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# Table of ConTenTs

Executive Summary	0
Foreword	2
Introduction	4
Model of Care Overview	9
Background	10
Quality and Governance in Children's Services	12
Building Paediatric Research in Ireland	14
Paediatric Workforce Planning	15
Integrated Care	18
Neonatal Model of Care	19
Conclusion	24
Appendices	25
Appendix 1: Authors, contributors and acknowledgements	26
Appendix 2: Key recommendations from each paediatric subspecialty model of care	ch 28
Appendix 3: Abbreviations and acronyms	42

# foreword

We earnestly believe that improving child health in Ireland will be realised by thinking differently, breaking traditional paradigms and joining together in a shared vision to tackle current and future challenges. This is the essence of this model of care. In the coming years, there will be a unique opportunity with the building of a new children's hospital, implementation of this agreed model of care, introduction of a new child health model of universal screening with additional support for vulnerable families, and further extension of the 'under six' contract with general practitioners. We must capitalise on these significant developments.

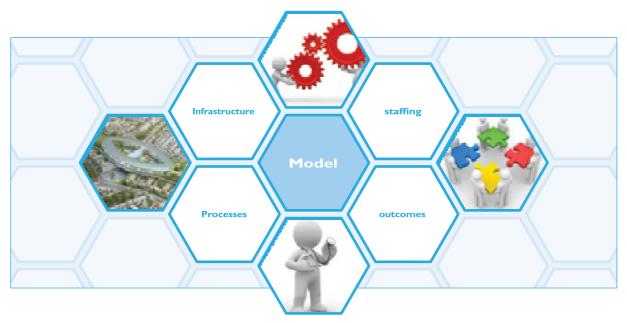
The future direction should be to provide as much care as close to home as possible, and to achieve this we must strengthen both primary and community care of children and adolescents. We must learn from international experience and work together across disciplines throughout the country to develop a child health service that meets the current and future needs of our children. We need to strengthen links between primary and secondary care, and provide additional support to general practitioners to manage childhood illness closer to home. Currently, rates of hospitalisation vary across the country and are too high in many places. We need to appropriately plan for new morbidities such as increasing incidence of obesity, diabetes and inflammatory bowel disease, the surge in atopic disease and allergy, and a growing need for childhood disability and child and adolescent mental health services.

The development of this national model of care commenced over four years ago, with visits to every paediatric unit and subspecialty. We listened carefully to the issues reported, and published the Review of Paediatric and Neonatal Services and Framework for Future Development in July 2013. The vision for this model of care came from discussions with paediatricians, trainees, nurses, health and social care professionals, general practitioners, parent groups and hospital management, as well as interactions with other national clinical programmes. Each paediatric subspecialty developed an agreed model for their service, and an extensive process of consultation was undertaken earlier in 2015. We held two town hall meetings with clinicians and managers during 2015 to allow discussion on proposed aspects of this model of care. The Programme working group was involved throughout the process, and the completed model of care has been approved by the Paediatric Clinical Advisory Group of the Faculty of Paediatrics, Royal College of Physicians of Ireland and the Health Service Executive. We are hugely thankful for the efforts of everyone that participated throughout this extensive process (see Appendix 1 for details).

#### The key components of this model of care are:

- Infrastructure (urgent and emergency care, inpatient and outpatient facilities)
- Staffing (doctors, nurses, health and social care professionals and others)
- Processes (standardisation of care pathways nationally)
- Outcomes (developing robust key performance indicators and outcome measures)

We have set out clear guidance on categorisation of neonatal and paediatric units so that local, regional and tertiary paediatric units can understand their roles, how they interface with each other, and the population that they serve. The model of care strongly advocates a hub and spoke model for paediatric services, facilitating delivery of the majority of care locally with outreach from tertiary paediatric subspecialties to the regional units. The development of general paediatric services is a key enabler of this model of care. General paediatricians see the undifferentiated child, and provide a vital interface between primary and community care, the emergency department and the hospital. Subspecialist support should be available if required in a timely manner, and the general paediatrician will act as a gatekeeper to accessing subspecialist services. We would like to see more general paediatricians developing areas of special interest, with outpatient clinics in these areas in conjunction with outreach from the tertiary service.



The next step of this process will be to develop an implementation strategy for this model of care in conjunction with all stakeholders and through the service structures of the hospital groups and community healthcare organisations. Workforce planning for doctors, nurses and healthcare professionals working in paediatric services is a critical element, and we need to evolve from a consultant-led to a consultant-delivered model of service delivery supported by expanded roles for nurses and health and social care professionals. There should be regular assessment of progress in implementation. The contents of this model of care must be updated in response to changing patient needs and will be regularly reviewed. We all need to embrace the principles of this model of care, and ensure that everyone working with children feels part of the process of implementation. Our children deserve no less.

Prof. Alf Nicholson

Dr. John Murphy

Joint Clinical Leads, National Clinical Programme for Paediatrics and Neonatology

# Introduction

#### National Clinical Programme for Paediatrics and neonatology

The National Clinical Programme for Paediatrics and Neonatology was established in 2011 as a joint clinical initiative between the Health Service Executive (HSE) and the Faculty of Paediatrics, Royal College of Physicians of Ireland (RCPI). Two clinical leads were appointed: Prof. Alf Nicholson (Paediatrics) and Dr. John Murphy (Neonatology). The overall aim of this Programme is to ensure high quality care is provided to children throughout Ireland, from the point of first contact.

The programme reports to the Faculty of Paediatrics, RCPI, the National Clinical Advisor and Group Lead for Acute Hospitals, HSE, and the National Director for Clinical Strategy and Programmes, HSE. Within the Faculty of Paediatrics there are two Clinical Advisory Groups (CAGs) associated with the programme:

- Paediatric CAG, chaired by Dr. Raymond Barry,
- Neonatal CAG, chaired by Prof. Martin White

The programme also has a multidisciplinary working group, which is involved in strategy development, providing a forum for advice on clinical and operational activities, advising on and supporting implementation projects, and as a channel for communications to relevant professional groups and other stakeholders from the Programme. All recommendations of the working group must be approved by the CAGs, and other stakeholders as appropriate, prior to implementation.

#### Review of paediatric and neonatology services and framework for future development

In 2012, the clinical leads and programme manager undertook an extensive process of engagement, which included a formal site visit to every paediatric unit in Ireland. The outcomes of these site visits were documented in Review of Paediatric and Neonatology Services and Framework for Future Development, which has been approved by the HSE. The framework document formed the basis for this national model of care for paediatric and neonatal services, which has been developed in collaboration with healthcare professionals working in the wide range of different paediatric subspecialties.

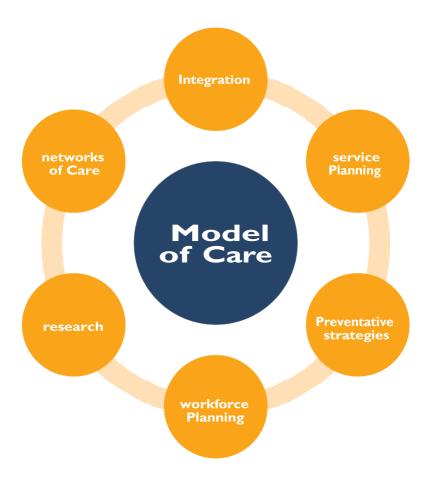
# The overall reflections based on these visits, and discussions with child health professionals across the country, included:

- There should be increased focus on health promotion, support for parenting and improving child and young person wellbeing.
- There is a need for greater child, young person and family involvement in the planning of child and adolescent services.
- Data which reflects the quality of service provision across the country is required. Quality metrics should be part of the clinical activity within all units. This is essential for continual quality improvement.
- There needs to be consistent and standard levels of clinical and corporate governance in paediatric units.
- An increasing child population has increased levels of referrals from primary care for both scheduled and unscheduled care. This has increased waiting times for scheduled care and the number of children and young people seen out of hours.
- The facilities available for children and young people while in emergency departments are often not appropriate, e.g. lack of audio-visual separation between and adults and children.

- There is agreement among departments that there should be a 'cut off age' for admission to paediatric services, and that this age should be 16 years. There are many issues in managing older adolescents in a paediatric environment.
- Tertiary services in Dublin are both fragmented and duplicated. Tertiary specialties should further develop
  national clinical networks. The new children's hospital will become the hub for paediatric care nationally,
  but a national model for integrated care is required to avoid the 'magnet effect' which the new development
  may create.
- There is a need to look at different models of acute care delivery (rapid response / paediatric assessment unit and short stay observation unit proposals) and the role of the general paediatrician should to be reviewed and expanded.

#### **Guiding principles**

In this document we set out a national model of care to underpin the delivery of healthcare for children both in the present and into the future. Key steps in its development were wide consultation with all healthcare professionals, involvement with parents and parent groups, a detailed analysis of the current clinical activity of all paediatric medical and surgical subspecialties, the current interface between primary, secondary and tertiary care services, and a study of how paediatric clinical care is distributed with reference to international best standards. Thus policy was developed from the ground up and we sought involvement and advice from those working in hospital management and community services throughout the process.



#### The vision for children's health services

This model of care aims to deliver services that are:

Essentially, all children should be able to access safe, high quality services in an appropriate location, within an appropriate timeframe, irrespective of their geographical location or social background. This requires the development of an integrated network for paediatric services nationally, with the new children's hospital as the hub and the regional and local paediatric units as the spokes.



#### The network must apply some fundamental principles:

- 1. Care should be provided as close to the child's home as possible, depending on their clinical needs
- 2. Care should be provided within the network at the appropriate level, in order to use resources efficiently
- 3. Where clinically appropriate, ambulatory care should be provided in preference to inpatient care

#### The sickest children and young people have better clinical outcomes if treated in a tertiary hospital that has:

- High caseload volumes across at least 35 subspecialties of paediatrics
- Advanced medical technology and underpinned by excellent information and communications technology
- · Child- and family-friendly facilities
- An integrated approach to innovation, service delivery, outreach, education and research
- A responsive paediatric and neonatal retrieval service

This will be achieved at the new children's hospital, where there will be national tertiary care, and secondary care for the greater Dublin area.

A seamless integrated network of care from primary to secondary to tertiary care is required with strengthening of local and regional paediatric units including:

- Implementation of a national electronic health record linking all care settings for children
- Agreed and standardised clinical guidelines implemented across the system
- Outreach from the tertiary centre to regional centres, with close working relationships and combined clinics with the local team
- Outreach from regional centres to local centres within the same hospital group
- Organisation of care for children with epilepsy, cystic fibrosis and type 1 diabetes on a regional basis based on the new group structure with integrated care pathway
- Sharing the new children's hospital brand across the network, and ensuring comparable infrastructure and facilities available in all units nationally

Integration of teams providing services for children and families in the community is also essential, with the establishment of multidisciplinary paediatric clinical networks recommended at community health organisation level to consolidate integration across the divisions of primary care, social care, mental health, and health and wellbeing.

Transfer back to general / community paediatrics

General Paediatrics

Community Paediatrics emergency Medicine

All hos can be larger

The diagram on the left shows the interdependies between general paediatrics, community paediatrics and emergency medicine with primary care and paediatric subspecialties.

The great majority of children are seen in primary care and every effort must be made to support general practitioners in the community by forging closer links between GPs and their local or regional hospital, regular CPD sessions, rapid response clinics, user-friendly algorithms for common conditions seen in primary care and GP access to diagnostics.

All hospitals providing services for children must be clear about what can be treated locally and what conditions need to be transferred to a larger centre or tertiary centre, as described in Table 1:

#### **local Paediatric units**

- Should be staffed by a minimum of 6WTE consultant paediatricians
- Acute paediatric emergency care and close liaison with primary care
- Strategic development of consultants with a special interest in cardiology, respiratory, endocrinology and community child health
- Development of special interest clinics with involvement of nursing and HSCPs
- Should consider the development of consultant extended day service with increase in consultants to 10WTE
- Should develop a strong ambulatory and community focus

#### regional Paediatric units

- Should be staffed by a minimum of 12WTE consultant paediatricians
- Special interest areas in respiratory, endocrinology, cardiology, allergy, neurology, dermatology, infectious diseases, paediatric emergency medicine and community child health, with outreach clinics to hospitals within group
- Regional hub for non-specialist paediatric surgery, orthopaedics, ophthalmology and ENT
- Comprehensive paediatric anaesthetics, pathology and radiology back up
- Regional child sexual assault service
- Close links to new children's hospital with co-run outreach clinics and shared care services
- Expanded roles for clinical nurse specialists and HSCPs

Table 1: Local and Regional Paediatric Units

The interface between primary care and secondary care is also critical, as with more support and access to diagnostics and expert opinion provided to general practitioners they will be less likely to refer to hospital out of hours. Every effort should be made to realign services so that common problems are managed in a local primary care setting.

# **Model of Care overview**

The national model of care for paediatric and neonatal services is structured as follows:

neonatology

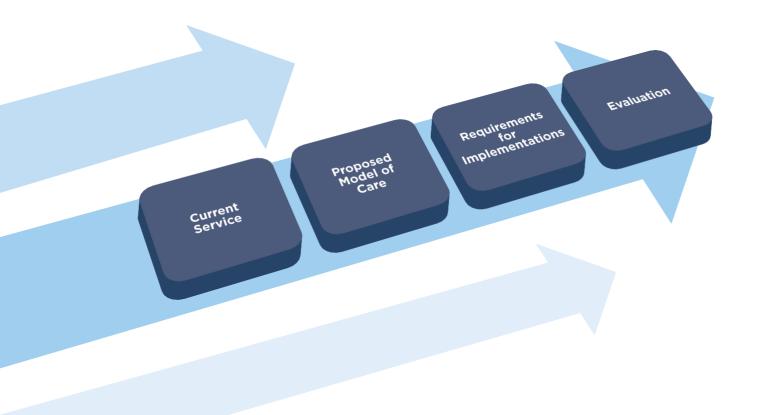
The model of care for neonatal services in Ireland has been completed, and was launched in November 2015 in advance of World Prematurity Day.

**Paediatrics** 

The first part of the paediatric model of care contains general sections on background, international models, integration, governance, quality, workforce and research. Next are sections concerned with services that interface between primary, secondary and tertiary care, including universal child health screening, community services for children with on-going health needs, and individual models of care for paediatric medical subspecialties and specialist surgical services for children.

In addition, the model of care for paediatrics should be considered along with other documents and work streams which contribute to the development of high quality services for children in Ireland, such as the Model of Care for Paediatric Anaesthesia, Improving Standards for General Paediatric Surgery, and the Model of Care for Urgent and Ambulatory Care Centres amongst others, as well as the National Child Health Steering Group and associated subgroups. It is intended that the model of care for paediatric services is a live document and will be updated as required, facilitating change as services develop. This will also allow us to add to the model in key areas such as primary care services for children over time.

The individual subspecialty sections of the model of care describe:



These sections provide many examples of existing good clinical practice and high quality services for children, as well as proposals for service developments that are consistent with our vision for children's health services and guiding principles. The hub and spoke model features strongly throughout, with clear guidance as to what should take place in local, regional and tertiary units, shared care and outreach clinics. The multidisciplinary team is core to the delivery of child- and family-centred services, and many subspecialties propose new and extended roles for nurses and health and social care professionals. The value of data and audit for improvement is continually emphasised, and this must be supported through information and communications technology (ICT) and data management support. Many subspecialties are keen to develop non-consultant hospital doctor training programmes, with some already in development. The issue of transition to adult services is highlighted for many chronic conditions, and must be a priority in our efforts to improve services. The key recommendations from each subspecialty model of care are outlined in Appendix 2.







#### **Model of care implementation**

The next phase of this process will be to develop an implementation strategy for this model of care in collaboration with the key stakeholders, hospital groups and community health organisations. We have continuously emphasised that this model of care provides a blueprint for neonatal and paediatric services into the future, and should form the basis for all planned service developments in this area over the next number of years. It is acknowledged that there are resource implications throughout this model of care, which is the primary reason an implementation strategy is essential. Paediatric services have been historically under-resourced in Ireland, and there is an urgent need now to address this in conjunction with the development of the new children's hospital in an integrated national network.

The Programme has engaged with the National Doctors' Training and Planning Unit in the HSE for medical workforce planning, and a similar exercise is required for nursing and health and social care professionals. Infrastructure and ICT need to support, not impede, the delivery of high quality services in all paediatric units. Patient flow can be improved through the development of agreed national care pathways, and standardisation of clinical care facilitated through clinical guidelines and algorithms. These measures are intended to reduce fragmentation and duplication of services, and prevent geographic variation. Meaningful outcome measures and key performance indicators need to be developed for paediatrics.

#### baCkGround

#### Ireland's child population

There were just over one million children living in Ireland in 2011 according to the Central Statistics Office. The number of children living in Ireland increased by 10.9% between 2006 and 2011, with the number of 0-4 year olds showing a larger increase (17.9%). This compares to an increase of 8.2% in the general population during this period. Within the European Union (EU), Ireland has the highest proportion of its population who are children, 25% compared to an EU average of 19%.

There were 69,267 births in Ireland in 2013, of which 5.5% were of low birth weight. This represents a 10% increase in the proportion of low birth weight babies over the previous decade. Irish birth numbers and rates peaked between 2008-2009 and a reducing trend has been evident since then. In 2011, the overall child mortality rate was 3.4 per 10,000; of which two thirds (65.6%) occurred in those aged less than 1 year (DCYA, 2012). The infant mortality rate in Ireland was 3.6 per 1,000. This was below the EU-27 average of 4.2 per 1,000. Infant mortality is significantly higher among lower income groups, and is 3.5 times higher among Travellers. The causes of deaths in children vary by age group and sex. In 2011, the largest single cause of child deaths was 'congenital malformations'. The mortality rate for boys was higher than that for girls (4.0 compared to 2.9 per 10,000).

#### Influences on the health of children

There are many social, cultural and environmental influences on health. While genetic make-up is set at conception, pre-natal and early childhood influences can affect gene expression, thus influencing child, and subsequent adult, health and well-being. There is also good evidence that adverse early childhood experiences increases the risk of, for example, heart disease, obesity, mental ill-health and diabetes, and can significantly reduce future cognitive ability. Other influences include maternal smoking during pregnancy, breastfeeding, maternal mental health, education and parenting styles, immunisation, housing and poverty.

#### health inequalities - foundations laid in early childhood

Health inequality and chronic disease in later life is caused by an unequal distribution of resources across individuals and families; not only in terms of wealth, but also in living conditions, levels of education, supportive families and parenting skills, social capital and community networks. These influences are evident at the individual and at the societal level and are cumulative over a person's lifetime.

'The foundations for virtually every aspect of human development –
physical, intellectual and emotional – are laid in early childhood.

What happens during these early years (starting in the womb) has lifelong effects
on many aspects of health and well-being – from obesity, heart disease and mental health
to educational achievement and economic status.' (Marmot, 2010)

An extensive body of literature now shows that many of the most common chronic diseases in adults – such as hypertension, diabetes, and stroke – are linked to processes and experiences occurring decades before, in some cases as early as pre-natally. This can happen due to the cumulative impact of adverse events in early childhood or due to disruptions occurring during sensitive developmental periods. Early environmental or social influences appear to have at least as much, if not more, impact than genes on the odds of having chronic problems in later life.

# QualITy and GovernanCe In Children's serviCes

#### designing Quality Paediatric services

Paediatrics has seen wonderful advances over recent decades. Developments such as vaccination, improved care of the newborn, surgical innovations and new medications have eliminated many of the historical perils and scourges of childhood that were familiar until recent times. Most children today can expect to live a long and healthy life. However, as modern healthcare has evolved and become more complex it has not always been possible to ensure that the components of our system interact and align in the way that we want. In contemplating a model of care we have a chance to pause and consider what we really want. There are two important facts to consider when viewing the model of care as a system. Firstly, modern systems rely on teams rather than individuals. This requires us to design for teamwork and communication so that teams have what they need to work together. Secondly, more important than pursuing excellence in any one part of the model of care is ensuring that all of its components, from home to hospital, fit together to achieve our goal:

Quality care and service for all children and families, in all parts of Ireland, all the time.

A model of care that will reliably deliver quality and value requires not only good planning but also the ability to manage for day-to-day excellence and to improve. There are many elements that will support the model of care but five are essential:

T.	Patient partnership	This requires a new relationship between patients and providers that recognises this and balances it with other demands such as cost, staff availability, location and the wishes of other patients. Focusing on the outcomes that matter to patients and their experience within the health system are important and can only be developed in partnership.
2.	Clinical leadership	Leaders shape a culture and create the conditions that enable staff to deliver quality care. Clinical leaders are particularly important because of their credibility and understanding of the complexity of the healthcare system. Clinical leaders need to be seen to act to the values of their organisations as well as speak to them.
3.	Governance	Governance provides the structures, agreed rules and standards that allow complex healthcare systems to achieve quality. It also provides accountability that is open, transparent and appropriately responsive. Governance must oversee learning systems that ensure that all organisational experience is used to improve.
4.	Improvement knowledge	Quality improvements methods focus on simple principles such as the importance of standardisation or ensuring that all activity must benefit the patient. All methods highlight the need to access the unique knowledge that frontline staff possess and the importance of involving them in any change process.
5.	data	Central to all theories of quality is the need for measurement and data. Without data it is impossible to show evidence of improvement. Better use of information technology to assist with data collection and analysis will support implementation of the model of care. Data may also be used to identify improvement opportunities.

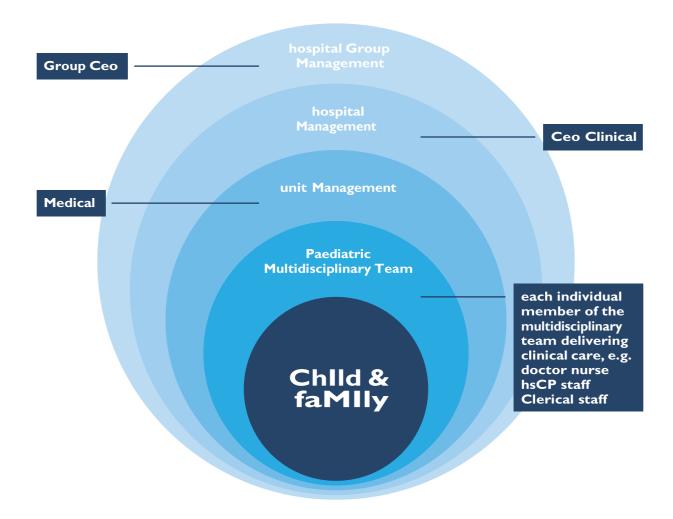
# **GovernanCe**

Paediatric and neonatology services are provided in various locations: stand-alone tertiary paediatric hospitals, paediatric and neonatology units in regional and local hospitals, neonatology units in maternity hospitals and community settings. Regardless of the setting, effective governance arrangements should recognise the interdependencies between corporate, financial and clinical governance across the service and integrate them to deliver high quality, safe and reliable healthcare.

Each individual working as part of a team in paediatric and neonatal services should:

- · Know the purpose and function of leadership and accountability for good clinical and social care
- Know their responsibility, level of authority and who they are accountable to
- Understand how the principles of clinical governance can be applied in their diverse practice
- Consistently demonstrate a commitment to the principles of clinical governance in decision making

The roles and responsibilities of individuals working in paediatric and neonatology teams are described throughout this model of care. It is recommended that each unit has a paediatric medical lead and nursing lead with protected time for service governance. Governance arrangements for the community healthcare organisations are currently under review. The suggested governance for quality and safety of a local or regional paediatric unit is as follows:



# bulldInG PaedlaTrIC researCh In Ireland

Clinical research that involves children is necessary in order to improve the understanding of childhood diseases, and to inform on how best to manage them. It needs to be more widely known that many medicines prescribed to children have not been tested in children. The evidence available as to how children may respond to medications, and the most appropriate dosages, are necessarily limited. The starting point should be that scientifically valid and ethically robust research, addressing questions of importance to the health of children and young people, is seen as intrinsically good.

Good clinical practice and the development of new treatments for children is underpinned by research – today's research is tomorrow's standard of care. It is acknowledged internationally that the best paediatric hospitals are those that are research active. Research must be a primary focus of both the new children's hospital and this national model of care for paediatrics and neonatology, and there is a unique opportunity to drive excellence in paediatric research in Ireland through integration with patient care and education. The establishment of the role of chief academic officer for the Children's Hospital Group will drive paediatric research at a national level.

#### supporting research

Culture provides a supportive context in which research is expected, encouraged, discussed, and valued. A productive research environment requires good governance, good leadership, and committed research staff. Essential services include mentoring programmes, continuing education courses, grant writing support, research funding, and encouragement for the attainment of higher degrees. Barriers to research include accessing funding and lack of protected time.

#### Recommendations to improve paediatric research on a national level (Modi et al., 2013) include:

- The formation of multidisciplinary, cross-institutional groups of clinical and non-clinical child health researchers and their access to diagnostic and laboratory facilities suitable for children
- A unified children's research network for drug studies and non-drug studies
- Regulatory assessment of research that is proportionate and based on consistent national criteria
- Expansion of research posts
- Improved research training for paediatric trainees
- Support for parents' and young people's advocacy
- Collaboration between children's research charities
- Closer integration of child health research with core health service activities supported by effective national data collection

There needs to be a shared national vision and agenda for paediatric research, with collaboration between hospitals, community services, universities and industry. Research programmes need to be patient-oriented and relevant to clinical care, and there needs to be engagement with patients and their families. There needs to be a means of capturing activity and reporting on paediatric research outputs nationally, as well as implementation and reporting on quality improvement projects in hospitals and in the community. The base of researchers performing quality paediatric research should be broadened, to include all healthcare professionals across all subspecialties and settings.

# PaedlaTrIC workforCe PlannInG

Health services for children in Ireland are entering a period of considerable change, and these changes require a modern and efficient paediatric workforce that can meet the health care needs of children and their families. Workforce planning for paediatrics must be in line with the vision and recommendations of this model of care. Care to patients and families should be provided by healthcare professionals working within a team structure. Expanded roles for nursing and health and social care professionals are necessary.

#### **Medical workforce Planning**

Currently, there are approximately 152WTE consultant paediatricians nationally. There is broad agreement among stakeholders engaged in the workforce planning process, including the RCPI Faculty of Paediatrics, the National Clinical Programme for Paediatrics and Neonatology, and the Children's Hospital Group that the number of paediatricians required for national implementation of the new model will be at least 395WTE. This recommendation equates to approximately 36WTE per 100,000 children today in the first instance, and should be done on a phased basis during the next five years.

#### There are a number of objectives to be addressed through appropriate medical workforce planning:

- Safe and timely children's services requires greater consultant input
- More services for children should be delivered in the community facilitating care as close to home as possible supported by consultant paediatricians.
- Future health need should be considered. This will require the incorporation of projections relating to:
  - demographic changes
  - alterations in disease incidence and prevalence
  - medical and therapeutic innovations
  - policy initiatives
  - technological advances
- The paediatric workforce should work in an integrated way to maximise opportunities for greater quality of care to children and their families.
- There should be a reversal in the ratio of non-consultant hospital doctors to consultants to 1:1.7 (currently approximately 1.7:1). The workforce needs to be re-balanced.
- The Irish health service should be self-sufficient in the production of medical graduates, with reduced dependency on international medical graduates (doctors who graduate from medical schools outside Ireland).

#### **Medical workforce Planning recommendations**

- General paediatrics is a key enabler of this model of care, and an increase in general paediatricians is required. Areas of special interest should support the implementation of a national hub and spoke model as described earlier.
- Consultant roles must be configured in such a way to enable flexible working both in terms of within the consultant role (allowing time for research, training, quality improvement) and also in terms of family-friendly working arrangements.

- A consultant-led paediatric service with a greater consultant presence is a key element for delivering better patient care in Ireland. This model will require the appointment of additional consultants and changes to working practices and rosters.
- Hospital groups and community health organisations should be supported to ensure the right skill set, at the right time, place and cost is provided to ensure uniform access to quality service.
- Workforce planning needs to consider the numbers of doctors being trained at undergraduate and postgraduate levels so that the future demand for additional consultants can be met.
- Undergraduate and postgraduate training programmes should be in line with this model of care.
- Consultants must be supported through dedicated time to participate in continuous professional development, service development, training of undergraduate and postrgraduate students, and research.

#### nursing workforce planning

Children's nurses lead on how services are standardised, and how children's nursing roles are developed so that children's healthcare services become more equitable. They are also committed to developing new and expanded roles, addressing education needs and work practices involved in evolving from hospital-based children's nursing towards more specialised community-based care for sick children and their families. A workforce survey was completed by the Programme in March 2015, identifying a number of pertinent issues and made a number of recommendations regarding nursing workforce planning.

#### nursing workforce Planning recommendations

- A detailed supply and demand modelling exercise should be undertaken which is aligned to this model of care in conjunction with the academic institutions.
- All children's nurses must be practically supported to undertake continuous professional development relevant to their role and clinical area.
- The role of the healthcare assistant (HCA) should be developed further to support paediatric care delivery. Paediatric HCAs should possess FETAC qualification.
- Nursing career pathways should be examined. Innovative nursing roles should be explored and developed to support new ways of working in line with the national model of care for paediatrics.
- Community children's nursing services should be developed to provide more specialised nursing care in the home environment.
- The retention of children's nurses post qualification and career opportunities for existing staff must be explored.
- Undergraduate training programmes for children's nursing must be reviewed and evolve in line with the changing needs of the health service and developments in education.

#### health and social care professional workforce planning

The development of health and social care profesional (HSCP) services for children in Ireland has been variable, dependant on geographical location and locally available paediatric resources. There have been high levels of inequity of access to paediatric HSCP services in tertiary paediatric, regional and local hospitals. This inequity is mirrored in the community where extensive local variation exists both between community areas, and between teams and disciplines within the same community area. Based on review of preliminary data on HSCP staffing levels in hospital and community services, the following recommendations emerged in relation to HSCP workforce planning.

#### health and social Care Professional workforce Planning recommendations

- A detailed workforce planning and measurement programme such as Clinical Redesign and Workload Measurement (CReW) should be rolled out across multidisciplinary teams, aligned with the vision of this model of care, in conjunction with the relevant universities.
- HSCP services for children need to be increased nationally, and should be led by paediatric clinicians at senior grade or above, which will allow provision of the necessary clinical governance, clinical supervision and support required for more junior staff working with children and families in a flexible manner based on the individual child's needs.
- Competency frameworks should be devised for each HSCP discipline working across the spectrum of
  paediatric and neonatology services with children and families (both hospital and community HSCPs) to
  ensure that each professional is clear about what is expected of them to fulfil their roles, and that
  discipline specific managers can support their staff by implementing the appropriate performance
  management cycle for each staff member.
- Paediatric services delivered by HSCP advanced practitioners should be embedded in the health service both at strategic and operational levels to ensure sustainability.
- Clinical governance for each professional working in either hospital groups or CHOs should be provided by their relevant head of discipline/senior, depending on the grade, to ensure adherence to professional standards, monitoring of clinical effectiveness and facilitation of appropriate continuous professional development via a performance review cycle.
- Paediatric HSCP continuous professional development must be encouraged across all hospital groups and community health organisations and managed in a consistent, standardised manner.
- Responsibility for recruitment should devolve to hospital groups and community health organisations, with increased local accountability for paediatric HSCP line managers.

# InTeGraTed Care

For the child and their family, integration means healthcare that is seamless, smooth and easy to navigate – a coordinated service which minimises both the number of steps in an appointment and the number of separate visits to a healthcare facility that are required. An integrated care pathway for children and young people that enables them to move from primary to secondary to tertiary care as required, and back again, is the cornerstone of the national model of care for paediatrics.

In mapping out a future model of care for paediatric healthcare services in Ireland, consideration needs to be given to emerging international trends in paediatric healthcare, in particular those that have demonstrated improved clinical outcomes for children and young people. Currently, the international focus is on:

- Delivering services as close to the child's home as possible, including community and home-based care
- Treating children in ambulatory settings wherever possible, and admitting for inpatient care only when necessary
- Concentrating expertise and experience in a single tertiary centre serving a critical mass population, and using this centre to support integrated networks of tertiary, secondary and primary care
- Reducing the average length of stay in hospital
- Creating inter-professional practices and interdisciplinary teams
- Standardising care processes throughout the healthcare network
- Use of information and communications technology to facilitate diagnosis and treatment and enable timely communication between clinical experts, secondary and primary care providers

#### Care for children with chronic conditions

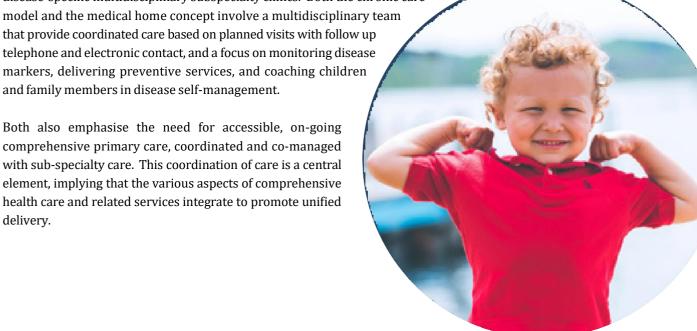
The present healthcare delivery system evolved in response to the need to deliver acute episodic care for infectious diseases, and was not designed to provide on-going care for complex chronic illness. Recent attempts to provide comprehensive coordinated care more effectively for individuals with complex diseases have

introduced the medical home concept, the chronic care model in primary care, and disease-specific multidisciplinary subspecialty clinics. Both the chronic care model and the medical home concept involve a multidisciplinary team that provide coordinated care based on planned visits with follow up

markers, delivering preventive services, and coaching children

and family members in disease self-management.

Both also emphasise the need for accessible, on-going comprehensive primary care, coordinated and co-managed with sub-specialty care. This coordination of care is a central element, implying that the various aspects of comprehensive health care and related services integrate to promote unified delivery.



# neonaTal Model of Care

Neonatology is one of medicine's great success stories of the past 30 years. Over the last decade, the rapid progress in morbidity and mortality reduction has continued. The clinical case mix has altered with an increasing emphasis on intensive care for extremely preterm infants and term infants requiring therapeutic hypothermia and persistent pulmonary hypertension of the newborn (PPHN).

The model of care for neonatology is the product of wide consultation with professional groups and parents who either provide or receive its services. The Programme met with neonatologists, paediatricians, neonatal nurses and health and social care professionals (HSCPs) who provide care to newborn babies. Discussions were held with parents whose babies receive care through the Irish Neonatal Health Alliance and the Irish Premature Babies Association. The views of all groups were considered in the development of this document, with the overall aim of designing systems that will provide quality care to every baby.

The organisation of neonatal services in Ireland is changing in response to managed clinical networks. The roles of medical and nursing staff have also changed with the implementation of the European Working Time Directive (EWTD) and the expanded role of the neonatal nurse through increased numbers of advanced neonatal nurse practitioners. Health and social care professionals must be included as part of the multidisciplinary neonatal team. It is imperative that Irish newborn care is in a position to embrace these international advances.

The three key components of national neonatal service delivery are infrastructure, manpower, and operating systems. The service delivery recommendations in this document have been benchmarked against international standards. Implementation strategies have been considered, with an emphasis on sustainability, as the model of care must be fit for purpose not just now but into the future. This is particularly important in neonatology, a specialty that is rapidly changing and advancing. The systems put in place need to be both reactive and proactive.

This document addresses the delivery of neonatal services in Ireland, and the integration between tertiary (Level 3), regional (Level 2) and local (level 1) neonatal units. It proposes how the three categories of the neonatal service should function. It describes how the current neonatal services operate nationally. It outlines how neonatology should change and advance with reference to best international practice. It provides a vision for the future of neonatology and describes how that vision can be implemented. It proposes the blueprint for a neonatal model of care for Ireland. The model is guided throughout by the triad of Quality, Access and Cost.

#### executive summary

- This model of care is intended to ensure sustainability in neonatal services in Ireland, and has three core objectives:
  - Improve safety and quality in the delivery of baby-centred care
  - Improve access to the appropriate services
  - Improve cost-effectiveness of services delivered
- The key values of a neonatal unit are: high quality clinical care, good governance, a stable effective workforce, a culture of teaching and training, succession planning, and being approachable, understandable and honest with parents.

- The annual number of births is a major driver of activity in all neonatal units. In 2013, there were just under 68,000 births.
- There are nineteen neonatal units in Ireland, which are classifed according to number of births into local, regional and tertiary neonatal units. There are 11 local units, 4 regional units and 4 tertiary units. There are 300 neonatal cots in total: 193 specialcare, 52 high dependency care and 55 intensive care.
- Neonatal care for a normal newborn infant is based on three key areas: screening, nutrition and immunisation.

screening	nutrition	Immunisation
Clinical examination Hearing test Blood spot screening test Hip ultrasound (high risk cases) Oxygen saturation	Feeding advice Lactation nurse input Discharge weight	BCG Provision of information

- The neonatology workload in the tertiary paediatric hospitals is increasing, and the current allocation of consultant sessions is inadequate.
- The National Neonatal Transport Programme provides a comprehensive 24/7 service, and is an essential component of an integrated neonatal clinical network. An efficient and effective retrotransfer service is required to facilitate transfer of stable infants from the tertiary neonatal units back to the local or regional units.
- Neonatal nursing is fundamental to the delivery of neonatal care. There are 4 categories of neonatal nursing: Intensive care, High Dependency care, Special care, and Surgical.
- The recommended ratios for neonatal nursing are: 1:1 in intensive care, 1:2 in high dependency care and 1:4 in special care.
- There are approximately 540WTE neonatal nurses nationally, and the current deficit is estimated at approximately 10% (54WTE). There needs to be increased numbers of advanced neonatal nurse practitioners and clinical nurse specialists.
- Health and social care professional services are essential in neonatal units, including dietetics, pharmacy, physiotherapy, medical social work, occupational therapy, speech and language therapy, and clinical psychology. Clinical engineers are required for ongoing maintenance of equipment in units. These areas have been underresourced previously, and need to be increased.

- Level 1 (local) neonatal units provide routine neonatal care to term infants, and special care to infants ≥32 weeks gestation. Infants of 30-31 weeks gestation can be cared for in Level 1 units if the appropriate staffing complement is available, i.e. 1:2 high dependency nursing ratios, middle grade and consultant staff.
- Level 2 (regional units) provide routine neonatal care to term infants, special care, high dependency care and short-term ventilation to infants >27 weeks gestation.
- Level 3 (tertiary units) provide the full spectrum of neonatal care to term and pre-term infants who are critically unwell. There should be sufficient clinical throughput to maintain clinical skills and expertise, with a minimum of 100 infants BW <1500g and/or 100 infants requiring assisted ventilation / CPAP.
- Tertiary neonatal centres must coordinate retinopathy of prematurity screening.
- Neonatal services should be integrated across hospital groups to form clinical networks, with each unit clear about the services provided and appropriately resourced.
- Neonatal resuscitation is an essential function of all units providing acute neonatal services, and should be standardised and improved.
- Therapeutic hypothermia is a complex treatment and should only be undertaken in tertiary neonatal units. The NNTP have developed a candidacy checklist that should be completed in all suspected cases of neonatal encephalopathy.
- A national register of infants undergoing therapeutic hypothermia should be established.
- All infants BW <1500g should have a neurodevelopmental assessment at 2 years. The Bayley III assessment is an accepted tool providing clinically useful information.
- Units caring for pre-term infants must be capable of safely and effectively providing parenteral nutrition until enteral feeding can be established.
- Extracorporeal membrane oxygenation (ECMO) is a life support in which venous blood is oxygenated outside the body and returned to the patient. There are approximately 5 infant ECMO cases in Ireland annually, with infants transferred to Sweden for this treatment at a cost of approximately €133,000 per infant. A working group should be establised to examine the feasibility of ECMO provision in Ireland.
- 1.23 A coordinated approach to national manpower planning is needed.
- The number of consultant neonatologists in the tertiary neonatal units, and the tertiary paediatric hospitals, is inadequate and should be increased.

- Paediatric radiology services are a priority support service requirement for any unit looking after newborn infants. Deficits in units outside Dublin and Cork should be addressed.
- All units should have a culture of teaching and training. Making neonatal research sustainable into the future remains a challenge, which is dependent on adequate funding and development of a culture of participating in research activities within all units.
- The recognition of Neonatology as a separate specialty on the Medical Council register is at an advanced stage. After five years, the trainee will receive the CCST in Neonatology. If the trainee also wishes to be on the General Paediatrics register, a further one year's training in general paediatrics will be required. It is hoped to commence the neonatal fellowship programme in July 2016, with the recruitment of 3-4 neonatal fellows.
- 1.28 Clinical governance structures should be positioned within the clinical governance structure of each hospital and hospital group. There should be an assigned medical director and nursing director and monthly department meetings.
- Agreed national standards should be implemented in all units. The Programme have developed a range of algorithms that provide a standard way of treating commonly occurring conditions in neonatal units.
- Performance indicators in neonatology fall under four categories: infrastructure, staffing, processes and outcomes.
- All units should contribute to the Vermont Oxford Network (VON) collaboration to record outcomes in infants BW <1500g and benchmark performance.

# ConClusion

This model of care sets out our vision for high quality, accessible healthcare services for children in Ireland, from birth to adulthood. It spans a range of care settings from community services to tertiary and quaternary care, and is the product of wide consultation and stakeholder engagement. It sets out requirements in a range of paediatric subspecialties for infrastructure, staffing and processes, and the expected outcomes for children accessing each service. Full implementation will require the development of a detailed plan for the next 5-10 years that must be embedded within the strategic plans of hospital groups and community health organisations, and should be prioritised in line with national policy.

The key messages from the national model of care for paediatric healthcare services in Ireland are:

This model of care supports both the development of the new children's hospital and an integrated national network for paediatrics, with strengthened roles for local and regional paediatric units.

Delivery of family-centred care as close to home as possible is at the centre of this model of care.

A model of care for paediatric primary care should be developed in consultation with GPs and other primary care providers.

Comprehensive transport and retrieval services for both newborns and children are essential.

Paediatric healthcare staffing levels need to increase as a matter of urgency, and workforce planning must



# **aPPendICes**

### appendix I: authors, contributors and acknowledgements

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- Senior Children's Nursing Network
- HSE Parent Reference Group
- Irish Society of Chartered Physiotherapists
- Association of Occupational Therapists of Ireland
- Irish Nutrition and Dietetic Institute
- Irish Association of Speech and Language Therapists
- Irish Association of Medical Social Workers

#### appendix 2: key recommendations from each paediatric subspecialty model of care

#### allergy

- The proposed national model of care for allergy is that of an integrated service crossing all care settings, with clear roles for primary, secondary and tertiary care.
- Additional staffing resources are required to facilitate development of the service.
- There is a significant need to educate healthcare professionals at all levels about allergy.

#### **Cancer services**

- Delivery of a central service in the new children's hospital, accommodating all tertiary/quaternary paediatric services.
- Extension of hematopoietic stem cell transplant resources, including dedicated haematopoeitic stem cell transplant physician and clinical psychologist.
- Employment of a neuro-oncology physician and a dedicated oncology physician with special interest in adolescent/young adult cancers.
- The employment of a dedicated neuropsychologist.
- Additional psychosocial input is required for children & families, including play therapy
- Promote interdependencies, specifically in the domain of rehabilitation, including the National Rehabilitation Hospital, Central Remedial Clinic, Community Disability Teams, early intervention teams and school aged teams who deliver rehabilitation to these children under the guidance of the tertiary clinical specialist therapist in a shared care model.
- Progress development of a dedicated adolescent/young adult cancer service, in conjunction with the adult medical haematology/oncology service in St. James's Hospital.
- In conjunction with the European Network for Cancer Research in Children and Adolescents, develop an electronic patient passport detailing the cancer diagnosis, treatment and clinical problems of each patient to aid long term follow-up and surveillance of all patients in Europe.
- There is significant potential to work in partnership with Northern Ireland and to accommodate patients requiring specialised quaternary paediatric oncology management, for example, bone marrow transplantation, early clinical phase I or II trials.
- Develop ICT infrastructure engage with the HSE/NCCP to work towards piloting electronic patient record and electronic medication/ chemotherapy prescribing (MOCIS – Medical Oncology Clinical Information System) in preparation for transition to a paperless new children's hospital.

#### **Cardiology**

- To implement the cardiology model of care nationally, the following is required:
- Implementation of the 14 International Working Group recommendations with oversight from the committees set up to coordinate and deliver on the required resources
- Funding of outreach clinics by each hospital group

#### Cardiology

- To implement the cardiology model of care nationally, the following is required:
- Implementation of the 14 International Working Group recommendations with oversight from the committees set up to coordinate and deliver on the required resources
- Funding of outreach clinics by each hospital group
- The appointment of paediatricians with a special interest in cardiology (two years training in cardiology) in Cork, Limerick and Galway. Dedicated HSCP staffing will also be required in these regional centres to complement the development of these paediatrician posts. There is a requirement for additional funding of 0.5WTE senior paediatric dietitian for each regional centre (Cork, Galway, and Limerick)
- Development of a robust adult transition service
- A clear national strategy must be developed to deal with the child with a likely innocent murmur
- There should be more formalised training of technicians
- The guidelines for trisomy 21 and cardiac screening (sudden cardiac death, pre-propranolol for infant haemangiomas and ADHD) need to be revised
- · The addition of advanced nurse practitioners to cardiothoracic surgery should be explored
- The paediatric cardiothoracic and paediatric cardiology higher surgical training fellowship programme should be developed
- A hybrid cardiac catheterisation laboratory whereby the theatre can act both as an operating theatre and catheterisation suite (due to open in early 2016)
- Increasing the role of CT/MRI with a diminished role for cardiac catheterisation to be explored
- Adult congenital heart disease surgery performed by congenital cardiothoracic surgeons to be developed. Further congenital cardiothoracic surgeon (i.e. fourth surgeon) appointee should have an adult focus.

#### Child and adolescent Mental health services (CaMhs)

- There should be a child-centred approach to mental health care and recovery that operates within a tiered system and holds the child and their needs at the centre of all care planning.
- A comprehensive mapping and resourcing of primary care provision for children with mental health and developmental problems, togetherwith a plan on howto augment the provision to deliver a comprehensive service for children at this level of care, is urgently needed.
- Resourcing of CAMHS teams in line with the recommendations of A Vision for Change together with resourcing of paediatric liaison psychiatry teams in both paediatric and acute hospitals and acute inpatient psychiatry beds for children and adolescents.
- Implementation of the CAMHS Standard Operating Procedures (2015) within CAMHS services nationally for community and inpatient care to ensure standardised and cohesive service delivery.
- National provision of CAMHS on call in paediatric and acute hospitals (Levels 3 and 4).
- Transition from CAMHS to adult mental health services must be planned and implemented smoothly and effectively, coordinated by a designated care worker.
- Development of outcome measures to monitor effectiveness of clinical interventions and patient/user/family satisfaction.
- Increase in Child and Family Services (Tusla) for children with social care needs, including out of hours services.
- Effective interagency working at all care levels is essential to respond comprehensively to the needs of children.

#### **Child Protection**

- The number of general paediatricians and paediatricians with a special interest in community child health in Ireland needs to be increased.
- A number of consultant paediatricians with a special interest in child protection need to be appointed in each hospital group to develop and lead the clinical aspect of the service and develop robust links with other agencies delivering this multidisciplinary service.
- There is an urgent need to provide a national clinical forensic service for children who have been victims of acute sexual assault. Three child sexual assault treatment units (CSATUs) should be developed nationwide.
- Each CSATU will require consultant paediatricians with a special interest in child protection with dedicated time within their posts to lead and provide the service.

#### **Cleft surgery**

- Increase cleft clinical nurse specialist posts by 2.5WTE across Temple Street and Crumlin, with development of the role of lead clinical nurse specialist.
- Increase consultant paediatric dentist sessions.
- Ensure access to psychology services for cleft lip and palate patients.
- Provide data management support to the Dublin Cleft Centre and Cork University Hospital, with appropriate ICT systems in place to facilitate data collection and analysis.
- Ensure appropriate equipment available for all multidisciplinary team members.

#### Community services for Children with ongoing health needs

- Increase paediatric HSCP staffing levels in primary care teams and primary care paediatric network teams, in order to provide safe, accessible and effective services.
- Increase senior paediatric HSCP staffing levels in primary care paediatric network teams, in order to
  provide appropriate leadership and clinical governance, and also in order to lead safe, high-quality,
  clinically effective service provision.
- Complete a mapping exercise in primary care, in order to establish the child population in each of the 90 primary care networks providing services to these networks, and also in order to establish the MDT staffing levels required to meet the health needs of this child population.
- Ensure that community healthcare professionals working with children have the appropriate paediatric skills and competencies.
- Enhance integration within and between teams, services and settings, so as to ensure a child-centred and family-centred service.
- Develop ICT capacity in line with HSE strategy.
- Develop appropriate outcome-based key performance indicators, in order to monitor the effectiveness of interventions.

#### Craniofacial surgery

- Due to the complex nature of patients with craniofacial conditions, optimal care is best accomplished by teams of interdisciplinary specialists. The team will include surgeons (plastic/craniofacial, neursurgery, maxillofacial), orthodontist, prosthodontist, paediatric dentist, clinical nurse specialist, psychologist, physiotherapist, speech and language therapist, occupational therapist, clinical service manager, clinical photographer and geneticist.
- The service should be centralised within the new children's hospital with seamless transition of both patients and their clinical information between, the clinics, the wards, and the operating theatre.
- A potential 'All-Ireland' craniofacial service is currently being discussed with consultant colleagues in Belfast. It is envisaged that the National Paediatric Craniofacial Centre will provide a 'hub and spoke' model whereby satellite clinics could be facilitated in the Royal Children's Hospital in Belfast and surgical aspects of care in Temple Street.
- Clinical outcome measurement and clinical audits should continue to be an integral part of the service.

#### **Critical Care**

#### executive summary for Paediatric Critical Care services (PCCs)

The Model of Care document for Paediatric Critical Care Service (PCCS) sets out clear pathways for the care of the critically ill child. This presentation can start at numerous points in a hospital setting in the Republic of Ireland (ROI). This document includes the categorisation of hospitals in the ROI receiving and admitting children at Local, Regional and SupraRegional level. It includes the pathway for a child receiving planned treatment who unexpectedly needs Paediatric Critical Care in the adult hospital setting.

The table sets out the minimum level of paediatric services which should be available for a hospital to achieve each of the respective hospital model designations.

#### **Paediatric Critical Care hospital Models**

#### Paediatric Critical Care hospital Models delivery framework

The framework complies with The Joint Faculty of Intensive Care Medicine of Ireland and The Intensive Care Society of Ireland National Standards for Paediatric Critical Care Services

Hospital Model (Report of the National Acute Medicine Programme 2010)	'Hanly' Report (Report of the National Task Force on Medical Staffing 2003)	ED	Paed Inpatient Ward *Level 0	Paed Inpatient Obs Unit *Level 1	Adult Anaes /ICM CCS Level 2 (HDU) Level 3 (ICU)	Paed Anaes.  Paed Medicine  Paed Surgery	Paed HDU *Level 1 (PHDU) *Level 2 (PHDU) R***	Paed CCS *Level 3, *Level 3s (PICU)	Paediatric Retrieval **PICU.ie Referral
Model 2 Hospital	<b>'Local'</b> Hospital	X	X	X	X	X	X	X	X
Model 3 Hospital	<b>'Major'</b> Hospital'	✓	✓	✓	✓	X	✓ Level 1	X	X
Model 4R Hospital (Regional)	<b>Regional</b> or <b>University</b> Hospital	✓	✓	✓	✓	<b>√</b> R	<b>√</b> R***	X	X
<b>Model 4S</b> (Supra-Regional)	<b>Children's</b> Hospitals	✓	✓	✓	✓	<b>√</b> S	<b>√</b> S	✓	✓

#### \*Joint Faculty of Intensive Care Medicine, National Standards for Paediatric

#### Critical Care Services 2013, Levels of Critical Care

- Level 0 Hospital ward clinical management
- Level 1 Higher level of observation;
- Level 2 Active management by critical care team to treat and support critically ill patients with primarily single organ failure (e.g. those requiring CPAP or greater);
- Level 3 Active management by the critical care team to treat and support those with two or more organ failures;
- Level 3S Level three with national service.

#### Table Legend:

ED = Emergency Department: Anaes = Anaesthesia: Paed = Paediatric: CCS = Critical Care Service: HDU = High Dependency Unit: R\*\*\*- HDU Level 2 and if required CPAP administered under the supervision of Consultant Paediatric Physician – see HDU outside Dublin sub-section

#### Main recommendations in Model of Care for Paediatric Critical Care services in rol

- It is essential that all hospitals with on-site inpatient and Emergency Department paediatric services, including admitting children who are or who may become critically ill be able to initiate Critical Care (includes Model 3, Model 4R and 4S as per Hospital Models Delivery Framework document). This includes assessment, resuscitation, stabilisation and initiation of critical care, and maintenance of such care until the Retrieval Team arrives or transfer out by the local team.
- Initiation of Paediatric Critical Care in a hospital setting (Model 3, 4R and 4S) should include communication with the Paediatric Critical Care team and National Retrieval Team. A single Emergency phone line is in place to facilitate this x 24/7.
- In each Hospital receiving and admitting children there should be a nominated Lead Paediatrician and Lead Anaesthetist responsible for the co-ordination of care of the critically ill child- (MOC Paediatric Anaesthesia 2014)
- Hospitals receiving and admitting children including Emergency Departments should comply with the Joint Faculty of Intensive Care Medicine of Ireland and the Intensive Care Society of Ireland National Standards for Paediatric Critical Care Services 2013.
- The national Paediatric Emergency Transport Service (PETS) will stabilisation, retrieval and repatriation medical service for critically ill infants, children and adolescents in Ireland in the context of a centralised model of paediatric critical care based in Dublin
- In certain time critical conditions and extreme emergencies, dependent on Local Team assessment it may be necessary for the Local Team to undertake the transport to the Tertiary Units
- Hospitals receiving and admitting children should apply standardisation of medical equipment and medical devices in conjunction with the National Retrieval and PCCS guidelines. This should include use of standardised concentrations for infusions.
- For Paediatric Critical Care the WTE number of Intensivists needs to increase to a minimum of 12 WTE.

Prioritisation of Nursing recruitment and retention is vital for the overall success of Paediatric Critical Care.

<sup>\*\*</sup>www.PICU.ie Bridge phone: 1890 213 213

#### dentistry

- There is a significant unmet dental treatment need for severely medically compromised children, children with significant intellectual / developmental / behavioural / psychosocial disabilities, children with complex inherited and acquired dental conditions and children with complex dental trauma who require treatment in a paediatric hospital. An increase from 2WTE to 6WTE consultant paediatric dentists is required at the new children's hospital.
- The appointment of consultant paediatric dentists at secondary care level in the regional paediatric
  units is strongly recommended to allow planning, organisation and provision of a coordinated paediatric
  dental service for children throughout the country in collaboration with the community primary care
  dental services.
- The integration of primary, secondary and tertiary care dental services with the National Clinical Programme for Paediatrics and Neonatology would be envisaged as an important component of the design of such a multidisciplinary team service model.
- Data concerning all children who are awaiting, and who have, dental treatment provided under general anaesthetic in public hospitals must be recorded on the inpatient and day case waiting lists and on the HIPE system.
- Data concerning the number of children who are treated under GA in the private sector on referral (with funding) from the HSE dental services, and procedures undertaken, should be recorded to inform future development and planning of a national dental service for children.

#### dermatology

Paediatric dermatology is an exceptionally high volume specialty, with >15,000 patient attendances across the three Dublin sites per annum. In order to plan for sustainability of a paediatric dermatology service at the new children's hospital, integrated with national services, we foresee the following as strategic priorities:

- Significantly increase the medical, nursing and health and social care professional staffing of the multidisciplinary team providing secondary and tertiary dermatology care at the national centre.
- Prioritise increase in consultant manpower to 8WTE. The service is currently provided across three sites by 3.4WTE and is in crisis. Waiting times for referrals are currently greater than 18 months; routine referrals are currently not being allocated appointments in two of the sites.
- Provide adequate space, streamlined patient flows and environment to deliver high volume ambulatory and inpatient tertiary dermatology services at the national centre.
- Develop and embed the roles of clinical nurse specialists (CNSs), nurse prescribing for all CNS posts and advanced nurse practitioners for chronic conditions / laser surgery.
- Prioritise timely access to laser therapy under anaesthesia at the national centre; this will necessitate additional theatre access (20 general anaesthetic slots/ week).
- Ensure dedicated access to MRI imaging and Interventional Radiology (IR) for vascular anomalies / neurogenodermatoses (current activity generates 5 MRI / 1 IR procedure per week).
- Provide business manager, data management and ICT resources to track clinical activities and facilitate electronic interface capability

- Develop adequately resourced national and regional clinical, research and education networks of multidisciplinary healthcare professionals to enable local and shared care. This will be necessary to fully enable the model of care.
- Embed protected time within consultant job descriptions for service management, direction of research and development and maintenance of education.

#### emergency Medicine

- Implement age range for paediatric emergency department attendances nationally the agreed age cut off for paediatric emergency care is 16 years (eve of 16th birthday)
- Implement audio-visual separation of children and adults in emergency departments
- The Irish Children's Triage System (ICTS) should be adopted as the national standard of triage for all acutely ill or injured children.
- Increase numbers of paediatric emergency consultants and children's nurses delivering front line paediatric emergency services. The safest, most efficient way to deliver care is to have senior decision makers available at peak times.
- Timely access to liaison psychiatry and CAMHS is essential for the provision of high quality, safe emergency care.
- Clear trauma protocols to be identified and implemented for children nationally.
- Ensure governance for all children aged 0 to 16 who are accessing acute care.

#### endocrinology

- Increase the medical, nursing, dietetic and health and social care professional staffing of the multidisciplinary team providing diabetes and endocrinology care.
- In the new children's hospital, develop designated lead clinicians in each of eight subspecialties of paediatric endocrinology, as outlined in this chapter.
- Provide data management and ICT resources, in order to track clinical activities and facilitate electronic interface capability.
- Prioritise timely access to paediatric endocrinology diagnostics.
- Provide adequate space and environment, in order to deliver ambulatory and inpatient tertiary endocrinology services at the new children's hospital and in regional centres.
- Implement national standards for paediatric diabetes care.
- Develop curricula for multidisciplinary postgraduate training in endocrinology in Ireland.

#### ear, nose and Throat (enT) surgery

- Increase consultant numbers, both whole time paediatric otolaryngologists and those with special interest in paediatric otolaryngology, with the immediate priority being tertiary units but also some increase will be required in the regional units.
- Increase in support staff nursing, health and social care professionals and administration to enable effective service provision.

#### **Gastroenterology**

- Significantly increase the medical, nursing and health and social care staffing of the multidisciplinary team providing tertiary gastroenterology care at the national centre.
- Prioritise timely access to paediatric endoscopy under anaesthesia at the national centre.
- Provide adequate space and appropriate environment to deliver ambulatory and inpatient tertiary gastroenterology services at the national centre.
- Provide data management and ICT resources, in order to track clinical activities and facilitate electronic interface capability.
- Develop national standards for paediatric endoscopy services, endorsed by the Faculty of Paediatrics.
- Restoration of a consultant-led paediatric hepatobiliary surgery service in Ireland.
- Increase multidisciplinary healthcare professional staffing of regional centres to enable local and shared care.

#### **General Paediatrics**

- General paediatrics has a central role in the future development of child health services in Ireland.
- Local and regional hospitals must have a clear understanding of their role in relation to provision of paediatric services.
- The number of general paediatricians needs to be increased nationally, and roles developed for ANPs, CNSs and HSCPs.
- Standards for paediatric units should be audited regularly.

#### **Gynaecology**

- There should be a designated lead clinician for paediatric and adolescent gynaecology. An expansion to 1WTE consultant is required.
- In a specialist centre, there should be at least one specialist nurse and an identified clinical psychologist.
- Transition clinics should take place between paediatric and adult services.

#### **Immunology and Infectious diseases**

Paediatric infectious diseases and paediatric immunology are two individual core subspecialties, a necessary part of any tertiary paediatric hospital, which must be adequately resourced if full health benefits are to be achieved. The existing service, based at Temple Street and Crumlin is defacto a national service and should be recognised and resourced accordingly.

#### Paediatric Infectious Diseases

- Reactivate the previously approved pID consultant post with sessional commitments to Tallaght, Crumlin and Coombe hospitals.
- To facilitate development of materno-infant infection service, reconfigure the associate specialist post (Rotunda) to consultant level and incorporate sessions in the new children's hospital.

- Prioritise the development of a national paediatric outpatient antimicrobial therapy service and resource appropriately with protected consultant sessions to provide national oversight.
- Prioritise development of rapid microbial diagnostic services.
- Increase availability of diagnostic imaging, in particular MRI and ultrasound imaging for children.

#### Paediatric Immunology

- The appointment of a second consultant in paediatric immunology is urgently required.
- To provide haematopoietic stem cell transplantation (HSCT) for infants and children with primary immunodeficiencies and autoinflammatory disorders in Ireland, a consultant specialising in HSCT should be appointed.
- To allow for more efficient and cost effective service delivery, as well as to allow training opportunities for paediatricians in training, the appointment of a specialist registrar in paediatric immunology is a necessity.
- Consideration needs to be given to incorporation of a screen for SCID in the neonatal screening programme.
- Provide full MDT services to include psychology, speech and language therapy, physiotherapy, occupational therapy, a data manager and expansion of immunology CNS provision.

#### laboratory Medicine

- Increase consultant paediatric pathologists in the Dublin maternity hospitals, as well as in the Cork, Limerick and Galway maternity hospitals.
- A minimum of 2WTE consultant chemical pathologists, giving full cross-cover to each other, are required in the new children's hospital, in order to provide a national service.
- An additional 2.9WTE clinical microbiologists are required.
- An additional transplant physician to support the bone marrow transplant programme for metabolic and malignant disease is required.
- The HSE Laboratory Modernisation Programme will result in significant changes to the way in which diagnostic laboratories operate in Ireland, following the establishment of a hub-and-spoke model whereby regional diagnostic laboratories (based in large tertiary hospitals) will provide laboratory medicine services to other hospitals (most likely determined by hospital group configurations). The implications of this programme for the new children's hospital remain unclear, but whatever configuration is chosen for the site, a robust, flexible, accessible, identifiable, accountable and renewable paediatric laboratory medicine service must be in place, in order to support the new children's hospital and regional paediatric care units.

#### **Metabolic Medicine**

- Increase multidisciplinary staffing levels at National Centre for Inherited Metabolic Disorders (NCIMD) at Temple Street in order to provide safe, accessible, efficient services for children with IMDs.
- Develop and implement protocols for appropriate transition of metabolic patients in Temple Street to
  enable appropriate and safe transfer of adult IMD patients to the adult metabolic service under formal
  arrangements between both hospitals (proposed: +1WTE consultant metabolic paediatrician at NCIMD).
  This has to incorporate the complex needs of this high-risk cohort, including their risk of acute metabolic
  decompensations. Transfer and transition from paediatric to adult metabolic services are at an early
  stage of development for these patients in Ireland as opposed to the UK and many continental European
  countries.
- Develop and implement protocols for future care standards, including expanded day care services, outreach clinics ('hub-and-spoke model') to improve paediatric care providers' ability to arrange for care within a reasonable driving distance for patients/families and to provide specialty care in patients' own communities where possible (proposed: +1WTE consultant metabolic paediatrician at NCIMD). In addition, more effective treatments for IMDs in children along with improved survival rates is leading to a higher requirements for specialised clinical service to provide satisfactory acute and long-term management. The overall aim is to improve quality of care and outcome and to reduce avoidable risk for this vulnerable cohort.
- Increase the metabolic service in Temple Street from five to seven days. Move to combined metabolic / general paediatrics admissions for metabolic patients where possible.
- An Irish MPS1H transplant service is required.

#### nephrology

- Support the provision of adequate staffing across all grades and disciplines within the service.
- Develop service infrastructure to support children and families in our care; and optimise the use of the available resources.
- Secure adequate systems to monitor patients and ensure safe and effective communication.
- Support and develop paediatric urology services.
- Build and open a new children's hospital as quickly as possible.
- Focus on quality by ensuring an evidence-based/research-oriented approach to the care of children with kidney disease.

#### neurodisability

- Increase paediatric neurodisability consultant posts to meet the healthcare needs of children with disability across network and specialist services.
- Increase the disability MDT staffing levels in order to provide safe, accessible and effective services.
- Develop standardised prioritisation systems for children to equitably access services.
- Develop standardised national integrated care pathways.
- Develop secure ICT systems to facilitate information-sharing between hospital and community services.
- Develop specific training rotations for NCHDs who wish to specialise in neurodisability.

#### neurology

- A managed clinical network for neurology should be implemented in Ireland, with outreach to regional paediatric centres, bringing together key professionals, and establishing well-defined integrated care pathways and clinical guidelines for each step of the pathway.
- Deficits in consultant paediatric neurologist posts, neurophysiology posts, and essential support services need to be addressed.
- An academic chair in paediatric neurology should be appointed.

#### neurosurgery

- All children up to 16 years of age will have their inpatient neurosurgical treatment on a single site in a children's hospital.
- Children with neurosurgical conditions will have adequate and timely access to outpatient review, inpatient treatment and surgery, made possible by ample bed and theatre availability.
- There should be adequate access to neuropsychology review for all children. Neurocognitive outcomes will be audited for all conditions where psychomotor impairment is possible.
- The Children's Neurosurgery Centre (CNC) will have intraoperative MRI to improve tumour resection rates and reduce operative morbidity.
- The CNC will have an interactive website which will have up to date publication of all audit results, information and videos for patients and health professionals and facilities for online referral.
- The CNC will have adequate HSCP staffing to maximise recovery from illness and surgery. HSCPs will report clinically to the consultant neurosurgeon and professionally to their line manager in their relevant department.
- Children recovering in the CNC will have timely access to rehabilitation beds and community rehabilitation outside the CNC.
- There will be dedicated neurosurgery ANP/physicians' assistants to work at the middle grade level for ward and outpatient management of neurosurgical patients.
- The CNC will have a dedicated data manager to spearhead data collection for audit and research.
- The CNC will have a close working relationship with services in regional hospitals and the community made possible through easy contact mechanisms, communication through the website and regular focused teaching days.

#### non-malignant haematology

- A second consultant with an interest in haemoglobinopathy is required urgently.
- Increase CNS posts for non-malignant haematology by 2WTE, and develop new ANP posts.
- Increase psychology services from 0.6WTE principal grade to 1WTE principal grade and 1WTE senior grade clinical psychologist.
- Increase physiotherapy input to benign haematology from 0.5WTE senior, to 1WTE senior and 1WTE staff grade.

#### ophthalmology

- Strengthen community ophthalmology services to see most of the common conditions.
- Increase outpatient clinics and operating sessions in Temple Street and Crumlin to address current demands, and improve clinic infrastructure at both sites.
- Additional consultant staffing is required in both Crumlin and Temple Street to meet growing demands on service.
- Provide full time specialist registrar posts in both Crumlin and Temple Street.
- Develop clinical nurse specialist roles in ophthalmology.

#### orthopaedics

- There are four levels of paediatric orthopaedic care services, with care bundles defined according to the complexity of care required
- A standardised care pathway for the detection and managment of DDH should be implemented nationally as follows:
  - All newborn infants should have a clinical hip examination by 24 hours of age.
  - If the hips are stable the infant should be re-examined at six weeks.
  - If the infant's hips are stable but he/she has a risk factor an ultrasound should be arranged at six weeks of age.
  - If the imaging test is abnormal an immediate orthopaedic referral is necessary.
- Paediatric trauma care should be in accordance with the British Orthopaedic Association Children's Orthopaedic and Fracture Care, with arrangements within hospitals/networks to treat the complex injured child appropriately.
- There is a need for a minimum of 10WTE paediatric orthopaedic surgeons to meet service demands
  nationally, with the first priority being to strengthen the paediatric service in Dublin by increasing
  paediatric orthopaedic surgeon numbers and ensuring adequate theatre and anaesthetic availability.
  Multidisciplinary team staffing resources will also require corresponding increase.
- An online multimedia education module should be developed to support primary care providers in the assessment and management of paediatric orthopaedic conditions.

#### **Palliative Care**

- Increase the paediatric palliative care staffing levels in order to provide a safe, accessible and effective service.
- Establish a database for collecting baseline data on children with life limiting conditions
- Enhance education and training of all staff working with children with life limiting conditions
- Develop integrated care pathways for neonatal and paediatric palliative care
- Enhance discharge planning
- Promote research in paediatric palliative care
- Enhance collaboration between the statutory and voluntary sector

#### **Pharmacy**

- Increase paediatric pharmacy staffing levels, in order to provide safe, accessible and effective services.
- Develop a robust national model of care for paediatric pharmacy.
- Formalise links between local, regional and tertiary paediatric pharmacy units.
- National guidelines or standards with regards to pharmacy resources for paediatric critical care should be developed.
- Paediatric specific policies are required for the provision of pharmacy services to children.
- Increase pharmaceutical input to paediatric research and medicines management.

#### radiology

- Increase the number of consultant paediatric radiologists, particularly outside Dublin. Two consultant paediatric radiologists each should be appointed to Cork, Limerick and Galway.
- The number of higher specialist trainees in paediatric radiology should be increased, and during the five year higher specialist training programme the paediatric radiology module should increase from two to three months.
- In Dublin, there is a need to expand and develop paediatric interventional radiology.
- At least one general radiologist working in a local paediatric unit should have a special interest in paediatric radiology.

#### respiratory

- Relieve respiratory subspecialists in the national tertiary centre of general paediatric workload, in order to enable them to concentrate on delivering and developing the subspecialty service.
- Increase multidisciplinary staffing levels in tertiary and regional units, in order to provide safe, accessible and effective services for children with complex respiratory diseases, including cystic fibrosis (CF), PCD, neuromuscular disease (NMD) and sleep-disordered breathing.
- Paediatric pulmonary function laboratory capacity (incorporating basic sleep laboratory services) is required in regional centres.
- Appropriate infrastructural facilities are required for patients with CF in the (currently six) specialist CF centres.
- Develop a standardised process for children requiring long-term mechanical ventilation, in order to enable discharge to the community and on-going review of appropriate resource allocation.

#### rheumatology

- Increase the paediatric rheumatology multidisciplinary team staffing levels in order to provide a safe, accessible and effective service.
- Implement the BSPAR / ARMA standards of care
- · Develop the hub and spoke model of rheumatology service provision
- Establish a dedicated clinical area for rheumatology services
- Build links with adult rheumatologists to facilitate the transition from paediatric to adult rheumatology services
- Develop data collection capability
- Develop specialist physiotherapy triage clinics to alleviate waiting lists (assessment of non-inflammatory conditions)
- Develop a joint clinic for slit lamp eye reviews, which is an essential part of management to take place on a three to four monthly basis.

#### specialist rehabilitation

- Each child will receive person-centred and family-focused appropriate care
- Children will receive different levels of expertise and specialisation at different stages in their rehabilitation journey:
  - Acute rehabilitation will be carried out alongside or immediately after active medical or surgical treatment (acute rehabilitation facility NPH)
  - Tertiary specialist rehabilitation will continue to be provided in the NRH
  - Community rehabilitation teams will deliver intermittent, multidisciplinary, goal based therapy of moderate intensity.
- Quality of care, access to specialist services and value will be measured and monitored

# appendix 3: abbreviations and acronyms

ADHD	Attention Deficit Hyperactivity Disorder
ANP	Advanced Nurse Practitioner
CAG	Clinical Advisory Group
CAMHS	Child and Adolescent Mental Health Services
CEO	Chief Executive Officer
CF	Cystic Fibrosis
CNC	Children's Neurosurgery Centre
CNS	Clinical Nurse Specialist
CReW	Clinical Redesign and Workload Measurement
CSATU	Child Sexual Assault Treatment Unit
DCYA	Department of Children and Youth Affairs
DON	Director of Nursing
ENT	Ear, Nose and Throat
EU	European Union
FETAC	Further Education and Training Awards Council
HCA	Healthcare Assistant
HSCP	Health and Social Care Professional
HSCT	Haematopoietic Stem Cell Transplantation
HSE	Health Service Executive
ICT	Information and Communications Technology
ICTS	Irish Children's Triage System
IR	Interventional Radiology
MDT	Multidisciplinary Team
MOCIS	Medical Oncology Clinical Information System
NCCP	National Cancer Control Programme
NCHD	Non-consultant Hospital Doctor
NCIMD	National Centre for Inherited Metabolic Disorders
NMD	Neuromuscular Disease
pID	Paediatric Infectious Diseases
RCPCH	Royal College of Paediatrics and Child Health
RCPI	Royal College of Physicians of Ireland
WTE	Whole Time Equivalent





