



# Understanding the contribution of sickle cell and thalassaemia specialist nurses

Full report July 2012

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Project supported by Roald Dahl's Marvellous Children's Charity



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## Letters of endorsement

### Sickle Cell Society

“The Sickle Cell Society was delighted to hear that the NHS Sickle Cell & Thalassaemia Screening Programme was funded by Roald Dahl’s Marvellous Children’s Charity to carry out a study into the provision of nursing for people with Sickle Cell Disease and Thalassaemia in England. Being part of the working group, I was able to bring my views as a patient and also share insights of the Society’s patients.

Improving patient care is the fundamental principal of the Sickle Cell Society and this study will continue to enhance the care patients receive. At the core of the study is the objective to incorporate specialist nursing care into the treatment plan of a patient, with the aim of providing a positive impact on patient care including the recovery time of people that endure a sickle cell crisis.

Closing gaps in the training programme and professional development for nursing staff will help to create the sought after nursing capability vital to sustainable long-term care.”

Anne Welsh

For and on behalf of The Sickle Cell Society

### UK Thalassaemia Society

“The UK Thalassaemia Society is proud to have been part of the project on SC&T Specialist Nurses. The importance of specialist nurses has been highlighted by the membership of this group and also by patients receiving vital care from specialist nurses.

The positive effects of having a specialist nurse in a thalassaemia unit have been continuously praised by patients we have spoken to and listened to throughout this project. The relationship between nurses and patients is extremely important to get right and having a specialist nurse is most definitely the way to continue working and to make sure there is the co-ordinated care required by both patients and nurses. Having a nurse in place can also have a very positive effect on patients during transition periods from paediatric to adult services which need sensitivity, understanding and specialist care.

Working in partnership with the NHS SC&T Screening Programme and Roald Dahl’s Marvellous Children’s Charity, the project has helped to focus on nursing services and should encourage further development and stability which in turn creates a good communicative and engaging relationship between patients and nurses.

Our thanks to all those involved with the project and praise to the dedication and commitment of the specialist nurses in particular. We hope that their positions remain to provide the stability needed for our patients.”

Sema Kiamil

Director, UKTS

## Section 1 Background to the study

The NHS Sickle Cell & Thalassaemia Screening Programme was funded by Roald Dahl's Marvellous Children's Charity to carry out a study into the provision and contribution of specialist nursing for people with Sickle Cell Disease and Thalassaemia in England. The aim was to explore the sustainable provision of high quality, specialist nursing care for affected children and adults. The perceived loss of specialist nursing posts in the current economic climate had previously been flagged and discussed at meetings of the All Party Parliamentary Group for Sickle Cell & Thalassaemia (APPG), and considerable support for such a project has been expressed by many stakeholders. The case for keeping and increasing specialist nursing posts has already been made for several other areas of practice including Parkinson's disease and rheumatology (Parkinson's UK 2011; Oliver & Leary 2012).

The project is extremely timely with the welcome developments concerning specialist commissioning for haemoglobinopathies in the NHS. An example is the recently launched guide *The National Haemoglobinopathies Project – a guide to effectively commissioning high quality sickle cell and thalassaemia services* (Nathwani 2011).

The Screening Programme convened a Working Group, chaired by Professor Elizabeth Anionwu, to advise it on the development and delivery of the study between October 2011 and April 2012. The group included specialist sickle cell and thalassaemia (SC&T) nurses drawn from both the acute and community sectors, together with representatives from patient groups (Sickle Cell Society and UK Thalassaemia Society), the Roald Dahl charity, the London Specialised Commissioning Group and the NHS SC&T Screening Programme. Members of the Working Group are given in Appendix A.

Dr Alison Leary was commissioned to join the Working Group as an expert researcher in modelling activity data to investigate more fully SC&T specialist nurses' activity. This work allowed identification of the huge number, variety and complexity of practices which SC&T specialist nurses undertake for patients across all ages and at all stages of the lifelong care pathway. In addition, Dr Leary was asked to undertake a literature review to look at the definition of SC&T specialist nurses and development of their roles in recent years.

## Section 2 Introduction

### 2.1 Sickle Cell & Thalassaemia: the conditions and prevalence in England

Sickle cell and thalassaemia affect haemoglobin – the substance in the blood that carries oxygen around the body. There is a wide family of inherited haemoglobin disorders – known as haemoglobinopathies – of which sickle cell disease is the most common.

Sickle cell disease affects the normal oxygen carrying capacity of red blood cells. When cells are de-oxygenated and under stress, they change from a flexible disc-like shape to a stiff, elongated sickle or crescent moon shape. When this happens, the cells cannot pass freely through small capillaries and form clumps which block the blood vessels. This in turn prevents oxygenation of surrounding tissue (hypoxia) causing pain known as a 'crisis'. Other symptoms can include severe anaemia, susceptibility to infections and damage to major organs.

The highest prevalence of sickle cell disease is among Black Africans and Black Caribbeans, although it is also found in other populations such as those with Mediterranean, South Asian and Middle East origins. In England, more than 12,500 people have sickle cell disease and it is estimated that there are around 380,000 healthy carriers. Newborn screening data for 2009/10 from the Screening Programme shows that one in seven babies of Black African origin and one in eight of Black Caribbean origin is a sickle cell carrier. Further figures are given in the table below.

Thalassaemia is the name given to a family of conditions where less haemoglobin than normal is produced. Of these the most serious are alpha thalassaemia major (which is incompatible with life and babies do not usually survive the pregnancy) and beta thalassaemia major – where a defect in the normal haemoglobin gene prevents the body from producing haemoglobin. This results in life threatening anaemia so people with beta thalassaemia major need regular blood transfusions for survival, and therapeutic treatment to clear excess iron from the body throughout their lives.

There are currently an estimated 300,000 healthy carriers of the beta thalassaemia gene variant in England, and more than 800 people with beta thalassaemia major. The highest prevalence is among Pakistanis, Cypriots, Italians, Greeks, Indians, Bangladeshis, Chinese and other South East Asian groups.

The NHS Sickle Cell and Thalassaemia Screening Programme is the world's first linked antenatal and newborn screening programme covering England and providing support and policy advice to the rest of the UK and internationally. Antenatal screening is offered to all pregnant women early in pregnancy and, where relevant, to fathers-to-be. The screening programme identified about 1 in 40 women as a carrier in 2009/10. The programme's aim is to identify, early in pregnancy, couples at risk of having a child with a haemoglobin disorder so that they can receive counselling and make informed choices about whether to have a test on their unborn baby.

Newborn screening for sickle cell is offered to all babies. Screening identifies babies with sickle cell disease so they can receive prompt – and potentially life-saving – treatment. About one in 2,000 babies is affected by sickle cell disease with about one in 70 babies identified as a carrier.

Babies identified with sickle cell conditions (data from the NHS Sickle Cell & Thalassaemia Screening Programme)

	Number	Rate per 1000 babies screened
2007/8	359	0.54
2008/9	360	0.54
2009/10	361	0.53
2010/11 DRAFT*	358	0.52

*'Significant' sickle cell conditions comprise FS, FSC and FS-other screening results*

*\*2010/11 data has not yet been published and is therefore draft data only*

Babies identified with sickle cell disease and carrier status by ethnicity for 2009/10 (data from the NHS Sickle Cell & Thalassaemia Screening Programme)

Screening data for 2009-10	Baby with sickle cell disease		Baby with sickle cell carrier status	
	Number	Rate per 1000 babies screened	Number	Rate per 1000 babies screened
White	7	0.01	968	2.00
Mixed	15	0.49	1405	46.17
Asian	17	0.27	1261	19.67
Black Caribbean	45	6.26	934	129.85
Black African	218	8.66	3612	143.45
Any other Black background	16	6.29	263	103.38
Other/not known	43	0.60	1361	18.88
TOTAL	361	0.53	9804	14.31



## 2.2 Defining specialist nursing practice

Specialist nursing practice has evolved in the UK within the last 30 years but can trace its roots back to the 19<sup>th</sup> century in the UK, North America and Canada. Work such as that by De Witt and Reiter (De Witt 1900, Reiter 1966) and the practice of Hildegard Peplau in the 1950s (Rust 2004) demonstrate that the concept of specialist advanced practice is not new. In the UK however, such practice has tended to evolve to meet local need rather than by design (Trevatt & Leary 2010a). In some specialisms there is now an interest in funding specialist nursing posts to meet specific areas of need in line with public policy or patient need, but this is still largely driven by the charitable or private sector (Breast Cancer Care 2008, RCN 2010, Macmillan Cancer Support 2011, Parkinson's UK 2011, MS Trust 2012).

There has been much debate in recent years regarding the definition of specialist and advanced practice. The terms 'specialist' and 'advanced' are often used to describe nursing roles in which nurses work to expert level; however, there is a lack of clarity in this area.

In terms of advanced practice the International Council of Nursing (ICN) definition (2002) is most commonly used:

*"A registered nurse who has acquired the expert knowledge base, complex decision-making skills and clinical competencies for expanded practice, the characteristics of which are shaped by the context and/or country in which s/he is credentialed to practice. A Master's degree is recommended for entry level." ICN 2002*

In the USA the term 'Clinical Nurse Specialist' and other advanced practice titles have robust frameworks and a degree of protection, as practitioners have to meet criteria and credentialing in order to obtain those titles (American Nurses Association 2012). In the UK such requirements do not exist apart from local agreements or best practice recommendations. Various groups publish definitions and there has been a considerable lobby to the Nursing and Midwifery Council to introduce a higher level of registration for such practitioners. This lobby includes interest groups of nurses such as the RCN Nurse Practitioner Forum which published a set of competencies and programme accreditations in 2008 (RCN 2008). Many nurse leaders agree with this position. The 2010 Prime Minister's Commission on Nursing recommended that



“The Nursing and Midwifery Council must regulate advanced nursing practice, ensuring that advanced practitioners are recorded as such on the register and have the required competencies.” (Central Office of Information [COI] 2010)

However, this has not yet occurred. The Department of Health (England) gave a position statement on advanced practice (DH 2010a), in response to the Council for Healthcare Regulatory Excellence findings that an additional level of registration was not necessary to protect the public (CHRE 2009). The Scottish Chief Nursing Officer commissioned an Advanced Practice Toolkit in 2008 (NHS Scotland 2008) – a result of this work was the publication of the Specialist-Generalist continuum (Fig. 1), in which specialist practice is a **context** of practice and advanced practice is a **level** of practice. This concept was re-enforced in a more recent publication by the Welsh Assembly, *A Framework for Advanced Practice* (NHS Wales 2010).

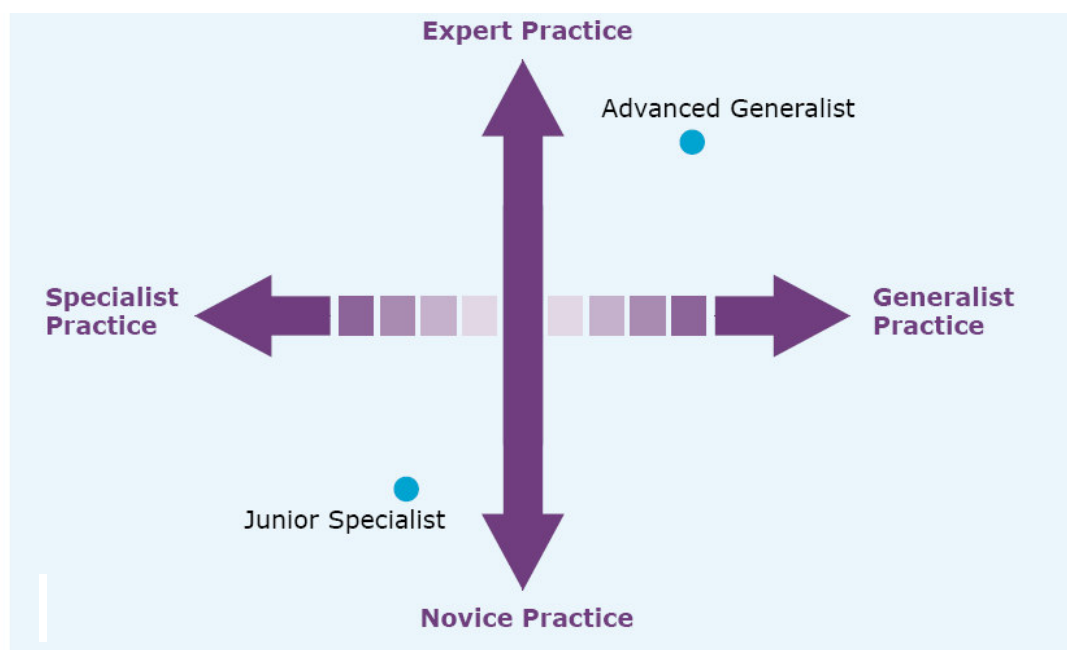


Figure 1. Relationship between Specialist and Advanced Practice (NHS Scotland, 2008)

Conceptually this seems sound. However, there is a question regarding the efficiency and productivity of the ‘junior specialist’ and whether the term ‘specialist’ should be reserved for those who are working at an advanced level in specialist practice rather than just within a specialist setting (Leary 2012).

Other bodies such as charities, educational providers, health policy makers and academics all seek to define specialist and advanced practice. The grey literature offers many competency-based documents

which provide those working in specialist practice with a way of defining practice for that specialism (RCN 2008, Macmillan 2011, RCN 2011). However many of these frameworks have little relevance to the efficiency contributions of these nurses – for example, the ability to proactively case manage or broker efficient care pathways such as admission avoidance (Leary et al 2008, Baxter & Leary 2011).

As specialist advanced practice nursing has developed in the UK, the number of titles has increased to the point where they risk dilution of the contribution. The Prime Minister's Commission recommends that *"Stakeholders must also consider how to reduce and standardise the proliferation of roles and job titles in nursing."* (COI 2010)

A recent census of the cancer nursing workforce found 48 different job titles among approximately 2000 nurses (Trevatt & Leary 2010a). Common titles are Clinical Nurse Specialist, Advanced Practitioner, Specialist Nurse and Advanced Nurse Practitioner. The lack of an agreed and clear definition causes confusion to patients, managers and commissioners (Trevatt & Leary 2010b).

### **2.3 Specialist nursing as a return on investment in long-term conditions**

The return on investment that specialist nurses represent has been unclear for a number of years. As practices tended to evolve, often driven by local or national policy, little evaluation was done of the impact of these roles and virtually no cost benefit analysis. Any evaluation tended to focus on the quality aspect of these roles using qualitative methodologies. While many of these studies were robust, the data they present does not translate into financial return on investment. In recent years there has been a growing body of evidence examining the added value in terms of quality, safety and efficiency.

There has been a lack of awareness by managers and even nurse leaders in some Trusts of the contribution of specialist advanced practice nurses to service redesign. This led the Prime Minister's 2010 Commission to recommend: *"The redesign and transformation of health and social care services must recognise nurses' leading role in caring for people with long-term conditions. Care pathways must be commissioned for service users that maximise the nursing contribution."* (COI 2010)

In relation to long-term conditions, this also makes sound economic sense. Specialist advanced practice nurses can generate additional activity (income) by offering services that need to be commissioned and they can also make existing services much more efficient and effective – as they have often been instrumental in starting the service, or have led on patient experience of the service.

In terms of economic evaluation there is a small but growing literature. Long-term conditions such as inflammatory joint and connective tissue disease, cancer, diabetes, Parkinson's disease, heart failure and multiple sclerosis have all demonstrated cost benefits associated with specialist advanced practice nurses. For example:

- Rheumatology: one whole time equivalent clinical nurse specialist demonstrates a positive cost benefit of around £300,000 pa by role substitution for a senior medical colleague, admission avoidance and saved GP time (RCN 2010, Oliver & Leary 2012)
- Advanced lung cancer: reassigning specialist nurse time from essentially secretarial work to proactive case management saved approximately £66,000 in acute bed days and unscheduled admissions for symptoms control in advanced disease for two WTE nurses (Baxter and Leary 2011)
- Cancers: a study commissioned by the Department of Health looked at different cost benefit models for specialist nurses providing one-to-one support in different cancers – the most conservative estimate was a saving of £19 million in England per projected year (*Frontier Economics* 2010)
- Parkinson's disease: two NHS Trusts recorded a saving of £80,000 by the work of specialist nurses in admission avoidance (Parkinson's UK 2011)
- Diabetes: a saving of £37,000 over 3.5 years was recorded by Mahaffey et al (2012). However compared with other studies this seems quite low, and appears to cover only patients who actually present in the emergency department rather than the complex rescue work (Silber et al 1992) and brokering of alternatives to unscheduled care which are a core component of the clinical nurse specialist role in long-term conditions (Leary et al 2008, Oliver & Leary 2012).

There is further literature on admission avoidance without any completed cost benefit analysis. For example, in Multiple Sclerosis the benefit of a collaborative approach to admission avoidance has been

demonstrated, with the nurse and patient managing care collaboratively and utilising services to avoid the need for admission – in this case by ambulatory use of steroids to prevent a crisis (Quinn 2011). Some other specialisms have examined return on investment – but they have done so in a fairly simplistic way without reference to the complexity of nursing work, by looking at aspects of role substitution and within a ‘handmaiden to the consultant’ model (Epilepsy Action 2010).

## **2.4 Specialist nursing in haemoglobinopathies (e.g. sickle cell disease & thalassaemia)**

Specialist advanced practice nursing in haemoglobinopathies has a rich historical and descriptive literature. Key authors and influencers such as Elizabeth Anionwu – who brought together community groups and healthcare professional groups in Brent to champion holistic care in the mid-1970’s (Anionwu 1977) – set the scene for the need for the specialist practitioner. Subsequent work has shown that the role is valued by patients and families and also by other professionals.

Unlike other specialisms such as cancer or other long-term conditions, the literature lacks peer reviewed empirical research into the contribution of specialist nursing in sickle cell and thalassaemia. However there is some comparative literature around nursing interventions. A paper examining ambulatory management (with the predominate intervention being transfusion) demonstrates an emphasis on proactive management and health promotion/self-management which is usually a nursing activity (Day et al 2011), and thus may form the basis for further evaluation. It was not made explicit in this paper however that transfusion is a nursing intervention.

The complexity of the work of the specialist nurse in sickle cell disease has been recognised in other health economies. The use of home healthcare specialist nurses in the USA has shown benefit in ambulatory management. By proactive management of pain and other crisis points, patients – particularly older patients – are more likely to stay in the ambulatory setting (Lee et al 2012). Patients with haemoglobinopathies, particularly sickle cell disease, are more likely to suffer from depression, depressive symptoms, distress and stigma. A study found that African Americans with sickle cell disease were three times more likely to suffer from depressive symptoms than those without – they are at risk for untreated depression, making psychological assessment vital (Coretta et al 2005). Haemoglobinopathy nursing is linked with cultural and transitional issues due to the nature of the diseases – for example, dealing with

pain not only in terms of pathophysiology but also in the cultural context. Sanders' 2010 study in the USA found that younger patients were likely to use taught self-management strategies, whereas older patients utilised prayer and hope (Sanders et al 2010). Others such as Harrison et al (2005) concluded that religious involvement probably plays a significant role in modulating the pain experience of African American patients with sickle cell disease.

There are many papers which challenge attitudes of staff in areas such as perception of pain. Pack-Mabien et al (2001) found that 63% of nurses caring for patients with sickle cell disease thought addiction was prevalent, and 36% were hesitant to administer high dose opioids. Pain is often managed at home by those with the ability to do so, as opposed to using unscheduled care services (Smith et al 2008). In addition pain and depression are inextricably linked in sickle cell disease (Levenson et al 2008). Managing pain, anxiety, biographical disruption and distress through self-management and prompt proactive case management (which includes the important socio-cultural dimensions when intervention is required) is likely to be a cost effective solution. Successive policy makers have been slow to recognise the needs of this population (Anionwu & Atkin 2001).

## **2.5 Development of specialist sickle cell and thalassaemia nursing services**

Two main groups of specialist sickle cell and thalassaemia nurses have emerged over the last three decades:

- Sickle Cell & Thalassaemia nurses based in the community: predominately SC&T genetic counsellors, the first post was established in Brent in 1979 (Anionwu, 1989) to address the unmet needs of affected families and those at risk of sickle cell and thalassaemia. The role included provision of information about the conditions – including screening and genetic counselling, support, and referral to appropriate agencies. There was significant growth of such posts over the next two decades, with most of the nurses having Black and Minority Ethnic (BME) origins (Anionwu, 1996a) and (prior to the current reconfiguration of the NHS) mainly based in Primary Care Trusts (Anionwu, 1996b). A few of these posts have evolved into today's community matron role, which has been introduced to provide high quality clinical nursing care in the community.

- Sickle Cell & Thalassaemia specialist nurses based in acute trusts: these posts emerged in Birmingham and London in the mid-1980s and early 1990s. The first examples included a specialist paediatric nurse in Birmingham; a specialist nurse caring for paediatric and adult patients with thalassaemia at the Whittington Hospital, London; and the appointment of an advanced nurse practitioner for adult patients with sickle cell disease at Guy's and St Thomas' Hospital, London. Recently there has been an increase in SC&T specialist nurses within the acute sector.

<b>Table 2.1 Number of Specialist Sickle Cell &amp; Thalassaemia Counsellors &amp; Clinical Nurse Specialists in 49 Boroughs/Cities in the UK (Anionwu 2009)</b>			
Post	Greater London	Outside London	Total
Sickle Cell & Thalassaemia Counsellor	34	49	83
Clinical SC&T Nurse Specialist - Acute	19	4	23
Total	53	53	106

This analysis was recently repeated (for England only) and the results are given below

<b>Table 2.2 Number of Specialist Sickle Cell &amp; Thalassaemia Counsellors &amp; Clinical Nurse Specialists<sup>#</sup> in ~ 50+ Boroughs/Cities in <i>England only</i> (Anionwu 2012)</b>			
Post	Greater London	Outside London	Total
Sickle Cell & Thalassaemia Counsellor	34	42	76
Clinical SC&T Nurse Specialist - Acute	29	10	39
Combined Counsellor & Acute	2		2
Total	65	52	117

# 1 service suspended – E Berkshire.

## Section 3 The study

### 3.1 Objectives of the Study

This study was set in the context of developing specialist commissioning arrangements for sickle cell and thalassaemia. It was designed to build on existing work assessing the value of specialist nursing, and to incorporate existing standards and frameworks in sickle cell and thalassaemia care and treatment. The study aimed to:

- calculate the current working population of whole time equivalent SC&T nurses in England
- identify the complexity of sickle cell & thalassaemia specialist nurse work in the context of acute and community care, including genetic counselling roles and subsequent contribution to care
- understand the current methods used by nurses to deliver high quality, efficient care across different demographic groups (for example, low prevalence populations)
- understand the value of the SC&T nurse role from patient and family perspectives
- understand how nurses in SC&T meet the Department of Health's Quality, Innovation, Productivity and Prevention agenda (QIPP)
- consider education and professional development available for sickle cell & thalassaemia nursing care, and identify any challenges to provision of and access to specialist education.

### 3.2 Methodologies used

#### The SC&T nursing population

To assess the population of SC&T specialist nurses and recruit volunteers to contribute data for analysis, a number of organisations were contacted. They included STAC (Sickle and Thalassaemia Association of Counsellors), FAST-N (Forum of Acute Sickle cell and Thalassaemia Nurses), the Royal College of Nursing IV/Haematology Network, the UK Forum for Haemoglobin Disorders (a multidisciplinary network) and finally, the Sickle Cell Society and the UK Thalassaemia Society.



## The complexity of SC&T nursing and its contribution to care

To model the work and complexity of specialist nursing practice, a number of data sets need to be mined. The work of nursing is complex (Hall 1964) and the work of **specialist** nursing has added complexity, in that it occurs in many different contexts or locations (Leary et al 2008).

Conventional research methods such as work sampling or time and motion studies do not capture this complexity in a meaningful way as they tend to focus on process (De Leon 1993, Raiborn 2004). As nursing work is not linear (Hall 1964, Leary et al 2008), its complexity cannot be captured by conventional time and motion or work sampling as there are eight dimensions to each nursing act (Leary et al 2008). An alternative is to build a representative model of the complex work using modelling techniques.

In haemoglobinopathy there is a rich historical literature, which was reviewed and mined. However, there is little empirical data on the complexity of nursing in this setting. In order to have an adequate data set to mine, a rapid data collection tool (The Cassandra Matrix™) was used (Leary 2011). Cassandra collects data in two dimensions (intervention performed and context/location of work). It is based on a much bigger data set that has been previously mined (Leary et al 2008, RCN 2010).

To examine the complex activity of the specialist nurse in haemoglobinopathies, the following items were mined: literature; historical literature for context; grey literature; unpublished data provided by the NHS SC&T Screening Programme regarding competency frameworks and outcomes; the published competency framework (RCN 2011); consensus data from a workshop held at the Royal College of Nursing; and data collected via the adapted Cassandra Matrix™. The Cassandra Matrix™ was adapted with specific items as a result of the data collected in the workshop and an iterative review of the literature. Four in-depth interviews were undertaken with those working at an advanced level of practice. These data were then mined. Data mining and pattern recognition techniques have been described elsewhere (Fayyad et al 1996).

## The patient and family perspective

A number of voluntary sector partners provided information about the value and contribution of SC&T nurses as perceived by patients and families, by undertaking patient experience work or offering recent, relevant data.

Four patient meetings were arranged in conjunction with the Sickle Cell Society and UK Thalassaemia Society – two involved mainly thalassaemia patients, and two mainly sickle cell patients. The data offered were subjected to thematic content analysis (Krippendorff 2004).

Consultation on this particular section of the report was sought specifically from patient bodies including NEBATA (North of England Bone Marrow and Thalassaemia Association), the Sickle Cell Society, UK Thalassaemia Society, SSCAT (Sheffield Sickle Cell and Thalassaemia Foundation) and the Bristol Patients Association, in addition to the general consultation process sought for the whole report.

## The Quality, Innovation, Productivity and Prevention (QIPP) agenda

The results of the activity analysis and the descriptive data of activity (from a nurse and patient perspective) were mapped against the DH Quality, Innovation, Productivity and Prevention (QIPP) framework. The QIPP challenge is a national Department of Health strategy involving all NHS staff, patients, clinicians and the voluntary sector. It aims to improve the quality and delivery of NHS care while reducing costs to make £20bn efficiency savings by 2014/15; and to reinvest savings to support the front line (NHS Improvement 2011).

## The educational and professional development needs of SC&T nurses

Four in depth interviews were undertaken with SC&T nurses regarding their activity which also elicited perceptions on education and organisational issues. In addition, a brief survey was undertaken of nurses present at the Sickle Cell & Thalassaemia Association of Counsellors (STAC) AGM in January 2012. The survey asked about educational and developmental activities undertaken; 22 nurses responded, and a summary of the results is included at Appendix B.

## Section 4 Results

### 4.1 The current population of SC&T nurses

Currently SC&T specialist nurses are affiliated to a variety of professional organisations, which makes a headcount of the population challenging. Many counsellors and some acute nurses are members of STAC (Sickle Cell and Thalassaemia Association of Counsellors) and/or FAST-N (Forum of Acute Sickle cell and Thalassaemia Nurses). There are plans to discuss the merger of STAC and FAST-N. In addition some nurses who are members of the Royal College of Nursing (RCN) have joined the newly established RCN IV/Haematology Network. There are also specialist sickle cell and thalassaemia nurses who do not belong to any organisation.

The project initially attempted to produce an overall database of specialist sickle cell and thalassaemia nurses in England, in collaboration with the above organisations. Acquiring these data proved to be extremely difficult – particularly getting accurate and up-to-date figures. There are a number of reasons for this, including the plethora of job titles used, changes in location and management structure due to current changes in the NHS, and no single organisation routinely collating this data. In addition, SC&T patients are generally under the medical management of haematologists, and may be nursed by specialist haematology nurses (who may have expertise in malignant haematology, but who are not SC&T specialist nurses). It has not been possible to conduct this survey within the timescale of this project. It is therefore recommended that a comprehensive census is undertaken of all relevant post holders within acute and community sectors of the NHS.

In the meantime an analysis was made in 2012 of the STAC list that has been maintained for many decades and results compared with a similar analysis undertaken in 2009 (Table 2.1). Although not comprehensive for the reasons set out above, this is a useful resource.

The 2009 analysis identified details of 106 specialist nurses within the UK. While equally divided between the Greater London region and elsewhere in the UK, 83 (78%) were SC&T counsellors and 23 (22%) were acute nurses.

The 2012 STAC list (Table 2.2) suggests that there are now around 117 SC&T specialist nurses in England including 76 counsellors, 39 acute nurses, and 2 combined counsellor-acute posts. With 41 SC&T nurses covering the acute sector in England, this equates to a caseload per nurse of 325. About 55% of specialist nurses are based in Greater London and 45% outside London.

## **4.2 Results of activity analysis & data mining**

The data collection and analysis has yielded several streams of data amenable to mining. The purpose of mining is to discover new knowledge through data (Fayyad 1996). These streams of data are presented here.

### **The activity of the specialist nurse in sickle cell and thalassaemia**

There were several streams of data contributing to activity analysis.

A one-day workshop yielded a rich source of data on context, activity and intervention and these were used to additionally populate the Cassandra Matrix™. These data were transferred onto Excel spreadsheets for collection and analysis (Appendix C)

The Cassandra Matrix™ is a self-reported two dimensional matrix which allows nurses to record events by intervention and context/place – for example, specialist symptom control (intervention) in a nurse led clinic (context).

Four interviews were conducted with specialists in haemoglobinopathy and 16 documents (annual reports, activity logs, appraisal sheets) were also submitted to the researcher. One participant was using the interrelational database Pandora (the antecedent to Cassandra) which was also mined (Leary et al 2008).

31 spreadsheets were returned; 26 were used in analysis. Spreadsheets that had recorded fewer than 100 events were excluded (spreadsheets needed at least 100 recorded items to be valid).

In total 8966 nursing events were captured over 1639 hours from a total of 22.8 whole time equivalents (WTE). The group was split into subsets of community (15 sheets) and acute (11 sheets). In addition to

WTE hours the nurses also recorded unpaid overtime. The mean unpaid overtime was 3 hours per week (range 0-10). Thus the assumed WTE equals 40 hours of activity.

Interview data (unstructured) was subjected to content analysis (Krippendorff 2004) for common themes and perceptions of contribution.

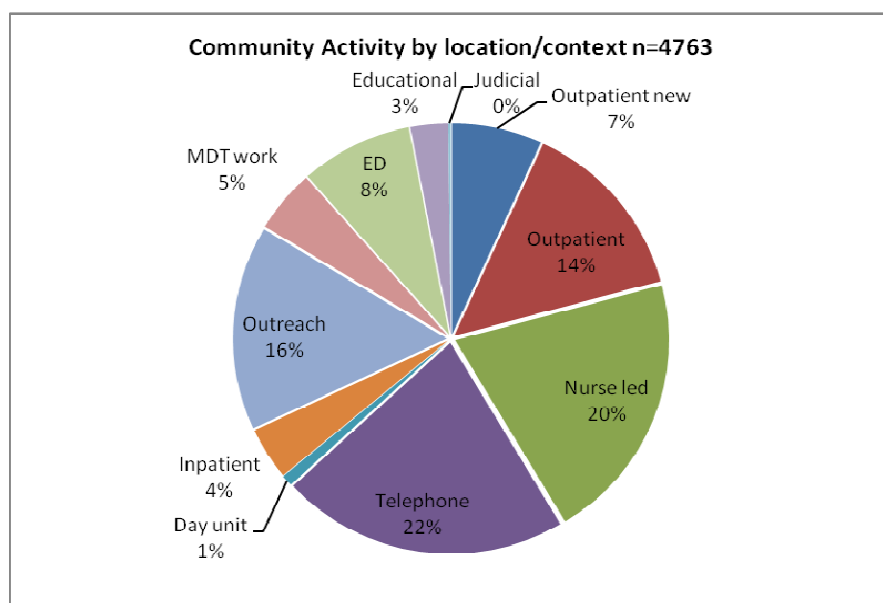
The activity data collected via Cassandra demonstrates a very wide range of complex activity similar to that of other long-term conditions (RCN 2010, Baxter & Leary 2011, Oliver & Leary 2012).

There are some striking differences however in terms of working context, referral patterns and activities. Some assumptions based on previous work are made – such as the specialist nurse spending at least 8% of their activity in teaching other members of staff.

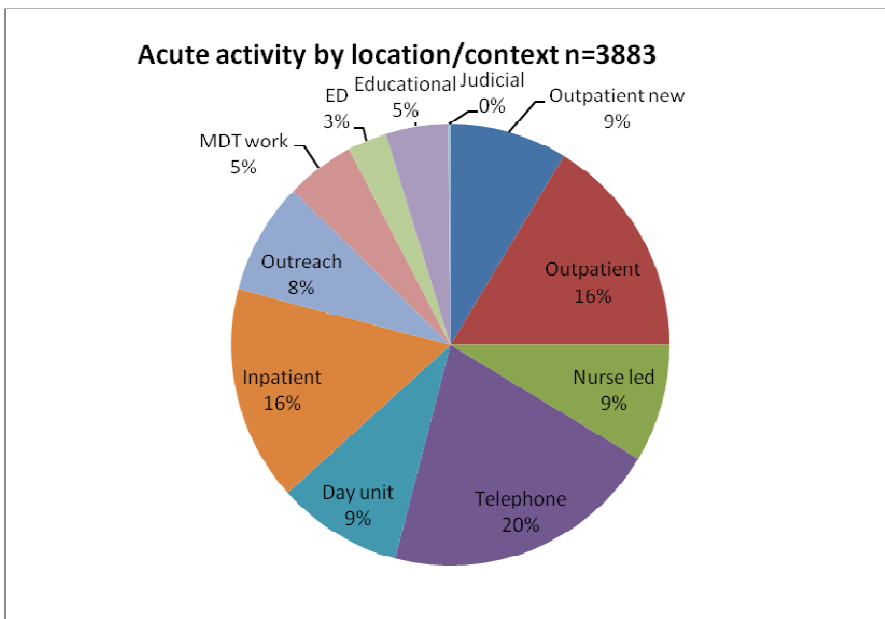
### Context and location of work

SC&T nurses work in a variety of contexts and physical locations. Figures 4.1 & 4.2 show the distribution of activity in terms of setting and context for example clinics, telephone work or other locations.

**Figure 4.1** The activity context of nurses working in the community (*MDT = Multidisciplinary team; ED = Emergency Department*)



**Figure 4.2** The activity context of nurses working in the acute setting (*MDT = Multidisciplinary team; ED = Emergency Department*)



Points to note:

- There were 19 events in total in the judicial system (probation & prison) although this is recorded at 0%
- Education (working with the education provider to plan care for example) varies little across the groups, at 3-5%
- Telephone activity is lower than other Clinical Nurse Specialist groups, where around 30% of activity is based on the phone (RCN 2010, Warren et al 2012, Oliver & Leary 2012). In contrast, much of the care is delivered in face to face settings such as clinics, outreach or emergency departments – perhaps reflecting the unpredictable and acute nature of sickle cell disease compared with other long-term conditions
- Nurse led clinics/services run in collaboration with (but independent of) medical colleagues (no doctor present)
- New and follow-up outpatients usually seen at a clinic within a consultant clinic.

## Activity by intervention and clinical dimension

The complex work of specialist nurses is clustered into different dimensions – clinical, administrative, education, teaching and research (Leary et al 2008). Cassandra collects only clinical and administrative activity data. Thus these data account for around 90% of nurse activity.

The distribution of activity is shown in Figures 4.3 & 4.4

Figure 4.3 The distribution of activity (community group)

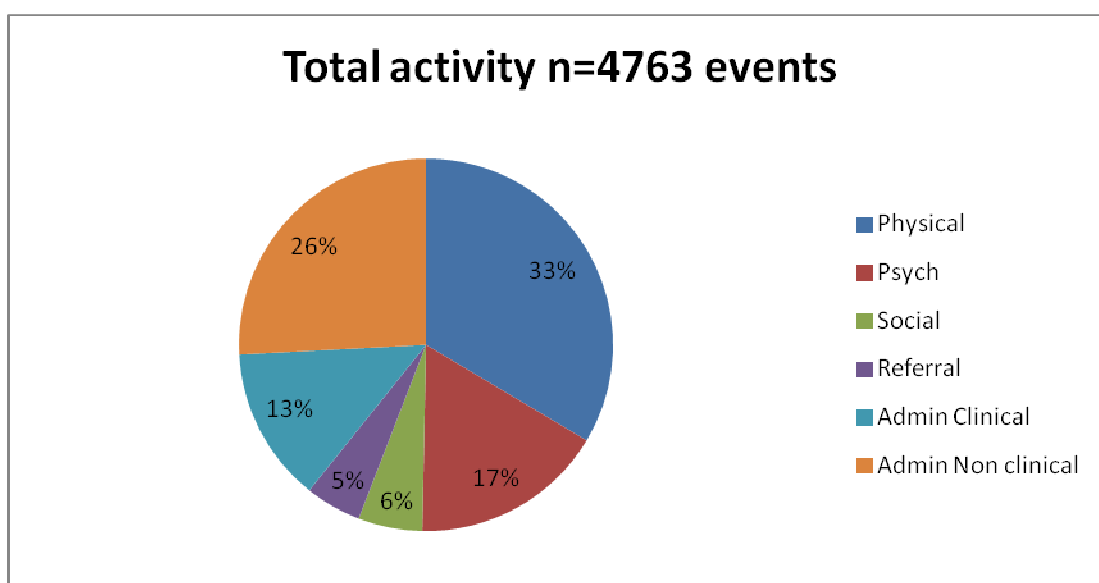
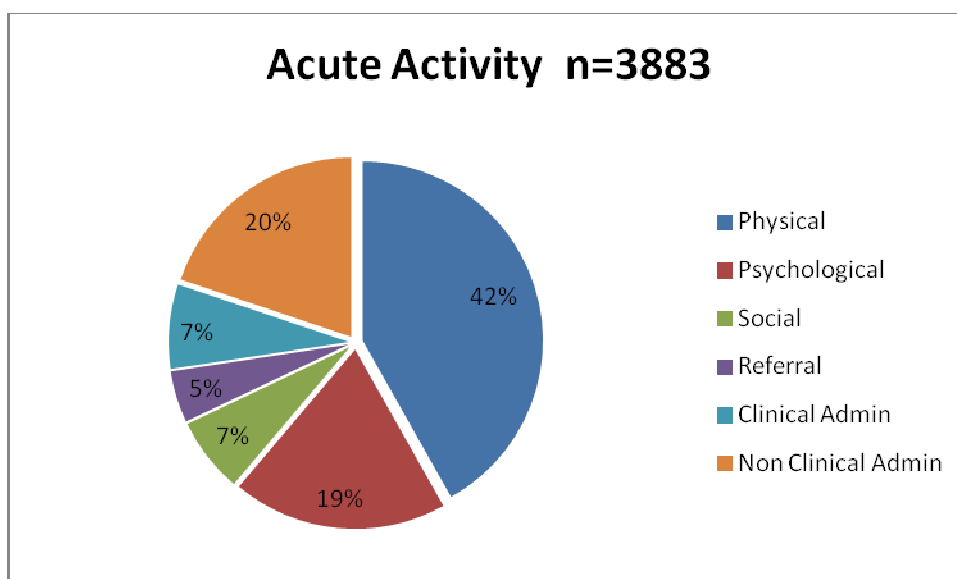


Figure 4.4 The distribution of activity (acute group)





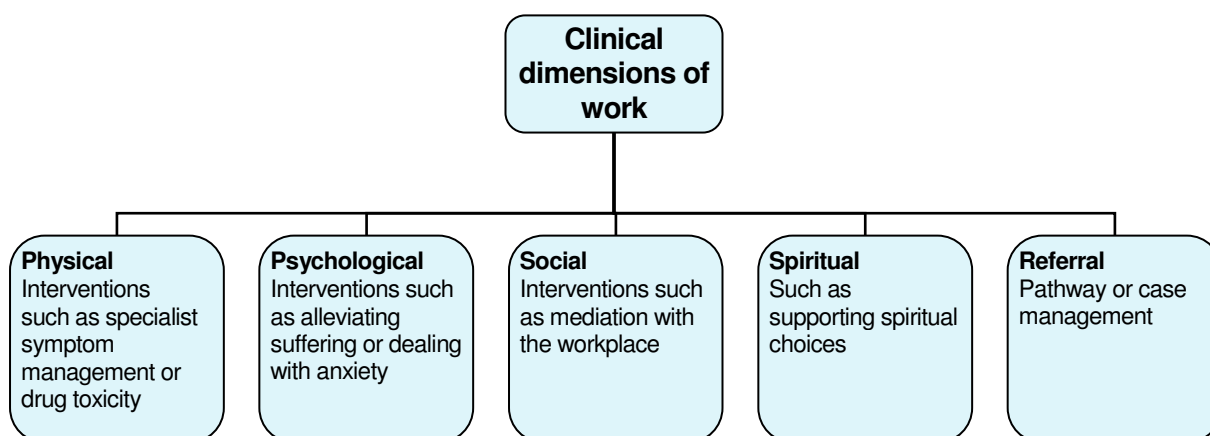
A considerable amount of activity (26% and 20%) is spent on non-clinical administration such as booking appointments, typing routine letters and routine data entry. It is likely that more clinical time could be released if this burden were alleviated through the appointment of dedicated administrative staff.

The psychosocial activity in both groups is high – over 20% of the total activity – reflecting the complex psychosocial issues discussed in the literature.

### The detail of clinical activity

The clinical intervention activity domain consists of the types and subtypes of intervention the nurses undertake. These are shown in Figure 4.5. Cassandra records a number of sub domains in the clinical activity dimension. It is possible therefore to examine each of the dimensions in detail for this group.

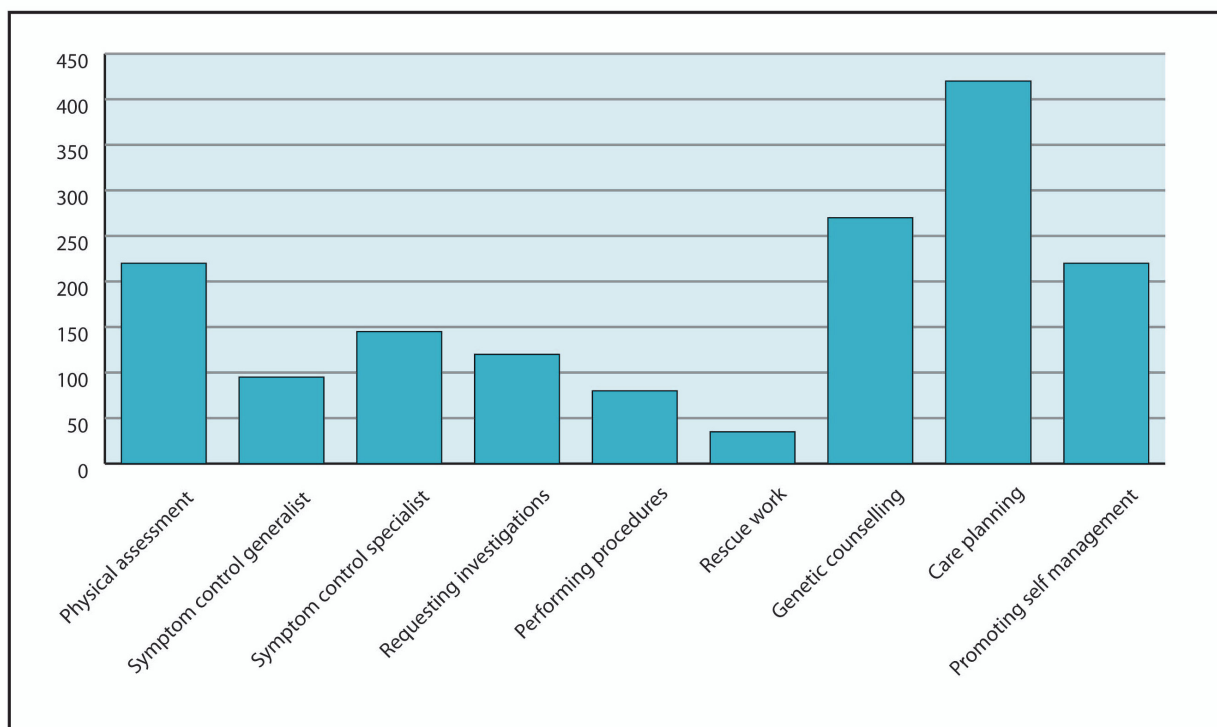
**Figure 4.5** The sub domains of clinical work (Oliver & Leary 2012)



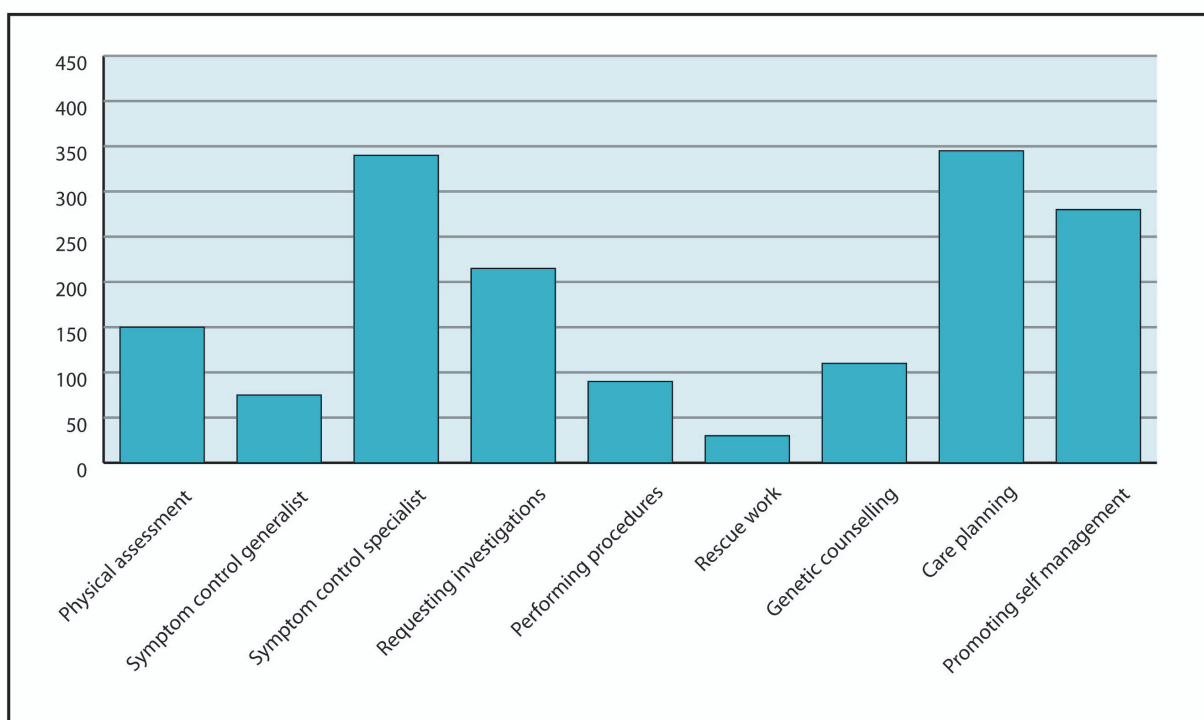
## The physical domain and interventions

Figures 4.6 & 4.7 show the activity of community and acute nurses in the physical activity domain.

**Figure 4.6** The distribution of activity in physical interventions (community); n=1598 nursing events (33% of total for community group)



**Figure 4.7** The distribution of activity in physical interventions (acute); n=1624 events (42% of total for acute group)



Care planning and promoting self-management strategies feature in both groups. This includes working with an extensive network of people (professionals and community groups) to achieve this (see box 4.1). Care planning and supporting self-management also correlate with the following psychological items of meeting information needs. The term 'genetic counselling' was used to describe a number of supportive and information-giving interventions (Anionwu 2001) in preparation for screening. These interventions also included the procedure itself and communicating the results.

The unremitting nature of sickle cell disease in particular, and the amount of nursing vigilance applied in the management of a multisystem disease, is reflected in these data and also in the interviews. The nurses described their vigilance work, understanding of risk, and using supported self-management to a point where they intervened. Nursing vigilance is well described (Meyer & Lavin 2005).

The acute group tended to provide specialist and complex symptom control more often and in the context of inpatient, outpatient and emergency care. The community nurses provided the majority of specialist symptom control within the context of outreach, nurse led clinic and telephone work.

*Performing procedures* ranged from low intensity venepuncture to exchange transfusion and central line insertion. These procedures require a high level of education, technical skill, nursing vigilance (observations, possible reactions, infections), brokering (for example with radiologists, radiographers, bed managers, scientists) and in terms of role substitution offer a viable cost effective alternative to medical staff.

### [The psychological domain and interventions](#)

During interview, respondents articulated the emotional effort they expended in dealing with the psychosocial aspects of sickle cell disease in particular. Much of this work was emotionally and clinically complex. One interviewee expressed this in terms of the bereavements of families and patients due to the disease, particularly the loss of children and repeated pregnancies that ended in stillbirth. Although not recorded in this study, the level of emotional effort in this specialism appears high.

The cultural dimension of haemoglobinopathy nursing permeates every aspect of the work of the specialist nurse. As has been seen in the literature, such care takes place in a cultural context. The nursing activity

accommodates this complexity and manages issues such as the taboo nature of the disease, on-going denial as a coping mechanism, complex psychological issues around the management of symptoms such as pain, and brokering with those who have influence in the community such as church leaders.

Figures 4.8 & 4.9 illustrate the psychosocial activity.

**Figure 4.8** The distribution of activity in psychological interventions (community)

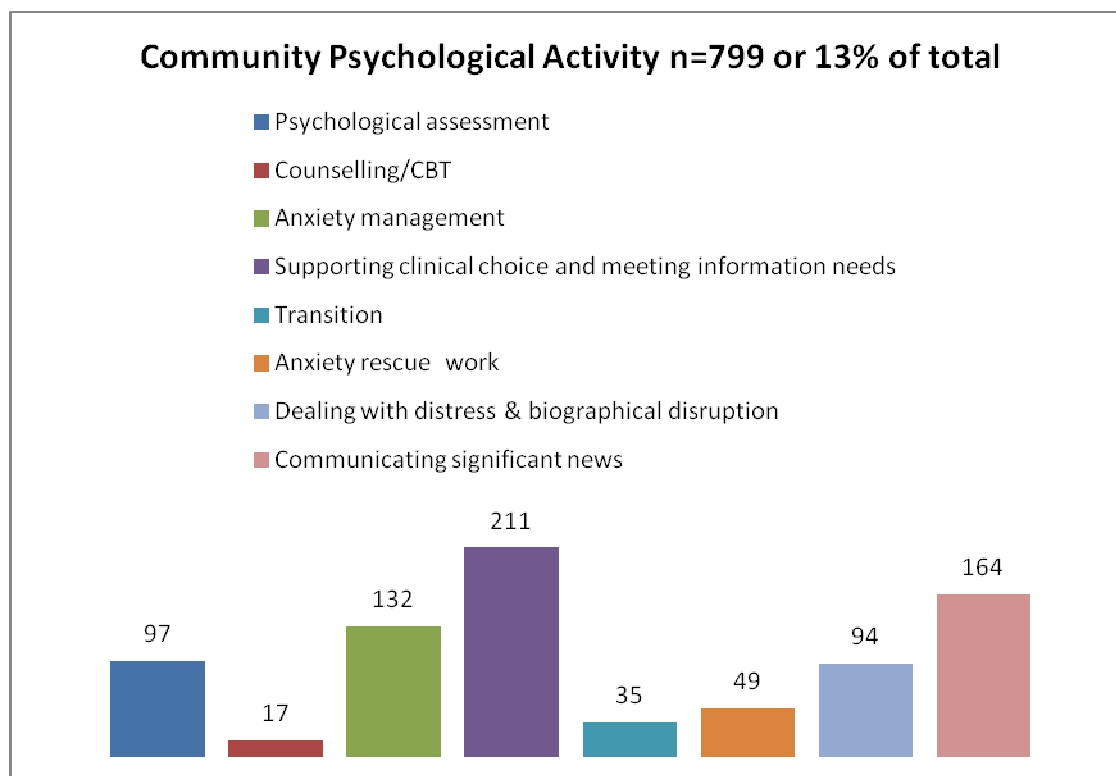
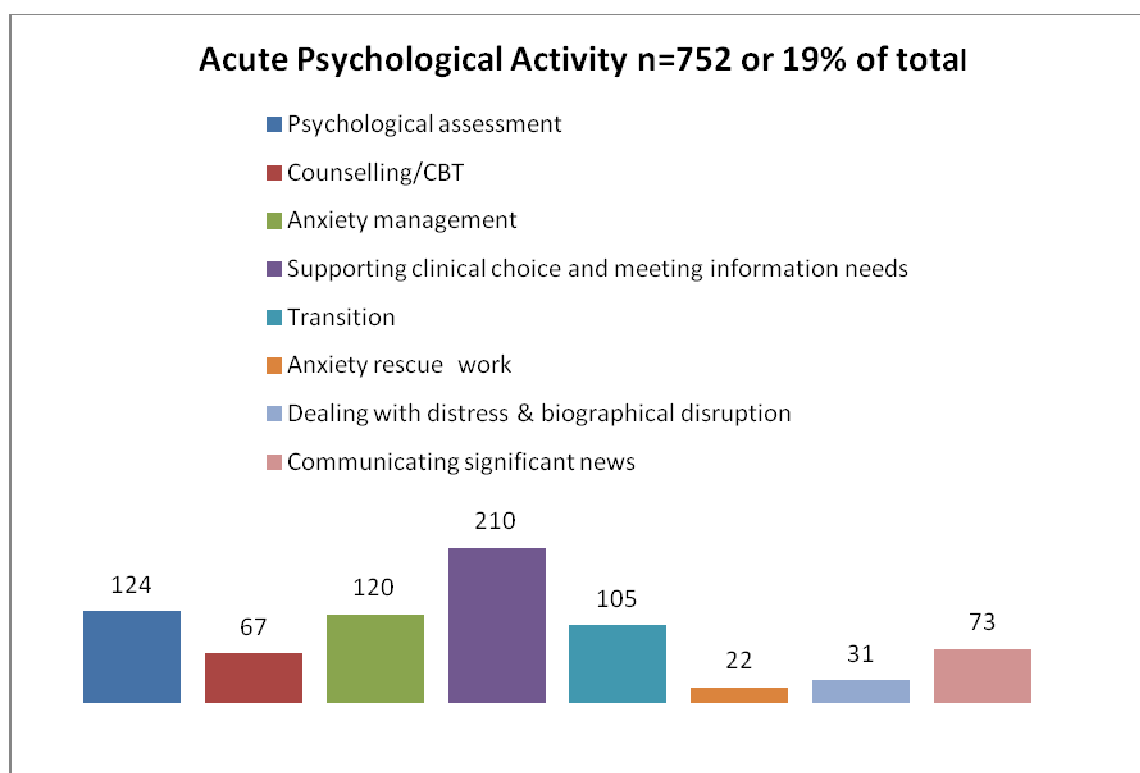


Figure 4.9 The distribution of activity in psychological interventions (acute)

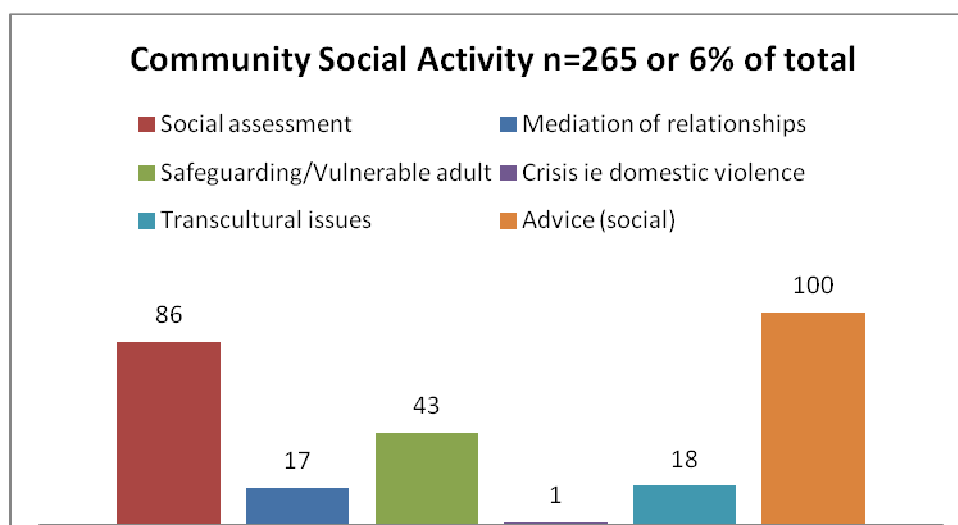


In common with other nurse specialists, activity is focused on meeting patient information needs and managing anxiety. In other studies previously described this usually correlates with supported self-management. Biographical disruption (Bury 1982) and communicating significant news was located in the clinical context of outreach and screening – usually with diagnosis. Haemoglobinopathies carry a huge burden in terms of quality of life (Thomas & Taylor 2002) and emotional processing is central to coping.

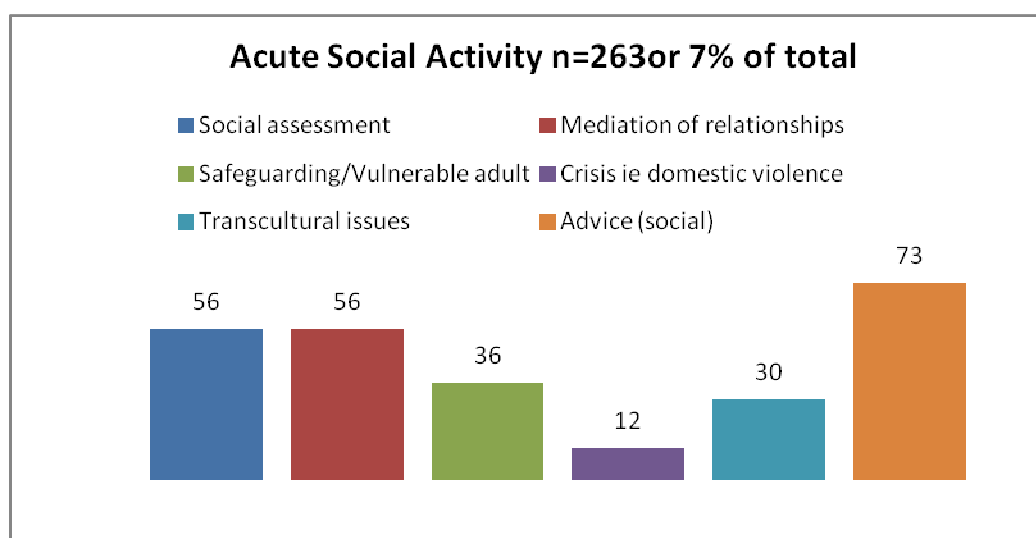
#### The social domain and interventions

Figures 4.10 & 4.11 show the social interventions. Much of this work was assessment and referral – for example to the very wide range of professionals in the nurses' professional network (Figure 4.12).

**Figure 4.10** The distribution of activity in social interventions (community)



**Figure 4.11** The distribution of activity in social interventions (acute)

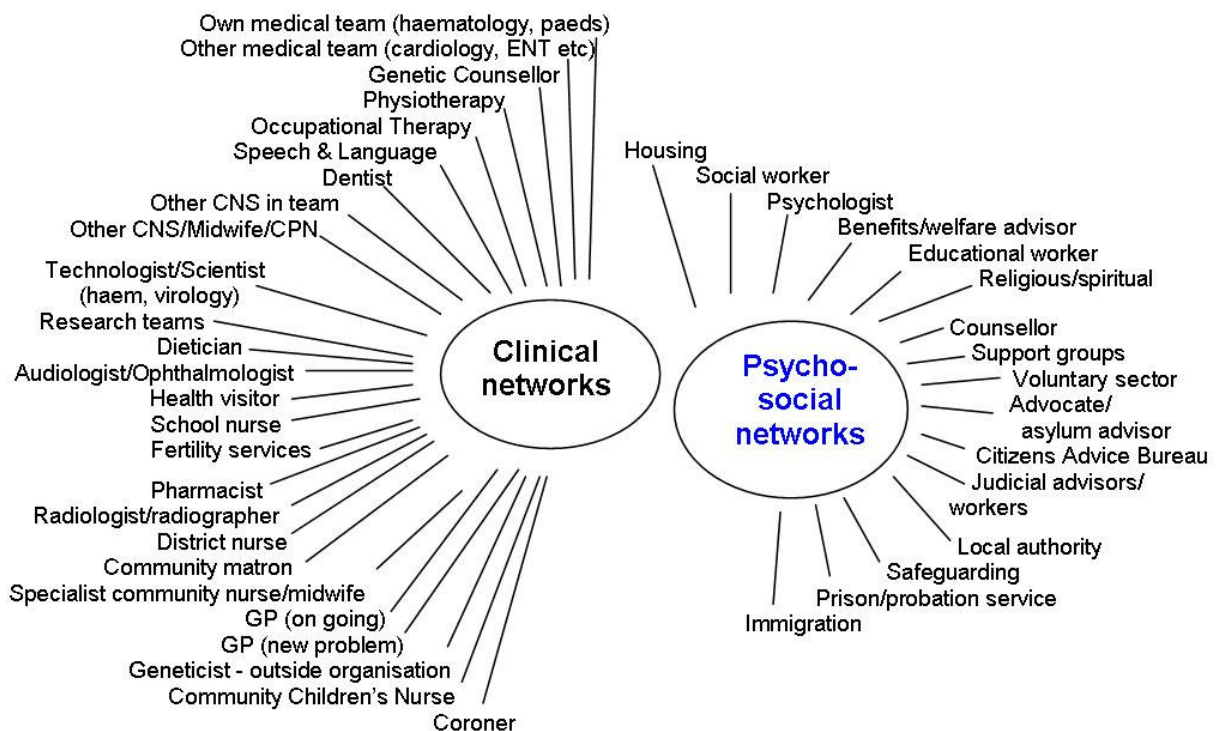


Aside from social assessment and advice/referral the other main intervention in this category was safeguarding/vulnerable adult/child issues. Although only 79 safeguarding issues were captured in over 8,000 nursing events the nurses expressed the need to record this type of event at the workshop (it has never been recorded in other specialisms using these techniques) due to the intense nature and complexity of these events when they do occur.

## The work of building networks and brokering care

The group had an extremely large network of professionals to which it referred and took referrals from. The group also brokered care with members of this network. The network is shown in Figure 4.12.

Figure 4.12 The extensive network of professionals and groups that specialist nurses utilise



### 4.3 Understanding patients' and families' perceptions of the value of SC&T specialist nurses

A key objective of the project was to understand the value and contribution of the SC&T nurse to patients and families. Data collected from the partner organisations elicited several themes including access to the specialist nurse; nursing or medical expertise; and attitudes of non-specialist staff (particularly in general practice and the emergency department).

Patients and families valued the co-ordination & management of care, including the work of brokering. They also valued SC&T nurses being the 'key accessible professional' able to apply expertise to a situation.



The key accessible professional:

*"My son goes every 4 weeks for a transfusion and 2 days before we have to go for the blood match, then we go for the transfusion that takes about 3-4 hours. We know the specialist nurse and she knows my son and if the nurse is there it all goes smoothly. If there is any problem, I go to the hospital. I think the nursing service is quite good."*

*"I go to my specialist nurse if I have a problem. Over the last 2 years I have had major life threatening problems with my condition and other infections and problems but without the committed help and advice from my specialist nurse to me and my family I don't think I would have pulled through as well as I have ... my family and I thank her from our hearts."*

*"I think they are very important to act as the key point of contact for the professionals on the team and they should apply the latest technical knowledge of treatment. They should also oversee and coordinate services so they are customised for me and my family and they should be empathetic to my needs."*

Role in advocacy and transcultural care:

*"When I am in hospital I know she will make the effort to come and see how I am doing, if my needs are being met and if I understand all that has been told to me and my family from the consultants and doctors."*

*"I asked the specialist nurse to go to the hospital/GP with me. I didn't want to do a transfusion [for religious/cultural reasons] and the specialist nurse talked to them."*

*"When you are ill, you can't deal with other things so a specialist nurse is very helpful."*

The lack of a specialist nurse or coverage – for example, if on leave (many SC&T nurses work as single-handed practitioners):

*"If my specialist nurse is away, I see/phone no one in particular, as no one is available."*

*"If I am sick in the day, I would come to the SC&T centre but sickle patients often get sick at night. The SC&T centre is only open day time."*

Using GP services and other non-specialist services was a prominent theme, and reactions were mixed – many patients preferred to access their specialist nurse rather than other services such as GPs:

*"Last time it was a massive mistake to go to my GP. I went with chest problems but I was sent to [a local hospital] for a heart check-up. I spent 7 hours in the hospital and was finally given a chest X-ray."*

*"I go to my GP only if I am ill, unrelated to sickle condition ailments. My GPs are always interested in my sickle cell condition but leave me exasperated when they ask me how long I have had the condition. Perhaps GPs need brief awareness of sickle cell if they have any patients at their practice."*

*"There is a very good GP [where I live] and there are growing numbers of sickle cell and thalassaemia patients."*

*"We see different GPs each time but it is not a problem as all the details are on the [IT] system."*

*"It's a waste of time going to my GP."*

Patients reported various examples of what they thought of as non-specialist, poor quality care which illustrate the importance of the educational role of SC&T nurses, performance monitoring, and clinical governance (including, and particularly, in A&E departments).

*"Good nurses in A&E listen and use my protocol so that I get pain relief straight away and I am discharged quickly (in about 8 hours). Bad nurses don't listen, don't use my protocol, delay giving me pain relief (maybe up to 90 mins before given) and I can be there for ages".*

*"I can be screaming with pain and the delay in getting pain relief looks like spite from the nurses."*

*"I dislike the hospital so much I won't go there - I haven't been there for 4 years."*

*"There have been problems with getting transfusion lines in. The nurses often are not very good at doing this and have to try many times to get the line in which is very distressing. On one night in A&E, it took 25 attempts to get the line in".*

*"Nurses have said that my child 'looks well, is smiling' but they are not well and may have to be re-admitted to hospital. Adults have been told 'you don't look as if you are in pain', but they are."*

*"All nurses should be respectful, non-judgmental, good listeners, responsive, flexible/adaptable, accessible. For example – they should bring bedpans as patients can't move when in pain; I often have to go many times and it is very difficult to walk even the smallest distances. They should make sure that I am clean – washed and clean change of clothes. They should oversee my taking my tablets and bring pain relief quickly and monitor its effect so that more can be given if necessary*

*or the dosage changed. They should ensure that I have been eating healthy food when I have my appetite back. They should reduce the amount of waiting time when I am discharged so that I can get home quickly and put into bed and [remain] in a resting state.”*

*“When I arrive with a crisis not taking me in immediately and treating my condition with oxygen and pain killers; if I am not looked after right away the stay in hospital and recovery time is significantly longer. Not knowing when to leave me so that I can rest. Not allowing my family to stay a little longer when I am depressed from my pain. Also trying to find a vein for intravenous injections of pain killer and fluids for more than 10 times with no luck and still wanting to carry on.”*

*“Ambulance staff ask a lot of questions – you should have a red sickle care and paramedic card”*

The comments above clearly identify how the patients/families/carers value the specialist SC&T nurses, how they impact on the quality of care they receive and where improvements can be made. The new NICE Guidelines on management of an acute painful sickle cell episode in hospital (NICE 2012b) require that such episodes are treated as an acute medical emergency which has significant implications for nursing practice. The guidelines emphasise the importance of the patient's individual needs and views including information and support requirements of both patients and their families/carers which also reflect recommendations in this report.

They provide crucial information for the nursing profession, NHS Specialist Haemoglobinopathy Commissioners and those in charge of educating any healthcare professional caring for patients with sickle cell disease or thalassaemia.

#### **4.4 Understanding how specialist nurses in SC&T meet the DH QIPP challenge**

The Quality, Innovation, Productivity and Prevention (QIPP) challenge is a national Department of Health strategy involving all NHS staff, patients, clinicians and the voluntary sector. It aims to improve the quality and delivery of NHS care while reducing costs to make £20bn efficiency savings by 2014/15; and to reinvest savings to support the front line (NHS Improvement 2011).

Much of the activity of specialist nurses is synergistic with the QIPP challenge. Quality is the most valued aspect of their roles in general; while patients particularly value the role of a key accessible professional (Leary 2012). Having accessible expertise is also valued by medical colleagues such as GPs (Oliver & Leary 2012, MS Trust 2012) – particularly the technical aspects of long-term conditions.

For example, one of the most striking findings of the 2010 National Cancer Patient Experience Survey relates to the impact of the Clinical Nurse Specialist. For every question in the survey, there are notable differences between data for patients with/without access to a Clinical Nurse Specialist – those with having significantly better results (DH 2010b).

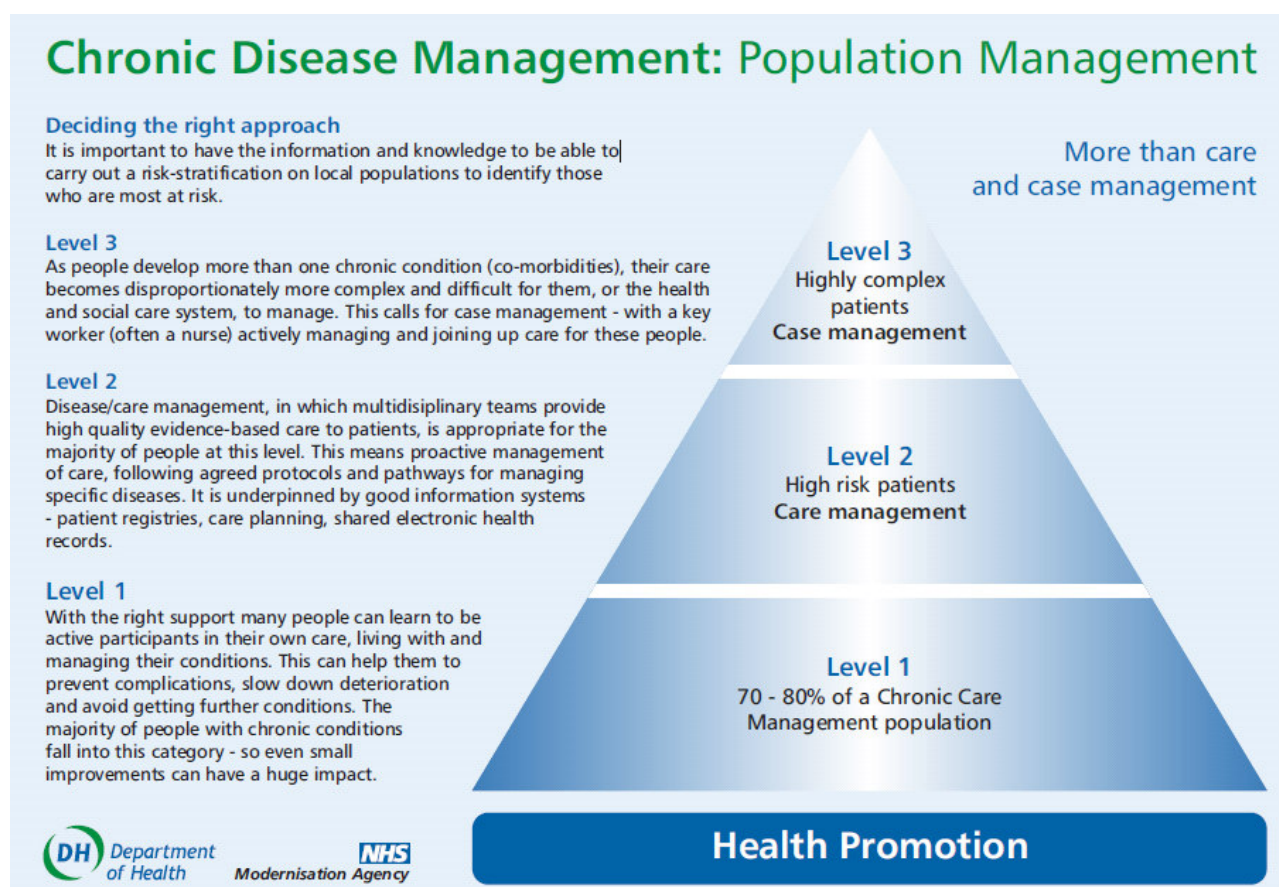
Quality aspects of care are also becoming more valued. The National Institute for Health and Clinical Excellence has recently issued quality standards advice to the Secretary of State (NICE 2012a) to be used in conjunction with the NHS Outcomes Framework (DH 2010c) – with the aim of providing commissioners with clear guidance on such standards. Quality standards will be reflected in the new Commissioning Outcomes Framework, and will inform payment mechanisms and incentive schemes such as the Quality and Outcomes Framework (QOF) and Commissioning for Quality and Innovation (CQUIN) Payment Framework (NICE 2012a).

In this study, the views of patients and families focused on the contribution by specialist nurses to quality of care. The accessible professional was cited as a high quality aspect of the service, as was sensitivity to transcultural issues; the application of technical expertise to areas such as symptom control; and aspects relating to co-ordination of care.

In terms of innovation, many nurses lead on service improvement, redesign and reform (Leary & Corrigan 2005, Barton & Mashlan 2011). This was reflected in the findings of this study. Many of the SC&T nurses offered examples of new and innovative practice that increased quality and productivity of services. Examples offered by nurses included a holistic exchange transfusion service; group education and self-management strategies; nurse-led ward rounds to facilitate discharge; supported self-help; interaction with local churches to improve health promotion; and education of non-specialist staff. In addition, much of the innovative practice increased productivity. SC&T nurses ran new and follow-up outpatient clinics which would previously have required a high level of haematology consultant time. Although not closely examined in this study, SC&T specialist nurses undertook work which may result in the avoidance of unscheduled admission via A&E – including undertaking an emergency department review; offering alternative destinations (such as supported visits to GP or outpatient appointments/drop in services); and supported self-management strategies. To explore this in detail would require further mapping, as data on admission avoidance patterns were not specifically collected.

The use of the DH model for caseload management and the development of a Community Matron (or senior CNS) role are examples of how SC&T specialist nurses have responded to cost efficiencies. A meeting of the All Party Parliamentary Group on Sickle Cell & Thalassaemia in March 2011 noted a Community Matron role established in one PCT that is estimated to have saved in excess of £70k in one year. Another Trust saved over 1,000 bed days through a nurse-led case management system. The case management model of chronic disease (DH) is shown in Figure 4.13.

**Figure 4.13** The chronic disease management model (DH 2004) – which many nurses have already implemented informally, via proactive case management and facilitated supported self-management.



Despite the high degree of service innovation and productivity gains it was perceived that specialist nurses often lacked support or recognition. This was acknowledged by the Prime Minister's Commission (COI 2010) which identified that there are often constraints (Barton & Mashlan 2011) in terms of management support or other organisational or cultural barriers – such as lack of support for educational activities, skill acquisition/application (e.g. physical assessment, prescribing) and administrative support. In addition, without proper management support there may be no cover for unplanned (or even planned) leave, so that patients are left without expert help for long periods.

The potential for specialist nurses in haemoglobinopathy to demonstrate their worth within the QIPP challenge is shown in Figure 4.14

Figure 4.14 Specialist nurses (working primarily with sickle cell patients) and the QIPP challenge



#### 4.5 Understanding the educational and professional development needs of SC&T nurses

Discussions with nurses, patients and commissioners invariably mention the importance of education and professional development to ensure that nursing care is high quality, efficient and meets patient needs.

In the survey of STAC nurses, 21 out of 22 (95%) said they had attended postgraduate or post-registration training, while 17 (77%) thought they needed further training in SC&T and 3 said they needed updates. Most of the training courses they attended were fairly short term (measured in number of days). Longer courses of a year or more were generally attended on a part time basis (one day per week etc), which may reflect work and family commitments. Several nurses expressed how extremely difficult they find getting

release from work for educational activities. Moreover, university course fees have risen considerably in recent years, which – combined with difficult economic conditions and cuts in NHS expenditure – puts real pressure on staff training budgets.

The survey results echo the general importance attached to and enthusiasm for education, including specific education for SC&T nursing. During interviews and workshops, several nurses expressed an interest in furthering their post registration education – particularly in advanced practice skills such as physical assessment and prescribing, and in technical knowledge in clinical management of SC&T.

Available education falls into two broad groups, depending on the focus of practice:

- Counselling roles – counselling ‘at risk’ couples (i.e. parents-to-be who may have a child with sickle cell disease or thalassaemia) and giving newborn screening results to parents of babies identified as having a haemoglobin variant – including carrier status
- Care of patients with sickle cell disease and thalassaemia.

### Courses audit

The SC&T Screening Programme asked the Florence Nightingale School of Nursing, King’s College London to undertake an investigation into sickle cell & thalassaemia training courses at postgraduate level. The findings give details of 35 courses with varied content and aimed at different levels of nursing.

### Education for counselling

The SC&T Screening Programme has developed courses and educational materials for those counselling at risk couples and giving newborn screening results to parents. Requirements for training are included in the Programme’s standards (NHS Sickle Cell & Thalassaemia Screening Programme, 2011). Standard AP4 sets out that ‘at risk couples’ must be counselled by practitioners who have undertaken the course in Professional Education for Genetic Assessment and Screening (known as PEGASUS) or equivalent (for example, the Genetic risk assessment and counselling module developed by the Florence Nightingale School of Nursing at King’s College in London, with support from the SC&T Screening Programme).



The SC&T Screening Programme hopes to offer bursaries to participants put forward by the Regional teams and who meet the necessary criteria, thereby ensuring counselling training continues despite the recession. Funding is in place for 2012/13 but it is not guaranteed for any future courses.

To further support the development of expert counsellors, and in particular to recognise the importance of giving correct and comprehensive advice to patients and their families in relation to genetically inherited conditions, the SC&T Programme is developing a competency framework in genetics for sickle cell & thalassaemia counselling. This framework includes core competences, learning outcomes and practice indicators.

#### Education for specialist advanced practice

A number of courses are available for nurses and midwives which include sickle cell and thalassaemia either as a main or minor component. As presentations are based on demand, these courses may not run regularly.

The SC&T Screening Programme supported the development of a competency framework – accredited by the Royal College of Nursing – to improve SC&T clinical nursing care (*Caring for people with sickle cell disease & thalassaemia syndromes: a framework for nursing staff*, NHS SC&T Screening Programme/RCN 2011). The RCN is supporting a follow-up project through its Intravenous & Haematology Network, focusing on implementation of clinical nursing competences within the workplace.

#### 4.6 The current provision of nursing services and the challenges that remain

The activity of SC&T specialist nurses is complex and requires experience, education and clinical acumen. The majority of the work would fulfil the definitions of advanced specialist practice discussed in the literature review.

Many challenges remain however. During interview, a number of organisational barriers were expressed such as the perceived lack of support for prescribing, lack of administrative support and in particular, lack of support with data collection. This is reflected in the amount of clerical work the nurses recorded – extrapolated to a year, it represents a considerable amount of non-clinical time which could be released to manage clinical care.

Many nurses found that their roles were being subjected to review processes by external non nurse management consultants – including collection of data in the form of time and motion studies, which are not valid for complex work. This has a negative impact on their own perception of the role, and many expressed feelings of lack of understanding from managers.

SC&T are long-term conditions affecting patients and families across the entire lifespan. Historically, SC&T nursing provision has been based in the acute or community sector. This could lead to some fragmentation of the management of care. Care should be provided on the basis of clinical need with equitable access, but this is a challenge for services with very high caseloads or wide geographical reach – such as low prevalence areas outside London.

Currently services are organised very differently throughout England. In many cases this reflects historical developments which have often been the result of an individual's drive and commitment to set up and develop services. Other centres have been set up in response to direct local need. Each has developed independently, so there are many variations in the way they are organised and the services offered. Moreover, there does not seem to have been a thorough review of service models/organisation from a strategic standpoint – therefore, although there are many examples of good practice, there has been no concerted plan to for them to be disseminated and implemented throughout England. In interview studies, nurses expressed difficulty at communicating the complexity of work to managers and even some nurse leaders. There is also a lack of uniformity in job descriptions and titles, making it difficult to communicate the role effectively.

Where services have different objectives, styles, priorities and management, it can be hard to ensure a high quality, seamless and efficient pathway for the patient while minimising costs and maintaining consistent and high quality services for all. SC&T specialist nurses reported working within various organisational structures:

- the 'one organisation' model, where all SC&T specialist nurses are organised and managed by one organisation (the specialist centre Trust)
- the 'many organisation' model where SC&T specialist nurses are employed by a Trust for hospital work (or different Trusts if there are separate hospitals for adults and children); the PCT for

community work; and charitable (or other) organisations commissioned to supply services such as giving screening results, counselling and patient support.

There appeared to be several instances where community and hospital teams worked independently of each other, each offering different services which may or may not overlap, with little coordination or overall management. While individual nurses and centres might be providing excellent patient care, such an approach can result in a disjointed and fragmented patient pathway leading to suboptimal use of resources (especially very precious nursing resources) and a confusing set of services for the patient.

Equally, there may be services supporting patients with other long-term conditions that could offer flexible, high quality care in SC&T if properly managed and coordinated. Such options should be explored and evaluated to ensure the best outcomes for SC&T patients.

#### [A service model in practice](#)

One SC&T centre is managed and funded by a large specialist mental health Trust. This Trust provides a wide range of community services, which are integrated health and social care services, jointly provided with the Local Authority. The SC&T centre offers a full nurse-led service which aims to reduce the need for patients to access more expensive hospital services, and to support those discharged from hospital (thereby minimising length of hospital stay).

## Section 5 Summary of findings

- Specialist advanced practice nursing in haemoglobinopathy is complex and made of many different interrelational activities
- Specialist nursing occurs across the life course (paediatrics to older adults) meaning specific needs at different times
- The haemoglobinopathy workforce is very flexible, with many nurses managing caseloads throughout the different age ranges (paediatrics, teenage, adult, older people and pregnancy)
- SC&T nursing takes place within a specific complex social and psychological paradigm which the nurses negotiate
- Much of the activity of SC&T nurses is managing complex symptoms and managing care of a multisystem disease
- Much of the haemoglobinopathy nurse activity is directed towards ensuring supported self-management. This has been shown to be a very cost effective method in other diseases such as cancer
- Haemoglobinopathy specialist nurses perform exceptionally well against the DH QIPP agenda
- Nurses in SC&T are keen to pursue a post registration education in specialist advanced practice.

And yet:

- A quarter of specialist haemoglobinopathy nurse activity is spent doing clerical work and data collection, which could be delegated to a lower band worker freeing up more clinical time
- Organisational and cultural barriers prevent development of the role in some organisations
- SC&T nurses report limited and decreasing access to post registration education due to financial constraints in the workplace (lack of funding for education or decrease in study leave)
- Haemoglobinopathy nurses contribute an average of 3 hours unpaid work per week (worth around £3,000 pa per WTE)

- There is unmet need (and therefore more nurses required) due to increasing prevalence of the disease (NICE, 2012b), numbers of admissions of patients with sickle cell disease (AlJuburi et al, 2012), and improved survival rates (Telfer et al, 2007)
- The specialist nurse population has no strategic national development programme to develop future post holders.

### Areas for further study

Areas for further study were identified during the project:

- It proved difficult to calculate the number of nurses engaged in this area of specialist practice – a census of nurses would be beneficial to inform workforce planning.
- The study gives a better understanding of the complexity of the work of the SC&T nurse. However, mapping this against patient pathways may well yield an optimum caseload number for the variety of services offered. Although there is some data on potential cost effectiveness, a cost benefit analysis may prove beneficial.
- There is a scarcity of empirical data on the effectiveness of nursing interventions in SC&T and work in this area is also likely to be of use.

## Section 6 Recommendations

This project has demonstrated the immense contribution of SC&T specialist nurses in providing affordable, expert and accessible care to patients who are from diverse ethnic backgrounds. To maximise the benefit of the role to patient care, the following recommendations are made:

- Commission SC&T specialist nurses where they are needed. Lack of expert care is costly in the long-term, causes distress and results in poor clinical outcomes & experiences. Patient/specialist SC&T nurse ratios should be on a parity with other long-term conditions.
- Undertake a full national census of current SC&T specialist nurse posts to gain a better understanding of the workforce and inform workforce planning.
- Safeguard the jobs of existing specialist SC&T nurses. Expert nursing care keeps people out of hospital (reducing costs) and living higher quality, healthier, productive lives (improving outcomes in line with the NHS Outcomes Framework).
- Release time to care, maximising the use of specialist nurse time. Clerical work can be delegated – for example, investing in clerical support/data collection staff would release about 5-7 hours per whole time equivalent per week back into clinical work.
- Focus specialist nursing resources on self-management and reducing complications. Help patients and their families to understand their conditions and look after themselves, preventing unscheduled admission where possible.
- Listen to patients and families. Regular work to capture their views and experiences ensures that nursing care meets patient needs. Support expert patients & carers to inform service delivery.
- Recognise and encourage a greater contribution to the DH QIPP agenda by engaging with specialist nurses. Trusts can increase productivity and use the insight that nurses provide to perform robust service reviews.
- Establish clear job descriptions to eliminate the multiplicity of job titles and define the role of the SC&T specialist nurse.
- Ensure access to appropriate accredited education and resources for specialist nurses. Offer support through bursaries, commissioned places and study time.

- Organise nursing services based on clinical need and to enable seamless, integrated specialist nursing care for the patient across acute and community settings.
- Offer equitable access to expert SC&T nursing care across all geographical areas.  
Given the variation in prevalence throughout England, there will be different service models and organisational structures according to local needs. However, the two principles of effective governance and the provision of equitable and seamless services based on clinical need are always paramount.
- Address the lack of health care research in sickle cell and thalassaemia.  
Recommendations will be more robust and will benefit from further research.

## Section 7 Acknowledgements

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## APPENDIX A: MEMBERS OF THE WORKING GROUP & OTHER CONTRIBUTORS

Elizabeth Anionwu	CHAIR OF WORKING GROUP and CO-AUTHOR Emeritus Professor of Nursing, University of West London (formerly Thames Valley University)
Alison Leary	MAIN RESEARCHER and CO-AUTHOR Independent Healthcare Consultant & Research Analyst with special interests in modelling complex systems, data mining and pattern recognition
Roma Haigh	SECRETARY OF WORKING GROUP  NHS Sickle Cell & Thalassaemia Screening Programme
Edith Aimiuwu	Clinical Nurse Specialist – Paediatrics, Whittington Hospital  Member of FAST-N, Roald Dahl sponsored specialist nurse
Lorna Bennett	Clinical Services Manager, Islington SC&T Centre  Also Lead on PEGASUS Training Course and Project Board Member for National Haemoglobinopathies Project  <i>Resigned January 2012 and replaced by Matty Asante-Owusu, Community Matron for Islington PCT who contributed virtually.</i>
Phil Daly	Clinical Nurse Specialist – Paediatrics, St Mary's Paddington  Member of FAST-N, Roald Dahl sponsored specialist nurse
Daksha Elliott	Lead Nurse Counsellor & Manager, Leicester SC&T Centre and Expert Working Party member for National Haemoglobinopathies Project
Brigid Keane/ Lindy Defoe	Regional specialist practitioners for Haemoglobinopathies in job-share to support antenatal & newborn screening in North East England
Collis Rochester-Peart	Service Manager & Clinical Lead for Haemoglobinopathies, SE London SC&T Centre; also former Chair of STAC and Expert Working Party member for National Haemoglobinopathies Project
Maureen Scarlett	Community Nurse Specialist in Haemoglobinopathies, Luton  Secretary of STAC and Expert Working Party member for National Haemoglobinopathies Project

### Nominated by Sickle Cell Society

Anne Welsh	Chair, Sickle Cell Society & sickle cell patient
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### Nominated by UK Thalassaemia Society

Sema Kiamil	Director, UKTS
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Nominated by Roald Dahl's Marvellous Children's Charity

James Fitzpatrick      Chief Executive, Roald Dahl's Marvellous Children's Charity

*Resigned from January 2012 – replaced by newly appointed Chief Executive – Richard Piper*

Specialist Occasional Members of Working Group

Nicola Howe      Senior Commissioning Manager

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Allison Streetly      Programme Director,

NHS Sickle Cell & Thalassaemia Screening Programme

Anne Yardumian      Haematology Consultant, North Middlesex Hospital

Chair of UK Forum on Haemoglobin Disorders and Expert Working Party  
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Other Contributors

Catherine Gough      Freelance Editor, Fine Words Ltd

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NHS Sickle Cell & Thalassaemia Screening Programme

Sekayi Tangayi      Service Manager & Specialist Nurse, Newham SC&T Centre and project  
initiator for development of SC&T clinical nursing competences

Neill Westerdale      Advanced Nurse Practitioner, Guy's & St Thomas' NHS Foundation Trust and  
Member of RCN IV & Haematology Network

**A particular acknowledgement is due to the SC&T specialist nurses who contributed data to this project.**

ROALD DAHL SUPPORTED PROJECT ON SC&T SPECIALIST NURSES

***SC&T Training Questionnaire – STAC AGM 19<sup>th</sup> January 2012***

**27 Responses collected**

NAME (*Please print*) .....

ORGANISATION.....

JOB TITLE.....

EMAIL (*Please write clearly*).....

**1. Have you attended any postgraduate/post-registration training for SC&T?**

*25 said yes     2 said no*

**2. Was the training in-house or did you go on a course? in-house/external course**

*23 mentioned “external courses”*

*3 mentioned “in house”*

**3. Who provided the training (eg name or university/Trust/other**

*(a) SC&T Screening Programme – PEGASUS x 16*

*(b) Middlesex University x 2*

*(i) 2 year MSc course*

*(ii) ENB No. 8 course*

*(c) Birmingham City University (before University Of Central England) x 1*

*(i) 5 day course “Care & Management of Adult & Child with a Haemoglobinopathy Disorder”*

*(d) GSTT – x 2*

*(i) 5 day course “Sickle Cell in Focus”*

*(e) KCL – x 5*

*(i) 3 month course x 3*

*(ii) Level 7 Module in Haemoglobinopathies x 1*

*(ii) no details x 1*

*(f) Thames Valley University TVU (now University of West London) x 7*

*(i) 3 months course, 1 day per week “SC&T and related conditions” x 3*

*(ii) 6 months course Level 6 “management & care of Clients with SC&T” x 2*

*(iii) no details x 2*

*(g) City University x 2*

*(i) 3 months, 2 days a week x 1*

*(ii) one year (2 semesters) level 3 course in Haemoglobinopathies – x 1*

*(h) Southbank University x 1*

*(i) 15 weeks, 1 day per week – Certificate in Management in SC&T x 1*

**PLUS**

*Attended several national & international courses/conferences in USA & Africa x 2*

**4. How long was the training (eg how many hours of learning involved/how many days)**

*No mention of learning hours*

*Apart from the 5 day PEGASUS course ,*

*5 day courses x 3 mentions; 3 months x 8 mentions; 6 months x 3 mentions;*

*1 year x 1 mention; 2 years x 1 mention - PS generally for 1 day or 2 days a week*

**5. Did you take a test/exam at the end ? yes/no**

*17 mentioned some sort of exam/assignment; 8 answered no test or assessment*

**6. Was it an accredited course ? yes/no**

*This question did not work very well as several people put that PEGASUS was an accredited course and that they received a certificate (of attendance).*

*Of the other courses, 17 courses were mentioned as accredited*

**7. If yes, please give qualification/Credits obtained at which level**

*Level 3 module x 2*

*MSC level 4 x 1*

*Certificate x 2*

*Level 6 x 3*

*Level 6 15 credits x 1*

*Level 6 20 credits x 3*

*Level 7 15 credits x 1*

*30 credits x 1*

*Diploma x 1*

*Pre ENB no8 x 2*

**8. Who paid for the course (eg you, your Trust/PCT) ?**

*3 responses mentioned paying all/some of course fees themselves*

*All other responses mentioned Trust/PCT etc*

**9. How much did the course cost (if known) ?**

*Only 4 responses for this question*

*(i) about £480 for City University 3 month course*

*(ii) about £1500 for City University 1 year course*

*(iii) £350 for Southbank University 3 month, 1 day per week course*

*(iv) £850 for King's College London course*

**10. Do you think you need any further training in SC&T ?    yes/no**

5 responses said “No” but out of these 3 said need updates; 17 said yes

**11. If so, briefly describe what you need**

Further training in clinical specialists using nursing competences; Haemoglobinopathies & genetics; Hands – on training including physical assessment, interpretation of results, requesting investigations; Want to attend Advanced Workshop at GSTT; Need to know how to access updates; Need training in physical assessments – Advanced Practitioners course - also training focusing on general counselling/CBT training to support clients with the disorders; More information and details around lab results and pathway; Updates on new improvements in the service; Continuous updates in both screening and care; Shadowing acute nurses; PEGASUS training; Need to be kept up to date with care, management & screening etc a lot of which can be obtained on line; Phlebotomy, management/leadership and auditing/data management ; Screening programme updates, ongoing and current project updates, and advances in SC&T medical management; Module in haematology; New competences in SC&T field; MSc level training; Post-registration courses in haematology, SC&T screening and PEGASUS.

**RH 25.5.2011**

## Appendix C: The Cassandra Matrix™ (Leary 2011)

SCT Jan2012	Outpatient new	Outpatient Follow up	Nurse led Clinic	Telephone	Day unit	Inpatient	Educational	Judicial	Totals
Physical Assessment			2	38			7		56
Symptom control Generalist									0
Symptom control specialist		1							2
Requesting investigations									0
Performing procedures									0
Rescue work (physical/drugs/iatrogenic reactions )						1			1
Genetic counselling							2		0
Care planning	2	2	2	28		21	1		67
Promoting self-management		3		50	1	1	7		57
Psychological assessment		2				4			9
Counselling/CBT									
Anxiety management				3	1				4
Supporting clinical choice and meeting information needs		1		11		1	6		15
Transition									14
Anxiety rescue work									0
Dealing with distress & biographical disruption			5	21	6	1			38
Communicating significant news									0
Social assessment				1					4
Mediation of relationships									0
Safeguarding/Vulnerable adult									0
Crisis ie domestic violence									0
Transcultural issues				1					1
Advice (social)				4					4
Advocacy (clinical)		1		4					5
Referral (clinical)									0
Referral (Psycho-social)									0
Chasing up/tracking		4		16					20
Clinical admin		2	5	57		7			89
Other administration work (non-clinical)		1		7					8
Data collection/input/audit		3		54					75
	2	20	14	295	8	36	23	0	469

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