going to go into the community and talk to people they know about Marie Curie services" (KW6, September 2015)

> " I think (KW) would train someone let them know everything that she knows and then hopefully then they can continue as and when they're needed so that'll be people within the local communities so that they're like a port of port of call for people wanting to find out more about the services" (SG2)

The value of recruiting volunteers from BAME groups was also commented on by other staff members in terms of creating a more welcoming and reassuring environment for people from minority backgrounds.

> "Patients want to have some familiarity when you're ill you want to know that the people looking after you at least have some insight and I think if you are of a certain culture and you are cared for totally by people of a different culture you feel vulnerable so (Names KW) tried to engage with members of society who might be volunteers ….even if you're in a bed and saw that the person who came and took your order for lunch or arranged the flowers or just volunteered looked similar to you and spoke some of your language that's got to be reassuring…and I think that you know hats off to somebody for thinking of that avenue as well" (HCP2 2)

> "A more diverse staff group will make it more welcoming for patients from more diverse backgrounds and I have noticed some of that…I have seen volunteers around the place" (HCP2 9)

5.5   PROJECT IMPACTS

A number of different impacts for the project were identified. These included: community knowledge and awareness; uptake and service use; raised staff awareness and changes to practice; a more inclusive and accommodating hospice environment; and practice sharing and wider influences on local and national organisations.

5.5.1 COMMUNITY KNOWLEDGE AND AWARENESS

A number of community stakeholders and hospice staff described increased knowledge and awareness of the hospice and palliative care services amongst community groups and the local BAME population. Several community participants discussed the extent and closeness of the network of community organisations which the project had helped bring together. This was seen to have promoted information sharing between groups and significantly raised the profile of the hospice amongst local grass roots organisations which work with BAME communities.

> "Marie Curie is there on the list it's um the links personally as well between staff members to broaden those links we've still got seventy five organisations…it's sort of spreads out though doesn't it? Ripple effect" (CM1)

> "The knowledge around the community groups networks that are out there…that's an enormous tool" (SG2)

> "The massive networks in connection that have been made across the (regional) area really promoting the service and the charity itself" (HCP2 1)

The network building and community consultation sessions were seen to have "opened up" communication and dialogue between local communities and the hospice, resulting not only in increased awareness of the hospice, and the variety of services provided, but importantly also a confidence amongst BAME communities that their needs would be met.

> "I think what she's done is she's opened the way for communication and dialogue…
> I think she's got us to talk really…and having that dialogue really with hospice … it's always been there but we've not really used it and we're like why don't they use it? you know so basically we're only going to use something if we feel comfortable to use it.… so it's important to do consultations." (CM5)

> "I think with with (KW) she's done well to actually publicise what Marie Curie do from my perspective because a lot of people in ethnic communities don't really know what what they're about and in fact when they go into a bit more depth they're quite surprised about how much Marie Curie do"(CM4)

"She's really embedded herself in communities … I think in time we probably will see more people contacting us it's just I think in some respect it's gaining their trust and getting the awareness out there as well"(HCP2 6)

Importantly, it was also considered that local communities had a better understanding of how to access the service and would be more likely to request a referral from their GP. One community member gave a specific example of a family that she knew of who were using the service and considered that this was indicative of more widespread knowledge and service use within the local community.

"They need it in the future they know it's there…if the GP don't tell them about it they know and they could ask for it because they're entitled to it as well" (CM2)

"Well they definitely said you know if they were in that circumstance they would speak to their GP about it they would mention that they would request it" (SG2)

"I visited a couple of times a few times and also what I've seen is I've seen even like um when like somebody's ill in the community and that the family will use the service and there was a boy recently he was diagnosed with a brain tumour and basically he'd taken to the hospice and he it'll be final his final days were there so it's nice that people are starting to use it" (CM5)

5.5.2 UPTAKE AND SERVICE USE

Following on from this increased awareness and confidence, there is also evidence of increased uptake and use of services by BAME groups. Hospice staff were asked whether they had noticed an increase in the number of BAME patients using Marie Curie services. Although a couple of staff felt that there had been no observable increase in their particular departments, the majority of staff felt that the hospice seemed more diverse now than at the start of the project, if the numbers still felt quite low. These observations were made in the spring and summer 2015.

"It definitely feels anecdotally that there's a more representative mix of patients coming through the hospice doors" (HCP2 7)

"I'm mainly working on the in-patient unit at the moment and I think that it might have so a little bit I think there has been a few more patients that you would class as being from sort of minority ethnic groups but I would never have expected a huge impact on the in-patient point of view and I'm guessing that um the community teams might have noticed more" (HCP2 9)

Unfortunately, because the hospice and Marie Curie do not monitor ethnicity consistently and in a robust way, analysis of ethnicity data to determine actual increase in uptake has been problematic and due to the large numbers of patients whose ethnic background is 'unrecorded', the data is not considered reliable. In response to this issue the key worker amended the Patient Profile form to improve recording of patient ethnicity data, and in the first half of 2014 retrospectively reviewed the files of patients from September 2012, adding missing information on ethnicity where possible (e.g. by asking the patient or completing from other parts of notes) and inputting this onto Marie Curie's Patient Information System, thus helping to establish a more accurate record of service use of BAME groups at the beginning and mid period of the project.

"The problem is we don't monitor ethnicity and in order for me to find that information out I have to physically go through the files of the people …so where it's left blank or not stated so I went through them..if they're not British they don't want to ask them so that's one of the fundamentals of the processes that we need to get right and change." (KW4, July 2014)

Based on this data, considerable year on year increases in the BAME patient population have been demonstrated, with the relative size of the BAME population roughly doubling from 2.70 to 5.39% in the project period. This is illustrated in the table and graphs below.

Table one: numbers of White British, BAME and 'unrecorded' patients using hospice and community services in project period.

Year	Total patients	Patients ethnicity recorded as White British	Patients ethnicity recorded as not stated / blank	Patients ethnicity recorded as minority ethnic	ME patients as % of total patients	% Increase in ME patients accessing services
Combined hospice and community patients						
2011/2012	1139	918	190	31	2.70%	
2012/2013	1019	786	193	40	3.90%	29.0%
2013/2014	1059	644	359	56	5.30%	80.6%
2014/2015	1113	509	544	60	5.39%	93.5%

Patient Ethnicity 2011/2012
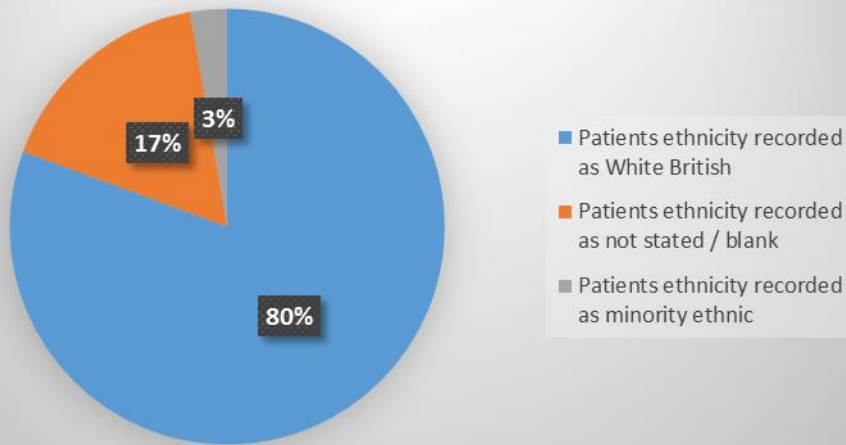
Patient Ethnicity 2014/2015
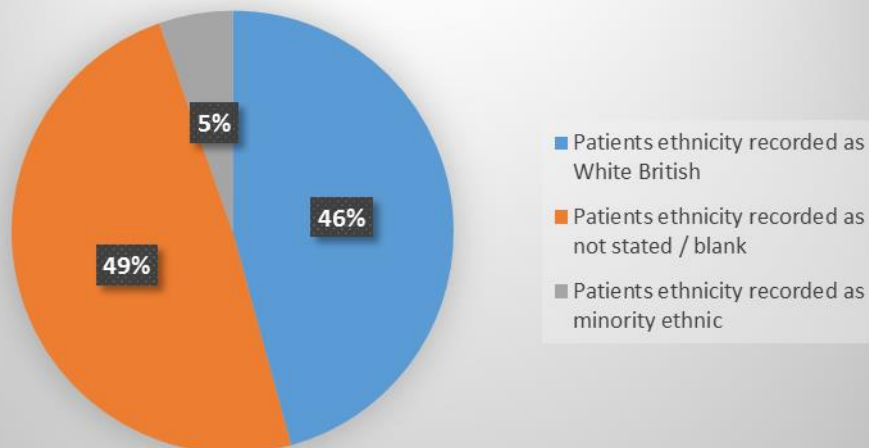
Unfortunately, what this data also reveals is the large increase (+32%) in the numbers of patients whose ethnicity was not recorded, which likely explains the striking (-34%) decline in the number of recorded White British patients.

This may in part be due to the compensatory efforts of the keyworker to retrieve and record ethnicity information in the earlier periods (as described above), but is also likely due to the high levels of staff turnover in the later period.

A further 74 people from BAME groups have been referred onto 21 other agencies after coming into contact with the hospice over the course of the project.

5.5.1 RAISED STAFF AWARENESS AND CHANGES TO PRACTICE

Increased staff awareness amongst hospice staff was widely identified as a key impact by our staff participants. Although one member of staff felt that they did not learn anything new, most staff spoke positively about the education sessions, which they felt encouraged them to critically reflect upon their own practice, understand more about the needs, beliefs and practices of different cultural groups and the potential implications of these for their roles.

> "I think um I found the scenario's quite useful because I think they were quite good at certainly getting you to look at both sides of the story um so I thought they were useful and I thought they were a really useful tool for us all as a team to just kind of make sure we are conscious of how we operated and you know just thinking through some of the things you take for granted and how you work" (HCP2 8)

> "I think one of the other things is sort of cultural competencies within the hospice and getting everybody you know the staff the day to day staff there being more confident caring for patients from different cultures understanding their needs and and their cultural beliefs and …practices" (HCP2 7)

Most hospice staff felt that there is now a generally raised level of awareness amongst staff of the need to improve access for BAME groups, the different needs of particular cultural and religious groups coming into the hospice and barriers that they may face, and the need for certain changes to be made to address these needs.

> "All the different categories of staff in the community and within the hospice itself have a better understanding of the needs of people and the barriers that they encounter coming in" (HCP2 4)

> " I think when you've got an awareness like that it's easy to move on then when actually changes are needed…so you need that step first so I think that's probably the biggest achievement" (HCP2 7)

> "We've gone from being the unconscious incompetent to being the conscious incompetent." (Project board)

The fact that these issues are now being "talked about" openly in the hospice was seen to be a critical first step towards achieving change and one of the main achievements of the project by some.

> "that's got people talking about it that's got to be the main achievement because people are talking about it they recognise hey here's a problem and we're talking about it and we're trying to do something about it um so I think that would have to be number one" (HCP2 2)

> "The point is you're talking about it so surely that's a good thing because it certainly wasn't being talked about before" (HCP2_8)

There was also discussion around changes made to personal practice as a result of the project. A small minority of staff felt that they were already working with cultural sensitivity and had not needed to make changes or adapt their practice.

"well everybody here's quite professional anyway so I don't think that um anything would need to change because I would like to think that everybody would treat everyone else the same" (HCP2 5)

"I don't think I've learned anything ground breaking that I didn't know before and that I haven't had incorporated into my practice anyway….I think probably it's just something that needs to be undertaken anyway you know just part of good practice really in respect of the project just you know about engaging with every all sort of people really isn't it and um making sure you're working appropriately and sensitively and all those sort of things really… "(HCP2 3)

Other staff however, felt that they had become more personally aware not only of the potentially different cultural needs and practices of BAME patients and families, but also of the importance of finding out about the individual needs of patients and families and to avoid 'falling into stereotypes' and making assumptions.

"I think just making people…to not make assumptions on some because of their ethnicity or religion but to actually to involve them whether it's a patients families other professionals in in their care and the best ways we can support them in the end of their life" (HCP2 1)

"Our staff are talking to patients and understanding their needs, whether religious or individual " (project board)

"I mean on the whole we liaise with the families and we are quite open with the families so they let us know if what if there's anything special we need to be doing around certain times of festivals and things like that"(HCP2 6)

Another example given of impact on staff practice included adaptations that were made to the training materials for volunteers, in terms of avoiding overly "Eurocentric" case studies and questions.

"the adaptations we made for the training for um volunteers wasn't massive at all you know the organisation of it the structure and the activities are still the same but

it was just making sure that things weren't necessarily um eurocentric in the in the questions we were working on in the case studies we were giving things like that. "(HCP2 1)

5.5.1 A MORE INCLUSIVE AND ACCOMMODATING ENVIRONMENT

Hospice staff and community members gave various examples of ways in which they felt the hospice was now better meeting the needs of patients and families from BAME groups. Members of the project board felt that the BAME patients and families which they had worked with had been pleased with the facilities, and the accommodating attitudes of staff.

> "We have had more people from black and minority ethnic groups, certainly in the last two years, there doesn't seem to be any barriers, everything's been fine…we've been able to work with what we've got" (Project board).

They also expressed their commitment, at a managerial level, to continue to find ways of supporting the particular needs of families, for example, becoming more flexible with regards to the release of bodies over the weekend to accommodate the death practices and burial requirements of Muslim families. Following the example of a hospice in Bradford, the management also explained how they were now open to the idea of allowing large families to bring in food and use their dining room, should this be needed.

> "it is about looking at individual needs and how we can support them and enable them to look after themselves." (Project board)

In terms of physical impact and changes to facilities, the newly developed 'quiet room' was widely discussed by both hospice staff and community members. Community members commented on the importance of having this appropriately equipped facility for enabling patients and visitors to pray whilst at the hospice.

> "The prayer facilities that was really important so because from the because what happens is no matter where we are we have to pray…because if if somebody's coming to visit somebody who's sick we're not going to stop our prayers…we need to pray and

ten visitors come and then it's prayer time and they say oh is there somewhere we can do our prayers?" (CM5)

"The ability to still be able to practice the faith um and have those sort of um you know whether it's safe spaces or um particular types of um settings whereby faiths are respected...and the pertinence about when you're providing end of life care obviously…" (SG1)

Many hospice staff also commented on how much better resourced, accessible and more widely used the room is now. This was seen to be important for enabling people to feel welcome and confident in using the hospice. Others also saw the benefit and value of room for people without religious belief who might appreciate the space for 'quiet contemplation.'

"Awareness of the new washing facilities at certain times of day prayer room you know sort of physical things that need to be in place to try and um at least make people feel welcome and that we could meet their needs." (HCP2 2)

"I think the quiet room is um brilliant and I'm very much a fan of visits not necessarily of a particular religion faith or belief in that it uh it's just something for quiet contemplation or presentation even or someone to have a quiet chat um it'd be uh yeah so I think that's great and it's also nice to be able to um direct people to that." (HCP2 1)

Community members and hospice staff also felt that patients' dietary needs were now better catered for following the projects engagement with the catering department. Hospice staff and members of the Steering Group also felt that the hospice had become more explicit about the provisions which can be made and facilities available, and the need for such communication to take place.

"I suppose the other thing that I've really noticed is around the provision of food for people so how (Names KW) has been able to work with the um kitchen in making that much more accessible so that people's dietary needs whereas you know we tend to cater for everybody's dietary needs there may be some a little bit specific is possible for people from different communities who need different things" (HCP2 4)

"Dietary requirements I think is something that's given to a patient as opposed to a patient having to ask" (SG1)

"I think sometimes there's assumption that they aren't there um I think we all we all need to be better in communicating that that they are there." (HCP2 1)

Several community members also commented on the positive attitudes of staff at the hospice in terms of perceived changes to staff norms and increased cultural awareness, and the subsequent contrast between nurse approaches at the hospice, which was felt to be welcoming and understanding of different cultural practices, compared with hospital experiences.

"A lot of them were down to (KW) really challenging the staff and the norms that had existed there really." (CM3)

"I think the nurses and the people who are treating the patients are much more aware." (CM5)

"I think the other nurses they do great jobs as well in the hospital but they're very always feel a bit cross and they don't understand our culture they're sometimes rude to us cos they see a group of us visiting you know but I don't think that's been that's been the case in the hospice." (CM5)

5.5.2 PRACTICE SHARING AND INFLUENCE ON LOCAL SERVICES AND ORGANISATIONS

There are also examples of wider project impacts, based on practice sharing between organizations and dissemination at local and national levels. At a local level, examples were given of how the project positively influenced another 'access' project within the hospice, of a visit from the local children's hospice to the new quiet room and contact made by the newly appointed engagement officer at the Sue Ryder hospice in Bedfordshire who is interested in learning from the project. In particular, it seems that the project influenced the practice of other local NHS and voluntary organisations represented on the steering

group. Community members on the steering group and a member of hospice staff explained how the project provided a good practice model and opportunity for shared learning in terms of improving access and addressing barriers to engagement for a wide range of groups with service access issues, and thus explained how the project had informed their own work and practices.

"Because it was already up and running the work that she was doing and as it has developed has um provided a role for good practice and learn and shared learning for the (names project) carers project…because part of our target on an all Wales basis is um to include people er from um BME communities um as well as um rurally isolated in areas." (HCP2 4)

"It's now become almost part of the mainstreaming of kind of you know general health and social care services and minority ethnic groups um that addressing that kind of disconnect because there is a complete lack of awareness of even basic services amongst minority ethnic groups in in Wales and it's become quite a instrumental player in in tackling that problem" (SG1)

"We've all learnt um both for the projects and but also for ourselves and we're taking that back to our own organisations and communities" (SG1)

The project board also noted how the keyworker was used as a resource by health professionals across the locality for providing advice and support for BAME patients and families, and that there was concern within the local health board about how to fill the gap that would be created when the project finishes.

"I've been to LHB meetings within the locality where they speak very highly of the work that she's done and recognize her as a local resource and somewhere they can go to." (Project board)

5.5.3 INFLUENCE ON NATIONAL AND EXTERNAL GROUPS

As the profile of the project developed, so too did the keyworker's involvement in external groups, suggesting recognition of her growing expertise in this field and opportunities for

the learning from this project to be shared and disseminated at much wider levels. The keyworker has been part of the Residential Care Review for the Older People's Commissioner, the Race Equality First Minority Ethnic Elders Advocacy Steering group and the Engage Community Voices Steering Group run by Sight Cymru. The keyworker has shared learning and contacts with the Tenovus BAME engagement programme, presented to the Local Medical Committee and to Marie Curie Senior Nurses working across Wales. The Welsh Government End of Life Annual Report also includes work from the project.

> "[local NHS End of Life Delivery Plan] mentions this particular project in their plan. it's a 2013 to 2016 plan so that's good... to expand links to review the outcomes of the Marie Curie BME link post and utilise this to inform the development and delivery of services...they have invited me to be part of their palliative care reference group" (KW 4, July 2014)

The project has also impacted positively on Marie Curie practice nationally. The most tangible example of this is in the learning scenarios described earlier which have been adopted by the education department at Marie Curie and will be made available on-line for all Marie Curie staff. The keyworker was also involved in the Marie Curie inclusion and diversity group which was looking to develop and implement a consistent system for recording patient data across the organisation. Several hospice staff also commented on the national influences of the project, and the relevance of the project for other hospices across the UK.

> "I think it's one of these one of the few projects um around the country that how um Marie Curie can maybe just you know take these some of these approaches UK wide for different hospices and nursing services and things like that..."(HCP2 1)

> "The work that (Names KW) has done has been highlighted in other areas of Marie Curie and so that feedback has been able to make an impact in that way so improve information and what's possible to be done which I think is can only be positive" (HCP2 4)

"I also tried to share that with some of our so the helper service runs in South Wales what I'm trying to do is share that information with the helper services around the UK which are ever expanding" (HCP2 1)

5.5.4 DISSEMINATION: PUBLICATIONS AND PRESENTATIONS

The keyworker has reported on the project at a number of events, including oral and poster presentations at the: All Wales Palliative Care Conference, October 2013; the 'Building Connections' Conference, March 2015; Marie Curie Research Conference, March 2015 and the Marie Curie Great Daffodil Appeal Launch at the Synedd in March 2014, following which the keyworker was invited to video link into the MCCC national executive board. In June 2014, the project was officially launched by the AM for Cardiff and Penarth and Deputy Minister for Tackling Poverty at an event attended by over eighty people. At this event the keyworker presented her report on the barriers to people from minority ethnic groups accessing palliative care, based on the extensive community consultations carried out during the project. A family member also spoke at the event to share their experiences of being supported by Marie Curie and a consultation session was carried out to inform the future work of the project. Much positive feedback was received about the event, which stimulated considerable interest in the barriers report and project, including from the Minister for Health and Social Services.

"He came over to my stand and um talked to me about the work that I'm doing and he was quite interested in what we're doing and he also wanted to know where people cos I told him about the 37% increase we've had of patients our service since I started compared to the two years before or eighteen months before…and I've followed that up with an e-mail." (KW4, July 2014)

"I went to one of the launches that um was hosted … and saw the diversity and the enthusiasm" (HCP2 2)

The project and the report on barriers to accessing palliative care (Nawaz 2014) were highlighted on a BBC Wales Today article in August 2014.[4] This attracted interest and requests for copies of the report from a wide range of stakeholder groups around the UK, including Lancaster University, Martin House Children's Hospice and NHS Oldham Clinical Commissioning Group. There have also been several articles published in internal and external publications, for example Marie Curie People (newspaper for staff and volunteers), Care Talk special edition on End of Life (October 2014). The keyworker has contributed case studies to a joint Hospice UK and Woolfe Institute publication on 'Bridging the gap between Muslims and hospices.'[5] Following a presentation at the Building Connections to Achieve Excellence in End of Life Care in Bristol 17th March 2015, the project was selected as a case study which was written up and published in the NHS transforming end of life care newsletter, August 2015, and is to be re-issued in Public Health England's National End of Life Care Intelligence Networks 'What we know now 2015 update'. These publications are disseminated to relevant senior managers across the NHS.

Several hospice staff commented on the effective dissemination and promotion of the project and the significance of events such as the Daffodil Appeal and project launch in terms of helping to give the project a "national stage."

> "The Marie Curie Daffodil appeal launch the year before last that I went to (Names KW) was one of the speakers at that I think it's had quite a national you know quite a national stage really in terms of the success of the project" (HCP2 7)

> "I think she has done lots of raising the profile of the hospice generally via many many different forums and community groups and in a political arena as well, so she's probably done lots of stuff that's got very little to do with minority ethnic groups and has done loads of PR for us generally" (HCP2 9)

> "I know she presents at a number of different conferences and those things you know the research and that she's found and built up the main networks with loads of

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[4] http://www.bbc.co.uk/news/uk-wales-south-east-wales-28733081.

[5] Ahmed S and Siddiqi N (2015) Bridging the Gap. Strengthening relations between hospices and Muslims of Britain. Woolfe Institute and Hospice UK.

local professionals and assembly members as well um you know which I think has really put Marie Curie the differences and changes they've been making on the map in South Wales" (HCP2 1)

The achievements of the project were also been acknowledged by Tony Burton (Vice Chair BLF) and Fflur Lawton, (Senior Head of Corporate Management BLF), who visited the project in September 2014, and described the potential of the shared learning to come from the project. The project has been chosen as an exemplary case study for the BLF website, and information on the project has been passed by the BLF to Cardiff Institute for the Blind to share good practice and contacts for their work with BAME people with sight issues.

"My visit to the Marie Curie hospice in Penarth gave me an opportunity to hear about the good work they do supporting BAME communities in south Wales to make best use of their services. Ensuring that Lottery funding makes a real difference to communities across the UK is really important to us. In this case hearing first hand from families affected by cancer and supported by the project was a powerful example of the significant difference that can be made." (TB)

"Seeing the work being done by Marie Curie to engage and support patients and their families was really moving. The project offers real opportunities to share learning and support the improvement of care for individuals and their communities." (FL)

In October 2015 a final event was held at local community centre to celebrate the success of the project. It was attended by around 60 stakeholders, and included talks from the Deputy Health Minister for Wales, a family member of a former BAME patient, the hospice manager and keyworker. The new DVD which showcases the hospice was played and the three volunteer community champions were presented with certificates. There were several stands publicising the hospice and other local organisations and delegates were given a copy of the DVD to take away and share within their networks. The event received very good

feedback from attendees, with all respondents rating the event positively, and more than 85% of attendees rating the different aspects of the day as very good or excellent.

5.6 THE PROJECT APPROACH: STRENGTHS AND CHALLENGES

5.6.1 STRENGTHS AND SUCCESS FACTORS

The keyworker, several community members and hospice staff considered that a key strength of the project was its multi-faceted approach and ability to work at different levels. It was described how the keyworker effectively engaged with people at strategic levels within Marie Curie, in political circles with assembly members, with service providers, health professionals and grassroots community organisations. This has helped to cultivate interest in, and commitment to the project from a broad spectrum of stakeholders.

> "I would say (KW) herself and her approach her experience and her knowledge and the fact that she can work on all levels that she can work at strategic level then within Marie Curie too and also she could then work with service providers to make them aware such as doctor's surgeries and people like that really hospitals too ….and then also working on the ground so she could work at all three levels on the ground at the grassroots level with grassroots people" (CM3)

> "They got engagement from such a wide group of people and I don't mean just patients or even different cultures I mean that they went from the assembly members so you had an AM who posted to different groups of people you know clinical groups, doctors, nurses, allied health professionals but then you had people who might be volunteers, politicians, managers you know so you had a wide group of people which went on and then had outcomes which she published and shared" (HCP2 2)

Many community members and a couple of hospice staff commented on the strength of the keyworker's approach to community engagement in terms of "getting people together", "getting the message out there" and having a real presence at the many community events and meetings which she attended. One community member also commented on the

effectiveness of the keyworker in "getting close to the ground" (CM4), which was seen to be essential for building trust with local groups.

> "She was out there trying to reach as many groups as she can because I think I was only involved with (names KW) and no one else from the project and I've seen her faces in so many events and so many meetings and she was getting the message out there" (CM2)

> "She's always sure that there was a leaflet in her pocket in her bag to give out wherever she went...her personality and just the fact she was always there had a real a real presence" (CM2)

The keyworker similarly identified her intensive initial efforts at community engagement as critical to the progress and success of the project, as this fostered trust and close relationships with local groups. The sharing of patient and family stories within local communities was also seen to be critical for encouraging people to take up services.

> "It was really important for me to spend as much time as I did in the community...just to be there and help to build trust and relationships with communities and community groups...It was also really important for us to share stories of people that have used the services and the experiences that they had and how much the hospice helped them" (KW6, September 2015)

The keyworker and hospice staff considered that the supportive relationships which the keyworker had built up with staff at the hospice had also been critical to the success of the project.

> "Internally building relationships with staff has been fundamental to the project, I don't think you could do one without the other" (KW6, September 2015)

Of noted importance here was the keyworker's integration and acceptance into the team, which was helped by sharing office space with the community team, regular attendance and involvement at meetings and an innovative approach to 'spreading the word' about her project.

"Real integration into the team…which worked really well in the community team cos she shared the office with the community team… so you know she might overhear a conversation or you sort of don't have to go upstairs and knock on the door so that works quite well that integration" (HCP2 7)

"Integration into the team so that (KW) really sees herself as a member of the team she's not somebody working behind a desk on the project…but will come to the end of MDT's if she can or will come to the morning meeting …people in the hospice know her and her role and I think that's probably been one of the key's really that integration" (HCP2 7)

"I say innovative because she looked at ideas as to how she could spread the word within the hospice as to what she was doing" (HCP2 2)

The keyworker also described how she made a conscious effort to involve a range of staff in the different aspects of the project, such as assisting with community events, as this "helped them to understand the need for this work." (KW6, September 2015) The launch event, followed by the high profile publications and media coverage discussed earlier, was also seen to have been a critical turning point for the project in terms of generating staff interest and commitment to the project.

"Key members of Marie Curie were invited and they came and saw what the project meant to people in the community" (KW6, September 2015)

"The more success it's had the more positive impact it's been having internally" (KW6, September 2015)

The establishment of a project board (Summer 2014), and an associated governance and accountability framework was seen to be another critical development. Members of the project board perceived the function of the board to be to 'keep everything on track', clarification on issues which arise, extra thinking space and support and a general 'steer' for the project. The keyworker considered this support essential to the successful implementation of many of the changes which needed to be made at the hospice.

"We discuss all the sort of main needs in the hospice includes in patient's needs as

well so we have a quiet room that was developed um and that is for all ethnicities and all beliefs and that includes those that don't have any belief as well so it was just um it was almost like a way of drawing information and drawing knowledge together as well and making sure things are in place that would be needed in case we had any ethnic minorities in the hospice for their spiritual need to be sort of covered as well" (HCP2 6)

"Having the project board has really helped me to engage the hospice staff in the work of the project" (KW6, September 2015)

Community members and hospice staff also discussed the personality of the keyworker as a factor which was critical to the project's success. The keyworker was seen to be easily approachable which enabled staff, community members and patients and families to feel comfortable asking questions and seeking advice and support from her.

"I was quite happy asking her um that the red dot that you see on the forehead of some um people why's it there um and she explained and so she very easily approachable" (HCP2 2)

"Very approachable and it's easy to talk to her so it's and that makes it much more positive to go and find out things" (HCP2 6)

"She was really approachable and friendly as well and they felt comfortable enough to ask any questions, to share any experience they already have with friends and family who passed away or still receiving treatment" (CM2)

Staff and community members also commented on the hard work and determination of the keyworker in driving the project, which helped get others "on board" and ultimately "get the job done."

"She's really hard working brilliant at her job engages very clear clearly says what what's what's achieved and how she wants people to engage I think (names keyworker) is quite exceptional and central to it" (CM1)

"As a person driving it has been (KW) and I think she if it wasn't for her skills and the way she is in herself I don't think It would have come as far as it has...she's very

committed she's very driven and she's get's the job done" (HCP2 6)

5.6.1 CHALLENGES AND GAPS

When asked for their views on the challenges or issues experienced by the project, many participants felt unable to comment beyond general reflection on likely funding constraints and the difficulties of working alone on a project.

Of great importance, however, and recognized as such by several members of staff, were the previously discussed difficulties with the recording of ethnicity and other data at the hospice. Although not seen as a fault with the project, this was seen as a critical area for improvement at the hospice and palliative care in Wales, and one which is also firmly on the agenda of both the hospice manager and central Marie Curie.

> "We don't collect the data very well in Wales on ethnicity of any of our patients really that come to palliative care really…that would be fab I think to be able to show electronically how much it improved and how much it needed to improve again to represent the population and I know they've collected some of that data but I think we could do a lot to sort of strengthen the robustness of the data that we collect" (HCP2 7)

In terms of engaging communities, a staff member felt that initial efforts at relationship building were probably the most challenging, and that the project would have become easier over time, while another considered that more preliminary work before the project started would have enabled the keyworker to "hit the ground running".

> "It's getting those initial steps through the door and into the community because it's breaking down barriers and letting people talk to us and talk to them as well so um I know at the beginning it was quite difficult and making those first sort of steps into the communities but now that she has I think things are a bit easier" (HCP2 6)

> "I think probably one of the initial difficulties that there was and I don't know how you tackle it is that there wasn't work done to say this is what's coming so that she

could hit the ground running…I know that she was on a tight timeframe to try and get outcomes" (HCP2 2)

Several staff members and a community member also felt that there may have been a small amount of initial staff resistance, or limited support for the project at the start. This was thought to be for a variety of possible reasons including "traditional views" and established ways of working, or staff feeling uncomfortable asking questions.

"I suppose the only thing would be really the traditional views and attitudes within this itself really and having to challenge those and make changes a change is very difficult to bring about especially when people have worked there for many years and they've set in their ways and used to the way things that work…it did feel like she had some challenges to face right at the start" (CM3)

"I think to start off with um you know being honest (KW) had a tough time because people didn't always buy into or perhaps felt less comfortable in asking well exactly what you're doing and you know how can I help or what does it mean you know and that may be because they didn't feel so comfortable asking those questions because you think oh am I being prejudice in some way… although I have to say (KW) never gave that off she will be quite happy to answer anything you know" (HCP2 2)

Other staff members felt that the challenge in engaging staff was more likely due to time constraints and were typical of all efforts at staff education and communication in a busy clinical environment.

"I don't think there's been resistance towards it um I don't know how much support and help she feels she's had from other all across the board I think lots of people are busy doing their own things so I don't think anybody's been particularly negative about her or her presence…but they may not have had much scope to help her regularly" (HCP2 9)

"I think it's been a challenge because any form of communication or education up until now has been a challenge with staff." (Project Board)

Only a very small minority of participants were able to identify any gaps or weaknesses in the project. One member of staff felt that it would have been beneficial if the project could have also engaged with other excluded groups such as the homeless or people with learning difficulties, while another felt that they still experienced difficulties using interpreters which although beyond the scope of the project is an area that still needs to be addressed. .

> "We do have easy access to interpreters but it's much more difficult when you're trying to do emotional work…I don't know how you would address it totally without perhaps employing people who can actually speak the language and maybe have that you know deeper understanding" (HCP2 8)

5.7   LEGACY AND THE FUTURE

5.7.1 NEED TO ENSURE SUSTAINABILITY

A key concern amongst hospice staff and community members was with how to ensure sustainability and achieve lasting change once the project ends. A couple of members of staff and a number of community members described their frustrations with the short termism of these kinds of projects and were concerned that the focus on access and equalities might get lost and the hospice may lose its presence in local communities. Community members reflected on their own experiences of working on similar projects and described how a loss of trust can sometimes develop amongst communities which experience multiple projects "come and go."

> "I think with any timed project like this there is a danger that 'cos we can look back through history um that after a timed project's finished that if you haven't got a dedicated person to move that agenda forward then the agenda falls off so I think where there's a hope that although um this is a project looking at the barriers that it would identify there is a need for someone to be in a role around engagement and around trying to improve that for the future so we'd like to see a a role be extended, because the danger is that any 3 year project or 2 year project that's funded once that ends that story ends" (SG1)

> "Sometimes they'd lose the trust of the people. They see projects come and go and by the time they start to do something in the community it finishes.. the thing is they keep giving funding for other projects….they cover the same things so why don't they leave the same project running" (CM2)

> "I would like to think that it wouldn't fizzle out but I got a feeling it might because there's no driving force behind it" (HCP2 5)

Following on from this concern, many participants also expressed views on what is needed or what would help to ensure a sustainable legacy for the project. The steering group and several hospice staff felt that ideally there would continue to be a role dedicated to the 'improving access' agenda, or at least have somebody or several staff 'champions' take on the role as part of their existing positions, following a period of 'shadowing' of the keyworker. It was also felt that this responsibility needed to be taken on at management level within the hospice.

> "There is a need for someone to be in a role around engagement and around trying to improve that for the future so we'd like to see a role extended, because the danger is that any 3 year project or 2 year project that's funded once that ends that story ends" (SG1)

> "I think it would be useful to have someone in post cos the confidence is lacking with certain people accessing health services right from the very like front …they need that person that they can be a point-of-call" (SG2)

> "It is down to champions and reminding people and continuing that work because I think it's difficult to change everybody's culture and thoughts really without having somebody leading on that who's going to continue to remind people" (HCP2 7)

It was similarly felt, by community members and staff, that there should be continued efforts at community outreach and engagement in order to "embed awareness" of hospice services at grassroots level in the "greater diversity of communities" of local communities.

> "The links that (KW) has made it would be a shame if they were lost really so you would hope that those could be maintained and build upon" (HCP2 8)

"It's always a time thing isn't it…communities don't always respond when you want them in the timeframes that we need and a bit of extra time to engage more widely with greater diversity of communities" (CM06)

Targeting younger generations to ensure that this awareness continues across generations, and mobilises the interest of those with the English language skills to volunteer and take the message back home was also seen to be a useful way forward.

"This kind of illness and help is needed for forever so therefore they shouldn't have a project that's only there for about two three years and then they end it… maybe in a year or so it wouldn't reach a generation that you know what I mean… it need to be there forever if the service if the problems exist" (CM2)

"I saw lots of different cultures visit the hospice and worked and met with them um it would have been nice if there was more engagement with um younger people and there were more volunteers perhaps who came you know because I think it's the younger people who are going to then influence and then speak the same language to take the message back home" (HCP2 2)

Practical suggestions which were put forward for sustaining community engagement and awareness included; incorporating this focus into core Marie Curie services, such as marketing; maintaining the stakeholder network and disseminating newsletters. The need to target GP awareness and referral practices was also discussed by a community member and hospice worker.

"Some sort of the stakeholder network or newsletter or just something very simple to keep the links with those agencies and those groups (CM1)

"Ensuring that doctors surgeries who have access to all communities and hospitals themselves have that awareness in them as well so that every single person that is in contact with those patients and that client group really realizes that they need to raise awareness"(CM3)

There was also felt to be a need for a continued commitment to diversity and cultural awareness training at the hospice, making use of and adapting existing resources from the

project such as the cultural calendar and learning scenarios.

> "One of the things that (KW) and her team has sent out in the year uh something as simple as an email out to all members of staff to say you know about different festivals coming up and what that might mean think that would be a very useful things to continue um to keep that in the the people's attention" (HCP2 4)

> " You know like using those scenarios can definitely be used in different ways whether it can be developed you know so that people can continuously thinking about how we respond…it would be nice to think that that could happen" (HCP2 8)

This was felt to be important not only for new staff but also to maintain awareness amongst current staff to ensure ongoing sensitivity and responsiveness to need.

> "You have a different turnover of staff so I think it's important like every the staff in the hospice all try and they have like part of their induction training like they regular training like about bereavement in different cultures and how we deal with a death it's different like with a um Indian community" (CM5)

> "You need that sort of constant reminder really somebody to raise that awareness of new members of staff as they come through and build on it in the existing (staff)…that awareness isn't necessarily built in to you, taught to you in your training so you know having one talk from somebody isn't gonna suddenly change the way you practice further more so I think it is sort of chipping away and it needs to be a sort of constant conversation really" (HCP2 7)

A community member and hospice worker also described a need to try to achieve greater diversity and cultural awareness in the work force by recruiting staff or volunteers from different backgrounds and those with experience of working in multi-cultural environments. It was felt that this would not only help promote cultural awareness by encouraging learning to take place between staff members, but would help to make the hospice a more familiar place.

"In the future I think they should definitely get staff members who are aware, it's not about the colour even or ethnicity it's about so that's somebody who really understands and who's trained in it you know." (CM5)

"I could be working in a place and I might be the only Muslim person but I can give out a whole lot of wealth of information…and I've always worked in a place that I'm the only Muslim in my profession and then I'd teach it like they I could go just ask me a question …so I think that's what they probably need to do" (CM5)

"I'd love to go on call on a Saturday and see somebody other than a white person behind the desk volunteering…what you need is more diversity in there…You want to see diverse people and so that when people cos those diverse people will go back to their own cultures talk about it and it won't be a scary place…" (HCP 2 2)

5.7.1 PROJECT LEGACIES

In line with these concerns, the keyworker has also focused on building an enduring and sustainable legacy, particularly in the final year of the project. Several pieces of work were identified which should help the project achieve this goal.

In terms of sustaining and expanding Marie Curie's engagement with local communities the volunteer champion program described in section 4.4.3, was seen to be an important way of delivering ongoing outreach and awareness raising within target communities, supported by resources and publications produced by the project such as the DVD and barriers report. Similarly, the learning scenarios and training materials described in section 4.3.1 will be incorporated into core staff training, whilst physical changes such as the quiet room, signage and IPads will remain once the project ends.

The keyworker has also consolidated the extensive knowledge and information that she has accumulated over the course of the project into a professionally produced resource pack.[6] It is intended that this can be used by hospice staff (and other stakeholders who request a copy) for signposting patients to appropriate organisations (e.g. help with making an Islamic

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[6] Marie Curie. Resource pack. Information to help support patients from black and minority ethnic communities. July 2015.

Will or emotional support), and also contains information on capturing ethnicity data and rituals around death or dying. A further pocket size guide on death and dying, incorporating material from a multicultural resource pack produced by NHS Scotland, has also been developed and distributed to staff.[7]

> "All of the communication I've collected over the three years around community based organisations and what they have to offer…we've put it together in a resource pack." (KW6, September 2015)

> "That availability of who to contact what groups and where to go as for me in the community is quite beneficial actually because sometimes I'll see a patient at home who might be quite isolated because knowing I can contact certain people maybe to support this patient as well" (HCP2 6)

As well as developing resources and programs that can extend beyond the project period the keyworker has looked to embed and delegate ownership and responsibility for these different areas of work so that they continue to be valued and managed once she is no longer in post. As part of the embedding process the keyworker has been part of all new staff inductions since August 2015, including at least 15 new doctor and nurse appointments. The volunteer champions program is being taken on by the Rehabilitation and Therapies Manager and working parties involving ward staff were used to develop the resource pack and introduce the IPads and CD players onto wards. Members of ward staff have also volunteered to maintain and update the resource pack and the cultural calendar has been adopted by the receptionist.

> "I've tried to engage the staff in the hospice in all the bits that I'm doing, so I've got them involved in the resource pack, how does it look? With the I Pads, do you want them, what do you need for them?...so they get ownership…so all elements in what we're doing we're trying to make sure there's ownership from the hospice." (KW6, September 2015)

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[7] Marie Curie. A Multi-Faith Resource for Healthcare Staff. 2015

These efforts at embedding the project and staff engagement were seen to have been effective by the project board which considered that staff felt committed to sustaining the focus of the project once it finishes.

> "I think what they've done with the project is they've made it that people don't want to lose it and I think that's the really important thing." (Project board)

6   DISCUSSION AND CONCLUSIONS

This evaluation has reported on five main thematic areas based on the interview and documentary data collected over the three year project period. These are; barriers to minority ethnic communities accessing palliative care; the project approach and activities of the keyworker; project impacts; strengths and challenges and legacy and the future.

A number of different barriers were identified by hospice staff and community members. The most salient reason perceived for low access was a lack of awareness of what palliative care is and knowledge of what services are available locally, as also identified in previous research (Elkan et al. 2007; Evans 2012; Gunaratnam 2007; Koffman et al. 2007; Randhawa et al. 2003). Other reasons included false assumptions made by health professionals that families 'look after their own' (Elkan et al. 2007; Firth 2004; Randhawa et al. 2004), language barriers (Elkan et al. 2007; Evans 2012; Randhawa et al. 2003; Worth et al. 2009), and uncertainty over whether the hospice can cater for religious needs and provide culturally appropriate care (Elkan et al. 2007; Gunaratnam 2007). The barriers identified by participants in the community consultations are also reported in detail in a separate publication (Nawaz 2014).

Three main areas of work were identified for the project. These related to: community engagement; staff education and awareness and changes to hospice facilities, resources and services. The keyworker has engaged intensively with local communities. A large network of community organisations was built up which helped to share information and support closer working between stakeholder groups. Similar to the successful strategies of previous engagement projects (Randhawa and Owens 2004, Gunaratnam 2007) the keyworker

conducted a series of community consultations and hospice tours, attended local events and over the course of the project produced multi-lingual, culturally representative promotional material, including a new DVD. These strategies helped to raise awareness of Marie Curie services amongst local communities and also enabled the keyworker to identify and respond to their needs and concerns. In order to raise staff awareness the key worker delivered teaching sessions, attended staff meetings and developed learning resources based on case scenarios, highlighting the potentially different needs of patients and families and how staff might address these in their roles. Information on religious and cultural events was regularly shared over e-mail, and the keyworker became a much valued point of contact and advice for staff with queries relating to individual patient needs.

Changes to hospice facilities, such as the re-development of a multi-faith quiet room, a more responsive catering policy and improvements in how facilities are communicated and signposted were introduced to ensure that the hospice was meeting the needs of different groups. Similar to the recent approach of a Bradford hospice, which involved individuals from BME communities in the delivery of services (Phillips and Taylor 2012), efforts were made to improve the volunteering opportunities for BAME groups, not only to help diversify the workforce and general hospice environment but also as a means of sharing information on Marie Curie within communities. Whilst in post the keyworker seemed also to demonstrate, and at least partly meet the need for a more culturally diverse workforce, by providing direct support to patients and families in terms of communication, signposting and simply being a more "familiar face."

In terms of impacts it was felt that there was an increased knowledge of hospice services amongst local BAME communities, including how to access these services, and a growing confidence that their religious and cultural needs could be met. Raised awareness and cultural sensitivity amongst staff were thought to have helped create an environment which was welcoming, responsive and positive towards the kinds of changes and adaptations that are needed to cater for diverse populations. Importantly, the hospice was also perceived by staff to be more diverse in terms of its patient population, as backed up by statistical evidence. Based on information collected on patient ethnicity at the hospice, these figures report an increase in the relative size of the BAME patient population from 2.7% to 5.4% (31 to 60 patients) in the period 2012 to 2015 (despite ongoing issues with the non-recording of

patient ethnicity). Across the Cardiff and Vale catchment area BAME groups make up 7.5 % of the total over 50 population (2011 census data), suggesting that BAME groups are now only slightly underrepresented in their use of services. However, further analysis of service use by each ethnic group would be needed to provide more meaningful information on equity of access and identify which ethnic groups are significantly under or over represented.

Several key strengths and success factors for the project have been identified. These included the multi-faceted approach of the project which involved a wide range of stakeholders, intensive community engagement, building positive and supportive relationships with hospice staff, and determination and dedication on the part of the keyworker. Challenges experienced by the project included some initial staff resistance, engaging with GP practices, on-going issues with the recording and monitoring of patient ethnicity data and going forwards ensuring a lasting legacy for the project. This concern with sustainability and legacy was shared by the keyworker and project board and prioritised in the final year of the project, with a number of resources and strategies identified. These included physical resources such as the quiet room and the information and learning resources developed by the project, the 'community champions' volunteering project, a continued commitment to diversity and awareness training for staff, and efforts made to foster staff ownership of these different areas of work.

6.1   METHODOLOGICAL LIMITATIONS AND IMPLICATIONS FOR FURTHER RESEARCH

There have been several factors limiting the methodology for this evaluation. Firstly, we were unable to undertake interviews with individuals from minority ethnic groups at the baseline stage of the project as planned, despite multiple recruitment attempts by the researchers and keyworker. Instead our assessment of barriers to access relied on the proxy perceptions of potential reasons from healthcare professionals, and perhaps more importantly the notes from the community consultations carried out by the keyworker. While research interviews with individuals from these communities would have provided a rich source of data and insight into community barriers the extent of the consultations carried out by the keyworker and the group facilitation techniques used were effective in

generating both breadth and depth on the topic area. These have been incorporated into this report and have been reported in detail by the keyworker in a separate publication (Nawaz 2014). The researchers (JB & EH) helped with group facilitation at the first of these sessions and assisted the keyworker in the design of the discussion schedule and analysis of the data.

Also absent from our evaluation were the voices of BAME patients and families which have used the services, and which would have provided valuable insights into their experiences of the hospice and nursing services. Although a self-administered questionnaire for service users was introduced and distributed in the final year of the project, none of these were returned. Semi-structured interviews would have provided a more suitable method of data collection but unfortunately this was beyond the resource capacity of the evaluation. Future research should look to capture the experiences of BAME patients and families, ideally by in depth qualitative methods.

We were also unable to recruit participants from our two proposed GP sites, despite gaining the necessary approvals and multiple approaches by the researcher to our collaborators at these sites. Whilst disappointing, this mirrors the difficulties experienced by the keyworker in engaging with GP practices and her subsequent decision to focus her efforts in other areas. Although difficult to conduct, future research with GP practices would be useful to explore the reasons perceived by GPs for inequitable access to palliative care between different ethnic groups, their own experiences and referral practices with these patient groups and what else from their point of view could be done to reduce inequity of access.

The limitations caused by the inconsistent and poor recording of ethnicity information for patients have already been discussed. This means that the data is not reliable and assessments of changes in uptake of services by BAME groups are not as robust or accurate as we would have liked, although still useful for demonstrating the reported increases in service use. Ideally, if recording practices and the quality of this data set improves, this information should also be broken down by ethnic group in order to identify which groups are still most underrepresented in their use of services.

6.2   CONCLUSION

To conclude, this three year project aimed at improving access to palliative care amongst BAME groups has achieved significant positive impacts and improvements in terms of community awareness and confidence in hospice services; staff awareness and approaches and hospice facilities, resources and services. Crucially, these changes have also been matched by a large increase in service use by BAME groups and a corresponding reduction in the inequity of access between White British and BAME populations. The project has also contributed positively to the work of other local and national service providers and organisations and can be considered a good practice model for other similar projects or roles working in this field.

7   REFERENCES

Bosma H, Apland L and Kazanjian A (2010) Review: cultural conceptualizations of hospice palliative care: more similarities than differences. *Palliative Medicine* 25 (5) 510 – 522.

Braun and Clarke, (2006) Using thematic analysis in psychology. Qualitative Research in Psychology. 2006; 3:77-101.

Capotorti F (1985) Minorities. In: Bernhardt R (ed.) *Encyclopedia of public international law*. Amsterdam: Elsevier, vol.8.

Coupland V, Madden P, Jack R, Moller H and Davies E (2011) Does place of death from cancer vary between ethnic groups in South East England? *Palliative Medicine* 25 (4) 314 – 322.

Department of Health. (2010) NHS End of Life Care Strategy: promoting high quality care for all adults at the end of life. London: DH Publications.

Elkan R, Avis M, Cox K, Wilson E, Patel S, Miller S, Deepak N, Edwards C, Staniewska S. & Kai J. (2007) The reported views and experiences of cancer service users from minority ethnic groups: a critical review of the literature. *European Journal of Cancer Care*: 16, 109–121

Evans N, Menaca A, Andrew E, BA, Koffman J, Harding R, Higginson I, Pool R, Gysels M (2012) Systematic Review of the Primary Research on Minority Ethnic Groups and End-of-Life Care From the United Kingdom. *Journal of Pain and Symptom Management* 43, 261-286.

Firth, S. (2004) 'Minority ethnic communities and religious groups', in Oliviere, D. and Munroe, B. (eds.) Death, Dying and Social Differences, Oxford: Oxford University Press, pp. 25-41.

Gunaratnam Y (2007) Improving the quality of palliative care. A Race Equality Foundation Briefing   Paper. http://www.betterhealth.org.uk/sites/default/files/briefings/downloads/health-brief1.pdf

Koffman J, Burke G, Dias A, Raval B, Byrne J, Gonzales J, Daniels C. (2007) Demographic factors and awareness of palliative care and related services. *Palliative Medicine,* 21 (2) 145-53.

Randhawa G, Owens A, Fitches R, Khan Z (2003) Communication in the development of culturally competent palliative care services in the UK: a case study. International Journal of Palliative Medicine. 9,1.

Randhawa G and Owens A (2004) The meanings of cancer and perceptions of cancer services among South Asians in Luton, UK. *British Journal of Cancer* 91: 62-68.

Welsh Assembly Government (2007) Health and Social Services Committee Review of cancer services for the People of Wales. Welsh Assembly Government.

Welsh Assembly Government (2008) Report of the Wales Palliative Care Planning Group. Welsh Assembly Government.

Worth A, Irshad T, Bhopal R et al. (2009). Vulnerability and access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland: prospective longitudinal qualitative study. *British Medical Journal* 338: b183 doi:10.1136/bmj.b183

Ethnic Group (2011 Census), Cardiff and Vale of Glamorgan	Number of residents	% of total population
White; English/Welsh/Scottish/Northern Irish/British	397010	84
White; Irish	3186	0.7
White; Gypsy or Irish Traveller	542	0.1
White; Other White	14214	3
Mixed/Multiple Ethnic Groups; White and Black Caribbean	4270	0.9
Mixed/Multiple Ethnic Groups; White and Black African	1989	0.4
Mixed/Multiple Ethnic Groups; White and Asian	2890	0.6
Mixed/Multiple Ethnic Groups; Other Mixed	2577	0.5
Asian/Asian British; Indian	8452	1.8
Asian/Asian British; Pakistani	6570	1.4
Asian/Asian British; Bangladeshi	4959	1
Asian/Asian British; Chinese	4622	1
Asian/Asian British; Other Asian	5249	1.1
Black/African/Caribbean/Black British; African	5378	1.1
Black/African/Caribbean/Black British; Caribbean	1574	0.3
Black/African/Caribbean/Black British; Other Black	1738	0.4
Other Ethnic Group; Arab	4881	1
Other Ethnic Group; Any Other Ethnic Group	2325	0.5
All usual residents	47246	100

9 APPENDIX TWO: DOCUMENTS ANALYSED

Document title	Date	Author	Type of document	Document ID
Discussion group: community members	26/11/2012	Key worker	Notes from group discussion	DG1
Discussion group: interpreters and health link workers	10/12/2012	Key worker	Notes from group discussion	DG2
Discussion group: Hindu community centre	29/07/2013	Key worker	Notes from group discussion	DG3
Project Report (July 2013)	01/07/2013	Key worker	Project update submission	PR1
Project Report (November 2013)	01/11/2013	Key worker	Project update submission	PR2
Project Report (July 2014)	01/07/2014	Key worker	Project update submission	PR3

Project Report (October 2014)	01/10/2014	Key worker	Project update submission	PR4
Project Report (January 2015)	06/01/2015	Keyworker	Project update submission	PR5
Outcomes for the BAME Project	22/10/2015	Keyworker	Outcomes report	PR6

Evaluating a Black and Minority Ethnic (BAME) community outreach project at the Marie Curie Hospice, Cardiff and the Vale: a survey of patients and families

What do you think about the Marie Curie services that you or your relative has been receiving?

Please let us know by answering the questions below

Once you've completed the questionnaire, please send it back to us in the stamped addressed envelope provided.

Or

If you would prefer to speak to a researcher about your experiences instead, we can telephone you or meet you at the hospice. If you would like to arrange a time for us to contact you please get in touch;

Emily Harrop: 02920 687184

This survey is aimed at patients and families who have used the Marie Curie hospice, or community nursing service, Cardiff and the Vale. The answers you provide will be used by the Marie Curie Palliative Care Research Centre, Cardiff University, to assess how well the hospice and/or nursing service are meeting the needs of their patients and families. Your completed questionnaire will only be viewed by the research team as part of their overall evaluation and <u>will not</u> be shared with the hospice or passed on to anyone else.

About your Marie Curie services:

1. Which Marie Curie services have you been using?

Hospice inpatient/ respite	☐	Hospice outpatient/ day centre	☐
Specialist nurse who visits home to assess me	☐	Marie Curie Nursing service/ Night time service	☐
Other (please state which)……………………………..	☐		

2. When did you or your loved one first start using these services?

. . . . (month) . . . . (year)

3. How did you first find out about these services?

Friend / Family	☐	Leaflet	☐
Community organisation (please state which)…………………	☐	My GP	☐
Website (please state which) …………………………………..	☐	Nurse or doctor at hospital	☐
Other (please state which)……………………………………	☐		

4. Who arranged for you to start using these services?

GP	☐	Nurse or doctor at hospital	☐
Community organisation (please state which)……………………	☐	Other (please state)……………………..	☐

5. How helpful have you found these services? (please tick one option)

Extremely helpful ☐   Quite helpful ☐   Not helpful ☐

Please explain your response:

6. Would you like to have accessed the services earlier on?

Yes ☐   No ☐

Please explain your response:

What would have made it easier for you to access these services?

7. How well do you feel these services have accommodated your religious or cultural needs? (eg dietary requirements, prayer facilities, language needs)

Very well ☐   Quite well ☐   Not well ☐

Please explain your response and make any suggestions for improvements:

8. Do you feel that you have any needs that have not been met? (Please tick either yes or no)

Yes ☐   No ☐

If you ticked **'Yes'** what were these needs?

What changes could be made to address these needs?

9. Have you experienced any problems or difficulties when using these services?

Yes ☐   No ☐

If **Yes**, please describe:

10. Is there any additional support, facilities, or information that you would like your hospice or nursing service to provide?

Yes ☐   No ☐

If **Yes**, please explain:

11. Are there any other ways in which these services could be improved for you or your loved one?

Yes ☐   No ☐

If **Yes**, please tell us how in the space below:

About you:

12. Are you:　　　Male　□　　　Female　□　　　Transgender □

13. What is your age?

0 – 14　□	15 - 24　□	25 - 34　□
35 - 44　□	45 - 54　□	55 – 64　□
65 - 74　□	75 - 84　□	85 +　□

14. Are you:

□　　Patient receiving support from Marie Curie services

□　　Relative or friend of patient receiving support from Marie Curie services (please state relationship)　. . . . .

□　　Other (please state)　. . . . .

15. What is your ethnic group?

A White

☐　British

☐　Any Other White background, *please write in*

_____

B Mixed

☐　White and Black Caribbean

☐　White and Black African

☐　White and Asian

☐　Any Other Mixed background, *please write in*

_____

C Asian or Asian British

☐　Indian

☐　Pakistani

☐　Bangladeshi

☐　Any Other Asian background, *please write in*

_____

D Black or Black British

☐　Caribbean

☐　African

☐　Any Other Black background, *please write in*

_____

E Chinese or other ethnic group

☐　Chinese

☐　Any other, *please write in*

_____

Many thanks for taking the time to complete this questionnaire. Please return it to us in the stamped addressed envelope provided in this pack.

If you have any questions or would like to know more about the evaluation, please get in touch with us using the details below.

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