Council for Children's Hospitals' Care

Report on the Inter-Hospital Referrals, and the Co-ordination and Sharing of Information

March 2003
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March 2003

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I. INTRODUCTION

A. Why the Sub-Committee on the Inter-Hospital Referrals and the Co-ordination and Sharing of Information was established:

The three paediatric hospitals in their proposals to the Department of Health and Children (February 1998) for the establishment of this Council stated: 'The Chairmen, Boards and staff of the three hospitals wish to collaborate more closely in order to maintain and improve the services available to children and their families... The Joint Council would be a joint working group which would identify specific actions needed to facilitate necessary changes and development'. They then made 13 specific proposals. The first three of these were:

1. Addressing organisational structure in a manner that looks to the long-term welfare of patients.

2. Ensuring that all children have access to necessary procedures and treatments, whatever the financial status of their families.

3. Promoting greater co-ordination of the care of the child/patient.

The hospitals' ninth proposal 'Facilitating an effective liaison between various specialist services involved in the delivery of care to a specified child, or groups of children' is also very relevant to the work of this Sub-Committee. These proposals then and the Department of Health and Children’s response to them (February, 1999) provide the context in which this Sub-Committee was established.

B. The Members of the Sub-Committee:

The National Children's Hospital, Tallaght:
Ms Catherine MacDaid
Ms Maura Connolly
Dr Peter Greally

The Children's University Hospital, Temple Street:
Dr Anne Twomey
Ms Rita O'Shea
Ms Anna Dermody

Our Lady's Hospital for Sick Children, Crumlin:
Mr Esmond Fogarty
Ms Emily Logan until February 2002, replaced by Ms Aileen Connolly
Ms Moira McQuaid

ERHA:
Mr Willie Rattigan
Chairperson of the Sub-Committee
Dr Helen Burke

Report Writer - Secretary:
Ms Joanne Doherty (until August 2002)
Ms Helen Byrne (since August 2002)
C. The Terms of Reference:

1. To identify the scope and method of co-ordination among the three hospitals in providing continuity of care for specific patients or patient groups and, where necessary, to make recommendations on how this co-ordination and co-operation can be improved.

2. Collect information from the three hospitals on current practice in regard to referrals.

3. Identify, as far as possible, the extent and type of patient referrals currently being made between the three children's hospitals and with other hospitals.

4. To review the procedures underpinning these referrals.

5. Always keeping in mind the best interests of the child, to make recommendations on how these procedures could be improved.

6. To develop procedures for sharing information relevant to the needs of the child and their family.

D. The Consultation and Data Collection Process:

In October 2001, the Council ratified the Terms of Reference and the Sub-Committee identified some accompanying questions. (See Appendix B)

It was agreed that the Chief Officer would meet with each of the three children's hospitals and the Directors of Nursing arranged these meetings. (See Appendix A for list of participants).

These meetings provided much information that was then collated, discussed and developed by the Sub-Committee into the first draft of this report. Further data collection enhanced the development of this report. The statistical data presented in this report is for 2001. Information on 2002 and 2003 can be obtained directly from the individual hospitals.

The referrals discussed in this report include referrals among the three children's hospitals in Dublin as well as referrals between the children's hospitals and hospitals throughout Ireland.

The Sub-Committee met on five occasions to work on succeeding drafts of this report.

E. The Report:

Section II describes the current pattern of referrals in the three Dublin children's hospitals.

Section III focuses on the problems that can arise in the current situation and indicates what needs to be addressed.

Section IV identifies what is currently working well and some models of best practice.

Section V draws some conclusions.

Section VI proposes 22 recommendations for implementation by the Council, the three hospitals and the ERHA.

The Council at its meeting on February 20th 2003 approved this report.
F: Acknowledgements:

The Council for Children's Hospitals' Care greatly appreciates the work that members of the Sub-Committee from the three children's hospitals put into producing this report. The Council thanks the Sub-Committee members and all those other colleagues in the three hospitals who contributed to the data collection and consultation process carried out for this report. Keen interest was shown in improving the referrals of children to the three paediatric hospitals in Dublin.

All comments, ideas and feedback were carefully considered by the Sub-Committee and Council and these contributed to the final recommendations included in the Report.
II. THE CURRENT PATTERN OF REFERRALS

The three very busy children's hospitals in Dublin receive numerous direct admissions through A&E, as well as referrals from the other hospitals in Dublin, from hospitals throughout the country and from general practitioners.

Table 1: Numbers of Beds and Admissions to Children's Hospitals in 2001 for In-Patients and Day Cases

<table>
<thead>
<tr>
<th></th>
<th>OLHSC</th>
<th>NCH</th>
<th>CUH</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>In Patient Admissions</td>
<td>11,671</td>
<td>5,125</td>
<td>7,338</td>
<td>24,134</td>
</tr>
<tr>
<td>Day Cases</td>
<td>6,363</td>
<td>3,979</td>
<td>3,560</td>
<td>13,902</td>
</tr>
<tr>
<td>Total Bed Days</td>
<td>58,936</td>
<td>14,741</td>
<td>31,025</td>
<td>104,702</td>
</tr>
<tr>
<td>Average Length of Stay</td>
<td>5.04</td>
<td>2.89</td>
<td>4.23</td>
<td>4.05</td>
</tr>
<tr>
<td>Total Number of Beds</td>
<td>254</td>
<td>73</td>
<td>136</td>
<td>463</td>
</tr>
</tbody>
</table>

Source: Figures supplied by the three children's hospitals

Referrals can be for secondary care, tertiary care or for a combination of both. All the hospitals provide whatever care is in the best interest of the patient, and at times this may result in referral to another hospital either for admission as an in-patient or for out-patient services.

Any transfer of a patient can impede the monitoring and treatment of the patient and cause additional stress on the patient, their family and the staff. Therefore, the most preferred option is, where possible and appropriate, to keep the child on site so that the services come to the child.

A. Types of Referrals

Paediatric and neonatal referrals can be for the tertiary specialty a hospital provides, for intensive care, or for a specific investigative procedure and may come from any part of the country. However, currently, other referrals for patients from outside the ERHA catchment area may be for care that could otherwise be provided at a local hospital, but referral to a paediatric hospital in Dublin is preferred.

1 Number of nights during inpatient stay, often used as a proxy measure for resource use and used as the dependent variable in DRG derivations.

B. What Determines Referrals?

Referrals are determined by the tertiary service the patient needs to access, by the consultants referring on to another consultant, by the maternity hospitals, general practitioners and by parents.

1. Maternity Hospitals
Newborn infants needing tertiary or secondary care are transferred to the children's hospitals depending on speciality of care required. Hospitals providing neonatal care also accept referrals from peripheral hospitals as requested. The National Neonatal Transport Service is used to transport infants up to six weeks of age from hospitals around the country to one of the neonatal intensive care units or the children's hospitals during the hours of 9am to 5pm.

2. Tertiary Service
Patients are referred to a hospital providing the relevant tertiary specialty. The specialty makes the choice of paediatric hospital clear.

3. Consultants
Consultant to consultant referral is rapid and effective, both parties can take responsibility, there is certainty in the communication and it can remove barriers to the referral. Consultants have their own affiliations that can facilitate access. However, this may result in a child being transferred away from its own community.
When the consultant is based at a different hospital, the patient may not be referred back to the original hospital so continuity of care would be maintained by the second consultant. This is determined by the consultant's preference. In the absence of clear guidelines, how the referral takes place is determined by who the consultant is.

4. General Practitioners
The choice of hospital can be determined by the general practitioner's personal knowledge and experience of the hospital or the consultants who work there, and the geographical proximity of the hospital.

5. Parents or Families Caring for the Child
Families are more assertive and confident nowadays in stating where they want their child to be hospitalised. Referrals back to the referring hospital may not happen because a family may prefer their child to remain at the hospital that has provided the specialist or intensive care. All of the hospitals consulted understood and respected the family's perspective and why they may choose to, or not to, have their child referred back to the original hospital.

6. Accident & Emergency Department
Direct referrals are also made from the hospital's A&E Department to another hospital for care. These referrals are determined by the clinical needs of the patient and bed availability in the hospital.
III. PROBLEMS THAT CAN ARISE WITH REFERRALS AND HOW THEY MAY BE ADDRESSED

A. Anxiety for the Patient and Family

The admission of a child to hospital is invariably stressful to both the child and the family. This stress can be increased when a child has to be transferred to another hospital. However, if a child has had to be transferred for specialist care, it is understandable that the parents may prefer the child to stay at the second hospital and not be referred back to the original hospital, in case they need re-referring. Families may have concerns and a lack of confidence that the hospital originally referring the child can provide the on-going care, particularly if the child is suffering from a serious chronic illness or has needed intensive care. The parents and the child usually establish a relationship with the multidisciplinary clinical team. As care is provided, staff, services and the environment become familiar to the family and child.

Referral of patients to another hospital away from their own community and network can place an additional emotional and financial stress on the family. Transport and costs for Dublin parents travelling between the north side of the city and the south side can be significant and even more so for families who live outside of Dublin. There is some financial assistance available for people with medical cards but other families on low incomes without a medical card may find the financial costs very difficult.

If facilities to treat a child are not available in their own health board area, the health board should provide reimbursement towards the costs of family visits. This should apply when the parents have a medical card or a low income.

B. Transmission of Information About the Child

Transfer of the patient with the chart, or photocopy of it, is recommended so that the information for managing the care accompanies the patient. If accurate up to date information is not transferred with the patient, this may impede the treatment of the child and the parent’s confidence in the quality of care may decrease.

The hospitals agree that the transfer letter, photocopied documentation and a verbal phone call to support the written material provides comprehensive information about a patient being referred. Photocopying information is accurate and minimises risk of error. Faxing of patient information may not be confidential, and can be difficult to access after hours. Inclusion of the full multidisciplinary team in this process ensures that other relevant information about the services the patient is receiving is exchanged e.g. speech and language therapy or physiotherapy.

Access to full information is important if a child presents at one hospital but has had significant surgery or treatment at another hospital. Communication about patients can be affected when a consultant is at a hospital only on occasional weekdays. Shared appointments of consultants between hospitals can create communication problems. Some of these problems can be addressed by a team approach where consultants cover for each other.
Out Patient Department referrals can be duplicated and triplicated. Parents are sometimes advised by their general practitioners and consultants to place children on waiting lists at the three hospitals and to attend which ever hospital first offers them an appointment. Contacting patients before the appointment, particularly those patients who have been waiting a long time, to ascertain that the appointment is still required, may reduce the numbers of non-attendances.

The development of common charts, referral forms and compatible information technology links between the three hospitals would greatly facilitate the exchange of accurate information. This would include electronic discharge summaries and inter-hospital access to electronic notes so that a patient's file can be accessed in all hospitals. Confidentiality issues would need to be addressed.

C. Translation and Interpreting Difficulties

Access to accurate information about a patient's medical and surgical history can be problematic when the parent or caregiver does not speak English. This has become a significant issue for hospitals. As Ireland's refugee and migrant population increases, the use of a 24-hour professional, confidential translation service would improve the access to accurate information about the patient. The interpreters providing the translation services must be familiar with medical terminology and, if possible, with the different medical teams.

The current situation could be improved by giving parents a copy of the discharge summary from the hospital as the nurse conveys the discharge information. A detailed report would be sent to the GP.

Training of staff in understanding beliefs about health in different cultures has begun in the hospitals but it requires additional funding from the ERHA.
D. Intensive Care Beds and General Beds

Table 2: General Bed and ICU Bed Numbers at the Children’s Hospitals

<table>
<thead>
<tr>
<th>2001</th>
<th>OLHSC</th>
<th>NCH (1)</th>
<th>CUH</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total No of Beds</td>
<td>254</td>
<td>73</td>
<td>136</td>
<td>463</td>
</tr>
<tr>
<td>Total No of ICU Beds</td>
<td>16</td>
<td>-</td>
<td>5</td>
<td>26</td>
</tr>
<tr>
<td>Total No of HDU Beds</td>
<td>5</td>
<td>3</td>
<td>4</td>
<td>7</td>
</tr>
</tbody>
</table>

Source: Figures supplied by the three children’s hospitals

Notes: (1) National Children’s Hospital, Tallaght has no ICU but has a High Dependency Unit (HDU)

Intensive Care Unit Beds

A more formal system of determining paediatric ICU bed availability in Dublin city is recommended. At present there is an ad-hoc knowledge of ICU bed availability on a daily basis, but this is insufficient. The senior anaesthetist is the person responsible for coordinating the allocation of ICU beds, in consultation with other consultants and nursing coordinators. Sometimes children awaiting referral to paediatric ICU beds are held in adult ICU beds around the country, when immediate referral is warranted.

The increasing need for neonatal intensive care beds can affect the availability of paediatric intensive care beds. At present 46% of all intensive care admissions to The Children’s University Hospital, Temple Street and Our Lady’s Hospital for Sick Children are for children under three months of age. The predicted “baby boom” may further impact on the availability of intensive care unit beds. Although the number of neonatal surgical cases remains reasonably static there is an increase in the demand for neonatal intensive care beds. Therefore, increasing the number of neonatal intensive care beds is the most effective way of ensuring that valuable paediatric intensive care beds remain available.

The development of clear guidelines for each ICU unit would help the management of neonatal patients both in the children’s hospitals and the peripheral hospitals. Knowing how many neonatal patients each unit could manage, whether they had designated nursing areas, how many patients could be ventilated, and what intensive care services are provided would be very helpful.

Access to ICU beds is not only dependent on the availability of a bed, but also on the availability of the specialty service the patient requires e.g. cardiology. Establishing
well-staffed and well-equipped step-down units throughout the country would alleviate the demand on ICU beds in the three children’s hospitals.

The Irish Medical Journal, March 2002, Volume 95 published a paper entitled Accessibility of Intensive Care Facilities in Ireland to Critically Ill Patients. Charles, Marsh et al (2002) undertook a survey to quantify the need for ICU beds, to determine the disparity between requests for ICU admission and bed availability, and to determine the associated impact on patient access to Intensive Care. The study included the two paediatric hospitals in Dublin with ICUs and found that they had a 95% occupancy rate, and that during the period of the survey a further 20 (30%) emergency referrals could not be admitted. Only 2% of these were because of a structural lack of beds and in 74% of the cases a shortage of appropriate paediatric intensive care nursing staff rendered the ICU bed unavailable. The paediatric ICUs operated at an occupancy rate of 26% over that advised by the European Society of Intensive Care Medicine and the Manpower Study for the Department of Health, UK.

The authors concluded that the provision of paediatric critical care in the ERHA is in crisis, that these units are also providers of that care for the whole country and that while the infrastructure is inadequate, this is not as big an issue as the provision of adequately trained nurses to staff the units.

General Beds
Unfortunately, it was not possible to gather comparable information on occupancy rates in 2001 from the hospitals. The representatives of the three hospitals reported that at times there are insufficient paediatric beds at the children’s hospitals which reflects the seasonality of acute paediatric illnesses. This can result in children needing a multidisciplinary investigation sometimes having to wait two or three weeks in a referring hospital, because of the lack of general beds available. Furthermore, when hospitals manage beds at a full occupancy rate no extra beds are available when there is extra demand e.g. during winter the demand for beds for children with bronchiolitis increases significantly.

Beds are closed for a variety of reasons, all of which affect the occupancy rate. Some of these reasons are:

(i) Staff shortages - there are limited numbers of trained paediatric nurses

(ii) Maintenance of buildings or equipment – refurbishing of wards or repairs to equipment may result in beds being closed temporarily

(iii) Needs of the patient – e.g. if considerable space is required for equipment, or if a patient needs care in a single room and none is available, this means a second bed is closed

(iv) Isolation care of patient – if the patient has to be nursed in isolation

A general bed pool across the three children’s hospitals was regarded by the Sub-Committee as of limited benefit and was seen as unnecessary bureaucracy. It was felt it would be a barrier to accessing general beds.
The bed managers and the admission office at each site look after the use of general beds at the three hospitals. Paediatric admissions through A&E tend to get busier later in the day and in the evenings so extending the opening hours of the admission office would help the hospitals respond to this.

E. Ambulance Service

A mobile paediatric intensive care ambulance is regarded as essential to provide the safest mode of transport for critically ill infants and children. It would ensure bed to bed transfer of intensive care patients. With the appropriate paediatric ICU staff and equipment on board the ambulance, the child is transferred with minimal compromise to care. Ideally, this would be a joint service across the three children's hospitals. The neonatal ambulance service in Dublin is working well and provides a model of what is needed for a paediatric ICU ambulance service. The neonatal ambulance service transported over 170 neonates in the first 12 months of operation. However, this service is limited by its operating hours of 9am – 5pm.

An ambulance service responsive to the needs of sick children being available 24 hours a day is recommended. However, there may be occasions when dealing with critically ill children who require prompt intervention that air transport would provide a better service. Provision of transport for children in non-emergency situations is also recommended. This would ensure that children without access to transport could attend ongoing specialist services such as physiotherapy or speech therapy as required. There are significant delays in transporting some patients from the children’s hospitals if the ambulance service waits for a request for a passenger on the return trip.

F. Referring Children Back to Local Hospitals

Referring patients back to a local hospital, even when it would be ideal for the child to receive care in the local community, can be difficult to implement. There are a variety of reasons why this may be so:

1) Limitations in specialised knowledge and techniques at the local hospital for the complexity of the care required.

2) Specialised equipment and the space needed may not be available at the local hospital.

3) Cost of long term nursing in a local hospital sometimes determines the response, in particular if full-time 24 hour nursing care is needed.

4) Transport back to a local hospital from one of the children's hospital's can be delayed if the ambulance service will only transport patients both ways, or if there is no nurse to travel with the patient.

G. Private V Public Status of Patient

All hospitals reported that they prioritise the patient’s clinical need, with the patient always treated irrespective of status. However, private status can mean that access to some services is quicker e.g. ENT.
Table 3: Public Bed and Private Bed Numbers at the Children’s Hospitals

<table>
<thead>
<tr>
<th></th>
<th>2001</th>
<th>OLHSC</th>
<th>NCH</th>
<th>CUH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public Beds</td>
<td></td>
<td>175</td>
<td>53</td>
<td>104</td>
</tr>
<tr>
<td>Private Beds</td>
<td></td>
<td>58</td>
<td>17</td>
<td>23</td>
</tr>
<tr>
<td>Non Designated Beds**</td>
<td></td>
<td>21</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Total Beds</td>
<td></td>
<td>254</td>
<td>73</td>
<td>136</td>
</tr>
<tr>
<td>Public Beds (%)</td>
<td></td>
<td>69%</td>
<td>77%</td>
<td>83%</td>
</tr>
</tbody>
</table>

Source: Figures supplied by the three Children’s Hospitals
** Non designated beds are HDU/ICU beds

Private beds are used for public patients as needed and vice versa. VHI and BUPA differ in their policy on hospital beds. The VHI system of designated beds was regarded, by the members of the Sub-Committee, as inappropriate in paediatrics. Paediatric care should always be based on the clinical needs of the child. BUPA was regarded as more flexible than VHI in approving funding for some investigations and post operative nursing care.
Table 4: Number of Public and Private Admissions in 2001 for In Patients and Day Cases

<table>
<thead>
<tr>
<th></th>
<th>OLHSC</th>
<th>NCH</th>
<th>CUH</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>2001</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public In Patients and Day Cases</td>
<td>11,263 (62.5%)</td>
<td>7,414 (81.4%)</td>
<td>7,516 (68.8%)</td>
</tr>
<tr>
<td>Private In Patients and Day Cases</td>
<td>6,771 (37.5%)</td>
<td>1,663 (18.3%)</td>
<td>3,054 (28%)</td>
</tr>
<tr>
<td>Unknown Status **</td>
<td>-</td>
<td>84 (0.9%)</td>
<td>359 (3.2%)</td>
</tr>
<tr>
<td><strong>Total Admissions</strong></td>
<td>18,034</td>
<td>9,104</td>
<td>10,929</td>
</tr>
</tbody>
</table>

Source: Figures supplied by the three children’s hospitals

** Unknown status can be public or private

It was noted by the Sub-Committee members that the public perception that “you get a better service privately” is not backed up in practice because of the comprehensive range of services available in the public health service.

H. Management of Infectious Diseases

The Council agreed that any modern paediatric hospital needs adequate facilities to treat children with infectious diseases. These children are best managed within a children’s hospital and not transferred to another site. Facilities for infectious diseases are limited in all of the three hospitals with The Children’s University Hospital, Temple Street being the most constrained.
IV. SOME EXAMPLES OF WHAT IS WORKING WELL IN REFERRALS

There are many aspects of referrals that work well and ensure the patient is receiving the best care available. The consultant-to-consultant referral, the choice of specialty, and the high quality of the information received with the referral are all examples of good practice. Referrals from other hospitals throughout Ireland also work well in most instances.

The three hospitals also identified several other models of good practice:

A. **Discharge Planning Protocols**
   Discharge planning needs to start at the time of referral and before admission. Guidelines are being developed for specific groups of patients e.g. oncology, cardiology. For these patients, referral to and from a hospital is clear from the beginning.

B. **Cardiology**
   Has a very clear referral process for emergencies with consultant-to-consultant referrals. The cardiac surgeons are available when needed. It is regarded as an excellent system, well known to nursing staff, with a well-developed structure. The Children's University Hospital, Temple Street noted the excellent access and ease of referrals to Our Lady's Hospital for Sick Children, Crumlin for echocardiograms, often at short notice.

C. **Telephone Advice Service**
   All hospitals provide telephone advice to outlying hospitals, general practitioners and parents. This service is provided by specialist consultants and nurses, and offers advice on initial best practice e.g. in the treatment of burns, or paediatric oncology and diabetes care.

D. **Shared Care Model**
   The paediatric oncology service and the paediatric diabetes service have developed protocols for information sharing and referrals. These particular services have an outreach component. The shared care may be with the hospital and a general practitioner or between two hospital consultants. If a child is receiving care from a number of health professionals e.g. a child with cystic fibrosis or asthma may be seeing a consultant, a nurse specialist, a dietician, a general practitioner, a social worker and a physiotherapist, the development of protocols ensures that the communication and responsibility for the care of the child is clear.

E. **Role of Paediatric Nurse in the Community**
   This is an important link to the community for the patient and caregiver at home as well as for the public health nurses. The Department of Health and Children is currently reviewing the role of the paediatric nurse in the community.

F. **Adolescents Transferring to Adult Service**
   It is strongly recommended that children with chronic illness have a formal transition from the paediatric service to the adult service. An example of best practice is children with cystic fibrosis who are counselled at age 15 about the process of transfer to the adult service and how it will emerge. Adolescents with diabetes, gynaecological and urological problems receive continuity of care between the paediatric and adult
service when both are available on one site. A seamless transition from paediatric to adult services can be more difficult to achieve when both services are not on the one site so clear referral guidelines are necessary to achieve a smooth transition.

Where a paediatric hospital is sited near an adult hospital, the management and funding of the paediatric hospital should be independent and not compromised by the needs of the adult service.

G. Shared Training and Education for Nurses
Training for the paediatric nurses from The Children’s University Hospital, Temple Street and Our Lady’s Hospital for Sick Children, Crumlin is linked to UCD and includes A&E and ICU courses. Study days and lectures are shared with The National Children’s Hospital, Tallaght thus providing on-going collegial support.

H. National Neonatal Transport Service
The National Neonatal Transport Service that is serviced by the maternity hospitals works well, with hospitals staffing the ambulance with consultant and nursing expertise. Each health board contributes to the funding of this national transport service. However, the operating hours of 9am-5pm does limit the use of this valuable service.

I. Dieticians
Dieticians from the three hospitals meet as a paediatric interest group every three months. They have developed an agreed information summary sheet, and know each other’s service. This helps when children are referred from one hospital to another.

J. Social Workers
The Social Workers from the three children’s hospitals meet together as members of the Head Social Workers group. Training has been shared on child protection issues and the social workers have agreed on a common data collecting process. Referrals between two hospitals may mean the roles of the social workers overlap and this is worked through between the two social workers e.g. referral for a child needing the paediatric oncology service.

K. Central Admissions Office Hours
Extended hours for the admission office or bed manager position is a good model, as paediatric A&E services get busier as the day progresses.

L. The National Children’s Hospital’s Links with Cheeverstown
This model works well because the patient is known to both hospitals, the referral process is secure for families, and there is no sense of competition between the two providers. The child is at the centre and both providers have a willingness to work together.
V. CONCLUSIONS:

There was consensus from the representatives of the three children’s hospitals on many of the issues covered in this report.

Underpinning the recommendations is the belief that a child and family centred service is what children need. This should mean that where possible, the health service comes to the child and that the sick child does not have to travel too far to access the health service. Transferring a child from one hospital to another is distressing for the patient and the family and creates an extra workload on staff. Ideally patients would remain on one site for their care, but occasionally, referral to another hospital is appropriate and necessary. The significant strain on the family’s emotional and economic resources when their child is transferred to another hospital, away from their local community, is widely acknowledged.

When referral is necessary, the Sub-Committee felt the referring consultant should have a continuing input into the care of the child who is being referred to another hospital and be able to follow the child and family for at least one consultation in the second hospital. This would ensure there is continuity of care and the referring consultant remains part of the decision making with the patient and the new consultant. When the child is referred back to the referring consultant, the reverse process should happen. This joint clinical privilege could be formalised and recognised across the three paediatric hospitals in Dublin.

The tertiary specialty, the consultants, the referring hospital, the parents or the general practitioners determine the choice of hospital for a patient. Parents may have a definite input as to whether or not a child is referred back to the referring hospital. The Council agreed that a central bed pool system is essential for improving access to ICU beds, but was regarded as of minimal use for general beds.

It is agreed that communication about patients would be greatly improved by information technology links between the hospitals, providing accurate and up to date information about children who are transferred to different hospitals. Sharing of medical records and discharge summaries electronically would make this information more accessible. Accessing accurate information from parents has become more challenging with the growing refugee and non-english speaking population in Ireland and some positive recommendations are made to improve information sharing about a patient.

Children at all three hospitals are always treated as a priority based on medical need, not on whether they are private or public patients. However, the status of a patient can affect waiting time for some procedures, e.g. ENT surgery and CT scans.

Referrals for adolescents are particularly complex and health care in a paediatric or adult unit may depend on the specialty and individual patient. An internal review of each hospital’s current practice would determine if clearer guidelines are needed.

In conclusion, some examples of best practice were identified as well as some problems in current referral practice. Enhancing communication between the hospitals and the development of some agreed guidelines would be helpful in retaining all that is working well with referrals between hospitals while reducing the problems outlined.
VI. RECOMMENDATIONS

The report concludes with some recommendations for the three children's hospitals, the Council for Children's Hospital's Care and the ERHA that will result in an improvement in the inter-hospital referrals process and the sharing of information about patients.

A. Development of Guidelines for Referrals

The three children's hospitals develop shared guidelines for referrals to and from other hospitals - including consultants, anaesthetists, nurses and other health professionals where necessary.

1. To establish a central pool for ICU and HDU beds that would include identifying each unit's capacity and management ability, available beds and facilitating direct admission to ICU or HDU.

2. Shared care guidelines for the care of patients with chronic conditions and also for interdisciplinary referrals e.g. physiotherapy, speech and language therapy, social work.

3. Development of a clear policy for the admission of patients from outside the ERHA region.

4. Reimbursement towards the cost of parental visits be provided by the health board if the child needs to be transferred for clinical reasons to another hospital that is away from home. This reimbursement is recommended for medical cardholders and those on low incomes.

5. Review of hospital policy for the care and referral of adolescents at each of the three hospitals.

B. Paediatric ICU Transport Service

6. A Paediatric ICU Transport Service for the ERHA region, based on the National Neonatal Transport Service model but would operate 24 hours a day, seven days a week.

7. The National Neonatal Transport Service to be extended to 24 hours a day.

C. Exchange of Information

8. Recognition and formalising of joint clinical privilege across the three paediatric hospitals in Dublin to provide continuity of care and participation in decision-making by the referring consultant, if requested.

9. A copy of a brief discharge summary with patient's diagnosis, treatment, plan for follow-up and medication information to be given to parents by the discharging nurse or doctor. This information is most beneficial in the event that the child
requires any further medical attention prior to the detailed report being received by
the GP. A detailed report is sent to the GP after discharge.

10. Twenty-four hour access to professional and confidential translation and
interpreting service.

11. Staff training in cultural awareness and refugee health issues to improve
knowledge and awareness of different cultural beliefs about health and illness with
adequate funding from the ERHA to provide for this.

12. The development of common charts, referral forms, request forms and compatible
information technology links between the three hospitals to facilitate the exchange
of accurate information.

13. Establish a policy for photocopying the relevant information and reports to
accompany patients on transfer to another hospital.

14. An information booklet about the three children's hospitals for GPs similar to the
Irish Medical Directory.

D. Service Development

15. Development of adequate facilities for managing infectious diseases on site at all
three children's hospitals.

16. Co-ordinator of care services in each hospital – for children with multiple needs,
who coordinates multiple appointments for the patient, and organises transfer and
photocopying of records in advance of OPD appointment.

17. Establish a central waiting list coordinator for some specialties. This would
include having a central person who knows the situation at each of the hospitals
and where a patient could access the service as soon as possible. This service
could include a circular to general practitioners informing them of the current
situation.

18. Managed clinical networks of care so that the child who needs referring elsewhere
for a specific service, does so, but is able to access all other services where they
live e.g. laboratory tests, physiotherapy.

19. A review of the overall psychiatric service for children and adolescents, including
inter-agency referrals and the urgent development of a psychiatric crisis unit for
adolescents.

20. Recommendation that prophylactic antibiotics for meningococcal contacts can be
administered free by after hours pharmacies, and not solely by the paediatric
hospitals which are currently the only after hours provider, free of charge. This is
not an appropriate use of A&E resources and often results in large numbers of
people attending to access this service. This is a community public health issue
and therefore is more appropriately provided in a community setting.
E. **Human Resources**

21. Review of education programmes for training of sick children’s nurses especially with consideration given to a direct entry integrated Bachelor of Science Degree in Sick Children’s/General Nursing leading to a RSCN/RGN qualification.

22. The role of the community paediatric nurse specialist to be developed to coordinate information and facilitate transfers of patients between hospitals and when the patient is discharged home.

In presenting these recommendations, the Sub-Committee regards all of them as important and looks forward to their implementation. However the Sub-Committee’s chair sought the guidance of the Sub-Committee to identify recommendations that they regarded as requiring urgent immediate implementation and those that could have an intermediate implementation timetable. This resulted in the recommendations being grouped together as follows.

**Recommendations for Immediate Action**

1. To establish a central pool for ICU and HDU beds that would include identifying each unit’s capacity and management ability, identifying the available beds and facilitating direct admission to ICU or HDU.

2. The three children’s hospitals to develop shared guidelines for referrals to and from other hospitals - including consultants, anaesthetists, nurses and other health professionals where necessary. The development of a clear policy for the admission of patients from outside the ERHA region.

3. Paediatric ICU Transport Service. A Paediatric ICU Transport Service for the ERHA region, based on the National Neonatal Transport Service model but open 24 hours a day, seven days a week. It is also recommended that the National Neonatal Transport Service be extended to 24 hours a day.

4. The development of common charts, referral forms, request forms and compatible information technology links between the three hospitals to facilitate the exchange of accurate information; an agreed policy for photocopying of the relevant information and reports to accompany patients on transfer to another hospital; an information booklet about the three children’s hospitals for GPs similar to the Irish Medical Directory.

5. A review of the overall psychiatric service for children and adolescents, including inter-agency referrals and the urgent development of a Psychiatric Crisis Unit for Adolescents

6. Review of education programmes for training of sick children’s nurses especially with consideration given to a direct entry integrated Bachelor of Science Degree in Sick Children’s/General Nursing leading to RSCN/RGN qualification. The role of the community paediatric nurse specialist to be developed to coordinate information and facilitate transfers of patients between hospitals and when the patient is discharged home.
7. Co-ordinator of Care Service for each hospital – for children with multiple needs, who coordinates multiple appointments for the patient, and organises transfer and photocopying of records in advance of OPD appointment. Shared care guidelines are recommended for the care of patients with chronic conditions and also for interdisciplinary referrals e.g. physiotherapy, speech and language therapy, social work. Managed clinical networks of care are recommended to ensure that a child who needs referring elsewhere for a specific service, does so, but is able to access all other services where they live e.g. laboratory tests, physiotherapy etc

**Recommendations for Intermediate Action**

8. Review of hospital policy for the care and referral of adolescents at each of the three hospitals.

9. Reimbursement towards the cost of parental visits be provided by the health board if the child needs to be transferred for clinical reasons to another hospital that is away from home. This reimbursement is recommended for medical cardholders and those on low incomes.

10. A copy of a brief discharge summary with patient’s diagnosis, treatment, plan for follow-up and medication information to be given to parents by the discharging nurse or doctor. This information is most beneficial in the event that the child requires any further medical attention prior to the detailed report being received by the GP. A detailed report is sent to the GP after discharge.

11. Recognition and formalising of joint clinical privilege across the three paediatric hospitals in Dublin to provide continuity of care and participation in decision-making by the referring consultant, if requested.

12. Twenty-four hour access to professional and confidential translation and interpreting service. Staff training in cultural awareness and refugee health issues to improve knowledge and awareness of different cultural beliefs about health and illness and adequate funding from the ERHA to provide this.

13. Development of adequate facilities for managing infectious disease on site at all three children’s hospitals

14. Recommendation that prophylactic antibiotics for meningococcal contacts can be administered free by after hours pharmacies, and not solely by the paediatric hospitals which are currently the only after hours provider, free of charge. This is not an appropriate use of A&E resources and often results in large numbers of people attending to access this service. This is a community public health issue and therefore is more appropriately provided in a community setting.

15. Establish a central waiting list coordinator for some specialties. This would include having a central person who knows the situation at each of the hospitals
and where a patient could access the service the fastest. This service could include a circular to general practitioners informing them of the current situation.
VII. APPENDICES

Appendix A

Names of People Participating in Feedback and Recommendations:

Our Lady's Hospital for Sick Children, Crumlin:

Ms. Emily Logan  Director of Nursing
Ms Moira McQuaid  General Manager
Ms Orla Keane  Clinical Nurse Manager ICU
Ms Joan Troy  Clinical Nurse Manager ICU
Ms Orla Callender  Clinical Nurse Manager A&E

The Children's University Hospital, Temple Street:

Ms Rita O'Shea  Director of Nursing
Ms Mary Walsh  Clinical Nurse Manager III
Ms Anne Marie Dowling  Clinical Nurse Manager III A&E
Ms Anna Dermody  Clinical Nurse Manager III ICU
Dr Liam Claffey  Consultant Anaesthetist
Dr Anne Twomey  Consultant Neonatologist

The National Children's Hospital, Tallaght:

Dr Mervyn Taylor  Consultant Paediatrician
Ms Síle Connell  Speech & Language Therapist
Ms Karen Fitzpatrick  Paediatric Clerical Coordinator
Ms Grainne Mallon  Dietician
Professor Hilary Hoey  Consultant Paediatrician
Ms Maura Connolly  Director of Nursing
Ms Elaine Quinn  Endocrinology Nurse Specialist
Dr Mary McKay  A&E Consultant
Ms Adrienne Brennan  Diabetes Nurse Specialist
Ms Karen Keegan  Dermatology Nurse Specialist

(People met individually and in groups at The National Children's Hospital)
Appendix B

Terms of Reference and Accompanying Issues and Questions

Terms of Reference

1. To identify the scope and method of co-ordination among the three hospitals in providing continuity of care for specific patients or patient groups and, where necessary, to make recommendations on how this co-ordination and co-operation can be improved.

2. Collect information from the three hospitals on current practice in regard to referrals.

3. Identify, as far as possible, the extent and type of patient referrals currently being made between the three children’s hospitals and with other hospitals.

4. To review the procedures underpinning these referrals.

5. Always keeping in mind the best interests of the child, to make recommendations on how these procedures could be improved.

6. To develop procedures for sharing information relevant to the needs of the child and their family.

Questions and Issues:

(i) Referrals of sick children from GPs and hospitals outside Dublin as well as within the ERHA. Do we need a system that will identify where a bed is available? Can we come up with a procedure that will smooth and fasten the transfer of a child from one hospital to another?

(ii) We need to review the procedures adopted where a consultant is shared between hospitals and a child may be referred back and forth. Does this need to be clearer in practice?

(iii) When a child is referred from hospital A to hospital B for specialist treatment, is that child referred back to hospital A for subsequent care or remain indefinitely with hospital B? Do we need a procedure to manage patient care from A to B and back to A?

(iv) Is adequate information shared by the hospitals re patient needs before and after treatment?

(v) What examples of best practice can be identified that could be adopted, if considered suitable to acute paediatric care?
Appendix C

Members of the Council for Children’s Hospitals’ Care

Chair of the Council: Dr Helen Burke

Chief Officer
Ms Joanne Doherty (until August 2002)
Ms Helen Byrne (since August 2002)

The National Children’s Hospital, Tallaght
Ms Catherine MacDaid Deputy Chief Executive Officer
Ms Maura Connolly Director of Nursing
Ms Melissa Webb Chairperson, The National Children’s Hospital Committee (until September 2002)
Mr Gerry Brady Chairperson, The National Children’s Hospital Committee (September 2002)
Professor Hilary Hoey Secretary, Paediatric Medical Advisory Committee
Dr Mervyn Taylor Chairman, Paediatric Medical Advisory Committee

Our Lady’s Hospital for Sick Children, Crumlin
Mr Paul Kavanagh Chief Executive Officer
Mr Frank Feely Deputy Chairman, Hospital Board
Ms Emily Logan Director of Nursing (until February 2002)
Ms Aileen Connolly Acting Director of Nursing (March-November 2002)
Mr Esmond Fogarty Chair, Medical Board
Mr Martin Corbally Secretary, Medical Board

Children’s University Hospital, Temple Street
Mr Paul Cunniffe Chief Executive Officer
Ms Justice Mary Finlay Geoghegan Chairperson, Hospital Board
Ms Rita O’Shea Director of Nursing
Dr John Murphy Chairman, Medical Board (until September 2002)
Dr Owen Hensey Chairman, Medical Board (since October 2002)
Dr Mary King Medical Board Representative

Eastern Regional Health Authority
Mr Jim Breslin Senior Commissioner, Planning and Commissioning Directorate (until September 2002)
Mr Willie Rattigan Service Planner for Acute Hospitals (since October 2002)