

# Children's Health Ireland

Strategy for Research 2021-2025







**CULTURE** 



**PEOPLE** 



**INFRASTRUCTURE** 





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CHI STRATEGY FOR RESEARCH 2021-2025 SUMMARY





#### 1 CHI STRATEGY FOR RESEARCH 2021-2025 – SUMMARY

#### Vision

Healthier children and young people throughout Ireland

#### Values

Child-centred • Compassionate • Progressive
We will act with Respect Excellence and Integrity

#### Mission

To promote and provide child-centred, research-led and learning informed healthcare, to the highest standards of safety and excellence, in partnership with each other, with children, young people and their families through a Network of children's services in Ireland, so that children and their families experience an excellent healthcare service that meets their needs

#### Culture

- Develop strong research engagement with children and their families
- Encourage and facilitate staff engagement in research
- Promote integration of research and clinical care to improve patient outcomes

#### **Strategic Themes**

#### People

- Support CHI staff to become research-active
- Develop and support highpotential researchers
- Support excellent CHI research leaders

#### Infrastructure

- Develop robust research support capability
- Acquire host institution status and build strong governance and sustainability

#### **Enablers**

Strategic Research Partnerships Children's Research and Innovation Centre

Research Governance

Funding

2

# FOREWORD 1: CHI CHIEF EXECUTIVE





#### 2 Foreword 1: CHI Chief Executive

We have often heard it stated, "Today's Research is Tomorrow's Care" and in keeping with our values for progressive, child-centered and compassionate care, I'm delighted to see the development of this strategy for research, progressed by the Research Strategy Steering Group (RSSG) over the last six months following extensive internal and external consultation and engagement. Children's Health Ireland (CHI) was established on 1 Jan 2019 under statutory legislation to govern and manage services in the existing children's hospitals in Dublin as a single entity well before we move to the new children's hospital on the campus shared with St James's Hospital. Our establishing legislation specifically articulates the remit and function of CHI to promote and embed research and education in the delivery of best in class care to the children and adolescents of Ireland.

The new children's hospital and its two ambulatory and urgent care centres will provide state of the art healthcare facilities for children and adolescents in Ireland, but these patients and their families need more than just the best buildings and infrastructure. If we want to provide the best healthcare outcomes for children and adolescents, then we must ensure that the treatment and care we deliver is also best in class. We believe very strongly, throughout CHI, that the way we can achieve this is through advancement of the 'triple mission' of integrated clinical care, education and research.

I can confirm that CHI is continuing with an unwavering commitment to research both at an executive and Board level. As part of our CHI Strategy Statement 2021 – 2025 we have committed to progressing the Children's Research and Innovation Centre (CRIC) on the campus shared with St James's' Hospital and to developing a Paediatric Academic Health Science Centre (PAHSC) with our four Dublin University partners and an Academic Health Science Network (AHSN) with all of our University partners throughout the island of Ireland to really drive home improvements in healthcare outcomes for children and adolescents. We have demonstrated this commitment by investing in the key roles of Academic Lead, Director of Education and Director of Research and Innovation (DORI), which will be key roles in the future Paediatric Academic Health Sciences Centre/Network (PAHSC/N). The Board of CHI has also approved a business case for the establishment of the Research and Innovation Office in CHI.

We are excited about the future of child health and paediatric research in Ireland, with CHI playing a central role in a coordinated national effort to improve the health outcomes of children and adolescents in conjunction with all service providers and our academic partners and funders. This strategy for research recommends the actions needed by many to make this a reality. Some of the key elements are already there, and with a collective and united purpose to implement this strategy for research, we can advance our triple mission of integrated clinical care, research and education that will benefit the children, adolescents and families we serve.

Thank you to all who contributed to and worked on developing this strategy for paediatric research and I look forward to supporting its implementation.



Eilísh Hardiman Chief Executive

Children's Health Ireland

FOREWORD 2:
DIRECTOR OF RESEARCH
& INNOVATION





#### 3 Foreword 2: Director of Research & Innovation

This inaugural CHI strategy for research is a vital milestone in our journey to becoming an internationally renowned academic children's hospital. I am enormously grateful to the Research Strategy Steering Group (RSSG) for their time, expertise, commitment and detailed consideration of the complex internal and external environment relating to research in CHI. We have had extensive input from colleagues in CHI, our university partners, funders, patient organisations, clinical colleagues across the country, international colleagues and benchmark sites. In particular, we were delighted to have more than 800 responses to our detailed stakeholder survey. This reflects the dedication, interest and commitment to research of our staff and colleagues.

With the formation of CHI, incorporating the unique strengths of our individual hospitals, and the need to realign all aspects of what we do prior to the move to our new facilities, we have a fantastic opportunity to design and implement structures that will allow us to excel in the future. This is a rare opportunity, and one we are keen to grasp with both hands. The CHI Board and executive have demonstrated a clear commitment to research since the establishment of CHI. This commitment, in addition to the commitment of our academic partners and foundation, will ensure that we have the support, expertise and drive to be able to implement the objectives outlined in this strategy.

Over many years our three hospitals have been supported by their respective charitable foundations. In the last year, and in parallel with the merging of the children's hospitals, their foundations have also merged to form Children's Health Foundation (CHF). We are indebted to the CHF family, our hospitals and the National Children's Research Centre (NCRC) for their support and dedication over many years in enabling paediatric research to grow and develop to a point where we are able to start the next chapter in our development as outlined in this inaugural strategy for research.

Through the implementation of this strategy, the Research and Innovation Office (RIO) in CHI wants to ensure that access to the relevant training and expertise is available to enable all staff across CHI to conduct research that is of the highest quality and has real impact for children and adolescents. We want to develop a reputation for excellence at all stages of research, from novices to researchers with established international profiles. We want new and existing staff to develop and foster a culture of curiosity and innovation. We want CHI to be known as an institution where research is just part of who we are, how we operate and what we do. With our collective commitment to research, we will never be satisfied with 'good enough'- we want to continuously improve, innovate and discover, and we want this not for CHI, but for the children and adolescents of Ireland, now and in the future.



Professor Paul McNally

CHI Director of Research & Innovation

# CHI VALUES, VISION AND MISSION





# 4 CHI Values, Vision and Mission



# In Living our **VALUES**, we will be:

Child-centred, Compassionate, Progressive and we will act with Respect, Excellence and Integrity



### Our VISION is:

Healthier children and young people throughout Ireland



To promote and provide child-centred, research-led and learning informed healthcare, to the highest standards of safety and excellence. We do this in partnership with each other, with children, young people and their families through a network of children's services in Ireland







\*CHI Values, Vision and Mission were developed and agreed as part of a Cultural Analysis process with the Boards and staff at the three children's hospitals in 2015

Crumlin | Temple Street | Tallaght | Connolly

Figure 1: CHI's Values, Vision and Mission

# INTRODUCTION AND BACKGROUND





# 5 Introduction and Background

International evidence now shows that research-active healthcare settings save lives and improve health outcomes for patients. CHI is a new organisation, the purpose of which is to ensure high quality, safe and effective healthcare for the sickest children in Ireland, who need highly specialist services, as well as local paediatric services for all children in the Eastern region of Ireland. In recognition of the core role of research in such healthcare provision, CHI's establishing legislation (Children's Health Act 2018) assigns the following object to the organisation:

"to facilitate, foster, promote and carry out research and innovation aimed at improving paediatric services and advancing medical and scientific knowledge relating to paediatric services through research and scientific investigation and inquiry"

Although integration of research into healthcare is relatively common in advanced healthcare settings internationally, it is poorly developed in Ireland. Accordingly, the explicit assignment of purpose regarding research and innovation in CHI's legislation sets a clear direction for the re-development of paediatric services in the new organisation. CHI stands out in Irish healthcare in this regard and now has the opportunity to 'hit the reset button' in developing and rolling out children's healthcare services built on excellent research, research that constantly strives to satisfy unmet clinical and operational need, in keeping with best healthcare practice internationally.

Research alone cannot improve clinical care. All over the world the best healthcare systems combine clinical service, education (training) of health professionals and research into in Academic Health Science Centres (AHSC's), usually via partnerships of major hospitals, universities and foundations. The triple helix of service, education and research serves to attract and train the best staff, retain and continually develop them through research, and deliver clinical service with the best outcomes for patients. Currently, CHI and its partners are planning and developing a paediatric AHSC and are extending its reach on an all-island basis via a PAHSN. This PAHSC/N is an integral part of Sláintecare implementation, Ireland's medium to long-term health service reform plan. The essence of Sláintecare is the integration of acute and community care in a manner that shifts the focus of healthcare from episodic disease management to health promotion, disease prevention and health maintenance through the life course.

Given the recent establishment of CHI, the mandate for research in its legislation, the emerging PAHSC/N, and the needs of the funders of paediatric research (State, private, philanthropy and charity), there is an urgent need for a clear strategy for research in CHI. This inaugural strategy for research must recognise the heritage and status of paediatric research in Ireland, the evolving nature of CHI and the relative positions of key funders. Most importantly, it must chart a clear course for paediatric research over the next five years as CHI establishes itself, moves to the new children's hospital and its CRIC and forms new partnerships. The strategy, as with all good strategies, will serve as a high-level roadmap to inform the acquisition and allocation of resources (people, funding, equipment) to help CHI achieve this strategic objective. Concurrently and importantly, CHI has completed its first overarching Strategic Statement which explicitly identifies one of our strategic priorities as:

With our academic partners, CHI will develop a Paediatric Academic Health Sciences Centre/Network that will fundamentally reshape the hospital university model of education, research and innovation to underpin a safer and more integrated model of care that includes progressing philanthropic funding for the Children's Research and Innovation Centre.

# CONTEXT





## 6 Context

CHI's strategy for research has to be delivered in a context that is highly complex, arguably more challenging than that in which typical PAHSC/Ns operate. CHI is leading on the transformation of paediatric services across its services at Temple Street, Crumlin, Tallaght and its ambulatory and urgent care centre at Connolly Hospital Blanchardstown. In 2021, CHI will open its second ambulatory and urgent care centre at Tallaght University Hospital followed later by the new children's hospital on the campus shared with St. James's Hospital. Each of the progenitor organisations comes with its own research programmes, governance and cultures and CHI is currently in the process of integrating these. Each also comes with its own academic partner relationships, developed over long periods of time. Furthermore, beyond its role in delivering acute paediatric services at its Dublin sites, CHI has a central role in the development and operationalisation of an integrated paediatric network of services and the PAHSN across the island of Ireland. This takes in the key clinical sites (regional hospitals and community areas) and academic partners in Cork, Limerick, Galway and Belfast, each with its own research programmes, cultures, system of governance and management.

Chronic underinvestment in health research by the Irish State over decades has brought its own challenges to the development of fit for purpose paediatric research structures. To bridge the gap, local solutions, that differ from international practice, evolved to fund, plan, manage, govern and deliver paediatric research in Ireland. Through the implementation of the recommendations in the CHI Research Governance Review (May 2019) and the current development of the PAHSC/N under the oversight of an Academic Partnership Group (APG), new systems to govern and fund paediatric research are underway. Whilst these matters are not directly in the scope of this CHI strategy for research, they are clearly important enabling factors that must be considered in rolling out the strategy.

A clear strategy for research is required by funders when they are considering where to allocate their resources. Accordingly, CHI must have a clear, coherent and compelling strategy for research to attract research funding from private, public, philanthropic and charitable sources. Due to significant underfunding of health research by the State, paediatric research in Ireland is particularly dependent on charity funding, for which it also competes with hospitals' needs to augment their own investments in infrastructure and environmental improvements. The CHF, formed by the recent merger of the Children's Medical Research Foundation and the Temple Street Foundation, invests over €6 million annually in paediatric research, which equated to more than €65 million for CHI over the past decade. CHF requires a clearly defined CHI research programme in order to plan, manage and deliver its fundraising campaigns. Accordingly, CHI must have a cogently defined strategy for research that persuasively connects the research effort to clinical delivery and outcomes for Ireland's children and has great public appeal. Communicating the merits of research and acknowledging CHI researcher's activities will be critical to enhance CHI's reputation for providing healthcare grounded in cutting edge research. Longer term, CHI, as observed in best practice paediatric sites internationally, should seek to attract much greater levels of external funding from competitive sources including national funding agencies, and international bodies like the EU.

Given the aforementioned context, the inaugural CHI strategy for research focuses on transitioning existing successful models of practice and expertise, getting the foundations right over the first few years of CHI's establishment in order to create the environment (culture, people and infrastructure) in which research can flourish and translate into improved care for the benefit of children and adolescents. This five-year strategy is the first instalment in a multi-decade initiative to promote and provide child-centred, research-led and learning informed healthcare, to the highest standards of safety and excellence and, in so doing, achieve the vision of healthier children and young people throughout Ireland.

# CHI'S PROGRESS TO DATE





# 7 CHI's Progress to Date

Although CHI is a relatively new organisation, established in January 2019, since its inception it has been laying some of the early foundations required to integrate research into paediatric healthcare. The key milestones of these early foundations are illustrated below.

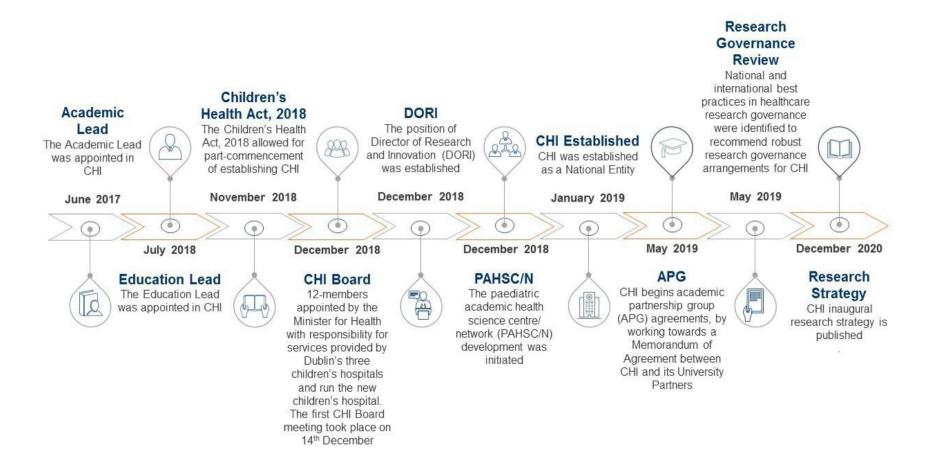


Figure 2: CHI Research and Innovation Milestones

To facilitate the development of its inaugural strategy for research, CHI formed the RSSG, see below for membership. The CHI RSSG engaged Mazars to conduct a rigorous stakeholder engagement process and gather opinions on what should be included in the strategy for research. Over a period of approximately six months, inputs were sought from a wide range of world-renowned, research-active children's hospitals (see Appendix 1), stakeholders (through extensive one-to-one interviews and group workshops, see Appendix 2) and a widely circulated survey (see Appendix 3). Under the guidance of the CHI RSSG, the information gathered from this exercise has been assessed and synthesised to develop this strategy for research.

#### CHI RSSG membership:

Name	Role
Professor Paul McNally	Chair of the RSSG and CHI DORI
Professor Owen Smith	CHI Academic Lead
Ms Denise Fitzgerald	CEO of CHF
Dr Jacinta Kelly	CEO of the NCRC
Professor Jonathan Hourihane	Professor of Paediatrics, CHI at Temple Street
Ms Carol Hilliard	Assistant Director of Nursing, CHI at Crumlin
Dr Hazel Ní Chonchubhair	CHI Academic Programme Manager

STRATEGIC THEMES, GOALS, INITIATIVES AND OUTCOMES





# 8 Strategic Themes, Goals, Initiatives and Outcomes

Given the context of paediatric research in Ireland and CHI's recent establishment (as described in Section 6), the inaugural CHI strategy for research focuses on getting the foundations right over the first few years of CHI's establishment in order to create the environment (culture, people and infrastructure) in which research can flourish and integrate into clinical care for the benefit of children. For this reason, in this strategy we do not specify priorities in particular research fields, scientific disciplines or related technologies. There are acknowledged strengths in Irish paediatric research, including CHI, and while these should be built on, our focus in this strategy is on supporting the foundational infrastructure, people and culture for research in CHI.

As the strategy is implemented over the next five years, CHI will establish a balanced portfolio inclusive of high-quality, impactful research (basic science, translational, clinical and clinical trials) that is driven by unmet clinical need. Evidence from world-leading paediatric services suggests that supporting interdisciplinary activities, ranging from basic research to public and population health, produces the best results in terms of translating research findings into improved health outcomes.

This five-year strategy is the first instalment in a multi-decade initiative to promote and provide child-centred, research-led and learning-informed healthcare, to the highest standards of safety and excellence and, in so doing, achieve the vision of healthier children and young people throughout Ireland. The vision, mission and values for CHI relate to the whole organisation, however the three strategic themes outlined below specifically relate to research at CHI.

The inaugural strategy for research is built upon three strategic themes:







Each theme is associated with several goals. In turn, each goal is underpinned by a set of initiatives with associated outcomes. These are illustrated in <u>Figure 3</u> and described in greater detail below.

#### Vision

Healthier children and young people throughout Ireland

#### Values

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We will act with Respect. Excellence and Integrity

#### Mission

To promote and provide child-centred, research-led and learning informed healthcare, to the highest standards of safety and excellence, in partnership with each other, with children, young people and their families through a Network of children's services in Ireland, so that children and their families experience an excellent healthcare service that meets their needs

#### 1

#### Culture

- Develop strong research engagement with children and their families
- Encourage and facilitate staff engagement in research
- Promote integration of research and clinical care to improve patient outcomes

## Strategic Themes

#### People

- Support CHI staff to become research-active
- Develop and support highpotential researchers
- Support excellent CHI research leaders

#### Infrastructure

- Develop robust research support capability
- Acquire host institution status and build strong governance and sustainability

#### **Enablers**

Strategic Research Partnerships

Children's Research and Innovation Centre

Research Governance

Funding

Figure 3: Overview of CHI strategy for research

#### 8.1 Strategic Theme 1: Culture

#### 8.1.1 Goal: Encourage and Facilitate Staff Engagement in Research

Patient outcomes are superior in hospitals with a robust research portfolio. As such, CHI aims to deliver a culture where staff engagement in research is expected and encouraged. A significant proportion of paediatric researchers in Ireland are in full-time clinical jobs and have received relatively little institutional support. Creating an environment that supports research demands a significant mind shift in how research is viewed in CHI. To start with, CHI wants to support those healthcare workers interested in performing research by providing encouragement, training and supports, and recognising their efforts.

Throughout the lifecycle of this strategy, promoting research activity for staff in all fields, at all career stages and education levels and celebrating the achievements of our research-active staff will be essential to establish CHI as a research-active organisation and Network. Connecting with our partners through the PAHSC/N will enable us to provide greater resources to staff seeking to engage with researchers in fields different to their own to foster a culture of collaborative research across our network of hospitals and our partner Higher Education Institutions (HEIs).

#### Initiatives:

- i. 'Recognise' research in CHI job campaigns, professional development, career laddering, promotions etc.
- ii. Increase opportunities for staff engagement in research by supporting early/entry level research projects (training, seed funding and practical support) and by providing the necessary resources (library access, software licenses etc.)
- iii. Foster a culture of continued healthcare improvement through research activities
- iv. Celebrate/recognise the on-going conduct and achievements of paediatric research through internal communications
- v. Encourage and support investigator participation in regional, national and international research organisations and associations as well as leadership roles in national and international research projects

- i. Change in culture towards a culture of curiosity linked to unmet clinical need
- ii. CHI staff, current and future, see themselves as potential healthcare researchers
- iii. Significant increase in CHI staff engaging in research activity
- iv. Funding application support provided to CHI researchers
- v. CHI staff encouraged to conduct research by managers and clinical leaders
- vi. Increase in training opportunities/programmes
- vii. Increase in funding secured by healthcare staff
- viii. Staff recognised/rewarded for performing research

#### 8.1.2 Goal: Develop Strong Research Engagement with Children and their Families

The children that we treat, and their families, are at the heart of CHI's mission. CHI's ability to advance research-led care is dependent on the participation of children and their families. Growing and improving our engagement with children and their families will allow CHI to connect with and fully realise the needs of those we seek to help. CHI will change the relationship we have with our patients and families to influence the kind of research we do, to inform them of CHI's research initiatives, to facilitate their participation and then keep them informed of the progress we are making.

Working with our patient advocate counterparts in organisations like the Irish Platform for Patient Organisations (IPPOSI), CHI will make our research participants ambassadors of research and celebrate their contribution to encourage greater patient participation and create a public face for our research activities.

#### Initiatives:

- i. Establish a Research and Innovation Communications Function that will drive two-way communication of CHI research activities with patients, the public and donors
- ii. Connect with patients and families to inform our research goals and promote access to the latest scientific findings
- iii. Establish a young person's advisory group for research in CHI
- iv. Ensure all children and families are optimally informed and encouraged to participate in research linked to their care in an effective and timely manner
- v. Celebrate and recognise children and their families as participants in research and keep them engaged during and after research (make them 'Ambassadors')

- i. Our research will have more impact on Irish patients and their families
- ii. Patients and families become integral players in the CHI research effort (research team members) and the research questions addressed by CHI are (increasingly) influenced by patients (tightening the coupling between research and unmet clinical need)
- iii. Generation and integration of an active patient/family community within the research community of CHI
- iv. Development of a cohort of patient/family ambassadors

# 8.1.3 Goal: Promote Integration of Research and Clinical Care to Improve Patient Outcomes

Integrating research, care and education improves health outcomes for patients. We want to drive awareness at all levels in CHI that research is an integral part of clinical care in modern, quality-driven healthcare environments. Collaboration across departments and areas of science will be critical to the success of this objective as CHI seeks to partner healthcare professionals with researchers and scientists to produce better treatments for our patients. CHI wants to make the process for integrating research into healthcare and education transparent and to recognise the efforts our staff are undertaking to make this possible.

Through the PAHSC/N, integrating research, care and education will be more streamlined than in the past. Direct links with our HEI partners will allow CHI to translate our research knowledge into improved outcomes and to create state of the art educational experiences. Creating placements for students in CHI sites and in turn creating teaching and learning positions in the HEIs for our researchers will further develop the partnership between research, care and education.

The continuous improvement cycle created by the three elements will serve to further research in CHI, improve patient care and outcomes, and educate and train emerging clinician researchers in CHI.

#### Initiatives:

- i. Through the PAHSC, work with the CHI executive and board to ensure that the highest priority is given to integration of research into clinical care
- ii. Ensure that research is recognised as a core part the work of CHI clinical staff when considering future resource and workforce planning
- iii. Take practical approaches to integration such as holding research meetings in clinical spaces, and clinical and teaching meetings in research spaces "anyone, anytime, anywhere"
- iv. Incorporate children and their families in the goal of integrating research into clinical care "anyone, anytime, anywhere"
- v. Celebrate/promote outstanding research initiatives, findings and achievements of our researchers for both the scientific and public realms
- vi. Develop mechanisms that foster integration across CHI e.g. awarding and recognising staff who achieve this
- vii. Recognise integration of research, care and education in professional development of individuals and at organisational level

- i. An understanding by patients, parents, staff and the public that research is part of our everyday work, and the reason we will never stop improving the care that we deliver to children
- ii. Enhanced integration across clinical care, research and education domains (in keeping with PAHSC/N model and objective of improved health outcomes)
- iii. Increased interdisciplinary research, driven by clinical need
- iv. Increased translation of research findings into new practices and care models
- v. Greater cohesion across CHI's workforce that supports the mutually reinforcing roles of research, care and education in pursuit of best practice

#### 8.2 Strategic Theme 2: People

#### 8.2.1 Goal: Support CHI Staff to Become Research-Active

Key to the successful delivery of this strategy is a highly skilled research workforce. Research will not happen at any CHI site without them. We want to recognise those who want to be research active and increase the numbers of staff engaging in research by removing some of the barriers that have been outlined in the survey we carried out as part of our strategy development process. This will involve encouraging staff at all career stages, across all disciplines, to engage in research. The focus will be on research excellence, big or small. If the idea is good enough, if the methodology is sound and if the research will benefit children, we will support it. It is our aim to give every staff member (anyone) who wants to become involved in research the opportunity to do so (anytime), the training to do so effectively and the supports to help them succeed (anywhere).

#### Initiatives:

- i. Develop appropriate supports, including research training programmes, to assist early-stage researchers in preparing for and conducting research
- ii. Establish and develop clear pathways for researchers to access support and advice
- iii. Develop and roll out a communications campaign to alert all CHI staff to research opportunities
- iv. Lower the barrier to entry for research by providing practical financial supports and seed funding to facilitate CHI staff participation in research
- v. Recognise and celebrate new entrants to research

- i. An increased awareness of, and appetite for, research in all CHI staff
- ii. A manifest change in the range and level of CHI staff/disciplines/sites engaging in research at entry level (widen the base)

#### 8.2.2 Goal: Develop and Support High Potential Researchers

In addition to providing supports for those stepping onto the research ladder for the first time (see <u>Goal 8.2.1</u>). At CHI we must enable promising early-mid career researchers to achieve their potential. This is essential in bridging the gap between starter researchers and established research leaders, and forming a coherent, end to end paediatric research system that is sustainable. Offering such mid-career supports will enable us to develop our own staff and to attract external talent. Moreover, such researchers will see CHI as a place to consolidate research independence and to foster the next generation of research leaders.

#### Initiatives:

- Identify high potential researchers in all disciplines and levels through evaluation of internal and external metrics
- ii. Provide career-stage appropriate training and supports to fast-track development of high potential researchers
- iii. Put in place a formal system of mentorship of promising researchers by experienced research leaders
- iv. Promote CHI as a destination for promising early career stage researchers

- i. A cohort of early career researchers with potential to be the next wave of researchleaders
- ii. CHI recognised as a destination of choice for high potential research clinicians
- iii. New areas of research excellence are spawned
- iv. A visible career path bridging entry-level researchers to research leaders

#### 8.2.3 Goal: Support Excellent CHI Research Leaders

Prior to the existence of CHI, paediatric research in Ireland had already developed key strengths in several distinct disease areas. In addition, Ireland is home to several talented and developed paediatric researchers who are highly recognised in their respective fields of study. CHI wants to continue the work being carried out in these areas and to promote the achievements of these research leaders and other members of their groups. These research leaders will help to advance our reputation nationally and internationally, to provide encouragement to up and coming researchers and to inspire patients and families. CHI will need to maximise on our existing strengths to nurture our areas of excellence and to attract new funding and highly skilled researchers. The strengths that have been developed thus far will be essential in the realisation of the other objectives in this strategy such as the integration of research, care and education. CHI has the opportunity to enrich the local research culture and talent pool and change the 'brain drain' culture that implies the best Irish researchers must pursue their dreams overseas.

#### Initiatives:

- i. Support existing pockets of excellence to act as magnets of attraction for skilled researchers and competitive funding
- ii. Enable and encourage the leaders to be highly visible throughout CHI as they inspire children and their families and CHI staff celebrate, recognise, advocate and promulgate
- iii. Use existing strengths to serve as platforms on which to deliver other strategic objectives in this strategy e.g. early career development for new researchers, integration of research, care and education etc.
- iv. Use existing strengths as platforms to develop new research areas (collaborative and interdisciplinary), new teams, and accessing new channels of external funding
- v. Support the hosting of international conferences, visiting speakers and fellows by research leaders

- i. Existing strengths are maintained
- ii. Existing strengths are used as a platform to develop new investigators/teams in new areas (off-shoots), particularly around interdisciplinary initiatives
- iii. Internationally credible research leaders in CHI CHI's reputation has increased and improved
- iv. CHIs strong international reputation promotes greater collaboration resulting in access to multicentre studies, trials and other activities that promote our reputation and bring financial rewards.

#### 8.3 Strategic Theme 3: Infrastructure

#### 8.3.1 Goal: Develop Robust Research Support Capability

To produce excellent research, CHI must have strong foundations to build upon. High quality, genuinely impactful research cannot be conducted effectively without the necessary facilities and infrastructure to support it. Services and facilities provided by CHI will be necessary to support a comprehensive array of research activity from start-up projects to complex, internationally competitive projects. The development of the RIO is an essential element of our research infrastructure moving forward. During the period of this inaugural strategy for research, the RIO will incrementally develop support functions for researchers to participate and succeed in research. Linking the RIO with Research Offices in HEIs across Ireland will provide opportunities to magnify the impact and benefit of the work that is carried out in CHI. This work is heavily dependent on <a href="Enabler 3">Enabler 3</a> (Implementing the recommendations of the CHI Research Governance Review) as many of the recommendations from the governance review are necessary to allow the RIO to function successfully.

As outlined in the following section, CHI hospitals have not historically had unique relationships with a single academic host institution. Through the CHF and its predecessor organisations, CHI hospitals have received considerable support to build the current research support infrastructure and to support research projects (through the NCRC and the hospitals). In the future it will be vital for CHI to work with state bodies, CHF, other funders and grant awarding bodies to ensure that sufficient resources are available to support the goals contained in this and subsequent strategies in relation to both infrastructure and project funding.

#### Initiatives:

- i. Build a RIO in CHI, incrementally adding research support services over time
- ii. Develop a clear and comprehensive plan to outline how support from CHF will contribute to CHI's ability to realise the goals of this and future strategies
- iii. Streamline the research quality management system (QMS) across CHI and integrate this with CHI's QMS
- iv. Implement a research approval and tracking system that will ensure quality, support researchers and measure all aspects of activity accurately
- v. Integrate the CHI RIO with key CHI functions (such as human resources, finance, operations, quality, directorates) and connect with HEI Research Offices to optimally align and deliver research support, avoid duplication etc.
- vi. Focus on developing productive partnerships with research performing organisations

- i. A centralised research support hub (RIO) that underpins a step change in CHI research activity and quality
- ii. A comprehensive, functioning range of research support services and processes for CHI researchers, patients and families
- iii. Research support functionality within CHI that lowers the barriers to entry into research for CHI researchers and patients/families
- iv. Increased level of grant applications and awards, increased award sizes and team sizes, increased networking and collaborations
- v. Up to date and accessible database of all research ongoing in CHI including key CHI research metrics
- vi. High quality research performing organisations want to work with CHI on research projects

# 8.3.2 Goal: Acquire Host Institution Status and Build Strong Governance and Sustainability

Major research funders have strict and demanding eligibility requirements in order for an organisation to become an approved host institution (approved to host grants). These requirements cover a range of areas such as the capacity to support, inter alia, the financial, governance, legal and technical aspects of grant application and management. Although CHI has four strong academic partners, and a strong relationship with all four together will form the basis of the PAHSC, none of these partners has a unique and dedicated role as the key academic partner to CHI. In the majority of academic teaching hospitals in Ireland, a single recognisable university partner is available to act as a host institution for its partner hospital(s) and allow grants to be accepted and managed effectively. In the absence of this unique arrangement, CHI will need to invest in the supports and services required to attain host institution status. To support its overall research ambitions, CHI needs to be able to host grants from major national and international funders. This will serve to provide the infrastructural supports required to enable CHI teams and patients/families to engage in productive research that translates into improved care.

#### Initiatives:

- Scope the major funder requirements for host institution eligibility and invest in identified gaps to build capability in supporting research activity
- ii. Integrate RIO functions with CHI corporate functions such as finance, human resources and quality and partner as appropriate with HEIs to deliver research support capability
- iii. Develop a business model to outline how CHI will attract and manage grant support and industry income to achieve financial sustainability
- iv. Secure host institution status with the major funders (Health Research Board (HRB), Science Foundation Ireland (SFI) etc.)

- i. CHI achieves host institution status with main state funders and is trusted/enabled to host major grants
- ii. CHI successfully hosts grants from funders related to research within CHI
- iii. A financial model that underpins financial sustainability
- iv. Funding opportunities for excellence

# KEY ENABLERS





# 9 Key Enablers

Successful delivery of the inaugural CHI strategy for research relies on several key enablers. These key enablers are not in the direct scope/remit of the strategy for research but without them the goals within culture, infrastructure and people cannot be achieved. They are described briefly as follows:









#### Strategic Enabler 1: Strategic Research Partnerships

Transforming paediatric healthcare in Ireland, as per the mission of CHI, is a highly complex undertaking. In any complex system, the resources (financial, human, technical etc.) required to change it are usually beyond the capability (competence and capacity) of any single organisation. By definition therefore, complex change usually requires sophisticated partnerships of separate organisations with differing capabilities that work collectively. This is true for CHI in transforming paediatric healthcare in Ireland. This principle of partnership must pervade all that CHI does. CHI must pursue and be pursued by relevant high-quality partners. A number of key partnerships already exist and/or are already under development by CHI; others should be developed during the period of this Strategy.

- Academic partnerships with HEIs underpinning the PAHSC/N model, as described in the <u>Introduction</u>.
   These academic partners are key in delivering education/training and research programmes
- Research partnership with the NCRC, the body that has supported a significant body of paediatric research in Ireland to date and continues to provide grant award management and wet lab and biosample services on site at CHI Crumlin
- Charity partnership with the CHF, CHI's central and underpinning charity partner, raising significant funds for research and serving as a key advocate and supporter for paediatric research in Ireland

The above represent some of the initial partnerships required to enable CHI's mission but these will evolve over time and many more will be required in the future, ranging from local authorities to private companies to international bodies.

#### Strategic Enabler 2: Children's Research and Innovation Centre

The CRIC will be a purpose-built research facility which will enable researchers to carry out basic science and translational research on location at the new children's hospital campus. CRIC will provide bench spaces and workspaces for all researchers. It will be a hub for research and innovation for the new Children's Hospital. It will provide biobanking, immunology, genomics, proteomics and a host of other molecular technologies that are germane to the transition to precision medicine. It will benefit from co-localising with Trinity College Dublin's Trinity Molecular Medicine Institute (TTMI). The CRIC will also provide meeting rooms and offices for researchers, both scientists and clinical, among other resources for CHI affiliated research. In the continuum of *bench-to-bedside* care, a key tenet of the academic health sciences model for CHI, the CRIC is the *bench* providing key infrastructure on site for basic and translational research.

#### Strategic Enabler 3: Research Governance

In 2019, shortly after its establishment, CHI commissioned an external review of Research Governance across its sites. The review examined best practice internationally and made a number of recommendations across key domains – including ethics, principles/responsibilities of health research, study approvals and inter-institutional agreements – to enable CHI to attain good/best practice status in research governance. Meaningful implementation of these recommendations is a prerequisite for successful implementation of CHI's inaugural strategy for research.

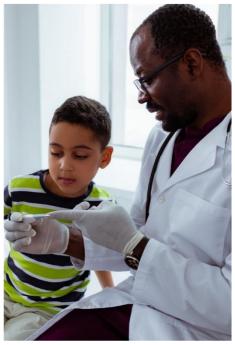
#### Strategic Enabler 4: Funding

In order to realise the ambition of this strategy and to provide CHI with the scale and sustainability of resources that it requires, a significant increase is required in both the level of funding and the diversity of funding sources of CHI's research efforts. It is clear from the study of advanced paediatric institutions which served as benchmark sites for this strategy, where care is research-led, that there is a significant investment in research by multiple parties. At these sites, public investment in research infrastructure allows significant leveraging of private and charitable funding, including philanthropic funding. This diversity of funding sources allows these institutions not only to achieve the scale of funding required for world class, research-led care but also to sustain funding when particular/individual funding sources experience downturns (i.e. optimal risk management of the funding environment). Funding of paediatric research, within and beyond CHI, is not in the direct remit of this strategic plan. However, it is a core enabler of the strategy's successful delivery.





**CULTURE** 



**PEOPLE** 



**INFRASTRUCTURE** 





HIGH LEVEL IMPLEMENTATION FRAMEWORK





# 10 High Level Implementation Framework













2021 2022 2023 2024 2025 YEAR 1 YEAR 2 YEAR 3 YEAR 4 YEAR 5

			I LAK I	I LAR Z	YEAR 3	ILAK 4	I LAK 3
heme	Goal	Objective	20%	40%	60%	80%	100%
	Encourage and Facilitate Staff Engagement in Research	'Recognise' research in CHI job campaigns, professional development, career laddering, promotions etc.				41	
		Increased opportunities for engagement in research and to facilitate research by providing early/entry level research projects (training, seed funding and support) and by providing the necessary resources (library access, software licenses etc.) – widen the pool of researchers					
		Foster a culture of continued healthcare improvement through research activities					
		Celebrate/recognise the on-going conduct and achievements in research – through internal communications					
		Encourage and support investigator participation in regional, national and international research organisations and associations as well as leadership roles in national and international research projects					
	Develop	Establish a Research and Innovation Communications Function that will drive two-way communication of CHI research activities with patients, the public and donors			<b>—</b>		
	Strong	Connect with patients and families to inform our research goals and promote access to the latest scientific findings	1				
iro	Research Engagement	Establish a young persons' advisory group for research in CHI			>		
with an	with Children and their	Ensure all children and families are optimally informed and encouraged to participate in research linked to their care in an effective and timely manner					
	Families	Celebrate and recognise children and their families as participants in research and keep them engaged during and after research (make them 'Ambassadors')					
	Promote Integration of Research and Clinical Care to	Through the PAHSC, work with the CHI executive and board to ensure that the highest priority is given to integration of research into clinical care					
Integration Reseat and Clin Care Impro		Take practical approaches to integration such as holding research meetings in clinical spaces, and clinical and teaching meetings in research spaces "anyone, anytime, anywhere"					
		Incorporate children and their families in the goal of integrating research into clinical care "anyone, anytime, anywhere"					
	Improve Patient	Celebrate/promote outstanding research initiatives, findings and achievements of our researchers for both the scientific and public realms					
	Outcomes	Develop mechanisms that foster integration across CHI e.g. awarding and recognising staff who achieve this					
	e e	Recognise integration of research, care and education in professional development of individuals and at organisational level					
_							





# **PEOPLE**









2021 2022 2023 2024 2025 YEAR 1 YEAR 2 YEAR 3 YEAR 4 YEAR 5

							ILAK
heme	Goal	Objective	20%	40%	60%	80%	100%
	Support CHI Staff to Become	Develop appropriate supports, including research training programmes, to assist early-stage researchers in preparing for and conducting research					
		Establish and develop clear pathways for researchers to access support and advice					
		Develop and roll out a communications campaign to alert all CHI staff to research opportunities					
	Research- Active	Lower the barrier to entry for research by providing practical financial supports and seed funding to facilitate CHI staff participation in research					
		Recognise and celebrate new entrants to research					
	Develop and Support High Potential Researchers	Identify high potential researchers in all disciplines and levels through evaluation of internal and external metrics					
People R		Provide career-stage appropriate training and supports to fast-track development of high potential researchers					
		Put in place a formal system of mentorship of promising researchers by experienced research leaders					
		Promote CHI as a destination for promising early career stage paediatric researchers			51		
	Support existing pockets of excellence to act as magnets of attraction for skilled researchers and competitive funding	Support existing pockets of excellence to act as magnets of attraction for skilled researchers and competitive funding					
	Support Enable and encourage the leaders to be highly visible throughout CHI as they inspire children and their families and recognise, advocate and promulgate	Enable and encourage the leaders to be highly visible throughout CHI as they inspire children and their families and CHI staff – celebrate, recognise, advocate and promulgate					
	Excellent CHI Research	Use existing strengths to serve as platforms on which to deliver other strategic objectives in this strategy e.g. early career development for new researchers, integration of research, care and education etc.					
	Leaders	Use existing strengths as platforms to develop new research areas (collaborative and interdisciplinary), new teams, and accessing new channels of external funding					
		Support the hosting of international conferences, visiting speakers and fellows by research leaders					

TODAY



# INFRASTRUCTURE









**2021 2022 2023 2024 2025** YEAR 1 YEAR 2 YEAR 3 YEAR 4 YEAR 5

Theme	Goal	Objective	20%	40%	60%	80%	100%
		Build a RIO in CHI, incrementally adding research support services over time	į.	*	33		
	Develop	Develop a clear and comprehensive plan to outline how support from CHF will contribute to CHI's ability to realise the goals of this and future strategies					
	Develop Robust	Streamline the research quality management system (QMS) across CHI and integrate this with CHI's QMS					
	Research Support Capability	Implement a research approval and tracking system that will ensure quality, support researchers and measure all aspects of activity accurately			1		
	Capability	Integrate the CHI RIO with key CHI functions (such as human resources, finance, operations, quality, directorates) and connect with HEI Research Offices to optimally align and deliver research support, avoid duplication etc.					
Infrastructure		Focus on developing productive partnerships with research performing organisations					
	Acquire Host	Scope the major funder requirements for host institution eligibility and invest in identified gaps to build capability in supporting research activity			·		
	Institution Status and	Integrate RIO functions with CHI corporate functions such as finance, human resources and quality and partner as appropriate with HEIs to deliver research support capability					
	Build Strong Governance and	Develop a business model to outline how CHI will attract and manage grant support and industry income to achieve financial sustainability					
	Sustainability	Submit applications for host institution status to the major funders (Health Research Board (HRB), Science Foundation Ireland (SFI) etc.)					

TODAY

# **APPENDIX**





# Appendix 1: Benchmark Consultations

In addition to stakeholder consultations, a benchmarking exercise was carried out with the following paediatric research institutions:

Table 1: Benchmark Consultations

Benchmark Organisations	Contact and Director Position			
Alder Hey Children's Hospital	Prof. Matthew Peak Co-Director of the National Institute for Health Research Alder Hey Clinical Research Facility for Experimental Medicine			
British Columbia (BC) Children's Hospital	Prof. Wyeth Wasserman  Executive Director and Vice President for Research, BC Children's Hospital			
Royal Children's Hospital Melbourne (RCH)	Dr Leanne Mills  Head (Chief of Staff) of Office of the Director, Research and Support Operations, Murdoch Children's Research Institute (MCRI)			
The Hospital for Sick Children, Toronto ('SickKids')	Prof. Michael Salter Chief of Research Emeritus at SickKids Prof. Meredith Irwin Paediatrician-in-Chief at SickKids			

#### A1.1 Alder Hey Children's Hospital

Alder Hey Children's Hospital is operational since 1914 and is one of Europe's biggest and busiest Children's Hospitals that treats common illnesses. 2015 saw the opening of a new state-of-the-art hospital including a new research, innovation and education centre. The Alder Hey Children's Hospital is a member of The Cheshire & Merseyside Health & Care Partnership and NHS Foundation Trust.

Alder Hey employs ~3,400 staff with 39 clinics and 11 community sites. More than 275,000 children are cared for on an annual basis. There are five university partners working in collaboration in Alder Hey including the University of Liverpool, Liverpool John Moores University, The University of Central Lancashire and Edge Hill University. Although the total income for Alder Hey is £294 million, only £3.5 million is allocated to research.

Alder Hey is a Centre of Excellence with leading research areas in children's medicine, infection, inflammation and oncology. Other areas of expertise include spinal, heart and brain conditions including muscular dystrophy, cardiac surgery, head and face surgery, childhood lupus and childhood epilepsy surgery (a joint service with the Royal Manchester Children's Hospital).

Alder Hey's vision is, "To build a healthier future for our children and young people as one of the recognised world leaders in research and healthcare". This is supported by their strategic aims

- 1. Be the provider of first choice for children, young people and their families
- Ensure all of our patients and their families have a positive experience whilst in our care
- 3. Deliver clinical excellence in all of our services
- 4. Ensure our staff have the right skills, competence, motivation and leadership to deliver our vision
- 5. Be a world class centre for children's research and development
- 6. Further improve our financial strength in order to continuously invest in services
- 7. Have a world class facility to deliver world class care

#### A1.2 BC Children's Hospital

BC Children's Hospital provides expert health care for seriously ill and injured children across BC including mental health care. The Hospital is the province's major treatment, teaching and research facility for child health, with 93,000 children cared for on an annual basis.

BC is publicly funded under the Provincial Health Service Authority and has been operational since 1923. Key research areas for BC include:

- Specialised paediatric surgery orthopaedics, urology, ear/nose/throat, ophthalmology and plastic surgery
- Programs for children with congenital or acquired heart disease
- Psychiatric services emergency care and treatment for eating disorders, mood disorders and attention deficit hyperactivity disorders
- Neurology and neurosurgery service for children and youth with serious disorders of the brain and nervous system
- Treatment of children with cancer and blood disorders, including bone marrow transplants and supportive and palliative care
- Integrated pain service for children and youth that provides much-needed help for children and youth with complex acute or chronic pain
- A medical genetics program addressing genetic diseases and family counselling
- HIV

BC Children's Hospital has one university partner, The University of British Columbia and two hospital partners, Sunny Hill Health Centre for Children and BC Women's Hospital + Health Centre. BC have a total income of CA\$78m dedicated to research from grants, contracts and agreements received from foundations, granting agencies and organisations, government, hospitals and universities. BC Children's Hospital has more than 1,000 researchers. Their key research themes are Childhood Diseases, Brain, Behaviour & Development, Healthy Starts and Evidence to Innovation. The facilities provided by BC Children's Hospital for research include an analytical core for metabolomics and nutrition, a biobank, an MRI research facility, core technologies at the Centre for Molecular Medicine and Therapeutics such as flow cytometry, histology and imaging and a tissue and disease modelling core.

#### A1.3 Royal Children's Hospital Melbourne

The RCH is a major specialist paediatric hospital in Victoria, Australia. RCH hosts a major paediatric trauma centre as well as a centre for cardiac and liver transplantation. RCH's campus partners include the MCRI and The University of Melbourne Department of Paediatrics, along with the RCH Foundation. It is a member of the Victorian Paediatric Clinical Network which seeks to implement the Department of Health Strategic Framework for Paediatric Health Services in Victoria. The new RCH has been delivered as a Public Private Partnership under the State Government's Partnerships Victoria model.

RCH is operational since 1870 with the MCRI since 1986. With over 4,000 staff and 1,200 researchers, the RCH estimates they have approximately 480 on-going research studies. These covers areas including cell biology, genetics, population health, clinical science, data science, infection and immunity and Victorian Clinical Genetics Services. The RCH has one university partner, the University of Melbourne which also partner with the MCRI. The RCH is part of the Melbourne Genomics Health Alliance including:

- MCRI
- University of Melbourne
- Royal Melbourne Hospital
- Walter and Eliza Hall Institute of Medical Research
- Commonwealth Scientific and Industrial Research
- Australian Genome Research Facility
- Peter MacCallum Cancer Centre
- Austin Health
- Monash Health

And is also a member of the Global Alliance for Genomics and Health, from which it receives substantial funding. The RCH is also a partner to industry organisations such as Diagnostica Stago, Bayer, Bristol Myers Squibb, Roche Diagnostics and Pfizer.

#### A1.4 The Hospital for Sick Children, Toronto 'SickKids'

The Hospital for Sick Children, branded 'SickKids', is a research-intensive hospital partnered with the University of Toronto. Their mission is to provide the best in family-centred, compassionate care, to lead in scientific and clinical advancement, and to prepare the next generation of leaders in child health. They were established in 1875 and provide expertise in the following areas

- Cell Biology
- Child Health Evaluative Sciences
- Developmental & Stem Cell Biology
- Genetics & Genome Biology
- Molecular Medicine
- Neurosciences & Mental Health
- Translational Medicine.

Excluding volunteers, there are 9,184 people who care for the sick children and approximately 10,900 in total including volunteers. Their research staff is comprised of 256 scientists, of these 157 are both clinicians and researchers also included in the clinical staff, 361 project and team investigators, where 50% of their time is committed to research and 50% clinical time, 735 research staff, 193 research operations staff and 157 core facilities research staff.

Research funding totals approximately CA\$245.5 million per year where 65% comes from research grants and awards, 33% from the SickKids Foundation and 2% from industry partnerships or commercialisation income.

The core facilities available to researchers at SickKids includes the following

- Analytical Facility for Bioactive Molecules
- SickKids-UHN Flow and Mass Cytometry Facility
- Nanoscale Biomedical Imaging Facility
- Imaging Facility
- Research MEG Facility
- Research MRI Facility
- SickKids Proteomics, Analytics Robotics & Chemical
- Biology Centre
- Structural & Biophysical Core Facility
- The Centre for Applied Genomics
- The Centre for Computational Medicine
- The Centre for PhenoGenomics
- TCP Mouse Mutant Repository
  - TCP Functional Genomics Core
  - TCP Mutant Model Production
- Zebrafish Core Facility

Researchers at SickKids have access to multiple databases such as The Chromosome 7 Project, Cystic Fibrosis Mutation Database, Labatt Family Heart Centre Biobank, cDNA Database, Michael and Amira Dan Brain Tumour Bank Network, The Paediatric Economic Database Evaluation Projects and the Research Institute Equipment Database. Like RCH SickKids are also members of the Global Alliance for Genomics and Health.

# Appendix 2: Stakeholder Consultations

A list of the stakeholders consulted as part of the strategy developed is outlined below

Table 2: Stakeholder Consultations

#### **Stakeholder Groups**

#### **CHI Executive**

Eilísh Hardiman, CHI Chief Executive

Stephen Flanagan, Chief Financial Officer

Prof. Neil O'Hare, Chief Information Officer (CIO)

Joe Gannon, Chief Operations Officer (COO)

Trevor Murphy, Director of Human Resources

#### **CHI Chief Information Officer**

Prof. Neil O'Hare. CIO

#### **PAHSC**

Prof. Michael Gill, Psychiatry and Head of Discipline at Trinity, Consultant Psychiatrist at St James' Hospital

Prof. Michael Keane, Medicine and Therapeutics at UCD, Consultant Respiratory Physician at St. Vincent's University Hospital

Prof. Hannah McGee, Psychology, Dean of Medicine & Health Sciences and Chief Academic Officer (CAO) at RCSI

Prof. Veronica Lambert, Children and Family Nursing at DCU

#### **Extension of PAHSC**

Prof. Eleanor Molloy, Chair of Paediatrics & Child Health at Trinity, Consultant Neonatologist & Paediatrician at the Coombe Women and Infant's University Hospital, CHI at Tallaght and CHI at Crumlin

#### **CHI Chief Academic Officers**

Prof. Helen Whelton, Head of the College of Medicine and Health at UCC, CAO to HSE South-South West Hospitals Group

Prof. Paul Burke, Chief Clinical Director for UL Hospitals Group, Consultant Vascular Surgeon at University Hospital Limerick

Prof. Deirdre Murray, Paediatrics and Child Health, UCC, Consultant Paediatrician and Clinical Lead for Paediatric Research

Prof. Clodagh O'Gorman, Chair of Paediatrics at UL, Consultant General Paediatrician at University Hospital, Limerick

Prof. Frank Casey, Consultant Paediatric Cardiologist in The Belfast Health and Social Care Trust

#### **Department of Health**

Muiris O'Connor, Assistant Secretary, Research and Development and Health Analytics Division

Teresa Maguire, Head of Research Services & Policy Unit, Research and Development and Health Analytics Division Rachel Kenna, Chief Nursing Officer

#### **Health Service Executive**

Dr Ana Terres, Assistant National Director, Research and Development

Dr Kevin Kelleher, Assistant National Director, HSE Health and Well-Being Public Health and Child Health Division

Dr Abigail Collins, Consultant in Public Health Medicine at the National Cancer Control Programme, Public Health Specialist Carmel Brennan, Programme Manager, National Healthy Childhood Programme

Paul Marsden, Project Manager, Child Health Screening Programmes

#### **NCRC**

Dr Jacinta Kelly, Chief Executive Officer (CEO)

#### **CHF**

Denise Fitzgerald, CEO

#### **HRB**

Dr Mairéad O'Driscoll, CEO

#### SFI

Dr Ciarán Seoighe, Deputy Director General

Dr Peter Clifford, Head of Strategy

#### **HRB-Clinical Research Coordination Ireland**

Dr Fionnuala Keane, COO

#### **Patient Groups and Patient Advocates**

Dr Derick Mitchell, CEO IPPOSI

Dr Avril Kennan, CEO, Health Research Charities Ireland

Wendy Costello, Patient Advocate, NCRC Scientific Advisory Committee

#### **Constituency Group 1**

Dr Patrick Walsh, Assistant Professor of Paediatric Immunology, TCD

Dr Michael Barrett, Paediatric Consultant Emergency Medicine, UCD Associate Professor, Women's & Children's Health

Trisha Hynds, Clinical Nurse Manager, Audit and Research, CHI at Crumlin

Norma O'Keeffe, Registered Advanced Nurse Practitioner Children's Pain, CHI at Temple Street

#### **Constituency Group 2**

Dr Grace O'Malley, Paediatric Physiotherapist and Clinical Researcher, RCSI and CHI at Temple Street

Dr Olga Piskareva, STAR Research Lecturer RCSI,

Prof. Edna Roche, Associate Professor of Paediatrics at Trinity, Paediatric Endocrinologist at CHI Tallaght

#### **Constituency Group 3**

Prof. Dubhfeasa Slattery, Consultant Respiratory and General Paediatrician CHI at Temple Street

Prof. Maureen O'Sullivan, Consultant Paediatric Pathologist, CHI at Crumlin

Dr Dylan Murray, Consultant Plastic Surgeon at CHI Temple Street and the Mater Hospital, Dublin, Clinical Lead at the National Paediatric Craniofacial Centre, Clinician Scientist at RCSI and Trinity Bioengineering Science institute

#### **Honorary Consultant NCRC**

Prof. Jonathan Bond, UCD Brendan McGonnell Professor of Paediatric Molecular Haemato-Oncology, CHI at Crumlin

# Appendix 3: Stakeholder Survey

A survey was designed and distributed in August 2020 as part of the development of the strategy. Research was required to understand

- What is important to various key stakeholder groups and key opinion leaders over the next five years regarding the CHI strategy for research?
- How is CHI perceived and, what drives these perceptions?
- What is the potential of CHI in terms of offering, service, users? Is there room forimprovement?
- What are the key drivers of emotional and intellectual appeal for these cohorts (i.e. how to win hearts and minds)?
- What is the reaction to and implicit testing of draft ambitions, vision, mission?

This survey was ultimately designed with the objective to help hone the CHI strategy for research for 2021-2025 to incorporate the voices of all stakeholders in Ireland.

A wide range of stakeholders were engaged including primary/community and acute healthcare professionals, academics, clinicians, scientists and patient advocates as described in <u>Figure 4</u>.



Figure 4: Survey Responses - Stakeholder Professions

The survey was distributed nationally with respondents from different Clinical Health Organisations (CHO) as depicted in <u>Figure 5</u>. The survey was designed by Mazars and approved by CHI using the information provided in the initial benchmarking consultations (see <u>Appendix 1</u>) and the stakeholder consultations (see <u>Appendix 2</u>) outlined in the previous sections.

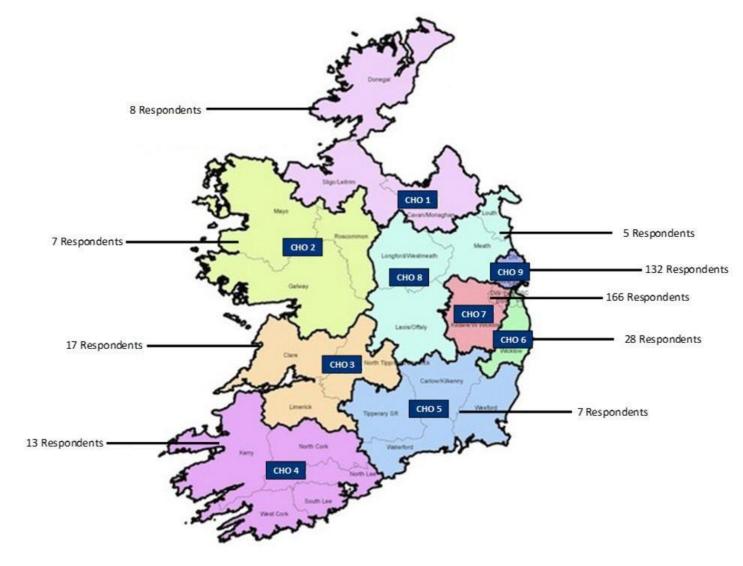


Figure 5: Survey Responses - Participant Locations

The survey explored stakeholders' views on five key themes, Structures and Relationships, Knowledge Transfer and Reputation, Funding and Resources, Processes, Technology, Digital and Data and Key Research Areas.

Overall 830 survey responses were received of which 502 were fully completed survey responses. All 830 survey responses were used in the analysis of stakeholders' viewpoints.

# Appendix 4: Strategy Acronyms

Table 3: Strategy Acronyms

Abbreviation	Full Name
AHSC	Academic Health Science Centre
APG	Academic Partnership Group
BC	British Columbia
CAO	Chief Academic Officer
CEO	Chief Executive Officer
CHF	Children's Health Foundation
CHI	Children's Health Ireland
CIO	Chief Information Officer
CRIC	Children's Research and Innovation Centre
DCU	Dublin City University
DORI	Director of Research and Innovation
HEI	Higher Education Institution
HRB	Health Research Board
HSE	Health Service Executive
IPPOSI	The Irish Platform for Patient Organisations, Science and Industry
MCRI	Murdoch Children's Research Institute
NCRC	National Children's Research Centre
PAHSC	Paediatric Academic Health Science Centre
PAHSN	Paediatric Academic Health Science Network
QMS	Quality Management System
RCH	Royal Children's Hospital Melbourne
RCSI	Royal College of Surgeons in Ireland
REC	Research Ethics Committee
RIO	Research and Innovation Office
SFI	Science Foundation Ireland
Trinity	Trinity College Dublin, The University of Dublin
UCC	University College Cork
UCD	University College Dublin
UL	University of Limerick



# In Living our **VALUES**, we will be:

Child-centred, Compassionate, Progressive and we will act with Respect, Excellence and Integrity



# Br. Record of the control of the con

# Our **VISION** is:

Healthier children and young people throughout Ireland

## Our MISSION is:

To promote and provide child-centred, research-led and learning informed healthcare, to the highest standards of safety and excellence. We do this in partnership with each other, with children, young people and their families through a network of children's services in Ireland







\*CHI Values, Vision and Mission were developed and agreed as part of a Cultural Analysis process with the Boards and staff at the three children's hospitals in 2015

Crumlin | Temple Street | Tallaght | Connolly