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Executive Summary

Background

The Marie Curie Fife Hospice at Home Model Pilot is a fully funded Integrated Care pilot in NHS Fife, which complements existing services and initiatives by developing the existing Marie Curie Service for generalist palliative care. The model includes registered nurses, healthcare assistants, health and personal care assistants and trained volunteers. These roles are coordinated by a Clinical Lead Nurse, with support from a volunteer manager and a senior nurse, with responsibility for linking with key members of acute and specialist Multi Disciplinary Teams (MDTs) and Primary Care to prevent admissions and facilitate discharges. The pilot began in April 2014 and ends in March 2016.

Evaluation

In April 2014, OPM was commissioned to conduct an evaluation of the Marie Curie Fife Integrated Care Pilot. The evaluation runs alongside the 18-month implementation phase of the service and addresses six themes:

- Profile of patients referred for palliative care.
- Patterns of patient access to palliative care services.
- Efficiency of service delivery both for patients and care providers.
- Individual services involved.
- Patient and carer experience.
- Overall delivery of palliative care, including quality and costs.

The evaluation included a scoping phase (May – July 2014) during which the evaluation team worked with Marie Curie to agree a methodology and work plan to address four questions around the six themes above. The research was split into two phases. Phase 1 included baseline interviews with stakeholders, a baseline survey of healthcare professionals, a patient/carer survey and development of patient/carer case studies. Phase 2 (February – September 2015) continued with the patient/carer survey and case studies, post implementation interviews with stakeholders, a post implementation survey of healthcare professionals and an economic assessment. Phase 2 also included an analysis of data in health records to determine any change in patterns of service use and used data from the pilot cohort and a matched control group.

Service Delivery

The Hospice at Home service provided 4,047 visits per year in the pilot evaluation period. It has increased the patient referral rate by 158 patients per year compared to the previous Marie Curie service in the area and increased the number of non-cancer patients receiving nursing care by 78%, from 27 to 48 patients per year.
How efficient is the new integrated model of care?

Feedback from healthcare practitioners clearly shows that the new service provides the right care at the right time to end of life patients. Some healthcare practitioners questioned the use of the service as a bridge to Homecare, suggesting it is not intended to supplement the Homecare service. However, the programme team see this as an appropriate use of the service.

The service is timely, and hospital-based staff reported there were no problems getting referrals into the service and no long waiting times for the service to start. Stakeholders valued the immediate availability of the nursing service compared to the local Homecare service, which could take days or weeks to put in place. They also valued the Helper Service.

Overall, the connection between the Hospice at Home model and the Homecare service was seen as working well. Marie Curie staff would contact the Homecare team to verify homecare has been put in place and reassure families that they would not leave until they knew homecare or another service was operational.

Communication across healthcare providers has improved. Awareness and knowledge of the service was high in all practitioner groups, gained through reading communication materials or discussion with colleagues.

Patients saw the service as well integrated. Healthcare practitioners initially cited a lack of clarity about the referral process but this was quickly resolved and is now seen to be working well.

Communication between Marie Curie and other healthcare professionals has improved. Particular value is derived from healthcare practitioners being able to speak directly to those coordinating the Marie Curie nurses to get immediate feedback on capacity. The local Helper Service also cited good communication with the local coordinating team as a key factor in ensuring that volunteers were well matched with patients, leading to patients being better supported.

Communication about a patient’s care works well, facilitated by annotating a patient’s Care Plan (patient-held document) or through discussion with the senior nurse at Marie Curie. However, Marie Curie nurses reported that out-of-hours communication between Marie Curie and district nurses was more difficult and time consuming with no direct telephone number in place.

The new service was seen as providing a valuable resource that enabled the release of clinical time. Marie Curie provides personal care which frees up district nurse time, allowing them to spend more time with patients doing clinical tasks, where they have the greatest expertise, and talking and listening to the patient and their families/carers.

The overnight service is particularly valuable to the local health economy and some practitioners suggest that it has led to fewer calls to the on-call nurse. More broadly, the impact of having regular contact with professional end of life carers was perceived as resulting in fewer calls to the doctor or 999.
The speed of the service to respond is somewhat compromised by the need to have particular paperwork in place, such as Care Plan, Do not Attempt Cardiopulmonary Resuscitation (DNACPR) and risk assessment. These challenges are familiar to the Marie Curie team and are currently being addressed.

What is the experience of the patient and their carers?

**Overall patients and carers held very positive views of the Hospice at Home service.**
This was reported directly by patients and carers as well as coming through in the feedback from healthcare professionals. 92% of the respondents to the patient/carer survey stated they are ‘extremely likely’ to recommend the service.

**82% of respondents to the patent/carer survey said the service had reduced their feelings of anxiety or worry and 88% reported they always received the right amount of support.** The care provided by the service enabled carers to take a break and spend more quality time with their loved one, whilst the night service enabled them to get some much needed rest.

**Mare Curie staff were viewed as professional, sensitive, caring and helpful by patients and carers,** and cited as always treating them with dignity and respect.

**The helper support was greatly valued by isolated patients, living alone or with a single carer.** In these cases, the helper was able to provide carer respite and help to counter isolation. Helpers and patients were well matched. However, the amount of time taken between training as a volunteer helper and getting PVG (protecting vulnerable groups) clearance caused delays in helpers being able to start work. There was also an issue with helpers not always receiving information about a patient’s changing needs in a timely manner.

**The Hospice at Home service was described by patients, carers and healthcare professionals as involving the patients in decisions around their own care.** Patients and carers were offered choice about the care they received on a daily basis and their preferred place of death, with 91% of respondents to the patient/carers survey stating the service allowed them to be cared for where they want to be. The evidence from this evaluation shows that the Marie Curie patients were more likely to die at home than in hospital and more likely to die at home than compared to their matched controls\(^1\).

**The quantitative data showed that 73.7% of patients receiving care under the pilot died at home, compared to 29.1% in the matched baseline group.** Whereas the pilot evaluation group spent 11.3% (approximately 3 days) of their last month in hospital, the matched control group spent 20.5% (approximately 6 days) of their last month in hospital.

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\(^1\) Each patient in the Marie Curie cohort under review has a matched control who appears in the matched control group. Matched controls are patients who look like Marie Curie cohort patients in terms of demographic, diagnosis and previous hospital use, that are taken from the population of palliative care patients prior to the new service model being put into place (i.e. they are similar in every way except they did not receive the Hospice at Home service).
The service is seen as highly flexible both in terms of the services provided and how individual visits are structured. Each patient is assessed in detail and offered the level of care they want, which may change throughout the course of the care; for example, if a patient’s condition deteriorates or the family can no longer cope. Nurses could offer longer visits, which enabled them to have meaningful conversations and build relationships with patients and their families, as well as undertaking personal care tasks.

**What is the Impact of the Integrated Care Pilot on Health Care Usage across Fife?**

58 patients (27.2%) in the pilot evaluation group experienced a hospital admission, compared to 86 (40.4%) of the matched control group. Of the nine A&E attendances experienced by the pilot patients, eight (89.3%) resulted in an in-patient admission. In comparison, of the 28 A&E attendances in matched baseline group, 25 (88.9%) resulted in an admission to hospital. The Hospice at Home patients spent 24% fewer days in hospital (772 days compared to 995) compared to the matched controls. Overall, patients receiving care under the pilot had an average length of stay which was 0.9 days shorter than the controls. However, per admission the average length of stay for the Hospice at Home patients was 3.1 days longer than those in the matched control group.

These results are supported by feedback from patients, carers and healthcare professionals, who cited the ability of the service to react quickly to situations of crisis; the connection between the service and homecare and district nurses; and the overnight service as being particularly important for avoiding hospital admissions.

**What is the Impact on Spend on End of Life Care?**

The Marie Curie Hospice at Home model of service delivery has reduced hospital costs of end of life care in Fife by £182,283 by reducing avoidable hospital admissions.

**Conclusions**

The Marie Curie Integrated Care pilot has implemented seamless care across agencies through a strong line of communication and information sharing. It has benefited a large number of patients and carers, offering them choice about the level of services they want and where they want to receive them, with the vast majority being able to die in their place of choice. It has reduced patient and carer levels of anxiety as a result of the Marie Curie nurses and helpers who are described as professional, sensitive, caring and helpful. Healthcare professionals are enthusiastic about the service and its positive impact on patients and carers and their own work. By providing personal care, the service has reduced the burden on district nurses who could focus on important clinical care. The service has reduced hospital admissions in the pilot group compared to a control group, moved care into the community and has the potential to significantly reduce NHS costs.

The evaluation did also note a small number of minor adjustments taking the service forward which could help the development of the service. Overall, this evaluation demonstrates that the model of care has a large positive impact on the quality of end of life care, working
collaboratively with other services, enabling improved patient outcomes and delivering efficiencies within the health economy.
1 Introduction

1.1 Background

The Marie Curie Fife Hospice at Home Pilot is a fully funded Integrated Care pilot in NHS Fife, which complements existing services and initiatives by developing the existing Marie Curie Service for generalist palliative care. The model includes registered nurses, healthcare assistants, health and personal care assistants and trained volunteers. These roles are coordinated by a Clinical Lead Nurse, with support from a volunteer manager and a senior nurse, with the responsibility for linking with key members of acute and specialist Multi Disciplinary Teams (MDTs) and Primary Care to prevent admissions and facilitate discharges. The pilot began in April 2014 and ends in March 2016.

To support the delivery of the pilot, Marie Curie received funding from the OAK Foundation. That funding covers an evaluation of the two year pilot and recruitment of 20 new staff comprising a senior nurse, health and personal care assistants and a Helper service manager and support team, supported by existing Marie Curie staff.

1.2 Evaluation of the Service

In April 2014, OPM was commissioned to conduct an evaluation of the Marie Curie Fife Hospice at Home Pilot model of care. The evaluation ran alongside the 18-month implementation phase of the service, delivering an interim report in February 2015 (See Appendix 1) and a final report in October 2015 (this report).

The Invitation to Tender (ITT) identified six key evaluation themes that focused on the impact of the new model of care. These were:

- Profile of patients referred for palliative care.
- Patterns of patient access to palliative care services.
- Efficiency of service delivery both for patients and care providers.
- Individual services involved.
- Patient and carer experience.
- Overall delivery of palliative care, including quality and costs.

The evaluation included a scoping phase (May – July 2014) during which the evaluation team worked with Marie Curie to agree a methodology and work plan to address these six themes. The research was split into two phases: phase 1 findings are in the interim report and phase 2 findings are provided in this report.

Phase 2 (February – October 2015) continued with: a patient/carer survey and case studies, post implementation interviews with stakeholders, a post implementation survey of healthcare professionals, an economic assessment and a full analysis of quantitative data. Details of each method are given in section 2.

1.3 About this Report

This report builds on the interim report published in February 2015. It summarises the requirements for the new service, describes the implementation model and presents some basic monitoring data on delivery. Section 2 of this report contains details of the methodologies used in the evaluation. The findings from each methodology are used to assess the impact on the pilot’s expected outcomes. Finally, the evaluation findings are summarised and a series of recommendations are presented.

1.4 Summary of the Pilot Approach

Integrated care is high on the agenda in Scotland. In response, Marie Curie, with the support of the then Cabinet Secretary for Health, Deputy First Minister and the OAK Trust, resolved to undertake a two year pilot of a new service model in Fife. The Marie Curie Fife Hospice at Home Pilot aims to improve the outcomes for patients and carers with palliative and end of life care in the community, whilst demonstrating the impact on the health and social care economy of an integrated coordinated community Marie Curie Nursing Service.

The new service offers prevention of crisis admission, planned care at home, supported discharge and a Marie Curie Helper Service. It builds upon the existing Marie Curie service, putting in place a small team of senior nurses, managed by Marie Curie’s clinical lead nurse, to provide a seven day service which accepts referrals from primary, specialist and acute care, as well as proactively identifying palliative care patients in acute hospitals suitable for discharge. The team coordinates a range of Marie Curie community based generalist palliative care. The senior nurses liaise with the District Nurses to agree the most appropriate package of Marie Curie care for the patient and then continue communication with the District Nurses to ensure the patient receives the best package of care for them. The senior nurse has an overview of need across Fife and the services available in the community, and can strategically coordinate and prioritise care across the whole area rather than just responding to individual requests on an ad-hoc basis.

The new service complements existing models, such as the single point of access (SPOA) and Hospital at Home, linking with current discharge pathways and primary care teams to avoid duplication. The senior nurse role is based with the SPOA District Nurse (DN) Team Leaders to facilitate this integration. An admin coordinator and volunteer manager support the senior nurse.
1.5 Expected Outcomes

The expected outcomes for the new service fall under three main headings:

**Quality of Care/Patient Satisfaction:**
- More patients supported.
- More non-cancer patients supported.
- Improved patient/ carer wellbeing.
- Patients involved in decisions.
- Patients realise their preferred place of care and death.
- Increased proportion of time at home in the last 6 months of life.

**Process/Efficiencies:**
- Patients supported while they wait for a care package to be put in place.
- Better communication across healthcare providers.
- Clinical time freed up for clinical activities.

**Cost benefits:**
- Increase in the patients discharged from acute settings.
- Decrease in proportion of deaths in acute settings.
- Decrease in the average length of stay in hospital for patients in the last 12 months.
- Reduction in admissions.
- Reduction in spend on care.
2 Methodology

2.1 Evaluation Questions

The evaluation brief from Marie Curie set out four key questions:

1. How efficient is the new integrated care model? In particular are patients able to access care in the community more quickly when discharged from Hospital or Hospice following the implementation of the pilot?

2. What is the impact of the integrated care pilot on each of the services (Hospice at Home and Helper services), with focus on place of death, and patient and carer wellbeing?

3. What is the experience of the patient and their carers through the end to end process of the care delivery model?

4. What is the overall impact of a coordinated approach to delivering palliative care services? In particular, what is the impact on: the total number of patients who receive services, admissions and time spent in acute settings at the end of life, the experience of the patient and their families, integrated working across healthcare providers, and the total costs of hospital care?

2.2 Scope

The evaluation focuses on the delivery of care by the Marie Curie pilot service between July 2014 and June 2015 (inclusive). Comparison of service provision has been analysed for the 12 month period (April 2013-March 2014) prior to the implementation of the integrated care pilot (the ‘before’ period) and the 12 month period (July 2014-June 2015) for which post-implementation data is available (the ‘after’ period). All tables have been added in appendices for further information.

2.3 Healthcare Professional Surveys

Baseline interviews were conducted with stakeholders involved in the design and implementation of the new service. These captured an understanding of the service prior to implementation and the drivers for the new service, as well as stakeholders’ attitudes and expectations of the new service, including perceived benefits and barriers. Our analysis is included in this report.

The purpose of the baseline survey of Healthcare Professionals was to capture feedback about their knowledge of the new Marie Curie Fife service pilot and identify the potential
opportunities for the service to improve palliative care. Between 70 and 80 questionnaires were distributed and 22 responses were received (around 30%). The survey took place between July and August 2014. The majority of the respondents were District Nurses (14, 64%). The remainder comprised of District Nurse Team Leaders (6, 27%) and ‘other’ (2, 9%).

For the follow-up survey, 37 professionals responded. The largest proportion of respondents were Marie Curie Health Care Assistants (11, 30%) and District Nurses (9, 24%). The remainder comprised of Palliative Care Specialist Nurses (4, 13%) and ‘Other’ (12, 33%). ‘Other’ included Service Manager, Social Work, Social Worker, Unit Manager in a Fife Council Care Home, Palliative Care Doctor and Consultant in Palliative Medicine.

### 2.4 Healthcare Professional Interviews

Interviews with Healthcare professionals captured feedback about the new service and investigated whether stakeholders and healthcare professionals felt the new service was successful and had improved on the previous service.

Eight qualitative interviews with stakeholders were undertaken (face to face and telephone) during July and August 2014. The interviews were designed to explore the palliative care landscape prior to the new service; views on the set up and early delivery of the service including any barriers and challenges encountered; the intended impacts of the service; and opportunities and challenges moving forward.

Sixteen follow-up interviews were conducted over the phone by two team members, throughout July and August 2015, to identify any impacts on patients, carers/families and the wider health and social care landscape and any aspects of the service that could be improved. Respondents are broken down by work area below:

<table>
<thead>
<tr>
<th>District Nurses and team leaders</th>
<th>5</th>
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<tbody>
<tr>
<td>Marie Curie staff – nurses, senior nurses and volunteer helpers</td>
<td>5</td>
</tr>
<tr>
<td>Hospital and hospice staff – Occupational Therapists, doctors</td>
<td>3</td>
</tr>
<tr>
<td>Social services – homecare assessors and managers</td>
<td>2</td>
</tr>
<tr>
<td>Other community staff – specialist palliative care nurses</td>
<td>1</td>
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</table>
2.5 Patient/Carer Survey (December 2014 – September 2015)

There was a total of 79 responses to the patient and carer survey, of which 60 were friends or family members completing the survey on behalf of a patient. Respondents had received the following services from Marie Curie: Marie Curie Nurse (during the day): 49; Marie Curie Nurse (overnight): 36; and Marie Curie Helper service: 17.

2.6 Case Studies (November 2014 – July 2015)

The case studies focussed on patients and their carers and the healthcare professionals involved in their care, to capture a rich and multi-perspective picture of the service and its impact on their daily lives. Interviews with case study participants were completed in July 2015.

The seven completed case studies are attached to this report in Appendix 8. A summary of the case study findings can be found in Section 5.5.

2.7 Quantitative Data Analysis

A key benefit anticipated for the new service is it will change patterns of service use across health and social care, potentially reducing the use of acute services and increasing the number of patients able to die at home. In order to analyse and quantify patterns of service use across the health and social care patient pathway, it is necessary to link data from the health care records of patients who receive the new Marie Curie service. To determine the impact in usage of acute services a matched comparison group of similar patients was identified.

OPM commissioned eDRIS (Electronic Data Research and Innovation Service) to undertake the linkage and analysis of data from Marie Curie and NHS Fife. Data regarding social care usage was requested from the local authority but was unfortunately not available for this analysis.

2.7.1 The matching process

The population from which the matched control group was selected was any Fife resident who had a hospital admission and who had died in the 18 months preceding the pilot. Patients from the pilot cohort were initially matched to the control group population using gender, age group, deprivation and Marie Curie diagnosis to identify a list of possible

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2 eDRIS is part of Public Health Intelligence (formerly ISD and HPS).
matches. Ten possible matches were identified for each patient in the pilot cohort. For each pilot cohort patient the time (number of days) between the first Marie Curie visit and date of death was derived. This time was then subtracted from the date of death of each of the possible matches in the control group in order to create an “index” date (which would be equivalent to the first Marie Curie visit date for the pilot group). Hospital usage (number of days in hospital) in the six months prior to the first Marie Curie visit (for pilot group) and index date (for control) was then calculated and used to select the best individual match for each patient in the pilot group. Thus each patient was matched, as closely as possible, to a patient in the control group using gender, age group, deprivation, Marie Curie diagnosis and number of days spent in hospital in the six month period prior to first Marie Curie visit date/index date. The cohorts were checked to ensure that no patient appeared in both cohorts.

Figure 1: Example of matching process
2.7.2 Results of matching process

In total, there were 275 patients supported over the pilot period. The matching approach was applied to these patients. Eleven pilot group patients were subsequently excluded from the matching process as no suitable match could be found, 20 patients were supported before the pilot period and were removed to ensure clarity of results and 31 patients had no death recorded at the point of data extraction and were likely still alive. Therefore, the final pilot and matched cohorts comprised of 213 patients in each cohort.

In summary:

- 100% match on gender
- Exact match in diagnosis in around 95% of cases where a definitive diagnosis was recorded (191 patients had a specific diagnosis recorded, 181 were matched to the same diagnosis). 22 patients had non-specific diagnoses (e.g. “Cancer”/“Non-cancer”) and these were matched accordingly to patients with any cancer or non-cancer diagnosis.
- Over 90% of patients matched within a 5 year age band either side of their own age band
- 92% of patients matched within one deprivation quintile either side of their own
- 85% matched within a 5 year age band either side of their own age band and within one deprivation quintile either side of their own
- Almost 82% of patients within +7 or -7 bed days in terms of hospital usage in the 6 months prior to first MC visit.

Once the matching process was complete, analysis of the hospital activity for both cohorts was undertaken. This work focussed on the number of hospital inpatient admissions and A&E attendances, average lengths of stay for hospital admissions, hospital specialties associated with admission, discharge destination for A&E attendances and time spent in the community compared to hospital. All of this analysis related to the time period between the first Marie Curie visit date/index date and date of death.

2.8 Economic Assessment

The final element of the evaluation was an economic assessment of the hospital costs associated with any activity seen in the pilot and matched cohort.

To assess the impact on hospital costs for end of life care across Fife, the economic assessment moves away from focusing directly on the period during which the pilot was in place. Instead, it uses the evidence from the pilot to inform an analysis of what the overall care costs would be for end of life patients under the Hospice at Home service in the next financial year of 2016/17.

All financial figures are presented as 2016/17 values to allow for comparison between years. Original costs provided for other financial years have been inflated or deflated by 2.5% in line with HM Treasury Guidance.
End of Life Care Provided under the Pilot

3.1 Introduction

This section of the report presents analysis of data regarding service use captured during the Hospice at Home pilot evaluation period, July 2014 to June 2015. The service usage is described to give a picture of activity under the pilot. Comparisons to the Marie Curie services provided in the baseline year (April 2013 to March 2014) are noted but it should be remembered that the previous Planned Variable service was very different in nature.

3.2 Overall Service Outputs

The pilot service has enabled 322 patients per year to receive end of life care in their home from Marie Curie. 275 patients were supported by the new nursing service and 79 households were supported with the Helper service, at least 47 of whom did not receive support from the nursing service. The total number of patients referred to the Marie Curie service has increased by 158 (96%) per year from 164 patients in the baseline year.

3.3 Marie Curie Helper Service

3.3.1 Referrals

Between July 2014 and June 2015, clients from 96 households were referred (in some households there are multiple clients) to the Marie Curie Helper Service in Fife.

The most commonly cited reasons for referral were social support (73%) and respite support (64%), with few records stating a reason of emotional or practical support.

The number of referrals per month gradually increased over the time of the pilot with six referrals per month in the first 6 months and 10.5 referrals per month in the second 6 months.

3 Multiple reasons could be cited for each referral.
3.3.2 Clients

79 households with one or more clients were supported with a visit or phone call over the time period under review (not all patents referred would have gone on to receive support).

The supported clients, who were people with a terminal diagnosis, were all over 40, with nearly three quarters (72%) of clients being over 70.

The majority of people with a terminal illness had a diagnosis of Cancer (78%) and resided in their own homes (91%). According to the Helper data records, of the 79 clients supported, 39% (n=32) were also supported by the Marie Curie Nursing Service, suggesting that overall the helper service supported an additional 47 clients than the nursing services over the evaluation period.

The majority of carers were either the spouse or partner (71%) or the child (24%) of the terminally ill person, and few were other relatives (2%) or had another relationship (e.g. neighbours, 4%).

3.3.3 Visits

Visits were delivered to support both the patient and their carers or family members. Overall in 94% of visits a person with a terminal illness was supported and in 25% of visits, a carer or family member was supported.

Table 1: Recipient of visit | Marie Curie Helper Database | July 14 to June 15

<table>
<thead>
<tr>
<th>Client</th>
<th>% Visits</th>
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<tr>
<td>Both (patient &amp; carer)</td>
<td>19%</td>
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<tr>
<td>Carer</td>
<td>6%</td>
</tr>
<tr>
<td>Patient</td>
<td>75%</td>
</tr>
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</table>

Since July 2014, Helper volunteers delivered 633 hours of support over 341 visits. On average, clients received around 8 hours of support across four visits. Table 2 and Figure 2 show that visits and hours have risen steadily since the start of the service.

Table 2: Activity | Marie Curie Helper Database | July 14 to June 15

<table>
<thead>
<tr>
<th></th>
<th>First 6 months</th>
<th>Last 6 months</th>
<th>Total</th>
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<tr>
<td>Visits</td>
<td>97</td>
<td>244</td>
<td>341</td>
</tr>
<tr>
<td>Hours</td>
<td>171.5</td>
<td>461.5</td>
<td>633</td>
</tr>
<tr>
<td>Clients</td>
<td>28</td>
<td>55</td>
<td>76</td>
</tr>
<tr>
<td>Visits per month</td>
<td>16</td>
<td>40</td>
<td>28</td>
</tr>
<tr>
<td>Hours per month</td>
<td>29</td>
<td>77</td>
<td>53</td>
</tr>
<tr>
<td>Clients per month</td>
<td>7</td>
<td>16</td>
<td>12</td>
</tr>
</tbody>
</table>
As with any new service, the number of referrals, visits and hours of support provided by the Helper service have all increased over the first year of service delivery (Table 2 and Figure 2. Using the last 6 months as a proxy for ‘normal delivery’ it is likely that in the future the service will support at least 16 clients with at least 40 visits per month over the next year. Given that the service is still growing, this would give a conservative annual estimate of 110 clients across 480 visits.

3.4 Marie Curie Nursing Service

3.4.1 Patient Profiles

The pilot service supported 275 patients in the pilot timeframe, 111 more than the previous model of the nursing service. On average 34 patients were supported per month under the Hospice at Home service compared to 23 per month under the previous service.

As with the Helper service, the number of referrals, visits and hours of support provided have increased over the first year of service delivery. Using the last 6 months as a proxy for ‘normal delivery’ (where 151 patients were supported) it is likely that in the future the service will support at least 302 patients per year.
The profile of patients receiving Marie Curie care is described below and across most indicators remains similar before and after implementation.

The age of patients remains stable between the baseline and pilot evaluation group, with largest group being aged 65-79 (46%) followed by patients aged over 80 years old (33%) and finally patients aged 40-64 (21%). There was one patient in the pilot evaluation group who was aged 18-39. The gender make-up also remains stable, with an almost even gender distribution in both periods.

A specific objective of the Hospice at Home service was to increase the number of non-cancer patients receiving end of life care each year and Table 3 shows that was achieved.

Table 3: Comparison of non-cancer patients by condition between baseline and pilot evaluation group

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Time Period</th>
<th>Planned Variable</th>
<th>Hospice at Home</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>%</td>
<td>Number</td>
</tr>
<tr>
<td>Bronchiectasis</td>
<td>0</td>
<td>0.0%</td>
<td>1</td>
</tr>
<tr>
<td>Cerebral infarction (CVA, stroke, cerebrovascular disease)</td>
<td>1</td>
<td>3.7%</td>
<td>2</td>
</tr>
<tr>
<td>Chronic ischaemic heart disease</td>
<td>0</td>
<td>0.0%</td>
<td>1</td>
</tr>
<tr>
<td>Chronic Obstructive Airway Disease (COPD &amp; COAD)</td>
<td>4</td>
<td>14.8%</td>
<td>6</td>
</tr>
<tr>
<td>Dementia (not Alzheimer's)</td>
<td>4</td>
<td>14.8%</td>
<td>7</td>
</tr>
<tr>
<td>Heart failure (congestive cardiac failure, CCF)</td>
<td>5</td>
<td>18.5%</td>
<td>6</td>
</tr>
</tbody>
</table>
The estimated prognosis at time of referral, as recorded by the District Nurse, for those patients is broadly consistent between the two periods, with most patients having a prognosis of weeks (52%) and a fairly even split between days (23%) and months (25%).

### 3.4.2 Patient Visits Provided

In total, the Hospice at Home service has provided 4,047 visits in the pilot evaluation period. As a result of the new Hospice at Home service model, where multiple patients are often supported in one nursing shift, a large proportion (80%) of visits were under 5 hours each, with patients receiving an average of 15 visits across the whole service.

The Hospice at Home service model is designed to offer a different type of care which is more tailored to patients' needs than that provided in the Planned Variable service. As such the profile of visits is very different when the two services are compared. In the Planned Variable service, 1,084 visits were provided, with an average of 7 visits per patient. In line with the focus on overnight care in the Planned Variable service, only 16% of the visits were under 5 hours as shown in the figure overleaf.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Visits</th>
<th>Percentage</th>
<th>Visits</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motor neurone disease (MND)</td>
<td>7</td>
<td>25.9%</td>
<td>9</td>
<td>18.8%</td>
</tr>
<tr>
<td>Multi-system failure (old age)</td>
<td>2</td>
<td>7.4%</td>
<td>3</td>
<td>6.3%</td>
</tr>
<tr>
<td>Multiple sclerosis (MS)</td>
<td>1</td>
<td>3.7%</td>
<td>1</td>
<td>2.1%</td>
</tr>
<tr>
<td>Parkinson's disease</td>
<td>0</td>
<td>0.0%</td>
<td>1</td>
<td>2.1%</td>
</tr>
<tr>
<td>Prostatic hypertrophy</td>
<td>0</td>
<td>0.0%</td>
<td>1</td>
<td>2.1%</td>
</tr>
<tr>
<td>Renal failure (acute)</td>
<td>0</td>
<td>0.0%</td>
<td>2</td>
<td>4.2%</td>
</tr>
<tr>
<td>Renal failure (chronic)</td>
<td>1</td>
<td>3.7%</td>
<td>1</td>
<td>2.1%</td>
</tr>
<tr>
<td>Unknown: non-cancer</td>
<td>2</td>
<td>7.4%</td>
<td>7</td>
<td>14.6%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>27</td>
<td>100.0%</td>
<td>48</td>
<td>100.0%</td>
</tr>
</tbody>
</table>
The responses from the healthcare professional survey are in line with the statistics of service delivery. Non-Marie Curie healthcare professionals were most likely to report having used or referred to Fast track- urgent home care (17 of 23 respondents). In addition, Planned overnight care in the home (15 of 23 respondents) and Planned day care in the home (13 of 22 respondents) was used by a high proportion of those who responded. By contrast, the helper service was used or referred to least by the Non-Marie Curie healthcare professionals (5 of 21 respondents).
4 How Efficient is the New Integrated Care Model?

4.1 Introduction

This section seek to the answer the question “How efficient is the new integrated care model?” and in particular whether patients are able to access care in the community more quickly when discharged from Hospital or Hospice following the implementation of the pilot. Healthcare professionals were impressed with how quickly the service was implemented.

‘In the past we’ve had patients fit enough to go home but by the time the service [Homecare] was available they weren’t and so they ended up stuck in the hospital until they died’ (hospital based staff).

78% HCPs felt quality of patient care had improved, 76% felt patients have better continuity of staff, 77% felt patients receive more coordinated packages of care at times when they need it and 84% felt that patients have confidence that MC and the NHS can work well together to provide the palliative care they want/need.

HCPs also felt that positive outcomes had been achieved for families. 46% felt that the stress felt by families had decreased, 46% felt that families and carers feel more supported and able to take time away from care and 43% felt that families and carers feel more in control of the care being provided.

4.2 Providing the Right Care at the Right Time

The surveys and interviews both suggested that the Hospice at Home service offered an improved level of access to end of life care, which meant that patients received the type of care they needed to remain in their own homes.

4.2.1 Availability of the Service

Healthcare practitioners described the availability of the Marie Curie services as good. In addition to positive comments in the interviews, within the healthcare practitioner survey only 4 of the 23 respondents reported ever being unable to access a service, with 2 of those relating to the Fast Track - Discharge service and 1 each for Fast Track – urgent care and Planned overnight care in the home.

A comparison between the before and after Healthcare Practitioner surveys shows that the experience of access to end of life care services in Fife has improved. Previously 45% of
respondents agreed or strongly agreed that “it is easy to access end of life care services in Fife”. This had increased to 67% within the follow up survey.

The availability within the service meant that patients were able to receive care at very short notice, unlike the local Homecare service which could take days or weeks to put in place. For this reason, the service was often used as a bridging service while patients were waiting for other services.

“I recently had a letter from a family who we’d involved Marie Curie Fast Track service [which] meant we got her discharged on Friday afternoon and she died in the early hours of Monday…We wouldn’t have been able to get that in place so quickly without Marie Curie.” (hospital based staff)

“They may not be able to get in the next day but they will the day after.” (Community-based staff)

Healthcare Practitioners noted in the survey that it would be beneficial if the Helper could also take on personal healthcare tasks.

“It is a great service but would be better if assistance to toilet could be incorporated as per the crossroads service.” (community based staff).

There were some concerns from community-based staff and Marie Curie nurses that the Marie Curie service was not adequately promoted. There might be periods where capacity in the service was very high and there was lots of room to take on new patients. It was noted that people were not always aware of the services so continuous promotion of the service was required to ensure referrals, such as visiting surgeries and handing out flyers. There was also a concern about the consistency of referrals across the area, for example, some GP practices referred more than others. It was also felt that the Fast Track service in particular, as a newer service, needed more promotion amongst district nurses, GP practices and hospitals.

“There are some areas in Fife I’ve worked almost 10 years and never had a patient from some practices, so they just don’t refer to Marie Curie for some reason. I think we need to have a look at who refers and who doesn’t refer, and try and target and promote the service to the district nurses and practices that don’t use Marie Curie at the moment. Because these practices have to have palliative care patients that need help.” (Marie Curie).

Hospital-based staff reported there were no problems getting referrals into the service and no long waiting times for the service to start. Although this was welcomed, there was a sense that the service was perhaps not being used to its full potential. However, it was noted that it seemed to be getting busier (especially the overnight service) and that capacity within the service was always likely to fluctuate rapidly due to the patient’s end of life stage.
“You might have two or three patients pass away within a day or couple of days, and only have one or two patients. But recently, when that’s happening, we’ve been getting another referral and that’s really good, because we’ve got this time and can be out there assisting and helping and supporting patient and family.” (Marie Curie).

### 4.2.2 Scope of Referrals and Links to Homecare

The perception of the fast-track service is that it is prioritised for patients in the last weeks of life. Several non-Marie Curie health and social care workers expressed a wish for the Fast Track service to be extended to palliative patients at any stage in their terminal illness, rather than in the very end stages of life. Some felt that palliative care patients at this earlier stage would also benefit from the service. Others found it difficult to assess whether a patient was approaching the end of life and therefore appropriate for the service. The service would therefore benefit from increased communications with the referrers and social care teams about the scope of the service and the prioritisation of patients.

“For certain patients their prognosis is poor and they’re absolutely appropriate for Marie Curie service but it’s more challenging when you’ve got patients you’re not sure what the prognosis is going to be, might live for a few weeks or it could be less, and so you don’t know are they appropriate or are they not? Marie Curie works so well with end-of-life patients and don’t want to then have them trying to support people it would be more appropriate to have homecare for.” (hospital based staff).

The scope of who should be referred has been considered by the programme team throughout the pilot and it is felt that it was an appropriate use of the service to act as a bridge between hospital and homecare services. Consequently, the Hospice at Home service was being used by wider palliative patients where there were delays in Homecare services. These cases are closely managed by the Hospice at Home team who have a clear understanding of when Homecare will be put in place. However, interviewees cited it as important that the Hospice at Home service is not seen to be replacing Homecare.

The use of the Hospice at Home service as a bridge to Homecare was creating concern among some patients and practitioners who felt there was a lack of clarity about when the Hospice at Home service might be withdrawn. One practitioner felt that the service could be withdrawn even if Homecare was not in place in time.

While the flexibility of the Hospice at Home service is of benefit to patients, it is important that there is clarity among other healthcare practitioners.

“Marie Curie is bridging the gap between the patient coming out of hospital and Homecare being in place. But that’s not what the Marie Curie service is
for, it’s meant to be for end-of-life care, not to supplement the Homecare service!” (community based staff).

Overall, however, the connection between the Hospice at Home service and the Homecare service was seen as working well. Marie Curie staff would contact the Homecare team to verify homecare has been put in place and reassure families that they would not leave until they knew Homecare or another service was operational.

"I know it can be quite distressing for some of the families when they’re getting Marie Curie Fast Track and they get to know the girls and they really think highly of them and then all of a sudden it stops and they don’t see them again. I think there could be a little bit more of a coordination and handover period.” (Marie Curie staff member).

While some Healthcare practitioners felt that moving between services could be stressful for patients and families, it appeared that coordination between the services had recently improved. Homecare staff were being educated about the availability and eligibility of the Hospice at Home service, whilst Marie Curie were given access to a local authority ‘matching service’ to identify available care from other providers in situations where they wanted to move a patient out of the end of life service.

4.3 Better Communication across Healthcare Providers

An important benefit reported by the healthcare practitioners was the extent to which the Hospice at Home service was working more effectively alongside other health and social care services.

4.3.1 Awareness of the Services

Awareness of the Hospice at Home service among Healthcare practitioners was high. Around 23 of the 24 (96%) non-Marie Curie healthcare practitioners who responded to the survey reported that they were aware and knew how to access the Fast Track-Urgent home care, Planned Overnight care and Planned day care. Slightly fewer respondents were aware of the Helper service and Fast-Track discharge service, with 19 and 16 out of the 24 respondents respectively being aware and knowing how to access the services.
For most aspects of the service respondents had seen service specific communication materials or become aware through a colleague at their organisation. 14 of the 24 non-Marie Curie respondents reported that they had attended an information session or workshop about the Hospice at Home service.

4.3.2 Perceived Integration of Service and Access

From the patient perspective, the Hospice at Home service was perceived to be well integrated with other services. 73 of the 78 (94%) respondents completing this specific question reported that they agreed or strongly agreed that there was sufficient communication between Marie Curie and other professionals.
There were mixed views from the healthcare practitioners about other aspects of the service. In other areas, such as perceptions around ‘seamless integration’ or the process being ‘efficient’, there was very little change from before the pilot. Responses to these questions were evenly split between those agreeing or disagreeing, with around a third reporting they neither agreed nor disagreed with the statements shown in Figure 7. Overall the perceptions were slightly more positive than negative, as was the case before the pilot.
Figure 8: Healthcare practitioner views of service and access

Interviewees were generally content with the way the referral process was integrated with other services. If the patient is not registered with the service, District Nurses phone the central office in Pontypool (where it was noted that staff are good) and are then transferred to the local team. If the patient is already registered with the service District Nurses contact the local coordination team directly. In some cases, it appears that after phoning Pontypool, referrers are given another number to ring to speak to the local team, rather than being put through directly.

“From the minute you pick up the phone it seems to be such a seamless service.” (community based staff)

However, other health professionals noted that there had been teething problems initially, which have since been solved. There was a lack of clarity around the referral process, particularly in the hospice and hospital context, because of the necessity of going through a District Nurse. In some cases, hospital-based staff contacted the local coordinator service initially to enquire about capacity. In addition, it had not always been clear who was responsible for elements of paperwork, with District nurses typically being required to complete an initial assessment before Marie Curie can provide care.

“I understand the referral does have to be made by the district nurse but what I would tend to do is phone [Marie Curie service coordinators in Fife]
to check availability before talking to families about it, so you don’t raise hopes and then contact the district nurse and have a conversation with them.” (hospital based staff).

Additional work had been undertaken by Marie Curie to streamline this process, which is discussed later in this section.

4.3.3 Communication between Marie Curie and other Healthcare Professionals

Interviewees suggested that the local contacts and local knowledge made a difference to working relationships and to the speed of response. They valued being able to speak directly to those coordinating the Marie Curie nurses as they could give them immediate feedback on capacity.

Within the healthcare practitioner survey, the perception of communication across healthcare providers was seen to improve. In the follow up survey 15 of the 23 (65%) respondents agreed or strongly agreed that there was good communication compared to 10 of 22 (45%) respondents before the pilot.

The local Helper Service is also cited as having good communication with the local coordinating team as a key factor in ensuring that volunteers were well matched with patients, leading to patients being better supported.

“You can get to know the people involved – sort of become part of the team you’re working with.” (community based staff).

Most interviewees reported that communication was positive and implemented by noting changes to a patient’s care in the Care Plan (patient-held document) or through the senior nurse at Marie Curie. It was also noted that Fast Track and Planned Care staff seemed to communicate well amongst themselves about patients and the Marie Curie service seemed to have become well integrated with other services.

“Sometimes patients feel like beforehand it was a different service coming in, but now more like part of the community team.” (community based staff).

However, Marie Curie nurses reported that out-of-hours communication between Marie Curie and district nurses was more difficult and time consuming. Where patients had many different healthcare professionals coming into their home, it was not always clear to them who was leading their care, and as a result on one occasion information was not passed on.

“If you have a patient who has a bit of a query, and you think it could be a question answered quite simply if you could just get in touch with district
nurse. But you have to go through out-of-hours, that’s our biggest bugbear really, can’t just have a number to get through to them. It takes about 40 minutes to go through whole process.” (Marie Curie).

4.4 Clinical Time Freed up for Clinical Activities

Overall the Hospice at Home service was seen as providing a valuable resource that enabled the release of clinical time. The impact on hospital usage is discussed in section 6. The section below considers the impact on services outside of hospital.

4.4.1 Quick provision of Additional Resources

The speed with which the service could be accessed was seen as crucial for end-of-life patients who were already in hospital (or a hospice) because of their life expectancy, as well as the concept of a ‘window of opportunity’ in which they could return home.

“There’s often a small window of opportunity to get someone home and for me that’s where Marie Curie works really well because they can respond within that small window whereas homecare usually couldn’t. By the time homecare came back with a package, the patient might be too ill to consider moving or the family’s too exhausted to manage it.” (hospital-based staff).

The speed of access continued when Marie Curie services were in place. For example, if the patient deteriorated, Marie Curie nurses could suggest additional or alternative services and get them in place quickly. The Hospice at Home service could provide care that would otherwise be provided by District Nurses or Homecare teams (if there was availability).

“Something I’ve found quite amazing is how things can so quickly get into a progression, which is great because that’s exactly what they need.” (Marie Curie).

Given the speed of access and availability, the Hospice at Home service was perceived as additional resource by Marie Curie nurses. The service was not perceived as a ‘nice to have’ but rather one of the regular services relied upon by the local healthcare teams to provide care when needed.

“It gives us another option. When we’re in a situation where somebody desperately wants to get home and they’re end of life, it means there’s a resource there that we wouldn’t have otherwise.” (hospital-based staff).
4.4.2 Taking Pressure off District Nurses (and other services)

The Marie Curie Hospice at Home service provided personal support and care. This freed up district nurse time allowing them to spend more time with their patients doing both clinical tasks, where they have the greatest expertise, and talking and listening to the patient and their families/carers. As a result of knowing that the high quality care is in place through Marie Curie, district nurses reported being able to become more flexible in their visits. They have confidence that the Hospice at Home service can maintain patients at home and give them the best possible care.

"It's always been part of [district nurse's] role to deliver clinical care particularly for terminally ill patients, but with the start of Marie Curie service it takes away the pressure on [district nurses] for the personal care.” (community-based staff).

"[District nurses] know they don’t have to rush in the morning to that particular patient. They know they’ve been looked after and if any problems then we’re getting in touch.” (Marie Curie).

As already noted, the overnight service is particularly valuable to the local health economy. The only other overnight care service available is the on-call nurse. As a consequence of the Hospice at Home service providing professional overnight care, some healthcare practitioners perceived that there had been fewer calls to the on-call nurse. Since the on-call nurse is only paid for the calls they attend, this is another potential financial saving achieved by the pilot.

"If it’s a trained member of staff sitting overnight, [I] don’t have to call out the on-call nurse…the on-call nurse is on call but she’s not sitting anywhere waiting, she only gets paid for her call out visits so she’ll be in bed somewhere, the service prevents them having to be called out…saves money for NHS too I suppose.” (community-based staff).

More broadly, the impact of having regular contact with professional end of life carers was perceived as resulting in fewer calls to the doctor or 999. Whereas family members or carers might not know how to deal with the complex needs of their loved one, having access to a Marie Curie nurse meant that they were less likely to call for medical help (in the perception of healthcare professionals).

"I think the family would be more likely to contact the doctor if they’re coping on their own and dealing with complex conditions. Marie Curie are there and that’s highly skilled people going in, must make it less likely to access local health services.” (community-based staff).
4.4.3 Concerns around Paperwork

The speed of the service to respond is somewhat compromised by the need to have particular paperwork in place, such as Care Plan, Do not Attempt Cardiopulmonary Resuscitation (DNACPR) and risk assessment. If people are discharged suddenly (particularly on a Friday afternoon) it can be difficult to get these things ready in time. The Marie Curie nurses need this information to safeguard themselves and the patient. However, district nurses are not always immediately available to complete this.

“The speed we have to work at and [as the] district nurses are out on their visits, we sometimes find it really hard to get hold of a district nurse. They always phone us back, but by the time they phone us back we’ve lost however many hours and we’re wanting them to drop what they’re doing, even though they’ve got lots of other work and make the referral, like now.” (hospital based staff).

Some interviewees felt that the service had an ‘over-the-top’ approach to risk assessment. In some cases the Marie Curie service had not been able to undertake certain tasks because a risk assessment was not in place for that task, which had a negative impact on patient care. On one occasion, this appeared to lead to reduction in trust in the service.

"I still had to go back to the office and type up a risk assessment when we’d removed the risk. We’re just making up things if you’re having to put a piece of paper there – all the more work for us." (community based staff).

There was some suggestion from Marie Curie nurses, district nurses and hospital-based staff that district nurses should not always have to take responsibility for doing the risk assessments and referrals. This was particularly an issue where the patient was already in hospital waiting to be discharged and was not known to the district nurse. Hospital staff would have to relay information about the patient to the district nurse, who would have to write up a risk assessment based on this information and then pass this information on to Marie Curie.

“I think if the patient is already at home it makes absolute sense, but if patient is actually in hospital that must be really difficult for the district nurse because they are the one passing on the information but it’s not really their information, if you know what I mean.” (hospital based staff).

These challenges are familiar to the Marie Curie team and ways of working are being adapted to facilitate a smoother transfer of information and speed up the referral process. It is too early to tell if these are being successful.
"What I’ve been doing is working with nurses on the ward to complete the risk assessment like the client handling part of it and emailing that to the district nurse so I know she has that information." (hospital based staff).

“We’re looking at whether you could get the risk assessment in place and do the referrals ourselves. If district nurse has not been involved and I have, it’s better because they don’t know the patient.” (community based staff).
5 What is the Experience of the Patient and their Carers?

5.1 Introduction

This section draws upon the patient/carer surveys, interviews and case studies to explore their experiences of the services and the impact of the service on their health and wellbeing and choices about their care.

5.2 Overall Experiences

Overall patients and carers held very positive views of the Hospice at Home service. This was reported directly by patients and carers, and was evident in the healthcare professionals’ feedback.

The patient/carer survey included a version of the NHS friends and family test, to assess the extent to which patients and carers would recommend the Hospice at Home service. Figure 9 provides the responses to this question, which are overwhelmingly positive with 72 of the 78 responses (92%) stating that patients and carers are ‘extremely likely’ to recommend the service.

Figure 9: “How likely are you to recommend Marie Curie services to friends and family if they needed similar care?” Patient/Carer survey

![Graph showing responses to the question](image)
5.3 Improved Patient/Carer Wellbeing

The type and quality of care provided by the Hospice at Home service have contributed to patient/carer wellbeing in several areas.

Patients and carers reported that the availability of the service reduced the level of anxiety they had about their care needs. Healthcare practitioners reported that the patients had complex needs spanning: pain management, domestic needs and coming to terms with their condition. This contributed to patients and carers describing themselves as being left feeling ‘helpless and anxious’. Figure 10 shows that the majority of patients and carers responding to the survey felt the Hospice at Home service helped reduce their feelings of anxiety. In total 61 of the 74 respondents (82%) either agreed or strongly agreed that the care had helped reduced feelings of anxiety or worry.

Healthcare professionals reported in the interviews that the Hospice at Home service reduced anxiety and stress because Marie Curie nurses spent time talking to the family and answering their questions. The Hospice at Home service will be just one of many services, and an important part of the care is helping patients and carers come to terms with all the different services. The flexibility to spend this time with families and carers was noted to be particularly important when carers themselves were elderly.
“[Patients] might be frightened about facing impending death and the symptoms are difficult to manage, like chronic pain.” (community-based staff).

"Because these are often elderly people their spouses are normally elderly with it. We can take our time each time we’re in and go through different things with them. I think people forget that the carer is normally elderly as well. They need time to adjust to these as well. If lots of services coming in and lots of information they can’t cope different things.” (Marie Curie).

A second impact described related to the ability of the service to support the family and carers. Results from the patient/carer survey in Figure 11 shows that 65 of the 74 respondents (88%) reported that the service “Always gave the right amount of support for family and carers”.

Figure 11: “Marie Curie provides the right amount of support for my family members and friends who care for me” – Patient / Carer survey

A key benefit for family and carers was being supported to take a break from caring responsibilities. Carers were described as needing a break for both practical and emotional reasons, and the service was able to provide this. In addition to being a benefit for patients, this support helps to prevent a ‘crisis’ where families or carers can’t cope, which otherwise the patient may have had to be admitted to hospital.

“[The patient's wife] had got to the point where she couldn't do it anymore, and she was visibly upset. [We] reassured her that we would be in twice a
day, you could see the relief on her face. She can’t go out the house because she can’t leave her husband so we know there’s planned care service there if she wanted to go out to the shops or to see a friend, we could get them to go in if she wanted that. Relief on their faces melts your heart sometimes.” (Marie Curie).

The overnight service was particularly valued as it provided a service which the district nurses were not able to. As well as providing support for families which are particularly strained by providing overnight care, the service kept patients out of hospital as there was no other service available overnight.

"Our biggest worry when we’ve got palliative care is that the family is up half the night and making themselves ill because they’re not getting enough sleep but with someone in they can relax a bit and take off some of the stress.” (community based staff).

An important part of supporting families is giving families and carers quality time with their loved one. As well as taking the care responsibilities over from families and carers, the trained professionals are able to perform the same tasks more quickly. Together, these provide more time for the family to spend with their loved one.

"If we’re taking away from the carer having to wash and dress and shave for the loved one, if somebody comes in and takes that away from them, then that gives them the time to spend with their loved one rather than have to do all these chores which I think as a carer takes an awful lot longer because they’re not trained, they’ve got the girls to go in and do the job quickly – give them a bit more quality of time together.” (Marie Curie).

5.3.1 The importance of Professional Staff

The quality of Marie Curie staff was credited by many other healthcare professionals as being central to the impacts achieved by the Hospice at Home service.

Interviewees felt Marie Curie was the most appropriate service for end of life because staff are trained in palliative care (and receive on-going training) and can bring sensitivity to an exceptionally difficult time. Interviewees gave positive feedback about the helpfulness and caring approach of the staff, including feedback from families which extended to letters and cards of gratitude.

‘[Marie Curie staff] are probably more skilled in terms of dealing with end of life than [homecare] carers – who are not as qualified in that’ (community-based staff).
The quality of the staff was experienced in the way in which they interacted with patients and 74 of the 74 (100%) respondents to the patient/carer survey reported that they were ‘Always’ treated with dignity and respect. Additionally 56 of the 74 (76%) disagreed or strongly disagreed that they had to repeat themselves a lot to those providing their care.

“The care my husband received was warm, sympathetic, professional and reassuring. Nothing was too much from sitting, holding his hand and talking to him quietly improved our last few days and he died peacefully and pain free.” [Patient survey response]

### 5.3.2 The Impact of the Helper Service

The helper support was greatly valued for more isolated patients, either on their own or with one member of the family or one carer looking after them. In these cases, the helper was able to provide carer release and help to counter isolation. The matching process between helpers and clients was successful and there was positive feedback on the potential to do bereavement visits.

"[The Helper Service is] something really positive to be able to offer…knowing the volunteers are selected in that way and have had training and matched up to be compatible [with the patient]." (hospital based staff).

However, it was noted that the time taken between training as a volunteer helper and getting PVG (protecting vulnerable groups) clearance, delayed being able to start as a volunteer helper. In addition, the separation of the helper service and the clinical service meant that helpers were not always given updated information about the medical situation of the patient as it developed.

### 5.4 Patients Choice and Realising Preferred Place of Death

The Hospice at Home service was described by patients, carers and healthcare professionals as involving the patients in decisions around their own care. This included both the care they received on a daily basis, as well as enabling patients to achieve their preferred place of death. The evidence in this section supports the quantitative evidence in Section 6, which shows that Hospice at Home patients were more likely to die at home that in the hospital.

**Outcome achieved:** Patients realise their preferred place of care and death

91% of respondents felt the Hospice at Home service allowed them to be cared for where they want to be.
The results in Figure 12 show that 67 of the 74 respondents to the patient/carer survey either agree or strongly agree that the Hospice at Home service has enabled them to be cared for where they want to be.

Figure 12: “Having Marie Curie services has allowed me to be cared for where I want to be (e.g. at home)” – Patient / Carer survey

![Bar chart showing responses to the question: How satisfied were you with the care you received during your stay?](chart)

Healthcare professionals interviewed commented that the service is very flexible about the level of care because each patient is assessed in detail, so they can have the level of care they need. This can also change throughout the course of the care, for example if a patient’s condition deteriorates or the family can no longer cope, there are additional services which can be used, or more visits can be introduced. This flexibility allows the patient and their family to have a choice over the care received throughout the service duration and nothing is put in place without their agreement. Marie Curie nurses were able to explain the different services offered to the patient and their family and they played an ongoing role in assessing what would be best for the patient.

The results from the patient/carer survey (shown in Figure 13) demonstrate that 69 of the 69 respondents felt that they were involved in decisions around their care either ‘Most of the time’ or ‘Always’.
A central part of a patient’s care is their choice around place of death. Many interviewees felt that the Hospice at Home service enables patients to die in the location of their choice which would not have been possible if patients had to rely on the other services. Patients and Healthcare practitioners felt that, in relation to hospital discharges in particular, other services were setup too slowly following a referral. This has been discussed in detail in Section 4 in regard to the efficiency of the new service.

"It’s made that journey home possible for people. The people I’ve been involved with, where I’ve had direct experience, if it wasn’t for Marie Curie they wouldn’t have got home." (hospital based staff).

Families and carers stated an important outcome of the Hospice at Home service was supporting them to fulfil their loved one’s wishes. It was further noted that this type of support has longer term benefits throughout the bereavement process, with families able to feel as though they had done all they could for their loved one.
"We’re able to fulfil people’s dying wish. Beneficial effect for the family after the loved one dies and they reflect back on the experience. It’s more positive if the person has been able to die in the place they want to die, surrounded by loved ones and receiving care from people skilled in end-of-life care." (Community based staff)

5.4.1 The Importance of Flexibility

In addition to the flexibility of the services provided (see section 4), flexibility within visits themselves was seen important to enabling patient choice. Healthcare professionals noted that Marie Curie nurses were able to spend longer at each visit (this was often compared favourably to homecare), thereby catering to the needs of the patient, including being able to have meaningful conversations with patients and their families, as well as undertaking personal care tasks. As well as providing more time for care, this flexibility allows the Marie Curie team to build relationships with patients and ensure that patient care is joined up across all the services (for example taking the time to complete the patient notes).

"We don’t have allocated times. It’s down to your patient and their needs, depends on the patient, how ill they are. Have to take things pretty slowly at times or sometimes it’s just a wee chat to give them assurance about things." (Marie Curie).

The flexibility of the service is built around Marie Curie’s experience of end of life care and the understanding that individual situations can change quickly. For example, families may be able to cope initially, but later need more support either because the patient’s support needs become greater, or the strain of caring becomes too much. Marie Curie nurses noted that they manage the changing needs by phoning the patient in advance of visits, enabling them to rearrange the timing of their visits, for example if a visit was needed sooner.

The mixture of service types available, and the management of resources at a local level, means that the right type of care can be provided for each patient when needed. Where the level of care needed changes, Marie Curie staff reported being able to recommend another aspect of the service which better meets the patients current needs (for example offering the out of hour or overnight service).

‘Sometimes it can be quite daunting for the family when you first come in, but if you’re going in later and things are getting quite stressful, you can say ‘do you remember that service that I was talking about?’ and quite often they’ll say ‘yes that would be great’" (Marie Curie).
5.5 Case Studies

As part of the evaluation, OPM undertook seven case studies with patients and their carers. Patients and carers were all highly positive about the Hospice at Home service and cited key benefits:

Taking time to talk

“She rings and tells me that somebody from Marie Curie is coming, and we’ll have a conversation, sometimes we’ll have a good laugh together.”

Helping the family to cope with discharge from hospital

“It made it a lot easier for [patient] to come home, knowing they had that care input.”

Relieving stress and anxiety

“It helps to know that there is so many nurses coming; I’m not on my own now. They are all that good, all this crowd that comes in, takes the anxiety away, well the anxiety is there but it’s a big help.”

Improving communication between healthcare professionals

“The district nurse and GP are always talking to each other, as is the palliative care nurse.”

A streamlined referral service

“It was care that was delivered at the right time and in the right place. It was just what was needed.”

Person-centred care

“For instance that the first thing to try and calm him down is juice, not just medication, music is calming, reading aloud from a book.”

Choice and quality of life

“He has a life at home, in hospital he would just be waiting to die.”

Staying at home and together
“For us at home he is the most important person, but in hospital he would just be one of many important people, and perhaps not the most ill.”

Case studies can be found in Appendix 8.
6 What is the Impact of the Integrated Care Pilot on Health Care Usage across Fife

6.1 Introduction

This report has already highlighted that the pilot end of life service is reaching more patients and providing them with more visits than the previous Planned Variable service, whilst also providing a high quality of patient experience. The evidence so far supports the claim that the pilot services are more effective than the previous Marie Curie Services.

This section of the report takes a different approach to assessing the impact of the pilot service. It considers what changes to healthcare usage across Fife have been achieved in relation to end of life patients, not just what changes have been achieved compared to the previous Marie Curie service.

6.2 Comparator Group

To assess the impact on the wider healthcare usage across Fife, it is necessary to compare the patients receiving care under the pilot to a sample drawn from the population of all end-of-life patients across Fife before the pilot was in place (whether or not they received Marie Curie previously).

As described in the methodology, this approach analyses the differences in hospital service usage during the end of life period for 213 matched pairs of patients.

- One member of each pair is a patient who received care under the pilot services. Their end of life period is defined as the time during which they were receiving care under the pilot.
- The other member of the pair is a patient who had at least one hospital admission in the 18 months preceding the pilot, and also died in that period. Their demographics, primary diagnosis and hospital usage prior to their end of life period are closely matched to the pilot patient. The duration of their end of life period is also matched to the pilot patient; the start date is defined by counting back from their date of death the number of days which their matched pilot patient was receiving care under the pilot.

The matched pairs design ensures that as many patient-level factors as possible are controlled for. A simple comparison of all Hospice at Home patients against all previous Planned Variable patients would not provide the confidence that the observed changes are the result of the pilot, instead of being the result of differences in the patient make-up.
In order to get the best possible matches and to robustly measure the key outcomes associated with hospital use at the end of life, the analysis focused on those patients who had joined the service and died within the evaluation period. Furthermore, as discussed in section 2.7, each patient was matched, as best possible, to a patient in the control group using gender, age group, deprivation, Marie Curie diagnosis\(^4\) and number of days spent in hospital in the six month period prior to first Marie Curie visit date/index date.

As a result of the above, a number of exclusions were applied to the dataset of the pilot patients. Of the 275 patients seen within the nursing service:

- 20 patients were also supported prior to the implementation of the new model of care delivery and therefore were not exclusively ‘Hospice at Home’ patients.
- 31 patients were excluded as there was no date of death recorded in the mortality statistics (these people were very likely still alive at the end of the pilot date range under review).
- 11 patients were excluded as they could not be matched on previous hospital use (before the index date).

While the decisions described above have influenced the attributes of the pilot patients included in the matched analysis, it should be remembered that each pilot patient is matched to a control patient who shares similar prior hospital usage. This process therefore serves to increase the validity of the conclusions that can be drawn from the matched analysis findings.

### 6.3 Reducing Hospital Admissions

The evidence from across the surveys, interviews and the quantitative data demonstrates that the service has resulted in a reduction in admissions to hospital.

**Outcome achieved: Reduction in admissions**

In total 58 patients (27.2%) of the pilot evaluation group experienced a hospital admission, compared to 86 (40.4%) of the matched baseline group.

#### 6.3.1 Patient and Healthcare Professional Perceptions

Both patients and Healthcare professionals believed that the pilot service had resulted in fewer patients being admitted to hospital where it could be avoided. In total 63% of patients agreed or strongly agreed that receiving care under the pilot meant they had not had to go to

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\(^4\) The diagnosis of the patient from Marie Curie records, as given by the referring body.
hospital or a hospice. Similarly Healthcare professionals believed that there had been a reduction in hospital attendances.

“Yes definitely - our hospital admissions, and also hospice admissions, have reduced.” (GP)

The unique offer of the overnight service was perceived by the healthcare professionals as being particularly important for avoiding hospital admissions. During the day there are other options available to care for patients, however, should a carer not be available overnight then healthcare practitioners believed the patient would typically be admitted to hospital. The overnight service is therefore able to prevent that admission.

“[The service has] certainly reduced hospital admissions, because if…the family member who is looking after them is unwell, sometimes people have to be admitted to hospital. But if there’s someone to sit overnight then they can be safe in their own home.” (community based staff).

The ability of the service to react quickly to situations of crisis was perceived as central to the avoidance of admissions. If the patient reaches a point where the family or carer is no longer able to cope, or there are no family available, the Marie Curie service is described as being able to step in to avoid a hospital admission.

“Things can come to a crisis because family can’t cope and that leads to hospital admission.” (community based staff).

The connection between the service and Homecare and district nurses was important to avoiding hospital admissions. The Marie Curie service was described as being able to ensure consistent care was available where there might otherwise be gaps in the other services provided, which often resulted in hospital admissions.

“[Marie Curie are] supplementing what’s there and you know if you join up all the bits you can sustain that.” (hospital based staff).

6.3.2 Quantitative Evidence

The perceptions of patients and healthcare practitioners are supported by the quantitative data, which shows that the patients receiving care under the pilot experienced fewer hospital admissions.

**Inpatient hospital admissions**

Over the duration of their end of life period, 58 patients (27.2%) in the pilot evaluation group experienced an inpatient hospital admission, with a total of 64 separate elective or non-
elective admissions. In contrast 86 (40.4\%) patients in the matched control group experienced an admission, with a total of 107 separate elective and non-elective admissions.\(^5\)

The number of hospital inpatient and A&E attendances is summarised in Figure 14 which shows the majority of admissions were non-elective for both groups.

**Figure 14: Number of in-patient hospital admissions and Accident and Emergency attendances (N= 153 patients in each group). Note, H@H is Hospice at Home**

![Graph showing the number of in-patient hospital admissions and Accident and Emergency attendances]

**A&E attendances and admissions from A&E**

The number of A&E attendances in each group shows a similar pattern to the in-patient admissions\(^6\), as shown in Figure 14. In total 6 patients (2.8\%) in the pilot evaluation group experienced an A&E attendance, with 9 attendances in total. This is compared to 25 (11.7\%) patients in the matched baseline group, with 28 attendances in total.

The small number of pilot patients experiencing an A&E attendance means that it is not possible to draw any meaningful conclusions regarding the extent to which the availability of pilot services is reducing admissions to hospital from the A&E department. Of the 9 A&E attendances experienced by the pilot patients, 8 (88.9\%) resulted in an in-patient admission. In comparison, of the 28 A&E attendances in matched baseline group 25 (89.3\%) resulted in an admission to hospital.

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\(^5\) The difference in the number of patients experiencing a non-elective admission was found to be statistically significant using Fisher’s exact test, \(p=0.01\), odds ratio 1.718. The number of elective admissions did not significantly differ across each group.

\(^6\) The difference in the number of patients experiencing an A and E attendance was found to be statistically significant using Fisher’s exact test, \(p<0.01\), odds ratio 4.573.
6.4 Discharges from Acute Settings

There is limited evidence available to show a direct impact on the timeliness of discharges. However, surveys and interviews suggest that discharges are being dealt with efficiently and appropriately. The Hospice at Home patients accrued fewer bed days than their controls and the quantitative evidence does suggest that this is mainly due to keeping people out of hospital (fewer admissions). The data shows that the average length of stay per patient is nearly 1 day shorter for the Hospice at Home patients, but the average length of stay per admission for the Hospice at Home patients is actually slightly longer than for the matched controls.

6.4.1 Patient and Healthcare Professional Perspective

The patient survey revealed that 31 of the 37 (84%) patients undergoing a discharge from hospital reported they were happy with the amount of time it took to be discharged post pilot. This is supported by the healthcare professional survey showed that 22 of all 39 (56%) respondents reported the pilot had enabled ‘More streamlined discharge from ward staff and OTs making referrals’.

Figure 15: “I am happy with the length of time it took to be discharged from hospital” – Patient / Carer survey

Hospital staff noted that the service had been able to prevent failed discharges by ensuring that services and equipment are in place quickly for people to go home. The result of the quick response rates meant that in addition to end of life patients, the pilot services had sometimes been used to facilitate discharge of palliative care patients while their homecare provision was put in place.
"I had one gentleman that we got the referral and we can be in the same day and it took two weeks for Homecare package to be set up, so [the] gentleman would’ve been in hospital for two weeks. So for a fortnight you’re talking about £3000. In the end the gentleman deteriorated and homecare didn’t go in in the end, which was actually good because they get that continuity of staff.” (Marie Curie).

6.4.2 Quantitative Evidence

It is possible to compare the average length of stay per hospital admission to understand the impact achieved on facilitating timely discharges. Table 4 shows the number of admissions and total days in hospital for each of the matched analysis groups. The reduction in number of admissions has already been discussed in section 6.3. Although the control group spent more days in hospital overall (and the average length of stay per patient is therefore shorter at 0.9 days), the average length of stay per admission is actually longer for the pilot patients. In total, the pilot evaluation group spent 772 days in hospital, with an average of 12.1 days per admission. In contrast, the matched control group spent a total of 955 days in hospital, with an average of 8.9 days per admission. Overall, patients in the pilot evaluation group spent 3.1 more days in hospital during each inpatient admission.

<table>
<thead>
<tr>
<th>Cohort Group</th>
<th>Admission Type</th>
<th>Total Length of Stay (days)</th>
<th>Total Number of Admissions</th>
<th>Average Length of Stay (days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Matched Baseline</td>
<td>Elective</td>
<td>77</td>
<td>6</td>
<td>12.8</td>
</tr>
<tr>
<td>(n=213)</td>
<td>Non-elective</td>
<td>878</td>
<td>101</td>
<td>8.7</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>955</td>
<td>107</td>
<td>8.9</td>
</tr>
<tr>
<td>Pilot</td>
<td>Elective</td>
<td>87</td>
<td>3</td>
<td>29.0</td>
</tr>
<tr>
<td>(n=213)</td>
<td>Non-elective</td>
<td>685</td>
<td>61</td>
<td>11.2</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>772</td>
<td>64</td>
<td>12.1</td>
</tr>
</tbody>
</table>

The evaluation did not set out to gather evidence to explore this finding in particular so explanations at this point are not proven. However, the longer average length of stay per admission in the pilot group may be the result of fewer inappropriate admissions that can be turned around relatively quickly (after incurring a cost to the NHS) compared to a considered, appropriate admission where there is a clear clinical need.
6.5 Reducing Deaths in Acute Settings

**Outcome achieved: Decrease in proportion of deaths in acute settings**
73.7% of patients receiving care under the pilot died at home, compared to 29.1% in the matched baseline group.

**Outcome achieved: Increase proportion of time at home in the last month of life**
Patients receiving care under the pilot spend 11.6% longer in the community compared to the matched baseline group.

6.5.1 Patient and Healthcare Practitioner Perspectives
Section 5 described how the service is enabling patients to have the choice of where they receive care and their place of death. Further evidence of the impact of the programme is available from the quantitative data.

6.5.2 Quantitative Evidence
The evidence shows that the time in the community experienced by the pilot evaluation group is 11.6% higher during their last month of life than patients in the matched control group. On average, patients within the pilot evaluation group spent 88.7% of their end of life period in the community, compared to 79.5% in the matched control group.

While the matching process identified pairs of patients who had a similar profile of hospital usage leading up to their first visit/index date, Table 5 shows that the time spent in hospital in the 6 months prior to death is also similar between the groups\(^7\). In contrast, the time spent in hospital in the last month prior to death is different. The pilot evaluation group spent 11.3% (approximately 3 days) of their last month in hospital when the matched control group spent 20.5% (approximately 6 days) of their last month in hospital.

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\(^7\) Note that the actual matching process examined the 6 months of hospital usage prior to first visit/index date, which is not the same as the last 6 months of life shown here, hence the match pairs between groups for the overall time in the community is not exact.
### Table 5: Proportion of time spent in hospital prior to death

<table>
<thead>
<tr>
<th></th>
<th>Time spent in hospital (%)</th>
<th>Time spent in community (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>6 months prior to death</td>
<td>1 month prior to death</td>
</tr>
<tr>
<td><strong>Cohort group</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Matched control patients</td>
<td>9.4%</td>
<td>20.5%</td>
</tr>
<tr>
<td>Pilot patients</td>
<td>5.6%</td>
<td>11.3%</td>
</tr>
</tbody>
</table>

In line with the amount of time spent in the community, patients in the pilot evaluation period were more likely to die at home, as opposed to within a hospital or hospice. In total 157 (73.7%) of the pilot evaluation patients died at home, substantially more than the 62 (29.1%) matched control patients who died at home.

Figure 16 illustrates the overall changes in recorded place of death. It can be seen that the patients in the pilot evaluation group are less likely to die in an NHS acute hospital or hospice than those in the matched control group.
7 What is the Impact on the Hospital Costs Associated with End of Life Care?

7.1 Introduction

This section compares the costs of hospital care for the previous Planned Variable service and the new service. The cost analysis demonstrates that the Hospice at Home service is capable of providing care for patients at a reduced cost when compared to the end of life care in Fife without Hospice at Home. The ability of the Hospice at Home service to avoid patients being admitted to hospital is the key financial success of this programme.

7.2 Costs of Hospital Services

<table>
<thead>
<tr>
<th>Costs of providing hospital care to end of life patients</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>With the Hospice at Home service:</strong> 275 patients cared for under the Hospice at Home service would incur a total hospital care cost of £482,954 over their end of life period.</td>
</tr>
<tr>
<td><strong>Without the Hospice at Home service:</strong> 275 patients cared for under the previous end of life care provision in Fife would incur a total hospital care costs of £665,236</td>
</tr>
</tbody>
</table>

The changes in hospital usage described above demonstrate that the Hospice at Home service is capable of reducing the amount of time end of life patients spend in acute care. To calculate the overall economic impact of this change, it is possible to assign a cost to each day which patients spend in hospital.

To assess the impact that the Hospice at Home service would have, the evidence on the hospital usage of the 213 matched pairs will be scaled up to reflect the 275 patients per year that the Hospice at Home service provided care for in the pilot year. This approach makes the assumption that patients under the Hospice at Home services in 2016/17 have the same profile of hospital usage as those patients in the matched pairs. In doing this, it is recognised that the 213 matched pilot patients do not include the 20 patients who were also supported prior to the implementation of the new model of care, the 11 patients that could not be matched on hospital use and the 31 patients who did not have a recorded place of death at the evaluation data cut-off date.
Table 7 summarises the hospital usage profiles used in the economic analysis and the costs for each activity type. The cost per activity is derived from NHS Scotland Health Service costs\(^8\),\(^9\), taking an average across Scotland\(^10\).

Table 7: Inputs to cost calculation: Hospital usage profiles and costs for 275 end of life patients either with or without Hospice at home (costs expressed in 2016/17 values)

<table>
<thead>
<tr>
<th></th>
<th>Acute admission</th>
<th>Accident and Emergency</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Elective</td>
<td>Non-Elective</td>
</tr>
<tr>
<td>Admissions</td>
<td>Bed days</td>
<td>Admissions</td>
</tr>
<tr>
<td>275 patients with Hospice at Home</td>
<td>4</td>
<td>112</td>
</tr>
<tr>
<td>275 patients without Hospice at Home</td>
<td>8</td>
<td>99</td>
</tr>
</tbody>
</table>

In line with the findings presented in Section 6, the Hospice at Home services are enabling patients to experience fewer admissions and therefore spend fewer overall days in hospital, as well as experiencing fewer A&E attendances.

As a result of the reductions in hospital usage, the overall costs of hospital care for each patient group are different. For 275 patients receiving care under the Hospice at Home services, their hospital usage costs over their end of life period are £182,283 less than if the Hospice at Home service were not available. Figure 17 illustrates the full costs for each patient group. Showing that without Hospice at Home, the total cost of hospital care for 275

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8 Speciality costs: [http://www.isdscotland.org/Health-Topics/Finance/Publications/2014-12-02/Costs_D040(X)-D040LS(X)_2014.xls](http://www.isdscotland.org/Health-Topics/Finance/Publications/2014-12-02/Costs_D040(X)-D040LS(X)_2014.xls)


9 The use of more detailed HRG codes was not possible within this analysis due to patient confidentiality concerns. The small number of patients under each HRG code would have made them individually identifiable, and therefore this data could not be shared with OPM.

10 An average cost across Scotland is chosen as 2013/14 cost books do not include Fife specific costs for all specialities observed in the matched cohorts.
patients is £665,236 while the total cost of hospital care with Hospice at home is £482,954. It can be seen that the majority of the costs incurred result from in-patient hospital admissions.

This cost analysis demonstrates that the Hospice at Home service is capable of providing care for patients at a reduced cost when compared to the end of life care in Fife without Hospice at Home. The ability of the Hospice at Home service to avoid patients being admitted to hospital is the key financial success of this programme.

It should be noted that the cost analysis does not present the total costs for all end of life patients in Fife, it only makes the comparison for those 275 patients who could receive care under the Hospice at Home service. As already noted earlier in this report, there is demand from across Fife’s healthcare practitioners for Marie Curie to increase the capacity of their service to include all terminally ill patients, and it is showing an increase in reach. If we were to account for these extra patients, there are likely to be further savings that could be made.

The savings described are based on direct changes in hospital activity alone and therefore do not account for the potential indirect savings that could result from providing support for patients’ families and carers (reducing carers’ breakdown for example).

Lastly, it should be noted that these results are based on the 213 patients supported by the new Marie Curie service, and their matched controls. It is worth further analysis with a cohort of patients supported over a longer period of time to understand the impact of the service more fully, particularly on those who receive support over a longer period of time.
7.3 Benefits of the Hospice at Home Model of Care

Prior to the implementation of the Hospice at Home model of care, Marie Curie provided a ‘Planned Variable’ (planned overnight care) service in the area. The new model of care, in aiming to be more integrated with other initiatives and services in the area, retained some of the original planned variable model by delivering planned care overnight. However, the Hospice at Home model added the much needed resource for care during the day and support for patients being discharged from hospital as well as a volunteer service to support patients earlier on in their end of life journey. The new model of care is overseen by a Clinical Lead Nurse who ensures effective communication across the different strands of the service and across health and social care professionals in the area. They ensure that information about the patient is up to date and they receive the most appropriate care for them and their families’ needs.

The evaluation has shown that the new model can reach significantly (95%) more patients and can offer care to more specifically meet the needs of patients in order for them to be cared for and die at home.

“I recently had a letter from a family who we’d involved Marie Curie Fast Track service with and that meant we got her discharged on Friday afternoon and she died in the early hours of Monday, and we wouldn’t have been able to get that in place so quickly without Marie Curie.” (hospital based staff)

The surveys of healthcare professionals in the area shows that the majority believe the service allows more efficient use of hospital beds and report being more confident that appropriate care is available and that the new service has enabled them to offer care to new patient types (See Appendix 16).

From the patient perspective, the Hospice at Home service was perceived to be well integrated with other services. Healthcare professionals reported that communication between Marie Curie and them was good, aided by the Senior Nurse. It was also noted that Fast Track and Planned Care staff seemed to communicate well amongst themselves about patients and the Marie Curie service seemed to have become well integrated with other services.

“From the minute you pick up the phone it seems to be such a seamless service.”
(community based staff)

“Sometimes patients feel like beforehand it was a different service coming in, but now more like part of the community team.” (community based staff).

Overall, the new model of care seems to offer integrated care to more people, reduces hospital activity and reduces cost for end of life patients supported by the model in Fife.
8 Recommendations

8.1 Clarify and Streamline the Referral Process

There is a great deal of paperwork involved in the referral process (Care Plan, Do Not Attempt Resuscitation DNAR and risk assessment) and delays in completing this mean patients experience delays in receiving care. The approach to risk assessment is cited as specifically onerous and detrimental to patients receiving timely care. Likewise, the need for District Nurses to be involved in paperwork for every patient was questioned. Therefore, a mapping exercise should be undertaken to capture paper and information flows, with the aim of streamlining the process and reducing potential blockages. This should include communication with the out of hours service, as this has been reported as difficult and time consuming with no single number to call.

8.2 Allow Closure with Staff

Several family members or carers felt they would benefit from having the opportunity to say good-bye and thank you to the team that provided care. They are not currently aware of any way in which they can get in touch directly with the right member of the team.

8.3 Maximise Utilisation

Many healthcare practitioners felt there were times which the service had extra capacity that was not being utilised. There is a demand across Fife for the high quality service and healthcare practitioners who could refer more patients. Therefore, consideration should be put into how the capacity can best be managed. A suggested approach is to reach out to areas which are traditionally disengaged from the Marie Curie services, such as primary care services.

8.4 Stakeholder Recommendations

The 11 responses containing suggested improvements from patients, carers and healthcare practitioners are included here in full:

“Reflecting on the initial stage of care when dad was discharged from hospital, I would say that the multi agency support package tended to mean in practice that all agencies arrived at a similar time. It wasn't that the service was not needed or appreciated, it would have been more effective, I think, if there had been some 'spacing out' in terms of timing. As dad has stabilised for the time being the Marie Curie...
Curie support is fantastic for us. The standard of care is gold standard really and much appreciated."

“Allow closure with staff involved. It would be nice to be able to say "thank you" once a patient has been sent to a hospice, if the patient dies, there isn't any further opportunity to contact the person who came to help and no indication of a local base to contact. They deserve recognition for their sterling work. Marie Curie provides a great deal of support at a distressing time.”

“Communicate when they are late or unable to attend.”

“I am selfish in saying I would like more time.”

“It would be good if we'd received notification that a carer would not be provided.”

“Maybe ability to take vital signs - blood pressure monitoring, temperature and pulse would be great.”

“More staff so that they are not so busy.”

“Provide more night care.”

“To provide end of life care (i.e. pain relief) when requested This caused the family a lot of frustration as they watched their family member struggle with agitation due to pain.”

“Wished they had started calling earlier in the first days of my husband's illness.”

“Would be more helpful if I could have cover more than once a week, but I understand they are very busy. It would take more pressures off my family as they all work full-time and I feel it is too much of a burden on them at times.”
9 List of Appendices

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Appendix 2  HCP Baseline Survey Sept 2014
Appendix 3  Marie Curie Team Follow up Survey August 2015
Appendix 4  Healthcare Professional Follow up Survey August 2015
Appendix 5  Baseline Stakeholder Topic Guide Phase 1
Appendix 6  Healthcare Professional Follow Up topic guide
Appendix 7  Patient/Carer Feedback Survey
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10 Glossary

Planned Variable

The provision of planned palliative nursing care for patients at the end of life stage of their illness. Visits can be from a Marie Curie registered nurse or health care assistant. Visits are requested by District Nurses through the Marie Curie’s UK referral centre and matched to nurse availability. Visits are usually 10pm to 7am, available 7 days per week, with a usual 1-4 visits per patient per week; day visits can also be requested.

Hospice at Home service

The provision of palliative nursing care for patients with a terminal diagnosis. Services are made up of Marie Curie registered nurses, health care assistants, health care assistants and volunteers locally coordinated and led by a Marie Curie Clinical Nurse Manager, with support from Marie Curie Senior Nurses and Helper (volunteer) Manager. Requests for care and support are made by agreed health care professionals to the senior nurse or volunteer manager and a flexible package of care agreed which can include a mix of shorter day visits, planned overnight visits and volunteer support.