Form 1: Preparation

Part A must be completed at the beginning of a Policy/function/strategy development or review, and for every such occurrence. (Refer to the Step-by-Step Guide for additional information).

Step	1 - Preparation							
1.	Title of Policy - what are you equality impact assessing?	New service model for Sickle Cell and Thalassaemia Service in Butetown as outlined in Service Specification for the Sickle Cell and Thalassaemia Genetic Counselling Service document March 2012.						
2.	Policy Aims and Brief Description - what are its aims? Give a brief description of the Policy (The What, Why and How?)							
3.	Who Owns/Defines the Policy? - who is responsible for the Policy/work?	Sharon Hopkins, Director of Public Health.						
4.	Who is Involved in undertaking this EqIA? - who are the key contributors to the EqIA and what are their roles in the process?	HaematologyMedical GeneticsLaboratory MedicinePatients, family and carersPaediatricsFriends of Sickle Cell and Thalassaemia Centre						

Step 1	- Preparation	
5.	Other Policies - Describe where this Policy/work fits in a wider context. Is it related to any other policies/activities that could be included in this EqIA?	 Equality, Diversity and Human Rights policy. Equality Act 2010. Strategic Equality Plan. Lone Working Policy. Together for Health. Our Healthy Future. Measuring inequalities 2011. NHS Sickle Cell and Thalassaemia Screening Programme. Standards for the Clinical care of Children and Adults with Thalassaemia in the UK 2008. Health Impact Assessment of the proposed accommodation changes to the Cardiff and Sickle Cell and Thalassaemia Centre 2011. BCSH Guidelines Significant Haemoglobinopathies: guidelines for screening and diagnosis 2010. Revised standards for English antenatal-neonatal screening programme 2011. Operational policy for the Cardiff Sickle Cell & Thalassaemia Centre 2002 South Glamorgan Health Authority District Policy for sickle cell, thalassaemia and related inherited red cell disorders 1994. EMQN Best Practice Guidelines for carrier identification and prenatal diagnosis of haemoglobinopathies.
6.	Stakeholders - Who is involved with or affected by this Policy?	Haematology, Medical Genetics, Laboratory Medicine, Midwifery and Paediatric departments, General Practitioners, Ante-natal Screening Wales. Sickle cell and thalassaemia patients, families and carers.

Step 1	- Preparation	
7.	What factors may contribute to the outcomes of the Policy? What factors may detract from the outcomes? These could be internal or external factors.	 Development of new patient and referral pathways. New born screening for Sickle Cell and Thalassaemia across Wales. Registration requirements for Genetic Counsellors. Communication of new pathways to patients and health care professionals. Engagement with public and monitoring of new service model. Up skilling of Genetic Counsellors with additional training. Organisational Change policy.

Form 2: Evidence Gathering

Equality Strand	Evidence Gathered	Doe	Does the evidence apply to the following with regard to this Policy/work? Tick as appropriate.								
Race	Equality Act 2010 Accessed 19/09/2012 Standards for the Clinical care of Children and Adults with Thalassaemia in the UK Accessed 08.03.12 Health Impact assessment of the proposed accommodation changes to the Cardiff Sickle Cell and Thalassaemia Centre 2011 Accessed 08.03.12 Better health Briefing 17 The social consequences of Sickle Cell and Thalassaemia : improving the quality of support A Race Equality Foundation Briefing Paper February 2012 Accessed 08.03.12 www.better-health.org.uk/briefings BCSH Guidelines Significant haemoglobinopathies: guidelines for screening and Diagnosis 2010 Accessed 08.03.12 Better Health Using evidence to promote race equality in health The social consequences of Sickle Cell and Thalassaemia: Improving the quality of support Race Equality Foundation 2010 Accessed 08.03.12 www.better-health.org.uk/briefings/social co consequences-Sickle-Cell-and-Thalassaemia Sickle Cell Anaemia. Focus on this condition in Disability History month. www.pcs.org.uk/en/equality/news/black members-newsletter.cfm Accessed 08.03.12	Eliminating Discrimination and Eliminating Harassment		Promoting Equality of Opportunity		Promoting Good Relations and Positive Attitudes		Encouraging participation in Public Life		Take account of difference even if it involves treating some individuals more favourably*	

Operational policy for the Cardiff Sickle Cell & Thalassaemia Centre 2002 <i>Accessed 19.09.2012</i> South Glamorgan Health Authority District Policy for sickle cell, thalassaemia and related inherited red cell disorders1994. <i>Accessed19.09.2012</i> EMQN Best Practice Guidelines for carrier identification						
and prenatal diagnosis of haemoglobinopathies J. Traeger-Synodinos1, J.M. Old2, M. Petrou3, R. Galanello4 <i>Accessed 19/09/2012</i> www.emqn.org/emqn/digitalAssets/0/235 HB eu.pdf ·						
Understanding the contribution of sickle cell and thalassaemia specialist nurses: a summary report May 2012 <u>sct.screening.nhs.uk</u> Accessed 02/07/2012						
Community& Vale Health Council CHC meeting report- Sickle cell and Thalassaemia service 2010 <u>www.wales.nhs.uk/sitesplus/897/page/48781</u> Accessed 08.03.12						
Sickle Cell and Thalassaemia Service Briefing paper 2012 Cardiff and Vale UHB <i>Accessed 08.03.12</i>						
Service Specification for the Sickle Cell and Thalassaemia Counselling Service March 2012 Accessed 17/12/2012						
Minutes of stakeholder meetings September 2011 and February 2012 <i>Accessed 08.03.12</i>						
Notes from meetings with representatives from Friends of Sickle Cell And Thalassaemia December 7 th 2011 October 16 th 2012 November 27 th 2012 <i>Accessed 17/12/2012</i>						

List of observations from FOSCT support group meeting 20/11/2012 Accessed 28.02.13					
Presentation by Friends of Sickle Cell and Thalassaemia Support Group February 2012 <i>Accessed 28.02.12</i>					
Race and social attitudes about sickle cell www.bioportfolio.com//35836/Impact-OfOn-Quality- Of-Care-In-Sickle-Cell-Patients.html Accessed 08.03.12					
www.sicklecellsociety.org WINTER NEWSLETTER 2011 Accessed 08.03.12					
www.ekhuft.nhs.uk//equality-and-human- rights/equality-impact-assessments/medicine-sickle cell guidelines Accessed 08.03.12					
Cardiff and Vale UHB Benchmarking UK Medical Genetics models for sickle cell and thalassaemia services Feb 2012 <i>Accessed 08.03.12</i>					
Knowledge and perceptions of haemoglobinopathy carrier screening among general practitioners in Cardiff Darren Shickle and Alison May 1989 <i>Accessed 08.03.12</i>					
Health Education Authority(1998)Sickle cell and Thalasaemia: achieving health gain. Guidance for commissioners and providers. Health education Authority, London hisweb.dmu.ac.uk/research/tasc.bibliography.html Accessed 08.03.12					

	Community& Vale Health Council CHC meeting report- Sickle cell and Thalassaemia service 2010 www.wales.nhs.uk/sitesplus/897/page/48781 Accessed March 2 nd 2012Welsh Health Impact Support Unit(2004)Improving Health and reducing Inequalities. A practical guide to Health Impact Assessment. Cardiff Institute of Society, Health and Ethics www.wales.nhs.uk/sites3/ Documents/52 Accessed 08.03.12Sickle Cell and Thalassaemia briefing for Minister February 2012 Accessed 08.03.12Understanding the contribution of sickle cell and thalassaemia specialist nurses: a summary report May 2012 sct.screening.nhs.uk Accessed 02/07/2012						
Disability	Equality Act 2010 Accessed 19/09/2012Standards for the Clinical care of Children and adults with Thalassaemia in the UK Accessed 08.03.12Health Impact assessment of the proposed accommodation changes to the Cardiff Sickle Cell and Thalassaemia Centre 2011 Accessed 08.03.12Sickle Cell Anaemia. Focus on this condition in Disability History month. www.pcs.org.uk/en/equality/news/black- members-newsletter.cfm Accessed 08.03.12Better health Briefing 17 The social consequences of Sickle Cell and Thalassaemia : improving the quality of support A Race Equality Foundation Briefing Paper February 2012 Accessed 08.03.12		\checkmark	~	\checkmark	\checkmark	

	Sickle Cell Anaemia. Focus on this condition in Disability History month. <u>www.pcs.org.uk/en/equality/news/black-</u> <u>members-newsletter.cfm</u> <i>Accessed 08.03.12</i>					
	Minutes of stakeholder meetings September 2011 and February 2012 <i>Accessed 08.03.12</i>					
	Notes from meetings with representatives from Friends of Sickle Cell And Thalassaemia December 7 th 2011 October 16 th 2012 November 27 th 2012 <i>Accessed 17/12/2012</i>					
	Presentation by Friends of Sickle Cell and Thalaessaemia Support Group February 2012 <i>Accessed 28.03.12</i>					
	www.sicklecellsociety.org WINTER NEWSLETTER 2011 Accessed 08.03.12					
	BCSH Guidelines Significant haemoglobinopathies: guidelines for screening and Diagnosis 2010 <i>Accessed 08.03.12</i>					
	Service Specification for the Sickle Cell and Thalassaemia Counselling Service March 2012 Accessed 17/12/2012					
	Sickle Cell and Thalassaemia briefing for Minister February 2012 <i>Accessed 08.03.12</i>					
	Knowledge and perceptions of haemoglobinopathy carrier screening among general practitioners in Cardiff Darren Shickle and Alison May 1989 <i>Accessed 08.03.12</i>					
Gender	Equality Act 2010 Accessed 19/09/2012	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark

	Standards for the Clinical care of Children and adults with thalassaemia in the UK Accessed 08.03.12 Better health Briefing 17 The social consequences of sickle cell and thalassaemia : improving the quality of support A Race Equality Foundation Briefing Paper February 2012 www.better-health.org.uk/briefings Accessed 08.03.12 Minutes of stakeholder meetings September and February 2012 Accessed 08.03.12 Presentation by Friends of Sickle cell and Thalaessaemia Support Group February 2012 Accessed 28.02.12 www.sicklecellsociety.org WINTER NEWSLETTER 2011 Accessed 08.03.12 BCSH Guidelines Significant haemoglobinopathies: guidelines for screening and Diagnosis 2010 Accessed 08.03.12 Sickle Cell and Thalassaemia briefing for Minister February 2012 Accessed 08.03.12					
Sexual Orientation	Equality Act 2010 <u>Accessed 19/09/2012</u> Standards for the Clinical care of Children and Adults with Thalassaemia in the UK <i>Accessed 08.03.12</i> Better health Briefing 17 The social consequences of sickle cell and thalassaemia : improving the quality of support A Race Equality Foundation Briefing Paper February 2012 <i>Accessed 08.03.12</i> www.better-health.org.uk/briefings	√	\checkmark	1	\checkmark	

	 Minutes of stakeholder meetings September 2011 and February 2012 Accessed 08.03.12 Presentation by Friends of Sickle Cell and Thalaessaemia Support Group February 2012 Accessed 28.02.12 www.sicklecellsociety.org WINTER NEWSLETTER 2011 Accessed 08.03.12 BCSH Guidelines Significant haemoglobinopathies: guidelines for screening and Diagnosis 2010 Accessed 08.03.12 Sickle cell and Thalassaemia briefing for Minister February 2012 Accessed 08.03.12 				
Age	 Equality Act 2010 Accessed 19/09/2012 Standards for the Clinical care of Children and Adults with Thalassaemia in the UK Accessed 08.03.12 Health Impact assessment of the proposed accommodation changes to the Cardiff Sickle Cell and Thalassaemia Centre 2011 Accessed 08.03.12 Better health Briefing 17 The social consequences of Sickle cell and Thalassaemia : improving the quality of support A Race Equality Foundation Briefing Paper February 2012 Accessed 08.03.12 Minutes of stakeholder meetings September 2011 and February 2012 Accessed 08.03.12 Presentation by Friends of Sickle cell and Thalassaemia Support Group February 2012 Accessed 28.02.12 www.sicklecellsociety.org WINTER NEWSLETTER 2011 Accessed 08.03.12 	N	$\overline{\mathbf{v}}$		

	BCSH Guidelines Significant haemoglobinopathies: guidelines for screening and Diagnosis 2010 <i>Accessed 08.03.12</i> Sickle cell and Thalassaemia briefing for Minister February 2012 <i>Accessed 08.03.12</i>					
Religion or Belief	 Equality Act 2010 Accessed 19/09/2012 Standards for the Clinical care of Children and Adults with Thalassaemia in the UK Accessed 08.03.12 The influence of faith and religion and the role of religious and community leaders in prenatal decision for Sickle Cell disorder and Thalassemia major www.ncbi.nim.nihgov/pubmed/16927359 Accessed 08.03.12 Better health Briefing 17 The social consequences of Sickle Cell and Thalassaemia : improving the quality of support A Race Equality Foundation Briefing Paper February 2012 Accessed 08.03.12 Minutes of stakeholder meetings September 2011 and February 2012 Accessed 08.03.12 Notes from meetings with representatives from Friends of Sickle Cell And Thalassaemia December 7th 2011 October 16th 2012 November 27th 2012Accessed 17/12/2012 Presentation by Friends of Sickle Cell and Thalaessaemia Support Group February 2012 Accessed 28.02.12 www.sicklecellsociety.org WINTER NEWSLETTER 2011 Accessed 08.03.12 			\checkmark	V	

Human Rights	······································										
not to be punis religion; to free	human right to: life; not to be tortured or treated in a degradir hed without legal authority; to respect for private and family lif dom of expression and of assembly; to marry and found a far e European Convention.	e, hom	e and	correspon	dence; to f	reedom	of the	ought, c	conscience and		
Welsh Language	 Standards for the Clinical care of Children and Adults with Thalassaemia in the UK <i>Accessed 08.03.12</i> Better health Briefing 17 The social consequences of sickle cell and thalassaemia : improving the quality of support A Race Equality Foundation Briefing Paper February 2012 <i>Accessed 08.03.12</i> Sickle Cell and Thalassaemia briefing for Minister February 2012 <i>Accessed 08.03.12</i> 		√	\checkmark	N		√		1		
	Sickle cell and thalassaemia briefing for Minister February 2012 Accessed 08.03.12										

* This column relates only to Disability due to the specific requirement in the Equality Act 2010 to treat disabled people more favourably to achieve equal outcomes. This is not applicable to the other equality strands.

Form 3: Assessment of Relevance and Priority

Equality Strand	Evidence: Existing evidence to suggest some groups affected. Gathered from Step 2. (See Scoring Chart A)	Potential Impact: Nature, profile, scale, cost, numbers affected, significance. Insert one overall score (See Scoring Chart B)	Decision: Multiply 'evidence' score by 'potential impact' score. (See Scoring Chart C)
Race	3	+2	+6
Disability	3	+1	+3
Gender	3	0	0
Sexual Orientation	3	0	0
Age	3	0	0
Religion or Belief	3	0	0
Welsh Language	2	0	0
Human Rights	3	+1	+1

Scoring Chart A: Evidence Available

3	Existing data/research
2	Anecdotal/awareness data only
1	No evidence or suggestion

Scoring Chart B: Potential Impact

-3	High negative	
-2	Medium negative	
-1	Low negative	
0	No impact	
+1	Low positive	
+2	Medium positive	
+3	High positive	

Scoring Chart C: Impact Decision

-6 to -9	High Impact (H)	
-3 to -5	Medium Impact (M)	
-1 to -2	Low Impact (L)	
0	No Impact (N)	
1 to 9	Positive Impact (P)	

FORM 4: (Part A) Outcome Report

New service model for Sickle Cell and Thalassaemia service in Butetown as outlined in Service Specification for the Sickle Cell and Thalassaemia Genetic Counselling Service document March 2012
Cardiff and Vale UHB
Gina Gwynne
Directorate Manger
Haematology, Clinical Immunology and Medical Genetics Department
 Each quality strand was discussed in detail with an overall low to medium positive impact agreed. Monitoring and audit will be a key in evaluating the new service model and ensuring that a robust service for patients will be maintained. Positives highlighted included Increased access over 52 weeks of the year. Enhanced nurse specialist role. Enhanced level of support and care required for patients who need inpatient intervention. Genetic Counsellor expertise in signposting, experience with patients who have a disability. Use of existing pathways. Existing referral meetings and Multidisciplinary Team Meetings.

Concerns highlighted included			
CONCERNS	ACTIONS TO MITIGATE		
Uncertainty as laboratory pathways had not been finalised.	Meetings have taken place and will continue to ensure pathways are finalised and robust prior to commencement of new service model.		
Sickle Cell may become lost within a bigger service area and lose its identity having a detrimental effect on the Sickle Cell and Thalassaemia community.	Weekly Multidisciplinary Team Meetings (MDT). Medical Genetics Service and Haematology Departments are located within one Directorate where the management team have responsibility for both departments.		
Lack of Genetic Counsellor(GC) expertise in sickle cell and thalassaemia with no specific training in these conditions which will effect all the strands within the equality impact assessment.	The Genetic Counsellors are qualified to Masters level. The AWMGS is an approved Genetic Counsellor training centre. A GC already employed by C&V LHB has experience of working with this client group in an area of South West England. Genetic Counsellors will attend relevant study days and conferences. Expertise from clinical service readily available.		
Issues with access to and visibility of the service since the transfer to the new Butetown Health Centre.	Signage has been agreed and will be installed in February 2013.		
Monitoring arrangements/ audit tools need to be agreed.	Have been agreed as outlined later in this document.		
Onus will be on GPs to refer with a possible reduction in referrals.	Referrals will be monitored .		
The sickle cell and thalassaemia community are a vulnerable group and the change in the service model will cause concern and anxiety to them.	Continue to work with Friends of Sickle cell and local community to help alleviate concerns.		

Service users may lose a holistic approach due to loss of co-ordinator role and the division of service to genetic and clinical.	The Medical Genetics and Haematology services will work closely together via the MDT. Identification of a project lead, the Service Manger for the All Wales Medical Genetics Service to oversee and monitor changes and be a contact point should concerns be highlighted.
There was particular concern raised in regard to the age section as it was difficult to agree a decision in regard to the ante -natal element of the service.	The pathways will follow the existing prenatal pathways as defined by Ante-natal Screening Wales and ensure a timely response to referrals so will be unchanged from the current process. Pre-conceptual, neonatal, young people, adolescents and older adults all have different needs from the service and will come into the service from different routes to include GP, family screening, prenatal advice, emergency stream etc. This is recognised and a wider range of experience of staff within the new model will improve our ability to meet the needs of this client group. Close monitoring is required and agreed actions include a weekly MDT, audit and pathway review.
Loss of database information (register) that is essential for service development	This will continue.
Loss of access by laboratory staff to full family information and additional information relevant to clinical care but held by Medical Genetics and not otherwise available	Relevant information will be accessible as required.
Loss of service at Butetown to include no open door service Reduced staffing.	Drop in clinics will be available. Staffing establishment has not been reduced and will include 2 full time clinical and 1 full time administrative staff.

No dedicated and 'sickle & thalassaemia'-friendly counselling space or meeting room.	Clinical room available daily but dedicated space has not been available since the transfer of services
	from the previous to current Butetown Health Centre in April 2012.
	Management team are working with Locality team to improve the clinical environment for patients and staff.
Loss of patient and community support for screening, not fulfilling the expectations expressed at the Health Impact Assessment regarding the sort of service the patients wish to have and which they have had in the past.	Screening will continue as required. New service model will be closely monitored.
Loss of robust communication links between the different parts of the service. Not listening to concerns of existing members of the team and implementing changes that undermine the existing very well joined-up aspects.	Communication will be led by weekly MDT and interaction will take place as required. Regular meetings have been held with the Sickle Cell and Thalassaemia team to discuss concerns. Impact of new service model will be closely monitored.
Increased costs due to disruption of a very well integrated service. Increased attendance of carriers seeking information and advice at haematology outpatient clinics.	The new service model has been assessed as cost neutral. There is no evidence to suggest that there will be an increase in outpatient attendances as the Clinical Nurse Specialist for Sickle cell and Thalassaemia will be based at Butetown Health Centre.
Harm done by misinformation caused by dismantling the current route linking diagnosis with the offer of counselling and information. Harm done by lack of consistency in information given.	The Genetic Counsellor staff who will provide counselling to patients are highly qualified. They will ensure that the patients are provided with the most up to date information available to enable patients to make informed choices. The All Wales Medical Genetics Service has a robust audit programme in place which will identify and shortfalls in the service.

Loss of equity in service to other genetic and hemaglobinopathy support services – it is believed by the FOSCT group that race is a factor in decision making.	An overall low to medium positive impact has been recognised. Monitoring arrangements in place. Any necessary actions will be taken forward, as appropriate.

Decision to Proceed to Part B Equality Impact Assessment:	No					
impact Assessment.	Please record reason(s) for decision					
	Following discussion by the stakeholders the change was					
	assessed as having a low to positive impact and that monitoring arrangements over the first 6 months would be sufficient to identify the impact of the service model change on					
	the delivery of patient care.					

Action Plan

You are advised to use the template below to detail any action that are planned following the completion of Part A or Part B of the EqIA impact, as well as any arrangements to collect data or undertake further research.

	Action(s) proposed or taken	Reasons for action(s)	Who will benefit?	Who is responsible for this action(s)?	Timescale
1. What changes have been made as a result of the EqIA?	Included an equality statement	To demonstrate the UHB commitment to the equality agenda	The Statement makes it clear that all our patients or carers or relatives will benefit in knowing that they will not be discriminated against due to any protected characteristic	The author of the Policy	Already completed
2. Where a Policy may have differential impact on certain groups, state what arrangements are in place or are proposed to mitigate these impacts?	1 Stakeholder meetings where model has been discussed with all parties prior to implementation	Community involvement	Staff and patients	Stakeholders	Already completed
	2 Development of new patient pathways	Clear direction to ensure a safe patient journey	Staff and patients	Genetics, Laboratory and medical staff	In progress

3.Commence weekly MDT meetings	To agree and confirm management plan	Staff and patients	Genetics, Laboratory and medical staff	On commencement of new model
4. Identification of a project lead to oversee and monitor changes and be a contact point should concerns be highlighted within the first 6 months	Monitor progress/ concerns	Staff and patients	Service Manager Genetics	Completed
5. Audit of positive tests in relation to referrals	Identification of any reduction in referrals.	Patients	Laboratory and genetics staff.	Following commencement of new model
6. Review in 6 months	Monitor progress/ concerns	Staff and patients	Stakeholders	6 months following commencement of new model

2. Justification: For when a policy may have adverse impact on certain groups, but there is good reason not to mitigate.	NA	NA	NA	NA	NA
4. Describe any mitigating actions taken?	NA	NA	NA	NA	NA
 Provide details of any actions planned or taken to promote equality. 	We have included an equality statement into the guideline that clearly states that the policy is applicable to all as appropriate to individual, service area and organisational circumstances.We would provide copies of the document in alternative formats, including Welsh if required as via appropriate Strategic Equality Plan and Welsh Language Scheme.	Cardiff & Vale UHB want to be explicit about its commitment to the equality agenda/legislation. To ensure that our services are accessible (to all).	Patients will be the primary beneficiaries which will impact positively on them, their families and/or carers as applicable. Any individual requiring our services as well as enhancing the organisations reputation.	Line managers, Ward and directorate/departm ent leads are responsible.	Dependent on individual request or clinical need.

Date:	February 11 th 2013		
Monitoring Arrangements:	 Medical Genetics already have a review mechanism in place where new pathways are reviewed on a 6 monthly basis. Continuous monitoring will be taken forward via th weekly MDT. Weekly referral meetings already take place where a management plan for each referral is agreed by the multidisciplinary team and will include sickle cell and thalassaemia referrals. Introduction of weekly MDT to review patients. These will be held at Butetown Health Centre and involve the medical, nursing and genetic counsellor staff where all aspects of patient care will be discussed. Monitoring of referrals and attendances. Audit of positive tests in relation to referrals. Identification of a project lead, the Service Manger for th All Wales Medical Genetics Service to oversee and monitor changes and be a contact point should concern be highlighted. A patient satisfaction survey prior to and 6 months following service model change. Mr Vaughan Gethin AM has agreed to chair a formal review in 6 months. 		
Review Date:	6 months from commencement of new service model		
Signature of All Parties:			
	Dr Jonathan Kell Haematology		
	Dr Annie Proctor Medical Genetics		
	Dr Andy Goringe .Laboratory Medicine		
	Dr Phil Connor Paediatrics		
	Friends of Sickle Cell and Thalassaemia		