

EQUALITY IMPACT ASSESSMENT

NAME OF SERVICE/POLICY/STRATEGY BEING ASSESSED:

End of Life Care Coordination Service

DETAILS OF LEAD COMMISSIONER OR CSU STAFF COMPLETING THIS SCREENING:

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APPROVED AND SIGNED BY RELEVANT DIRECTOR:

Name	Dr Jonathan Evans			
Title	Clinical Lead for Long Term Conditions and End of Life			
Date	8 th September 2015			

1. PLEASE GIVE A <u>BRIEF</u> DESCRIPTION OF THE **S**ERVICE/POLICY/STRATEGY AND ITS AIMS/OBJECTIVES:

The South Gloucestershire End of Life Care Coordination Centre will act as the single point of access for community end of life services.

The Care Coordination Centre will organise packages of care for palliative care patients in respect of the following services: Private home care for CHC eligible patients; Palliative Care at Home Team; Hospice at Home; Marie Curie Nursing Services and nursing care from a nursing agency.

The Care Coordination Centre will provide service advice and signposting for the palliative care patients who have been referred to the service and their carers/families, in part via a website page

The Care Coordination Centre will provide a central point of communication relating to care packages for palliative care patients and health and social care professionals.

The Care Coordination Centre will make sure care plans are in place and are updated and shared across agencies.

The Care Coordination Centre will coordinate information regarding palliative care services in South Gloucestershire, providing a signposting function for professionals, in part via a page on their website.

The Care Coordination Centre will provide commissioners and providers with information relating to demand and capacity for services.

The Care Coordination Centre will ensure equipment is ordered through Medequip, ensuring delivery and the collection of equipment for patient's whose care they are coordinating (ensuring the equipment is collected within 5 days of death).

2.	IS THIS SERVICE/POLICY						
	New 🖂	Existing	Refreshed				

3.	Who is this Service	POLICY/STRATEG	Y LIKELY TO HAVE	AN IMPACT ON?
	Patients 🛚	Carers 🖂	Visitors 🖂	Staff 🔀
	Other [Please star	te who]		

4. WHAT EVIDENCE ARE YOU USING TO INFORM THIS ASSESSMENT?

SOURCE	Date	Details of Evidence [hyperlink to documents]
Demographic (including Census) data		The age profile of South Gloucestershire's population is broadly consistent with the national average, although the population age structure varies considerably across the district.
		South Gloucestershire is host to the University of the West of England which has some 35,000 students, most of whom live in the area during term time.
		The population will become older up to 2035 as life expectancy increases and people from the post-war 'baby boom' age.
		This will have a profound effect on services in the near and the long term for two reasons. Firstly, people of 85 years and over are in need of health and care services to a much greater extent than those in younger age groups. In South Gloucestershire as a whole, their numbers will nearly triple from an estimated 5,400 in 2010 to 15,300 in 2035. The second issue concerns the balance between older and younger people. In 2010, the so-called 'dependency ratio' of people aged 0-15 years and 65 years and over, as a percentage of people of working age 16-64 years, was 54%; in 2035 it will be nearly 68%. In 2010, there was an estimated four4 people of working age to every person over 85 years; this is expected to fall to 3 by 2035. In particular, the numbers of family members in the middle age groups – traditionally those who provide much informal care to elderly relatives – will fall during this time, at the same time as the number of people in very old age rises. 1,875 people died in South Gloucestershire during 2013/14 and 44% of these deaths were in acute hospital settings. Mori surveys state that 63% of people say they would prefer to die at home with 29% saying they want to die in hospital.

SOURCE	Date	Details of Evidence [hyperlink to
		According to the latest Office of National Statistics (ONS) figures from the 2011 census, 5.7% of South Gloucestershire's population is estimated to be of Black and minority ethnic (BME) origin – which is around half the national average. For more information consult the South Gloucestershire Joint Strategic Needs Assessment, available from http://hosted.southglos.gov.uk/JSNA/South%20Glos%20JSNA%202013%20v4%2005031
Research Findings		The Parliamentary and Health Service Ombudsman published a report in 2015 called 'Dying without dignity'. This highlights some of the recurring themes that come up in complaints about end of life care. It identifies the key themes as being: • Not recognising that people are dying and not responding to their needs • Poor symptom control • Poor communication • Inadequate out of hours services • Poor care planning • Delays in diagnosis and referrals for treatment Under the theme of 'poor care planning' the report states that 'the failure to plan adequately often leads to the lack of co- ordinated care'. The Dying without Dignity report is available here: http://www.ombudsman.org.uk/ data/assets /pdf file/0019/32167/Dying without dignity r eport.pdf
Recent Consultations and Surveys		A consultation event was held on 2 nd June 2015. Health professionals and third sector organisation representatives attended from St Peter's Hospice, Sirona, Age UK, NBT, UHBristol, SG CCG, University of Bristol, Bristol CCG, Bristol Community Health and Marie Curie.
Results of: ethnic		This is a new service and there is a key performance indictor for Sirona, who will be

SOURCE	Date	Details of Evidence [hyperlink to
monitoring data; and any equalities data from the local authority / joint services; or Health inequality data Anecdotal information from groups and agencies within South Gloucestershire	Date	providing the service, to collect equality monitoring data about the patients receiving the service, monthly. As a result, this data will be available in the future and will be reviewed by the provider and commissioner to ensure all groups are accessing the service. If not, corrective action will be taken. A consultation event was held on 24 th June 2015. Professional and lay representatives attended from: Carers Support Centre, Healthwatch, Bluebird Home Care, South Gloucestershire Deaf Association, Woodland Burial, Action Against Hearing Loss, South Gloucestershire Disability Equality Network, Milestones Trust and Age UK. At the event delegates were asked to consider how the proposed Coordination service might adversely impact on the 9 protected characteristics. The comments made at the event are documented in the sections below. The Healthwatch South Gloucestershire Annual Report 2013/14 offers some general information about what South
		Gloucestershire residents are concerned about. Salient points that relate to the 9 protected characteristics have been incorporated into the sections below. The report can be downloaded from here: http://healthwatchsouthglos.co.uk/wp-content/uploads/2015/01/HEALTHWATCH_A
		R South-glos-Final.pdf Two members of the project group attended the Healthwatch South Gloucestershire open
		meeting on the 16 th July 2015 and consulted with the 26 people in attendance. They also consulted with 14 members of the Dhek Bhal's carers group on the 29 th July 2015. The feedback received from both these events are incorporated into the sections below.
Comparisons between similar functions / policies		Equality Impact Assessments have been requested from other End of Life Care Coordination Centres, but we have not received any as yet.

SOURCE	Date	Details of Evidence [hyperlink to documents]
elsewhere		•
Analysis of PALS, complaints and public enquires information		There was one PALS issue raised through South, Central and West Commissioning Support Unit regarding pain relief during 2014/15.
		UH Bristol reported 3 complaints around End of Life Care for the year 2014/15. One was concerned with hospital care, one about communication of diagnosis and one about process.
		The report from NBT PALS and complaints has yet to be received.
Analysis of audit reports and reviews		None available
Other:		

5. ASSESSMENT OF THE EFFECTS OF THE SERVICE/POLICY/STRATEGY ON THE PROTECTED CHARACTERISTICS [EQUALITY GROUPS]

Assess whether the Service/Policy has a positive, negative or neutral impact on the Protected Characteristics.

- Positive impact means promoting equal opportunities or improving relations within equality groups
- Negative impact means that an equality group(s) could be disadvantaged or discriminated against
- **Neutral impact** means that it has no effect currently on equality groups

Please answer Yes or No in the following table and provide reasons accordingly:

Assessment of Impact of Policy/Service on Protected Characteristics [Equality Groups]					
Protected	Positive	Negative	Neutral	Please provide reasons for your answer and any	
Characteristic	Impact	Impact	Impact	mitigation required	
Age [Children and Young people 0 to 19; Older People 60+]	Yes			The Healthwatch South Gloucestershire Annual Report 2013/14 states that the top priority in South Gloucestershire is young carers. It is important that the service recognises these and ensures there is appropriate support for them during the end of life care for the person they care for and beyond. At the consultation group on 24 June 2015 it was mentioned that not all people receiving end of life care will be elderly. Staff may find it harder to support younger patients dying and may require extra support in these cases. Family members of younger people dying may require different bereavement support, for example, the loss of a child may evoke a different response to the loss of an elderly parent. It was mentioned that there is a grant for funeral costs for people under 60 – the care coordination service needs to be aware of this and how to access it, so they can include this	

		information on their website page.
		Younger, working people at the end of life may need welfare support and this should be one of the services that the care coordination service can sign-post to.
		For children at the end of life, it is important that the service helps them to maintain as normal a life as possible if this is important to them, for instance, if they want to continue going to school. The service might also want to consider how to support them answering questions from their peers.
		The group discussed issues of isolation for older people at the end of life who may not have many friends or relatives close by.
		The South Gloucestershire Strategic Needs Assessment 2013 states that 15% of people are described as having limitation in activities of daily living (disability).
Disability Physical Impairment; Sensory Impairment; Mental Health; Learning Difficulty; Long-Term Condition	Yes	The group that met on 24 June 2015 were keen to ensure that the service is accessible and that interpreters for people with hearing loss are booked for people that need them ahead of their appointment and without the onus being on the patient or a family member to request this.
		The group also discussed the disabilities and access requirements of bereaved friends and relatives and suggested that the care coordination service ensures that any vulnerable dependents of the patient are considered.
		The need for advocacy was highlighted by the group on the 24 June 2015 as patients with limited communication skills

		still need to be able to ensure that their wishes are understood and met. The role of the healthcare professional in facilitating families to have difficult conversations was recognised and highlighted.
Gender Reassignment [Trans people]	Yes	At the consultation event on 24 June 2015 the group agreed that it is important to ensure that the service has a personcentred approach so that staff establish what being transgender means to each particular patient. The group discussed potential issues such as dementia confusing a person's identity. They also looked at how side effects of palliative care drugs might have an impact on hormone therapy or on characteristics that help patients reinforce their identity; for example hair growth/loss. It was mentioned that it may be important for female patients to have their make-up applied and that if this is the case it should be included in their care provision.
		The group felt that it will be important that care staff have a key contact for equality issues such as transgender people to seek advice from as required.
Race	Yes	At the consultation event on 24 June 2015 issues around using children as interpreters were discussed. It was recognised that this may not always be appropriate and that the service may need to insist on supplying an external interpreter.
		The need for interpretation services was also raised at the Dhek Bhal Carers session on 29 July 2015. Those present agreed that face to face interpretation services are preferable to using a telephone interpretation service as

people who are feeling ill may find it hard to speak and using sign language is possible face to face. Healthwatch South Gloucestershire report access to interpretation services as a recurring issue. It also highlights that patients may want interpreters of the same sex, particularly if they require personal care or an intimate examination. The group were concerned that some communities do not currently access end of life care services. It was suggested that the service is talked about at local community events so that people not often heard are aware of the support available and how to access it. Sirona staff need to have an understanding of different cultural practices around death. The participants at the Dhek Bhal Carers session on 29 July 2015 raised the fact that some people may want to die in the country of their birth and the care coordination service should be able to sign-post people to their GP if they need permission to travel. It is important that GPs pass on all their information about patients so that interpreters can be booked and information can be printed in the correct language and size of font. The group mentioned traveller communities and the need for Sirona to work closely with those organisations that support traveller communities.

		It was also mentioned that some patients and family members may have racial prejudices and it is important to ensure that staff are not victims of this. The group that met on 24 June 2015 discussed some of the religious codes that patients and their families may observe, but recognised that they could not be aware of all them. It was agreed that the service needs to be aware of the last rites for the main religions. It was recognised that some people's beliefs may not be part of a specific, recognised religion and therefore this needs to be established as part of the advanced care planning so that everyone's wishes are met. The group were concerned that there may be instances
Religion or Belief	Yes	The group were concerned that there may be instances where carers' legal responsibilities conflict with religious beliefs and that this needs to be communicated appropriately.
		The group wondered if, in some instances, religious leaders can give permission for patients and carers to abstain from certain religious codes and suggested that Sirona ensures they have contact details for the main religious leaders in the area.
		The group mentioned that for some religious groups it is important that family members care for dying relatives and that these groups may be missing out on support. The group were keen to ensure that support is offered but without interfering.
Gender [Male or Female]	Yes	At the consultation event on 24 June 2015 and the Dhek Bhal Carers session on 29 July, both groups noted that some patients may have a preference for a female or male

		carer. Sirona assured them that they establish if there is a carer preference at the outset and ensure that this is met. It was noted that this is as important for staff as it is for patients.
Sexual Orientation	Yes	The group on 24 June 2015 discussed the need to ensure that care staff are aware of who the patients significant other (or others) is/are, as there could be instances where this person is not accepted or recognised by extended family members. Advanced care planning is essential to ensuring that patients' wishes are met. It was also noted that paperwork may need to be completed to ensure that partners are recognised as next of kin. It is important to ensure that staff are trained to expect diversity and not to assume everyone is heterosexual. For patients dying in hospital or in a hospice, it is important
		to ensure that partners can stay with them, regardless of their sexual orientation, and that they are protected from any prejudices from other patients.
Pregnancy and		At the consultation event on 24 June the group discussed issues around patients that may receive an end of life diagnosis while pregnant. The Care Coordination service needs to ensure that it includes coordination of obstetric and antenatal care as well.
maternity	Yes	The group recognised that issues around pregnancy, maternity and fertility may be very emotional and that staff should be able to bring in outside agencies and the voluntary sector to support this. Patients and partners may want to be able to freeze their sperm or eggs for future use and the care coordination service should be able to sign-

		post for support with this if required. The importance of communicating clearly and effectively with young children was emphasised. The group discussed infant death and supporting parents to make the most of any time they have with their child before
		death and to support them in visiting their child in the mortuary if required. The group on 24 June 2015 discussed some of the issues that patients and staff may face with regards to marriage, civil partnership and common-law marriage. The service needs to be clear about what partners and spouses can and cannot consent to on behalf of the patient. It was noted that in some cases children may be next of kin rather than partners, for instances, where there has been a re-marriage.
Marriage or civil partnership	Yes	It was mentioned that some couples that are not married, may want to marry quickly if one partner is at the end of the life and that it would be helpful if the Care Coordination service could sign-post those couples to somewhere that could support them with this. It was noted that the Care Coordination service will be based in Kingswood Civic Centre where births, deaths and marriages are recorded and this will help staff support patients with these processes.

6. ELIMINATING DISCRIMINATION, HARASSMENT AND VICTIMISATION

The NHS Standard Contract has been used to commission Community Health Services from Sirona. Service Condition 13 of the NHS Standard Contract prohibits discrimination on the basis of the nine protected characteristics set out in the Equality Act 2010, and specifically relates to 'Equality of Access, Equality and Non-Discrimination. While Service Condition SC14 requires Sirona to take account of the spiritual, religious, pastoral and cultural needs of Service Users and must liaise with the relevant authorities as appropriate in each case.

Sirona staff training is mandatory with 3 yearly updates for equality and diversity covering how to report a concern.

Adverse event forms are filled in by staff and referred to the safeguarding team if they witness harassment or victimisation of vulnerable patients.

Sirona has a customer care complaints policy where the complainant is involved in decisions about how their concern or complaint is handled. Sirona have a service user engagement approach which is based on the principle of 'nothing about me, without me'.

Sirona are also firmly committed to promoting an organisational culture which values diversity and equality of opportunity and to preventing discrimination in all aspects of our employment practices and services.

7. ADVANCE EQUALITY OF OPPORTUNITY

At the consultation event on 24th June, representatives from South Gloucestershire Deaf Association, Action Against Hearing Loss, South Gloucestershire Disability Equality Network, Milestones Trust, Healthwatch, Bluebird Home care and Age UK attended. The engagement with these organisations, representing people with protected characteristics resulted in a comprehensive action plan for Sirona to implement when establishing and running the End of Life care Coordination Centre.

Implementation of the action plan will ensure that patient and carers with protect characteristics are equally able to access services. Sirona will take steps to seek views and encourage representation from people with protected characteristics in Service User Groups.

In addition, Sirona consulted with members of the South Asian community at Dhek Bhal on the 29th July to ensure that race equality is considered and that Black and Minority Ethnic Communities are consulted about the service and made aware of how to access it. Sirona agreed to provide Dhek Bhal with information about the service once it is operational for them to circulate to the Black and Minority Ethnic Communities in South Gloucestershire.

South Gloucestershire Deaf Association have asked Sirona to confirm which aids they will use for communicating with deaf people either face to face or while using other means of communication, such as a text phone. Sirona will ensure the service is accessible for people who are deaf or have some hearing loss.

8. FOSTER/PROMOTE GOOD RELATIONS BETWEEN PEOPLE

Sirona will take appropriate actions to promote understanding between people with protected characteristics and those who don't share those characteristics and tackle prejudice between different groups. This will be through communication about the service; explaining the reason for providing interpreting services and signposting service users, carers and health and social care staff members to other services for certain protected characteristics via the End of Life page on the Sirona website.

Sirona have consulted with carers by attending the Carer's Advisory Partnership Board for South Gloucestershire which has a good representation from all groups across South Gloucestershire.

Sirona will ensure access to interpretation services for people with hearing loss and for people whose first language isn't English to ensure they can all access services.

Sirona have a 'Taking it Personally' approach, which was developed by staff, for staff. It ensures all service users feel welcome, valued, supported and safe and are shown courtesy and respect at all times.

9. HAVE YOU SET UP OR ARRANGED FOR ANY OF THE FOLLOWING:

Attribute	Yes	No	If Yes, please describe what these are, If	
			No, please give reasons.	
Equality Monitoring Systems	Yes		Sirona are implementing the computer system EMIS, and when the service starts, the equality monitoring will take place using EMIS	
Equality Related Performance Indicators	Yes		This is a new service and there is a key performance indictor for Sirona, who will be providing the service, to collect equality monitoring data about the patients receiving the service, monthly. As a result, this data will be available in the future and will be reviewed by the provider and commissioner to ensure all groups are accessing the service. If not, corrective action will be taken.	
Implementation of the EIA action plan	Yes		There is a key performance indicator in the service specification requiring Sirona to implement the EIA action plan when establishing and providing the service. They are required to audit if all actions have been implemented and provide the results of this audit in their first annual report. South Gloucestershire CCG will add the service specification to the existing Sirona contract via a contract variation.	

10. ACTION PLAN

Ref	Issue	Action Required	Milestone	Lead Officer
1	Age	Sirona to ensure counselling support is available to staff, particularly for those involved in caring for younger end of life patients. For the service to be able to sign post people to Click Sargent if appropriate.		
		For the service to be aware of the grant to help towards funeral costs for people who die before they are 60.		
2	Disability	Sirona to ensure the Care Coordination service is able to identify those patients that require an interpreter/signer and arrange this ahead of their appointment, without prompting from the patient. For the scope of the care coordination service to		
		include ensuring care provision/ referrals for any vulnerable dependents of the deceased. To ensure that the		
		communication training Sirona staff receive enables them to facilitate difficult discussions amongst families and act as advocate for the patient.		
		Sirona to investigate using text phone to ensure people who are deaf can contact the service.		

Ref	Issue	Action Required	Milestone	Lead Officer
3	Race	Sirona to ensure that hard		
		to reach communities are		
		aware of the support		
		available and how to		
		access it.		
		Equality training for		
		Sirona staff to include an		
		overview of different		
		cultural practices around		
		death.		
		The service needs to		
		work closely with those		
		organisations that support		
		traveller communities.		
		The service needs to		
		ensure interpreters are		
		available as required that		
		the written information is		
		provided in the correct		
		language. The service		
		also needs to be mindful		
		as to when it might not be		
		appropriate for children or		
		family members to act as		
		interpreters. Sirona needs to establish		
		if patients harbour any		
		racial prejudices and to		
		ensure that staff are not		
		put into a vulnerable		
		position.		
		position.		
4	Lesbian Gay and	Sirona staff receive		
-	Bisexual	equality and diversity		
		training so that		
		assumptions about		
		patients sexuality are not		
		made.		
		For the service to be able		
		to sign-post/ support		
		patients to do any		
		necessary paperwork to		
		ensure their significant		
		other is recognised as		
		next of kin.		
5	Religion, Faith or	Sirona to ensure they		
	Belief	have, and keep up-to-		
		date, a list of religious		
		leaders and their contact		

Ref	Issue	Action Required	Milestone	Lead Officer
		details should they need		
		advice on religious		
		matters.		
		Sirona to identify religious groups that may not be		
		accessing the end of life		
		care service and ensure		
		that they are aware of the		
		support available (without		
		interfering)		
	1=		T	
6	Transgender	Sirona should have a		
		named equality lead so that staff can seek advice		
		on equality issues if		
		required.		
		Sirona to ensure that the		
		Care Coordination service		
		has a person-centred		
		approach and care is		
		tailored to individual's		
		requirements.		
7	Sex [Gender]	Sirona to continue to		
•	ock [ochaci]	establish if there is a		
		preference for a female of		
		male carer and ensure		
		this preference is met.		
	December and	For the comice to be able		
8	Pregnancy and Maternity	For the service to be able to sign-post patients to		
	Materinty	support regarding fertility		
		services for freezing eggs		
		or sperm if required.		
		Sirona staff to receive		
		communication training to		
		communicating with		
		children.		
		Sirona staff to receive training for supporting		
		bereaved parents, for		
		example, with access to		
		the visit their child in the		
		hospital mortuary if		
		requested.		
9	Marriage or Civil	Sirona staff need to be		
	Partnership	clear about issues around		
		consent and when a		
	<u> </u>	partner or spouse can		

Ref	Issue	Action Required	Milestone	Lead Officer
		and cannot give consent.		
		Sirona staff should have		
		access to advocacy and		
		support services for		
		families where there may		
		be complications or		
		disputes around next of		
		kin.		
10	General	On-going involvement will		
		be inclusive, to ensure all		
		voices are heard.		

11. APPROVAL

- a) The South Gloucestershire CCG Clinical Operation Executive approved this Equality Impact Assessment on the 14th July 2015. They require the End of Life Care Coordination Project Group to review how the action plan is being implemented in the design and running of the service in February 2016 to ensure the action plan is being implemented in the design of the service. The Clinical Lead on the End of Life Care Coordination Project Group will update the Clinical Operational Executive on how the action plan is being implemented.
- b) Implementation of the Equality Impact Assessment Action Plan is a key performance indicator for this service and SG CCG will review details of how the actions have been implemented in the first Annual Report for the service provided by Sirona.
- 12. DATE EQIA COMPLETED: 2ND SEPTEMBER, 2015
- 13. REVIEW DATES: 9TH FEBRUARY 2016