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Health Impact Assessment of the proposed accommodation changes to the Cardiff Sickle Cell and Thalassaemia Centre

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Date: 27 April 2011

Version: v2a FINAL

Publication/ Distribution:

- Health Impact Assessment Steering Group, including the Friends of the Sickle Cell and Thalassaemia Centre
- Participants who attended the Health Impact Assessment Participatory Workshop
- Wales Health Impact Assessment Support Unit
- Cardiff and Vale University Health Board
 - Executive Team
 - Primary, Community and Intermediate Care Division
 - Specialist Services Division
- Cardiff and Vale Community Health Council
- Cardiff Council
- Public Health Wales

Purpose and Summary of Document:

This report considers the health impact assessment of proposed accommodation changes to the Cardiff Sickle Cell and Thalassaemia Centre. It considers existing service provision, referrals to the Sickle Cell and Thalassaemia Centre, the residency of users and of the black and minority ethnic population as a whole, the discussions that occurred at a participatory workshop and the information collated by the Friends of the Sickle Cell and Thalassaemia Centre. Conclusions and recommendations for service delivery are presented.

Contents

		Page number
1.	Main recommendation	2
2.	Executive Summary	2
3.	Introduction	4
	3.1 The Cardiff Sickle Cell and Thalassaemia Service	5 5
	3.2 The Cardiff Sickle Cell and Thalassaemia Centre	
4.	Background to the proposal	11
	4.1 Service proposal	11
	4.2 Discussions on the service proposal	12
5.	Health Impact Assessment	12
	5.1 Scoping stage	13
	5.2 Participatory Workshop	14
6.	Conclusions	20
7.	Recommendations	21
8.	Next Steps	21
9.	Appendices	21
	9.1 Organisations invited to the HIA Workshop	
	9.2 Invitation to the HIA Workshop	
	9.3 Agenda for the HIA Workshop	
	9.4 Attendance by Organisation and numbers	
	9.5 HIA Tool	
10.	References	27

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1. Main recommendation

The key recommendation of this report is as follows:-

- The preferred and recommended site of the Sickle Cell and Thalassaemia Centre is within the Butetown area as part of the Loudoun Square facility. This base should be its sole location.

2. Executive summary

Sickle cell, thalassaemia and other severe haemoglobin disorders are rare inherited anaemias requiring specialist life-long treatment to prevent severe complications and improve survival. It is estimated that 80 patients, although this figure could be higher than 100, have haemoglobin disorders, mainly from south, west and mid Wales and approximately 13,700 individuals in Wales are likely to be carriers, around 4000 of these living in Cardiff and the Vale of Glamorgan.

Patients, carriers of the trait, carers and families receive treatment and support from the Sickle Cell and Thalassaemia Service (of Cardiff and Vale University Health Board). The service is delivered through the Cardiff Sickle Cell and Thalassaemia Centre (based at Butetown Health Centre) and the laboratory and medical services for adults and children at the University Hospital of Wales and the Children's Hospital for Wales.

Service delivery proposals proposed that the Sickle Cell and Thalassaemia Centre relocate from the Butetown Health Centre to the re-developed Cardiff Royal Infirmary, retaining some clinic sessions in Butetown at the new Loudoun Square facility. Following communication and correspondence over a number of years between the Cardiff and Vale University Health Board (and previously Cardiff Local Health Board) and the Friends of the Cardiff Sickle Cell and Thalassaemia Centre, it was agreed to conduct a health impact assessment of the service proposal on the health of the population with sickle cell and thalassaemia and on their service access needs.

This report of the health impact assessment considers best practise in service provision, referrals to the Sickle Cell and Thalassaemia Centre, the residency of users and of the black and minority ethnic

population as a whole, the discussions that occurred at a participatory workshop and the information collated by the Friends of the Sickle Cell and Thalassaemia Centre.

The conclusions and recommendations that may be drawn include:-

- Members of black and minority ethnic communities live across South Wales but the main areas of residency are within Cardiff
- Those communities with a high prevalence of sickle cell and thalassaemia live mainly in the Butetown, Riverside and Adamsdown areas of Cardiff, with the highest population numbers in Butetown
- Referrals to the Sickle Cell and Thalassaemia Centre have increased year on year for the last ten years, with the higher referral rates being received from Butetown, Grangetown, Riverside, Adamsdown and Plasnewydd
- Members of black and minority ethnic communities are more likely to access services that reflect their culture and beliefs
- Positioning the Sickle Cell and Thalassaemia Centre across two sites would reduce service access and cause confusion amongst users
- The preferred and recommended site of the Sickle Cell and Thalassaemia Centre is within the Butetown area as part of the Loudoun Square facility. This base should be its sole location.
- The service provided by the Sickle Cell and Thalassaemia Centre is valued by the users but requires attention to ensure it develops into an effective, comprehensive and innovative provision. Robust data collection and liaison and co-ordination with other support services require attention.

3. Introduction

Sickle cell, thalassaemia and other severe haemoglobin disorders are rare inherited anaemias, of a similar birth incidence rate to that of cystic fibrosis and phenylketonurea, requiring specialist life-long treatment to prevent severe complications and improve survival. The highest prevalence occurs in people of African, African-Caribbean, Middle East, India, South East Asia and the eastern Mediterranean origin (in particular, Cypriot). Population estimates by ethnic group show that Cardiff has the largest percentage (10%) of non-White people in Wales (StatsWales 2009) and the prevalence of the haemoglobin disorders reflects the population trend (Public Health Wales 2010). Additionally, although Wales is considered a low risk area by the National Screening Committee, the antenatal screening programme for sickle cell identified nearly half of the screened pregnant women in the Cardiff & Vale area as high risk because of their ancestry (Public Health Wales 2010).

It is estimated that 80 patients, although this figure could be higher than 100, have haemoglobin disorders, mainly from south, west and mid Wales (Public Health Wales 2010). With regards to the predicted number of carriers, based on population estimates and percentage of ethnic minority residents in Wales in 2005, approximately 13,700 individuals in Wales are likely to be carriers, and around 4000 of these are living in Cardiff and the Vale of Glamorgan (Public Health Wales 2010).

The proportion of carriers of a haemoglobin disorder also needs to be considered in service development. For example, up to one in four black Africans carries the sickle cell trait and one in six Cypriots carries the beta thalassaemia trait. It is estimated that 9% of black and minority groups in the UK are carriers of a haemoglobin disorder (Health Education Authority 1998).

Provision of a comprehensive care programme, involving professionals from a range of health and social care agencies, has been identified as a means of offering optimal care for patients and their families and has been shown to reduce mortality and morbidity leading to decreased use of the NHS and ultimately, financial savings (Atkin and Anionwu 2010).

3.1 The Cardiff Sickle Cell and Thalassaemia Service

In June 2010, Public Health Wales undertook an epidemiological overview of the existing service provision for haemoglobinopathies in Cardiff and the Vale of Glamorgan and presented options for future service delivery. The report found that

- the Cardiff and Vale service is provided by a small multidisciplinary team of medical, nursing (including the Cardiff Sickle Cell and Thalassaemia Centre) and laboratory staff
- the service is a virtual service delivered through the Cardiff Sickle Cell and Thalassaemia Centre (based at Butetown Health Centre), the laboratory services and the medical services for adults and children at the University Hospital of Wales and Children's Hospital for Wales.

The overall service was identified as an example of best practice, meeting the main requirements (about 85%) for a regional specialist service but with some gaps, notably links to medical genetics, psychology and social worker sessions and formalised all Wales network arrangements (Public Health Wales 2010).

The remainder of this report refers to the Sickle Cell and Thalassaemia Centre based at Butetown Health Centre.

3.2 The Cardiff Sickle Cell and Thalassaemia Centre

The Cardiff Sickle Cell and Thalassaemia Centre is the only haemoglobinopathies advisory resource in Wales delivering on key standards within the framework of care for haemoglobinopathy patients (Public Health Wales 2010). The Centre provides support and advice to patients, carers and carriers; coordinates work between primary care/community and haematology; advises on genetic counselling; maintains the population based register of patients and their families; liaises with the Antenatal Screening Programme (and the proposed neonatal screening programme); educates the public and various groups of health professionals through a range of initiatives; and accepts referrals from across and outside the Cardiff and Vale area.

Referrals to the Sickle Cell and Thalassaemia Centre have increased since its establishment in 1986. Data for the last ten years highlights that referrals show an upward trend. Approximately 400

patients from the Cardiff and Vale area were referred in 2010, compared to approximately 200 in 2001. Table 1 illustrates the numbers of referrals for each year since 2001. It is based on postcode data, including when no valid postcode data was available.

Table 1 Referrals to the Sickie Cell and Thalassaemia Centre 2001-2010

	Referrals from Cardiff and Vale			Referrals from outside of Cardiff and Vale			Overall total number of referrals
	Valid postcode data available	No valid postcode data available	Total	Valid postcode data available	No valid postcode data available	Total	
2001	181	24	205	23	29	52	257
2002	201	43	244	35	34	69	313
2003	217	43	260	29	45	74	334
2004	274	37	311	26	50	76	387
2005	283	29	312	20	60	80	392
2006	259	32	291	17	58	75	366
2007	315	31	346	20	63	83	429
2008	325	12	337	27	74	101	438
2009	381	20	401	41	64	105	506
2010	394	24	418	32	62	94	512

Source: data collated by Cardiff and Vale University Health Board and analysed by the Public Health Wales Observatory

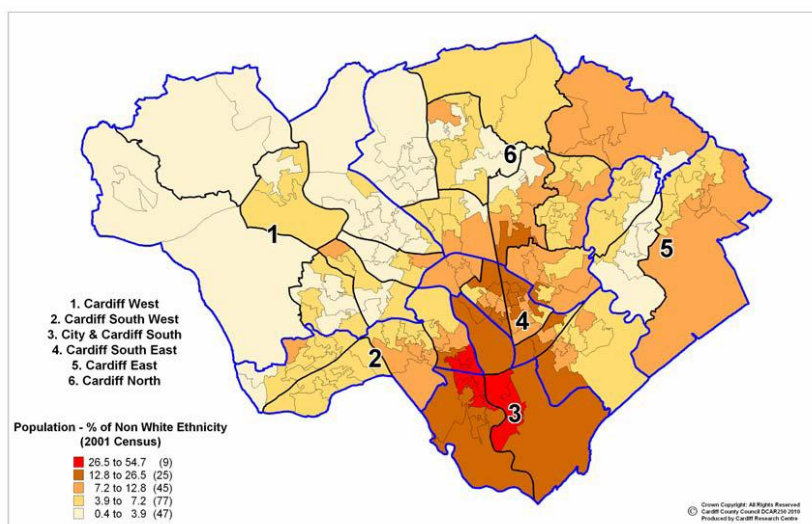
Place of residence of patients and carriers of the trait tend to follow the residency of black and minority ethnic communities. Across Wales, in 2001 the Census reported that 2.1% of the population are from ethnic minority groups with 6.7% from the Cardiff and Vale University Health Board area.

The Office for National Statistics produced population estimates by ethnic group (mid-2001 to mid-2007) for England and Wales and for constituent administrative areas (Government Office Regions in England, counties and local authorities), by age and sex. It showed that the overall estimated percentage of ethnic minorities in Wales is 2.9%, and that areas with the highest number of non-White people are Cardiff (10% n=32,000), Newport (5.3% n=7400), the Vale of Glamorgan (4% n=5000) and Swansea (3.3% n=7600). It is widely recognised that these figures are under-estimates and more recent data by StatsWales (2009) suggests that 3.6% of the Welsh population are from ethnic minority groups with 13.8% in

Cardiff, 6.6% in Newport, 2.6% in the Vale and 5.3% in Swansea reporting to be from non-White backgrounds.

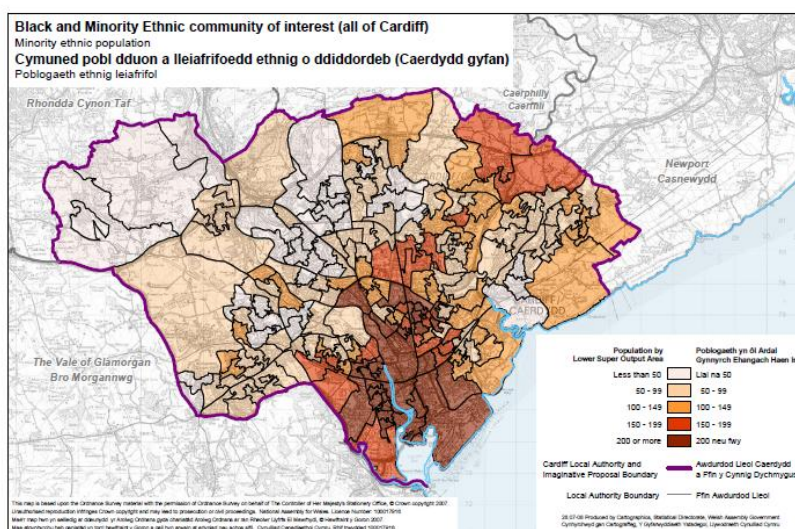
The following maps in Figures 1 to 4 highlight the spatial variation in Cardiff of the minority ethnic population. The maps were accessed from the ASK Cardiff website and the Welsh Assembly Government Communities First website. Figures 1 to 4 use the statistical geography of Lower Super Output Areas (LSOA). LSOAs facilitate the interpretation and use of data at a level below local authority county boundaries. There are 203 LSOAs in Cardiff each having a minimum population of 1000.

Figure 1 Percentage of Population of Non-White Ethnic Origin (Census 2001)



Source: ASK Cardiff

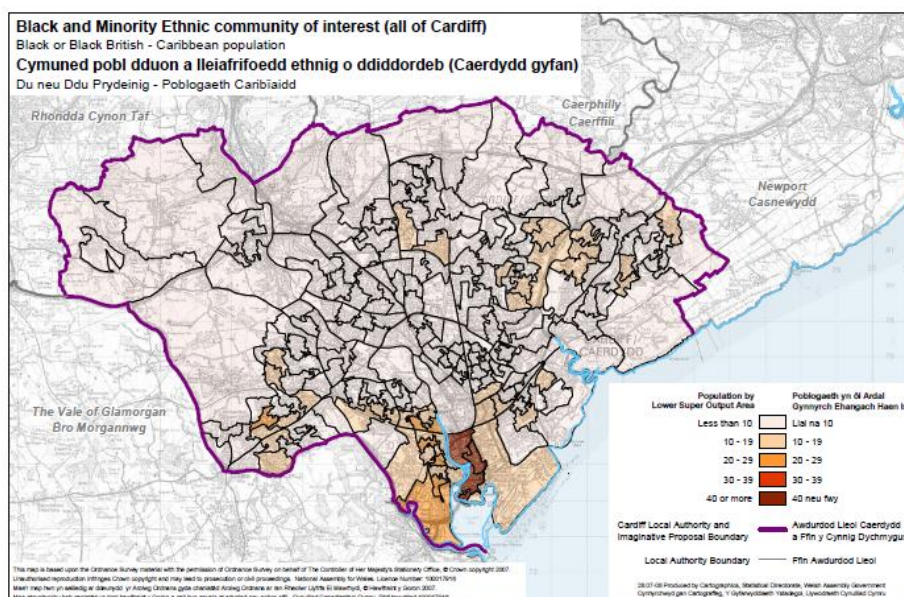
Figure 2 Population (those who identify themselves as part of the minority ethnic population) by Lower Super Output Area of people (2001)



Source: Communities First Welsh Assembly Government

Figures 1 and 2 illustrate that, in 2001, Cardiff's non-white population lived throughout the city with a large proportion living in the Riverside, Grangetown, Butetown, Adamsdown, Splott, Plasnewydd and Cathays areas.

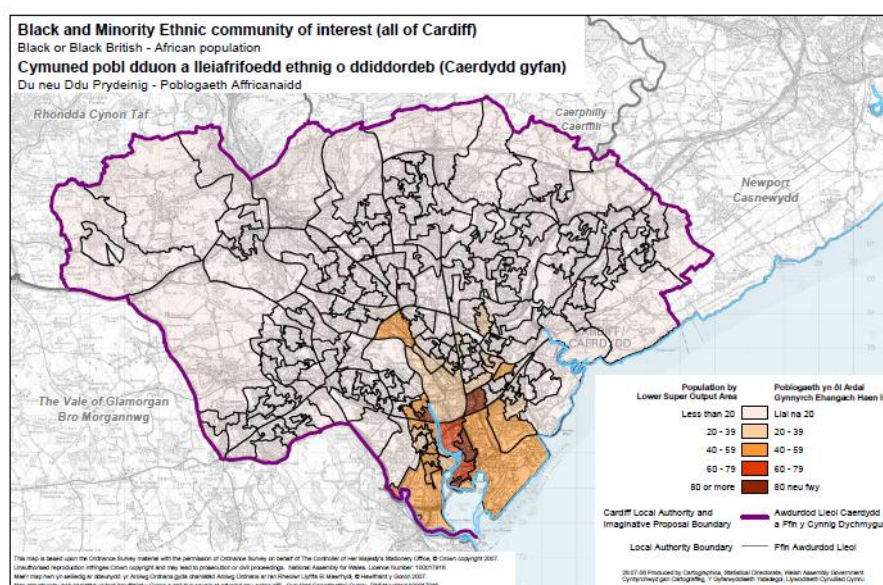
Figure 3 Population (those who identify themselves as Black or Black British-Caribbean) by Lower Super Output Area



Source: Communities First Welsh Assembly Government

Figure 3 illustrates that those who identify themselves as Black or Black British-Caribbean (a population group with a high prevalence rate for sickle cell, thalassaemia and other severe haemoglobin disorders) live mainly in the Butetown area but with some living elsewhere in smaller population concentrations.

Figure 4 Population (those who identify themselves as Black or Black British - African) by Lower Super Output Area

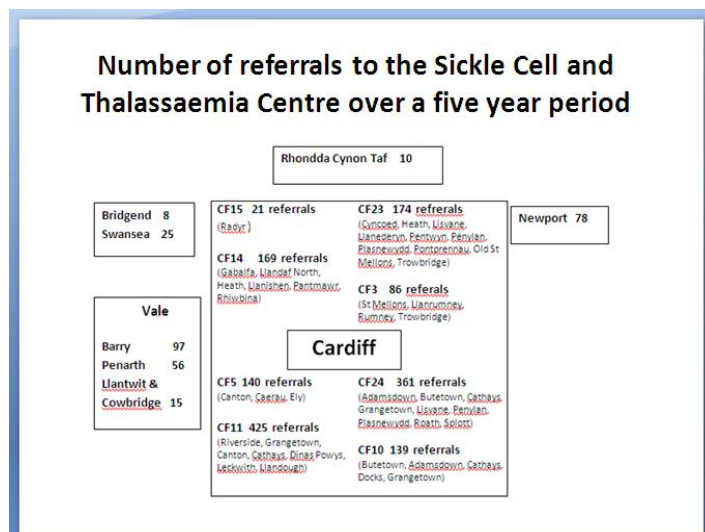


Source: Communities First Welsh Assembly Government

Figure 4 illustrates that those who identify themselves as Black or Black British-African (a population group with a high prevalence rate for sickle cell, thalassaemia and other severe haemoglobin disorders) live mainly in the Butetown, Riverside and Adamsdown areas but with some living elsewhere in smaller population concentrations.

The Cardiff Sickie Cell and Thalassaemia Centre collate referral data by postcode, which can be used to illustrate where people referred to the Centre actually live. This data was partly accessed and interpreted prior to the Health Impact Assessment Workshop and presented at the workshop in a format as shown in Figure 5.

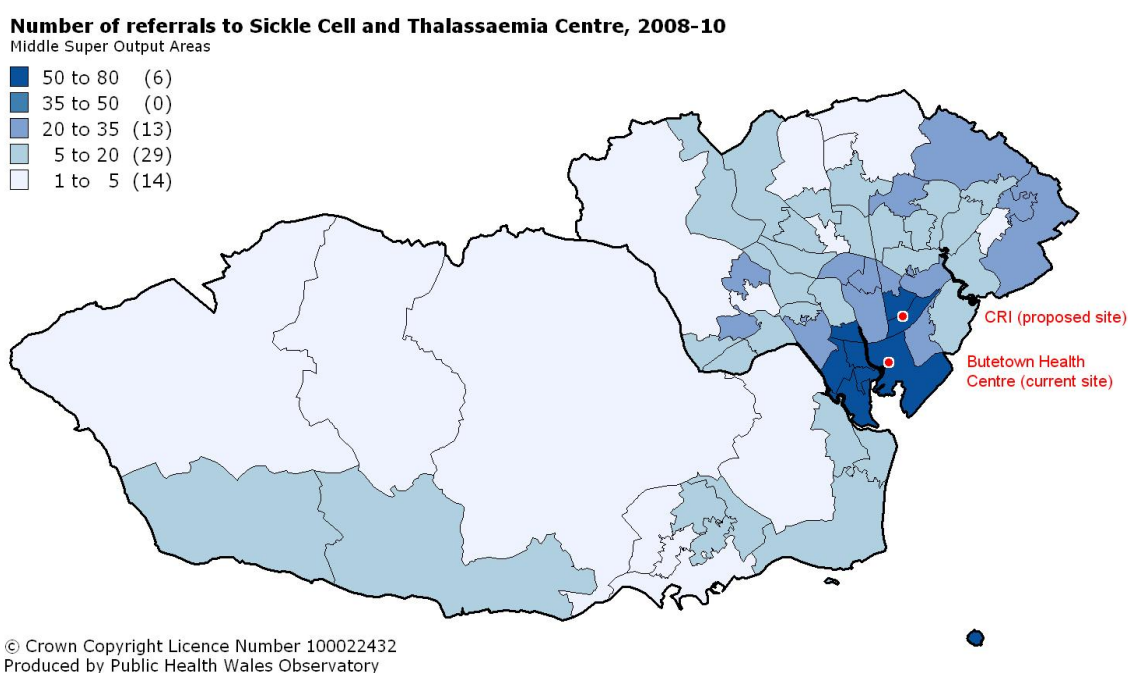
Figure 5



Source: Cardiff and Vale University Health Board

Following the workshop, further interpretation of the postcode data was possible and the following map (Figure 6) depicts residency of those referred to the Sickle Cell and Thalassaemia Centre during the years 2008, 2009 and 2010. Figure 6 uses the statistical geography of Middle Super Output Areas (MSOA) which facilitates the interpretation and use of data at a level below local authority county boundaries. There are 47 MSOAs in Cardiff each having a minimum population of 5000.

Figure 6



Source: data collated by Cardiff and Vale University Health Board and analysed by the Public Health Wales Observatory

Figure 6 highlights the areas from which the largest numbers of referrals to the Centre were received in 2008-2010. Referrals from the MSOAs containing Butetown, Grangetown, Riverside, Adamsdown and Plasnewydd were higher than from other MSOAs. As no referrals were received at the second highest rate (35-50), Figure 6 additionally illustrates that the areas within the six MSOAs with the high rate (50-80) were different from the rest.

With regards to referrals from outside Cardiff & Vale, in 2008-10, 44 were from Newport residents, 12 from Rhondda Cynon Taf, 10 from Caerphilly, 9 from Swansea, and very small numbers were from other local authority areas.

A number of referrals could not be mapped due to missing or invalid postcodes, including 56 referrals from Cardiff & Vale residents and 200 referrals from outside Cardiff & Vale

The previous figures illustrate the likely and actual residency of those with the condition or a carrier of the trait for sickle cell or thalassaemia disease. The majority live in areas of deprivation (Cardiff Needs Assessment, Ask Cardiff 2010) which are characterised by poor population health and inequality in access to medical and health care services.

4. Background to the proposal

4.1 Service proposal

In the 'Local Services Meeting Local Needs' (2005) consultation document on the development of health services for residents of central and eastern Cardiff, the then Cardiff Local Health Board proposed that the Cardiff Sickle Cell and Thalassaemia Centre transfer to the new Locality Health and Treatment Centre at Cardiff Royal Infirmary (CRI). The rationale for this was based on a high level needs assessment of the area and policy of bringing together specialist services that work mainly with vulnerable groups, including black and minority ethnic groups. As a result of public and professional consultation, the proposal was amended to ensure that the Sickle Cell and Thalassaemia Centre also retained a strong presence in the Butetown Health Centre.

In the Loudoun Square Development Business Justification (November 2009), the Cardiff and Vale University Health Board

again proposed that the Cardiff Sickle Cell and Thalassaemia Centre transfers to the new Locality Health and Treatment Centre at Cardiff Royal Infirmary. Within the proposal, there was recognition of the need to retain a strong presence in the new Loudoun Square facility to reflect the high level of need within the local population. It is understood that this service proposal translates into office accommodation at the new Locality Health and Treatment Centre at Cardiff Royal Infirmary and weekly sessions at the new Butetown Health Centre in Loudoun Square.

4.2 Discussions on the service proposal

Since 2005, various discussions on the proposal have been held with the Friends of the Sickle Cell and Thalassaemia Centre and the responsible health service body (Cardiff Local Health Board initially and, since 2009, Cardiff and Vale University Health Board). Copies of the resulting correspondence are available.

In 2010, the Director of Public Health (Executive Director of Cardiff and Vale University Health Board) agreed a number of actions with the Friends of the Sickle Cell and Thalassaemia Centre, including the undertaking of a health impact assessment. It was proposed to assess the impact on the health of patients, carers, families and carriers of the trait of the proposed move of the Sickle Cell and Thalassaemia Centre from Butetown Health Centre to the Cardiff Royal Infirmary.

5. The Health Impact Assessment

Health Impact Assessment (HIA) is a combination of procedures, methods and tools by which a policy, programme or project may be judged as to its potential effects on the health of a population, and the distribution of those effects within a population (WHIASU 2004). It uses the wider determinants of health model as its basis and uses a broad definition of health.

It is a participatory process where organisations and community members share views and concerns about a proposal or service development and identify solutions to any issues causing conflict.

Inherent in the process is the notion of an asset based (people centred) approach to health. Asset models accentuate positive capability to identify problems and activate solutions which promote

the self esteem of individuals and communities, leading to less reliance on professional services (Bartley 2006). Rather than being problem focussed and negative, the approach is one of working with, listening to, and showing respect for individuals and communities.

The Welsh Assembly Government is committed to developing the use of health impact assessment as a key part of its strategy to improve health and reduce inequalities. HIA is also a tool adopted by the World Health Organisation Healthy Cities Network for Phase IV (2005-2009) and Phase V (2009-2013). Cardiff became a member of this Network in 2009.

The HIA was conducted in line with the Wales Health Impact Assessment Support Unit Guidance (2004) and the following section reports on the HIA undertaken, which comprised of a scoping stage and a participatory workshop.

5.1 Scoping Stage

The scoping stage was undertaken by a Steering Group comprised of representatives from the

- Friends of the Sickle Cell and Thalassaemia Centre
- Sickle Cell and Thalassaemia Centre
- Cardiff and Vale Public Health Team (Cardiff and Vale University Health Board)
- Wales Health Impact Assessment Support Unit

Representatives from the Cardiff and Vale Community Health Council, the Ethnic Minorities Communities First Team and additional representatives from the Cardiff and Vale University Health Board were unable to attend the initial meeting.

The meeting of the Steering Group identified

- Stakeholders to be invited to and the venue for, the participatory workshop
- Service development issues.

5.2 Participatory Workshop

The purpose of the participatory workshop was to identify

- The impact of the proposed move of the Sickle Cell and Thalassaemia Centre on the health and well-being of the users of the service
- Actions to maximise the positive impacts and minimise the negative impacts

5.2.1 Methodology

The workshop was planned to be held at a community venue on a date and at a time convenient to community members to allow access and involvement in the event.

Invitations were sent to a range of stakeholders identified during the scoping stage of the HIA. A list of the organisations invited may be found in Appendix 1 and the invitation in Appendix 2. The HIA Workshop followed a standard structure, with the inclusion of information giving presentations at the start (Appendix 3).

5.2.2 The Workshop

The workshop was held on Tuesday 18 January 2011 at the Greek Cypriot Association of Wales Community Centre (Greek Church Street, Butetown) from 5pm to 9pm. Thirty-nine individuals attended, 19 of whom were from the Friends of the Sickle Cell and Thalassaemia Centre. A list of the numbers and organisations that attended may be found in Appendix 4.

The Workshop commenced with introductions followed by short presentations on

- The proposal, the functions of the Sickle Cell and Thalassaemia Centre and initial data on where people who are referred to the Centre live
- Services planned for the new Loudoun Square facility and the re-developed Cardiff Royal Infirmary (CRI)
- Health Impact Assessment

The remaining time available was allocated to working through the HIA tool (Appendix 5) that considered various aspects of health and well-being. Key issues were recorded on prepared flipchart paper.

5.2.3 Assessment Overview

- **The Workshop**

The discussions focused on the access and quality of services element of the HIA tool. Other issues were recorded, in particular service development issues, but little time was spent on discussing other dimensions suggested by the HIA tool. Participants felt that it was not appropriate to allocate time to discussing the impact of the proposal on lifestyles, for example. Community members were angry about the number of meetings attended over a number of years and the perceived lack of progress and/or decision. A feeling of not being listened to was expressed.

Feedback on the workshop indicated that further clarity of the process, and adhering to the process, would have been helpful.

Below presents the key issues raised as recorded.

Access and quality of services	
Positives	Negatives
<ul style="list-style-type: none"> • Other services available at CRI (but people do not feel they would use them and, if they did need to use them, their GP would refer them) 	<ul style="list-style-type: none"> • Centralisation of services – communities miss services that are open to them. • Threatening to communities • Lack of familiarity • CRI does not reflect the community affected by Sickie Cell and Thalassaemia – Butetown does. • Those with poor mobility will struggle to access the services at CRI • Majority of patients and carriers are from Butetown • Access to GPs (would not be possible at CRI) • No relevant services or facilities near the CRI site • Need for a community base • Feel of building (hospital setting is intimidating) • Butetown has supported and helped to develop a quality service • Economic issue – difficult to organise across two sites • Do not want to be split across two sites • Lack of drop in facility within community will impact on the provision of information on lifestyles

A further access and quality of service issue raised included the belief that the service provided by the Sickie Cell and Thalassaemia Centre had changed since the reduction in staffing levels. It was felt that less support was available and, in order not to overburden the staff, patients and their families contacted the Centre less often.

Additional issues highlighted included

- Information on the availability of primary care services at both locations was required

- Information required on the proposed timescales for the redevelopment of the Butetown Health Centre and the Cardiff Royal Infirmary
- Lack of progress in appointing a Coordinator of the Sickle Cell and Thalassaemia Centre
- A feeling of the community 'not being heard' was verbalised
- Open access to services facilitates use by the community
- Access to social services, housing services and benefit/funding support is required, the Sickle Cell and Thalassaemia Centre acting as the conduit.

As the discussion progressed, it became apparent that considering mitigation actions to enhance the positives and minimise the negatives was not appropriate. The over-riding view of the patients, carers and families present was that the Sickle Cell and Thalassaemia Centre should be solely based in Butetown to reflect the community it serves and be forward thinking, innovative and excellent. It was felt that the service being split across two sites would cause confusion and reduce access.

- **From the Friends of the Sickle Cell and Thalassaemia Centre**

Prior to the Workshop, members of the Friends of the Sickle Cell and Thalassaemia Centre developed and agreed a report on the positives and negatives of the proposed move of the Centre from Butetown Health Centre. The document is reproduced below, as agreed at the Workshop.



**Proposed Move of the Sickle Cell & Thalassaemia Centre from Butetown
Response from Friends of Sickle Cell & Thalassaemia support group
18th January 2011**

Voluntary and community organisations continue to highlight the marginalisation of these conditions and remain an important voice in developing service provision and advocating on behalf of those with the conditions and their families Anionwu & Atkin 2010

Thank you to Cardiff Sickle Cell & Thalassaemia Team, Prof Karl Atkin & FOSCT support group
Acting Chair Faye Walker 2011

**Proposed Move of the Sickle Cell & Thalassaemia Centre from Butetown
Response from Friends of Sickle Cell & Thalassaemia support group
18th January 2011**



Positives to stay in Butetown

- In the heart of the oldest BME community in Wales, over 70% of our communities first language is not English.
- Community based service which reflects the diversity of the community where it's based.
- We wish to remain in Butetown cohesive (consistent) community *"Community engagement which attempts to raise people's understanding of the conditions and make it part of their broader health literacy, can be an important step forward in facilitating informed choice"* Kelly, 2007 cited in Anionwu & Atkin 2010
- Current discrete & sensitive service has been researched to meet service users & community needs *"Innovative, sensitive and empowering provision providing culturally sensitive care is well documented"* (Dyson, 2005)
- Great access to local transport, close to central train station
- GP's can be consulted immediately
- Access to resources e.g. services users own GP's, Communities 1st, Butetown Community Centre, Greek Community Centre, Mosques, Churches, Menfa *"coping with a sickle cell or Thalassaemia disorder is not associated wholly with intrapersonal factors. Family support the response of services and access to material resources are equally important"* (Rouse, 2009)
- Link workers on hand.

Negatives to move to CRI

- Moving the provision away from the heart of the BME Community most affected by the condition
- Fragmented service proposed: presence in Butetown & main service in CRI
- Poorer service provision for service users, carers & community
- Move not shaped by users/supporter voices *"Institutional racism might also explain some of the problems faced by individuals and their families"* (Elander et al., 2004 cited in Anionwu & Atkin 2010)
- No GPs
- No link workers?
- Parking a problem
- Unfair to move BME services away from patients' homes and from the oldest BME communities in Wales
- SC & Thal services as been treated less favourably to other services- Cystic Fibrosis Fibrosis has its own unit
- No research undertaken, no service coordination, no evidence-based practice, no inter-agency collaboration *"Lack of planning and structural support has resulted in unequal service provision, and that the delivery of specialist nursing"*

Thank you to Cardiff Sickle Cell & Thalassaemia Team, Prof Karl Atkin & FOSCT support group
Acting Chair Faye Walker 2011

**Proposed Move of the Sickle Cell & Thalassaemia Centre from Butetown
Response from Friends of Sickle Cell & Thalassaemia support group
18th January 2011**

Positives to Stay in Butetown

- Area is the based of The Welsh Assembly Government & the Bay development, well know across Wales
- Most of the referral from Butetown, Riverside & Surrounding area



Negatives to Move to CRI

- *"care both in the community and in the acute sectors needs to be reviewed, starting with an understanding of the needs of the patients themselves"* (Sickle Cell & Thalassaemia Annual report 2009/10)
- The move will have an adverse impact on different groups within the service
- We are not a vulnerable group we are a disadvantaged group based on our race & disability we feel discriminated against- within this process our concerns have been ignored and we are still unclear about the provision at the CRI will look like
- Unlawful – not in line with current legislation undertake impact assessment when making any significant changes to existing policies and procedures

Thank you to Cardiff Sickle Cell & Thalassaemia Team, Prof Karl Atkin & FOSCT support group
Acting Chair Faye Walker 2011

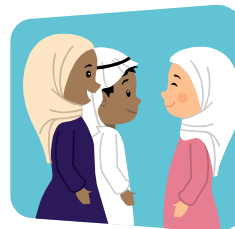


There are at least 14,500 people with sickle cell disorder living in the UK (National Screening Committee for Sickle & Thalassaemia, 2006)

Inherited blood disorder that affects an estimated 12,500 to 15,000 people, mainly from black & minority ethnic communities in the UK (Hobson, 2008 cited in Anionwu 2008). This compares with an estimated 8,000 by the genetic disorder Cystic fibrosis (www.cftrust.org) that primarily affects white individuals.

The definition of a low prevalence area is one where sickle cell births are below 1.5 per 10,000 . Cardiff & Vale (2.1 sickle cell births per 10,000 births) is therefore a high prevalence area-the only one in Wales (Personal communication from Professor B Modell WHO) -enabling the development of expertise here that can be shared elsewhere.

- In the UK, between 700 and 1000 people have beta Thalassaemia major aka Thalassaemia major) about 65 per cent of whom are under eighteen years old



Thank you to Cardiff Sickle Cell & Thalassaemia Team, Prof Karl Atkin & FOSCT support group
Acting Chair Faye Walker 2011

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Thank you to Cardiff Sickle Cell & Thalassaemia
Team, Prof Karl Atkin & FOSCT support group
Acting Chair Faye Walker 2011

6. Conclusions

The key conclusions that may be drawn from this work include:-

- Referrals to the Sickle Cell and Thalassaemia Centre have increased year on year for the last ten years
- During the years 2008-2010, a high proportion of referrals were received from Butetown, Grangetown, Riverside, Plasnewydd and Adamsdown
- Members of black and minority ethnic communities live across South Wales but the main areas of residency are within Cardiff
- Those communities with a high prevalence of sickle cell and thalassaemia live mainly in the Butetown, Riverside and Adamsdown areas of Cardiff, with the highest population numbers in Butetown
- Members of black and minority ethnic communities are more likely to access services that reflect their culture and beliefs
- Positioning the Sickle Cell and Thalassaemia Centre across two sites would reduce access and cause confusion amongst users
- The preferred site of the Sickle Cell and Thalassaemia Centre is within the Butetown area as part of the Loudoun Square facility

- The service provided by the Sickle Cell and Thalassaemia Centre is valued by the users but requires attention to ensure it develops into an effective, comprehensive and innovative provision. Its coordinating function requires strengthening.

7. Recommendations

This report has considered the existing service provision, referrals to the Sickle Cell and Thalassaemia Centre, the residency of users and of the black and minority ethnic population as a whole, the discussions that occurred at the participatory workshop and the information collated by the Friends of the Sickle Cell and Thalassaemia Centre.

The recommendations of this report are:-

1. The Sickle Cell and Thalassaemia Centre should be positioned in Butetown at the new Loudoun Square facility
2. The service provided by the Sickle Cell and Thalassaemia Centre should not be split across two sites
3. The services provided by the Sickle Cell and Thalassaemia Centre require leadership and development to ensure effective and quality provision. Robust data collection and liaison and co-ordination with other support services requires attention in the very near future.

8. Next steps

This report will be considered and discussed within the Cardiff & Vale University Health Board and agreed recommendations implemented following further discussions with key stakeholders.

9. Appendices

- 9.1 Organisations invited to the HIA Workshop
- 9.2 Invitation to the HIA Workshop
- 9.3 Agenda for the HIA Workshop
- 9.4 Attendance by Organisation and numbers
- 9.5 HIA Tool

9.1 Organisations invited to the HIA Workshop

	Organisation
Academia	York University
	University of Glamorgan
	Cardiff University
HIA Facilitators	Wales Health Impact Assessment Support Unit
	Cardiff & Vale Public Health Team
Cardiff & Vale University Health Board	Sickle Cell and Thalassaemia Service (Centre)
	Sickle Cell and Thalassaemia Service (Lab)
	Sickle Cell and Thalassaemia Service (Screening) /Public Health Wales
	Sickle Cell and Thalassaemia Service (Paediatric Oncology)
	Sickle Cell and Thalassaemia Service (Adult Haematology)
	Sickle Cell and Thalassaemia Service (Psychology)
	Sickle Cell and Thalassaemia Service (Nursing)
	Sickle Cell and Thalassaemia Service (Haematology, Clinical Immunology and Genetics)
	Sickle Cell and Thalassaemia Service (Haematology)
	Multi-Cultural Health and Information Resources Centre
	Community Nursing Service
	Equality Advisor
	Locality Manager
General Practitioners	
Cardiff Council	Youth service
	Social Services
Housing	Cardiff Community Housing
	Red Sea House (Taff Housing Association)
Groups and organisations	Friends of Sickie Cell and Thalassaemia Centre
	Greek Cypriot Association of Wales
	Butetown Community Centre
	Ethnic Minorities Communities First Team
	Butetown Communities First team
	Barnardo's
Community Health Council	Cardiff and Vale Community Health Council
National organisations	UK Thalassaemia Society
	Sickle Cell Society

9.2 Invitation to the HIA Workshop

From: Susan Toner (Public Health Wales)
Sent: 10 December 2010 16:30
Subject: Health Impact Assessment Workshop of the proposed move of the Sickle Cell and Thalassaemia Centre on 18 January 2011. 5pm-9pm
Attachments: Booking form .doc; WHIASU Bilingual info sheetPHW2010.doc

Dear All

The Director of Public Health of Cardiff and Vale University Health Board has asked the Wales Health Impact Assessment Support Unit to undertake a rapid health impact assessment of the proposed move of the Sickle Cell and Thalassaemia Centre from Butetown Health Centre to the redeveloped Cardiff Royal Infirmary. There is also recognition of the need to maintain a strong presence at the new Loudoun Square facility.

Health Impact Assessment is a process which helps organisations assess the potential impact of their decisions on people's health and well-being and to develop actions to enhance the positive and reduce any negative consequences.

A key element of this health impact assessment will be a participatory stakeholder workshop, where individuals will be brought together to discuss the proposed move of the Centre. A report will be written following the workshop and submitted to the Director of Public Health.

You have been identified as a key individual in this process, and I would like to invite you to join us at the participatory stakeholder workshop, which will take place at the **Greek Cypriot Association of Wales Community Centre on 18 January 2011 from 5pm to 9pm.** Light refreshments will be provided.

I would be grateful if you could complete and return the attached booking form to confirm that you are able to attend the workshop. Also attached is a short summary about health impact assessment.

I will send you an agenda for the workshop nearer the time but in the meantime, if you have any queries please contact me.

I look forward to working with you

Best wishes

Sue

Susan Toner

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Mewnwrwyd/Intranet: www.publichealthwales.wales.nhs.uk

9.3 Agenda for the HIA Workshop



Proposed move of the Sickie Cell and Thalassaemia Centre

Health Impact Assessment Participatory Workshop

**Greek Cypriot Association of Wales Community
Centre,
Greek Church Street, Butetown**

18 January 2011 from 5pm to 9pm.

Agenda

- | | |
|--------|---|
| 5 pm | Arrival and buffet |
| 5.30pm | Welcome and introductions |
| 5.45pm | Sickie Cell and Thalassaemia Centre <ul style="list-style-type: none">• Overview and background to proposed move• Presentation on outline plans for Loudoun Square and Cardiff Royal Infirmary |
| 6.20pm | Outline of Health Impact Assessment |
| 6.30pm | Assessment (using appraisal tool) |
| 7.30pm | Break (20 mins) |
| 7.50pm | Assessment (using appraisal tool) |
| 8.15pm | Development of actions and recommendations |
| 8.45pm | Summing up and evaluations
Next steps and reporting |
| 9pm | Close |

9.4 Attendance by Organisation and numbers

	Organisation	Numbers of participants
Academia	Cardiff University	2
	York University	apologies received
	University of Glamorgan	apologies received
HIA Facilitators	Wales Health Impact Assessment Support Unit	1
	Cardiff & Vale Public Health Team	1
Cardiff & Vale University Health Board	Sickle Cell and Thalassaemia Service (Centre)	2
	Sickle Cell and Thalassaemia Service (Lab)	1
	Sickle Cell and Thalassaemia Service (Paediatric Oncology)	1
	Sickle Cell and Thalassaemia Service (Adult Haematology)	1
	Sickle Cell and Thalassaemia Service (Nursing)	apologies received
	Sickle Cell and Thalassaemia Service (Haematology, Clinical Immunology and Genetics)	1
	Community Nursing Service	2
	Equality Advisor	1
	Locality Manager	1
Cardiff Council	Social Services	apologies received
Groups and organisations	Friends of Sickle Cell and Thalassaemia Centre	17
	Greek Cypriot Association of Wales	1
	Butetown Community Centre	1
	Ethnic Minorities Communities First Team	1
	ABCD	1
Community Health Council	Cardiff and Vale Community Health Council	1

9.5 Health and well-being determinants checklist

1. Lifestyles	<ul style="list-style-type: none"> • Diet • Physical exercise • Use of alcohol, cigarettes, non prescribed drugs • Sexual activity • Other risk taking activity
2. Social and community influences on health	<ul style="list-style-type: none"> • Family organisation and roles • Citizen power and influence • Social support and social networks • Neighbourliness • Sense of belonging • Local pride • Divisions in community • Social isolation • Peer pressure • Community identity • Cultural and spiritual ethos • Racism • Other social exclusion
3. Living/environmental conditions affecting health	<ul style="list-style-type: none"> • Built environment • Neighbourhood design • Housing • Indoor environment • Noise • Air and water quality • Attractiveness of area • Community safety • Smell/odour • Waste disposal • Road hazards • Injury hazards • Quality and safety of play areas
4. Economic conditions affecting health	<ul style="list-style-type: none"> • Unemployment • Income • Economic inactivity • Type of employment • Workplace conditions
5. Access and quality of services	<ul style="list-style-type: none"> • Medical services • Other caring services • Careers advice • Shops and commercial services • Public amenities • Transport • Education and training • Information technology
6. Macro-economic, environmental and sustainability factors	<ul style="list-style-type: none"> • Government policies • Gross Domestic Product • Economic development • Biological diversity • Climate

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