Celebrating Life:

A service evaluation of an innovative palliative care community engagement project

Project team:

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SUMMARY

The Celebrating Life workshops are innovative public health in palliative care approach to community engagement, aimed at exploring issues around death and understanding of and access to palliative care. They are focused on engaging older people from diverse and minoritised communities at community centres in two areas of North London: Gospel Oak and Haringey. The overall aim of the workshops is to encourage death literacy, by exploring and improving participants' understanding and engagement with palliative care and advance care planning, and knowledge of Marie Curie services.

A service evaluation was undertaken with the aim of examining and exploring the effectiveness of the Celebrating Life Workshops. The specific objectives of the service evaluation were: to assess community engagement, to understand the topics and questions raised by participants, and to examine improvements in the workshop participants' knowledge. The workshop facilitator collected anonymous data on improvement and engagement through a show of hands, and recorded qualitative data on the key topics and concerns raised by the participants through de-identified notetaking. This was a service evaluation and did not require ethical approval.

Eight workshops were held between August-October 2023. The workshops were attended by 185 participants. The participants were 96% female and 4% male. The ethnicity of participants was: Bangladeshi (55%), African (31%), Indian (4%), Iranian (4%), Fillipino (2%), Irish (5%). There were six key themes, in the topics and concerns raised by the participants about death, dying and palliative care. These were: Filial Cultures, Death is not openly discussed, Hospice is a foreign concept, Stigma within communities and pervasive institutional mistrust, Caregiving is a gendered expectation, Reflections on being a palliative care research and being a Patient Public Involvement.

The Celebrating Life workshops were effective in improving knowledge of the participants (n=185) on:

- **Palliative care and access**: 97% no knowledge before, 99% had good enough working knowledge after
- **Decision-making and advanced planning**: 98% no knowledge before, 79% had good enough working knowledge afterwards
- **Marie Curie services**: 98% no knowledge before, 90% had good enough working knowledge afterwards

Overall, the facilitator felt that facilitating the workshops was both a challenge and a privilege. The themes raised by the participants indicated major barriers to accessing palliative care. However, the workshops were effective in improving the participants' knowledge across all measures. Therefore, continuing these workshops could help to ameliorate inequity in palliative care access for people from diverse communities across North London. It is our hope that this report will positively inform Marie Curie services in North Central London and can be used in a wider context both within and outside Marie Curie to provide insight into co-design of services to meet local need.

BACKGROUND:

Marie Curie is one of the leading voices in promoting equity in palliative care. Its research is consistently underpinned by this ideal. Yet, racial inequalities have long existed within healthcare (Byrd et al., 2003). Although recognised as a fundamental obligation, equitable palliative care is affected by socio-economic inequities (Smith et al., 2022), institutional racism (Bailey et al., 2021) and systemic hierarchies (Dahlin, 2023). Patients from diverse communities are more likely to request more aggressive and life-sustaining treatments towards the end of life (Johnson et al., 2011), access emergency departments more (Brown et al., 2018), have longer hospital stays and more hospital deaths (Barnato et al., 2007), less likely to receive palliative care (Sharma et al., 2015) and have markedly less Advance Care Plans (ACP) recorded (Muni et al., 2011, Carr, 2011).

North London- Local Need:

Local area: Gospel Oak

Queen's Crescent Community Association (QCCA) is based in Gospel Oak, which is an area of high and relative multiple socio-economic deprivation, in the North London Borough of Camden. Gospel Oak has a relatively older population profile with older people aged 65+ account for 14.1% of the population (opendata.camden.gov.uk, 2020). Households Below Average Income (HBAI) local measures suggests that 30.8% of children in Gospel Oak ward live in poverty (Households Below Average Income local measures 2016, © HMRC, 2019). Gospel Oak is ranked the 8th most deprived relatively socio-economically deprived ward in London (*English Indices of Deprivation 2019, © MHCLG, 2019*).

In 2015, forty percent of people aged over 65 lived alone in Gospel Oak (Camden Neighbourhood Profile, 2015). In 2013, more than a third of the population of Gospel Oak was born outside the UK (Camden Neighbourhood Profile, 2015).

Local area - Haringey

Tottenham pensioners' group meets monthly at Tottenham Green Leisure Centre in Haringey. Figures from the Office of national statistics (ONS) report that seventeen percent of the population was income-deprived in Haringey in 2019. Of the 316 local authorities in England (excluding the Isles of Scilly), Haringey is ranked 42nd most income-deprived**.** Haringey has poorer outcomes compared to rest of London for mortality, frailty (hospital admissions for adults 65 years and over) and mental health. Fifty two percent of the population of Haringey was female in 2021, compared to forty-eight percent males for the same census. Over 50s comprised 28% of Haringey's population in 2021. In 2023, two thirds of people in Haringey are from Black, Asian, Minority Ethnic or other white ethnic groups (Haringey Public Health Report, 2023, Haringey.gov.uk). Almost half of Haringey's wards are within the most deprived wards in England – these are mostly in the east of the borough. 16% of Haringey's population are living with a long-term health condition, and nearly 6% are living with two or more long term conditions. Communities in the east of the borough have the highest diagnosed prevalence of diabetes (8%) and hypertension (13%) which are both significantly higher than the GP Federation average for these conditions (Haringey Annual Public Health Report, 2023). Cancer, heart attacks and strokes, which remain the biggest causes of death in the borough.

History of the community engagement Project:

In 2023, QC community centre ran a series of three Compassionate Cafes for the local community in Gospel Oak. Compassionate Cafes are part of Compassionate Communities UK, a community-led movement (https://compassionate-communitiesuk.co.uk). Compassionate Cafes are sometimes known as "Death Cafes", they are an informal space for people to talk about issues surrounding death, dying, life-limiting illness and bereavement. The aim of a Compassionate Cafe is to reach out to members of the community who are experiencing loss, bereavement or maybe affected by life limiting illness themselves (Richards, et al 2020).

In the original series of Compassionate Cafes at QCCA, there were engagement issues for people from minoritised ethnic groups attending the sessions. At the second and third sessions a lot of time was taken up by the need for translation into different languages. The session attendees and the translator (who is also an employee at QCCA) requested that the Research Nurse run some special sessions for them as she is multilingual in the languages of the local community. The Older People's service co-ordinator at QCCA was in agreement, and the research nurse designed a special workshop session aimed at people from minoritised ethnic groups, some of whom have limited English language proficiency.

After the first session, it was clear that the workshops were very popular and successful in engaging local people from minoritised ethnic groups. As requested by the attendees, and in consultation with the QCCA Older People's Services Co-ordinator, the Research Nurse agreed to run a series of coffee morning workshops to explore and improve minority ethnic communities understanding and engagement with palliative care, and support health literacy. Further workshops were requested in Haringey. Tottenham Pensioners' Group invited the Research Nurse to run workshops on illness, death and bereavement after hearing the Research Nurse talk about these subjects at a legacy and fundraising event at Lauderdale House in London. These workshops have been named the Celebrating Life project.

The Celebrating Life Project:

The Celebrating Life workshops are innovative community engagement workshops currently running at Queen's Crescent Community Association and Tottenham Pensioners' Group in North London UK. The workshops involve engagement with minority ethnic communities attending the Queen's Crescent Community Centre and with Tottenham Pensioners Group in North London to explore the perceptions of death, dying and bereavement of minoritised populations and the barriers that they may face in accessing palliative care and to promote the knowledge and skills that people need to make it possible to gain access to, understand, and make informed choices about end of life and after death care options.

Over a series of chai and coffee morning workshops with minority ethnic communities in local community centres, conversations, storytelling and remembrance are facilitated, to encourage reflection on what matters most in peoples' lives currently and who and what informs their treatment choices in advancing frailty and increasing symptom burden towards the end of life. Attendee's knowledge of Marie Curie as a leading end-of-life charity is ascertained, and information shared on Marie Curie services.

The aims of the workshops are:

- To enable people to engage, in an informed way, with issues of death, dying and bereavement.
- To promote death knowledge, i.e. the factual knowledge and understanding of the death system and the dying process, including what palliative and end of life care involves and who provides it.
- To facilitate confidence and ability to talk about death, dying, and bereavement with family, friends or health and social care professionals about issues like end of life wishes and care planning.

The rationale behind the workshops is based in public health literature. Improving death literacy is a key construct in public health approaches to palliative care.

1. Knowledge and understanding of palliative care impacts on access (Collins et al., 2020)
2. Agency around an individual's end of life wishes and goals of care reduces the distress facing their loved ones, who would otherwise be left to make decisions on their behalf (Silva et al., 2016)
3. Avert potential conflict between different health professionals, family members and care agencies (DOH, 2021)
4. Avert the possibility of aggressive treatments at the end of life, or death at a place that they do not wish (Prince-Paul et al., 2017)
5. Foster a whole-community approach to supporting those experiencing dying and bereavement, and thereby potentially provide community-based respite to family and informal carers who are at risk of exhaustion, poor mental health and burnout from the stress of caring (Carers NI, 2018).

The overall aim of the Celebrating Life workshops is to explore and improve people from minority ethnic communities' understanding and engagement with palliative care, knowledge of Marie Curie as a palliative care provider, and to support health literacy.

SERVICE EVALUATION METHOD:

Service evaluation overall aim

To examine and explore the effectiveness of the Celebrating Life Workshops.

Objectives

- To assess community engagement with the workshops
- To understand the different themes, topics and questions raised by workshop participants
- To examine improvements in workshop participants' knowledge about Marie Curie, palliative care and care planning.

Setting

The Celebrating Life workshops. The participants are people from minority ethnic populations living in two areas of high deprivation in North London. The workshops are held fortnightly at Queen's Crescent Community Centre from August-December 2023, and three workshops with Tottenham Pensioners' Group in June, September and November 2023.

The lead facilitator is Rekha Vijayshankar, Research Nurse. The co-facilitators are: (1.) Queen's Crescent Community Association: Mary Pierce, Older Person's Service Co-ordinator, Queen's Crescent Community Association, North London (2.) Beverley Samaroo, Secretary Tottenham Pensioner's Group, Tottenham Green Leisure Centre, North London

Sample and eligibility

Data will be collected from all workshops. There will be no sub-selection of workshops. Data will be recorded anonymously and in aggregate. Qualitative and improvement data will not be recorded on from those who do not give verbal consent and opt out at the beginning.

Data collection methods

Demographic data - To assess community engagement, quantitative aggregated anonymised demographic data will be recorded for each workshop. The facilitator will record the information in a data collection sheet at the workshop. The types of data that will be recorded are:

- Date of workshop
- Number of attendees

- Ethnicity of attendees
- Gender of attendees

Qualitative descriptive data - To understand the different themes, topics and questions discussed at the workshops qualitative data will be captured from the workshops. The facilitator will make written de-identified notes immediately after the workshops. She will capture information on the major themes and topics discussed and the kinds of questions and concerns of the participants. She will also record relevant quotes, which will be anonymous and de-identified of any personally identifiable aspects.

Improvement measure – To assess improvements in participants' knowledge and understanding. The facilitator will take a show of hands at the beginning and end of each workshop on the topics of Marie Curie services, palliative care and care planning. The number of people will noted down in a data collection sheet by the facilitator anonymously.

Data collector:

The research nurse/workshop facilitator will make detailed notes for each session and record quantitative data in the data collection sheets.

Consent:

Written informed consent is not required because the data is generalised, anonymised and aggregated. However, out of ethical practice verbal informed consent will be sought and obtained but not recorded from all attendees before proceeding. The facilitator will inform the attendees of the anonymised data she will collect and the purpose of the data collection. No qualitative or improvement data will be recorded for those who do not give consent at the start.

Ethical considerations:

Individuals displaying any signs of distress will be signposted to support from the Marie Curie wellbeing team, GP. The workshop will be temporarily suspended, and individual supported by the facilitators and Queen's Crescent Community Association staff and by Tottenham Pensioners' Group

Data Collection and Storage

Anonymised data will be collected in the form of Field-notes, images, spreadsheets, survey data. Quantitative data was collected by a show of hands. The impact of the workshops was measured by a simple show of hands at the beginning and end of each workshop. Anonymised data will be stored on a MC password protected laptop held by the main facilitator until 01 AUG 2024 A data management plan (DMP) has been created. See Appendix 1

Data analysis

Quantitative data will be analysed using Excel. Qualitative themes were drawn from field notes.

Approvals:

The NHS Health Research Authority (HRA) online decision tool called 'Is this research?' was utilised. The result was this service evaluation is not research and therefore does not require ethical approval. See attached certificate in Appendix 2.

However, approvals were sought and obtained for this service evaluation to go ahead:
Debbie Ripley, Associate Director, Strategic Partnerships and Manager, London Place (Verbal)
Dr Philip Lodge, Medical Director, Marie Curie, London Place (Verbal)
Martyn Watson, Community Engagement Manager, Marie Curie, London Place (Written)

FINDINGS:

Community engagement with the workshops:

A total of eight workshops were undertaken, from August-October 2023. Participants from both Queen's Crescent Community association and Tottenham Pensioners Group verbally agreed to an audience each with the London senior leadership team in November 2023, as a gesture of gratitude to acknowledge them for their participation and to ascertain their needs for MC service delivery in North London. Debbie Ripley, Associate Director, attended the groups on November 2nd and November 28th 2023, and were well received.

The demographics of these groups are:

Ethnicity	**No. of Participants**
Bangladeshi	101 (55%)
African	57 (31%)
Indian	7 (4%)
Iranian	8 (4%)
Fillipino	3 (2%)
Irish	9 (5%)
TOTAL	**185 (100%)**

Gender	**No. of Participants**
Male	7 (4%)
Female	178 (96%)
TOTAL	**185 (100%)**

Themes, topics and questions raised by workshop participants:

1. **Filial Cultures**: Participants told us that they were essentially filial cultures with communal decision making as a family unit. They also said that mostly these decisions were male-led, either by the father as the head of the family, or the eldest son. Views of the female members of the family were sought, acknowledged and often included in the decision making on all matters, including decisions at the end of life and ritualistic adherences after death.

2. **Death is not openly discussed:** The participants told us that death is seldom mentioned in family conversations. Death is spoken of in euphemistic terms. Terms like "When God calls" or "When the fruit is ripe, it will fall". As the facilitator further explored the symbolism of the euphemistic language for death, participants described how their religion informed the meaning and purpose behind birth, life and death. A vast majority of participants described themselves as religious, and a small number said they believed in a "Higher Power" or "Nature" and described themselves as "Spiritual, not religious". Both groups (those who called themselves religious and those who described themselves as spiritual) accepted that they cognised of death as a process informed by their religion and spirituality, although it was enacted in a bio-medical context. Participants agreed in their definition of a "good death". It had three main components: 1. Pain was well controlled 2. Family was present 3. They had completed all unfinished business (practical like making wills, or emotional like saying goodbyes, seeking and giving forgiveness) and "let go" with a "heart as light as a feather" "falling into the arms of peace, final rest". They agreed that they were not frightened of death per se, but of the process of dying and uncontrolled or poorly controlled palliative symptoms- mainly pain, nausea and breathlessness. Participants associated death with age related morbidity and frailty, and participants agreed that death in younger years or violent deaths participants were unnatural and unnecessary. There appeared to be an unacknowledged stigma against these deaths, which the participants validated. Religion informed after death practices. For example, all the Bangladeshi and Iranian participants were Muslims and wanted to be buried after death. The Indian participants were Hindus who chose to be cremated, as this was in keeping with their death rites. People from Black, African and Caribbean communities preferred to be buried in the main, although a small proportion were accepting of cremation. Fillipino participants opted for cremation. Cost effectiveness was a popular

consideration in the overarching context on religious framework informed after death rites and funerals across board.

3. **Hospice is a foreign concept**: To the vast majority of participants, the idea of a hospice was culturally alien. In these communities, death happens either at home or increasingly in hospitals. They did not understand what hospice care entailed. When the facilitator shared information about Marie Curie as a palliative care charity, she encountered pervasive mistrust of palliative care provision outside of the NHS infrastructure. Participants told us of popular assumptions in their communities like:

"You see madam, we don't know what hospice means. For us, we know hospital only. So we think dying means home or hospital. Back home poor people dying home and rich people in private ward".

"Will they allow my family to visit me in hospice? Can they stay with me? How much do you charge for a room and food. Will social service pay for my stay at Marie Curie?"

Participants were aware of the Marie Curie Daffodil, but did not know anything about Marie Curie beyond that. There was a perception that Marie Curie was not different to Macmillan Cancer care, or that it was a part of NHS like Royal Free hospital and North Middlesex hospitals (hospitals in the catchment area of the participants).

The vast majority of participants did not understand terms like care planning, DNACPR forms, power of attorney, and will making.

"We don't fill forms. We scared. So we say no I don't want care plan. Who knows what they want from us".

Language barriers and language discordant care was a major challenge, especially for the people from the Bangladeshi and Iranian populations. These populations are known to live in socio-economic disadvantage, with low literacy levels.

"My GP talk about Care plan. He say get your son to do translate. I feel ashamed I not English speaking well".

"Camden council is all online. Health information is online in English. My mother has very poor English, she could not go to school either here or back home because of how poor we were, so we have to do all her translation and filling out of forms. I can see how much she does not like that depending upon us. She would take me to see the doctor about her female problems and I would have to face the school authorities who said well your mother needs to learn English if she wants to live here".

Participants reported that language barriers made them feel "invisible", unable to advocate for their needs or their wishes. Low levels of health literacy made them access unplanned care out of fear.

"I English no good. So my daughter call 999 because we scared I am death."

"I don't know what's happening in disease (weekly dialysis). No one tell me what to expect. My BP get high. I get scared sometime. I go to A and E. I am tired like this. Death is good for me".

Participants described how they leave healthcare decisions to the clinicians, although they were doubtful that decisions had been taken in their best interest or the rationale for decision making explained to them adequately.

"When my doctor not look like me, what does he know about me. Why he care?"

"Every time I go, I see new doctor, new nurse. I get very nervous. My English no good, so I shake my head yes yes yes".

"We in our community don't think about place of care, place of death as you were saying in your talk. God's will prevails. Why should we waste time thinking about these sad things. What will be will be. If God decides I die in hospital, I am ok. He says die at home, I am fine".

4. **Stigma within communities and pervasive institutional mistrust:** A small number of Bangladeshi and Iranian participants at Queen's Crescent Community Association started a discussion on stigma within communities against certain "major health problems" like Cancer, Dementia, Mental Health Disorders (Bipolar disorder, Schizophrenia, Depression) that led to late disclosures and suffering with poorly controlled symptoms often leading to unscheduled emergency attendances and prolonged hospital admissions. As the facilitator explored this theme further with the participants at Queen's Crescent and introduced the topic for

conversations at Tottenham Pensioners Group, a robust discussion ensued. Comments like the quotes below, framed the conversation:

"We say all is good, I am good..but actually there is problem. There is disease and we will not go to the doctor. We will go to the quack, the shaman…but postpone going to the doctor".

"We don't talk about it you know. We not tell our families about our health problems. We want it to be secret".

Participants agreed that poor health literacy and poor knowledge of their health morbidities and its prognosis, fuelled misinformation on symptom control drugs further. Some participants were not convinced that opioids provided effective symptom relief as they had the lived experience of friends and family with poorly controlled symptoms or opioid associated complications like constipation.

Opioids like Morphine that are commonly used in palliative care are believed to be "evil", expediting death and to be avoided as much as possible.

"I think morphine will make death come quick. I don't want it".

"Morphine make my aunt loose so much weight and become so weak. It made her lose all her hair. She looked scary after morphine".

Participants reported experiencing systemic racism in the UK in most walks of life, but particularly in education, employment and in criminal justice system. They recalled the plight of their parents and grandparents during the colonial era and were disappointed with the treatment received by the Windrush generation.

"I don't want my body cut and my heart and liver taken out by NHS after I die, but the T NHS will pay for our bodies to be sent back home".

They recalled with pride the sacrifices made by their forefathers to the cause of the British empire, particularly during the two world wars, and bitter that trials like the Tuskegee trial were considered acceptable. Colonial memories are shared as family stories. Modern healthcare infrastructure is deemed full of cultural micro and macro aggressions.

> *"My sister had a photo of God next to her bed. The nurses say to the doctor that lady with the monkey photo next to her. My sister say they kill my soul by talking like that".*
>
> *"My nurse say you brown people always eat halal curry. Hospital food not like your food. What she mean?".*
>
> *"I ask my doctor, you speak Bengali. I understand better then. He says only at home. Here I am not allowed. I feel so sad. Why he ashamed of being Bangladeshi or what my husband say?".*

5. **Caregiving is a gendered expectation:** Participants agreed that female caregiving was the accepted norm across their communities. They discussed how caregiving was an expectation in familial structures, an extended responsibility of being in a family unit. These expectations meant that female caregivers had significantly greater levels of strain compared to male caregivers. Female caregivers described how they generally set higher standards of care provision for themselves, were more likely to have multiple dependents to care for, less likely to receive support or recognition from family and friends and were more likely to have other roles or responsibilities to maintain outside of caregiving for the dying person. Female participant all reported that they felt unprepared to manage new caregiving tasks in their family units, felt helpless when unable to control medical crises, and uncertain about their abilities to fulfil their role as a caregiver successfully.

> *"Caring very hard. It make me tired, angry, sad…I feel helpless you know. How much can family support you? They have their own lives".*
>
> *"For me continuity of care is important. They must be culturally sensitive though as my mum does not speak English very well, and they must respect our customs inside our home".*

They also reported feeling "overlooked" when others did not express appreciation for their work or did not provide an adequate amount of assistance and support. They reported deliberately withdrawing from social interactions to avoid awkward conversations with others who have not experienced caring for a person and were therefore unable to truly understand what they were going through.

Older adults and their caregivers are not averse to using technology – but helpful to keep the website/app simple to operate, and jargon free. Ideally no more than one to two clicks away to access information. Hospice at home was accepted a good idea by a majority of participants if a holistic system will address physical, psycho-socio-spiritual, and financial challenges in a culturally sensitive manner tailored to the caregivers including but not limited to support groups, respite care, education, counsellors, and financial planning.

6. **Reflections on being a palliative care research and being a Patient Public Involvement:** Participants appeared generally unaware of research in palliative care in general or that Marie Curie was the biggest charity funder for research in death and dying. None of the participants knew about the Marie Curie "Dying in Poverty campaign", nor of the current survey in palliative care priorities.

"Hey sister, you want to know my view on research. All posh people talking about us….do they really care? Ha ha ha…more like care about making a name for themselves from our problems. Big university people sit in posh conferences and shake their head …tut tut poor lonely black people and brown peoples they have "researched"….and accept awards for "great work" for us…while we live in damp and die in squalor. Has any of their research mean better care for us lot. Not really? Sorry, we are not fodder".

" My imam said some big university want your opinion on research and give you some money "for your time". I say I don't need money. I need her (facilitator) telling the truth about poor people like me and my estate peoples….not wasting time writing reports no one listens to. What they call it ..yes, campaign- campaign for them to be famous on newspaper you mean".

Quantitative Findings:

92% of participants (170 participants) described themselves as religious, and 8% (15 participants) said they believed in a "Higher Power" or "Nature" and described themselves as "Spiritual, not religious".

Of the 185 participants who attended the workshops, there were 4 District Nurses (2 from Indian community and 2 from African backgrounds).

98 % of participants (181 participants) did not have much knowledge of health infrastructure in the country.

58% of participants (108 participants) expressed an interest in the Marie Curie Wills service,

66 % of participants said that they did not discuss DNACPR forms (called "Red Form") with their families as it was "too sad" to talk about death.

97% of participants (180 participants) said they had no knowledge of research in palliative care; 3% of participants had been PPI participants themselves or known of family who had been involved in PPI.

69% of participants (128 participants) welcome a virtual hospice ward at home and thought that it was a "good idea".

Improvements in workshop participants’ knowledge about Marie Curie, palliative care and care planning.

The workshops demonstrated a significant improvement in participant knowledge across the three domains as below:

Knowledge of Palliative Care *what it is, who offers it, how to access, where to seek help and support*		Knowledge of Autonomy *what it means in palliative care decision making, knowledge of ACP*		Knowledge of Marie Curie *What are our nursing services in London, Wills service, ACP service*	
BEFORE	AFTER	BEFORE	AFTER	BEFORE	AFTER
No Knowledge 180(97%)	0	No Knowledge 181 (98%)	0	No Knowledge 181 (98%)	0
Some Knowledge 1	2 (1%)	Some Knowledge 0	39 (21%)	Some Knowledge 4	18 (10%)
Good Enough Working Knowledge 4 (3%)	183 (99%)	Good Enough Working Knowledge 4	146 (79%)	Good Enough Working Knowledge 0	167 (90%)

REFLECTION:

Limitations:

There may be a potential risk of bias as the facilitator shares the ethnic background of some of the participants. Sharing ethnic background enables insight into cultural values and norms where ethnically concordant. The facilitator sought to mitigate the bias by having a translator translate the conversation, and she made notes from the translation. There is however still some risk of bias as the translator was known to the participants and lived in Gospel Oak, as the participants.

The Research Nurse facilitating these workshops was also the person undertaking the analysis. All quotes are from her handwritten notes. This may introduce an element of bias.

The Bangladeshi community may be over-represented in the group as five of the eight works were undertaken at QCCA (with a high percentage of Bangladeshi population demographically) and three workshops were undertaken at Tottenham (there was no participant who declared their ethnicity as Bangladeshi at Tottenham).

Discussion:

Facilitating these workshops was a challenge and a privilege in the context of extant cultural taboos, lack of knowledge about Marie Curie and pervasive institutional mistrust. Yet, over time a warm and mutually trusting rapport was established which enabled the collection of rich data which can potentially inform Marie Curie service delivery, Marie Curie Research priorities, other hospices wanting to understand engagement with resource poor minority ethnic communities, and North London Commissioning bodies.

Differential access to information and services concerning disease prevention, treatment, and management is influenced by various factors, such as lower health literacy, financial barriers, limited decision-making power among women, and traditional notions of masculinity among men, all of which impact health behaviours.

Institutional mistrust that minority ethnic patients may harbour towards the healthcare system is the result of their historical and ongoing mistreatment – it is not the cause of nor the driver for racial health inequity and their disproportionate suffering. Institutional mistrust is also motivated by current and extant systemic racism and cultural micro and macro aggressions in clinician behaviour, approach, and manner.

Accessible linguistically concordant literature is helpful in building disease specific knowledge for cancer and non-cancer morbidity patients, available online, or in print at community centres, GPs, hospice helplines. Accessible linguistically concordant literature about ACP is helpful for ACP engagement. This can be made accessible when available online, or in print in community centres, GPs.

Traditional gender role norms and expectations reinforced the ideology that women were “natural” care providers. Hospital deaths imply less informal caregiver burden-esp. financial, and its effects on psycho-social and on larger family (including children). This is especially the case in the context of language barriers and its incumbent poor self-efficacy, and the consequent inability to navigate the welfare system for support.

Culturally sensitive, ideally race and/or language concordant continued uninterrupted quality care provided by caregivers who can function as a team with the family has emerged as a defining factor in care. Continuity of care was deemed very important unanimously.

In the UK, it is estimated that informal caregivers contribute to more than £67 billion pounds a year in cost savings for the NHS (Cottagiri et al., 2019). Yet, support for informal caregivers, especially for those from resource-poor minority ethnic backgrounds is scarce and ad-hoc (Veloso et al., 2016, Reigada et al., 2015, Mayland et al., 2021). Ethnic minority populations made up 60% of London population in 2023 (ONS), and (40% of population in Camden, and 67% in Haringey, were from Black and South Asian communities in 2023).

Research shows that although global majority populations (African Caribbean and South Asian communities) access primary care at the same rate as the local White British population in the UK, they are less likely to access mental health services (Livingston et al., 2001). Intra-cultural stigma against morbidities like cancer and mental ill-health undermine help seeking (Eylem et al., 2020, Kapadia et al., 2020, Knifton, 2012). Other barriers like language differences, socio- economic disadvantage and systemic racism further contribute to isolation and access to services in palliative care.

An informal, community-based volunteer led language concordant psycho-social and practical support for patient and family caregivers undergoing palliative care at home on the lines of the Kerala Neighbourhood network in palliative care can provide family caregiver support. The Neighbourhood Network Palliative Care has been evidenced to enhance medication compliance, provide better emotional support, earlier symptom identification and social and spiritual support is facilitated (Kumar, 2007).

Higginson et al., 2022, in their recent International Access Rights and Empowerment Mortality follow back study of the last 3 months of life (IARE 1) study suggest *"improving community palliative care and informal care support should be a focus for future investment".* Caregiver burden is emotionally expensive (Higginson et al., 2021), and the extant "sadly white, middle class" bereavement care provision (Selman et al., 2021) is uniquely inadequate to meet the needs of resource-poor minoritized and marginalised in the UK.

Traditional gender role norms and expectations reinforced the ideology that women were "natural" care providers. Hospital deaths imply less informal caregiver burden-esp. financial, and its effects on psycho-social and on larger family (including children). This is especially the case in the context of language barriers and its incumbent poor self-efficacy, and the consequent inability to navigate the welfare system for support.

Participants were not familiar with Advance Care Planning. They did not understand how it could help improve the quality of care received towards the end of life. The idea of care planning for end of life was not considered to be of interest to them, as they had little knowledge about it, and trusted their clinicians to deliver care that was most appropriate.

RECOMMENDATIONS:

<u>For Celebrating Life Workshops</u>:

- The Celebrating Life workshops have shown that minoritised communities in North London found the workshop engagement useful in improving their knowledge of palliative care, of care planning and of Marie Curie services. Participants described that they found the trust building with the facilitator helped them verbalise their concerns about health for themselves and their loved ones. They acknowledged that advance care planning will be useful, and that they needed support with this. They also suggested that multi-disciplinary health and social care professionals attending the workshops would be very useful in supporting them with practical matters (for example, with understanding their medication regime, supporting them with care planning, signposting to the right services to seek help from, navigating online platforms etc.). Marie Curie London Place Community Engagement team are well placed to continue with this engagement, supported by the patient and family support team (made up of from health, social care and chaplaincy professionals and volunteers).

- Share the findings from the Celebrating Life workshops amongst hospices locally and nationally, and in national conferences like Hospice UK conference.

For Marie Curie:

Building trust through regular engagement with poor minoritised and marginalised populations is vital to deliver service that is relevant and culturally appropriate. This report recommends further research into developing the role of a link worker with a view to build trust, support and advocate for health and social care needs of palliative patients and their family caregivers from resource-poor minoritised and marginalised communities, in N London. An internal small research grant application is proposed to be made in the next call (Spring ’24), to explore the role of link worker working collaboratively with multi-professional network of health, allied therapy, social care and spiritual support professionals in North London.

- Support for family caregivers in chronic health morbidity was described as very important by the participants in the Celebrating Life workshops. Literature has also evidenced the usefulness of practical and psychosocial support for patients and their family caregivers. This report recommends further exploration of models like the Neighbourhood Network in Palliative Care (Kumar, 2007) to understand how the Marie Curie Volunteer workforce may support family caregivers of palliative patients.
- Make health information on palliative care visible and easily accessible in community centers in their catchment areas, GP practices (leaflets on Will Making service and Care Planning service) and on MC website. Telephone number for Marie Curie helpline to be made available on Marie Curie literature and leaflets.

For ICB commissioners:

- To routinely collect data on the outcomes of care or people’s experience, to reflect the specific needs and preferences of people from different ethnic minorities and religions,

- To involve people in saying what is needed with patient participation groups (PPG's) in GP practices and Patient and Public Involvement Groups in research studies,
- To take an overview of all the services as a whole and how well they fit together.

CONCLUSION:

Compassionate, culturally appropriate and equitable care at the end of life is a fundamental healthcare obligation. This lens is underpinned by three core tenets of person-centred holistic care: Feeling Safe, Feeling Heard and Feeling Acknowledged. Our project with resource-poor minority ethnic and marginalised populations revealed major barriers to equity in end-of-life care for these populations. Our recommendations are facilitators to service delivery that is equitable, person-centred and culturally appropriate. It is our hope that this report will positively inform Marie Curie services in North Central London and can be used in a wider context both within and outside Marie Curie to provide insight into co-design of services that meet local need. The core question remains: "Are we equal enough for our needs to be recognised?". How we respond to the call will be the test of our commitment to equity in palliative care.

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APPENDIX 1

University of Leeds Data Management Plan (DMP) Template

Researcher Name	REKHA VIJAYSHANKAR
Project Title	CELEBRATING LIFE
Faculty	
~~KRISTAL Reference Number (if applicable~~)	
Supervisor(s) name (if applicable)	GEMMA CLARKE
Funder	NOT APPLICABLE
Scheme	NOT APPLICABLE
Research Start Date	AUG 2, 2023
Research End Date	DECEMBER 2023
Ethical review number	NOT APPLICABLE
DMP review due	

Date	Version	Author	Change notes

Please provide a brief overview of your project including proposed research methods

Title:

Celebrating Life Project.

Aim:

Promoting equity in palliative care by supporting death literacy and autonomy in decision making amongst minority ethnic populations in North London.

Objective:

Engagement with minority ethnic communities attending the Queen’s Crescent Community Centre in North London to promote the knowledge and skills that people need to make it possible to gain access to, understand, and make informed choices about end of life and after death care options.

Over a series of six workshops with minority ethnic communities in local community centres, the objective is to undertake conversations, storytelling and remembrance, to facilitate and encourage reflection on what matters most in their lives currently and who and what informs treatment choices in advancing frailty and increasing symptom burden towards the end of life.

- To enable people to engage, in an informed way, with issues of death, dying and bereavement.
- To promote death knowledge, i.e.. the factual knowledge and understanding of the death system and the dying process, including what palliative and end of life care involves and who provides it.
- To facilitate confidence and ability to talk about death, dying, and bereavement with family, friends or health and social care professionals about issues like end of life wishes and care planning.

1. What data will be produced? What data will be used from other sources?

   What digital data will you generate? Field-notes, images, spreadsheets, survey data.
   What original software will you generate? -NONE
   What third party data will you reuse?-NONE

2. Where will data be stored? How will data be structured? Include file formats and approximate volume.
   Estimate how much data you will produce over time – do you have enough storage?- DATA COLLECTED WILL BE STORED IN A LOCAL MC ENCRYPTED LAPTOP. NO ADDITIONAL STORAGE REQUIRED.
   Do you know what University storage is available and how to access it? NOT APPLICABLE
   What file formats and software will you use? MS WORD, MS EXCEL
   Do you have a logical file naming convention and directory structure? YES
   How will you use versioning so you can identify the current version of documents / data? NUMERICAL ORDERING OF VERSIONS
   How will data generated in the field be saved to safe University storage? NOT APPLICABLE

3. Access to data during the project. Give details of collaborators and any controls.

   Have you discussed data sharing with your research collaborators/ supervisor? YES
   Who needs to access data during the research? How will they access data? SUPERVISOR WILL ELECTRONICALLY ACCESS DATA THROUGH FILE SHARING VIA MC ENCRYPTED EMAIL
   Do you need a data sharing agreement? (see also section 4.) NO

4. Ethics and legal compliance: are there any ‘special’ requirements for your data? Any contractual or consent issues? Key policies (internal and external)

Have you read the University’s Information Protection Policy? Data must be assessed for sensitivity and storage in line with this policy YES
Are you familiar with the University’s advice on data protection and GDPR? YES
Does your research funder have specific data management and sharing requirements? NOT APPLICABLE
Are there other policies and protocols you need to be aware of and observe? For example, NHS codes of practice? NOT APPLICABLE
Will you anonymise your data? YES
Should some data be destroyed? When and how? ALL DATA COLLECTED WILL BE DESTROYED FROM THE MC ENCRYPTED LAPTOP ON 1 AUG 2024
How and where will you record any participant consents and/or contractual requirements which impact data management and sharing? The DMP can be a good place to record this information. VERBAL CONSENT WILL BE GAINED.

5. How will data be documented and described? Methodologies and protocols.

Will others understand your data? Write documentation. Make sure table and spreadsheet values are clearly labelled. YES
What information about data collection methodology will be recorded? VERBAL CONSENT
Is it important for the research to be reproducible? Why/why not? What additional documentation will be required? NOT A RESEARCH PROJECT. NO ADDITIONAL DOCUMENTATION REQUIRED.
Will you write software? Where will this be documented and stored for future use? NOT APPLICABLE

6. Training and support

What training do you need for data gathering, organisation, analysis or presentation? N/A
Are there relevant courses available at the University? Online? Who can provide support? SUPPORT PROVIDED BY SUPERVISOR

7. What are the plans for data sharing beyond project partners? Include justification if some of your data needs to be restricted. Include data and code. Include repository.

Have you considered reasons for and against sharing data? DATA WILL BE SHARED WITH SUPERVISOR, MC LINE MANAGER, MC POLICY TEAM, N LONDON ICB COMMISSIONERS
Will data be openly available to everyone or will there be access restrictions? ANYONE OTHER THAN THOSE MENTIONED ABOVE WILL NEED TO SEEK WRITTEN PERMISSION FROM THE SUPERVISOR AND THE RESEARCH NURSE. DECISION TO SHARE WILL BE MADE ON A CASE BY CASE BASIS WITH DISCUSSION BETWEEN THE SUPERVISOR AND THE RESEARCH NURSE
If your research involves people, have you obtained appropriate consent for data sharing? YES VERBAL CONSENT WILL BE OBTAINED

Can your data be released immediately, or should you embargo (delay access to) the data? DATA WILL BE RELEASED TO THIRD PARTIES AFTER CONSULTATION BETWEEN SUPERVISOR AND RESEARCH NURSE

How long will / should data be available ? UNTIL JULY 31, 2024

Will you use a data repository? Which one? Are there subject specific data repositories in your field? NOT APPLICABLE

8. What Intellectual Property will be generated? How will IP be protected and exploited?

Will you be applying for a patent? NO

Will your research have commercial applications? NO

Do you need to contact the Commercialisation team in the Research and Innovation Service? NO

Have you read the University Intellectual Property Policy? YES

9. Who is responsible for managing the data? What resources will you need?

Who is responsible for data at different stages in its lifecycle? RESEARCH NURSE

On projects with complex data management requirements, different types of role should be specified. NOT APPLICABLE

How will best practice and guidance be shared across the project partners? DISSEMINATION OF RECOMMENDATIONS TO INTERNAL STAKEHOLDERS WITHIN MC AND COMMUNITY STAKEHOLDERS

Are sufficient resources (skills, people, storage, technology) available to deliver your plan? YES

10. Ongoing data curation / data housekeeping - you may find it useful to include a retention table

What data will you keep? Who decides? NO. OF ATTENDEES, GENDER, ETHNICITY, ANONYMISED COMMENTS . DECISION MADE THROUGH MUTUAL DISCUSSION BETWEEN RESEARCH NURSE AND SUPERVISOR

Where will data be kept and for how long. ON MC ENCRYPTED LAPTOP UNTIL 31 JULY 2024

Who needs to know what data exists on the network, where it is, how it should be managed and how long it should be retained? RESEARCH NURSE AND SUPERVISOR

End of Project

At the end of a project and/or before you leave the institution, you should ensure that data and research materials are deposited with the School or a trusted data repository and documented in such a way that they can be found and understood.

Dataset name	Location	Person responsible

University of Leeds Data Management Plan (DMP) Template: Prompt Sheet

1. What data will be produced or used? (Including original software)

- ☐ What physical data will you study? (e.g. artefacts, samples, paper archives, etc.)
- ☐ What digital data will you generate? (e.g. field-notes, images, spreadsheets, audio interviews, survey data, annotated bibliography, etc.)
- ☐ What original software will you generate?
- ☐ What third party data will you reuse?

2. Where will data be stored? How will data be structured?

- ☐ Estimate how much data you will produce over time – do you have enough storage?
- ☐ Do you know what University storage is available and how to access it?
- ☐ What file formats and software will you use?
- ☐ Do you have a logical file naming convention and directory structure?
- ☐ How will you use versioning so you can identify the current version of documents / data?
- ☐ How will data generated in the field be saved to safe University storage?

3. Access to data during the project. Give details of collaborators and any controls.

- ☐ Have you discussed data sharing with your research collaborators/ supervisor?
- ☐ Who needs to access data during the research? How will they access data?
- ☐ Do you need a data sharing agreement? (see also section 4.)

4. Ethics and legal compliance: are there any ‘special’ requirements for your data?

- ☐ Have you read the University’s Information Protection Policy? Data must be assessed for sensitivity and storage in line with this policy https://it.leeds.ac.uk/it?id=kb_article&sysparm_article=KB0011140
- ☐ Are you familiar with the University’s advice on data protection and GDPR? https://dataprotection.leeds.ac.uk/
- ☐ Does your research funder have specific data management and sharing requirements?
- ☐ Are there other policies and protocols you need to be aware of and observe? For example, NHS codes of practice?
- ☐ Will you anonymise your data?
- ☐ Should some data be destroyed? When and how?
- ☐ How and where will you record any participant consents and/or contractual requirements which impact data management and sharing? The DMP can be a good place to record this information.

5. How will data be documented and described? Methodologies and protocols.

- ☐ Will others understand your data? Write documentation. Make sure table and spreadsheet values are clearly labelled.
- ☐ What information about data collection methodology will be recorded?
- ☐ Is it important for the research to be reproducible? Why/why not? What additional documentation will be required?
- ☐ Will you write software? Where will this be documented and stored for future use?

6. Training and support

☐ What training do you need for data gathering, organisation, analysis or presentation?

☐ Are there relevant courses available at the University? Online? Who can provide support?

7. What are the plans for data sharing beyond project partners?

☐ Have you considered reasons for and against sharing data? Will data be openly available to everyone or will there be access restrictions?

☐ If your research involves people, have you obtained appropriate consent for data sharing?

☐ Can your data be released immediately, or should you embargo (delay access to) the data?

☐ How long will / should data be available for?

☐ Will you use a data repository? Which one? Are there subject specific data repositories in your field?

8. What IPR will be generated? How will IPR be protected and exploited?

☐ Will you be applying for a patent? Will your research have commercial applications? Do you need to contact the Commercialisation team in the Research and Innovation Service?

☐ Have you read the University Intellectual Property Policy? http://ris.leeds.ac.uk/downloads/download/600/university_of_leeds_ipr_policy

9. Who is responsible for managing the data? What resources will you need?

☐ Who is responsible for data at different stages in its lifecycle?

☐ On projects with complex data management requirements, different types of role should be specified.

☐ How will best practice and guidance be shared across the project partners?

☐ Are sufficient resources (skills, people, storage, technology) available to deliver your plan?

10. Ongoing data curation / data housekeeping - you may find it useful to include a retention table

☐ What data will you keep? Who decides?

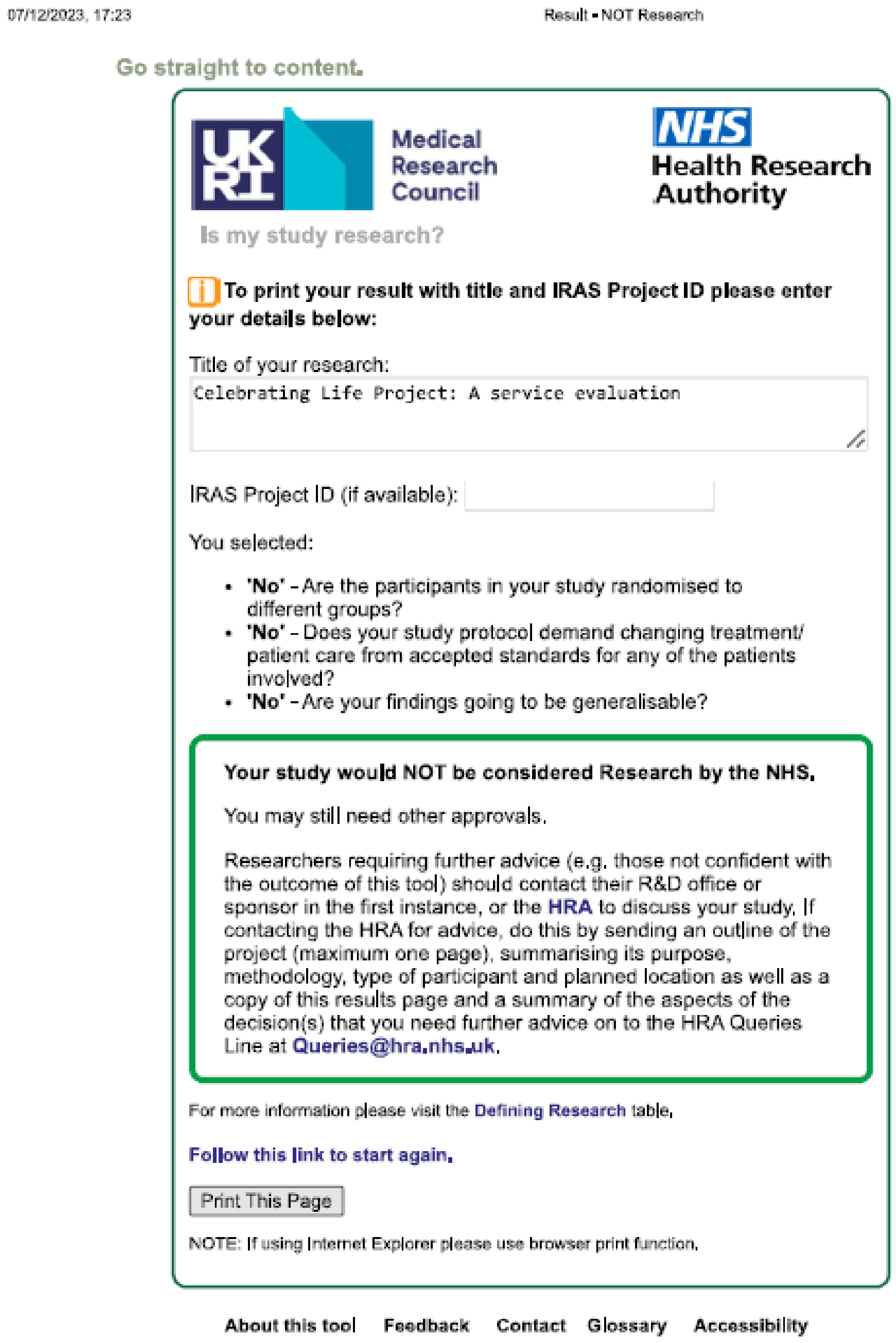
☐ Where will data be kept and for how long.

☐ Who needs to know what data exists on the network, where it is, how it should be managed and how long it should be retained?

Don’t forget to review and update your data management plan regularly

But I don’t have any data! *Anything can become research data if it is used for research purposes – data is not just numbers on a spreadsheet. Think creatively about the materials you are using and producing: what could be shared with other researchers who are interested in your work; what could be reused to produce new insights? Any evidence or material which underpins or sheds light on your findings, your academic publications, your thesis or your project can be considered research data.*

APPENDIX 2



Is my study research?

To print your result with title and IRAS Project ID please enter your details below:

Title of your research:

`Celebrating Life Project: A service evaluation`

IRAS Project ID (if available):

You selected:

- **'No'** - Are the participants in your study randomised to different groups?
- **'No'** - Does your study protocol demand changing treatment/ patient care from accepted standards for any of the patients involved?
- **'No'** - Are your findings going to be generalisable?

Your study would NOT be considered Research by the NHS.

You may still need other approvals.

Researchers requiring further advice (e.g. those not confident with the outcome of this tool) should contact their R&D office or sponsor in the first instance, or the **HRA** to discuss your study. If contacting the HRA for advice, do this by sending an outline of the project (maximum one page), summarising its purpose, methodology, type of participant and planned location as well as a copy of this results page and a summary of the aspects of the decision(s) that you need further advice on to the HRA Queries Line at **Queries@hra.nhs.uk**.

For more information please visit the **Defining Research** table.

Follow this link to start again.

NOTE: If using Internet Explorer please use browser print function.

APPENDIX 3

Workshop Plan:

Fortnightly workshop at Queen’s Crescent Community Association

At Tottenham Pensioner’s Group, this plan was condensed to topics on Workshops 1 and 2 held in August 2023, topics on Workshops 3 and 4 discussed in September 2023, and topics in Workshop 5 discussed in October 2023.

Workshop 1:

- Introducing Palliative Care
- Introducing Marie Curie
- Exploring cultural and religious norms surrounding death and dying (how death and dying is perceived, how death and dying are spoken about, last rites)

Workshop 2:

- Exploring “What Matters to you” in increasing frailty
- Exploring understanding of and access to local health systems in the context of illness and advancing frailty.

Workshop 3:

- Exploring understanding of Care Planning (Introducing the topic)
- Exploring engagement with Care Planning (Perceptions of care planning in minority ethnic communities)

Workshop 4:

- Exploring cultural frameworks that inform engagement with autonomous health decision making?
- What do I worry about?
- Who do I take my worries to?
- Who are the important people I would like to know about my health and be involved in decisions about my health?

Workshop 5:

- Where would I like to die?
- What is most important to me in the final days of my life?
- After death: How would I like my body to be treated? Buried or Cremated

APPENDIX 4:

Feedback collected with a show of hands, before and after each workshop on the following questions :

1. Knowledge about MC (who we are, what we do in the hospice and in the community)
   (Previous knowledge likert scale 0-3: 0= No knowledge; 1=Some knowledge; 2=Fair knowledge; 3= Full knowledge)

2. Knowledge about palliative care (what it is, what it is not)
   (Previous knowledge likert scale 0-3: 0= No knowledge; 1=Some knowledge; 2=Fair knowledge; 3= Full knowledge)

3. Knowledge about care planning
   (Previous knowledge likert scale 0-3: 0= No knowledge; 1=Some knowledge; 2=Fair knowledge; 3= Full knowledge)