

The Royal Children's Hospital, Melbourne

The Adolescent Model of Care

Report on external consultancy

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Key messages

- Adolescents have been identified as a significant group (15% of all admissions) among the patients receiving treatment and care at the Royal Children's Hospital Melbourne; mapping their journey reveals that a minority of young people arrive at 'youth friendly' destinations.
- In order for our aspirations for a new Adolescent Model of Care to be realised, some important changes in culture, attitude and function need to be achieved; the opening of the new RCH in 2011 has engendered a sense of urgency in addressing challenges and opportunities.
- The RCH Executive is asking the Centre for Adolescent Health to drive a range of hospital-wide initiatives in order to improve the quality of care that is delivered to young people.
- An overarching goal is to create a set of principles for the treatment of all adolescents in the hospital. Key elements will involve identifying vulnerable young people through more consistent approaches to psychosocial screening and developing clearer pathways to more specialist care. This will require the development of new initiatives together with a stronger focus on staff capacity building.
- The design of the new hospital (predominantly single rooms and a focus on patient and family centred care) enables the Adolescent Model of Care to incorporate a hybrid model combining the best of developmental and organic approaches; a crucial element is the retention of an adolescent ward as a mechanism to create a critical mass of expertise for adolescent inpatients within the RCH.
- Within the context of a holistic model of care, both structural (youth friendly spaces), and programmatic (life-long learning, peer support, creative expression) issues need to be addressed.
- Well coordinated approaches to promoting greater self management skills in young people with chronic disease and transition to adult health care is seen as critical to the future health of young adults with chronic disease.
- There is strong support for the current plans to develop a Youth Advisory Council as a key initiative in building a health service organisation inclusive of young people's voices and which promotes their active involvement in the development of the services and structures that aim to support them.
- Restructuring of outpatients will be required to make them more 'youth friendly'.
- There is a need for better integration between hospital-based and community-based youth health services, as well as the provision of education services that support the continuum of learning between school, hospital and home.
- A defining principle for change concerns developing more cooperative partnerships among key groups in order to achieve a more informed,

coordinated and effective approach to the needs and issues of young people.

- In moving from the current reality to the vision of the Adolescent Model of Care, it will be necessary to identify milestones and capabilities, ensure that the developmental process is ongoing, and evaluate outcomes. How these questions will be resolved remains to be addressed.

Adolescent Model of care: Executive Summary

The Royal Children's Hospital (RCH), via the Centre for Adolescent Health (CAH), is a recognised leader in adolescent health care, research, training and advocacy, both within Australia and internationally. The advent of the new hospital provides the impetus to create a more integrated and better coordinated *Adolescent Model of Care*, essentially making developmentally appropriate, holistic care for adolescents everybody's business and, in partnership with other relevant stakeholders, positioning CAH as the principal driver of change across RCH.

The scope and purpose of the review of the Adolescent Model of Care is to:

- Map the current adolescent patient journey and identify any current issues;
- Consider best practice and evidence based care in relation to current practice (identify gaps);
- Develop a model of care for the treatment of adolescents (12 – 18 years) including inpatients (adolescent ward, and other wards including day medical), outpatients, teaching and learning, peer support programs, transition, mental health and allied health services;
- Advise on the skills, competencies and training required by RCH staff to deliver the recommended model of care; and
- Monitor the implementation of the new model of care, both now and into the future, particularly in the transition to the new Hospital.

Where are we now?

The current organisation of adolescent medical/health services includes:

- A well functioning adolescent ward with committed and skilled staff, a diverse and challenging case mix, and hospital-wide conceptual support. 25% of all RCH adolescent inpatients are admitted to the ward.
- Seventy-five per cent of adolescent inpatients are admitted to other wards with varying degrees of interaction with Adolescent Medicine staff.
- There is a range of support programs that function on the adolescent ward, including a recreation program, a specialist music therapist, and limited access to educational support.
- Other wards have various levels of programmatic support eg the Oncology program funds a music therapist.
- The Chronic Illness Peer Support program (known as ChIPS) is an empowering group program for chronically ill young people.
- A new model of patient and family centred education support is currently being implemented by the RCH Education Institute, providing access to teaching and learning for every adolescent admitted to the adolescent ward.

- A range of outpatient clinics is provided at the Centre for Adolescent Health, mostly by sessional adolescent medicine staff and mostly using a private practice model.
- Adolescents attend general paediatrics and subspecialty outpatient clinics within the RCH. In these environments they are generally seen with younger patients.
- Clinical services to adolescents are also provided by the Centre for Community Child Health and the Integrated Mental Health Program.
- Adolescent Forensic Health Service and Young People's Health Service, both under the auspices of CAH, provide health care to high risk youth within juvenile justice facilities at Parkville and to young people within the central business district.

What do we want to be?

Best practice in adolescent health/medicine is largely based upon a developmental model of care, the interpersonal skills of practitioners, and a focus on health, education, wellbeing, quality of life and function. The adolescent physician thinks as much about the person with the illness in the context of family, school and community as they do about the illness itself.

In the new Adolescent Model of care, a young person admitted or referred to the RCH, whether for medical, surgical or psychiatric/psychosocial reasons, will receive developmentally and culturally sensitive care within a youth friendly environment irrespective of where and by whom they are seen or treated; young people will also have a voice in the development, implementation and monitoring of services and programs within the Hospital.

RCH is providing the Centre for Adolescent Health with the opportunity to do in an acute care/medical setting, what they have been able to achieve in population health, community care, education and research, viz to develop a cutting edge, evidence-based clinical and research program in adolescent health. In recognising that special skills and insights are required, RCH Executive and senior staff are asking the CAH to coordinate a hospital-wide approach to this endeavour. Key outputs will include:

- Create a set of principles for the treatment of all adolescents in the hospital, promulgate routine psychosocial screening, support the role of 'adolescent liaison nurses', clarify referral pathways; expand the existing adolescent medicine consultation service; and strengthen evaluation and clinical research;
- Undertake training and capacity building with all relevant staff; and
- Work to establish a more integrated/collaborative model of care at inpatient, outpatient and community levels by working in partnership across RCH and linking more effectively with other stakeholder groups.

The envisaged Adolescent Model of Care in the new hospital, however, as articulated by the RCH executive and staff, is broader in its aspirations and scope. It includes the following key elements:

- A 'bigger picture approach' rather than 'too many little solutions', reflecting the desire for a more informed, coordinated and effective approach to the needs and issues of young people;
- Recognition of the potential benefits of the more flexible hospital design with centralised facilities and programs for adolescents;
- A hybrid inpatient model of care that bridges the medical/organ systems and developmental/adolescent oriented models, with *a dedicated adolescent ward* functioning as a critical mass for inpatients from which to support and promote 'best practice' adolescent care for all inpatients;
- Dedicated youth-friendly spaces with appropriate facilities and programs for adolescents across RCH with consideration of cohorted adolescents within sub-specialty areas;
- Endorsement of a wider *adolescent medicine consultation model* for inpatients and an *outpatient shared care model* in adolescent subspecialty clinics;
- Strong collaboration with RCH Education Institute and Department of Education and Early Childhood Development to build a hospital-wide culture and service inclusive of teaching and learning and strengthen the continuum of learning between the hospital, school and home;
- Strengthened peer-support, with a particular focus on enabling the Chronic Illness Peer Support (ChIPS) program to have a greater impact within the population of young people with chronic conditions;
- Expanded creative arts activity in support of a *positive youth development* approach;
- Culturally competent care for indigenous and refugee/new immigrant young people;
- A range of improvements in the delivery of outpatient clinical services provided by Adolescent Medicine, General Paediatrics and subspecialty departments;
- A greater focus on building the capacity of young people with chronic diseases to engage in a developmentally appropriate level of self management of their condition;
- A more organised approach to transition care via the development of a well articulated policy with built in accountabilities, innovative new facilities and programs;
- Better linkage between hospital and community based health and education services and programs, with referral pathways out to youth friendly community based services (eg following treatment of high risk young people in emergency department);
- Consistent with the extended age of achievement of common social milestones, extension of the age of young people to which the RCH

provides care to at least 19 years, with the recognition that within specific programs, the age extends into young adulthood;

- Stronger consideration of the health care needs of 18-25 year olds within the Victorian health care system.

How do we get there?

Major challenges include: addressing the need for cultural change (promoting a more positive view of young people and their needs); identifying and responding to education and training requirements for hospital staff; fostering closer working relationships among stakeholder groups; and seeking creative ways to lessen the distance/disconnect between current and proposed arrangements and what we know about best practice.

Potential payoffs and opportunities presented by the implementation of a new model of care include: enhanced clinical skills, improved referral pathways, better transition care, improved psychosocial screening and responsiveness, and health and wellbeing benefits for young people within and beyond the RCH.

Recommendations to the RCH Executive concerning the introduction of the Adolescent Model of Care (details provided in Main Report):

- (1) Shore up clinical leadership by the Centre for Adolescent Health: support measures to enable adolescent physicians to become more visible on the wards and more operationally involved with general paediatrics and subspecialty medicine; promulgate hospital-wide approaches for psychosocial screening of adolescent patients; provide team-based support for the newly appointed Deputy Director of Adolescent Medicine in his challenging hospital-wide role; provide a strengthened focus on evaluation and clinical research.
- (2) Resolve the issue of what constitutes 'best practice' inpatient care by embracing a hybrid model; this should include an identified adolescent ward as a critical mass that drives excellence in adolescent inpatient care, together with developmentally appropriate facilities and programs for adolescents, co-horted within general paediatric and subspecialty areas; embrace a culture and innovative practice inclusive of health, life-long learning, peer support and creative expression.
- (3) Improve the outpatient model of care, prioritising a multidisciplinary approach, and strengthening clinical services for high risk youth.
- (4) Establish an organisation-wide approach to transition care as a cornerstone of best practice with chronically ill adolescents being treated in a tertiary paediatric institution.
- (5) Develop a hospital-wide approach to professional education/capacity building in adolescent health and a culture that promotes and recognises the correlation between health, connection to learning and positive life trajectories.

- (6) Promote meaningful participation by young people via the creation and maintenance of a Youth Advisory Council (YaC).
- (7) Foster opportunities to build cooperative partnerships among stakeholder groups, in particular between Adolescent Medicine and Integrated Mental Health Service; resolve current turf issues surrounding the care of young people with eating disorders.
- (8) Identify milestones and capabilities in the implementation of the Adolescent Model of care to ensure that the developmental process is ongoing, and evaluate outcomes.

1. Background

There is a high demand for the Royal Children's Hospital Melbourne (RCH) to manage a wide range of young people with highly complex health care issues at all levels of care: as inpatients, outpatients and in the community.

The scope and purpose of the review of the Adolescent Model of Care is to:

- Map the current adolescent patient journey and identify any current issues;
- Consider best practice and evidence based care in relation to current practice (identify gaps);
- Develop a model of care for the treatment of adolescents (12 – 18 years) including inpatients (adolescent ward, and other wards including day medical), outpatients, peer support programs, transition, mental health and allied health services;
- Advise on the skills, competencies and training required by RCH staff to deliver the recommended model of care; and
- Monitor the implementation of the new model of care, both now and into the future, particularly in the transition to the new Hospital.

Among the ways forward, the Hospital Executive has proposed a realignment of priorities by the Centre for Adolescent Health to include a greater focus on RCH. Specifically, Adolescent Medicine & Adolescent Health Services (the clinical arm of CAH) is being asked to provide greater clinical leadership in hospital-based adolescent health care, to become more visible on the wards, and more operationally involved with general paediatrics and subspecialty medicine.

An Adolescent Model of Care Steering Group was established (meeting initially on 5th March 2009 and monthly thereafter) to advance the review process, liaise with the external consultant, and consider recommendations arising out of these deliberations for the provision of final advice to the RCH Executive. In March 2009 the CEO of the RCH engaged Clinical Professor David Bennett, Head of the NSW Centre for the Advancement of Adolescent Health, to undertake a review of the Adolescent Model of Care.

This report has been developed using a combination of RCH 'adolescent journey' findings and materials, interviews with current and past RCH staff, research evidence, published best practice standards, and expert consensus (See Appendix A). Warm appreciation is expressed to the many people consulted, for the candid and helpful manner in which they have shared their views and suggestions.

While the task is clearly a challenging one, there is firm commitment by all involved to seek change and improvement, and hopefulness in finding a constructive way forward. It is in this spirit that the report is being provided.

2. Where we are now?

The Royal Children's Hospital Melbourne (RCH) is the major children's hospital in Victoria, providing a full range of ambulatory and inpatient infant, child and adolescent health services, including mental health services and health promotion and prevention programs. While tertiary paediatrics also exists at Monash Medical Centre (which has an Adolescent Unit) and there are significant paediatric units at other hospitals, RCH has become a recognised leader in adolescent health care, research and training, both within Australia and internationally. This reputation clearly rests on the pioneering and ongoing work, leadership and advocacy undertaken by the Centre for Adolescent health.

2.1 A snapshot of the Centre for Adolescent Health

Adolescent clinics and an adolescent ward were established at the RCH in the early 1980s. The Centre for Adolescent Health (CAH) was established in 1991 'in order to help develop the evidence base around youth health and wellbeing and to provide leadership in adolescent health' (see Appendix B).

Organisationally, CAH has an overall Director (Prof Susan Sawyer), a Deputy Director of Adolescent Medicine (functionally clinical leader – newly appointed Dr Robert Roseby), a Director of Research (Prof George Patton), and other personnel in coordinating positions. There is a voluntary Developmental Board, made up of business people and other stakeholders which assists with fundraising, strategic development and relationship building roles.

CAH has evolved over the past 18 years to become a major academic 'centre of excellence' in Australia with a staffing of around 120 and a multitude of projects and activities grouped under three main arms of operation:

- (1) *Research*: main focus is on health risk behaviours and factors which protect young people from harm; success in attracting NHMRC and other major research grants and projects in partnership with prestigious international research groups (eg Prof Richard Catalano in Seattle, USA); an impressive track record in publications in influential peer-reviewed journals (including the recent inaugural Lancet series).
- (2) *Practice and Learning*: 'working collaboratively with communities in building the capacity of professionals and organisations to enhance the wellbeing of young people'; CAH offers postgraduate degrees in Adolescent Health and Welfare through the University of Melbourne - more than 350 post-graduate students from around Australia and the Region have been awarded the *Graduate Diploma in Adolescent Health and Welfare*.
- (3) *Adolescent Medicine*: includes specialist adolescent physicians and multidisciplinary staff involved who provide inpatient care at the RCH

(through the Adolescent Medicine unit), outpatients (at the Centre for Adolescent Health), and peer support (Chronic Illness Peer Support program known as ChIPS).

- (4) *High Risk Youth Health Services*: includes the Adolescent Forensic Health Service (funded by Youth Justice (DHS) to provide primary care, forensic services and health promotion to young people on custodial orders) and the Young People's Health Service (which targets highly vulnerable young people who are homeless or at risk of homelessness within the CBD (funded primarily by DHS as well as a smaller aliquot from the Federal Government and the RCH).

The responsibilities of the Deputy Director (a key player in the Adolescent Model of Care) include: providing clinical leadership and clinical governance at CAH and RCH, throughout inpatient and ambulatory services; working to ensure high quality, evidence based clinical services for young people by CAH and RCH; providing high level interface within CAH, RCH and the broader community.

CAH also makes major contributions to adolescent health policy at local, national and international levels and has strong links with national and international professional groups including: Royal Australasian College of Physicians (RACP); Society for Adolescent Medicine (SAM); International Association for Adolescent Health (IAAH); and World Health Organisation (WHO).

The importance of the international profile of CAH within the field should not be dismissed or ignored...It provides a tremendous boost for dedicated physicians trying hard to advocate for adolescent health in other hospitals and around Australia and the rest of the world. It also advertises RCH as a centre of excellence to the rest of the world. This role must not be lost. Dr Andrew Kennedy.

CAH acknowledges that a key challenge is a lack of funds for senior strategic and business development activities:

Too often this has meant that we have failed to capitalise on many of the potential benefits of our work beyond the specifics of the task itself. For example, we may publish excellent research, but it too often fails to influence policy. We may develop the evidence to inform approaches to teaching and training, but have failed to embed this into wider systems supporting teaching and training (1).

The RCH provides funds to run the Adolescent Medicine activities of the CAH which also receives some funding through DHS to support the management and leadership costs that accrue from it being larger in scope than simply a clinical

program. However, the majority of the Centre's research and its practice and learning activities are not funded by the RCH or through DHS funds.

2.2 The current adolescent patient journey

The adolescent patient journey at RCH, as part of the work of the *Adolescent Model of Care Steering Group*, has been comprehensively analysed. The inpatient pathway from admission to discharge and what happens to outpatient referrals are visually depicted in diagrams generated by the Service Redesign Unit. Thought-provoking 'affinity diagrams' accompany this material, outlining current and future challenges related to use of space, resources and system issues. At this point, a minority of adolescents arrive at 'youth friendly' destinations.

RCH also faces some age-range dilemmas:

- RCH has had a 16 year limit for new inpatients but is currently considering 19 years as the official cut off for transfer to adult care for certain cohorts of patients;
- Chronic Illness Peer Support (ChIPS) welcomes young people aged 12 – 25 years to participate in its activities, although the entry level is effectively restricted to 19 years;
- Adolescent Forensic Health Service (AFHS) has a 10 – 21 year range, as determined by the Victorian Government;
- Young People's Health Service (YPHS) is funded by DHS to provide services from 12 – 25 years.

In some instances these differences are appropriate, for example, where work with 18 – 25 year olds is in accordance with funding arrangements. However, such diversity in age ranges also reflects (and causes) confusion about how best to identify and respond to young people with health care needs. It should be noted that the American Academy of Pediatrics has recently extended the purview of Pediatrics to 21 years!

Current inpatient service model

The adolescent ward established by Dr John Court in the early 1980s was based on 'a chronic illness model', but 'gradually this has been extended to include all comers'. Ward 3 East has 22 beds and an occupancy rate of over 90%. Twenty-five per cent of all adolescent admissions to RCH aged 12 years and over are housed in Ward 3 East, of whom 14% are under Adolescent Medicine's bed card.

Any child over 10 years of age can be admitted to the ward, from all general and subspecialty medical and surgical units as well as directly from the emergency department. The majority of cases are admitted under general paediatrics and general surgery as well as certain subspecialties (particularly respiratory, gastroenterology, child development & rehabilitation). These teams do not necessarily consult with or refer their cases to Adolescent Medicine.

Eating disorders constitute around 25% of all inpatients on the adolescent ward (3E), approximately 6 beds; in 2008, of 314 admissions to the Adolescent Medicine unit, 80 were children and adolescents with eating disorders. In 2006 there was a major spike in eating disorder admissions. Regional funding arrangements have allowed a new funding model to be implemented over the past 12 months which has facilitated a more manageable number of patients. A weekly multidisciplinary meeting of Adolescent Medicine inpatients is held involving adolescent physicians, nurses, mental health professionals from the Integrated Mental Health Service (IMHS), the creative expressionist and music therapist. Review of the inpatient protocols has recently been undertaken as the service is moving to an approach based on Family Based Treatments where possible. While there is currently no day program, the new model of care supports the development of a step-down process eg via day care, which is currently limited by lack of funding.

Many adolescents - 86% of adolescent admissions overall - are housed on other wards including Neurology, Children's Cancer Centre, Burns Unit and others. Some staff, both on 3E and elsewhere, consider that 'adolescents on subspecialty wards are less well cared for' than on Ward 3 East.

A major strength of Ward 3 East is the 'skilled team of adolescent-oriented nurses' while outside of 3E, nurses tend to have 'little interest and skill' in dealing with adolescent patients (hence 'the challenge of maintaining adolescent nursing skill sets in the new hospital'). Another affirmation comes from Mental Health:

One advantage of 3E from the IMHP point of view has been the development of a partnership that shares management of complex co-morbid disorders. Being on a general ward under a medical 'bed-card' has also been less threatening for patients/parents and medical staff, than a dedicated psychiatric unit.

Ward 3 East accepts a predictable level of complexity and confusion, with different teams rounding at different times and having their own allied health staff. Most nursing staff 'enjoy the diversity' and in general do not want to cater for 'only highly complex cases', while others think the case mix is possibly 'too broad and diverse' and could 'live without some of the simpler cases' when they move to the New Hospital.

Adolescent Medicine is involved in case coordination of complex cases ('case management is something we do well') but there is potential for expanding the role. This could be achieved, for example, by monitoring the developmental and psychosocial needs of 3 East patients under other than adolescent physicians, eg at a regular multidisciplinary meeting, and/or introducing *adolescent nurse practitioners* or 'youth workers' with a range of generic responsibilities.

The Consultation and Liaison Service (part of the Integrated Mental Health Service) is readily consulted in relation to 'a clear mental health issue' and works in close liaison with Adolescent Medicine.

Patients come in under the Adolescent Medicine unit if the patient is of an appropriate age and there are clearly psychological/behavioural issues and/or there are multiple medical problems which require one unit to overview the problems; all appropriate patients are referred to mental health. Dr Andrew Court.

The RCH Education Institute is currently implementing a new model of patient and family centred education support, providing access to teaching and learning for every adolescent admitted to the adolescent ward.

"I have never seen so many teenagers engaged in learning on the ward, and especially in the learning space. It's great to see them all in there engaged each morning. Meagan Hunt, Music Therapist and ChIPS Program Worker.

Prior to this model there was no formal structure for in-hospital schooling (approximately ten years ago, in the context of short bed days and relatively empty classrooms, the Department of Education and Early Childhood Development (DEECD) closed schools in hospitals). Therefore educational input must be requested on an individual basis, an arrangement widely seen to be inadequate and ineffective.

(Hospitalised teenagers) just lie in their beds and seem isolated and bored...even when given laptops, they don't always use them. Jenni Jarvis, Director of Nursing.

Allied Health services impact on adolescent health care throughout the Hospital. However, while Play Therapy is provided for all age groups, there is no play therapist or Occupational Therapist specifically for adolescents, and physiotherapists 'may not have specific training to work with adolescents'. Similarly, there is a very highly regarded music therapist who works part time on the adolescent ward. Through the RCH, the Adolescent Medicine unit funds a full time recreation officer for the adolescent ward.

The involvement of young people in music and other arts programs '*engages them in their environment which leads to increased engagement with their treatment*'. Compliance, general behaviour and well being are seen to improve. This work, currently undertaken at a level well short of optimal, recognises the right that adolescents have to access recreation appropriate to their needs (2) and that social interaction with their peer group is vital at this stage of a young person's life (3).

General Medicine: Both Adolescent Medicine and General Medicine each have around 300 adolescent separations (12–18 years) per annum, representing 100% of discharges for Adolescent Medicine and 5% of discharges for General Medicine (Figure 1). General Medicine reports being ‘well supported by the mental health consultation-liaison team’ but having less direct involvement with the adolescent medical team: ‘*While admission policies vis-à-vis General Medicine and Adolescent Medicine works well, some fine tuning could occur*’ (comment by Mike South); currently there is no protocol indicating which admissions should go to Adolescent Medicine or General Paediatrics. However, all adolescents presenting with drug overdoses (mostly paracetamol) are admitted under Adolescent Medicine and there is interest in a review of the medical management of adolescents with poisoning being undertaken.

Neurology: Neurosciences has multiple programs, a good relationship between neurology and neurosurgery and multidisciplinary approaches. Three per cent of all adolescent inpatients are on the neurology ward, some of whom are sent to Ward 3 East, eg long-stay kids with muscular dystrophy. While staffing includes ‘wonderful nurses’ neurology would like to see the expertise of Adolescent Medicine ‘coming up to neurology’.

Mental health services: The Integrated Mental Health Program consists of: Banksia Adolescent Psychiatry Unit (WGH); Hospital Consultation & Liaison Service – with ED MH clinicians; Hospital Psychology Service; and Academic Child Psychiatry Unit. The Integrated Mental Health Service (IMHS) Director commenced at RCH in February 2007 and has set out to create ‘a coherent model of mental health care supported by specialist skills’. An FTE of 110 staff including six psychiatrists work at RCH in relation to inpatient care (but as required by DHS regional program funding constraints, ‘there is no psychiatry staff to provide outpatient follow-up for kids with co-morbid conditions’). An inpatient unit (Banksia House) at Footscray has 12 beds for 12 – 15 year olds (which will return to be part of new RCH in 2012). There are other challenges for outpatients due to different criteria for various programs (eg Orygen).

Current outpatient service model

Hospital outpatient clinics (See Figures 2, 3 & 4):

There are 45,245 adolescent outpatient attendances

- Orthopaedics sees 6749: 15% of all adolescent attendances, and representing 38% of their workload.
- Adolescent Medicine sees 5389: 12% of all adolescent attendances, and representing 100% of their workload.
- General Medicine sees 4312: 9.5% of all adolescent attendances, and representing 18% of their workload.

Other than in the adolescent outpatient clinics run by CAH (as described below), young people are generally mixed in with younger children. There is a recognised paucity of psychosocial assessment and support incorporated into general and subspecialty clinics. Gastroenterology, for example, has a focus on an 'ambulatory care model' but sees a pressing need for 'more psychosocial support'. They will refer to mental health if they identify or suspect frank depression or if there is a psychological crisis but in general they 'have difficulty with psychosocial problems' and want 'better connections'. A valued monthly gastroenterology clinic conducted at CAH by Tony Catto Smith (abdominal pain, diagnostic questions re feeding disorders, IBD) has had to cease recently due to high gastroenterology workload at RCH.

Adolescent Medicine

Outpatient clinics under CAH's auspice are currently based in William Buckland House where morning and afternoon sessions are held 5 days per week. In 2007-8, there were 6054 bookings with 5044 attendances.

While there is a broad range of cases, more than 50% are young people with eating disorders, who also make up the majority of contacts. The *Multidisciplinary Anorexia Nervosa Assessment Clinic* has been running for over 12 months, involving paediatricians, Dr Andrew Court from the Consultation-Liaison Team, two clinicians from CAMHS, an eating disorder nurse and dietician. An outpatient ED meeting is held on Tuesdays 12–1 pm. A treatment clinic is being set up on site with CAMHS workers using Family Based Therapy (Maudsley Approach) in conjunction with paediatricians providing medical monitoring.

Other clinic sessions cater to individual teenagers or families depending on the clinician and need; joint work involving medical and psychosocial staff is not routinely undertaken. The clinics focus on obesity, chronic fatigue syndrome, gynaecology (child and adolescent), and other more general medical and behavioural presentations including depression and school related issues. A high risk nurse based clinic has recently been established at the CAH, staffed by YPHS nurses.

While the Centre is clearly responsive to demand, guidelines regarding intake could be made clearer. On Wednesday mornings 8.30 – 9.30 am there is an Education Meeting for ongoing professional development (once a month this is a Clinical Quality & Safety Meeting with a communication focus). There is an awareness of the need for regular multidisciplinary meeting to review, for example, the more complex cases.

Specialists who work in the outpatient clinics use a holistic approach to patient care in which young people are treated in a respectful, confidential and non-judgmental way. Clinics operate as a private practice with multiple clinicians doing one or 2 clinics a week, few being on site more than half time. While this

approach has allowed an increase in capacity by paediatricians over the years, sessional arrangements make it difficult for medical staff to be appropriately involved in strategic planning, review and audit within CAH, let alone to play a more meaningful role within the RCH more widely. This issue is well recognised within the CAH.

High Risk Youth Health Services (community-based service model):

Clinical services under the auspices of the CAH focus on young offenders and homeless young people:

- Young People's Health Service (YPHS)
- Adolescent Forensic Health Services (AFHS)

Young People's Health Service (at Frontyard, in the CBD) provides an off-site, free and confidential service for young people, addressing the range of health issues from skin problems and aches and pains to serious infections (eg hepatitis B and C), drug and alcohol and mental health problems. A co-location model enables young people to also access assistance with housing, Centrelink, legal issues, job placement and employment training. A weekly clinic at CAH has recently been initiated to improve access to specialist resources and to better coordinate care for young people at risk at the RCH. This service is primarily funded by the State government program grant.

Adolescent Forensic Health Service delivers services to young offenders under both custodial and community orders through a multidisciplinary staff team of 25.6 EFT - nurses, medical officers, psychiatrists, psychologists, social workers, dual diagnosis clinicians, health promoters, criminologists and creative arts therapists. Services include primary health care, mental health care, offence specific programs (including sex offending and violence), health education and promotion programs, alcohol and other drug treatment, dual diagnostic care, clinical counselling and group based interventions to young people accessing the service.

AFHS is a unique multidisciplinary service that offers a holistic approach to health care. We treat every young person as an individual, understanding they have different and often complex needs. We work with young people to improve their health, reduce risk taking and offending behaviour and help them take responsibility for their lives (4).

While all young people in detention are patients of the RCH and their files are maintained on site, the work undertaken by AFHS is not recognised or included in RCH statistics and therefore invisible in hospital reports. The same is true for the important work undertaken by the YPHS.

Given the high level of crossover between AFHS and YPHS - the same cohort of high risk youth and similar approaches (primary health care, health promotion,

mental health counselling etc) - the two services have recently been organisationally joined within the one CAH program known as 'High Risk Youth Health Services'.

3. What do we want to be?

Best practice in adolescent health/medicine is largely based upon a developmental model of care, the interpersonal skills of practitioners, and a focus on health, education, wellbeing, quality of life and function. The adolescent physician thinks as much about the person with the illness in the context of family, school and community as they do about the illness itself.

In the new Adolescent Model of care, a young person admitted or referred to the RCH, whether for medical, surgical or psychiatric/psychosocial reasons, will receive developmentally and culturally sensitive care within a youth friendly environment irrespective of where and by whom they are seen or treated; young people will also have a voice in the development, implementation and monitoring of services and programs within the Hospital.

RCH is providing the Centre for Adolescent Health with the opportunity to do in an acute care/medical setting, what they have been able to achieve in population health, community care, education and research, viz to develop a cutting edge, evidence-based clinical and research program in adolescent health. In recognising that special skills and insights are required, RCH Executive and senior staff are asking the CAH to coordinate a hospital-wide approach to this endeavour. Key outputs include:

- Create a set of principles for the treatment of all adolescents in the hospital, promulgate routine psychosocial screening, support the role of 'adolescent liaison nurses', clarify referral pathways; expand the existing adolescent medicine consultation service; strengthen evaluation and clinical research;
- Undertake training and capacity building with all relevant staff; and
- Work to establish a more integrated/collaborative model of care at inpatient, outpatient and community levels by working in partnership across RCH and linking more effectively with other stakeholder groups.

The envisaged Adolescent Model of Care in the new hospital, however, as articulated by the RCH executive and staff, is broader in its aspirations and scope. It includes the following key elements:

- A 'bigger picture approach' rather than 'too many little solutions', reflecting the desire for a more informed, coordinated and effective approach to the needs and issues of young people;
- Recognition of the potential benefits of the more flexible hospital design with centralised facilities and programs for adolescents;
- A hybrid inpatient model of care that bridges the medical/organ systems and developmental/adolescent oriented models, with *a dedicated adolescent ward* functioning as a critical mass for inpatients from which to support and promote 'best practice' adolescent care for all inpatients;

- Dedicated youth-friendly spaces with appropriate facilities and programs for adolescents across RCH with consideration of co-horted adolescents within sub-specialty areas;
- Endorsement of a wider *adolescent medicine consultation model* for inpatients and an *outpatient shared care model* in adolescent subspecialty clinics;
- Strong collaboration with RCH Education Institute and Department of Education and Early Childhood Development to build a hospital-wide culture and service inclusive of teaching and learning and strengthen the continuum of learning between the hospital, school and home;
- Strengthened peer-support, with a particular focus on enabling the Chronic Illness Peer Support (ChIPS) program to have a greater impact within the population of young people with chronic conditions;
- Expanded creative arts activity in support of a *positive youth development* approach;
- Culturally competent care for indigenous and refugee/new immigrant young people;
- A range of improvements in the delivery of outpatient clinical services provided by Adolescent Medicine, General Paediatrics and subspecialty departments;
- A greater focus on building the capacity of young people with chronic diseases to engage in a developmentally appropriate level of self management of their condition;
- A more organised approach to transition care via the development of a well articulated policy with built in accountabilities, innovative new facilities and programs;
- Better linkage between Hospital and community based health and education services and programs, with referral pathways out to youth friendly community based services (eg following treatment of high risk young people in emergency department);
- Consistent with the extended age of achievement of common social milestones, extension of the age of agreed cohorts of young people to which the RCH provides care to at least 19 years, with the recognition that within specific programs, the age extends into young adulthood;
- Stronger consideration of the health care needs of 18-25 year olds within the Victorian health care system.

It should be noted that the Centre for Adolescent Health 'strongly supports the model being proposed, recognises the importance of actively engaging a broader range of RCH staff to further develop this model to ensure its success, and is committed to actively working towards a more integrated approach to adolescent health across RCH'.

3.1 A snapshot of the New Hospital

The new hospital has five floors and an innovative, contemporary design based on international trends and developments. Largely driven by concerns about infection control there is an increasing move towards inpatient hospital accommodation being provided in single rooms. In the new RCH, beds are 'acuity adaptable', the overall concept being 'a room is a room is a room'. *"We hope we've got flexibility without compromise on quality of care."*

Inpatient facilities: An *inpatient unit* consists of 30 beds (24 single rooms and 3 double rooms) in 'pods' of 12/12 and 6, with 2 X 30 bed units (ie 60 beds) co-located on one floor. Each pod has a staff base with line of sight to each room. Supporting this layout is one interstitial workstation between every two inpatient rooms for direct supervision of the patient. For each 30 bed inpatient unit, there are two treatment rooms and two interview rooms, a central workroom and reception point. This is supported by a separate suite of administrative workstations/offices for staff.

On each floor there is a play therapy area with *a corner set aside for adolescents*. On one floor there is a *shared recreation area* accessible for adolescents from throughout the Hospital (excluding patients from mental health, which has its own facility), encompassing a lounge/living room, a games room, an internet café, a 'wet area' (for messy creative activities) and a disabled toilet. It appears there is the potential for these activities to be separate as some are social (games) and some private (internet and lounge – to catch up with friends).

The *Mental Health Unit* consists of 16 beds with four adjacent 'co-located beds' for adolescent mental health patients with high physical care needs. These co-located beds can be locked at either side depending on need. The Unit includes its own recreational space and a school classroom. (Note: There is a 9 bed unit adjacent to Mental Health which could be assigned to Adolescent Medicine, although a larger designated would be preferable.)

The *Starlight Room* on the Ground Floor is a spacious area including a bean bag cinema that the Starlight Foundation will fit out and run (as per their formal proposal). Starlight has also offered to run programs in the adolescent recreation facilities.

'Outpatient neighbourhoods': There are 60 consulting rooms based on the concept of outpatient 'pods' (groups of rooms) for flexible, shared usage.

In the new RCH, there is a shared consulting space for Adolescent Medicine, Community Child Health and Mental Health which includes a designated waiting area for adolescents. This space is adjacent to the Paediatric Forensic Health Service (PFHS) and the Gatehouse program with a shared area for groups & screening observational activity.

An interpreter reception/service will be located at the entrance to outpatients, while others can be booked into outpatient clinics. This is seen as limited in terms of properly addressing *the needs of indigenous and refugee/new immigrant children and young people* and is part of a broader operational issue for the Hospital in terms of cultural sensitivity and cultural competence (5, 6).

A central open area, bright and spacious, has a section identified as a 'youth friendly space' and in other waiting areas consideration may be given to 'age appropriateness'. Overall, the design/decoration/facility needs of different age groups require further deliberation (see Appendix C).

3.2 An opportunity to strengthen links with community-based services

The hospital's service plan is currently under review as part of strategic planning for the new hospital. There are some concerns about the broad scope of services provided in some specialties at RCH (eg in General Medicine, 'patients come from all over Victoria including those requiring primary and lower level secondary care that would be better dealt with at local hospitals with paediatric services').

The strategic plan will therefore include 'what to cut'. For example, RCH is looking at its primary catchment area as a 10 km radius for primary health care, Victoria-wide for tertiary care. However, 'the approach to restructuring referrals is not just a contraction; we need to promote networking outside the hospital' – an issue having relevance to linkage with and support of community based youth health services (taken up in the next section).

4. How do we get there?

Moving between where we are now and what we want to be presents some significant challenges, including:

- addressing the need for cultural change (promoting a more positive view of young people and their health and developmental needs);
- identifying and responding to education and training requirements;
- fostering closer working relationships among stakeholder groups; and
- seeking creative ways to lessen the distance/disconnect between current and proposed arrangements and what we know about best practice.

Recommendations to the RCH Executive concerning the introduction of the Adolescent model of care include:

(1) Shore up clinical leadership by the Centre for Adolescent Health

"...it is essential RCH delivers best practice in adolescent care across all wards of the hospital as has been achieved by the Centre in the community setting". Dr Christine Kilpatrick, CEO

As succinctly summarised in Prof Susan Sawyer's briefing paper, 'What constitutes an 'adolescent friendly' children's hospital?' (Appendix B):

'Best practice' elements of an adolescent model of care encompass: quality of care with an emphasis on 'integration and collaboration'; developmentally appropriate health care supported by appropriate professional skill sets; developmentally appropriate spaces; consumer engagement and the need for an active youth advisory council.

The Centre for Adolescent Health, already cognisant of what needs to be done, is willing to rise to the challenge. In anticipation of the move to the new hospital in 2011, CAH is being asked to drive a range of initiatives in the new Adolescent Model of Care. Primarily through the *Adolescent Medicine* unit (the RCH focused clinical arm of the CAH), the CAH will provide clinical leadership with a view to making hospital-based clinical care for adolescents and their families stronger, more integrated and better coordinated. Primarily, this could be undertaken via implementation of an expanded adolescent medicine consultation role, fostering a process that prioritises patients who do not access adolescent focussed programs, undertaking training and capacity building activities (addressed further below), as well providing a stronger focus on evaluation and clinical research (with the assistance of the Director of Research, CAH, Professor George Patton).

Implementation opportunities include:

- Becoming more visible on the wards and more operationally involved with general paediatrics and subspecialty medicine (for example, by giving regular grand rounds, attending and providing input at general paediatrics and certain subspecialty meetings);
- Promulgating psychosocial assessment via the HEADSS exam (7-9), a good bridging/delineating assessment instrument for determining an adolescent's risk profile (but not a 'tick box' exercise; responding to the information gained requires developmental expertise); exploring the potential for internet based approaches in its use with adolescents hospital-wide;
- Better supporting the Adolescent Medicine & Adolescent Health Services arm of CAH, in particular considering team-based support for the newly appointed Deputy Director (the experience of a previous 'clinical leader' included frustration, exhaustion and burnout: *'...one person among a sea of part time clinicians can only do so much and gets tired'*.)
- Identifying opportunities for clinical research to inform future best practice: an example of past work is the research undertaken around psychosocial screening; of current and evolving research - that associated with the Eating Disorders Program which will unfold over the next several years; other potential projects could better link Adolescent Medicine and General Paediatrics...

Clearly the Centre for Adolescent Health will not be able to do this alone. Other departments, with the support of the Hospital Executive (and perhaps monitoring by the Steering Committee), must be willing to both embrace the relationship with the CAH, and contribute to an upgrading of service delivery where needed at all levels. Potential obstacles include: resistance to change within the organisation; lack of 'buy in' by medical and other professional staff; disagreement about aspects of the model of care; and professional competitiveness between disciplines.

While welcoming and embracing this set of challenges (and others), and fully supporting the model being proposed, CAH fears the potential consequences of further stretching its existing resources, believing that opportunity costs could lead to a reduction in its important academic and advocacy roles. It would indeed be unfortunate if this body of work, that has been so effective in moving the field forward, both in Australia and beyond, were to be compromised.

(2) Resolve the issue of what constitutes 'best practice' inpatient care by embracing a hybrid model consisting of an adolescent ward plus...

The evolution of hospital design across the 20th Century reflects a shift in healthcare philosophy from what has been described as a *system empowerment paradigm* to a *patient empowerment paradigm*. Hospitals have changed from being large institutional structures dominated by function and medical process, to being environments oriented around patients' needs and wellbeing (10).

This trend has relevance to the placement of adolescent patients in the new hospital, an area of controversy in developing the Adolescent Model of Care.

While in practice the more simple cases do not routinely make it into the adolescent ward where the more complex cases are prioritised, a clear rationale for an 'adolescent ward' (along the lines of Ward 3 East) is being sought by the CEO, whose desire is to ensure best practice in adolescent health care across RCH.

- Nobody would question that NICU is the best hospital environment for a sick neonate (as well as for nursing staff and the hospital), with localisation of all necessary equipment and expertise; a skilled neonatal nurse can sense a subtle change in condition and respond to it.
- A nurse with adolescent skills will equally have the clinical skills to identify health and developmental concerns and, with assistance, know how to respond. They are more likely to like adolescents (the substrate they're working with) which makes them an important part of treatment - staff who don't like adolescents should not work with them (just as a surgeon who doesn't like blood shouldn't do surgery).

Maintaining and building staff skills in working with adolescent patients (especially nursing) is a critical issue for the Hospital. Dr Andrew Kennedy articulates the argument as follows:

Australia arguably leads the world in adolescent inpatient care in children's hospitals with large dedicated adolescent wards in Sydney, Melbourne and Perth...The nursing expertise in particular will be lost, I fear, if adolescents are dispersed. They provide a wealth of experience in managing, in a developmentally appropriate way, adolescents with a variety of medical, surgical and psychological issues. Some adolescents will need to be on their organ specific ward, eg oncology, cardiology. The pool of senior nurses on an adolescent specific ward can then provide support and training for nurses on these other wards...

The recently released *Standards for the Care of Children and Adolescents in Health Services* (11) states that ‘...ideally, adolescents should only be admitted to a designated adolescent area’, a recommendation echoed in numerous other policy documents (12, 13, Appendix C).

An adolescent ward offers a range of generic benefits (11-15):

- Enables consideration of developmental needs alongside illness management
- Facilitates ‘positive youth development’ in hospital via skilled and caring staff and through the provision of supportive programs and activities (*positive youth development* includes the provision of opportunities, experiences and support to build personal strengths and assets necessary for positive development, irrespective of disease)
- Respects adolescents’ natural desire to be housed with their own age group rather than within specialty based areas
- Facilitates an evidence-to-action approach to considering the needs, views and preferences of young people and involving them in decision making about their health care
- Avoids child protection concerns/co-location issues with younger children
- Represents a therapeutic milieu for teenagers with physical and co-morbid mental health problems (eg teenagers with eating disorders and other complex chronic illnesses) and enhances self management.
- Is ‘appropriate for teenagers with changing needs during recovery phase of hospitalisation’ or for coordinated rehabilitation-type admissions
- Facilitates transition care and links with community services
- Ensures maintenance of adolescent nursing skills and facilitates house-staff training

We are still some way away from a time when the specific health needs of adolescents and young adults will routinely be recognised by health professionals. Until that time, a dedicated adolescent ward provides a focal point from which a hospital can promote best practice in adolescent health. Delivery of effective health care and training of junior medical and nursing staff are much easier if there is a critical mass of patients in one area and the relevant expertise on hand. Further, if tertiary children’s hospitals do not recognise and support the needs of this age group, there will be less incentive for general hospitals providing paediatric and adolescent health care to do so.

Specialty based services (eg oncology, neurology, burns) are, on the other hand, a fact of life in a major children’s hospital. As stated in a recent report on hospital services for young people in Scotland (12): (specialty based services) ‘reflect the desire to ensure that care is led and provided by those with appropriate expertise and is also seen to offer organisational efficiency through clustering patients, and the staff caring for them, in a single area. Such an arrangement does, however, *focus largely on the patient’s clinical condition rather*

than their wider needs as an individual – an issue particularly relevant to young people who find themselves cared for alongside...very young children’.

Recurring or prolonged admissions to an organ system-based ward where the disease (diabetes, CF, IBD) is repeatedly emphasised while the adolescents themselves are secondary, can lead to failure to identify the breadth of health and developmental concerns affecting the young person (eg significant school absence, social isolation, mental health concerns, drug use) that in turn can compromise their health through, for example, poor adherence.

At a more personal level, this comment by an RCH parent captures the essence of the concern:

I have found that, although the level of medical care has been excellent throughout the hospital, on wards other than the adolescent unit, it seems that some of the emotional and mental needs of my son have not been met. This is not to say that he has been neglected in any way, but more to point out that the adolescent unit and staff have had more experience with the 13 to 18 year old age group. This age group is very challenging and need more access to staff and programs designed for their needs. Noelle Duits.

Single rooms may address the desire young people often have for privacy, but they may also hinder opportunities for redressing social isolation that is a common feature of young people with chronic disease. Such socialisation can equally have the advantage of preventing the pattern of withdrawal and depression that can accompany periods of ill health and can be aggravated by isolation (12).

Practical realities in a single room environment:

- Privacy needs will be met (eg on ward rounds, showering and toileting)
- Developmentally appropriate programs & activities can be provided on site or at strategic locations elsewhere (that latter requiring that adolescents travel to possibly distant locations)
- Family Centred Care has both advantages and limitations (eg there may be no family, a too busy family, an ‘awful family’).

Options and opportunities

The ‘best practice’ challenge with inpatients, therefore, is to equalise the focus on the ‘illness’ and on the adolescent with the illness, ie integrate and strengthen the two approaches (organ system-based and developmental), ensure that the necessary skill sets are available (medical and allied health; team skills), and create nurturing environments for adolescents where positive youth development is promoted, irrespective of the reason for admission and where they are managed within the hospital.

It is anticipated that Adolescent Medicine will continue to admit a diverse range of patients under their own bed card. Also, for the reasons stated above, they will continue to support adolescent nursing staff in their desire to retain the broad based skills and interests pertaining to their current work on Ward 3 East. Considerations in regard to ward arrangement for cohorted adolescents:

- Based on longstanding experience in Ward 3 East and demonstrated best clinical practice in hospital-based adolescent health care, the ideal scenario would be the inclusion of *a mixed ward of at least commensurate or ideally, larger size* in the new hospital. This option has strong support among Steering Group members including Family Advisory Council representatives and the young people consulted.
- An opportunity exists for cohorting *adolescents with eating disorders and other complex conditions such as psychosomatic disorders* in a 12 bed pod adjacent to the mental health unit (on the other side of the flexible/co-managed 4 room pod for high dependency patients) or, as at present, medically unstable eating disorder cases undergoing re-feeding could remain co-located with undifferentiated admissions, including teenagers with acute illness or injury, overdoses and behaviour problems. In both situations, nurses need to be specifically trained in how to look after patients with eating disorders and other complex chronic illness, including how to support each other! A challenge with this arrangement of cohorting together the most complex patients the difficulty this could lead to in retaining quality nursing staff due to the burden of the patient load.
- For *acute undifferentiated medical cases* (often shorter stay/less complex) admitted directly under Adolescent Medicine, a case can be made for grouping such patients in a 12 bed pod near General Medicine. This would have a range of potential benefits such as: forging closer links with general paediatricians (fostering shared care arrangements and facilitating house staff training), maintaining/extending relevant nursing skill sets in different sites rather than only in an 'adolescent ward', and facilitating collaborative research.
- For *adolescent inpatients in subspecialty areas* (including surgery), given the different cultural/structural environment of the new hospital, mini-pods of 4 rooms could be used when needed (a model similar to that used in some General Hospitals treating children and adolescents), although as with current practice, the admission of those who don't need specialist nursing or technology would also suggest they could be managed within a larger adolescent ward.

As noted above, the four *mental health co-located beds* are earmarked for adolescent patients with co-morbid mental health and medical problems - a small number, given the likely caseload of such presentations. Advocacy for these particular beds came jointly from IMHS and the CAH. While it would be most appropriate for Adolescent Medicine to be prioritized for their use and it is currently assumed that this will be the case, three issues need to be resolved, as outlined in the IMHP submission to the Steering Group:

- Which patients will be given priority in this special area, ie what will be the criteria for admission?
- What will be the functional coordination and arrangements for integrated care, with Adolescent Medicine and possibly other departments
- What is the optimal staffing?

The manner in which these issues are sorted out, and the decisions finally taken, will impact on the future relationship between Adolescent Medicine and IMHS.

In all these scenarios, there is a need to *cohort adolescent nursing skill sets*. The concept of 'adolescent liaison nurses' who could function peripatetically around the hospital (like Clinical Nurse Consultants at The Children's Hospital at Westmead in Sydney), has been proposed; 'youth workers' could also play a helpful role in supporting adolescent inpatient health care hospital-wide.

Another challenge here is to identify the 'adolescent at risk' anywhere within RCH, irrespective of reason for admission. Possible mechanisms include promulgation of routine psychosocial assessment for inpatients (as mentioned above) and a review and clarification of referral pathways to Adolescent Medicine as part of an expanded *adolescent medicine consultation model*. In this context, the instigation of a more integrated system of care for inpatients has been proposed, *linking Mental Health, Adolescent Medicine and Social Work*, together with the granting of increased nursing authority to refer adolescents for formal psychosocial assessment.

Education and creative arts programming: The quality of the inpatient experience for young people, beyond the nature of their physical surroundings and the developmental sensitivity of staff, is largely dependent on what there is to do. The challenge here is 'to embrace a culture and innovative practice inclusive of health, life-long learning, peer support and creative expression'. Adolescents in hospital need better access to school education, as encapsulated in the vision of Glenda Strong, Director, RCH Education Institute:

If we were a school, we would have access to resources, programs and support. The Education Institute plans to work with the Department of Education and Early Childhood Development to establish, in the new hospital, a 'de-schooled school' featuring vibrant and interesting, developmentally appropriate learning spaces with internet access.

Adolescents with chronic conditions also need access to peer-support. There was strong support from the Steering Committee for enhancing the role of the ChIPS program to make it more accessible to a larger number of adolescents.

We have never met anyone from ChIPS, so yes we would like to see this statement come to fruition. Suzanne Emery, Parent of an RCH patient.

Adolescents also need opportunities to participate more readily in music and other creative arts activities (16-18). Providing developmentally appropriate opportunities for experiential learning, personal growth and empowerment, through a range of creative arts and living skills activities in a peer group environment, epitomises the *positive youth development* approach to young people in hospital. To the greatest extent possible, these interventions should be taken up and enhanced as integral aspects of the Adolescent Model of Care.

(3) Improve the outpatient model of care, prioritising a multidisciplinary approach, and strengthen clinical services for high risk youth

Centre for Adolescent Health: The following recommendations draw largely upon those made in a 2005 review of clinical services (19):

- Strengthen 'core adolescent medicine' via a reduction in the number of clinicians currently working in the clinics (ie fewer doctors doing more sessions), diversify responsibility for the training of fellows and junior medical staff, and strengthen the involvement of allied health staff.
- Consider the introduction of an intake service
- Introduce a number of dedicated clinics operating holistically with allied health professional and clinical staff
- Introduce a multidisciplinary meeting to review complex cases as a quality assurance activity (to bring general outpatient services at CAH into line with the relative sophistication of the current eating disorder model)
- Strengthen integration across all areas of CAH with all team members being encouraged to become involved in research and education programs
- Improve and coordinate funding opportunities to allow for further development of clinical programs.

Hospital based adolescent clinics

"Young people frequently report finding the design and content of waiting areas largely focussed on the needs of younger children...In practice the pattern of outpatient provision for young people may be as important as the environment. Depending on activity levels, and also other issues arising from the management of transition, consideration should be given to providing some clinics specifically for young people. In such circumstances the ethos and approach adopted can be better tailored to their increasing maturity and emerging independence and issues

such as clinic timing can be organised to minimise educational disruption – a key issue for those with chronic conditions requiring frequent attendance” (12).

- Promote the concept of *adolescent subspecialty clinics* (adolescent cohorts within general and subspecialty clinics) by grouping adolescent patients on certain clinic days, eg cystic fibrosis, renal disease, diabetes; incorporate preparation for transition.
- Create opportunities for the involvement of an adolescent physician playing a secondary supervision role or seeing patients alongside the sub-specialist; this shared care model is ‘not hard to organise and everyone benefits’
- Realign expectations to include longer consultations, raise developmental awareness among clinicians, and implement psychosocial history taking as a routine element of assessment and care (as developmental expertise grows within subspecialties, this intervention would be time-limited)
- Explore ways of securing increased social work support for outpatient clinics.
- Establish a group of clinicians to review outpatient referral pathways, including a potential role for Adolescent Medicine as ‘first port of call’ with certain types of cases (eg those more clearly requiring bio-psychosocial assessment and management).

Caring for ‘most at risk adolescents’:

- Review the adolescent health issues that the hospital currently focuses on in relation to the needs of the community to ensure best use of available resources
- Identify and create internal opportunities for the integration of community-based programs across RCH departments, thus enabling AFHS and YPHS to become more operationally included in the Adolescent Model of Care
- Create a specific pathway for the assessment and care of young mothers with babies in hospital, a group often at high risk
- Provide expert psychosocial screening for the 2-3 high risk young people who present to the Emergency Department each day with accidental injury, self harm, substance abuse or other acute health or behavioural problem; while IMHS picks up on suicide attempters, the broader health risk issues in this group are not addressed.
- Take up the challenge of accessing and treating the broader range of high risk kids (including but not only those presenting to RCH), drawing upon the expertise residing within AFHS and YPHS, and advocate for joined-up clinical service delivery
- Consolidate and expand CAH’s role in the care of the ‘most at risk adolescents’ (eg adolescents in out of home care) by developing the capacity and skills of the service sector to meet their needs, including the development of models for liaison with other health, education and community services involved with this group (20).

(4) Establish an organisation wide approach to transition practice.

To understand transition, we must understand adolescent development. This development encompasses a broad range of changes, many of which seem unrelated to healthcare transition. However, these changes all are linked together to create a competent adult who will be able to thrive in the adult healthcare system...Promoting healthy development in adolescents will enhance transition from childhood to adulthood and from paediatric to adult care (21).

While transfer/referral to adult services is sometimes undertaken without the preparation associated with sound transition care practice, in general, 'RCH experiences difficulties in moving kids on' (eg those needing cranio-facial and plastic surgery, cardiac surgery) and transition is seen by the CEO and others, as 'a problem needing to be addressed by a programmed approach'. As noted above, new admissions to the RCH are not accepted over 16 years of age, a policy out of kilter with the developmental and health care needs of sick and injured adolescents (22). Efforts are afoot (in NSW as well) to limit costs by restricting intake to a children's hospital in this way which, without careful discussion with adult colleagues, may not be the most effective approach.

By RCH recently considering an official cut-off at 19 years for certain cohorts of patients, the RCH may set an example for other children's hospitals to follow in this aspect of transition care. However, the adolescent health field has major concerns over the fate of older adolescents and young adults with chronic and disabling conditions, a group for which the adult health system appears to have little empathy or expertise. In this regard it is pleasing to see that the RACP is committed to providing training in adolescent health to adult medicine trainees as well as those in paediatric medicine. The principles of good transition to adult care practice are well described (22-25).

A true transition process as defined by 'the planned, purposeful movement from child-centred to adult-oriented health care systems' with preparation, education, and embedded in an adolescent health care model is currently not generally in place at RCH. Sarah McNee, Transition Coordinator.

In addition to the appointment of a full-time Transition Care Coordinator, the RCH has established a Transition Advisory Council and developed a Transition Strategic Plan. Investment in evaluation of the outcomes of young people transferring to the adult health sector is also encouraged. A slate of highly appropriate recommendations, as presented to the Adolescent Model of Care Steering Group, should receive careful consideration:

- Negotiate with relevant stakeholders, including DHS to increase the arbitrary numerical overage cut off to 19 for certain cohorts of patients

- Develop a transition policy and an evidence-based transition model of care
- Undertake an adult services gap analysis for specific conditions
- Establish Key Performance Indicators (KPIs) within divisions & departments with clearly stated responsibility/accountability for actions ('with policy and programmatic support from the transition Coordinator')
- Identify a 'transition budget' with dedicated departmental funding for transition coordination
- Develop an adolescent health e-learning package to up-skill clinicians in adolescent health care
- Support existing and develop new adult services including a stronger focus on evaluation of health outcomes and training of adult providers
- Create 'a dedicated, purpose built area for the promotion, facilitation and future growth of transition practice at RCH' (incorporating a range of innovative, youth-engaging facilities).

It is worth noting that leadership in the issues surrounding transition to adult health care internationally has come from the field of Adolescent Medicine.

The Family Advisory Council strongly endorses the above measures in the context of promoting improved coordination of care for adolescents with complex chronic illness (an area of evident weakness in the hospital at large) (26). Further, in the words of Prof Susan Sawyer, *'good transition care also needs to focus on supporting the changing role of families and young people around self management of their condition in adolescence (and) working towards a greater capacity for self management and more independent care as young people mature'*.

(5) Develop a hospital wide approach to professional education and capacity building in adolescent health.

Children's hospitals are a key site for both basic and advanced training in adolescent health (13). What is required includes: *'knowledge of adolescent development, competence engaging young people in their health care, skills in psychosocial history taking, promotion of transition to adult care, and knowledge of community based services. Young people with complex developmental, behavioural or mental health problems equally require paediatricians with the competence to address these concerns'* (27).

Paediatricians 'want and need training in adolescent medicine'. As most adolescents on Ward 3 East and all adolescents on other wards are under the care of general and subspecialty paediatricians (medical and surgical), 'senior medical staff would benefit from awareness raising/training re adolescents' needs'. This sentiment is well expressed by Dr Zoe McCallum:

I was concerned that, as a General Paediatrician who has been a clinician at RCH for 12 years and sees approx 50% adolescents/young people in my 4 clinics a week and on a 20 patient ward round (usually only 10% adolescent inpatients), I still feel that I only just know how to touch the surface of a consultation with a young person. In fact, the time I spend facilitating CAH Staff in teaching HEADSS screening to my own medical students (completing their Child and Adolescent Health term at RCH) is the only form of professional development I feel I get and I really value that, both as a refresher and a point of contact with clinicians who have true expertise in working with young people.

Providing a more organised, 'hands on' teaching program for all paediatric trainees, and other hospital staff who work with adolescents', appears a somewhat daunting challenge. The equation is not simply one of teacher/expert and pupil, but includes multiple elements related to workforce development. Colleagues in New Zealand have recently reviewed worldwide experience in this area and created a framework for *workforce development in youth health* (www.youthhealthworkforce.co.nz) that will be helpful to examine.

In addressing professional education and training issues, the CAH is in a strong position to build upon the recently developed curriculum and teaching resource on adolescent health developed by the Royal Australasian College of Physicians, in which the Centre (through Prof Sawyer) played a pivotal role. The RACP supports a three tiered approach to training in adolescent health:

- (i) A generic module-based training aimed at basic trainees in both adult and paediatric medicine;
- (ii) Advanced training in Adolescent Medicine to be incorporated within sub-speciality and general training of those with a major interest in adolescents (eg endocrinology, gastroenterology, genetics, haematology/oncology etc);
- (iii) Subspecialty training in Adolescent Medicine, for the small number of future leaders of this process.

Other useful educational resources might also be used, including the recently updated *GP Resource Kit 2nd Edition* (www.caah.chw.edu.au/resources) (28) which has a focus on communication and youth-friendly consultation skills, cultural competency, health risk behaviours and detailed information on the use of the HEADSS exam.

The highly diverse cultural backgrounds of patients at RCH present staff with challenges in achieving good health outcomes. 'Cultural competency' involves a practitioner's capacity to reflect on their own culture, develop empathy for people from other cultures, and apply appropriate communication and interaction skills in clinical encounters (6). Recent Australian research at two children's hospitals (5) explored the interaction between staff and patients/families and included

participant observations in the wards and at clinical meetings. While many staff were seen to negotiate difference quite well, the research revealed that constraints in their ability to meet the needs of families were often related to broader systemic factors. These findings have implications for child and adolescent health policy and practice at RCH.

(6) Promote meaningful participation by young people via the creation and maintenance of a Youth Advisory Council (YaC).

Surveys of what young people want show that 'having a voice' and feeling they have some control over what's happening in their lives (agency), feeling comfortable and secure in their environment (security), and having a positive sense of self (identity), are important ingredients for their wellbeing (28). In the realm of youth health services, young people like staff who make an effort to introduce themselves, basic rules and guidelines, being asked for input, and being given realistic and honest feedback.

The YaC is a group of young people who have been given the job of making the Royal Children's Hospital better for young people by providing them with the opportunity to have input into Hospital decisions that affect them.

The RCH Executive has approved the establishment of the Youth Council (YaC) as a key component of the Adolescent Model of Care. Based on accepted principles of meaningful youth participation (29), the CAH and the RCH Education Institute have proposed a framework including: purpose, organisation, funding, member selection, member responsibilities and committee evaluation. Important considerations in relation to the Youth Council include:

- Promote the RCH focus on patient and family centred care
- Meet approximately 10 times per year to provide advice about how the hospital can better involve young people in care and planning
- Have strong links with RCH Executive, while drawing upon the expertise and networks of the CAH and other relevant departments, including Education Institute
- Become involved in planned projects which will create a greater sense of purpose and meaning, rather than merely responding to an ad hoc consultative approach (eg play a helpful role in designing and implementing new hospital models of care, and in the development and review of programs for adolescent patients)
- Have a dedicated project/support worker.

(7) Foster opportunities to build cooperative partnerships among stakeholder groups

Collaboration in advancing adolescent health involves developing cooperative partnerships across disciplines and sectors to achieve a more informed, coordinated and effective approach to the needs and issues of young people. Basic principles of collaboration include:

- Building trust and sharing values, interests and power
- Developing a strategic plan with agreed outcomes
- Creating a mechanism for functioning (eg regular case conferences)
- Undertaking periodic reviews of progress
- Considering cost effectiveness...

Between CAH, General Paediatrics and Centre for Community Child Health

The Adolescent Model of Care reflects a system where the specialty of Adolescent Medicine (characterised by expertise in the developmental phrase of adolescence) intersects with 'organ-based' specialties (with expertise in the care of organ systems). General paediatricians and surgeons manage most of the adolescents receiving treatment and care at RCH, acquiring them either as they grow up with childhood illness, or as acutely ill teenagers admitted through emergency department. There would be benefit, especially in the area of *acute medical care*, from increased mutual appreciation and complementarity between the two services. For example, as Dr Jenny Proimos points out in relation to clinical research:

A closer relationship between Adolescent Medicine and General Medicine could facilitate greater involvement in clinical research with adolescents; if conducted collaboratively, this would further consolidate the relationship, improve research skills for young trainees and consultants (helping them get a handle on clinical research early in their careers) and upgrade the clinical research track record for Adolescent Medicine.

Of the adolescent patients under General Paediatrics, some with more complex problems are transferred entirely to Adolescent Medicine or referred for shared care, either via inpatient consultation or an outpatient appointment. In certain instances, however, there is confusion among staff (within both general paediatrics and subspecialty teams) about whom to refer to, which means that sometimes Adolescent Medicine ends up with cases that *don't necessarily need medical input* and for whom the appropriate mental health backup is not necessarily available.

There is consensus among RCH staff that referral pathways need to be reviewed and clarified, a range of interventions identified, and a body of work undertaken around what constitutes *mental health* and what constitutes *adolescent medicine*. Adolescents with identified psychosocial difficulties that increase health risk behaviours or complicate cooperation in health care are those requiring particular consideration. Consideration of clinical approaches for those with undifferentiated

but common symptoms such as abdominal pain and headache are another group. It is in this context too, that Adolescent Medicine will establish and articulate developmentally appropriate health care principles and practice guidelines for the wider care of adolescents at the RCH, including the principles of transition.

Similarly to the CAH, but with a focus on younger children, the Centre for Community Child Health (CCCH) applies a developmentally appropriate, systemic, holistic model of care where psychological and social domains are given appropriate weight. Where there is an overlap in client group, for example, early adolescents with attention deficit hyperactivity disorder (ADHD), an opportunity exists for some cross fertilisation of expertise and management approaches.

Between CAH and the Integrated Mental Health Service

IMHP operates as a tier 3 specialist mental health service which emphasises severe, complex mental disorders with high risk, while Adolescent Medicine and CCCH operate as general paediatricians (supported by allied health staff) with an emphasis on development, family, school and community systems, and psychosocial care, which includes *the provision of mental health care*. Notwithstanding potential boundary tensions, the situation is considered manageable as, by virtue of the *presence or absence of physical health problems*, the boundaries are reasonably clear.

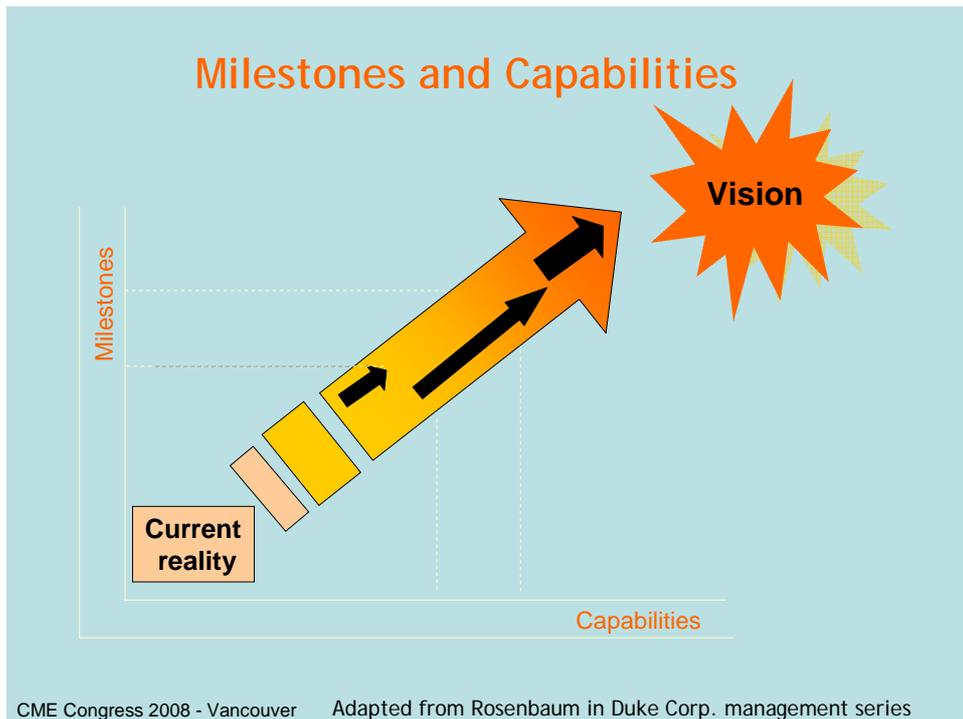
An area of complexity concerns the management of adolescents with eating disorders. The ED model of care has been driven by Adolescent Medicine which currently treats all eating disorder cases at RCH, regardless of age. Psychiatrist Andrew Court, who appears to serve as the main bridge between IMHP and CAH, does 6 sessions with Consultation Liaison Psychiatry (part of IMHP) and works closely with the adolescent medical team. He provides 2 sessions in the ED program as part of the multidisciplinary team (focusing primarily on family-based care) and participates in a weekly ward round on Ward 3 East at which all eating disorder inpatients are reviewed. In this context he states:

'I am treated as an equal member of the team...my view is that our roles – within the adolescent team – are pretty clear and I think we work well together...mainly because of a trust developed over time rather than secondary to any formal process'.

Notwithstanding sensitivities around moving towards a more functional and mutually supporting partnership-based model of care, especially with eating disorders, there is a belief that the two department can work together, especially (in the words of Dr Peter Birlson) 'in situations where individually we don't make much progress, but together we can add value'. For example, collaboration could occur in teaching and liaising with nursing staff around mental health issues and in exploring the question of what Mental Health can provide to adolescent care throughout the hospital.

(8) Identify milestones and capabilities in the implementation of the Adolescent Model of care to ensure that the developmental process is ongoing, and evaluate outcomes.

In moving from the current reality to the vision of excellence represented by the Adolescent Model of Care, decisions on items for early action, versus interventions requiring longer term and ongoing processes, will need to be taken by the Steering Group. It is hoped that energy for this undertaking will be maintained and the goodwill manifested to date will continue to prevail.



5. Conclusion

Adolescent health falls outside biological paradigms, clinical medicine and its usual classifications, and (outside) the classic distinctions between physical and mental health, between medical and social aspects of health, and between curative and preventive care (30).

Having an appreciation of the complex and multifaceted nature of adolescent health is a necessary prerequisite for planning and implementing optimal care for young people. In reviewing its multi-layered work with adolescents, the Royal Children's Hospital Melbourne has embarked upon a timely and significant quality assurance project, the outcomes of which will have ramifications for hospital-based adolescent health care throughout Australia

Potential payoffs and opportunities presented by the implementation of a new Adolescent Model of Care include: enhanced clinical skills in the Hospital workforce, improved referral pathways, better transition care, improved psychosocial screening and responsiveness, and health and wellbeing benefits for the young people who are within the RCH's remit to treat. Of particular importance is the retention of an adolescent ward as an integral aspect of optimal inpatient care for young people in a tertiary children's hospital.

Finally, the spirit in which this ambitious project has been undertaken is not primarily one of implicit or explicit criticism of what is already in place. The consultation leading to this report has brought to light many areas of professional excellence in clinical care for young people at all levels, alongside aspects clearly deserving of further examination. Throughout the organisation, interest in the project and commitment to 'getting it right' remain high. There is reason for optimism that the efforts involved will prove to have been worthwhile.

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Figures – Separations, attendances and workloads

Figure 1. Separations

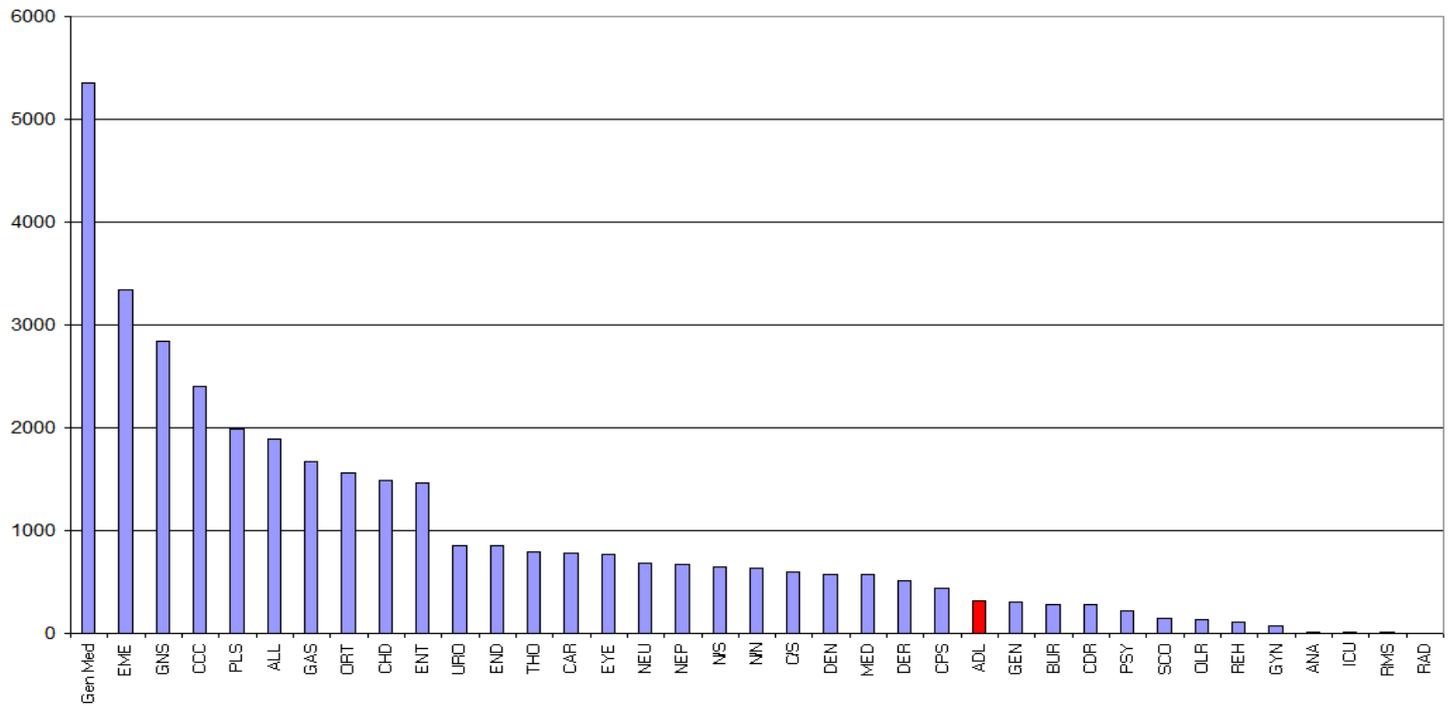


Figure 2. Outpatient Attendances

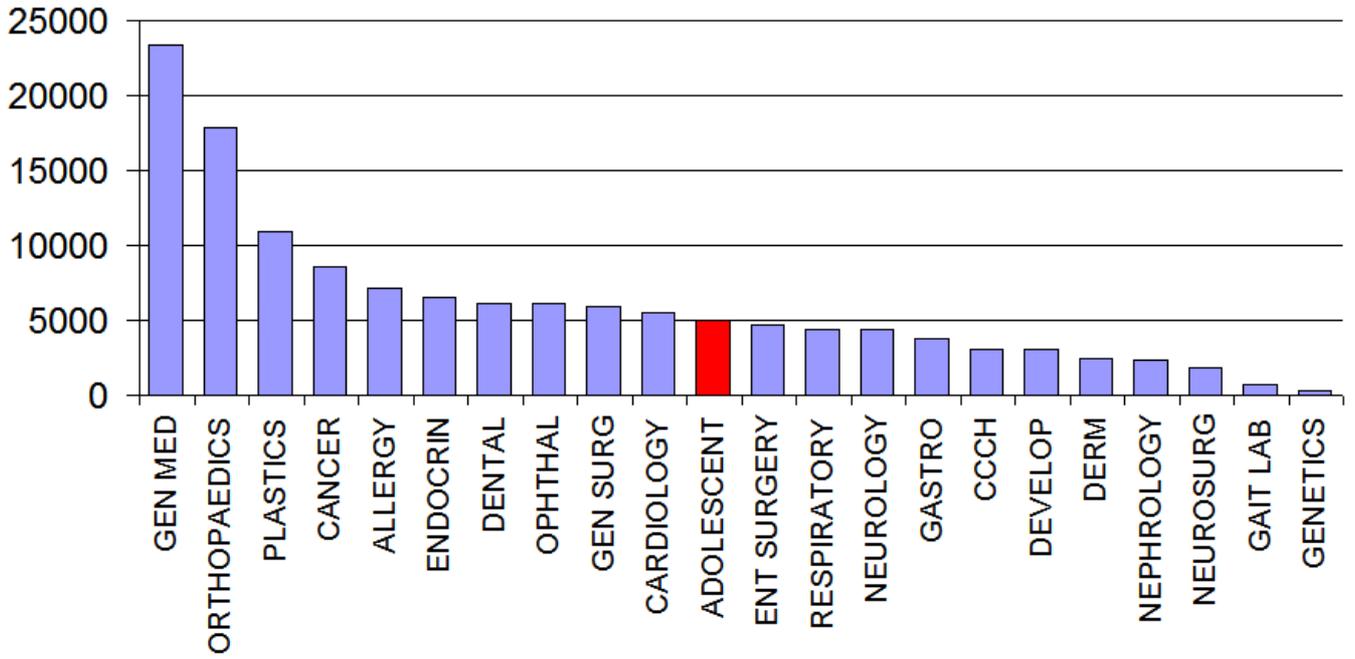


Figure 3. Outpatient Attendances 12-18 years of age

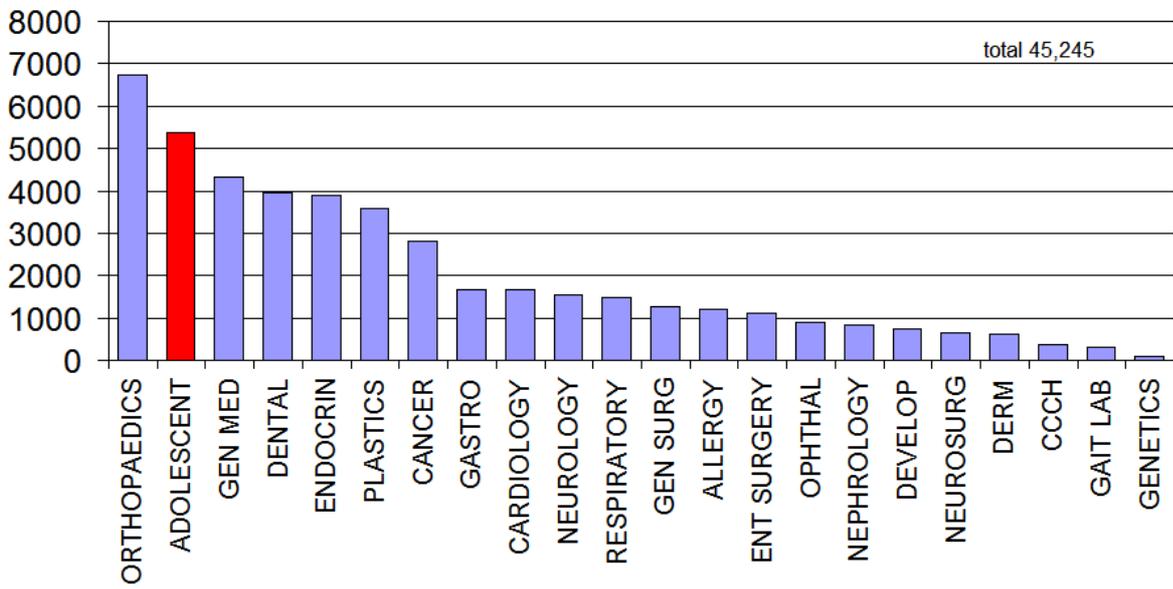
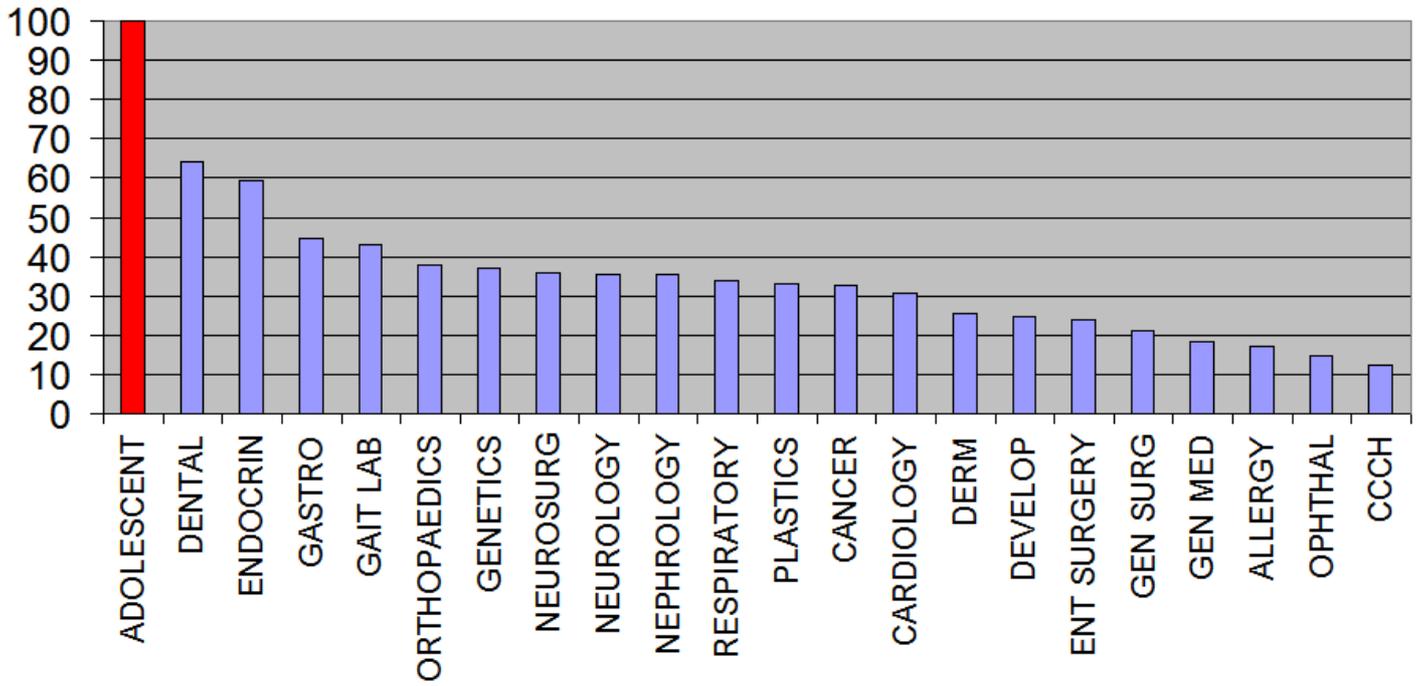


Figure 4. **12-18 year olds as % of
Departments Outpatient workload**



Appendix A – Sources of information, advice and support

Interviews were held with the following RCH personnel:

- Peter Birleson – Director, Integrated Mental Health Services
- Tony Catto-Smith – Director, Gastroenterology
- Caroline Clarke - Executive Director, Medical Services
- Janet Costello - Family Advisory Council
- Andrew Court - Paediatric Psychiatrist
- Noel Cranswick – General Medicine
- Beth Dunn - Educational Play Therapist
- Harm Hoen – Family Advisory Council
- Jenni Jarvis – Executive Director, Nursing
- Christine Kilpatrick – Chief Executive Officer
- Andrew Johnson – Nurse Unit Manager, Adolescent Ward
- Andrew Kennedy - Paediatrician and Adolescent Physician
- Andrew Kornberg – Director Neurology
- Charlene MacLeod - Director, Strategy and Service Planning
- Zoe McCallum - General Paediatrician
- John Macrow – Service Redesign Unit
- Susan Medlin – Manager New Hospital
- Frank Oberklaid – Director, Centre for Community Child Health
- Jenny Proimos – Adolescent Physician/Senior Consultant
- Fiona Sanders - Director, Ambulatory Services
- Susan Sawyer – Director, Centre for Adolescent Health
- Glenda Strong – RCH Education Institute
- Mike South – Director, General Medicine
- John Stanway – Executive Director, Clinical Support Services
- Nikki Teggelove - Adolescent Medicine

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Appendix B – ‘What constitutes an ‘adolescent friendly’ children’s hospital?’ Briefing Paper by Prof Susan Sawyer

This briefing paper addresses the following issues:

- the changing nature of adolescent health care now reflecting ‘a complex set of interactions between biology and behaviour’ rather than lying within the traditional domains of paediatric and adult specialist practice;
- the complexity and confusion of differing age ranges used for data sets, policy and practice;
- Australian milestones in adolescent health care and training over the past 30 years with particular reference to the contributions of the Centre for Adolescent Health;
- the case for adolescent wards underpinned by considerations such as consumer feedback (*longstanding evidence that teenagers prefer to be housed with their peers*), quality of care (*strong anecdotal evidence*), safety issues (*avoids child protection concerns and ensures appropriate staffing skills*), and staff satisfaction and retention (*nurses on adolescent wards like working with this age group and also enjoy/prefer the diversity of cases in a mixed ward environment*);
- ‘best practice’ elements of an adolescent model of care encompassing: quality of care with an emphasis on ‘integration and collaboration’; developmentally appropriate health care supported by appropriate professional skill sets; developmentally appropriate spaces; consumer engagement and the need for an active youth advisory council.

Appendix C - Children and young people's experience of hospitalisation

Edited extract from *The Emergency Department Project*, Association for the Wellbeing of Children in Healthcare, April 2009 (used with permission).

The impact of hospitalisation and hospital environments on children is well documented and the process of humanising the hospital experience and environment for parent and child has been going on for some decades (Bishop, 2008; Hutton, 2005; Lindheim, Glaser & Coffin, 1972; Olds).

Although research with children and young people themselves into their experience of hospitalisation and hospitals is limited, attributes applicable to all hospital departments have been identified in such research. These include the aesthetics of the environment, the volume of age-appropriate activities there are available, receiving a warm welcome by the hospital community, receiving appropriate information and participating in their own healthcare management (Bishop, 2008; Blumberg & Devlin, 2006; Hutton, 2003, 2005; Moules, 2004).

From the earliest research on children's experience of hospitalisation, or with children and adolescents in hospital environments, there has been a number of persistent themes:

- Personal considerations include the need to provide opportunities for self-care management, confidentiality, competence, control and choice (Lindheim, Glaser & Coffin, 1972; Olds, 1991; Rivlin & Wolfe, 1985).
- Social considerations include the need for social support and social contact with friends and families (Lindheim, Glaser & Coffin, 1972; Olds, 1991).
- Organisational considerations involve the need to provide adequate cognitive stimulation, and access to recreational and learning activities (Lindheim, Glaser & Coffin, 1972; Olds, 1991; Rivlin & Wolfe, 1985).
- Physical environmental considerations include the need for personal space, privacy, independent movement and comfort within the environment (Lindheim, Glaser & Coffin, 1972; Olds, 1991; Rivlin & Wolfe, 1985).

More recent research has supplemented these findings and added further considerations for all domains including considerations for the physical environment such as the **need for age-appropriate spaces and interiors, especially for adolescents** (Blumberg & Devlin, 2006; Carney et al., 2003;

Hutton, 2002, 2003, 2005; Kari, Donovan, Li & Taylor, 1999; Tivorsak, Britto, Klosterman, Nebring & Slap, 2004); respecting the importance of having personal possessions for patients and being able to personalise their bed area (Blumberg & Devlin, 2006; Shepley, Fournier, & McDougal, 1998); identifying a preference for colour and artwork in the environment (Blumberg & Devlin, 2006; Coad & Coad, 2008; Sharma & Finlay, 2003); and identifying the importance of having access to gardens in the hospital environment (Sherman, Shepley & Varni, 2005; Sherman, Varni, Ulrich, & Malcarne, 2005; Whitehouse et al., 2001).

Social considerations such as understanding the importance of having access to school (Kari et al., 1999; Liabo, Curtis, Jenkins, Roberts et al., 2002); understanding the importance of good provision for families and their needs (Hall, 1990; Hopia, Tomlinson, Paavilainen & Aestedt-Kurki, 2005; Liabo et al., 2002); and the need for active support, professionalism, respect and friendliness from staff (Liabo et al., 2002, Moules, 2004) have also been established in recent research.

Organisational considerations include the need for **the provision of age-appropriate activities, especially for adolescents** (Blumberg & Devlin, 2006; Carney et al., 2003; Hutton, 2002, 2003, 2005; Kari, Donovan, Li & Taylor, 1999; Tivorsak et al., 2004); and the need for information that supports children's and **adolescents' understanding of their own situation and their capacity to participate in their own healthcare management** (Hallstrom & Elander, 2003; Liabo et al., 2002; Moules, 2004; Smith & Callery, 2005). Food and its quality, variation, and choice were also important considerations for adolescents (Blumberg & Devlin, 2006; Carney et al., 2003).

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Appendix D – Healthcare design and hospitalisation research

Extract from PhD Thesis by Bishop, K.G. (2008) *From their perspectives: Children and Young People's experience of a paediatric hospital environment and its relationship to their feeling of well-being*. The University of Sydney, Sydney. Available online at <http://hdl.handle.net/2123/3962> (used with permission)

An Overview of Healthcare Design Research

There is little doubt that the role of the environment in health and healing processes is of increasing concern to healthcare providers, architects, planners, and researchers (Devlin & Arneill, 2003). Between 1998 and 2006, there have been a number of major reviews of healthcare design research which reveal that the volume of research in the area has increased tenfold in that time (Devlin & Arneill, 2003; Phiri, 2006; Rubin et al., 1998; Sherman, Shepley & Varni, 2005a; Ulrich & Zimring, 2004).

There is also an increasing body of research that shows changes made to the social and physical environments for patients, benefit medical outcomes and this has fuelled interest in the relationship between environment and health outcomes (Lawson, Phiri & Wells-Thorpe, 2003; Stichler, 2001; Ulrich, 1992a; Ulrich et al., 1991).

The evolution of hospital design across the 20th Century reflects a shift in healthcare philosophy from what Verderber and Fine (2000) describe as a system empowerment paradigm to a patient empowerment paradigm. Hospitals have changed from being large institutional structures dominated by function and medical process, to being environments oriented around patients' needs and well-being (Verderber & Fine, 2000). Changes in the approach to hospital design have consistently reflected changes in models of care and medical technology (Shumaker & Pequegnat, 1989).

Increasingly, an emphasis has been placed on the experience of hospitalisation from the patient's perspective, resulting in an emphasis on the attractiveness of buildings, on creating an uplifting environment, on reincorporating nature as a therapeutic element, and on recognising a patient's right to privacy and control. The scale of hospital buildings has become smaller and spaces more intimate, with a greater variety of spaces. The interior décor has become more sensitive to making patients feel more at home with greater colour and textural variation and the use of everyday furniture and fabrics (Malkin, 1992; Verderber & Fine, 2000).

These changes have reflected changes in models of care that have become more patient-centred. Models such as the Planetree Model, (Lindheim, Glaser & Coffin, 1972; Martin, Hunt & Conrad, 1990; Martin et al., 1998) which operate on

principles of respect, comfort and support, and seek to provide coordinated and integrated care for patients (Beatrice, Thomas & Biles, 1998), have become the dominant healthcare models. Patients have reported a greater degree of satisfaction with hospitalisation when they have been cared for under these conditions (Martin et al., 1998). In these models of care, patient comfort, empowerment and control are understood as central to patients' well-being.

An emphasis on creating a holistic healing environment became the focus during the 1990s, in response to shifts in the sensibility surrounding patient's experience of hospitalisation (Malkin, 1992). Definitions of what these environments consist of are still largely unsupported empirically for many patient populations, including children and young people. Drawing from several reviews of the literature, however, it is possible to identify some of the main considerations from the patient's perspective.

The major considerations include aspects of the social, organisational and the physical environment. The influence of these considerations is discussed either in relation to their impact on patients' stress, or for their impact on patients' overall satisfaction with hospitalisation and the hospital environment. More research exists which is concerned with identifying and minimising stressors in the hospital environment, than research that is concerned with making recommendations for supportive measures for patient well-being. At this stage, there has been very little of either type carried out with populations of children and young people.

Key aspects of the social environment include having access to, and control over social contact with friends, family and other patients; having control over and access to privacy; and having access to support (Lawson et al., 2003; Rubin et al., 1998; Shumaker & Pequegnat, 1989; Ulrich, 1995, 1999; Ulrich et al., 1991; Ulrich & Zimring, 2004).

Key aspects of the organisational environment include having access to supportive facilities and amenities; attention to cleanliness, maintenance and tidiness; and access to information (Bruster et al., 1994; de Vos, 2006; Harris et al., 2002; Lawson et al., 2003).

Key aspects of the physical environment are often categorised. Several commentators have offered frameworks of categories (de Vos, 2006; Dijkistra, 2006; Harris et al., 2002; Ulrich & Zimring, 2004). Harris et al. (2002) offer a particularly comprehensive and useful set of categories. In their study into patient satisfaction in a hospital environment they found that environmental satisfaction was a significant predictor of overall satisfaction. As part of their study, they conceptualise three levels of considerations within the physical environment. These include the ambient environment, architectural features and interior design features.

The ambient environment includes features such as the lighting, noise levels, temperature and odours in the environment. Patients report that having control over these environmental attributes is linked to satisfaction (Fottler, Ford, Roberts & Ford, 2000; Harris et al., 2002) and likewise not having control over these attributes is reported as causing stress (Baker, 1984; Topf, 1994, 2000; Ulrich, 1992b, Ulrich et al., 1991; Ulrich & Zimring, 2004).

The architectural features include relatively permanent characteristics such as the spatial layout, design configuration (e.g. shared versus single rooms), the scale of the hospital, room size and window placement, number and kinds of facilities and amenities, and having access to views, nature and outdoor areas (Cooper Marcus & Barnes, 1999; Lawson & Phiri, 2003; Ulrich, 1984, 1999).

The interior design features include less permanent characteristics such as the furniture, colour, texture, artwork, plants, aesthetic qualities of the hospital, and the legibility of the building through signage and maps (Carpman & Grant, 1993; Fottler et al., 2000; Shumaker & Reizenstein, 1982). Harris et al. (2002) note that there has been little research focusing on the interior design of hospitals but note that it is a belief held by many design and healthcare professionals that aesthetically pleasing environments enhance patient satisfaction and experience of hospitalisation (Behrman, 1997; Cooper Marcus & Barnes, 1999; Fottler et al., 2000; Friedrich, 1999; Malkin, 1992; Ulrich, 1992a, 1999).

Ulrich's theory of supportive design

A central body of work in healthcare design research is from Ulrich (1991a, 1991b, 1992b, 2000, 2001). Ulrich is focused on identifying the direct and indirect relationships between the designed environment of healthcare facilities and clinical outcomes for patients. Ulrich's (1991b) theory of supportive design in healthcare settings encompasses the assumption that "supportive surroundings facilitate patient's coping with the major stress accompanying illness. The effects of supportive design are complementary to the healing effects of drugs and other medical technology, and foster the process of recovery" (p. 97).

The starting point for Ulrich's (1991b) theory is that most patients experience considerable stress in healthcare settings in response to two things primarily: their illness and its repercussions, and the nature of the physical environment. He argues that patient stress has a variety of negative psychological, physiological and behavioural impacts on patient wellness (Ulrich, 1991a, 1991b, 1992b, 2000, 2001). Ulrich's main argument is that minimising environmental stress equates directly to supporting patient wellness.

Ulrich's (1991b) theory of supportive design suggests that patient well-being is linked to situational control, access to social support, and positive distractions within the environment. He argues that the importance of a patient's sense of control over their physical and social surroundings in influencing stress and

wellness is well documented in research. Patient control spans two particular domains: control over the effects of illness, and control over the features in the sociophysical environment that patients do not like and cannot alter.

Access to social support is significant in Ulrich's research also (Ulrich, 1991b, 1992b, 2000; Ulrich & Zimring, 2004). Patients who have access to frequent support from family and friends, experience less stress and higher levels of wellness.

Access to positive distractions is a more complex notion than the concepts of situational control and social support. It concerns providing patients with adequate amounts of positive sensory stimulation and addresses in what forms that stimulation may be beneficial or detrimental. In particular, Ulrich (1991b, 1992b, 2000, 2001) discusses the positive effect of patients' exposure to nature, natural views (Ulrich, 1981, 1984, 1999), artwork and entertainment on patients' experience of stress (Ulrich, 1992b).

Healthcare Design Research in Paediatric Settings

Research with children and young people in hospital settings is much more limited than it is with adults. However, the research available indicates that many of the same aspects of a hospital environment influence children and young people's satisfaction with the hospital and hospitalisation. Characteristics of the social, organisational and physical environments continue to be influential in patients' response to the hospital setting.

Personal control continues to be a central consideration. In a long-term study conducted in a psychiatric hospital, Rivlin and Wolfe (1985) identified young people's need for personal control, including control over privacy, confidentiality, time management and activity choice.

Olds (1991) also identified personal control as one of the four criteria that should be addressed in children's hospital design. She identified control over such things as social contact, privacy and personal space as essential to individual well-being. She also identified the need for children to experience competence regularly whilst in a hospital, move independently throughout an environment, and feel comfortable, by receiving optimal levels of stimulation to keep actively and positively engaged.

Lindheim, Glaser and Coffin's (1972) work also made many recommendations for paediatric design along similar arguments based on holistic human needs. They made a series of developmental age-related recommendations that encompass the need to provide adequate cognitive stimulation, access to recreational and learning activities, opportunities for social contact and self-care management, opportunities for personal space, privacy and confidentiality and individual control.

In relation to the physical environment specifically, research has recommended that new considerations are introduced in paediatric environments that differ from adult hospitals. These include the need for age-appropriate activities and spaces (Hutton, 2002, 2003; Tivorsak et al., 2004), the need to accommodate families and their needs, so that they can fulfil their role in supporting their children (Hall, 1990; Hopia, Tomlinson, Paavilainen & Astedt-Kurki, 2005; Sheldon, 1997), and the need to provide for peer social interaction, particularly amongst adolescents (Blumberg & Devlin, 2006).

Recent research with adolescent and child patients has identified the following key environmental attributes within the hospital environment that support patient experience. For children and young people:

The need for age-appropriate activities, spaces and interiors, especially for adolescents (Blumberg & Devlin, 2006; Carney et al., 2003; Hutton, 2002, 2003, 2005; Kari, Donovan, Li & Taylor, 1999; Tivorsak et al., 2004)

Importance of having access to school (Kari et al., 1999; Liabo, Curtis, Jenkins, Roberts et al., 2002)

Importance of having personal possessions and being able to personalise their bed area (Blumberg & Devlin, 2006; Shepley, Fournier, & McDougal, 1998)

Preference for colour and artwork in the environment (Sharma & Finlay, 2003)

Preference for medical equipment and paraphernalia to be hidden as much as possible (Tivorsak et al., 2004)

Importance of having access to gardens to escape, and for something to do (Sherman et al. 2005a; Sherman, Varni, Ulrich, & Malcarne, 2005b; Whitehouse et al., 2001).

Importance of good provision for families and their needs (Hall, 1990; Hopia et al., 2005; Liabo et al., 2002).

Preference for 'home-like' qualities in the environment (Runeson et al., 2002; Tivorsak et al., 2004)

For adolescents (in particular):

A preference for their own ward (Blumberg & Devlin, 2006; Hutton, 2003; Kari et al., 1999; Sharma & Finlay, 2003)

- A preference for adolescent wards to be located near children's wards rather than near adult wards (Sharma & Finlay, 2003)
- A preference for bright colours, without emblems of childhood such as cartoon characters (Blumberg & Devlin, 2006)
- The need for social spaces specifically for their own age group (Blumberg & Devlin, 2006; Hutton, 2005)
- The need for both single and shared rooms in adolescent wards (Blumberg & Devlin, 2006; Hutton, 2002; Miller, Friedman & Coupey, 1998)
- The need for control over privacy (Blumberg & Devlin, 2006; Hutton, 2002, 2003; Kari et al., 1999; Sharma & Finlay, 2003)

- The importance of access to television, music and a telephone (Blumberg & Devlin, 2006; Hutton, 2003, 2005)
- A preference for access to additional activities such as games rooms, gyms and kitchens within the hospital environment (Blumberg & Devlin, 2006; Hutton, 2003, 2005).

Children's Experience of Hospitalisation

Very little of the recent research listed above focused exclusively on environmental considerations. Rather they usually emerged as part of a more comprehensive list of considerations within children and young people's experience of hospitalisation which will be explored in the next two sections of this chapter. These considerations helped to refine both the broad and the specific subject areas within children and young people's experience of hospitalisation that were addressed in the current study.

In their consultation with children and young people aged up to 18 years about their response to health services in the UK, Liabo et al. (2002) identified a range of considerations in addition to the environmental attributes already listed from this study. These included:

- The importance of having family present
- The need for having enough to do
- The need for active support from staff
- The need for friendliness and respect and use of appropriate language from staff (this was used by participants to assess the quality of their communications with professionals)
- The need for information
- The need to maintain confidentiality

Runeson et al. (2002) in their study into boys' needs during hospitalisation, identified two different situations of need that occur in hospital including threatening and non-threatening situations. In threatening situations such as pain and discomfort, four categories of needs were identified: to feel in control of the situation, to have parents nearby, the familiar (that which reminds them of home), and the need for integrity (control over privacy). In non-threatening situations, six categories of need were identified: activity, new experiences, information, participation in their own healthcare, praise and recognition (for self-management), and needs related to physical resources (e.g. food and drink).

In a study conducted by young people themselves into children and young people's response to the quality of care in a hospital, the participants created a list of factors that, in combination, affected participants overall rating of the hospital as excellent (Moules, 2004). These included:

- The need for good technical skills displayed by staff to minimise pain and do things carefully

- The importance of friendly staff – who are willing to spend time and to talk with patients
- The need to give young people respect by listening to them and considering their need for privacy
- The need for good information and good explanation about what is happening

In addition to these studies which have produced overall recommendations, others have dwelt on specific aspects of children's and their family's experience. Children have identified that their family's experience whilst they are in hospital, is very important to them. Hopia et al. (2005) identified five ways to support the needs of parents and families in hospital which contribute to the family's experience. These included:

- Reinforcing parenthood (by clarifying their role)
- Looking after the child's welfare (by instilling confidence in the system of care and by showing an interest in the child)
- Sharing the emotional burden
- Supporting the everyday coping of families
- Creating a confidential care relationship with the whole family

Another key area identified in children's experience is the management of information, its type, volume and delivery, and the opportunities to participate in decisions affecting their own healthcare. Hallstrom and Elander (2003) state that "having a voice in decision making helps the child to develop a sense of himself as a person and gives the parents a feeling that they are part of a team giving their child optimal care during hospitalization" (p. 367). Smith and Callery (2005) found that patients aged 7 to 11 years could identify their own information needs and felt there was too little information provided ahead of their operation or admission.

Young, Dixon-Woods, Windridge and Heney (2003) found that children with chronic illness felt constrained by their parents' role in managing the information that they received. They reported feeling marginalised as a result. Ishibashi (2001) also found that children and young people had a clear interest in receiving information about their condition but that it was important that this information be age-appropriate.

In summary, the findings from this body of research reveal that the considerations for children in hospital include:

- Friendly, supportive and respectful contact with staff
- Competence from staff in their treatment of patients
- The need for sufficient, age-appropriate information and explanations of what is happening
- Appropriate inclusion and provision for families (respect for the need for continuity of care)

- The need for sufficient activities
- The need for control over privacy
- The need for patients to participate in their own healthcare management

Adolescents' Experience of Hospitalisation

Special considerations, in addition to many of the needs listed for children are recommended for adolescents. There is clearly a need for a greater emphasis to be placed on age-appropriateness for this age group.

Research has indicated that adolescents were more sensitive to the treatment received from staff and whether it was age-appropriate, respectful or condescending (Moules, 2004). They were also aware of the age-appropriateness of available activities and spaces to carry them out (Hutton, 2003; Tivorsak et al., 2004). Adolescent participants wanted more lenient visiting hours policies to socialise with friends (Blumberg & Devlin, 2006). They required a greater range of activities and greater access to, and control over them (Hutton, 2003; Tivorsak et al., 2004), including a greater range of recreational facilities (Blumberg & Devlin, 2006). In Hutton's (2003) study, having age-appropriate activities was viewed as a coping strategy. Activities were used to prevent boredom and remain positively engaged in the experience of hospitalisation, which participants felt would lead to improved health.

Social interaction and having access to peers was more important for adolescents than having regular contact with family (Blumberg & Devlin, 2006). In Blumberg and Devlin's (2006) study, participants valued having a 24 hour visiting policy for families but it was not so important that parents stayed overnight. Carney et al. (2003) found that continuity of care was more important for younger children.

Access to, and control over, privacy was found to be more important for adolescents (Blumberg & Devlin, 2006; Hutton, 2002, 2005; Sharma & Finlay, 2003). Adolescents appeared to be divided in most studies as to whether they would like to share a room or have a private one. This preference was divided between some adolescents who felt a need for privacy and others who preferred to have company (Blumberg & Devlin, 2006; Miller et al., 1998).

Hutton (2002, 2005) outlined a conceptualisation of space for adolescents in hospital which included private space and shared space. Private spaces included their bedrooms, bathrooms, treatment areas and telephone. Shared spaces included social zones and places. The recommendation was that adolescents' needs for both should be respected.

Blumberg and Devlin (2006) also stated that personalisation of the bed area and being able to bring in personal belongings was very important for adolescents. This was linked to establishing their identity and their level of comfort in the environment. They went as far as to say that being able to personalise the bed

area was more important to their participants than the appearance of the ward room and its appropriateness for age.

Food and its quality, variation, and choice were also an important consideration for adolescents (Blumberg & Devlin, 2006). Carney et al. (2003), who also received feedback that the food, as well as the television and computer games was of importance, suggested that these considerations may be linked to adolescents trying to find some continuity with their home environment within the hospital.

The summary of the research in this chapter provides a basis for conceptualising the characteristics of hospital environments and hospital experience that are important to children and young people, and which can impact on their experience of hospitalisation. The following chapter will discuss literature on children's participation as a preferable approach to researching children's experience.

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