Developing a Resource for Nurses Caring for Children with Liver Disease or Liver Transplant in New Zealand

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Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Signed

Karyn Sanson
Date

Acknowledgements

Abstract

Paediatric liver transplant has become an accepted mode of treatment in New Zealand for children with end stage liver disease and more recently to allow improved quality of life. The program is based at Starship but provides a national service. Currently 58% of the 140 children, pre and post liver transplant, case managed by the nurse specialist service live outside the greater Auckland region. They are cared for using a shared care philosophy by regional nursing and medical staff with Starship specialist support (Starship Gastroenterology Nurse Specialist Database June 2011).

Many centres have only one or two children and are being cared for by teams with limited experience of chronic liver disease and transplant. Due to the subspecialist nature of the patient group, accessing quality information can be time consuming and challenging for nurses. Increasing workload of the Starship specialist team has highlighted the need for a robust and relevant resource which is easily accessed by shared care nurses to guide patient care.

The aim of this practice project was to develop an evidence-based, peer-reviewed nursing resource which contains the related anatomy, physiology and pathophysiology, along with evidence-based monitoring and intervention recommendations. Best practice in Project Management (Australian College of Project Management, 2001) and Larrabee's Model for Evidence-Based Practice Change (Larrabee, 2009) methodology were implemented to guide the project through a series of phases; from assessing the need for change, and development of the resource, through to planning for implementation and evaluation of the resource outcomes.

Chapter One

The aim of this practice project was to develop an evidence-based, peer reviewed resource for nurses throughout New Zealand who care for children with chronic liver disease and/or liver transplant. The resource package contains relevant anatomy, physiology and pathophysiology, along with evidence based monitoring and intervention recommendations. It is anticipated that this resource will empower regional nurses to perform a thorough and relevant nursing assessment, develop an appropriate plan of care and provide consistent information for families.

This chapter will provide information on the history of liver transplant internationally and in the New Zealand context. It will also consider the concept of shared care. The practice initiative being developed and the resources currently available to shared care nurses within New Zealand are also outlined in this chapter.

History of Liver Transplantation

Liver transplant was first performed on a human by Starzl in 1963, however success did not come until 1967 when six adult patients underwent liver transplantation over a two year period with the longest survival time being 30 months (Keeffe, 2000) . Between 1967 and 1979, 84 children received liver transplants. Patient survival at two years post-transplant was only 30% (Otte, 2002). Success rates remained low over the next few years and the procedure was considered experimental by many until the advent of a new class of medications in the 1980s. Calcinurin inhibitors were a new form of immunosuppression, the first of which was Cyclosporin, introduced in 1980. This class of immunosuppressants was critical to the on-going development of transplantation and the improvement in survival rates (Keeffe, 2000). Continuing developments in surgical techniques, managing patient haemostasis during surgery, organ preservation between donor and recipient and many other innovations have improved transplant outcomes throughout the decades to the present day (Keeffe, 2000).

Currently, liver transplant is considered a mainstream mode of treatment for those with end-stage liver disease and more recently, for those whose quality of life would be significantly improved by liver transplantation. Survival rates are now reported in

years not months and one and three year rates are being reported routinely along with five and 10 year post-transplant survival data. In the United States, paediatric liver transplant survival is between 75-85% at 5 years and 60-80% at 10 years post-transplant (United Network for Organ Sharing, 2011).

The New Zealand Liver Transplant Service

The New Zealand Liver Transplant Unit (NZLTU) was set up in 1997. It is a national service based at Auckland City Hospital. Prior to 1997 New Zealand adults were offered transplant under Ministry of Health contracts in Sydney and Brisbane. Children were offered transplant via contract with the Brisbane Transplant Unit with children and their families continuing to travel to Brisbane for liver transplant until the paediatric contract was awarded to the NZLTU in 2002. The New Zealand paediatric program is a national service based at Starship Hospital with its funding and transplant surgical care being delivered from the NZLTU. The location of the two services, Auckland City Hospital (Adult) and Starship Childrens' Hospital on a shared campus benefits children and families by allowing transplant surgery to occur within the larger adult operating theatres, whilst post-operative care utilises the paediatric expertise within Starship.

The NZLTU performs approximately 40 transplants per year in total, with the number of children growing from 5-8 per year in the period 2002 to 2008 to 12 children in 2010 (Starship Clinical Nurse Specialists, 2011). Children require liver transplant for a number of reasons, the most common being congenital malformations of the biliary tree, such as Biliary Atresia which makes up 52% of the New Zealand paediatric liver transplant cohort. However there are also a variety of hereditary and metabolic disorders which require transplant as shown in Figure 1
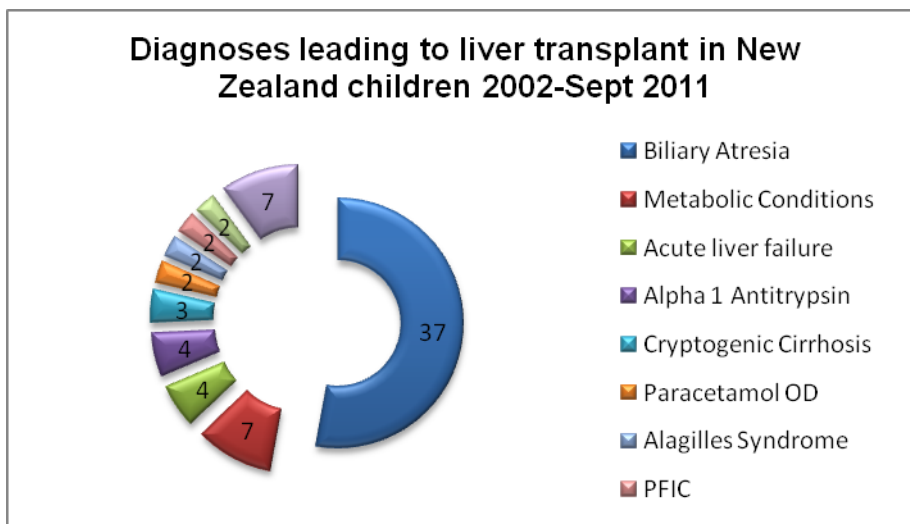
Figure 1; Diagnoses leading to transplant in NZ Children (by patient number)

The youngest child transplanted to date was three months old and a mere six kg in weight at the time of transplant. Approximately 50% of the children who have liver transplants in New Zealand receive their transplant before the age of two years indicating that paediatric diseases often progress rapidly to end stage liver failure.

Children come to Starship from all over New Zealand with all District Health Boards sharing the care of liver transplant recipients with Starship. Many children are from small towns and rural areas adding to the complexity of setting up individual care arrangements for each child. In addition to the children transplanted within the NZLTU program, the long term care of those previously transplanted in Brisbane is now the responsibility of the Starship team.

The paediatric multidisciplinary team consists of three surgeons, who perform both adult and paediatric transplant surgery, four paediatric gastroenterologists based at Starship, and one part-time paediatric gastroenterologist based in Christchurch, all of whom are supported by a Starship multidisciplinary team. This team includes radiologists, sonographers, clinical nurse specialists, specialist dietitians, social workers and pharmacists. These professionals provide support to their regional counterparts who are unlikely to be paediatric or specialty trained. Allied health professionals including counsellors and physiotherapists also play significant roles in patient and family care, however these services are extremely limited for children and families living away from the tertiary care setting.

Whilst the NZLTU is young in comparison to many international centres who commenced transplant programs in the 1980's and 90's, outcomes are equivalent and in some cases better than comparable units. Whilst obtaining individual centre survival statistics can be challenging in many countries, centres within the United States (US) do publish survival rates. The Childrens' Hospital of Pittsburgh states a 94% patient survival at three yrs post-transplant against a US average of 88% (Children's Hospital of Pittsburgh, 2011). As at November 30, 2011 there have been 73 children transplanted within the NZ paediatric program and survival rates are 98.6% at one year and 96.1% at five years post transplant (Nurse Specialist Database, 2011).

Shared Care Model of Service Delivery

Children are referred to the Starship Gastroenterology Service (SSH) most often for assessment of prolonged jaundice. The Clinic Nurse Specialists (CNS) become involved once a diagnosis of liver disease, which is likely to become chronic or require liver transplant during childhood or adolescence, is made. If the family reside within the greater Auckland region then SSH remains the primary care team liaising directly with the General Practitioner (GP) for primary health issues from this point through until transfer to adult care. If the family reside outside Auckland then the aim is to share care with the multidisciplinary team of the District Heath Board (DHB) where the child lives.

The composition of these shared care teams varies greatly by location. The child will always have a GP and a paediatrician allocated, however, neither is likely to have had significant experience in paediatric liver transplant and access to the paediatrician varies greatly. Some paediatricians are based in towns other than the child's own, in some cases up to three hours drive away and only attend outreach clinics. The frequency of these outreach visits varies greatly between regions from one to two times per month to a little as twice a year. Other paediatricians are present on a part time basis and some are full-time and easily accessible to families.

Many regional centres have paediatric community nursing staff that take the lead in day-to-day monitoring and liaise with the paediatrician directly. In a few cases, this role is taken on by the GP or the GP nurse depending on services available in the

area. Communication between the local team members and Starship is mainly by phone and email. Children with liver disease and those in their first year post-transplant are particularly fragile with complex needs requiring the healthcare team to have a good understanding of liver disease and transplant complications. This understanding enables early recognition of complications and changes to care requirements so that the SSH team can be alerted to provide support and guidance regarding the response. There are transplant outreach clinics in place in Christchurch three monthly but small patient numbers in other centres are not sufficient to justify outreach clinics elsewhere. The children require comprehensive annual reviews which include specialist ultrasounds and other examinations only available at Starship, therefore children will return to Starship for these reviews. The shared care arrangement continues until transfer to adult services.

Although not formally evaluated, it appears that sharing care provides a number of significant benefits for the child, their family, the child's health practitioners and the DHB. Shared care significantly reduces disruption to families with the potential to noticeably reduce time spent away from home. The support of family and friends is a vital component in parental coping and keeping children linked with their peers, promoting strong social and cognitive development. The shared care model minimises disruption to this support. The challenges of striking a balance between meeting the child's medical needs and psychosocial needs are significant. The impact of isolating a child from peer relationships is consistently reported throughout the literature as having a negative impact on the psychosocial and cognitive development of the child with chronic illness (Miller, 1995). This balance can be met partly by using a shared care model. The impact on siblings is less well reported but it would be reasonable to extrapolate the same findings to this group.

Financial implications of having a child with chronic illness are also addressed through use of the shared care model as it assists in reducing parental leave from paid employment and the costs associated with travel and other additional costs associated with living away from home. Access to appropriate local services such as social work, dental care and developmental support is maximised through accessibility to normal public health systems. General paediatrician involvement is maintained and promoted in this model. Financial savings to the regional DHB

through savings in travel and accommodation costs along with the potential for increasing local knowledge through experience are additional benefits associated with the shared care model of health care delivery.

A key component of shared care is that Starship team supports local teams in managing the clinical needs of children locally whenever it is safe and appropriate to do so. This is achieved through on-going communication of clinical management and changes in condition, along with provision of guidance in assessing and addressing clinical changes. The recent Starship quality audit suggests that shared care is working from the shared care nurses' perspective. It is evident that the CNS service is meeting the goals of being an accessible and valued resource with all shared care nurses reporting use of the Starship team as a resource and 49% reporting they contact it weekly, fortnightly or monthly for guidance. This same audit also found that a large proportion (84%) of shared care nurses rated the team as "very" or "extremely' useful and the Starship team as being the "most' useful resource for 66% of the shared care nurses (Appendix 1).

However, shared care also involves significant challenges. Currently the CNS service manages approximately 150 children with chronic liver disease or post-transplant. At the time of writing 56% (84) of these children live outside the greater Auckland region, spread through 16 of the 17 non-Auckland DHBs. Many of the children are the only child with chronic liver disease or transplant managed by the local paediatrician, GP and nursing team. This creates unique hurdles to overcome. Families are aware that their child has a rare condition and the local pool of knowledge is likely to be limited, creating additional anxiety as they return home with a child who has been newly diagnosed, or has progression of a potentially life-threatening disease. Services they considered standard at Starship, such as micro collect phlebotomy for blood tests and rapid reporting of blood test results are not available. This may result in venous blood samples being taken because local teams are not trained in microcollect techniques. Blood tests are often referred to other labs for analysis resulting in delays in processing. Cumbersome systems prevent easy access to published results and further delays information being available for clinical decision making. Systems vary within each DHB. Knowledge of particular results and treatments in the field of liver disease and transplant is imperative to correct clinical

decision making. Whilst nurses often hold the vital front line role in clinical assessment in the community, with such small numbers of patients it is hard for nurses to justify allocation of additional resources, be it their own, or that of the DHB, for training and education.

The Practice Initiative: supporting shared care nursing teams:
The recent Starship quality audit (Appendix 1) demonstrated that nursing members of shared care teams work in varied roles and varied practice locations. Currently 48% of nurses are based solely in the community setting, 43% in combined hospital and community roles and only 10% are fully hospital based (Appendix 1). Within this group some have a mandate to case manage families, whist others have an acute care focus and pass on findings to others without the mandate for more comprehensive management This creates additional challenges for the CNS's in providing timely and effective clinical practice support and promoting care based on current best practice in the regional setting.

Experience, knowledge and skills are very difficult to gain and maintain when the exposure to liver transplant in New Zealand is extremely limited. The audit reflected the rarity of transplant when it identified that only 25% of nurses who are involved in the shared care of children with liver disease or transplant have cared for more than five children either pre-or post-transplant throughout their whole career. This is despite the fact that 95% of shared care nurses are a highly experienced group having been practicing for more than 10 years (Appendix 1). Low levels of confidence in managing these patients were also demonstrated with only 50% of nurses feeling "slightly confident" in caring for transplant patients and none reported feeling extremely confident (Appendix 1). Therefore, while the shared care model is advantageous to both families and the DHB funders and providers, there is also a considerable challenge involved in managing a complex, small group of children spread across a large geographical area.

Children under the NZ paediatric program have their healthcare requirements met in a variety of clinical settings ranging from subspecialist professionals in the tertiary (Starship) setting through to general paediatricians and GPs based in secondary and primary health care settings. The increasing numbers of children with liver disease

and liver transplant in New Zealand has reduced the ability for the CNS service to provide the level of support directly to shared care nurses as it has in the past. Due to the geography and population spread throughout many small centres in New Zealand, growing numbers do not always correlate with growth in the knowledge and experience of individual nurses. When children reside outside the four main centres, it will be more likely that new nurses will enter into a shared care arrangement with the Starship team rather than additional patients being cared for by a nurse already engaged in the shared care process. Therefore the case load and experience of individual shared care nurses with children with liver disease is likely to remain low or at the same levels seen in the recent audit.

Currently Available Resources for Shared Care Nurses:

Due to the subspecialist nature of the patient group, accessing quality information can be time consuming and challenging for nurses, particularly those working in regional areas. Given the competing demands of community roles, it is unlikely that shared care nurses will be able to spend hours searching for information in a subspecialist field in order to implement it in practice for one patient in a case load of many. Lack of time, workplace culture, lack of access to resources, poor understanding and/or lack of confidence in critical appraisal are all barriers to basing practice on evidence. (Brown, Wickline, Ecoff, & Glaser, 2009).

If shared care nurses are reporting feeling only slightly confident in clinical care it is likely that they will feel even less confident in critical appraisal of the literature and determining the most appropriate care for children with liver failure or pre/post-transplant. Whilst there have been enormous advances in web based and electronic resources available to nurses in recent years it cannot be assumed that every nurse will gain the information they need without support. Doran et al (2007) describe an explosion of information accessible through the internet, but that this has not resulted in nurses readily accessing the information due in part to increasing workloads. Access barriers to online information remain significant for nurses due to a number of other factors including IT skill base, confidence in critiquing the literature and access to computer terminals (Gosling, Westbrook, & Spencer, 2003). This is particularly relevant in community settings which is where almost all of the shared care nursing roles are based (Doran et al., 2007). A study undertaken by Royle et al (2000) found that written resources and textbooks were accessed by two thirds of

nurses on a weekly basis and this was second only to discussion with colleagues. Therefore the availability of a resource containing information which is specific to the context and is current and easily accessible should improve patient care.

Currently nurses rely almost exclusively on information disseminated from Starship with 92% of nurses reporting they use Starship Guidelines to support their care delivery (Appendix 1). However, the heavy use of local colleagues (80%) and very low use of databases such as Medline and CINAHL (24%) may suggest limited use of current evidence-based practice (Appendix 1). This situation is not unique to shared care nurses, nor to New Zealand, but is consistent with studies such as those by Doran et al., Gosling et.al. and Royle et.al. who describe a myriad of barriers to evidence based practice, all of which are relevant in this setting (Doran et al., 2009; Gosling et al., 2003; Royle et al., 2000).

Currently there is one nurse specific resource book about liver disease available in New Zealand. This book is only in use at Starship and is not provided to other centres because it has not been developed specifically for the New Zealand context, does not currently reflect best practice and requires additional content to reflect the continuum of care from pre-to post-transplant. The book was written by the author in 2003 as part of a quality initiative and provides background information to up skill and assess the competence of nurses in the tertiary setting of the Royal Children's Hospital (RCH), Melbourne. With permission of the RCH, the author brought the electronic version back to New Zealand. Some of the information in the book is now out of date, several sections are not relevant to New Zealand and other relevant topics are not addressed. The book covers liver disease only and does not address transplant related care. The needs of nurses outside the tertiary care setting are not addressed.

<u>Project aim</u>

The aim of this practice project is to develop an evidence-based, peer-reviewed resource for nurses throughout New Zealand who care for children with chronic liver disease and/or liver transplant. The format and content topics of this resource will be driven by the input of regional shared care nurses.

For ease of reading, this report will be divided into four chapters. Chapter two will focus on the methodology used to support the project. Chapter three puts a spotlight on development of the resource itself. Finally, chapter four provides an opportunity for discussion of some of the challenges and learning opportunities the project provided.

Chapter Two

In this chapter I will discuss the models used to support the project. Stakeholder identification and involvement in the project will be considered. A synopsis of the survey of shared care nurses will be presented and acknowledgement will be given to an overview of the driving and restraining forces related to the project.

Development of the project management model:

There are two distinct components to this practice project. The first is the development and implementation of a project management process. This will provide the framework for the successful development of a peer-reviewed, evidence-based resource and its implementation into clinical care throughout New Zealand.
The second component is the development of the resource itself.
This includes;

- Identification of information required in the resource
- Detailed review and critique of the literature
- Assessing the alignment of the literature with current practice and addressing any misalignment

Identification of an appropriate model to guide the practice project proved to be more challenging than anticipated. Several models were reviewed. These included Rosswurm and Larrabee's Model for Change to Evidence-Based Practice, (Rosswurm & Larrabee, 1999) along with the tools to assist with the integration of evidence into practice developed by the Centre for Clinical Effectiveness (Centre for Clinical Effectiveness, 2009). Whilst both of these provide guidance, particularly in relation to Evidence-Based Practice (EBP) and nursing, both are focussed on implementing a single practice change and neither provided the detail required to ensure all aspects of a complex project were addressed and that risks were identified and mitigated to assist in a successful outcome in a complex environment. The Australian College of Project Management (ACPM) Best practice in project management model was also reviewed (Australian College of Project Management, 2001). This model is based outside the health care setting; but previous experience

of using it successfully within the healthcare environment particularly with larger projects warranted its inclusion. The model has a number of common themes inherent in every project and the authors support adaptation of the methodology across a number of settings (Australian College of Project Management, 2001, 2010). ACPM acknowledges that there is an element of risk and provides steps and significant detail to cover all aspects of a project. However, some of the detail is designed for corporate situations requiring very different reporting processes to those which are required for this project. Therefore, Larrabee's revised model for evidence-based practice change in conjunction with the ACPM model has been used for this project to ensure all aspects of project management are addressed. Table 1 illustrates the aspects of each of the two models and how it was possible to integrate the various phases for use in this project.

Table 1 Project management model

Adapted from Larabee (2009) and ACPM (2001)		
Phase	**Model for Change to EBP**	**Project Management Additions**
Step One Assess the need for change	Include stakeholders Collect internal data about current practice Compare internal with external data Identify the problem Link the problem with intervention and outcomes	**Phase One: Concept** Undertake options analysis Develop scope definition Draft preliminary project plan Draft business case/ project costing
Step Two Locate the best evidence	Identify types and sources of evidence Review research concepts Plan the search and review Conduct the search	
Step Three Critically analyse the evidence	Critically appraise and weigh the evidence Synthesize best evidence Assess feasibility, benefits and risks of new practice	

Adapted from Larabee (2009) and ACPM (2001) continued		
Phase	Model for Change to EBP	Project Management Additions
Step Four Design the practice change	Define proposed change Identify resources required Plan Implementation process Define outcomes	**Phase Two: Development** Confirm scope definition Detailed risk analysis Draft schedule of work Allocation of resources "The Project Planning Cycle" Stakeholder update
Step Five Implement and evaluate change in practice	Implement pilot study Evaluate process and outcome and costs Develop conclusions and recommendations	**Phase three: Implementation** The "Project Planning Control Cycle" Project reporting
Step Six Integrate & maintain the change in practice	Communicate recommended change to stakeholders Integrate into standards of practice Monitor process and outcomes. Celebrate and disseminate results	**Phase Four: Finalisation** Confirm receipt of deliverables Confirm procedures for outstanding maintenance

Projects which are well planned are more effective as they better verify targets, enforce commitments, act as a basis for control, clarify risks and allow resource planning to occur (Australian College of Project Management, 2001).

Larrabee's Model for Evidence Based Practice Change

Assessing the need for change (Step One):

The increasing numbers of children with liver disease and liver transplant in New Zealand has reduced the ability for the CNS service to provide the level of support directly to shared care nurses in the way it has done in the past. Due to the geography and population spread throughout many small centres in New Zealand, growing numbers of children needing care do not always correlate with growth in knowledge and experience of individual nurses. As discussed in the previous

chapter shared care nurses experience with children with liver disease is likely to remain low therefore there is an identified need for an accessible evidence based resource for nurses caring for these children/families.

Identifying and including stakeholders

When planning any project, identification of stakeholders is paramount to the success of a project. Stakeholders are people who are involved with or affected by a project giving them the potential to support the project or, potentially, create barrier(s) to completion (Australian College of Project Management, 2001; Cole, 1998).

Key stakeholders:

- Shared Care Nurses
- Paediatric teams at other DHBs in NZ
- Starship Gastroenterology/ Liver Team

  - Medical specialists
  - Nurse specialists
  - Pharmacists
  - Social workers

  - Surgeons
  - Dietitians
  - Consult liaison psychiatrists
  - Play therapists

- Immune Deficiencies Foundation New Zealand IDFNZ
- ADHB Quality group
- Graphic design team
- Printers
- Nurse Advisor/ Nurse Leader for Child Health
- Starship Medical Specialties Business Manager
- Ministry of Health/ National District Health Board
- Starship Webmaster

<u>Why they are stakeholders and how they will be included;</u>

<u>Key Stakeholder- Shared Care Nurses</u>

Shared Care nurses are the focus of this practice project as they will be the recipients of the end result. Involvement in the process included opportunistic informal conversations, and, as will be described later in this chapter and in chapter three, a formal survey was completed pre-and will be repeated post-resource development. Project updates have occurred as key milestones have been met and will continue to occur throughout the project. Eight shared care nurses were selected and actively participated in a peer review of the resource and contributed to the resource content.

<u>Key Stakeholder-Starship Gastroenterology/ Liver Team</u>

The content quality of the resource will reflect on the whole team not just the author(s). The contents of the resource are multidisciplinary with sections on medications, nutrition and social work support. Each of these needs input and/ or peer review by the discipline involved in order to maintain the quality of information. This was achieved by having the specialist team members from each discipline review the resource prior to its dissemination to the shared care nurses.

<u>Key stakeholder – Immune Deficiencies Foundation New Zealand (IDFNZ)</u>

Kids Foundation is the charitable arm of IDFNZ that supports this group of children and their families. They work closely with the CNS service and informal discussions have occurred over a period of time prior to commencing the project. During these discussions the Kids Foundation indicated that they would become a financial supporter of the graphics and printing costs associated with this project. Formal discussions have occurred and regular stakeholder updates will occur throughout the project including the sharing of evaluation results.

<u>Stakeholder- Nurse Advisor/ Nurse Leader</u>

As this project is primarily a nursing resource, quality and risk management processes at ADHB require consultation with and approval of the Starship Nurse

Advisor/Nurse Leader. Publication of the internal audit tool and survey results within this report also required her approval. This was granted following discussions and e-mail correspondence with the nursing leadership at Starship. Starship nursing management will also continue to be appraised of progress during the implementation and evaluation phases.

<u>Stakeholder -Starship Medical Specialties Business Manager</u>
The business manager of the service also has a role in the project as she fits into the nurse specialist reporting lines and can assist/ prevent allocation of resources as necessary. Stakeholder updates have been and will continue to be provided as part of best practice in project management quality reporting systems.

<u>Stakeholder- ADHB Quality Group</u>
ADHB has specific quality assessment and sign off processes which are required in order to have information displayed on the internal and external websites. The team have been made aware of the project and processes have been followed appropriately.

<u>Stakeholder- Ministry of Health/ National District Health Board (NDHB)</u>
The Starship Gastroenterology Service has been recognised as being extremely vulnerable due to limited resources available nationally. Therefore the service was included within the NDHB review and development projects team. This was an attempt to address the issues which make the service vulnerable and improve equity of access to the service for all New Zealand children. The NDHB is therefore a stakeholder in this project due to the project being recorded as part of the associated nursing work stream and progress is being monitored as part of on-going service assessment.

<u>Webmaster</u>
The Webmaster was a late addition to the stakeholder list in response to the survey results regarding format of the resource. This person has intricate knowledge of how and where this document may sit within the Starship website and the software, technology and process requirements to ensure it can be displayed in this medium. This person will be responsible for loading the resource, creating links between

documents etc. Regular updates to ensure scheduling of work will continue throughout the project.

<u>Key Stakeholder –Graphic design team</u>

Whilst in many circumstances this team may be considered service providers, in the project management model, they are considered stakeholders. ADHB graphics was initially approached to provide preliminary costing information and graphics expertise because of their experience with medical drawings. The input from this team was significant in the development of the resource. Unfortunately, after initial discussions appeared positive regarding their involvement, the decision was made by this team to withdraw due to the size of the project. Because this decision was made seven weeks after a detailed quote was requested, significant delays in the graphic design component of this project occurred. However, the project planning and control cycle was followed and adjustments made to the project accordingly. After further discussions with the IDFNZ Kids Foundation (sponsoring this component), a new graphic design team were identified and Creative Bite was selected and engaged in the process. Clear lines of communication and deadline management will be crucial with this graphic provider to ensure the project remains on track.

<u>Stakeholder- Printing companies</u>

Printing companies, like the graphic design team, could also be considered service providers in some circumstances, but were initially included in the list of stakeholders as the intention at the beginning of the project was to produce a printed resource. However, once the medium changed, they were removed from the list prior to any contact occurring.

<u>Indirect Stakeholders</u>

This resource is being created in order to support the provision of quality care to children with liver disease or liver transplant and their families. Therefore they are the ultimate recipients of the outcome of the project. On that basis I consider them to be indirect stakeholders.

The Survey

Approvals

Auckland University of Technology (AUT) policy states that any research or teaching involving human participants (with some exclusions) must receive approval from the AUT Ethics Committee (AUTEC) or another, approved, ethics committee.

This quality audit appeared to meet exclusion criteria 6.8. "Observational studies in public places in which the identity of the participants remains anonymous and compilation of the data does not involve any harmful or objectionable activity" (AUT University, 2012). However, to ensure this was the case an "Application for ADHB institutional approval for Observational Studies and Audits (Expedited Review)" was submitted to the Northern X Regional Ethics Committee. This committee confirmed that the audit survey discussed in the following section of this report did not require ethics approval (NTX/11/EXP/212). Approval to use the internal audit/survey within this report was requested and granted on behalf of ADHB by the Starship Nurse Advisor and the Gastroenterology Service.

Audit process

In order to assess the current situation accurately and provide a basis for evaluation, a quality audit tool was developed. This was in the form of a survey and was distributed to the nurses outside the greater Auckland region already sharing care with the CNS team. The group being surveyed was limited to a cluster sample only, as there was the potential to create significant bias by sampling a random population of nurses whose contact with the shared care program was unknown (The University of Texas at Austin, 2011). In order to address this, a screen of the database ensured that only shared care nurses currently caring for children with liver disease or transplant were identified and surveyed. To open the survey out to all nurses in regional centres including those not currently caring for a child with liver disease or transplant created so many known and unknown variables that the results would not have reflected the group of interest accurately. Twenty-eight nurses known to the CNS service were sent the link to the survey.

Method of Survey delivery

Surveys can be conducted using a variety of formats. In this instance an electronic web based survey was deemed the most suitable for several reasons.

The survey offered the respondents clear anonymity and minimised the number of steps required by respondents to complete the data and return it. This method also negated the costs associated with print and postage. In addition, the web-based software allowed easy collation of data and the survey could be saved and repeated at a later date for evaluation purposes with minimal effort.

The potential for a significantly reduced response rate has been reported in the literature in association with web-based surveys. This was taken into account and counter strategies including email reminders were put in place to minimise this risk

Assessing competence vs. confidence

 Several discussions occurred between various members of the Starship team, fellow nurses and AUT staff regarding the use of an assessment of competency as part of the audit tool.

The RCH learning package, which provided the base for the resource being developed, was designed to be used as the basis of on-going competency assessment in the tertiary setting of RCH Melbourne. At RCH, all specialty ward staff being assessed were exposed regularly to children with liver disease and through the transplant continuum and so a consistent baseline level of knowledge could be anticipated and expected.

However the clinical course of patients with liver disease varies substantially from child to child. Some children can survive with chronic liver disease for a number of years whilst others will deteriorate rapidly from a variety of life threatening complications. This variation, in combination with the small patient numbers seen by shared care nurses in New Zealand, does not provide a uniform baseline from which to measure meaningful competency. Each individual nurse's experience will vary greatly depending on the child's clinical course. Whilst this experience may inform future practice, it would be difficult to measure competency across all aspects of patient care.

Assessing competency usually occurs within the employing organisation or as an agreed tool during a formal learning process and can be used for many reasons including risk management, certification and recertification of professionals and measuring organisational performance (Kak, Burkhalter, & Cooper, 2001).

These uses infer that the person initiating the assessment is in a position of power and has control to change the outcomes. Whilst nursing competency is an important consideration in care provision, it was not deemed appropriate for Starship CNS Service to measure the competency of nurses practicing outside the organisation who may have potentially very different practice settings and support structures. Competency measurement therefore would not be included in the resource package and therefore would not be measured as part of the audit.

The Survey Questions

The survey questions were developed using Survey Monkey Software via the Survey Monkey website http://www.surveymonkey.com using Survey Monkey best practice guidelines.

The first part of the survey obtained general demographic data. This included career length, level of nursing post graduate academic qualifications, experience in nursing children with liver disease and or transplant and the context of their practice role i.e. whether they were based in the community or hospital setting.

The second part of the survey asked a variety questions related to the current resources in use and which ones they find most useful (Appendix 1). Gaining a baseline understanding of the information currently used by shared care nurses to support their practice is important in determining if a new resource is required, what it should include, and the format in which it should be provided. Not only does this information give some insight into the direction of resource development but will also provide a base for evaluating the impact of the resource ultimately provided.

The survey concluded with questions regarding the topics which they would like to see included in the resource as a way of determining the content of the resource.

Trial of the survey questions

Once the questions were written, it was important to assess that the questions met best practice standards. That is, that they were clear, concise, relevant and required minimal effort to answer (SurveyMonkey, 2011). In addition, the flow of the questions and length of time the survey required to be competed is important. The questions were trialled on a group of 5 nurses all based at Starship. This group included CNS colleagues, a ward staff nurse, a nurse educator and the authors AUT project supervisor. Each provided slightly differing feedback on the survey and subsequently questions were refined.

The Survey Process

Twenty eight shared care nurses were contacted via email and the practice project was explained along with the purpose of the survey. Contact details were supplied to ensure nurses were able to contact the author if they had any problems completing the survey and it was reiterated that the respondent's answers would be anonymous. A two week timeframe was allowed for completion of the survey and the final date for submission supplied within the email. An email reminder was sent out to all five days before the cut-off date, as reminders are known to substantially improve response rates in internet-based surveys (Braithwaite, Emery, de Lusignan, & Sutton, 2003).

Survey Findings

The full survey can be found in Appendix 1.

Survey Response Rates

Twenty eight nurses were contacted, provided with the internet web link and instructions to complete the survey. Twenty Five nurses responded. To determine the response rate the following calculation was used;

| Number of completed surveys | <u>25</u> | X 100 = **89%** |
| Number of participants contacted | 28 | |

This response rate is situated well above average response rates for both online and email surveys where the norms are 30% and 60% respectively (SurveyMonkey, 2011).

Most questions were completed by all 25 nurses with the exception of questions 1, 6, 8, 10, 11 and 14 which were completed by 24 nurses.

Survey Results Summary

Demographics;

All nurses responding to the survey would be considered experienced nurses with 95.8% practicing for more than 10 years and the remainder for more than 5 years. Every nurse is employed outside the ADHB tertiary care setting. Only one nurse is purely hospital based with the others spread evenly between community and combined hospital and community roles. Forty percent of the nurses hold a post graduate certificate, a further 28% had continued their post graduate education to diploma level and 8% had obtained a postgraduate masters. This rate of post graduate qualifications is higher than that reported by the general nursing population in 2010 (14%, 9% and 6% respectively) (Nursing Council of New Zealand, 2010) and may have influenced the responses to survey question 7. These responses provided helpful information in determining the level at which the resource needed to be written.

Twenty five percent of nurses had cared for more than five children with liver disease/ liver transplant in their nursing career, but just 8% (two nurses) of that group reported caring for more than 10. In addition, 48% of nurses responding to the survey have only managed one to two patients in their current role. Small numbers of patients over long periods of time, create challenges in gaining and maintaining experience. The numbers reported, and the geographical spread of children with liver disease or transplant throughout New Zealand, do correlate well with these results.

Current confidence levels;

Nurses were asked to rate their level of confidence on a four point scale from "*Not at all confident*" to "*Extremely Confident*". Reponses were evenly divided between "*slightly confident*" and "*moderately confident*" with no nurse reporting as being *"not at all confident"* or "*extremely confident".* One nurse did not answer the question.

Current use of resources

Several questions were asked in this area to ascertain which currently available resources were used most, the topics of interest and the resource the nurses found most useful.

This was also an opportunity to find out more about the support currently offered by the CNS service, so the survey included information about the frequency of contact with the CNS service for information or advice and how useful it was.
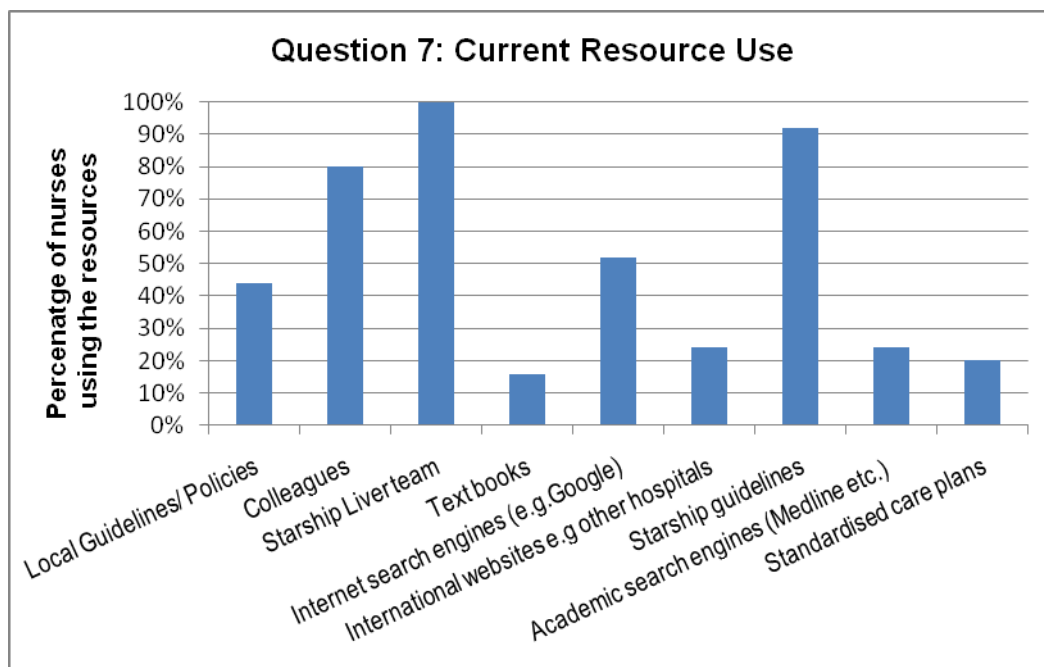
Figure 2; Resources currently used to support practice.

 A number of resource options were supplied, as indicated in Figure 2. Participants use all of the resource options provided in the survey. All nurses reported that they use the Starship team as support, closely followed by Starship Guidelines (92%) and local colleagues (80%). Other popular resources include local guidelines/ policies and internet search engines such as Google (52%).

Academic search engines (CINAHL /Medline) and text books rated much lower at 24% and 16% respectively. Use of resources such as the standardised nursing care plans, which were only used by 20% of the nurses, may have been influenced by lack of direct public access to the documents.
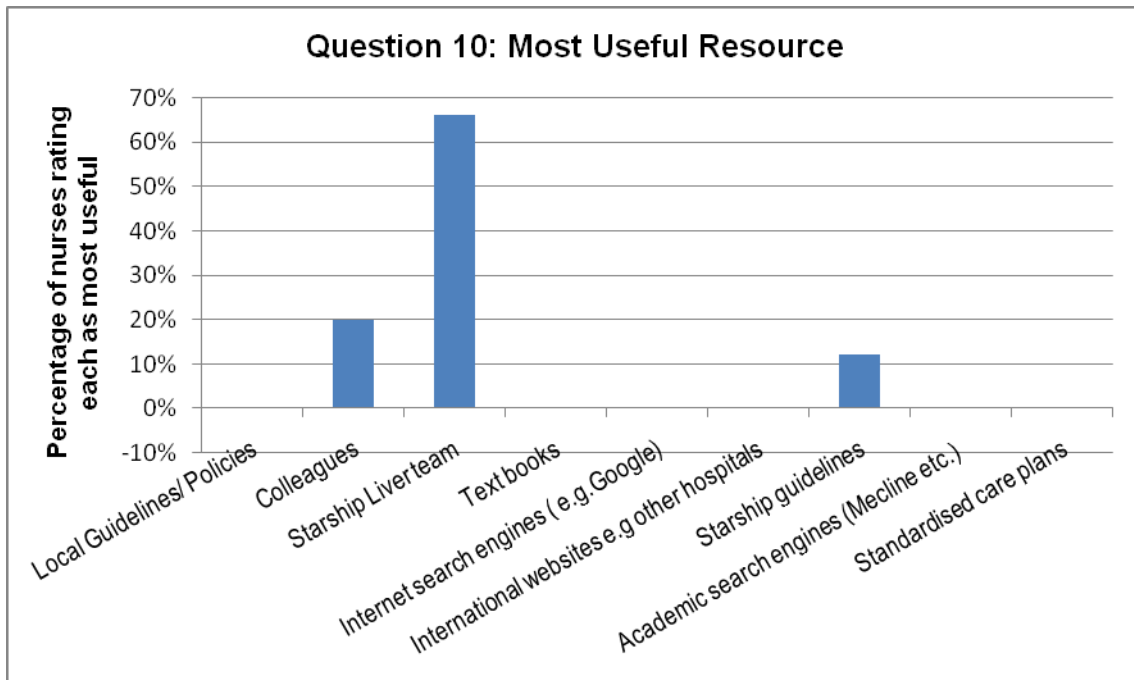
Figure 3; most useful resources

When asked which resource the nurses find most useful the Starship team was rated highest (66.7%), followed by colleagues at 20.8%. Starship Guidelines were found helpful by the remainder with no other category being nominated (refer figure 3). Almost half of the nurses reported contacting the Starship team at least monthly with almost 30% reporting they make contact at least fortnightly. 84% responded that they found the service "very" or "extremely" useful.

Resource development:

Questions 12 -14 focussed on considerations for the new resource being developed to support shared care nurses.
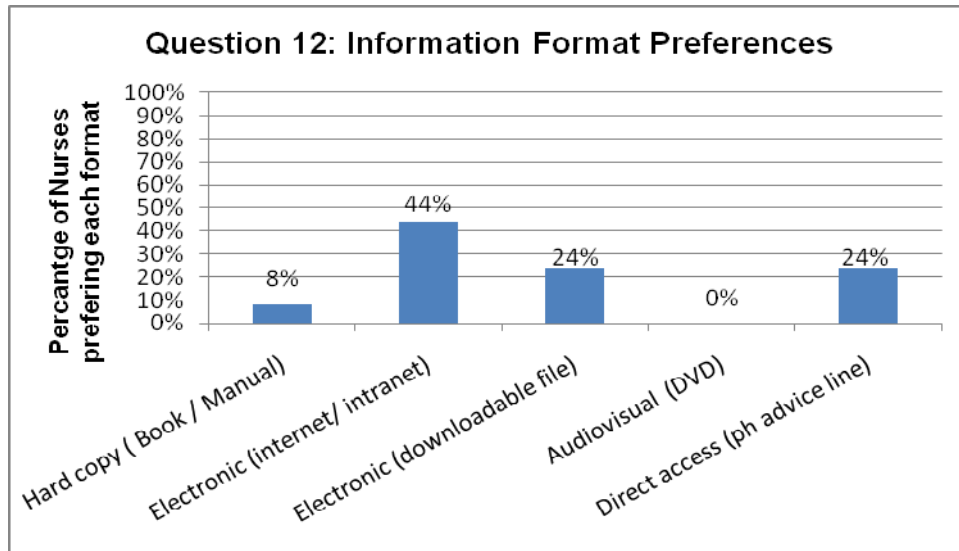
Figure 4; Information format preferences

In relation to format of the resource, 68% of nurses preferred a web based or downloadable electronic resource. Direct access via a phone advice line was preferred by 24% of the nurses. Hard copy book or manual rated much lower at only 8% and no nurse preferred an audio visual format (see Figure 4). Given my initial reading regarding preferred medium (as discussed in chapter one) and plans for a printed book/ manual, the responses from the nurses created the need for further assessment of options and a return to my project plan for major adjustment.
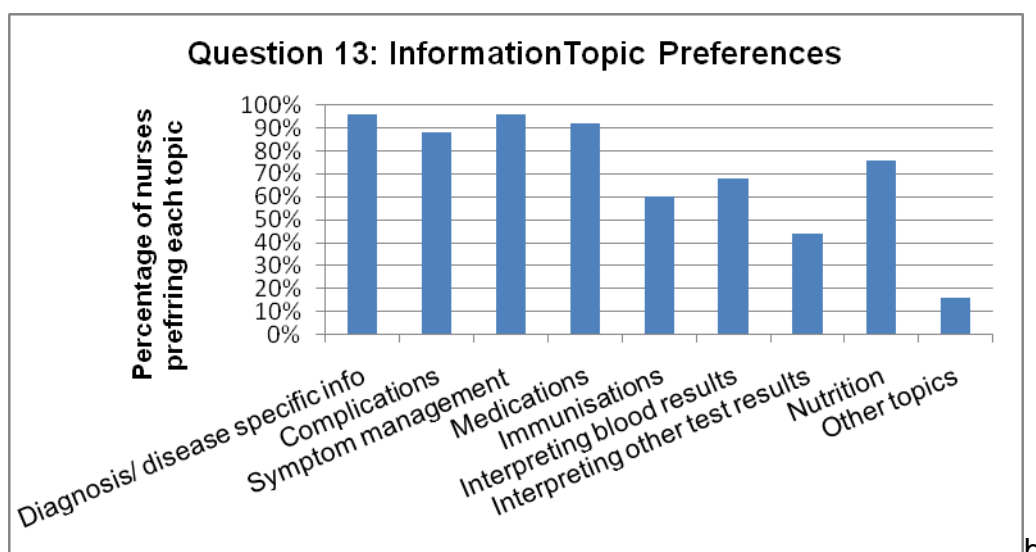
b

Figure 5; Information topic preferences

The sorts of information the nurses are looking for included information about disease or diagnosis specific information e.g. Biliary Atresia (96%), symptom management (96%), medications (92%) and complications of liver disease and transplant (88%) (see Figure 5). The opportunity to provide other topics was present and two nurses provided additional information. One suggestion was to include regional and national support services available to families. Specific information about assisting families to make the adjustment back to normal life was also suggested. Other comments such as "all of the above" and "anything covering the care of these children" were also made.

The final question in the survey related to the willingness to pay for a new resource if it were available. This question was included as it provided valuable information about cost recovery through sales as an option during formulation of budgets and negotiation with stake holders regarding resource allocation.

One nurse skipped this question and only 37% said they would be willing to consider paying for the resource with 63% stating they would not.

Step Two: Locating the best evidence

Literature searches were performed to identify the types of resources currently used by nurses to support their practice. A mix of CINAHL, Medline and Google scholar data-bases were used with a variety of search terms and MeSH headings. These terms included nursing education, continuing education, online learning, computer-based learning, online resource and health care education.

An extensive review of educational needs or learning methods was outside the scope of this project and the search was undertaken primarily to ensure there was

not a substantial gap between the projects planned outcomes and general knowledge on the subject.

Step Three: Critically analyse the evidence

There appeared to be very limited published research directly relating to the provision of resources for nurses practicing outside an organisation. Most of the literature related to the provision of online courses and therefore resource provision was being supported by a formal educational process and not being provided in isolation. However one meta-analysis did find that there were positive effects from online learning when compared with no intervention and that the effects may be consistent with those experienced in traditional face-to-face learning situations (Cook et al., 2008). This information, in combination with the findings from the project survey suggests that a web-based resource would be of value in assisting shared care nurses to deliver evidence-based care.

Step Four: Design the practice change

The aim of this practice project will be to develop an evidence-based, peer-reviewed resource for nurses throughout New Zealand who care for children with chronic liver disease and/or liver transplant.

Steps five and Six: Implement, evaluate integrate and maintain practice change

Due to the time constraints of this practice project steps five and six, will not be reported in this project report. However the plans for implementation, evaluation and strategies for sustainability of the practice project have been developed and will be discussed in chapter three.

ACPM Additions

Phase One: Concept

In addition to the activities outlined in Larrabee's model, the ACPM indicates the need to define the scope of the project and develop a project plan which includes projected project costs.

The project planning was benefitted substantially from learning from previous projects. This included the process required for graphic design as well as issues involving sustainability of a relevant resource in the long term.

<u>Funding sources and budget considerations</u>

Identifying funding requirements and the potential sources of funding for any project needs to occur as early in the project planning phase as possible. Funding availability has a powerful influence on the feasibility of any project regardless of its size. Not only can lack of funding impact on the project starting but its availability can impact on the quality of the project result(s) and the timeframes required for completion.

Budgeting for the project was challenging. There were multiple costs associated with the project and sources for funding were varied according to the type of cost and amount. There was no funding available within the Starship Gastroenterology service to meet any project costs so external sources were required.

There are four techniques required for cost estimation, these are:

- Subjective - guesses or individual perceptions
- Statistical - based on historical data and overall quantities
- Comparative - based on previous similar work
- Empirical – based on real experience or observation e.g. quote

Budgeting during project planning usually requires a combination of all four of these (Australian College of Project Management, 2001). This project was no exception. Some costs such as Survey Monkey membership and postage costs were fixed (empirical) so could be accurately anticipated during planning. However, actual graphics development and printing costs which required the greatest allocation of funding could only be estimated based on a combination of comparative subjective and statistical data, that is; what was currently contained in the learning package and my vision of the additional sections. The reasons for these methods being used was due to the size and detail contained in the end document being heavily reliant on the findings from the literature and peer review process. The budget was used as a basis for discussion with the IDFNZ Kids Foundation General Manager and the agreement to proceed obtained.

The budget for the project was heavily impacted by the change from hardcopy to web-based format in the early phases. The large costs associated with printing the document were negated.

Table 2; Budgeted costs

Item	Value		Source of funds
SurveyMonkey Membership 12 Months		$300	AUT Masters Funds
Postage/ Envelopes		22.91	AUT Masters Funds
Printing of drafts for peer review	Total Cost	$64.00	AUT Masters Funds
Graphics design Quote 3	Estimate based on subjective and comparative knowledge $5-6000 Creative Bite Not for profit price $2000		IDFNZ Kids Foundation Funds
Graphic Design Program Adobe CS5.5 InDesign 7.5	3 copies for 3 PCs	$1128	Scholarship Grant
Paid project hours	192 hours	$3856	Scholarship Grant

Phase Two: Development

Design:

The force field analysis developed by Kurt Lewin is a well-known and effective tool to use when designing a plan for change. Craig and Smyth (2002) describe it as a method of identifying factors which are expected to promote or support the process along with those which may hinder it. Force field analysis includes four steps (Cole, 1998);

- Clearly stating the goal of change
- Identification of stakeholders
- Identification of driving and restraining forces
- Evaluation of the strength of the identified forces.

Steps one and two have been described on pages 13 and 15-17.

Identification of driving and restraining forces and their strengths:

This force field analysis allows us to identify and quantify the resources required to implement the change successfully on a rating scale 1-10. One denotes minimal strength and 10 is the most powerful in its ability to promote or restrain the process. Adding the ratings up allows an objective measure of the driving and restraining forces against each other.

Table 3 Force field analyses

Driving forces	Rating	Restraining forces	Rating
IDFNZ Kids Foundation project support	9/10	Cost of development, particularly drawings and graphic design	9/10
Starship Gastroenterology team support	8/10	Webmaster	7/10
Scholarship Grant	9/10	ADHB Quality Group	7/10
Practice Project time constraints	8/10	Current workload creates conflicting priorities, potentially creating project delay or cancellation.	4/10
Shared Care Nurse Survey Results	8/10	ADHB Management	3/10
Existence of shared care relationships prior to the project commencing	3/10		
Total	**50**		**27**

Driving forces for the project

IDFNZ

The support of IDFNZ Kids foundation was rated as the highest driving force. This organisation is crucial in the delivery of funds to obtain the graphic drawings and design essential to the delivery of the resource in an effective educational format. The granting of the scholarship came late in the project cycle.

The Judith Phillipson Trust Scholarship

The scholarship involved the allocation of money for dedicated project time and for software, enabling on-going updates of the resource by the CNS service and so addressed the issues around maintenance and sustainability of the resource. The scholarship expectations also provided timeframes for reporting which will assist in completion beyond the scope of the practice project.

Time Constraints

The existence of time constraints around development of the resource related to the project and the attachment of this project to an academic program could be perceived as both a barrier and an enabler. Given the conflicts of time allocation between clinical workload, post graduate studies, life in general and the project, it was beneficial to develop the resource within post graduate study. This reduced the time allocation conflicts and promoted its priority for completion therefore making it a strong driving force.

The Starship gastroenterology team support for the project was also rated highly as without team support it would not have been considered.

Survey results showing current lack of nurse confidence, clear messages for format of a resource and anecdotal shared care nurses enthusiasm for the project, provided some great enablers for this project. The pre-existing relationships with shared care nurses also promoted the value of the project and assisted in obtaining peer review and anticipated post-implementation evaluation.

Restraining forces

ADHB Quality Group

The ADHB/ Starship Quality Group provides the process and quality controls on all information presented within the Starship intranet and internet sites. It could be perceived as extremely powerful as it has ultimate sign off, however its expectations are consistent with evidence-based practice and so are aligned with the practice project principles substantially mitigating the risk rating.

<u>Webmaster</u>

The webmaster has control of what is to be published on the Starship website. The webmaster must respond to the quality and risk mitigation strategies imposed by the organisation. The risk of being unable to publish is in part mitigated by following the Quality Group sign off process and the early involvement of the webmaster to identify any technical issues, as well as stakeholder updates throughout the project. There is also the availability of an alternative website should there be any unanticipated issues.

<u>Current workload</u>

Dedicating time for project work not part of core activity remains a challenge. Careful project management which includes acknowledgement of conflicting deadlines early and subsequent development of risk mitigation strategies will need to occur throughout the practice project and beyond. The availability of some funded time has reduced the impact of this risk to the project substantially.

Having identified the potential driving and restraining forces the focus now turns to implementation planning in order to minimise the potential for the restraining forces to prevent or disrupt change in practice.

Phase Three: Implementation

The Project Planning Cycle Tool
The project planning and control cycle (see Figure 6) was used extensively throughout the project to provide an anchor and a framework to move forward when unforeseen circumstances threatened to derail the project. Circumstances requiring use of the cycle included the survey feedback indicating strong preference for a web-based resource over the planned printed book and also the graphics issues as discussed on page 17.
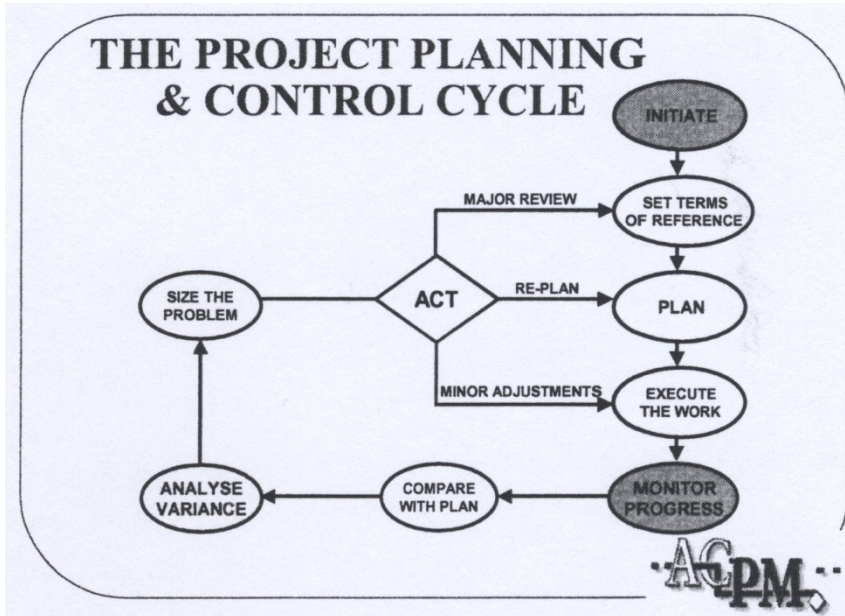
Figure 6: Project planning and control cycle

Phase Four: Finalisation

Confirm procedures for outstanding maintenance.

Sustainability of the resource is reliant on the ability to maintain it as a document which reflects current knowledge and practice. This is challenging in a field which changes so rapidly. The strategies to address this will be discussed in chapter three.

Chapter Three

Background of the resource

As discussed previously, the resource being developed is based on the Liver Disease Learning Package for Nurses written by the author in 2003 whilst working at the Royal Children's Hospital (RCH) Melbourne. The impetus for development of this document was the acknowledgement that the nursing care of children progressing through the liver transplant continuum was incredibly challenging due to complex and variable pathophysiological changes resulting in a variety of clinical courses. Nurses needed an understanding of these underlying changes and their implications so they could provide safe and effective care. Support for the project was gained from clinicians, management and the RCH Clinical Quality and Safety team. These colleagues supported the author through the process of identifying the relevant information, incorporating it into a book to be used as the basis for staff competencies and implementing it into practice on the RCH medical specialties ward. Forty copies of the package were professionally printed; hard copies were retained by the ward for general use, as was the electronic version. Additional copies could be purchased by staff for personal use with proceeds from sales being returned to the ward budget. There were a number of key learning points from the project which have been brought to this practice project and will be discussed as part of project management considerations in chapter four.

In 2007 the author left RCH to return home to New Zealand and commenced employment at Starship Hospital (SSH). The electronic version of the book was brought by agreement with RCH. The resource was seen as more relevant to the Starship ward setting than other information currently available and has been adopted as a resource. It soon became apparent that shared care nurses would benefit from a resource developed with the shared care context in mind and the Liver Disease Learning Package became the basis for an extensive revision and substantial expansion to cover the entire transplant continuum from diagnosis of liver disease to long term post-transplant management.

Permission to use the package

Discussions with the RCH clinicians and Educational Resources Centre (ERC) have determined that whilst the author is able to use the written content of the package as a base, use the diagrams or graphics created by ERC would require purchasing them at significant cost.

Determining the Content

Being clear about the scope of the document was essential to the process of determining content and maintaining an achievable goal. It was determined during scoping that the resource would include only those diagnoses which commonly lead to transplant in childhood and currently have input from the CNS service. The resource would reflect the continuum of care from diagnosis, through the development of chronic liver disease and liver failure. It would also include acute liver failure. The resource would continue along the postoperative course incorporating long-term follow up.

In order to contain the project as one which was consistent with the resources available, there were a number of exclusions. These exclusions included aspects of care which do not require specialist knowledge to that required in general paediatric nursing care e.g. central venous line care, cultural care and general adolescent health issues. Diseases which are rarely seen by transplant services, or that rarely lead to transplant in childhood, were also not included. Viral hepatitis A and B were two diagnostic groups deliberately excluded from the resource for the same reasons. Multiple discussions occurred within the Starship multidisciplinary team concerning which topics should be incorporated. Discussions were held with medical, nursing, nutrition, pharmacy, social work, psychology professionals and cultural support workers. The base document was screened and topics no longer relevant removed by agreement. A list of relevant topics for inclusion was then developed by the CNS service. See Appendix 2; resource contents page.

Determining the structure;

The intended use of the document was determined during scoping of the project. The primary objective of the document is for it to be used as a reference point to support nurses in their care provision. This objective provides a framework for the way in which the information is structured.

The complexity of the information included suggested that the document needed to be broken into sections to allow for easy access to particular topics appropriate to an individual patient as clinical need dictates. The sections developed in the RCH learning package were maintained and refined to allow for the new content. Discussion also occurred regarding how to identify and highlight key points for each topic that may not be immediately obvious, but could significantly impact on a shared care team's ability to care for a child in a given situation. For example there are specific medications available for treatment of gastrointestinal bleeding occurring as a complication of liver disease. Previous experience however had taught us that not all hospitals have these medications in stock. The addition of a prompt to check and possibly organise to have the medication readily available when risk factors for bleeding have been identified, may make a significant difference to the outcome for a child in an emergency situation. The addition of a "*Shared Care Note*" at the end of each relevant topic was added to the structure of the resource in an attempt to address this issue.

Literature search strategies

Muir Gray defines evidence based practice (EBP) as being "an approach to decision making in which the clinician uses the best evidence available, in consultation with the patient, to decide upon the option which suits that patient best." (Walsh, 2010, p. 27).

Evidence-based practice is seen by many as being fundamental in the delivery of high quality healthcare regardless of profession (Walsh, 2010). The key objective of the resource is that it will be evidence based and will support the delivery of evidence based practice by shared care nurses.

There are five essential steps which form the foundations of EBP. These are

1. Ask an answerable question,

2. Search the literature for articles of relevance,

3. Critique the literature to determine quality and relevance to the question,

4. Incorporate the research evidence identified with clinical expertise and patient preferences,

5. Evaluate the effectiveness of the application of evidence into practice (Centre for Clinical Effectiveness, 2009).

Steps One-to-four were followed for each topic in the resource in order to provide a sound base for initial decision making by shared care nurses and the completion of steps four and five during care delivery. Each question was developed using the PICO tool. The PICO tool provides a framework to develop a question which is answerable using standard literature search strategies. It assists in identifying the components of the question being asked including population, intervention, comparison and outcome (Centre for Clinical Effectiveness, 2009).

Initial searches focussed on identifying relevant systematic reviews via databases such as Cochrane, as these provide a well-recognised system for critiquing the evidence. Numerous search terms were used and a number of potential reviews identified. However, many were comparing medications, thus outside the scope of nurses and only one was relevant to the information required for the resource. A single search through CINAHL using the Boolean Phrase "liver transplant", applying related words and limiting it to infants and children, published post 2000 in English was run. This search resulted in just 133 articles covering a huge variety of subjects. Many were not relevant to the purpose of the search. Asking a single question was not appropriate to obtain the variety of information required for each section or topic and, in many cases, multiple search terms and strategies were required in order to address all aspects of a topic.

As has previously been acknowledged in this report, obtaining information on subspecialist topics, particularly in relation to paediatrics is challenging at best and this foray through the literature was no exception! After ascertaining the lack of systematic reviews, using Cochrane and CINAHL Medline and Google Scholar were added as search engines. Each search used a variety of search terms, limiters and expanders to cross check that relevant results were not indirectly omitted. Trends appeared as the searches continued and it was noted that many of the most relevant

articles were being published in the Pediatric Transplantation Journal. This is the official journal of the International Pediatric Transplant Association (IPTA). This organisation and the journal are held in very high regard in the transplant professional community and therefore meet all the criteria for being reliable sources of information. However, access is limited to IPTA members but as the author holds membership of this organisation access to information from this source on almost all topics was possible. As descriptive information on liver anatomy, basic physiology of the liver and pathophysiology of liver disease was not included within journal articles, this information was sourced from contemporary text books on the subject.

The inclusion of consensus of expert opinion in the resource was frequent due to a lack of reliable evidence being available.

<u>Evidence vs. Consensus of Expert Opinion</u>

A key component of this resource was that it be evidence-based.

It is widely acknowledged that there are multiple levels of evidence ranging from Level 1 evidence, obtained from systematic reviews to Level 4, which is based on single cases or case series (Centre for Clinical Effectiveness, 2009). However, in order to address evidence-based practice, other considerations such as clinician experience must also be taken into account (Ciliska, Pinelli, DiCenso, & Cullum, 2001). During the process of literature review, clear themes emerged regarding the availability of evidence in relation to the type of topic being searched. The majority of the evidence was Level 4 evidence as will be discussed in chapter four. Topics which involved the use of a medication such as the use of octretotide in the management of bleeding oesophageal varices (a complication of liver disease) and transplant immunosuppression medications, had a wealth of literature to draw from and a number of quality systematic reviews. For topics associated with radiological or surgical interventions, there were significant amounts of Level 1-2 evidence available. This was particularly so if alternative management methods were available.

Level 1 and 2 evidence was freely available on topics such as the incidence and causes of biliary strictures along with surgical and interventional radiology procedures to manage these.

However, this changed to medium to low Levels (3 and 4) evidence, when the topic of the nursing management of an externally draining stent was searched. In spite of a number of attempts over the last few years to identify any literature on this topic, it appears none has been published. In cases such as this, care recommendations had to be supported almost exclusively by expert opinion and extrapolation from similar clinical situations.

Once the resource had been written using the best available evidence, the first draft of the resource was then reviewed by specialist medical, nursing and allied health colleagues to ensure accuracy of medical information prior to the next phase of the project.

Peer review of resource:

Peer review is generally considered to be essential to academic quality (Christenbery, 2011). In this project, peer-review held an important place in determining the safety, appropriateness and usefulness of the content of the resource. In order to ensure a quality peer review a peer review group was established.

The peer review group comprised

Starship team members:

- 1 Medical specialist
- 1 CNS
- 1 Dietitian
- 1 Pharmacist
- 2 Social workers

Non Starship members:

- 1 Community RN from within the greater Auckland region
- 8 Shared care RNs from various locations around New Zealand

Each person was chosen for a specific purpose.

A number of steps were taken to minimise the risk of information sent out for review being retained and implemented in practice before completion of the resource. However, there continued to be a small degree of risk, so ensuring accuracy of information prior to any dissemination remained important. The Starship team

members were engaged earlier in the process than the rest of the review group. The purpose of their involvement was primarily to ensure the information contained in the resource was an accurate reflection of current knowledge and practice within each discipline.

This group also played a secondary role in providing feedback on ease of reading and grammar.

Once the group had reviewed the resource and appropriate revisions were completed, the resource was then released to the rest of the peer-review group.

A community nurse from greater Auckland was selected because she was likely to have had more opportunities to manage children with liver disease and transplant than the shared care nurses. This nurse would bring a different perspective than the others and may provide additional insight into community-based issues not already addressed in the resource.

A call for peer review volunteers was sent out to the entire shared care nurses group who had been surveyed. Twelve shared care nurses volunteered.

From these nurses, five were selected from different geographical locations. This acknowledged the nurses expertise and understanding of their own local environment and the variety of support structures and resource challenges they may encounter in their practice. Three nurses within this group decided to pass the resource onto a colleague working in an equivalent role, resulting in eight shared care nurses being involved in the peer review process. I believe this behaviour reflected the shared care nurses commitment and enthusiasm for the project.

In addition to geographical location, shared care nurses were also selected for the peer review based on their history of engagement with the Starship CNS service. One of the shared care nurses had no previous engagement with the CNS service, some had intermittent involvement with the service and the others had a long-standing, strong relationship with the CNS service. Whilst the eight nurses involved in the peer review process may not be truly representative of the group the resource is targeted at, project timelines meant that a pragmatic decision had to be made to select nurses who were able to review and provide feedback within a limited timeframe.

Peer review process

Due to the specialist nature of the content, previous knowledge held by the nurses of this practice project and the specific target audience, blind peer review was not possible and open review occurred.

Following consultation with the peer review group in regard to their preferred option for review, paper copies were posted to the group. Paper copies significantly reduced the risk of the document being modified in any way other than that which was intended or being copied and coming into circulation prior to completion. The authors' skills in the collation process were also taken into consideration, as well as previous experience with the review of the RCH learning package.

Paper copies were posted out along with a return addressed, post-paid envelope. Reviewers were asked to complete the review and return their copy via post within a three week period. A reminder was sent at the end of the second week via email. All reviewers completed the review and all documents were returned, although the timeframe was extended to four weeks. The reviewers' responses suggested that the resource will become valuable for these nurses and their on-going engagement with the project will be important.

Comments made by reviewers included:
"Fabulous work Karyn, a wonderful resource"
"It's a meaty booklet .....but does have ease to go from one topic to another"
"The use of shared care notes- I like very much"
"Thanks for this and for including those who will read it in the process"
And finally, a note on one comprehensively reviewed, somewhat tattered copy: "Dear Miss, I am sorry for the state of my homework. My brother dropped his lunch on it.... No excuse for all the scribbles that is my fault alone – sorry"

Themes from the peer review:

Three key issues emerged from the peer review.

The first related to the order of the first three sections. This was consistently reported as needing to change. The draft went out with anatomy and physiology first, followed by complications of liver disease and then common diagnoses leading to liver disease. In response to the feedback this order was changed to anatomy and physiology, then diagnoses, followed by complications.

The second issue focussed on the "Shared Care Note" following most sections. This had substantial support and many responses included the need to highlight it in some way to make it more visible. This will be addressed as part of the layout design.

The section written by the SSH social workers was the third issue, as it created some confusion, with many asking if the service was national and could be accessed by the shared care teams in the same way as the CNS service. The feedback resulted in additional information being provided to clarify the service available to shared care services.

Alongside the main issues there were a number of comments placed indicating sections the reviewers really liked, found confusing, or wanted more detail. These comments were spread throughout the resource and comments were taken into account and addressed in the final document.

Graphics within the resource

Diagrams and pictures have been included in the resource, as, when used appropriately, they do improve learning and comprehension (Butcher, 2006). Butcher also reported that simplified diagrams help most and that there is a further learning advantage when diagrams have been designed to highlight the essential relationships necessary to understand the situation being described (2006).During development of the first draft of the resource, diagrams were identified via a number of sources which contained elements which linked with the topic being discussed.

Several diagrams were excellent representations but various copyright issues prevented their inclusion.

The identification of the graphic designers was facilitated by the IDFNZ Kids Foundation. The Creative Bite design team took on this role. Key considerations of the final presentation set up of the resource will include its web presentation to encourage web-based use. However, it will also need to have a print option which delivers acceptable quality print outcomes. This allows shared care nurses to obtain paper copies of if required.

At the time of this report the text for the resource has been completed and the graphics team are in possession of the completed document and a detailed brief on the diagrams required

Future Plans

Completion of the resource

The resource will go through a standard approval and sign off process with the graphics company. The document will then be provided through the software program purchased as part of this project, so that the document can be updated quickly and efficiently as changes to clinical care occur and other resources can be linked to it as they become available.

 The ADHB quality process for uploading information onto the Starship website will then be followed. Initial discussions with the quality team have indicated that the process used for the resources' development does meet its expectations and that this will be a simple sign-off process and will not delay upload.

Step Five Implementation and Evaluation

Implementation

Implementation of the resource has two phases. Phase one is the launch of the resource to gain initial awareness. Phase two is the on going dissemination of the resource to new shared care nurses as required.

Launch

The planned launch date is the end of July 2012.

The resource will be made available online via the Starship website.

Dissemination will occur through a number of channels;

- Shared Care nurses - an email will be sent to all shared care nurses informing them of the launch.

- The Paediatric Society of New Zealand - Permission is being sought to raise awareness via their communication channels.

- New Zealand Nurses Organisation (NZNO) journal Kai Tiaki Nursing via a letter to the editor.

- Starship Nurses will be made aware via a presentation by the author at a nursing grand round.

- Emails will be sent to key nurses within the ADHB such as the Nurse Educator, Clinical Nurse Specialist and Senior Nurse Groups.

- Transplant Nurses Association of Australasia - A presentation abstract will be submitted to the association for the November 2012 conference in Melbourne.

On-going Dissemination

On-going informal dissemination may occur via search engines such as Google and Bing as the development of the web based section will include the use of key words to facilitate the appearance of the document in search results. Dissemination of the resource via a web link to be included in Starship discharge documentation has been added to the core list of activities performed by the CNS service at the time of transfer of care to the shared care team. This information will be provided to nurses on an ad hoc basis when children are part of a new shared care relationship.

A shared care nurse email distribution list which has been developed and maintained will be used to alert nurses to any updates or revisions.

Evaluation

The aim of this practice project was to develop an evidence based, peer reviewed resource for nurses throughout New Zealand who care for children with chronic liver disease and/or liver transplant. The projected outcome is that the availability of the resource will improve the confidence of shared care nurses caring for these children in their clinical setting. This can only occur if the resource is current and meets the educational needs of this group of nurses. The results of the survey discussed in chapter two will form the baseline data for evaluation of this outcome 12 months post-implementation. The survey will be repeated using the same methods as the pre survey and include the same questions. This survey will include additional questions regarding the content and layout of the resource ensuring that it is continuing to meet the needs of shared care nurses.

Results from this survey will then inform resource revision and re-evaluation of the resource as required.

Step Six: Integrate and Maintain

Sustainability

Sustainability of the resource and maintaining currency of the relevant information is challenging in a situation of rapidly changing knowledge and practice such as in the field of transplantation. As a web based resource, costs associated with printing, reprinting and updates will be avoided. This should ensure economic sustainability of the resource. The availability of the document in a software program accessible by the CNS service is paramount to the sustainability goal. This has been achieved and it is anticipated that changes will be able to be made relatively effortlessly in this format, allowing regular updates without substantial time commitments or need for on-going maintenance funding. Literature searches have been set up for various topics to run automatically on a regular basis and post notification of potential new evidence.

The CNS service now has ownership of a number of graphics and these will be able to be used for teaching and parent resources providing, additional indirect benefits from the project.

Potential Further Development

The initial thinking was that completion of the resource would be the end point. However as the project has progressed it has become apparent that it will provide a centre point for future development. The development and use of web links will enable access to other pieces of information being developed such as other relevant nursing resources and parent focussed information.

<u>Chapter Four</u>

This practice project has been both extremely challenging and rewarding.
In this chapter the challenges related to the resource and the project methodology used will be discussed. Some of the benefits and challenges associated with sponsorship of the project will also be examined. There have been a number of positive changes that have occurred through this project, along with the acquisition of new knowledge and reinforcement of previous knowledge which also require recognition.

<u>The Challenges</u>

<u>The Resource</u>

Developing a resource covering the two major medical specialties of liver disease and liver transplant in children involved identifying, critiquing and presenting combined literature and practice information on approximately 40 interrelated topics (Appendix 2). These topics all required independent searches and clinical discussions with medical specialists to draw best practice conclusions for inclusion in the resource. However, during this project it became apparent that there appeared to be limitations in relation to both the quantity and the quality of the literature.

In this field, it appears that it is more likely for research to be undertaken and published if the authors or subjects are influenced by the following forces.
Firstly, if there are externally driven requirements for evidence e.g. drug licensing such as for the United States (US) Food and Drug Administration (FDA) approval.
Secondly, mandatory outcome reporting requirements in a number of countries have resulted in large databases. An example of this is transplant outcomes being reported to the United Network for Organ Sharing (UNOS) in the US. Common databases like this create banks of available outcome information which improves the quality of the information being used to form the basis of further study or inform

practice. Thirdly, if the outcome of the study provides potential gains to a business or organisation's reputation, e.g. development of a new piece of equipment or procedure. In the case of many US centres, profiling expertise is essential in the competitive healthcare setting, and this can be done through reporting positive outcomes within programs which are equal to or better than other reputable centres. On the reverse side, there was likely to be less information published about negative outcomes such as complications of a procedure which could be perceived by outsiders or potential patients as reflecting lower quality care. Rarely did articles discuss the failure of a treatment unless it was being used as a benchmark against a better outcome being achieved by the authors. This was particularly challenging when addressing nursing issues related to medical complications as this literature is not yet supported by high-level evidence.

Difficulties were also encountered in relation to the context and relevance of some information in relation to children with liver disease. For example, most studies investigating the action of immunisation in people with compromised immune systems were performed using people with Human Immunodeficiency Virus (HIV). Much less was published for renal transplant recipients and even fewer numbers of studies were available for liver transplant recipients perhaps reflecting the patient numbers for each of the diagnostic groups. This meant that in a number of my topics I had to defer to consensus of opinion and extrapolate findings from the HIV and renal transplant groups to liver transplant patients in order to guide practice.

<u>Models used to guide the project</u>

Initial assessment of available models to guide the project clearly showed that there was no one model which provided the level of detail which would support the entire project from inception, through the phases of gathering evidence, to implementation and evaluation of the completed resource. Evidence-based practice models had a strong focus on accessing and collating best evidence but provided lesser guidance on other aspects of project management such as budgeting or change management principles. Project management models were most often derived from major corporate developments or change management theories and thus contained highly prescriptive business model tools such as highly complex budget spread sheets and

reporting frameworks which are valid in many projects but were not required to their full extent in this project. In order to address these issues, as already described, the author used a combination of The Model for Evidence Based Practice Change (Larrabee, 2009) and Best Practice in Project Management (Australian College of Project Management, 2001).

The Model for Evidence-Based Practice Change was a revision by the author of a previous version; Model for Change to Evidence-Based practice by Rosswurm and Larrabee (Rosswurm & Larrabee, 1999). Initially use of the 1999 model was attempted due to lack of awareness of a revised model. The first two steps; Assessing the need for change as step one, and linking the problem, intervention and outcomes as step two created confusion. Combining the two steps seemed necessary, but perhaps this was due to a misunderstanding of the model. Discussion with colleagues who had used the model revealed that this had been experienced by others and drew attention to the fact that Larrabee had developed a revised model which combines steps one and two in recognition of this same issue (Larrabee, 2009). It was therefore the revised model which was used to direct the practice project. As the project progressed it became obvious that step five; implement and evaluate was only partially relevant to this project, as a pilot study was not feasible, nor required, and was in part replaced by the peer-review. Therefore implementation, integration and maintenance were considered within the same step.

The best practice in project management model was viewed as an adjunct to the evidence-based practice model and only those aspects which applied to the project and not already present were included in the planning. Extremely useful topics from the project model included the emphasis on project scoping. When developing a resource of this sort it is tempting to "just see where it leads" and respond to every request for topic inclusion or greater detail. Spending time in the initial phases of the project to create clear scope boundaries allowed the development of realistic goals and for the project to remain achievable. The business model budgeting also allowed all the cost implications to be considered early and although the complex budgeting suggested in this model was not fully utilised consideration of budgetary issues will result in excellent outcomes for the resource in the long term.

Sponsorship; Benefits and Challenges

Obtaining sponsorship for aspects of the project via various sources has contributed positively to the quality of the resource now and into the future. It has allowed professional drawings to be completed and professional document design, creating a far superior look to the document than would have been able to be created without this resource. Involvement of graphics specialists has ensured the layout will encourage web based use. The sponsorship has provided learning opportunities in regards to working with a graphics design team outside healthcare and directly with a charitable organisation in a non-clinical way. These learning benefits are in addition to those recognised at the commencement of the project.

The scholarship funding has allowed dedicated time for the project and this has moved the project forward significantly in terms of quality and timelines. The ability to maintain the document as a current resource and build it further into the future without the need for further funding or major rewriting is exciting. However, with each source of sponsorship there have been a set of expectations which had to be managed alongside the existing expectations. The drawings being developed for this resource will also be used in the parent information book being developed by a colleague and this has enabled two resources to be developed from one source of charitable funding. However, the IDFNZ wish to launch the parent resource as part of other celebrations bringing the timeline for completion of the drawings forward and created workload conflicts with university-imposed deadlines. The scholarship also comes with expectations for project progress reports and formal presentations not included in original workload planning. This reinforced the need to involve stakeholders early, keep them informed and clarify any expectations and time frame requirements.

The Format of the Resource

The clear preference for an electronic resource either in downloadable form or web-based form was a huge surprise. Whilst nurses do integrate internet technology into

their working days in the inpatient ward setting (Morris-Docker, Tod, Harrison, Wolstenholme, & Black, 2004), the author had been unaware until now of the increasing accessibility to and acceptance of electronic resources in the community healthcare setting. The project planning and control cycle tool proved excellent in accommodating this change in direction as it not only acknowledged that such major changes do occur as a normal part of a project, but it allowed for the development of a response in a constructive way. It also ensured that the primary project goals would still be met, although in a different medium.

Thoughts from the Survey

It was noted in the survey results that the post graduate certificate and diploma level qualification levels were approximately three times higher in the survey group than in the general New Zealand nursing population (Nursing Council of New Zealand, 2010). This raised the question whether the level of post graduate education influenced the use of current resources?

Given the focus on evidence-based practice throughout post graduate nursing education, an assumption could be made that there would be a greater level of confidence in accessing and critiquing the literature and that it would have influenced the choice of resources accessed by the nurses in the survey group. However, in spite of the high numbers of nurses in the survey having completed some post graduate education, the use of academic databases remained low at just 24%, suggesting this assumption may be wrong. The survey's intent did not include understanding why resource preferences occurred and so did not ask questions which may have clarified this situation. However, this survey may potentially form the basis of future research in understanding the unique needs of New Zealand nurses and inform future resource development.

Future Directions

The initial goal was to develop an evidence-based, peer reviewed resource for shared care nurses in New Zealand. At the time of writing the content is now complete and awaiting graphic design. Implementation of the resource will be an exciting time and will be followed in the future by peer evaluation. The modification from hard copy to electronic media has opened a new world of possibilities. It can be updated effectively and efficiently with minimal resource use and remain reflective of current evidence and practice. In addition, it provides a platform to link to other resources for nurses, regardless of their geographical position. Discussions have already occurred with the webmaster and ADHB quality group with regard to linking additional nursing resources such as nursing care plans. There are now plans for the development of additional parent information resources, using best practice principles for development. Links will be developed from the resource to allow greater access and allow the shared care nurses to supply families with consistent information at appropriate times.

The journey through this practice project has allowed the author to step back and critically analyse many aspects of the care of children with liver disease and liver transplant and their families in New Zealand. The project has created opportunities to better understand the organisation within which the author works and how it links with external providers of both health and non-health related services. It has created a myriad of questions still needing to be answered with regards to what shared care really is, what promotes shared care and what the barriers are to improving shared care relationships.
Whilst in terms of the university component the project has come to an end, it now feels as though it is the beginning of something different and much bigger than ever anticipated.

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Appendix One

Survey Results

Nursing resources in NZ

Question 1;

How long have you been practicing as an RN?		
Answer Options	Response Percent	Response Count
0-5 yrs	0.0%	0
5-10 yrs	4.2%	1
10+ years	95.8%	23
answered question		24
skipped question		1

Question 2

How many children have you cared for before or after liver transplant during your career?		
Answer Options	Response Percent	Response Count
0	0.0%	0
1-2	28.0%	7
2-5	48.0%	12
5-10	16.0%	4
10+	8.0%	2
answered question		25
skipped question		0

Question 3

In your current role, how many children have you cared for before or after liver transplant?		
Answer Options	Response Percent	Response Count
0	4.0%	1
1-2	48.0%	12
2-5	40.0%	10
5-10	4.0%	1
10+	4.0%	1
answered question		25
skipped question		0

Question 4

Choose the option which best describes where your current role is based?

Answer Options	Response Percent	Response Count
Hospital-Inpatient ward only	4.0%	1
Hospital-Outpatient clinics only	0.0%	0
Hospital-Combination of inpatient and outpatient clinics	4.0%	1
Community only	44.0%	11
Combination of community and hospital based care	48.0%	12
	answered question	25
	skipped question	0

Question 5

What is your highest level of academic quailfication in Nursing		
Answer Options	Response Percent	Response Count
Undergraduate Bachelor (or similar)	24.0%	6
Post Graduate(PG) Certificate	40.0%	10
PG Diploma	28.0%	7
PG Masters	8.0%	2
PhD	0.0%	0
	answered question	25
	skipped question	0

Question 6

How confident do you feel when caring for a child before or after liver transplant?						
Answer Options	Not at all confident	slightly confident	moderately confident	Extremely confident	Rating Average	Response Count
confidence level	0	12	12	0	2.50	24
					answered question	24
					skipped question	1

Question 7

What resources do you currently use to support your care of children before and after liver transplant? (Please tick all which apply)

Answer Options	Response Percent	Response Count
Local Guidelines/Policies	44.0%	11
Colleagues	80.0%	20
Starship liver team	100.0%	25
Text books	16.0%	4
Internet search engines (e.g. google)	52.0%	13
International Websites (eg other hopsitals)	24.0%	6
Starship Guidelines	92.0%	23
Academic search engines (Medline, CINAHL etc)	24.0%	6
Standardised nursing care plans	20.0%	5
Other (please describe)		0
	answered question	25
	skipped question	0

Question 8

On average how often would you estimate you contact the Starship team for information or advice?

Answer Options	Response Percent	Response Count
Never	0.0%	0
Occasionally	50.0%	12
Monthly	20.8%	5
Fortnightly	20.8%	5
Weekly	8.3%	2
More than weekly	0.0%	0
	answered question	24
	skipped question	1

Question 9

How useful do you find the Starship team as a resource?

Answer Options	Not at all useful	Slightly	Moderately	Very	Extremely useful	N/A	Rating Average	Response Count
Usefulness	0	0	4	11	10	0	1.00	25
							answered question	25
							skipped question	0

Question 10

Please select the resource you find MOST helpful

Answer Options	Response Percent	Response Count	
Local Guidelines/Policies	0.0%	0	
Colleagues	20.8%	5	
Starship liver team	66.7%	16	
Text books	0.0%	0	
Internet search engines (e.g. google)	0.0%	0	
International Websites (eg other hopsitals)	0.0%	0	
Starship Guidelines	12.5%	3	
Academic search engines (Medline, CINAHL etc)	0.0%	0	
Standardised nursing care plans	0.0%	0	
	answered question		24
	skipped question		1

Question 11

What aspect of patient care do you MOST often look for information about?			
Answer Options	Response Percent	Response Count	
Disease or diagnosis specific information (Eg Biliary Atresia)	45.8%	11	
Complications	45.8%	11	
Symptom management	54.2%	13	
Medication	33.3%	8	
Immunisation	12.5%	3	
Interpreting blood results	16.7%	4	
Interpreting other test results	4.2%	1	
Nutrition	29.2%	7	
Other (please specify)		2	
	answered question		24
	skipped question		1

Question 12

How would you MOST prefer to access this information? (please select one answer only)			
Answer Options	Response Percent	Response Count	
Hard copy (Book/ Manual)	8.0%	2	
Electronic via internet/ intranet	44.0%	11	
Electronic via downloadable file	24.0%	6	
Audio Visual tools e.g DVD	0.0%	0	
Direct access e.g phone advice line?	24.0%	6	
Other (please specify)		0	
	answered question		25
	skipped question		0

Question 13

What information topics would you like to see covered in a nursing resource?		
Answer Options	Response Percent	Response Count
Disease or diagnosis specific information (Eg Biliary Atresia)	96.0%	24
Complications	88.0%	22
Symptom management	96.0%	24
Medication	92.0%	23
Immunisation	60.0%	15
Interpreting blood results	68.0%	17
Interpreting other test results	44.0%	11
Nutrition	76.0%	19
Other Topics (please specify)	16.0%	4
	answered question	25
	skipped question	0

Question 14

If this resource was not freely available through your service would you consider paying for it?		
Answer Options	Response Percent	Response Count
Yes	37.5%	9
No	62.5%	15
	answered question	24
	skipped question	1

Appendix Two

Resource contents page

CONTENTS