

Health Scrutiny Committee Review of End of Life/ Palliative Care Services

Recommendation Implementation

	Recommendation	Who sent to/ leading on response	Response	Progress (as at October 2016)
1	It is recommended that Nottingham City Clinical Commissioning Group ensures that all GP practices are aware of the need for and importance of their involvement in palliative/end of life care and the importance of using EpaCCs to ensure that all relevant details are recorded in relation to each individual patient.	Nottingham City Clinical Commissioning Group	<p>Accepted</p> <p>End of Life Care nurses already attend GP practice Gold Standard Framework meetings to help identify patients with End of Life care needs and to encourage and support practices in the recording of these patients on EPaCCS. They also explain the patient benefits of using the system.</p> <p>The CCG receives monthly reporting on EPaCCS usage at practice level. The reports show that the number of EPaCCS records is continually increasing and that there are 624 active referrals, or 21% of people who die in Nottingham City annually. They also show a wide variation in system usage across practices.</p> <p>The CCG will use one of its Macmillan funded GPs to support practices who are identified as low users of EPaCCS. It will monitor improvements in system uptake through the existing monthly reports.</p>	<ul style="list-style-type: none"> • All Nottingham City CCG practices have received an email highlighting the inter-practice variation in the use of EPaCCS, a reminder that practices should expect to have between about 0.8 and 1.0% of its registered population recorded on EPaCCS, and the advantages to the patient in terms of continuity of care of being recorded on EPaCCS. • Practices have been directed to the EPaCCS project team if they having any training requirements. • Practices have been sent their EPaCCS usage information along with all the other City practices so they can compare their performance with their peers. This will be repeated on a quarterly basis. • Practice usage of EPaCCS has been part of the 2016/17 practice visit programme. The practice visit programme involves GPs meeting with practices to provide informal advise on areas where they are performing less well than their peers, and share areas of good practice. Practices were asked to consider how they may increase their EPaCCS usage. • We are investigating improving the EMIS EPaCCS template which is reported to be long and confusing. • The CCG is developing a Vulnerable Adults “local enhanced service” for

				<p>2017/18 that will incentivise practices to</p> <ol style="list-style-type: none"> 1) register end of life patients on EPaCCS and 2) register patients earlier. <p>Since April 2016 the number of active patients on EPaCCS has increased from 624 to 798, and from 21% of people who die in Nottingham City annually to 28%.</p>
2	<p>It is recommended that Nottingham University Hospitals NHS Trust review the level of need, including on acute wards, for the services of the Hospital Palliative Care Team at weekends and ensure services are in place to meet that need.</p>	<p>Nottingham University Hospitals Trust</p>	<p>The report and recommendations were discussed at NUH's' Quality Assurance Committee (sub-committee of Trust Board attended by Chair, Chief Executive, Chief Nurse and Medical Director) in April 2016. The action following this meeting was for a Consultant in Palliative Medicine to work with the Better for You Team (team that supports change and transformation) to model the effect of providing a seven day service within the current establishment. This will be reported back to the Quality Assurance Committee.</p>	<p>Work is underway to review specialist palliative care provision and availability at NUH in response to the Committee's review, the 2015 NUH CQC inspection and the National End of Life Care Dying in Hospital Audit. This work is being reported to the Quality Assurance Committee (a sub-committee of the NUH Trust Board). A review has been carried out by the Better For You Team. The Committee felt that further detail on the modelling was required to make a decision on the best way for NUH to provide a seven day service. A data collection exercise commenced on 1 October to run for six months. A further update will be provided at that stage.</p>
3	<p>It is recommended that Nottingham CityCare Partnership</p> <ol style="list-style-type: none"> a) consult with service users and carers to assess whether the Community End of Life service is delivered in a way that means patients and carers feel supported and cared for at weekends and bank holidays in a way that is equivalent to that experienced Monday to 	<p>Nottingham CityCare Partnership</p>	<ol style="list-style-type: none"> a) Patient satisfaction survey to be devised and completed re end of life care received from CityCare Services including community nursing to determine satisfaction of weekend service provision. <p>To be completed and recommendation available by end June 2016</p> <ol style="list-style-type: none"> b) Feedback received from satisfaction surveys to be reviewed and an action plan developed. Any actions identified out of the scope of the 	<p>See attached update from Nottingham CityCare Partnership</p>

	<p>Friday; and</p> <p>b) respond to any issues raised in the consultation to ensure that patients and carers feel supported and cared for at weekends and bank holidays in a way that is equivalent to that experienced Monday to Friday.</p>		<p>current provider contract to be feedback with City CCG.</p> <p>To be completed by end July 2016.</p>	
4	<p>It is recommended that Nottingham City Clinical Commissioning Group and Nottingham City Council ensure that the new Carer's Strategy addresses the potential for social isolation of carers and how providers can support carers either at risk of social isolation or experiencing social isolation.</p>	<p>Nottingham City Clinical Commissioning Group</p> <p>Nottingham City Council</p>	<p><u>CCG response</u></p> <p>Accepted</p> <p>Nottingham City CCG and Nottingham City Council are working together on a Strategic Review of support for carers. This means we are looking at all the ways in which we support carers, including wider situations which may affect how carers feel, and their ability to continue to care. The purpose of this review is to look at how we can improve carers' quality of life through improving early identification and support for carers, in line with the Care Act.</p> <p>By identifying carers earlier and ensuring our statutory health and social care services are also able to identify carers we will be able to support carers before they reach crisis point which is normally when a carer starts to feel most isolated.</p> <p>The Strategic Review also aims to promote the inclusion of carers as expert partners when developing the package of care for the cared for person.</p>	<p>Nottingham City CCG and Nottingham City Council are currently out to tender for a carers hub, carers respite and young carers service. This tender has been informed by conducting a strategic review of support for carers across the city and the objectives of the future carers hub will be:</p> <ul style="list-style-type: none"> • Carers will have better access to information about what support is available, and where to go for that support • Carers will have improved access to Carers' Assessments, and support should it be required • Carers will be supported to plan for unexpected situations before they arise • Carers will be supported to remain mentally and physically well, to fulfil their educational and employment potential, and to have a family and community life • Carers will be involved in designing local care provision, and in planning individual care packages, from the outset • Carers will be empowered, will become more resilient and will feel better able to cope in their caring role.

				<p>In addition to the revised objectives the provider of the new service will be expected to specifically target activities at identifying and engaging hidden carers from the following priority groups as these are some of the most vulnerable citizens in the city:</p> <ul style="list-style-type: none"> • Carers from BAME backgrounds • Carers of someone with a mental health condition • Carers who themselves have a learning disability • Carers who themselves have a mental health condition • Carers in mutual caring situations <p>All findings from the strategic review will inform the carers JSNA and joint strategy.</p>
5	<p>It is recommended that Nottingham City Clinical Commissioning Group and Nottingham City Council ensure that the new Carer's Strategy identifies mechanisms for ensuring carers are aware of the support available to them and how to access it.</p>	<p>Nottingham City Clinical Commissioning Group</p> <p>Nottingham City Council</p>	<p><u>CCG response</u></p> <p>Accepted</p> <p>Consultation with carers so far has suggested that easy access to information and support is key in maintaining and improving their health and wellbeing. There are a wealth of services which provide support and advice available, however they are currently fragmented.</p> <p>Following feedback from stakeholders we are aiming to develop a new model for carer support which mirrors the approach Nottinghamshire County Council have taken by providing carers and healthcare professionals with a 'golden number' that they can phone for any carer related needs.</p> <p>The single point of access - 'golden number' - will effectively act as a triage hub to ascertain what support the carer needs, provide telephone</p>	<p>The joint tender requires the provider to establish and operate a range of support services, which will form a single point of contact for carers in Nottingham City. This Carers' Hub must form the central element of the carers' pathway to ensure an integrated approach to services for carers that shall increase the levels of carers identified and support appropriate intervention through direct delivery, signposting or referral. Appropriately trained staff must assess the individual needs of each carer, work with the carer to develop a plan to meet the carer's needs, and follow through this plan to ensure the carer's needs are met as fully as possible.</p> <p>In order to achieve this the provider shall:</p> <p>A. Provide a single point of access for carers including a website providing comprehensive information for carers</p>

support and make the necessary onward referrals. We currently have two services in the city that are delivering this method of support and we are aiming to align these services to reduce duplication and improve ease of access.

- and a staffed phone line
- B. Carry out wide promotion of the service including awareness raising of what being a carer is, and where to go for information on support available for carers, including proactive outreach specifically targeting BAME carers
- C. Carry out an assessment of carers' needs, appropriate to the level of support required. This will form the statutory Carers Assessment, in line with the requirements of The Care Act 2014
- D. Develop support plans following on from the Carers Assessment, in line with the requirements of The Care Act 2014.
- E. Provide contingency planning for emergencies, for carers to ensure that support is available should an emergency occur involving the carer or the cared-for person. This must include the development/utilisation of a Carers I.D. card.
- F. Provide group support sessions, regular drop-in sessions and telephone support
- G. Signpost and refer carers to the most appropriate resource or service for them as individuals, including:
 - i. Managing all referrals to the Carers Respite service
 - ii. Managing all referrals to counselling provided through this contract
 - iii. Identifying young carers (aged under 18 years old) within families and referring them to the Young Carers services
 - iv. Signposting to specific training relating to the condition of the cared-for person, provided by other providers
 - v. Collating information on resources available to support carers in

				<p>Nottingham City</p> <p>H. Work with Health and Social Care professionals to provide</p> <p>vi. Information and support for professionals to identify carers and refer them for support</p> <p>vii. Training for professionals on working with carers</p> <p>viii. Regular communications and updates on referrals and services</p> <p>I. Provide a regular counselling service specifically for carers - face to face and telephone counselling options must be provided</p> <p>J. Engagement and involvement of carers</p> <p>K. Co-ordinate a programme of training – carer training only to be delivered directly, plus signposting carers to training by other providers</p> <p>L. Develop support for young adult carers aged 18+</p> <p>All findings from the strategic review will inform the carers JSNA and joint strategy.</p>
6	<p>It is recommended that Nottingham City Clinical Commissioning Group as the commissioner and all providers that they commission produce robust Equality Impact Assessments, which include explicit reference to access to services for people from BME groups and how the range of needs of individuals from BME groups will be considered when receiving palliative/ end of life care.</p>	<p>Nottingham City Clinical Commissioning Group</p>	<p>Accepted</p> <p>The CCG will request that all providers of commissioned End of Life and palliative care services complete new Equality Impact Assessments with explicit reference to access for BME groups and how their needs will be met, considering all aspects of race, religion and belief.</p> <p>This will be completed by October 2016.</p>	<ul style="list-style-type: none"> • The End of Life Co-ordination Service, Community Macmillan service and Macmillan Nottingham Cancer Support Service have an updated their EIAs. • The Palliative and End of Life Specialist Rehabilitation service has been re-procured and will start on 1st December 2016. An EIA has been requested. The tender documentation included a specific question on how the provider will ensure patients from protected characteristics will have equality of access to the service. Extracts from the successful bidders response are given below:

				<p>“In line with the Equality Act 2010, CityCare operates a system at an organisational level to collect demographic information against the nine protected characteristics, and is committed to undertaking Equality Impact Assessments on all new or amended policies and functions. Support in completing EIAs is provided by our dedicated E&D Officer to ensure the process is embedded. CityCare's 'Happy to ask, happy to tell' guide supports staff to ask questions in a dignified and respectful manner. Demographic information is included in the monthly data reporting process using SystemOne and since 2015 evidence of activity in relation to protected characteristics has been embedded within our quarterly 'patient, service user and public engagement report'. This will be extended to the team.”</p> <p>“Information is analysed to identify whether activity is representative of the local population profile, and where required appropriate action plans are developed to target unrepresented communities. Should a gap be identified, CityCare will use a range of techniques to work with local community partners to develop trust, increase understanding of the barriers to engagement, and develop innovative solutions which meet the specific needs of these patient groups. For example, we have worked with the Carer's Federation CityCare to develop services for the travelling community, enabling nurses to build trust and to offer discreet and private services within a non-clinical environment.</p> <p>“There is a great diversity of religious</p>
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				<p>beliefs and cultural practices amongst Nottingham City's diverse communities. It is therefore important to include this in our holistic assessment process and ensure the individual's specific beliefs inform our ongoing approach to care. An example of the partner members' successfully collaboration in responding to identified inequalities can be demonstrated in their participation in Nottingham City's BME community as part of the Pacesetters project. The project looked specifically at the different religious and spiritual needs of those within the Muslim and Christian communities of Nottingham City at the end of life, engaging with local communities and community leaders to review whether current provision meets these needs. The project highlighted community attitudes to cancer diagnosis within the Muslim community and the negative connotations of this, dissuading patients to access health services. Positive actions implemented as a result of the project included:</p> <ul style="list-style-type: none"> – Arranging clinics and/or events on days that do not clash with religious commitments such as Friday prayers of festivals; – Cultural training for staff to ensure that they are mindful of religious requirements when discussing nutrition and diet with citizens.”
7	It is recommended that Nottingham City Clinical Commissioning Group sets relevant targets/ standards for services to BME groups in the service specification when	Nottingham City Clinical Commissioning Group	<p>Partially accepted</p> <p>The CCG feels that it is not appropriate to include specific targets for BME groups in palliative/end of life care service specifications. The CCG is required to commission services that</p>	<p>The CCG did not agree to set targets / standards for service to BME groups but committed to include the monitoring of access by all protected characteristics in service review meetings, with providers required to produce remedial action plans if</p>

	<p>agreeing Service Level Agreements with providers of palliative/ end of life care, so that these can be monitored and sanctions applied if the provider fails to implement them.</p>		<p>are equally accessible to all. Whilst this would reasonably be expected to result in service usage by people from protected characteristic groups in line with their representation in the local community, there may be factors outside the control of the provider that prevent this.</p> <p>However, monitoring of access by all protected characteristics will be included in service review meetings, with providers required to produce remedial action plans if protected groups are under-represented. Implementation of action plans will be monitored through contract meetings, and ultimately sanctions can be applied if action plans aren't implemented.</p>	<p>protected groups are under-represented. Implementation of action plans will be monitored through contract meetings, and ultimately sanctions can be applied if action plans aren't implemented.</p> <p>This will be incorporated into the February 2017 contract review meeting for the End of Life Co-ordination service and the March 2017 contract review meeting for the Palliative and End of Life Specialist Rehabilitation service.</p>
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Report to Health Scrutiny regarding End of Life consultation: November 2016

Recommendations and outcomes

It is recommended that Nottingham CityCare Partnership

- a) consult with service users and carers to assess whether the Community End of Life service is delivered in a way that means patients and carers feel supported and cared for at weekends and bank holidays in a way that is equivalent to that experienced Monday to Friday.**

In response to this recommendation CityCare devised a survey to be sent out to patients and carers receiving services from the CityCare End of Life team. Patients were identified who were receiving care as part of the End of Life pathway but at a stage where they or their family members/carers were able to deliver feedback. The survey was designed to specifically capture whether people had a different experience of care from Monday to Friday as compared to weekends and bank holidays (see survey example attached).

The initial method to implement the survey was for members of the Patient and Public Engagement Team (people not directly involved in patient care) to contact people by telephone. It was felt that this would improve the response rate as opposed to a postal survey. However this proved to be difficult. Many people had answerphones on and it did not seem appropriate to leave a message. One family member told us that the person he cared for had sadly died a couple of days before, earlier than expected. He praised the nursing care that she had received but did not want to respond to a formal survey and was very upset. Another person became very tearful and said that she was not able to give feedback at that time.

As a result of the telephone calls and our concerns about disturbing people we sent a written survey out to 20 people explaining the reason for the survey and providing a stamp addressed envelope along with information regarding how to respond by e-mail, website or phone. 3 people responded.

Survey responses.

All 3 people felt that they/the person they cared for received all the care they needed during the week (Monday to Friday).

All 3 people felt that they/the person they cared for received all the care they needed at weekends and bank holidays.

All 3 said they had not noticed any difference in the care they received outside of normal hours, at weekends or bank holidays.

All 3 said that they felt their care needs were being met.

2 comments were recorded:

“Unfortunately x passed away in June (the survey was sent out in October). The care he had I was happy with.”

“Got good support from all involved”.

Other information.

In addition to the specific survey, the Patient and Public Engagement team has reviewed the on-going feedback received in relation to services including community nursing both in and out of hours. No comments or concerns have been recorded in relation to care and treatment out of hours. No complaints have been recorded in relation to this issue. Compliments reflect high levels of satisfaction with the out of hours community nursing service.

- b) respond to any issues raised in the consultation to ensure that patients and carers feel supported and cared for at weekends and bank holidays in a way that is equivalent to that experienced Monday to Friday.**

Not applicable due to information above.

Kate Whittaker.

Head of Patient and Public Engagement.

Patient and Family Member Feedback Survey

We would like to ask you some questions about the service you have received. Your feedback will be anonymous and we will not be asking for any information like your name or address. Your honest feedback will help improve this service.

Please mark one answer for each question

Are you the...

Patient

Family member/Carer

Please can you tell us what services you/the person you care for currently receives? For example District Nursing, Respiratory Care etc.

	Strongly agree 😊😊	Agree 😊	Neither agree nor disagree 😐	Disagree 😞	Strongly disagree 😞😞
Please mark one for each question					
I/the person I care for receives all the care they need during the week (Monday to Friday).	😊😊	😊	😐	😞	😞😞
I/the person I care for receives all the care they need at weekends and on bank holidays	😊😊	😊	😐	😞	😞😞

	Yes 😊	No 😞
Have you noticed any differences in the care you receive in the evening or at weekends and bank holidays? If 'Yes', please explain below:		

Do you have any further comments?

Thank you for taking the time to complete this survey. Your feedback will help us to improve our services.

Getting feedback from all communities (OPTIONAL)

The following questions are for monitoring purposes only. The information is kept confidential and accessibility is strictly limited. **You need only complete this part of the form if you feel comfortable doing so.** You may find that some questions are not relevant to you, or that you feel comfortable answering some questions but not others.

Why do we collect this data?

All organisations providing health and social care services are required to collect data about the people who use their services. These categories include age, disability, gender and gender identity, ethnicity, religion or belief, pregnancy, marriage/civil partnership and sexual orientation. The information is used to ensure that we are not discriminating against particular groups of people, and that our services meet particular needs.

Will it be shared with anyone?

We are obliged to share some information with our commissioners (the NHS and local authority organisations that pay for us to provide your services). They are bound by the same confidentiality and information security rules as we are: your information will still be secure.

THIS INFORMATION WILL BE HELD IN CONFIDENCE AND WILL NOT BE ATTRIBUTED TO ANY INDIVIDUAL.

If you feel comfortable providing some or all the information below please tick the appropriate box.

Age: 0 - 17 18 -30 31 -65 65 and over

Ethnic Origin

White: British Irish Any other White background (including Traveller)
Please specify _____

Mixed: White & Black Caribbean White & Black African White & Asian
Other Mixed Please specify _____

Asian/Asian British: Indian Pakistani Bangladeshi
Other Asian Please specify _____

Black or Black British: African Caribbean Other Black
Please specify _____

Other ethnic group: Chinese Other ethnic group Please specify _____

Disability: Do you consider yourself to have a disability or long term condition?

Yes No If yes, please specify _____

Prefer not to say