

# An Evaluation of the Cardiff and Vale University Health Board Weekend and Bank Holiday Specialist Palliative Care Clinical Nurse Specialist Service

Evaluation Report

August 2019



Canolfan Ymchwil Gofal Lliniarol  
Marie Curie  
Palliative Care Research Centre

CARDIFF CAERDYDD



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Cardiff and Vale  
University Health Board

## 1. Acknowledgements

### Thank you

Thank you to the staff who so generously shared their time, experiences and perspectives for the purpose of this evaluation. As a result of your participation, we now have an in-depth understanding of the service triumphs, challenges and improvement opportunities.

Thanks also to Research Assistants Hannah Scott and Elin Baddeley at the Marie Curie Palliative Care Research Centre, Cardiff, and to Andrea Rich, Clinical Nurse Specialist Palliative Care at Cardiff and Vale University Health Board, for support with data analysis and interpretation.

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### Commissioned by

Specialist Palliative Care Service, Cardiff and Vale University Health Board, Cardiff.

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## 2. Glossary

### a. Abbreviations

ACP	Advance Care Plan
CNS	Clinical Nurse Specialist
CVUHB	Cardiff and Vale University Health Board
DN	District Nurse
DNAR Form	Do Not Attempt Resuscitation Form
GP	General Practitioner
MCPCRC	Marie Curie Palliative Care Research Centre
OOH	Out of Hours
PRN medicines	Medicines that are taken Pro re nata, (Latin) meaning as needed
SPC	Specialist Palliative Care
TTHs	To Take Home (medications)
The service	The weekend/bank holiday SPC CNS service that has been evaluated

### b. Text Key

Extracts of free text from the survey responses and interview transcripts are included in the report to add context to the discussion and convey the tone and language used by service staff. To assist the reader, some grammatical corrections have been made. However, this has been undertaken with caution to ensure the meaning of the text has not been altered.

Text surrounded by square brackets [as shown here], denote text that has been added by the researcher for readability purposes. Ellipses (...) indicate where passages of text have been removed to shorten extracts.

Identifiers accompany the extracts of text to show how the information was shared and in which setting the staff member worked:

<b>S</b>	Survey
<b>I</b>	Interview
<b>H</b>	Hospital
<b>C</b>	Community

Examples:

- **S9 H Q8:** shows the extract came from Survey respondent 9 who works in the Hospital setting in response to survey Question 8.
- **I2 C Ref 1:** shows the extract came from Interviewee number 2 who works in the Community setting. Ref 1 shows it's the first extract of text from this transcript that was coded to the theme being discussed.

### 3. Introduction

The Cardiff and Vale University Health Board (CVUHB) Specialist Palliative Care (SPC) service offers specialist advice, support and symptom management to people with progressive non-curable illnesses, their families and allied professionals throughout the hospital inpatient and community areas. The service is delivered through collaboration and integration with City Hospice and Marie Curie.

Many non-emergency health services are provided 9-5pm and during Monday to Friday, leaving core and emergency services to provide care at weekend; traditionally SPC Services developed in this way. However, CVUHB, in line with the rest of Wales, have provided a SPC Clinical Nurse Specialist (CNS) service at weekends and bank holidays since 2010.

The weekend/bank holiday SPC CNS service model has evolved over time in response to clinical demand, internal service reviews and service improvements. Staff delivering the service voiced the opinion that there is growing service demand and workload at weekends across the community and hospital areas for Palliative Care; coupled with the projected population growth and aging expected for the local area, this reinforced the need for an independent service review to ensure that going forward, the service is fit for purpose, service users receive timely and appropriate care, and staff feel well supported to deliver the service.

In 2018, the Marie Curie Palliative Care Research Centre (MCPCRC) was commissioned by the CVUHB Specialist Palliative Care Service to review the weekend and bank holiday SPC CNS service, 'the service'. The evaluation focused on gaining a deeper understanding of the current provision, identifying aspects of the service that work well, the challenges, and improvement opportunities.

The following report provides an overview of the review findings and makes recommendations to support the future sustainability and development of the service.

## 4. Executive summary

The review has identified aspects of the service that work well, service challenges and improvement opportunities. Recorded service activity has been measured and described and key differences between the weekday and weekend/bank holiday service have been identified.

Staffs' commitment to the provision of high-quality care became evident through the review, and the wellbeing of service users emerged as paramount. Staff were genuinely interested in helping to improve the service and there was a high level of consensus among CNSs and managers on the service challenges and improvement opportunities. Their perspectives are clearly communicated throughout this report under thematic headings. Many of the identified themes are interconnected. Accordingly, improvements in one area have the potential to impact positively on others.

### a. Service design

The values, resources, systems and processes of three organisations have been brought together to deliver a single weekend and bank holiday service that supports those who are most sick, and most in need, at home and in hospital. The tri-organisational collaboration required to develop and maintain it should be celebrated.

Whilst a clear written core service offer was absent, the service foci were said to be (1) support for known and new patients with urgent specialist palliative support needs, and (2) the review of those who had adjustments to medications late in the week. (3) CNS support to other health professionals was an important feature in the hospital setting. The type and intensity of patients seen at weekends was said to be a key difference when compared to the week, with CNSs often supporting patients/families unknown to them.

The majority of staff said they had all or almost all the clinical skills, knowledge and experience required for weekend and bank holiday working. Staff induction was thought to be ample by most, although some staff still felt daunted, despite having worked several weekend shifts.

The impact of lone working at weekends was a recurring theme throughout the review. Informal support networks had been developed within teams which enabled on-duty CNSs to discuss complex patients with SPC colleagues. The on-call SPC Registrars and Consultants offered CNSs essential weekend and bank holiday clinical support.

Whilst CNSs said their skills were most effectively used when working within the boundaries of their specialist role, one in four said they regularly performed duties outside it, primarily to ensure the timely fulfilment of patients' needs.

Staff described having an extended role at weekends/bank holidays. This included increased decision-making responsibilities in relation to complex patients who might ordinarily receive consultant support during the week. The added responsibility and time implications of

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*'...we've embraced the shift at the weekend and to providing an out of hours service whereas ... other specialties haven't yet made that leap ... so we have been a bit ahead for timing in doing that ... the strengths of that ... without a doubt, erm, we're providing ... a better, a more robust, erm, service for patients and families that they weren't getting ten years ago. ... we're addressing their ... urgent needs ... in a more timely and responsive way than we ever were...'*

(Hospital-based interviewee)

”

“

*'I think the 7 day working in itself is a success. I know hospital admissions are avoided thanks to this service and it is a great reassurance to patients and their families that there is someone to contact over the weekend if they need to ... patients have an advocate over the weekend when they may otherwise encounter health professionals who do not have all their background information ...'*

(Community-based survey respondent)

”

“

*'CNSs are often expected to absorb non-specialist work to ensure the safety of their patients. It is my opinion that some of this is due to the demands upon GP OOH / District Nursing Teams...'*

(Community-based survey respondent)

”

answering and triaging all incoming calls at weekends was highlighted by community staff. The wider geographic and hospital site remit was thought to be a disadvantage.

Despite the assertion that the CNS role is extended at weekends, many suggested further increasing their remit to include prescribing in order to reduce delays in symptom management for patients. The ability to undertake chest and abdomen examinations and neurological assessment was suggested as another way to enhance patient care.

The ability of CNSs to complete their workload in contracted hours varied, with two in three CNSs stating this was always or was frequently achieved. Some thought service quality and equity were sustained through working additional hours. The distances between home visits, traffic conditions, and late calls that result in home visits were all cited as reasons community staff worked late. Finishing work on time was thought to be more achievable in the hospital setting on days when two nurses were on shift. The manageability of the weekday caseload was thought to impact on the weekend workload due to overspill.

A marked difference in CNS numbers at weekends/bank holidays when compared to weekdays was observed. Whilst the caseload and referral criteria were said to be more focused at weekends, this did not appear to adequately compensate for the staff reduction and extended remit they described. Some CNSs said that the weekend/bank holiday workload had become unmanageable due to the number and complexity of patients needing support. The future sustainability of the weekend/bank holiday service with existing resource was questioned.

Additional staffing was frequently proposed as a way to improve the service and CNSs experiences of delivering it. Proposals were cautious. The anticipated advantages of having two staff members available in each setting on each shift included less travel between hospital sites and patients' homes, improved efficiency of call handling and patient triage, more time available to spend with patients and families, easier access to peer support, confidence in shared decision-making, improved staff safety and reduced feelings of isolation, pressure and stress. Opportunity costs to the weekday service were a consideration.

## b. Service Delivery

Most staff felt the demands on the CNS role had changed over time. Demand was said to fluctuate with quiet shifts being rare. Greater awareness and acceptance of the service was thought to have influenced an increase in calls and referrals, including for those with a non-cancer diagnosis; yet the need for greater awareness of the service among ward staff was proposed, which suggests the possibility of untapped demand.

CNSs described the unpredictable nature of weekend/bank holiday shifts and the challenge of simultaneously managing planned and unplanned referrals. Triage and prioritising patients was seen as a vital, yet complex part of the role.

The need for a cross-organisationally agreed written referral criteria, and education on appropriate referrals for CNSs and allied professionals were proposed as ways to prevent referral of routine work and to make the CNSs caseload more manageable. The amount and quality of information written on handover sheets was said to affect the assessment and prioritisation of patients. Use of a single standardised referral form was suggested. Completion of advice sheets that document all CNS telephone and face to face contacts with patients/families was said to be time consuming. Some CNSs completed paperwork after their contracted hours at home.

“

*'... I would prioritise for safety, for stress levels and for the CNSs erm sanity I think you need to have two of them on on a weekend.'*

*(Community-based interviewee)*

”

“

*'It literally comes down to numbers... and demand, you know ... it's ... a huge geographical area. Where you have fifteen nurses ... on a ... weekday ... you have one nurse on a weekend. ... and whilst you don't necessarily plan visits like you would on a normal day, it's the not knowing what's coming in ... it can be difficult, you know, and sometimes you can't get off the phone.'*

*(Community-based interviewee)*

”

A number of factors were said to affect service efficiency. Community staff described feeling under pressure because of the need to answer the phone whilst carrying out other tasks, and taking incoming calls was said to interrupt and delay planned face to face visits. CNSs from both settings said time was wasted travelling. In particular, the time spent travelling between patient homes was thought to be excessive due to the vast geographical area CNSs must cover. Peripatetic working across settings was proposed.

Despite the Canisc record system being described as clunky and time consuming, the routine digital recording of all patient contacts by all providers was proposed as a way to improve efficiency and information sharing on known patients. It was thought access to digital records could be improved through provision of extra computers for hospital-based CNSs and the use of portable devices such as tablets and laptops for those in the community.

Inter-professional relationships with, access to, and support from allied professionals, were said to affect service delivery and patient wellbeing. The demands on and availability of other health and care services during weekends and bank holidays were cited as factors that influenced the need for CNSs to absorb non-specialist work. Tasks such as taking drug charts to ward doctors and out of hours GPs aimed to hasten support to patients by plugging gaps left by limited seven day working in other areas. The failing of some dedicated pharmacies to hold adequate stock of palliative care drugs was cited as another drain on time that could impact on patients' quality of life. Limitations to the SPC clinical telephone support available to CNSs were highlighted, including call back delays and the unavailability of face to face patient review.

### c. Service outcomes and impact

Weekend and bank holiday access to specialist, rather than generalist palliative support, was believed to have helped maintain the wellbeing of patients and families. Continuity of care and better symptom management to known patients, timely support for urgent new referrals, and the ability to make safe changes to medications on a Friday were cited as key benefits. Seven day access was thought to help patients, family members, and the allied staff who work with them, to feel reassured, more confident, and well supported. Some community CNSs believed acute hospital admissions were avoided due to their intervention.

The majority of staff felt weekend working had an impact on the weekday service. Positive influences included relieving pressure on staff during the week and continuity of advice and symptom management for patients and families. Some thought that staff rota planning limited any adverse effects on the weekday service. Others said taking time back for weekend hours worked, disrupted weekday service continuity and added to colleagues' workloads. Accommodating other absences, including staff sickness and annual leave were said to make it more difficult to balance resources across seven days. Small teams were thought to be most affected.

“

*'I feel that my weekend / bank holiday time is mostly spent on travel, documentation and general paperwork. Much of this time could be spend clinically with patients in the community setting. Clinical time is often interrupted by the pressure to answer in-coming calls, re-evaluate and triage your day to respond to patients in an appropriate fashion...'*

(Community-based survey respondent)

”

“

*'...I think there may be times when patients probably could have had more of our time where we could have listened a bit longer... where you're not being rushed off to drive to the edges of the city to see the next person. Erm, but that's just a sacrifice we have to make, and ... you use your clinical judgement to make that decision when it's safe to do and when it's not...'*

(Community-based interviewee)

”

“

*'... the patient[s] have access to specialist palliative care nurses, advice and experience on the weekend which is great, and if we weren't there, they wouldn't have that, and they'd suffer for it. I think we add to the out of hours, it's important that we're there... unfortunately people deteriorate and die out of hours, they don't all die Monday to Friday 9 to 5. It's life isn't it.'*

(Community-based interviewee)

”

Whilst it was proposed that increased staffing at weekends/bank holidays would reap many benefits, the potential sacrifice this might impose on weekday provision was discussed. For smaller teams, the proposition was said to be untenable with their existing resources, as it could potentially threaten service sustainability as a whole.

Staff commented on the rewarding yet demanding nature of the work. The role was often described as emotionally and physically draining. A range of factors were thought to contribute to this including the type and complexity of patients, the level of decision-making in relation to them, and shift patterns across seven days. Some felt isolated due to lone working. Procedures for lone working and risk assessment were said to be different in the community on weekends/bank holidays. It was proposed that this may have repercussions for staff safety.

CNSs said they strived to achieve equity of support during the weekend/bank holiday and some believed it was accomplished. Staff from both settings said that patients received the same support for symptom control at weekends as they did during the week. Some said clinical work was prioritised over support for emotional distress. Community-based CNSs said that in principal, all known patients have equal access to the service as they are given the number to call. Conversely, ward staff act as gatekeepers to the service for those in hospital. There was a suggestion that there may be access inequity for inpatients in hospitals other than the primary district general hospital.

Some CNSs said the extended remit and reduced staffing levels at weekends limited their ability to carry out face to face visits, potentially introducing difference in the way support is delivered to weekend/bank holiday service users. Some thought that weekend time constraints reduced how long they could spend with patients. Several staff acknowledged that the service had to be different at weekends due to reduced resources.

#### d. Key differences

Six key differences between the week day and weekend/bank holiday service were identified:

- **Type and intensity of patients:**  
Predominantly urgent cases at weekends, as opposed to a mix of non-urgent and urgent need in the week. Patients/families often unknown to the CNS at weekends.
- **Patient care focus:**  
Primarily clinical support at weekends, less focus on emotional/holistic care as is provided during the week.
- **Staffing levels:**  
Greatly reduced staffing at weekends, with just one community CNS and one or two hospital-based CNSs on duty.
- **Lone working:**  
Reduced peer support, different risk assessment and safety procedures at weekends.
- **Task and geographic deviation:**  
Managing all incoming calls/pagers, and covering the entire community geographic remit/all hospital sites at weekends.
- **External infrastructure:**  
Reduced availability of SPC colleagues and allied health and care professionals at weekends. Also, different and/or extended processes to access their advice and patient support.

“

*‘... it is very isolating ... although there are other ... teams around you you’re essentially working on your own ... so definitely works better on the Saturday with the two people, ... if it’s a complex person then often, erm, they can discuss that person ... and develop a plan together.’*

*(Hospital-based interviewee)*

”

“

*‘... you know, it is a challenging job, stressful, because when it’s busy, it’s really hard to prioritise ... Still learning all the time ... because there’s just so many different diseases and treatments ... but I like it as well ... you know, it is rewarding, oh yeah, that’s important.’*

*(Community-based interviewee)*

”

## e. Service activity

The available data shows established service activity, analysis of which suggests an increase of activity across the service as a whole.

The service primarily supported patients residing in their own homes and district general hospitals. Despite the comments of some CNSs that support to people with non-cancer diagnoses was increasing, those with cancer accounted for 80 and 90 percent of patient referrals to the hospital and community teams respectively.

Symptom control was most commonly recorded as the reason for referral, which indicates that the majority of referrals aimed to elicit clinical support. The yearly average of 255 new referrals and unplanned reviews shows the responsive nature of the service, as ensuing action could have reduced the time patients and families waited to receive urgently needed support, and averted hospitalisation of patients residing in the community. Either of which could have positive implications for the health and wellbeing of service users, the latter facilitating savings in inpatient care costs.

Follow up data gives an indication of how the service is positioned to support consistency of care to known service users with anticipated needs. The Data showed a growing monthly average of 135 to 159 referrals over two years. It was not possible to track how many of these referrals resulted in the provision of care; however, the work involved in the task of referring should be recognised, particularly as data on the source of referrals showed that the majority of community referrals came from the SPC team.

Face to face contacts with patients and families were shown to be stable across three years, which might reflect staff views that capacity thresholds had been reached. A plateau in demand could be another explanation. An increasing number of non-direct contacts via pager and telephone were recorded. The majority of these were carried out by the community staff. This supports their comments on growing activity in this area and could also reflect the logistics of providing a service across a large geographic area. The increase in the overall number of telephone/pager contacts could reflect an increase of patients, and/or an increase in contacts per patient. The growing number of calls made to other health care professionals could be a proxy for complex cases and indicates the need for cross-functional support for patients at weekends and bank holidays.

Whilst available data on referrals for staff support were limited, it indicates that the hospital-based CNSs received a substantial number of monthly referrals for this purpose.

Through the review it emerged that the data set and descriptors used by the three organisations to record service activity differed slightly, which made data aggregation more complex. Implementation of a tri-organisationally agreed minimum data set would significantly improve ease of whole service reporting.

Currently the activity data captured by the service does not include any that specifically shows the impact of the intervention on service users. Means to evidence service outcomes for patients, family members and professionals should be investigated, so that the benefits of the service can be fully understood and communicated.

## f. Conclusion

The extension of the service from five to seven days has facilitated specialist support to those most in need of it seven days a week. Recording and reporting of patient and family outcomes is now required to show the true value of the service through their eyes. Cancer patients do represent the majority of people referred to the service, ensuring accessibility for those with other illnesses is therefore important.

The unification of three service providers has offered a level of flexibility and complexity to service delivery. Analysis of the service activity data clearly suggests whole service growth; however, activity does not automatically translate into increased efficiency and effectiveness. If this growth persists in the absence of system and process improvements and/or staff growth, there may be future implications for the wellbeing of staff and for those the service is intended to support.

The CNSs' commitment to best care for patients and families shone through during the review. The challenges of the role were also brought into sharp focus. The levels of staff stress and the impact of lone working on CNSs must be recognised and improvement strategies should be explored.

Gaps in seven day working in the wider health and care provision clearly impact on CNS activity. A high level of CNS good will is evident and without it, patients' quality of life would suffer. Inevitably, time spent on work outside the CNS remit reduces the time available to carry out tasks within it. Accordingly, whilst CNS prescribing was strongly advocated by staff as a means to prevent symptom management delays for patients, a wider health care system solution may be needed.

Staff perspectives on the strengths and limitations of the evolved service and improvement suggestions have been clearly communicated through this report. Actions are now needed to support the next phase of service evolution. Consideration of opportunity costs to the weekday service should be integral to any plans for service change.

## g. Recommendations

Implications for practice have been identified through the review. The following recommendations for consideration aim to support future service sustainability and development. An action research approach to some of the recommendations may help to identify the advantages and opportunity costs to the service and its beneficiaries.

Through tri-organisational collaboration:

1. Develop and widely disseminate a clearly defined core offer, which describes the aims and objectives of the service, who can benefit from it, and how to access it, giving consideration to equity of access.
2. Agree the minimum dataset needed for reporting on service activity, giving consideration to the most appropriate outcomes to assess service impact, effectiveness, and cost effectiveness, ensuring the time cost of recording is proportionate to the reason for it.
3. Identify mechanisms for gathering and reporting patient/family and staff service user outcomes for the weekend/bank holiday service. Their views on how to improve the service may also be valuable.
4. Review systems and processes to optimise inter-organisation communication and information sharing including, appraisal of referral/handover documentation, and assessment of the feasibility and resource implications of the routine digital recording of patient contacts by all three SPC providers.
5. Consider ways to reduce the burden of lone working and workload on staff wellbeing and safety, including process/system change and/or increased staffing.
6. Investigate how the burden of call management on staff could be lessened, including increased staffing and/or utilisation of resources outside the CNS team.
7. Consider ways to reduce travel inefficiency, including the potential revision of the geographic remit of community staff and/or peripatetic working across settings.
8. Assess the cost and efficiency benefits of increased computer/remote device access for CNSs at weekends.
9. Review the CNS training portfolio giving consideration to the feasibility and potential risks and benefits of introducing patient assessment training and CNSs prescribing.
10. Instigate discussion with relevant parties regarding the impact of out of hours prescribing delays on patient wellbeing and the need to identify ways to overcome this challenge.

## 5. Background

The CVUHB is a large NHS health board covering the City of Cardiff and the Vale of Glamorgan. It provides two district general hospitals, two community hospitals, a mental health inpatient unit and a primary/community care service. The Population Needs Assessment<sup>1</sup> estimated there to be 357,160 people living in Cardiff, and 127,592 living in the Vale of Glamorgan in 2015. A 10% increase in the Cardiff population is expected in the next ten years with much of this growth being attributed to over 65's. The projected 1% population growth in the Vale masks the significant increase expected in the number of people aged 65 or over. By 2025, it is estimated that an additional 50,000 people will need health and wellbeing services and that much of this growth will be among people aged 85 or over, with a greater need for health care<sup>2</sup>. CVUHB's Shaping our Future Wellbeing Strategy<sup>3</sup> outlines that:

*'Care at the end of life must also be at the forefront of service design, ensuring that people die with dignity, in a place of their choosing, irrespective of their underlying disease.'* (p.15)

Over the last decade, the focus on seven day NHS services has intensified with the so called 'weekend effect' where it has been disputed and challenged that there is an effect on mortality, discharge and readmissions for those people admitted to hospital at the weekend<sup>4</sup>.

The demand in Wales for 24/7 SPC advice and support is evident in all health care settings and at home with a predicted 23,000 of the overall population in Wales needing palliative care at any one time<sup>5</sup>. It is critical that urgent referrals which account for 40% of all referrals are seen and acted upon quickly<sup>5</sup>; in addition, Marie Curie data<sup>6</sup> highlights that a person in the last year of life in the UK has between one and three emergency admissions, with a proportion of those being at the weekend and bank holidays – supporting the need for a weekend SPC CNS service.

Originally, the national impetus to develop services for seven day Palliative Care was provided through the National Institute for Clinical Excellence<sup>7</sup> (NICE) which highlighted the need for seven-day face to face contact. Although the recommendations did not specify that the face to face contact should be a nurse, it has been interpreted nationally to mean the Clinical Nurse Specialist. In line with this recommendation, the National Standards for Specialist Palliative Care Cancer Services<sup>8</sup> included a standard for seven-day working, compliance with which was March 2009.

The All Wales Palliative Care Planning Group Review of Palliative Care Services, made a number of recommendations about services across Wales<sup>9</sup>. Consequently, an Implementation Group, led by Baroness Finlay, was developed to identify key priorities and co-ordinate developments with a move to seven day working for CNSs as one of the priorities. There was a small amount of funding identified to support this development in the One Wales funding allocation for palliative care, including the funding of weekend and bank holiday Agenda For Change enhancement costs, announced in the Ministerial Letter<sup>10</sup> (July 09), and the Implementation of Palliative Care Report<sup>11</sup>. There was All Wales agreement over the collection of a Minimum Data Set, which was adapted from the UK National Council for Palliative Care Minimum Data Set collection<sup>12</sup>.

## a. Rapid review

A rapid review of literature was carried out in order to gain further understanding of the challenges and opportunities for seven day working, and to identify any best practice models within the context of overall palliative care provision at weekends<sup>13</sup>. The review aimed to answer the question: *What is the impact and effectiveness of the 7 Day CNS service on palliative care patients and their families?* Ten studies fulfilled the inclusion criteria and were reviewed in full. The key findings are shown below:

*'The majority of papers identified describe service evaluations. There is very limited evidence of prior assessment of need, nor of modelling around differences between weekday and weekend general health and social care provision, which might underpin service design. In essence, most are a description of a modified extension of weekday services. There was evidence within the evaluations of significant changes to management of patients in the last 48 hours of life (Birks 2015, Halls 2013). Although none described the level of unmet need prior to service implementation, two papers described sequential evaluations demonstrating increased activity over time as services became embedded (Birks 2015, Rowlands 2012).*

*One paper (Gallagher 2013) describes qualitative interviews with local district nurses prior to the setup of a community seven day service. Key themes emerged relating to clarity of communication between [District Nurse] DNs, GPs and CNS teams, clarity on role descriptions and defined criteria for new referrals, which were incorporated into the CNS role description at weekends. One other paper highlights the potential benefit of nurse independent prescribing in a community setting (Webb 2011), describing 65 prescribing episodes over a 6 month period.*

*No papers were found which interrogated the differences in hospital and community general care provision which would impact on their weekend service model, nor on the opportunity costs to other parts of the weekday service. None of the papers addressed patient/carer perception of need. No papers identified specific service components which were seen as core, and service models were too similar to seek differences in provision and outcomes.'* (P.1)

The full text rapid review including information on evidence reliability and reference list can be downloaded from: <http://palliativecare.walescancerresearchcentre.com/palliative-care-evidence-review-service/>

## b. Service description

### Weekday service

The CVUHB Specialist Palliative Care Service includes a secondary care team, two third sector commissioned community teams and a third sector commissioned Hospice inpatient 28 bedded unit. This differs from some Health Board areas where there might be one single service provider covering all sectors. A CVUHB/Marie Curie funded 7-day Hospice at Home Service is delivered by Marie Curie Health Care Support Workers.

CVUHB provides inpatient palliative care and outpatient support in two district general hospitals (the University Hospital of Wales and the University Hospital Llandough), two community hospitals (Barry and St David's) and a mental health unit at Llandough.

The City Hospice provides a service to the City of Cardiff, including community hospice care and a day therapy centre. Marie Curie provides a community service to the Vale of Glamorgan and provide a hospice inpatient service and day therapy services.

### Weekend and bank holiday service

The weekend and bank holiday SPC service is a modified extension of the weekday service, delivered by a greatly reduced staff of Clinical Nurse Specialists, as opposed to the full multi-disciplinary team which operate Monday to Friday.

The approach to seven-day service implementation and levels of service maturity differ across the UK. Using the first two of the four levels of seven day working provision identified by NHS Improvement as a descriptor<sup>14</sup>, in broad terms,

the CVUHB weekend and bank holiday SPC service falls somewhere between level one and two, in line with the original focus to close the patient pathway service gap:

*'Level 1- Services limited to one department or a service that is beginning to deliver some services beyond the 8am - 6pm Monday to Friday service. This could be extended working days and some weekend services, however, does not deliver equitable services irrespective of the day of the week.*

*Level 2 - Services that are delivered seven days per week, but not always offering the full range of services that are delivered on week days. This limited range of services goes beyond "on call" and emergencies only and facilitates some clinical decision making and discharge, though is likely to be one service and not integrated with other service delivery.'* (P.7)

The CNSs aim to provide specialist advice and support with symptom control to people with non-curable illnesses and their families. The geographical scope of the service at weekends and bank holidays has the same footprint as that covered during the week. The service is delivered in the community and hospital settings.

### *The community service*

On weekends and bank holidays, the community SPC service is provided by Marie Curie & City Hospice. There is a single Band 6 or 7 CNS allocated for the entire Cardiff and Vale community area during this time.

Marie Curie provides a CNS for one in four weekends and are based at the Marie Curie Hospice. City Hospice provides a CNS for three in four weekends and are based at Cardiff Royal Infirmary. These rota arrangements have recently changed. Up until April 2018 each provider covered alternate weekends.

### *The hospital service*

The Hospital SPC service is provided by CVUHB SPC team staff. There are two band 7 CNSs on a Saturday and one on a Sunday. There are two CNSs on for each Bank holiday shift. The service remit includes two district general hospitals (the University Hospital of Wales and the University Hospital Llandough), two community hospitals (Barry and St David's) and a mental health unit at Llandough.

## 6. Methodology

The aim of the study was to undertake an evaluation of the CVUHB weekend and bank holiday SPC CNS service. The objectives of the evaluation were to:

1. Measure and describe recorded service activities
2. Identify what aspects of the service work well
3. Identify challenges and improvement opportunities
4. Develop recommendations to support future service sustainability and development.

A mixed method approach was taken to fulfil these objectives involving four core activities:

1. Rapid review of literature
2. Surveys of CNS staff employed to deliver the service on weekends and bank holidays
3. Interviews with CNS staff employed to deliver the service on weekends and bank holidays and service managers
4. A retrospective observational study of service activities.

As the review was an evaluative study of a specific existing service intervention, ethical approval was not required. Details of the methodology for the survey and Interviews are described in the following section. The methodology used and results of the retrospective observational study of service activities are contained within its own section.

## Survey of CNS staff

The survey was administered by a researcher at the MCPCRC using 'Online Surveys' (formerly Bristol Online Survey). It utilised a range of question types, including rating scale and open-ended questions designed to help respondents share their views and experiences about delivery of the service on weekends and bank holidays.

The survey questions were influenced by key themes/topics identified in the rapid review of literature as well as discussion with an SPC Clinician and Lead Nurse. A Research Partner reviewed the questions to ensure the public voice and interest was considered.

The survey aimed to gain CNSs' views in relation to:

- CNS skills, knowledge, experience and clinical support
- Service demands including perception of demand, workload and working within the CNS remit
- Impact of weekend working on the weekday service
- Service efficiency
- Service strengths and successes.

See Appendix 1 for the survey questions.

A letter of invitation to complete the survey and live survey web link was emailed directly to service managers through the Lead Nurse in Palliative Care at CVUHB. Managers then cascaded the email to staff.

The survey contained information about the aim and objectives of the survey and consent pages. Any CNS that opened the survey and indicated they did not agree to consent to participate would have received an automatic response thanking them for their time and directing them away from the survey.

The survey was open for a total of fifteen days from 5th to the 20th June 2018. Only CNS staff employed to deliver the SPC CNS service in the CVUHB region on weekends and bank holidays were invited to participate. Service managers, CNS staff employed by other trusts/services and allied health professionals were not eligible to take part.

The target sample size was a minimum of four responses from each of the hospital and community settings.

Survey responses were downloaded from BOS in Excel format and were then labelled with a response number. The response data were then split into two separate files by data type: quantitative data and qualitative data.

Quantitative data were uploaded to SPSS 23 software that supports the statistical analysis of data. Descriptive statistics were used to describe responses to rating scale questions. Due to the relatively small sample size, both percentages and number of observations available for each question are presented in the report. Percentages have been rounded to the nearest whole number.

Qualitative data were uploaded to NVivo 11 software that supports the organisation and analysis of unstructured text. Thematic analysis enabled free text comments to be analysed and described<sup>15</sup>. The catalogued responses were read line by line and relevant text was isolated, interpreted and allocated codes or themes. Data from six surveys were independently analysed by two researchers and used to develop themes. A list of key themes was agreed through discussion and later used as a framework to code the remaining surveys. An iterative process was used where any new themes emerging from the data were discussed and agreed upon. A third researcher supported this process where agreement could not be reached. For the purposes of confidentiality and bias limitation, co-author and the Lead Nurse for Palliative Care Service, Mel Lewis, had no access to the qualitative data and played no part in the analysis and development of themes.

## Interviews with CNS staff and Service Managers

The interviews aimed to explore in more detail, the key topics and gaps in information identified through the survey. Questions focused on the positives of current practice and improvement opportunities in relation to:

- If and how the weekend and weekday services are different
- How patients are identified
- How caseloads and referrals are managed
- The logistics of travel between hospital sites and between patient homes
- Access to patient information
- Inter-disciplinary relationships with and support to/from allied professionals
- Compensatory rest and pay
- Service equity for patients and their families.

See Appendix 2 for the interview topic guide.

CNSs employed to deliver the CVUHB SPC CNS service on weekends and bank holidays and service managers, were eligible to participate in the interviews. A letter of invitation to attend an interview, information sheets and consent forms were cascaded by email to service managers through the Lead Nurse in Palliative Care at CVUHB. Managers then cascaded the email to staff. Interested parties replied direct to the researcher undertaking the interviews.

The target sample size was a minimum of one service manager and two CNSs from each of the three providers.

The face to face interviews were digitally recorded, although some notes were also made at the time of interview. To support a reflexive approach to data analysis and reduce the potential for researcher bias, a reflective account was written and discussed with a second researcher after each interview.

The audio files were transcribed verbatim following the MCPCRC transcription Standard Operating Procedure to ensure data protection, anonymity and confidentiality. Interviewees were given the opportunity to review and comment on their transcript to ensure accuracy of meaning before data analysis was undertaken.

The transcripts were uploaded into Nvivo11 and interview data was analysed using the coding framework and thematic approach described in the previous section.

## SECTION ONE: QUALITATIVE DATA

### 7. Survey and interview results

#### a. Staff participation

A total of 18 surveys were completed online by CNS staff employed to deliver the service. Eight of 18 respondents were employed to work in the hospital setting, the remaining 10 worked in the community. Both City Hospice and Marie Curie community staff participated in the review through the survey.

A total of 12 semi-structured interviews were conducted with CNSs and service managers from each of the three service providers. The interviews were carried out face to face at the MCPCRC offices in Cardiff, between September 10th and October 2nd 2018. They lasted between one and one and a half hours. Each provider was represented at interview in the following ways: Marie Curie – three CNSs and one service manager, City Hospice – four CNSs and one service manager, CVUHB – two CNSs and one service manager.

## b. Thematic structure

The results from the surveys and interviews are reported together under thematic section headings. Where relevant, the interplay of themes is discussed within sections so that all related factors are described. Divergent views and topics identified by individuals are represented.

Three major (superordinate) themes and seventeen subthemes were identified through analysis of the survey responses and interview transcripts. These are outlined in the following table:

<b>SERVICE DESIGN</b>
<b>CROSS-ORGANISATIONAL COLLABORATION</b> How the three organisations work together to deliver the single service.
<b>SERVICE USER CHARACTERISTICS</b> Features or qualities belonging typically to the people using the service that serve to identify them.
<b>STAFF KNOWLEDGE AND SKILLS</b> CNSs theoretical and practical understanding of specialist palliative care and proficiencies developed through training or experience required for weekend and bank holiday working.
<b>WORKLOAD &amp; CONTRACTED HOURS</b> The amount of work allocated to CNSs and the time designated for this purpose.
<b>STAFF REMIT BOUNDARIES</b> The limits of the area of work CNS staff are responsible for.
<b>STAFFING LEVELS</b> The number of people employed or on duty to deliver the service.
<b>SERVICE DELIVERY</b>
<b>SERVICE DEMAND PERCEPTIONS</b> Staff perceptions of external demand or desire for the service.
<b>SERVICE EFFICIENCY</b> Staff perceptions of the extent to which the service achieves maximum benefit to patients/families with minimum wasted effort, time or expense.
<b>CROSS-SITE AND COMMUNITY TRAVEL</b> The journey and practicalities of travel between hospital wards, patient homes or other sites.
<b>PATIENT RECORDS</b> The recording of and access to patient information.
<b>CASELOAD MANAGEMENT AND REFERRALS</b> The process of dealing with and controlling the number of cases/calls the CNS is concerned with at one time including the act of referring patients/families for CNS support.
<b>SPECIALIST CLINICAL ADVICE AND SUPPORT</b> CNSs Inter-professional relationships with, access to and support from specialist clinical staff.
<b>ALLIED SERVICES</b> CNSs inter-professional relationships with access to, and support from services outside the SPC field.
<b>SERVICE OUTCOMES AND IMPACT</b>
<b>SERVICE BENEFICIARIES</b> Those who benefit from the service and how.
<b>SERVICE EQUITY</b> The ways in and extent to which equal service access is provided to those with a recognised need for support.
<b>STAFF WELLBEING</b> The marked effect or influence of the CNS role on staff wellbeing.
<b>IMPACT ON WEEKDAY SERVICE</b> The marked effect or influence of the weekend/bank holiday service on the weekday service.

### c. Service design

The Service design major theme outlines the key users of the weekend service and the assets and resources available from within the SPC team to deliver it. The theme is broken down into six sub-themes:

i.	<b>CROSS-ORGANISATIONAL COLLABORATION</b> How the three organisations work together to deliver the single service.
ii.	<b>SERVICE USER CHARACTERISTICS</b> Features or qualities belonging typically to the people using the service that serve to identify them.
iii.	<b>STAFF KNOWLEDGE &amp; SKILLS</b> CNSs theoretical and practical understanding of specialist palliative care and proficiencies developed through training or experience required for weekend and bank holiday working.
iv.	<b>WORKLOAD &amp; CONTRACTED HOURS</b> The amount of work allocated to CNSs and the time designated for this purpose.
v.	<b>STAFF REMIT BOUNDARIES</b> The limits of the area of work CNS staff are responsible for.
vi.	<b>STAFFING LEVELS</b> The number of people employed or on duty to deliver the weekend/bank holiday SPC service.

#### i. Cross-organisational collaboration.

This section relates to how the three organisations work together to deliver the single service.

Cross-organisational collaboration and communication was highlighted by staff as a major service strength. The cultural shift embraced by the three providers to deliver the service across seven days, filling the former void in weekend and bank holiday specialist palliative support, was highlighted as a key success by staff. Experienced, supportive teams and the commitment of CNSs were thought to underpin service delivery and benefit patients. Confidence in their CNS peers was said to be a 'significant strength'.

Communication across CNSs based in the two main hospital sites was said to be working well to agree weekend referrals. Cross-communication between the community and hospital teams was also thought to be good. Other strengths highlighted by staff included reciprocal support and positive relationships with allied professionals.

Whilst staff celebrated this cross-organisational achievement, they also highlighted areas for refinement that might improve service delivery. These are discussed under the relevant section headings within this report.

*I 10 H Ref 12: '... we've embraced the shift at the weekend and to providing an out of hours service whereas ... other specialties haven't yet made that leap or that link. Erm, so we have been a bit ahead for timing in doing that and embracing that ... the strengths of that have been that without a doubt, erm, we're providing more, a better, a more robust, erm, service for patients and families that they weren't getting ten years ago. ... we're addressing their needs, erm, or their urgent needs should I say, ... in a more timely and responsive way than we ever were. ... and we're providing that service, er, across the whole area so even though some of it's a bit clunky, ... at the end of the day that person sees a nurse face to face ... or has the opportunity to see a nurse face to face and that's, er, invaluable for some of these people that are feeling vulnerable and, erm, and worried, particularly patients at home that are often, erm, isolated and alone particularly at weekends. ... it's filling, er, a void for that individual and often hopefully preventing readmission and crisis at home, erm, and likewise in hospital, er, addressing urgent pain symptom problems that maybe people maybe wouldn't have had the experience of dealing with previously, er, at the weekend.'*

*I 5 H Ref3: 'I think the key strengths within our team are that we are on the whole a very experienced team. Like I say we've got a couple of nurses who are less experienced and do get more stressed about the weekend ... so like I said if there was a junior staff we, we're all happy for them to ring us on our day off or whatever, and ask, just ask for some advice. Erm, and the same with the consultants, ... if they've been seeing a patient during the week they'd be happy, they'd say ring us on the mobile and we'll just chat things through with you. ... Erm, other strengths... Er, that's probably the main one.'*

**I 3 C Ref3:** ‘... It’s not bad and we help each other. If people have got [things] on we just swap with each other and lovely team to work for, they’re great. They’re lovely. If someone’s got a wedding or something on and they, cos everybody’s sort of rota’d in and then things happen. We work for each other. ... no it’s brilliant here.’

**I 12 C Ref4:** ‘Well I think that the joint working is good I think it’s, the fact that we erm have to communicate a lot with [names organisation] over the on-call working erm it’s good that we keep that contact with them, we sort of know what’s going on with each other’s services. Erm you know [deleted], [deleted] and [deleted] is meant to be one area and I think that the patients should get the same service regardless of erm where they live. Erm [pause] yeah so I think it’s good that it is a joint thing this collaborative working.’

**S 16 H Q12:** ‘... team member support and flexibility to provide extra cover at short notice is a strength of our team. Confidence in each other is a significant strength. Informal support from our Cardiff and Vale palliative consultants on weekends in a crisis is much appreciated.’

**S 9 H Q14:** ‘The service is excellent and communication within the team is good. Also communication between c[ommunity] p[alliative] c[are] t[eam] and hospital. Both ... are empathetic of each other’s work load and address needs as patients are admitted or discharged. ... ’

## ii. Service user characteristics

This section relates to the features or qualities belonging typically to the people using the service that serve to identify them.

The survey responses suggested that the nature of patients and families supported on weekends and bank-holidays is different to their usual weekday caseload, with the service being targeted primarily at adults with urgent and unstable symptoms and complex care and support needs. Through the interviews, CNSs in both the hospital and community setting explained that the service was targeted at patients with high level support needs. A hospital-based CNS described a colour coded rating system based on patient care needs, with only those in the red category being seen at weekends/bank holidays. Patients requiring a medication review due to changes being prescribed late in the week were also prominent users of the service. Some CNSs said in addition to a subset of patients with urgent needs and their families being seen at weekends/bank holidays, the kind of support offered was also more clinically targeted. This is discussed in more detail in the Staff remit boundaries and Service equity sections. Ward staff were also said to benefit from CNS advice and support.

**I 7 H Ref1:** ‘So yeah, so the main differences are the intensity of the type of patient we get ... we traffic light our patients so they’re red if they really need lots of care, amber okay we probably wouldn’t see those at the weekend and green which we only see once a week so on a weekend you’d only see the red ones.’

**I 10 H Ref 1:** ‘... So those patients that are complex with changing symptom needs, ... maybe had their drugs changed on a Friday and may need to be reviewed on a Saturday erm, or those families that are, erm, very distressed might need review er, and those patients that are, erm, dying, but maybe having symptom problems alongside that. ... So it’s different because we’re only seeing the complex and urgent patients at the weekend.’

**I 5 H Ref1:** ‘... I feel that on the weekend we’re concentrating more on, erm, difficult symptoms so the more complex things, so someone who’s maybe particularly symptomatic, possibly somebody who is end of life, and maybe someone or families who are really, erm, struggling emotionally so we’re dealing with the more complex things. ... ’

**I 12 C Ref2:** ‘... they are the same I guess sometimes the only difference would be is that they ring cos they may’ve hit a crisis point. So there’s quite often erm, all patients are complex but they’re likely to be the more, in the more complex range of patients.’

**I 2 C Ref1:** ‘... we wouldn’t have to see our caseload. ... it’s more [pause] emergency calls I suppose.’

### iii. Staff knowledge and skills

This section relates to CNSs theoretical and practical understanding of specialist palliative care and proficiencies developed through training or experience that are required for weekend and bank holiday working.

The survey asked staff if they felt they had the necessary clinical skills, knowledge and experience to deal with the cases they encounter on the weekends and bank holidays. In their free text responses to the question, many said they had all or almost all the skills, knowledge and experience required.

**S 17 H Q7:** *'Have the specialist skills and knowledge to cover clinical work load and can access advice if needed.'*

**S 5 C Q7:** *'Most of the time and if there are situations that I feel are outside of my remit as a CNS then advice can be easily sought via the on-call registrar or consultant.'*

**S 10 H Q7:** *'Over the time I have been working weekends, I certainly feel my confidence has grown. The challenges that weekend and bank holiday working has given me has on the whole been an important learning curve and has facilitated my professional development. There are times where I have felt out of my depth but it's at these times that I seek advice from the on-call palliative care consultant or registrar.'*

CNSs from both settings talked about the process of preparation for weekend/bank holiday working. The time frame between joining the SPC teams to working weekends was thought to be at least six months. CNSs said their employers ensured that competency levels were achieved and they felt ready to undertake the task before their first weekend/bank holiday shift. Shadowing was thought to help staff feel prepared. One community CNS said they would have appreciated the support of another staff member on their first weekend shift. Better access to patient records was suggested as another way to help staff feel prepared. See the Patient records section for information on accessibility of patient information.

One hospital-based CNS said that only more experienced team members worked alone on weekend/bank holiday shifts, with newer staff working a Saturday with a colleague. Some community-based CNS described how 'very scary' and 'daunting' their first lone shift was and the sense of relief when it ended. One CNS explained that their misgivings continued to linger. This was due to working with unknown patients without access to their full information. However, s/he believed that nurses developed skills and ways of working to circumvent this issue.

**I 3 C Ref 1:** *'Oh, we had good training actually, ... it was a good couple of months and made sure ... we knew what we were doing and that they were confident that we would be alright, but in actual fact you shadow somebody and then when I did actually do my first, er, out of hours ... I had a contact with my, one of the team leaders anyway if I needed anything. So you could always ring and ask ....'*

**I 10 H Ref 2:** *'They'd come into the team and gain, er, at least six months experience before we're starting to put them on at the weekend. ... And then they wouldn't be on their own at the weekend, so. ... So it would be more to do with their overall, erm, competencies and managing that, so it would be looked at as a whole.'*

**I 4 C Ref 1:** *'I think it's about six months, ... which I think is about the norm. ... I did go out with one of the girls on a Saturday, for a few hours, to see how things work, and my colleagues had said, you know, any problems, give me a ring. But yeah, still very, very daunting. Very relieved when it was over, and it had all gone okay. [Laughs].'*

**I 9 C Ref 1:** *'... I think the first weekend, I shadowed somebody just to get a sense of how it all works um and then when I did the weekend, ... somebody who worked weekends normally, who had experience of doing them, kind of like just worked alongside me, ... was there if there was any sort of "What do I do?" in these situations. It, it's daunting when you first do, well it is, and I still say it's daunting now. Um cos you never know what you're gonna get in on the weekends, um you don't know all the patients, so it's always a bit, a bit difficult and Services are not quite the same on the weekend and as much as you're dealing with Out of Hours GP's ...'*

**S 4 C Q7:** *'I always find the thought of a weekend on-call daunting as you just don't know what to expect. I know however that I can always contact the on-call Dr to ask for advice if I need to. As a relatively new Palliative care CNS I am continuously learning. My first on-call weekend was 6 months after starting in this role - it was very daunting and I would have appreciated working with someone else for the first weekend.'*

The complexity of patients and the challenging nature of symptoms and decision-making during the weekend and bank holiday were highlighted. The importance of the on-call doctor as a source of advice and support was emphasised. CNSs said they also referred to GPs where appropriate, and drew on each other for support. Having two CNSs on shift in the hospital setting made this easier. CNSs said support arrangements had also been made within teams which is discussed in more detail in the Specialist clinical advice and Staff wellbeing sections. Care plans and guidelines were thought to be helpful in directing staff. Problem solving skills were said by one interviewee to be essential to the CNS skill set, and particularly important at weekend/bank holidays due to lack of seven day working in other fields.

**S 16 H Q7:** *'I feel confident with dealing with the majority of cases encountered on weekends/BH. If difficulties are anticipated, our team usually aims to provide a weekend plan. I feel confident in knowing how to access additional help or support from Palliative medic on-call for any situation that I feel less confident in dealing with, or I would refer to the medical team on-call within the hospital. ...'*

**S 18 H Q7:** *'Not always some of the patients can be more complex that have been seen by consultants or registrar in the week and then needing review by a CNS. There is often a plan of what may be required for these patients at the weekend which is helpful as I wouldn't always know what to do.'*

**S 9 H Q7:** *'On the whole yes and find that there is appropriate support from the on-call consultant or our own consultants who have said to ring them if patient particularly complex and well known to them.'*

**S 7 C Q7:** *'... I feel I have a good knowledge base to help guide me in most situations but am more than happy to call for advice from other colleagues and refer to guidelines etc whenever there is something unknown. We see patients with such a diverse range of illnesses I think there are times when a situation presents itself that really challenges you and requires an MDT approach to resolve.'*

Staff named specific skills that they believed would enhance their role. The belief that CNS prescribing would be of benefit to staff and service users was particularly prominent among community staff. At interview, CNSs explained they were in favour of undertaking the prescribing course to facilitate timely support to patients. However, the scale of this undertaking, including the commitment required to attend the course and complete the associated coursework was a consideration. Potential complications for implementation were also highlighted. See the Allied services section for more on this.

The desire to undertake patient chest and abdomen examinations and neurological assessment were communicated through the survey. A CNS who had completed the patient assessment module believed it had enhanced his/her confidence in physical assessment and verbal history taking. The inability to independently admit patients to the acute setting and the benefit of having basic equipment such as a thermometer and blood pressure monitor available were mentioned.

**S 1 C Q7:** *'... I strongly believe that the ability to prescribe would enhance the weekend/bank holiday experience for the weekend CNS, patients, families, DN's and GP's. But recognise that there is a huge amount of work to be undertaken to ensure that the CNS' ability to prescribe is not abused for more generalist work (e.g. to further substitute the work of the GP OOH service). Having said this, the issue of Community Nurse Prescribing should become a high priority for discussion.'*

**I 3 C Ref 10:** *'I mean it's a big thing to do cos you need prescribing and everything to be able to do it ... it would have to be sort of for end of life drugs ... , to go in, write down for a syringe driver or write down for basic sort of PRN doses would be handy cos I could just go in and do it, ... it would make things quicker, flow better, but then maybe it is the role of the doctor, I don't know ... . Yeah, I think it would be easier if we could prescribe certain end of life drugs and do the drug chart for them but it is a huge responsibility you know isn't it?'*

**I 7 H Ref 1:** *'Yeah, well if we could prescribe that that would be good, we've got access to do the erm non-medical prescribing but that has got it's pros and cons with it really ... it's quite a big responsibility and it's a really difficult course to do as well and very time consuming ... it's a year the course but it's the amount of work that's with it [...] it's very intense ...'*

**S 11 C Q7:** *'I do feel I have the knowledge skills and experience but do not have the clinical skills to examine chest and abdomen undertake neurological assessment. I do not have the prescribing ability to change PRN medication or syringe driver medication on drug chart or write prescription for new supply of medication. I am unable to admit patients directly to the acute sector but I am able to discuss and arrange admission to the in-patient hospice if I discuss with On-call Palliative Medicine Consultant.'*

**S 14 C Q7:** *'I feel that I have developed my knowledge and skills over the years to enable me to deal with problems over the weekend. However I don't have medical experience of patient examinations such as chest examinations etc. I also feel that it would be helpful to be an independent prescriber to be able to make changes to medications and give prescriptions.'*

**S 7 C Q7:** *'... I have completed a patient assessment module and feel this has helped give me confidence in physically assessing patients along-side verbal history taking. I do feel that as CNS' it would be incredibly beneficial to us to undertake the prescribing module, if only to have a more thorough understanding of the drugs we are recommending and titrating with the GP's. ... '.*

One community CNS proposed that the knowledge and experience that staff develop and draw on might relate to the socio-economic and cultural characteristics of patients and families living in the areas they usually cover during the week. S/he believed that working in a wider area during weekends/bank holidays exposed staff to different challenges. How cultural awareness could impact on patient interactions and advice was given as an example.

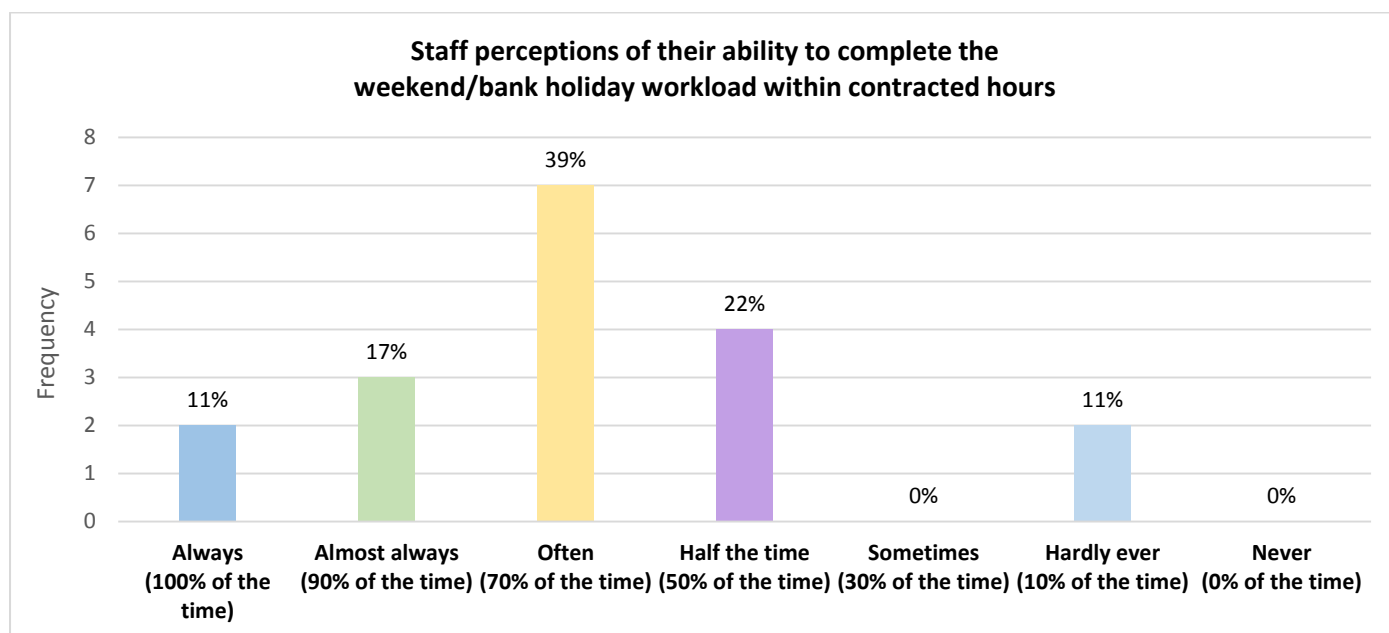
**I 6 C Ref2:** *'... you're used to your area, and then suddenly on a weekend you're opened up, and so everyone's area, and they've all got different needs and, and issues. As well as their clinical issues. ... clinically I think the patient would get the same, because it's the same clinical advice. I think it depends on how experienced the nurse is in dealing with the additional issues. ... I can think of an example where there was a gentleman that was ... fasting ... but he was dying and it wasn't appropriate ... he was actually doing himself harm, ... there are exceptions within their faith to say that actually you're so unwell, you don't need to fast, but if you don't know it's that period of the year, then you may not have asked the question ...'*

One hospital-based CNS suggested a knowledge exchange between the hospital and community services would help staff give more accurate information to patients about service availability in each setting. In particular, having better understanding of how the services are operated, how they prioritise work, and the challenges they face were mentioned.

**I 5 H Ref 4:** *'... what would be handy is, ... more understanding of ... stresses over the weekend ... So they [community CNSs] maybe understand how we manage all weekend and the pressures we've got and that we understand them. So we could maybe give a better service that way if we understand each other's areas? Erm, so we would know if we're talking to families ... what is offered more in the community, erm, what sort of service they're likely to get, ... I think for general as well, as well as weekend. ... I don't know how the, the team decided whether they're going to face to face review a patient or ... telephone or whatever, ... I don't know how they prioritise their patients and, and what their work load is and what, what complexities they've got to deal with. ... '*

#### iv. Workload and contracted hours

This section relates to the amount of work allocated to CNSs and the time designated for this purpose during a weekend/bank holiday shift.



The survey asked staff if they were able to complete the weekend/bank holiday workload within their contracted (9 to 5) hours. Their responses showed that this was either always or frequently achieved by two thirds of respondents (12 of 18 or 67%). Four CNSs (22%) said this was achieved about half the time, the remaining two (11%) said they hardly ever completed their work within contracted hours.

At interview, staff said they worked weekends/bank holidays every four to six weeks in the hospital setting and every six to eight weeks in the community. CNSs acknowledged that the workload can fluctuate on weekends and bank holidays in line with demand. CNSs indicated that on days when they had to work over their hours, a six o'clock finish was not unusual. One community CNS said lunch breaks were a scarce luxury. Some staff suggested working extra hours served to sustain service quality and equity.

**S 16 H Q5a:** *'Although planned reviews are kept to an agreed maximum number where possible, the workload is unpredictable in that unplanned reviews and new referrals can be received by bleeps or telephone referrals, therefore difficult to manage in the allotted time as often single team member on a weekend day.'*

**I 6 C Ref1:** *'... You can have a very, very quiet shift. Where you only get a couple of phone calls ... and then at other times it rings relentlessly, you're giving advice, ... you've got upset patients on the phone that need you to visit and you just can't get there. So ... the volume of work can fluctuate much more on a weekend ... it's very rare that it's quiet. ...'*

**S 1 C Q5a:** *'In my experience, it is rarely possible to provide a service (of the same quality as Monday-Friday) within contracted hours.'*

**I 6 C Ref7:** *'... we try our best and we work late. I think on the whole people do [get an equitable service], but probably to our detriment [laughs]...'*

Greater awareness of the service was thought to have increased the workload. CNSs said they were taking more advice calls and referrals and seeing more patients, which in turn created additional paperwork. Some community CNSs explained that lack of time to complete the relevant documentation during busy shifts meant this task had to be done after working hours, sometimes at home. An early start was thought necessary by one CNS in order to familiarise themselves with referral documentation before the phone was diverted at nine am.

The distances between home visits, traffic conditions and late calls that result in home visits were all cited as reasons community staff work late. As mentioned in the Cross-site and community travel section, a travelling time logging exercise carried out by one community service provider was said to have shown travel to be the main reason that staff were exceeding their contracted hours. GP call back delays were also thought to sometimes prolong the day. The need to work additional hours was said by one CNS to be more likely on a three day weekend.

One interviewee said that current service data capture did not show the hours staff work, length of visits/phone calls or travelling time. S/he believed that such data would show staff working significantly over their contracted hours.

*S 7 C Q5a: '... It is more usual that writing up my notes well exceeds the 5pm finish and I often finish these for a couple of hours once I am home.'*

*S 12 C Q5a: 'Due to the amount of visits that need to be done on some shifts. The necessary unplanned nature of the day means that sometimes large distances need to be travelled in between patients. ... If phone calls keep coming through it can be difficult to keep up with paperwork so this often needs to be completed at the end of the day ...'*

*S 4 C Q5a: 'Receiving a late call which results in a home visit, the amount of visits and the logistics of the visits. Writing up notes at the end of day when it has been busy.'*

*I 2 C Ref 1: '... so you can get people phoning you up to, like, you know, four, half past four. ... so, yeah, generally we'd still go out and see them. ... It's often ... that you finish at sort of six, so seven's probably late. So often ... I don't have time to write everything up so I often end up taking that home and doing that at home. That's not unusual necessarily.'*

*I 4 C Ref1: 'I mean I might get a call at quarter to five and you finish at five, and you can't really say no ... There's been times when I've worked over, or I've had to finish writing notes and things after, you know, after five o'clock, probably a few times.'*

*S 9 H Q5a: 'This particularly happens on a 3/7 weekend.'*

*I 11 C Ref 3: '[The numbers] might show some increase [in demand] but not the erm amount of time we spend on the telephone or in the house. I think it would show that people are probably working way over seven and a half hours. I think it would show that if there was two on it would most probably be a shorter day for them, most of them do their paperwork at night you know cos they can't finish by day. ... I prefer to stay until I've done it but you know others have got to get home so they'll take their paperwork with them yeah.'*

Through the survey, one CNS stated that the need to work outside contracted hours on weekends and bank holidays had reduced since the development of new referral criteria. Another expressed the belief that it was the altered level of care and fewer patients seen at weekends that facilitated their ability to complete their work within contracted hours. One interviewee said the workload-related stress previously felt by hospital staff when the service was introduced with existing resource had diminished. This was attributed in part to enhanced staffing levels. Finishing work on time was thought to be more achievable in the hospital setting on days when two nurses are on shift.

*S 10 H Q5a: 'Initially when we started delivering this service it was common place to finish late, however, since developing the criteria for what patients we list for face to face review has resulted in a more manageable case load. We have also increased the number of CNS' on a Saturday - we potentially cover 5 different sites.'*

*S 11 C Q5a: 'We have become experienced at prioritising the needs of patients within our period of on duty. If we delivered the same level of care and contacted the same number of patients as we would on a weekday we would hardly ever complete the workload within the contracted hours.'*

*S 6 H Q5a: 'We are usually able to complete our workload as ... there are 2 CNS working so the workload is shared. ...'*

*S 18 H Q5a: 'Most of the time I have been able to complete given workload within contracted hours. However I know that as a team covering the weekend service people have had to work late due to unpredictable increased demands ...'*

**I 5 H Ref1:** *'Erm, I suppose the other thing to say is that when the service was set up, I felt it was set up very rushed, it was very pressurised to be set up. Erm, there was no budget to set it up, so it was set up with existing staff available, and it feels like it's continued in that same vein in a way. Erm, like I say we've, you know, we have now managed to, erm, have an extra nurse on the Saturday, but I feel there were probably a few years where some of the staff on the team were very, very stressed by the amount of work load they had to deal with and complexities of the patients they had to work with.'*

One hospital-based CNS said that the End of life Care Decision Tool had helped reduce workload as it guides and enables ward staff to support patients themselves. However, resistance from some staff to use the tool because of the time it takes to familiarise themselves with it was noted.

**I 7 Ref 2:** *'So I mean the end of life care decision has helped us tremendously ... So it's when we're thinking a patient[s] ... life will be ended within sort of twenty-four to seventy-two hours ... there's a tool, there's a booklet that the doctors fill in with the family ... and it's all about you know hydration and food and things like that, at the back of that booklet there is a really clear comprehensive erm suggestion of what medication to give for those sorts of circumstances. So whereas before we would see probably everybody or ninety-nine percent of people who were nearing the end of their life ... now if they haven't got any complications using that end of care decision tool we can ... say do you want to use that and obviously if you've got any queries or anything then obviously we'll come up but erm. You know if everything's straightforward and ... the patient isn't suffering ... they're just having the medication as prescribed erm then we probably don't need to be involved with that particularly. ... although we still have a lot of phone calls to ask us to be involved but then once we suggest the tool they usually look through that and they can deal with it then ... So that has taken some of the pressure off now.'*

**I 7 Ref 3:** *'... it's been our responsibility to teach the wards the new tool ... and obviously you're getting new doctors every so often ... So it's trying to get them to use it as well instead of erm, cos a lot of the time they'll say well no just you tell me cos it takes me ages to read it ... But that's not particularly what ... working at the weekends is about really is it ...'*

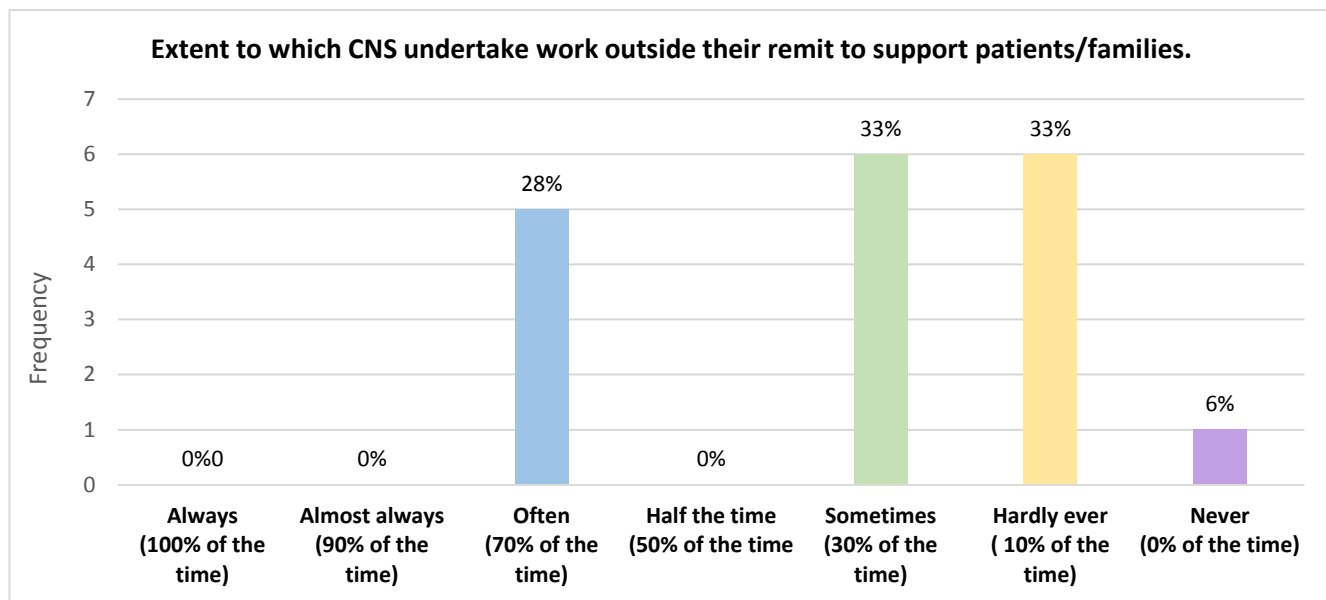
The topic of appropriate weekday caseload size was introduced by one community CNS during interview. S/he said that recent recommissioning had resulted in staff having a more appropriate size caseload. This was thought to have enabled staff to effectively support patients in the week, reducing crisis on weekends and bank holidays. They went on to suggest that a review of the weekend workload and what can feasibly be delivered is needed. Changing working hours to accommodate preparation time was also suggested.

**I 6 C Ref3:** *'... the nurses have ... appropriate sized caseloads now that they're able to see patients effectively so you don't get patients that should have been seen that weren't seen that deteriorated and end up in crisis on the weekend, so that helps the volume of work on the weekend.'*

## v. Staff remit boundaries

This section relates to the limits of the area of work CNS staff are responsible for.

The survey asked staff if they ever undertook work outside their remit as a CNS in order to support patients or their families. Their responses showed that 1 in 4 (28%) CNS often did and 1 in 3 (33%) sometimes did. One in 3 (33%) said they hardly ever performed duties outside their role. Just one CNS said they never did. There was no discernible response pattern between settings.



Whilst some CNSs said they recognised their input was most effective if they kept to their specialist role, others explained they undertook work outside their remit primarily to ensure the timely fulfilment of patients' needs.

The demands on, and availability of, allied professionals including GPs, ward doctors and nurses was thought to influence the need to absorb non-specialist work. Facilitating write-up of prescriptions and drug chart changes were frequently mentioned. Often this involved physically taking charts and prescriptions to ward doctors, out of hours GPs and patient homes. Talking with relatives of unknown patients in lieu of ward doctors and spending time with patients who had no other support locally were mentioned.

**S 1 C Q6a:** 'CNSs are often expected to absorb non-specialist work to ensure the safety of their patients. It is my opinion that some of this is due to the demands upon GP OOH / District Nursing Teams. However, CNS' may be able to reduce their own workload by being more vigilant in their own referrals to the weekend CNS. ...'

**S 7 C Q7a:** 'The nature of this role often requires work outside of our CNS remit I would say and that is the case every day of the week. Sometimes this involves taking drug charts to be re prescribed for patients, collecting prescriptions if patients are unable or extended periods of time spent with people who may not have family/friend support nearby.'

**S 11 C Q6a:** 'Due to overstretched OOH GP service often have to take community drug chart to OOH centre to ensure changes are made in a timely way. Often DN do not ensure there is enough medication for the weekend and no provision of gel spray for mouth care so time taken up organising prescriptions.'

**S 8 H Q6a:** 'This depends according to staffing levels on ward, I will assist if it ensures that my patient is attended to in a timely fashion. One example is overseeing TTHS completed correctly and liaising with pharmacy for a fast track patient, and collection of TTHS when ready.'

**S 9 H Q6a:** 'Communication with relatives about seriously ill patients that aren't known to us as ward Drs have not had these conversations. Organising discharges i.e. getting TTHS from pharmacy - taking drug charts to other wards to get medications prescribed as Dr too busy to come and patient symptomatic and can't wait.'

Hospital-based CNSs said they sometimes gave general care and information on the wards if asked by patients/visitors or helped with crisis management. Ward staff expectations of CNSs were thought to be higher during weekend and bank holidays due to a limited availability of doctors.

**S 17 H Q6a:** *'Occasionally assist general care on wards if time of crisis (e.g. seeing patients at risk of fall). But generally keep to specialist role as know my input is most effective this way.'*

**S 18 H Q6a:** *'Mostly keep to my role although there are inevitably situations where patients may ask with help with their care.'*

**S 10 H Q6a:** *'Personally I have had experiences of making clinical decisions that I would deflect to one of our consultants during mon-Friday hours. The ward staff place more expectations on us on weekends/bank holidays due to the reduced number of doctors available. Family support can be more difficult if patients deteriorate unexpectedly over this period- often we are expected to give the families the support around this. If a doctor has not been able to assess the patient, this situation can be tricky.'*

CNSs mentioned having to deal with unfitting referrals. Some community staff said their weekday role did not include managing incoming calls as it did at the weekend. Carrying out this task was felt to add pressure on staff and limit their ability to carry out face to face visits. See the Caseload management and referrals section for more on this.

**S 12. C Q6a:** *'Sometimes calls can come through from the hospice that should have been sent to a GP to review rather than CNS.'*

**S 1 C Q6a:** *'... Some CNS' request that the weekend CNS contacts patients that could possibly wait until within normal working hours. ... '*

**I 7 H Ref 2:** *'Erm sometimes on the weekend when you get referrals to go out and see somebody ... sometimes I think it's sort of like a quick fix by asking palliative care to do it. So you know if we've got time we will go up and support them ... but some of the things erm they could probably do their selves on the ward before they get to us but that's the same as in the week to be honest ...'*

**I 9 C Ref 4:** *'[during the week] we've got ... a community line, where all the calls go into and then somebody takes those calls off and triages them and goes through them. And if you need to deal with it, if it specially needs to be a CNS, they'll ring you and let you know. ... that for us is what helps our working week ... Otherwise we'd never get out and see anybody ... [which is] kind of what happens on the weekend ...'*

CNSs from both settings described having increased decision-making responsibilities at weekends and bank holidays and the pressure they felt as a result. A hospital-based CNS explained that in the week, new patients are seen by the most appropriate member of the palliative care team. However, as the only SPC resource on weekends/bank holidays, the CNS sees all new patients needing SPC support. CNSs explained that they review and make decisions about patients who might ordinarily be seen by a consultant in the week. The willingness of consultants on the team to be contacted on weekends and bank holidays about complex patients known to them was appreciated. Community CNSs said the increased weekend remit included patients usually seen by the other service provider during the week. Lack of access to information about these patients was mentioned.

**I 9 C Ref 1:** *'I don't like weekends. ... I think that there's an awful lot of responsibility ... because we cross cover so um, we, we don't just cover [our] patients, we cover um the [names organisation] side of, of it as well. And you don't have access to all the information on those patients, whereas with our own ... I know I can access the information on the one system, or I can put my hands on their notes if I need to. ... But you, you develop the skill ... it's something that you develop ...'*

**I 10 H Ref 1:** *'So the infrastructure's one thing, ... so if new patients come in you are the only person there who's gonna be able to pick those patients up er, whereas in the week then it might go to a different member of the team who is most appropriate ... it maybe that the first person to see them might be a doctor ... It might well be an occupational therapist if the main issue is okay we need this person home as soon as possible, so it might be not necessarily a nurse on the team. Erm, so that's different because whatever, ... comes through you're the person who's gonna be doing the first assessment. ... that individual's gonna be your patient whoever comes through ...'*

**I 5 H Ref 1:** *'I think it works well that knowing someone is available to talk to, erm, so knowing you're not the, the be all and end all. ... you know, because ... a lot of the teams in the hospital will write in the notes, erm, await palliative care review and that's quite a big responsibility really and you think, oh my gosh they're doctors who can't ... make a decision, they waited for me to make a decision, so that's quite a big thing to have on your shoulders ...'*

**I 5 H Ref 2:** *'... I think we've got very supportive consultants ... if they've had complex patients during the week they're usually happy for us to ring them directly, erm, for advice ... So that, you know it is quite difficult that you've got a consultant possibly seeing a complex patient all week and then they hand it over to the nurse on the weekend to carry on that care. When, you know, they might have been struggling with those symptoms all week ...'*

Whilst CNSs recognised the need to ensure the effective delivery of the service within their current remit, many suggested that expanding their role to include assessment and prescribing would improve service efficiency and be of benefit to patients and allied professionals. This is discussed in more detail in the sections on Staff knowledge and skills, and Allied services.

**I 6 C R1:** *'Erm, obviously we don't want to be taking on more work because we need, we need to make sure we're effective on what we're already doing, but I think having the ability to prescribe in the community would be helpful, erm, I think personally having the ability to do your clinical assessments and diagnosis so you can, you can, if I could do a neurological assessment it would save the GP having to come out.'*

## vi. Staffing levels

This section relates to the number of people employed or on duty to deliver the service.

The topic of staffing levels was mentioned often through the survey and interviews and is discussed in this report under several themes including Staff wellbeing, Workload and contracted hours, Service demand perceptions, Cross site and community travel, and Impact on the weekday service.

Staff explained that one CNS delivered the community service at weekends/bank holidays and that the weekend work was shared between the two providers. In the hospital, two staff members worked Saturdays and one on Sundays. Two CNSs worked bank holidays where possible.

When asked at interview what the key differences were between the weekday and weekend/bank holiday service, one community-based CNS simply said: *'One nurse to fifteen in a week.'* They went on to contextualise this comment:

*'It literally comes down to numbers, I think and demand, you know, ... it's roughly I think about fifteen nurses covering a very large geographical area, you know, from say the borders of [PLACE NAME] to the western Vale borders ... that's a huge geographical area. Where you have fifteen nurses doing that on a sort of weekday ... you have one nurse on a weekend. ... and whilst you don't necessarily plan visits like you would on a normal day, it's the not knowing what's coming in ... it can be difficult, you know, and sometimes you can't get off the phone.'* (I 9 C Ref 2).

As discussed in the Workload and contracted hours section, some staff said the weekend/bank holiday workload had already become unmanageable for one staff member due to the numbers and complexity of patients needing support. Others questioned the future sustainability of the weekend/bank holiday service with existing staff levels. One CNS proposed a review of caseloads and ways of working might help to find ways to mitigate this issue. However, additional staffing was frequently suggested by CNSs in both settings as a way to improve the service and their experience of delivering it. Hospital-based staff said they had personally experienced the benefits of having two CNSs working on Saturdays and wished to extend this to the rest of the weekend.

All who suggested a staff increase proposed having in each setting, either two staff members on each day of the weekend/bank holiday shift, or to target resources by having a second person on-call to come in if needed. The potential benefits of such an arrangement were thought to be numerous.

It was proposed that increased staffing would help to mitigate challenges caused by the unpredictable workload, facilitate peer support and confidence in shared decision-making, reduce travel between hospital sites and patients' homes, improve efficiency of call handling and triage, lessen the workload, allow staff to spend more time with patients and families, reduce the isolation, pressure and stress felt by staff and improve staff safety.

**I 11 C Ref 12:** *'... I would prioritise for safety, for stress levels and for the CNSs erm sanity I think you need to have two of them on on a weekend.'*

**I 10 H Ref 2:** *'... So we started off with one nurse on each day erm, but soon found ... that the work load was too much and too stressful, so we, erm, adjusted the working week to, erm, to put two staff on on a Saturday.'*

**I 7 H Ref 2:** *'... it's the intensity and a bit of the isolation cos you know you're working on your own really although we have had a second nurse bought in for a Saturday and on a bank holiday we're gonna have a second nurse now. Which we definitely need and wonder how on earth we did it before ...'*

**I 5 H Ref 11:** *'I think having two of you in, at least you can talk things through, you know, this one was really complex yesterday and wants to talk, can I have a little bit more time to go and see that one today, you know?'*

**S 1 C Q9a:** *'I feel that my weekend / bank holiday time is mostly spent on travel, documentation and general paperwork. Much of this time could be spend clinically with patients in the community' setting. Clinical time is often interrupted by the pressure to answer in-coming calls, re-evaluate and triage your day to respond to patients in an appropriate fashion - this may be resolved with a second member of staff on duty.'*

Staff proposed the second staff member could carry out one of two roles. Either the workload was simply shared between two CNSs, or one CNS could carry out the clinical role whilst a second staff member, with the right skill mix, could manage and triage incoming calls and liaise with GPs, district nurses and others as needed.

Some CNSs believed that the person triaging the calls should be a CNS to enable them to effectively support patients, make decisions and reduce the workload of the other team member. Others suggested a registered nurse would have the requisite skills to undertake the role. There were contradicting views on the value an administrative role might add. One CNS suggested another member of the hospital-based SPC team, such as a registrar or consultant, could work weekends. A community CNS said how useful a shadowing trainee GP had been in triaging calls and changing drug charts.

*S 1 C Q13: 'When working a weekend / bank holiday I greatly welcome any help and support. It is my opinion that many (if not all) of the issues encountered on a weekend may be resolved by increasing the number of staff working on a weekend/bank holiday. This may not necessarily mean additional clinical members of staff, but will require further work to identify the required skill mix of any additional staff.'*

*S 12 C Q13. '... on busier shifts it would be useful to have someone able to triage calls and chase GP calls, less distance to have to travel ... .'*

*I 2 C Ref 1: '... you need a certain amount of knowledge to be able to, to triage the calls and see which ones need to be seen and to deal with questions that people might have that they don't necessarily need a visit. So you can ... yeah, I think it would have to be a nurse.'*

*I 12 C Ref6: '... we've thought about ... either having possibly two CNSs on at the weekend erm but of course that's got resource implications. Erm maybe having a band five so a registered nurse ... working with the CNS so ... they could ... triage calls... , some of these phone calls a registered nurse would be able to deal with erm cos they could be simple sort of medication issues or you know I've got some pain ... .'*

*I 4 C Ref2: '... admin wouldn't really be helpful. There needs to be someone with specialist experience, so you can share the workload basically, on a really busy day.'*

*I 5 H Ref 10: 'I think the way the service is set up at the moment it would have to be a CNS or a doctor, so we tend to have registrars or consultants on the team, so either of them. I don't think any other role, like having an occupational therapist on for the weekend, erm, would be beneficial. Erm, because the services they need to contact to move things forward are not available on the weekend.'*

*I 3 C Ref 4: 'I've had sort of a GP student doctor come out with me and they've been brilliant because they've been doing the messages while I've been driving and then they can do, if they're qualified and the right stage of being qualified can do some of the drug charts for us which is great, that's a huge help.'*

Hospital-based staff proposed the additional staff member would allow for the two main sites to be covered in a similar way to the current Saturday arrangement. Community-based staff said this might allow the area to be split between two CNSs, thus reducing the distance and time travelled. Alternatively, it would allow community staff to travel together, one managing calls whilst the other drove and carried out clinical work. One staff member thought this would improve CNS safety, for example, by carrying out joint visits to new referrals, as is the practice during the week. The option of having the staff member with the telephone at base with computer access was suggested as a way to improve access to patient information. It was proposed this could resolve the lone working issues and enable staff from one community provider to be stationed at their usual base at weekends, allowing staff to carry out their usual work on quieter shifts.

*S 2 C Q13. 'One nurse on-call in Cardiff and one nurse on in the Vale.'*

*S 6 H Q13: '2 staff to work both days to cover both sites equally.'*

*S 4 C Q13: 'For more than one nurse to be on-call so that the areas can be covered adequately, phones answered and a quality service given. I know this would mean more on-calls but I personally wouldn't mind that.'*

**S 7 C Q13:** ‘... having 2 nurses on-call together would certainly allow for less hectic working! One could answer calls whilst one drove, or one stay at base with computer access etc. This would also allow paperwork to be finished in a more timely manner and not at home at the end of the day!’

**I 2 C Ref 1:** ‘... I think it would be beneficial to have two people on-call just because of the times when the work load is really high, um, but then when the days when the work load is quite low I guess if there were two of us on then we would [be] based at the [place name], so we would be able to get on with other work. Cos if you’re stuck down in [location] you can’t do anything. You can’t get on with your own work ...’

As discussed in the Cross-site and community travel section, two staff suggested removing boundaries between the hospital and community to use the staff resource as a whole. It was proposed that this would reduce travel time and maximise the benefit of having four CNSs on shift.

**I 11 C Ref 13:** ‘... you could almost think of them revolving round couldn’t you, you know if there’s two on in the hospital and they’re not that busy then why can’t that one come out and the same with the community, if there’s two community nurses on and they’re not that busy why can’t they go into the hospital to help them but it doesn’t work like that does it? You know we’re all boundaried but you would wonder why you can’t have this mix on on a weekend you know. It might work yeah but ... I don’t know the hospital and how busy they are or anything erm I can only see what we’re doing. I just feel as it’s panning out they just need two on, definitely need two on.’

As discussed in the Impact on weekday service section, CNSs said the delivery of the weekday service could be compromised if an additional staff member was routinely assigned at weekends/bank holidays with existing resources. Some said that the expansion of the CNS staffing resource as a whole would be required to sustainably achieve the proposed level of cover at weekends.

Some community staff proposed that the area each service provider covered in the week could or should be retained at weekends. Staff thought this could potentially enable each provider to put on one CNS at weekends/bank holidays or get maximum benefit from two, as the time wasted travelling across the entire region was thought to limit the advantage. However, one staff member said they believed that the cross-provider communication, which centred on the weekend/bank holiday provision, supported service equity for patients across the region. They also stated that such an arrangement could not be supported by one community organisation, as the small team could not provide sufficient cover across seven days.

**S 16 H Q13:** ‘Two team members on each day would significantly ease the pressure, however current staff resources make this too difficult to manage as the rest of the week would be too depleted. Hopefully there is a case for an increase in staff number to reflect recent caseloads.’

**I 5 H Ref 12:** ‘... because, erm, you’re having to give someone a day off in the week. You’d have less staff to cover the week, erm, so ideally you’d need to recruit more staff wouldn’t you, to cover the whole service at the level you want it covered.’

**I 2 C Ref 1:** ‘... the obvious thing ... is that the two services split because ... so (names organisation) cover (names area) ... it’s a long way to go down to see the, the patients who are in (place name) and things like that. That’s the only way I can think of it, that you can reduce the amount of traveling or if you have two people on-call. So one person covers a certain area and somebody else covers the other area.’

**I 12 C Ref 6:** ‘Erm at one point there was talk that we would do our own, so (names organisation) do their on-call we would do our on-call that’s something that I wouldn’t favour. ... I think that the joint working is good I think it’s, the fact that we erm have to communicate a lot ... over the on-call working erm it’s good that we keep that contact with them, we sort of know what’s going on with each other’s services. Erm you know [place name], [place name] and [place name] is meant to be one area and I think that the patients should get the same service regardless of erm where they live. ... it’s good that it is a joint thing this collaborative working. ... being a smaller team ... to put a nurse on every weekend. ... It would be really difficult to do that with a team of that size.’

As discussed in the impact on the weekday service, CNSs felt consistency of service delivery across seven days was more easily achieved when there was a full complement of staff. However, difficulties were thought to arise when teams had to accommodate other absences such as staff sickness and annual leave. Some staff talked about historic staffing issues in their teams. One CNS said there had been difficulties recruiting and retaining staff in their organisation. Issues with retention were thought in part to be because existing CNSs didn't have time to support new employees due to the size of their weekday caseload. This was said to have created a repetitive cycle. Another CNS spoke of issues with retention, believing re-banding the role to a higher grade had improved this. Despite these challenges, staff said that the weekend and bank holiday shifts had always been covered. The fact that there are two community providers was said to be an advantage as there are two resources to draw from.

*I 10 H Ref 12: 'We've never been in a situation where we haven't been able to provide ... a nurse over that period of time. So we know we have just about enough resource erm, ... but to provide ... more people on at the weekend you know obviously would take more resource, but as it is we've managed in both areas to cover those slots even in the winter, even in the snow we've managed to always provide the service. So, erm, you know so there's ... great, er, commitment from all the services.'*

One community-based staff member proposed staffing levels could be more balanced across the week by extending the entire SPC CNS service across seven days so that CNSs worked their hours across a seven rather than five day week. The benefit of this was thought to be fewer gaps in provision but also less focus on emergency calls on weekends/bank holidays, as the service would operate in the same way across seven days.

*I 11 C Ref 1: 'I mean the other way of working is to just make it an ordinary day. So in the future it would just be that we just work seven days a week as normal just like a ward functions, just like any other place functions and after five of course, as it does in the week you would have to go to an out of hours. But then it would be really seven, seven working you know the teams just working and just take days off in the week and just cover it. ... It would just be the CNSs ... there'd be less gaps and people would just be seen there would be none of this emergency visits on a weekend ...'*

#### d. Service delivery

The service delivery major theme focuses on service systems and processes, including the interplay with services delivered by allied professionals. Service delivery is broken down into seven sub-themes:

vii.	<b>SERVICE DEMAND PERCEPTIONS</b> Staff perceptions of external demand or desire for the service.
viii.	<b>SERVICE EFFICIENCY</b> Staff perceptions of the extent to which the service achieves maximum benefit to patients/families with minimum wasted effort, time or expense.
ix.	<b>CROSS-SITE AND COMMUNITY TRAVEL</b> The journey and practicalities of travel between hospital wards, patient homes or other sites.
x.	<b>PATIENT RECORDS</b> The recording of and access to patient information.
xi.	<b>CASELOAD MANAGEMENT &amp; REFERRALS</b> The process of dealing with and controlling the number of cases/calls the CNS is concerned with at one time including the act of referring patients/families for CNS support.
xii.	<b>SPECIALIST CLINICAL ADVICE AND SUPPORT</b> CNSs Inter-professional relationships with, access to and support from specialist clinical staff.
xiii.	<b>ALLIED SERVICES</b> CNSs inter-professional relationships with, access to and support from services outside the SPC field.

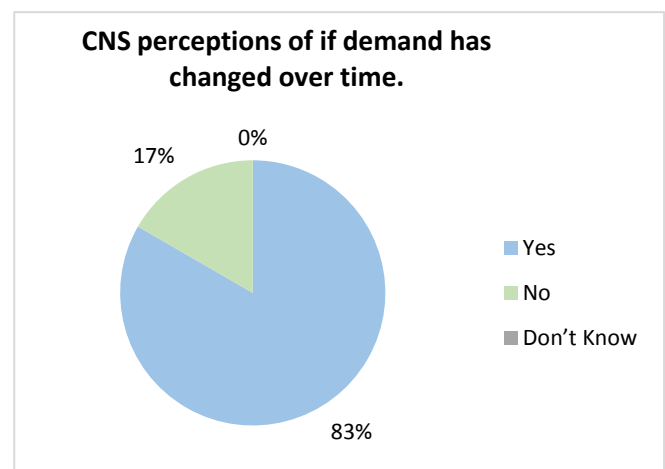
##### i. Service demand perceptions

This section relates to staff perceptions of external demand or desire for the service.

The survey asked staff if they felt the demands on the CNS role at weekends/bank holidays had changed over the period they had been working. The majority, 15 of 18 (83%) said they had.

Some staff who had recently started working weekend/bank holiday shifts had opposing views on the growth of service demand. The degree to which other staff felt demand had increased varied widely from 'slightly' to 'significantly' and 'massively'.

It was acknowledged through the interviews that demand can fluctuate from one weekend to another, but quiet shifts were said to be rare. Demand for the service across seven days was said to have grown. Many of those who said they had experienced an increase in weekend demand attributed this to greater awareness and acceptance of the service which had led to more calls and referrals. This included increased utilisation by those with a non-cancer diagnosis. However, as described in the Caseload management and referrals section, CNSs suggested greater service awareness among ward staff is still needed. If this is correct, there could be some untapped demand.



**S 6 H Q4a:** 'I have only been covering the weekends recently so have not during this short period seen a change.'

**S 8 H Q4a:** 'I have only been working weekends ... for last few months. I do feel the demands have increased on staff as more are aware of the 7 day working.'

**I 7 H Ref1:** '... it's far, far more intense. Sometimes you have quieter weekends than others obviously erm and that's not so bad ... but it's got so busy now that the service has been accepted and utilised ... So when I first started in it not everybody would use us ... whereas now everybody especially like the non-cancer erm units and that use [us] ...'

**I 5 C Ref1:** *'It's certainly got busier with us, erm, now more people know about the service so when we first set up, not many people, well that's obvious, not many people knew ... we were working seven days a week, but now they know that, erm, and we certainly get more pagers and people contacting us on the weekends.'*

**I 2 C Ref1:** *'I think it was quieter back then ... it's got a lot busier ... just more patients and more calls and ... more unwell patients in the community, maybe, it's just generally busier. Back then you used to have quieter on-calls whereas you don't generally get them now.'*

**S 10 H Q13:** *'... On-going education to clinical areas to ensure staff are aware of our service and the criteria for referring to the weekend service.'*

Survey responses showed staff believed the intensity and complexity of patients had increased alongside patient numbers. This was echoed through the interviews. Advances in treatments were thought to be helping some people to live longer. This was felt to be creating a larger pool of patients and families to support across seven days. The increased time it might take to support patients/families with complex support needs was described. One interviewee stated that this type of service demand was not captured through recording practices.

**S 9 H Q4a:** *'The amount and intensity of patients and their families have increased massively. So much so there are 2 of us working for at least one of the 2/7 weekend and 2 of the 3/7 weekends.'*

**S 11 C Q4a:** *'Increased numbers of patients with complex palliative care needs in community. ... '*

**S 18 H Q4a:** *'Patients can often be more complex at the weekend and bank holiday requiring one or more visits and families that require support...'*

**I 8 C Ref 1:** *'you know, people's cancer journey, or life limiting illness journey, can sometimes you know, with the advances in treatments and symptom control and investigations, you know, sometimes that journey can be longer for some people. And I think that adds to the length of time patients are on our caseload. Um, means there are more numbers of patients involved with our service and that you know, on a weekend, it means there are more people accessing the service.'*

**I 11 C Ref 1:** *'... People live longer they go through a lot of different treatments. So the longer they live the more complex they become, the more complex their symptoms become. ... psychologically families you know, husbands, teenage children living maybe with a mum that's really poorly you know and has been poorly for month after month you know it's very difficult for them to deal with it on an everyday basis you know their lives go up and down. So, and on a weekend sometimes you can guarantee pain will escalate or vomiting will escalate. So it's not a sort of house if you've got all that around you, you can just pop in and pop back out it takes longer. Sometimes it comes to a head you know when everybody's home at a weekend you know, everybody's been in work and school and then suddenly the Saturday it all goes whoosh.'*

The grade and capacity of allied service staff working in hospitals at weekends/bank holidays was thought to impact on SPC service demand. Revised referral criteria, additional staff and Advance Care Planning were thought to have helped manage demand.

**S 16 H Q4a:** *'As awareness of our service availability increased, so therefore did our workload. If there is less ward medical cover on general wards, this impacts on our workload as ward staff contact our team for reviews as an alternative to get patients seen.'*

**S 17 H Q4a:** *'... Patients in the acute service are covered with less experienced clinical teams on the weekend or staff that are less familiar with them and they value our input to direct care.'*

**S 1 C Q4a:** *'I have personally experienced greater demand upon the community CNS role and attribute this to increasing volumes of workload and the associated e-documentation and paperwork. In turn this greater overall volume of work results in more travel to conduct more community face to face visits. The city of Cardiff is growing in size and travel time is increasing.'*

**S 10 H Q4a:** *The service over time has changed for a multitude of reasons. 1. Increased awareness of the 7 day service within the health board saw an increase in urgent new referrals being made. 2. We developed a referral criteria and expected level of patient case load to be seen. Initially our daytime case load could be in excess of 14/15 patients- we agreed that this was not sustainable therefore amendments to what patients we would put on the list to be reviewed were agreed. ...'*

**S 14 C Q4a:** *'I feel that the demands on the service have developed and changed since implementation but some issues and problems we are dealing with have also changed. I feel that there is better planning in the week with ACP and anticipatory prescribing and as a result should be less crisis management.'*

During interview, two CNSs employed by one of the community service providers said they thought referrals from the other organisation had diminished. The reason for this was unknown, but one CNS thought this may be related to recent changes brought about by recommissioning.

**I 2 C Ref 8:** *'... people don't seem to be doing that run to [names local area] so much. I don't know why that is. I've no idea. But, um, the [names organisation] side of things seems to be quieter than it used to be.'*

**I 4 C Ref 1:** *'To be honest, I don't know why, but we don't have that many referrals from [names organisation] at the moment. Yeah, there's ... each week, you know, when we're on-call, there's not that many referrals coming through from [name], and I don't know the reason why. ... I think it's changed. Well, it will have changed because [of recommissioning] ... back in April, ... but it's changed drastically, it seems. ... I don't know if they're having staffing issues, or ... it would be interesting to see how many phone calls come through from [name] patients, and to see if we've had a referral on them, you know. But no, we don't seem to get many.'*

One community CNS explained that whilst the number of patients and the complexity of cases had changed since weekend and bank holiday working began, the service had not. Staff suggested increasing the staff recourse to meet current and potential future demand. See the Staffing levels section for more on this.

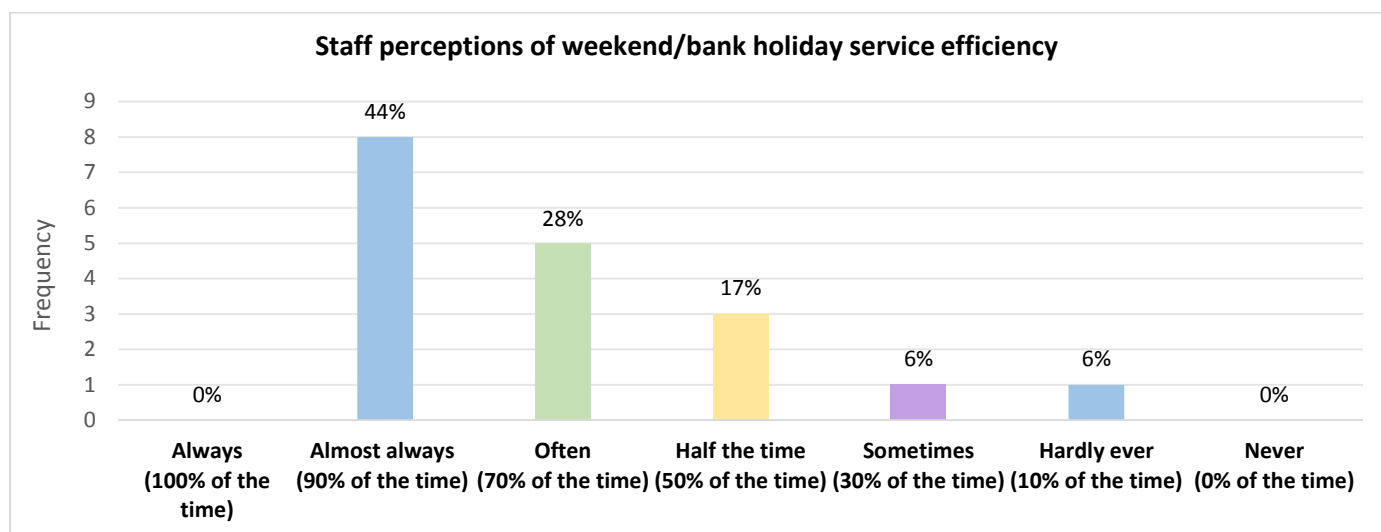
**I 12 C Ref2:** *'... The service hasn't changed as far as I'm aware very much since its inception which I believe, well I dunno whether it was 2011 or whether it was even before that. Erm things have changed a lot since then, ... numbers of patients but more complexity of patients and I think the demand on that service has been increasing.'*

**I 9 C Ref1:** *'I know that that's something that's been discussed previously, possibly trialling, um more than one nurse on the weekend, ... or trialling a Triage Nurse, so somebody that can do the phone calls and ... you do the visits and things. I think its numbers more than anything, it just comes down to numbers really, um, to meet the demand.'*

**I 8 C Ref2:** *'So I'm not sure you know, in the future, whether one nurse on for both areas is sustainable. Really, err we're managing at the moment but um, you know, if there's additional demand and the wide area, err it might be that we'll get more people on-call. ... '*

## ii. Service efficiency

This section relates to staff perceptions of the extent to which the service achieves maximum benefit to patients/families with minimum wasted effort, time or expense.



The survey asked CNSs if they felt the service is delivered efficiently on weekends/bank holidays. Just under three quarters of respondents (13 of 18 or 72%) thought it was almost always or often delivered efficiently. One CNS said this however was thanks to CNS and consultant expertise. Another mentioned sometimes corners were cut in order to see everyone.

Service efficiency was raised by staff in relation to a range of topics. It is therefore a thread that runs through this evaluation report, discussed in the relevant sections in relation to each particular theme.

**S 18 H Q9a:** ‘... I feel [efficiency is often achieved] ... as patients put on for review have complex needs or unstable symptoms and a good reason for review at weekend. These are the patients that couldn't be left 48hrs over the weekend or bank holiday without a review and therefore it is achieving an essential service for both patients family and for ward staff.’

**S 13 C Q9a:** ‘I feel with one CNS on-call it is almost impossible to deliver efficiency over weekend and bank holidays. I don't feel patients and their families are having full benefit of the services that they have during the week, I feel it's too busy for one person to provide support and effective care during these periods.’

**S 14 C Q9a:** The workload can be difficult to predict and it is not always possible to visit every patient due to large geographic areas covered and dealing with weekend traffic. It is important to prioritise which patients need to be visited.

**S 6 H Q9a:** ‘Sometimes difficult to be effective when day is planned and urgent referrals are made. Sometimes cutting corners is needed to be able to see and review everyone.’

## iii. Cross-site and community travel

This section relates to journey and practicalities of travel between hospital wards, patient homes or other sites.

Staff explained they travelled primarily for two reasons: to see patients/families and to facilitate write-up and fulfilment of prescriptions and drug chart changes, with the latter being outside the CNS remit. Community staff explained that pulling over to answer calls and take information whilst driving to patient's homes, sometimes impacted on the timely execution of planned visits and their ability to finish work on time. At interview, a hospital-based CNS described a similar issue with receiving and responding to pager bleeps whilst driving from one hospital to another. Community staff communicated the pressure they felt to answer the phone whilst driving but pointed out that the use of hands free equipment isn't or shouldn't be used due to lack of insurance cover and for staff safety.

**S 7 C Q4a:** ‘... Personally, I have found it quite difficult having to pull over in the car numerous times en route to patient visits to answer incoming calls whilst trying to document details etc. and still attend visit in a timely manner. Fielding calls whilst in the car can also be challenging as obviously we have no access to patient notes whilst on the road.’

**I 7 H Ref4:** ‘... Usually if you're going to community hospitals the main hospital's got problems as well and everything and that so you're a couple of minutes down the road and your bleep's going off again and you know it's just a bit nightmarish and things but erm it's just the way it goes isn't it?’

One CNS highlighted the way in which three organisations had come together to provide a consistent service across the region as a success, but also commented on the amount of travel this involves. CNSs explained that their geographic/hospital site remit is much larger on weekends/bank holidays, covering up to five hospitals or the whole of Cardiff and the Vale of Glamorgan community as opposed to weekdays, when cross-hospital site travel is more limited and community staff support patients linked to small clusters of GP surgeries. This larger remit was said to necessitate more travel between hospital sites and greater distances between home visits.

Travelling time between home visits was said to increase from around five minutes in the week to as much as forty-five minutes on weekends/bank holidays due to distances between patient homes. Travel between the main two hospital sites at weekends was estimated to be forty-five minutes to an hour.

**I 2 C Ref1:** ‘Normally it's kind of around four, four, five calls [in a day] maybe, but the distances in between them can be quite big. So that's another issue. It's just the driving that you're doing in between.’

**I 2 C Ref2:** ‘... in my working week I cover a certain area. ... So I drive there and then generally the calls are in that area. You might have somebody who lives a little bit out, um, but you ... it might be five minutes in between houses, whereas it could be in [names local area] ... then you've got to go and see somebody in [names local area] ... so they're a good a half an hour, 45 minutes, in the car, when you've got an eight hour day. It's quite a long ... long chunk out of the day.’

**I 4 C Ref1:** ‘Yeah, so at the moment, I'm based in [place name] ... and I cover [place name], which is a bit of a way from my base, so it takes me a good 20 minutes to get there, 20 minutes to get back. When I'm there, I'm there for the day, so I can you know, fit in a lot of patients, and I'm not travelling too far in between each patient. Whereas on the weekend, like I said you can be all over the place. From one end of [place name] to the other, and then out in [place name], [place name], [place name], back to [place name]. So logistically it can be an absolute nightmare, and the time wasted getting I suppose if you had another member of staff, you could go to all those places.’

CNSs from both settings said time was wasted travelling. Hospital-based staff said they took working across two main sites into account when planning, aiming to avoid going to a site more than once in a day. However on occasions this was unavoidable. Having a staff member in each of the main District General Hospital sites on a Saturday was said to help meet demand. Visits to the community hospitals and mental health unit were less frequent but were also required at times.

One interviewee explained that community staff in their organisation had logged travelling times between visits for a period of time. S/he recalled this showed forty minutes between each patient and on one occasion a Rugby event meant the CNS took one and a half hours to get across the city. S/he believed travel time between patients to be the main reason staff worked over their hours. As a result of this exercise, their planning approach was adjusted so that visits could be clustered together. However, the unknown element in the form of incoming calls was still a recognised issue.

**S 16 H Q9a:** ‘We aim to manage the day taking into account logistics of working across 2 main sites ... and would aim to avoid having to return to a different site more than once in a day.’

**S 3 H Q9a:** ‘If one CNS is covering both hospitals time can be wasted travelling between sites to review patients.’

**I 10 H Ref 1:** ‘... ideally one of the nurses would go out to [location], erm, cos there tend to be less patients in that area, er, so maybe they might review two patients and then come back to the main hospital ... then trying to get back across the city before, if the traffic builds up as well is really important cos you could be stuck in the car for an hour so, erm, so usually we try and do those calls if we can in the morning and try and get back to another shift [laughs].’

**I 10 H Ref 2:** ‘I mean there are occasions when ... they’ve had to go back across erm, because, er, I think something’s happened ... So sometimes they’ve had two journeys. ... Sometimes there’s three hospitals involved in the same day, er, although that’s more of a rare thing that is still a possibility.’

**I 11 C Ref 3:** ‘... it just showed how long they were taking in between erm visits. [...] It showed the travelling time was the main reason they were going over their hours. So not the number of visits. Well it could’ve been the number of visits but it was mainly to do with that they were taking like forty minutes in travelling time and then when visiting the thing they’re taking like one and a half hours to travel and then another time it was rugby day so somebody got stuck in town and you know it was like one and a half hours just to get to the other side you know and nobody moved out of your way cos you’re in an ordinary car. So yeah it was quite interesting to, so then we tried to look at how we plan our day. ’

Community CNSs described covering a large geographic area with a single staff member. The growth of the city and weekend traffic conditions were thought to have increased travelling times and the large distances between patient’s homes was thought to make it harder to react to urgent situations. Lack of familiarity with areas was highlighted as time consuming and hindered staff ability to prioritise calls.

Telephone contact and assessments were said to be undertaken in lieu of face to face assessments where travelling times or working hours prohibited a visit in person. Some Staff felt this was less helpful to patients or impacted on service equity.

**S 5 C Q13:** ‘The service is limited in what it can offer. There is currently only one CNS covering a large geographical area and this makes it difficult to react to urgent situations should they arise.’

**S 2 C Q4a:** ‘Higher number of calls - traffic chaos-plus events closing the roads around Cardiff.’

**I 1 C Ref 5:** ‘It can be quite difficult ... it’s getting used to the traffic and I don’t know the areas very well. So you tend to know your own area but when I have to go to a patient in [Place name] I just have to put it in the satnav and go and that can be difficult cos if I’ve got a couple of patients and I’m not sure of areas I have to try and prioritise. So you have to plan your journey a bit better so positives I don’t know if there is any positives of driving.’

**I 3 C REF 1:** ‘... but sometimes when you’re out and about and you have phone calls it’s just, you don’t know the areas so it’s more time consuming.

**S 3 H Q11a:** ‘If you are very busy in one hospital, occasionally you will need to do telephone assessments of patients in other sites because you do not have time to drive between sites. This is usually [hospital name] or the community hospitals.’

**S 5 C Q9a:** ‘Much of the contact during this period is via telephone which is not always helpful to the patient/carers. It would not be possible to see everyone due to the limited resources and the geographical area covered.’

Hospital staff suggested an additional CNS on each shift would allow for the two main sites to be covered. Community staff suggested splitting the community area between two CNSs would reduce travelling time/distances.

Using the hospital and community resource as a whole was suggested by two interviewees. Peripatetic working, where staff are allocated visits based on proximity rather than the community/hospital setting was proposed as a way to maximise the value of the staff resource.

Permitted use of bus lanes was proposed. It was pointed out that taxi’s and motorbikes benefit from their use. The fact that CNS vehicles are not recognisable to the public was mentioned and a marked pool car was suggested. The idea that a marked/pool car could be registered as an ambulance was shared.

**I 10 H Ref5:** 'Um so there's time wastage travelling between home, homes then really. ... if we did separate on-calls ... for [NAME OF PLACE], and then there's an on-call for [NAME OF PLACE], in that they would be more contained.'

**I 8 C Ref2:** '... in some ways we could use the resource as a whole, so we have a nurse in the community, we have a nurse in the hospital. Erm, so in some areas they have one team ... maybe that we, that is something we'd want to look at in time is using that resource better, so if there's a nurse, ... near one of the hospitals, ... and there's a need for someone to be reviewed in that hospital that we could use that resource more effectively, that they could actually, erm, pick up that patient rather than the nurse having to make that journey across the city.'

**I 11 C Ref7:** '... there's this regulation apparently ... if you register your car as an ambulance which apparently you can with the council then you can go in a bus lane. So he suggested we have a pool car in [place name] where we put stickers on it and just register it and we can go in bus lanes allegedly.'

#### iv. Patient records

This section relates to the recording of, and access to, patient information. This topic was mentioned in relation to service efficiency, service demand perceptions, and staff knowledge and skills.

Staff described the importance of being able to access and familiarise themselves with up to date patient information. Through the interviews, staff explained that the extent to which they used digitised records differed between providers with some digitally recording all patient contacts and others being more reliant on paper notes, digitally recording only key information such as initial assessments.

They talked about the computer systems Canisc<sup>1</sup> used by the SPC team and other professionals to document interactions with patients, and Clinical Portal<sup>2</sup> which offered other information such as test results. The benefit of Canisc records was described as ease of access to information, which one CNS said enhanced patient care.

Community CNSs said Canisc records were particularly useful when getting unexpected advice calls or unplanned referrals for patients and families not personally know to them. The degree of usefulness in these circumstances depended on which organisation usually provided weekday support to the patient, the extent to which they digitise records being the key factor. Some community CNSs said that being based on a different site at weekends compared to the weekday meant they had no access to their paper patient records, thus limiting the availability of information.

**S 1 C Q12:** 'I feel that there are huge benefits associated with CNS e-documentation (CaNISC) in normal working hours. Colleagues ... utilise CaNISC and I am able to easily read an up-to-date account of recent events. Therefore enhancing patient care.'

**I 8 C Ref 2:** '... access to Canisc is fantastic ... if there's somebody that you've got no information about. You can see when they were diagnosed, when they were involved with the Palliative Care Service, what their recent bloods were and whether they've had any scans recently, you know. That's great, but we can access a portal system as well, um, which again has got, you know, whether they've been admitted to hospital recently ... letters and things like that so. ... providing they're all working ... there's nothing wrong with the actual system, ... that's good ... '

Whilst staff across the three providers said there were benefits to digital records, two staff members described the Canisc system as 'clunky' and others said they were sometimes frustrated by problems accessing it. Staff explained they can only access patient information once the patient is registered with the palliative care team. Registering new patients was said to be time consuming and therefore often impractical on weekend/bank holiday shifts.

<sup>1</sup> <http://www.wales.nhs.uk/nwis/page/52601> 'Canisc, is an online computer system primarily holding information from a patient's interactions with health professionals in: Cancer Services, Cancer Centres, Palliative Care.'

<sup>2</sup> <http://www.wales.nhs.uk/nwis/wcp> 'The Welsh Clinical Portal makes test results and a wide range of electronic documents, such as transfer of care documentation, theatre notes, referral and outpatients' letters available wherever the patient receives care in Wales, regardless of geographical or organisational boundaries.'

**S 4 C Q8a:** *'Have had problems accessing Canisc on occasions.'*

**I 12 C Ref 7:** *'... we do have access to some information on the CaNISC system but [ ...] well it's an old clunky system so it's a bit frustrating but at least we do have some information. On the other providers patients yeah. If it's one of our patients then we've got up to date information, of course we should have up to date information.'*

**I 10 H Ref 1:** *'... in both the hospice and in the hospital, erm, that's relatively straightforward, the nurses can access the information. ... not always in the timeliest way because they might need to go back to the office to access some of that because they don't have the, erm, access to the relevant database on the wards. So sometimes that can be frustrating. ... the community teams ... have access to the patients that they're reviewing. If it's a new patient then that becomes a bit more complicated so then again they need to go back to base to get access er, information about that patient or they may need to be in touch with the on-call consultant who can access, er, remotely access, er, anybody's, erm, data ... '*

Hospital staff said ward access to Canisc could be problematic. Finding relevant information was said to be time consuming, taking 20 or more minutes, and as wards often had a single computer, CNSs had to go back to base for access. Community CNSs said they had no means of access to patient information on the road. As discussed in the Cross site and community travel section, CNSs emphasised the impracticality of travelling back to base. Some staff explained it was possible to call the local hospice or on-call palliative care consultant if they really needed access to patient information, although this was thought to rarely happen.

System issues with Canisc and Clinical Portal were said by one community CNS to have prevented weekend access on half the occasions s/he had worked the weekend/bank holiday shift. The absence of a Canisc browser on ward computers was also mentioned. Despite these drawbacks, increased use of digital records was seen as potentially positive by CNSs and something that some believed teams were already working towards. One interviewee said cross-organisational work to improve the flow of information between the three providers had been slow but successful. Information gateways between NHS and third sector providers was thought to have influenced the pace of progress in this area.

**I 10 H Ref 1:** *'... the difficulty on the ward is sometimes there's one computer and so it's really hard for ... nurses to sit there for half an hour and try and wade through somebody's oncology records ... just to get the information that you want, so the latest scans and various things so it could take a while for you to go to each different aspect of the database to look at it. So, and to find the exact information that you want, so it's not a quick fix usually.'*

**I 4 C Ref 3:** *'... you know, you're answering the phone, like I said, in [place name], you might not know the patient, you might not have a referral on the patient, you can't get hold of Canisc or portal sometimes ... it's happened on half of the occasions I've been on-call, where I haven't been able to access it. Because there's been a problem with, ... but the connection or whatever.'*

**I 10 H Ref 3:** *'... the organisations ... [are] trying to join up as much as we can the information flow across the areas cos of course they're third sector, so they can't get access to the NHS, ... So over time that's evolved and they can now all get access to that erm, but obviously there were steps to go through to get to that process around governance that we had to address, so nothing's a quick fix really it's about trying to, erm, slowly look at ways to improve things and to, erm, to get one system across the whole area basically.'*

Staff from both settings spoke of how challenging it could be having no background information to help inform decision-making. Community staff spoke of undertaking on-the-spot assessments in patient's homes and said that facts about diagnosis and patient history were sometimes misrepresented by relatives or the patients themselves. Despite this, CNSs said as specialists, they knew which questions to ask in order to elicit the necessary information to make an assessment.

**S 13 C Q7:** *'it is difficult when you do not know the patient and do not have access to patients' medical history to give advice. This could be if you receive a call whilst on visits and are not able to have access to Canisc or portal. Sometimes you are so busy you have no chance to get back to base to get this information.'*

**S 7 C Q4a:** *'... . Fielding calls whilst in the car can also be challenging as obviously we have no access to patient notes whilst on the road.'*

**S 2 C Q9a:** *'Unable to access information if out in car and not able to go back and access CANISC/portal'.*

**I 3 C Ref10:** *'... having access to some more information if we're out on the road because there are, you know when it's quiet there isn't a problem which isn't very often. Er, when we're busy we're, it's really difficult to get information. I mean it's not an issue because we are clinical nurse specialists in a way so we know what we're looking at and if we're really concerned obviously we get the doctor out anyway so you know, but it's just for, it's just nice to have a lot of information, access to information if we need it when out and about.'*

Hospital and community-based CNSs proposed a number of ways to improve access to patient records. These included the routine digital recording of all patient contacts by the SPC service providers that do not currently do so. Some suggested handover notes on patients/families shared with the on duty CNS in preparation for the weekend could be held electronically, as could the advice sheets completed over the weekend detailing the telephone and face to face support given. Some CNSs thought that whilst the current faxing of advice sheets worked well, recording directly onto a system such as Canisc could improve efficiency and mitigate the need to complete advice sheets after contracted hours. See the sections on Workload and contracted hours and Caseload management and referrals for more on completing documentation after contracted hours.

Provision of extra computers for CNSs and use of portable devices such as tablets and laptops were suggested. District Nurses use of remote devices to access the Paris<sup>3</sup> system when in the community was suggested as a model that could be considered for CNS use. Some community CNSs suggested access to online information could also be facilitated by having two CNSs working the weekend/bank holiday shift, as one could stay at a computer to access information.

**S 5 C Q13a:** *'Access to up to date patient information. Currently you may have a telephone call about a patient who is not known to you and you do not have access to their most up to date notes. ... A system where notes and reviews can be shared such as Canisc.'*

**I 8 C Ref 2:** *'it is time consuming filling out the advice sheets, ... on average we'd have about twenty telephone contacts, for every one of those contacts, it has to be documented on an advice sheet. ... Everyone we see and everyone we have telephone contact with ... you know, all their identifiers are on there, and their diagnosis and medication ... it's quite time consuming. ... if it could be done electronically but you know, we haven't got enough sort of computers and we haven't got laptops to be able to remotely do it ... . But if something could be done about ... the time element really of completing all of them. But ... you know, it gets shared well, even though it's time consuming to enter all that information, you know, [names organisation] have it on a Monday morning, and we've got to have it on a Monday to start our phone calls, um and deal with any changes. So, so it works well from a communication point of view.'*

**S 17 H Q14:** *'Access to full Canisc.'*

**S 18 Q13:** *'Better IT systems access to Canisc at ward level.'*

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<sup>3</sup> <http://www.cardiffandvaleuhb.wales.nhs.uk/news/42297> 'PARIS is a system which was introduced across Cardiff and Vale University Health Board to provide core clinical information for staff across Acute and Community Mental Health, District Nursing, Health Visiting, Community Podiatric Therapies and Community Child Health.'

## v. Caseload management and referrals

This section relates to the process of dealing with, and controlling the number of cases/calls the CNS is concerned with at one time, including the act of referring patients/families for CNS support. This theme was often mentioned in the survey results and was further explored at interview.

### i. Referral criteria

It was thought that greater awareness of the service had increased the unplanned caseload. Hospital-based staff explained that growing demand had previously necessitated referral criteria review. However, the survey and interviews showed that staff in both settings felt re-evaluation of referral criteria is needed along with education on appropriate weekend/bank holiday referrals for CNSs and allied professionals. A need for greater CNS scrutiny of their requests for telephone review and encouragement of community patients to call if needed were also suggested.

**S 10 H Q4a:** *'[...] We developed a referral criteria and expected level of patient case load to be seen. Initially our daytime case load could be in excess of 14/15 patients - we agreed that this was not sustainable therefore amendments to what patients we would put on the list to be reviewed were agreed.'*

**S 1 C Q6a:** *'Some CNS' request that the weekend CNS contacts patients that could possibly wait until within normal working hours. ...'*

**S 8 H Q13:** *'Need re-evaluate staff understanding of service and what team can deliver - what are their expectations - need for ongoing education, support, their rationale for referral? ... Feel strongly that a lot of things on weekend could have been sorted prior to this ...'*

**I 1 C Ref 8:** *'I try and encourage my patients to ring if there's a problem because if you've planned ahead well, and patients will have different issues on a weekend. ... I am conscious of what I'm passing onto my colleagues.'*

At interview, some staff explained there was no written referral criteria. Whilst CNSs recognised that all staff are specialist and referrals are based on their professional expertise, the potential for variation in nurse perception of patient need was also recognised. Some CNSs suggested a cross-organisationally agreed written referral criteria might reduce referral of routine work and make the caseload more manageable at weekends/bank holidays.

**I 1 C Ref9:** *'I don't know if there's any written criteria, whether that was setup to start with. Erm a lot of the criteria was around patients that were dying and support for the family so we used to get a lot of them. ... I think it's just down to your own judgement.'*

**I 12 C Ref9:** *'I think it's cross organisational. So, so when we're on-call erm you know it's clear the types of things, so it would be the same criteria for both organisations yeah. ... I mean that's why we're doing this cos it does just need reviewing cos I think it hasn't changed since it was setup ten, fifteen years ago maybe'.*

**I 12 C Ref17:** *'... you know having some kind of referral criteria for the seven/seven working. ... you don't wanna have such strict criteria that ... people are missing out but you don't wanna be doing routine work on a weekend ... that can be done by somebody else or doesn't need to be done every day... '.*

**I 6 C Ref13:** *'... you're a clinical nurse specialist and you know your patient [that you're referring]. ... but there are times when you phone patients [that have been referred] and they don't need you to come there. And that's a phone call which may only take 15 or 20 minutes, but on a busy day, 15 or 20 minutes is enough for you to get out of the office into the car, and into a patients house.'*

## ii. Referral process

CNS explained that the weekend/bank holiday caseload in both settings consists of planned and unplanned referrals as described below:

The *planned caseload* was said to be established through CNS referral of patients/families known to the SPC service who are thought to require review or support over the weekend/bank holiday. The nurse working the weekend shift is provided with handover notes for each referral which include requests that the CNS on duty makes contact by telephone or conducts a face to face visit. Notes on patients to be aware of in case they call over the weekend are also shared. Referrals were routinely made within the hospital or community setting. Cross-referrals between these disciplines were said to be rare, usually related to the discharge or admission of patients and were often verbal in nature.

The *unplanned caseload* was said to consist of incoming calls or bleeps to the nurse(s) on shift. Whilst 'just in case' forms might have been provided for some of the calls received by the CNS on shift, others may be completely unexpected and the patient might never have had contact with the SPC service before. In the hospital setting, the nurse based at the main hospital site holds the pager and responds to/manages the incoming requests from allied staff for advice calls and patient review. In the community, the CNS takes incoming calls direct from patient/families and allied professionals who require advice and support or a visit.

**I 1 C Ref 6:** *'They fax yeah and we fax to them as well. Erm because it's just a way of communication to know what patients need to be contacted because if you think of the amount of patients ... we carry caseloads of between thirty and forty patients each ... and [Place name] ... they've probably got a caseload of the same size. So you have to pick from those caseloads and prioritise the patients that would need support on a weekend ...'*

**I 10 H Ref 11:** *'... I suppose what we're starting with on a Saturday is our own, er, case load for all the sites ... [patients] known to our service, so we're selecting those patients off that list, er, however, ... anyone can call about any of those patients, the total list... or they could be referring a new patient. So, erm, that could come from doctor, nurse at the weekend. ... however, the new patients that are referred, er, may not necessarily be seen, ... you might think do you know what this could be dealt with on a week day because the issue about this patient's discharge, for example, ... something we could deal with with the whole team on the Monday. So they may reject that referral for that day but pass it over to the Monday.'*

## iii. Handover sheets – Planned referral of known patients to the service.

At interview, CNSs spoke at length about the referral process. The handover sheets giving information on known patients who might need support during the weekend/bank holiday were thought by most to work fairly well as a means of communication. Handover sheets for complex cases were said to be followed with a phone call. Handover sheets were thought to limit the number of calls where staff had no patient/family information however, it was acknowledged that surprises could never be completely eliminated. Some CNSs explained that the sheets allowed staff to give useful information that might not otherwise be included in medical notes such as a particular relative who should be contacted or has a particular issue.

**I 11 C Ref 5:** *'... it's just making sure you handover your patients so that we're all aware of what's out there so there's no surprises, there's always surprises but you know the least surprise the better.'*

**I 3 C Ref 3:** *'... we've got a written handover on that and then they'll generally give a verbal handover when they're giving you that information, so you've got a good idea, you know obviously patients are really poorly, really end of life, we've set up this syringe driver, they're on that much medication you might need to tweak it, you might need to visit them, they've had a problem with nausea, can you just check that their nausea's settled for the weekend.'*

*I 11 C Ref 2: '... So if they're expecting somebody to dip on a weekend or if they think somebody needs more symptom control and needs a visit we fax over information by four thirty on a Friday. Erm so they would fax to us or we would fax to them ... if there's something really difficult going on then ... you would still follow up with that phone call. Well it highlights the you know the more erm deteriorating patients but it doesn't always capture everybody but it does capture a lot of the patients. Erm I think that's as good as that's gonna get.'*

*I 6 C Ref 6: 'Sometimes it's nice to know the little quirks about patients, ... I can think of a couple off the top of my head that I saw months ago. ... the wife was very, very, very anxious that her husband was dying, obviously, but she was more anxious than most people in that position, you wouldn't necessarily write on, in the medical notes that the, the wife is extremely anxious. But when we're speaking to each other we can say she will be very anxious and then they know that that's normal, set a baseline.'*

*I 8 C Ref 5: '... I think it works quite well at the moment because the handover sheets you know, the individual nurse is completing them, so you are able to put, you know, additional information on there, specific that maybe you wouldn't wanna put on a CANISC system, like, I don't know, contact ... this particular son and maybe one particular relative has got problems, so you can, you can put the specifics ...'*

One community CNS explained that the quality of the information written on the handover sheet can affect the on duty CNS's assessment and prioritisation of patients. S/he suggested that insufficient notes were sometimes a result of weekday caseloads leaving little time to write comprehensive notes. It was also proposed that the forms used by individual providers asked for varying levels of information. Omission of prompts for important details such as telephone number meant this information was not always provided. It was proposed that use of a single referral form across providers, such as the All Wales Referral Form, would help standardise the process and ensure all necessary information is captured. This individual also said they started an hour early to read the referral forms, so they weren't trying to find and familiarise themselves with the information whilst patients were on the phone. Having an additional person at the start of day to answer calls was suggested as a way to enable the CNS to review handover notes in their working hours.

*I 6 C Ref 6: 'Erm, there's lots of problems, somebody maybe referring on a Friday, asking you to phone a patient on a Saturday. And they're busy from their normal working week and at ten to five realised, oh I've got to my advice score for the weekend and will quickly scribble down ... sparse amounts of information on that referral. When I read that on Saturday morning, I'll see that, compare it to the others and I may put it low down on my list. Erm, with hindsight, once I've spoken to them, I might have spoken to them earlier in the day, they may have needed a visit. ... It's, it's a minefield. ... But then if you haven't got time to write good quality documentation in the week because of the volume of the work in the week, it impacts on the out of hours. In my opinion.'*

*I 6 C Ref 9: '... It depends on the referrer so I know that there are colleagues of mine that will refer and write a very, very, very comprehensive referral which is really helpful. When you're that one person on that weekend and there are other of my colleagues that will write very limited information and then I need to do a big more digging, and reading around the patient, erm, which is not so helpful. ... although it's standardised in the sense that we have a form and we have boxes that we need to fill out. Erm, people are busy, boxes get missed, people don't write as much as you'd always like them to ... we all use different referral forms, which is not helpful. ... there are standardised referral forms that we would use in normal working hours but that doesn't seem to apply on the weekend, so maybe we should just start using the one form, instead of having all these different bits of paper passed between us.'*

#### *iv. Advice sheets – Records of weekend/bank holiday patient contacts.*

Staff explained that over the course of the weekend they document all their telephone and face to face contacts with patients/families on advice sheets which are then faxed back to the patients usual CNS by Monday morning. CNSs said that from a communication point of view this worked well, however writing the information could be time consuming. Some staff said on busy days they completed paperwork after their contracted hours, either in the office or at home. CNSs suggested digital records might make documenting contacts quicker and make it easier to share information. See the Patient records section for more on this.

One hospital-based CNS said the handover notes work well but proposed a verbal handover could enhance this process. S/he acknowledged that this may not be popular suggestion with colleagues as it would require them to work the day after their weekend/bank holiday shift. Some community CNSs explained that this practice was already in place in their organisation, which allowed patients to be discussed in the Monday multi-disciplinary meeting and gave opportunity to review decisions made and outstanding actions.

**I 7 H Ref 16:** *'But maybe some continuity so that you're in on a Monday to handover because you write everything down in the notes which everybody may think is enough and that, so it's good communication there but if you're actually there you could verbally handover if you needed to and stuff. When I worked in other teams we were always there on a Monday to handover but I don't know how popular that would be with the team so.'*

**I 3 C Ref 11:** *'... we'd have a sheet then of the visits I've made, the time I made them who I saw, who I spoke to, I literally document everything down and then that, when we go back at the weekend and we finished on the Monday we'll have our MDT we'll discuss every patient that we've seen virtually and the other doctors are there so if there's anything, we've got them listening to the handovers as well which is really good. ... you know if we're worried about anything, about any decisions or you know do we need to do this they're just listening. Generally, it's absolutely fine, but it's nice that they're there, they like to know what's going on with our patients obviously and if there's anything we need to do that we haven't thought of maybe they can contribute towards that, so it's really good I think.'*

#### **v. Managing unplanned referrals.**

The importance of care planning in the week and the positive impact it can have on the levels and type of weekend/bank holiday work was mentioned by staff in both settings. Some CNSs said forward planning had reduced the number of weekend/bank holiday referrals and crisis calls, whilst others said greater attention to pre-planning is needed. See the Allied services section for CNS comments on anticipatory prescribing.

**I 1 C Ref 3:** *'... there's a lot of planning in the week to build up to a weekend which I think that's probably changed from when seven/seven working started. So there's a lot more focus on getting like medications available, looking at do not resuscitate forms so you don't have a crisis on community and you're not running around doing these things.'*

**S 1 C Q6a:** *'... CNS could ensure their own patients are well-managed on a Friday to pre-empt issues on the weekend/bank holiday.'*

Staff frequently described the unpredictable nature of weekend/bank holiday shifts and the challenge of simultaneously managing planned and unplanned referrals. Triage and prioritising patients was seen as a vital, yet complex part of the role. Whilst staff suggested improvements to the referral process for known patients, comments made through the survey and interviews showed unplanned referrals can make caseload management complex. Although planned reviews were said to be intentionally limited in number, staff explained that the unpredictability of unplanned referrals and advice calls can impact on planned visits with late referrals adding to time pressures.

**I 5 H Ref 6:** *'... it's just working through and trying to prioritise which ones need seeing first, which patients. ... is difficult because you know that your team on a Friday have put these patients down for a reason ... they feel that they're all a priority, so then for you then prioritise maybe someone coming into A&E, needing seeing first, rather than someone on the list is, is difficult, but what I would hope for is that the people in the hospital who are already known to us have actually got a plan of care already and that the ward team are following that plan of care ...'*

**I 4 C Ref 1:** *'... you will sort of split up your referrals into those that need to be contacted and those that you need to be aware of. And then you will work your way through your telephone calls, ... [and] who you've got to visit, and then try and put them in order. But whilst you're doing that, your phone can ring at any time, ... random calls, so you haven't got a referral on either, ... so in the week, you're only looking after your own caseload, who you obviously you'll know, ... and obviously you'll get unexpected calls. So you might have to alter your visits, or put in an extra one, but it's more predictable.'*

At interview, two community-based CNSs expressed the view that most weekend/bank holiday visits are unplanned. Another pointed out that during the week, all patients seen are known to them, so even unexpected requests for support come from patients on their caseload. Knowledge of the geographic area was also thought to make it easier to plan and manage the caseload during the week.

Taking calls from patients and families for whom CNSs had no information was said to make it more difficult to assess need and increased the time it took to deal with the call. At times callers could unintentionally give misleading information. One CNS explained that whilst choosing to review electronic notes and call the patient/family member back could take more time, it facilitated better familiarisation with the facts to inform decision-making.

*I 9 C Ref 1: ‘... some people will be flagged up that for you to be aware of, these might ring in, but very often it’s the people that are not flagged up that are ringing in with problems.’*

*I 2 C Ref 1: ‘But during the weekend ... you’re not sort of managing your caseload. You’re just managing the calls that come in, so other nurses may have asked you to phone somebody. Or you may know that you’re almost definitely going to have to go and see one particular patient but most of the visits that you do would be unplanned.’*

*I 9 C Ref 1: ‘So I have to work differently on the weekends ... to how I work in a week, so um because I’d, I’d have an, an area, a patch and so I know how long it’s gonna take me to get there, I know my patients, ... generally, you have a sense of how long you’re gonna need, um and how long it’s gonna take you. You know, on the weekend, that’s, that can’t happen ...’*

#### *vi. Incoming call management*

Community staff described feeling under pressure because of the need to answer the phone whilst carrying out other tasks. Some said taking incoming calls at times interrupted their face to face clinical work with patients. Pulling over to answer calls and take information whilst enroute to patient’s homes was said to sometimes impact on their planned schedule. It was proposed that having a staff member to triage calls would free up CNS time to carry out visits. These points are explored further in the Cross-site and community travel, Staff remit boundaries and Workload and contracted hours sections.

*S 7 C Q4a: ‘Personally, I have found it quite difficult having to pull over in the car numerous times en route to patient visits to answer incoming calls whilst trying to document details etc and still attend visit in a timely manner. Fielding calls whilst in the car can also be challenging as obviously we have no access to patient notes whilst on the road.’*

*I 9 C Ref 10: ‘... if you had somebody triaging the calls, that would make a big difference, if you had somebody doing the phone calls and then somebody doing the visits, you can get out and you can be surprised how quickly you can get across from one place to another, but you know, it’s, it’s when you’re having to do all the bit in between that makes that difficult.’*

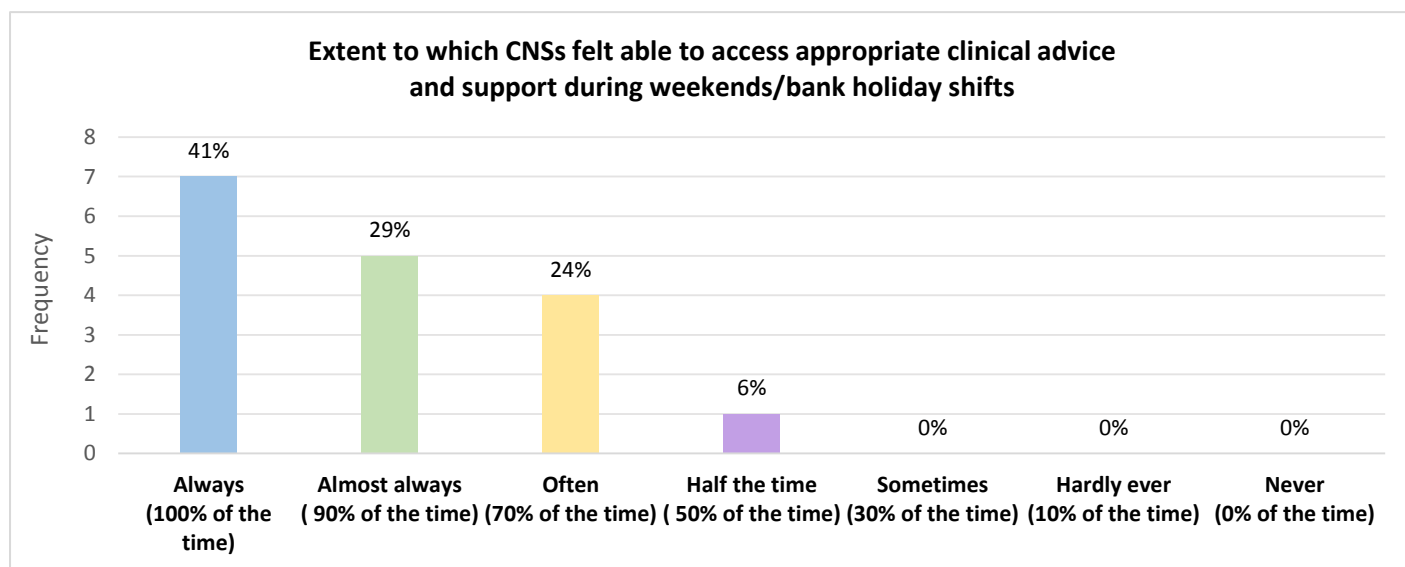
*RI6 C Ref 6: ‘... Erm, you just have to do your best. You phone the patients that you have to phone but then often if you, you could be on the phone and, and you’ve got a voice mail message that’s been left while you’re on the phone to somebody else. Which is equally about a need and you’ve just got to try and make triage of what you’ve got and what’s coming into, based on their needs.’*

## vi. Specialist clinical advice and support

This section relates to CNSs inter-professional relationships with, access to and support from, specialist clinical staff.

CNSs said clinical advice and support was an integral part of the infrastructure that assists the delivery of the SPC service at weekends and bank holidays. They explained that as well as Registrar support at weekends, there is a 24 hour a day Consultant telephone advice service available to all clinicians including the CNSs working in hospitals and community areas across South East Wales. The service is accessed via a call to the hospice. The calls are answered by a triage nurse, who then passes the inquiry on to the registrar or consultant.

The survey asked CNSs if they felt able to access appropriate clinical advice and support during weekends/bank holidays if needed. The question was answered by 17 of the total 18 staff members who completed the survey. Seven of 17 respondents (41%) said they could always access appropriate clinical support during this time. Nine of 17 CNSs (53%) said this was almost always or often the case. A single respondent (6%) said they could access appropriate clinical half the time. The options of sometimes, hardly ever and never were chosen by no one.



As described in the Staff knowledge and skills section, the importance of the on-call SPC doctor as a source of advice and support was apparent, with some CNSs believing it to be essential, as one CNS explained:

**S 18 H Q12:** *'Having an on-call Dr in place for CNS to contact as needed is good as working at the weekend can feel very isolating and often challenging depending on the patients so this support is essential.'*

The list of on-call SPC consultants was thought to be useful and although some staff accessed their support infrequently, availability of this resource was said to be reassuring. Staff said that the on-call SPC doctors were supportive and helpful despite the potential challenges associated with them not knowing the patient. One Hospital-based CNS explained that accessing doctors on general wards could be difficult, another said it was good to know that they were not the *'be all and end all'* in decision-making'.

**S 18 H Q8a.** *'If I have needed to speak to a palliative care Dr on-call this hasn't usually been a problem and whoever I have spoken to has been supportive and helpful, which can always be difficult over the phone for a patient not known to them and that they are unable to see face to face.'*

**S 8 H Q8a:** *'Have not had any problems accessing clinical advice from palliative perspective, but extremely difficult to access the doctors on-call in general hospital.'*

**I 5 H Ref2:** *'I think it works well that knowing someone is available to talk to, erm, so knowing you're not the, the be all and end all. ... you know, because, ... a lot of the teams in the hospital will write in the notes, erm, await palliative care review and that's quite a big responsibility ..., so that's quite a big thing to have on your shoulders and you think, oh gosh. So, it's quite good to know that if I couldn't make a decision then I've got someone else I could discuss it with.'*

Whilst CNSs clearly valued the support they received from the on-call SPC doctor, some said they occasionally experienced challenges accessing support. This included having to wait long periods before the telephone was answered and not having requests for advice calls returned.

**S 11 C Q8a:** *'Availability of advice is there but difficulty getting through to hospice on phone lines at times often ringing for long periods when they are busy and have to wait for site manager to field calls.'*

**S 13 C Q8a:** *'most of the time if I need advice a palliative reg or consultant will ring me back for advice, however there have been occasions where I haven't had phone calls returned.'*

CNSs said although they could always access support, this was usually given by telephone meaning the doctor was reliant on the CNS's description of the situation rather than seeing the patient first-hand. This kind of telephone support was said to be more time consuming than the weekday arrangements because of the time taken to assimilate all the relevant patient information in advance of the call so it can be relayed to the on-call doctor. Waiting for call backs from the on-call doctor was another factor.

A number of CNSs commented on the reluctance or inability of the on-call SPC doctor to conduct face to face medical review on weekends/bank holidays due to the wide region of Wales they cover. This was thought to be a disadvantage in comparison to weekday support, particularly where cases were complex. One staff member talked about the potential to provide a local solution to the gap in access to face-to face medical review in future, through availability of a local medical team member.

**S 6 H Q8a:** *'... Usually straightforward to contact weekend palliative community CNS. Complex patients that require a face to face palliative medicine review is more difficult as due to logistics this is not always possible.'*

**S 1 C Q8a:** *'I mostly feel well supported by my medical colleagues. However, not all of the doctors are willing to visit patients in the community.'*

**I 10 H Ref2:** *'... you have to take time to make sure that you know ... as much as you can about that patient before you ring them so you've got all the facts and figures that you need erm, ready to, erm, give a handover and get the advice you need. So there needs to be more perhaps preparation whereas obviously in the week, er, it's likely that the doctors surrounding you would know ... what's going on with that patient and of course, so the weekend then is going to be telephone advice and not face to face advice (coughs) from a consultant. So that's because, erm, they're taking calls from the whole region, so obviously they can't, erm, you know they can't, er, drive to every area to review patients.'*

**I 3 C Ref3:** *'So there's always somebody on that we can ring, speak to. Yeah, drugs, querying things going on, ... advice on more difficult cases there is always somebody there. ... It's just a bit more time consuming cos you're ringing them you'll be in the home with the patient you're ringing them to get the information then they're ringing you back and then you discuss things and then you might need to get the out of hours doctor as well, so it's all a bit, but then that's the way it is isn't it? But it does work, it does work.'*

**I 10 H Ref4:** *'Erm, and ideally in the future erm, we'd like to be in a position where we had a face to face, erm, member of our medical team that maybe we could access at the weekend ... I mean our local medical team, so rather than the regional. ... obviously it's easier if people are complex so they can have a face to face review erm, and so, erm, you know obviously the consultants are very good at, erm, asking the right questions over the phone and trying to get the personal information out and I guess having that opportunity for someone to come in and review the patient. Also, if on a Friday you know that somebody's gonna be really complicated at the weekend then you can plan that rather than waiting for a crisis or waiting for something to happen, you can plan a review, a medical review. ... like all services you're looking to ... make improvements all the time ... , but even a step nearer to being able to provide, erm, you know face to face medical review if we needed that then, and sometimes, ... we can achieve that now if there was somebody who was very seriously sick, one of the consultants potentially would come in erm, but that's a big ask because obviously looking at the whole area erm, but being able to, erm, provide a local solution to that erm, might be what we'd want to move towards in the future.'*

Some staff talked about the influence of contextual factors on the usefulness and type of advice on-call SPC doctors might give. This included awareness of ways of working, service set-up and facilities in the hospital or community area. One CNS commented that the on-call doctor's usual work setting may have an impact on the type of advice they give, such as the medications and doses they prescribe. S/he said that prescription of drugs not routinely used in acute settings or doses higher than the norm outside hospices might make doctors more disinclined to take advice, although ward doctors' lack of action on advice was said by some CNSs to sometimes be an issue in general.

*I 5 H Ref 8: '... I think it's useful having someone who knows the health board, erm, rather than someone ... Who doesn't know ... areas. ... I think consultants who work mainly in maybe hospices, erm, probably have got a different take on things ... they've approached things maybe differently. ... I think it's sometimes the setting ... , so they might be more used to using one drug in a certain setting than something we're used to in the hospital, so possibly if we then suggest that to one of the doctors in the hospital there'll be more wary of using that drug because they've never used it before, maybe. ... Possibly with doses as well, they might use maybe higher doses in hospices, I don't know. I just feel that possibly they use different doses in hospices than they might in the acute setting. Erm... I don't know, maybe I shouldn't have said that maybe.'*

As described in the Staff wellbeing section, CNSs spoke of the benefits of support arrangements that had been made within teams with CNSs, lead nurses/service managers and consultants making themselves available by telephone to those working the weekend/bank holiday shift. One staff member suggested there were advantages to community CNSs being based at the hospice due to access to support from other medical professionals.

*I 5 H Ref 3: 'I think within our team, I think we've got very supportive consultants and if they've got complex, if they've had complex patients during the week they're usually happy for us to ring them directly, erm, for advice rather than going to the on-call consultant who doesn't know these patients. So that, you know it is quite difficult that you've got a consultant possibly seeing a complex patient all week and then they hand it over to the nurse on the weekend to carry on that care. ... But like I say ... they usually are happy for us to ring them if, if the plan they've put in place isn't working and you think right, oh gosh, this isn't working, they're still vomiting, or they've still got loads of pain what do I do, at least we've got that, you know, it feels like we've got that back up as well.'*

*I 2 C Ref 2: '... So during the week we would have our Registrar and our Consultant who we would be able to ask for advice ... I guess there's more of a chance that they'll know the patient.'*

*I 12 C Ref 1: 'There is support I mean that's a positive, there's always a consultant on-call erm so if they're struggling with you know a patient that's become very complex or symptom control issues that they're not sure of erm there's always a consultant on-call. Erm [pause] I guess the (names organisation) nurses have the advantage of erm [pause] having the hospice, having the inpatient unit erm because they can you know there's nurses and doctors so they feel supported I think by being in the building because there's always other healthcare professionals around. There's doctors, there's junior doctors around, there's senior nurses around ... So they do feel supported that way by the hospice erm on a weekend.'*

## vii. Allied services

This section relates to CNSs inter-professional relationships with, access to and support from services outside the SPC field. See the Specialist clinical advice and support section for information about support for CNSs from within the SPC field.

Whilst this evaluation is focused on the weekend and bank holiday SPC CNS service, this section recognises that the SPC service is part of an interconnecting network of services that work together, performing activities in parallel or one after another, to pursue a common goal. In this context, this section describes CNSs expressed views and experiences about the way in which they relate to allied services and any impact this might have on the SPC service being evaluated and to service users.

Infrastructure differences at the weekends were said to be one of the key differences about weekend working and that this influenced CNSs approach to their work. Lack of seven day working in other fields was said to elevate the

importance of problem solving skills and raise the expectations of ward nurses and care staff due to limited availability of doctors. The demands put on CNSs were thought to be affected by the capacity of other services.

CNSs described having strong and often good relationships with a small group of allied professionals outside the SPC field. In the hospital setting these were ward doctors and nurses. Community CNSs said they worked closely with District Nurses and GPs. The importance of prescribing and pharmacy access was clear in both settings.

CNSs mostly described having positive relationships with District Nurses (DNs) who were said to often have good palliative care knowledge. Pressures on the DN service on weekends and bank holidays were noted. Some CNSs highlighted the role of DNs in planning to ensure adequate stocks of medications and gel sprays for weekends/bank holidays. Ward nurses and doctors were mentioned by CNSs primarily in relation to prescribing. CNSs spoke at length about working with GPs, prescribing and medication. These themes therefore have their own sub-sections below.

### General Practitioners

This section relates to CNSs inter-professional relationships with general practitioners (GPs) and access to GP services.

Community CNSs described having regular contact with GPs during weekend/bank holiday shifts. They depicted a complimentary and reciprocal relationship where each gave advice and performed tasks in support of patients' wellbeing.

Through the interviews, CNSs indicated that out of hours GP support is a key factor in achieving timely symptom control for patients living in the community. Some CNSs said they had good quality, efficient support from the out of hours GPs. CNSs made comparisons between the weekday and weekend/bank holiday GP service. They talked about there being an extended, more time-consuming process in place to access out of hours GPs on weekends. They explained access involved the CNS making a phone call which is triaged by a nurse and passed onto a doctor, who then returns the CNS's call. After a conversation about the patient, either a prescription is written up for collection or information is relayed to another GP to carry out a home visit/patient assessment. Some CNSs said that when this system worked, it worked really well, but that this wasn't always the case. Some CNSs believed it was easier to get prescriptions written up and patients assessed in the week. GP shortages at weekends and increasing demand on the out of hours GP service were thought to be contributing to service delays.

**I 1 C Ref2:** *'Out of hours GPs are different because it's different GPs that work a weekend but they usually work really well with us ... they've got a busy service as well. So any time I've rung up on a weekend to speak to a GP they always come back to me and kinda, they've visited a patient if they've needed to ...'*

**I 12 C Ref1:** *'... if you go and see somebody on a ... Wednesday erm something's changed for that patient ... they need medication changing ... GPs in surgery you can ring the GP, talk to the GP and you can easily get that done in a timely way, well hopefully. ... on a weekend, you first of all have to ring the on-call out of hours GP which is triaged ... and they ring you back, they do prioritise palliative care patients but you then have to wait for them to ring you back, you're then talking to a GP that doesn't know the patient either. Erm that service is stretched and so sometimes it can be a few hours before you can even get a GP there to see the patient ...'*

**S 12 C Q4a:** *'... The out of hours GP service also seems to be under increasing strain and not always able to adequately support our service.'*

**I 2 C Ref 4:** *'Um, probably the out of hours GP support isn't as good at the weekend at all because, obviously, the GPs don't know the patients and sometimes the cover isn't great so you'll have periods during a Saturday or a Sunday where there aren't GPs on.'*

CNSs said that although the out of hours GP service aimed to return calls within 20 minutes, and that calls about palliative patients were usually prioritised, there were sometimes long delays in getting a call returned. Delays were also caused if the CNS was unable to take the call due to being with another patient. One CNS said chasing calls had workload implications, and they didn't have time to follow up unreturned calls to GPs on busy days. One CNS said in these circumstances the GP had occasionally given the CNS their mobile number to avoid having to go back through the out of hours call system, which had been helpful.

Some staff based in the same place as the out of hours GP service felt this made it easier to access GP support, although others felt this benefit was overstated. A dedicated line for CNSs to call was proposed as a way to speed up access to out of hours GPs. Locating a prescribing doctor in the west of the service region was also proposed as a way to improve out of hours GP service accessibility for patients.

Several staff members said that on weekends and bank holidays there could be long delays, sometimes of up to eight hours, between the CNS requesting a GP home visit and the assessment taking place. These delays were said to impede timely symptom management for patients at weekends and bank holidays, ultimately having a negative effect on their quality of life. Delays in out of hours GP response times were also said to sometimes impact on CNSs ability to finish work on time.

*S 2 C Q12: 'Good GP support but they can have limited numbers which increases patient waiting times for adequate medication or review-can be up to 8 hours.'*

*I 2 C Ref 3: 'when you're trying to do something and you've got ... other calls constantly coming in, or you're trying to contact GPs and they're not getting back to you, when things are getting delayed. Which doesn't generally happen during the week. Things are ... it's easier to get things done with the GPs during the week.'*

*I 2 C Ref 7: 'If you are quiet then you'd be chasing it up and you'd be phoning and saying you hadn't had a call back yet. But ... when you go back and forth to other patients and then the work's piling up that you need to try and get sorted out, you don't ... just don't have to time to chase it.'*

CNSs said they occasionally undertook work outside their role to expedite the write up of drug chart changes and prescriptions, and to ensure timely support and patient safety. CNS prescribing was proposed by several staff as a way to improve efficiency. This is discussed in more detail in the Staff remit boundaries section and the Prescribing and medication subsection that follows. Occasions when trainee GPs had worked with community CNSs at weekends were said to have sped up drug chart changes.

*S 14 C Q6a: 'The practicalities in community on a weekend can be difficult to manage such as having medication prescribed or changes made to a syringe driver in a timely manner. It can sometimes be quicker taking a drug chart to OOH GP to have it prescribed. This is not something that can be done for every patient and it depends on CNS workload that day.'*

*S 12 C Q12: ... We often have trainee GPs with us now at weekends which can be helpful in getting patients reviewed quicker and changes made to drug charts.'*

CNSs said they had more opportunity to perform joint patient assessments with GPs during the week and that they were more likely to perform their roles separately during the weekend/bank holiday due to limited capacity to synchronize visits. One CNS said this sometimes meant that GPs made decisions they wouldn't have 'gone along with' if they had been present during the assessment.

It was suggested that some out of hours GPs would benefit from increased palliative care knowledge and experience. In particular, it was suggested that improved knowledge of drugs, doses and how to complete drug charts would have efficiency benefits for CNSs, GPs and patients. Examples were given where dose calculations had been too low and where information had been written in the wrong place on the drug chart, necessitating a second visit for the GP and delaying symptom control for the patient. It was proposed that use of the All Wales Symptom Guidance by out of hours GPs could help with drug calculations. Increased out of hours GP staffing levels was also put forward as a way to improve availability of support to CNSs and patients.

*I 3 C Ref 1: '... I am quite surprised by their, by the GP's slight lack of knowledge in, erm, palliative care. ... we get a lot of out of hours GP's, some are brilliant and that's not everybody mind, but they might not be experienced in palliative care and I suppose as CNS's we're here to help and advise them but sometimes they're unsure how to write the drug charts out or they're not sure what they should be giving ... , we're talking about palliative like pain relief and things, [...] this is a brilliant book and I can't believe that everyone [hasn't] got one. ... it's got all the medications you, you know you should be giving. ... it gives you a guide ... it's well worth having.'*

**I 4 C Ref 6:** *'And generally speaking I think the GPs out of hours, could do with more education about palliative care prescribing. There was one occasion where ... a GP had gone out to prescribe a syringe driver, had written completely the wrong dose of morphine, far too much less than it should have been, and so I had to ask the GP. The GP said "oh well, we'll sort it out tomorrow". And obviously that wasn't acceptable, so I had to ask the GP "no, you're going to have to go back out". They couldn't bring the chart out, so you're going to have to go back to that patient's house and prescribe the correct dose ... They ... hadn't converted the oral dose correctly, ... you know, we've got like a little palliative care guidelines, ... which has got all the conversions, so something as simple as having a little booklet like that, and they can use the guidance, ... on that occasion, if I hadn't of gone ... had to review that patient, nobody would have known about it until perhaps the Monday, and that patient would have been in pain. ...'*

## Prescribing and medication

This section relates to the authorisation for use of medication and access to medication.

Prescribing and access to medication was mentioned by CNSs across a range of topics including staff knowledge and skills, service efficiency, cross-site and community travel and staff remit boundaries.

### Access to prescribing

CNSs in both settings explained that the current system for writing up drug chart changes and prescriptions can be slower on weekends and bank holidays than during the week. Limited availability of out of hours GPs and hospital-based medical staff, an extended process to access out of hours GPs on weekends and delays in GP visits were cited as key contributing factors. As discussed in the GPs subsection, community CNSs based in the same building as the out of hours GPs were thought by some to facilitate faster access to GPs for prescribing.

Community CNSs explained that obtaining a prescription on weekends often required family members to collect them from the out of hours GP. As discussed in the Cross-site and community travel section, the location of the out of hours GP services was said to be a time and distance disadvantage for those living farthest away. One CNS commented that it sometimes felt like a lot of work to make a simple change. Others said that travelling to collect prescriptions and fulfil them at pharmacies used up time some family members could not afford to waste during their loved ones last days of life. The logistics of collecting prescriptions and visiting pharmacies for family members who didn't drive or where they were the only caregiver, were said to be particularly problematic. It was proposed by one CNS that locating a prescribing doctor in the west of the region would improve the out of hours GP service accessibility.

Whilst CNSs recognised that facilitating write-up of prescriptions and drug chart changes by personally transporting documents between ward doctors, out of hours GPs and patients was outside their remit, they said they did this in order to ensure the timely fulfilment of patients' needs. See more on this in the Staff remit boundaries section.

**I 9 C Ref 1:** *'... if they need new medications or things, they have to pick up prescriptions anyway, which we can't do. ... often we'll ask a relative to do that, there are some instances where if it's just the chart that needs changing and you needed it done quickly, you know, you would do that, you know, again trickier on the weekend, cos you're thinking about Geographic's and things um. It's (sighing) sometimes it feels, it, it can be a lot of work if you just want something simple changed, um you know, and if we were able to prescribe, that would make things easier, but we're a long way off that.'*

**S 7 C Q6a:** *'The nature of this role often requires work outside of our CNS remit I would say and that is the case every day of the week. Sometimes this involves taking drug charts to be re prescribed for patients, collecting prescriptions if patients are unable ...'*

**S 11 C Q6a:** *'Due to overstretched OOH GP service often have to take community drug chart to OOH centre to ensure changes are made in a timely way ...'*

**S 8 H Q6a:** *'... I will assist if it ensures that my patient is attended to in a timely fashion. One example is overseeing TTHS completed correctly and liaising with pharmacy for a fast track patient, and collection of TTHS when ready.'*

**S 9 H Q6a:** *'... Organising discharges i.e. getting TTHS from pharmacy - taking drug charts to other wards to get medications prescribed as Dr too busy to come and patient symptomatic and can't wait.'*

CNSs explained that their role is advisory and that whilst they can make suggestions, the decision to act lies with the doctor. One hospital-based CNS described having a trusting relationship with medical staff, but at times felt frustrated and restricted by the CNS advisory role.

Doctors' perceptions of drugs and ways of administering them were thought to sometimes affect their willingness to act on CNS advice. The perception of syringe drivers being a tool only used at end of life was specifically mentioned. Lack of senior medical staff to support decision-making of more junior doctors was also said to delay decisions and symptom management. The time taken to reach an agreement on the course of action in these circumstances was thought to be protracted at weekends. One CNS said it can take up to five hours before the junior and senior medic have opportunity to meet. Better access to hospital-based medical teams for review of patients and prescribing was desired.

**I 7 H Ref 12:** *'... It's just frustrating really you know cos ... your role is restricted by what other people will do following ... cos obviously we just suggest and so if the doctors think that it's not I mean normally they would ring us ... there's quite a trusting relationship between palliative care and the medical staff and things so erm if they're not sure then they'll bleep us.'*

**I 5 H Ref 2:** *'... so in essence we're meant to be an advisory service so we could suggest what to do to the medical team ... but then it's up to them ... to take on board the suggestions or not. ... So not all the time they would agree with you. ... sometimes you feel that, erm, because there's ... less senior staff off to make decisions, especially if it's, erm, maybe in regard to end of life and decisions say to stop treatment, although you can clearly see this person's dying, there's no senior doctor on to make that decision, so you find that the junior team, ... are more reluctant to accept your advice because they've got no one to support them higher up in the decision making. Erm, so you can sometimes spend time trying to find someone more senior to come and review the patient to agree with what ... you're saying and trying to make it more of a, at a joint decision really. Erm, and you can sometimes find that you could suggest something, you could ask the team to do it and because there's no one senior to say yay or nay, you know, nothing gets done. ... there's less, less senior people to make that decision, so say you, you might decide, erm, er, to start a patient on a syringe driver, sometimes doctors can see syringe drivers, you know, the pumps to give the medication. Erm, as end of life things, although we can use them, you know, whenever. It's not just end of life, it's just a different way of giving medication.'*

CNSs felt the ability to prescribe would enhance the SPC service by increasing efficiency. This view was expressed most often by community CNSs. It was felt CNS prescribing would cancel out the need to travel to out of hours GPs and other wards to change drug charts and collect prescriptions, which would benefit patients and their families, GPs, ward doctors, District Nurses and CNSs. One CNS highlighted that CNS prescribing would enable drug charts to be retained and changed at home which would mean pro re nata (PRN) medications, could be given to patients if required.

Some staff described the high level of influence they already had on what was prescribed. Some staff said they believed some CNS colleagues had already completed the prescribing course, but did not perform this task as it is outside the current limits of the CNS role. Others believed this was the way forward, with one CNS suggesting staff were trained ready for when the system changes.

Whilst CNS prescribing was proposed as a way to expedite symptom control for patients, it was also pointed out there may be risk of these skills being used to substitute out of hours GPs service. As discussed in the Staff knowledge and skills section, the commitment required of CNSs to undertake the course and system-related barriers to implementation such as budgetary arrangements were highlighted. One CNS indicated that there may be different budgetary arrangements in the hospital and community setting. Some staff suggested that CNSs could be permitted to make changes to doses on charts rather than prescribe new drugs. It was thought this approach might limit the extent to which CNS prescribing could deplete budgets held by others. One community CNS said that the SPC doctors approached prescribing in this way.

**I 7 H Ref 1:** 'Yeah, well if we could prescribe that that would be good, we've got access to do the erm non-medical prescribing but that has got its pros and cons with it really ... it's quite a big responsibility and it's a really difficult course to do as well and very time consuming ... it's a year the course but it's the amount of work that's with it [...] it's very intense ...'

**I 11 C Ref 2:** *There's certain times on the weekend whereby there's something needs to be increased on the patient's chart but because none of us are prescribers then that can't be done so we have to wait for a GP to do it or the relative will take the chart to [deleted] and have the chart changed. So that does hold up things. So in the future which is the way we have to go, way forward we have to do nurse prescribing and therefore they would change the chart themselves. ... We can't do the full hog because we don't hold a budget for drugs. So we wouldn't ever be allowed to prescribe erm different drugs cos it's the GPs that hold the budget. ... That's the only bit in the community, even our erm doctors they don't prescribe. Because of the budget ... So if our doctors go out they still have to ring the GP and ask them to prescribe. ... they wouldn't alter [a drug chart] without erm telling the GP ...'*

**I 9 C Ref 3:** 'Um, because ultimately what you're doing is you're making all the suggestions, and the GP's just going "Yeah okay" to another prescription and changing charts, if that's what required. ... so you've kind of done all the work, you're the one that's saying that's what you need and this is what, you know, how we need to do it, how we need to give it. ... and ultimately the responsibility still lies with the prescribing GP, doctor in hospital, but very often, they don't ask any questions, they just do what you ask them to do. So you've got all the responsibility but you just can't put your signature to it.'

#### *Access to medication*

CNSs from both settings said that forward planning was an important part of their role. Anticipatory prescribing and stocks of 'just in case' medications were said to help maintain symptom management for known patients and mitigate any weekend crises. One hospital-based nurse said that they supported planning on wards by encouraging nurses to order extra stock of drugs they'd used a lot of during the week and by making them aware of non-stocked drugs that would need to be ordered.

CNSs highlighted the role of District Nurses in forward planning for community patients, with some stating they could do more to ensure there are adequate stocks of medications and gel sprays for the weekend/bank holidays. Failure to do this was said to create extra work for stretched District Nurses, CNSs and GPs on the weekend and put unnecessary burden on families.

**I 1 C Ref 1:** 'So erm like we have like just in case medications, anticipatory prescribing so there's a big drive to get all of these drugs in place. Cos weekends you've got different issues where the pharmacies are not open all the time, we don't have access to erm pharmacies at night and the last thing you want is for a family to be running around in the middle of the night looking for drugs. So we try and plan a lot more in the week which can kind of take off from the weekend as well. ... Cos patients are isolated in community as well they're on their own at home with different levels of support, some patients are literally on their own as well. ... at least if the medication is in the house and it's prescribed as a sub-cut medication ... if a patient was really agitated at least if it was prescribed the district nurses could administer it.'

**I 7 H Ref 13:** 'If there's anything been prescribed new on a Friday then it's always in your mind, well it's always in your mind anyway but particularly on a Friday that the staff nurse who's looking after that patient orders the drug because the worst thing ever is it's been prescribed and then ... the drug's not available ... . So that's really frustrating and usually they're ... the less common drugs that aren't available but erm you know if they've gotta wait then they've gotta wait even longer for their symptoms to be controlled haven't they so. I can't remember the hours of pharmacy they're open both days on till lunchtime ... Yeah so you've just gotta make sure that you get your request in but obviously if you've got ten patients to see you can't see them all in the mornings can you ... So you try and be prepared on a Friday which is sort of like for everything really ... like for all eventualities ... but then particularly for medications you try and make sure that the nurse orders it on a Friday so that the patients aren't waiting around for drugs ...'

**I 3 C Ref 12:** ‘... it’s important that the DN’s, if they know, erm, that things are changing that they’ve got enough stock because a few times ... we haven’t got stock. We order ... But so should district nurses because there’s district nurses giving the injections and .... setting up syringe drivers and being fair they’re brilliant sometimes (laughs), but you do get occasions on a Saturday, oh, we haven’t got enough ... to set up, the syringe driver or we’re running out of, er, injectables ... that’s silly cos you then have to ring the out of hours GP, get a prescription ... or the district nurses can or the family ... , then the family have to go down and pick it up and then find a pharmacy that’s holding the stock and then get the stock back, set up the syringe drivers or injectables... it doesn’t happen all the time, but it does happen and it’s really unnecessary for the family.’

**S 11 C Q6a:** ‘... Often DN do not ensure there is enough medication for the weekend and no provision of gel spray for mouth care so time taken up organising prescriptions.’

Limited pharmacy opening hours on weekends and bank holidays emerged as an important driver for anticipatory prescribing and stocking just in case medications. As described above, the other motivation being reduced access to doctors for prescribing. One Hospital-based nurse said they didn’t understand why the hospital pharmacy wasn’t open the same hours across seven days when patients’ drug doses change on weekends too. Whilst hospital pharmacy opening hours are limited on weekends, CNSs explained that there is an on-call pharmacist that can be brought in if really needed. The option of loaning drugs from other wards was also highlighted.

CNSs said that community pharmacy opening hours are also reduced on weekends and bank holidays. They explained that there are dedicated pharmacies in the community that should stock palliative care drugs. Some said that this system worked well. This was balanced by comments highlighting barriers to access, including distances of pharmacies from patients’ homes and stock issues.

Despite there being dedicated pharmacies for palliative care drugs, CNSs said some failed to hold adequate stock. This meant there were sometimes difficulties obtaining medications which had implications for symptom control for patients and impacted on staff and families, who were required to make multiple phone calls to locate the drugs and extra journeys to collect them. Issues with pharmacists dispensing part of a prescription were highlighted by one CNS. This was said to create work for CNSs, GPs and families, who in these circumstances had to arrange for a new prescription for the outstanding drugs to be written, collected, and then fulfilled at another pharmacy. One CNS said some dedicated pharmacies are well stocked and proposed that sharing their model of practice with others would facilitate improvement. Access to a 24 hour pharmacy was also suggested.

**I 5 H Ref 4:** ‘... it’s still difficult in the hospital because pharmacies are only open in the mornings. ... in the week it’s ... a full day. Erm, so it’s only open Saturday morning till something like 1pm, and Sunday I’m not even sure if it’s open on a Sunday ... so it’s much more difficult if you want to change medication and the staff haven’t got it on the ward. Although staff can sometimes ... sign it out from one ward onto another ward although it’s not best practice really, probably. ... I can’t really understand why pharmacy aren’t open 9 to 5 on a weekend when, erm, patients’ medication does change on the weekend ... there is an on-call pharmacist that you can call in ... but I don’t think the health board like doing that.’

**I 4 C Ref 4:** ‘Well, again it’s knowing which pharmacies are open, which ones stock the palliative, so we’ve usually got a list. But there have been problems with stock, so again, you can spend a bit of time finding out which pharmacy’s got that ... and which pharmacy is easier for the patient to access ...’

**I 8 C Ref 3:** ‘... there’s certain pharmacies ... that are meant to keep a stock of Palliative Care medicines, um. And they’re quite well distributed ... I can only comment on, on my sort of area really, but I know that um there’s one ... that is extended opening times, sometimes they’re open till half past six ... But again if it’s beyond that time, then you’re delayed until the following morning. You won’t be able to start medication. ... sometimes, depending on what it is, ... we can’t access [it] on the weekend ... say ... Fentanyl preparations. ... wouldn’t be perhaps standard medication ... But sometimes you know, even though these pharmacies are meant to be holding medication ... they don’t have it, um, so then the patient’s relatives have to run around to different pharmacies trying to get hold of it. And if it’s on a prescription with something else, they’re stuck then, if that chemist holds on to the prescription, because it means they have to access the GP again, they shouldn’t, they should say “We haven’t got both items, would you like to take it to another pharmacy?” ...’

## e. Service outcomes and impact

The service outcomes and impact major theme focuses on changes that have occurred as a result of the service being implemented and how it might have affected the lives of service users and staff, as described by staff. Service outcomes and impact is broken down into four sub-themes:

i.	<b>SERVICE BENEFICIARIES</b> Those who benefit from the service and how.
ii.	<b>SERVICE EQUITY</b> The ways in and extent to which equal service access is provided to those with a recognised need for support.
iii.	<b>STAFF WELLBEING</b> The marked effect or influence of the CNS role on staff wellbeing.
iv.	<b>IMPACT ON WEEKDAY SERVICE</b> The marked effect or influence of the weekend and bank holiday service on the weekday service.

### i. Service beneficiaries

This section outlines who benefits from the service and how, as described by staff through the survey and interviews.

The CNSs highlighted patient benefit as a key outcome of the weekend and bank holiday SPC service being implemented. In particular, the availability of seven day specialist rather than generalist palliative support was thought to be a great advantage to patients and their families.

The weekend provision was said to offer continuity of care, facilitate better symptom management to known patients, and facilitate timely support for urgent new referrals and known patients whose symptoms had changed. The ability to make safe changes to medications on a Friday, and weekend access for families that CNSs might not otherwise get opportunity to see during the week were mentioned. The ability to organise weekend discharges and facilitate rapid discharges on a Monday were also said to be an advantage, helping to facilitate more timely transitions between care settings. Hospital admissions were thought to have been reduced during weekends and bank holidays as a result of the service intervention.

CNSs said there was growing awareness of the service and how to access it among families and allied professionals. This was viewed as a success, which some thought had helped to improve equity of access. Weekend access was believed to have helped maintain the emotional wellbeing of patients and family members by helping them to feel reassured, more confident and well supported during this time. Allied professionals caring for palliative patients were thought to benefit in a similar way. Some CNSs said they too felt comforted knowing patients had an advocate with knowledge of their support needs over the weekend/bank holiday.

**I 6 C Ref 6:** *'... the patient[s] have access to specialist palliative care nurses, advice and experience on the weekend which is great, and if we weren't there, they wouldn't have that, and they'd suffer for it. I think we add to the out of hours, it's important that we're there. They get that specialist advice which they wouldn't have if we weren't there. ... unfortunately people deteriorate and die out of hours, they don't all die Monday to Friday 9 to 5. It's life isn't it.'*

**S 12 C Q12:** *'Patients can feel more confident that there is someone to contact at the weekend if needed. This support could not currently be provided by the OOH GP service. Patients are able to receive specialist rather than generalist palliative care. Hospital admissions can be reduced at the weekend. ... '*

**S 14 C Q12:** *'I feel that patients have good awareness of the service and know how to contact CNS. There can also be good continuity of care especially when making changes to care on a Friday as the patient can be reviewed on a weekend.'*

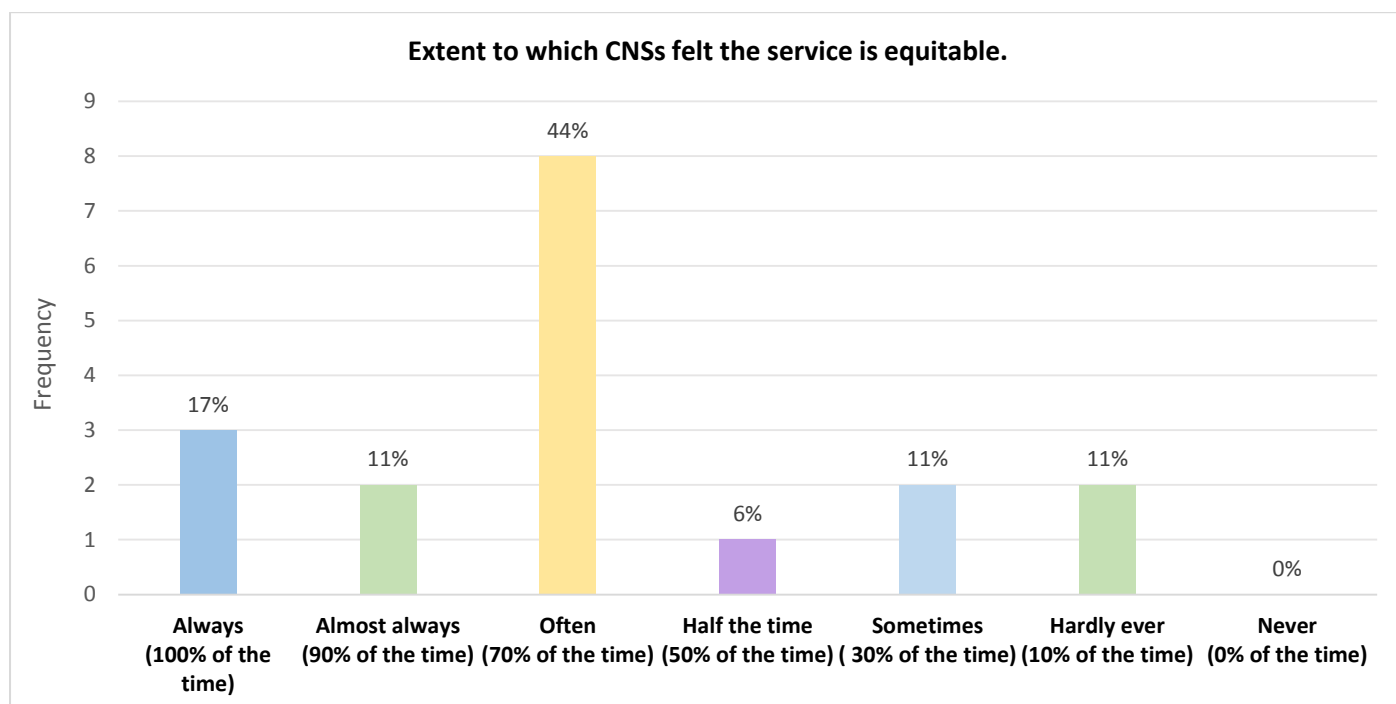
**S 17 H Q12:** *'1. It provides a 7 day week specialist cover. Symptom control and specialist support available every day. 2. It allows to support new referrals/discharges over weekend. 3. Get to meet families you may not see in week. 4. Allows for safe titration/changes of meds on Friday. 5. Can give opportunity on suns to prep for rapid discharge Monday.'*

**S7 C Q12:** *'I think the 7 day working in itself is a success. I know hospital admissions are avoided thanks to this service and it is a great reassurance to patients and their families that there is someone to contact over the weekend if they need to. ... Being able to handover information to colleagues doing the same role as myself is also reassuring that my patients have an advocate over the weekend when they may otherwise encounter health professionals who do not have all their background information ...'*

## ii. Service equity

This section relates to the ways in, and extent to which, equal service access is provided to those with a recognised need for weekend/bank holiday support.

The survey asked staff if they felt the service was equitable. Three of 18 respondents (17%) said equity was always achieved, over half (10 of 18 or 55%), said this was the case almost always or often. Two CNSs (11%), said equity was sometimes achieved; two others (11%) said that service equity was hardly ever realised.



Free text survey comments reinforced the view of some that the service is equitable. Others explained that whilst they strive to achieve equity, they had encountered barriers which could prevent this. One hospital-based CNS explained that referral of unknown patients was reliant on allied ward staff acting as gatekeepers to service access for patients, potentially introducing inequity between wards. Staff indicated equity could also be variable due to other factors including volume of work, time constraints, distance between patients' homes/hospital sites, limited access to patient information and CNS access to support.

**S11 C Q11a:** *'All patients have equal access to our service.'*

**S1 C Q11a:** *'It is my opinion that CNS strive to provide an equitable service, but rarely achieve this due to the volume of work, time constraints and inability to fully familiarise yourself with patients documentation of a weekend/bank holiday.'*

**S2 C Q11a:** *'Not enough time/capacity to see everyone.'*

**S4 C Q11a:** *'Again it depends on the amount of calls and visits for one person.'*

**S12 C Q11a:** *'The later the calls come in for visits the more pressure there can be on time.'*

**S5 C Q11a:** *'This is difficult to determine and can be dependent on who is asking you to review the patients and their expectations.'*

At interview, staff talked about the extent to which equity was achieved and made comparisons between the weekday and weekend/bank holiday service. They also discussed potential differences in access to support between patients needing specialist input during the weekend.

### Comparison of weekday and weekend/bank holiday SPC support.

Staff talked about providing the best service they could at weekends with the available resources. One CNS said that whilst their perception was that the service should be seamless across seven days, realistically the weekend/bank holiday provision and the way staff approached their work had to be different from the weekday due to diminished resources.

As described in the Service user characteristics and Staff remit boundaries sections, staff said weekend support was targeted at patients/families with urgent and unstable symptoms and complex care and support needs. The focus of weekend/bank holiday support to this patient sub-set was said to be mostly clinical rather than holistic care. CNS support to allied professionals was said to be the same across seven days.

*I 8 C Ref1: 'I mean that our focus, from [names organisation] point of view is that it should be a seamless service. So I would hope that the recommendations and the symptom control suggestions ... would be the same as what I would discuss on a weekday. And I'd be sorry if we had to lose that to be. A different type of service, although you have to be realistic in that you've got a team of eight to eleven nurses delivering that service on a weekday, whereas on the weekend there's one nurse. ... so from a similarity point of view ... there are certain things that we cannot access, like equipment and additional care and things on a weekend [that] we can access Monday to Friday. But err as far as symptom control, it should be no different on a weekend, as it is on a weekday.'*

*I 5 H Ref1: '... if you could see staff needing support ... you'd offer the same support ... on a weekend, as you would during the week. Erm, I am aware that at times knowing that I've got ... seven or eight more patients to see ... when I've gone to see patients, I focus solely on symptoms and not actually opened up the conversation about support for patients. Okay? So I know that I, I haven't got time to deal with that, so, erm, ... if they were obviously distressed well you would, wouldn't you? But if, if it was just sort of saying, you know, how are you doing today, or, you know, how are you dealing with all this. I probably wouldn't have those kind of conversations.'*

*I 12 C Ref2: 'Erm I think from the CNS there probably is because the CNS you know if there's somebody that needs visiting the CNS will go out and visit that patient but on a weekend the, the whole service is different not just the palliative care service.'*

*I 10 H Ref2: '... it would depend on the urgency of your need ... so, erm, as I say, I think if that's something that could be dealt with with the rest of the team around then it might be that they might suggest that they come back to you about that whereas if there were urgent needs then of course they would deal with them so, but you can't possibly give ... the same, erm, service from one person that you can from the whole supportive team around you. So the service is different and something has to change.'*

CNSs from both settings expressed the view that patients got the same support with symptom control at weekends as they did during the week. Several stated that symptom management took precedence over anxiety or emotional distress, although one CNS said support in both these areas was the same at weekends. Community-based staff said that face to face visits to support people with anxiety could usually be fitted in during the week, but that this was more likely to be done by phone on weekends and bank holidays.

Some said that managing phone calls during these periods was a duty they did not perform during the week and that this task limited time available to carry out face to face visits, potentially introducing difference in the way support is delivered to weekend/bank holiday service users. Time constraints were said by some to limit the amount of time staff could spend with patients at the weekend when compared with the week. Additional staffing was proposed as a way to restore balance in some of these areas. See the Staffing levels section for more information.

**I 6 C Ref 1:** *'Again I think it can vary, depending on the weekend, how busy it is. Erm, I'm sure we all try our absolute best to ensure that they have the same, kind of equal service, it's equitable, but the reality is I'm sure on a busy weekend they probably don't, erm, we will respond to the person that's most in need and do our best. I'm sure it doesn't happen hugely often because we try our best and we work late. Erm, yeah, but I think there may be times when patients probably could have had more of our time where we could have listened a bit longer in the patient's home, where you're not being rushed off to drive to the edges of the city to see the next person. Erm, but that's just a sacrifice we have to make, and ... you use your clinical judgement to make that decision when it's safe to do and when it's not. I think on the whole people do, but probably to our detriment [laughs].'*

**I 7 H Ref4:** *'Erm holistically it would be slightly different because of the other services not being around at the weekend. But for symptom control and erm you know emotional things and that if they, it would be the same yeah, yeah it would be the same.'*

**I 2 C Ref1:** *'... we prioritise things I suppose, um. [Pause] So I think they do [get an equitable service] but sometimes people may expect more of you than you can give at the weekend so you would prioritise the sicker patients to go out and see whereas you might have somebody who's very anxious and they might want you to go and visit them but if you don't have time, you know If you've got lots of other patients then you're trying to support them a bit more over the telephone. That would be the only thing, but I think you can't, you know, you can't possibly go and see everybody.'*

**I 10 H Ref1:** *'I think if they, so if they were urgent symptom needs or urgent, er, you know some family were in a crisis then the team would see them without a doubt erm, but I'm just saying if there were things that could wait until the week then it'll be essential to you know re-plan and book those for the week days. Erm, so do they have the same support? Well you can't provide the same service at the weekend with one person that you can provide with the whole team in the week so essentially it's going to be different erm, it's gonna be, the amount of support is gonna be different.'*

#### Parity of support for weekend/bank holiday service users.

CNSs said they did their absolute best to ensure that all patients and families needing access to the service during the weekend/bank holiday received equity of support, with some believing it was accomplished. One CNS commented that service equity during these periods may sometimes be at CNS expense as staff worked late to achieve it.

Staff talked about the need to triage and prioritise patients that needed support during the weekend. One hospital-based CNS said that it's generally those referring that depict the urgency of patient support needs and at times this could be misleading. Community CNSs spoke about the challenge of prioritising patients with similar levels of need who lived some distance apart. In these circumstances the distinction was when support was given rather than if.

**I 4 C Ref1:** *'Not always, because you can only be at one place at one time. ... sometimes you do have to prioritise who you go and see first, so somebody might be waiting, with the best will in the world, like I say, you can only be in one place at one time. But like the example I gave earlier. The lady who lived [place name] and I was in [place name]. So it would have been better if I could have gone seen her earlier, but I couldn't.'*

**I 5 H Ref3:** *'... if you've got more time to spend with the patients and the families at the weekends, you're giving them a far more equitable service ... compared to the same as the week. So, in the week you don't feel as pressured, you might have a few patients but you know the patients you've got are different complexities through the week, you're not seeing all the complex ones. Erm, so the complex ones, say you've got 10 complex patients on your books in the whole team, you know, you might only have two of those on a Monday as the rest of the patients will be shared out amongst the team. The rest of your patients might be just follow ups or, erm, some discharge planning, that sort of thing, but on the weekend, there's 10 complex patients for the whole day. So those complex patients might take an hour each which is fine during the week but on a weekend you can't spend an hour each on 10 patients. ... So... so you'd feel like you were doing your job well because you're not pressurised to move on from that patient, erm, yeah, and I think you'd feel less stressed for the whole thing because it doesn't give you a good feeling when you're having to rush from patient to patient. '*

**I 7 H Ref1:** *'Erm they'll get equal access to the service but they get prioritised on the information we get given. So obviously if you've just got somebody who's just been diagnosed but is asymptomatic ... you score them for like pain control, erm nausea and vomiting and obviously secretions, constipation and things like that and emotional distress and everything. So if they're not scoring very high on that then erm they won't get priority over somebody who is scoring high but that's exactly the same as in the week ... So they do get equal access or they should get equal access cos obviously it's the people who're referring to us isn't it that depicts that really ... sometimes ... they sound as though they're really urgent when the nurse is talking to you but when you break it down ... it's not something that we can do particularly as a specialist palliative care team but I think everybody does get fair access to us. Based on the information ... we get given ...'*

At interview, one community-based CNS said that in principal, all patients have equal access to the service as they are given the telephone number to call. Conversely, through the survey, hospital-based CNSs said that referral of patients was reliant on allied ward staff who act as gatekeepers to patient access to the service. Some hospital-based CNSs suggested there may be inequity for patients staying at hospitals other than the main site at weekends, as these patients may not be added to the review list due to staff capacity and travelling times between sites.

**I 1 C Ref1:** *'... all our patients are aware of the out of hours service so whenever we see a patient they're given the out of hours contact details. So I suppose in that sense you could say they have got equal access.'*

**S 16 H Q11a:** *'It relies on our team identifying known patients needing weekend review. If patients are admitted and require palliative input, they would only be reviewed by our team if the hospital medical team or the community palliative team alerted us to their admission. Some patients requiring palliative intervention therefore may not receive reviews as we would be unaware of them.'*

**S 3 H Q11a:** *'If you are very busy in one hospital, occasionally you will need to do telephone assessments of patients in other sites because you do not have time to drive between sites. This is usually [place name] or the community hospitals.'*

**S 6 H Q11a:** *'Not sure if [place name] patients are given same consideration when it comes to reviewing on weekend.'*

**S 8 H Q11a:** *'... I feel other hospitals other than [place name] do not have an equitable service, this is mainly due to the fact that generally there is one nurse on for all sites and therefore numbers are capped and sometimes patients are not added to the weekend list in other hospitals for this reason.'*

### iii. Staff wellbeing

This section relates to the marked effect or influence of the role on staff wellbeing; i.e. Their state of being comfortable, healthy, happy and safe.

Through the survey and interviews, CNSs described how weekend and bank holiday working affected their wellbeing. Some took the opportunity to say how rewarding they found the role which offered a degree of balance to comments on the demanding nature of the work.

Some CNSs explained that at times, they or their team members felt daunted by or dreaded working the weekend/bank holiday. The inherent unpredictability of these shifts, lack of colleague support and issues accessing patient information were thought to be contributing factors. CNSs in both settings said lone working could feel isolating, despite allied professional teams working during these periods.

**S 4 C Q7:** *'I always find the thought of a weekend on-call daunting as you just don't know what to expect. I know however that I can always contact the on-call Dr to ask for advice if I need to.'*

*I 11 C Ref 5: 'So there are good bits to it you know. Erm I actually quite enjoy doing on-calls but I suppose I'm just thinking of [others in the team] and they just find it really stressful doing them they start to dread it on the Friday when they know they're on-call ... because it's so unpredictable now. It's because they're on their own. I think if there was two of them they'd be fine, I don't know if that would help the traffic [laughter] it would help their stress levels ... maybe for them it would help them and it would make them more confident in their decisions and things like that.'*

*I 10 H Ref 2: '... the service is unpredictable ... so then that does put that individual under stress or at risk if, erm, you know suddenly they have an influx of people. Erm, also it is very isolating ... although there are other ... teams around you you're essentially working on your own ... so definitely works better on the Saturday with the two people, ... if it's a complex person then often, erm, they can discuss that person ... and develop a plan together.'*

*I 4 C Ref1: '... you know, it is a challenging job, stressful, because when it's busy, it's really hard to prioritise, you know, you can't be in two places at once, so that's difficult. Still learning all the time, which you do in this job, because there's just so many different diseases and treatments and ... but I like it as well, it's ... you know, it is rewarding, oh yeah, that's important.'*

*I 4 C Ref2: '... Well, the out of hours service basically, you're on your own, I mean, you have got a doctor at the end of the phone if you need to speak to them, but it's ... I find it even now, I've probably only done about six or seven on-call weekends and bank holidays, that I find it quite daunting, going in, because you just don't know ... If you're going to be really busy, and you ... don't know what's going to be at the end of the phone. And you haven't always got all the information you need ... if you feel a little bit ... like you know, you've got a problem and you want to discuss it with one of your colleagues, you haven't got that support. So that is quite isolated, yeah.'*

*S 18 H Q12: '... working at the weekend can feel very isolating and often challenging depending on the patients ...'*

Some described the role as emotionally and physically draining or exhausting. This was in part attributed to the type and complexity of patients. The level of decision-making in relation to the complex patient caseload at weekends was a factor. See the Staff remit boundaries section for more on this. At interview, one CNS described sometimes feeling emotionally and physically shattered and explained how this fatigue had led them to close down conversations, although this situation was also said to present in the week at times.

*S 9 H Q14: 'Many times I feel exhausted having done the weekend so much so that I try to not arrange anything for the evening.'*

*S 3 C Q14: 'I feel that the weekend service works well but can be emotionally draining as well as physically draining for the CNS working. This is usually due to the complexity of the patients that they see, these patients are usually seen by the consultant or doctor during the week. I feel that this is not always recognised except by the other hospital CNSs working.'*

*I 5 H Ref3: '... I know you're not seeing all the patients that are known to the team, you only see the more complex ones. But they're the ones that can be taking up your time and you know, more, more stressful aren't they? They're not the ones where you just, you sort out their social situation or, or, erm, decide on the place of care and things like that, you're doing more of the stressful stuff on the weekend.'*

*I 5 H Ref5: '... sometimes you know you might get to the end of the day and you are, it's the same during the week though, you could be absolutely shattered, you might have seen three or four families and you think I really cannot deal with anymore, you know. So that, those times you might close the conversations down a bit as well. You just might be either sort of physically and mentally exhausted, and you really just haven't got any more emotion to give, you know ...'*

Shift patterns were discussed, with community-based staff stating they had in the past worked between eight and 12 days straight before having a day off. One CNS suggested this could potentially compromise staff and patient safety. Alterations to shift patterns allowing a day off before working the weekend were thought to have improved the experience of staff employed by one provider. See more on this in the Impact on the weekday service section.

**S 1 C Q10a:** *'After working a weekend, CNS rarely have the ability to immediately take their "day-off owing", leaving the CNS frequently working up to 12 days in a row. This is exhausting and some may even suggest impacting on CNS and patient safety.'*

**S 12 C Q10:** *'... I have found it much less tiring that we can now have a day off the week before the on-call weekend due to working 4 ten hour shifts. It was difficult doing 8 days in a row previously.'*

**I 2 C Ref1:** *'When we used to do the eight days in a row, it's just exhausting. I think it's really, I think it's really tiring and you dread it all week whereas now because we get, potentially, have a day off during the week it's just ... it's much more manageable. I think. You're not as tired doing it.'*

Some hospital-based CNSs said they preferred working shifts when they had the support of a second nurse. It was suggested by some long-serving staff that newer staff in particular benefited from weekend peer support, to which they had easy weekday access. The on-call palliative care doctor was mentioned as an essential source of support, although having a second CNS on shift as an intermediary in decision-making was clearly valued. In some cases, informal support arrangements had been made within teams with CNS and consultants making themselves available to those working the weekend/bank holiday shift by telephone.

**I 10 H Ref 3:** *'... So it definitely works well to have the two people on on the Saturday and the Bank Holiday ... staff are much happier since we made that change er, and feel less stressed and ... the weekends are more manageable particularly if they only have one day to manage on their own or one day in which they often know the case load.'*

**I 11 C Ref6:** *'... they don't like being on-call on their own. Erm I can see that more and more you know and we've got a younger team now as well. So even though they've got you know the experience to work in a weekday when they've got lots of people around them supporting them and they can just pick up the phone and ask the doctor or you know or ask one of us, on a weekend I think they find it a bit more scary.'*

Rostering two staff members to work each shift was suggested by hospital and community-based staff as a way to improve their experience of weekend and bank holiday working. CNSs proposed this would improve CNS safety, offer peer support, give opportunity for shared decision-making, and reduce stress and anxiety. See the Staffing levels section for more on this.

Community CNSs described the pressure they felt due to competing priorities such as having two patients with equally pressing needs at opposite ends of the city. Being unable to answer the ringing telephone knowing someone in need of help was calling was cited as another cause of stress. One CNS said that lack of time meant that staff felt pressured to move on to the next patient which resulted in them having negative feelings.

**I 3 C Ref2:** *'... you know obviously if you're driving, by the time you go in to see a patient you could be there an hour, it could be like five, six phone calls, well it could be urgent so that I find quite difficult and quite stressful ...'*

**I 5 H Ref 6:** *'So... so you'd feel like you were doing your job well because you're not pressurised to move on from that patient, erm, yeah, and I think you'd feel less stressed for the whole thing because it doesn't give you a good feeling when you're having to rush from patient to patient.'*

Mechanisms for community CNS safety were discussed at interview. Staff explained that there are alert procedures in place to highlight known risks, in which case two staff should attend home visits. Risks associated with unknown aspects of weekend and bank holiday working such as unfamiliar and potentially unsafe areas of the city and vicious pets were mentioned.

One staff member highlighted differences in weekday and weekend practice that could potentially affect CNS wellbeing. On weekdays, two SPC staff were said to always undertake the first visit to a newly referred patient, with this initial assessment including a review of risk. This process was thought to differ on the weekend due to community CNS lone working. Risk assessment during this period was thought not always to be possible and personal alarm systems purchased for nurses were said to have gone unused. Concern about a potentially ineffective lone working call system was also shared. This hinged on the belief that the process relied on the vigilance of other staff who had

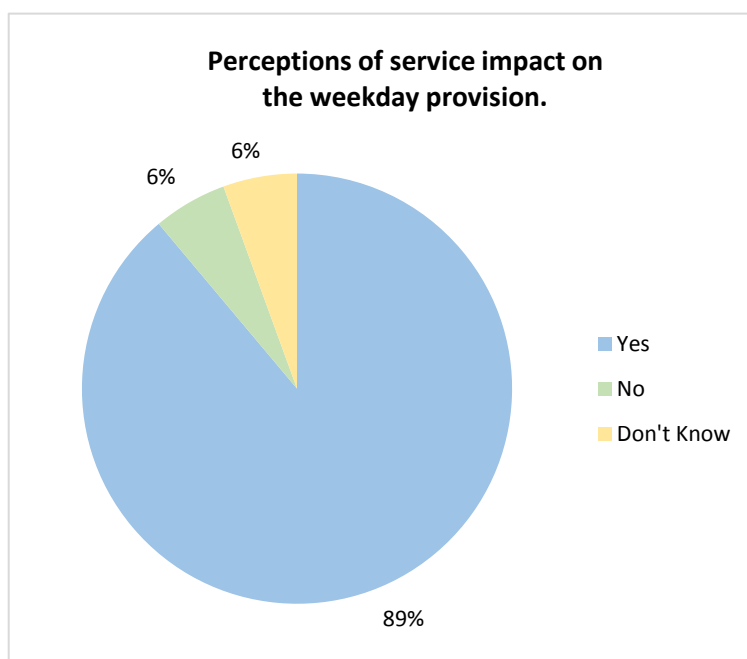
their own busy workload. The interviewee said this meant at times staff out in the community could have disappeared unnoticed.

**I 11 C Ref2:** ‘... on a weekend ... when they go out to see patients they ring into [names organisation] and they let them know where they're going. To be perfectly honest with you that is not the safest way to do it because [names organisation] staff are under pressure themselves. So they sometimes don't even realise when they haven't rang back in. So there've been a few times when you know they could've disappeared off the face of the earth and nobody would've noticed. So there's those bits on a weekend that are worrying. ... in the weekdays ... [the team] write on the board where they're going what time they're going to a house, what time they should leave that house and there's always somebody in the office monitoring it. So if say their third patient they're suddenly late getting to and we have a call from the patient saying they haven't arrived then we can ring them and say just, where are you, what are you doing. They have got devices, they have sort of personal alarms ... but nobody uses them so we do know our patients. ... On a weekday nobody goes into a house they don't know unless it's a double visit. It would either be the erm doctor and a nurse or it would be the two nurses. So they never do lone working on a weekday. No, so we do a risk assessment on that first visit whereas we don't always get that opportunity on a weekend.’

#### iv. Impact on weekday service

This section relates to the marked effect or influence of the weekend/bank holiday service on the weekday service and includes staff views on the offsetting of time or payment for weekend and bank holiday hours worked.

The survey asked staff if they felt the weekend/bank holiday service had an impact on the weekday service. The survey responses showed that the majority of staff (16 of 18 or 89%) felt that it did. This included positive influences including relieving pressure on the weekday service, continuity of advice and patient symptom management. These positives were echoed through the interviews.



**S3 H Q10a:** ‘It releases the pressure on a Friday and a Monday knowing that complex patients are being reviewed over a weekend and also new referrals are seen if they are symptomatic.’

**S4 C Q10a:** ‘If the service wasn't there it would definitely impact on the weekday service - coming in on a Monday to potentially many issues that wouldn't have be dealt with on the weekend.’

**S7 C Q10a:** ‘I think it positively impacts on the week day service. I know my patients feel comforted knowing there is someone on the end of the phone who knows their situation and their wishes. I like to get the updates on Monday morning of what's gone on over the weekend ... Obviously depending on the amount of interaction my patients have had over the weekend has an impact on my workload the following week ...’

**I 7 H Ref2:** ‘... the continuity is better erm working on the weekend as well cos obviously that's the other time you'd probably put extra patients on if it's somebody you know and you can actually get to see their family at the weekend if they've been working all week ...’

Whilst some staff said there was limited impact on the weekday service due to adequate rota coverage, others described how taking time back can deplete weekday staffing levels, affect weekday service continuity and reduce the time available to spend with their usual caseload.

**S 12 C Q10a:** *'shift rota is adequately organised to provide cover during the week if someone is off'*

**S 11 C Q10a:** *'Our employer only gives us one day off in lieu for working the weekend therefore this minimally impacts on our caseload management during the week. We are paid for the other day which is nice but it can be exhausting working 6 days including 2 on-call shifts.'*

**S 5 C Q10a:** *'The need to take time back for working the weekends results in days away from your usual clinical case load.'*

**S 10 H Q10a:** *'Staff levels in the week can be distributed particularly if annual leave sickness etc.'*

**S 14 C Q10a:** *'It can have a direct impact on the CNS team in the week as staff need days off in the week.'*

**S 16 H Q10a:** *'It ensures palliative management and advice is consistent which is positive. However, less staff available during the week obviously has an impact on weekday resources.'*

Compensatory rest and pay were prominent topics in the survey responses and was explored in more detail through the interviews.

Staff accounts of the arrangements for offsetting of time and payment for hours worked showed all three organisations compensated staff for weekend/bank holiday hours, worked through time in lieu and enhanced pay. However, each organisation seemed to approach this slightly differently. It appeared that two providers gave a day back in time for each day worked. There were some discrepancies in accounts from CNSs employed by the third, a community provider, with some CNSs saying they got half a day back per day worked and others saying hours equivalent to those worked were given back the following week by working shorter days and taking a day off.

When asked about enhanced pay, nurses employed by all providers said they were unsure of the rate and/or which days qualified for these payments. However, some said the payment was a decent sum that helped financially. Staff spoke positively about organisation of rotas. They said shifts were planned around the service and CNSs home life, within teams swapping shifts at their own discretion.

**I 11 C Ref 1:** *'[CNSs] get erm paid for two days overtime and then they get a day off in the week as well. ... just get one day yeah, seven and a half hours back.'*

**I 3 C Ref 6:** *'Yeah, so we work Saturday and Sunday. So generally we work eight until six, ... our choice to be honest and then we have a day off a week and then if we're doing a weekend we would work nine until five that week and then we'd have a toil day, a Tuesday, so we'd have one day off, but our hours are shorter.'*

**I 10 H Ref 1:** *'... what works well I think is ... the team kind of pull together. ... if they've got something that they want to attend then they you know have the flexibility where they can swap in and out of weekends ... if it fits with the team and it fits with the service and what's going on that day, ... because ... many of the nurses are juggling the weekends with families or with child care and things so it's trying to ... be responsive to those other needs as well.'*

**I 9 C Ref 2:** *'... you work two days on the weekend, so you then have to take those two days back. It's at the discretion of the team, how you take those, whether that's one day either side of the weekend or you know, or at the moment we ... tend to work a long stretch and then tag two onto a weekend ...'*

Some staff felt the impact of compensatory rest on the weekday was minimal, for example, one CNS said it was no different to the arrangements for annual leave. The ability to forward plan usual caseload related work in advance of weekend working was also thought to mitigate weekday disturbance.

It appeared that arrangements for taking time owed differed across providers. There were also differences within teams linked to CNSs usual weekday shift patterns. Those working four long days a week for example, said they were able to take a day off the Thursday before a weekend shift whilst other staff worked longer stretches.

**I 3 C Ref 2:** *'... then you'll look after each other's if you're off for a day or annual leave. ... you've got your toil. I suppose it's fair to say if you're off that day cos you've got the Tuesday off your team cover your patients that day but generally you would have done everything unless you've got somebody obviously end of life and then they'll just come and visit them but we tend to do that for each other anyway so I don't think it's any different.'*

**I 9 C Ref 4:** *'And you can plan, that's a good thing, you can plan for it, cos we know our weekends in advance, so you can plan around when you're gonna take your days off and things. So you, you're prepared for that, with your patients, like you would be if you were taking annual leave and stuff. So I suppose because our weekends are planned out and we know when we're gonna work um. Um you can factor that in, when you're thinking about your everyday working diaries, that so. It's difficult [laughing].'*

**I 12 C Ref 1:** *I think the services do it slightly differently. Erm we do it so that whoever works Saturday and Sunday then takes those two days at another time and of course the issue with that is that they have to take that out of their working week the Monday to Friday working week.*

**I 2 C Ref 1:** *'So we all, we all work slightly different hours ... Some of us work 8am to 6pm, four days a week. And others work 9am to 5pm, five days a week. So when they do their on-call they work eight days in a row. So we don't do that when we're doing 8am to 6pm, cos we often might have a Thursday off before the on-call. Which is a lot easier [cough]. Then we do 9am to 5pm the week after but we have the Tuesday off.'*

**I 4 C Ref 3:** *'It's tiring, because you're doing eight days, full days on the trot, before you have a day off. ... so you're doing a ... not physically stressful, but mentally quite a draining job It's quite a lot to do in a row ... by the time you get to ... your day off, you're ready for it, big time.'*

Even though many staff believed the service facilitated weekend continuity for patients and families, conversely some said taking time back could disrupt weekday continuity for service users and that it added to the workload of colleagues required to cover the caseload of those taking time owing. Some said this inconvenience was minimal where there was a full complement of staff. Difficulties were thought to arise when teams had to accommodate other absences, including staff sickness and annual leave. This was said to be particularly problematic for smaller teams. An example was given where staff taking annual leave and time owed meant a single CNS was required to cover the caseload of three nurses. The number of weekends covered was also said to increase the impact on weekday service delivery for smaller teams.

**I 5 H Ref 1:** *'... it's quite bitty for us, but also for the patients as well. 'Cause they're seeing lots of different people, erm, but then that also impacts on the week. Because for us to work the weekend we have to have a day off in the week, so there's less continuity throughout the week as well.'*

**I 1 C Ref 1:** *'... it has an impact on the whole team ... because we have to cover each other's caseloads. So that's something to consider with weekend working cos if we have more staff on the weekend but they may not be needed so it's taking them off in the week, so they're better there in the week when it's busier.'*

**I 9 C Ref 2:** *'We haven't got people off sick, we haven't got people on annual leave, so, so it's okay but if you're in a situation where you are short, um, and then when you're having to find two extra days to take out ... of a busy caseload and you're working up against it, cos you're short, that could be tricky um. But if you're working at full capacity it's, it's manageable and it works okay.'*

**I 4 C Ref 3:** *'... you're one team member down on a Tuesday, which can make a difference, and then ... there's three in my team for example, so if one's on annual leave for a week, and then the other one's off, time owing in lieu from the weekend, so then I'm on my own. As I think I am next week for example ... we've each got 30, 40 patients in our caseload ... I'll minimise how many calls, visits, I book in that day, try and accommodate that, and then that leaves me trying to fit in all my patients in the rest of the week.'*

Other commitments connected to CNS staff roles and the functioning of the service were said to limit when compensatory rest could be taken. This included handovers, team meetings and teaching. As discussed in the Staff wellbeing section, some community-based staff said they had worked eight days or more in a row before being able to take a day off.

Whilst CNSs highlighted challenges in balancing the needs of the service and staff across seven days, no improvements to the way this is managed were suggested. And although staff proposed on numerous occasions that an additional staff member on each weekend/bank holiday shift might remedy some of the challenges they encounter during these periods, they were keen to emphasise the potential consequence this might have on weekday provision if the overall staff resource remained the same.

**I 10 H Ref 1:** *'... most palliative care teams are reasonably small ... I think some areas even do maybe one in three, one in four, ... so maybe holidays and sickness is gonna impact on that. So all that would have to be factored in ... So it's trying to manage that resource the best we can, so although we know the Sundays are busy, also the week days are very busy so, and that's when most of the referrals will come through in the week ... , it's trying to balance ... being responsive as you can in the week and responsive as you can at the weekend and ... trying to meet all the other needs of the service over that time, ... so there are conflicting constraints ... in the week day maybe don't get at the weekend, so it's trying to manage that so that we can provide a more you know rounded service.'*

**I 6 C Ref 4:** *'It's hard to find the time to take it back ... If you've got a particularly busy weekend, you're shattered by Monday. ... if you're taking a day before the weekend and the day after the weekend we try and avoid the Friday before, because you need to be there to have that verbal handover and receive your paper faxed handovers.'*

**I 3 C Ref 2:** *'It's fine. Yeah, you're fine. I mean you are tired aren't you when you've worked the week before, but you need the Tuesday off, generally it's a Tuesday, they don't like you going longer than that ... We have a handover of all the information and everything that's happened and then you have the Tuesday off then but it works well, it works really well. ... it works quite well ...'*

## f. Qualitative data conclusion

Thematic analysis and reporting of the survey and interview data have satisfied the evaluation objectives to identify aspects of the service that work well, service challenges and improvement opportunities. Key differences between the week day and weekends service have also been described. Recommendations to support future service development and sustainability have been influenced by the expressed views and experiences of service staff. These are outlined in the Recommendations section.

The cultural shift and cross-organisational cooperation demonstrated by the three providers through the development and delivery of a single weekend and bank holiday SPC CNS service is an achievement that should be celebrated. So too should the commitment of CNSs who spoke of doing all that they could to ensure timely support to patients, including some working extra hours and undertaking work outside their remit to facilitate this. Supportive inter-professional relationships with allied service staff provide positive footings to support service delivery.

CNSs brought the challenges of the role into sharp focus. In particular, the complex nature of patients needing support, the unpredictability of the workload, the multiplicity of tasks, and feelings of frustration over time wasted came to the fore. The intensity of the work and the impact of lone working were openly represented.

CNSs and service managers gave constructive suggestions for service improvement, with many proposing expanding the role to plug gaps left by limited seven day working in other areas, conflicting with their expressed concerns about existing workload and service efficiency. Although factors such as time wasted on travel, accessing and documenting patient information do have an impact on service efficiency, inevitably, time spent on work outside the CNS remit will reduce the time available to carry out tasks within it. Accordingly, whilst staff expressed the view that CNS prescribing would prevent delays in symptom management, the burden this could put on the service should be considered. Nevertheless, the potential impact of prescribing delays during weekends and bank holidays on patient quality of life is an important issue that has been raised. The CNSs' proposal that there is need for change in prescribing practice could be an important lever for discussion.

Staff were cautious in their proposals for increasing staffing, recognising the implications of offsetting this resource with weekday provision. They made a persuasive argument that access to two staff members on each shift in each setting could have wide-ranging advantages, including a reduction in the challenges mentioned above. The belief that this resource increase would grant more timely support to patients and allow staff to spend more time with them were seen as important benefits. The ways in which additional staffing could safeguard the wellbeing of CNSs themselves, including reduced feelings of isolation, stress and anxiety should not be undervalued.

The growth of the service from five to seven days has facilitated support to those most in need of it seven days a week. Staff perspectives on the strengths and limitations of the evolved service have been clearly communicated through this report. Actions are now needed to support the next phase of service evolution.

## SECTION TWO: QUANTITATIVE DATA

### 8. Retrospective observational study aim and objectives

This section of the report focuses on the activities carried out by the service and includes data on specific settings.

#### a. Aim and objectives

The aim was to measure and describe the activities carried out and recorded during weekends and bank holidays by the community and hospital based CNSs. Alongside this aim the objectives were to:

1. To determine what key activities are recorded
2. To study new referral activity
3. To study if workload might change over time

The methodology used to address this component of the evaluation is reported in full in Appendix 3.

#### b. Data analysis and presentation

Descriptive statistics was used to analyse the data. Data was captured consistently across all the sites as described in Appendix 3. Whilst three providers deliver a single service, there is no single recording system to log service activity. Instead, the two community providers separately record their activity for the weekends/bank holidays they work. Recording of hospital activity is also split, with the main district general hospital activity being recorded separately to activity in the other hospitals. Therefore, for the purpose of communicating the activity across the whole service, the data are presented as four different sites in the same way that it was recorded.

**Site 1 and 2** refer to the activities of the two community service providers. **Site 3** is the larger district general hospital, the University Hospital of Wales. **Site 4** encompasses activity at the University Hospital Llandough district general hospital, two community hospitals, one in the Vale (Barry Hospital) and one in the City (St David's Hospital), as well as a mental health unit at Llandough. See the background section for additional service information.

It is important to note that as weekend/bank holiday shifts are shared among the two community providers, therefore, reporting in relation to site 1 and 2 represent data captured on different weekends but for the same geographic area. Whereas reporting in relation to sites 3 and 4 is for the same time period but for different hospitals as described above.

### 9. Retrospective observational study results

The results are presented under three headings:

- a. Referral activity (e.g. number of referrals);
- b. Service activity (e.g. Number of face to face contacts with patient/family) and;
- c. Service user characteristics (e.g. patient location, diagnosis, reasons for referral).

Tables 1 to 5 describe the activities as counted at each participating site. We have estimated part of the data provided from site 2 so that we could have, where possible, at least 3 years of data observation. The time period represented by the data reflects activity of the service during a well-established phase of its existence.

## a. Referral activity

This section gives information on the number of new referrals and unplanned reviews and follow up referrals. Tables 1 and 2 show the referral activity in relation to patients unknown and known to the service.

### i. New referral & unplanned review

New referrals and unplanned reviews relates to *unplanned activity* over the weekend/bank holiday. I.e. the referral of patients/families not known to the weekday SPC service, and those known to the weekday SPC service who have unanticipated specialist support needs during the weekend/bank holiday.

New referrals and unplanned reviews are key indicators of the service activity over the weekends and bank holidays, because it indicates the responsive nature of the service which may reduce the time patients and families wait to receive urgently needed support, and avert hospitalisation of patients residing in the community. Either of which could have positive implications for the health and wellbeing of service users.

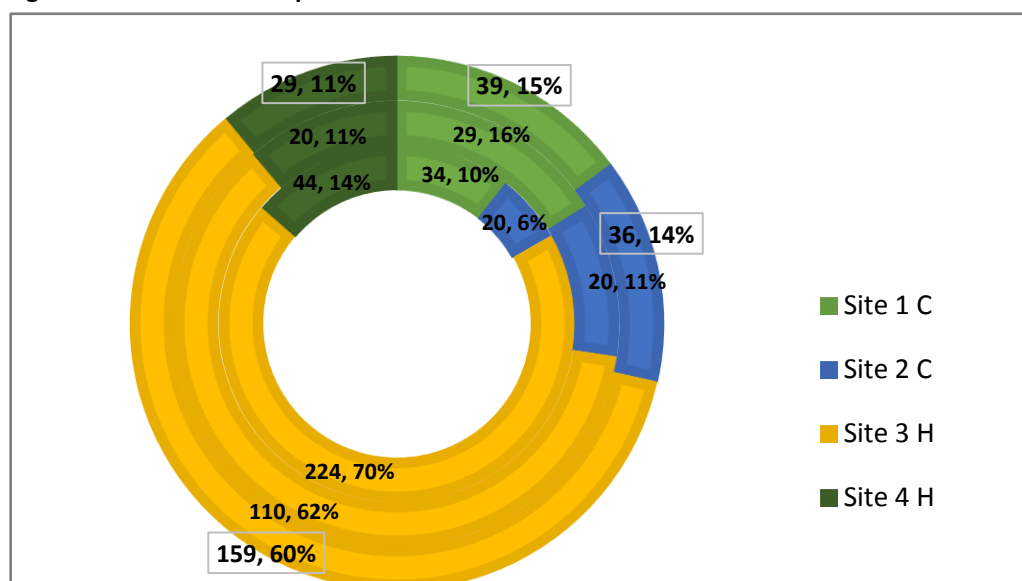
From April 2015 to March 2018, a combined total of 764 new referrals and unplanned reviews were supported by the service (Table 1). Hospital sites had higher levels of activity in relation to new referrals and unplanned reviews compared to the community sites (Fig 1). This might be expected as hospital inpatients are more likely to be in an unstable condition. The larger district general hospital referrals accounted for between 60 and 70 percent of all new and unplanned referrals to the service over the three year period. Referrals across the two community service providers were similar.

**Table 1: New referral & unplanned review**

	Jan 14 to Mar 14	Apr 14 to Mar 15	Apr 15 to Mar 16	Apr 16 to Mar 17	Apr 17 to Mar 18	Apr 18 to Jun 18	Mar 18 to Apr 19**
Site 1 Community	16	50	34	29	39	12	48
Site 2 Community	--	--	20	20	36 <sup>1</sup>	--	--
Site 3 Hospital	--	148	224	110	159	--	--
Site 4 Hospital	--	29	44	20	29	--	--
<b>Total</b>			<b>322</b>	<b>179</b>	<b>263</b>		

1. Includes estimates from January 2018 to March 2018 [(5+24)\*1.25]

**Fig 1: New referral and unplanned review**



## ii. Follow Up

Follow up relates to *planned activity* for the weekend/bank holiday. I.e. referral of patients/families known to the weekday SPC service, believed to need support over the weekend/bank holiday. Follow up gives an indication of how the service is positioned to provide continuity of specialist support to patients and families by bridging the gap over weekends and bank holidays.

Data was only available for the whole service for two financial years (Table 2). In total, 3521 follow up referrals were made across the service in the two year period. The data seems to suggest an increase in follow up numbers with the monthly average rising from 135 referrals in 2016/17 to 159 in 2017/18. This also reflects the data recorded by site 1 over five years, albeit the site did record a reduction of follow up in 2016 (Fig 2).

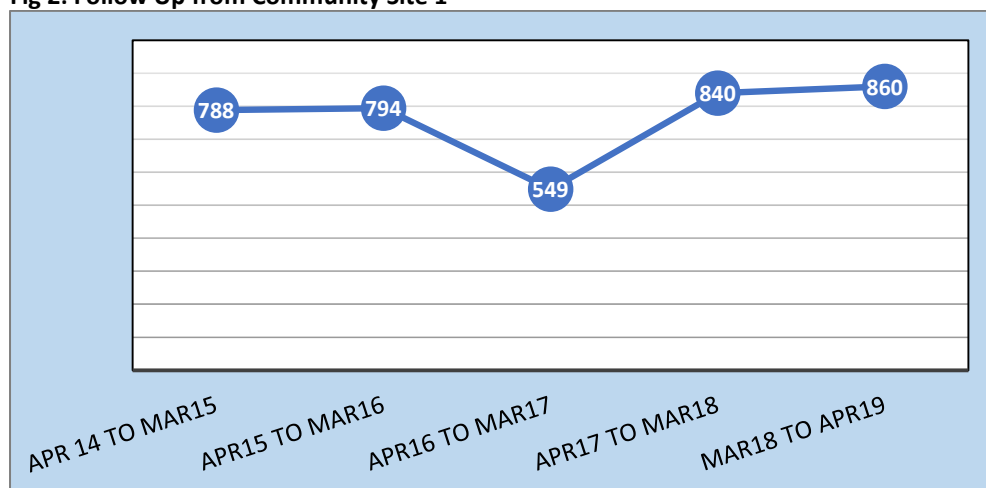
Whilst the data suggests an 18% increase in follow up over the two years (Table 2), a larger time window should be observed going forward to ascertain if this is a trend. It should be noted that the follow up data includes referrals which give information on those who might call in for support. As these 'just in case' referrals don't always result in support being needed, follow up gives an indication of the planned activity only.

**Table 2: Follow Up**

	Jan 14 to Mar 14	Apr 14 to Mar 15	Apr 15 to Mar 16	Apr 16 to Mar 17	Apr 17 to Mar 18	Apr 18 to Jun 18	Mar 18 to Apr 19**
Site 1 Community	122	788	794	549	840	215	860
Site 2 Community	--	--	463	304	248 <sup>1</sup>	--	--
Site 3 Hospital	--	--	--	658	666	--	--
Site 4 Hospital	--	--	--	106	150	--	--
<b>Total</b>				<b>1617</b>	<b>1904</b>		

1. Includes estimates from 13/08/17 to March 2018 [(93\*100)/37.5]

**Fig 2: Follow Up from Community Site 1**



## b. Service activity

The data on face to face contacts, non-direct contacts with patients and families, and non-direct contacts with health professionals described in this section map out the activity carried out by the service. These are reported in Tables 3 to 5.

### i. Face to face contacts

Face to face contacts relates to the number of contacts where a patient or family member was supported in person by a CNS during the weekend/bank holiday. In addition to showing service activity levels, the data could be an indicator of unmet need for face to face specialist support prior to the seven day service being implemented.

Over the three financial years for which data from all four sites were available, the total number of face to face contacts varied between 1,066 to 1,036 (Table 3). This corresponds to an average of nine visits per working day across the whole service. The number of face to face contacts were highest in the hospital setting (Fig 3). This might be explained by the geographic remit in the community, as distance between patients may influence the number of face to face contacts that are feasible in a working day. Lower staffing levels in the community may also be a factor.

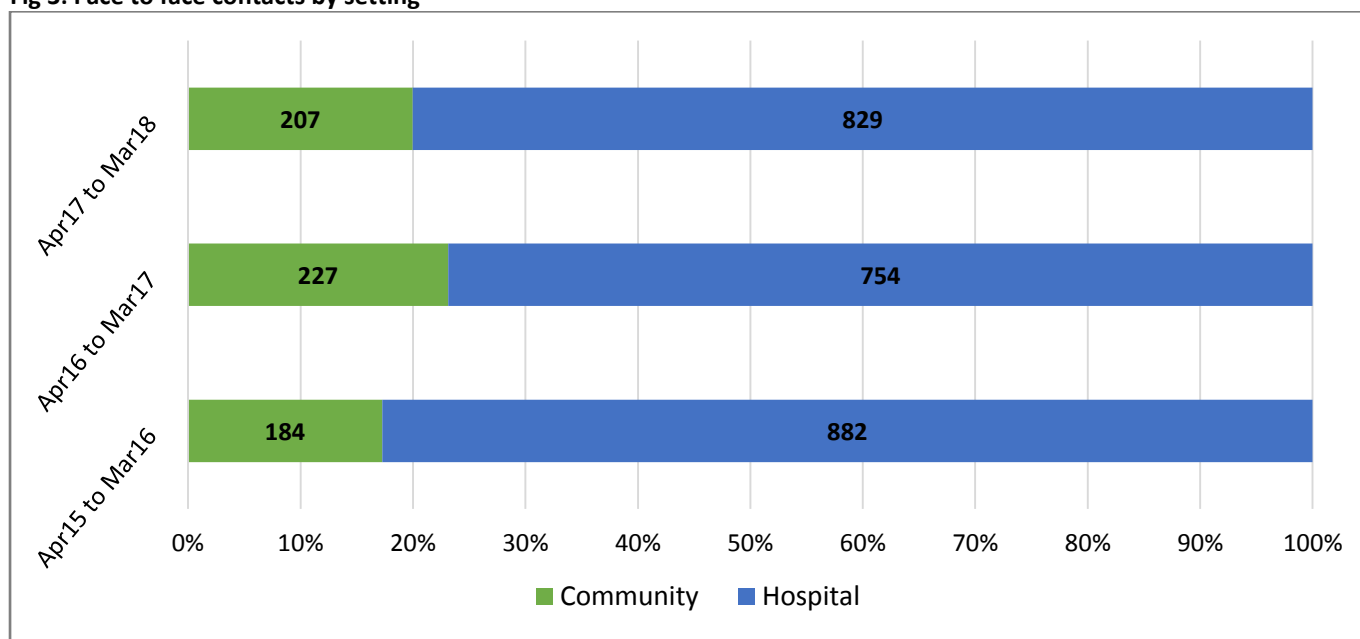
The three years of data shows activity at a point where the service is well established. Face to face contact levels across the three years are stable, as shown by the minimal difference in daily average across the three years of less than one contact (Table 3). This suggests that either the demand is stable and/or the service is operating at full capacity in relation to their ability to conduct face to face visits.

**Table 3: Face to face contacts**

	Jan 14 to Mar 14	Apr 14 to Mar 15	Apr 15 to Mar 16	Apr 16 to Mar 17	Apr 17 to Mar 18	Apr 18 to Jun 18	Mar 18 to Apr 19**
Site 1 Community	21	103	86	121	136	38	152
Site 2 Community	--	--	98	106	71 <sup>1</sup>	--	--
Site 3 Hospital	--	625	704	660	715	--	--
Site 4 Hospital	--	177	178	94	114	--	--
<b>Total</b>			<b>1066</b>	<b>981</b>	<b>1036</b>		
<b>Daily average</b>			<b>9.35</b>	<b>8.92</b>	<b>9.09</b>		

1. Includes estimates from January 2018 to March 2018. 71 [(12+45)\*1.25]

**Fig 3: Face to face contacts by setting**



## ii. Non-direct contacts

Non-direct contacts relate to telephone calls and pager calls made between the CNSs, patients, families and other professionals. A total of 4,475 non-direct contacts were recorded over a three year period. The average of non-direct contacts increased by nearly 40% from April 2015 to March 2018 (Table 4). Both hospital and community sites carried out an increasing number of non-direct contacts (Fig 4). The majority of non-direct contacts were carried out by the community sites, which may reflect the logistics of the service provision, mentioned above.

The increase in the number of contacts could reflect an increase of patients, an increase of contacts per patient or a combination of the two. The latter could be an indication of more complex patient cases, though the data did not include the details around this. However, calls made to other health care professionals could be a proxy for complex cases. It also shows the potential need for cross-functional support for patients at weekends and bank holidays.

The community sites kept a record of the contacts made by the CNSs to other health professionals (Table 5). The daily average of contacts varied from 5.75 to 9.05 between April 2015 and March 2018, marking an over 50% increase in the number of contacts over the three years.

**Table 4: Community and hospital non-direct contacts**

	Jan 14 to Mar 14	Apr 14 to Mar 15	Apr 15 to Mar 16	Apr 16 to Mar 17	Apr 17 to Mar 18	Apr 18 to Jun 18	Mar 18 to Apr 19**
Site 1 Community	134	527	620	745	823	212	848
Site 2 Community	--	--	547	453	547 <sup>1</sup>	--	--
Site 3 Hospital	--	98	111	295	302	--	--
Site 4 Hospital	--	46	49	48	33	--	--
<b>Total</b>			<b>1327</b>	<b>1541</b>	<b>1705</b>		
<b>Daily average</b>			<b>11.64</b>	<b>14.00</b>	<b>14.96</b>		

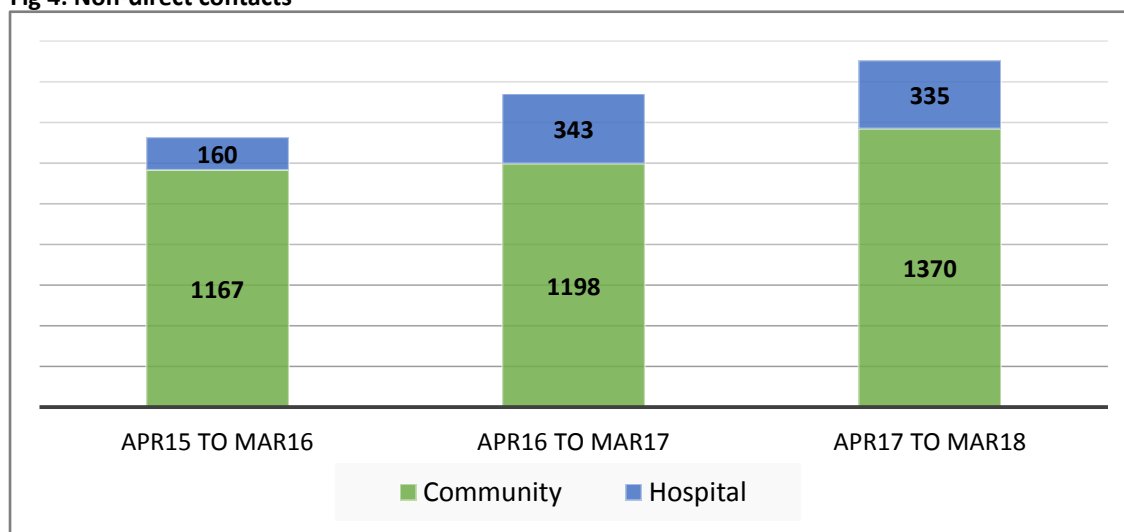
1. Includes estimates from January 2018 to March 2018 [(148+290)\*1.25]

**Table 5: Non-direct contact with HCP's from community sites**

	Jan 14 to Mar 14	Apr 14 to Mar 15	Apr 15 to Mar 16	Apr 16 to Mar 17	Apr 17 to Mar 18	Apr 18 to Jun 18	Mar 18 to Apr 19**
Site 1	116	531	443	548	646	150	600
Site 2	--	--	212	308	386 <sup>1</sup>	--	--
<b>Total contacts with HP</b>			<b>655</b>	<b>856</b>	<b>1032</b>		
<b>Daily average</b>			<b>5.75</b>	<b>7.78</b>	<b>9.05</b>		

1. Includes estimates from January 2018 to March 2018 [(104+205)\*1.25]

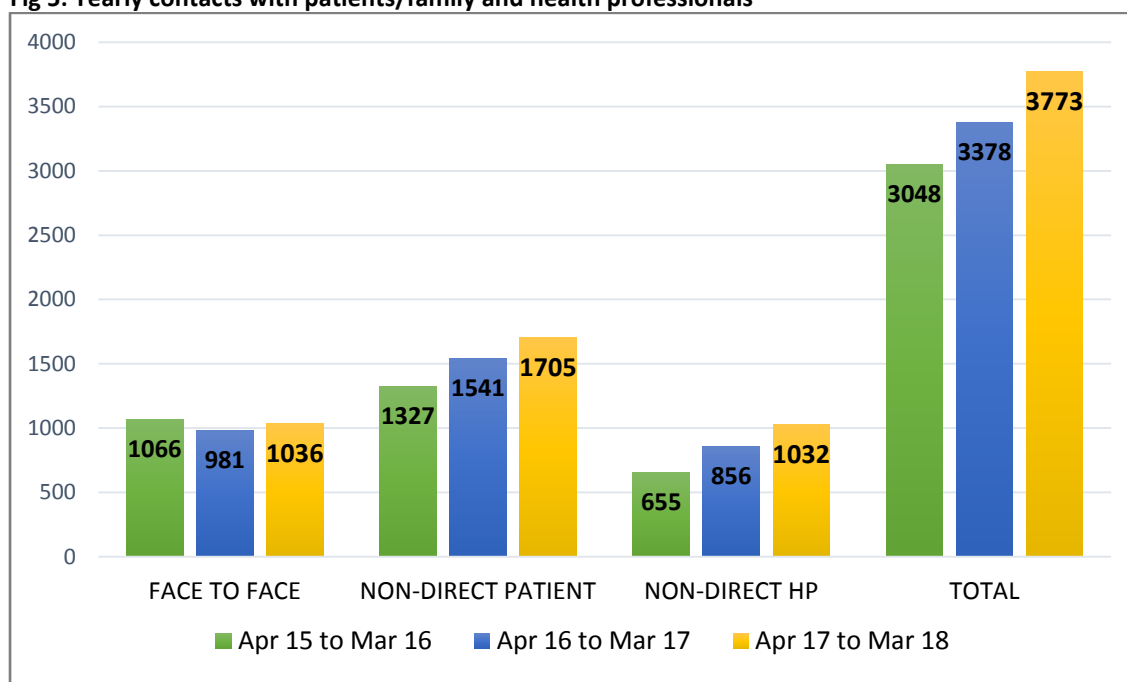
**Fig 4: Non-direct contacts**



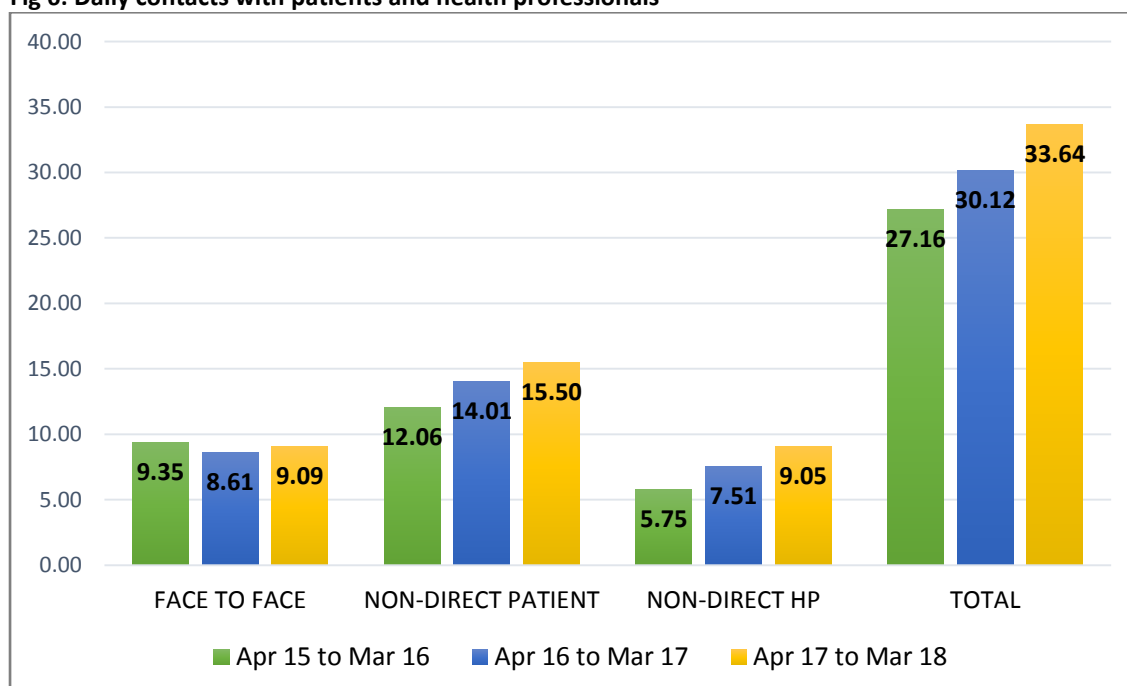
### iii. Summary of service activity

Face to face contacts, non-direct contacts and contacts with other health professionals were combined to obtain an estimate of the overall level of service activity between April 2015 and March 2018 (Fig 5). The data suggests an increase in workload. A 24% increase in contacts over the three year period was recorded, which equates to a rise from 27 to 34 contacts per day (Fig 6). As described above, the growth relates primarily to the non-direct activity, as face to face contacts appear to be stable. If this trend persists, there may be implications for service staff, for service delivery, and for those the service is intended to support. For example, continuation of this trend, in the absence of any staff growth, could increase workload pressure which might compromise the quality of care received by patients at weekends and bank holidays. With time, this might annul the benefits the service was set out to achieve and could negatively impact on staff wellbeing. Appendix 4 gives additional details of the variation of weekend workload.

**Fig 5: Yearly contacts with patients/family and health professionals**



**Fig 6: Daily contacts with patients and health professionals**



#### iv. Facilitated/rapid discharges to homes and transfer to hospice

The community team indicated instances where they facilitated transfer of patients from hospital back to the community. Similarly, the hospital team indicated assisting transfer from hospital to hospice or to a specialist oncology unit. Instances of transfers recorded were few, which suggests this is not a primary function of the service.

#### v. Number of avoidable admissions

As part of routine recording, the community CNSs were asked to give an estimation of the number of probable acute hospital admissions avoided. It is difficult to estimate the number of admissions that might have been avoided due to the service intervention, so it came as no surprise that the two sites produced very different estimates. As a result, the data could not be collated together. Nonetheless, we can use the lower estimates to have an appreciation of how the service might have impacted on acute admissions avoidance. This has important implications for both patients' health and wellbeing and the impact on use of hospital beds. For example, the data provided from one of the community sites which serves an average of 800 patients per year, suggested that an average of 21 hospital admissions per year could have been avoided. Based on a maximum expected length of stay, non-elective inpatient cost is estimated at £1,603 per patient<sup>16</sup>. This would equate to a saving of around £33,000 a year in hospital admissions whilst ensuring that the patients can remain in their home or other preferred place of residence.

### c. Service user characteristics

This section describes the contextual characteristics of those using the service.

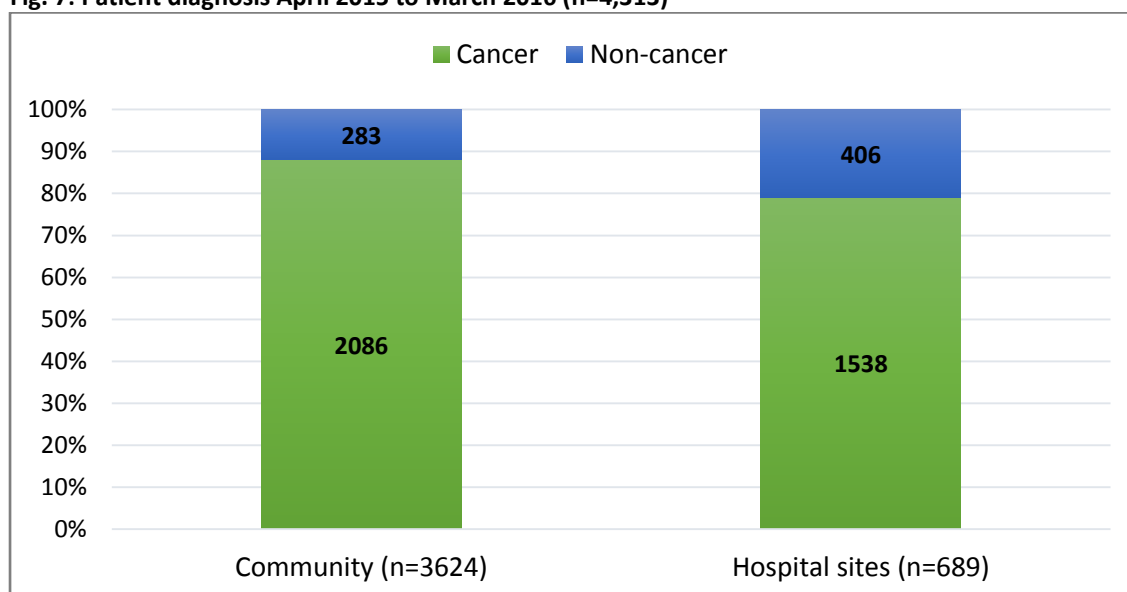
#### i. Patient location

All the available data showed 94% of the patients seen by the community CNSs lived in their own home. Only 5% lived in the nursing homes, and a handful were located in residential care homes, acute and community hospitals. Similarly, only 2% of the patients followed by the hospital CNSs were based in a community hospital. Therefore, the service most commonly supported District General Hospital patients.

#### ii. Patient diagnosis

The data on complete cases were only available for 1 year, April 2015 to March 2016. The data suggests that nine in 10 referrals to the community CNSs were cancer patients. This number reduces to eight in 10 for the hospital setting (Fig 7). It is important to note that whilst cancer was recorded as the patient diagnosis, a proportion will have had comorbidities.

**Fig. 7: Patient diagnosis April 2015 to March 2016 (n=4,313)**



### iii. Source of referral

Source of referral relates to the origin of referrals to the weekends/bank holiday service. Data on source of referral were collected for different time windows by different sites. All the available data showed the majority of referrals recorded by the community CNSs (72%) were made by the SPC teams. Patients and families (19%) and community health professionals (6%) were the main other contributors to referrals to the community-based CNSs. Hospital CNSs collected data only on referrals from acute care professionals and community care professionals. These accounted for 78% and 22% percent of recorded referrals respectively.

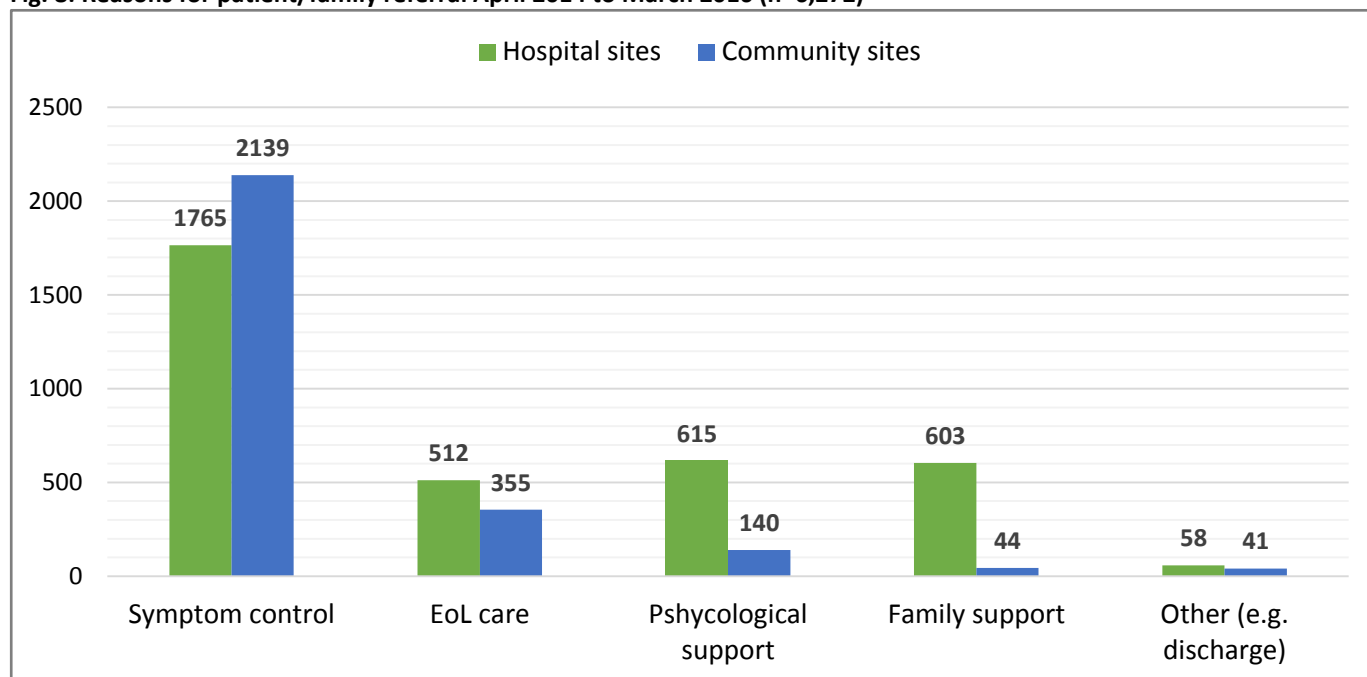
### iv. Reason for referral

#### *Support to patients and families*

Complete data on reason for patient/family referral was only available for two financial years (April 2014 to March 2016). The data is presented in Fig 8. Please note that CNSs might have attended to more than one aspect of a patient's and family's needs and may have recorded multiple activities (e.g. symptom control and psychological support) whilst some might have only recorded the main reason for referral (e.g. symptom control).

The data shows that symptom control was most recorded as the reason for referral in both settings. End of Life care was the second most recorded reason for referral in the community. Psychosocial and family support was more commonly recorded as a reason for referral in the hospital setting.

**Fig. 8: Reasons for patient/family referral April 2014 to March 2016 (n=6,272)**



#### *Support to staff*

The hospital CNSs recorded data where the reason for referral was staff support. Complete data was only available for one financial year (April 2015 to March 2016). The annual total of referrals for the purpose of hospital staff support was 803 which gives a monthly average of 67. This is an indication of the level of specialist support that hospital-based CNSs are providing to ward staff at weekends and bank holidays. In future, it may be useful to collect data on staff outcomes to evidence the impact of the service on other health professionals.

#### d. Quantitative data conclusion

The retrospective observational study has succeeded in its aim to identify the key activities recorded by the service, to study new referrals to the service and provide an indication of how workload might change over time.

The data clearly suggest an increase of activity across the service as a whole. The current data captured by the service does not include any specific data needed to show the impact of the intervention on patients and family outcomes. However, the number of new referrals and unplanned reviews can, to some extent, be linked to better health and wellbeing for service users. Similarly, in the hospital setting, the high numbers of face to face reviews suggests patients and families benefit from individualised care and support.

On average, the service supports 255 new and unplanned referrals each year. By acting as the first port of call for those needing urgent specialist support, the service has the potential to avoid patient crises which could otherwise turn into costly A&E attendances and inpatient admissions. The number of people who require palliative care steadily grows and, as result, the demand on treatment services is set to increase. From an economic perspective, it is important to bear in mind that the allocation of resources towards one initiative imposes sacrifices measured by the benefits forgone by the alternative uses of those resources (i.e. opportunity cost). It is therefore important to evidence the impact of the service. Hence in future, it would be useful to routinely collect data on patients' and family outcomes. Impact of staff receiving CNS support may also prove valuable.

### 10. Review conclusion

The extension of the service from five to seven days has facilitated specialist support to those most in need of it seven days a week. Recording and reporting of patient and family outcomes is now required to show the true value of the service through their eyes. Cancer patients do represent the majority of people referred to the service, ensuring accessibility for those with other illnesses is therefore important.

The unification of three service providers has offered a level of flexibility and complexity to service delivery. Analysis of the service activity data clearly suggests whole service growth; however, activity does not automatically translate into increased efficiency and effectiveness. If this growth persists in the absence of system and process improvements and/or staff growth, there may be future implications for the wellbeing of staff and for those the service is intended to support.

The CNSs' commitment to best care for patients and families shone through during the review. The challenges of the role were also brought into sharp focus. The levels of staff stress and the impact of lone working on CNSs must be recognised and improvement strategies should be explored.

Gaps in seven day working in the wider health and care provision clearly impact on CNS activity. A high level of CNS good will is evident and without it, patients' quality of life would suffer. Inevitably, time spent on work outside the CNS remit reduces the time available to carry out tasks within it. Accordingly, whilst CNS prescribing was strongly advocated by staff as a means to prevent symptom management delays for patients, a wider health care system solution may be needed.

Staff perspectives on the strengths and limitations of the evolved service and improvement suggestions have been clearly communicated through this report. Actions are now needed to support the next phase of service evolution. Consideration of opportunity costs to the weekday service should be integral to any plans for service change.

## 11. Review Recommendations

Implications for practice have been identified through the review. The following recommendations for consideration aim to support future service sustainability and development. An action research approach to some of the recommendations may help to identify the advantages and opportunity costs to the service and its beneficiaries.

Through tri-organisational collaboration:

1. Develop and widely disseminate a clearly defined core offer, which describes the aims and objectives of the service, who can benefit from it, and how to access it, giving consideration to equity of access.
2. Agree the minimum dataset needed for reporting on service activity, giving consideration to the most appropriate outcomes to assess service impact, effectiveness, and cost effectiveness, ensuring the time cost of recording is proportionate to the reason for it.
3. Identify mechanisms for gathering and reporting patient/family and staff service user outcomes for the weekend/bank holiday service. Their views on how to improve the service may also be valuable.
4. Review systems and processes to optimise inter-organisation communication and information sharing including, appraisal of referral/handover documentation, and assessment of the feasibility and resource implications of the routine digital recording of patient contacts by all three SPC providers.
5. Consider ways to reduce the burden of lone working and workload on staff wellbeing and safety, including process/system change and/or increased staffing.
6. Investigate how the burden of call management on staff could be lessened, including increased staffing and/or utilisation of resources outside the CNS team.
7. Consider ways to reduce travel inefficiency, including the potential revision of the geographic remit of community staff and/or peripatetic working across settings.
8. Assess the cost and efficiency benefits of increased computer/remote device access for CNSs at weekends.
9. Review the CNS training portfolio giving consideration to the feasibility and potential risks and benefits of introducing patient assessment training and CNSs prescribing.
10. Instigate discussion with relevant parties regarding the impact of out of hours prescribing delays on patient wellbeing and the need to identify ways to overcome this challenge.

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## 13. Appendix

### Appendix 1: Staff survey questions

# Clinical Nurse Specialist Staff Survey: Weekend and Bank Holiday Specialist Palliative Care CNS Service Evaluation.

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## Page 1: About the survey

**Background:** In response to NICE recommendations that supportive and palliative care services for adults should include seven-day face-to-face contact; a seven day service was introduced in 2011 in the Cardiff and Vale University Health Board region. Delivered by Clinical Nurse Specialists (CNS), the service extended the 5 day Monday to Friday service to include 9am -5pm on weekends and bank holidays.

Cardiff and Vale University Health Board, in collaboration with the Marie Curie Palliative Care Research Centre, are undertaking an evaluation of the Specialist Palliative Care CNS service.

**Purpose:** We are undertaking a survey to explore the views of CNS staff employed to deliver the service to help identify what aspects of the service work well, what the challenges are and to identify improvement opportunities. The survey results will also help to inform face-to-face discussions with a subset of CNS's, alongside a review of service models in other parts of the UK.

**Results:** The survey results will be published in an evaluation report alongside information taken from interviews and routinely collected service data in autumn 2018. This information will be used to help inform the future development and sustainability of the service.

## Page 2: Instructions for completion

- This survey contains 14 questions and should take around 20 minutes to complete.
- It should be completed by Clinical Nurse Specialists that are currently employed to work weekends and bank holidays as part of the seven day Specialist Palliative Care Service for the Cardiff and Vale University Health Board Region only.
- Please add comments in the free text boxes that you feel are relevant or important. This is your chance to share your views and experiences about the service in your own words. Please also include comments where you feel an area of importance has not been addressed, or where you feel additional or alternative questions would be appropriate.
- The survey can be completed in more than one sitting if required by clicking the '**finish later**' link at the bottom of the page. You will be taken to a page giving the survey's closing date and a 'finish later' URL. You can either bookmark your unique URL in your browser, or ask for it to be emailed to you. Without this, you cannot return to your part completed survey.
- You can navigate the survey and edit answers up to the point you click the '**finish survey**' button.

If you have any questions relating to this survey or the service evaluation, please email Alisha Newman, Research Associate at [newmana3@cardiff.ac.uk](mailto:newmana3@cardiff.ac.uk) or call 029 20687948.

**Thank you** for supporting the evaluation of the weekend and bank holiday service by completing this survey today.

## Page 3: Consent to participate

**Voluntary participation:** Participation in this survey is voluntary and you may choose not to answer some or any of the survey questions.

**Confidentiality:** The full survey results will be seen by Marie Curie Research Centre staff only, who are undertaking part of the evaluation on behalf of the Cardiff and Vale University Health Board Palliative Care Service and the All Wales End of Life Board. The survey does not ask for your name or employer information that might identify you. Any other information you share that might identify you or others will be anonymised.

**Data protection and usage:** For the purposes of this survey Cardiff University is the data controller. All data collected in this survey will be held securely by the survey software provider (Jisc) under contract and then retained by the Marie Curie Palliative Care Research Centre at Cardiff University in accordance with the General Data Protection Regulations (2018). Cookies, personal data stored by your Web browser, are not used in this survey.

By participating in this survey, you are agreeing that we can include your survey responses and anonymised extracts of text in future reports. They may also be published in professional journals, presented at professional conferences and in educational settings. The survey data may be used for future research.

**Risks & benefits:** When using the internet, there can be a risk of compromising privacy, confidentiality and/or anonymity. We have taken the precaution of using Online surveys (formerly Bristol Online Survey) to minimise this risk.

By participating in this survey you have the opportunity to share your opinions and experiences to influence the future development and sustainability of the Cardiff and Vale University Health Board CNS Palliative Care Service.

**Contact information:** To ask a question about this survey or the service evaluation, please email Alisha Newman, Research Associate at [newmana3@cardiff.ac.uk](mailto:newmana3@cardiff.ac.uk) or call 029 20687948.

**Consent:** By agreeing to participate in this survey, you imply that you have read and understood the information above and that you are aged 18 or over.

---

1. Do you agree to participate in this survey? \* Required

☐ Yes

☐ No

## Page 4: Setting and length of service

2. In which setting do you currently deliver the specialist palliative care service on weekends and bank holidays? \* *Required*

- ☐ Hospital
- ☐ Community

3. How long have you been part of the CNS team delivering the weekend and bank holiday specialist palliative care service?

- ☐ Less than 1 year
- ☐ 1 to 3 years
- ☐ 4 to 5 years
- ☐ 6 or more years

## Page 5: Service demands

4. Do you feel the demands of the CNS role on weekends/bank holidays have changed over the period you have been working?

- ☐ Yes
- ☐ No
- ☐ Don't know

4.a. Please explain why you have chosen the option above. Please give examples if it will help you to illustrate your point. There is no word limit.



5. Are you able to complete the weekend/bank holiday workload within your contracted hours?

- ☐ Always (100% of the time)
- ☐ Almost always (about 90% of the time)
- ☐ Often (about 70% of the time)

- ☐ Half the time (about 50% of the time)
- ☐ Sometimes (about 30% of the time)
- ☐ Hardly ever (about 10% of the time)
- ☐ Never (0% of the time)


5.a. Please explain why you have chosen the option above. Please give examples if it will help you to illustrate your point. There is no word limit.

6. During a weekend/bank holiday shift, do you ever undertake work that is outside your remit as CNS in order to support patients or their carers?

- ☐ Always (100% of the time)
- ☐ Almost always (about 90% of the time)
- ☐ Often (about 70% of the time)
- ☐ Half the time (about 50% of the time)
- ☐ Sometimes (about 30% of the time)
- ☐ Hardly ever (about 10% of the time)

☐ Never (0% of the time)

6.a. Please explain why you have chosen the option above. If you do undertake work outside your remit as CNS during a weekend/bank holiday shift to support patients or their carers, please give some examples of the things you do.

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## Page 6: Staff skills, knowledge, experience and support

7. Do you feel you have all the necessary clinical skills, knowledge and experience required to deal with the cases you encounter on weekends/bank holidays? Please give examples if it will help you to illustrate your point. There is no word limit.



8. Do you feel able to access appropriate clinical advice and support during weekends/bank holidays if needed?

- ☐ Always (100% of the time)
- ☐ Almost always (about 90% of the time)
- ☐ Often (about 70% of the time)
- ☐ Half the time (about 50% of the time)
- ☐ Sometimes (about 30% of the time)
- ☐ Hardly ever (about 10% of the time)
- ☐ Never (0% of the time)

8.a. Please explain why you have chosen the option above. Please give examples if it will help you to illustrate your point. There is no word limit.

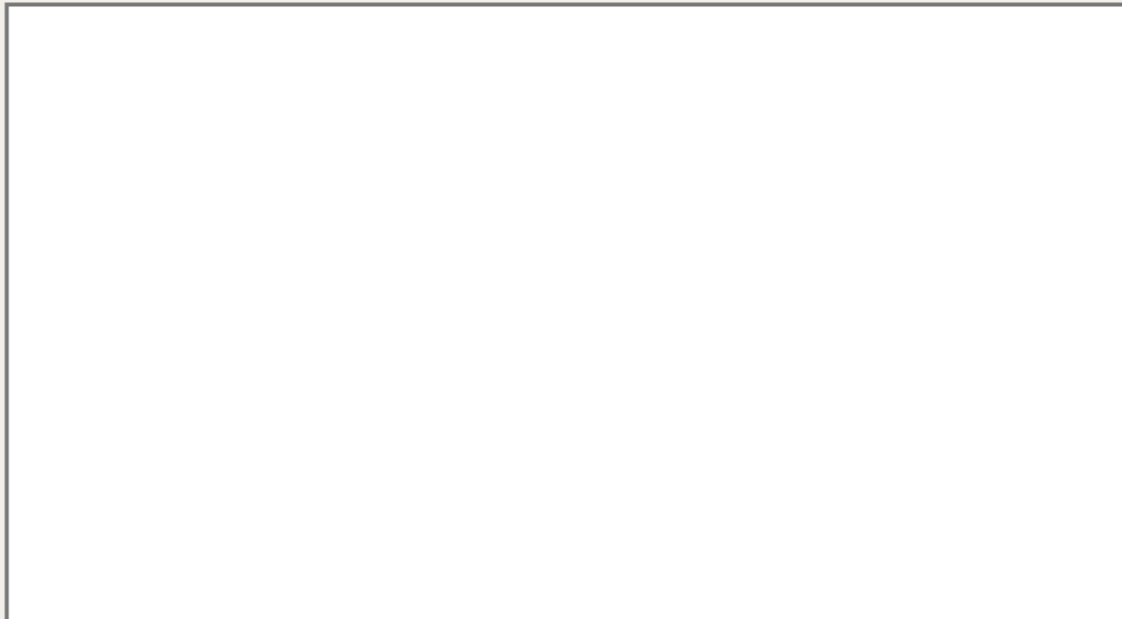
A large, empty rectangular box with a thin black border, intended for the user to provide an explanation and examples. The box is centered below the question and occupies a significant portion of the page.

## Page 7: Service efficiency, equity and impact

9. Do you feel that the service is delivered efficiently on weekends/bank holidays? I.e. achieves maximum benefit to patients/families with minimum wasted effort, time or expense?

- ☐ Always (100% of the time)
- ☐ Almost always (about 90% of the time)
- ☐ Often (about 70% of the time)
- ☐ Half the time (about 50% of the time)
- ☐ Sometimes (about 30% of the time)
- ☐ Hardly ever (about 10% of the time)
- ☐ Never (0% of the time)

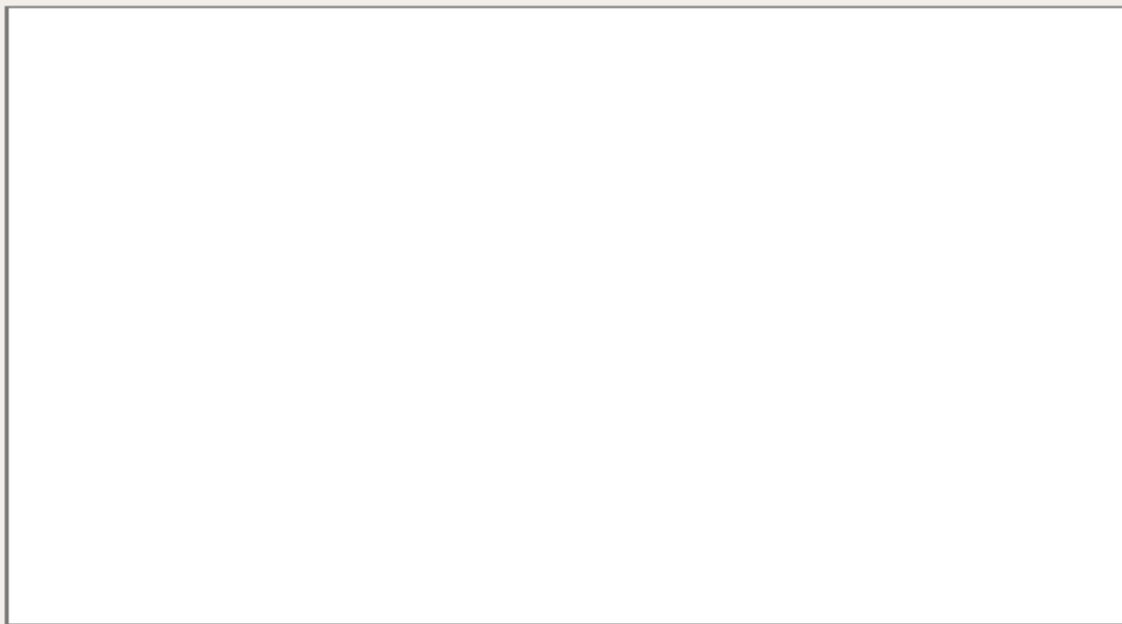
9.a. Please explain why you have chosen the option above. Please give examples if it will help you to illustrate your point. There is no word limit.



10. Do you feel the weekend and bank holiday service has an impact on the weekday service?

- ☐ Yes
- ☐ No
- ☐ Don't Know

10.a. Please explain why you have chosen the option above. Please give examples if it will help you to illustrate your point. There is no word limit.



11. Do you feel the service is equitable? I.e. delivered in a way that gives equal access to everyone identified as needing weekend/bank holiday support?

- ☐ Always (100% of the time)
- ☐ Almost always (about 90% of the time)
- ☐ Often (about 70% of the time)
- ☐ Half the time (about 50% of the time)
- ☐ Sometimes (about 30% of the time)
- ☐ Hardly ever (about 10% of the time)
- ☐ Never (0% of the time)

**11.a.** Please explain why you have chosen the option above. Please give examples if it will help you to illustrate your point. There is no word limit.

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## Page 8: Service strengths and improvements

12. What aspects of the weekend/bank holiday service work well, what are the strengths and successes of the service?

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13. What aspects of the weekend/bank holiday service could be improved and how might these improvements be achieved?



**14.** Is there anything else you would like to share about the delivery of the weekend/bank holiday specialist palliative care CNS service? This may include topics you feel are important but haven't been addressed through the survey, or alternative questions you think we should have asked.



## Page 9: Thank you

**Thank you** for sharing your views and experiences through this survey, your answers have been submitted.

As part of the service evaluation, the Marie Curie Palliative Care Research Centre hopes to interview six CNSs about their experiences.

If you'd like more information about the interviews, or have any questions about the survey or evaluation please contact Alisha Newman, Research Associate by email: [newmana3@cardiff.ac.uk](mailto:newmana3@cardiff.ac.uk) or call 02920687948.

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## Appendix 2: Interview topic guide

Interview aim: to explore key topics and gaps identified in the survey, differences between the weekday and weekend/bank holiday service. What works well and improvement opportunities.

For ease of speech, the weekend and bank holiday service will be described as the Out of Hours (OOH) service.

### 1. Background

Aim: To get an idea of interviewees nursing history generally and their experience of working at the SPC service being evaluated specifically.

- a) I'm interested to know how long you've been nursing.
- b) Have you been a specialist palliative care nurse for long?
- c) Do you have any extra relevant skills to palliative care?
- d) How long have you been in this job?
- e) When did you start doing the OOH shifts?

### 2. Service comparison

Aim: to discover if/how different the OOH/weekday services are and what the differences are from interviewee perspective.

- a) In your opinion, what do you think are the key similarities and differences between the OOH and weekday service? (*Note - Service > Patients & families > Staff*)
- b) You mentioned (.....) can you tell me more about that?

### 3. Caseload management and referrals

Aim: To get an understanding how patients are identified, whether this process is effective and how it might be improved. To understand if/how unplanned caseload impacts on planned work. Identify positives of current practice and improvement opportunities.

#### *Planned caseload*

- a) As I understand it, at the start of an OOH shift you have a planned caseload of patients on a list, how are the patients that go on the list identified?
- b) What do you think are the key similarities and differences OOHs compared to week days?
- c) What do you think works well about this process?
- d) Is there anything that could be better about this process?
- e) In your view, do you get any inappropriate referrals on the list? What & why?
- f) Do you have any suggestions for improvement?

#### *Unplanned Caseload*

- g) Can you tell me how you manage the unplanned calls and requests for support coming in alongside your existing patient list?
- h) What do you think works well about this process?
- i) Is there anything that could be better about this process?
- j) Do you have any suggestions for improvement?

### 4. Travel across hospital sites and the CVUHB region

Aim: to understand if/how the greater number of hospitals/geographic area covered during an OOH shift makes a difference when compared to the weekdays. Identify positives of current practice and improvement opportunities.

- a) Can you tell me about the similarities and differences in the area you cover OOH compared to week days?  
(Note – acute/community hospital functions the same?).
- b) What are the positives in relation to the area you cover OOH?
- c) Is there anything that could be better in relation to the area you cover OOH??
- d) Do you have any suggestions for improvement?

## 5. Service equity

Aim: To find out if interviewees believe access to the service is equitable OOH. To find out if there is parity of support OOH and weekdays.

### *Equity of access to referred patients*

- a) Do you feel everyone referred for OOH support gets equal access to the service?
- b) What is good about patients/families access to the OOH service?
- c) Is there anything that could be better about patients/families access to the OOH service?
- d) Do you have any suggestions for improvement?

### *Parity of support OOH/weekdays*

- e) Do you feel the patients/families seen by the OOHs service receive the same SP care and support OOH as they would if they presented with the same support needs on a weekday?
- f) What are the positives about the SPC support given by your team OOH?
- g) Is there anything that could be better about the SPC support given by your team OOH?
- h) Do you have any suggestions for improvement?

## 6. Access to patient records

Aim: To get an understanding of how records are accessed, if and how access is different OOH. Identify positives of current practice and improvement opportunities.

- a) Can you tell me about how you access patient records during an OOH shift?
- b) What do you think are the key similarities and differences OOHs compared to week days?
- c) What are the positives of the way you currently access records?
- d) What could be better about access to records?
- e) Do you have any suggestions for improvement?

## 7. Allied services

Aim: to discover if/how support from allied health and social care services is different OOH to weekdays from interviewee perspective. To understand if the SPC offered to allied services is different OOH. Identify positives of current practice and improvement opportunities.

### *Allied services support for SPC team*

- a) Do you get the same support from other health and social care professionals OOHs as you do on a weekday?
- b) What do you think are the key similarities and differences OOHs compared to week days?
- c) What are the positives in relation to allied service support OOH?
- d) Is there anything that could be better in relation to allied services support OOH?
- e) Do you have any suggestions for improvement?

### *Support for allied staff from the SPC Team*

- f) Is the SPC support available to other health and social care professionals the same OOH as it is on a weekday?
- g) What do you think are the key similarities and differences OOHs compared to week days?
- h) What are the positives in relation to the SPC support offered to other H&SC professionals OOH?
- i) Is there anything that could be better in relation to the SPC support available to other H&SC professionals OOH?
- j) Do you have any suggestions for improvement?

#### *Community SPC /hospital SPC cross collaboration*

- a) Do you interact with the hospital/community SPC team much during OOHs shifts?
- b) What do you think are the key similarities and differences between week days and OOHs interactions?
- c) What works well?
- d) Could anything be better?
- e) Do you have any suggestions for improvement?

### **8. Prescribing, medication and equipment**

Aim: to find out what processes are involved in accessing prescriptions, medications and equipment OOH, if it's different to weekdays and how. Positives of current practice and improvement opportunities.

#### *Prescriptions*

- a) Can you tell me how prescriptions are handled during an OOH shift?
- b) What do you think are the key similarities and differences OOHs compared to week days?
- c) What currently works well?
- d) Is there anything that could be better?
- e) Do you have any suggestions for improvement?

#### *Medication*

- f) Can you tell me about access to medication OOH?
- g) What do you think are the key similarities and differences OOHs compared to week days?
- h) What currently works well?
- i) Is there anything that could be better?
- j) Do you have any suggestions for improvement?

#### *Equipment*

- k) Can you tell me about access to equipment OOH? (*Note- syringe drivers, beds, commodes etc.*)
- l) What do you think are the key similarities and differences OOHs compared to week days?
- m) What currently works well?
- n) Is there anything that could be better?
- o) Do you have any suggestions for improvement?

### **9. SPC Service staffing**

Aim: To discover if staffing levels are thought to be adequate for the OOH caseload. Identify positives of current practice and improvement opportunities.

- a) Can you tell me about SPC staffing levels OOH?
- b) What are the key similarities and differences OOHs compared to week days?

- c) What are the positives of the current OOH staffing levels?
- d) Is there anything that could be better in relation to OOH staffing levels?
- e) Do you have any suggestions for improvement?

*Note: if suggest extra staff:*

- Do you have any experience of different models of OOH care?
- Would the extra staff need to be CNS or could other skills/role be valuable in supporting patients and families/CNS?

#### **10. Compensatory rest and pay**

Aim: To get an understanding of the compensatory arrangements for weekend working, if the interviewee is satisfied with this arrangement or would they prefer something different. If so, what?

- a) When you've worked a weekend or bank holiday, what are the arrangements for taking time back? *(Note - Time and money?)*
- b) What works well about this arrangement?
- c) Is there anything that could be better?
- d) Do you have any suggestions for improvement?
- e) Does this arrangement impact on the weekday service? If so, How?
- f) Do you have any suggestions for improvement?

#### **11. Relationships**

Aim: To find out what relationships are like OOHs, are they different to weekdays and how. The positives about OOHs relationships and where things could be better.

- a) Can you tell me about the relationships you have with the patients and families you see and the people you work with OOH?
- b) What are the key similarities and differences OOHs compared to week days?
- c) What is good about your relationships OOH?
- d) Is there anything that could be better?
- e) Do you have any suggestions for improvement?

#### **12. Strengths and limitations**

Aim: to identify key strengths of the service and priorities for improvement

- a) Overall, what do you think are the key strengths of the service and why?
- b) Which areas do you think should be made a priority for improvement and why?

#### **13. Other service models**

Aim: to identify other service models/ways of working that could inform the approach to OOH SPC service delivery in the future.

- a) Do you have any knowledge or experience of other OOH service models or ways of working that we could learn from or might be adapted for use for the OOH SPC service?

#### **14. Close**

- a) Is there anything else you'd like to say?





**THANK YOU**


## Appendix 3: Retrospective observational study methodology

### a. Data collection time window

Table 6 lists the time window of available data from each site. The time window of data varied from a minimum of 33 months to 54 months. In order to gain a better understanding of any underlying pattern of activity level, some data were imputed, these are presented by the grey area.

**Table 6: Time window of recorded data**

	2014	2015	2016	2017	2018	2019	Months of data (imputed)
Site 1							61 (7)
Site 2							39 (6)
Site 3							48 (0)
Site 4							48 (0)

 Imputed time window

The areas in grey indicate missing data which were imputed to ease the analyses, details are given in the section on data accuracy, data inconsistency and missing data.

### b. Data capture

Table 7 lists the information recorded by the community palliative care providers and analysed for this report. The data collections forms were designed to enable staff to collect key aspects of palliative care activity such as patients newly referred, direct (face to face) and non-direct (i.e. telephone/pager) contact with the patients. In addition to this, contextual information about the patients, such as patient's location and diagnosis, were also recorded.

**Table 7: Items recorded from the two community sites**

Items recorded	Site 1	Site 2*
<b>Patient-related activity</b>		
Number of patients newly referred to team	✓	✓
Number of patients already known to team (i.e. follow ups)	✓	
Number of direct contacts patient/relative (i.e. face to face contact)	✓	✓
Number of indirect contacts patient/relative (e.g. telephone contact)	✓	✓
Number of indirect contacts with health professionals	✓	
<b>Source of referral</b>		
Patient / Relative	✓	
Family/ Lay Carer	✓	
Community Care Professional	✓	
Acute Care Professional	✓	
Specialist Palliative Care	✓	
Other	✓	
<b>Patient location</b>		
Own Home	✓	✓
Nursing Care Home	✓	✓
Residential Care Home	✓	✓
Acute Hospital	✓	✓
Community Hospital	✓	✓
Hospice	✓	✓
Other	✓	✓
<b>Reason for referral</b>		
Pain & Symptom Management	✓	
Psychosocial Support	✓	
Last Days of Life	✓	

	Family	✓	
	Other	✓	
<b>Diagnosis</b>			
	Cancer	✓	✓
	Non cancer	✓	✓
Community Patients		✓	
Number of probable acute hospital admission avoidances as assessed by the SPC CNS		✓	
HOSPITAL PATIENTS		✓	
Number of facilitated/rapid discharges to home/ other care setting		✓	

**\*Items collected from site 2 since August 2017**

Up to August 2017 both community sites collected the same data, however, starting from August 2017 one of the two community sites focused recording on fewer items; these are identified in the last row of table 2.

Table 8 lists the items recorded by the hospital-based service. The two sites (one service) collected the same data and this broadly matched the data collected by the community-based services. However, starting from April 2016, the two hospital sites changed the data capture; these sites stopped collecting a few items and introduced the collection of new items.

**Table 8: Items recorded by the two hospital sites**

Items	Site 3 and site 4*	Site 3 and site 4**
<b>Patient-related activity</b>		
New referrals	✓	✓
Unplanned reviews	✓	✓
Non-direct contact with patient/relative	✓	✓
Face to face contact with patient/relative	✓	✓
One off advice	✓	
Discharge	✓	
Hospice transfer	✓	
RIP	✓	
New Referral seen		✓
Advice only		✓
Unmet demand		✓
Planned allocation (i.e. follow up)		✓
Pager		✓
<b>Reason for referral</b>		
Symptom management	✓	
End of life	✓	
Psychosocial	✓	
Family support	✓	
<b>Diagnosis</b>		
Cancer	✓	
Non cancer	✓	
Staff support	✓	
Source of referral	✓	
Acute hospital	✓	
Community hospital	✓	
Discharge	✓	
Hospice transfer	✓	
Unmet demand		✓

**\*Data collected until December 2015**

**\*\*Data collected from April 2016**

**c. Taxonomy used across sites**

From tables 7 and 8 it emerged that, for some of the items, community and hospital sites adopted a different taxonomy. The Lead Nurse for the CVUHB SPC service worked with the service managers of City Hospice and Marie Curie to identify the items which shared the same meaning. Following this, data could be added across sites. These items are listed in the Table 9. Some of the

items could not be matched because they reflected site-specific activity, for example, discharge would apply to the hospital setting only.

**Table 9: Matching between taxonomy used across the sites**

Community data	Hospital data
Number of pts already known to the team	Planned allocation (patients identified prior to weekend for review)
Number of direct contacts pt/relative	Face to face reviews(patients assessments)
Number of indirect contacts pt and relative	Non-direct (plus pager)(advise to those caring for pt)
Last days of life	EOL care (advice for pts in last days of life)
Reason for referral (other)	Discharge and transfer to Hospice (negotiating/planning care or transfer)

Unless specifically mentioned, all the data was analysed. When a new identified item could not be combined with other data, it was analysed separately. For instance, “pager” could be added to “non-direct” whereas “unmet demand” could not be added to any other pre-existing variable and it had to be analysed separately.

#### d. Data analysis and presentation

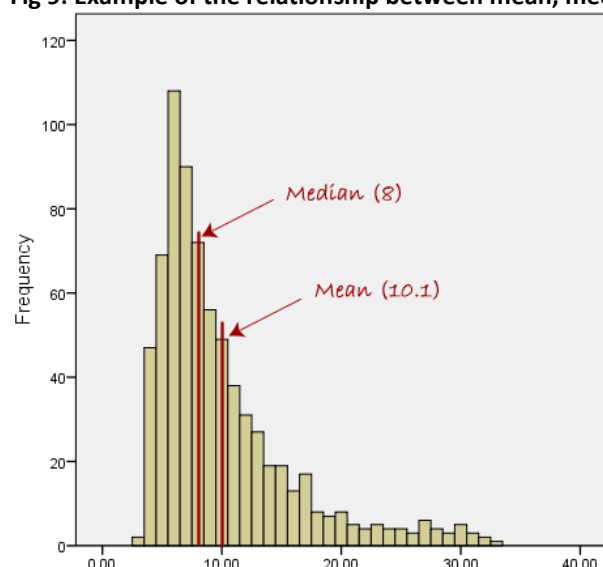
Descriptive statistics was used to analyse the data. The variables listed in tables 7 and 8 were arranged into key groups reflecting:

- 1) Referral process (e.g. number of referrals);
- 2) Service activity (e.g. Number of face to face contacts with patient/family) and ;
- 3) Service user contextual characteristics (e.g. patient location, diagnosis, reasons for referral).

For service activities, yearly statistics were determined. In addition to this, weekend’s data were extracted from each site to determine the mean and the median levels of activity.

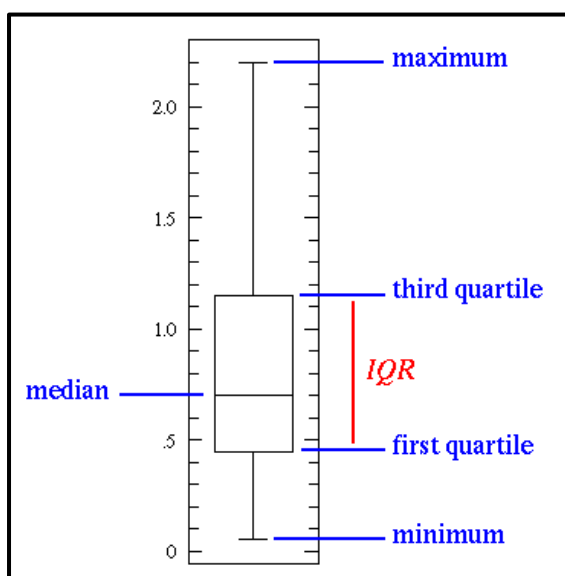
The median represents the middle term of an ordered list of data, it denotes the threshold that separate the 50% highest observations from the 50% lowest (or vice versa). For example, Fig 9 represents a case where mean and median are quite different, this is because the data holds a few extreme values and they increase the mean value. This is a very useful measure of workload.

**Fig 9: Example of the relationship between mean, median and data distribution**



In addition to this, measures of dispersions were calculated, the minimum, the maximum value and the interquartile range were calculated, Fig 10, gives an example.

**Fig 10: Description of dispersion of data around the median**



Maximum and minimum represent the highest and the lowest value for a determined variable whereas the Inter Quartile Range (IQR) includes 50% of the observations. These summary statistics add valuable information for service providers and commissioners because they offer a better picture of how the data is distributed, how workloads over weekends vary and they can be used to identify points of crisis for the service providers.

The rest of the items were mainly presented via proportions, histograms and pie charts as they aimed to reflect the contribution of each part of a categorical variable, for instance the analysis of patients prognosis aimed mainly at assessing the proportion of cancer and non-cancer patients treated across sites and whether these proportions changed over time.

Data was grouped according to the NHS financial year to facilitate statistics comparison which might incorporate changes from one financial year to another.

#### e. Data accuracy, data inconsistency and missing data

Outliers were investigated to identify any typo error. It was not possible to validate the data accuracy against any other data collection mechanism, however, having data that span over several time observations allowed identification of sudden changes in the pattern and assess if these could be reasonably explained.

For some of the items there was no data entered, however, this was not necessarily associated to a missing data; it could reflect the fact that zeros are possible but simply not reported. Table 10 reproduces a section of the data from one site across two weekends. For the variable “number of patients newly referred” the data entries included zeros and non-zero values. As a result, it can be plausible that if the value is not reported it might be a zero. Whereas for “number of direct, face to face contacts” you would expect that at least one patient was seen across the all service. Hence, the unreported value is more likely a reflection of a true missing data.

**Table 10: Example of when missing data were converted into zeros**

Date	Sat	Sun	Sat	Imputation
Number of patients newly referred to team	1	X	3	Assumed Zero
Number of direct, face to face contacts patient / relative	1	2	X	Remaining Missing
Number of indirect / telephone contacts patient/relative	3	6	9	
Number of indirect / telephone contacts	2	8	5	

As described above, in the data collection time window section, time window varied across sites. As a result, in order to maximise the use of the available data the following analysis approaches were used:

1. Data were imputed for site 2 for the data missing from January to March 2016 and 2017 (indicated in grey in Table 1). The missing data were imputed so that data across sites could be added to provide an estimate of activity across all services.
2. In order to appreciate any possible trend, site 1 data were imputed from June 2018 to March 2019.

Data were imputed assuming that the pattern of data did not change between the imputed and the available data window. For instance, when imputing the data from Jan to Mar it was assumed that the data available for the remaining nine months represented the 75% of all the data.

f. **Data captured across sites and over time**

Table 11 describes the days, weekends and bank holiday weekends activity reported by each site. As it can be appreciated from the table both community and hospital sites have a balanced input in terms of working days/weekends across the different time windows. The table also offers an appreciation of the data available for analysis.

**Table 11: Data recorded across sites**

Site		Jan 14 to Mar 14	Apr 14 to Mar 15	Apr 15 to Mar 16	Apr 16 to Mar 17	Apr 17 to Mar 18	Apr 18 to June 18
Site1	Days	12	53	57	60	58	25
	Weekends	6	22	24	26	24	11
	Bank Holiday Weekends	0	3	3	1	3	1
Site2	Days	--	12 <sup>1</sup>	52	38 <sup>2</sup>	39 <sup>3</sup>	--
	Weekends	--	6 <sup>1</sup>	23	15.5 <sup>2</sup>	15 <sup>3</sup>	--
	Bank Holiday	--	0 <sup>1</sup>	2	2 <sup>2</sup>	3 <sup>3</sup>	--
Site3 &4 H	Days	--	111	113	111	115	--
	Weekends	--	46	44	45	47	--
	Bank Holiday Weekends	--	5	7	6	6	--

1. **Data recorded from January 2014 to March 2014**
2. **Data recorded from April 2016 to December 2017**
3. **Data recorded form April 2017 to December 2018**

The sum of the working days carried out at each site would give the total number of days the model of care was delivered per year. For site 2, a complete data sets of working days were only available for the time window April 2015 to March 2016 (see Table 6). However, given the very little change across the different time windows and given that 75% of 52 (9 out of 12 months) is 39, we used 52 days to impute the working days for site 2 for the time windows April 16 to March 17 and April 17 to March 18. By doing this we could estimate the number of days with activity recorded across the three years, these were respectively 334, 334, and 338 (see last row in Table 11).

## Appendix 4: Analysis of variation of weekly workload

In addition to daily averages, it was important to study how workloads varied across weekends. Mean, median, minimum, maximum and Interquartile (IQR) were calculated. Details of these summary statistics for the financial year 2017/18 are reported in Tables 12 to 15 below.

Tables 12 and 13 give an indication of how weekend workload can vary across the community services. CNSs from the community sites had a maximum of 66 and 43 non-direct contacts. In addition to this, 50% of the weekend's workload varied between 12 to 32 and 17 to 26 face to face visits.

In terms of face to face contacts, hospital-based statistics indicate that CNSs carried out as many as 23 face to face contacts over one week-end (Tables 14 and 15). The Inter Quartile Range also tells us that for 50% of the weekends, the CNSs carried out between 5 and 23 face to face contacts and that for 25% of the weekends, the CNSs carried out 15 or more face to face contacts respectively.

**Table 12: Weekends average activity from site 1**

Activity	April 2014 to March 2015	April 2015 to March 2016	April 2016 to March 2017	April 2017 to March 2018
	Mean(min, max) Median (IQR)	Mean(min, max) Median (IQR)	Mean(min, max) Median (IQR)	Mean(min, max) Median (IQR)
New referral & unplanned review	1.24 (0 to 5) 1.00 (0 to 2)	1.85 (0 to 7) 1.00 (0 to 2)	1.39 (0 to 4) 1.00 (0.00 to 2.00)	1.88 (0 to 8) 2.00 (0 to 2.5)
Follow Up	36.14 (5 to 63) 38.00 (27 to 48)	31.00 (8 to 53) 35.00 (17 to 45)	34.50(16 to 50) 33.50 (22.75 to 45.5)	32.42 (13 to 63) 34.00 (20.75 to 47.75)
Face to face contacts	4.12 (1 to 13) 3.00 (2 to 5.5)	4.30 (1 to 9) 4.00 (2 to 7)	4.12 (0 to 8) 4.00 (3 to 5.5)	4.83 (1 to 9) 4.50 (3 to 6.25)
Non-direct contact and pager	23.68 (6 to 39) 23.00 (20 to 27.5)	26.30 (5 to 51) 25.00 (18 to 33)	28.65 (15 to 47) 30.00 (22 to 33)	25.67 (10 to 66) 23.50 (11.75 to 32.25)
Non-direct contact HP	20.08 (7 to 42) 17.00 (13to 26)	18.83 (10 to 36) 17.00 (13 to 23)	21.79 (4 to 45) 20.50 (15.25 to 30)	21.41 (8 to 44) 21.00 (15.50 to 24.5)

**Table 13: Weekends average activity from site 2**

Activity	April 2014 to March 2015	April 2015 to March 2016	April 2016 to March 2017	April 2017 to August 2017
	Mean(min, max) Median (IQR)	Mean(min, max) Median (IQR)	Mean(min, max) Median (IQR)	Mean(min, max) Median (IQR)
New referral & unplanned review	--	0.48 (0 to 5) 0.00 (0 to 0.5)	1.15 (0 to 9) 0.00 (o to 2)	0.57 (0 to 2) 0.00 (0 to1)
Follow Up	--	19.76 (4 to 31) 20.00 (15 to 25.5)	15.70 (0 to 30) 18.00 (8 to 23)	10.86 (3 to 20) 10.00 (9 to 13)
Face to face contacts	--	3.05 (0 to 9) 2.50 (1 to 5)	5.48 (0 to 15) 4.00 (3 to 7)	2.94 (0 to 9) 2.00 (1 to 4)
Non-direct contact and pager	--	19.45 (6 to 32) 19.00 (15.25 to 25.5)	21.33 (0 to 37) 22.00 (16 to 25)	22.06 (7 to 43) 20.00 (17.25 to 26.75)
Non-direct contact HP	--	8.94 (1 to 27) 7.00 (4 to 12.5)	13.96 (0 to 27) 15 (8 to 18)	16.17 (4 to 34) 15.00 (11.25 to 23)

**Table14: Weekends average activities from site 3**

Activity	April 2014 to March 2015	April 2015 to March 2016	April 2016 to March 2017	April 2017 to
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	March 2018			
	Mean(min, max) Median (IQR)	Mean(min, max) Median (IQR)	Mean(min, max) Median (IQR)	Mean(min, max) Median (IQR)
New referral & unplanned review	2.60 (0 to 8) 2.00 (2 to 4)	3.77 (0 to13) 3.00 (2 to 5)	2.63 (0 to 6) 2.00 (1 to 3)	2.46 (0 to 6) 2.00 (1 to 3)
Follow Up	--	--	13.54 (3 to 21) 13.00 (11 to 17.50)	11.84 (5 to 21) 11.00 (10 to 15)
Face to face contacts	10.96 (4 to 17) 11.00 (8 to 14)	11.81 (4 to 19) 12.00 (9 to 14)	13.59 (3 to 26) 14.00 (10.50 to 17)	12.70 (5 to 23) 12.00 (10.25 to 15.00)
Non-direct contact and pager	1.77 (0 to 5) 1.50 (0.25 to 3)	2.00 (0 to 9) 1.00 (1 to 2)	6.22 (0 to 12) 5.00 (4 to 9)	5.46 (0 to 15) 5.00 ( 3 to 7.75)

**Table 15: Weekends average activity from site 4**

Activity	April 2014 to March 2015	April 2015 to March 2016	April 2016 to March 2017	April 2017 to March 2018
	Mean(min, max) Median (IQR)	Mean(min, max) Median (IQR)	Mean(min, max) Median (IQR)	Mean(min, max) Median (IQR)
New referral & unplanned review	0.60 (0 to 4) 0.00 (0 to 1)	1.28 (0 to 7) 1.00 (0 to 2)	0.30 (0 to 3) 0.00 (0.00 to 0.00)	0.44 (0 to 2) 0.00 (0 to 1)
Follow Up	--	--	3.37(0 to 7) 4.00 (2 to 5)	4.03 (0 to 15) 3.00 (2 to6)
Face to face contacts	4.12 (1 to 9) 4.00 (2 to 6)	4.89 (1 to 12) 5.00 (3 to 6.75)	3.00 (0 to 8) 3.00 (1 to 5)	3.21 (0 to 16) 2.00 (1 to 5)
Non-direct contact and pager	1.03 (0 to 4) 1.00 (0 to 1.5)	1.11 (0 to 4) 1.00 (0 to 2)	1.52 (0 to 4) 1.00 (1 to 2)	1.94 (0 to 5) 2.00 (1 to 3)

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