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# Towards a healthy life course for all



*The importance of children's hospitals in creating a healthier Europe*

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The European Children's Hospitals Organisation  
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*Towards a Health Life Course for All - The importance of children's hospitals in creating a healthier Europe* was written by Jennifer McIntosh at the European Children's Hospitals Organisation (ECHO). Additional input was provided by Ruben Diaz and Claudia Cifuentes at the ECHO Secretariat.

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## **About ECHO**

The European Children's Hospitals Organisation (ECHO) is a new and growing organisation representing leading tertiary care children's hospitals across Europe. ECHO advocates for children's health and their access to the best quality care through the collaborative work of children's hospitals.

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## Executive Summary

### **An urgent need to improve child health**

There is a pressing need for governments and health systems to focus on the health of children and young people. In fact, multiple organisations including the WHO, UNICEF, and the Lancet are calling for a renewed focus on child and adolescent health. The recent COVID-19 pandemic highlights the need to strengthen all health systems, including those for children. Children and young people are also calling for action, demanding that we act now to create a world where they can thrive. It is up to all of us not to fail them.

### **A child's right to health**

All children and young people have the right to the highest attainable standard of health and to the healthiest possible start in life. These rights are enshrined in the United Nations Charter on the Rights of the Child and are non-negotiable. This means developing health systems and policies that:

- Offer young people the same level of high quality that adults receive.
- Ensure access to specialists that meets their unique needs.
- Invest in research on diseases unique to the paediatric population.

### **ECHO: Working across Europe to improve child health**

Children's hospitals are part of the solution to improving child health, both now and in the future. By caring for the youngest patients, children's hospital help set kids on the course for good health that lasts well into adulthood. The European Children's Hospitals Organisation (ECHO) is a new organisation made up of leading tertiary care children's hospitals across Europe aimed at leveraging the power of children's hospitals to promote and protect child health. By bringing these hospitals together, ECHO aims at establishing the pan-national infrastructure required to improve access, quality and efficiency of healthcare.

#### **Children's hospitals play a critical role in advancing child health.**

Children's hospitals are an important part of the public health system that:



Provide a range of services, from primary to highly specialized care.



Ensure communities have a highly skilled paediatric workforce.



Treat the majority of children and young people with complex chronic and rare diseases.



Drive innovation that benefits children and adult patients.

## **The future could be bright: recent advances in child health**

Although there are many health challenges facing children and young people, there is also reason for optimism. Infant mortality has decreased, and children are surviving into adulthood with diseases that used to be untreatable, like cystic fibrosis, cancer, and congenital heart disease. Children's hospitals have been instrumental in many of these advances. Paradoxically, past improvements in child health have contributed to current challenges around providing care for increasingly complex patients.

## **An ageing population increases the need for excellence in paediatrics**

Investing in child health is the right thing to do for children and young people but is also good for communities and the economy. As the population of Europe continues ageing, children able to reach adult age in good health will be even more important to society. In addition to pressure on health systems, more will be expected of caregivers. For families caring for children and young people with complex or chronic illnesses this will be especially demanding.

## **Health system challenges to improving child health in Europe**

Children and young people face global threats to their health, but there are also local challenges. Barriers to quality improvement, issues with access, and a lack of focus on diseases specific to children and young people all impact the health of children and young people in Europe. Taken together, these factors create an urgent need to focus on and invest in the health of children and young people. The box at the right summarises challenges to improving child health in Europe.

## **Solutions to global challenges in child health**

Ensuring all children in Europe have access to the best possible care will require pan-European collaboration between hospitals, policy makers and legislators. By working together, we can develop solutions to the most pressing issues facing children today (Figure 1). Strategies include:

### **Summary of health system challenges to improving child health in Europe**

#### *Barriers to high quality care*

- Limited paediatric pan-European data available for quality improvement
- Insufficient support for paediatric patients transitioning to adult services

#### *Ongoing issues with access*

- Geographic variation in health outcomes
- Shortages in highly specialised paediatric healthcare providers

#### *Limited investment in child-specific conditions*

- New therapies are needed for child-specific conditions
- Inadequate reimbursement to support complexity of caring for complex and rare conditions

## Improving the quality of healthcare

- **Address the data gap** through the definition of comparable paediatric data sets and investment in data infrastructure and analytics that support the application of artificial intelligence in paediatrics.
- **Improve transition from paediatric to adult care** by supporting the identification and implementation of best practices, including new reimbursement schemes.

## Ensuring equitable access

- **Reduce paediatric workforce shortages.** Children deserve access to highly skilled paediatric healthcare providers, no matter where they live. This means having access to subspecialists and paediatric nurses.
- **Eliminate geographic disparities in health outcomes** by ensuring all children's hospitals can provide the best clinical practices and have access to highly specialised paediatric healthcare providers. Patients should also have access to the care provided by centres of excellence.

## Supporting research targeting children and young people

- **Incentivise and promote the development of new therapies for paediatric-specific diseases.** Rare diseases and childhood cancer are areas of research that need particular attention. This should be accompanied by new incentives to help bring new drugs to market.
- **Invest in paediatric focused research** that includes basic, clinical and health services research.

It is possible to create a world where all children of today and tomorrow, and especially those afflicted with complex chronic or rare diseases, can thrive and meet their full potential. Nevertheless, there is no time to lose—it is up to all of us to act now and put the health of children first and foremost.

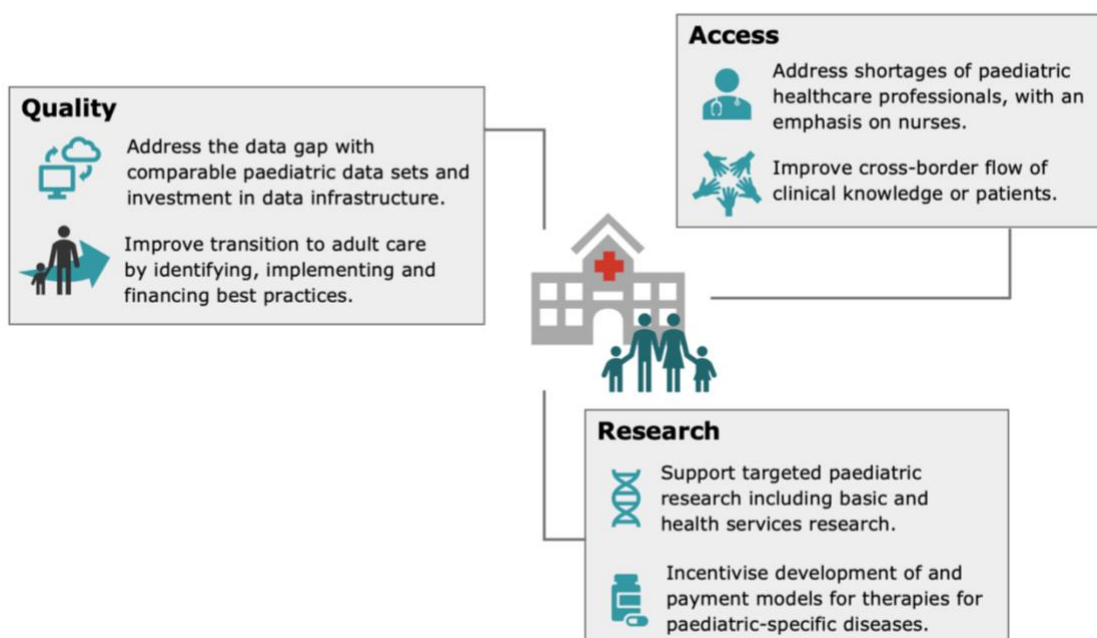


Figure 1. Health system initiatives to support child health in Europe

## An urgent need to improve child health

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There is a pressing need for governments and health systems to focus on the health of children and young people. The climate crisis, growing economic inequality, forced migration, and the impacts of structural racism have all contributed to slowing or reversing recent improvements in child health.<sup>1,2</sup> During the recent COVID-19 pandemic social isolation, school closures, missed or delayed medical care, increased family stress, and the loss of state safeguarding structures all took their toll on the health of children and young people across the globe.

These are global challenges with local consequence that require decisive action. But they are not insurmountable. In fact, they represent opportunities and a time for hope. Hope in the possibility of what we can create by working together now. Hope as a basis for action, not a substitute for inaction that is both grounded in our present reality and inspired by a shared vision of our children's futures. Children and young people demand that we act now to create a world where they can thrive and meet their full potential. It is up to all of us not to fail them.

### Global calls to focus on child health

The benefits of investing in child health go beyond the individual, with implications for future generations and society as a whole. This recognition has led institutions and authorities around the world to call for a renewed focus on child health. Citing an unprecedented threat to the health and livelihood of children, the Lancet is dedicating its 2020 science-based advocacy campaign to child and adolescent health.<sup>1</sup> Likewise the World Health Organization named adolescent health as one of the top ten global health challenges for the next decade.<sup>3</sup>

WHO-UNICEF-Lancet Commission calls for comprehensive cross-sector investment in child health to support lifelong, intergenerational health of individuals and communities.

Perhaps most powerful, a recent WHO-UNICEF-Lancet Commission calls for comprehensive cross-sector investment in child health to support lifelong, intergenerational health of individuals and communities.<sup>4</sup> These calls reflect, in part, the fact that the needs of children and young people have been increasingly overlooked as healthcare systems face continued pressures from rising costs and an ageing population. It is time to refocus and put the needs of children and young people first and foremost.

## Children’s hospitals are part of the solution

Children’s hospitals have a central role to play in promoting the health of children, young people, and communities. The European Children’s Hospitals Organisation (ECHO) is a new organisation made up of leading tertiary care children’s hospitals across Europe whose mission is to advocate for children’s health and their access to the best quality care through the collaborative work of its members. By harnessing the collective power of children’s hospitals, ECHO can help identify and implement solutions to help improve the health and wellbeing of children and young people across Europe.

## A child’s right to health

A child’s right to the highest attainable standard of health and the healthiest possible start in life is enshrined in the United Nations Convention on the Rights of the Child.<sup>5</sup> These rights are universal, applying to all children and young people, including those with complex, rare, or chronic conditions. As a society, there is a collective responsibility to ensure these rights are protected and promoted. Part of doing this means developing health systems and policies that:

- Offer the same level of high-quality healthcare service delivery, monitoring, and evaluation to children and young people that adults receive.
- Ensure all children have access to the healthcare and specialists that meets their unique developmental and psychosocial needs.
- Invest in research on diseases and conditions unique to the paediatric population and the health systems that serve them.

### Who is a child?

The United Nations Convention on the Rights of the Child defines a child as an individual up to 18 years of age.<sup>5</sup>

Although this definition is commonly used, variations exist. In their flagship report, “Being Young in Europe Today,” Eurostat defines a child as someone aged 0-14 and a young person as aged 15-29 years.<sup>6</sup> This discrepancy can create challenges in healthcare planning and assessment. Most children’s hospitals see patients from birth to 18 years of age, making it difficult to find pan-European health statistics for the population they serve.

For the purposes of this paper the terms child, young person, or paediatric will refer to individuals less than 18 years of age unless otherwise specified.

## The future could be bright: recent advances in child health

Although there are many health challenges facing children and young people, there is also reason for optimism. Globally, since 1990 the mortality of children



under five has been cut by more than half.<sup>7</sup> In Europe there have also been dramatic drops in infant mortality. Between 1965 and 2009 infant mortality dropped from 28 per 1,000 live births to just 3.5.<sup>8,9</sup> New technologies and treatments are allowing children to increasingly survive complex chronic and rare diseases that were once fatal. A cystic fibrosis diagnosis used to mean that a child would die before reaching age 20. Now the median survival is 50 years.<sup>10-12</sup> Among children with cancer, 80% are disease-free after five years thanks to new treatments. Survival is also increasing for other childhood illnesses like congenital heart disease and preterm birth.<sup>13,14</sup>

Children's hospitals have been instrumental in many of these advances through the pioneering work of their researchers and clinicians. Paradoxically, past improvements in child health have contributed to current challenges faced by many hospitals. For example, improved life expectancy for children with complex chronic conditions means there is an increased need for financing costly therapies and coordinating transition to adult care. Children's hospitals are ready to take on these and other challenges facing children today, but they cannot do it alone. Cross-sector investment in child health is needed to continue building on past success and create the future our children deserve.

## **ECHO: Connecting children's hospitals across Europe**

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ECHO was established in 2017 to address current and future challenges of child health in Europe. Although children's hospitals play a unique role in serving individual patients and supporting public health, to date there has been no unified voice representing this stakeholder in Europe. ECHO seeks to be the voice of children's hospitals, bringing the needs of patients, families, and those who care for them to the forefront of the health policymaking process.

### **Improving child health in Europe through collaboration**

ECHO's mission is to "advocate for children's health and their access to the best quality care through the collaborative work of its members." ECHO is grounded in the belief that we are stronger together and that the future of healthcare lies in teamwork and collective action. An active network of children's hospitals is essential for addressing the health challenges facing children and young people in Europe today. By bringing leading tertiary care paediatric hospitals together, ECHO aims at establishing the pan-national infrastructure required to improve access, quality and efficiency of care.

### **An end-user network to affect change**

ECHO's work strengthens individual hospitals which in turn supports the health policy priorities of the European Commission. As an end-user network, ECHO is poised to help turn EU health policy objectives into reality. Table 1 lists the

Commission priorities for 2019-2024, with examples of ways that ECHO is actively supporting these priorities.

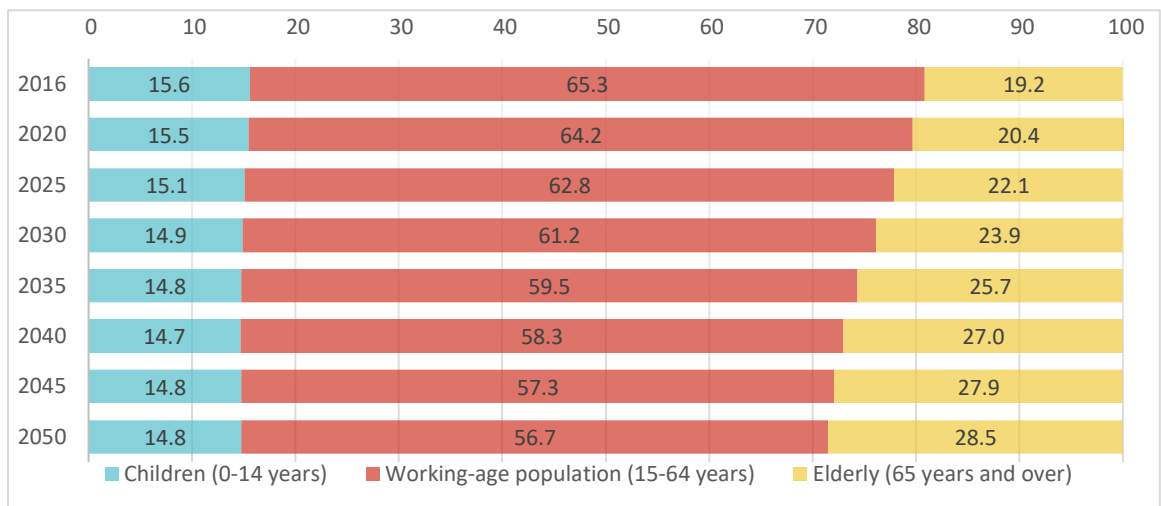
**Table 1. ECHO support of European Commission (EC) priorities**

EC Priority	Children’s hospitals help support these policies by:
<b>An economy that works for people</b>	Developing new and creative jobs in an increasingly complex healthcare environment; Providing patient-centred care and co-designing services to promote social inclusion and equity.
<b>A European Green Deal</b>	Leveraging the collective voice of children’s hospitals to call for increased attention to climate change; Reducing the environmental impact of children’s hospitals through responsible sourcing of food, creating greener more efficient buildings, and reducing pharmaceutical waste.
<b>A Europe fit for the digital age</b>	Implementing pilot projects to establish data sharing systems for benchmarking and quality improvement; Developing paediatric artificial intelligence applications and algorithms.
<b>Promoting European way of life - fundamental rights</b>	Centring our work the rights of children and young people, including the right of all children to the healthiest start in life; Ensuring equal access to high-quality specialist care by participating and providing leadership within the European Reference Networks.
<b>A new push for European democracy</b>	Actively engaging members, including patients, healthcare professionals, and managers, in public consultations and the health policy making process.
<b>A stronger Europe in the world</b>	Conducting internationally recognised basic and clinical research while forming partnerships with children’s hospitals around the world.

A unique feature of the ECHO network is that members are CEOs or hospital managers who can affect change at an institutional level. It also means that policy recommendations made by ECHO are informed by a systems view of care delivery from across Europe. Appendix I details for ECHO’s conceptual framework for improving child health.

## **An ageing population increases the importance of strong paediatric healthcare services**

Investing in child health is the right thing to do for children and young people, but it is also good for communities and the economy. As the population of Europe continues ageing, children able to reach adult age in good health will be even more important to society, creating an urgent need to shore up the systems caring for them.



**Fig. 1: Population, by broad age group as defined by Eurostat, EU-28, 2016-2050**

### **Caring for children in the future: same demands with fewer resources**

The next 20 years will see significant demographic changes in Europe. The proportion of adults in Europe aged 65 and over will increase from 20.4% of the population in 2020 to 27.0% in 2040 while the number of children aged 0-14 years will remain relatively constant (Figure 1).<sup>15</sup> The implication is that organisations caring for children will be taking care of roughly the same number of children, but in healthcare systems that will be more stressed by the needs of an older population.

### **Fewer caregivers but with more responsibilities**

Healthy children depend on healthy families. An ageing population will create stress on caregivers, with implications for people at both ends of the age spectrum. Between 2019 and 2040 the old-age dependency ratio<sup>a</sup> will climb from 31.0 to 46.4 with the young-age dependency ratio<sup>b</sup> increasing slightly from 24.1 to 25.2.<sup>15</sup> The result is that over the next 20 years working aged adults will have increased responsibilities in caring for ageing family members, without a decrease in responsibilities of caring for children and young people.

This is important in any family but becomes especially significant when children and young people have complex or chronic illnesses requiring intensive family support. Investing in healthcare systems that support not just children, but the entire family will alleviate some of the strain of caregivers, allowing them to fully participate in other aspects of society. Health system challenges to improving child health.

<sup>a</sup> The old-age-dependency ratio is the ratio between the number of persons aged 65 and over (age when they are generally economically inactive) and the number of persons aged between 15 and 64. The value is expressed per 100 persons of working age (15-64).

<sup>b</sup> The young-age dependency ratio is the ratio of the number of young people at an age when they are generally economically inactive, (i.e. under 15 years of age), compared to the number of people of working age (i.e. 15-64).

## Health system challenges to improving child health

Children and young people face global threats to their health, but there are also local challenges. Barriers to high quality care, issues with access, and a lack of focus on paediatric specific diseases all impact the health of children and young people in Europe. Taken together, these factors create an urgent need to focus on and invest in child health.

### Quality care

Children and young people have the right to high quality healthcare services with sufficient resources dedicated to monitoring and evaluating those services, but this need is not always met.

### ***Child-specific data supports quality improvement***

In order to benchmark against their peers to improve the efficiency and effectiveness of the care they deliver children's hospitals need comparable child-specific pan-European data. These data should reflect the ages of patients treated by children's hospitals and include process and outcomes measures. Pan-European data is critical as in many countries there may only be one or two tertiary care children's hospitals. Currently, health system reporting tends to focus on adult conditions utilising broad, readily available data. Children and young people can be an afterthought.<sup>8</sup> For example, Eurostat provides information on the type of hospital beds for adults (i.e. curative, rehabilitative, or psychiatric) by country and region, but there is no way to distinguish which beds are for paediatric patients.<sup>16,17</sup>

As healthcare starts incorporating digital platforms to store and process clinical data, the application of artificial intelligence to improve diagnostic and therapeutic interventions at all levels and stages of clinical care will likely become a reality. The robustness of these tools will depend on the sampling size and diversity of data available. In paediatrics, these efforts

#### **Summary of Health system challenges to improving the health of children and young people in Europe**

##### *Barriers to high quality care*

- Limited paediatric pan-European data available for quality improvement
- Insufficient support for paediatric patients transitioning to adult services

##### *Ongoing issues with access*

- Geographic variation in health outcomes
- Shortages in highly specialised paediatric healthcare providers

##### *Limited investment in child-specific conditions*

- New therapies are needed for child-specific conditions
- Inadequate reimbursement to support complexity of caring for complex and rare conditions

will require sharing clinical data between large networks of children's hospitals that serve as reference centres in different regions and countries across Europe.

### ***Supporting young people transitioning to adult care***

An important issue for young people is transitioning from the paediatric health system to adult care. Even if young people are receiving the highest quality treatment in a children's hospital setting, transitioning to adult care can cause significant disruptions.<sup>18</sup> Young people may be inadequately supported through the process, resulting in disengagement and worsening health outcomes.<sup>19,20</sup> This is especially true for patients with complex chronic or rare diseases who may need coordinated health and social care and care beyond 18 years of age. Although guidelines on transition exist, there is no accepted best practice. Reimbursement and incentives for facilitating a smooth transition from paediatric to adult care are also lacking, putting the health of some of the most vulnerable young people at risk.

### **Access to child-centred care**

It is important to remember that children and young people are not little adults. They have distinct biological, emotional and developmental needs necessitating their own unique health services. Access to these health services is a right of all children that must be supported regardless of where they live.

### ***Good health is not equally available to all children and young people in Europe***

Where a child lives in the EU can be a major determinant of their health status. The infant mortality in some Eastern European countries is 70% higher than the EU average and over three times higher than countries with the lowest infant mortality rates.<sup>9</sup>

#### **Providing high quality child-centred care with transition support units**

Children's hospitals across Europe are working to improve the transition process from paediatric to adult care. At Necker-Enfants Malades University hospital in Paris they designed and implemented a unique and first-of-its kind transition unit to support young people moving to adult care called La Suite-Necker. Beyond helping young people deal with the medical issues, La Suite offers support on issues that all young people deal with like sexuality, nutrition or obesity.

Other examples of innovative practices exist. At Great Ormond Street Hospital for Children in London the Young People's Forum teamed up with GOSH Arts to create a booklet with advice from patients for patients. And in Barcelona at Sant Joan de Déu Children's Hospital they created a transition team lead by social workers, providing an integrated view of the transition process.

Other indicators of infant health, like low birth weight, also show significant variation by country.<sup>21</sup> Outcomes of chronic disease can also differ, with the control of diabetes varying both between and within countries.<sup>22,23</sup> There are also significant disparities in cancer outcomes. The 5-year survival rate varies by as much as 20% between countries and within country disparities also exist.<sup>24</sup> What we have in Europe is a situation where your postal code is more influential on your health than your genetic code.

### ***Children need specialised paediatric healthcare providers***

To be as healthy as possible children and young people need a workforce trained to meet their unique physical and psychological needs. Across Europe there are shortages of healthcare providers with paediatric subspecialty training. These shortages are even more pronounced in the availability of specialised nursing. Nurses working in tertiary care children's hospitals take care of complex and often critically ill patients and are a critical part of the paediatric workforce. Providing this level of care requires additional training or certification, with some countries implementing paediatric nursing residencies. Increasingly, hospitals across Europe are facing nursing shortages due to a variety of factors including an ageing workforce, low levels of enrolment in nurse training programmes, or competition for existing nurses<sup>25</sup>. These shortages are predicted to continue or even worsen in the future. To ensure children and young people have access to high quality care, investment in the paediatric workforce is needed.

### **Investment in child-specific conditions and technology**

Another significant challenge to improving the health of children and young people is the limited number of treatment options for diseases specific to this population. Currently in the EU between 17.8 and 30.3 million people have a rare disease, with 69.9% of these starting in childhood.<sup>26</sup> For many of these diseases there are limited or no treatment options.

#### **Increasing access to specialised care with the European Reference Networks**

Patients with complex and rare diseases can have trouble finding the highly specialised care they need. To address this, patients, non-governmental organisations and the EU Commission worked together to create the European Reference Networks (ERNs). This initiative aims to increase patient access to providers with the appropriate expertise and have been essential for helping children get the care they need. Because children's hospitals are often reference centres for treating rare diseases, paediatric specialists have played a lead role in designing and implementing ERNs. The ERNs are an example of how collaboration between hospitals can lead to better access to care and health outcomes across Europe.

To address this, in 2007 the European Medicines Agency enacted regulations to promote research on medicines for children. These have been successful in increasing the number of medicines indicated for children, but the increases have been primarily in therapeutic areas that overlap with adult medical care.<sup>27,28</sup> Many conditions specific to children, like paediatric cancer, remain neglected.<sup>29</sup> This is significant, as childhood cancer is the leading cause of non-accidental death in children in Europe.

In addition to a lack of medicines for children, there is also a lack of medical devices that address the specific needs and physiology of children and young people. In many cases paediatricians are forced to use devices designed for adults “off-label” to treat younger patients.<sup>30</sup>

Finally, there is a disproportionately small portion of research funds spent on health topics dedicated to children, and child health services research lags behind other areas of paediatric research.<sup>31</sup> Children and young people have the right to adequate investment in research to support their health and wellbeing.

### ***New reimbursement models to reflect increasingly complex patients***

As the numbers of children and young people with complex chronic and rare diseases live longer, children’s hospitals are playing an important role in coordinating and helping integrate their care. This includes integration between hospital and primary care as well as integrating health and social care. Although the paediatric community has long recognised the importance of integrated care, payment and organisation of integrated care models lag behind, limiting a hospital’s ability to implement recognised best practices.<sup>32</sup>

Patients with complex chronic and rare diseases also pose challenges to hospital financing. Children’s hospitals are often regional and national

### **Innovation driven by children’s hospitals that improve child health**

Recognising the need for paediatric-specific innovation, children’s hospitals are forming partnerships and creating innovation ecosystems to meet the unique needs of their patients.

Helsinki University Hospital - New Children’s Hospital is part of the CleverHealth Network where they are using the Internet of things to remotely monitor children with type 1 diabetes to improve patient outcomes and quality of life for the whole family.

Children’s hospitals are also using 3D printing to create tools and devices that perfectly fit paediatric patients and to simulate and train for complex surgeries. Meyer Children’s Hospital and the Department of Industrial Engineering of the University of Florence teamed up to form T3DDY, a joint laboratory aimed at introducing highly innovative 3D technologies into the hospital’s clinical practice.

reference centres for rare diseases. Because these patients are concentrated in children's hospitals, the cost per patient can be higher than in other settings.<sup>33</sup>

## The role of children's hospitals

Children's hospitals are anchors in paediatric healthcare and are part of the solution to addressing the health challenges facing children and young people. They provide a range of highly specialised healthcare services, from in-utero surgery to adolescent mental health, that help set the course for lifelong health. Children's hospitals also ensure communities have an adequate and highly skilled paediatric workforce. This includes not only training physicians but also other healthcare providers working with children including nurses, social workers, psychiatrists, or pharmacists. Importantly, children's hospitals are the only source of comprehensive paediatric subspecialty training, making sure communities have expertise needed to treat the most complex cases.

In addition to clinical care and training, children's hospitals are also major drivers of research and innovation that benefit children and adult patients alike. New medicines and medical devices for kids are often developed, tested, and brought to market in collaboration with researchers at children's hospitals. From bench research on the mechanism of diseases to collaborations with community care providers, children's hospitals also help support health promotion and disease prevention.

The way children's hospitals care for patients is also important. They are special places, designed for and by children and young people where their rights are respected and taken seriously. They are places where children and young people are not simply seen as 'little adults' but are offered care in a child- and family-centred environment tailed to their needs. In fact, most children's hospitals have active parent and patient councils

### Children's hospitals play a critical role in advancing child health.

Children's hospitals are an important part of the public health system that:



Provide a range of services, from primary to highly specialized care.



Ensure communities have a highly skilled paediatric workforce.



Treat the majority of children and young people with complex chronic and rare diseases.



Drive innovation that benefits children and adult patients.



guiding programming and policy making. But most important, no matter how sick they are, kids can still be kids in a children's hospital.

### ***Promoting health out of the hospital***

Children's hospitals contribute to broader public health in multiple ways. One significant way is promoting health across the lifespan. There is a growing body of evidence that long-term health is influenced by early-life interventions, including the in-utero period.<sup>34</sup> This is an area of research and care children's hospitals excel in. As we continue looking for ways to promote lifelong health and support healthy communities, children's hospitals will be an important part of the solution.

Another way children's hospitals support public health is by educating the public and working with patient organisations to address their needs, both in and out of hospital. And the expertise of children's hospitals and the trusted role they play in the community strategically positions them to be key partners in the development and implementation of policies to support child health.

## **Solutions to global challenges in child health**

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Across Europe communities, face similar challenges to improving the health of children and young people. Addressing these challenges will require pan-European collaboration between hospitals, policy makers and legislators (Figure 2). By working together, we can develop solutions to some of our most pressing issues facing children today.

### **Improving quality of healthcare**

Improving the quality of healthcare for children and young people will require a comprehensive approach that:

- ***Addresses the data gap.*** As the EU and member states continue investing in digital health systems, the needs of children and young people must be considered. Comparable paediatric data sets to improve process, outcomes, and access should be developed. Investment in a pan-European data infrastructure focused on paediatrics is also needed to ensure all children's hospitals can benefit from new data sharing and analytics initiatives.
- ***Facilitates transition to adult care.*** Investment in identifying and implementing best practices on transition from paediatric to adult care for patients with complex chronic and rare diseases is also critical to improving the quality of healthcare for young people in Europe.

### **Ensuring equitable access**

No matter where a child lives in the EU, they should have the equitable access to the healthcare services they need. Eliminating geographic disparities will require initiatives that:

- **Address paediatric workforce shortages.** New strategies need to be developed to ensure tertiary children’s hospitals have the paediatric healthcare workforce necessary to care for patients, no matter where they live. Specific emphasis needs to be placed on the paediatric nursing workforce as they are in short supply across Europe.
- **Improve cross border flow of clinical knowledge or patients.** Continued emphasis on promoting cross border networks that share successful clinical practices and to improve outcomes will improve local delivery of specialised care. In instances when the delivery of care is best concentrated in a centre of excellence, mechanisms to allow cross-border patient treatment are needed to ensure equitable access.

### Supporting research targeting children and young people

EU initiatives like Horizon Europe and the EU Beating Cancer Plan should have mechanisms to support paediatric-centred research. Specifically, support is needed to:

- **Develop new therapies for paediatric-specific diseases.** Investment in basic and clinical research to support the development of new therapies in conditions specific to children are needed. This should be accompanied by new incentives to help bring these drugs to market.
- **Improve paediatric health-systems research.** Support for research on the development and implementation of new financing mechanisms and care delivery models to support care of complex patients are needed to support the increase in expenditures linked to novel treatments derived from advances in biomedical research.

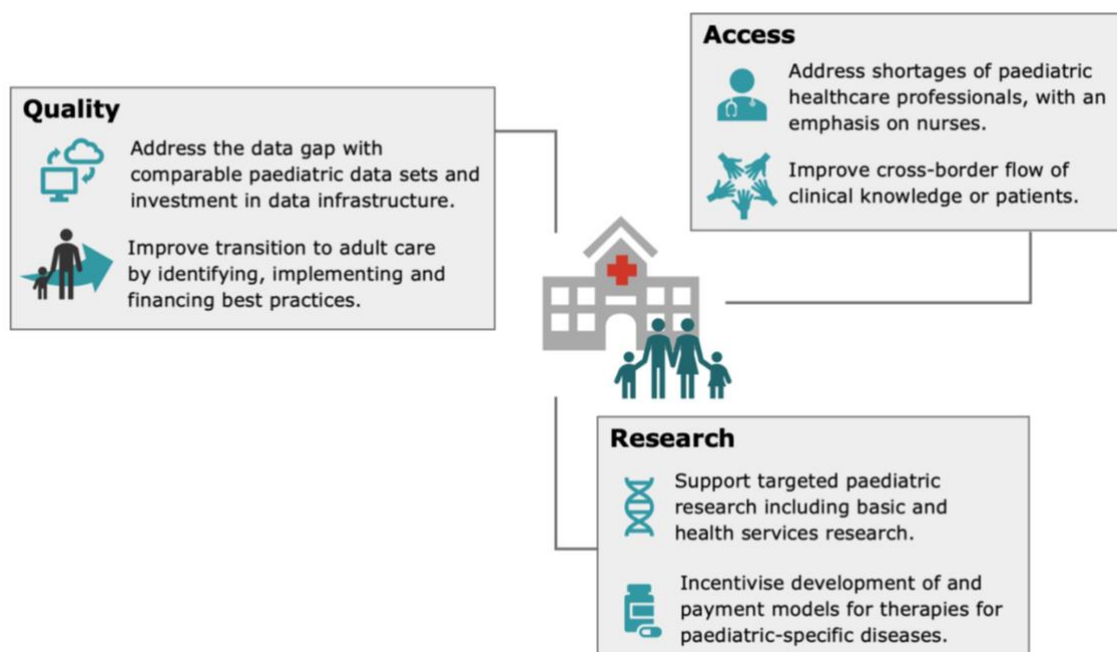


Figure 2. Health system initiatives to support child health in Europe

## Conclusion

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It is possible to create a world where all children, especially those with complex chronic or rare diseases, can thrive and meet their full potential. This will require coordinated, cross-sector action actively involving all stakeholders from patient to policy makers and everyone in between. Children's hospitals are ready to be part of the solution to ensure children across Europe have the best start in life. But there is no time to lose—it is up to all of us to act now and put the health of children first and foremost.

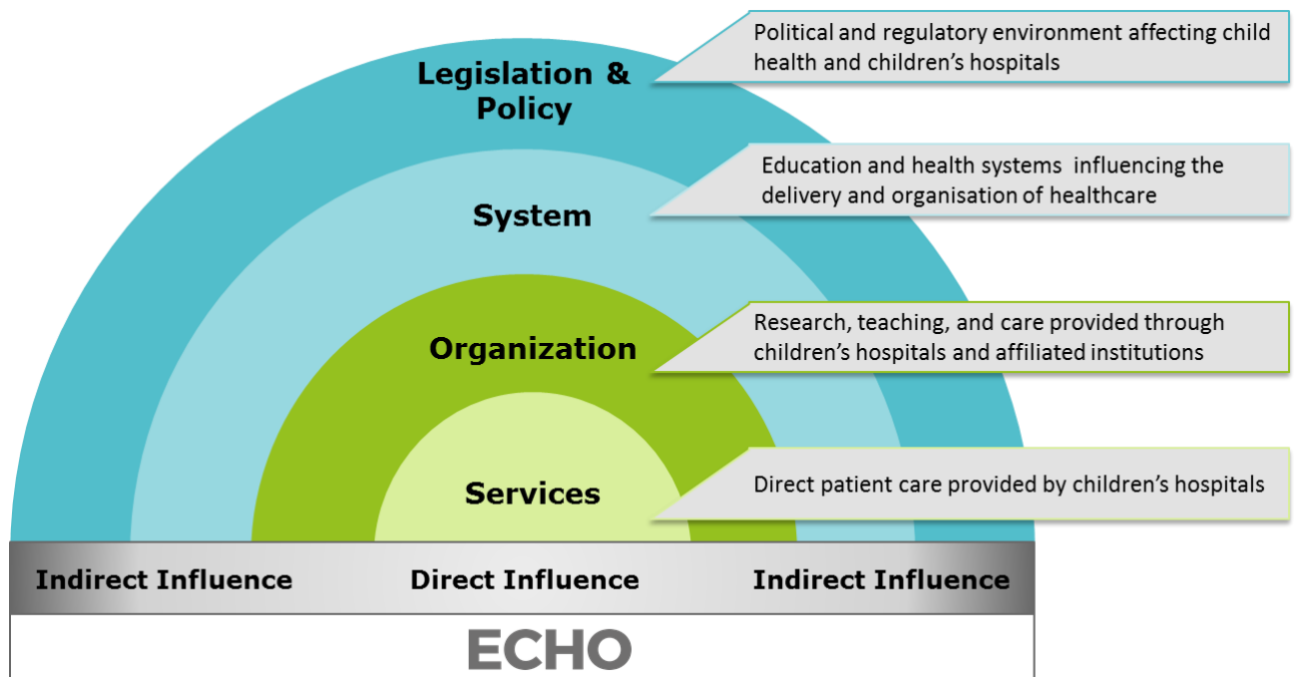
## Appendix I: ECHO conceptual framework

### **Applying a systems approach to improving child health**

ECHO takes a systems approach to improving the health of children and young people (Figure 3). The ECHO conceptual model is based on the Rainbow Model of Integrated Care that considers different dimensions of healthcare from a primary care perspective.<sup>35</sup> This approach was adjusted to reflect the different dimensions of tertiary care where ECHO can act. Part of this process included adding a new dimension of legislation and policy.

An integrated care framework was selected because improving child health will only happen by working across the ecosystem that influences child health. Furthermore, increasing value depends partially on the cost of providing care, which is most often controlled at the health system or policymaking dimension. ECHO works with its members directly on the dimensions of health services and organisational (hospital) level issues, and works with partners to indirectly influence health systems and the legislative and policy environment that children's hospitals operate in.

**Figure 3. ECHO Conceptual Framework to Improve Child Health**



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