Equality Impact Assessment

1. Topic of assessment

EIA title:	Dementia Navigator Service

EIA author:	Melanie Nunn

2. Approval

	Name	Date approved
Approved by[1]	Shelley Head 	09/11/2018

3. Quality control

Version number	V2	**EIA completed**	07/11/2018
Date saved		**EIA published**	

4. EIA team

Name	Job title (if applicable)	Organisation	Role
Melanie Nunn	Commissioning Manager	Surrey County Council	Dementia Commissioning Lead
Katie Newton	Contract and Commissioning Support officer	Surrey County Council	Commissioning Support
Winnie Turay	Procurement Specialist	Surrey County Council	Procurement Lead

[1] Refer to earlier guidance for details on getting approval for your EIA.

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Marion Heron	Commissioning Manager for Mental Health	Guildford & Waverley CCG	CCG Lead

5. Explaining the matter being assessed

What policy, function or service is being introduced or reviewed?	The Dementia Navigator service is funded by both health and social care. The original service was set up in response to the joint Surrey County Council / NHS Surrey Commissioning Strategy and Mental Health Service for Older People 2010-2015 which identified the need for improved information, guidance and support for individuals, their families and carers post diagnosis. The NHS Shared Planning Guidance asked every health and care system to come together to create their own ambitious local blueprint for accelerating implementation of the Five Year Forward View i.e. to ensure that there will be place-based, multi-year plans built around the needs of local populations. We have been jointly working to achieve better outcomes and high quality co-ordinated care for Surrey residents through greater integration and alignment of health and social care services. This has resulted in the co design and production of two Dementia Strategies covering the current STP footprints of Surrey (Surrey Heartlands and East and Surrey Heath) for 2016-2021. From these strategies our vision for all the residents of Surrey is: The referral pathways to the service are largely through the clinical pathways within each CCG following dementia diagnosis. Personalised support plans are created by clients as and when they need to access the support. Sharing advanced plans that are led by the person who has dementia before they lose capacity to make decisions about how their needs are met.

	Maximise the use of all voluntary / statutory support and community networks at the right time for individuals.
What proposals are you assessing?	A Dementia Navigator Service was initially jointly commissioned in 2011. There has been little change made to the service specification since that time. The Dementia Navigator service is now due for re-tender and continues to be jointly health and social care funded. The aim of the service is to provide all people living with dementia and their carers to live in dementia friendly communities where they feel empowered and know where to go to seek information, advice and help. That they have access to the care and support that enables them to live well at home for as long as possible and die with dignity. They make connections and networks of support within their local communities to remain living well, safely and independently. The service will: • Signpost people with dementia and their carers to connect to and engage with appropriate support and services within their communities, including making ongoing referrals and supporting people to access these services. • Provide individuals with information and advice in order to empower them to remain as healthy and independent as possible in their home with choice and control over their lives, linking health and social care support and to encourage them to make plans for their future. • Provide information and support on life planning and preparation for a potential crisis e.g. consideration of legal issues through the Mental Capacity Act 2004 (Power of Attorney). Provide tools and links to help individuals and their

	carers to prepare and make contingency plans for crisis management and end of life care as appropriate. • Interact with the individual and carer as and when required throughout their dementia journey, responding to their needs from simple 1:1 interventions through to a more complex needs-led service. Providing emotional support either face to face or regular telephone contact, share guidance and facilitate access to appropriate health and social care professionals on appropriate occasions during the progression of the condition and as and when individuals/ carers request this.
Who is affected by the proposals outlined above?	The proposals will affect: • People who been diagnosed with dementia and their family/carers living in Surrey/or have a registered GP in one of CCG areas that contribute to the funding of this service. • Staff employed by the current Provider of the service • Health Professionals and partners (Acute Providers, Community Health, District and Boroughs etc) / Mental Health providers across the system within Surrey who can receive or make referrals via the Dementia Navigator service.

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6. Sources of information

Engagement carried out
As part of the retender exercise the following partners and stakeholder groups were engaged and consulted with: • CCG clinical commissioners with a lead for Mental Health • Clinical Professionals • Co-Commissioners (CCG and SCC) • Procurement • Finance • Legal • User and Carer Groups • District and Borough Community Services • Potential providers across the market A series of meetings and workshops were held to gather feedback and views on how this current service operated and what improvements could be made. • 08/01/2018 Health and Social Care Commissioners and Dementia leads workshop and feedback • 06/02/18 NW Surrey Dementia Partnership Board Meeting • 26/04/2018 District and Boroughs Dementia Navigator review workshop • 10/05/2018 Elmbridge Carers Support group (Users and Carers of people living with dementia) Presentation and feedback session • 21/05/2018 Presentation and feedback session Camberley Users and Carers Drop in session • 22/05/2018 Stake holder and market event, presentation and feedback Feedback from all the events was generally positive about the current delivery but identified that stronger connections were needed between the Dementia Navigator service provider and a range of organisations and agencies to ensure visibility and accessibility to the service by people across Surrey. Closer working relationships could

be explored further between Districts and Boroughs and Dementia Navigator service to ensure that maximum use of community based services and resources available are taken up by people living with dementia in their local areas.
Data used
• Performance monitoring / KPI data from current provision • Joint Strategic Needs Assessment • Public Health Data / Department of Health data • Historical data from previous contracts supporting people with dementia

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7. Impact of the new/amended policy, service or function

7a. Impact of the proposals on residents and service users with protected characteristics

Protected characteristic[2]	Potential positive impacts	Potential negative impacts	Evidence
Age	People of any age who have been diagnosed with dementia or carers of any age will be able to access the service empowering them with, information and advice, support to remain living independently or continuing to manage to support as a carer. The service will also focus on flexible service delivery approach to support people of working age who have been diagnosed with early onset dementia and their carers /families.	No envisaged negative impacts as eligibility is still based on having a clinical diagnosis of dementia and on either being a Surrey Resident or having a Surrey based GP.	The NHS Dementia Calculator states that at December 2015 there were 15,269 people in Surrey with dementia[3] which the Joint Strategic Needs Assessment predicts will rise to 19,000 by 2020[4]. The effect of an ageing population will impact on the numbers of people living with dementia, the health and social care needs of people living with dementia, and the needs of their carers. In Surrey just fewer than 14,000 older people are estimated to have dementia, this equates to around 1 in 12 older people (over 65). By 2020 this is predicted to rise to 17,000 older people. It is estimated that there are around 100 people with learning difficulties who have been diagnosed with dementia across Surrey. In respect of the positive impacts there is some focus on increasing the accessibility for people being diagnosed with young onset dementia and ensuring they have support to continue in their daily roles and responsibilities in their life. (Employment / Education/ Parenting / Social and emotional support) Most people with dementia are over the age of 65. It's estimated that 2%-5% of people with dementia are under 65. That's 16,400 –

[3] NHS Dementia Calculator (Guildford and Waverley 1597, East Surrey 1392, North East Hampshire and Farnham 401, NW Surrey 8540, Surrey Downs 2587, Surrey Heath 752)
[4] Projecting Older People Population Information (POPPI) and Projecting Adult Needs and Service Information (PANSI)

			41,000 cases in the UK. Some rare forms of dementia can affect people in their 30s, 40s and 50s. 7.1% of all people over the age of 65 have dementia. A person's risk of developing dementia rises from one in 14 over the age of 65 to one in six over the age of 80. Over 42,000 people under 65 have dementia in the UK (5.2% of the total).
Disability	People with Disabilities' who have been diagnosed with dementia can access this service. There will be a more focused approach with Individuals diagnosed with Early Onset dementia, particularly individuals with Learning Disability living in the community.	Safeguarding issues need to be considered, particularly for people with learning disabilities or mental health needs, who may be more vulnerable in some community situations. Providers and carers of people with Learning disability and a diagnosis of dementia may miss out on support or services that will support them in their caring role.	People with Down's syndrome are the most at risk group for developing Alzheimer's disease within the population. This is because there is a clear genetic link between Alzheimer's disease and trisomy 21 (Down's syndrome) – an extra chromosome 21.Studies vary in their estimates, but indicate that as many as 20% of those over the age of 65 with learning disabilities meet the criteria for dementia (Cooper 1997), compared to the 1% prevalence rate in the general population at the same age from the Eurodem Consortium (Hofman et al 1991). • However, for people with Down's syndrome the rate is much higher. Studies have indicated that the prevalence rate can be as high as 75% at age 60 years or older (Lai & Williams 1989). People with Down's syndrome who develop dementia are more likely to develop other co-morbid difficulties at a greater rate and at an earlier stage than other people with dementia. This includes significant mobility issues, depth perception problems and the development of late onset epilepsy. • There are estimated to be around 21,800 adults with a learning disability in Surrey in 2017 and 9,086 adults with autism, of whom 4,655 with a learning disability and 2,071 with autism are over the age of 65. (PANSI/POPPI estimates). • By 2030 it is expected, with population growth and longer life expectancy, that there will be 23,986 people with a learning disability and 10,083 people with autism, 7,383 of whom will be adults. Population growth is largest in the older adult group,

			who are likely to require additional care and support associated with old age (Draft JSNA, 2018). Of these, an estimated 4,586 adults will have a moderate or severe learning disability; 1,028 will have a severe learning disability and this is estimated to increase to 4,907 by 2030. • Population estimates outline that there are 5,700 children with learning disabilities and 2,700 with autism in Surrey, of whom 647 are 16-17 year olds with learning disabilities and 97 have autism. 897 18-25 year olds have autism and this is projected to increase to 988 by 2030. • 5,403 people with a learning disability were known to local GPs in 2016/17; however the recording of autism is not as reliable (approx. 27% of the projected population when nationally that % is 23%).
Gender reassignment	People who have been diagnosed with dementia can access this service regardless of gender reassignment	There is limited specialist community provision for gender reassignment, individuals may be isolated or estranged from their families this limiting their opportunities to ask for help or access this service.	The report "Gender Variance in the UK: Prevalence, Incidence, Growth and Geographic Distribution (June 2009)" includes information on the geographical distribution of the transsexual community. This distribution is based on an estimation of the implied prevalence of people who have presented with gender dysphoria (a condition where a person feels that they are trapped within a body of the wrong sex) in individual police authorities. For Surrey, the estimation is 37 per 100,000 persons 16 and over. If this figure is applied to the 2015 estimate of Surrey's 16+ population then the estimated number is 348[5]. There is currently no data available regarding the Transgender community. On the matter of issues faced by trans people Gender Identity Research and Education Society (GIRES) state in their literature[6] that: • Many find that their families reject them

5 http://www.gires.org.uk/assets/Medpro-Assets/GenderVarianceUK-report.pdf
6 http://www.gires.org.uk/assets/supporting-families.pdf

			• Sometimes, despite being protected by employment law, they are made to feel very uncomfortable at work, as well as elsewhere It takes great courage for trans people to reveal their true gender identities.
Pregnancy and maternity	People who have been diagnosed with dementia can access this service.	N/A	There is no data available.
Race	People who have been diagnosed with dementia can access this service regardless of their race.	The service will need to do some targeted work with some ethnic/ cultural groups for whom Dementia is not recognised and support available to them is not accessed in the traditional manner.	• According to the 2011 census, the majority of the population of Surrey (945,780) 85% are white British, with 2300 (0.2%) usual residents identifying themselves as Gypsy / Irish traveller. • North West Surrey is the most diverse CCG with12.5% of its population from non-white ethnic groups. • Elmbridge has the highest proportion 10.4% in all other white groups (including Irish, Irish Gypsy traveller and other white). • Although the proportion of the population from black and minority ethnic groups is smaller in Surrey than in the country as a whole, this varies between local authorities and clinical commissioning groups. This provides a challenge to ensure that the needs of these small communities and individuals are appropriately met. It is essential to work across partner organisations to ensure a good understanding of the varying needs this diversity brings. Furthermore, some minority ethnic groups may be hard to reach because of language or differences in culture which contribute to inequalities.

<table>
<tr>
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<td>In the 2011 census, the proportion of the Surrey population who do not describe themselves as white was 8.6%. This proportion is currently concentrated amongst those below the age of 65[7].
<table>
<tr><th></th><th>White</th><th>Mixed/ multiple ethnic group</th><th>Asian/ Asian British</th><th>Black/ African/ Caribbean/ Black British</th><th>Other Ethnic Group</th></tr>
<tr><td>18-64</td><td>620,578</td><td>10,472</td><td>44,546</td><td>9,163</td><td>6,529</td></tr>
<tr><td>18-65 as %</td><td>89.77%</td><td>1.51%</td><td>6.44%</td><td>1.33%</td><td>0.94%</td></tr>
<tr><td>65+</td><td>189,260</td><td>676</td><td>3,532</td><td>437</td><td>561</td></tr>
<tr><td>65+ as %</td><td>97.32%</td><td>0.35%</td><td>1.82%</td><td>0.22%</td><td>0.29%</td></tr>
</table>
There are significant pockets of black and minority ethnic groups, for example in Elmbridge, Epsom and Ewell and Woking. Gypsies Roma and Travellers (GRT) are some of the most disadvantaged and excluded communities in our society. As at July 2016 there were 694 Gypsy and Traveller Caravans in Surrey.[8]</td>
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<tr>
<td>Religion and belief</td>
<td>People who have been diagnosed with dementia can access this service regardless of their religion</td>
<td>Individuals who have specific religious beliefs associated with their culture may not easily access the dementia navigator service. Some targeted work may be done by building connections and links</td>
<td>Over the last decade the proportion of Christians in Surrey has decreased from 74.6% in 2001 to 62.8% in 2011. The proportion of people reporting “No religion” increased from 15.2% to 24.8%. There was an increase in all other main religions.</td>
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7 POPPI/PANSI 2011

8 Gypsy and Traveller Caravan Count DCLG on Surreyi.

		with specific communities and religious leaders who may be able to assist with supporting individuals to access the service.	
Sex	People who have been diagnosed with dementia can access this service.	Men in their caring role may not access this service proactively whilst being a carer (as most carers are women) until a crisis occurs.	In the UK 61% of people with dementia are female and 39% are male. This is mostly because women tend to live longer than men and as dementia becomes more common as we age, more women develop the condition. 820,000 people in the UK have dementia (dementia Consortium) 15.4% of women died due to Alzheimer's disease and other dementia's in 2016 in the UK. It was the leading cause of death for women. 8.0% of men died due to Alzheimer's disease and other dementias in 2016 in the UK. It was the second leading cause of death for men. Women are 2.3 times more likely to provide care for someone with dementia for over 5 years. 49% of Surrey residents are male, while 51% are female. This is aligned with the UK as a whole.[9] According to the 2011 census 80% of Surrey males are economically active compared to 68% of women.
Sexual orientation	People who have been diagnosed with dementia can access this service.	The Lesbian, Gay, Bi sexual and Transgender (LGBT) individuals who have been diagnosed	The UK Government estimates that 6% of the population are lesbian, gay or bisexual. Applying this to 2017 population estimates for Surrey, there may be around 57,000 people aged 16+

[9] ONS Population estimates 2015 by gender

	Sexual orientation would not be a barrier to accessing this service.	with dementia may not access the service, if they believe they will be stigmatised. Additional consideration and empathy may need to be evidenced by the provider when dealing with same sex couples. Lesbian, Gay and Bi sexual, transgender, individuals may be isolated or estranged from their families, this limiting their opportunities to ask for support or accessing this service.	and 4,000 aged 11-15 who identify as lesbian, gay or bisexual[10]. It is likely this is a conservative estimate as the true number of people identifying themselves as lesbian, gay or bisexual, is more realistically estimated as being 9-10% of the population. According to the 2011 census 0.7% of Surrey residents identified themselves as same sex couples. LBGTQ experience poorer health outcomes than their peers – through the effects of bullying and social stigma associated with their sexuality, and through adoption of risky behaviours that are often used as a coping strategy[11].
Marriage and civil partnerships	People who have been diagnosed with dementia can access this service. Individuals in either marriage of same sex partnership can have equitable access to this service and support.	There are no negative impacts for people in marriage of civil partnership to the access and support this service can offer.	According to census data from 2011 there are 482,257 people in Surrey who are married or in a civil partnership 1,602 of whom are in same-sex civil partnerships[12].

10 JSNA Chapter: The Surrey Context – People & Places
11 JSNA Chapter: Lesbian, gay, bisexual and transgender
12 Surrey-i Census 2011 dataset

Carers[13]	The service should assist the carer to build contingency and advanced plans with regard to options for resilience and ongoing support to continue in their caring role as the dementia disease progresses. Dementia has a greater impact on women as the majority of carers are women. This service can be accessed by any carer to support them in their caring role.	Carers and families may feel an obligation to provide more care and support than they feel able to cope with. Caring responsibilities may fall disproportionality on women who are traditionally perceived as taking on a caring role within the family or community and may therefore be reluctant to access the support through this service.	Taking the number of carers from the 2011 Census as a percentage of the total Surrey population, and applying that to future population projections, we can estimate that in 2016 there were 115,216 carers of all ages living in Surrey. This equated to 10% of the population. An estimated 17% of carers provided more than 50 hours unpaid care per week and 28% provided more than 20 hours unpaid care per week.[14] There are estimated to be approximately 14,750 young carers living in Surrey.[15] According to Carers UK's analysis of the 2001 Census findings, those caring for 50 hours a week or more are twice as likely to be in poor health as those not caring (21% against 11%). This can be due to a range of factors including stress related illness and physical injury[16] The 'Healthy Lives Healthy People' 2010 report stated that carers who care for 50 hours a week or more are 80% more likely to have health impacts. It also stated that carers providing 20 hours per week or more are likely to sustain a physical injury such as back strain.[17]

7b. Impact of the proposals on staff with protected characteristics

[13] Carers are not a protected characteristic under the Public Sector Equality Duty, however we need to consider the potential impact on this group to ensure that there is no associative discrimination (i.e. discrimination against them because they are associated with people with protected characteristics). The definition of carers developed by Carers UK is that 'carers look after family; partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid. This includes adults looking after other adults, parent carers looking after disabled children and young carers under 18 years of age.'
Dementia Consortium

Alzheimers Research UK

[14] Census 2011 population projections

[15] Census 2011 population projections and University of Nottingham. *Kids who Care*, 2010. Available from: http://www.bbc.co.uk/news/education-11757907

[16] Carers UK. *In Poor Health,* 2004. Available from: http://static.carers.org/files/in-poor-health-carers-uk-report-1674.pdf

[17] Department of Health. *Healthy Lives Healthy People*, 2010. Available from: https://www.gov.uk/government/publications/healthy-lives-healthy-people-our-strategy-for-public-health-in-england

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Protected characteristic	Potential positive impacts	Potential negative impacts	Evidence
Age	This is a longstanding service which has been commissioned since 2011. The impact on operational and/or clinical staff relates to those employed by organisations that specifically adhere to legislation and policy that protects the characteristic groups. In respect of ensuring Service Provider compliance the agreed Terms and Conditions drafted by the Commissioning Organisations have put in place a requirement for the Provider to be compliant with the Equalities Act 2010 which includes all legislation in respect to discrimination by the protected characteristics e.g. Age. Furthermore, as part of the tender exercise the Service Provider is required to state their compliance to relevant legislation and confirm they have an equalities policy in place which can be verified by the Commissioners.	N/A	

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Disability	As above	N/A	N/A
Gender reassignment	As above	N/A	N/A
Pregnancy and maternity	As above	N/A	N/A
Race	As above	N/A	N/A
Religion and belief	As above	N/A	N/A
Sex	As above	N/A	N/A
Sexual orientation	As above	N/A	N/A
Marriage and civil partnerships	As above	N/A	N/A
Carers	As above	N/A	N/A

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8. Amendments to the proposals

Change	Reason for change
Delivery of services across CCG boundaries instead of District and Boroughs to match the funding each CCG area gives to the service.	The referral pathways to the service are largely through the clinical pathways within each CCG following dementia diagnosis.
Improved access for people with Learning Disability who have been diagnosed with Dementia. Improved access to people diagnosed with Early Onset Dementia.	Following consultation improved clinical pathways and targeted approach by Dementia Navigator service to engage with people with Learning disability and diagnosed with dementia – connecting to providers who support people in supported living environments for people with Learning Disability. Also focus on flexible service delivery approach to support people of working age who have been diagnosed with early onset dementia and their carers /families.
Targeted focus on building connections with support organisations across local communities for resilience building and sustainability of support for individuals diagnosed with dementia and their carers. With a focus preparing contingency and advanced plans to manage as the disease progresses to reduce the risk of crisis management and or acute admissions to Hospital / NH placements.	To empower individuals living with dementia and their carers to build resilience and sustainability of support and reduce the risk crisis management. Sharing advanced plans that are led by the person who has dementia before they lose capacity to make decisions about how their needs are met. Maximise the use of all voluntary / statutory support and community networks at the right time for individuals.
Improved KPI and performance measurements focused on CCG areas to evidence delivery of service to local populations.	Previous contract measurements were countywide. Health governance structures and CCG / STP boundaries changing since previous contract retender.

9. Action plan

Potential impact (positive or negative)	Action needed to maximise positive impact or mitigate negative impact	By when	Owner
The positive impacts will be incorporated during the implementation period of the contract for full	Negotiation with the Service Provider regarding points outlined in section 7.	1st June 2019	Melanie Nunn/ Marion Heron

realisation from the start of the contract. There are some foreseen negative impacts relating to the proposed changes to this well-established service as reasoned in section 7 for either service users or staff.			

10. Potential negative impacts that cannot be mitigated

Potential negative impact	Protected characteristic(s) that could be affected
There is a recognition that there may be potential changes within CCG / STP boundaries that are emerging which impact on clinical governance structures the commitment to the level of funding, accessibility for people receiving the service and geographical areas for service delivery across the county. This may result in people not receiving a timely or equitable service, leading to other statutory and non-statutory services being approached to provide support either earlier than they need to or responding to a crisis.	All of the above who access the current services

11. Summary of key impacts and actions

Information and engagement underpinning equalities analysis	As part of the review of the Dementia Navigator service and re-tender process stakeholder groups were engaged and consulted with. These included: • CCG clinical commissioners with a lead for Mental Health • CCG Mental Health Collaborative • Clinical Professionals • Co-Commissioners (CCG and SCC) • Procurement • Finance • Legal • IMT • Users / carers Dementia Support groups • District and Boroughs

	A series of meeting and workshops were held to collate feedback and views on how this current service operated and what improvements could be made.
Key impacts (positive and/or negative) on people with protected characteristics	In respect of the negative impacts there is no proposed change to eligibility criteria for this service. In respect of the positive impacts people in receipt of this service will experience the following enhancements over the existing service: • Improved accessibility and targeted approach to individuals with a Learning disability who have been diagnosed with dementia and those people of working age who have been diagnosed with Young Onset Dementia. • Improved support for individuals diagnosed with Dementia and their carers across ethnic groups and harder to reach groups living in Surrey, to empower and build connections with local support networks, agencies and organisations to build resilience to continue living in their communities. Overall this improved service based on enhancements above will lead to better outcomes and improved "Customer Experience". • Better and improved outcomes from KPI performance measures to share across Health and Social care systems reflecting the needs of the populations of people and their carers living with dementia in the communities.
Changes you have made to the proposal as a result of the EIA	There are no changes to the proposal as a result of the EIA.
Key mitigating actions planned to address any outstanding negative impacts	There are foreseen negative impacts relating to the proposed changes to this well-established service as reasoned in section 7 for either service users or staff. • Safeguarding issues need to be considered, particularly for people with learning disabilities or mental health needs, who may be more vulnerable in some community situations. • The service will need to do some targeted work with some ethnic/ cultural groups for whom Dementia is not recognised and support available to them is not accessed in the traditional manner. • The Lesbian, Gay, Bi sexual and Transgender (LGBT) individuals who have been diagnosed with dementia may not access the service, if they believe they will be stigmatised.

	Additional consideration and empathy may need to be evidenced by the provider when dealing with same sex couples.
Potential negative impacts that cannot be mitigated	There are foreseen negative impacts relating to the proposed changes to this well-established service as reasoned in section 7 for either service users or staff. • There is limited specialist community provision for gender reassignment, individuals may be isolated or estranged from their families this limiting their opportunities to ask for help or access this service.