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Final Report

Lost in Transition:

Exploring how young people with cancer are transitioned from child to adult services across different healthcare systems.



Image Sources: The Teenage Cancer Trust and Macmillan Cancer Support

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Acknowledgements

The original impetus for this study and report emerged from working with the United Kingdom Children and Young People's Cancer Community Nursing education group and sharing views and ideas with Ms Susanne Cruickshank, a colleague specialising in adult oncology nursing at Edinburgh Napier University.

A systematic literature review through the Joanna Briggs Institute (2012) revealed the scarcity of literature exemplifying the experiences of young people transitioning from child to adult services. In addition, the inconsistencies in the care models being employed internationally were also revealed (National Institute of Health for Clinical Excellence 2005, National Cancer Survivorship Initiative 2012).

It was clear that the challenge of appropriate and effective patient transition was a cause for concern nationally and internationally.

This report presents a series of recommendations pivotal to improving the overall experience for young people transitioning to new care paths and drive forward improvements to best clinical practice.

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Abstract

Cancer nursing care across the United Kingdom over the past 20 years has dramatically improved for children and young people with cancer (Department of Health 2007). Today around 70% of young people diagnosed with cancer survive into adulthood, albeit with long term health complications. This raises the contemporary concern of how best to transition these patients to an adult focused care regime (National Cancer Institute 2012).

In the United Kingdom alone there are approximately 1,400 new cases of cancer in children under the age 15 years of age each year. In the 15-to-24 year olds, there are approximately 1,900 new cases per year (National Cancer Intelligence Network 2008). The types of cancer that affect young people are different to the cancers that strike children and adults (Children Cancer Leukaemia Group 2012) and these individual patients and their families require specific expert care.

It is therefore crucial that care is provided in an age appropriate setting. It is estimated that many of these young people with cancer are not treated within a setting appropriate for their age (National Institute of Clinical Excellence 2005). The majority of these patients are not currently considered for entry into clinical trials (Hollis and Hooker 2009) which ultimately impacts on the overall cancer survival and recovery from the disease.

The experience of young people living with or beyond a cancer diagnosis is vital to the overall understanding of the cancer journey. Once a child or young person reaches a certain age, transition of care from a child to adult service should begin in an age appropriate, planned and seamless way (Royal College Nursing 2004). McCann (2012) found in a recent study that all health professionals, young people and their families need to be too ready for transition. In order to achieve this appropriate planning and preparation for the transition needs to be put in place.

This report and associated review of the literature reveals the wide discrepancy in the transition models currently being implemented for young people and their families with cancer. Some are transitioned to adult services at a well-defined and clearly communicated juncture, such as age or on completion of their treatment regime. Many others remain within the children's oncology/haematology specialist service late into adulthood with no clear model of transition (Department of Health 2007). In addition it is recommended that all young people are given the opportunity to decide when and where they would prefer to be treated (Royal College of Physicians of Edinburgh 2008, National Cancer Action Team 2012). For example the National Institute of Clinical Excellence (2005) suggests that young adults aged 19 years and above may make an informed choice on their place of care.

The development and introduction of appropriate and effective transition models is now emerging as one of the most important factors within the individual patients overall cancer journey experience.

This report compares the various transition models currently being utilised across the United Kingdom (Scotland, Northern Ireland, England and Wales), Finland (Lahti) and the United States America (North Carolina). The specific objectives of this report are to:

- Develop an understanding of national and international transitional practices.
- Establish if patients are given a genuine choice regarding their place of care.
- Identify how nurses (undergraduate and postgraduate) are prepared to care for young people with cancer as they transition from child to adult services.
- Strengthen links between the Children and Young People's Cancer Community Nursing education group and international partners.
- Create a clinical / academic writing team to further explore this important area.

This report presents a series of recommendations to further improve nursing practice and advance the care delivery for this patient group and their families. These recommendations will be presented at a European or International conference, and published through a high impact academic journal and a peer review journal during 2013. It is also the author's intention to take forward a number of the recommendations made in this report through applying for further research grants early in 2013.

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Final Report

1. Background to the Study

Cancer is an important cause of mortality and morbidity in all age groups, but childhood cancer is relatively rare compared to cancer in young people and adults (Children Cancer and Leukaemia Group (CCLG) 2012). Over the past 20 years cancer nursing across the United Kingdom (UK) has dramatically improved for children and young people with cancer (Department of Health 2007). Today around 70% of young people diagnosed with cancer survive into adulthood, albeit with long term health complications. This raises the contemporary concern of how best to transition these patients to an adult focused care regime (National Cancer Institute 2012).

In the UK alone there are approximately 1,400 new cases of cancer in children under the age 15 years of age each year. In the 15-to-24 year olds, there are approximately 1,900 new cases per year (National Cancer Intelligence Network 2008). The types of cancer that affect young people are different to the cancers that strike children and adults (Children Cancer Leukaemia Group 2012) and these individual patients and their families require specific expert nursing care.

It is fundamental to the patient's treatment and recovery experience that care is provided in an age appropriate setting (National Institute of Clinical Excellence, (NICE) 2005). Currently many of these young people with cancer are not being treated within a setting appropriate for their age (NICE 2005). The majority of these patients are also not considered for entry into clinical trials (Hollis and Hooker 2009) which ultimately impacts on the overall cancer survival and recovery from the disease.

It is important that as patients mature into adulthood, care pathways are clearly defined (National Cancer Survivor Initiative (NCSI) 2012). These should consider the individual age, cancer type and the future risks of late

effects from treatment as well as the personal needs of the young person and their family (DH 2007).

Across the UK, young people with cancer usually begin their cancer journey within children's services. The initial cancer diagnosis is normally made at the appropriate primary treatment centre (PTC). Depending on the agreed treatment protocol and the needs of the patient and family, treatment is then delivered within the shared care centre (SCC) or home environment (Gibson and Soanes 2008).

Agreed treatment protocols available in the UK include the introduction of intensive multi-agent chemotherapy, combined with radiotherapy, surgery and bone marrow transplant as required (CCLG 2012). All treatments meet and comply with necessary national and international standards (Gibson and Soanes 2008, NICE 2005).

A national review of children's services has provided a real impetus for change and has become a high priority area for the UK Government and national charities such as the Teenage Cancer Trust (TCT), MacMillan and Cancer Leukaemia in Children (CLICsargent), (Scottish Government 2012, NICE 2005). Research has shown that as the young person survives they are at significant risk of developing late complications following treatment for cancer whether this is physical, emotional and psychological (Grinyer 2007).

As young people transition to adult services they are moving into a more independent and responsible phase of their lives and are encouraged to take responsibility for their own health care. Going forward it is important to empower these young people to make decisions regarding their own health care, yet there is lack of a clear approach which may impact on their ability to achieve this (Eshelman-Kent et al 2009). McCann (2012) established that young people require appropriate 'readiness' for transition to be effective. In order to allow for this preparation health professionals must strive to ensure that the planning and preparation for this transition is communicated well before the actual transition occurs. A vital element to this success is for all

health professionals to work consistently together between the children's and adult services.

It should be recognised that each individual young person may find this emotionally and psychologically difficult and that further research regarding these specific challenges is required.

The majority of adult cancer care, in comparison to children's services, is delivered on a speciality focused basis, such as neurology or haematology. Anecdotally, young people report experiencing adult services which are fraught with many difficulties and challenges, such as not being able to have a parent/carer stay overnight and restricted visiting during the day. As a result many patients and their families may have difficult transition experiences that will negatively impact on this important phase in their lives.

In order for the transition of these patients with cancer to be seamless, nurses caring for this patient group and their families require a sound knowledge and understanding of the needs of this patient group. This will help nurses to care for patients appropriately and deliver a positive transition experience to the adult services.

Not every nurse has the unique qualities required to care for young people with cancer and their families (Gibson 2005). Overall, the number of young people with cancer in our society is small, in comparison with the number of adults with cancer (Information Statistics Department 2012, CCLG 2012). Yet, as this specialty grows the demand for expert specialist nursing care intensifies.

To assist with the implementation of an appropriate and effective transition pathway this study explores how young people with cancer are transitioned from a child to adult service across 6 countries: the United Kingdom (Scotland, Northern Ireland, England and Wales), Finland (Lahti) and the United States of America (North Carolina).

2. Introduction

This study formally began in February 2012. National and international contacts across the UK, Finland and the United States America (USA) were already well established through the Children and Young People's Cancer Community Nursing (CYPCN) education group and the development and delivery of the international aspects of the Bachelor Nursing (BN) programme at Edinburgh Napier University (ENU). A detailed project plan was prepared, with the final report and recommendations being available by December 2012.

The countries visited were Northern Ireland (Belfast), Wales (Cardiff) Scotland (Glasgow and Edinburgh) England (London), Finland (Lahti) and the USA. (North Carolina). Please refer to **Appendix 1** for the detailed itinerary.

3. Study Aims

Empirical research specifically focusing on young people with cancer as they transition from child to adult services is scarce. The key objectives of this report were to:

- Develop an understanding of national and international transitional practices.
- Establish if patients are given a genuine choice regarding their place of care.
- Identify how nurses (undergraduate and postgraduate) are educated and prepared to care for young people with cancer as they transition from child to adult services.

The remaining two objectives were explored and these are detailed in the final section of this report.

- Strengthening links between the Children and Young People's Cancer Community Nursing (CYPCN) education group and international partners to share nursing practices and education.

- Creating a clinical / academic writing team to further explore this important area going forward.

4. The Approach

As part of the plan for the programme of visits, a semi-structured interview schedule was developed to ensure that the required information required was collected. Interviews were recorded and transcribed verbatim. Field notes were also taken to capture parts of the recorded interview that were missed. Although not an empirical research study, informed consent was given prior to and on the day of the visit but not all participants agreed to be recorded. Please refer to **Appendix 2** for the interview schedule. All participants had various experiences and roles to relay and discuss relative to the services offered to young people with cancer and their families regarding transition.

5. Definition Transition

As the study progressed it soon became apparent that transition and the age group being included required clarification. As the literature reports, transition is an essential part of the trajectory cancer journey for each individual cancer patient, yet not all hospital services offer this. The literature defines transition as “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated health care systems” and should be a planned and regularly reviewed, to ensure a smooth transition to adult services (Blum et al 1993 p2, NCSI 2012, RCPE 2008). This definition is the one given for the purpose of this study.

The age group referred to in the literature identifies common terms such as teenager, adolescent, young person and young adult. For the purpose of this report a clearly defined age group of young people between 15 – 24 years of age will be used. The main reason for this definition is that young people under 15 years of age will normally be nursed in a children’s hospital or TCT. This group of patients have been described as the ‘lost tribe’, implicitly acknowledging there are no clear pathways of care in place as they transition

from children's to adult services within the cancer trajectory (Kelly and Gibson 2008). Transition is therefore crucial from the child to adult services and must be seen as is a critical part of the young person's cancer experience.

6. Nurse Education and Preparation

Currently there is inconsistency and lack of standardisation in the way in which oncology nurse education is embedded and delivered within individual Higher Educational Institutions (HEI's) nursing programmes (McInally et al 2010), specifically in relation to young people. Nursing programmes in the UK are validated by the Nursing, Midwifery Council (NMC) (2010) and although oncology nurse education and preparation is not mentioned explicitly nurses must be fit for purpose by the time they register as newly qualified nurses (NMC 2010). Nurse education and preparation to care for young people with cancer is currently seen as a pertinent issue and will be discussed in this report (European Network for Cancer Research in Children and Adolescents (encca) 2012).

7. Current Service Analysis

In order to establish best available practice in transition arrangements, 6 countries were visited: the 4 countries within the UK, Finland and the USA. As part of considering the transition arrangements in more detail, **Table 1** presents an overview of the cancer statistics, services for young people with cancer, and the nurse education available at undergraduate and postgraduate level for each country visited.

Table 1: Country Comparisons	Northern Ireland	Wales	Finland	USA	England	Scotland
Country population (millions)	1.811	3.643	5.426	314.936	53.093	5.254
Number of patients diagnosed per annum (15-24 years).	70	90	46	11,381	1,691	176
Patient choice – place of care	x	✓	x	x	✓	x
TCT available	x	✓	x	x	✓	✓
Transition pathway	x	x/✓	x	x	x/✓	x
Follow-up services	✓	✓	✓	✓	✓	✓
Nurse education – undergraduate	✓	x	x	x	✓	✓
Nurse education – postgraduate	x	x	x	x	✓	x

Sources: (The World Population Clock 2012, ISD 2012, Cancer Research UK 2012, Finnish Registry 2012, National Cancer Institute America 2012).

8.1 Northern Ireland (Belfast)

Introduction

The number of young people diagnosed with cancer per year in Northern Ireland is approximately 70 per year (Northern Ireland Cancer Register (NICR) 2012). The children's services within Belfast have 8 inpatient beds with two beds for teenagers and young people. The age range seemed to vary from 13 years to 20 years. There is no TCT available.

Current Transitional Practices

Visiting the children's hospital in Belfast revealed that there is no model of transition available for young people with cancer between the child or adult services. There is a transitional model that works well for haemophilia patients as they transition between services and this seems to work extremely well between the children's and adult services.

The vital element in the appropriateness and effectiveness of this model is that the children's and adult services communicate from the beginning of the transition process which begins at 11-12 years of age. The patient will transition at the age of 16 years of age once they are fully aware of their own individual needs as a person living with haemophilia, and can take some responsibility for their own health care needs. Self-awareness and independence are an important element of the success of the transition. This transition model is supported by the findings from other studies that have explored transition for other chronic illnesses (Eshelman-Kent, 2009).

There is a late effects clinic for children and young people and this can include seeing these patients well into adulthood within the children's service.

Informed Choice

The Northern Ireland Cancer Centre (NICC) is very proactive in ensuring that young people with cancer are high on their agenda. The NICC reported that the choice of care options appeared to be dependent upon the patient's local postcode. This came to light through government policy in Northern Ireland, regional need and from the individual patients themselves. Patients reported that in fact they do not like being away from home (*require travelling to the one specialist hospital in Belfast*) and most did not like to be around sick children. The NICC is now trying to build upon a good model of care for the young person with cancer but are aware that no one model will fit all.

Nursing Education and Preparation

Nurse education and preparation covers the issue of young people with cancer and transition along with other chronic illness pathways in the 2nd and 3rd year of the undergraduate child health nursing programme. Young people living with or beyond a cancer diagnosis are also involved in the delivery of nurse education and clinical placements are available for some student nurses. These placements are limited and not all students will have this experience. There is no post-registration nurse education regarding young people with cancer or the concept of transition.

8.2 Wales (Cardiff)

Introduction

Cardiff has a new children's hospital which opened in 2009 and has a designated cancer services for children and young people. There are on average 90 young people diagnosed with cancer per year in Wales. At the children's hospital they have 13 inpatient beds (0-14years). There is a TCT unit for 14-25 year olds with 8 in-patient beds.

Current Transitional Practices

Transition of care from child to adult services is not essential here as most children from age 14 years are treated within the TCT unit. However the age of the child / young person is. An example of this is where a young person of 14 years or older may not want to stay in the TCT without a member of their family being with them overnight. Within the TCT because the age range is 14-24 years the age of the young adult can also be problematic. A transition pathway from the TCT to adult services has not yet been established; hence the reason there was patient's up to the age of 25 years.

The children's ward is staffed with child health nurses whilst the TCT is staffed with both child health nursing staff and adult staff nurses. Adult staff nurses have found this area of care problematic and difficult to adapt to nursing this group of patients. The TCT Nurse Manager firmly believes that it is "not the skills of the unit but the passion for this type of work that is required for this role to be successful". There is a Lead Nurse for the TCT.

Follow-up clinics are established through a late effects clinic with a designated nurse specialist. This service has recently been developed and now has two distinct clinics, one for young people up to 18 years of age, and the other for 18 years of age and over. Within the service for 18 years and over the oldest patient is 45 years of age.

Informed choice

Young people are given the choice on whether they want to be cared for within the children's ward or TCT, where the bed situation allows. The options available to young people regarding their place of care was not so clear (NICE 2005).

Nursing Education and Preparation

Transition is threaded throughout the undergraduate child health nursing undergraduate programme delivered by Cardiff University. There is no educational provision in the adult nursing programme. There is a BSc pathway for children and young people with cancer but this will be discontinued by end 2012. There is nothing at post-graduate level in Cardiff but staff from the TCT has accessed the PgCert in Cancer Care for Teenagers/Young Adult offered by Coventry University. Clinical placements are limited and only available through the children's ward, not the TCT. All nursing staff within the TCT requires education and training in relation to this group of patients. Training and education is seen as vital within this service.

In-house study days are readily available for all new nursing staff within the TCT unit. The list below highlights some of the distinct nursing practices that are unique to the young person with cancer, The TCT nurse manager has ensured that these specific areas of specialist care are addressed for all nursing staff.

- Non-compliance with treatment
- Nausea and vomiting regimens
- Pain assessment tools
- Chemotherapy prescription charts
- Percutaneous Intravenous Cannula (PIC) Lines
- Lumbar Puncture and Bone Marrow Aspirate (LP/BMA) (general anaesthetic / entanox / guided imagery).

The nurse manager discussed these issues in particular as areas of care where nurse education and training was essential. Most of the registered

nurses were not competent in these areas of nursing care and the TCT nurse manager felt that these were important points to identify for future developments.

8.3 Finland (Lahti)

Introduction

Health care in Finland consists of a highly decentralised, publicly funded health care system and a much smaller private health care sector, similar to the UK. In Finland there is approximately 46 young people diagnosed per year (Finnish Cancer Registry (FCR) 2012). Helsinki and Tampere are the two PCT's closest to Lahti. Lahti hospital has a 10 bedded children's ward for children with cancer and other medical conditions and is the SCC for young people with cancer as well as the adult oncology ward. There is no TCT in Lahti. The children's ward offers supportive care for children and young people with cancer up to 18 years of age. Follow-up care is within the specialist hospital in Tampere.

Current Transitional Practices

Transition of care from child to adult services is not available in Lahti. Follow-up and transitional care is within one of the five University hospitals in Finland caring for children and young people with cancer. Tampere is the nearest to Lahti.

Informed choice

Young people 18 years and over are given a choice on whether they want to be nursed in the children's ward or adult oncology ward. However this is dependent on where the young person was initially diagnosed and the prevailing bed situation.

Nursing Education and Preparation

It is important to stress that in mainland Europe the nursing curriculum is generic and takes 4 years to complete. Not all nursing students have a clinical placement where they will experience caring for young people with cancer.

Cancer nursing is not taught specifically within the undergraduate or postgraduate nursing programme at Lahti University. They do have specific scenarios that are taught within the undergraduate nursing programme through Problem Based Learning (PBL). This is the main learning and teaching approach at this University. Nurses who work with young people with cancer have no clinical preparation.

The Principal Lecturer (PL) Hannele Tiittanen, explained as they do not have and expert within this specialist field they cannot offer this nurse education. The PL would like to discuss this further as a shared learning opportunity for nursing students.

8.4 USA (Asheville)

Introduction

The number of young people diagnosed with cancer per year in USA is approximately 11,381, based on statistics from 2000 to 2009 (National Cancer Institute, USA 2012). A total of 19 patients between the ages of 15-24 were diagnosed with cancer at Mission 2011.

There is no universal system of healthcare as there is in the UK or Finland.

The healthcare system consists of:

- Medicaid - government-funded healthcare for those on low incomes.
- Medicare - government-funded healthcare for over - 65.
- Employer-funded health insurance - paid through salary deduction.
- Military veterans - receive healthcare via government-run scheme.
- State Children's Health Insurance Programme - coverage for children whose parents do not qualify for Medicaid.
- Uninsured - treated in emergency rooms only.

There are federal government funded programmes, with the biggest being Medicaid and Medicare. Generally it is up to individuals to obtain health insurance. Most get coverage through their employers, but others sign up for private insurance schemes. Therefore for young people aged between 15 and

- 24, care is dependent on where and when the initial cancer diagnosis was made and the individual oncologist. Young people are eligible for care until their 18th birthday through the Medicaid (state insurance) system.

The USA comprises 50 states and 2 dependent territories (Dominion Republic and Puerto Rico). Each of the 50 states is divided into counties. The state of North Carolina is divided into 100 counties. Asheville is a city in the county seat of Buncombe County. Children's cancer care is delivered at Mission Children's Hospital in Asheville and consists of a 7 intensive inpatient treatment area and an outpatient unit delivered at Zeis Children's Cancer Center where they can see a number of young people per day.

Current Transitional Practices

It would appear that many young people who are living with a cancer diagnosis and beyond are treated within the children's services, with the child's cancer specialist continuing to be paid for their care. As a consequence, there is no formal transition is available in Asheville but late effects clinics are in the process of being introduced.

Informed choice

Choice for young people aged 15-24 years is dependent on where and when the initial cancer diagnosis is made and the individual oncologist they are referred to. Young people are eligible until their 18th Birthday through the Medicaid (state insurance). After this it is up to the young person themselves and the type of insurance cover they receive where they will be seen for follow-up care. Most are still within the children's service under the care of the paediatric oncologist.

Nurse Education and Preparation

Nurse education is generic and similar to Finland. There is limited educational content covering young people with cancer in the undergraduate nursing programme at Western Carolina University (WCU) and a restricted number of placements for nursing students. There is no educational provision around the concept of transition. There are no post-graduate modules available currently

at WCU. Nurses who eventually work in this area of care have no preparation to care for young people with cancer either in the children's or adult services.

8.5 England (Central London)

Introduction

Within central London there are two main hospitals caring for young people with cancer - Great Ormond Street (GOS) and the University College London Hospital (UCLH).

GOS care for patients in the 0-12 years range and UCLH who also care for 0-12 year old patients depending on cancer diagnosis and all young people 13-24 years. Each year approximately 1,691 young people in England are diagnosed with cancer.

Current Transitional Practices

Both hospitals utilise shared care well. UCLH has a newly built unit which has a TCT unit for 13-24 year olds. The TCT is a 19 bedded unit. Both GOS and UCLH have a late effects nurse with a robust transitional pathway in place. Staff from both hospitals communicate well and are considering a rotation of staff to further improve communication and co-ordination. Transition of care is in place for the child moving to the TCT, but arrangements are not so clear when transitioning from the TCT to adult services. This is similar to the transitional services available for young people in Cardiff.

Informed choice

Patients are offered a choice regarding their place of care, but this can be dependent on the overall bed situation. This resembles practices within some of the other countries visited. The TCT is staffed with both child health and adult nurses.

Nurse Education and Training

Nurse education for central London is provided by South Bank University and has Practice Educators in place from both the GOS and UCLH hospitals. Both

hospitals appear to be well established and resourced in comparison to other parts of the UK, Finland and USA. There are clinical placements for nursing students in both hospitals. There is some content in the undergraduate nursing programme in year 3 and at post registration level there is more in-depth material around the young person with cancer. Transitional care is being planned for 2013.

8.6 Scotland (Glasgow and Edinburgh)

Introduction

Across Scotland each year, there is approximately an average of 176 young people diagnosed with cancer (Information Statistics Department (ISD) 2012). The Managed Service Network (MSN) was established in the summer 2012 and has been instrumental in the development and delivery for cancer services in Scotland, especially for young people with cancer and their families (Scottish Government 2012).

Current Transitional Practices

Covering the West of Scotland is Glasgow's Yorkhill Children's Hospital which has 22 inpatient beds and a 6 bedded TCT unit for patients in the 13-16 year old bracket. The TCT unit is on a separate level from the children's cancer ward. This unit is staffed separately and has both child and adult nurses. There is also a TCT unit for 16-25 years with 10 beds, but this is located at the adult hospital across the city.

There is no TCT Lead Nurse but there is a consultant who is both paediatric and adult qualified working across both sites to ensure the smooth transition of the patients. This is done in conjunction with the TCT ward staff. There is no transition protocol from the children's ward to the TCT or from the TCT to the adult services. When transition does take place, it is dependent upon the age of the patient and where there is an available bed.

To the East of the country is Edinburgh's Royal Hospital for Sick Children which has an 8 bedded children's ward and a 2 bedded TCT. The inpatient

children's ward treats patients in the 0-13 years range and the TCT cares for young people aged 13 to 16 years of age. In reality however, the age range seemed to vary from 13 years to 20 years of age.

There is a transitional clinic for the neuro-oncology young people within Edinburgh's adult oncology services. These clinics are held on the third Friday of every month for young people aged between 16-24 years and the clinic can accommodate around 5-7 individuals per month. The clinic is to support young people and their families to transition into the adult services, but is based on the individual patient and their circumstances. This service has developed due to colleagues in adult clinical oncology and neurology who are keen to care for these patients in the right way.

There is also a late effects clinic on the paediatric site but nothing on the adult site apart from the neuro-oncology.

Glasgow has a follow-up clinic where young people are seen by the paediatric oncologist and the team at the children's hospital. Edinburgh has a late effects clinic also within the children's service.

Informed choice

Young people are not always given a choice in Edinburgh or Glasgow regarding their place of care. This is dependent on the prevailing bed situation and resources. In Scotland young people are encouraged to be engaged in any decision making regarding their care which is appropriate to their age & capacity. The document Getting it Right for Every Child (GIRFEC) outlines the key principles that must be applied to ensure that young people are involved and informed fully regarding the planning of their care (Scottish Government 201).

There is wide variation in how young people with cancer are transitioned in Scotland with many still in the children's oncology service long into adulthood. Not all of these young people will be given a choice and although there is a

large TCT service in Glasgow this is not the case for Edinburgh. There are plans afoot for a new TCT build at the adult oncology site for 2013.

Nurse Education and Preparation

Nurse education and preparation is sparse within the undergraduate nursing programmes. It is currently in the 2nd year at ENU and there is plans to add this to the post graduate programme with support from adult oncology colleagues. Clinical placements are limited but most students who request this speciality are offered this experience. Glasgow and Edinburgh utilise a 'hub and spoke' placement.

There are plans to develop care for the young person with cancer and transition within the postgraduate nurse education at Edinburgh Napier University 2013.

9. Key Issues and Best Practice

With all 6 services now reviewed, the following sections of the report will discuss key issues and best practices identified and present a series of recommendations for improvements to future practice.

Current Transitional Practices

Currently young people with cancer are treated and cared for within a mixture of children's wards, TCT and adult services across the 6 countries. There is wide variation in how young people with cancer are transitioned. It was clear there is a need for a supportive and seamless transition between the child and adult services, and indeed the TCT and adult services.

There are currently 16 TCT units in UK, however not every country had a TCT or equivalent. For the countries with a TCT there seemed to be a problem with some young people who either felt too young or too old to be nursed within this area of care. There are examples of good transition models that could be utilised to improve care for young people, such as the model used for haemophilia patients in Belfast and London at GOS and the UCLH.

Informed Choice

Where appropriate, young people should be actively involved in their healthcare and offered an informed choice of where they would prefer to be treated (NICE 2005, DH 2007, RCPE 2008). However, this can be difficult for young people who are initially faced with a cancer diagnosis and struggling to come to terms with the possible ramifications of such a diagnosis. According to NICE (2005) young people aged 19 and over may make an informed choice to where they receive their cancer treatment.

Family Centred Care (FCC) is at the centre of children's nursing within the UK. The care is planned with the child, the family, the nurse and other health care professionals (Coyne et al 2011). The concept of children's nursing has deep roots within this model where health care professionals strive to work in partnership by negotiating the care where and when appropriate.

This approach becomes problematic in the TCT and adult services where the care is focused on the patient being empowered to take responsibility for their own health care. For example within the children's service the parents/family is encouraged to stay with their child. However in the TCT or adult services the visiting is restricted to set visiting times and most do not always provide a FCC model.

The care delivery for individuals with cancer, to one which promotes a FCC model where independence and self-awareness is encouraged and necessary may be problematic for some patients and their family as one parent expressed "***it is often not clear who is in the driving seat***". Services that are tailored to meet the individual needs of the young person and their family are necessary. Implementing a FCC care across all services would be beneficial to the overall experience for the whole family.

Nurse Education and Preparation

Nurse education and preparation is currently seen as an important issue and needs to be fully addressed within the UK, Finland and the USA. This study highlights that there is inconsistency and variation in the undergraduate

programmes and limited post registration nurse education, specific to the care of young people with cancer and indeed transition. There is a PgCert in Cancer Care for Teenagers/Young Adults Teenagers which is delivered through Coventry University and delivered internationally as an online blended module, but this type of learning will not suit every practitioner.

For nurses, the emerging competencies which will be required to care for young people with cancer have already been recognised by the Royal College of Nursing (RCN) (2010). It is clear that nurses working within this specialist area will need to collaborate to provide the best possible care for young people with cancer. Nurses will require to be prepared both educationally and practically so they have the skills set and knowledge base to care efficiently and effectively for this patient group.

10. Recommendations

This report highlights that it is not just transition from the child to adult services that is important but also from the TCT to adult focused services. There is wide variation in the way young people with cancer are transitioned if indeed they are transitioned at all. Services require to be evaluated taking into account what the young person's needs are. From this study it is clear that no one pathway/model will suit all and that a certain amount of flexibility will be required.

Choice of place of care needs to be addressed but this is difficult when not all young people will have access to the same services. It is recommended that choice should be given where the individual is able to make a choice. Implementing a planned and carefully prepared transition for the young person, the family, and the health care professionals across the services would support this.

Based on the findings from this study, a number of recommendations are made in **Table 2** below. These recommendations are crucial to improve young people's experiences of transition both nationally and internationally.

Service Provision and Management	<ul style="list-style-type: none">• The development of a core UK and international transitional care pathway is now required to smooth the transition of young people into appropriate adult services. This core pathway must be modular, flexible, easy to understand and focused on the requirements of the specific patient group.• Service provision should not be solely defined by the age of the young patient. Care arrangements should meet the needs of individual patients rather than categorising the needs of individual patients only by specified age brackets.• The review of the TCT's currently underway in England needs to be extended across the rest of the UK. Such a comprehensive review would contribute towards future service design and contribute to a more consistent and effective set of arrangements across the UK for all patients. This would also reduce the negative impacts of the 'post-code' lottery in health care provision.• In addition, there should be an evaluation of the effectiveness of available follow-up care services such as survivorship, late-effects and transitional clinics.• Within the age groups discussed, a Family Centred Care ethos should be adopted in all relevant situations. There should be sufficient consideration given to the needs of the individual patient and their families regarding visiting arrangements, communication methods, over-night stays and their emotional well-being.
Inter-professional Working	<ul style="list-style-type: none">• All healthcare professional across the child and adult services must now accept the need for improved and consist planning and communication

	<p>around making transition as smooth as possible for patients. Once this general acceptance is in place, care teams can then prepare the detailed arrangements between services to begin the implementation of appropriate transition pathways. This change in culture can be challenging, but is the primary pre-cursor to the introduction of effective and appropriate transition pathways.</p>
<p>Individual / Person</p>	<ul style="list-style-type: none"> • Moving on to adult focused care is a challenge for young people with cancer and their families. Young people and their families require help and assistance to prepare for transition. This support will include a timeline regarding the cancer journey and highlighting when changes in care delivery or arrangements can be expected. • Further research into the changing expectations of young people and their families is now required to ensure that the service provision can deal with such a complex and specialist patient group.
<p>Nurse Education and Training</p>	<ul style="list-style-type: none"> • Nurse education and preparation across the UK and internationally is varied and inconsistent. • As the incidence of young people with cancer grows, nurses will require a specific skill set and knowledge to care for young people with cancer and their families. HEI's and service providers must work collaboratively to increase nurse education in this specialised area. • Specific nurse education and preparation for caring for young people with cancer and effective transition must be embedded within the core programme modules. • Through the CYCPN group and HEI partners in WCU and Lahti University nurse education at post

graduate level is being considered. Education to prepare nurses to care for this specialist group of patients is required. This would be through online and face to face learning teaching and assessment.

- Adult colleagues in HEI's and service provision who are specialist in the field of oncology/haematology nursing need to work together to share expertise.
- More opportunities for clinical placements for student nurses within their nursing programme is now required.

11. *The Way Forward*

This report has provided an overview of the current arrangements in the 6 countries regarding transition of young people with cancer. Findings suggest that health care practices around transition for young people with cancer vary considerably. There needs to be clear transitional care pathway for young people with cancer transitioning from children's to adult service or indeed from a TCT to adult services.

Links have been strengthened between CYPCN education group and international professionals through the sharing of nursing practices and education. An international working group has been established and there are plans ahead to widely disseminate some of the recommendations from this work both nationally and internationally.

Appendix 1 – The Itinerary

Country	Location & Date	Schedule
Northern Ireland (Belfast)	Queens University / Children's Hospital. 13th February - 17 February 2012	<p>Belfast was the first visit organised by Dr. Jayne Price. A structured schedule was prepared prior to the visit:</p> <ul style="list-style-type: none"> • Queens University, School of Nursing – Dr. Jayne Price • Royal Belfast Hospital for Sick Children - Fionuala Diamond Senior Staff Nurse & two student nurses (2nd and 3rd year) • Northern Ireland Cancer Fund for Children - Liz Osborne Social Worker • Northern Ireland Cancer Centre (NICC) (adult services)- Suzanne Mooney (Social Worker/Research Fellow)
Wales (Cardiff)	Cardiff University / Children's Hospital 20 February - 24th February 2012	<p>The second visit was organised by Melda Price (Lecturer in Children and Young People's Nursing)</p> <ul style="list-style-type: none"> • Cardiff University – Melda Price & Sian Bill (Lecturer in Children and Young People's Nursing) • Cardiff Children's Hospital & TCT Unit (Elizabeth Yeoman's (Practice Educator) & Jenny Labaton (TCT Nurse Manager).
Finland (Lahti)	Lahti University and Children's Ward 28th April - 6th May 2012	<p>Lahti was the third visit organised by PL Hannele Tiittanen. A structured schedule was prepared prior to the visit:</p> <ul style="list-style-type: none"> • Lahti University School of Nursing - Hannele Tiittanen • Lahti Hospital children's ward - Mari Riuttanen (Staff Nurse)

England (London)	GOS and UCLH 14th - 21st May 2012	<p>The fourth visit was organised by Caroline Knott (Clinical Nurse Specialist). A structured schedule was prepared prior to the visit:</p> <ul style="list-style-type: none"> • University College London Hospital (UCLH) – Caroline Knott • Great Ormond Street Hospital (GOS) – Julie Bayliss (Lead Cancer Nurse) and Saddhasura Denton (Nurse Specialist).
USA (North Carolina, Asheville)	Mission Hospital and Western Carolina University 25th June – 2nd July 2012	<p>Asheville was the fifth visit with Professor Sharon Metcalfe. A structured schedule was prepared prior to the visit:</p> <ul style="list-style-type: none"> • Western Carolina University, School of Nursing – Professor Sharon Metcalfe and Bonnie Garner Assistant Professor, Pediatrics. • Mission Hospital Children’s Cancer Unit - Anne Bowers Clinical Research Nurse
Scotland (Glasgow and Edinburgh)	Glasgow Children’s Hospital and Edinburgh Royal Hospital Sick Children and Western General Hospital (Transition clinic) 30th July – 6th August 2012	<p>Glasgow and Edinburgh were the final visits. A structured schedule was prepared prior to the visit by myself:</p> <ul style="list-style-type: none"> • Glasgow Children’s Ward and TCT – Michelle Welsh (Practice Educator) and Gillian Paton (Practice Educator) • Edinburgh RHSC – Dr. Angela Edgar (Paediatric Oncology Consultant) Patricia Hutchison (Social Worker)

Appendix 2 – Questions

Theme	Specific Issues	Probes
1) General Approach to Young People's Transition	<ul style="list-style-type: none"> a) How would you describe your approach to young people with cancer moving from a child service to an adult service? b) What are the services available for young people? c) What is the age range you use to refer to young people? d) What terminology do you use to describe the care of young people moving to adult care? e) If not, how do you describe this period? 	<ul style="list-style-type: none"> a) For example: Do you use the term transition to describe the young person's move into adult care?
2) Specific Transition Arrangements & Considerations	<ul style="list-style-type: none"> a) Who is responsible within your organisation for young people who survive into adulthood in your region/across the country? b) Are there differences between district generals and specialist centres? c) Do you offer survivorship clinics? d) What health professionals are still involved with the young person when they complete treatment, and for how long? e) Are young people given a choice? f) Do you monitor over time for physical and physiological effects from treatment? g) What do you think are the strengths and weaknesses of the current 	

	approach to transition? h) What changes, if any, would you like to make to the current system?	
3) Staff Education and Training	a) What nurse education and training around young people with cancer is there in the undergraduate and postgraduate programmes? Anything in-house? b) How are the nurses prepared to care for young people as they transition or after the transition?	

References

Blum, R., Garell, D., Hodgman, C., (1993) Transition from child-centred to adult health-care systems for adolescents with chronic conditions: a position paper of the Society for Adolescent Medicine, *Journal Adolescent Health*, 14, pp. 570-576.

Children Cancer and Leukaemia Group (CCLG) (2012) Childhood Cancer
Available at: <http://www.cclg.org.uk/>
Accessed 12th December 2012

Coyne, I., Gallagher, P., (2011) Participation in communication and decision-making: children and young people's experiences in a hospital setting *Journal of Clinical Nursing* 20, (15-16), 2334–2343,

Department of Health (2007) *The cancer reform strategy*. The Stationery Office, London.

European Network for Cancer Research in Children and Adolescents (2012) Education
Available at: <http://www.encca.eu/>
Accessed 12th December 2012

Eshelman-Kent D, I., Gilger, E., Gallagher, M (2009) Transitioning survivors of central nervous system tumours: challenges for patients, families, and health care providers. *Journal of Pediatric Oncology Nursing*. 26 (5) 280-294

Finnish Registry for Cancer (2012) Cancer Incidence
Available at: <http://www.cancer.fi/syoparekisteri/en/>
Accessed 12th December 2012

Gibson F (2005) Evidence in action: fostering growth of research-based practice in children's nursing. *European Journal of Oncology Nursing*. 9 8-20

Gibson F, Soanes, L., (2008) *Cancer in Children and Young People*. Wiley. England

Grinyer, A., (2007) *Young People Living with Cancer, implications for policy and practice*. Open University Press. London.

Hollis, R., Hooker, L., (2009) Improving Outcomes: Update on Progress. *Paediatric Nursing*. 21, (4), 14-18.

Information Services Division (2012) *Cancer in Young People*

Available at: <http://www.isdscotland.org/>

Accessed 12th December 2012

Kelly, D., Gibson, F., (2008) *Cancer care for Adolescents and Young Adults*. Blackwell Publishing, Oxford.

MacMillan Cancer Support (2012)

Available at: <http://www.macmillan.org.uk/Aboutus/AboutUsHome.aspx>

Accessed 12th December 2012

McCann, L., (2012) Transition or transfer? An experiential perspective on moving from paediatric to adult cancer services. Unpublished thesis, University of Dundee

McInally, W., Masters, H., Key, S., (2012) The impact of paediatric oncology education on clinical practice - A phenomenological study *European Journal of Oncology Nursing*. 16(5):498-504.

National Cancer Intelligence Network (2012)

Available at <http://www.ncin.org.uk/home.aspx>

Accessed 12th December 2012

National Institute for Health and Clinical Excellence (2005) *Guidance on cancer services: improving outcomes in children and young people with cancer*. NICE, London.

National Health Service Improvement Cancer Survivorship (2012)

Available at:

<http://www.improvement.nhs.uk/cancer/SurvivorshipLivingWithandBeyondCancer/TeenageandAdultAftercarePathway/tabid/336/Default.aspx>

Accessed 12th December 2012

National Cancer Survivorship Initiative (2012) Children and Young People

Available at: <http://www.ncsi.org.uk/>

Accessed 12th December 2012

Northern Ireland Cancer Registry (2012) Cancer Incidence

Available at: <http://www.publichealth.hscni.net/directorate-public-health/service-development-and-screening/northern-ireland-cancer-registry>

Accessed on 12th December 2012

Royal College of Nursing (2010) an integrated career and competence framework for nurses working in the field of children and young people's cancer care

Available at

http://www.rcn.org.uk/_data/assets/pdf_file/0005/408254/004172.pdf

Accessed 12th December 2012

Royal College of Physicians of Edinburgh (2008) *Think transition, developing the essential link between paediatric and adult care*. RCPE, Edinburgh.

Royal College of Nursing (2004) *Adolescent transitional care, Guidance for nursing staff* RCN London

The Scottish Government (2012) *Cancer Plan for Children and Young People in Scotland 2012-15: Managed Service Network for Children and Young People with Cancer in Scotland*, The Scottish Government, Edinburgh.

The Scottish Government (2012) *A Guide to Getting it Right for Every Child*

Available at: <http://www.scotland.gov.uk/Resource/0039/00394308.pdf>

Accessed 12th December 2012

The Teenage Cancer Trust (2012)

Available at: <http://www.teenagecancertrust.org/>

Accessed on 12th December 2012

The World Population Clock (2012)

Available at: <http://www.worldometers.info/world-population/>

Accessed On 12th December 2013