Evaluation -

North East London Advance Care Planning

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May 2022

Table of Contents

Thanks to the families and carers who willingly shared their experiences, along with Lynne MacInnes, Adenike Akinbami and the rest of the Marie Curie team for their support with this evaluation.

1. Background

1.1 What is ‘Coordinate My Care’?

Coordinate My Care (CMC) was developed at London’s Royal Marsden hospital as a way of recording an individual’s end-of-life care wishes, ensuring these wishes are at the centre of their medical care. Although end-of-life services are usually only provided in the final year of a person’s life, launch of the CMC service provided a new vehicle for capturing end-of-life wishes and offering advanced care plan decisions to be documented by more people, not only those with a terminal diagnosis. Furthermore, launch of the platform facilitated sharing of these advanced care plans across the London health system, ensuring these were at the centre of both planned and unplanned care.

“[Patients] can express the issues that make the difference - to them.”

-Marie Curie Nurse

Coordinate My Care enables patients to work with their care providers – usually their GP – to discuss and record their wishes and enable those plans to be shared with urgent care providers, during the ‘out-of-hours’ period when urgent care may be required. It does this through a web-based interface that asks essential questions about their care, including their medical needs, as well as their preferences for any social, nursing, spiritual, and cultural needs. At all times the patient can review their plans on their smartphones.

Once a CMC urgent care plan is created, care providers such as their GP’s out-of-hours provider, 111 or the ambulance service will automatically be alerted that the

patient has an urgent care plan and can treat accordingly[1]. Updates can be made by the patient, their family or care staff by contacting the GP for them to make the amendments.

The service is increasingly popular and effective:

- The number of people with an active CMC plan has increased from 16,593 in 2018 to over 39,566 in 2021[2].
- 77% of people with a CMC plan achieve their preferred place of death[3]. Nationally 49% of people die at their usual place of residence[4].
- 21% of people with a CMC plan died in hospital, compared with 47% nationally[5].
- CMC state their plans save London Clinical Commissioning Groups (CCG) £2,100 per patient[6].

1.2 CMC Decommissioned

Despite its relative success, CMC was unsuccessful in tendering for a London regional contract extension and as a result was decommissioned on 31st March 2022. Following a competitive tender process, the pan-London Strategic Commissioning Group selected 'Better' to provide the technical infrastructure to co-

[1] https://www.intersystems.com/uk/resources/detail/coordinate-care-enabling-patient-choice-matters/

[2] https://www.coordinatemycare.co.uk/downloads/cmc-impact-annual-report-2021.pdf

[3] https://www.coordinatemycare.co.uk/downloads/cmc-impact-annual-report-2021.pdf

[4] https://www.nuffieldtrust.org.uk/resource/end-of-life-care#background

[5] https://www.coordinatemycare.co.uk/downloads/cmc-impact-annual-report-2021.pdf

[6] https://www.coordinatemycare.co.uk/downloads/cmc-impact-annual-report-2021.pdf

create and further develop urgent care plans across London and replace CMC[7]. 'Better' was due to go live across London on 1 April 2022, with existing CMC care plans migrated onto the new system.

1.3 Covid-19 Demonstrates a Clear Need for Quality Advanced Care Plans

By April 2020, during the first wave of the Covid-19 outbreak, deaths in the UK had doubled compared to the previous 5-year average[8]. The rapid uptick in mortality as a result of the pandemic created concerns around the risk of 'blanket' Do Not Attempt Resuscitation (DNAR) decisions in the face of such significant challenges and pressures. In fact, around this time, the Care Quality Commission wrote[9] to adult social care providers and GP practices with a statement alongside the British Medical Association, Care Provider Alliance and Royal College of General Practitioners:

> 'THE IMPORTANCE OF HAVING A PERSONALISED CARE PLAN IN PLACE, ESPECIALLY FOR OLDER PEOPLE, PEOPLE WHO ARE FRAIL OR HAVE OTHER SERIOUS CONDITIONS HAS NEVER BEEN MORE IMPORTANT THAN IT IS NOW DURING THE COVID 19 PANDEMIC…SUCH ADVANCE CARE PLANS MAY RESULT IN THE CONSIDERATION AND COMPLETION OF A DO NOT ATTEMPT RESUSCITATION (DNAR) OR RESPECT FORM. IT REMAINS ESSENTIAL THAT THESE DECISIONS ARE MADE ON AN INDIVIDUAL BASIS…IT IS UNACCEPTABLE

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[7] https://www.swlondon.nhs.uk/ourwork/connectingyourcare/urgent-care-planning-application/

[8] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregisteredweeklyinenglandandwalesprovisional/weekending14january2022

[9] https://www.cqc.org.uk/news/stories/joint-statement-advance-care-planning

> FOR ADVANCE CARE PLANS, WITH OR WITHOUT DNAR FORM COMPLETION TO BE APPLIED TO GROUPS OF PEOPLE OF ANY DESCRIPTION. THESE DECISIONS MUST CONTINUE TO BE MADE ON AN INDIVIDUAL BASIS ACCORDING TO NEED.'

Although in some places, decisions about DNAR were suboptimal[10], work quickly began at a national and regional level to mitigate for this. The aims were to maintain quality of care and ensure that patient wishes remained central to end-of-life planning and care. More than 27,000 CMC care plans were uploaded between March and September 2020, with 90% including evidence of discussion and decision on CPR, compared to 88% pre-Covid-19[11]. While this might not seem like a significant increase, this occurred in the context of a rapidly evolving pandemic and more limited resource to engage with patients and families. The pandemic demonstrated the importance of digital advanced care planning, with the ability to share this data effectively and efficiently across multi-agencies involved in providing care.

1.4 Marie Curie adapts to Covid-19

Marie Curie is an end-of-life care charity that supports people with advanced serious illness. Marie Curie nurses provide home care for thousands of people with terminal illnesses across the UK every year. The nurses also provide practical and emotional support for families and carers. Marie Curie provides the largest number of hospice beds outside the NHS.

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[10] https://www.cqc.org.uk/publications/themed-work/review-do-not-attempt-cardiopulmonary-resuscitation-decisions-during-covid

[11] https://www.coordinatemycare.co.uk/wp-content/uploads/2021/02/Use-of-DNAR-in-the-first-wave-COVID-19.pdf

Marie Curie was commissioned to support with end-of-life planning during the peak of the Covid-19 pandemic through working with patients, families and care givers to complete and update CMC care plans. Due to shielding and social isolation guidelines at the time, the standard practice of visiting patients in their homes to undertake care planning was impossible. Marie Curie responded by rapidly moving to a remote service model in March 2020. Staff conducted conversations with patients and families via telephone and video and used various remote technologies to communicate with relevant health professionals and other stakeholders.

2. Marie Curie's BHR ACP Service

2.1 Establishing an Advance Care Planning Service in BHR

In March 2021, Barking, Havering and Redbridge (BHR) CCG commissioned Marie Curie to build on successful implementation in other areas of London and deliver a remote Advance Care Planning (ACP) Service across BHR. This was partly driven by increasing concern across BHR regarding low uptake of CMC and poor quality of completion, particularly within care home settings (0.32% of people living with a CMC plan compared with 0.52% London-wide[12]). National targets set for 2020/21 and 21/22 to increase completion of ACPs within care homes meant there were both internal and external drivers to improve utilisation of CMC. The anticipated benefits of delivering this service were:

- Releasing clinical time - through reducing demand on GPs and other health professionals who would otherwise be asked to initiate and complete ACPs for their population
- Ensuring better uptake of CMC as a tool for ensuring more people who need it have an ACP
- Improved outcomes for patients and families - for example ensuring more people are able to die at their chosen place of death
- Greater understanding about the successes and limitations of a remote clinical support model for completion of ACPs in BHR

[12] CMC Commissioner extract April 2021 figures

- The service may also provide support and advice on best interest assessments.

2.2 Delivery Model

The project launched as a 7-month service in May 2021 due to conclude in December 2021. The BHR advance care planning model was a nurse-led service (see Appendix C for the job description) with the majority of nurse time dedicated to creating or updating an ACP.

The model (Figure 1) accepted referrals from GPs for people living in care homes. If an informal referral came from any other source, then it would be highlighted to the GP for a formal referral. Once a Marie Curie nurse reviewed the referral, they would make contact with the care home to access further information and to arrange a remote interview.

Once an ACP was completed, it would be quality checked and published by a GP. The expected total time taken to create or update an ACP is between 2 and 2.5 hours.

The Clinical Nurse Manager was expected to audit at least 10% of records internally, to ensure completeness of the records, feedback as to the nurse's views of stakeholder relationships for each audited file, and an assessment of the Clinical Nurse Manager's view of the content quality. The Clinical Nurse Manager was also expected to hold supervision meetings with the end-of-life team, along with regular team meetings.

If a patient lacked mental capacity to give consent to the process, then the service would work with the patient's family member or advocate who holds a Lasting Power

of Attorney (LPA). This process is guided by previous work and research developed by Marie Curie and partners[13].

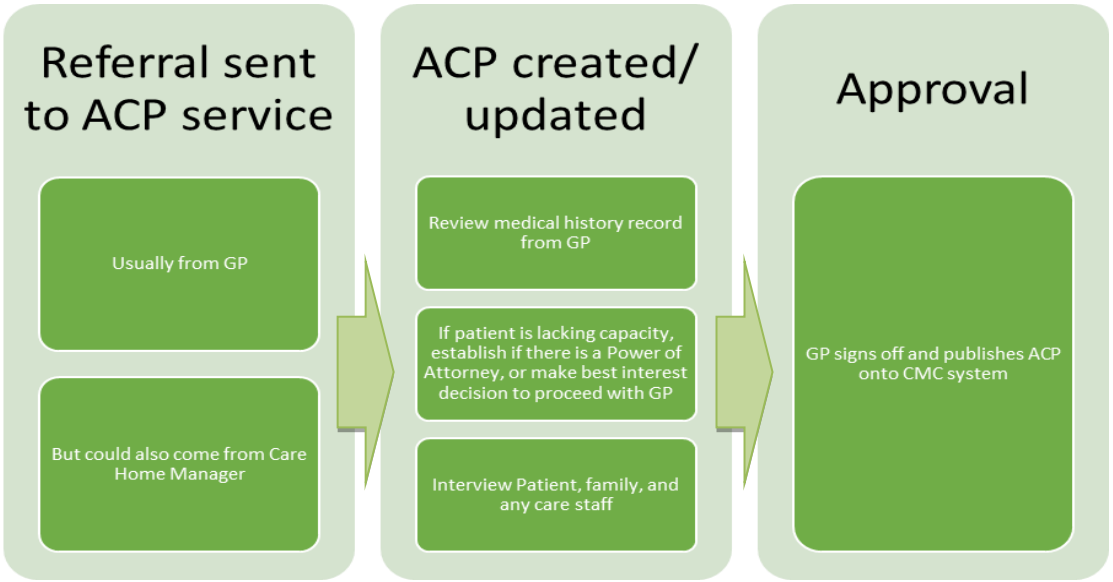

Figure 1. The BHR ACP Service process

2.3 Equipping Staff to Work Remotely

As this is still a relatively new model for Marie Curie, the charity took steps to ensure that staff were equipped and trained to conduct ACPs remotely and had internal support structures in place. For example, Marie Curie's Health and Safety Lead completed a remote desk station assessment for each remote worker, providing staff with an appropriate laptop computer, monitor and webcam, office chair and desk as well as a phone and headset. Staff were also provided with an NHS mail account so they could view medical records securely.

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[13] Including research reports such as 'Rules of thumb: end of life care for people with dementia': http://www.yhscn.nhs.uk/media/PDFs/mhdn/Dementia/Bulletin/2021/January%202021/F427a%20Rule%20of%20thumb%20dementia%20guideV7.pdf

CMC provides users with 10 hours of online training. The clinical nurse manager would provide a digital introduction to CMC to nurses who had not used it before and CMC reception staff would provide access to the CMC system. Marie Curie provides internal CMC support and has an extensive training programme which takes 22 hours to complete. Full breakdown of training is included in Appendix A.

3. Evaluating the Service

3.1 Evaluation Partner

Care City is a non-profit Community Interest Company co-founded by the London Borough of Barking & Dagenham and North-East London Foundation Trust. Its mission is to create a happier, healthier older age for East Londoners. Care City delivers its mission through research, innovation and workforce development working with partners across North East London.

3.2 Methodology

Care City was asked by Marie Curie to undertake an independent, pragmatic evaluation of their delivery of Coordinate my Care (CMC) as part of their Advance Care Planning service in BHR during the period of May 2021 to January 2022.

The objectives of this evaluation are to explore and understand:

- the implementation of CMC processes within BHR
- the impact of the service on patients, nursing and primary care staff
- the key successes and challenges of the project
- the potential for scaling up the project beyond the initial seven months.

Care City will draw on previous Marie Curie Advance Care Planning evaluation reports and frameworks to complete a mixed-methods evaluation, drawing on both qualitative and quantitative data. Qualitative data is derived from semi-structured interviews with Marie Curie staff and service stakeholders and quantitative data was provided by CMC and the Marie Curie data team. Overall, this included the

following, undertaken between January and April 2022:

- Desktop research into CMC, its application during the Covid-19 outbreak, rapid service development within Marie Curie in response to Covid-19
- 4 Interviews with Marie Curie service staff
- Review of Marie Curie role profiles and training logs
- Review of quantitative BHR ACP service data
- Review of internal BHR ACP service audit
- Review of quantitative CMC data
- 7 Interviews with service stakeholders

The evaluation only looked at the BHR service and other Marie Curie remote ACP services were considered out of scope.

4. Findings

This section will present the key findings from the quantitative project data provided by CMC and Marie Curie, along with a summary of key qualitative themes which emerged from interview data.

Quantitative data provided from CMC and Marie Curie included:

- CMC Commissioners Extract evaluation report - These are a series of 6 worksheets of CMC statistical data, divided geographically per local authority, from April 2021 to February 2022 published at the request of various commissioners.
- Marie Curie BHR ACP service anonymised referrals spreadsheet.
- Marie Curie BHR ACP service anonymised audit spreadsheet.

To triangulate quantitative data and explore some issues at further depth, a number of semi-structured, qualitative interviews were undertaken towards the end of the service and after service completion. A number of important themes emerged from interviews with:

- Marie Curie BHR ACP staff, including one manager and three nurses
- 2 BHR Care Home managers
- 2 BHR GPs
- 5 Family members of those who received support from the BHR ACP service

4.1 Key Findings - Quantitative Data

- The number of people in BHR with a CMC plan increased:
    - In total population (827,384) from 2926 to 3120 (0.02%)
    - In care homes from 1516 to 1606 (5.9%)
- 191 out of 259 (75%) of the referrals to the service resulted in a published CMC plan, with the majority of those not completed due to receipt outside of the contracted service period
- The length of time to complete a CMC plan was consistent, taking 4.2 hours to complete the plan.
- Extrapolating the CMC financial savings model results in estimates of around £242,200 savings for the CCG. For every £1 spent on the service the CCG saved £6.92
- When the service ended, the average monthly number of people who died with a CMC plan recording their preferred place of death increased from 14.3 to 16 (11%).

4.1.1 Numbers of CMC Plans in BHR

Sadly COVID-19 resulted in a high number of deaths in care homes, and new patients struggled to gain access to quarantined homes.[14] The majority of COVID-19 related deaths occurred in 2020/21. Due to this rapid increase in demand, GPs were encouraged, at a national level and for a defined time period to focus intense

[14] https://www.nuffieldtrust.org.uk/news-item/covid-19-and-the-deaths-of-care-home-residents

resource on ACP. This created a spike in the 2020/21 figures. As GPs withdrew resource from ACP and returned to their normal work, this also contributed to lower ACP figures for 2021/22.

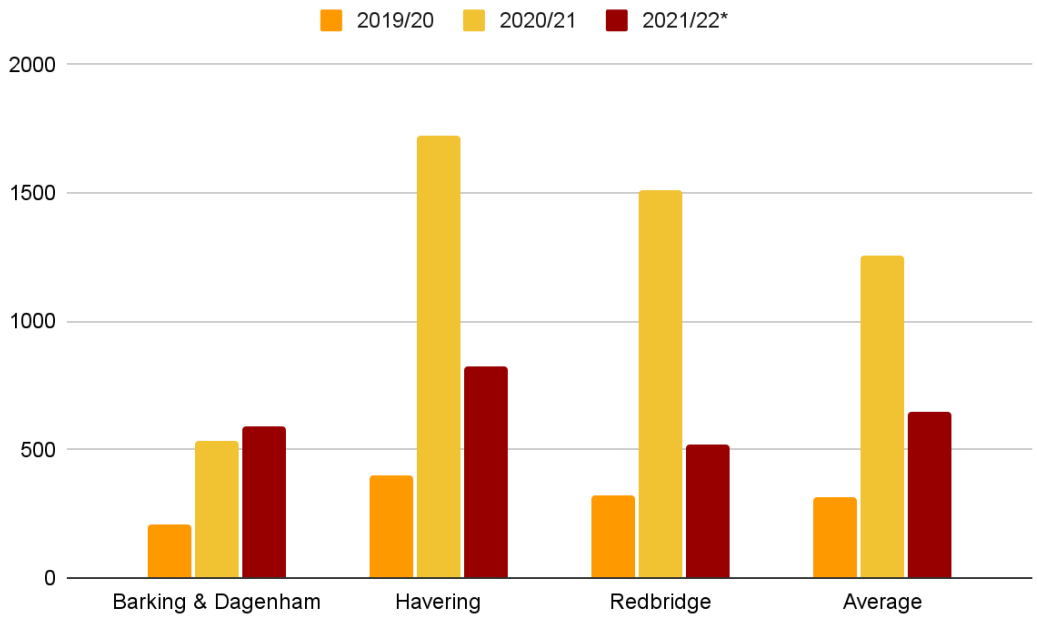

Figure 2. The number of published CMC in BHR over the past 3 years

**2021/22 was not complete when figures taken, information for this year to Feb 22*

Figure 2 shows that if we take 2019/20 as a benchmark for 'normal' ACP rates, and consider 2020/21 as an outlier due to the reasons above, there was a noticeable increase in 2021/22 (106%) in published CMC plans in BHR. Given that this aligned with the implementation of the Marie Curie service, this could be a result of the service implementation.

There are a number of services, mainly GPs, who along with the Marie Curie BHR ACP service completed CMC plans. From May 2021 to February 2022 the number of people in the total population of BHR (827,384) with a CMC plan increased from 2926 (0.35%) to 3120 (0.37%).

Most people with CMC plans are living in care homes. There are several factors that affect how many people have a CMC plan in a care home, especially as so many are near the end of their life. But overall, during the delivery of Marie Curie's BHR ACP Service, the number of people with a CMC plan went up (Figure 3) from an average of 502 people per borough to 533 people per borough (6.2% increase in the area). This is potentially even more significant given the decrease in numbers of people living in care homes after Covid-19 due to the high mortality inflicted by the pandemic.

Havering presented a slightly different picture, in that the numbers reduced by the end of the delivery period. However, this may be related to the fact that it became widely known that CMC was being decommissioned which meant some local teams felt it may not be worth investing time into updating CMC plans.

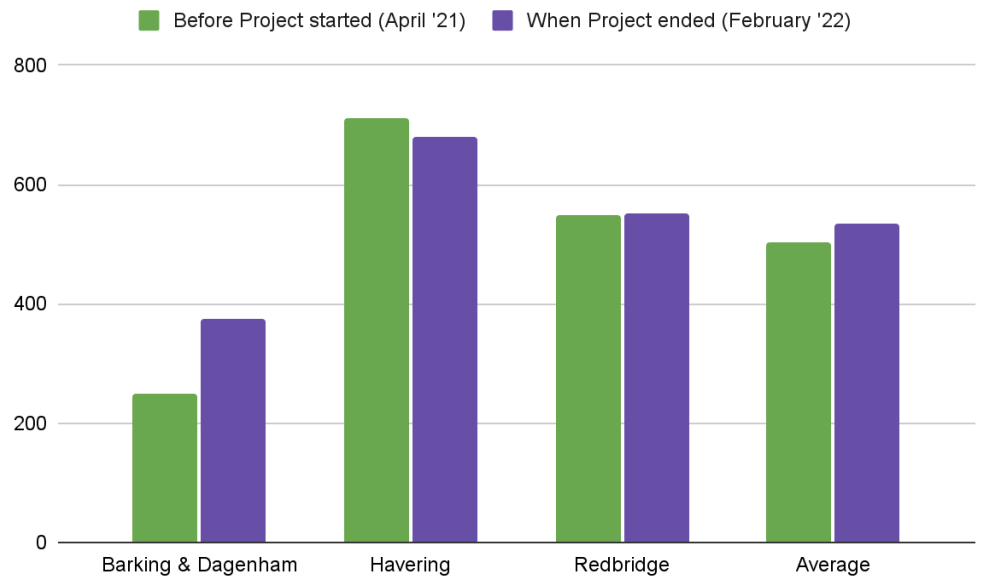

Figure 3. The number of people in a care home with a CMC

4.1.2 Referral Numbers

The BHR ACP Service received **249** referrals during its 10 months of operation. A total of 191 (76.7%) of referrals resulted in the creation or update of an ACP:

- 132 were created (53%)
- 59 were reviewed (23.7%)
- 58 were incomplete (23.3%)

Of the 191 referrals that resulted in a created or reviewed CMC plan, 187 (98%) were published by GPs. Reasons for failures to publish included the death of a patient between the creation of the plan and when it was published (1 referral), and GP delays (3 referrals). The BHR ACP is still chasing the GPs to publish these three outstanding CMC plans, and the delay seems to be down to GP workload, rather than an issue with quality of the plan.

The reasons for the 58 incomplete referrals included:

- 31 patients were referred after the service had used its budget (53.4%)
- 13 patients did not have a GP to approve the plan (22.4%)
- 8 patients died before the plan could be completed (13.8)
- 6 patients were transferred to: another care home; hospital; their home; or an unknown location (10.4%)

Those which were incomplete due to referral after the service was ending would have been returned to the referrer. However, inevitably some time cost was incurred in administering these incomplete plans.

4.1.3 Referral Rates

The BHR ACP service worked with 5 GP Clinical Leads who supported 6 care homes across BHR. There was a mixed level of referral rates received from each of the GP Clinical Leads (Figure 4). This might be due to the varying number of patients each GP is responsible for, or the level of engagement with the BHR ACP service. It's worth noting that GP 4 sent just 1 referral but took the longest time (115 days) to publish the report once they had received it, compared to GP 5 who sent the largest number of referrals but was 10.4 days below the average length of time to publish a CMC. It could be inferred that referral rates may be closely linked to engagement levels from the GP.

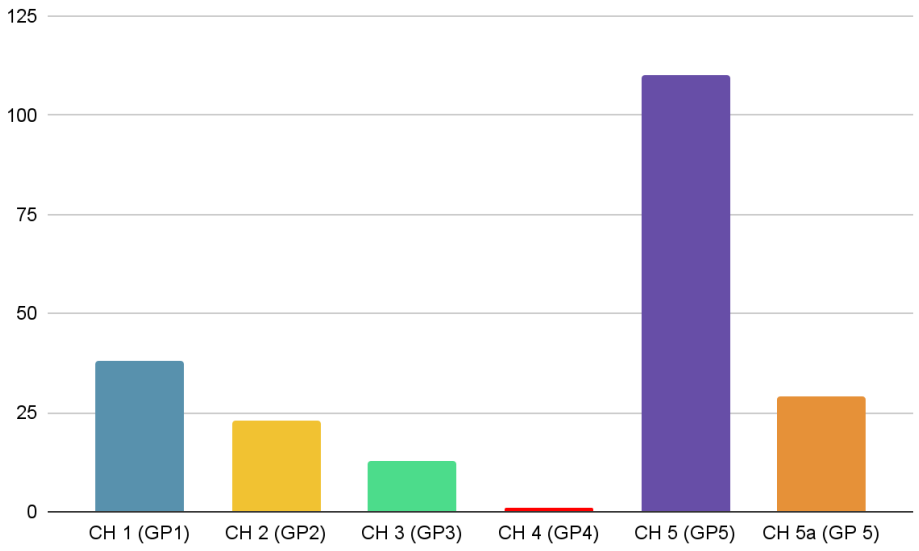

Figure 4. The number of CMCs per Care Home (CH) and GP by BHR ACP Service

South West London (SWL) commissioners were able to provide direct contact details for GPs to the SWL service. This reduced administration and ensured effective communication lines between the ACP nursing team and primary care staff. Unfortunately, this could not be provided by BHR. Therefore, the administration

burden of identifying GP contact names and contact details fell to the Marie Curie team. This took a significant amount of time and the Marie Curie team faced a number of challenges with GP engagement which is expanded upon in more detail later in this section.

4.1.4 Referral to completion timeframes

Referrals were received over a five-month period from May to October 2021, with a peak in July 2021 (Figure 5). The first CMCs were created/reviewed by June 2021, a month after the service began, and continued at a fairly consistent rate until December when the project ended. CMCs were published by GPs in a tentpole fashion, with peaks in July 2021, October 2021 and February 2022, which seems to have been to fit around the schedules of the GPs.

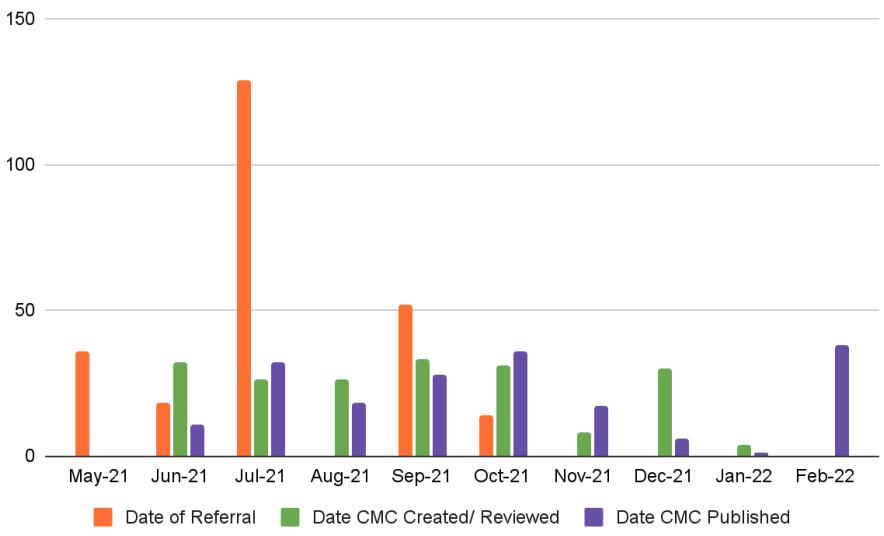

Figure 5. The timeline of how referrals were handled at BHR ACP Service

Regardless of which nurse was completing the CMC plan or their workload, the time taken to complete the plans remained fairly consistent, with an average of 4.2 hours (Figure 6) taken to complete a CMC plan (with a standard deviation of 1.7 hours),

taken over an average window of 10.6 weeks (with a standard deviation of 3.9 days). This is longer than the 2.5 hours estimated when creating the model for the service.

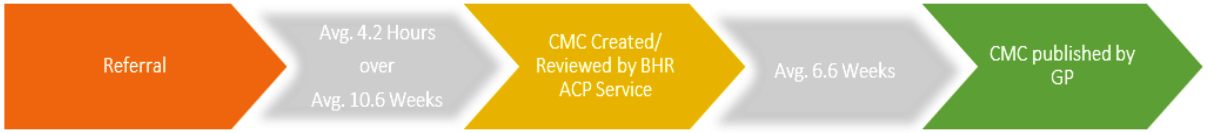

Figure 6. The average time taken to complete the stages of a CMC in BHR

There also does not appear to be a significant difference between the length of time taken to complete a newly created CMC plan (4 hours 30 mins) compared to updating and reviewing an existing CMC plan (4 hours 24 minutes).

Factors Influencing Timeframes

The most significant determinant of the length of time from referral to publishing ACPs was the time taken to access data and communicate with care homes, primary care teams and family. This was related to several issues, firstly, BHR ACP staff reported that reviewing and extracting relevant information from the medical notes was the lengthiest element of the process. Where patients had been placed in a care home during the Covid-19 outbreak then it was also possible that the local GP had no record or little record of them, which would prolong the time taken to access and review their medical history. Typically, staff said it would take GPs 2 to 3 days to respond to any requests they made for additional information or approval of the report. For many patients, Marie Curie staff needed to make more than one request to the GP for further information, further prolonging the time from receipt of referral to successful initiation of the plan.

Secondly, BHR ACP service staff were unable to access care home records directly, as many were in a paper form located on-site. Instead, they would have a brief interview with the care home manager or care workers. This could present a

challenge as care staff found it difficult to be available to support the process or to discuss new residents they did not know. Marie Curie staff also reported that, due to the restrictions of the pandemic, it took a long time to contact care home staff via telephone simply because of the large volume of calls they were receiving from professionals and families.

A further factor influencing referral timelines was the fact that decisions made for those lacking capacity had to be made with a person holding an LPA, and these powers had to be verified through the Office of the Public Guardian (OPG), which would take between 3-10 days. There are 2 types of LPA: 1) health and welfare and 2) property and financial affairs. Staff reported that at times this created confusion for family members who held an LPA for property and financial affairs but not for health. If no one was available with a relevant LPA then the service would ask for a capacity assessment and best interest decision to proceed as outlined in the Mental Capacity Act 2005[15].

Language and family support also emerged as key issues impacting timeframe, these are explored further in section 4.2.4.

4.1.5 Preferred Place of Death

A primary focus of CMC plans is to ensure that patients are able to die in their preferred location. As such, the completion of the preferred place of death section within a CMC plan and supporting patient's wishes around this is one proxy measure of success of CMC implementation. Nevertheless, this section is the element of CMC plans most frequently incomplete. This may be related to the rapid changes occurring in the final year of life and the fact that this is often a challenging section to

[15] https://www.scie.org.uk/mca/practice/best-interests

discuss with patients, with patient reluctance often cited as a key reason for this section remaining incomplete.

Figure 7 shows how many people died with a CMC record that contained their preferred place of death. The numbers are below 30 people per month, with a snapshot at the beginning and at the end of the service. During the delivery period of the BHR ACP service, Havering had the large change from beginning to end with a rise from 20 to 28 in deaths of patients who had specified their preferred place of death on their CMC plan. The proportional view over time is recorded in Figure 8.

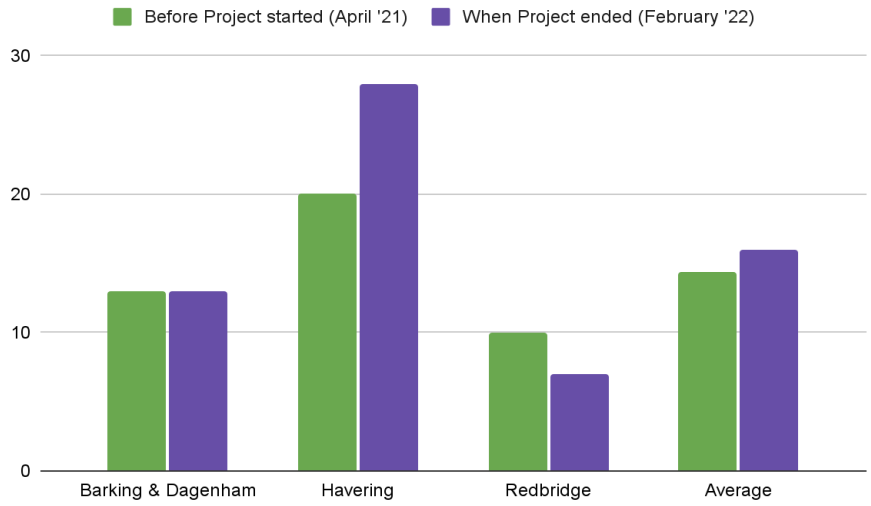

Figure 7. The number of people who died with CMC recording preferred place of death

In comparison Figure 8 shows the monthly trend as a percentage of those who died. BHR does not stray too far from the London-wide average.

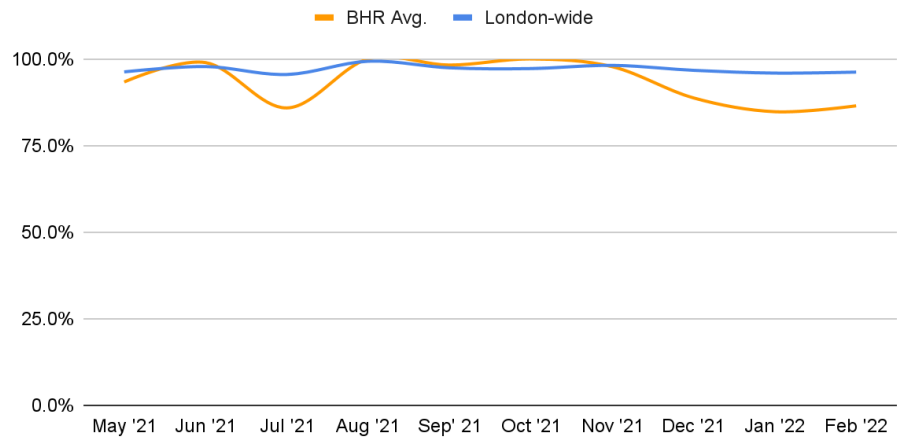

Figure 8. The percentage of people each month who died with CMC which recorded their place of death preferences

Whilst the Marie Curie BHR ACP service had an impact on the recording of where a person would prefer to die, it had less agency over whether this was achieved. The reasons why someone may not die in their preferred location include care staff not being able to access the CMC, COVID restrictions, health complications, local facilities, the training of local staff and other factors.

On average the percentage of people dying in their preferred location with a CMC plan went from 76% just before the service to 70% at the end of the service (Figure 9). The number of actual deaths per borough for people with a CMC record are quite small (typically less than 30), so any changes each month can make what appear to be significant statical impacts.

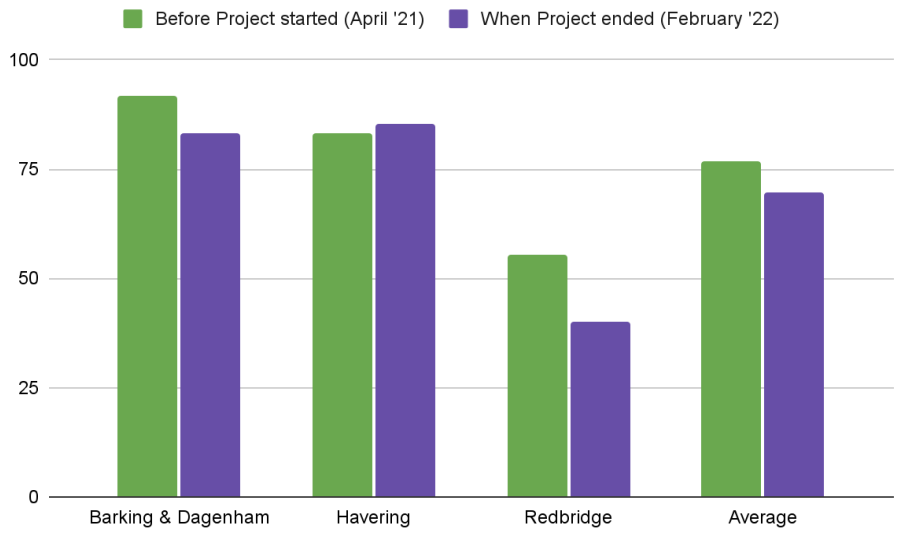

Figure 9. Percentage of people with a CMC dying in their preferred location

Figure 10 shows the monthly trend as a percentage of those who died. BHR does not stray too far from the London-wide average.

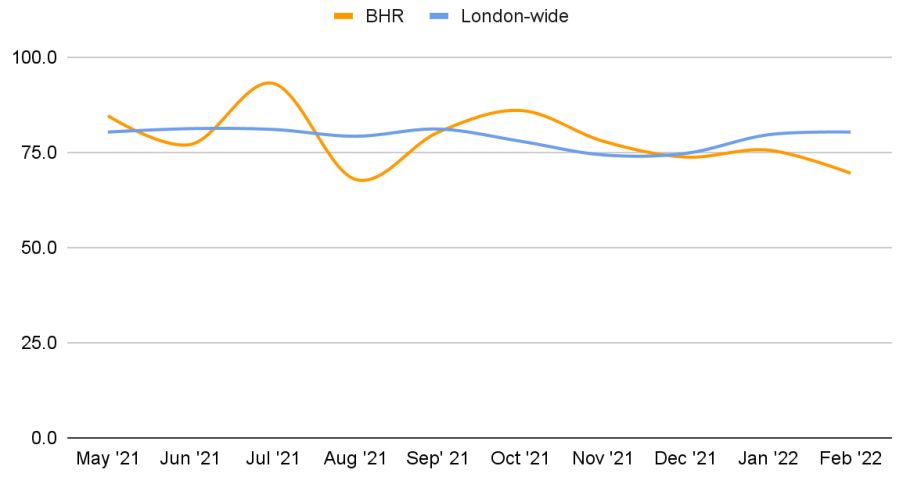

Figure 10. Percentage of people with a CMC dying in their preferred location on a monthly basis

Havering, which had the highest increase in records of preferred location of death, also saw an increase in the percentage of people dying in their preferred location (from 83% to 85%). Whilst further analysis would be needed to establish cause and

effect, there could be a correlation between an increase in records of preferred location of death and an increase in the proportion of people dying in their preferred location.

4.1.6 Quality of Care Plan Completion

As described earlier in the report, Marie Curie staff conducted audits of initiated and completed CMC plans throughout the duration of the BHR ACP. Audit figures show that 32 of the 249 records (12%) were audited, which is higher than the required 10%.

Audits were undertaken by the Clinical Nurse Manager. The audit tool was divided into nine domain areas that were rated from 'incomplete' to 'satisfactorily completed'. Auditing showed that the service was of a high standard with over 90% of the plans audited rated 100%.

There was one domain 'Ceiling of treatment - discussion' which was the reason why some plans were not rated 100%. Rather than 'Satisfactorily completed,' some of these had 'limited' ratings, denoting a limited conversation took place. The rationale given by the nursing team was that this was mainly due to complex family issues.

The audit tool also reinforced the staff comments about the importance and impact of good professional working relationships with the local services they were working with. All 32 plans rated GP engagement as 'Good.' 30 out of the 32 audited plans rated engagement with the care home as 'Good' with the remaining two rated as 'Fair'. However, conversely this also highlights a limitation of the audit tool because we know from interviews with staff that engagement with some GP and primary care teams was much more challenging than revealed within the audit document. The audit data only reports on GPs who engaged with the Marie Curie Team – those GP services which did not make many referrals, refused or were unable to engage with

the service were not included within the audit and, as a result, the audit data offers a one-dimensional view of the relationship between staff and GP services which lacks depth and nuance.

4.1.7 Anticipated Cost Savings

Given the data and resources available for this evaluation, we are unable to provide a detailed analysis of the financial efficiency of this service. CMC provide a financial savings calculator which enables a high-level analysis of the costs savings achieved through implementation. However, the company have an interest in producing positive cost-saving data and more detailed, objective analysis would provide more robust findings[16].

Nevertheless, this calculator indicates that utilising CMC to publish ACPs saves £2,100 for each new patient completing a plan.[17] This means that for the 132 new patients supported to publish a CMC plan there was an estimated total saving of £277,200 to the CCG. After considering the total cost to BHR CCG of implementing the service, this results in an estimated saving of **£242,200**. Effectively, this means for every £1 spent on the service, the CCG had an estimated saving of £6.92.

These are conservative figures that do not include the cost benefits of the CMC plans that were reviewed, only those that were created.

During the course of service delivery 187 CMC plans referred to the service were published. Based on the budget for the service, the cost per published ACP was £187.16. This represents 8.9% of the £2,100 CCG saving estimate from CMC.

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[16] https://www.coordinatemycare.co.uk/wp-content/uploads/2021/07/NIA-case-study-Coordinate-My-Care.pdf

[17] https://www.coordinatemycare.co.uk/downloads/cmc-impact-annual-report-2021.pdf

4.2 Key Findings - Qualitative Data

A number of key themes emerged during interviews with staff, patients and stakeholders which centred around:

- Workforce innovation - Building a new delivery model for Advance Care Planning which delivered benefits to staff and service users
- Staff development – by maximising retention, supporting development, and optimising training
- Service scope and limitations – including CMC limitations
- Family support and education - importance of early and effective communication with families and the use of inclusive language

4.2.1 Workforce Innovation

One of the most significant themes that emerged during interviews and discussion with staff, families and clinical teams centred around the rapid workforce innovation which enabled this service to deliver during a challenging period. This involved the workforce adaptations, recruitment, training and support of staff and offers useful insights for future projects and service design.

Workforce Adaptations for BHR

The role of workforce adaptations, including shift of some responsibility from care staff and GPs to the virtual ACP team occurred frequently in the data. In general, participants expressed that the shift to the new model delivered through the service facilitated a new way of multidisciplinary team working. The nursing team providing an important adjunct role in support of GPs and care home staff, creating the

opportunity for a more joined up ACP pathway and more effective working as part of an MDT team.

"Barking was so good. You felt you were part of a team working with the GP. We had a really good working relationship." - Nurse

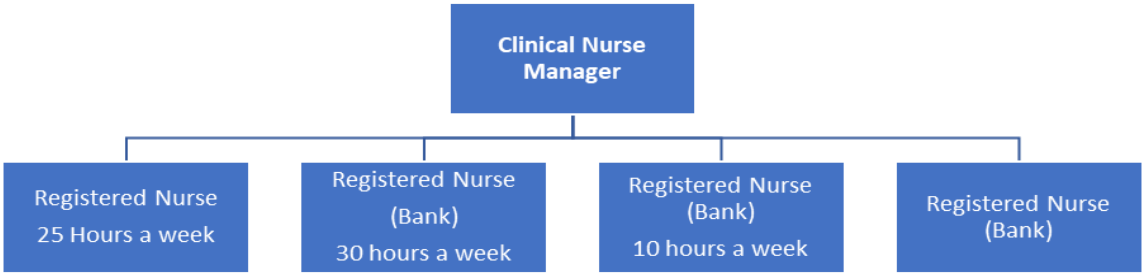

Figure 11. The BHR service structure

The ACP service was underpinned by a new workforce model within Marie Curie. The delivery team were supported through a new supervision structure which included virtual senior clinical support. The service was overseen by a Clinical Nurse Manager, who also manages other services, and delivered by four Marie Curie registered nurses (Figure 11). The Clinical Nurse Manager spent 7-10 hours per week exclusively managing the BHR nursing team.

Staff received weekly rather than the usual monthly team meetings, with ad hoc meetings in between to manage any issues. It was felt that more frequent meetings were necessary for those working remotely to ensure they received adequate support in adapting to the innovative delivery model along with sufficient clinical supervision.

Working remotely provided the opportunity to have group discussions at times that were more convenient for all. Some staff reported that they were able to hold meetings with whole families from all over the world via Zoom to establish best practices for the patient.

"How many [family members] would you get to a care review? And then they would say they would but then just not turn up. Now with the Zoom...some had families from all over the world were able to connect" - Nurse

"I could talk to the local family and relatives in Scotland at the same time" – Nurse

The service had some accrued hours within the budget which had not been used by December 2021, so this allowed the team to continue delivering support with CMC until Feb 2022.

Working across the boundaries

Feedback from GP's indicated that the model complemented the work of primary care and the remote model was helpful in improving efficiencies. GP's often faced challenges around obtaining consent from families and provision of the virtual ACP service enabled this role to transfer to the nursing team, alleviating some pressure on primary care staff. However, Interviews with GPs revealed that they were keen to retain responsibility for publishing CMC plans. Future ACP services may want to explore roles and responsibilities in the End-of-Life ACP pathway further, with potential for further responsibility to be moved to the nursing team.

"It went fine. They took some of my workload so from my perspective it was great." - BHR GP

"What can I say? Fantastic? They were wonderful, it made it so much easier for me, gave me my time back. Just fantastic" - BHR GP

For care home staff, the Marie Curie model also offered efficiencies and support. In particular, staff recognised the value of the additional expertise provided through Marie Curie staff in initiating and undertaking difficult, often highly sensitive conversations with families and carers. Some care home reported that it is often difficult to initiate these conversations with families and carers, despite engaging with them on a daily basis. Having external support and access to advice enabled staff to feel more confident and supported, as well as supporting their own wellbeing.

"We see them every day, we can't ask these questions, so it's nice to have [Marie Curie] asking those things that we can't. It's too sensitive for our staff to talk about resuscitation." - Care Home Manager

Unanticipated benefits

One of the unanticipated benefits of the new service model was the significant impact on both staff and families in terms of travel time. This had an impact on families in terms of saving money, improving wellbeing and connectedness and releasing time for their other caring duties.

"It makes more sense for us. You could just speak over the phone rather than driving for an hour." - Family

"Covid was a difficult time, well for everybody, I couldn't see my [relative]. No one could. But talking to the service using the remote technology meant I was still connected and the nurses who made that happen for our advanced care planning conversations were wonderful. What a gift." – Family

"I spoke to one family member, she was working, she had three kids, she couldn't come down to see [the patient] and she just felt so guilty, but I could talk with her quickly over the phone and she loved that." - Nurse

"One person told me that this phone call has saved them two hours travelling" – Nurse

4.2.2 Staff Development

Maximising retention

This service represented an innovative new model of end-of-life care planning, providing more flexibility for patients and families but also for staff. The impact on staff, releasing staff time which would otherwise be underutilised emerged as an important factor throughout the data. At the outbreak of Covid-19, charities like Marie Curie faced some difficult decisions. Marie Curie had a number of staff with their own health issues who needed to shield and due to changes in service delivery they faced the possibility of needing to furlough a number of the workforce. However, through developing an innovative remote service, they were able to retain staff in work whilst also expanding the pool of potential employees to those who had health conditions which may otherwise have prevented them from travelling to work or working in a face-to-face role.

"I enjoyed working [in the service]. Despite my back problems, where I would not normally be able to do much. I felt I was still able to use my 45 years nursing skills to help." - Nurse

Through establishing the remote service, Marie Curie could redeploy potentially furloughed staff, not just locally, but from across the country, ensuring they retained

the skills and experience of staff who otherwise may have left the workforce. In the beginning there were 21 bank nursing staff working in South West London as this was how many staff were available due to furlough, but when commissioned it was estimated only 4 were needed to run the BHR ACP service.

Furthermore, in order to adapt to the challenges of the pandemic and meet demand, Marie Curie redesigned its workforce model for delivery of CMC in BHR. Although the charity does not utilise the NHS Agenda for Change (AfC) staffing scale, the nurses working on this project were working at an equivalent to AfC Band 5. Within the NHS, responsibility for undertaking CMC plans would ordinarily be led by staff working within roles at the minimum level of a Band 6, most often a Band 7.

Therefore, the service provided through the BHR ACP tested a new hub and spoke model with less experienced staff working closely under the supervision of a senior clinical team lead. This decision was based on the reasoning that DNAR and CPR documentation would be countersigned by a senior clinician and staff would have more contact with the senior clinical lead through regular remote working and meetings. Nursing staff told us they were initially worried about this change, but developed confidence as the service was implemented and they observed the high levels of support provided to them.

"My clinical assessment skills now mean I can have the conversations and I feel confident. And [if] there was an issue I would come away, talk to the team and get my brain time to focus." – Nurse

"I learned things we hadn't really done before, like Office of Public Guardian, we would come together and share what we learned and discuss what to do, you needed that." – Nurse

"Before this [pandemic] I would have said Advanced Care Planning would have to be done face to face or that was the best. I still think it's the best, however I think [remote] really does work and it can be done, in a quality way." - Team Manager

Supporting development

Audits were undertaken by the Clinical Nurse Manager and two members of the nursing team throughout the service delivery period. As well as testing a new model of delivery, this service offered significant development opportunities for staff who otherwise may not have accessed these. For example, through building confidence in remote working technology, staff who had planned to completely leave nursing on retirement are now considering ongoing work in a remote capacity.

In a health and care sector which is struggling under intense workforce pressures, retaining skilled staff through innovative deployment models offers significant opportunities for service delivery. For example, one nurse told us:

"[This project has] built my confidence in technology. I hated using it, but now I teach others how to use Teams and Zoom." - Nurse

Other staff reported how working in the service helped them expand their skills in record keeping and communication.

"COVID has made us more proactive. I have confidence now in technology and I'm more effective in my communication." - Nurse

Optimising training

Staff told us that they valued the training programme provided by Marie Curie. This

programme was adapted specifically for the role, including intensive support around utilising the CMC platform for staff who were unfamiliar with this technology. This provided them with the skills to deal with challenging situations, enabling them to effectively defuse potential conflict and create positive conversations with families and patients. It was felt that this training is essential to support this workforce model and enable lower banded staff to feel confident and able to deliver within this role.

"In terms of confidence, my clinical skills have improved...my assessment training meant I could now assess my patients...My research skills have improved and now I can know what to look out for." - Nurse

Peer mentoring was another key development that staff reported as an innovation that staff frequently referred to, with staff having regular individual remote discussions along with team meetings. Staff believed this project granted them a chance to share a better understanding of the impact of the Mental Capacity Act 2005, including deprivation of liberty and the types of powers of attorney.

4.2.3 Service Scope and Limitations

Interviews with staff and families also unearthed some important insights around the scope of a remote service and possible limitations. These are important to consider for future, similar delivery models.

Service Scope

When considering the scope and limitations of the remote service, staff felt that the remote service would work for most people but would not be appropriate for those in the last week or few days of life. This is because remote consultations often took longer to complete, with communications between GPs, care homes and the Office

of Public Guardian often taking a few days to be processed before the nurse could continue.

In addition, some staff expressed concern around accessibility of the remote model for some individuals such as people with communication difficulties.

"Those with hearing problems really, they struggle to hear you over the iPad. Vice versa speech problems, it was hard to hear" - Nurse

However, other staff suggested that accessibility could be improved through additional time and utilising accessibility adaptations within virtual meeting software/platforms. Nevertheless, accessibility is a challenge which needs further consideration with a detailed equalities impact assessment undertaken as part of the service design.

A final limitation expressed by staff was their frustration at often feeling as if they could not give some individuals the time they needed. For many patients, loneliness and isolation were a frequent issues and these individuals needed a wider support network, outside of the scope of the ACP service.

"Most [patients] were fine, but they wanted to talk, even though they are [in the care home] they say they don't have anyone to speak to and you listen and what can you do? We give them time to talk, but they need more." - Nurse

CMC Platform Limitations

The nursing staff highlighted a few challenges with the CMC platform that impacted on their ability to work effectively. It is critical that health and social care staff can work effectively together in end-of-life care and the fact that CMC plans could not be

accessed by care home staff was seen to be a significant limitation to the service and a barrier to effective interdisciplinary working.

“Often [care home staff] are the ones who will have to act on the information in the plan, having a live digital version rather than a printout after the fact means they have the latest information.” - Nurse

The CMC platform also presented a few usability challenges. For example, CMC web pages would ‘time out’ if a member of staff took too long to write their notes, leading to lengthy manual work-arounds such as writing notes in a separate word processing document and then copying and pasting into the CMC portal.

“It's so frustrating, you would spend an hour writing a beautiful plan then go to press save and ‘boom’ you were logged out” - Nurse

“Some of the problems we have with the IT you lose the plan; you have to refresh and log in again and do it all over again” - Nurse

A final limitation was that Marie Curie staff believed CMC’s minimum dataset was not holistic enough for quality support. To resolve this, the service held engagement meetings with ambulance crews to find out what would be the most useful data to hold. For example, CMC plans did not include recording ways to manage anxiety or crisis situations. Ambulance crews also asked if they could know how far away the patient’s next of kin or friends might live – often they were within walking distance and could help but were not included in the records.

"[A patient] with advanced dementia used to spend their time putting ties on their teddy bear. This was not in their notes, so [the patient] was often distressed during hospital admissions. Including this information in the

CMC helped health staff to ensure the bear was brought in with [the patient] for hospital admissions and reduce their distress. - Nurse

4.2.4 Family Support and Education

Interview with families who had experienced the service revealed a high level of satisfaction with the service provided. Families reported that they experienced compassion, kindness respect and felt confident in the knowledge and expertise provided by the service. This service played an important role in supporting families to navigate unfamiliar and difficult decisions.

"[They were] sympathetic. Marie Curie was first class. Excellent support over a horrible difficult time." - Family

"A wonderful service that really gave you time to get the plan just right." - Family

"The work they did was a treasure." - Family

However, in-depth discussions with families who had experience of the service, alongside reflections from nursing staff also revealed some gaps in support and education for families and care-givers supporting loved ones at end-of-life. Many families were unprepared or unwilling to engage in end-of-life discussions and there seemed to be a significant gap in service provision across BHR in supporting relatives through this difficult period. This was outside of the scope of the service, but does indicate an important local gap in provision across BHR.

The importance of language

Interviews with family and staff provided particular insight around the importance of initial family support, preparing families and carers to engage effectively with the

ACP service. In addition, language was also highlighted as an important factor in enabling families to feel included and supported during end-of-life planning.

Firstly, it became clear throughout the data that for some patients, even being contacted by the Marie Curie service was difficult and traumatic, mainly due to the charity's known connection with end-of-life care. This meant some patients were reluctant to engage with the ACP team. Staff felt there was a role for referrers to play in preparing patients and families for referral to the service, particularly setting expectations about what the service will provide. Some family members reported feeling uncomfortable after receiving a call *'out of the blue'*. This exposed a potential gap in communication between referrers and family members. It would be beneficial for referrers to check understanding with families and carers who are often balancing complex information from a wide range of health and care professionals at a particularly distressing time.

"I got this call 'out of the blue' as it were, and I heard 'Marie Curie', and their brand is to do with cancer care, so I didn't see how this service fitted in with what I expected them to do. It leaves you on the back foot." - Family

"It took me a while to know what [Marie Curie] did, how they were different from the care workers at the home." - Family

"I had this conversation about advanced care planning, but I didn't know who it was, I didn't realise it was Marie Curie who did that, I thought they were nurses from the care home." – Family

"When I first started calling family members I would say 'I'm from Marie Curie', and immediately you could hear their fear. They know us for our end-of-life work, for them just hearing our name was enough." – Nurse

Some of this feedback was received during service implementation and the ACP attempted to mitigate this in two ways. Firstly, patients and family members would be contacted by the care home manager, someone they were familiar with, to inform them about the service and prepare them for the initial phone call with the Marie Curie team. Secondly, families were also provided with the Marie Curie head office contact details so they could verify their identity and access additional support in the long term.

Interviews with clinical staff and family members told us that patients and family members frequently reported not understanding some of the clinical language and acronyms used in advanced care planning. For example, families reported not understanding the terms 'care plan' or 'CPR' or 'DNAR'

"They mentioned a lack of capacity and DNAR, and I was like, this means what? But they explained it all beautifully." - Family

During a traumatic period for families and patients it is even more important that clinical teams and care staff use language which is accessible and, where the patient wishes it, that families are provided with support to engage effectively with end-of-life planning. Families often express surprise and dismay at the low chance of recovery of relatives in care homes, even when they have received a terminal diagnosis.

"You don't normally think straight, I lost my mother…now I was going to lose my father, and I found it hard to understand, to take in, what they were saying, but I look back and think [Marie Curie] was really supportive" - Family

This can create much additional pain for families and relatives. In addition, there is often confusion about the meaning of DNAR, equating DNAR with not providing any health support or pain relief. Families are often not aware of the low likelihood of recovery from CPR for patients living in care homes as well as the amount of pain it causes in the last moments of life[18]. Marie Curie staff felt that a lot of time was spent reassuring family members and that more resources should be available to explain these points.

ACP discussions allowed for staff to educate and provide relief through a discussion of topics that often go overlooked because they fall under 'taboo' and caused concern, which benefited families.

"Most felt that CPR meant 'trying to save a person'. They had no idea that CPR is one of many procedures and that for many older ones it could turn a quiet death into a painful, violent death." – Nurse

[18] https://www.bmj.com/company/newsroom/patients-overestimate-the-success-of-cpr/#:~:text=Patients%20in%20previous%20studies%20have,%25%20for%20in%2Dhospital%20arrests.

5. Recommendations

This evaluation delivered a number of important insights and related recommendations:

Clear information pathways:

- Develop a clear process or pathway which ensures that when individuals move or are transferred from the Marie Curie service, initiated plans should transfer with them.
- There were some gaps in records for patients referred after the service had reached budget, this should be mitigated/planned for in future service design.

Pre-implementation communication and local engagement:

- Marie Curie should work with commissioners to ensure adequate communication and promotion of ACP services. This communication should clearly demonstrate how the service can support primary care and should continue beyond the initial launch of the service.
- At the minimum, an expectation of the CCG to provide an introduction letter to all GPs about the service and a named point of contact for GPs and primary care staff.
- To further support communication around ACPs, establishing a direct communication pathway between the remote service and clinical lead GPs may support in more efficient creation and publishing of ACPs.

Service planning and financial forecasting

- Given that timelines were much longer than anticipated in the service planning

and design, findings from this report should be used to inform future service design and budget planning.

Data sharing

- The lack of shared data in this project meant that MC staff spent significant time contacting GPs to secure accurate medical histories. This highlights the need for more effective and efficient models of data sharing between care providers. There is a risk that in attempting to alleviate demand on GPs, the service could actually be increasing administration demands on busy GP practices, adding to telephone demands without a dedicated route of communication.

Family education and information

- Marie Curie has excellent information and resources for families and carers. However, this project still revealed significant knowledge gaps amongst families and caregivers about core elements of the end-of-life pathway. Marie Curie may wish to explore this further to ensure information is accessible and visible to families and carers engaging with ACP services. Those interviewed for this evaluation highlighted particular knowledge gaps in end-of-life care planning and the rights and responsibilities of those with Powers of Attorney.

Building on successful workforce innovation and embedding in future service design

- Provide opportunities for staff to work to the top of their licence with robust systems of supervision and support

- Undertake digital skills analysis across the organisation and implement learning from the remote service implementation to address digital skills gaps

- Work with staff who may be considering retirement or leaving clinical service provision to create redeployment opportunities within virtual services – consider developing case studies from staff who have worked on the virtual service as examples of alternative employment models and to support retention

- Encourage peer mentoring and supervision as a model of staff learning and development

Digital inclusion and accessibility

- The move to a virtual service was a necessity predicated by the Covid-19 pandemic. This model worked for many people and realised many unanticipated benefits for both staff and patients. However, this model is not universally beneficial, and for some people who perhaps lack the digital skills or infrastructure or who have other accessibility needs a different model is required. Scale-up of this virtual service would need to consider ways to increase inclusion and access and ensure that it provides alternatives for those who cannot access digital resources or platforms.

Further evaluation and learning

- Internal audit tools are helpful; however, in order to further evaluate and understand the service implementation, external audit of records would have provided additional value. In addition, peer reviews by staff from other services within the charity could have provided another valuable perspective and learning.

6. Conclusion

"I'm passionate about this service, I think it's working and should carry on, and should be disseminated across the country." - Team Manager

The Marie Curie BRH ACP Service bridged a gap in end-of-life provision and provided a new model of supporting advanced care planning across BHR. The service was well received by commissioners, clinical teams, care homes as well as families and care givers.

The service demonstrated how a virtual ACP service can support patients and staff, retain vital workforce skills, overcome digital skills gaps and build a strong and confident workforce. The BHR remote service enabled staff who were close to retirement or unable to undertake physical nursing duties to continue to deliver valuable work and utilise their skills.

This project demonstrated that effective virtual training and visible senior support can overcome barriers such as lack of confidence or digital skills gaps. Furthermore, staff were empowered to work to the top of their licence through a thorough training programme, consistent and empathetic supervision and a robust support framework.

Rapid workforce adaptation in response to the Covid-19 pandemic provided significant opportunity for learning and this innovative virtual service creates a blueprint for scale and a new opportunity to retain, support and develop valuable staff. The service demonstrated that advanced care planning, previously only delivered in person could be effectively and compassionately delivered through virtual and remote means. This new model provided the opportunity for family

members and carers, who may ordinarily be precluded due to travel or other personal caring responsibilities, to feel present and involved in decision making.

Future service design should consider communication strategies, both with GPs and families as well as ensuring family and carer information is accessible and relevant. More work should be undertaken to improve accessibility of the service to those who may be digitally excluded or face other accessibility challenges. However, despite the limitations to the pilot, this model offers an opportunity to rethink workforce strategy and models and deliver significant efficiencies in end-of-life service design and delivery.

Acronyms

ACP - **Advance Care Planning** - Advance care planning offers people the opportunity to plan their future care and support, including medical treatment.

BHR - Barking and Dagenham, Havering and Redbridge

CCG - **Clinical Commissioning Groups** - CCGs commission most of the hospital and community NHS services in the local areas for which they are responsible

CMC - **Coordinate My Care** - A system used to record advanced care plans

CPR - **Cardiopulmonary Resuscitation** - An emergency procedure consisting of chest compressions often combined with artificial ventilation

DNAR - **Do Not Attempt Resuscitation** - A document issued and signed by a doctor, which tells other medical professionals not to attempt cardiopulmonary resuscitation as it would be considered medically futile

GP - **General Practitioner** - First point of contact for patients not facing urgent health needs. They treat acute and chronic illnesses, provide preventive care and health education to patients of all ages

LPA - **Lasting Power of Attorney** - A legal document that lets a person appoint one or more people (known as 'attorneys') to help them make decisions or to make decisions on their behalf if they cannot make their own decisions

OPG - Office of the Public Guardian - A government body that polices the activities of deputies, attorneys and guardians who act to protect the affairs of people who lack the mental capacity for making decisions about such things

SWL - South West London

Terminology

Bank - The term refers to a pool of (or bank) people that an employer may call on when they need to cover shifts, holidays or just need extra staff as and when.

End-of-Life – End-of-life care refers to health care of patients with a terminal illness or terminal condition. It usually refers to the last year of life, although for some people this will be significantly shorter. The term palliative care is often used interchangeably with end-of-life care.

Mental Capacity - Having mental capacity means being able to make and communicate your own decisions

Remote - communications that take place via technology from different geographical locations, as opposed to face-to-face communications. This can be done via a telephone call or using video communications technology such as Zoom or Microsoft Teams.

Appendices

CARE CITY

Appendix A - Training

Standard training for ACP Services:

- Safeguarding Adults (includes Mental Capacity)
- Safeguarding Children
- Data Protection (GDPR)
- Equality & Diversity
- RN Medicines Management Portfolio
- Anti-Bullying and Harassment
- Dynamic Risk Assessment
- Records Management/Keeping
- PREVENT
- Dementia - long course (7 modules)
- Dementia – short
- Mental Health
- Learning disabilities
- Autism

- Fundamentals of Palliative Care

Bespoke training added for the benefit of the BHR ACP service:

- Session led by a liver consultant from St George's Hospital for the purpose of understanding end-of-life care needs in these particular patients.
- Advance care planning project link
- Webinars from Social Care Institute for Excellence – a series of teaching webinars on Mental Capacity
- Training regarding Lasting Power of Attorney for Health (LPA) and verifying the validity of an LPA.
- A booklet on having courageous conversations on the phone at EOL
- Webinar on Advance Care Planning from Dr Sam Lund – Royal Trinity Hospice, Wandsworth.

Appendix B - Interview Topic guide

Included below are the topic guides for the development of this evaluation report. They were developed to ensure consistency with previous evaluation reports from other parts of London.

Interview with clinical service lead

Service

- Why was the service commissioned? What are its aims?
- How long has CMC been used in the service? When did it start?
- Which boroughs used your service?
- How many residents did the service support?
- What are the main benefits of using CMC?
- What changes did you make to the service throughout its duration?

Staff

- How many staff are involved? And at what levels?
- Can you send over role profiles for these roles?
- How much resource was supplied by MC? (staff/resources)
- Were there any delays with onboarding staff for the project? And if so how have you overcome these?

- How often do you hold team meetings for all staff?

Plans

- Where can I get statistics of the plans/hours taken? No of plans created/updated and when
- Who has responsibility for creating the care plans?
- Who has responsibility for reviewing the care plans?
- How were CMC users selected? What was the scope?
- How many plans were created? Renewed?
- How many residents refused? Do you have a breakdown of reasons given?
- How many residents were able to die in their preferred place?
- What changes to the service did you make as a result of the pandemic?

Quality

- Who would audit the plans and how many were audited?
- What resources do you use to maintain quality within the service?
- How many complaints? Safeguarding? Compliments did you receive? Involving which group of stakeholders?
- What training do the staff receive? Professional development/CMC/Quality processes?
- How many hours of training do the staff receive? How many did the service

use?

- What overall reflection do you have of the service?

Interview with Service staff

- What would a typical CMC process look like and how long does it take?
- Who do you work with to create the CMC?
- What changes to the service did you make as a result of the pandemic?
- What lessons do you feel were learnt from the process?
- What were you provided with by MC to complete your role?
- Onboarding includes being provided with equipment, NHSmail CMC accounts, orientation pack and mentoring/training - are these fit for purpose or are more resources needed?
- How long does it take to complete a plan?
- How long does it take the plan to be approved?
- How much time does it take to complete the process on average?
- Which timeframes were the most difficult to work in and why?
- Do you have any feedback from patients? Other stakeholders?
- What are your overall reflections of the service?

Patient/family service survey

This survey was developed by the Health Innovation Network, we used it as a topic guide for consistency.

Completing this survey should take less than 5 minutes.

Are you:-

- A care home resident
- The friend or relative of a care home resident

Have you spoken to a specialist nurse (from Marie Curie) in the last few weeks about your/your relatives wishes and care preference to create an electronic record known as a CMC record?

- Yes
- No
- Can’t remember

Have you spoken to a member of care home staff in the last few weeks about a CMC record for yourself or your relative?

- Yes
- No
- Can’t remember

Did you feel sufficiently prepared to have these discussions?

- Yes
- No
- Unsure

Do you feel you were given enough time to discuss your wishes if you/your relative became more unwell?

- More than enough time
- Enough time
- It felt a little rushed
- Not enough time at all
- Other comments (Free text note)

How did you feel about the conversations? (tick as many as apply)

- I was pleased to be asked about my wishes
- I felt confident services would know more about me in an emergency
- I found the conversations reassuring
- I found the conversations upsetting
- I felt happy to have these conversations by phone
- Other comments (free text)

Appendix C – Marie Curie Job Description

Job title: Registered Nurse

Department: Marie Curie Nursing Service

Reports to: Clinical Nurse Manager/ Senior Nurse

Accountable to Regional Manager

Grade: MC Pay Scale Nursing Service - Clinical

Job Purpose/ Summary

The Marie Curie Nursing Service is a community based palliative care service whose aim is to support patients and their carers within the community setting. This will usually be the patients' own home. This role involves linking and collaborating with other health and social care providers in primary, secondary, independent and voluntary care, to promote communication and seamless care and support for patients and their carers. The service is deployed in geographical regions which contain a series of smaller teams that are designed to provide a supportive staffing network.

The Marie Curie Registered Nurse will work alongside the Clinical Nurse Manager and Senior Nurse in a locally defined team, to assist where required in the delegated management supervision of a team of Healthcare Assistants and delivery of the service. The Marie Curie Registered Nurse will work collaboratively with District Nursing Teams, the NHS Out-of-Hours Service, the Palliative Care Co- ordination Centre, other Marie Curie Nurses and other palliative care service providers, in order to provide a proactive approach to delivering patient care in the locality to ensure an integrated and co-ordinated service.

Key Relationships

- Patient, families and carers
- Regional Manager
- Clinical Nurse Manager
- Marie Curie Senior Nurse
- Marie Curie Nurses and Healthcare Assistants
- Marie Curie Referral Centre
- Practice Development Facilitators
- District Nurses
- Other members of the Primary Healthcare Team
- Regional Human Resource Team

Accountabilities (Duties & Responsibilities)

- Provide appropriate clinical care, to enable palliative care patients and their carers to receive care in their place of choice and to be able to stay within their own home
- Be proactive in developing collaborative relationships with other care providers.
- Work within clear protocols and guidelines to deliver seamless care.
- To work within operational and clinical procedures that are currently in place

and to highlight any gaps or concerns to the Clinical Nurse Manager and/ or Senior Nurse as appropriate.

- To demonstrate assessment skills and be able to plan, implement and evaluate patient care.
- To be responsible for the management of patient care during the visit
- To adhere and be professionally accountable to the NMC Code of Professional Conduct
- To act as an educator and advisor to the team and patients and families/ carers and to provide advice, support for the carers and family according to their needs and the level of intervention required during the shift.
- To communicate and liaise where appropriate with the DN & Community Nursing Team to receive and provide handover and updates.
- To work independently as well as alongside other team members or other professionals when required.
- To ensure continuity of patient care by communicating and liaising with medical and nursing colleagues, providing accurate and timely reports of any changes in the condition of the patient.
- Maintain accurate records in order to reduce the risk of errors.
- To understand the systems for accessing the Marie Curie and local NHS policies and procedures, for example infection control and drug policies.
- To maintain a level of knowledge, skill and competence related to current drugs/therapies in the treatment of pain and other symptoms and administer

medication according to the drug/prescription chart as required.

Clinical and Leadership Responsibilities

- To assist the Clinical Nurse Manager and Senior Nurse in ensuring integration with other NHS and voluntary sector services.
- To assist the Senior Nurse as required, in the management supervision of a group of Healthcare Assistants in a locally defined team. This will include appraisals, return to work interviews, induction support and mentorship as delegated by the Senior Nurse/Clinical Nurse Manager.
- To escalate any problems or concerns relating to the management supervision of staff, to the Senior Nurse
- To observe and monitor clinical and policy developments in the locality and share these with the Clinical Nurse Manager, Senior Nurse and the wider nursing team.
- To represent (when required) the service at meetings in the absence of the Clinical Nurse Manager or Senior Nurse e.g. CCG/Health Board/MDT/DN/GSF meetings.
- To undertake (when required) the organisation and delegation of tasks/ duties to other members of the team as appropriate during the shift.
- To take on any additional responsibilities that may be required as part of the role.
- To be responsible for managing performance of staff as appropriate (when required) and to escalate appropriately to a senior manager.

- To contribute and participate in the appraisal framework and be responsible for own personal development.

- To develop and maintain an awareness of budgeting, exercising care and economy wherever appropriate.

Learning and Development Responsibilities

- To gain experience and skills in clinical practice, facilitation and learning, management and leadership.

- To maintain awareness of professional responsibilities by reading current, relevant literature and by taking up opportunities for personal and professional development, in order to meet the requirements to maintain registration to practice.

- To actively contribute to the learning and development of staff in a locally defined team

- To assist in the training and development of Healthcare Assistants and complete assessors training as required.

- Undergo such training as may be required to carry out competently the needs of the job.

- Support the charity in the development and cascading of patient career education to support staff and carers to fulfil their caring role.

Governance and Quality Assurance

- To support the charity in the development of operational and clinical guidelines for the service.

- To uphold quality initiatives that improve ‘customer care’ and enhance the interface between staff, patients and carers.

- To assist the Clinical Nurse Manager and Senior Nurse in ensuring that appropriate evaluation mechanisms are in place to make certain that the service delivered to patients is of the highest quality.

- To assist the Clinical Nurse Manager and Senior Nurse with all aspects of clinical governance as directed, particularly in relation to participating in the investigation of complaints and incidents as required.

- To use evidence-based practice to develop and maintain high quality patient care and ensure the continuous improvement of the Marie Curie Nursing Service.

- To be aware of personal responsibilities in relation to the maintenance of a safe environment and identification of potential risks for all staff, patients, and carers, taking action when required.

- To assist in the delivery of clinical supervision in a locally defined team (when required).

- To lead and participate in auditing the service and ensuring that recommendations from audits lead to effective changes to practice and service delivery

- To be IT competent in order to make full use of mobile phones, e-mail, the internet and on-line training.

- Participate in obtaining user feedback and supporting changes to practice and service delivery to optimise patient and carer experience.

Physical activities required by the role include but are not limited to patient handling, frequent standing, sitting, walking, climbing up and down stairs, kneeling and crouching to attend to patient needs (including in an emergency situation) and load handling.

Our Values and Behaviours

To promote a culture in the working environment which demonstrates Marie Curie values of always being compassionate, making things happen, leading in our field and people at our heart - by displaying the following positive behaviours:

- Treat others as you would like to be treated.
- Listen to, and support others and make time to do so.
- Seek, acknowledge and value others experiences and contributions.
- Acknowledge other's beliefs.
- Treat others fairly and equally.
- Encourage others to treat all with respect.
- Challenge the behaviour of staff who do not show respect to others.
- Be honest and trustworthy.

General

In addition to the specific duties and responsibilities outlined in this job description, all Marie Curie employees should be aware of their specific responsibilities towards the following:

- At all times to act as an ambassador of Marie Curie to patients and their

relatives, to colleagues and members of the public

- Marie Curie is committed to encouraging volunteering throughout the organisation and as such the post holder will be expected to support and respect volunteers, and may be asked to work alongside or supervise a volunteer as part of their role whilst working at Marie Curie.
- Marie Curie operates a no-smoking policy. The post holder should either be a non-smoker or be prepared not to smoke in **any** Charity premises, grounds or vehicles or when on Marie Curie business outside the office.
- Adhere to all health and safety and fire regulations and to co-operate with the Charity in maintaining good standards of health and safety.
- Adhere to all information governance, privacy and security policies, standards, guidelines and procedures; practise and promote secure behaviours.
- Adhere to all Marie Curie policies and procedures at all times.
- Actively promote and support the safeguarding of vulnerable adults, young people and children, observing and adhering to Marie Curie policies on safeguarding.
- Uphold ethical and professional standards and not behave in a manner that is likely to bring the Charity into disrepute.
- Promote and sustain a responsible attitude towards equal opportunities and diversity within the Charity.
- Demonstrate a commitment to on-going registration requirements or any national professional or occupational standards associated with the role.
- Demonstrate a commitment to on-going learning and development and to

participate in any training relevant to the role.

- For designated roles, the post holder will be responsible for health & safety, information governance, business continuity planning and/or risk management (these responsibilities will be notified on appointment).

This job description is not exhaustive. It merely acts as a guide and may be amended to meet the changing requirements of the charity at any time after discussion with the post holder.

Person Specification

Job title: Registered Nurse

Criteria	Essential	Desirable	How assessed
Skills/ Abilities	• Communicate with people in a diplomatic and tactful manner • Ability to work in a complex and stressful environment and demonstrate appropriate coping mechanisms. • Ability to quickly identify and solve problems and take action to address issues • Ability to use own initiative • Ability to work in an unsupervised setting • Able to use a mobile phone, text messaging, e-mail, on-line training and the internet	• Experience in Supervision/ Line Management	• Application form • Interview
Knowledge	• Up to date awareness of nursing care for patients with palliative care needs • Up to date awareness and understanding of specific needs of palliative care patients in the terminal phase. • Must have knowledge and be able to use Information technology such as Microsoft Office packages (Word,		• Application form • interview

	Excel, Outlook etc.) to record and monitor patient care activity		
Qualifications, training and education	• RN Registration Level 1, with relevant post –registration qualification, e.g. ENB 931or Diploma in Palliative care or equivalent • Willingness to undertake necessary Diploma level modules and/ or any additional education & training as required by the role	• Degree in Palliative/ cancer care or equivalent	• Application form
Experience	• Experience in NHS or other relevant care setting in palliative care • Experience of working in a palliative care environment e.g. hospice • Experience of working in the community		• Application form • Interview

Other requirements	• Demonstrate a commitment to continual professional development • Hold a current and valid driving licence and have access to a vehicle which includes business insurance cover • In areas/services where there is the use of a pool car, hold a current and valid manual driving licence • Willingness to work unsocial hours • Access to email and the internet • Must be able and willing to support a flexible approach to working patterns and locations		• Application form • Interview

Marie Curie recognizes the provisions within the Equality Act 2010, reasonable adjustments to these criteria will be considered where appropriate.

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