The Royal Children's Hospital Melbourne

Centre for Adolescent Health

# Towards an Adolescent Friendly Children's Hospital


## ADOLESCENT FRIENDLY HOSPITAL SURVEY (2011 baseline assessment)

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Finally, we wish to thank the many adolescent patients and their parents whose views are represented within this report.

# EXECUTIVE SUMMARY

## WHAT THE RCH IS DOING WELL

Indicators of healthcare engagement by adolescents and parents were generally very positive. This included the extent that patients and families felt welcomed at the hospital, as well as the friendliness of staff.

## WHERE THERE IS ROOM FOR IMPROVEMENT

In terms of patient and family centered care, both adolescents and parents reported high levels of feeling respected by RCH staff. However, there was room for improvement in other indicators of patient-centered care, such as the extent to which adolescents felt able to ask questions of clinicians, and the proportion of adolescents who wanted greater involvement in consultations.

There was also evidence that both the physical environment and the resources provided (including support for social connections and learning) did not fully meet young people's needs.

## WHAT THE RCH IS NOT DOING WELL

There is significant room for improvement around the use by staff of evidence-based clinical practices with young people. Survey questions specifically focused on clinical guideline-recommended practices of confidentiality, routine psychosocial assessment, supporting self-management, and transition to adult healthcare. There was distinct room for improvement in clinical practices across each of these areas.

In 2009, the RCH commissioned a report about the provision of healthcare to adolescents at the hospital. This report identified "pockets of excellence", but was also explicit that best practice healthcare for adolescents was not being universally provided. In addition to the report recognising the growing number and proportion of adolescent patients managed by the hospital, it highlighted that:

- the health issues affecting adolescents require different responses from the hospital as a system (as compared to younger children);
- the hospital needs to engage more effectively with young people themselves as they mature (not just with their parents), in order to promote young people's growing capacity for self-management; and
- the high rate of 'drop out' of young people following transfer to adult services is concerning, and suggests that adolescents are insufficiently engaged in the process of transition to adult healthcare.

In 2010, the RCH committed to the strategic objective of implementing an adolescent model of care to promote the hospital as a whole to become more adolescent friendly. The Centre for Adolescent Health was asked to take the lead with this work.

# EXECUTIVE SUMMARY

The Centre for Adolescent Health embarked on a series of activities that set out to address three questions:

(i) what are the indicators of adolescent friendly healthcare for adolescent patients in a hospital setting;

(ii) how do we measure adolescent friendly healthcare in a hospital setting; and

(iii) what is the adolescent friendliness of the healthcare provided by the RCH as rated by our adolescent patients and their parents?

In the absence of an agreed set of indicators in the literature, and in consultation with the RCH Youth Advisory Council, we developed a set of indicators and then reviewed the literature to identify what questionnaire could be used to populate these. None was available, which meant we were required to develop our own survey instrument, the Adolescent Friendly Hospital Survey. We then undertook a survey of a representative cohort of inpatients and outpatients, and their parents, in order to understand what the RCH was doing well and where there was room for improvement.

Responses were obtained from 787 adolescents and 943 parents. The response rate of around 35% is consistent with institution-wide surveys of this type. Comparison of responders and non-responders suggested no systematic bias, which provides confidence about the representativeness of these results.

# EXECUTIVE SUMMARY

## RECOMMENDATIONS

These results provide high level evidence to support a series of recommendations that have been developed in order to improve the quality of healthcare provided to adolescents at The Royal Children's Hospital, the ultimate goal of this work.

### 1. Organisational

- **Convene an Adolescent Friendly Hospital Steering Committee:** That the previous Adolescent Model of Care Steering Committee is reconvened as an 'Adolescent Friendly Hospital Steering Committee' to provide advice on the recommendations from this report.
- **Promote 'adolescent-friendly' spaces and resources:** That the Youth Advisory Council is engaged to provide suggestions on how to make ambulatory and inpatient environments more appropriate for adolescents.

### 2. Training and professional development

- **Increase professional development opportunities:** That within the suite of professional development activities at The Royal Children's Hospital, that priority is given to all staff being able to gain the required attitudes and skills to provide confidential healthcare and undertake routine psychosocial assessment, and how to promote adolescents' growing capacity for self management and transition to adult healthcare.
- **Develop clinical practice guidelines:** That clinical practice guidelines are reviewed to ensure that the policy environment supports clinical staff developing the required attitudes and skills to provide confidential healthcare and routine psychosocial assessment, and promoting adolescents' growing capacity for self management and transition to adult healthcare.
- **Develop orientation resource:** That an orientation training resource is develop for non-clinical staff (such as receptionists, ward clerks, kitchen staff, and cleaners) to support more 'adolescent friendly' interactions with adolescents, and more customer-focused interactions with parents.

### 3. Monitoring progress

- **Refine survey:** That the Adolescent Friendly Hospital Surveys are revised in order that a briefer instrument is available for a subsequent survey by The Royal Children's Hospital (and other hospitals).
- **Review and cost alternative recruitment strategies:** The concentration of outpatients and wards within the new Royal Children's Hospital suggests that efficiencies may be able to be gained from on-site recruitment, rather than sending the questionnaire home.
- **Undertake a further Adolescent Friendly Hospital Survey:** That a second whole-of-hospital survey be undertaken in the next 18-24 months in order to assess whether the adolescent friendliness of healthcare at the RCH has improved.

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# BACKGROUND

The landscape of health has dramatically changed over the past few decades: technological advances have altered virtually every aspect of healthcare delivery; improved survival from diseases that were commonly fatal in early life has resulted in chronic conditions in childhood and adolescence becoming more prominent; other problems with major effects on development that have become common are behavioural and emotional disorders.[1,2] Over the same time patients and families have come to have higher expectations of the healthcare system and have greater access to health information than ever before. Healthcare services have become more accountable to government in relation to financial performance, efficiency, consumer engagement and quality.

Adolescence has also changed over time. It now starts earlier and ends later than ever before, a change that has significant implications for the health of adolescents.[3] This has been reflected in an increase of around 5-10 years in the upper age of specialist children's services. Instead of 'ending' at around 14 years, most specialist children's hospitals in Australia now extend to 18-19 years,[4] while many community based services for children and adolescents now extend to 24 years. The World Health Organisation defines adolescence as 10-19 years old.[5] Managing health across adolescence is thus core work for children's hospitals such as The Royal Children's Hospital (RCH).

## ADOLESCENT FRIENDLY HEALTH SERVICES

In 2002, the World Health Organisation coined the term 'Adolescent Friendly Health Services' to refer to a framework for promoting the quality of healthcare delivered to young people.[5] This framework is based on health services that are accessible, acceptable, appropriate, equitable and effective. Over the past decade, the terms 'youth friendly' and 'adolescent friendly' have gained currency as shorthand for quality healthcare services for young people.[4,6,9]

In addition to managing their presenting conditions, paediatric services are also expected to help children and adolescents gain the skills to look after their health as they mature (referred to as self-management).[4,6] Health services are expected to provide anticipatory guidance around health related behaviours and states that primarily have their onset in the adolescent years (eg smoking, alcohol, emotional disorders). Such routine psychosocial assessment is especially relevant in specialist services as young people with chronic health conditions have both a higher burden of mental disorder than healthy adolescents[1] and a higher attributable risk from health risk behaviours.[7,8] Furthermore, growing recognition that adolescent cognitive development extends to the mid 20's creates a very different impetus for the need to actively support young people (and their families) as they transfer from paediatric to adult health services that, historically, have not had a strong developmental perspective.

# BACKGROUND

Adolescent healthcare policies and clinical practice guidelines from multiple professional organisations (eg American Academy of Pediatrics, Society for Adolescent Health and Medicine, British Paediatric Society, Royal Australasian College of Physicians) are highly consistent about what constitutes adolescent friendly or quality healthcare for adolescents.[6, 10]

However, there are concerns that the highest quality of healthcare is not being delivered to adolescents in specialist children's health services, including children's hospitals.[11-13] Specific concerns relate to the lack of *appropriate healthcare*. For example, the recent Australasian charter on the healthcare rights of children and young people in health services highlighted 11 healthcare rights that underpin developmentally appropriate healthcare.[14] These include the right that young people have to information in a form that is understandable; the right to participate in decision-making and to make decisions about their care appropriate with their capacity; the right to express their views and to be heard and taken seriously; and the right to have their privacy respected. A self-audit of 15 Australian children's services showed that *none rated their service as performing well* across all domains. Most self-rated as poor or only moderate in what might be considered basic aspects of healthcare delivery. (CHA, personal communication)

### CLINICAL PRACTICE GUIDELINES PROMOTE:

- routine psychosocial assessment;
- provision of confidential healthcare;
- support of young people's growing capacity for self-management; and
- transition to adult healthcare for those with chronic health conditions.

*There are concerns that the highest quality of healthcare is not being delivered to adolescents in specialist children's health services, including children's hospitals.*

## Review of Adolescent Healthcare at the RCH

In 2009, the RCH commissioned a report about the provision of healthcare to adolescents at the hospital.[15] This report identified that while there were "pockets of excellence", best practice healthcare for adolescents (as identified by clinical practice guidelines) was not being universally provided. In addition to the report recognising the growing number and proportion of adolescent patients managed by the RCH, it highlighted three key challenges for the RCH (see box).

In response, the RCH committed to the strategic objective of implementing an adolescent model of care to promote the hospital as a whole to become more adolescent friendly. The Centre for Adolescent Health was asked to take the lead with this work.

### CHALLENGES FOR THE RCH

- the health issues affecting adolescents require different responses from the hospital as a system (as compared to younger children);
- the hospital needs to engage more effectively with young people themselves as they mature (not just with their parents), in order to promote young people's growing capacity for self-management; and
- the rate of 'drop out' of young people following transfer to adult services is concerning, and suggests that adolescents are insufficiently engaged in the process of transition to adult healthcare.

# BACKGROUND

A hospital-wide Adolescent Model of Care Steering Committee was convened by Mr John Stanway, RCH Executive Director Clinical Support Services. In addition to acknowledging the importance of adolescent friendly practice for our patients and families, this committee recognised the opportunity to contribute to the evidence base around quality healthcare for adolescents. Consistent with the growing policy emphasis on patient-centered care, it also recognised the importance of including the voices of adolescents within this process as consumers of their own healthcare.

An evaluation sub-committee was established. An initial goal was to obtain a cross-sectional assessment of the adolescent friendliness of healthcare at the RCH by surveying a representative sample of the hospital's adolescent patients and their parents. This was with the objective of identifying what the RCH is doing well and what areas require greatest improvement. This knowledge was required to provide focus for subsequent interventions, the benefit of which could then be measured by repeated cross–sectional assessment.

We identified the value of involving RCH staff to help identify what the RCH is doing well and where there is room for improvement. A series of focus groups of RCH staff has been undertaken, which will be separately reported.


## First Steps

While clinical guidelines are highly consistent around four elements of adolescent friendly practices (confidential healthcare, routine psychosocial assessment, self management support and transition to adult healthcare), these guidelines provide insufficient information about indicators and measurement of adolescent friendly practice within a hospital setting.

We therefore undertook a systematic review of the literature, which showed that while different authors used different terms (eg experience of care, satisfaction with healthcare, quality of care, patient and family-centred care, adolescent friendly care), the underlying constructs were largely overlapping.

The review revealed that there was very little consistency about how 'adolescent friendly' healthcare was measured from the perspective of consumers (whether adolescents or parents), and that the notion of indicators was largely absent from this literature. The review did not find evidence that other children's hospitals were engaged in the strategic task of improving the quality of healthcare provided to adolescent patients and their families.

# BACKGROUND

The absence of agreed indicators around an 'adolescent friendly' hospital or even adolescent friendly healthcare suggested a series of "next steps".

Having undertaken these steps, we would then be in a position to survey the hospital's adolescent patients and their families to measure the adolescent friendliness of our healthcare. This would provide the baseline data which, together with the staff evaluations, would inform the second stage of this work, which is to identify priorities for intervention.

### NEXT STEPS

(i) develop a conceptual framework for an 'adolescent friendly' hospital, from the perspective of both consumers and clinicians;

(ii) develop a set of indicators of quality healthcare within a hospital setting;

(iii) identify whether any existing measures could be used to populate these indicators; and if not;

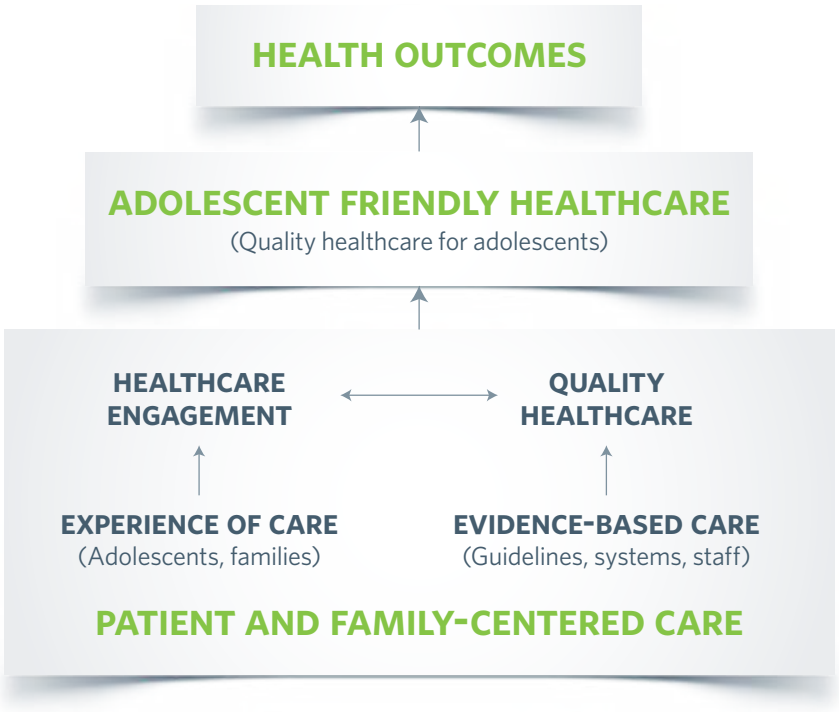
(iv) develop a survey measure to populate these indicators; and

(v) survey a representative hospital sample.

## Conceptual framework for an adolescent friendly hospital

We developed a conceptual framework for an adolescent friendly hospital that was derived from (i) the evidence-base around 'adolescent-friendly' healthcare (including WHO frameworks and the principles of adolescent health and medicine) (ii) the principles of patient and family centred care,[16] informed by a series of consumer consultations with the RCH's newly formed Youth Advisory Council and (iii) a systematic review of the literature. This framework postulates two distinct constructs or themes that determine health outcomes in adolescents, as outlined below and on the following page.

*Figure 1. Conceptual framework for an 'adolescent friendly hospital'*



# BACKGROUND

The *figure 1* framework postulates that two distinct aspects of healthcare contribute to the provision of adolescent friendly healthcare (quality healthcare for adolescents), which underpins health outcomes in adolescence and beyond. The first component relates to the critical aspect of **healthcare engagement** by young people and their families. The underpinning construct to healthcare engagement is adolescents' and families' experience of care. This reflects both the quality of engagement by staff as well as wider engagement by the hospital as a system around, for example, how welcome young people feel in attending a children's hospital, and the age-appropriateness of the physical spaces and services it provides (eg peer support, connections to friends). It is important that clinicians pay increasing attention to the attitudes and beliefs of adolescents themselves as they mature (in addition to ongoing communication with parents). Active engagement helps set expectations around current self management practices (eg adherence with treatment), and future engagement with adult health services (eg transition to adult healthcare).

The second component relates to the provision of **quality healthcare** as achieved through the delivery of evidence based practices. Such practices do not relate to the specific management of an individual medical condition (which this framework assumes is already provided), but rather, relates to the use of clinical practices that help identify the common health issues that affect adolescents (eg substance use, mental disorder) and the common knowledge and skills that they need to negotiate future healthcare. This includes routine psychosocial assessment, the provision of confidential healthcare, and support for self management and transition to adult healthcare. This component is strongly influenced by hospital policies and guidelines, as implemented by our staff.

These two constructs are interrelated; evidence-based practices are unable to be delivered to young people if they and their families are not appropriately engaged in their healthcare. What is also apparent is that application of evidence based practices (eg confidentiality) positively influences young people's engagement with healthcare.

Underpinning these two components is the notion of patient and family-centred care, a key principle of healthcare delivery at the RCH.

*Evidence-based practices are unable to be delivered to young people if they and their families are not appropriately engaged in their healthcare.*

## Indicators of an adolescent friendly hospital

Having developed a conceptual framework, our next step was to develop a set of indicators of adolescent friendly healthcare within a hospital. The criteria we used were based on the Australian Institute of Health and Welfare and WHO criteria for indicators.[7,11] This process was undertaken by reviewing the literature, consulting with local and international experts in adolescent health, and through a series of consultations with young people within the Youth Advisory Council.

*Figure 2. Indicators of adolescent friendly healthcare within a hospital setting*

| ADOLESCENT INDICATORS | PARENT INDICATORS |
|---|---|
| **1. WELCOME IN THE HOSPITAL** | |
| Proportion of adolescent patients who felt welcome in the hospital at their last episode of care. | Proportion of parents who felt welcome in the hospital at their child's last episode of care. |
| | Proportion of parents who felt that their child was welcomed by the hospital at their last episode of care.** |
| **2. AGE APPROPRIATE ENVIRONMENT** | |
| Proportion of adolescent patients who believed that the hospital provided an age appropriate environment for them. | Proportion of parents who believed that the hospital provided an age appropriate environment for their child. |
| **3. RESPECTED BY CLINICIANS** | |
| Proportion of adolescent patients who felt respected as a person by their treating team* at the hospital, at their last episode of care. | Proportion of parents who felt respected as a person by their child's treating team at the hospital at their child's last episode of care. |
| | Proportion of parents who felt their child was respected as a person by their treating team at the hospital at their last episode of care.** |
| **4. UNDERSTANDING OF HEALTH INFORMATION** | |
| Proportion of adolescent patients who fully understood the health information provided to them at their last episode of care | Proportion of parents who fully understood the health information provided to them at their child's last episode of care. |
| | Proportion of parents who felt that their child fully understood the health information provided to them at their last episode of care.** |
| Proportion of adolescent patients who believed they received enough information from their treating team about their medical problems at their last episode of care | Proportion of parents who believed they received enough information from their child's treating team about their child's medical problems at their last episode of care. |
| **5. INVOLVEMENT IN DECISIONS ABOUT CARE OR TREATMENT** | |
| Proportion of adolescent patients who felt sufficiently involved in decisions about their care and/or treatment at the last episode of care. | Proportion of parents who felt that their child was sufficiently involved in decisions about their care and/or treatment at their last episode of care. |
| **6. COMFORT ASKING QUESTIONS ABOUT HEALTH AND WELLBEING** | |
| Proportion of adolescents who felt comfortable to ask questions about their health and wellbeing while at the hospital, at their last episode of care. | Proportion of parents who felt that their child felt sufficiently comfortable to ask questions about their health at their last episode of care.** |
| **7. HEALTH RISK AND PSYCHOSOCIAL BEHAVIOURS DISCUSSIONS** | |
| Proportion of adolescent patients who have had discussions about health risk behaviours and psychosocial issues with their treating team in the past 12 months. | Proportion of parents who think their child had discussions about health risk behaviours and psychosocial issues with their treating team in the past 12 months.** |
| **8. CONFIDENTIALITY DISCUSSIONS** | |
| Proportion of adolescent patients who have had confidentiality discussed with them by the treating team in the past 12 months. | Proportion of parents who have had confidentiality discussed with them in the past 12 months. |

* Treating team includes medical, nursing, allied health and technical staff

** Questions asked of parents as a proxy for their child.

# BACKGROUND

| ADOLESCENT INDICATORS | PARENT INDICATORS |
|---|---|
| **9. TIME ALONE IN CONSULTATIONS** | |
| Proportion of adolescent outpatients over the age of 14 years who have spent at least some of a consultation alone without their parents at the last episode of care. | Proportion of parents who feel it is important for adolescent outpatients over the age of 14 years to spend some of their consultation alone with members of their treating team. |
| **10. SELF-MANAGEMENT** | |
| Proportion of adolescent patients who have had a discussion with their treating team about self management within the past 12 months. | Proportion of parents who have had a discussion within the past 12 months with their child's treating team about their child's growing capacity for self management and the changing role of a parent as their child matures. |
| **11. TRANSFER TO ADULT HEALTH SERVICES** | |
| Proportion of adolescent patients aged 16 and above who feel prepared/confident about leaving the RCH and transferring to adult health services in due course. | Proportion of parents of adolescents aged 16 years and above who feel confident about their child leaving the RCH and transferring to adult health services in due course. |
| **12. SUPPORTED TO CONTINUE EDUCATION** | |
| Proportion of adolescent inpatients who felt sufficiently supported to continue their education at their last admission. | Proportion of parents who felt that their child was sufficiently supported to continue their education at their child's last admission. |
| **13. CONNECTION TO EXTERNAL SOCIAL SUPPORTS** | |
| Proportion of adolescent inpatients who felt sufficiently connected to their external social supports during their last admission. | |

* Treating team includes medical, nursing, allied health and technical staff

** Questions asked of parents as a proxy for their child.

Approximately half of the indicators relate to healthcare engagement while the other half relate to evidence based care which underpins quality healthcare. For example, one indicator of engagement is the proportion of adolescents who fully understood the information provided to them at their last episode of care (admission or outpatient visit). Another indicator of healthcare engagement is the proportion of adolescents who felt respected.

Indicators of quality healthcare delivery to adolescents refer to the last 12 months and include the proportion of adolescents whose doctors had discussed confidentiality with them, the proportion of adolescents whose doctors had undertaken psychosocial assessment, and the proportion of adolescents with a chronic condition whose treating team had discussed transferring to adult heath care in the future.

Given the hospital's focus on patient and family-centred care, it was considered important to assess the level of healthcare engagement of parents (or carers/guardians) as well as adolescents; the majority of our patients still live with their families during adolescence, and the engagement of their parents with the RCH is critical to their role in supporting their children manage their health.

As healthcare can be delivered by doctors, nurses and other clinical staff (eg allied health, technicians), distinct questions were asked about adolescent and parent engagement with each of these groups of clinicians.

# BACKGROUND

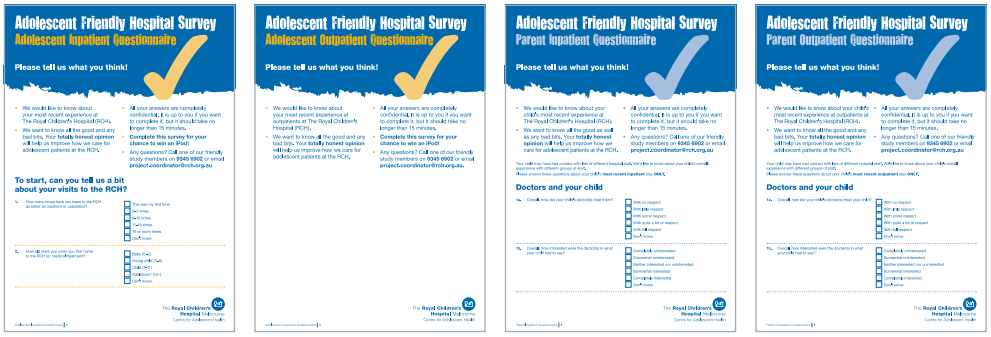
## Survey development, validation and piloting

Having developed a conceptual framework for an adolescent-friendly hospital and a set of indicators to measure this, we returned to our systematic review of measurement of adolescent friendly healthcare (from the perspective of adolescents) in order to identify possible survey tools and determine how well these addressed our set of indicators. For this purpose, we also searched the grey literature and considered various unpublished tools, including a new survey that was still being developed by the Picker Institute at this time (Young People's Experience of Hospital Health Care Survey). None of these instruments was deemed suitable, mostly because they (i) did not address our key indicators, but also because of (ii) inadequate survey development processes (ie lack of rigour), and (iii) insufficient developmental focus.

In association with the RCH Youth Advisory Council, we then developed a survey to measure the set of indicators that was called the 'Adolescent Friendly Hospital Survey'. Separate surveys were developed for adolescents and parents, each with an inpatient and outpatient version. The parent survey sought both the parent's perceptions of the quality of engagement by the hospital with their adolescent (eg whether information provided was understood by *their son or daughter*, whether *their son or daughter* felt welcome at the hospital) as well as with them as parents (eg whether *they* understood information provided to them, and whether *they* felt welcome at the hospital). Thus, in addition to the adolescent's assessment, we also set out to use the parent survey as a proxy for their children's assessment. This was because we did not know how reliable adolescents (especially younger adolescents) might report this information, nor did we know how congruent parent and adolescent assessments would be.

Following this process of face validation, we recruited 25 adolescent inpatients and their parents to determine whether the questions addressed the constructs we wished to measure (construct validity) and to ensure the appropriateness of the wording of questions and response options. Minor modifications took place as a result. Piloting of the questionnaire with these same 25 adolescents and their parents confirmed that the surveys took about 15-20 minutes to complete. The surveys were then formatted for completion using (i) a pen and paper version, (ii) an on-line version, and (iii) the option to complete by telephone (CATI survey).

*Figure 3. The cover of the four questionnaires*



# BACKGROUND

## Ethics approval

Approval was obtained from the RCH Human Ethics Committee to survey adolescents and parents using the newly developed Adolescent Friendly Hospital Surveys. Informed consent was required by both the parent and the adolescent, and was based on completion of the survey. An opt-out option was available if a selected family did not wish to participate.

## Participant recruitment and tracking

A representative sample of 12-18 year old patients (age, hospital department and inpatient/outpatient status) was then identified. The participant recruitment and tracking process involved a highly detailed process that was developed in collaboration with RCH Decision Support and Clinical Epidemiology and Biostatistics Unit (CEBU). This is described in detail in Appendix 1. Patients could only be surveyed once, even if they had multiple visits to different departments during the survey period. Parents could be surveyed more than once if the hospital visit related to another child.

## Sampling

Different sampling approaches were required for inpatients and outpatients in order to recruit a representative sample. The survey had initially been planned for late 2010. This was delayed until February 2011 as analysis showed that December-January were atypical months for the RCH. We planned to survey over a 3 month time period.

The details of the sampling approach for outpatients (OPs) and inpatients (IPs) are described in Appendix 2.

# RESULTS

## Description of sample

**Adolescent and parent responses are detailed in the participant flow diagram (Figure 4). There were 943 parent responses (response rate 37%) and 787 adolescent responses (response rate 35%). Demographic characteristics for responders and non-responders were compared in order to identify any systematic biases between the two groups. This showed the profile of responders and non-responders was remarkably similar (Figure 5) which provides confidence about the representativeness of the sample.**

The overwhelming majority of respondents completed the pen and paper version of the questionnaires; 4% of adolescents and 5% of parents completed the on-line questionnaires.

The demographic details of the sample are provided in Figure 6. For adolescents, the proportion of males was slightly higher (53%) than females (47%). Eighty seven percent of parent responses were completed by mothers.

We set out to recruit adolescents between 12-18 years old. Our sample has a balanced distribution of responses between 12 and 16 years of age, with each year constituting around 17% of the overall sample. There is a smaller proportion of 17 and 18 year olds, who constituted 10% and 5% respectively of the sample.

Over 1 in 4 parents reported that they were born outside Australia with a similar proportion reporting they spoke a language other than English at home. Nearly 1 in 10 adolescents were born outside Australia and nearly 1 in 5 reported speaking a language other than English at home.

The sample included experienced users of the RCH; over half of adolescents and parents reported that they had visited the RCH on 10 or more occasions.

While about 1 in 3 of the sample reported that infancy was the time of their first contact with the RCH, another 1 in 3 of the sample reported that adolescence was the time of their first contact with the RCH. The reminder are scattered across the interval age period.

A detailed breakdown by unit and ward for adolescent outpatients and inpatients is reported in Appendix 3 and 4.

# RESULTS

*Figure 4. Participant flow diagram*

# RESULTS

*Figure 5. Comparison of responders and non-responders*

| | PARENTS | | ADOLESCENTS | |
|---|---|---|---|---|
| | RESPONSE % (N) | NO RESPONSE % (N) | RESPONSE % (N) | NO RESPONSE % (N) |
| **Visit Type** | | | | |
| Outpatient (OP) | 67.4 (636) | 70.1 (1139) | 66.2 (521) | 70.4 (1254) |
| Inpatient (IP) | 32.6 (307) | 29.9 (485) | 33.8 (266) | 29.6 (526) |
| **SEIFA Quartiles*** | | | | |
| 1 | 13.8 (130) | 15.7 (254) | 14.6 (115) | 15.1 (269) |
| 2 | 17.4 (164) | 16.0 (260) | 17.0 (134) | 16.3 (290) |
| 3 | 34.7 (327) | 37.0 (600) | 33.6 (264) | 37.3 (663) |
| 4 | 34.1 (321) | 31.4 (509) | 34.7 (273) | 31.3 (557) |
| **Department (OP)** | | | | |
| Adolescent Medicine | 8.6 (55) | 9.7 (110) | 7.9 (41) | 9.9 (124) |
| Medical Units | 48.4 (308) | 50.8 (579) | 48.8 (254) | 50.5 (633) |
| Surgical Units | 42.9 (273) | 39.5 (450) | 43.4 (226) | 39.6 (497) |
| **Ward (IP)** | | | | |
| Adolescent Ward | 20.8 (64) | 21.0 (102) | 20.3 (54) | 21.3 (112) |
| Day Medical | 21.8 (67) | 12.0 (58) | 20.7 (55) | 13.3 (70) |
| Medical Wards | 9.8 (30) | 10.9 (53) | 9.8 (26) | 10.8 (57) |
| Day Surgical | 24.4 (75) | 28.7 (139) | 24.8 (66) | 28.1 (148) |
| Surgical Wards | 23.1 (71) | 27.4 (133) | 24.4 (65) | 26.4 (139) |
| **Medical Unit (IP)** | | | | |
| Medical | 63.8 (196) | 64.9 (315) | 62.8 (167) | 65.4 (344) |
| Surgical | 36.2 (111) | 35.1 (170) | 37.2 (99) | 34.6 (182) |
| | M (SD) | M (SD) | M (SD) | M (SD) |
| **Mean Age of Child (SD)** | 14.50 (1.78) | 14.51 (1.76) | 14.46 (1.77) | 14.53 (1.77) |

%=within-group percentages

*Index of Relative Socio-economic Advantage and Disadvantage (IRSAD)

# RESULTS

*Figure 6. Sample demographics*

| | PARENT (943) N (%) | ADOLESCENT (787) N (%) |
|---|---|---|
| **Adolescent age (years)** | | |
| 12 | - | 136 (17.3) |
| 13 | - | 135 (17.1) |
| 14 | - | 147 (18.7) |
| 15 | - | 127 (16.1) |
| 16 | - | 125 (15.9) |
| 17 | - | 78 (9.9) |
| 18 | - | 39 (5.0) |
| **Parent age (years)** | | |
| 25-34 | 14 (1.5) | - |
| 35-44 | 371 (40.9) | - |
| 45-54 | 458 (50.5) | - |
| 55-64 | 58 (6.4) | - |
| >65 | 6 (0.7) | - |
| **Gender** | | |
| Female | 810 (86.5) | 369 (46.9) |
| **Country of Birth** | | |
| Australia | 697 (74.5) | 712 (91.9) |
| **Language other than English spoken at home** | | |
| Yes | 213 (23.2) | 127 (16.9) |
| **ATSI*** | | |
| Yes | 13 (1.4) | 14 (1.8) |
| **Number of visits to RCH** | | |
| First Time | 72 (7.8) | 77 (10.1) |
| 2-5 times | 215 (23.3) | 166 (21.8) |
| 6-10 times | 140 (15.2) | 108 (14.2) |
| 11-15 times | 99 (10.7) | 78 (10.2) |
| 16 times | 398 (43.2) | 333 (43.7) |
| **Age (years) at first RCH appointment** | | |
| Infant (0-2) | 317 (33.8) | 253 (34.5) |
| Young child (3-6) | 142 (12.9) | 98 (15.1) |
| Child (7-11) | 177 (19.3) | 148 (18.9) |
| Adolescent (12+) | 291 (34.0) | 258 (31.6) |

*Aboriginal and Torres Strait Islander

## Results

This report combines inpatient and outpatient responses, as there were no statistically significant differences between these. Questions related to the use of various spaces within the RCH and questions about aspects of education were only asked of inpatients.

Analysis of the 744 matched pairs (responses from a parent and adolescent within one family) was undertaken to determine whether there were significant differences between adolescent responses and adolescent proxy responses (the parent asked to report on behalf of their child). As there were no significant differences, responses from adolescents are reported. Where parent responses are reported, they reflect parents' own experiences at the RCH.

We have chosen to report key results as graphs with the intent of demonstrating the major areas where the RCH is performing well and where there is room for most improvement. These are presented using a traffic light colour coding scheme. Green is used to refer to the proportion of responses where the indicator was met; amber is used where the indicator was partially met; red was used when the indicator was not met. A summary of the results is reported at the end of the results section on page 27.

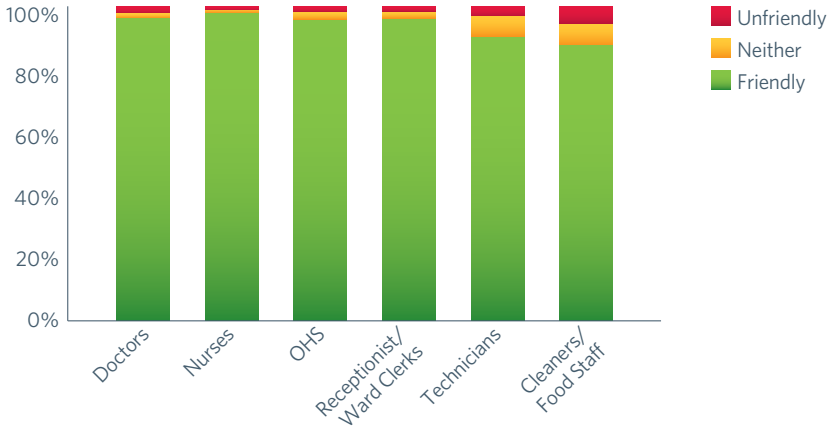
At the end of each survey, respondents were encouraged to make any additional comments. These responses have been thematically grouped and examples of quotes are included to highlight particular issues.

## A. Healthcare engagement (experience of care)

### Level of friendliness

Adolescents and parents reported a high level of friendliness from RCH staff members: over 80% of staff were reported to be friendly.

*Figure 7 Adolescent rating of staff friendliness*




*(OHS refers to other health staff eg allied health, technicians)*

Staff who were not clinically trained (e.g. receptionists, ward clerks, cleaners and food staff) were reported by both adolescents and parents to be less friendly than clinically trained staff, although this was not statistically significant.

Despite these reassuring results, a minority of negative comments were powerful in their critique of hospital practice and suggest specific ways in which we can improve.

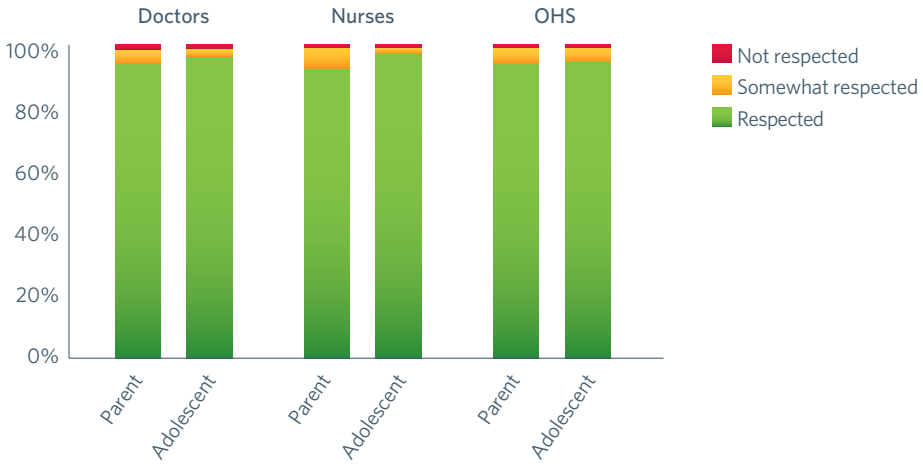
*"I have been so impressed with how the staff remember my son from one visit to the next – they chat with him about things going on in his life and ask about things they had discussed previously. The staff always have a smile and a laugh, which is great." (Parent)*

# RESULTS

## How respected adolescents and parents felt

Feeling respected is an important aspect of patient and family centered care. A high level of respect was reported by adolescents and parents; over 95% reported they felt fully or mostly respected by their treating team. There were no differences in the level of respect reported about doctors, nurses or other health staff.

*Figure 8 Level of respect reported by adolescents and parents*

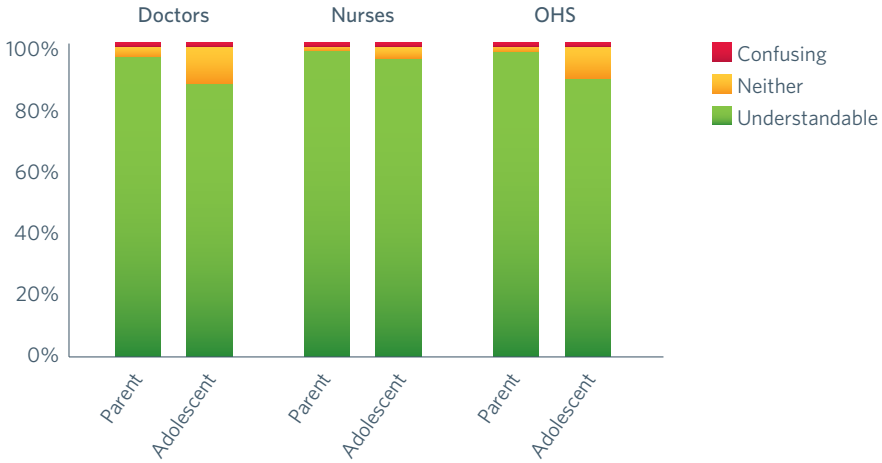



*"I don't think either of us felt part of the process. The doctor barely spoke to us until I specifically engaged her and introduced myself." (Parent)*

## Clarity of explanations

A high proportion of adolescents and parents reported understanding the health information provided to them by members of the treating team: over 85% reported that explanations were understandable.

*Figure 9 Clarity of staff explanations*




*"The RCH need to spend a bit more time explaining to the child what's going to happen to them because when we get scared we don't listen." (Adolescent)*

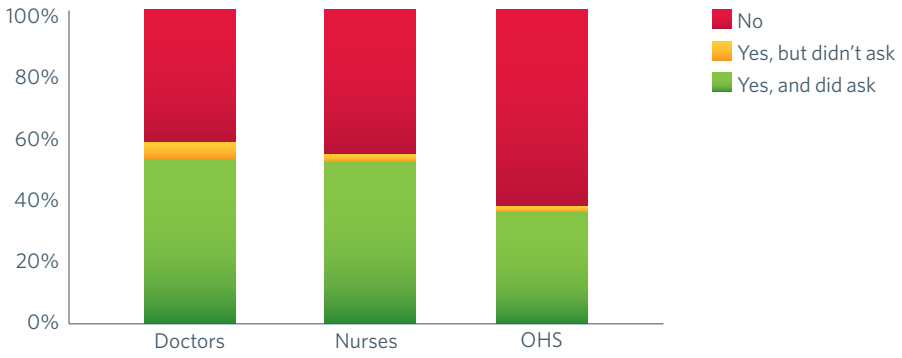
*"...when I'm having an appointment with my doctor, he usually only talks to my parents about stuff, and uses my name in the third person, like I'm not even there..." (Adolescent)*

There was a non significant trend towards more parents than adolescents reporting that health information was understandable.

However, about one in ten adolescents who had questions did not ask them, suggesting opportunities for improvement in clinical practices.

*"I think she didn't ask because she felt that she would not be heard or listened to as much as if I had asked." (Parent)*

*Figure 10 Proportion of adolescents who wanted to ask questions*




*"I don't know if this is just me, but I really would like to be told what's happening to me." (Adolescent)*

*"I felt as if I would sound stupid if I asked a basic question." (Adolescent)*

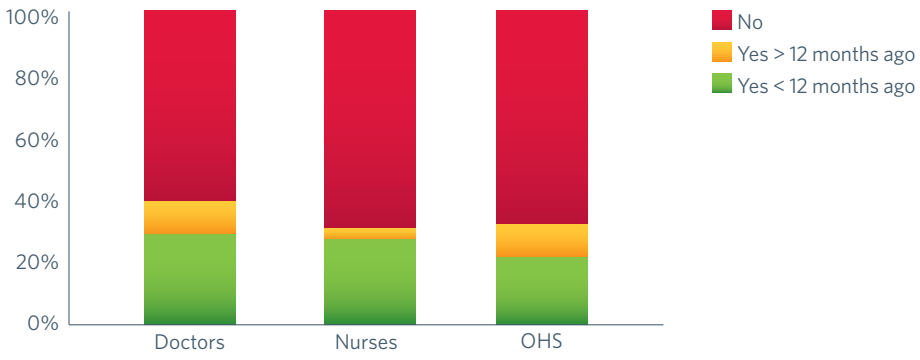
## B. Evidence based practices

The four key areas of enquiry around evidence based practice within the questionnaire were around indicators of confidentiality, routine psychosocial assessment, self management and transition to adult healthcare.

### Discussions of confidentiality

About one in four adolescents had had discussions of confidentiality by doctors, nurses and other health staff in the past 12 months, while about one in three had had discussions at some stage. Over 60% of adolescents had never had any staff member at the RCH discuss confidentiality with them. There was no association with age ie confidentiality was not discussed more often with increasing age.

*Figure 11 Discussion of confidentiality, by clinician type*



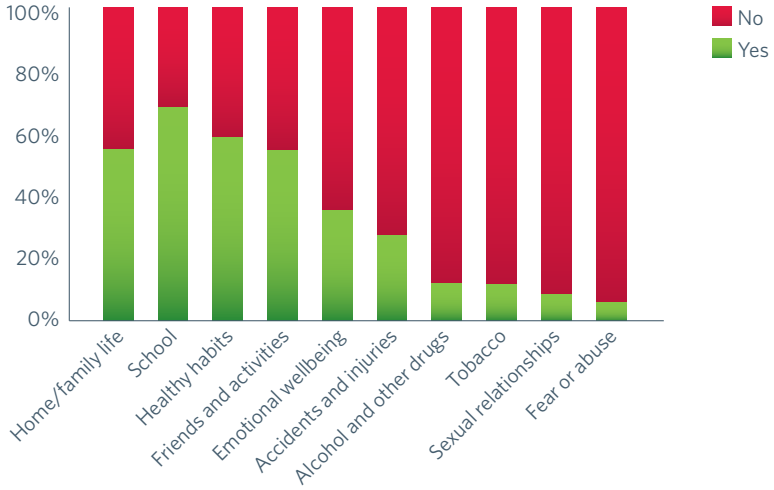
# RESULTS

### Psychosocial assessment

Approximately two out of three adolescents reported being asked about home, school, friends and activities and healthy habits (food, physical activity). An even smaller proportion had ever been asked about more sensitive aspects of substance use, sexual health and fear and abuse. The more sensitive the topic, the less likely it was assessed. The topic least reported to be assessed was fear or abuse in relationships (including within the family); only 6% of adolescents reported that a doctor has asked about this in the last 12 months. There was no association with age ie psychosocial assessment was not more likely to be undertaken with older adolescents.

*"I would have liked some more information about mental health related to my condition." (Adolescent)*

*Figure 12. Discussion of specific aspects of psychosocial history, within the last 12 months*




*"I never really felt comfortable asking about drugs. I would have liked more information about the effects of combining certain drugs with certain prescription medications." (Adolescent)*

### Promotion of self management

An 'adolescent friendly' hospital is one that both supports and promotes young people's engagement in their own healthcare.

*"...she (the doctor) asks me about my feeling, she tries to give me confidence and support so one day I can succeed." (Adolescent)*

Around two thirds (69%) of young people were satisfied with the extent of their involvement within consultations. However, nearly one in five (18%) wanted more involvement. A further 13% were satisfied without any involvement in their healthcare.

*"When doctors are explaining things or asking me questions, they speak to me as if I am younger than I am...I don't like being treated younger than I am and I would like to be more involved in issues concerning me..." (Adolescent)*

# RESULTS

Just over one third (35%) of older adolescents with chronic conditions reported having had any discussion about them taking a more active role in their own healthcare as they got older.

Linked to this, as previously stated, half of all adolescents had questions at their last consultation or visit that they failed to ask.

### Discussion of transition to adult healthcare

Questions about transition to adult healthcare were asked of adolescents aged 16 years and older (and their parents) who reported they had a health condition expected to last for longer than 12 months.

About a quarter of adolescents (25%) reported that anyone at the RCH had talked with them about transferring to adult health services in the last 12 months. About a third (33%) reported they had received the "right amount" of information about their future healthcare needs. However, just under half (46%) reported feeling prepared to transfer their healthcare from the RCH to adult healthcare services when the time came. Similarly, only around a third of parents (35%) reported that, within the last 12 months, anyone at the RCH had talked with them about their child's care being transferred to adult healthcare services, and only about half of parents (45%) felt prepared about their child's care transferring from the RCH to adult health services when the time came.

*"I'm pleased now as I have gotten older in the past year I feel like the staff are treating me less as a child and more as an adult. This will make going to an adult hospital a lot easier." (Adolescent)*

*Figure 13. Amount of information received about adult health services*

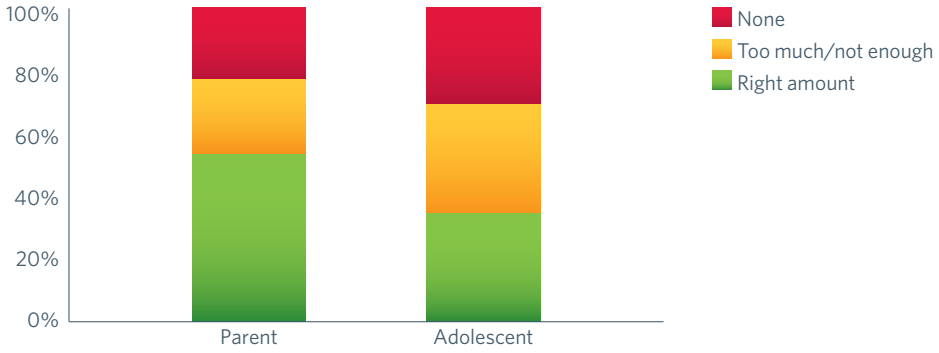
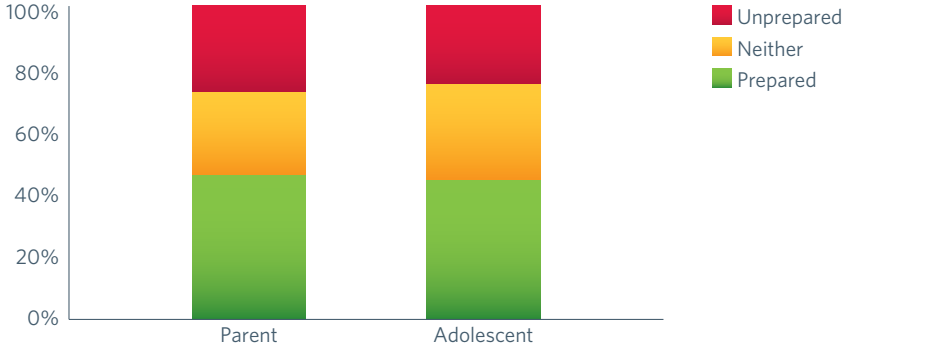



*Figure 14. Preparedness to transfer to adult health services in due course*



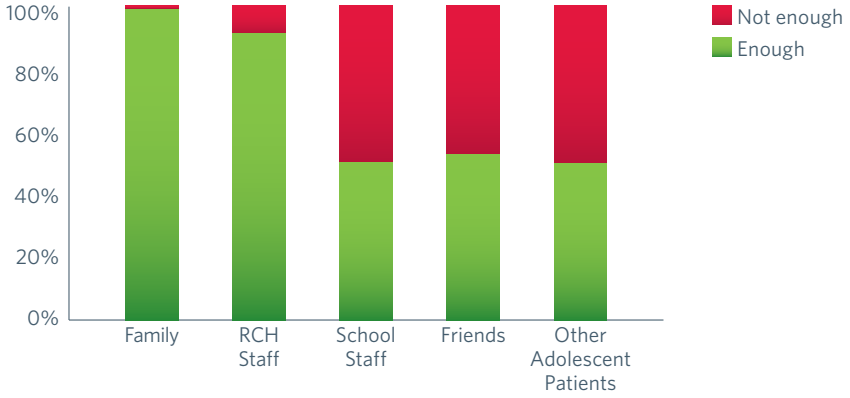

*"...my doctor is excellent. She directs questions to me and encourages independence and responsibility in me." (Adolescent)*

## C. Developmentally appropriate resources and the physical environment

Questions covered the appropriateness of the hospital's physical, recreational and educational environment for adolescents, and their parents.

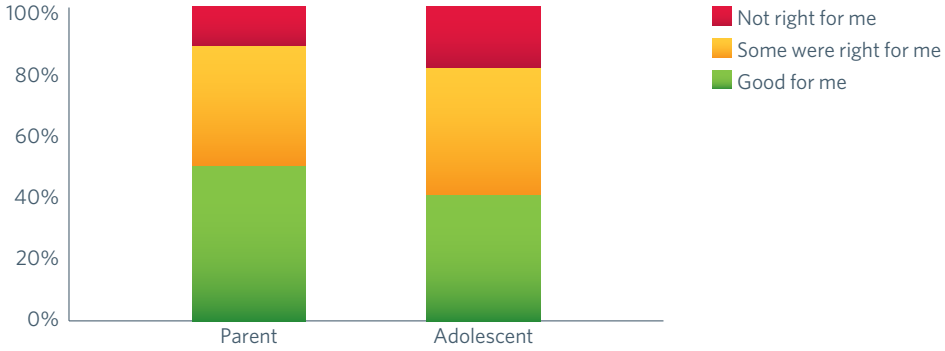
In contrast to the majority of adolescents who were satisfied they had enough access to their parents and to RCH staff while inpatients, only about 50% reported enough access to their friends, other adolescent patients, and their teachers at school.

*Figure 15. Adolescent rating of the extent of access to different people*




Both adolescent inpatients and their parents were asked to rate the appropriateness of RCH spaces and activities. Only about half of parents and adolescents rated these as being good or appropriate for them.

*Figure 16. Appropriateness of RCH spaces and activities*




*"When I stayed for five days there wasn't much that I could do because I was in a room full with babies. Next time I would like to be in a ward with children my own age so I have other people to talk to other than my mum." (Adolescent)*

*"The activities in the waiting room for day surgery were geared for younger patients." (Adolescent)*

*"Many of the staff treated me like a two year old and that make me feel embarrassed. Not to mention the environment of the hospital is embarrassing as well." (Adolescent)*

*"Not enough to do while waiting for appointments – all games are either being used or too young to play." (Adolescent)*

# RESULTS

*"When I visited the outpatient department I feel out of place and would like an area more targeted for teenagers but I am not confident about going to an adult health service. When I visit the outpatient department and there are lots of toddlers running around and babies crying, it is a bit off-putting and agitating..." (Adolescent)*

Many suggestions were made from young people about the value of making inpatient, day-patient and outpatient spaces more appropriate for adolescents.

# RESULTS

Adolescent (A) indicators: proportion of adolescents meeting indicator

| NUMBER | INDICATOR/VARIABLE | % |
|---|---|---|
| A1 | Welcome in the hospital | |
| | Felt welcome at: | |
| | The RCH in general | 91.47 |
| | Ward/unit area | 94.57 |
| | Cafeteria(s) | 83.29 |
| | Waiting rooms (e.g. radiology) | 80.63 |
| | The outpatient clinic area | 88.82 |
| | Recreation, art and education areas | 85.23 |
| | Staff friendliness: | |
| | Doctors | 96.46 |
| | Nurses | 98.07 |
| | Other health staff | 95.96 |
| | Reception clerks | 90.46 |
| | Technicians (e.g. x-ray, eye test) | 96.25 |
| | Cleaners, food staff | 87.70 |
| A2 | Age appropriate environment | |
| | Bored during their stay at the RCH | 23.83 |
| | RCHs areas and activities are appropriate for adolescents | 40.16 |
| | Used RCH facilities at last admission | |
| | Cafeterias | 34.63 |
| | Starlight room | 14.73 |
| | Garden | 18.29 |
| | Playground | 5.41 |
| | 3 East Recreation room | 12.79 |
| | Play therapy room | 1.96 |
| | Music therapy | 8.30 |
| | DVD entertainment | 36.47 |
| | Starlight portable entertainment systems | 15.23 |
| | Hospital-provided laptops | 23.26 |
| | Own laptop | 23.94 |
| A3 | Respected by clinicians | |
| | Felt respected (at least "quite a bit") by their doctor(s) | 96.35 |
| | Felt respected (at least "quite a bit") by their nurse(s) | 97.36 |
| | Felt respected (at least "quite a bit") by their other health staff | 94.56 |
| A4 | Understanding of health information | |
| | Doctor(s) explained things clearly (at least "fairly understandable") | 86.95 |
| | Nurse(s) explained things clearly (at least "fairly understandable") | 95.02 |
| | Other health staff explained things clearly (at least "fairly understandable") | 88.60 |
| | The information received from the hospital staff was consistent | 90.49 |

# RESULTS

| NUMBER | INDICATOR/VARIABLE | % |
|---|---|---|
| | Received the right amount of information about condition | 85.27 |
| | Received the right amount of information about treatments | 82.82 |
| | Received the right amount of information about medications | 73.21 |
| A5 | Involvement in decisions about care or treatment | |
| | Felt sufficiently involved in decisions about care | 68.81 |
| A6 | Comfort asking questions about health and wellbeing | |
| | Asked doctor(s) questions | 52.26 |
| | Asked nurse(s) questions | 51.52 |
| | Asked other health staff questions | 35.57 |
| A7 | Health risk and psychosocial behaviours discussions | |
| | Psychosocial Assessment (>=5 items screened) | 34.63 |
| | Home/family life | 54.98 |
| | School | 68.27 |
| | Healthy habits (eating/exercising) | 58.80 |
| | Your friends and activities | 54.63 |
| | Accidents/injury/safety (e.g. bike helmets/water safety) | 27.55 |
| | Cigarette smoking | 12.03 |
| | Alcohol, marijuana and other drug use | 11.84 |
| | Sexual relationships, safe sex, contraception | 8.54 |
| | How you're managing emotionally | 35.48 |
| | Fear or abuse in relationships | 6.01 |
| A8 | Confidentiality discussions | |
| | Doctor(s) discussed confidentiality | 28.99 |
| | Nurse(s) discussed confidentiality | 27.33 |
| | Other health staff discussed confidentiality | 21.85 |
| A9 | Time alone in consultations | |
| | Spent at least some of the consultation alone without parents (if over 14 years old) | 28.28 |
| A10 | Self- management | |
| | Had a discussion with their treating team about self-management within the last 12 months | 34.46 |
| A11 | Transfer to adult health services | |
| | Doctors, nurses or other health staff talked about transferring to adult health services within the last 12 months | 24.60 |
| | Received the "right amount" of information about the future healthcare needs of their condition | 33.33 |
| | Feel prepared about transferring from the RCH to adult health services | 45.71 |
| A12 | Supported to continue education | |
| | Continued their education | 45.11 |
| | Continued with their own education | 27.07 |
| | School teacher helped | 4.89 |
| | Parent/guardian helped | 8.27 |
| | Friends helped | 2.26 |

| NUMBER | INDICATOR/VARIABLE | % |
|---|---|---|
| | Hospital teacher helped | 8.65 |
| | Hospital teacher's group activities | 5.64 |
| A13 | Connection to external social supports | |
| | Amount of contact | |
| | Enough contact with family | 91.38 |
| | Enough contact with usual school staff | 50.53 |
| | Enough contact with friends | 51.92 |
| | Enough contact with staff at RCH | 85.96 |
| | Enough contact with patients your age | 49.07 |
| | Methods of contact | |
| | Patient contacted external network by mobile | 29.70 |
| | Patient contacted external network by hospital phone | 5.64 |
| | Patient contacted external network online, email or SMS | 21.43 |
| | Patient contacted external network through their visits | 9.02 |
| | Patient did not contact external network | 6.39 |
| | External network contacted patient by mobile | 28.20 |
| | External network contacted patient on hospital phone | 14.29 |
| | External network contacted patient online, email or SMS | 20.30 |
| | External network contacted patient by visits | 26.69 |
| | No contact from external network | 2.63 |

Parent indicators: Proportion of parents meeting indicator

| NUMBER | INDICATOR/VARIABLE | % |
|---|---|---|
| P1 | Welcome in the hospital | |
| | Felt welcome at: | |
| | The RCH in general | 90.20 |
| | Ward/unit area | 93.62 |
| | Cafeteria(s) | 69.57 |
| | Waiting rooms (e.g. radiology) | 85.96 |
| | The outpatient clinic area | 86.48 |
| | Staff friendliness: | |
| | Doctors | 96.73 |
| | Nurses | 95.95 |
| | Other health staff | 96.19 |
| | Reception clerks | 88.16 |
| | Technicians (e.g. x-ray, eye test) | 95.18 |
| | Cleaners, food staff | 90.58 |
| P2 | Age appropriate environment | |
| | Appropriateness of RCH's areas and activities | 49.17 |
| P3 | Respected by clinicians | |
| | Felt respected (at least "quite a bit") by their doctor(s) | 94.19 |

# RESULTS

| NUMBER | INDICATOR/VARIABLE | % |
|---|---|---|
| | Felt respected (at least "quite a bit") by their nurse(s) | 92.46 |
| | Felt respected (at least "quite a bit") by their other health staff | 93.97 |
| P4 | Understanding of health information | |
| | Doctor(s) explained things clearly (at least "fairly understandable") | 95.47 |
| | Nurse(s) explained things clearly (at least "fairly understandable") | 97.36 |
| | Other health staff explained things clearly (at least "fairly understandable") | 97.07 |
| | The information received from the hospital staff was consistent | 87.04 |
| | Received the right amount of information about condition | 87.63 |
| | Received the right amount of information about treatments | 86.10 |
| | Received the right amount of information about medications | 78.93 |
| P5 | Involvement in decisions about care or treatment | |
| | Felt adolescent was sufficiently involved in decisions about care | 75.49 |
| P8 | Confidentiality discussions | |
| | Doctor(s) discussed confidentiality | 26.20 |
| | Nurse(s) discussed confidentiality | 17.48 |
| | Other health staff discussed confidentiality | 21.53 |
| P9 | Time alone in consultations | |
| | Important for adolescent to have time alone | 26.14 |
| P10 | Self- management | |
| | Had a discussion within the past 12 months with their child's treating team about the child taking a more active role in their own healthcare | 35.00 |
| P11 | Transfer to adult health services | |
| | Parents feel prepared about their child transferring from the RCH to adult health services | 45.37 |
| P12 | Supported to continue education | |
| | Felt child was supported to continue their education | 78.79 |

# SUMMARY

This report describes a series of activities that set out to robustly address three questions:

(i) what are the indicators of adolescent friendly healthcare for adolescent patients in a hospital setting;

(ii) how is adolescent friendly healthcare measured in a hospital setting; and

(iii) what is the adolescent friendliness of healthcare provided by the RCH, as rated by our adolescent patients and their parents?

The whole-of-hospital survey of 787 adolescent patients and 943 parents identified that there are areas of practice around which the hospital is doing very well, and areas around which there is room for improvement. These results provide high-level evidence about the focus of subsequent interventions to improve the quality of healthcare provided to adolescents at the RCH, which is the overarching objective of this work.


This survey was undertaken in the year that the RCH moved to a new site. While it is to be expected that the move to the new RCH will change the experience of adolescents and parents at the hospital, aspects of evidence based practice would not be expected to change as a result of the move.

In the absence of published data, we were uncertain how the responses of adolescents would differ from parents. In this first survey, in addition to asking parents about their own experiences with RCH staff, we also asked them to act as a proxy for their child by asking them to tell us what they thought their child would say. It was pleasing that even young adolescents appeared able to respond to these questions. This suggests that subsequent versions of the parent questionnaire can be shortened to focus on parent experiences alone.

Similarly, we were uncertain about how similar or different would be reports about the practices of different groups of RCH staff (eg doctors, nurses, and other health staff such as allied health and technicians). Results were sufficiently similar to suggest that the next version of the Adolescent Friendly Hospital Survey groups some RCH clinical staff together.

# RECOMMENDATIONS

## 1. Organisational

- **Convene an Adolescent Friendly Hospital Steering Committee:** That the previous Adolescent Model of Care Steering Committee is reconvened as an 'Adolescent Friendly Hospital Steering Committee' to provide advice on the recommendations from this report.
- **Promote 'adolescent-friendly' spaces and resources:** That the Youth Advisory Council is engaged to provide suggestions on how to make ambulatory and inpatient environments more appropriate for adolescents.

## 2. Training and professional development

- **Increase professional development opportunities:** That within the suite of professional development activities at The Royal Children's Hospital, that priority is given to all staff being able to gain the required attitudes and skills to provide confidential healthcare and undertake routine psychosocial assessment, and how to promote adolescents' growing capacity for self management and transition to adult healthcare.
- **Develop clinical practice guidelines:** That clinical practice guidelines are reviewed to ensure that the policy environment supports clinical staff developing the required attitudes and skills to provide confidential healthcare and routine psychosocial assessment, and promoting adolescents' growing capacity for self management and transition to adult healthcare.
- **Develop orientation resource:** That an orientation training resource is developed for non-clinical staff (such as receptionists ward clerks, kitchen staff and cleaners) to support more 'adolescent friendly' interactions with adolescents, and more customer-focused interactions with parents.

## 3. Monitoring progress

- **Refine survey:** That the Adolescent Friendly Hospital Surveys are revised in order that a briefer instrument is available for a subsequent survey by The Royal Children's Hospital (and other hospitals).
- **Review and cost alternative recruitment strategies:** The concentration of outpatients and wards within the new Royal Children's Hospital suggests that efficiencies may be able to be gained from on-site recruitment, rather than sending the questionnaire home.
- **Undertake a further Adolescent Friendly Hospital Survey:** That a second whole-of-hospital survey be undertaken in the next 18-24 months in order to assess whether the adolescent friendliness of healthcare at the RCH has improved.

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# APPENDIX

## Appendix 1. Participant recruitment and tracking

The participant recruitment and tracking system involved a highly detailed process that we developed in collaboration with CEBU and RCH Decision Support.

1. Patient attends an outpatient (OP) appointment or is discharged from inpatient (IP) care.
   a. Patient details are provided daily by RCH Decision Support. Data include IP/OP status, unique patient identifier number, age, sex, department, date of appointment or discharge, length of stay (IP), primary postal address and parent telephone number/s.
   b. Patient details entered into patient tracking database created in REDCap which will ensure participants are both eligible (age, department), and are not duplicated.
2. Questionnaire information pack is sent to the parent of eligible adolescents at the home address. The pack contains parent information (cover letter, plain language statement, opt out return slip, **parent** questionnaire, reply-paid envelope, and details for completing the questionnaire online or over the phone), and a separate sealed pack for the **adolescent**.
3. Returned mail and telephone responses were manually entered by the research staff. Online survey data were electronically entered into REDCap by the adolescents and parent as they completed the survey.
4. Follow up contact by telephone was attempted 7-10 days after the inpatient had left hospital or the hospital outpatient appointment had been attended if the questionnaires had not been returned and the parent/adolescent had not opted out of the study. Attempts to contact by telephone were ceased after 3 attempts and if no contact was made by 30 days.
5. To maximise the response rate and thus the statistical power of the study, a number of response-enhancing techniques were employed: the survey was provided in a variety of modes (paper-based questionnaire, online survey or telephone interview) and an incentive was offered to adolescents who completed the questionnaire (entry into a draw to win a raffled prize of an iPod).

## Appendix 2. Approach to sampling

**Outpatients (OPs):** Over 30,000 OPs are seen annually at the RCH. We developed a sampling strategy to obtain a representative sample of adolescents from departments that see >150 adolescents a year over a two month period. Based on 2010 data, 6,087 outpatients were expected to be seen in any typical two months in these departments. We planned to survey 1198 adolescents, with the quotas for each department set so that the proportion of adolescents from each department surveyed would reflect the quotas seen in any typical period of time at RCH. The total sample size was selected to ensure that >100 young people would be recruited from the five departments who see the most adolescents (Orthopaedic Surgery, General Paediatrics, Endocrinology, Dental Services, Adolescent Medicine), giving us a sufficient sample size to detect changes in responses for these departments over time. For example, for a department with 100 young people surveyed at each wave, we would be able to detect a 15% improvement in response from 75% to 90% with 80% power at 95% significance level. All eligible patients were asked to participate until the quotas for each department were met. We assumed that the random nature of hospital appointments would ensure that a random sample would be achieved.

**Inpatients (IPs):** In 2010, the RCH had around 6,000 unique adolescent admissions. We decided to use a census approach: the survey was sent to all eligible adolescents and

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a parent over the three month sampling period. Based on 2010 data, it was expected that around 1041 adolescents would be discharged from 14 selected wards/units in the two month period. If we assumed a 70% response rate, 729 adolescents and their parents would participate with >100 recruited from the 3 wards that see the most adolescents (Day Surgical Unit, Day Medical Unit, and the Adolescent Unit).

**Exclusion criteria:** For each survey, adolescents who attended the RCH multiple times during the study period (as either IP or OP) were only invited to participate after their first contact. A small number of parent/guardian(s) would be approached more than once if more than one child was seen during the enumeration period. For IPs, wards/units were excluded if (i) they were not physically based in the hospital (e.g. RCH@Home) or (ii) if patients were transferred to another unit before discharge (eg ICU).

Appendix 3. Participating adolescent outpatients (n=521), by department

| DEPARTMENT | N (%) |
|---|---|
| Adolescent Medicine | 41 (7.87) |
| Allergy | 14 (2.69) |
| Cardiac services | 34 (6.52) |
| Clinical Oncology | 20 (3.84) |
| Community Child Health | 7 (1.34) |
| Dental Service | 45 (8.64) |
| Dermatology | 10 (1.92) |
| Developmental Medicine | 12 (2.30) |
| Endocrinology | 50 (9.60) |
| Gastroenterology | 29 (5.57) |
| General Paediatrics | 42 (8.06) |
| General Surgery | 7 (1.34) |
| Haematology | 1 (0.19) |
| Mental Health | 3 (0.58) |
| Nephrology | 16 (3.07) |
| Neurology | 32 (6.14) |
| Neurosurgery | 12 (2.30) |
| Ophthalmology | 7 (1.34) |
| Orthopaedic | 82 (15.74) |
| Otolaryngology | 6 (1.15) |
| Plastic and Maxillofacial Surgery | 28 (5.37) |
| Respiratory Medicine | 18 (3.45) |
| Urology | 5 (0.96) |

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Appendix 4. Participating Adolescent Inpatients (n=266), by ward and unit

| WARD | N (%) |
|---|---|
| Adolescent Unit | 54 (20.30) |
| Ambulatory Care (3) | 55 (20.68) |
| Banksia | 4 (1.50) |
| Children's Cancer Centre | 3 (1.13) |
| Children's Neuroscience Centre | 18 (6.77) |
| Day Surgical Unit | 66 (24.81) |
| Fifth Floor Medical | 5 (1.88) |
| Ward 4 Main | 42 (15.79) |
| Ward 4 North | 12 (4.51) |
| Ward 7 West | 7 (2.63) |

| MEDICAL/SURGICAL UNIT | N (%) |
|---|---|
| Adolescent Medicine | 19 (7.14) |
| Allergy | 8 (3.01) |
| Cardiac Surgery | 4 (1.50) |
| Cardiology | 2 (0.75) |
| Child Cancer Centre | 6 (2.25) |
| Clinical Haematology | 5 (1.88) |
| Dermatology | 4 (1.50) |
| Developmental Medicine | 1 (0.37) |
| Endocrinology | 15 (5.64) |
| Gastroenterology | 36 (13.5) |
| General Medical Units (4) | 11 (4.13) |
| General Surgery | 34 (12.78) |
| Gynaecology | 2 (0.75) |
| Medical Imaging | 2 (0.75) |
| Nephrology | 2 (0.75) |
| Neurology | 12 (4.51) |
| Neurosurgery | 11 (4.13) |
| Orthopaedic | 39 (14.66) |
| Otolaryngology | 7 (2.63) |
| Plastic Surgery | 29 (10.90) |
| Psychiatry | 4 (1.50) |
| Rehabilitation | 1 (0.37) |
| Respiratory Medicine | 5 (1.88) |
| Urology | 7 (2.63) |

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