

Screening Programmes

Sickle Cell and Thalassaemia

Single Equality Scheme
2010-2013

November 2010



WITHDRAWN APRIL 2019

CONTENTS

ABBREVIATIONS		2
ACKNOWLEDGEMENTS		
FOREWORD		4
EXECUTIVE SUMMARY	Ω	 5
INTRODUCTION		<u>9</u>
	SLATIVE CONTEXT OF THE STINGLE EQUALITY SCI ELOPING OUR SINGLE EXCALITY SCHEME	
DEVELOPING THE SINGLE EQUALITY SCHEN	ME – HEALTH AND RESISLATIVE CONTEXT 12	
THE IMPLICATIONS FOR DEVELOPING THE	SINGLE EQUAL Y SCHEME	14
SECTION TWO – THE PROGRAMME'S STRATEG	GY AND THE SINGLE EQUALITY SCHEME	15
STRATEGIC ROLE OF THE PROGRAMME	AND IMPLICATIONS FOR DEVELOPING THE S	
	N STRATEGIC OBJECTIVES OF THE PROGRAME	
SECTION THREE – SETTING PRIDRITIES, DEVEL	LOPING THE ACTION PLAN AND REPORTING ON	PROGRESS 21
MANAGING AND DELIVERING EQUALITY -	ACTION PLAN	22
GOVERNANCE MONITORING AND REVIEW	VING ARRANGEMENTS FOR THE SINGLE EQUALI	TY SCHEME . 33
ALPE-VICES		36



ABBREVIATIONS

The Programme – The NHS Sickle Cell and Thalassaemia Screening Programme

EqIA -**Equality Impact Assessment**

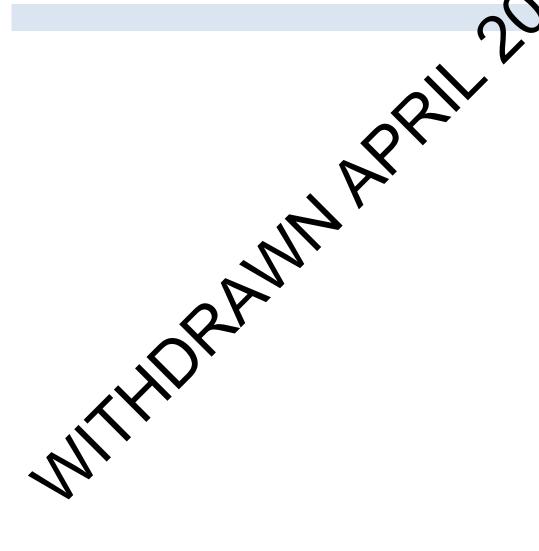
SES -

WITHDRAWN APRIL 2011 NSC-



ACKNOWLEDGEMENTS

The Programme wishes to thank the members of the Screening Programme Steering Committee, all our other diverse stakeholders - Screening Programme partners, healthcare professionals, user and carer representatives, other supporters and voluntary sector partners - as well as our external consultants and the Programme Centre team who have all provided invaluable feedback and input into the development of our Single Equality Scheme.





FOREWORD

Welcome to NHS Sickle Cell and Thalassaemia Screening Programme's 'Single Equality Scheme'.

This comprehensive strategy shows our commitment to equality, an issue which is fundamental to our very existence.

The conditions for which we screen disproportionately affect people from ethnic minor ties. Furthermore, the prevalence of these conditions is uneven across the country — with a much higher concentration in London and urban areas. Since we were established in 2001, we have worked hard to place sickle cell and thalassaemia in the mainstream of the NHS and to provide icreening fairly and accessibly across the whole of England.

Our Single Equality Scheme is a natural extension of this work. It denons rates our determination to put equality at the heart of everything we do – from developing po cy to supporting the delivery of services. We believe that a single scheme – rather than several smaller ones covering each equality strand – is the best way to ensure that equality is embedded in every project.

Of course, the Scheme is not just about promoting fairlies, and equality. It also ensures that we fulfil our statutory duties under the Equalities Act (2010). We are determined to get rid of all forms of unlawful discrimination based on racial group, or ability, gender, age, religion or belief, sexual orientation and gender reassignment in our colleges and functions.

We have always seen as central the input of sovice users, carers and the voluntary sector as well as the wide range of professionals valo deliver and manage services. This Scheme will continue to evolve and we actively seek feedback and suggestions. We will review and revise the document and our actions in line with the feedback we receive.

Please do send your comments/Suggestions to Dr Patricia Connell, Business Manager, NHS Sickle Cell and Thalassaemia Schemog Programme, King's College London, 7th Floor, Capital House, 42 Weston Street, London, SN 2 (D, or by email to: haemscreening@kcl.ac.uk

For a large print version of this document please contact: The Communications Team, NHS Sickle Cell and Thalassa mia Screening Programme, King's College London, 7th Floor, Capital House, 42 Weston Street, London, SE1 3QD or by email to: haemscreening@kcl.ac.uk

The Most Reverend and Right Honourable
Dr John Sentamu, Archbishop of York
Chair, Steering Committee
NHS Sickle Cell and Thalassaemia Screening Programme

Dr Allison Streetly OBE
Programme Director
NHS Sickle Cell and Thalassaemia Screening
Programme



EXECUTIVE SUMMARY

The NHS Sickle Cell and Thalassaemia Screening Programme is committed to tackling inequality, eliminating discrimination and harassment and promoting equality of opportunity for all. We aim to ensure that:

- screening services are accessible to and accessed by all communities who need the
- services are quality assured and sensitive to users' needs.

Our Single Equality Scheme sets out how we will achieve these aims.

This is the first Single Equality Scheme (SES) developed by an English national Screening Programme. It builds and expands on work we have already done to promote equality and diversity, brings together different strands, and emphasises our core purpose — to provide an effective and appropriate screening programme. We hope that it will also serve as a model for other screening programmes within the NHS.

The SES has three sections, which will be developed an applated over the next three years to ensure they remain relevant:

- **Section One** outlines the external health and legislative context of the SES, and the Programme's general approach to developing our SES;
- Section Two outlines the Program in 's strategic role and implications for the development of the SES;
- Section Three details the step taken by the Programme to establish our SES priorities, the Action Plan for the next three years, and arrangements to monitor and report on progress of the Plan.

This Executive Summary focuses on Sections two and three.

Strategic role of the Programme and implications for developing the single equality scheme

The Programm is unlike a conventional public sector body, because it cannot be described as an organisation at it is a national programme led by a Programme Director managed by the National Screening committee (NSC).

The Programme acts as an intermediary, setting the standards and policies determining how screening is delivered. It does not deliver a service in the way that an NHS Trust does; therefore functions and policies relevant to its general duties have been drawn from the Service Level Agreement. A Service Level Agreement outlines our key objectives and deliverables for the period 2010-2013, and provides the framework for the Programme's annual work plans.

Inward and outward facing

In order to deliver the SES, we first have to address those issues that are within our direct control – such as policies and standards and professional development. Alongside these are broader issues that may be outside our direct control, but affect our ability to promote equality. Here we propose to



extend our influencing role to ensure a consistently high quality across commissioning and provider services.

Establishing priorities for the single equality scheme

From the broad list of recommendations initially made in the report of an external Equalities review, an extensive range of priorities was listed for remedial action.¹ As already mentioned, this list suggested a programme of work far beyond our resources and capacity, and therefore required further refinement. The list was discussed and agreed by the Programme's Management committee against transparent criteria which were outlined in the Context report, our resources and our capacity to deliver. Two of the criteria in particular addressed limitations of relouices and capacity:

- taking account of work in progress elsewhere with the Programme and the NSC and its potential impact on gaps and weaknesses identified; and
- use of pre-determined prioritisation criteria capacity im dications, synergy with work in progress, coverage of all equality strands and potential providest impact.

The committee then agreed a list of priorities which have be reviewed and agreed by our Steering Group. Our agreed priorities cover the following equality treas/strands:

- Gender
- Age
- Religion or belief
- Disability
- Race

These were the areas of most relivante to existing and potential clients, and other stakeholders.

The areas of work within the Action Plan over the next three years are as follows:

- 1) Programme Standards
- 2) Data collection and performance management
- Accessibility
 - a) Language
 - b) Disabilities
- 4) Outcach
 - a) Public outreach
 - b) Engaging men
 - c) Faith communities
 - d) Black and Minority Ethnic communities
 - e) Young people
 - f) Other under-represented groups

¹ The criteria by which this prioritisation in the report was achieved is detailed in the Context Report (pp. 37-38, 2009). The same criteria were used in a transparent process by the Management Team in order to refine the list of priorities.



Page | 6

- 5) Professional Development
- 6) Primary Care Engagement
- 7) Embedding Equalities
- 8) Joint equalities work with UK National Screening Committee and alignment with other National Initiatives.

Action Plan: 2010-2013

The Single Equality Scheme (SES) will set out how we intend to meet our duties as public body. It will be implemented through an action plan which will help us to:

- be systematic in the way we promote the equality strands;
- set a development agenda with realistic objectives;
- assign responsibilities;
- meet our legislative duties.

The action plan will be implemented over a three year period. It sets out:

- the goals we want to achieve to meet our objective of promoting equality and diversity and tackling discrimination;
- the actions required to make this hap

We have grouped the outcomes and actions according to priorities drawn from our stakeholder consultation, and recommendations from the earlier Equalities review. These priorities will be delivered over a three year period \$2/10=2013\$) and are detailed in the Action Plan that is outlined within the SES report.

Equality Impact Assessments

Equality Impact Asses means (EqIAs) form a strand of work within the SES Action Plan. The main purpose of conducting an EqIA is to pre-empt the possibility that any of our standards, functions or policies could affect some groups unfavourably. It should also reduce the risk of our policies, functions and standards having a negative impact.

The Plag stame is required to screen all policies, standards and functions to establish if they need a full impact assessment. The process for screening and assessing policies, standards and functions will be outlined in the Programme's EqIA template which was developed as part of the earlier Equalities Review.

If we find that policies, standards or functions may not be appropriately ensuring equality, an action plan will be drawn up; and remedial action prioritised to address any negative impact. In future, equality will be considered when new policies or standards are being drafted. All new policies or standards must be screened and if necessary, fully assessed.



Charting Performance

Performance on the SES will be reviewed at least annually, and monitored as follows:

- The Programme's Steering Group will monitor progress at each of its six-monthly meetings.
- We will chart the progress against the Action Plan.
- An annual Equalities Report covering the progress on the SES and the action planwill be provided to the Steering Group and will be included in the annual report.

Revising the SES and Action Plan

The Programme will revise the SES every three years, working with all stakeholders to take into account information gathered, including the outcomes of impact assessments, and incorporating any feedback received, as appropriate.

Publishing the Scheme

The Scheme and action plan will be published and circulated atternally and externally. The SES will be published in a clearly signposted area of our integrate for employees to view, and on our external website for the general public. Copies will be a cilb le in different formats on request. The Action Plan will be published on our Website, where we vill chart the progress against each of the actions.

We will also publish the results of each Equality Impact Assessment. Full EqIAs will include consultation with relevant stakeholders, and copies will be available on request, and sent to those who took part in the consultation, where feasible. The results of full EQIAs will be made available on the Programme website and if the Programme's Annual Report. We will also publish the annual Equalities Progress Report in the Annual Report.



INTRODUCTION

The NHS Sickle Cell and Thalassaemia Screening Programme (the Programme) was established in 2001 to deliver:

- timely antenatal sickle cell and thalassaemia screening for all women and couples. Je ping them make informed decisions
- newborn sickle cell screening to achieve the lowest possible childhood death rate and to minimise the impact of sickle cell disorders on children's health;
- a **linked programme** that ensures the professionals involved have the understanding needed to deliver screening effectively and sensitively.

Sickle cell and thalassaemia are more likely to affect minority. This communities – particularly people whose families come from Africa, the Caribbean, the Mariterranean, Middle East, India, Pakistan, South America or south and south-east Asia. In Britain sinkle cell is most common in people of African and Caribbean descent – at least 1 in 7 (Black African) and 1 in 8 (Black Caribbean) are sickle cell carriers, compared with 1 in 540 for White Aitish counterparts.² This is a distinct health inequality.

In 2006, the government identified contin rious health inequalities between different communities and socioeconomic groups calling for the NHS to address them in a targeted, innovative and culturally sensitive way v coalition's plans for health are detailed in a recent White Paper³ which includes the vision of a patient-led NHS and plans to reduce health inequalities. The White Paper also affirms an NHC to Eliminates discrimination and reduces inequalities in care.' An assessment of the White Paper concludes that these plans should have a positive impact and help tackle current inequalities.4 also enshrined in the NHS Constitution which states that 'The NHS provides a compre service, available to all irrespective of gender, race, disability, age, sexual orientation, religion ion o belief. ... At the same time, it has a wider social duty to promote equality through the s it provides and to pay particular attention to groups or sections of society where vements in health and life expectancy are not keeping pace with the rest of the population.

⁵ Department of Health, 2010. *The NHS Constitution for England*. London, HMSO, p.3. Available at: http://www.dh.gov.uk/prod consum dh/groups/dh digitalassets/@dh/@en/@ps/documents/digitalasset/dh 113645.pdf (accessed on 11th October 2010).



² Street, A. Latmovic, R., and Henthorn, J. 2010. *J Clin Pathol*, **63**, 626-629. Available at: https://ion.bhy.com/content/63/7/626.full.pdf (accessed 13 October, 2010).

³ Department of Health, 2010. *Equity and excellence: Liberating the NHS*. London, HMSO. Available at: http://www.dh.gov.uk/prod consum dh/groups/dh digitalassets/@dh/@en/@ps/documents/digitalasset/dh 117794.pdf (accessed on 4 October 2010).

⁴ Department of Health, 2010. Equity and excellence: Liberating the NHS - Initial Equality Impact Assessment (EqIA). London, HMSO. Available at: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_117350.pdf (accessed on 4 October 2010).

The Programme will also aim to align its Equality work with that of the recently created NHS Equality and Diversity Council. The Council will be producing guidelines for NHS staff on the Equalities Act, and finalising a tool for NHS organisations called the Equalities Delivery System.

The Programme is committed to tackling inequality, eliminating discrimination and harassment and promoting equality of opportunity for all. We aim to ensure that:

- screening services are accessible to and accessed by all communities who need the
- services are quality assured and sensitive to users' needs.

Our **Single Equality Scheme** sets out how we will achieve these aims.

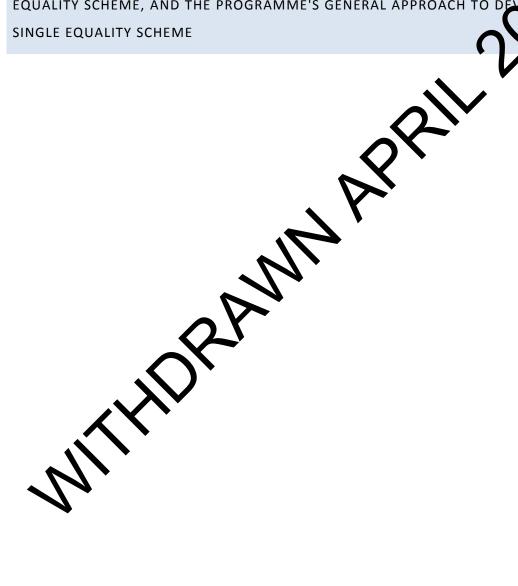
This is the first Single Equality Scheme (SES) developed by an English national Screening Programme. It builds and expands on work we have already done to promote equality and diversity, brings together different strands, and emphasises our core purpose — to provide an effective and appropriate screening programme. We hope that it will also se we as a model for other screening programmes within the NHS.

The SES has three sections, which will be developed and updated over the next three years to ensure they remain relevant:

- **Section One** outlines the external hearth and legislative context of the SES, and the Programme's general approach to developing our SES;
- **Section Two** outlines the Programme's trategic role and implications for the development of the SES:
- **Section Three** details the stars taken by the Programme to establish our SES priorities, the Action Plan for the next area years, and arrangements to monitor and report on progress of the Plan.



SECTION ONE — EXTERNAL HEALTH AND LEGISLATIVE CONTEXT OF THE SINGLE EQUALITY SCHEME, AND THE PROGRAMME'S GENERAL APPROACH TO DEVELOPING OUR SINGLE EQUALITY SCHEME





DEVELOPING THE SINGLE EQUALITY SCHEME - HEALTH AND LEGISLATIVE CONTEXT

HEALTH INEQUALITIES

Overall, health is improving in the UK, but there are enduring health inequalities affected by gender, disability, age, ethnicity, where people live, and how wealthy they are. In particular, there are specific health issues which have a disproportionate impact on people from Black and Majority Ethnic (BAME) communities. Screening has been shown to lessen the impact of disease and reduce the number of deaths through early detection and treatment, but equality of access remains a problem.

Tackling health inequalities is a complex undertaking, which initiatives like Equal vachemes, Impact Assessments and Race Equality Impact Assessments aim to address. The *No Patient Left Behind* report complements this approach⁹. It advocates a model of flexible per analysed care that is part of mainstream healthcare, rather than offering separate services to b. Whi groups in an effort to meet their needs.

A Single Equality Scheme provides a framework for malicareaming equality in the work of the Programme. It also:

- supports the development of systems that address gaps and weaknesses in our current standards, policy and practice in relation to equality
- provides a useful format for publishing transfor equality information, including our equality objectives.

NATIONAL LEGISLATIVE REQUIREMENTS

Legislation is another major driver for a Single Equality Scheme.

The new Equality Act 2010 all s to provide a "... cross-cutting legislative framework to protect the rights of individuals and advance equality of opportunity for all; to update, simplify and strengthen the previous legislation; and to deliver a simple, modern and accessible framework of discrimination law which projects addividuals from unfair treatment and promotes a fair and more equal society." (Government Equalities Office Website)¹⁰. The Act will simplify the law by bringing together (and replace of anti-discrimination legislation:

Equal Pay Act 1970



⁶ House of Commons Health Committee, Health Inequalities Third Report of Session 2008–09 Volume I, (HC286–I[Incorporating HC 422-i to vii, Session 2007-08)) London: The Stationery Office Limited.

⁷ Improving Opportunity, Strengthening Society – A third progress report on the Government's strategy for race equality and community cohesion. Volume 1, Communities and Local Government, 2009

⁸ Fell, G. and Gregory, I. 2007. *Equality review: National Screening Programmes – A scoping report for the National Screening Committee*. London: National Screening Committee.

⁹ Lakhani, M. 2008. *No Patient Left Behind: How can we ensure world class primary care for black and minority ethnic people?* London, Department of Health.

¹⁰ http://www.equalities.gov.uk/

- Sex Discrimination Act 1975
- Race Relations Act 1976
- Disability Discrimination Act 1995
- Employment Equality (Religion or Belief) Regulations 2003
- Employment Equality (Sexual Orientation) Regulations 2003
- Employment Equality (Age) Regulations 2006
- Equality Act 2006, Part 2
- Equality Act (Sexual Orientation) Regulations 2007

The Act will also create a new 'Equality Duty' for public bodies covering 7 strands: ace, disability, gender, age, sexual orientation, gender reassignment and religion or belief. The hist three of these have already been introduced, and the rest will follow in April 2011. Many public sector organisations have decided to roll all these duties into one scheme – a single equality scheme (SES). This is the approach we have adopted.

More detailed information about equality and the law is available from the Equality and Human Rights Commission website: www.equalityhumanrights.com



THE IMPLICATIONS FOR DEVELOPING THE SINGLE EQUALITY SCHEME

DEVELOPING A SINGLE EQUALITY SCHEME IN THE PROGRAMME

A Single Equality Scheme helps us to communicate and manage our equality commitments and actions more effectively. It demonstrates that our approach goes beyond statutory compliance, and ensures that equality and diversity are brought into the mainstream of our activities.

We have sought to encompass all areas of equality and diversity, applying the same standar's to race, gender, disability, age, religion or belief and sexual orientation. Equality and diversity is the responsibility of everyone in the Programme. We will focus on:

- developing work we have already undertaken to promote equality of opportunity
- complementing and building on existing and planned policies and standards to ensure equality underpins the work we do across the organisation
- reflecting and proactively addressing the requirements of the developing equality legislation.

The Programme commissioned an external Equalities Review in 2003-2009, 11 to

- address the broader themes of equality
- focus on best practice
- inform the development of our Single Scheme.

The review involved:

- i. consultation with stakeholders shout current gaps and weaknesses in the Programme standards and current practice in relation to equality;
- ii. analysis of the result.
- iii. prioritising equality is ues (or themes);
- iv. identifying repodit action;
- v. taking guidance on conducting Equality Impact Assessments.

Some of the issues that emerged from this review may well apply to other national screening programmes, with whom we also plan to explore:

- workwe can do together to address equality issues;
- particular issues that need to be prioritised and tackled separately by separate programmes.

¹¹ Community Regeneration Partnership 2009. *NHS Sickle Cell and Thalassaemia Screening Programme:* Equality Screening Context Report. The Report details the full methodology of the review, including details of the evidence collected from the consultations, and how the evidence was used. The methodology will not be outlined here.



WITHDRAWN APRIL 20 SECTION TWO – THE PROGRAMME'S STRATEGY AND THE SINGLE EQUALITY SCH. M



STRATEGIC ROLE OF THE PROGRAMME AND IMPLICATIONS FOR DEVELOPING THE SINGLE EQUALITY SCHEME

The Programme is unlike a conventional public sector body, because it cannot be described as an organisation. It is a national programme led by a Programme Director managed by the National Screening Committee. It is currently hosted by King's College London and subject to a Service Level Agreement (SLA) negotiated between the College and the Department of Health. The SLA outlines our key objectives and deliverables for the period 2010-2013, and provides the framework for the Programme's annual work plans. It covers the following areas: policy; governance, engagement and equality; evaluation; implementation; communication; training and education; service development and value for money; quality improvement; clinical network interface with the programme; and organisational development.¹²

The Programme acts as an intermediary, setting the standards and policies determining how screening is delivered. It does not deliver a service in the way that at NHS Trust does; therefore functions and policies relevant to its general duties have been drawn from the Service Level Agreement.

As a national Programme, we also face further challenges in proparing and implementing a SES:

- Reconciling national policies with local delivery.
- Balancing priorities between what we have the mandate to change and where we need to influence others to make change;
- Achieving consistency in the range and quality of services delivered locally by Trusts;
- Putting equalities at the heart of obsactivities, recognising the overarching objective for reducing health inequalities:
- Adding value rather than creating bureaucracy.

INWARD AND OUTWARD FACING

In order to delive the SES, the Programme's dual role and relative responsibilities must be recognised. First we have to address those issues that are within our direct control – such as policies and standards and professional development. Alongside these are broader issues that may be outside an direct control, but affect our ability to promote equality. Here we propose to extend our influencing role to ensure a consistently high quality across commissioning and provider services.

¹² Department of Health, 2010. Agreement on Hosting Arrangements for the Provision of Services for the NHS Sickle Cell and Thalassaemia Screening Programme between Department of Health and King's College London. London, Department of Health.

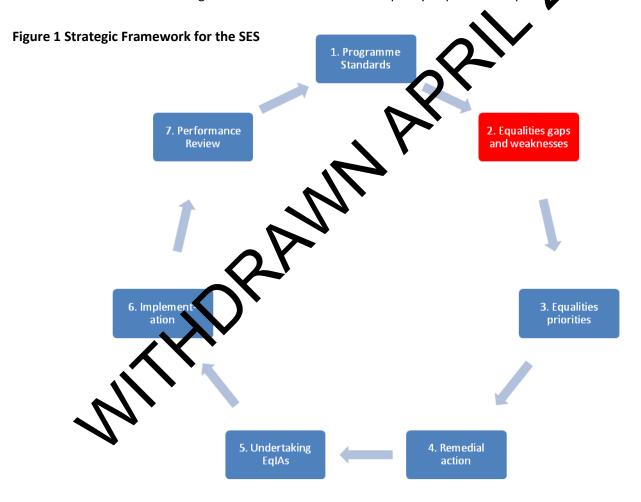


SINGLE EQUALITY SCHEME

ENSURING STANDARDS AND PRACTICES

The Equalities Review was conducted in the context of the Programme Standards¹³ as the framework for meeting our Equalities duties. The Standards apply to all aspects of Programme management and delivery (including delivery by Trusts). They define objectives (Programme outcomes), assessment criteria, minimum and achievable standards (quantifiable targets) and levels of reporting. We aim to achieve at least the Core Standards. However, the Equalities review suggests that against some Standards there is either general under-achievement; under-achievement in relation to particular equality strands; or an inability to provide evidence of successful achievement. This is the ontext for the Single Equality Scheme.

For the SES to be successful, it must add value at both strategic and operational levels. Figure 2 below outlines a strategic framework for the SES, demonstrating its links of the Programme Standards and its management within the mainstream quality improvement process.



The SES harnesses steps 2-4 and provides the resources required for step 5.

¹³ NHS Sickle Cell and Thalassaemia Screening Programme, 2006. *Standards for the linked Antenatal and Newborn Screening Programme*. London, UK National Screening Committee.



The steps in the cycle are described below:

Programme Standards

The Programme Standards are the driver and ultimately the policy against which performance is measured. They are in the process of being updated; meanwhile, the 2006 Standards continue to apply. The cycle illustrated above will contribute to the ongoing review and updating of the Programme Standards.

Equalities gaps and weaknesses

This stage identified gaps and weaknesses in the service or its provision that affected the Programme's ability to fulfil its equalities objectives. This was the purpose of the consultation exercises, the findings of which were reported in the Context Report.

Equalities Priorities

The Consultation exercise sought to identify gaps and weaknesses, and was rightly not limited in scope by practical considerations of resource or capacity. However, it suggested a much greater programme of work than we could deliver, so we had to rende and prioritise – a process which is outlined below.

Remedial action

The remedial actions outlined in this document are those for which the Programme is responsible (such as strategic guidance and operational support). Other remedial actions which rely on external bodies for delivery (such as resourcing and implementation) are covered elsewhere – for example, in Regional Teams' Objectives.

Undertaking Equality In pact Assessments (EqIAs)

EqlAs form part of the Action Plan for the Programme's SES. They will be undertaken on agreed remedial actions by the people responsible, and will include appropriate training to ensure the process it sustainable.

Implementation

Implementation of remedial actions and attendant EqIAs will be undertaken by the Programme in keeping with agreed timescales.

Performance Review

The quality improvement framework is currently under review. The plans for developing equality objectives and standards will form part of the SES, and will be incorporated into the new Programme



Standards. These will provide performance targets and indicators for the quality improvement process.

Performance assessment against Programme Standards will determine whether or not further work is needed to close previously identified gaps – in which case the cycle resumes from Stage 4. Remedial actions do not need to be new actions. The continuation of existing actions to meet the SES requirement is incorporated, subject to compliance with the policy for EqIA review (for example, every three years).





EQUALITY VALUES AND PRINCIPLES WITHIN STRATEGIC OBJECTIVES OF THE PROGRAME

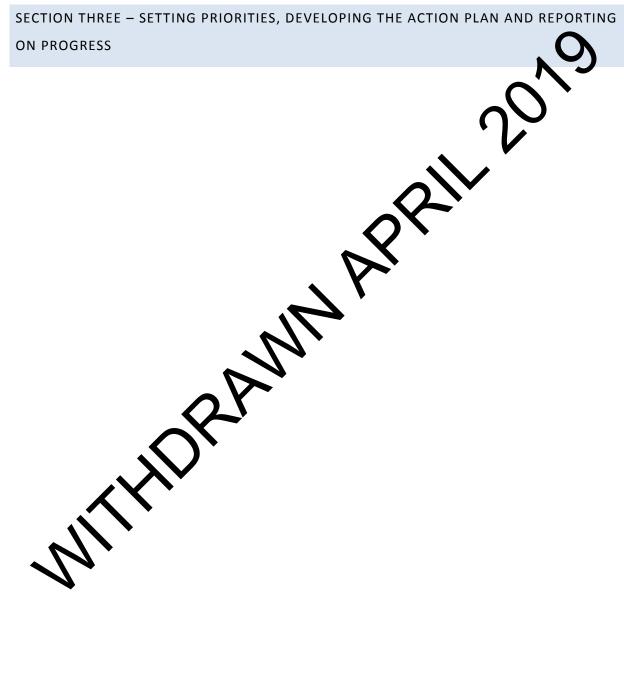
The Programme's commitment to equality and diversity was led by a drive to continuously improve our working practices, so that we create an organisation recognised both internally and externally for welcoming diversity and promoting equality. In addition, we needed to meet legislative requirements under the public sector Equality Duties.

The Programme is committed to mainstreaming the principles of equality and diversity through the standards, policies and practices we develop. We aim to do this by:

- ensuring that our policies, standards and practices
 - are inclusive;
 - do not have an adverse impact on different groups;
 - are equally accessible to all at risk groups;
 - deliver the same quality and outcomes of service to all patients, irrespective of ethnicity, sexual orientation, gender, disability, age religion or belief;
- improving our ability to respond to the needs of customers and stakeholders;
- increasing the satisfaction of patients and at risk groups by providing appropriate information and services;
- becoming an exemplar on race, disability gender and other equality issues in relation to both employment practice and lervice delivery – by positive promotion and proactive demonstration;
- employing a diverse we know which improves our ability to understand and reflect the diverse needs a patients and stakeholders;
- consulting effect eleand involving a wide range of people, so our work is shaped by their voice.



SECTION THREE - SETTING PRIORITIES, DEVELOPING THE ACTION PLAN AND REPORTING





MANAGING AND DELIVERING EQUALITY - ACTION PLAN

ESTABLISHING PRIORITIES FOR THE SINGLE EQUALITY SCHEME

From the broad list of recommendations initially made in the report of the Equalities review, an extensive range of priorities was listed for remedial action.¹⁴ As already mentioned, this list suggested a programme of work far beyond our resources and capacity, and therefore—equired further refinement. We had to prioritise to ensure that the action plan was deliverable and achievable, setting challenging but realistic objectives. The list was discussed and agreed by the Programme's Management Committee against transparent criteria which were outlined in the Context report, our resources and our capacity to deliver. Two of the criteria in particular addressed limitations of resources and capacity:

- taking account of work in progress elsewhere with the Programme and the NSC and its potential impact on gaps and weaknesses identified and
- use of pre-determined prioritisation criteria canacity implications, synergy with work in progress, coverage of all equality strands and potential for quickest impact.

The committee then agreed a list of priorities which have been reviewed and agreed by our Steering Group. Our agreed priorities cover the following equality areas/strands:

- Gender
- Age
- · Religion or belief
- Disability
- Race

These were the areas of Nost relevance to existing and potential clients, and other stakeholders. The areas of work within the Action Plan over the next three years are as follows:

- 9) Programme Standards
- 10) Data Alection and performance management
- 11) Accessibility
 - a) Language
 - b) Disabilities
- 12) Outreach
 - a) Public outreach

¹⁴ The criteria by which this prioritisation in the report was achieved is detailed in the Context Report (pp. 37-38, 2009). The same criteria were used in a transparent process by the Management Team in order to refine the list of priorities.



Page | 22

- b) Engaging men
- c) Faith communities
- d) Black and Minority Ethnic communities
- e) Young people
- f) Other under-represented groups
- 13) Professional Development
- 14) Primary Care Engagement
- 15) Embedding Equalities
- 16) Joint equalities work with UK National Screening Committee and alignment with other National Initiatives.

ACTION PLAN: 2010-2013

The Single Equality Scheme (SES) sets out how we intend to meet ou duties as a public body. It will be implemented through an action plan which will help us to:

- be systematic in the way we promote the equality strands;
- set a development agenda with realistic objectives.
- assign responsibilities;
- meet our legislative duties

The action plan will be implemented or three year period. It sets out:

- the goals we want to achieve to meet our objective of promoting equality and diversity and tackling discrimination
- the actions regard to make this happen

We have grouped the outcomes and actions according to priorities drawn from our stakeholder consultation and recommendations from the earlier Equalities review. These priorities will be delivered over a three year period (2010-2013) and are detailed in the Action Plan that follows.



SINGLE EQUALITY SCHEME

FIGURE 3 – Single Equality Scheme Action Plan: 2010-2013

Outcomes	Actions	Baseline issue addressed	rimaly equality errand targeted	Target Completion Timescale	Lead
PROGRAMME STANDARDS		2			
Equality standards incorporated into Programme Standards Performance management against equality standards DATA COLLECTION AND PERFO	Incorporate equality standards within the review and re-issue of the Programme Standards. ORMANCE MANAGEMENT	Need to review Programme Standards and incorporate equality standards Need to manage performance against revised standards.	All	Review Sept 2010; Consultation Oct- Dec 2010; Publish by 31/3/11; Dissemination March/April 2011	ED
Collection of Equality data Decision-making informed by reliable evidence	i. Data collected and performance assessed in the NIGB approved project on Newborn outcomes. ii. Monitoring and supporting the outstanding units to achieve full implementation of the Family Origin Questionnaire in Low and High Prevalence areas; lines upporting the collection of ethnicity data	Significant gaps in current management information systems leading to gaps in equality data	All	i. Implementation start Sept 2010; Report to NIGB Feb 2011 ii. On-going iii. Throughout	i. ED/RL ii. CG



Outcomes	Actions	Baseline issue addressed	Primary equality strand argeted	Target Completion Timescale	Lead
ACCESSIBILITY	on bloodspot card iv. FOQ inclusion in Read and Snomed dictionaries; v. FOQ roll-out and adoption by suppliers	PIL		period iv. Jan 2011 v. Dec 2012	iii-v. RL
Language Support		D.			
Reliable interpretation services available	i. Provision and use of Language Line interpretation services ii. Review of 'required' languages il forwing the development of tailored materials iii. Translation of relevant materials iv. Annual report available in hard copy for those who don't have access to computers	Patchy provision of high quality resources for interpretation at relevant points along the screening pathway Need to produce information in different formats and languages	Race/Ethnicity	i. July 2010 ii. Dec 2011 iii. Jan 2011	i. ED ii. LA/KS/KJ iii. LA/KS/KJ
Disability					
Information and services provided in a format appropriate for individuals	Build to previous accessibility report and a valop information in accessible formats	Need to ensure that information and services are tailored to meet relevant	Disability	July 2011	LA/KS/KJ



Outcomes	Actions	Baseline issue addressed	Primary equality strand argeted	Target Completion Timescale	Lead
with a disability OUTREACH		disability requirements			
Public Outreach		21/			
Communications strategy ensuring access to and communication with a range of clients including under- represented groups, and delivering appropriate and accurate information Engaging Men	i. Development of Public Outreach programme ii. Implementation of Communications Strategy	Gaps in acce is to and communication with otherwise under-represented communities identified Gaps in information provided to ensure that all clients are making informed choices	All	i. Nov 2010 ii. Dec 2011	LA/KS/KJ
Strategies developed to increase uptake of male partner screening Screening and diagnosis services accessible to all mothers and their partners across the equality strands	i. Define minimum and achievable standards for partners on dendifical carrier mothers to be offered screening ii. Conduct gender research around partner take up of screening including review of trategies to engage men (esp. fathers –to-	Low uptake of male partner screening Reluctance of some health professionals to offer screening to male partners	Gender	i. Review Sept 2010; Consultation Oct- Dec 2010; Publish by 31/3/11 ii. Start September 2010	i. ED ii. LA/KS/KJ



Outcomes	Actions	Baseline issue addressed	Primary equality strand argeted	Target Completion Timescale	Lead
Programme Standards for offering partner screening are met Faith Communities	be) in screening iii. Develop strategy to engage men in screening			iii. May 2010	iii. LA/KS/KJ
Effective communication and joint-working with faith communities to reduce stigma about SC&T	Public Outreach project working with Faith Communities to reduce barriers to access due to religion or belief.	Limited success in accessing faith communities in order to reduce a standards at large and take up the grounds of religion or belief	Religion or belief	ТВС	LA/KS/KJ
Black and Minority Ethnic Con	nmunities				
Information and services ensuring access, and the delivery of appropriate services to clients from all communities	i. Communications campaigns largeting BAME communities ii. Public Outreach work targeting affected communities iii. Initiativas ta abdress stigma e.g. APPG	Some cultural resistance to screening	Race/Ethnicity	Dec 2013	LA/KS/KJ
Young People		ı	1		
Development of appropriate strategies to communicate	Join't work with the NSC to develop and implement Schools project to educate young	Inability to reach disengaged young people in order to	Age	ТВС	AS



Outcomes	Actions	Baseline issue addressed	Primary equality strand argeted	Target Completion Timescale	Lead
with young people about screening	people about screening and genetics and having preconception testing options	communicate about screening			
Other Under-represented Gro	ups				
Appropriate information and advice provided to women in Detention Centres Appropriate information and advice provided to men in Prisons	i. Collaborate with organisations involved in the welfare of asylum seekers and refugees to improve access ii. Provision of appropriate screening information and advice for women in Detention Centres iii. Provision of appropriate screening information and advice for melvir phisons	Difficulty reaching asylum seeker directly keeping track of women entering the country to have babies Difficulty engaging men in screening	Gender Race	Dec 2013	i. LA/KS/KJ
Professional Development			•		
Nursing and counselling competence in delivering screening achieved	i. Develop competencies for Nurses ii. Develop effective strategies for delivering courselling in primary care	Gaps in SC&T screening competencies for Nurses Shortcomings in counselling	All	TBC	AS/ED overall RH (Nursing



Sustainable, accredited specialist training for SC&T screening provided Practitioners are accredited for having the necessary skills and knowledge to deliver an effective SC&T counselling service Counselling and follow up services are delivered to predetermined standards Practitioners are trained to respond to and recognise equalities issues that may impact on the counselling service being delivered The PEGASUS Specialist Practitioner Course is more accessible to all specialist counsellors Vi. Dankop sysem for ensuring fair access to Spstialist bourse III. Develop counselling resources for primary care (Comp) Comp) Comp) Need to provide accedited and sustainable makes of professional development of professional	Outcomes	Actions	Baseline issue addressed	Primary equality strand argused	Target Completion Timescale	Lead
	specialist training for SC&T screening provided Practitioners are accredited for having the necessary skills and knowledge to deliver an effective SC&T counselling service Counselling and follow up services are delivered to predetermined standards Practitioners are trained to respond to and recognise equalities issues that may impact on the counselling service being delivered The PEGASUS Specialist Practitioner Course is more accessible to all specialist	iii. The requirement for professional development for frontline health professionals to be included within Programme Standards iv. Establish a compulsory standard for SC&T counselling and processes for accreditation of prior experiential learning (APEL) v. Review the 'Diversity awares as in practice' module of the Specially Practitioner Course to address gap and wealtnesses in PEGASUS' current as grage of equalities and diversity vi. Develop system for ensuring fair access to	Need to provide accredited and sustainable me hour of professional development. Review of FIGASUS training underway, which will inform professional development objectives.			. ,



Outcomes	Actions	Baseline issue addressed	Primary equality strand argeted	Target Completion Timescale	Lead
Primary Care Engagement		•			
Effective engagement of primary care in joint-working on screening Information and counselling services provided by GPs are informed and reliable Embedding Equalities	Project to review and develop strategies to engage primary care staff Develop an updatable resource that provides GPs with relevant and accurate information about sickle cell and thalassaemia, who can get it, good practice guides on counselling and local sources of support i.e. Regional Coordinators, specialist counsellors and specialist third sector organisations offensy sickle cell and thalassaemia support survey. Working with RCGPs to exploit mechanisms for reviewing and certifying the callity of information and counselling services provided by GPs.	Inconsistent levels of awareness/known dgs among GPs	All	Dec 2013	ED/LA
J .					I
Process in place to embed equality impact assessments in existing and future policies and practices	i. Devr op SES and obtain Steering Group approval ii. Previde EIA training (workshop) to Rougamme Centre staff using tailored EIA	Need to develop EqIA with approval of Steering Group ii. Need to ensure that all relevant Programme Centre	All	i. SG Approval Nov 2010 ii. Nov 2010	PC
Programme services are	Guidance and Toolkit developed by	staff are aware of and			



		equality strand targeted	Completion Timescale	
consultants conducting Equalities Review. ii.b Undertake Equality Impact Assessment of Programme Standards, Communications Materials (workshop) iii. Produce priority list (high, medium and low) for conducting EqIAs on policies, strategies, services and functions. Develop an EIA rollout plan. Conduct initial screening on Programme policies, strategies, services and functions for EIA.	understand the importance of the EIA process. Staff are skilled in carrying out EIAs on new and existing policies strategies, services and functions. iii/iv. Med to ensure that EIA process is fully embedded within in Programme.		iii. March-July 2011/	
iv. Conduct full Equality Impact Assessment on all high priority policies, strategies services and functions to ensure that here are no negative impacts on any equality strands; embedding equality impact assessments processes in the Plagramme v. Report on Equalities Manitoring section within the Annual Report vi. Review the SES and revelop SES for next three-years.	v. Need to monitor and report progress on SES actions.		v. October 2012; October 2013. vi. Autumn 2013	
ii.l Pr Miii.lo sti El. Pr fu iv. or str as v. wi	b Undertake Equality Impact Assessment of ogramme Standards, Communications aterials (workshop) Produce priority list (high, medium and w) for conducting EqIAs on policies, rategies, services and functions. Develop an A rollout plan. Conduct initial screening on ogramme policies, strategies, services and nctions for EIA. Conduct full Equality Impact Assessment all high priority policies, strategies rvices and functions to ensure that there is no negative impacts on any equality rands; embedding equality impact sessments processes in the Phygramme Report on Equalities Manitoning section ithin the Annual Report	the EIA process. Staff are skilled in carrying out EIAs on new and existing policies strategies, services and functions. Develop an A rollout plan. Conduct initial screening on orgamme policies, strategies, services and nctions for EIA. Conduct full Equality Impact Assessment all high priority policies, strategies rvices and functions to ensure that there e no negative impacts on any equality rands; embedding equality impact assessments processes in the Plagramme Report on Equalities Maintoning section ithin the Annual Report Review the SES and revelop SES for next the EIA process. Staff are skilled in carrying out EIAs on new and existing policies strategies, service and functions. iii/iv. N. ed to ensure that EIA process is ully embedded within an Programme.	the Undertake Equality Impact Assessment of ogramme Standards, Communications aterials (workshop) Produce priority list (high, medium and w) for conducting EqIAs on policies, rategies, services and functions. Develop an A rollout plan. Conduct initial screening on ogramme policies, strategies, services and nctions for EIA. Conduct full Equality Impact Assessment all high priority policies, strategies rvices and functions to ensure that there e no negative impacts on any equality rands; embedding equality impact assessments processes incree Programme Report on Equalities Manitoning section ithin the Annual Report Review the EES and revelop SES for next the EIA process. Staff are skilled in carrying out EIAs on new and existing policies, strategies, service and functions. iii/iv. N. ed to ensure that EIA process is ully embedded within an Programme. vilvin an Programme.	the EIA process. Staff are skilled in carrying out EIAs on new and existing policies, strategies, services and functions. Develop an Ar ollout plan. Conduct initial screening on ogramme policies, strategies, services and nctions for EIA. Conduct full Equality Impact Assessment all high priority policies, strategies, roughly in policies, roughly in policies, roughly in policies, strategies. Report on Equalities Marintoning section thin the Annual Kept at Review the SES and severe policies for next.



Outcomes Joint equalities work with UK	Actions National Committee for Screening and other Nat	Baseline issue addressed	Primary equality strand argeted	Target Completion Timescale	Lead
Work jointly with NSC and other Programmes to facilitate the development of	i. SES is published on website and disseminated through intranet	Need to develop consistent approach across programmes, and to facilitate aqualities	All	i. March 2011 ii. March 2011	PC
Equality Schemes across all Programmes	ii. Share learning from development of SES with UK National Committee for Screening	learning across programmes Net a traincorporate learning		iii. March 2011 – February 2013	
Align the SES work with other National Initiatives	iii. Work to ensure that the SES is aligned with relevant national Initiatives.	from national initiatives.			



SINGLE EQUALITY SCHEME

EQUALITY IMPACT ASSESSMENTS

Equality Impact Assessments (EqIAs) form a strand of work within the SES Action Plan. As this strand will underpin and embed all SES work, it is essential to cover the role of EqIAs in detail.

An EqIA is a way of systematically and thoroughly assessing the effects that a standard, function or policy (actual or proposed) is likely to have on different aspects of equality. This could be in relation to groups or individuals, or issues such as race, disability, gender, age, religion or belief, sexual orientation and gender reassignment. The impact identified may be positive, negative or n utra-

For the Programme, the main purpose of conducting an EqIA is to pre-empt the possibility that any of our standards, functions or policies could affect some groups unfavourably. It should also reduce the risk of our policies, functions and standards having a negative impact.

The Programme is required to screen all policies, standards and functions to establish if they need a full impact assessment. The process for screening and assessing policies standards and functions will be outlined in the Programme's EqIA template which was developed as part of the earlier Equalities Review.

If we find that policies, standards or functions may not be appropriately ensuring equality, an action plan will be drawn up; and remedial action pricitized to address any negative impact. In future, equality will be considered when new policies are sundards are being drafted. All new policies or standards must be screened and if necessary, fully assessed.

Training for Programme Centre State

Programme Centre staff were trained at a workshop to ensure that they undertake Equality Impact Assessments competently, possonsistently. Also, in the spirit of collaboration and shared learning, places at the workshop were offered to representatives from the other screening programmes. Further training will be proceeded for Programme Centre staff as necessary.

GOVERNATICE, MONITORING AND REVIEWING ARRANGEMENTS FOR THE SINGLE EQUALTY SCHEME

Responsibility for the SES

A fundamental principle is that equality and diversity activities and considerations are embedded within organisational management and normal operational delivery. Ultimately the Programme Centre through the Steering is responsible for the SES and its effective implementation. In practice this responsibility can only be discharged through the whole organisation sharing in it and contributing to its delivery. Collective responsibility will be met through the Table below:



	Responsibility	Role
Stewardship	NHS Sickle Cell and Thalassaemia Steering Group	Monitoring progress against SES action plan
Management	Programme Centre	Prioritise activities within the action plan and allocate recources to deliver activities as remain
Delivery	a. Programme Centreb. Regional Co-ordinators;	Delivery of activities and promotio of he ses
	c. Regional Teams d. Health Professionals	

Table 1: Single Equality Scheme - Roles and Responsibilities

Charting Performance

Performance on the SES will be reviewed at least annually, and monitored as follows:

- The Programme's Steering Group with onitor progress at each of its six-monthly meetings.
- We will chart the progress against the Action Plan.
- An annual Equalities Report covering the progress on the SES and the action plan will be provided to the Steering aroun and will be included in the annual report.

Revising the SES and action Flan

The Programme was revise the SES every three years, working with all stakeholders to take into account information gathered, including the outcomes of impact assessments, and incorporating any feedback tectived, as appropriate.

Publishing the Scheme

The Scheme and action plan will be published and circulated internally and externally. The SES will be published in a clearly signposted area of our intranet for employees to view, and on our external website for the general public. Copies will be available in different formats on request. The Action Plan will be published on our Website, where we will chart the progress against each of the actions.

We will also publish the results of each Equality Impact Assessment. Full EqIAs will include consultation with relevant stakeholders, and copies will be available on request, and sent to those



who took part in the consultation, where feasible. The results of full EQIAs will be made available on the Programme website and in the Programme's Annual Report. We will also publish the annual Equalities Progress Report in the Annual Report.

WITHDRAWN APRIL 20'



SINGLE EQUALITY SCHEME

APPENDICES

APPENDIX A. DATA COLLECTION

SES Focused Consultation and Revision

A consultation was conducted on the SES, over a five week period. It was a focused exercise targeting twenty key contacts comprising representatives from: other screening programmes; the national Screening Committee; voluntary sector partners; midwifery professionals; counselling professionals and regional teams.

The content of the SES had been consulted on at several stages – from the external Equalities review and the stakeholder consultation which was conducted as part of this review; the formulation and development of the Scheme and development of strategic priorities, the circulation of the draft SES to stakeholders (including staff from other screening Programmes) and its subsequent revision, as well as the most recent focused consultation. The triangulation of feedback and consultation methods both formal and informal allowed us to receive useful input that fed into the revision of the SES throughout its development. This multi-stage feedback process is perhaps, effected in the low response rate to the final formal consultation exercise which received three responses from a mail-out targeting twenty respondents, and which may arguably reflect a degree of saturation.

APPENDIX B. GLOSSARY OF TERMS

Black and Minority Ethnic (BAME) - The terms are relay used to describe the range of minority ethnic communities and groups in the UK. It can be used to mean the main Black and Asian and Mixed racial minority communities or it can be used to include all minority communities, including white minority communities.

Consultation — Asking for view on services or policies from service-users, staff, decision-making groups or the general public Consultation can include a range of different ways of consulting, e.g. focus groups, surveys and quast annaires or public meetings.

Disability - The legal of finition for the purposes of the DDA 2005 is 'A physical or mental impairment which has a substantial and long-term adverse effect on a person's ability to carry out day-to-day activities.' However, this definition sees people under what is known as the "Medical Model of Disability". By contrast the "Social Model of Disability", views disability as the way in which society fails to must the needs of disabled people, for example, producing information that is not readily accessible to a section of society; travel infrastructure that does not make adequate (or any) provises for alternative forms of mobility.

Discrimination - Treating an individual or group differently and less favourably than others under comparable circumstances. It may be based on a person's race, ethnic origin, gender, disability, age, religious or other belief, or their sexual orientation. It may be unlawful and can include harassment.

Diversity – Appreciating diversity goes beyond the mere recognition that everyone is different; it is about valuing and celebrating difference and recognising, valuing and taking account of people's different backgrounds, knowledge, skills and experiences, and recognising that everyone through their unique mixture of skills, experience and talent has their own valuable contribution to make.



SINGLE EQUALITY SCHEME

Equalities – This is a short hand term for all work carried out by an organisation to promote equal opportunities and challenge discrimination, both in employment and in 'carry out' functions and delivering services.

Equality – A commitment to ensuring real equality of opportunity and access exists for all, regardless of their ethnicity, disability, gender, age, sexual orientation, faith/belief or transgender status and a commitment to the removal of discrimination.

Ethnicity – Racial origin or cultural background.

Ethnic minority – Group differentiated from the main population of a community by recial right or cultural background.

Ethnic monitoring – Recording the ethnic background of people so that it is so sible to see, for example, what proportion are from black and ethnic minority populations.

Language Line – A telephone interpreting service, which uses an interpreter on the phone to interpret between, for example, a doctor or nurse and a patient who does not speak English.

Equality Impact Assessment – A process to ensure a policy, function or service does not discriminate against anyone from the protected equality strands.

Equality Impact Assessment – Equality Impact Assessment's a way to make sure individuals and teams think carefully about the likely impact of policies or procedures, strategies, functions and services, to identify any unmet needs, and to provide a basis for action to improve services where appropriate. It systematically assesses and records the actual, potential or likely impact of a service, policy or project – or a significant charlie in a service, policy or project - on different groups of people. The consequences of policies and projects on particular groups are analysed and anticipated so that, as far as possible, any mentative consequences can be eliminated or minimised and opportunities for ensuring equality of the maximised.

Equality Strands – Groups of people identified and protected by Equality legislation – includes race/ethnicity, disability gender, sexual orientation, faith/belief and transgender.

Monitoring – The process of regularly reviewing achievements and progress towards goals.

Outreach The efforts by individuals in an organisation or group to connect its ideas or practices to the efforts of other organisations, groups, specific audiences or the general public.

Per vivance management - Systematic management practices and monitoring systems which support people so that they can achieve their work objectives.

Policy - A broad statement of the principles of how to proceed in relation to a specific issue, such as a policy on how to provide services for particular needs e.g. services for people who misuse drugs or alcohol.

Primary care services - Services which are people's first point of contact with the NHS. They are provided by primary health care teams working in the community, usually based in GP surgeries or



health centres. Primary care workers include GPs, practice nurses, health visitors, district nurses and many others.

Professional development - Education and training for professionals throughout their working life to keep them up-to-date and develop new skills and attributes as appropriate to their changing work.

Public bodies – A collective term for organisations which are controlled by the State and publicly funded, such as the NHS, local authorities, and the police, fire, probation and prison services; often also called public sector agencies.

Public involvement – Process of working with members of the public so that they can have a say in how health services are planned and run.

Single Equality Scheme – Document explaining how an organisation's equality objective will be met within the work of the organisation, with specific regard to the seven equality strands. The SES will outline an Action Plan detailing specific objectives, activities, and the timetable following the outcomes, as well as persons with responsibility for the actions.



WITHDRAWN APRIL 2019



The NHS Sickle Cell and Thalassee nia Screening Programme

is based at King's College Land

Tel: 020 7848 663****

Fax: 020 7848 6020

Email: haemscreening@kcl.ac.uk

Visit our website: sct.screening.nhs.uk