



HEALTH SCRUTINY COMMITTEE

Meeting :Thursday 15th November 2007

Review of the Configuration of HAEMOPHILIA Services for London and the South East – Possible formation of a Joint Health Overview and Scrutiny Committee

PURPOSE OF REPORT:

For Members to decide whether the Committee wishes to form part of a Joint Health Overview and Scrutiny with the London Borough of Croydon and 42 other Local Authorities to consider the Pan Thames Haemophilia Consortium review of the configuration of services.

SUMMARY:

1. Introduction

The Secretary of State for Health issued a Direction about joint health OSCs in July 2003 relating to consultations by NHS bodies under the Health and Social Care Act where people from more than one local authority area may be affected by proposed variations or developments to NHS services. In these circumstances, all health OSCs consulted must decide whether they consider the proposals to be “substantial”. Those health OSCs that do consider them to be substantial must form a joint health OSC to deal with the consultation and to respond on behalf of their communities

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. 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.

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 £104M

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. They have made a formal 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.

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 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 both 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

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

² The administration of clotting factors to prevent bleeds

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 is inadequate. Not all trainees get good comprehensive haemostasis training and this is viewed as the major reason that insufficient numbers of junior doctors progress on to consultant posts. In addition, there are a lack of dedicated training facilities and no ring-fenced time for Haemostasis training in general Haematology services.
- **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 £104M. 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.

³"Review of Commissioning Arrangements for Specialised Services" (May 2006) Sir David Carter/DH
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A Project Board has been convened

PCT Chief Executive (Chair) Caroline Taylor, Chief Executive, Sutton & Merton PCT and Chair of the PTHC
Out of London Commissioner (Vice Chair) Stephanie Newman, Director of Specialised Commissioning, Kent, Surrey & Sussex

Department of Health Julia Stallibrass, Specialised Services Team Leader

Public Health Dr Dianne Addei, Consultant in Public Health Medicine, SWL Specialised Commissioning Team

London SHA Hannah Rich, Director of Strategy (papers only)

Haemophilia Society Chief Executive, Haemophilia Society

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, Lead Commissioner, Pan Thames Haemophilia Consortium

Universities Michael Farthing – TBC

Trusts Dr David Keeling, Oxford Radcliffe Hospital

UKHCDO Dr Charles Hay, United Kingdom Haemophilia Centre Doctor's Organisation

Paediatric Nurse Representative TBC

King's Fund TBC

Project Lead Lucie Waters, Head of Specialised Commissioning,

SWL Specialised Commissioning Team

Bridget Emanuel, Project Manager, SWL Specialised Commissioning Team

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

ISSUES FOR CONSIDERATION

3. 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.

3.1. Surrey

Is presently the third largest user of the service behind Essex and Kent

Number of patients treated 2005/06 = 80

Number of patients treated 2006/07 = 77

Early discussions with Kent have led me to believe that their Health Scrutiny Committee will be delegating authority to the London Borough of Croydon.

As at 25 October 2007 no other local authority had informed the London Borough of Croydon of its intention to participate in a joint overview and scrutiny committee.

RECOMMENDATIONS:

The Committee may wish to consider whether it has the time, capacity and resources to invest in another Joint Health Overview and Scrutiny Committee or whether it is prepared to delegate authority to the London Borough of Croydon.

NEXT STEPS:

London Borough of Croydon to be notified of the Decision of the Surrey Health Scrutiny Committee

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Sources/background papers:

Letter from PCT to Local Authorities See Attached

Letter to other LA Authithys

Patient Numbers Spreadsheet

Pre Consultation Engagement Table

Project Board Membership Details

London Specialised Commissioning Group NHS – Annual Report 2006/07

Centre for Public Scrutiny Consoltations by specialised services – A Practical guide for health overview and scrutiny committees

<http://www.cfps.org.uk/pdf/publications/42.pdf>