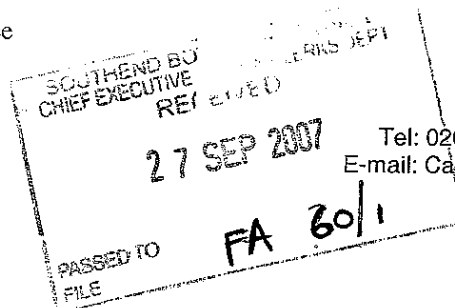


The Chair
Community Services Scrutiny Committee
Southend-on-Sea Borough Council
Civic Centre
Victoria Avenue
Southend-on-Sea
Essex SS2 6ER



Headquarters
Leon House
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19 September 2007

Dear Scrutiny Colleague,

Re: Possible Joint Health Scrutiny Committee on the Review of Configuration of Haemophilia Services

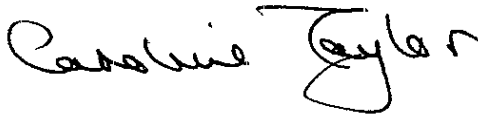
Croydon Primary Care Trust is the host organisation of the Pan Thames Haemophilia Consortium (PTHC), the largest single purchaser of Haemophilia services in the UK, covering a population of 15 million people across London and the South East of England. The Consortium brings together 10 acute Trusts and 48 Primary Care Trusts, covering 44 Local Authority areas: there are approximately 3,000 people with inherited clotting disorders in the geographical area covered. Not all patients will require treatment every year as there is a wide range of severity: the budget for Haemophilia care services in 2007/8 is c. £90M.

The PTHC has commissioned a Review of the configuration of services across London and the South East: the attached briefing paper outlines the drivers for change, the proposed process and the timescale. We are currently at the early stages of the Review – undertaking a needs assessment and extensive pre-consultation engagement with stakeholders across the area.

Croydon Council's Health and Social Care Scrutiny Sub-Committee is of the view that changes which arise from the Review process could well constitute a substantial change to service provision and therefore warrant scrutiny. We would like to formally offer you an invitation to join a Joint Health Scrutiny Committee across our Local Authority boundaries in anticipation of a formal consultation exercise in 2008/9. The likely formal consultation arising from this initial engagement phase will be on one or more proposed models of care for the Pan Thames area.

As you can see from the appendix to the briefing paper, we have detailed the number of residents in your area (average over two years) affected by this Review. If you require any further information to assist you in your deliberations on joining the Joint Health Scrutiny Committee, then please do contact me or Project Director Lucie Waters on the contact numbers or addresses below.

Yours sincerely,



Caroline Taylor
Chief Executive, Croydon PCT
Chair, Project Board, Review of Configuration of Haemophilia Services

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Project Board Chair
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Lucie Waters
Project Director
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Dear Scrutiny Colleague,

**Possible Joint Health Scrutiny Committee
on the Review of Configuration of Haemophilia Services**

As you will have seen from the Croydon PCT letter, Croydon's Health & Social Care Scrutiny Sub-Committee has been approached by the PCT in relation to the review of the configuration of haemophilia services commissioned by the Pan Thames Haemophilia Consortium (PTHC).

As Chair and Vice-Chair of the Sub-Committee, we have advised Croydon PCT that the review may give rise to proposals for change in the delivery of haemophilia care services that constitute a substantial variation in the provision of such services.

This letter is to canvass interest in participation in the creation of a Joint Overview & Scrutiny Committee to provide a consolidated response to the review process and outcomes. We appreciate that the summer recess is not the most convenient time for either Members or Officers, but since 44 different local authorities are covered by the services provided by the PTHC we are keen to initiate consultation with colleagues as early as possible.

Clearly your respective Health Scrutiny Committees will need to agree formally whether they wish to participate, but an early indication of initial thoughts would enable us to begin planning the mechanisms to take this forward in the most efficient and effective way possible.

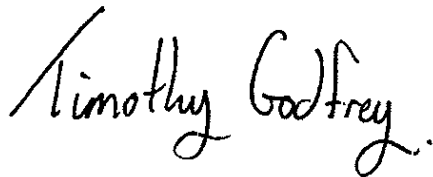
Croydon Scrutiny Officers will be contacting you electronically to confirm local details and to facilitate early discussions, but formal meetings would need to be held to agree terms of reference and any final recommendations or report.

The Croydon Scrutiny team looks forward to building on our excellent working relationship with Croydon PCT and to working with Scrutiny Members and Officers across London and the South East in taking forward this process



Contact details of the relevant Croydon Scrutiny Officers are given below: Trevor Harness will be leading during the initial stages of making contact with other local authorities, but given the potential scale of the work could we please ask that you also copy Joan Matlock into your e-mails.

Yours sincerely,



Councillor Timothy Godfrey
Chair of Croydon Health & Social
Care Scrutiny Sub-Committee



pp. Councillor Graham Bass
Chair of Croydon Health & Social
Care Scrutiny Sub-Committee

Croydon Scrutiny Officers:

Trevor Harness
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Scrutiny Support Team Manager
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London Borough of Croydon
Democratic & Legal Services Division
Policy & Corporate Services
Department
Taberner House
Park Lane, Croydon, CR9 3JS.

PAN THAMES HAEMOPHILIA CONSORTIUM

BRIEFING PAPER: REVIEW OF THE CONFIGURATION OF HAEMOPHILIA SERVICES FOR LONDON AND THE SOUTH EAST

1. Introduction

The Pan Thames Haemophilia Consortium (PTHC) is the largest single purchaser of Haemophilia services in the UK, covering a population of 15 million people across London and the South East of England. The Consortium brings together 10 acute Trusts and 48 Primary Care Trusts, covering 44 Local Authority areas: there are approximately 3,000 people with inherited clotting disorders in the geographical area covered. Not all patients will require treatment every year as there is a wide range of severity: the budget for Haemophilia care services in 2007/8 is c£90M. Patient numbers by Local Authority area are attached in *Appendix 1*.

The Consortium is hosted by Croydon PCT as part of the Specialised Commissioning arrangements across London and the South East. This sees individual PCTs take specific responsibility for the host arrangements of one or more of the thirty-five different services classified as "specialised" by the National Definition Set, and managed on a consortium basis, on behalf of others.

For a number of reasons – detailed later in this document – the PTHC has initiated a review of the configuration of services. This review process may result in a "substantial" service change and therefore require scrutiny.

1.1 Haemophilia Care

Haemophilia (and related inherited clotting disorders¹) is a disorder in which the blood fails to clot. The most common form, primarily affecting males, is caused by a gene mutation related to the clotting protein (Factor VIII) and is inherited with women being the carriers and men inheriting the disorder. The disorder in its severe form is a very serious condition: a male child born with severe haemophilia with no access to treatment would have a life expectancy of ten to fifteen years of age. About 1 in 8,000 of the population has a bleeding disorder (including all degrees of severity).

Clinical support and treatment for people with Haemophilia has changed exponentially over the last thirty years – firstly with the introduction of prophylaxis² and secondly with the advent of recombinant (i.e. laboratory manufactured and free from blood borne virus) clotting factors. Patients can also now receive a regular delivery of clotting factor products to their door through a variety of 'home delivery' schemes. These advances have greatly improved both the life expectancy and quality of life for people with Haemophilia and their families.

At the same time, these developments have had the impact of significantly reducing hospital admissions for this patient group: the introduction of home

¹ Inherited Bleeding Disorders – the PTHC covers the costs of treatment for people with Haemophilia A, Haemophilia B, von Willebrands and a variety of rare associated disorders.

² The administration of clotting factors to prevent bleeds

delivery has meant that some patients with well managed Haemophilia only need attend a single annual clinic appointment as a check up. Across the country, this has led to a loss of expertise in general haematology departments and more recently a series of closures and/or ad hoc centralisation of specialised Haemophilia services.

1.2 Growth

There has been significant year-on-year growth in the care costs associated with Haemophilia in the last 10 years. The United Kingdom Haemophilia Centre Doctor's Organisation (UKHCDO) estimate an annualised increase of 10% in the amount of clotting factor needed to treat patients, which relates to the following:

- An increase in the number of people with Haemophilia in the population due to birth rate (1:7000 male births). One in three babies born with haemophilia is a spontaneous mutation of the gene i.e. born to a family with no previous history of clotting disorders.
- An increase in acquired haemophilia due to the demographic increase in the older population (up to 4 cases per million)
- The greatly enhanced quality of life for people with Haemophilia with near normal life expectancy.

1.3 Drivers for Change

Despite substantial success in key outcome areas over the last few years, the PTHC has determined that the service configuration is not 'fit for purpose' for the future. Key amongst the drivers for change are:

- **Medical Leadership:** there is a national shortage of consultant haematologists (55 unfilled consultant posts nationally at March 2006) with posts in malignant haematology being preferred by those completing their training. Within the PTHC area, there are currently seven vacant posts – some filled with locum staff and some remaining vacant – leaving both single handed services and some running only on locum leadership. In addition, there are a further four posts (including three Chairs) which will become vacant through retirement within the next three to five years. It is very unlikely that appointments can or will be made to these posts with the current number of small services.
- **Medical Training:** Within the current curriculum, the time set aside for haemostasis and thrombosis only provides a basic understanding of the subject and, as haemophilia is mainly dealt with on an out-patient and domiciliary basis, there is little in-patient experience. This lack of in-depth experience and low contact time is viewed as the major reason that insufficient numbers of junior doctors are attracted to progress on to consultant posts. There is also a lack of dedicated training facilities and these need to be identified in approving training programmes. Sufficient time needs to be ring-fenced for Haemostasis training and this must be properly reviewed in the yearly assessments. Post CCT credentials are currently being discussed which may act as a route into the speciality for more mature trainees.

- **Quality and Safety:** audits of patient care have shown considerable variation in clinical practice. This will be further exacerbated by the growing gaps in medical staffing and leadership described above.
- **Networks:** the PTHC area lacks a formal 'hub' and 'spoke' network of services that would ensure patients are cared for in services appropriate to the level of support required; new patients are accurately identified and transferred; and general haematology services caring for single figures of patients with haemophilia are required to transfer them to more appropriate services. Until PTHC centres are fully staffed, it is not possible to pursue this workstream, leaving some patients vulnerable to sub-standard care in small non-specialised units.
- **Finance:** Expenditure by the PTHC has doubled in the space of six years from £45M in 2001/02 to the current year's budget of c £90M. There is a responsibility on behalf of the Consortium to demonstrate the very best value for money in the services commissioned.
- **Policy Context:** The Carter Review of Specialised Services³ places responsibility with commissioners for designating all providers of specialised services against nationally agreed sets of criteria by 2010. The aim of this is to drive improvements in health and service delivery as well as addressing financial and capacity issues.

It is for these reasons that the PTHC is proposing a review of the configuration of Haemophilia services. A key outcome from this Configuration Review project will be a specific or series of model(s) of care and service specification that will be used to define the shape of services for the next decade or more.

A Project Board has been convened and the membership is attached for information as *Appendix 2*.

2. Review Programme

The Review is just entering its second phase:

Phase	Key	Timescale
I. Needs Assessment	Understanding the current and future need for services, making the case for change.	November 2006-Sept 2007
II. Stakeholder Engagement & Generation of Service Models	Pre-consultation engagement programme with stakeholders. Generation of models of care and agreeing quality standards Agree preferred service model.	April 2007-March 2008
III. Tender/Designation	Formal consultation process	Services to commence

³"Review of Commissioning Arrangements for Specialised Services" (May 2006) Sir David Carter/DH

Phase	Key	Timescale
	Undertake a tendering exercise or alternatively move to designation in line with Carter programme. Six months notice to current providers	April 2009

A programme of significant **pre-consultation** stakeholder engagement has been planned and is in the process of being taken forward: a table is attached as *Appendix 3*.

3. Conclusion

It is very likely that whatever model is generated will constitute significant service change: the current configuration has come about through the historical development of acute services in London and is out-with the experience in other areas of the country (where there is a maximum of one adult and one paediatric centre in each major city) and overseas. In comparison, the whole of Spain (population of 40 million) has just 3 Comprehensive Care Centres.

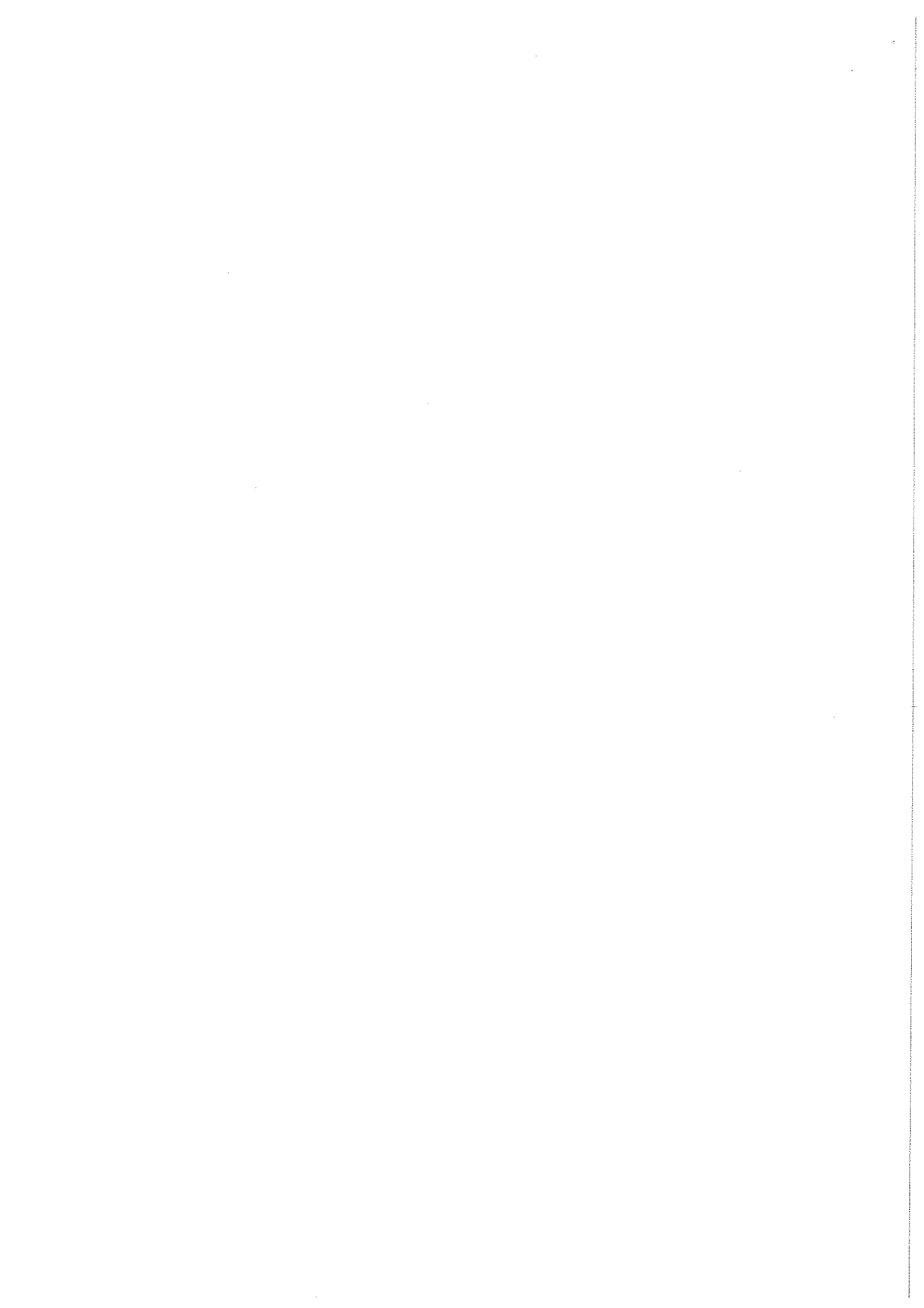
Croydon Borough Council will be leading the process of Health Scrutiny: covering a small number of patients over a very large area presents particular issues for scrutiny and we invite you to be part of this planned process during 2008/9.

Lucie Waters

Project Director, Strategic Review

July 2007

Local authority	Patients Treated (05/06)	Patients Treated (06/07)
Kent County Council	132	138
Essex County Council	80	100
Surrey County Council	80	77
Hertfordshire County Council	61	69
West Sussex County Council	65	59
LB of Barnet	49	38
LB of Islington	31	30
LB of Greenwich	16	30
LB of Enfield	30	30
LB of Brent	27	30
LB of Lambeth	20	29
LB of Haringey	23	28
LB of Bromley	22	28
LB of Ealing	41	26
LB of Westminster City	19	24
LB of Lewisham	10	24
LB of Wandsworth	18	23
LB of Redbridge	23	23
LB of Tower Hamlets	16	22
LB of Newham	22	22
LB of Hackney	21	22
LB of Waltham Forest	24	21
LB of Camden	17	21
LB of Hounslow	25	20
LB of Croydon	18	20
LB of Hammersmith & Fulham	29	19
LB of Hillingdon	17	17
East Sussex County Council	21	17
LB of Richmond Upon Thames	25	16
LB of Harrow	17	16
LB of Sutton	17	15
LB of Southwark	18	15
LB of Barking And Dagenham	9	15
LB of Merton	16	15
Medway Unitary Authority	14	14
Luton Unitary Authority	0	14
LB of Havering	19	13
Brighton And Hove Unitary	14	15
LB of Kensington & Chelsea	17	12
Southend-On-Sea Unitary Authority	7	11
LB of Kingston Upon Thames	10	11
LB of Bexley	11	11
Thurrock Unitary Authority	10	9
Bedfordshire County Council	0	9
	1161	1218



Pan-Thames Haemophilia Consortium Strategic Reconfiguration of Services

Project Board Membership

PCT Chief Executive (Chair)	Caroline Taylor, Chief Executive, Croydon PCT and Chair of the PTHC
Out of London Commissioner (Vice Chair)	Stephanie Newman, Director of Specialised Commissioning, Kent, Surrey & Sussex
National Specialised Commissioning Group	Julia Stallibrass, Head of Specialised Services Commissioning
Public Health	Dr Dianne Addel, Consultant in Public Health Medicine, Croydon PCT
London SHA	Hannah Rich, Deputy Director of Strategy & Commissioning (PAPERS ONLY)
Haemophilia Society	Christopher James, Chief Executive, Haemophilia Society (<i>with effect from 2nd July 2007</i>)
Other Patient Rep	Tbc
Royal College of Pathologists	Professor Adrian Newland, President, Royal College of Pathologists
Royal College of Physicians	Dr Peter Collins, Consultant Haematologist, Cardiff
Lead Commissioner	Michele Davis, Pan Thames Haemophilia Consortium
Universities	Professor Ghulam Mufti, Haematologist, King's College (<i>tbc</i>)

APPENDIX 2

Trusts	Dr David Keeling, Oxford Radcliffe Hospital
UKHCDO	Dr Charles Hay, United Kingdom Haemophilia Centre Doctor's Organisation
Paediatric Nurse Representative	Vicky Vidler, Nurse Consultant (Paediatric Haematology), Sheffield Children's Hospital
King's Fund	Bernie Brooks, Senior Fellow, King's Fund
Project Director	Lucie Waters, Croydon PCT
Project Manager	Bridget Emanuel, Croydon PCT

CONFIGURATION REVIEW: PRE-CONSULTATION ENGAGEMENT

Stakeholder Group/Engagement Activity	Project Board	Research	Letter	OSC	PHIC	Meetings
1 Patients - Haemophilia Society	✓				✓	
2 Patients - mild/moderate/severe + parents + co-morbidities		✓				
3 Patients - Trust PPI sub groups			✓			
4 Patients - "hard to reach" groups		✓				
5 Clinical Staff*	✓					
6 Trust Executive Teams			✓			✓
7 NHS London	✓					
8 Department of Health	✓					
9 Royal College of Pathologists	✓					
10 Royal College of Physicians	✓					
11 United Kingdom Haemophilia Centres Doctor's Organisation	✓					✓
12 Universities	✓					
13 Primary Care Trusts	✓					✓
14 London Assembly (Joanne McCartney, Chair, Health & PS Cmt)			✓			
15 Local Authorities				✓		

* Clinical Staff Group: this includes consultant medical staff, senior nursing staff, junior medical staff - interviewed through research groups. Clinical Staff are also represented through Royal College representatives, Trust Clinical representatives and RCN representatives on the Project Board.

